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ORIGINAL ARTICLE

Prevalence of Norwegian patients diagnosed with childhood cancer, their working ability and need of health insurance benefits

T. B. JOHANNESEN[1,2], F. LANGMARK[2], F. WESENBERG[3] & K. LOTE[1]

[1]*Department of Medical Oncology and Radiotherapy, The Norwegian Radium Hospital, N-0310 Oslo, Norway,* [2]*The Norwegian Cancer Registry, Institute of Population-based Cancer Research, N-0310 Oslo, Norway, and* [3]*Department of Pediatrics, National Hospital, Oslo, Norway*

Abstract

The object of this study was in a population-based material to investigate the prevalence of patients diagnosed with childhood cancer, and compared to the general population to assess working ability, yearly income and need for health insurance benefits in patients surviving at least five years after treatment for childhood CNS tumours or hematological malignancies. During the period January 1, 1970 to December 31, 2002 the prevalence in the Norwegian population of patients diagnosed with any childhood cancer increased from 12.2 (473/3 888 305) to 65.1 (2944/4 524 066) per 100 000 population. The proportion of survivors in need of any health insurance benefit was for CNS tumours 47.1% and for hematological malignancies 21.0%. The proportion in the age group 16–67 receiving disability pension for CNS tumours was 94/454 (20.7%) compared to 21/575 (3.7%) for patients treated for hematological malignancies ($p < 0.001$). Of patients given radiotherapy 25/70 (35.7%) received disability pension, compared to 90/959 (9.4%) in unirradiated patients, $p < 0.001$. Yearly income and working ability was particularly low for CNS tumour survivors.

This study illustrates loss of working capability associated with pediatric cancer and treatment and long-term requirement of health insurance benefits.

Prevalence of a disease reflects the combined patterns of incidence, survival and deaths due to other causes, and is a useful basis in planning health care services, ensuring patients' adequate medical follow-up. Since necessary data of a whole population is difficult to obtain [1,2], prevalence data has only recently become available and is often estimated in statistical models of incidence and survival trends. Registration of cases still living having been diagnosed with cancer requires a consistent and long period of surveillance and a complete follow-up so that prevalence is not underestimated [2,3].

Long-term survivors of most pediatric cancers experience an excess of deaths compared with the general population [4–6]. Significant increases in morbidity associated with treatment-related complications have been found up to 25 years after initial diagnosis [4,5,7].

Late effects of chemotherapy given for childhood cancer may include risk of second cancers, cardiopulmonary and renal morbidity, or cognitive- and endocrine dysfunction [8,9]. Radiotherapy may further enhance these effects, causing growth disturbances, lower levels of intellectual and academic functioning and increase the risk of second malignant neoplasms [10–13].

Late adverse effects of radiotherapy to the central nervous system (CNS) may develop after a latency period of several years [14,15].There is considerable late morbidity and mortality among brain tumour patients [16,17]. Survivors of childhood leukemia have an increased risk of late effects which are more common following treatment given at young age and when radiotherapy is included [13,18,19].

A substantial number of childhood cancer survivors experience later limitations in psychosocial functioning affecting marital status, education, employment and living situation [20]. Accurate data on long-term childhood cancer survivors' need of health insurance benefits are scarce. This information may be difficult to obtain and is, compared to survival and late-effects, much less reported. Many long-

Correspondence: Tom B. Johannesen, 7th Floor, Department of Medical Oncology and Radiotherapy, The Norwegian Radium Hospital, Montebello, 0310 Oslo, Norway. Tel: +47 22 93 40 00/ +47 40 87 98 83. Fax: +47 22 93 59 42. E-mail: tomj@trollnet.no

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term survivors of childhood cancer have no medical insurance [12] or cannot obtain this-, and types of benefits differ.

The object of this study was to investigate in a population-based material the prevalence of patients treated for childhood cancer and particularly assess working ability, yearly income and need of health insurance benefits of those treated for CNS tumours and hematological malignancies compared to the general population.

Materials and methods

The Norwegian Cancer Registry and prevalence data

The Norwegian Cancer Registry has received nationwide data since 1953 on all cases of malignant neoplasms together with benign tumours of the CNS. The mandatory reporting is based on four sources of information: 1) copies of all pathology and autopsy reports from all laboratories in the country, 2) registration forms filled in by clinicians giving the localisation, extent of disease and treatment, 3) copies of all death certificates that mention neoplastic disease and 4) all hospital discharge diagnosis. The Norwegian population of 4.5 million is well defined and stable with regard to migration. Each individual is uniquely identified with date of birth together with a five-digit number to ensure that cases are not registered twice or lost to follow-up. If the registry receives a report from a laboratory of pathology but no clinical report the clinician is contacted. Also if information on a death certificate is not in accordance with the files of the Cancer Registry this is investigated further. If patients are reoperated or have surgery several years after initially being diagnosed only by radiological methods, the database is continuously updated according to the submitted further histological reports. Age was defined as age at time of initial tumour diagnosis. Results of quality control have indicated that the data from the Norwegian Cancer Registry are valid for population-based studies [21].

Prevalence in the whole population was defined as the proportion of cases alive by December 31 each year having been diagnosed with cancer before 15 years of age. For analysis of total prevalence in the time period January 1, 1970 to December 31, 2002, patients diagnosed from the year 1953 were included. All malignant cases were included in addition to all benign tumours of the CNS. No cases were lost to follow-up and none were known only from the death certificate. Date of vital status was obtained from the Statistics Norway, Registry of Causes of Death. Childhood cancer was defined as cancer diagnosed below 15 years of age.

A separate analysis was done for patients treated for CNS tumours and hematological malignancies diagnosed 1970–1997 and alive by December 31, 2002. In this analysis, patients diagnosed before 1970 were excluded.

The Norwegian Social Insurance Scheme

Everyone in Norway including foreign citizens is insured under the National Insurance Scheme if they are either resident or working as employees in Norway. The National Insurance Scheme is financed by the State together with contributions by employers and employees. Entitled benefits are: medical benefits, disability pensions, basic benefits and attendance benefits.

In the case of sickness a medical benefit of up to 100% of yearly income may be given for up to one year. After this, disability pension may be granted if the working capacity is permanently reduced by at least 50% due to illness or injury in a person aged between 16 and 67. The calculation of this disability pension is based on years in work and income at time of disability. Persons having become disabled before working capability are credited with a minimum yearly pension of Euro 14 723.

If a disability involves extra expenses a basic benefit is granted, ranging Euro 940–4710 per year. Basic benefit is granted in the following cases: prostheses, support bandages, extra costs of running/operation of technical aids, transport, guide dog, costs of text telephone, higher cost of special dietary needs and clothing.

An attendance benefit is granted if the disabled person needs special attention, ranging Euro 1686–10 113 per year. Attendance benefit may be awarded if there is a need for special supervision, for example, extra nursing and need of special care. Also when there is the need for special supervision, care and training, help with getting up/going to bed, eating and personal hygiene. If family members provide help beyond that which can reasonably be expected they may receive part of the benefit.

Patients, benefits and working ability

In the time period January 1, 1970 to December 31, 1997 a total of 3432 children (of less than 15 years at diagnosis) were diagnosed with cancer in Norway. Children with a hematological malignancy (n = 1042, 30.4%) and children with a primary CNS tumour (n = 1208, 35.2%) were selected for further analysis. Classification was according to the International Classification of Diseases for Oncology

Version 2 (ICD-O-2) and cases selected were of codes C42 and the CNS sections of C70, C71, C72 and C75 with corresponding histologies. Two cases were diagnosed incidentally at autopsy and were therefore excluded together with twenty-one patients who had emigrated. Patients still alive by December 31, 2002 were analysed concerning their working capability and whether they were receiving any kind of State health insurance benefit. Data for the patients and the general population were obtained from The Norwegian Social Insurance Scheme. Age at follow-up was defined as age by December 31, 2002.

Statistical analysis

The SPSS 13.0 statistical program was used for data analysis. Testing for tendency of difference in proportions was done by Fisher's exact test or χ^2 test. A confidence interval of 95% was chosen and a p-value <0.05 was considered statistically significant.

Results

Prevalence

During the period January 1, 1970 to December 31, 2002 the prevalence in the Norwegian population of patients diagnosed in 1953 onwards and treated for childhood cancer increased from 12.2 (473/3 888 305) to 65.1 (2944/4 524 066) per 100 000 population. The proportion of these childhood survivors alive at the end of 2002 is shown in Table I. During the period 1970 to 2002 the prevalence of patients surviving five years or more after diagnosis of childhood cancer increased from 6.3 (244/3 888 305) to 51.9 (2348/4 524 066) per 100 000 population. Number of children either under treatment or having been treated for cancer increased from 316 in 1970 to 1023 in 2002 corresponding to a prevalence among children of 33.3 (316/950 212) and 112.9 (1023 /906 300) per 100 000 children, respectively. To shed light on the unobserved prevalence arising from before 1953 patients who were alive in 1970 and diagnosed with cancer in childhood 1953–1957 were analysed. Of a total of 591 cases, 66 were still alive. Concerning the missed cases one would expect the prevalent cases diagnosed prior to 1953 to be approximately 10 cases per year or less. Assuming 200 cases missed, the prevalence reported for 1970 will be underestimated by approximately one third.

Prevalence of all patients diagnosed with a tumour of the CNS or a hematological malignancy in childhood is shown in Figure 1. During the study period the prevalence of patients diagnosed with a childhood hematological malignancy increased from 1.6 to 18.7 per 100 000 population. The prevalence of patients in the population diagnosed with childhood CNS tumours increased from 3.0 to 17.6 per 100 000. By the end of the study period the prevalence of persons less than 50 years of age diagnosed with either hematological malignancy or CNS tumour in childhood was 53 per 100 000 population.

Benefits and working ability in patients treated for CNS tumours or hematological malignancies

Of patients diagnosed with either CNS tumour or hematological malignancy during 1970–1997 a total of 1144/2227 patients (51.4%) had survived five years and were still alive at follow-up. Histological classification of patients surviving five years or more and alive at the last follow-up is shown in Table II. The percentage of patients receiving any kind of health insurance benefit was for CNS tumours 258/548 (47.1%) and for hematological malignancies 125/596 (21.0%), $p<0.001$. The percentage of patients receiving basic benefit or attendance benefit was for CNS tumours 229/548 (41.8%) and for hematological malignancies 122/596 (20.5%), $p<0.001$. Proportions of patients alive by December 31, 2002 in need of basic benefit or attendance benefit five or more years after treatment are shown in Table III.

The number of patients in the age group 16–67 receiving disability pension at time of follow-up was for brain tumours 94/454 (20.7%) compared to 21/575 (3.7%) patients treated for hematological malignancies ($p<0.001$). Age at time of confirmed permanent disability was nearly identical for CNS versus hematological disorders (mean 18.0 years, range 16.0–32.9 versus mean 18.5 years

Table I. Prevalence in Norway by December 31, 2002 of patients diagnosed with any cancer before 15 years of age in the time period 1953–2002. Prevalence proportion is shown by age groups and whole population.

Age groups (years)	0–4	5–9	10–14	15–19	20–24	25–34	35–44	45–54	55–64	65+	Total
Patients alive (n)	140	382	501	421	395	592	329	143	41	0	2944
Population ×1000 (n)	293	309	309	272	275	657	667	611	487	673	4524
Freq. pr 100 000 population	47.8	123.6	162.1	155.8	143.6	90.1	49.3	23.4	8.4	0	65.1

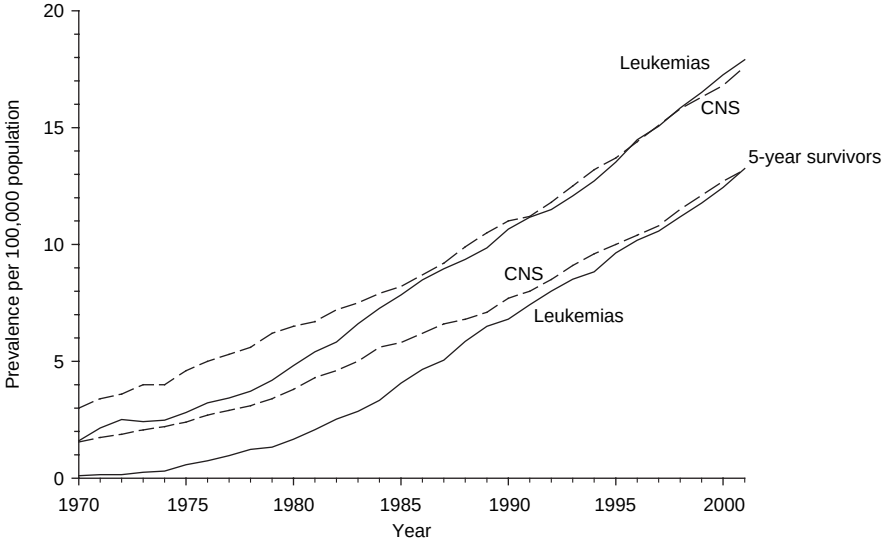

Figure 1. Known prevalence in the whole Norwegian population of cases treated in childhood for a malignancy of the CNS or hematological system. Patients diagnosed from the year 1953 are included. Prevalence of patients alive 5-years or more after diagnosis is also shown. Maximum age of the known childhood survivors was 31 years in 1970, 51 years in 1990 and 63 years in 2002.

16.0–28.9, p = 0.3). All except one of these young patients received the lowest possible rate of disability pension.

Of patients given radiotherapy the amount receiving disability pension was 25/70 (35.7%), while this proportion in patients not having received radiotherapy was 90/959 (9.4%), p < 0.001.

In the working age group 25–44 years at follow-up the proportion of patients receiving disability pension was for CNS tumours 79/222 (35.6%) compared to 13/202 (6.4%) for those treated for hematological malignancies, (p < 0.001). Of all persons in Norway in this age group the proportion receiving disability pension was 3.4% (50 032/1 322 663).

Table II. Histological classification of patients diagnosed with childhood cancer of the CNS or haematological system 1970–1997 surviving 5 years or more and alive by December 31, 2002.

Classification of tumours	n	%
Brain and CNS tumours (n = 548)		
Pilocytic astrocytoma	87	15.9
Diffuse astrocytoma	117	21.4
Medulloblastoma	48	8.8
Ependymoma	20	3.6
Oligodendroglioma/ mixed glioma	54	9.9
Other tumors of neuroepitelial tissue	52	9.5
Tumours of meninges	40	7.3
Tumors of sellar region	23	4.2
Germ cell tumours	6	1.1
Other brain tumours	67	12.2
Unbiopsied brain tumours	34	6.2
Haematological malignancies (n = 596)		
Acute lymphatic leukemia	487	81.7
Acute myelocytic leukemia	66	11.1
Acute leukemia NOS	33	5.5
Others	10	1.7

Yearly income of patients and working ability in age group 26–44 years at time of follow-up is shown in Table IV. Data for the general population of the same age is also shown. Yearly income and working ability were especially low for survivors of childhood cancer of the CNS.

Discussion

Prevalence

This study illustrates a more than fivefold increase over the last decades in the prevalence of survivors of childhood cancer in Norway. At the end of the study period more than one child per 1000 children was found to have been diagnosed with cancer. Prevalence of cancer overall has in the EUROPREVAL study been estimated to 2% [3]. This study shows further that more than 0.06% of the population had been diagnosed with cancer in childhood. The number of patients surviving five years or more after treatment also increased threefold during the study period. Increase in prevalence may be due to increases in survival, with five-year survival for all cancers combined at present being more than 75% in the Nordic countries [22]. The increase in prevalence has implications for planning of health care services, follow-up for cancer recurrence, secondary cancers and late effects of treatment.

Norway has had a well-functioning Cancer Registry covering the entire population since 1953 but cases diagnosed before this time and still alive without recurrence will not show in these known prevalence data. Such bias of unobserved cases will

Table III. Number of patients diagnosed with childhood cancer of the CNS or haematological system 1970–1997 surviving 5 years or more and alive by December 31, 2002 and needing basic benefit or attendance benefit, shown by age group. No patients were alive above 44 years of age.

Age group (years)	5–14 n (%)	15–24 n (%)	25–34 n (%)	35–44 n (%)	Total n (%)
Basic benefit					
CNS	55/132 (42)	53/194 (27)	39/144 (27)	15/78 (19)	162/548 (30)
Hemat.	37/162 (23)	37/232 (16)	12/172 (7)	0/30 (0)	86/596 (14)
Whole population	18 313/910 328 (2)	9629/546 993 (2)	10 912/656 724 (2)	16 742/667 006 (3)	55 596/2 781 051 (2)
Attendance benefit					
CNS	85/132 (64)	67/194 (35)	30/144 (21)	12/78 (15)	194/548 (35)
Hemat.	60/162 (37)	39/232 (17)	8/172 (5)	0/30 (0)	107/596 (18)
Whole population	21 023/910 328 (2)	8770/546 993 (2)	4073/656 724 (0.6)	5437/667 006 (0.8)	39 303/2 781 051 (1.4)

affect the degree of completeness especially in recently established registries and for cancer sites with good prognoses [3] and considering the time period in this material one would expect this number to be low.

Figure 1 illustrates the increase in survival of patients treated for a tumour of the CNS and especially those treated for a hematological malignancy. Increasing incidence of brain tumours in the very young has recently been described [23] and may contribute to the increasing prevalence. Survivors diagnosed during the latest two decades may especially have had benefit from improved imaging techniques, safer surgery, and therapeutic regimens designed to reduce late morbidity and mortality [24].

Benefits and working ability

The proportion of patients in need of health insurance benefit was for CNS tumour patients 47.1% compared to 21.0% for those with hematological malignancies, illustrating the high degree of long-term morbidity in CNS patients. An attendance benefit due to special attention or supervision was needed in 35% of CNS tumour survivors. Significantly more CNS tumour patients had permanent disability benefit compared to patients treated for hematological malignancies. Permanent disability was also significantly associated with radiotherapy. This may be due to late-effects of radiotherapy, while on the other hand there is a possibility of selection bias in that those given radiotherapy might have had worse prognostic factors than those not given this treatment. An increased risk of adverse outcomes with regard to working ability has been shown in survivors who received radiation therapy and in patients diagnosed at younger ages [24].

There is a continuing increase in long-term cancer survivors and cancer is no longer only an issue for individuals and their families but also for the workplace and society in general. There have also been major changes in the proportion of survivors who have undergone intensive treatment. A high proportion of CNS survivors were unemployed while the rate among hematological malignancy was only slightly above the general population. Of all adult survivors of childhood cancer those treated for CNS tumours and acute leukemia are particularly at risk for educational deficits [25]. Survivors of CNS tumours have been found to have a lower educational level than survivors treated for leukemia/non-Hodgkin lymphoma [26]. After childhood cancer 55% of American CNS survivors are working [27] versus 67–86% of non-CNS tumour survivors [27,28]. Annual income less than Euro 15 000 per year has been reported for 55–76% of CNS-tumour survivors [24,27] and in 21% of patients with tumours in other sites or leukemia [27]. Ten percent

Table IV. Yearly income and working ability of survivors aged 25–44 years in Norway diagnosed with childhood cancer of the CNS or haematological system 1970–1997 surviving 5 years or more by December 31, 2002 together with income of the whole population of the same age.

Yearly income, Euro	CNS n (%)	Hemat. malignancy n (%)	Whole population n (%)
<10 000	31 (14)	30 (15)	74 760 (6)
10–29 999	35 (16)	55 (27)	664 486 (56)
30–50 000	62 (28)	77 (38)	366 441 (31)
>50 000	15 (7)	27 (13)	41 276 (3)
Not working	79 (36)	13 (6)	50 126 (4)
Total	222 (100)	202 (100)	1 197 089 (100)

of American CNS tumour patients have been reported to be in the highest income bracket [27]. When comparing patients treated for brain tumour or hematological malignancies to the whole population, a larger fraction of treated patients in this study were found in the lowest income brackets. On the other hand, in working survivors a slightly larger fraction belonged in the two highest income brackets for both groups of survivors compared to the general population.

This study does not shed light on issues such as quality of life and clinical symptoms for the individual patient. Since the health insurance system covers all citizens these population based data may serve as a description of an overall status of working ability and need of health insurance benefits. In studies which are not population based a significant number of survivors are often lost to follow-up or decline to participate, presenting a potential bias because the survivors in this group may have had more difficulties in economic areas than survivors that participate or can be traced [27,29–31]. Also cancer patients contacted by phone reveal a higher percentage of problems [31].

Working ability may not also be considered important facing life-threatening disease. The economic consequences associated with the disease and treatment may be just as serious as worries over the potential for recurrence [32]. This study illustrates loss of working capability in long-term survivors of childhood cancer and the long-term need of health insurance benefits. Clinicians should be advised to inquire about the economic well-being of the patient and family, and responses may spur referrals to obtain needed assistance. The increases in prevalence illustrate the increasing need of long-term follow-up and care for these patients.

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