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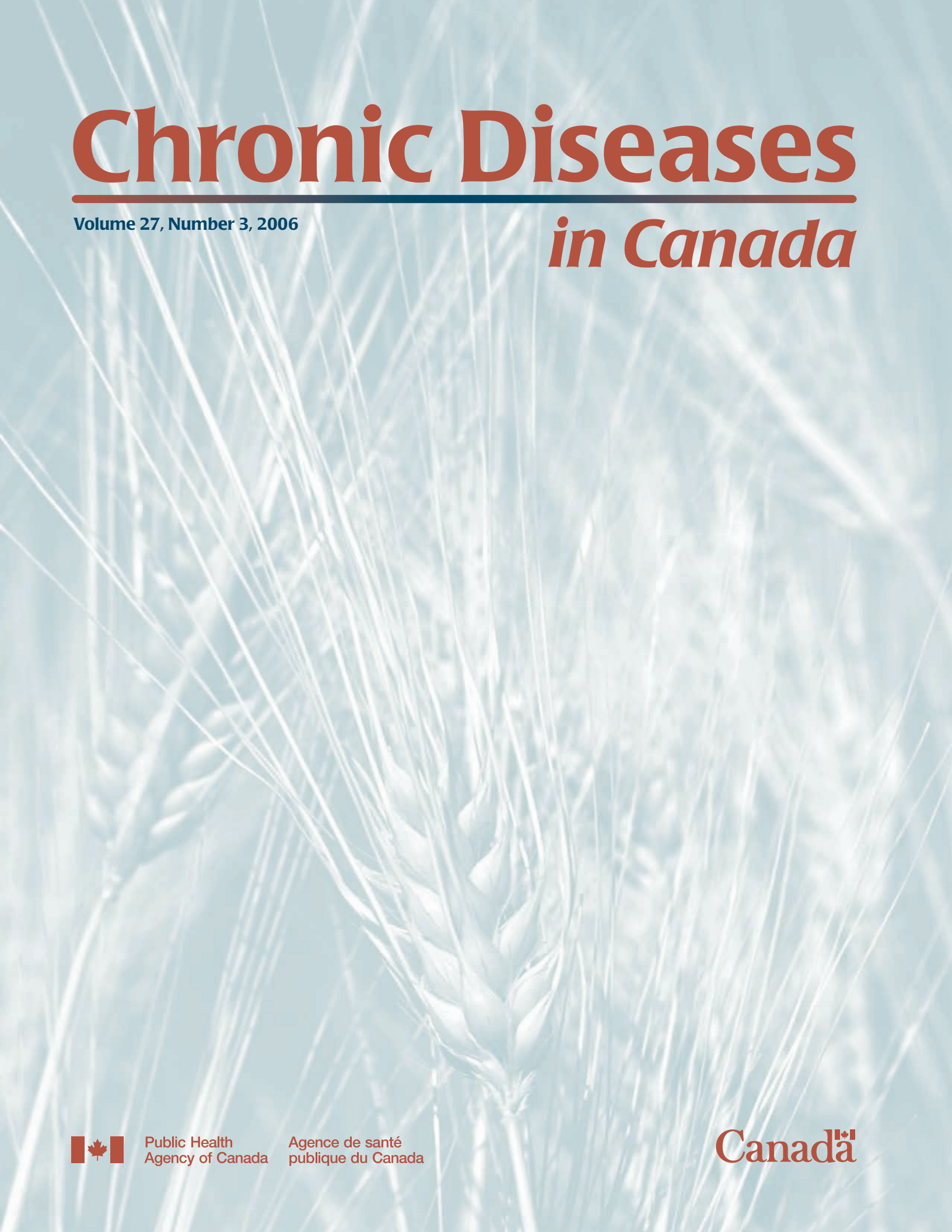

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Assessment of mental health and illness by telephone survey: Experience with an Alberta mental health survey

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Abstract

Mental health is an emerging priority for health surveillance. It has not been determined that the existing data sources can adequately meet surveillance needs. The objective of this project was to explore the use of telephone surveys as a means of collecting supplementary surveillance information. A computer-assisted telephone interview was administered to 5,400 subjects in Alberta. The interview included a set of brief, validated measures for evaluating mental disorder prevalence and related variables. The individual subject response rate was 78%, but a substantial number of refusals occurred at the initial household contact. The age and sex distribution of the study sample differed from that of the provincial population prior to weighting. Prevalence proportions did not vary substantially across administrative health regions. There is a potential role for telephone data collection in mental health surveillance, but these results highlight some associated methodological challenges. They also draw into question the importance of regional variation in mental disorder prevalence—which might otherwise have been a key advantage of telephone survey methodologies.

Key words: *mental health, methods, surveillance, telephone surveys*

Introduction

Several features distinguish surveillance from other forms of health investigation. First, data collection is driven by a need for evidence rather than by research hypotheses.[1] Second, surveillance data are collected routinely or in an ongoing way, and data collection is integrated with analysis and interpretation, usually leading to the production of a surveillance product.[2] Chronic illnesses,[3] including mental illnesses (www.who.int/whr/2001/en/), now rank among the most important public health issues. A need for enhanced chronic disease surveillance has been identified nationally[4] and a lack of progress towards this goal has received criticism at the national level (www.oag-bvg.gc.ca/domino/reports.nsf/html/20020902ce.html).

Mental illnesses may pose some particular challenges for surveillance. One challenge is the relative paucity of available data. The Public Health Agency of Canada's on-line chronic disease surveillance utility (www.oag-bvg.gc.ca/domino/reports.nsf/html/20020902ce.html) focuses on mortality, which does not address the most important sequelae of mental illness: impaired functioning and quality of life. The national health survey capable of region-level inference, the general health iterations of the Canadian Community Health Survey (www.statcan.ca/english/concepts/hs/index.htm), have only addressed two mental disorders, substance dependence and major depression, the latter only as optional content (www.statcan.ca/english/concepts/health/cycle3_1/pdf/cchs3documentation.pdf).

Improved mental health care might lead to increased service utilization because of increased accessibility or it might lead to diminished utilization because of improved population mental health. For these reasons, utilization statistics, such as physician billing data and hospital separations, provide incomplete information. Despite this, and perhaps because of the availability of such data to key stakeholders in government, they have assumed a preeminent role in mental health surveillance. One recent project concerned with the identification of mental health indicators (http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page = indicators_mental_e) resulted in a prototype report that consisted largely of data on hospital separation, inpatient hospital-days and length of stay. Similar analyses comprised the bulk of a recent Manitoba report.[5]

Efforts have been made to extend the scope of data available for mental health surveillance in Canada. Most notable in this regard is the 2002 Canadian Community Health Survey, Mental Health and Wellbeing (CCHS 1.2), which has provided a wealth of data about mental health and illness. Unfortunately, it

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is not clear whether this type of survey will ever be repeated in the future, so its role as a source of surveillance data is uncertain. Furthermore, surveillance systems should be responsive to stakeholder needs[1] and it is not clear that large, specialized national surveys can be sufficiently responsive, for example, to needs manifesting at the health region level. The answer to this question depends at least partially on the extent to which key variables differ across geographical regions. If there is a high level of consistency across the country and a high level of consistency in the priorities of stakeholders, large-scale national projects may suffice.

Telephone surveys represent a potential mechanism for filling gaps in mental health surveillance and these methods have been employed in Canadian studies. Fournier explored the application of telephone survey methods in Quebec.[6,7] In Saskatchewan, depression data deriving from the Saskatchewan Health and Dynamics Survey has recently been reported by D'Arcy.[8] The Winnipeg Area Survey has generated prevalence data for several anxiety disorders.[9–12] In Calgary, the Calgary Health Region is currently carrying out a baseline telephone survey of generalized anxiety disorder in the region, building upon earlier studies of depression in Calgary and adjacent rural areas.[13] Wild et al. used a telephone survey to evaluate the prevalence of alcohol-related problems and interest in self-help materials in Alberta.[14] Computer-assisted telephone interviews (CATI) may be the only feasible method of data collection in geographically dispersed areas (see review of strengths and weaknesses of CATI by Choi).[15]

A project exploring the application of telephone survey methods for mental health surveillance in Alberta was initiated by the Alberta Mental Health Board in association with researchers from the University of Calgary. To guide the project, two consultative committees were initially formed. One of these was the Project Advisory Committee, consisting of decision makers from within the mental health care system. The other was the Technical Advisory Committee, which included epidemiologists, biostatisticians and health services researchers. Under the direction of the investigators and the advisory committees, three projects were undertaken: 1) a content priorities survey, 2) a consensus workshop, and, 3) a population survey. This paper's objectives are to summarize our experience with the project, present some key findings and draw attention to several key methodological issues.

The content priorities survey targeted 110 key informants from the mental health system in Alberta. The target population included representatives of regional health authorities, senior program or service managers, government representatives, academic researchers and the Alberta Mental Health Board. Fifty eight of these subjects (52.7%) responded to the survey. Among the respondents were representatives of 16 of the 17 health regions in Alberta in 2003. The number of health regions in the province was subsequently reduced to nine in April 2003. The survey identified four priority areas for regional data collection: prevalence, service use, impact of disorders on functioning and quality of life. Of these priorities, only service-use data was routinely available to regional stakeholders.

The second project was a workshop to determine a course of action. This was held in Calgary on October 18, 2002. It was attended by 11 experts from government, health regions and academia, the investigative team and a professional facilitator. A plan for action was formulated which emphasized the potential value of using primary data collection to enhance the availability of data in the areas identified by the content priorities survey. It was decided that an initial survey should be conducted and that the target population for this should be the general household population in Alberta.

Methods

Sampling procedures

Alberta has a population of 2.97 million, dispersed over an area of 661,190 km^2. The population is 80% urban and 20% rural. The health care system is currently divided into nine health regions, with populations (within the 18–64 year age range targeted by this survey) ranging from 757,741 in the Calgary Health Region to 45,824 in the Northern Lights Health Region. A map showing the Alberta health regions is available at: www.statcan.ca/english/concepts/health/cycle3_1/maps/alta_alb.pdf. Because of the vast geographical areas involved, telephone survey methods (rather than "face to face" interviews) were considered necessary. Since a high priority was placed by the stakeholders on region-specific estimates, a stratified sample was chosen. Precision-based sample size estimates determined that 95% confidence intervals of plus or minus 2% for attributes with a frequency of five percent could be achieved with a sample size of N = 600 per region. The target sample size was therefore set to N = 5,400.

Data collection was carried out by the population survey unit associated with the Quality Improvement and Health Information (QIHI) portfolio within the Calgary Health Region. A listing of provincial residential telephone numbers is maintained and updated by the survey unit. A random sample of these numbers was initially selected. Since unlisted numbers were not included in this database, there was concern that bias might be introduced in the event that households with unlisted numbers differed from those with listed numbers. The strategy of changing the final digit in the telephone number was adopted as a means of ensuring that non-listed numbers could also be included in the sampled list.[16] A value of 1 was added to each of the randomly selected numbers. This "plus one" approach avoids the need to identify working "blocks" of telephone numbers encountered other random-digit dialing protocols,[17] and avoids the clustering inherent in such sampling procedures. When a household was reached, the "next birthday" method[18] was used to randomly select a single subject from the household.

Measures

The telephone interview administered to selected subjects included the Mini Neuropsychiatric Interview (MINI),[19] which is a brief diagnostic interview. The MINI was developed jointly at the University of South Florida and the

National Institute for Mental Health in Paris. The MINI is not a single instrument, but rather a "family" of instruments that have been modified over time in response to modifications occurring to DSM criteria with the release of *DSM-IV*.[20] The MINI was originally developed for use in primary care, where it was felt that a brief structured interview could lead to improved detection by allowing non-physician clinical staff to derive preliminary psychiatric diagnoses.[19] In keeping with the original goal of the MINI as a case-finding tool for primary care, the development process emphasized sensitivity over specificity. In community surveys, due to a lower base-rate, even high specificity might lead to overestimation of prevalence since a small false positive rate could give rise to a considerable proportion of false positive results in a sample where the vast majority of respondents do not have the condition being evaluated. Validation data for the MINI was originally reported in two European papers,[21,22] and subsequently was summarized in a paper published in the *Journal of Clinical Psychiatry*.[19] When compared to the SCID-P (a gold standard semi-structured interview) the MINI was found to be 96% sensitive and 88% specific. In the validation sample, a positive predictive value of 87% was achieved. However, in a community sample (which would probably have a lower point prevalence than the clinical validation sample) a lower predictive value might be expected. In the Paris validation study, the CIDI (long form) was used as a validation standard and 94% sensitivity and 79% specificity were reported. Estimates of the test-retest reliability of the MINI have ranged from 1.0[19] to 0.64.[23]

The general concept of a mental disorder in *DSM-IV* involves the requirement for a clinical syndrome but also a requirement that the syndrome be associated with significant distress, or an impact on functioning.[24] The latter requirement is intended to help to distinguish mental disorders from non-pathological expressions of depressive symptoms (e.g., an adjustment disorder resulting from stressful life events). One brief instrument resembling the MINI, called the Patient Health Questionnaire (PHQ), incorporates this concept of altered functioning by including an "interference" item, which asks whether symptoms interfered with life activities, whatever these may be.[25] This approach addresses a concern raised by Narrow et al.[26] that inconsistencies in diagnoses arising from lay-administered psychiatric interviews often relate to indicators of clinical significance, such as interference with activities. The Narrow et al. study, which was a re-assessment of prevalence data from the Epidemiological Catchment Area studies in the United States[27] and the National Comorbidity Survey,[28] also used help-seeking behaviors as an index of clinical significance (e.g., taking medications, seeing a health professional). These characteristics were not used as clinical significance indictors in the current project. The concern that precluded their use was an effort to avoid the creation of tautological definitions of diagnosis in relation to some of the study's key objectives—in particular, the goal of developing a way of monitoring health care use and treatment receipt in relation to diagnosis.

The interference item from the current study had the following wording: "How much did any of the problems we just talked about interfere with your life or activities?" The response options were read to the respondent: a lot, some, a little and not at all. The analysis by Narrow et al. used interference items from the NCS ("How much did your [symptom(s)] ever interfere with your life or activities—a lot, some, a little, or not at all?") and ECA ("Did [symptom(s)] interfere with your life or activities a lot?"). The PHQ item is worded as follows: "... how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?"

The interview also included a generic quality of life instrument, the EuroQoL EQ-5D (www.euroqol.org/index.htm) and a measure of disability, the World Health Organization's Disability Assessment Schedule (WHO DAS II).[29] In addition, items evaluating demographic variables and health care utilization were included. Interviewers working on the project were experienced telephone interviewers with the QIHI unit, and the data collection was preceded by a series of training sessions incorporating both didactic instruction and practice.

Analysis

There are a variety of determinants of selection probabilities in telephone surveys: the number of telephone lines reaching each household and the number of household residents. An initial sampling weight was calculated by dividing the number of household residents by the number of voice-telephone lines into the household. The demographic characteristics of the sample were then compared to the demographic distribution of the target population within each health region. Data for the 18–64 age group (reflecting the survey's eligibility criteria) from the Alberta Health Care Insurance Plan Stakeholder Registry was used for this purpose. This is a database of registrants in the provincial health care insurance plan. The relevant tables were provided by the Health Surveillance Branch of Alberta Health and Wellness (www.health.gov.ab.ca). The telephone sample was found to overrepresent women, especially those over the age of 35, and to underrepresent men, especially those under the age of 50. For these reasons, an adjustment was made to the sampling weights so that the results would closely approximate the age and sex distribution of the underlying population. Another set of sampling weights were calculated on a region-by-region basis and these sets of weights were used for making region-specific estimates. To account for the regionally stratified sampling, the weights used in the provincial estimates were also multiplied by the inverse of the stratified sampling probability, with the sampling probability being defined as the regional sample size (N = 600) divided by the population of the region. All analyses used the survey ("svy") commands in Stata, version 8.0.[30]

Results

In total, 29,941 telephone numbers were dialed. Of these, 6,121 were not working numbers, 3,048 were businesses and 2,525 were fax machines. There were 143 blocked calls and in 1,453 cases it was not possible to get past answering machines or

TABLE 1
Prevalence proportion estimates and 95% confidence intervals of MINI*-defined major depression (current) in survey respondents, with clinical interference thresholds (N=422)

Interference threshold response	N	Unweighted estimates %	Unweighted estimates 95% CI	Weighted estimates %	Weighted estimates 95% CI
No interference requirement	422	7.8	7.1-8.6	7.7	6.9-8.4
"A little" interference	384	7.1	6.4-7.8	7.0	6.3-7.7
"Some" interference	297	5.5	4.9-6.1	5.3	4.7-5.9
"A lot" of interference	182	3.4	2.9-3.9	3.2	2.7-3.7

* MINI – the MINI Neuropsychiatric Interview

voice mail. A small number (N = 101) were busy each time called and 1,701 numbers rang but were never answered. At the time that the study was terminated, there were 376 numbers in the process of follow-up, which included 148 households. In 2,644 households, there were no eligible residents and in 377 it was not possible to successfully communicate with a householder because of a language barrier. In total, 11,680 numbers contacted an eligible household.

There were 4,512 household-level refusals (39% of households contacted), so that 7,168 subjects were selected for inclusion. There were 146 subjects who were never contacted because they were not at home during any of the call-back attempts and 82 who were not contacted because the study ended while they were in process. There were 6,940 individual subjects who were contacted in person by an interviewer and asked to provide assent for participation. Of these, 95 did not speak English, there were 1,314 refusals and 121 interrupted interviews, so that interviews were complete in 5,410 instances. Complete data were collected from 5,383 of these subjects. If the individual response rate is calculated as the proportion of eligible subjects who did not refuse or interrupt the interview, the response rate was 78%. If those who were selected but never contacted are counted as individual non-responders, the response rate was 75%.

The unweighted mean age of the sample was 40.8 years. The weighted mean age was 39.2 years. The unweighted sample included 2,087 men (38.8%) and 3,296 women (61.2%). The weighted proportions of men and women were 47.8% and 52.2%, respectively. The marital status of 65.6% of subjects was married, 11.7% were divorced, widowed or separated and 22.6% had never married. Most (60.2%) of the subjects had more than secondary-level education (grade 12 graduation), 36.3% reported a secondary-level education and only 3.5% had less than a secondary-level education.

The direct application of the MINI diagnostic algorithms (without the interference item) tended to produce prevalence estimates higher than what would be predicted based on the literature. Addition of the interference item in the diagnostic algorithms had the expected effect of reducing the estimated prevalence for each disorder. Table 1 shows weighted and unweighted estimates for one disorder, major depression, with application of several interference thresholds. Estimated prevalence predictably diminished as the requirement for interference with activities was made more stringent. Since the MINI detects current major depressive episodes, the requirement for "a lot" of interference with current activities might be seen as a suitable requirement for identification of clinically significant cases. Consistent with this idea, the prevalence associated with this threshold was 3.2%. This estimate is slightly higher than that of the recent Canadian National Survey of Mental Health and Well-being (CCHS 1.2), which placed the thirty-day prevalence at 1.8%[31] but lower than the 4.9% point prevalence reported from the National Comorbidity Survey in the United States.[32] The ECA study reported a 2.2% thirty-day prevalence[33] and the Edmonton study reported a 2.3% estimate.[34] The weighted estimates tended to be slightly lower than the unweighted estimates for major depression, probably because of the female preponderance in the unweighted data. However, the differences were small.

A similar relationship was observed when the interference criterion was applied to other disorders. For example, the twelve-month prevalence of alcohol dependence

TABLE 2
Prevalence proportions and 95% confidence intervals of mood disorders in survey respondents†, by Alberta provincial health region

Health region	#	Prevalence proportions and 95% confidence intervals: Major depressive episode* (14 day) %	CI	Dysthymia** (2 year) %	CI	Any mood disorder* %	CI
Chinook	1	2.7	(1.2-4.2)	0.9	(0.1-1.8)	4.8	(2.8-6.8)
Palliser	2	3.4	(1.8-5.0)	0.9	(0-1.7)	5.0	(3.1-6.9)
Calgary	3	3.7	(2.0-5.4)	0.9	(0.1-1.6)	5.7	(3.6-7.7)
David Thompson	4	2.3	(1.1-3.5)	1.1	(0.2-2.0)	3.9	(2.3-5.5)
East Central	5	4.2	(1.4-6.9)	1.6	(0.7-2.5)	6.3	(3.3-9.3)
Capital	6	3.1	(1.5-4.8)	1.4	(0.4-2.4)	6.7	(4.4-9.1)
Aspen	7	6.8	(3.4-10.2)	0.7	(0-1.5)	8.3	(4.8-11.7)
Peace Country	8	2.1	(1.0-3.1	1.5	(0-2.9)	3.8	(2.3-5.3)
Northern Lights	9	3.0	(1.4-4.7)	1.1	(0.2-2.1)	4.9	(2.9-6.9)
Alberta (total)		**3.2**	**(2.7-3.7)**	**1.2**	**(0.9-1.5)**	**5.4*** **	**(4.8-6.1)**

† Respondents were assessed using the Mini Neuropsychiatric Interview.

* Clinical significance component of the prevalence definition required "a lot" of impairment.

** Clinical significance component of the prevalence definitions required any reported impairment.

*** Includes bipolar disorders.

TABLE 3
Prevalence proportions and 95% confidence intervals of substance-use disorders in survey respondents*, by Alberta provincial health region

Health region	#	Prevalence proportions (95% confidence intervals)				
		Alcohol		Other substances		Any substance-use disorder
		Dependence (12 month)	Abuse (12 month)	Dependence (12 month)	Abuse (12 month)	(12 month)
Chinook	1	1.0% (0-2.0)	2.1% (0.8-3.7)	2.1% (0.5-3.5)	1.6% (0.1-3.0)	6.2% (3.6-8.7)
Palliser	2	3.6% (1.7-5.5)	4.2% (1.7-6.7)	1.2% (0-2.6)	1.6% (0-3.2)	9.2% (5.9-12.5)
Calgary	3	3.8% (2.1-5.5)	1.9% (0.1-3.0)	2.4% (1.0-3.9)	1.6% (0.6-2.6)	7.9% (5.5-10.4)
David Thompson	4	4.8% (0.2-9.5)	4.6% (0.3-8.8)	3.0% (0-7.6)	2.5% (0.8-4.2)	11.7% (5.6-17.8)
East Central	5	6.6% (2.5-10.7)	1.2% (0.4-2.1)	1.5% (0-3.1)	1.9% (0.2-3.6)	9.5% (5.3-13.8)
Capital	6	3.1% (1.7-4.5)	1.9% (0.4-3.4)	1.6% (0.7-2.6)	1.6% (0.2-3.0)	6.6% (4.4 -8.9)
Aspen	7	4.6% (2.6-6.6)	1.4% (0.3-2.5)	1.4% (0.2-2.6)	1.8% (0-3.8)	7.7% (4.8-10.7)
Peace Country	8	3.9% (1.8-6.0)	1.2% (0-2.5%)	1.9% (0.4-3.5)	1.7% (0.1-3.2)	6.7% (3.9-9.6)
Northern Lights	9	4.6% (2.5-6.7)	1.2% (0.5-2.2)	1.4% (0.2-2.6)	0.3% (0-0.7)	6.4% (3.9-8.9)
Alberta (total)	–	**3.6% (3.0-4.1)**	**1.9% (1.5-2.4)**	**1.6% (1.2-2.0)**	**1.5% (1.1-1.8)**	**7.1% (6.4-7.9)**

* Respondents were assessed using the Mini Neuropsychiatric Interview.

according to the MINI was 5.2%, which is consistent with some published estimates (see discussion below). When any reported interference was incorporated into the definition, the prevalence became 3.6% and when "a lot" of interference was required, the prevalence was 0.9%. For dysthymia, the study's prevalence estimates were most consistent with the literature when "some" interference was required. Adoption of this threshold seems justifiable in the sense that a lower level of interference is expected from dysthymia than from current major depression, yet some amount of interference with functioning seems reasonable as a means of ensuring that the cases identified were of clinical significance.

Prevalence proportion data from the MINI interview for mood disorders, substance-use disorders and anxiety disorders are presented in Tables 2–4. These specific estimates reflect the application of the interference criterion as described above: a lot of interference for major depression, at least some interference for dysthymia and no requirements for substance-use disorders. For reasons similar to those for dysthymia, anxiety disorders were required to be associated with at least some interference with functioning in order to be considered clinically significant. The MINI produces period prevalence estimates covering variable periods of time. For major depression, past fourteen-day prevalence was assessed; for dysthymia the prevalence period was the past two years. For anxiety and substance-use disorders, the MINI produces twelve-month period prevalence estimates. None of these tabulations provided evidence of regional variations in mood disorder prevalence. The final row of the Tables 2–4, therefore, presents the provincial prevalence proportions estimates, which seem preferable for reasons of precision.

The MINI evaluates current major depressive episodes and current (past 30 days) manic or hypomanic episodes. However, not unexpectedly (as the sample size was calculated based on a five percent attribute frequency), the prevalence proportions of current hypomanic episodes (0.8%; 95% CI: 0.5-1.0) and manic episodes (0.5%; 95% CI: 0.3-0.7) were too low for the data to support region-specific estimation.

Generalized anxiety disorder is not included as a separate column in Table 4 because the prevalence proportions resulting from the MINI syndromal definition and this level of clinical significance resulted in an unrealistically high prevalence proportion estimate, 9.6%. When "a lot" of interference with functioning was required, the prevalence dropped to 4.2% (95% CI: 3.6-4.7).

The MINI includes a diagnostic module for eating disorders. In this survey no subjects met diagnostic criteria for anorexia nervosa. The prevalence proportion of bulimia nervosa was 1.2%. With the addition of the clinical significance criteria requiring interference, the estimated prevalence of bulimia nervosa was 0.9% (95% CI: 0.7-1.2). The odds ratio for the female sex in bulimia was 3.2 (95% CI: 1.6-6.3).

While regional variations in prevalence were not identified in this analysis, sizable differences in relation to age and sex were observed. Figure 1 shows the prevalence proportions of major disorder categories by sex. As expected mood and anxiety disorders were more common in women and substance-use disorders were more common in men. Figure 2 presents the same prevalence proportions estimates stratified by age. The highest prevalence proportions of mood and anxiety disorders occurred in the 26–44 year age group, whereas substance-use disorders were most frequent in the 18–25 age group. No significant associations were observed between prevalence of these disorders and level of education.

Mood disorders were more common in divorced, widowed or separated subjects (9.7%, 95% CI: 7.4-12.0) than in married (including common-law) subjects (4.5%, 95% CI: 3.8-5.2) or never-married subjects (5.7%, 95% CI: 4.3-7.1). A similar pattern was observed for anxiety disorders. For

TABLE 4
Prevalence proportions and 95% confidence intervals of anxiety disorders in survey respondents†, by Alberta provincial health regions

Health region	#	Prevalence proportions (95% confidence intervals)			
		Panic disorder (Lifetime)	Agoraphobia* (Current)	Social phobia (30 day)	Any anxiety disorder**
Chinook	1	1.9% (0.2-1.6)	1.6% (0.4-2.8)	1.8% (0.5-3.2)	4.3% (2.4-6.1)
Palliser	2	1.3% (0.3-2.3)	1.5% (0.4-2.5)	2.3% (0.9-3.7)	4.4% (2.6-6.2)
Calgary	3	1.0% (0.1-1.8)	2.1% (0.7-3.5)	2.6% (1.1-4.0)	5.1% (3.2-6.9)
David Thompson	4	1.1% (0.4-1.9)	1.2% (0.4-2.0)	1.5% (0.4-2.5)	4.7% (2.9-6.4)
East Central	5	1.3% (0.4-2.2)	1.3% (0.4-2.1)	2.8% (0.1-5.4)	5.9% (3.0-8.8)
Capital	6	0.9% (0.2-1.6)	2.2% (0.8-3.5)	2.6% (1.4-3.9)	6.0% (3.9-8.1)
Aspen	7	2.9% (0.4-5.3)	1.0% (0.3-1.7)	2.5% (0.4-4.6)	7.5% (4.1-10.9)
Peace Country	8	1.4% (0.5-2.3)	1.1% (0.2-2.0)	2.1% (0.9-3.3)	3.7% (2.2-5.1)
Northern Lights	9	0.7% (0-1.3)	1.7% (0.7-2.8)	1.9% (0.8-2.9)	4.4% (2.5-6.3)
Alberta (total)	**–**	**1.4% (1.0-1.7)**	**1.5% (1.2-1.9)**	**2.2% (1.8-2.7)**	**5.1% (4.5-5.6)**

† Respondents were assessed using the Mini Neuropsychiatric Interview.

* Includes two MINI categories: panic disorder with agoraphobia and agoraphobia with panic symptoms but no panic disorder, associated with at least "some" impairment in functioning.

** Category includes generalized anxiety disorder. Clinical significance criteria required "a lot" in interference with function.

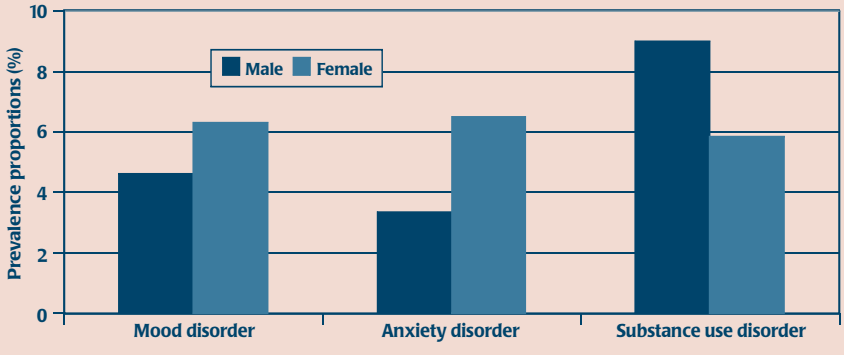
substance-use disorders, a gradient was observed, with 4.3% (95% CI: 3.6-5.0) of married subjects, 8.2% (95% CI: 6.1-10.4) of divorced, widowed or separated subjects and 14.7% (95% CI: 12.4-17.1) of never-married subjects having one of these disorders. The possibility of confounding by age, however, is suggested by Figure 2. The high prevalence of substance-use disorders in never-married subjects could be accounted for by the younger age of these subjects. With married subjects comprising the baseline group, the odds ratio for never-married subjects was 3.9 and for divorced, widowed or separated subjects, it was 2.0. After adjustment for age using logistic regression, both categories continued to have an elevated prevalence of substance-use disorder, but the difference between them disappeared. The age adjusted odds ratio was 2.3 (95% CI: 1.7-3.0) for never-married subjects and 2.4 (95% CI: 1.7-3.4) for divorced, widowed and separated subjects.

The disability and quality of life results were most striking in relation to comorbidity. The WHO DAS II produces a variety of scaled outputs that are consistent with the WHO ICF classification system (www3.who.int/icf/icftemplate.cfm), which is based on a division of body structures, body functions, participation and environment. Figure 3 presents the proportion reporting any problems in the function "understanding and communicating", and a participation scaling, "participation in society". As the number of MINI conditions increased, the proportions reporting no deficits decreased. One output of the EuroQol is an analogue scale of globally perceived health, called the "health thermometer". With increasing comorbidity, these global perceptions of health declined substantially (see Figure 4).

Discussion

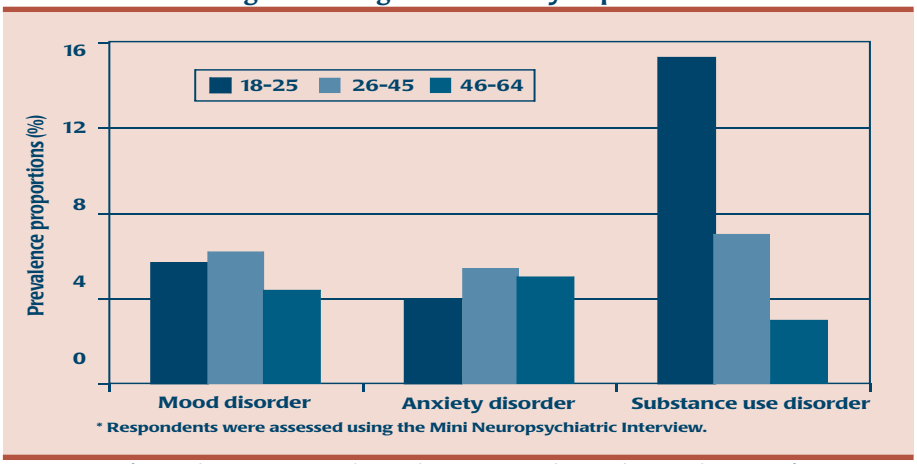
Any attempt to use telephone surveys for mental health surveillance will encounter certain challenges, most prominently involving measurement and subject selection. Within the domain of measurement, one problem is that although several brief instruments have been developed for various mental disorders,[25,35,36] these have rarely been validated in general population samples. A partial exception is the CIDI Short Form, which was developed using data collected during the National Comorbidity Survey.[37] However, concerns have been raised about the validity of this instrument.[38,39] With all of these instruments, the specificities reported by their validation studies raise concern about over-

FIGURE 1
Sex distribution of prevalence proportions (%) of major disorder diagnostic categories* in survey respondents



* Respondents were assessed using the Mini Neuropsychiatric Interview.

FIGURE 2
Age distribution of prevalence proportions (%) of major disorder diagnostic categories* in survey respondents



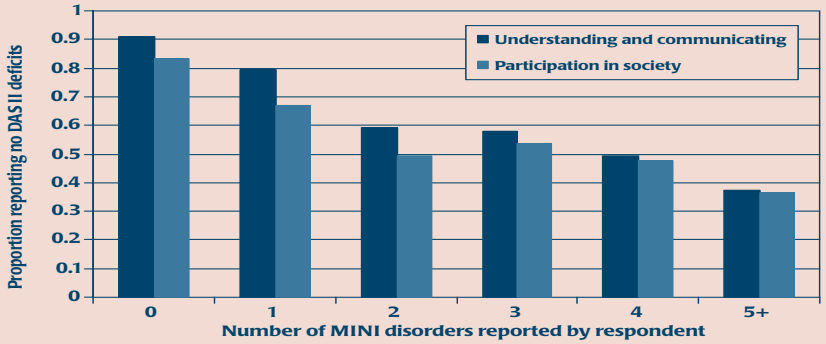
* Respondents were assessed using the Mini Neuropsychiatric Interview.

estimation of prevalence in general population surveys. With the CIDI Short Form for major depression, this has seemed to be the case.[40] There is only one population-based study that used the Patient Health Questionnaire (major depression section) and this found a prevalence proportion of 3.8% for current major depression.[41]

The procedure employed in this study to identify potential false positive diagnostic results was the application of an interference item similar to that used by the Patient Health Questionnaire. Imposing a requirement for higher levels of interference resulted in lower prevalence estimates, many of which were consistent with the existing literature. In the following paragraphs, the estimates deriving from this study are compared to published estimates and reviews in the literature. However, it should be noted that the augmentation of the MINI diagnostic algorithms by the addition of an interference criterion was an *ad hoc* procedure in the sense that it was suspected, but not known, before the data were analyzed that such a procedure would be necessary. As such, it cannot be claimed that the procedure for adjusting the prevalence estimates is replicable. However, the general approach makes sense both in terms of its consistency with the *DSM-IV* approach to diagnosis and the analysis of inconsistencies in survey output reported by Narrow et al.[26]

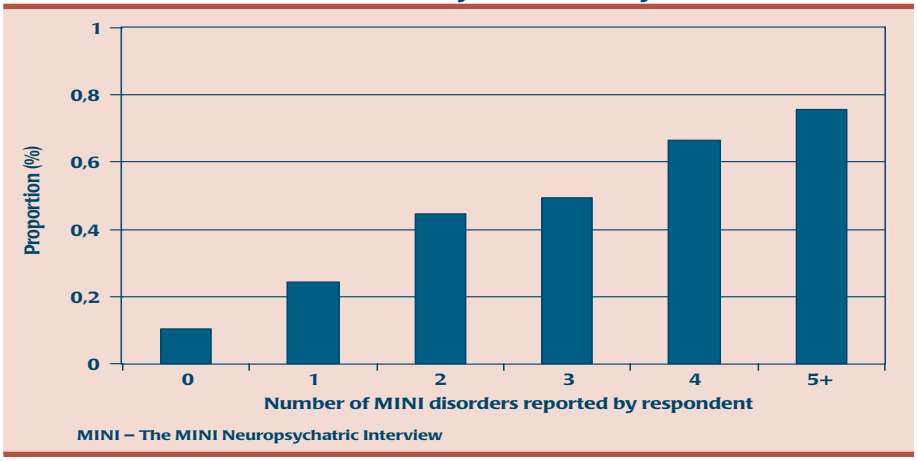
In the case of depressive disorders, a review of prevalence studies by Wittchen et al.[42] reported a median and range of point prevalence proportion estimates from published studies as 3.1% (range: 1.5-4.5), which is consistent with the estimate reported here. The Australian National Mental Health Survey, using ICD-10 criteria, reported a thirty-day prevalence proportion nearly identical to that reported here: 3.3%.[43] A recent systematic review by Waraich et al.[44] arrived at a "best estimate" of annual dysthymia prevalence of 2.0% (95% CI: 1.3-2.8), which is slightly higher but not inconsistent with the 1.2% (95% CI: 0.9-1.5) identified in this study. The Australian National Mental Health Survey reported a 1.1% one-month and 1.3% twelve-month prevalence proportion of ICD-10 dysthymia. Narrow et al.[26] produced revised twelve-month prevalence proportion estimates of 1.6% from two large American epidemiological surveys.[26] The Narrow et al. estimate for the twelve-month prevalence proportion of any substance-use disorder was 6.0% (compared to 7.1% in this survey). Narrow et al. reported that alcohol use disorders (5.2%) were much more common than other substance-use disorders (1.7%), which is the same pattern seen in this study. However, the Canadian Mental Health and Well-being Survey reported a lower (national) twelve-month prevalence proportion of alcohol dependence and drug dependence, 2.6% and 0.7%, respectively.[45] Finally, the overall twelve-month prevalence proportion of alcohol or substance-use disorders observed in this survey resembles a "best estimate" reported in a recent structured review of prevalence studies.[46] A puzzling feature of the substance-use disorder prevalence estimates is that the prevalence proportion of dependence exceeded that of abuse. This probably results from the structure of the MINI, which skips the abuse questions when criteria for dependence are met. A variable prevalence of panic disorder has been reported in previous studies, with the most notable discrepancy being a higher prevalence proportion (3.5%) in the National Comorbidity Survey[28] than in earlier studies. The lifetime prevalence proportion of panic disorder reported here is consistent with international estimates deriving from studies using methods comparable to those of the Epidemiologic Catchment Area studies, 1.5%[47] and the Alberta estimate from the Canadian Mental Health and Well-

FIGURE 3
Proportion of survey respondents reporting no impairment on two WHO DAS II scalings, "Understanding and communicating" and "Participation in society", by MINI comorbidity status



WHO DAS II – World Health Organization's Disability Assessment Schedule
MINI – The MINI Neuropsychiatric Interview

FIGURE 4
Proportion of survey respondents scoring < 70/100 on the EuroQol EQ-5D Health Thermometer, by MINI combidity status



MINI – The MINI Neuropsychatric Interview

being Survey (1.7%),[45] noting that the latter estimate was for twelve-month prevalence. The Narrow et al. revised estimate for the twelve-month prevalence of panic disorder was 1.4%.[26] A review by Kessler and Wittchen [48] placed the twelve-month prevalence of generalized anxiety disorder at three to five percent. Few studies have reported the thirty-day prevalence of social phobia, which is the estimate that the MINI produces, most reporting lifetime or twelve-month period prevalence.[49] For example, the Canadian Mental Health and Well-being survey reported a twelve-month Alberta prevalence proportion of social phobia of 3.1%,[45] which seems consistent with the 2.2% reported here. A point estimate was reported by the Australian National Mental Health Survey, using ICD-10 criteria: 1.4%.[43]

Another set of challenges to the use of telephone survey methods in mental health surveillance involves subject selection. The target population for this study consisted of household residents and can be expected to underrepresent institutionalized and homeless populations. In order to provide comprehensive coverage of the population, parallel sampling strategies, or alternative surveillance procedures for these populations would need to be developed. The National Population Health Survey conducted by Statistics Canada, for example, initiated an institutional survey that runs in parallel to the household residents' survey[50] in order to deal with this issue. Broader concerns related to the validity of random digit dialing as a sampling strategy for mental health surveys cannot be fully addressed by this project. A large proportion of telephone numbers sampled could not be reached and there was an appreciable extent of household non-response. The exact proportions in these various categories could not be determined because the availability of call-screening technology may have resulted in disinterested household refusals not being reached or not answering their phones. If factors related to willingness to participate in the survey, either at the household or residential level, are also related to mental health status, then selection bias may have been introduced.

The approach taken in this project to the evaluation of clinical significance differs from that usually adopted in psychiatric epidemiology. More lengthy structured diagnostic interviews, such as the Composite International Diagnostic Interview (CIDI),[51] typically assess clinical significance at the level of specific syndromes or even symptoms, incorporating probes (very similar to those used in this survey enquiring about help-seeking, medication taking and interference) to evaluate the clinical significance of syndromes or symptoms. However, in the current study, clinical significance probes were administered in an omnibus fashion, enquiring about interference using a single set of items covering all reported syndromes and symptoms. This allowed the interview to be quite brief (the total interview took, on average, approximately 20 minutes, which is considered a reasonable limit for maintenance of response rates in telephone surveys), yet preserved the ability to evaluate probable clinical significance of the syndromes identified. This approach, however, does not allow confirmation of clinical significance for each disorder separately when comorbid disorders are present.

A survey of this size requires the investment of considerable resources. However, the use of telephone survey methods kept total costs down to approximately $40 per subject. This total cost included not only direct interviewing costs, but also associated infrastructural and start-up costs. Geographical sampling procedures, even those involving sampling clusters in multiple stages, would have been considerably more expensive. On the other hand, the increasing use of call-screening and voice messaging may lead to higher costs for telephone surveys in the future by requiring more frequent follow-up calls to identify and interview selected households and subjects. These same factors may lead, in the future, to unacceptably low response rates or bias. The use of telephone survey methods, as opposed to the "face to face" interviewing that is generally employed in epidemiological surveys, may make it more feasible to repeat surveys of this type periodically, an essential element of surveillance.

Periodic monitoring of mental health across time in the same population could provide a useful set of population mental health indicators. This would enhance the capacity of decision makers to attach measurable goals to their policy decisions and to better target services towards recognizable needs within the population. However, it cannot be convincingly argued that telephone surveys are the preferred method for accomplishing these goals. The lack of regional differences found in this study might suggest that provincial (or, by extension, even national) samples may be sufficient to achieve the surveillance goals identified by the stakeholders. With the various unresolved measurement issues, future work will need to explore procedures for gaining valid estimates with brief measures. The challenges involved

should not be underestimated since the extent of agreement even between more lengthy structured interviews and clinical interviews is not generally impressive.[52–54] Furthermore, if a suite of brief, valid measures can be identified, it may increase the scope of what can be feasibly accomplished by large national efforts such as the CCHS. Similarly, the challenges associated with telephone sampling are likely to intensify with advancing technology and heightened concerns about privacy. Despite these uncertainties, as Canada's national approach to chronic disease surveillance is taking shape, it seems reasonable that telephone survey methods should remain "on the table" as potential contributors to mental health surveillance.

Acknowledgements

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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]

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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.

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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

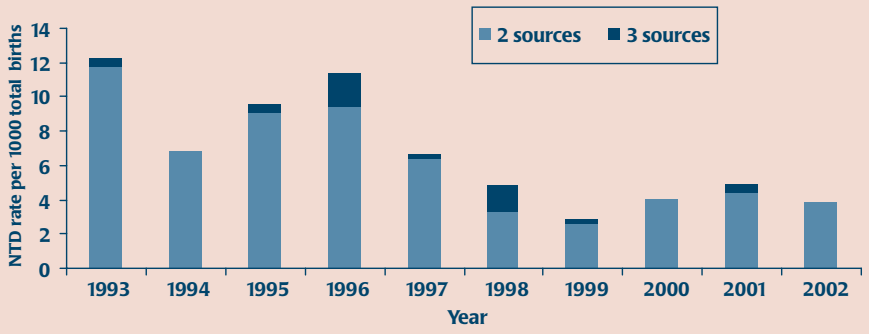
Of the 173 NTD cases ascertained in this study, 136 were diagnosed prenatally (78.6%). The primary diagnosis was made after an ultrasound examination in 92 cases and after an amniocentesis in the other three. No information was available for the remaining 41 cases. The percentage of cases with a prenatal 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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Epidemiology of hepatocellular carcinoma in Canada, 1995: Analysis of death certificates

Susie ElSaadany and Antonio Giulivi

Abstract

A descriptive analysis of hepatocellular carcinoma (HCC) deaths in Canada for 1995 was undertaken. Cases (ICD-9 155.0) were identified from the Statistics Canada annual mortality file; age-adjusted death rates by age, sex and province were calculated. Antecedent causes and conditions leading to death listed on the death certificate, including viral hepatitis infection and cirrhosis, were examined, in addition to birthplace information. The 403 cases identified resulted in an annual age-standardized mortality rate of 2.11 deaths per 100,000 persons among men and 0.64 deaths per 100,000 persons among women. Mean age at death was 65.5 years with male-to-female ratio approximately 3:1. Compared to the age-standardized rate for birthplace of Canada of 0.96 per 100,000 (95% CI: 0.84, 1.10), the age-standardized mortality rates were significantly elevated for birthplace of Europe 1.72 (95% CI: 1.37, 2.28), Asia 5.17 (95% CI: 4.11, 6.44), and non-significantly elevated for all other countries 1.54 (95% CI: 0.94, 2.39). In total, 60 patients (15 %) were reported to have had viral hepatitis; sufficient information was not provided for the remainder. Of the total population, 8.7 % were reported to have had viral hepatitis B and 5.2 % had viral hepatitis C. Information on cirrhosis was provided in 103 (26 %) of cases. Of these, the largest proportion (45 %) was of unknown type while 23 patients (22 %) had alcohol-related cirrhosis. Prevalence of antecedent causes was slightly lower than reported previously and may be considered minimum estimates since inadequate information was provided in over 50% of deaths.

Key words: *death certificates, hepatitis B, hepatitis C, hepatocellular carcinoma, liver cirrhosis*

Introduction

Hepatocellular carcinoma (HCC) is a common malignancy worldwide. It ranks as the fifth most common cancer, accounting for five to six percent of all newly diagnosed cancers in both sexes.[1] The global incidence of HCC varies substantially between geographical regions, ethnic groups, and men and women.[2] International variation is noteworthy because of the low incidence in North America, northern Europe, Latin America and India, and the high incidence in East and Southeast Asia and sub-Saharan Africa. Intermediate rates are reported in regions adjacent to the high-risk areas and in southern Europe.[1] Independent of race and geography, rates for men are at about three times those for women. Estimated Canadian incidence rates for liver cancer using a world standard population were reported in the database Globocan 2002 by the International Agency for Research on Cancer (IARC) as 4.0 per 100,000 among men and 1.4 per 100,000 among women. For men and women, corresponding rates in Eastern Asia were 36.9 and 13.4 and 27.8 and 13.4 in middle Africa, repectively.[3] For the period 1992–2001, the average annual percent change of HCC incidence rates in Canada was 3.7% among men and 1.8% among women.[4]

Chronic hepatitis B virus (HBV) infection is by far the most important risk factor for HCC in humans. It is estimated that 80% of HCC worldwide is etiologically associated with HBV.[2] In developed countries, the prevalence of hepatitis C virus (HCV) infection correlates with HCC incidence and mortality rates.[5] Dietary aflatoxin exposure, excessive alcohol intake, cigarette smoking, oral contraceptive use in women, androgen use in men and primary hemochromatosis disease also are risk factors for HCC, but they play a relatively minor role in the development of the disease.[6]

Since standard vital statistics data specify only the underlying cause of death and do not provide information on HBV infection or other antecedent causes or risk factors, such as place of birth, an epidemiologic analysis of HCC in Canada was conducted using additional death registration information. The listed antecedent causes and conditions contributing to death from the medical certificate of death were examined at Statistics Canada in order to identify known HCC antecedent causes, such as type of cirrhosis, alcoholism and viral hepatitis infection.

Methods

The year 1995 was chosen for this analysis as this was the last year of data available at the time of the data capture of the underlying and contributing causes of death reported on the death certificate. This additional information is not available on the regular Canadian annual mortality file. For deaths where ICD-9 Code 155.0 was coded

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as the underlying cause of death,[7] information from the death registration not routinely available was manually extracted at Statistics Canada and the data entered into a SAS dataset. Antecedent causes of death and other significant conditions leading to death listed on the death certificate were reviewed for mention of viral hepatitis and cirrhosis. Age-standardized mortality rates were calculated per 100,000 persons using the direct method with five-year age groups and the 1991 Canadian population as the standard.[8] Age of the deceased, sex, birth country/province and autopsy indication were collected. The birth country category was created by classifying the birth country and city information from the death registration into one of four categories: Canada, Europe, Asia and other. Populations by birth country among Canadians were obtained from the 1996 census.[9]

There was some concern that contributing causes not reported on the death certificate may not necessarily mean the person did not have the disease. For purposes of comparison with the mortality results, inpatient hospital morbidity records with HCC as the tabulating diagnosis for fiscal 1995–1996 and 2002–2003 were extracted from data provided by the Canadian Institute of Health Information and comorbidity examined (other causes listed on the discharge abstract). For morbidity when only ICD-9 coding was available, non-A non-B hepatitis was used as a surrogate for hepatitis C and the percentage compared to provinces in 2002–2003 which used ICD-10, for which a specific hepatitis C code was available. Chi-square tests for contingency tables using exact conditional inference were obtained with the EXACT statement of the SAS procedure FREQ.[10]

Results

In 1995, 403 deaths were reported in Canada with HCC coded as the underlying cause. The annual age-standardized mortality rates were 2.11 deaths per 100,000 persons among men and 0.64 deaths per 100,000 persons among women. The male-to-female death ratio is approximately 3:1. The mean age at death was 65.5 years (median age 68 years). Approximately 90% of the deaths were in persons 50 years of age and older (Table 1). The ASMR was found to be the highest in the 70–79 age group. The country of birth distribution indicated that most of the deceased cases were born in Canada (51.9%), Europe (20.8 %), and Asia (20.8%) while other and missing birthplaces accounted for 6.5%of HCC deaths (Table 1). Compared to the age-standardized rate for Canadian birthplace of 0.96 per 100,000 (95% CI: 0.84, 1.10), the age-standardized mortality rates were significantly elevated for European birthplace (1.72; 95% CI: 1.37, 2.28), Asia (5.17; 95% CI: 4.11, 6.44), and non-significantly elevated for all other countries (1.54; 95% CI: 0.94, 2.39).

TABLE 1
Hepatocelluar carcinoma deaths in Canada and age-standardized rate* per 100,000 by sex, age group, province of residence and country of birth (1995)

Characteristics		Number of deaths	Age-standardized rate	(95% CI)
Sex	Male	294	2.11	(1.88, 2.37)
	Female	109	0.64	(0.53, 0.77)
Males				
Age group (years)	0-39	8	0.09	(0.04, 0.18)
	40-49	28	1.28	(0.87, 1.83)
	50-59	50	3.55	(2.66, 4.65)
	60-69	96	8.61	(7.01, 10.5)
	70-79	88	12.6	(10.2, 15.5)
	80+	24	8.84	(5.77, 13.0)
Females				
Age group (years)	0-39	4	0.05	(0.01, 0.11)
	40-49	5	0.22	(0.08, 0.51)
	50-59	13	0.92	(0.51, 1.54)
	60-69	30	2.50	(1.72, 3.53)
	70-79	36	3.89	(2.76, 5.33)
	80+	21	4.01	(2.54, 6.04)
Province of residence	NF & Labrador	2	0.43	
	PEI	0	0.0	
	NS	8	0.84	(0.38, 1.62)
	NB	4	0.54	(0.16, 1.38)
	QC	115	1.61	(1.33, 1.93)
	ON	175	1.58	(1.35, 1.83)
	MB	14	1.13	(0.63, 1.87)
	SK	10	0.82	(0.41, 1.49)
	AB	33	1.39	(0.97, 1.94)
	BC	42	1.07	(0.78, 1.44)
	YK	0	0.0	
	NWT & Nunavat	0	0.0	
Country of birth	Canada	209 (51.9%)	0.96	(0.84, 1.10)
	Europe	84 (20.8%)	1.72	(1.37, 2.28)
	Asia	84 (20.8%)	5.17	(4.11, 6.44)
	Other	19 (4.7%)	1.54	(0.94, 2.39)
	Missing	7 (1.7%)		–
Total		403		

* Standard population used is 1991 Canadian population for men and women combined

An autopsy was reported in 9% of the HCC cases (results not shown). Based on province of residence, this ranged from zero to a maximum of 30% in Saskatchewan (three out of ten deaths). The percentage of cases in which the autopsy information was used in assigning the cause of death was not available in the Statistics Canada database for 1995 or earlier years, pending a system redesign.

For the HCC patients, Table 2 indicates whether, from the listed cause-of-death fields reported in the medical death certificate, hepatitis was identified as present. A total of 60 cases (15%) were reported to have had hepatitis. The largest percentages of deaths reported to have had hepatitis were found in the 40–69 age groups for both males and females. The null hypothesis of a uniform proportion among all age-sex-specific categories was rejected ($p = 0.002$). The highest proportion reported with viral hepatitis were hepatitis B cases (8.7% of total), followed by those reported to have had hepatitis C (5.2%). Less than two percent of total cases were reported to have had hepatitis of unknown type. Less than one percent of total cases were reported to have had both hepatitis B and C and these cases are included in the marginal totals for hepatitis B and C above.

For comparison, hospital admissions were used as a second source of information. Age-standardized admission rates for HCC with non-A non-B hepatitis reported as comorbidity had increased from 0.19 per 100,000 to 0.43 from 1995 to 2002, a larger increase than for hepatitis B or alcoholic cirrhosis. The percentage of cases reported to have had non-A non-B hepatitis increased from 5.5 in fiscal year 1995–96 to 15.1 in 2002–03. Provinces using ICD-10 in 2002–03 reported a similar percentage: 15.0 for hepatitis C specifically. Over the same period, the percentage of admissions reported to have had hepatitis B increased only from 8.7 to 11.3.

Cirrhosis was reported in the cause of death fields for 103 (26%) of the total number of cases (Table 3). Of these, alcohol consumption was reported in 23 deaths (22% or 5.7% of total deaths), followed by hepatitis in 14 cases (14%). Twenty cases (19%) of cirrhosis were reported due to other factors, while for 46 deaths (45%) the causes of cirrhosis were not stated. The hypothesis of a type-of-cirrhosis uniform distribution among men and women with the disease was not rejected ($p = 0.11$). When using hospital morbidity data, over the period 1995 to 2002, the percentages of HCC admissions reported to have had alcoholic cirrhosis were relatively constant at 11.2 and 12.6, respectively.

Discussion

This study is unique in its extraction of listed contributing causes of death from death registrations for the purpose of gathering additional, more complete information not reported in the Vital Statistics database. Rates of HCC mortality in Canada for 1995 were consistent with the findings of previous studies. Rates were higher for men than women and an increased risk was observed for immigrants from Europe and especially from Asia, compared to persons born in Canada. These results are consistent with higher incidence rates observed in these areas.[3]

A concern with an analysis based on death certificates is that absence of an antecedent cause may not ensure the absence of disease, resulting in an underestimation of prevalence or minimum estimates. Studies on completeness of death certificates in this regard were not available. The percentage of deaths reported to have had hepatitis among men and women were similar, although the information was not provided for 85% of deaths. Nevertheless, the figure of five percent of 1995 death certificates indicating the presence of hepatitis C was similar to the percentage of hepatitis C comorbidity available from hospitalization data. This comorbidity percentage had increased to about 15% in the fiscal year 2002–2003. An examination of temporal trends in electronic records from 172 United States Veterans Administration hospitals reported that the percentage of the overall rate associated with HCV increased from 7.5 to 18.3 between 1993–1995 and 1996–1998.[11] The increase in rates of HCC associated with HCV was greater than those associated with HBV or alcohol-induced cirrhosis. On the other hand, the frequency of HCV seropositivity in seven other studies in the United States, including 1,429 persons with HCC, was reported to be higher at 27%.[11]

An indication of cirrhosis was provided in only 26% of all HCC cases. Reporting on the type of cirrhosis was also incomplete. In our study, a large proportion (45%) of records had cirrhosis listed on the medical death certificate but without further specification, making it difficult to accurately identify the antecedent or co-existent causes as stages in the disease process. The percentage of deaths reported to have indicated alcoholic cirrhosis on the death certificates (six percent) was lower than

TABLE 2
Hepatitis status of hepatocellular carcinoma deaths in Canada*, by sex and age group (1995)

	Age group	Number and percentages of reported cases of hepatitis	Total
Male			
Age group (years)	0-39	4 (50.0%)	8
	40-69	35 (20.1%)	174
	70+	8 (7.1%)	112
Female			
Age group (years)	0-39	0 (0.0)	4
	40-69	9 (18.8%)	48
	70+	4 (7.0%)	57
Total		60 (14.9%)	403

* Obtained from medical records of death

Pearson chi-square test for uniform proportions with 5 df = 20.9, p=0.002 (exact test)

TABLE 3
Cirrhosis status of hepatocellular carcinoma deaths in Canada*, by sex (1995)

Sex	Type of cirrhosis (% of total)				
	Alcohol	Hepatitis	Other	Not stated	Total
Male	22 (24.2)	10 (11.0)	16 (17.6)	43 (47.3)	91
Female	1 (8.3)	4 (33.3)	4 (33.3)	3 (25.0)	12
Total	23 (22.3)	14 (13.6)	20 (19.4)	46 (44.7)	103

* Obtained from medical records of death

Pearson chi-square test for independence 3 df = 5.85 p=0.11 (exact test)

the 11% reported from the Canadian hospital comorbidity data and the 28% from the United States Veterans Administration hospitals.

An examination of medical records and hospital admission records would enhance the ability to accurately identify the type of cirrhosis as well as confirm the absence of these antecedent or co-existent causes when not present on death certificates. Alcoholic cirrhosis for example, has been found to be underestimated using cause-of-death information from medical death certificates when compared to autopsy and coroner reports.[5]

As in many other studies, the use of ICD-9 code 155.0 denoting primary liver cancer was used as a surrogate for HCC. Medical certificates of death in the current study were selected solely based on the ICD-9 code of 155.0 being reported as the underlying cause of death. A particular concern with this method may include the possibility of cases of metastatic liver cancer, or other rare types of primary liver cancer, being reported as HCC.[12,13]

The causes of death reported in the medical certificate of death may not always be accurate. The two main reasons given for inaccurate cause-of-death data are erroneous clinical diagnoses and incorrect entering of a diagnosis.[14–16] Our review of listed contributing cause-of-death data did not have access to clinical or complete autopsy information. The present study shows the need and importance for physicians to complete death certificates as fully and accurately as possible since valuable epidemiologic information may be derived from this source and future health care decisions may be made based on such studies.

The three main risk factors associated with HCC in Canada are infection with HCV, with HBV and alcoholic cirrhosis.[17,18] Many epidemiological studies have concluded that chronic infection with either HBV and HCV is a major risk factor for HCC. Our study showed that HBV infection was reported on nine percent of the HCC death certificates, while five percent of deaths were reported to have had HCV. This trend is expected to increase over the next two decades due to the chronic nature of HBV and HCV infections. It has been suggested that approximately 240,000 Canadians are infected with HCV.[19] Major risk factors, such as intravenous drug use, needle sharing, transfusion of unscreened blood and blood products and unsafe sexual practices in the 1960s and 1970s, have been associated with the transmission of HBV and HCV infections. The long latency period between HBV and HCV infection and cancer, combined with a large pool of persons to be chronically infected with hepatitis C, may account for some of the HCC cases.[20,21] Progression of cirrhosis after infection with Hepatitis C infection can take 20 years on average. Once cirrhosis is established, HCC occurs at an annual rate of one to four percent.[22]

Consumption of alcohol, especially at high levels and over prolonged periods, increases the risk of HCC. In Canada, a decline in alcohol consumption has been observed amongst persons age 14 and over.[23] Similar observations have been cited in Australia and the US.[5,12,13] Furthermore, there has been a pronounced decrease in alcoholic cirrhosis mortality in Canada in the past decade. In this study, medical certificates of death identified very few cases where cirrhosis due to alcohol consumption was specified as an underlying cause of death. Alcohol-related cirrhosis is, nevertheless, considered a major risk factor where the incidence of chronic viral hepatitis is low.[6]

It is expected that the incidence and mortality of heptacellular carcinoma will increase in Canada and other Western countries over the next several years. The evidence suggests that persons infected with HBV and HCV will represent a greater proportion of cirrhosis, leading to HCC. Prevention strategies, such as hepatitis B vaccination, hepatitis C awareness campaigns and anti-alcoholism programs, would be expected to reduce the incidence of HCC.

While most current studies suffer from obstacles (e.g., small size, limited follow-up or selection bias) that create controversy around the opinion that treatment of both hepatitis B and C may reduce the incidence of HCC, it is likely that prevention or elimination of hepatitis C infection will prevent HCC particularly if patients are treated before the onset of cirrhosis. It is possible that treatment will delay the progression to HCC, but the extent of the delay is unknown (Personal communication via e-mail. Dr. Morris Sherman. Associate Professor of Medicine, University of Toronto. November 11, 2002). This is less certain for hepatitis B, as permanent eradication of the virus does not occur, and the permanency of viral suppression is unclear.

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Building connections for young adults with type 1 diabetes mellitus in Manitoba: Feasibility and acceptability of a transition initiative

Norma Van Walleghem, Catherine A MacDonald and Heather J Dean

Abstract

During the transition from pediatric to adult diabetes care there is often a high rate of medical dropout and increased rates of acute and chronic complications. Building Connections: The Maestro Project was initiated in September 2002 by the Diabetes Education Resource for Children and Adolescents and the City of Winnipeg Regional Health Authority in Manitoba, Canada to examine the feasibility and acceptability of an administrative support and systems navigation service for young adults with type 1 diabetes. The participation rate on February 28, 2005 was 78.9% (373/473). Of the 323 young adult participants 18 to 30 years of age, 127 requested 230 community contacts for access care and education. Specifically, 46 re-referrals were made for specialty care (adult endocrinologists or general internists), 34 contact numbers were given for family physician care, and there were 121 contacts to reconnect with diabetes education and counseling services and 29 contacts for an optometrist. The first 2½ years of the project have demonstrated the feasibility and acceptability of this model of service for young adults with type 1 diabetes as they move from pediatric to adult care.

Key words: *adolescents, transition, type 1 diabetes, young adults*

Introduction

The transition from pediatric to adult health care is a period of increased vulnerability for young adults (YA) with chronic disease and one that presents unique challenges for them, their parents and the health care providers who serve them. While many YA with type 1 diabetes are successful in establishing support and ongoing follow-up after transfer, up to 50% of youth in this population have reported difficulties with transition.[1] Manitoba data confirms reports from other Canadian centers that 25% to 35% of YA are lost to medical follow-up within three years of transfer from pediatric clinics.[2–7]

The rate of acute complications, such as diabetic ketoacidosis (DKA) with excess morbidity and mortality, is high in this group and non-adherence to diabetes care can lead to severe chronic complications before individuals reach the maturity of their late 20s.[8] Despite intensive educational and management treatments, many are not successfully achieving optimal diabetes self care and face "worse than expected" long-term clinical and psychological outcomes.[9–11] Preconception counseling for young women with type 1 diabetes during this period is essential to achieving adequate glycemic control before and during pregnancy to prevent congenital anomalies.

In Canada from 1997–2000, there were 134 deaths in persons with diabetes age 20 to 29 years, a death rate more than three times higher than that of 20 to 29 year olds without diabetes.[12] A recent database study by Roberts[13] confirmed this increased risk of death at a young age. YA with type 1 diabetes under 30 years of age admitted to hospital had a nine times greater risk than the general population of dying in the subsequent three years, not only from natural causes, but from suicide. DKA is the single most common cause of mortality in people with type 1 diabetes under the age of 40, according to a British Diabetic Association cohort study.[14] It is important to note that, after diagnosis, DKA is 100 percent preventable. Deliberate insulin omission is the most common precipitating factor of DKA. Insulin omission may result from depression, which is two to three times more prevalent in people with diabetes, either due to abuse or neglect of the individual or in those going through teen rebellion. Omission may also result from "diabetes burnout", needle phobia or fears of weight gain/eating disorder.[15]

Arranging effective transfer to adult medical services is now a necessary part of caring for all youth with chronic disease. This transfer may be difficult not only because of the chaotic and uncertain life stage, but also because of the fundamental differences in service delivery and in the philosophies of various allied health professionals, and the sometimes difficult integration between them. Studies have recently been published that used non-medical case management to encourage routine diabetes care visits, provide information and emotional support, monitor adherence and foster problem-solving skills in patients with type 1 diabetes without offering medical advice.[16,17] Case managers were college graduates with no formal medical education, trained by the research and medical staff. In each study, the authors concluded that use of non-medical case management was a cost-effective approach to improving outcomes in their patients. This may

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prove to be an important model to provide seamless transition from pediatric to adult diabetes care, especially in places where no specialized clinic for YA with type 1 diabetes exists.

One of the goals of the 1998 Manitoba Diabetes Strategy was to develop a specialized, dedicated program for YA (age 18 to 25 years) with type 1 diabetes to assist in transition from pediatric to adult care.[18] Until this goal could be attained, the Diabetes Education Resource for Children and Adolescents (DER-CA) and the City of Winnipeg Regional Health Authority's Young Adult Diabetes Working Group initiated and piloted a novel model of surveillance in September 2002 to facilitate transition for this vulnerable population. The program is called Building Connections: The Maestro Project. The objective of the program is to increase the rate of medical follow-up and education of YA with type 1 diabetes in the provinces of Manitoba, northwestern Ontario and southeastern Saskatchewan, and thus reduce their morbidity and mortality from complications of diabetes. The purpose of this article is to examine the feasibility and acceptability of this administratively based transitional support and systems navigation service for young adults 18 to 30 years of age with type 1 diabetes.

Diabetes care for children, adolescents and young adults in Manitoba

In Manitoba, 95% of youth with type 1 diabetes 0 to 18 years of age are followed at the DER-CA in a centralized program at Children's Hospital.[19,20] The DER-CA team consists of three pediatric endocrinologists, one clinical associate, two clinical nurse specialists, two dietitians and a social worker, all certified diabetes educators. The team sees a youth three to four times annually and uses a case manager system to ensure coordinated care. A formal transition program is initiated for all youth at 13 years of age and continued until transfer to adult care at age 18 years. Transition topics include smoking, drugs, alcohol, driving, sexuality, contraception and preconception counseling and surveillance, as well as education on the potential long-term complications of diabetes and options available for adult care. The DER-CA has a transition checklist and a resource booklet that is used in all stages of preparing for transition; these are given to the YA during their last visit to the center.

Presently, there is no centralized, coordinated, integrated program of care, nor education and support for individuals with type 1 diabetes in the adult care system in Manitoba. Approximately 80 youths are transferred annually to various adult medical clinics and education centers in Winnipeg and rural Manitoba. There are nine adult endocrinologists practicing in Winnipeg and a number of diabetes education teams across the province with varying levels of expertise in the care of YA with type 1 diabetes. Each regional health authority has a regional diabetes program, although their mandate is primarily complications risk factor assessment and prevention of type 2 diabetes, particularly targeting older adults and people of First Nations heritage.[21]

Description of the transition program

The Maestro Project maintains a database of YA 16 to 30 years of age with type 1 diabetes in Manitoba, northwestern Ontario and southeastern Saskatchewan. The project provides a centralized, coordinated, community-based navigation service for the care, education and support of diabetes in Manitoba. The "Maestro", an administrative project coordinator, maintains telephone and e-mail contact with YA to provide the support and to help identify barriers to accessing appropriate health care services. The Maestro works closely with community-based resource centers in both Winnipeg and the regional health authorities involved in diabetes education to facilitate follow-up and referrals and enhance community linkages for service. Introductory letters were sent to all adult endocrinologists and diabetes education centers to promote the project and explain the referral process.

The Maestro Project initiated several alternate methods of service delivery for YA. These include a comprehensive Web site (www.maestroproject.com), a bimonthly newsletter archived regularly on the project Web site, a casual evening drop-in group every four to six weeks and evening group educational dinner events. These events are designed to encourage socialization with peers, to introduce and facilitate relationships with community diabetes educators, endocrinologists, researchers and other service providers. The events are an opportunity for YA to ask questions and receive expert information on diabetes management, pregnancy, research, new technologies and other relevant topics in a relaxed, non-threatening, non-medical environment.

Method

Graduates of the DER-CA prior to the creation of the Maestro Project (i.e., from 1995 to August 31, 2002) with birth years between 1977 and 1984 were contacted by telephone and letter, inviting them to participate. Those graduating from the DER-CA after September 1, 2002 were referred with verbal consent to the Maestro Project at transfer to adult care. In August 2004, adolescents 16 to 18 years of age attending the DER-CA were given the option of early referral to the Maestro Project whereby they could receive the newsletters, take part in events and activities, and become familiar with the Maestro program. Referrals were also received directly from community physicians, diabetes educators and health workers. There were also self-referrals from YA diagnosed after age 18 years.

The Maestro contacted each participant biannually to inquire about the participant's access to care and diabetes services, as well as health status associated with any diabetes complications. During the first contact, the Maestro recorded baseline demographic information and recorded the following variables: date of last visit to physician; type of physician seen for diabetes care; number of visits to diabetes physician, other physicians, diabetes educators, psychologists, social workers or mental health workers, public health nurses or optometrists, and; date of last dilated eye exam or retinal photography. All information was self-report by participant and was related specifically to

the diabetes care and education received in the previous 12-month period prior to baseline assessment. If there had been no contact with any health professional in the previous 12-month period, the Maestro offered to reactivate and facilitate a referral to an adult endocrinologist and diabetes education center. During each subsequent follow-up contact, the Maestro repeated the same questions to record the number of medical and/or educational visits since the previous contact.

The Maestro also recorded the following self-reported medical outcomes at the time of initial assessment and during subsequent follow-up contacts: 1) number of pregnancies lasting longer than 12 weeks, 2) number of live births, 3) number of cardiovascular events (myocardial infarction or stroke), 4) number of limb amputations, 5) incidence of end stage renal disease requiring dialysis or kidney transplantation, 6) legal blindness, and 7) death. These self-reported medical outcomes will be used to describe the frequency of chronic complications in participants over time. These medical outcomes will be reported in future manuscripts, along with the outcome data on access to services in the community.

During every initial and follow-up contact, the Maestro also asked the following questions: "Is there anything else that I can help you with?" and "Do you have any questions for me?" The Maestro then recorded these anecdotes in the notes section of the database for diabetes-related concerns, problems and stories that were disclosed by participants. Anecdotes will be analyzed in 2006 by qualitative analysis for content and related themes and will be used to illustrate the perceived barriers to accessing medical care and education in the adult health care system for participants.

Results

Five hundred and twenty-six adolescents and YA were registered in the Maestro Project in the 30 months between September 1, 2002 and February 28, 2005. The Maestro excluded 53 YA who had died, moved out of province, had had resolution of secondary diabetes or for whom contact information was unavailable (Figure 1). Thus, there was a total of 473 (i.e., 526 less 53) potential participants. Ninety-four YA were not responsive despite repeated efforts to contact by letter, telephone or e-mail (Group 2A & 2B). There were six other YA who declined participation (Group 2C). Thus, on February 28, 2005, the participation rate was 373/473 or 78.9%. Fifty of the 373 participants were age 16 to 18 years and were still followed at the DER-CA (Group 3A). The remainder of the activities of the project described in this report excludes this adolescent group. Forty-one of the remaining participants were aged 26 to 30 years (group 3C) and the descriptive activities of this group are included in the following results.

Of 323 participating YA age 18 to 30 years, 204 lived in the Winnipeg area and 108 lived in rural Manitoba. Eleven were from neighboring communities in northwestern Ontario and southeastern Saskatchewan, and were seasonally employed or were attending school in other provinces, but continued to receive their diabetes care and follow-up primarily in Winnipeg.

Of 323 participating YA age 18 to 30 years, 167 were graduates of the DER-CA before August 2002, 106 were referred directly to the project after September 2002 at graduation from the DER-CA, 30 were referred by community health professionals and 20 were self-referred.

TABLE 1
Project referrals and community connections made within the Maestro Project from September 1, 2002 to February 28, 2005 Number of unique young adults = 127.

Number of referrals & community contacts	Total
To an endocrinologist	46
To a general practitioner	34
To a diabetes education centre	83
To a registered nurse	33
To a registered dietitian	1
To a social worker	4
To an optometrist	29
Total	230

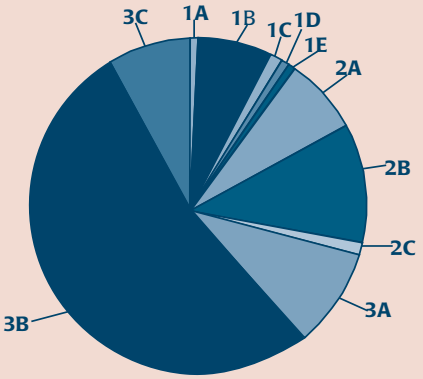
As seen in Table 1, of the 323 participants 18 to 30 years of age, 127 requested 230 community contacts for assistance to access care, education or optometry services. From September 1, 2002 thru February 28, 2005, 46 re-referrals were made for specialty care (adult endocrinologists or general internists) and 34 contact numbers were given for family physician care. Contact numbers were given out to 121 participants to reconnect with diabetes education and counseling services and 29 for optometrists. In addition to these direct community linkages, 111 partici-

FIGURE 1
Participation of young adults (YA) with type 1 diabetes in Maestro Project on February 28, 2005. N = 526

YA excluded, N = 53
- 1A: Deceased, N = 5
- 1B: Moved, N = 34
- 1C: No contact information, N = 6
- 1D: Transient secondary diabetes, N = 4
- 1E: Follow-up outside MB, N = 4

YA not responsive, N = 100
- 2A: >25 years of age, N = 36
- 2B: 18-25 years of age, N = 58
- 2C: Declined, N = 6

YA participating, N = 373
- 3A: 16-18 years of age, N = 50
- 3B: 18-25 years of age, N = 282
- 3C: 26-30 years of age, N = 41



pants contacted the Maestro 203 times for other related information. Approximately 50 percent of the contacts occurred in the first nine months of the program.

Discussion

The passage from childhood to adult life is a very challenging time for young people and their families. Youth with chronic health conditions face two simultaneous transitions: a developmental transition (from childhood to adolescence to adulthood) and a situational transition (from pediatric to adult health care). They may also have a third transition—from relative health to sickness—depending on the progression of their illness.[22] Efforts need to be made to ensure that YA and their families are well supported during this transition, thus building a strong foundation for their adult life. Strategies are also necessary to reduce the high rates of mortality and morbidity from preventable causes in this age group.

The concept of a "navigator" has been described in the literature.[23,24] Different models exist, although common functions include assisting patients with accessing and coordinating services, providing emotional support and assisting with advocacy. The Maestro project is a unique program designed to lend this support and help YA and families navigate through the complex adult health care system. From the literature, it is clear that more research is needed to describe and evaluate the efficacy of different models of transition, such as this initiative. The first 2½ years of the Maestro Project have demonstrated the feasibility and acceptability of an administrative systems navigation service for YA with type 1 diabetes in Manitoba. The next phase is formal evaluation of the impact of this model on surveillance and medical outcomes.

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