

Chronic Diseases in Canada

Volume 29 • Number 3 • 2009

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Chronic Diseases in Canada
a publication of the Public Health Agency
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Indexed in Index Medicus/MEDLINE

To promote and protect the health of Canadians through leadership, partnership, innovation and action in public health.
— Public Health Agency of Canada

Published by authority of the Minister of Health.
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ISSN 0228-8699

This publication is also available online at www.publichealth.gc.ca/cdic
Également disponible en français sous le titre : *Maladies chroniques au Canada*

Validation of perinatal data in the Discharge Abstract Database of the Canadian Institute for Health Information

K. S. Joseph, MD, PhD (1) and J. Fahey, MMath (2) for the Canadian Perinatal Surveillance System

Abstract

We compared perinatal information submitted to the Canadian Institute for Health Information (CIHI) hospitalization database with information submitted to the Nova Scotia Atlee Perinatal Database (NSAPD) in order to assess the accuracy of the CIHI data. Procedures such as Caesarean delivery were coded accurately (i.e. sensitivity of 99.8%; specificity of 98.7%). Postpartum hemorrhage, induction of labour and severe intraventricular hemorrhage also had sensitivity and specificity rates above 85% and 95%, respectively. Some diagnoses, defined differently in the two databases, were less accurately coded, e.g. respiratory distress syndrome (RDS) had a sensitivity of 50.9% and a specificity of 99.8%. Restriction to more severe forms of the disease improved accuracy, e.g. restriction of RDS to severe RDS in the NSAPD and identification of severe RDS in the CIHI database, using codes for RDS and intubation, resulted in a sensitivity of 100% and a specificity of 99.6%. Our study supports the use of CIHI data for national surveillance of perinatal morbidity, with the caveat that an understanding of clinical practice and sensitivity analyses to identify robust findings be used to facilitate inference.

with information in the DAD. False positive rates for Caesarean, vacuum and forceps deliveries, preterm labour and episiotomies were < 1%; however, the false positive rates for other indicators were high (e.g. medical induction of labour, 12.8%; third degree perineal lacerations, 40.3%). Similarly, false negative rates were low for some indicators (e.g. < 1% for Caesarean deliveries, third degree lacerations, respiratory distress syndrome (RDS), pre-eclampsia / eclampsia), but high for other indicators (e.g. fetal asphyxia/fetal distress, 23.6%; medical induction of labour, 38.3%; rare neonatal conditions, 41.3%; rare congenital conditions, 53.9%).

Key words: *perinatal, surveillance, database, maternal, infant, morbidity, respiratory distress, discharge abstract data*

Two concerns were voiced within the Canadian Perinatal Surveillance System (CPSS) Maternal Health and Fetal and Infant Health Study Groups who routinely use CIHI data for perinatal surveillance purposes.⁹⁻¹³ First, detailed analyses of phenomena such as amniotic fluid embolism,¹² postpartum hemorrhage¹³ and other conditions⁹⁻¹¹ have shown patterns that are congruent with clinical expectation, and suggest a higher level of data quality than that observed in the re-abstraction study. Another reason for questioning the high error rates in the re-abstraction study was related to the technical aspects of the stratified sampling (and the weighted calculation of population rates of false positive and false negative errors). Several error rates were relatively small in the study sample, but were substantially inflated after the population weights were applied. The most serious inflation was observed for third degree perineal

Introduction

Perinatal health surveillance in Canada relies on data from various sources, including vital statistics databases and hospital discharge databases.¹⁻³ Although vital statistics data on births and fetal and infant deaths remain an important source for documenting temporal trends and regional variations in perinatal health, the decline in mortality rates in recent decades has shifted the focus of perinatal surveillance increasingly towards monitoring trends and patterns in serious morbidity. This is particularly true with regard to serious maternal morbidity⁴ and serious neonatal morbidity.^{5,6}

The quality of hospitalization data from the Canadian Institute for Health Information (CIHI) Discharge Abstract Database (DAD) is an important concern. Although previous studies have concluded that this data source is suitable for surveillance purposes,⁷ a recent medical chart re-abstraction study, commissioned by the Canadian Perinatal Surveillance System (CPSS) and carried out by CIHI, showed variable quality with regard to several indicators of perinatal health.⁸ The study on hospital discharges in 1999/2000 included hospitals selected randomly after stratifying by geography and size and type of hospital. The charts of 385 newborns and 872 mothers were re-abstracted by CIHI classification specialists and compared

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lacerations (i.e. false positive rate in the sample, 5.6%; in the population, 40.3%); rare neonatal conditions (i.e. false negative rate in the sample, 1.6%; in the population, 41.3%); and rare congenital conditions (i.e. false negative rate in the sample, 3.1%; in the population, 53.9%).

Consequently, we decided to reassess the accuracy of the DAD information by comparing the perinatal data in the DAD with data in the NSAPD. The latter database, which is smaller and clinically focused, is believed to have a relatively high degree of accuracy with regard to diagnoses and procedures.

Methods

During a brief period in 2002, the perinatal data pertaining to newborns and mothers in Nova Scotia were simultaneously coded for both the DAD and the NSAPD. Although the coding rules for the two databases were different, the availability of data under the two independent systems for 6194 mothers and 6315 newborns permitted an evaluation of the DAD data for quality assessment purposes. The mothers and newborns included in this duplicate coding were not selected by gestational age or outcome, and represented all of the deliveries/ births that occurred during a specific period.

The NSAPD is a clinically focussed, population-based database that stores detailed information from antenatal and medical charts. The information is extracted by trained personnel using standardized forms. An ongoing data quality assurance program, which carries out periodic abstraction studies, has shown the database information is reliable. The database has been used to validate the vital statistics, birth-and-infant-death-linked files at Statistics Canada.^{14,15} Perinatal information for the DAD was also collected by trained personnel in Nova Scotia under the CIHI data abstraction rules. For the period in question, the data were coded using International Classification of Diseases Revision 10 (ICD-10-CA) codes for diagnostic information and the Canadian Classification for Health Interventions (CCI) codes for interventions/procedures.

We compared diagnoses and interventions/procedures of interest between the two databases, assuming the NSAPD represents the gold standard. Rates of sensitivity (i.e. proportion of true [NSAPD] positives identified as being positive by the DAD) and specificity (i.e. proportion of true [NSAPD] negatives identified as being negative by the DAD) were calculated along with exact binomial 95% confidence intervals (CI). An evaluation of gestational age estimates from the two sources was also carried out using agreement statistics (i.e. weighted kappa and the intraclass correlation coefficient). For this analysis, gestational age was grouped into clinically relevant prognostic categories routinely used by the Canadian Perinatal Surveillance System (< 20, 20 to 21, 22 to 23, 24 to 25, 26 to 27, 28 to 31, 32 to 33, 34 to 36, 37 to 41, 42 to 45 weeks and unavailable). The specific diagnoses and interventions/procedures identified for assessing the accuracy of the DAD data were based on clinical and public health relevance and on the definitional compatibility of the diagnoses and interventions/procedures in the two databases.

Results

According to the DAD, the rate of preterm delivery (i.e. proportion of women with information on gestational age who delivered prior to 37 completed weeks) was 9.1% (95% CI 8.4 to 9.9%), whereas this rate was 8.8% (95% CI 8.1 to 9.6%) according to the NSAPD. The rate of postterm delivery (i.e. delivery at or after 42 completed weeks) was 0.6% (95% CI 0.5 to 0.9%) and 2.1% (95% CI 1.8 to 2.5%) according to the DAD and the NSAPD, respectively. No gestational age information was stated for 54 women in the NSAPD and for 7 women in the DAD (i.e. 47 women with missing gestational age in the NSAPD had a gestational age between 37 and 41 weeks, according to the DAD). Of the 543 women who had a preterm delivery according to the NSAPD, 495 were coded as having delivered preterm according to the DAD (i.e. sensitivity of 91.2%). Of the 5597 women who delivered at term or postterm gestation according to the NSAPD, 5531 were coded as having

delivered at term or postterm gestation according to the DAD (i.e. specificity of 98.8%). A detailed examination of the data on preterm delivery showed that 64 (i.e. 97%) of the 66 women coded as having delivered preterm by the DAD (but at term/postterm by the NSAPD) were at 36 weeks gestation according to the DAD, i.e. a large proportion of the false positive errors were due to a minor one-week difference in gestational age. Similarly, 31 of 48 (i.e. 65%) of the women who delivered at preterm gestation according to the NSAPD, but at term or postterm gestation according to the DAD, were at 37 weeks of gestational age at delivery according to the DAD. The weighted kappa statistic assessing the agreement between gestational age from the DAD data and gestational age from the NSAPD data was 0.75 (i.e. 95% CI 0.72 to 0.78), and the intraclass correlation coefficient was 0.86 (i.e. 95% CI 0.83 to 0.88).

Table 1 shows the sensitivity and specificity rates for several maternal health indicators. Most indicators in the DAD showed a high degree of accuracy. Sensitivity rates of 85% to 90% were noted for blood transfusions, induced labour and any gestational hypertensive disorders. There was good agreement between the many specific types of induction procedures/agents coded in the DAD and induction of labour coded in the NSAPD. For example, the 29 women who, according to the DAD, had labour induced through a combination of routes and involving the use of an oxytocic agent, were also coded as having their labour induced according to the NSAPD. The main discrepancy between the two databases occurred for cases where the DAD coded labour as having been induced by artificial rupture of membranes, whereas the NSAPD coded many such cases (i.e. 45 of 191) as having artificial rupture of membranes, but not as having been induced. Since artificial rupture of membranes after the onset of labour does not constitute labour induction, this discrepancy probably reflects a coding error in the DAD (i.e. assuming the information in the NSAPD is correct). Discrepancies were also noted for the diagnosis of hypertension in pregnancy. This was expected, because of the varied subtypes of hypertensive disorders in

TABLE 1
Validity of maternal data from the Discharge Abstract Database of the Canadian Institute for Health Information, using data from the Nova Scotia Atlee Perinatal Database as the gold standard (based on 6194 mothers, Nova Scotia, 2002)

Indicator	Sensitivity (%)	95% CI	Specificity (%)	95% CI
Preterm delivery (< 37 weeks)	91.2	88.5 to 93.4	98.8	98.5 to 99.1
Postpartum hemorrhage	90.2	86.2 to 93.3	98.2	97.8 to 98.5
Blood transfusion	85.7	42.1 to 99.6	99.8	99.6 to 99.9
Induction of labour	89.2	87.7 to 90.6	96.9	96.4 to 97.4
Caesarean delivery	99.8	99.5 to 100.0	98.7	98.3 to 99.0
Perineal laceration to – 1st degree	91.7	89.7 to 93.3	97.9	97.4 to 98.4
– 2nd degree	97.7	96.8 to 98.3	99.1	98.7 to 99.4
– 3rd degree	97.1	92.7 to 99.2	99.9	99.8 to 100.0
– 4th degree	94.7	74.0 to 99.7	99.9	99.8 to 100.0
Hypertension - chronic	83.3	73.6 to 90.6	99.9	99.8 to 100.0
Gestational hypertension with proteinuria (vs. severe PIH or HELLP)	75.2	67.5 to 81.8	99.5	99.3 to 99.7
Any gestational hypertensive disorder (vs. mild or severe PIH or HELLP)	87.9	85.0 to 90.4	99.6	99.4 to 99.8

Preterm delivery refers to women delivering before 37 completed weeks of gestation.

PIH denotes pregnancy induced hypertension.

HELLP denotes hemolysis, elevated liver enzymes and low platelets count syndrome.

pregnancy and the different labelling/classification schemes used by the NSAPD and the ICD-10-CA system.

Table 2 presents the assessment of infant health indicators among the 6315 newborns. The false negative rate for bacterial sepsis was high (i.e. sensitivity of 38.4%). This rate improved when cases in the DAD were also identified using adult codes for sepsis in addition to newborn codes. The more serious grades of intraventricular hemorrhage and fracture of the clavicle were accurately coded in the DAD, while RDS had the same discrepancies as hypertensive disorders of pregnancy (i.e. RDS classification is highly detailed in the NSAPD and differs from the diagnostic entities in the ICD-10-CA system). Nevertheless, combining an ICD-10-CA code of RDS with a procedure code of intubation in the DAD resulted in virtual agreement with a diagnosis of severe RDS in the NSAPD. Severe RDS in the NSAPD refers to RDS requiring assisted ventilation. Fetal/birth asphyxia was essentially not coded in the DAD (i.e. sensitivity of 14.3%, Table 2).

Discussion

Our study confirmed that major procedures such as Caesarean delivery were coded accurately in the DAD of CIHI. It also showed that the information on more minor diagnoses (e.g. first to fourth degree perineal lacerations) and more challenging diagnoses and procedures (e.g. induction of labour, which is easily confused with augmentation of labour) was also reasonably accurate. Similarly, gestational age—a difficult entity to capture accurately, given different methods of ascertaining gestational age—showed a relatively high degree of agreement between the two sources. The overall preterm birth rates were non-significantly higher in the DAD compared to the NSAPD, whereas postterm birth rates were significantly lower. Although these differences were relatively small, the direction of the differences suggests a greater influence of early ultrasound (and, hence, greater accuracy) on gestational age estimates in the DAD. In comparison with menstrual date-based estimation of gestational age, early ultrasound dating tends to slightly increase preterm birth rates and substantially lower postterm birth rates.¹⁶⁻¹⁸ The disagreements in the two databases arose mainly with regard to variably defined diagnostic entities, such

as bacterial sepsis and RDS. Nevertheless, identifying bacterial sepsis using both neonatal and adult codes for sepsis and confining RDS to “any respiratory distress” or to a severe form of RDS resulted in relatively accurate information for the DAD.

The serious discrepancy between the NSAPD and the DAD with regard to fetal/birth asphyxia is to be expected and is not a reflection of data inaccuracy in the DAD. Studies have shown that this diagnostic label has essentially disappeared¹⁹ from the clinical lexicon due to malpractice concerns, even though the clinical entity remains essentially unchanged in its frequency.²⁰ Thus, it is rarely captured in the DAD system, where coders identify cases only if the term “asphyxia” is documented in the medical chart, while the NSAPD continues to identify the condition based on its clinical components.

This study was carried out using medical records from 2002, a time when Nova Scotia first began to implement the ICD-10-CA coding in its hospitals. Since the ICD-10-CA system is substantially different from the previous version, some coding errors may have occurred in 2002 that would have been resolved with continued use. One possible example of this may be seen with regard

TABLE 2
Validity of neonatal data from the Discharge Abstract Database of the Canadian Institute for Health Information, using data from the Nova Scotia Atlee Perinatal Database as the gold standard (based on 6315 live births, Nova Scotia, 2002).

Indicator	Sensitivity (%)	95% CI	Specificity (%)	95% CI
Bacterial sepsis	38.4	28.1 to 49.5	99.7	99.5 to 99.8
Bacterial sepsis (adult/neonatal codes)	67.4	56.5 to 77.2	99.6	99.4 to 99.8
Intraventricular hemorrhage, grade 3, 4	88.9	51.8 to 99.7	100.0	99.9 to 100.0
Fracture of clavicle	91.7	61.5 to 99.8	100.0	99.3 to 100.0
Respiratory distress – any (vs. any)*	94.2	90.8 to 96.6	96.6	96.1 to 97.1
– RDS (vs. RDS)	50.9	43.1 to 58.6	99.8	99.7 to 99.9
– RDS (vs. severe RDS)	96.3	89.6 to 99.2	99.6	99.4 to 99.8
– any RDS + intubation (vs. severe RDS)	100.0	95.5 to 100.0	99.6	99.4 to 99.8
Fetal/birth asphyxia	14.3	6.4 to 26.2	99.3	99.1 to 99.5

* Any code vs. any code refers to an evaluation of any respiratory distress code in CIHI vs. any respiratory distress code in the NSAPD.

RDS vs. RDS refers to a respiratory distress syndrome code in CIHI vs. a respiratory distress syndrome code in the NSAPD.

RDS vs. severe RDS refers to a respiratory distress syndrome code in CIHI vs. a severe respiratory distress syndrome code in the NSAPD.

Any RDS + intubation refers to an evaluation of a respiratory distress syndrome code in CIHI plus an intubation code vs. a severe respiratory distress syndrome code in the NSAPD.

to the bacterial sepsis of the newborn codes, which had a poor sensitivity rate arising at least partly because adult sepsis codes were used. Presumably, such errors would have been corrected as familiarity with the ICD-10-CA system increased.

The improved diagnostic accuracy of diseases, such as RDS in the DAD with the restriction to more severe forms of the disease, suggests that researchers using these large hospitalization databases should routinely carry out sensitivity analyses to assess the robustness of their findings. Familiarity with the clinical culture and changes in clinician habits (e.g. knowledge of the declining use of terms, such as birth asphyxia)^{19,20} is a critical factor in appropriately interpreting patterns in large databases. A multi-disciplinary approach to research using such databases is probably the most appropriate approach.

One limitation of our study arose because, in most instances in Nova Scotia, the same health-records personnel coded medical charts for both the DAD and the NSAPD. This may mean that agreement between the two systems is higher than would be expected if the two systems were fully independent. On the other hand, both systems have detailed rules regarding coding (including criteria for diagnosis and specified parts of

the medical chart from which information is to be extracted). These coding rules are evident in the discrepancies in diagnoses for which standard diagnostic criteria were unavailable.

Other potential limitations of our study include the assumption that the NSAPD, a smaller, clinically focused database with a data quality assurance program, is more accurate than the DAD. This assumption, though tenable, is unlikely to hold with regard to all of the information in the two databases. For example, the CIHI database collects information on blood and blood products in much greater detail than the NSAPD does. Furthermore, the NSAPD algorithm for determining gestational age relies solely on menstrual dates and a pediatric examination of the newborn infant. Conversely, gestational age in the DAD could represent a better estimate, because it also incorporates early ultrasound information.^{16–18}

Finally, our assessment was limited to one Canadian province and, hence, may not be generally applicable to other provinces/territories, or even to Nova Scotia at a different time. Nevertheless, the relatively high level of accuracy observed in our study is encouraging and more in line with the expectations of CPSS investigators

who have worked with DAD data^{9–13} than the results of the abstraction-re-abstraction study.⁸

In summary, our study compared information in the DAD with that from a smaller clinically focused database, showing that the DAD information was accurate for many of the diagnoses/procedures examined. Furthermore, less accurate diagnoses, typically observed in the case of variably defined clinical entities, can be improved using combined codes and a restriction to more severe forms of the disease. This study therefore supports the use of the data in the CIHI DAD for national perinatal surveillance and research, with the caveat that appropriate inference rests on an understanding of clinical practice and the use of sensitivity analyses to identify robust findings.

Acknowledgements

This study was funded by the Maternal and Infant Health Section, Health Surveillance and Epidemiology Division of the Public Health Agency of Canada. We are grateful to the Reproductive Care Program of Nova Scotia for access to the data.

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Validity of autism diagnoses using administrative health data

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Abstract

It is necessary to monitor autism prevalence in order to plan education support and health services for affected children. This study was conducted to assess the accuracy of administrative health databases for autism diagnoses. Three administrative health databases from the province of Nova Scotia were used to identify diagnoses of autism spectrum disorders (ASD): the Hospital Discharge Abstract Database, the Medical Services Insurance Physician Billings Database and the Mental Health Outpatient Information System database. Seven algorithms were derived from combinations of requirements for single or multiple ASD claims from one or more of the three administrative databases. Diagnoses made by the Autism Team of the IWK Health Centre, using state-of-the-art autism diagnostic schedules, were compared with each algorithm, and the sensitivity, specificity and C-statistic (i.e. a measure of the discrimination ability of the model) were calculated. The algorithm with the best test characteristics was based on one ASD code in any of the three databases (sensitivity = 69.3%). Sensitivity based on an ASD code in either the hospital or the physician billing databases was 62.5%. Administrative health databases are potentially a cost efficient source for conducting autism surveillance, especially when compared to methods involving the collection of new data. However, additional data sources are needed to improve the sensitivity and accuracy of identifying autism in Canada.

Introduction

The prevalence of autism spectrum disorders (ASDs) and autism, specifically, is reported to have been increasing over time.¹⁻⁴ If this is in fact correct, there would be major implications for the education system and agencies that provide services for these children: the availability of support and services will not match the increasing demands on the education system and health service providers. To date, there have been isolated efforts in Canada to estimate the prevalence of ASDs in some jurisdictions, but there are currently no systems in place to routinely monitor and report autism incidence and prevalence. Active surveillance of autism, conducted

by population screening, provides excellent prevalence information, but is expensive and generally limited to short-term investigations.¹ Passive surveillance using existing databases provides a relatively inexpensive method to derive ongoing, population-based prevalence estimates.

The broad continuum of associated cognitive and neurobehavioural disorders, of which autism is the most extreme, are called pervasive developmental disorders (PDDs) or autism spectrum disorders (ASDs).^{1,5} According to the diagnostic criteria of the International Classification of Diseases (ICD-10) by the World Health Organization (WHO), PDDs include childhood autism, atypical autism, Rett

syndrome, other childhood disintegrative disorders, overactive disorders associated with mental retardation and stereotyped movements, Asperger's syndrome, other pervasive developmental disorders and unspecified pervasive developmental disorders. Childhood autism, atypical autism and Asperger's syndrome represent the more common diagnoses. In this study, we use the term ASD, which is equivalent to PDD, except that ASD does not include Rett syndrome and childhood disintegrative disorder, both of which are extremely rare.

In 1985, Bryson et al. made the first effort to estimate autism prevalence in Canada by screening all children (i.e. $n = 20\,800$) aged 6 to 14 years in a specific geographic area of Nova Scotia and conducting follow-up diagnostic assessments for children who screened positive (i.e. $n = 46$).⁶ Of the 46 children who screened positive, 21 children fell within the relatively narrow autism spectrum that was defined at the time (i.e. most, if not all, of whom would meet the more stringent criteria for autistic disorder).⁷

More recently, researchers in Canada have used existing data to estimate ASD prevalence. Ouellette-Kuntz et al. reported estimates of the prevalence of PDDs among children 15 years or younger during 2002 in the provinces of Prince Edward Island (PEI) and Manitoba.⁸ In PEI, cases were identified by the Department of Social Services and Seniors and the Department of Education; parental consent was required for the researchers

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to collect the information. In Manitoba, cases were identified through referrals to the Children's Special Services program of the Department of Family Services and Housing. PDD prevalence rates among 1- to 15-year-olds in both provinces were similar (i.e. 2.84 per 1000 in Manitoba and 3.52 per 1000 in PEI). Fombonne et al. reported prevalence (of PDDs) based on a population of children registered at a large Anglophone school board in the Montreal area on October 1, 2003 (i.e. n = 27 749).⁹ In Quebec, school boards submit information on children with PDDs and other disorders to the Ministry of Education in order to receive supplemental funding. In this 2003 survey, a total of 180 identified children had been diagnosed with a PDD (i.e. rate of 6.5 per 1000), 61 of whom were specifically diagnosed with autism.⁹ In summary, surveillance and reports of autism prevalence in Canada are infrequent and variable rates have been reported.

To date, administrative health databases have not been used in Canada to estimate autism incidence or prevalence, although they have been used to estimate the incidence and prevalence of other conditions; e.g. algorithms have been developed and tested using administrative data for determining the incidence and prevalence of childhood asthma, osteoporosis, diabetes mellitus and diabetic macular edema.¹⁰⁻¹³ In a study to evaluate the validity of ICD codes from administrative hospital discharge data, Quan et al.¹⁴ compared ICD-9 and ICD-10 coding (i.e. the coding systems used in the administrative health databases) with medical chart data for 32 clinical conditions (ASD was excluded from the conditions assessed). They found that detection rates (e.g. sensitivity) varied by condition from 82% for renal failure to 9% for weight loss.¹⁴

Administrative health databases are a potential source for determining autism prevalence, but the validity of ASD diagnoses from administrative health data must be determined before these databases are used to measure the prevalence of autism in a population. Based on a cohort of children born in Nova Scotia between 1989 and 2002, we used administrative health databases linked to a "gold standard"

clinical autism database to assess the accuracy of autism diagnoses ascertained from administrative health databases.

Methods

This study was based on data from a retrospective cohort study designed to examine prenatal, obstetrical and neonatal factors related to the development of autism. A cohort of all children born in Nova Scotia between 1989 and 2002 was identified from the Atlee Perinatal Database, i.e. a population-based database of all hospital births in Nova Scotia. The cohort of births was linked to the administrative health databases at the Population Health Research Unit at Dalhousie University. Data linkage was accomplished using encrypted health card numbers, common to all data sources. The cohort of children born between 1989 and 2002 were followed, by way of the administrative health databases, until December 2005.

For residents of Nova Scotia, as in the rest of Canada, access to hospital and physician services is universal within a system of publicly funded health care. For this study, three administrative health databases in Nova Scotia were used to identify diagnoses of autism spectrum disorders (ASD), i.e. the Hospital Discharge Abstract Database (available since 1989); the Medical Services Insurance (MSI) Physician Billings Database (available since 1989); and the Mental Health Outpatient Information System (MHOIS) Database (available since 1992). The Hospital Discharge Abstract Database includes diagnoses, which are noted in the medical chart and abstracted upon discharge. The MSI Physician Billing Database included a physician diagnostic code(s), which was sent to the provincial agency that handled payment for these insured services. The MHOIS Database was used for all outpatients seen in the mental health clinics and day patients in mental health day-treatment programs. Diagnoses were recorded by psychiatrists or psychologists, or both. An ASD diagnosis was defined from these administrative databases by an ICD-9 code 299 or an ICD-10 code F84 from any primary or secondary diagnostic field.

Seven algorithms were derived from combinations of requirements for single or multiple ASD claims from the three administrative databases. For example, in one algorithm, a child was considered to have an autism diagnosis if there was at least one autism code from the hospital discharge database; autism codes from the other databases were not required. The algorithm allowing for the most "hits" for an autism diagnosis was required for at least one ASD claim from any of the three aforementioned databases.

"Gold standard" diagnoses were obtained from a clinical database generated by the Autism Team of the IWK Health Centre. Referrals to the Autism Team were made largely by health care professionals and some teachers in the Halifax Regional Municipality to assess children with suspected autism. The IWK Autism Team consisted of pediatricians, psychologists, social workers, psychiatrists, speech-language pathologists, occupational therapists and nurses. Final determination of diagnoses was made by psychologists and/or pediatricians or psychiatrists, who led or co-led the diagnostic teams and was based on the Autism Diagnostic Interview – Revised, the Autism Diagnostic Observation Schedule and clinical judgment using DSM-IV-TR.¹⁵⁻¹⁷ These instruments and criteria were consistent with recommended practice parameters for diagnosing ASDs.^{18,19} Diagnoses made by the Autism Team, considered the "gold standard," were recorded in a database starting in 2001.

The linkage between the Atlee Perinatal Database, the administrative health databases and the "gold standard" data was accomplished using a multi-step procedure to ensure anonymity. The first step was the creation of a "cross-walk file," which included a unique number assigned to all individuals in each of the databases, along with their encrypted health card number. A third party used a sophisticated algorithm to encrypt health card numbers, assigned to every individual in the province and a common field in each data source). Finally, the requested variables from each file were linked back to the "cross-walk file," using the unique encrypted number

TABLE 1
Comparison of algorithms¹ using combinations of autism spectrum disorder (ASD) diagnoses from three administrative health databases compared to a “gold standard” diagnosis

Type of administrative data			Comparison of results to “gold standard”				Test characteristics of algorithms		
Hospital data (# of times ASD coded)	Physician billing data (# of times ASD coded)	Mental health outpatient data (# of times ASD coded)	# True positives	# True negatives	# False positives	# False negatives	Sensitivity	Specificity	C-statistic
≥ 1			21	86	2	155	11.9%	97.7%	0.55
	≥ 1		105	75	13	71	59.7%	85.2%	0.72
		≥ 1	29	81	7	147	16.5%	92.0%	0.54
≥ 1	≥ 1	≥ 1	122	68	20	54	69.3%	77.3%	0.76
≥ 1	≥ 1		110	73	15	66	62.5%	83.0%	0.74
≥ 1	≥ 2	≥ 2	75	78	10	101	42.6%	88.6%	0.67
≥ 1	≥ 2		65	82	6	111	36.9%	93.2%	0.65

¹Algorithms based on autism code(s) from more than one database indicates that an autism diagnosis was assigned if an autism code was used in either of the databases indicated.

assigned to the individuals in each database, and a linked, anonymous analysis file containing data elements from each data source was generated.

Diagnoses of children assessed by the “gold standard data” (i.e. the IWK Autism Team) from 2001 to 2005 were compared to ASD diagnoses from each of the seven algorithms, based on the administrative health databases. The accuracy of each algorithm was evaluated by calculating the sensitivity, specificity and a C-statistic (i.e. a nonparametric estimate of the area under a receiver operating characteristic curve that provides a measure of a method’s ability to predict an autism diagnosis). C-statistic scores range from 1.0 for a “perfect” test with a sensitivity and specificity of 100%, to 0.5 for a method that was unable to discriminate.²⁰

For the true ASD cases that were missed by the administrative databases (i.e. false negatives [FN]), codes for other psychological conditions were examined. In addition, codes that occurred both before and after the date of the true (i.e. “gold standard”) diagnosis were evaluated. Various factors were evaluated for those patients who had an autism code in one of the administrative databases, but who were not given an ASD diagnosis after assessment by the Autism Team (i.e. false positive [FP]). These included the number of incorrect claims; the years when

these ASD claims occurred, whether the incorrect claims occurred after the IWK negative diagnosis date; and whether there had been other claims made in relation to psychological conditions. Sensitivity and specificity rates were compared for maternal and infant factors, such as low birth weight and maternal age (available from the Atlee Perinatal Database), to determine if certain characteristics were associated with the accuracy of autism diagnoses based on administrative health data.

Approval for this study was obtained by the Research Ethics Board of the IWK Health Centre.

Results

The IWK Autism Team evaluated 270 patients linked to the overall study cohort of children born in Nova Scotia. According to the team’s assessment, there were 176 confirmed ASD cases and 88 non-cases (i.e. 6 had undetermined diagnoses and were dropped from further analysis). All remaining 264 children had at least 2 years of administrative data available following the date of their birth. When seen by the Autism Team, 58% of the children were 4 years or younger; only 12% of the children were 10 years or older when the team saw them. The majority of confirmed cases were coded with a general diagnosis of ASD, without any specific autism diagnosis noted.

Table 1 shows the definition of each of the seven algorithms tested, along with the sensitivity, specificity and C-statistic associated with each algorithm. The algorithm with the highest C-statistic (i.e. 0.76), the highest sensitivity (i.e. 69.3%) and a specificity of 77.3% was the algorithm that defined an ASD diagnosis by at least one claim in any of the three administrative databases. Using this algorithm, 190 of the 264 children were correctly diagnosed. There were 20 FPs and 54 FNs, which were examined in more detail to help explain the inaccuracies in the administrative databases.

An examination was made of the 54 FN children diagnosed with ASD by the Autism Team, but who did not have an ASD claim in any of the three databases, to see if other claims might have been systematically recorded instead of ASD. Of the 54 FNs, 46 children had at least one MSI physician billing claim for neurotic disorders, personality disorders and other non-psychotic mental disorders (i.e. ICD-9 codes 300-316). Of these 46 children, 35 (i.e. 76%) had an ICD-9 code of 315 (i.e. “specific delays in development”) coded at least once. This code occurred in 22 children before the Autism Team diagnosis date and in 26 children after; some children had an ICD-9 code of 315 before and after the Autism Team diagnosis date.

TABLE 2
Comparison of the number of autism spectrum disorder (ASD)
claims per child among false positives and true positives

Database	Frequency of ASD claims per child	False positives	True positives
		# children (%) (n = 20)	# children (%) (n = 122)
Hospital	1 or more	2 (10%)	21 (17%)
	2 or more	1 (5%)	7 (6%)
MSI	1 or more	13 (65%)	104 (85%)
	2 or more	4 (20%)	55 (45%)
MHOIS	1 or more	7 (35%)	29 (24%)
	2 or more	7 (35%)	23 (19%)
Any of 3 databases	1 or more	20 (100%)	122 (100%)
	2 or more	11 (55%)	74 (61%)

The number of ASD claims from each of the three databases was compared between the 20 FP children and the 122 TP children (see Table 2). For the 20 FPs, 2 children (i.e. 10%) had ASD coded from Hospital Discharge Data, 13 (i.e. 65%) from MSI Physician Billing Data and 7 (i.e. 35%) from MHOIS Data (see Table 2). Among the 13 subjects from the FP group with one or more ASD claims from the Physician Billing Database, 4 of 13 (i.e. 31%) had more than one ASD claim in the Physician Billing Database, compared to 55 of 104 (i.e. 53%) of the true positives. Among the MHOIS claims for the FP group, all had more than one MHOIS claim for ASD. Of the 122 TPs, 21 (i.e. 17%) had hospital claim(s), 104 (i.e. 85%) had MSI claim(s) and 29 (i.e. 24%) had MHOIS claim(s); 27 (i.e. 22%) had claims from 2 databases and 5 (i.e. 4%) had claims from all 3 databases (data not shown). While most ASD claims from the hospitalization and MHOIS databases occurred after the Autism Team diagnosed TPs, 55 of 104 (i.e. 53%) of children had MSI claim(s) before this date. Other than ASD codes, the most common code used was ICD-9-CM 315 (“specific delays in development”), which was recorded equally before and after the Autism Team diagnosis date.

Sensitivity and specificity values were compared according to maternal and neonatal characteristics (see Table 3). The sensitivity of the administrative data in identifying an ASD diagnosis was similar across most factors, including for males

(i.e. 69.7%) and females (i.e. 66.7%). The sensitivity of the administrative data in identifying an ASD diagnosis was not significantly lower for children with a major congenital anomaly (i.e. 55.6%) compared to children without an anomaly (i.e. 69.9%). The sensitivity was not significantly higher among children outside of Halifax County compared to residents of Halifax County (i.e. 75.0% versus 68.1%), although specificity was lower (i.e. 66.7% versus 80.0%, respectively).

Discussion

In the current study, we used codes from three administrative health databases to evaluate multiple algorithms for their accuracy in identifying autism among children in Nova Scotia. Although the overall study cohort included all children born in Nova Scotia between 1989 and 2002, only children seen by the Autism Team (between 2001 and 2005) who linked to the study cohort were included in this validation study. Based on the algorithm defining autism by at least a single claim in any one of the hospitalizations, the physician billing or the outpatient mental health databases, the ability of administrative health databases in Nova Scotia to correctly identify children with autism was moderately successful (i.e. sensitivity of 69%). Most of the true ASD cases who were incorrectly identified within the administrative data (i.e. FNs) had codes indicating some other non-psychotic psychological disorder or developmental delay, suggesting that physicians may have

been reluctant to use an autism code before an autism diagnosis was verified.

A strength of this study was the quality of the autism diagnosis in the “gold standard” population. However, the “gold standard” diagnosis was limited to children who were referred to the Autism Team. It should be noted that children in this validation study without an ASD diagnosis when assessed by the Autism Team would have had some behavioural and/or developmental feature that warranted referral to the Autism Team. Therefore, the false positive rate observed in this study is likely higher, and the specificity lower, than it would have been had we been able to establish a “gold standard” diagnosis for all children in the administrative databases. Nevertheless, the specificity we observed was reasonably high (i.e. 77%), an estimate which is likely below the true specificity. Other algorithms tested in this study had more stringent requirements for defining autism (e.g. two physician claims required), and therefore had better specificity than the one-claim algorithm, albeit at the expense of reduced sensitivity.

In order to improve the detection rate observed in this study, other data sources would be required. In Canada, information on ASD diagnoses is available from regional school boards in some areas or from some provincial Departments of Social Services or Family Services, as previously discussed. The use of education data sources (i.e. alone or in conjunction with clinical data) and data from other government-administered programs have been used to identify autism cases in the United States. The Centers for Disease Control and Prevention have established a multi-source surveillance network for ASD and other developmental disabilities.²¹

Children 8 years of age with ASD who reside within one of the 16 states comprising part of the network area were identified in a two-phase process. First, children suspected of having an ASD were identified through screening and abstraction of records from multiple sources within clinical and education records. In phase two, the abstracted behavioural data were scored

TABLE 3
Comparison of sensitivity and specificity of autism spectrum disorder (ASD) diagnoses using administrative data compared to “gold standard” diagnoses, according to maternal and neonatal factors

Factor	Number	Sensitivity (95% CI)	Specificity (95% CI)
Maternal age			
< 35	218	71.2% (63.2 to 78.1)	77.2% (66.8 to 85.2)
≥ 35	46	62.2% (46.1 to 76.0)	77.8% (44.3 to 94.7)
County of residence			
Halifax County	214	68.1% (60.0 to 75.1)	80.0% (69.1 to 87.8)
Outside Halifax	50	75.0% (57.7 to 87.0)	66.7% (43.6 to 83.9)
Birth weight			
< 2500 g	15	72.7% (42.9 to 90.8)	75.0% (28.9 to 96.6)
≥ 2500 g	234	69.1% (61.7 to 75.7)	77.4% (67.3 to 85.1)
Major congenital anomaly*			
Yes	13	55.6% (26.6 to 81.2)	100% (45.4 to 100)
No	247	69.9% (62.5 to 76.4)	76.5% (66.2 to 84.5)
Sex			
Male	231	69.7% (62.0 to 76.4)	80.3% (69.8 to 87.8)
Female	33	66.7% (45.2 to 83.0)	58.3% (31.9 to 80.7)
Birth order			
First born	145	69.8% (60.0 to 78.1)	77.6% (64.0 to 87.1)
Second or higher	119	68.8% (57.9 to 77.9)	76.9% (61.5 to 87.6)

* A major anomaly is defined as a defect of structure or function that is present at birth and affects length of life, impacts quality of life or requires surgery.

by clinicians to determine whether they met the ASD case definition. The rates varied somewhat between sites, with an overall mean prevalence rate of 6.6 per 1000 eight-year-old children.²² Extensive quality assurance activities were incorporated into the network to maximize data quality and consistency.

Newschaffer et al. used a national source of administrative data (i.e. the United States Department of Education, Office of Special Education Programs) to examine trends in ASD between 1992 and 2001. However, limitations of these data were noted, in particular with the specific classification of impairment and the likelihood of underestimating autism prevalence based on special education data alone.²³ In California, individuals with autism (and other conditions) are eligible to receive services through the Department of Developmental Services. Eligibility is based on diagnoses provided by qualified health care professionals. Croen et al.²⁴ used these data to estimate autism prevalence. They suspected that their observed prevalence

of 12.3 per 10 000 children for the years 1987 to 1994 was an underestimation, since approximately 20% to 25% of the children who were eligible to receive services were not enrolled in the program.²⁴

In Canada, all provinces and territories have administrative data that include hospitalizations and physician visits. In Nova Scotia, the addition of an outpatient mental health database increased the sensitivity of ASD diagnoses by about 7%, compared to the sensitivity using only hospitalization and claim data regarding physician visits. On the other hand, the specificity increased by about 6% when the mental health outpatient data were excluded. Since relatively few children were hospitalized for (or with) autism (i.e. 12% of the true cases had an autism code from the hospitalization data), this source, by itself, was inadequate to determine autism diagnoses in a population. However, an autism diagnosis in the hospitalization database was very likely correct. Although we explored ICD codes that were used other than ASD codes, their use was too

inconsistent to suggest an algorithm that would improve the false positive or false negative rates.

Research or surveillance of health conditions using administrative health databases has advantages over other data collection methods. Administrative health databases are available in all Canadian provinces and territories and provide a source for a large number of population-based cases, likely at a lower cost than would be possible with newly collected data. In addition, diagnoses are entered into the databases without knowledge of underlying exposure-outcome hypotheses. However, there are limitations to using administrative data, particularly with respect to the accuracy of diagnoses that are being used for billing purposes (as is the case with the Physician Billing Database).

Given that we measured maximum sensitivity at 69%, it is likely that administrative health data alone would underestimate the true incidence and prevalence, as observed in this study. This would suggest that additional data sources are necessary to enhance the detection rate of ASD diagnoses from existing databases, since it is unlikely that a single source of administrative data will provide a complete accounting of all autism cases in Canada. Although challenging, the jurisdictions should work together toward acquiring standard data from multiple sources to enable ongoing, passive surveillance of ASDs in Canada.

Acknowledgements

This project was funded by Cure Autism Now (i.e. now Autism Speaks). Linda Dodds was supported by the Clinical Research Scholar Award from Dalhousie University and the New Investigator Award from the Canadian Institutes of Health Research. The authors thank the Reproductive Care Program of Nova Scotia and the Population Health Research Unit of Dalhousie University for data access. Although this research is based partially on data obtained from the Population Health Research Unit, the observations and opinions expressed are those of the authors and do not represent those of the Population Health Research Unit.

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Associations between chronic disease, age and physical and mental health status

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Abstract

This paper examines the associations between chronic disease, age, and physical and mental health-related quality of life (HRQOL), using data collected in 10 studies representing five chronic conditions. HRQOL was measured using the SF-36 or the shorter subset, SF-12. Physical Component Summary (PCS) and Mental Component Summary (MCS) scores were graphed by condition in age increments of 10 years, and compared to age- and sex-adjusted normative data. Linear regression models for the PCS and MCS were controlled for available confounders. The sample size of 2418 participants included 129 with renal failure, 366 with osteoarthritis (OA), 487 with heart failure, 1160 with chronic wound (leg ulcer) and 276 with multiple sclerosis (MS). For the PCS, there were large differences between the normative data and the mean scores of those with chronic diseases, but small differences for the MCS. Female gender and comorbid conditions were associated with poorer HRQOL; increased age was associated with poorer PCS and better MCS. This study provided additional evidence that, while physical function could be severely and negatively affected by both chronic disease and advanced age, mental health remained relatively high and stable.

Key words: *age, chronic disease, mental health, physical health, HRQOL, status, SF-36, SF-12*

Background

Health-related quality of life (HRQOL) is a primary concern with chronic conditions and is often used as a research outcome in both clinical trials and observational studies. A useful characteristic of a generic measure of HRQOL is the ability to compare across different diseases to assess burden of illness.¹ HRQOL is a particularly relevant outcome in chronic disease, where a cure is often unavailable and health goals involve living with and managing one's condition.^{2,3}

A growing body of research has examined HRQOL in a variety of diseases, and many studies have identified significant

impairments.⁴⁻¹⁰ HRQOL has also been examined in the general population, providing normative data for comparative purposes.^{4-6,11} However, while chronic disease typically has a significant negative impact on the physical aspects of health, mental health status may remain relatively unaffected. This has been demonstrated in studies on individual conditions,¹²⁻¹⁷ as well as in two multiple-condition studies: one focusing on allergies, arthritis, congestive heart failure, chronic lung disease, hypertension, diabetes and ischemic heart disease,¹ and another that compared multiple sclerosis (MS), osteoarthritis (OA), renal disease and renal transplants.² Additional research into the effect of multimorbidity, taking into account

the effect of both the number and severity of comorbid conditions, also identified an inverse association between the number and severity of conditions and HRQOL,^{18,19} particularly in the physical domains.^{18,19}

Cross-sectional evidence suggests that while the physical aspects of HRQOL decline as age increases,^{2,4} mental health remains stable across age categories, or may even improve.^{2,4,21} This observation is further supported with longitudinal data. HRQOL tends to be stable over three²² to five²³ years, but if there are changes, it is the physical aspects of HRQOL which tend to decline while mental aspects improve.²³

The purpose of this study was to examine the relationship between age and physical and mental aspects of health for people with different chronic conditions. Research objectives included a comparison of the physical and mental health status across diseases, as well as an examination of the association between age and HRQOL, while controlling for key variables available across all databases. We hypothesized that the physical aspects of HRQOL would be substantially lower in those with chronic disease as compared to a normative population, and that it would also be lower in older versus younger age groups, while the mental aspects of HRQOL would be similar to the normative data and be relatively unaffected by disease group or increased age.

Herein, we examined data collected in ten Canadian studies representing five conditions, including renal failure, hip and knee OA, congestive heart failure (CHF,

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TABLE 1
Characteristics of the ten studies

Study	n	Inclusion criteria	Exclusion criteria	Age Mean (SD)	PCS Mean (SD)	MCS Mean (SD)
Renal failure	129	Age 18 years > 6 months duration	Acute/reversible cognitive impairment	59.4 (14.7)	33.2 (11.8)	50.1 (11.2)
Osteoarthritis (hip)	177	Able to consent	Revisions, fractures	67.6 (11.2)	24.4 (6.6)	49.4 (12.5)
Osteoarthritis (knee)	189	Able to consent	Revisions, fractures	68.6 (8.8)	26.2 (7.9)	50.9 (12.4)
CHF (usual vs. transitional care)	191	Speak English or French	Unable to consent	75.7 (9.9)	29.9 (8.2)	51.0 (9.6)
CHF (partners in care)	296	Speak English or French	Unable to consent	72.7 (12.0)	31.5 (8.8)	46.7 (11.2)
Chr. wound (uptake of evidence)	117	Speak English or French	Unable to consent	74.1 (12.5)	32.3 (9.9)	48.8 (10.7)
Chr. wound (two models of care)	211	Speak English or French	Unable to consent	68.4 (13.9)	35.7 (9.8)	49.1 (11.2)
Chr. wound (bandaging RCT)	180	Speak English or French	Unable to consent	67.1 (16.1)	39.5 (10.9)	50.6 (10.2)
Chr. wound (new service delivery)	652	Speak English or French	Unable to consent	72.2 (13.7)	31.8 (9.6)	47.9 (12.0)
Multiple sclerosis*	276	Clinically definite MS Communicate verbally	Cognitive impairment duration > 12 months	46.5 (10.1)	33.5 (10.6)	46.0 (12.2)

CHF: congestive heart failure;

Chr.: chronic;

SD: standard deviation;

PCS: physical component summary;

MCS: mental component summary

two studies), chronic wounds (leg ulcer, four studies) and MS. While HRQOL data do exist for these conditions, little of it is Canadian, and the opportunity to compare these five conditions is new, thus adding to the body of knowledge about the impact of chronic disease on HRQOL. These findings will also be of interest to those who provide care to patients with these conditions.

Methods

Details of the 10 studies are described below and are presented in Table 1. Data were collected at baseline through a combination of patient interview (SF-36 or SF-12, sociodemographic data) and chart review (clinical data). Ethics approval for each study was obtained from the Queen's University and Affiliated Teaching Hospitals Research Ethics Board or the Ottawa Health Research Institutes Ethics Board, as well as site-specific institutional reviews, where applicable. An application for the combined analysis was approved by the Queen's Research Ethics Board (approval number EPID-227-06).

Measures

The Medical Outcomes Trust 36-item health survey (SF-36)⁴ and its 12-item subset, the SF-12,⁵ are among the most widely used instruments to measure

HRQOL.^{4,5} The SF-36 and SF-12 measure eight self-reported aspects of HRQOL, including physical function, physical role, bodily pain, general health, vitality, social function, emotional role and mental health. The Physical Component Summary (PCS) and Mental Component Summary (MCS) are standardized to a mean of 50, with a score above 50 representing better than average function and below 50 poorer than average function.^{5,6} Previous work by Ware et al. has noted a high degree of correspondence between the PCS and MCS obtained from the SF-36 and SF-12. Regression analyses to reproduce the PCS and MCS scores for the SF-36 using the SF-12 scores had R² values in excess of 0.90 for both.⁵ In addition, an examination of the actual scores across 17 population and disease subgroup comparisons indicated that the average SF-36 and SF-12 PCS and MCS scores differed by less than one point, suggesting that the interpretation is the same and that comparisons are valid.⁵

Databases and participants

The renal failure database included all consenting patients receiving hemodialysis at Kingston General Hospital (KGH) and its affiliated satellite units in Kingston, Ontario. The SF-36 version 1.0 was administered at a routine hemodialysis visit. The hip and knee OA databases included all consenting

primary elective total hip and total knee replacement patients on the waiting lists of five orthopedic surgeons in Kingston. The SF-36 version 1.0 was administered at the time of the six-week pre-surgical assessment.

The two CHF databases included all patients who had a diagnosis or exacerbation of CHF at hospital admission. Data for the first study (i.e. Usual Care versus Transition Care) were collected during hospitalization at two medical units of the Civic Campus at the Ottawa Hospital. Data for the second study (i.e. Partners in Care: CHF Study) were collected from patients recruited from 10 sites, including inpatient units, and community and specialty clinics in Ontario, New Brunswick, Manitoba and Illinois. HRQOL was assessed at the time of study entry using the SF-12 version 1.0. Although most were inpatients at the time of enrolment, they were seen early in their admission and the stays were typically brief. As most of the items on the SF-12 reference the past four weeks, the data are considered representative of the time when they were not hospitalized.

The chronic wound database (i.e. leg ulcers) was based on four studies, including the Prospective Study of the Uptake of Evidence-Based Guidelines in the Community; the

Effectiveness and Efficiency of Two Models of Delivering Care to Chronic Wound Population;¹⁶ the Chronic Leg Ulcers in the Community Pre- and Post-Implementation of a New Service Delivery Model;¹⁷ and a Randomized Control Trial (RCT) of the Effectiveness of Two Compression Technologies. Patients were recruited from sites in Ontario (i.e. Ottawa, Kingston, Toronto, Hamilton, Niagara, Kitchener-Waterloo and London), Manitoba (i.e. Winnipeg) and Saskatchewan (i.e. Regina and Saskatoon). SF-12 version 1.0 (version 2.0 for the RCT) data were collected as part of the baseline assessment.

The MS database included all consenting individuals with an appointment at the MS Clinic in Kingston over a one-year period. Two weeks before their appointment, patients received a package containing the SF-36 version 1.0 and a sociodemographic questionnaire. Those who consented returned the completed package at their appointment.

Data management and statistical procedures

All project databases were entered into SPSS (version 14.0 for Windows, Chicago, Illinois, 2005) for scoring and analysis. For the combined analysis, the variables contained in each, as well as the associated coding, were examined to find the common variables across the 10 databases. Key variables contained in each database were age, gender, whether the patient lived alone, cardiovascular disease, diabetes and “additional” comorbidities.

The definition for cardiovascular disease included hypertension, as this was important for the renal failure population. However, for the CHF group, it included cardiovascular disease *other than* congestive heart failure to avoid multicollinearity. While this resulted in a somewhat different adjustment for cardiovascular disease across the chronic conditions, it was felt that a crude adjustment was preferable to no adjustment at all. The diversity of the patient populations also resulted in the collection of different comorbidities. For example, very few comorbidities were collected for the MS sample, while a lengthy list was compiled for the heart failure studies.

As a result, only two comorbidities plus a category of “additional comorbidities” (i.e. defined simply as yes/no) could be drawn from each of the databases, and included comorbidities ranging from depression and sleep disorders to cancer, stroke and myocardial infarction. Variables such as education level, marital status, severity of disease and socio-economic status were not consistently collected across all databases. Patients under 25 years were excluded, as there were too few for comparison (i.e. two OA, four renal failure, three MS).

To facilitate comparison, age was categorized in 10-year increments as in the Canadian normative data for the SF-36.¹¹ Once the 10 databases were collapsed into 5 condition-specific databases, the mean PCS and MCS scores were graphed by age group and condition, and compared to age- and sex-adjusted normative data.¹¹ Linear regression models were developed for the PCS and the MCS, controlling for condition, age group, gender, living circumstances, cardiovascular disease, diabetes and additional comorbidities. All two-way interactions were also assessed. The condition with the highest mean age (i.e. CHF) was used as the reference condition, while the reference age group used was 25 to 34 years.

Results

Response rates and demographics

The 10 individual study sample sizes ranged from 117 to 652 participants, with a combined sample size of 2418. The characteristics of patients in the five chronic conditions are displayed in Table 2. In all studies, the participation rates were high (i.e. > 77%). For the renal failure database, 129 of 155 (83.2%) provided consent, and age ranged from 25.5 to 89.8 years. For OA, 880 patients were eligible and 673 agreed to participate, for a response rate of 76.5%. However, chart review was done after surgery and, consequently, only 366 participants had complete data, since 307 were still awaiting surgery at the study’s end. Participant age ranged from 30.0 to 89.0 years, with a similar number of patients awaiting a total hip or knee replacement (i.e. 177 and 189, respectively).

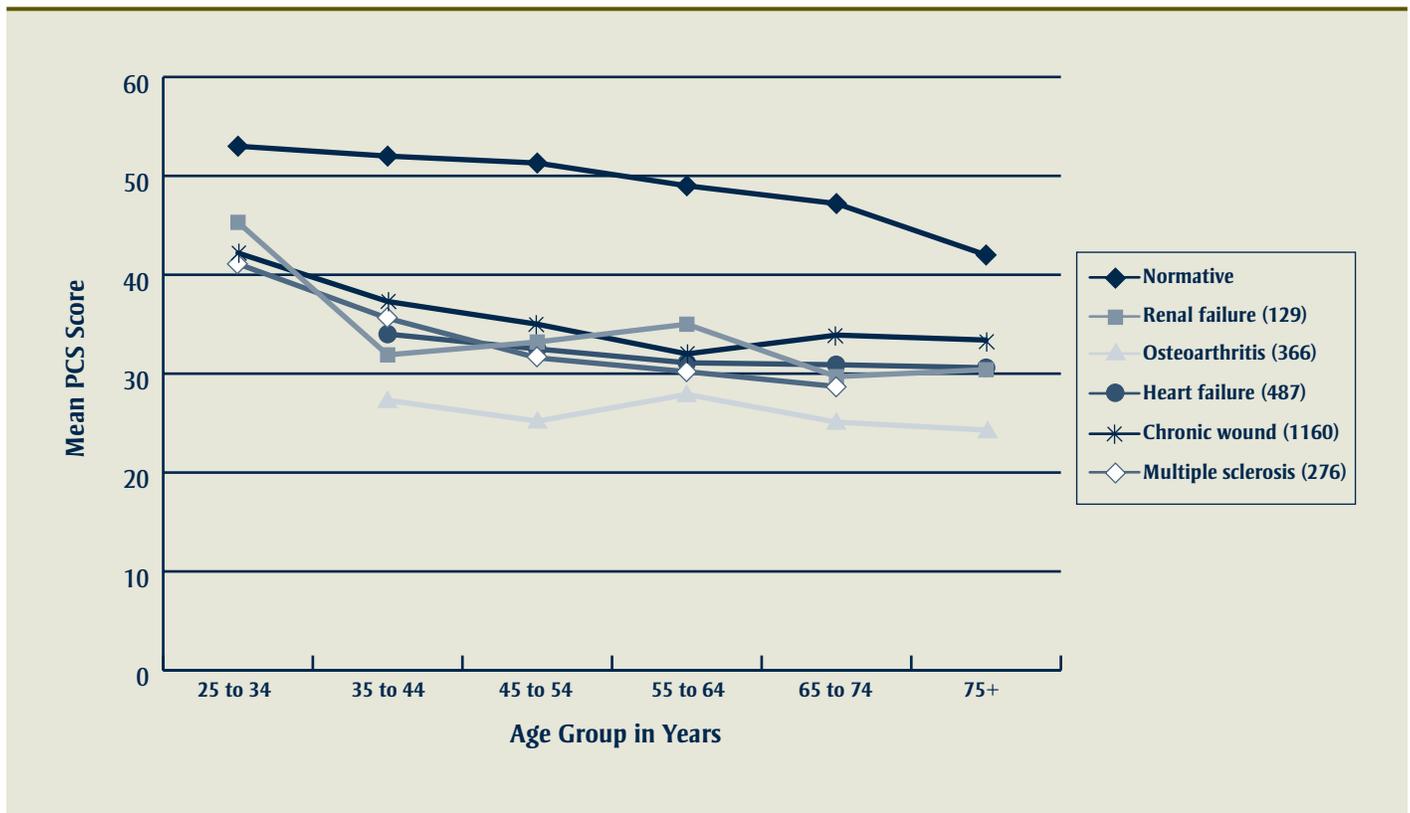
The heart failure database contained 487 of 506 eligible patients (i.e. 96.2%) who completed the HRQOL questionnaire. Patients ranged in age from 31.0 to 102.0 years. Four databases were represented in the chronic wound sample, and 1160 of 1470 (i.e. 78.9%) patients completed the SF-12; ages for this sample ranged from 25.0 to 102.0. For MS, 300 of 363 patients (i.e. 82.6%) agreed to participate, with 276 completing the SF-36. This sample was the youngest, with ages ranging from 25.0 to 77.0 years, and only 10 individuals over 65 years. It also had far more women (i.e. 203) than men (i.e. 73), compared to the other studies where gender was more balanced.

Descriptive statistics, physical component summary

Figure 1 contains the graph of the mean values for the PCS for each age group by condition; the means and 95% confidence intervals are presented in the accompanying table. The differences between the normative data and the mean values of those with each of the chronic diseases were large, demonstrating a significant burden of illness. The renal failure group showed the greatest variation by age group, while the OA sample consistently had the lowest scores.

When examining all chronic diseases as a group (n = 2418), an initial decline levelled off as age increased. Starting with the 25 to 34 year age group and ending with the 75-plus age group, the mean values for the PCS were 41.4 ± 10.1; 35.3 ± 11.7; 32.3 ± 10.3; 31.3 ± 9.3; 30.6 ± 9.6; 31.5 ± 10.0. The 10-point difference between the youngest (i.e. 41.4) and oldest (i.e. 31.5) groups was similar to the drop in the normative sample. Examining each disease group separately, this pattern was less clear, with some conditions (e.g. OA 55 to 64 and chronic wound 65 to 74) showing somewhat higher scores at older ages than in the adjacent, younger group. However, the confidence intervals were wide and overlapped for some conditions, suggesting that even though the differences were sometimes large, they were not necessarily statistically significant.

FIGURE 1
Physical Component Summary scores by disease and age group

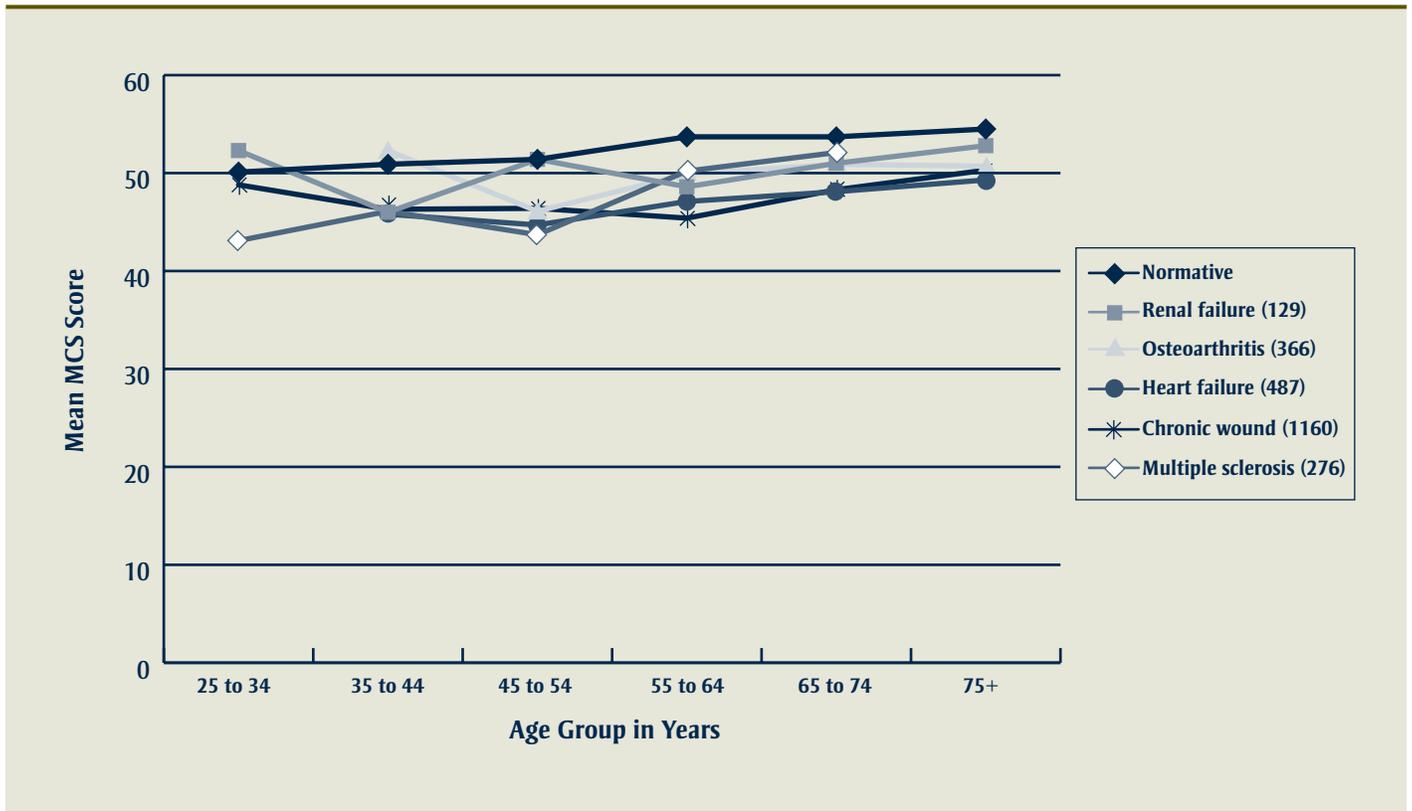


Footnote: Means and 95% CIs by age group, physical component summary

Sample (n)	25 to 34 years	35 to 44 years	45 to 54 years	55 to 64 years	65 to 74 years	75+ years
Normative	53.0 52.2, 53.7	52.0 51.3, 52.7	51.3 50.9, 51.7	49.0 48.6, 49.3	47.2 46.8, 47.6	42.0 41.5, 42.5
Renal failure (129)	45.3 36.8, 53.7	31.9 25.0, 38.7	33.2 27.0, 39.3	35.0 31.4, 38.6	29.7 26.1, 33.2	30.4 23.8, 37.1
Osteoarthritis (366)	n/a	27.3 21.0, 33.6	25.2 23.1, 27.3	27.9 25.6, 30.2	25.1 24.1, 26.2	24.3 22.8, 25.7
Heart failure (487)	n/a	34.0 21.6, 46.3	32.5 28.8, 36.2	31.1 28.8, 33.4	30.9 29.4, 32.3	30.6 29.6, 31.6
Chronic wound (1160)	42.2 37.2, 47.3	37.3 33.2, 41.4	35.0 33.1, 36.9	32.0 30.6, 33.5	33.9 32.7, 35.1	33.4 32.6, 34.2
Multiple sclerosis (276)	41.1 37.6, 44.6	35.6 33.4, 37.9	31.6 29.6, 33.7	30.2 27.7, 32.8	28.7 22.2, 35.3	n/a

Data were not graphed and 95% CIs were not calculated when the sample size was < 5.

FIGURE 2
Mental component summary scores by disease and age group



Footnote: Means and 95% CIs by age group, physical component summary

Sample (n)	25 to 34 years	35 to 44 years	45 to 54 years	55 to 64 years	65 to 74 years	75+ years
Normative	50.1 49.2, 51.1	50.9 50.1, 51.7	51.4 51.0, 51.8	53.7 53.4, 54.0	53.7 53.4, 54.0	54.5 54.1, 54.9
Renal failure (129)	52.3 45.5, 59.0	46.0 38.6, 53.4	51.4 47.1, 55.6	48.6 44.5, 52.6	51.0 46.8, 55.2	52.8 47.6, 58.1
Osteoarthritis (366)	n/a	52.3 37.6, 67.0	46.1 42.4, 49.8	49.9 46.2, 53.5	50.9 49.0, 52.7	50.7 48.2, 53.1
Heart failure (487)	n/a	45.8 34.7, 56.8	44.7 39.2, 50.1	47.1 44.1, 50.1	48.1 46.4, 49.9	49.3 47.9, 50.6
Chronic wound (1160)	48.8 42.8, 54.9	46.3 42.5, 50.2	46.4 44.4, 48.4	45.4 43.3, 47.5	48.3 47.0, 49.7	50.3 49.4, 51.2
Multiple sclerosis (276)	43.1 38.6, 47.7	46.1 43.7, 48.5	43.7 41.1, 46.4	50.2 46.8, 53.5	52.1 41.7, 62.4	n/a

Data were not graphed and 95% CIs were not calculated when the sample size was < 5.

TABLE 2
Sample characteristics for the five conditions

Characteristic	Renal Failure n = 129	Osteoarthritis n = 366	Heart Failure n = 487	Chronic Wound n = 1160	Multiple Sclerosis n = 276
	n (%)	n (%)	n (%)	n (%)	n (%)
Age group					
25 to 34 years	9 (7.0)	1 (0.3)	2 (0.4)	17 (1.5)	29 (10.5)
35 to 44 years	14 (10.9)	7 (1.9)	7 (1.4)	42 (3.6)	94 (34.1)
45 to 54 years	20 (15.5)	40 (10.9)	22 (4.5)	120 (10.3)	90 (32.6)
55 to 64 years	38 (29.5)	56 (15.3)	58 (11.9)	150 (12.9)	53 (19.2)
65 to 74 years	31 (24.0)	157 (42.9)	136 (27.9)	267 (23.0)	8 (2.9)
75+ years	17 (13.2)	105 (28.7)	262 (53.8)	564 (48.6)	2 (0.7)
Female	54 (41.9)	202 (55.2)	236 (48.5)	649 (55.9)	203 (73.6)
Live alone	25 (19.4)	79 (21.6)	195 (51.5)	420 (36.2)	35 (12.7)
Comorbidities					
Cardiovascular*	110 (85.3)	152 (41.5)	373 (76.6)‡	701 (60.4)	47 (17.0)
Diabetes	45 (34.9)	13 (3.6)†	158 (32.4)	368 (31.7)	12 (4.3)
Additional	91 (70.5)	79 (21.6)	435 (89.3)	805 (69.4)	122 (44.2)

	Mean ± SD				
Age	59.4 ± 14.7	68.1 ± 10.0	73.9 ± 11.3	70.9 ± 14.2	46.5 ± 10.1
PCS	33.2 ± 11.8	25.3 ± 7.3	30.9 ± 8.6	33.8 ± 10.2	33.5 ± 10.6
MCS	50.1 ± 11.2	50.2 ± 12.5	48.4 ± 10.9	48.7 ± 11.5	46.0 ± 12.2

SD: standard deviation;

PCS: physical component summary;

MCS: mental component summary

* Cardiovascular includes hypertension

† Insulin-dependent diabetes only for the OA group

‡ Other than heart failure for the heart failure group

Descriptive statistics, mental component summary

Figure 2 contains the graph of the mean values for the MCS; the means and 95% confidence intervals are presented in the accompanying table. For those under 45 years, the sample sizes and resulting wide confidence intervals preclude valid comparisons for all but the MS sample aged 25 to 34 years, and both the MS and the chronic wound sample aged 35 to 44 years. In all three comparisons, those with the chronic disease scored substantially lower than the normative sample. The highest mean value for age groups over 55 years was in the normative sample, but the differences between the normative and condition-specific samples were small and, therefore, of questionable clinical significance. The MS sample had the lowest mean values for two age groups (i.e. 25 to 34 and 45 to 54 years), while

the chronic wound sample had the lowest values for those in the 55 to 64 year age group. Several disease groups overlapped at the lowest value for the remaining three age groups.

When all samples were combined (i.e. n = 2418), mean MCS values were fairly stable for participants aged 25 to 54 years, after which there was a steady improvement by age category. Starting with the 25 to 34 year age group and ending with the 75-plus age group, the mean values for the MCS were 46.6 ± 11.7; 46.4 ± 11.9; 45.8 ± 11.7; 47.4 ± 12.7; 49.1 ± 11.1; 50.1 ± 11.2. This increase in the older groups was similar to the normative sample. Within a disease, however, this pattern was less clear, with most diseases showing declines until the age group of 45 to 54 years. At this point, the mean MCS appeared to increase for all but the chronic wound sample, which

increased after 55 years of age. However, as for the PCS results above, the confidence intervals were often wide and overlapping, and thus the data must be interpreted with caution.

Data were also grouped by gender within each disease to see if the pattern held true for both men and women. This was the case (data not shown); therefore, the results were not reported separately for men and women.

Regression analyses

Tables 3 and 4 contain the linear regression model for the PCS and MCS, respectively. Although all two-way interactions were tested, only two attained statistical significance in each model, all with negative coefficients (i.e. renal* additional comorbidities and chronic wound* additional comorbidities for the PCS; and

TABLE 3
Linear regression model for the physical component summary

Physical Component Summary ($r^2 = 0.14$)	Coefficient	95% CI	p-value
Constant	44.1	41.3, 46.9	< 0.001
Condition (reference = heart failure) (0 = no, 1 = yes)			
Renal Failure	0.9	-1.0, 2.8	0.367
Osteoarthritis	-8.6	-10.1, -7.1	< 0.001
Chronic Wound	1.9	0.9, 3.0	< 0.001
Multiple Sclerosis	-1.5	-3.2, 0.3	0.099
Age group (reference = 25 to 34 years)			
35 to 44 years	-5.4	-8.2, -2.5	< 0.001
45 to 54 years	-7.7	-10.4, -5.0	< 0.001
55 to 64 years	-8.1	-10.8, -5.4	< 0.001
65 to 74 years	-7.9	-10.6, -5.2	< 0.001
75+ years	-8.2	-10.9, -5.5	< 0.001
Gender (0 = male)			
Cardiovascular Disease (0 = no)	-1.1	-1.8, -0.4	0.001
Diabetes (0 = no)	-2.1	-3.1, -1.2	< 0.001
Additional Comorbidities (0 = no)	-3.5	-4.3, -2.6	< 0.001

Living circumstance was not significant ($p = 0.52$)

CI: confidence interval

TABLE 4
Linear Regression Model for the Mental Component Summary

Mental Component Summary ($r^2 = 0.05$)	Coefficient	95% CI	p-value
Constant	48.4	45.0, 51.7	< 0.001
Condition (reference = heart failure) (0 = no, 1 = yes)			
Renal Failure	3.2	0.9, 5.5	0.006
Osteoarthritis	0.5	-1.3, 2.3	0.572
Chronic Wound	0.1	-1.1, 1.4	0.843
Multiple Sclerosis	-0.3	-2.4, 1.8	0.755
Age group (reference = 25 to 34 years)			
35 to 44 years	0.3	-3.1, 3.7	0.861
45 to 54 years	-0.1	-3.4, 3.2	0.963
55 to 64 years	2.1	-1.2, 5.3	0.218
65 to 74 years	3.9	0.7, 7.1	0.019
75+ years	5.3	2.1, 8.5	0.001
Gender (0 = male)			
Cardiovascular Disease (0 = no)	-0.8	-1.7, -0.1	0.042
Diabetes (0 = no)	-1.6	-2.7, -0.5	0.006
Additional Comorbidities (0 = no)	-2.6	-3.7, -1.5	< 0.001

Living circumstance was not significant ($p = 0.85$)

CI: confidence interval

OA* additional comorbidities and MS* additional comorbidities for MCS). Given the limitations of the variable for additional comorbidities (described earlier), only the main effects were presented in the models.

The PCS model accounted for 14.4% of the variation in outcome. The OA sample scored significantly lower than the heart failure sample, while the chronic wound sample scored significantly higher than the heart failure sample. The difference between the MS and the heart failure sample approached significance. The renal failure sample did not differ significantly from the heart failure sample. All age groups scored significantly lower than the reference age group of 25 to 34 years. Men tended to have higher scores than women. Cardiovascular disease, diabetes and additional comorbidities were all associated with significantly lower mean PCS scores. Living circumstance was not a significant predictor of PCS.

The MCS model accounted for only 4.6% of the variation in outcome. The similarity between the scores seen in Figure 2 was evident here as well, with only the renal failure sample scoring statistically significantly better than the heart failure sample. For the most part, the effect of increased age was positive and was statistically significant for age groups over 65 years. Women tended to score more poorly than men, as they did on the PCS. The effect of comorbidities was negative, although of borderline significance for cardiovascular disease. Living circumstances were not significantly associated with MCS.

Discussion

These data suggest a strong negative association between physical health status and both chronic disease and advanced age. However, mental health status remains relatively stable across disease groups and age groups. This phenomenon has been identified in other health conditions^{1,2,4,13-21} and the Canadian normative data,¹¹ and is confirmed by the results of our analysis of five chronic conditions studied here.

The effect of advanced age on the PCS is strikingly negative, with effect sizes ranging from a five-point to an eight-point drop

even after controlling for condition, gender and comorbidities. This is supported by the literature^{2,4} and is not only statistically significant, but highly clinically relevant, given that a two- to three-point difference is likely to be clinically important.⁶ Only two other variables had a large effect, with the OA sample scoring an average of 8.6 points lower than the reference sample of heart failure; those with additional comorbidities also scored 3.5 points lower than those who did not have other comorbidities. However, it is likely that these estimates are conservative, given that the differences are relative to heart failure (i.e. used as reference group). Comparisons with a healthy population as reference category would likely show greater differences, but these data are only available in aggregate form.

Few variables had an effect size that exceeded two to three points on the MCS. Renal failure patients scored an average of 3.2 points higher than the reference category. Those with advanced age (i.e. 65 to 74 years and 75-plus years) scored higher (i.e. four points and five points, respectively) than the reference age group, which supports the literature on the effect of age on mental health.^{2,4,21} Additional comorbidities had a large negative association with the MCS, as those with additional comorbidities scored an average of 2.6 points lower than those without additional comorbidities. These findings are consistent with results from other studies that assessed the impact of the number of comorbidities on HRQOL.^{18–20, 24,25}

These results provide useful insights into the burden of illness experienced by persons with these chronic conditions. The finding that physical health status declines with increased age and disease burden is not new.^{1–3} However, these data provide useful estimates of the relative effect of age across five different diseases and confirm previous findings that identify declining physical function, but stable mental function, in those with chronic disease and/or increased age. These findings can also have important implications for the care and treatment of persons with these conditions. While it is not possible to predict when physical function is likely to decline for a specific case, the results can

identify those at greater risk. In addition, evidence of better mental health in older age groups and in those whose illness has been diagnosed for some time may allow health care providers to focus in particular on the mental health of those recently diagnosed with a chronic disease.²¹ The finding that, on average, women had lower scores than men on both the PCS and the MCS suggests that they may be particularly vulnerable. Finally, the strong negative association between the comorbidities (i.e. cardiovascular, diabetes and “other comorbidities”) and both mental and physical health status has been noted in other studies,^{18–20,24} suggesting that those with multiple comorbidities may be at greater risk for poor HRQOL outcomes.

The results should be interpreted within the limitations of the study. These data were obtained from 10 databases, with underlying study designs that varied in both purpose and methodology. As a result, only six variables were consistently collected across all databases; no consistent information was collected regarding illness severity, socio-economic status, education and social support, which are commonly associated with HRQOL. As a result, variables that are important determinants of physical (e.g. severity of illness) and/or mental health status (e.g. education and social support) could not be tested, thereby limiting our ability to develop the predictive models. Moreover, almost half (i.e. 48%) of the subjects had chronic leg ulcers as the chronic disease, which limits the ability to generalize the findings.

In addition, one of the six variables (i.e. additional comorbidities) was based on the comorbidities collected within each study. Since some studies collected more than others, participants in those studies would be more likely to have a positive value for this variable. Moreover, there is increasing evidence that the severity as well as the number of comorbidities was an important consideration,^{19,20} and these data were not consistently collected within our studies. Future research would benefit from considering both factors, preferably with the use of a validated comorbidity index. Despite these limitations, this crude

adjustment for illness severity seemed preferable to no adjustment.

Furthermore, sample sizes within the age groups for certain diseases were quite low. There were too few young patients with OA and heart failure, and too few older patients with MS to graph these age/disease groups. Even in cells with greater than five patients, some of the numbers were quite low. Consequently, large confidence intervals often overlapped, indicating that the results did not necessarily attain statistical significance even when the difference appeared large. Finally, our data are cross-sectional and the age stratification is not the equivalent of a cohort that is followed over time.

Nevertheless, these data provide compelling evidence that, while physical function can be severely and negatively affected by both chronic disease and advanced age, mental health remains relatively high and stable, adding to the growing body of knowledge regarding the impact of increased age and chronic disease on HRQOL. Additional research with other disease groups, and longitudinal research in particular, will provide further insight into the complex relationship between chronic disease, physical health status, mental health status and advancing age.

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Statistical modelling of mental distress among rural and urban seniors

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Abstract

The senior population is growing rapidly in Canada. Consequently, there will be an increased demand for health care services for seniors who have mental illness. Seniors are more likely to live in rural areas than younger people; therefore, it is important to identify the differences between rural and urban seniors in order to design and deliver mental health services. The main objective of this paper was to use the National Population Health Survey (NPHS) to examine the differences with regard to mental distress between rural and urban seniors (i.e. 55 years and older). The other objectives were to investigate the long-term association between smoking and mental health and the long-term association between unmet health care needs and the mental health of seniors in rural and urban areas. The mental distress measure was examined as a binary outcome. The analysis was conducted using a generalized estimating equation approach that accounted for the complexity of a multi-stage survey design. Rural seniors reported a higher proportion of mental distress [OR = 1.16; 95% CI: 0.98, 1.37] with a borderline statistical significance than urban seniors. This finding was based on a final multivariate model to study the relationship between mental distress and location of residence (i.e. rural or urban) as well as between smoking and self-perceived unmet health care needs, adjusting for other important covariates and missing outcome values. A significant correlation was noted between smoking and mental health problems among seniors after adjusting for other covariates [OR = 1.26; 95% CI: 1.00, 1.60]. Participants who reported self-perceived unmet health care needs reported a higher proportion of mental distress [OR = 1.72; 95% CI: 1.38, 2.13] compared to those who were satisfied with their health care.

\$14.4 billion.⁶ By 2020, depression will be the second leading cause of the overall world illness burden, after ischemic disease.⁷⁻⁸ Advances in neuroscience and behavioural medicine have shown that mental disorders are the result of complex interactions among biological, psychological and social factors.⁸ There has been adequate research on the mental health of rural seniors, but very few rural-urban comparison studies have been conducted on seniors. It is important to identify differences between rural and urban seniors in order to design and deliver appropriate mental health services. Proper statistical analysis of available national longitudinal datasets allows for the investigation of important risk factors for mental distress. These factors can lead us to identify high-risk groups at early stages and will help us target our preventive measures to lessen the future economic burden on the health care system.⁹

Key words: *mental health, rural seniors, longitudinal data, National Population Health Survey, generalized estimating equations, bootstrap weights, missing data*

The authors of this paper will use the National Population Health Survey (NPHS)¹⁰ from Statistics Canada to examine (1) the rural and urban differences in mental distress; (2) the long-term association between smoking and mental distress; and (3) the long-term association between unmet health care needs and mental health among seniors who live in rural and urban areas. Urban areas are defined as continuously built-up areas with a population concentration of 1000 or more, and a population density based on the previous census¹¹ of 400 or more people per square kilometre; other areas are defined as rural.

Introduction

Seniors are one of the fastest growing population groups in Canada, as reported by Statistics Canada. By 2021, there will be almost seven million seniors (i.e. 65 years of age or older), representing 19% of the population.¹ Seniors are more likely than younger people to live in rural areas (24% versus 21%) and are also more likely to reside in smaller urban areas.¹ Rural seniors often live in isolation, and due to a lack of social interaction, they may be at a higher

risk of developing mental health problems compared to their urban counterparts. Furthermore, this isolation may increase the likelihood of rural seniors reporting lifestyle habits such as smoking and alcohol consumption, which helps aggravate mental health problems.²⁻⁴ Mental illness accounts for 30% of disability claims, i.e. \$15 to \$33 billion annually in Canada.⁵ A recent Canadian study estimates that the annual cost of treated and non-treated mental health problems in Canada is

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Methods

Longitudinal NPHS dataset

Data from the National Population Health Survey (NPHS) were used in this analysis. The NPHS is a longitudinal study¹⁰ of a Canadian national sample. The original survey included 17 626 subjects sampled in 1994/95 (i.e. cycle 1), with the aim of following or recontacting them every 2 years for up to 20 years. To be included in the survey, respondents must have completed at least the general component of the questionnaire in 1994/95.¹² Except in the province of Quebec, the NPHS employed a stratified two-stage design (i.e. clusters and dwellings) based on the Labour Force Survey (LFS) from Statistics Canada. In Quebec, the NPHS sample was selected using a two-stage design similar to that of the LFS from dwellings participating in a health survey organized by Santé Québec (the 1992/1993 Enquête sociale et de santé [ESS]).¹³ Base sample sizes for each province were determined using the Kish allocation, which balanced the reliability requirements at national and provincial levels. A minimum of 1200 households in each province was needed to ensure a specified reliability by sex and broad age groups. Populations on First Nations reserves, on Canadian Forces bases and in some remote areas of Quebec and Ontario were excluded from the household components of the survey. Data were weighted to reflect the sample design, non-response adjustments and post-stratification.

The same individuals were surveyed repeatedly, which allowed for the investigation of the effects of baseline- and time-varying risk factors on longitudinal changes in mental health. Conclusions drawn from such longitudinal studies are stronger compared to cross-sectional studies, because some information on the sequence of events is available.¹⁴ In most situations, longitudinal data are incomplete. There are several approaches for the analysis of incomplete longitudinal data. A binary logistic regression model can be fitted using a method based on improbability, i.e. the Generalized Estimating Equation (GEE) approach,¹⁵ assuming that the dropouts are not missing completely at random (MCAR). Another approach for

analysis of incomplete longitudinal data are pattern mixture models formulated by Little,¹⁶⁻¹⁸ assuming that dropouts are not MCAR. The pattern mixture model is a solution to the non-response problem in survey data. The first step in applying the pattern mixture model approach is to divide the subjects into groups depending on their missing data pattern. If subjects are measured at six time points, then there are 64 (2⁶) possible missing data patterns. A between-subject variable is created by grouping the missing data patterns. This between-subject variable can be used in the longitudinal data analysis as another covariate. In this paper, pattern mixture models were examined with GEE-based models for National Population Health Survey data.

Distress scale: National Population Health Surveys (NPHS)

From the relatively wide range of mental health indicators available in the NPHS, we chose the distress measure based on a subset of items from the Composite International Diagnostic Interview (CIDI). The outcome of interest consisted of six questions developed by Kessler and Mroczek of the University of Michigan.¹⁹ The distress scale is comprised of various CIDI items that inquired about feelings of sadness, nervousness, restlessness, hopelessness, worthlessness and the feeling that everything was an effort.¹¹ Additional items clarified whether these symptoms occurred “a lot,” “somewhat,” “a little,” “more than usual,” “the same,” or “less than usual” compared to the previous month. Based on the above questions, a distress scale was derived for each of the six cycles. This derived variable determines the respondent’s distress scale. Scores on the distress scale range from 0 (i.e. no distress) to 24 (i.e. highly distressed). Details can be found in the NPHS derived variable directory.¹¹

Subpopulation

This study was limited to the population group aged 55 years and older as of the initial survey in 1994/95. There were 4444 participants in the subpopulation and 16 052 observations in the longitudinal analysis. The main factors of interest are location of residence, smoking status and drinking status. Other demographic and socio-economic variables in previous

mental health studies²⁰⁻²³ that are included in these analyses are sex, age, marital status, education level, total household income, self-reported general health index, geographical area, any chronic condition, physical activity within the last three months, and self-perceived unmet health care needs.

Modelling distress as a binary response

It was interesting to investigate how the response vector evolved over time and to observe how it related to a set of explanatory variables. The distress scale was highly skewed, and we decided to recode it according to the literature²³⁻²⁴ and the suggestions of a geriatric psychiatrist. As distress was recoded to a binary scale (i.e. categories: no/low [0-5 scale] and moderate/high [6-24 scale]), it seemed natural to consider a binary model. We fitted the GEE-based binary regression model²⁵⁻²⁶ using the GENMOD procedure in SAS.²⁵⁻²⁹ This procedure allowed us to select different specifications of working correlation matrices (i.e. independent, first-order autoregressive [AR(1)], exchangeable and unstructured). We selected the model with an unstructured covariance structure, which gave us the smallest standard errors.³⁰ The GENMOD is based on Liang and Zeger’s method,²⁸⁻²⁹ which accounts for the within-subject dependencies only, due to the repeated measurements over time. To account for the complexities of the multi-stage stratified clustered design, the bootstrap resampling method was used to calculate the correct variance around a given estimate. This was achieved using both the “Bootvar” SAS macro³⁰⁻³² and the bootstrap weights provided by Statistics Canada.^{10,12} The “Bootvar” macro was modified to apply to the generalized estimating equations method.^{31,34} The approach used to study the effect of missing data was the GEE-based pattern mixture model.

Statistical analysis

Univariate analyses were conducted to examine the relationship between the distress scale and the main factors of interest, as well as demographic and socio-economic variables at $\alpha = 0.20$ significance level. The next step was to conduct the multivariable analysis to determine the effects of all potential covariates and/or interactions

on the distress scale. All potential covariates and interaction terms were included concurrently in the model. Variables that were significant at $\alpha = 0.05$ level or of scientific interest, as well as missing data patterns, were retained in the final model.

Results

In 1994, 20% of the general population of Canada were seniors. Among seniors, there were more female seniors (i.e. 56%) compared to male seniors. In rural populations, 22% of residents were seniors and in urban populations, 20% of residents were seniors. There was a higher percentage of male seniors (i.e. 53%) in rural areas, but a higher percentage of female seniors (i.e. 58%) in urban areas. Our main interest in conducting this analysis was to compare mental distress between rural and urban seniors. We started the statistical analysis by exploring these differences in baseline characteristics, presented in Table 1 and summarized below.

Comparison of mental distress between rural and urban seniors

The percentage of the moderate- or high-distress category among seniors was 17% in rural areas and 16% in urban areas, respectively. The proportion of the moderate- or high-distress category for all age categories varies from 12% to 25% for rural seniors and from 14% to 19% for urban seniors. In the moderate- or high-distress category, there was a slightly higher percentage (i.e. 22%) of rural female seniors compared to urban female seniors (i.e. 20%). In addition, female seniors had a higher distress level compared to male seniors in both rural and urban areas. The proportion of moderate or high distress levels was higher for rural seniors who were single, married, common-law spouses or in a partnership compared to their urban counterparts. Both rural and urban Quebec residents had a higher proportion of moderate or high distress than rural and urban seniors in other regions. In both rural and urban areas, respondents with low education levels had a higher proportion of moderate or high distress compared to post secondary graduates, and a higher proportion of respondents with low income were in this distress category than

high income seniors. Moreover, seniors who were less involved in social activities reported a higher proportion of moderate or high distress in both rural and urban areas. The seniors who were current smokers had a higher prevalence of moderate or higher distress in both rural and urban areas compared to non-smoking seniors. Non-drinkers had a higher proportion (i.e. 21%) of moderate or high distress compared to current drinkers in rural and urban areas.

There was a higher prevalence of moderate or high distress in respondents, (1) with any chronic condition compared to persons without a chronic condition; and (2), without any physical activity within the last three months compared to respondents with any physical activity. In addition, seniors with self-perceived unmet health care needs had a higher prevalence of moderate or high distress than those whose health care needs were perceived to have been met. This proportion was higher in urban areas (i.e. 49%) compared to rural areas (i.e. 43%).

Figure 1 illustrates the rural and urban comparison of self-perceived unmet health care needs. This suggests that seniors in rural areas were more likely to have unmet health care needs than their counterparts in urban areas from 1996 to 2002. This apparent increase over time could be due to aging. Figure 2 illustrates the reasons for not getting self-perceived needed health care for rural and urban seniors from 1994 to 2004. The most common reasons for not meeting the health care needs of rural seniors were difficult access to health professionals (i.e. 40%) and seniors choosing not to see health professionals (i.e. 25%). For their urban counterparts, the most common reasons for a lack of seniors' health care were difficult access to health professionals (i.e. 20%) and other reasons (i.e. 45%), which included too busy, didn't get around to it, didn't know where to go, transportation problems, language problems, and personal or family responsibilities. It was also interesting to note that both rural and urban seniors (i.e. 33% and 26%, respectively) who reported moderate or high distress were more likely (i.e. more than 6 times within past 12 months) to visit their family doctor.

Participants in rural areas were less likely to see their family doctor (i.e. 18%) compared to their urban counterparts (i.e. 14%).

Univariate analysis results

Analyses were conducted to examine the relationship between the distress scale, the main interest factors and the demographic and socio-economic variables mentioned above. The preliminary analysis showed that the variables of sex, education level, age group, marital status, income level, general health, geographic area, smoking status, any chronic condition, physical activity, self-perceived unmet healthcare needs and location of residence were related to the mental distress scale at significance level of $\alpha = 0.20$. Alcohol consumption was not shown as a risk for mental distress in the preliminary analysis and it was not used in the model.

Multivariable analysis results

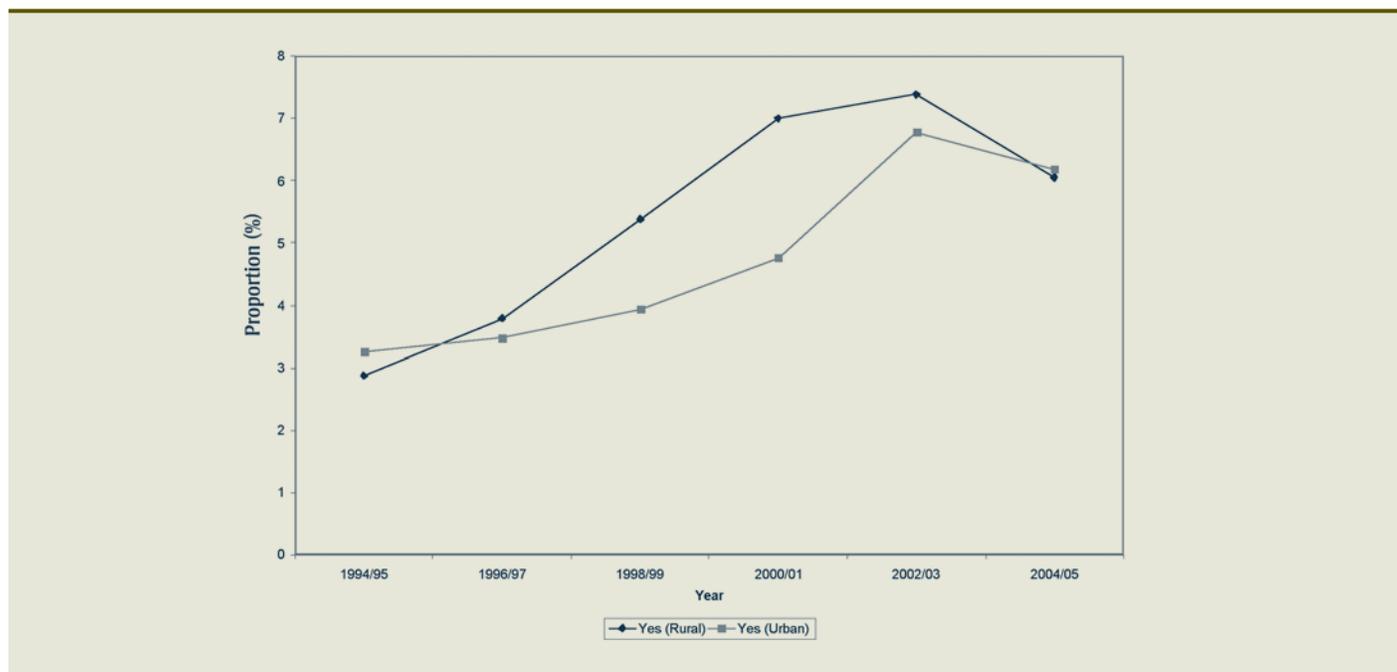
Table 2 explains the four missing patterns. We can contrast completers (i.e. those who completed all six cycles) versus those who missed one cycle, completers versus those who missed two or more cycles, and completers versus people who died within six cycles.

We included the missing patterns and covariates to the multivariate model. This multivariate analysis was based on a generalized estimating equations approach, with the results given in Table 3. This model is called GEE-based pattern mixture model. In this analysis, several important interaction terms were tested (i.e. sex and smoking, sex and physical activity, etc.) and none were significant.

Included in the model for the purpose of the generalized estimating equations procedure were age, sex, marital status, location of residence, geographic area, income level, education level, smoking status, general health status, any chronic condition, physical activity within the last three months and self-perceived unmet health care needs.

All of these variables were retained for the final model of the relationship between covariates and mental distress among

FIGURE 1
Self-perceived unmet health care needs of rural and urban seniors over time



seniors (i.e. 55 years and older). The odds ratios reported for all covariates predicting mental distress took into account the relationship of each of these variables with each outcome at each cycle. All reported odds ratios were adjusted for all other variables in the model. The odds ratios demonstrate the likelihood that those with poor self-rated general health status would have greater mental distress compared to those with excellent self-rated general health status. This takes into account the changes in the status of self-rated general health over a two-year follow-up period to produce an overall estimate of the association for each relationship. A similar interpretation can be applied to each of the other variables in the model for mental distress.

The following results were obtained based on the final multivariate model used to study the relationship between location of residence, smoking and mental distress, adjusting for other important covariates and the pattern of missing data. Rural seniors (i.e. 55 years and older) reported a higher proportion of mental distress [OR = 1.16; 95% CI (0.98 to 1.37)] than urban seniors. A significant association was evident among seniors with mental health problems and smoking after adjusting for other covariates

[OR = 1.26; 95% CI (1.00 to 1.60)]. Senior non-completers had significantly higher proportions of mental distress compared to completers [OR = 1.44 (1.13 to 1.82), OR = 1.39 (1.10 to 1.76) and OR = 1.68 (1.36 to 2.06) respectively]. A significantly higher proportion of female participants reported mental distress compared to male participants [OR = 1.79 (1.47 to 2.17)]. Separated, widowed or divorced participants reported a significantly higher proportion of mental distress compared to single participants [OR = 1.48 (1.08 to 2.03)]. Participants from Quebec reported a significantly higher prevalence [OR = 1.57 (1.20 to 2.06)] of distress compared to Ontario participants, while Atlantic residents reported a lower prevalence [OR = 0.68 (0.53 to 0.87)] of distress compared to Ontario participants. Senior participants who did not complete their secondary school education had a higher prevalence [OR = 1.36 (1.07 to 1.72)] of distress compared to post-secondary graduates. Participants who reported their general health index as “poor,” “fair” or “good” had a higher prevalence of mental distress compared to those who reported “excellent” general health. Senior participants who had any kind of chronic condition had a higher prevalence of mental distress [OR = 1.60 (1.29 to 1.99)] compared to those without

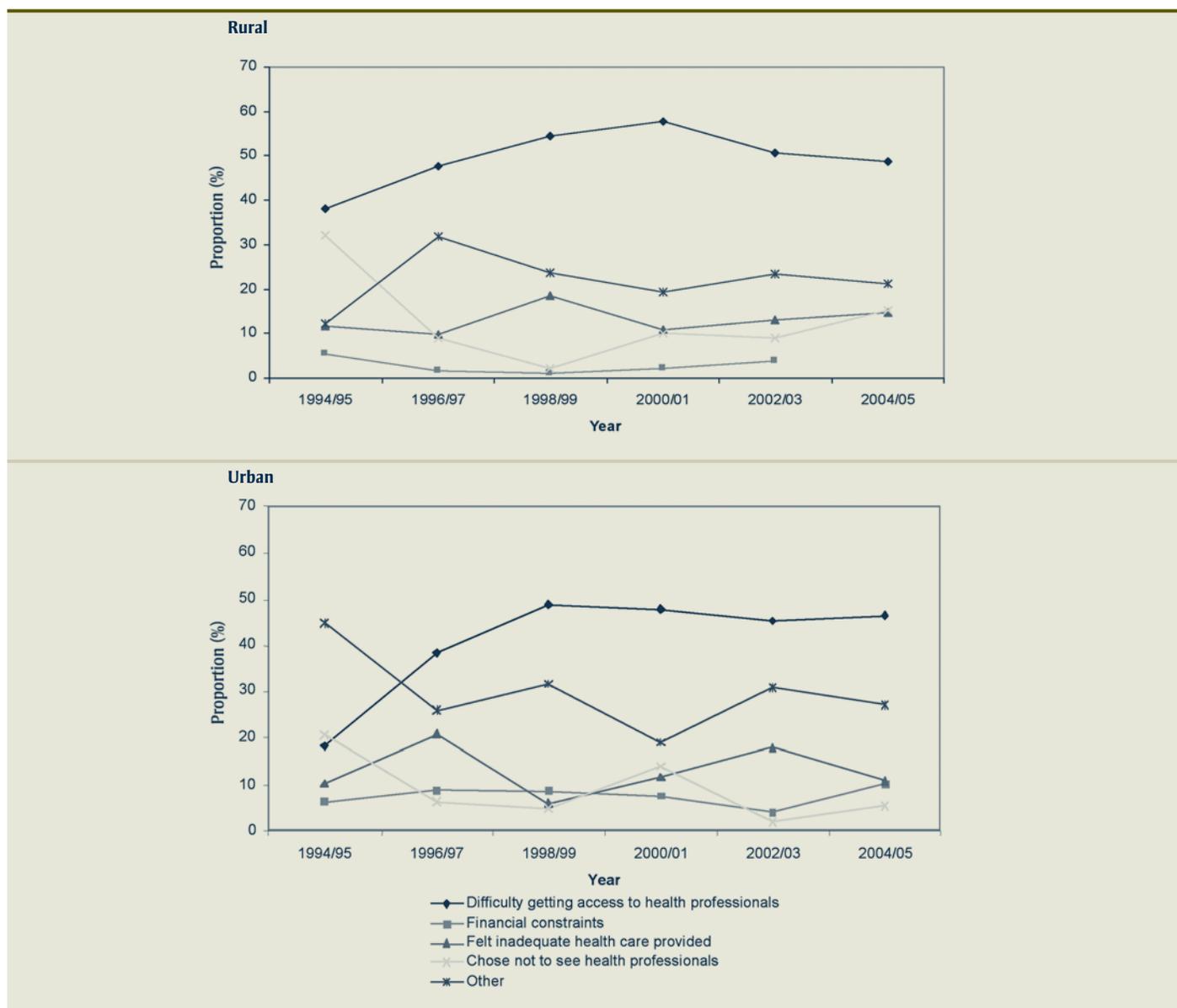
chronic conditions. Participants who had engaged in physical activity within the last three months had a lower prevalence [OR = 0.82 (0.70 to 0.95)] of mental distress compared to those who had not. For variety of reasons, participants who reported self-perceived unmet health care needs had a higher proportion of reporting mental distress compared to those who reported satisfied health care needs [OR = 1.72 (1.38 to 2.13)]. The highest proportion of respondents listed the main reason for unsatisfied health care needs as difficulty getting access to health care professionals.

The model, adjusted for the pattern of missing values, is presented here. With and without adjusting for missing values, there were slight differences in parameter estimates, standard errors and ORs. Therefore, a GEE-based pattern mixture model helps us to remove the bias of estimates due to missing outcome values.

Discussion

Until now, there has been no proper statistical analysis of the mental health of Canadian seniors that accounts for both the complexities of longitudinal NPHS data (i.e. six cycles) and the hierarchical nature formed by using a multi-stage complex

FIGURE 2
Reasons for not getting needed health care in rural and urban areas



survey design. Moreover, this analysis was adjusted for missing outcome values, which will remove the bias of estimates. There were significant differences among baseline characteristics (i.e. sex, marital status, geographic areas, education level, income level, social support, smoking status, drinking status, general health index, physical activity and self-perceived unmet health care needs) and among location of residence (i.e. urban and rural).

We observed that rural seniors reported a higher proportion of high mental distress than urban seniors. In addition, there was

a significant long-term association between smoking and mental distress. Our results revealed that there was a significant long-term association between self-perceived unmet health care needs and mental health among seniors (i.e. 55 years and older) who live in both rural and urban areas.

Most mental health studies using longitudinal data sets as afforded by the NPHS have focussed on depression. In our study, the outcome is mental distress. Other findings of our study were consistent with those studies. Stephens et al.²² reported that there is no relationship between mental

health and adequate incomes; our results also revealed this finding. According to Stephens et al.,²³ physical and mental health problems were related. We also observed that respondents who reported lower general health status were associated with mental distress. Our observation of better mental health in males than in females was consistent with the findings of Stephens et al.²³ and Østbye et al.³⁵ Similar to the findings of Stephens et al.,²³ chronic physical health problems were closely associated with mental health.

TABLE 1
Baseline demography and other information by location of residence for 1994

	Mental health (moderate/high) – rural counterparts	Mental health (moderate/high) – urban counterparts	<i>p</i> -value
Demographic information			
Age group			
55 to 59	19.1	15.7	< 0.0001
60 to 64	13.5	17.4	< 0.0001
65 to 69	16.6	14.8	< 0.0001
70 to 74	12.5	16.3	< 0.0001
75 to 79	24.6	13.8	< 0.0001
80 and older	18.2	19.4	0.1579
Sex			
Male	11.8	11.0	< 0.0001
Female	22.2	19.8	< 0.0001
Marital Status			
Married/common-law/partnership	17.1	13.7	< 0.0001
Separated/widowed/divorced	14.5	21.6	< 0.0001
Single	22.6	13.9	< 0.0001
Geographical area			
Atlantic	19.8	12.0	< 0.0001
Quebec	24.7	23.0	< 0.0001
Ontario	13.1	14.4	< 0.0001
Prairies	14.6	14.9	0.0039
British Columbia	10.2	11.3	< 0.0001
Socio-economic status			
Education level			
Less than secondary school graduation	19.1	22.5	< 0.0001
Secondary school graduation	13.9	13.1	< 0.0001
Some post-secondary	13.8	10.5	< 0.0001
Post-secondary graduation	13.5	11.1	< 0.0001
Income level			
Low	22.7	22.7	1.0000
Middle	16.6	14.8	< 0.0001
High	4.4	10.7	< 0.0001
Social support			
Social involvement score			
Low	19.6	19.6	1.0000
Moderate	16.4	16.8	< 0.0001
High	15.1	11.4	< 0.0001
Lifestyle			
Smoking status			
Current smoker	19.2	20.5	< 0.0001
Ex-smoker	15.5	15.5	1.0000
Non-smoker	17.4	14.7	< 0.0001

TABLE 1 (continued)
Baseline demography and other information by location of residence for 1994

	Mental health (moderate/high) – rural counterparts	Mental health (moderate/high) – urban counterparts	p-value
Drinking status			
Current drinker	15.5	13.7	< 0.0001
Ex-drinker	19.1	21.3	< 0.0001
Non-drinker	21.3	21.2	0.4252
Health-related:			
General health status			
Poor	65.1	58.9	< 0.0001
Fair	32.0	33.5	< 0.0001
Good	13.6	14.5	< 0.0001
Very good	6.4	6.2	< 0.0001
Excellent	2.2	7.3	< 0.0001
Any chronic condition?			
Yes	18.8	18.8	0.2812
No	10.9	7.6	< 0.0001
Physical activity within the last three months?			
Yes	14.3	14.7	< 0.0001
No	31.5	24.1	< 0.0001
Self-perceived unmet health care needs			
Yes	42.5	48.9	< 0.0001
No	16.2	15.0	< 0.0001
Reasons for not getting health care†			
Difficulty getting access to health professionals	47.2	61.5	
Financial constraints	F*	30.8	
Felt inadequate health care provided	F*	31.7	
Chose not to see health professionals	29.2	30.2	
Other	66.1	58.2	
Number of consultations – family doctor within last 12 months			
None	11.9	8.2	< 0.0001
1 to 6 times	13.4	15.1	< 0.0001
More than 6 times	32.8	25.8	< 0.0001

F* - Due to confidentiality small percentages are not reported.

†p-values are not reported.

TABLE 2
Missing distress data patterns over six cycles

Description	Percentage
Completed all six cycles	38.43
One cycle missing	11.87
Two or more cycles missing	20.80
People who died within six cycles	28.90

TABLE 3
Odds ratio (OR) and their 95% confidence interval (95% CI) based on multivariate binary logistics regression (GEE-based pattern mixture model) of the prevalence of mental distress

	OR (95% C.I.)	
Drop:	One missing	1.44 (1.13, 1.82)
	Two or more missing	1.39 (1.10, 1.76)
	Died within six cycles	1.68 (1.36, 2.06)
	Completers	Reference
Age Group:	55 to 59	1.76 (1.31, 2.35)
	60 to 64	1.49 (1.13, 1.97)
	65 to 69	1.21 (0.93, 1.59)
	70 to 74	1.07 (0.84, 1.38)
	75 to 79	1.01 (0.80, 1.27)
	80 and older	Reference
Sex:	Female	1.79 (1.47, 2.17)
	Male	Reference
Marital Status		
	Married/common-law/partnership	1.19 (0.87, 1.64)
	Separated/widowed/divorced	1.48 (1.08, 2.03)
	Single	Reference
Location of residence		
	Rural	1.16 (0.98, 1.37)
	Urban	Reference
Geographical area		
	Atlantic	0.68 (0.53, 0.87)
	Quebec	1.57 (1.20, 2.06)
	Ontario	Reference
	Prairies	1.00 (0.80, 1.25)
	British Columbia	0.87 (0.67, 1.13)
Socio-economic status		
Education level		
	Less than secondary school graduation	1.36 (1.07, 1.72)
	Secondary school graduation	1.28 (0.94, 1.73)
	Some post-secondary	1.11 (0.84, 1.47)
	Post-secondary graduation	Reference
Income level		
	Low	1.30 (0.89, 1.89)
	Middle	1.20 (0.88, 1.64)
	High	Reference
Life-style		
Smoking Status		
	Current smoker	1.26 (1.00, 1.60)
	Ex-smoker	1.10 (0.92, 1.31)
	Non-smoker	Reference

In contrast to the findings of Stephens et al.²³ about the province of residence, we found that there is a significant difference in the mental distress of seniors in some geographic areas. Participants from Quebec reported a high proportion of high mental distress compared to their Ontario participants; Atlantic residents reported a lower proportion of high mental distress compared to their Ontario participants.

There is a possibility of reverse causation, which is shown by other researchers.³⁶⁻⁴⁰ Murphy et al.³⁶ reported that smoking at baseline was not related to a subsequent incidence of depression. In addition, they found that participants who become depressed are more likely to begin or continue smoking compared to participants who never become depressed. Lasser et al.³⁹ reported that persons with mental health problems are about twice as likely to smoke. Saffer et al.⁴⁰ found that persons with a history of mental health problems are 94% more likely to smoke compared to persons with no history of mental health problems. This paper focused on investigating the long-term association between mental health and smoking. To determine the direction of any causation, a special analysis is required. The NPHS measures self-reported, unmet health care needs by asking, "During the past 12 months, was there ever a time when you felt that you needed health care, but you didn't receive it?" A "yes" response was tabulated as an unmet need. Because of the wording of the question addressing unmet needs, it is not possible to distinguish situations in which people did not receive services at all from situations in which they were not received in a timely manner. Chen et al.⁴¹ (2002) and Sanmartin et al.⁴² (2002) reported that individuals with chronic conditions, including pain or distress were more likely to report problems with the health care delivery system. Several studies⁴³ of seniors' health reported that the health care system only marginally improved the overall health of the senior population. Our results, which correspond with the findings of the above studies, suggested a possible reverse causation. In this sense, the unmet needs are the effect of the distress, not the cause. To determine the direction of any causation, further analysis is required.

TABLE 3 (continued)
Odds ratio (OR) and their 95% confidence interval (95% CI) based on multivariate binary logistics regression (GEE-based pattern mixture model) of the prevalence of mental distress

	OR (95% C.I.)
Health-related:	
General health status	
Poor	12.14 (7.69, 19.18)
Fair	5.26 (3.51, 7.88)
Good	2.74 (1.85, 4.06)
Very good	1.31 (0.89, 1.95)
Excellent	Reference
Any chronic condition*	
Yes	1.60 (1.29, 1.99)
No	Reference
Physical activity within the last three months	
Yes	0.82 (0.70, 0.95)
No	Reference
Self-perceived unmet health care needs	
Yes	1.72 (1.38, 2.13)
No	Reference

* denotes one or more chronic conditions

These results can be used to improve the design and delivery of mental health services to rural and urban seniors. The results can also be used to target methods to reduce smoking among seniors who live in rural and urban areas, and address the causes of unmet health care needs. Better design and delivery of services may result in cost savings in terms of seniors' psychotherapy appointments, emergency room visits, medication use and consequent productivity loss.

Acknowledgements

We would like to thank the Public Health and the Agricultural Rural Ecosystem (PHARE) program of the CIHR for funding for this research. We would also like to thank the Remote Data Access services of Statistics Canada. Our special thanks to Dr. Lilian Thorpe, Geriatric Psychiatrist, for her valuable comments to improve this paper.

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Factors associated with the adoption of a smoking ban in Quebec households

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Abstract

The home represents an important source of exposure to environmental tobacco smoke for non-smokers, including children, who live with smokers. Our goal is to identify the sociodemographic factors associated with the adoption of smoking bans in “smoker households” in Quebec. Selected associations are compared with three other Canadian provinces (Ontario, British Columbia and Nova Scotia). This is a cross-sectional study involving 2648 respondents. Logistic regression analysis is employed. Few smoker households in Quebec (21%) have a ban on smoking; the presence of a non-smoker is strongly linked to the existence of such a ban; the presence of a child under the age of 6 is less strongly associated with the adoption of a ban in Quebec than in the other provinces, and the presence of an adolescent shows no association whatsoever. In addition to the child health benefits of household smoking bans, greater emphasis should be placed on the impact that such bans can have on children’s future smoking behaviour. One option from a health promotion standpoint might be to organize a campaign aimed at non-smokers who live with smokers, in order to urge them to be less tolerant of environmental tobacco smoke.

Key words: *environmental tobacco smoke, smoke-free home, sociodemographic factors, Quebec households*

Introduction

The harmful health effects of environmental tobacco smoke (ETS) on non-smokers are now well-established.¹⁻³ In Canada, measures to limit exposure to ETS have been introduced in workplaces and in a variety of public places as well.¹ Numerous studies have shown that such measures not only improve the health and comfort level of non-smokers, but also reduce smokers’ consumption of tobacco products.⁴

However, the home remains an important source of exposure to ETS, particularly for pre-school children. The favourable response to smoking restrictions in public places and places of work and the diminishing social acceptability of smoking suggest that such measures could be extended to the private sphere. In Ontario, the proportion of non-smokers who favour a complete ban on smoking in the presence of small children increased by 15.4% between 1992 and 1996, while opposition to such measures on the part of smokers decreased by 8.6% during the same period.⁵

There is only limited data on smoking bans in Canadian households. A 1995 study carried out by Health Canada with households that included children aged 12 or younger found that 19% of such households had a complete ban on smoking, 44% had a partial ban, and 37% had no restrictions.⁶⁻⁷ However, the response rate for this study was only 50%.

Despite a remarkable reduction in the prevalence of smoking, Quebec remains above the Canadian average in terms of ETS exposure. According to the most recent Canadian Tobacco Use Monitoring Survey (CTUMS) conducted in 2006, the prevalence of Quebecois children aged 0 to 17 who are exposed to ETS in the home is 21.6%, compared to 11.2% in Canada as a whole.⁸

As far as we know, there are no population data describing the effect of sociodemographic factors on the adoption of household smoking bans in Quebec. The objective of this study is to identify the sociodemographic characteristics of households and respondents most strongly associated with the existence of a smoking ban in Quebec households that include at least one smoker, and to establish comparisons with three other Canadian provinces (Ontario, British Columbia and Nova Scotia).

i Measures to limit exposure to ETS are in place even in the “private” environment of the car: under a new Ontario law that came into effect on January 21, 2009, charges can be laid against any person found smoking in a vehicle that is also carrying a child under the age of 16.

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Methodology

This is a cross-sectional population study. The data are derived from the National Survey on Environmental Tobacco Smoke in the Home and were collected between June 2001 and January 2002 by the Institute for Social Research at York University, under the direction of the Ontario Tobacco Research Unit (OTRU).

The sampling and questionnaires have already been described.⁹ In brief, the initial sample comprised 14 600 households; respondents were asked to complete an initial questionnaire to determine the smoking status of their households, as well as the presence of children under the age of 18. In order to gather information on smoking bans, a second sample of "smoker households" was selected. In this sample, households that included at least one adult smoker and a child were over-represented since the goal was to obtain a sample size that was sufficiently large for statistical analysis; on the basis of these criteria, 5000 households from every province in Canada were selected. From these households, 2648 smoker households with and without children were selected in four provinces (Quebec, Ontario, British Columbia and Nova Scotia). While the original survey extended to all parts of Canada, Ontario and British Columbia were selected in order to compare Quebec with provinces that show better smoking ban prevalence rates in the literature, and Nova Scotia was selected because it is comparable to Quebec, with the exception of its cultural context.

A smoker household is defined as a household in which at least one person aged 18 or over smokes cigarettes, cigars, cigarillos or a pipe on a daily or occasional basis. Although information was collected on every smoker in any given household, few people under the age of 18 live away from their parents and are in a position to establish their own household smoking rules.⁹

Participants were selected on the basis of computer-generated telephone numbers. Information was collected using a questionnaire that was administered with the aid of computer-assisted telephone

interviewing (CATI) technology. To ensure an optimal response rate, a maximum of 14 calls were made to any number for which contact was not established on the first call; 10 of these calls were made in the evening or on weekends.

The dependent variable is the household smoking ban. A smoke-free household is a home in which all occupants refrain from smoking inside at all times. The behaviour of visitors and guests with respect to household smoking bans was not taken into account. Smoking bans were measured on the basis of people's response to the following question: "Do you smoke cigarettes, cigars, cigarillos or a pipe at home every day, from time to time, or not at all?" In cases where the household had more than one smoker, the question was put to the respondent for every other smoker. This information provided a means of defining a variable with two response levels: (1) a complete household smoking ban; or (2) a partial ban or no ban.

The results are expressed as weighted prevalence ratios. A weighting system was introduced in order to take into account the unequal probability of households being selected on the basis of their composition, since smoker households with children were more likely to be selected than those with no smokers or children. We also needed to take into account the unequal distribution of households by province of origin. A weighting coefficient was assigned to each type of household.

Initially, univariate unconditional logistic regression was used to identify the variables most strongly associated with the adoption of a household smoking ban. Then, a multivariate analysis was performed. Provincial variations in the effect of a sociodemographic characteristic on the adoption of a smoking ban were evaluated using a logistic regression model that was stratified for the province and adjusted for the other characteristics. To avoid the problem of collinearity, variables contributing the same information were not included in the model at the same time. The weighted prevalence ratios thus obtained were used to estimate the association between each variable and the

presence of a household smoking ban with a confidence interval of 95%.

These statistical analyses were performed using SAS software.

Results

Sociodemographic characteristics and household smoking ban prevalence

A total of 2648 respondents representing households with at least one adult smoker agreed to complete the questionnaire in the four provinces. The survey response rate was 62%. Tables 1 and 2 present the characteristics of respondents and households respectively. The proportion of female respondents was slightly greater than that of male respondents; more than half of all respondents were in a couple relationship. Close to 50% had a high-school education or less. Sixty-three percent of respondents were cigarette and/or pipe, cigar or cigarillo smokers; 80% of these smokers smoked every day. Slightly over one third of the households had at least one child; in 37% of cases that child was under the age of 6. In Quebec, 949 smoker households agreed to complete the questionnaire. The characteristics of the Quebec sample are comparable to those of the total sample. Given the large number of missing values for household income, the effect of this variable was not included in the analysis of associations.

The weighted prevalence of household smoking bans in Quebec is 21%; this is significantly different from the rates observed in Ontario and British Columbia which were, respectively, 43.7% ($p < 0.0001$) and 52.1% ($p < 0.0001$), but not statistically different from the rate observed in Nova Scotia (32%) ($p = 0.64$).

Factors associated with the adoption of a household smoking ban in Quebec

Table 3 presents the results of the univariate and multivariate analyses. Several respondent characteristic variables are significantly associated with the adoption of a household smoking ban in a univariate analysis, but this is no longer the case once other variables are taken into account. Thus, the age, gender and smoking status of respondents have no impact on the

TABLE 1
Characteristics of respondents in the provinces of Quebec, Ontario, British Columbia and Nova Scotia

Variables	Quebec			Ontario			British Columbia			Nova Scotia			Total ^a		
	n ^b	% ^c	%W ^d	n	%	%W	n	%	%W	n	%	%W	n	%	%W
Age group (in years)															
18-24	156	16.5	22.0	165	14.0	19.2	52	14.7	19.2	18	13.8	19.1	391	15.0	20.1
25-64	718	76.1	70.5	949	80.8	75.1	267	75.6	71.1	103	79.2	73.5	2037	78.3	72.9
≥ 65	69	7.3	7.5	61	5.2	5.7	34	9.6	9.6	9	6.9	7.4	173	6.6	7.0
Total	943			1175			353			130			2601		
Gender															
Women	549	57.8	56.0	669	55.5	52.8	194	53.7	49.2	66	50.0	42.9	1478	55.8	52.9
Men	400	42.1	44.0	537	44.5	47.2	167	46.3	50.8	66	50.0	57.1	1170	44.2	47.1
Total	949			1206			361			132			2648		
Smoking status															
Current smoker	646	68.4	63.5	814	68.0	62.9	222	61.7	57.0	97	74.0	71.8	1779	67.5	62.6
Former smoker	137	14.5	15.8	157	13.1	15.1	59	16.4	47.0	16	12.2	12.2	369	14.0	15.5
Non-smoker	162	17.1	20.7	227	18.9	22.0	79	21.9	26.0	18	13.8	16.0	486	18.5	21.9
Total	945			1198			360			131			2634		
Marital status															
Living with a spouse	560	59.4	58.9	695	58.1	57.0	205	57.1	56.5	84	63.6	63.6	1544	58.7	57.8
Single/separated/divorced	383	40.7	41.1	502	41.9	43.0	154	42.9	43.5	48	36.4	36.4	1087	41.3	42.2
Total	943			1197			359			132			2631		
Education level															
Bachelor's degree or higher	132	14.0	13.3	218	18.4	18.6	70	19.5	20.5	15	11.6	14.5	435	16.6	17.0
Post secondary	318	33.8	35.6	564	47.6	47.1	186	51.8	51.1	25	19.4	18.9	1093	32.4	33.1
Secondary or lower	491	52.2	51.1	402	34.0	34.3	103	28.7	28.4	89	69.0	66.6	1085	51.0	49.9
Total	941			1184			359			129			2613		
Perception of ETS as															
An important health problem	566	59.9	59.8	844	70.4	70.0	257	71.4	71.4	96	73.3	74.2	1763	67.9	67.1
A health problem of little or no importance	380	40.1	40.2	354	29.6	30.0	103	28.6	28.6	35	27.7	25.8	872	33.1	32.9
Total	946			1198			360			131			2635		
ETS in the workplace															
Complete ban	370	70.9	70.3	472	78.3	78.9	143	90.5	89.6	31	68.9	66.0	1016	76.8	77.3
Partial ban	131	29.1	29.7	131	21.7	21.1	15	9.5	10.4	14	31.1	34.0	291	23.2	22.7
Total	501			603			158			45			1307		

a The total may differ from the sample size (2648) due to missing values.

b n represents the size of the sample.

c % represents unweighted proportions.

d %W represents weighted proportions. A weighting coefficient was assigned to each type of household to take into account the unequal probability of a household being selected on the basis of its composition.

TABLE 2
Characteristics of households in the provinces of Quebec, Ontario, British Columbia and Nova Scotia

Variables	Quebec			Ontario			British Columbia			Nova Scotia			Total ^a		
	n ^b	% ^c	%W ^d	n	%	%W	n	%	%W	n	%	%W	n	%	%W
Presence of ≥ 1 adult non-smoker															
Yes	576	60.7	68.9	719	59.6	68.8	225	62.3	70.0	72	54.5	61.7	1592	60.1	68.7
No	373	39.3	31.1	487	40.4	31.2	136	37.7	30.0	60	45.5	38.3	1056	39.9	31.3
Total	949			1206			361			132			2648		
Presence of a child															
Yes	449	47.3	35.5	621	51.5	39.8	171	47.4	35.2	64	48.5	37.7	1305	49.3	37.7
No	500	52.7	64.5	585	48.5	60.2	190	52.6	64.8	68	51.5	62.3	1343	50.7	62.3
Total	949			1206			361			132			2648		
Age of the child															
5 or under	155	34.6	33.3	236	38.5	38.1	69	41.1	41.0	20	31.7	32.3	480	37.2	36.8
6-17	293	65.4	66.7	377	61.5	61.9	99	58.9	59.0	43	68.3	67.7	812	62.8	63.2
Total	448			613			168			63			1292		
Family context															
Adult non-smoker and child	282	29.7	24.8	370	30.9	26.6	108	30.2	26.6	29	22.1	17.4	789	29.9	25.6
Adult non-smoker, no child	293	30.9	44.1	342	28.5	42.0	114	31.8	43.0	42	32.1	44.3	791	30.0	42.9
Adult smoker and child	166	17.5	10.7	243	20.3	12.8	60	16.8	9.7	34	25.9	17.0	503	19.1	11.8
Adult smoker, no child	207	21.8	20.4	243	20.3	18.6	76	21.2	20.6	26	26.9	21.3	552	21.0	19.6
Total	948			1198			358			131			2635		
Family income															
> 95,000	63	8.6	10.5	144	15.7	19.8	30	11.1	12.3	10	9.7	11.8	247	12.2	15.2
55,000-95,000	158	21.3	22.8	256	28.0	27.7	79	29.4	31.4	16	15.5	16.8	509	25.1	26.2
≤ 55,000	519	70.1	66.7	516	56.3	52.5	160	59.5	56.3	77	74.8	71.4	1272	62.7	58.6
Total	740			916			269			103			2028		

a The total may differ from the sample size (2648) due to missing values.

b n represents the size of the sample.

c % represents unweighted proportions.

d %W represents weighted proportions. A weighting coefficient was assigned to each type of household to take into account the unequal probability of a household being selected on the basis of its composition.

adoption of a smoking ban, nor does the respondent's status as a single or attached person. The perception of ETS as a major health problem has an effect that falls within the range of statistical significance. The education level of respondents has an influence on the adoption of a smoking ban, with an adjusted prevalence ratio (PR) of 3.26 (95% confidence interval [CI] 2.0 to 5.3).

The impact of each household characteristic on the adoption of a household smoking ban remains constant regardless of whether the other variables are taken into account. The most influential characteristic of all

is the presence of an adult non-smoker, which is associated with a fourfold increase in the probability that a household smoking ban will be in place when compared to households in which all the adults are smokers. The presence of a child appears to have little influence on the decision to adopt a household smoking ban. In fact, the impact of this characteristic varies depending on the age of the child: the presence of a child under the age of 6 significantly doubles the probability that smoking restrictions will be in place, while the presence of a pre-adolescent or adolescent child does not appear to have a significant impact. When both a child and an adult non-smoker live

in a given household, the chances that a household smoking ban will be in place are seven times greater than in households that do not include one or the other.

Comparisons between Quebec and the other provinces

Table 4 presents provincial variations in the adjusted effect of each sociodemographic characteristic on the adoption of a household smoking ban. Certain variables were found to have an effect in all four provinces, although the degree of influence varied. Thus, the presence of an adult non-smoker in the household is the characteristic most strongly associated with household

TABLE 3
Crude and adjusted prevalence ratios (PRs) related to the adoption of a smoking ban (SB)
in Quebec households, by sociodemographic variable

Variables	n ^a	SB (%W) ^b	Crude PRs	Adjusted PRs ^c
Respondent variables				
Age group (in years)				
18-24	156	29.5	2.4 (1.2-5.0)	0.71 (0.3-1.8)
25-64	718	18.1	1.3 (0.7-2.5)	0.65 (0.3-1.4)
≥ 65	69	13.0	1.0	1.0
Gender				
Women	549	21.1	1.24 (0.9-1.7)	1.38 (0.9-1.9)
Men	400	17.7	1.0	1.0
Smoking status				
Non-smoker	162	29.6	2.45 (1.6-3.7)	1.09 (0.7-1.7)
Former smoker	138	31.9	2.73 (1.8-4.1)	1.46 (0.9-2.4)
Current smoker	649	14.6	1.0	1.0
Marital status				
Living with a spouse	560	19.8	1.76 (1.0-3.0)	0.82 (0.4-1.5)
Single	241	24.1	2.24 (1.3-4.0)	1.21 (0.6-2.5)
Separated/divorced	142	11.3	1.0	1.0
Education level				
Bachelor's degree or higher	134	31.0	3.5 (2.2-5.5)	3.26 (2.0-5.3)
Postsecondary	319	28.2	3.1 (2.1-4.5)	2.73 (1.8-4.1)
Secondary or lower	438	11.0	1.0	1.0
Perception of ETS as				
An important health problem	566	23.3	1.8 (1.3-2.6)	1.46 (1.0-2.1)
A health problem of little or no importance	380	14.2	1.0	1.0
Household variables				
Presence of ≥ 1 adult non-smoker				
Yes	576	27.6	4.70 (3.1-7.2)	3.81 (2.3-6.4)
No	373	7.5	1.0	1.0
Presence of children				
Yes	449	21.8	1.29 (0.9-1.8)	1.32 (0.9-1.9)
No	500	17.8	1.0	1.0
Age of the child (in years)				
≤ 5	155	27.7	1.79 (1.2-2.7)	1.9 (1.1-3.1)
6-17	293	18.8	1.08 (0.7-1.6)	1.1 (0.7-1.6)
No children	500	20.7	1.0	1.0
Effect of family context				
Adult non-smoker and child	283	28.6	7.1 (3.7-13.8)	6.5 (3.0-13.9)
Adult non-smoker, no child	293	26.6	6.5 (3.3-12.5)	5.6 (2.7-11.6)
Adult smoker and child	166	10.2	2.0 (0.9-4.5)	2.4 (1.0-5.5)
Adult smoker, no child	207	20.7	5.3	1.0

a The total may differ from 949, due to missing values.

b SB proportions are weighted.

c Prevalence ratios have been adjusted for the other variables.

smoking bans; this characteristic is associated with an almost fourfold increase in the probability that smoking will be banned in the home in Quebec and Nova Scotia, but only a twofold increase in British Columbia. The second variable associated with the adoption of a household smoking ban is the presence of a child under the age of 6; however, the association is weaker and non-significant in Quebec, whereas in Nova Scotia and Ontario it significantly triples the likelihood that a household smoking ban will be in place. The presence of a child over the age of 6 was found to have an effect only in British Columbia, where the presence of children was observed to have a remarkably uniform impact, regardless of age.

Other characteristics were found to have an influence that varies by province. The presence of a child of any age is associated with the adoption of a household smoking ban in Ontario and British Columbia; although non-significant, the strength of this association in Nova Scotia approaches 2. In British Columbia, the probability that a household smoking ban will be in place is 4 times greater among adults aged 18 to 24 and 25 to 64 than among those aged 65 or over. The influence of a person's smoking status can be observed in Ontario, where former smokers are significantly more likely to adopt a smoking ban than non-smokers and current smokers. The education level of respondents was significantly associated with the adoption of household smoking restrictions in Quebec and Ontario. Neither gender, nor the presence or absence of a spouse appeared to influence the adoption of a smoking ban in any of the provinces included in the study.

Discussion

The presence of an adult non-smoker in households that include at least one smoker is the factor most often associated with the adoption of a household smoking ban in Quebec and the three other provinces in this study. This confirms the findings of Borland in Victoria, Australia,¹⁰ who found that smokers in mixed households were 4.7 times more likely to always smoke outside the home than smokers in an all-smoker household (95% CI 3.7 to 6.0). However, the impact of this variable is less

TABLE 4
Variations in the effects of sociodemographic characteristics on the adoption
of a smoking ban, by province

Variables	Quebec PR ^a (95% CI)	Ontario PR (95% CI)	BC PR (95% CI)	Nova-Scotia PR (95% CI)
Respondent variables				
Age group (in years)				
18-24	0.7 (0.4-1.2)	1.86 (1.09-3.2)	3.6 (1.5-8.6)	1.0 (0.4-2.4)
25-64	0.5 (0.3-0.8)	1.42 (0.91-2.2)	3.5 (1.7-7.2)	1.3 (0.3-5.1)
≥ 65	1.0	1.0	1.0	1.0
Gender				
Women	1.3 (0.9-1.8)	1.3 (1.0-1.6)	1.1 (0.7-1.7)	0.8 (0.4-1.7)
Men	1.0	1.0	1.0	1.0
Smoking status				
Non-smoker	1.2 (0.8-1.8)	1.2 (0.8-1.6)	0.5 (0.3-0.9)	0.5 (0.1-1.5)
Former smoker	1.5 (0.9-2.3)	1.6 (1.1-2.3)	0.5 (0.2-0.9)	1.5 (0.5-4.8)
Current smoker	1.0	1.0	1.0	1.0
Marital status				
Living with a spouse	0.6 (0.4-1.1)	1.0 (0.7-1.4)	0.8 (0.4-1.4)	0.9 (0.3-2.3)
Single	1.0 (0.5-1.7)	1.0 (0.6-1.5)	0.9 (0.5-1.8)	0.9 (0.3-2.8)
Separated/divorced	1.0	1.0	1.0	1.0
Education level				
Bachelor's degree or higher	2.8 (1.7-4.5)	2.4 (1.7-3.4)	1.6 (0.9-2.9)	1.5 (0.5-4.6)
Postsecondary	2.4 (1.6-3.4)	1.5 (1.1-2.0)	2.1 (1.2-3.5)	2.2 (0.5-5.7)
Secondary or lower	1.0	1.0	1.0	1.0
Perception of ETS as				
An important health problem	1.5 (1.0-2.1)	1.3 (0.9-1.7)	1.5 (0.9-2.5)	1.6 (0.6-4.1)
A health problem of little or no importance	1.0	1.0	1.0	1.0
Household variables				
Presence of ≥ 1 adult non-smoker				
Yes	3.8 (2.4-5.9)	3.5 (2.6-4.7)	2.4 (1.5-3.9)	3.7 (1.6-8.8)
No	1.0	1.0	1.0	1.0
Presence of children				
Yes	1.2 (0.9-1.8)	1.8 (1.4-2.3)	2.6 (1.6-4.1)	1.9 (0.9-4.3)
No	1.0	1.0	1.0	1.0
Age of the child (in years)				
≤ 5	1.6 (1.0-2.6)	3.0 (2.1-4.2)	2.5 (1.4-4.7)	3.5 (1.2-10.5)
6-17	1.01 (0.7-1.5)	1.3 (0.9-1.8)	2.7 (1.6-4.6)	1.4 (0.6-3.5)
No children	1.0	1.0	1.0	1.0
Effect of family pressure				
Adult non-smoker and child	5.7 (2.8-11.3)	6.6 (4.3-10.2)	6.3 (3.1-12.5)	7.9 (1.9-32.8)
Adult non-smoker, no child	5.3 (2.7-10.5)	4.1 (2.6-6.3)	2.4 (1.2-4.7)	4.1 (1.0-16.3)
Adult smoker and child	2.0 (0.9-4.5)	2.2 (1.4-3.5)	2.5 (1.2-5.3)	2.2 (0.5-9.6)
Adult smoker, no child	1.0	1.0	1.0	1.0

a Prevalence ratios have been adjusted for the other variables.

pronounced in British Columbia, which suggests that smokers are themselves sufficiently aware of the harmful effects of ETS to adopt a household smoking ban of their own accord, or have a greater willingness to smoke outdoors; British Columbia has a more temperate climate than the other provinces included in this study. From a health promotion standpoint, this suggests a need to consider campaigns that target non-smokers who live with smokers. Unlike classic campaigns that exhort smokers to go outside to smoke, a campaign urging non-smokers to show less tolerance with respect to environmental tobacco smoke might well contribute to a reduction in ETS exposures.

Surprisingly, the presence of children (all ages combined) in smoker households in Quebec is not linked to the adoption of smoking bans, as was found to be the case in British Columbia and Ontario. However, the situation is somewhat improved if the child is under the age of 6. While the presence of a child appears to have only a weak influence on the adoption of household smoking bans in Quebec, progress has nonetheless been made since 1996, when a Statistics Canada study found that neither the presence of a child, nor the age of the child, had any influence on smoking in the home.⁷ Still, these data are not particularly encouraging in light of the positive impact that household smoking bans have been shown to have on the prevalence of smoking in adolescence. Indeed, a number of authors, including Farkas,¹¹ have found that adolescents who live in smoke-free households were only 74% as likely to be smokers as adolescents who live in households where there are no smoking restrictions. Farkas also observed that adolescents who already smoke are twice as likely to stop smoking if they live in a smoke-free household. Wakefield¹² has observed that transition through the different stages of tobacco addiction was significantly slower for adolescents who reported that their household had a smoking ban. The results of our study have important operational implications for public health programs, since they suggest parents are more inclined to adopt a smoking ban when their children are young but become less inclined to do so

as their children age. In addition to the link between child health and household smoking bans, greater emphasis should be placed on the impact of smoking bans on children's future smoking behaviour.

The perception of ETS as an important health issue also has an impact that falls within the range of statistical significance. The proportion of respondents who viewed ETS as a health problem of little or no importance was substantial in 2001 (40%). Although that proportion has probably declined since the data were collected, it remains a variable of considerable interest from a public health perspective by virtue of the fact that it is modifiable.

Contrary to the findings of some authors, the adoption of household smoking bans was not linked to the gender of respondents in Quebec or in the three other provinces in this study. These results differ from those of Gilpin¹³ and Merom¹⁴ who found that women adopt such household policies significantly less often than men, with odds ratios of 0.72 CI (0.61 to 0.84) and 0.84 CI (0.72 to 0.96) respectively. As far as the age of respondents is concerned, we observed that this characteristic had no influence on the adoption of smoking bans in Quebec households. This is surprising, given that participants aged 18 to 24 belong to a generation whose members are better informed about the harmful effects of ETS and are more likely to have small children at home.

The strength of this study resides in the potential to identify the factors which are associated with the presence of a smoking ban in "smoker households" in Quebec. In public health, it is crucial to be able to identify factors that can explain at least part of a problem that affects the population and are viewed as modifiable. The results of this study suggest that ETS in the home is at least partly modifiable if a less tolerant, non-smoking adult lives with a smoker and if the perception of ETS as an important health problem increases. The results also suggest that parents are less likely to perceive the benefits of a household smoking ban when their children are 6 or older. These hypotheses, once confirmed, will serve as

a basis for modifying health promotion interventions. In fact, a Chinese study¹⁵ on the predictive factors of lax household smoking bans points to the presence of a smoking partner (odds ratio = 2.78, $p < 0.05$).

One might argue that these data are too old, since they date back to 2001. However, the results of this study remain fully relevant for a number of reasons. To begin with, the study constitutes the only epidemiological index currently at our disposal, as it is the first study of its kind to include a representative sample of the Canadian population; also, as far we know, no other study has ever been published on the factors associated with the adoption of household smoking bans in Quebec. As such, the results of this study will ultimately lend themselves to comparisons with future studies. Finally, the results of the 2006 Canadian Tobacco Use Monitoring Survey (CTUMS) show that these data are still relevant, since Quebec remains above the Canadian average in terms of household second-hand smoke exposure for children aged 0 to 17; in Quebec, 18.4% of children aged 0 to 11 and 25.8% of children aged 11 to 17 are regularly exposed to ETS, compared to 3% and 7% respectively in British Columbia, 5% and 8.9% in Ontario, and 10.5% and 18% in Nova Scotia.⁸

Quebec's *Tobacco Act*, which prohibits smoking in many places (health care facilities, daycare centres, social services, schools and institutions of higher learning, sports and recreational facilities, arts and cultural facilities, public transit) has been in place since 2001. On May 31, 2006, smoking was prohibited in bars and restaurants as well. This new measure, combined with the *Tobacco Act*, will no doubt have an impact on the social acceptability of smoking, but its effect on household smoking bans is unlikely to be so great as to invalidate the results of the present study.

This study comprises a few limitations that should be noted. The response rate of 62% is modest and, as such, may cast doubt on the reliability of household smoking ban data. However, it is well within the range of response rates routinely obtained with

the method used. Indeed, survey response rates have been trending downward in recent years, compared to the 1970s, 1980s and 1990s.^{15,16}

Moreover, dividing the household smoking ban variable into two categories (complete household smoking ban and occasional/no ban) tends to group into the latter category both households that have never had a ban and households in which a ban exists but is occasionally disregarded. Although having three categories might have provided a more accurate reflection of reality, our interest lies in households that have a complete smoking ban, since our goal is to identify the variables associated with such bans; furthermore, the small size of certain sub-groups limited our options in this regard.

As for the weighting of prevalence estimates in this study, the coefficients should have been calculated on the basis of the distribution of households as reflected in national statistics. In the absence of such statistics, these coefficients were obtained on the basis of the distribution of households participating in the survey, which constitutes a reliable estimate of national data. Consequently, the estimated prevalences in our study are probably close to the real numbers.

Finally, the results for Nova Scotia should be interpreted with prudence, given the small sample size ($n = 132$). This factor makes it difficult to distinguish between an absence of association and the study's inability to detect an association where one exists.

Conclusion

The performance of Quebec's tobacco control strategy, the diminishing social acceptability of smoking, and legislation that prohibits smoking in public places and workplaces have brought about a reduction in smoking prevalence. However, Quebec's children do not all enjoy the benefits of these changes and remain more exposed to ETS than children in other parts of Canada. The results of this study provide a more accurate profile of children's exposure

to ETS in the home. They suggest that children who live in smoker households that do not include any adult non-smokers are at greater risk of exposure to ETS than those who live with at least one adult non-smoker. These findings also suggest that the adoption of a smoking ban is viewed as acceptable for younger children but less so for older children, which could have important operational implications for public health programs. The strong association between the presence of adult non-smokers and the adoption of household smoking bans also raises health promotion implications and suggests that intervention campaigns aimed at non-smokers who live with smokers should incite the former to be less tolerant of environmental tobacco smoke in the home.

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Workshop/conference report

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) program and Interdisciplinary Research Symposium on Disabling Fatigue in Chronic Illness

E. Stein, MD (1); M. MacQuarrie, BSc MRP LLB (2)

Background

This program at the University of Calgary was the first comprehensive program on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) held in Canada. There were three parts: a continuing medical education program for physicians, a research symposium on fatiguing illnesses and a public lecture. ME/CFS is one cause of disabling fatigue. ME/CFS alone is a serious medical condition that affects between 150 000¹ and 340 000² Canadians. The core symptoms have been described by Fukuda et al.³ and were further refined in the *Canadian Consensus Guidelines for the Diagnosis and Treatment of ME/CFS*.⁴

Program

The physician program was divided into two segments: Part I (October 24, 2008) covered the diagnosis and assessment of patients with ME/CFS and Part II (November 7, 2008) covered clinical management.

A full-day interdisciplinary research symposium on disabling fatigue in chronic illness took place on November 8, 2008, in a mix of plenary and concurrent sessions. This symposium was organized to assist in both the development of a collaborative research agenda to understand disabling fatigue in chronic disease as well as in the

knowledge transfer process among health care professionals, researchers and the Canadian public. Disabling fatigue exists in numerous chronic conditions, including autoimmune disorders, chronic infection, chronic liver disease, pulmonary and heart disease, ME/CFS, overtraining and stress syndromes, some psychiatric conditions and fatigue due to unknown causes.

The plenary sessions included Karin Olson, RN, PhD, University of Alberta (Conceptual Model of Fatigue: The Edmonton Fatigue Framework); Leonard Jason, PhD, DePaul University (Epidemiology and Case Definition of ME/CFS); Nancy Klimas, MD, University of Miami (Biological Markers in Disabling Fatigue); Bryan Kolb, PhD, University of Lethbridge (Neuroplasticity and Implications for Disabling Fatigue); and a video of Gerry Thomas, with a patient perspective.

Dr. Olson presented the Edmonton Fatigue Framework (EFF), a proposed etiological model of fatigue based on 15 years of research with five populations experiencing fatigue: those with cancer, depression and ME/CFS, as well as shift-workers and recreational runners. In this model, fatigue (subtyped as tiredness, fatigue and exhaustion) is considered a behavioural marker of the inability to adapt to stress

and is secondary to changes in muscle endurance, sleep quality, cognitive function, dietary intake and other factors.⁵

Dr. Klimas, an internationally renowned research immunologist and clinician, profiled current work, including dynamic modelling using an exercise stressor model, showing that one must stress a subject with ME/CFS to get reliable differences versus controls. Mathematical modelling by Gordon Broderick, PhD (Computational Biology, University of Alberta and one of Dr. Klimas' team) is identifying which biomarkers could serve as a diagnostic test for ME/CFS.⁶

Dr. Jason spoke about the definition, prevalence and social impact of ME/CFS and, in the concurrent session, about a four-arm, non-pharmacological intervention study in ME/CFS. Both of his presentations underscored the importance of properly identifying and subtyping ME/CFS patients. Not every ME/CFS patient reacts to treatment in the same way.

Dr. Bryan Kolb (Director of the Canadian Centre for Behavioural Neuroscience at the University of Lethbridge and author of the classical textbook, *Fundamentals of Human Neuropsychology*⁷) reviewed the literature on brain plasticity and implications for ME/CFS. He made the

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Submitted by Ellie Stein, MD, (Chair, Program Committee) on behalf of the Planning Committee: Drs. Terrie Brandon (Family Medicine, Calgary); Brian MacIntosh (Kinesiology, University of Calgary); Karin Olson (Nursing, University of Alberta); Steve Simpson (Medicine, University of Calgary); Elaine Stapon (Family Medicine, Calgary); and Ms. Glenda Wong (Department of CME, University of Calgary).

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provocative hypothesis that the increased prefrontal volume post “effective cognitive behavioural therapy” reported by de Lange et al.⁸ may have been due to the impact of the therapy on depression rather than ME/CFS. Many symptoms, including depression and stress, correlate with structural changes in the prefrontal cortex.

The concurrent sessions were also filled with some very stimulating findings, including:

- Bruce Dick, PhD (Departments of Anesthesiology and Pain Medicine and Psychiatry, University of Alberta), presented work on cognitive function in fibromyalgia.⁹ He reported that the spatial span test was the most difficult task for people with fibromyalgia and that cognitive function did not improve in the short term with pain intervention. However, patients on long-term opiate treatment did better on cognitive tests overall than those who were not on opiates.
- Patrick Neary, PhD (Kinesology and Health Studies, University of Regina), presented his data on prefrontal cortical oxygenation, as measured by near-infrared spectrophotometry during exercise to exhaustion.¹⁰ There was no difference at rest between the ME/CFS and control groups, but with exercise, both the total haemoglobin and oxygenated haemoglobin were reduced in the ME/CFS group. He has shown in unpublished work that oxygen flow to the brain is slow to recover when patients with ME/CFS stand up. This reinforces the need for provocation testing in ME/CFS.
- Carey Johnson, MD (private practice, Calgary), presented his observations that approximately 50% of patients with Eilers Danlos (ED) syndrome have clinical features meeting the *Canadian Consensus Guidelines for the Diagnosis and Treatment of ME/CFS*; the other 50% have the typical features of connective tissue disorder, but not chronic fatigue, sleep disorder, pain or sensory sensitivity. He has a study in progress to identify genetic markers for this subgroup of ED patients.

- Neil Skjodt, MD (Medical Director, Edmonton Sleep Institute; Director of Research, Canadian Sleep Institute), noted that the sleep irregularities in ME/CFS were, for various reasons, not getting specialized attention. He suggested a more appropriate sleep assessment protocol for these patients.

Other thought-provoking and informative presentations were given by:

- Denise Adams, BSc (PhD candidate, University of Alberta), on Traditional Chinese Medicine for the Treatment of Chronic Fatigue: A Systematic Review;
- Brian MacIntosh, PhD (Kinesology, University of Calgary), on Measuring Peripheral vs. Central Fatigue;
- Lynn Marshall, MD (Environmental Health Clinic, Women’s College Hospital, Toronto), on Functional Impairment in an Environmental Clinic Sample;
- Kathleen Pierson, MD, PhD (Department of Psychiatry, University of Calgary), on Measuring Fatigue in Early Psychosis;
- Steve Simpson, MD, FRCP(C) (Psychiatry, University of Calgary; Consulting Psychiatrist, Tom Baker Cancer Centre), on the Management of Cancer Fatigue;
- Mark Swain, MD, FRCP(C) (Professor of Medicine, University of Calgary), on Disabling Fatigue in Inflammatory Disorders; and
- Mark van Ness, PhD, Staci Stevens, MSc, and Kylie Kumasaka, PhD candidate (Pacific Fatigue Laboratory, University of the Pacific, California), on Metabolic Dysfunction in ME/CFS.

The public lecture on November 9, 2008 featured Nancy Klimas, MD, giving an update on ME/CFS research, Alison Bsted, MD, FRCP(C) (private practice, Toronto), providing clinical pearls¹¹ and a tag team of Stevens, van Ness and Kumasaka presenting on Exercise Tolerance in ME/CFS.

Podcasts (i.e. audio and slides only) of the ME/CFS continuing medical education program and the public lecture are currently available free of charge. To view the podcasts go to: <http://podcast.med.ucalgary.ca/groups/cfs/weblog/>. The research day is not a podcast, although handouts from many of the presentations are available on the University of Calgary Continuing Medical Education site, at www.cme.calgary.ca.

Conclusion

There were many coinciding concepts from various presenters in different fields, specifically, the interrelation of all body systems and the need to take an interdisciplinary approach to understanding ME/CFS and disabling fatigue in chronic illness. The opportunity for so many disciplines to gather and benefit from “cross-talking” and the fertilization of ideas was immense, and new ideas and collaborations are ongoing. The objective of the symposium to develop a collaborative research agenda was ambitious. Meeting this objective will take time, effort and funding.

Acknowledgements

This program was co-endorsed by the University of Calgary, Faculty of Medicine, and the University of Alberta, Faculty of Medicine and Dentistry. It was supported by Alberta Health and Wellness, the Public Health Agency of Canada and the Canadian Institutes of Health Research. The ME-FM Society of Alberta was a major sponsor. Other sponsors (in alphabetical order) were Bayda Ludwar Law Firm, Cambrian Drug Mart, Ferring Pharmaceuticals, Genuine Health, Metagenics, Pfizer Canada, Script Pharmacy and Varsity Natural Health Center. The podcasts are available thanks to sponsorship from the Alison Hunter Memorial Foundation (www.ahmf.org).

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Book review

Dissonant disabilities: women with chronic illnesses explore their lives

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Editors: Diane Driedger and Michelle Owen

Published: Canadian Scholars' Press Inc./Women's Press: April, 2008: Toronto

Format: Paperback; 258 pages

ISBN: 978-0-88961-464-2

As the title implies, this compelling collection of essays examines the discordant lives of women living with chronic illnesses. The content is meaningful, not only to those afflicted with similar conditions, but also to a wide audience—including physicians, researchers, policy-makers and the general public—who will benefit from both the scholarship of this presentation and the unique perspectives that detail each enlightening story.

This anthology by women with chronic illnesses provides a forum for the discussion of shared barriers and is the first anthology of its kind in Canada. The distinguishing feature of this book is the first-hand accounts of illnesses shared by those directly experiencing the disease versus accounts of the disease process or self-help treatments based on a medical model. While the authors had every intention to represent a variety of women, they acknowledge the level of privilege with respect to time and ability required to submit an essay and the resulting disproportionate representation of women from academia and women with post-secondary educations.

The authors' selection of articles poignantly identifies issues significant to the lives of women living with a range of chronic illnesses, including physical, cognitive, visible, invisible and contested illnesses. The authors chose to restrict this anthology to women to highlight the increased prevalence of chronic illnesses among women and to raise awareness of prevailing risk factors, including psychosocial and socioeconomic determinants. Each essay

shares the personal story of a woman with a particular illness, her challenges and accomplishments with the illness itself and her environment, including the institutional policies that affect her home and working life.

The definition of disability used throughout the book is based on the social model where disability is viewed as the inability of society to account for those with impairments, thereby excluding them from mainstream society. The social model sees the lack of a ramp as the problem and not the use of a wheelchair. This form of discrimination and social oppression is paralleled to racism or sexism. The authors further discuss historical perspectives of disability that saw a person with a disability as being in a constant state of sickness, lacking independence and wanting to get well. These attitudes linger today and come to surface as a common theme uniting the stories in the book shared by the women from various cultural and socioeconomic backgrounds. For the reader with a chronic illness, these common struggles are easily identified with and when their outcomes are positive, they serve as a source of inspiration; when negative, they arouse empathy. For the health policy-maker, these stories should inspire change.

The authors' portrayal of the lives of women with chronic illnesses was not meant as an in-depth description of the epidemiology of each condition, but a presentation of the facts of daily life for each woman, supported by current research and legislative evidence. To

balance the discussion of barriers faced by women with chronic illnesses, the authors saw fit to include essays demonstrating the strong will and resistance these women have to existing social ideas.

The book is divided into five parts. In each section, different women with chronic illnesses share key concepts that form the barriers they face and show their resistance to prevailing social norms. In Part One: "Clashing Expectations," the focus is on societal attitudes towards women with chronic illnesses and the isolating feelings of shame, doubt and powerlessness evoked when expectations of continual production are unmet. In this section, the authors raise awareness of the "changing landscape" of health experienced by women with chronic illnesses and society's lack of acceptance of this fluctuation in functioning and, to a greater extent, society's expectation of "soldiering on" despite illness.

In Part Two: "Unpredictable Bodies," the focus is on idealizations of the female body and the impact of chronic illness. To emphasize the far-reaching and global nature of women's struggles with chronic illnesses, including body dissatisfaction, the authors wisely included essays discussing the effects of Western society's preoccupation with weight on the cultural expectations of Asian nations. An essay focusing on women with chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivities recognizes the duality of experiencing a chronic illness: the knowledge that you are the same person while you become a different

person. When dealing with a contested illness the situation only intensifies as the medical community or employers fail to validate the limitations of these women. The authors recognize the importance of association with others who have the same illness in order to overcome such ambiguities and gain comfort in the shared experiences of others.

In Part Three: “Disturbing Work,” the authors explore how women with chronic illnesses both disturb work and find work disturbing. The authors chose an essay describing the life of a driven researcher whose ambitions eventually led to a chronic state of anxiety. For anyone associated with academia, this story draws many parallels and helps to identify the early warning signs of mental and physical exhaustion and the steps to take to prioritize one’s health and wellness. In contrast, the next essay in this section describes the challenges faced by a young woman with a chronic illness seeking a graduate degree. This story highlights the inflexibility of institutional policies to recognize the uncertainty germane to chronic illness.

In Part Four: “Shifting Relationships,” the many relationships women with chronic illnesses must develop and negotiate are examined. The authors highlight the impact of chronic illness not only on the person directly affected, but also on how those who provide financial, emotional or physical support are challenged and adapt. Finally, in Part Five: “Traversing Dissonance,” the authors inspire readers with uplifting stories of how women with chronic illnesses deal with the often contradictory barriers to societal participation and how some barriers are transformed into new opportunities for growth, such as gaining a sense of control, experiencing new challenges and setting new goals. The book concludes by leaving the reader with a philosophical dilemma: “Can a society that is ideologically (if not economically) committed to preventing, avoiding or ending most forms of involuntary suffering appreciate people who are suffering?” This highlights the common theme of the book, namely, the need to reform society’s

structural (environmental) and conceptual acceptance of women with chronic illnesses.

The authors’ purpose for compiling this series of stories told by women with chronic illnesses was to portray the many different ways a disability may infiltrate the lives of those affected. Each personal narrative gives a glimpse into the life of a different woman—young or old, early or late into her career. The reader grows to appreciate how chronic illness affects her daily routine, her life ambitions and all those around her. What sets this book apart is its ability to relay the limitations faced by women with chronic illnesses while simultaneously demonstrating their strength and resilience, combining strong feminist ideals with critical disability theories.

This unique perspective serves many who interact with women with chronic illnesses. For the physician, it emphasizes the needs of a potential patient – needs that may reach beyond medication, such as life- or stress-management, or exercise and nutritional counselling. For the policy-maker, it introduces the concept of uncertainty in one’s daily physical and mental functioning, for which there should be some flexibility in place. Researchers and epidemiologists will find the contents of this book useful when developing conceptual models, for example, examining the role of psychosocial barriers to recovery for those with chronic illnesses. Finally, for the general public, the stories shared in this book foster an understanding and respect for the challenges faced by women with chronic illnesses.

The authors were successful in their attempt to provoke thought among their readers. They acknowledge the gaps in the literature and share their hope that more work in the area of critical disability studies will follow.

Announcements

Chronic Disease Update listserv

The Public Health Agency of Canada encourages you to subscribe to the Chronic Disease Update listserv. We are pleased to offer you a way to receive information on the work of the chronic disease team. Keeping our colleagues and clients informed about work in progress, new projects and programs, and opportunities for collaboration is a priority for us. Thank you for your interest in our work.

<http://www.phac-aspc.gc.ca/cd-mc/maillist-eng.php>

Conferences

7th International Conference on Diet and Activity Methods

June 5-7, 2009
Washington, D.C.
<http://icdam.org/>

Canadian Public Health Association Conference

June 7-10, 2009
Winnipeg, Manitoba
<http://www.cpha.ca/en/conferences/conf2009.aspx>

International Scientific Conference on Nutraceuticals and Functional Foods

June 9-11, 2009
Zilina, Slovakia
<http://www.foodandfunction.com/>

20th World Diabetes Congress

October 18-22, 2009
Montreal, Quebec
<http://www.worlddiabetescongress.org/>

Canadian Cardiovascular Congress

October 24-28, 2009
Edmonton, Alberta
http://www.cardiocongress.org/English/Home_EN.html

Third International Chronic Disease Conference

November 23-26, 2009
Calgary, Alberta
<http://www.cdmcalgary.ca/index.php?lang=english>

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Chronic Diseases in Canada (CDIC) is a quarterly scientific journal focussing on the prevention and control of non-communicable diseases and injuries in Canada. Its feature articles are peer reviewed. The content of articles may include research from such fields as epidemiology, public/community health, biostatistics, the behavioural sciences, and health services or economics. CDIC endeavours to foster communication on chronic diseases and injuries among public health practitioners, epidemiologists and researchers, health policy planners and health educators. Submissions are selected based on scientific quality, public health relevance, clarity, conciseness and technical accuracy. Although CDIC is a publication of the Public Health Agency of Canada, contributions are welcomed from both the public and private sectors. Authors retain responsibility for the contents of their papers, and opinions expressed are not necessarily those of the CDIC editorial committee nor of the Public Health Agency of Canada.

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Cross-Canada Forum: For authors to present or exchange information and opinions on regional or national surveillance findings, programs under development or public health policy initiatives (maximum 3,000 words). Abstract not required.

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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 3B8 key words (preferably from the Medical Subject Headings (MeSH) of Index Medicus).

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

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