Cancer Epidemiology 55 (2018) 104–109

Contents lists available at ScienceDirect

Cancer Epidemiology

journal homepage: www.elsevier.com/locate/canep

Methodology

Childhood cancer registration in New Zealand: A registry collaboration to asssess and improve data quality

Kirsten R. Ballantine[a,b,*], Susan Hanna[c], Scott Macfarlane[b,d], Peter Bradbeer[d,e], Lochie Teague[d], Sarah Hunter[d], Siobhan Cross[a], Jane Skeen[d]

[a] Children's Haematology/Oncology Centre, Christchurch Hospital, Christchurch, New Zealand
[b] National Child Cancer Network, Auckland, New Zealand
[c] New Zealand Cancer Registry, Ministry of Health, Wellington, New Zealand
[d] Starship Blood and Cancer Centre, Starship Children's Hospital, Auckland, New Zealand
[e] Department of Pathology and Laboratory Medicine, Auckland City Hospital, Auckland, New Zealand

ARTICLE INFO

Keywords:
Data quality
Cancer registry
Children
Completeness
Accuracy
Incidence

ABSTRACT

Aim: To evaluate the completeness and accuracy of child cancer registration in New Zealand.
Methods: Registrations for children aged 0–14 diagnosed between 1/1/2010 and 31/12/2014 were obtained from the New Zealand Cancer Registry (NZCR) and the New Zealand Children's Cancer Registry (NZCCR). Six key data fields were matched using National Health Index numbers in order to identify and resolve registration discrepancies. Capture-recapture methods were used to assess the completeness of cancer registration. RESULTS: 794 unique cases were reported; 718 from the NZCR, 721 from the NZCCR and 643 from both registries. 27 invalid cancer registrations were identified, including 19 residents of the Pacific Islands who had travelled to New Zealand for treatment. The NZCCR provided 55 non-malignant central nervous system tumour and 16 Langerhans cell histiocytosis cases which were not registered by the NZCR. The NZCR alerted the NZCCR to 18 cases missed due to human error and 23 cases that had not been referred to the specialist paediatric oncology centres. 762 cases were verified as true incident cases, an incidence rate of 166.8 per million. Registration accuracy for six key data fields was 98.6%. According to their respective inclusion criteria case completeness was 99.3% for the NZCR and 94.4% for the NZCCR. For childhood malignancies covered by both registries, capture-recapture methods estimated case ascertainment at greater than 99.9%. CONCLUSION: With two national registries covering childhood cancers, New Zealand is uniquely positioned to undertake regular cooperative activities to ensure high quality data is available for research and patient care.

1. Introduction

Cancer registries are an essential component of a cancer surveillance and control programme, providing a solid baseline for research, clinical practice and public health policy and evaluation [1]. The usefulness of cancer registries is dependent on the quality of the data; specifically the *timeliness* of reporting, *comparability* between registries and over time, the *accuracy* of data recording, and the *completeness* of case ascertainment [2,3].

The registration of childhood cancers presents additional challenges for cancer registries as, due to the rarity of cancer in childhood, even a small number of systematic errors and omissions can have a major impact on the incidence and survival rates reported [4]. In addition, the spectrum of cancers that affect children are quite distinct from those which are diagnosed in adulthood [5]. This has led to a growing number of specialist paediatric cancer registries established worldwide [4]. These specialist registries typically classify cancers according to the International Classification of Childhood Cancers (ICCC) [5], and are often in the position to collect substantially more treatment and outcome data than general cancer registries [4]. International collaborations such as the EUROCARE project [6] and International Incidence of Childhood Cancer [7], have led to the development of rigorous data validation procedures to ensure greater comparability between registries and to drive improvements in data quality. In addition, a few countries with access to two independent sources of paediatric cancer notifications have been able to utilise these to identify registration errors and/or estimate case ascertainment [8–12].

Since January 1 2000, New Zealand childhood cancers have been registered by two independent registries; the New Zealand Cancer Registry (NZCR) and the New Zealand Children's Cancer Registry

* Corresponding author at: National Child Cancer Network NZ, Children's Haematology Oncology Centre, Christchurch Hospital, Private Bag 4710, Christchurch 8140, New Zealand.
E-mail address: kirsten.ballantine@cdhb.health.nz (K.R. Ballantine).

https://doi.org/10.1016/j.canep.2018.06.001
Received 1 March 2018; Received in revised form 1 June 2018; Accepted 3 June 2018

(NZCCR). The NZCR is a population-based registry which includes key demographic information and detailed pathological information for all primary malignant tumours first diagnosed in New Zealand. The NZCCR was established at the request of the Ministry of Health for use in individual patient care, service delivery planning, statistical reporting, and child cancer research. With ethical approval to operate as an opt-out registry, the NZCCR collects demographic, diagnostic and treatment information for all children with cancer who are referred to New Zealand's two specialist paediatric oncology centres. It is integrated with the Late Effects Assessment Programme National Database which is used primarily by Clinical Nurse Specialists for planning and documenting the long-term follow up of patients who have completed their cancer treatment. The seamless integration of the NZCCR and the LEAP National Database removes unnecessary duplication of data input and provides additional data elements, including comprehensive chemotherapy, radiotherapy and surgical information and graded treatment-related events for approved research purposes.

As a long-established population-based registry, the New Zealand Cancer Registry plays an important role in New Zealand research and healthcare decision-making yet few studies have evaluated its data quality [13–15]. To date, only one study has assessed the completeness and accuracy of childhood cancer registrations in New Zealand; a comparison of the NZCR 1990-1993 childhood cancer registrations with the Children's Cancer Registry, a predecessor of the NZCCR overseen by clinicians from the five regional paediatric oncology centres in operation at this time [8]. While the completeness of registration was high for the NZCR – ascertaining 97% of the confirmed incident cases of childhood cancer for the period – registration errors such as the erroneous coding of benign conditions as malignancies were 'more common than expected', with nearly 10% of the total NZCR notifications being subsequently identified as invalid. In contrast to the over-reporting of the NZCR, the Children's Cancer Registry held only 85% percent of the total cancers diagnosed as some children were treated exclusively by specialists in other medical disciplines. It was therefore only through matching both registries that New Zealand child cancer incidence and survival could be accurately reported.

Ethical approval for data sharing between the NZCR and NZCCR and the use of the National Health Index (NHI) number – a unique seven digit personal identification number used in all health records – provides us with the opportunity to thoroughly assess the quality of child cancer data in New Zealand. The primary aim of this study was to determine the accuracy and completeness of child cancer registration for the 2010–2014 period. In addition, we aimed to produce updated child cancer incidence rates, to detect any gaps in national paediatric oncology referral pathways, and to identify future improvements which can be made to NZCR and NZCCR cancer registration practices.

2. Materials and methods

2.1. Data fields

All new cancer cases for children under the age of 15 years diagnosed between January 1 2010 and December 31 2014 were obtained from the NZCR and the NZCCR. Descriptions of the two data sources are provided in Fig. 1. Data fields included the NHI number, date of birth, sex, date of diagnosis, topography, morphology, ICCC-3 diagnostic group and subgroup, and date of death. Topography was classified by the NZCR according to the Australian modification to the 10th edition of the International Classification of Diseases (ICD-10-AM) [16] and by the NZCCR according to the World Health Organisation (WHO) International Classification of Diseases for Oncology Third Edition (ICD-O-3-1) [17]. Morphology was coded according either to the ICD-O-3 or its first revision (the ICD-O-3-1) [17]. The ICD-O-3-1 incorporates the morphology and behaviour code revisions from the 'WHO Blue Books' published between 2007 and 2010 [18–20] and was adopted by the NZCCR from the 1/1/2010 and the NZCR from the 1/1/2014. As the NZCR does not classify cancers according to the ICCC, the ICCC-3 [5] diagnostic group and subgroup for NZCR registrations were derived from the morphology and topography according to the ICCC recode produced by the National Cancer Institute [21].

Datasheets from the NZCCR and NZCR were merged and discrepancies were resolved through co-operation between a senior NZCR Clinical Coder and the NZCCR Registry Manager. New Zealand residency at the time of diagnosis was established using patient management systems and clinical summaries. Date of birth and sex were verified using patient management systems. Death registrations were provided by the Ministry of Health. For reconciling differences in date of diagnosis and ICCC-3 diagnostic group/subgroup histopathology reports were used as the gold standard. Prior to the correction of detected errors, the registrations held by each registry were evaluated according to completeness and accuracy. Accuracy between the two registries was defined as within one month for date of diagnosis and exact for date of birth, sex, ICCC diagnostic group, ICCC diagnostic subgroup, and date of death.

2.2. Statistical analysis

Statistical analyses were performed in SAS v9.3 (SAS Institute, Inc, Cary, NC). Incidence rates were calculated as the average annual number of cases per million person-years and age-standardised to the World Standard Population. The denominators were annual mean population-estimates produced by Stats NZ based on national census data. 95% confidence intervals (95% CI) were calculated assuming the cases were drawn from a Poisson distribution.

Two-source capture-recapture methods were used to determine the total number of incident cases that would have been expected if ascertainment had been complete and to thereby estimate the completeness of New Zealand child cancer registration. Independence of sources was assumed and the estimator of the number of incident cases in the population was defined as $a + b + c + (b \times c)/(a + 1)$ where a is the number of registrations notified by both registries, b by the NZCR only, and c by the NZCCR only [22]. The analyses were conducted by sex, age group, ICCC diagnostic group/subgroup, and for all childhood cancers combined. Only cases which were covered by both registries were included in capture-recapture estimates. This resulted in the exclusion from the capture-recapture estimates of non-malignant central nervous system (CNS) tumours, which the NZCR does not register, and Langerhans cell histiocytosis (LCH), due to differences in the timing of adoption of the ICD-O-3-1 in which all variants of LCH were reclassified as malignant.

3. Results

3.1. Accuracy

Table 1 shows that a total of 54 corrections were made for the 643 cases registered by both registries, representing an error rate of 1.4% across the 3858 data items assessed for six core data fields. The NZCCR recorded 12 single-digit typos for the date of birth which resulted in errors ranging from 2 days to 10 years and had not recorded six deaths which had occurred within the study period. Nineteen errors were identified in topography or histology which resulted in the diagnosis being assigned to a different ICCC diagnostic group (n = 8, 1.2%), or subgroup (n = 11, 1.7%). In many cases the discrepancies in ICCC classification and/or date of diagnosis were the result of a revision of disease morphology based on further diagnostic testing, particularly for children enrolled in international collaborative trials.