

# Chronic Diseases

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## Table of Contents

### 49 Effectiveness of letters to Cape Breton women who have not had a recent Pap smear

*Grace M Johnston, Christopher J Boyd, Margery A MacIsaac,  
Janice W Rhodes and Robert N Grimshaw*

### 57 Deprivation and stroke mortality in Quebec

*Jérôme Martinez, Robert Pampalon and Denis Hamel*

### 65 Do healthy food baskets assess food security?

*Tasnim Nathoo and Jean Shoveller*

### 70 The role of lay panelists on grant review panels

*Anne Monahan and Donna E Stewart*

### 75 The use of complementary and alternative therapies by people with multiple sclerosis

*Stacey A Page, Marja J Verhoef, Robert A Stebbins,  
Luanne M Metz and J Christopher Levy*

### 80 Calendar of Events

### Information for Authors (on inside back cover)

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# Effectiveness of letters to Cape Breton women who have not had a recent Pap smear

Grace M Johnston, Christopher J Boyd, Margery A MacIsaac, Janice W Rhodes and Robert N Grimshaw

## Abstract

Nova Scotia, and especially Cape Breton, has high cervical cancer incidence and mortality rates. Letters were sent to 15,691 unscreened and 6,995 under-screened women from Cape Breton Island encouraging them to obtain a Pap test. Controls were 61,510 unscreened women and 32,996 under-screened women in mainland Nova Scotia who were not sent letters. For this cohort study, the provincial Health Card Number database and Provincial Cytology Registry were linked. Having a Pap smear was associated with having received a letter (OR = 1.64), having been previously under-screened rather than unscreened (OR = 1.85), with youth and with higher income (OR = 1.13). After receiving a letter, women in Aboriginal, Mixed Black, Acadian, and rural communities had smear rates similar to those of other women. Being previously unscreened, rather than under-screened, was associated with higher rates of abnormalities (OR = 1.62), indicating greater need for early detection and treatment to prevent invasive cancer. While one-time letters to women improved the Pap smear screening rates, multiple, continuous interventions are needed to make a more substantive improvement in these rates.

**Key words:** cost; evaluation; letter intervention; Pap smear; screening

## Introduction

Cape Breton Island has low rates of Pap smear screening and high rates of cervical cancer incidence and mortality compared with mainland Nova Scotia. Nova Scotia has had high cervical cancer rates compared with those of Canada (Figure 1).<sup>1</sup> Participation in regular, high-quality Pap smear screening by all eligible women has been recognized as the most effective means of decreasing incidence and mortality rates from invasive cervical cancer. In 1991, in response to recommendations in numerous Canadian reports,<sup>2-4</sup> Nova Scotia instituted an organized cervical screening program.

In the mid 1990s, a case-control study was carried out of the Pap smear histories of Nova Scotia women with a diagnosis of invasive cervical cancer. From this screening

failures study, it was seen that the majority of invasive cancer cases occurred among women who were unscreened or under-screened at the time of diagnosis.<sup>5</sup>

In 1997, the Nova Scotia Gynaecological Cancer Screening Program (GCSP) received funding from Health Canada's Population Health Fund, for a multifaceted Pap screening intervention in Cape Breton.<sup>6</sup> As part of this three-year project, letters were sent to under-screened and unscreened women in Cape Breton asking them to go to their physician or to a clinic for a Pap smear. This paper reports the findings from the evaluation of the letter intervention.

Letters of invitation to women have been successful to varying degrees.<sup>7-14</sup> Sometimes they have been accompanied by enhancements, such as questionnaires,<sup>7</sup> appoint-

ments,<sup>10</sup> media campaigns<sup>11</sup> and behavioural prompts.<sup>13</sup> None of these studies has been population based, with personalized letters to unscreened and under-screened women only, i.e., excluding women who had had recent Pap smears. The strength of this Nova Scotia study is in the use of the long-standing, Provincial Cytology Registry (PCR), which is linked to the provincial Health Card Number (HCN) file to identify unscreened and under-screened women and send them personalized letters. Both the PCR and HCN databases use the same unique personal identifier.

Maritime Medical Care (MMC) is a private, nonprofit company that administers the payment of physician billing claims and the HCN registration of everyone covered by the publicly funded, universal physician and hospital insurance for the province of Nova Scotia. The PCR, which is the responsibility of the GCSP, identifies all Pap smears performed in Nova Scotia since January 1988.

## Methods

### Identifying the study subjects and their screening status

With approval from the Nova Scotia Department of Health, MMC identified 360,587 women who were 18 years and over, had a provincial HCN and resided in Nova Scotia between June 1998 and April 1999. The 61,929 women living on Cape Breton Island represent 17.2% of this population. The age range for the letter intervention and its evaluation is consistent with the provincial screening guidelines.<sup>15</sup>

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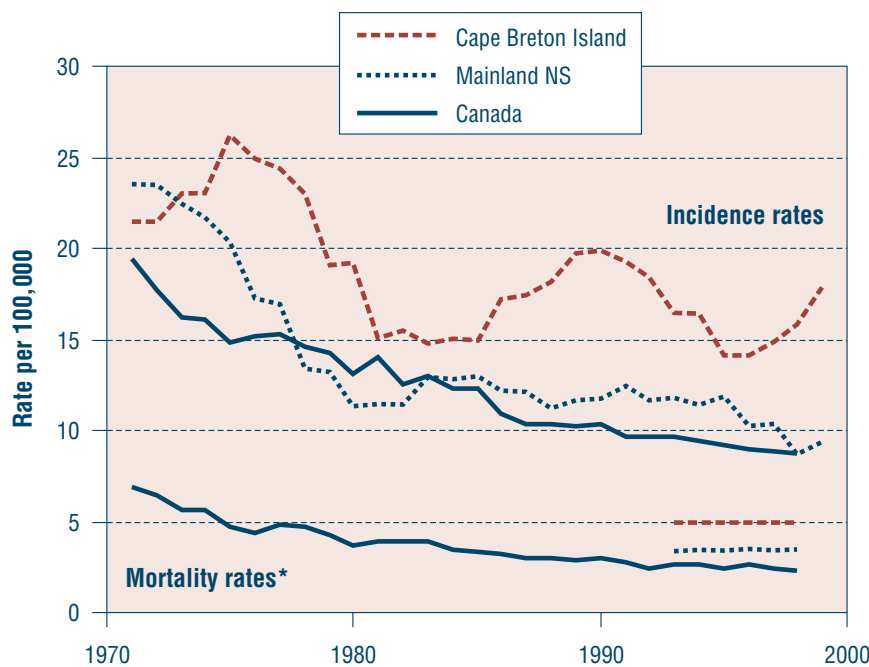
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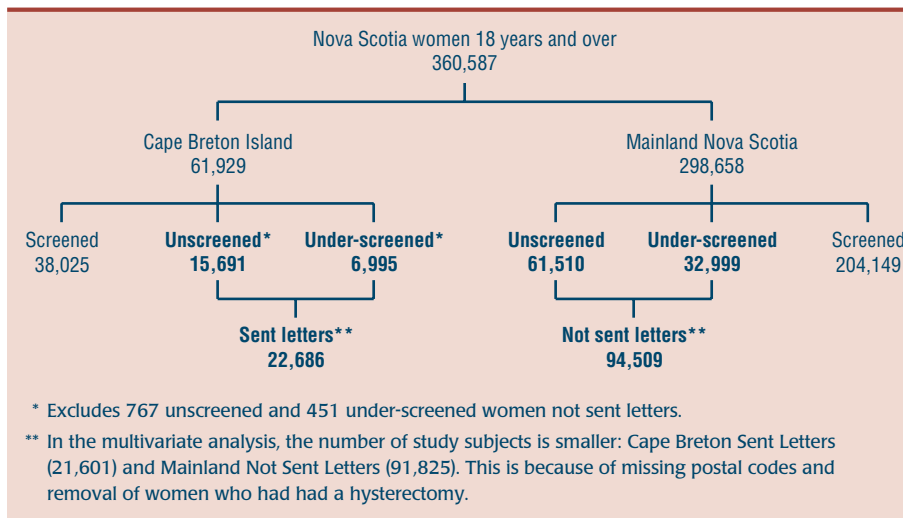


**FIGURE 1**  
Cervical cancer incidence and mortality, Cape Breton Island, mainland Nova Scotia and Canada, 1971–1999



\* Since postal and county codes are not available in the mortality database prior to 1992, mortality rates for Mainland Nova Scotia and Cape Breton cannot be reported.

**FIGURE 2**  
Study subjects



The MMC database is believed to be an accurate source from which to identify women living in the province. MMC carries out a weekly death clearance of its HCN file using electronic Vital Statistics death registrations. Names are also removed if people do not

renew their HCNs upon notification of expiry. The accuracy of the HCN database is supported by the fact that the 1996 Statistics Canada census shows a comparable number (360,450) of Nova Scotia women aged 18 years and over.

MMC linked the HCN and the PCR databases to identify the screening status of all women in Nova Scotia. *Unscreened* women were defined as those having had no Pap smear recorded in the PCR from January 1988 to their letter mailing date. *Under-screened* women had had one or more Pap smears recorded between January 1988 and December 1994 but none recorded from January 1995 to the letter mailing date. *Screened* women had had one or more Pap smears recorded between January 1995 and the letter mailing date.

Letters were sent to Cape Breton women who were unscreened (15,691) and under-screened (6,995). Mainland Nova Scotia women who were unscreened (61,510) and under-screened (32,999) were the controls and were therefore not sent letters (Figure 2). The date on which a letter would have been sent if the woman had been in the letter intervention group was used to define the screening status of control group women. Age was used as a proxy to identify this date (Table 1).

During data validation prior to data analysis, an additional control group was defined when 1,218 under-screened and unscreened Cape Breton women aged 34, 54, 55 and 64 were identified as never having had letters sent to them. This unanticipated natural experiment was used to validate the main study findings.

All women were tracked in the PCR to determine whether they had a *subsequent Pap smear*, which was defined as the first Pap smear performed within six months after the letter mailing date, or the age-related date for the controls.

### Mailing the letters

MMC sent the letters in six mailings based on the age group of the women. The sizes of the age groups were selected to stagger the additional workload created for physicians and laboratories as a result of the letter intervention. The first mailing, in June 1998, was sent to under-screened and unscreened women aged 25, 45, 65 and 85 years in Cape Breton to provide a measure of the response in terms of subsequent smear rates by age and to plan the mailing of the remaining letters.

**TABLE 1**  
**Validation of age as a proxy for mailing date: Cape Breton mailing dates**  
**to previously under-screened and unscreened women by age group**

Age	Letter date						No letter*
	June 15, 1998	November 23, 1998	December 15, 1998	January 28, 1999	March 2, 1999	April 8, 1999	
25, 45, 65, 85	1,406	0	0	7	1	9	11
35-44	0	3,109	3	2	1	0	302
46-54	0	2	2,634	0	2	2	608
18-24, 26-34	0	3	1	4,103	0	0	285
55-64	0	2	4	0	2,759	5	777
66-84, 86+	0	3	1	1	3	8,595	187

\* Includes the 1,218 women aged 34, 54, 55 and 64 who were controls in addition to women who were not sent a letter because they had had a complete hysterectomy.

The letters were addressed to individual women, asking them to make an appointment with their family physician or other appropriate service to have a Pap test. An information brochure about Pap smears was enclosed. A postage-paid envelope and tear-off reply were provided for the women to indicate why they did not think they needed a Pap smear, to ask questions or raise concerns. If a woman had questions about Pap tests or the letter, she was advised that she could also contact her physician or a public health nurse, or could call a toll-free number provided. The letter was signed by the medical director of the GCSP and the president of the provincial medical association. The letter was in English only; a needs assessment determined that having the letter in French or another language was not needed in Cape Breton.

Information obtained from the first mailing, in June 1998, indicated that having had a hysterectomy was a common reason for not attending for a Pap smear. Therefore, in the remaining five mailings, from November 1998 to April 1999, letters were not sent to women who had had a complete hysterectomy, as identified by linkage to provincial physician billing claims from April 1988 to the letter mailing date, and to records of hysterectomy available before 1988.

### **Validation steps**

After the first mailing, 197 women who had been sent a letter but did not have a Pap smear in the subsequent six months

were contacted by telephone to verify that the letters had been received and understood.

After all the letters had been mailed, MMC returned a file identifying all 360,587 women to the GCSP for data analysis. Mailing dates were verified by comparing cancellation stamp dates on letters returned to the GCSP to letter-sent dates in the MMC database. Letter tear-off replies that were received were tabulated. To verify that age was a good proxy for mailing date, a table of age group by mailing date was prepared.

Since there is a lag time in the PCR receiving Pap smear results, in November 1999, before data analysis, the screening histories were re-checked in the PCR database. Women were re-coded as screened if they had had a Pap smear after January 1, 1995, and before their letter mailing date or proxy mailing date for controls.

### **Study outcome and covariate measures**

The major study outcome or dependent variable investigated was having a subsequent Pap smear after a letter. A secondary outcome was detection of a cervical cell abnormality on a subsequent Pap smear. An abnormality was defined as any Pap smear result with a PCR code other than negative or unsatisfactory. The goal of gynecological screening is the early detection of cell abnormalities to enable early treatment and prevent the development of invasive malignancy. Thus, both increas-

ing the screening rates and taking into account any changes in the rates of detection of abnormalities are important in the evaluation of a screening intervention. The intervention cost was calculated in relation to each additional smear and abnormality detected.

Predictors of the outcomes were investigated. As described already, previous screening status was defined as of the letter mailing date (Table 1). The women's ages were computed as of December 31, 1997, from birth dates provided by MMC. MMC postal codes were classified as urban or rural by Canada Post. Statistics Canada conversion tables were used to link postal codes to census enumeration areas (EAs). These EAs were then linked to the 1996 Statistics Canada census data to create community demographic measures for each woman. Using ecological proxies introduces a conservative bias to the analysis – actual covariate associations may be underestimated when aggregate data for EAs are used as a surrogate for data at the level of the individual woman.<sup>16,17</sup>

Since median household income for native reservations was unavailable in 1996 census reports, the mean income for females aged 15 years and older in an EA was used. Income cut points were chosen to give an approximately equal number of Nova Scotia women in three income groups ( $\leq$  \$12,500 per annum for low income, between \$12,500 and \$17,500 for middle income and  $\geq$  \$17,500 for high income).

Studies have shown low rates of cervical cancer screening among Black and Aboriginal women.<sup>18,19</sup> The Aboriginal people in Nova Scotia are heavily concentrated on a few reservations. At least two-thirds of the population of reservation EAs were Aboriginal, whereas no other EA had more than one-third. Hence, a woman in our study was considered to be from an Aboriginal community if she resided in a community with a majority Aboriginal population. Although there are more Black than Aboriginal residents of Nova Scotia, Black people are more dispersed. No Cape Breton EA had more than 15% of Black residents. A woman was coded as being from a Mixed community if her EA was at least 10% Black, and was considered to be from a Francophone community if at least 50% of the residents of her EA had French as their mother tongue.

Two-dimensional cross-tabulations and chi-square statistics were used in the univariate analyses. Logistic regression was used to describe multivariate associations. Across the province, 4,025 women (1.1%) did not have a postal code in the MMC database. Using the provincial hospital separations database from April 1992 to March 1998, 8,663 Nova Scotia women were identified as having had a hysterectomy. Those who had had a hysterectomy and those with a missing postal code were excluded from the regression analyses reported.

## Results

### Validation steps

From the telephone survey of the 197 randomly selected women conducted after the first mailing, there were no misunderstandings and few concerns regarding the intent of the letter. The women felt that the letter was a great idea for others, but they were too busy to obtain a Pap smear, did not like having a Pap smear or did not feel they needed one.

To verify that age was a good proxy for the mailing date, a table of age groups by mailing date was prepared for the Cape Breton under-screened and unscreened women. A 99.8% match was found (Table 1).

Cancellation stamp dates were used to verify the letter mailing dates provided by MMC. Letters were actually mailed up to

nine days after the date provided by MMC. Therefore, a correction was made in the MMC mailing date before data analysis.

Of the 22,686 letters mailed, 594 replies (2.6%) indicated that the woman had moved or the address was incorrect, and 38 (0.2%) reported that the woman was deceased. There was no upper age cut-off in the mailing, so many elderly women received letters.

One hundred and twenty-five women were sent a letter by MMC but were coded in the final study data set as Cape Breton screened (37), or mainland screened (50), under-screened (13) or unscreened (25). In the analysis of subsequent smears, these 125 women were removed. Sending letters to 37 Cape Breton screened women probably resulted from a failure to receive all Pap smears in a timely manner before linkage and mailing. The mainland women probably moved from Cape Breton to the mainland between the time that MMC had them listed as a Cape Breton resident and the date that MMC released the study dataset for analysis.

### Subsequent smears

Table 2 gives subsequent smear rates by demographic characteristics. Women who received a letter were more likely to get a Pap smear (odds ratio [OR] = 1.64) than women who did not get a letter (Table 3). Previously unscreened women were less likely than previously under-screened women to get a Pap smear (OR = 0.54). Subsequent smears were inversely associated with age. Residing in a community with a female income of over \$17,500 was associated with an increased likelihood of getting a subsequent Pap smear (OR = 1.13). Language, ethnic group and urban/rural status had no statistically significant relation to the probability of getting a subsequent Pap smear. Sensitivity analysis showed that removal of the study subjects who had had a complete hysterectomy resulted in negligible impact on the multivariate odds ratios.

Using the tear-off reply, women indicated the reasons why they did not get a Pap smear after receiving a letter. Six hundred and forty-eight women (2.9%) said that they had had a hysterectomy. Some of these indicated that they were uncertain

whether they required a Pap smear or not; we were not able to determine whether they had had subtotal or total hysterectomies. One hundred and seventy-six (0.8%) stated that they had had a recent Pap smear; for 150 of these (85%), smears were found in the PCR. Other replies were from 47 who said that they were too old; 24 were too impaired, e.g., with Alzheimer's, multiple sclerosis, mental retardation, were in a nursing home or would require a general anesthetic; nine had never been sexually active; and three had no family physician. These women were not removed from the analysis since their equivalents in mainland NS could not be identified and their removal had little impact; the subsequent smear rate in Cape Breton among under-screened and unscreened women increased by 0.06% with their removal.

Many women indicated that they planned to have a Pap smear. For some, a Pap smear was reported more than six months after receiving a letter. Of the 22,686 letters sent, only four replies expressed negative comments; thanks were expressed in 29 tear-off replies.

### Abnormal smear rate

The purpose of screening is the early detection and treatment of abnormal cells to prevent the development of invasive malignancies. Along with increasing the screening rate, it is important, therefore, to consider differences in rates of detection of abnormal smears in a complete assessment of the impact of the letter intervention. Table 4 gives abnormal smear rates among the subsequent smears for previously unscreened, under-screened and screened women. Among Nova Scotia women, having an abnormal smear was significantly associated with having been screened (OR = 1.61) or with being unscreened (OR = 1.62) versus having been under-screened, being younger than 40 versus 40 to 59 years (OR = 1.74), having low income (OR = 1.80) and rural residence (OR = 1.48) (Table 5). Being from a predominantly French area decreased the risk of an abnormal smear (OR = 0.34). The letter intervention increased the abnormal smear rate (OR = 1.31), but this was not statistically significant ( $p = 0.26$ ).

**TABLE 2**  
**Subsequent Pap smear rates: percentage of Nova Scotia women who had a smear within six months of actual or proxy letter mailing date by previous screening status and demographic characteristics**

Factor	Level	Screened		Under-screened*		Unscreened*	
		Cape Breton (no letter) <i>n</i> = 38,025	Mainland (no letter) <i>n</i> = 204,149	Cape Breton (letter) <i>n</i> = 15,691	Mainland (no letter) <i>n</i> = 32,999	Cape Breton (letter) <i>n</i> = 15,691	Mainland (no letter) <i>n</i> = 61,510
Age	≤ 29	29.8	33.8	14.9	10.4	10.5	9.5
	30–44	28.0	29.9	13.8	8.5	7.4	5.8
	45–59	24.4	26.1	12.5	7.1	6.5	3.6
	60–74	18.5	20.7	9.9	4.8	3.1	2.0
	≥ 75	8.6	11.9	4.3	2.1	1.1	0.7
Residence	Rural	25.6	27.6	11.3	6.5	5.3	3.0
	Urban	26.1	29.7	11.4	6.6	4.4	4.5
Income	≤ \$12,500	25.2	27.4	10.9	6.6	5.6	3.1
	\$12,500–17,500	26.1	28.2	11.5	6.6	4.7	3.2
	≥ \$17,500	26.5	29.6	13.1	6.5	5.4	4.6
Aboriginal community	< 50% Aboriginal	25.9	28.6	11.2	6.6	5.0	3.6
	≥ 50% Aboriginal	22.9	25.6	19.0	1.8	5.7	7.5
Mixed community	< 10% Black	25.9	28.6	11.5	6.5	5.0	3.6
	≥ 10% Black	24.1	28.4	7.8	6.5	4.9	3.9
French community	< 50% French	25.7	28.5	11.5	6.6	5.1	3.7
	≥ 50% French	28.6	32.2	9.7	6.3	4.6	2.0

\* The 1,218 under-screened and unscreened Cape Breton women aged 34, 54 55 and 64 who did not receive a letter are omitted, since their percentages need to be interpreted in the context of their small cell counts.

**TABLE 3**  
**Logistic regression analysis of Pap smears among previously under-screened and unscreened Cape Breton (CB) women following a letter intervention, as compared with no intervention**

Factor	Level	CB letters ( <i>n</i> = 21,601) versus mainland no letters ( <i>n</i> = 91,825) odds ratio (95% confidence interval)	CB letters ( <i>n</i> = 21,601) versus CB no letters ( <i>n</i> = 1,218) odds ratio (95% confidence interval)
Letter intervention	No	1.00	1.00
	Yes	1.64 (1.53–1.74)	1.69 (1.39–2.07)
Previous screening status	Unscreened	0.54 (0.51–0.57)	0.48 (0.43–0.53)
	Under-screened	1.00	1.00
Age (years)	18–29	9.30 (8.20–10.54)	6.98 (5.51–8.83)
	30–44	5.83 (5.14–6.61)	5.09 (4.02–6.43)
	45–59	4.50 (3.96–5.10)	4.38 (3.47–5.54)
	60–74	2.66 (2.33–3.04)	2.74 (2.15–3.48)
	≥ 75	1.00	1.00
Income	≤ \$12,500	1.00	1.00
	\$12,500–\$17,500	0.98 (0.91–1.05)	0.96 (0.85–1.07)
	≥ \$17,500	1.13 (1.04–1.24)	1.13 (0.92–1.38)
Aboriginal community	< 50% Aboriginal	1.00	1.00
	≥ 50% Aboriginal	1.01 (0.79–1.30)	1.10 (0.84–1.45)
Mixed community	< 10% Black	1.00	1.00
	≥ 10% Black	0.95 (0.82–1.11)	0.81 (0.53–1.26)
French community	< 50% French	1.00	1.00
	≥ 50% French	0.88 (0.73–1.06)	0.93 (0.72–1.20)
Urban/rural status	Urban	1.05 (0.98–1.11)	0.98 (0.88–1.10)
	Rural	1.00	1.00

**TABLE 4**  
**Percentage of abnormal smears by geographic area and**  
**previous screening status (*n* = 360,587)**

Previous screening status	Cape Breton	Mainland NS
Unscreened	3.92	1.92
Under-screened	1.25	1.27
Screened	2.03	1.51

**TABLE 5**  
**Logistic regression analysis of factors associated with abnormal smears among**  
**women in Nova Scotia (*n* = 70,263)**

Factor	Level	Odds ratio (95% confidence interval)
Letter intervention	No	1.00
	Yes	1.31 (0.82–2.07)
Previous screening status	Screened	1.61 (1.09–2.37)
	Under-screened	1.00
	Unscreened	1.62 (1.03–2.52)
Age (years)	18–39	1.74 (1.40–2.14)
	40–59	1.00
	≥ 60	1.15 (0.86–1.55)
Income	≤ \$12,500	1.80 (1.49–2.18)
	\$12,500–\$17,500	1.39 (1.19–1.62)
	≥ \$17,500	1.00
Aboriginal community	< 50% Aboriginal	1.00
	≥ 50% Aboriginal	0.94 (0.46–1.91)
Mixed community	< 10% Black	1.00
	≥ 10% Black	0.92 (0.65–1.31)
French community	< 50% French	1.00
	≥ 50% French	0.34 (0.20–0.60)
Urban/rural status	Urban	1.00
	Rural	1.48 (1.29–1.70)

### Cost-benefit

The overall subsequent Pap smear rate among previously unscreened and under-screened mainland women was 4.6%. The rate among women receiving letters in Cape Breton was 6.9%. This implies that there were 508 additional smears obtained from hard-to-reach Cape Breton women as a result of the letter intervention. This estimate is conservative, since historically Cape Breton rates were lower than mainland Pap smear rates.

Each Pap smear was estimated to cost \$27.91 for each normal smear and \$31.68 for each abnormal smear; abnormal smears are reviewed by a pathologist, which increases the cost. The total letter intervention cost, including the database linkage, postage, stationery, receipt of the tear-off returns, as well as physician and laboratory time for the extra smears, was estimated to be \$69,497 or \$2.42 per letter. The cost per letter would be lower if all unscreened and under-screened women in

the province were sent letters, and these mailings became an ongoing process. The costs of follow-up colposcopy and treatment were not determined. The letter intervention cost less than \$140 per additional smear obtained, or \$6,950 per abnormality detected early by screening, given that 1.94% of smears were abnormal.

### Discussion

The gold standard design for evaluating an intervention is the randomized controlled trial. A double blind placebo letter intervention trial was not possible. Women would know whether or not they received a letter asking them to go for a Pap smear. An unblinded randomized trial was possible. However, it was not possible to ascertain any contamination effect of women in communities who received letters discussing their letters with other women who had not received a letter or with their physicians, who would be caring for both intervention and control women. Therefore, a geographically defined cohort design was used.

The intervention and control cohorts were selected so that the study findings would be a conservative estimate of any actual difference. Historically, the women in Cape Breton, where the intervention occurred, were less likely to go for screening than mainland women. Thus any difference observed between the responses of Cape Breton women receiving a letter asking them to get a Pap smear in comparison to mainland women who did not get a letter was likely to underestimate the actual impact of the letter intervention.

The study findings were validated by an unanticipated “natural experiment”. Unscreened and under-screened Cape Breton women aged 34, 54, 55 and 64 were not sent letters, as planned in the design. When the subsequent smear rates for these women were compared with those of the Cape Breton women receiving a letter, the findings were essentially the same as those found in the primary comparison of mainland women not sent letters (Table 3).

The study findings were compared with the findings reported for other geographic areas. The magnitude of increased screen-



ing among under-screened and unscreened Cape Breton women who received letters was similar to the increase reported by others.<sup>7,11,13,14</sup> As in other studies, the Nova Scotia study demonstrates that obtaining a subsequent smear varies inversely with age, is greater for under-screened than unscreened women and increases with income. Further comparison is not straightforward for many reasons, such as differences in age groups;<sup>7,9-11</sup> inclusion of women who have had hysterectomies<sup>7,9,11,13</sup> or not;<sup>10,12,14</sup> and method of determining Pap smear histories, e.g., central registries,<sup>7,14</sup> HMO databases,<sup>9</sup> physician practice registers,<sup>10</sup> self-report<sup>12</sup> and health insurance claims.<sup>13</sup> Definitions of unscreened and under-screened vary.<sup>7,10,13</sup> Studies may include invitations to women regardless of screening status.<sup>11</sup> There is also variation in follow-up time for the intervention.<sup>7,10-14</sup>

Unique contributions of our research are the inclusion of an analysis of community ethnicity and language as well as identification of factors associated with abnormal smear rates. Lower screening rates have been reported in North America among women from Black and Aboriginal communities and among women whose first language differed from the main language used in screening programming and promotion. However, the question remained regarding how these subgroups of women respond to a formalized, personal letter asking them to get a Pap smear. Our results show that their subsequent smear rates are similar to those of other women of the same age, income and prior screening history.

Abnormal smears were detected more frequently among women who had received a letter (OR = 1.31), although this was not statistically significant. Prior screening history (screened or unscreened versus under-screened), being younger, having a lower income and living in a rural community were all associated with an increased risk of detection of an abnormal smear. The association between being screened and a higher rate of abnormal smears is explained by the fact that all Pap smears are included in this analysis: diagnostic, follow-up, symptomatic and asymptomatic screening. When other factors were controlled for, women in Aboriginal and Mixed

communities did not have significantly higher rates of abnormal smears. The significantly lower rate of abnormalities detected among women from Francophone communities was not anticipated. We may have something to learn from these Acadian communities regarding cervical cancer prevention.

While it is easier to prompt under-screened than unscreened women to attend for a Pap smear using a letter of invitation, the yield in terms of greater detection and opportunity for early treatment to reduce the rate of invasive disease may well be greater among the unscreened than under-screened women. The two groups require different strategies. Unscreened women need to get a first screen. For women who lapse in their screening practices, the most cost-effective interval between Pap smears must be determined.

The one-time Nova Scotia letter intervention had some impact. However, letters signed by patients' physicians have been shown to be more effective than "anonymous" letters.<sup>12</sup> Other studies have also demonstrated additional benefits with the use of enhancements.<sup>9-11</sup>

Other interventions (peer educators, physician practice profiles, nurses trained to do Pap testing) were developed and piloted in Cape Breton after the letter intervention and so did not influence the letter intervention findings reported here, but they have the potential to further improve screening rates. An exception was peer education outreach in the Aboriginal communities, which occurred concurrently with the letter intervention. However, the number of women reached during the time of the study reported here was limited. Publicity surrounding the three-year Health Canada project may have had some impact, but this was not likely substantial since previously screened women in Cape Breton had a subsequent Pap smear rate (24.3%) that remained lower than in the mainland (26.7%).

The letters were accepted and valued by Cape Breton women, as has been found elsewhere.<sup>20</sup> Ronco et al.<sup>21</sup> defined an organized program as one in which personal invitations are routinely sent. In Finland, reminder letters are sent every five years to eligible women aged 30 to 60 years.<sup>22</sup> The

findings reported here provide information to enable further development of letters of invitation processes in combination with other interventions to improve Pap smear screening in Canada and other countries.

The goal of a good Pap smear screening program is to find and effectively treat pre-invasive (i.e., abnormal) cases.<sup>23</sup> Knowing both screening and abnormal smear rates helps target screening interventions and, conversely, may justify extending the screening interval for women at lower risk of abnormal smears. Cervical cancer is preventable if detected early, but one in three women will die of the disease if it is not detected and treated at the pre-invasive stage. The authors believe that the mailing of letters to unscreened and under-screened women, ideally signed by the woman's own physician, is worth the cost incurred to save the lives of women. We also conclude that multiple, continuous interventions, including letters to women, physician practice profiles, nurse service providers and community educators, are needed to further improve the Pap smear rates of hard to reach women in Nova Scotia.

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# Deprivation and stroke mortality in Quebec

Jérôme Martinez, Robert Pampalon and Denis Hamel

## Abstract

*Stroke is an important cause of disability and death in Quebec. Among the primary risk factors for stroke, certain socioeconomic characteristics of individuals and living environments appear to play a central role. The purpose of this article is to examine the links between material/social forms of deprivation and stroke mortality in a group of 4,339 individuals aged 25 to 74 years who died between 1994 and 1998. The socioeconomic profile of these persons was estimated on the basis of the enumeration area in which they resided. The Poisson regression technique was used to estimate the relative risk (RR) of mortality by deprivation level. Our results show the presence of a mortality gradient for both material and social forms of deprivation, where the relative risks of mortality of the most disadvantaged group and the most advantaged group are, respectively, 1.34 and 1.35. Despite the existence of a system of universal health care, inequalities in mortality persist and need to be taken into account when implementing intervention programs.*

**Key words:** access to health care; deprivation; mortality; Quebec; social inequalities; stroke

## Introduction

Stroke is one of the primary causes of death around the world,<sup>1</sup> as well as in Canada,<sup>1-3</sup> and ranks as the third cause of death in Quebec.<sup>4</sup> It is also one of the primary causes of hospitalization, costing Canada close to 2.8 billion dollars in 1993<sup>2</sup> and resulting in 20,000 hospitalizations each year in Quebec. Stroke therefore represents a major burden on society, particularly since it results in significant and sometimes very severe forms of incapacity and disability in half of its victims.<sup>5,6</sup> Although stroke mortality has decreased in recent years,<sup>2,4</sup> it nonetheless remains a major health problem, one which will only be accentuated in our aging population.<sup>7,8</sup>

People do not suffer strokes by chance: we now know that numerous risk factors come into play. Age is recognized as a major factor,<sup>2,3,5,9,10</sup> since approximately three-quarters of all strokes occur in persons aged 65 or more. Due to their longer life expectancy, women experience more

strokes than men, but men have a greater chance of being affected at every age.<sup>4</sup>

Certain physiopathological factors such as hypercholesterolemia, diabetes, obesity, hypertension, atherosclerosis and a history of cardiovascular disease (CVD) are also associated with strokes.<sup>1-3,5,9-15</sup> In many cases, these factors are linked to lifestyle habits and specific behaviours, such as smoking, alcoholism, poor dietary habits, and inactivity. The influence of these factors on stroke incidence and mortality rates is widely recognized around the world.<sup>1-3,9,11-18</sup>

There is also an association between stroke and a number of factors connected with the health system. For example, some studies have demonstrated that access to care (as in specific diagnostic techniques such as tomography and angiography), as well as wait times and the length of hospital stays, may be associated with stroke incidence, severity and mortality.<sup>19-24</sup>

Many of these factors, such as unhealthy lifestyle habits and poor quality health services are linked – through complex mechanisms and processes which are still obscure – to the socioeconomic conditions in which deprived persons live. Numerous social and health surveys conducted in Quebec and elsewhere have shown higher levels of tobacco and alcohol consumption and lower levels of regular physical activity among socioeconomically deprived individuals who live in disadvantaged environments.<sup>25-31</sup> The effect of certain demographic, economic, and social characteristics on hospitalization wait times and, as a consequence, on the severity of illness in stroke patients has also been demonstrated.<sup>19-24</sup> Other studies have demonstrated the effect of these same characteristics on access to care, the quality of medical follow up, the type of treatment given,<sup>6,24,32,33</sup> the length of hospital stays, and the level of functional and cognitive recovery in stroke patients.<sup>6,34-36</sup>

Thus, the socioeconomic characteristics of individuals and their living environments, both in childhood and adulthood,<sup>37-41</sup> are generally recognized as factors which influence health in general,<sup>29,42-46</sup> as well as CVD<sup>37,41,47-51</sup> and stroke<sup>12,16,39,40,52-59</sup> risks in particular. The characteristics most commonly associated with higher stroke incidence and mortality rates include low income, lack of education, and being a member of an unskilled socio-occupational category. It has also been observed that strokes tend to be more severe and are associated with a higher rate of mortality in persons who live alone and are socially isolated, since such persons are less able to call for and obtain the assistance they need in a timely manner.<sup>12</sup>

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A number of studies have uncovered highly specific territorial variations in stroke incidence and mortality. In the United States, for example, eleven south-western states form what is commonly referred to as the "Stroke Belt."<sup>60-62</sup> In the United Kingdom, the northern and north-western regions of Wales experience higher mortality rates than does the south-east,<sup>40</sup> whereas in Scotland, mortality rates are lower in rural areas than in urban centres.<sup>63</sup> The reasons for these territorial disparities are still not fully understood, but demographic, socioeconomic, and lifestyle differences, as well as disparities in access to care between rural and urban areas, are thought to play a role.<sup>56</sup>

In short, numerous factors can influence stroke incidence, severity and mortality. Of these, demographic and socioeconomic characteristics appear to play a key role, either directly or indirectly through lifestyle and certain characteristics of the health care system.

In this study, we will examine in greater detail the links between socioeconomic conditions and stroke mortality in Quebec. The province plans to develop a surveillance system which will enable it to estimate stroke incidence, prevalence and survival, as well as gain a better understanding of stroke risk factors, and establish the service consumption profiles of persons who suffer them.<sup>64</sup> This study will be the first in a series of initiatives which are intended to address the links between socioeconomic conditions and stroke.

Our study is the first in Quebec and the third in Canada to deal specifically with socioeconomic conditions and stroke mortality. It uses an index which distinguishes between two forms of deprivation, namely material and social deprivation, whereas earlier studies on this topic have emphasized the material dimension, in the form of income and socio-occupational status.<sup>24,37,45,46,49,52,53,61</sup> This index, which is of an ecological nature, rests on a territorial scale which is more finely calibrated than those normally used in the literature and therefore provides a more accurate estimate of deprivation.

## Data and methods

### Deprivation index

The theoretical and methodological underpinnings of the deprivation index used in this study are derived from the ideas and work of P. Townsend<sup>65</sup> and from the abundant literature on the links between socioeconomic conditions and health. For Townsend, deprivation comprises two dimensions: the material and the social. The first refers to deprivation of the goods and conveniences of everyday life; the second to the fragility of social networks, from the family to the community.

The index is based on a microgeographic unit, namely the enumeration area (EA).<sup>66</sup> This is statistically the smallest census unit (750 persons, on average<sup>a</sup>) and is homogeneous from a socioeconomic standpoint. Another far from negligible advantage of using EAs is that they can be linked to the postal code zones which are recorded on all health records in Quebec, thus making it possible to estimate the deprivation level of stroke victims. However, not all EAs were considered when developing the index. Excluded were sparsely populated EAs (fewer than 250 persons), EAs corresponding to multiple housing – health care facilities in particular – and EAs located in the northern regions of Kativik and Terres-Cries-de-la-Baie-James. Accordingly, the deprivation index covers 96% of the Quebec population, or close to 7 million residents.

The index incorporates six indicators corresponding to two distinct dimensions – the material and the social – which were obtained through principal component analysis (by applying Varimax rotation to ensure a measure of independence between the dimensions). This type of analysis makes it possible to group within a single dimension the indicators for which variations at the EA level are relatively similar, as well as to distinguish, across more than one dimension, the indicators in which variations follow a different profile. The material dimension primarily reflects variations in the proportion of persons who do not have a high-school diploma, as well as variations in employment/popula-

tion ratios and average income, while the social dimension reflects variations in the proportion of persons who are separated, widowed or divorced, who live alone or in single-parent families. All of these indicators (except for the proportion of single-parent families) have been adjusted for population age and sex, in order to even out any disparities between enumeration areas with respect to these characteristics.

For both dimensions, the Quebec population was distributed into deprivation quintiles (groups of 20%), ranging from the most advantaged (quintile 1) to the most disadvantaged (quintile 5). Since the two dimensions are relatively independent of each other from a statistical standpoint, the Quebec population can be distributed anew by cross-tabulating the quintiles in order to determine which population group is the most advantaged (quintiles 1 and 1) and most disadvantaged (quintiles 5 and 5) in material and social terms, as well as those which occupy a position somewhere between the two extremes. In Quebec, each deprivation quintile comprises close to 1,400,000 persons and cross-tabulation of the quintiles corresponds, on average, to 280,000 persons (minimum: 223,000 and maximum: 325,000). The most deprived population in both material and social terms comprises 325,000 persons and the least deprived is composed of 315,000.

### Mortality

All stroke deaths (ICD9: 430 to 438) in persons aged 25 to 74 years which occurred between 1994 and 1998 are included in our analysis (Table 1). This age group constitutes a public health intervention target since mortality in this category is considered to be avoidable, at least in some cases.<sup>67-70</sup> In Quebec, approximately 30% of all stroke deaths occur in this age group.

A material and social deprivation quintile was attributed to 86% of all deceased persons in this group (Table 1). This percentage diminishes slightly with age, particularly in women, a fact which is linked to the significant number of seniors who reside in long-term care facilities (LTCFs) and seniors' residences. Statistics Canada does not produce certain socioeconomic data for enumeration areas which correspond to these facilities.

<sup>a</sup> This is the average population of the enumeration areas considered in developing the deprivation index.



**TABLE 1**  
**Stroke deaths in persons aged 25 to 74 years,**  
**with deprivation index, by age and sex, Quebec, 1994 to 1998**

Sex	All deaths	With deprivation index	
Age	<i>n</i>	<i>n</i>	%
<b>Men</b>			
25–44 years	163	144	88.3
45–54 years	274	244	89.1
55–64 years	620	545	87.9
65–74 years	1,760	1,489	84.6
<b>Total</b>	<b>2,817</b>	<b>2,422</b>	<b>86.0</b>
<b>Women</b>			
25–44 years	169	156	92.3
45–54 years	262	246	93.9
55–64 years	417	378	90.6
65–74 years	1,361	1,137	83.5
<b>Total</b>	<b>2,209</b>	<b>1,917</b>	<b>86.8</b>

According to statistics provided by the Ministère de la Santé et des Services sociaux,<sup>71</sup> approximately one quarter of all LTCF residents are between 25 and 74 years of age, whereas the annual number of deaths among these residents corresponds to slightly more than 8% of all deaths in the aforementioned age group. In fact, it is likely that the contribution of LTCF residents to stroke deaths in persons between the ages of 25 and 74 is greater still, since stroke sequelae are an important factor associated with LTCF stays.<sup>72</sup> The ability to assign a deprivation index on the basis of cause of death gives added credence to this assertion. Although 14% of individuals between the ages of 25 and 74 who died as a result of a stroke could not be assigned a deprivation index, the percentage of persons who died from other causes and to whom no deprivation index could be applied was 10%.

In addition to the deprivation index values, the age, sex and area of residence of stroke victims were also taken into account. Area of residence refers to four major geographic areas: the Greater Montreal area, the other metropolitan areas of Quebec, average size cities (10,000 to 100,000 inhabitants), and small towns and rural communities (fewer than 10,000 inhabitants). Age and sex are important stroke risk factors, whereas the area of residence can be

associated with variations in deprivation and also reflects, at least in part, access to specialized hospital and medical resources, which is another stroke-associated factor.

### Analysis strategy

Relative risks (RRs) of mortality were calculated with the aid of the Poisson regression modelling technique<sup>b</sup> for each material and social deprivation quintile. RR is adjusted to account for differences in age, sex and area of residence (in categorical form) between the persons in each quintile. The reference group is the most advantaged quintile; consequently, its RR is set at 1.00. The value of the other quintiles expresses the relative risk of mortality of these quintiles in relation to the most advantaged quintile. For example, an RR of 1.30 indicates that the mortality rate for the quintile in question is 30% higher than that of the reference group. Similarly, to estimate the combined effect of the material and social dimensions of deprivation on mortality, it is necessary to multiply the RR associated with one dimension by the RR of the other dimension, since the Poisson regression model is multiplicative from the standpoint of RR.

<sup>b</sup> The Poisson regression technique was performed with the aid of the SAS GENMOD procedure.

Since the goal of this study is to demonstrate the role of deprivation in stroke mortality, a four-part modelling strategy was adopted:

- A model adjusted for age and sex, designed to estimate the separate impact of the two forms of deprivation (Models 1 and 2).
- A model adjusted for age and sex, designed to estimate the impact of each form of deprivation, while taking into account the other form of deprivation (Model 3).
- A model adjusted for age, sex and area of residence (Model 4).
- A final model, adjusted for age, sex and area of residence, which takes into account interactions between variables (Figure 1).

Certain double interactions between variables were examined, one example being those linking sex with other variables and those linking the two forms of deprivation. The resulting final model is, in our view, the one which most accurately summarizes the link between deprivation and stroke mortality.

## Results

The number of stroke deaths is generally higher among men than women in the various age groups (Table 1) and relative risk confirms this (Table 2, Model 1; RR = 1.47). Age-related growth in the number of deaths and in the mortality rate is quite marked: the risk of death in the 65–74 age group is 30 times higher than in the 25–44 age group.

Beyond any differences observed with respect to age or sex, belonging to the most materially disadvantaged group increases the risk of dying of a stroke by approximately 40% relative to the most advantaged group (Table 2, Model 1). A similar discrepancy in mortality risk (albeit a slightly smaller one at 30%) can be observed with respect to social deprivation (Table 2, Model 2). When both forms of deprivation (material and social) are considered at the same time in relation to stroke mortality, the contribution of each form of deprivation changes little and

**TABLE 2**  
**Relative risk of death (RR) and confidence interval (CI) in persons aged 25 to 74 years,**  
**by age, sex, material and social deprivation and region, Quebec, 1994–1998**

Indicator <sup>a</sup>	Model 1		Model 2		Model 3		Model 4	
	RR	CI (95%)	RR	CI (95%)	RR	CI (95%)	RR	CI (95%)
<b>Sex</b>								
Men	1.47	1.38–1.56	1.49	1.40–1.58	1.48	1.39–1.58	1.48	1.40–1.58
Women	1.00	–	1.00	–	1.00	–	1.00	–
<b>Age</b>								
65–74 years	33.71	29.91–37.99	33.60	29.80–37.86	33.40	29.63–37.64	33.18	29.43–37.40
55–64 years	9.73	8.53–11.08	9.75	8.55–11.11	9.76	8.56–11.11	9.72	8.52–11.07
45–54 years	3.90	3.37–4.50	3.89	3.37–4.50	3.93	3.40–4.54	3.92	3.39–4.53
25–44 years	1.00	–	1.00	–	1.00	–	1.00	–
<b>Material deprivation</b>								
Quintile 5 (disadvantaged)	1.40	1.27–1.54			1.40	1.27–1.54	1.34	1.21–1.49
Quintile 4	1.32	1.19–1.46			1.31	1.18–1.44	1.27	1.14–1.41
Quintile 3	1.27	1.14–1.40			1.26	1.14–1.40	1.24	1.12–1.37
Quintile 2	1.13	1.02–1.25			1.13	1.02–1.25	1.12	1.00–1.24
Quintile 1 (advantaged)	1.00	–			1.00	–	1.00	–
<b>Social deprivation</b>								
Quintile 5 (disadvantaged)			1.31	1.18–1.45	1.30	1.18–1.44	1.34	1.21–1.49
Quintile 4			1.16	1.04–1.28	1.16	1.05–1.29	1.19	1.07–1.32
Quintile 3			1.08	0.98–1.20	1.09	0.98–1.21	1.10	0.99–1.22
Quintile 2			1.01	0.91–1.12	1.01	0.91–1.13	1.01	0.91–1.13
Quintile 1 (advantaged)			1.00	–	1.00	–	1.00	–
<b>Region</b>								
Greater Montreal CMA <sup>b</sup>							0.91	0.83–0.99
Other CMAs							0.96	0.87–1.07
Medium-sized cities							0.97	0.87–1.09
Small towns and rural areas							1.00	–

<sup>a</sup> All indicators are statistically significant ( $p < 0.01$ ) except the region ( $p = 0.1143$ ).

<sup>b</sup> Greater Montreal census area; CMAs: other Quebec census metropolitan areas.

remains statistically significant (Table 2, Model 3).

On the other hand, the region of residence – metropolitan, urban or rural – appears not to be associated with stroke mortality, at least not on the basis of the generally recognized criteria of statistical significance (Table 2, Model 4). We nonetheless note a trend which translates into a higher mortality rate in small towns and rural areas and a lower rate in the Greater Montreal area.

Analysis of the interaction between variables revealed only one statistically signifi-

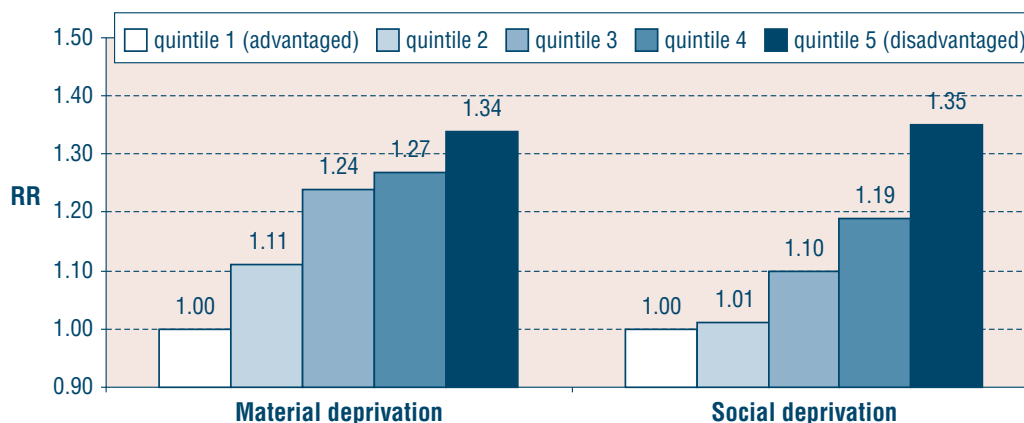
cant interaction, which is between age and sex. Adding this interaction to Model 4 (Table 2) produces a final estimate of the influence of deprivation on stroke mortality in Quebec (Figure 1). Once again, a sustained progression in mortality risk, based on one or the other form of deprivation, can be observed. By combining the two forms of deprivation, one can conclude that the relative risk of stroke mortality is approximately 80% higher (material RR = 1.34 X social RR = 1.35) in persons who are both materially and socially disadvantaged than in those who are advantaged in these two areas.

## Discussion

This study demonstrates that the risk of stroke mortality in Quebec increases with the level of deprivation of individuals, regardless of whether the deprivation is material or social, and that the combination of both forms of deprivation further increases the risk of mortality.

Despite certain methodological differences, our results corroborate those of numerous studies on material deprivation (income, education, socio-occupational status) and stroke mortality.<sup>37,39,50–54,56,73–77</sup> In Canada, two studies which used an ecological proxy

**FIGURE 1**  
**Relative risk of death by stroke according to material and social deprivation, Quebec, 1994–1998**



for income (the forward sortation area in one case, the neighbourhood in the other) demonstrated appreciable disparities in stroke mortality based on this characteristic. In Ontario, Kapral et al.<sup>75</sup> observed a higher mortality rate after 30 days and after one year in stroke patients belonging to the lowest income quintile, relative to those in the highest quintile. Similarly, in all census metropolitan areas in Canada, Wilkins<sup>76</sup> found greater differences in stroke mortality in 1986 than in 1971 between the lowest and the highest income quintiles. Similar disparities are also found in other parts of the world. One international study conducted by Kunst et al.<sup>55</sup> in eleven countries of Western Europe and in the United States showed that manual workers in all of these countries had higher rates of stroke mortality than non-manual workers, ranging from 18% in Spain to 74% in England and Wales, for men between the ages of 45 and 59 years. In younger men (30–44 years) these disparities were even more marked, whereas in older men (60–64) the differences in mortality rates between occupational categories tended to decrease. Quebec's material RR of 1.34 (Figure 1) would place it among the countries situated in the middle range such as Sweden, France, the United States and Switzerland.

Our deprivation measure also includes a social dimension whose ultimate impact on stroke mortality is identical to that of the material dimension when adjusted by region (Figure 1). This has been demon-

strated in studies on social exclusion conducted elsewhere, such as the Australian study by Burnley and Rintoul,<sup>12</sup> which clearly demonstrated the effects of marital status on stroke mortality. Married men and women between the ages of 40 and 74 experience standardized mortality rates which are distinctly lower than those of their single counterparts. The stress caused by social exclusion and the inability to summon help when a stroke occurs may explain these disparities in mortality rates.<sup>12,29,38</sup>

The influence of deprivation on stroke mortality is linked to numerous risk factors, particularly unhealthy lifestyle habits, such as alcohol abuse, smoking and inactivity. Our study did not permit us to directly verify the influence of these habits on stroke mortality; however, it is clear that in Quebec<sup>25–28</sup> and elsewhere,<sup>29,30,78–80</sup> these habits are closely linked to deprivation. For example, the *Enquête sociale et de santé* 1998 shows that married persons are less likely to smoke (27%) or to have a poor diet (12%) than single persons (38.6% and 20% respectively). Similar patterns can be observed when comparing those who are highly educated with those who have little education (smoking: 21% vs. 47%; poor diet: 12% vs. 18%), or when comparing high and low income individuals (smoking: 22% vs. 46%; poor diet: 13% vs. 33%). Disparities have also been observed with respect to physical activity: only 17% of persons who are well edu-

cated do not exercise, as opposed to 42% of those with less education.

The influence of deprivation on stroke mortality is also linked, at least in part, to access to health services. Although Quebec has a universal health care system, disparities in medical and hospital service use patterns are discernible according to income, education, and level of material and social deprivation.<sup>28,66</sup> As we have seen elsewhere, these disparities may be having an impact on hospitalization and treatment wait times following a stroke, a factor which can have a determining influence on the severity of patients' sequelae and their chances of survival.<sup>19–23</sup> Unfortunately, our results do not permit us to further characterize the influence of deprivation on access to health services and stroke mortality in Quebec.

The differences in mortality observed between urban and rural environments (Table 2, Model 4) are more easily linked to clear variations in Quebec's health care system. Although these differences are not statistically significant, they do confer a distinct advantage on the Greater Montreal area. Maheswaran et al.<sup>56</sup> observed a similar advantage in England between London and its rural periphery in the case of persons over the age of 65. In Quebec, differences in mortality rates are associated with significant disparities in the use of health services and the distribution of specialized hospital and medical resources,<sup>81–83</sup> which give Montreal the advantage. As demon-

strated in Montreal, access to the kinds of specialized resources usually found in university medical centres increases patients' chances of survival and recovery following a stroke.<sup>84</sup> It is also possible that the unequal distribution of these resources may have an impact on the quality of prevention efforts, including the control of high blood pressure, hypercholesterolemia, smoking and diabetes, all of which are major risk factors for stroke.

Clearly, we will only gain a better understanding of the health care system's influence on stroke mortality once we have a complete epidemiological surveillance system for stroke. The system which we propose for Quebec will involve the anonymous matching of data derived from the hospitalizations database, the Quebec health insurance database – which provides data on medical consultations and the use of medications – and the deaths database.<sup>64</sup> The system will enable us to estimate the influence of deprivation on health service consumption, as well as to follow patients through the health system, from the home to the medical clinic, and from the hospital to the nursing home or long-term care facility. It will then be possible to estimate the average length of hospital stays following a stroke, as well as the number of readmissions for subsequent strokes.

Moreover, this system will make it possible to take into account a larger number of health indicators and to establish stroke incidence and survival measurements. It will also be possible to take into account the issue of co-morbidities which are sometimes associated with physiopathological risks, such as diabetes, hypertension, or a history of CVD.

The proposed system will be operational in the medium term. In the meantime, this study will provide an initial estimate of the social inequalities associated with stroke mortality in Quebec by examining two forms of deprivation (material and social). Despite the existence of a universal health care system in Quebec, this study serves as a reminder that there are persistent disparities in stroke mortality rates.

Our study demonstrates the importance of targeting interventions to materially and

socially deprived groups, in order to attenuate the impact of certain stroke risk factors, such as hypertension, smoking, poor diet and inactivity. Despite the mixed results obtained with a heart disease prevention program which was recently undertaken in a low-income neighbourhood of Montreal,<sup>85</sup> certain program activities relating to physical exercise, smoking, and the control of hypertension and cholesterol levels achieved encouraging results.

This study also demonstrates the desirability of working to achieve a fairer distribution of material and social resources in society. Access to resources such as stable employment, adequate income, appropriate housing, and strong support systems constitutes a major daily concern for those who experience deprivation. As the authors of the heart disease prevention program in Montreal<sup>85</sup> have stated, it will be difficult for people living in conditions of deprivation to view the activities associated with these kinds of programs as a priority so long as their basic economic needs have not been met.

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# Do healthy food baskets assess food security?

Tasnim Nathoo and Jean Shoveller

## Abstract

*Developing indicators to measure the different facets of food security presents numerous conceptual and methodological challenges. This paper adopts an ecological framework to reflect on these issues through an examination of the Healthy Food Basket (HFB) tool. The HFB tool is used to measure food security conditions by determining the cost and availability of a group of foods in a shopping basket across a range of stores in different regions and neighbourhoods. The paper discusses the ability of the HFB tool to describe micro-, meso- and macro-level influences on food security and the use of the ecological model in developing complementary and alternative strategies for understanding and monitoring food security.*

**Key words:** ecological model; food security; measurement; nutrition indicators

## Introduction

Different understandings of the term “food security” can create serious challenges to adopting multisectoral approaches that address food security issues. In a recent survey, Power et al.<sup>1</sup> found significant variations among Canada’s registered dietitians regarding the conceptualization of the term. The dietitians responded with a wide range of understandings of the term, including food safety, food as a basic human right, adequate food to maintain health, sustainable agricultural systems, affordability, charitable food distribution systems and individual choice of personally acceptable foods. *Canada’s Action Plan for Food Security*<sup>2</sup> adopts the definition of food security that emerged from the World Food Summit: “Food security exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life.”

*Canada’s Action Plan for Food Security* also lists, as a priority, the development of a monitoring system for food insecurity. It identifies the need for “a comprehensive

set of agreed-upon indicators to determine the nature, extent and evolution of food insecurity, both to develop appropriate responses and to monitor their effectiveness.” Developing indicators to measure the different facets of food security presents numerous conceptual and methodological challenges.

This paper adopts an ecological framework to reflect on the different dimensions of food security and discusses complementary and alternative strategies for understanding and monitoring food security. It examines a commonly used tool to measure food security conditions: the Healthy Food Basket (HFB) tool (also called the Nutritious Food Basket), which has been used in Canada for nearly half a century. Although the HFB tool is used to describe food security conditions, it is not clear which dimensions of food security are best captured and understood through the use of HFB data.

The HFB tool determines the cost and availability of a group of foods in a shopping basket across a range of stores in different regions and neighbourhoods (see

Table 1). Although the results from HFB surveys have been used widely to inform many policies and programs, including those related to social welfare and nutrition, the adequacy and comprehensiveness of the HFB tool in describing food security conditions at the micro (individual), meso (community) and macro (population) levels remains to be determined.

## Applying an ecological framework to the HFB

Ecological theory asserts that a reciprocal and dynamic interrelation exists between the individual and subsystems of the environment.<sup>3–5</sup> Ecological theory and approaches are not new, and they are widely used to examine the determinants of population health.<sup>6,7</sup> Using an ecological framework to examine the HFB provides an opportunity to examine micro-, meso- and macro-level influences on food security. At the most basic level, the micro level, the analysis pertains to individual activities, roles and interpersonal relationships in a given setting;<sup>4</sup> the meso-level analysis examines relations among groups across settings; and the macro level pertains to socio-cultural and policy-level influences that may originate with institutions.

The different components of food security, such as food availability in a community, individual food consumption and sustainable agricultural production, are determined by a combination of micro-, meso- and macro-level influences. The HFB tool has been used to answer questions at the micro level, such as “What does it cost to feed a family with food that is nutritious, acceptable and sufficient in quantity?” It has also been used to examine meso-level questions, such as “Are healthier foods readily

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available to people in different communities or regions?” as well as macro-level questions, like “How should the social security system be structured to enhance the ability of the poor to purchase healthy food?”

Information from food basket surveys has been used in a wide range of program and policy applications, including the development of educational material on nutrition and dietary guidelines, to promote access to healthy foods in remote and rural areas, and to assess the adequacy of welfare food allowances. Many advocacy groups, professional organizations and public institutions also use such information as an indicator of food insecurity conditions in communities across Canada and to promote and support policy development to increase access to healthy foods.

## Reflecting on the HFB from an ecological perspective

### Micro level

Individual and household incomes are important determinants of food choice. At the micro level, the HFB has been used primarily to assess the ability of individuals to afford healthy food. For example, the HFB tool can assess the cost of a diet that reflects basic nutrient and calorie needs, and this information can be used to demonstrate the (in)adequacy of income support allowances to provide individuals and families with the means to afford a healthy diet. Community nutritionists in British Columbia have used the HFB tool to produce an annual report, *The Cost of Eating in B.C.*, which demonstrates how families of four on income assistance and single parent families (in which the parent works full time at a minimum wage job) have great difficulty in meeting their shelter and food needs and other basic necessities with their limited incomes.<sup>8</sup>

In interpreting HFB estimates at the micro level, important cautions should be considered. When used in this way, the HFB tool, like the U.S. Department of Agriculture household food security scale,<sup>9</sup> focuses on financial constraints to individual and household food security. It also tends to equate food insecurity with hunger. It

**TABLE 1**  
**Deriving and using the HFB tool**

The HFB tool is constructed and implemented in many different ways. A general outline of the process is described below.	
<b>Constructing the basket</b>	<p>Foods are selected on the basis of several criteria:</p> <ul style="list-style-type: none"> <li>■ Quantities in the basket must reflect nutritional needs (e.g., foods with little nutritional value are not included in the basket).</li> <li>■ Selected foods must reflect current food-purchase and food-consumption patterns.</li> <li>■ Items in the basket must be widely available across stores in the area to be surveyed and be available during all seasons of the year.</li> </ul>
<b>Conducting the survey</b>	Survey is conducted in a sample of stores. Depending on the aims of the survey, stores may be stratified according to various characteristics, including store size or location. Generally, the lowest price for each food item is selected. Efforts are made to ensure comparability across brand names and package size.
<b>Calculating the cost of the HFB</b>	<p>The total cost of the HFB is derived through the following procedures:</p> <ul style="list-style-type: none"> <li>■ The average price for each food item is calculated from across the stores.</li> <li>■ The quantity of each food item is scaled to a common purchase unit (e.g., some stores may have yogurt in 500 g containers while others may have 750 g containers).</li> <li>■ Foods are weighted according to their relative importance within each food group.</li> <li>■ Nutrient needs are met by adjusting food group quantities. Thus, the weighted average cost for each food group is multiplied by the quantity required for different age and sex groups. Food quantities are multiplied by the number of individuals in a household (typically a family of four).</li> </ul>
<b>Comparing HFB basket costs</b>	<p>The cost of the HFB is used for multiple purposes:</p> <ul style="list-style-type: none"> <li>■ Total HFB cost may be compared with social assistance allowances.</li> <li>■ HFB costs may be compared across neighbourhoods.</li> <li>■ HFB costs may be compared over time in select settings.</li> </ul>

does not measure the other broad concepts included in definitions of food security (e.g., food safety, sustainable agriculture) nor does it identify individuals or groups who may be vulnerable to food insecurity for other reasons (e.g., many elderly or disabled people who may not have physical access to food). HFB assumes that people with higher incomes do not experience food insecurity, and it is not able to capture differences in food security levels that may exist between individuals and households with limited incomes (e.g., individuals receiving social assistance in an urban area may have higher housing costs and less money to allot to food). In addition, the HFB is not sufficiently flexible to capture

understandings of food security that may be culturally specific, an important issue for consideration in Canada’s highly multi-cultural society.

The HFB is sometimes used to determine what it might cost an individual to eat healthy food (e.g., to estimate the costs as part of a student loan) or to feed people in group homes, extended care facilities or homeless shelters. However, it should be remembered that the contents of the HFB are generally derived from population-level food consumption patterns.<sup>8,10–12</sup> Although the cost of the HFB can be altered to reflect the nutritional requirements for different age and sex groups, it should be remembered that these values as well as the food



consumption patterns that the basket is derived from are based on *averages* (e.g., they do not reflect individual differences in activity and metabolism or special dietary needs). By making inferences about individuals from a tool derived from population-level data, researchers and food security planners may be in danger of committing an ecological fallacy. Because food consumption patterns vary significantly among individuals, the statistical and theoretical assumptions underpinning population-level analyses do not necessarily translate directly to the individual or micro level. Thus, the HFB tool may be effective in assessing which *populations* may be economically vulnerable to food insecurity, but it provides, at best, only a proxy for *individual* or *micro-level* food security.

### Meso level

At a micro level, we are concerned with the ability of individuals to afford a healthy diet. At a meso level, the analysis is focused more on whether affordable food is available to the individual in his or her community. For example, meso-level forces may include how communities respond to hunger (e.g., the presence or absence of food banks or soup kitchens in the community), the variety and mix of retail food outlets and the existence of municipal by-laws that support events such as farmers' markets.

Physical access to food in local areas is a growing concern, and several researchers have used the HFB tool in an urban context to answer meso-level questions like "Does a healthy food basket cost more in poorer areas?" Several studies have shown that a healthy food basket is more expensive and the items in the basket are less available in poorer urban areas;<sup>13-18</sup> thus, groups of individuals or families with low incomes face both economic and physical barriers to a healthy diet.

Many users have cautioned against comparing HFB estimates at the meso level across communities and regions. Although researchers have found differences between extremely different urban neighbourhoods, there is some evidence that the HFB tool may not be able to adequately capture the influence of local context on people's food

choices.<sup>11,16</sup> For example, the HFB tool cannot account for the influence of different market share of stores in different communities or different buying patterns in different regions. As well, communities are not precisely defined and, in fact, subcommunities may overlap with each other – for instance, many communities may include a variety of economically diverse neighborhoods, which may be located adjacent to one another. In these cases, members of the different neighbourhoods may cross boundaries to shop in the same stores. This issue can be important when a comparison is made of different neighbourhoods in an urban region where food access is more strongly influenced by factors such as transportation and store location rather than by geographical boundaries.

In this situation, researchers and food security planners may be in danger of committing an atomistic fallacy. A relation may exist at the micro level (e.g., individuals with low income may not have equal access to the foods in a healthy food basket); however, it may not necessarily hold at the meso level (e.g., the average cost and availability of food items in a healthy food basket may be equal across neighbourhoods). This subtle, yet important, flaw in the logic of HFB has the potential to mislead researchers and planners in their efforts to promote food security in Canada. Thus, the HFB tool has the capacity to indicate whether healthy foods are available to groups of individuals in their local environments, but it fails to provide sufficiently sensitive information regarding the impact of micro-level food consumption patterns on food security within and across communities.

### Macro level

Macro-level determinants of food security include socio-cultural and policy-level influences. It is within this complex context that HFBs are implemented. The HFB tool does not directly measure the impact of specific socio-cultural or policy-level influences – rather, it describes the cost of a pre-specified list of foods across a number of stores, which represent one facet of food security that is influenced by macro-level forces. Thus, the HFB represents one indicator of the potential impact of macro-level

changes. However, on its own, HFB provides an insufficient reflection of the overall complex myriad of factors affecting food security.

Although the HFB tool may be able to provide limited information about *why* food security conditions are changing, data from HFB surveys can be used in conjunction with other indicators (e.g., prevalence of nutrition-related disease, income inequality, unemployment rates) to inform changes in social, health and agriculture systems. For example, the HFB tool has provided insights into the question of "How should the social security system be structured to enhance the ability of the poor to purchase healthy food?" and has been used to demonstrate the inadequacies of welfare allowances.

## Discussion

The HFB tool appears to be an effective tool to monitor one of the key determinants of individual food security, food affordability. It has the capacity to identify local differences in cost and access to healthy food. However, the HFB does not appear to have the capacity to adequately or comprehensively monitor the nutritional health of the population.

At present, we have several indicators that indirectly measure food security, and these measures focus on issues of hunger (e.g., growth of food banks and increasing use of emergency feeding programs). Although hunger is a growing concern in Canada, over-nutrition and malnutrition remain concerns for a large percentage of the population. Food costing techniques have long been used to monitor the affordability of an adequate diet to prevent hunger and malnutrition. Cancer, heart disease and strokes, all related to nutrition, are the three leading causes of death in Canada, and obesity is a concern of nearly half of the Canadian population.

Although epidemiology has been successful in demonstrating the relation between nutrition and individual health (e.g., vitamin deficiencies), at a macro level the causal pathways between nutrition and the health of the population are subtler and are less clearly understood. The HFB is an

intrinsically appealing food-costing tool, but it is not sufficiently sophisticated to document the influence of institutional and sociological phenomena on food availability, cost and consumption patterns at the population level.

Food affordability and access, as measured by the HFB, represent one piece of the food security puzzle. In order to understand the context of individual food consumption, we need to pay greater attention to the impact of macro-level influences, such as changes in global governance, methods of food production and the composition of the retail food industry, as well as to the role of cultural change and technological developments.

Adopting an ecological framework to understand the influences of food security and population-level nutrition demands an examination of these structural and contextual influences. Although ecological approaches have typically been used to identify and address factors associated with each level of influence, the capacity to examine simultaneously the *interactions* among micro-, meso- and macro-level determinants has been underused. For example, environmental degradation, loss of biodiversity and the advancement of monoculture have resulted from complex *interactions* among micro-, meso- and macro-level forces. Thus, a more complete adoption and implementation of ecological approaches hold promise for developing new insights into the different facets and dimensions of food security.

## Conclusions

This analysis describes the parameters within which the HFB tool should continue to be used. The HFB provides a proxy estimate of individual food affordability and accessibility. We recommend that it continue to be used to address these aspects of food security at the micro level. The tool has practical appeal because it can be implemented easily and quickly at low cost. We suggest that interpretation of the tool could be further improved by comparing the cost of the HFB to the proportion of individual income spent on food. This approach would account for fluctuations in food basket costs and income levels and

would be another tool to monitor food security change over time.

As food affordability and access is only one component of a comprehensive understanding of the food security question, we also wanted to use this examination of the HFB as an opportunity to stimulate thinking about complementary and alternative approaches to understanding food security. An ecological approach can clarify the appropriateness of using specific tools at each level of analysis (micro, meso, macro) as well as emphasize the importance of the interactions across levels. The field could benefit significantly from the development of new tools to assess both meso- and macro-level influences on food security. While traditional research approaches are unable to untangle the complex web of interactions across the micro, meso and macro levels, new statistical and methodological tools developed in other disciplines could be applied to the problem of food security.

At the level of practice, an ecological framework may also reinforce an understanding that interventions must move beyond an exclusive focus on individual (micro level) food security. New approaches are required to achieve population-level improvements in food security. Policies and programs that are informed by research that captures the *interactions* between individuals and more “upstream” social, cultural and institutional influences hold promise for improving nutrition at the population level.<sup>19–21</sup> To increase our understanding of the reciprocal and dynamic interrelations that exist between individuals and various subsystems within their environments requires a more ecological approach to research and program/policy planning.

Newly emerging mixed-method research approaches<sup>6,22</sup> and multi-level modelling techniques<sup>23</sup> hold promise for developing more ecological understandings of food security and nutritional health at the population level, because they allow us to examine interactions across levels of influence while controlling for both the atomistic and ecological fallacies. By adopting an ecological perspective, research agencies and other stakeholders dedicated to pro-

moting population health should be encouraged to investigate these important issues using these innovative research approaches. Findings from such research could then be used to inform the development of more progressive, comprehensive and population-based policies and programs to promote equitable access to healthy food by all groups of the population.

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# The role of lay panelists on grant review panels

Anne Monahan and Donna E Stewart

## Abstract

*The purpose of this study was to investigate the attitudes of scientists and lay people participating in National Cancer Institute of Canada (NCIC) grant review panels towards the inclusion of non-scientists in the review process. Questionnaires were sent to the 126 scientists and 24 lay panelists who participated in NCIC's grant reviews in 1998. Survey topics included lay member selection, the role of the lay panelist and suggestions for improving the process. Data were analyzed qualitatively, and quantitatively using SPSS. Sixty-one of the 126 scientists (48.4%) and 16 of the 24 lay panelists (66.7%) completed the survey. Female scientists were significantly more supportive than male scientists of the selection of cancer patients/survivors/advocates as lay members ( $p = 0.01$ ), but overall their responses were more similar to those of their male colleagues than of the lay respondents. There were significant differences between the lay and scientist respondents on lay member responsibilities ( $p = 0.01$ ), the format of lay grant review ( $p = 0.04$ ), lay member contribution to panel discussion ( $p = 0.01$ ), and understanding of the lay role ( $p = 0.02$ ).*

**Key words:** Canada; cancer; consumer advocacy; patient advocacy; peer review

## Introduction

When Sharon Batt, Canadian breast cancer survivor, wrote of her experiences with the scientific, health care, and political establishment in *Patient No More: The Politics of Breast Cancer*,<sup>1</sup> she symbolized a growing awakening among cancer patients and survivors to the importance of becoming politically conscious about their illnesses. At the foundation of this "consciousness-raising" phenomenon was a conviction that scientists and the cancer patient community were fundamentally at odds with each other in their approaches to cancer research and treatment. Specifically, as Batt put it, "cancer researchers privilege the extension of the patient's life above all other priorities, regardless of the discomfort of the treatments entailed, while the [breast] cancer patient seeks ways of enhancing quality of life, investigating preventive therapies, and limiting the harshness of painful treatments."<sup>1</sup>

At no other time in recent memory has the community of patients been so effective in making their unique voice heard. The circumstances converging to produce this trend are complex and multivariate, but no doubt relate to the demise of reliance on "experts" over the last century, defiance of the previously unquestioned wisdom of traditional authority figures, and the role of the media in debunking previously sacrosanct ideas of authority and expert opinion. The movement at bottom arises from the optimistic ideal that ordinary people can truly influence change in what might sometimes seem to be monolithic bureaucratic communities of government and science.

The aspirations of cancer advocates were first embodied in the U.S. Army's Breast Cancer Research Program, which since 1993 has included "consumers" (e.g., breast cancer survivors) in the grant review process. Since 1995, these consumers have participated as full voting members and colleagues of the scientists in the peer review system.

The U.S. Army program defines "consumer advocates" as those who have "first-hand experience with breast cancer as affected persons and are active in breast cancer advocacy organizations."<sup>2</sup> The inclusion of such advocates in the process is intended to broaden discussion beyond hard-core science issues to encompass the patient/survivor perspective.

The Canadian system has responded similarly. Emblematic of this trend has been the coming together of the Canadian Breast Cancer Research Initiative (CBCRI), begun in 1993 as a partnership among the foremost Canadian research bodies, the federal government, and the major breast cancer advocacy groups. The CBCRI is the primary impetus behind the funding of breast cancer research in this country. Its inception stemmed in large part from the advocacy efforts of breast cancer survivors and women in Parliament, who insisted that greater efforts be undertaken to fight the disease. These calls for action culminated in the National Forum on Breast Cancer, held in Montreal in 1993, where a consensus emerged that a centralized initiative in funding was needed to sustain research into a cure for the disease. At the core of this consensus was the notion that government and the scientific community must be held accountable for their decisions, and that the ordinary citizen with a vested interest in these decisions must be given a voice. The role of the consumer, then, was elevated as a vehicle through which the scientific and governmental communities could be made more accountable to the public at large and discussion at the table of scientific and governmental decision-making could be injected with a unique societal, humanistic voice.

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Since 1997, the National Cancer Institute of Canada (NCIC), traditionally the most significant funding organization in the country for cancer research, has made its grant review process more patient-centred by including two non-scientists on each of 12 panels in its grant application review process. The NCIC has drawn from a list of nominees from about 50 organizations to fill its lay panel positions. Resumes and letters written by those nominating the lay candidates have been reviewed by a small panel, and then panelists have been chosen randomly from those candidates approved. Since the lay “experiment” began, the NCIC has undertaken informal assessments of the climate in which the lay panelists were received by the scientists. While “no negative comment has been heard by the NCIC staff from any panel member,”<sup>3</sup> this is the first comprehensive survey of either lay or scientist panelists.

## Objectives

A survey of the 24 lay and 126 scientist panelists who participated in the NCIC’s grant review process in 1998 was conducted to ascertain the opinions of both groups on the lay panelist role. The study’s jumping-off point was simply this: has the scientific establishment recoiled at attempts by the consumer advocacy movement to “share ownership of the research ‘property’” as has been suggested by Batt.<sup>1</sup> The present study thus aimed to examine how both groups, lay and scientist panelists, view the legitimacy and significance of the lay role. Given that most of the consumer advocates are women and most of the scientists are men, do gender differences figure into this equation? How similar are the lay panelists’ and scientists’ characterizations of the interaction they experienced on their respective panels, and what suggestions do they have for improving that interaction? Framing this inquiry was a desire to investigate lay panelists’ views on their own preparedness for the process and how orientation sessions could better accommodate their needs in this regard, as well as both groups’ views on the criteria that should be involved in the selection of lay panelists.

## Methods

All scientists (126) and lay panelists (24) who had served on the NCIC scientific grant review panels in 1998 were surveyed within four months of their participation. Two separate surveys with overlapping questions were distributed by mail. Each survey consisted of a mixture of closed-ended (multiple choice) and open-ended questions derived from informal feedback already gathered from lay panelists and from discussion with key informants. The surveys were divided into several sections, including lay member selection, orientation and preparation (of each respective group), the lay panelist role, experience on the panel, suggestions for improving the process, and evaluation and feedback. Survey responses were analyzed both qualitatively for themes and illustrative quotes (by both investigators), and quantitatively by using SPSS to determine frequencies and the results of chi square tests. Only themes and quotes agreed to by both authors were selected for inclusion.

## Results

Sixty-one of the 126 scientists (48.4%) and 16 of the 24 lay panelists (66.7%) completed and returned the survey. Of the 16 lay respondents, 13 were women; of the 43 scientists who identified their sex, 9 were women.

### Lay member selection

No significant difference between the lay and scientist panelists was found on the question of lay member selection and background.

However, the scientist respondents were more supportive of having cancer patients/survivors sit as lay panelists than the lay respondents themselves (65.0%,  $n = 26$  versus 50.0%,  $n = 8$ ). This position was reversed with regard to support for having cancer advocates as lay panelists (75%,  $n = 12$ , of lay panelists versus 47.6%,  $n = 19$ , of scientists) (Table 1).

In addition, there were significant sex differences among the scientist respondents on this issue. All the female scientists ( $n = 9$ ) supported choosing both cancer patients/survivors and relatives of patients/survivors as lay members, as compared with only 54.8% ( $p = 0.01$ ) and 45.2% ( $p = 0.003$ ) of their male counterparts respectively ( $n = 31$ ). The proportion of female scientists supporting cancer advocates (77.8%) was similar to that of the lay respondents, in contrast to the proportion among male scientists (38.7%) ( $p = 0.04$ ).

### Lay panelists’ roles and responsibilities

When asked if it would be beneficial for lay panelists to sit as observers for a year before assuming full responsibilities, 77.0% of scientists agreed, as compared with only 43.8% of lay respondents ( $p = 0.01$ ). However, all lay panelists felt that some form of orientation session was desirable. A large minority (29.4%) of lay panelists believed that lay review of grant applications should approach that undertaken by the scientists (in the form of an overall numeric rating), as compared with only 4.8% of scientist respondents with this view ( $p = 0.04$ ).

**TABLE 1**  
**Attitudes Toward Lay Member Background**

	Male scientists ( $n = 31$ )*	Female scientists ( $n = 9$ )*	Lay respondents ( $n = 16$ )
Choose cancer patients/survivors	17 (54.8%)	9 (100.0%)	8 (50.0%)
Choose relatives of patients/survivors	14 (45.2%)	9 (100.0%)	9 (56.3%)
Choose cancer advocates	12 (38.7%)	7 (77.8%)	12 (75.0%)

\* All scientists did not answer the question about their sex.

The lay respondents clearly viewed themselves as fulfilling an ambassadorial role. In fact 94.1 % of lay respondents characterized themselves as representatives of the grant review process for their affiliated organizations or the general public. Nevertheless, they expressed ambivalence about their contribution to panel discussion. Although a majority of lay panelists believed that the lay contribution served a worthwhile purpose, only a minority of them (37.5%) characterized it as “significant”. However, clearly a majority of both lay and scientist panelists endorsed the legitimacy of the lay “experiment”.

### Interaction on the panel

There was no significant difference between the male and female scientists on how highly they rated the interaction between lay and scientist panelists. Female scientists had a mean rating of 8.33 (highest score of 10), as compared with a mean of 7.17 by their male counterparts. (There was likewise no significant difference between lay and scientist panelists on this point.)

The female scientists responded in ways more similar to their male scientist counterparts than to the lay respondents: 66.7% of female and 67.7% of male scientists believed that lay panelists had “brought a different perspective” to panel discussions. Furthermore, a majority of both male (96.4%) and female (100.0%) scientists believed that an awareness existed on their panels that the lay participants were fulfilling a legitimate role. Both the male and female scientists disagreed that scientists need to better understand the lay role, 72.4% and 77.8% respectively responding “no” to this question.

By contrast, there were significant differences between the lay and scientist respondents on these issues. All the lay panelists as compared with 69.8% of scientists ( $p = 0.01$ ) agreed that lay panelists brought a “different perspective” to the discussions (Table 2). While 91.7% of scientists ( $n = 55$ ) believed there was an understanding on their panels that lay members were providing a legitimate contribution, only 76.5% of lay respondents ( $n = 14$ ) believed that such an awareness existed ( $p = 0.08$ ). Moreover, 62.5% of lay panelists as

**TABLE 2**  
**Lay members contribution to panel discussion**

	Scientist respondents ( <i>n</i> = 61)		Lay respondents ( <i>n</i> = 16)	
	Agree	Disagree	Agree	Disagree
Lay members played a significant role	14 (23.8%)	47 (76.2%)	6 (37.5%)	10 (62.5%)
Lay members brought a different perspective	43 (69.8%)	18 (30.2%)	16 (100%)	0

against only 30.0% of the scientists ( $p = 0.02$ ) agreed that scientists need to better understand the lay role.

## Discussion

### Lay member selection

Lay respondents’ comments on the selection of lay panel members suggested an emphasis on advocacy as a prerequisite to sitting on the panel. As one lay member put it, lay participants “need some knowledge and experience in the cancer community”; to be “just interested” is not enough. For scientist panelists, intelligence and level of education were more important criteria in the selection of lay members. As one scientist stated: “Any interested individual willing to learn about the peer review process and participate in the panel review meetings who has the capacity to undertake this work” should be considered for inclusion on the panel.

With respect to scientific expertise, one scientist asserted that lay members “should have some familiarity with the content so they can make meaningful comments.” One of the scientists suggested that cancer patients and survivors possessed an inherent bias that rendered them the most inappropriate candidates for panel participation. This notion contrasted markedly with the lay view that to attempt to acquire scientific expertise would result in the loss of the unique lay viewpoint. Indeed, a clear majority – 75.0% – of the lay respondents indicated they were opposed to the inclusion of a basic science review in their orientation, preferring instead an overview of types of cancer and cancer research (75.0% chose this option), a lay glossary of scientific terms (75.0%), and an introduction to

the grant review process itself (93.8%). In the same vein, one female scientist argued that far from being tainted with bias, the lay member serves as a “reality [or] relevance” check on the scientists, as the lay panelist does not harbour an “agenda”.

Although lay respondents clearly favoured the idea of cancer advocates sitting as lay panelists, they seemed to support a particular kind of advocacy. Hence, while only 50.0% of lay panelists would choose cancer patients/survivors and 56.3% of them would choose relatives of patients/survivors as lay panelists, 93.8% of lay respondents saw members of cancer organizations as the preferred pool of potential lay members. This finding suggests that the background of these lay respondents may be dominated by an organizational, as opposed to a personal, cancer experience. Their view of advocacy may be correspondingly shaped by this circumstance. In contrast, the women scientists (as distinct from their male counterparts) favoured all varieties of cancer advocates, including patients and survivors, as mentioned previously.

### Lay member roles and responsibilities

Although only a minority of respondents, scientists and lay panelists affirmed that lay panelists had “played a significant role”, most of the lay respondents were not prepared to endorse the suggestion of having lay members serve as mere observers for a year before becoming full-fledged panelists. One put her feelings succinctly when she said that “to go through all the effort that is required to review the grants, then to sit as an ‘observer’ would be difficult for me.” Evidently, the “observer” question

represented a kind of boundary line that most lay members were unwilling to traverse, given the fundamental legitimacy they saw as embodied in their role.

Indeed, a majority of the lay respondents believed that they had brought a different perspective from that of the scientists to the panel discussions. All the lay respondents reported that they had provided feedback about their grant review experience to their affiliated organizations, and every one of them believed that this communication had had an impact. One noted that support group members were pleased to hear that professionals were listening to laymen/survivors.

A clear majority of lay respondents viewed themselves as ambassadors of the grant review process to the general public. Lay respondents seemed to possess a vision of their role, however tentatively and vaguely defined, as one not only encompassing the relevance of the human perspective (putting “a face on the cancer patient”) within the panel setting but also serving as a conduit between the scientific community and a public that is generally unaware of the inner workings of research and indeed of grant review itself.

As at least one scientist remarked, the lay members perpetually emphasized that “science must... be publicly accountable.” Another noted that the lay panelists looked at research proposals with new, untutored eyes, thereby bringing a fresh angle to discussion: “they saw some grants with ‘simple’ science to be more valuable than the scientists on the panel.”

The scientists were effectively divided among a majority who invested at least some legitimacy in the lay role, and a minority who saw lay members as irrelevant and expendable. Most of the criticism in this regard hinged on the failure of the lay participants to speak the language of science, which most of the scientists viewed as central to the analysis of the grant application. The process, at times, broke down because each group was speaking at cross-purposes with the other.

Some scientist respondents disparaged the extra time entailed by the inclusion of lay panelists. As one wrote, “[the lay panel-

ists] took up a great deal of time asking questions ... scientists felt obligated to provide lengthy explanations of scientific points that were very difficult for lay members to understand.” How widespread this disaffection with the lay role was among scientists remains unclear, in part because of the difficulties in achieving forthrightness in reporting on questionnaires of this nature. Furthermore, it may be that those respondents with negative views are more readily heard because it is they who arguably relay their feedback most promptly, and express their opinions most fully.

### **Interaction on the panel**

No significant difference emerged between lay and scientist respondents on the rating of the interaction on their respective panels. Comments of both groups emphasized the pivotal importance of the chairperson of each panel in helping to define the lay role and to structure the form of lay participation. One scientist commented that lay participation was characterized by “poor integration, misunderstanding,” and a sense that the lay members were “‘left out’.” Another alluded to the crucial involvement of the chairperson in setting the tone for lay participation, asserting that at least one chairperson “did not always provide opportunity for inclusion ... [of] their concerns.”

One lay panelist remarked that during the few instances in which she and her lay counterpart offered comments, the scientists consistently listened to them; she believed that in a few cases the lay contributions changed “the course of events.” Moreover, virtually every one of the lay panelists commented on the new respect and appreciation that the process had inspired in him/her for the work of scientists and the depth of cancer research. The scientists echoed this positive interpretation of rapport on the panel. One scientist described an easy give-and-take interaction, observing that the lay members were encouraged to join any discussion during the panel meeting when they felt they could contribute. Another remarked that the lay panelists he had worked with had performed a “wonderful job”.

At the same time, a substantial minority of the lay panelists contended that interaction

could be improved by offering the lay members more of a voice on the panel. As one of the lay members noted, the lay panelists would feel that their contribution was more valued if some measure of the relevance of comments offered could be factored into the final ranking decision.

### **Limitations of the study**

The survey involved a relatively small sample and a response rate slightly below 50% for the scientists. To help formulate the survey questions, NCIC and one of the investigators had interviewed several scientist and lay panelists to ascertain their opinions about the new process. The response rate to the survey may have been reduced if these individuals felt it unnecessary to respond again, in writing. The few female scientist respondents made more detailed analysis difficult. It is questionable, too, given the small sample, how representative of cancer advocates the lay respondents may have been: their emphasis on organizational links (such as with the Canadian Cancer Society) may not be typical of the cancer advocates who sit on the U.S. Army panels, for example.

### **Conclusions**

The lay members were clearly impressed with the dedication and hard-working nature of the scientists, along with the breadth and depth of cancer research that is being undertaken in Canada. Many of them feel insecure about their contribution, but believe that their confidence will grow with continued experience. They unanimously endorse the legitimacy of lay participation and feel it is an undeniable success. Both theory and practice, they say, must progress, in the sense that the lay role should be better defined and communicated to the scientists and lay members in the hope of improving panel rapport. That definition must be continually shaped by the NCIC, which has taken the lead in Canada in including lay members in the grant review process.

The scientist respondents, for their part, represent a heterogeneous group. The extent of their acceptance of lay participation is encouraging; yet, intermingled with

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this optimism in some cases is doubt about whether lay inclusion is worthwhile. Hence, although a majority of the scientist respondents supported the legitimacy of the lay presence, a minority opposing the lay contribution (at least in its current form) made their voice heard through this survey.

The expansion of grant review, which uncharacteristically positions scientists and lay persons together in pursuit of a common goal, has gone some way toward breaking down the barriers between these 'two solitudes', toward making science more publicly accountable, and toward providing a window onto the world of the scientist.

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# The use of complementary and alternative therapies by people with multiple sclerosis

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## Abstract

*Complementary and alternative medicine (CAM) refers to therapeutic approaches not considered part of conventional medicine. A survey was mailed to sample of patients with multiple sclerosis (MS). The response rate was 440/673 (65%). Mean sample age was 48 years; 75% were female. Respondents ranged from mildly to severely impaired. Seventy percent used CAM primarily to improve health and manage the symptoms of MS. Most consumers reported positive effects. Lack of knowledge was the most common reason given for not using CAM. Patient education, physician-patient dialogue, and continued research and regulation of CAM are important to the well being of CAM consumers.*

**Key words:** *alternative medicine; complementary therapies; health surveys; multiple sclerosis*

## Introduction

Complementary and alternative medicine (CAM) refers to a broad range of health care products and practices that fall outside the Western biomedical paradigm. The popularity of CAM has been well documented, driven by such factors as the need for personal control, an increased interest in holism and an increasing prevalence of chronic disease.<sup>1,2</sup> Despite such widespread acceptance, the safety and efficacy of most CAM has not been clearly established. Nor is the practice of CAM uniformly regulated, leaving consumers with inconsistent standards of care.<sup>3,4</sup>

Multiple sclerosis is a recurrent inflammation of central nervous system white matter leading to myelin destruction and progressive neurological impairment. Conventional therapeutic approaches in multiple sclerosis (MS) focus on slowing disease progression and alleviating symptom experience. Although numerous pharmacological inter-

ventions are available, their effectiveness and tolerability vary across patients.<sup>5</sup>

Very few studies have described CAM use in MS and several among them are limited by small sample sizes and low response rates.<sup>6-8</sup> A broad range of therapies have been identified with the consumption of vitamins, herbs and special diets being more commonly used products, while chiropractic, acupuncture and massage are among the more commonly used practices.<sup>6-9</sup>

The present study describes CAM used by a large sample of adults with MS in southern Alberta, Canada.

## Methods

**Sample size determination:** Calculations were based on estimating the proportion of MS patients who used complementary therapies to  $\pm 5\%$  with 95% confidence. Based on previous research, we conservatively estimated that CAM is used by 50%

of MS patients.<sup>7,8</sup> To obtain our desired level of precision, a sample of approximately 390 people was needed. Allowing for a 50% response rate, 780 people were required for the survey.

**Study population.** The Calgary MS Clinic is the only source of neurological care for patients with MS in Southern Alberta (i.e., south of Red Deer). The MS clinic database was set up in 1993 and has captured all patients referred to the clinic since then. Referrals are made by physicians on the basis of known or suspected MS. At the time of sample selection, the clinic database contained information, including Expanded Disability Status Scale scores,<sup>10</sup> on 2,600 people. Based on a reported prevalence of MS in Alberta of 217/100,000<sup>11</sup> and a 1999 population of approximately 1.3 million in southern Alberta,<sup>12</sup> the expected number of cases is 2,821. The database therefore captured about 93% of all expected cases.

Patients for whom an address was not known, those known to be deceased, and those who had not given blanket consent to be approached for research projects were dropped from the database. Exclusion criteria defined by the researchers were people under 18 years of age and those whose diagnosis was possible or probable MS (vs. clinically definite and lab-supported MS). After these exclusions, a sampling frame of 1,335 remained. The database was then stratified by impairment level derived from the EDSS score yielding the distribution shown in Table 1. All people described as very severely impaired were included in the final sample as were the nine people

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**TABLE 1**  
**Distribution of sampling frame and study sample**

Impairment level (EDSS scores)	Sampling frame (n)	Study sample (n)
No recorded score	9	9
None-mild impairment (EDSS 0–2.5)	545	240
Moderate impairment (EDSS 3.0–5.5)	367	241
Severe impairment (EDSS 6.0–8.0)	365	241
Very severe impairment (EDSS 8.5–9.5)	49	49
Total	1,335	780

for whom a score was not recorded. The remaining 742 subjects required were systematically and equally drawn from the remaining three impairment levels resulting in a total sample of 780. The distribution of the study sample is also illustrated in Table 1.

*Procedure.* A covering letter, questionnaire and postage-paid return envelope were distributed by mail in June 2000. A postcard reminder was sent out four weeks later.

*Questionnaire.* Complementary therapies were defined both in the covering letter and within the questionnaire as “those therapies or remedies not part of mainstream or regular medicine”. Data pertaining to CAM use were collected using a self-report questionnaire developed for the purpose of the study.

The development of the questionnaire was guided by other investigations that examined the use of CAM generally<sup>13–15</sup> and those that examined the use of CAM by people with MS.<sup>7,9</sup> The Expanded Disability Status Scale was included within the questionnaire.<sup>10</sup>

Experts in the respective areas of questionnaire construction, CAM and MS, reviewed the questionnaire at different stages of development. In addition, five outpatients from the MS Clinic volunteered to review the questionnaire in response to a poster requesting assistance. These individuals were asked if they found that the questions were clear and easy to answer. They were

also asked for their opinion on the structure and content of the questionnaire. The comments provided by these reviewers were all different, revealing no systematic problem with the questionnaire. Their suggestions were useful and enhanced certain items by expanding response options and clarifying wording. Finally, the revised questionnaire was pilot-tested on a small sample of people drawn from the clinic database ( $n = 20$ ). These people were asked both to complete the questionnaire and to answer a one-page form evaluating the questionnaire itself. Eight people completed the questionnaire review. No problems were identified with respect to the length of time required to complete the questionnaire or the clarity of the questions. No items were identified as causing difficulty in responding.

The final questionnaire contained 70 items. The response format included a combination of closed-ended and short answer options. Questions addressed demographic factors, disease factors and CAM use. To assess CAM use, people were asked to study a list containing the names of therapies and place checkmarks against any they had used specifically for their MS within the past two years. This list contained a broad range of CAMs identified in the literature and through questioning staff in the MS clinic. In addition, subjects were asked to describe therapies they used that were not identified within the list. People were given the opportunity to provide general comments on CAM. A subsection of

the questionnaire dealt specifically with cannabis use. These results are reported elsewhere.<sup>16</sup>

*Analyses.* Data were entered into STATA 6.<sup>17</sup> Descriptive statistics were used to summarize responses. Multiple logistic regression was used to identify factors associated with CAM use ( $\alpha = 0.05$ ). Variables considered in this model were standard demographic characteristics (age, marital status, education, income) as well as characteristics related to MS (pattern of MS, disability level, time since diagnosis, use of conventional medication, comorbidities). As sex can act as an effect modifier, interaction terms were created between this variable and age, income, education, disability, medication use, comorbidities and pattern of MS. All variables and interaction terms were entered into the model. Backwards, stepwise regression was performed with the resulting models evaluated using the likelihood ratio chi-square test. The interaction terms were evaluated first followed by the predictor variables in order of decreasing magnitude of the p-value.

The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary.

## Results

*Sample:* Of the 780 surveys mailed, 107 were undeliverable (e.g., subjects moved, deceased). Four hundred and forty completed questionnaires were received (response rate  $440/673 = 65\%$ ). Seventy-five percent of respondents were female, a slightly greater proportion than in the general MS population. Mean age was 48 years (standard deviation [SD] = 10.9). Most people were married or in common-law relationships (73%). The majority had at least high school education (94%). Close to one-third were working either full- (22%) or part-time (8%). Median family income was in the range of \$40–\$49,000.00.

*Disease characteristics:* Mean age of disease onset was 31 (SD = 9.5), with mean age at diagnosis 36 (SD = 9.4). Forty-four percent described their pattern of MS as relapsing-remitting, 23% as secondary progressive, 10% as primary progressive and 4% as progressive relapsing (19% unknown).

**TABLE 2**  
**Products, practices and practitioners**  
**used by >10% of CAM consumers**

<b>CAM product/practice</b>	<b>n (%)</b>
<b>Vitamins/minerals</b>	
Multivitamins	187 (61%)
Vitamin C	148 (48%)
Vitamin E	122 (40%)
B vitamins	118 (38%)
Magnesium	73 (24%)
Selenium	57 (19%)
Zinc	55 (18%)
Vitamin A	49 (16%)
<b>Body therapies</b>	
Massage	133 (43%)
Chiropractic	92 (30%)
Reflexology	44 (14%)
<b>Natural/herbal therapies</b>	
Garlic	51 (17%)
Ginkgo biloba	47 (15%)
Ginseng	46 (15%)
Cannabis	45 (15%)
Aroma therapy	30 (10%)
<b>Mind/body therapies</b>	
Relaxation/meditation	74 (24%)
Yoga	51 (17%)
Music therapy	30 (10%)
Imagery/visualization	31 (10%)
<b>Spiritual therapies</b>	
Prayer	112 (36%)
<b>Nutritional therapies</b>	
Evening primrose oil	130 (42%)
Nutritional supplements (e.g., Matol®, Shaklee®, Mannatech®)	56 (18%)
<b>Energy therapies</b>	
Acupuncture	68 (22%)
Magnetic therapy	37 (12%)
<b>Other therapies</b>	
Removal of mercury amalgams	43 (14%)
<b>Traditional medical system</b>	
Traditional Chinese Medicine	37 (12%)
<b>Practitioners</b>	
Chiropractor	61 (20%)
Massage therapist	59 (19%)
Acupuncturist	36 (12%)

The degree of disability experienced ranged from mild (8%), through moderate (47%), severe (38%) and very severe (7%). One third of the sample reported having a comorbidity. Conventional medications were used by 60% of respondents for treatment of MS-related symptoms.

*CAM use:* Seventy percent of respondents had used CAM within the past two years ( $n = 309/440$ ; 95% CI = 66–75%). Over 100 different practices and products were described. Just over one third of respondents ( $n = 110$ , 37%) reported visiting a complementary practitioner and 11 different types of practitioners were accessed.

Twenty therapies and three types of practitioners were used by at least 10% of CAM consumers (Table 2). The median number of therapies an individual consumer reported using was 7 (inter-quartile range [IQR] = 5–12).

Vitamins and minerals were the most frequently reported category of products used with 79% of CAM consumers taking some combination of them. It could be argued that these products are not necessarily complementary or alternative. Excluding people who only used vitamins and minerals reduced the proportion reporting CAM use marginally from 70% to 68%. This difference was not statistically significant. Similarly, the use of traditional medical systems may overlap with individual practices and products (e.g., Traditional Chinese Medicine and acupuncture, herbal remedies) and could inflate the estimate of CAM use. Excluding those people who only used traditional medical systems reduced the number reporting CAM use from 309 to 308. This difference was not statistically significant. Vitamins/minerals and traditional medical systems were therefore retained in subsequent analyses.

Although a small number of people reported experiencing negative effects from CAM (5%), the vast majority perceived positive effects (72%). Therapies most often cited as beneficial were massage therapy, acupuncture and cannabis. The most common reasons for using CAM were to improve health (68%), to lessen the symptoms of MS (61%) and a belief that it couldn't hurt (55%). Reasons most frequently endorsed for not using CAM

were lack of knowledge about these therapies (42%) and satisfaction with the care provided by conventional practitioners (20%).

Information on CAM was obtained most commonly from the media (50%), or from family/friends (50%). The median amount of money spent on CAM in the past three months was \$100.00 (IQR = 45.00–\$300.00).

The majority of people indicated that their general practitioners and neurologists knew of their CAM use (77% and 62% respectively). Most indicated they had volunteered this information to their physicians, rather than being asked about it.

CAM consumers were not distinguished by age, marital status, education, income, disability level, pattern of MS, time since diagnosis or use of conventional medication. However, sex and income interacted to predict CAM use. Specifically, men with higher income were less likely to use CAM (OR = 0.19; CI = 0.065–0.54;  $p = 0.002$ ). Among women, income was unrelated to CAM use (OR = 0.69; CI = 0.39–1.21;  $p = 0.20$ ).

## Discussion

The proportion of respondents with MS indicating they had used CAM within the past two years (70%) was higher than those found in two earlier surveys (64% and 55%) that examined CAM use by this group.<sup>7,8</sup> This variation could be due to a number of factors including the increasing popularity of CAM, differences in the definition and measurement of CAM or differences in the populations surveyed.

The use of CAM by the general public has increased steadily since the 1950s and the evidence suggests this trend will continue in the foreseeable future.<sup>18</sup> This has been illustrated by a number of surveys conducted in Canada. Studies conducted in the early 1990s suggested that 20–22% of Canadians had used CAM.<sup>19,20</sup> An Angus Reid Group survey, conducted in 1997, reported that 42% of its respondents had used alternative medicines and practices. In 1999, the Fraser Institute reported 50% had used CAM.<sup>21</sup> Focusing specifically on CAM practitioner use, data from the Canadian National Population Health Sur-



veys conducted in 1994/95, 1996/97 and 1998/99 demonstrated steady increases in the proportion of Canadians consulting CAM practitioners (15%, 16% and 17% respectively).<sup>2</sup>

In addition to the passage of time, the relatively high prevalence of CAM use by this study sample likely reflects the fact that the participants have a chronic illness. CAM usage among the chronically ill tends to be higher than in the general population.<sup>22,23</sup>

Problems comparing the results of utilization surveys have been recognized. In particular, differing definitions of CAM (e.g., named therapies vs. open-ended questions) and differences in the time periods of use addressed (e.g., used in last six months vs. lifetime use) contribute to considerable variation in the prevalence of use reported.<sup>24</sup>

The sampling frame for this study consisted of those who had already given blanket consent to be approached for research. This group of patients may therefore be more open to trying new therapies or seeking out other therapeutic options, which may have resulted in an inflated estimate of CAM use for this patient group.

Although a substantial proportion of people in this survey reported their physicians knew of their CAM use, this tended to be due to the patient having volunteered the information. Conventional practitioners should be aware that many people with MS are using CAM and should initiate dialogue with their patients about CAM use. Where possible, health care professionals should be conversant with therapies commonly accessed by this patient group to help patients make informed, safe and appropriate choices, and to monitor patients using CAM. The current practice of the MS Clinic at Foothills hospital, for example, is to discourage people receiving interferon beta (Betaseron®) from consuming CAM products that could potentially affect the liver as interferon beta has been associated with serious liver dysfunction. While it is impractical to expect health professionals to be knowledgeable about all forms of CAM, the principles of evidence-based medicine can be applied to CAM as in any other area of practice.

Slightly over one third of respondents had visited a complementary practitioner; this is consistent with previous research.<sup>9</sup> It is interesting to note that while 30% of CAM users indicated they had received chiropractic treatment, only 20% reported seeing a chiropractor. Similar discrepancies are evident with CAM users receiving massage (43% vs. visiting a massage therapist 19%) and acupuncture (22% vs. visiting an acupuncturist 12%). This discrepancy raises two issues. First, it emphasizes the need for researchers to be clear in how they measure and report the use of CAM. Second, it suggests that chiropractic, massage and acupuncture services are being provided by a variety of practitioners. Some practitioners may be trained in a variety of disciplines — for example, Doctors of Traditional Chinese Medicine practice acupuncture and naturopaths may provide massage therapy. This discrepancy does, however raise the possibility that interventions are being provided by those whose scope of practice does not include the given treatment. Chiropractors, for example, are regulated by statute across Canada and the practice of this discipline is limited by law to those licensed by the profession.<sup>25</sup> Health care professionals and consumers need to be aware of practice standards to guide their use of CAM practitioners. Public interests will be further safeguarded by the continued development of regulatory bodies for CAM practitioners in disciplines of proven efficacy. Although some are well regulated by professional member organizations either by statute or voluntarily (e.g., chiropractors, naturopaths, massage therapists), others lack coordinated forms of representation. The establishment of regulatory bodies for CAM practitioners will help to ensure educational consistency and professional practice standards.

Many people appeared to operate under the assumption that CAM is not harmful and the belief that CAMs “couldn’t hurt” was a factor motivating use for a substantial proportion of respondents. Moreover, as indicated by respondents, information on CAMs is obtained primarily from the media or from family/friends. Public education initiatives on the known risks and benefits of therapies and products avail-

able will help consumers to make informed decisions.

CAM has frequently been criticized for a lack of evidence on its safety and efficacy. The conclusions of most utilization studies of CAM include calls for rigorous research of these approaches and the current study is no exception. There are very few studies assessing the safety and efficacy of any CAM in MS.<sup>26</sup> This study has identified specific CAM practices and products used most often by respondents and this information may be used to set research priorities for evaluation of CAMs in this patient group.

The results of this study demonstrate that people with MS are likely to be using some type of CAM. The interests of CAM consumers with MS will be well served by dialogue between conventional health care practitioners and patients, public education and continued research and regulation of these products and practices.

## Acknowledgements

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# Calendar of Events

<b>August 3–8, 2003</b> <b>Helsinki, Finland</b>	“Global Action for a Tobacco Free Future” 12 <sup>th</sup> World Conference on Tobacco or Health	Conference Secretariat CongCreator CC Ltd. Ms Aira Raudasojä and Ms Hanne Heikkinen PO Box 762, 00101 Helsinki, Finland Tel.: + 358 9 4542 190 Fax: + 358 9 4542 1930 E-mail: <a href="mailto:wctoh2003@congcreator.com">wctoh2003@congcreator.com</a> < <a href="http://www.wctoh2003.org">http://www.wctoh2003.org</a> >
<b>September 15–18, 2003</b> <b>Atlanta, Georgia, USA</b>	“Comprehensive Approaches to Cancer Control – The Public Health Role” CDC’s 2003 Cancer Conference	Conference co-sponsors include: Centers for Disease Control and Prevention American Cancer Society Chronic Disease Directors National Cancer Institute North American Association of Central Cancer Registries Toll-free: 1 877 426-2746 E-mail: <a href="mailto:info@cancerconference.net">info@cancerconference.net</a> < <a href="http://www.cancerconference.net">http://www.cancerconference.net</a> >
<b>September 21–25, 2003</b> <b>Orlando, Florida, USA</b>	5 <sup>th</sup> International Symposium on the Role of Soy in Preventing and Treating Chronic Disease	American Oil Chemists’ Society PO Box 3489 Champaign IL 61826-3489 USA Tel.: (217) 359-2344 Fax: (217) 351-8091 E-mail: <a href="mailto:meetings@aocs.org">meetings@aocs.org</a> Information: Mindy M. Cain at: <a href="mailto:mindyc@aocs.org">mindyc@aocs.org</a> < <a href="http://www.aocs.org/meetings.soy03">www.aocs.org/meetings.soy03</a> >
<b>November 27–29, 2003</b> <b>Montréal, Quebec</b>	“ASTHMA EDUCATION Assessment, application, evaluation: The cycle of success” Canada’s Sixth National Conference on Asthma and Education (ASED 6) Presented by the Canadian Network For Asthma Care (CNAC) and hosted by the Quebec Asthma and COPD Network	Information: A. Les McDonald, Executive Director Canadian Network For Asthma Care 6 Forest Laneway, Suite 1607 Toronto, Ontario M2N 5X9 Tel.: (416) 224-9221 Fax: (416) 224-9220 E-mail: <a href="mailto:ased@cnac.net">ased@cnac.net</a> < <a href="http://www.cnac.net">www.cnac.net</a> >
<b>June 13–16, 2004</b> <b>Milan, Italy</b>	“Positioning Technology to Serve Global Heart Health” 5 <sup>th</sup> International Heart Health Conference	The International Advisory Board of the International Heart Health Conference E-mail: <a href="mailto:sihh@g8cardio.org">sihh@g8cardio.org</a> < <a href="http://www.g8cardio.org">www.g8cardio.org</a> >

## Congratulations to Dr. Bernard Choi

A 1998 article published in CDIC by Dr. Choi has been designated required reading for a public health informatics course at Johns Hopkins University.

Choi BCK. Perspectives on epidemiologic surveillance in the 21<sup>st</sup> century. *Chronic Dis Can* 1998;19:145–51. < [http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/cdic-mcc/19-4/b\\_e.html](http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/cdic-mcc/19-4/b_e.html) >

As author of this article, Dr. Choi was recently invited to participate and speak at the World Congress on Risk in Brussels, Belgium and is now a member of an international group preparing a white paper on data standards.

# CDIC: Information for Authors

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Chronic Diseases in Canada (CDIC) is a peer-reviewed, quarterly scientific journal focusing on the prevention and control of non-communicable diseases and injuries in Canada. This may include research from such fields as epidemiology, public/community health, biostatistics, behavioural sciences and health services. CDIC endeavours to foster communication on chronic diseases and injuries among public health practitioners, epidemiologists and researchers, health policy planners and health educators. Submissions are selected based on scientific quality, public health relevance, clarity, conciseness and technical accuracy. Although CDIC is a Health Canada publication, contributions are welcomed from both the public and private sectors. Authors retain responsibility for the contents of their papers, and opinions expressed are not necessarily those of the CDIC Editorial Committee or of Health Canada.

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**Cover letter:** Signed by all authors, stating that all have seen and approved the final manuscript and have met the authorship criteria of the Uniform Requirements and including a full statement regarding any prior or duplicate publication or submission for publication.

**First title page:** Concise title; full names of all authors and institutional affiliations; name, postal and e-mail addresses, telephone and fax numbers for corresponding author; separate word counts for abstract and text.

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**Abstract:** Unstructured (one paragraph, no headings), maximum 175 words (100 for short reports); include 3–8 key words

(preferably from the Medical Subject Headings (MeSH) of Index Medicus).

**Text:** Double-spaced, 1 inch (25 mm) margins, 12 point font size.

**Acknowledgements:** Include disclosure of financial and material support in acknowledgements; if anyone is credited in acknowledgements with substantive scientific contributions, authors should state in cover letter that they have obtained written permission.

**References:** In “Vancouver style” (consult Uniform Requirements and a recent CDIC issue for examples); numbered in superscript (or within parentheses) in the order cited in text, tables and figures; listing up to 6 authors (first 3 and “et al.” if more); without any automatic reference numbering feature used in word processing; any unpublished observations/data or personal communications used (discouraged) to be cited in the text in parentheses (authors responsible for obtaining written permission); authors are responsible for verifying accuracy of references.

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