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Measuring Self-Reported Sunburn: Challenges and Recommendations

Jean A Shoveller and Chris Y Lovato

Abstract

Sunburn is a major preventable risk associated with the development of malignant melanoma and basal cell carcinoma. It is considered a key epidemiological concept to assess in prevention research and a core component of routine behavioural surveillance and program evaluation efforts. This review examined 38 English-language survey instruments and research reports published between 1990 and 1999 that used self-report data or parent-proxy reports of sunburn outcome. A qualitative review of the instruments and reports identified several methodological issues: the conceptual and operational definitions of sunburn, the recall period, and the use of self-reports and parent-proxy reports. As there was little consistency in definitional issues or recall periods across the studies, it is difficult to meaningfully compare their findings. We examine key issues that program evaluators and researchers should consider in determining the strengths and limitations of various definitions, measures and approaches and include recommendations for measurement of sunburn and for further research.

Key Words: *prevention; skin cancer prevention; surveys*

Introduction

Skin cancer has been described as an emerging public health problem in North America in terms of morbidity, mortality, health care costs, and personal disfigurement. In 1999, 740 Canadians died of malignant melanoma and approximately 66,000 new cases of skin cancer were diagnosed.¹ In 2000, 47,700 new cases of melanoma were diagnosed in the United States. It is estimated that this form of cancer will kill 7,700 Americans during the upcoming year.² Cumulative exposure to ultraviolet radiation from sunlight and other sources seems necessary for the development of squamous cell carcinoma, while solar exposure received as a result of sunburn, may be more important in the development of cutaneous malignant melanoma and basal cell carcinoma, especially amongst people who may have high melanocyte density or who may be genetically predisposed.³⁻¹⁰

Given the emerging magnitude of this health problem in North America,¹¹⁻¹⁴ the number of practitioners and researchers working in skin cancer prevention has increased rapidly over the past decade. Since melanoma and non-melanoma skin cancers may have distinct

patterns of occurrence and etiology, this review focuses on sunburn as an important risk factor, and therefore a key outcome, associated primarily with cutaneous malignant melanoma and basal cell carcinoma.^{15,16} Other outcomes, such as cumulative lifetime sun exposure, may be more relevant to the etiology of squamous cell carcinoma and may demand different measurement and prevention strategies.

Hill et al.¹⁵ suggested that a sunburn is a useful outcome for researchers and prevention program evaluators to assess because it “can be taken as an objective indication that a biologically effective dose of ultraviolet radiation (UVR) has been received, regardless of the measured amount of environmental UVR.” These authors asserted that sunburn is a good “after the fact” indicator of inadequate sun protection behaviour and concluded that sunburn represented a good measure of the “UVR dose received.” They also pointed out that since sunburn is at least partly under the control of the individual, it represents a worthwhile focus for those interested in evaluating prevention programs.

Author References

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While increasing numbers of program evaluations, behavioural surveillance surveys and case-control studies have measured sunburn using self-reported data, concerns have been raised about the validity and reliability of these data.¹⁶⁻¹⁹ A lack of standardized approaches to measuring self-reported sunburn has also prevented advancement in this area.

It is important to recognize that no single method of measurement is capable of addressing the needs of all epidemiological researchers and program evaluators working in the area of skin cancer prevention. Age at exposure to severe sunburn may be critical to understanding the etiology of melanoma, but less relevant to a program evaluation designed to improve current sun protection behaviour. To improve program planning, evaluation, and research in these areas, it is important to be able to make meaningful comparisons across studies. We need to be able to compare how sunburn rates in one community might differ from those in other regions. We must also be able to meaningfully compare results to determine if one intervention approach is more effective than another in reducing sunburn.

There is little information to guide researchers and practitioners in assessing existing self-reported measures of sunburn and comparing sunburn results across studies. There is little discussion in the literature to help practitioners and researchers select self-reported measures and study approaches that best fit their particular aims. This paper reviews examples of various definitions, questions, and study approaches used to assess self-reported sunburn. We discuss the implications of using self-reported sunburn data on reliability and validity and address some practical issues concerning measurement.

Methods

A search was conducted in various electronic databases, Medline and CAB HEALTH CD-ROM, HealthStar, CancerLit, Social Sci Search and EMBASE, to identify and retrieve relevant published literature. To meet the preliminary study eligibility criteria, the literature must have been a primary research report that included or focused on sunburn as a behavioural outcome, and/or an intervention or descriptive study associated with melanoma and basal cell carcinoma prevention or epidemiology, written or published in English between 1990 and 1999. Additional reports were located by hand-searching selected cancer prevention journals and reference lists from retrieved articles. In all but a few cases, copies of survey instruments were obtained by contacting the authors. We chose to focus our review on the past decade because during this time skin cancer has begun to emerge as an important health issue in North America and has become a more widespread issue for program planners, practitioners and researchers.

This review focuses on studies that used self-report and/or parent-proxy reports of sunburn. It does not include studies that used the term "sunburn" for measuring a

person's propensity to sunburn (i.e., as a measure of phenotype), nor does it include studies that focused exclusively on knowledge or attitudes concerning sunburn. We assessed the studies independently and resolved disagreements about eligibility through discussions until consensus was reached. Information on study approaches, definitions, questions or survey items, and an assessment of the quality of the instrument (including reliability and validity, where provided) was extracted and summarized. We then conducted a qualitative synthesis of the extracted information to identify key issues related to the reliability and validity of sunburn measures.

Results

Description of studies reviewed

This paper presents a critical review of 38 published reports and unpublished survey instruments that assessed self-reported sunburn as a behavioural outcome. All studies relied on self-reports of sunburn as a primary outcome. Of the reports reviewed, 13 studies^{15,20-31} were conducted with adults from the general population, 10³²⁻⁴¹ with adolescents or youth, 11⁴²⁻⁵² with parents, and four⁵³⁻⁵⁶ with adult dermatology patients or individuals identified through cancer registries. Nearly half of the studies (n = 16) were conducted in the US or Canada.^{21,22,26,27,30,32,38-40,43,47,48,50-52,55} Eleven (n = 11)^{15,23,25,28,31,33,34,36,37,44,49} were conducted in Australia and New Zealand, and eleven were conducted in Europe (including the UK).^{24,29,35,41,42,45,46,53,54,56} Most studies (n = 35) were descriptive in nature and relied on cross-sectional surveys or structured interviews, although three used a case-control study design.^{53,55,56} Table 1, which can also be viewed at <<http://www.healthcare.ubc.ca/shoveller/home.html>> summarizes the studies and instruments included in this review.

On analyzing the information extracted from each article and instrument, we identified three issues that warrant further discussion:

- conceptual and operational definitions of sunburn;
- recall periods; and
- use of self-reported data and parent-proxy reports.

Conceptual and operational definitions

No standardized conceptual or operational definition of what constitutes the presence of sunburn was widely used across the studies. In some reports and instruments, researchers appeared to assume that respondents have an implicit understanding of the concept "sunburn". For example, one survey provided no operational definition for respondents to use as a reference point, asking only if individual sunbathers had "ever had an obvious case of sunburn."²⁴ In contrast, another study was very specific in asking whether sunburns were "so severe that they produced blisters or pain lasting two or more days."²²

TABLE 1
Review of Self-Report Sunburn Reports

Author (Year)	Population	Study Purpose/ Method	Construct Measures	Measures of Self-Reported Sunburn
Autier et al. ⁵³	CM patients Germany, France, Belgium (418 CM, 438 healthy)	Retrospective case-control	Sunburn experienced during childhood	Not provided, but age categories of recall were 5–9 and 10–14 years.
Baade et al. ²⁰	Adults in Queensland, Australia 1988, n = 1699 1991, n = 2317	2 cross-sectional telephone surveys	Sunburn during previous Sunday and severity of sunburn	Not provided, but reported whether respondent “was sunburnt on Sunday”. Also reported that severity of burns had decreased since 1988, but did not include items.
Banks et al. ³²	Adolescents attending pediatric office (n = 220) in Virginia, USA	15-item survey of adolescents	Number of blistering sunburns	Not provided, but reported that 33% admitted to experiencing a blistering sunburn during the previous two summers.
Blizzard et al. ³³	Random sample of 14–15-year-old students (n = 364) in Tasmania (AU) 1992, prior to summer 1993, after summer	2 cross-sectional surveys completed by students in consultation with parents	<ul style="list-style-type: none"> No. of painful sunburns during lifetime/past summer Body parts burnt Frequency of sunburns 	1992: Sunburns (pain lasting 2+ days) last summer Never, 1 to 5 times, 6+ times Sunburns (pain lasting 2+ days) during lifetime Never, 1 to 5 times, 6-10 times, 11+ times 1993: Sunburns (pain lasting 1+ days) last summer Never, 1 time, 2 to 5 times, 6+ times Sunburnt less often than usual Sunburnt as often as usual Sunburnt more often than usual
Bourke & Graham-Brown ⁴²	Parents in UK (n = 238) with children <14 years	Interviews with parents re: sunburns among their children	Frequency of sunburn at home and on sun-holidays abroad	“Do your children ever get sunburnt?” Never Sometimes (1/yr) Often (several /yr) Always
Brandberg et al. ⁵⁴	Patients in Sweden with DNS-D2 (n = 54), mean age 33 years	Sun-related behaviour diary during 1 month (June or July, 1994) 6-month post-diary mailed survey Assessed agreement between diary and recall of same time period on survey	Number of sunburns	“How often do you get burns (pain and redness in the skin) when sunbathing?” (Four response categories from “Never” to “Very often”.)
Broadstock et al. ³⁴	Students 12–17 years of age (n = 2524 males and n = 2480 females)	School-based survey conducted in 72 secondary schools in Australia	Sunburn during previous summer	
Campbell et al. (unpublished)	Alberta adults (n = 500 females, 500 males)	RDD telephone survey during July–September, 1992	<ul style="list-style-type: none"> Sunburn previous Sunday, previous Saturday, previous weekday Body part burned Type of burn Blisters Treatment of burn Burn at work 	“Did you get sunburnt yesterday? What about Saturday? What about last (read weekday)? Yes/No” “Where did you get burnt? Where else? 30 categorical responses re: body part burned” “What of the following statements best describes the burn on you (read part burnt)? Red without being tender, red and tender, red, tender and blistered” “Are the blisters weeping? Yes/No” “How did you treat your sunburn?” “Were you at your regular job when you got sunburnt?” Yes/No weekday? Saturday? Sunday?”
Dennis et al. ²²	18–50 year old adults in Washington state (n = 717)	RDD telephone survey during 1990–1991	Severe sunburns over 3 time periods (childhood, teen years, past 5 years)	No items included in report. Number of severe sunburns. “Sunburns were defined as sunburns so severe that they produced blisters or pain lasting 2 or more days.”

TABLE 1 (continued)
Review of Self-Report Sunburn Reports

Author (Year)	Population	Study Purpose/ Method	Construct Measures	Measures of Self-Reported Sunburn
Douglass et al. ²³	21-year old New Zealanders (n = 909)	Self-report survey	<ul style="list-style-type: none"> • Number of burns • Type of burn • Factors related to reduction in burns 	<p>"How do you think the following activities affect your risk of getting melanoma? Please tick. Getting a severe sunburn? Increase my risk, decrease my risk, have little effect, have no effect."</p> <p>"Do you have fewer sunburns now than you did when you were age 15? Please tick. No/Yes, If yes, why is this so? Open ended."</p> <p>"Since the age of 15, have you been sunburned so badly that you got blisters or were in pain for two or more days? Please tick. No/Yes"</p> <p>"If you went out in the sun at the beginning of summer without protection for 15 minutes, which one of the following would happen to your skin? Please tick. Get sunburned and not tan later, get sunburned but tan later, get tanned but not sunburned."</p>
Eiser & Arnold (unpublished)	Residents (n = 107) and visitors (n = 108) in England during May 1995	Beach survey on attitudes and behaviours	<p>Sunburn history</p> <p>Frequency of sunburns</p>	"ever had an obvious case of sunburn, if so, how many times" (response categories: <5, 5–10, >10, scored 0 for never to 4 for more than 10)
Hall ⁴³	Instrument only, no report. US survey.	National telephone survey with parents re: children's sun-related behaviours and parental attitudes	<ul style="list-style-type: none"> • Susceptibility to sunburn • Sunburn during past year • Frequency of sunburn during past year • Sunburn during past weekend • Painful sunburn • Attitude towards sunscreen to protect child from burn • Importance of child's risk of sunburn 	<p>"If, over the course of the summer, (CHILD) goes out in the sun repeatedly without sunscreen or sun block or protective clothing, which one of these things would happen to his/her skin? Categories: repeated sunburns. By sunburns I mean reddening of the skin that lasts at least 12 hours. A mild tan, A moderate tan, A deep tan, Other, refuse, don't know"</p> <p>"Has (CHILD) had a sunburn within the past year? Yes/No"</p> <p>"How many times has (CHILD) been sunburned in the last year? Number of sunburns ____"</p> <p>"Did (CHILD) get a sunburn during the past weekend? Yes/No"</p> <p>Was the sunburn painful? Yes/No"</p> <p>"Routinely using sunscreen on (CHILD) is not necessary because he/she doesn't burn." 7-point Likert-like scale from "strongly agree" to "strongly disagree".</p> <p>"Is (CHILD)'s tendency to burn important, unimportant, or neither, in influencing sunscreen use? Would you say slightly, somewhat or very (Unimportant/Important)?" 7-point Likert-like scale from "Very important" to "Very unimportant".</p>
Harrison et al. ⁴⁴	Children age 1–6 years born in North Queensland Australia (n = 506)	Survey and naevi assessment and mapping	Previous history of sunburn	No sunburn items included.
Hill et al. ¹⁵	Adults in Melbourne, Australia (n = 1655), stratified sampling so that approx. 2/3 were <35 years of age	Telephone survey conducted weekly for 13 weeks during summer of 1987–88 Recall period was preceding weekend or holiday	<ul style="list-style-type: none"> • Presence of sunburn during previous weekend • Type of burn • Body part burned • Activity when burned 	<p>No items included in report.</p> <p>No sunburn v. with sunburn</p> <p>Type of sunburn, having erythema that was tender, or becoming blistered, reddening of the skin after being in the sun."</p> <p>Body parts: 14 categories</p> <p>Activity when burned: 8 categories: sport (non-water), water sport, active recreation, passive recreation, work in garden, work at home, paid work, unclassified.</p>
Hill et al. ²⁵	Adult residents of Melbourne, Australia (n = 4428)	Telephone interviews in the summer of 1988, 1989 and 1990. Recall of previous weekend	<ul style="list-style-type: none"> • Sunburn previous day • Sunburn on Saturday • Type of burn • Body part burned 	No sunburn items included.

TABLE 1 (continued)
Review of Self-Report Sunburn Reports

Author (Year)	Population	Study Purpose/ Method	Construct Measures	Measures of Self-Reported Sunburn
Holly et al. ⁵⁵	White women age 25–59 years, in San Francisco Bay area diagnosed with CMM (n = 452 cases, 930 controls)	Population-based case-control	<ul style="list-style-type: none"> • Sunburns during childhood • Type of sunburn • Frequency of sunburn • Sunburn during vacations or while living in tropics 	<p>“Which of the following <u>best</u> describes your exposure to the sunshine when you were a child up to age 12? I got severe and/or frequent sunburns, I got moderate and/or infrequent sunburns, I rarely burned or they were very mild or I got no burn”</p> <p>How many sunburns that caused <u>pain</u> for two or more days do you recall during the last year?” Open-ended.</p> <p>And how many the year before last? Open-ended.</p> <p>Now please tell me which category best describes how many sunburns that cause <u>pain</u> for two or more days that you recall: a) during elementary school, grades 1–8? during high school grades 9–12? during the ages of 23–30? If over 30, over age 30? None, 1–3, 4–6, 7–9, 10–20, More than 20.</p> <p>Have you even been sunburned so as to cause pain for two or more days? Yes/No</p> <p>If yes, how often has this occurred?</p> <p>a) Altogether over the last 10 years?</p> <p>b) Between your 15th and 25th birthday? (for subject over 30 years of age)</p> <p>What areas of your body were affected when you were <u>last</u> sunburned that severely? Yes/No</p> <p>Face? Back or shoulders? Chest? Arms? Legs?</p> <p>Holiday or living in tropics:</p> <p>When you were (age), did you ever get a blistering sunburn? Under 5 years old? 5–12 years? 13–19 years, 20–39 years, 40 to today? Yes/No</p> <p>When you were (age), how many times did you get a blistering sunburn?” Same age categories as above, but open-ended response options.</p>
Hughes et al. ³⁵	Students (age 12+ years) from 7 areas in England (n = 543)	Pre-post questionnaire to assess the impact of an educational intervention. Pre (May 1990), post (September 1990).	Sunburn during summer months	“Did you get sunburnt during the school summer holidays?”
Jarrett et al. ⁴⁵	Mothers (n = 200) attending a pediatric department	Mothers were interviewed about their youngest children, up to a maximum of 3 per family (only children under 20 years of age were included). Information was obtained on 416 children.	Number of times their children had been sunburnt in previous year	Sunburn was defined as more than 1% of the total body area going red several hours after exposure to the sun.
Kakourou et al. ⁴⁶	Greek mothers with children age 1–12 years (n = 315) attending walk-in pediatric outpatient department	Mothers interviewed by 2 pediatricians between September and November 1993	Number of blistering sunburns (parents and children)	No sunburn items included in report.

TABLE 1 (continued)
Review of Self-Report Sunburn Reports

Author (Year)	Population	Study Purpose/ Method	Construct Measures	Measures of Self-Reported Sunburn
Leinweber ²⁶	Skiers in Alberta	Telephone interview as a follow-up to on-hill survey at the gondola at Sunshine Mountain in Banff	Sunburn presence Body part burned Severity of burn Action related to burn treatment Rationale for burn Previous skiing related burn	<p>"Did you get a sunburn on 'ski day'? Yes/No"</p> <p>"What area of your body was sunburned? Face, ears, nose, neck, arms, hands, legs, other."</p> <p>"Which was the worst area that was burned? Same options."</p> <p>"Which of the following statements best describes the (worst) burn? Red without being tender, Red and tender, but NOT blistered, Red, tender and blistered."</p> <p>"When did you notice the sunburn? During skiing, After I had finished skiing for the day."</p> <p>"What did you do when you realized you were burned? Nothing, Used sunscreen, Moisturizer. Lotion, etc, Spent some time inside, Covered with clothing, Went to physician/pharmacist."</p> <p>"Why do you think you got burnt? I didn't protect my skin until I'd already been out for a while, I must have missed that area when applying sunscreen, The sunscreen must have worn off, I got burnt through sunscreen, I got burnt through clothing, Other."</p> <p>"Have you had a sunburn while skiing this Spring prior to 'ski day'? Yes/No/Did not ski. How many times were you burned?"</p>
Lescano et al. ⁴⁷	Parents with children age 3–8 years in Florida (n = 88)	On-beach interview with parents in Hollywood and Fort Lauderdale, FL July 1993–April 1994.	Lifetime sunburn history for child and parent	No sunburn items included.
Lowe et al. ³⁶	Random sample of grade 7–11 students in Queensland, Australia in later summer 1991 (n = 3655)	Self-administered survey	Perceived severity of sunburn	"Getting sunburnt occasionally doesn't do any harm."
Maducdoc et al. ⁴⁸	Parents with children having skin types I–IV and age 12+ years in Galveston, TX (n = 82)	On-beach survey	Number of children with previous painful sunburn	No sunburn items included.
McGee et al. ²⁸	Adults age 15–65 years living in one of 5 cities in New Zealand and Australia (n = 1243)	Telephone interview	<ul style="list-style-type: none"> • History of sunburn • Sunburn during past weekend • Body part sunburned • Type of burn 	<p>"Apart from the weekend just finished, have you ever been sunburnt so badly you got blisters or were in pain for two or more days? Yes/No/DK"</p> <p>"Did you get at all sunburnt on Sunday just passed? By sunburnt we mean any amount of reddening of the skin after being in the sun. Yes/No/DK"</p> <p>"Did you get at all sunburnt on the Saturday just passed? Yes/No/DK"</p> <p>Which part or parts of you got sunburnt at the weekend? 15 options for body parts"</p> <p>"Which part was burnt worst? Same 15 options"</p> <p>"Which of the following statements best describes the burn on your _____? (worst burn) Red, without being tender or sore, Red, and tender or sore, Red, tender or sore, and blistered, DK"</p>
McGee et al. ⁴⁹	Parents with children age 0–10 years living in one of 5 cities in New Zealand and Australia (n = 325)	Parents were interviewed by telephone about their own and their children's sun-related behaviours. Interviews were conducted on Monday evenings and the recall period included specific weekends between January 22 and March 27, 1994.	<ul style="list-style-type: none"> • Presence of sunburn on one or more of the designated weekends. • Type of sunburn • Description of worst sunburn • Body part sunburned 	No sunburn items included.

TABLE 1 (continued)
Review of Self-Report Sunburn Reports

Author (Year)	Population	Study Purpose/ Method	Construct Measures	Measures of Self-Reported Sunburn
McGee et al. ³⁷	Students in the Auckland region (n = 345)	Survey of random samples of students from each of the schools located in Auckland (schools were selected deliberately to reflect a cross-section of the SES of the area)	Presence of severe sunburn during previous summer months	No sunburn items included.
Melia & Bulman ²⁹	Adults age 16+ in England (n = 2025)	Random sample interviewed by census workers in October, 1993	Frequency of sunburns during past 12 months Type of sunburns	"During the last 12 months how many times have you had the following types of sunburn: Sunburn causing reddening of the skin that lasted overnight but with no skin soreness? Once, Twice, 3 times, 4 or more, not in last 12 months. Reddening and soreness of the skin lasting for 1-2 days but no blistering? Same options. Reddening and soreness of the skin lasting for more than 2 days but no blistering? Same options. Reddening and soreness of the skin lasting for more than 2 days together with blistering? Same options."
Miller et al. ⁵⁰	Random sample of parents residing in Falmouth, Massachusetts (n = 404, 1997; n = 401, 1994)	40-item telephone survey, recall of lifetime history of sunburn	Presence of a painful sunburn in lifetime	"Has your child ever had a painful sunburn? Yes/No"
Newman et al. ³⁰	Random sample of San Diego residents (n = 864), April 1994	39-item telephone survey, recall of lifetime history of sunburn	Number of blistering sunburns in lifetime	"How many blistering sunburns have you had in your lifetime? None, 1-5, 6-10, 11-15, 16-20, more than 20."
Oliphant et al. ³⁸	Students in grade 9-12 (13-19 years of age) from a suburb near St. Paul, MN (n = 1008)	Self-administered survey with 40 items. Completed during homeroom. Also included a survey that went home for parents to complete regarding their own sun-related behaviours.	<ul style="list-style-type: none"> • Number of sunburns during past 12 months. • Pain from sunburn • Sunburn from tanning bed • 1 Knowledge item 	<p>"How many times in the last 12 months did you get a sunburn that blistered or peeled from the sun? Not at all, Once, Twice, More than twice."</p> <p>"Did the pain from the sunburn last 2 or more days?"</p> <p>"Has your skin ever blistered or peeled from a sunburn as a result of using a tanning bed?"</p> <p>"As long as I don't get a sunburn from a tanning booth or bed, I am safe from skin cancer. True/False/DK"</p>
Reynolds et al. ³⁹	6 th Grade students in Alabama (n = 509)	Survey administered in schools by research assistants. Questions read aloud by RAs.	<ul style="list-style-type: none"> • Number of sunburns during previous summer and previous (Labor Day) weekend • Type of sunburn 	Types of burn included: Painful burns Burns causing blisters
Robinson et al. ⁴⁰	Teenagers 11-19 years in metro Chicago and rural Illinois. Stratified by SES (n = 658)	RDD household telephone survey within each SES stratum	Number of sunburns during past year	"About how many times have you gotten sunburned in the past year, when your skin got red and hurt? Select none or give the number of times."
Rodrigue ⁵¹	Caucasian mothers of children age 6 months - 10 years in US. Non-probability sample recruited through letters from PTA (n = 55)	Telephone interview in August to determine assignment to intervention conditions, then follow-up interview in November.	<ul style="list-style-type: none"> • Lifetime Hx of sunburn (Parents) • Painful sunburns in past 6 months (Child) • Painful sunburns in past 6 months (Parent) • 2 Knowledge items 	<p>"No. painful sunburns <u>you</u> have had in your lifetime: _____"</p> <p>No. painful sunburns <u>child</u> has had in last 6 months: _____"</p> <p>No. painful sunburns <u>you</u> have had in last 6 months: _____"</p> <p>"In young children, a bad sunburn can cause: dehydration, delirium, irregular hear beat, dangerously low blood pressure, all of the above"</p> <p>"Doctors recommend treating a child's sunburn by: rubbing in a moisturizing lotion, applying alcohol to the affected area, soaking the affected area in lukewarm water, dabbing on a calamine lotion that has an antihistamine, all of the above."</p>

TABLE 1 (continued)
Review of Self-Report Sunburn Reports

Author (Year)	Population	Study Purpose/ Method	Construct Measures	Measures of Self-Reported Sunburn
Shoveller et al. ²⁷	Probability sample of adults living in Canada (n = 4,023)	RDD telephone survey conducted in September 1996	<ul style="list-style-type: none"> • Sunburn during past 3 months • Type of sunburn • Body part sunburned • Activity when sunburned 	During June to August, how many times have you had the following types of sunburns . . . A blistering burn that required medical attention? A blistering burn that did not require medical attention? Redness or sensitivity, with peeling? Redness or sensitivity, with no peeling? Which part of your body was most seriously sunburned? List of body parts What were you doing when you received your most serious sunburn during June to August? Taking part in or watching outdoor recreation activities Sitting or lying out in the sun Working outside Using an artificial method of tanning Driving Other (Specify)
Stender et al. ³¹	Caucasian sunbathers at beaches and parks in eastern Denmark, including parents with children younger than 10 years (n = 805)	Interviewers approached sunbathers wearing bathing suits. A sub-sample of 207 received a pre-paid postcard survey to complete and return regarding what time they actually left the park.	<ul style="list-style-type: none"> • Likelihood of sunburning • Sunburns despite protection. 	Respondents were asked if they always, sometimes, seldom or never were sunburned when not using sunscreen in the spring. All subjects were asked if they ever experienced sunburn despite sunscreen use. Those who answered "no" were further asked if they ever experienced "to turn red" despite sunscreen use.
Westerdahl et al. ⁵⁶	Adults age 15–75 in Sweden (n = 400 melanoma patients, 640 controls)	Population-based matched case-control. Case finding from Tumour Registry.	<ul style="list-style-type: none"> • Number of painful sunburns • Age at time of sunburn • Episodes of blistering sunburns • Formation of ulcers due to excessive sun exposure 	No sunburn items included.
Wichström ⁴¹	National probability sample of Norwegian senior high school students in 1992 (n = 15,863)	Survey	Type of sunburn last summer	"Did you get sunburned last summer? Yes, got very strongly burned (deep crimson colour, very sore, blisters, and skin peeling off big flakes after the burn), Yes, got strongly burned (clearly red, soreness, skin peeling off), Yes, got quite burned (red, some soreness, some skin did peel off), Yes, got slightly burned, No burn."
Zinman et al. ⁵²	Parents with children presenting at ER in Halifax, Canada (n = 925)	4 part survey administered to parents presenting with children at IWK ER during August, 1993	<ul style="list-style-type: none"> • Parental experience with painful sunburns • Parental beliefs about susceptibility of child to sunburns • Child's previous experience with painful sunburn • 1 knowledge item 	"Have you ever had a blistering sunburn? Yes/No" "Does a blistering sunburn in childhood increase your risk of skin cancer? Yes/No" "Compared to other Nova Scotia children of similar age and sex, your child's chance of getting a sunburn in the next month are: Much below average, Below average, A little below average, Average, A little above average, Above average, Much above average."

Sunburn has also been defined in terms of the physical characteristics associated with it, such as redness, tenderness, blistering, and peeling of skin. Skiers, in one example, were asked to select from the following categories the term that best described their worst burn:

- Red without being tender;
- Red and tender, but not blistered; or
- Red, tender and blistered.²⁶

Some studies also asked respondents to self-report on the frequency with which they had been sunburned or had received a particular type of sunburn. For example, one study asked parents to describe their children's sunburn frequency using the following: "Do your children ever get sunburnt? Never; Sometimes (once per year); Often (several times per year); and Always."⁴² A different survey assessed the frequency of painful sunburn among students in the Australian state of

Tasmania using the following categories: “Never, 1 time, 2–5 times, 6+ times.”³³ In these studies, respondents provided data in the form of categorical variables. In other reports and instruments, open-ended questions were used to collect self-reported sunburn data in the form of continuous variables. For example, a case-control study of female dermatology patients used an open-ended response option to assess the number of sunburns received during the past year.⁵⁶

In a study of Australian students³³ that compared data from two cross-sectional surveys conducted in 1992 and 1993, the problems of inconsistent approaches to defining self-reported sunburn type and frequency are well illustrated. As the authors note, comparisons between results from the two surveys were difficult to make because sunburn was defined and measured differently in each survey. In the 1992 survey, sunburn was defined as “pain lasting 2+ days,” while in 1993, “1+ days” was the reference point. In addition, the categorical response options available for reporting frequency of sunburn differed in each survey. Girls appeared to be more likely to report higher rates of sunburn in the 1992 survey than the 1993 survey. On the other hand, boys seemed to be more likely to report higher rates of sunburn in the 1993 survey. No conclusions could be drawn on these differences, however, since they could be due to differential definition and measurement of self-reported sunburn.

Recall period

There was considerable variation in recall periods across the studies. Depending on the purpose of the study, some researchers focused on lifetime sunburn history and others focused on a specific period. For example, 12 reports and instruments included a measure of sunburn history that asked respondents to report on sunburns received during any point in their lifetimes.^{24,28,30,31,33,38,42,47,50,52,55} Two studies asked respondents to recall sunburns received at specific ages, although the categories provided varied between these two studies.^{54,56} The term “sunburn history” was used frequently in published reports and instruments to refer to recollections of experiences with sunburn over the course of a defined recall period (e.g., lifetime, childhood, past year). Many studies (n = 21) asked respondents to self-report on their sunburn history using a recall period of one year or less, including previous day or weekend,^{15,20,21,25,26} previous summer or past year,^{27,29,32,35,37,38,41,46,50,54} or some combination of past year, previous summer and past weekend.^{28,33,39,43,51,55} The remainder of the reports or instruments we reviewed did not define a recall period.

Use of self-reported data and parent-proxy reports

All of the studies included in this review relied on either self-reported data or parent-proxy reports. Most studies did not describe measures of reliability or validity associated with the self-reported data. Although self-reported sunburn was rarely validated or verified in

the studies reviewed for this paper, one study used a sun-behaviour diary to verify self-reported sunburn.⁵⁴ There were no significant differences between diary and survey reports in this study, although there was a tendency among those with multiple burns to underestimate the absolute number of sunburns when completing the self-report survey. The correlation between the number of sunburns reported in the diary and those reported on the survey was $r = 0.60$, $d.f. = 40$, $P < 0.001$. In another study, Shoveller et al.²⁷ described inconsistencies between self-reports in a national survey on protection and self-reported sunburns. That is, the self-reported prevalence of protection was much higher than would be expected given the large proportion of sunburns reported.

Use of parent-proxy data describing children’s sunburns also presents problems when comparing results across studies. Eleven of the 38 reports assess children’s sunburns using parent-proxy reports.^{42–52} None of these studies uses comparable conceptual definitions or recall periods, which makes it difficult to accurately compare results across them. For example, Kakourou et al.⁴⁶ asked parents to estimate the number of blistering sunburns they and their children had experienced during the previous three summers. In a study of children presenting at emergency rooms, Zinman et al.⁵² administered a survey to parents to assess if their children had “ever had a blistering sunburn”.

While self-report and parent-proxy report data may be of questionable validity, all of the publications included in our review relied on these measurements. It is difficult to determine whether differences in results found when comparing across studies are real or due to differences in the way questions are asked, or due to the validity of self-report data. Few authors discussed the limitations of relying exclusively on self-reported data, although Autier et al. (1995)⁵³ indicated that the lack of effectiveness of sunscreens in protecting against melanoma may be influenced by measurement error, either because they did not measure an unknown confounder or because they inaccurately assessed a variable known to influence sunburn outcomes. Intervention effects may not be observed because they do not exist. Eiser and Arnold²⁴ also argued that without independent validation or means of determining the consistency of the criteria for identifying a case of sunburn, self-reported findings should be interpreted with caution. They posited that a previous history of sunburn may reflect not only skin type, but may also be an indicator of past protective behaviour. Overall, there has been very little research to independently establish the validity and reliability of sunburn recall.

Discussion

Three major issues associated with the reliability and validity of sunburn measures were identified as a result of reviewing the 38 reports and instruments included in this study:

- conceptual and operational definitions of sunburn;

- recall periods; and
- use of self-reported data and parent-proxy reports.

There is little consistency across the studies included in this review in definitional issues or recall periods. In addition, all of the findings of the studies we reviewed rely on self-reported data or parent-proxy reports. Thus, it is difficult to meaningfully compare findings across these studies.

In studies where respondents were asked open-ended questions about the frequency with which they were sunburned and the type of sunburn they received, it is possible to derive an overall score that reflects the severity and frequency of sunburn. These data may be important in estimating overall risk since it is biologically plausible to assert that more frequent and severe sunburns could be associated with increased risk of malignant melanoma and basal cell carcinoma. This kind of information may also help program planners to tailor public health messages on sunburn prevention.

Although no single method of measurement may be able to meet the needs of both epidemiologists and program evaluators, self-reported data are central to both. Concerns about measurement of sunburn may differ significantly depending on the intent of the study. The three case-control studies^{53,55,56} reviewed in this article provide useful examples of the need to develop measures tailored to the purpose of particular studies. For example, epidemiological researchers may be more likely to undertake case-control studies requiring approaches to measuring sunburn that account for the age at which sunburns occurred. Program evaluators, however, may be more likely to measure the number of sunburns received before or following an intervention to demonstrate changes in patterns of exposure or protective behaviours. As has been suggested by other researchers,¹⁶⁻¹⁹ reliance on self-reported data is an important problem facing researchers and practitioners working in the area of skin cancer prevention. Since self-reported measures of sunburn are widely used to assess risk, the development of standardized approaches to measuring this outcome represents an important area for further investigation. While technology, such as the colorimeter, has been used to assess sun exposure,¹⁹ self-reported measures are likely to remain the most widely used approaches to measuring sunburn since they tend to be most feasible and cost-effective for surveillance and evaluation purposes.

Program evaluators and researchers interested in assessing sunburn outcomes face some unique methodological challenges compared with other health behaviours or outcomes. For example, data collected during the summer season on recent sunburns (e.g., during the previous weekend) may vary within the region where the data are collected due to a number of factors, including variations in the weather, ultraviolet (UV) radiation levels (monitored by Environment Canada), and altitude. Reports on recent sunburns may be more susceptible to this sort of variability than reports

on sunburn outcomes received during a longer recall period, although some studies, such as program evaluations, may require more time-specific information.

The seasonal nature of sun-related behaviours in many parts of the world presents additional challenges to skin cancer prevention researchers and practitioners. Deciding the best time of year to collect behavioural outcome data becomes important, particularly in locations such as Canada, the UK and the northern US where sun exposure tends to be seasonal. In most of North America, behaviours that are typically associated with sunburn are highest during the peak UV season during the summer or early autumn. Some researchers have attempted to collect data closer to the summer months, when sunburn is most likely to occur; however, there is little consensus among researchers on the best time of year to do so. Since response rates to large, population-based surveys are typically lower during the summer months, researchers who are interested in estimating the prevalence of sunburn at the population level should collect data in early September, but not beyond late October.

Ideally, researchers and practitioners should be able to compare results across studies with some degree of confidence. We found that the wide variation of measurement approaches to assessing sunburn made such comparisons difficult. Of the 38 studies we reviewed, we were able to identify only three that were sufficiently similar in approach to permit this kind of comparison. In Table 2, we compare reported rates of sunburn across these three studies. Each study used telephone interviews with large probability samples of adults living in Canada, Australia or New Zealand and used comparable questions to assess the frequency and severity of sunburn. It is important to note the methodological differences between these studies, including the timing of the data collection and differences in recall periods. The Canadian survey was completed in four consecutive weeks during early autumn and relied on recall of sunburn experienced several months before the survey, while the New Zealand and Australian studies were completed on a weekly basis over the summer months and asked respondents to report on sunburns received during the previous weekend. Nevertheless, these three studies warrant discussion since they were all conducted with large probability samples and their results have influenced intervention approaches in their respective jurisdictions.

Two studies conducted in the southern hemisphere found similar rates of sunburn using similar items and recall periods (e.g., previous weekend) to assess sunburn. In comparison, the Canadian study used an item that focused on sunburns received during the previous year and found higher rates of sunburn than the studies conducted in Australia and New Zealand. It is plausible to assert that differences in reported sunburn prevalence may arise because Australia and New Zealand have in place long-standing and aggressive prevention programs, whereas Canada has only recently begun to address skin

TABLE 2
Impact of measurement on differential effects across studies

Author (Year)	Measurement of sunburn prevalence	Findings
Shoveller et al. ²⁷	During June to August, how many times have you had the following types of sunburns. . . A blistering burn that required medical attention? A blistering burn that did not require medical attention? Redness or sensitivity, with peeling? Redness or sensitivity, with no peeling?	50% of adults had one or more sunburns of any type during the previous 3 summer months
Hill et al. ²⁵	Did you get at all sunburnt yesterday? What about on Saturday? Sunday? Saturday Neither day?	10% of men and 5% of women reported any degree of sunburn during the previous weekend
McGee et al. ²⁸	Did you get at all sunburnt on Sunday just passed? By sunburnt we mean any amount of reddening of the skin after being in the sun. Yes? No? Don't know? Did you get at all sunburnt on the Saturday just passed? Yes? No? Don't know?	12% of respondents reported sunburn on the preceding Saturday and/or Sunday

cancer prevention. However, differences in reported sunburn prevalence rates between the studies conducted in Australia/New Zealand and Canada also may be due to differences in recall period and/or the unreliability of self-reports.

Recommendations for measuring sunburn and for further research

What should program evaluators and researchers consider in determining the strengths and limitations of various definitions, measures and approaches to assessing sunburn or examining the results of studies assessing sunburn? The most critical issue to consider is how the data will be used (e.g., program evaluation, population-level behavioural risk factor surveillance, or case-control study). Program evaluators are likely to need data that focus on individual episodes of sunburn during an intervention period. In contrast, those conducting surveillance research require questions that yield data pertaining to population estimates of prevalence patterns that can be compared over time to assess shifts in behaviour across an entire population. Reports on sunburn outcomes over a more extended recall period, such as the previous summer, may be sufficient for the purposes of program planning. Alternatively, researchers conducting case-control studies require measures that generate information on the frequency and severity of previous critical incidents of sunburn during specific age periods (e.g., less than 18 years of age).

We recommend that program evaluators and researchers tailor their approaches to sunburn measurement to the context within which their research is conducted and to how they plan to use the data. More standardized approaches to measurement, however, would help practitioners and researchers address some of the validity and reliability issues identified above. In Canada, we have attempted to develop a consensus on approaches to

measuring sunburn to improve the comparability of results across studies. During the 1998 Canadian National Workshop on Measurement of Sun-Related Behaviours a group of practitioners and researchers working in this area developed several recommendations on measuring self-reported sunburn.¹⁶

In summary, the workshop participants made three recommendations on the assessment of sunburn for inclusion in omnibus style behaviour surveillance surveys and program evaluations. Sunburn is:

- an indirect measure of sun exposure and protection;
- important in the etiology of melanoma and basal cell carcinoma; and
- a relatively memorable and distinct event.

Sunburn was identified as the most important outcome to assess in omnibus style or program evaluation surveys, where space is often limited. The recommendations are perhaps less well suited for use in case-control studies. They are suitable for assessing sunburn outcomes using personal interviews, telephone surveys, or self-administered survey formats (see Table 3). They use a recall period of one year, since sunburns are not typically routine or frequent events, and were designed to capture data on both the frequency and severity of sunburns sustained during the previous year. In Canada, it is recommended that surveys using these recommendations are most appropriately conducted during the late summer or early autumn.

Further research is required to establish the reliability and validity of the recommendations presented in Table 3. Although few studies have attempted to validate self-reported sunburns, it is encouraging to note that one study, which used a sun-behaviour diary to verify self-reported sunburn, ascertained good correlation between self-reported items and diary entries. Future research

TABLE 3
Recommended core questions for measuring sunburn

Recommended questions
SQ1: A sunburn is any reddening or discomfort of your skin that last longer than 12 hours after exposure to the sun or other UV [ultraviolet] sources, such as tanning beds or sunlamps. In the past year, has any part of your body been sunburned? Yes/No Universe: All respondents
SQ2: Did any of your sunburns involve blistering? Yes/No Universe: Respondents who had a sunburn in previous year
SQ3: Did any of your sunburns involve pain or discomfort that lasted for more than one day? Yes/No Universe: Respondents who had a sunburn in previous year

may benefit from using this combination to measure the frequency and severity of sunburn. Additionally, research should be undertaken to develop and test self-report items that could be used in case-control studies.

Conclusion

Because sunburn is one of the most important indicators of risk for melanoma and basal cell carcinoma, it is important to improve the way this outcome is measured. Currently, a lack of standardized measurements inhibits comparison of results across studies and presents a serious barrier to progress in this area of research. Improvements in the measurement of self-reported sunburn can serve to enhance the overall quality of data collected during routine behavioural surveillance and program evaluation efforts. By collecting better quality data, researchers, planners and evaluators can work together more effectively on program and policy strategies to prevent skin cancer.

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Assessment of Hand-Arm Vibration Syndrome in a Northern Ontario Base Metal Mine

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Abstract

The objectives of this study were to determine the prevalence of hand-arm vibration syndrome (HAVS) in 617 workers at a base metal mine in northern Ontario and to educate, advise, and make recommendations on the prevention of HAVS. Workers who were employed at the mine between 1989 and 1994 and who continued to live within a 100 km radius of the mine were sent a self-reported questionnaire to identify individuals with possible vibration-induced symptoms in their upper extremities. Of the 162 workers who attended a medical examination, 50% were diagnosed with HAVS and 26% had other diagnoses, some having multiple afflictions e.g., both HAVS and carpal tunnel syndrome (CTS). No vibration-induced symptoms were reported in the 35% of workers who were clinically normal. Ongoing commitments to technological improvements, mandatory and regular rest periods, and continuing educational sessions on the syndrome should help to reduce the prevalence of this disease.

Key Words: hand-arm vibration syndrome (HAVS); mining; personal protective equipment (PPE); prevention; risk factors; tactometry; vibration

Introduction

In 1862 a French physician, Dr. Maurice Raynaud, identified a condition, now called Raynaud's Phenomenon, in which a blanching of the fingertips occurred with exposure to the cold.¹ A condition in which similar symptoms result from exposure to vibrating tools was first investigated in North America by Dr. Alice Hamilton in 1911.² It is known as hand-arm vibration syndrome (HAVS) or as Raynaud's Phenomenon of occupational origin, vibration-induced white finger (VWF), dead finger, traumatic vasospastic disease and vibration syndrome. HAVS is a complex syndrome caused by the constriction of blood vessels in the fingers, and involves circulatory, sensory, motor and musculoskeletal disturbances.³ The blanching of the fingertips becomes more frequent and severe with prolonged vibration exposure; continued exposure can extend the blanching along the length of all of the fingers and thumbs.

In mines, vibration exposure can result from the use of hand-held tools such as a jackleg drills, long-hole drills, stopers, various impact wrenches and smaller hand tools typically utilized on a daily basis. The jackleg drill is so named because it has a heavy metal support at the bottom that helps steady it as the miner is collaring the hole and provides leverage as the drill is being pressed forward.⁴ The jackleg drill is used to drill holes in the stope, a step-like excavation underground to mine vertical or steeply inclined deposits in successive layers where the broken ore can be drawn by gravity to prepare the rock for blasting. The long-hole drill is used in drifts, or horizontal passages underground, for the same purpose as the jackleg drill. A drift follows the vein, as distinguished from a crosscut that intersects it, or a level or gallery, which may do either.⁵ The stoper is similar to a jackleg drill in design but is used to drill into the ceiling of the area being blasted to allow protective bolting and screening to be applied to prevent loose rock from dropping and injuring the workers.⁶ The impact

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wrenches and hand tools are required for equipment maintenance and to change drill bits.

The prevalence of HAVS so concerned the miners at a northern Ontario base metal mine that the mine's joint health and safety committee asked the Occupational Health Clinics for Ontario Workers Inc. (OHCOW) to investigate. A multidisciplinary team of OHCOW staff and associates initiated, designed and carried out a study of HAVS among the mine workers intended to identify and provide a medical assessment for any worker who was willing to participate. A personal diagnostic report was provided to each participating worker and forwarded to his or her family physician with the worker's consent. An educational seminar was also held for miners, mine workers and interested members of the community on the health effects of vibration exposure, risks of future exposure, treatment, rehabilitation and disability-related benefits.

Methods

Study Population

This study was conducted at a base metal mine located in northern Ontario. Both management and union personnel agreed to work jointly with OHCOW to determine the prevalence of HAVS in the mine workers. The OHCOW team included occupational health physicians and nurses, an ergonomist, an occupational hygienist, an information technician, support staff and executive directors.

Phase I

A self-reported initial questionnaire was created for this project and was mailed to 617 workers who lived within a 100 km radius of the mine and were employed there from 1989 to 1994. The questionnaire was designed to identify those individuals who met the criterion of reported numbness (i.e., reduced sense of touch in one or more fingers, one or more times per week), paresthesias (i.e., tingling in one or more fingers, one or more times per week) or finger whitening. Of the 617 workers, 402 (65.2%) completed and returned the questionnaire.

Phase II

Two hundred and eighty-eight workers reported potential HAVS-like symptoms (e.g., finger numbness, paresthesia and finger whitening) and were sent a more extensive self-reporting questionnaire. This second questionnaire requested information on demographics, complete work history, medical history, lifestyle patterns and hobbies.

Phase III

The workers who had completed the second questionnaire were contacted and appointments were scheduled for tactometry testing and review of the second questionnaire by OHCOW staff. Of those 288 workers, 182 (63.2%) agreed to be assessed.

Phase IV

The grip strength, pinch grip testing and index finger temperature of each worker was recorded by OHCOW staff. Occupational health nurses recorded the results of each worker's blood pressure, Tinel and Phalen Tests, Dellon's Modified Pick-up, wrist extension and flexion (range of motion), and pulp-to-palm tests,* then reviewed each worker's history, blood pressure and test results with the OHCOW physician before he or she interviewed and examined the worker.

A diagnosis was made based on the findings from the testing performed as described in Phases III and IV, and the worker was advised. An individual consultation note was delivered to the worker and to the family physician with the worker's written consent. If the occupational health physician deemed it necessary, the family physician was informed of his or her recommendations for further diagnostic testing to determine the severity of the disease, methods of treatment, rehabilitation and disability-related benefits.

Phase V

A well-attended educational seminar was held at the local community centre for interested workers, family members and the general public. HAVS was explained in detail, as were its causes, diagnosis, treatment and prevention. A further discussion of the known health effects of smoking on the human body resulted in a recommendation that stopping smoking could reduce the severity of HAVS as well as improve a person's overall health. The seminar was followed by a question and answer period.

Phase VI

The data were entered into a FoxPro^{®12} database. Statistical Package for the Social Sciences (SPSS^{®13}), a comprehensive data analysis package for use in research and business, was used to tabulate frequencies, percentages and descriptive statistics.

Results

Of the 402 respondents to the first questionnaire, 288 (72%) reported potential HAVS-like symptoms. One hundred and eight-two (63%) participants were assessed. Prior to completion of the final phase of the study, 20 (11.0%) of the participants withdrew, mainly due to

* The Tinel's sign is considered positive when the median nerve is tapped at the wrist⁷ and a tingling sensation is experienced in area(s) of the hand. Acute flexion of the wrist for 60 seconds (Phalen test) in some but not all patients or strenuous use of the hand increases the paresthesia.⁸ Dellon's Modified Pick-up Test requires increasing discrimination for object recognition.⁹ The Moberg Pick-up Test requires the subject to pick up a series of 10 to 12 small objects of various sizes from a table surface and place them in a small container.¹⁰ The wrist extension and flexion or range of motion of the wrists is measured in degrees with a goniometer, an instrument for measuring angles.¹¹ The pulp-to-palm test measures the ability of the patient to touch the palm of his or her hand with the third digit of that hand.

	HAVS, n = 81 (s.d.)	no HAVS, n = 81 (s.d.)
Mean Age (yr.)	46.2 (10.5)	43.4 (10.9)
Mean Height (cm)	175.0 (6.8)	176.0 (6.9)
Mean Weight (kg)	87.3 (13.1)	86.5 (13.9)
Mean BMI (kg/m ²)	28.5 (3.6)	27.9 (3.9)
Employment with mine (yr.)	18.1 (8.1)	16.5 (8.8)
Total employment (yr.)	23.7 (9.5)	19.7 (9.7)
Use of vibrating tools (yr.)	18.3 (9.1)	11.6 (9.1)
Age at first use (yr.)	23.1 (4.7)	28.5 (12.3)
Time since first use (yr.)	23.1 (10.4)	14.8 (10.8)

* Twenty (20) participants who withdrew from the study before examination and diagnosis by a physician were excluded from the analysis

ICD-9¹⁹	Total Diagnosed (%)
Hand Arm Vibration Syndrome (HAVS) 443.0	81 (44.5)
Carpal Tunnel Syndrome (CTS) 354.0	27 (14.8)
Raynaud's Phenomenon 443.0	3 (1.6)
Other – 722.6, 493.9, 726.3	12 (6.6)
No Diagnoses V65.5	56 (30.8)
Procedure not carried out for other reasons V64.3	20 (11.0)

* Twenty (20) participants withdrew from the study before examination and diagnosis by a physician were excluded from the analysis

Some participants may have more than one diagnosis e.g., HAVS with secondary diagnosis of CTS

relocation to another community and/or employer. The results are reported for the 162 participants who completed all four phases of the study.

The demographics for the study participants appear in Table 1. The mean age for the group was 44.8 years (standard deviation 10.8) with approximately 22 years of employment and 15 years of vibratory tool use. Fourteen (8.6%) of the participants did not identify any use of vibrating tools. In these cases, the participant's current age was used as a surrogate for "age at first use (in years)", and "time since first use (in years)" and "use of vibrating tools (in years)" were considered to be nil.

With respect to diagnosis (Table 2), 81 (50.0%) of all participants were diagnosed with HAVS and 27 (16.7%) were diagnosed with CTS. Three participants (1.9%)

Occupations	HAVS (%) (n = 81)	No HAVS (%) (n = 81)	Overall
Salaried, Management and Supervisory Positions (11–, 211–, 215–, 7710, 8110, 8580)	7 (8.6)	9 (11.1)	16 (19.7)
Occupations in Labouring and other Elemental Work, Mining and Quarrying (7718, 7719)	45 (55.6)	29 (35.8)	74 (91.4)
Mineral Ore Treating Occupations (8111, 8113, 8116, 8118)	3 (3.7)	10 (12.3)	13 (16.0)
Maintenance Occupations (83–, 85–, 873–, 878–, 879–)	22 (27.2)	27 (33.3)	49 (60.5)
Other (includes clerical, surface drivers, etc.)	4 (4.9)	6 (7.4)	10 (12.3)

	HAVS, n = 81 (%)	no HAVS, n = 81 (%)	Overall
Hypertension	17 (21.0)	12 (14.8)	29 (35.8)
Migraine	8 (9.9)	4 (4.9)	12 (13.5)
Carpal Tunnel Syndrome (CTS)	13 (16.0)	11 (13.6)	24 (29.6)
Diabetes	5 (6.2)	3 (3.7)	8 (9.9)
Angina	6 (7.4)	1 (1.2)	7 (8.6)
Heart Attack	4 (4.9)	2 (2.5)	6 (7.4)
Noise Induced Hearing Loss (NIHL)	32 (39.5)	23 (28.4)	55 (67.9)

* The twenty (20) participants who withdrew from the study were not included in this analysis

were diagnosed with Raynaud's Phenomenon that was not due to hand-arm vibration exposure. Some participants experienced multiple afflictions raising the percentage to over 100.

The data for current/last job with the mine appear in Table 3. Most (136, 84.0%) of the participants held production or maintenance jobs, either underground or on the surface. Sixteen (9.9%) of the participants held management, supervisory or salaried positions. The remainder of the participants held a variety of jobs, including clerical and surface drivers.

Table 4 displays the differences between participants diagnosed with HAVS (n = 81) and those not diagnosed with HAVS (n = 81) in relation to their self-reported medical histories. For all the health-related conditions examined, those with HAVS more frequently reported health problems than those without HAVS. Thirty-two participants with HAVS (35.9%) had noise-induced

TABLE 5
Hobby activities reported by study participants

Hobby	HAVS (n = 81)	No HAVS (n = 81)	Overall
Snowmobiling	26 (32.1)	29 (35.8)	55 (67.9)
Cutting firewood, chainsaw use	17 (21.0)	10 (12.3)	27 (33.3)
Fishing	15 (18.5)	12 (14.8)	27 (33.3)
Lawn care	12 (14.8)	13 (16.0)	25 (30.8)
ATV	9 (11.1)	5 (6.2)	14 (17.3)
Hunting	6 (7.4)	6 (7.4)	12 (14.8)
Motorcycling	6 (7.4)	10 (12.3)	16 (19.8)

TABLE 6
Smoking History (n = 162*)

	HAVS n = 81 (%)	No HAVS n = 81 (%)	Overall (%)
Previous smoker	74 (91.4)	61 (75.3)	135 (83.3)
Current smoker	41 (50.6)	24 (29.6)	65 (40.1)
Non-smoker	33 (49.4)	37 (70.4)	70 (59.9)

* Twenty (20) participants withdrew from the study before examination and diagnosis by a physician.

"Previous Smoker" captures workers who may still be smoking and also smoked in the past; therefore, the numbers are greater than n = 162

TABLE 7
Tools Used (n = 162*)

	HAVS n = 81 (%)	No HAVS n = 81 (%)	Overall n = 162 (%)
Jackleg	49 (60.5)	21 (25.9)	70 (43.2)
Stoper	40 (49.4)	16 (19.8)	56 (34.6)
Impact wrench	22 (27.2)	20 (24.7)	42 (25.9)
Hand tools	12 (14.8)	12 (14.8)	24 (19.1)
Longhole drill	7 (8.6)	3 (3.7)	10 (6.2)

* Twenty (20) participants withdrew from the study before examination and diagnosis by a physician.

hearing loss (NIHL) compared to 23 (28.4%) of unaffected participants. Participants with HAVS also reported a greater incidence of hypertension, diabetes, migraine and heart attack.

Diagnostic test results, which included index finger pad temperature and pinch and grip strength, showed no statistically significant differences between those diagnosed with HAVS and those without. Due to the study design, the differences between the HAVS and the non-HAVS group were insignificant.

The smoking histories of the participants appear in Table 6. Surprisingly, over 80% of all participants reported that they had smoked. Of the participants

diagnosed with HAVS, 74 (91.4%) reported that they formerly smoked and 41(50.6%) reported that they were current smokers. As smoking is well known to have a vasoconstrictive effect on the peripheral vascular system, it is presumed that smoking may be a factor contributing to the development of VWF.¹⁴

The data on equipment and tool usage appear in Table 7. Over 60% of participants diagnosed with HAVS reported that they had used a jackleg drill; only 25% of those not diagnosed with HAVS reported having used this piece of equipment. Approximately two and a half times as many of the participants diagnosed with HAVS reported using a stopper than those who did not.

Discussion

This study was designed to be a screening tool for the detection of HAVS in miners. If the test results showed a possible diagnosis of HAVS, the workers were referred to their doctor for further testing in a vascular laboratory. Due to the design of the study, workers who reported no symptoms were not included in the testing and examination phases. The study was only able to show the prevalence of HAVS among the workers who completed the initial questionnaire on the possible symptoms of the syndrome.

At the mine studied, the miners were regularly required to use hand-held vibratory tools such as jackleg drills, long-hole drills, stoppers, various impact wrenches and hand tools. Over the years, use of these tools can cause circulatory and neurological changes. The cold and wet underground mining environment is another consideration.¹⁵ On comparing the frequency of use of vibrating equipment, it was found that the workers suffering from HAVS operated equipment such as chainsaws and all-terrain vehicles (ATVs) more often. Although the findings were of interest, the study design did not allow conclusive analysis of these results.

It is apparent from the frequency of HAVS among workers exposed to vibrating equipment that technological improvements and education are required to reduce the prevalence of this syndrome in the mining industry. Anti-vibration devices such as rubber grips, anti-vibration gloves, and better tool design and maintenance should reduce the amount of vibration, as should keeping the hands warm and dry by wearing water-resistant gloves and maintaining core body temperature. It is known that the risk of HAVS increases with continuous exposure, length of exposure and a history of smoking. It is recommended that regular vibration-free periods (10 minutes per hour) be implemented, perhaps by alternating tasks with vibrating and non-vibrating tools. Workers should also be advised to grip the tool as lightly as possible, allowing the tool to do the bulk of the work.

Withdrawal from the source of the vibration appears to be the most effective way to halt, and in some cases reverse, the progression of HAVS. Avoidance of smoking is important as it represents a known aggravating factor and increases the severity of HAVS symptoms. The

adoption of and adherence to threshold limit values (TLVs®)¹⁶ developed as guidelines to assist in the control of health hazards, and vibration codes and standards have been recommended for the control and prevention of HAVS.¹⁷

Educational sessions are recommended for workers at risk, stressing the importance of using anti-vibration equipment to lessen the exposure. The sessions should include how to prevent HAVS from developing and, if a positive diagnosis has been made, how to prevent further deterioration. Other factors that impact on HAVS, such as smoking (vasoconstrictor), hobbies (hand tools, recreational vehicles) and medical conditions (hypertension, diabetes), should be discussed.

The National Institute for Occupational Safety and Health (NIOSH) recommends that occupational health professionals, workers and employers should consider the seriousness of HAVS. It also recommends that engineering controls, medical surveillance, work practices and personal protective equipment be used to reduce exposure to vibrating hand tools and to help identify HAVS in its early stages among workers likely to be at risk.¹⁸

Limitations

There were several limitations to this study that are worthy of mention. As the questionnaires were self-reported, it was difficult to obtain accurate and complete information on work exposures, personal protective equipment or personal and leisure activities. The design of the study limited accurate reporting because the questionnaire prompted the workers to add comments that could not be analyzed.

The mine at which the study was carried out was in a remote area of northeastern Ontario, was slated for closure and had a workforce that had already been significantly reduced. It was difficult to communicate with the workers, especially those who had found other employment and had relocated. The workers came from a variety of educational backgrounds; it is possible that some did not fully comprehend the questions, and their answers may not have been accurate. The initial screening was based on the workers' self-reported symptoms, which may not have been present or were not severe enough to be detected. The company was not requested to provide information on the condition or maintenance of the vibratory tools used in the mine, or on the monitoring of exposure to them. Neither the company nor the union was requested to provide information on due diligence or the monitoring of HAVS exposure. These factors did not permit precise data entry, which subsequently affected the results extracted from the database.

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Validity of the US Behavioral Risk Factor Surveillance System's Health Related Quality of Life Survey Tool in a Group of Older Canadians

Stephanie Ôunpuu, Larry W Chambers, Christopher Patterson, David Chan and Salim Yusuf

Abstract

Investigators at the Centers for Disease Control and Prevention in the US have developed a brief survey tool to measure health-related quality of life (HRQOL-4). In order to support use of such tools in surveillance, it is important to assess their validity in different groups. Subjects were 926 non-institutionalized men and women (age ≥ 65 years) who completed a health exam and questionnaire. Results indicated that physical and mental health and physical activity limitation were each related to self-perceived health. Compared with subjects who reported excellent health, those with poor self-rated health reported a more than 17-fold increase in the number of unhealthy days in the previous 30. While responses to questions addressing psychosocial factors were most consistently associated with the HRQOL item relating to mental health, responses to health and health behaviour questions were more consistently associated with items related to physical health. This study demonstrated that the HRQOL-4 is not only accepted by older adults in a self-administered format, but also stands up to tests of its validity.

Key Words: health-related quality of life; population health; surveillance

Introduction

Health-related quality of life (HRQOL) is an extraordinarily broad and complex concept that encompasses both physical and mental health. During an era when life expectancy is increasing, the goal is to reduce the number of years lived with poor health (compression of morbidity) despite the cumulative health effects associated with normal aging and pathological disease processes. This makes the measurement of HRQOL particularly relevant to an aging population. The Institute of Medicine in the United States (US) has recently recommended that HRQOL measures be included as "Community Profile Indicators."¹ Information on trends in health status and the identification of high-risk subgroups will guide health policy by tracking the impact of health programs and assist in the allocation of resources among competing programs.

Investigators at the Centers for Disease Control and Prevention (CDC) in the US have developed a brief

survey tool to identify health-related quality of life in adult populations.² The four-item "Health Related Quality of Life" core module (HRQOL-4) was developed through expert discussions convened by the CDC, and measures self-perceived health, recent physical and mental health, and recent activity limitation (Figure 1). The conceptual relationship between the four questions on the HRQOL core module is presented elsewhere.² Question 1 of the HRQOL core module focuses on self-rated health, a categorical health item that encapsulates present, past and anticipated health on a scale of excellent, very good, good, fair or poor. Questions 2 and 3 assess the number of days in the past 30 when physical and mental health were not good, and are considered mutually independent. Together they are hypothesized to explain the recent health aspects of question 1. Question 4 is included as a global measure of activity limitation (number of days of activity limitation due to poor health in the past 30 days), and can be interpreted as an indicator of severity for

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FIGURE 1
Health-related quality of life: core module questions included in the SHINE study and taken from the US Behavioral Risk Factor Surveillance System

1. Self-Perceived Health

Would you say that in general your health is:

- a. Excellent
- b. Very good
- c. Good
- d. Fair, or
- e. Poor?

2. Recent Physical Health

Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

_____ days

3. Recent Mental Health

Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

_____ days

4. Recent Activity Limitation

During the past 30 days for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

_____ days

responses to questions 2 and 3. The “unhealthy days index” (unHDI), defined as the number of recent days with reported poor physical or mental health, is calculated by summing the total number of *not good* days reported for recent physical and mental health (HRQOL items 2 and 3), with 30 days as the highest assigned value.³

The HRQOL core module questions are clear, result in few cognitive difficulties, and when compared with the more lengthy and standardized health measures, such as the SF36, appear to have acceptable construct, criterion and known-groups validity for healthy adults as well as adults with chronic health conditions and disabilities.^{4,5} The module is being used in the US Behavioral Risk Factor Surveillance System (BRFSS), a state-based telephone survey that conducts over 100,000 interviews annually across all 50 states. It has also been included in at least four population health surveys in Canada⁶ (A Michalos, personal communication). In order to support its use in surveillance, it is important to assess its validity in different population groups and in direct comparison with a variety of alternative health measures.

In 1998 the Seniors Health Investigation Network (SHINE) study of 926 older adults (≥ 65 years of age) was conducted in four family practices located in the central-west region of Ontario. The pilot study documented the prevalence of risk factors, morbidity and disability among older adults and the use of preventive

manoeuvres recommended by the Canadian Task Force on Preventive Health Care.⁷ Data were collected through participation in a health examination, completion of a questionnaire, and health record review. The HRQOL core module was included in the study questionnaire. Here we report on selected measurement properties of the HRQOL for this older age group.

Method

Sample

Subjects were recruited from one family practice in Hamilton and three practices in Dunnville. The sampling frame consisted of all non-institutionalized men and women (age ≥ 65 years) who were ambulatory and had visited one of the participating practices within the last 18 months. Residents of long-term care facilities, those who required a proxy respondent, were being actively treated for cancer or other terminal disease, or who did not provide informed written consent were considered ineligible.

Letters of invitation were sent to all patients who were living in the community and had attended the physician’s office within the previous 18 months. The letter included a description of the study, a copy of the SHINE questionnaire, and a consent form. These patients were invited to call their physician’s office and register for a SHINE clinic. Reminder postcards were mailed to non-responders within one month, followed by a telephone call to determine their interest and eligibility. Where contact was made and the individual was ineligible, the reason was documented. In order to assess differences between responders and non-responders, some demographic information was collected from those who were eligible but unwilling to participate.

Data Collection

One SHINE clinic was held on-site at the practice, and the other was located at a well-known building on the town hospital property. SHINE clinics were organized as a series of stations: physical measures (blood pressure, heart rate, weight, height, waist and hip circumference); physical performance measures (lower extremity function,⁸ grip strength, cognitive performance measures (Mini-Mental State Examination,⁹ Clock test,¹⁰ and laboratory tests [one 20 mL blood sample]). At each station, a trained research assistant took measurements according to a standardized protocol. The SHINE questionnaire covered demographics, health history, medication use, HRQOL core module (Figure 1) and other psychosocial factors. SHINE participants were asked to complete the questionnaire prior to attending their clinic. All questionnaires were reviewed and queries resolved before each participant left the clinic.

The items on the questionnaire were compiled using previously validated sections from other questionnaires. Depression was measured using the National Centre for Health Statistics short-form question: “During the past 12 months was there ever a time when you felt sad, blue,

downhearted or depressed for two weeks or more in a row?"¹¹ Locus of control, defined as the level of perceived control over one's own health and over life, was measured using a series of six scale items (strongly agree – strongly disagree) developed by Bobak and Marmot and validated for a variety of health outcomes in central and eastern Europe.¹² A locus of control score (minimum 6 to maximum 24) was calculated for the six items. Participants were grouped by quartile with the first quartile representing the lowest locus of control level. Level of social integration, which includes items measuring both the quantitative characteristics of the extended social network and its function (i.e. belongingness, practical help and appraisal support), was assessed using a series of six questions tapping these dimensions.¹³ Social integration scores for all participants were grouped into quartiles, with the lowest quartile representing the lowest level of social integration.

We included three other measures of health status in the analysis. First, participants were asked to report their lifetime history of 18 common health problems (e.g. high blood pressure, high blood cholesterol, diabetes, heart attack, cancer by site, etc). Responses were categorized into 0, 1–2, 3–4 or 5+ health problems. Second, an estimate for 10-year coronary heart disease risk was calculated based on gender, age, smoking status, blood pressure, total serum cholesterol, and self-reported history of diabetes using guidelines developed by the Second Joint Task Force of European and other Societies on Coronary Prevention.¹⁴ Finally, we assessed lower extremity function using a method developed by Guralnik et al.⁸ that incorporates static balance, walking speed, leg strength and transfer ability. Scores for lower extremity function were grouped into quartiles for women and men separately, with the lowest quartile representing the lowest level of physical function.

Physical activity was measured using the Habitual Activity Estimation Scale adapted for older adults.¹⁵ A participant was considered active if the usual amount of time expended on moderate and vigorous activity exceeded 150 minutes in a week. Tobacco use was measured as current/former/never smoker.¹⁶

Analysis

We conducted a series of analyses to determine the validity of the HRQOL-4 in this group of Ontario adults. Spearman rank correlation analyses were carried out to study the relationship among the four HRQOL questions, and between these questions and the summary unHDI. We hypothesized that the relationships observed among the four variables would replicate those observed in the USA² and in a recent survey of Ontario adults,⁶ and would reflect the conceptual model described above. Concurrent validity was assessed using five logistic regression models with the five dependent variables being each of the HRQOL core module questions and the unHDI. Responses to self-rated health were dichotomized as excellent/very good/good versus fair/poor. Responses to each of the other three questions and the

unHDI were categorized into dichotomous dependent variables (0 and ≥ 1 days in the past 30).¹⁷ The independent variables were socio-demographic (education, income), psychosocial (locus of control, social integration, depression), physical health (history of illness, risk of coronary heart disease, physical function), and behavioural (smoking, physical activity) factors. Per the conceptual model, we hypothesized that the psychosocial variables would be related to the HRQOL mental health question, the physical health and behavioural variables would be related to the HRQOL physical health and activity limitation questions, and the self-rated health and unHDI would be related to both mental health and physical health variables. Logistic regression analyses were carried out with the 741 subjects who answered all items in the analysis.

Results

A total of 1,952 letters of invitation were distributed. Of these, 337 patients were ineligible, 582 refused to participate, and no contact was made with 107 patients. The final sample size was 926 patients. The response rate, calculated as number of subjects/(total invites – no contact – ineligible) was 61%. Of those who were eligible but did not participate in the study, 66% (n = 385/582) were willing to answer a few brief questions. There were no differences between study participants and non-responders on current smoking status and family history of memory loss. The two groups differed with respect to education and gender (i.e. a greater percentage of participants had at least a secondary school education and were female in comparison with non-responders) (Table 1).

TABLE 1
Comparison of SHINE participants with non-responders

	Study participants (n = 926)	Non-responders (n = 385)	p-value
Current smoker	12.6%	11.5%	0.557
Family history of memory loss	15.9%	12.9%	0.186
Achieved at least secondary school education	55.5%	34.9%	<0.0001
Males	40.3%	57.0%	<0.0001

Mean age of study participants was 73.2 years and 60% of the sample was female. Thirty-two percent (n = 292) of subjects reported either excellent or very good health, and 21% (n = 195) of subjects reported fair-to-poor health.

Overall, SHINE participants reported an average of 5.2 unhealthy days during the 30 days preceding the survey. In general, participants reporting low locus of

control, low social integration, a recent history of depression, a positive history of health problems, being inactive, and those having poor lower extremity function had a higher unHDI. For each of these variables, a gradient of increased unHDI was observed across each of the quartiles/response options (Table 2).

Spearman rank order correlations indicate that physical health, mental health and activity limitation were all moderately related to self-perceived health. Recent activity limitation was strongly correlated with the unHDI (Table 3). Compared with participants who reported excellent health, those with poor self-rated health reported a more than 17-fold increase in the unHDI (Figure 2).

Results of the logistic regression analyses indicated that the psychosocial variables were associated with each of the dependent variables (Table 4). For example, those indicating a positive history of depression were 1.99 times more likely to report fair/poor health than those with no recent history of depression. The same group was 1.84 times more likely to report at least one day of poor physical health, 3.63 times more likely to report at least one day of poor mental health, and 2.35 times more likely to report at least one day of activity limitation. These relationships are reflected in Model 5 (Table 4), which indicates that those with recent history of depression were 2.82 times more likely to have one or more unhealthy days than were those with no recent depression. Relationships of a similar magnitude were seen for locus of control (odds ratios [ORs] of 1.67 and 3.29 for poor physical and mental health in the low versus high locus of control quartile comparisons), and social integration (ORs of 2.35 and 1.68 for poor mental health and unHDI in the low versus high social integration comparison). As presented here, these odds ratios are simultaneously adjusted for all other variables in the model.

A history of multiple illnesses was associated with increased risk of fair-to-poor self-rated health, at least one day of poor physical health or activity limitation, and the unHDI, but not with recent poor mental health. Inactivity was associated with increased risk of poor-fair health and at least one day of activity limitation, but not with the other HRQOL-4 measures. Tobacco use was not associated with any of the dependent variables included in any of the five models (Table 4).

Discussion

The HRQOL-4 core module used in the U.S. Behavioral Risk Factor Surveillance System is based on subjective evaluations of health and functional status. The four core questions are attractive because of their face validity as shown by the hundreds of thousands of BRFSS respondents who willingly answered these questions by telephone over the last decade. The core HRQOL-4 module is used as a general measure that is broadly applicable across different population groups

and diseases. We have demonstrated with the SHINE study that the HRQOL-4 core module is not only accepted by older adults in a self-administered format (922 of 926 participants completed all four questions), but also stands up to tests of its validity.

The direction and magnitude of the relationships between self-perceived health status and recent physical health, mental health and activity limitation in this group of older adults were consistent with those reported for adults of all ages living in the same geographic area,⁶ and with those reported elsewhere for the US population.² The 17-fold difference in unHDI among older adults with self-reported poor versus excellent health is consistent with a 10-fold difference seen among the general adult population,¹⁸ and provides some insight into the explanatory abilities of these brief, simple questions. The magnitude of this relationship supports inclusion of a continuous variable such as the unHDI, which more clearly illustrates the extreme differences in perceived mental and physical health at the ends of the “poor health – excellent health” continuum.

In this study, we quantified the relationships of the HRQOL-4 measures with alternative measures of health status, and other factors considered to influence health status. These analyses provide insights into the aspects of health tapped by the HRQOL, and enable a crude level of calibration for the unHDI. For example, SHINE participants with a positive history of depression reported an average unHDI of 10.6 days, compared with 3.7 days among those with no depression. Participants with five or more health problems reported an average unHDI of 8.7 days compared with 3.1 days among those with no health problems. This general pattern of association (i.e. increased unHDI with increasing levels of compromised health) was consistent across several variables addressing different aspects of self-reported health. While these are crude, unadjusted relationships, the consistent gradient observed for most of the variables analyzed provides some measure of construct validity for the unHDI.

Results of the logistic regression analyses provide estimates of the magnitude of the relationship between the HRQOL core variables while adjusting for all other variables in the analysis. The psychosocial variables (locus of control, depression, social networks) were important in all five models. Further, all three psychosocial variables contributed significantly to the mental health model. These results support the validity of the question on mental health. The poor association observed between self-perceived health and recent mental health limitation indicates that many subjects did not consider their mental health status to be a major component of their general health. However, specific aspects of mental health measured in this survey appear to be encapsulated in responses to the other health measures included in the HRQOL.

TABLE 2
Distribution of sample and mean (SD) number of unhealthy days by various socio-demographic, psychosocial, health and behavioral characteristics, SHINE study

Explanatory Variables	Distribution of sample		Unhealthy days		Explanatory Variables	Distribution of sample		Unhealthy days	
	Percent	Number	Mean	Standard deviation		Percent	Number	Mean	Standard deviation
1. Socio-demographic variables					3. Health variables				
Age (years)					CHD risk ^a				
65–74	64.2	592	5.1	8.3	Low (<10%)	20.6	185	4.7	8.2
75–84	30.0	277	5.0	8.5	Mod (10–20%)	49.4	443	5.4	8.6
≥85	5.7	53	6.2	8.6	High (>20%)	30.0	269	4.7	8.0
Household income					Number of health problems ^b				
>\$50,000	21.3	181	5.0	8.3	0 illnesses	9.3	86	3.1	6.5
\$40-49,000	9.4	80	3.3	5.4	1–2 illnesses	40.5	373	3.9	7.3
\$30-39,999	15.3	130	5.1	8.4	3–4 illnesses	34.5	318	4.2	8.3
\$20-29,000	26.1	222	4.8	8.0	≥5 illnesses	15.7	145	8.7	10.6
<\$20,000	27.9	237	5.8	9.4	Lower extremity function				
Education					4 th quartile (high)	10.1	94	3.8	9.8
University	6.7	57	6.0	8.8	3 rd quartile	28.1	262	4.1	7.8
College/Trade	36.0	307	4.7	8.4	2 nd quartile	25.3	236	4.5	8.7
Secondary	12.8	109	4.4	7.2	1 st quartile (low)	34.4	321	7.8	11.8
Primary	44.5	379	5.4	8.6	4. Health Behaviour				
2. Psychosocial variables					Tobacco use				
Locus of control					Never	49.4	457	4.7	8.0
4 th quartile (high)	20.7	190	3.6	7.3	Former	37.9	351	5.2	8.6
3 rd quartile	26.2	241	3.2	6.8	Current	12.6	117	5.8	9.0
2 nd quartile	26.3	242	5.1	7.9	Physical activity ^c				
1 st quartile (low)	26.8	246	7.9	10.0	Active	16.2	151	3.1	5.9
Depression					Inactive	83.8	781	5.4	8.7
No	79.9	737	3.7	7.0	^a CHD risk: risk of coronary heart disease event during the next 10 years. ^b Health problems included: hypertension, dyslipidemia, high blood/urine sugar, diabetes, myocardial infarction, angina, stroke, cancer (colon, lung, breast, prostate, skin), arthritis or rheumatism, Parkinson's disease, asthma or bronchitis, osteoporosis, hearing loss, other. ^c Active defined as ≥150 minutes per week of moderate + vigorous activity.				
Yes	20.1	185	10.6	10.8					
Social integration									
4 th quartile (high)	22.1	201	3.6	7.2					
3 rd quartile	24.9	227	4.0	7.2					
2 nd quartile	25.4	231	5.2	8.7					
1 st quartile (low)	27.7	252	7.0	9.4					

TABLE 3
Spearman's rank correlation coefficients between self-perceived health variables in the SHINE study

	Self-perceived health	Recent physical health ^a	Recent mental health ^a	Number of unhealthy days ^a
Recent physical health	0.37 ^b			
Recent mental health	0.17 ^b	0.40 ^b		
Recent activity limitation	0.27 ^b	0.45 ^b	0.28 ^b	0.90 ^b

^a Responses categorized as follows: 1) none, 2) 1–2 days, 3) 3–7 days, and 4) 8 or more days.
^b p<0.01

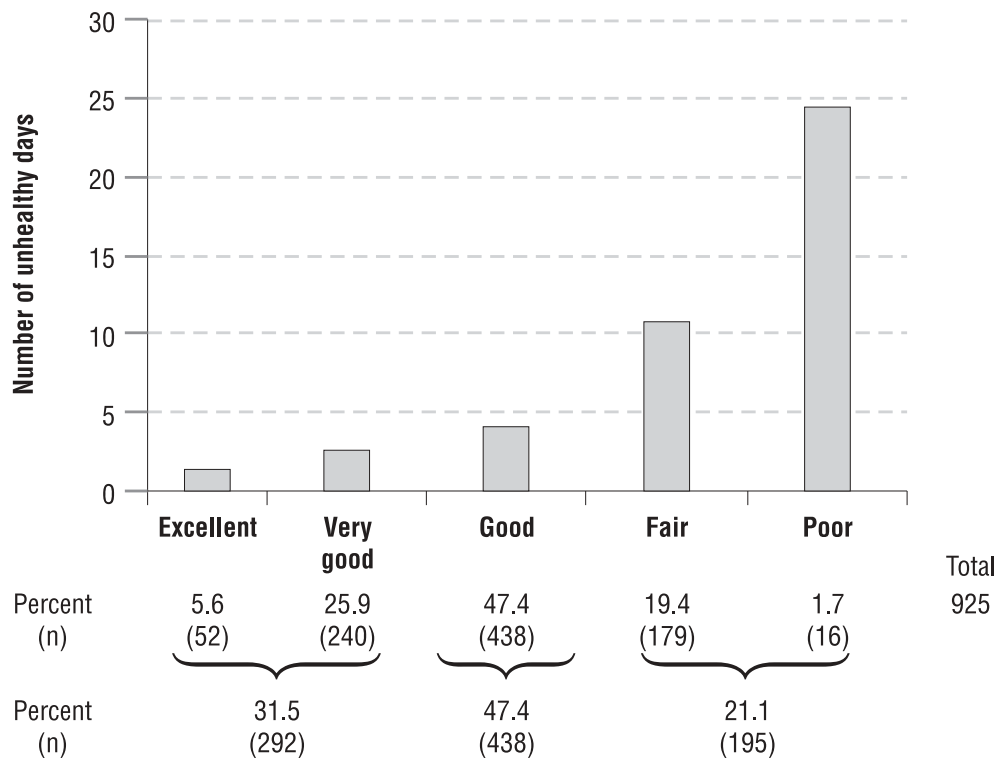
TABLE 4
Association of sample characteristics with poor/fair self-perceived health, and 1+ unhealthy days, days of poor physical health, mental health or activity limitation in the past 30 days, final adjusted models (n = 741), SHINE study

	Model 1: Self-perceived health		Model 2: Physical health		Model 3: Mental health		Model 4: Activity limitation		Model 5: Unhealthy days	
	OR ^{a,b}	CI	OR	CI	OR	CI	OR	CI	OR	CI
1. Sociodemographic variables										
Age	1.01	0.98–1.05	0.97	0.95–1.00	0.99	0.96–1.03	0.98	0.94–1.02	0.98	0.95–1.01
Household income										
≥\$50,000	1.0		1.0		1.0		1.0		1.0	
\$40-49,000	0.85	0.33–2.24	0.95	0.51–1.77	0.99	0.47–2.07	1.13	0.48–2.66	1.29	0.69-2.41
\$30-39,999	1.00	0.47–2.15	1.25	0.73–2.14	1.34	0.71–2.52	0.84	0.38–1.82	1.22	0.71-2.10
\$20-29,000	1.42	0.75–2.70	1.03	0.64–1.65	0.87	0.49–1.52	0.97	0.50–1.85	1.10	0.69-1.78
<\$20,000	1.36	0.74–2.52	0.91	0.57–1.47	0.73	0.41–1.27	1.06	0.57–1.97	0.83	0.51-1.35
Education										
University	1.0		1.0		1.0		1.0		1.0	
College/Trade	1.41	0.43–4.61	0.76	0.36–1.58	0.85	0.36–1.99	0.93	0.34–2.53	0.82	0.39-1.74
Secondary	1.34	0.42–4.29	0.69	0.34–1.41	0.87	0.39–1.97	0.69	0.26–1.82	0.74	0.36-1.54
Primary	2.33	0.76–7.19	0.77	0.38–1.55	0.76	0.34–1.68	0.61	0.24–1.58	0.83	0.41-1.70
2. Psychosocial variables										
Locus of control										
4 th quartile (high)	1.0		1.0		1.0		1.0		1.0	
3 rd quartile	0.90	0.45–1.82	0.83	0.51–1.34	0.93	0.48–1.79	1.66	0.78–3.51	0.91	0.51-1.60
2 nd quartile	1.28	0.66–2.49	1.43	0.90–2.28	2.31	1.27–4.19	1.86	0.90–3.82	1.35	0.76-2.40
1 st quartile (low)	1.66	0.87–3.17	1.67	1.04–2.68	3.29	1.81–5.97	1.96	0.96–4.02	1.69	0.92-3.10
Depression										
No	1.0		1.0		1.0		1.0		1.0	
Yes	1.99^c	1.22–3.25	1.84	1.23–2.76	3.63	2.37–5.55	2.35	1.44–3.80	2.82	1.82-4.37
Social integration										
4 th quartile	1.0		1.0		1.0		1.0		1.0	
3 rd quartile	1.17	0.62–2.19	1.37	0.85–2.19	1.41	0.77–2.59	1.44	0.72–2.84	1.53	0.96-2.45
2 nd quartile	0.81	0.43–1.53	1.25	0.78–1.99	1.83	1.01–3.30	1.04	0.52–2.09	1.48	0.93-2.35
1 st quartile	0.71	0.38–1.34	1.37	0.86–2.19	2.35	1.31–4.20	1.45	0.76–2.80	1.68	1.05-2.70
3. Health variables										
CHD risk										
Low (<10%)	1.0		1.0		1.0		1.0		1.0	
Mod (10-20%)	1.07	0.60–1.91	1.20	0.78–1.84	1.56	0.93–2.63	0.98	0.55–1.73	1.23	0.80-1.90
High (>20%)	0.94	0.49–1.79	0.97	0.59–1.60	1.01	0.55–1.86	0.55	0.28–1.09	0.90	0.54-1.49
Health history										
0 illnesses	1.0		1.0		1.0		1.0		1.0	
1–2 illnesses	3.56	0.80–15.88	0.99	0.54–1.79	1.31	0.60–2.87	2.77	0.81–9.52	0.98	0.55-1.75
3–4 illnesses	6.90	1.56–30.47	1.41	0.77–2.59	1.90	0.87–4.19	3.08	0.89–10.69	1.40	0.77-2.55
>5 illnesses	18.48	4.08–83.73	3.06	1.54–6.07	2.10	0.89–4.97	5.95	1.66–21.36	2.77	1.39-5.52
Lower extremity function										
4 th quartile (high score)	1.0		1.0		1.0		1.0		1.0	
3 rd quartile	1.82	0.57–5.76	0.97	0.54–1.72	0.64	0.32–1.30	0.55	0.23–1.31	0.91	0.51-1.60
2 nd quartile	3.42	1.11–10.54	1.40	0.78–2.51	1.04	0.52–2.08	0.94	0.41–2.15	1.35	0.76-2.40
1 st quartile (low score)	5.26	1.71–16.18	1.85	1.01–3.39	1.07	0.52–2.19	1.81	0.80–4.11	1.69	0.92-3.09

TABLE 4 (continued)
Association of sample characteristics with poor/fair self-perceived health, and 1+ unhealthy days, days of poor physical health, mental health or activity limitation in the past 30 days, final adjusted models (n = 741), SHINE study

	Model 1: Self-perceived health		Model 2: Physical health		Model 3: Mental health		Model 4: Activity limitation		Model 5: Unhealthy days	
	OR ^{a,b}	CI	OR	CI	OR	CI	OR	CI	OR	CI
4. Health Behavior										
Tobacco use										
Never	1.0		1.0		1.0		1.0		1.0	
Former	1.13	0.70–1.81	0.98	0.69–1.40	0.66	0.43–1.00	1.05	0.65–1.70	0.83	0.58–1.19
Current	1.69	0.89–3.22	0.93	0.56–1.55	0.77	0.42–1.40	1.66	0.86–3.21	0.92	0.54–1.54
Physical activity										
Active	1.0		1.0		1.0		1.0		1.0	
Inactive	2.78	1.30–5.92	1.13	0.73–1.75	1.08	0.62–1.86	2.35	1.45–3.80	1.17	0.76–1.80
^a C.I. = 95% confidence Interval, O.R. = Odds Ratio ^b Odds ratios for categorical variables represent comparisons with the referent group (OR = 1.0) after adjustment for all other variables in the model. Odds ratios for continuous variables represent odds ratios per unit increase in that variable after adjustment for all other variables in the model. ^c Bold lettering indicates p<0.05										

FIGURE 2
Mean unhealthy days by self-rated health, SHINE study (n = 921)



While the psychosocial variables were most consistently associated with the HRQOL item relating to mental health, the health and health behaviour variables were more consistently associated with HRQOL items

related to physical health. For example, subjects with a history of five or more illnesses had greater likelihood of reporting poor-to-fair self-perceived health, and at least one day of poor physical health or activity limitation.

However no relationship was observed between health history and presence of at least one day of poor mental health. A low score on the functional performance measures was associated with at least one day of poor physical health. Inactivity was associated with poor/fair self-perceived health and at least one day of physical activity limitation. No relationship was observed for either of these variables with the mental health question. Another validation study with American adults over 18 years of age similarly found that the HRQOL core items correlated with individual SF-36 scales in a manner consistent with *a priori* expectations. It was reported that “not good” mental health days correlated most strongly with the mental and the emotional scales, and least strongly with the physical functioning scale. The activity limitation question, which is based on both physical and mental health, correlates with each of the SF-36 scales.³

In another population-based sample of adults over 18 years of age, we found that increased household income, younger age and nonsmoking were positively associated with health status as measured by the HRQOL variables.⁶ The lack of association for the same variables in the SHINE study may be explained by the different age groups studied. The lack of association of smoking with the HRQOL global measures, for example, could be due to the survivor effect (the sicker smokers may have died). Household income may be less relevant in this group of older adults who are mostly retired, although this contrasts with findings from older US adults in the BRFSS.¹⁹ These differences between our findings and those elsewhere may reflect a selection bias in the SHINE study (i.e. those most ill were excluded from attending a clinic) and more uniformly available health and social services in Canada. It is interesting that there is no association observed between any of the HRQOL variables and age in the adjusted models, as one might expect an association between age and health in the over 65 population. It may be that individuals who attended a SHINE study clinic represented a relatively healthier group of older people with more positive attitudes about their health, who enjoy relatively good health status. Indeed disability, which is positively associated with age, precluded 48% of those ineligible from attendance at a SHINE clinic.

The response rate achieved in this survey (64%) is comparable to other population-based surveys of older adults. However caution is advised when interpreting the results, as we are unaware of the ages of those who did not participate, and are therefore unaware of whether the sample is representative of all age groups over 65 years. The large sample size for SHINE has permitted us to demonstrate both the ease of completion of HRQOL-4 core module questions by older adults and their measurement characteristics. Consistent relationships between the four questions and the unHDI have now been demonstrated in several independent studies. The SHINE data have confirmed that the items have construct and concurrent validity.

The proposed Canada Well-being Measurement Act²⁰ calls for the development and regular publication of measures to indicate the well-being of people and communities. The healthy days index will be used in the United States’ 2010 Objectives for the Nation²¹ to monitor national progress in achieving health for all. Inclusion of this brief survey instrument in surveillance programs is valuable as it will provide insights into health trends both over time and seasonally, to identify relationships between health and its determinants, and to identify high-risk groups. This information is useful for policy development, evaluation of programs, and to justify more detailed studies of health in specific groups. The accumulating evidence for its validity with Canadian samples support its inclusion in both national and local population health surveys in Canada. Indeed, this broad use would provide additional benefits of community ownership and participation that occur when data are collected nationally and locally and then shared.

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Canadian Cancer Society Information Services: Lessons Learned About Complementary Medicine Information Needs

Joanna L Eng, Debbie A Monkman, Marja J Verhoef, Darlene L Ramsum and Jennifer Bradbury

Abstract

The use of complementary and alternative medicine (CAM) in cancer patients is very common. However, currently valid and reliable information on CAM treatments for cancer is limited. The purpose of this study was to identify the information needs of those who called the Canadian Cancer Society's Cancer Information Service (CIS) requesting information on CAM. CIS information specialists completed two-page questionnaires for 109 callers who inquired about CAM therapies. Findings show that the majority of callers were women between the ages of 30 and 59, and that most of their questions concerned the safety and/or effectiveness of herbs and compounds like Essiac and 714X. Information specialists generally utilized one or more of four resources upon receiving a CAM-related call. These resources, while mostly Canadian and reviewed by content experts, are not specific to the type of cancer and are no longer the most up to date. To address this issue we have included an appendix that outlines some current CAM resources and websites for cancer patients.

Key Words: *alternative medicine; information seeking; neoplasms*

Complementary and Alternative Medicine (CAM) has been defined broadly as “a group of therapeutic or diagnostic disciplines that exist largely outside the institutions where conventional health care is taught and provided”.¹ Based on this definition, CAM encompasses a large number of therapies such as acupuncture, herbal treatments, vitamins and minerals, mind-body interventions and faith healing.

Cancer patients are some of the most avid users of complementary and alternative therapies. A systematic review of the prevalence of CAM use in cancer in Western developed countries shows that it ranges from 7–64%.² In a recent Canadian survey of cancer patients Leis et al found that 44% were using CAM.* Although most patients use CAM in addition to conventional cancer treatments, research suggests that there is a small group of patients who forgo conventional treatment in favor of CAM.³ Common reasons for the use of CAM include hoping for a cure or reducing the size of the

tumor, ameliorating the side effects of conventional cancer treatment, strengthening the immune system, improving well-being and hope, and taking control of cancer management.⁴ Cancer patients have made it clear that they want more and better access to information about CAM,^{5,6} and that they would want their health care professionals to be more interested in, more informed about and more willing to discuss CAM.⁷ So far, little is known about cancer patients' use of CAM information services. With limited help from the mainstream medical community, patients are researching and exploring CAM therapies on their own. This can be an overwhelming task since this area lacks agreed-upon rules of evidence⁸ and many CAM approaches for cancer have not been assessed scientifically.

The increased interest in alternative cancer treatments has been noted by the Canadian Cancer Society, which offers a cancer information telephone service (CIS) to individuals across Canada. They estimate that

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* Leis et al. Use of complementary therapies by cancer patients in 6 Canadian provinces. Presented at the annual meeting of the Canadian Association of Psychosocial Oncology, Winnipeg, May 2001.

approximately 1,300 calls per year, or 2% of their total call volume, are about CAM. The information specialists who answer the calls have a number of resources available to them, but it is not known whether these resources adequately provide callers with the information they require. Recognizing the need for coordinated and quality information services, the Tzu Chi Institute for Complementary and Alternative Medicine and the Canadian Cancer Society–BC and Yukon Division, strategic partners in the provision of information to cancer patients, conducted this study to identify the information needs of those who call the CIS to ask about topics relating to complementary and alternative therapies. This information will assist the CIS in further developing its services and will also be relevant to the many other cancer agencies that provide information on CAM. Ultimately, information on safe and efficacious CAM treatments will improve the well-being of cancer patients.

Methods

CIS information specialists conducted a small-scale audit of callers' information needs using a structured questionnaire composed of nine multiple-choice and two open-ended questions developed specifically for this study. The open-ended questions addressed the gap between the needs of the callers and the information available. The remaining questions addressed caller demographics, information requests on CAM products and therapies, and the resources provided to the caller. The questionnaire was translated into French so that French-speaking CIS information specialists and callers could also be included in the study. It was necessary to keep the questionnaire as brief as possible, because the CIS information specialists completed the questionnaire immediately after each call. The Canadian Cancer Society's four Cancer Information Service Centres, located in Montreal, Hamilton, Regina and Vancouver, all participated in the study. The directors of each of the four CIS offices reviewed the questionnaire prior to its distribution.

The study sample included all callers who made general or specific inquiries to a CIS information specialist at any of the four information centres about complementary or alternative cancer therapies over a four-month period, from June through September of 1999. At the end of this period, all of the completed questionnaires were collected. The questionnaires were first coded and then summary measures were calculated using SPSS version 10.0.⁹ Content analysis was used to categorize the issues arising in the open-ended questions.

Results

During the data collection period, 109 CAM-related calls were recorded to the four CIS centres across Canada. Ontario residents were the most frequent callers (40%) followed by residents of Quebec (30%). British Columbians placed third (15%), calling more than residents from Alberta, Manitoba, New Brunswick and the United States combined (13%). In three cases the province where the caller resided was not recorded.

Eighty percent of the sample was female. In two instances gender was not identified. Most callers (47%) were between the age range of 30 and 59. Only 12% of respondents were under age 30 and only 21% were age 60 or older. In all other instances the age of the caller was not recorded.

Overwhelmingly, questions on CAM were related to cancer treatment (97%) rather than prevention. Most callers inquired about breast cancer (22%) followed by lung (8%) and liver (6%) cancer. In 31% of the calls, the queries were about cancer in general and cancer type was not specified. The remaining calls concerned a variety of cancers including brain, bladder, cervical, colorectal, kidney, ovarian, and melanoma.

Most callers (88/109) requested information on specific CAM topics. Fifty-seven different topics were requested, with an average of 1.43 queried per call (s.d. = 0.81). Many callers (25%) asked about more than one (from two to six) topic. The top five CAM topics queried were: 714X (N = 17), Essiac (N = 16), nutrition (N = 9), overall efficacy (N = 8) and Shark's Cartilage (N = 7). Forty-four other CAM topics were queried only once each (See Table 1).

TABLE 1
CAM therapy query by CIS Centre

Topic of Query	CIS Cancer Information Centre				Total
	Vancouver, B.C.	Regina, Sask.	Hamilton, Ontario	Montreal, Quebec	
714X	—	8	3	6	17
Essiac	3	2	8	3	16
Nutrition	—	1	3	5	9
Efficacy	1	1	4	2	8
Shark's Cartilage	1	1	3	2	7
Drug Interactions	—	3	3	—	6
Practitioner Selection	—	2	3	—	5
Herbs and Compounds	—	1	2	1	4
Green Tea	—	—	1	2	3
Energy Flow	1	1	1	—	3
Acupuncture	1	—	—	1	2
Hydrazine Sulphate	1	—	—	1	2
General Safety	1	—	1	—	2
Other Inquires	8	13	10	13	44
TOTAL	17	33	42	36	128

TABLE 2
Information sources referred to by CIS
information specialists

Information Referral Source	Frequency	%
<i>A Patient's Guide to Choosing Unconventional Therapies</i> ¹⁰	58	53
<i>Canadian Cancer Encyclopedia</i> ¹¹	50	46
Community services resources	32	29
<i>A Guide to Unconventional Cancer Therapies</i> (Ontario Breast Cancer Information Exchange Project) ¹²	27	25
Canadian Breast Cancer Research Initiative booklets ¹³⁻¹⁸	21	19
<i>Selected List of CAT's Websites</i> (Handout) ¹⁹	13	12
27 other organizations (national/international)	40	37

CIS information specialists relied on a number of sources when providing callers with information. The top two were: *A Patient's Guide to Choosing Unconventional Therapies*,¹⁰ for 53% of callers and the *Canadian Cancer Encyclopedia*¹¹ for 46% of callers. Other information sources utilized are shown in Table 2.

One overriding theme was identified when the open-ended questions, in which the information specialists were to make additional comments, were examined. Many information specialists suggested a need for more specific information on CAM treatments for particular cancers, so that the best resources or information could be provided according to cancer type. While the current resources are helpful, the information is very general and not cancer-specific. The information specialists also used this section to report that a number of people called to ask "permission" to use a particular therapy.

Discussion

Fewer CAM-related calls than expected were made to the CIS centres over the four-month period. In fact, CAM-related calls represented only 0.5 % of all the calls placed to CIS during this period, which is lower than the yearly CAM-call ratio of 1.8%. One possible reason could be that for logistical reasons, the CIS requested that the data be collected over the summer months, which tend to be the lowest call volume months for the centres. This, however, should not affect the ratio of CAM to non-CAM calls if call volume drops in general. It is also possible that questionnaires were not filled out for all the CAM-related calls if the information specialists were too busy. It is impossible to know how many calls were missed, because the information specialists were not asked to keep track of such calls. Although the sample for this study was small, age and gender distributions are consistent with results of other larger studies that have examined CAM use in Canada.²⁰ Consistent with existing findings on CAM information seeking, women placed the majority of CAM-related calls. This may reflect the tendency of women to take a more active role than men in acquiring and reviewing

health-related information.²¹ Although this study was limited by the smaller than expected sample, it still provides valuable information on an area where little research has been conducted. The study was also limited by the fact that the data were collected indirectly, by the information specialists, and not directly from the callers. It is possible that callers' needs are not represented as accurately as possible. The low percentage of callers in BC is surprising and it is not clear how this should be explained.

Providing credible information on each of the 57 different types of CAM topics on which information was requested is a very difficult task due to the current lack of a solid evidence base in this field. Indeed, complementary and alternative medicine is still viewed by many as an emerging field, with few agreed-upon rules of evidence. This area of information provision is made even more challenging by the differences in the underlying assumptions between conventional medicine and CAM. While conventional medicine demands a diagnostic and/or physiological approach to research, CAM is based on a very different understanding of health, tending to focus on restoring balance rather than treating symptoms. This has consequences for CAM research, which does not always fit in to the randomized control trial model – the gold standard in conventional medicine research. Without a solid evidence base, providing valid and reliable CAM resources is a challenge.

Herbs and compounds were the basis for most of the callers' questions. Essiac and 714X were the most asked about of these and, therefore, should potentially be the first area examined when looking at what information to provide to callers. While there has been some research done on these compounds, the studies are not cancer-specific and not conclusive in their findings. Information specialists frequently relied on *A Patient's Guide to Unconventional Therapies*¹⁰ and the *Canadian Cancer Encyclopedia*¹¹ to answer questions. These resources, however, are somewhat inadequate due to their inability to specifically address the vast array of CAM-related questions being asked. For example, some information specialists expressed frustration over not being able to give CAM information specific to cancer type. This is not surprising given that most CAM resources have been found to be treatment-focused rather than diagnosis-specific.

Results showed that the CIS *Selected List of CAT's Websites*¹⁹ was referred to far less than the other available resources. This could be an indication that many callers still do not have access to the Internet or may be unaware that CIS has a website. Since useful CAM information is available online, callers could be encouraged to access the Internet, perhaps through courses at their public library. This may not be a viable solution for everyone, as some may not be physically well enough or familiar enough with computers to do so.

The reliance on the materials listed in Table 2 is consistent with internal CIS policies. The CIS approves third-party materials for distribution by reviewing the organizations that publish the materials, and the materials' scientific accuracy and relevance to CIS callers. During a call, information specialists are asked to refer to "approved" CAM references, which are listed in the database and would come up in a search with CAM as the topic. The sources used by the information specialists are consistent with those in the database.

Most callers wanted specific suggestions and advice or "permission" to use a therapy. Since as many as one half of cancer patients do not disclose their use of CAM therapies to their physicians,²²⁻²⁵ it stands to reason that they would seek permission and reassurance to use these therapies elsewhere. However, this is in conflict with the CIS mandate, which requires that only information, not advice, opinions or permission, be provided to callers. This policy, though necessary, contributes to the frustration of callers trying to obtain information on CAM.

This study highlights the fact that both the information specialists and the callers need new and better resources to deal with questions about CAM. Although CIS resources were found to be insufficient to address all of the CAM issues, this is not surprising in light of the fact that the increase in CAM in Canada is a relatively new phenomenon. To illustrate the range of resources available and to aid organizations like CIS in selecting resources that are up to date and in line with their mandate, we have included an appendix of CAM resources (see Appendix). This appendix is intended for use by practitioners and health information providers. It should be noted that this list is not comprehensive, nor is it intended to take the place of the current CIS resources, which continue to be useful and have been carefully reviewed by content experts. It is meant to complement those resources already in use and as a further step in assisting cancer patients with their disease management decisions.

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APPENDIX

CAM and Cancer Information Resources

This list contains some of the better known resources on CAM and cancer, from a variety of different perspectives and in a variety of different formats.

1. BC Cancer Agency Library/Cancer Information Centre. *Unconventional Cancer Therapies*. 3rd edition. Vancouver: BCCA, 2000. <http://www.bccancer.bc.ca/uct/> (accessed November 19, 2001)
This BC Cancer Agency resource for patients and their families pulls together both the pros and cons of 46 of the most asked-about cancer therapies. Information is taken from the original source material and supplemented with the professional opinion that is given in the evidence-based literature.
2. Boik, John. *Natural Compounds in Cancer Therapy*. Oregon Medical Press, 2001.
A scholarly review of the actions and potential clinical use of over three dozen carefully selected natural compounds, including systematic examination of the molecular actions, pharmacology, toxicology, and potential clinical use of natural compounds as anticancer agents.
3. Center for Mind-Body Medicine. *Comprehensive Cancer Care: Integrating Alternative and Complementary Therapies*. Conference Proceedings. 1998, 1999, 2000. Washington DC. <http://www.cmbm.org> (accessed November 19, 2001)
This conference, held annually since 1998, is sponsored by the Center for Mind-Body Medicine in Washington, DC. Tapes can be purchased and selected transcripts are on the website. The book *Comprehensive Cancer Care* by James Gordon is based on the information presented at the conferences, along with the expertise of the Center staff and experience of clients. The website also provides a list of *Cancer Resources and Links* under the "Resources" section.
4. Diamond, W. John; W. Lee Cowden; Burton Goldberg. *An Alternative Medicine Definitive Guide to Cancer*. CA: Future Medicine, 1997.
This book describes the cancer treatment plans of 23 alternative physicians, and describes many types of alternative therapies for cancer. Though mostly uncritical, it is a useful resource for describing the many practices and therapies that patients may ask about. It should be supplemented with more current, research-based information.
5. Labriola, Dan. *Complementary Cancer Therapies: Combining Traditional and Alternative Approaches for the Best Possible Outcome*. California: Prima Health, 2000.
Labriola, a naturopathic doctor, presents a detailed guide for consumers on combining alternative and conventional approaches, including approaches for specific types of cancer. Unfortunately, the book is not referenced.
6. Lerner, Michael. *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer*. Cambridge: MIT Press, 1994. Available at <http://www.commonweal.org/choicescontents.html> (accessed November 19, 2001)
This book is frequently cited, though somewhat dated, as a detailed resource explaining and evaluating a wide range of complementary therapy programs. The full text of the book is available free of charge on the Commonwealth website.
7. National Center for Complementary and Alternative Medicine (US). *National Cancer Institute (NCI) CAM Information*. <http://nccam.nih.gov/nccam/fcp/factsheets/> (accessed November 19, 2001)
NCI's fact sheets on various alternative therapies for cancer in both concise and in-depth format.
8. *Office of Cancer & Complementary & Alternative Medicine (US)* <http://occam.nci.nih.gov/> (accessed November 16, 2000)
Activities of the Office and clinical trials in progress.
9. Canadian Health Network, Complementary & Alternative Health Centre. *Quick Search: Alternative Health & Cancer*. http://www.canadian-health-network.ca/1alternative_health.html (accessed November 19, 2001)
Links to reliable Canadian organizations' web resources on cancer and CAM for consumers.
10. Duke Comprehensive Cancer Center. *Guide to Complementary / Alternative Therapies for Cancer Patients*. <http://www.cancer.duke.edu/PatEd/CAM.asp> (accessed November 19, 2001)
An example of a patient resource from a cancer care center.

APPENDIX (continued)
CAM and Cancer Information Resources

Database Searching

Searching for current journal literature on CAM and cancer should include both biomedical databases as well as CAM databases. These include:

- CANCERLit
- MEDLINE/PubMed
- CAM on PubMed (a subset of MEDLINE's CAM-related references)
- Embase (important for European literature, herbal medicine and CAM journals)
- NAPRAAlert (natural health products)
- IBIDS (dietary supplements)
- AMED (alternative and allied medicine)
- MANTIS (manual therapies)
- AltHealthWatch (includes peer-reviewed CAM journals among consumer magazines)

For a more complete listing of CAM databases, see the Rosenthal Center's website (<http://cpmcnet.columbia.edu/dept/rosenthal/Databases.html>)

When searching MEDLINE and other databases, it is important to use appropriate subject headings as search terms. These medical subject headings (MeSH) relate to CAM and should be used when searching MEDLINE. Some MEDLINE search interfaces automatically explode MeSH (e.g., PubMed). Important MeSH for CAM include:

- Alternative Medicine – exploding this term will include most of the alternative practices from herbal medicine to colour therapy
- Plant extracts – exploding this term will include specific plant extracts
- Herbs
- Plants, medicinal – exploding this term includes specific medicinal plants
- Antineoplastic agents – phytogetic
- It is important to also use keywords, particularly for specific natural health products (e.g., PC-SPES, green tea)

Book Review

Evaluating Health Promotion: Practice and Methods

Edited by Margaret Thorogood and Yolande Coombes

London (England): Oxford University Press, 2000;

184 pp; ISBN 0-19-263169-1; \$43.75 (CDN)

Edited by two members of the Health Promotion Research Unit of the Department of Public Health and Policy in the London School of Hygiene and Tropical Medicine, with contributions from their colleagues in the Unit, this book is a timely contribution to the debate about evaluation in health promotion. It provides clear descriptions of key methods and their limitations and strengths, as well as examples of their use. It also provides a context for these materials by discussing the concepts and development of health promotion and evaluation as fields.

The position that the editors and authors take on evaluation in the book are pluralistic, eclectic and very much in keeping with current advanced thinking in health promotion. Similar positions are expressed in a number of recent documents, including a recently released book on evaluation in health promotion published by the European Office of the World Health Organization (WHO) edited by myself and members of a WHO-EURO Working Group on Health Promotion Evaluation. The unique contribution of this book is the clarity with which the arguments are presented and the practical examples that illustrate the points the authors make. The chapters on historical approaches to evaluation and on simulation models were particularly interesting.

On the other hand, as is true of any book of this nature, this one has its limitations. For one, it tends to draw its material mainly from the United Kingdom, although it does from time to time refer to material from other countries, including the United States and Canada. For another, although it does refer to “participative” or, as we tend to call it, “participatory” research, in my view it does not give it the prominence that it deserves in the context of a book about evaluation in health promotion. Perhaps a chapter on this topic might be a useful addition to the next edition of the book, as this approach is not only very compatible with health promotion, but also has features, such as special ethical issues, of which anyone studying or working in health promotion should be aware.

Nevertheless, this is an excellent book that provides a fine introduction to evaluation issues in health promotion for both students and practitioners, and I would recommend it highly to these audiences.

Irving Rootman, PhD

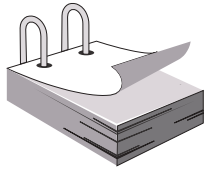
Professor, Department of Public Health Sciences and
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Announcement

Important changes to *Chronic Diseases in Canada*

This combined Volume 22, Nos. 3 and 4, is the last issue of *Chronic Diseases in Canada* to be released in 2001.

Watch for our new redesigned format in January 2002.



Calendar of Events

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Tel.: (33) 1 40 05 38 02
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E-mail:
construction.issa@cramif.cnamts.fr
<www.cramif.fr>

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Fax: (416) 864-9916
E-mail: julianq@on.lung.ca
<www.on.lung.ca>

February 27–March 1, 2002
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“Cultivating Healthier Communities Through Research, Policy and Practice”

16th National Conference on Chronic Disease Prevention and Control

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Prevention Research Centers Program

Terrye Hornsby
Tel: (301) 588-6000 x 270
Fax: (301) 588-2106
E-mail: thornsby@kevrinc.com
<www.cdc.gov/nccdphp/conference>

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2403–65 Broadway Avenue
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Division of Continuing Studies
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<www.hp2002.uvic.ca>

May 7–11, 2002 Montréal, Quebec	“ISSFAL 2002 – Dietary Fats and Health” 5 th Congress of the International Society for the Study of Fatty Acids and Lipids	ISSFAL 2002 Secretariat c/o Golden Planners Inc. 301–126 York Street Ottawa, Ontario K1N 5T5 Tel.: (613) 241-9333 Fax: (613) 565-2173 E-mail: info@goldenplanners.com <www.issfal.org.uk>
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August 18–22, 2001 Montréal, Quebec	“Epidemiology and Modern Public Health” 16 th World Congress of Epidemiology World Epidemiological Association <i>Call for abstracts deadline: March 15, 2002</i>	Events International Meeting Planners 759 Square Victoria, Suite 300 Montréal, Quebec H2Y 2J7 Tel.: (514) 286-0855 E-mail: iea2002@eventsintl.com <www.iea2002.com>

CDIC: Information for Authors

Chronic Diseases in Canada (CDIC) is a peer-reviewed scientific journal published four times a year. Contributions are welcomed from outside of Health Canada as well as from within this federal department. The journal's focus is 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 about 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, 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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Regular Feature Articles: Maximum 4,000 words for main text body (excluding abstract, tables, figures, references) in the form of original research, surveillance reports, meta-analyses, methodological papers, literature reviews or commentaries

Short Reports: Maximum 1,200 words (as above)

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Book/Software Reviews: Usually solicited by the editors (500–1,300 words), but requests to review are welcomed

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Submit manuscripts to the Editor-in-Chief, *Chronic Diseases in Canada*, Population and Public Health Branch, Health Canada, Tunney's Pasture, CDIC Address Locator: 0602C3, Ottawa, Ontario K1A 0L2.

Since CDIC adheres in general (section on illustrations not applicable) to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" as approved by the International Committee of Medical Journal Editors, authors should refer to this document for complete details before submitting a manuscript to CDIC (see <www.cma.ca/publications/mwc/uniform.htm> or *Can Med Assoc J* 1997;156(2):270–7).

Checklist for Submitting Manuscripts

- 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
- Second title page:** Title only; start page numbering here as page 1
- 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
- Tables and Figures:** Each on a separate page and in electronic file(s) separate from the text (**not imported into the text body**); as self-explanatory and succinct as possible; not duplicating the text, but illuminating and supplementing it; not too numerous; numbered in the order that they are mentioned in the text; explanatory material for tables in footnotes, identified by lower-case superscript letters in alphabetical order; figures limited to graphs or flow charts/templates (no photographs), with software used specified and titles/footnotes on a separate page
- Number of copies:** Four complete copies, including tables and figures; 2 copies of any related supplementary material

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