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Death certificate notifications in the Swiss Childhood Cancer Registry: assessing completeness and registration procedures

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Summary

QUESTIONS UNDER STUDY: Completeness is important in cancer registration. Identifying areas to improve registry procedures might help to maximise completeness. We examined characteristics of childhood cancer cases that were registered via death certificate notification (DCN) rather than during life, and estimated completeness of the Swiss Childhood Cancer Registry (SCCR).

METHODS: We analysed data from all children who died from cancer in Switzerland between 1985–2009 at age <16 years (n = 978), and checked whether they had been registered in the SCCR. We used multivariable logistic regression to compare characteristics of DCN cases with deceased SCCR cases, and the DCN-to-incidence and mortality-to-incidence ratio method to estimate completeness for different diagnostic periods.

RESULTS: Among 978 deceased children with cancer, 126 (12.9%) were registered via DCN. Those with tumours of digestive organs (odds ratio [OR] 5.1; 95% confidence interval [CI] 1.9–13.7), tumours of endocrine glands (OR 4.5; 95% CI 1.6–12.3), and brain tumours (OR 3.1; 95% CI 1.7–5.5) were more likely to be DCN cases than those with leukaemia. Neonates (OR 14.1, 95% CI 5.3–37.3), infants (OR 7.5; 95% CI 3.1–18.0) and 14–15 year olds (OR 2.4; 95% CI 1.2–4.9) were more likely to be DCN cases than 1–4 year olds. The DCN proportion was particularly high in infants who lived in rural regions. Estimated completeness of the SCCR increased from 85% for 1985–89 to ≥95% for 1995–2009.

CONCLUSIONS: Childhood cancer registration in Switzerland was quite complete, but registration must improve for infants, particularly neonates, and children diagnosed with hepatic, endocrine and brain tumours.

Key words: *paediatrics; childhood cancer; registry; completeness*

Introduction

Population-based cancer registration monitors the cancer burden in a region and creates a database for epidemiological research [1, 2]. All incident cases should be registered to complete the data set [3]. Inconsistent registration of subgroups (e.g., a tendency to miss certain cancers, or undercount age groups) can bias estimates [4]. Cancer registries can use death certificates to gather information on unregistered cancer patients. The completeness of a population-based cancer registry can be estimated on the basis of the proportion of cases registered posthumously, via a death certificate [4–7]. Registration procedures can be improved by comparing patients identified through death certificates with cases registered during life.

In its first three decades, the Swiss Childhood Cancer Registry (SCCR) was primarily notified of incident cases by paediatric cancer centres. A previous study compared the SCCR's completeness with regional cancer registries for 1985–2004 and found that 22% of childhood cancer patients in regional registries had not been registered in the SCCR [8]. These missed cases were registered retrospectively for the whole study period, and the SCCR revised its registration procedures. The SCCR now relies on a variety of notification sources (paediatric cancer centres, other hospitals, pathology laboratories, regional cancer registries).

This study determined the completeness of the SCCR's updated registration process by investigating the number of children who first came to its attention via death certificate notification (DCN) [9–11]. We aimed to: (1) describe the number of childhood cancer cases identified via DCN; (2) describe patient groups that were more likely not to be registered during life; and (3) estimate completeness of the SCCR for different periods based on the proportion of DCN cases.

Materials and methods

The Swiss Childhood Cancer Registry

The SCCR was founded in 1976 by the Swiss Paediatric Oncology Group, the association of the nine specialised paediatric cancer centres (PCCs). The SCCR registers malignant solid tumours, leukaemias and lymphomas, central nervous system (CNS) tumours (both malignant and benign), and Langerhans cell histiocytosis diagnosed in children <21 years in Switzerland [9, 11]. Children diagnosed with cancer before they reach 15, and older adolescents diagnosed with typical paediatric tumours, are usually treated in one of the PCCs. A data manager in each PCC actively notifies the SCCR of new cases, usually within a month of diagnosis. In previous decades, some children were treated outside PCCs, for example for leukaemia, in smaller paediatric hospitals or adult haematology departments, or, for CNS tumours, in neurosurgery departments [8]. In 2007, the SCCR started validating and improving completeness of registration by comparing retrospectively the dataset of the SCCR with datasets of regional (cantonal) cancer registries [12].

Each diagnosis registered in the SCCR is classified according to the 10th revision of the International Classification of Diseases (ICD), topography and morphology of the third revision of the ICD for Oncology (ICD-O-3), and according to the third edition of the International Classification of Childhood Cancer (ICCC-3) [13–15]. The SCCR updates vital status and date of death based on routine queries to municipal registries in Switzerland. The SCCR also receives information on cancer mortality from the Swiss Federal Statistical Office (SFSO), including all death certificates that list neoplasm as cause of death for Swiss residents [10, 16].

Study design

We determined if all children whose death certificates mentioned cancer were registered in the SCCR at time of diagnosis. We included all records that listed one or more causes of death as cancer: underlying cause of death; intermediate and immediate cause of death; and up to two causes not directly linked to the train of morbid events. Until December 31 1994 the SFSO coded according to ICD-8 (3-digit codes 140-209, 225 and 238); from January 1 1995 on according to ICD-10 (codes C00-C97, D33 and D43; table 1). We classified types of cancer according to sub-blocks of the ICD-8 and ICD-10 systems (table 1). The categories "Tumours of digestive organs", "Tumours of bone, cartilage and connective tissue" and "Tumours of endocrine glands" overlapped in the 3-digit system of ICD-8 and ICD-10 so we used these. Tumours of the nervous system do not overlap in the ICD-8 and ICD-10 sub-blocks, so we adapted the grouping slightly, differentiating between "Brain tumours" and "Tumours of other parts of the nervous system". We also included neoplasms of benign or uncertain behaviour of the brain (ICD-8, 225; ICD-10, D33.0 – D33.2 and D43.0-D43.2), since they are used in the ICCC-3 and are usually included in childhood cancer registries. We divided the sub-block that includes neoplasms of lymphatic and haematopoietic tissue into "Lymphoma" (ICD-8, 200-203; ICD-10, C81-C86) and "Leukaemia" (ICD-8, 204-207; ICD-10, C91-C96).

We included records from children resident in Switzerland who died before age 16 years between January 1 1985, and December 31 2009. We defined a case as a DCN if cancer was mentioned on the death certificate, but the child had not been registered in the SCCR [4].

We extracted the dataset from the SCCR on December 31 2013, which gave us an interval of at least 4 years between diagnosis and notification from sources other than death certificates. Since death certificates in Switzerland are anonymous, we first used probabilistic linkage to link records from death certificates to deceased persons from the SCCR. We used variables present in both datasets (sex, date of birth, date of death and municipal number at date of death). Next, we double-checked linkage results manually and verified unclear cases.

Data analysis

We used STATA version 13.1 for statistical analyses (StataCorp. 2005. Stata Statistical Software: Release 13.1 StataCorp LP, College Station, TX, USA). We categorised type of cancer into eight subgroups (table 1). We categorised age at death into neonatal period (<28 days), infancy (age 28–365 days), and 1–4, 5–9, 10–13 and 14–15 years. For comparison, we used the same age categories as previous studies in Switzerland [8]. We used a classification of the SFSO to distinguish "urban" (main urban centres or urban agglomeration around centres) and "rural" (towns without surrounding agglomeration and rural communities) municipalities [17]. We classified three official language regions: German, French, and Italian/Romansh. For each child, we categorised a binary variable to signal if the community they lived in was covered by a regional cancer registry at time of diagnosis.

Table 1: Classification of types of cancer based on ICD-8 and ICD-10.

Type of cancer (ICD-8/10 main groups)	ICD-8[a]	ICD-10[b]
Tumours of digestive organs	150–159	C15–C26
Tumours of bone, cartilage and connective tissue	170–171	C40–C41, C45–C46, C48–C49
Brain tumours (benign and malignant)	191, 225	C71, D33.0–D33.2, D43.0–D43.2
Tumours of other parts of nervous system	192	C47, C72
Tumours of endocrine glands	194	C73-C75
Lymphoma	200–203	C81-C86
Leukaemia	204–207	C91-C95
Other tumours	140–207 excluding the above mentioned	C00–C96 (excluding the above mentioned)

[a] International Classification of Diseases 8th revision
[b] International Classification of Diseases 10th revision

First, we computed the proportion of DCN cases with 95% confidence intervals (CIs) among all deceased cases in the SCCR, and then in subgroups defined by period of diagnosis and patient characteristics.

Second, we determined characteristics associated with DCN registration, comparing DCN cases with deceased SCCR cases. Associations are presented as odds ratios (ORs) with 95% CI, where an OR of less than one indicates decreased likelihood that a person was registered in their lifetime. Our multivariable model included all variables significant at the $p < 0.05$ level in the univariable regression, plus sex. We tested all exposure variables for interaction with period of death. Since we found no significant interactions these were not included in the final multivariable model. Reference categories for logistic regression analysis were those with the largest number of individuals: sex (male); type of cancer (leukaemia); age at death (1–4 years); municipality (urban); language region (German); and, coverage by regional cancer registration (yes), or as the first category for year of death (1985–1989). In a *post-hoc* analysis, we continued to explore data from infants, because of their high risk of DCN notification. Since the absolute number of infants was small, we categorised cancers into broader groups. We used Fisher's exact test and likelihood ratio tests to test statistical significance, and added interaction terms to the regression models to assess effect modification. All p-values were two-sided; a p-value of < 0.05 indicated statistical significance.

Third, we used the formula proposed by Parkin et al. to estimate completeness of the SCCR based on the proportion of DCN cases [5]. An estimate of completeness (C_{SCCR}) is given by

DCN:I represents the DCN to incidence ratio, defined as the number of DCN cases divided by the total number of diagnosed cancer cases (including the number of DCN cases) in a specific period. We defined mortality to incidence ratio (M:I) as the number of deaths divided by the number of new cases diagnosed in that period. We defined incident cases as all cancers (ICCC-3 main groups I-XII) diagnosed in Swiss resident children up to 16 years between 1985–2009. As required by the method, the number of incident and mortality cases included DCN cases to estimate completeness. For DCN cases, we approximated the date of diagnosis by the date of death.

Results

Proportion of DCN cases among all children who died from cancer

From January 1985 to December 2009, cancer was mentioned on the death certificate of 978 children. None mentioned more than one cause of death related to cancer. Of these 978 children, 852 (87%) were registered in the SCCR during lifetime and 126 (13%) were registered as DCN cases (table 2). This proportion declined over time, from 26% in 1985–1989, to 5% in 2005-2009 (table 2). Among deceased SCCR patients, the mean age at diagnosis was 6.0 years (4.4; range 0.0–15.9), and the mean time from diagnosis to death was 2.02 years (2.2; range 0.0–14.7). None of the exposure variables contained missing values.

Characteristics of childhood cancer patients notified via death certificates

The proportion of DCN among deceased childhood cancer patients differed significantly ($p < 0.05$) between type of cancer, age at death, language region, and coverage by regional cancer registration (table 2). DCN detected 27% percent of children with tumours of digestive organs, but only 8% of those with leukaemia. DCN proportion was highest in children who died during the neonatal period (<28 days, 50%) or during infancy (28 days–365 days, 30%) and lowest (9%) among those who died aged 1–4 years. DCN proportion ranged regionally from 20% to 14% and 6% in Italian, German and French speaking areas, respectively; and from 17% in regions without cancer registries to 7% in regions covered by a regional cancer registry. DCN proportion tended to be higher in rural municipalities (15%) than in urban municipalities (12%), but was not statistically significant ($p = 0.185$). We found no difference by sex ($p = 0.485$).

In the multivariable logistic regression, DCN remained more common among children with tumours of digestive organs (OR 5.1, 95% CI 1.9–13.7), tumours of endocrine glands (OR 4.5, 95% CI 1.6–12.3), and brain tumours (OR 3.1, 95% CI 1.7–5.5) than among those with leukaemia. We detected more DCN cases in neonates (death at <28 days, OR 14.1, 95% CI 5.3–37.3) and infants beyond the neonatal period (death at day 28–365, OR 7.5, 95% CI 3.1–18.0), and in teenagers (death at age 14–15 years, OR 2.4, 95% CI 1.2–4.9) than in children who died at age 1–4 years. DCN cases were less frequent among those who lived in regions covered by regional cancer registries (OR 0.4, 95% CI 0.2–0.6). In the multivariable model, language region was no longer significantly associated with DCN. We did not find any evidence for an interaction between year of death and the other exposure variables.

Subgroup analysis for infants

Among 74 infants who died of cancer in their first year of life, 28 (38%) were notified via death certificate (table 3). In contrast to the findings for older children, in infants, the DCN proportion did not decrease over time, but remained high (31%) even in the most recent period. The proportion of DCN cases was high for both girls and boys, and for all types of cancer. It was higher for infants who lived in rural municipalities (68%) than for those who lived in urban municipalities (27%). It was also higher for children who lived in a region without a regional cancer registry (51%) than in a region covered by regional cancer registration (21%). The causes of death of all 28 infants identified by death certificate were verified by autopsy. In 12 cases, the death certificate noted the place it was issued; six (50%) were issued by neonatal wards, three (25%) by a private practitioner, two (17%) by intensive care units, and only one (12%) by a paediatric oncology ward.

Estimate of completeness of the SCCR

A total of 4 435 children were diagnosed with cancer during the study (including DCN cases); 978 died from cancer. The DCN:I ratio was 0.03; the M:I ratio was 0.22 (table 4). We used the formula proposed by Parkin et al. to estimate 91% completeness over the whole study period [5]. Completeness increased significantly over study time, from 85% in 1985–1989, to 90% in 1990–1994, 95% in 1995–1999, 95% in 2000–2004 and 96% in 2005–2009 (table 4). This increase is explained by the decreasing number of DCN cases, and counteracted partly by the decreasing M:I ratio, which fell from 0.318 in 1985–1989 to 0.167 in 2005–2009 (table 4). The M:I ratio decrease between the first to the second time period was mainly influenced by an increase in incident cases (694 vs 902). In later periods, incidence was more stable and the M:I ratio was influenced mostly by the decreasing number of deaths (239 in 1990–1994 to 155 in 2005–2009).

Discussion

Main findings

This first study on DCN registration in the SCCR found that DCN proportions varied widely between patient groups. It provided the first estimates of completeness of childhood cancer registration in Switzerland. Age was the best predictor of DCN registration: infants who died from cancer (in particular, neonates) were most likely not to have been registered while alive, as were teenagers who died at 14–15 years. Children with rare tumours such as tumours of digestive organs and tumours of endocrine glands, and children with brain tumours were also very likely to miss

Table 2: Characteristics of childhood cancer cases notified via death certificate .

	Deceased children with cancer[a]	DCN cases		Univariable analysis		Multivariable analysis[d]	
Variable	**n**	**n**	**% (95% CI)**	**OR (95% CI)[b]**	**p-value[c]**	**OR (95% CI)[b]**	**p-value[c]**
All patients	978	126	12.9 (10.9–15.1)				
Gender					0.485		0.606
Male	556	68	12.2 (9.8–15.2)	1		1	
Female	422	58	13.7 (10.8–17.4)	1.1 (0.8–1.7)		1.1 (0.7–1.7)	
Type of cancer mentioned on death certificate					0.006		<0.001
Tumours of digestive organs	34	9	26.5 (14.2–43.8)	4.1 (1.8–9.8)		5.1 (1.9–13.7)	
Tumours of bone, cartilage and connective tissue	97	8	8.2 (4.2–15.7)	1.0 (0.5–2.4)		0.7 (0.3–1.8)	
Brain tumours (benign and malignant)	261	39	14.9 (11.1–19.9)	2.0 (1.2–3.4)		3.1 (1.7–5.5)	
Tumours of other parts of nervous system	63	13	20.6 (12.3–32.5)	3.0 (1.4–6.2)		1.5 (0.6–3.3)	
Tumours of endocrine glands	54	7	13.0 (6.3–24.9)	1.7 (0.7–4.2)		4.5 (1.6–12.3)	
Lymphoma	45	7	15.6 (7.5–29.4)	2.1 (0.9–5.2)		1.7 (0.6–4.4)	
Leukaemia	325	26	8.0 (5.5–11.5)	1		1	
Other tumours	99	17	17.2 (10.9–26.0)	2.4 (1.2–4.6)		2.4 (1.1–5.0)	
Age at death					<0.001		<0.001
<28 days	30	15	50.0 (32.5–67.5)	10.1 (4.4–23.5)		14.1 (5.3–37.3)	
28 days–365 days	44	13	29.6 (17.9–44.7)	4.3 (1.9–9.3)		7.5 (3.1–18.0)	
1–4 years	245	24	9 (6.0–13.3)	1		1	
5–9 years	301	29	9.6 (6.0–13.5)	1.1 (0.6–1.9)		1.2 (0.6–2.2)	
10–13 years	215	23	10.7 (7.2–15.6)	1.2 (0.7–2.2)		1.5 (0.8–2.9)	
14–15 years	143	24	16.8 (11.5–23.9)	2 (1.1–3.8)		2.4 (1.2–4.9)	
Year of death					<0.001		<0.001
1985–1989	221	58	26.2 (20.8–32.5)	1		1	
1990–1994	239	36	15.1 (11.1–20.2)	0.5 (0.3–0.8)		0.5 (0.3–0.8)	
1995–1999	168	12	7.1 (4.1–12.2)	0.2 (0.1–0.4)		0.1 (0.1–0.3)	
2000–2004	195	12	6.2 (3.5–10.5)	0.2 (0.1–0.4)		0.2 (0.1–0.3)	
2005–2009	155	8	5.2 (2.6–10.0)	0.2 (0.1–0.3)		0.1 (0.0–0.2)	
Municipality					0.185		–
Urban	679	81	11.9 (9.7–14.6)	1			
Rural	299	45	15.1 (11.4–19.6)	1.3 (0.9–1.9)			
Language region					0.001		0.121
German	714	103	14.4 (12.0–17.2)	1		1	
French	215	13	6.1 (3.5–10.2)	0.4 (0.2–0.7)		0.5 (0.3–1.0)	
Italian/Romansh	49	10	20.4 (11.3–34.1)	1.5 (0.7–3.1)		1.1 (0.5–2.4)	
Regional cancer registration					<0.001		<0.001
Yes	371	25	6.7 (4.6–9.8)	0.4 (0.2–0.6)		0.4 (0.2–0.6)	
No	607	101	16.6 (13.9–19.8)	1		1	

CI = confidence interval; DCN = death certificate notification; OR = odds ratio; SCCR = Swiss Childhood Cancer Registry

[a] This includes all deceased children registered in the SCCR and DCN cases

[b] From logistic regression models

[c] From likelihood ratio test

[d] Multivariable analyses are adjusted for all variables shown

registration in the SCCR. Infants who lived in more remote regions were more often registered via DCN. The proportion of DCN cases was lower in regions covered by regional cancer registries (7% compared to 17%), but not 0%. Completeness of the SCCR improved during the study period. It has been about 95% since 1995.

Main findings in the context of other findings

Likelihood of DCN registration varied most between age groups and between tumour types. We found only one international study that investigated patient characteristics associated with death certificate only (DCO) cases in southeast England from 1987–1989 [18]. It included cancer cases of all age groups; place of residence, age, sex, survival time and place of death (e.g. oncology ward, general hospital or home) were independent predictors of DCOs among deceased patients. In that study, the likelihood of DCO registration varied most between places of death: those who died in an extraregional hospital were more often DCO registered than those who died in a National Health Service (NHS) acute hospital. Unfortunately, we had no information on place of death, but the SCCR employs data managers in all nine PCCs in Switzerland, so we assume that most DCN cases died outside paediatric oncology centres and thus were not registered. Children with brain tumours, for example, may have been treated in neurology or neurosurgery wards. Infants were likely to have been treated in neonatal wards or paediatric intensive care units, with no paediatric oncologist involved, which might also explain the high proportion of DCN among in-

Table 3: Characteristics of infant cancer cases identified via death certificate notification.

	Deceased infants with cancer[a]	DCN cases		
Variable	**n**	**n**	**% (95% CI)**	**p-value[b]**
All patients	74	28	37.8 (27.3–49.6)	
Sex				0.343
Male	34	15	44.1 (28.2–61.4)	
Female	40	13	32.5 (19.6–48.8)	
Type of cancer mentioned on death certificate				0.122
Tumours of digestive organs and endocrine glands	10	5	50.0 (20.9–79.1)	
Tumours of bone, cartilage and connective tissue	11	4	36.4 (13.4–67.9)	
Brain tumours (benign and malign) and tumours of other parts of nervous system	25	7	28.0 (13.6–49.0)	
Lymphoma/Leukaemia	14	3	21.4 (6.6–51.2)	
Other tumours	14	9	64.3 (36.2–85.1)	
Year of death				0.449
1985–1989	17	9	52.9 (29.3–75.3)	
1990–1994	19	5	26.3 (10.9–50.9)	
1995–1999	12	4	33.3 (12.3–64.1)	
2000–2004	13	6	46.2 (21.3–73.1)	
2005–2009	13	4	30.8 (11.3–60.7)	
Language region				0.355
German	55	20	36.4 (24.5–50.1)	
French	13	4	30.8 (11.3–60.7)	
Italian/Romansh	6	4	66.7 (23.2–93.0)	
Linkage with cantonal registry				0.009
Yes	33	7	21.2 (10.2–38.9)	
No	41	21	51.2 (35.8–66.4)	
Municipality				0.002
Urban	55	15	27.2 (16.9–40.8)	
Rural	19	13	68.4 (44.1–85.6)	

CI = confidence interval; DCN = death certificate notification; SCCR = Swiss Childhood Cancer Registry

[a] Deceased patients registered in the SCCR and DCN cases

[b] From Fisher's exact test

Table 4: Completeness of the Swiss Childhood Cancer Registry during different time periods, calculated using the DC-M:I method.

Year	Children with cancer[a]	Children deceased due to cancer[b]	DCN cases	DCN:Incidence ratio[c]	M:I[e]	Completeness (%)
1985–2009	4 435	978	126	0.0284	0.2205	90.9
1985–1989	694	221	58	0.0836	0.3184	84.8
1990–1994	902	239	36	0.0399	0.265	90
1995–1999	898	168	12	0.0134	0.1871	94.5
2000–2004	1 005	195	12	0.0119	0.194	95.3
2005–2009	936	155	8	0.0085	0.1656	95.9

DCN = death certificate notification; M:I = mortality to incidence ratio; SCCR = Swiss Childhood Cancer Registry

[a] Childhood cancer cases registered in the SCCR and DCN cases

[b] Deceased cases registered in the SCCR and DCN cases

[c] Number of DCN cases divided by the number of all childhood cancer cases

fants in rural regions. Parents might first visit a local practitioner or general oncologist before traveling to a distant PCC. As we expected, regions covered by regional cancer registries had a lower proportion of DCN than regions without registries (17% vs 74%). However, DCN cases did not disappear completely in covered regions, suggesting that some DCN cases are not registered in some regional cancer registries. Several factors could have contributed to the declining proportion of DCN for childhood cancer over time. First, the organisational structure of the SCCR changed, which might have helped reduce the proportion of DCN. Important mile stones were: (1) introduction of financial rewards to the PCC for case notification in 1990; (2) the change from paper files to an electronic database in the mid-1990s; (3) incorporation of the SCCR into the Institute of Social and Preventive Medicine at the University of Bern in 2004, where case registration procedures were reorganised and the search for missing cases and missing data intensified. Second, the number of regional cancer registries has grown since 1970, and SCCR data exchange with these registries might have lowered the proportion of DCN. Switzerland has no specialised clinics for adolescents, so patients are cared for in many different institutions throughout the country. This makes registration difficult, and we assume higher DCN proportions in adolescents.

We estimated completeness of the national childhood cancer registry based on the proportion of DCN cases. We had no direct comparison data for this. In the New Zealand Cancer Registry (NZCR), Dockerty et al. estimated completeness for childhood cancer registration (age at diagnosis 0–14 years) using a three-source capture-recapture approach. Completeness was 99% during 1990–1993, assuming independence of the sources [19]. In the UK, Kroll et al. used a two-source capture-recapture approach to estimate completeness for the National Registry of Childhood Tumours (NRCT) (age at diagnosis 0–14 years) [20]. The authors estimated a completeness of 99% during 2002–2003, assuming sources were independent. General cancer registries, one of the sources in the British study, cover the whole population in the UK, and this might explain why they are more complete than Swiss registries, where, in the past, only some regions were covered by regional cancer registries. In Brazil, two-source capture-recapture completeness estimates for childhood cancer in three cities were 77%, 54% and 31% [21]. Brazil's relatively low completeness estimates are consistent other emerging countries, where it is difficult to register cancer patients. However, directly comparing these results might be hard, since capture-recapture and the DC and M:I method depend on different assumptions and have different limitations.

Strengths and limitations

This study was strengthened by available mortality data and additional information on individual patients. This allowed us to analyse characteristics of DCN cases in detail. Because we could access original death certificates, we validated und updated coded causes of death. We used death certificates to manually double-check results of the record, changing record linkage from probabilistic to deterministic. Overall mortality data in Switzerland are 97% complete [22]. The SFSO reports that the missing 3% is mainly due to Swiss citizens living abroad. This population is not relevant for cancer registration.

The way we used death certificates could cause reporting bias. Cancer may have been over-reported on death certificates, increasing DCN proportions, and causing underestimation of reported completeness. Cancer may also have been under-reported on death certificates, decreasing DCN proportions and causing us to overestimate completeness. But we had access to all causes of death (underlying, consecutive and contributing) and we assume that virtually all cancers detected and diagnosed by clinicians were mentioned on death certificates. Cancer diagnoses listed on the death certificate may have been systematically misclassified, changing DCN proportions for specific childhood cancers. Coded causes of death also limit our study. We coded causes of death with ICD-8 and ICD-10, which define only a few histological types of cancer, and thus we could not classify some tumour types diagnosed in children, such as neuroblastoma and other peripheral nervous cell tumours (ICCC-3 main group IV), soft tissue and other extraosseous sarcomas (ICCC-3 main group IX) or germ cell tumours, trophoblastic tumours, and gonadal neoplasms (ICCC-3 main group X) [13, 14]. We were also limited by the small number of study subjects in some analyses, which caused wide confidence intervals. Completeness estimates should also be interpreted with caution. The DC and M:I method assumes that the probability of death is the same in registered and unregistered cases [4]. If cancer survival between registered and unregistered children is not the same, this assumption is violated. For example, if fewer unregistered than registered cases survive, the true total incidence would be overestimated and completeness underestimated. We do not know the true number of unregistered cases who did not die. The DC and M:I method also assumes that incidence and mortality ratios were relatively constant throughout the period for which we estimate completeness [4]. We needed to make this assumption because our method is based on the M:I ratio. Since M:I ratios changed over time (table 2), we divided the study period into 5-year periods so the M:I ratios in each period would be more stable.

Main message

Our results suggest high completeness of childhood cancer registration in Switzerland. The SCCR will revise its registration procedures for infants, particularly neonates, and children diagnosed with tumours of digestive organs, tumours of endocrine glands and brain tumours to ensure that most childhood cancer cases diagnosed in Switzerland will be detected and included, and to maximise completeness.

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