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A proposed care model for a complex chronic condition: multiple chemical sensitivity

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1. Introduction

One of the major challenges to delivering effective health care to patients with complex, chronic health problems is that health systems have been designed to deal with acute episodic illness. This has led to increasing specialization in treatment of disease, focused on individual body systems and indeed one part of one organ. When a person becomes acutely ill and requires expertise that cannot be managed by a primary care physician they are referred for specialized care. As the population ages we are seeing more chronic health conditions which require long term management, often punctuated by episodes requiring acute care. As the burden of chronic disease has increased it has been recognized that management becomes more complex when there are interacting problems like hypertension, cardiac disease and diabetes. Individual “diseases” are more easily managed, but when there are multiple diagnoses, management becomes more difficult. Fortunately many of these chronic conditions have clear guidelines for monitoring and treatment, and even where there can be several problems in the same patient the guidelines are followed. However, patients who develop more difficult problems in more than one body system often end up with treatment from multiple specialists. Coordination of the efforts of the various specialists usually rests in the hands of primary care physicians, which presents many challenges (Henningsen et al 2003, Verhaak et al. 2006). In Canada, family physicians provide primary care and for the most part work independently, not within a team of other health professionals. Most family physicians have a heavy workload and usually see many patients during fairly short visits. Patients with multiple, interacting problems present a major challenge for family physicians (Fink & Rosendal 2008). When someone is chronically ill with multiple conditions, they often see different clinicians at different sites. This increases the risks of errors and of poor care coordination. Undoubtedly this increases suffering for the individual and higher health care costs for society. These issues have been recognized in the elderly population and the speciality of geriatrics has developed which specializes in the management of the frail elderly (Rockwood et al 1994). Frailty is more likely with more health problems or deficits (Rockwood et al 2004), and the most frail individuals present greater challenges in management.

No such specialization has developed in dealing with younger patients with multiple interacting problems and it is much more difficult for primary care physicians to manage poorly understood chronic illnesses. Often these chronic illnesses are not recognized as specific illnesses or diseases, but only as chronic problems with medically unexplained symptoms. These kinds of problems present major challenges and we know that they are common in Western populations. Chronic fatigue syndrome is known to affect between 400,000 and 900,000 adults in the United States (Jason et al 1999, Reyes et al 2003). About 16% of Californians report that they are unusually sensitive to chemicals and 6.3% have been diagnosed with environmental illness (Kreutzer et al 1999). Hypersensitivity to chemicals leading to illness has also been reported to affect about 13% of a population in Georgia, United States (Caress and Steinemann 2004). Chronic illnesses, which are not well understood are common problems which place a significant burden on health care systems. There are several, major challenges to effective care. It takes longer to make a diagnosis (Stockl 2007), to identify solutions and offer recommendations for the multiple problems. Another issue is being able to offer treatment recommendations which are evidence based and in accordance with published guidelines. This is impossible if the patient seeking help has medically unexplained symptoms, or is diagnosed with a condition such as multiple chemical sensitivity, chronic fatigue syndrome or fibromyalgia, since widely accepted guidelines do not exist. So what kind of care can be provided when the physician is faced with a patient who is experiencing life-changing ill health and who reports extensive suffering and disability? The physician may well ponder various questions such as "Which specialist is able to help?" or "What can I offer for treatment?" or "Where can I find the time to listen to the various complaints?"

In one prospective study of 300 new patients referred to a neurology clinic, 11% had symptoms which were not at all explained by organic disease and a further 19% were only somewhat explained (Carson et al 2000). The authors concluded that these patients were disabled, distressed and deserved more attention. Being unable to fully understand the disease process or to make a specific diagnoses should not prevent provision of appropriate health care. Indeed there are reports of various approaches to help individuals and alleviate suffering, for example by offering cognitive behavioral therapy (Martin et al 2007). Sumathipala (2007) reviewed published literature for the highest level of evidence on the efficacy of treatment for patients with medically unexplained symptoms, and concluded that there was more evidence for cognitive behavioural therapy improving the health of these patients than for any other form of therapy.

The term medically unexplained symptoms was probably first used by de Figueiredo (1980) when describing a case of Briquet's syndrome, a recognized psychiatric disease. Since that introduction, the term has been used to describe any condition that lacks structural pathology in the tissues (Nettleton 2006; Binder 2004; Smythe 2005). It is obvious from the literature on medically unexplained symptoms, that many authors have a psychological or psychiatric background, and therefore interpret the illness as being secondary to psychopathology. There is little discussion of the biological aspects of the illnesses diagnosed in patients with unexplained medical symptoms. Another label that is applied to these difficult and complex patients is somatization disorder, or that the symptoms are manifestations of somatization. To identify the illness as somatization disorder is not appropriate for this patient population with chronic ill health. To make such a diagnosis symptom onset must occur before the age of 30. Furthermore common associated features

include loss of touch and pain sensation, inconsistency in history and antisocial behaviour (DSM-IV-TR 2000). Patients with chronic health problems which include the diagnoses of multiple chemical sensitivity, fibromyalgia and chronic fatigue syndrome do not show these features and there is no evidence that psychiatric or psychological therapies alone cure the problems. Somatization disorder is not an appropriate diagnosis but might be used as a descriptive term to define the illness behaviour in which an individual communicates psychological distress through unexplained physical symptoms (Ford 1997; Bluui and Horopf 1997). It is recognized that in a wide variety of health problems patients can experience some relief of suffering with appropriate psychological treatment.

A survey of chronically ill adults in eight different countries reviewed the experiences of patients with chronic conditions and with complex health care needs (Schoen et al 2008). These authors pointed out that the goals for treatment of chronic illness are different from managing acute episodic illness. When health systems are designed to deal with acute illness the goal is usually cure rather than seeking to prevent complications and delaying deterioration. The major intention of any form of health care is to alleviate suffering which is frequently achieved in a system focusing on acute care when cure is possible. When cure is not possible, this becomes more difficult and suffering may increase secondary to inappropriate treatment or iatrogenic complications. This is well recognized in the management of the frail elderly in acute hospitals. It is not surprising that the study of Schoen and others (2008) found significant variation in care of patients with chronic illness in different countries. The authors conclude that there is a need to integrate care for the chronically ill patient around the patient, supported by information systems that provide timely and relevant information and enable effective and efficient care. Integrating care around a patient means adopting a biopsychosocial approach to care, paying equal attention to biology and psychology. Patients are referred to the Nova Scotia Environmental Health Centre because they are ill and suffering. In the absence of any recognized effective approach to care we adopted the concept of person-centred patient care. In this chapter we review the development of this approach in the management of patients with multiple chemical sensitivity and offer it as a model for management of chronic disease.

2. Multiple Chemical Sensitivity

The Nova Scotia Environmental Health Centre was established in 1994 to provide care for environmentally sensitive patients and to conduct research into the diagnosis, pathogenesis and management of patients with multiple chemical sensitivity. The Department of Health of the province of Nova Scotia was responding to the need expressed by patients and physicians. Since the opening of the center the demand for clinical care has been high.

Multiple chemical sensitivity has been identified as a disorder which is characterized by reactivity to environmental chemicals. Controversy exists as to the etiology and possible pathogenesis. Controversy continues as to whether it is a disease or an illness, and in the absence of identifiable structural pathology, most refer to it as an illness. If it is accepted as a distinct problem then what is the pathogenesis? Is it physical or psychological? This example of Cartesian dualism has been discussed for many years by physicians, patients and society at large. Since this is a poorly understood problem, many have concluded that this disorder is psychological and should be treated as a psychological problem. Yet there is little evidence that psychological or psychiatric treatment alone has helped patients

(Davidoff & Fogarty 1994). Labelling a difficult to understand problem as a psychological problem is often problematical and once the Nova Scotia Environmental Health Centre was established in 1994 many patients were referred on their insistence that they were not psychologically ill, that there was "something else going on". It soon became clear that some patients were extremely stressed or anxious, and some were depressed. However, because of their traumatic experiences with other health professionals, it was difficult at first to address these issues without first establishing an alliance with the patient. Any approach was seen as yet another physician diagnosing the illness as being "all in your head."

In order to be able to address psychological issues, if present, it became necessary to gain trust and confidence and to validate the patient's illness experience. It was not difficult to recognize that the patients referred to the Nova Scotia Environmental Health Centre and who fulfilled the criteria for a diagnosis of Multiple Chemical Sensitivity, were ill. Indeed, it is generally accepted that people diagnosed with this condition are ill and experience a wide range of symptoms, even if there is no agreement as to whether this is a single disease. Mark Cullen(1987) provided a research definition of this condition, which he referred to as multiple chemical sensitivities. This has led to other, improved definitions, which are more valuable in clinical settings to establish a diagnosis (Nethercott et al 1993, Bartha et al 1999). The best available case definition was reached by consensus and published in 1999 (Bartha et al 1999). Multiple chemical sensitivity is diagnosed in a patient when the following six criteria are met;

1. The symptoms are reproducible with repeated chemical exposure
2. The condition is chronic
3. Low levels of exposure result in manifestations of the syndrome
4. The symptoms improve or resolve when the incitants are removed
5. Responses occurred to multiple, chemically unrelated substances
6. Symptoms involve multiple organ systems

The diagnosis of Multiple Chemical Sensitivity is made when all six criteria are fulfilled and can be made alongside other diagnoses such as asthma, allergy, migraine, chronic fatigue syndrome, fibromyalgia, irritable bowel syndrome, depression, panic attacks or interstitial cystitis. Implicit in this consensus definition is the recognition that there is wide variability in the clinical presentation and in the degree of disability among patients. Disability can be minimal or total. The experience at the Nova Scotia Environmental Health Centre is that up to half our patients are disabled to the extent that they have to stop work or discontinue education. Symptom severity can vary from being mild to severe, including life-threatening anaphylaxis. Patients with multiple chemical sensitivity experience physiological dysfunction in various body systems manifest by the development of symptoms upon exposure to a triggering substance or a new environmental situation. Exposure can be by ingestion, inhalation or topical application to the skin. Environmentally sensitive individuals can experience dysfunction in more than one body system at the same time. Irritation of the airways can lead to rhinitis, sinusitis, cough, hoarseness, laryngeal stridor or asthma. Central nervous system dysfunction, present in most patients, leads to complaints of being unable to concentrate, to think clearly, to complete multistep tasks, to recall items from memory or to lay down new memories. This collection of symptoms is often referred to as "brain fog". Inevitably there are mood changes in association with the symptoms, such as irritability, anxiety and depression.

In a detailed study of 351 patients referred to the Nova Scotia Environmental Health center and diagnosed with multiple chemical sensitivity, it was found that 80% of the patients were female and 37% fell within the 40 to 49 year age group (Joffres et al 2001). The major symptoms experienced by this patient population were divided into two categories -

1. Generalized symptoms such as fatigue, difficulty in concentrating, forgetfulness and irritability:

2. Irritative symptoms such as sneezing, hoarseness of voice and irritated eyes.

In the medical literature, occupational exposure has been reported to lead to the development of multiple chemical sensitivity, for example 13% of 160 solvent exposed workers (Gyntelberg et al 1986). Multiple chemical sensitivity has also developed in workers exposed to organophosphate pesticides (Cone and Sult 1992; Tabershaw and Cooper 1966) and tunnel workers exposed to gasoline contaminated soil (Davidoff et al 1998). However, in at least half the patients seen at NSEHC there is no identifiable toxic exposure. Although etiology is often unclear and pathogenesis is obscure, MCS patients who are ill share common features. The most obvious is the reactivity to modern environments that the majority of the healthy population can tolerate.

As noted above patients who are diagnosed with multiple chemical sensitivity also have overlapping problems such as fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, interstitial cystitis, asthma, reactive upper airways dysfunction, irritant vocal cord dysfunction, temporomandibular disorders, myofascial pain syndrome, migraine, chronic pain disorder, or post-traumatic stress syndrome. These patients have often been categorized as having medically unexplained symptoms or somatization. Yet it is possible to demonstrate biological changes of physiological dysfunction. For example in the patients with multiple chemical sensitivity, hypersensitivity to chemicals can be objectively demonstrated. This is done by exposing individuals to the presence of common household products without their knowledge (but with their consent and full ethical approval) and monitoring physiological changes (Joffres et al 2005). This is important in many patients to be able to obtain objective confirmation of hypersensitivity, but also because the state of high arousal in the nervous system can also be identified. This helps in management. There is evidence in the medical literature that other biological changes are found, such as increased nociceptive flexion reflex in fibromyalgia (Desmeules et al 2003, Banic et al 2004), in chronic pain and whiplash (Banic et al 2004), and in irritable bowel syndrome (Coffin et al 2004). There may be an absence of structural pathology, yet dysfunction can be objectively demonstrated. The common pathophysiological finding in these groups of patients is central sensitivity, and the illness is best described as Central Sensitivity Syndrome (Yunus 2000, 2007, 2008). It is obvious that these patients who are chronically ill and disabled have a mix of biological changes and psychological issues. It will become clear that if this is the case then to alleviate suffering, physical and psychological issues need to be addressed together.

3. Many challenges to health care

It can be seen that the care of patients with multiple chemical sensitivity offers many challenges. Even though there is a great deal of controversy with regards to the very existence of this health problem, patients are identified with complex chronic ill health and share similar clinical features and symptoms. These patients attend the Nova Scotia Environmental Health Centre seeking help in understanding their health problem and for

alleviation of suffering. A continuing challenge has been the belief that the Nova Scotia Environmental Health Centre will offer treatments that are not available elsewhere and will be successful in eradicating the problem. Many patients exhaustively search for a cure or for the reason that they are ill and their focus often is narrowed down to specific symptoms. It is a great challenge for any patient to accept the limited effectiveness of treatment for the various symptoms. Furthermore, that the best route to better health lies in addressing aspects of their health which do not seem to be immediately linked to any specific symptoms or single diagnosis. Closely linked to this is the challenge to accept responsibility for self-management and decreasing reliance on health professionals.

As our experience with patients referred for consultation continued, and the diversity of patients increased, more challenges to care became apparent. Most patients had seen a wide variety of health professionals yet remained symptomatic and ill. A high percentage of patients stated that not only were they intolerant of most modern buildings, including hospitals and doctors offices, but they found that any treatment offered often made them worse. It is extremely challenging for a physician to be faced with an ill, disabled patient who cannot access usual health care facilities or refuses to take a pharmaceutical that would normally be considered appropriate for relief of symptoms. When symptoms are found in multiple body systems, the level of distress in the patient increases and the challenges to the physician rise exponentially. This leads to more visits to a doctor's office, to hospital or to the emergency room. At the time of referral to the Nova Scotia Environmental Health Centre the mean physician visits per patient were 2 to 3 times the average for the population of Nova Scotia (Fox et al 2007). Many patients had seen a number of different health professionals but were still seeking help, and reported increasing difficulty in finding health facilities that they could tolerate. Prior to the establishment of the Nova Scotia Environmental Health Centre it was determined that the only way to begin to understand the nature of this illness and to be able to help individuals was to create a facility which provided an environment in which environmental stress was reduced to a practical minimum. This has been another challenge, the need for continued vigilance in maintaining acceptable air quality and the financial constraints related to this.

As more patients were seen, it became clear that the current approaches to treatment were unsatisfactory, and no guidelines were available which would identify which treatment was useful. Some treatments had been developed which were claimed to reduce environmental sensitivity but for which there was little supportive evidence. Sometimes treatment was counter-productive, not only failing to help patients get to a higher level of health, but aggravating symptoms. For example, treating patient as if allergic may do more harm than good. Patients who are extremely sensitive to modern environments that the majority of the population tolerates, usually state that they are allergic. However there is no evidence that allergic mechanisms account for the symptoms of chemically sensitive patients. This belief has led to the development of diagnostic and treatment methods closely related to the concept of allergy. This presented major challenges since treatment methods were controversial and research into the various approaches was essential before treatment could start. An example of this was the use of a form of testing for sensitivities known as provocation/neutralization. Some treatment options depended upon the accuracy of this testing and it was an expensive proposition for any patient. Early research revealed the difficulties with this approach and we were unable to validate the claim that chemical sensitivity could be accurately defined by this form of testing (Fox et al 1999). Testing

provided results which were unreliable and we had to discard one of the mainstays of treatment and seek other approaches.

Another challenge to appropriate treatment occurs when the illness is looked at as a purely physical phenomenon, for example as a result of toxic overload and psychological aspects ignored. Conversely, if it is concluded that the symptoms are not physical, but psychological, then the label of “somatization” is applied. This does not improve diagnostic accuracy nor help in understanding the patho-physiology. In this case focusing on the psychological or emotional aspects alone does nothing to relieve symptoms. An individual who recognizes that a scent triggers asthma or migraine is advised to avoid exposure, rather than to enter counseling and continue being exposed.

Despite the many challenges, we recognized that all patients showed a varied mixture of problems which included evidence of structural pathology, no structural pathology but clear evidence of physiological dysfunction or evidence of psycho-pathology and associated psychosocial issues. A major challenge in health care of these patients was to decide which type of physician should be providing care. Family medicine is only speciality in medicine which trains physicians to be prepared to manage patients of all ages, either sex and any kind of problem. The various constraints for primary care physicians in dealing with these complex problems have already been discussed. There are no other specialists available with appropriate training in the types of chronic illness that were being referred to the environmental health centre. As patient needs were identified, the team of health professionals expanded. However the approach retained features of the traditional medical model in as much as the consulting physician remained the source of entry into the various treatment programs at the centre. We need appropriately developed guidelines or protocols for care, but treatment to alleviate suffering cannot wait until all the evidence is firmly in place. This is a continuing challenge and care which does not harm has been developed, accompanied by research to evaluate the different approaches. Hopefully clear management guidelines may be developed in the future.

4. The emergence of multidisciplinary management for multiple chemical sensitivity

Programs of care, with emphasis on patient education and self-management, were developed, evaluated and modified as required. Initially, the rationale for education of patients to reduce environmental stress, was the evidence accumulated from many patients that there were triggers in the environment that led to symptoms and worsening of health. Furthermore, reducing environmental stress reduced symptoms and helped patients restore health. Physicians and nurses therefore educated patients on how to manage, and create a personal environment which was free of identifiable triggers like fragrances, thus reducing the environmental stress to a practical minimum. Patients were not educated to shut themselves away even though many had done so for some time before being seen. All patients receive some basic educational material on management of their health problems. Since the approach to care begins with a shift towards healthy lifestyle choices and, as the clinic is dedicated to care of individuals with environmental sensitivities, patients were required to change personal care products to fragrance free products. If symptomatic relief was possible, then it was offered, obviously dictated by the nature of the problem and the tolerance of the individual to the different approaches. Examples of symptomatic relief

included the provision of medication for pain relief. However, many patients had limited tolerance to pharmaceuticals and in this situation, analgesia was provided using topical preparations of pharmaceuticals. If a magnesium load test revealed high retention of administered magnesium, then parenteral magnesium was given to relieve fatigue and generalized muscle pains. Obviously other conditions might be identified at the time of initial consultation, such as celiac disease or hypothyroidism and these were treated appropriately. Some patients were obviously de-conditioned as a result of their illness and it was logical to advise exercise. During physiotherapy assessments it became clear that reactions identical to those triggered by the environment, could be triggered by exercise. We also recognized that reactions and symptoms could be triggered by emotions, even in a clean environment. Many patients complained of "brain fog" and so psychology was added. The increased patient case load and limited number of accessible personnel lead to development of programs in which groups could be taught skills of self management and ways to increase their resiliency and self-efficacy. Patients are taught practices that can be continued at home, or when less sensitive, in the community. Our overall approach in groups and for individuals was based on changing behaviour and increasing capacity to cope.

A significant number of our patients were disabled and could not prove their illness with objective testing and evidence of structural pathology. A rehabilitation specialist who was able to coordinate the various aspects of rehabilitation was one of the first additional professionals to be added. Over time other professionals have been added to the health care team, namely dietary and occupational therapy. As mentioned, in the early days the physician referred the patients to the different programs as problems were identified. Some patients were found to be profoundly dysfunctional with limited tolerance for any activity. They required individualized therapy to help control symptoms and assist in the process of change or transformation. For example certain forms of psychotherapy, craniosacral therapy, therapeutic touch or guided imagery may shift perceptions from illness and despair to one of hope for improved health.

Patients were offered programs to learn skills to manage stress, and to retrain the often dysfunctional autonomic nervous system. One such workshop teaches the HeartMath® tools such as FreezeFrame® and Heart Lock in® (Childre and Martin 1999). The techniques or tools learned in these programs are known to improve focus, creativity, and emotional clarity, as well as reducing stress and anxiety. They are easily learned techniques and after the initial workshop patients can practice and check their abilities when attending the centre for another appointment, by using a computer program - emWave PC. As patients monitor their own progress they are also learning important principles of self-management. An important aspect of the workshop is to present the scientific evidence that it is possible to reduce anxiety and to alter hormone levels (increasing DHEA and reducing cortisol) by regular practice of these techniques and without the necessity of additional pharmacotherapy (McCraty et al 1998). The HeartMath tools help in the process of change, and integration of mind and body. From the initial consultation, throughout all treatment programmes, we emphasize the importance of both mind and body, not separate but integrated.

This approach is the basis of another program that has been developed, based upon the mindfulness based stress reduction work of Jon Kabat Zinn (Kabat-Zinn 1990. Kabat-Zinn et al 1992). This program runs for 10 weeks and is called the Body mind awareness program (BMAP) and teaches mindfulness meditation and yoga. Evaluation has shown the benefit of

this approach with reduction of symptoms and improved coping skills (Sampalli et al 2009). Since our patient population is drawn from all the Atlantic Provinces with some patients coming from other parts of Canada, this program cannot be completed by these patients, since it requires attendance one day a week for 10 weeks. We also offer a 4 day intensive program to introduce patients to these techniques and practices and to encourage continued self-learning and practice.

Although we may not fully understand all the contributing factors to illness in any individual, we can identify factors that limit health and decrease resiliency. For example, inability to express emotions or suppression of emotions may lead to physical symptoms (Abbas et al 2009) which can be helped with short term dynamic psychotherapy. If this is identified as an issue during the psychosocial assessment then appropriate psychotherapy is recommended. With improved health, reduction of symptoms and decreased disability return to work can be considered. If the person became ill in the workplace where there was significant environmental stress, such as an autobody shop or hairdressing salon, then it is likely that a change in employment is necessary to maintain health and prevent recurrence of illness. In this situation a group workshop, Prior Learning Assessment Recognition, which helps individuals take full stock of their accomplishments and potential, is offered to assist in change and prepare for work return.

It is difficult to provide a simple prescription to move a patient from the desire for recovery to the pre-morbid state of health, to a willingness to explore, discover and accept a new state of wellness. After some initial therapy it is hoped that the patient develops the capacity to participate in group programs which help in continuing transformation as they learn to live more fully with their present condition and focus on potential rather than limitations. We have found that as perceptions shift, and allostatic load decreases, health improves.

5. Impact of treating the whole person

Out of necessity, the treatment approach at the Nova Scotia Environmental Health Centre incorporated the concept that in managing health, we cannot separate mind from body. Furthermore, our medical interests could not be restricted to those illnesses that only show clear cut and easily demonstrable structural pathology. There has always been a need to carefully evaluate the programs that were introduced and we have evaluated the impact of this multidisciplinary treatment approach using a symptoms questionnaires (Fox et al 2007). This work has shown that after the patients begin treatment at the centre, the number of physician visits, of all types, reduced. We looked at 563 patients who had been referred to the centre by physicians in the province of Nova Scotia. Each patient completed a 217 items symptom questionnaire of 13 body systems (Joffres et al 2001). Each patient at the NSEHC had a health care insurance number. This number was sent to the agency in charge of encryptions along with a unique identification number. The encrypted number was then sent to the population health research unit, Dalhousie University, which linked the administrative data through the encryption number and merged with basic questionnaire variables using the identification number. The population health research unit was responsible for analysis. There was no possibility to link individual data with the healthcare utilization information at any stage of the process, thus protecting privacy of each patient. Ethical approval to perform these record linkages was obtained from Dalhousie University Research Ethics Board. Individual patients were included in the study if they were eligible

for health care coverage in the entire pre-and post-periods of study. This insured that patients were eligible to receive the same services in both periods. The pre-period was data that were extracted from one year before consultation, and the post-period was indicative of the information until 2002. Three cohorts of patients were studied namely 1998 1999 and 2000 and followed until 2002. The mean physician visits in the 1998 and 1999 cohorts dropped close to the Nova Scotia average in the year 2000 and stayed for the next two years. By the time the study took place, the Nova Scotia Environmental Health Centre had been in existence for several years and the multidisciplinary, holistic approach to management had gradually developed in response to our clinical experience. Review of the number of physician visits before and after admission to the centre indicated that these patients with “untreatable illnesses” were responding to some form of treatment. At least, the number of physician visits was dropping. We also looked at the cost of healthcare. All physician/patient encounters were extracted, not just office visits. Multiple records with the same medical services insurance, date of service, location, and doctor were considered as a single visit, with the cost of the multiple records summed accordingly. Data for the Nova Scotia population were extracted in a similar fashion. The denominator used to calculate rates for the Nova Scotia population referred to the mid-year population of those eligible for health coverage in the province. Prevalence rates for hospital diagnoses were based on the primary diagnostic field only. Age for the Nova Scotia sample was calculated at the mid-fiscal year and for the patient cohorts was calculated as age at first visit. For the 1998 cohort, standardized costs in the Nova Scotia Environmental Health Centre population dropped from \$527 to \$328 per person (38%) between 1997 and 2002, whereas provincial averages increased by 19% during that same period. The 1999 cohort showed a decrease of 8% from \$403 to \$371, whereas the provincial average increased by 14%. The 2000 cohort shows the environmental stress(patient) group decreasing by 21% from \$528 in 1999 to \$418 in 2002. Overall, in a two-year period preceding and following active involvement in the NSEHC, standardized costs for physician care fell by 17%, whereas they increased by 9% in the Nova Scotia population. We found that there was a decrease in costs for both specialists and general practitioner visits, but the decrease for specialist costs was not as sharp.

The decrease in mean physician visits was seen at all levels of symptom severity scores, and was more important in those with high initial scores. The symptom severity scores were obtained from the questionnaire. Symptom scores were calculated as the frequency of occurrence of symptoms since the beginning of the illness (scale 1-4; rarely, from time to time, most of the time, all the time) multiplied by the severity (Scale 1-3 low, moderate, high). Therefore the maximum score for each question was 12, and the minimum zero. A global score was calculated for each patient, which was the mean score computed as the sum of all scores divided by the number of questions.

This study has limitations in that it was not possible to complete a full cost benefit analysis. Although we cannot conclude that there was a decrease in total healthcare costs our data certainly suggests a reduction in physician visits.

At the time of developing the questionnaire for our patient population we completed a validation study to determine effectiveness and sensitivity of the questionnaire. In addition to the 217 symptom questions in 13 sections there were opportunities to complete open ended questions. Patients were asked to complete this questionnaire at the time of their illness and they often took 2 to 3 hours for completion. Such a lengthy questionnaire was not practical for repeated use in follow up, and so we identified the top 15 symptoms and used

them for follow up. There are 30 questions in total in this abbreviated questionnaire, NSEHC-BREF, with 22 questions on symptoms and 8 questions on the overall health. The maximum score for each question is 12, frequency multiplied by severity. The lowest score possible is 0. A decrease in the score indicates improvement. SAS 9.1 was used to conduct this analysis of the results.

The average time for completion of the abbreviated questionnaire is 15 minutes. Our intention was to use this questionnaire in an attempt to capture changes over time, which would be equated with better health. We approached approximately 500 patients with a diagnosis of multiple chemical sensitivity (Fox et al 2008). It should be noted that many of these patients had other chronic conditions such as chronic fatigue syndrome or fibromyalgia. All patients had completed the original questionnaire, and were grouped into the following categories

1. 6 month to 1 year of treatment at the Centre
2. 1 to 2 years
3. 2+ years treatment.
4. Discharged

A total of 183 patients the first three categories, still receiving treatment at the Nova Scotia Environmental Health Centre were included in the study and 109 patients who had been discharged. Patients showed a statistically significant improvement in the overall health in such categories as health since ill, too ill to do housework and limited contact with people to avoid exposures. Some symptoms improved early on, showing statistically significant change within the first year such as the complaint of a stronger sense of smell or a tight chest. Some improvement of irritative symptoms such as nasal stuffiness and sinus congestion were observed in the one year and above group. Loss of voice, hoarseness and irritated eyes, took longer to improve showing sudden improvement in the 2+ and discharged groups.

Symptoms which might be considered more generalized, such as difficulty in concentrating, difficulty in making decisions, tiredness not relieved by sleep, muscle spasms and cramps showed significant improvement in all categories of patients. Irritability, forgetfulness and trouble finding the right words took slightly longer but did show significant change after one or two years of treatment. When fatigue is identified as a problem or tiredness without energy, improvement was shown in the group who were discharged or who had been in treatment for more than two years. They were inconsistent changes in some of the other symptoms.

It is challenging to measure change in chronic health conditions such as multiple chemical sensitivity, particularly when there are multiple diagnoses and multiple care providers. We know that with the passage of time, individuals change. This study helps us to identify whether health changes occur with time and the nature and extent of symptom changes. In the future it will be important to look at control populations to determine the effect of passage of time alone on overall health. Furthermore, we need to look more closely at the different aspects of our management approach to determine what is most important.

6. Introduction of multidisciplinary assessment at the start of treatment

With the passage of time it became clear that some issues were not addressed until after the patient had been attending the centre for some time, leaving open the possibility that if dealt

with earlier, improvement would have started earlier. Furthermore, if the initial focus of treatment was only on physical issues at first, we wondered if this contributed to the reluctance of some patients to consider the impact of emotion on physical problems and delay or exclude the possibility of psychological help. It was decided that all patients should be assessed by all professional disciplines at the beginning of their care so that the various issues could be identified and if appropriate, managed early on in the course of treatment. All patients then recognized that we were completing careful assessments, psychological and physical, and were less likely to be reluctant. Over 4 years ago we began a series of planning meetings to find the best way of incorporating multidisciplinary assessment at the commencement of care for all new patients of the Nova Scotia Environmental Health Centre. The outcome of these planning meetings was the introduction of the multidisciplinary assessment following the initial consultation by a physician at the centre. The revised care management scheme is outlined in the following paragraph. Figure 1 shows a schematic of the Nova Scotia Environmental Health Centre care model for complex and chronic conditions. The initial consultation lasts for one and a half hours and much information is gathered. The physician develops a problem list and identifies the various diagnoses that can be made. Recommendations are made which include whether the patient should return to the centre for a multidisciplinary assessment. This decision is not based upon a particular diagnosis, but rather on whether the patient has a chronic illness and clinical features which support the presence of central sensitivity (Yunus 2008). Most patients seen have a diagnosis of multiple chemical sensitivity often in association with fibromyalgia or chronic fatigue syndrome. Some patients have evidence of some new sensitivities but the major problem is not multiple chemical sensitivity rather fibromyalgia or chronic fatigue syndrome. There are an increasing number of patients who are ill, often enough to be disabled from work, where the question is asked if their illness is related to the environment, and who do not fulfill the consensus criteria for multiple chemical sensitivity, chronic fatigue syndrome or fibromyalgia. Such a person is referred for multidisciplinary assessment since it is clear that they are disabled and we conclude that they may well benefit from this approach to management.

At the time of the initial interview the patient has completed the detailed 217 item questionnaire, and is then asked to complete a one week dietary record and a two week record of activity (measured by a pedometer) in which they also record sleep pattern, pain level and fatigue level. They return for a morning in which they are seen by the various health professionals - nurse, dietician, psychologist or psychotherapist, coordinator of rehabilitation and occupational therapist (initially the team included a physiotherapist). The team meets together to discuss findings, interpretations and recommendations for treatment following completion of the assessments. A set of recommendations are agreed upon and the physician then meets with the patient to discuss further treatment. During this interview recommendations may change as the availability of the patient and other circumstances become clear.

The treatment plan depends upon the patient's willingness to learn self-management and to make necessary changes to restore health. Even though most patients are ill enough to seek medical help, and about half are so disabled that they have to stop work, it may take some time for an individual to accept that they have a significant illness and that they need to change. Old habits are hard to break and for some patients unhealthy life style habits such as smoking or heavy alcohol consumption need to be addressed at the outset. When there

are other clear stressors such as a poor diet or excessive consumption of cola drinks or caffeine containing beverages this is often the focus, and the dietician plays a major role in care early on. Patients may also require guidance on pacing their activities, this is apparent from the records which each patient has completed. Other recommendations depend upon the most prominent features.

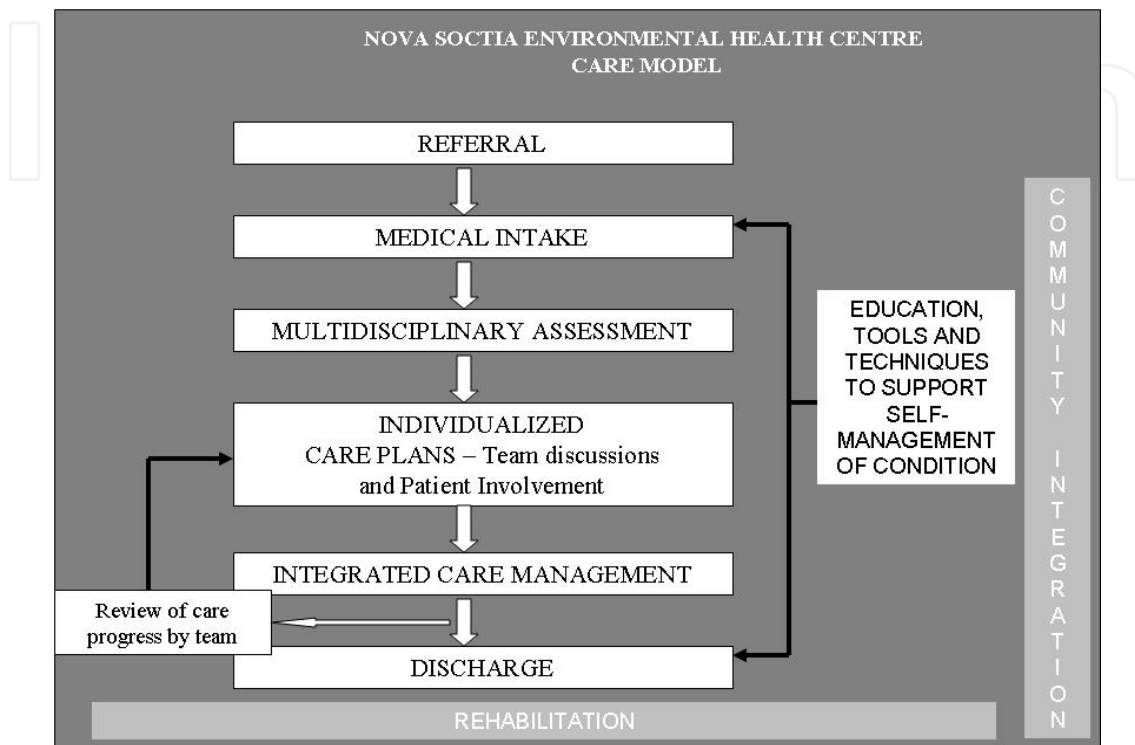


Fig. 1. Schematic of the Nova Scotia Environmental Health Centre Model of Care

If the patient is disabled and unable to work then proof of disability is often the highest priority. This can be most challenging when objective findings are not present. In this situation initial management at the Nova Scotia Environmental Health Centre may be in confirming the presence of environmental sensitivity by objective testing (Joffres et al 2005) and providing evidence of impaired functional capacity – if possible with a formal functional capacity evaluation by a professional familiar with this type of health problem.

Once the treatment plan is developed and the individual problems are addressed we are left with ill, disabled patients who are prepared to make changes to gain better health and return to work. Since our goal is to alleviate suffering we have created an environment to favour self-healing. We seek to foster salutogenesis (the creation of health) and decrease the impact of pathogenesis (the creation of suffering or disease). The salutogenic theory was proposed by Anton Antonovsky (1979). Antonovsky proposed that in managing chronic disease the emphasis should be to encourage movement towards health, and that a major consideration in health promotion needs to be enhancement of what he refers to as a sense of coherence (Antonovsky 1996). Our approach initially developed as we learned that many factors contributed to the illnesses that our patients experienced and if we were to alleviate suffering we needed to address these various aspects. As we have learned more of the nature of these illnesses the rationale or scientific underpinning of our approach has been validated.

7. Results of multidisciplinary assessment

By emphasizing the integration of mind and body and by introducing psychosocial assessment at the same time as detailed physical/biological assessments, we are able to focus our therapeutic efforts in the most appropriate area. All patients need help in reducing contaminants - whether from the outer (environmental stress) or inner (emotional) environments. The balance of emphasis varies between patients and this can be determined early on in the course of management.

At the time of introducing multidisciplinary assessments for all patients who were to receive treatment at the centre, we decided to follow progress in a variety of ways. Each program is evaluated through research to measure treatment efficacy. In addition, each patient completed the 217 item questionnaire at the time of initial consultation. Each patient also completed the NSEHC-BREF questionnaire (Fox et al 2008) after 6 months of treatment, after 1 year and after 2 years. The same patients have been followed throughout. In this section, the results from a group of 250 patients who went through the multidisciplinary assessments are presented.

Period of time follow up	6m-1yr (n=250)			1 - 2 yr (n=153)			2+ yr (n=65)		
	Pre Mean (SD)	Post Mean (SD)	p-value	Pre Mean (SD)	Post Mean (SD)	p-value	Pre Mean (SD)	Post Mean (SD)	p-value
Rating of health since onset of illness	3.52 (1.2)	4.22 (1.5)	0.05	3.64 (1.2)	5.35 (1.4)	<0.0001	3.45 (1.2)	5.4 (1.2)	<0.0001
Limitation contact with people to avoid exposures	2.75 (1.1)	1.82 (1.2)	0.02	2.88 (1.1)	1.7 (1.2)	0.01	2.72 (1.1)	1.9 (0.9)	0.02
Feel too ill to do housework	3.6 (0.8)	3.1 (1.2)	0.05	3.45 (0.8)	2.8 (1.01)	0.001	3.82 (1.02)	2.5 (1.1)	0.002

Table 1. Changes measured in overall health in patients who received multi-disciplinary assessments at commencement of treatment

Since the original study using the NSEHC-BREF the major change that has occurred has been the introduction of the multidisciplinary assessment. The population of patients is similar and the main programs of treatment have remained the same. The results before and after introduction of the multidisciplinary process have been compared.

Period of time in follow up	6 mth - 1 yr		1 -2 years		More than 2 years	
	Pre-	Post	Pre-	Post	Pre-	Post
Pre-Multi-disciplinary assessment	2.9	3.03	3.5	3.1	3.5	3.3
Post-Multi-disciplinary assessment	2.75	1.82	2.88	1.7	2.72	1.9

Table 2. Pre- and Post-introduction of Multidisciplinary assessment - Question 2. Limit contact with other people to avoid exposure

Two hundred and fifty patients have completed the NSEHC-BREF questionnaire between 6 and 1 year, 153 have completed the questionnaire between 1 and 2 years and 65 have now gone beyond 2 years. The length of treatment and the specific type of therapy varies but the results are of great interest.

In the first study (pre-assessments), the patients were different in each group and this is reflected in the variation in the initial score, prior to treatment as shown in Table 2. There was no significant change after treatment at 6 months or 1 year. Only at 2 years did the change reach statistical significance (p-value 0.02). In the post-multidisciplinary assessment set of results, the changes across time periods are captured in the same group of patients. The variation in the pre scores is due to the changes in the sample size at the three time periods. In contrast to the pre-assessment results, the reduction of this symptom was statistically significant for each of the 3 time periods. This is a significant difference in this patient population which demonstrates that chemically sensitive patients learned faster to cope with being sensitive and did not perceive the same need to limit contact with others to reduce chemical exposures. It would appear that from the outset, the patients experience some gains in health that changes their behaviour. This needs further exploration.

Looking at the 8 questions pertaining to irritative symptoms in the eyes and respiratory system, the changes are comparable between the two studies. The results for the patients seen after the introduction of assessments are shown in Table 3. In the 2 year group, there were only 65 patients and for the symptoms of burning eyes there was no improvement seen. In the previous study, (Fox et al 2008) there were 118 patients in this group and this symptom had improved at 2 years (p value 0.05). The improvement in question 2 was similar and reached significance at 2 years (p-value <0.0001) for the pre-assessment patients. It can be seen in Table 3 that this symptom showed significant improvement in all of the post-assessment groups. All other questions were comparable, showing similar changes in the same time periods.

In the post-assessment group, all of the questions which asked about more generalized symptoms - namely difficulty in concentrating, forgetfulness or poor memory, feeling light headed, irritability, tiredness not relieved by sleep, fatigue or very tired without energy and muscle pain or ache not related to exercise showed significant improvement in the first cohort between 6 months and 1 year (Table 4). In contrast, the follow up study prior to the introduction of the assessment process did not show the same degree of improvement. There was no significant change in the first time period (6 months to 1 year) in four of the questions in this cohort - namely forgetfulness; irritability; fatigue or very tired without energy; and muscle pain, ache without exercise.

Question	6m-1yr (n=250)			1 - 2 yr (n=153)			2+ yr (n=65)		
	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	2.8 (2.1)	2.7 (2.2)	0.7	3.1 (2.7)	2.9 (2.5)	0.4	3 (3.2)	2.6 (2.5)	0.07
Itchy eyes	2.15 (2.4)	1.22 (1.5)	0.0008	3.2 (3.8)	2.33 (2.3)	0.0009	2.5 (2.3)	1.01 (1.4)	<0.0001
Stuffy or full sinuses	5.2 (4.9)	4.7 (3.5)	0.9	5.1 (4.9)	3.3 (3.7)	0.008	5.4 (5.6)	2.8 (2.4)	<0.0001
Stronger sense of smell	3.95 (3.3)	2.35 (2.5)	0.08	4.2 (3.8)	2.2 (1.9)	0.02	3.5 (2.8)	1.6 (1.1)	0.03
Usually acceptable odours were sickening	4.8 (3.5)	4.4 (3.6)	0.4	5.2 (4.6)	4.5 (3.7)	0.09	4.9 (4.1)	3.1 (3.5)	0.01
Tight chest	2.6 (1.9)	1.1 (1.8)	0.01	3.5 (3.1)	1.3 (1.7)	0.0006	2.5 (1.6)	1.5 (1.2)	<0.0001
Hoarse or loss of voice	2.7 (1.9)	2.2 (1.3)	0.5	3.2 (2.4)	2.6 (3.2)	0.5	2.9 (3.5)	1.3 (1.1)	<0.0001

Table 3. Changes in symptoms in eyes, nose, throat and respiratory systems

8. Emergence of interdisciplinary care

As the various health professionals have worked together in an increasingly integrated fashion it has become clear that timely and relevant collaborative care management is important to deliver seamless care for individuals with complex health conditions such as multiple chemical sensitivity. The consistent themes of self-management and self awareness or mindfulness are introduced early on in the care. The core principles of support and education for a patient reinforced by all health professionals include raising awareness of one's capacity, pacing of activities, healthy lifestyle choices and maintaining a balance between avoidance of situations that trigger symptoms and engaging in life which inevitably brings environmental and other stresses. We reinforce the need to be aware of body signals and introduce techniques to reduce high levels of arousal in the nervous system. Members of the health care team try to model this balance in their treatment strategies to encourage reduced arousal. Different health professionals work together to deliver educational programs and workshops, for example mindfulness is the basis for a nutritional workshop entitled "Mindful eating". We meet regularly to ensure that our

approaches support one another and more importantly assist the patient in moving towards health. We foster an environment of trust and of hope but at the same time of recognizing what our limitations are and that not all illnesses and disease can be fully alleviated. If disability persists, then it needs to be accepted. It is still possible to move along the continuum between health and disease, towards health – particularly as concepts of what it means to be healthy shift. In this way the management has become interdisciplinary.

Period of time follow up	6m-1yr (n=250)			1 – 2 yr (n=153)			2+ yr (n=65)		
	Pre Mean (SD)	Post Mean (SD)	p-value	Pre Mean (SD)	Post Mean (SD)	p-value	Pre Mean (SD)	Post Mean (SD)	p-value
Difficulty concentrating	5.0 (4.9)	3.1 (2.5)	0.01	5.8 (4.6)	2.8 (2.4)	0.0002	6.2 (3.5)	2.9 (2.3)	<0.0001
Forgetfulness / poor memory	3.2 (2.8)	1.7 (1.5)	0.004	4.6 (3.3)	2.1 (2.5)	0.0009	4.9 (4.1)	1.2 (1.4)	<0.0001
Feeling light headed	4.4 (3.3)	2.3 (2.1)	0.05	4.8 (3.9)	2.1 (2.8)	0.009	5.9 (5.7)	2.5 (2.1)	<0.0001
Irritability	3.2 (3.1)	1.3 (2.6)	0.07	3.5 (2.4)	1.4 (1.3)	0.04	3.8 (2.4)	1.2 (1.1)	<0.0001
Tiredness not relieved by sleep	7.2 (4.8)	4.5 (3.1)	0.004	7.9 (5.2)	4.9 (2.5)	0.003	6.5 (4.2)	2.9 (2.5)	0.0001
Fatigue, very tired, without energy	5.9 (3.1)	3.2 (1.9)	0.0001	5.4 (3.5)	2.1 (1.8)	0.0002	6.2 (5.4)	1.3 (1.1)	<0.0001
Muscle pain or ache not related to over exercise	4.8 (2.9)	2.9 (1.4)	0.03	4.5 (2.6)	2.1 (1.4)	0.004	4.1 (3.5)	3.7 (1.1)	0.2

Table 4. Changes measured in blood/gland, muscle, joints and nervous system

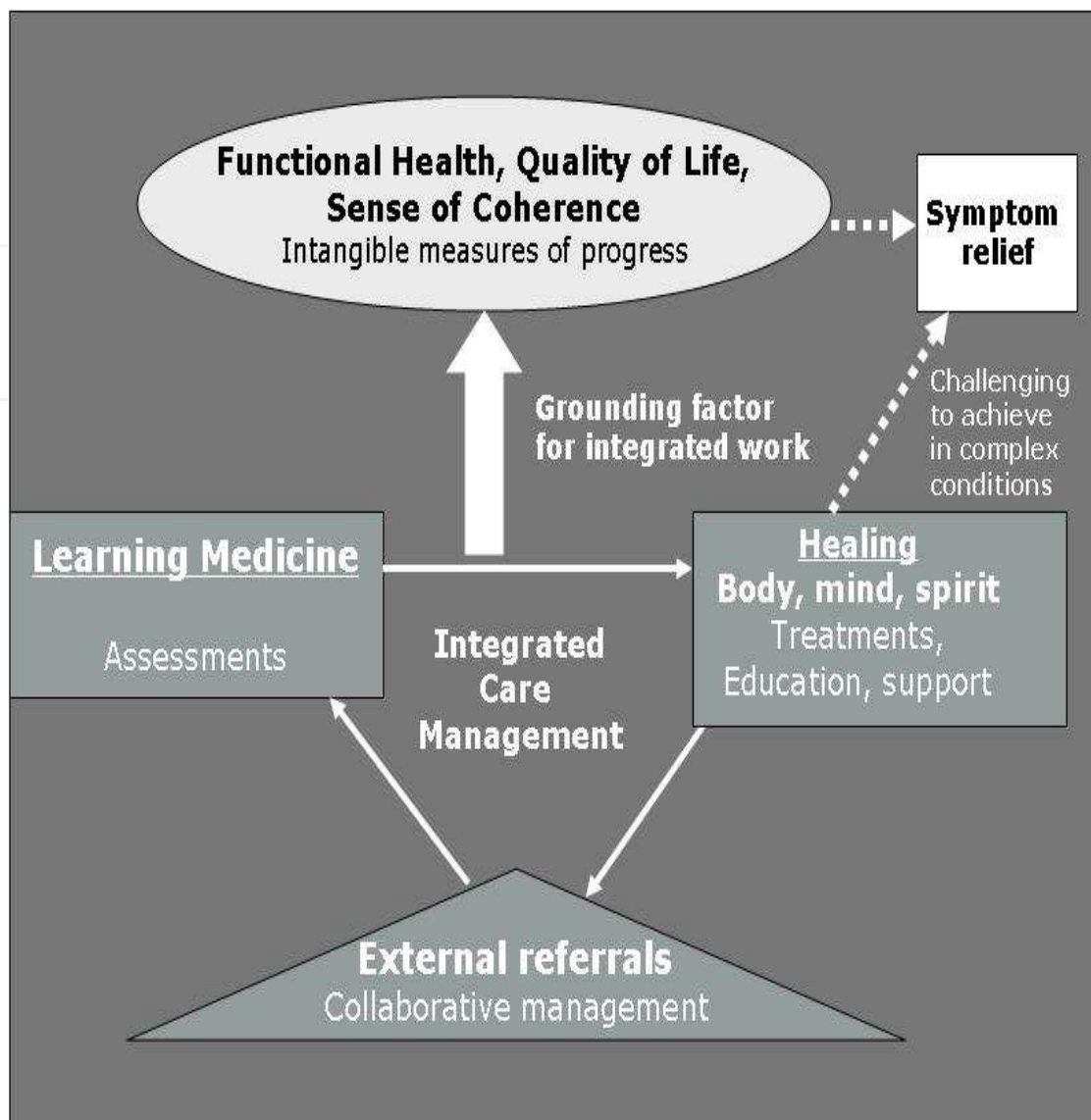


Fig. 2. Integrating care for complex conditions

In working together as a team, each individual brings their unique skills and perspectives to focus on particular problems and treat different aspects. The focus of each clinician may be upon one particular symptom at one time. At the same time, the collective focus needs to be on improved quality of life for the patient, through better function. The need to maintain this goal of increased coherence towards salutogenesis has become more apparent with time and will be part of our continued development as a team. The principles are represented schematically in Figure 2.

The adoption of a patient-centred approach to management is consistent with the evidence that already exists in the medical literature that there is great variability between patients. Various subgroups have been identified in patients diagnosed with fibromyalgia (Turk et al 1998, Giesecke et al 2003, Harris et al 2005) and treatment outcomes vary between the different sub-groups (Turk et al 1998).

The various conditions that are seen at Nova Scotia Environmental Health Centre share a common characteristic and that is central sensitivity (Yunus 2008). Central sensitivity has

been objectively confirmed in fibromyalgia, irritable bowel syndrome and temporomandibular problems. Our clinical experience allows us to postulate that the same phenomenon exists in patients with multiple chemical sensitivity. The physiology of central sensitivity is activation of nociceptors of the A-delta and C fibers at the peripheral tissues by bradykinin, serotonin, prostaglandins and substance P. This follows inflammation that may be caused by even minor trauma. A variety of changes cause an escalation of hyperexcitability of second-order neurons, giving rise to hypersensitivity to various peripheral stimuli. When pain results it can be enhanced by emotion and selective attention. It is clear that other factors are likely to affect central sensitivity namely genetics, sympathetic overactivity, endocrine dysfunction, viral infection, peripheral nociceptor generators like arthritis, poor sleep, environmental stimuli like weather, noise and chemicals, trauma and psychosocial distress. It is hoped that with time we will gain a better understanding of these issues and move further upstream to prevent descent into ill health. Our approach which developed over several years addresses these various issues. We have shown that improvement in an individual's ability to manage their own health problems accompanies reduction of symptoms. Clearly the earlier that each person can learn what is important in fostering health, the more likely it is that health is maintained and disability reduced.

Many of our quality and research initiatives are aimed at improving the collaborative environment among multidisciplinary clinicians that are involved in the care management of patients. These initiatives include revision of the Centre's care model, standardizing clinical assessments and exploring semantic interoperability to the multidisciplinary clinical vocabulary (Sampalli et al 2010). The Centre's revision of the care model shown in figure 2, is geared towards shifting the focus of the care team into a layer of modelling a patient's health above the level of symptom management. In the new model, the functioning of the care team will be integrated around more meaningful outcomes such as coherence, quality of life and function. The primary objective of this shift is to center the care team's efforts towards the salutogenic approach of enabling self-efficacy and coherence in patients. The Centre's efforts will also continue towards standardizing clinical vocabulary and assessment tools used by the multidisciplinary clinicians in order to facilitate a higher level of shared understanding and coherence in the collaborative functioning of clinicians.

9. Conclusion

The limited treatment options and the inability for most patients to find any kind of effective medical treatment lead to the establishment of the Nova Scotia Environmental Health Centre. The multidisciplinary approach grew out of the recognition of the complex interactions that span multiple health dimensions and appear to govern the well-being of individuals with this illness; and the ineffectiveness of uni-dimensional treatment models in addressing the multitude of symptoms. It soon became clear that improving health of both body and mind alleviated suffering and reduced disability.

The care model for a complex chronic illness discussed in this chapter focuses on multiple chemical sensitivity. The findings reported here are undoubtedly relevant to other complex, chronic illnesses of uncertain etiology when there is often limited understanding of pathogenesis. We have shown that poorly understood chronic medical conditions which result in significant health care costs and disability can be helped by an interdisciplinary approach which focuses on movement to health – salutogenesis rather than pathogenesis.

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Possibilities of medical intervention have thrived over the last decades. Our knowledge about mechanisms of the development of diseases and factors influencing it has increased. Effective treatment requires a holistic approach that takes into consideration aspects at first sight not related to a course of a specific disorder. This book contains a few chapters focusing on issues related to health management. The chapters are arranged in an order reflecting multidimensionality of issues constituting this theoretical and practical area - starting from the studies focusing on a general, administrative level, to considerations related to situations of individuals suffering from a specific illness. The discussed problems concern different age groups - children, adults and the elderly. We hope that readers professionally engaged in healthcare - both theoretically and clinically - will find it interesting, useful and inspiring.

How to reference

In order to correctly reference this scholarly work, feel free to copy and paste the following:

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