



Quest

Newsletter



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Quest 112, Fall 2017

mefminfo@mefmaction.com

Special Issue

Under-Served and in Great Need

What the Canadian Community Health Survey

2005, 2010, 2014 tells us about

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia

Commentary

by Margaret Parlor

Under-Served and in Great Need

Statistics from the 2005 Canadian Community Health Survey (CCHS) showed that health and social systems in Canada were doing a very poor job of serving people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM). One of the declared purposes of the survey is to provide information to government organizations to plan, implement and evaluate health and social programs. Despite the alarming statistics from 2005, there was little response from government organizations. Statistics for 2010 and 2014 show that Canadians with ME/CFS and FM continued to be under-served and in great need.

While Quest has published statistics from the 2005, 2010, and 2014 surveys separately, this issue of Quest focuses on patterns over time. We look at characteristics of the ME/CFS and FM communities (age, gender and disability) and at health care utilization, but the primary focus of our analysis is on key variables that show how well health and social systems are supporting the ME/CFS and FM communities.

There are some variables which should be of paramount concern to government departments and agencies at the

federal, provincial, territorial and local levels because they provide important information on how well the health and social systems are responding to the needs of a group. These key variables include:

- unmet health care needs,
- one's sense of community belonging,
- income (poverty),
- food insecurity, and
- unmet home care needs.

While the provincial and federal governments have had access to information from the CCHS since the first cycle data was released in May 2002, the National ME/FM Action Network only became aware of the information following the release of two articles. The first was published in the Public Health Agency of Canada journal in 2006 using the 2001 data. The article focused on describing the group of Canadians with FM – prevalence, age, gender, etc. The second was published by Statistics Canada in 2007 using 2003 data and entitled “Medically Unexplained Physical Symptoms” to refer to ME/CFS, FM and Multiple Chemical Sensitivities. Like the first article, this article focused on group characteristics and not on an evaluation of the services (or lack thereof) offered by health and social systems.

In 2009, the National ME/FM Action Network jumped in with analysis from the 2005 survey. Our analysis found

that people with ME/CFS and/or FM fared badly in terms of these key variables. The 2005 data sent clear signals that health and social systems were not working well for people with ME/CFS or FM. The statistics from 2010 and 2014 show no improvement.

What was happening (or not happening) during this period? And what do officials need to understand when they do step forward to help?

The statistics will not improve unless health and social systems come to grips with the problems. When the systems understand the issues, changes will begin.

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CCHS Basics:

The Canadian Community Health Survey (CCHS) is based on interviews with a random selection of Canadians aged 12 or older. It was originally a biannual survey that ran in 2001, 2003 and 2005. Respondents were asked if they were diagnosed with various chronic conditions. CFS, FM, and Multiple Chemical Sensitivities (MCS) were on the list.

In 2006, the survey became an annual survey. The number of respondents each year was half the number that had been in each of the first three cycles. The questions on CFS, FM and MCS were dropped from the questionnaire. The Network led a campaign to have these three conditions reintroduced, and officials agreed to include these chronic conditions in the years 2010 and 2014.

The survey was redesigned for the period 2015-2022. The sampling methodology was changed, as were the questionnaire and the instructions to interviewers. Because of these changes, Statistics Canada cautions against comparing data from 2015 onward with pre-2015 data. It was decided to include CFS, FM and MCS on the questionnaire in four of the eight years (2015, 2016, 2019 and 2020).

Data from the CCHS is personal and sensitive. Therefore, access to the data is carefully managed. Basic information from the survey is released free of charge. The Network relies primarily on the “Public Use Microdata File” which is provided free of charge and allows us to explore data in some depth. Unfortunately, this file is not released for months after the initial release. We will be asking Statistics Canada to make the tables referenced in this report available when each cycle of data is released.

Note that the CCHS questionnaire asks about “Chronic Fatigue Syndrome”. In 2015, an instruction to interviewers was added instructing them to accept the answer “Myalgic Encephalomyelitis”. In this report, we use the term ME/CFS interchangeably with CFS.

The survey description, written when the survey was first developed, included the following sentence: “*Federal and provincial departments of health and human resources, social service agencies, and other types of government agencies use the information collected from respondents to plan, implement and evaluate programs to improve health and the efficiency of health services.*”

Issues: ME/CFS

By 2005, there were several vague definitions of ME/CFS in general use. ME/CFS was widely thought of as a condition that could be addressed through the psychosocial strategies of Cognitive Behaviour Therapy and Graded Exercise Therapy. This attitude signaled to health and social staff as well as to family, friends and the public that patients were malingering and that their behaviour should be ignored or discouraged. ME/CFS was not considered as real or important. Only one study into ME/CFS was funded by the Canadian Institutes of Health Research (CIHR) between 1999 and March 2005 for a total of less than \$300,000. ME/CFS was not served by any medical specialty, though there were small provincial clinics in Ontario and Nova Scotia established in the 1990s to deal with Multiple Chemical Sensitivities that were asked to deal with ME/CFS and FM as well.

Not everyone agreed with the vague definitions or the psychosocial model. There were researchers, clinicians, healthcare workers, support groups and patients who knew that this approach was wrong. The National ME/FM Action Network was among them. We convinced Health Canada to appoint an expert panel to develop clinical diagnostic and treatment protocols. The expert panel's diagnostic criteria provided an alternative to the vague definitions in use. The expert panel's treatment protocols were based on the view that ME/CFS was real and biomedical and could be helped by informed interventions. But health and social systems paid scant attention.

In late 2009, the prestigious journal *Science* published an article associating ME/CFS with the retrovirus XMRV. The possibility that ME/CFS could have a physical basis shook up the health community. While the XMRV explanation later fell apart, the idea that ME/CFS was biomedical gained ground and research interest increased. Research, while still poorly funded, is leading to interesting and important findings.

The psychosocial approach reared up again in 2011 with the publication of analysis from the UK PACE trial which supposedly showed that Cognitive Behaviour Therapy and Graded Exercise Therapy do help. The publication allowed health and social systems to continue to think of patients as malingerers, or at least think that there is too much uncertainty around ME/CFS to get involved. This study has been shown to be methodologically seriously flawed. There have been calls for its retraction, but it is

still officially on the books to this day.

The US government's Agency for Healthcare Research and Quality was asked to review the literature around behavioural therapy and exercise for ME/CFS. Their analysis concluded that these strategies had benefits. They also recommended that a fuzzy definition of ME/CFS no longer be used. They then redid their literature review excluding studies based on the fuzzy definition. Their original conclusions did not hold. This demonstrates what should be obvious, that definitions matter and that studies based on one definition cannot be used to draw conclusions for a group of people selected using a different definition.

As a result of the varying quality of studies and the shifting definitions, the published literature is a mixed bag of good studies and poor studies, of applicable studies and non-applicable studies. With few practicing clinicians, there are few clinical studies. With few resources committed to research, there are big gaps in research coverage.

The standard approach for establishing clinical guidelines is to rely on the published literature. This methodology simply doesn't work in cases like this where the literature is problematic. The Quebec government learned this when their review of clinical guidelines gave the highest score to a set of psychosocial guidelines. Fortunately, this was about the time the XMRV study was released and Quebec did not implement those guidelines.

Excellent clinical guidance is available. Over the years, patients, caregivers, clinicians and researchers from around the world have come together to share experiences, monitor developments and discuss issues. Over time, this network has developed expertise and judgment. Over time, valuable clinical guidance documents have been produced. Key documents are available under Medical Resources on our website.

CIHR, the federal government funding agency, has started to take notice of ME/CFS. In September 2014, it held a workshop on "chronic pain and fatigue" thinking incorrectly that was equivalent to FM and ME/CFS. It would not be until August 2016, when CIHR was blindsided by a peer reviewer from the psychosocial camp, that CIHR began to understand how strong the opposition to the biomedical model still is.

Despite the statistics and despite the changing understanding of ME/CFS, the clinical and social systems have done little to address the situation, leaving patients

under-served and in great need. One exception is the introduction of a clinical and research program in BC. This program and the pre-existing programs in Ontario and Nova Scotia are much too small to meet the demand, but they do provide focal points for moving forward.

In summary, during the 2005-2014 period, the biomedical approach to ME/CFS gained ground, researchers became more involved and the ME/CFS community has become stronger and more insistent. However, health and social systems have paid little attention, so these advances have not translated into better care and support. We see in the data that people with ME/CFS are still dealing with high levels of unmet needs, social isolation, poverty and food insecurity. Misinformation and stigma are still very influential and there is a very real danger that system interventions will be negative rather than positive.

We call on health and social systems to look at the data, to listen closely to the ME/CFS community and to actively address the health and social issues experienced by the community and confirmed by the data. There are three points to emphasize.

- Understand that ME/CFS is not the same as chronic fatigue. Chronic fatigue can be triggered by hundreds of factors such as reaction to medications, stress, overwork, depression, anxiety, poor nutrition, lack of exercise or insomnia. This is not what ME/CFS is about. ME/CFS was well described by Health Canada's expert panel. This description should be the basis for moving forward.
- Adopt the biomedical model. The psychosocial model has been around for decades and has left people under-served and in great need. The psychosocial model needs to be firmly rejected, and action is needed to counteract the stigma and exclusion that it has caused.
- Think big. There are very large gaps in Canada's health and social systems. Research funding for ME/CFS should be tens of millions of dollars a year, not tens of thousands. Hundreds of specialist clinicians are needed, not just a few here and there. Disability and social programs need to ensure that Canadians with ME/CFS have equitable access.

Issues: FM

In 2005, there seemed to be consensus around a diagnostic criteria for FM. The FM expert panel appointed by Health Canada built on the prevailing definition developed by the American College of Rheumatology which defined FM around widespread pain and tender points. There seemed to be consensus that FM was real and biomedical. CIHR provided \$1.8M for six research studies between 1999 and March 2005. Rheumatologists were serving patients, along with the clinics in Ontario and Nova Scotia. Several new drugs were in the pipeline and would be approved for use over the next few years.

Everything seemed fine on the surface, but below the surface not all was well. The 2010 CCHS data gave a signal - it showed an increase in the unmet health care needs of the FM group to the point that FM showed the highest rate of all chronic conditions in that year.

At the time, we thought the increase could be related to the new drugs - "perhaps patients had difficulty finding doctors to prescribe the medications, perhaps the medications did not meet their expectations, or perhaps there was too much emphasis on medication and not enough on other treatments."

Looking back, there was an additional dynamic at play. Rheumatologists were becoming frustrated with FM. While their frustration would not become obvious until a survey of Ontario rheumatologists was published in 2012, a commentary published in the Journal of Rheumatology in 2009 asked whether rheumatology should be involved in FM at all. By the time of the 2010 survey, rheumatologists may already have been withdrawing their services and some of those still providing services may not have had their heart in it.

In 2010, an international group of rheumatologists proposed new diagnostic criteria for FM (which were modified in 2011 and 2016). The 2010 criteria incorporated additional symptoms noted by Health Canada's expert panel on FM including activity reduction, cognitive difficulties and sleep disturbance. The test for tender points was dropped, partly because it was not widely known. While the new criteria recognizes the multi-symptom nature of FM, they may also be vague enough to make the resulting cohort heterogeneous. People can experience pain, activity reduction, cognitive difficulty and sleep dysfunction due to many causes. The purpose of diagnostic criteria is to describe the medical

problem and to point toward appropriate treatment. If diagnostic criteria are too generic, then the treatment recommendations become generic and essentially meaningless.

In 2012, an ad hoc team released “Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome in Adults.” The document was compiled using the standard guideline development process including literature reviews. The FM literature is plagued by the same issues as the ME/CFS literature—inconsistent cohort selection, inconsistent quality of research, few clinical studies and research gaps. Of the 46 recommendations in the 2012 guidelines, 33 were assessed in whole or in part as level D or consensus, meaning that those recommendations were based on opinion rather than evidence.

The document made a number of recommendation that deserved debate. These include the adoption of the 2010 proposed diagnostic criteria, assigning responsibility for FM to family doctors without ensuring that there was a specialist area to support them, encouraging all FM patients to remain at work or return to work, and recommending graded exercise therapy despite not raising the topic of exertion intolerance. The document claims to believe in the biomedical basis of FM, but the tone is distinctly psychosocial.

Despite the flimsy evidence base for a report purporting to be evidence-based, the Canadian Pain Society and the Canadian Rheumatology Association endorsed the guidelines, they were posted on the Canadian Medical Association guidelines website where they remain to this day, they were publicized within the medical community and they were posted publicly on the internet.

The prevalence figures for FM increased between the 2010 and the 2014 survey. This could be related to the higher profile FM received in the medical community, the use of the new definition, and/or advertising to consumers by drug companies suggesting that people raise the possibility of FM with their health providers.

Surprisingly, the 2014 cohort showed a higher degree of disability than the 2010 cohort. This suggests that the new diagnostic criteria were capturing a different and sicker group of patients than the old diagnostic criteria were capturing. Why this would be the case is not obvious and this issue urgently requires investigation. However, a serious implication of this is that conclusions reached using older diagnostic criteria cannot be validly used for

the new group. As the ME/CFS experience showed, you cannot apply conclusions based on one selection criteria to a group selected using different criteria.

The cause of FM is still unclear and little research is underway to figure this out. The American College of Rheumatology points to “involvement of the nervous system, particularly the central nervous system (brain and spinal cord)” and adds that “Fibromyalgia is not from an autoimmune, inflammation, joint, or muscle disorder.” The 2012 Canadian Fibromyalgia guidelines describe FM as “neurophysiologic”. Meanwhile, the American Neurological Association and the Canadian Neurological Society don’t even mention FM on their websites. FM has been lost in the shuffle.

In summary, several changes occurred around FM over the 2005-2014 period – the introduction of new diagnostic criteria, the dropping of responsibility for FM by rheumatology without it being picked up by another specialty, and the introduction and advertising of new drugs. The statistics show that the FM community has grown in numbers and has become more disabled. It remains under-served and in great need. The FM community needs urgent attention.

We call on health and social systems to look at the data, to listen closely to the FM community and to actively address the health and social issues experienced by the community and confirmed by the data. Here are some steps that are needed:

- Review diagnostic criteria for FM to ensure that a meaningful group is being identified.
- Endorse a biomedical model for FM. The psychosocial model, the idea that FM is not real or serious, is alive. It needs to be firmly rejected, and the stigma and exclusion that it causes need to be addressed.
- Think big. There are very large gaps in Canada’s health and social systems for FM. Research funding should be tens of millions of dollars per year, not tens of thousands. Clinical expertise is needed. This illness is too common and too complex to be left exclusively to busy family doctors. Disability and social programs need to ensure that Canadians with FM have equitable access.

Trends in the Canadian Community Health Survey Data - 2005, 2010, 2014

by E. Halapy and M. Parlor

Introduction

We have previously presented statistics on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM) from the 2005 (Quest 80), 2010 (Quest 88, MEAO Quantitative Data Report) and 2014 (Quest 108) Canadian Community Health Surveys (CCHS). In this document, we present the 2005, 2010 and 2014 CCHS results alongside one another in order to look for patterns over time. We discuss the conditions separately as each has its own story.

Technical notes and a comprehensive set of tables can be found on the National ME/FM Action Network website: see Resources→Quest Newsletters→2017, Quest 112 supplement.

The CCHS is a cross-sectional survey based on interviews with a random sample of Canadians. The issue of sampling is important to keep in mind when reviewing the results. In the 2010 and 2014 surveys, each respondent represented almost 500 Canadians on average, and in the 2005 survey, each respondent represented over 200 Canadians on average. Different people are selected to participate in each survey, and numbers can fluctuate simply because of who is selected. As a result, it may not be clear whether a change in the data is due to sampling or to actual change. For example:

- The data show that the proportion of people with ME/CFS who are female decreased from 69% in 2005 to 66% in 2010 to 63% in 2014. We suspect that this is a real shift because the number of people included in

the calculation is relatively large, the drop happened in steps over two periods, and the drop is possible in the real world.

- The number of people with ME/CFS who reported mobility problems increased from 22% in 2010 to 26% in 2014. We suspect this is due to sampling because there were fewer people included in the calculation than in the example above, shifts of 3 or 4% occurred for the other chronic conditions, and there is no reason to think that people with ME/CFS would encounter more mobility problems during that period.

The following analysis presents statistics on all of the chronic conditions collected on the CCHS in addition to ME/CFS and FM. Results for chronic condition groups are based on data extracted directly from the source file. No adjustments have been made to standardize the data for variables such as age and gender; therefore, this analysis does not show how the various chronic condition groups would compare if they had similar compositions. No adjustments have been made for co-existing conditions and the same individual may be part of several chronic condition groups.

The chronic conditions in the following graphs are sorted by results for 2014, except for Graph 7 which is sorted by results for people less than 65 years of age.

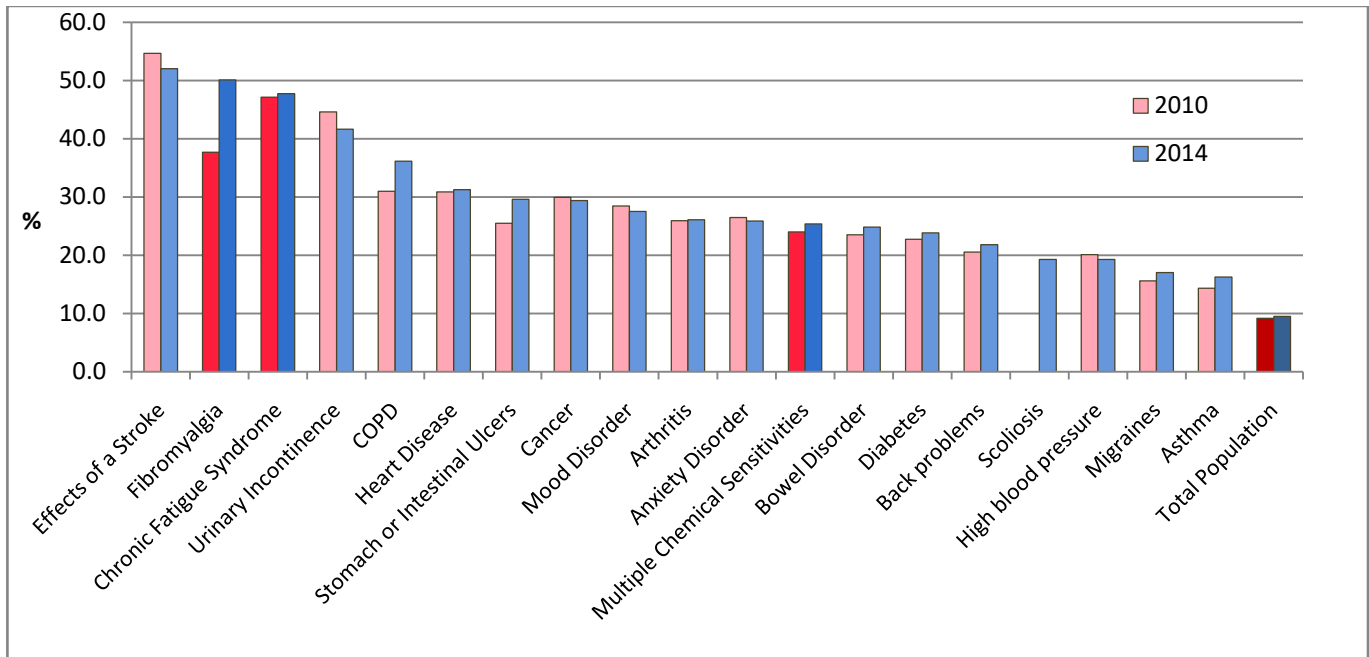
This analysis is based on the Statistics Canada Canadian Community Health Survey Public Use Microdata File, 2014, 2010, 3.1 (2005), and custom tabulations generated by Statistics Canada. All computations, use and interpretation of these data are entirely that of the National ME/FM Action Network.

Table 1: Prevalence of ME/CFS, FM and MCS among Canadians Aged 12 and Older, 2005, 2010 and 2014

Chronic Condition	2005		2010		2014	
	No. with Condition	%	No. with Condition	%	No. with Condition	%
CFS	333,800	1.2	411,500	1.4	407,600	1.4
FM	389,800	1.4	438,800	1.5	518,800	1.7
MCS	598,600	2.2	800,300	2.8	722,400	2.4
CFS and/or FM	628,500	2.3	755,900	2.6	808,700	2.7
One or more	1,135,200	4.2	1,414,700	4.9	1,427,600	4.8

Source: Statistics Canada, Canadian Community Health Survey, 2005, 2010, 2014, Public Use Microdata Files

**Graph 1: Canadians Aged 12 and Older Needing Help with Tasks
According to their Chronic Health Condition, 2010 and 2014**



Source: Statistics Canada, Canadian Community Health Survey, 2010, 2014, Public Use Microdata Files

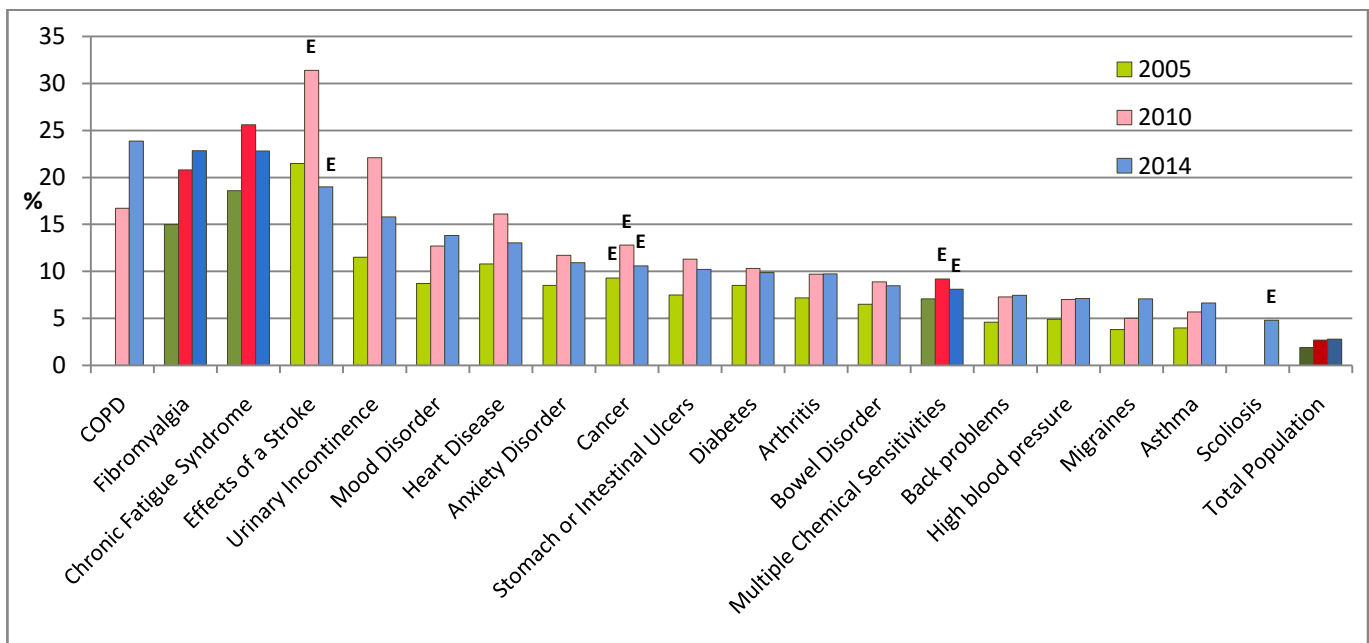
COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

Needing help with tasks is comprised of six activities of daily living: needs help preparing meals, getting to appointments/running errands, doing housework, personal care, moving about inside the house, and looking after personal finances

Note: Definition changed after 2005 and 2005 results are not comparable

**Graph 2: Canadians Aged 18-64 who are Permanently Unable to Work
According to their Chronic Health Condition, 2005, 2010 and 2014**



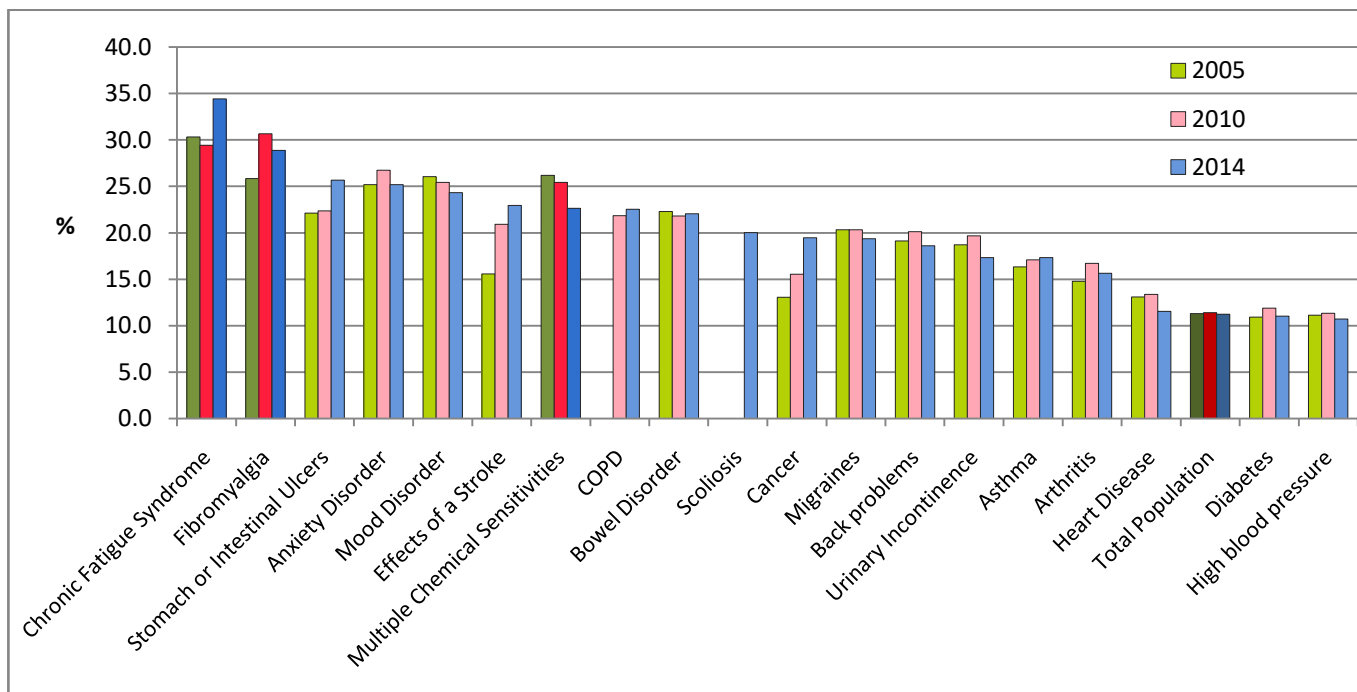
Source: Statistics Canada, Canadian Community Health Survey, 2005, 2010, 2014, Public Use Microdata Files

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

COPD = ages 35+; Urinary Incontinence = ages 25+

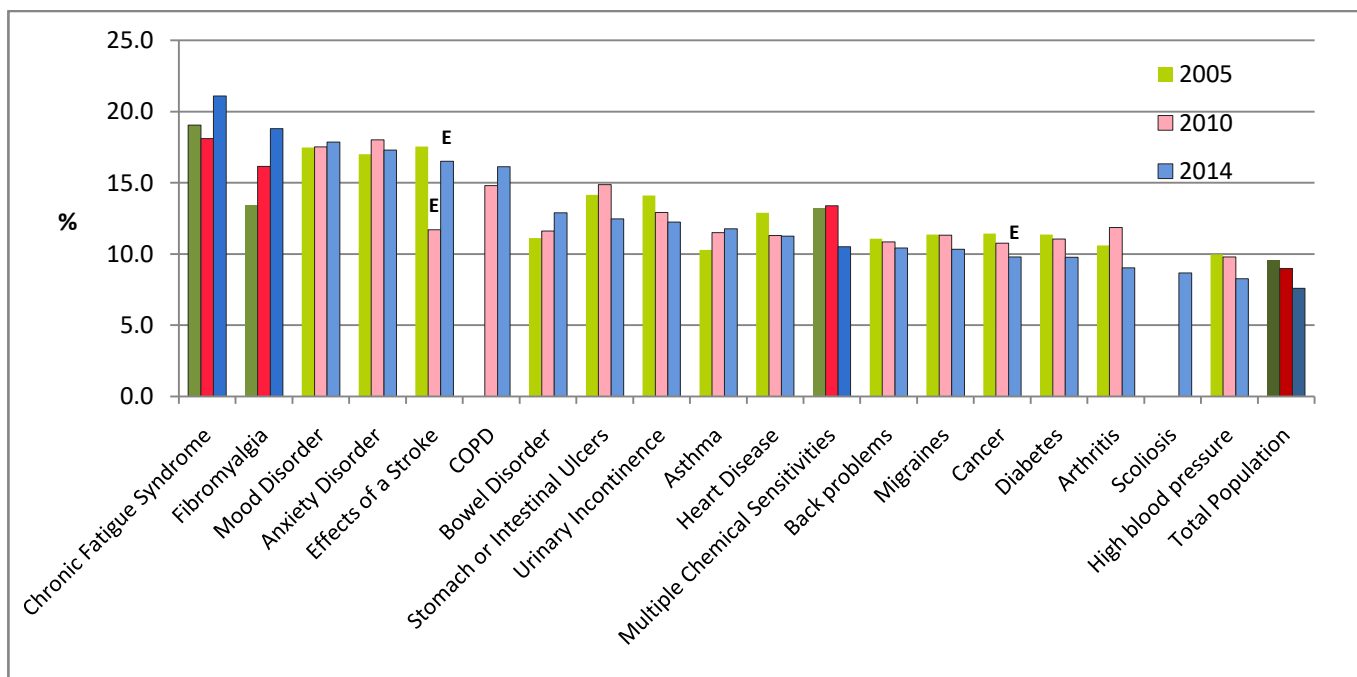
^E Use with caution (Coefficient of Variation between 16.6% and 33.3%)

**Graph3: Canadians Aged 12 and Older Reporting Unmet Health Care Needs
According to their Chronic Health Condition, 2005, 2010 and 2014**



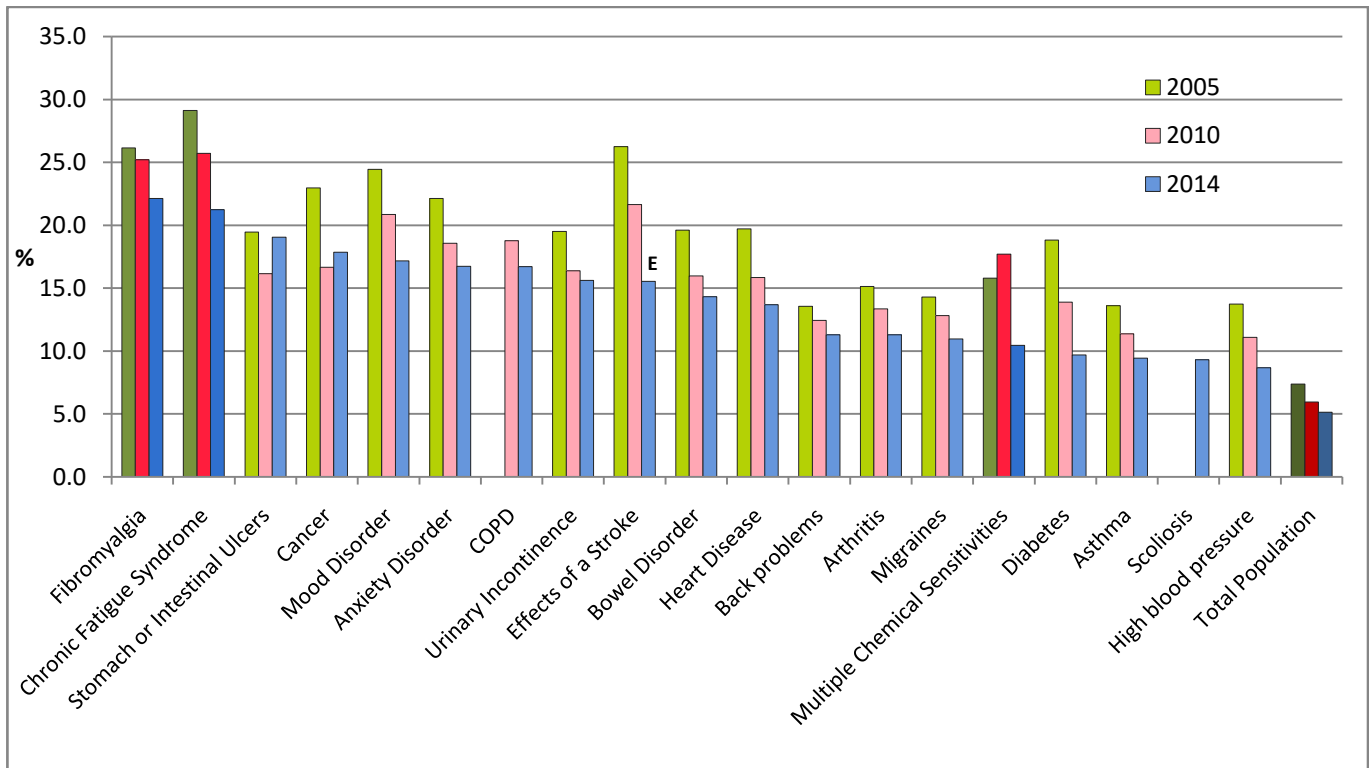
Source: Statistics Canada, Canadian Community Health Survey, 2005, 2010, 2014, Public Use Microdata Files
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

**Graph 4: Canadians Aged 12 and Older Reporting a Very Weak Sense of Community Belonging
According to their Chronic Health Condition, 2005, 2010 and 2014**



Source: Statistics Canada, Canadian Community Health Survey, 2005, 2010, 2014, Public Use Microdata Files
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+
^E Use with caution (Coefficient of Variation between 16.6% and 33.3%)

Graph 5: Canadians Aged 12 and Older Having 10+ Consultations with a Family Doctor in the Previous 12 Months According to their Chronic Health Condition, 2005, 2010 and 2014



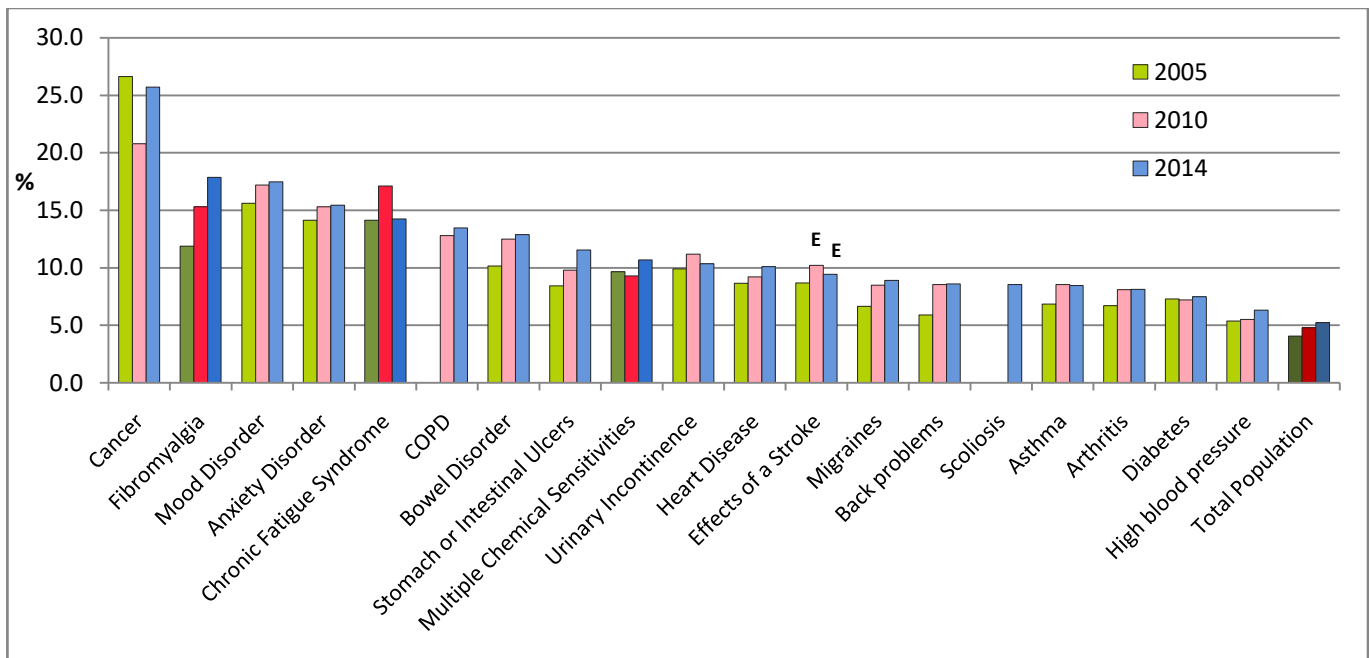
Source: Statistics Canada, Canadian Community Health Survey, 2005, 2010, 2014, Public Use Microdata Files

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

^E Use with caution (Coefficient of Variation between 16.6% and 33.3%)

Graph 6: Canadians Aged 12 and Older Having 5+ Consultations with a Specialist/Other Doctor in the Previous 12 Months According to their Chronic Health Condition, 2005, 2010 and 2014



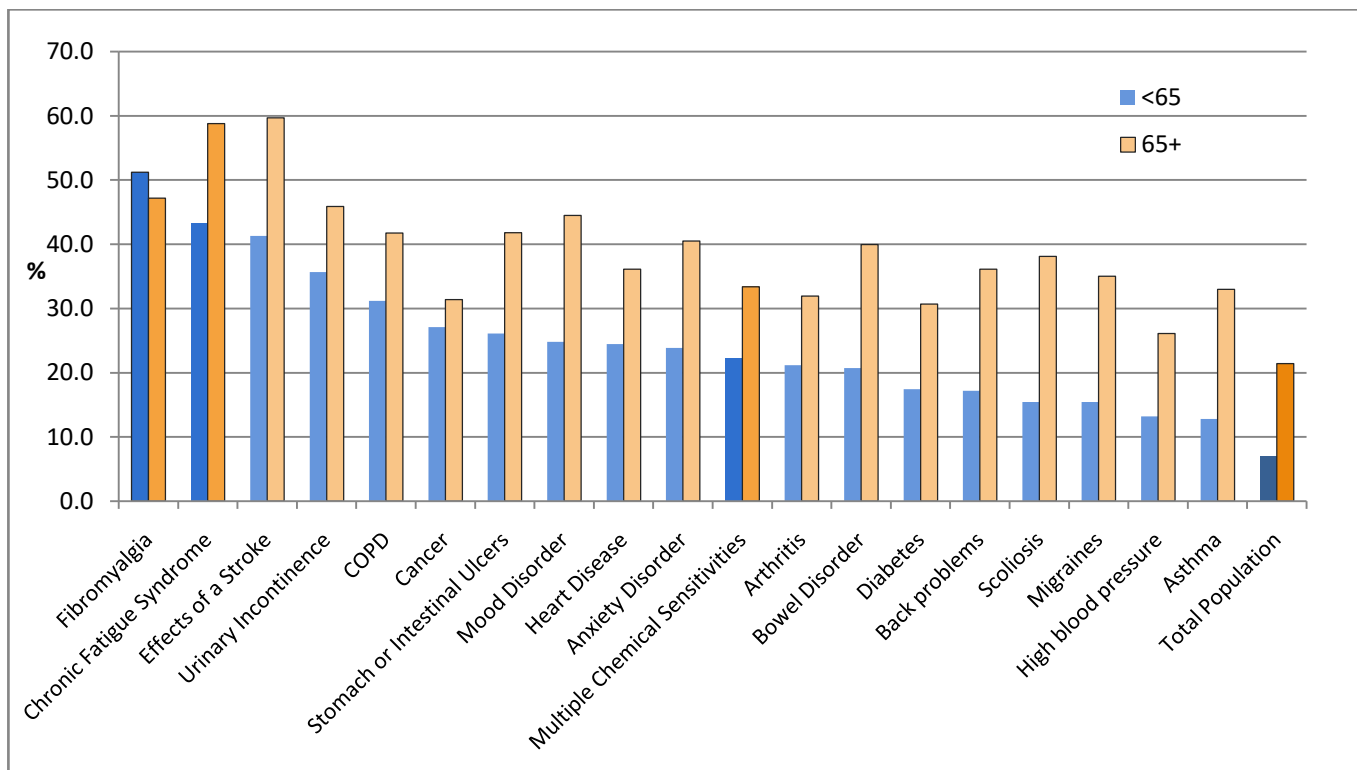
Source: Statistics Canada, Canadian Community Health Survey, 2005, 2010, 2014, Public Use Microdata Files

COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)

Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

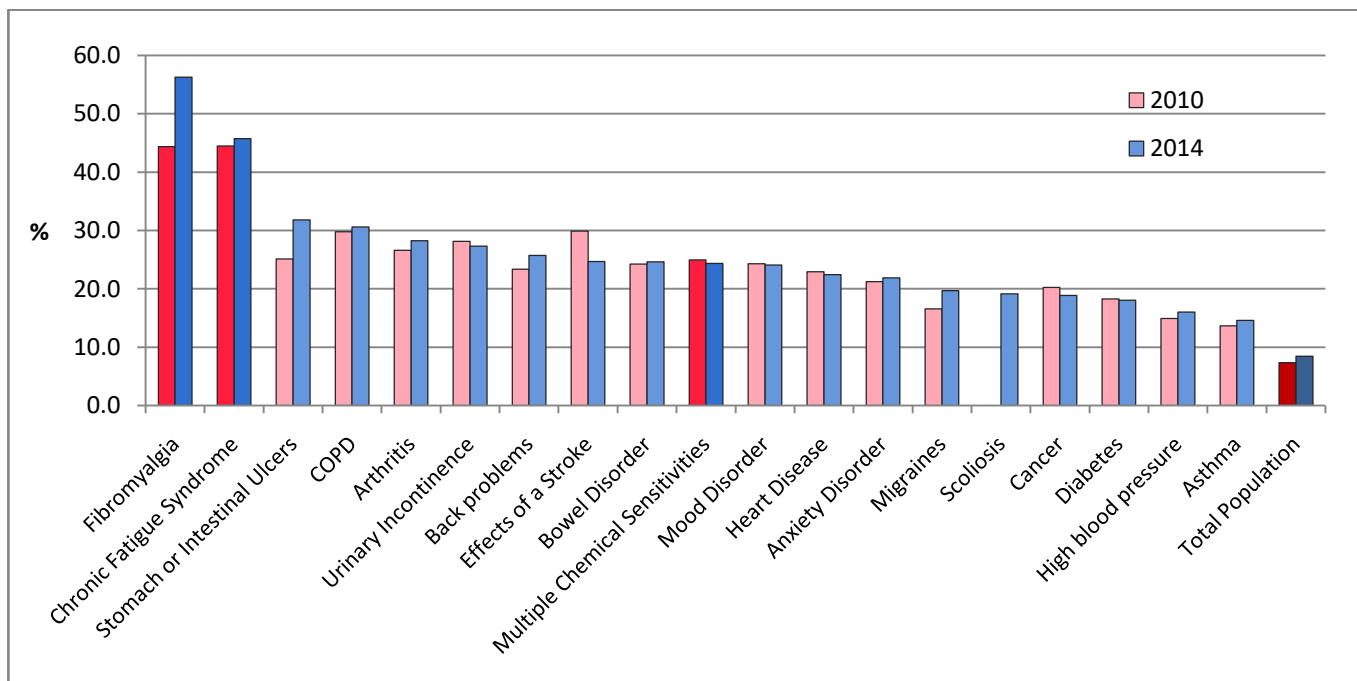
^E Use with caution (Coefficient of Variation between 16.6% and 33.3%)

**Graph 7: Canadians Aged 12 and Older Needing Help with Tasks
According to their Chronic Health Condition by Age Group (< 65 years, 65+ years), 2014**



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+

**Graph 8: Canadians Aged 12 and Older with Moderate or Severe Pain
According to their Chronic Health Condition by Age, 2010 and 2014**



Source: Statistics Canada, Canadian Community Health Survey, 2010, 2014, Public Use Microdata Files
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+; COPD = ages 35+; Urinary Incontinence = ages 25+
 Moderate or Severe pain = Pain prevents some or most activities
 Note: In 2005 pain was collected in British Columbia only and 2005 results are not comparable

Trends: ME/CFS

In 2014, the number of people with ME/CFS was approximately 408,000 or 1.4% of the Canadian population, which is similar to that in 2010 and slightly greater than that in 2005 (Table 1). In 2014, the large majority of those with ME/CFS were of working age (70%) and female (63%), but these proportions decreased from their highest levels in 2005 (79% and 69%, respectively).

The CCHS statistics have shown that people with ME/CFS experience high levels of disability and functional impairment. For example, almost half of the people with ME/CFS needed help with tasks (47% in 2010 and 48% in 2014) (Graph 1). Their rates of mobility problems, cognitive difficulties and pain levels are all among the greatest reported on the survey. In general, none of the disability indicators for ME/CFS have shown much change over time. The consistency over time helps confirm that these high levels are not sampling abnormalities, and demonstrates the serious disability that comes with ME/CFS. (Note that an analysis of 2010 CCHS data by the Public Health Agency of Canada (Rusu et al. 2015) found that those with ME/CFS and FM had a high level of needing help with tasks, even after adjustments for age, gender, socioeconomic factors and co-morbidities.)

The other indicators that we routinely monitor represent various aspects of the health and social systems. There has been no improvement in the findings among those with ME/CFS for these other indicators over time.

Throughout this period, those who are of working age (18-64 years) with ME/CFS showed high rates of being permanently unable to work (a variable which is affected by the individual's disability as well as by the workplace's willingness to accommodate). The rate was greater than 20% in both 2010 and 2014 (Graph 2).

The rate of unmet health care needs for those with ME/CFS was fairly steady between 2005 and 2010, and then peaked in 2014 at 34%. This was the greatest rate reported among any of the chronic conditions on any of the three surveys evaluated (Graph 3). Those with ME/CFS have consistently fared badly in this key indicator of the health system. Although the consistency over time helps confirm these are not sampling abnormalities, it also suggests there has been a lack of progress over the nine year time period.

The proportion of those with ME/CFS experiencing

a very weak sense of community belonging was fairly similar over time and also reached its peak value in 2014 (21%) (Graph 4). Those with ME/CFS had the greatest rates for this key indicator of social isolation on all three surveys. As with unmet health care needs, the consistency strengthens the findings, but it also suggests the lack of progress in improving the conditions for those with ME/CFS.

There was a reduction in those having 10+ consultations with a family doctor among those with ME/CFS (from 29% in 2005 to 21% in 2014) (Graph 5). At first glance, this may appear as a decrease in health care utilization by people with ME/CFS, but this reduction was seen among almost all chronic conditions as well as the total population suggesting a broad phenomenon. Those with ME/CFS continued to have high rates of family doctor consultations in relation to the other conditions.

The rates for having 5+ specialist consultations remained more consistent over time among most chronic conditions. Those with ME/CFS followed this pattern and were among those who made frequent visits to specialists (Graph 6). It is interesting to ask why someone with ME/CFS would be seeing specialists since there are very few specialists in Canada. It is possible that they are seeing specialists for particular symptoms or for co-morbid conditions.

It is not possible to directly compare the measures of unmet home care needs, household income and household food insecurity over time due to changes in definitions and provinces sampled on each CCHS survey. Nonetheless, the proportions of people with ME/CFS who experienced unmet home care needs have been high on all three surveys evaluated. The proportions of people with ME/CFS experiencing poverty and food insecurity in 2014 are particularly alarming with one quarter having a household income of less than \$20,000 that year and over one quarter experiencing household food insecurity. This reflects the long-term and disabling nature of the condition combined with the lack of adequate health and social support.

After reviewing the findings for the three surveys, we can state that those with ME/CFS consistently fared badly for indicators reflecting the health and social systems. The consistency across three surveys strengthens the findings, but also shows a lack of progress over time. In fact, in 2014, two key indicators – unmet health care needs and having a very weak sense of community belonging

– reached their peak levels, while the rates of poverty and food insecurity were extremely high. According to the CCHS data, those with ME/CFS in Canada remain under-served and in great need.

Trends: FM

The 2005, 2010 and 2014 statistics have each shown that FM faces challenges and neglect by the health and social systems. The characteristics of the FM cohort, however, demonstrate changes over time which warrants comment.

The proportion of Canadians with FM increased slightly over time from 1.4% in 2005 to 1.7% in 2014 (Table 1). By 2014, the actual number of people across Canada with FM exceeded half a million. Most of the growth occurred from 2010 to 2014 and was concentrated among women aged 45 and older. In 2014, a large majority of those with FM were of working age (71%). This proportion is lower than the 79% observed in 2005 due to growth in the number of seniors with FM. The proportion of people with FM who were female was 83% in 2005, 79% in 2010, and 82% in 2014. FM has the highest proportion of females of all the chronic conditions surveyed.

There have been notable changes in the level of disability among those with FM. The proportion of those with FM needing help with tasks rose from 38% in 2010 to 50% in 2014. This surpassed the rate for those with ME/CFS, and was a more marked increase than that observed for any other chronic condition (Graph 1).

Given this finding, we further examined the 2014 data by age group (<65 and 65+ years of age) knowing that seniors require more help with tasks than people of younger ages. The proportions needing help with tasks increased markedly for seniors for each chronic condition and the total population as expected. The striking exception was for FM where the proportion needing help with tasks among those aged 65+ was slightly lower than that among those <65 years of age (47% vs. 51%). For the younger age group, people with FM showed a very high rate of disability (Graph 7).

Another variable showing the increase in the level of disability in 2014 among those with FM is pain. For most chronic conditions and for the total population there were mild increases in the proportion of people experiencing moderate or severe pain from 2010 to 2014. The increase in pain levels for those with FM was much greater, rising from 44% in 2010 to 56% in 2014 (Graph 8). People

with FM also experienced some increases in mobility problems, cognitive difficulties, and being permanently unable to work.

These changes in measures of disability over time among those with FM are the most noteworthy changes in statistics for either ME/CFS or FM observed to date. It is possible that the new FM diagnostic criteria are identifying patients with more disabling symptoms and more complex medical issues or that FM cases with an increased number of other chronic co-morbid conditions are being diagnosed. Additional monitoring of disability statistics over time is needed to confirm these findings.

The changes over time with respect to FM for the remaining indicators that we routinely monitor are less remarkable compared to the findings for disability, and have shown no improvement. Several of the results do, however, support the finding of increased disability among those with FM in 2014.

The rate of unmet health care needs for those with FM peaked in 2010 at 31% and then decreased slightly to 29% in 2014 (Graph 3). As with ME/CFS, those with FM consistently show high rates of unmet health care needs over time.

The proportion of those with FM experiencing a very weak sense of community belonging increased over time from 13% in 2005 to 19% in 2014 (Graph 4). This trend is opposite to that observed for the total population, and shows a high rate of social isolation among those with FM.

There was a reduction in those having 10+ consultations with a family doctor among those with FM as observed among almost all chronic conditions and the total population, possibly indicating a broad phenomenon as previously mentioned (Graph 5). Similar to those with ME/CFS, people with FM continued to have high rates of consultations with a family doctor.

The rates for having 5+ specialist consults remained more consistent among most chronic conditions, while those with FM showed evidence of an increase from 12% in 2005 to 18% in 2014 (Graph 6). The use of specialists among those with FM may be further indication of the increase in their level of disability and medical complexity.

As previously mentioned, it is not possible to compare the figures for unmet home care needs, household income and household food insecurity over time, but

Prevalence Figures from CCHS 2015 and 2016

Data from the 2015 CCHS was released in March 2017. Data from the 2016 CCHS was released on September 27, 2017.

Statistics Canada has advised us that “Due to the changes to the frame, sampling and content, the 2015 reference year is considered to be not directly comparable to past cycles of the CCHS. As such, we are considering the new data as a break in the series and advising users to not make direct comparisons between 2015 and previous years. “

This is all the data for ME/CFS, FM and MCS for 2015 and 2016 that has been released by Statistics Canada free of charge at this time. The Network believes that the information in the tables on our website are important public information, and that 2015 and 2016 versions of these tables should be freely available to the health and social system and to the public

	Number, 2016	%, 2016	Number, 2015	%, 2015
Fibromyalgia				
Total	522,000	1.7%	493,600	1.6%
Males	106,300	.7%	97,200	.7%
Females	415,700	2.7%	396,400	2.6%
Chronic Fatigue Syndrome				
Total	581,600	1.9%	561,500	1.9%
Males	208,300	1.4%	195,100	1.3%
Females	373,400	2.4%	366,400	2.4%
Multiple Chemical Sensitivities				
Total	1,008,400	3.3%	940,500	3.1%
Males	268,900	1.8%	284,900	1.9%
Females	739,500	4.8%	655,600	4.3%

these indicators show particularly high rates in 2014. Unmet home care needs among those with FM was especially high at 16%. This finding could also support the high level of disability among the FM population and subsequent need for further home care support.

Collectively these findings show the same message as that for ME/CFS -- that there has been a lack of progress in the health and social systems and that those with FM remain under-served and in great need.

A Note on Multiple Chemical Sensitivities

Generally, the overall degree of disability experienced by the MCS community (measured by variables such as needing help with tasks, being permanently unable to work, and experiencing pain) is moderate, higher than the degree of disability experienced by the general public and similar to the degree of disability experienced by a number of other chronic conditions. It is important to note that this is a group average and that there are people within the group who are very disabled.

Generally, the overall degree of health care utilization (measured by visits to family doctors and specialists), is again moderate, higher than the utilization by the general public and similar to the utilization by a number of other chronic conditions.

And generally the overall degree of health and social disadvantage (measured by unmet health care needs, sense of community belonging, food insecurity, unmet home care needs, and poverty) is moderate as well.

What is striking about MCS is its prevalence. The Canadian Community Health Survey shows prevalence figures of 599,000 in 2005, 800,000 in 2010 and 722,000 in 2014. We have the advantage of seeing prevalence figure for 2015 (940,000) and for 2016 (just over 1,000,000 people).

Our first observation is about the 2014 prevalence figure. While there are concerns about comparing figures from before 2015 with the figures for 2015 and later due to changes in the survey, the 2014 figure is out of line in the time series. That suggests that there was a problem with the 2014 sample for MCS (which can happen by chance).

We were already unsure how to interpret the data, and this finding suggests that it is advisable to be cautious about drawing conclusions about MCS using the 2014 data.

Our second observation concerns the prevalence levels in general. MCS is a medical condition that does not have an ICD (International Classification of Diseases) code, meaning that it is not recognized by the World Health Organization. It does not have diagnostic and billing codes in any jurisdiction in Canada. It has received less than \$40k in CIHR funding since 1999. And yet the survey consistently finds that hundreds of thousands of people report that they have been diagnosed with MCS by a health professional.

There is a great need to find out why a health system that does not acknowledge MCS is giving so many people a diagnosis of MCS. And with so many people being diagnosed with MCS, it is important to figure out what the health and social systems can do to address their needs.

The Need for Additional Statistics and Analysis

The Canadian Community Health Survey has been a very valuable source of statistics on ME/CFS and FM, but more data are needed and more can be done to take advantage of data that exist. Here are some recommendations. Many or all would apply to Multiple Chemical Sensitivities as well.

- That ME/CFS and FM be included on the CCHS every year. These conditions are scheduled for inclusion on the CCHS in 2019 and 2020, but not in 2017, 2018, 2021 or 2022.
- That the tables that support this document be recognized as important public information and that they be generated and released by Statistics Canada every time a new cycle of data is released.
- That more complex studies using the CCHS data be undertaken such as examining issues while standardizing for key variables like age and gender or looking at the role of co-morbidities.
- That the quality of CCHS data be assessed. Canadian prevalence figures for CFS are generally higher than those from other countries and the prevalence figures for FM seem to be lower. CCHS respondents are asked if they have various chronic conditions “which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health professional”. Are respondents answering correctly and, more interestingly, how are health professionals making these diagnoses and are they missing cases?
- That data collection for ME/CFS and FM characteristics and symptoms be standardized. A key reason is comparability for research purposes. There is a major initiative underway in the US to agree on common data elements for ME/CFS. At a minimum Canada should be monitoring this work. Preferably, Canada would be participating in these discussions.
- That there be diagnostic and billing codes for ME/CFS and FM in administrative systems in all Canadian jurisdictions and that this information be analysed and used.
- That longitudinal data for ME/CFS and FM be developed. The CCHS is cross-sectional, choosing a different group of people to interview each time. There is a need for data to study the evolution of the illnesses and their impact on individuals over time.
- That special studies of ME/CFS and FM be undertaken for topics not covered by CCHS such as economic impact, disability adjusted life years (DALYs), human resources serving the communities, housing needs, pediatric cases and care giving.
- That clinical studies be undertaken to compile data to assess the impact of various treatments.
- That research funding statistics by condition be publicly available as is done in the US and Australia.
- That the Canadian Survey on Disability be reviewed to ensure it includes the disabilities experienced by Canadians with ME/CFS and FM.

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