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Youth attitudes towards tobacco control: A preliminary assessment

Bronwen J Waller, Joanna E Cohen and Mary Jane Ashley

Abstract

The attitudes of Ontario youth toward the sale and price of cigarettes, making smoking against the law, and tobacco company truthfulness were assessed in 2001 and compared to adult attitudes in 2000 and youth attitudes in 2003. Youth were more supportive of restricting cigarette sales and raising prices than adults, and more likely to agree that the government should make smoking against the law, but they were less distrustful of tobacco companies. In 2003, youth were more supportive of sales restrictions and making smoking illegal, and more distrustful of tobacco companies, than in 2001. More comprehensive assessments and continued monitoring of youth attitudes are needed.

Key words: adult; attitudes; cigarettes; tobacco control; tobacco industry; youth

Introduction

Public support for tobacco control is an important underpinning of programs and policies to reduce the health toll of tobacco use. The attitudes of adult Canadians toward tobacco control measures have been examined,¹⁻⁴ but there are no reports about these attitudes among Canadian youth.

Since youth are often the focus for tobacco control interventions, information on how youth themselves regard these measures and how their attitudes may be changing over time could be informative. As well, evidence of youth support may be a persuasive element in increasing political will to enact strong tobacco control policies.^{5,6} However, it is necessary to put youth attitudes in context; in particular, how they compare with the attitudes of adults in the same jurisdiction.

We compared the attitudes of youth and adults in Ontario to restrictions on sales and cigarette price increases. Attitudes toward making smoking against the law and distrust of tobacco companies were also assessed, as were changes in youth attitudes over a two-year period.

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Methods

Sources of data

Youth data were obtained from the 2001 and 2003 Ontario Student Drug Use Surveys (OSDUS).^{7,8} Students from grades 7 through secondary school were sampled using a two-stage selection of school and class stratified by region and type of school ($n = 3818$ in 2001; $n = 6616$ in 2003). OAC students were excluded from this analysis.

Adult attitude data were obtained from the 'Q2000' study ($n = 1607$), a population-based telephone survey of Ontario adults 18 years and older, conducted in 2000.⁹ Respondents were sampled using random digit dialing and random selection of an individual in the home.

Survey questions

The questions examined in the OSDUS were:

- Do you strongly agree, somewhat agree, somewhat disagree or strongly disagree that there should be fewer places where cigarettes can be sold;

- Do you strongly agree, somewhat agree, somewhat disagree or strongly disagree that in order to decrease smoking, the price of cigarettes should increase by one dollar per pack (not included in the 2003 OSDUS);
- Do you strongly agree, somewhat agree, somewhat disagree or strongly disagree that the government should make smoking tobacco against the law; and
- When it comes to the effects of smoking on health, do you think the tobacco companies always tell the truth, often tell the truth, rarely tell the truth, or never tell the truth.

The only differences in wording in the 'Q2000' survey were in the questions about price ('that the price of cigarettes should increase by *at least* one dollar per pack'), and making smoking against the law ('that the government should make smoking tobacco *illegal*').

Data analysis

The 2001 OSDUS and the 'Q2000' were combined into one data set, as were the 2001 and 2003 student surveys. Common variables for primary sampling unit, stratum, and probability weight were created, and the complex survey designs of the merged data sets were taken into account using Stata software.¹⁰ To measure support for sales and price policies and making smoking against the law, the "strongly agree" and "somewhat agree" categories were collapsed, and to measure distrust of tobacco companies, the categories "rarely tells the truth" and "never tells the truth" were collapsed.

Design-based F tests were used to compare youth (2001 survey) and adults, and youth in the 2001 and 2003 surveys.¹¹ Youth and adults were also compared within smoking sub-populations. Adults were compared to each grade level of students, from grades 7–12. Due to the multiple tests performed, $p < 0.01$ was set as a stringent level of statistical significance.

Results

Sales and price policies

Overall, youth in Ontario were more supportive than adults of cigarette price increases and sales restrictions (Table 1). Non-smoking youth were more supportive than non-smoking adults. There were no differences between the smoking subgroups. Students in Grades 7–9 were much more supportive of the sales and price options than adults, whereas students in Grades 10–12 had attitudes close to those of adults (Table 2).

Making smoking against the law

Youth were overall more likely than adults to agree that the government should make

smoking against the law (Table 1). Non-smoking and current smoking youth were also more likely than adults to agree with this statement, but daily smokers were not. Support for this statement was higher for youth across all grades than for adults (Table 2).

Distrust of tobacco companies

Youth overall and in all smoking status subgroups were less distrustful of the tobacco companies than their adult counterparts (Table 1). This differential was also consistent across all grades (Table 2).

Youth attitudes in 2001 and 2003

Youth surveyed in 2003 were more likely to agree that the government should make smoking against the law and were more distrustful of tobacco companies, compared to students surveyed in 2001 (Table 3). The increase in support for fewer cigarette retail outlets over the two-year period approached significance ($p = 0.014$).

Discussion

We found more overall support among youth than among adults for sales restrictions and

price increases. Non-smokers and younger students, in particular, were comparatively more supportive of these policy measures. As well, overall support among youth for sales restrictions increased between 2001 and 2003. However, higher levels of support compared to adults were not found among the older students. If the observed differentials persist as younger youth age into adulthood, this would bode well for the future acceptability of these control measures. Continued monitoring of youth attitudes is needed to determine the sustainability of youth support for these measures with aging.

Overall youth were also more likely than adults to agree that the government should make smoking against the law and the level of agreement among youth increased between 2001 and 2003. This assessment may provide an indication of the rising social unacceptability of smoking, and, if so, the findings are encouraging.¹²

The lower levels of distrust of the tobacco industry, in youth overall and in all subgroups, compared to adults, may warrant attention. Again, we cannot determine with certainty whether these youth may 'grow into' skepticism about the industry as they age; the by-

TABLE 1
Support for tobacco control and perceptions of the tobacco industry among youth (Y) and adults (A) in Ontario, overall and by smoking status*

	% Strongly agree/agree							
	Overall		Non-smokers		Current smokers		Daily smokers	
	Y	A	Y	A	Y	A	Y	A
There should be fewer places where cigarettes can be sold	78	71	89	77	43	51	36	48
	$p < .001$		$p < .0001$		ns		ns	
In order to decrease smoking, the price of cigarettes should increase by \$1 per pack	71	62	80	69	39	38	33	32
	$p < .0001$		$p < .0001$		ns		ns	
The government should make smoking against the law	60	31	71	36	24	15	20	16
	$p < .0001$		$p < .0001$		$p < .01$		ns	
Tobacco companies rarely/never tell the truth	59	79	61	81	53	72	52	70
	$p < .0001$		$p < .0001$		$p < .0001$		$p < .001$	

* Smoking status was defined using the criteria of each survey. In the Ontario Student Drug Use Survey, a current smoker was defined as someone who smoked at least one cigarette during the past 12 months, while a daily smoker smoked one or more cigarettes a day. A current smoker in the 'Q2000' was defined as someone who smoked daily, almost every day, or occasionally, and a daily smoker was someone who smoked daily or almost every day.

ns = not statistically significant

TABLE 2
Support for tobacco control and perceptions of the tobacco industry among youth (Y) and adults (A) in Ontario, by school grade (youth)

	% Strongly agree/agree											
	Grade 7		Grade 8		Grade 9		Grade 10		Grade 11		Grade 12	
	Y	A	Y	A	Y	A	Y	A	Y	A	Y	A
There should be fewer places where cigarettes can be sold	92	71	87	71	80	71	71	71	67	71	69	71
	<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .01		ns		ns		ns	
In order to decrease smoking, the price of cigarettes should increase by \$1 per pack	83	62	78	62	72	62	66	62	59	62	65	62
	<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .01		ns		ns		ns	
The government should make smoking tobacco against the law	79	31	74	31	59	31	51	31	45	31	55	31
	<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .001		<i>p</i> < .001	
Tobacco companies rarely/never tell the truth	66	79	60	79	61	79	49	79	61	79	60	79
	<i>p</i> < .001		<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .0001		<i>p</i> < .0001	

ns = not statistically significant

grade breakdown did not show increasing distrust with higher grade, indicating that lower levels of distrust were not limited to younger ages. However, youth surveyed in 2003 were more distrustful of the tobacco industry than youth surveyed two years earlier. Continued monitoring of youth attitudes toward the tobacco industry is warranted. Tobacco control programs that incorporate a tobacco industry

denormalization strategy appear to be effective in decreasing youth smoking.¹³⁻¹⁷

Adult non-smokers in Ontario^{1,2} and elsewhere¹⁸⁻²⁰ have been found to be more supportive of tobacco control measures than smokers. This pattern is also evident in youth, as non-smoking youth appear to be particularly supportive of tobacco control measures.

This study has limitations. Students enrolled in schools and present on the day of the survey were sampled. Thus, the views of school dropouts and absentees were not captured. These youth may be at higher risk of smoking and less supportive of tobacco control measures.⁷⁻²¹ As well, the youth and adult surveys used different data collection methods: a written self-report in a classroom and a telephone survey at home, respectively. This may have affected the comparability of findings.

Further, the concepts explored, particularly tobacco industry denormalization and the social unacceptability of smoking, are complex. It is questionable whether they can be examined adequately by single questions. In a study of Ontario adults regarding the tobacco industry and its products, distrust of the industry was just one of eight measures that comprised a reliable tobacco industry denormalization scale.²² Clearly, the findings of this study only provide a preliminary indication of the attitudes of youth to smoking and the tobacco industry. Fuller exploration of these constructs in youth is needed.

TABLE 3
Support for tobacco control and perceptions of the tobacco industry among youth in Ontario, by year of survey

	% Strongly agree/agree	
	Year of survey	
	2001	2003
There should be fewer places where cigarettes can be sold	78	82
	ns	
In order to decrease smoking, the price of cigarettes should increase by \$1 per pack	71	Not asked in the 2003 survey
	na	
The government should make smoking against the law	60	70
	<i>p</i> < .0001	
Tobacco companies rarely/never tell the truth	59	66
	<i>p</i> < .001	

ns = not statistically significant

na = not applicable

Acknowledgements

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Inequalities in health and health services delivery: A multilevel study of primary care and hypertension control

Paul J Veugelers, Alexandra M Yip and Frederick Burge

Abstract

Delivery of health services is an important determinant of health. Restricted availability and access may result in health inequalities. To determine the extent of geographic variation in the delivery of health services and its effect on the health of community residents in terms of under-diagnosis and under-treatment of hypertension, we carried out a multilevel study of participants in the 1995 Nova Scotia Heart Health Survey (n = 3,094). We used individual level survey data and health status measurements linked to geographical level information to examine the importance of adequate delivery of health services to the diagnosis and treatment of hypertension in the universal health care setting of the province of Nova Scotia. The delivery of primary care services across Nova Scotia varied moderately with physician visit rates ranging from 3.3 to 5.5 visits per resident per year. There were neither substantial nor statistically significant differences in the diagnosis and treatment of hypertension among residents of communities varying in the delivery of health services. We concluded that a geographic variation in the delivery of primary care services is a public health concern that is not consistent with the objectives of universal coverage of health services; however, it was not confirmed to result in health inequalities.

Key words: *community health; epidemiology; health services; hypertension; medically underserved area; primary health care; small area comparisons*

Introduction

Investigations in the past decade have revealed that contextual factors such as income inequality, neighborhood deprivation, and unemployment rate may affect the health of individuals.^{1,2} Studies using multilevel methods have been increasingly employed to examine the independent effect of these contextual factors as distinct from the more widely investigated individual-level risk factors such as age, sex, and lifestyle risk factors. These multilevel studies have shown, although not consistently, that neighbourhood factors, in particular socio-economic characteristics of residential areas, affect health independent of

individual-level risk factors.³⁻⁹ Various mechanisms within communities and neighbourhoods have been suggested, including the delivery of health services.^{2,7,8,10}

Geographic variation in the delivery of health services has been reported in various Western countries, including those with universal access health care systems that remove the basic financial barrier to accessing care.¹¹⁻¹⁵ Local policies, staffing shortages, physician practice styles, transportation, and health-seeking behaviour may all contribute to this geographic variation in availability and access to care and potentially affect the health of the residents of these communities and

neighbourhoods.¹⁶ State, metropolitan, and county level comparisons revealed that lower physician-to-patient ratios were associated with poorer health, emphasizing the potential that inadequate delivery of health services may universally result in inequalities in health.¹⁷⁻²²

To further our understanding of the potential health effects of inequalities in the delivery of health services, we conducted a multilevel study examining whether the diagnosis and management of hypertension were hampered in geographies with restricted availability and access to primary health care. More specifically, we sought to determine whether individuals living in areas with restricted availability and access to primary health care are 1) less likely to be diagnosed with hypertension; 2) more likely to have undiagnosed hypertension; 3) less likely to be on medication for hypertension; and 4) more likely to have untreated hypertension.

Methods

Individual-level information

As our primary objective is to study the independent importance of the context of health services delivery, it is important to adjust for other factors that affect the health of individuals and that may include both individual and other contextual determinants. Individual-level determinants were taken from the 1995 Nova Scotia Heart Health Survey, conducted among non-institutionalized adults aged 18 years and older, stratified by age, sex,

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and four health regions. The population-based sampling frame consisted of 5,578 people selected from the provincial health registry, of whom 83% were located. Three percent were screened out because of pregnancy, breastfeeding, or mental or physical health precluding participation. Of those remaining, 3,227 (72%) completed an in-home interview, conducted by a trained public health nurse, which consisted of a comprehensive questionnaire on risk factors and two measurements of blood pressure, taken at the beginning and end of the session. Of those interviewed, 2,653 (82%) attended a clinic session, which included measurement of height and weight for the calculation of body mass index (BMI).²³

Individual-level confounders considered include age, sex, smoking status, BMI, presence of selected chronic conditions (diabetes, previous myocardial infarction, peripheral vascular disease, and previous stroke), household income, educational attainment, and self-rated health. Age was analyzed as a categorical variable broken into ten-year age groups. Gross household income on the questionnaire was coded using a response tree as follows: Participants were first asked if income totalled less than or greater than \$20,000. If the latter, participants were then asked for further refinement, indicating whether income totalled less than or greater than \$40,000. Responders to the first part of the question may have chosen not to elaborate upon the second part. Therefore, some of the responses were grouped “≥ \$20,000”, an amount that overlaps with the groups “\$20,000–39,999” and “≥ \$40,000”, although participants in each of these groups are distinct. Educational attainment was categorized by highest diploma or degree obtained, as follows: “did not complete secondary”, “completed secondary”, and “completed post-secondary diploma or degree”.

We excluded from the analysis 133 participants (4.1%) with missing information on smoking status, chronic conditions, education, self-rated health, or the outcomes of interest. As BMI and household income had large proportions of missing data (BMI was available only for those who attended the clinic session, while income was an elective question), these

participants were retained in the analysis as a missing category for each variable.

Contextual-level measures

In previous work, we subdivided the province of Nova Scotia (populated by approximately 940,000 residents) into 64 functional geographies or contexts, based on Census Consolidated Subdivisions in rural areas and on Enumeration Area groupings (“neighbourhoods”) in urban areas.²⁴ In the present study, at the level of these 64 geographies, we considered three contextual covariates: 1) local socioeconomic conditions, 2) local health status, and 3) the covariate of interest – access and availability of health services. Local socioeconomic status was considered as a potential contextual-level confounder because the importance of its contextual effect on the health of individuals is becoming established and its substantial variation throughout the 64 geographies has been demonstrated.²⁴ The measure of local socio-economic status, average household income of these geographies, was drawn from the 1996 Canada Census. Also, because local health will determine local demand for health services, the second contextual covariate – local health status – was considered as a potential contextual confounder. The measure of local health, local life expectancy for the year 1995, was calculated from mortality as reported in provincial vital statistics and from projected population counts based on the Canada Census.^{25,26}

In state, metropolitan and county level comparisons, researchers have used physician-to-patient ratios as a proxy for access and availability of primary health care.^{17–22} As this is a small area comparison and some physicians may have more than one practice in different areas, or may also be working part time or long hours, we evaluate *the number of physician visits per resident* rather than *the number of physicians per resident*.²⁷ The number of physician visits per resident was derived from 1995 physician claims on the provincial health insurance plan which captures all health services of Nova Scotia residents.²⁷ To overcome differences in age and gender throughout the 64 geographies, we standardized the number of primary care physician visits per resident in this respect. For each of the 64 geographies, we also generated empirical Bayesian

estimates for number of primary care physician visits and for life expectancy, to overcome over-dispersion – the phenomenon of unstable small area estimates resulting from varying population sizes.²⁸ Hierarchical or multilevel methods generate such empirical Bayesian estimates and allow for spatial smoothing.^{28,29} Here we considered a multilevel model whereby information of the 64 geographies and their adjacent geographies were pooled (level 1) resulting in robust estimates of the geography-specific life expectancies (level 2). In this model, at level 1, we weighted proportional to the inverse of the standard error of the life expectancy estimates. This methodology is described in more detail elsewhere.²⁴

Data linkage

The linkage and analysis of data for this study were approved by the Health Sciences Human Research Ethics Board of Dalhousie University, Halifax, Nova Scotia, Canada. The original sampling frame of the survey contained residential postal codes, allowing linkage to one of the 64 geographies and its information on local socio-economic status, local life expectancy, and local health care use.³⁰ Nine survey participants (0.3%), however, did not have valid postal codes and therefore could not be linked. They were excluded from the analysis, resulting in an effective study sample of 3,094 participants.

Statistical approaches

The independent importance of contextual characteristics to individuals’ health was examined using multilevel logistic regression and hierarchical software.²⁹ The contextual characteristics, local socio-economic conditions, local health status and the covariate of interest, access and availability of health services, were considered as level 2 covariates. Individual characteristics and health outcomes were considered as level 1 variables. We examined the following four health outcomes: 1) previously diagnosed hypertension, 2) presence of undiagnosed hypertension, 3) self-reported use of antihypertensive medication, and 4) presence of untreated hypertension. The presence of hypertension was defined as an average measured diastolic blood pressure of 90 mmHg or

greater, in keeping with the Canadian clinical practice guidelines in effect at the time of the survey.³¹

To demonstrate a 25% reduction in the number of individuals diagnosed with hypertension in geographies having the lowest levels of primary health care use (more than 5% below provincial average), the statistical power needed was calculated to be 94% for an alpha level of 0.05. Statistical analyses were conducted using S-Plus and HLM.²⁹

Results

Table 1 presents the individual and contextual characteristics of the 3,094 Nova Scotia Heart Health Survey participants who had complete information and were included in the present analyses. Between 5% and 6% of participants reported having been previously diagnosed with diabetes, myocardial infarction, or peripheral vascular disease, and 2.4% with stroke. Of the 3,094 participants, 868 (28%) had been previously diagnosed with hypertension. Of the remaining 2,226 participants, 148 (6.6%) had undiagnosed hypertension, that is, on the day of the participants' interview their average measured diastolic blood pressure was 90 mmHg or greater. Among all 3,094 participants, there were 457 (14.8%) on antihypertensive medication at the time of interview. Of the remaining 2,637 participants, 228 (8.6%) had untreated hypertension, that is, they were not currently taking medication and their diastolic blood pressure was 90 mmHg or greater.

The average number of visits to primary care physicians across the 64 Nova Scotia geographies ranged from 3.3 to 5.5 visits per resident per year (Figure 1). Of all participants, 19 percent (588) lived in areas where the age-sex standardized estimates of primary care physician use was less than 95% of the provincial average, 59.5% (1,842) lived in near-average primary care physician use areas, and 21.5% (664) lived in areas where primary care physician use was estimated to be more than 5% above the provincial average (Table 1).

Table 2 presents the independent associations of the contextual factors with the health outcomes of interest, adjusted for the contextual factors and individual differences with respect

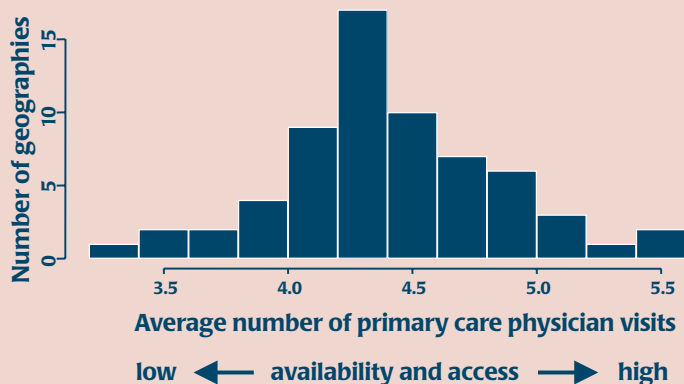
TABLE 1
Characteristics of Nova Scotia Heart-Health Survey participants (n = 3,094)

Characteristic	N (%)	
Age (years)	< 30	660 (21.3)
	30–39	561 (18.1)
	40–49	471 (15.2)
	50–59	439 (14.2)
	60–69	363 (11.7)
	≥ 70	600 (19.4)
Female	1,555 (50.3)	
Body mass index	≤ 27	1,374 (44.4)
	> 27	1,071 (34.6)
	Missing	649 (21.0)
Smoker	945 (30.5)	
Diabetes	171 (5.5)	
Myocardial infarction	173 (5.6)	
Peripheral vascular disease	154 (5.0)	
Stroke	74 (2.4)	
Income	< \$20,000	720 (23.3)
	≥ \$20,000	100 (3.2)
	\$20,000–39,999	760 (24.6)
	≥ \$40,000	949 (30.7)
	Missing	565 (18.3)
Education	Did not complete secondary	1,072 (34.7)
	Completed secondary	996 (32.2)
	Post-secondary diploma or degree	1,026 (33.2)
Self-rated health	Not too satisfied or not at all satisfied	281 (9.1)
	Somewhat satisfied	1,363 (44.1)
	Very satisfied	1,450 (46.9)
Diagnosed hypertension	868 (28.0)	
Undiagnosed hypertension (n = 2226)†	148 (6.6)	
Antihypertensive medication	457 (14.8)	
Untreated hypertension (n = 2,637)‡	228 (8.6)	
Contextual household income	< \$35,000	504 (16.3)
	\$35,000–39,999	1,388 (44.9)
	\$40,000–44,999	394 (12.7)
	≥ \$45,000	808 (26.1)
Contextual life expectancy	Decreased by > 0.5 year	990 (32.0)
	Within 0.5 year of provincial average	1,244 (40.2)
	Increased by ≥ 0.5 year	860 (27.8)
Contextual physician use	> 5% below average	588 (19.0)
	Within 5% of provincial average	1,842 (59.5)
	≥ 5% above average	664 (21.5)

† The 868 participants with diagnosed hypertension were not considered.

‡ The 457 participants on antihypertensive medication were not considered.

FIGURE 1
Availability and access to primary care physicians by geography within Nova Scotia, Canada



using antihypertensive medication or having untreated hypertension were neither substantially nor significantly different among residents of areas that varied with respect to income, life expectancy, or primary care services use (Table 2).

The associations presented in Table 2 were not substantially different from estimates of models in which we had adjusted for individual level confounders only. We also considered covariates as tertiles and as continuous variables rather than categorical variables. Model modifications, in this regard, did not substantially alter the observed associations between local health services use and the outcomes of interest.

Discussion

Cardiovascular disease is the leading cause of death in Canada and in most Western countries. Hypertension is an important risk factor for cardiovascular disease, but, unfortunately, awareness and control of this condition remains relatively low, making it an important public health concern.^{32,33} Similarly, a shortage of primary care practitioners is a major public health concern in many Western countries – particularly in rural and deprived areas.^{34–36}

to age, sex, smoking, BMI, chronic conditions, household income, educational attainment, and self-rated health. The likelihood of being diagnosed with hypertension was neither substantially nor significantly different among geographies that varied with respect to income, life expectancy, or primary care services use: Relative to areas with the lowest levels of services use (less than 95% of the provincial average), the odds ratios for areas with middle

levels (within 5% of the provincial average) or increased levels of services use (more than 5% higher than the provincial average) were only marginally elevated. Undiagnosed hypertension was less likely to occur in high-income areas (average income \geq \$45,000), areas with near average and high life expectancy, and areas with reduced use of primary care. However, these differences were also not statistically significant. Moreover, the likelihood of

TABLE 2
Contextual differences in hypertension diagnosis and management independently of individual-level and other contextual-level differences

Contextual factor	Diagnosed hypertension OR (95% CI)*	Undiagnosed hypertension OR (95% CI)*	On antihypertensives OR (95% CI)*	Untreated hypertension OR (95% CI)*
Local household income				
< \$35,000	1	1	1	1
\$35,000–39,999	1.00 (0.80–1.25)	1.04 (0.67–1.63)	1.13 (0.83–1.56)	0.80 (0.53–1.21)
\$40,000–44,999	1.13 (0.79–1.62)	0.81 (0.43–1.54)	1.25 (0.85–1.85)	0.88 (0.43–1.82)
\geq \$45,000	1.02 (0.75–1.40)	0.71 (0.41–1.24)	0.92 (0.68–1.24)	0.89 (0.55–1.42)
Local life expectancy				
Decreased by > 0.5 year	1	1	1	1
Within 0.5 year of average	0.98 (0.77–1.25)	0.62 (0.39–1.01)	1.10 (0.79–1.54)	0.66 (0.41–1.04)
Increased by \geq 0.5 year	0.99 (0.76–1.29)	0.86 (0.49–1.51)	1.00 (0.73–1.36)	0.77 (0.44–1.35)
Local primary care use				
> 5% below average	1	1	1	1
Within 5% of average	1.05 (0.81–1.36)	1.33 (0.76–2.32)	0.81 (0.55–1.20)	1.31 (0.77–2.22)
\geq 5% above average	1.04 (0.74–1.45)	1.53 (0.81–2.89)	0.92 (0.61–1.39)	1.42 (0.78–2.59)

* Odds ratios (95% confidence intervals) adjusted for individual risk factors of age, sex, smoking, body mass index, presence of chronic conditions (diabetes, myocardial infarction, peripheral vascular disease, stroke), household income, educational attainment, and self-rated health and for the contextual factors listed in the table.

Availability and access to primary care may affect the diagnosis and management of hypertension. We therefore hypothesized that residents of areas with restricted availability and access would be 1) less likely to be diagnosed with hypertension, 2) more likely to have undiagnosed hypertension, 3) less likely to be on antihypertensive medication, and 4) more likely to have untreated hypertension. The present study could not confirm any of these hypotheses.

Although geographic factors for cardiovascular outcomes have been addressed in various studies using individual level information,^{3,37-40} the importance of adequate delivery of primary health care has only been addressed in studies using geographically aggregated information.¹⁷⁻²² With respect to the latter, in the US, state and metropolitan level comparisons revealed higher life expectancy and reduced mortality in geographies with a high primary care physician-to-population ratio independent of socio-economic differences.^{18,20} Based on these observations, the authors had suggested that an increase in the number of primary care physicians would be an effective and feasible means of addressing adequacy of primary care availability and access in order to improve population health.²⁰ Gulliford observed a similar association in England, but indicated that 'in England the association between supply of primary care doctors and mortality might be largely explained by confounding'.²¹ Unlike the US, the UK and Canada have universal access health care systems through which primary care availability and access to all residents is addressed. As a consequence, local differences in the use of primary care services are expected to be smaller in settings with universal health care and likely account for the varying study findings. This seems consistent with findings of an international comparison within the Organization for Economic Cooperation and Development (OECD) countries demonstrating better health outcomes in countries with better primary care systems.⁴¹

To overcome ecological bias in studies of primary health care, Gulliford had suggested the conduct of studies with 'data collected at the individual as well as area level'.²¹ The present study did collect data at both levels and analyzed the data as distinct individual level

and contextual level factors. The contextual level factor of interest, the delivery of primary health care services, may affect the health of individuals in various ways. For example, residents of geographies with serious shortages of primary care physicians may experience difficulties in finding a regular doctor, difficulties in scheduling appointments, shorter consultation times, and greater emphasis on acute rather than preventive care. Other factors that may vary geographically and affect the health of individuals include local policies, staffing shortages of primary care personnel other than physicians, practice styles, transportation, and health-seeking behaviour.¹⁶ The present study also differs from previous work in that it compared small areas to serve the informational needs of health policy makers operating at a community or neighbourhood level.²⁴ Because physicians may have more than one practice or work part-time or long hours, the evaluation of physician visit rates may provide more accuracy in small area comparisons than physician-to-patient ratios that have been applied in comparisons at the state, metropolitan, or district health authority level.¹⁷⁻²²

Of the 64 geographies, 28 deviated more than 5% and six deviated more than 10% from the provincial average. We are not aware of any other small area studies of physician visit rates as a point of reference for our observations, which hampers us in our judgment of whether the observed variation is modest or large. We expressed geographic variation in terms of percentage deviation from the provincial average. One may perceive the percentage deviation as relatively modest; however, in terms of absolute numbers of health care services and costs they represent large differences. In addition, even modest geographic variation in family physician services use may result in a disproportionately larger variation in preventive health services as physicians in understaffed areas may aim to maintain the level of acute services and selectively reduce the number of preventive services, such as the management of hypertension. The present study demonstrated that the latter is not a concern. The present study also provides a point of reference for future studies on geographic variation in health services and their impact on health. Such future analyses may include an updated analysis in Nova Scotia: This is particularly relevant as understaffing of primary care

personnel has worsened since 1995. These analyses may also examine other health outcomes amenable to primary care intervention, such as participation in breast, cervical, and prostate cancer screening. Furthermore, future analyses should include the evaluation of the health impact of geographic differences in availability and access to specialist and hospital services. This is pertinent as we previously demonstrated that geographic variation in the use of specialist and hospital services exceeded that for use of family physicians,²⁷ and that this variation has a substantial potential to affect health outcomes among residents.⁴² All these future studies may follow the multilevel approaches as applied in the present study.

In summary, we observed moderate geographic variation in availability and access to primary care in Nova Scotia, but we did not confirm consequent disparities in the diagnosis and management of hypertension among provincial residents. Nevertheless, variation in the delivery of health services does not appear consistent with the objectives of universal coverage of health services.

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Research on Alzheimer's caregiving in Canada: Current status and future directions

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Abstract

In December 2002, a national workshop was held in Ottawa to guide research directions for the caregiving of people with Alzheimer's disease in Canada. Prior to the workshop, a search was conducted to identify Canadian-based investigators who have conducted research related to caregiving of individuals with cognitive impairment, Alzheimer's disease and other dementia, identify relevant Canadian research studies, and provide an overview of results and themes emerging from this research. This paper summarizes findings from our search for Canadian studies, research themes identified at the national workshop in Ottawa, and recommendations from the workshop. The report first outlines patterns of caregiving and subsequently focusses on the impact of different ways of assisting Alzheimer's caregivers. It concludes by outlining the methodological challenges of observational and intervention studies related to Alzheimer's caregiving and recommendations on how to increase Canada's capacity to conduct research on Alzheimer's caregiving.

Key words: aging; Alzheimer's disease; caregivers; caregiving; cognitive impairment; dementia

Introduction

Considerable research has been conducted on the caregiving of individuals with Alzheimer's disease in Canada; there is a need to take stock of what has been learned and to decide what directions future research endeavours should take. Accordingly, in December 2002, the University of Ottawa Institute on Health of the Elderly associated with the SCO Health Service, in collaboration with the Canadian Institutes of Health Research (CIHR) Institute of Aging, the CIHR Institute on Gender and Health, and the CIHR Partnerships and Knowledge Translation Portfolio, held a two-day national research workshop to guide

research directions for caregiving to people with Alzheimer's disease in Canada. Prior to the workshop, a search for Canadian studies was undertaken to:

- identify current Canadian-based investigators who have conducted research related to caregiving of individuals with cognitive impairment, Alzheimer's disease and other dementias (will be referred to as Alzheimer's disease);
- identify relevant Canadian research studies; and
- provide an overview of results and themes emerging from this research.

This paper summarizes findings from our search for Canadian studies, research themes identified at the national workshop in Ottawa, and recommendations from the workshop.

Methods

Search strategy for Canadian research on Alzheimer's caregiving

This search focussed on studies carried out in Canada. Once we fully understand what has been accomplished in Canada, we can review findings from other countries and determine how well these findings apply in the Canadian context. This search, therefore, was a first and necessary step in the process of reviewing the international caregiving literature for people with Alzheimer's disease. For comprehensive reviews of the international literature, see references 1 to 6. The search strategies we used allowed us to locate 1,525 references, 111 of which met the inclusion criteria for this study. The following website provides a detailed description of the search methods and a list of the references that met the inclusion criteria for this review: <http://www.medicine.uottawa.ca/research/eng/institutes.html>.

Ottawa workshop process

The workshop brought together researchers, clinicians, policymakers, and governmental and non-governmental representatives from across Canada, as well as Richard Schulz, from the University of Pittsburgh, an

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international leader in the field of caregiver research. After a poster session and greetings from Réjean Hébert, Scientific Director of the CIHR Institute of Aging, the first half-day of the workshop consisted of a plenary presentation on findings from our search of Canadian research on Alzheimer's caregiving and a panel discussion from one non-governmental, one governmental, and one clinician representative on needs of research users. On the second day of the workshop, the working group recommended CIHR initiatives to stimulate caregiver research.

Preparation of the report

This report was based on the findings from the search for Canadian studies on Alzheimer's caregiving, the national workshop deliberations, and feedback received from both participants and invitees who made suggestions and comments on the drafts. It concludes with a discussion on how to build capacity for this research in Canada. The report was submitted to the CIHR in May 2003.

Results

For each of the following topics, refer to Table 1 for research questions/areas identified for future research on Alzheimer's caregiving in Canada.

Patterns of caregiving

Who provides the care? Family members and friends are the main source of care for individuals with Alzheimer's disease who live in the community.⁷ In fact, family and friends provide 75% to 85% of the care needed by frail Canadian seniors,^{8,9} particularly spouses and adult children (who in some cases are seniors themselves).^{10,11} Typically, one family member, most likely a woman,^{7,11,12} takes on most of the responsibility, assuming the role of primary caregiver. Women assist most often in the areas of homemaking and personal care and men assist most often with home maintenance, transportation and financial issues.¹³

What type of care is provided? The caregiving role is complex and ill-defined but generally includes practical assistance with basic and instrumental daily living activities and personal care, emotional support, mediation with

TABLE 1
Research questions/areas identified for future research on Alzheimer's caregiving in Canada

1. Patterns of caregiving

1.1 Who provides care?

- How is the role of caregivers of individuals with Alzheimer's disease changing?
- What would encourage men to assume different caregiving roles than women?
- How do Canadian culture, health and human services, and geographic landscape contribute to who provides care and how care is provided?
- Do changes occur over time in the amounts of informal and formal care received by caregivers and their recipients?
- How important are networks of Alzheimer's disease care for family, friends, voluntary sector members, professionals, and individual caregivers?

1.2 What type of care is provided?

- Do care recipients prefer to have women taking care of their personal and homemaking needs?
- How often are men asked to provide personal and homemaking care?
- What cultural differences exist in terms of access to, demand for, and expectations of support among caregivers of seniors with dementia?
- Do patterns of caregiving differ according to the availability of informal and formal caregiving services in a community?

1.3 How can we characterize caregiver transitions?

- Do needs and use of services fluctuate over time due to the nature and stages of Alzheimer's disease?
- What are the pathways in and out of the caregiver role and from moderate to highly demanding levels of caregiving?
- What type of research is needed to understand the caregiving process for current seniors and those of the future?
- What is the quality and nature of caregiver and care-recipient relationships?
- What types of work-family interfaces and/or conflicts exist?
- What types of social networks, support networks, and care networks exist for caregivers?
- How is caregiving affected by stages of illness?

1.4 How much care is provided?

- How well do formal services offered across Canada match needs?

2. Negative aspects of caregiving

2.1 What is the financial strain of caregiving?

- The costs of caring for people with dementia.
- The costs of homecare, health care professionals, medications, supplies.
- Care recipients' and caregivers' ability to cover costs.

formal organizations and service providers, financial help, and possibly sharing a household.^{10,14} Population surveys often are limited as caregivers and care recipients have difficulty distinguishing among the various types of professionals that visit their homes.

How can we characterize caregiver transitions? Caregiving is typically an evolving long-term process. Schulz¹⁵ describes the trajectories that caregivers and care recipients experience, as well as the appraisals and health effects associated with each phase in this model (see Figure 1). Future longitudinal and cross-sectional studies will be important in helping us to assess the role of transitions in caregiving. National population surveys of caregivers such as the Canadian Longitudinal Study on Aging¹⁶ and the National Population Health Survey (<http://www.statcan.ca/english/concepts/nphs/>) will provide in-depth data on caregiver transitions to guide future policies and practices in Canada.

How much care is provided? In the Canadian Study of Health and Aging (CSHA), community-dwelling older subjects with dementia received an average of 63 hours of informal assistance from their primary caregivers per month; those without dementia received help for an average of 44 hours per month from a primary caregiver.¹¹ Even after institutionalization, caregivers in Canada generally continue to provide some degree of assistance to care recipients.^{7,11,17,18} Use of health services differs from demand, that is, the extent to which services are actually used. For example, “need”, as judged by the prevalence rates of health problems found in epidemiological studies, may be much higher than actual use.¹⁹

Negative aspects of caregiving

What is the financial strain of caregiving? Hux and colleagues²⁰ conducted a formal analysis of caregiving costs for people with Alzheimer’s disease using CSHA data. The annual societal cost of care per person increased with the severity of Alzheimer’s disease, from \$9,451 (CDN) for mild cases to \$36,794 (CDN) for severe disease.

Institutionalization comprised the main portion of this cost for those with severe disease. In Manitoba in 1991, the cost of providing strictly health and social services was \$2,343

TABLE 1 (continued)
Research questions/areas identified for future research on Alzheimer’s caregiving in Canada

2.1	What is the financial strain of caregiving? (continued)	<ul style="list-style-type: none"> The responsibility for paying the costs. The differences in costs in caring of individuals with Alzheimer’s disease compared to caring for people with other diseases.
2.2	What are the effects of caregiving on caregiver’s ability to work?	<ul style="list-style-type: none"> How does caring for individuals with Alzheimer’s disease impact employed caregivers? How does caring for individuals with Alzheimer’s disease impact employers?
2.3	Do Canadian workplaces support caregivers of people with Alzheimer’s disease?	<ul style="list-style-type: none"> Workplace policies and programs to assist caregivers of individuals with Alzheimer’s disease. The impact of personnel policies that allow employees to take sick days to care for their family and long-term leaves of absence with protection of benefits (similar to parental leave).
2.4	What are the effects of caregiving on physical and psychological health?	<ul style="list-style-type: none"> The way in which different types of environmental, social, and emotional supports affect the health of caregivers. The effects of caregiving on family caregivers, care recipients, and family members of the caregivers Alternative conceptual frameworks, such as Pearlín’s model of caregiving, should be used as the theoretical basis for research on the health effects of caring for people with Alzheimer’s disease.
3. Positive Aspects of Caregiving		
3.1	What are the positive aspects to caregiving?	<ul style="list-style-type: none"> The types of caregivers that are most likely to report positive aspects to caring. Whether alternative approaches to supporting Alzheimer’s caregivers enhances the positive aspects of their caring.
4. Interventions for Alzheimer’s caregivers		
4.1	Respite care	<ul style="list-style-type: none"> The percentage of people who use respite care. The barriers to respite care. Accessibility and effectiveness of respite care, and Types of respite care provided in Canada.
4.2	Local, provincial, and federal approaches	<ul style="list-style-type: none"> How can local, provincial and federal decision-makers work together to develop and evaluate initiatives similar to the Ontario’s Strategy for Alzheimer’s Disease and Related Dementias?
4.3	The interface between informal and formal caregiving.	<ul style="list-style-type: none"> Research evidence to support the models that interface between informal and formal caregiving is needed. Alzheimer’s caregiving should be a special focus of this research.

for people with dementia, \$1,882 for people with cognitive impairment, not dementia (CIND) and \$1,101 for people with normal cognition.²¹ The cost of supplies, medications, renovations, and equipment were reported to be a financial strain to 25% of Canadian informal care providers.^{14,22} The economic impact of taking time off work, lost and postponed career opportunities, and the loss of a job can also have detrimental effects on caregivers' long-term financial well-being.^{14,23} In order to pay for out-of-pocket expenses, some informal caregivers have to adjust their budgets and draw on savings, which can affect their long-term economic well-being and quality of life.

What are the effects of caregiving on the caregiver's ability to work? In the first phase of the CSHA, one third of employed unpaid caregivers reported work disturbances due to caregiving; these disturbances were reported twice as frequently among caregivers of people with Alzheimer's disease.⁷ Caregivers are often left with little option but to use sick days and vacation to provide care.

Do Canadian workplaces support caregivers of people with Alzheimer's disease? Medjuck, Keefe, and Fancey²⁴ investigated the extent to which existing workplaces assist women to balance employment and elder care responsibilities, drawing on workplace policies and interview data from 246 female caregivers of older kin from 37 workplaces in Nova Scotia. Their findings revealed a childcare bias in family-friendly policies, a gender bias in policy formulation, and a focus on workplace productivity rather than employee well-being. They concluded that current workplace policies do not take into consideration the complex needs and diverse situations of employed women providing care for older adults.

What are the effects of caregiving on physical and psychological health? Thirty percent of Alzheimer caregivers of individuals experience depression; fewer experience physical health problems due to their roles and responsibilities.^{7,12,25} The link between caregiver tasks and caregiver health is complex. Caring for a community-dwelling Alzheimer's disease sufferer, combined with low levels of social support, has been associated with negative psychological and health outcomes.²⁶ Caregiving also restricts social and recreational inter-

TABLE 1 (continued)
Research questions/areas identified for future research on Alzheimer's caregiving in Canada

4.4 Changes to the physical environment.	<ul style="list-style-type: none"> The contribution of alterations to the physical environment on overall quality of life of the Alzheimer's caregivers should be assessed.
4.5 Financial Assistance	<ul style="list-style-type: none"> Do Alzheimer's caregivers benefit from taxation policies? How effective are taxation policies? What are the limitations of taxation policies? Additional financial and workplace informal caregiver support policies including those that would benefit Alzheimer's caregiving should be introduced and evaluated.
4.6 Governmental workplace supports	<ul style="list-style-type: none"> Research needs to consider whether employment insurance policies adequately provide for the long-term needs of caregivers and care recipients. Do these policies positively impact caregivers of seniors with Alzheimer's disease who are participating in the labour force? What alternate types of workplace and governmental supports could assist these caregivers? Studies of interventions targeted at individual caregivers and community initiatives that support Alzheimer's caregiving should be conducted. Policy makers, practitioners, caregivers, and researchers should work together to deliver and evaluate informal caregiver interventions.
5. Methodological challenges of observation and intervention studies	
5.1 Measures of the outcomes of Alzheimer's caregiving	<ul style="list-style-type: none"> Research on appropriate and sensitive outcome measures of concern to different constituencies (caregivers, care recipients, health and human service staff, employers, government funders, policy makers, and legislators).
5.2 Design and implementation of studies of interventions to support caregivers	<ul style="list-style-type: none"> Discussions on levels of change in outcome measures that are considered meaningful. Examinations of ways of refining approaches to research design, measurement and evaluation. Interventions that target "high risk"/"high response" caregivers, such as those who live alone and respond well to assistance in the home. Estimations of sample size prior to study inception that take into account high levels of study participant attrition while also trying to tackle ways to decrease attrition. Recruitment of representative samples of caregivers. Consideration of optimal methods for determining clinical and policy significance of the findings.

actions and reduces energy for other activities.^{14,23} Canadian studies have found a number of factors that influence negative health outcomes, including increased frequency of behavioural problems, care recipients' functional and cognitive impairments, and caregiver personality traits.²⁶⁻³³

Positive aspects of caregiving

What are the positive aspects to caregiving? Canadian investigators have found that not all aspects of caregiving are negative.^{34,35} Caregivers report a number of personal benefits to caregiving, such as companionship, fulfillment, extending quality of life, and enjoyment.³⁴ The rewarding aspects of caregiving are often overlooked and under-researched. It is important to understand how benefits relate to outcomes.³⁶ Caregivers demonstrate considerable variability in response to their roles and responsibilities, and not all caregivers are overburdened and unable to cope.¹⁴

Approaches to assisting Alzheimer's caregivers

There are three approaches to designing and evaluating interventions.³⁷ The first involves developing multi-component interventions that are offered to all caregivers. This approach is relatively easy to implement and evaluate but may not be flexible to individual needs. The second approach involves designing targeted or tailored interventions that attempt to reach types of caregivers, types of care recipients, and stages of caregiving. Targeted and tailored interventions can be complex, expensive to implement and should be grounded in theory. They do, however, allow interventions to be matched with caregivers and care recipients. A third approach is to develop local community interventions involving local Alzheimer's disease society branches and other interest groups that would volunteer their time to assist informal caregivers. Interventions should be developed in collaboration with caregivers, who can identify the most effective strategies. Present and former caregivers of individuals with Alzheimer's disease should be interviewed to learn what information, training, and support they wish they had had.

TABLE 1 (continued) Research questions/areas identified for future research on Alzheimer's caregiving in Canada	
<p>5.2 Design and implementation of studies of interventions to support caregivers (continued)</p>	<ul style="list-style-type: none"> • Study designs that go beyond general population or clinical samples to include marginalized and understudied caregivers (e.g., those who live in rural communities or in inner cities), minority groups (e.g., Aboriginal and First Nations caregivers), and those whose mother tongue is neither English nor French.
<p>6. Increasing capacity</p>	
<p>6.1 How do we increase capacity for Alzheimer caregiver research in Canada to ensure the proposed research is carried out?</p>	<ul style="list-style-type: none"> • Researchers from many disciplines and locations with different research skills should work together to advance knowledge on building community capacity. • By expanding CIHR Research Personnel Awards: university-based faculty who spend 40% or more of their time doing caregiver research could be eligible. • Research on support of informal caregivers of individuals with Alzheimer's disease should be improved in Canada by using national surveys and registries and by having regular conferences to identify and develop a network of Canadian caregiver researchers. • To increase research relevance and dissemination of results, involve informal and formal caregivers in the design, implementation, and interpretation of research on support of informal caregivers of individuals with Alzheimer's disease. • Develop a Canadian consortium or clearinghouse (for example, through the Alzheimer's Society) whose mandate is to continually and systematically update knowledge in the field of informal caregiving of individuals with Alzheimer's disease and to determine the most effective channels for disseminating this information. • Conduct systematic evaluations of the effects of knowledge translation efforts. As part of this initiative in Canada, form an international collaboration to systematically review the world literature (for example, using International Cochrane Collaboration and Campbell Collaboration mechanisms and criteria).

What types of Canadian studies of interventions for Alzheimer's caregivers have been completed to date?

Our search for Canadian studies discovered eleven Alzheimer's caregiver intervention studies published since 1990. Pilot studies were excluded from the review. Studies that examined the impact of dementia management medications for care recipients on caregiver costs were also excluded. However,

several recent studies have examined this issue,³⁸⁻⁴⁰ and further work is needed to determine the effects that prescription and non-prescription medications used for dementia management have on those caring for seniors with dementia.

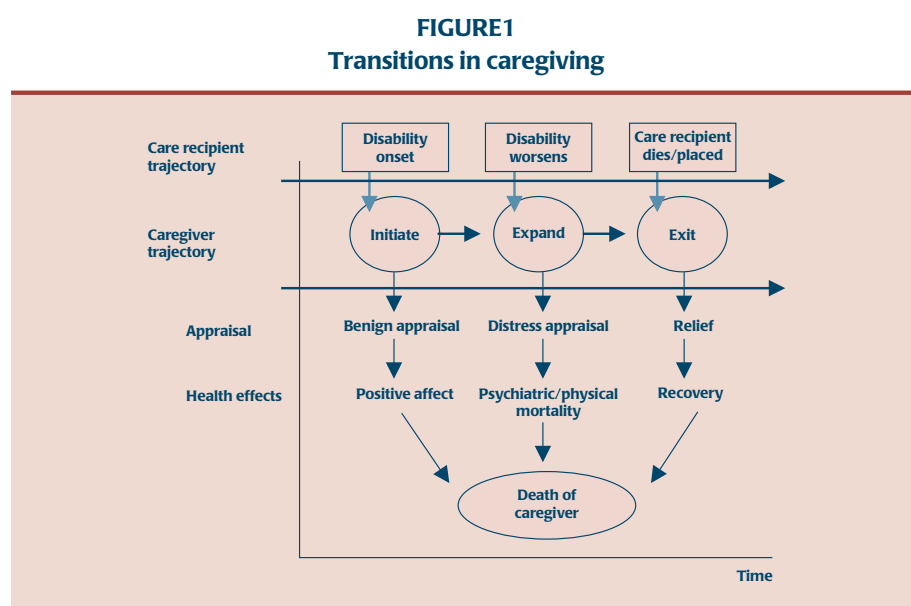
In response to criticisms that traditional support groups for unpaid caregivers of people with dementia were ineffective,⁴¹ recent Canadian studies of interventions targeted at individual Alzheimer's caregivers have

emphasized theoretically based cognitive and behavioural group interventions. These programs are typically designed to increase caregivers' self-efficacy⁴² and to provide individual caregivers with tools for coping with psychological distress associated with caring for the cognitively impaired, such as problem-solving skills, assertiveness training, and cognitive restructuring.⁴²⁻⁴⁴

The interventions for caregivers of people with Alzheimer's disease vary. One approach is to facilitate problem-solving skills in caregivers. Roberts and colleagues⁴⁴ developed an individualized problem-solving intervention. Their 'therapy' sessions consisted of the following steps: problem orientation, problem definition and formulation, generation of alternatives, decision-making, and solution implementation and verification.

Another type of intervention is the provision of respite care.⁴⁵ This may involve attendants coming to the house to look after the care recipient while the caregiver leaves the home or stays in the home but tends to non-caregiver tasks; adult daycare or day hospital programs; or respite beds in a facility where the care recipient stays for days or weeks. Usually respite care is promoted to help care recipients avoid leaving their homes and being placed in a long-term care facility and to decrease caregiver burden.

Other interventions have employed a combination of approaches.⁴⁶⁻⁴⁷ For instance, Mohide and colleagues⁴⁸ designed an intervention with a combination of caregiver-focussed health care, education about Alzheimer's disease and caregiving, assistance with problem solving, regularly scheduled in-home respite, and access to a self-help family caregiver support group. A similar randomized controlled trial employed a combination of information, social support, skills training, and behaviour modification.⁴⁶ Hébert and colleagues⁴⁷ designed a multifaceted support group program with information on Alzheimer's disease, techniques for solving behavioural and emotional problems, and relaxation techniques. Hébert and colleagues^{49,50} also developed a psycho-educative group intervention aimed at improving caregivers' ability to deal with stressful demands encountered in caring for individuals with Alzheimer's disease. Their 15-week



program was designed to help participants with their cognitive appraisals of stressful situations and to provide mechanisms for coping with them.

What do we know in Canada about interventions targeted at community, provincial or national levels?

In addition to interventions targeted at individual Alzheimer's caregivers, studies need to evaluate community-based strategies that target families of caregivers, formal care providers, communities and policy-makers (see Figure 2 for examples). Research needs to focus on systems of community care that support caregivers, such as dementia care networks, local Alzheimer's societies, and relationships between central and local governments. While there are several of these types of initiatives in Canada, there are few systematic evaluations of community-level or policy interventions. The following section describes existing initiatives and suggestions for future research.

Home and community supports

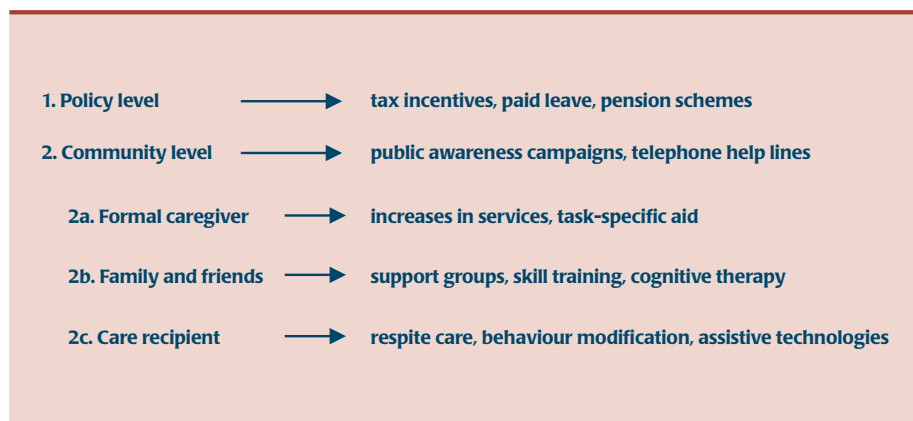
Local, provincial and federal approaches. Ontario's Strategy for Alzheimer's Disease and Related Dementias,⁵¹ a unique policy initiative in Canada, introduced policies related to informal caregiving that overlap at the provincial and local levels. The Alzheimer's Society of

Ontario has expanded the number of local branches that are responding to the Strategy's initiatives. Initiatives directly related to caregiving include public awareness, information, education and research on caregiving. The Ontario Ministry of Health and Long-Term Care is conducting a systematic evaluation of this initiative.

The interface between informal and formal caregiving. Researchers have proposed different models of caregiving to illustrate how informal and formal health care systems can be connected. The task specificity model of caregiving states that the structure of the task determines the source of care.⁵² Others^{53,54} argue that increasing provision of formal services is commensurate to, and parallels, decreases in informal care. A third model suggests that patterns of assistance follow an orderly hierarchical selection process determined by individual preferences.⁵⁵ The supplementary model⁵⁶ states that formal care supplements the informal care that caregivers provide.

Changes to the physical environment. New knowledge about the design of facilities could be made available to Alzheimer's caregivers whose care recipient is still at home. This would include new technologies developed to enable medical monitoring, such as blood pressure monitoring of people in their homes.⁵⁷ Another possibility is the use of computer programming based on artificial

FIGURE 2
Examples of interventions at multiple levels



critical times” (p. 183). The 2003 federal budget reflected these recommendations by expanding Employment Insurance to provide compassionate care leave for those caring for a child, parent, or spouse who is gravely ill and dying. This bill was recently defeated. Several provinces (British Columbia, Quebec, and Ontario) have also introduced statutory provisions for family leave without loss of pay.

The above results suggest that there is inadequate information related to general, targeted, and community interventions for Alzheimer’s caregivers upon which to base policies to support these caregivers. This work would encourage spin-off studies and partnerships with governmental (e.g., Statistics Canada) and non-governmental agencies and among funding agencies (e.g., CIHR and the U.S. National Institute on Aging).

Methodological challenges of observation and intervention studies

Measures of the outcomes of Alzheimer’s caregiving

Based on a systematic review of intervention trials in the international literature,⁶ four measurement constructs were identified for assessing outcomes of intervention studies: *quality of life*, for example, caregiver burden, coping mechanisms, social support, and marital adjustment; *symptoms of psychological distress*, such as depression or anxiety; *social significance*, such as health care utilization, costs to the health care system, or impact on institutionalization; and, *social validity* such as satisfaction with care processes. Both observational and intervention studies conducted in Canada used one or more of these constructs, with few using the same methods of measuring them.

Design and implementation of studies of interventions to support caregivers

Most of the located Canadian randomized controlled intervention studies reported limited effects, with no meaningful reductions in caregiver burden.^{43–46,48,61} While differences sometimes emerged immediately following the intervention,^{43,46} they did not endure over

intelligence techniques and algorithms to make Alzheimer’s disease patients less reliant on their in-home caregiver, for example, when washing their hands.⁵⁸

Financial assistance

Tax credits, direct allowances and pension schemes are other ways of providing tangible assistance to caregivers that can be less costly than the direct expenditures involved in implementing services. Canadian taxation policies that support informal caregivers include the Disability Tax Credit, the Infirm Dependent Tax Credit, the Medical Expenses Tax Credit and the Caregiver Tax Credit. Eligibility for the Caregiver Tax Credit excludes spousal caregivers, caregivers who do not reside with the care recipient and caregivers of individuals with an income that exceeds \$15,453. Consequently, 90% of Canadian caregivers are ineligible for this tax credit, which has a maximum amount of \$560.⁵⁹

Direct compensation in the form of pension credits and allowance policies (such as the attendant allowance provided by Veterans’ Affairs Canada and the policy implemented by the Government of Quebec that provides \$600 per year for respite services) are different ways of compensating caregivers. Currently, the Canadian Pension Plan (CPP) does not provide benefits to employees whose caregiving responsibilities prevent them from participating in the labour force. However, the CPP allows employees to exclude zero earnings spent while caring for a child under the age of seven from pension calculations. A similar

policy for elder care would mean that reduced earnings during the caregiving period would not result in lower future pension benefits. Major amendments to the CPP require the approval of at least two-thirds of the provinces and may be associated with increased costs to individuals and employers to compensate for their extension.

The benefits of policies such as such as tax credits, pension schemes, caregiver leaves, and payment to caregivers may be inadequate to support informal caregivers of individuals with Alzheimer’s disease. New financial and workplace informal caregiver support policies are needed. They could be evaluated by surveys to determine the support that Canadians give to policies that support caregivers of individuals with Alzheimer’s disease. Each policy that is implemented should be linked with an appropriate evaluation.

Governmental workplace supports

In September 2002, the federal government agreed to modify existing programs to allow Canadians to provide compassionate care for a gravely ill or dying child, parent, or spouse without putting their jobs or incomes at risk (Speech from the Throne, September, 2002). The Kirby Committee also recommended that employment insurance benefits be provided to relatives assisting the terminally ill, and the Romanow Commission⁶⁰ recommended that the federal government “develop proposals to provide direct support to informal caregivers to allow them to spend time away from work to provide necessary home care assistance at

time. The exception to the above was a multi-centre randomized controlled trial⁴⁹ that reported significant differences between caregivers in the control group and those in the intervention group in terms of reactions to, and frequency of, behavioural problems, particularly disruptive behaviours.

Methodological problems inherent in intervention studies may partially account for their limited effects. Seven randomized controlled trials have been published in Canada.^{43-46,48,49,61} The overall sample sizes for the seven studies ranged from 21 to 158, with a mean sample at outset of the study of 67. However, six of the seven trials had high levels of subject attrition^{43,44,48,49,61} because of death or institutionalization of the care recipient, which may have led to having too few subjects to demonstrate statistically significant results. Several studies mentioned difficulties in recruiting subjects, which could have resulted in non-representative samples of caregivers, for example, those with more time for caregiving or caregivers with moderate levels of burden. Interpreting the practical implications of significant results is difficult because one cannot determine whether the changes are clinically meaningful or relevant to policy.

The above-mentioned problems with intervention studies are consistent with those highlighted by Schulz and colleagues in their review of 43 international intervention studies published since 1996.⁶ This review reveals that caregiver interventions evaluated to date are short-lived, involve outcomes of minor importance, and do not have an appreciable impact on the quality of life or psychological functioning of caregivers of individuals with Alzheimer's disease. This lack of impact may be due to methodological problems in the studies or to the fact that the interventions do not have the ingredients required to have an important enough effect on caregivers.

How do we increase capacity for Alzheimer's caregiver research in Canada to ensure the proposed research is carried out?

One of the obstacles facing Alzheimer's caregiver research in Canada is the limited number of researchers in the field. A national effort should be established to support

existing research and to attract newcomers to this field.

Caregiver researchers require more input from interdisciplinary groups in universities and communities (for example, psychiatry, geriatrics, neurology, sociology, community development, and psychology) and more time to spend on their research. Education programs should include more research practicums that allow students to develop advanced research skills. Faculty should also be released from teaching to allow for more time spent on research; the Social Sciences and Humanities Research Council of Canada (SSHRC), for example, has a program through which faculty can apply for release time from courses to pursue research.

National conferences on caregiving would also continue a dialogue related to the learning needs and development of people with research interests in informal Alzheimer's caregiving. Additionally, if the number of intervention studies for caregivers of individuals with Alzheimer's disease is to increase (a need identified in the December 2002 Workshop), opportunities for established social scientists to change their research programs must be established. During their retraining, social scientists would develop skills in areas such as alternative research designs, methods of monitoring, coordinating and conducting randomized controlled trials and related intervention research designs, alternative trial enrollment strategies, randomization techniques, and analyses, such as "intent to treat" analyses. The Canadian Health Services Research Foundation's Career Re-Orientation Award is an example of an initiative to help increase the number of health services researchers.

Finally, research on caregiving of individuals with Alzheimer's disease must include an examination of the best methods for disseminating the results of studies and of collaborating on methods of research. Researchers should incorporate users of research in the research process.

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The Late Effects Study: design and subject representativeness of a Canadian, multi-centre study of late effects of childhood cancer

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Abstract

The Late Effects Study of the Canadian Childhood Cancer Surveillance and Control Program was designed to assess psychosocial and physical health outcomes among survivors of childhood cancer compared to general population controls. The objectives of this paper are to describe the design and methodology of the multi-centre, retrospective cohort study, present clinical characteristics of the survivor population, and evaluate the representativeness of study controls. Response rates were 63% for survivors ($n = 2,152$) and 49% for controls ($n = 2,432$). Survivors with germ cell tumours and carcinomas were slightly under-represented among participants as were those who received more intense or multiple series of therapy. Study controls were similar to Census individuals based on marital and work status but did have a slightly higher level of education and income. Otherwise, no large or systematic differences were found. Thus, these long-term survivors and population controls can be validly studied to evaluate whether and to what extent survivors experience an excess of psychosocial or physical health problems compared to similarly aged Canadians who have never had cancer.

Key words: adolescence; cancer; child; population controls; quality of life; study design; survivors

Introduction

Childhood cancer is the leading cause of death from disease in Canadians less than 20 years of age. Each year, approximately 1,300 children and adolescents are diagnosed with cancer in Canada.¹ Despite this, in Canada and other developed countries, survival of childhood cancer patients has risen remarkably in the past 30 years due to the use of aggressive, multi-modal therapies. Today, over 75% of children diagnosed with cancer will survive five or more years post-

diagnosis.^{2,3} Currently, it is estimated that one in every 900 adults in the United States is a survivor of childhood cancer.⁴ However, the long-term implications of both the disease and its treatment are only beginning to be understood.

In 1992, Health Canada announced the Canadian Childhood Cancer Surveillance and Control Program (CCCSCP), a collaboration involving several stakeholders concerned with childhood cancer including Health Canada, pediatric oncology centres, pro-

vincial cancer registries, universities, and voluntary agencies. The program was designed to complement provincial cancer registry and clinical trials data by collecting information on the complete childhood cancer continuum. To achieve its goal, the program included three main study components: Etiology, Treatment and Outcome Surveillance, and Late Effects. The overall aim of the Late Effects Study was to describe the psychosocial and physical health outcomes among survivors of childhood cancer compared to general population controls of the same age and sex with no history of cancer. This is the first in a series of manuscripts to be produced from the Late Effects Study. Subsequent papers will include those reporting on the outcomes of health-related quality of life, academic and social achievements, health-related behaviours, health service use, and reproduction.

The objectives of this manuscript are to describe the Late Effects Study design and methodology, to present the clinical characteristics of the survivor population, and to evaluate the representativeness of the study controls.

Methods

Design

The CCCSCP Late Effects study was a multi-centre, retrospective cohort study of

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childhood cancer survivors and population controls. Thirteen pediatric oncology centres^a with survivors from every province and territory in Canada participated. Data were collected between January 1997 and February 2000. The research ethics boards of the participating pediatric oncology centres, provincial cancer registries, and provincial health insurance agencies approved the study protocol.

Subjects

Survivors of childhood cancer were eligible to participate if they were diagnosed with a first malignancy before 20 years of age^b in 1981 to 1990, survived five years post-diagnosis, were alive at the time of study, and had sufficient language skills in either English or French to complete the questionnaire. Childhood cancer was defined according to the International Classification of Childhood Cancer (ICCC)⁵ which is based on the ICD-O-2 morphology and topology codes. In eastern Canada (Nova Scotia, Newfoundland, Quebec, and Ontario) only eligible survivors diagnosed and/or treated in the participating pediatric oncology centres were identified for the study. In Western Canada (Manitoba, Saskatchewan, Alberta, and British Columbia), survivors who met the eligibility criteria but were not seen at one of the pediatric oncology centres were identified through the provincial cancer registry.

Study controls were selected to resemble the survivors except for having no cancer history. Thus, population-based controls frequency matched to survivors by age and sex within each province were recruited. Control subjects were eligible to participate if they reported no previous cancer diagnosis and had sufficient language skills in either English or French to complete the questionnaire. A 1:1 survivor to control ratio was planned. In three of the eight provinces (British Columbia, Manitoba, and Quebec), eligible controls were identified through the provincial health insurance agency, which maintains a comprehensive list of residents to provide universal health care coverage. In the other five provinces (Alberta,

Saskatchewan, Ontario, Newfoundland and Nova Scotia) random digit dialling (RDD) was used to identify eligible control subjects due to restrictions on access to provincial health insurance data.

Two private firms that maintain banks of operating 10-digit telephone numbers conducted the random digit dialling. The first three digits identify the province of residence. Individual banks of operating numbers were randomly selected and the final two digits were removed and regenerated using a computer program that randomly chooses a number from 00 to 99. This method was repeated until the full sample was drawn. RDD thus allows the identification of potential control subjects with both listed and unlisted numbers. Each telephone number was called at least five different times during the week before being removed from the sample as an unscreened number. Eligible controls who agreed to participate during the initial call were placed in the correct age/sex strata. Once the stratum quotas were filled, the information was forwarded to the pediatric oncology centre responsible for recruitment and follow-up.

Data collection

Essentially similar procedures were used at each participating centre. The required numbers of survivors and controls from the pediatric oncology centres, the provincial cancer registries, and the provincial health insurance agencies were randomly selected from the sampling frames provided. All controls identified by RDD were included for recruitment. A clinical research assistant from each centre was assigned to recruit the selected subjects. Telephone and address information for study subjects and/or their parents were provided with the lists of eligible subjects. Information on current family physician was also obtained, if available, as an additional resource to locate subjects. Contact information was often out of date, in which case electronic telephone directories were used to trace subjects and/or their parent(s).

Initial contact was generally made by mail using a personalized letter explaining the study, its objectives, and the criteria for participation. However, due to varying requirements of the research ethics committees, initial contact was made by telephone in some centres using prepared scripts. After consent was obtained by mail or telephone, the questionnaires were sent by mail and up to two follow-up calls were made to remind subjects to return their questionnaires. Reminder calls were made three weeks after initial mailing and two weeks after the first follow-up call. Up to 12 attempts with a minimum of five attempts were made at different times during the day and days of the week to reach respondents who had not returned their questionnaires. Centres that contacted their subjects by telephone first, rather than by letter, had the highest response rates. Response rates were also slightly higher in centres that mailed a reminder letter signed by the pediatric oncologist after the follow-up telephone calls.

Information on psychosocial and physical health outcomes was gathered using two age-appropriate questionnaires, one for respondents who were under 16 years of age at study and one for those who were 16 years and older. Where possible the questionnaires included previously validated measures with known psychometric characteristics (Table 1). Subjects 16 years and older at the time of study completed a self-report questionnaire while a parent or guardian responded for subjects less than 16 years old. Both questionnaires were estimated to take between 45 minutes and one hour to complete, based on the results of the feasibility study undertaken prior to the main study.

For survivors, clinical information was extracted from the treatment medical record at the oncology centre. Information obtained included cancer type, site, and morphology; stage at diagnosis; treatments undergone including chemotherapy, surgery, and radiotherapy; and outcomes, such as relapse and death, which occurred at the treating institution.

^a Participating centres included: British Columbia Children's Hospital, Alberta Children's Hospital, Cross Cancer Institute, Allan Blair Cancer Centre, Saskatoon Cancer Centre, Manitoba Cancer Treatment and Research Foundation, Chedoke-McMaster Hospital, Hospital for Sick Children, Hôpital Ste-Justine, Montreal Children's Hospital, Centre Hospitalier de l'Université Laval, Isaac Walton Killam Children's Hospital, Janeway Child Health Centre.

^b In British Columbia, Alberta, Saskatchewan, and Manitoba subjects 0 to 19 years old at diagnosis were included. In Ontario, Quebec, Nova Scotia, and Newfoundland subjects 0 to 17 years old at diagnosis were included.

TABLE 1
Instruments used in the Late Effects questionnaires, by construct measured

Construct/outcome measured	Adult questionnaire	Child questionnaire
Health-related quality of life	MOS 36-Item Short form health survey (SF-36) Includes: Physical functioning Role limitations – physical Bodily pain General health perceptions Vitality Social functioning Role limitations – emotional Mental health	CHQ (Child Health Questionnaire), PF-50 (Parent Form, 50 items) (24). Includes: Physical functioning Role limitations – physical General health perceptions Bodily pain Role limitations– emotional Self-esteem Mental health General behaviour Parent’s mental health (from SF-36)
Multi-attribute health status	Health Utilities Index (HUI II & III) (25). Includes: Sensation Vision Mobility Hearing Emotion Cognition Speech Ambulation Self-care Dexterity Pain	Health Utilities Index (HUI II & III) (26). Includes: Sensation Vision Mobility Hearing Emotion Cognition Speech Ambulation Self-care Dexterity Pain
Physical health	Children’s Cancer Survivor Study (CCSS). Assesses problems in specific body systems; also includes questions on reproductive ability and pregnancy outcomes	Children’s Cancer Survivor Study (CCSS) (28). Assesses problems in specific body systems
Stress – acute and chronic	Life Stress Checklist (29) plus items from Quebec Health Survey (30): measures stressful life events in the past year. Chronic Stress Scale (31): Measures chronic/ongoing stress	Children’s Life Stress Scale (32). Measures both chronic and acute stress
Social and academic functioning	CCSS (see above) includes measures of school and academic problems and sexual relationships	Items from the Child Behaviour Checklist (33) that assess child’s social competence and academic performance
Self-esteem	Self-Esteem Scale (34)	In CHQ (see above)
Confidants	The Greater New Haven Child Health Study (35). Includes number, relation, visits with close individuals	Ontario Child Health Survey (36) and Child Behaviour Checklist (see above). Includes number, relation, visits with close individuals
Health resource use	Ontario Health Survey (37). Includes visits to health professionals, emergency rooms, and overnight stays in hospital	Ontario Health Survey (37) includes visits to health professionals, emergency rooms, and overnight stays in hospital
Satisfaction with Life	Satisfaction with life scale (38)	
Optimism	Life Orientation Test (39)	
Health-related behaviours	CCSS (see above) includes questions on use of tobacco and alcohol, preventive care, physical activity	

TABLE 2
Socio-demographic characteristics of survivors and controls

	Survivors (n = 2,152)		Controls (n = 2,432)	
	n	%	n	%
Sex				
Male	1,100	51.1	1,177	48.4
Female	1,052	48.9	1,255	51.6
Age				
Mean (SD)	18.9 (6.8)		19.0 (7.3)	
Range	6 to 37		6 to 37	
Ethnicity (% Caucasian)				
Maternal	1,806	83.9	2,008	82.6
Paternal	1,835	85.3	2,043	84.0
Region of residence in Canada				
West ¹	979	45.5	973	40.0*
Central ²	886	41.2	1,113	45.8*
East ³	287	13.3	346	14.2

¹ Includes British Columbia, Alberta, Saskatchewan, and Manitoba.

² Includes Ontario and Quebec.

³ Includes New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland.

* p < 0.01

Sample size

A target sample size of 2,000 completed questionnaires from both survivors and controls was set to provide 80% power to detect a difference in mean scores of 5% or more for psychosocial outcomes or a relative risk of 1.5 for common and 2.5 for rare physical outcomes, when stratified by major diagnostic category and age at study (< 16 years, > 16 years). The number of subjects targeted by each centre was proportional to the size of its patient population. An over-selection of subjects ensured that the targeted sample size was achieved.

Analysis

Response rates were calculated by dividing the number of subjects who returned completed questionnaires by the total number of eligible subjects, including those who were lost to follow-up or refused to participate. Subjects considered lost to follow-up included passive refusals (i.e., subjects who agreed to participate but never returned their questionnaires) as well as subjects who were never located. Some of the survivors who were never located may have been deceased.

For control subjects identified by RDD, the denominator of the response rate included a proportion of unscreened telephone numbers. Unscreened numbers consisted of unanswered numbers as well as answered numbers where the interviewer was not able to complete the screening process. The number added to the denominator of eligible RDD subjects was estimated by multiplying the number of unscreened telephone numbers by an estimated probability that each would have resulted in the identification of an eligible subject. The estimated probability was calculated by dividing the *n* of successfully screened telephone numbers resulting in the identification of eligible subjects by the *n* of successfully screened telephone numbers.

Among survivors, clinical characteristics for participants were compared to those who refused to participate and those lost to follow-up. Characteristics assessed included major diagnostic group, age at diagnosis, year of diagnosis, types of treatments received, and number of treatment series completed during therapy. A treatment series included chemotherapy, radiation therapy and/or surgery and usually followed a predetermined protocol. More than one treatment series occurred when the initial planned treatment was extended

due to incomplete or lack of response or after a relapse.

Study controls were compared to Canadian Census data to assess the extent to which controls resembled the Canadian population.⁶ Parental socio-demographic information was used for the comparisons of controls < 16 years of age at study. Key variables common to our study and the census included: achieved education, marital status, work status, and personal income. Census data from 1996 were used as this was the census year closest to the year the majority of subjects were recruited. Comparison with Census data was done by province, weighted by sample size, sex, and age. Because the Census data are reported in five-year age groups the study controls compared were limited those who were 20 to 44 years of age at study. This group represented 74% of all study controls.

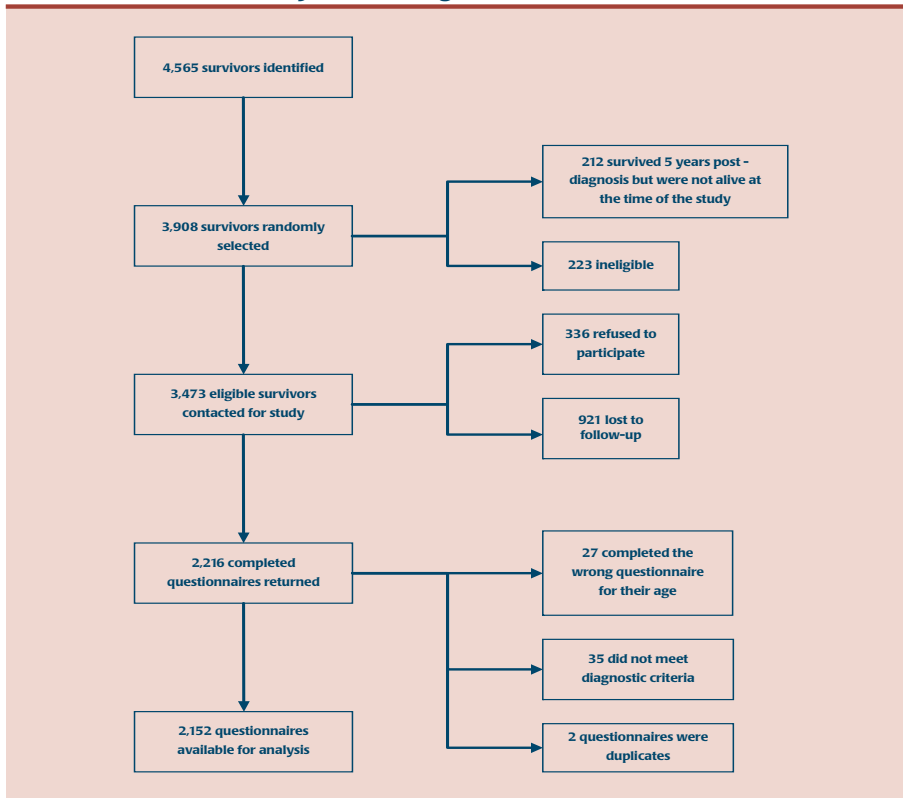
Chi-square tests were used to compare the socio-demographics of study survivors and controls, and to compare the clinical characteristics of participant survivors to survivors who refused to participate and to survivors who were lost to follow-up. Cells that contributed to the significant difference between columns were highlighted. Due to the large number of comparisons made only alpha values below 0.01 were reported.

Results

Three thousand four hundred and seventy three eligible survivors and 5,063 eligible controls were selected for study. Questionnaires were completed and returned for a total of 2,216 survivors and 2,507 controls (Figures 1 & 2). After removing questionnaires completed by subjects who were later determined to be ineligible (e.g., out of age range, diagnosis not included in the ICCC) there were 2,152 survivors and 2,432 controls available for outcome analysis. Response rates were 63.1% (2,152/3,409) for survivors and 48.8% (2,432/4,988) for controls.

Response rates for survivors by ICCC major diagnostic category were over 60% with the exception of survivors of bone tumours, germ cell tumours, and carcinomas that are more commonly found in older children. The response rates for these cancers were 57.4%, 50.2% and 43.9%, respectively. Response

FIGURE 1
Study flow-through of survivor cohort



rates were highest for survivors of neuroblastoma (82.1%) and hepatic carcinomas (72.7%), while survivors of the remaining diagnostic groups had response rates between 60% and 70%.

Socio-demographic characteristics of study survivors and controls are shown in Table 2. Approximately 50% of survivors and controls were male and the average age at study was 19 years. The large majority of subjects reported Caucasian ethnicity, followed by Asian (3.5%) and multiple ethnicities (3.0%). Similar and substantial proportions from each group were residing in Central or Western Canada.

The distribution of clinical characteristics for participant and non-participant (refusals and lost to follow-up) survivors is shown in Table 3. Over half of the survivors were diagnosed with leukemia, lymphoma or central nervous system tumours, regardless of their participation status. Compared to the participant survivors, those lost to follow-up were significantly more likely to be germ cell tumour or carcinoma survivors and less likely to have been diagnosed with leukemia. Accordingly, the average age at

diagnosis was significantly lower among participating survivors (seven years) compared to survivors who were lost to follow-up (nine years), and participants were more likely to have been diagnosed in the latter part of the decade (1987 to 1990). Survivors who participated were also more likely to have received all three forms of therapy (chemotherapy, radiation therapy, and surgery) compared to survivors who were lost to follow-up. Finally, survivors who were lost to follow-up were less likely to have had more than one treatment series compared to participants.

Sociodemographic characteristics of study controls were generally similar to those of the population as reported in the 1996 census (Table 4). Approximately 60% of the controls and census individuals were married or living in common-law relationships and nearly three quarters of subjects in both cohorts were employed either full or part-time. Some differences were noted in education and income levels: the control subjects reported a higher level of education and personal income compared to the census individuals.

FIGURE 2
Study flow-through of control cohort

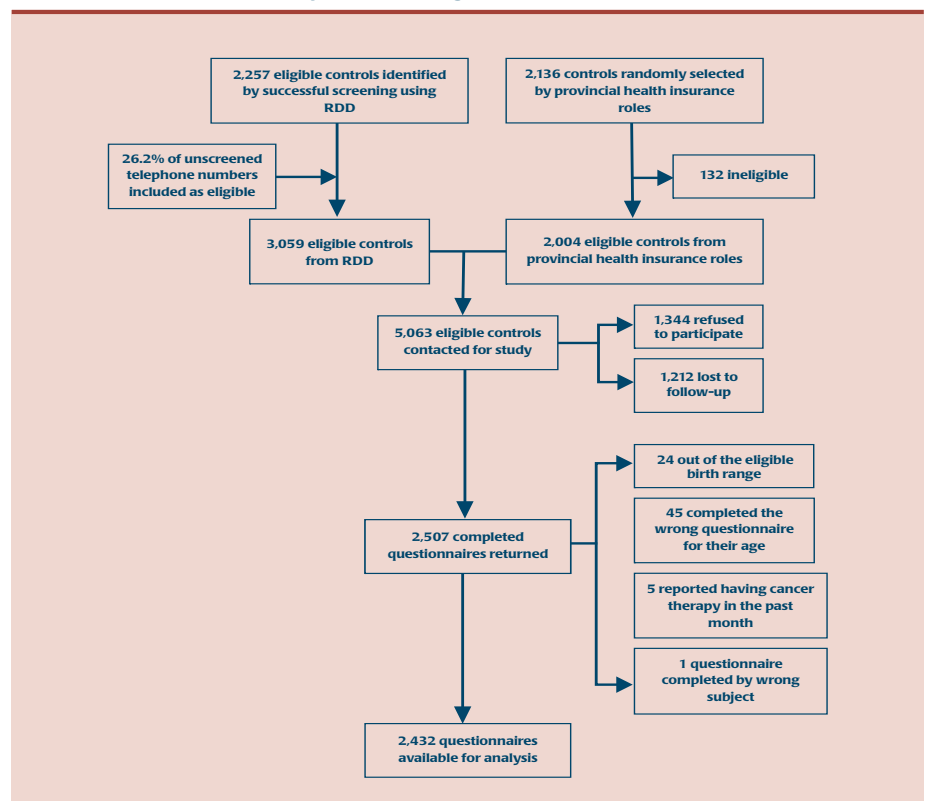


TABLE 3
Clinical characteristics of survivors, by participation in study

	Participants (n = 2,152)		Refusals (n = 313)		Lost to follow-up (n = 631)	
	n	%	n	%	n	%
Diagnosis						
Leukemia	634	29.5	87	27.8	113	17.9*
Lymphoma	371	17.2	52	16.6	125	19.8
CNS	362	16.8	54	17.3	107	17.0
Neuroblastoma ¹	110	5.1	20	6.4	27	4.3
Renal	155	7.2	18	5.8	32	5.1
Bone	85	4.0	19	6.1	25	4.0
Soft-tissue	144	6.7	15	4.8	38	6.0
Germ-cell	101	4.7	25	8.0	50	7.9*
Carcinomas	100	4.7	14	4.5	86	13.6*
Other ²	90	4.2	9	2.9	28	4.4
Age at diagnosis						
Mean (SD)	7.3 (6.0)		8.1 (5.9)		9.4 (6.4)*	
Range	0 to 19		0 to 19		0 to 19	
Year of diagnosis						
1981 to 1983	465	21.6	64	20.5	190	30.1*
1984 to 1986	607	28.2	95	30.4	192	30.4
1987 to 1990	1,080	50.2	154	49.2	249	39.5*
Treatment modalities						
Chemotherapy only (C)	282	13.1	49	15.6	116	18.4*
Surgery only (S)	345	16.0	55	17.6	166	26.3*
Radiation only (R)	44	2.0	15	4.8*	38	6.0*
C+S	411	19.1	42	13.4	95	15.1
C+R	396	18.4	68	21.7	84	13.3
R+S	222	10.3	33	10.5	60	9.5
C+R+S	419	19.5	41	13.1	44	7.0*
Missing treatment information	33	1.5	10	3.2	28	4.4*
Treatment series³						
One	1,895	88.1	289	92.3	604	95.7
Two or more	256	11.9	24	7.7	27	4.3*

¹ Includes other sympathetic nervous system tumours (n = 7).

² Includes retinoblastoma (n = 95), hepatic (n = 30) tumours, and unknown (n = 2).

³ Number of treatment series is missing for one participating survivor.

* p < 0.01 for comparison with participating survivors.

Discussion

The national, multi-centre design employed in the Late Effects Study resulted in the identification of a cohort of children, adolescents, and young adults who survived childhood cancer and a population-based comparison group of similar age and sex with no cancer history. Although study participation was not as high as anticipated, we believe these two groups can be validly compared to evaluate whether and to what extent survivors experience an excess of psychosocial or physical health problems.

First, the long-term survivors who participated in the study had clinical characteristics that were similar to those of survivors who either refused to participate or were lost to follow-up. This suggests they were representative of all children and young adults diagnosed with cancer in Canada before the age of 20 in 1981 to 1990 and were alive during the study period. With the exception of cancers more commonly diagnosed in older children (i.e., germ cell tumours and carcinomas) response rates did not vary by cancer type. Specifically, the lower participation among survivors of germ cell tumours and carcinomas likely reflects the

difficulty in recruiting young adults rather than the loss of eligible subjects with a particular treatment or outcome. This is further reflected in the older average age at diagnosis and earlier period of diagnosis among survivors who were lost to follow-up. As well, carcinoma and germ cell tumour survivors were less likely to receive multi-modal care, possibly due to their earlier period of diagnosis as well as their cancer type, with more than two-thirds receiving surgery only or surgery with chemotherapy. Finally, over 90% of survivors with carcinoma and germ cell tumours reported no relapses during therapy.

Second, by design, the population controls recruited for study have similar age and sex distributions to the survivors. They are also similar in terms of ethnic origin and area of residence in Canada. With considerable information on potential confounding factors available for both survivors and controls, any differences that might affect the outcomes of interest can be statistically controlled during analyses. Thus, we are confident that any differences observed when comparing the physical and psychosocial health of survivors and controls can be attributed to having survived childhood cancer.

Third, the population controls successfully recruited for our study closely resembled individuals of the same age and sex from the general Canadian population. Proportions of study controls and those identified in the census who were married or living common law or employed full- or part-time during the study were virtually identical. However, our controls had higher educational and income levels compared to census individuals. Observed differences in personal income may be explained in part because census income was adjusted to 1995 dollars whereas our participants were recruited from 1997 to 2001.

It should be noted that we used stringent standards to define the number of eligible individuals to be included in the denominator of the response rate. In our calculation of response rates we used the total number of eligible subjects as the denominator, not the number of subjects who agreed to participate. Furthermore, some of the survivors considered lost to follow-up may have, in fact, died in the time between surviving five years and being

TABLE 4
Socio-demographics of study controls compared to the
1996 Canadian Census, 20 to 44 years of age¹

	Controls (n=1793)		1996 Census ² (n = 10.9 x 10 ⁶)
	n	%	%
Education³			
< High school	219	12.4	23.1
High school	553	31.2	26.4
> High school	1,001	56.5	50.5
Marital status³			
Married or common law	1,119	62.9	59.2
Divorced, separated, or widowed	77	4.3	7.7
Never married	583	32.8	33.1
Work status³			
Employed	1,293	72.4	73.2
Unemployed	52	2.9	8.0
Not in labour force ⁴	442	24.7	18.8
Income^{3,5,6}			
None	48	3.0	5.7
< \$30,000	730	45.3	64.6
\$30–\$59,999	528	32.8	24.3
> \$60,000	304	18.9	5.4

¹ Includes 74% of control cohort.

² Census adjusted to the age, sex, and provincial distribution of controls.

³ Missing information for study controls: education (n = 20, 1.1%), marital status (n = 14, 0.8%), work status (n = 6, 0.3%), income (n = 48, 2.7%).

⁴ Not in labour force includes full-time homemaker, student, not working due to health (or child's health) or other reason.

⁵ Includes household income for parents of child controls, and personal income for adult controls and Census subjects.

⁶ Income for Census subjects adjusted to 1995 Canadian dollars.

recruited for study, artificially inflating the number of eligible survivors. As well, we included an estimated proportion of unscreened calls recruited by RDD in the total number of eligible control subjects, which may have also inflated the denominator and lowered the estimated response rate. Still, our response rates of 63% for survivors and 49% for controls are similar to other large case-control studies of cancer.⁷⁻⁹ For example, using the same method of calculating participation, the U.S. Childhood Cancer Survivor Study achieved response rates of 69% for survivors (14,054 out of 20,275) and 61% for sibling controls (3,585 out of 5,857).¹⁰ Modest response rates are worrisome if it is assumed that those who are harder to reach differ in substantial ways from their easier-to-recruit counterparts. If they did, participants could differ from the target population.¹¹⁻¹⁸ In the data presented here we have demonstrated the absence of any large or

systematic differences among the participating survivors compared to non-participants and study controls compared to census individuals. Moreover, many authors suggest that slight differences between participants and non-participants should not greatly affect estimates of risk.^{11,15,16,19,20}

The most formidable challenge in conducting this multi-centre, retrospective study was locating and recruiting study subjects. This challenge was confounded by having to solicit the participation of a cohort of young adults, a group known to be highly mobile, more difficult to reach, and least likely to participate in such studies.²¹ Although we used a number of techniques known to help recruitment (personalized letters, follow-up contacts, stamped return envelopes, contacting participants prior to sending out the questionnaire) we can also speculate on additional ways participation

could be improved in future studies.^{22,23} Contacting subjects by telephone first, rather than by letter, seems to help. More follow-up attempts with subjects who have been contacted but have not returned their questionnaires would likely improve participation. A final, practical suggestion for other researchers in such circumstances is to consider the use of small symbolic monetary incentives to improve participation among those contacted. It has been demonstrated that such incentives can be effective in increasing participation in population-based cohort studies of long-term cancer survivors.²⁴

In summary, the results of this first report of the CCCSCP Late Effects Study indicate the long-term childhood cancer survivors and population controls can be validly compared to evaluate whether and to what extent survivors experience an excess of psychosocial or physical health problems. Papers currently in preparation by our group comparing both adult and child survivors to their respective controls can thus be interpreted as representing the nature and extent of any late effects of cancer diagnosed during childhood in Canada.

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Methods for estimating the labour force insured by the Ontario Workplace Safety & Insurance Board: 1990–2000

Peter M Smith, Cameron A Mustard and Jennifer I Payne

Abstract

This paper presents a methodology for estimating the size and composition of the Ontario labour force eligible for coverage under the Ontario Workplace Safety & Insurance Act (WSIA). Using customized tabulations from Statistics Canada's Labour Force Survey (LFS), we made adjustments for self-employment, unemployment, part-time employment and employment in specific industrial sectors excluded from insurance coverage under the WSIA. Each adjustment to the LFS reduced the estimates of the insured labour force relative to the total Ontario labour force. These estimates were then developed for major occupational and industrial groups stratified by gender. Additional estimates created to test assumptions used in the methodology produced similar results. The methods described in this paper advance those previously used to estimate the insured labour force, providing researchers with a useful tool to describe trends in the rate of injury across differing occupational, industrial and gender groups in Ontario.

Key words: denominators; Labour Force Survey; Ontario Workplace Safety & Insurance Board coverage; surveillance; work-related injury

Introduction

Between 1991 and 2000, the annual number of lost-time work-related injuries reported to the Ontario Workplace Safety and Insurance Board (WSIB) declined by approximately 32%, from 155,500 to 104,000.¹ However, understanding whether there has been a reduction in work-related injury rates, and whether these reductions are consistent across population subgroups (i.e., younger age groups, short-tenure employees, female workers and

different occupational groups) has been hampered by the absence of accurate denominators describing these key dimensions of the insured workforce in Ontario.

The WSIB estimates the proportion of Ontario labour force participants it insures using reported payrolls from employers who pay insurance premiums. This estimate was not designed for research use, however, and it is limited in three key ways:

1. These estimates are only reported across each of the WSIB 16 major industry sectors (WSIBIS). Information on other equally important subgroups for work-related injury analysis such as occupation,^{2,3} gender³ and hours of work per week⁴ are not included in the payroll database.
2. The estimates represent only the employees covered under one of the two WSIB insurance schedules,^{5,a} although injury claim data is available for employees covered under both schedules.
3. Since the individual salaries^b of employees and total payrolls were used to create these estimates, not the actual number of employees, they may not provide an accurate reflection of the total number of people insured by the WSIB.

Given the limitations in the WSIB payroll data estimates, research on the epidemiology of work-related injury in Ontario has most commonly opted to use alternate sources to calculate injury rates. Rael,^{6,7} and Brooker and colleagues,⁸ have both used LFS and Census data to generate denominator counts for injury rate calculations within specific industry and occupational subgroups. Both approaches adjust the LFS data to exclude the self-employed population^c and those labour

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^a Unlike other provinces in Canada, the Ontario WSIB has two coverage schedules. Companies that opt to pay premiums in return for coverage for the costs of compensation of work injuries are covered under what is referred to as schedule 1. The WSIB also covers a group of companies that opt not to pay insurance premiums throughout the year, but in turn are required to personally cover the costs of accident claims filed by their employees. This population is referred to as schedule 2. There is no administrative definition of what type of firms are likely to be covered under either schedule, and firms can move from schedule 1 to schedule 2 and vice-versa. In 2002, the WSIB estimated the size of the schedule 2 workforce to be 479,000 people, which includes 94,000 federal government employees. In comparison the estimated size of the schedule 1 workforce is approximately 3.4 million.

^b Annual salary estimates were capped at a maximum of \$60,600 in 2001. Therefore, the proportion of a salary that is greater than this amount is not included in the WSIB estimate.

^c The self-employed population is defined as individuals or companies consisting of one employee.

force participants who were unpaid family workers, as these groups are excluded from coverage under the WSIA.

Zakaria and colleagues⁴ have extended these methods, proposing that calculation of LFS counts should be reported as Full-Time Equivalents (FTEs)^d, using reported hours usually worked per week. Adjusting for hours worked per week provides more accurate estimates of exposure time in estimating injury risk in female and youth population groups, which are more likely to work part-time. To date, Zakaria has only used these methods to generate estimates for the entire labour force population in Ontario.

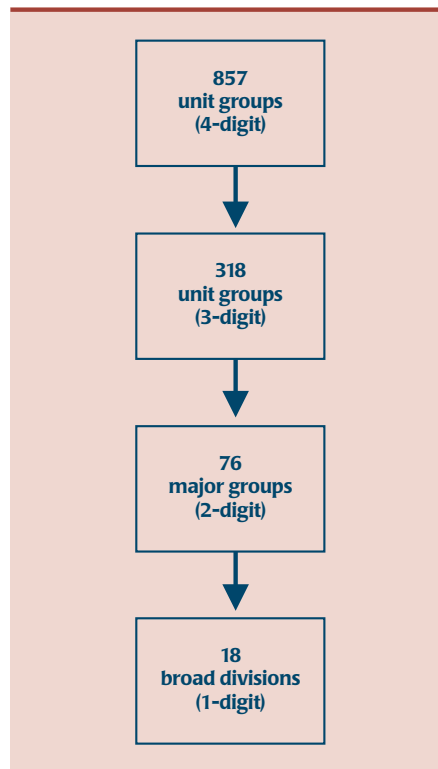
Removing the self-employed population and unpaid family workers, however, does not fully capture Ontario's complicated work-related injury legislation. The majority of companies in Ontario have mandatory coverage for workplace injuries from the WSIB, for which they in return pay insurance premiums. However, there are two other groups of insurance coverage in Ontario. Some companies (predominantly educational institutions and municipal and regional government agencies) are covered under an alternate insurance schedule, referred to as "schedule 2". These companies do not pay insurance premiums, but are still required to report all workplace injuries to the WSIB. Other companies have

optional coverage; it is not mandatory that they pay premiums to the WSIB. These companies can cover their employees with the WSIB if they so choose. This group includes employees engaged in barbering, shoe shining, veterinary work, in the offices of dentists, physicians and lawyers, in funeral directing and embalming, photography, and in the majority of the finance and insurance industries.^{5,9} Other labour force participants without mandatory insurance coverage include casual employees and people who work off-site. Therefore, only permanent, on-site employees working for companies covered under either schedule 1 or schedule 2 must report injuries to the WSIB.

Business fit into one of these three groups depending on the industry in which they primarily operate. The WSIB groups companies in Ontario into over 800 different industry segments, referred to as classification units (CU).¹⁰ Each CU is directly comparable to the most detailed level of the Standard Industrial Codes 1980 (SIC80), the primary industrial grouping used by Statistics Canada. The structure of the SIC80 is presented in Figure 1.

It should be possible to determine the proportion of the labour force insured by the WSIB with population-based data at the SIC unit group level. Unfortunately, differentiation of industry segments within population level

FIGURE 1
The structure of the standard industrial code 1980



surveys such as the Labour Force Survey and Census only occurs at the level of the 318 minor groups contained in the SIC80 (three-digit level). Within a given three-digit minor group, some of the four-digit unit groups may be compulsorily covered, and others may have optional coverage.^e Therefore, each of the three-digit minor groups of the SIC80 can be assigned to one of the following three categories:

1. Those composed of four-digit unit groups which all must report workplace injuries to the WSIB (235 [74%] of the 318 minor groups).
2. Those composed of four-digit unit groups with mandatory insurance coverage, and others with optional insurance coverage (41 of the 318 minor groups).
3. Those composed of four-digit unit groups all with optional insurance coverage with the WSIB (42 of the 318 minor groups).

TABLE 1

Data available from the LFS and Census for the calculation of denominators for the Ontario labour force

Labour Force Survey		Census
Years Available	1990–2000	1991 and 1996
Occupation	SOC91 (3d) * Gender SOC91 (3d) * FT/PT SOC91 (3d) * Self-employed	SOC91 (4d) * Gender SOC91(3d) * SIC80 (3d)
Industry		SIC80 (3d) * SOC91 (3d)
Gender	Gender * SOC91 (3d) Gender * FT/PT * SOC91 (3d)	Gender * SOC91 (4d)

SOC91(3d) = SOC91 at the 3-digit level

SOC91(4d) = SOC91 at the 4-digit level

FT/PT = Hours of work (full-time or part-time)

LFS = labour force status (self-employed/not self employed)

SIC80(3d) = SIC80 at the 3-digit level

WSIBIU = WSIB industrial Unit

^d One full-time equivalent = 2,000 hours worked per year.

^e It should be noted that some classification units have mixed coverage status. For example, some companies within a classification unit, such as those which are publicly run, are required to be covered, whereas privately run companies within the same classification unit are not required to have coverage.

In this paper we propose to build on previous attempts to estimate the size and composition of the insured labour force in Ontario. Following Rael^{6,7} and Brooker⁸ we will use LFS and Census counts, adjusted for the self-employed population and unpaid family workers. Following Zakaria,⁴ we will present our denominator counts as full-time equivalents. However, in addition we will adjust our LFS counts for industry groups with optional WSIB coverage and groups with mixed coverage. We will compare these estimates, at an aggregate level, to estimates of the total labour force and the non-self-employed labour force. We will further present these estimates across all major occupational and industrial groups, stratified by gender. We will examine the sensitivity of our estimates using alternate assumptions. Finally, we will demonstrate the utility of these denominators by presenting a series of injury rates, using WSIB injury claim data as the numerator, with a series of alternate denominator estimates.

Data sources for Ontario labour force estimates

The Labour Force Survey (LFS)

Coverage

The LFS, conducted by Statistics Canada, produces estimates of the working-age population (employed, unemployed and non-labour force participants) using a sample of less than 1% of the Canadian population. The LFS follows a complex, rotating panel sample designed to efficiently estimate month-to-month changes in the Canadian labour force.¹¹

Measures

Important variables included in the LFS are labour force participation; gender; age; usual working hours per week; occupation; and industry.

Data available

Statistics Canada provided custom tabulations of the Ontario labour force by occupation, coded to the Standard Occupational Code 1991 (SOC91) at the three-digit level (139 separate groups), stratified by gender, labour force

TABLE 2
Summary of variables available within different Ontario injury and labour force data sources, 1990–2000

Numerator descriptive information	Denominator			
	WSIB claims	WSIB pay roll	LFS	Census
Occupation	Yes	No	Yes	Yes
Industry	Yes	Yes	Yes	Yes
Gender	Yes	No	Yes	Yes
Hours of work	Yes	No	Yes	Yes
Schedule1/schedule2	Yes	Yes	No	No

status (self employed versus not self employed) and hours of work (full-time versus part-time) for the years 1990 through 2000.

Canadian Census data

Coverage

The Canadian Census long form samples approximately 20% of the Canadian population and collects information on different types of labour force participation.

Measures

The Census gathers information on labour force participation over the previous seven days, as well as information on occupation,

industry, gender, age and hours usually worked per week. Due to its larger sample size, the Census is able to report occupation at a more detailed (four-digit) level than that provided in the LFS, which is reported at the three-digit level.

Data available

We obtained data from the 1991 and 1996 Census by SOC91 at the four-digit level (503 separate groups), stratified by gender. We also had a matrix of three-digit SOC91 (139 groups), by three-digit Standard Industrial Code 1980 (SIC80) (296 groups^{6f}) for both 1991 and 1996.

TABLE 3
Full-time equivalent weights for full-time and part-time labour force participants stratified by gender, 1990–2000

Year	Males		Females	
	Full-time	Part-time	Full-time	Part-time
1990	1.087	0.390	1.018	0.432
1991	1.083	0.387	1.019	0.423
1992	1.088	0.382	1.021	0.422
1993	1.093	0.394	1.024	0.427
1994	1.098	0.403	1.019	0.466
1995	1.097	0.401	1.022	0.430
1996	1.095	0.401	1.019	0.429
1997	1.069	0.407	1.005	0.439
1998	1.070	0.414	1.001	0.447
1999	1.069	0.411	1.019	0.452
2000	1.068	0.417	1.019	0.452

Note: Full-time equivalent weights were calculated by multiplying the monthly average of hours worked per week by 52 (the number of weeks in the year). This resulted in FTE estimates of over 1 for both male and female labour force participants. Self-employed population and labour force participants in the finance and federal and provincial government have been removed from each of these estimates.

^f Some of the 318 minor groups are combined.

FIGURE 2
Steps for estimating the insured labour force in Ontario

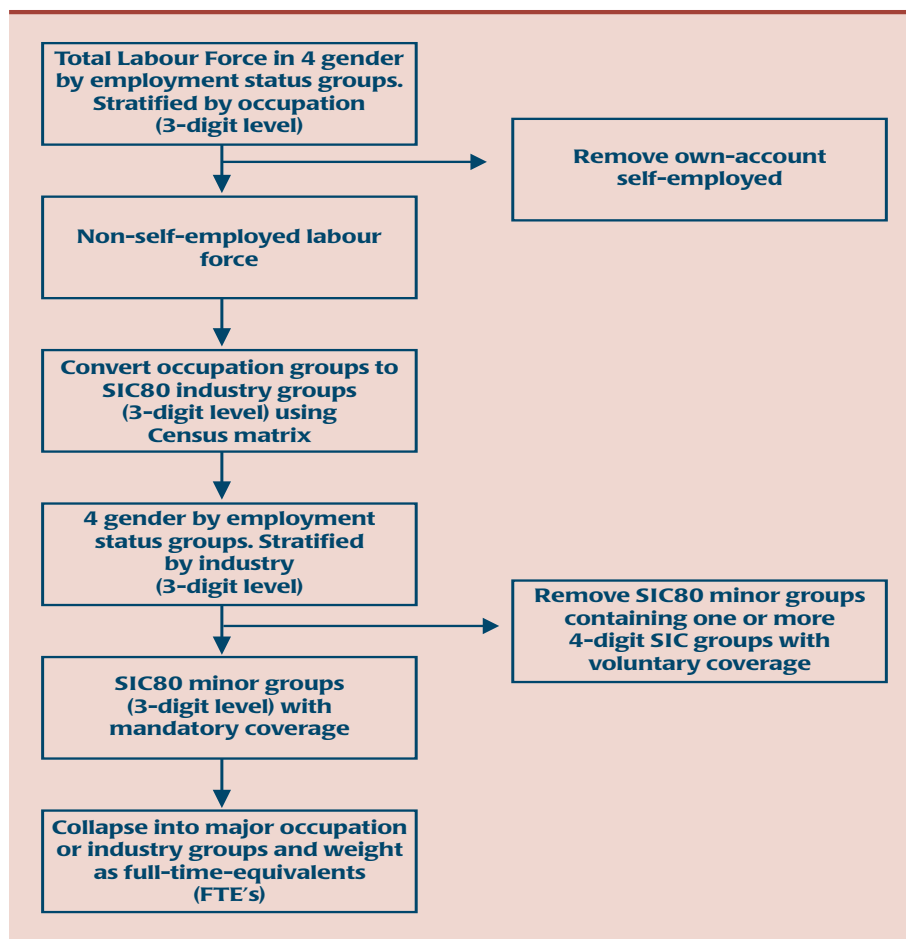


Table 1 provides a description of the data from the LFS and Census used in the calculation of our denominator estimates.

A summary of the measures included in our estimates of the Ontario labour force from the sources listed above are described in Table 2. The information provided in the WSIB injury claims, and from the WSIB payroll denominators, are also included for comparison purposes.

Methods and analysis

Our main study objective was to create a series of denominators that could be used in conjunction with WSIB lost-time injury reports in Ontario, using the LFS and Census. These denominators would be stratified by the major occupational and industrial groups, as well as gender. A secondary objective was to investigate the reliability of our estimates by comparing them to alternative estimates generated using different assumptions.

Steps for estimating the insured labour force by gender and occupation

A flowchart describing each of the steps below is presented in Figure 2.

1. The initial adjustment made to the LFS counts was the removal of self-employed labour force participants. This was done at the three-digit occupational level.

TABLE 4
Comparing estimates from the LFS after adjustments for self-employed population and those industry groups with mixed or voluntary insurance coverage, 1990–2000

	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
A. Total Labour Force ^a	5,533,000	5,543,800	5,541,500	5,581,100	5,574,300	5,619,700	5,695,300	5,801,400	5,914,300	6,070,800	6,227,900
B. Employed only	5,191,300	5,015,700	4,948,900	4,973,800	5,039,200	5,130,600	5,180,800	5,313,400	5,490,000	5,688,100	5,872,100
C. Non-self Employed Only	4,794,078	4,713,930	4,628,112	4,573,512	4,573,211	4,646,611	4,683,158	4,694,503	4,842,576	4,983,870	5,150,503
D. Sch1 and Sch2 Only ^b	3,283,060	3,200,175	3,080,538	3,004,692	2,971,427	3,013,089	3,024,352	3,054,338	3,154,092	3,241,560	3,349,729
E. FTE estimate of Sch1 and Sch2	3,170,586	3,044,715	2,915,535	2,860,692	2,861,289	2,892,794	2,904,931	2,886,751	2,991,296	3,085,758	3,195,270
F. FTE estimate adjusted ^c	2,996,474	2,800,506	2,673,665	2,642,591	2,677,733	2,727,116	2,730,918	2,731,470	2,849,709	2,952,977	3,070,344

^a Includes employed population and those people looking for work.

^b NSE Population with three-digit SIC codes in appendix I and appendix II removed.

^c Estimate of schedule 1 and schedule 2 FTE estimate adjusted for percentage of population looking for work.

TABLE 5
Estimates of the mandatorily insured labour force in Ontario stratified by occupational group and gender, 2000 only

Major occupational group	Males (N)	Females (N)	Males (FTE)	Females (FTE)
A. Management occupations	169,810	82,192	175,789	80,905
B. Business, finance and admin	191,078	378,908	195,163	343,739
C. Natural and applied sciences	199,346	48,024	203,867	48,021
D. Health	13,992	108,178	14,601	88,244
E. Teachers and professors	16,720	24,395	16,949	22,331
F. Occupations in art, culture, rec and sport	11,926	16,915	11,771	15,183
G. Sales and service	361,054	496,806	345,452	394,147
H. Trade, transport, equipment op	553,640	36,034	550,986	35,659
I. Occupations unique to primary industry	44,068	14,255	41,656	13,507
J. Occupations unique to processing, manufacturing and utilities	392,809	189,580	408,630	188,668
Total	1,954,442	1,395,287	1,964,864	1,230,405

Steps for estimating the insured labour force by gender and industry

To estimate the insured labour force by industry and gender, steps 1 through 4 from the occupation and gender estimation were followed.

1. Each three-digit minor group from the SIC80 was collapsed into one of the 18 major industrial groups. Some of the major industrial groups were very small in size. Where counts within an industrial group were less than 4,000, the estimates were suppressed.
2. To create a comparable series of FTE counts, each full-time and part-time labour force participant was assigned a full-time equivalent weight using the same methods used to generate the occupational estimates.

Sensitivity analyses

To test the reliability of our denominator estimates and to reflect the assumptions we used in their generation, we tested two alternate methods and compared these to our original estimates:

1. In step 2 the gender X employment status groups were generated assuming the ratio of full-time to part-time labour force participants was the same in the employed and self-employed populations. We sought to examine how much the FTE estimates for each major occupational and industrial group would change if we assumed that all the self-employed population was working full-time.
2. A relevant issue, given the nature of the LFS, was the accuracy of the annual estimate of the Ontario labour force. As quarterly estimates were also available, we investigated changes in FTE estimates across major occupational and industrial groups when using high and low quarterly three-digit occupational counts.

2. The non-self-employed population was then separated into four groups on the basis of gender and hours of work. These were males working full-time (MFT), males working part-time (MPT), females working full-time (FFT) and females working part-time (FPT). Because the self-employed labour force counts were not stratified by full-time and part-time status, this step assumed that the proportions of full-time to part-time labour force participants are similar in both the self-employed and non-self-employed populations.
3. To adjust the LFS counts for industries likely excluded from insurance coverage required that the occupational counts be converted to industrial counts. This conversion used the matrix from the 1991 and 1996 census of three-digit SOC91 and three-digit SIC80. For the years 1992–1995 a proportional matrix, based on the 1991 and 1996 matrix was calculated. For the years 1997 through 2000, the 1996 matrix was used. Using this matrix the four gender X employment status groups were converted from three-digit SOC91 to three-digit SIC80.
4. To accurately estimate the population required to report work injuries only those three-digit minor groups of the SIC80 composed of four-digit unit groups required to report injuries were kept. The minor groups of the SIC80 with mixed coverage (some four-digit unit groups in schedule 1 and/or schedule 2 and others with optional coverage) are listed in Appendix I. Those three-digit SIC80 groups with only voluntary coverage requirements are listed in Appendix II.
5. Using the same SIC80 X SOC91 matrices, each three-digit SOC91 count was then collapsed into one of the 10 different one-digit major occupational groups. At the completion of this step we had our four gender X employment status groups, stratified by 10 major occupational groups.
6. The final adjustment was to weight each full-time and part-time labour force participant as a FTE. These weights were generated using the public use files of the LFS and are presented in Table 3.

TABLE 6
Estimates of the mandatorily insured labour force in Ontario stratified by industrial group and gender, 2000 only

Major occupational group	Males (N)	Females (N)	Males (FTE)	Females (FTE)
Agricultural and related	29,823	17,762	28,503	16,258
Fishing, trapping, logging and forestry	4,172	–	4,081	–
Mining, quarrying and oil	20,532	4,299	20,933	4,078
Manufacturing	708,400	327,712	729,577	316,796
Construction	207,660	35,498	204,365	32,805
Transport and storage	102,130	32,905	101,765	30,563
Communication and utilities	92,356	48,038	92,703	44,485
Wholesale trade	156,016	95,819	158,787	89,281
Retail trade	251,356	302,966	244,409	245,053
Finance and insurance	6,833	12,529	7,076	11,527
Real estate operator and insurance agent	–	–	–	–
Business service	63,179	47,130	65,025	44,059
Government service	120,161	119,841	122,289	110,401
Educational service	–	–	–	–
Health and social service	36,037	135,293	36,460	113,147
Accommodation, food and beverage	133,371	195,690	126,437	155,144
Other service	22,418	18,821	22,454	15,882
Total	1,954,442	1,395,287	1,964,864	1,230,405

Results

Objective one: Comparing aggregate LFS estimates after adjustments for excluded groups and hours of work, 1990–2000

Table 4 presents the total labour force counts after each adjustment described in the methods, as well as the final aggregate FTE estimates. Between 1990 and 2000, 65% – 68% of the non-self-employed labour force worked in industry groups with mandatory insurance coverage.

Objective two: Creation of a series of denominators for the mandatorily insured labour force by major occupational and industrial group stratified by gender

Table 5 presents the total person count and total full-time equivalent count for the insured Ontario labour force, by major SOC91 group,

stratified by gender for the year 2000. Given the larger percentage of females working part-time, the differences after adjusting total counts for hours worked per week (FTEs) were greater in the female population than the male population.

Table 6 presents the same series of estimates separately for male and female labour force participants, stratified by major SIC80 industrial group. Industrial sector counts below 5,000 FTEs were suppressed.

Objective three: Examining the sensitivity of the mandatorily covered labour force estimates

Differences in the FTE estimates under the assumption that all self-employed labour force participants work full-time were minor. For both men and women, the largest differences were observed in primary industries and the occupational groups of management, health, and trade and transport.

Differences relative to seasonal variation in employment were more substantial. For both men and women the largest differences were reported in the agriculture, logging and forestry industries. The largest occupational changes were in occupations unique to primary industry and art, culture, recreation and sport. These tables are not included, but available upon request from the authors.

Objective four: Calculation of injury rates using WSIB injury claim data and alternate denominator estimates

Table 7 presents injury rates by occupation and gender groups using different denominator estimates. The absolute change in injury rate between different denominator estimates is also presented. Removal of the self-employed population results in higher injury rate estimates across all occupation and gender groups.

Restricting both lost-time injury claims and denominator estimates to include only those industry groups with mandatory insurance coverage resulted in an overall increase in injury rate estimates in both males and females. However, decreases in injury rates were observed between particular occupational groups, such as sales and service occupations, trade, transport and equipment operators, and occupations unique to processing, manufacturing and utilities.

Calculating rates of lost-time injuries per 1,000 full-time equivalents produced greater increases in female injury rates compared to males due to the higher percentage of females who are part-time labour force participants.

Discussion

From the results of this paper we suggest that a series of equally important adjustments should be made to LFS and Census data if they are to be used to provide denominator estimates for WSIB lost-time injury data numerators. At the aggregate level each of our adjustments to the LFS increased the injury rate across both males and females. We believe this methodology enables a more accurate picture of the size and distribution

TABLE 7
Comparing lost-time injury rates across gender and occupational groups using different denominator estimates, 2000 only

Total labour force Major occupational groups	Rate per 1,000 persons		Change in injury rate	
	Males	Females	Males	Females
A. Management occupations	1.67	3.48	–	–
B. Business, finance and admin	11.90	3.79	–	–
C. Natural and applied sciences	2.82	2.59	–	–
D. Health	13.32	19.37	–	–
E. Teachers and professors	2.65	5.55	–	–
F. Occupations in art, culture, rec and sport	2.94	1.93	–	–
G. Sales and service	17.57	14.12	–	–
H. Trade, transport, equipment op	35.45	41.21	–	–
I. Occupations unique to primary industry	13.89	10.67	–	–
J. Occupations unique to processing, manufacturing and utilities	43.40	34.24	–	–
All occupations	20.8	11.6	–	–
Non-self-employed labour force				
Major occupational groups				
A. Management occupations	2.46	4.88	0.80	1.40
B. Business, finance and admin	13.35	4.11	1.45	0.32
C. Natural and Applied sciences	3.20	3.00	0.38	0.41
D. Health	23.69	21.30	10.37	1.93
E. Teachers and professors	3.02	5.98	0.36	0.43
F. Occupations in art, culture, rec and sport	4.73	2.87	1.79	0.94
G. Sales and service	20.01	16.36	2.43	2.24
H. Trade, transport, equipment op	44.36	53.42	8.91	12.21
I. Occupations unique to primary industry	27.53	19.64	13.65	8.97
J. Occupations unique to processing, manufacturing and utilities	44.69	35.04	1.29	0.80
Total labour force	25.1	13.2	4.30	1.63
Mandatorily covered labour force				
Major occupational groups				
A. Management occupations	3.00	7.12	0.54	2.24
B. Business, finance and admin	18.88	5.51	5.52	1.40
C. Natural and applied sciences	3.63	3.29	0.43	0.29
D. Health	26.94	19.98	3.26	1.32
E. Teachers and professors	4.78	7.95	1.77	1.98
F. Occupations in art, culture, rec and sport	7.71	4.61	2.99	1.75
G. Sales and service	19.29	17.14	0.71	0.79
H. Trade, Transport, equipment op	43.77	51.92	0.59	1.50
I. Occupations unique to primary industry	28.03	19.78	0.49	0.14
J. Occupations unique to processing, manufacturing and utilities	42.49	33.17	2.19	1.86
Total labour force	29.6	16.8	4.51	3.62

TABLE 7 (continued)
Comparing lost-time injury rates across gender and occupational groups using different denominator estimates, 2000 only

Mandatorily Covered Labour Force (FTE's) Major Occupational Group	Rate per 1,000 persons		Change in injury rate	
	Males	Females	Males	Females
A. Management occupations	2.90	7.23	0.10	0.11
B. Business, finance and admin	18.48	6.07	0.40	0.56
C. Natural and applied sciences	3.55	3.29	0.08	0.00
D. Health	25.82	24.49	1.12	4.51
E. Teachers and professors	4.72	8.69	0.06	0.74
F. Occupations in art, culture, rec and sport	7.82	5.14	0.10	0.53
G. Sales and service	20.16	21.61	0.87	4.46
H. Trade, transport, equipment op	43.98	52.47	0.21	0.55
I. Occupations unique to primary industry	29.65	20.88	1.62	1.10
J. Occupations unique to processing, manufacturing and utilities	40.85	33.33	1.65	0.16
Total labour force	29.5	19.1	0.16	2.26

of the insured labour force in Ontario across major occupational and industrial groups.

Direct comparison with our results and those of Rael^{6,7} and Brooker⁸ are not possible due to different year of study in the case of Rael and the presentation of rate information in the case of Brooker. Our fully adjusted denominator estimates are approximately 28% lower than those previously presented by Zakaria,⁴ reflecting the exclusion of industrial groups with either mixed or voluntary insurance coverage.

These estimates should be interpreted in light of the following limitations. Part-time labour force participants were given a uniform weighting for the calculation of FTEs. It is likely that the total hours worked per week by part-time labour force participants differs across occupation and industry groups. Using Zakaria et al.'s⁴ formula to determine the hours usually worked per week by each part-time labour force participant will provide greater accuracy.

Neither our LFS counts of the self-employed population, nor the matrix of occupation and industry were stratified by gender. Differences in female and male labour force participation across each of these areas may reduce the validity of our estimates. Future studies using denominator estimates should endeavour to obtain initial LFS and Census

counts stratified by gender, with the self-employed population already removed.

There are a number of strengths in the denominator series produced by these methods. In spite of the limitations listed above, sensitivity analyses of the assumptions concerning self-employment and seasonality did not unearth serious limitations in estimates for either men or women.

Our confidence in the validity of these estimates, at the aggregate level, is further strengthened in assessing the injury rates within each of the subgroups of insurance coverage (mandatory coverage versus mixed insurance coverage versus no insurance coverage). After standardizing rates for different gender and industry compositions, the rate in the mandatory coverage group was 23.7 per 1,000 FTE's. Within the mixed group, where we would expect injury reports to be fewer given that some companies are mandated to report injuries, the injury rate per 1,000 FTE's was 19.8. Finally, the voluntary coverage group, where the number of injury reports should be the lowest, had a injury rate of 6.8 per 1,000 FTE's.

The rates and relative risks, presented in Table 7 demonstrate the importance of accurate denominators to calculate injury rates. Adjustment for labour force participants with either uncertain or voluntary insurance

coverage increased the overall injury rate in men by 10 injuries per 1,000 FTE's, with a similar absolute increase in the predicted injury rate for women.

Further, injury rates in particular occupational groups were more sensitive to the labour force survey adjustments. The rate of injury for males working in occupations in art, culture, recreation and sport, and occupations unique to primary industry, both increased by over 100%. Rates of injuries for males in health care occupations increased by 94%, teachers and professors increased by 77%, management occupations by 74%, and occupations in business and finance by 55%. Similarly, injury rates for females in art, culture, recreation and sport (167%), management occupations (108%), primary industry occupations (97%), and those in business and finance (60%) all substantially increased.

Suggested guidelines for the use of denominator data with WSIB injury claim numerators

While these methods have a wide range of possible applications for research on work-related injury in Ontario, we make the following suggestions regarding their use in calculating injury claim rates:

1. With each level of increased detail there is an increased risk of inaccuracy in the concordance between WSIB injury claim data and LFS occupational and industrial classification estimates. Therefore we recommend the use of denominators only by major occupational and industrial groups.
2. Where possible, particularly in relation to industrial groups, we recommend combining smaller groups (e.g., fishing and trapping with logging and forestry) to make larger groups.
3. When reporting injury rates for two different groups (e.g., males and females) we suggest emphasizing differences in relative risks between groups as opposed to actual claim and denominator numbers, as any measurement errors in the calculation of injury rates are likely to be randomly distributed across genders.
4. The denominator estimates and injury counts used in this paper are for both the schedule 1 and schedule 2 insured labour force. It has been suggested, due to differences in the direct cost burden for injured employees, that the claim management process may differ between the two schedules. We therefore recommend caution when comparing rates in occupational or industrial groups that may contain a large proportion of schedule 2 employees (e.g., education and government service industries and occupational groups of teachers and professors) with other groupings of employees.

Conclusion

We feel that the methods used in this paper have advanced previously used methods for the calculation of the insured labour force in Ontario. By using these methods, researchers will be able to describe the epidemiology of injury across different occupational, industrial and gender strata, both cross-sectionally and over time.

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APPENDIX I
Minor groups from the Standard Industrial Classification (1980) with mixed insurance coverage

3-digit SIC	Description	3-digit SIC	Description
022	Services Incidental to Agricultural Crops	835	General Administrative Services
023	Other Services Incidental to Agriculture	837	Economic Services Administration
051	Forestry Services Industry	851	Elementary and Secondary Education
452	Service Industries Incidental to Air Transport	852	Post-Secondary Non-University Education
453	Railway Transport and Related Service Industries	854	Library Services
454	Water Transport Industries	855	Museums and Archives
455	Service Industries Incidental to Water Transport	862	Other Institutional Health and Social Services
458	Other Transportation Industries	863	Non-Institutional Health Services
459	Other Service Industries Incidental to Transportation	864	Non-Institutional Social Services
481	Telecommunication Broadcasting Industries	866	Offices of Other Health Practitioners
493	Water Systems Industry	867	Offices of Social Services Practitioners
501	Farm Products, Wholesale	912	Lodging Houses and Residential Clubs
563	Lumber and Building Materials, Wholesale	914	Recreation and Vacation Camps
659	Other Retail Stores	961	Motion Picture, Audio and Video Production and Distribution
712	Business Financing Companies	966	Gambling Operations
751	Operators of Buildings and Dwellings	972	Laundries and Cleaners
759	Other Real Estate Operators	979	Other Personal and Household Services
771	Employment Agencies and Personnel Suppliers	992	Automobile and Truck Rental and Leasing Services
772	Computer and Related Services	995	Services to Buildings and Dwellings
774	Advertising Services	999	Other Services n.e.c.
779	Other Business Services		

APPENDIX II

Minor groups from the Standard Industrial Classification (1980) with only voluntary insurance coverage

3-digit SIC	Description	3- digit SIC	Description
021	Services Incidental to Livestock and Animal Specialties	776	Offices of Lawyers and Notaries
032	Services Incidental to Fishing	777	Management Consulting Services
033	Trapping	841	International and Other Extra Territorial Agencies
483	Other Telecommunication Industries	853	University Education
702	Chartered Banks and Other Banking Type Intermediaries	859	Other Educational Services
703	Trust Companies	865	Offices of Physicians, Surgeons and Dentists, Private Practice
704	Deposit Accepting Mortgage Companies	869	Health and Social Service Associations and Agencies
705	Credit Unions	963	Theatrical and Other Staged Entertainment Services
709	Other Deposit Accepting Intermediaries	964	Commercial Spectator Sports
711	Consumer Loan Companies	965	Sports and Recreation Clubs and Services
721	Portfolio Investment Intermediaries	969	Other Amusement and Recreational Services
722	Mortgage Companies	971	Barber and Beauty Shops
729	Other Investment Intermediaries	973	Funeral Services
731	Life Insurers	981	Religious Organizations
732	Deposit Insurers	982	Business Associations
733	Property and Casualty Insurers	983	Professional Membership Associations
741	Security Brokers and Dealers	984	Labour Organizations
742	Mortgage Brokers	985	Political Organizations
743	Security and Commodity Exchanges	986	Civic and Fraternal Organizations
749	Other Financial Intermediaries n.e.c.	993	Photographers
761	Insurance and Real Estate Agencies	996	Travel Services

An epidemiologically-based needs assessment for stroke services

Duncan JW Hunter, Heather J Grant, Mark PH Purdue, Robert A Spasoff, John L Dorland and Nam Bains

Abstract

Stroke is amenable to the entire spectrum of health services, ranging from prevention of its risk factors, to the treatment of acute stroke and rehabilitation and palliation of stroke. The aim of this study was to determine the number of persons with the capacity to benefit from evidence-based effective stroke services. Population-based survey and registry data along with published, evidence-based recommendations for services were used to determine the number of persons in Eastern Ontario with stroke (including risk factors, acute stroke and chronic stroke) and their related need for services (including prevention programs, diagnostic services, treatment of acute stroke and rehabilitation). These estimates were then compared to the actual provision of these services. Estimates of the need for effective services exceeded the provision of all services with the exception of pharmacologic treatment for diabetes mellitus and carotid endarterectomy for acute stroke. The approach was able to identify both the under-provision and over-provision of evidence-based effective services for stroke. This study has shown that an epidemiologically-based needs assessment could be a useful basis for the planning of health services.

Key words: needs assessment; provision of health services; stroke

Introduction

How many and what type of health services for stroke ought to be provided at the population level? The answers to these questions depend very much on the 'need' for these services and the way that need is defined. Defining need is problematic because of the many different ways that the term is used. Need has been distinguished in terms of whether it is defined by experts (normative) or by persons with poor health status (felt or expressed) as well as by how it is measured (comparative, demand, and use).^{1,2} These distinctions are theoretical and their practical use is debatable. The issue is further muddled by the confusion between a need for health, achieved by broad social improvements, and a need for health services, those interventions traditionally

provided by doctors, nurses and other allied health professionals

In practice, four approaches to assessing the need for health services are used. The first and perhaps the most common use is *opinion*, and it arises when providers of health services or community representatives are surveyed about their views on the type and amount of services needed. Although these opinions will be informed by experience, they may not be based on any objective measures or upon evidence of effectiveness. While this approach may be the most common way that health needs are identified, it is often criticized for its lack of objectivity and its reliance on the opinion of those who have a vested interest in maintaining a service.

The second way to assess the need for health services is through the use of capitation-based or needs-based funding formulae; this is more accurately a process of *resource allocation*. Its use arose from observations in the UK that regions with the highest utilization rates were also the poorest, and were receiving fewer health care resources. This resulted in the creation of the Resource Allocation Working Party (RAWP) which was charged with finding more equitable ways of distributing resources to those regions with greater need.³ The formulae used typically consist of information on the age and sex composition of the community, and are usually modified by the standardized mortality ratios (SMRs) as a surrogate measure of the healthiness of the population.⁴ Capitated formulae have also been used to allocate other resources, especially to estimate the requirement for physicians.⁵

Third, the need for health services is defined in terms of *utilization* of health services (e.g., the number of persons discharged from hospital) or awaiting treatment (demand). Utilization in each area may be compared to an overall standard or benchmark. The problem with this approach is that the standard may be arbitrary or based on historical patterns of utilization that bear little connection with current reality, i.e., due to the emergence of new treatments and evidence that commonly accepted treatments may be ineffective.⁶ Further, existing patterns of care will identify both inappropriate use by consumers and inappropriate demand induced by providers, neither of which are components of necessary provision.⁷

The final approach has been referred to as '*epidemiologically-based needs assessment*' or '*population requirement*'.^{8,9} The key features

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are: 1) it is population based; 2) it allows for the incorporation of evidence of effectiveness (systematic reviews, consensus statements, guidelines); and 3) it provides estimates of absolute numbers of required interventions. An intervention may include health promotion, disease prevention, primary care, secondary care, rehabilitation and palliative care. The UK National Health Service has lead the way in this area since its 1991 reforms that emphasized the importance of assessing the health needs of its populations.¹⁰ While estimates of the need have been identified for prostatectomy, primary hip replacement surgery, cataract surgery and radio-therapy for lung cancer, the approach has never been used to estimate the requirement for stroke services.¹¹⁻¹⁵

Stroke is an important contributor to morbidity and mortality in Canadians. It has been estimated that it is the third leading cause of death in Canada.¹⁰ Further, it is amenable to the entire spectrum of health services, ranging from prevention of its risk factors, to the treatment of acute stroke and rehabilitation and palliation of chronic stroke. Would it be possible to estimate the number of persons in the population at each of these stages and link them with proved effective services?

The aim of this study is to examine the feasibility of carrying out an epidemiologically-based needs assessment in the Canadian context using population health data, using stroke as an example. Specifically, the objectives are: 1) to estimate the number of persons in the population with stroke with the potential to benefit from effective interventions (population requirement); and 2) to determine the number of stroke-related health services provided to individuals to examine whether or not gaps exist between the two.

Methods

A number of population-based data and published, evidence-based recommendations for services were used to determine the number of persons in the population with risk factors for stroke, acute stroke or chronic stroke, along with their related requirement for stroke services (prevention programs, diagnostic services, treatment of acute stroke and rehabilitation). The study population was the 1996 population in Eastern Ontario aged 25

years and older ($n = 1,021,910$). The population requirement estimates were then compared with provision data taken from routinely collected administrative data. The five main steps were:

- estimating the incidence and prevalence of stroke;
- identifying effective stroke services;
- estimating the population requirement for stroke;
- estimating the provision of services; and
- measuring the gap between requirement and provision.

Each of these steps is described in more detail below.

Estimating the occurrence of stroke

The prevalence of risk factors for stroke was estimated by applying age and sex-specific prevalence estimates for each risk factor to the 1996 population in Eastern Ontario¹⁶ and then summing to estimate the overall frequency of each risk factor. The 1996/97 Ontario Health Survey¹⁷ and the Canadian Heart Health Survey database¹⁸ were used to estimate the prevalence of stroke risk factors, with the exception of atrial fibrillation and transient ischemic attacks, which were taken from other published sources.¹⁹⁻²³

In the absence of Canadian incidence data, the incidence of acute stroke was taken from a stroke registry in Auckland, New Zealand and applied to the Eastern Ontario population.²⁴⁻²⁷ Estimates of 7-day and 28-day survival were derived from a number of international registries, covering a total of 7,984 strokes.²⁸⁻³²

The prevalence of chronic stroke associated with one or more disabilities was taken from the 1990 Ontario Health Survey.³³ These age-sex-specific prevalence estimates were applied to the 1996 Eastern Ontario population to calculate the estimated frequency of chronic stroke cases in the region. The number of stroke cases dying within 1 to 28 days in Eastern Ontario in 1996 was derived by linking discharge data from the Canadian Institute for Health Information and the Registered Persons Database that provides the death date, where

applicable, for persons with a valid Ontario health card.³⁵ A summary of the data sources used to measure the prevalence of risk factors, acute stroke and chronic stroke, along with their references, is presented in Table 1.

Identifying recommended stroke services

A list of stroke services was compiled through an extensive literature search of medical and health care journals, and supplemented through consultation with experts recruited from relevant provider and consumer advocacy groups. Additional literature searches of Medline and the Cochrane Library database were undertaken to gather evidence of effectiveness. For this study, an “effective” health service was one for which there exists evidence demonstrating its effectiveness in preventing or treating stroke and/or controlling a stroke-related risk factor. Initial searches identified practice guidelines and consensus statements about services of interest, as these reports provided useful summaries of the overall evidence. A search was also performed to identify systematic reviews or meta-analyses of clinical trials that addressed the effectiveness of each service. Searches that did not yield meta-analyses were repeated, targeting the next highest level of evidence, randomized controlled trials (RCTs). Services not found to have been investigated by RCTs were subjected to a third literature search with no restrictions to study design. The quality of evidence for health service effectiveness was rated using a four-point scale adapted from the U.S. Agency for Health Care and Policy Research³⁵ Each study was summarized in tables with the following information: 1) non-pharmacologic or pharmacologic; 2) specific type of service; 3) level of evidence, 4) endpoint and 5) treatment effect. In total, 150 different studies were appraised. A summary of the effective interventions, along with the source of the recommendations, is presented in Table 2.

Estimating the population requirement

Health services aimed at risk factors were classified as either non-pharmacologic, pharmacologic or surgical. Estimates of the use of

specific risk factors were identified from the literature and used to determine the proportion of at-risk individuals who could benefit from each type of intervention. The health services targeting the treatment of acute stroke were grouped into three general categories: core stroke services, restricted stroke services, and rehabilitation services (i.e., speech, occupational and physiotherapy). Restricted stroke services were defined as those services that should be provided to only a proportion of acute stroke patients due to reasons of expense, supply, potential adverse events or expected lack of benefit. They include thrombolytic therapy, brain and vessel imaging tests, carotid endarterectomy and rehabilitation

therapy. Prevalence estimates of these indications among stroke cases were then identified from the literature and supplemented by consultation with experts. These were then used to determine the proportion of stroke cases in need of each restricted service.

Estimating the provision of services

The provision of preventive interventions aimed at modifying existing factors was examined. All estimates of pharmacologic intervention for stroke-related risk factors were taken from the 1996 Canadian Disease and Therapeutic Index database, drug treatment

data collected quarterly from a sample of 652 office-based Canadian physicians by specialty.³⁶ These data can be used to estimate total treated incidence by diagnosis. Estimates of medication use for diabetes and hypertension were taken from 1996/97 Ontario Health Survey data.³⁷ Information about provision of treatment for hospitalized stroke cases was taken from the Canadian Institute for Health Information hospital database.³⁸ The Ontario Ministry of Health and Long-Term Care Fee-for-service claims database was examined to provide an estimate of the number of stroke cases not hospitalized in Eastern Ontario in 1996.³⁹ The inpatient and same-day surgery databases were used to determine the number

TABLE 1
Sources of risk factor, acute stroke and chronic stroke prevalence estimates

		Data source (year)	Study type
Risk factor	Heavy alcohol consumption	Ontario Health Survey (1996/97) ¹⁷	Survey
	Atrial fibrillation	Framingham Study ²⁰ Western Australia survey ²¹ Rochester survey ²² Cardiovascular Health Study ²³	Survey
	Diabetes	Ontario Health Survey (1996/97) ¹⁷	Survey
	Hypercholesterolemia	Canadian Heart Health Survey (1986–1992) ¹⁸	Survey
	Hypertension	Canadian Heart Health Survey (1986–1992) ¹⁸	Survey
	Obesity	Canadian Heart Health Survey (1986–1992) ¹⁸	Survey
	Low physical activity	Canadian Heart Health Survey (1986–1992) ¹⁸	Survey
	Smoking	Ontario Health Survey, Eastern (1996/97) ¹⁸	Survey
	Ischemic heart disease	Ontario Health Survey (1996/97) ¹⁷	Survey
	Transient ischemic attack	Rotterdam Study (1990–1993) ¹⁹	
Acute stroke	Immediate death	Shanghai registry (1984–1991) ²⁸ Barcelona Stroke Registry (1998) ²⁹ Rosamond, et. al. (1999) ³⁰ Arcadia Stroke Registry (1999) ³⁴	Registry
	Alive after onset	Shanghai registry (1984–1991) ²⁸ Barcelona Stroke Registry (1998) ²⁹ Rosamond, et. al. (1999) ³⁰ Arcadia Stroke Registry (1999) ³¹	Registry
	Alive one week after onset	MONICA (1993/94) ³²	Monitoring
	Alive 28 days after onset	Shanghai registry (1984–1991) ²⁸ Barcelona Stroke Registry (1998) ²⁹ Rosamond, et. al. (1999) ³⁰ Arcadia Stroke Registry (1999) ³¹	Registry
	Death 8–28 days	Shanghai registry (1984–1991) ²⁸ Barcelona Stroke Registry (1998) ²⁸ Rosamond, et. al. (1999) ³⁰ Arcadia Stroke Registry (1999) ³¹	Registry
Chronic stroke	Independent	Ontario Health Survey (1990) ³³	Survey
	Dependent on others	Ontario Health Survey (1990) ³³	Survey

of persons in Eastern Ontario in 1996 with a diagnosis of stroke who received either an imaging of the brain, non-invasive imaging of the vessels, or a carotid endarterectomy.⁴⁰

No provincial database maintains information on two of the restricted stroke procedures: conventional cerebral angiography and thrombolytic therapy. Therefore, information for these two therapies was collected from each of four local centres that performed conventional

cerebral angiographies in 1996. The number of persons who received recombinant-tissue plasminogen activase (r-tPA) in the first year of its availability was taken from the Canadian Activase for Stroke Effectiveness Study.⁴¹ All the rehabilitation units in Eastern Ontario were surveyed to collect information on rehabilitation therapy for stroke. The Ontario Homecare Administrative Systems Database was employed to determine the number of persons with a stroke-related disability in 1996. This

count was determined by the number of persons receiving homecare services who had a primary or secondary diagnosis of stroke.⁴²

Results

Risk factors

An estimated 203,000 persons (19.9% of the population aged 25 +) in Eastern Ontario have hypertension, the most important risk factor

TABLE 2
Source of recommendations for effective stroke-related health services

	Type of intervention	Source of recommendations
Risk Factor		
Hypertension	Non-pharmacologic Pharmacologic	British Hypertension Society ⁽⁴³⁾ British Hypertension Society ⁽⁴³⁾
Obesity	Non-pharmacologic	U.S. National Institutes of Health ⁽⁴⁴⁾
Low physical activity	Non-pharmacologic	U.S. National Institutes of Health ⁽⁴⁴⁾
Smoking	Non-pharmacologic Pharmacologic	AHCPR Clinical Practice Guideline on Smoking Cessation ⁽⁴⁵⁾ AHCPR Clinical Practice Guideline on Smoking Cessation ⁽⁴⁵⁾
Hypercholesterolemia	Non-pharmacologic: Fasting lipoprotein analysis Non-pharmacologic: Dietary intervention Pharmacologic	Canadian Lipoprotein Conference Ad Hoc Committee Guidelines ⁽⁴⁶⁾ Canadian Lipoprotein Conference Ad Hoc Committee Guidelines ⁽⁴⁶⁾ Working Group of Hypercholesterolemia and other Dyslipidemias ⁽⁴⁷⁾
Heavy alcohol consumption	Non-pharmacologic	Canadian Diabetes Association ⁽⁴⁸⁾
Diabetes mellitus (type II)	Non-pharmacologic Pharmacologic	Canadian Diabetes Association ⁽⁴⁹⁾ Canadian Diabetes Association ⁽⁴⁹⁾
Atrial fibrillation	Pharmacologic	Canadian Cardiovascular Society Consensus Conference on Atrial Fibrillation ⁽⁵⁰⁾
Transient ischemic attack	Non-pharmacologic Pharmacologic Surgical	Stroke Council, American Heart Association ⁽⁵¹⁾ Stroke Council, American Heart Association ⁽⁵¹⁾ Canadian Neurosurgical Society Recommendations ⁽⁵²⁾
Ischemic heart disease	Non-pharmacologic Pharmacologic	American Heart Association Consensus Panel Statement ⁽⁵³⁾ American Heart Association Consensus Panel Statement ⁽⁵³⁾
Acute Stroke Services		
Surgical	Carotid endarterectomy	Canadian Neurosurgical Society Recommendations ⁽⁵²⁾
Thrombolytic therapy	r-tPA therapy Streptokinase	American Heart Association ⁽⁵⁴⁾ American Heart Association ⁽⁵⁴⁾
Imaging of the brain	Computed Tomography (CT) Magnetic Resonance Imaging (MRI)	American Heart Association ⁽⁵⁵⁾ American Heart Association ⁽⁵⁵⁾
Imaging of the vessels	<i>Non-invasive:</i> Ultrasonography or Magnetic Resonance Angiography (MRA) <i>Invasive:</i> Conventional Cerebral Angiography	American Heart Association ⁽⁵⁵⁾ American Heart Association ⁽⁵⁵⁾
Rehabilitation therapy		AHCPR Rehabilitation Guideline ⁽³⁵⁾

TABLE 3
Population requirement estimates for stroke services, Eastern Ontario, 1996

	Intervention	Estimated population need	Provision	Discrepancy (provision – need)	% Need met	
Risk factor	Hypertension	1. Non-pharmacologic	203,000	123,800	-79,200	61
		2. (1) and pharmacologic	142,100	137,200	-4,900	97
	Low physical activity	1. Non-pharmacologic	397,800	NA*	–	–
	Obesity	1. Non-pharmacologic	343,100	26,400	-316,700	8
	Smoking	1. Non-pharmacologic	282,500	NA*	–	–
		2. (1) and pharmacologic	268,400	12,300	-256,100	5
	Heavy alcohol consumption	1. Non-pharmacologic	35,500	NA*	–	–
	Hypercholesterolemia	1. Fasting lipoprotein analysis	177,200	NA*	–	–
		2. (1) and dietary	124,000	65,600	-58,400	53
		3. (2) and pharmacologic	35,400	15,300	-20,100	43
	Atrial fibrillation	1. Pharmacologic	17,800	7,700	-10,100	43
	Ischemic heart disease	1. Non-pharmacologic	55,200	NA*	–	–
		2. (1) and pharmacologic	55,200	20,400	-34,800	37
	Transient ischemic attack	1. Non-pharmacologic	13,600	NA*	–	–
		2. (1) and pharmacologic	13,600	5,000	-8,600	37
3. (2) and surgical		3,000	195	-2,805	7	
Diabetes mellitus	1. Non-pharmacologic	39,100	29,200	-9,900	75	
	2. (1) and pharmacologic	18,500	28,600	+10,100	155**	
Acute stroke services	Thrombolytic therapy	403	52	-281	13	
Imaging of the brain	CT	3,419	1,006	-2,413	29	
	MRI	342	145	-197	42	
Imaging of the vessels	Ultrasonography	3,419	432	-2,987	13	
	Radiographic angiography	274	168	-106	61	
Surgical	Carotid endarterectomy	137	196	59	143**	
Rehabilitation	Speech, occupational, physiotherapy	1,846	1,385	-461	75	
Chronic stroke with disability	Assistance with activities of daily living	4,312	1,435	-2,877	33	

NA* Data not available

** A percentage over 100 corresponds to an over-provision of the intervention.

for stroke; between 23 % and 48 % of strokes are related to the presence of hypertension. The estimated prevalence of other risk factors for stroke was: low physical activity (397,800), obesity (343,100), smoking (282,500), hypercholesterolemia (177,200), ischemic heart disease (55,200), diabetes (41,200), heavy alcohol consumption (35,500), atrial fibrillation (17,800) and transient ischemic attack (13,600). A number of beneficial pharmacologic and non-pharmacologic interventions were identified.

Acute stroke

An estimated 3,525 persons suffered a stroke in 1996. Of these, 3,419 persons surviving immediately after stroke onset required 'core' acute stroke services. These services included: diagnostic tests, prevention of recurrent stroke, prevention of venous thromboembolism, patient/family support, assessment of disability and screening for rehabilitation in hospital. Of the 3,419 immediate survivors, 3,031 were estimated to have required hospitalization and

2,926 survived 28 days after stroke onset. Diagnostic tests required computerized tomography (CT) imaging of the brain ($n = 3,419$), magnetic resonance imaging (MRI) ($n = 342$), and further invasive imaging procedures ($n = 273$). Three hundred and thirty three of the 3,419 stroke survivors would potentially have benefited from r-tPA therapy, while an estimated 137 survivors would have benefited from carotid endarterectomy.

Chronic stroke

It was estimated that 1,846 survivors of acute stroke would require rehabilitation therapy as a result of suffering a stroke in 1996. These therapies were required for the treatment of several conditions including physical immobility, cognitive deficits, communication disorder, swallowing disorders, impaired bladder or bowel function, sleep disturbances and sexual impairments. An estimated 4,312 persons who survived a stroke in 1996 or earlier were estimated to require ongoing assistance performing their activities of daily living.

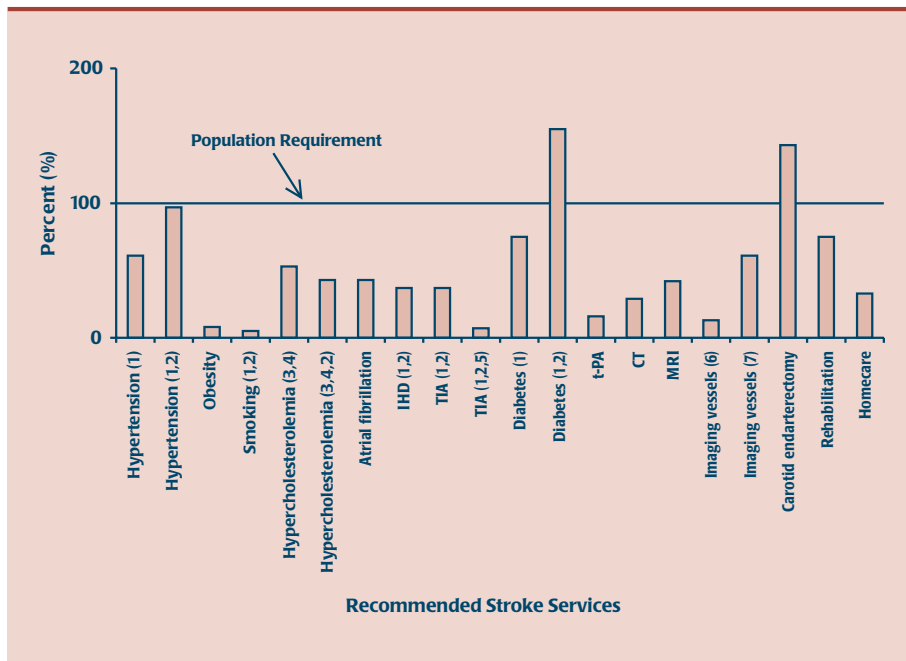
Comparison of estimated need with provision of services

When these needs were compared to the actual provision of services, there was a slight net over-provision of carotid endarterectomy procedures (137 required versus 196 provided) and a large net over-provision of pharmacologic therapy for diabetes (18,500 required vs. 28,600 provided). There was unmet need for all other health services targeting acute and chronic stroke including r-tPA therapy (333 required versus 52 provided), CT imaging (3,419 required versus 1,006 provided), MRI imaging (342 required versus 145 provided), ultrasonographic imaging of the vessels (3,419 required versus 432 provided), radiographic angiographies of the vessels (274 required versus 168 provided) and assistance in performing activities of daily living (4,312 required versus 1,435 provided). Table 3 presents a summary of the gap between the need for stroke services and the actual provision of effective stroke services.

Discussion

This study found that it was feasible to use population health data to estimate the requirement for health services. Estimates of the population requirement for stroke services exceeded the provision of all services, with the exception of pharmacologic treatment for diabetes mellitus and carotid endarterectomy for acute stroke. The identification of gaps between estimated need and actual provision in local populations may be a useful way to plan the delivery of health services.

FIGURE 1
Percent of need for stroke services that was provided, population requirement, for evidence-based stroke services, Eastern Ontario, 1996



* Diabetes refers to diabetes mellitus. (1) non-pharmacologic, (2) pharmacologic, (3) fasting lipoprotein analysis, (4) dietary, (5) surgical, (6) non-invasive, (7) invasive.

Before any conclusions may be drawn, the possible limitations of this study should be identified. These include:

- the application of data from other jurisdictions to local populations;
- the methods used for identification and linkage of effective services with each dimension of stroke;
- the methods used to measure the provision of services;
- the inability to match those who require services with recipients of stroke-related health services; and
- problems with emerging evidence.

Where available, local data were used to estimate the population requirement for services. In some cases (e.g., atrial fibrillation and transient ischemic attacks) local data were unavailable and estimates from outside Canada were applied to local populations. For example, utilization data from Rochester, Minnesota were used to estimate the requirement for acute hospitalization. Given that the

proportion of Rochester stroke cases receiving hospitalization (86%) is relatively higher than other reported proportions, we may have overestimated the requirement for hospitalization of stroke services in Eastern Ontario.

Comprehensive lists of health services targeting each stroke-related condition were compiled, and for each health service a summary of the best available evidence of effectiveness was reported. However, for the majority (over 150) of health services identified, too little detail was available to allow evidence of effectiveness of each health service to be described.

In many instances it was difficult to obtain measures of provision of services. This was particularly true for the number of people reached by health promotion programs targeting specific stroke risk factors because it is unknown what proportion of people reached by the promotion actually had the risk factor of interest. Therefore, the estimates we were able to obtain from the public health units regarding the number of persons who were heavy alcohol consumers, infrequent exercisers, and smokers were considered unreliable and excluded from this report. Most estimates of the

number of people who received pharmacologic interventions for the various stroke risk factors were taken from the 1996 Canadian Disease Therapeutic Index database. When comparing estimates of need to provision counts, with the exception of diabetes, there is a consistently large apparent under-utilization of pharmacologic interventions. The 1996/97 Ontario Health Survey reported counts of medication use much closer to our estimates of need. Strict guidelines have been developed for the use of r-tPA in Canada.⁵⁶ The proportion of acute stroke cases arriving at an emergency care centre within three hours of onset who would qualify to receive r-tPA has not yet been reported in Canada.⁵⁷ Therefore, the model estimate of 333 persons who could potentially benefit from r-tPA may be an overestimate.

Our estimate of the number of acute stroke survivors receiving rehabilitation therapy was derived from reports from the rehabilitation units in Eastern Ontario. These units supplied data only for those people who received occupational therapy, speech therapy or physiotherapy services. Furthermore, not all rehabilitation units reported statistics for people receiving rehabilitation therapy services on an outpatient basis. Under-reporting of these services would tend to underestimate the number treated.

Although we have estimated the total services needed and received, we have no way of knowing whether the services provided went to the people who needed the services. In other words, there is likely to be a mismatch between need and provision, at the individual level, known as the ecological fallacy. An apparent under-service therefore indicates the net under-service, and thus is the lower limit of the unmet need: to the extent that services were provided to persons who did not need them, the unmet need is actually greater. Similar arguments apply to over-provision of services. A review of the medical records of a sample of persons receiving a certain intervention could determine what proportion of them had the indication for that intervention. By subtraction, this would allow estimation of appropriately provided services, unmet need, and over-provision of services.

A final limitation of this study is the lag period between conducting the literature searches and the emergence of new treatments. For example, intravenous anocrod and endovascular treatment are two acute stroke treatments that are currently being reviewed in the literature, but are not yet in widespread use in Ontario.^{50,58-61} The challenge in conducting epidemiologically-based needs assessment lies in keeping up to date with the changing health care environment, while relying on rigorous peer-reviewed published evidence.

In general, estimates of the population requirement for stroke services exceeded the actual provision of these services. Many of the indications for treatments were taken from American sources where the health system is more technology driven, leading to more intensive provision of services. Applying American standards of service provision to Canadian populations could generate requirement estimates that would be considered excessive by Canadian standards. Nevertheless, the results of this study suggest that there is at least some under-provision of stroke services in Eastern Ontario.

A report examining hospital survey results of stroke care in Ontario points to resource allocation and waiting times to receive services as an explanation for under servicing.⁶² This report noted that not all hospitals have equipment such as computed tomography and magnetic resonance imaging scanners necessary to diagnose the cause of acute stroke. The median waiting time for a scan for patients classified as 'urgent' was two hours at hospitals with a CT scanner and 12 hours at hospitals without this technology. The median waiting time for all patients was 12 hours at hospitals with the equipment and 24 hours at hospitals without the equipment.⁶³ The same argument can be made for other procedures such as invasive and non-invasive imaging of blood vessels. If a centre lacks adequate testing facilities and qualified staff to perform procedures, patients who could benefit may not receive required services.

This approach to measuring need represents an improvement in planning health services in a region for two reasons. First, it measures need largely without relying on health service

utilization data, which, as a proxy for need, can be biased by supply of services and historical patterns of care. Secondly, it estimates need using recent population characteristics (i.e., 1996 population census data). The precision of such estimates of projected need will be limited by the ability to predict future population changes, as well as any changes in the prevalence of stroke-related conditions.

Future research using the population requirement approach could take several directions. The risk factor frequencies are not independent of one another; it is therefore problematic to add the frequency estimates of different risk factors calculated from this model. For example, the sum of the estimated frequencies of high blood pressure and smoking in Eastern Ontario will not approximate the frequency of individuals in the region who smoke or who are hypertensive. We took the approach of considering the risk factors one at a time. Given the importance of synergistic effects of multiple risk factors, future research is needed to examine the distribution of individuals with multiple risk factors or types of disabilities for purposes of better-informed planning.

This study tested a method to estimate the population requirement and provision of effective stroke services in Eastern Ontario. These results suggest an over-provision of interventions related to diabetes mellitus and carotid endarterectomy, while all other stroke services were under-provided. This study has shown that an epidemiologically-based needs assessment could be a useful tool for planning health services.

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Do work-related breast cancer risks in pre-menopausal women depend on family history?

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Abstract

Our objective was to determine work-related pre-menopausal breast cancer risks that depend on a woman's family history of the disease. In a large case-control study, 318 women with breast cancer and 340 healthy women completed a mailed questionnaire. All of the women were pre-menopausal and controls were matched to cases by age. All risk estimates were adjusted for women's smoking history and whether they reported a prior breast biopsy. There was an odds ratio (OR) of 6.9 (95% confidence interval: 1.5–31.9) for breast cancer among pre-menopausal women with no family history if they ever worked in material processing occupations. Among women with a family history of breast cancer, there was an OR of 6.4 (0.7–55.9) if they ever worked as miscellaneous salesclerks and salespersons of commodities, and an OR of 5.7 (0.6–50.9) if they ever worked in department stores. Despite changes in the OR, none of the estimates were significantly different in women with and without a family history.

Key words: breast cancer; disease susceptibility; family history; industry; occupation

Introduction

Breast cancer is the most commonly diagnosed malignancy among women in British Columbia (BC) Canada. About 2,700 women in BC were diagnosed with breast cancer in 2003 and about 640 died from the disease.¹ Established breast cancer risk factors include age, family history of breast cancer, previous benign breast disease, and hormonal factors such as age at menarche and parity.² A family history of breast cancer can occur because of shared genetic factors among relatives, shared environment among relatives, or by chance. Germline mutations in BRCA1 and BRCA2 account for 15%–20% of families in which there is more than one woman with breast cancer,³ and other genes may explain additional familial clustering.⁴ There is substantial variation in breast cancer incidence rates around the world⁵ and the probability of a family history also depends on local disease rates.⁶ (If disease

rates are increased in a population, there is a greater probability that a family member will be affected.) Finally, the probability of familial clustering depends on the number, type, and age of relatives in a family.⁶

A large population-based case-control study of breast cancer was conducted in BC during 1988 and 1989.^{7–9} That study reported a significantly-increased pre-menopausal breast cancer risk for electronic data processing operators, barbers and hairdressers, women in sales and material processing occupations, and in the food, clothing, chemical and transportation industries. Many studies have investigated the association between occupations and breast cancer, but the findings are inconsistent. Goldberg and Labreche reviewed 115 studies of occupation and breast cancer published between 1971 and 1994 and concluded that there was some, albeit limited, evidence of increased breast cancer risk among women

working in the pharmaceutical industry, and among cosmetologists and beauticians.¹⁰ They also found some evidence of an increased risk for chemists, for workers with electromagnetic field exposure, and for workers exposed to solvents. An updated review in 2001 drew similar conclusions.¹¹

A family history of breast cancer might indicate that a woman has increased susceptibility to the disease. This seems particularly likely for pre-menopausal breast disease because an early age of diagnosis itself suggests predisposition. Several studies have found that women with a family history of breast or ovarian cancer have different breast cancer risks associated with reproductive factors than do women without a family history.^{12–15} A recent US study found that women under age 50 with a family history of breast or ovarian cancer appeared to have increased breast cancer risks associated with medical radiation.¹⁶ We hypothesize that pre-menopausal women with a family history might have increased breast cancer risks as the result of work-related factors. In this analysis, we wanted to identify occupations and industries that differentially affect risk in women with and without a family history of breast cancer.

Methods

We analyzed data from a large case-control study of breast cancer.^{7–9} Cases were all women under age 75 who were diagnosed with breast cancer in BC between June 1, 1988 and June 30, 1989. Controls were women who were randomly selected from the 1989 provincial voters list and age-matched to the cases. One thousand, four hundred and eighty-nine (1,489) cases were

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identified, and 1,502 controls were selected. All of these women were mailed a questionnaire that asked, among several things, about their occupational history and their family history of breast cancer. Upon its return, each questionnaire was reviewed for completeness and women were telephoned about missing information. A total of 1,018 cases and 1,025 controls completed the questionnaire, yielding a response rate of 68% in each group. Women were considered pre-menopausal if they were either menstruating or had undergone a hysterectomy without oophorectomy and were under 50 years of age. Women were considered post-menopausal if they had undergone natural menopause or a bilateral oophorectomy, or if they had undergone a hysterectomy with ovarian conservation but were 50 years of age or older. There were 318 cases and 340 controls who were pre-menopausal, and women participating in the study gave written, informed consent. Approval for the study was granted by the Behavioural Research Ethics Committee at the University of British Columbia.

The study questionnaire asked women whether they had ever had a breast biopsy, and the answer was interpreted as evidence of prior benign breast disease. It also asked women whether they had smoked more than 100 cigarettes in their lifetime, the age they began smoking, whether they had ever quit (and for how long), and the average number of cigarettes that they smoked each day.

With regards to their occupational history, the questionnaire asked women to describe every job they had ever held for a year or more. Details of each job included its title, the dates that it began and ended, whether the work was part-time or seasonal, the duties involved, the name of the employer and where the job was located. The questions were presented in a tabular format and an example was provided. This simplified both answering the questions and interpreting the responses. Occupations were coded according to the Canadian Standard Occupational Classification¹⁷ (SOC) and the Canadian Standard Industrial Classification¹⁸ (SIC). In each system, the most specific groups are defined by four-digit codes. Groups based on the first two or three digits of those codes define broader occupational and industrial classes.

A positive family history of breast cancer was defined when women reported having a mother or sister with breast cancer. The women in this analysis were mostly Caucasian with some post-secondary education, and had been pregnant at least once.⁹ The main differences between the case and control groups were 1) 17% of cases and only 8% of controls had a prior breast biopsy (suggesting prior benign breast disease; $p < 0.05$ for difference) and 2) 23% cases reported more than 20 pack-years of cigarette smoking as compared to 16% as reported by controls ($p < 0.1$).⁹ The data are the same as those described in the original analysis of occupational breast cancer risk (i.e., ref 9).

We restricted the analysis to occupational and industrial groups in which there was at least one case and one control with and without a family history of breast cancer, and at least five women with a family history and five women without a family history in total. These restrictions were adopted to avoid conclusions based on the absence of observations (although this itself might be considered evidence) and provide a minimum level of statistical stability in the results. Following these restrictions, we analyzed risks for four-digit occupational and industrial codes. When there were insufficient data in a four-digit group, broader groups defined by three-digit and two-digit codes were used.

Logistic regression was used to calculate the odds ratio (OR) as an estimate of the relative risk for breast cancer. Separate analyses were performed for women with and without a family history of breast cancer. We estimated relative risks adjusting for age (in years) and factors that were significant in a previous analysis:⁹ pack-years of cigarettes smoked (in three categories: 0, < 20 and ≥ 20) and history of breast biopsy (any or none). Logistic regression was also used to test whether there was a significant interaction between family history and occupation/industry. All tests were two-sided with an alpha of 5%.

Results

Sixteen percent (16%) of cases and 7% of controls had a family history of breast cancer. The OR estimates associated with occupation and industry groups are given in Table 1. The

mean OR for all occupational and industrial groups was 1.2 (range: 0.4–4.2), adjusting for family history. Restricting analyses to women with a family history, the mean OR for the same groups was 1.6 (range: 0.3–6.4), and 1.3 (range: 0.3–6.9) when the analysis was restricted to women without a family history. There were two occupational groups and one industrial group in which there was a roughly five-fold or greater difference in breast cancer risk for women with and without a family history of the disease. Among women with a family history of breast cancer, there was an OR of 6.4 if they ever worked for a year or more as miscellaneous salesclerks and salespersons of commodities (SOC 5135). The corresponding OR was 1.3 for women without a family history. This job group excludes supervisors, technical sales occupations and commercial travellers. Among women with a family history of breast cancer, there was an OR of 5.7 if they ever worked for a year or more in department stores (SIC 6411). The corresponding OR was 0.9 for women without a family history. Women without a family history of breast cancer had an OR of 6.9 if they ever worked for a year or more in material processing occupations (SOC 81/82). The corresponding OR was 0.6 for women with a family history. This job group includes occupations involving the processing of mineral ores, metals, stone, chemicals, rubber, plastic, textiles, food and wood. All models were adjusted for women's smoking history and whether they reported a prior breast biopsy. Models fitted using all women yielded no significant interactions involving family history and occupational group, industrial group, or other model variable.

Discussion

After adjustment for known risk factors, we identified occupational and industrial groups for which there was a substantial increase in pre-menopausal breast cancer risk depending on whether women had a family history of the disease. There was a seven-fold increase in the relative risk of breast cancer among pre-menopausal women with no family history who were ever employed in material processing occupations. There was a six-fold increase in the relative risk of breast cancer among pre-menopausal women with a family history

TABLE 1

Relative risk of pre-menopausal breast cancer associated with ever being employed in an occupation or industry for one year or more: number of cases, number of controls (Cntls), odds ratio (OR) and 95% confidence interval (95% CI). A family history is defined as having a mother or sister who ever had breast cancer. Occupation and industry groups are ordered according to the first 2 digits of the SOC or SIC code, then the 3rd digit and 4th digit where they are present

Occupation / Industry ¹	All women OR ²	Women without a family history			Women with a family history		
		Cases	Cntls	OR ³ (95% CI)	Cases	Cntls	OR ³ (95% CI)
SOC 1149: Miscellaneous managers and administrators ⁴	0.9	13	18	0.8 (0.4–1.8)	6	1	1.9 (0.2–19.8)
SOC 117: Occupations related to management and administration	1.3	12	15	1.0 (0.4–2.2)	4	1	2.3 (0.2–23.6)
SOC 273: Elementary and secondary school teaching and related occupations	1.0	29	30	1.1 (0.7–2.0)	5	4	0.6 (0.1–3.2)
SOC 313: Nursing, therapy and related assisting occupations	0.7	35	47	0.8 (0.5–1.3)	5	3	0.6 (0.1–3.0)
SOC 3158: Dental hygienists and dental assistants	0.4	3	9	0.4 (0.1–1.4)	3	2	0.8 (0.1–5.2)
SOC 4111: Secretaries and stenographers	0.8	46	67	0.8 (0.5–1.2)	13	4	1.8 (0.5–6.6)
SOC 4113: Typists and clerk-typists	0.5	12	26	0.4 (0.2–1.9)	4	3	0.6 (0.1–3.2)
SOC 4131: Bookkeepers and accounting clerks	1.1	41	38	1.3 (0.8–2.1)	7	5	0.3 (0.1–1.3)
SOC 4133: Cashiers and tellers	0.7	24	39	0.7 (0.4–1.2)	4	2	0.7 (0.1–4.5)
SOC 4171: Receptionists and information clerks	1.4	23	18	1.4 (0.7–2.7)	5	1	3.0 (0.3–29.7)
SOC 4197: General office clerks	1.0	23	34	0.8 (0.5–1.5)	8	3	1.5 (0.3–6.7)
SOC 5130: Supervisors: sales occupations, commodities	0.9	9	7	1.4 (0.5–3.9)	4	2	0.6 (0.1–4.2)
SOC 5135: Miscellaneous sales clerks and salespersons, commodities ⁵	1.7	43	41	1.3 (0.8–2.2)	10	1	6.4 (0.7–55.9)
SOC 6125: Food and beverage serving occupations	1.1	16	24	0.8 (0.4–1.6)	7	2	2.1 (0.4–11.5)
SOC 81/82: Processing occupations	4.2	11	2	6.9 (1.5–31.9)	3	2	0.6 (0.1–4.8)
SIC 10: Food industries	4.0	15	5	3.7 (1.3–10.3)	5	1	3.0 (0.3–28.2)
SIC 60: Food, beverage and drug industries, retail	1.1	21	25	1.0 (0.6–1.9)	5	1	2.1 (0.2–21.5)
SIC 6411: Department stores	1.0	28	35	0.9 (0.5–1.6)	8	1	5.7 (0.6–50.9)
SIC 65: Miscellaneous retail store industries ⁶	1.2	16	13	1.3 (0.6–2.9)	5	3	0.3 (0.04–1.8)
SIC 7021: Chartered banks	1.0	16	20	1.0 (0.5–2.0)	3	2	0.7 (0.1–4.7)
SIC 77: Business service industries	1.0	32	38	1.0 (0.6–1.7)	4	2	0.8 (0.1–4.9)
SIC 82: Provincial and territorial government service industries	0.7	17	28	0.7 (0.4–1.3)	4	1	2.6 (0.3–25.5)
SIC 851: Elementary and secondary education	1.0	39	40	1.1 (0.7–1.8)	8	4	1.1 (0.3–4.9)
SIC 8611: General hospitals	1.0	48	51	1.1 (0.7–1.8)	6	4	0.5 (0.1–2.3)
SIC 8653: Offices of dentists, general practice	0.4	3	10	0.3 (0.1–1.3)	3	2	0.8 (0.1–5.2)
SIC 9211: Restaurants, licensed	1.9	13	12	1.5 (0.7–3.5)	5	2	1.1 (0.2–6.7)

¹ SOC and SIC refer to the Canadian Standard Occupational Classification [ref 17] and Canadian Standard Industrial Classification [ref 18] respectively.

² As reported in Band et al (2000) [ref 9], adjusted for age, family history, smoking and whether the woman has ever had a breast biopsy.

³ Adjusted for age, smoking and whether the woman has ever had a breast biopsy.

⁴ Excludes managers and administrators associated with government, science, teaching, health, personnel, industrial relations, sales, advertising, purchasing, construction, farming, transportation and communication. Includes executive secretaries and various occupations in " ... publishing houses, newspaper firms, professional associations, real estate firms, public utilities and warehouse complexes." [ref 17 p 55].

⁵ Excludes supervisors, technical salespersons and commercial travellers. Includes occupations " ... concerned with selling commodities in wholesale and retail trade establishments, and applying knowledge of characteristics, quality and merit of items sold." [ref 17 p 127].

⁶ Excludes industries related to food, beverages, drugs, shoes, apparel, fabric, yarn, furniture, appliances, automotive vehicles and general merchandise stores. Includes book and stationery stores; florist, lawn and garden centres; hardware, paint, glass and wallpaper stores; sporting goods and bicycle shops; musical instrument and record stores; jewelry stores and watch and jewelry repair shops; camera and photographic supply stores; toy, hobby, novelty and souvenir stores.

if they had ever worked in department stores, and a five-fold increase if they had ever worked as miscellaneous salesclerks and salespersons of commodities. None of the differences between women with and without a family history were statistically significant. Earlier analysis of this data found significantly increased OR estimates of 1.7 and 4.2 for breast cancer among pre-menopausal women who ever worked as miscellaneous sales clerks and salespersons, and in materials processing occupations – regardless of whether they had a family history of breast cancer.⁹ Our analysis indicates these risks are highly dependent upon whether the woman has a family history.

A family history of breast cancer can result from genetic or environmental factors, but individual cases within a family might not be caused by the same exposures. All of the women in a family might have inherited susceptibility, but the co-factor that exploits this susceptibility could come from several sources. The genes responsible for a family history might not affect cancer directly, but rather affect a process such as DNA repair, chemical metabolism or cell cycling. Where members of a family share a genetic deficiency in DNA repair capability, DNA damage might occur as the result of exposure to sunlight or pesticides. A family history might also be the result of a non-genetic factor such as shared environment or shared lifestyle amongst family members.

The hypothesis that motivated our analysis is that family history of breast cancer is a marker of increased disease susceptibility and, as a consequence, women with a family history might experience greater risks as the result of work-related exposures. Our results are consistent with a recent study of disease risk in the relatives of women with breast cancer.¹⁹ This study concluded that a high proportion of breast cancers arises in a susceptible minority of women. Other studies suggest that the susceptibility might be due to multiple alleles that affect processes related to hormones or tumor suppression.^{4, 20, 21} Work in department stores might entail elevated exposure to artificial lighting. This is consistent with the hypothesis that sunlight exposure decreases breast cancer risk. If the work is performed in the evening, the result is also consistent with the hypothesis

that light-at-night (LAN) increases a woman's breast cancer risk. Unfortunately, we had no data as about LAN or sunlight exposure to test these hypotheses directly.

For either the LAN or sunlight hypothesis, the increased risk might only be applicable to women with a susceptibility to the exposure, and where the susceptibility is familial. Alternatively, the results could be due to a confounding factor that is familial, such as a tendency towards indoor or sedentary work. Many people find work through a family member's employer and factors that affect familial clustering might also appear to affect their occupation. Furthermore, a woman's child-rearing experience has a direct effect on her work experience outside the home. It has been suggested that working women might have fewer children, have their first child at a later age, and breast-feed their children less.²² We attempted to adjust for this phenomenon by estimating breast cancer risks after correcting for known confounders identified in earlier analyses. This also allowed us to compare the relative risk estimates with those of earlier results. Recent studies in Canada²³ and Finland²⁴ have shown that breast cancer risk is reduced for women who are more physically active. The role of physical activity is especially interesting because of the apparent complexity of body-weight's effect in determining breast cancer risk. Unfortunately, information about physical activity was not available in our study and we could not test for this factor's effect directly.

We adjusted our analyses for factors that were significant in earlier analyses of the same data, thereby allowing us to compare the results. Our analysis considered only pre-menopausal breast cancer risk, but not whether a woman's family history of breast cancer was a post-menopausal or pre-menopausal one. A family history of breast cancer is dependent on a woman's age and family size.¹² Someone with no family history of cancer at age 20 might have several affected relatives by age 40. Likewise, someone from a large family is more likely to have an affected relative than is someone from a small family, unless increased family size is somehow associated with a reduced disease risk. The BC study matched case and control groups by age. The study did not match the groups based on family size, but

this is not expected to influence results unless family size is somehow associated with a woman's job history.

The information used in the study was obtained by a self-administered questionnaire, and reporting bias can occur if women with breast cancer respond to questions differently than healthy women. The questions were worded to minimize this phenomenon, and the questionnaire was designed with the same intention. Occupational and industrial risks were based on job titles, and these titles might encompass jobs with very different duties and exposures. Finally, caution is necessary when interpreting these results because of the number of occupations and industries we considered. In a case-control study, even a reasonably large one, the number of women reporting any particular occupation or industry will be small. The numbers will be smaller still when split according to whether or not a woman has a family history of breast cancer. Our main analysis estimated relative risk estimates separately for women with and without a family history of breast cancer. We also fitted models for each of the 26 occupational and industrial groups to test for an interaction between women with and without a family history, and none of the differences was statistically significant. However, three of the differences were roughly five-fold or more and this should not be ignored.

In studies of breast cancer and occupation, few associations have been found consistently. The lack of consistency might be explained by a difference in the underlying susceptibility of women. The allowable exposures in a workplace are typically based on risks that affect all employees. An alternative strategy would be to set exposure limits based on the most susceptible group.

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Book Review

Misconceptions about the Causes of Cancer

Lois Swirsky Gold, Thomas H Slone, Neela B Manley and Bruce N Ames, editors

Vancouver, British Columbia, The Fraser Institute, 2002

xiv + 141pp; ISBN 0-88975-195-1; \$19.95 (CDN)

Misconceptions about the Causes of Cancer argues that the debate about unproven cancer causes diverts attention and resources away from establishing health policies and interventions to address the well-established avoidable causes of cancer, including smoking and dietary factors. Such argument has been widely popularized in the field of risk regulation in the US by Aaron Wildavsky¹ from Berkeley and John Graham from Harvard University.² These ideas have made their way into US jurisprudence in looking at the costs of environmental, health and safety regulation.

In many respects, the complex arguments turn on three points: a) what is the acceptable public price of one life saved by a regulatory intervention; b) to what extent are high-cost/low-yield regulations impeding other more effective preventive health services; and c) if we let everyone get wealthy, we will be safer without regulatory intervention, and high-cost/low-yield regulatory intervention is impeding our wealth and potentially our health. In the extreme, this position reduces to the idea that the cost of regulation should be put back into the hands of the taxpayer and the resulting gain in wealth would result in better overall health. This philosophy resonates with the ideologically libertarian Fraser Institute since it accords with the notion of minimal government interference in regulatory matters.

Three of the authors, Swirsky Gold, Slone and Manley, are affiliated with the Carcinogenic Potency Project at the University of California, Berkeley. The fourth author, Ames, is well known in toxicology and as a former Berkeley professor and is currently Senior Scientist at Children's Hospital Oakland Research Institute.

The authors identify nine misconceptions about what causes cancer, and discuss each of these in the context of current research. In Chapter 1, entitled, "Misconception 1 – Cancer

rates are soaring in the United States and Canada", the authors draw on data from the National Cancer Institute of Canada that show a decline in overall cancer mortality rates in Canada; however, this decline, as they point out, is primarily due to selected cancers (stomach, cervix and colorectal). They cite a similar decline in the United States. *Misconceptions about the Causes of Cancer* does not report cancer incidence; it states changes in incidence rates over time which are complicated by more recent screening programs, diagnostic innovations and changes in lifestyle trends. Nevertheless, it seems irresponsible of the authors to dismiss the fact that increases in the population and population aging will contribute to dramatic increases in cancer incidence, thereby placing greater demands on the cancer delivery system.³

Eight more chapters are dedicated to misconceptions about synthetic chemicals, pesticides, assessment of carcinogenic hazards, and regulation of environmental risks. These chapters advance the central thesis that environmental risk factors are far down the list of known carcinogens. For example, the authors point out that most of the studies of potential environmental carcinogens are based on animal models that involve substantially higher dose levels (the "bioassay design") than humans would incur in their lifetimes. They also argue that it is not possible to generalize the results to human beings due to inter-species differences.

There is also a misconception, the authors state, that synthetic chemicals pose greater cancer risk than natural chemicals. Their research shows, however, that "... a high percentage of both natural and synthetic chemicals are rodent carcinogens at the MTD [maximum tolerated dose] and that tumor incidence data from rodent bioassays are not adequate to assess low-dose risk". Chapter 7 presents this analysis and summary ranking of several potential human cancer hazards (synthetic and

natural), based on the authors' previously published work. This index, the "human exposure/rodent potency index" (HERP), was used to rank the potential cancer risks. Compared to many common exposures, the HERP index shows that synthetic pesticides rank comparatively low in potential carcinogenic hazard. Furthermore, the authors state that solid scientific evidence does not exist to support a relationship between pesticides and other synthetic chemicals and the disruption of hormone levels that could lead to the development of certain cancers (e.g., breast cancer).

Finally, in Chapter 9, the authors maintain that existing and proposed regulations to deal with these potential risks are very expensive, and divert scarce funds away from cancer prevention initiatives and policies supported by science. Once again, this tradeoff position of the dubious costs of regulation represent a US public policy tradition which is not without its detractors within the US public policy debate, and a tradition which is not necessarily embraced by other advanced nations. This regulatory debate on what is considered to be a legitimate health or safety regulation limiting trade and what is an unfair trade practice is being fought daily in the corridors of the World Trade Organization.⁴

Misconceptions about the Causes of Cancer adheres to its main argument that existing science does not support claims made about the carcinogenic effects of synthetic chemicals. This little book is not, however, without its limitations. No clear or systematic methodology is presented for identifying and selecting studies from the published literature to support the line of argument. No review criteria are provided. The authors appear to rely primarily on their own research when citing references to support their conclusions. The text is primarily narrative; levels of evidence are not used to assess the quality of the science to support or refute claims made about

potential cancer risks. Finally, the authors skip the major area of occupational exposures and human cancers.

In addition, there is no discussion of the relationship between the environment and cancers in young adults. For example, there are good studies linking pesticide use among farmers and wood dust among forestry workers to non-Hodgkin's lymphoma.⁵ Both exposures require regulatory interventions to prevent high concentrations of environmental carcinogens in small numbers of highly exposed populations. Likewise, while it is accurate to say that the overall pattern of cancer mortality is in decline in North America, the growth in some cancers in young adults, such as non-Hodgkin's lymphoma, a cancer which has grown by 3.9% annual increase in males, and 5% annual increase in females in Canada from 1987 to 1996, remain unexplained. While infectious factors may be important, environmental factors and occupational exposures remain important suspects in the rise of this cancer.

The absence of environmental evidence does not mean that evidence does not exist. It doesn't mean it does exist either – simply that we have no evidence yet. Despite the controversy attending the science surrounding the use of ornamental pesticides, the Supreme Court of Canada, invoking the precautionary principle, has indicated that municipalities have the right to introduce bans on the use of ornamental pesticide.⁶ Apparently our own Supreme Court does not subscribe to the Wildavsky-Graham position.

Policymakers should read *Misconceptions about the Causes of Cancer*. The authors have provided some evidentiary basis for their argument, even if it is a selective reading of the literature in the tradition of US environmental regulation.

We are convinced that special consideration should be given to identifying an appropriate balance between current regulations and resources attached to those cancer risks for which there is established scientific support (those where the burden suggests a strong focus on smoking, diet, physical inactivity, sun exposure). Ongoing research into potential environmental and occupational risks must be supported, however, and each national

jurisdiction must develop its own approach to regulatory processes in the field of environment, health and safety. On balance, it is not clear in our view whether *Misconceptions about the Causes of Cancer* lights the way for Canada.

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Calendar of Events

16–20 April, 2005 Anaheim/Orange County, CA, USA	American Association for Cancer Research 96 th Annual Meeting	American Association for Cancer Research 615 Chestnut St., 17 th Floor Philadelphia, PA 19106-4404 USA Tel.: (215) 440-9300 Fax: (215) 440-9313 < http://www.aacr.org/ >
28 April–1 May, 2005 Winnipeg, Manitoba	National Research Forum for Young Investigators in Circulatory and Respiratory Health	Susan Zettler c/o Institute of Cardiovascular Sciences St. Boniface General Hospital Research Centre R3021–351 Taché Avenue Winnipeg, MB R2H 2A6 < http://www.yiforum.ca/ >
27– 30 June, 2005 Toronto, Ontario	Joint SER/CSEB Meeting	< http://www.epiresearch.org/ > < http://www.cseb.ca/ >
21– 24 August, 2005 Nashville, Tennessee, USA	21 st International Conference on Pharmacoepidemiology & Therapeutic Risk Management	Tel.: (301) 718-6500 Fax: (301) 656-0989 E-mail: ispe@paimgmt.com < http://www.pharmacoepi.org/meetings/index.cfm >
21– 25 August, 2005 Bangkok, Thailand	XVII International Epidemiological Association World Congress on Epidemiology	< http://wce2005.org/index.htm >
25–29 September, 2005 Pretoria, South Africa	17 th Conference of the International Society for Environmental Epidemiology	Deadline for Abstracts: March 31, 2005 ISEE 2005 Conference Organizing Committee School of Health Systems and Public Health University of Pretoria PO Box 667 Pretoria 0001 South Africa Tel.: + 27 31 266 2384 Fax: + 27 31 266 2380 E-mail: confcall@yebo.co.za < http://www.isee2005.co.za >
23–24 October, 2005 Salt Lake City, UT, USA	14 th Annual Meeting International Genetic Epidemiology Society	< http://www.biostat.wustl.edu/~genetics/iges/meetings.html >
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