



Ontario
Trillium
Foundation



Fondation
Trillium
de l'Ontario

THE QUANTITATIVE DATA

Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS),
Fibromyalgia (FM), Myalgic Encephalomyelitis/
Chronic Fatigue Syndrome (ME/CFS)

APPENDIX TO
THE ONTARIO CENTRE OF EXCELLENCE IN
ENVIRONMENTAL HEALTH BUSINESS CASE

With funding from
ONTARIO MINISTRY OF HEALTH AND LONG-TERM CARE
ONTARIO TRILLIUM FOUNDATION

Compendium 2/4 of the Business Case for an OCEEH

Erika Halapy, Epidemiologist
with Margaret Parlor, Statistical Analyst, President,
National ME/FM Action Network

Acknowledgements:
Arron Service, CHC Decision Support Specialist
Varda Burstyn, Environmental Health Expert

October 2013

Contents

Executive Summary..... 5

1.0 Introduction and Methodology..... 8

 1.1 INTRODUCTION..... 8

 1.2 METHODOLOGY 8

2.0 THE DATA 11

 2.1.1 Prevalence in Canada and Ontario..... 11

 Table 1: Prevalence of ES/MCS, FM and ME/CFS among Canadians aged 12 and older, 2005 and 2010 11

 Table 2: Number of Canadians with Chronic Conditions based on their Reported Diagnosis by a Health Professional, 2010 12

 Table 3: Prevalence of ES/MCS, FM and ME/CFS according to Age and Gender, Canada, 2010..... 12

 Table 4: Age and Gender Distributions of Canadian Population aged 12 and older with ES/MCS, FM and/or ME/CFS, 2010..... 13

 Table 5: Prevalence of ES/MCS, FM and ME/CFS among Ontarians aged 12 and older, 2005 and 2010 14

 Summary: 14

 2.1.2 Prevalence by Ontario Local Health Integration Network (LHIN)..... 16

 Table 6: Prevalence of ES/MCS, FM and ME/CFS by Ontario Local Health Integration Network, 2010 16

 Summary: 18

 2.2 Profile of Level of Impairment 19

 Table 7: Canadian Population who are Permanently Unable to Work According to their Chronic Health Condition, 2010 19

 Table 8: Canadian Population who Need Help with Activities of Daily Living According to their Chronic Health Condition, 2010..... 20

 Table 9: Indicators of Functional Impairment among Canadians with ES/MCS, FM and/or ME/CFS, 2010 22

 Summary: 23

 2.3 Demographics and Functional impairment: Results from the Environmental Health Clinic, Toronto, Ontario, 2005-2006..... 24

 Table 10: Diagnoses of the EHC Patient Population, 2005-2006 24

Summary:	25
2.4 Profile of Health Care Utilization	26
Table 11: Consultations with Medical Doctors in the Previous 12 Months among Canadians according to their Chronic Health Condition, 2010	26
Table 12: Mean Number of Visits to Medical Doctors in the Previous 12 Months by Patients of the Environmental Health Clinic (EHC) in Toronto, Ontario, 2005-2006	28
Table 13: Health Care Utilization Related Variables from a Survey by the Myalgic Encephalomyelitis Association of Ontario (MEAO), 2011	29
Table 14: Percentage Decline in Physician Visits by Patients with ES/MCS Following Consultation at the Nova Scotia Environmental Health Centre	29
Table 15: Consultations with Health Professionals in the Previous 12 Months among Canadians according to their Chronic Health Condition, 2010	30
Summary:	32
2.5 Profile of Unmet Health and Home Care Needs	34
Table 16: Canadians Reporting Unmet Health Care Needs according to their Chronic Health Condition, 2010	34
Table 17: Proportion of Women with ES/MCS, FM and/or ME/CFS who consulted an Alternative Care Provider according to their Unmet Health Care Needs, Ontario, 2005	35
Table 18: Ontarians Reporting Unmet Home Care Needs according to their Chronic Health Condition, 2005 and 2010	35
Table 19: Ontarians Receiving Home Care in the Past 12 Months according to their Chronic Health Condition, 2005 and 2010	36
Table 20a: Proportion of Ontarians Receiving Home Care Services with Costs Covered in Whole or in Part by the Government among those Receiving Home Care Services according to their Chronic Health Condition, 2005	37
Table 20b: Proportion of Ontarians Receiving Home Care Services with Costs Covered in Whole or in Part by the Government among those Receiving Home Care Services according to their Chronic Health Condition, 2010	37
Table 21: Insurance Coverage for Prescription Medications among Ontarians according to their Chronic Condition, 2005	38
Summary:	38
2.6 Profile of Socioeconomic Disadvantage	40
Table 22: Canadian Population Experiencing Moderate or Severe Household Food Insecurity according to their Chronic Health Condition, 2010	40

Table 23: Canadian Population who have Household Income less than \$15,000 according to their Chronic Health Condition, 2010.....	41
Summary:	41
2.7 Profile of Social Impact	42
Table 24: Canadian Population Experiencing Difficulty in Social Situations according to their Chronic Health Condition, 2005	42
Table 25: Canadian Population who have a Very Weak Sense of Community Belonging according to their Chronic Health Condition, 2010	43
Table 26: Canadian Population Reporting Discrimination or Unfair Treatment due to their Health Problem among those with a Reduction in Activities according to their Chronic Health Condition, 2005	43
Summary:	44
2.8 LIMITATIONS	45
2.9 CONCLUSIONS	45
2.10 ACKNOWLEDGEMENTS	46
2.11 REFERENCES	46

Executive Summary

The objective of this analysis was to evaluate a broad range of health-related characteristics in order to provide the reader with an outline of the circumstances surrounding people living with Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS), Fibromyalgia (FM) and/or Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The presentation of this quantitative data is meant to complement the compelling information gathered from personal interviews and focus groups conducted with people living with ES/MCS, FM and/or ME/CFS.

The primary source of data included in this report is the Canadian Community Health Survey (CCHS), a population-based cross-sectional survey implemented by Statistics Canada in 2000¹⁻³. As part of the survey, respondents are asked about chronic conditions that have been diagnosed by a health professional. A number of relevant characteristics, measures of disability, measures of health care utilization and measures of unmet health care needs were examined from the 2005 and 2010 CCHS. For each variable, estimates for the total Canadian population as well as for four chronic health conditions (cancer, diabetes, effects of a stroke and heart disease) that are well known, disabling and affect a significant proportion of the population are presented as comparison groups. Individuals may have any number of chronic health conditions at any one time, and chronic health condition groupings therefore, are not independent. Other studies included in this report are based on patient populations from the Environmental Health Clinic (EHC) in Toronto⁸, ON, and the Nova Scotia Environmental Health Clinic (NSEHC)⁹.

In 2010, the number of people with one or more of ES/MCS, FM or ME/CFS surpassed 1.4 million in Canada with over half a million in Ontario alone. The prevalence of one or more of ES/MCS, FM or ME/CFS increased from 4.2% in 2005 to 4.9% in 2010, and similarly from 4.2% in 2005 to 5.0% in 2010 in Canada and Ontario, respectively. Increases were also observed for each of the conditions individually, but were most notable for those with ES/MCS. A comparison with the number of cases of other well-known chronic diseases indicates that ES/MCS, FM and ME/CFS are not rare. The majority of those affected are ages 45-64, a time in people's lives when they have the potential to be employable and contribute to the economy and society. In addition, the majority of people with the conditions are women, and this has further implications regarding issues of parenting and family cohesiveness, among others.

Measures of functional impairment such as needing help with activities of daily living (including housework, preparing meals and running errands) and being permanently unable to work indicate that people with ES/MCS, FM and/or ME/CFS are at least as disabled and in some cases more disabled than people with other chronic conditions such as cancer and diabetes. The levels of impairment for certain disability measures in people affected with ME/CFS are akin to or approach those for people living with the effects of a stroke. Several chronic conditions such as stroke and cancer are commonly associated with older age, which is also a time when needing help for tasks increases. People with ES/MCS, FM and/or ME/CFS are on average middle-aged and yet, still require high rates of assistance with activities

of daily living. The EHC patient population was found to have lower scores for functional status than the average scores of Canadians with comparable age and sex⁸, which are consistent findings.

A high number of consultations with physicians (both family doctor/GP and other doctors/specialists) in the previous 12 months were found with both the CCHS and EHC populations. This may reflect the complexity of ES/MCS, FM and ME/CFS as well as their associated co-morbidities. The results suggest that people with ES/MCS, FM and ME/CFS require medical support, but might not be receiving effective care for their conditions. Results from a prospective cohort study at the NSEHC found a decrease in physician visits after consultation at the clinic⁹. These findings are indicative of the effect a multidisciplinary holistic approach can have in reducing health care utilization rates. The decreases in utilization were naturally associated with decreases in health care costs. Interestingly, people with ES/MCS, FM and/or ME/CFS also consistently demonstrated the greatest proportions having a consultation with other health professionals (such as chiropractors, physiotherapists and massage therapists). This suggests that people with the conditions are looking for effective care and therapies outside of conventional medicine, and the fact that the majority of costs for other health professionals are out-of-pocket suggests that the motivation for people to find help is great.

There was a wide range in self-perceived unmet health care needs in the previous 12 months among those with chronic health conditions. Unmet health care needs were clearly the highest among those with FM, ME/CFS and ES/MCS followed by those living with the effects of a stroke. Those with FM were more than two and a half times as likely as to report unmet health care needs than those in the general population, while those with diabetes reported a similar level of unmet health care needs compared to the general population. People with ES/MCS, FM and ME/CFS are most likely to report that their health care needs are unmet despite the high physician consultation rates observed, further contributing to the view that people with these conditions are receiving ineffective care or are experiencing barriers to and deficits in care.

Those living with the effects of a stroke and with cancer were most likely to receive home care services, and furthermore, they were most likely to have the services paid for. This is in spite of the disability measures, which indicated that those with ES/MCS, FM and/or ME/CFS can be as disabled as people with other chronic conditions. One reason for this could be that the health delivery models for cancer and stroke that have been accepted for government funding include home-based care. A model of care including a home-based component for people with ES/MCS, FM and/or ME/CFS has not been accepted at the governmental level. Since many people with ES/MCS, FM and/or ME/CFS needing these services have to assume the costs of care privately, lower rates of home care overall may also be due to financial barriers.

Lack of reliable access to healthy food in adequate quantities as demonstrated by moderate and severe household food insecurity was highest among those with ME/CFS, followed by those with ES/MCS and FM. The finding for those with ME/CFS was almost three times that of the general population, while those with heart disease and cancer had similar or possibly lower levels of household food insecurity compared to the general population. In addition, approximately 10% of people with ES/MCS, FM and/or

ME/CFS had household income below \$15,000. High rates of household food insecurity and low income among people with ES/MCS, FM and ME/CFS may be due to reduced employment income or the inability to work altogether. Results from the EHC patient population found that people with the conditions could only work 9.4 hours/week on average, and this was reduced for those with multiple diagnoses⁸. Food insecurity may also be perpetuated by practical challenges for those requiring assistance with grocery shopping and meal preparation not receiving the services they need. The EHC study showed that patients living in areas with higher socioeconomic status had better scores for physical function, bodily pain and general health⁸. This suggests that people with more access to financial resources may be able to afford helpful treatments (such as those with other health professionals), needed home care services (such as groceries and housework), and other health and social services that may not be accessible to those with lower income.

Some limitations of the data include the possibility of underreporting due to lack of awareness on how to diagnose the conditions. Further analyses examining the effects of age, gender and co-morbidities are also needed. Despite these limitations, a consistent pattern in relation to ES/MCS, FM and ME/CFS clearly emerged across a variety of factors related to measures of disability, socioeconomic status, health care utilization and unmet health care needs. There was also consistency in results between the other sources of data included in this report and the population-based CCHS. Collectively the findings show that those living with ES/MCS, FM and/or ME/CFS represent a very large, disabled and disadvantaged cohort, that have specific health care needs that are not being met. Resultant impacts are likely far reaching and significantly affect families/caregivers, communities and society. Given the extent and impact of the conditions, increased surveillance and further research involving longitudinal studies are strongly needed.

1.0 Introduction and Methodology

1.1 INTRODUCTION

The primary source of data included in this report is the Canadian Community Health Survey (CCHS), a population-based cross-sectional survey implemented by Statistics Canada in 2000 with the goal of collecting information on health status, health care utilization and health determinants of Canadians in order to support health surveillance and inform program planning¹.

The objective of this analysis of the CCHS as well as other relevant sources of data was to evaluate a broad range of health-related characteristics in order to provide the reader with an outline of the circumstances surrounding people living with Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS), Fibromyalgia (FM) and/or Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) within a Canadian health care context. Because the target population for the larger project is Ontario, we examined prevalence of the conditions within Ontario more closely. The presentation of this quantitative data is meant to complement the compelling information gathered from personal interviews and focus groups conducted with people living with ES/MCS, FM and/or ME/CFS. Those findings as well as additional research, detailed recommendations for a model of care and service delivery system and broad policy change are contained in the document titled 'Recognition, Inclusion and Equity, the Time is Now: Perspectives of Ontarians Living with ES/MCS, ME/CFS and FM', which is a separate Appendix to the Ontario Centre of Excellence in Environmental Health Business Case.

1.2 METHODOLOGY

The Canadian Community Health Survey (CCHS)

Information on the CCHS is collected from Canadians aged 12 and older living in private dwellings¹. Excluded are: those living on Indian Reserves and on Crown Lands, institutional residents, full-time members of the Canadian Forces and residents of certain remote regions. Data from approximately 98% of Canadians aged 12 and older are captured.

The survey was originally biennial with approximately 130,000 respondents in each cycle. In 2007 it was redesigned to have ongoing annual data collection with approximately 65,000 respondents each year. Three sampling frames are used to select the sample of households chosen for interview. Responses are weighted and Canadian Census information is used to produce population projection counts.

Questionnaires are administered by trained interviewers either in person or on the telephone using computer assisted interviewing. Although participants are self-reporting their conditions, diagnosis by a health professional is stipulated. The question regarding chronic health conditions is asked as follows:

Now I'd like to ask about certain chronic health conditions which you may have.

We are interested in "long-term conditions" which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health professional.

Interviewers then read a list of chronic health conditions and ask:

Do you have ...?

"Chronic Fatigue Syndrome", "Multiple Chemical Sensitivities" and "Fibromyalgia" were three of the chronic conditions initially asked of all participants biennially beginning in 2000/2001. After 2005, the variables were dropped from the survey; they were, however, re-introduced in 2010, but only for a one year collection cycle. The variables are next scheduled for collection in 2014.

For the purposes of this report, we refer to the conditions by their comprehensive names. "Chronic Fatigue Syndrome" is "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)" and "Multiple Chemical Sensitivities" is "Environmental-Sensitivities/Multiple Chemical Sensitivity (ES/MCS)"; "Fibromyalgia (FM)" remains the same. Given that the three conditions are related and that a number of individuals experience one or more, we have evaluated the conditions individually and at times, in combination.

In keeping with our objective to illuminate the various circumstances surrounding people living with these conditions, we examined a number of relevant characteristics, measures of disability, measures of health care utilization and measures of unmet health care needs. For each variable examined, we have provided estimates for the total Canadian population as a reference. In addition we selected four chronic health conditions (cancer, diabetes, effects of a stroke and heart disease) that are well known, disabling and affect a significant proportion of the population as additional comparison groups. Individuals may have any number of chronic health conditions at any one time, and chronic health condition groupings therefore, are not independent.

The questions on ES/MCS, FM and ME/CFS were asked most recently in 2010 and prior to this in 2005; as a result, data from these years are presented in this report. This analysis is based on the Statistics Canada's Canadian Community Health Survey 2010 Public Use Microdata File², the Statistics Canada's Canadian Community Health Survey 3.1 Public Use Microdata File³ and custom tabulations generated by Statistics Canada. All computations, use and interpretation of these data are entirely that of the Myalgic Encephalomyelitis Association of Ontario (MEAO).

When conducting the analysis with the Public Use Microdata Files, the appropriate weight field was applied. Data quality was examined, and any estimates with unweighted counts less than 30 and/or with a Coefficient of Variation (CV) greater than 33.3% have been excluded. 95% confidence intervals were derived using Approximate Sampling Variability Tables provided by Statistics Canada. Design effect is taken into account and the resulting estimates are conservative. The estimates in this report that are from custom tabulations (based on either a data request for this project or from a previous data request

by the National ME/FM Action Network) were generated using the Master File housed at Statistics Canada, which allowed for the generation of exact confidence intervals using bootstrapping techniques. Estimates from this source are noted in the tables.

Surveys are based on a sample of individuals and are naturally associated with sampling variability. The CV provides an indication of the magnitude of this sampling variability as do the confidence intervals. Estimates with large CVs are noted in the tables (E: use with caution).

Previous analyses of ES/MCS, FM and ME/CFS with CCHS data have been conducted. This report drew extensively on the ground-breaking work with CCHS data by Margaret Parlor, Statistical Analyst and President, National ME/FM Action Network^{4,5}. Other studies include an analysis of 2003 CCHS data published by Statistics Canada⁶. Most recently an analysis of 2005 CCHS data examining alternative health care practitioner consultations was published, and we have incorporated some of their findings for those with ES/MCS, FM and ME/CFS⁷.

Other sources of data from Canada and Ontario

Other sources of information included in our descriptive profile of the population living with ES/MCS, FM and/or ME/CFS include studies based on patient populations from the Environmental Health Clinic (EHC) located at Women's College Hospital in Toronto, Ontario⁸, and the Nova Scotia Environmental Health Clinic (NSEHC)⁹, recently renamed Integrated Chronic Care Service.

A large community-based survey of 875 people with ME/CFS was conducted in 1996 in order to evaluate the symptoms and characteristics associated with the condition¹⁰ and we have alluded to these results. In addition, the MEAO conducted a survey in 2011 with 600 respondents from across Canada (and some from the USA) with the conditions¹¹. This survey asked various questions regarding time to diagnosis, number of health professionals seen and encounters with health professionals. Some of these results have also been included.

2.0 THE DATA

2.1.1 Prevalence in Canada and Ontario

In 2010, the number of Canadians with one or more of ES/MCS, FM or ME/CFS surpassed 1.4 million. This figure represents an increase of almost 300,000 cases since 2005 (Table 1). The prevalence of one condition or more increased from 4.2% in 2005 to 4.9% in 2010. Although increases were observed for each of the conditions individually, the rise in the number of cases of ES/MCS from under 600,000 in 2005 to just over 800,000 in 2010 is most notable.

Table 1: Prevalence of ES/MCS, FM and ME/CFS among Canadians aged 12 and older, 2005 and 2010

Condition	No. with Condition 2005	% with Condition (95% CI)	No. with Condition 2010	% with Condition (95% CI)	Percentage increase 2005 to 2010
ES/MCS	598,680	2.2 (2.1, 2.3)	800,560	2.8 (2.6, 3.0)	34%
FM	389,830	1.4 (1.3, 1.5)	438,980	1.5 (1.4, 1.7)	13%
ME/CFS	333,900	1.2 (1.2, 1.3)	411,560	1.4 (1.3, 1.6)	23%
One or more	1,135,420	4.2 (4.0, 4.3)	1,415,150	4.9 (4.6, 5.2)	25%
Target Population in Canada*	27,132,000		28,890,500		6%

CI = Confidence Interval

* Those who answered “don’t know” or who refused to answer the question are excluded from the target population estimate when calculating the % with the condition

Source: Statistics Canada, Canadian Community Health Survey, 2005 and 2010 (master data file)

When examining the number of Canadians reporting a diagnosis of various chronic conditions by a health professional, those with ES/MCS, FM and/or ME/CFS outnumber those living with the effects of a stroke, Alzheimer’s disease and other dementias, Multiple Sclerosis and Parkinson’s disease (Table 2). When the three conditions are combined, they represent an illness burden similar to that of heart disease and greater than that of cancer.

Table 2: Number of Canadians with Chronic Conditions based on their Reported Diagnosis by a Health Professional, 2010

Chronic condition	No. with Condition
Diabetes	1,841,500
Heart disease	1,431,500
One or more ES/MCS, FM, ME/CFS	1,415,000
ES/MCS	800,500
Cancer	553,500
FM	439,000
ME/CFS	411,500
Effects of a stroke	312,500
Alzheimer's or other dementia	111,500
Multiple Sclerosis	108,500
Parkinson's disease	39,000

These numbers do not include those living in institutions

Numbers have been rounded

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

The prevalence of the conditions by age groups reveals that for ES/MCS and FM, the prevalence peaks at age 45 (3.9% and 2.5%, respectively), while for ME/CFS the prevalence peaks at age 65 and older (2.2%) (Table 3). For FM, there is even a slight decrease in the prevalence in those aged 65 and older. Prevalence is higher in women for all three conditions. Among those with FM, women had four times the prevalence of men (2.4% vs. 0.6%).

Table 3: Prevalence of ES/MCS, FM and ME/CFS according to Age and Gender, Canada, 2010

Condition	% with Condition	95% Confidence Interval
ES/MCS		
Age 12-24	1.1	(0.8, 1.4)
Age 25-44	2.1	(1.7, 2.5)
Age 45-64	3.9	(3.4, 4.4)
Age 65+	3.9	(3.4, 4.4)
FM		
Age 12-24	0.1 ^E	(0.1, 0.2)
Age 25-44	1.0	(0.7, 1.3)
Age 45-64	2.5	(2.1, 2.9)

Age 65+	2.2	(1.9, 2.5)
ME/CFS		
Age 12-24	0.4 ^E	(0.3, 0.6)
Age 25-44	1.1	(0.9, 1.4)
Age 45-64	1.9	(1.6, 2.2)
Age 65+	2.2	(1.9, 2.5)
ES/MCS		
Male	1.6	(1.3, 1.8)
Female	4.0	(3.6, 4.3)
FM		
Male	0.6 ^E	(0.4, 0.9)
Female	2.4	(2.1, 2.6)
ME/CFS		
Male	1.0	(0.8, 1.1)
Female	1.9	(1.6, 2.1)

^E Use with caution (CV between 16.6 and 33.3)

Source: Statistics Canada, Canadian Community Health Survey 2010 (master data file)

An examination of the age distribution for those with ES/MCS, FM and/or ME/CFS demonstrates that the majority of those affected are aged 45-64 (Table 4). Younger people (aged 12-24) are also affected, in particular with ES/MCS (8%) and ME/CFS (6%). The age distribution is similar for all three conditions. The gender distributions show that by far, the majority of those living with these conditions are women; the range varies from 66% of those with ME/CFS to 79% of those with FM.

Table 4: Age and Gender Distributions of Canadian Population aged 12 and older with ES/MCS, FM and/or ME/CFS, 2010

Condition	AGE (%)			
	Age 12-24	Age 25-44	Age 45-64	Age 65+
ES/MCS	8	24	46	22
FM	2 ^E	22	54	23
ME/CFS	6 ^E	25	45	24

Condition	GENDER (%)	
	Male	Female
ES/MCS	28	72
FM	21 ^E	79
ME/CFS	34	66

^E Use with caution (CV between 16.6 and 33.3)

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

A breakdown of the number of cases in Ontario shows that the 2010 prevalence of one condition or more is 5.0% (Table 5), similar to the national value of 4.9% reported in Table 1. There were only slight variations in the prevalence estimates of the individual conditions when compared to the national values. The greatest number of cases was observed for ES/MCS (n=292,660 in 2010), which is consistent with the results for Canada. The growth in one or more of the conditions from 2005 was also similar between Ontario and Canada, but slightly greater growth was observed for ME/CFS and for FM in particular, in Ontario.

Table 5: Prevalence of ES/MCS, FM and ME/CFS among Ontarians aged 12 and older, 2005 and 2010

Condition	No. with Condition 2005	% with Condition (95% CI)	No. with Condition 2010	% with Condition (95% CI)	Percentage increase 2005 to 2010
ES/MCS	217,920	2.1 (1.9, 2.3)	292,660	2.6 (2.2, 3.0)	34%
FM	161,300	1.5 (1.4, 1.7)	196,800	1.8 (1.4, 2.1)	22%
ME/CFS	137,870	1.3 (1.2, 1.5)	181,110	1.6 (1.4, 1.9)	31%
One or more	439,230	4.2 (3.9, 4.4)	568,120	5.0 (4.5, 5.6)	29%
Target Population in Ontario*	10,570,000		11,260,000		7%

CI = Confidence Interval

* Those who answered “don’t know” or who refused to answer the question are excluded from the target population estimate when calculating the % with the condition

Source: Statistics Canada, Canadian Community Health Survey, 2005 and 2010 (master data file)

Summary:

The number of Canadians and Ontarians affected with ES/MCS, FM and/or ME/CFS is staggering, and a comparison with the number of cases of other well-known chronic diseases indicates that these conditions are by no means rare. While many chronic disabling conditions are known to be associated with increasing age (e.g., cancer, heart disease and stroke), ES/MCS, FM and ME/CFS are, in contrast, most common among the middle aged. They are most likely to occur during a time in people’s lives when they have the potential to be highly productive, employable and contribute to the economy and society. Although the CCHS does not collect information on children below age 12, cases of ES/MCS, FM and ME/CFS also occur among younger children, and the conditions thus have the potential to impact people’s lives from a very early age. The data also clearly highlight that the majority of people with the conditions are women, a finding that has further implications regarding issues of parenting, family cohesiveness, poverty and respect from health care professionals, among others.

To our knowledge, comprehensive national and provincial statistics on all three conditions do not exist prior to the implementation of the CCHS in 2000. To date, information has been collected on four regular CCHS cycles, but these are prevalence estimates based on cross-sectional data. Given the large number of people affected and evidence of an increase in the number of cases, longitudinal studies and active surveillance as with other major chronic diseases are warranted to determine the incidence rates and facilitate research, prevention and control.

2.1.2 Prevalence by Ontario Local Health Integration Network (LHIN)

The prevalence of one condition or more was highest in the South East (6.8%), Champlain (6.7%) and North Simcoe Muskoka (6.7%) LHINs, and was lowest for the Toronto Central (3.2%) and Central East LHINs (4.0%) (Table 6). The data should be interpreted with caution as the Coefficients of Variation are large and some of the variation is likely due to sampling. This is particularly true when examining ES/MCS, FM and ME/CFS individually where the sample sizes are smaller. Nonetheless, the pattern observed for prevalence of the individual conditions by Ontario LHIN did remain consistent with that seen for having one or more of the conditions overall: the South East, Champlain and North Simcoe Muskoka LHINs had consistently higher rates, while the Toronto Central and Central East LHINs had consistently lower rates.

Table 6: Prevalence of ES/MCS, FM and ME/CFS by Ontario Local Health Integration Network, 2010

Local Health Integration Network	Target Population*	Condition	No. with Condition	% with Condition	95% Confidence Interval
Erie St. Clair	545,500	FM	9,500 ^E	1.7 ^E	(1.1, 2.4) ^E
		ME/CFS	10,100 ^E	1.9 ^E	(0.9, 2.8) ^E
		ES/MCS	10,900 ^E	2.0 ^E	(1.3, 2.8) ^E
		One or more	27,200	5.0	(3.7, 6.3)
South West	813,000	FM	17,500 ^E	2.2 ^E	(1.4, 3.0) ^E
		ME/CFS	12,700 ^E	1.6 ^E	(0.9, 2.3) ^E
		ES/MCS	19,900	2.5	(1.7, 3.2)
		One or more	42,900	5.3	(4.1, 6.5)
Waterloo Wellington	635,000	FM	6,100 ^E	1.0 ^E	(0.4, 1.5) ^E
		ME/CFS	6,100 ^E	1.0 ^E	(0.4, 1.5) ^E
		ES/MCS	17,500 ^E	2.8 ^E	(1.6, 3.9) ^E
		One or more	27,100 ^E	4.3 ^E	(2.9, 5.7) ^E
Hamilton Niagara Haldimand Brant	1,198,500	FM	21,800 ^E	1.8 ^E	(1.1, 2.6) ^E
		ME/CFS	21,200 ^E	1.8 ^E	(0.8, 2.7) ^E
		ES/MCS	27,200 ^E	2.3 ^E	(1.5, 3.1) ^E
		One or more	59,100	4.9	(3.6, 6.3)
Central West	713,000	FM	F	F	F
		ME/CFS	15,700 ^E	2.2 ^E	(0.9, 3.6) ^E
		ES/MCS	25,300 ^E	3.6 ^E	(1.51, 5.6) ^E
		One or more	34,800 ^E	4.9 ^E	(2.7, 7.1) ^E

Mississauga Halton	978,000	FM	F		F		F
		ME/CFS	F		F		F
		ES/MCS	F		F		F
		One or more	57,500	^E	5.9	^E	(2.8, 8.9)
Toronto Central	1,023,500	FM	F		F		F
		ME/CFS	10,500	^E	1.0	^E	(0.4, 1.7)
		ES/MCS	16,100	^E	1.6	^E	(0.8, 2.4)
		One or more	32,600	^E	3.2	^E	(2.0, 4.4)
Central	1,489,000	FM	F		F		F
		ME/CFS	20,200	^E	1.4	^E	(0.5, 2.2)
		ES/MCS	26,900	^E	1.8	^E	(0.9, 2.7)
		One or more	69,200	^E	4.7	^E	(2.8, 6.5)
Central East	1,341,500	FM	18,900	^E	1.4	^E	(0.8, 2.0)
		ME/CFS	17,400	^E	1.3	^E	(0.6, 2.0)
		ES/MCS	23,600	^E	1.8	^E	(1.0, 2.6)
		One or more	54,200		4.0		(2.8, 5.3)
South East	415,500	FM	8,800	^E	2.1	^E	(1.2, 3.1)
		ME/CFS	F		F		F
		ES/MCS	17,300	^E	4.2	^E	(2.5, 5.9)
		One or more	28,400		6.8		(4.9, 8.8)
Champlain	1,058,500	FM	30,200	^E	2.9	^E	(1.3, 4.4)
		ME/CFS	26,100	^E	2.5	^E	(1.4, 3.5)
		ES/MCS	38,400	^E	3.6	^E	(2.2, 5.1)
		One or more	71,300		6.7		(4.8, 8.6)
North Simcoe Muskoka	388,500	FM	8,100	^E	2.1	^E	(0.7, 3.4)
		ME/CFS	11,000	^E	2.8	^E	(1.3, 4.4)
		ES/MCS	13,600	^E	3.5	^E	(1.8, 5.2)
		One or more	25,900	^E	6.7	^E	(4.4, 8.9)
North East	476,000	FM	8,600	^E	1.8	^E	(1.1, 2.5)
		ME/CFS	10,200	^E	2.2	^E	(1.3, 3.0)
		ES/MCS	14,000	^E	2.9	^E	(1.9, 4.0)
		One or more	28,200		5.9		(4.6, 7.3)
North West	184,500	FM	3,800	^E	2.1	^E	(1.1, 3.1)
		ME/CFS	3,400	^E	1.9	^E	(0.9, 2.8)
		ES/MCS	5,300	^E	2.9	^E	(1.6, 4.2)

One or more 9,800 5.3 (3.7, 7.0)

^E Use with caution (CV between 16.6 and 33.3)

F Too unreliable to be published

* Those who answered “don’t know” or who refused to answer the question are excluded from the target population estimate when calculating the % with the condition

Number with the conditions rounded to nearest 100

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

Summary:

Although the interpretation of these regional data are cautioned, there are patterns that have emerged, which suggest factors involved other than sampling variability. The full explanation for these results, however, is not yet clear.

There may be clustering of cases in regions due to differences in awareness, acceptance and diagnostic practices of the conditions by health care practitioners. For example, the Ottawa Environmental Health Clinic and the presence of several other physicians who specifically assess and treat the conditions, located in the Champlain LHIN (and bordering with the South East LHIN), have large catchment areas, and may account for a large number of diagnoses as well as contribute to a culture of medical understanding and acceptance in the region. But this does not account for large prevalence in North Simcoe Muskoka, or the pattern of lower prevalence of the conditions in the Toronto Central and Central East LHINs. The lower overall prevalence in the Toronto Central and Central East LHINs may also slightly lower the provincial average of 5.0% due to their large sizes.

There may also be true differences in the underlying incidence of the conditions by region. For example, tick-borne illnesses such as Lyme Disease are known to be associated with chronic fatigue and pain, and there may be variation in infection rates around the province. In addition, certain regions may have higher rates of pollution contributing to higher rates of ES/MCS. The North West is known for widespread forest pesticide spraying and mercury poisoning; pesticide use is higher in agricultural regions; and, pollution and smog are most problematic along Lakes Erie and Ontario. At the same time, a number of these regions do not have specialists known for diagnosing and treating the conditions, and true occurrence of the conditions may be underreported. Discerning differences by region is challenging with the available data due to the unknown extent of the regional variation in diagnostic practices.

2.2 Profile of Level of Impairment

Being permanently unable to work is a well-known measure indicating level of disability. Those with chronic conditions in general experience higher levels of being permanently unable to work than the total population (Table 7). Although there are overlaps among the chronic conditions groupings, when evaluating the proportion of Canadians permanently unable to work according to their chronic health condition, the results are telling. Canadians with ME/CFS in particular experience high levels of being permanently unable to work (24.0%), which is similar to the finding for those living with the effects of a stroke (23.6%). Those with FM also have a high rate and followed closely behind (20.6%). Further, those with ES/MCS have a similar level to those with cancer and diabetes.

Table 7: Canadian Population who are Permanently Unable to Work According to their Chronic Health Condition, 2010

Chronic Condition	% Permanently Unable to Work	95% Confidence Intervals
ME/CFS	24.0	(19.1, 28.8)
Effects of a stroke [§]	23.6	(19.3, 27.9)
FM	20.6	(16.0, 25.3)
Heart disease [§]	12.0	(10.0, 14.0)
Cancer [§]	9.8	(7.6, 12.0)
ES/MCS	9.7	(7.8, 11.7)
Diabetes [§]	9.1	(8.1, 10.1)
Total population [§]	2.7	(2.5, 2.9)

Ages 15-75 included in this table

§ Includes 2009 and 2010 data

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

Needing help with activities of daily living is a routine measure of functional status and extent of disability. An overall summary measure for needing help with tasks indicates that those living with the effects of a stroke (51.9%) and those with ME/CFS (47.2%), followed by those with FM (37.7%) require very high levels of assistance with activities of daily living (Table 8). Those with ES/MCS require a similar level of assistance as those with cancer and diabetes, and the rates are greater than those for the total population.

For individual tasks of daily living such as needing help with housework, preparing meals and running errands, the proportions of people living with the effects of a stroke and with ME/CFS that require assistance consistently remained the highest. Housework is cited most often as the task people with chronic conditions including ES/MCS, FM and ME/CFS need help with.

Table 8: Canadian Population who Need Help with Activities of Daily Living According to their Chronic Health Condition, 2010

Activities of Daily Living	% who need help with tasks	95% Confidence Intervals
Needing Help with Tasks		
Effects of a stroke [§]	51.9	(48.5, 55.3)
ME/CFS	47.2	(41.9, 52.4)
FM	37.7	(32.7, 42.7)
Heart disease [§]	29.6	(27.9, 31.4)
Cancer [§]	27.5	(24.9, 30.1)
ES/MCS	24.0	(20.9, 27.1)
Diabetes [§]	22.7	(21.3, 24.1)
Total population [§]	8.9	(8.6, 9.1)
Tasks Need Help With		
Housework		
Effects of a Stroke	41.3	(36.6, 46.0)
ME/CFS	39.3	(34.2, 44.3)
FM	31.4	(26.6, 36.3)
Cancer	24.1	(20.3, 27.9)
Heart Disease	24.1	(21.3, 26.8)
ES/MCS	19.0	(16.1, 21.9)
Diabetes	17.1	(15.4, 18.9)
Total Population	6.6	(6.3, 6.9)
Meals		
Effects of a Stroke	27.0	(22.8, 31.2)
ME/CFS	20.8	(16.5, 25.2)
Cancer	14.2	(11.2, 17.3)
FM	13.0	(9.6, 16.4)
Heart Disease	12.4	(10.0, 14.7)
ES/MCS	9.9	(7.5, 12.3)
Diabetes	9.3	(7.7, 10.9)
Total Population	3.5	(3.2, 3.7)
Getting to Appointments/Errands		
Effects of a Stroke	45.3	(40.3, 50.2)
ME/CFS	34.0	(29.1, 38.9)

FM	22.9	(19.2, 26.6)
Heart Disease	21.1	(18.9, 23.3)
Cancer	20.2	(16.6, 23.7)
ES/MCS	16.8	(14.1, 19.4)
Diabetes	16.4	(14.7, 18.2)
Total Population	6.0	(5.7, 6.3)
Personal Care		
Effects Stroke	21.6	(17.5, 25.6)
ME/CFS	11.9	(8.9, 14.9)
Cancer	9.7	(7.2, 12.1)
Heart Disease	8.0	(6.7, 9.4)
FM	6.3 ^E	(3.9, 8.7)
Diabetes	6.2	(5.0, 7.4)
ES/MCS	4.9	(3.7, 6.1)
Total Population	2.2	(2.1, 2.4)
Moving About Inside the House		
Effects Stroke	13.6	(10.2, 16.9)
ME/CFS	10.2	(7.4, 12.9)
FM	6.8 ^E	(4.4, 9.2)
Cancer	5.6 ^E	(3.7, 7.5)
Heart Disease	5.3	(4.1, 6.5)
ES/MCS	4.7	(3.5, 5.9)
Diabetes	4.5	(3.3, 5.7)
Total Population	1.6	(1.4, 1.7)
Looking After Personal Finances		
Effects Stroke	29.3	(24.7, 34.1)
ME/CFS	19.7	(15.4, 24.0)
Cancer	12.4	(9.0, 15.7)
Heart Disease	11.7	(9.4, 14.0)
Diabetes	8.7	(7.3, 10.1)
FM	8.6	(6.5, 10.8)
ES/MCS	7.7	(5.5, 9.8)
Total Population	3.4	(3.2, 3.7)

^E Use with caution (CV between 16.6 and 33.3)

§ Includes 2009 and 2010 data

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

An analysis with 2003 CCHS data by Park and Knudson (2007)⁶ also found high percentages of people with ES/MCS, FM and/or ME/CFS needing help with activities of daily living. For instrumental activities of daily living (defined as housework, preparing meals and getting to appointments/errands), those with ME/CFS (43%), FM (37%) and ES/MCS (22%) had significantly higher rates ($p < 0.05$) than those in the general population without the conditions (7%). Similarly for other activities of daily living (such as personal care and moving about inside the house), those with ME/CFS (15%), FM (11%) and ES/MCS (6%) had significantly higher rates ($p < 0.05$) than those without the conditions (2%). They further adjusted for socio-demographic factors and found the associations remained statistically significant.

Specific indicators of severe functional impairment based on cognition, mobility and pain for people with the three conditions are listed in Table 9. The sample sizes for cognition and mobility estimates are small and should be interpreted with caution, but the pattern indicates that a sizeable proportion of people with the conditions have severe cognitive or mobility issues. Pain prevents most activities in over one quarter of people with ME/CFS. The proportions are lower for FM (21.4%) and ES/MCS (10.1%), but are still substantive.

Table 9: Indicators of Functional Impairment among Canadians with ES/MCS, FM and/or ME/CFS, 2010

Functional Impairment	% with Impairment	95% Confidence Intervals
Cognition Health Status		
Very forgetful or a great deal of difficulty thinking		
ES/MCS	5.6 ^E	(3.5, 7.7)
FM	8.5 ^E	(5.1, 11.9)
ME/CFS	11.1 ^E	(7.3, 14.9)
Mobility Trouble		
Requires mechanical support or wheelchair		
ES/MCS	6.0 ^E	(3.4, 8.1)
FM	9.2 ^E	(5.5, 12.9)
ME/CFS	9.9 ^E	(6.2, 13.6)
Requires help from people or cannot walk		
ES/MCS	2.9 ^E	(1.4, 4.4)
FM	4.9 ^E	(2.3, 7.5)
ME/CFS	8.0 ^E	(4.5, 11.4)
Pain		
Prevents some activities		
ES/MCS	14.9	(11.4, 18.3)
FM	23.0	(18.0, 28.0)
ME/CFS	18.2	(13.4, 23.1)

Prevents most activities		
ES/MCS	10.1	(7.5, 12.7)
FM	21.4	(16.5, 26.3)
ME/CFS	26.2	(20.7, 31.8)

^E Use with caution (CV between 16.6 and 33.3)

Source: Statistics Canada, Canadian Community Health Survey, 2010 (public use microdata file)

Summary:

Overall these results indicate that people with ES/MCS, FM and/or ME/CFS are at least as disabled and in some cases more disabled than people with other well-known chronic conditions. The findings that the levels of impairment for certain disability measures in people affected with ME/CFS are akin to or approach those for people living with the effects of a stroke are most notable. It is important to note that several chronic conditions such as stroke and cancer are commonly associated with older age, which is also a time when needing help for tasks increases. People with ES/MCS, FM and/or ME/CFS are on average middle-aged and yet, still require high rates of assistance with activities of daily living.

The levels of disability among people with ES/MCS, FM and/or ME/CFS are also substantially elevated in comparison to the general population. Despite slight differences in groupings of activities of daily living, a similar range in proportions of those requiring assistance were found between the previous analysis conducted with the 2003 CCHS⁶ and the present analysis with more recent 2010 data. This demonstrates the consistency in findings from different samples over time. The additional analysis with adjustment for socio-demographic factors in the 2003 study further strengthens the findings.

Much of the functional impairment among people with ES/MCS, FM and ME/CFS can be due to severe fatigue, sleep dysfunction, chronic headaches, neurological and neuro-muscular manifestations, plus a host of other multi-system symptoms that are not captured in the available measures of disability. This may be particularly true for ES/MCS, where serious reactions to symptom triggers are not captured in the questions. Such exposures can sometimes render individuals incapacitated for days or weeks at a time, or even provoke deterioration into a more severe state of the condition. Lack of relevant information makes it difficult to understand the needs of people with these conditions and can serve to understate the extent of the problem.

The high levels of those permanently unable to work likely reflect significant impairment experienced by people with chronic conditions; but could also reflect less than adequate workplace accommodations which may prevent some from participating in the workforce.

2.3 Demographics and Functional impairment: Results from the Environmental Health Clinic, Toronto, Ontario, 2005-2006

Data from a chart review of 128 patients attending the Environmental Health Clinic (EHC) in Toronto, Ontario between January 2005 and March 2006 were analyzed for demographic factors and functional status based on the Short Form (SF)-36⁸. Patients were on average 44.6 years of age and mostly female (86.7%). The majority had stopped work (68.0%), and the average number of years between symptom onset and discontinuing work due to their health was three years. A breakdown of diagnoses of these patients in comparison to the breakdown in the Canadian population is shown in Table 10. These results indicate that the EHC is more likely to assess patients with multiple diagnoses and in particular, those diagnosed with both FM and ME/CFS.

Table 10: Diagnoses of the EHC Patient Population, 2005-2006

Chronic Condition	EHC* N (%)	Canadian Population** N (%)
ES/MCS only	41 (32.0)	659,000 (46.6)
FM only	11 (8.6)	298,300 (21.1)
ME/CFS only	26 (20.3)	247,200 (17.5)
ES/MCS, FM	4 (3.1)	46,300 ^E (3.3)
ES/MCS, ME/CFS	8 (6.3)	70,000 (4.9)
FM, ME/CFS	27 (21.1)	69,100 (4.9)
ES/MCS, FM, ME/CFS	11 (8.6)	25,300 (1.8)
≥ 2 diagnoses	50 (39.1)	210,700 (14.9)

^E Use with caution (CV between 16.6 and 33.3)

*Source: Lavergne MR et al. (2010)⁸.

**Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

The EHC patient population was found to have lower scores for functional status according to the eight SF-36 subscales (bodily pain, energy and fatigue, emotional well-being, general health perceptions, physical functioning, emotional role limitations, physical role limitations and social functioning) than the average scores of Canadians with comparable age and sex⁸. This was particularly true when patients had multiple diagnoses. In multivariate regression analysis, FM was found to be significantly associated with poorer functional status on the majority of SF-36 subscales, while ME/CFS was significantly associated with lower physical functioning and emotional wellbeing.

Summary:

The EHC in Toronto, Ontario is the only government-funded clinic assessing patients with ES/MCS, FM and ME/CFS in the province. Those patients referred to the EHC may be more likely to have greater severity of symptoms and prolonged duration of illness. This notion is supported by the finding of a greater proportion of patients diagnosed with one or more of the conditions, which are known to be more severe cases, than in the general Canadian population. The general pattern of middle aged, mostly female cases with a high proportion that are unable to work and have high levels of functional impairment are consistent with findings observed on the CCHS.

2.4 Profile of Health Care Utilization

In 2010, the majority of Canadians (77.3%) consulted with their family doctor/GP within the previous 12 months (Table 11). People with chronic conditions were more likely to have consulted with their family doctor than the general population, but there was not much variation according to health condition.

When examining the proportions of people consulting their family doctor/GP 10 or more times, among those who had a consultation, people with chronic conditions had more consultations than the general population, and more variation according to health condition was evident. Those with ME/CFS, FM, living with the effects of a stroke and ES/MCS had the greatest proportions (>20%) having 10 or more consultations with a family doctor/GP.

People with chronic conditions were more likely to have consulted with a specialist or other physician than the general population, and among the chronic conditions, those with cancer were most likely to have had a consultation (72.8%). Those with ME/CFS (30.4%), FM (29.5%) and cancer (29.1%) had the greatest rates having 5 or more specialist/other physician consults (among those who had a consultation), while those with ES/MCS (21.3%) had a similar proportion to those living with the effects of a stroke (22.3%).

Table 11: Consultations with Medical Doctors in the Previous 12 Months among Canadians according to their Chronic Health Condition, 2010

Consultation with Medical Doctor	% with Consultation	95% Confidence Intervals
Consulted with Family Doctor/GP		
Heart Disease	93.5	(92.2, 94.8)
FM	93.0	(90.5, 95.6)
Cancer	93.0	(90.8, 95.1)
Effects of a Stroke	92.8	(90.1, 95.5)
Diabetes	92.1	(90.4, 93.8)
ME/CFS	91.9	(89.4, 94.3)
ES/MCS	89.2	(86.8, 91.6)
Total Population	77.3	(76.8, 77.8)
10+ Consultations with Family Doctor/GP		
ME/CFS	28.7	(24.2, 33.2)
FM	27.5	(22.1, 32.9)
Effects of a Stroke	24.1	(19.4, 28.7)
ES/MCS	20.5	(16.6, 24.3)
Cancer	18.7	(15.4, 21.9)
Heart Disease	17.5	(15.5, 19.6)
Diabetes	15.6	(13.8, 17.5)

Total Population	8.3	(7.9, 8.7)
Consulted with a Specialist/Other Doctor		
Cancer	72.8	(69.0, 76.6)
Heart Disease	57.3	(54.7, 60.0)
ME/CFS	57.0	(52.1, 61.9)
FM	52.0	(46.5, 57.5)
Effects of a Stroke	49.4	(44.4, 54.4)
ES/MCS	47.1	(43.0, 51.2)
Diabetes	45.8	(43.2, 48.3)
Total Population	30.3	(29.7, 31.0)
5+ Consultations with a Specialist/Other Doctor		
ME/CFS	30.4	(24.1, 36.6)
FM	29.5	(22.3, 36.8)
Cancer	29.1	(24.7, 33.6)
Effects of a Stroke	22.3	(15.3, 29.2)
ES/MCS	21.3	(16.2, 26.3)
Diabetes	16.8	(14.3, 19.3)
Heart Disease	16.6	(14.0, 19.2)
Total Population	16.1	(15.2, 17.0)

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

The previous analysis with 2003 CCHS data also noted high rates of medical consultations. Specifically, 33% of those with ME/CFS, 29% of those with FM and 17% of those with ES/MCS consulted their family doctor/GP 10 or more times within the previous 12 months⁶. This was in comparison with 11% of those with other chronic conditions (consisting of a mixed group of 15 other diseases including the four comparators in this report as well as additional conditions such as asthma, back problems and high blood pressure), and with 7% of those in the general population without the conditions. Those with ME/CFS (53%), FM (47%) and ES/MCS (43%) were also more likely to have consulted with a specialist versus those with other chronic conditions (33%) and those without the conditions (26%). The differences in rates of consultations between those with ES/MCS, FM and/or ME/CFS and the comparison groups were statistically significant ($p < 0.05$).

For patients of the Environmental Health Clinic, the mean number of visits to family physicians in the previous 12 months was 10.7, while for other physicians (including specialists) it was 13.7. This is in comparison to 2.9 and 0.79 for the general population, respectively (Table 12). Multivariate regression analysis found that higher numbers of visits to family physicians was significantly associated with lower scores on general health, while higher numbers of visits to other physicians was associated with lower scores on physical function⁸.

Table 12: Mean Number of Visits to Medical Doctors in the Previous 12 Months by Patients of the Environmental Health Clinic (EHC) in Toronto, Ontario, 2005-2006

Study Population	Mean no. of visits in previous 12 months	Standard Deviation
Environmental Health Clinic Patient Population		
Family physicians	10.7	8.7
Other physicians	13.7	18.2
Canadian Population		
Adults aged 30-64		
Family physicians	2.9	4.3
Other physicians	0.79	2.0
Women aged 30-64		
Family physicians	3.4	4.6
Other physicians	0.98	2.2

Source: Adapted from Lavergne MR et al. (2010)⁸

A community-based survey of 875 people with ME/CFS in Ontario conducted in 1996 reported extensive use of hospitals, medical specialists, medical and alternative therapies and emotional counselling¹⁰. Because this study did not report the exact numbers found on the survey, they cannot be included, but the overall finding is consistent with those reported from other sources.

An unpublished survey of over 600 respondents conducted by the MEAO¹¹ found that for the majority of people, several years elapsed before they received a diagnosis of ES/MCS, FM and/or ME/CFS (Table 13). For greater than 50% of the respondents, it took four or more years for a diagnosis to be reached, and for an astounding 19.0%, the time to diagnosis was greater than 10 years. Further to this, the vast majority of people (76.6%) visited three or more physicians prior to receiving their diagnosis, with 12.4% requiring visits to 10 or more physicians.

Table 13: Health Care Utilization Related Variables from a Survey by the Myalgic Encephalomyelitis Association of Ontario (MEAO), 2011

Health Care Utilization Related Variables from MEAO Survey	Total Sample No. (%)
Time to diagnosis (years)	
≤ 1	127 (21.2)
2-3	167 (27.9)
4-5	91 (15.2)
6-10	100 (16.7)
>10	114 (19.0)
No. of doctors seen prior to diagnosis	
1-2	141 (23.4)
3-4	191 (31.7)
5-6	119 (19.7)
7-9	77 (12.8)
10+	75 (12.4)

Source: Myalgic Encephalomyelitis Association of Ontario (2011)¹¹

The Nova Scotia Environmental Health Centre (NSEHC) uses a multidisciplinary holistic approach of care to treat those with ES/MCS. Data from a prospective cohort study (with three cohorts enrolled in 1998, 1999 and 2000) conducted at the NSEHC showed a decrease in physician visits after consultation at the clinic⁹. The overall yearly decline from the year prior to initial consultation until end of follow-up in 2002 ranged from 8.0%-10.6% for the three cohorts (Table 14), and the decline in mean physician visits per person per year dropped close to the provincial average in 2000. A decrease in the mean number of physician visits was found for all levels of symptom severity, but was greatest among those with the highest severity scores (31% for the 1998 cohort). These decreases in health care utilization were naturally associated with decreases in health care costs.

Table 14: Percentage Decline in Physician Visits by Patients with ES/MCS Following Consultation at the Nova Scotia Environmental Health Centre

Year of initial consultation at the NSEHC	Yearly decline in physician visits between 12 months prior to initial consultation and 2002
1998 Cohort	9.1%
1999 Cohort	8.0%
2000 Cohort	10.6%
Nova Scotia Population	1.3%

Source: Adapted from Fox et al. (2007)⁹

People with ES/MCS, FM and/or ME/CFS consistently demonstrated the greatest proportions having a consultation with other health professionals (Table 15). The pattern indicates that a greater proportion of those with FM tended to have consultations with chiropractors, physiotherapists and massage therapists. Consultation rates with acupuncturists and homeopaths or naturopaths were lower overall than for the other health professionals.

Table 15: Consultations with Health Professionals in the Previous 12 Months among Canadians according to their Chronic Health Condition, 2010

Consultation with Health Professional	% with Consultation	95% Confidence Intervals
Consulted with Chiropractor		
FM	18.3	(13.7, 22.8)
ME/CFS	15.4	(11.2, 19.6)
ES/MCS	14.3	(11.8, 16.8)
Total Population	11.5	(11.0, 11.9)
Diabetes	9.8	(8.4, 11.2)
Cancer	9.2	(6.3, 12.0)
Heart Disease	8.9	(7.3, 10.4)
Effects of a Stroke	6.3 ^E	(3.9, 8.6)
Consulted with Physiotherapist		
FM	19.4	(15.5, 23.4)
ES/MCS	15.5	(12.5, 18.5)
ME/CFS	15.1	(11.2, 19.0)
Effects of a Stroke	12.8	(9.5, 16.1)
Cancer	12.0	(9.2, 14.8)
Heart Disease	10.4	(8.9, 11.9)
Diabetes	10.1	(8.6, 11.6)
Total Population	9.9	(9.5, 10.3)
Consulted with Psychologist		
ME/CFS	13.6	(9.7, 17.4)
FM	8.9 ^E	(4.7, 13.1)
ES/MCS	8.3	(5.9, 10.7)
Effects of a Stroke	5.2 ^E	(2.5, 7.9)
Heart Disease	3.8	(2.6, 5.1)
Total Population	3.8	(3.5, 4.1)
Cancer	3.6 ^E	(2.1, 5.1)
Diabetes	2.5	(1.8, 3.1)

Consulted with Social Worker or Counsellor

ME/CFS	12.8	(9.7, 15.8)
ES/MCS	11.2	(8.8, 13.6)
Effects of a Stroke	11.2	(7.9, 14.6)
FM	9.2	(6.8, 11.6)
Cancer	8.0	(5.7, 10.3)
Diabetes	5.7	(4.7, 6.8)
Heart Disease	5.4	(4.3, 6.5)
Total Population	4.9	(4.6, 5.1)

Consulted with an Alternative Care Provider*[§]

FM	28.3	(24.8, 31.8)
ES/MCS	27.4	(24.6, 30.2)
ME/CFS	24.1	(20.6, 27.6)
Total Population	13.7	(13.4, 14.0)
Cancer	12.3	(9.8, 14.8)
Effects of a Stroke	9.1	(6.5, 11.6)
Diabetes	8.5	(7.3, 9.7)
Heart Disease	8.1	(7.0, 9.3)

Consulted with Massage Therapist*

FM	17.3	(14.4, 20.1)
ES/MCS	15.2	(13.1, 17.3)
ME/CFS	12.6	(9.9, 15.4)
Total Population	9.0	(8.7, 9.2)
Cancer	5.3	(3.6, 7.1)
Effects of a Stroke	5.3 ^E	(3.4, 7.3)
Diabetes	4.2	(3.4, 5.0)
Heart Disease	4.2	(3.3, 5.0)

Consulted with Acupuncturist*

ES/MCS	6.3	(4.8, 7.7)
FM	5.8	(4.1, 7.6)
ME/CFS	5.1 ^E	(3.3, 6.8)
Cancer	3.6 ^E	(2.2, 5.0)
Effects of a Stroke	3.3 ^E	(1.7, 4.9)
Total Population	2.5	(2.4, 2.7)
Diabetes	2.4	(1.8, 3.1)
Heart Disease	2.3	(1.6, 3.0)

Consulted with Homeopath or Naturopath*

FM	7.9	(5.8, 9.9)
----	-----	------------

ES/MCS	7.8	(6.2, 9.5)
ME/CFS	7.1	(5.0, 9.1)
Cancer	2.4 ^E	(1.3, 3.6)
Total Population	2.4	(2.2, 2.5)
Diabetes	1.6	(1.1, 2.2)
Heart Disease	1.5	(1.0, 2.0)
Effects of a Stroke	F	

^E Use with caution (CV between 16.6 and 33.3)

F Too unreliable to be published

*These questions were no longer asked in 2010; data are from 2005

§Includes: Massage Therapist, Acupuncturist, Homeopath or Naturopath

Source: Statistics Canada, Canadian Community Health Survey, 2005 (public use microdata file) and 2010 (master data file)

Summary:

The high number of consultations with physicians (both family doctor/GP and specialists) as found with the CCHS and EHC populations may reflect the complexity of ES/MCS, FM and ME/CFS, as well as their associated co-morbidities. Family physician visits are sometimes restricted to one reason per visit, and therefore people with complex chronic conditions may require numerous follow ups. These conditions also affect multiple systems, and as a result, patients may be referred to several specialists. The results suggest that people with ES/MCS, FM and ME/CFS require medical support, but might not be receiving appropriate care for their conditions. The long times to diagnosis and large number of physicians visited prior to diagnosis found on the MEAO survey are suggestive of the lack of awareness and knowledge in diagnosing the conditions, and may also indicate that people with ES/MCS, FM and ME/CFS are, in fact, receiving ineffective care. High utilization will result in increased health care costs. The 1996 community-based survey conducted among Ontarians with ME/CFS concluded that due to ‘the extensive use of all medical services, CFS is a substantial drain on our health care system with little, if any, benefit in return for such costs’¹⁰.

In contrast, the results from the NSEHC for ES/MCS are indicative of the effect that a multidisciplinary holistic approach can have in reducing health care utilization rates. The observed decreases in health care utilization directly translated into decreases in health care costs as documented in the study. The NSEHC has been in operation nearly twenty years, is well-known in the province and is well-integrated into the health care system.

The high number of consultations with other health professionals among those with ES/MCS, FM and ME/CFS suggests that people with the conditions are looking for effective care and therapies outside of the conventional medical profession. The higher consultations with chiropractors, physiotherapists and massage therapists among those with FM are consistent with a condition of widespread pain. The fact that the majority of the costs for other health professionals are out-of-pocket suggests that the

motivation for patients to find help is great. In light of what we know about the financial hardship faced by people with long-term chronic health conditions, financial barriers likely reduce ongoing access to these treatments, accounting for lower overall consultation rates observed with certain professionals such as acupuncturists and homeopaths or naturopaths. Participants in the qualitative study reported these modalities as helpful and also indicated that high costs for these treatments are in fact, an issue.

2.5 Profile of Unmet Health and Home Care Needs

There is a wide range in self-perceived unmet health care needs in the previous 12 months among those with chronic health conditions (Table 16). Unmet health care needs were clearly the highest among those with FM (30.7%), ME/CFS (29.4%) and ES/MCS (25.5%) followed by those living with the effects of a stroke (21.1%). Those with FM were more than two and a half times as likely as to report unmet health care needs as the general population. Interestingly, those with diabetes had a similar level of unmet health care needs as those in the general population.

Table 16: Canadians Reporting Unmet Health Care Needs according to their Chronic Health Condition, 2010

Unmet Health Care Needs	% with Unmet Health Care Needs	95% Confidence Intervals
FM	30.7	(24.6, 36.8)
ME/CFS	29.4	(25.1, 33.7)
ES/MCS	25.5	(21.9, 29.0)
Effects of a stroke	21.1	(16.1, 26.0)
Cancer	15.5	(12.3, 18.8)
Heart disease	13.4	(11.6, 15.2)
Diabetes	11.9	(10.2, 13.6)
Total population	11.4	(10.9, 11.9)

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

A recently published analysis of 2005 CCHS data by Williams et al. (2011)⁷ examined consultations with alternative health care providers (including massage therapists, acupuncturists and homeopaths or naturopaths) among Ontario women aged 18 and older living with ES/MCS, FM and ME/CFS according to their self-perceived unmet health care needs (Table 17). For all three conditions, women who reported having unmet health care needs were significantly more likely to consult with an alternative care provider than women who did not report having unmet health care needs.

Table 17: Proportion of Women with ES/MCS, FM and/or ME/CFS who consulted an Alternative Care Provider according to their Unmet Health Care Needs, Ontario, 2005

Unmet Health Care Needs	Alternative Care Provider Consultation		
	ES/MCS*	FM*	ME/CFS*
Yes	34%	38%	42%
No	24%	27%	24%

* p< 0.01

Source: Adapted from Williams et al. (2011)⁷

An examination of self-perceived unmet home care needs in the previous 12 months among Ontarians (in 2010 home care questions were only asked of Ontario residents) reveals a similar pattern as that for unmet health care needs (Table 18). Some of the 2010 numbers should be interpreted with caution, but those living with ME/CFS and the effects of a stroke in particular, reported the highest rates of unmet health care needs in both in 2005 and in 2010.

Table 18: Ontarians Reporting Unmet Home Care Needs according to their Chronic Health Condition, 2005 and 2010

2005 Chronic Condition	% with Unmet Home Care Needs	95% CI	2010 Chronic Condition	% with Unmet Home Care Needs	95% CI
ME/CFS	13.2	(9.4, 17.1)	ME/CFS	12.3 ^E	(7.3, 17.4)
Effects of a Stroke	10.6	(7.3, 14.0)	Effects of a Stroke [§]	10.7	(7.4, 14.1)
FM	10.4	(7.2, 13.7)	FM	7.8 ^E	(4.3, 11.4)
ES/MCS	7.1	(5.2, 8.9)	ES/MCS	7.7 ^E	(4.8, 10.6)
Heart Disease	6.5	(5.1, 7.9)	Heart Disease [§]	6.5	(5.0, 8.0)
Diabetes	5.3	(3.9, 6.6)	Cancer [§]	5.3 ^E	(3.3, 7.3)
Cancer	4.0 ^E	(2.5, 5.5)	Diabetes [§]	5.0	(3.8, 6.2)
Total Population	1.7	(1.5, 1.9)	Total Population [§]	1.9	(1.7, 2.2)

^E Use with caution (CV between 16.6 and 33.3)

Includes ages 18 and older

[§] Includes 2009 and 2010 data

Source: Statistics Canada, Canadian Community Health Survey, 2005 and 2010 (master data file)

Those living with the effects of a stroke and with cancer had the greatest proportion of people receiving home care services in both 2005 and 2010 (Table 19). Although there is some overlap in the chronic condition groupings, those living with the effects of a stroke were more than twice as likely as those

with ME/CFS to receive these services in 2005, and more than one and a half times as likely in 2010. A further examination of home care services funded in whole or in part by the government indicates that those living with the effects of a stroke or with cancer continued to receive the greatest proportion of home care services.

Table 19: Ontarians Receiving Home Care in the Past 12 Months according to their Chronic Health Condition, 2005 and 2010

2005			2010		
Received Home Care Services	% Receiving Home Care	95% CI	Received Home Care Services	% Receiving Home Care	95% CI
Total Receiving Home Care Services			Total Receiving Home Care Services		
Effects of a Stroke	36.2	(30.4, 41.9)	Effects of a Stroke	36.4	(29.2, 43.7)
Cancer	29.2	(24.2, 34.1)	Cancer	26.2	(20.5, 32.0)
Heart Disease	18.0	(16.0, 20.0)	ME/CFS	21.0 ^E	(14.1, 28.0)
ME/CFS	17.1	(13.1, 21.1)	Heart Disease	20.2	(17.1, 23.4)
FM	16.1	(11.8, 20.4)	FM	18.2 ^E	(10.1, 26.4)
Diabetes	14.0	(12.2, 15.8)	Diabetes	13.6	(11.4, 15.8)
ES/MCS	12.0	(8.3, 15.7)	ES/MCS	9.1 ^E	(5.5, 12.8)
Total Population	4.9	(4.6, 5.2)	Total Population	5.8	(5.3, 6.4)
Cost covered in whole or in part by Government			Cost covered in whole or in part by Government		
Effects of a Stroke	26.1	(21.0, 31.1)	Effects of a Stroke	24.3	(18.1, 30.6)
Cancer	22.3	(17.8, 26.8)	Cancer	17.4	(12.8, 21.9)
Heart Disease	11.1	(9.6, 12.7)	Heart Disease	12.7	(10.3, 15.2)
Diabetes	8.8	(7.5, 10.2)	ME/CFS	9.9 ^E	(4.9, 14.9)
ME/CFS	8.7 ^E	(5.9, 11.5)	Diabetes	7.9	(6.2, 9.5)
FM	5.2 ^E	(3.2, 7.1)	FM	6.7 ^E	(2.3, 11.0)
ES/MCS	4.8 ^E	(2.8, 6.7)	ES/MCS	4.3 ^E	(2.8, 5.8)
Total Population	2.8	(2.6, 3.0)	Total Population	3.0	(2.7, 3.3)

^E Use with caution (CV between 16.6 and 33.3)

Includes ages 18 and older

Source: Statistics Canada, Canadian Community Health Survey, 2005 and 2010 (master data file)

When examining the proportion of people receiving home care services where the cost is covered in whole or in part by the government out of the total receiving home care services, those with cancer and living with the effects of a stroke were most likely to have their home care services paid for. Although some of these numbers should be used with caution, the pattern indicates that those with ES/MCS, FM

and ME/CFS were the least likely to receive publically funded home care services in both 2005 and 2010 (Table 20a and 20b).

Table 20a: Proportion of Ontarians Receiving Home Care Services with Costs Covered in Whole or in Part by the Government among those Receiving Home Care Services according to their Chronic Health Condition, 2005

Chronic Condition	% of Home Care Services covered by the Government among those Receiving Home Care Services	
Cancer	76.4	(67.2, 85.6)
Effects of a Stroke	72.1	(63.5, 80.7)
Diabetes	63.2	(56.4, 70.0)
Heart Disease	62.0	(56.4, 67.5)
Total Population	56.4	(53.2, 59.5)
ME/CFS	50.9	(39.0, 62.9)
ES/MCS	39.8 ^E	(24.8, 54.7)
FM	32.2 ^E	(20.3, 44.0)

^E Use with caution (CV between 16.6 and 33.3)

Includes ages 18 and older

Source: Statistics Canada, Canadian Community Health Survey, 2005 (master data file)

Table 20b: Proportion of Ontarians Receiving Home Care Services with Costs Covered in Whole or in Part by the Government among those Receiving Home Care Services according to their Chronic Health Condition, 2010

Chronic Condition	% of Home Care Services covered by the Government among those Receiving Home Care Services	
Effects of a Stroke	66.5	(54.2, 78.7)
Cancer	66.3	(51.7, 80.8)
Heart Disease	63.0	(53.9, 72.1)
Diabetes	58.0	(48.1, 67.8)
Total Population	50.6	(45.5, 55.7)
ES/MCS	47.3 ^E	(27.3, 67.3)
ME/CFS	46.9 ^E	(27.4, 66.5)
FM	36.6 ^E	(12.8, 60.5)

^E Use with caution (CV between 16.6 and 33.3)

Includes ages 18 and older

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

Table 21 shows the total proportion of Ontarians (this question was only asked in Ontario) with various chronic conditions that have prescription medication insurance. In general there is little variation across condition or differences between the total population and those with a chronic condition, although the pattern indicates that those with cancer (81.3%) may be more likely to have coverage than those with ME/CFS (72.3%). Coverage for those with FM was 77.3%.

Table 21: Insurance Coverage for Prescription Medications among Ontarians according to their Chronic Condition, 2005

Insurance Coverage	% with Insurance	95% Confidence Intervals
Prescription Medications		
Cancer	81.3	(75.1, 87.5)
Diabetes	80.5	(76.8, 84.2)
Heart Disease	78.9	(75.3, 82.6)
FM	77.3	(70.8, 83.7)
Effects of a Stroke	77.1	(70.0, 84.2)
Total Population	76.2	(75.4, 77.0)
ES/MCS	74.3	(69.1, 79.5)
ME/CFS	72.3	(66.1, 78.5)

In 2010, these questions were only asked in Nunavut

Source: Statistics Canada, Canadian Community Health Survey, 2005 (public use microdata file)

Summary:

The findings indicate that people with ES/MCS, FM and ME/CFS are most likely to report unmet health care needs. This is despite the high physician consultation rates described in the previous section, further contributing to the view that people with these conditions are receiving inappropriate care or are experiencing barriers to and deficits in care. The finding that Ontario women with unmet health care needs were more likely to consult with an alternative care provider supports the idea that patients are willing to look outside of conventional medicine when they are not satisfied with their care, where they are able to assume the costs themselves.

Although further investigation is needed into reasons for unmet health care needs, the proportion of those with ES/MCS, FM and/or ME/CFS reporting unmet health care needs (25.5%-30.7%) seems low given the lack of coordinated care for these conditions. Lower proportions than would be expected may be due to the unwillingness to state how one truly feels with an interviewer (social desirability bias), or due to the timeframe of the question (unmet needs in the previous 12 months), which may be less

relevant for people who have been dealing with the conditions for several years or even decades, though alternative explanations likely exist.

The disability measures in section 2.2 indicated that, in some ways, those with ME/CFS can be as disabled as those living with the effects of a stroke, and that those with FM or ES/MCS are at least as disabled as those with other chronic conditions including cancer. Nonetheless, the pattern indicates that people with cancer and living with the effects of a stroke are most likely to receive home care services and, furthermore, they are more likely to have the services paid for. One reason for this could be that the health delivery models for cancer and stroke include home-based care such as nursing, physiotherapy, occupational therapy, nutritional counselling and housekeeping, and that these models of care have been accepted for government funding. A model of care including a home-based component for people with ES/MCS, FM and/or ME/CFS has not been accepted at the governmental level, but could have many benefits. In addition, ES/MCS, FM and ME/CFS are poorly recognized and understood chronic conditions; their seriousness may be underestimated when home care services are allocated. Finally, since many people with ES/MCS, FM and/or ME/CFS needing these services may have to assume the costs of care privately, lower rates of home care overall could also be due to financial barriers. Various possible explanations combined with expressed unmet home care needs in Table 18 indicate that the findings around home care services require further investigation.

The level of coverage for prescription medications presented in Table 21 does not differ markedly among chronic condition groupings. While the Ontario Drug Plan covers residents over age 65, a further examination of these data among seniors reveals underreporting of coverage (data not shown). Full reporting would increase the overall coverage rates, but more so for those with chronic conditions such as cancer and diabetes, which have, on average, an older aged cohort than those with ES/MCS, FM and ME/CFS.

Not all Ontarians with chronic conditions including ES/MCS, FM and ME/CFS have prescription medication coverage, and their needs must be taken into account. Coverage of medications is particularly important for those with FM who rely on pain medication to alleviate their symptoms. Those without coverage may not be able to afford the medications they need, which can result in further disability. Comprehensive drug coverage is also important for those with ME/CFS and ES/MCS for the purposes of being able to obtain medications to address chronic and insidious infections. Some of the antibiotics and antiviral drugs needed are expensive and not all are included in the Ontario formulary. Chronic infection in ME/CFS and ES/MCS is likely undertreated in Canada, and many people with the conditions may not be aware of this important dimension of treatment and would not have considered it as an unmet need.

2.6 Profile of Socioeconomic Disadvantage

Food security is a measure of reliable access to healthy food in adequate quantities. Canadians with ME/CFS reported the highest levels of moderate or severe household food insecurity (20.4%). This finding was almost three times that of the general population. Those with ES/MCS (14.7%) and FM (12.9%) also had high levels of moderate or severe household food insecurity (Table 22). The pattern indicates that those with heart disease and cancer had similar or possibly lower levels of moderate or severe household food insecurity compared to the general population.

Table 22: Canadian Population Experiencing Moderate or Severe Household Food Insecurity according to their Chronic Health Condition, 2010

Chronic Condition	% who are Food Insecure	95% Confidence Intervals
ME/CFS	20.4	(16.0, 24.7)
ES/MCS	14.7	(11.6, 17.9)
FM	12.9	(9.4, 16.4)
Effects of a stroke [§]	11.7	(9.3, 14.1)
Diabetes [§]	8.8	(7.8, 9.8)
Total population [§]	7.2	(6.9, 7.4)
Heart disease [§]	6.9	(5.9, 7.9)
Cancer [§]	5.8	(4.1, 7.6)

Does not include data from PEI and New Brunswick (question was not asked)

§ Includes 2009 and 2010 data

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

Less variation among chronic health conditions is seen when examining households with income less than \$15,000 annually (Table 23). People with any chronic condition had a greater rate of low income than the total population, with the exception of those with cancer, who had a similar level as the total population. The pattern shows that those with ME/CFS, ES/MCS, FM and living with the effects of a stroke tended to have the highest proportions with lower income.

Table 23: Canadian Population who have Household Income less than \$15,000 according to their Chronic Health Condition, 2010

Chronic Condition	% with Income less than \$15,000	95% Confidence Intervals
ME/CFS	11.7	(8.6, 14.8)
ES/MCS	10.6	(8.1, 13.2)
Effects of a stroke [§]	10.3	(8.3, 12.4)
FM	10.0	(7.6, 12.5)
Heart disease [§]	8.2	(7.2, 9.2)
Diabetes [§]	8.1	(7.0, 9.2)
Cancer [§]	5.4	(4.2, 6.6)
Total population [§]	4.6	(4.4, 4.8)

§ Includes 2009 and 2010 data

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

Summary:

High rates of household food insecurity and a substantive amount of people (approximately 10%) with household income below \$15,000 among people with ES/MCS, FM and ME/CFS may be due to reduced employment income or the inability to work altogether due to high levels of disability as discussed in section 2.2. Results from the EHC patient population found that people with the conditions could only work 9.4 hours/week on average, and this was reduced for those with multiple diagnoses⁸.

Other reasons for low income include difficulties in obtaining and retaining long-term disability, or the low monthly benefit of provincial support such as ODSP. Lower income may have also contributed to onset of the conditions in the first place. Food insecurity may be perpetuated by intolerances to particular foods and expensive costs of alternative ingredients. There may also be practical challenges for those requiring assistance with grocery shopping and meal preparation not receiving the services they need.

The EHC study showed that patients living in areas with higher socioeconomic status had better scores for physical function, bodily pain and general health⁸. This suggests that people with more access to financial resources may be able to afford helpful treatments (such as those with other health professionals), needed home care services (such as groceries and housework), and other health and social services that may not be accessible to those with lower income.

2.7 Profile of Social Impact

Experiencing difficulty in social situations is a summary measure which encompasses difficulty making new friends and maintaining friendships, difficulty dealing with unknown people and difficulty starting and maintaining conversations. Those with ME/CFS and living with the effects of a stroke experienced the greatest degree of difficulty in social situations (27.0% and 26.0%, respectively) (Table 24). Among those with FM, 17.8% experienced difficulty in social situations, followed by 11.8% of those with ES/MCS.

Table 24: Canadian Population Experiencing Difficulty in Social Situations according to their Chronic Health Condition, 2005

Chronic Condition	% Experiencing Difficulty in Social Situations	95% Confidence Intervals
ME/CFS	27.0	(23.4, 30.6)
Effects of a Stroke	26.0	(22.2, 29.7)
FM	17.8	(14.9, 20.8)
ES/MCS	11.8	(9.9, 13.7)
Heart Disease	10.0	(8.8, 11.3)
Cancer	9.9	(7.6, 12.2)
Diabetes	8.1	(7.0, 9.2)
Total Population	4.5	(4.3, 4.7)

Question was not asked in 2010

Source: Statistics Canada, Canadian Community Health Survey, 2005 (public use microdata file)

People with chronic conditions expressed a greater sense of very weak community belonging than the total population (Table 25). Similar to patterns throughout this report, those with ME/CFS in particular expressed that they felt a very weak sense of community belonging, followed by those with FM and ES/MCS.

Table 25: Canadian Population who have a Very Weak Sense of Community Belonging according to their Chronic Health Condition, 2010

Chronic Condition	% with Very Weak Sense of Community Belonging	95% Confidence Intervals
ME/CFS	18.1	(14.0, 22.2)
FM	16.1	(10.9, 21.3)
ES/MCS	13.4	(10.7, 16.1)
Effects of a Stroke [§]	12.6	(10.2, 15.1)
Heart Disease [§]	10.7	(9.3, 12.1)
Cancer [§]	10.2	(8.3, 12.1)
Diabetes [§]	10.2	(9.1, 11.2)
Total Population [§]	8.9	(8.6, 9.2)

§ Includes 2009 and 2010 data

Source: Statistics Canada, Canadian Community Health Survey, 2010 (master data file)

In 2005, Canadians reporting a reduction in activity due to a long-term health condition (approximately 8 million Canadians) were asked if they had ever experienced discrimination or unfair treatment due to their health condition as shown in Table 26. Those with ME/CFS (27.5%) and FM (25.3%) and ES/MCS (23.3%) reported the highest proportions experiencing such treatment by far. Interestingly, people with cancer reported a lower level of discrimination or unfair treatment than the total population.

Table 26: Canadian Population Reporting Discrimination or Unfair Treatment due to their Health Problem among those with a Reduction in Activities according to their Chronic Health Condition, 2005

Chronic Condition	% Reporting Discrimination	95% Confidence Intervals
ME/CFS	27.5	(23.2, 31.7)
FM	25.3	(21.6, 28.9)
ES/MCS	23.3	(19.9, 26.6)
Effects of a Stroke	13.2	(9.9, 16.5)
Total Population	11.6	(11.0, 12.2)
Diabetes	11.4	(9.6, 13.2)
Heart Disease	9.9	(8.4, 11.5)
Cancer	6.8 ^E	(4.5, 9.2)

Question was not asked in 2010

Source: Statistics Canada, Canadian Community Health Survey, 2005 (public use microdata file)

Summary:

Experiencing difficulty in social situations highlights the social impact these illnesses have in addition to the significant physical impairments previously discussed. Participants in the qualitative study reported difficulty maintaining friendships after becoming ill. Social difficulties could be due to the high levels of disability and resulting in an inability to engage in regular activities, but could also be due to the lack of understanding and awareness surrounding these conditions and the special needs they necessitate. As a result, experiencing a very weak sense of community belonging as observed for those with ES/MCS, FM and/or ME/CFS is not surprising. The qualitative study has illustrated that in their most severe forms, all three of the conditions are isolating.

Reports of discrimination and unfair treatment are suggestive of the lack of understanding and accommodation provided to people with these conditions. It is not known from the available CCHS data in what circumstance (medical, workplace or social) the reported discrimination was experienced, but our qualitative research has suggested that it occurred in all of these realms. Experiencing discrimination or unfair treatment could further contribute to a weak sense of community belonging and isolation.

2.8 LIMITATIONS

I) Of the Data

- Children under age 12 are not evaluated in the CCHS and are known to have ES/MCS, FM and ME/CFS.
- Safe and suitable housing is a large need for this population, and is not a factor investigated on the CCHS.
- When respondents have more than one chronic condition, it is not possible to know which condition they are considering when answering the questions on the CCHS.
- The use of survey data is based on self-reported information by respondents without verification.
- Variations in diagnostic practices have the ability to influence morbidity statistics. Lack of awareness of how to diagnose the conditions as well as lack of acceptance and willingness to diagnose the conditions may result in underreporting. Education and use of the Canadian Consensus Guidelines for ME/CFS and 1999 validated criteria for ES/MCS, and a resolution in the new debate over diagnostic criteria for FM would eventually result in more consistent diagnosing of the illnesses and allow for true variation in rates of disease to be more readily detected.
- Information on ES/MCS, FM and ME/CFS was only collected for a one year period in 2010, while information on other chronic conditions was collected over a two-year period from 2009 to 2010. There are pertinent questions on the CCHS which could not be explored in this analysis due to lack of a sufficient sample. Other conditions also have regular collection on each cycle of the CCHS, while ES/MCS, FM and ME/CFS are next scheduled for collection in 2014.
- Due to the cross-sectional nature of the CCHS, temporality may be an issue with certain factors such as income. It is difficult to know if people became ill and then earned less income, or if they had lower income, which was a contributing factor in the onset of their condition. Longitudinal studies or modules examining personal history would help to clarify such relationships.

II) Of the Analysis

- Age and gender are associated with the conditions as well as the factors examined. Some previous analysis adjusting for their effects has been conducted, but further detailed examinations with multivariate analyses controlling for their effects are warranted. In addition, because people may have any number of chronic health conditions at any one time, there is overlap among the chronic health condition groupings, both among those examined in this report as well as other conditions asked about on the CCHS and beyond. Further analyses distinguishing the effects of co-morbidities and controlling for their effects are also needed.

2.9 CONCLUSIONS

Despite the aforementioned limitations, a consistent pattern in relation to ES/MCS, FM and ME/CFS clearly emerged across a variety of factors related to measures of disability, socioeconomic status,

health care utilization and unmet health care needs. There was also consistency in results between the other sources of data included in this report and the population-based CCHS. Collectively the findings show that those living with ES/MCS, FM and/or ME/CFS represent a very large, disabled and disadvantaged cohort, that have specific health care needs that are not being met. Resultant impacts are likely far reaching and significantly affect families/caregivers, communities and society.

Given the extent and impact of the conditions, increased surveillance including frequent collection on the CCHS and further research involving longitudinal studies are strongly needed.

2.10 ACKNOWLEDGEMENTS

The authors thank Dr. Lynn Marshall, Environmental Health Clinic, OCEEH Steering Committee and Medical Advisory Committee, Eleanor Johnston, OCEEH Steering Committee, and Jennifer Rayner, Epidemiologist and CHC Decision Support Specialist, for their helpful reviews.

2.11 REFERENCES

1. Statistics Canada. 2011. User Guide, 2010 and 2009-2010 Microdata files, Canadian Community Health Survey (CCHS) Annual Component. http://www23.statcan.gc.ca/imdb-bmdi/pub/document/3226_D7_T9_V8-eng.htm (accessed Oct. 21, 2013).
2. Statistics Canada. 2011. Canadian Community Health Survey, Annual Component (2009-2010, 2010), Public Use Microdata File. Statistics Canada Catalogue no. 82M0013XCB. <http://www5.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=82M0013X&chprog=1&lang=eng> (accessed July 26, 2013). All computations, use and interpretation of these data are entirely those of the author.
3. Statistics Canada. 2006. Canadian Community Health Survey, Cycle 3.1 (2005), Public Use Microdata File. Statistics Canada Catalogue no. 82M0013XCB. <http://www5.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=82M0013X&chprog=1&lang=eng> (accessed July 26, 2013). All computations, use and interpretation of these data are entirely those of the author.
4. National ME/FM Action Network. Quest Newsletter. Communication #80. Spring-Summer 2009. http://www.mefmaction.com/images/stories/quest_newsletters/Quest80springsummer2009.pdf (accessed Oct. 21, 2013).
5. National ME/FM Action Network. Quest Newsletter. Communication #88. Summer 2011. http://www.mefmaction.com/images/stories/quest_newsletters/QUEST88Summer2011.pdf (accessed Oct. 21, 2013).
6. Park J, Knudson S. Medically Unexplained Physical Symptoms. Health Reports 2007;18(1).

7. Williams AM, Kitchen P, Eby J. Alternative health care consultations in Ontario, Canada: A geographic and socio-demographic analysis. *BMC Complementary and Alternative Medicine* 2011;11:47.
8. Lavergne MR, Cole DC, Kerr K, Marshall LM. Functional impairment in chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity. *Can Fam Physician* 2010;56:e57-65.
9. Fox RA, Joffres MR, Sampalli T, Casey J. The impact of a multidisciplinary, holistic approach to management of patients diagnosed with multiple chemical sensitivity on health care utilization costs: an observational study. *The Journal of Alternative and Complementary Medicine* 2007;13:223-229.
10. Stirling G, Reid DW, Pollard J, Ondrack M. Symptoms and characteristics of CFS. A survey of 875 Ontario residents. *The CFIDS Chronicle* Summer 1996;2-5.
11. Myalgic Encephalomyelitis Association of Ontario (MEAO). 2011. [Patient survey] Unpublished raw data. http://www.meao.ca/files/Reaching_Out_2011_Spring.pdf (accessed July 26, 2013).