



## Using the common sense model to design interventions for the prevention and management of chronic illness threats: From description to process

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In this article, we discuss how one might use the common sense model of self-regulation (CSM) for developing interventions for improving chronic illness management. We argue that features of that CSM such as its dynamic, self-regulative (feedback) control feature and its system structure provide an important basis for patient-centered interventions. We describe two separate, ongoing interventions with patients with diabetes and asthma to demonstrate the adaptability of the CSM. Finally, we discuss three additional factors that need to be addressed before planning and implementing interventions: (1) the use of top-down versus bottom-up intervention strategies; (2) health care interventions involving multidisciplinary teams; and (3) fidelity of implementation for tailored interventions.

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Our goal is to illustrate how the common sense model of self-regulation (CSM), specifically its *dynamic, self-regulative (feed back) control feature and its system structure*, can serve as the basis for developing interventions for improving chronic illness management and reduce the burden of these conditions. The past 20 years of CSM research has focused on two sets of factors that *describe* the relationship between care seeking and patient management of chronic illness; (1) patients' representations of illnesses and treatments and (2) how patients appraise somatic changes, that is symptoms and function (Cameron, Leventhal, & Leventhal, 1993; Horne, 2003; Skelton & Croyle, 1991). Selected examples include studies of seeking medical care in response to ambiguous (Cameron, Leventhal, & Leventhal, 1995) and prolonged symptoms (Mora, Robitaille, Leventhal, Swigar, & Leventhal, 2002), both of which are affected by the appraisal of duration (time line); the misattribution of cardiac symptoms to indigestion due to their location and sensory feel (Bunde & Martin, 2006); and the inability to understand or the misattribution of symptoms of congestive heart failure to ageing because they are chronic, located in organs other than the heart, and different in what would be expected from a heart attack, for example chest pain (Horowitz, Rein, & Leventhal, 2004).

The CSM is a complex, multi-level framework depicting the process of self-regulation of health and illness. Data indicate that individuals rely on a set of 'mental tools', Prototype Assembly and Appraisal Checks (PACs) to evaluate the meaning of somatic stimuli; location, duration, sensory pattern, severity, etc., are examples of PACs used to understand chronic conditions such as hypertension (Meyer, Leventhal, & Gutmann, 1985), diabetes (Skinner & Hampson, 2001), asthma (Halm, Mora, & Leventhal, 2006; Mora, Halm, Leventhal, & Ceric, 2007), HIV (Horne, Buick, Fisher, Leake, & Weinman, 2004), attributions of symptoms to ageing (Leventhal & Prohaska, 1986; Mora *et al.*, 2002), and attributions to psychological stress (Cameron, Leventhal, & Leventhal, 1993). The representations or mental hypotheses formed by these check processes affect the individuals emotional state and influence what (if anything) they will do in response to those symptoms. Thus, the active processing or assignment of meaning and the creation of emotional reactions to somatic stimuli affects the selection of coping mechanisms, and the creation of plans for specific actions and expectations respecting the consequences (feedback from) these actions; (e.g. symptom decline within an expected time frame). Coping decisions will differ as a function of the meaning individuals assign to their symptoms (i.e. their illness representation) and this interpretive process will reflect their past illness experience, societal expectations, information from friends, media, and medical practitioners. The model has been instrumental in understanding how individuals self-regulate chronic illness and studies have explored the model in relation to treatment seeking, medication adherence, patients' attribution of symptoms of chronic illness to stress or ageing, as well as the relationship of mental models to somatic experiences, distress and psychological disorders (Hagger & Orbell, 2003; Leventhal, Musumeci, & Leventhal, in press; Leventhal, Weinman, Leventhal, & Phillips, 2008; for a history of the model see Leventhal & Diefenbach, 1991).

Although many studies have sought to *describe* how patients match somatic experiences to illness representations and how this affects care seeking and self-management, very few experimental studies or randomized trials have used the CSM in attempts to *influence* the process of self-regulative illness management (for exceptions see, de Ridder, Theunissen, & van Dulmen, 2007). To use the CSM for developing and testing interventions in clinical settings it is essential to integrate the variables in the

descriptive feature of the CSM, with the model as a *dynamic*, control system. Specifically, the five domains of CSM, *identity, time line, consequences, cause, and control*, need to be integrated with the features of a control system which include output expectations and monitoring of the change between current status and desired endpoints. This integration must be implemented at both the abstract and experiential levels of the five domains of illness and treatment representations. Available data suggest two possible ways to use the CSM to influence the process of chronic disease management: (1) from the top-down and (2) from the bottom-up. The implementation can proceed by using concrete/behavioural strategies (i.e. from the bottom-up) or abstract/cognitive strategies (i.e. from the top-down).

In the sections that follow, we will spell out the interventions we are testing for diabetes and asthma. Each uses multiple, CSM based strategies to influence how patients think, feel and act with regard to their condition. The diabetes intervention uses a bottom-up, concrete/behavioural approach. This 'bottom-up' approach begins with a focus on behaviour to create an overarching view of diabetes as a chronic condition that requires consistent self-regulation and use of an objective monitoring device. The asthma intervention begins with a 'top-down' or abstract/cognitive component to provide patients with a conceptual framework for asthma so they can recognize that asthma is present when they are asymptomatic. This step is necessary as approximately half of our patients with asthma perceive asthma as present only when they have symptoms, a model that is inconsistent with the use of medication to control inflammation when asymptomatic. This 'top-down' approach creates an overarching cognitive representation of asthma as chronic and treatable, and provides patients with a model to correctly interpret bottom-up inputs generated by their actions, (i.e. the effects of the corticosteroid medications that are inhaled when asymptomatic) and a time frame (i.e. weeks, rather than days) for experiencing these effects (i.e. less breathlessness when physically active). It should be noted that we do not perceive these strategies as mutually exclusive, nor do we suggest that they are unique to the disease domains presented - far from it. We expect that while patients may benefit from beginning with one strategy versus the other, successful interventions will integrate the two.

#### ***Diabetes: Substituting volition for automatic, homeostatic control***

Our recent review of longitudinal and randomized trials of self-monitoring of blood glucose (SMBG) with type 2 diabetes focused on the degree to which SMBG was conceptualized as a shift in the control of blood glucose from an automatic, non-conscious, homeostatic control system to a system with volitional or conscious control (McAndrew, Schneider, Burns, & Leventhal, 2007). In individuals without diabetes, food intake increases blood sugar levels and stimulates a cascade of hormonal responses which regulate digestion and blood sugar levels (Kruger, Martin, & Sadler, 2006). Blood glucose control is poor in patients with type 2 diabetes because of low insulin output and/or insufficient insulin sensitivity. The resulting chronic elevation of blood glucose can lead to arterial degeneration and damaging of the retina, kidneys, heart, and loss of sensation in the feet resulting in ulceration and possible amputation.

The goal of interventions for patients with type 2 diabetes is to create a volitional system that can substitute for the dysfunctional homeostatic system. The CSM proposes that common sense regulation of physical health and illness is influenced by the patients' subjective perceptual-experiential cognitions and affect (e.g. symptoms, moods, experienced dysfunction). These subjective experiences are interpreted and

matched to models or prototypes of illness, the default prototype being that for 'acute' illness. Thus, when a person feels good, s/he is likely to conclude s/he is healthy; if s/he feels fatigued and or vaguely discomfited s/he may feel stressed; if specific symptoms are present, for example headaches, sore throats (*location, pattern*), that lasts for several hours (*duration*) s/he is likely to perceive her or himself as acutely sick (Cameron *et al.*, 1993). Patients with diabetes use subjective cues as do individuals without diabetes: they experience, report, and attribute somatic changes, (i.e. symptoms and functional changes), to both hyper and hypoglycemia (Diamond, Massey, & Covey, 1989) and these somatic indicators are mapped into their concept of diabetes and are targets for self-management (Wagner, Schnoll, & Gipson, 1998).

As the symptom focused interpretation and behavioural controls of the acute illness prototype that individuals with diabetes bring to self-management is incompatible with the asymptomatic, chronic nature of this condition, symptom focused management can disrupt the formation of the behaviours needed for effective, volitional management. Specifically, if the patient uses subjective cues (symptoms) to *identify* the illness and these cues have little or no relationship to variability in blood glucose detected by objective indicators, self-management may have little or no effect on controlling elevated blood sugar levels. Replacing automatic control with volitional control requires, more than knowing what to do, (e.g. dietary change, exercise, and/or use of oral medication); it must include how and when to do it (*time line*), appropriate expectations as to response outcomes (*causal* connection between the action and the illness model), reliance on objective rather than subjective indicators (*identity*: meter not symptoms as criteria for control) for evaluating the efficacy of treatment (*control and consequences*). This volitional control system needs to be integrated into daily behaviour (*an action plan*) and to become automatic. In sum, knowing what, how, and when to act while holding correct expectations as to outcomes, and knowing when and how to monitor outcomes (e.g. assess blood glucose levels 2 hours after eating) are clearly volitional, consciously regulated actions during the early phase of learning how to monitor the effects of meals, activities and medications on blood glucose levels. The construction of this control or feedback loop combines top-down and bottom-up processes, the higher order, executive mechanisms (top-down) guide specific actions (e.g. eating, exercising), and when these actions are executed properly they both control blood sugar and most importantly for effective, long term self-management, checking blood sugar values reshapes the representations of illness and treatment; a bottom-up effect.

We are testing an intervention that integrates cognitive and behavioural techniques within the context of both the bio-medical model of blood sugar variation, and patient's common sense frameworks for illness and treatment. The intervention is designed to allow patients to teach themselves to become expert self-managers. The bottom-up (concrete/behavioural) feature of the intervention allows patients to see how specific behaviours such as types and amounts of food intake raise blood glucose levels, and how specific activities (walking) and the combination of food intake and activities can lower and cancel the elevations of glucose from eating by using SMBG. The process requires teaching skills for SMBG, selecting actions and time frames for SMBG, and developing an action plan to conduct SMBG in one's daily environment. Patients make brief entries on a written monitoring form to focus them on the effects of their actions (i.e. on objective targets) and to evaluate the validity of any expectations that were based on somatic cues. Satisfaction with treatments and the formation of stable, automatic and effective self-management is a product of the availability, intelligibility and meaning assigned to

observed changes in these indicators in response to specific behavioural strategies (See Rothman, 2000). At the early, learning stage, monitoring of the effects of life-style behaviours is a highly deliberative, conscious and time consuming process. We expect that the frequency of monitoring can be reduced as the process becomes increasingly automatic. Once control is well established, a monitoring schedule can be devised to 'check' on the overall adequacy of management and the stability of control.

This intervention also highlights the compatibility between CSM and cognitive behavioural techniques and theory (CBT). In CBT for psychological disorders, there is a theory for what is maintaining the disorder and treatment focuses on changing the maladaptive behaviours and cognitions (Beck, 1995). CSM provides the theory for what is maintaining poor self-regulation in medical disorders: the patient's cognitive and perceptual conceptualization of their illness, and deregulation of the individual's somatic feedback loop. As the theory incorporates cognitive and behavioural concepts, cognitive and behavioural skills can be used to modify the behaviour and challenge maladaptive cognitions.

***Asthma: Representations of illness and treatment as acute/episodic and/or chronic***

A consensus statement for the role of primary care practitioners in the management of asthma focused on the need: 'To identify the patient-related reasons for poor control' and 'incorporate patient perspectives into the routine review of asthma in primary care' (Horne *et al.*, 2007). These needs were in addition to the need to improve the checks for assessing and monitoring asthma control, and matching the type and dose of medication to individual patient's needs. Thus, consensus participants believed it necessary to provide a 'common sense rationale for the necessity of treatment that is consistent with the patient's common sense model of asthma and their goals for asthma control', to 'elicit and address specific concerns about treatment', and to 'prescribe a convenient treatment regimen tailored to address practical barriers to adherence', that is an action plan.

The intervention we are designing for patients with a history of poorly controlled asthma is consistent with the above recommendations; it focuses on patients' representations of asthma and asthma treatment. The 'top-down' focus of the implementation is based on data showing that many patients represent and manage asthma in an acute and/or episodic manner, consistent with the episodic experience of symptomatic and life threatening attacks. For example, Horne and Weinman (2002) reported that community dwelling patients with asthma were less likely to believe it necessary to use controller/preventer medications (used between attacks when asymptomatic) and were actually less adherent if they perceived asthma as an acute rather than a chronic condition. Consistent with these findings, Halm *et al.*'s (2006) interviews with patients hospitalized with primary or secondary diagnoses of asthma showed that patients who believed they had asthma *only when they had symptoms*, were less likely to believe in the importance of using controller/preventer medication when asymptomatic, and less likely to use these medications 1 and 6 months following hospital discharge. In addition, compared to those with a chronic model, half as many patients who held a symptom based-episodic model reported using a peak flow meter and they were less likely to have visited their practitioners to discuss asthma treatment when asymptomatic.

We are designing an intervention that helps patients see asthma as chronic and controllable rather than as an acute, uncontrollable condition. Interviews strongly

suggest that many patients are unaware that their current self-management strategy is symptom based and episodic. Having patients review their medication use, both how and when they use controllers/preventers (i.e. daily medications) and quick relievers (i.e. as needed medications), lets them see the illness model that underlies self-treatment. When a typical patient was asked, 'Do you think you have asthma all of the time or only when you have symptoms?' after reviewing her use of both medications, she responded, 'Given what I just told you, I guess I have to say that I only have it when I have symptoms'. Once the patient recognizes her implicit illness and treatment representations, she can be provided with and encouraged to use a behavioural management and monitoring system consistent with the chronic nature of asthma. The intervention model provides valid objective and subjective feedback consistent with good control by distinguishing between controller/preventer and reliever medication, and providing clear expectations for each: i.e. for controller/preventer medications: (1) they are to be used when asymptomatic (change in illness identity); (2) they suppress inflammation (causal feature of treatment representation); (3) inflammation is always there (time line); and (4) patients may not feel any benefits when taking the controllers/preventers (consequences and asymptomatic identity). The fifth step resembles the bottom-up approach in the diabetes intervention. It calls for daily use of a peak flow meter and performance of a daily activity (e.g. climbing stairs) that has elicited breathlessness, as a way of monitoring change in lung function. This monitoring is paired with consistent use of medication and provides both an objective and subjective means of monitoring the effect of medication. Step 5 reformulates time line and control beliefs (i.e. while asthma is chronic, symptoms are predictable and controllable, though disease is not cured). Thus, each step of CSM is built into a picture of a dynamic system for controlling the underlying illness, and action plans are drawn both for taking medication, and for monitoring outcomes. The expectation of improved peak flow values and decreased breathlessness and decreased reliance on quick relievers with activity embeds expectations of objective and subjective indicators as consequences of effective medication use.

#### **Top-down or bottom-up and prototype appraisal checks**

Whether an intervention should flow from experience to concept (bottom-up) or from concept downward (top-down), will depend upon the specific chronic condition, the demands set by the patients, that is whether they ask for and require abstract explanations before engaging in behavioural strategies or need to acquire appropriate expectations and experience respecting how specific behaviours affect both objective and subjective targets for self-management. In short, the decision to begin from a cognitive (top-down) or behavioural perspective (bottom-up) will likely depend upon whether a patient managing a specific condition attributes or represents symptoms and functional changes to an inappropriate model (needing to reattribute somatic events - a top-down approach), or whether the patient fails to perceive or intuitively grasp the effects of specific behaviours on both objective and subjective targets (bottom-up approach). A recent study by de Ridder *et al.* (2007) provides excellent preliminary evidence of marked changes in the patient practitioner interaction when the practitioner focuses either on patient models of illness (illness representations) or action plans. In comparison to a behaviourally focused interaction on action plans (bottom-up), a focus on patient's illness representations (top-down) elicited more patient questions about the presenting illness. The focus on action plans

(bottom-up) elicited more discussion about psychosocial issues related to treatment and life-style behaviours in the home environment than the focus on illness representations (top-down). The investigators provide an extremely detailed picture of the effects of practitioner focused CSM intervention on the clinical exchange.

How a practitioner implements a top-down or bottom-up approach will also be affected by the mental checks involved in appraising the meaning of disease and treatment experience. Appraisal checks, such as symptom location, duration, sensory pattern, and severity, are involved in matching experienced somatic and/or functional changes to illness prototypes, for example whether the experience is a symptom of an acute cardiac problem, a head cold, an indicator of a chronic condition such as hypertension, diabetes, or of stress or ageing. Problems can arise when these checks create an excellent match between experience and an inaccurate prototype. For example, when an elderly individual experiences chronic swelling of the feet and moderate breathlessness, the location and duration of these changes fit an ageing prototype and do not necessarily relate to congestive heart failure: the mental checks locate heart symptoms in the chest (not the feet), as painful or crushing pressure in the chest as sensory features (not moderate), and as acute (rather than chronic) (Bunde & Martin, 2006; Horowitz *et al.*, 2004). A top-down intervention that connects these symptoms with the representation of congestive heart failure may be more difficult given the persuasiveness of the specific symptoms appraisals and it is likely that a patient will vacillate between a medical and common sense interpretation of his or her experience. On the other hand, if symptoms such as those reported by patients with diabetes do not connect to an alternative disease model, (i.e. location, duration, etc., do not lead to a clear misattribution), the process of control can be linked to frequently repeated behaviours that can be evaluated objectively (i.e. SMBG), a behavioural or bottom-up approach is likely best.

#### ***The system: Who does what?***

If it takes multiple iterations over many months to create a functioning multidisciplinary team to reduce infections from intubation among patients in intensive care (Stead & Starmer, 2007), how much more time will it take to create teams that include patients and families for managing chronic illnesses? If we take diabetic neuropathy as an example, what will be the role of the physician, nurse, podiatrist, patient, and family members when managing the neuropathic complications of diabetes? If patients feel they are 'getting better' as neuropathy has progressed to the point where they no longer experience symptoms and need to check their feet and avoid walking barefoot, which team member will help them to see the dangers associated with the loss of sensations, walking barefoot, cutting toe nails, and failing to inspect feet regularly to avoid ulceration and foot amputation? What are the tasks for the physician, podiatrist, patient, and family, and how do these participants coordinate to insure effective implementation? Resolving the discrepancy between patient (no pain = I am okay) and practitioner perceptions (no pain = neuropathy) of neuropathic risk at both an abstract and experiential level, and the ability to generate a coherent link between cognitive representation of risk factors and specific actions, are critical for initiating and sustaining effective foot self-care behaviours (Vileikyte, in press; Vileikyte *et al.*, 2006). The team must be integrated and intervene from the top-down, (i.e. reshaping of cognitive representations of neuropathic risks), and the bottom-up, (i.e. behavioural skills training that can be evaluated objectively).

### **Fidelity of implementation**

Two themes appear to dominate thinking on the future of health care: (1) Patient-centered (individualized) care for prevention and control of chronic and infectious illness and expanding the healthy life-span and (2) The need for evidence based practice. Both themes were evident at the 2007 Annual Meeting of the Institute of Medicine of the National Academies of Science. Little was said however, about how such evidence was to be generated respecting the delivery of care, and nothing was said about the need for evidence regarding the behavioural processes required for communication and effective self-management. The rules proposed by health psychologists for generating evidence for the effectiveness of behavioural interventions, fidelity in: (1) how treatment is delivered; (2) how it is received (uniformity in understanding of the treatment); and (3) how it is enacted (uniformity in patient performance of treatment specific actions), meet the bio-statistical requirements for fastidious clinical trials (Feinstein, 1983). They conflict, however, with the generation of evidence for individualized or patient-centered treatment. Patients bring an array of expressed genes and an array of expressed prototypes of self, illness, and treatment to pharmacological and behavioural interventions. Patient-centered treatment must incorporate therefore, evidence respecting the interactions among biological and behavioural intervention and the moderating biological properties and cognitive affective representations of the patient. Trials can be 'fastidious' if interventions are in fact tailored to specific illnesses and patients while taking into account particular sociocultural contexts.

### **Final comment**

If behavioural health research is to contribute to the prevention and control of chronic illness as well as to behavioural theory, the design, implementation, and testing of interventions will be at the top of its agenda. Behavioural interventions work, but their widespread adoption requires they be effective *and* efficient from the perspective of the health care system, family, and patient (Leventhal *et al.*, in press, 2008). Developing and testing system-based interventions requires integrated, multidisciplinary research teams whose members contribute at every step in design and implementation. Only then can we achieve the integration of behavioural, bio-medical, and the beliefs of patients and families in specific institutional and cultural contexts that will reap both substantial health benefits for patients and deep satisfaction for the investigators and practitioners participating in this adventure.

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