Trends in cancer prevalence in Quebec

Rabiâ Louchini, Michel Beaupré, Alain A Demers, Patricia Goggin and Clermont Bouchard

Abstract

Cancer prevalence is of prime interest in public health because of its use in estimating the disease's burden on the heath care system. This study's objective was to estimate five-year prevalence of tumours from 1989 to 1999 and ten-year prevalence of tumours from 1994 to 1999 in the Province of Quebec (Canada). Five-year prevalence was used to represent tumours for which people are more likely to obtain primary treatment; ten-year prevalence included those tumours in addition to tumours that can be considered cured but still need follow-up. Information was extracted from the Quebec Cancer Registry. Prostate cancer was the most prevalent malignancy among males (25%, five-year prevalent tumours), while breast cancer was most prevalent among females (38%, five-year prevalent tumours). For both sexes, the greatest observed prevalence increase was for endocrine glands. On average, five-year prevalence proportions were 16% higher in men than in women; those of ten year were 14% higher in men. Furthermore, the largest differences were observed for bladder and lung cancer. The change in cancer prevalence in Quebec was dependent on the tumour site.

Key words: *cancer, prevalence, Quebec*

Introduction

Cancer prevalence, defined as the proportion of people in a given population that have previously been diagnosed with cancer at a point in time, is of prime interest in public health because of its use in estimating the disease burden on the health care system. Prevalence, which integrates in a single measure disease incidence and survival, provides an estimate of the number of individuals potentially requiring cancer treatment. In turn, this estimate can be used for planning and allocating resources.

According to recent statistics,[1] cancer has become the leading cause of mortality in Quebec. This recent trend is expected to remain unchanged for some time as mortality rates from heart diseases, the former main cause of death, continue to decrease.[2,3] Life expectancy at birth has steadily risen in the last 20 years, and the likelihood of surviving many cancers has improved and resulted in a constantly increasing number of people living with a history of the disease.

Cancer control has evolved considerably in the past decades and has resulted in major changes in the delivery of cancer-related services. The advent of costly new drugs, for example, challenges planners that have to operate within limited budgets and make sure the population receives the best care possible. In this context, measures like prevalence are essential tools. The objective of this study was to estimate the burden of cancer in the Province of Quebec. Five-year prevalence proportions are presented for the 1989 to 1999 time period and ten-year prevalence proportions are presented for the period between 1994 to 1999.

Methods

Multiple cancers

Prevalence can refer to the number of people living with cancer (person-prevalence) or the number of cancers (tumour-prevalence) in the population. Person-prevalence considers only the first primary malignant cancer diagnosed in each person whereas tumour-prevalence considers all primary malignant cancers in a person, irrespective of whether these are the first or are subsequent cancers. This second indicator, which is more pertinent for estimating the cancer burden on the health care system,[4] was retained for our analyses.

Interpretation of prevalence statistic

For many cancer planning services, incidence is an important measure. Incidence data, and especially incidence trends, can be directly used to predict how many new patients will seek assistance for diagnosis, primary treatment, and possibly a second round of treatment.[5] Incidence, however, gives limited information on the total number of people who may need treatment or services. Prevalence, on the other hand, gives a better sense of this number, especially for several years following a diagnosis, when service utilization tends to be highest. Prevalence provides relevant information for practical use: (i) planning health services; (ii) allocating health resources; (iii) administering medical care facilities; (iv) designating appropriate research expenditures; and (v) assessing the relative burden of cancer with respect to mortality and life quality deprivation.[6]

Author References

Rabiâ Louchini, Patricia Goggin, Clermont Bouchard, Institut national de santé publique du Québec, Quebec City, Quebec, Canada
Michel Beaupré, Department of Health and Social Services, Quebec City, Quebec, Canada
Alain A Demers, Department of Epidemiology and Cancer Registry, CancerCare Manitoba; Department of Community Health Sciences, University of Manitoba, Winnipeg, Manitoba, Canada
Correspondence: Rabiâ Louchini, Institut national de santé publique du Québec, 945 Wolfe Avenue, 3rd Floor, Ste-Foy, Quebec, Canada G1V 5B3; fax: (418) 643-5099; e-mail: Rabia.louchini@inspq.qc.ca

Five-year prevalence is a measure that has been widely used[7–11] because it groups cases that are more likely to be undergoing primary treatment for their cancer. These are also cases with high risk of recurrence and which have to be followed closely. The ten-year prevalence measure includes, in addition to many of the cases mentioned above, people who can be considered cured (i.e., low probability of recurrence), but who still need follow-up, although not as intensively.

Incidence and mortality data

Incident cases of cancer diagnosed between 1984 and 1999 were extracted from the Quebec Cancer Registry (QCR). The registry population is the Quebec population as a whole and it uses hospitalization and day surgery records to identify cases. The date of diagnosis recorded in the QCR is the date of discharge from the treatment hospital. Prevalence was determined from the diagnosis date.

In order to determine the vital status of a cancer patient reported to the QCR, the incidence file was linked to the 1984–99 Quebec Death File. The linkage of these two files is described in the report *Cancer Survival of Newly Diagnosed Cases, Quebec 1992*.[12]

Counting method

Prevalence was calculated using incidence and mortality data from 1984 to 1999. Prevalent cases were calculated according to the counting method used by Feldman[13] and by Gail.[14] This method estimates prevalence by counting the number of patients who have remained alive during a specific period of time. In other words, prevalence is the sum of incident cases during a given period minus the number of deaths among them.

Five- and ten-year prevalence proportions are presented. The age, derived from the calendar year, was considered in calculating the annual prevalence proportions. For example, the age of a forty-four-year-old person diagnosed with lung cancer in 1994 would be 48 in 1998. The International Classification of Diseases 9th Revision (ICD-9) was used for reporting cancer sites.

Three indicators were calculated: the number of prevalent cases, the crude prevalence and the age-standardized prevalence. The crude and age-standardized prevalence data were presented in order to allow readers to perceive the true prevalence in the province, while making jurisdiction comparisons possible. The population used for prevalence calculations was provided by the Institut de la statistique du Québec (Statistic Institute of Quebec). Prevalence data were standardized to the 1991 Canada census population.

Trends and annual percent change (APC) were estimated using the Joinpoint Regression Program (v2.7).[15] The APC was calculated using the log-linear model, where the APC is equal to 100 * (e^m – 1) and m is the estimated slope of the regression line. The *p*-value presented with the APC is the *p*-value of the slope of the log-linear regression model. One inflexion point was allowed in the regression models. Trends of prevalence were calculated from 1989 to 1999 for five-year prevalence and from 1994 to 1999 for the ten-year trend.

Results

Number of prevalent cases of cancer

The number of five-year prevalent invasive tumours in 1999 was 97,615 (46,333 in males, 51,282 in females), while the ten-year prevalent number was 153,682 (71,726 in males, 81,956 in females) (Tables 1 and 2).

Among men, prostate cancer was the most prevalent malignancy (25 percent of all five-year prevalent tumours; 27 percent of all ten-year prevalent tumours), followed by colorectal cancer (16 percent of all five-year prevalent tumours; 15 percent of all ten-year prevalent tumours) and lung cancer (14 percent of all five-year prevalent tumours; 12 percent of all ten-year prevalent tumours).

Among women, breast cancer was the most prevalent malignancy, accounting for more than a third of all cases (38 percent of all five-year prevalent tumours and 39 percent of all ten-year prevalent tumours). Cancers of the reproductive organs were the second most prevalent, accounting for 14 percent of all five-year prevalent tumours and 15 percent of all ten-year prevalent tumours. Colorectal cancers ranked third with 13 percent of all five- and ten-year prevalent tumours.

Crude prevalence

Prevalence by cancer site varied between 1994 and 1999 (Tables 3 and 4). For both males and females, the largest observed increase was for endocrine glands, followed by "bone, soft tissue and melanoma" for males, and breast for females. Interestingly, five-year prevalence was more often lower in 1999 in males than in females. Although five-year cancer prevalence increased for females, it decreased for males. Ten-year prevalence increased for both.

To put these data in a different perspective, we estimated the percentage of the 1999 Quebec population (3,613,436 men, 3,709,558 women) with a history of cancer. Overall, 1.3 percent of the male population and 1.4 percent of the female population had received a diagnosis of cancer in the previous five years and were still living in 1999. The percentages for men and women diagnosed in the previous ten years were 2.0 and 2.2, respectively.

For men, prostate cancer was the most prevalent. Of the men alive in 1999, approximately 0.32 percent had been diagnosed with prostate cancer in the previous five years. This percentage was 0.54 percent for the ten-year prevalence.

Among the 1999 female population, prevalence was the highest for breast cancer. About 0.53 percent of women in Quebec require active care (five-year prevalence) for breast cancer and 0.20 percent for colorectal cancers.

TABLE 1
Number of five-year prevalent tumours, by sex, site and calendar year, Province of Quebec (1989–1999)

Cancer site	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
Male											
Prostate (185)	7,589	7,971	8,502	9,465	10,927	12,349	12,892	12,915	12,652	12,016	11,482
Lung (162)	6,564	6,667	6,751	6,622	6,805	6,819	6,695	6,688	6,618	6,617	6,532
Colorectal (153-154)	5,890	6,020	6,301	6,337	6,403	6,634	6,749	6,854	6,862	7,025	7,266
Bladder (188)	3,660	3,777	3,896	3,996	4,183	4,377	4,489	4,499	4,528	4,560	4,626
Other lymphatic and haemopoetic tissue (200-203)	2,746	2,831	2,942	2,913	2,995	3,032	3,069	3,141	3,188	3,259	3,295
Lip, oral cavity, pharynx (140-149)	1,928	1,930	1,950	1,844	1,807	1,779	1,711	1,663	1,646	1,628	1,590
Larynx (161)	1,490	1,449	1,446	1,411	1,368	1,413	1,443	1,417	1,330	1,308	1,326
Kidney & other & unspecified urinary organs (189)	1,458	1,543	1,618	1,667	1,667	1,697	1,736	1,713	1,744	1,807	1,898
Leukaemias (204-208)	1,289	1,345	1,419	1,323	1,275	1,289	1,318	1,292	1,304	1,326	1,357
Stomach (151)	1,134	1,080	1,162	1,109	1,069	1,071	1,066	1,097	995	994	1,019
Brain and nervous system (191-192)	663	685	727	661	671	732	785	795	792	794	749
Pancreas (157)	572	527	568	552	564	569	607	591	582	624	645
Melanoma (172)	512	557	579	629	631	675	698	753	774	807	877
Testicle (186)	473	514	591	620	659	664	663	661	682	682	691
Esophagus (150)	287	312	305	278	289	327	319	323	338	348	350
Thyroid (193)	249	253	254	252	282	302	330	350	385	393	429
All sites (140-208)*	38,431	39,516	41,110	41,657	43,560	45,636	46,570	46,764	46,483	46,296	46,333
Female											
Breast (174)	13,870	14,247	14,798	15,308	15,773	16,263	16,781	17,386	17,836	18,687	19,542
Colorectal (153-154)	6,053	6,235	6,171	6,250	6,359	6,521	6,522	6,447	6,487	6,624	6,686
Lung (162)	2,512	2,711	2,975	3,196	3,362	3,546	3,671	3,768	3,888	3,972	4,122
Corpus uteri (182)	2,889	2,933	2,962	2,980	3,020	3,137	3,173	3,099	3,146	3,215	3,201
Lymphatic and haemopoetic tissue (200-203)	2,515	2,611	2,682	2,661	2,707	2,697	2,764	2,790	2,905	2,931	2,925
Ovary (183)	1,444	1,479	1,557	1,526	1,682	1,774	1,883	1,974	2,003	1,986	2,013
Bladder (188)	1,281	1,255	1,333	1,352	1,400	1,473	1,538	1,510	1,530	1,552	1,582
Thyroid (193)	684	728	735	812	870	930	1,005	1,095	1,139	1,227	1,329
Kidney & other & unspecified urinary organs (189)	1,055	1,099	1,159	1,147	1,147	1,134	1,185	1,197	1,185	1,227	1,286
Cervix uteri (180)	1,545	1,440	1,416	1,374	1,361	1,365	1,358	1,373	1,325	1,288	1,257
Leukaemias (204-208)	1,014	1,056	1,039	1,059	1,060	1,061	1,067	1,023	1,034	1,025	1,110
Melanoma (172)	620	654	702	720	744	816	846	889	886	921	950
Lip, oral cavity, pharynx (140-149)	680	681	685	662	660	696	664	666	686	719	722
Stomach (151)	756	754	733	724	711	694	685	646	647	656	658
Brain and nervous system (191-192)	532	542	553	536	554	577	605	670	674	680	623
Pancreas (157	512	534	554	535	528	586	537	585	633	647	612
Larynx (161)	322	345	375	350	350	342	336	344	347	340	327
Esophagus (150)	96	125	129	137	136	138	126	136	125	146	146
All sites (140-208)*	40,697	41,791	42,917	43,553	44,626	45,898	46,919	47,735	48,625	50,058	51,282*

* All sites exclude non-melanoma skin cancer (ICD-9 173) and undefined sites (ICD-9 196 to 199).

TABLE 2
Number of ten-year prevalent tumours, by sex, site and calendar year, Province of Quebec (1994–1999)

Cancer site	1994	1995	1996	1997	1998	1999
Male						
Prostate (185)	16,502	17,373	17,845	18,355	18,906	19,593
Colorectal (153-154)	9,845	10,035	10,275	10,366	10,562	10,957
Lung (162)	8,865	8,760	8,692	8,594	8,614	8,560
Bladder (188)	6,848	7,039	7,166	7,272	7,414	7,617
Lymphatic and haemopoetic tissue (200-203)	4,585	4,655	4,779	4,866	4,924	5,037
Kidney & other & unspecified urinary organs (189)	2,620	2,702	2,766	2,810	2,885	2,974
Lip, oral cavity, pharynx (140-149)	2,771	2,698	2,663	2,622	2,574	2,527
Larynx (161)	2,342	2,325	2,306	2,202	2,151	2,206
Leukaemias (204-208)	1,867	1,905	1,922	1,923	1,933	1,966
Stomach (151)	1,518	1,508	1,534	1,421	1,404	1,421
Melanoma (172)	1,023	1,082	1,165	1,213	1,266	1,362
Testicle (186)	1,101	1,151	1,213	1,270	1,310	1,324
Brain and nervous system (191-192)	1,058	1,112	1,140	1,128	1,141	1,112
Pancreas (157)	705	741	713	687	735	759
Thyroid (193)	507	536	561	597	633	685
Esophagus (150)	401	394	402	409	422	436
All sites (140-208)*	65,430	66,986	68,182	68,805	69,989	71,726
Female						
Breast (174)	26,239	27,086	28,223	29,177	30,520	31,899
Colorectal (153-154)	10,265	10,268	10,213	10,266	10,480	10,644
Corpus uteri (182)	5,494	5,567	5,523	5,563	5,662	5,738
Lung (162)	4,466	4,622	4,816	4,989	5,202	5,455
Lymphatic and haemopoetic tissue (200-203)	4,181	4,284	4,324	4,452	4,505	4,538
Ovary (183)	2,622	2,747	2,878	2,906	2,978	3,085
Bladder (188)	2,438	2,462	2,475	2,506	2,573	2,655
Cervix uteri (180)	2,571	2,485	2,470	2,399	2,365	2,346
Thyroid (193)	1,546	1,656	1,766	1,878	2,025	2,197
Kidney & other & unspecified urinary organs (189)	1,868	1,937	1,992	1,983	2,023	2,070
Leukaemias (204-208)	1,567	1,580	1,576	1,593	1,570	1,649
Melanoma (172)	1,327	1,379	1,465	1,474	1,534	1,619
Lip, oral cavity, pharynx 140-149)	1,131	1,087	1,086	1,113	1,156	1,172
Brain and nervous system (191-192)	856	882	948	967	992	952
Stomach (151)	1,046	1,014	964	954	944	943
Pancreas (157	723	684	729	759	774	742
Larynx (161)	569	575	594	590	589	583
Esophagus (150)	168	160	168	160	176	184
All sites (140-208)*	72,600	73,997	75,719	77,199	79,597	81,956

* All sites exclude non-melanoma skin cancer (ICD-9 173) and undefined sites (ICD-9 196 to 199).

TABLE 3
Crude five-year prevalence (per 100,000) of cancer, by site and sex in the Province of Quebec (1989–1999)

Cancer site	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	APC*
Male												
Prostate (185)	221.5	230.3	244.3	270.1	309.4	347.5	361.0	359.9	351.1	332.5	316.8	89-95: 9.4/95-99: 4.5
Colorectal (153-154)	171.9	173.9	181.0	180.8	181.3	186.7	189.0	191.0	190.4	194.4	200.5	1.4
Lung (162)	191.6	192.6	194.0	188.9	192.7	191.9	187.5	186.4	183.7	183.1	180.2	89-94: -0.1/94-99: -1.1
Bladder (188)	106.8	109.1	111.9	114.0	118.4	123.2	125.7	125.4	125.7	126.2	127.6	89-95: 2.8/95-99: 0.3
Lymphatic and haemopoetic tissue (200-203)	80.1	81.8	84.5	83.1	84.8	85.3	85.9	87.5	88.5	90.2	90.9	1.2
Kidney & other & unspecified urinary organs (189)	42.5	44.6	46.5	47.6	47.2	47.8	48.6	47.7	48.4	50.0	52.4	1.5
Lip, oral cavity, pharynx (140-149)	56.3	55.8	56.0	52.6	51.2	50.1	47.9	46.3	45.7	45.1	43.9	-2.7
Leukaemias (204-208)	37.6	38.9	40.8	37.7	36.1	36.3	36.9	36.0	36.2	36.7	37.4	-0.6
Larynx (161)	43.5	41.9	41.5	40.3	38.7	39.8	40.4	39.5	36.5	36.2	36.6	-1.6
Stomach (151)	33.1	31.2	33.4	31.6	30.3	30.1	29.9	30.6	27.6	27.5	28.1	-1.8
Melanoma (172)	14.9	16.1	16.6	17.9	17.9	19.0	19.5	21.0	21.5	22.3	24.2	4.6
Brain and nervous system (191-192)	19.3	19.8	20.9	18.9	19.0	20.6	22.0	22.2	22.0	22.0	20.7	1.3
Testicle (186)	13.8	14.8	17.0	17.7	18.7	18.7	18.6	18.4	18.9	18.9	19.1	89-92: 9.2/92-99: 0.4
Pancreas (157)	16.7	15.2	16.3	15.7	16.0	16.0	17.0	16.5	16.2	17.3	17.8	0.9
Thyroid (193)	7.3	7.3	7.3	7.2	8.0	8.5	9.2	9.8	10.7	10.9	11.8	89-92: 0.5/92-99: 7.1
Esophagus (150)	8.4	9.0	8.8	7.9	8.2	9.2	8.9	9.0	9.4	9.6	9.7	1.4
All sites (140-208)†	1,121.5	1,141.6	1,181.2	1,188.6	1,233.4	1,284.3	1,304.1	1,303.3	1,290.1	1,281.2	1,278.3	89-95: 2.7/95-99: -0.6
Female												
Breast (174)	393.8	400.1	412.6	424.1	433.9	445.0	457.2	471.7	482.1	503.8	525.2	89-97: 2.6/97-99: 4.4
Colorectal (153-154)	171.8	175.1	172.1	173.1	174.9	178.4	177.7	174.9	175.4	178.6	179.7	0.4
Lung (162)	71.3	76.1	82.9	88.5	92.5	97.0	100.0	102.2	105.1	107.1	110.8	89-93: 7.5/93-99: 2.8
Corpus uteri (182)	82.0	82.4	82.6	82.6	83.1	85.8	86.4	84.1	85.0	86.7	86.0	0.6
Lymphatic and haemopoetic tissue (200-203)	71.4	73.3	74.8	73.7	74.5	73.8	75.3	75.7	78.5	79.0	78.6	0.9
Ovary (183)	41.0	41.5	43.4	42.3	46.3	48.5	51.3	53.6	54.1	53.5	54.1	3.4
Bladder (188)	36.4	35.2	37.2	37.5	38.5	40. 3	41.9	41.0	41.4	41.8	42.5	1.9
Thyroid (193)	19.4	20.4	20.5	22.5	23.9	25.4	27.4	29.7	30.8	33.1	35.7	89-91: 3.7/91-99: 6.9
Kidney & other & unspecified urinary organs (189)	29.9	30.9	32.3	31.8	31.6	31.0	32.3	32.5	32.0	33.1	34.6	1.0
Cervix uteri (180)	43.9	40.4	39.5	38.1	37.4	37.3	37.0	37.3	35.8	34.7	33.8	-2.0
Leukaemias (204-208)	28.8	29.7	29.0	29.3	29.2	29.0	29.1	27.8	28.0	27.6	29.8	-0.3
Melanoma (172)	17.6	18.4	19.6	19.9	20.5	22.3	23.0	24.1	23.9	24.8	25.5	89-96: 4.6/96-99: 2.1
Lip, oral cavity, pharynx (140-149)	19.3	19.1	19.1	18.3	18.2	19.0	18.1	18.1	18.5	19.4	19.4	89-96: -0.9/96-99: 2.7
Stomach (151)	21.5	21.2	20.4	20.1	19.6	19.0	18.7	17.5	17.5	17.7	17.7	89-97: -2.7/97-99: 0.4
Brain and nervous system (191-192)	15.1	15.2	15.4	14.8	15.2	15.8	16.5	18.2	18.2	18.3	16.7	2.1
Pancreas (157	14.5	15.0	15.4	14.8	14.5	16.0	14.6	15.9	17.1	17.4	16.4	1.6
Larynx (161)	9.1	9.7	10.5	9.7	9.6	9.4	9.2	9.3	9.4	9.2	8.8	89-91: 6.0/91-99: -1.5
Esophagus (150)	2.7	3.5	3.6	3.8	3.7	3.8	3.4	3.7	3.4	3.9	3.9	1.7
All sites (140-208)†	1,155.3	1,173.7	1,196.6	1,206.6	1,227.7	1,255.8	1,278.2	1,295.1	1,314.4	1,349.4	1,378.2	1.8

* APC: annual percent change. Unless other specifications indicated, APCs were calculated for 1989 to 1999.

Years are indicated as follows: e.g., 1989 to 1993 = 89-93.

† All sites exclude non-melanoma skin cancer (ICD-9 173) and undefined sites (ICD-9 196 to 199).

TABLE 4
Crude ten-year prevalence (per 100,000) of cancer, by site and sex in the Province of Quebec (1994–1999)

Cancer site	1994	1995	1996	1997	1998	1999	APC*
Male							
Prostate (185)	464.4	486.5	497.3	509.4	523.2	540.6	2.9
Colorectal (153-154)	277.1	281.0	286.4	287.7	292.3	302.3	1.6
Lung (162)	249.5	245.3	242.2	238.5	238.4	236.2	-1.1
Bladder (188)	192.7	197.1	199.7	201.8	205.2	210.1	1.6
Lymphatic and haemopoetic tissue (200-203)	129.0	130.3	133.2	135.0	136.3	139.0	1.5
Kidney & other & unspecified urinary organs (189)	73.7	75.7	77.1	78.0	79.8	82.1	2.0
Lip, oral cavity, pharynx (140-149)	78.0	75.5	74.2	72.8	71.2	69.7	-2.1
Larynx (161)	65.9	65.1	64.3	61.1	59.5	60.9	-2.0
Leukaemias (204-208)	52.5	53.3	53.6	53.4	53.5	54.2	0.5
Stomach (151)	42.7	42.2	42.8	39.4	38.9	39.2	-2.1
Melanoma (172)	28.8	30.3	32.5	33.7	35.0	37.5	5.3
Testicle (186)	31.0	32.2	33.8	35.2	36.3	36.5	3.5
Brain and nervous system (191-192)	29.8	31.1	31.8	31.3	31.6	30.7	0.5
Pancreas (157)	19.8	20.7	19.9	19.1	20.3	20.9	0.5
Thyroid (193)	14.3	15.0	15.6	16.6	17.5	18.9	5.7
Esophagus(150)	11.3	11.0	11.2	11.4	11.7	12.0	1.5
All sites (140-208)†	1,841.4	1,875.8	1,900.2	1,909.6	1,936.9	1,978.9	1.3
Female							
Breast (174)	717.9	737.9	765.7	788.7	822.7	857.3	3.6
Colorectal (153-154)	280.9	279.7	277.1	277.5	282.5	286.1	0.4
Corpus uteri (182)	150.3	151.7	149.8	150.4	152.6	154.2	0.4
Lung (162)	122.2	125.9	130.7	134.9	140.2	146.6	3.7
Lymphatic and haemopoetic tissue (200-203)	114.4	116.7	117.3	120.3	121.4	122.0	1.3
Ovary (183)	71.7	74.8	78.1	78.6	80.3	82.9	2.7
Bladder (188)	66.7	67.1	67.1	67.7	69.4	71.4	1.3
Endocrine glands (193-194)	46.3	49.4	52.3	55.2	59.0	63.6	6.4
Cervix uteri (180)	70.3	67.7	67.0	64.8	63.8	63.1	-2.1
Thyroid (193)	42.3	45.1	47.9	50.8	54.6	59.0	6.8
Kidney & other & unspecified urinary organs (189)	51.1	52.8	54.0	53.6	54.5	55.6	1.5
Leukaemias (204-208)	42.9	43.0	42.8	43.1	42.3	44.3	0.4
Melanoma (172)	36.3	37.6	39.7	39.8	41.4	43.5	3.5
Lip, oral cavity, pharynx 140-149)	30.9	29.6	29.5	30.1	31.2	31.5	0.8
Stomach (151)	28.6	27.6	26.2	25.8	25.4	25.3	-2.4
Brain and nervous system (191-192)	23.4	24.0	25.7	26.1	26.7	25.6	2.2
Pancreas (157	19.8	18.6	19.8	20.5	20.9	19.9	1.2
Larynx (161)	15.6	15.7	16.1	15.9	15.9	15.7	0.2
Esophagus (150)	4.6	4.4	4.6	4.3	4.5	4.9	1.7
All sites (140-208)†	1,986.4	2,015.9	2,054.3	2,086.8	2,145.7	2,202.6	2.1

* APC: annual percent change. Unless other specifications indicated, APCs were calculated for 1994 to 1999.

† All sites exclude non-melanoma skin cancer (ICD-9 173) and undefined sites (ICD-9 196 to 199).

Age-standardized prevalence

Trends in age-standardized five- and ten-year prevalence of selected sites are presented in tables 5 and 6. The age-standardized prevalence was higher for men than women for all cancer sites except endocrine glands. On average, five-year age-standardized prevalence was 16 percent higher in men than in women and ten-year was 14 percent higher between the two sexes. The largest differences were observed for bladder and lung cancer.

Five- and/or ten-year age-standardized prevalence cases decreased for colorectal, lung, prostate, oral, larynx and stomach among males and colorectal, corpus uteri, cervix uteri and stomach among females, whereas they increased for melanoma, testicle and thyroid for males and lung, ovary, thyroid, melanoma and breast among females.

Discussion

This is the first study reporting on cancer prevalence in Quebec. Our results show that, from 1994 to 1999, the ten-year prevalent number of tumours decreased for stomach and lung among males, and for stomach and cervix uteri among females, though it increased for other cancer sites. The decrease in the number of prevalent tumors of stomach cancer is explained by the smaller number of new cases of these tumors.[16] Overall, the results indicate an increase in the number of Quebec residents who have been living with a diagnosis of cancer. However, five- and ten-year prevalence data decreased for a few sites, such as lung cancer, for which a decrease was observed in men but not for women.

The reduction in the number of smokers among men[17] is most likely the reason why there is the difference in trends between the two sexes. The decrease in corpus uteri cancer prevalence is related to a decrease in incident cases.[16]

Age-standardized prevalence cases of cancer were higher in males than females, even though the total number of prevalent cases was higher for women than for men. Two factors have contributed to this situation. First, cancer occurs at a relatively earlier age among women, especially genital and breast cancers. Second, the male population is smaller than the female one, particularly in older age groups, where the majority of cancers occur.

While lung cancer is the second most frequent malignancy for men, it ranks third in terms of prevalence because of the low survival probability associated with it.

As prevalence reflects both incidence and survival, cancer sites like breast that have a high incidence rate and survival probability also have a high prevalence.

In addition, screening activities can affect prevalence not only because of the diagnosis of indolent cancers that would otherwise not have been diagnosed, but also because early stage tumours are usually easier to cure. This addition of indolent and/or early stage tumours to the incident number may be particularly important after the start of screening.[16,18] For example, the introduction of the prostate specific antigens (PSA) test for the detection of prostate cancer in the early 1990s generated a rapid increase of the incidence curve, which later stabilized and returned to its expected level when guidelines were published. The age-standardized prevalence of prostate cancer in Quebec varied accordingly to this pattern. Organized breast screening was implemented in 1998 in Quebec. Its impact on prevalence should be more gradual than was the impact on prostate prevalence because breast screening services were progressively put in place in the late 1980s.[17] Cancer screening can also allow removal or destruction of precancerous tissues, contributing to the reduction of incidence and, consequently, the prevalence of those cancers. Such is the case with cervical and colorectal cancer.

The baby boom following World War II, the increasing life expectancy and the consequent increase in the number of elderly people are expected to create a steady increase of prevalent cases of cancer in Quebec for the next 20 to 30 years. This increase will be compounded by improvements in treatment and early detection of more types of cancers. This situation will generate a demand on health and social services that planners need to account for. It is, however, important to interpret the current results with caution.

An increase in prevalence could be associated with an increase in incidence or an improvement in survival. If the increase in prevalence is mostly associated with an increase in incidence outside the screening context, this would indicate disturbing deficiencies in the fight against cancer. On the other hand, if the increase in prevalence is largely associated with prolonged survival, the fight is being won. However, whatever the cause, an increase in prevalence means a greater demand for health services. Because life expectancy is increasing, cancer prevalence is rising and significantly adding to the socio-economic burden.[19]

The interpretation of prevalence presupposes that cancer is irreversible and permanent for a period of five or ten years and that affected people require health services more intensively than the general population for that whole time period, whether for specialized treatments, for detection of metastasis or to monitor recurrences. These people can also suffer from reduced capabilities on a more or less permanent basis and may require rehabilitation services or psychological help. The intensity of services, however, can vary considerably depending on the cancer type, the stage of the tumour and the length of time since diagnosis. Prevalence constitutes a heterogeneous group of individuals with different types of malignancies, some of which have been diagnosed recently and are under active treatment, while others can be in long-term remission or even considered cured. According to Micheli et al.[7], the first two years following a cancer diagnosis constitute a period of treatments and recovery from secondary effects of treatments. The next three years are a period of high recurrence and intense monitoring. The following five years are a period of lesser probability of recurrence, when many people can be considered cured, although monitoring is usually recommended. These factors should be taken into consideration in resource man-

TABLE 5
Age-standardized (1991 Canadian population) five-year prevalence (per 100,000) of cancer, by site and sex in the Province of Quebec (1989–1999)

Cancer site	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	APC*
Male												
Prostate (185)	303.1	305.6	312.4	336.1	375.7	411.4	419.2	410.0	390.5	359.9	334.4	89-93: 6.6/93-99: -6.5
Colorectal (153-154)	212.7	209.5	212.9	210.5	209.1	212.3	211.2	209.4	204.9	203.6	205.2	-0.4
Lung (162)	226.6	223.8	221.1	213.2	215.8	212.6	204.5	200.6	193.7	189.3	182.2	89-94: -1.3/94-99: -2.9
Bladder (188)	133.8	133.9	133.6	134.1	137.3	140.9	141.7	139.2	136.5	133.8	131.4	89-95: 1.1/95-99: -2.0
Lymphatic and haemopoetic tissue (200-203)	88.8	89.3	91.1	88.6	90.0	89.1	88.9	89.7	89.4	90.1	89.3	0.02
Kidney & other & unspecified urinary organs (189)	49.6	51.0	52.0	52.8	51.7	51.6	51.5	49.9	49.9	50.4	51.7	-0.1
Lip, oral cavity, pharynx (140-149)	65.2	63.3	62.6	58.0	55.5	53.7	50.2	47.7	45.9	44.1	42.0	-4.5
Leukaemias (204-208)	45.1	45.6	47.3	43.5	40.8	41.0	41.3	39.9	39.2	39.3	39.4	-1.8
Larynx (161)	49.5	47.0	45.7	43.5	41.3	41.7	42.0	40.8	37.5	36.4	36.3	-2.9
Stomach (151)	41.6	38.7	40.1	37.5	35.1	35.0	33.5	33.5	29.8	29.3	29.0	-3.7
Melanoma (172)	16.4	17.2	17.6	18.8	18.8	19.5	19.8	21.0	21.0	21.5	23.0	3.1
Brain and nervous system (191-192)	20.2	20.5	21.7	19.4	19.3	20.9	22.2	22.2	21.9	21.9	20.2	0.6
Testicle (186)	13.4	14.4	16.6	17.4	18.4	18.6	18.7	18.6	19.4	19.6	20.0	89-92: 9.6/92-99: 1.4
Pancreas (157)	20.6	18.4	19.2	18.2	18.2	18.2	18.7	18.0	17.1	17.9	18.3	-0.8
Thyroid (193)	7.6	7.5	7.4	7.2	8.1	8.5	9.1	9.6	10.4	10.5	11.4	89-92: -1.5/92-99: 6.3
Esophagus (150)	10.2	10.7	10.4	9.1	9.1	10.3	9.6	9.6	9.7	9.8	9.5	-0.6
All sites (140-208)†	1,369.6	1,364.3	1,379.5	1,370.4	1,405.3	1,443.3	1,442.4	1,418.9	1,376.4	1,337.2	1,304.9	89-95: 1.1/95-99: -2.8
Female												
Breast (174)	371.1	372.0	376.7	382.1	386.1	390.6	395.9	403.0	405.6	417.3	427.9	1.4
Colorectal (153-154)	158.8	159.0	153.0	151.5	150.8	151.6	148.8	144.3	141.7	141.8	139.9	-1.3
Lung (162)	66.6	70.2	75.3	79.4	82.1	85.2	86.7	87.6	88.6	88.8	90.6	89-93: 5.6/93-99: 1.2
Corpus uteri (182)	76.5	75.9	74.8	74.0	73.6	75.1	74.6	71.7	71.4	71.8	70.0	-0.8
Lymphatic and haemopoetic tissue (200-203)	67.4	68.5	68.9	67.4	67.6	66.5	67.1	66.8	68.3	68.0	66.7	-0.1
Ovary (183)	38.9	39.0	40.4	38.9	42.1	43.8	45.8	47.3	47.2	46.1	45.6	89-97: 3.0/97-99: -1.7
Thyroid (193)	18.9	19.7	19.6	21.5	22.9	24.3	26.1	28.3	29.1	31.1	33.6	89-91: 2.8/91-99: 6.6
Bladder (188)	33.7	32.1	33.2	32.9	33.5	34.5	35.3	34.0	33.8	33.5	33.5	0.3
Cervix uteri (180)	42.4	38.6	37.3	35.8	34.9	34.6	34.2	34.0	32.6	31.4	30.5	-2.7
Kidney & other & unspecified urinary organs (189)	28.0	28.6	29.4	28.5	28.0	27.2	27.9	27.7	27.0	27.4	28.1	-0.4
Melanoma (172)	17.0	17.5	18.4	18.6	19.0	20.4	20.9	21.7	21.2	22.0	22.4	89-96: 3.5/96-99: 1.3
Leukaemias (204-208)	27.5	28.0	27.1	27.1	26.5	26.1	26.0	24.4	24.3	23.9	25.6	-1.4
Lip, oral cavity, pharynx (140-149)	18.0	17.7	17.4	16.5	16.3	16.9	15.9	15.6	15.8	16.3	16.1	89-96: -1.9/96-99: 1.3
Brain and nervous system (191-192)	14.7	14.7	14.8	14.2	14.6	15.1	15.8	17.2	17.3	17.1	15.5	1.6
Stomach (151)	19.8	19.2	18.1	17.3	16.6	15.9	15.4	14.3	14.0	13.9	13.7	89-97: -4.4/97-99: -1.0
Pancreas (157	13.4	13.6	13.7	12.9	12.4	13.5	12.3	13.1	13.8	13.9	12.8	-0.03
Larynx (161)	8.6	9.0	9.6	8.8	8.6	8.3	8.0	8.1	8.0	7.6	7.3	-2.1
Esophagus (150)	2.5	3.2	3.2	3.3	3.2	3.2	2.9	3.0	2.7	3.1	3.0	-0.1
All sites (140-208)†	1,085.9	1,088.1	1,091.0	1,086.6	1,093.5	1,105.4	1,111.8	1,112.7	1,112.4	1,125.2	1,131.6	-0.43

* APC: annual percent change. Unless other specifications indicated, APCs were calculated for 1989 to 1999.

Years are indicated as follows: e.g., 1989 to 1993 = 89-93.

† All sites exclude non-melanoma skin cancer (ICD-9 173) and undefined sites (ICD-9 196 to 199).

TABLE 6
Age-standardized (1991 Canadian population) ten-year prevalence (per 100,000) of cancer, by site and sex in the Province of Quebec (1994–1999)

Cancer site	1994	1995	1996	1997	1998	1999	APC*
Male							
Prostate (185)	564.8	579.8	581.0	580.5	579.9	582.9	0.4
Colorectal (153-154)	320.1	319.0	319.4	314.5	311.6	314.5	-0.5
Lung (162)	278.9	270.3	263.5	254.2	249.0	240.8	-2.9
Bladder (188)	223.2	225.2	224.0	221.2	219.6	219.5	-0.5
Lymphatic and haemopoetic tissue (200-203)	134.5	134.5	136.1	136.1	135.7	136.2	0.3
Kidney & other & unspecified urinary organs (189)	80.5	81.1	81.6	81.2	81.3	81.7	0.2
Lip, oral cavity, pharynx (140-149)	85.0	80.6	78.1	74.7	71.2	68.1	-4.3
Larynx (161)	70.6	68.9	67.5	62.9	60.4	60.7	-3.4
Leukaemias (204-208)	59.5	59.6	59.3	57.9	57.2	57.2	-1.0
Stomach (151)	50.0	48.2	47.7	43.1	41.8	41.0	-4.3
Testicle (186)	30.6	31.8	33.4	35.2	36.4	37.0	4.2
Melanoma (172)	29.7	30.7	32.5	33.0	33.9	35.8	3.7
Brain and nervous system (191-192)	30.1	31.3	31.8	31.2	31.4	30.1	-0.1
Pancreas (157)	22.9	23.0	22.0	20.4	21.3	21.6	-1.6
Thyroid (193)	14.3	14.8	15.3	16.0	16.9	18.1	4.9
Esophagus (150)	12.7	12.0	12.1	11.9	12.0	12.0	-0.8
All sites (140-208)†	2,095.3	2,100.6	2,095.2	2,062.9	2,048.3	2,046.5	-0.6
Female							
Breast (174)	626.7	634.8	649.7	658.3	675.7	692.5	2.0
Colorectal (153-154)	237.2	232.8	227.1	222.8	222.6	220.9	-1.4
Corpus uteri (182)	130.9	130.5	127.1	125.6	125.5	124.7	-1.1
Lung (162)	107.0	108.8	111.6	113.3	115.8	119.3	2.2
Lymphatic and haemopoetic tissue (200-203)	103.0	104.1	103.8	105.3	105.2	104.6	0.3
Ovary (183)	64.7	66.7	68.9	68.4	69.2	70.2	1.5
Bladder (188)	56.8	56.3	55.6	55.0	55.3	55.9	-0.4
Cervix uteri (180)	64.2	61.4	60.1	58.0	56.4	55.5	-2.9
Thyroid (193)	40.0	4204	45.0	47.4	50.7	54.6	6.4
Kidney & other & unspecified urinary organs (189)	44.8	45.7	46.1	45.0	45.0	45.1	-0.1
Leukaemias (204-208)	38.8	38.8	38.2	38.1	37.2	38.6	-0.5
Melanoma (172)	33.1	33.9	35.5	35.0	36.2	37.5	2.3
Lip, oral cavity, pharynx 140-149)	27.3	25.9	25.4	25.6	26.1	26.1	-0.5
Brain and nervous system (191-192)	22.4	23.0	24.5	24.9	25.2	24.1	1.9
Stomach (151)	23.8	22.6	21.1	20.4	19.8	19.4	-4.0
Pancreas (157	16.6	15.5	16.2	16.5	16.5	15.4	-0.5
Larynx (161)	13.8	13.7	13.9	13.6	13.2	12.9	-1.3
Esophagus (150)	3.9	3.6	3.7	3.4	3.7	3.8	-0.4
All sites (140-208)†	1,741.1	1,744.8	1,756.4	1,757.8	1,780.1	1,799.5	0.7

* APC: annual percent change. Unless other specifications indicated, APCs were calculated for 1994 to 1999.

† All sites exclude non-melanoma skin cancer (ICD-9 173) and undefined sites (ICD-9 196 to 199).

agement planning. Five-year prevalence is probably the most important measure to take into account since it includes people under primary treatment who suffer the most from the effects of their treatment. In terms of health care, they represent the cancer patients the most likely to impose a high demand on the system.

Incidence and death are key elements in the calculation of prevalence and the quality of these measures will directly impact the prevalence accuracy. A recent case ascertainment study conducted by the Quebec Cancer Registry (QCR) showed that 92% of all cancer cases histopathologically confirmed are declared in the QCR.[20] However, declaration is significantly lower for cancers of the prostate (67%), bladder (86%) and cutaneous melanoma (65%). As the long-term survival of these cancers is relatively high, it is reasonable to assume that their prevalence was significantly underestimated.

Cancers of unspecified sites or nature (ICD-9 196 to 199) accounted for nearly three percent of the annual count of new invasive cases (ICD-9 140 to 208; excluding 173) in Quebec.[16] Although these are malignant tumors of secondary or unspecified sites, they require health care involving direct and indirect costs.

Non melanoma skin cancer (NMSC, ICD-9 173) was excluded from the analysis because they are seldom reported to the Quebec Cancer Registry. Canada has an estimated 78,000 new cases for 2005,[18] and Quebec approximately 18,250 new cases. Although they do not normally require hospitalization or day surgery and are considered low-cost cancers, they are numerous and should be taken into consideration.

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Validity of death and stillbirth certificates and hospital discharge summaries for the identification of neural tube defects in Quebec City

Fassiatou Tairou, Philippe De Wals and Adrien Bastide

Abstract

The objectives of this study were 1) to assess the validity of different databases which identify neural tube defect (NTD) cases in the population, and 2) to examine the temporal trends in NTD rates and the impact of prenatal diagnoses among pregnancies referred to a tertiary care hospital in Quebec City, Canada, from 1993 to 2002. Infant death and stillbirth certificates were a highly reliable source for ascertaining NTD cases, but their overall sensitivity was poor (13%). Med-Echo had very good sensitivity (92%), but there were many coding errors in the database and some diagnostic categories were not specific for NTD. The average NTD prevalence proportion was 6.5/1,000 births during the entire study period, decreasing from 12.2/1,000 in 1993 to 3.9/1,000 in 2002. Overall, 78.6% of NTD cases were diagnosed prenatally and the pregnancy was terminated in 52.6% of these. These two proportions were stable over the study years. To conclude, the combination of hospital discharge summaries and infant death and stillbirth certificates is a highly sensitive method for the ascertainment of NTD cases, including terminations of pregnancies, but medical records must be reviewed to exclude coding errors and to clarify unspecific diagnostic categories.

Key words: *ascertainment, birth defects, database, neural tube defects, prenatal diagnosis, surveillance, validity*

Introduction

In Canada, recommendations on the use of folic acid supplements by women planning a pregnancy or capable of becoming pregnant were issued in 1993–1994 by Health Canada, the Society of Obtetricians and Gynaecologists of Canada and the Canadian Task Force on the Periodic Health Examination.[1–3] Fortification of a large variety of cereal food products with folic acid became mandatory in 1998.[4] In Quebec, the first evaluation of the impact of this program on the epidemiology of neural tube defects (NTDs) was performed using provincial administrative databases: stillbirth certificates (SBC) and infant death certificates (IDC), as well as computerized hospital discharge summaries (Med-Echo).[5] In Quebec City, an additional source of information was available, namely the computerized results of prenatal ultrasound examinations (Res-Echo) performed at the Saint-François d'Assise Hospital (SFAH). The objectives of the present study were to assess the validity of the different sources for the identification of NTD cases, and to examine the temporal trends in NTD rates and the impact of prenatal diagnosis among pregnancies referred to this tertiary care hospital from 1993 to 2002.

Methods

The study population included live births, stillbirths and terminations of pregnancies (because of fetal anomaly) at the SFAH from late 1992 to 2002. NTD cases were classified according to the nomenclature proposed by Nevin and Weatherall.[6] The three main categories were anencephaly (including craniorachischisis and inencephaly), spina bifida or meningomyelocele, and encephalocele (including exencephaly). Spina bifida occulta and sacral lipomeningocele were excluded. Spina bifida occulta is a common defect that is not diagnosed during the neonatal period.[6] Sacral lipo(myelo)meningocele is thought to be embryologically distinct from (myelo)meningocele; folic acid does not seem to be effective for its prevention.[7]

Med-Echo records including a main or a secondary diagnostic code compatible with NTD were identified for the period July 1992 to March 2002. The ninth revision of the *International Classification of Diseases* (ICD-9) was in use during the study period and codes of interest were infants with a neural tube defect (ICD-9: 740.0 to 742.0) and women with a fetus affected by a central nervous system malformation (ICD-9: 655.0). For infant death and stillbirth certificates, the tenth revision of the *International Classification of Diseases* (ICD-10) was adopted in 2000. The provincial databases were reviewed to identify records with a code for anencephaly (ICD-9: 740; ICD-10: Q00), for spina bifida (ICD-9: 741; ICD-10: Q05), or for encephalocele (ICD-9: 742.0; ICD-10: Q01). A file generated by Res-Echo, a computerized system for recording results of obstetrical ultrasound examinations at the SFAH, provided a list of pregnant women who had an examination indicating a fetus with an abnormality of the central nervous system. Hospital records were identified and medical notes were reviewed to ascertain all diagnoses.

Author References

Fassiatou Tairou, Philippe De Wals, Department of Social and Preventive Medicine, Laval University, Quebec City, Quebec, Canada
Adrien Bastide, Maternal and Child Health Center, Quebec City University Hospital Center, Quebec, Canada
Correspondence: Philippe De Wals, Département de médecine sociale et préventive, Université Laval, Pavillon de l'Est, Local 1110, 2180, Chemin Sainte-Foy, Quebec City, Quebec, Canada G1K 7P4; fax: (418) 656-7759; e-mail: Philippe.Dewals@msp.ulaval.ca

The denominator figures for live births and stillbirths were provided by the SFAH. A large proportion of NTD-affected pregnancies were terminated, so to prevent classification bias in calculating yearly prevalence proportions, a theoretical birth date was calculated for each NTD case, assuming a gestation of 40 weeks (date of birth/abortion less gestation length in weeks plus 40 weeks). The predictive positive value (PPV) of a source or of a diagnostic code was defined as the proportion of records which were true NTDs. The relative sensitivity of a source or of a diagnostic code was defined as the proportion of NTD cases identified from this particular source or diagnostic code, relative to the total NTD cases identified from all sources and codes combined.

TABLE 1
Distribution of neural tube defect (NTD) cases, by source of ascertainment at the St-François d'Assise Hospital (Quebec City)

Source			Number of cases	% of total
Death and stillbirth certificates	Med-Echo[1]	Res-Echo[2]		
+	+	+	22	12.7
+	+	–	0	0.0
+	–	+	0	0.0
–	+	+	43	24.9
+	–	–	0	0.0
–	+	–	94	54.3
–	–	+	14	8.1
All sources			173	100.0

+ The case was ascertained by the source.

[1] Quebec computerized hospital discharged summary database

[2] Computerized results of prenatal ultrasound examinations at the Saint-François d'Assise Hospital

The data were analyzed using SAS software.[8] Prevalence proportions with their 95% confidence intervals were calculated using an exact method. The Cochrane-Armitage test for trends in proportions was performed with statistical significance set at five percent. The study protocol was approved by the Quebec University Hospital Centre's Research Ethics Committee and access to provincial databases was authorized by the Quebec Access to Information Commission.

Results

Validation of sources

Provincial death records identified 14 infant deaths and eight stillbirths at the SFAH with an NTD diagnosis. A review of the medical records showed that the main cause of death was correct in all cases; the PPV was thus 100 percent.

The Med-Echo file contained 235 records mentioning a mother who had a fetus with a malformation of the central nervous system. Duplicate records were eliminated, so 178 mothers remained. A NTD-affected pregnancy was confirmed in 99 cases, another anomaly of the central nervous system was present in 62 cases, a malformation of another system or organ in ten cases, and another condition not considered a congenital malformation in the remaining seven cases. The PPV of the ICD-9 code 655.0 was 90% (161/178) for any malformation of the central nervous system and 56% (99/178) for NTDs.

The Med-Echo file contained 41 records of infants less than one year old with an NTD diagnosis. The code was incorrect in five cases: Another malformation of the central nervous system was present in four cases and a congenital anomaly of another organ in the remaining case. Therefore, the PPV of ICD-9 codes 740.0 to 742.0 was 88% (36/41). In the Med-Echo file, 24 NTD cases were identified under the mother and again under the child.

From the SFAH's Res-Echo file, we identified 133 pregnant women whose computerized record mentioned an anomaly of the central nervous system. In five cases, the medical records could not be found. Therefore, we reviewed 128 cases: 79 matched the definition of NTD and 49 did not (another anomaly of the central nervous system was present in 19 cases, a congenital malformation of another system or organ in 15 cases and another fetal condition not considered as a congenital malformation in the remaining 15 cases). The PPV for NTDs of this source was therefore 62% (79/128).

Combining the various information sources, a total of 173 NTD cases were identified (Table 1). The relative sensitivity of the different sources for ascertaining NTD cases was as follows: death and stillbirth certificates – 13% (22/173), Med-Echo – 92% (159/173) and Res-Echo – 46% (79/173). All the NTD cases identified in death and stillbirth certificates were also identified in Med-Echo. The majority of the 14 NTD cases missed by both SBCs/IDCs and Med-Echo were medical terminations of pregnancy (three cases of anencephaly, two of encephalocele and six spina bifida cases). Two stillbirths were also missed (one case of anencephaly and one of encephalocele), and a single live birth with spina bifida was not identified.

NTD prevalence proportion

The ascertainment of NTD cases having an expected date of birth in 1992 was incomplete and rates were not provided for that year. When the data analysis is limited to cases where the expected date of birth was between January 1, 1993 and December 31, 2002, 168 NTD cases were identified: 68 were live births, 14 stillbirths and 86 pregnancy terminations (Table 2). During this period, there were 26,210 live births and 220 stillbirths at the SFAH. There was a general downtrend in the number of births, except for a sudden increase in 1997. If we consider the absolute frequency of NTDs, we note a decline that began in 1998, continued in 1999 and then stabilized. Because of the combined effect of the increase in the total number

TABLE 2
Prevalence of neural tube defects (NTDs) at the St-François d'Assise Hospital (Quebec City) by pregnancy outcome (1992–2002)

	Year											
	1992[1]	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	All years combined
Number of live births	–	2,182	2,161	2,173	2,003	3,435	3,300	3,066	2,908	2,437	2,545	26,210
Anencephaly	0	0	2	1	2	3	0	0	1	0	0	9
Encephalocele	0	0	2	1	2	0	3	0	0	0	0	8
Spina bifida	0	10	5	7	7	9	2	1	7	1	2	51
All NTDs	0	10	9	9	11	12	5	1	8	1	2	68
Proportion/1,000	–	4.6	4.2	4.1	5.5	3.5	1.5	0.3	2.7	0.4	0.8	2.4
Number of stillbirths	–	22	22	21	15	27	31	16	24	18	24	220
Anencephaly	0	1	1	0	1	0	2	1	1	1	0	8
Encephalocele	0	0	0	0	1	0	0	0	0	0	0	1
Spina bifida	0	2	0	0	0	2	0	1	0	0	0	5
All NTDs	0	3	1	0	2	2	2	2	1	1	0	14
Proportion/1,000	–	136.4	45.5	0	133.3	74.1	64.6	125.0	41.7	55.6	0.0	59.3
Number of pregnancy terminations												
Anencephaly	1	4	3	4	4	2	1	2	0	2	4	27
Encephalocele	0	3	0	1	0	0	2	0	0	0	2	8
Spina bifida	4	7	2	8	5	8	5	4	3	8	2	56
All NTDs	5	14	5	13	9	10	8	6	3	10	8	91
Total births	–	2,204	2,183	2,194	2,018	3,462	3,331	3,082	2,932	2,455	2,569	26,430
All NTDs	5	27	15	22	22	24	15	9	12	12	10	173
Proportion/1,000	–	12.2	6.9	10.0	10.9	6.9	4.5	2.9	4.1	4.9	3.9	6.5

[1] Ascertainment of NTD cases in 1992 was incomplete and proportions were not calculated.

of births in 1997 and the decline in the number of NTD cases in 1998, the total prevalence proportion started to decline substantially in 1997 and stabilized from 1998 on.

If we visually examine the long-term trend with two or three information sources (Figure 1), we reach the same conclusion, i.e., a decline in the prevalence proportion of NTDs, starting in 1997 and followed by stabilization.

Prenatal diagnosis and induced abortion

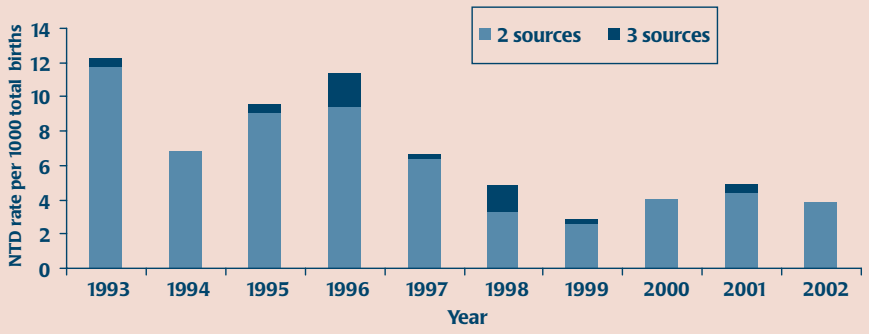
Of the 173 NTD cases ascertained in this study, 136 were diagnosed prenatally (78.6%). The primary diagnosis was made after an ultrasound examination in 92 cases and after an amniocentesis in the other three. No information was available for the remaining 41 cases. The percentage of cases with a prenatal diagnosis was 91% (40/44) for anencephaly, 76% (85/112) for spina bifida and 65% (11/17) for encephalocele. There was no significant trend in these percentages from 1993 to 2002. Overall, 52.6% (91/173) of NTD-affected pregnancies ended in induced abortion. The percentages were 61.4% (27/44) for anencephaly, 50% (56/112) for spina bifida and 47% (8/17) for encephalocele. There was no significant trend in these percentages between 1993 and 2002.

Discussion

Infant death and stillbirth certificates are a highly reliable source for ascertaining NTD cases, but their sensitivity is poor (13%). Indeed, NTD cases among terminations of pregnancy and living infants are not reported. On the other hand, the hospital administrative database Med-Echo has very good sensitivity (92%), but predictive value is low. It relies on the ICD-9 diagnostic category 655.0, which includes all anomalies of the central nervous system occurring in foetuses, but the database unfortunately contains many coding errors. Consequently, a valid analysis of the epidemiology of NTD based on hospital discharge summaries necessitates a complementary review of medical records. Currently, the Canadian Congenital Anomalies Surveillance System relies solely on this source and hospital records are not systematically reviewed.[9]

During the years covered by our study, the SFAH acted as a reference center for high-risk pregnancies in the Quebec City region. In 1996–1997, four maternity units were closed in Quebec City, resulting in a higher proportion of low-risk pregnancies referred to the SFAH. At the same time, food fortification was implemented in Canada. In the present study, it is impossible to disentan-

FIGURE 1
Total prevalence of NTDs, by number of sources* of information at the St-François d'Assise Hospital in Quebec City (1993–2002)



* Two sources = infant death and stillbirth certificates + Med-Echo;
Three sources = infant death and stillbirth certificates + Med-Echo + Res-Echo.

gle the possible effect of these two factors on the observed decreasing prevalence proportion of NTDs. Population-based studies, not hospital-based studies, are needed to assess the impact of folic acid food fortification on the epidemiology of NTDs. Such studies have been conducted in Newfoundland and Labrador[10] and in Nova Scotia,[11] and indicate a 78% to 54% decrease in the prevalence of NTD after fortification was implemented.

The prenatal ultrasound examination was introduced in Canada in the early 1970s and became routine in the mid 1980s. In 1994, the Society of Obstetricians and Gynaecologists of Canada recommended one examination between the 16th and 20th week of gestation to screen for malformations.[12] Under ideal conditions among high-risk pregnancies, prenatal sonography has been found highly sensitive (97%) and specific (100%) for the diagnosis of NTD.[13] Results may be different in a routine screening program. Among unselected pregnancies in 11 European regions, 96% of anencephaly cases were identified prenatally, but this occurred for only 68% of spina bifida cases.[14] In a 1992 study in the Estrie-Monteregie area of the Province of Quebec, all anencephaly and encephalocele cases were identified prenatally and the pregnancies terminated, but prenatal diagnoses were not made for 60% of spinal lesions.[15] At the SFAH, 79% of NTD cases were detected prenatally and the pregnancy was terminated in 53% of cases during the period 1993 to 2002. In the present study, there was no attempt to identify the reason why so many NTD cases were not detected prenatally nor why they were detected later on. This could be the objective of a subsequent quality control survey.

Conclusion

The combination of hospital discharge summaries and infant death and stillbirth certificates is a highly sensitive method for the ascertainment of NTD cases in the population, but medical records must be reviewed to exclude coding errors and to clarify imprecise diagnostic categories. During the period 1993 to 2002, there was no apparent increase in the proportion of NTD cases with a prenatal diagnosis and pregnancy termination. A large population-based study is currently underway in Quebec, relying on hospital discharge summaries and infant death and stillbirth certificates—as well as the review of medical records—in order to assess the real impact of folic acid food fortification.

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