Measuring health outcomes of a multidisciplinary care approach in individuals with chronic environmental conditions using an abbreviated symptoms questionnaire

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Keywords: multiple chemical sensitivity, multidisciplinary, chronic conditions

Introduction

Chronic environmental conditions are a growing concern and a significant burden to the health care system due to the magnitude of the problem (Geertrudis and Van Den Bos 1995; Weiss and Sullivan 2001; Kipen and Fiedler 2002; Litt et al 2004; Druss et al 2001; Bowles 2006) and lack of efficient and effective management strategies (Thea and Vliet 2004).

The Nova Scotia Environmental Health Centre (NSEHC) is a medical facility for treating chronic conditions with probable links to the environment, such as multiple chemical sensitivity (MCS), chronic fatigue syndrome (CFS), fibromyalgia (FM) and other chronic conditions. The management of such conditions is a controversial subject with limited documentation or evidence of support for any particular approach (Litt et al 2004). For most of these conditions there are no specific guidelines to treatment that have been shown to reverse the condition (Hessl 1987; Ziem and McTamny 1997; Sparks 2000; Hoffres et al 2001). The complexity of these problems, with overlapping

diagnoses, symptoms in many body systems and suspected environmental triggers, often leave the medical practitioner baffled. From our experience of managing these patients we find various contributors to impaired health, including physical, psychological, social and environmental factors affect the symptoms reported by patients. The relative contributions of these factors may vary between patients or in individual patients over time. The complex interactions of these factors determine the severity of the symptoms and the overall clinical presentation. This understanding is crucial to the management of these patients where severe symptoms may exist in the absence of any objective physical or physiologic findings (Katon and Walker 1998). The management scheme thus requires the involvement of a multidisciplinary teamof clinicians in order to ensure that all aspects of the patient's health are addressed.

Adopting a symptom-based, patient-centred and multidisciplinary care approach that encompasses all aspects of the patient's health is the care model used in the management of the patients at the Centre. The crux of the treatment is in assisting the patient toward self-management by providing the necessary care, support and education. Our care model is in line with Health Canada's 12 Determinants of Health (WHO) and the chronic model of care (Wagner et al 2001). The care provided at the Centre is individualistic and the care team comprises of a multidisciplinary team of clinicians (Pollard 2004) which includes a physician, nurse, physiotherapist, psychologist/psychotherapist, dietician and rehabilitation coordinator. The patient is actively engaged in the multidisciplinary team decisions and in the development of the individualized care plan through regular discussions with their care coordinator at the Centre, their physician. The care management scheme at the NSEHC is divided into specific phases of intervention to effectively assist the patient towards self management of their condition. The management begins with in-depth evaluation and patient education, a phase of passive and baseline intervention by the care providers, a phase of intervention with patient being an active participant, a phase of collaborative self management phase with the involvement of the care providers and concluding with self management by patients.

Care at the Centre begins with a comprehensive evaluation of the patient's condition by the multidisciplinary care team. A variety of diagnostic tests including balance assessment using a sway tester, exposure testing in a controlled environment chamber, and psychodiagnostic by a psychologist are conducted during this phase. This information gathering phase also includes administering several validated questionnaires such as Symptoms Checklist Inventory (SCL-90R), Fibromyalgia Impact Questionnaire along with holding detailed interviews that cover a broad range of physical, psychological, social and environmental aspects of illness. Based on the outcome of the evaluation, some baseline education and information tools are offered to patients to enhance the understanding of their illness. As patients go through this phase, further tests and inquires regarding the health condition may be done by the health care team to obtain clarity about the patient's illness. Preliminary intervention schemes that are generic in nature such as dietary intervention, stress management, rehabilitation support, building physical and emotional resiliency may be offered while the patient specific care plan is being developed by the care team. As detailed aspects of a patient's condition become evident, the care team generates an individualized care plan for the patient which involves a focused treatment approach that directly relates to the outstanding aspect of the patient's illness which may be pain and fatigue management using a graded exercise therapy or addressing psychological symptoms with an emotion-focussed treatment approach. During this phase, the patient becomes an active participant of their care management. Tools and community integration schemes for self management are identified for every patient during this phase and the care team collaboratively facilitates this change for a period of time with exit point of care being self management of the condition by the patient.

Treatment approaches offered to provide symptomatic relief include desensitization for classical allergies, physiotherapy for deconditioning, systemic and topical pharmaceutical agents for pain relief, intravenous nutrients for fatigue or relief of musculo-skeletal pain, heat depuration (sauna) and exercise. In the absence of any therapy that is known to reverse the underlying condition, other individualized approaches are used to help patients manage their problems and achieve a higher level of health. Stress, environmental or emotional, is addressed with counselling, craniosacral therapy or guided imagery, and on a group basis with mindfulness based stress reduction, Wellness and FreezeFrame[®] programs. Environmental stress is also managed by reducing exposures. The treatment modalities are all designed to coach, educate and train the patients to use the techniques in the self management of their condition.

A study conducted at the Centre looked at the prevalence of major symptoms in 351 patients at the Centre. The major prevalent symptoms identified by thestudy were displayed in multiple body systems. General symptoms such as difficulty concentrating, fatigue, forgetfulness, and irritability were found to be present from the start of illness. Those related to irritation such as congested sinuses, itchy or burning eyes, and hoarseness or loss of voice were more common after exposure to environmental irritants (Joffres et al 2001).

Since the symptoms displayed by the patients affect multiple body systems, it was deemed important to develop a tool that measured and captured the changes in all of the body systems. A detailed questionnaire based on the Toronto Health Survey questionnaire (McKeown-Eyssen et al 1994) was developed and validated for use at the Centre on individuals with chronic environmental conditions. This questionnaire contains modifications from the original version based on feedback to the Toronto investigators, from focus groups involving patients, practitioners and pilot testing. Changes to original questionnaire included reducing the length of the questionnaire by adding more open-ended questions to capture perceived provocation of symptoms related to exposures. The language of the questionnaire was simplified and made politically sensitive. A general health section covered patients' health status since the beginning of their illness. The next section focussed on limitations in their daily activities due to their illness and a section on health problems documented major conditions diagnosed by a physician. The section on symptoms addressed symptoms that the patients may have experienced since the start of their illness, frequency and intensity, and whether or not these symptoms occurred or got worse after identified exposure. Open-ended questions provided space for patients to list the type of exposures that might have been associated with occurrence of their symptoms. This was followed by their family history, demographic characteristics, employment history, socio-economic status and information related to the completion of the questionnaire. A validation study was conducted to determine the effectiveness and the sensitivity of the NSEHC symptoms questionnaire. The study examined the prevalence of 217 symptoms in 13 sections/systems. It was the first attempt to describe the type, frequency, and severity of the most common symptoms experienced by an environmentally sensitive population. A total of 385 (47%) questionnaires were returned, and data were analyzed on 351 individuals. Participants tended to be women (80%), middle-aged individuals (37% age 40-49 years), and those in higher educational groups (28% completed university), but there was wide variation in demographic variables. The results from this study helped generate the top symptoms that were prevalent in this patient population. General symptoms such as difficulty concentrating, fatigue, forgetfulness, and irritability dominated the overall prevalence of symptoms

since the start of their illness. Those related to irritation such as sneezing, itchy or burning eyes, and hoarseness or loss of voice were more common after exposure to environmental irritants. Ranking of symptoms using severity scores was consistent between men and women. Overall scores were higher in women, in participants who were separated or divorced, and in low-income groups. The top 15 symptoms reported in this study following an exposure are as shown in Table 1.

As a follow up to this study, another study was conducted to evaluate the impact of a multidisciplinary treatment approach on the top reported symptoms in the patient population. The results from this pilot study are reported in this paper. The abbreviated version of the NSEHC symptoms questionnaire, NSEHC-BREF was created to capture the changes in the top reported symptoms over various time periods of follow up since the commencement of treatment at the Centre. In the NSEHC-BREF, an introductory overall health related question and an open-ended question at the end used to capture any other incidents or changes that may have impacted the health status were also used. The sections on family history, demographic characteristics, employment history, socio-economic status and information related to the

 Table I Prevalence of the top 15 symptoms reported since the start of the illness and ranked by sex in individuals with MCS following an exposure

Symptoms	Males N = 70%	Females N = 281%		
	N = 70%	IN = 201 %		
Sneezing/runny or congested nose without a cold	60	68		
Itchy eyes	59	65		
Difficulty concentrating	47	56		
Other headache	41	54		
Burning eyes	46	52		
Hoarse of loss of voice	29	54		
Stuffy or full sinuses	44	47		
Forgetfulness/poor memory	33	49		
Tight chest	34	48		
Usually acceptable odors were sickening	41	45		
Fatigue, very tired, without energy	40	44		
Difficulty making decisions	34	45		
Trouble finding the right words	31	46		
Irritability	43	43		
Feeling light-headed	37	44		

% indicates percent of patient having the symptom.

completion of the questionnaire were excluded since these changes are captured in the multidisciplinary interviews and in the main symptoms questionnaire. The NSEHC-BREF is seen as more of a follow up tool to measure the impact of treatment on the top reported symptoms. The idea around capturing changes in these specific symptoms related to exposure is to study the degree of symptoms management achieved with treatment in individuals with MCS. Thus the overall objective of this study was to examine the type and extent of changes observed in the top reported symptoms as an outcome of the multidisciplinary treatment over various time periods of follow up. The scores from NSEHC-BREF were compared to the scores measured using the main symptoms questionnaire.

Methods

Subject selection and recruitment

Approximately 500 patients with a diagnosis of MCS (Bartha et al 1999) in combination with CFS or FM were approached for participation. Patients were selected under the following categories: 6 month to 1 year of treatment at the Centre, 1 to 2 years of treatment at the Centre, 2+ years to a maximum of 5 years of treatment at the Centre and discharged patients. A total of 183 active patients participated in the study under the following categories: 6 months to 1 year of treatment at the Centre, 2+ to a maximum of 5 years of treatment. Patients who agreed to participate were mailed out the abbreviated questionnaire along with the consent form.

Outcome measure and data analyses

The Nova Scotia Environmental Health Centre abbreviated symptoms questionnaire, NSEHC-BREF was used to monitor changes in health over various time periods after enrolment to the Centre.

The symptom scores were computed as the frequency of occurrence of symptoms 7 days prior to their filling out the NSEHC-BREF (rarely, from time to time, most of the time, all the time, rated as 1–4) multiplied by the severity (low, moderate, high, rated 1–3). Therefore the maximum score for each question is 12, the minimum being 0. The global score is a mean score computed as the sum of all scores divided by the number of symptoms. Comparison of symptom scores from the NSEHC-BREF was made against the detailed questionnaire scores that have already been computed for each patient at the Centre. SAS 9.1 was used to conduct the statistical analysis for the study. There are 30 questions in total in the NSEHC-BREF with 22 questions on symptoms and 8 questions on the overall health. The time required to complete the questionnaire is approximately 15 minutes.

The Capital District Health Authority Research Ethics Board approved this study.

Results

A total of 183 active patients and 109 discharged patients participated in the study. About 250 active patients and 250 discharged patients were approached for participation.

Table 2 shows the demographical details for the subjects who participated in the study. The response rate from the female participants was higher than the male participants.

Table 3 shows the overall improvement in health in the different groups of patients tested. Patients showed statistically significant improvement in their overall health under categories such as health since ill 0.05 (6 months–1 year), <0.0001 (1–2 years, 2+ years, discharged); too ill to do housework 0.05 (6 months–1 year), 0.008 (1–2 years), <0.0001 (2+ and discharged); limit contact with people to avoid exposures 0.9 (6 months–1 year), 0.09 (1–2 years), 0.02 (2+ years) and <0.0001 (discharged).

Tables 4 and 5 show changes in symptoms grouped under different categories. Table 4 captures changes observed in eyes, nose, throat and respiratory symptoms. Stronger sense of smell and tight chest showed consistent and early changes of statistical significance with 0.02 (6 months–1 year), 0.008 (1–2 years), <0.001 (2+ and discharged) and 0.03 (6 months–1 year), 0.0007 (1–2 years), <0.0001 (2+) and 0.02 (discharged) respectively. Nose symptoms such as usually acceptable odors were sickening and stuffy or full sinuses were observed in the 1 year and above groups. Hoarse of loss of voice and itchy eyes showed sudden improvements in 2+ and discharged groups.

Table 5 shows changes in health measured in blood and gland, nervous system and muscle and joints. Symptoms showing consistently significant improvement in various time periods of follow up include Symptoms such as difficulty concentrating 0.01 (6 months–1 year), 0.003 (1–2 years) and <0.0001 (2+ and discharged); difficulty making decisions 0.007 (6 months–1 year), 0.002 (1–2 years) and <0.0001 (2+ and discharged); tiredness not relieved by sleep 0.002 (6 months–1 year), 0.01 (1–2 years) and <0.0001 (2+ and discharged); and muscle spasms and cramps 0.02 (6 months–1 year), 0.002 (1–2 years), and 0.002 (2+ years and discharged). Symptoms

Table 2 Demograp	Table 2 Demographics											
Active N = 182			Discharged N = 109									
Periods of time follow up	6 month- I-2 years I year		2+ years	6 month- 3 years	3–5 years	5+ years	Total					
Age												
Mean (SD)	47.3 (10.3)	48.5 (8.7)	50.8 (10.5)	54.7 (10.7)	52.8 (10)	52.7 (12.3)	53.3 (10.8)					
Range	25–62	30–64	18–74	30–75	19–75	19–78	19–78					
Sex	Number of Pa	rticipants										
Male	I	0	20	5	5	7	17					
Female	31	32	99	22	44	25	92					

such as irritability, forgetfulness and trouble finding the right words showed significant changes in the groups past 1 year of treatment. Fatigue and tiredness without energy showed sudden improvements in 2+ and discharged groups. Inconsistent changes were observed in categories such as bruise easily, muscle pain and sensitive to temperature changes.

Discussion

The prevalence of unexplained symptoms and reactivity is on the increase in the recent years (Caress and Steinemann 2004). Many patients of the Centre have spent several years trying to find the right clinicians who can understand their illness and help them manage it (Geertrudis and Van Den Bos 1995; Druss et al 2001). When they are first seen at the Centre, patients often present a very negative perspective of the health system and are very dysfunctional on account of their existing symptoms.

Measuring changes in chronic health conditions such as MCS is often challenging with patients having multiple

diagnoses and multiple care providers. The goal of multidisciplinary care approach at the Centre is to provide an individualized care approach for its patients with timely evaluation of the presenting symptoms and integrated care delivery by multidisciplinary care providers. Black et al (2000) have described the possible effects of time over treatment in a 9-year follow up study of individuals with MCS. However, it is important to identify the type of symptoms that change and the extent of these changes if we are to determine whether it is the treatment or simply the passage of time that contributes to improvements in health. If there are positive changes in health, then a qualitative study can clarify the potential reasons for these changes. It is also challenging to identify any one treatment that may have had an impact on the improvement in health symptoms (Rundall et al 2002; Richardson and Engel 2004). It may be a combination of treatments in addition to education and lifestyle changes that is impacting the health of an individual. The objective of this study was to quantify the effects of an integrated care approach in the

Period of time follow up	6 m–l y	year* (n =	32)	I–2 yea	I-2 years (n = 32)			2+ years (n = 118)			Discharged (n = 109)		
	Pre Mean (SD)	Post Mean (SD)	p-value										
Health since ill	3.03 (1.1)	3.59 (1.4)	0.05	2.63 (1.3)	4.18 (1.5)	<0.0001	2.6 (1.1)	3.9 (1.4)	<0.0001	2.94 (1.3)	4.29 (1.3)	<0.0001	
Limit contact	2.9	3.03	0.9	3.5	3.1	0.09	3.5	3.3	0.02	3.4	2.7	<0.0001	
with people to avoid exposures	(1.1)	(1.2)		(1.1)	(1.2)		(1.1)	(1.2)		(1.1)	(1.3)		
Too ill to do housework	3.2 (0.9)	2.8 (1.01)	0.05	3.2 (0.7)	2.4 (1.1)	0.0008	3.5 (0.8)	2.9 (1.01)	<0.0001	3.2 (0.7)	2.5 (1.1)	<0.0001	

*6 months to I year.

Table 3 Changes measured in overall health

Period of time follow up	6 m-1 year* (n = 32)			I-2 years (n = 32)			2+ years (n = 118)			Discharged (n = 109)		
	Pre Mean (SD)	Post Mean (SD)	p-value	Pre Mean (SD)	Post Mean (SD)	p-value	Pre Mean (SD)	Post Mean (SD)	p-value	Pre Mean (SD)	Post Mean (SD)	p-value
Burning eyes	2.4 (3.3)	1.9 (2.5)	0.06	2.8 (3.2)	2.5 (3.4)	0.4	3.4 (3)	2.4 (2.8)	0.05	3 (2.4)	1.7 (2.3)	
ltchy eyes	2.2 (2.9)	2.3 (2.9)	0.8	2.7 (2.7)	2.8 (2.7)	0.9	3.6 (2.5)	2.5 (2.5)	<0.0001	3.5 (2.2)	2.3 (2.7)	<0.0001
Stuffy or full	4.7	4.3	0.7	5.2	2.9	0.006	4.8	3.1	<0.0001	4.7	3.7	0.01
sinuses	(3.6)	(3.7)		(4.1)	(3.4)		(3)	(2.9)		(3.2)	(2.9)	
Sneezing/runny nose without a cold	5.5 (4.6)	3.0 (3.6)	0.001	7 (5)	4.3 (5)	0.006	5.1 (3.6)	3.1 (3.5)	<0.0001	4.2 (3.4)	3.5 (3.5)	0.1
Stronger sense of smell	4.5 (4.9)	2.3 (3.4)	0.02	6.5 (5.7)	3.2 (4.1)	0.008	7.2 (4.6)	3.1 (3.7)	<0.0001	6.6 (4.8)	3.4 (4.2)	<0.0001
Usually acceptable odors were sickening	4.7 (3.8)	3.9 (3)	0.34	4.9 (3.7)	3.4 (3.1)	0.09	5.4 (3.9)	2.8 (3)	<0.0001	4.5 (4.1)	2.4 (3.6)	<0.0001
Tight chest	2.4 (2.4)	1.2 (1.6)	0.03	4.3 (3.7)	2.2 (3.1)	0.0007	3.4 (2.9)	2.2 (2.8)	<0.0001	2.8 (2.6)	1.9 (2.6)	0.02
Hoarse or loss of voice	2.7 (3.2)	2.8 (3.7)	0.8	3. I (3.8)	2.6 (3.5)	0.5	3.9 (3.4)	2.8 (3.4)	<0.0001	3.9 (3.3)	2.2 (2.7)	<0.0001

Table 4 Changes measured in eyes, nose, throat symptoms and respiratory systems

*6 months to I year.

MCS population regardless of the type of individualized care prescribed to the patient.

The pilot study has helped us identify a useful tool that will allow us to measure health changes in patients with MCS. The abbreviated questionnaire was used to focus the attention on the nature and extent of changes in the top reported symptoms in the MCS group. The results are promising evidence of the effectiveness of the NSEHC-BREF in measuring changes at various time periods of follow up.

The pilot study showed some interesting changes in the top reported symptoms in various categories and at various time periods of follow up. Some changes were more consistent than others. Observed changes in nose and nervous systems such as improvement in stuffy sinuses and concentration match our clinical observations. Some of the inconsistencies in bruise easily and sensitivity to temperature changes raise questions on being captured as top symptoms related to exposures in this sensitive population in our previous research. This study has provided some preliminary results on the nature and extent of symptom changes in MCS using an abbreviated questionnaire. This study has also shown that there may be benefits in considering a more comprehensive approach to treating these individuals displaying symptoms in multiple body systems rather than a rigid treatment protocol that either treats the physical or the psychological symptoms. The study does have its limitation which needs to be addressed in order to draw more meaningful conclusions.

Limitations

There were limitations to the study design in which the primary objective was to evaluate the effectiveness an abbreviated symptoms questionnaire in measuring changes in health related to a multidisciplinary treatment approach. The study was neither randomized nor longitudinal in design. So, while it is interesting to observe the type of symptoms that changed and reached statistical significance, it is impossible to comment beyond that since the same individuals were not followed at the different time periods. It is also crucial to have controls in the study in order to determine the impact of passage of time in the observed improvements in health.

Conclusions

Despite the study limitations, the pilot was a useful first step to observe the changes in health in MCS patients undergoing a multidisciplinary care approach with the abbreviated symptoms questionnaire. The study helped identify an outcome tool that measures the overall effect of treatment over a period of time rather than trying to identify or isolate the effects of a particular treatment. The outcome of this

Period of time follow up	6 m–1 year (n = 32)			I-2 yea	I-2 years (n = 32)			2+ years (n = 118)			Discharged (n = 109)		
	Pre Mean (SD)	Post Mean (SD)	p-value										
Difficulty concentrating	4 (3)	2.0 (3.2)	0.01	5.5 (4.4)	2.4 (3.3)	0.0003	6.7 (3.2)	3.2 (3.6)	<0.0001	6.2 (3.4)	3.8 (3.4)	<0.0001	
Difficulty making decisions	3.9 (3.9)	2.3 (3.1)	0.007	5.1 (4.1)	2.3 (3.1)	0.002	5.6 (3.7)	2.8 (3.2)	<0.0001	4.5 (3.6)	2.2 (2.7)	<0.0001	
Trouble finding the right words	4. l (3.4)	4.7 (3.5)	0.44	5.8 (4.4)	3.8 (3.9)	0.07	5.7 (3.7)	4.0 (3.7)	<0.0001	5.0 (3.5)	3 (3)	<0.0001	
Forgetfulness/poor memory	3.7 (3.5)	2.7 (2.9)	0.14	4.6 (4.0)	2.2 (2.8)	0.004	6.4 (3.5)	3.1 (3.3)	<0.0001	6 (3.8)	4 (3.4)	<0.0001	
Feeling light headed	4. l (3.2)	2.9 (3)	0.06	4.3 (3.2)	2.4 (3)	0.01	4.3 (2.8)	3.0 (3.0)	0.08	3.1 (3)	2. I (2.7)	0.003	
Irritability	3.6 (3.4)	2.7 (2.8)	0.3	3.5 (3.6)	1.7 (2.1)	0.01	4.6 (2.9)	2.8 (2.8)	<0.0001	4.5 (3.2)	2.6 (2.5)	<0.0001	
Bruise easily	5.7 (4.2)	5.3 (4)	0.6	5.9 (4.5)	4. l (4.4)	0.1	4. l (3.8)	4.2 (4)	0.9	4.1 (4)	2.8 (3.6)	0.01	
Tiredness not relieved by rest/sleep	6. l (4.2)	3.2 (3.5)	0.002	7 (4.6)	5.1 (4.3)	0.01	7.7 (3.8)	4.8 (4.5)	<0.0001	6.7 (3.5)	4.3 (3.3)	<0.0001	
Sensitive to tempera- ture change	6.7 (4.4)	3.5 (3.7)	0.0003	6.5 (4.3)	4.6 (4.4)	0.1	5.6 (4.4)	4.1 (4.1)	0.004	3.5 (3.8)	4.4 (4)	0.2	
Fatigue, very tired, without energy	5.2 (3.5)	4.7 (4.5)	0.5	6.2 (4.6)	5.6 (4.2)	0.3	7.6 (3.7)	5.1 (3.9)	<0.0001	6.5 (3.4)	4.8 (3.3)	<0.0001	
Muscle pain or ache not related to over exercise	3.7 (3.6)	3 (3.4)	0.5	5.1 (4.6)	3.7 (3.5)	0.09	5.5 (4.2)	4.5 (4.3)	0.02	4.6 (3.8)	4.6 (3.8)	0.9	
Muscle spasms/ cramps	4.5 (3.5)	2.5 (4.3)	0.02	3.8 (4.8)	1.8 (3.6)	0.002	3.9 (3.3)	2.7 (3.3)	0.002	3.3 (3.3)	2.3 (3.3)	0.002	

Table 5 Changes measured in blood/gland, muscle joint and nervous system

study clearly warrants further research into the efficacy of the multidisciplinary approach in MCS in a longitudinal and randomized study design.

Disclosures

The authors have no conflicts of interest to disclose.

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