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Small Numbers, Big Challenges: Adolescent and Young Adult Cancer Incidence and Survival in New Zealand

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Purpose: This study was undertaken to determine cancer survival and describe the unique spectrum of cancers diagnosed among New Zealand's adolescents and young adult (AYA) population.
Methods: Registrations for 1606 15–24 year olds diagnosed with a new primary malignant tumor between 2000 and 2009 were obtained from the New Zealand Cancer Registry and classified according to AYA diagnostic group and subgroup, age, sex, and prioritized ethnicity. Age-standardized incidence rates (IRs) per million person years and 5-year relative survival ratios were calculated.
Results: Cancer incidence was 228.6 per million for adolescents aged 15–19 years and 325.7 per million for young adults aged 20–24 years. Overall IRs were consistent across all ethnic groups but there were unique ethnic differences by tumor group including a higher incidence of bone tumors, carcinoma of the gastrointestinal tract, and gonadal germ cell tumors among Maori, a higher incidence of leukemia among Pacific peoples, and a higher incidence of melanoma among non-Maori/non-Pacific peoples. Five-year relative survival for adolescents (75.1%) and AYA overall (80.6%) appeared poorer than had been achieved in other high-income countries. Maori (69.5%) and Pacific (71.3%) AYA had lower 5-year survival compared to non-Maori/non-Pacific peoples (84.2%).
Conclusion: The survival disparities observed require further investigation to identify and address the causes of these inferior outcomes. The newly established AYA Cancer Network Aotearoa has been tasked with improving cancer survival and care and ensuring equality of access for New Zealand AYAs with cancer.

Keywords: incidence, survival, ethnicity, disparities

Introduction

When it comes to adolescents and young adult (AYA) cancer services, New Zealand's geographical size, small population, cultural diversity, and the structure of its health system presents some unique challenges. Spread over two islands and with a land area equivalent to that of the United Kingdom, New Zealand's population is a comparatively small 4.6 million. Most cancer treatment is undertaken within the public health system; six tertiary adult oncology centers receive national referrals for radiotherapy, intensive chemotherapy, specialist surgery, and bone marrow transplant, while the remaining regional centers provide less complex chemotherapy and supportive care. All children under the age of 15, and some older teenagers, have their cancer care coordinated by a specialist multidisciplinary team based in one of New Zealand's two specialist pediatric cancer units. There are no distinct AYA cancer units and the decision on whether, for example, a 16-year-old adolescent with a high suspicion of cancer is referred to a pediatric or adult unit is determined on an *ad hoc* basis.

In the early 2000s a rapidly emerging and compelling body of international literature had identified a lack of progress in

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survival improvements for AYAs relative to other age groups and it was increasingly apparent that neither the traditional adult medical-based model or pediatric family-based model of cancer care were achieving optimal outcomes for this ''lost tribe.''[1–3] At the same time as countries such as the United States, Canada, Australia, and the United Kingdom were establishing nationally organized cancer programs to address the unique needs of AYAs,[4–7] New Zealand clinicians set out to improve cure rates, entry onto clinical trials, and psychosocial care for their AYA patients.[8] This culminated in the development and national implementation of the AYA Cancer Service Specifications in 2009.[9] The AYA Service Specifications established specialist AYA cancer multidisciplinary teams within the six regional cancer centers, which included representatives from adult and pediatric oncology and hematology. AYA key workers were appointed to case-manage the care needs of AYA cancer patients and their families.

The 2009 AYA Service Specifications defined New Zealand AYA as 12–24 years, although it was acknowledged that some flexibility would be needed to ensure that the cancer care provided would best meet the unique treatment and psychosocial needs of the patient.[9] New Zealand's definition of AYA for service delivery purposes is similar to the 13–24 year Teenager and Young Adult age range used in the United Kingdom,[10] the 15–24 year range largely favored elsewhere in Europe,[11–13] and the 15–25 years in Australia's national service framework.[14] However, it is a narrower definition than the 15–29 years widely adopted in epidemiological studies,[15–20] or the 39 year upper age limit favored by the United States National Cancer Institute and LIVESTRONG.[21–23] Applying the 12–24 year age range, an average of 180 AYA were diagnosed in New Zealand on an annual basis between 2000 and 2009. Figure 1 highlights the geographical challenges that this presents with many AYA potentially travelling considerable distances to receive some, if not all, of their treatment at one of the six regional cancer centers or two specialist children's cancer units.

In 2012 the Ministry of Health established a national AYA Advisory Group to oversee a process to evaluate the effectiveness of existing AYA cancer services and provide recommendations for the future. During this review it became evident that there was little objective data pertaining to the current cancer burden among AYA and this analysis was commissioned to determine cancer incidence and survival for AYA, including comparisons with international benchmarks and within-group comparisons by age, sex, and ethnicity. New Zealand has a unique cultural and ethnic mix of peoples of Maori, Pacific, and European origin, and as such we have unique patterns of cancer in our population. There are known disparities in cancer survival in the adult population, with Maori and Pacific Island peoples having significantly worse outcomes.[24] However, a recent analysis had shown comparable survival according to ethnicity for childhood cancer.[25] This study sought to determine whether ethnic survival disparities existed for the AYA population once differences in the spectrum of cancers diagnosed had been accounted for.

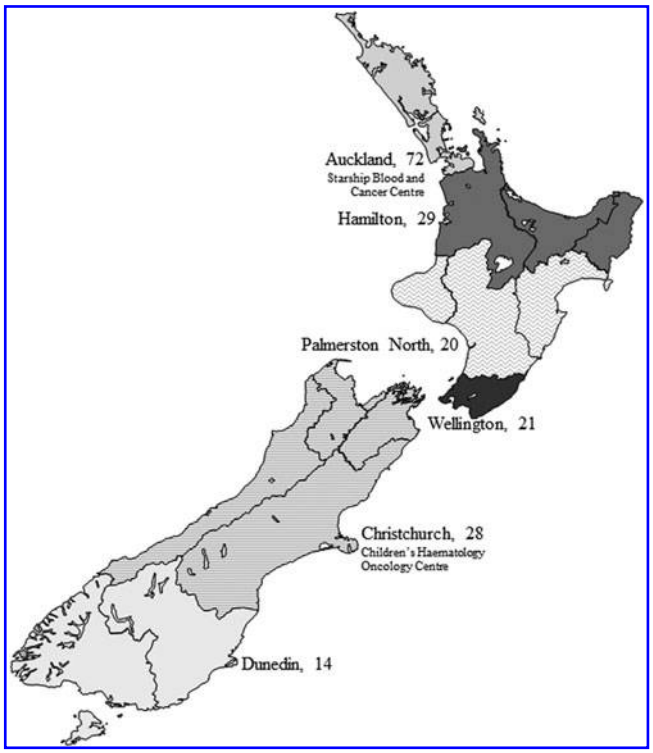

FIG. 1. Average annual number of AYA (12–24 years) diagnosed with cancer in New Zealand between 2000 and 2009 by AYA regional cancer center.

Methods

Data sources and variables

Diagnostic and demographic data for 1606 new primary malignant tumors diagnosed between the January 1, 2000 and December 31, 2009 in the 15–24 year age group were obtained from the New Zealand Cancer Registry (NZCR). Data items included patient National Health Index number, ethnicity, sex, age at diagnosis, date of diagnosis, coded tumor site, coded morphology, and basis of diagnosis. Ninety-eight percent of cases were histologically verified, indicating high data quality. Follow-up for vital status was determined through record linkage to the National Mortality Collection. Cancer registrations for younger adolescents aged 12–14 years were not included in this study as this group of patients were treated exclusively within the pediatric service and had therefore already been included in similar analyses of the New Zealand Children's Cancer Registry.[25,26]

The NZCR is a population-based registry that holds detailed pathological and demographic information for all malignant tumors diagnosed in New Zealand with the exception of squamous and basal cell skin cancers. Nonmalignant central nervous system (CNS) tumors are not registered, while *in situ* cancers are registered but excluded from all incidence reporting. The NZCR uses two coding systems; the International Classification of Diseases and Related Health Problems to classify the tumor site,[27] and the International Classification of Diseases for Oncology (ICD-O-3) to classify tumor morphology.[28] The tumor site and morphology codes were used to reclassify all tumors according to both the International Classification of Childhood Cancers third edition (ICCC-3),[29] and the Surveillance Epidemiology and End Results (SEER) AYA Site-Recode Groupings,[30] an ICD-O-3 update to the AYA

classification scheme developed by Barr et al.[31] Although the ICCC-3 is often used to classify cancers diagnosed in adolescents, and sometimes those aged up to 25 years, the AYA classification scheme is recognized as better accounting for the pediatric and adult malignancies that commonly affect the AYA population.[31,32] All tumors in this study were categorized according to both the ICCC-3 and AYA classification schemes to maximize the potential for making comparisons with published data.

Classification of ethnicity

Ethnicity was classified using a prioritized ethnicity system. According to Ministry of Health ethnicity data protocols, individuals may self-identify with up to three ethnic groups. For the purpose of this analysis each respondent was assigned to a single ethnic group using a priority system: Maori, Pacific peoples, and non-Maori/non-Pacific peoples. A prioritized ethnicity classification is often used in the New Zealand health and disability sector to ensure that ethnicity of Maori and Pacific peoples, who have higher health needs than other New Zealanders, are reliably recorded, and better reflect the cultural mix of our population.[33] When prioritized ethnicity is applied to 2006 census data, the 15–24 year AYA population comprised of 17.7% Maori, 7.1% Pacific peoples, and 75.2% non-Maori/non-Pacific peoples (13.2% Asian, 1.0% Other Ethnicity, 4.7% ''Not Elsewhere Included,'' and 56.3% European/New Zealander).

Statistical analysis

Age-specific incidence rates (IRs) per million inhabitants were calculated based on person-years derived from the annual estimated resident population by age and sex provided by Statistics New Zealand. Age-standardized rates were estimated by the direct method using the 2006 census population. 95% confidence intervals (CIs) were calculated assuming the cases were drawn from a Poisson distribution. Relative risk (RR) estimates were calculated for sex. All incidence calculations were conducted using SAS® software v9.3 (SAS Institute, Inc., Cary, NC).

A survival analysis was performed with all cases followed until death or December 31, 2010, whichever came first. To avoid bias, 10 AYA patients whose cancer diagnosis was based on death certificate only, autopsy only, or who had a survival time of 0 days were excluded from the survival analysis. Relative survival is the ratio of observed survival and the expected survival from comparable life tables. Observed survival was determined using record linkage to the National Mortality Collection and expected survival data were calculated according to the Ederer II method,[34] using life-tables for the total resident population produced by Statistics New Zealand based on 2006 census data. The observed and expected survival data were used to calculate 5-year relative survival estimates using the Stata® MP 12.1 statistical software package (StataCorp., College Station, TX).

Ethical approval was granted by the New Zealand Health and Disability Multi-region Ethics Committee (MEC/12/EXP145).

Results

Overall cancer incidence

In the 10-year period from 2000 to 2009, there were 1606 new primary malignant cancers diagnosed in New Zealand's 15–24-year AYA population. The number of AYA cancer cases per age group, RR for men to women, and cancer incidence by diagnostic group are shown in Table 1. Forty-three percent of all AYA cancers diagnosed were among adolescents aged 15–19 years ($n = 690$, IR = 228.6 per million; 95% CI: 211.5–245.6) and 57% were among young adults aged 20–24 ($n = 916$, IR = 325.7 per million; 95% CI: 304.6–346.8). Lymphoma ($n = 136$, 19.7%) and leukemia ($n = 102$, 14.8%) were the two most common cancers seen in adolescents. By young adulthood these were replaced by melanoma ($n = 210$, 22.9%) and carcinomas ($n = 209$, 22.8%). Male AYA were at increased risk of developing acute lymphoblastic leukemia (ALL; RR = 1.7; 95% CI: 1.1–2.6), non-Hodgkin lymphoma (RR = 1.8; 95% CI: 1.2–2.8), and gonadal germ cell tumors (RR = 5.2; 95% CI: 3.8–7.2) and decreased risk of developing thyroid carcinomas (RR = 0.2; 95% CI: 0.2–0.4) or melanoma (RR = 0.7; 95% CI: 0.5–0.8).

Incidence by ethnicity

There was little variability in overall AYA cancer incidence by ethnicity; Table 2 shows that cancer incidence for the 15–24 year population for the 2000–2009 period was 287.3 per million for Maori (95% CI: 254.2–320.3), 277.6 per million for Pacific peoples (95% CI: 226.4–328.8), and 280.1 per million for non-Maori/non-Pacific peoples (95% CI: 264.2–295.9). However, there was significant variability in incidence according to cancer type. Melanoma incidence among non-Maori/non-Pacific AYA was 68.0 per million (95% CI: 60.2–75.8) compared to just 9.8 per million for Pacific peoples (95% CI: 0.2–19.5) and 6.9 per million for Maori (95% CI: 1.8–12.0). For Pacific peoples, leukemia incidence (61.4 per million; 95% CI: 37.3–85.5) was significantly higher than that of non-Maori/non-Pacific peoples (27.3 per million; 95% CI: 22.3–32.2). For Maori, bone tumor incidence was notably higher at 32.6 per million (95% CI: 21.5–43.7) compared to 14.9 per million for non-Maori/non-Pacific peoples (95% CI: 11.3–18.6). The incidence of germ cell tumors among Maori (70.1 per million; 95% CI: 53.8–86.4) was also significantly higher than seen in Pacific peoples (19.7 per million; 95% CI: 6.0–33.3) or non-Maori/non-Pacific peoples (37.5 per million; 95% CI: 31.7–43.3). Also of note was the very high frequency of gastric cancer in the Maori AYA population. Of the 22 AYA diagnosed with gastric cancer within the 10-year period, 18 (81.8%) were of Maori ethnicity.

Overall cancer survival

Table 3 shows 5-year relative survival estimates for the main AYA diagnostic groups and subgroups by age group, ethnicity, and gender. Overall 5-year survival for AYA 15–24 years ($n = 1596$) was 80.6% (95% CI: 78.4–82.6). By AYA diagnostic group, 5-year survival ranged from 48.5% (95% CI: 38.1–58.1) for bone tumors to 93.7% for melanoma and skin carcinomas (95% CI: 90.1–96.0). Of the common diagnostic subgroups, survival of over 90% was achieved for thyroid cancer (100.3%), Hodgkin lymphoma (94.6%; 95%

Table 1. Number of Tumors, Sex Ratio, and Cancer Incidence Rate per Million in the New Zealand Adolescent and Young Adult Population 15–24 Years of Age, Classified by the Adolescent and Young Adult Classification Scheme, 2000–2009

AYA diagnostic group and subgroup[a]	*15–19 years,* n *(%)*	*20–24 years,* n *(%)*	*15–24 years* n *(%)*	*15–24 years IR per million*[b] *(95% CI)*	*15–24 years Male/female ratio (95% CI)*
Leukemias	102 (14.8)	78 (8.5)	180 (11.2)	30.9 (26.4–35.4)	1.3 (1.0–1.8)
Acute lymphoblastic leukemia	55 (8.0)	28 (3.1)	83 (5.2)	14.3 (11.2–17.4)	1.7 (1.1–2.6)
Acute myeloid leukemia	34 (4.9)	39 (4.3)	73 (4.6)	12.5 (9.6–15.4)	1.0 (0.6–1.5)
Lymphomas	136 (19.7)	118 (12.9)	254 (15.8)	43.6 (38.2–49.0)	1.2 (1.0–1.6)
Non-Hodgkin lymphoma	48 (7.0)	40 (4.4)	88 (5.5)	15.1 (12.0–18.3)	1.8 (1.2–2.8)
Hodgkin lymphoma	88 (12.8)	78 (8.5)	166 (10.3)	28.5 (24.2–32.8)	1.0 (0.7–1.4)
CNS tumors[c]	50 (7.3)	45 (4.9)	95 (5.9)	16.3 (13.0–19.6)	1.0 (0.7–1.5)
Astrocytoma	15 (2.2)	26 (2.8)	41 (2.6)	7.0 (4.9–9.1)	1.5 (0.8–2.8)
Osseous and chondromatous neoplasms	82 (11.9)	23 (2.5)	105 (6.5)	18.2 (14.7–21.6)	1.5 (1.0–2.2)
Osteosarcoma	38 (5.5)	10 (1.1)	48 (3.0)	8.3 (6.0–10.7)	1.8 (1.0–3.2)
Ewing tumor	38 (5.5)	12 (1.3)	50 (3.1)	8.6 (6.3–11.0)	1.2 (0.7–2.1)
Soft tissue sarcomas	38 (5.5)	44 (4.8)	82 (5.1)	14.0 (11.0–17.1)	1.0 (0.6–1.5)
Other soft tissue sarcoma	23 (3.3)	30 (3.3)	53 (3.3)	9.1 (6.6–11.5)	1.0 (0.6–1.7)
Germ cell and trophoblastic neoplasms	86 (12.5)	154 (16.8)	240 (14.9)	41.0 (35.8–46.1)	4.6 (3.4–6.2)
Germ cell and trophoblastic neoplasms of gonads	75 (10.9)	143 (15.6)	218 (13.6)	37.2 (32.3–42.1)	5.2 (3.8–7.2)
Melanoma and skin carcinomas[d]	93 (13.5)	210 (22.9)	303 (18.9)	51.6 (45.8–57.4)	0.7 (0.5–0.8)
Carcinomas	86 (12.5)	209 (22.8)	295 (18.4)	50.2 (44.5–56.0)	0.4 (0.3–0.5)
Thyroid carcinoma	25 (3.6)	61 (6.7)	86 (5.4)	14.6 (11.6–17.7)	0.2 (0.2–0.4)
Carcinoma of gastrointestinal (GI) tract	22 (3.2)	50 (5.5)	72 (4.5)	12.3 (9.4–15.1)	1.2 (0.8–1.9)
Miscellaneous specified neoplasms	14 (2.0)	26 (2.8)	40 (2.4)	6.8 (4.7–8.9)	0.9 (0.5–1.6)
Unspecified (malignant) neoplasms	3 (0.4)	9 (1.0)	12 (0.8)	2.0 (0.9–3.2)	—[e]
Total AYA cancers	690 (100)	916 (100)	1606 (100)	274.7 (261.2–288.1)	1.0 (0.9–1.1)

[a]Excludes diagnostic subgroups where fewer than 40 cases were recorded.
[b]Age-standardized to the New Zealand 2006 population.
[c]Excludes nonmalignant CNS tumors.
[d]Excludes squamous and basal cell skin carcinomas.
[e]Relative risk was not calculated due to the small number of cases.
AYA, adolescents and young adult; CI, confidence interval; CNS, central nervous system; IR, incidence rate.

CI: 88.5–97.6), and gonadal germ cell tumors (94.3%; 95% CI: 89.8–97.0). Five-year survival for females was 83.5% (95% CI: 80.5–86.1) compared to 77.8% survival for males (95% CI: 74.7–80.7). Adolescent survival of 75.1% (95% CI: 71.4–78.4) was significantly poorer than the 84.6% achieved for young adults (95% CI: 82.0–86.9). Although not reaching statistical significance, there was a marked difference in 5-year survival for adolescent patients with leukemia (60.0%; 95% CI: 48.9–69.5) and young adults (78.8%; 95% CI: 66.8–86.9).

Survival by ethnicity

An analysis by ethnicity identified significant differences between ethnic groups both in overall 5-year survival and in outcome by cancer diagnosis. Table 3 shows Maori and Pacific peoples had a significantly poorer 5-year relative survival compared to non-Maori/non-Pacific peoples; survival for Maori was 69.5% (95% CI: 63.4–74.8), Pacific peoples was 71.3% (95% CI: 61.7–79.0), and non-Maori/non-Pacific peoples was 84.2% (95% CI: 81.8–86.2). Although the survival gap narrowed when melanoma cases were excluded, 5-year survival for Maori (69.0%; 95% CI: 62.8–74.4) and Pacific AYA (70.2%; 95% CI: 60.3–78.1) remained over 10% poorer than for non-Maori/non-Pacific peoples (80.9%; 95% CI: 78.0–83.5). The ethnic disparity in survival was most evident in the adolescent 15–19 year group, with overall survival for Maori at 65.8% (95% CI: 56.3–73.8) and Pacific peoples at 65.6% (95% CI: 51.7–76.5), while survival for non-Maori/non-Pacific peoples was 78.9% (95% CI: 74.8–82.5). Survival for each ethnic group reflects ethnic differences in the spectrum of cancers diagnosed and associated rates of cure; however, there was some evidence of ethnic disparities in outcome within the same cancer diagnostic groups, including a notable but not statistically significant difference in 5-year survival for the 38 Maori AYA diagnosed with leukemia (50.3%; 95% CI: 31.9–66.1) compared to survival for non-Maori/non-Pacific AYA (74.2%; 95% CI: 64.4–81.8).

Discussion

The overall incidence of cancer in the New Zealand AYA population are comparable to those reported from other high-income countries.[12,35–38] The distinct age-related pattern of cancer in the 15–19 compared with the 20–24 year age groups

Table 2. Cancer Incidence per Million in the New Zealand Adolescent and Young Adult Population 15–24 Years of Age by Prioritized Ethnicity, Classified by the Adolescent and Young Adult Classification Scheme, 2000–2009

AYA diagnostic group and subgroup[a]	*Maori*		*Pacific Peoples*		*Non-Maori/ non-Pacific Peoples*	
	n *(%)*	*IR per million*[b] *(95% CI)*	n *(%)*	*IR per million*[b] *(95% CI)*	n *(%)*	*IR per million*[b] *(95% CI)*
Leukemias	38 (13.1)	37.5 (25.6–49.4)	25 (22.1)	61.4 (37.3–85.5)	117 (9.7)	27.3 (22.3–32.2)
Lymphomas	35 (12.0)	34.6 (23.1–46.0)	19 (16.8)	46.7 (25.7–67.7)	200 (16.6)	46.6 (40.1–53.1)
CNS tumors[c]	11 (3.8)	10.9 (4.4–17.3)	4 (3.5)	9.8 (0.2–19.5)	80 (6.7)	18.6 (14.6–22.7)
Osseous and chondromatous neoplasms	33 (11.3)	32.6 (21.5–43.7)	8 (7.1)	19.7 (6.0–33.3)	64 (5.3)	14.9 (11.3–18.6)
Soft tissue sarcomas	23 (7.9)	22.7 (13.4–32.0)	7 (6.2)	17.2 (4.5–29.9)	52 (4.3)	12.1 (8.8–15.4)
Germ cell and trophoblastic neoplasms	71 (24.4)	70.1 (53.8–86.4)	8 (7.1)	19.7 (6.0–33.3)	161 (13.4)	37.5 (31.7–43.3)
Melanoma and skin carcinomas[d]	7 (2.4)	6.9 (1.8–12.0)	4 (3.5)	9.8 (0.2–19.5)	292 (24.3)	68.0 (60.2–75.8)
Carcinomas	61 (21.0)	60.2 (45.1–75.3)	32 (28.3)	78.6 (51.4–105.9)	202 (16.8)	47.1 (40.6–53.6)
Miscellaneous specified neoplasms	10 (3.4)	9.9 (3.8–16.0)	4 (3.5)	9.8 (0.2–19.5)	26 (2.2)	6.1 (3.7–8.4)
Unspecified (malignant) neoplasms	2 (0.7)	2.0 (0.0–4.7)	2 (1.8)	4.9 (0.0–11.7)	8 (0.7)	1.9 (0.6–3.2)
Total AYA cancers	291 (100)	287.3 (254.2–320.3)	113 (100)	277.6 (226.4–328.8)	1202 (100)	280.1 (264.2–295.9)

[a]Excludes diagnostic subgroups where fewer than 40 cases were recorded.
[b]Age-standardized to the New Zealand 2006 population.
[c]Excludes nonmalignant CNS tumors.
[d]Excludes squamous and basal cell skin carcinomas.

represents the transition from the pediatric spectrum of disease into that seen in adults and serves to highlight the wide range of cancers that affect the AYA population.[39] There were no unusual or unexpected differences in incidence by sex observed. The predominance of melanoma in New Zealand females is similar to that seen in Australia and the finding of increased risk for male AYA of developing ALL, non-Hodgkin lymphoma and gonadal germ cell tumors has been observed in other populations.[35–38]

There were many notable significant ethnic differences in cancer incidence for AYA by diagnostic group. Melanoma was the most common cancer overall among 15–24 year olds, yet the incidence of melanoma among Maori and Pacific peoples was the lowest of any of the specified AYA diagnostic groups. Pacific AYA had a significantly higher incidence of leukemia compared to non-Maori/non-Pacific peoples. This, combined with the finding that Pacific children had the highest incidence of leukemia of the three prioritized ethnic groups in the same time period,[26] suggests that the incidence differences may arise from a biological predisposition to leukemia among young Pacific people, which warrants further investigation. Among Maori, bone tumors were significantly more common, a novel finding in the New Zealand AYA population and of particular concern given survival outcomes for bone tumors were the poorest of any diagnostic group. Another unique and notable observation in this age group was the high frequency of gastric cancer among Maori AYA. This likely represents the known population-based familial association between gastric cancer and mutations in the E-cadherin gene.[40] Such cases were most likely diagnosed as a result of the targeted screening program that exists for those identified as potential carriers of this gene mutation.

In comparison with other published AYA survival, New Zealand's overall 5-year relative survival for the 15–24 year age group of 80.6% was strikingly lower than the 5-year relative survival of 87% reported by the EUROCARE consortium for the 2000–2002 period and the 5-year observed survival of 85% reported by Canada for the 2001–2005 period.[13,36] It is in the adolescent rather than the young adult population in which these disparities are most evident. New Zealand cancer survival for those aged 15–19 years (75.1%) was significantly lower than the 81.8% survival reported by the U.S. SEER database for 2002–2008 and 81% reported by Canada for 2001–2005.[35,41] While survival for Hodgkin lymphomas, germ cell tumors, melanomas, and thyroid carcinoma, all at above 90%, appear on a par with international benchmarks,[12,13,36,41,42] there is evidence to suggest that survival for adolescents diagnosed with malignant bone tumors, soft tissue sarcomas, and CNS tumors was poorer than has been achieved in the United States and Canada within a similar time period.[35,41] In addition, New Zealand adolescent ALL survival of 57.6% was considerably lower than the 75.9% survival achieved for adolescents enrolled on Children's Oncology Group (COG) clinical trials at this time,[43] highlighting the importance of improving access to clinical trials for those adolescents not receiving treatment at either of New Zealand's COG-affiliated pediatric centers.[44,45]

Of particular concern is the clear evidence of survival disparities according to ethnicity, with 5-year relative survival for AYA 13%–15% lower for Pacific peoples and Maori than for non-Maori/non-Pacific peoples. Survival disparities

TABLE 3. FIVE-YEAR RELATIVE SURVIVAL AMONG NEW ZEALAND'S ADOLESCENT AND YOUNG ADULT POPULATION (15–24 YEARS) FROM 2000 TO 2009 BY AGE, SEX, AND ADOLESCENT AND YOUNG ADULT DIAGNOSTIC GROUP AND SUBGROUP

	Sex (15–24 years)		*Prioritised ethnicity (15–24 years)*			*Age Group*		
	Male	*Female*	*Maori*	*Pacific Peoples*	*Non-Maori/ Pacific Peoples*	*Adolescents 15–19 years*	*Young adults 20–24 years*	*Total AYA 15–24 years*
AYA diagnostic group and subgroup[a]	*5-year relative survival (95% CI)*	*5-year relative survival (95% CI)*	*5-year relative survival (95% CI)*	*5-year relative survival (95% CI)*	*5-year relative survival (95% CI)*	*5-year relative survival (95% CI)*	*5-year relative survival (95% CI)*	*5-year relative survival (95% CI)*
Leukemias	62.5 (51.4–71.8)	75.8 (63.7–84.4)	50.3 (31.9–66.1)	67.7 (45.5–82.6)	74.2 (64.4–81.8)	60.0 (48.9–69.5)	78.8 (66.8–86.9)	68.2 (60.1–74.9)
Acute lymphoblastic leukemia	58.2 (42.0–71.4)	70.4 (50.6–83.5)	45.2 (19.5–68.1)	73.0 (37.2–90.6)	67.1 (52.2–78.4)	57.6 (42.3–70.2)	73.8 (52.3–86.8)	63.1 (50.9–73.1)
Acute myeloid leukemia	63.5 (43.7–78.1)	77.9 (58.3–89.1)	63.9 (32.1–83.9)	61.3 (30.3–81.9)	76.1 (58.0–87.3)	60.6 (40.3–76.0)	79.6 (60.8–90.2)	70.9 (57.5–80.7)
Lymphomas	88.7 (81.6–93.3)	90.2 (81.4–95.0)	83.9 (64.2–93.4)	89.8 (64.3–97.6)	90.2 (84.3–94.0)	90.2 (82.3–94.7)	88.2 (80.0–93.2)	89.2 (84.0–92.9)
Non-Hodgkin lymphoma	77.6 (63.4–86.9)	81.4 (59.4–92.3)	69.6 (35.9–88.0)	91.3 (51.0–99.1)	79.4 (66.2–88.0)	78.4 (61.6–88.6)	79.6 (63.1–89.4)	78.8 (67.6–86.6)
Hodgkin lymphoma	96.1 (87.1–99.1)	93.4 (82.8–97.6)	95.3 (69.7–99.6)	87.8 (38.8–98.4)	95.0 (87.9–98.1)	96.5 (85.7–99.4)	92.6 (82.2–97.1)	94.6 (88.5–97.6)
CNS tumors[b]	58.8 (42.4–72.1)	63.0 (45.7–76.1)	46.3 (14.6–73.6)	—[c]	63.8 (51.1–74.0)	54.8 (38.6–68.4)	67.9 (50.8–80.3)	60.9 (49.3–70.7)
Astrocytoma	57.4 (34.7–74.8)	72.9 (42.6–89.0)	66.8 (5.4–94.8)	—[c]	64.3 (45.3–78.2)	56.9 (27.4–78.3)	66.5 (43.5–82.0)	63.2 (45.4–76.6)
Osseous and chondromatous neoplasms	44.2 (31.3–56.3)	55.3 (37.9–69.7)	37.0 (19.6–54.5)	60.8 (20.7–85.6)	52.5 (39.2–64.3)	50.0 (38.0–60.9)	43.5 (23.2–62.3)	48.5 (38.1–58.1)
Osteosarcoma	46.4 (27.0–63.7)	58.2 (31.7–77.6)	38.0 (12.1–64.3)	60.1 (2.5–93.4)	54.9 (35.7–70.6)	51.3 (33.5–66.6)	49.3 (17.4–75.2)	50.8 (35.2–64.5)
Ewing tumor	34.7 (17.8–52.3)	53.1 (28.0–73.0)	33.3 (12.1–56.5)	50.1 (5.8–84.7)	47.6 (27.0–65.6)	45.9 (28.4–61.8)	33.5 (10.3–59.2)	42.9 (28.3–56.7)
Soft tissue sarcomas	60.7 (43.0–74.4)	65.1 (47.1–78.3)	54.1 (31.2–72.3)	28.7 (1.5–69.3)	71.2 (55.9–82.0)	51.8 (34.0–66.9)	72.1 (54.7–83.8)	62.8 (50.6–72.9)
Other soft tissue sarcoma	72.0 (49.3–85.9)	57.1 (34.5–74.5)	56.5 (24.5–79.4)	40.2 (1.1–83.2)	70.2 (51.2–83.0)	61.7 (37.4–78.9)	66.7 (45.0–81.5)	64.7 (49.0–76.6)
Germ cell and trophoblastic neoplasms	92.2 (86.9–95.4)	95.3 (82.0–98.9)	90.5 (79.0–96.0)	71.6 (25.9–92.2)	94.5 (89.3–97.3)	91.2 (81.7–96.0)	93.6 (88.0–96.7)	92.7 (88.2–95.6)
Germ cell and trophoblastic neoplasms of gonads	94.4 (89.2–97.2)	94.2 (78.1–98.7)	90.8 (77.9–96.5)	80.2 (20.4–97.1)	96.1 (91.1–98.5)	93.9 (83.4–98.0)	94.6 (89.0–97.5)	94.3 (89.8–97.0)
Melanoma and skin carcinomas[d]	91.0 (84.0–95.2)	95.4 (90.9–97.8)	85.9 (33.5–98.1)	100.3[e]	93.8 (90.1–96.1)	92.1 (83.8–96.3)	94.3 (90.0–96.9)	93.7 (90.1–96.0)
Other and unspecified carcinomas	71.0 (59.4–79.9)	86.3 (80.6–90.5)	75.7 (62.2–85.0)	77.2 (57.9–88.6)	84.7 (78.6–89.2)	83.3 (73.2–89.8)	81.7 (75.4–86.5)	82.0 (76.9–86.2)
Thyroid carcinoma	100.5[e]	100.2[e]	100.3[e]	100.3[e]	100.2[e]	100.2[e]	100.3[e]	100.3[e]
Carcinoma of gastrointestinal tract	53.5 (36.4–67.9)	50.8 (31.1–67.5)	62.6 (38.3–79.6)	50.2 (11.1–80.7)	47.1 (30.8–61.9)	51.0 (27.4–70.5)	53.3 (37.9–66.5)	52.5 (39.7–63.8)
Misc. specified neoplasms	73.7 (47.6–88.4)	50.2 (31.2–67.6)	59.5 (24.3–82.7)	50.1 (5.8–84.7)	64.0 (41.8–79.7)	56.5 (27.3–77.8)	64.9 (43.1–80.1)	61.5 (44.1–74.9)
Unspecified malig. neoplasms	86.2 (33.6–98.4)	100.2[e]	—[c]	50.1 (0.6–91.3)	100.4[e]	100.4[e]	87.8 (38.9–98.5)	91.3 (51.0–99.1)
Total AYA cancers	77.8 (74.7–80.7)	83.5 (80.5–86.1)	69.5 (63.4–74.8)	71.3 (61.7–79.0)	84.2 (81.8–86.2)	75.1 (71.4–78.4)	84.6 (82.0–86.9)	80.6 (78.4–82.6)

[a]Excludes diagnostic subgroups where fewer than 40 cases were recorded.
[b]Excludes nonmalignant CNS tumors.
[c]Five-year relative survival could not be calculated as no cases had a full 5 years of follow-up.
[d]Excludes squamous and basal cell skin carcinomas.
[e]CIs cannot be calculated where there were either no deaths or no survivors within the period.

have been identified for other AYA minority populations but the reasons for these disparities are not yet well understood.[46–50] As comparisons by AYA diagnostic group provided evidence of poorer survival for Maori with leukemia, future studies should examine whether there is ethnic variation in the frequencies of cytogenetic abnormalities which are associated with an unfavorable prognosis, as has been identified in the United States. Similarly, the higher incidence of bone tumors for Maori begs the question of whether ethnic differences in tumor biology might contribute to the particularly poor survival outcomes that were identified for this group. The finding that there were no ethnic survival disparities in New Zealand's child population during the same time period suggests that comparable survival for AYA can be achieved,[25] and that improvements to the AYA model of care, such as ensuring access to culturally appropriate health services, will be integral to improving survival outcomes for Maori and Pacific patients.

There are many factors that are known to impact AYA cancer survival, which were outside the scope of this study, and unexamined variables such as disease staging at presentation, duration between symptom onset and diagnosis, clinical trial participation, patient socioeconomic status, and treatment adherence may have contributed to the survival disparities that were identified.[1,21,47] Given that there are only a small number of tertiary centers with the resources to provide treatment for complex tumors in New Zealand, it is possible that those AYA who had to travel further for treatment, who were treated in multiple centers, or who received treatment in a center less experienced with the patient's particular disease had poorer survival outcomes. Future AYA survival analyses should utilize the recent improvements made by the NZCR in the collection of disease staging information and the standardization of data items collected by the AYA key workers in their respective centers.

An additional study limitation is the use of the prioritized ethnicity classification system, which goes against the principle of self-determination for the high proportion of New Zealand's younger population who identify with more than one ethnic group. Prioritized ethnicity has been shown to considerably understate the population count for Pacific peoples, with more than 20% of AYA who identified with a Pacific ethnic group in the 2006 census classified as Maori according to the prioritized system.[52] In addition, the combining of diverse ethnic groups, such as the absorption of Asian prioritized ethnicity into non-Maori/non-Pacific peoples, has potentially masked some ethnic incidence and survival differences that did exist in New Zealand during the study period.

On average, only 161 AYA aged 15–24 were diagnosed with cancer each year between 2000 and 2009 and for some specific cancers, such as osteosarcoma and Ewing tumors, the numbers were in the single digits. The rarity and wide spectrum of AYA cancers highlight the enormous challenges that New Zealand faces with regards to delivering high-quality, age-appropriate AYA cancer services across the country and also presents us with considerable challenges in the reporting of our data. The small number of AYA diagnosed with cancer, even over a 10-year period, results in wide CIs and makes it difficult to make meaningful comparisons by age group, sex, and ethnicity at an AYA diagnostic group or subgroup level. We must therefore strike a balance between interpreting our findings cautiously and the potential harm in not acting until we have improved the precision of our statistical estimates by accumulating several more years of cases. For example, this study identified that 5-year relative survival for Maori with leukemia was 24% lower than survival for non-Maori/non-Pacific peoples. Although this survival difference was not statistically significant, it would be advisable for researchers and AYA service providers to proceed on the assumption that there *is* a survival gap for Maori with leukemia and to commence research and initiatives that target this group.

As a wider issue, while a key original aim for this analysis was to compare New Zealand AYA cancer incidence and survival to that reported by other high-income countries we found that there were significant barriers to making meaningful cross-country comparisons. This was due to differences in the statistical methodologies between studies and the lack of a universally adopted AYA age range or classification system for AYA cancers. A universally adopted AYA cancer classification scheme and international consensus for AYA age groupings for use in study reporting, as was successfully implemented for childhood cancer in the 1980s,[53] would encourage greater research collaboration and greatly assist in formulating etiologic hypotheses, monitoring survival improvements, and identifying international best practice to improve AYA cancer outcomes.

Conclusion

This is the first time that incidence and survival data pertaining specifically to AYA cancers in New Zealand has been published. It has highlighted the wide spectrum of cancers that we can expect to see among New Zealand's small AYA population and provided definitive patient numbers to inform decision making around national AYA cancer services. The survival analysis has shown New Zealand achieves excellent survival outcomes for many common AYA cancers such as lymphomas, germ cell tumors, melanomas, and thyroid carcinomas and has also identified some specific cancers, namely bone and soft tissue sarcomas, CNS tumors, and adolescent ALL, where the overall survival does not currently appear to meet international benchmarks. In addition, comparisons according to age and ethnicity have provided clear evidence of the existence of survival inequalities for adolescents when compared to our pediatric and young adults patients and for our Maori and Pacific AYA compared with those of other ethnicities.

Following the completion of the incidence and survival analysis, and an AYA Patient Experience and Service Evaluation that had been conducted concurrently, the AYA Advisory Group made their recommendations to the Ministry of Health regarding the future delivery of AYA cancer services. In December 2013, the Ministry of Health acknowledged that New Zealand can and should be doing better for our young people and announced increased funding for AYA cancer services and the establishment of the AYA Cancer Network Aotearoa. Using a model based on the National Child Cancer Network, which had been successfully implemented in 2012, the AYA Cancer Network Aotearoa brings together health professionals and support providers from many disciplines and organizations with a shared aim to ensure that all AYAs diagnosed with cancer, regardless of geography, have

equitable access to high quality medical and psychosocial care. While New Zealand's small cancer workforce and low annual AYA cancer patient numbers do provide us with considerable challenges, they also, by necessity, encourage close collaboration across services and presents us with unique opportunities to develop innovative solutions that can be implemented nationally in a relatively short time period. By 2017 the AYA Cancer Network Aotearoa will have produced a comprehensive national strategy for AYA cancer care to address these health inequalities and improve the outcomes for New Zealand AYA diagnosed with cancer.

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