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The burden of cancer in 25–29 year olds in New Zealand: a case for a wider adolescent and young adult age range?

Kirsten Ballantine, Victoria Utley, Heidi Watson, Michael Sullivan, Ruth Spearing

Due to our small population and geographic spread, New Zealand faces unique challenges in providing high-quality, comprehensive adolescent and young adult (AYA) cancer services. A 2000–2009 15–24-year analysis showed poorer survival for Māori and Pacific Peoples and for AYA diagnosed with certain cancers such as bone tumours. This has led to a major national focus to improve the outcomes for our AYA population, including the establishment of the AYA Cancer Network Aotearoa in 2013 and the release of the AYA Standards of Care in May 2017. In this paper we report a comprehensive analysis of the incidence and outcome for 25–29 year-old cancer patients. In addition, this paper introduces the AYA Cancer Network and provides the New Zealand medical community with an overview of some the current issues in AYA oncology, including the lack of a clear AYA age range and barriers to increasing clinical trial participation rates for this at-risk population.

Compassion from a palliative care perspective

Antonio Fernando, Conor Rea, Phillipa Malpas

Compassion lies at the heart of good medical care, particularly for the most vulnerable end-of-life patients. However, even though compassion is crucial and central to medical care, it is poorly researched. Our goal was to understand patients’ experiences of compassion and lack of compassion so that we can inform doctors and nurses what compassion is and is not from a dying patient's perspective. We found that though compassion is so valuable and treasured by patients, it is not that complicated and in fact is "cheap", meaning it does not take much time and effort from the clinicians. Dying patients see compassion as clinicians connecting with them, talking to them in a way that can be understood, treating them with respect, showing some interest in them and having a positive presence for them.

Increasing rates of people identifying as transgender presenting to Endocrine Services in the Wellington region

John W Delahunt, Hayley J Denison, Dalice A Sim, Jemima J Bullock, Jeremy D Krebs

Before 2000 there were only a few people referred to the Wellington Endocrine clinic for gender reassignment treatment each year. The numbers increased a little in the first decade of this century, but have increased further from 2010 and 2011—from about 20 cases each year to 91 in 2016. As treatment during a change in gender identity involves psychological and counselling support, hormone therapy and possibly reassignment surgery, medical services should plan to provide facilities to meet this increase in need.

The effect of trampoline parks on presentations to the Christchurch Emergency Department

Lloyd Roffe, Scott Pearson, Johnathan Sharr, Michael Ardagh

Christchurch saw a significant increase in trampoline-related injuries after the opening of two new parks. These injuries involved an older group of children, affected predominantly the lower limbs and were more severe than those reported from the use of domestic trampolines. Consistent with past research, the trampoline park allowing multiple users had a higher proportion of presentations and more injuries requiring operative intervention.
Type of cows’ milk consumption and relationship to health predictors in New Zealand preschool children

Hajar Mazahery, Carolyn Cairncross, Cathryn Conlon, Lisa Houghton, Jane Coad, Carlos Camargo Jr, Cameron Grant, Pamela von Hurst

The New Zealand Ministry of Health recommends that children drink 2–3 serves of (preferably) reduced-fat milk after the age of two years. We investigated milk consumption in New Zealand preschool children and found that most children drank cows’ milk, but that the majority drank full-fat milk. Consumption of low- or reduced-fat milk was influenced by several sociodemographic factors, including age, maternal education, ethnicity and residential region, with Māori and Pacific children, and those living in the South Island, more likely to drink full-fat milk. Identification of the factors which influence milk type consumption in children provides guidance for targeted interventions to improve milk consumption behaviours in children.

Rates of unsuspected thyroid cancer in multinodular thyroid disease

Miriam Karalus, Jade AU Tamatea, Helen M Conaglen, Michael Dray, Goswin Y Meyer-Rochow, John V Conaglen, Marianne S Elston

In this paper we assessed the rates of thyroid cancer identified by the pathologist after surgical removal of the thyroid gland when cancer was not suspected prior to surgery. Removal of the thyroid was performed for a reason other than the suspicion of cancer such as pressure symptoms from a large gland (goitre) or overactivity of the gland. Of the group with normal thyroid hormone levels, 8% had an incidental thyroid cancer and of those with an overactive thyroid gland, 10% of patients has a thyroid cancer identified on routine pathological assessment of the specimen. Most of these incidental cancers were small and of a type which would be expected to be unlikely to alter survival even if diagnosis had been delayed.

A systematic review of leadership training for medical students

Oscar Lyons, Bruce Su’a, Michelle Locke, Andrew Hill

Leadership is increasingly being recognised as an essential requirement for doctors. Many medical schools are in the process of developing formal leadership training programmes. A wide range of leadership curricula have shown some degree of effectiveness, including short interventions, but few studies have measured effectiveness at the system and patient levels. Further research is needed investigating objective and downstream outcomes, and use of standard frameworks for evaluation will facilitate effective comparison of initiatives.
Adolescents and young adults with cancer in New Zealand—understudied and underserved

Heidi Watson, Rochelle Moss

Every year in New Zealand around 200 adolescents and young adults (AYA) aged 12 to 24 years are told they have cancer. Survival rates for New Zealand AYAs lag behind international comparisons by 7%. This means in the past 10 years, 49 more 15–19 year-old New Zealanders have died of cancer than we would expect. Thirty-four (69%) of these deaths were Māori or Pacific youths, even though they account for less than 30% of cancer diagnoses in this age group.1

Internationally over the past 20 years, improvement in survival rates for the AYA cancer population have not been as significant as those seen in either paediatric or adult cancer.2–4 There are many factors that may contribute to this “AYA survival gap”, including low clinical trial participation, treatment adherence issues and differences in the type of cancers young people present with, disease biology and tolerance of therapy.5–8 In addition, due to cancer being relatively rare in this age group, primary healthcare providers and AYAs themselves may not consider cancer as a possibility, potentially leading to diagnostic delays9 resulting in poorer treatment outcomes.10,11

“When I went to the doctor they told me it was normal…I went to the doctor at least six times before I was diagnosed.” AYA patient

What distinguishes AYA from paediatric and adult cancer care?

The additional burden of a cancer diagnosis coincides with an already challenging time in which a young person is making the physical, psychological and cognitive transition from childhood to adulthood. Developmentally, young people are becoming increasingly independent and autonomous, are initiating intimate relationships and are beginning to make important education and career-related decisions.12–14 Developmental stage also impacts on the management of their care—there is strong evidence suggesting a significant portion of AYAs experience challenges with adherence.6,13 Developmental priorities such as peer influence can also compete with the demands of healthcare.15 AYA cancer patients therefore have unique needs that neither the paediatric nor the adult approach to management completely addresses.16

“I was numb. I mean what did cancer mean for my plans for university? I was already planning my courses. What about life and marriage and even kids? I hadn’t thought about kids before but now I had to. And I had to think about how to tell my girlfriend. What would it mean for our relationship?” AYA patient

Evidence has shown that when we try to fit young people into existing structures and services their needs are often not met. Young people tend to sit on the periphery of cancer care, and they often fall into a “no man’s land” between paediatric and adult cancer services.17 Furthermore, New Zealand faces additional challenges in its geographical size, small population and cultural diversity. Some smaller DHBs will only see an average of one or two new AYA cancer patients each year, raising the issue of how to ensure young people have equitable access to the highest standard of care.

Where are the gaps?

A Ministry of Health-endorsed review of AYA cancer services in New Zealand undertaken in 2013 highlighted the value of the existing AYA keyworker role but it also identified several gaps in care delivery. These gaps included a lack of clear guidelines and supporting structures for AYA cancer services, which resulted in clinical practice.
variation, including time to diagnosis, adoption of treatment protocols, availability of clinical trials, information sharing and participation in multidisciplinary teams. The review also highlighted inconsistencies in the collection, monitoring and reporting of AYA data. Moreover, the survival analysis completed raised a number of significant and alarming concerns regarding disparities and inequalities in outcome for certain ethnic, disease-specific and age-related populations within the AYA cohort as mentioned previously.

A way forward for AYA cancer care in New Zealand

While recognising our shortcomings is an important step in creating change, too often the rest of the climb is abandoned. Consequently, strong advocates in New Zealand committed to the idea that the review would only be the first in a long line of actions aimed at addressing unmet needs for AYAs. This commitment combined with the success of the Child Cancer Network and the example set by countries such as the US, Australia and the UK resulted in New Zealand recognising the need for a national framework. The purpose of this framework was to ensure a nationally consistent, well-coordinated and collaborative approach to addressing the needs of the relatively small numbers of AYAs with cancer.

This national framework took the form of The AYA Cancer Network Aotearoa in 2014, charged with providing strategic direction and leadership of AYA cancer care in New Zealand. It is a membership organisation and national resource for health and social providers delivering AYA-specific clinical guidance, support, tools and project management. The Network promotes collaboration across regional and institutional boundaries and helps facilitate the development of innovative initiatives to address unmet needs. An example has been the establishment of working groups that aim to provide sound advice and recommendations on specific areas of care such as early identification of AYA cancers. Simultaneously the Network is developing the national strategy to be released next year. This strategy will address high-priority issues such as improved access to clinical trials, development and monitoring of MDTs, workforce development and more. Overall it will showcase an optimal model of care tailored to the unique needs of AYAs while ensuring equitable access to high-quality medical and supportive care regardless of where AYAs live.

Setting the standard and beginning the climb

Key pieces of work have been, or are being, undertaken to guide the strategy’s development. The first of these has been the creation of the AYA Cancer Standards of Care (SOC). The SOC describe the core elements of cancer care and are a guide and resource for providers to understand and strive to provide optimal care for this age group. The SOC cover a vast array of topics from the diagnostic process to fertility preservation, to psychosocial care, to age-appropriate environments and more. The SOC compliment the previously published 11 national tumour standards to provide a combined comprehensive overview of best care for AYAs.

The SOC are intended for a wide audience, extending across all organisations and institutions that work with AYAs with cancer, including the education sector, the health sector, social services and non-governmental organisation (NGO) providers. The standards are significant as they represent a move away from a model of care that traditionally centred on trying to fit young people into existing structures and services. Instead they aim to explore innovative ways of delivering appropriate and effective care to the meet the distinct needs of the AYA population while recognising the complexities of the New Zealand health system. The Network recognised the importance of informing young people and whānau on the quality of services and care they should expect to receive when diagnosed with cancer. Therefore a series of short videos were developed with AYAs themselves to reflect these standards in a user friendly and age-appropriate manner. It is central to the Network that AYAs are given the platform to self-advocate and shape the Network’s messages and goals. In fact every step taken by the Network is supported and guided by consumer input—who better to say what young people want than young people themselves? Both the SOC and the youth videos are readily available on the Network website, which we encourage readers to view and utilise.
The Network recognised the risk that the standards would become just another document shelved among a long line of dusty books. Consequently a specially designed online self-review tool was created and is being used by providers across the country to promote and encourage the implementation of these standards of care. This online tool is a world first for AYA cancer care and it allows users to collaboratively implement the AYA standards of care in driving quality initiatives locally and nationally. It has also been an effective way of raising the AYA profile.

Data collection and monitoring

Planned regular analysis of the New Zealand Cancer registry data is to now occur providing the Network with evidence of emerging trends in AYA cancer and to evaluate how service improvements and changes have impacted survivorship. Patient information and service delivery data collection has also been standardised, allowing the Network to undertake activities such as monitoring clinical trial participation in order to identify and address barriers to improving access for AYAs.

When do you stop being defined as a young adult?

An area of research that has been undertaken following the recognition of a gap in data relates to revisiting the potential causes of the survival disparities identified in 2013. This has included a national retrospective review of specific AYA cancers and also a study of cancer in the older 25–29 year population. While this age group is currently excluded from the ‘AYA definition’ in New Zealand, internationally they are grouped within this cohort due to the discovery that they experience similar disparities and challenges that younger AYAs confront. Does this translate to New Zealand and if so should we follow suit and extend our age range? The following article explores this important question further.

Conclusion

The establishment of the Network and the subsequent development of services, tools and structures to address the disparities within New Zealand’s AYA cancer population has been an essential and exciting path to weave. However, unfortunately alone, it is not enough. For the Network to flourish and for its goals of equitable, high-quality care for AYAs to be ascertained it relies on the participation and collaboration of the whole sector. For more information and to become a member of the network, please go to http://ayacancernetwork.org.nz. The website provides clinical guidance and resources, current and past research, training opportunities, existing AYA clinical and support services locally and nationally.

“IT pains me that there are many like myself who unwillingly have to face the brutality of this sickness. But knowing that something... now exists to navigate and enhance the care we as rangatahi receive has me eternally grateful.” AYA patient

Competing interests:
Nil.

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Compassion defined: it’s time for doctors to step up

Kate Grundy, Amanda Landers

Compassion is a word that means different things to different people. It is a nebulous concept and, along with the terms dignity and suffering, is often considered “soft” and not particularly relevant clinically. Mainstream literature has tended to focus on “compassion fatigue” among healthcare professionals rather than on the delivery of compassionate care to our patients. It is therefore very encouraging to see research being conducted into compassion from the patient perspective within the New Zealand context, and for it to be published in a journal with broad readership. We congratulate the authors for their work and recommend that readers ponder on their own practice and consider how to be more attentive to this issue.

Everyone in health accepts it is important to be compassionate, but the busyness and complexity of modern clinical practice tends to push it to the periphery. Like communicating bad or serious news, it can be seen as hard to do well and something that needs a great deal of time, when time is so often in short supply. In this article by Fernando et al, the voices of articulate and thoughtful patients are heard as they reflect on the meaning and importance of compassion. They have given their time and energy even as they face the end of their lives. They have framed these complex concepts in a way that helps make the delivery of care in a compassionate manner more understandable and achievable, and in our view they have created a vision for the future of healthcare in our country.

Four themes were identified by the 20 patients who contributed to the Fernando study. The first theme is connection, and is completely unsurprising. It is how we function as human beings and is even more critical at times of stress such as acute or progressive illness. Establishing a clinician-patient relationship requires a connection to be made, both from an intellectual perspective as well as an emotional one. The two are intimately entwined. Making a connection and seeing the patient as the priority is the foundation of the therapeutic relationship. Sometimes patients come to palliative care battle-scarred and demoralised by previous clinical interactions. In these situations engaging with them and “seeking to understand” their needs is often able to facilitate an instant connection.

Connection encompasses understanding and empathy, both of which need to be exhibited and modelled in the clinical setting.

The second theme, presence and warmth, describes the way patients wish to experience our care, using words such as being positive, uplifting and friendly. Sometimes it is “as simple as sharing a smile or a joke”. It encompasses both physical and emotional elements. Practising in this way does not cross professional boundaries as was once believed, neither does it minimise or trivialise the issues. It may not require long periods of time but does need insight into how we behave and present ourselves to patients.

Respect as a theme encompasses virtues such as being heard, not being judged, and being valued as a “full person”. It requires eye contact, openness and honesty. Often health professionals appear to compartmentalise medical issues, separating them from other aspects of their patient’s lives and regarding them as less important. This is inappropriate and completely dismisses the importance of community, the need to maintain roles and relationships and the capacity for support to exist outside of institutionalised healthcare. It is important for patients to be treated as “intelligent individuals” and not as conditions or numbers.
They want us to be “fully present”—to be attentive. This is another skill that doctors can and should learn, encourage and value.

The final theme is caring. The Fernando et al paper describes this as a complex theme incorporating many subthemes; encouragement, reassurance, support, comfort, commitment, responsiveness and sensitivity. Everyone reading this list would want to be treated this way in our health system and would want this for their loved ones, especially (but not only) if they are facing a life-threatening diagnosis. With the power balance in favour of the medical professional, this is the least we can do for the people we are treating.

Despite this study being restricted to hospice patients, and involving mainly older people from one centre, our collective experience across the wider health system would suggest that the findings are generalisable to the vast majority of people facing life-limiting illness in every healthcare setting. It is commendable that the study includes patients from several cultural backgrounds including Asian and Pacific but a deeper exploration of the cultural perspectives around compassion would be valuable.

It is interesting to compare and contrast this local paper with studies done internationally. Sinclair et al recently published a paper in a palliative care journal outlining the distinction that patients themselves make between sympathy, empathy and compassion. The term compassion was remarkably described as “altruistic, proactive and subtle”. In palliative care, these intriguing concepts are often debated and discussed, but across the wider health system there is generally not the forum to do so. The words sympathy, empathy and compassion are commonly used interchangeably but it is clear that they are quite different from the patient experience.

Communication is also a recurring theme when considering the patient-healthcare provider relationship and needs to be supported at all levels. Communication skills training (throughout our careers, not just at undergraduate and trainee levels) as well as opportunities for peer review and reflective practice should be widely available and universally supported.

Ideally, a whole of system view of compassion in healthcare is needed, not just a personal or professional one. A report released by the National Health Service (NHS) in the UK for nurses, midwives and care staff in May 2016 focuses on this issue. The report is called “Leading change, adding value”. It describes “overwhelming support for the 6Cs: compassion, care, commitment, courage, competence, communication” and identifies compassion as the “foundation of our value base”. A similar focus here in New Zealand would be extremely timely and transformational.

For doctors to truly heal those who require our skill and guidance, we need to find not only empathy, but compassion, that virtue which our patients state is central to medicine.

Competing interests: Nil.

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The burden of cancer in 25–29 year olds in New Zealand: a case for a wider adolescent and young adult age range?

Kirsten Ballantine, Victoria Utley, Heidi Watson, Michael Sullivan, Ruth Spearing

ABSTRACT

AIMS: New Zealand currently defines the adolescent and young adult (AYA) group for cancer services as young people 12–24 years of age, while other countries favour a designation of 15–29 years. This study was undertaken to compare cancer incidence and survival among 25–29 year olds to New Zealand’s younger AYA population and to assess survival for our 15–29 year population against international benchmarks.

METHODS: Diagnostic and demographic information for cancer registrations between 2000 and 2009 for 25–29 year olds was obtained from the New Zealand Cancer Registry. Incidence rates (IR) and five-year relative survival estimates were calculated according to AYA diagnostic group/sub-group, sex and prioritised ethnicity.

RESULTS: 1,541 new primary malignant cancers were diagnosed (IR: 588 per million). Five-year relative survival was 85%, but was significantly lower for Māori and Pacific peoples (both 77%) compared to non-Māori/non-Pacific peoples (88%). In the overall 15–29 year AYA cohort, disease-specific outcomes for bone tumours (46%) and breast cancer (64%) were inferior to international standards.

CONCLUSION: New Zealand 25 to 29 year olds are at twice the risk of developing cancer as those 15–24 years. Given that the survival disparities identified were remarkably consistent with those for younger AYA, consideration should be given widening New Zealand’s AYA age range.

A dolescent and young adult (AYA) oncology is described as “the interface of paediatric and adult oncology”. A diverse range of cancers affect this age group, including cancers such as acute leukaemia more commonly seen in children, malignant bone tumours which peak in the teenage years, and cancers that are most common in the AYA population such as thyroid carcinoma, Hodgkin lymphoma and gonadal germ cell tumours. Although the majority of cancers diagnosed among AYAs do not appear to be linked to environmental or inherited factors, following adolescence there is a dramatic increase in the incidence of cancers with an environmental influence, such as malignant melanoma and cervical carcinoma.

A relative lack of improvement in the survival of AYAs with cancer compared to younger and older age groups was first recognised two decades ago. This has been attributed to a range of factors such as biological differences in the presenting disease, a lack of research on cancer in this age group, limited access to and participation in clinical trials, treatment adherence issues and a low awareness of cancer risk among the AYA population and primary healthcare providers leading to delays in diagnosis. From a service perspective, AYA patients with cancer have often fallen through the gap between paediatric and adult cancer services, resulting in some patients being referred to centres less experienced in treating their disease,
inconsistency in treatment and follow-up services, and a lack of access to psychosocial resources appropriate for this age group. In order to support the facilitation of evidence-based and age-appropriate care for young people, the New Zealand AYA Service Specifications were introduced nationally in 2009. Central to this was the recommendation to establish AYA multidisciplinary teams in the tertiary centres which incorporated the existing adult and paediatric cancer services, and the funding and employment of six regional AYA Key Workers. AYA patients continued to be referred to the relevant services for cancer treatment—such as medical oncology, haematology and paediatric oncology—but were also now referred to the AYA cancer service. The aim was to coordinate the range of complex cancer services required for AYA that involve many disciplines/professional groups and cross organisational, district and institutional boundaries.

The optimal age range for the care of cancer patients in the AYA population is the subject of ongoing international debate. Some argue that a defined AYA age range is a prerequisite for advancing AYA clinical care and research, while others call for a more flexible approach which considers the developmental and psychosocial needs of the individual patient in conjunction with the underlying biology of their disease. Generally Europe, the UK and Australia define AYA as 15–24 years of age, the US Surveillance Epidemiology and End Results (SEER) programme and the Canadian Cancer Society favour 15–29 years, while for epidemiological studies, the upper bound may be up to 45 years or more. In New Zealand the AYA Cancer Service Specifications define AYA as 12–24 years of age, consistent with two key Ministry guiding documents—“Youth Health: A Guide to Action” and “Youth Development Strategy Aotearoa”—and similar to the definition adopted by major charitable supporter of this age group, CanTeen. However, in New Zealand, the 12–15 year age group is already encompassed by existing comprehensive paediatric oncology services. Moreover, those aged 25–29 years often have similar psychosocial issues to their younger peers; a cancer diagnosis may greatly impact their relationships, physical appearance and career goals during a developmental period in which establishing a strong sense of identity is crucial. The AYA Cancer Service Specifications acknowledge the limitations of defining AYA solely in chronological terms and emphasise that referral pathways should be determined according to what best meets the treatment and psychosocial needs of the individual patient and their whānau.

In 2012, a 2000–2009 AYA cancer incidence and survival analysis was undertaken at the request of the AYA Advisory Group. The analysis identified unique ethnic differences in the spectrum of cancers diagnosed in the 15–24 year population, including a higher incidence of bone tumours and gonadal germ cell tumours among Māori, leukaemia among Pacific peoples and melanoma among non-Māori/non-Pacific peoples. Five-year relative survival in New Zealand (80.6%) appeared poorer than had been achieved in other high-income countries, particularly for AYA with bone tumours (48.5%). Overall five-year relative survival was poorer for Māori (69.5%) and Pacific peoples (71.3%) compared to the non-Māori/non-Pacific 15–24 year population (84.2%). The following year, the AYA Cancer Network Aotearoa was established by the Ministry of Health and charged with providing strategic direction and leadership of cancer care for the 12–24 year age group. However, given that the framework for AYA cancer care is currently under development by the AYA Cancer Network and that the AYA age range extends up to 29 years in many other countries, it is timely to provide data pertaining to the burden of cancer among our 25–29 year population. This study was undertaken to identify the spectrum of cancers specifically affecting New Zealanders aged 25–29 years and to determine whether the ethnic survival disparities and poorer outcomes for some tumour groups observed in the 15–24 year population are also evident for the upper AYA age bracket. In addition, this study aimed to assess New Zealand’s cancer survival for the wider 15–29 year group against international benchmarks.
Method

Diagnostic and demographic data for 1,541 registrations of new primary malignant tumours diagnosed among those aged 25–29 years old between 1 January 2000 and 31 December 2009 were obtained from the New Zealand Cancer Registry (NZCR). Squamous and basal cell carcinomas and non-malignant central nervous system tumours were not included in this analysis as such cases are not notifiable to the registry. The data items provided were National Health Index number, ethnicity, sex, date of birth, date of diagnosis, date of death, coded tumour site, coded morphology and basis of diagnosis. Cancers were re-coded according to the AYA Cancer Classification Scheme17 using the site-recode scheme developed by Surveillance, Epidemiology End Results (SEER).18 The AYA Cancer Classification Scheme has 10 major diagnostic groups and 32 diagnostic subgroups and uses a combined morphology/site classification system suitable for both the paediatric and adult malignancies which affect the AYA population. The 25–29 year analysis replicated the methodology of the earlier 15–24 year AYA analysis to aid age-group comparisons.15-16 In addition, the 25–29 year dataset was combined from the 15–24 year dataset from the original AYA analysis in order to make survival comparisons with published studies, which more commonly define the AYA population as encompassing those aged 15–29 years of age.

Ethnicity was classified using a prioritised ethnicity system; Māori, Pacific peoples and non-Māori/non-Pacific peoples. When prioritised ethnicity is applied to 2006 census data, the 25–29 year AYA population comprised of 15.7% Māori, 6.9% Pacific peoples and 77.4% non-Māori/non-Pacific peoples (12.9% Asian, 1.2% Other Ethnicity, 5.3% ‘Not Elsewhere Included’ and 58.0% European/New Zealander).

Age-specific incidence and relative survival estimates were calculated using SAS® and Stata® software. Incidence rates (IR) per million inhabitants were calculated based on person-years derived from Statistics New Zealand’s annual estimated resident population by age and sex. Relative risk (RR) estimates were calculated for males compared to females and 95% confidence intervals (CIs) were calculated assuming the cases were drawn from a Poisson distribution. Five cases informed by autopsy or death certificate only or with a survival of zero days were included in incidence counts but excluded from the survival analyses. Relative survival estimates were derived from the observed survival data, using record linkage to the National Mortality Collection, and expected survival data, calculated according to the Ederer II method using life-tables produced by Statistics New Zealand based on 2006 census data. All cases were followed up until death or 31 December 2010, whichever came first. Ethical approval was granted by the Multi-region Committee of the Health and Disability Ethics Committee (MEC/12/EXP145).

Results

Between 2000 and 2009 there were an average of 154 primary malignant tumours diagnosed each year among New Zealanders aged 25–29 years (IR: 588 per million; 95% CI: 558–617). This was approximately equal to the annual number of cancers diagnosed among those aged 15–24 years (n=161, IR: 275 per million; 95% CI: 261–288)15 and greater than the annual number of new diagnoses in the entire child population aged 0–14 years (n=133, IR: 149 per million; 95% CI: 141–157).19 Figure 1 shows that of the 10 major diagnostic groups, the most common cancers were carcinomas (33.4%), melanomas (24.6%) and germ cell tumours (16.4%) with most of the remaining tumour groups recording only a very small number of cases on a national annual basis. Table 1 reports cancer incidence by ethnicity and sex according to AYA diagnostic group and subgroup. Cancer incidence was higher for females (n=841, IR: 626 per million; 95% CI: 584–669) than males (n=700, IR: 547 per million; 95% CI: 507–588), but this difference was not statistically significant. Males were significantly more likely than females to be diagnosed with germ cell tumours (RR 14.5, 95% CI 9.9–21.2) and leukaemias (RR 1.8, 95% CI 1.1–3.0) and significantly less likely to be diagnosed with genitourinary tract carcinomas (RR 0.1, 95% CI 0.1–0.2), melanoma (RR 0.6, 95% CI 0.5–0.7), thyroid cancers (RR 0.2, 95% CI 0.1–0.3) and breast carcinomas.
Figure 1: Average annual number of new cancer cases among young adults aged 25–29 years in New Zealand, 2000–2009.

Table 1: Cancer incidence per million among New Zealand’s 25–29 year old population by sex and prioritised ethnicity, 2000–2009.

<table>
<thead>
<tr>
<th>AYA diagnostic group and selected subgroups</th>
<th>Sex</th>
<th>Prioritised ethnicity</th>
<th>Total 25–29 years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Relative risk</td>
</tr>
<tr>
<td>1. Leukaemias</td>
<td>43</td>
<td>34</td>
<td>25 19</td>
</tr>
<tr>
<td>1.1 Acute lymphoid leukaemia</td>
<td>11</td>
<td>9</td>
<td>7 5</td>
</tr>
<tr>
<td>1.2 Acute myeloid leukaemia</td>
<td>19</td>
<td>15</td>
<td>11 8</td>
</tr>
<tr>
<td>2. Lymphomas</td>
<td>92</td>
<td>72</td>
<td>76 57</td>
</tr>
<tr>
<td>2.1 Non-Hodgkin lymphoma</td>
<td>50</td>
<td>39</td>
<td>33 25</td>
</tr>
<tr>
<td>2.2 Hodgkin lymphoma</td>
<td>42</td>
<td>33</td>
<td>43 32</td>
</tr>
<tr>
<td>3. Central nervous system tumours</td>
<td>39</td>
<td>31</td>
<td>24 18</td>
</tr>
<tr>
<td>4. Osseous and chondromatous neoplasms</td>
<td>12</td>
<td>9</td>
<td>5 4</td>
</tr>
<tr>
<td>5. Soft tissue sarcomas</td>
<td>20</td>
<td>16</td>
<td>14 10</td>
</tr>
<tr>
<td>7. Melanoma and skin carcinomas</td>
<td>138</td>
<td>108</td>
<td>241 180</td>
</tr>
<tr>
<td>8. Carcinomasb</td>
<td>100</td>
<td>78</td>
<td>414 308</td>
</tr>
<tr>
<td>8.1 Thyroid carcinoma</td>
<td>17</td>
<td>13</td>
<td>92 69</td>
</tr>
<tr>
<td>8.2 Other carcinoma of head and neck</td>
<td>18</td>
<td>14</td>
<td>15 11</td>
</tr>
<tr>
<td>8.4 Carcinoma of breast</td>
<td>0 2</td>
<td>101</td>
<td>75</td>
</tr>
<tr>
<td>8.5 Carcinoma of genitourinary tract</td>
<td>15</td>
<td>12</td>
<td>155 115</td>
</tr>
<tr>
<td>8.6 Carcinoma of gastro-intestinal tract</td>
<td>45</td>
<td>35</td>
<td>42 31</td>
</tr>
<tr>
<td>9. Miscellaneous specified neoplasms</td>
<td>12</td>
<td>9</td>
<td>15 11</td>
</tr>
<tr>
<td>10. Unspecified neoplasms</td>
<td>9 7</td>
<td>10</td>
<td>7 4</td>
</tr>
<tr>
<td>Total cancers diagnosed</td>
<td>700</td>
<td>547</td>
<td>841 626</td>
</tr>
</tbody>
</table>

AYA: adolescent and young adult; IR: incidence rate (per million); CI: confidence interval.

Relative risk was not calculated due to the small number of cases for one or both groups.

Due to the small number of cases diagnosed within the 10-year period, incidence rates for diagnostic subgroups ‘8.3: Carcinomas of trachea, bronchus, and lung’ (six cases) and ‘8.7: Carcinomas of other and ill-defined sites’ (eight cases) were not reported in the table.
Cancer incidence among 25–29 year olds was 532 per million for Pacific peoples (95% CI: 422–643), 626 per million for non-Māori/non-Pacific peoples (95% CI: 591–662) and 727 per million for Māori (95% CI: 641–813). Although the ethnic differences in overall cancer incidence were not yet statistically significant, several notable ethnic differences were observed in the spectrum of AYA cancers diagnosed. Melanoma was rare among Māori (IR: 34 per million) or Pacific peoples (IR: six per million) but importantly it still accounted for nearly one-third of all cancers diagnosed among non-Māori/non-Pacific peoples in this age group (IR: 195 per million). Compared to non-Māori/Pacific peoples, Māori had a significantly higher incidence of gonadal germ cell tumours (IR: 207 per million c.f. 88 per million) and carcinomas (IR: 307 per million c.f. 190 per million), particularly breast carcinomas (IR: 79 per million c.f. 36 per million).

### Table 2: Five-year relative survival among New Zealand’s 25–29 year old population by sex and prioritised ethnicity, 2000–2009.

<table>
<thead>
<tr>
<th>AYA diagnostic group and selected subgroups</th>
<th>Sex</th>
<th>Prioritised ethnicity</th>
<th>Total 15–29 years</th>
<th>Total 15–29 years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Māori</td>
<td>Pacific peoples</td>
</tr>
<tr>
<td></td>
<td>5-year survival (%)</td>
<td>95% CI</td>
<td>5-year survival (%)</td>
<td>95% CI</td>
</tr>
<tr>
<td>1.1 Acute lymphoid leukaemia</td>
<td>81</td>
<td>43–95</td>
<td>72</td>
<td>26–92</td>
</tr>
<tr>
<td>1.2 Acute myeloid leukaemia</td>
<td>64</td>
<td>38–81</td>
<td>42</td>
<td>13–69</td>
</tr>
<tr>
<td>2. Lymphomas</td>
<td>85</td>
<td>74–91</td>
<td>81</td>
<td>70–89</td>
</tr>
<tr>
<td>2.1 Non-Hodgkin lymphoma</td>
<td>81</td>
<td>66–90</td>
<td>69</td>
<td>50–82</td>
</tr>
<tr>
<td>2.2 Hodgkin lymphoma</td>
<td>89</td>
<td>72–96</td>
<td>90</td>
<td>73–97</td>
</tr>
<tr>
<td>6.1 Germ cell and trophoblastic neoplasms of gonads</td>
<td>98</td>
<td>95–99</td>
<td>100</td>
<td>95–99</td>
</tr>
<tr>
<td>7. Melanoma and skin carcinomas</td>
<td>91</td>
<td>84–95</td>
<td>97</td>
<td>93–98</td>
</tr>
<tr>
<td>8. Carcinomas ^{c}</td>
<td>78</td>
<td>68–85</td>
<td>83</td>
<td>78–86</td>
</tr>
<tr>
<td>8.1 Thyroid carcinoma</td>
<td>101</td>
<td>b</td>
<td>99</td>
<td>93–100</td>
</tr>
<tr>
<td>8.2 Other carcinoma of head and neck</td>
<td>95</td>
<td>65–100</td>
<td>91</td>
<td>51–99</td>
</tr>
<tr>
<td>8.4 Carcinoma of breast</td>
<td>65</td>
<td>53–74</td>
<td>47</td>
<td>25–66</td>
</tr>
<tr>
<td>8.5 Carcinoma of genitourinary tract</td>
<td>86</td>
<td>54–97</td>
<td>93</td>
<td>87–96</td>
</tr>
<tr>
<td>8.6 Carcinoma of gastro-intestinal tract</td>
<td>63</td>
<td>46–76</td>
<td>52</td>
<td>33–69</td>
</tr>
<tr>
<td>Overall survival</td>
<td>86</td>
<td>83–89</td>
<td>85</td>
<td>82–87</td>
</tr>
<tr>
<td>Overall survival (excluding melanoma)</td>
<td>85</td>
<td>82–88</td>
<td>80</td>
<td>76–83</td>
</tr>
</tbody>
</table>

^aFive-year relative survival and 95% confidence intervals could not be calculated as no cases had a full five years of follow-up.

^bConfidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period.

^cDue to the small number of cases diagnosed within the 10-year period, survival estimates for diagnostic subgroups ‘8.3: Carcinomas of trachea, bronchus, and lung’ (six cases) and ‘8.7: Carcinomas of other and ill-defined sites’ (eight cases) were not reported in the table.
Overall five-year relative survival estimates for the 25–29 year population (85%; 95% CI: 83–87%; see Table 2) were very similar to the survival reported in the earlier AYA analysis for 20–24 year olds (85%; 95% CI: 82–87%), but significantly higher than survival for adolescents aged 15–19 years (75%; 95% CI: 71–78%).

Five-year survival for carcinomas overall was 82% although this varied considerably according to diagnostic subgroup, ranging from 99% for the 109 individuals diagnosed with thyroid carcinoma to 33% for the six 25–29 year olds diagnosed with “carcinoma of the trachea, bronchus and lung”. There were no five-year survival differences for the 25–29 year population according to sex, but marked differences according to ethnicity. Five-year relative survival was 88% in non-Māori/Pacific peoples, significantly higher than the 77% survival estimate for both Māori and Pacific peoples. Although not reaching statistical significance, there were noteworthy differences in five-year survival for Māori compared to non-Māori/non-Pacific 25–29 year olds diagnosed with CNS tumours (34% c.f. 68%), and bone tumours (17% c.f. 43%). When melanoma cases were excluded, Māori five-year survival (76%) remained 9% lower than for non-Māori/non-Pacific peoples (85%).

Discussion

The relative rarity of cancer in the 25–29 AYA age group and spectrum of cancers differs significantly from that seen in the mature adult population. While many cancer diagnoses in the 25–29 AYA group are similar to the younger AYA group (lymphomas, melanoma and gonadal germ cell tumours) this age group also sees the emergence of other cancers less commonly seen in the 15–24 age bracket, namely carcinomas of the breast, gastrointestinal and reproductive tracts. In addition, there are marked ethnic and gender differences in the spectrum of cancers diagnosed.

New Zealand’s overall cancer incidence for 25–29 year olds of 588 per million was comparable to the incidence reported for the US and Canada within a similar time period. A notable exception is the incidence of melanoma, which is considerably higher than has been reported elsewhere for this age group, but in keeping with New Zealand’s known high rates of melanoma due to our ethnic composition and geographical location.

For the 25–29 year group, five-year survival varied considerably across the tumour groups. Five-year relative survival for many diagnostic groups such as germ cell tumours (98%) and melanoma (95%) was high and in line with international benchmarks. However, bone tumour survival for 25–29 year olds was just 31%. When combined with the 15–24 data, New Zealand bone tumour survival for 15–29 year olds was 46%, 20% lower than achieved in Australia during a comparable time period. Regardless of the model for service delivery across the age spectrum, the data provides compelling evidence of the need for a coordinated national approach to improve the outcomes for those AYA diagnosed with this rare and complex group of tumours. In addition, poorer survival outcomes were identified for AYA with breast cancer. New Zealand’s five-year relative survival for AYA 15–29 years diagnosed with breast carcinomas was 64%, while Australia, the US and Germany all reported survival of over 80% for a similar time period.

This analysis showed that overall survival for Māori and Pacific 25–29 year olds diagnosed with cancer is lower than that for non-Māori/non-Pacific peoples. However, the small number of cases has restricted ethnic comparisons at a diagnostic group level and the survival disparities may be attributed, in part, to the different patterns of cancer in our ethnic populations. When melanoma cases were excluded, five-year relative survival for Māori remained significantly poorer than for non-Māori/non-Pacific peoples. Combining the 25–29 year cohort with those aged 15–24 years provided a larger cohort and stronger evidence of five-year survival disparities for Māori 15–29 year olds compared with non-Māori/non-Pacific peoples, with differences of around 20% recorded for Māori diagnosed with bone tumours (33% c.f. 52%), CNS tumours (40% c.f. 65%) and leukaemias (53% c.f. 73%). Māori women appear to be at higher risk of both developing breast cancer in young adulthood as well as dying of their disease (five-year survival: 43% c.f. 69%).
These ethnic survival disparities may be multifactorial, and include delays in diagnosis, differential access to treatment or possible biological differences.\textsuperscript{25} For example, studies in the US have shown that survival is poorer for Black AYAs diagnosed with breast cancer compared to Whites, that Blacks diagnosed with breast cancer are much more likely to have triple-negative breast cancer than Whites and that reception of treatment among AYAs with breast cancer varies by ethnicity.\textsuperscript{26–27} Although it was beyond the scope of the present study, future qualitative and quantitative research is needed in order to explore such factors as cytogenetics, disease staging at presentation, referral pathways, treatment adherence and access to culturally appropriate psychosocial support, which may explain and address the ethnic survival disparities which were identified.

Widening New Zealand’s definition of AYA from its current 12–24 years to 12–29 years potentially has resource implications. Based on the 2000–2009 cancer registrations, the number of patients eligible for support from AYA cancer services, such as Key Worker coordination, would increase by 84%, although this would be lessened if simple treatable cancers such as localised melanoma were excluded. The national standards for the care of AYA with cancer, launched by the AYA Cancer Network in May 2017, describe the standard of care that all AYA are entitled to receive from the time of their diagnosis to well beyond treatment.\textsuperscript{28} Given that the AYA Cancer Network Aotearoa has only recently been established and already has a number of priorities, a case could be made for focusing only on improving cancer services for patients aged 12–24 years. However, many of the AYA standards, such as encouraging the harmonisation of treatment approaches with evidence-based treatment protocols and improving access to appropriate clinical trials, may also benefit 25–29 year olds without necessarily having a manifest impact on clinical workloads.

There is evidence for the AYA population that enrolment in open clinical trials, or treatment of specific diseases—such as acute leukaemia and sarcomas—according to paediatric rather than adult protocols, confers overall survival advantages.\textsuperscript{29,30} Yet access and enrolment on open collaborative clinical trials in the AYA age group has historically been poor. In contrast to the AYA experience, children with cancer have benefited greatly from access to international collaborative clinical trials leading to a progressive improvement in overall survival over the last 30 years. The two paediatric oncology units in Auckland and Christchurch are members of multiple international clinical trials consortia, including the US-based Children’s Oncology Group and many European disease-specific clinical trials groups. Many clinical trials available in New Zealand for children and adolescents include extended age ranges into the adult age group; COG clinical trials for leukaemia, lymphoma, solid and brain tumours are typically eligible for patients up to 29 years while the current European Ewing Sarcoma trial (EE08) is open to patients aged up to 50 years.

Unfortunately, many barriers currently exist that limit the ability of adult cancer centres to enrol patients onto these trials outside the two children’s cancer centres. Low likely annual accrual often precludes membership to the trials group or renders the huge resource involved with opening and recruiting to an individual trial difficult to justify in an existing clinical research programme. Equally, barriers exist for paediatric institutions opening adult cooperative group trials. Recently the US National Cancer Trials Network (NCTN) system, which is a US-Government supported cancer collaborative group trials programme run through the National Cancer Institute, has moved to allow centres that have membership to the NCTN via a particular collaborative group (COG or one of four adult groups) to open studies that are run by the other groups. The rationale for this is to increase access for AYA. Given the same institutional barriers currently exist for patients aged 25–29 years as for younger AYA, initiatives by the AYA Cancer Network to facilitate AYA participation in international collaborative clinical trials are likely to also directly benefit 25–29 year olds. Similarly, cancer prevention and symptom awareness campaigns which target young people and their primary healthcare providers may also lead to earlier diagnosis and improved survival outcomes for this older AYA group.
Clinicians in adult cancer services are highly experienced in treating the melanomas and carcinomas, which together account for 58% of cancers diagnosed in the 25–29 population, yet they may be less familiar in addressing the complex psychosocial needs of this patient group given that they account for such a small proportion of their overall caseload. Conversely, the majority of 12–14 year olds have a paediatric cancer and are cared for under child cancer services, which already provide comprehensive psychosocial wrap-around care. Given that there is no evidence of survival disparities for 12–14 year olds, there is some debate around whether AYA cancer services should continue to prioritise and resource the care of this age group. By not routinely supporting 12–14 year olds, resources would become available to provide additional support, such as access to AYA Key Workers, for those 25–29 year old cancer patients identified as high risk due to psychosocial or disease factors.

The main findings of this additional analysis of AYA aged 25–29 years are remarkably consistent with the findings from the earlier analysis of AYA aged 15–24 years; namely the poor survival for those young people diagnosed with bone sarcomas, and the poorer overall cancer survival for Māori and Pacific peoples. In addition, it provides evidence of poorer outcomes for young people, particularly Māori, diagnosed with breast cancer. The study highlights that although it may be more convenient from an organisational or research perspective to apply a chronological age range for AYA, it leads to the exclusion of patients who would benefit from being included in the AYA community. The data presents a compelling case for expanding the AYA upper age limit in New Zealand and applying a more flexible approach with regards to who can access AYA cancer services. A tiered model of service delivery for this age group could be considered, whereby the AYA Service Specifications prioritise clinical service delivery, such as Key Worker coordination, to the 15–24 year old age group and the AYA Cancer Network provide national oversight, advocacy, and strategic direction for cancer care for AYA aged 12–29 years.

Competing interests:
Dr Utley reports grants from The University of Otago during the conduct of the study.

Acknowledgements:
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Compassion from a palliative care perspective
Antonio Fernando, Conor Rea, Phillipa Malpas

ABSTRACT
BACKGROUND: Compassion is a core virtue in medicine and lies at the heart of good medical care. It connects us to each other and reflects our need for relationships with others.
AIM: Our aim is to explore how palliative care patients perceive, understand and experience compassion from health professionals, and to inform clinical practice.
METHODS: Seven hospice managers in the North Island of New Zealand were contacted and invited to join the study. Twenty participants expressed a desire to participate and were involved in semi-structured face-to-face interviews. A set of questions guided the interviewers with interviews lasting between 15–60 minutes.
RESULTS: In regards to the question, what is your understanding of compassion?, four central themes emerged: connection, presence and warmth, respect and caring. When asked, what advice can you give to trainee health professionals?, participants articulated four themes: connecting with patients and talking in a way they can understand, treating the person with respect, showing interest in them and being a positive presence for them.
CONCLUSIONS: Compassion was seen as a connection between the carer and the patient. Compassion is having a positive presence and warmth; an attitude of respect and caring. The main advice given by research participants to enhance compassion is for doctors and nurses to connect, to talk in a way that can be understood, and show interest and respect to patients facing the end of their lives.

Compassion is a core virtue in medicine and lies at the heart of good medical care. Its Latin derivation translates as, “with suffering”, thus compassion has a cognitive component; “it requires an imaginative indwelling into the condition of another, requiring identification with the victim” and suggests more than mere acts of basic care. In addition to cognitive and emotional perspective taking, compassion involves the additional step of wanting to alleviate suffering. It is “humble and powerful”, as an emotion, and requires a “complex subtextivity on the part of both the physician and patient”. Housset describes compassion “as the respectful awareness of being touched by the other person’s suffering”. Linked to sympathy and empathy, compassion connects us to each other and reflects our need for relationships with others.

Many professional codes of practice and standards of conduct are founded on the principles of trust, respect, dignity and compassion. Compassionate care improves health outcomes and patients’ care experiences. Bramley and Matiti explored patients’ experiences of compassion within nursing care and found that when nurses’ empathetic behaviour was felt by patients, the positive impact on overall wellbeing was clear. One patient spoke of her isolation in a side room and how speaking with a nurse about her isolation “just made me feel so much better”. Conversely, a lack of compassionate care can exacerbate existential neglect and increase suffering as was evidenced in the Mid Staffordshire NHS Trust report that highlighted the “appalling suffering of many patients”. One of the recommendations of the report called for the Nursing and Midwifery Council to consider an aptitude test to be undertaken by aspirant nurses that would explore “attitudes towards caring, compassion and other necessary professional values”.

ARTICLE
In discussing his diagnosis of malignant mesothelioma at age 57, Sweeney\textsuperscript{20} describes a sense of dislocation, lack of care, “one is left with the feeling that the professional does not care about me”, and isolation—“What I have always feared in illness was anonymity, being packaged, losing control, not being able to say ‘this is who I am’. In the end, one is left alone, here, in the kingdom of the sick.”

Compassionate care at the end of life is central to dying well. It encompasses listening and spending time with the patient, empathetic rapport and bedside manner, listening and respecting patients, and helping patients manage the hospital environment.\textsuperscript{21–23} A number of studies have explored patients’ perceptions of their care;\textsuperscript{24,25} care from the perspective of health professionals\textsuperscript{26–28} and compassion fatigue among health professionals.\textsuperscript{29–31} As far as we are aware, no studies have addressed the concept of compassion solely from the perspective of palliative care patients. All patients deserve compassionate care but more so at the end of life when patients are vulnerable, often isolated, suffering emotionally and physically and are facing imminent death. Such patients offer important insights, which may assist in optimising their quality of life until death by addressing their physical, psychosocial, spiritual and cultural needs.\textsuperscript{32}

The aim of our study was to explore how palliative care patients perceive, understand and experience compassion from health professionals, and to inform clinical practice.

Method

Setting/participants

Seven hospice managers in the North Island of New Zealand were contacted and invited to join the study. The research team discussed with the hospices the plans and aim of the study, the rationale for the research and the requirements of the hospice involved. While four hospices agreed to participate in the study, most participants came from the first hospice that signed up for the study. Nurse coordinators contacted eligible participants who were advanced palliative care patients, gave them a copy of the participant information sheet and the consent form and then emailed the researchers with the willing participants’ name, contact number(s) and diagnosis. Twenty-seven agreed to be initially contacted by the research team by phone while 21 individuals indicated their desire to be involved; one person refused when she realised she knew of one of the researchers so she was excluded in the final list of participants. Ethical approval was sought and gained by the University of Auckland Human Participants Ethics Committee (UAHPEC) for three years (Reference number 013082). As per committee requirements, all participant information collected was anonymised, and transcribed interviews stored securely on password-protected computers. Involvement in the study was voluntary and individuals gave their written consent before interviews commenced. Participants were advised that they could stop the recording device at any time. The digital recordings and transcripts will be securely kept for a period of six years as per UAHPEC requirements. Recruitment of participants took place from November 2014 and January 2015.

The study population consisted of four males and 16 females with a mean age of 61.35 years. Fifteen participants identified as Pakeha/European descent, three identified as Asian, one as Māori/European and one participant was from the Pacific Islands. In terms of diagnoses, 18 participants had advanced, metastatic cancer, and two had end stage emphysema/COPD.

Eighteen interviews were conducted in the participants’ own homes. One was interviewed in the hospice and another participant in an interview room at the University of Auckland. As per their preference, most participants were interviewed alone while five had a family member with them during the interview. Participants were given a $20 voucher as token of appreciation.

Data collection

Semi-structured face-to-face interviews were undertaken. AF and CR conducted the interview process. No relationship was established with participants prior to study commencement. A set of questions guided the interviewers (See Table 1), however the style of the interview was conversational, allowing deviations from the key questions to capture a richer perspective of compassion from participants. Participants were interviewed once lasting between 15–60 minutes with the interviews averaging around 30 minutes. Each interview was digitally recorded on two recording devices.
Data analysis

Thematic analysis was employed as a research tool because it gives a rich and detailed account of complex data. Such an approach allows for the identification of central thematic categories from interview data related to participants’ understandings of compassion, their experiences of compassionate care and experiences of a lack of compassion. Analysis of the dataset was undertaken by AF, CR and PJM. The researchers independently immersed themselves in the verbatim interview transcripts, noting down how prevalent themes were articulated by participants as well as repeated patterns which resulted in potential coding themes. During subsequent meetings these were discussed and debated until final themes were confirmed. This ensured a rigorous and consistent method of analysis. The research team followed the COREQ protocol for reporting of qualitative data.

Results

What is your understanding of compassion?

Four central themes emerged from analysis of the interview transcripts: connection, presence and warmth, respect and caring. A number of sub-themes emerged throughout the refinement process and provided structure and support to the themes identified. Although we distinguish the four themes as separate groupings for ease of comprehension, they are intimately woven together and in fact cannot be seen as wholly separate from each other.

Connection

Within the theme of connection, several subthemes emerged, including understanding, empathy and sympathy. The connection between participants and doctors and nurses was often exemplified by their strong relationships and the depth of sharing they experienced. The connection was seen as an intellectual ('I understand') and emotional ('I feel') state. It bound the patient and health professional together. This was powerfully illuminated by the participant who spoke about the registrar she had never met who, when she walked into the room said:

“I've just been reading your notes, you've had a terrible year. And you know to me I just thought, oh you, I could feel that connection, like she had really read the notes and understood it.” (Female, 58 years, European)

Being able to identify with the participant by understanding their situation and connecting with them through physical touch were articulated as part of what it is to be compassionate;

“…it's somebody who can empathise, try and put themselves in another person's shoes. From the point of view of trying to care for that person…” (Female, 75 years, European)

“…the big difference is those who touch you, strange as it sounds, they just don't have to say anything. Come in and put the hand on your back, rub your arm, sometimes hold your hand and say ‘how are you feeling today’ and things?” (Male, 73 years, European)

Presence and warmth

The subthemes providing structure to this theme included, being positive, uplifting, warm-heartedness and friendliness.

<table>
<thead>
<tr>
<th>Table 1: Interview schedule.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is your understanding of compassion?</strong></td>
</tr>
<tr>
<td><strong>Have you experienced a health professional who was compassionate?</strong></td>
</tr>
<tr>
<td>• Can you tell me about that experience?</td>
</tr>
<tr>
<td>• In what way did that person show compassion?</td>
</tr>
<tr>
<td><strong>Have you experienced a health professional who showed a lack of compassion?</strong></td>
</tr>
<tr>
<td>• Can you tell me about that experience?</td>
</tr>
<tr>
<td><strong>Do you have any advice to doctors or nurses about compassion?</strong></td>
</tr>
<tr>
<td><strong>Why is compassion important to you as a patient?</strong></td>
</tr>
</tbody>
</table>
For many participants, compassion was a felt presence of a professional who was pleased to see them, was sincere and was there for them. Sometimes compassion was as simple as a smile or sharing a joke.

“...he is always happy to see you... he never acts as if there is anything else he needs to do, except see you”. (Female, 48 years, European)

“...he is warm, his aura is really lovely you know. He greets you with a smile every time and he will chuckle away with you”. (Female, 47 years, European)

Respect
A number of subthemes were identified and included, being heard and being listened to, professionalism, non-judgemental, being valued as a full person, honesty and openness, eye contact and dignity.

Being attentive to the varied challenges arising for participants as they faced the enormity of their situation was central to their understanding of compassion. Several participants spoke of the importance of being treated as intelligent individuals and not merely as a medical condition or a number.

“I am respected for who I am not because I have got cancer or because I am undergoing chemotherapy. I'm just respected for being”. (Female, 46 years, European)

“It's people being honest with you. Not treating you as if you are an idiot. It's people that treat me with respect, people who give me information. People who give me time to ask questions”. (Female, 46 years, European)

For others, compassion was demonstrated by being fully present in the encounter and being on time.

“He is very, very caring, and he is never late for his appointments...because you know the worst thing you can do is go to the doctors and sit down and wait for three quarters of an hour”. (Female, 69 years, European)

Caring
Caring was a complex theme that incorporated a number of subthemes, including encouragement, reassurance, support, comfort, love, being the focus of care, commitment, responsiveness and sensitivity in relieving suffering.

When participants were asked their understanding of compassion, many spoke of it as entailing care. Care reflected attention and sensitivity to the moment.

It was about comfort and encouragement when life was difficult and circumstances required support. Participants often gave examples of care that involved kindness;

“We just chat about things and they put their arm around me when I am crying”. (Female, 69 years, European)

and sensitivity in the relief of suffering;

“I got cramp in my legs and he went down on his knees on the floor in his surgical gumboots, massaging my calves to make me comfortable”. (Female, 55 years, European)

Have you experienced a health professional who was compassionate?
When asked this question, many participants immediately gave an example of what compassionate entailed.

“I was dealing with this stoma and they were teaching me whilst I was in hospital how to manage it. And sometimes I would have blowouts like you wouldn't believe. And I was virtually lying in it. And those lovely nurses that were there, they had to clean me up. I thought if those people can do that for me I will never complain again, so that really touched me”. (Male, 73 years, Māori)

A compassionate nurse who exemplified the qualities of kindness and thoughtfulness, and whose action was supererogatory in nature was articulated by one woman who said:

“Oh there was yes one nurse. Because when I got admitted I didn’t have any hair, and it was winter time. And it was cold. And I asked them if they had any head gear because I just gone in. And there was nothing on the ward but one of the nurses went down to her car and she had a knitted cap which she brought up to me, and that to me that was really compassionate”. (Female, 75 years, European)

Have you experienced a health professional who showed a lack of compassion?
Participants recalled situations when they felt rushed, devalued, dismissed and misunderstood by health professionals. Struggling to understand what was being said and feeling that one wasn’t being listened to also typified some experiences where a lack of compassion was revealed by participants.

One man recounted the conversation he had with the oncologist who;
“…tells me I’m going to, my hair’s going to fall out and this is going to happen. Chemo's going to work for a while and then you’re going to be dropping dead in December. I said ‘thank you very much mate’”. (Male, 60 years, European)

Another participant recounts the situation of a man in his ward who was having difficulty breathing;

“And I could tell what he was going through and the nurses they knew he was going to die. But she didn’t touch him. She just sat there, she might as well have been knitting, watching him die. And I got really angry”. (Male, 73 years, European)

Both compellingly communicate their sense of frustration and anger at the lack of compassion.

What advice can you give to trainee health professionals?

Four themes emerged from the data and underpin the importance of connecting with patients and talking in a way they can understand, treating the person with respect, showing interest in them and being a positive presence for them. These were central to the advice given to trainee health professionals.

“Just try not to be judgemental because you really don't know what has gone on in that person's life and how they have gotten to this point”. (Female, 60 years, European)

“Don’t be too quick, take time to communicate with the patient”. (Female, 70 years, Asian)

They need to “look after their own well-being so that they don’t become needy themselves”. (Female, 48 years, European)

Why is compassion important?

By far the most significant answer given in response to this question was that health professionals recognise the vulnerability of patients near the end of life. Participants spoke of needing guidance and help along the dying trajectory and what to expect as death approached. Feeling safe, relaxed and comfortable, as well as being encouraged were also articulated by participants.

“…you are just a number that's how you feel and you feel just a number. And you are not a number. You are a person and you have got feelings and you know you have got this terrible illness that you know you are not going to live through it”. (Female, 69 years, European)

“When you have cancer, especially in a metastatic situation you need to feel loved and cared for. You need that. You need to know that somebody really does give a damn”. (Female, 47 years, European)

“(compassion) it is a free service…and it can make such a difference if you...but it's got nothing to do with a medical outcome but often it's what you remember”. (Female, 48 years, European)

Discussion

Compassion is an expectation in the medical care of all patients. Specifically palliative care patients, who are especially vulnerable as they face imminent death, need genuine compassionate care. Though there is a need to explore palliative care patients' perspectives of compassionate care, there are no studies to date that inquired of these patients' voices regarding compassion. This study addresses this gap in knowledge by exploring how palliative care patients understood and experienced compassion from health professionals. They also shared their insights as to how doctors and nurses can become more compassionate.

In this study, several themes of compassionate care emerged. Compassion was seen as a connection between the carer and the patient. Compassion is having a positive presence and warmth; an attitude of respect and caring. All the participants in this study witnessed and experienced compassionate care towards them from doctors and nurses. Most have also seen or experienced health professionals who showed lack of compassion where they felt devalued, not listened to or just plainly ignored. The main advice given by research participants to enhance compassion is for doctors and nurses to connect, to talk in a way that can be understood and show interest and respect to patients facing the end of their lives.

Our findings are very similar to results reported from previous research on hospital patients and a mixed sample of older patients with chronic diseases. The themes of caring, being treated as a person instead of a checklist, and clinicians making time or being available to patients were also mirrored in previous studies. The simple act of a physical connection by means of touch was also seen as a powerful way of showing compassion. A further study mentioned the experience of positive presence and warmth by the clinician.
positive presence is a patient's perception that the clinician chooses to be there, and to consciously and quietly be with the patient. Compared to other descriptors of compassion, presence and warmth are harder to operationalise and appear less concrete, but patients cherish and emphasise these experiences.

As expected in this study, examples of lack of compassion from clinicians and nurses are the antithesis of participants' experiences of compassion. Participants talked about not being valued, not being listened to or simply being ignored. Similarly, a previous study noted staff making elderly patients wait to use the toilet because of staff shortages as an example of lack of compassion. The issue of not giving time in the current healthcare climate is complicated because of competing pressures to see more patients while spending more time performing administrative work and documentation. However, while participants in a previous study understood that staff are pressured timewise, patients said that a compassionate act can be fleeting and not necessarily time consuming.

In the Transactional Model of Compassion, compassion and barriers to compassion are seen as emergent from dynamic but interrelated influences of clinician, patient and system factors. In this and previous studies, patients focused only on the clinician: those clinicians who were seen as dismissive, not listening, uncaring and not involved. Patients in this study did not mention other factors that may contribute to a lack of compassion, including system issues (e.g., a chaotic ward environment or a busy ICU) and difficult patients and families. Systemic factors, particularly the busy nature of the clinical job, were identified in a previous study as an issue that prevents clinicians from giving time.

In relation to the current two-fold definition of compassionate care, that is, empathy or perspective taking with subsequent relief of suffering, patients in this study viewed compassion in a broader sense. They talked about compassion as involving a particular quality of relationship which is warm with a positive presence and respect, which may not necessarily be part of pain or symptom relief. They also talked about an interaction which involved connection and care. Compassion “can be as quick and as easy as a gentle look or a reassuring touch”. With this in mind, a more nuanced description of medical compassion is an emotional and/or cognitive perspective, with a motivation to relieve suffering in a caring manner.

Conclusion

This is the first study we are aware of that explored how palliative care patients perceive, understand and experience compassion from health professionals, and how these understandings may inform clinical practice. It is well known that in most industrialised countries, the population is rapidly aging, highlighting the importance and significance of end of life services. Though compassion is central to dying well, practicing compassion is “free” and cost neutral, will benefit patients at the end of life, as well as their families and potentially the clinicians themselves.

In terms of limitations, the study is not generalisable to the palliative care population because we only focused on a small sector of patients who were under hospice services. Despite the study being open to all palliative care patients within the hospices approached, the average age of participants was 61 years, thus we did not hear from younger patients who may have had different perspectives on compassion and compassionate care. Even though several hospices within the greater metropolitan Auckland area were approached, most patients came from one hospice where the nurse coordinator was very organised and efficient in recruitment. The sample was not ethnically diverse, with the majority of participants identifying as New Zealand European. As our study was undertaken in urban areas it did not encompass patients in some rural areas that may not have access to hospice services. We suggest further research incorporating these factors be undertaken.

Strengths of the study include its focus on a specific, very vulnerable patient population whose voice on compassion has not been heard. The data was rich and clear themes emerged, which were consistent with previous studies. The findings add to our knowledge of what is important to patients facing the end of their lives within the context of compassion and compassionate care.
Competing interests:
Nil.

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Increasing rates of people identifying as transgender presenting to Endocrine Services in the Wellington region

John W Delahunt, Hayley J Denison, Dalice A Sim, Jemima J Bullock, Jeremy D Krebs

ABSTRACT

AIMS: Overseas clinics specialising in management of transgender people have noted a marked increase in the numbers of people requesting therapy in the last few years. No data has been presented for New Zealand. We therefore reviewed the number of transgender people seen in the Wellington Endocrine Service to assess if the pattern was similar and assess any potential problems for service delivery.

METHODS: Using hospital records, we reviewed the new appointments of people who were referred for advice on gender reassignment and seen in the Wellington Endocrine Service from 1990 to 2016.

RESULTS: In total, 438 people who identified as transgender attended the clinic at least once in this period. There has been a progressive increase in number of people identifying as transgender presenting to the clinic, particularly since 2010. In addition to increasing overall numbers, there has been in particular increase in referrals for people under age 30, as well as an increasing proportion of people requesting female-to-male (FtM) therapy so that it is now approaching the number of people requesting male-to-female therapy (MtF).

CONCLUSION: The pattern observed is comparable to changes reported overseas. These changes have practical consequences for the delivery of both secondary and primary level healthcare, requiring an increased focus on clinical coordination between the relevant medical services and their links to the primary services sector.

The sense of gender identity develops separately to sexual orientation and the external genitalia, and develops to differing degrees between individuals. Neuroanatomic (nervous system structures including brain anatomy) differences between genders develop at an early age and are reinforced by behavioural and endocrine changes in childhood and adolescence. There is also evidence of genetic contribution to gender behaviours.

Transgender is a term used to describe when an individual’s sense of gender identity does not correspond with their birth sex. Gender affirmation treatment may include hormone therapy and gender affirming surgery to develop the physical characteristics of the affirmed gender, and guidelines for assessment and treatment are available. The ‘non-binary’ nature of gender identity is well recognised; not all people with feelings of gender incongruence identify completely with a single gender role, and may not want medical or surgical therapy.

Initial estimates of the prevalence of people identifying as transgender were taken from the experience of specialist transgender clinics internationally. They provided estimated rates in the order of 1/37,000 of the general population for male to female (MtF) and 1/100,000 for female to male (FtM), and an annual incidence of people who identified as transgender of about 0.15/100,000 population.
More recently, population surveys have suggested a much higher and increasing incidence of transgender identity in adults and adolescents.10,11 A telephone survey of households in Massachusetts found 0.5% of 28,000 respondents identified themselves as transgender.12 Data from the American Behavioral Risk Factor Surveillance System (BRFSS) taken from 19 States and one Territory in 2014 found 0.53% of their population identified as transgender (95% confidence intervals 0.46, 0.61) with MtF 0.28%, FtM 0.16%, ‘gender nonconforming’ 0.08%.13 Kuyper et al analysed data from an online Dutch Sexual Health population study conducted in 2012.3 There were 8,064 participants aged between 15 and 70 years included in the gender assessment analysis. Of the natal men (people who were assigned male at birth), 1.1% had gender incongruence (with a stronger identification with the cross-natal gender) while 4.6% were ambivalent towards their natal gender (having an equal identity between the two genders). Of the natal women, 0.8% were gender incongruent, 3.2% gender ambivalent. A fifth of those who were ambivalent about their gender also disliked their body but only one half of these natal men and a quarter of these natal women wanted therapy to change their appearance.3

There has not been a formal study of the prevalence of transgender identity in the general or adolescent population in New Zealand.11,14 However, the Youth ’12 survey of 8,166 teenagers in Auckland included a question on sense of gender. Overall, 1.2% reported being transgender, 2.5% reported being not sure about their gender and 1.7% reported that they did not understand the question.15 Other than this study, there are few data on the prevalence of people identifying as transgender in New Zealand, and no indication as to whether the prevalence is increasing as it is in other countries. Statistics New Zealand is proposing to introduce items related to gender identity in the 2018 census questionnaire.16 We were aware of an increase in referrals in Wellington. The aim of this study was to examine the temporal trends in referral patterns for transgender in the greater Wellington region and identify any potential problems for service delivery.

Method

We reviewed the new appointments of people who were referred for advice on gender reassignment hormone therapy and seen in the Wellington Endocrine Service for Capital & Coast District Health Board (DHB) from January 1990 to the end of 2016. These included people referred from outside the Capital & Coast DHB region, principally from the adjacent Hutt Valley DHB. Data from an in-house audit of transgender referral numbers indicates that around a quarter of people were referred from the Hutt Valley DHB and less than 5% were referred from other regions.17 We did not include people from the Hutt Valley who are managed in their local Endocrine service, though this number will be small. The combined Wellington and Hutt Valley population is about 470,000.18

People who identified as transgender and attended the Wellington Endocrine Service were identified by separate methods over three time-periods. This was primarily because of changes in patient record systems over the 26-year time period (paper to electronic). Prior to 2006, the Wellington Endocrine Service kept paper records of all outpatient appointments on site. The clinic consultant (JWD) and a charge nurse independently extracted the relevant data using these outpatient lists and matched these to the confidential files.

In June 2006 a new patient management IT system was introduced, and so for the next period (June 2006 to May 2013) relevant records were identified from the patient management software records using the key words: ‘gender’; ‘gender’ with descriptors (assessment, reassessment, identity, etc), specifically ‘gender dysphoria’, ‘transgender’, ‘transsexual’, ‘transsexual’, ‘transvestite’ and these words repeated as nouns (‘ism’). The results were cross-checked with the Endocrine clinic confidential record folders which had been kept for transgender outpatients. The few additional records found were included in the data extraction.

A prospective record of referrals has been kept separate from the hospital electronic files from January 2013. These have been used to complete the study period.
People who identified as transgender were recorded for their first visit, or year of referral if seen in the following year. Due to increased numbers, some people referred in 2015 were not seen until 2016, and some referred in 2016 were seen in 2017. For those people who had been referred but not seen in the current year, age was calculated for the day of referral, not the day of appointment.

We classified each person as seeking endocrine treatment for ‘male-to-female’ (MtF) or ‘female-to-male’ (FtM) change. This includes individuals who were not seeking complete gender transition, and who may identify as ‘non-binary’. All people attending for hormone therapy to modify their biological sex, or help support their awareness of self in a cross gender identity, were included. We have not included data on ancillary diagnoses or the outcome of therapy.

### Results

The number of people who identified as transgender presenting to Endocrine outpatients for each year is given in Table 1 and Figure 1. In total, 438 people who identified as transgender attended the clinic at least once over the interval 1990 to end of 2016 (Table 1).

**Table 1:** Number of people identifying as transgender presenting to the Wellington Endocrine Service each year (1990 to end of 2016).

<table>
<thead>
<tr>
<th>Year</th>
<th>Male to female</th>
<th>Female to male</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Median age</td>
<td>Minimum age</td>
</tr>
<tr>
<td>1990</td>
<td>2</td>
<td>27.9</td>
<td>19.3</td>
</tr>
<tr>
<td>1991</td>
<td>7</td>
<td>23.8</td>
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<tr>
<td>1992</td>
<td>4</td>
<td>20.7</td>
<td>17.5</td>
</tr>
<tr>
<td>1993</td>
<td>0</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>1994</td>
<td>2</td>
<td>22.2</td>
<td>17.7</td>
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<td>1995</td>
<td>7</td>
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</tr>
<tr>
<td>1996</td>
<td>3</td>
<td>29.3</td>
<td>21.7</td>
</tr>
<tr>
<td>1997</td>
<td>3</td>
<td>36.0</td>
<td>18.9</td>
</tr>
<tr>
<td>1998</td>
<td>5</td>
<td>30.6</td>
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<tr>
<td>2016</td>
<td>51</td>
<td>25.6</td>
<td>17.4</td>
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<tr>
<td>Totals</td>
<td>290</td>
<td>148</td>
<td>438</td>
</tr>
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Since about 2000, and particularly since 2010, there has been a progressive increase in the number of people identifying as transgender presenting to the clinic (Figure 1A and 1B). This pattern is observed for both groups (MtF and FtM). In 2000 to 2007, annual first attendance rates were between eight and 15 people who identified as transgender. In 2016, the total number of referrals of people who identified as transgender totalled 92 (51 MtF, 41 FtM).

In addition to increasing overall numbers, there has been a particular increase in referrals both for people who identified as transgender under age 20 and for those in the middle age bracket (20 to 30 years) (Figures 1A and 1B). While there had been a variable increase in the absolute numbers for each age bracket, including a similar trend for those older than 30, the proportion of people who were in the oldest age group became less for each year. Specifically...
considering referrals for people less than age 18, prior to 2012 there had been 12 MtF, five FtM cases and after 2011 there were eight MtF and seven FtM.

These data are further summarised in Table 2. In absolute and percentage terms for the proportions of subjects in each age group, the greatest increase was in the combined young adult (20 to 30 years) groups. To assess if there was a significant change in age of people presenting, a time point of 31 December 2011 was chosen around which to compare the data. The proportions of people in each age group are statistically significantly different between the time periods, as assessed by Pearson's Chi squared tests (Table 2). Repeated analyses using the proportions around the previous two and subsequent one year did not significantly change the statistical results (data not shown).

Prior to 2002, few people presenting to the Endocrine service identified as FtM (about one person each year). This was lower than the number of people who identified as MtF presenting each year (around five people). Between 2002 and 2009, this number began to increase so that there were about one to four people who identified as FtM annually. Since 2012, there has been a proportionately greater increase in the number of people who identified as FtM, now approaching the number of people identifying as MtF, with the ratio over the previous five years now 1.37:1.

These numbers represent a small component of a general endocrine new patient clinic case numbers in Wellington. Over the period 2006 to 2013, 2.8% of new Endocrine referrals were for transgender outpatients. In 2016, 6.8% of new people who identified as transgender seen in Endocrine outpatients (excluding diabetes) were attending for gender reassignment hormone therapy.

Table 2: Age-groups of people presenting to the Wellington Endocrine Services before and after 31 December 2011.

<table>
<thead>
<tr>
<th>Age group</th>
<th>Time period n (%)</th>
<th>Chi-squared statistic (df)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Before 2012</td>
<td>2012 and after</td>
<td></td>
</tr>
<tr>
<td>MtF and FtM combined</td>
<td>195 (54.4)</td>
<td>242 (30.3)</td>
<td>28.598 (2)</td>
</tr>
<tr>
<td>&lt;20 years</td>
<td>30 (15.4)</td>
<td>56 (23.1)</td>
<td></td>
</tr>
<tr>
<td>20–30 years</td>
<td>59 (30.3)</td>
<td>116 (47.9)</td>
<td></td>
</tr>
<tr>
<td>&gt;30 years</td>
<td>106 (54.4)</td>
<td>70 (28.9)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>149 (54.4)</td>
<td>141 (30.3)</td>
<td></td>
</tr>
<tr>
<td>MtF only</td>
<td>15.568 (2)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>&lt;20 years</td>
<td>20 (30.4)</td>
<td>26 (18.4)</td>
<td></td>
</tr>
<tr>
<td>20–30 years</td>
<td>43 (28.9)</td>
<td>66 (46.8)</td>
<td></td>
</tr>
<tr>
<td>&gt;30 years</td>
<td>86 (57.7)</td>
<td>49 (34.8)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>149 (54.4)</td>
<td>141 (30.3)</td>
<td></td>
</tr>
<tr>
<td>FtM only</td>
<td>8.094 (2)</td>
<td>0.017</td>
<td></td>
</tr>
<tr>
<td>&lt;20 years</td>
<td>10 (21.7)</td>
<td>30 (29.7)</td>
<td></td>
</tr>
<tr>
<td>20–30 years</td>
<td>16 (34.8)</td>
<td>50 (49.5)</td>
<td></td>
</tr>
<tr>
<td>&gt;30 years</td>
<td>20 (43.5)</td>
<td>21 (20.8)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>46 (30.3)</td>
<td>101 (23.1)</td>
<td></td>
</tr>
</tbody>
</table>

MtF = male-to-female.
FtM = female-to-male.
Discussion

Our study is the first to assess trends in transgender presentation to an endocrine service in New Zealand, and thus contributes new data to the international discussion. Our results demonstrate increase in the number of people identifying as transgender presenting to services for treatment, particularly among the young adult age-group, as well an increasing proportion of FtM persons. The increasing numbers of transgender and non-binary young people has significant implications for health-providers involved with the care of these individuals, particularly with regard to expertise, experience and access to training, for this age group.

An increasing rate of presentation at younger ages and a change in the proportion of people presenting as MtF and FtM has been recognised in major centres overseas. Leinung et al reviewed their experience in New York with 140 transgender people, finding a stepwise increase in referrals over the three five-year intervals with an increase in FtM proportion. There was a reducing age at referral from a median age of 40 years initially to 30 years in 2009, with the details of scatter of ages not listed.

Judge et al reported on their clinic experience in Ireland from 2005 to 2014 with 218 patients showing a pattern comparable to our own, with an increase in referrals year on year, from six people who identified as transgender in 2005 to 55 in 2013.

Specialist clinics for transgender children and adolescents have included Aitken et al who reported results from two clinics (in Toronto and in Amsterdam). There were 748 people who identified as transgender in all, with annual referrals increasing progressively from about 2003 to 2013. There was also a change in the proportions of MtF and FtM people, with a MtF preponderance before 2006 and a FtM preponderance over 2006–2013. Wood et al also reported an increase in referrals to a specialist child and adolescent psychiatry clinic in New York.

While other studies have found an increase in adolescent individuals presenting, we are not aware of comparable data showing an increase in presentation in young adults (the 20 to 30 age group). The people in this age group include a few established transmen and transwomen who have moved to Wellington from other regions. The other people newly presenting may represent a group of adolescents who have delayed their decision to seek help, or reflect a general increase in referrals from all ages.

Although we have detected an obvious rising trend in the number of people who identify as transgender presenting to our services, we cannot predict the future incidence of case presentation. The prevalence of self-reported transgender identity among teenagers suggests there will be a continuing increase of individuals requesting advice or hormone therapy. The recently reported Statistical Standard for Gender Identity proposed by Statistics New Zealand will provide local and national perspectives on this data in the future. It is important to bear in mind that a significant proportion of adults with gender ambivalence or gender incongruence will not seek hormone or surgical therapy.

We did not study specific factors which have contributed to the change reported here. However, we can speculate on some probable contributing factors, some which are relevant internationally, and some which are specific to the Wellington Endocrine Services.

First, increasing presentation to services of people who identify as transgender seems likely to be related to the increasing societal awareness and acceptance of gender diversity. In addition, many people who identify as transgender attending our service report spending time searching the internet prior to referral, accessing mainstream information, others' experiences, and many have linked with other people who identify as transgender through internet discussion and support groups. Access to the internet and discussion with peers may affirm a sense of transgender identity, improve understanding regarding options and increase confidence, leading to requests for physical transition options.

It seems likely there is also an increasing awareness that a change of gender appearance is a practical option with hormone therapy. Some people may not be able to express their gender with confidence or safety without the benefits of hormone. Consequently, the previous requirement for a duration of ‘real-life-experience’ is no longer reinforced. Hormone therapy allows individuals to make a physical transition...
towards their affirmed gender at a time of their choosing, potentially minimising some of the social difficulties of transition. While the stages and doses of transgender hormone therapy should be adjusted for an individual’s requirements, endocrine therapy itself now has few difficulties.26–28

Since 2004, the primary sector has developed specialised general practises for adolescents, both in Wellington (2004) and the Hutt Valley (1996 then 2005). These provide counselling, support and group discussion for teenagers. Referral to the Endocrine Service has been a recognised, further step in management. There is also a drive for some GPs to receive specialist training in this field, to prescribe hormones therapy at the primary health level, with guidance from endocrinologists.

Historically, the Endocrinologists in Wellington have been prepared to accept referrals for consideration of hormone therapy in adults without assessment from a mental health professional,9 because resource constraints limited access to such assessments within the public health system. This was restricted to adults with a long-standing sense of gender incongruence. Generally they were started on a trial of low-dose hormone therapy pending a more formal psychosocial evaluation, when, and if, this became warranted.17 Data from our previous survey of clinicians in New Zealand suggests that this approach was not nationwide.29 Therefore, it may have resulted in disproportionately increased referrals in comparison. Data from other clinics in New Zealand would give an indication of whether these factors have influenced the increasing trend in presentation observed. Due to the exponential rise in referral rates to the Wellington Service, and changes in personnel including the recruitment of a clinical psychologist, the referral pathway has now been adjusted, including a comprehensive psychosocial assessment conducted within the Unit, prior to initiating hormone therapy.

The rising presentation of gender dysphoria and the complexities of issues faced by these individuals added to the increasingly younger age of presentation warrant development of multidisciplinary services, which should include primary care teams, mental health professionals, secondary endocrine, paediatric and ultimately a range of surgical specialists.20 Currently there is limited access to surgical services in the public sector in New Zealand and access to publicly-funded psychological assessment appears to vary by region, adding to the difficulties faced by individuals who identify as transgender seeking treatment.29

Decision making through the time of adolescence may not be equivalent to that in older people and may possibly respond to social context to a greater extent.14,31–32 Given that gender identity may alter or evolve over time, the therapeutic pathways which were developed for older transgender subjects may need revision for the teenage population.21,33 Transgender youth are at a higher risk for poor psychosocial health than their non-transgender peers. Numerous studies have found that transgender youth have a higher prevalence of behavioural and emotional problems, including anxiety, depression, self-harm and suicide than is expected in the general population.21,34–37 Access to psychosocial services is therefore crucial for providing holistic and comprehensive care for these individuals.20 In general, published studies discuss the recognised satisfactory outcomes for teenagers and adults in transgender programmes but do not provide data on people who might be counselled to defer transition, or who stop or are intermittently compliant on hormone therapy. Further, it is important to be aware that at present, developmental trajectories for transgender youth are not yet well understood due to the lack of robust research,14,21 and in providing a gender- affirming model of care we should not assume that individuals are necessarily seeking a complete gender change.8 While many gender non-conforming young people with or without gender dysphoria will go on to be transgender or have gender dysphoria as adults, others, particularly those presenting before puberty, will not.14,38,39 A better understanding of what may predict or influence these developmental trajectories is needed to aid clinicians in their treatment recommendations.14 A prospective audit of the outcome of transgender management in adolescents at, probably, five and 10 years also seems advisable.40
Limitations

We have no direct knowledge of the referral patterns in the other regions in New Zealand so that these results cannot be seen as representative of the practice in other regions, although in line with international experience we presume there has been a parallel increase of awareness of gender issues. Similarly, these data only capture referrals to the Endocrine Service; the Wellington Sexual Health Service (WSHS) also support people who identify as transgender, and Wellington Paediatric Endocrine service has seen people who identify as transgender, particularly presenting before age 16. In addition, the neighbouring DHB, Hutt Valley, have an endocrine unit which provides services for people who identify as transgender. It is possible that the increase we have observed is due to the referral pattern moving from one service to another over time. However, the WSHS is not a primary referral service for transgender management, and clinicians at the Wellington Paediatric Endocrine service and Hutt Valley DHB confirmed they had seen very few transgender cases over the most of the period of this audit, from 1990 to about 2013, and have retained a few in their clinics in the last 3–4 years (Esko Wiltshire, personal communication, 18 October 2017, and Raymond Bruce, personal communication, 17 October 2017).

We have not been able to confirm through an independent check of outpatient records that the people who identified as transgender in our records of former audits, prior to 2006, represent all those referrals who identified as transgender, although they were checked to the best of our ability at the time. This difficulty will not influence the changes reported since 2006, which have been monitored through both clinic and electronic records. The data for 2013 to 2016 have been recorded prospectively on referral, with the initial case assessment confirmed subsequently.

In conclusion, an increase in rates of referral provide a challenge to the health system in general and to clinicians to develop the skilset to support and select hormone therapy programmes for individuals seeking transgender services. An integrated and multidisciplinary approach, which includes primary care as well as secondary care Endocrine, Sexual Health, Mental Health and Paediatric services, is required.

Competing interests:
Nil.

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The effect of trampoline parks on presentations to the Christchurch Emergency Department

Lloyd Roffe, Scott Pearson, Johnathan Sharr, Michael Ardagh

ABSTRACT

AIMS: To analyse trampoline-related injuries suffered after the opening of two new trampoline parks in Christchurch.

METHODS: Data was collected from three 90-day periods. All trampoline-related injuries were collected from electronic documentation and coding. Those injured after both arenas opened were contacted and a semi-structured interview performed.

RESULTS: In the 90 days after both parks opened there were 602 claims for trampoline-related injuries with 106 hospital presentations (55% male). This was a significant increase (p<0.01) from one year earlier (333 claims, 37 hospital presentations) and the 90 days prior to their opening (201 claims, 15 hospital presentations). Most injuries affected an older group of children, aged between 10–14 years (26%, n=28), compared to the other two periods (p<0.01). There was also a greater proportion of lower-limb injuries (52%, n=55) compared to the other two periods (p<0.01). Thirty-six required hospital admission, with 29 operations and an average length of stay of 2.11 days. One trampoline park allowed two or more people to use the same trampoline at the same time, and had over twice as many presentations (33%, n=35) than the other trampoline park (14%, n=15).

CONCLUSIONS: Christchurch saw a significant increase in trampoline-related injuries after the opening of two new parks. These injuries involved an older group of children, affected predominantly the lower limbs and were more severe than those reported from the use of domestic trampolines. Consistent with past research, the trampoline park allowing multiple users had a higher proportion of presentations and more injuries requiring operative intervention.

For the young and those young at heart, trampolining is an enjoyable pastime. It has benefits for children; improving fitness, balance and motor performance. Trampoline parks have become a worldwide sensation since the first one was opened in Las Vegas in 2004. As of 2014 the International Association of Trampoline Parks (IATP) estimated there were 280 existing parks in North America alone. These parks vary but typically consist of single trampolines, foam pits and multiple ‘courts’—one or more trampolines adjoined to form one large surface which is surrounded by either walls or angled trampolines. Despite padding, initially ad hoc park rules and now defined (but voluntary) safety standards, injuries to patrons continue to occur—much like the history of trampolines in the home setting. The last review of trampoline use in New Zealand was completed 22 years ago by Chalmers et al, well before the popularity of trampoline parks. The authors audited a 10-year period and found trampoline-related injuries were increasing from 3.1 per 100,000 in 1979 to 9.3 per 100,000 in 1988. A recent Australian study showed that rates of trampoline-related injuries are continuing to increase. The authors found a 70.82% increase in trampoline injuries nationally across all age groups in the period 1 July 2002 to 30 June 2011.
that American emergency department presentations for injuries sustained at trampoline parks have been increasing between 2010 and 2014 with no change in home trampoline injury rates.\textsuperscript{6}

Factors identified to increase the risk of suffering an injury while using a trampoline include age, multiple simultaneous users and falling from the trampoline.\textsuperscript{7} Those aged five to nine years have the highest frequency of injury following trampoline use.\textsuperscript{5} Previous analysis of trampoline-related injuries in those under 16 years have found that approximately 80\% occurred on the trampoline, and between 60–80\% of those were with two or more children on it at one time.\textsuperscript{8–11} The risk of injury with multiple users is greater for the lighter playmate.\textsuperscript{12} Falling from a trampoline can cause severe injury and accounts for approximately a quarter of trampoline-related injuries.\textsuperscript{7,13,14}

Trampoline parks are a new and exciting trend for children (and adults), encouraging them to be active and engage with each other. There is currently little evidence assessing their injury profile and impact on communities. This study aims to assess the effect the opening of two new trampoline parks had on Christchurch Hospital Emergency Department attendance. A further aim is to analyse the types of injuries suffered, subsequent treatment and review relevant literature to provide recommendations for standards that should be followed in such large trampoline centres.

Figure 1: Timeline of Period A (20 August 2015–18 November 2015), B (21 May 2016–19 August 2016) and C (20 August 2016–18 November 2016). ‘X’ represents the opening of both trampoline parks.

Methods

This retrospective descriptive study was conducted at Christchurch Hospital, which is the major tertiary provider of healthcare to the Canterbury region in New Zealand. It services a population of 510,000 with 7.2\% Māori and 2.0\% Pacific Islander. In 2016, there were 300 trauma admissions to Christchurch Hospital. In New Zealand, major trauma is defined as a patient with an Injury Severity Score (ISS) of greater than 12.\textsuperscript{15} Christchurch Emergency Department attendance is approximately 95,000 presentations annually.

Three 90-day time periods were identified relative to the opening of both trampoline parks: Period A (control period; 20 August 2015–18 November 2015), the 90 days one year earlier; Period B (control period; 21 May 2016–19 August 2016) the 90 days prior to opening and; Period C (study period; 20 August 2016–18 November 2016), the 90 days after both parks had opened (Figure 1). Patients were eligible for inclusion in the study if they presented to hospital within any of the three periods after suffering a trampoline-related injury. A trampoline-related injury was classified as an injury the treating clinician directly attributed and coded to being secondary to the use of a trampoline. Patients were excluded if they were injured outside of the study periods, not injured because of trampoline use or injured outside of the Christchurch region.
To best capture all individuals who had suffered trampoline-related injuries, each period was analysed in a variety of ways. Firstly, the Canterbury District Health Board (CDHB) Decision Support Unit searched the diagnostic codes of all admitted patients, and the trauma type codes of all presentations to the emergency department, for ‘tramp’ or ‘trampoline’. All findings were then manually sorted to ensure those captured had presented after using a trampoline. From this information demographic (age and sex) data, injury diagnosis, injury treatment and length of hospital stay were collected. Secondly, the CDHB operating theatre booking system was used to manually review all orthopaedic operations conducted during each period and record those which involved patients who were injured during trampoline use. The only procedures undertaken on trampoline-related injuries during each period were orthopaedic other than one tooth extraction. This ensured to our best efforts that no major trauma requiring operative intervention would be missed from our data collection.

The Accident Compensation Corporation (ACC) of New Zealand is a publicly funded organisation that provides treatment for accidental injuries. The ACC is also involved in injury prevention strategies and recording statistics of accidental injuries in New Zealand. The ACC provided Christchurch-wide data for each period about all trampoline claims, all lower leg fracture claims in Christchurch and all trampoline and lower leg fracture claims in Christchurch.

Following local human ethics approval (New Zealand Northern A Regional Ethics Committee 17/NTA/1) information sheets were distributed to all those identified in Period C. One week after participants had received the information sheets they were then contacted via telephone. The primary contact as listed by each patient was used to identify either the patient or caregiver needed to complete the questionnaire. For those under the age of 16, parents were contacted if not listed as primary contact. Verbal consent was then acquired and a standardised dialogue was used to fill a questionnaire. The questionnaire collected additional data regarding location of injury, mechanism of injury, number of trampoline users at time of injury and the degree of adult supervision (Appendix 1).

Data collected was analysed using SAS 9.3 computer software. The data was skewed and therefore analysed using a non-parametric Kruskal-Wallis test to see if there was any overall difference among the three time periods. A p-value of 0.01 suggests such difference exists and hence multiple pairwise testing was done to further determine which pair dominates the detected differences. Bonferroni correction has been accounted for, so pairwise comparison is considered significant only if the p-value is less than 0.0167 (ie, 0.05/3).

Results

There were 602 trampoline-related ACC injury claims in Christchurch and 106 hospital presentations during Period C (both parks open). This was a significant increase (p<0.01) in comparison to both Period A (333 injury claims, 37 hospital presentations) and Period B (201 claims, 15 hospital presentations) (Table 1). All injuries sustained in Periods A and B occurred on domestic/home trampolines. There was a significant difference (p<0.01) in length of stay (LOS) between Period C and both Periods A and B (Table 1). Those injured in Period C who were admitted to hospital stayed for one additional day compared to the other two periods (Table 1). The following analysis applies to the 106 hospital presentations in Period C.

As reported in Table 1, of hospital presentations during Period C the median age was 13.5 years (IQR=8–21). This represented a significantly older population (p<0.01) than those in Period A (med=5) and Period B (med=11). Figure 1 shows the distribution of injuries involved an older population than those in Period A and B (p<0.01). In period C, most injuries occurred to those in the 10–14 years age group (26%, n=28). There was no significant difference (p=0.51) in sex among all periods with the overall proportion of males composing 52% (n=82/158) and females 48% (n=76/158) respectively.
Table 1: Hospital presentations by sex, age, admission, length of stay and anatomical location of injury during all three examined periods.

<table>
<thead>
<tr>
<th></th>
<th>Period A</th>
<th>Period B</th>
<th>Period C</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of cases</td>
<td>37 15%</td>
<td>15 10%</td>
<td>106 54%</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18 48.6%</td>
<td>6 40%</td>
<td>58 54.7%</td>
<td>0.51</td>
</tr>
<tr>
<td>Female</td>
<td>19 51.35%</td>
<td>9 60%</td>
<td>48 45.28%</td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>5 (4–12)</td>
<td>11 (4–13)</td>
<td>13.5 (8–21)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Range</td>
<td>1–24</td>
<td>1–41</td>
<td>1–44</td>
<td></td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–4</td>
<td>17 45.95%</td>
<td>4 26.66%</td>
<td>15 14.15%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>5–9</td>
<td>7 18.92%</td>
<td>2 13.33%</td>
<td>16 15.09%</td>
<td></td>
</tr>
<tr>
<td>10–14</td>
<td>8 21.62%</td>
<td>7 46.66%</td>
<td>28 26.42%</td>
<td></td>
</tr>
<tr>
<td>15–19</td>
<td>4 10.81%</td>
<td>0 0.00%</td>
<td>17 16.03%</td>
<td></td>
</tr>
<tr>
<td>20–24</td>
<td>1 2.70%</td>
<td>1 6.66%</td>
<td>13 12.26%</td>
<td></td>
</tr>
<tr>
<td>25+</td>
<td>0 0.00%</td>
<td>1 6.66%</td>
<td>17 16.03%</td>
<td></td>
</tr>
<tr>
<td>Hospital admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21 57%</td>
<td>2 13%</td>
<td>70 66%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>No</td>
<td>16 43%</td>
<td>13 87%</td>
<td>36 34%</td>
<td></td>
</tr>
<tr>
<td>Length of stay (days)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>1 (1–2)</td>
<td>1 (1–1)</td>
<td>2 (1–3)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Range</td>
<td>1–3</td>
<td>1–1</td>
<td>1–8</td>
<td></td>
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<tr>
<td>Anatomical location of injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head</td>
<td>2 5.41%</td>
<td>2 13.33%</td>
<td>5 4.72%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Neck/trunk</td>
<td>2 5.41%</td>
<td>0 0.00%</td>
<td>15 14.15%</td>
<td></td>
</tr>
<tr>
<td>Upper limb</td>
<td>23 62.16%</td>
<td>9 60.00%</td>
<td>31 29.25%</td>
<td></td>
</tr>
<tr>
<td>Lower limb</td>
<td>10 27.03%</td>
<td>4 26.67%</td>
<td>55 51.89%</td>
<td></td>
</tr>
</tbody>
</table>

The Abbreviated Injury Scale (AIS)\textsuperscript{16} was applied and is an anatomy-based injury severity scoring system, with a scale from 1 (minor) to 6 (unsurvivable). The median AIS in Period A was 2 (IQR=1–2), Period B was 2 (IQR=1–2) and Period C was 1 (IQR=1–2). There was no significant difference (p=0.59) in AIS between each period (Table 1).

The types of the main injuries for hospital presentations are summarised in Figure 2 and were predominantly fractures in all periods—Period A 59% (n=22/37), Period B 73% (n=11/15) and Period C 49% (n=52/106). In Figure 2 ‘Other’ injuries include open wounds, dislocations and head injuries.
The response rate to the questionnaire conducted was 60% (n=64/106). No patients declined to be interviewed. Parents/caregivers completed 44 (69%) of the verbal questionnaires. Of those presenting to hospital in Period C; 42% (n=44/106) were injured on a home trampoline, 47% (n=50/106) at a trampoline park with 11% (n=12/106) injured at an unknown location. Thirty-six (34%) were admitted to hospital and 29 (27%) required operative intervention. Operations performed in Period C are reported in Table 2. There was a greater number of surgeries performed on those injured on a home trampoline, and these mostly affected the upper limbs (13/17) (Table 2). All but one of the lower limb and spinal operative procedures were performed on patients injured at a trampoline park (Table 2). Table 2: Operations performed on patients injured during Period C grouped by site where injury occurred. Other includes a Tendo-achilles repair, clavicle open reduction internal fixation (ORIF), hip spica, tooth extraction and anterior cruciate ligament repair.

<table>
<thead>
<tr>
<th>Operation</th>
<th>Home</th>
<th>Trampoline park</th>
<th>Unknown</th>
<th>Total number of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supracondylar open/closed Reduction internal fixation</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Forearm manipulation</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Spinal stabilisation</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Lower limb open/closed reduction Internal fixation</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Patella tendon exploration/repair</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>17</strong></td>
<td><strong>10</strong></td>
<td><strong>2</strong></td>
<td><strong>29</strong></td>
</tr>
</tbody>
</table>
There was a significant difference (p<0.01) in the anatomical location of injury in Period C compared to Periods A and B, with most injuries occurring to the lower limbs (Table 1). Of those injured while both trampoline parks were open (Period C), 29% (n=31/106) suffered upper-limb injuries and 52% (n=55/106) suffered lower-limb injuries. The remaining injuries affected the head (5%, n=5/106) and neck/trunk (14%, n=15/106). Head injuries were composed of two broken noses, two dental injuries and one concussion. Lower-limb injuries occurred in 76% (n=38/50) of patients injured at a trampoline park (Figure 3). Sixty-two percent (n=27/44) of hospital presentations injured on a home trampoline had upper-limb injuries (Figure 3). Two or more people were on the trampoline in 30% (n=32/106) of cases, a single user in 29% (n=31/106) and an unknown number in 41% (n=43/106) of cases. Unknown data includes questionnaire respondents who were uncertain of the number of users or where it is not stipulated in medical documentation for those who did not complete the questionnaire.

There were seven cervical spine, four thoracic spine and three lumbar spine injuries. Of these two were cervical spine fracture/dislocations and two were thoracic spine fractures. The remainder were soft tissue injuries. One thoracic and two cervical spine injuries required admission and surgical intervention with stabilisation—all occurred at a trampoline park. One of those children sustained a life-changing unstable cervical fracture/dislocation.

Trampoline Park One had 35 hospital presentations, which was over twice as many as Trampoline Park Two (n=15). Eight of those 35 injured at Trampoline Park One were admitted for surgical treatment while two of those injured at Trampoline Park Two needed surgery.

**Discussion**

After the opening of two new trampoline parks the Christchurch Hospital Emergency Department saw a three-fold increase in the number of trampoline-related hospital presentations (Table 1). These presentations were unique in that they affected an older paediatric population with predominantly lower-limb injuries. A significant increase in operative procedures was required to treat trampoline-related injuries with two involving stabilisation of severe cervical spine injuries.

In contrast to past literature about home trampolines, this study found that a significantly older paediatric population was being injured after the two trampoline parks opened. The average age of injury was 13.5 years (IQR=8–21) after both parks opened and five years (IQR=4–12) the year
prior when only home trampolines were in use. Kasmire et al compared the demographics of trampoline park versus domestic trampoline injuries and found similarly, that older children were being injured at parks. It has been extensively reported that most injuries sustained on home trampolines affect those aged under 10 years. Twenty-eight percent of those injured after the opening of both trampoline parks were over the age of 25 years. This indicates that future research pertaining to trampoline parks should not be restricted to paediatric populations as it risks missing a proportion of those being injured.

Upper-limb injuries often occur after falling from a trampoline. Lower-limb injuries were more common in those injured at trampoline parks compared to home (Figure 3). It is unclear if this reflects a smaller number of upper-limb injuries or that trampoline parks have an intrinsically greater risk of lower-limb injuries. Reasons for a greater risk of lower-limb injuries could include that park trampolines are based at ground level with much padding, reducing the height and force of any falls off the side of a trampoline. This lessens the effect of the injury mechanism of falling from a trampoline on to an outstretched arm, which is the most common cause of upper-limb injury. However, these parks also have ledges which can be leapt from, opportunities for multiple simultaneous trampoline use and are often used for organised sports such as volleyball/dodgeball. Due to the altered utilisation of trampolines in these settings the forces transmitted through the lower limbs could be much greater. This causes the most common mechanism of injury at a trampoline park to be due to landing—putting the lower limbs at risk. Appropriate consideration and placement of hard framework and surrounding padding is important to reduce the risk of patrons landing on them with force, thereby reducing the incidence of lower-limb injuries.

The trampoline park that allowed more than one user on a trampoline at a time had a greater proportion of hospital presentations and surgeries than its comparator. Multiple users on a single trampoline is a known risk factor for injury at trampoline parks and on home trampolines. Outside of the simple mechanisms of users colliding with each other or becoming entangled and falling awkwardly is the transference of force. Menelaws et al showed using a biomechanical model that two users bouncing out of synchronisation produces a transfer of energy from the larger to the smaller mass. This amplifies the relative height of the fall and produces a recoiling hard surface for which the smaller individual is not appropriately flexed and prepared. This mechanism in conjunction with a park full of differently sized individuals using multiple trampolines together could be an additional contributor to the over-representation of lower-limb injuries. The allowance of more than one user on a trampoline at a time could account for the disproportionate rate of injury in one park compared to the other and should be avoided.

Having adult supervision and restricting the performance of flips performed on trampolines would likely reduce the risk of serious neck injuries. Cervical spine injuries are often the most potentially catastrophic of all injuries suffered on trampolines and can occur with the performance of flips/somersaults. These injuries often occur after a fall onto the trampoline mat. Trampoline parks typically have an area devoted to the performance of flips by untrained patrons into foam pits. No data is present to discern the injury rate of flipping into a foam pit but this activity is likely to propagate the performance of such activities on a home trampoline (if not elsewhere at the park). The prevalence of cervical spine injuries has led both the American and Canadian Paediatric Associations to advise against the use of home trampolines. Intuitively, adult supervision should produce a safer environment but multiple studies have reported 30–50% of trampoline injuries occur in spite of adult supervision. The restriction of flips in addition to limiting multiple simultaneous trampoline use would likely be the most effective way to reduce the overall incidence of injuries and specifically cervical spine injuries.

Limitations of this study include the underestimation of injuries, rate of injury reporting and unknown rate of exposure. This study is reliant upon patient presentation and
accurate documentation of whether a trampoline was involved in the mechanism of injury. This was mitigated by searching multiple hospital databases with the use of broad search terms such as ‘tramp’ and ‘trampoline’. Despite this the study is likely to have captured a lower number of injuries than occurred. Relative risks are unable to be compared as the underlying rate of exposure to trampolines is unknown. The demographics of the individuals presenting to the trampoline parks were unavailable to the authors as was the exposure rate occurring in private homes.

This study reports the incidence rate of injuries in the new wave of trampoline use, which has not been previously analysed. Future research regarding the injury profile of trampoline parks should be conducted to give greater understanding of their impact on emergency department presentations. There is currently very little in terms of recommendations from regulatory bodies on the safe operation of trampoline parks and further evidence would provide them a greater base to make decisions based on participant safety. Based on these findings, recommendations for the safe operation of trampoline parks should include:

1. Notification to caregivers that trampolining carries a risk of significant injury
2. Use of trampolines should be restricted to a single person at a time
3. Consideration of the placement of structures, netting and padding should be taken and frequently inspected
4. Somersaults and flips should not be condoned even in the presence of foam pits and adult supervision
5. Supervising adults should be actively observing patrons, adequately trained and recognise the risk factors for injury as listed above

Conclusion

There has been a significant increase in trampoline-related injuries since the opening of two new parks in Christchurch. These injuries are unusual in that they involve an older paediatric population, affect predominantly the lower limbs and are more severe than those reported from the use of domestic trampolines. Consistent with past research, the trampoline park allowing multiple users had a higher proportion of presentations and more injuries requiring operative intervention. These observations support the need for increased research regarding trampoline park injury profiles—including collection of data in non-paediatric populations—and appropriate regulation to avoid significant injury to patrons.
Appendix 1: Trampoline questionnaire.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Age:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of injury:</td>
<td></td>
</tr>
<tr>
<td>Injury:</td>
<td></td>
</tr>
<tr>
<td>Injury Score – Abbreviated Injury Scale (AIS):</td>
<td></td>
</tr>
</tbody>
</table>

Home
Trampoline Park One
Trampoline Park Two
Unknown

Location:
Mechanism of injury:

Fall:
- Somersault/foam pit
- Onto trampoline bed
- Onto floor (padded)
- Onto floor (non-padded)
- Onto trampoline structure

Non-fall:
- Collision with person
- Collision/crush with object
- Other

1
2
3+

Number of users:
- Yes – direct
- Yes – indirect
- No

Adult Supervision:
*Direct = adult actively watching and engaged with the individual using the trampoline.
Indirect = trampoline user was being overseen by adults in a large setting.
Competing interests:
Nil.

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REFERENCES:


Type of cows’ milk consumption and relationship to health predictors in New Zealand preschool children

Hajar Mazahery, Carolyn Cairncross, Cathryn Conlon, Lisa Houghton, Jane Coad, Carlos Camargo Jr, Cameron Grant, Pamela von Hurst

ABSTRACT

AIMS: New Zealand dietary guidelines recommend children from two years of age consume low- or reduced-fat milk. We aimed to investigate the predictors of type of milk consumption in preschool children.

METHODS: Data were drawn from a cross-sectional study which enrolled preschool children (2–<5 years, n=1,329) from throughout New Zealand.

RESULTS: Cows’ milk was consumed regularly by 88% of children. Of these, 26% consumed plain low- or reduced-fat milk, while 74% consumed full-fat milk. The adjusted odds of consuming plain low- or reduced-fat milk were increased in older children: three-year old (OR=1.80, 95% CI 1.29–2.50); four-year old (OR=1.93, 95% CI 1.38–2.72) versus two-year old children, and were decreased in Māori (OR=0.56, 95% CI 0.36–0.88) and Pacific children (OR=0.32, 95% CI 0.12–0.86) compared with New Zealand European children. Approximately 18% of children were overweight/obese. The odds (adjusted for socio-demographic characteristics) of consuming plain low- or reduced-fat milk were increased in overweight children (OR=1.74, 95% CI 1.20–2.54) than normal weight children.

CONCLUSIONS: The type of milk consumed by preschool children varies with child demographics and anthropometry. Further research is warranted to investigate caregivers/parents’ knowledge about dietary guidelines and to determine the causal relationship between obesity and milk type consumption. The findings of the current study may have important implications for developing and shaping interventions and in helping shape public health policy and practice to promote cows’ milk consumption in preschool children.

Cows’ milk, the most commonly consumed dairy product among children, is a rich source of macronutrients (including protein, carbohydrate and fat) and micronutrients (e.g., vitamins B2, B12, and A, and minerals calcium and potassium). Milk consumption has been associated with better diet quality and with meeting dietary nutrient intake requirements. Milk consumption has also been shown to favourably affect bone health in children. Accrual of good peak bone mass by the end of the growth period has been shown to have a protective effect on low bone mineral density and fracture risk early in life, and bone loss and osteoporosis later in life. Furthermore, consumption of milk/dairy products during childhood has been shown to be positively related to linear growth and inversely related to body mass index (BMI), adiposity and the risk of overweight and obesity, all of which are important indicators of nutritional status and health.

The New Zealand Ministry of Health recommends that children and young people from age two to 18 years consume 2–3 servings of milk or dairy products each
day, preferably from low- or reduced-fat options. In the light of the rising prevalence of paediatric obesity and the significance of obesity in the aetiology of non-communicable diseases (eg, type 2 diabetes), reduced- or low-fat milk and milk products are recommended from the age of two years because they provide less energy and fat (including saturated fat) and more protein and calcium than regular fat varieties. Despite the repeated emphasis on the importance of milk and dairy products in children’s diets, consumption is below the recommendations for a large proportion of the population in high-income countries including Australia and New Zealand. Based on the New Zealand National Children’s Nutrition survey conducted in 2008/2009, approximately 22% of children and young people never consume milk. Furthermore, low- or reduced-fat milk was consumed by approximately 25% of New Zealand children in the 2002 survey. Prior studies have shown that milk consumption is influenced by age, sex, ethnicity, parental education, household size, socioeconomic status, medical conditions (lactose intolerance and milk allergy) and weight status. Some of these factors (including, but not limited to, ethnicity, socioeconomic status and overweight/obesity) are also associated with the type of milk consumption during childhood. The consumption of low- or reduced-fat milk has been consistently reported to be higher in some ethnic groups and in children of higher socioeconomic status. For instance, the New Zealand 2002 National Children’s Nutrition survey suggests that low- or reduced-fat milk consumption is higher in New Zealand European than Māori and Pacific children. Among children and adolescents in the US, low- or reduced-fat milk consumption is higher in children from households of higher versus lower socioeconomic status and in children of non-Hispanic white ethnicity compared with non-Hispanic black and Hispanic ethnicity. However, the relationship between overweight/obesity and milk fat content is less clear. While some researchers reported a positive relationship between regular milk fat content and increased risk of overweight/obesity, some have found no relationship and others reported an inverse relationship. Given these discrepancies in epidemiological data, lack of randomised controlled trials and the current emphasis of dietary guidelines on promoting low- or reduced-fat milk consumption in children, further investigation is warranted. To the best of our knowledge, no epidemiological research exists addressing both the pattern of type of milk consumption and its determinants in New Zealand preschool-aged children.

Therefore, the aims of this cross-sectional analysis were: (1) to investigate the type of milk usually consumed among preschool children living in New Zealand; and (2) to investigate the sociodemographic characteristics that correlate with milk type consumed by these children.

Methods

We investigated sociodemographic factors and medical conditions associated with the type of milk consumption in preschool children living in New Zealand, and explored the relationship between type of milk consumed and overweight/obesity. Data were drawn from a nationwide cross-sectional study named Te Ra Whakaora (Sunshine and Health). Study design and data collection methods for this study are described briefly below, with further details reported elsewhere.

Study design

Preschool children aged 2 to <5 years from throughout New Zealand were enrolled in this study from August to October 2012. It is important to note that the data is five years old, though to the best of our knowledge, this study is the latest nationwide investigation of milk consumption pattern in New Zealand preschool children and no such a large study has been published since then. Data were collected via paper or online questionnaires. The 59-item study questionnaire comprised of questions describing the child’s demographics, medical history and eating habits. Questions were directed to the main caregiver/parent. Anthropometric measurements (weight and height) were obtained during the child’s visit at testing centres. The collection of data took place at 54 testing centres (49 community pharmacies, Human Nutrition Unit at Massey University, Auckland, University of Otago and Dunedin, two Auckland health services who carry before school check for four-year
old children, and a Wellington general practice clinic) in 17 New Zealand cities and towns with a good geographical coverage achievement. The study participants were recruited using a variety of techniques including sending emails advertising the study, displaying flyers and posters in early childhood education centres and kindergartens in close proximity to testing centres, distributing press releases to media outlets, and interviews on two radio stations and a Sunday evening TV news programme.

The primary recruitment method was the purchase of access to an email database of the online services company that contains 160,000 families with newborn and young children (up to seven years old) and provides products and information for parents. Over a 10-week period, 2,267 families expressed their interest, of whom 1,812 families enrolled in the study and 1,329 families provided information regarding sociodemographic characteristics and milk consumption pattern. Ethical approval for this study was obtained from the Health and Disability Ethics Committee, Northern Region, reference number NTX/12/04/036, and a parent/caregiver of each child provided written informed consent for participation of their child in the study.

**Dependent variables**

Milk consumption was described in this study using a multiple response question. Parents were asked to indicate if the child usually consumed cows' milk and to specify the type of milk the child usually consumed. The latter included the following options: Standard (blue top), Lite (light blue top), Trim (green top), Anchor Calci Plus, Anchor Mega, Anchor Superblue and Meadowfresh Calcitrím or Calcistrong. This question was followed by a free-text option for the recording of brand name or type if it was not included in the list. These options together with options that the parents/caregivers provided were then collapsed into two categories according to their sugar and fat content; 1) fat- and sugar-containing dairy milks that comprised of standard fat cows' milk, unpasteurised/raw cow's milk, full-fat flavoured cows' milk and full-fat goat's milk, and 2) plain low- or reduced-fat cows' milks (including both fortified and non-fortified cows' milk). Throughout this paper, we use the term “full-fat cows' milk” to refer to all “fat- and sugar-containing milks” because a small number of children consumed other types of milk (eg, goat's milk, n=6 and flavoured milk, n=13) and their effect on the findings would be negligible. Furthermore, the significance of independent variables on the consumption of each individual milk type could not be determined due to a very small number of children in each milk type category. Please refer to Supplementary Tables 1 and 2 for the nutritional content of different types of dairy milk and type of milk consumed by children. For those children who consumed more than one type of milk, the priority was given to the full-fat cows' milk (eg, if a parent/caregiver reported child consuming both standard fat and light blue top cows' milk, the child was assigned to the “full-fat cows' milk” group). To investigate the effect of including children who drink both low- and high-fat milk as high-fat milk drinkers, sensitivity analyses were performed while excluding those children. The findings are presented in Supplementary Table 3. Exclusion of those children had no effect on findings (comparable ORs), and therefore the results presented in the results section includes those drinking both low- and high-fat milk as high-fat milk drinkers.

**Independent variables**

The questionnaire content allowed for description of the child's demographics and medical conditions and mother's educational level. Parents/caregivers were asked to record their child's age and sex, and list all ethnicities they identified for their child. For analytical purposes, ethnicity was then assigned using the following prioritisation; Māori > Pacific > non-European other > New Zealand European. Parents/caregivers also provided information on who cared for their child during the day, and if attending a formal preschool education centre (eg, daycare, preschool or kindergarten) and for how many hours per week. Factors affecting milk consumption in daycare centres have been previously studied,31 but data regarding the relationship between milk consumption and daycare attendance are lacking.
Parents/caregivers described their highest educational qualification obtained: intermediate or secondary school with no qualification; school certificate (New Zealand National Certificate of Education Achievement level 1, NZ NCEA, or similar overseas qualification); completed high school certificate (NCEA level 2 and 3 or similar overseas qualification); full-time study since leaving school; and university degree or diploma. Parental/caregiver education was then classified into three groups; no secondary qualification, secondary qualification or post-secondary qualification.

Socioeconomic status was determined using the New Zealand Index of Social Deprivation, a census-based measure. Geo-coding of residential address was performed using ArcGIS geographic information system software (Eris, Redlands, California), along with the subsequent allocation of deprivation index. Each household was allocated to a national household deprivation index of 1 to 10 (with 1 being the least deprived and 10 the most deprived decile of households). These deprivation index scores were then collapsed into five categories; deprivation indices 1 & 2, 3 & 4, 5 & 6, 7 & 8 and 9 & 10 together. Residential address was used to establish latitude, with the country then separated into three regions accordingly, northern (34-38°S), central (39-42°S) and southern (43-46°S) New Zealand.

Parents/caregivers were asked if the child had ever had any food allergies and, if they reported that their child had a food allergy, were provided with a short list of foods commonly associated with allergic reactions in preschool-aged children (eg, milk, egg, peanut, seafood and an open-text option). Finally, parents/caregivers were asked if their child was diagnosed with any specific conditions, including celiac disease, Crohn’s disease, cystic fibrosis and other inflammatory bowel disorders. Lactose intolerance and/or milk sensitivity symptoms overlap with symptoms of these diseases.

Weight and height were measured without shoes by the trained testers, using household non-calibrated scales and wall-mounted measuring devices. Body mass index (BMI) percentile for age and sex was calculated, and then classified into three groups; normal, overweight or obese (based on the cut-offs provided by Cole et al (2000)).

Statistical analyses
Statistical analyses were performed using IBM SPSS version 21.0 (IBM Corp; Armonk, NY, USA). Descriptive statistics were used to report the proportion of preschool children consuming milk and type of milk and other categorical independent variables. We investigated the relationship between potential variables and milk and type of milk consumption using cross-tabulation. Predictors of cows’ milk consumption and cows’ milk type consumption were assessed employing binary logistic regression analysis (univariable and multivariable). Household size and number of children in household were not included in the regression analyses because they were not associated with type of cows’ milk consumption (preliminary cross-tabulation analysis). To avoid the violation of multicollinearity and incomplete information from the predictors (due to many variables with many categories) and because there was a strong relationship between maternal education and ethnicity (a larger proportion of New Zealand European versus Pacific children (82% vs 58% P<0.0001) had mothers with post-secondary education, we ran two regression analyses including either of the mentioned independent variables and report the results of each in separate tables. Imbalanced data with binary outcome variables are associated with biases in the estimated probability of an event. We investigated the models to determine if all the assumptions were met and which model had a better model fit (assessing -2 log likelihood). We also added interaction terms into the models to investigate for interaction effects between variables but no significant results were observed. Associations were described using adjusted odds ratios (OR) and 95% confidence intervals (CI).

Results
Participants’ socio-demographic characteristics by cows’ milk consumption
Table 1 shows the characteristics of the study population by cows’ milk consumption. A larger proportion of children were within the 2–3 year-old category, were of New Zealand European ethnicity, had mothers with post-secondary qualification, lived in households with <3 children, and had New Zealand European ethnicity.

Statistical analyses
Statistical analyses were performed using IBM SPSS version 21.0 (IBM Corp; Armonk, NY, USA). Descriptive statistics were used to report the proportion of preschool children consuming milk and type of milk and other categorical independent variables. We investigated the relationship between potential variables and milk and type of milk consumption using cross-tabulation. Predictors of cows’ milk consumption and cows’ milk type consumption were assessed employing binary logistic regression analysis (univariable and multivariable). Household size and number of children in household were not included in the regression analyses because they were not associated with type of cows’ milk consumption (preliminary cross-tabulation analysis). To avoid the violation of multicollinearity and incomplete information from the predictors (due to many variables with many categories) and because there was a strong relationship between maternal education and ethnicity (a larger proportion of New Zealand European versus Pacific children (82% vs 58% P<0.0001) had mothers with post-secondary education, we ran two regression analyses including either of the mentioned independent variables and report the results of each in separate tables. Imbalanced data with binary outcome variables are associated with biases in the estimated probability of an event. We investigated the models to determine if all the assumptions were met and which model had a better model fit (assessing -2 log likelihood). We also added interaction terms into the models to investigate for interaction effects between variables but no significant results were observed. Associations were described using adjusted odds ratios (OR) and 95% confidence intervals (CI).
children, lived in the northern region or spent 11–20 hours/week rather than less or more time in daycare/preschool/kindergarten. A larger proportion were of lower deprivation indices than higher deprivation indices (the highest deprivation index is the most deprived area).

Of the total study population, 104 (8%) parents/caregivers reported their children had a milk allergy, and seven (0.5%) reported their children had a medical condition that may affect cows' milk consumption. Seventeen percent (221/1,315) of children were classified as either overweight or obese.

For a detailed breakdown of types of milk consumed by children, refer to Supplementary Table 2. Approximately 88% (1,166/1,329) of parents/caregivers reported their child consumed cows' milk, 8% (163/1,329) not consuming cows' milk, and 4% (53/1,329) not consuming any type of milk. The proportion of children consuming cows' milk varied by parental report of the child having a milk allergy ($\chi^2=198.5, P<0.0001$); parental education ($\chi^2=12.4, P<0.01$) and ethnicity ($\chi^2=7.4, P=0.06$). The odds of drinking cows' milk were decreased for children with versus those without cows' milk allergy (44% vs 91%, OR=0.06, 95% CI 0.04–0.10) and increased for children of mothers with no secondary versus post-secondary educational qualifications (96% vs 86%, OR=4.83, 95% CI 1.68–13.89) and for Māori versus New Zealand European children (94% vs 87%, OR=2.46, 95% CI 1.20–5.03).

### Table 1: Socio-demographic characteristics of preschool children by cows' milk consumption.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Total (n=1,329)</th>
<th>Cows' milk consumption</th>
<th>P value*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (n=1,166)</td>
<td>No (n=163)</td>
<td></td>
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<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td>0.80</td>
</tr>
<tr>
<td>2-year-old</td>
<td>496 (37)</td>
<td>432 (87)</td>
<td>64 (13)</td>
</tr>
<tr>
<td>3-year-old</td>
<td>448 (34)</td>
<td>393 (88)</td>
<td>55 (12)</td>
</tr>
<tr>
<td>4-year-old</td>
<td>385 (29)</td>
<td>341 (89)</td>
<td>44 (11)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td>0.36</td>
</tr>
<tr>
<td>Female</td>
<td>684 (49)</td>
<td>574 (89)</td>
<td>74 (11)</td>
</tr>
<tr>
<td>Male</td>
<td>681 (51)</td>
<td>592 (87)</td>
<td>89 (13)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
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<tr>
<td>New Zealand European</td>
<td>926 (70)</td>
<td>801 (87)</td>
<td>125 (14)</td>
</tr>
<tr>
<td>Māori</td>
<td>174 (13)</td>
<td>163 (94)</td>
<td>11 (6)</td>
</tr>
<tr>
<td>Pacific</td>
<td>44 (3)</td>
<td>40 (91)</td>
<td>4 (9)</td>
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<tr>
<td>Other</td>
<td>185 (14)</td>
<td>162 (88)</td>
<td>23 (12)</td>
</tr>
<tr>
<td><strong>Maternal education</strong></td>
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<tr>
<td>Post-secondary qualification</td>
<td>1,072 (81)</td>
<td>925 (86)</td>
<td>147 (14)</td>
</tr>
<tr>
<td>Secondary qualification</td>
<td>124 (9)</td>
<td>113 (91)</td>
<td>11 (9)</td>
</tr>
<tr>
<td>No secondary qualification</td>
<td>133 (10)</td>
<td>128 (96)</td>
<td>5 (4)</td>
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<td><strong>Socioeconomic status</strong></td>
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<td>0.30</td>
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<tr>
<td>Deprivation index 1 &amp; 2</td>
<td>343 (26)</td>
<td>290 (85)</td>
<td>53 (16)</td>
</tr>
<tr>
<td>Deprivation index 3 &amp; 4</td>
<td>331 (25)</td>
<td>297 (90)</td>
<td>34 (10)</td>
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<tr>
<td>Deprivation index 5 &amp; 6</td>
<td>287 (22)</td>
<td>253 (88)</td>
<td>34 (12)</td>
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<tr>
<td>Deprivation index 7 &amp; 8</td>
<td>227 (17)</td>
<td>202 (89)</td>
<td>25 (11)</td>
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<tr>
<td>Deprivation index 9 &amp; 10</td>
<td>141 (11)</td>
<td>124 (88)</td>
<td>17 (12)</td>
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Table 1: Socio-demographic characteristics of preschool children by cows’ milk consumption (continued).

<table>
<thead>
<tr>
<th>Residential region</th>
<th></th>
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<tr>
<td>Northern</td>
<td>651 (49)</td>
<td>559 (86)</td>
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<tr>
<td>Central</td>
<td>378 (28)</td>
<td>341 (90)</td>
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<tr>
<td>Southern</td>
<td>300 (23)</td>
<td>266 (89)</td>
</tr>
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<table>
<thead>
<tr>
<th>Household size (number of children)</th>
<th>0.52</th>
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<tr>
<td>&lt;3</td>
<td>942 (71)</td>
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<tr>
<td>≥3</td>
<td>387 (29)</td>
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<table>
<thead>
<tr>
<th>Daycare attendance (hours)</th>
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<tbody>
<tr>
<td>0</td>
<td>192 (14)</td>
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<tr>
<td>1–10</td>
<td>257 (19)</td>
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<tr>
<td>11–20</td>
<td>460 (35)</td>
</tr>
<tr>
<td>21–30</td>
<td>234 (18)</td>
</tr>
<tr>
<td>30+</td>
<td>186 (14)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cows’ milk allergy</th>
<th>&lt;0.0001</th>
</tr>
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<tbody>
<tr>
<td>No</td>
<td>1,225 (92)</td>
</tr>
<tr>
<td>Yes</td>
<td>104 (8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medical conditions (that might affect milk consumption)</th>
<th>0.23</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>1,322 (99)</td>
</tr>
<tr>
<td>Yes</td>
<td>7 (1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BMI (calculated for age and sex) (n=1,315)</th>
<th>0.13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>1,094 (83)</td>
</tr>
<tr>
<td>Overweight</td>
<td>173 (13)</td>
</tr>
<tr>
<td>Obese</td>
<td>48 (4)</td>
</tr>
</tbody>
</table>

BMI, body mass index; CI, confidence intervals; OR, odds ratio. All values are reported as n (%).

*Cross-tabulation, P<0.05 considered significant.

The highest deprivation index is the most deprived area.

bOut of the 46 cows’ milk drinkers who reported having cows’ milk allergy, 16 (34.8%) children drank lactose-free cows’ milk.

cThe focus was on medical conditions with symptoms overlapping those of milk allergy/lactose intolerance. Medical conditions identified in these children were celiac disease (n=4), cystic fibrosis (n=1) and inflammatory bowel disorder (n=1).
Pattern and predictors of different types of cows’ milk consumption

Of 1,166 cows’ milk consumers, 307 (26%) consumed plain low- or reduced-fat milk. For a detailed breakdown of type of milk included in each category and their consumption in these children, refer to Supplementary Table 2. Type of cows’ milk consumption was associated with age, ethnicity, maternal education and residential region (Table 2). The odds of consuming plain low- or reduced-fat milk was increased for three-year old (OR=1.80, 95% CI 1.29–2.50) and four-year old children (OR=1.93, 95% CI 1.38–2.72) compared with two-year old. The odds of consuming plain low- or reduced-fat milk were lower in Māori (OR=0.56, 95% CI 0.36–0.88) and Pacific Island children (OR=0.32, 95% CI 0.12–0.86) than children of New Zealand European ethnicity and in children living in central (OR=0.50, 95% CI 0.36–0.70) and southern regions (OR=0.65, 95% CI 0.46–0.92) than in northern region. When maternal education was replaced with ethnicity, the results for all variables were comparable (data not reported here), and the odds of consuming plain low- or reduced-fat milk were lower in children of mothers with no secondary qualification (OR=0.57, 95% CI 0.34–0.95) and secondary qualification (OR=0.59, 0.36–0.97) than those of mothers with post-secondary qualification (17% and 19% vs 28%, respectively).

Type of milk consumption was associated with BMI percentiles (calculated for age and sex); with overweight children having an increased odds of consuming plain low- or reduced-fat cows’ milk (OR=1.74, 95% CI 1.20–2.54) compared with normal weight children. Medical conditions (known to affect milk consumption) were not entered in the logistic regression analysis because there were only five children with one of these.

<table>
<thead>
<tr>
<th>Variables†</th>
<th>Plain low- or reduced-fat cows’ milk 307 (26.3)</th>
<th>Full-fat cows’ milk 859 (73.7)</th>
<th>Association with cows’ milk consumption type*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Univariable OR (95% CI)</td>
<td>Multivariable OR (95% CI)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-year old</td>
<td>84 (19)</td>
<td>348 (81)</td>
<td>Reference category</td>
</tr>
<tr>
<td>3-year old</td>
<td>116 (30)</td>
<td>277 (70)</td>
<td>1.74 (1.26–2.40)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.29 (1.80–2.50)</td>
</tr>
<tr>
<td>4-year old</td>
<td>107 (31)</td>
<td>234 (69)</td>
<td>1.90 (1.36–2.64)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.93 (1.38–2.72)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand European</td>
<td>228 (28)</td>
<td>573 (72)</td>
<td>Reference category</td>
</tr>
<tr>
<td>Māori</td>
<td>32 (20)</td>
<td>132 (80)</td>
<td>0.59 (0.39–0.90)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.56 (0.36–0.88)</td>
</tr>
<tr>
<td>Pacific Island</td>
<td>5 (13)</td>
<td>35 (87)</td>
<td>0.36 (0.14–0.93)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.32 (0.12–0.86)</td>
</tr>
<tr>
<td>Other</td>
<td>43 (27)</td>
<td>119 (73)</td>
<td>0.91 (0.62–1.33)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.83 (0.56–1.24)</td>
</tr>
<tr>
<td>Residential region</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern</td>
<td>177 (32)</td>
<td>382 (68)</td>
<td>Reference category</td>
</tr>
<tr>
<td>Central</td>
<td>65 (19)</td>
<td>276 (81)</td>
<td>0.51 (0.37–0.71)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.50 (0.36–0.70)</td>
</tr>
<tr>
<td>Southern</td>
<td>65 (24)</td>
<td>201 (76)</td>
<td>0.70 (0.50–0.97)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.65 (0.46–0.92)</td>
</tr>
<tr>
<td>BMI (calculated for age and sex)</td>
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<td></td>
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</tr>
<tr>
<td>Normal</td>
<td>238 (25)</td>
<td>714 (75)</td>
<td>Reference category</td>
</tr>
<tr>
<td>Overweight</td>
<td>53 (33)</td>
<td>106 (67)</td>
<td>1.50 (1.05–2.15)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.74 (1.20–2.54)</td>
</tr>
<tr>
<td>Obese</td>
<td>12 (27)</td>
<td>32 (73)</td>
<td>1.13 (0.57–2.22)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1.48 (0.73–3.01)</td>
</tr>
</tbody>
</table>

†Variables included in the multivariate analysis were age, sex, ethnicity, deprivation index, residential region, milk allergy and body mass index (BMI, calculated for age and sex). Model x² (14)=61.08, P<0.0001.
*When ethnicity was replaced with maternal education, the same variables were found to be significant predictors of type of cows’ milk consumed (with comparable ORs).
*Cows’ milk type consumption was coded as 1 = full-fat milk and 2 = plain reduced- or low-fat milk.
Discussion

In the study, the majority of children were reported as consuming cows' milk, however only 26% of these children consumed plain low- or reduced-fat cows' milk despite guidelines recommending low-fat milk for all children >2 years of age. The odds of consuming plain low- or reduced-fat cows' milk were increased in older children, those of New Zealand European ethnicity and among children of mothers who have a post-secondary education and living in the Northern regions. We also identified an association between type of milk and overweight, with the odds of consuming plain low- or reduced-fat cows' milk increased in overweight but not obese children compared with children with a normal BMI.

The smaller proportion of children consuming plain low- or reduced-fat cows' milk (than full-fat milk) in our study mirrors the findings of other reports from New Zealand and the US, showing that approximately 26% and 13–21% of children, respectively, consumed lower-fat milk varieties. These data highlight the fact that most parents/caregivers do not adhere to the dietary guidelines which recommend reduced-fat and low-fat milk be given to children.

The odds of consuming plain low or reduced milk were increased for three- and four-year old compared with two-year old children (an average of 9% increase in the proportion). These results confirm the findings of Scharf et al (2013) and Fox et al (2010) who reported an approximately 8% difference in the proportion of four-year old children who consumed lower-fat milk alternatives than two- and three-year old children. However, the 2002 New Zealand National Children's Nutrition survey did not find any relationship between age and type of milk consumed. It is worth noting that preschool children were not included in the 2002 survey, and different variables other than age (including, but not limited to, peer and environmental influences) could be involved in shaping food choices in older children. It is also important to note that there are two sets of guidelines that are applicable to the two-year old age group in New Zealand; the 0–2 and 2–18-year old guidelines. While the 0–2 guidelines recommend no more than 500ml of milk, all of which should be whole milk, the 2–18 dietary guidelines recommend 2–3 servings of dairy products that should be of low-fat alternatives. Therefore, some parents/caregivers of 2-year old children given that their children potentially (depending on interpretation of age) fall into both sets of recommendations might have uncertainty about choosing the appropriate set of guidelines.

Ethnicity and maternal education, but not socioeconomic status, were significantly associated with type of cows' milk consumed by children. Children of New Zealand European origin or of mothers with post-secondary qualification had increased odds of consuming plain low- or reduced-fat milk compared with Māori or Pacific children or children of mothers with no secondary qualification. Ethnicity and maternal education have consistently been reported to be significant determinants of milk and type of milk consumption, with non-white or less educated populations being more likely to consume full-fat varieties. The reasons for the differences in the type of milk consumed in some ethnic groups likely involves culture, socioeconomic status, environment and education (and possibly interactions among these variables). Among these characteristics, maternal education seems to be the strongest predictor, though other ethnicity-related factors not explored in this study (like taste preferences and acceptability) might also be involved. Evidence suggests that parental knowledge of nutrition guidelines about milk (as well as parental dietary pattern) influences the amount of milk served to 2–8-year old children. Thus, educating parents/caregivers who have a high degree of control over the environment and experiences of their preschool child is of particular importance in delivering information to young children.

Interestingly, the odds of consuming plain low- or reduced-fat cows' milk was lower in children living in Central and Southern regions of New Zealand than those living in the Northern region. The reason for this geographical relationship is unclear (because the association persisted beyond adjustment for other sociodemographic factors and overweight/obesity), though an explanation for such finding could be that those living in central and southern regions of New Zealand who participated in the study might have been from rural areas where dairy farmers are more likely to feed their children full-fat milk. Further research is warranted to better elucidate such relationship.
Overweight but not obese children had higher adjusted odds of drinking plain low- or reduced-fat cows’ milk than normal weight children. A lack of statistical significance for the association of obesity with milk type could potentially be due to small numbers of children who were obese (n=44, 4% of total sample). Our findings are inconsistent with the findings of LaRowe et al (2007) and O’Connor et al (2006) who reported no statistically significant relationship between milk fat content and overweight/obesity. It should be noted that the former study group reported higher BMI in 2–5-year old children consuming 2% fat milk (reduced fat) than those consuming lower-fat milk (1% fat).26,28

Our findings, however, confirm those of Vanderhout et al (2016) who also reported a significant inverse relationship between milk fat percentage and BMI z-score (adjusted for milk volume consumed), and children consuming standard fat milk having a 0.72 [95% CI, 0.68–0.76] lower BMI z-score than those consuming lower-fat milk alternatives.29 A similar relationship has also been reported from a longitudinal study of preschool-aged children born in 2001 in the US; Scharf et al (2013)29 reported increased odds of overweight/obesity in preschool children consuming low- or reduced-fat milk than those consuming higher-fat milk alternatives. The former study group also found that children consuming lower-fat milk alternatives (1% vs 2% fat) were more likely to become overweight between two and four years,27 a finding confirmed by some evidence from adults. Data from the US-based Women’s Health Study showed that women aged 45 years and over, with normal weight to begin with, gained significantly less weight with higher dairy intakes.40 Interestingly, only high-fat dairy products, and not low-fat dairy products, were associated with significantly less weight gain.40 Those in the top fifth of the high-fat dairy product intake range had a significant 8% lower risk of becoming overweight or obese.

It is important to note that the cause and effect relationship cannot be determined from these observational studies. Our findings may reflect the fact that parents/caregivers of overweight children or in families where overweight/obesity is prevalent may intentionally give their children lower-fat milk to lower the risk of overweight/obesity (per dietary guidelines). Some authors, however, hypothesise that lower-fat milk alternatives may increase children’s caloric intake from other foods because fat has a satiating effect.41 It is important to note that the cause of obesity is multifactorial, with a full range of socio-demographic factors that affect physical activity and dietary practices (with dietary fat being just one of the many components involved), and therefore, randomised controlled trials are required to disentangle the direction of causality (the relationship between obesity and milk fat content).

In the light of high and increasing prevalence of paediatric overweight/obesity and serious overweight/obesity-related comorbidities,48 the dietary guidelines around low- or reduced-fat milk alternatives seem prudent. Individuals are advised to reduce their energy intake through decreasing dietary fat intake as a weight gain management strategy. Theoretically, replacing one serving of standard fat milk with low- or reduced-fat milk alternatives may reduce daily fat intake by approximately 5–8g which equates to a reduction in daily energy intake by 45–72 kcal/serving of milk. However, the downside of promoting a low-fat diet for weight management has been acknowledged by experts. It has been suggested that a singular focus on reduction of total and saturated fat can be counterproductive, because dietary fat is typically replaced by refined carbohydrates and refined carbohydrates are likely to be more detrimental to health compared to total and saturated fat.49

Our study has several limitations. The type of cows’ milk consumed by children in the study was reported by parents/caregivers and was not assessed directly. Furthermore, information regarding the type of milk parents/caregivers drink was not collected. Parents/caregivers dietary habit may play a major role in what they provide their children. The enrolled sample of children was not representative of the New Zealand preschool population. We enrolled a larger proportion of parents/caregivers with higher socioeconomic status and higher education and of children with lower BMI. Compared to the data from New Zealand Health Survey (2015/16), the rate of overweight/obesity was lower in our study population (32% vs 17%, respectively). With regard to the obesity-type of milk consumption relationship, we lacked data on other sources of dairy products, frequency and volume of milk consumed, total energy intake, types of food consumed and physical activity.
Therefore, we could not adjust for these well-established confounders. Finally, given the cross-sectional nature of this study, causal inferences cannot be made. However, our study is the first in New Zealand to investigate the relationship between sociodemographic factors and type of milk consumption, and to explore the association between type of milk consumed and overweight in preschool children.

In conclusion, we found that most children drank cows’ milk (88%), the prevalence of consuming plain low- or reduced-fat milk was low in preschool children (26%), and was influenced by several sociodemographic characteristics, including age, maternal education, ethnicity and residential region. There was no relationship between consumption of full-fat cow’s milk and overweight/obesity. Identification of the determinants of milk type consumption in children provides guidance for targeted interventions to improve milk consumption pattern in children. It is also of high significance to investigate whether the dietary guidelines are clear for parents/caregivers or people advising them. We found that consumption of plain low- or reduced-fat milk was associated with an increased odds of overweight but not obesity. This finding may suggest that parents/caregivers of overweight children are more likely to adhere to dietary guidelines to manage weight gain in children. However, this hypothesis is assumed to be true only if parents/caregivers have an accurate perception of their young children’s normal weight status. Further research is warranted to better elucidate the reasons for obesity-type of milk consumption relationship.

**Supplementary Table 1: Nutritional information of different types of dairy milk.***

<table>
<thead>
<tr>
<th>Milk types</th>
<th>Nutrients/100 ml</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Energy (kj)</td>
<td>Protein (g)</td>
<td>Fat total (g)</td>
<td>Carbohydrate (g)</td>
<td>Calcium (mg)</td>
</tr>
<tr>
<td><strong>Anchor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard blue top</td>
<td>260</td>
<td>3.3</td>
<td>3.3</td>
<td>4.8</td>
<td>117</td>
</tr>
<tr>
<td>Lite</td>
<td>194</td>
<td>3.3</td>
<td>1.5</td>
<td>4.9</td>
<td>117</td>
</tr>
<tr>
<td>Trim</td>
<td>156</td>
<td>4.0</td>
<td>0.1</td>
<td>5.0</td>
<td>133</td>
</tr>
<tr>
<td>Superblue</td>
<td>272</td>
<td>5.0</td>
<td>2.8</td>
<td>4.8</td>
<td>164</td>
</tr>
<tr>
<td>Mega</td>
<td>243</td>
<td>5.0</td>
<td>2.0</td>
<td>5.0</td>
<td>160</td>
</tr>
<tr>
<td>Calci+</td>
<td>193</td>
<td>5.8</td>
<td>0.2</td>
<td>5.2</td>
<td>190</td>
</tr>
<tr>
<td>Zero lacto blue</td>
<td>260</td>
<td>3.3</td>
<td>3.3</td>
<td>4.0</td>
<td>117</td>
</tr>
<tr>
<td>Zero lacto trim</td>
<td>156</td>
<td>4.0</td>
<td>0.1</td>
<td>5.0</td>
<td>133</td>
</tr>
<tr>
<td><strong>Meadow Fresh</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard blue top</td>
<td>270</td>
<td>3.9</td>
<td>3.3</td>
<td>4.7</td>
<td>135</td>
</tr>
<tr>
<td>Lite</td>
<td>210</td>
<td>4.0</td>
<td>1.5</td>
<td>4.8</td>
<td>135</td>
</tr>
<tr>
<td>Trim</td>
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<td>4.1</td>
<td>0.4</td>
<td>4.9</td>
<td>140</td>
</tr>
<tr>
<td>Calci Trim</td>
<td>190</td>
<td>5.9</td>
<td>0.2</td>
<td>4.8</td>
<td>190</td>
</tr>
<tr>
<td><strong>Calci Strong</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chocolate flavoured milk</td>
<td>270</td>
<td>4.4</td>
<td>1.5</td>
<td>8.4</td>
<td>145</td>
</tr>
<tr>
<td>Strawberry flavoured milk</td>
<td>260</td>
<td>4.4</td>
<td>1.5</td>
<td>7.9</td>
<td>145</td>
</tr>
<tr>
<td>Banana flavoured milk</td>
<td>260</td>
<td>4.4</td>
<td>1.5</td>
<td>7.5</td>
<td>145</td>
</tr>
<tr>
<td>Goat’s milk*</td>
<td>243</td>
<td>2.9</td>
<td>3.3</td>
<td>4.2</td>
<td>NR</td>
</tr>
</tbody>
</table>

NR, not reported
*All nutritional information is based on product Nutrition Information Panel, unless otherwise stated.
**Derived from http://www.meadowcrofffarm.co.nz/products/goats-milk
**Supplementary Table 2:** Detailed description of milk consumption (by type) among preschool children (n=1,329).

<table>
<thead>
<tr>
<th>Milk and type of milk consumption</th>
<th>n (%)</th>
<th>Description</th>
</tr>
</thead>
</table>
| Does not drink dairy milk        | 163 (12) | • Milk added on cereals only otherwise the child doesn’t drink milk (n=7)  
|                                  |       | • Breast milk (n=5)  
|                                  |       | • Toddler formula (n=37)  
|                                  |       | • Plant milk (n=81, including soy, rice, almond and oat milk)  
|                                  |       | • No milk at all (n=54) |
| Drinks dairy milk*               | 1,166 (88) | |
| Full-fat cows' milk**            | 859 (74)† | • Standard blue top milk (n=852)  
|                                  |       | • Goat's milk (n=6)  
|                                  |       | • Flavoured milk (n=13)  
|                                  |       | • Standard fat lactose-free milk (n=15)  
|                                  |       | • Toddler formula in combination with other milks from this group (n=34)  
|                                  |       | • Breast milk in combination with other milks from this group (n=9) |
| Plain low- or reduced-fat cows' milk | 307 (26)† | |
| Light                            | 198 (17)† | • Standard light milk (n=198)  
|                                  |       | • Toddler formula in combination with other milks from this group (n=5) |
| Trim                             | 49 (4)† | • Standard trim milk (n=48)  
|                                  |       | • Lactose free trim milk (n=1)  
|                                  |       | • Breast milk in combination with other milks from this category (n=1) |
| Fortified                        | 63 (5)† | • Anchor calciplus (n=24)  
|                                  |       | • Anchor Mega (n=10)  
|                                  |       | • Anchor Superblue (n=6)  
|                                  |       | • Meadow fresh calcitrim or calcistrong (n=23)  
|                                  |       | • Breast milk in combination with other milks from this category (n=2)  
|                                  |       | • Toddler formula in combination with other milks from this category (n=4) |

*Milk type was collapsed into two categories; fat- and sugar-containing milk (that comprises of standard-fat milk (blue top), flavoured milk, goat’s milk and raw/unpasteurised milk) and plain low- or reduced-fat milk (that comprises of light milk, trim milk and fortified low/reduced-fat milk).

**The term “full-fat cows' milk” is used to refer to “fat- and sugar-containing dairy milk” because only 13 (1%) parents reported their children consuming flavoured milk and six parents reported their children consuming goats' milk. Some children consumed more than one type of milk. When two or more types of milk were consumed, the priority was given to the higher fat content (eg, if a parent/caregiver reported child consuming both standard and low- or reduced-fat milk, the child was assigned to full-fat cows’ milk group, n=118).

†Percentage of children who consumed dairy milk (n=1,166).
### Supplementary Table 3: Sensitivity analysis excluding children who consumed both full-fat and low-fat cow’s milk (n=118). Factors predicting type of milk consumption (plain low- or reduced-fat milk vs full-fat cows’ milk) in the 1,048 preschool children who consumed milk.

<table>
<thead>
<tr>
<th>Variables†</th>
<th>Plain low- or reduced-fat cows’ milk 307 (29)</th>
<th>Full-fat cows’ milk 741 (71)</th>
<th>Association with cows’ milk consumption type* (Multivariable OR (95% CI))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-year old</td>
<td>84 (22)</td>
<td>299 (78)</td>
<td>Reference category</td>
</tr>
<tr>
<td>3-year old</td>
<td>116 (33)</td>
<td>235 (67)</td>
<td>1.84 (1.31–2.59)</td>
</tr>
<tr>
<td>4-year old</td>
<td>107 (34)</td>
<td>207 (66)</td>
<td>1.88 (1.33–2.66)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand European</td>
<td>228 (32)</td>
<td>485 (68)</td>
<td>Reference category</td>
</tr>
<tr>
<td>Māori</td>
<td>32 (22)</td>
<td>116 (78)</td>
<td>0.54 (0.34–0.84)</td>
</tr>
<tr>
<td>Pacific Island</td>
<td>5 (14)</td>
<td>32 (86)</td>
<td>0.29 (0.11–0.77)</td>
</tr>
<tr>
<td>Other</td>
<td>43 (29)</td>
<td>107 (71)</td>
<td>0.76 (0.51–1.15)</td>
</tr>
<tr>
<td>Residential region</td>
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<tr>
<td>Northern</td>
<td>177 (36)</td>
<td>317 (64)</td>
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</tr>
<tr>
<td>Central</td>
<td>65 (20)</td>
<td>253 (80)</td>
<td>0.45 (0.32–0.64)</td>
</tr>
<tr>
<td>Southern</td>
<td>65 (28)</td>
<td>171 (72)</td>
<td>0.63 (0.44–0.89)</td>
</tr>
<tr>
<td>BMI (calculated for age and sex)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>238 (28)</td>
<td>619 (72)</td>
<td>Reference category</td>
</tr>
<tr>
<td>Overweight</td>
<td>53 (22)</td>
<td>187 (78)</td>
<td>1.84 (1.24–2.73)</td>
</tr>
<tr>
<td>Obese</td>
<td>12 (29)</td>
<td>29 (71)</td>
<td>1.51 (0.73–3.12)</td>
</tr>
</tbody>
</table>

†Variables included in the multivariate analysis were age, sex, ethnicity, deprivation index, residential region, milk allergy and body mass index (BMI, calculated for age and sex). Model $\chi^2$ (15)=68.57, $P<0.001$.

When ethnicity was replaced with maternal education, the same variables were found to be significant predictors of type of cows’ milk consumed (with comparable ORs).

*Cows’ milk type consumption was coded as 1 = full-fat milk and 2 = plain reduced- or low-fat milk.
Competing interests:
HM was funded to write this manuscript with a summer studentship from Fonterra Cooperative Group (Auckland, New Zealand). The funder had no input into the collection and analysis of the data, and provided peer review of the writing of the manuscript. Te Ra Whakaora study was funded by the New Zealand Health Research Council (Auckland, New Zealand).

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REFERENCES:


Rates of unsuspected thyroid cancer in multinodular thyroid disease

Miriam Karalus, Jade AU Tamatea, Helen M Conaglen, Michael Dray, Goswin Y Meyer-Rochow, John V Conaglen, Marianne S Elston

ABSTRACT

BACKGROUND: Previously the risk of concomitant thyroid cancer in multinodular goitre (MNG) has been reported as approximately 4%. Cancer risk in toxic MNG was often considered lower than for non-toxic MNG, due to a possible protective effect of TSH suppression. However, recent American data suggest an approximately 18% risk of occult malignancy in both toxic and non-toxic MNG.

AIMS: To assess malignancy risk in a New Zealand population undergoing thyroidectomy for MNG.

METHODS: Single-centre study of patients undergoing thyroidectomy for MNG from 1 December 2006 to 30 November 2016.

RESULTS: Six hundred and two patients underwent surgery for MNG (448 non-toxic and 154 toxic). Of these, 95/602 (16%) had thyroid cancer. After excluding patients operated for preoperative suspicion for cancer, 30/401 (8%) patients with non-toxic MNG and 15/151 (10%) with toxic MNG had unsuspected or occult thyroid cancer (p=0.358). Patients with toxic MNG were less likely to undergo preoperative fine needle aspiration than those with non-toxic MNG (34% vs 52%, respectively p=0.0001). Two-thirds of unsuspected thyroid cancers were incidental micropapillary carcinomas and unlikely to alter survival irrespective of therapy.

CONCLUSION: Malignancy rates in MNG are higher than historically reported, although most unsuspected cancers are unlikely to alter mortality even if diagnosis is delayed.

Multinodular goitre (MNG) is common particularly in iodine-deficient regions. Animal studies demonstrate an increased proliferative rate of thyroid follicular cells in iodine deficiency, suggesting that low iodine intake may promote thyroid cancer. It has been proposed that these rapidly proliferating cells are more vulnerable to mutagens and therefore deleterious genetic changes.

Rates of follicular thyroid cancer (FTC) and anaplastic thyroid cancer in particular have been reported to be higher in populations with endemic goitre, possibly due to chronic TSH stimulation, alone or in combination with other growth factors or goitrogens. Papillary thyroid cancer (PTC), comprising at least 80% of all thyroid cancer, appears to be relatively less common in areas of iodine deficiency than those with high or moderate iodine intake. Iodine levels have historically been low in New Zealand. However, with adequate fortification of table salt, since 1938 and iodised salt in bread from 2009, iodine intake in New Zealand is now considered adequate.

For patients with a typical MNG, clinicians typically quote the risk of thyroid cancer as being approximately 4%, however recent data suggests this may be incorrect. A North American study of 2,551 patients undergoing thyroidectomy, after excluding patients with an FNA consistent with malignant or indeterminate disease, demonstrated a 15.6% rate of thyroid cancer: 6.1% in patients with Graves’ disease, 17.5% in non-toxic nodular goitre, 18.3% in toxic nodular goitre and 4.5% in a solitary toxic nodule. The mean cancer size was 1.1cm and most (89.9%) were of papillary subtype. In contrast, a recent
Australian study showed a much lower rate of thyroid cancer with a comparable rate of PTC in patients with non-toxic MNG (5%) to those with thyrotoxicosis (Graves’ disease or toxic MNG, 6.4% and 6.8%, respectively). Similarly, a 2013 meta-analysis of five studies demonstrated a cancer incidence of 5.9% for patients with TMNG and 4.8% in those with a toxic adenoma.9

While New Zealand data on solitary cold nodules has been reported (17% cancer in a series of 100 consecutive surgically resected nodules)11 and Graves’ disease (6.8%),12 we currently have no local information on thyroid cancer rates in patients with multinodular disease. For MNG it is unknown if the international experience is applicable to the New Zealand population due to differences in micronutrient intake, carcinogen and goitrogen exposure, and genetic background. In addition, if most of the unsuspected thyroid cancers identified are micropapillary carcinomas (papillary thyroid cancer <10mm) it may not alter patient outcome if these are not identified, as the risk of dying from disease is extremely low irrespective of therapy.13–15

The aim of this study was to determine the rate of incidental thyroid cancer in a New Zealand population undergoing thyroid surgery for multinodular goitre and to identify the proportion of cancers likely to be clinically significant.

Methods

A retrospective review of all patients undergoing thyroidectomy was conducted over a 10-year period from 1 December 2006 to 30 November 2016 at Waikato Hospital, Hamilton, New Zealand, including operations performed at the private hospitals in the Waikato region.

Patients were identified from hospital coding and surgical databases. The diagnosis of non-toxic multinodular goitre (NTMNG) was based on the diagnosis of a multinodular goitre with a normal TSH level in the six months prior to surgery and no previous history of treatment for thyrotoxicosis. A toxic multinodular goitre (TMNG) was based on the presence of a multinodular goitre with a suppressed TSH <0.3mU/L, or if anti-thyroid medication was required to maintain a normal TSH and no use of exogenous levothyroxine. Patients with Graves’ disease were excluded.

Indications for surgery were determined from clinical notes. All preoperative ultrasound reports were reviewed for confirmation of diagnosis as well as for presence of features suspicious for malignancy. Results from preoperative cytology by fine needle aspiration (FNA) were reviewed for features of malignancy. Results of imaging, FNA and clinical letters were used to establish the clinical suspicion of malignancy leading to surgical treatment. All pathology reports were reviewed for final histological diagnosis. Standard pathology preparation and examination of thyroid specimens in our institution is 3–4mm slices.

Ethical approval for the project was granted by the Northern A Health and Disability Ethics Committee (16/NTA/127/AM01).

Statistical analysis was conducted using Statistica (data analysis software system, version 11. StatSoft Inc. 2012. Tulsa, OK 74104, USA) and involved descriptive statistics, followed by non-parametric comparisons. An alpha level of 0.05 was used for all statistical tests.

Results

A total of 602 patients underwent surgery for MNG during the time period studied. Of these, 448 were non-toxic and 154 toxic MNG. The median age of patients with a NTMNG was 49 years with 86% female, while the median age of patients undergoing surgery for a TMNG was 56 years and 93% were female. Demographic details are shown in Table 1.

Overall, 95/602 (16%) of patients undergoing surgery for multinodular disease had concomitant thyroid cancer. Of the TMNG group, 18 patients (12%) were diagnosed with thyroid cancer (Tables 1 and 2). In three of these cases there was preoperative suspicion for the presence of malignancy (one FNA of undetermined significance, and two in which the preoperative FNA was suggestive of PTC). After excluding these three cases, 15/151 patients (10%) had unsuspected/occult thyroid cancer. Of these 15 cases, all were PTC (12 of which were micropapillary carcinomas, ie, <10mm). Two of the 15 patients with unsuspected cancer had metastatic disease identified postoperatively (in one case nodal recurrence two years after surgery and the
other intrathoracic disease seen on post-ablative imaging). Both patients had multifocal PTC (20mm maximal diameter at initial surgery) and had received adjuvant radioiodine therapy.

Of the 448 patients who underwent surgery for a NTMNG, 77 patients (17%) had thyroid cancer (Tables 1 and 2). In 47 cases there was preoperative clinical suspicion of cancer (based on clinical, radiological and/or cytology assessment). After excluding these 47 cases, 30/401 (7%) patients had unsuspected/occult thyroid cancer. Of these 30 cancers, 25 were PTC (19 micropapillary), four follicular (all MIFC), and one medullary thyroid cancer. In only one case was there nodal or metastatic spread (a 70mm PTC within a massive MNG).

Patients with TMNG were less likely than those with a NTMNG to undergo a preoperative FNA (34% vs 52%, p=0.0001).

During the same time period an additional 24 patients underwent hemithyroidectomy for a solitary toxic nodule. No cases had preoperative suspicion for malignancy. In only one case was an occult cancer identified (3mm PTC in the centre of the toxic nodule).

Table 1: Demographic characteristics of study sample.

<table>
<thead>
<tr>
<th></th>
<th>TMNG</th>
<th>NTMNG</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total group (N=154)</td>
<td>No cancer (N=136)</td>
</tr>
<tr>
<td><strong>Age: (years)</strong></td>
<td><strong>Median (IQR)</strong></td>
<td><strong>Median (IQR)</strong></td>
</tr>
<tr>
<td></td>
<td>56 (45–63)</td>
<td>56 (44–63)</td>
</tr>
<tr>
<td><strong>Gender: N (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>141 (92%)</td>
<td>124 (91%)</td>
</tr>
<tr>
<td>Male</td>
<td>13 (8%)</td>
<td>12 (9%)</td>
</tr>
<tr>
<td><strong>Ethnicity: N (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NZE/Other European</td>
<td>83 (54%)</td>
<td>76 (56%)</td>
</tr>
<tr>
<td>Māori</td>
<td>58 (38%)</td>
<td>50 (37%)</td>
</tr>
<tr>
<td>Asian</td>
<td>6 (4%)</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>Pacific Peoples</td>
<td>1 (1%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>MEELA</td>
<td>2 (1%)</td>
<td>2 (1%)</td>
</tr>
<tr>
<td>Not stated</td>
<td>4 (3%)</td>
<td>4 (3%)</td>
</tr>
</tbody>
</table>
| **IQR = Interquartile Range; NZE = New Zealand European; MEELA – Middle Eastern, Latin American, African.**

Table 2: Cancer size and subtype.

<table>
<thead>
<tr>
<th>Cancer subtype</th>
<th>TMNG*</th>
<th>NTMNG*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total group N=18</td>
<td>Unsuspected N=15</td>
</tr>
<tr>
<td>PTC—total</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>- Micropapillary &lt;10mm</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>MIFC*</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Hurtle cell</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>MTC</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Poorly differentiated—insular/anaplastic</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

*One patient in each group had two cancer types.
Discussion

We have demonstrated an overall rate of thyroid cancer of 16% in patients undergoing surgery for multinodular thyroid disease. However, in 53% of these patients, cancer was suspected preoperatively. Interestingly only 3/18 patients with a TMNG were suspected to have cancer preoperatively compared to 47/77 of those with a NTMNG. In our cohort, all patients underwent ultrasound examination but not all patients who had biochemistry and ultrasound imaging consistent with TMNG underwent nuclear medical imaging. Therefore, in our patients a hypervascular nodule on ultrasound imaging in a patient with a TMNG may not have been recognised as a potentially malignant lesion and instead assumed to be a toxic nodule. In our institution in general we avoid FNA examination of toxic nodules as these often demonstrate atypical features such as a microfollicular pattern. Given the treatment of choice for a small thyroid cancer without any sonographic evidence of lymphadenopathy is identical to the treatment for TMNG (ie, total thyroidectomy) we believe this approach is reasonable and more cost effective than universal thyroid nuclear medicine scanning of all thyrotoxic patients. In the setting of a MNG only suspicious nodules should be targeted for FNA, and in the event of a total thyroidectomy occurring without any significant delay most intrathyroidal nodules <4cm do not require biopsy as it would not change surgical management (other than consideration of prophylactic central compartment neck dissection in the setting of papillary or medullary thyroid cancer). However, each patient should be evaluated on his or her own merits. Obvious exceptions include likely extrathyroidal extension, associated laryngeal nerve palsy and radiological evidence of cervical lymphadenopathy.

While recent reports suggest that a suppressed TSH does not exclude the development of thyroid cancer patients with a TMNG appeared to have a lower degree of suspicion for cancer in patients with a TMNG. This is supported by the lower rate of FNA in this group, although the rate of unsuspected/occult thyroid cancer was not different in the TMNG group when compared to those with NTMNG (9.9% vs 7.5%, respectively). The overall cancer rate between the two groups was also not different (11.7% in TMNG vs 17.2% in the NTMNG cohort). While these cancer rates may be of concern to patients, it is reassuring that most (12/15) of the unsuspected cancers in a TMNG were micropapillary. While micropapillary thyroid carcinomas not uncommonly involve local lymph nodes and can be associated with distant metastases in rare cases, the risk of dying from disease is extremely low irrespective of therapy. As such, it is likely that for most patients not identifying a micropapillary carcinoma would not result in any increased morbidity or mortality and may avoid both the anxiety that often comes with a diagnosis of cancer and the potential disadvantages of overtreatment. This differs from the recommendation by Smith et al, who suggest that the high cancer rates in patients with TMNG should impact the clinical decision in terms of choice of definitive therapy. In that study of 164 patients with TMNG the largest unsuspected cancer was 1.5cm, although two patients did have local lymph node involvement. In patients with a TMNG the usual alternative therapy to surgery is radioiodine (RAI) and it is possible that RAI, even at the low doses used for thyrotoxicosis, may be of therapeutic benefit and result in ablation of an incidental papillary microcarcinoma.

Our findings demonstrate a significantly lower rate of unsuspected cancer than that reported by Smith et al. The reasons for this are unclear. One limitation of these retrospective studies is the lack of standardisation of pathological examination of the specimen. The rate of microcarcinomas in particular will be influenced by how carefully the specimen is examined. Smith did not report histology section thickness or whether all three pathologists performed the same slice thickness when sectioning the samples, but of note there was no difference in identified cancer rates between the three institutions within that study. Our cancer rates are closer to that of two Australian studies. It is possible that our populations are better matched in terms of risk factors (eg, both are currently deemed iodine adequate). However, another possibility is that pathological examination of the thyroid
is similar across both countries with both New Zealand and Australian pathologists undergoing similar training and presumably following the Royal College of Pathologists of Australasia guidelines. However, these guidelines are relatively recent and so there would have been less standardisation in the earlier years of the cohort. In addition, not all pathologists in our centre come through Australasian training and therefore some may not follow these guidelines. Furthermore, the entire thyroid gland is not examined microscopically with some blocks taken from routine or random parts of the gland while others are selected due to abnormal gross appearance or texture. As such it is likely that we may be underestimating the true incidence of unsuspected thyroid cancer. The hypothesis that the higher rate of cancer identified may be related to increased pathological sampling is supported by a study which demonstrated an increase in thyroid cancer diagnosis in retrosternal goitre over time from 3.6% to 7.5%, which was associated with increased pathological sampling of resected specimens.

In summary, we have demonstrated that cancer in a multinodular goitre is common. However, it is likely that most of these occult thyroid cancers are not clinically significant and will not increase mortality. As such we would not necessarily recommend surgery over RAI for TMNG because of concerns regarding cancer risk in the absence of other indications for thyroidectomy.

**Competing interests:**
Nil.

**Acknowledgements:**
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A systematic review of leadership training for medical students
Oscar Lyons, Bruce Su’a, Michelle Locke, Andrew Hill

ABSTRACT
BACKGROUND: Leadership is increasingly being recognised as an essential requirement for doctors. Many medical schools are in the process of developing formal leadership training programmes, but it remains to be elucidated what characteristics make such programmes effective, and to what extent current programmes are effective, beyond merely positive learner reactions. This review's objective was to investigate the effectiveness of undergraduate medical leadership curricula and to explore common features of effective curricula.

METHODS: A systematic literature search was conducted. Articles describing and evaluating undergraduate medical leadership curricula were included. Outcomes were stratified and analysed according to a modified Kirkpatrick's model for evaluating educational outcomes.

RESULTS: Eleven studies met inclusion criteria. Leadership curricula evaluated were markedly heterogeneous in their duration and composition. The majority of studies utilised pre- and post-intervention questionnaires for evaluation. Two studies described randomised controlled trials with objective measures. Outcomes were broadly positive. Only one study reported neutral outcomes.

CONCLUSIONS: A wide range of leadership curricula have shown subjective effectiveness, including short interventions. There is limited objective evidence however, and few studies have measured effectiveness at the system and patient levels. Further research is needed investigating objective and downstream outcomes, and use of standard frameworks for evaluation will facilitate effective comparison of initiatives.

Effective leadership is vital in implementing health improvements at both clinical and system levels. In health, effective leadership involves utilising social influence and advocacy to anticipate and act on health challenges for a positive outcome. Ineffective leadership has been shown to have an adverse effect on team performance and patient outcomes. Effective leadership, however, significantly improves these outcomes and therefore many major health institutions have incorporated effective leadership as a core competency skill expected of health professionals.

To address this demand, leadership training has since been implemented within medical school curricula, from pre-clinical to clinical and later through to residency and beyond. Although leadership programmes have been well received by both medical students and faculty, little objective data is available to analyse outcomes, and little is known of how such skills translate beyond medical school. Further, determining the optimum time to implement such courses remains unclear. This systematic literature review therefore aims to collate studies that have incorporated leadership courses within medical school curricula, and have evaluated their effectiveness in an objective manner.

Methods
Search strategy and information sources
This systematic review was performed in accordance to the PRISMA statement (Preferred Reporting Items for Systematic Reviews and Meta-analysis). Five databases were systematically searched: Excerpta Medica database (EMBASE); Education Resources Information Centre (ERIC);
Medline; PsychINFO; and PubMed (National Library of Medicine). Keywords were “leadership”, “medical student” and “education”, and were also mapped to medical subject headings (MeSH terms) and exploded. The initial search was completed on 20 May 2016 by OL and ML. Reference lists of articles that were selected for full text review were manually searched for additional studies.

Article selection
The title and abstract screen was performed independently by two authors (OL, ML). All articles concerning leadership training and medical students were selected for full text review. Full text reviews were performed (OL, BS). The Kirkpatrick model for assessment of training outcomes with the BEME modification32 was applied to studies measuring level 2 or higher, as shown in Table 1. This selection criteria allows for objective outcomes to be analysed.

Inclusion and exclusion criteria
Studies where a leadership training intervention was described and implemented within a medical students’ population, and having outcomes reported at Kirkpatrick’s level 2 or higher were included in this review. Studies without a full text available, and not in English were excluded.

Data abstraction
Data from included studies were abstracted into a Microsoft® Excel® (2013) spreadsheet using a modified BEME coding sheet by two authors (OL, BS). Any uncertainties were resolved by consensus.

Data analysis
Study outcomes were categorised according to the BEME modification to Kirkpatrick’s model for evaluation of effectiveness of teaching. This model has been used by several BEME collaborations and was recently adapted by Steinert et al for leadership initiatives in medicine.32

Risk of bias
Risk of bias was evaluated according to the Cochrane Handbook for Systematic Reviews of Interventions.33 This tool assesses bias through seven areas: random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, selective reporting and other sources of bias. Each study was given an overall quality rating (1=low; 5=high) and reviewers were asked to comment on strengths and weaknesses.

Table 1: Description of Kirkpatrick’s levels for evaluating educational outcomes and levels.

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 2A</td>
<td>Change in attitudes</td>
<td>10 (91%)</td>
</tr>
<tr>
<td></td>
<td>Changes in the attitudes or perceptions among participant groups towards leadership, management and/or administration.</td>
<td>10 (91%)</td>
</tr>
<tr>
<td>Level 2B</td>
<td>Change in knowledge or skills</td>
<td>5 (45%)</td>
</tr>
<tr>
<td></td>
<td>For knowledge, this relates to the acquisition of concepts, procedures and principles; for skills, this relates to the acquisition of thinking/problem-solving, psychomotor and social skills.</td>
<td>5 (45%)</td>
</tr>
<tr>
<td>Level 3A</td>
<td>Behavioural change (self-reported)</td>
<td>9 (82%)</td>
</tr>
<tr>
<td></td>
<td>Documents the transfer of learning to the workplace and changes to professional practice, as noted by participants.</td>
<td>10 (91%)</td>
</tr>
<tr>
<td>Level 3B</td>
<td>Behavioural change (observed)</td>
<td>7 (64%)</td>
</tr>
<tr>
<td></td>
<td>Documents the transfer of learning to the workplace and changes to professional practice, as noted by a third party.</td>
<td>7 (64%)</td>
</tr>
<tr>
<td>Level 4</td>
<td>Results</td>
<td>4 (36%)</td>
</tr>
<tr>
<td></td>
<td>Change in the system/organisational practice refers to wider changes in the organisation, attributable to the educational programme.</td>
<td>4 (36%)</td>
</tr>
</tbody>
</table>

Number refers to the studies which demonstrated outcomes at each level, and percentages (out of 11 studies) are included. For level 2a/b and 3a/b, an additional combined number has been added. Level 1 was not included in this review, as discussed in the text.
Results

In total, 1,248 unique papers were identified and screened, of which 11 studies were included in review (Figure 1). Ten of the studies reported positive outcomes while one reported a neutral outcome. A summary of included studies is shown in Table 2. The majority of the included studies were quasi-experimental, with two randomised controlled trials and two observational studies.

Table 2: Summary of included studies.

<table>
<thead>
<tr>
<th>Author</th>
<th>Study design</th>
<th>Intervention (follow-up)</th>
<th>Learners (n)</th>
<th>Outcome summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bergman²⁵</td>
<td>Quasi-experimental repeated measures</td>
<td>Short course (no long-term follow-up)</td>
<td>Clinical (160)</td>
<td>Level 2a Increased openness to learning about healthcare team members. Subgroup changes: increased “attitudes to openness and group dynamics” and “openness in the professional role”</td>
</tr>
<tr>
<td>Carufel-Wert²⁶</td>
<td>Observational</td>
<td>Longitudinal (no long-term follow-up)</td>
<td>Both (50)</td>
<td>Level 2a Increased interest in taking leadership positions; increased desire to remain in medical school</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Level 2b Increased perceived ability to be an effective leader</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Level 3a Increased interactions with those in the leadership group</td>
</tr>
</tbody>
</table>

Figure 1: PRISMA Flow diagram.
Table 2: Summary of included studies (continued).

<table>
<thead>
<tr>
<th>Article (Year)</th>
<th>Study Design</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coleman (2012)</td>
<td>Quasi-experimental repeated measures</td>
<td>Short course (followed up at 8 months and 18 months)</td>
<td>Both (11)</td>
</tr>
<tr>
<td>Goldstein (2009)</td>
<td>Quasi-experimental repeated measures</td>
<td>Short course (no long-term follow-up)</td>
<td>Pre-clinical (&gt;24)</td>
</tr>
<tr>
<td>Hunziker (2010)</td>
<td>Randomised controlled superiority trial</td>
<td>Workshop (followed up at four months)</td>
<td>Pre-clinical (237)</td>
</tr>
<tr>
<td>Meier (2012)</td>
<td>Quasi-experimental repeated measures</td>
<td>Short course (no long-term follow-up)</td>
<td>Clinical (17)</td>
</tr>
</tbody>
</table>
**Table 2:** Summary of included studies (continued).

<table>
<thead>
<tr>
<th>Author and Year</th>
<th>Study Design</th>
<th>Intervention Duration</th>
<th>Control Group</th>
<th>Intervention Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meurling (2013)</td>
<td>Quasi-experimental repeated measures</td>
<td>Workshop (no long-term follow-up)</td>
<td>Clinical (54)</td>
<td>Level 2a: No change in mental strain or concentration, Level 3a: Increased self-efficacy scores, Level 3b: No significant changes except increased frequency of sum-ups, Level 4: No change (no groups achieved this in any scenario)</td>
</tr>
<tr>
<td>Smith (2007)</td>
<td>Quasi-experimental repeated measures</td>
<td>Short course (11 months)</td>
<td>Both (23)</td>
<td>Level 2a: Improved attitude towards leadership behaviours, Level 2b: Increased skills (self-reported, not tested), Level 3a: Higher exhibition of leadership behaviours, Level 3b: Completion of project in 13/23 students, Level 4: Projects reached &gt;600 students at 11 institutions (self-reported)</td>
</tr>
<tr>
<td>Warde (2014)</td>
<td>Quasi-experimental repeated measures</td>
<td>Short course (no long-term follow-up)</td>
<td>Pre-clinical (20)</td>
<td>Level 2a: No change in Relational Coordination Scale scores, Level 3a: No change in Leadership Practices Inventory scores</td>
</tr>
<tr>
<td>Wayne (2010)</td>
<td>Randomised controlled superiority trial</td>
<td>Tutorial (no long-term follow-up)</td>
<td>Pre-clinical (158)</td>
<td>Level 2a: Interviewees indicated more positive attitude towards leadership, Level 3a: Interviewees indicated acting as leader as a result of the instruction, Level 3b: Percentage female leaders increased from 27% to 47%</td>
</tr>
</tbody>
</table>

Intervention specifically addresses the length of intervention rather than curriculum content, which is described in the text. Outcome summaries are stratified according to the modified Kirkpatrick framework as described in Table 1.
Setting

Eight of the 11 studies were conducted in the US, two in Sweden and one in Switzerland. The majority of these were in single centres. Two studies selected participants from across the US and Canada, and one study included all eligible participants across six MD-MBA conjoint degree programmes in the US.

Participant selection

Participant numbers ranged from 11 to 237 as shown in Table 2. Most studies included a subgroup of a medical school cohort, with one including an entire cohort and three including participants from multiple medical schools. One study did not report the number of participants.

There was significant variation in selection criteria and the number of participants. Three of the 11 studies evaluated a compulsory component of a course: two of these allowed students to opt out of the evaluation, though not the training itself; one did not allow students to opt out of the evaluation. Four studies offered open, optional training and evaluation to an entire cohort or from the portion of a cohort enrolled in a particular elective. The remaining four studies required participants to submit a written application, and chose a small number of students judged to already have significant leadership potential.

Intervention

Interventions varied in the setting, materials, length of course and stage of the programmes evaluated.

Course implementation

Four studies focused on pre-clinical students, three on clinical students and four on both (see Table 2).

Course intervention setting

Most studies incorporated some component of experiential and reflective learning, though the format of this was generally poorly reported. Three studies used a simulation centre for their study. Two studies employed a practical community component, and Wayne et al utilised a small-group tutorial for their study. Methods of reported teaching included readings, discussions, simulation, community projects and video instructions, in various iterations.

Course duration

The durations of the intervention were markedly heterogeneous and ranged from the addition of two sentences to a standard instruction, to implementing a longitudinal course over a degree.

Seven studies comprised workshops conducted either in a single day or in short courses of one week to one semester in duration. Only one study delivered their initiative in more than one discrete course.

Course programmes utilised

Carufel-Wert et al and Sherrill et al evaluated existing programmes, whereas the other nine studies evaluated new or significantly altered programmes. Eight studies assessed outcomes immediately post-intervention only. Longer-term outcomes were assessed in three studies only: at four months; 11 months; and separately at eight and 18 months.

Course outcomes

Outcomes were assessed at Kirkpatrick level 2 in 10 studies, at level 3 in 10 studies, and at level 4 in four studies (see Table 1). The majority of these outcomes were self-reported.

Included study goal

Included studies had varied aims and objectives. Eight studies broadly evaluated a new or existing leadership intervention for its utility in medical students. The remaining three studies had main intentions to outline student characteristics, determine whether gender bias in leadership could be reduced and to explore individual experiences and behaviours of leaders and followers, respectively.

Study design

Each quasi-experimental study utilised repeated measures without a control group. Two studies elected to conduct both the pre- and post-intervention surveys concurrently at the end of the intervention.

Carufel-Wert et al and Sherrill et al conducted cross-sectional studies of participants post-intervention, and relied on participants to attribute outcomes to the intervention subjectively.
Data collection methods

The most commonly used data collection tool was a self-reported written questionnaire, utilised in nine of the 11 studies.18–20,22–24,26–28 Self-efficacy was used in six studies as a proxy for objective ability.18,19,22,23,27,28 Video analysis was employed in three studies,21,27,28 with the observers specifically blinded to participant status (pre- or post-intervention) in two studies.27,28 Interviews were conducted as part of the evaluation in four studies.18,20,22,25 Only one study used direct observation as the main evaluation tool.25

Study quality/overall risk of bias

The mean study quality score was 3.1 out of a possible five. Randomisation was used in two studies,21,25 with participant blinding conducted in only one study.25 Included participants were in several trials either an elite subgroup of medical students19,23,24 or a small subgroup.18,20,22,27,28 Results were self-reported in the majority of studies.18–20,22–24,26–28

Discussion

This systematic review identified 11 studies investigating the effectiveness of leadership training programmes in medical school at outcome levels beyond Kirkpatrick level 1. There was a diversity of methods employed in these studies, in terms of length, type, materials, setting and stage of medical students. The reported results demonstrate that despite this diversity, programmes were broadly found to improve knowledge and skills of leadership, influence attitudes and promote leadership behaviour in medical students. There were indications that there may be positive downstream outcomes, though these were not well described.

Despite heterogeneity, studies produced broadly positive results. This leads to some tentative suggestions for future design of leadership programmes. Interventions tended to utilise a combination of didactic learning, tutorials and reflective learning. The effectiveness of a programme within medical school did not seem to be influenced by preclinical or clinical implementation, suggesting that both may be effective. Furthermore, because all durations of intervention showed positive results, long and complex courses may not be required to achieve positive change; short, punchy courses with clear objectives may well be as effective. Given already packed curricula and the financial benefit of running courses of short duration, this would be a valuable area to explore further.

This review differed from those previously published by focusing on outcomes at Kirkpatrick level 2 or higher. While this limited the number of studies eligible for inclusion, it enabled the authors to highlight more objective outcomes. The increase in studies reporting these higher-level outcomes is in line with recommendations from previous reviews,19 and could indicate an increased awareness of researchers of the need to establish firm outcomes.

Over the last decade there has been a marked increase in the number of medical schools offering leadership curricula. A literature search by O’Connell and Pascoe in 2004 only returned 15 articles with any degree of relevance.34 Ten years later, despite using more specific search terms, Webb et al found 45 articles, each describing a curriculum to teach leadership to undergraduate medical students.17 While a significant proportion of medical knowledge is imparted didactically, role modelling and practical experience remain vital to medical education.35,36 Given variation in clinical experiences and role models encountered by students,36,37 and the increased importance placed internationally on development of clinical leadership abilities,8–12,14–16,38 it is logical that medical programmes should move towards formal leadership training.

One of the clear limitations of the studies reviewed was a lack of objective measures of effectiveness of leadership training. There is an established connection between self-efficacy and leadership, but it remains a subjective measure of leadership effectiveness. Whereas clinical ability has been reliably assessed via an Objective Structured Clinical Examination (OSCE),39 and teaching ability has been assessed via an Objective Structured Teaching Examination (OSTE),19,40 there is not yet an established means of objectively measuring leadership effectiveness. In order for the quality of different interventions to be compared, it is important for a reliable measurement tool to be developed and accepted within
the literature. Furthermore, the use of a standardised framework for evaluation of training programmes (such as Kirkpatrick’s model) and the reporting of results in a systematic manner based on such frameworks will enable future reviewers to more easily ascertain components and characteristics of leadership training curricula that determine their success.

The lack of a widely-accepted definition of clinical leadership and what it entails further complicates training, assessment and comparison of approaches. Definitions of leadership present a plethora of core attributes that may or may not have been covered by the curricula evaluated in the included studies. A consensus on the definition of clinical leadership may help streamline future courses and facilitate more robust and comparable evaluation based on an objective definition.

Despite a search strategy designed for high sensitivity, the lack of standardisation of medical education article databases necessitates parallel approaches to literature searching as employed in this review, and increases the risk of missing relevant publications.43 The limited utilisation of established frameworks for evaluation of teaching required the researchers to categorise research outcomes manually and in some cases required consensus decisions. Heterogeneity of interventions and evaluations precluded meta-analysis, and reduced the external validity of conclusions made.

**Conclusion**

In summary, the evidence evaluated by this review supports further development and evaluation of leadership training programmes in medical schools. There is broad agreement in the studies reviewed that the programmes evaluated resulted in positive outcomes for learners. Objective measures of leadership training effectiveness need to be developed however, and an emphasis placed on evaluation of systemic and patient outcomes. The reviewers recommend that further research focuses on the use of recognised training evaluation frameworks for their research and reporting, and on the evaluation of objective and downstream outcomes. Further standardisation will afford increased applicability and comparability to studies. This will be an important step towards elucidating characteristics of programmes which are important for success.
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We write concerning the Report on Euthanasia for the New Zealand Medical Association by Grant Gillett. His report, for many of us, proved difficult to read. It is both confusing and confused, sometimes conflating relevant and irrelevant issues, and parts of it are inaccurate. His claims are not well supported by the copious data available in the public domain.

Gillett’s claims to represent other doctors are debatable. The NZMA is an organisation to which fewer than 50% of doctors subscribe; clearly it does not represent all of us, nor has it seen fit to obtain the current views of its membership. We congratulate the NZ Nurses Organisation which has done so, and has issued a new position statement favourable to Voluntary Assisted Dying (VAD) to support the views of its membership.

What 70–80% of New Zealanders want, according to repeated surveys, are sound, well-drafted laws with appropriate safeguards to enable sane, rational, dying adult New Zealanders to be able to access help to end their lives; when, where and with whom they choose; in order to end or avoid irreversible suffering that is unbearable to them. Either by taking appropriate prescribed medicine themselves or by accessing medical help to do so. These principles and safeguards are well described in the End of Life Choice Bill (David Seymour) at present in Parliament, and the first reading has now been passed by a large majority.

To address some of the themes in Gillett’s paper:

1. Hippocratic Oath and sanctity of life—the Hippocratic Oath is now rarely used, although the basic assumption “in favour of life” is still a central tenant to medical practice. However, for the individual, life is precious only when it is worthwhile. An existence of unbearable suffering is not one many of us would choose, and in this situation death is not the worst thing.

2. Hospice/palliative care (H/PC)—there need be no conflict between H/PC and VAD as shown in other legalised jurisdictions eg, Belgium, Oregon, the Netherlands and Canada. They can and do work together in synergy. Where legalisation of VAD has occurred, referral to H/PC is often a mandatory part of the process of accessing such help, and VAD advocates support of the development of excellent H/PC. As a result, H/PC funding has increased and the quality of the services has improved. However, it has been shown across the world that H/PC cannot prevent all suffering. An Australian study in 2016 showed that 10–20% of patients on H/PC programs experience unbearable pain/suffering as they die. H/PC is generally good at providing pain relief, however, pain is no longer the most feared issue. Fears of being helpless/hopeless and unable to end it rate higher. Furthermore, there is, as elsewhere, a major shortage of palliative care experts in New Zealand, H/PC.
remains relatively underfunded and access to care and quality of care is variable. Four times as many patients die in rest homes as in hospice, and often the expertise available to prevent suffering is totally inadequate.  

3. Vulnerable patients—there is no evidence that vulnerable patients are at risk of abuse from VAD. Government reports, studies and information from the major patient advocacy groups (including disabled and elderly representatives) clearly demonstrate this fact. Data from Oregon suggests that those who access their legislation are the better educated, not the poor, elderly or disabled. Gillett suggests that “life ending acts without explicit consent” are a problem in Belgium. The authors in the first reported study in 2010 which suggested that this is relatively common, have gone back and made a more detailed study. They reported in a second paper in 2014 that most of these patients were simply having symptom treatment with the usual drugs, ie, sedative drugs, similar to what New Zealand doctors often give at the end of life, not euthanasia drugs.

4. Conflating suicide with VAD—irrational suicide is totally different from VAD. Irrational suicide—such suicide is impulsive, often violent and causes extreme distress to family and friends. Almost always the mental condition which leads to the act is treatable and hence reversible.

VAD is where at the request of the patient, the physician prescribes appropriate medication, which the patient takes themselves to end their life, or the physician directly administers the medication, usually intravenously. Both types of VAD are beneficial to the patient, prevent suffering, are a compassionate act from the doctor, respectful of the patient’s autonomy, a logical extension of medical treatment and allow the relatives and friends to say goodbye before the ravages of disease and intense sedation make this impossible.

They also allow some ceremony and spiritual and religious involvement. Knowing that such an option is available to them also gives the patient peace of mind; even if eventually they do not use it, it improves quality of life and may promote prolongation of life.

Irrational suicide replaces life with death, but VAD replaces a bad death with a good one.

Quote: “It is insulting to assume that patients who request VAD are clinically depressed. Most are just realistic. They know what lies ahead and they would rather not continue with it. Let’s be honest; despite our best efforts, some deaths are simply too horrible to believe.”

5. Does VAD encourage irrational suicide?—There is no evidence that VAD encourages suicide. Luxembourg, Switzerland and Belgium have decreased rates. Oregon statistics are the same as they were more than 10 years prior to legalisation. The Netherlands rate (10/100,000) is the same as 10 years prior to legalisation, and is lower than most of the other European countries not legalised, and New Zealand, which is over 15/100,000 includes the highest teen suicide rate in the world.

6. Bonding between patients and relatives at end of life—while this time can undoubtedly be a precious time, it can also be a time of unbearable suffering for the person dying and for those who care about them and for them; each bad death affects many people.

In the submissions to the Select Committee on Assisted Dying there are over 1,000, describing exactly such deaths, written by relatives who have been left with horrible memories. Such traumatic deaths are never forgotten and cast a long shadow.

7. Abandonment of the patient—Gillett states that “many people need support and reassurance that they are not being abandoned”. Possibly the worst form of abandonment is when the doctor because of his/her ideology refuses to listen and act on the request of the patient for help to die. There
is abundant literature from legalised jurisdictions to show that when the doctor listens and offers help, that individuals feel a sense of empowerment, and the reassurance of a way out helps them with the remainder of their life, often prolonging it. Furthermore, they develop a strong trust in their doctor. Katherine Morris, Surgical Oncologist, New Mexico, describes her experience supporting the above where she assisted some patients to die.11

8. Severe brain damage and severely compromised children—Gillett discussed both these issues at length, and although interesting in themselves, they are irrelevant to proposed VAD legislation in New Zealand, which requires a minimum age of 18 and the patient to be competent.

9. Futility—Gillett explores the academic ethical issues around futility. Suffice it to say that both H/PC and VAD accept that some situations are clearly futile and alter the directions of their treatment, as do many doctors in their routine practice, eg, withdrawal of life support in intensive care.

10. What do doctors and nurses really think about VAD?—The limited evidence we have from surveys of New Zealand doctors is that 35–50% support VAD.12–14 The NZ Nursing Organisation (70,000 members) has a position statement supporting VAD, as does the Australian Nursing Federation. Surveys have indicated that 65–70% of nurses in New Zealand are supportive of VAD.14 Formal evidence is only part of the picture, and anecdotal evidence suggests that many doctors are neutral or supportive but fear admitting this openly in the current organisational climate. Gillett suggests that doctors are not at all supportive and should keep out of the area of assisted dying due to the moral problems. To many doctors the moral issues associated with not being able to relieve suffering in the way that the patient wants, constitute a greater moral burden, and some disobey the law and deliberately help patients die illegally.15 The Royal Australian College of General Practitioners now supports VAD as does the Australian Medical Students Association—the coming generation of doctors.

The Canadian Medical Association (2014) states that “physicians are committed to providing high-quality care at the end of life. They are also committed to maintaining their patients’ quality of life. There are rare occasions where patients have such a degree of suffering, even with access to palliative and end of life care, that they request medical aid in dying. In such a case, and within legal constraints, medical aid in dying may be appropriate. The CMA supports patients’ access to the full spectrum of end of life care that is legal in Canada. The CMA supports the right of all physicians, within the bounds of existing legislation, to follow their conscience when deciding whether to provide medical aid in dying...”.

It is obvious that there is gathering support from doctors across the world, and this increases as legalisation occurs and doctors realise that abuse is not occurring.

To conclude, it is unfortunate that the NZMA has given approval to this Gillett paper on euthanasia. The report is not independent, in that Gillett is an overt opponent of VAD, and furthermore has been on the Ethical Committee of the NZMA, which has also consistently opposed VAD. With the strong likelihood that VAD will be legalised in both New Zealand and Australian States in the near future, it is important that medical practitioners and representative bodies such as the NZMA and Colleges recognise the expressed community need and are involved in the changes necessary to draft good safe legislation in response.
LETTER

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Nil.

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Publication and authorship challenges experienced by medical students involved in biomedical research

Ibrahim S Al-Busaidi

Physician-scientists are defined as individuals who combine clinical practice with biomedical research. By virtue of their integrated experiences in clinical practice and biomedical research, physician-scientists are well positioned to advance the field of medicine. Most future physician-scientists develop an interest in pursuing a career in academic medicine at some point during their medical training. This interest is often kindled and further reinforced by positive research experiences working with established physician-scientists.

Unfortunately, recent reports indicate that the size of the physician-scientist workforce is declining. Engaging medical students in research is regarded a key factor in reversing this trend and revitalising academic medicine. Although early involvement in research is associated with improved short-term and long-term academic productivity and increased interest in a research-focused medical career, disincentives to a career in academia may actually arise as an unintended consequence of these educational efforts.

Negative early research experience has been found to be a major factor in discouraging medical students from entering academic careers. Medical students report lack of acknowledgement of their contributions to research projects as a key barrier to further participation in research. When involved in research, students are often tasked with data collection and subsequently excluded from manuscript preparation and publication. This is complicated by students’ naiveté regarding what constitutes substantial participation in the research process, the level of involvement that warrants acknowledgement or authorship. More worryingly, even when junior scholars have contributed significantly to the research effort, their expectations for authorship membership and order may not be fulfilled, thus discouraging and stifling continued interest in academia. These factors may serve as early deterrents for medical students who may be oriented towards academic medicine. Furthermore, missed opportunities by senior researchers to encourage and mentor aspiring medical students may contribute to the already leaky physician-scientist workforce.

Medical students need the ability to navigate the collaborative research process competently in order to achieve the kind of positive experience that may foster continued interest in research. Aiming to improve medical students’ knowledge of one aspect of this process, basic publication ethics, this article outlines two authorship-related conflicts commonly encountered by medical students and provides guidance about how to avoid/manage them.

1. Authorship status

Scenario: “After being approached by a resident conducting a residency programme-required research project, I agreed to participate in data collection with the view to be included as an author. The project was published but I was not listed as a co-author. Has my name been wrongly omitted?”
Ethical and accepted practices

Authorship requires fulfillment of the four criteria based on the Vancouver guidelines put forward by the International Committee of Medical Journal Editors. All contributors who do not qualify for authorship (such as by participating in either data collection or manuscript proof reading) should be listed in the acknowledgement section with a description of their contribution(s).9

Recommendations

• Medical student research involvement is often limited to information gathering or data processing.6 This by itself does not justify authorship.
• At the outset of research involvement, determine your expected contribution and whether it meets authorship criteria.
• Consider using a written co-author agreement, formal or informal, to clearly establish roles of collaborators and facilitate open and honest communication between individuals involved in the project.

2. Order of authorship

Scenario: “After I drafted the manuscript for publication from my summer studentship, my supervisor submitted the article after reviewing it with me being the second author. May I protest this decision?”

Ethical and accepted practices

• Authorship order should be a joint decision of the co-authors.9
• Some research groups list authors alphabetically followed by a description of each author’s contribution.
• It is common practice that the first author is granted to the project member who has made the greatest contribution to the project, often the one who drafts the manuscript. Other factors may play a major part in deciding authorship order include proposal writing and obtaining research funding.

Recommendations

• Whenever possible, discuss and decide on the membership and order of authorship early in the research process and summarise the decision, preferably in writing.10
• In cases of disputed authorship:
  Pre-publication: Inform your supervisor that you are unhappy about this decision. If no progress is made, consider appealing to the head of department or research office in which the project was conducted.
  Post-publication: First discuss this with the other authors. Often, it is necessary to inform the journal’s editor and involve the concerned institution(s).

Conclusion

There is a perceived lack of awareness regarding publication ethics among medical students and novice researchers.8 Addressing this problem should start in medical school through the introduction of publication ethics teaching, preferably as part of literature appraisal and research methodology training. Furthermore, students involved in research should familiarise themselves with basic publication ethics and the Vancouver guidelines put forward by the International Committee of Medical Journal Editors.4 To prevent authorship disputes, the following issues should be discussed and documented in writing early in the research collaborative process: 1) degree and nature of contribution to the project and whether authorship criteria are met by each contributor, 2) order of authorship and 3) a written co-author agreement.

Positive research experiences during medical school have the potential to contribute immensely to the development of the physician-scientist workforce, the backbone of academic medicine. Medical students interested in research should be guided by structured programmes to promote research opportunities, offer full and authentic participation in research and provide an inspiring research environment and mentorship. Future research should focus on overcoming the above described challenges and exploring ways to improve medical student research and mentoring experiences.
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We would like to thank Dr Alamri¹ for his interest in our recent article² evaluating research opportunities available to medical students in New Zealand. We identified a range of formal and informal student research training opportunities, which Dr Alamri has classified as short-, medium- or long-term in duration.¹ The amount of time dedicated to different research projects may vary considerably, reflecting the variety of research opportunities on offer to medical students in New Zealand.²,³ The duration of an undergraduate research activity generally reflects the degree of a student’s commitment to an academic career pathway, and it is unlikely that a student’s first research experience will be a long-term project such as an intercalated BMedSc(Hons) or a PhD. Most students will engage in undergraduate medical research in a step-wise progression from involvement in short and simple research projects (eg, summer studentships and clinical audits) to longer and more complex projects (eg, intercalated thesis-based degrees). However, Australasian medical students do not necessarily view this as a “straightforward pathway”,⁴ perhaps reflecting the lack of defined training pathways for clinical academics in these countries.⁵ The establishment of well-defined undergraduate and postgraduate training pathways for clinical academics may support students in New Zealand and Australia to pursue this career route.⁴,⁵

We note with interest Dr Alamri’s correspondence with the Auckland Medical School regarding the intercalated MBChB/PhD programme.¹ Based on one of the present authors’ personal experiences, The University of Auckland does not currently offer a formal intercalated MBChB/PhD pathway similar to Otago’s.² For a medical student to enter a PhD programme without having a prior research-based degree (eg, Master’s), or to “convert” from a BMedSc(Hons) to a PhD, a student would require dispensation from the Board of Graduate Studies, an option which has not previously been tested at The University of Auckland. We look forward to the establishment of a formalised MBChB/PhD pathway at The University of Auckland, similar to that currently offered at Otago and other overseas universities.⁶,⁷ Intercalated higher degree programmes have been shown to be very successful in developing clinical academics,⁸,⁹ though the uptake of these opportunities in New Zealand is very low.³,⁷,⁹ Furthermore, medical students’ attitudes towards and involvement in, and outcomes of the MBChB/PhD programme at The University of Otago have not been studied.²

Multi-centre student-led collaborative research projects present a novel opportunity for students as a short-term extracurricular research activity. Students and trainees may each contribute a relatively small part to a larger study, helping with local participant recruitment and data collection. Collaborative studies have become very popular in the UK and Europe, and are now beginning to emerge in Australasia; the student and trainee-led IMAGINE study run by the EuroSurg Collaborative is a recent example of such an opportunity.¹⁰

While the duration of a research project is an important factor to consider when evaluating opportunities available to students, there are numerous other factors influencing a student’s overall success. These include student motivation, the quality of the project itself, quality of supervision/mentorship, availability of financial support, protected time, and flexibility for family and work-life balance.²,⁴ If motivated students are identified, supported and provided with
structured opportunities to meaningfully engage with research during medical school, they will enjoy their time in academia, will engage in subsequent, longer-term scholarly and research activities and ideally will be retained in an academic training pathway.

The academic community should promote research as an important aspect of excellence in patient-centred care, aiming to move beyond the “CV-filler” or “tick-box” mentality held by some students.

As research opportunities at the undergraduate and postgraduate levels continue to emerge and develop in New Zealand, it is important that these are incorporated into defined, flexible pathways for the training of clinical academics.4,5 If students and trainees are supported during their research experiences, they will be more likely to have positive experiences, and continue to make long-term contributions to academic medicine throughout their careers.

Competing interests:
Nil.

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Grant Gillett in his Report on Euthanasia for the New Zealand Medical Association suggests that it is a permissive law change which has seen abortion change from being a stigmatised, backroom activity to being an acceptable alternative for a woman with an unwanted pregnancy, and uses this example to warn of the risks that permissive legislation may bring to societal moral standards. Some may refer to this as the slippery slope argument although Gillett does not go as far as this, stating it is unclear whether such slopes exist. There are many other factors which have contributed to the change in attitude to abortion and it is unhelpful in this context to link the 1977 abortion legislation to any pending legislation on euthanasia. Since a peak of 20.8 abortions per 1,000 women aged 15–44 years in 2003, the general abortion rate has gradually and significantly declined to 13.5 in 2016 without any change in the law.¹

Abortion and euthanasia share some superficial similarities. Both involve loss of life and have been practised outside clinical contexts for aeons but are increasingly medicalised partly for reasons of safety. Both involve the person most concerned making decisions for themselves that are forbidden by some religions. Compassion is a common feature of both. However there are substantive differences:

- Most obviously they occur at opposite ends of the life span, raising different issues.
- Abortion is more time sensitive; the earlier it happens, the safer it is for the woman.
- Abortion is now a common gynaecological procedure affecting one in four women in OECD countries. Euthanasia, where permissible, is uncommon.
- Euthanasia is a possibility for anyone on the gender spectrum. Abortion is a woman’s issue and has historically been subject to all the oppressions and degradations associated with being a woman in a patriarchal society hostile to women’s autonomy.
- To some, euthanasia is possibly more ethical than abortion, because the patient is competent and actually makes the request themselves whereas the life that is lost in abortion is decided by another.

With legislation now in the form of David Seymour’s End of Life Choice Bill currently before Parliament may the arguments for legislation be treated on their merits and not be confused by reference to abortion.

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Nil.

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Effectiveness of a third dose of MMR vaccine for mumps outbreak control

Immunisation with two doses of the measles-mumps-rubella (MMR) vaccine as part of a childhood vaccination programme led to a 99% reduction in reported cases of mumps. In the US however, there have been many recent outbreaks of mumps even in those vaccinated. This report concerns a study which has evaluated the effectiveness of a third dose for outbreak control and assessed for waning immunity.

Over 20,000 university students were involved. 98.1% had received two doses of MMR. Over 4,000 were given a third dose of MMR. The subsequent incidence of mumps was significantly reduced in those who had been given a third dose of MMR.

These findings suggest that the campaign to administer a third dose of MMR vaccine improved mumps outbreak control and that waning immunity probably contributed to propagation of the outbreak.


Risk of post-pregnancy hypertension in women with a history of hypertensive disorders of pregnancy

What is the timing and trajectory of post-pregnancy hypertension risk after hypertensive disorders of pregnancy? This is the topic reviewed in this comprehensive study from Denmark.

The authors estimated cumulative incidences of post-pregnancy hypertension over the decade after a first birth in women with and without hypertensive disorders of pregnancy. Approximately 500,000 women were involved in the study. Among women with a hypertensive disorder of pregnancy in their first pregnancy, 14–32% (depending on age at delivery) developed hypertension in the decade postpartum, compared with 4–11% of women with normotensive first pregnancies.

The high risk persists for more than 20 years. The researchers suggest that cardiovascular disease prevention in these women should include blood pressure monitoring initiated soon after pregnancy.

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Exenatide once weekly versus placebo in Parkinson's disease

Exenatide, a glucagon-like peptide-1 (GLP-1) receptor agonist, has neuroprotective effects in preclinical models of Parkinson's disease.

In this paper, the researchers report on a randomised placebo controlled trial on the use of this drug in the clinical setting. Sixty-two patients with moderate Parkinson's disease were randomised to receive a weekly subcutaneous injection of 2mg of exenatide or placebo for 48 weeks in addition to their regular medication.

The neuroprotective effects noted in the preclinical models were also seen in this randomised trial. The conclusions reached were that exenatide had positive effects on practically defined off-medication motor scores in Parkinson's disease, which were sustained beyond the period of exposure. Whether exenatide affects the underlying disease pathophysiology or simply induces long-lasting symptomatic effects is uncertain. Exenatide represents a major new avenue for investigation in Parkinson's disease, and effects on everyday symptoms should be examined in longer-term trials.

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URL:
Sarcoma of Shoulder
Successfully Treated by Radium

Reported by L. E. BARNETT, F.R.C.S., Professor of Surgery, Otago University, and P. D. CAMERON, M.D., Radiologist, Dunedin Hospital

NOTES BY L. E. BARNETT

J.W.M., aged 34, weighing 11st. 12lb., consulted me on 12th August, 1913, complaining of numbness and weakness, swelling, and discoloration of right arm, noticed for nine months. Within the last few days he became aware of a lump growing in the region of the right shoulder and root of the neck. On examination an irregular rounded mass the size of a medium potato, hard and somewhat fixed, can be made out in the right supraventricular region extending towards the back, also an indefinite swelling underneath the pectoral muscles just below the clavicle and fixed to the thorax, and several enlarged glands in the right axilla.

An exploratory operation was performed on 16th August, 1913, the idea being to carry out the removal of the whole upper limb, clavicle and scapula (forequarter amputation) if feasible. On dividing the pectoral muscles it was found that an extensive mass of what looked like sarcomatous growth was infiltrating the ribs and intercostal muscles and pleura and reaching deep into the axilla and under the clavicle. I then decided to abandon all idea of radical operation, and simply removed a piece of the tumour for microscopic investigation and closed the wound. Dr. W. S. Roberts, Pathologist to the University, reports as follows: “The growth is a sarcoma with round and slightly spindle cells, accompanied by a homogeneous and also a fibrous stroma with a tendency to an alveolar arrangement.”

I gave a bad prognosis, but thought I would try and do something to stay the onward progress of a malady ordinarily so tragic in its methods of attack.

On the eleventh and fourteenth day after the operation I administered into the buttocks .45 gramme of neosalvarsan. I may say, however, that there was no syphilitic history or manifestations, and I gave arsenic because I think it sometimes has a good effect in malignant diseases. After seven weeks from the operation I noted, however, that the shoulder lump and axillary swellings were decidedly larger, and I arranged that Dr. Cameron should apply the small quantity of radium that was available at that time, making up for the smallness of quantity by the duration of the exposure (about twelve hours).

From this date a slow but steady improvement set in. I saw him from time to time and was very gratified to find the tumour masses obviously shrinking. The swelling and discoloration of the hand and arm also subsided. I last saw him three months ago, on 24th August, 1917; he had just married and was on his honeymoon tour. He weighed 12st. 4lb., and was the picture of health. His affected arm was perfectly restored in all its functions, and there was no sign of the tumour; one gland about the size of a large broad bean could be felt in the axilla.

In the course of many years one comes across, at rare intervals, remarkable cases of improvement or disappearance of tumour formations. Occasionally such cases are of a granulomatous, possibly syphilitic, nature. The case here recorded, I feel convinced, was a sarcoma, and I ascribe its disappearance to the marvellous powers of radium, which, though it often disappoints—perhaps more often than not—is nevertheless a substance destined to play a very prominent part in the treatment of new growths.
NOTES BY P. D. CAMERON

J.W.M., sent to me by Dr. Barnett with a diagnosis of inoperable sarcoma, right shoulder region, and a request to administer a large dose of radium.

On 7th October, 1913, applied the two radium applicators so as to get a crossfire effect towards the centre of the tumour for twelve hours, the rays from each applicator being filtered through thin rubber, one sheet tea lead, six sheets of black paper, and a layer of lint.

The applicators are each of 500,000 activity, containing 10 m.g. radium bromide in the one case, radium bromide transformed into the sulphate in the other, the former being in an ebonite box with mica window, the latter a varnish apparatus.

J.W.M. was asked to report again in five weeks’ time, but I did not see him again till 5th July, 1915.

On this date he told me that the mass commenced to subside eight days after treatment, and that it had completely disappeared in six weeks. He has been working hard and feels thoroughly well.

On examination there was no trace of the tumour and no difference from a normal chest could be detected.

In the axilla there was still a small gland about the size of a little finger nail and soft.

I am of opinion that the disappearance of the tumour was due to the radium application, and this is in accordance with the experience of others as expressed in the latest report of the Radium Institute, London, to 31st December, 1916, where it was stated, “The result in cases of sarcoma if treated before dissemination into the internal viscera was usually good.” And “The response of lympho sarcoma was very remarkable, the growths commencing to shrink within a few days of the termination of the treatment and rapidly disappearing.”
Faulty doctor to comply with CPD requirements

Charge
The Tribunal considered a charge against Dr Brabant (the Doctor). The charge alleged that between 2012 and 2016 the Doctor failed to comply with the Medical Council’s requirements for continuing professional development (CPD), its recertification requirements through “Inpractice” and that he made two false entries in his Inpractice portfolio in 2014.

The Professional Conduct Committee (the PCC) alleged that these continued failures and the false entries demonstrated a deliberate disregard for professional responsibilities, and amounted, either separately or cumulatively, to professional misconduct.

Background
It was clear to the Tribunal that the Medical Council had made considerable efforts to engage with, and assist the Doctor to achieve compliance with his CPD requirements.

The Doctor did not engage with the Tribunal process and did not attend the meeting.

Finding
The Tribunal found, on a cumulative basis, the charge of professional misconduct was established.

The Tribunal considered the extended history of non-compliance made this an exceptional case. The conduct could not be explained by simple oversight, a period of ill health or a lapse of judgment. The Tribunal found the conduct had been sustained over a long period and had been the subject of so much communication from the Medical Council and Inpractice, that it could only be viewed as deliberate by the Doctor.

The Tribunal considered the failure to CPD and recertification requirements over such a lengthy period, raised serious public safety and professional standards concerns. The public and the profession are entitled to expect that registered health practitioners will diligently attend to their CPD activities and comply with all recertification requirements.

Penalty
The Tribunal censured the Doctor, fined him $3,000 and ordered him to pay costs of $15,918. The Tribunal further ordered that for 18 months he must practise under supervision.

The focus of the supervision is to be on the Doctor’s engagement and participation in his recertification requirements, professional responsibility and any matters that the Medical Council considers appropriate. The cost of the supervision is to be met by the Doctor.

The Tribunal further directed publication of its decision and a summary.

A full copy of the decision can be viewed at http://www.hpd.org.nz/ChargeDetails.aspx?file=Med16/372P

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