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Personal factors influencing agreement between expert and self-reported assessments of an occupational exposure

Heather K Neilson, Andrea Sass-Kortsak, WY Wendy Lou and James T Purdham

Abstract

This study aimed to identify personal factors associated with expert and respondent agreement on past occupational exposure. Epidemiologic data was collected from 1995 to 1998 in a community-based, case-control study of prostate cancer. Using longest jobs and excluding agreement on “never” exposure, self-reported and expert estimates of ever/never exposure, by skin or ingestion, to polycyclic aromatic hydrocarbons were compared. Agreement between respondents and the expert was 53.9% (N = 1,038), with overreporting being more common than underreporting relative to the expert (31.8% versus 14.4%). In multiple logistic regression models, white-collar occupational status was significantly associated with overreporting (odds ratio [OR] = 0.142; 95% confidence interval [CI]: 0.095-0.211; blue-collar versus white-collar), while age was associated with underreporting (OR = 1.077; 95% CI: 1.043-1.112; one-year increase). Neither job satisfaction nor risk perception appeared to confound other associations. In future studies, overreporting by white-collar workers might be avoided by providing clearer definitions of exposure, whereas elderly respondents may require aids to enhance exposure recall.

Key words: epidemiologic measurement, expert opinion, logistic models, occupational exposure, questionnaires, retrospective studies

Introduction

Choosing the best method of occupational exposure assessment when designing community-based, case-control studies of chronic disease etiology is a significant challenge faced by epidemiologists. Although “expert” assessment of exposure has been regarded as a more valid¹⁻³ and reliable⁴ approach than others, it has not always been used in the past and may not be feasible, given financial constraints.⁵ Additionally, the quality of this practice can vary in community-based settings⁶ in which “experts” is often subjectively defined.

Self-reporting of exposure is a logical alternative to expert assessment. While

this method continues to be used on its own,⁷⁻¹⁰ it has also been used by experts¹¹ and with job exposure matrices¹² to help estimate exposure. In retrospective research, self-report data can be obtained in a consistent manner across industries, unlike occupational hygiene measurements, which may not exist or may vary in quality, the latter depending on when and why the measurements were taken.^{13,14} In contrast to the use of job titles or job exposure matrices, self-reporting provides individual estimates of exposure. Despite these advantages, however, reports have described only fair-to-substantial repeatability of self-reported exposures^{15,16} and wide-ranging values for inter-method reliability,¹⁷⁻²⁰ with workers in one study recalling only 2.6% of the exposures reported by an expert.²⁰

If the factors that influence valid and reliable self-reporting of exposure can be better understood, so can the research that was based on self-reports. Also, in future studies, the validity of risk estimates derived from self-reports might be improved through adjustments in questionnaire design and better-informed decision making in data analysis.

Attempts to identify influential factors have been made.^{15,17,18,20-23} However, some studies may not have controlled adequately for confounding^{15,17,24} or may have failed to discriminate between under- and overreporting of exposure^{15,21,22} when there may be different factors involved in each case. While logic suggests that attitudes, such as risk perceptions and job satisfaction, may lead to underestimation or exaggeration of exposure, we have not found any study examining attitudes in this context.

This study aimed to identify personal characteristics that increase the risk of exposure misclassification in a community-based, case-control study of cancer—exposures that are the most difficult to assess. Logistic regression modeling was used to study the effects of demographic factors and attitudes on inter-method reliability²⁵ (criterion validity²⁶), with control for confounding. Reliability was measured by comparing self-reports to corresponding expert assessments of exposure, which was considered to be the gold standard for the purposes of this study. Use of data from the Northeastern Ontario

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Men's Health Study conducted in Ontario, Canada²⁷ allowed for these analyses.

Materials and methods

Epidemiologic study of prostate cancer

The Northeastern Ontario Men's Health Study is a community-based, case-control study of occupational and other risk factors for prostate cancer.²⁷ Ethics approval was obtained from the Laurentian Hospital Research Ethics Board in Sudbury, Ontario, Canada. Cancer cases were identified through the Ontario Cancer Registry. Cases were defined as men having primary, histologically confirmed prostate cancer (ICD9-185²⁸) diagnosed between January 1995 and December 1998. Consent to contact cases was first acquired from physicians named on pathology reports, and agreement to participate was obtained by telephone. Eligible cases were living in one of nine Statistics Canada census divisions in northeastern Ontario and were aged 45 to 84 years at the time of diagnosis. Controls were randomly selected from the same census divisions using residential telephone listings and were 2:1 frequency matched based on five-year age group. Eligible controls reported never having had prostate cancer prior to January, 1995. If prostate cancer was diagnosed after that time, these men were deemed cases.

Questionnaires were offered in English and French and subsequently administered by mail or telephone. Prior to the study, translation of the entire English questionnaire into French was reviewed for full compatibility with Franco-Ontarian dialects. Each respondent was required to provide a work history, including job titles and start and end dates for every job held longer than one year. Respondents were asked a number of questions about each job (years worked, industry, name and description of employer, hours of work, job duties, location, level of activity, job satisfaction, odours and use of respiratory protective equipment). An exposure checklist was completed, in which the respondents indicated whether they ever had been exposed to (and if so, with what frequency and intensity) 14 chemical and physical agents (e.g., lubricating oils and

greases, asphalt fumes, pesticides, metals and metal compounds). On a separate checklist developed for the purposes of this study, each respondent indicated his risk perception of ten agents (not including polycyclic aromatic hydrocarbons [PAH]). They were specifically asked, "On a scale of 1 to 5, where 1 means 'not harmful' and 5 means 'extremely harmful', please circle the appropriate number that indicates to what extent you believe that exposure to each of following is harmful to human health."

Data collection began in March, 1996 and was completed by December, 1999. The response rate for cases was 72.8% and for controls was 46.4% (if hang-ups were considered as refusals, or 53.1% if considered ineligible).

Expert exposure assessment

Photocopies of completed work histories were given to an expert assessor who was a chemical engineer and occupational hygienist with 12 years experience. For each job, the expert assigned exposure ratings while blinded to cancer status. Exposures were rated as ever/never having occurred and also according to frequency, magnitude and duration. The expert used a simpler definition of exposure frequency than did the respondents, as well as a more objective definition for magnitude, based on occupational exposure limits (Table 1). Also, whereas the expert assessed many exposures in chemically specific terms (e.g., PAH exposure by skin or ingestion), the respondents were presented with more familiar terminology (e.g., lubricating oils and greases).

In assessing exposures, the expert first considered the entire work histories provided by the case or control and then applied his own knowledge, experience and, if necessary, consulted other experts, the scientific literature and/or occupational hygiene documentation from key industries in northeastern Ontario. To maintain consistency across similar jobs, handwritten notes were kept of all non-zero exposure ratings, along with any other pertinent information. Industrial and occupational codes based on Statistics Canada's systems of Standard Industrial

Classification (SIC)²⁹ and Standard Occupational Classification (SOC)³⁰ were also assigned.

Measurement of reliability and its determinants

The aim of this study was to analyze jobs of greatest relevance to estimating risk of cancer; in particular, each respondent's longest held job was used as the unit of observation. Of 2,388 respondents (8,279 jobs), 2,351 respondents/jobs were eligible for this analysis after excluding 1) eight jobs starting less than one year before date of diagnosis (or date of initial contact for controls); 2) 37 respondents with more than one job and at least one job of unknown duration (138 jobs); and 3) 5,782 jobs that were not of the longest duration, or were jobs tied for the longest (in such cases, the earliest held job was used). Forty-one respondents (and 41 longest held jobs) with missing assessments were excluded from PAH-specific analyses, resulting in a sample size of 2,310 respondents/jobs. For these analyses, 1,272 cases of agreement on no exposure were removed (55.1%) since it was believed that reliability in these cases would depend more on the low likelihood of exposure than on personal factors of interest.

Exposure to PAH served as a focus for two reasons. First, this exposure is occupationally prominent and is a postulated risk factor for prostate cancer.³¹⁻³³ Second, PAH exposure was assessed similarly by the expert and respondents. Whereas respondents assessed exposures to lubricating oils and greases, the expert assessed PAH exposure via skin/ingestion. However, this comparison was thought to be valid given that exposure to lubricating oils and greases mainly occurs via the skin, with the exception of oil mists.

A dichotomous index of exposure was used for analyses. Ever/never exposure assessments were compared since this index of exposure was used similarly by the expert and respondents (i.e., the index "ever exposed" in Table 1). Expert and respondent assessments of frequency and magnitude of exposure were not compared on account of differing interpretations, in which case other factors related to

TABLE 1
Indices of exposure to polycyclic aromatic hydrocarbons
used by respondents* and expert

Index of exposure	Respondents	Expert
Ever exposed	Yes, No	Yes, No
Frequency	None Monthly Weekly Daily	None Less than daily Daily
Magnitude	None Low Medium High	None < 50% OEL** 50% - 100% OEL > 100% OEL
Duration	Not assessed	None < 2 hours per day or shift > 2 hours per day or shift

* Participants in the Northern Ontario Men's Health Study

**OEL – Occupational Exposure Limit

agreement would have been difficult to distinguish.

While the selection of independent variables for analysis was driven largely by *a priori* hypotheses, the sample size needed to reliably estimate risk was also considered.³⁴ Eleven independent variables were ultimately chosen. One variable designated “occupational group” categorized workers as blue-collar or white-collar. To create these categories, unit group-level Standard Occupational Classifications (SOCs) assigned by the expert were first collapsed into Broad Occupational Categories defined by Statistics Canada,³⁰ and then into blue- and white-collar status whereby blue-collar occupations were defined by Broad Occupational Categories H, I, J (see Figure 1). Average risk perceptions were derived from a risk perception summation scale (Cronbach's $\alpha = 0.92$, indicating internal consistency and a reliable scale).^{35,36} An average of all the risk perception scores in the scale was used for analysis. For each respondent, if more than four of the ten items on the risk perception checklist were missing, the respondent's average risk perception score was also recorded as missing.

Eleven characteristics of respondents who under- and overreported ever/never exposure to PAH, respectively, were compared to those who agreed with the expert, using univariable and

then multivariable logistic regression models. Underreporters were excluded from overreporting models and vice versa. “Overreporting” occurred if the respondent reported workplace exposure, but the expert reported no exposure for him, whereas “underreporting” was the opposite pattern.

It was postulated that confounding effects of attitude variables could have important implications in the interpretation of studies such as this one. To investigate the role of risk perceptions in self-reporting, associations were measured between 1) average risk perceptions and reliability; and 2) average risk perceptions and four factors associated with risk perceptions in the literature: age,^{37,38} education level,^{37,38} cultural group,³⁹ and occupational group.^{37,40}

The same analyses were performed for job satisfaction in relation to cultural group, occupational group and age, respectively.⁴¹ It was believed that if associations 1) and 2) were both statistically significant, this would be suggestive of a confounding or an intermediate role.^{26,42}

Statistical methods

All statistical analyses were conducted using SAS® version 8.2 for Windows⁴³ and a significance level of 0.05. Reliability was measured as percent agreement and percent under- and overreporting, respectively.

Multiple logistic regression models were built using stepwise variable selection. To assess selection bias, respondents with missing values for “average risk perceptions” were compared to those without missing values using chi-square and Wilcoxon rank sum tests. Descriptive statistics for model subgroups were compared to those of the study population as a whole.

Results

Respondent characteristics are shown in Table 2. The mean age for the respondents in this analysis was 68.7 years, with over 72% of respondents being 65 years or older at the time of interview. The majority of respondents (80.3%) reported no formal education beyond high school, most were English-speaking (56.0%), and blue-collar occupations were slightly more prevalent than white-collar (57.2% versus 42.8%). More than half of the subjects had jobs of

FIGURE 1
Standard Occupational Classification (SOC) definitions –
Broad occupational categories

A	Management occupations
B	Business, finance and administrative occupations
C	Natural and applied sciences and related occupations
D	Health occupations
E	Occupations in social science, education, government service and religion
F	Occupations in art, culture, recreation and sport
G	Sales and service occupations
H	Trades, transport and equipment operators and related occupations
I	Occupations unique to primary industry
J	Occupations unique to processing, manufacturing and utilities

Source: Statistics Canada: Standard industrial classification, 1980.²⁹

TABLE 2
Characteristics of respondents*, frequencies and percentages (N=2,310)**

		N	%
Age	45 - 59	277	12.2
	60 - 64	355	15.6
	65 - 69	618	27.1
	70 - 74	562	24.7
	75 - 86	468	20.5
Highest education level attained	Elementary	755	32.9
	Secondary	1,087	47.4
	Post-secondary	453	19.7
Cultural group	English-Canadian	1,288	56.0
	French-Canadian	491	21.3
	Other	523	22.7
Occupational group	Blue-collar	1,319	57.2
	White-collar	986	42.8
Time elapsed since job ended (years)	0 - 9	495	21.5
	10 - 19	823	35.8
	20 - 52	984	42.8
Job duration (years)	4 - 19	538	23.4
	20 - 39	1,498	65.0
	40 - 71	268	11.6
Number of jobs	≥ 5	594	25.7
	2 - 4	1,318	57.1
	1	398	17.2
Job satisfaction***	High	2,098	91.5
	Indifferent	122	5.3
	Low	74	3.2
Average risk perception†	Low	202	10.9
	Medium	197	10.6
	High	1,453	78.5
Questionnaire administration mode	Mail	1,745	75.6
	Telephone	564	24.4
Cancer status	Case	729	31.6
	Control	1,581	68.4

* Participants in the Northern Ontario Men's Health Study

** Totals may not equal 2,310 due to missing values

***High - highly satisfied or satisfied; Indifferent - neither (indifferent); Low - highly unsatisfied or unsatisfied

† High - average score ≥ 3.5 on a scale from 1 to 5, indicating extremely harmful; Medium - average score > 2.5 and < 3.5, indicating medium harm; Low - average score ≤ 2.5, indicating little harm

longest duration ending more than a decade before they completed the questionnaire (median = 11.0 years), and these jobs were still ongoing for 212 respondents (9.2%). The mean job duration was 27.3 years and the median number of jobs held was 3.0. As might have been expected when jobs were held the longest, the vast majority of respondents reported being satisfied or highly satisfied with these jobs (91.5%). Average risk perception scores were generally high, with a median of 4.1

on a scale from 1 to 5 (5 indicating the most harm).

A substantial number of scores for average risk perception were missing (458/2,310; 19.8%). Respondents with missing values were significantly more likely to have only elementary school education ($p < 0.0001$), less likely to be English-Canadian ($p = 0.039$), were significantly older ($p < 0.0001$) and were more likely to be blue-collar workers ($p < 0.0001$).

There was no significant difference between the groups in terms of cancer status ($p = 0.53$).

The majority of respondents agreed with the expert on having had no PAH exposure (55.1%; 1,272/2,310). Before excluding these respondents, percent agreement was 79.3, with overreporting being more common than underreporting (14.3% [330/2,310] versus 6.5% [149/2,310]). Kappa was equal to 0.54 and sensitivity and specificity were both 0.79. By excluding those who agreed with the expert on no exposure, agreement fell to 53.9% (N = 1,038), resulting in 31.8% overreporting and 14.4% underreporting; sensitivity remained at 0.79.

Subgroups used to study under- and overreporting contained 543 and 700 respondents, respectively, and were similarly distributed across 11 variables. Compared to the study population as a whole, PAH subgroups had fewer respondents with post-secondary education (8.7% in the underreporting subgroup and 13.1% for overreporting, versus 19.7% for study population); were more frequently blue-collar workers (89.9% for underreporting and 77.4% for overreporting, versus 57.2%); and were less likely to complete questionnaires by mail (69.4% for underreporting and 68.7% for overreporting, versus 75.6%). Subgroups were otherwise distributed similarly to the study population.

The results of univariable analyses are presented in Table 3. Three statistically significant associations were found with PAH underreporting, including a positive association with age (odds ratio [OR] = 1.077 for every one-year increase in age; 95% CI: 1.043-1.112). Time since job completion was also significant, with the odds of underreporting being higher for jobs ending a decade or more before interviews than for jobs held more recently (OR = 2.342; 95% CI: 1.324-4.143 for 20 years or more; OR = 2.065; 95% CI: 1.225-3.484 for 10 to 20 years). Third, a graded effect was observed with job duration whereby underreporting was not as likely

TABLE 3
Odds ratios (OR) and 95% confidence intervals (CI) from univariable logistic regression models for risk of under- and overreporting exposure to PAH* (ever/never) in jobs held the longest by respondents**

Independent variable		Underreporting			Overreporting		
		N	OR	95% CI	N	OR	95% CI
Age	Each one-year increase	543	1.077***	1.043, 1.112	700	0.991	0.971, 1.012
Highest education level attained	Elementary	233	2.111	0.851, 5.238	260	0.370***	0.228, 0.603
	Secondary	263	1.449	0.581, 3.613	348	0.485†	0.305, 0.773
	Post-secondary	47	1.000		92	1.000	
Cultural group	French-Canadian	138	1.250	0.756, 2.066	157	0.681	0.459, 1.010
	Other	134	0.989	0.582, 1.682	172	0.842	0.580, 1.223
	English-Canadian	271	1.000		371	1.000	
Occupational group	Blue-collar	488	0.866	0.449, 1.706	542	0.142***	0.095, 0.211
	White-collar	55	1.000		158	1.000	
Time elapsed since job ended (years)	≥ 20	130	2.342†	1.324, 4.143	140	0.645†	0.421, 0.988
	10 - 19	208	2.065†	1.225, 3.484	258	0.891	0.634, 1.253
	< 10	205	1.000		302	1.000	
Job duration (years)	< 20	128	0.436†	0.193, 0.982	180	0.958	0.529, 1.738
	20 - 39	365	0.761	0.385, 1.502	459	0.915	0.529, 1.582
	≥ 40	50	1.000		61	1.000	
Number of jobs	≥ 5	122	0.959	0.485, 1.896	179	1.416	0.868, 1.738
	2 - 4	336	0.876	0.487, 1.576	414	0.874	0.563, 1.359
	1	85	1.000		107	1.000	
Job satisfaction	High	477	0.526	0.209, 1.326	621	1.000	0.342, 1.180
	Indifferent	44	0.338	0.098, 1.173	53	0.635	0.533, 2.612
	Low	22	1.000		26	1.180	
Average risk perception	Low	55	1.140	0.576, 2.256	69	1.000	0.455, 1.755
	Medium	61	0.898	0.448, 1.800	77	0.893	0.607, 1.705
	High	427	1.000		554	1.017	
Questionnaire administration mode	Mail	377	0.838	0.534, 1.315	481		0.602, 1.159
	Telephone	166	1.000		219		
Cancer status	Case	180	0.925	0.588, 1.455	235	1.010	0.731, 1.396
	Control	363	1.000		465	1.000	

* PAH = Polycyclic aromatic hydrocarbons

** Participants in the Northern Ontario Men's Health Study

*** $p < 0.0001$

† $p < 0.01$

‡ $p < 0.05$

for jobs of shorter duration as for jobs 40 years or more in duration (OR = 0.436; 95% CI: 0.193-0.982 for jobs less than 20 years; OR = 0.761; 95% CI: 0.385-1.502 for 20 to 39 years).

In terms of PAH overreporting, men with less education were significantly less likely to overreport PAH exposures than respondents with post-secondary education (OR = 0.370; 95% CI: 0.228-0.603 for elementary school; OR = 0.485; 95% CI: 0.305-0.773 for secondary school),

and blue-collar workers had lower odds of overreporting than white-collar workers (OR = 0.142; 95% CI: 0.095-0.211). Overreporting was also less common for jobs completed at least 20 years earlier than for jobs held in the decade prior to interviews (OR = 0.645; 95% CI: 0.421-0.988). Graded effects were also observed for this variable.

Using stepwise variable selection, the only variable that entered the multivariable model for PAH underreporting was age

(Table 4). With respect to overreporting, occupational group was the only variable in the final model, again showing overreporting to be less common in blue-collar than white-collar workers.

Final models were checked statistically in several ways. When predictor variables were selected using backward or forward selection techniques (p -entry/removal = 0.15), both final models contained the same variables as selected when using stepwise variable selection, demonstrating model

TABLE 4
Odds ratios (OR) and 95% confidence intervals (CI) from multiple logistic regression models for risk of under- and overreporting exposure to PAH* (ever/never) in jobs held the longest by respondents**

Model outcome	Parameter	OR	95% CI
Underreporting***	Intercept		
	One-year increase in age	1.077	1.043, 1.112
Overreporting†	Intercept		
	Occupational group‡	0.142	0.095, 0.211

* PAH = Polycyclic aromatic hydrocarbons

**Participants in the Northern Ontario Men's Health Study

***N_{agreement} = 436, N_{underreporting} = 107

† N_{agreement} = 436, N_{overreporting} = 264

‡ Blue-collar vs. white-collar occupations

robustness. The assumption of linearity between the continuous variable “age” and log odds ratios in the underreporting model was confirmed graphically, using the Mantel-Haenzsel chi-square test for trend ($p < 0.05$). Adding non-significant variables to each model did not change the influences of the significant factors, age and occupational group (i.e., beta coefficients changed by less than ten percent), with one exception: addition of the variable “time since job completion” to the model for PAH underreporting slightly decreased the effect of age by 12.8%, but the effect remained statistically significant.

Since the number of exclusions relied heavily on the risk perception variable, there was concern that inclusion of this variable may have biased the results. Therefore, both models were fit again excluding average risk perceptions, thereby including respondents with missing values. The same variables remained statistically significant. However, in the PAH underreporting model, respondents who were highly satisfied with their jobs were less likely to underreport PAH exposure than those who were unsatisfied (OR = 0.401; 95% CI: 0.175-0.916). Also, French Canadians had higher odds of underreporting than did English Canadians (OR = 1.629; 95% CI: 1.046-2.535).

It was hypothesized that attitudes might behave as confounders or intermediate variables in associations between various personal characteristics and reliability. However, no significant associations were found. Though, due to the scarcity of respondents with low job satisfaction

(N = 22), this result may not have been valid. By combining the “low” and “indifferent” job satisfaction categories to increase category sample size, there was still no evidence of an intermediate or confounding role for job satisfaction.

Discussion

These results suggest the reliability of PAH exposure self-reporting in community-based studies may depend on 1) the likelihood of exposure (i.e., reports of negative exposure were typically reliable), and 2) certain respondent characteristics, such as age and occupational group.

It was not surprising to observe a significant positive association between age and PAH underreporting, since exposures could naturally be forgotten over time or may not have been realized in jobs held decades earlier. Similar results have been reported in the past for asbestos¹⁷ and heavy metal exposure.¹⁸ The fact that age has consistently been found to *not* influence work history reporting (e.g., reporting of job titles and dates of employment)^{24,44-47} suggests this effect may be specific to exposure reporting. Time since job completion also appeared to be weakly associated with PAH underreporting after controlling for age. It is possible that a more precise variable (i.e., using category widths < 10 years) or some account for job start date might have revealed a stronger trend.

The finding that white-collar workers were significantly more likely to overreport than blue-collar workers was convincing given the strengths of these associations:

over seven-fold higher odds for PAH overreporting in white-collar workers were found compared to blue-collar (OR¹_{blue vs. white-collar} = 7.0). As well, the direction of the association was plausible. While white-collar workers, overall, would have had fewer direct exposures to PAH than blue-collar workers, they may have had a greater awareness of these agents in the workplace. For some, this may have been accompanied by misinterpretation and exaggeration of “exposure”. Ahrens *et al.* did not observe this influence,¹⁷ but they provided a definition of exposure and respondents specified whether “direct” or “bystander” exposure occurred. Even more detailed definitions have been provided in other questionnaires.⁴⁸ In contrast, respondents in this study were simply asked to “describe your exposure to the following”, with a subsequent exposure checklist. However, van der Gulden *et al.* similarly asked, “Have you ever worked with...or been exposed to...in your job?”,¹⁵ and like Ahrens *et al.*, did not observe differences between occupational groups. An alternative reason for the present finding may have been the focus on workers who were more likely to have been exposed, unlike the latter studies that analyzed cases of agreement on no exposure (presumably groups with more white-collar workers).

In this study, neither underreporting nor overreporting was associated with cancer status, in agreement with past studies.^{15,17,23} Therefore, the observed inconsistencies between expert and respondents would translate into non-differential misclassification error in estimating prostate cancer risk, which would likely bias risk estimates towards the null value and therefore underestimate risk.⁴⁹

In regards to risk perceptions, it is noteworthy that the items in this study concerned harm to “human health” in general, rather than personal health risk. Although a correlation between perceptions of personal risk and societal risk has been observed,⁵⁰ people may perceive risks to themselves to be lower than risks to the general population.^{50,51} Therefore, questions of personal risk might have resulted in different associations with

personal exposure reporting. Nevertheless, the present findings should be regarded as informative and novel, given this may have been the first attempt to examine risk perceptions in this context.

The study of the role of job satisfaction in self-reporting was an additional strength of this study, as no other group has explored this possibility to our knowledge. However, the associations observed should be interpreted cautiously given the few respondents reporting low job satisfaction. The validity of this finding might have been improved if more than one questionnaire item were used to measure this attitude. Similarly, different techniques for assessing risk perceptions have been used in the past⁵²⁻⁵⁴ and if applied to this study, may have elicited different responses.

Although the different ways in which PAH exposures were assessed by the expert and respondents could have lowered internal validity, the effect was probably minimal. Whereas respondents reported exposures to lubricating oils and greases, corresponding expert assessments focused on skin contact and/or ingestion of all possible sources of PAH. In a discussion with the expert, however, it was learned that lubricating oils and greases were typically the only skin/ingestion PAH exposure with the exception of some unusual exposures to tar.

The validity of the expert assessments may be viewed as a possible limitation of this study. More specifically, the associations observed could reflect the expert's strengths (i.e., the expert may have been more knowledgeable about more recent exposures or blue-collar occupations, thereby leading to better agreement on these jobs and poorer agreement on others). Exposures that are highly dependent on human technique would also be more difficult for an expert to assess. Using more than one expert in future studies might help to alleviate this problem since assessments would draw from a broader range of personal knowledge and experience, and more extensive consultation with the literature. However, others have rationalized,^{55,56} as do the present authors, that expert

ratings are more objective and consistent than self-reports. Some industry-based validity studies support this idea.^{3,57} In the community-based setting, Fritschi *et al.* found that three experienced expert raters working independently were able to identify 64%, 70% and 80% of past occupational exposures, respectively, across a variety of workplaces.⁵⁸ As well, in the present study, we observed no statistically significant trends in over- or underreporting across three time periods of expert assessment (PAH exposures were sorted in order of expert assessment and then split into tertiles; trends in percent under- and overreporting were $p > 0.05$, respectively, in Mantel-Haenszel chi-square tests for trend), thus providing some evidence of expert consistency over time (data not shown). Furthermore, the associations we observed with age and occupational group were both plausible and consistent with *a priori* hypotheses and past research, thereby also supporting the use of the present expert.

In terms of generalizability, it should be recognized that the factors involved in "all jobs" reporting may differ from job of longest duration reporting²⁰ and factors may differ for current versus past exposures. Questions also remain about the validity of these findings for other exposures that are less easily sensed than lubricating oils and greases, or queried using less familiar terminology.⁵⁹ Our findings may not extend to respondents less than 45 years of age or to females since it is possible these groups may have different attitudes and occupational characteristics than the men in this study. Moreover, the present analyses were based on subgroups that excluded respondents for whom exposures were improbable (i.e., white-collar workers and post-secondary educated men). Modeling results may therefore only extend to similar populations in which exposure is conceivable; namely, industry-specific groups or subgroups of community-based populations similar to this.

Many aspects of these analyses are relevant to studies of long-latency disease. First, this study focused on exposure reporting for job held the longest, which is useful for studying diseases resulting

from cumulative exposures. Second, recall in this study was primarily retrospective (90.8%), with jobs ending 11 to 12 years prior to questionnaire completion on average. Third, PAH exposure is currently of interest to occupational epidemiologists and continues to be assessed by way of retrospective self-report in community-based studies of cancer.⁹

In Canadian males, who were mainly blue-collar and 69 years of age on average, different personal characteristics were found to be associated with PAH under- and overreporting. There was a strong association between white-collar status and overreporting, which could have arisen from misinterpretation of exposure terminology on the questionnaire.^{8,56} In addition, older respondents under-reported more often than younger respondents, suggesting memory probes may be needed to enhance recall in older populations if poor memory is to blame. If awareness of exposure underlies the effect of age, improved recall by older respondents should be anticipated, given the increase in workplace safety education programs implemented in Canada since the 1980s.⁶⁰ In all further work of this kind, it is recommended that under- and overreporting be distinguished from each other and potential confounding be controlled adequately. There may also be a need to distinguish between factors influencing exposure and work history reporting since our findings suggest they could differ (e.g., the variable "age"). Further analyses similar to this are encouraged, perhaps using an improved gold standard, such as an expert panel.

Acknowledgments

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Services for children and youth with chronic health conditions: Views of pediatricians in British Columbia

Anton R Miller, Magda Recsky, Mojgan Ghazirad, Michael Papsdorf and Robert W Armstrong

Abstract

Canadian research on health services for children and youth with chronic health conditions (CHC) is limited. In a postal survey, pediatricians in British Columbia rated the quality and safety of health care services for children with chronic medical conditions (Ch-Med) lower (mean rating \pm SD on a seven-point scale: 4.86 ± 1.02) than services for children with acute conditions/injuries (5.97 ± 1.01), and lowest for children with chronic developmental, behavioural and mental health conditions (Ch-DBM; 3.06 ± 1.17). To improve health care services for CHC, respondents especially favoured improving access to community-based services and resources and to medical specialists and specialized facilities, and the implementation of alternative models of care. Respondents indicated that physician care of children with CHC could be enhanced by extending the physician's role, better integrating medical with other aspects of care and adopting more flexible payment mechanisms. Findings suggest the need for enhancement and innovation in medical services for children with CHC, especially Ch-DBM, but also that solutions need to take account of CHC subcategory, geographic factors and differences in practitioner readiness to embrace change.

Key words: children, chronic health conditions, disabilities, health services, pediatricians

Introduction

Existing health care systems are not well designed to deal effectively with chronic health conditions (CHC)¹ although new models of care that enshrine the principles of chronic disease management have been proposed and are being implemented to address the care needs of this population.²⁻⁵ These important efforts focus largely on the highly prevalent CHC of adults, such as diabetes, hypertension and cardiovascular disease. Although CHC have been identified as one of the primary challenges to current child health delivery systems and policies,⁶ there has been little recognition within the policy or research communities of the problem of CHC among children and youth (hereinafter referred to simply as

“children”). Up to 18% of all children are affected by a chronic condition affecting physical, mental or developmental health,⁷ and approximately 6% of children have complex and disabling CHC that require services over time from providers across multiple sectors.⁸ CHC may have a significant adverse impact on children and families^{9,10} and care of children with CHC accounts for between 60 and 80% of all child health expenditures.^{11,12}

The difficulties that parents experience in accessing and coordinating services for their children with CHC have been documented¹³ and health and social policy recommendations for services for children with disabilities have been published,¹⁴ but few studies have examined how care providers view

services for children with CHC. Pediatricians play a central role in care of children with CHC, both as front-line service providers and advocates. They experience the successes and challenges of the services system on a daily basis and their cooperation is needed for implementation of new initiatives. Community pediatricians devote at least 50% of their consultation time, on average, to care of children with chronic conditions,¹⁵ but anecdotal experience suggests that numerous factors may impede the ability of physicians to play a truly integrated role in the broader management of children with CHC.

Chronic disease management models present opportunities for physicians to enhance the care they provide to their adults patients. These models are characterized by care that is planned, structured, evidence-based and continuously evaluated, that explicitly values collaboration between primary and specialist providers and between professional disciplines, that emphasizes prevention and self-management, and that uses information technology.^{2-5,16} By proposing alternative and innovative ways of providing care, however, such models challenge status quo arrangements and may be resisted or rejected by physicians. There has been little attention to formulating chronic disease models that are suitable for children, though chronic conditions among children present some unique features.¹⁷ In this study, we surveyed pediatricians in the Canadian province of British Columbia (BC) to ascertain their perceptions and views

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regarding services for CHC and how services might be improved, and their attitudes towards alternative and innovative models of care for children with CHC.

Methods

Study design and population

The study was conducted via a postal survey of all registered pediatricians in BC. Physicians with a specialty certification in pediatrics were identified from a database held by the College of Physicians and Surgeons of BC. To be considered eligible to participate in the study, physicians needed to be in active pediatric practice in BC and devoting at least 25% of their patient-care hours to ambulatory patients.

Setting

BC's population of approximately 4.2 million¹⁸ is spread over a large and geographically diverse area, with highest density in the Greater Vancouver Regional District (GVRD). The BC Children's Hospital - Sunny Hill Health Centre for Children complex (BCCH-SH), located in Vancouver, is the province's main tertiary care pediatric referral and academic centre and provides specialized medical and supportive services to children and families throughout BC. The administrative responsibility for health services in BC is vested in five regional health authorities and one specialized provincial authority. BC is served by approximately 4,500 general and family physicians, 270 pediatricians and 450 psychiatrists,¹⁹ including an estimated 50 child psychiatrists. General and family practitioners provide for most of children's primary care needs, with pediatricians and psychiatrists providing mainly consultative services. Most community-based pediatricians are paid on a fee-for-service (FFS) basis, with some also contracting their services on an hourly or part-day basis, known as "sessional arrangements". An increasing number of hospital-based subspecialists are in an alternative funding plan. The costs of "medically necessary services" are covered by a universal, government-run, single payer insurance system.

Survey instrument and procedures

A 15-item questionnaire was developed by the authors to cover four topic areas. Topic 1 involved an overall evaluation of health care services for children in BC. Respondents were asked to rate the BC health care system's ability to provide safe, high-quality care to 1) children with chronic medical conditions (Ch-Med) "such as asthma, diabetes, cancer, and arthritis"; 2) children with chronic developmental, behavioural or mental health conditions (Ch-DBM) "such as developmental delays and disabilities, behavioural problems, attention-deficit/hyperactivity disorder, fetal alcohol syndrome, and depression"; 3) children with acute and/or life-threatening illnesses and injuries; and 4) healthy children and youth (well-child and preventive care). Topic 2 enquired about seven measures to improve care for children with CHC in BC. Topic 3 covered structural and organizational aspects of the community care of a child with CHC, using a series of linked questions about physician roles, remuneration and care setting. Topic 4 sought views on the most appropriate role for child psychiatrists in care of children with chronic behavioural, emotional and mental health problems.

CHC were defined as "associated with limitation of functions, disfigurement, dependency on medication, special diet or medical technology for functioning or control of the condition, or need for more than typical use of medical or related services, or need for special services over time at home or school".²⁰ In recent years, a "non-categorical" approach to the identification and study of CHC among children has been advocated that emphasizes commonalities and consequences among specific conditions.²¹ We made a distinction between Ch-Med and Ch-DBM in the questionnaire to explore whether physicians discern differences between classes of chronic conditions in terms of service needs.

Respondents' views were assessed *quantitatively*, using five- or seven-point scales to measure ratings of effectiveness or

agreement with various statements, and *qualitatively* through narrative comments. Information was also obtained on pediatrician demographic and practice characteristics, including the proportion of their time engaged in different kinds of clinical and non-clinical activities.

A pilot version of the questionnaire was reviewed and tested by three pediatricians (a community-based generalist, a hospital-based generalist and a hospital-based subspecialist) and a health services researcher with expertise in questionnaire design. Their feedback regarding the tool's clarity, ease of use and relevance was incorporated into the final version.

Questionnaires, along with a cover letter explaining the study and a stamped return envelope, were mailed to 273 potential participants. A dual-purpose thank you/reminder letter was sent to all potential participants two weeks after the initial mailing and a second questionnaire package was sent two weeks after that to those who had not replied. To check on the eligibility status of physicians who failed to respond, we phoned the offices of physicians whose office addresses raised doubts about their being in active pediatric practice with an ambulatory component.

Statistical analysis

Chi-square tests were used to compare characteristics of participants and non-participants (for whom data were available from the College registry). Paired and independent sample *t*-tests, between groups and repeated measures analyses of variance (ANOVA), and chi-square tests were conducted to determine the statistical significance of various differences. A significance level of $p < 0.05$ was used, except in the blocks of questions under Topic 3, where the Bonferroni correction was applied to adjust for multiple comparisons and maintain the family-wise alpha at 0.05 within each block of items. The effect size estimate, Cohen's *d*, was calculated to aid the interpretation of differences in various exploratory analyses, noting the convention that $d = 0.5$ represents a medium effect.²²

Question-specific narrative comments were collected and reviewed by one of the authors (AM), and subjected to an iterative process of thematic analysis. Because there was considerable overlap of comments from one section of the questionnaire to other sections, a group of three reviewers worked independently to identify predominant, overarching themes from the survey as a whole, based on robustness of appearance of comments within and across sections and questions. The group then defined a set of overarching themes by consensus.

Results

Participants

Of the 273 questionnaires mailed, 186 were returned: 119 fully completed, 4 not completed and 63 indicating that the respondents did not meet eligibility criteria for participation. Amongst the 87 physicians who did not return a questionnaire, 13 were eventually deemed ineligible to participate and the remaining 74 were classified as eligible non-participants. The participation rate among eligible pediatricians was therefore 60.4% (119/197).

Demographic and practice characteristics of survey participants (N = 119) are presented in Table 1, alongside available data on eligible non-participants (N = 78). No statistically significant differences were found on any of the variables. Analysis of demographic data showed a high degree of overlap between pediatrician type and practice setting. Almost all general pediatricians (65/68; 96%) were based outside of the BCCH-SH tertiary referral centre area. Most subspecialist pediatricians (40/51; 78%) were based at BCCH-SH, with the remainder distributed almost equally between GVRD and other addresses. Given this overlap, we elected to use practice setting rather than pediatrician type in further subgroup analyses.

Topic 1. Overall evaluation of health care services for children in BC

Pediatricians rated the BC health care system as highly effective in its ability to provide safe, high-quality care to children with acute and/or life threatening conditions (mean rating \pm SD: 5.97 ± 1.01 , on a seven-point scale), significantly less effective for children with Ch-Med (4.86 ± 1.02 ; see Figure 1 for statistical relationships) and least effective of all for children with Ch-DBM (3.06 ± 1.17). Ratings for well-child and preventive care were intermediate (4.26 ± 1.29), but not analyzed further as this aspect of care was not a primary focus in this study.

Pediatricians who spent more than the median amount of time caring for children with Ch-DBM rated the quality of services for Ch-DBM lower than those who spent less time (2.76 ± 1.21 vs. 3.32 ± 1.07 , respectively; $t = 2.64$; $p = 0.009$; $d = 0.49$).

An interesting, though statistically non-significant, trend was also observed for incrementally lower ratings of care of Ch-DBM with increasing remoteness from the tertiary referral centre. Tertiary referral centre pediatricians rated care of this population at $3.34 (\pm 1.18)$, compared with $3.05 (\pm 1.28)$ for GVRD pediatricians and $2.76 (\pm 0.98)$ for pediatricians practicing in other areas ($F [2, 114] = 2.5$; $p = 0.087$).

Topic 2. Measures to improve the care of children with CHC in BC

Pediatricians responded favorably to all seven measures presented as possible ways to help improve the care of children with CHC in BC (Table 2), but three options were rated as more effective than the others (overall $F [6, 103] = 26.987$, $p < 0.001$). The measure “Improving access to community-based assessment and treatment services and supportive resources” was rated significantly higher

TABLE 1
Characteristics of survey participants and eligible non-participants and chi-square significance of differences

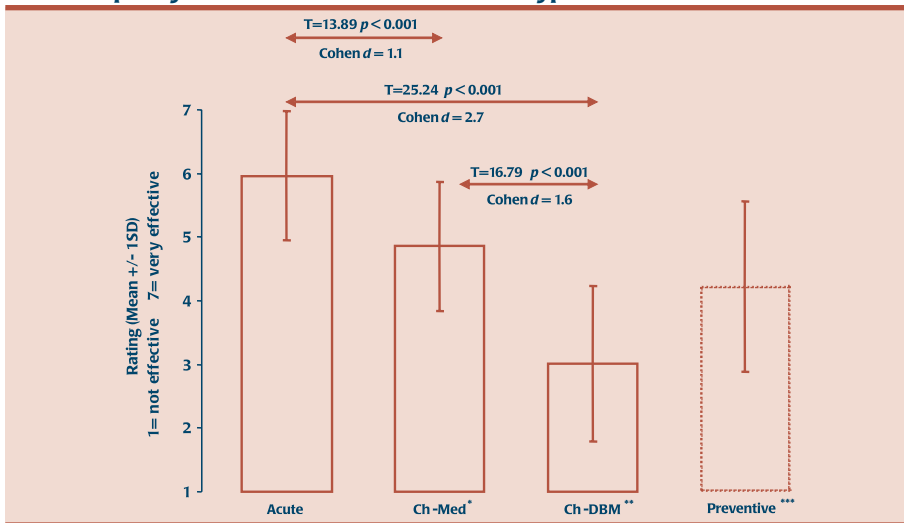
	Study participants (N=119)		Eligible non-participants (N=78)		p-value*
	N	%	N	%	
Sex (% female)	48	(40.3)	30	(38.5)	0.792
Years since MD graduation					0.234
≤ 20	56	(47.1)	30	(38.5)	
> 20	63	(52.9)	48	(61.5)	
Type of pediatrician					0.465
General pediatrician	68	(57.1)	45	(57.7)	
Subspecialty pediatrician	51	(42.9)	27	(34.6)	
Unknown			6	(7.7)	
Practice setting by health authority					0.535
Provincial health services authority	43	(36.1)	23	(29.5)	
Vancouver Coastal Health Authority	24	(20.2)	21	(26.9)	
Fraser Health Authority	20	(16.8)	16	(20.5)	
Other health authority (Northern, Interior, Vancouver Island)	32	(26.9)	18	(23.1)	
Practice setting by office address					0.225
Tertiary referral center (BCCH-SH**)	43	(36.1)	24	(30.8)	
GVRD***	39	(32.8)	35	(44.9)	
Other	37	(31.1)	19	(24.4)	

* Pearson's chi-square (2-sided)

** British Columbia Children's Hospital – Sunny Hill Health Centre for Children

***Greater Vancouver Regional District

FIGURE 1
Rated ability of British Columbia health care system to provide safe, high quality care to children with different types of health conditions



* Ch-Med = Chronic medical conditions

** Ch-DBM = Chronic developmental, behavioural and mental health conditions

***Preventive care was not a primary focus of the study.

than all the other options, and the measures “Improving access to medical specialists and specialized facilities” and “Alternative models of care for children with chronic health conditions” were rated higher than all the remaining options. In subgroup analyses limited to the three highest-rated measures, no differences were found by practice setting or by a median split in the amount of time spent in care of Ch-Med or Ch-DBM, with one exception: Pediatricians who spent more time in care of Ch-Med rated the measure “Improving access to medical specialists and specialized facilities” more highly than those who spent less time in care of Ch-Med (5.7 ± 0.93 vs. 5.3 ± 1.15 ; $F [1, 116] = 4.08$; $p = 0.046$; $d = 0.38$).

A number of respondents offered qualifying comments related to the measure “Alternative models of care for children with CHC”. Comments included caveats regarding the efficiency of alternatives such as interdisciplinary community-based care teams, and the physician’s role and compensation within them. Several respondents suggested that an appropriate role for physicians is as team leaders and educators. Respondents also noted difficulties in recruiting and retaining allied health professionals, especially with expertise in mental health

assessment and intervention, to such teams in more remote communities.

When asked to list any other measures that might improve care of children with CHC in BC, a few respondents mentioned the need to acknowledge chronic health conditions; the need for better training and education in chronic conditions for health

professionals; and the possibility of integrating and coordinating school services with health and social services.

Topic 3. Structural and organizational aspects of community care for children with CHC

Table 3 presents options for improving the structural and organizational aspects of care within four categories, highlighting the “most preferred option” (identified by repeated measures ANOVA) within each category.

1. Respective roles of family physicians, general pediatricians and pediatric (or mental health) subspecialists

Respondents clearly indicated a preference for routine care being provided by a pediatrician, with pediatric subspecialist (for Ch-Med) and/or child psychiatrist (for Ch-DBM) support. However, respondents did not actually disagree that routine care could be provided by a family physician supported by a general pediatrician, with a slightly higher agreement level for this proposition for Ch-Med than Ch-DBM (3.13 ± 1.16 vs. 2.69 ± 1.05 , respectively; $d = 0.4$).

TABLE 2
Rated effectiveness of proposed measures to improve care for children with chronic health conditions in British Columbia

	Mean*	SD	p-value
Improving access to community-based assessment and treatment services and supportive resources (e.g., psychologists, counselors, support and info. agencies)	6.10	0.932	< 0.001**
Improve access to medical specialists and specialized facilities	5.45	1.110	< 0.001***
Alternative models of care for children with chronic health conditions (e.g., interdisciplinary community-based care teams)	5.40	1.195	< 0.001***
Remuneration by alternatives to fee-for-service billing (e.g., sessional arrangements)	4.88	1.432	
Improved access to or sharing of patient clinical data	4.72	1.402	
Educational interventions aimed at physicians (e.g., continuing medical education/CME)	4.53	1.281	
Changing existing fee-for-service schedules	4.41	1.695	

* Rated on seven-point scale “to indicate the extent to which you feel each of the following might help to improve the care of children with chronic health conditions in BC” (1 = not effective; 7 = very effective).

** Mean statistically higher than all others

***Mean statistically higher than all non-bolded options

SD = standard deviation

2. *Methods of physician remuneration*

Respondents preferred a mixed remuneration arrangement of FFS and sessional payments for physician services to Ch-Med. For Ch-DBM, by contrast, mixed FFS and sessional arrangements were not rated significantly differently from purely sessional payment arrangements. Solely FFS arrangements were the least preferred option, though there was no strong disagreement for this method of remuneration for either Ch-Med (agreement level 2.81 ± 1.18) or Ch-DBM (2.37 ± 1.02 ; d for Ch-Med vs. Ch-DBM = 0.4).

3. *Best care setting for physicians*

Respondents strongly agreed that physician care for children with chronic conditions, whether Ch-Med or Ch-DBM, is best provided as part of a team in an interdisciplinary setting, rather than solo from the physician's office. There was clear disagreement with the notion of a physician working solo to provide care for Ch-DBM.

4. *Extent of physician's role in care of children and youth with CHC*

An extended range of care services (i.e., traditional direct care plus case

conferencing with other health and non-health professionals) emerged as the "preferred option" for Ch-Med. For Ch-DBM, an extended range and full range of care services (i.e., extended plus gathering and reviewing data from community settings, follow-up contact with other health and non-health professionals) were both preferred options.

In subgroup analyses conducted to examine factors associated with pediatricians' preferred options for structural and organizational aspects of community care, physician sex, years since MD graduation, practice setting and amount of time spent in care of

TABLE 3
Preferred options for British Columbian physicians for structural aspects of care of children with chronic medical (Ch-Med) and chronic developmental, behavioural and mental health conditions (Ch-DBM)

	Level of agreement* Mean (SD)	
	Ch-Med	Ch-DBM
Physicians' respective roles:		
Best arrangement is routine care by ...		
... family physician supported by general pediatrician	3.13 (1.16)	2.69 (1.05)
... family physician supported by pediatric sub-specialist (or child psychiatrist, for Ch-DBM)	2.51 (1.08)	2.68 (1.09)
... pediatrician supported by pediatric sub-specialist (or child psychiatrist, for CH-DBM)	3.98 (1.00)	4.06 (0.94)
Physician remuneration:		
Physician's time is best remunerated under ...		
... fee-for-service arrangement	2.81 (1.18)	2.37 (1.02)
... sessional arrangement (with appropriate fees)	3.29 (0.95)	3.63 (1.02)
... mixed fee-for-service and sessional arrangements	3.78 (0.95)	3.72 (0.98)
Physician care setting:		
Irrespective of specialty of physician, best arrangement is physician providing care as ...		
... a solo professional in his/her office	2.43 (1.00)	2.10 (0.89)
... part of a team in an interdisciplinary setting	4.26 (0.71)	4.41 (0.66)
Extent of physician's role:		
Irrespective of specialty of physician, physician's role should be to provide ...		
... traditional direct care**	3.38 (0.98)	3.17 (0.96)
... an extended range of care***	3.79 (0.89)	3.86 (0.85)
... a full range of direct and indirect care†	3.44 (1.20)	3.57 (1.18)

Boldface numbers represent most highly endorsed option within each block of items.

* Rated on five-point scale "to indicate your degree of agreement/disagreement regarding the community care of a child with Ch-Med or Ch-DBM" (1 = strongly disagree, 5 = strongly agree). SD = standard deviation

** Traditional direct care: interview, examination, counseling of patient and family

***Extended range of care: above (**) plus case conferencing with other health and non-health professionals

† Full range of direct and indirect care: above (***) plus gathering and reviewing data from community settings, and follow-up contact with other health and non-health professionals

Ch-Med and Ch-DBM were not related to pediatricians' most preferred options for these aspects of care. In many instances, however, tertiary-centre-based and community pediatricians disagreed in relation to the least preferred option. Tertiary referral-centre-based pediatricians disagreed more strongly with the propositions that the physician's time is best remunerated under fee-for-service arrangements; that the best arrangement is a physician providing care as a solo professional from his/her office; and that the physician's role should be to provide traditional direct care (all p 's < 0.015; data available on request). Moreover, a significant minority of community-based pediatricians, especially those based in the GVRD, expressed agreement that fee-for-service is the best method of remuneration for treating Ch-Med (41.0% for GVRD and 30.6% for other addresses vs. 7.5% for tertiary-centre-based pediatricians; $\chi^2 = 21.83$, $p < .001$) and/or with solo care as the best arrangement (27.0% for GVRD and 8.3% for other addresses vs. 5.0% for tertiary centre pediatricians; BCCH; $\chi^2 = 26.64$, $p < .001$). Also, a majority of GVRD-based pediatricians (62.5%) expressed agreement that traditional direct care is the best arrangement for treating Ch-Med (vs. 45.9% of pediatricians from other addresses and 39.0% for BCCH; $\chi^2 = 15.43$, $p = .004$). The pattern of findings was the same for Ch-DBM, except that there was less support overall for traditional direct care being the best arrangement, and only a trend for GVRD-based pediatricians to express agreement with this option (52.5% of GVRD pediatricians vs. 44.4% of pediatricians from other addresses, and 25.6% of tertiary centre pediatricians; $\chi^2 = 8.37$, $p = .079$). Looking at individuals who agreed with more than one of these "conservative" or status quo arrangements, there seems to be a small but significant group of GVRD-based pediatricians (compared with pediatricians from other settings) who are hesitant regarding possible innovative arrangements for Ch-Med ($\chi^2 = 16.51$, $p = .011$). In particular, 40% of GVRD-based pediatricians endorsed agreement with two or three of the three arrangements (that fee-for-service, solo care from one's office and traditional direct

care are best options), compared to 21.6% of pediatricians based in other communities and 4.8% of tertiary centre pediatricians. The data suggest the existence of a similar, though smaller, group that favors status quo arrangements for Ch-DBM ($\chi^2 = 15.83$, $p = .015$) with 30% of GVRD-based pediatricians endorsing agreement with two or three of these same arrangements, compared to 13.5% of pediatricians based in other communities, and none of the tertiary centre pediatricians.

Amongst the narrative comments collected under Topic 3, many referred to the difficulty of identifying a single "best arrangement" for responsibility for care between family physicians, general pediatricians and subspecialist pediatricians. Respondents noted that much depends on the nature and complexity of the chronic condition and on local expertise and resources. Several respondents, including one who identified his or her practice setting as rural, noted that they and their staff were already providing a full range of services, but without due compensation for "indirect care" activities. Other comments mentioned the importance of multidisciplinary approaches and the possibility of establishing "virtual teams". Many respondents mentioned an important potential role for nurses (including nurse practitioners and nurse clinicians) in relation to Ch-Med.

Topic 4. Role of child psychiatrists

In contrast to the lack of support pediatricians expressed for routine care of children with Ch-Med or Ch-DBM to be provided by family physicians supported by pediatric subspecialists (or child psychiatrists), respondents showed no clear preference when asked whether child psychiatrists should primarily serve as a resource to pediatricians or to family physicians (mean \pm SD level of agreement on five-point scale was 3.40 ± 1.18 vs. 3.45 ± 1.05 , respectively). This suggests that, in care of children and youth with mental health problems, specifically, pediatricians may be open to family physicians playing an integral role. Some narrative comments alluded to the "bulk of child psychiatry (being) done by general

pediatricians ...we need child psychiatrists as consultants and educators", while others mentioned that few general pediatricians have the knowledge or training for this kind of work (mental health), or the desire to be extensively involved in it, at the expense of their "medical" work.

Overarching themes in narrative comments

The following themes emerged as predominant across the survey as a whole: 1) the potential importance of interdisciplinary, community-based team approaches in providing services to this population of children, with the caveats noted previously and with comments that these approaches need to be responsive to local conditions; 2) the desirability of flexible methods of physician remuneration based on geographical location and range of care provided; 3) improving access to care, especially for mental health and subspecialty services, and in rural areas; 4) the place of triage in providing care for children with CHC; 5) the need to support families of affected children by creating networks and linkages in their communities; and 6) measures to augment communication and clinical data transfer between care providers.

In relation to triage, many respondents endorsed a system of care in which family physicians handle routine, intercurrent problems among children with CHC; pediatricians manage the underlying CHC with support from tertiary subspecialists and proper remuneration; and tertiary centres and subspecialists confine themselves to dealing with the most complex of clinical situations. However, a number of respondents expressed frustration with "dysfunctional" triage, in which specialized hospital clinics take on primary and secondary care roles for patients with CHC, and subspecialists such as child psychiatrists manage "straightforward mental health problems such as attention-deficit/hyperactivity disorder". A preponderance of responses suggested that, with a sound triage model and somewhat better support in their offices, pediatricians could manage Ch-Med without major departures from

current practice, but that meeting the needs of patients with Ch-DBM would require more extensive reorganization and innovation.

Discussion

Chronic health conditions among children have received limited attention from health services researchers and planners, especially in Canada. The findings of this survey provide a valuable overview of how front-line pediatricians view the status of health and related services for children with CHC, and possible ways to improve them, as well as clues to understanding pediatricians' readiness to embrace the newer models of care that might be needed.

Survey participants gave high marks to services for children with acute or life-threatening illnesses, lower marks to services for children with chronic medical problems and lowest marks to services for children with chronic developmental-behavioural and mental health problems. In addition to their overall ratings, participants' comments throughout the questionnaire reflected concerns about services for children with CHC in general and serious concerns about Ch-DBM in particular. The fact that the lowest ratings for adequacy and quality of services for Ch-DBM came from pediatricians who were most involved in the care of these children adds poignancy and significance to the situation. It is also disturbing that many of the structural and organizational aspects of care that are currently operational were rated as the "least preferred option" for care of children with CHC, and most notably for Ch-DBM.

For Ch-Med, a common pattern of responses in narrative comments indicated that a measured series of non-radical changes would go a long way towards addressing current deficiencies. Such measures include a combination of more support to pediatricians (including the involvement of advanced practice nurses and better access to medical specialists and specialized facilities), a more consistent and efficient system of triage, perhaps a more flexible way of remunerating

physicians for the care they provide to these children and families, and better methods of exchanging clinical information. A number of these measures—specifically closer integration of primary and specialist care,²³ closer collaboration and partnership with highly skilled nurses,²⁴ and better clinical information systems^{25,26}—are components of widely accepted models of chronic disease care for adults.

For Ch-DBM, beyond a more functional system of triage and improvements to the exchange of clinical data, respondents suggested the need for 1) better access to the community-based assessment, treatment and supportive services required for the health and well-being of these children and their families; 2) solutions to a pervasive shortage of professionals with mental health expertise; 3) remuneration methods that would be even more flexible, and perhaps substantially different than for Ch-Med, recognizing the need for substantial indirect care services for this population; and 4) new and alternative models of care, such as interdisciplinary community-based care teams, provided that safeguards to ensure accountability and efficiency were in place. Support for such teams specifically ranged from enthusiastic to guarded in this survey, but interdisciplinary and inter-agency collaboration and integration are becoming standards of care for CHC, particularly for complex and disabling conditions.²⁷⁻²⁹ Innovative ways to deliver care characterized by continuity and coordination that are being implemented in various parts of the world include the "medical home" concept of community care that promotes care coordination,³⁰ the "wraparound approach" for children and youth with serious emotional and behavioural conditions,³¹ and, in the United Kingdom, assignment to families of key workers.^{32,33} A feature shared by these approaches is the strategic deployment of nursing and allied health professionals within care teams to address the range of services needed by this population of patients and their families.

While pointing to a number of pressing gaps, the results of this study also suggest that solutions will need to take account of

differences between Ch-Med and Ch-DBM, geographic setting and physicians' readiness for change. Though sometimes difficult to demonstrate statistically, pediatricians in this survey appeared to perceive differences between Ch-Med and Ch-DBM in terms of service needs. Responses to the block of questions on structural and organizational aspects of community care suggest that pediatricians recognize the special challenges of managing Ch-DBM in terms of expertise, time and the need to communicate across settings and disciplines. Furthermore, responses throughout the questionnaire highlighted the issues of access to and coordination of services for this population as most pressing, adding weight to similar concerns articulated previously by parents and policy analysts.^{13,14}

In terms of geography, many respondents noted that solutions for remote areas may differ from those for major urban centres. Innovative methods have recently been proposed or piloted to address the situation of children with special needs and disability in more remote parts of Canada, including an increased role for paraprofessionals,³⁴ and telehealth for mental health needs.³⁵ Present findings support the need to include such possibilities when developing and planning services for children in BC. Another option could be to pilot in smaller communities in BC and Canada modified versions of chronic disease models from adult health care. Because most childhood CHC are not encountered frequently in the practice of an individual general or family physician, "chronic condition teams", consisting of medical, nursing and allied health service providers and compensated by mixed FFS and sessional arrangements, could provide services within defined geographic catchment areas to children with a range of CHC.

In this study, geographic or practice setting differences also seemed to underpin differences between physicians in their readiness to embrace new roles and reimbursement mechanisms. Although community-based pediatricians overall were not rejecting of alternative and new arrangements for physicians in providing care to CHC, they were relatively more inclined to be accepting of fee-for-service

arrangements, solo care from the physician's office and a traditional "medical role" with these children and families. Tertiary referral centre pediatricians, on the other hand, were the group most rejecting of these status quo arrangements, which pertain to typical community settings. In addition, some community pediatricians appeared to be more strongly supportive of status quo arrangements than others. In particular, a subgroup of community pediatricians situated in reasonably close proximity to the tertiary referral centre for the province, were the most accepting of status quo arrangements. Presumably such a setting allows physicians to enjoy the benefits of traditional practice arrangements, while their patients enjoy access to specialized resources and supports at the hospital. This situation can, however, lead to the kind of "dysfunctional triage" mentioned earlier, and may also undermine the principle of a clearly defined role for primary care and community-based practitioners in care of children with CHC.

The care of children and youth with chronic behavioural, emotional and mental health problems remains a vexing issue for policy makers, and it was notable that pediatricians in BC are not claiming priority over family physicians in obtaining resource support from child psychiatrists. Efforts to instill an awareness and interest in CHC early in the educational curricula of all physicians,³⁶⁻³⁸ adequate training in child mental health concerns, and appropriate nursing and allied health professional supports are all likely to be helpful in creating interest and confidence amongst community physicians, pediatricians and family physicians, who could potentially work on specialized chronic condition teams and could take a larger role in care of children with mental health issues.³⁹⁻⁴¹

Strengths and limitations

Strengths of this study include the breadth of the survey sample, which is representative of all pediatricians in practice in the province of British Columbia, and a relatively good response rate for a postal survey of physicians.⁴² The inclusion of a qualitative component allowed for more

insight into and expansion of the quantitative data and a wider and more authentic range of views than are possible in a purely forced-choice format.⁴³

Limitations of the study include the fact that this was an original survey, designed in the absence of a validated instrument to cover this content area. Nevertheless, the survey questionnaire has high face validity, especially as an instrument to ascertain respondents' views in a descriptive way. Though the response rate from eligible participants was quite high, relative to other physician surveys,⁴² a 60% response rate also means that the views of a substantial minority of pediatricians in BC were not represented. However, it was reassuring to find no significant differences between participants and non-participants based on background characteristics. Finally, there may be limits to the applicability of our respondents' views to other jurisdictions.

Conclusion

This survey's results indicate that a health care system set up to deal with acute illnesses in an otherwise healthy population fails to meet the health needs of children with CHC. There are many challenges to reforming health services for children, especially when considering the alternatives that are increasingly being adopted for adult chronic disease management.^{2,3} For example, the needs of children with CHC differ from those of adults¹⁷ and only a prototypic chronic disease management model appropriate for children and youth has yet been described (NICHQ Care Model for Child Health⁴⁴). Nevertheless, innovative approaches are increasingly being explored and implemented across the world,^{27,30,31} and the feasibility of these and other "home-grown" approaches needs to be pursued and examined in Canada.

Pediatricians in BC are clearly concerned about the accessibility and quality of health services for children with CHC, particularly for developmental and mental health. They are generally supportive of change and innovation in the way that services are organized and delivered, and

in their own roles, although certain subgroups, defined in part by proximity to the provincial specialized children's hospital, may be less embracing of change. The findings of this survey also suggest that solutions may need to take account of differences between subcategories of CHC and of geographic factors.

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Pharmacists' attitudes, role perceptions and interventions regarding smoking cessation: Findings from four Canadian provinces

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Abstract

Pharmacists in Ontario, Quebec, Saskatchewan and Prince Edward Island were surveyed in 2002 regarding their professional involvement in smoking cessation. In all provinces, at least 70% had positive attitudes toward smoking cessation. At least 50% thought that pharmacists have important roles in motivating patients to quit and in most aspects of motivating, assisting and referring patients. However, in all provinces, less than 40% had intervened in various ways in the past year with more than one half of their patients who smoked. Advising cutting down or quitting, attempting to increase motivation to quit and suggesting the use of nicotine replacement therapy were the most often performed interventions. Consistent inter-provincial patterns of differences in attitudes, role perceptions and interventions were not found. Some differences in attitudes and role perceptions were found between pharmacists practicing in provinces either banning or not banning tobacco sales in pharmacies, but there was no difference in overall interventions. The findings provide a baseline for provincial monitoring of pharmacists' professional smoking cessation attitudes, role perceptions and interventions. They also may inform tobacco control initiatives.

Key words: pharmacists, smoking cessation, attitudes, professional roles, interventions, Canada

Introduction

Now that nicotine replacement therapy (NRT) is available without prescription in Canadian pharmacies,¹ pharmacists are on the front line of contact with smokers who are considering NRT as an aid in smoking cessation. In fact, pharmacists may be the first or only health professional with whom some smokers interact regarding smoking cessation.

There is wide endorsement at the professional level for the increased involvement of pharmacists in helping their patients to quit smoking. In Canada, a group of national health professional organizations, including the Canadian Pharmacists Association, developed a *Joint Statement on*

Smoking Cessation, advocating that professionals be actively involved in prevention, cessation, protection and advocacy.² Organizations of pharmacists in the United States and worldwide also firmly support the increased involvement of pharmacists in helping their patients to quit smoking. The American Society of Health-System Pharmacists' (ASHP) position statement on smoking cessation³ urges pharmacists to implement the Agency for Healthcare Research and Quality guidelines⁴ for smoking cessation and to offer smoking cessation services. In 2005, the ASHP launched the Pharmacy Partnership for Tobacco Cessation, which is concerned with developing national educational initiatives and other resources for pharmacists in the United States.⁵ In 2003,

the International Pharmaceutical Federation (FIP) issued a statement of policy on the role of the pharmacist in promoting a tobacco-free future⁶ and in 2004, a World Health Organization (WHO) meeting of health professional organizations adopted a code of practice for health professional organizations regarding tobacco control.⁷ The Global Network of Pharmacists Against Tobacco has grown out of the FIP and WHO initiatives.⁸

Despite the critical positioning of pharmacists with respect to smoking cessation interventions, studies have shown that only a minority of pharmacists routinely advise their patients on this subject.⁹⁻¹⁷ In Canada, little attention has been paid to the smoking cessation interventions of pharmacists or to factors that may be related to these practices. We have published descriptive findings from the only survey that has addressed these interventions in detail.¹⁸ Overall, this study found that only about a third of respondent pharmacists reported that, in the past year, they intervened in some way with one half or more of patients they knew to be smokers. Using data from this survey, it was also shown that knowledge and skills, attitudes and perceptions of roles are strongly related to smoking-related interventions by pharmacists.¹⁹

In Canada, no provincial-level data have been published on pharmacists' smoking cessation attitudes and practices, nor on their perceptions regarding their professional roles in smoking cessation. With respect to developing national tobacco

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control initiatives involving pharmacists, it is important to know if there are consistent differences to be taken into account across provinces in the attitudes, practices and role perceptions of pharmacists. Pharmacists in Canada are licensed to practice by provincial regulatory bodies and many belong to province-based professional associations, both of which have interests in maintaining and upgrading standards of professional practice. The availability of province-specific data will be useful to these bodies as they develop, fund or endorse tobacco control initiatives aimed at increasing the involvement of pharmacists with their patients who smoke. Province-specific data may also stimulate the development of other provincial initiatives to increase the involvement of pharmacists with patients who smoke—for example, programs or policies developed under the aegis of departments of health. The data also may serve as a baseline for monitoring changes in practice within provincial settings, and they may point to other measures needed to assess the effectiveness of provincial interventions aimed at increasing the involvement of pharmacists with their patients who smoke. To these ends, we report provincial-level findings from our survey of Canadian pharmacists with respect to attitudes toward smoking and smoking cessation, perceptions of professional roles regarding smoking cessation, and reported interventions with patients who smoke. We also examine these findings with respect to provincial legislation regulating the sale of tobacco products in pharmacies.

Methods

Survey

Random samples of practising community pharmacists in Ontario (N = 745), Quebec (N = 450) and Saskatchewan (N = 310) and a list of all pharmacists in Prince Edward Island (N = 131) were obtained with the help of the professional association or licensing body in each province. The provinces were chosen to give a mix of provincial policy regarding tobacco sales in pharmacies, population smoking rates and geographical distribution. (When the

survey was conducted, tobacco was banned from sale in pharmacies in Ontario and Quebec, but not in those in Saskatchewan or Prince Edward Island.)

The survey procedures were based on the Dillman method.²⁰ Each pharmacist in the sample received an introductory letter from his or her provincial pharmacists' association or regulatory authority one week before the anonymous questionnaire was mailed. A reminder postcard was mailed to the entire sample one week after the questionnaire, with two follow-up mailings to non-respondents. Data were collected in the summer and fall of 2002.

Questionnaire

A questionnaire was drafted after review of the literature for relevant issues and consultation with pharmacists and representatives of pharmacy associations. It was pre-tested in individual and group interviews with practising pharmacists and through a mailing to selected pharmacists who had agreed to help with the pre-test. The revised questionnaire included questions concerning the attitudes of pharmacists toward smoking cessation, perceptions of their professional roles regarding patients who smoke and practices with respect to these patients. The questionnaire was translated into French for use in Quebec and reviewed by a francophone professor of pharmacy. Pharmacists in any of the provinces could request material in either language.

Respondents

A total of 996 completed questionnaires were returned. The response rates were calculated according to the American Association for Public Opinion Research Guidelines,²¹ which removes from the denominator those who could not be reached, those who were ineligible (e.g., not in practice, retired) and those who were estimated to be ineligible from the non-respondents (i.e., surveys that were not returned). The response rates were 70.3%, 74.2%, 71.4% and 79.4% for Ontario, Quebec, Saskatchewan and Prince Edward Island, respectively. Pharmacists who reported spending less than 5% of

their time in patient contact roles (N = 13; 1.3%) or who spent less than eight hours per week in their primary pharmacy work setting (N = 23; 2.3%) were excluded from further analysis, leaving 962 questionnaires for analysis. Two respondents had spent less than 5% of their time in patient contact and less than eight hours per week in their primary setting. Of the remaining questionnaires, 41%, 31%, 20% and 8% were from pharmacists in Ontario, Quebec, Saskatchewan and Prince Edward Island, respectively. The provincial findings reported in the tables are presented from left to right, according to the diminishing size of respondent groups.

Descriptive statistics regarding the respondents themselves and the size of the communities in which they practiced are provided in Table 1. There were provincial differences in the sex of the respondents and in the time elapsed since obtaining a pharmacy baccalaureate degree (a proxy measure of age). As well, there were marked provincial differences in the populations of the communities in which the respondents practiced. Pharmacists in Ontario and Quebec more often practiced in large cities and less often in small towns. However, tobacco use among pharmacists was similar across the provinces. In all four provinces, less than 6% of respondents were current users of tobacco.

Analysis

Descriptive analyses, including percentages and confidence intervals, were calculated using SAS software, version 9.1 (SAS Institute Inc., Cary, NC). Analysis of variance, chi-square tests and Fisher's exact tests of association were used where appropriate for comparing personal and practice characteristics across the four provinces. Province-specific percentages were not weighted because within each province every pharmacist had an equal probability of being selected.

Factor analysis

Factor analysis of the ten questions used to assess attitudes toward smoking cessation and interventions with patients who smoke revealed that these items comprised three

groups (Table 2): positive attitudes toward smoking cessation (proportion of variance explained = 0.29; Cronbach's alpha = 0.81), negative attitudes toward smoking cessation (proportion of variance explained = 0.35; Cronbach's alpha = 0.83), and economic-related attitudes toward smoking cessation interventions (proportion of variance explained = 0.15; Cronbach's alpha = 0.80). Factor analysis of the eleven questions used to assess perceptions of pharmacists' clinical roles regarding patients who smoke showed that these questions formed two groups (Table 3): assessing and motivating patients (proportion of variance explained = 0.35; Cronbach's alpha = 0.88) and assisting, referring and following up (proportion of variance explained = 0.13; Cronbach's alpha = 0.85). Factor analysis of the 12 items used to assess interventions within the past year with patients who smoke (Table 4) did not reveal any groupings.

The factor analyses were used to develop summary attitude, role and intervention scores that could be compared across provinces. Summary scores for each of the

three attitude factors and the two role factors were calculated by summing the ordinal responses within each factor. For the positive and negative attitude factors, the responses could range from a low of 4 to a maximum of 16. The economic-related attitudes factor ranged from a low of 2 to a maximum of 8. The responses were weighted so that higher mean scores would indicate more positive attitudes, more negative attitudes and more economic-related concerns, respectively. Of the two role factors, the assessing and motivating patients factor ranged from a low of 3 (representing little belief that these should be important roles for pharmacists) to a maximum of 12 (representing strong belief in the importance of these roles). Similarly, the assisting, referring and following up role factor ranged from a low of 8 to a maximum of 24. Finally, one summary intervention score was created from all 12 questions used to assess individual smoking cessation interventions. It ranged from a minimum of 12 to a maximum of 60, with higher values representing interventions with greater proportions of patients who smoke.

Provincial comparisons with respect to tobacco sales policy

The four provinces were grouped into either those allowing sales of tobacco products in pharmacies (Saskatchewan and PEI) at the time of the survey or those prohibiting sales (Ontario and Quebec).

Each of the six summary scores was modelled onto the policy status using robust generalized linear modelling, controlling for the community size in which the primary practice was located. Prior to modelling, each of the personal and practice characteristics presented in Table 1 was tested for association with each of the summary score outcomes, and with "sales policy" taken separately. Only "community size" met our *a priori* criteria of an association with at least one attitude score, one role score, the intervention score and with sales policy, each at the 0.10 significance level. Respondents were asked if the size of the community in which they practised was 1) less than 25,000; 2) 25,000 to 99,999; 3) 100,000 to 500,000; or 4) more than 500,000 (Table 1).

TABLE 1
Personal and practice characteristics of surveyed Canadian pharmacists from four provinces (2002)

Characteristic	Ontario (N=391)	Quebec (N=297)	Saskatchewan (N=192)	Prince Edward Island (N=82)	p-value ^a
Personal					
Sex (% female)	50.3	64.5	56.8	54.2	0.002
Mean years since degree earned (and standard deviation)	20.4 (11.0)	14.8 (12.0)	19.8 (12.3)	14.2 (10.9)	< 0.001
Tobacco use (%)					
Current	3.1	5.7	5.7	3.7	0.523
Former	19.2	21.9	18.2	19.8	
Never	77.8	72.4	76.0	76.5	
Practice					
Population of community where practising (%)					
< 25,000	20.5	32.4	45.8	56.8	< 0.001
25,000 – 99,999	17.4	26.7	13.0	43.2	
100,000 – 500,000	29.9	17.9	41.2	0.0	
> 500,000	32.2	23.0	0.0	0.0	

^a Chi-square and Fisher's exact tests were used to compare pharmacists across the four provinces with regard to sex, tobacco use and population of community where practising. Analysis of variance was used to compare time elapsed since pharmacists' degree earned, across the provinces. A p-value of > 0.05 was considered not significant.

Results

Attitudes toward smoking cessation

The factor analysis showed that the ten questions regarding attitudes toward smoking cessation fell into three groups, which we called positive attitudes, negative attitudes and economic-related attitudes (Table 2). More than 70% of pharmacists in all four provinces held positive views about smoking cessation. Much smaller percentages had negative views and economic-related concerns. However, at least one quarter of pharmacists in each province agreed that there is little economic incentive for pharmacists to advise on quitting smoking. Although there was some overall inter-provincial variation in seven of the ten attitudes, a clear consistent pattern of provincial differences was not evident.

Perceptions of professional roles

Factor analysis of the eleven questions concerning the professional clinical roles of pharmacists with respect to smoking and smoking cessation revealed two groups, which we called “assessing and motivating patients” and “assisting, referring and following up”. With regard to assessing and motivating patients, more than 50% of pharmacists in all provinces agreed that motivating patients to quit was an important role (Table 3). Pharmacists in all four provinces viewed assessing patient’s readiness to quit as a somewhat less important role, and less than 50% of pharmacists in all provinces thought that asking patients if they smoke and assessing patient’s dependence on smoking were important roles. There was inter-provincial

variation in how pharmacists viewed the importance of three of the four roles, with pharmacists in Ontario tending to be less likely to perceive these roles as important.

With respect to assisting, referring and following up, more than 50% of pharmacists in all four provinces endorsed six of the seven roles as being important. The role of advising patients about the use of NRT (gum or patches) was very strongly endorsed by more than 80% of pharmacists in all four provinces. There was generally less endorsement for the importance of following up progress in quitting, particularly among pharmacists in Ontario and Saskatchewan. Although there was inter-provincial variation in perceptions of all of these roles, a clear consistent pattern of provincial differences was not discernable.

TABLE 2
Attitudes of surveyed Canadian pharmacists towards smoking cessation, by province (2002)

Attitudes towards smoking cessation ^a	Ontario (N=391)	Quebec (N=297)	Saskatchewan (N=192)	Prince Edward Island (N=82)	p-value ^b
Percent agree (95% Confidence interval)					
Positive attitudes					
Most smokers can quit if they really want to	81.4 (76.7 - 86.0)	84.2 (79.2 - 89.2)	78.0 (72.9 - 83.1)	75.9 (70.6 - 81.2)	n.s.
Relief of withdrawal symptoms is important for successfully quitting	92.1 (87.3 - 96.9)	94.9 (89.8 - 100.0)	89.1 (83.7 - 94.5)	92.7 (86.9 - 98.6)	n.s.
With most smokers, pharmacists can be effective in promoting smoking cessation	89.0 (84.3 - 93.8)	96.6 (91.4 - 100.0)	89.1 (83.7 - 94.5)	94.0 (88.1 - 99.8)	< 0.001
Patients appreciate it when I provide smoking cessation advice	92.3 (87.5 - 97.1)	98.3 (93.1 - 100.0)	94.2 (88.7 - 99.8)	90.4 (84.6 - 96.1)	0.002
Negative attitudes					
When a person has been smoking many years, there isn't much point in trying to quit	5.9 (4.4 - 7.4)	3.4 (2.2 - 4.5)	2.1 (1.2 - 3.0)	1.2 (0.5 - 1.9)	n.s.
Talking with smokers about quitting will discourage their return as customers	12.5 (10.4 - 14.7)	2.1 (1.1 - 2.9)	10.9 (8.9 - 13.0)	8.4 (6.6 - 10.3)	< 0.001
Most patients don't want unsolicited advice from their pharmacist	35.1 (31.7 - 38.6)	21.8 (19.0 - 24.7)	34.9 (31.3 - 38.5)	20.5 (17.6 - 23.3)	< 0.001
Counselling patients about quitting smoking is a thankless task	24.4 (21.5 - 27.4)	8.4 (6.6 - 10.2)	26.0 (22.9 - 29.2)	9.6 (7.7 - 11.6)	< 0.001
Economic-related attitudes					
Advising about smoking cessation takes time away from more profitable activities	19.7 (17.0 - 22.4)	17.0 (14.5 - 19.5)	12.0 (9.8 - 14.1)	4.8 (3.4 - 6.2)	0.003
There is not much economic incentive for pharmacists in advising about quitting smoking	37.6 (34.0 - 41.1)	31.5 (28.2 - 34.9)	44.3 (40.3 - 48.3)	30.1 (26.7 - 33.5)	0.020

^a Attitudes are grouped according to a factor analysis.

^b For each attitude, a chi-square test was used to compare pharmacists who strongly agreed/somewhat agreed with the statement to those who strongly disagreed/somewhat disagreed across the four provinces. A p-value of > 0.05 was considered not significant (n.s.).

TABLE 3
Surveyed Canadian pharmacists' perceptions of important roles in smoking cessation, by province (2002)

Role should be important for pharmacists ^a	Ontario (N=391)	Quebec (N=297)	Saskatchewan (N=192)	Prince Edward Island (N=82)	p-value ^b
Percent (95% Confidence interval)					
Assessing and motivating patients					
Asking patients if they smoke	30.6 (27.3 - 33.9)	45.8 (41.8 - 49.8)	34.4 (30.8 - 37.9)	34.9 (31.3 - 38.6)	< 0.001
Assessing patient's dependence on smoking	28.6 (25.5 - 31.8)	43.8 (39.9 - 47.7)	30.2 (26.8 - 33.6)	42.2 (38.1 - 46.2)	< 0.001
Assessing patient's readiness to quit	43.0 (39.2 - 46.7)	46.0 (42.0 - 49.9)	46.4 (42.3 - 50.4)	56.6 (52.0 - 61.3)	n.s.
Motivating patients to quit smoking	56.6 (52.5 - 60.8)	69.1 (64.5 - 73.8)	62.5 (57.8 - 67.2)	69.9 (64.8 - 75.0)	0.004
Assisting, referring and following up					
Giving patients pamphlets or other brief tips on quitting smoking	78.3 (73.7 - 82.9)	85.2 (80.2 - 90.2)	82.3 (77.1 - 87.5)	90.4 (84.6 - 96.1)	0.022
Counselling patients on behavioural techniques for quitting smoking	63.8 (59.4 - 68.1)	56.0 (51.7 - 60.3)	70.3 (65.4 - 75.2)	69.9 (64.8 - 75.0)	0.006
Advising patients about the use of NRT gum or patches	88.8 (84.0 - 93.5)	97.3 (92.1 - 100.0)	91.2 (85.7 - 96.6)	97.6 (91.6 - 100.0)	< 0.001
Referring patients to a physician for help in quitting smoking	66.1 (61.7 - 70.5)	53.7 (49.5 - 57.9)	78.1 (73.0 - 83.3)	83.1 (77.6 - 88.7)	< 0.001
Referring patients to a smoking cessation program or a 1-800 Quit Line	65.6 (61.2 - 69.9)	55.7 (51.4 - 60.0)	62.5 (57.8 - 67.2)	81.9 (76.4 - 87.4)	< 0.001
Following patients' progress in quitting smoking	39.0 (35.4 - 42.7)	52.7 (48.5 - 56.9)	44.0 (40.0 - 48.0)	63.9 (58.9 - 68.8)	< 0.001
Advising patients on the use of bupropion to quit smoking	59.1 (54.8 - 63.3)	79.1 (74.2 - 83.9)	64.9 (60.2 - 69.7)	73.5 (68.2 - 78.7)	< 0.001

^a Role perceptions are grouped according to a factor analysis.

^b For each role, a chi-square test was used to compare pharmacists who thought the role should be important for pharmacists to those who thought pharmacists should have some role or no role at all, across the four provinces. A p-value of > 0.05 was considered not significant (n.s.).

Interventions

Twelve questions were asked about specific interventions in the past year with patients who smoke. The factor analysis did not reveal any groupings. In all four provinces, less than 50% of pharmacists indicated that they performed each intervention in the past year with more than half their patients who smoked (Table 4). Advising cutting down or quitting, attempting to increase motivation to quit and suggesting the use of NRT were consistently the most likely interventions to be performed by pharmacists in all four provinces. Inter-

provincial variation was found for five of the twelve interventions, but no clear consistent pattern of provincial differences was evident.

Provincial policy regarding the sale of tobacco in pharmacies

Pharmacists practising in provinces banning tobacco sales in pharmacies had more positive attitudes regarding smoking cessation than did pharmacists practising in provinces where tobacco sales were permitted (Table 5). There was no statistically significant difference in negative attitudes.

Economic-related concerns were more likely to be reported by pharmacists practising in the provinces not allowing tobacco sales. With respect to role perceptions, there was no difference between the two groups in how pharmacists viewed the importance of assessing and motivating patients. However, pharmacists in the provinces permitting tobacco sales were more likely to view assisting, referring and following up as important roles. Reported interventions, however, were similar between the pharmacists practising in provinces differentiated by pharmacy-tobacco-sales policies.

TABLE 4
Frequency of surveyed Canadian pharmacists' smoking cessation interventions
with their patients who smoke, by province (2002)

Intervention in the past year with more than half of patients who smoke ^a	Ontario (N=391)	Quebec (N=297)	Saskatchewan (N=192)	Prince Edward Island (N=82)	p-value ^b
	Percent (95% Confidence interval)				
Discussed the effects of smoking on health	21.4 (18.6 - 24.2)	15.4 (13.0 - 17.9)	16.7 (14.1 - 19.2)	17.1 (14.5 - 19.7)	n.s.
Discussed the health effects of second-hand smoke	14.2 (11.9 - 16.5)	8.1 (6.3 - 9.8)	9.4 (7.5 - 11.3)	6.2 (4.6 - 7.7)	0.025
Assessed readiness to quit smoking	22.7 (19.9 - 25.6)	17.2 (14.6 - 19.7)	19.8 (17.0 - 22.6)	22.0 (19.0 - 24.9)	n.s.
Advised cutting down or quitting smoking	33.0 (29.6 - 36.4)	29.3 (26.0 - 32.6)	28.7 (25.4 - 31.9)	28.1 (24.7 - 31.4)	n.s.
Attempted to increase motivation to quit	33.6 (30.2 - 37.0)	34.3 (30.8 - 37.9)	31.1 (27.6 - 34.5)	28.1 (24.7 - 31.4)	n.s.
Counselled on behavioural techniques for quitting smoking	23.5 (20.5 - 26.4)	20.5 (17.7 - 23.2)	20.3 (17.5 - 23.1)	21.0 (18.1 - 23.9)	n.s.
Gave pamphlets or other brief tips on quitting smoking	30.2 (27.0 - 33.5)	19.8 (17.1 - 22.5)	23.4 (20.4 - 26.4)	32.9 (29.3 - 36.5)	0.006
Referred to a smoking cessation program or 1-800 Quit Line	13.7 (11.4 - 16.0)	5.7 (4.2 - 7.2)	4.7 (3.3 - 6.1)	24.4 (21.3 - 27.5)	< 0.001
Suggested use of NRT gum or patch	36.1 (32.6 - 39.6)	32.9 (29.4 - 36.3)	26.6 (23.4 - 29.7)	34.2 (30.5 - 37.8)	n.s.
Referred to a physician for help in quitting smoking	21.0 (18.2 - 23.8)	22.9 (20.0 - 25.8)	14.1 (11.8 - 16.5)	14.6 (12.2 - 17.0)	n.s.
Suggested obtaining a prescription for bupropion from a physician	15.5 (13.1 - 18.0)	5.4 (3.9 - 6.8)	14.6 (12.2 - 17.0)	7.4 (5.6 - 9.0)	< 0.001
Followed up on progress in quitting smoking	18.5 (15.9 - 21.1)	31.2 (27.8 - 34.6)	20.4 (17.6 - 23.2)	21.0 (18.1 - 23.9)	< 0.001

^a Interventions are listed as assessed in the questionnaire. A factor analysis did not identify any groupings.

^b For each intervention, a chi-square test was used to compare pharmacists who said they performed this role with more than half of their patients who smoke to pharmacists who did so less often, across the four provinces. A p-value of > 0.05 was considered not significant (n.s.).

TABLE 5
Canadian pharmacists' attitudes, role perceptions and interventions, by their provincial policy on the sale of tobacco in pharmacies (2002)

	Provinces banning sales (Ontario and Quebec) (N = 688)		Provinces allowing sales (Saskatchewan and Prince Edward Island) (N = 274)		Adjusted p-value ^c
	Mean score ^a	SD ^b	Mean score ^a	SD ^b	
Attitudes					
Positive	13.51	1.89	13.16	2.10	0.019
Negative	6.65	1.92	6.64	1.71	0.527
Economic-related	3.92	1.48	3.71	1.38	0.016
Role perceptions					
Assessing and motivating patients	9.56	1.74	9.63	1.72	0.780
Assisting, referring and following up	18.42	2.40	19.00	2.21	0.001
Intervention score	29.08	10.78	27.97	10.43	0.632

^a A higher mean factor score indicates more positive attitudes, more negative attitudes, more economic-related concerns, more perceptions that roles are important and more interventions

^b Standard deviation

^c Adjusted for size of community

Discussion

The findings of this study concerning the very strong positive attitudes of pharmacists in all four provinces toward smoking cessation are encouraging, especially because negative attitudes and economic concerns were much less commonly expressed. The generally strong positive attitudes are matched by strong support for pharmacists' professional roles in most aspects of motivating, assisting and referring patients who smoke. However, the lesser degree of support observed among pharmacists in all four provinces for assessing smoking status, dependence and readiness to quit, and following up on progress in quitting suggests that provincial and national programs should address these clinical aspects to better prepare pharmacists for their central role in smoking cessation.

The positive attitudes of pharmacists toward smoking cessation and the generally strong support for some professional roles are not reflected in the level of reported smoking cessation interventions. With respect to the twelve smoking cessation practices examined, fewer than 50% of pharmacists in each studied province had intervened in the last year with more than half of their patients who smoke. Clearly, there is much room for improvement. Given the wide endorsement at the professional level for the increased involvement of pharmacists in helping their patients to quit smoking, the findings underline the need for tobacco control initiatives to be aimed at increasing the professional involvement of pharmacists in smoking cessation.

An array of factors may underlie a failure to intervene with smoking patients, including personal ones, such as educational preparation; environmental factors in the pharmacy settings (e.g., lack of dedicated counselling space); and practice factors (e.g., insufficient time and lack of management support).^{9,16,18} For example, with respect to education preparation, in a separate study with our respondents, we showed that those with higher levels of self-assessed basic pharmacologic and applied health-

science knowledge were more likely, when compared to counterparts who felt less knowledgeable, to undertake the various clinical interventions, independent of attitudes, perceptions of roles, sex, smoking status and years of practice.²² It is also noteworthy that at least one quarter of respondents in each province agreed that there is little economic incentive for pharmacists to advise on quitting smoking, suggesting that economic concerns may also be barriers to intervention. These issues need to be addressed in provincial and national programs aimed at increasing the interventions of pharmacists with their patients who smoke.

Although some inter-provincial differences were found, clear patterns were not discernable for the most part. What was clear, however, was the relative consistency among pharmacists across the four provinces in attitudes, role perceptions and interventions. Although pharmacists in all provinces had strong positive attitudes, the statement "Most smokers can quit if they really want to" was the least supported attitude measure among pharmacists in each of the four studied provinces. Negative attitudes were much less strongly held, but the strongest support in all provinces was for the statement "most patients don't want unsolicited advice from their pharmacist". Pharmacists in all four provinces consistently reported the lack of financial incentive in advising patients about quitting smoking as the more important of the two economic-related issues examined. Pharmacists in all four provinces consistently viewed advising patients about the use of NRT and giving patients pamphlets or other brief tips on quitting smoking as the first and second most important roles for their profession. With respect to reported interventions, advising cutting down or quitting, attempting to increase motivation to quit and suggesting the use of NRT were consistently among the top three interventions performed by pharmacists in all four provinces. These findings suggest that national programs to increase the involvement of pharmacists with patients who smoke are likely to be viewed similarly by pharmacists in all provinces.

Despite the relative consistency of findings across the four provinces, some potentially interesting inter-provincial differences were found. For example, with respect to roles, pharmacists in Saskatchewan and Prince Edward Island appeared more inclined than their counterparts in Ontario and Quebec to view referral to a physician as an important role. Further, with respect to interventions, although for the most part pharmacists reported they did not suggest that their patients obtain prescriptions from their physicians for bupropion, at least twice as many pharmacists in Ontario and Saskatchewan, compared to those in Quebec and Prince Edward Island, reported that they had made this suggestion in the past year to more than half of their patients who smoked. Further investigation of some inter-provincial differences may be warranted.

Although pharmacists practising in provinces banning tobacco sales in pharmacies had more positive attitudes toward smoking cessation, and pharmacists practising in provinces permitting tobacco sales in pharmacies were more likely to view the roles of assisting, referring and motivating patients as important, overall interventions with patients who smoke were similar between these two groups of pharmacists differentiated by provincial sales policies. This suggests that the provincial policy with respect to tobacco sales in pharmacies may not be an important factor underlying the interventions of pharmacists with patients who smoke. Pharmacists practising in provinces where tobacco sales were not permitted had more economic-related concerns than pharmacists practising in provinces allowing tobacco sales. We are uncertain as to why this is the case.

Limitations

This study has limitations. The data were collected by a mailed self-report questionnaire and are subject to response bias. However, the possibility of response bias is minimized when response rates are high, as they were with respect to all four provinces. Data cannot be valid without a high response rate. The Dillman method²⁰

used for collecting the data in this survey is well documented and widely used in mail surveys. The questionnaire was pre-tested in individual and group interviews with practising pharmacists and through a mailing of selected pharmacists who had agreed to help with the pre-test. These procedures help to increase the face validity of the survey findings. In addition, responses concerning pharmacists' interventions are consistent with expectations from previous studies of pharmacists.^{9,16} The data are cross-sectional and causal relationships cannot be inferred. Attitudes and perceptions of roles are unlikely to have been fully explored by the limited questions asked. Qualitative research might be useful in further defining these complex constructs. Multiple testing may result in some significant associations by chance. Nonetheless, several associations are highly significant and unlikely to be a result of type I error. The results of these analyses should be viewed as hypothesis generating, providing a baseline for further research.

Implications

Efforts are under way in some provinces and nationally to highlight the roles of pharmacists in smoking cessation and better prepare them for these roles. For example, the Clinical Tobacco Intervention program in Ontario trains pharmacists, physicians and dentists to intervene with smokers.²³ The Representative Board of Saskatchewan Pharmacists is developing smoking cessation specialist training for pharmacists and the Canadian Pharmacists Association is developing a smoking cessation training program for Canadian pharmacists.²⁴ A survey and curriculum workshop on smoking cessation for faculty involved in the undergraduate education of Canadian pharmacists has been held²⁵ and the educational needs of Canadian community pharmacists have been assessed.²² These undertakings indicate a clear appreciation nationally and provincially of the central role that pharmacists can play in smoking cessation and the need to enhance the efforts of Canadian pharmacists in this regard. The findings of the

present study provide a baseline against which progress toward the realization of this central role can be assessed in four provinces. They also provide a basis for national and provincial program and policy development designed to increase the involvement of pharmacists in smoking cessation.

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Eliciting Canadian population preferences for health states using the Classification and Measurement System of Functional Health (CLAMES)

Cameron N McIntosh, Sarah Connor Gorber, Julie Bernier and Jean-Marie Berthelot

Abstract

A major objective of the Population Health Impact of Disease in Canada (PHI) research program was to obtain Canadian-specific preferences for health states associated with various diseases, in order to estimate the morbidity component of summary measures of population health embodying the Canadian experience of disease. In this study, preferences for health states were elicited from lay panels (N=146) in nine Canadian communities (Vancouver, Edmonton, Saskatoon, Toronto, Ottawa, Montréal, Québec, Moncton and Halifax); the study was conducted from January to June of 2003. Information on health states was presented to raters using the CLAssification and MEasurement System of Functional Health (CLAMES), which assesses functional capacity using 11 health status attributes, each with four to five levels ranging from normal to severely limited functioning. Preferences for 238 health states classified by CLAMES were elicited using the standard gamble (SG) technique in both individual and group exercises. Mean preferences for these health states were then used to estimate the parameters of a log-linear scoring function for CLAMES. The function provides a convenient method of computing preference scores for any health state classified by CLAMES, without the need for direct measurement in surveys. Further, the SG appears feasible in group settings.

Key words: Canadian health state preferences, classification and measurement system of functional health, Population Health Impact, preference-based scoring function, standard gamble

Introduction

A major objective of the Population Health Impact of Disease in Canada (PHI) research program was to obtain Canadian-specific preferences for health states associated with various diseases, in order to estimate the morbidity component of summary measures of population health (SMPH) embodying the Canadian experience of disease. Health state preference scores quantify the perceived desirability of particular health states, typically in terms of a continuum bounded by 0 (i.e., death) and 1 (i.e., full health).^{1,2}

Within the context of burden of disease research, health state preference scores are used to weight the time spent in sub-optimal health states, in order to compute SMPH that integrate information on both mortality and morbidity.³

Thus far, however, the health state preferences used in burden of disease studies have been largely those of medical experts,⁴ who may not constitute a representative sample of the general population.⁵ If health state preferences are to form part of the evidence base for broad health care policy and planning,

then the preferences of those ultimately affected by any decisions in the health sector should figure into the process.⁵⁻⁸

The current article describes three methodological steps required to obtain Canadian-specific preferences for health states linked to different diseases: 1) the use of a generic tool—the CLAssification and MEasurement System of Functional Health (CLAMES)—for communicating information about health states to raters; 2) the implementation of standard gamble (SG) protocols for measuring health state preferences in panels of lay Canadians; and 3) the use of a preference-based scoring function to compute a tariff (i.e., a summary health-related quality of life [HRQoL] value) for all health states classified by the CLAMES instrument.

Materials and methods

The CLAMES instrument for classifying health states

To represent the impact of various diseases on physical, mental and social functioning and to convey information on health states to raters, a standardized tool was created, namely the CLAssification and MEasurement System of Functional Health (CLAMES; see Table 1). CLAMES contains 11 health status attributes borrowed and adapted from three leading generic health status instruments: the Health Utilities Index Mark III (HUI3),⁹ the Medical Outcomes Study Short-Form 36 (SF-36)¹⁰ and the European Quality of Life

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TABLE 1
The CLAssification and MEasurement System of Functional Health (CLAMES) Instrument

Attribute	Level	Description
Pain or discomfort*	1	Generally free of pain and discomfort
	2	Mild pain or discomfort
	3	Moderate pain or discomfort
	4	Severe pain or discomfort
Physical functioning**	1	Generally no limitations in physical functioning
	2	Mild limitations in physical functioning
	3	Moderate limitations in physical functioning
	4	Severe limitations in physical functioning
Emotional state*	1	Happy and interested in life
	2	Somewhat happy
	3	Somewhat unhappy
	4	Very unhappy
	5	So unhappy that life is not worthwhile
Fatigue**	1	Generally no feelings of tiredness, no lack of energy
	2	Sometimes feel tired and have little energy
	3	Most of the time feel tired and have little energy
	4	Always feel tired and have no energy
Memory and thinking*	1	Able to remember most things, think clearly and solve day-to-day problems
	2	Able to remember most things but have some difficulty when trying to think and solve day-to-day problems
	3	Somewhat forgetful, but able to think clearly and solve day-to-day problems
	4	Very forgetful, and have great difficulty when trying to think or solve day-to-day problems
Social relationships**	1	No limitations in the capacity to sustain social relationships
	2	Mild limitations in the capacity to sustain social relationships
	3	Moderate limitations in the capacity to sustain social relationships
	4	Severe limitations in the capacity to sustain social relationships
	5	No capacity or unable to relate to other people socially
Anxiety***	1	Generally not anxious
	2	Mild levels of anxiety experienced occasionally
	3	Moderate levels of anxiety experienced regularly
	4	Severe levels of anxiety experienced most of the time
Speech*	1	Able to be understood completely when speaking with strangers or friends
	2	Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know you well
	3	Able to be understood partially when speaking with strangers and people who know you well
	4	Unable to be understood when speaking to other people
Hearing*	1	Able to hear what is said in a group conversation, without a hearing aid, with at least 3 other people
	2	Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but require a hearing aid to hear what is said in a group conversation with at least 3 other people
	3	Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but unable to hear what is said in a group conversation with at least 3 other people
	4	Unable to hear what others say, even with a hearing aid
Vision*	1	Able to see well enough, with or without glasses or contact lenses, to read ordinary newsprint and recognize a friend on the other side of the street
	2	Unable to see well enough, even with glasses or contact lenses, to recognize a friend on the other side of the street but can see well enough to read ordinary print
	3	Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint but can see well enough to recognize a friend on the other side of the street
	4	Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint or to recognize a friend on the other side of the street
Use of hands and fingers*	1	No limitations in the use of hands and fingers
	2	Limitations in the use of hands and fingers but do not require special tools or the help of another person
	3	Limitations in the use of hands and fingers, independent with special tools and do not require the help of another person
	4	Limitations in the use of hands and fingers, require the help of another person for some tasks
	5	Limitations in the use of hands and fingers, require the help of another person for most tasks

* Adapted from HUI3

** Adapted from SF-36

***Adapted from EQ-5D

Five-Dimensions Index Plus (EQ-5D).^{11,12} CLAMES focuses on individuals' capacities (i.e., what they are able to do) with respect to the various attributes, each of which has four or five levels ranging from normal to severely limited functioning. A complete health state is represented by an 11-tuple

or list of attribute levels; thus, 10,240,000 health states are possible within the system.

The HUI3 was adapted (see Table 1) to broaden its scope by using attributes from the SF-36 and EQ-5D. The attribute "Social

Relationships" was added to help classify health states in which limitations in the ability to maintain social relationships are a defining feature (e.g., Asperger's syndrome, schizophrenia). The HUI3 ambulation attribute was expanded to include a broader range of physical limita-

tions resulting from disease (e.g., stroke). The addition of attributes “Anxiety” and “Fatigue” also assisted in the classification of disease-related limitations. Focus groups with members of the lay population, as well as consultation with experts in multi-attribute health status instrumentation, assisted in refining the content of the CLAMES framework.

The health states

Since it was infeasible to directly measure preferences for all possible health states generated by CLAMES, a subset of 238 health states was taken into the field in order to obtain data for building a scoring function. Twelve of these states were “marker states”⁹ to be tested by all participants. These states were chosen to span the intermediate range of morbidity between full health and death. An additional 189 states consisted of health states associated with actual diseases, as well as some hypothetical health states created to ensure that all levels of all attributes appeared at least once. These health states permitted an econometric (or statistical) approach to developing a scoring function for CLAMES.^{13,14} Another 37 states in which all attributes were at the best level—except one attribute, which was set at its worst level (forming a “corner state”) or an intermediate level (forming a “pure state”)—allowed for the use of a decomposed approach to modeling the observed preference scores.^{9,13}

Laminated cards (see Table 2) were used to present the classification of functional limitations for each of the 238 health states to raters. The health states were identified by a randomly allocated two-letter code, rather than disease labels, in order to reduce the influence of participants’ idiosyncratic experience with or knowledge of the diseases on the preference measurement exercises. Further, to minimize the cognitive load imposed on participants,¹⁵ the cards did not always explicitly present all 11 attributes. The cards always contained six core attributes (i.e., Pain or Discomfort, Physical Functioning, Emotional State, Fatigue, Memory and Thinking, and Social Relationships) that were expected to be most commonly affected by the various health states under

study. For these attributes, a blank space beside the attribute name denoted no limitations on that attribute. For the remaining five supplementary attributes (i.e., Anxiety, Speech, Hearing, Vision, and Use of Hands and Fingers), an attribute was included on the card only if it was affected by the health state. Participants were instructed that the absence of information about limitations meant there were no limitations; they were provided with reference booklets on CLAMES that contained all the attributes.

Participants

Lay panels consisting of 8 to 11 participants each were assembled for the preference measurement exercises. Recruitment was carried out through market research agencies in the following nine Canadian communities: Vancouver, Edmonton, Saskatoon, Toronto, Ottawa, Montréal, Québec, Moncton and Halifax. Participants

were selected using a combination of pre-existing research databases, random digit dialling and advertising in local newspapers. In all, 146 individuals participated in 14 panels nationwide.

Screening questionnaires and quota sampling were used to help ensure that each group included a mixture of socio-demographic and other characteristics (i.e., age, sex, education, income, marital and immigrant status, rural versus urban dwellers, and activity limitations). The market research agencies also worked with contacts in other organizations (e.g., student, senior and immigrant associations) in order to help fill the quotas. Some of the study activities were carried out on weekends in order to facilitate representation of the working population. (More information on the recruiting strategies is available from the authors upon request).

TABLE 2
Sample health state cards

Health state: UF	
You have problems with the following:	
Pain or discomfort	Moderate pain or discomfort
Physical functioning	Severe limitations in physical functioning
Emotional state	Very unhappy
Fatigue	Most of the time feel tired and have little energy
Memory and thinking	Very forgetful and have great difficulty when trying to think or solve day-to-day problems
Social relationships	Severe limitations in the capacity to sustain social relationships
Anxiety	Mild levels of anxiety experienced occasionally
Speech	Unable to be understood when speaking to other people
Vision	Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint but can see well enough to recognize a friend on the other side of the street
Use of hands and fingers	Limitations in the use of hands and fingers, require the help of another person for some tasks
Health state: ML	
You have problems with the following:	
Pain or discomfort	Moderate pain or discomfort
Physical functioning	Mild limitations in physical functioning
Emotional state	
Fatigue	Sometimes feel tired and have little energy
Memory and thinking	
Social relationships	
Anxiety	Mild levels of anxiety experienced occasionally

The preference measurement exercises were conducted from January to June of 2003. Four of the sessions were conducted in French (two in Quebec, one in Ontario and one in New Brunswick), while the remaining ten were conducted in English. Each session, which lasted approximately six hours, included both group and individual measurement exercises. In order to minimize variance due to facilitator effects, an experienced bilingual facilitator from Statistics Canada's Questionnaire Design Resource Centre led each session using a standardized script; additional support was provided by one of the study team members (SCG or JB).

The preference measurement exercises

After an introduction about the purpose and implications of the research program, the Visual Analogue Scale (VAS)¹⁶ was used as a training exercise. Specifically, the VAS—a thermometer-like instrument marked in single, equal interval units ranging from 0 to 100 (i.e., from the least to the most desirable health state)—was used to rank-order the twelve marker states in terms of desirability. For assigning rankings to the health states, participants were asked to imagine living in those states for the rest of their lives, as well as to think about the impact of the health states on their lives in terms of their current family and work situations, usual activities such as social roles, leisure activities and lifestyle. Further, they were asked to consider the health care services and social support that were currently available to them. This strategy was aimed at facilitating full consideration of how the health states would affect one's personal circumstances, in order to help ensure completeness of preferences. This exercise, while not directly providing the cardinal measures of utility necessary for scaling the CLAMES instrument, served to familiarize panellists with the health state terminology and classification system used in the study, and the concept of expressing personal preferences regarding health states.¹⁷

Preferences were then elicited for the twelve marker states in a group exercise

using the standard gamble (SG) technique, which is based on expected utility theory.¹⁸⁻²¹ In the SG procedure, preferences for a given health state are assessed in terms of participants' willingness to undergo a specific treatment, which has a probability of either restoring them to full health or causing death. A ping-pong approach is used to vary the probability of treatment success (see Appendix for further details). A paper-and-pencil variant of the standard gamble was adapted from protocols developed at McMaster University¹⁹ and the University of York.²⁰ A member of the McMaster team provided consultation regarding the modified protocols; the protocols were also refined in accordance with the results of earlier qualitative pre-testing.

The SG was first conducted as a group exercise for the 12 marker states. During this exercise, participants were asked to carefully consider how the health states described on the cards would impact their own lives in terms of their current family and work situations, usual activities, social roles and social support.

After assigning a preference score to each marker state, participants were encouraged to present their initial preference scores on individual whiteboards and share within a group discussion the reasons for their choices. Participants were given the opportunity to change their initial preference ratings after the discussion. Consensus was not required; the purpose of the discussion session was to ensure common interpretations and understandings of the health states. In order to provide balance to the discussion and ensure that dominant personalities did not take over the conversation, the facilitator made sure that everyone had equal time and opportunity to talk. Further, participants' seats were moved during breaks in order to help control for any possible undue influences associated with sitting in what might be considered more "powerful" positions (i.e., at the end of the table). In order to assess the effect of the discussion sessions, paired sample *t*-tests were conducted on the pre- and post-discussion mean preference scores for the 12 marker states.

Following the SG group exercise, the preference scores for the other health states were elicited in two individual exercises, using the same procedures (described in the Appendix). For the first individual exercise, each participant was assigned a series of 10 additional health states randomly generated from a pool of 193 states (the 189 health states noted previously plus four marker states from the group exercises). For the second individual exercise, participants were randomly assigned a series of four health states from the pool of 37 corner and pure states. The number of preference ratings obtained for each health state in the individual exercises ranged from 6 to 20.

Data cleaning: Inconsistency checks

The data for participants having higher than expected numbers of inconsistent responses were removed prior to analysis. Ten pairs of health states having an obvious severity ordering were identified,²² and participants' scores were examined to identify their rates of inconsistency, defined as the proportion of pairs for which they rated the less severe health state as more severe. A natural cutoff point was established based on the frequency distribution of the inconsistencies (i.e., the point at which a sharp drop in the number of participants occurred). Having a total number of inconsistencies above this point was considered to be a sign of more serious misunderstanding or misinterpretation of the preference elicitation exercise, and all responses for these participants were removed from the analysis. A total number of inconsistencies at or below this point was viewed as representing a more natural amount of measurement error.

Test-retest exercise

One panel (N=10) was reconvened to repeat the marker state portion of the preference measurement exercise one month later, in order to assess the test-retest reliability of the measurement protocols. Paired sample *t*-tests of the difference between the mean preference scores on each of the marker states from Time 1 to Time 2 were used to determine

the stability of the estimates between the first and second measurements.

Developing a preference-based scoring function

Mean scores based on directly measured preferences for the 238 health states were used to estimate the parameters of a log-linear scoring function that would transform scores on the 11 CLAMES attributes into a single score.

As a preliminary step, a linear regression model was used to estimate mean preference values for each level of each CLAMES attribute, in order to verify that the ordering of the values was consistent with the severity of the attribute levels. In this analysis, the mean preference scores for the 238 health states were regressed onto 37 dummy independent variables, each corresponding to an attribute set at a specific, less-than-best level. For this analysis, each health state was weighted in accordance with the number of preference ratings it received. The weighting was applied to reflect the fact that preferences for some states were measured with better precision than others, due to their being rated by a larger number of participants.

Next, the following log-linear function was used to estimate the parameters:

$$\ln(p) = \sum_{i=1}^{11} \sum_{j=1}^5 I_{ij} x_{ij} \quad [1]$$

or

$$p = \prod_{i=1}^{11} y_i$$

where p represents a health state preference score, I_{ij} is an indicator that takes a value of 1 if attribute i is at level j (0 otherwise), x_{ij} represents the parameter or utility weight associated with a specific level of a given attribute and y_i is the appropriate parameter estimate obtained via regression analysis. The multiplicative form of this model assumes that the contribution of a specific level on a given attribute to the overall preference for a health state is relative to one's standing on the other attributes, as opposed to being absolute.

(Other functional forms were tested, such as a decomposed model and an additive statistical model with interaction terms, but these are beyond the scope of this paper. Additional information is available from the authors upon request.)

One further adjustment was made because the preference scores for health states ranged from 0 (death) to 1 (full health), and by construction a log-linear model has an asymptote that prevents having a score of 0. Values were "stretched" downwards towards 0 using a scaling parameter, in this case, the lowest possible value estimated by the function or the preference score for the health state where each attribute is set at its worst level of severity. Formally, one would calculate an adjusted or rescaled preference score as follows:

$$p_{adj} = \frac{\prod_{i=1}^{11} y_i - \lambda}{1 - \lambda} \quad [2]$$

where λ is the scaling parameter.

The function was evaluated in terms of its ability to reproduce the mean health state preference scores, using the following global indices of goodness-of-fit: Mean Error (ME), Mean Squared Error (MSE) and the Weighted Mean Squared Error (WMSE).

Results

Participants: A socio-demographic profile

The socio-demographic profile of the panel participants, alongside that of the Canadian population in 2003 (based on Cycle 2.1 of the 2003 Canadian Community Health Survey; CCHS),²³ is shown in Table 3. Most of the participants (65%) were under 50 years of age and there were more women than men. Between one fifth and one quarter of participants had an activity limitation, lived in a rural area or had immigrated to Canada. Each panel had at least one participant from a rural area; one panel included only rural dwellers. For the most part, the socio-demographic profile of the sample was reasonably similar to

that for the Canadian population in 2003. The sample had somewhat lower income, was younger and had higher education when compared with the general population.

Inconsistency rates

Table 4 shows the distribution of inconsistent responses for the ten pairs of health states having an obvious ranking in terms of severity. A natural cut-point was observed between those with four and five inconsistent responses (i.e., 60% or more responses deemed inconsistent), and resulted in the removal of the responses of seven individuals (i.e., 5% of the total sample); all subsequent analyses were therefore based on data obtained from 139 participants.

Descriptive statistics: Health state preference scores

Table 5 summarizes the results of the standard gamble group exercises, based on responses from 139 raters across all nationwide focus groups. Pre-discussion mean scores ranged from 0.98 (YD) to 0.29 (UF). The highest scores (associated with the least severe functional limitations) imply that participants would be willing to risk very little to avoid these health states. The standard errors of the pre-discussion mean scores for the marker states were quite small (≤ 0.02).

For each marker state, some of the preference scores were revised following the discussion. The number of changes ranged from 8 (NW) to 50 (BZ); a larger number of changes tended to be associated with the states showing more severe functional limitations. For five of the more severe marker states, the t -tests indicated a statistically significant, though small, impact of the discussion; the post-discussion mean preference scores were lower than the pre-discussion mean preference scores. The standard errors of the mean preference scores did not change as a result of the discussion sessions.

Figure 1 displays the mean preference scores for the remaining 226 health states plotted against their standard errors. Since these states received fewer preference ratings than the marker states (i.e., 6 to 20 versus 139), the standard errors are

TABLE 3
Demographic characteristics of participants and Canadian population (2003)

	Participants (%)	Canadian population* (%)
Age		
18-29	22	19
30-39	24	17
40-49	19	19
50-59	16	15
60-69	13	10
70 and above	6	10
Sex		
Male	45	49
Female	55	51
Income		
< \$20,000	19	11
\$20,000 - \$39,999	29	21
\$40,000 - \$49,999	12	10
\$50,000 - \$59,999	14	10
\$60,000 - \$79,999	14	17
\$80,000 +	13	31
Education		
Some high school or graduation	31	45
Some college or diploma	28	35
Some university or degree	34	15
Post university	6	5
Activity limitation	21	18
Rural resident	24	19
Immigrant to Canada	20	21

Note: Numbers may not add up due to rounding

*Source: Canadian Community Health Survey, Cycle 2.1, 2003

TABLE 4
Distribution of inconsistent responses

Number of errors*	Number of individuals
0	3
1	13
2	53
3	41
4	29
5	4
6	1
7	1
8	0
9	1
10	0

*Higher preference score given to the health state with the logically lower score

TABLE 5
Results of group exercise for twelve marker states

Marker state	Classification		Initial mean and standard error		Post-discussion score change		Final mean	t-statistic	p-value
					#	%			
YD	211111	11111	0.98	0.00	9	6.5	0.98	-0.91	0.36
NW	211211	21111	0.96	0.00	8	5.8	0.97	-1.56	0.12
ML	321211	21111	0.93	0.01	14	10.1	0.93	-1.80	0.18
GM	123222	21111	0.88	0.01	10	7.2	0.88	-1.34	0.18
IG	123223	31111	0.86	0.01	19	13.7	0.85	1.26	0.21
MV	332213	31111	0.85	0.01	10	7.2	0.85	-0.31	0.77
EK	333423	31111	0.73	0.01	20	14.4	0.72	1.88	0.06
FO	131254	21111	0.72	0.02	48	34.5	0.67	5.70	< .0001
VV	334323	31111	0.59	0.02	22	15.8	0.58	2.54	0.012
BZ	441314	31111	0.46	0.02	50	36.0	0.42	4.27	< .0001
NN	444444	31111	0.33	0.02	31	22.3	0.29	4.23	< .0001
UF	344354	24134	0.29	0.02	25	18.0	0.26	3.61	0.004

Note: Health states were presented with random alphabetic codes.

generally higher (≤ 0.18) than those obtained for the marker states.

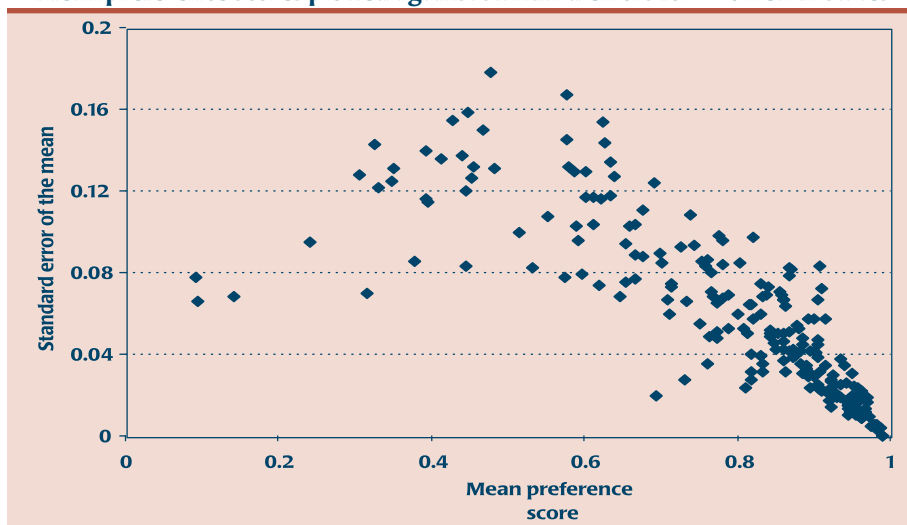
Test-retest reliability

Table 6 presents the results of the paired sample *t*-tests comparing the post-discussion mean preference scores between Time 1 and Time 2. Only the mean preference ratings for health states BZ and NN were significantly different between Time 1 and Time 2, at the 0.05 level.

Fitting the log-linear function

Table 7 displays mean preference values for each level of each CLAMES attribute, as derived from the linear regression. Some adjustment was required to accommodate the ordering of these values—a collapse of levels 1 and 2 for Emotion; levels 1 and 2 for Fatigue; levels 3 and 4 for Fatigue; levels 2, 3 and 4 for Memory and Thinking; levels 1 and 2 for Speech; and levels 3 and 4 for Speech—before estimating the parameters of the log-linear scoring function (see Equations 1 and 2). In addition, preliminary estimation of parameters yielded values greater than 1 for level 2 of the Social Relationships and Vision attributes. Therefore, these para-

FIGURE 1
Mean preference scores plotted against standard errors for 226 health states



meters were fixed at 1 and the model was re-estimated. The function provided a good overall fit to the mean preference scores (ME = -0.005; MSE = 0.005; WMSE = 0.002).

The scaling parameter λ , corresponding to the state in which each attribute is set at its worst level, is 0.115. With the scaling parameter applied, global model fit decreased slightly (ME = 0.024; MSE = 0.008; WMSE = 0.005). The final set of parameter estimates obtained for all attribute levels,

as well as a practical and user-friendly version of the log-linear function, are displayed in Table 8.

Table 9 displays the directly measured mean preference scores for the 12 marker states, based on preferences elicited in both the group (final, post-discussion scores) and individual exercises, alongside those produced by the scoring function with the scaling parameter λ applied. For health states with a directly measured preference score above 0.8, the function fits the data very well. For health states with lower preference scores, the function tends to underestimate the preference score, due to the nature of the scaling adjustment.

Discussion

Preference scores for a subset of 238 health states classified by CLAMES were elicited from panels of lay Canadians using the standard gamble in both group and individual exercises. A log-linear function provided a good fit to the observed mean preference scores and can compute a preference score for any health state possible within the CLAMES framework.

Strengths of the protocols

The integrity of the measurement protocols, as evidenced by stability in health state preferences over time, could be due to several methodological strengths. First, the

TABLE 6
Mean scores for test and re-test (paired samples *t*-test)

Health state	Mean		<i>t</i> -value	<i>p</i> -value*
	Time 1	Time 2		
YD	0.988	0.990	1.000	0.343
NW	0.983	0.974	-1.000	0.343
ML	0.960	0.965	0.434	0.675
GM	0.958	0.950	-0.550	0.596
IG	0.915	0.924	0.546	0.599
MV	0.889	0.899	0.294	0.775
RD	0.877	0.930	1.301	0.225
EK	0.790	0.774	-0.509	0.623
FO	0.764	0.788	0.654	0.529
VV	0.685	0.750	1.073	0.311
BZ	0.495	0.595	2.491	0.034
UF	0.431	0.575	1.942	0.084
NN	0.287	0.428	2.303	0.047

Note: These are the marker states and another health state, RD, which was considered by the group as an example.

*Two-tailed

TABLE 7
Adjusted mean for each attribute level*

Attribute	Level				
	1	2	3	4	5
Pain and discomfort	1.00	0.98	0.97	0.77	n/a
Physical functioning	1.00	0.97	0.93	0.83	n/a
Emotion	1.00	1.03	0.96	0.85	0.79
Fatigue	1.00	1.00	0.95	0.96	n/a
Memory and thinking	1.00	0.98	0.93	0.99	0.85
Social relationships	1.00	0.98	0.95	0.90	0.86
Anxiety	1.00	0.99	0.97	0.90	n/a
Speech	1.00	1.00	0.98	0.99	n/a
Hearing	1.00	0.95	0.93	0.88	n/a
Vision	1.00	0.97	0.99	0.92	n/a
Use of hands and fingers	1.00	0.97	1.00	0.94	0.90

Notes:

*The reference group for the adjustment is level 1 for all other attributes.

n/a - There is no level 5 on this attribute.

measurement protocols, which included introductory training exercises using the VAS, were developed on the basis of well-established methods^{19,20} as well as expert consultation, and applied in a standardized manner across all participants and groups.

Second, the standard gamble (SG) method, considered by some experts as the “gold standard” preference measurement technique,⁹ is the only preference elicitation method that produces true “utilities” (i.e., preferences measured under uncertain conditions) in accordance with von Neumann-Morgenstern expected utility theory.²¹ Since the SG involves risk, it is

regarded as highly appropriate in the context of health care decision making.¹⁷ In addition, qualitative pre-testing indicated that participants preferred the standard gamble to the Time Trade-Off (TTO) technique because it was easier to understand and some participants considered the Person Trade-Off (PTO) to be ethically objectionable; one focus group member refused to do the PTO. (For further description of these techniques, see Dolan et al.²²)

Third, a trained and experienced facilitator from Statistics Canada’s Questionnaire Design Resource Centre was involved from

the early stages of developing the protocols and conducted all sessions, both English and French, in order to eliminate variance due to facilitator effects.

Fourth, the health states were identified with randomly allocated two-letter codes rather than the name of the disease they represented (e.g., ML represented type II diabetes). This strategy may have minimized bias due to misunderstanding about particular diseases: Other studies have reported that different preference scores were obtained for the same disease when presented with and without labels.²⁴ The

TABLE 9
Observed and function-generated preference scores for twelve marker states

Marker state	Classification	Observed	Function
YD	211111	11111	0.98 0.98
NW	211211	21111	0.97 0.96
ML	321211	21111	0.93 0.91
GM	123222	21111	0.88 0.86
MV	332213	31111	0.85 0.85
IG	123223	31111	0.85 0.81
EK	333423	31111	0.72 0.70
FO	131254	21111	0.67 0.63
VV	334323	31111	0.58 0.52
BZ	441314	31111	0.42 0.33
NN	444444	31111	0.29 0.20
UF	344354	24134	0.26 0.17

Health states are presented in descending order of observed scores.

TABLE 8
Parameter estimates for log-linear model

Attribute level	Pain and discomfort	Physical functioning	Emotional state	Fatigue	Memory and thinking	Social relationships	Anxiety	Speech	Hearing	Vision	Use of hands and fingers
	y ₁	y ₂	y ₃	y ₄	y ₅	y ₆	y ₇	y ₈	y ₉	y ₁₀	y ₁₁
1	1	1	1	1	1	1	1	1	1	1	1
2	0.98	0.983	1	1	0.985	1	0.985	1	0.958	1	0.985
3	0.954	0.949	0.919	0.952	0.985	0.955	0.982	0.956	0.938	0.93	0.985
4	0.704	0.681	0.719	0.952	0.985	0.915	0.833	0.956	0.897	0.884	0.985
5	n/a	n/a	0.663	n/a	0.784	0.821	n/a	n/a	n/a	n/a	0.784

Notes:

A preference score for any health state classified by CLAMES can be calculated using the following simplified functional form:

Padj = [(y₁ * y₂ * y₃ * y₄ * y₅ * y₆ * y₇ * y₈ * y₉ * y₁₀ * y₁₁) - 0.115]/0.885, where y is the appropriate parameter estimate from Table 8.

n/a - There is no level 5 on this attribute.

removal of labels also avoided the presentation of unrealistic scenarios to participants (e.g., experiencing influenza or a heart attack for the rest of their lives).

Contribution to preference measurement

The present work demonstrates the potential for measuring health state preferences in small groups using facilitator-led and self-completion methods. Paper-based, self-completion approaches to the standard gamble used elsewhere have performed reasonably well; one study showed that health state preference scores derived from paper-based, self-completion methods were very highly correlated ($R^2 = 0.88$) with those obtained using a more sophisticated, computer-based version of the SG (which was similar to the interviewer-based approach).²⁵ However, to our knowledge, paper-based, self-completion SG techniques have not been implemented in group settings prior to the current study. Although the reliability of individual preferences have been found to be moderate to low over time, the reliability of group preferences has tended to be higher.²⁶

Significant discrepancies between some of the pre- and post-discussion mean preference scores for the marker states suggest that preferences for some health states were developed further via discussion. The more severe health states were more likely to change after discussion, possibly because members of the general public are not likely to experience these health states. In line with the current findings, both Fischhoff²⁷ and Feeny¹⁷ suggest that in the domain of health, people develop their preferences through a deliberative process, although a small study by Stein et al.²⁸ did not support this empirically.

The discussion was considered necessary in the present study because there were 11 attributes to consider and only six core attributes affected by a health state were shown on the laminated card, unless there was a limitation on other attributes. However, the mean preferences for severe health states were actually lower after discussion: The expected focusing effect where raters zero in on affected attributes

and disregard those at normal functional levels was not observed. Further, it does not appear as though there was excessive bias brought about by the group discussion sessions, given that the standard errors did not change as a result of the group discussion sessions.

The scoring function

Log-linear models such as the one estimated here have performed well with preference data obtained using other instruments, most notably the EQ-5D in the Australian Burden of Disease study.²⁹ Although we tested other models for CLAMES, such as an additive statistical model and a multiplicative “decomposed” model,⁹ they did not yield as good a fit to our standard gamble data as the log-linear model.

Limitations

Although the results of the current study are encouraging in a number of respects, some limitations should be noted. First, our panels were not fully representative of the Canadian population, though efforts were made to ensure that the sample was heterogeneous as to socio-demographic and health characteristics, so that the preferences would reflect a variety of personal and contextual factors.

Second, the levels of some attributes had to be combined before estimating the preference-based scoring functions, since the corresponding weights were not ordered as theoretically expected. It is possible that the small sample size provided an insufficient number of preference ratings to obtain clear empirical differentiation between attribute levels close in terms of actual impact on functional status. Third, it should be noted that CLAMES contains a larger number of attributes (i.e., 11) than are typically used on preference-based health status tools. The “magical number seven (plus or minus two)”¹⁵ as a limit to the number of items individuals can process at once has been used to justify the limit of nine attributes for other multi-attribute classification systems.¹⁷ However, we chose to provide more detailed information, as we felt that it was a justifiable trade-off because we did not use disease labels and therefore

participants required more complete information on functional health to understand the health state.

As for the function, the scaling parameter may have introduced some downward bias when computing preferences for health states having low mean preference scores. This was intended to counteract the upward bias introduced by the inability of our preference measurement exercise to produce negative scores for states that may have been perceived as “worse than death.”

Fourth, although the group SG exercise appeared to work well, we did not directly compare our results to the traditional, professional interviewer-administered one-on-one preference elicitation survey.¹⁹ Efforts were made to preserve the integrity of the original method here (e.g., a member of the McMaster team reviewed the protocols). However, a specific objective of future research might be to examine the degree of convergence in preferences obtained from the group method and the traditional one-on-one approach.

Finally, due to constraints on resources, the current study did not attempt to replicate or validate the results of the log-linear modeling of the standard gamble scores with additional, directly measured preference data. Further work to assess both intra-survey and out-of-sample predictive validity of the function would thus strengthen this work.^{9,30}

Contribution to policy decisions

The preference-based scoring function presented here allows for the convenient calculation of preference scores for any of the 10,240,000 health states possible within the CLAMES framework, providing wide coverage of health states that might be encountered in research and clinical practice. Within the PHI research program, the preference scores will contribute a comparable measure of severity of functional limitations across health states, which will serve as an important component of summary measures incorporating morbidity and mortality from specific diseases. The preference scores used in the construction of the function were obtained

from laypersons in the Canadian societal context, which is particularly desirable given the cultural and economic influences on health.³¹ The preferences of the general public are appropriate for health state preferences that contribute to policy and priority setting in the health care sector.⁶⁻⁸ As Dolan³² notes, “we are all potential patients.” The use of average preferences is conducive to fairness in health care decision making, since the scores can reflect the input of multiple perspectives (i.e., within a heterogeneous sample, as used here) but at the same time are not unduly biased in favour of particular sub-groups.

Conclusion

We obtained health state preference scores in a group setting using the SG technique. Provided that training of participants and standardized measurement procedures are in place, these methods appear to provide a viable and economical means of carrying out preference measurement. These

observed preferences were used to build a preference-based scoring function for CLAMES, which was subsequently used to quantify health-related quality of life for numerous health states within the context of the Population Health Impact of Disease in Canada research program. Two related articles describe, respectively, how CLAMES was used to develop preference scores for health states related to cancer³³ and how these preference scores were used in the calculation of health-adjusted life years (HALYs) lost to cancer in Canada in 2001.³⁴ Future work will use CLAMES to examine the impact on health-related quality of life of other diseases and health conditions.

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APPENDIX

Paper-and-pencil version of standard gamble and description of search procedure

The standard gamble (SG) presents raters with a hypothetical scenario consisting of two alternatives. The first alternative is a lottery in which a treatment, sometimes referred to as a “magic pill”, has a probability p of restoring participants to full health for the remainder of their lives and a corresponding probability $1 - p$ of killing them instantly. The second alternative is to simply remain with certainty in some other intermediate (i.e., less than full) health state under investigation (e.g., Health State X) for the rest of their lives. The probability p of succeeding at the lottery is systematically varied until the participant reaches his or her indifference point, that is, the point at which he or she cannot decide whether to gamble to escape Health State X or to stay in it for life. If values of 0 and 1 are assigned to immediate death and full health, respectively, then in accordance with the axioms of expected utility theory, the participant’s preference for Health State X is simply p at the indifference point.

The standard gamble response sheet used in this study is displayed in Figure A. To minimize measurement bias resulting from reference or framing effects, an iterative, “ping-pong” approach was used to locate the indifference point. Specifically, starting at a 100% probability of gaining full health via the lottery, participants were instructed to ping-pong through the chances of gaining full health, moving toward the indifference point from both extremes of the continuum simultaneously (e.g., 100%, 0% ... 2%, 98%, etc.), until they rejected Choice A at probability p but accepted Choice A at probability p plus one unit; in other words, the point at which their answer changed from Choice A to Choice B. The response sheet has 2% intervals at the top and bottom to obtain finer elicitation for very high and very low utility values; the remaining intervals are each 5%.

FIGURE A
Standard gamble response sheet

Health State: _____

Choice A		Choice B
Chances of Full Health (%)	Chances of Immediate Death (%)	Health State on Card (%)
100	0	100
98	2	100
95	5	100
90	10	100
85	15	100
80	20	100
75	25	100
70	30	100
65	35	100
60	40	100
55	45	100
50	50	100
45	55	100
40	60	100
35	65	100
30	70	100
25	75	100
20	80	100
15	85	100
10	90	100
5	95	100
2	98	100
0	100	100

INITIAL ANSWER: _____

FINAL ANSWER: _____

For example, a participant might choose the lottery (Choice A) at a 75% chance of gaining full health, yet elect to remain in the health state under study (Choice B) once the chances of gaining full health were reduced to 70%. Since the maximum indifference interval is the distance bet-

ween these two values, the midpoint (i.e., 72.5%) is taken as a proxy for the true indifference point or utility for the health state of interest. All indifference points were calculated by the facilitator, who led the participants through the procedure for each marker state.

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Population health impact of cancer in Canada, 2001

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Abstract

Summary measures of population health that incorporate morbidity provide a new perspective for health policy and priority setting. Health-adjusted life years (HALYs) lost to a disease combine the impact of years of life lost to premature mortality and morbidity, measured as year-equivalents lost to reduced functioning. HALYs for 25 cancers were estimated from mortality and incidence in 2001 in Canada; population-attributable fractions were estimated for major risk factors contributing to these cancers. Results from this analysis indicate that Canadians would lose an estimated 905,000 health-adjusted years of life to cancer for 2001, including 771,000 to premature mortality and 134,000 to morbidity from incident cases (years discounted at 3%). Most of the estimated premature mortality was due to lung cancer; morbidity was largely due to breast, prostate and colorectal cancers. An estimated one quarter of HALYs lost to cancer were attributable to smoking and almost one quarter were attributable to alcohol consumption, lack of fruit and vegetables, obesity and physical inactivity combined. These results are a significant advance in measuring the population health impact of cancer in Canada because they incorporate morbidity as well as mortality.

Key words: *burden of disease, cancer, DALY, HALY, health status indicators, population health, quality of life, summary measures*

Introduction

Cancer claimed the lives of over 65,000 Canadians in 2001 and it accounts for the most premature mortality among diseases in terms of potential years of life lost.¹ The impact of cancer morbidity is much harder to quantify, despite reliable and systematic reporting of cancer incidence in Canada.

Individuals living with cancer experience a range of physical, emotional and social limitations that affect their health-related quality of life. By measuring the severity of these limitations and incorporating them into summary measures that quantify both morbidity and mortality, we can gain a better picture of how cancer affects Canadians.

To date, some measures of population health, such as health-adjusted life expectancy, have incorporated morbidity using utility scores from national population health surveys.^{2,3} Disability-adjusted life years lost to disease have been estimated for British Columbia⁴ using Canadian mortality data as well as disability weights and epidemiologic data from an Australian burden of disease study.⁵ The World Health Organization estimated morbidity in Canada for its Global Burden of Disease study⁶ using disease patterns and disability weights not specifically developed for Canada.

The present study, the Population Health Impact of Disease in Canada (PHI),⁷ builds on the methods used in the aforementioned burden of disease studies by its focus on

estimating the combined impact of mortality and morbidity due to cancer in the Canadian context. Its main advancements over previous work are that it is based on a description of cancer progression and treatment consistent with patterns observed in Canada, uses extensive Canadian epidemiologic data, accounts for comorbidity at onset of cancer and, for the first time, uses preference scores elicited from lay Canadians to weight for the severity of various cancer-related health states.⁸

This article presents the first results of the PHI, providing estimates of health-adjusted life years (HALYs) lost to 25 cancers in Canada, as a sum of the years lost to premature mortality in 2001 and the lifetime morbidity due to cancer diagnosed in 2001. These burdens were allocated using population-attributable fractions to five risk factors: alcohol consumption, lack of fruit and vegetable consumption, obesity, physical inactivity and smoking.

Methods

This exercise was undertaken to estimate health-adjusted life years (HALYs) lost to cancer incidence and mortality in the year 2001. The impact of cancer mortality was measured in terms of the number of years of life lost due to premature death. Morbidity was estimated as the time lost to reduced functioning, weighted for severity, across cancer-related health states typical in the Canadian context.

The data to support these detailed estimates were obtained primarily from Canadian sources, supplemented with

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sources from the United States, from literature review and expert consultation (Table 1).^{7,9-27}

Calculating health-adjusted life years (HALYs) lost to cancer

Health-adjusted life years lost to each of 25 cancer sites (c) was calculated, by sex (s) and standard five-year age groups (a), as the sum of the years of life lost through premature mortality (YLLs) and year-equivalents lost to reduced functioning (YERFs). (YERFs are analogous to YLDs [years of life lived with disability] used by the World Health Organization in its burden of disease study. The change in terminology was modified to emphasize functional health rather than disability.)

$$HALY_{c,a,s} = YLL_{c,a,s} + YERF_{c,a,s}$$

Calculating years of life lost to cancer mortality (YLLs)

The mortality component of the calculation was measured as the years of life lost due to premature mortality. We calculated YLLs by sex (s) and age group (a) for each cancer site (c), as the number of deaths (M), multiplied by the remaining life expectancy at the average age of death (L):

$$YLL_{c,a,s} = M_{c,a,s} * L_{c,a,s}$$

Mortality rates were calculated using 1999 data,^{9,10} the last year for which cause of death was classified using the *International Classification of Diseases 9th Revision* (ICD-9), and applied to the 2001 population to estimate the number of cancer deaths in 2001, by age group and sex. The remaining life expectancy associated with deaths in 2001 was based on Canadian projected cohort life tables.¹¹

Calculating year-equivalents lost to reduced functioning (YERFs)

Morbidity was estimated as year-equivalents lost to reduced functioning (YERFs) due to cancer. In their simplest form, YERFs are calculated as the product of incidence and duration, weighted for severity of limita-

Data	Source
Mortality counts	Statistics Canada, Vital Statistics: Death Database ⁹
Population counts	Statistics Canada, Population estimates 0-90+ Canada – Provinces 1971-2001 ¹⁰
Life expectancies	Statistics Canada, Canadian Projected Cohort Lifetable, Lifepaths 41 ¹¹
Year-equivalents lost to reduced functioning (YERF) estimates	
Preference scores	Population Health Impact of Disease in Canada program ⁷
Starting health of population	National Population Health Survey, 1994-95 (Ages 5-14) ¹² Canadian Community Health Survey, 2000-01 (Ages 15+) ¹³
Diagnosis	Incidence: Canadian Cancer Registry (CCR) ¹⁴ Duration of diagnostic state: Simunovic M et al., 2001 ¹⁵
Staging	Surveillance, Epidemiology, and End Results (SEER) Program ¹⁶
Treatment	Duration and distribution to treatments: Expert consultation ¹⁷
Remission	Distribution to remission states: Expert consultation ¹⁷
Case fatality	Surveillance, Epidemiology and End Results (SEER) Program ¹⁶
Terminal and palliative	Duration: Expert consultation ^{17,18}
Survival	Surveillance, Epidemiology and End Results (SEER) Program ¹⁶
Population-attributable fraction (PAF) estimates	
Risk factor exposure	All risk factors except smoking: Canadian Community Health Survey, 2000-01 ¹³ Smoking: Estimated using Peto-Lopez method ¹⁹ and lung cancer mortality from Canada ^{9,10} compared with American reference population (American Cancer Society CPS II ²⁰ data from the Victorian Burden of Disease Study ⁴)
Relative risks	Alcohol: All sites except breast cancer: English et al., 1995 ²¹ ; Breast cancer from Australian Institute of Health and Welfare, 2001 ²² Lack of fruit and vegetables: New Zealand Ministry of Health, 1999 ²³ Obesity: All sites except rectal cancer: Mao Y et al., 2004 ²⁴ ; Rectal cancer from Pan et al., 2002 ²⁵ Physical inactivity: Australian Institute of Health and Welfare, 1999 ²⁶ Smoking: Centers for Disease Control and Prevention, 2002 ²⁰

Note: These data are documented in workbooks available online^{7,27}

tions. The course and treatment of cancer, however, is a rather complex series of health states: Cancer patients progress from diagnosis, through a treatment phase to a remission period, and possibly to a palliative and terminal care phase or to death from another cause (Figure 1). Although the experience of living with cancer may vary from patient to patient, for practical reasons, we limited our estimates to the health states along typical pathways that affect most patients.

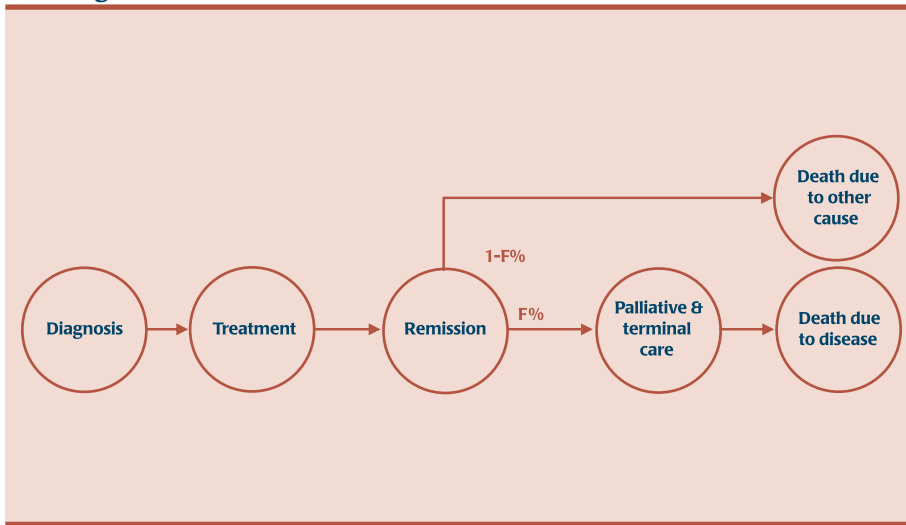
In total, 21 health states related to cancer were identified and described using literature review and expert opinion.²⁸ These included several health states that describe quality of life at diagnosis of cancers with very good, fairly good or poor prognosis; nine treatment states, including surgery

(in-patient, out-patient, bone marrow transplantation), radiotherapy (curative or palliative), chemotherapy (mild, moderate or severe effects) and hormonal therapy; four remission states that represent the long-term effects following surgery, chemotherapy, hormonal therapy or radiotherapy and include the residual effects of having cancer; and health states for palliative and terminal care.

More precisely then, YERFs were calculated as the product of incidence (I), duration in years (D) and weight of severity of limitations (W), for each combination of cancer site (c), stage at diagnosis (g), health state (e), sex (s) and age group (a):

$$YERF_{c,a,s} = \sum_g \sum_e [I_{c,a,s,g,e} * D_{c,a,s,g,e} * W_e]$$

FIGURE 1
Progression of health states related to course of cancer and its treatment



Notes:

1. Case fatality (F) is used to determine the proportion dying from cancer and from other causes. Distributions to treatment and subsequent health states are based on cancer site, stage, age group and sex.
2. Some individuals do not have treatment, so they proceed from diagnosis to a health state “no treatment” that lasts until palliative care begins. This health state is grouped with remission health states for practical purposes.

Incidence

Incidence counts of cancer, defined as cases of first primary malignant tumours, were obtained from the Canadian Cancer Registry.¹⁴ Incidence rates were calculated using the three most recent years of complete data (1997-1999) and applied to the 2001 population to estimate the incidence of cancer in 2001, by cancer site, age group and sex.

Cases were distributed by stage at diagnosis because stage is a determinant of treatment and predictor of survival outcomes and was thus expected to lead to a more refined estimate of morbidity. Comprehensive Canadian staging data were not available, so we used data from the US Surveillance, Epidemiology and End Results (SEER) program.¹⁶ Incident counts (SEER, 1998-2000) were distributed to localized, regional and distant stages by sex and age group (0-49, 50-74, 70+).

Expert consultation¹⁷ was used to estimate the proportion of cases that would receive

each type of treatment for the different cancers. Case fatality rates were used to determine the proportion of cases that would receive palliative and terminal care. To estimate the proportion of cases dying from each cancer, we generated cause-specific Kaplan-Meier survival curves for each cancer site by stage, using SEER*Stat 5.0 software and SEER follow-up data for the period 1975-2000.¹⁶

Duration

An initial health state at diagnosis was estimated to last 37 days on average.¹⁵ The average durations of treatment, which vary by cancer site and stage at diagnosis, were obtained through expert consultation.¹⁷ For those dying of cancer, duration of palliative care was assumed to last five months and terminal care one month.^{17,18} The duration of remission was calculated as the average observed survival time less the time spent in the diagnostic, treatment and palliative/terminal health states.

Average observed piecewise survival times were estimated from SEER data (1975-

2000) for each cancer site, by stage, sex and age group. Cause-specific survival duration was also estimated from SEER, using the methods described earlier for case fatality.

Weight for severity of limitations

In the YERF formula, preference scores are expressed as disutility weights (W) to weight health states according to the severity of reduced functioning. Preference scores are measures of utility that range from 0 (dead) to 1 (full health). The preference scores for the 21 cancer-related health states used in this analysis are shown in Table A of Appendix A.^{1,7,8,28,29} They were derived by classifying the impact of the health state across eleven attributes (each with four to five levels) using the CLAssification and MEasurement System of Functional Health (CLAMES).^{7,8,29} CLAMES is a generic tool used to measure health-related quality of life.

In certain situations, we combined the impact of two health states to represent the impact of having both at the same time: The impact at diagnosis of cancer was assumed to continue through the treatment phase; remission states were possible after various combinations of treatment; and the population was assumed to be in partial health prior to the onset of cancer in 2001. We assumed that the impact of these combined health states could be estimated as the product of the preference scores of each individual health state, as has been done elsewhere.²⁶

The measure of partial health for the starting population was estimated by age group using Health Utilities Index Mark3 (HUI3)^{30,31} from the Canadian Community Health Survey, 2000-01 (CCHS)¹³ for ages 15 and over and from the National Population Health Survey, 1994-95 (NPHS)¹² for age groups 5-9 and 10-14, and we assumed full health for those under age five. We used the HUI3 as a proxy for preference scores since population preference scores measured by CLAMES were not available.

Attribution to risk factors

HALYs, YLLs, and YERFs lost to each cancer site were allocated to five risk factors (alcohol consumption, lack of fruit and vegetable consumption, obesity, physical inactivity and smoking) using population-attributable fractions (PAFs). The population-attributable fraction represents the proportion of disease in the population attributable to a particular risk factor³² and can be used to estimate the impact at the population level if that risk factor were removed. The risk categories were based on relative risk data from the literature, with a priority on the most recent Canadian sources (Appendix B, Tables B1–B5).^{20–26}

Prevalence of exposure by risk factor category was obtained from CCHS 2000-01¹³ for all risk factors except smoking. The effect of smoking on cancer involves a lag between exposure and disease initiation, as well as changing exposure over time. We used the Peto-Lopez method¹⁹ to estimate the cumulative exposure to smoking, based on a comparison of lung cancer mortality in Canada in 2001^{9,10} and lung cancer mortality in smokers and non-smokers in an American reference population.²⁰

Discounting

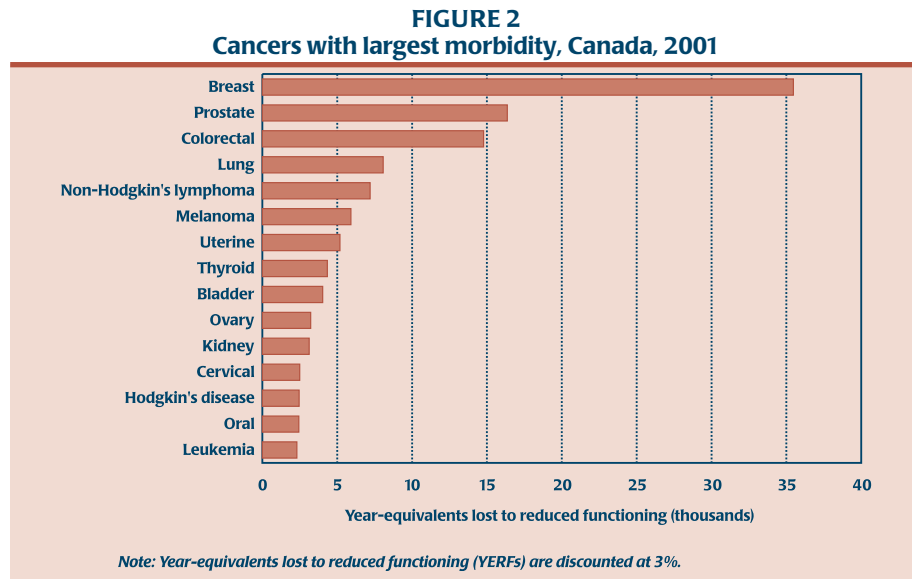
Discounting is a method that gives more preference to the present than the future. Discounting future years at a specific rate (r), the YLL and YERF formulae described earlier become:

$$YLL_{c,a,s} = M_{c,a,s} * (1 - e^{-rL_{c,a,s}}) / r$$

$$YERF_{c,a,s} = \sum_g \sum_e [I_{c,a,s,g,e} * (1 - e^{-rD_{c,a,s,g,e}}) * e^{-rT_{c,a,s,g,e}}] / r * W_e$$

The time from diagnosis to the beginning of the health state (T) is required to discount the health state at the appropriate time in the future. (We use the time of patient registration in the Canadian Cancer Registry as a proxy for the time of diagnosis.)

The results presented here are discounted at 3% according to Canadian guidelines for economic evaluation.³³ Age weighting



was not used in these estimates since it raises controversial issues.^{34,35}

Results

Morbidity and mortality differences by cancer site

An estimated 905,000 health-adjusted life years (HALYs) would be lost to cancer in Canada from incidence and mortality in 2001 (Table 2). (Estimates for HALYs, YLLs and YERFs have been rounded to the nearest 1,000 here.) Lung cancer accounted for 221,000 years or almost one quarter of the years lost, followed by breast and colorectal cancers. Premature mortality

accounted for 85% (771,000) of HALYs lost to cancer, including 213,000 years of life lost to premature mortality from lung cancer alone.

The remaining 15% of HALYs lost to cancer (134,000) were lost to morbidity. As shown in Figure 2, breast cancer accounted for 35,000 year-equivalents of reduced functioning, more than four times as many as lung cancer. The overall incidence of breast cancer was roughly the same as lung cancer; the difference in morbidity is mainly because breast cancer is diagnosed at an earlier stage than lung cancer and has much longer survival times (Table 3). The impact of morbidity was greater for

FIGURE 3
Distribution of incidence and morbidity by stage at diagnosis for the six cancers with the largest morbidity, Canada, 2001

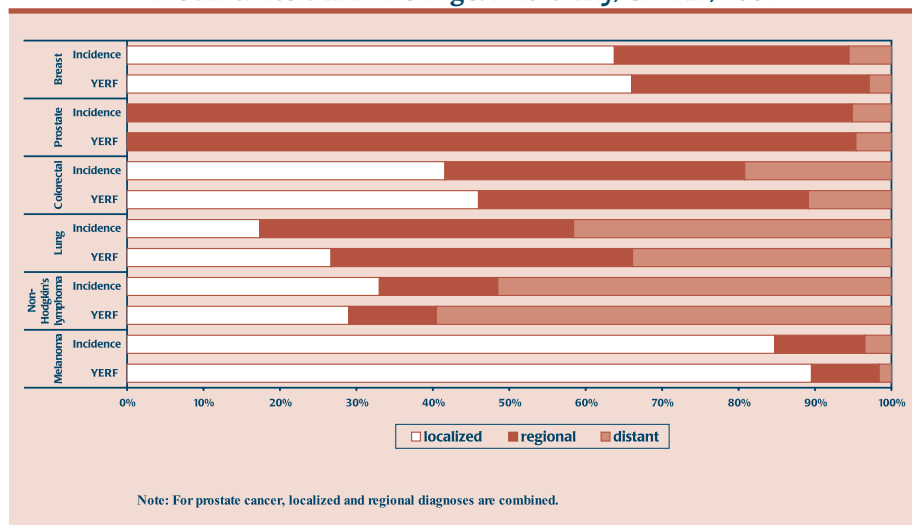


TABLE 2
Estimated health-adjusted life years (HALYs) lost to cancer and proportion that is morbidity,
by sex and cancer site, Canada, 2001

ICD-9 code	Cancer site	HALY			YERF as proportion of HALY		
		Total	Male	Female	Total (%)	Male (%)	Female (%)
140-149	Oral	15,896	10,892	5,004	15	15	17
150	Esophageal	17,088	12,473	4,615	3	3	3
151	Stomach	25,458	14,955	10,503	6	7	6
153-154, 159.0	Colorectal	105,217	54,107	51,111	14	14	14
155	Liver	16,816	10,651	6,164	3	3	3
156	Gall bladder	6,125	2,375	3,750	6	6	6
157	Pancreatic	37,700	18,746	18,953	3	3	3
161	Laryngeal	6,958	5,499	1,459	14	14	12
162	Lung	220,745	126,380	94,365	4	3	4
170-171	Bone and connective tissue	10,473	5,322	5,150	15	15	14
172	Melanoma	16,560	9,011	7,549	36	30	43
173	Non-melanoma skin*	2,525	1,604	920	16	10	27
174	Breast	105,896	—	105,896	33	—	33
180	Cervical	9,814	—	9,814	25	—	25
182, 179	Uterine	13,218	—	13,218	39	—	39
183	Ovarian	23,285	—	23,285	14	—	14
185	Prostate	46,950	46,950	—	35	35	—
188	Bladder	18,692	13,065	5,627	22	22	20
189	Kidney	19,443	11,820	7,623	16	16	17
191-192	Brain	27,399	15,132	12,266	8	8	8
193	Thyroid	6,002	1,553	4,449	72	60	77
200, 202	Non-Hodgkin's lymphoma	38,608	21,008	17,600	19	17	20
201	Hodgkin's disease	4,917	2,809	2,107	50	48	53
203	Multiple myeloma	14,221	6,962	7,259	10	11	9
204-208	Leukemia	29,416	16,414	13,003	8	8	8
All sites 140 to 208 not listed above	All other cancers	65,647	33,923	31,724	10	13	7
140-208	TOTAL	905,067	441,652	463,415	15	12	17

Notes:

All estimates are discounted at 3%.

— not applicable

*Data for non-melanoma skin cancers are underestimated due to reporting problems.

HALY is sum of years of life lost due to premature mortality (YLL) and year-equivalents lost to reduced functioning (YERF).

both colorectal and prostate cancers than for lung cancer.

The six cancers shown in Figure 3 accounted for 65% of morbidity due to cancer. Melanoma had the sixth largest impact in terms of morbidity, even though its impact was not large in terms of mortality (ranking 15th). For sites such as breast, prostate, and colorectal cancers, localized and regional diagnoses accounted for the majority of morbidity due to cancer, partly because survival is longer, but also

because of the larger proportion diagnosed at these stages.

For lung cancer, however, regional and distant diagnoses accounted for 39% and 34% of morbidity, respectively, even though survival for localized diagnoses is almost 14 times as long as for distant diagnoses and almost three times as long as for regional diagnoses (Table 3). This is mainly because regional and distant diagnoses each account for more than twice as many cases as localized diagnoses.

Palliative and terminal care together accounted for about 45% and 63% of morbidity associated with regional and distant diagnoses, respectively, due to severity of functional limitations and the larger proportion of individuals who die from later-stage disease.

Table 3 shows, too, that the duration of the remission period is also a major contributor to morbidity. For cancers with long remission periods, such as localized breast cancer, remission contributed 96% of the

TABLE 3

Estimated morbidity due to cancer, by health state and stage at diagnosis, for selected cancer sites, Canada, 2001 (continued)

Cause-specific survival (mean years)		Localized		Regional		Distant	
		22.4		16.9		5.0	
Health state		# of cases	YERFs	# of cases	YERFs	# of cases	YERFs
BREAST CANCER							
At diagnosis		11,966	107	5,764	53	1,039	48
Treatment	surgery inpatient	3,087	67	5,073	113	364	16
	surgery outpatient	7,204	109	0	0	0	0
	chemo mild toxicity	0	0	0	0	0	0
	chemo moderate toxicity	2,872	394	3,689	515	478	131
	chemo severe toxicity	0	0	0	0	0	0
	radio curative	5,145	73	2,536	36	0	0
	radio palliative	0	0	0	0	270	10
	Remission	surgery alone	3,829	4,656	1,153	1,116	114
chemo alone		0	0	0	0	166	27
radio alone		0	0	0	0	104	25
surgery and chemo		1,316	2,598	1,383	2,174	146	55
surgery and radio		3,590	8,361	231	428	0	0
chemo and radio		0	0	0	0	62	24
surgery and chemo and radio		1,556	4,674	2,306	5,516	104	60
no treatment*		1,675	2,103	692	691	343	422
Palliative care		2,241	204	2,701	294	937	144
Terminal care		2,241	64	2,701	93	937	45
TOTAL			23,411		11,029		1,032
Cause-specific survival (mean years)		Localized		Regional		Distant	
		21.1		15.2		2.9	
Health state		# of cases	YERFs	# of cases	YERFs	# of cases	YERFs
COLORECTAL CANCER							
At diagnosis		6,976	80	6,581	76	3,221	143
Treatment	surgery inpatient	6,558	148	6,450	146	2,287	94
	surgery outpatient	0	0	0	0	0	0
	chemo mild toxicity	628	88	3,488	488	0	0
	chemo moderate toxicity	0	0	0	0	1,417	374
	chemo severe toxicity	0	0	0	0	0	0
	radio curative	0	0	197	3	0	0
	radio palliative	0	0	0	0	0	0
	Remission	surgery alone	5,930	4,961	2,962	1,727	1,127
chemo alone		0	0	0	0	258	10
radio alone		0	0	0	0	0	0
surgery and chemo		628	853	3,291	3,115	1,160	105
surgery and radio		0	0	0	0	0	0
chemo and radio		0	0	0	0	0	0
surgery and chemo and radio		0	0	197	284	0	0
no treatment*		419	485	132	106	676	200
Palliative care		1,487	135	3,072	332	2,978	469
Terminal care		1,487	43	3,072	105	2,978	148
TOTAL			6,793		6,381		1,605

TABLE 3 (continued)
Estimated morbidity due to cancer, by health state and stage at diagnosis, for selected cancer sites, Canada, 2001

Cause-specific survival (mean years)		Localized		Regional		Distant	
		11.0		3.9		0.8	
Health state		# of cases	YERFs	# of cases	YERFs	# of cases	YERFs
LUNG CANCER							
At diagnosis		3,222	49	7,623	117	7,720	351
Treatment	surgery inpatient	2,095	52	1,220	31	0	0
	surgery outpatient	0	0	0	0	0	0
	chemo mild toxicity	0	0	0	0	0	0
	chemo moderate toxicity	258	20	4,269	340	3,783	514
	chemo severe toxicity	0	0	0	0	0	0
	radio curative	741	21	4,498	127	0	0
	radio palliative	0	0	0	0	3,629	131
Remission	surgery alone	1,869	751	534	55	0	0
	chemo alone	0	0	1,067	77	1,776	1
	radio alone	322	133	1,067	112	1,621	1
	surgery and chemo	0	0	0	0	0	0
	surgery and radio	161	124	229	45	0	0
	chemo and radio	193	128	2,744	465	2,007	3
	surgery and chemo and radio	64	64	457	116	0	0
no treatment*		612	444	1,525	283	2,316	10
Palliative care		2,235	279	6,966	1,079	7,623	1,310
Terminal care		2,235	88	6,966	341	7,623	414
TOTAL			2,154		3,187		2,734

Notes:

YERF estimates are discounted at 3%

*included with remission health states, although not strictly speaking a remission period

Morbidity is quantified by year-equivalents lost to reduced functioning (YERFs).

morbidity, while treatment contributed 3%. By contrast, the remission period for distant-staged lung cancer, which is generally ongoing care, is very short and contributed less than 1% towards morbidity. The morbidity associated with treatment of these cases was relatively small (24%) because treatment options are limited for advanced lung cancer. The longer remission period associated with distant-staged colorectal cancer accounted for an estimated 24% of morbidity, while treatment accounted for 29%, and palliative and terminal care 38%.

Attribution to risk factors

Based on the relative risk data used, an estimated 25% of HALYs lost to cancer were attributable to smoking; 11% were attributable to lack of fruit and vegetable consumption, 6% to physical inactivity,

5% to obesity and 2% to alcohol (Table 4). The total HALYs attributable to these five risk factors could be as much as 49%. Smoking accounted for 14,000 lung cancer deaths and 188,000 health-adjusted life years lost to lung cancer. Because most of the HALYs lost to each cancer site were due to mortality, the attribution of YLLs to these risk factors was similar (data not shown).

A somewhat different picture emerged for morbidity. Smoking contributed 87% of morbidity due to lung cancer, but only 9% of morbidity due to cancer overall. Of the overall morbidity due to cancer, 12% was attributable to lack of fruit and vegetable consumption, which was assumed to have an impact across all sites. Physical inactivity accounted for an estimated 31% and 23%, respectively, of morbidity due to colorectal and breast cancers.

Discussion

This analysis indicates that Canadians would lose an estimated 905,000 health-adjusted life years from mortality and incidence of cancers in 2001—771,000 through years of life lost to premature mortality (YLLs) and 134,000 through morbidity, measured by year-equivalents lost to reduced functioning (YERFs). Lung cancer had the largest impact due to the large number of years lost to premature mortality, followed by breast, colorectal and prostate cancers. Breast cancer was the leading cause of morbidity, with levels higher than the morbidity of prostate and colorectal cancers combined. Although morbidity accounted for about 15% of total impact of cancer as measured by HALYs, it represents a substantial impact on quality of life. About one quarter of HALYs lost to cancer overall was attribut-

TABLE 4
Attribution of deaths, health-adjusted life years (HALYs) and morbidity to five risk factors (percentages) for selected cancer sites, Canada, 2001

	All cancers	Breast	Colorectal	Lung	Prostate
Total deaths	64,825	5,002	8,242	17,504	3,849
Smoking	27	0	0	82	0
Lack of fruit and vegetables	9	9	8	10	6
Physical inactivity	5	20	26	0	0
Obesity	4	8	10	0	2
Alcohol	2	4	0	0	0
Total HALYs	905,067	105,896	105,217	220,745	46,950
Smoking	25	0	0	85	0
Lack of fruit and vegetables	11	12	11	12	10
Physical inactivity	6	22	29	0	0
Obesity	5	8	12	0	4
Alcohol	2	5	0	0	0
Total morbidity	134,280	35,471	14,779	8,075	16,362
Smoking	9	0	0	87	0
Lack of fruit and vegetables	12	13	12	12	12
Physical activity	9	23	31	0	0
Obesity	6	7	13	0	4
Alcohol	2	5	0	0	0

Notes: HALY and morbidity estimates are discounted at 3%.

Morbidity is quantified by year-equivalents lost to reduced functioning (YERFs).

able to smoking; almost one quarter was attributable to the other risk factors combined. For overall morbidity due to cancer, however, a larger portion was attributable to lack of fruit and vegetable consumption than to smoking. These results are a significant advance in measuring the population health impact of cancer in Canada because they incorporate morbidity as well as mortality.

Our work uses preference scores elicited from the Canadian lay population, based on specific health state descriptions. Canadian preference scores for 21 health states related to cancer indicate the severity of functional limitations at diagnosis, during treatment, remission and palliative/terminal care. These allow for the change in severity of limitations across various treatments and subsequent health states and were applied to the effects of 25 cancer sites diagnosed at three different stages. Previous work in the Netherlands³⁶ and Australia²⁶ based disability weights on health states for diagnosis and treatment

for some cancer sites. Our Canadian estimates go further by incorporating distributions and durations for a wider range of health states by age group, sex, and stage at diagnosis.

In addition, this work is novel in that the weights for severity of health states were calculated relative to the average health status for that age group, to take into account the reality that Canadians, especially as they age, are not usually in full health. Thus, individuals diagnosed with cancer are not, on average, in full health before developing cancer and they would not be expected to return to full health even if the effects of disease were completely removed. If we had assumed the population was in full health prior to the incidence of cancer in 2001, the estimated YERF would have been 159,000 (data not shown). This was 19% more than our estimate of 134,000, based on an assumption of partial health, highlighting the importance of accounting for comorbidity.

Several limitations of these estimates remain. Although Canadian incidence data for cancer were readily available, they were not available by stage. These estimates thus rely on American data for stage distribution and survival by stage. Comparison of these American data with Canadian data for several cancer sites indicated that they could provide interim data pending the availability of Canadian data. Average survival times by cancer site calculated from SEER and from the Canadian Cancer Registry¹⁴, using similar years of data, were comparable.

Another data gap highlighted by this study is the proportion of patients receiving various types of treatments and the duration of those treatments. While the quality of life associated with treatment was significantly diminished, the relatively short durations of treatment in cancers with very good prognosis and the low proportions receiving treatment in cancers with poor prognosis resulted in low contributions towards the total estimate of morbidity. Sensitivity analyses around these data elements would provide a range of morbidity outcomes to help determine if this is a significant limitation.

A second general limitation resulted from the need to limit the number of health states feasible for such estimates. While every effort was made to establish the main pathways through the course of cancer and its treatment, some oversimplification was inevitable. For example, the health states for remission are not specific to stage at diagnosis or prognostic category. Our estimates thus assume that after treatment all individuals return to a similar level of functional limitation regardless of the extent of disease at diagnosis. In addition, we limited our estimates to first primary cancers, so recurrences are not explicitly included, overlooking any reduction of health status during subsequent diagnostic and treatment phases. These both would tend to underestimate morbidity.

A third limitation is that the classification tool we used to obtain preference scores, CLAMES, has not been validated as a tool

for measuring health-related quality of life. As a new tool, CLAMES has not been adapted for a population survey, so comparability studies of CLAMES and HUI3 (which has been measured on the CCHS and NPHS) have not yet been conducted. However, CLAMES and HUI3 are both utility-based multi-attribute instruments and have seven attributes in common.

Three other limitations inherent in this approach have been widely discussed elsewhere. First, population-attributable fractions by nature overestimate the total attribution to risk factors because they do not account for overlap of the impact of risk factors that often occur together. The relative risks that contribute to these population-attributable fractions do not likely account for all confounding and interactions of risk factors.³² Moreover, risk factor prevalence was based on self-reported survey data, which may underestimate levels of obesity and smoking and overestimate the amount of physical activity and fruit and vegetable consumption.

Second, while the relative risks used were selected from recent high quality epidemiological studies, they are subject to some uncertainty due to sample size and possible measurement error. Some researchers have questioned the benefit of fruit and vegetable consumption to reduce the risk of cancer.³⁷ The attributable fractions should be interpreted with some caution.

Third, the cell-based approach to calculating summary measures oversimplifies the course of disease and its treatment and does not readily accommodate consideration of comorbidity from additional diseases. This is a particular concern among the older population groups because a larger proportion have more than one disease or health condition.

A microsimulation model for cancer now being developed as part of the PHI research program takes a more dynamic approach, incorporating comorbid conditions and considering previous and subsequent disease events and changes in risk factors over time.⁷ This approach will allow us to

perform, much more realistically and directly, “what-if” scenarios about potential interventions such as “How would different smoking rates affect cancers over the next ten years?”

Policy perspective

The estimates provided here are for cancer, a disease affecting many Canadians. Although the morbidity is not high for cancer compared with mortality, it has a substantial impact in terms of quality of life. The methods used here will be particularly useful in providing comparable estimates for other diseases such as arthritis, which have high morbidity. These methods contribute to a broad framework to measure and compare the relative impact of the major diseases and risk factors that affect Canadians, allowing standardized and comparable measures of both mortality and morbidity across diseases. This is particularly important when assessing the overall effect of risk factors across disease groupings.

Most of the mortality and morbidity related to lung cancer was attributable to smoking. However, for other cancers (e.g., breast and colorectal) both mortality and morbidity were primarily attributable to other risk factors such as physical inactivity, inadequate fruit and vegetable consumption, and obesity. While sensitive to the assumptions of relative risk, comparing the impact of risk factors on cancers and other diseases at the population level may help focus prevention strategies.

These estimates allow a closer look at the potential factors contributing to morbidity across the stages at diagnosis and throughout the course of treatment, remission and palliative care. This provides an additional perspective on interventions. Cancers that are mostly diagnosed early (e.g., breast) contribute a substantial amount of morbidity from long periods of remission. However, cancers diagnosed at a later stage (e.g., lung) contribute, in addition to mortality, substantial morbidity because the severity of limitation is far greater for advanced disease.

Interventions that promote early diagnosis and treatment, such as screening, can reduce mortality and, to some extent, morbidity due to cancer. However, a lengthy remission phase may still contribute substantially to morbidity. On the other hand, interventions that prevent cancer, such as diet and physical activity, have the potential to reduce morbidity even further.

Upstream risk factors, such as income level, may play a significant role in the distribution of the prevalence of the stated cancer risk factors, and may thereby indirectly affect mortality and morbidity. This could potentially be evaluated as a “what-if” scenario using this study’s underlying cell-based model.²⁷ For instance, the prevalence of the cancer risk factors could be estimated for the poorest and richest quartiles of the population; the difference of HALYs attributed to each risk factor could be an indication of the impact of income distribution.

Conclusions

These results are a significant advance in measuring the population health impact of cancer in Canada because they incorporate morbidity as well as mortality. These estimates of HALYs lost to cancer among Canadians demonstrate how morbidity measures can inform health policy and priority setting. The morbidity associated with living with cancer is a substantial component of the total HALYs lost to cancers, even though it is not as large as the impact of mortality. The methods used here will be useful in examining the impact of other diseases for which morbidity is even larger. The methods presented here also provide new insights about the potential impact of specific risk factors such as diet and physical activity. The combined impact across all cancers and all diseases may be substantial. Moreover, diet and physical activity are integral to healthy living in general, and provide an opportunity to increase both quantity and quality of life.

APPENDIX A

TABLE A
Preference scores* for 21 cancer-related health states

At diagnosis	
Very good prognosis	0.891
Fairly good prognosis	0.853
Poor prognosis	0.809
Metastatic disease	0.439
Childhood acute lymphoblastic leukemia	0.732
Chronic lymphocytic leukemia	0.940
Treatment	
Surgery in-patient	0.732
Surgery out-patient	0.853
Radiotherapy curative	0.781
Radiotherapy palliative	0.507
Chemotherapy mild toxicity	0.750
Chemotherapy moderate toxicity	0.742
Chemotherapy severe toxicity	0.706
Hormonal therapy	0.896
Bone marrow transplantation	0.864
Remission	
After surgery	0.894
After radiotherapy	0.891
After chemotherapy	0.926
After hormonal therapy	0.912
Palliative care	0.484
Terminal care	0.179

Source: Population Health Impact of Disease in Canada program^{7,8,29}

* Preference scores measure the relative preference for a health state on an interval scale between 0 (dead) and 1 (full health)

Note: Cancers were classified into the prognostic categories based on the death-to-incidence ratio and using Canadian Cancer Statistics.¹ This is described elsewhere.²⁸

APPENDIX B

Population-attributable fractions were estimated for each risk factor by cancer site (c), age group (a) and sex (s):

$$PAF_{c,a,s} = \sum_i [Pe_{c,a,s,i} * (RR_{c,a,s,i} - 1) / (1 + Pe_{a,s,i} * (RR_{c,a,s,i} - 1))]$$

where Pe is the proportion of the population exposed to the risk factor, RR is the relative risk of developing or dying of cancer due to the exposure (shown in Tables B1 to B5) and index i represents the risk category.

TABLE B-1
Alcohol consumption

	Low	Hazardous	Harmful
Definition (drinks/day):			
Male	0.26 - 4.0	4.01 - 6.00	> 6
Female	0.26 - 2.0	2.01 - 4.00	> 4
Relative risks:			
Oral cancer	1.45	1.85	5.39
Esophageal cancer	1.80	2.37	4.26
Liver cancer	1.45	3.03	3.60
Laryngeal cancer	1.83	3.90	4.93
Breast cancer (female only)	1.14	1.41	1.59

Note: Reference category is 0-0.25 drinks per day.

Source: All sites except breast cancer: English et al., 1995²¹
Breast cancer: AIHW, 2001²²

TABLE B-2
Lack of fruit and vegetable consumption

Definition: at risk if less than five servings per day, according to age				
Relative risks:				
Age	< 45	45 - 64	65 - 74	75 +
Relative risk for all cancers	1.40	1.30	1.20	1.10

Note: Reference category is five or more servings per day, all ages.

Source: New Zealand Ministry of Health, 1999²³, cited in Mathers et al., 1999²⁵

**TABLE B-3
Obesity**

Definition: body mass index ≥ 30 kg/m ²		
Relative risks:		
	Males	Females
Stomach cancer	1.36	0.92
Colon cancer*	2.16	1.77
Rectal cancer*	1.78	1.44
Pancreatic cancer	1.43	1.63
Breast cancer		
pre-menopausal**	na	1.13
post-menopausal**	na	1.66
Prostate cancer	1.27	na
Ovarian cancer	na	1.95
Bladder cancer	1.35	1.15
Kidney cancer	3.15	2.42
Non-Hodgkin's lymphoma	1.42	1.54
Multiple myeloma	2.16	1.92
Leukemia	1.41	2.01

*relative risks combined for colorectal cancer, assuming two thirds colon and one third rectal cancer

**used age 50 as proxy for menopause

Note: Reference category is body mass index < 30 kg/m² (i.e., not obese).

Source: All sites except rectal cancer: Mao et al., 2003²⁴

Rectal cancer: Pan et al., 2004²⁵

**TABLE B-4
Physical inactivity**

Relative risks:		
	Inactive	Moderately active
Colorectal cancer	1.70	1.21
Breast cancer (female only)	1.40	1.27

Note: Reference category is "active".

Source: Mathers et al., 1999²⁶

**TABLE B-5
Smoking**

Relative risks:	Males		Females	
	Current smoker	Former smoker	Current smoker	Former smoker
	Oral cancer	10.89	3.40	5.08
Esophageal cancer	6.76	4.46	7.75	2.79
Pancreatic cancer	2.31	1.15	2.25	1.55
Laryngeal cancer	14.60	6.34	13.02	5.16
Lung cancer	23.26	8.70	12.69	4.53
Cervical cancer	n/a	n/a	1.59	1.14
Bladder cancer	3.27	2.09	2.22	1.89
Kidney cancer	2.72	1.73	1.29	1.05

Note: Reference category is "never smoked".

Source: National Center for Chronic Disease Prevention and Health Promotion, 2002²⁰

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Variations in injury among Canadian adolescents by urban-rural geographic status

Xuran Jiang, Dongguang Li, William Boyce and William Pickett

Abstract

Injuries are the leading cause of morbidity and mortality among Canadian adolescents. Rural adolescents may be disproportionately affected by these traumatic events. Differences in risk for injury between rural and urban adolescents remain understudied. We compared adolescent reports of medically attended injury by urban-rural geographic status using a representative national sample of Canadian adolescents. The study involved an analysis of a national sample of Canadian adolescents aged 11 to 15 years (N = 7,235) from the 2001-2002 WHO/Health Behaviour in School-aged Children survey. Respondents were classified into five geographic categories according to school addresses. Several differences in risk for injury were documented by urban-rural geographic status. Adolescents from rural regions were more likely to report medically treated injury compared with the reference population from large metropolitan areas. These patterns of medically attended injury suggest that prevention and intervention programs could be better targeted to the needs of specific geographic populations of Canadian youth.

Key words: adolescent, geography, injury, urban-rural

Introduction

Childhood injury is an important yet understudied issue in Canada. While annual age-standardized mortality rates due to injury among Canadian adolescents decreased substantially from 1979 to 2002 (20.9 per 100,000 to 8.1 per 100,000),¹ injuries still account for approximately 56% of all observed adolescent deaths, or more deaths than from all other causes combined in this group.² Children and adolescents living in rural areas may be disproportionately affected. Traumas from motor vehicle crashes,³ bicycle-related injuries,⁴ firearm injuries,⁵ agricultural work-related injury⁶⁻⁷ and suicide⁸ all increase with increasing rurality and remoteness. Injuries are also associated with substantial costs in terms of lost

potential, disability, treatment and rehabilitation.⁹ In rural areas, consequences of injury tend to be more severe due to more challenging living environments,¹⁰⁻¹¹ lack of access to medical care services¹² and differences in behavioural norms.¹³⁻¹⁴

In Canada, few studies have specifically examined the more general injury experiences of rural adolescents. Most existing epidemiological research focuses solely on fatal injuries⁵ or has been confined to a single province.^{3,8} Patterns in risk for injury by degree of rurality have not been characterized. We therefore used Canadian records from the 2001-2002 World Health Organization/Health Behaviour in School-aged Children (WHO/HBSC) survey, along with a specially constructed, fixed geographic code (the modified Beale

urban-rural code) to study this issue. Our focus was on examining adolescent injury patterns by urban-rural geographic status to ultimately inform preventive efforts.

Methods

Study population and procedures

The HBSC is a World Health Organization collaborative, multinational, cross-sectional survey which was designed to provide information on the health outcomes and health behaviours of young people.¹⁵ Canadian records (N = 7,235) analyzed here were collected in 2002 by the Social Program Evaluation Group at Queen's University in partnership with the Public Health Agency of Canada. The cross-national HBSC research protocol was followed.¹⁵ A cluster sample design was used, with the school class being the basic cluster.¹⁵⁻¹⁶ The survey was conducted in school classes and teachers were asked to administer the questionnaire. The time frame for filling out the questionnaire was one school class session (about 45 minutes). Within each province, samples were selected to represent distributions of schools by size, geographic location (urban and rural), language and religion.^{15,17} The Canadian sample is representative of students in grades 6-10 and the sample was designed to be self-weighting. Ethics approval was obtained from the Queen's University General Research Ethics Board and subject consent was obtained at the school board, parent and student levels.

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Measurements

Variables used in this study were obtained from the 2002 HBSC self-report questionnaire containing 122 core questions about health behaviour (e.g., substance use, bullying, sexual health), demographics (e.g., age, gender, socioeconomic status) and other relevant health outcome variables (e.g., injury).¹⁵

Injuries

The Canadian version of the HBSC asked questions about injuries that occurred during the “twelve months prior to the survey, and were treated by a doctor or nurse.” Response options were “I wasn’t...”, “1 time”, “2 times”, “3 times”, “4 times or more.” Examples of medical attention included being admitted to hospital, requiring a visit to an emergency department or receiving medical care in a doctor’s office. Limitation of the study of injury reports to medically treated events is a widely accepted and frequently used approach.¹⁵ Self-reports of injuries have also been found to be reliable and comprehensive indicators of the incidence of injury among 11- to 15-year-old adolescents.¹⁸ The one-year period of recall was used to be consistent with past research practice and to maximize levels of recall.¹⁹

Students who reported at least one medically treated injury were asked to identify their most important injury event and describe the nature of this injury (medical sequelae), injury type (e.g., sports or fighting related), treatments administered and whether it led to at least one day lost from school or other normal activities.¹⁵ In subsequent analyses that excluded non-severe injury events, analyses were based on “serious injuries”, defined in this study using a version of the Modified Abbreviated Injury Score (MAIS) developed by HBSC researchers.²⁰ These included injuries that resulted in 1) treatment for the injury and hospital admission overnight; 2) the student missing at least one full day of school or usual activities; or 3) an operation due to an internal injury.

Geographic status

A standard geographic classification system commonly called the “Beale urban-rural coding system” was used to group respondents according to urban-rural geographic status.²¹ Beale codes for each census division are made available for research purposes from Statistics Canada. In the HBSC database, the postal code for each participating school was linked to a specific census division (CD). These CDs were subsequently coded into one of the five following geographic categories: 1) *large metropolitan regions* are “a central and most populous census division of a census metropolitan area (CMA) with a population greater than one million, or remaining CDs within or partially within a CMA with a population greater than one million;” 2) *medium metropolitan regions* are “CDs containing, within or partially within a CMA with a population between 250,000 and 999,999;” 3) *small metropolitan regions* are “CDs containing, within or partially within a CMA/Census Agglomeration (CA) with a population between 50,000 and 249,999;” 4) *non-metro-adjacent regions* are “CDs that share a boundary with a CMA/CA that has a population greater than 50,000;” 5) *rural regions* are “CDs that do not share a boundary with a CMA/CA that has a population greater than 50,000.”

The cities of Montreal, Toronto and Vancouver are examples of large metropolitan regions. Medium metropolitan areas include cities like Winnipeg, Halifax and Calgary. Small metropolitan areas include smaller cities (e.g., Regina, Kingston); non-metro-adjacent regions include smaller towns (e.g., Lanark ON; Duncan BC); and rural areas include communities such as Bishop Falls NF, Chandler QC and The Pas MB.

The Beale urban-rural coding system was originally developed by the United States Department of Agriculture to classify the location of counties within an urban-rural continuum.²¹ This system has been used to examine urban-rural differences for a range of health indicators including injury,²²⁻²³

cancer²⁴ and physical activity.²⁵ This system has been adapted to be compatible to the Canadian context by using census divisions, which are roughly equivalent to counties in the United States.^{21,26} Unlike other definitions of “rural” used by Statistics Canada, which have an emphasis on population size and density, this classification system contains both hierarchical (size) and settlement context components. Though the original U.S. classification scheme had eleven categories, the system for Canada uses six.²¹ In the present study, the original six Canadian categories were collapsed into five in order for sufficient cell sizes to generate stable estimates.

Covariates

Additional variables considered in this analysis included age, sex and socioeconomic status (SES). Age and sex are standard demographic factors and are also risk factors for injury. SES is a fundamental determinant of health for both individuals and communities.¹⁶ Low SES levels are related to a variety of negative health outcomes, including injury.²⁷ Prior Canadian studies reported that rural students were more likely than urban ones to be from families with lower SES backgrounds.

Analysis

Statistical analyses were conducted using SAS, version 8.2 [SAS Institute Inc., Cary, NC]. Prevalence rates of medically treated injury were calculated along with associated 95% confidence intervals. A design effect of 1.2 (i.e., standard errors for estimates were multiplied by 1.2) was used to account for the clustered nature of the data.^{15,17} All analyses were stratified by the five geographic categories (large metro, medium metro, small metro, non-metro-adjacent and rural). Sub-analyses were conducted by gender and three age groups in years (i.e., <13; 13 to <15; ≥15). Medically treated injuries and serious injury were further described by injury type, nature of injury and their immediate treatments. Rates of medically treated injury by geographic categories were compared using the Cochran-Armitage trend test²⁸ and the chi-square test.

TABLE 1
Study population characteristics by Beale geographic categories

	Geographic categories										p-value
	Large metro N=1,066		Medium metro N=1,654		Small metro N=1,757		Non-metro- adjacent N=1,213		Rural N=1,545		
	N	%	N	%	N	%	N	%	N	%	
Age groups (years)											< 0.0001
< 13	424	39.8	592	35.8	698	39.7	540	44.5	544	35.2	
13 to < 15	362	34.0	573	34.6	645	36.7	443	36.5	649	42.0	
≥ 15	280	26.3	489	29.6	414	23.6	230	19.0	352	22.8	
Sex											0.21
Boys	477	44.8	767	46.4	843	48.0	537	44.3	733	47.4	
Girls	589	55.2	887	53.6	914	52.0	676	55.7	812	52.6	

Data source: WHO/Health Behaviour in School-aged Children survey for Canada, 2001-2002.

Results

Sample

A total of 7,235 students (3,357 boys and 3,878 girls) from 171 schools participated in the 2001-2002 Canadian HBSC survey. Table 1 displays the demographic characteristics of respondents by degree of rurality (1,066 from large metro; 1,654 from medium metro; 1,757 from small metro; 1,213 from non-metro-adjacent; and 1,545 from rural regions). While there was little variation in the proportions of respondents by sex, the distribution by age group was significantly different ($p < 0.0001$) across the five Beale groupings.

Medically treated injuries

Over half of the study population reported one or more medically treated injury by a doctor or nurse during the 12 months prior to the survey (Table 2). Annual rates of injury were statistically higher in boys than in girls (59.1% versus 50.1%; $p < 0.001$); this was true in all three age groups included in this study ($p < 0.001$). Approximately 54% of the injured youth reported multiple injuries (two or more during the year). Medically treated injury rates were consistently higher in rural, non-metro-adjacent, small metro and medium metro areas, compared with large metro areas. Statistically significant dif-

ferences in injury risk were observed by geographic status within the two sexes and three age groups (data not shown).

Serious injuries

Approximately 27% of the respondents reported serious injuries according to the HBSC Modified Abbreviated Injury Score criteria.²⁰ Overall, annual reported rates of reporting serious injury were higher in rural (i.e., rural and non-metro-adjacent) areas than in the urban (i.e., large metro and medium metro) areas (Table 2). Statistically significant urban-rural differences in injury risk were identified for the two sexes and three age groups (data not shown).

TABLE 2
Annual rate (R) and 95% confidence interval (CI) of medically treated and serious injuries in Canadian adolescents, by Beale geographic categories

	Geographic categories										p-value
	Large metro N=1,066		Medium metro N=1,654		Small metro N=1,757		Non-metro- adjacent N=1,213		Rural N=1,545		
	N	R (CI)	N	R (CI)	N	R (CI)	N	R (CI)	N	R (CI)	
Medically treated injuries											
Any injury	507	48 (44,52)	899	55 (52,58)	992	57 (54,60)	671	56 (52,59)	836	54 (51,57)	0.01* (0.0002**)
2 times or more	279	26 (23,30)	479	29 (27,32)	553	32 (29,34)	347	29 (26,32)	455	30 (27,32)	0.21* (0.06**)
3 times or more	136	13 (10,15)	238	14 (12,17)	299	17 (15,19)	185	15 (13,18)	226	15 (13,17)	0.25* (0.03**)
Serious injuries	224	21 (18,24)	433	26 (24,29)	527	30 (28,33)	328	27 (24,30)	421	27 (25,30)	0.004* (<0.0001**)

* Trend test

**Chi-square test

Data source: WHO/Health Behaviour in School-aged Children survey for Canada, 2001-2002

TABLE 3
Annual rate (R) and 95% confidence interval (CI) of serious injuries in Canadian adolescents, by key descriptors and Beale geographic categories

	Geographic categories										p-value
	Large metro N=1,066		Medium metro N=1,654		Small metro N=1,757		Non-metro-adjacent N=1,213		Rural N=1,545		
	R	(CI)	R	(CI)	R	(CI)	R	(CI)	R	(CI)	
Location											
Sports area	12	(10,15)	18	(16,20)	15	(13,17)	14	(12,16)	14	(12,17)	0.61* (0.002**)
Home	9	(7,11)	10	(9,12)	11	(10,13)	15	(13,18)	13	(11,15)	<0.0001* (<0.0001**)
School, education area	11	(8,13)	10	(8,12)	10	(8,12)	10	(8,12)	10	(8,11)	0.56* (0.91**)
Activity											
Sports, organized or other	25	(22,28)	29	(27,32)	26	(24,29)	26	(24,29)	25	(23,28)	0.41* (0.06**)
Transportation	7	(5,9)	8	(6,9)	8	(7,10)	9	(7,11)	9	(7,11)	0.03* (0.03**)
Fighting	2	(1,2)	1	(1,2)	2	(1,3)	1	(1,2)	2	(1,3)	0.70* (0.80**)
Nature of injury											
Broken bone or dislocation	9	(7,11)	13	(11,15)	16	(14,19)	16	(13,18)	15	(13,17)	<0.0001* (0.0001**)
Sprain or strain	26	(23,30)	32	(29,35)	31	(29,34)	31	(28,35)	30	(27,33)	0.25* (0.03**)
Laceration	17	(15,20)	18	(16,20)	19	(17,22)	21	(18,23)	17	(14,19)	0.95* (0.06**)
Head or neck injury	6	(4,7)	8	(7,10)	10	(8,12)	10	(8,12)	9	(7,11)	0.005* (0.0008**)
Immediate treatment											
Doctor's office/clinic	22	(19,25)	25	(22,27)	20	(18,23)	22	(19,25)	25	(23,28)	0.21* (0.004**)
Emergency room	8	(6,10)	12	(10,14)	18	(16,21)	15	(12,17)	12	(10,14)	0.007* (<0.0001**)
Hospital overnight	3	(1,4)	3	(2,5)	5	(3,6)	3	(2,5)	3	(2,4)	0.64* (0.06**)

* Trend test

**Chi-square test

Data source: WHO/Health Behaviour in School-aged Children survey for Canada, 2001-2002

Location, activity, nature of injury and treatment

Table 3 presents annual rates of adolescent most serious injury by location, activity, nature and treatment. Sports-related injuries were prominent in both sexes and all five geographic areas (ranging from 19% to 36%). Sports areas were the most common location of injury for both boys (17%) and girls (13%), followed by home (11% for boys and 12% for girls) and school or education areas (10%). Youth from more rural (i.e., rural and non-metro-adjacent) areas were more likely to be injured at home compared to those from the most urban (i.e., large metro and medium metro) areas for both males

($p = 0.002$) and females ($p < 0.0001$). Sprains and strains (31%); lacerations (18%); broken bones or dislocations (15%); and head or neck injuries (9%) were the leading natures of injuries reported. In general, these injuries were more commonly reported by adolescents from more rural areas. Approximately 22% of females and 24% of males visited doctor offices or clinics; 12% of females and 15% of males went to an emergency room; and 2% of females and 5% of males required an overnight hospital stay for the injury. Adolescents from more rural areas reported proportionally higher occurrences of emergency room visits, with the highest occurrences reported in small metropolitan areas (21% for females in these areas).

Statistically significant differences were identified for emergency room visits in comparisons between males ($p = 0.007$) and between females ($p = 0.0006$) from the five geographic areas.

Discussion

Our analysis identified disparities in injury rates and patterns among Canadian adolescents by geographic status. Overall, living in more rural areas was associated with higher risks for injury. Statistically significant differences in risk for injury by urban-rural status were found for both medically treated injuries and serious injury events. Interestingly, while males reported proportionally higher occurrences

of both medically treated and serious injuries compared with females, a generally wider geographic disparity in injury rates was observed among females.

The finding of an increased risk for injury among youth living outside metropolitan centers is consistent with earlier studies conducted in Canada,³⁻⁴ the United States^{22,29,30} and other countries.¹⁰ With few exceptions^{4,22,29} most of these studies have examined “urban” and “rural” populations as dichotomies, and thus did not fully capture geographic patterns in injury risk. Studies that have examined the urban-rural continuum reported that children living in the most rural and remote regions experienced the highest risks for injury and serious injury.^{4,22,29}

In the present study, while prevalence of injury was generally higher in more rural areas compared with large metropolitan areas, the highest risks for injury were not always observed among adolescents residing in the former. In fact, adolescents from small metro areas reported the proportionally highest occurrences of any medically treated injury, serious injury and emergency room visits, although there is overlap between these 95% confidence intervals and those from other areas. This discrepancy may reflect differential injury patterns or may be due to differences in nature of injury,²² definitions used for the terms “injury” and “serious injury”, geographic classification systems⁴ or composition of the study population.^{4,29} An alternative explanation is that though people living in the most rural areas may be at higher risk, these populations also have limited access to medical care facilities and must travel long distances to reach health services. Therefore, the prevalence of medically treated injuries appears to be artificially lower among rural Canadian populations than it actually is.

A number of methodological issues warrant consideration. Urban-rural comparisons such as ours are useful in drawing attention to particular types of communities or locations that may be associated with

health problems, although geographic studies in general have limited ability to shed light on critical determinants and how they operate to affect youth health. Variations in injury risks, for example, may in fact be due to underlying cultural differences in risk taking,³¹ poverty,³² care-seeking behaviours³³ or service availability.³³ To identify specific place and health determinants, comparisons between similar locations (for example, between small urban areas) would be useful. For example, increased density of traffic in suburban areas can lead to injury risk for young pedestrians.³⁴ Similarly, crime and violence in large urban areas are associated with increased fighting injuries.³⁵⁻³⁶ However, these studies also assume that aggregate behaviours or characteristics at the area level are equally important for residents of those areas. This assumption is obviously not always valid.

Our study had a number of strengths. First, this research is original in that it examines injury patterns among Canadian adolescents by geographic status. We did this by using a large and nationally representative sample of Canadian adolescents. Most Canadian studies on this topic have a provincial or regional focus.^{3,8} Second, the use of the modified Beale urban-rural classification provides us with an improved perspective on geographical influences on school-aged children health in Canada. Third, this survey was administered according to a standard protocol, and names and other personal identifiers were not collected in order to improve data accuracy as well as to ensure confidentiality. Past validation efforts have shown this approach to the collection of health data results in higher rates of participation and better and more accurate self-reported data.³⁷ Finally, the fact that all data were compiled as part of a general health survey (i.e., no focused questions/hypotheses were provided to the participants) limited the potential for information bias.³⁷

Several limitations of the study should also be noted. First, the present study was based on self-reported measurements of injury, which is subject to errors in recall.¹⁹

However, self-reports are a common and accepted method of measuring injuries, and adolescents aged 11 to 15 years have been shown to provide accurate reports of personal injury experiences.¹⁸ Second, since data were collected on a single day, students absent from school were unable to participate. Those who may have missed school due to injury (especially serious injury) were therefore not represented. This would result in underestimates of injury rates. Third, only the most serious injury from the 12 months preceding the study was considered in some analyses. This too resulted in an underestimation of the number of injuries that actually occurred. Fourth, use of school-level data to infer urban-rural status of students may lead to misclassification of the urban-rural status since rural children and youth attending urban schools will be classified as “urban students” and vice versa. Many students classified as “urban” come from rural areas and are bused to urban schools. This misclassification of urban-rural status may bias the results towards no effect. Fifth, the cross-sectional nature of the study obviously limits exploration of causal pathways. Finally, our analysis included multiple comparisons and so statistically significant results should be interpreted with caution.

The urban-rural gradients in risk for injury identified in this study indicate potential inequalities in adolescent health. If these risk disparities are confirmed in other populations, the next obvious step is to identify underlying causes of these inequalities. This should include focused study of injury-related risk factors as well as injury treatment patterns by geographic status. With respect to prevention, while rural adolescents are at significantly higher risk for injury compared to their urban counterparts, very few injury prevention strategies have been designed specifically to meet the needs of these most disadvantaged populations.³⁸ There is a need for prevention initiatives to be targeted specially at the needs and social context of non-urban adolescent populations. These strategies need to be informed by the injury patterns observed here, as well as

by the acute and underlying determinants of injury that are most prevalent in these adolescent cultures.

Conclusions

This study represents one of the first attempts, to our knowledge, to compare patterns of medically treated injury from all causes among Canadian school-aged adolescents by urban-rural geographic status. Higher risks of injury were observed among adolescents from more rural areas when compared to those from large metropolitan areas. Adolescents from small metro areas reported the proportionally highest occurrences of both medically treated injury and serious injury. These findings emphasize the importance of conceptualizing the term “rurality” as a continuum instead of a dichotomy. Studies focusing on the health of adolescents in small metro areas and rural areas are needed to fully understand these patterns. As ours is the first population-based study that has examined these issues in a nationally representative sample of Canadian adolescents, replication of our analyses in different settings or contexts is also warranted.

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Determinants of high birth weight by geographic region in Canada

Lise Dubois, Manon Girard and Fabiola Tatone-Tokuda

Abstract

This study aims to analyze the determinants of high birth weight (> 4000 grams) by various geographic regions of Canada. Analyses were performed using the data from cycles 1 to 4 (1994-2001; N=20,002 children) of the Canadian National Longitudinal Survey of Children and Youth (NLSCY). Children were grouped into five geographic residential area categories: the Atlantic provinces, Quebec, Ontario, the Prairie provinces and British Columbia. Determinants analyzed in the study include sex, gestational age and birth rank of children; maternal age and education; maternal smoking during pregnancy; family type; family socioeconomic status (SES) and maternal health (postpartum depression; hypertension and prescription drug use during pregnancy). In comparison to Quebec, the odds of giving birth to a high-birth-weight child were 25% higher in Ontario, 41% higher in the Atlantic provinces and 53% higher in British Columbia. In Quebec, non-smoking mothers of higher SES had increased odds of delivering a baby weighing more than 4000 grams, while in British Columbia, the odds of having a birth weight greater than 4000 grams doubled for children of non-smoking mothers from the lowest SES quintiles. The relationship between social disparities and macrosomia was found to vary by geographic region.

Key words: birth weight, geographical determinants, demographic factors, socioeconomic factors, Canada

Introduction

A birth weight of more than 4000 g has been implicated as a risk factor for many immediate and long-term health concerns, including complications with childbirth, childhood and adult morbidity, and obesity at different ages.¹⁻⁷ High birth weight has also been associated with increased rates of cesarean delivery; obstetrical brachial plexus palsy (OBPP); childhood brain tumours (astrocytomas); childhood leukemia (acute lymphoblastic leukemia and acute myeloid leukemia); Wilms tumour (nephroblastoma); type 2 diabetes; diabetes-associated mortality; childhood asthma; prostate cancer; increased fat mass in adolescence; and overweight and obesity from childhood through adulthood.^{2,4,8-22}

Despite this evidence, mean birth weight and the proportion of infants weighing more than 4000 g at birth is on the rise in Canada and in many other developed and developing countries, including Sweden, the United Kingdom and Denmark.²³⁻³¹ For Canada (with the exclusion of Newfoundland and Labrador, due to data unavailability), Wen et al. reported that the proportion of infants weighing more than 4000 g at birth rose from 10.57% for the period 1981-1983 to 12.11% for the period 1995-1997.³¹ More recent statistics demonstrate a mean of 12.8% Canadian babies who were born weighing 4000 g or more between 2002 and 2004 (a mean of 12.5% of babies were born weighing \geq 4000 g, when excluding Newfoundland and Labrador for comparability pur-

poses).³²⁻³⁴ A similar increase in birth weight was found in Denmark from 1990 to 1999, where mean birth weights rose by 45 g for all infants and 62 g for those born at term, and the percentage of infants with a high birth weight (> 4000 g) rose from 16.7% to 20.0% over the ten years observed.²⁷

Certain maternal, infant and lifestyle characteristics have been suggested as determinants to the increasing trend in mean birth weight evident in various countries over the years. In particular, higher birth weights have been associated with higher maternal age and level of education; non-smoking mothers; low caffeine intake; high prepregnancy weight and height; high pregnancy weight gain; increased maternal body mass index (BMI); multiparity; gestational age greater than 40-42 weeks; gestational diabetes; male infants; higher family SES; maternal ethnic origin; and married status.^{1,3,5,7,20,26,30,35-39} However, not all these factors have been shown to consistently maintain a significant association with high birth weight across all regions and populations observed. In a study from Sweden, socioeconomic indicators were no longer significantly related to variations in birth weight after controlling for smoking habits.³⁹ Xu et al. also reported no significant relations to maternal age, education and occupation in a study from China.⁴⁰ With conflicting findings such as these, it is unclear whether determinants typically associated with increased rates of macrosomia can be generalized to all regions. Even though antenatal health care practices vary by region, few studies have controlled for geographic differences

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in their analyses. In fact, a majority of studies on high birth weight have been localized to a particular hospital or region and do not assess for geographic variations.

From a population health perspective, it is important to have a thorough understanding of the determinants involved across geographic regions in order to develop effective public health strategies to counter the trend of higher birth weight prevalence in certain population subsets.

Thus, the aim of this study is to analyze how characteristics including sex, gestational age and birth rank of children; maternal age and education; maternal smoking during pregnancy; family type; family SES; and maternal health (postpartum depression; hypertension and prescription drug use during pregnancy) function as population determinants of high birth weight. Another aim is to assess how these characteristics may vary in their influence on high birth weight across the geographic regions of Canada.

Methods

The analyses were performed using the data from the four cycles of the Canadian National Longitudinal Survey of Children and Youth (NLSCY) (cycle 1 in 1994-95; cycle 2 in 1996-97; cycle 3 in 1998-99; and cycle 4 in 2000-01). The NLSCY is a survey conducted by Statistics Canada and Human Resources Development Canada (HRDC) to monitor the development of Canadian children from birth to adulthood. The survey began in 1994, collecting data on a representative sample of about 25,000 Canadian children between birth and 11 years of age. Follow-up data collection every two years thereafter and through adulthood focussed on factors influencing children's social, emotional, behavioural and physical development. Cross-sectional samples were added in cycles 2, 3 and 4 to provide representative sample estimates.

Information for the NLSCY was collected via telephone interviews from the mothers of children under study. Data collected was weighted by a factor based on the inverse of the selection probability, the

probability of a non-response and both the post-stratification and attrition rates to ensure that the data was longitudinally representative of same-age children in the total population.

Using the first four cycles of the NLSCY, the present study performed statistical analyses on data of children between birth and three years of age for whom birth data was available. Analyses were based on individuals with no missing values for any of the studied variables. Of the 20,798 singleton babies having a reported birth weight, the data of 20,002 (96%) were analyzed. The impact of missing data was analyzed by conducting with-and-without analyses. Missing data were excluded from the analyses since they had no impact on the results.

Reported birth weight, adjusted for gestational age, was used to analyze factors related to birth weights over 4000 g (high birth weight) across various geographic regions of Canada. Although several definitions and cutoff points have been used to classify high birth weight (macroscopic) infants, using the 4000 g marker has shown merits in the prediction of parturition-associated and fetal morbidity, whereas using the 90th centile to classify Large-for-Gestational-Age (LGA) infants is a better marker for investigating underlying causes and outcomes related to gestational age.⁴¹ In an assessment of adverse outcomes associated with various macrosomic birth weight categories, Boulet et al. also demonstrate that grade 1 macrosomia (> 4000 g) is most useful to identify increased risks associated with labor and newborn complications, whereas grade 2 (> 4500 g) and grade 3 macrosomia (> 5000 g) are better predictors of increased risks of neonatal morbidity and infant mortality, respectively.¹ The criteria chosen by experts to distinguish high birth weight infants has also differed depending on whether it is used in epidemiological research or in decision making for care in a clinical practice setting.⁴² Given the present study's aim to observe associations in a population, the 4000 g marker was deemed appropriate in order to include all levels of risk associated with high birth weight.

Information about birth weight and gestational age were obtained from mothers' responses to the following questions from the NLSCY: 1) "Was he/she born before or after the due date?"; 2) "How many days or weeks before or after the due date was he/she born?"; and 3) "What was his/her birth weight in kilograms and grams or pounds and ounces?"

The proportions of high birth weight infants by maternal, family and child characteristics and by geographic region are presented in Table 1. The children belong to one of five areas of residence categories: the Atlantic provinces (New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador), Quebec, Ontario, the Prairie provinces (Manitoba, Saskatchewan, Alberta) and British Columbia. Territories (Yukon Territory, Northwest Territories and Nunavut) were not included in the analyses.

Factors analyzed in relation to high birth weight for children in the sample included sex and birth rank of the child; maternal age and education; maternal smoking during pregnancy; family type; family SES; and maternal health (postpartum depression; during pregnancy, hypertension and consumption of prescription drugs). These characteristics were selected in accordance with previous associations with high birth weight from the literature.

The SES measure was based on Willms and Shields' indicator.⁴³ It is a complex measure derived from a composite score of family income, parents' level of education and the occupational prestige scale of the parents.

Maternal hypertension during pregnancy was documented through a "yes/no" response to the following question from the NLSCY: "During the pregnancy with ___, did you suffer from: ... high blood pressure?" Likewise, information about maternal prescription drug usage during pregnancy and maternal depression was obtained through "yes/no" responses to the questions "Did you take any prescription medications during pregnancy with ___?" and "After ___'s delivery, did

you/her/his mother suffer from: ... postpartum depression?"

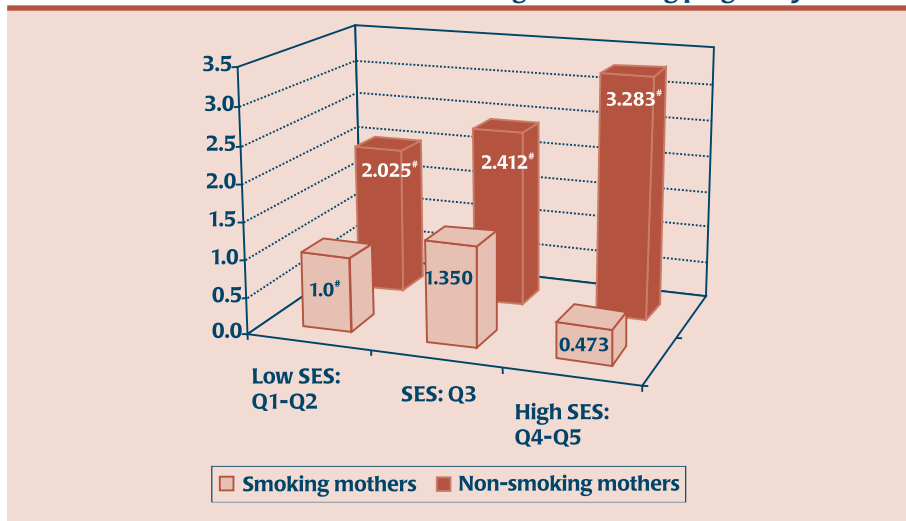
Statistical analyses were performed on weighted data using SAS (version 8.2). Data from each cycle was regrouped. Cross-sectional weights for each dataset were used. This procedure may have resulted in an underestimation of the variances. Consequently, the statistical significance level was established at 0.01. All variables were treated as categorical variables. Preliminary associations between the independent variables and birth weight were verified through a chi-square test on contingency tables. Independent variables found to be significantly associated with birth weight were included in multivariate analyses. Adjustments for potential confounders and odds ratios (OR) estimates, as well as their confidence intervals, were made with logistic regressions. The logistic regression was first assessed without any interactions; then all possible interactions between the studied independent variables were further examined by province and for Canada as a whole.

Results

Univariate analysis (Table 1) pointed to various factors associated with high birth weight in Canada. Provincial differences were observed. The prevalence of high birth weight was highest in British Columbia and lowest in Quebec. Boys, second- or later-born children, children born to older, more educated and non-smoking mothers, children from two-parent families or those from higher SES families were more likely to have a high birth weight. Maternal health was also related to high birth weight (e.g., not suffering from postpartum depression; during pregnancy, not having hypertension nor taking prescription drugs).

When analyzing these variables by Canadian region, each of the variables examined in the present study were found to associate with high birth weight in the provinces of Quebec and Ontario. In Quebec, the prevalence of high birth weight was higher for mothers aged 30 to

FIGURE 1
Adjusted^a odds ratios^b of high birth weight (> 4000 g) of infants born in Quebec, by socioeconomic status strata (SES - in quintiles), for the interaction observed between SES and maternal smoking status during pregnancy



^a Adjusted for gestational age, birth rank and sex of baby, mother's age group and maternal health.

^b Reference group for the dependant variable is 3000-4000 g.

^{*} Reference group for the characteristic.

* p ≤ 0.0001

Source: National Longitudinal Survey of Children and Youth, Cycles 1-4, 1994-2001.

34 years and lower for mothers comparatively older or younger. In Ontario, a greater proportion of mothers with, during pregnancy, neither hypertension nor prescription drug use delivered high-birth-weight infants. In the Atlantic provinces, three variables (sex of baby, maternal non-smoking status during pregnancy and two-parent family) were associated with high-birth-weight deliveries. In the Prairie provinces, sex and birth rank of baby, maternal non-smoking during pregnancy and maternal non-hypertension were all related to high birth weight. In British Columbia, sex and birth rank of baby, mothers' education, maternal non-smoking during pregnancy and family SES, as well as maternal hypertension during pregnancy, were related to high birth weight. These results indicate that not all the factors associated with birth weight inequalities in some provinces feature in the results from the Atlantic and Prairie provinces.

A multivariate analysis was performed, taking all these factors into simultaneous consideration (Table 2). Thus, in Canada,

the odds of giving birth to a high-birth-weight child were 25% higher in Ontario, 41% higher in the Atlantic provinces and 53% higher in British Columbia, when compared to Quebec. Within Quebec, being born into the highest socioeconomic quintiles increased the odds of having a high birth weight by 51%, in comparison to children born there into the lowest SES quintiles. In British Columbia, however, being born in the middle SES quintile lowered the odds by 45%. In these two provinces, maternal health remained related to high birth weight, and a non-smoking status during pregnancy was not related to high birth weight in British Columbia when all other factors were taken into simultaneous consideration.

The interaction between family SES and maternal smoking during pregnancy was examined for the provinces of Quebec (Figure 1) and British Columbia (Figure 2), taking into consideration all other variables in the multivariate model. In Quebec, in comparison to children born to smoking mothers from the lowest SES quintiles, the odds of a high birth weight

TABLE 1
Proportion of infants weighing over 4000 g^a at birth in Canada, by maternal, family and infant characteristics, and by region of residence

Characteristic	Categories	%	Canada	Atlantic provinces	Quebec	Ontario	Prairie provinces	British Columbia
Region of residence	Atlantic provinces	7.3	15.2***	15.2	—	—	—	—
	Quebec	23.1	10.6	—	10.6	—	—	—
	Ontario	38.8	13.6	—	—	13.6	—	—
	Prairie provinces	18.4	12.4	—	—	—	12.4	—
	British Columbia	12.4	17.4	—	—	—	—	17.4
Sex of infant	Male	51.4	16.7***	18.4***	13.0***	17.1***	16.7***	21.7***
	Female	46.6	9.6	11.8	7.9	9.9	8.0	12.9
Birth rank of infant	First	40.7	10.4***	13.2	9.0*	9.7***	10.1***	13.7***
	Second	38.8	15.3	16.9	11.5	16.4	14.5	18.6
	Third or later	20.5	16.1	17.8	11.3	16.7	14.7	25.1
Age group of mother (years)	< 25	19.6	11.3***	11.6	9.8***	11.1***	12.0	13.4
	25 - 29	32.8	13.3	15.7	9.9	14.2	12.2	18.3
	30 - 34	32.8	14.3	17.5	13.3	13.9	13.0	17.4
	≥ 35	15.3	13.6	15.8	7.5	14.3	12.5	20.0
Mother's highest educational level	No high school dipl.	14.2	10.4***	12.4	8.1***	9.2***	11.9	16.8**
	High school dipl.	38.3	13.4	13.9	9.9	13.2	13.7	18.9
	College	27.6	14.5	17.4	12.1	15.8	12.1	16.9
	University	19.5	13.6	17.0	11.9	14.3	11.4	15.5
Maternal smoking during pregnancy	Non-smoker	79.2	15.2***	18.1***	11.7***	15.5***	14.2***	19.6***
	Smoker	20.8	6.7	7.6	5.6	5.9	7.8	9.5
Family type	Two parent	88.4	13.5***	15.9***	10.8***	13.8***	12.7	17.6
	Single parent	11.6	11.3	11.1	8.4	12.1	9.7	15.6
Family socioeconomic status	Quintile 1	21.2	11.2***	12.6	8.6***	11.0***	10.7	17.9***
	Quintile 2	19.8	11.5	14.5	8.1	11.0	13.3	15.4
	Quintile 3	19.5	13.5	15.7	11.5	13.4	13.5	15.8
	Quintile 4	19.7	14.2	17.8	11.5	14.9	11.4	17.5
	Quintile 5	19.7	15.4	17.1	13.7	15.8	14.6	17.6
Maternal postpartum depression	No	90.6	13.4***	15.4	10.7*	14.1***	12.3	17.3
	Yes	9.4	10.9	11.7	9.0	8.6	13.3	15.5
Maternal hypertension during pregnancy	No	90.0	13.3***	15.4	9.9***	13.9***	12.8**	17.4***
	Yes	10.0	14.7	15.7	14.1	13.0	12.2	23.8
Maternal use of prescription drugs during pregnancy	No	73.4	13.2***	15.2	9.2***	14.1***	12.5	17.3
	Yes	26.6	14.0	15.9	12.7	12.9	13.4	20.8
Mean		—	13.26	15.2	10.6	13.6	12.4	17.4

^aAdjusted for gestational age

Chi-square test of association between the characteristic and the dependant variable: * $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$

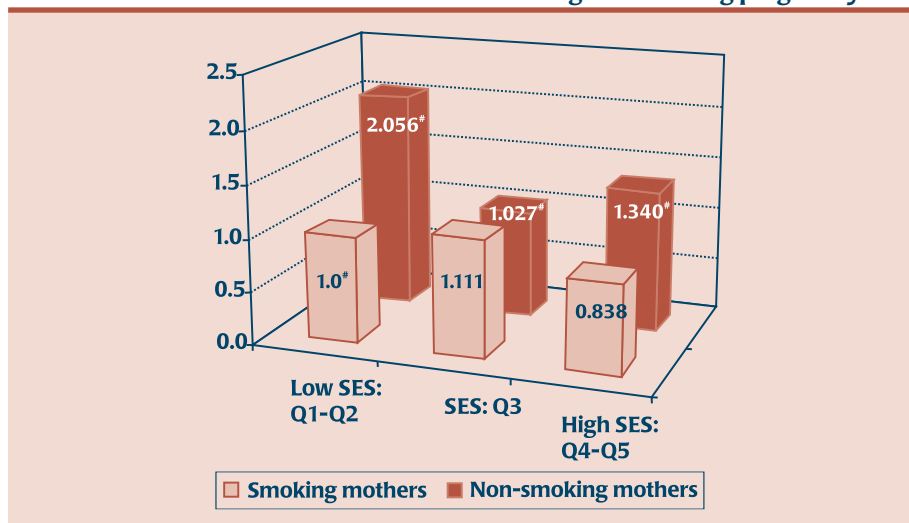
Source: National Longitudinal Survey of Children and Youth, Cycles 1-4, 1994-2001.

increased with higher SES quintiles for children born to non-smoking mothers. While in British Columbia, the odds of a high birth weight doubled for children of

non-smoking mothers from the lowest SES, but high birth weight was not associated with the middle (3) nor higher (4-5) SES quintiles. In other Canadian provinces,

there was no significant interaction between high birth weight and maternal smoking during pregnancy (data not shown).

FIGURE 2
Adjusted^a odds of high birth weight (> 4000 g) of infants born in British Columbia, by socioeconomic status strata (SES - in quintiles), for the interaction observed between SES and maternal smoking status during pregnancy



Discussion

In a developed country such as Canada, where the standard of living is high and antenatal care is freely available to all pregnant women, what are the main determinants of high birth weight? The analyses indicate that high birth weight varies geographically, even when maternal, family and child characteristics are taken into consideration. British Columbia was

^a Adjusted for gestational age, birth rank and sex of baby, mother's age group and maternal health.

^b Reference group for the dependant variable is 3000-4000 g.

[#] Reference group for the characteristic.

* $p \leq 0.0001$

Source: National Longitudinal Survey of Children and Youth, Cycles 1-4, 1994-2001.

TABLE 2
Adjusted^a odds ratio^{b,c} for high birth weight (> 4000 g) of infants born in Canada, by region of residence

Description	Category	Canada	Atlantic provinces	Quebec	Ontario	Prairie provinces	British Columbia
Region of residence	Atlantic provinces	1.411 (1.053-1.891)					
	Quebec	1					
	Ontario	1.250 (1.025-1.524)					
	Prairie provinces	1.132 (0.898-1.428)					
	British Columbia	1.526 (1.195-1.950)					
Sex of infant	Male	1.947 (1.684-2.251)	1.829 (1.118-2.992)	1.810 (1.289-2.542)	1.897 (1.505-2.390)	2.343 (1.666-3.324)	1.929 (1.313-2.883)
	Female [#]	1	1	1	1	1	1
Birth rank of infant	First*	1	1	1	1	1	1
	Second	1.620 (1.370-1.914)	1.368 (0.772-2.424)	1.580 (1.071-2.331)	1.773 (1.359-2.313)	1.607 (1.072-2.408)	1.424 (0.921-2.200)
	Third or later	1.801 (1.473-2.202)	1.701 (0.859-3.369)	1.603 (1.001-2.580)	1.924 (1.390-2.663)	1.633 (1.029-2.591)	2.172 (1.265-3.729)
Maternal smoking during pregnancy	Non-smoker	2.332 (1.859-2.926)	2.977 (1.421-6.236)	2.311 (1.394-3.832)	2.582 (1.735-3.843)	2.027 (1.251-3.286)	1.705 (0.931-3.125)
	Smoker [#]	1	1	1	1	1	1
Family socio-economic status	Q1 + Q2 [#]	1	1	1	1	1	1
	Q3	0.913 (0.746-1.118)	0.900 (0.445-1.824)	1.187 (0.747-1.886)	0.886 (0.629-1.249)	1.079 (0.692-1.684)	0.551 (0.327-0.929)
	Q4 + Q5	1.026 (0.860-1.224)	0.926 (0.508-1.685)	1.507 (1.002-2.265)	1.079 (0.815-1.429)	0.896 (0.581-1.382)	0.677 (0.420-1.091)
Maternal postpartum depression	No	1.152 (0.888-1.495)	1.207 (0.519-2.811)	1.022 (0.529-1.976)	1.203 (0.780-1.857)	0.880 (0.511-1.516)	1.748 (0.877-3.482)
	Yes [#]	1	1	1	1	1	1
Maternal hypertension during pregnancy	No [#]	1	1	1	1	1	1
	Yes	1.469 (1.166-1.851)	1.223 (0.618-2.419)	1.722 (0.944-3.143)	1.399 (0.954-2.051)	1.087 (0.616-1.918)	2.204 (1.244-3.907)
Maternal use of prescription drugs during pregnancy	No [#]	1	1	1	1	1	1
	Yes	1.180 (1.006-1.383)	1.192 (0.711-1.998)	1.571 (1.102-2.241)	0.950 (0.732-1.232)	1.122 (0.774-1.626)	1.742 (1.118-2.713)

^aAdjusted for gestational age, mother's age and all other factors in the model

^bOdds ratios are presented with their 99% confidence intervals ()

^cReference group for the dependant variable is 3000-4000 g

[#]Reference group for the characteristic

Source: National Longitudinal Survey of Children and Youth, Cycles 1-4, 1994-2001.

observed to have the highest level of high birth weight, whereas Quebec had the lowest. This finding is interesting as, although high birth weight is associated with parental obesity,³ in Canada, Quebec and British Columbia are among the provinces with the lowest prevalence of adult obesity.⁴⁴ High birth weight did not follow this same pattern across geographic areas.

Overall, the odds of high birth weight were found to be higher for non-smoking women than for women who reported smoking during pregnancy, as smoking restricts growth *in utero*. This association is consistent with prior research findings in this area.^{1,5,24,26,30} Furthermore, the results indicate that in smoking women, high birth weight does not vary by socioeconomic status; this is true for both Canada as a whole and for each region considered independently.

Consistent with Nordstrom and Cnattingius's³⁹ findings, socioeconomic differences were no longer found to play a significant role as determinants of high birth weight in the Atlantic and Prairie provinces when all factors were taken into consideration at the multivariate level. However, in Quebec and British Columbia, social disparities did exert an influence on the prevalence of high birth weight in *non-smoking* women. For non-smoking women in Quebec, socioeconomic status was positively associated with increased odds of delivering a high-birth-weight infant, where the odds of this increased for women of higher socioeconomic status. By contrast, the influence of socioeconomic status was negative for non-smoking mothers of British Columbia, where the odds of delivering a high-birth-weight infant were greater for women of low socioeconomic status. This finding emphasizes the need for future studies and a greater understanding of these self-reported data in their relation to high birth weight. Additionally, given this observation, the findings suggest a need to develop health interventions that are region specific in their efforts to prevent macrosomic births, addressing the key determinants particular to each region. For

example, interventions to prevent high-birth-weight deliveries in non-smoking mothers should target those of low socioeconomic status in British Columbia and mothers of high socioeconomic status in Quebec.

Another interesting finding of the present study is the positive association between maternal hypertension and the increased odds of having a high-birth-weight infant. Boulet et al.¹ also report this association. However, a large body of literature also demonstrates an association between maternal hypertension and increased risks of small-for-gestational-age (SGA) infants, especially emphasized for particular ethnic groups.⁴⁵⁻⁴⁶ In their studies from northern and central Alberta (Canada) and a study from China, Xiong et al. support this U-shaped association between maternal hypertension and increased risks of both low birth weight-SGA infants and high birth weight-LGA infants.⁴⁷⁻⁴⁹ They further demonstrate that the effect of gestational hypertension varies by gestational age: Gestational hypertension associates with decreased birth weight in pre-term infants. Yet in babies born at term, gestational hypertension does not significantly associate with birth weight.⁴⁸ Given our analyses' adjustments for gestational age and other determinants of high birth weight, the finding that hypertension was only associated with high birth weight in British Columbia at the multivariate level emphasizes the need for further studies to investigate other potential moderators of this association within geographic regions.

The authors acknowledge the limitations of this study, specifically its inability to explain the mechanisms underlying these regional variations in the determinants of high birth weight. Other determinants not available in the present study may merit consideration in future analyses. For example, research has shown that characteristics such as maternal height, weight, BMI, ethnicity, gestational diabetes and pregnancy weight gain also relate to high birth weight.^{5,20,24,26,30,35,37,50} Certain studies also reveal that some ethnic groups have higher rates of infants born with high birth

weights, despite lower SES.^{35,51} Maternal diet may also warrant further consideration in future analyses of geographical variations in macrosomia. For example, maternal fish intake during pregnancy has been found to associate with an increased rate of fetal growth and birth weight.⁵²⁻⁵³ Future studies may consider monitoring whether the geographic variances in the influence of SES on high birth weight persist with the inclusion of these additional factors.

As a potential limitation, a mention must be made regarding the possibility of recall error in the indicator used to assess infant birth weight, though there is no reason to suspect *a priori* any geographic differences in distribution in this regard.

No other population-based studies to our knowledge have examined nationwide variances in the determinants of high birth weight by geographic region. Although the prevalence of high birth weight must be addressed nationwide, findings of the present study emphasize that certain geographic regions in Canada require special attention for their higher prevalence of high-birth-weight babies.

From a theoretical perspective, the results of the present study emphasize the need to re-examine possible causal pathways driving the differences in associations of high birth weight between geographic regions, taking into consideration individual, social and environmental variables. Practical implications would be to ensure that health practitioners remain aware of possible regional variances in groups most at risk for delivering high-birth-weight infants. Naïvely implementing a nationwide health promotion strategy, rather than a strategy specific to each region, may unintentionally neglect true high-risk populations particular to each region, thereby decreasing the effectiveness of health promotion efforts.

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Calendar of Events

15-17 November 2007 Toronto, Ontario, Canada	National Cancer Institute of Canada Making Connections: A Canadian Cancer Research Conference	e-mail: mdixon@cancer.ca < http://www.ncic.cancer.ca >
15-17 November 2007 Halifax, Nova Scotia, Canada	Canadian Network for Asthma Care Conference	< http://www.cnac.net/english/main.html >
20-23 November 2007 Montreal, Quebec, Canada	11 ^{es} Journées annuelles de santé publique	< http://www.inspq.qc.ca/jasp/ >
25-28 November 2007 Rio de Janeiro, Brazil	2 nd International Cancer Control Congress	< http://www.cancercontrol2007.com >
22-27 January 2008 Sarasota, Florida, USA	Diabetes Mellitus, Insulin Action and Resistance	< http://www.keystonesymposia.org >
6-8 March 2008 Prague, Czech Republic	2 nd International Conference on Hypertension, Lipids, Diabetes and Stroke Prevention	< http://www.kenes.com/strokeprevention2008 >
7 March 2008 Sacramento, California, USA	34 th Diabetes Symposium	< http://www.ucdmc.ucdavis.edu/cme/conferences >
9-12 April 2008 Prague, Czech Republic	1 st International Congress of Hypertension and Cardiometabolic Risk	< http://www.kenes.com/prehypertension >
18-19 April 2008 Halifax, Nova Scotia, Canada	13 th Annual Atlantic Canada Cardio- vascular Conference	e-mail: mary_ann_robinson@dal.ca < http://www.cme.medicine.dal.ca/CME_calendar.htm >
18-21 May 2008 Buenos Aires, Argentina	XVI World Congress of Cardiology	< http://www.worldheart.org >
4-8 June 2008 Winnipeg, Manitoba, Canada	5 th World Conference on Breast Cancer	< http://www.wcbcf.ca >
17 June 2008 London, England	Type 2 Diabetes	< http://www.rcplondon.ac.uk/event/ >
27-31 August 2008 Geneva, Switzerland	International Union Against Cancer UICC World Cancer Congress	< http://www.uicc-congress08.org/ >
24-27 September 2008 Vienna, Austria	6 th World Stroke Congress	< http://www.kenes.com/stroke2008 >
October 30 - November 2 2008 Barcelona, Spain	2 nd World Congress on Controversies in Diabetes, Obesity, Hypertension	< http://www.codhy.com/ >

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