Making sense of illness in the absence of diagnosis: patients' and physicians' narratives of medically unexplained symptoms.

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ABSTRACT

The aim of this study was to improve medical understanding of patients' illness experience and everyday thinking about physical distress, by focusing on patients' and physicians' narratives of medically unexplained symptoms. Semi-structured interviews were held with 16 Canadian and immigrant patients from two primary care clinics in Montreal, and separately with their physician. Detailed content analysis reveals that, despite the absence of diagnosis, both patient and physicians hold complex and dynamic models of illness. Physicians' explanations rely almost exclusively on biomedical constructs, whereas patients' models of illness draw from a much wider range of sources of experience and authority. Despite regular follow-up, physicians have very limited access to the intricate networks of meaning revealed in their patients' interviews. In fact, although there is some common ground of understanding, patients and physicians show low congruence of their models, and much discrepancy in the expected outcome and management. Eliciting patients' illness narratives rather than focusing on narrow biomedical issues offers promising possibilities for physicians to negotiate meaning with their patients. The richness of patients' models provides potential avenues leading out of the clinical impasse of medically unexplained symptoms.

RESUME

L'objectif de ce projet et de contribuer à améliorer la compréhension des médecins quant à l'expérience de maladie de leurs patients et à leur raisonnement de santé à travers les récits de maladie de patients souffrant de symptômes médicalement inexpliqués, et de leurs médecins. Des entretiens semi structurés ont été conduits avec 16 patients canadiens et immigrants récents de deux cliniques de médecine de famille de Montréal, et avec leurs médecins. L'analyse de contenu détaillée révèle que malgré l'absence de diagnostic, les patients et les médecins possèdent tous deux des modèles de raisonnement complexes et dynamiques. Les explications des médecins sont essentiellement calquées sur le paradigme biomédical, alors que celles des patients se basent sur un grand nombre de sources d'expériences et de savoirs. Malgré un suivi régulier de leurs patients, les médecins ont un accès très limité aux réseaux de signification élaborés qui sont révélés dans les récits de leurs patients. En fait, malgré un terrain d'entente commun, il y a une mauvaise congruence entre les modèles des patients et des médecins, ainsi que de nombreuses contradictions quant à leurs visions respectives du pronostic attendu et de la prise en charge nécessaire. L'obtention des récits de maladie des patients plutôt que la cristallisation du problème sur des données biomédicales restrictives offre des possibilités prometteuses de négociation du sens des symptômes avec le patient. La richesse de son modèle nous fournit des pistes potentielles pour sortir de l'impasse clinique des symptômes médicalement inexpliqués.

I. INTRODUCTION

Medically unexplained symptoms (MUS) are patients' symptoms for which the physician cannot pinpoint a precise diagnosis. They are felt complaints which cannot be rendered tangible by an objective test.

The definition of the problem itself is problematic in biomedicine, and the issue of which label to use for this type of situation is far from being solved. But regardless of the definition used, MUS represent a frequent and costly medical problem, associated with much distress and disability for the patient and increased frustration and management difficulties for the clinician. Considerable research has focused on associated factors and patients' characteristics, but little has been written on the patients' understanding of this particular situation of -so called- absence of medical explanations, or on the physicians' perception of his patient's predicament.

This project involves detailed content analysis of interviews with Canadian and immigrant patients, and with their primary care physician in the context of MUS. This research aims to contribute to improving medical understanding of patients' illness experience, and to clarify the extent to which social, cultural and psychological factors are integrated in everyday thinking about physical distress. Gaining insight on patients' own mode of understanding their symptoms should contribute to the development of an effective and practical framework for physicians when managing the complex situation of patients with MUS.

Analysis of the patients' interviews will focus specifically on 1) the types of explanations given for the symptoms, 2) patients' sources of expertise for these explanations, 3) the different types of knowledge structures patients rely on for their symptom explanations. These interviews will then be compared to the analysis of their physicians' interview, in particular with the physicians' own explanations and with the knowledge and understanding they may have of their patient's explanations.

History and definitions

Historically, various terminologies have been used to describe situations where the symptoms receive no clear diagnosis, each with its attached explanation. The initial concept of *hysteria* appeared in Antiquity and signified physical disease caused by the displacement of a freely migrating uterus, as corroborated by the famous Greco-Roman gynaecologist Soranus (Veith, 1956). This notion went unchallenged through the middle ages and for almost two millennia. The genesis of the modern concept of somatization appeared in the 17th century, when the role of nervous force and nervous energy were central in the theory and practice of medicine and many symptoms were explained as resulting from disorders of the nervous system (Fabrega, 1991). In 1682 Thomas Sydenham defined hysteria as a malady of women, hypochondriasis being the male counterpart, and describes them as disturbances of both the mind and the body due to a disorder of the animal spirits, thus contradicting its widely accepted uterine origin (Veith, 1956). He mentions the influence of emotional stress on the nervous system and enumerates a number of physical changes or symptoms resulting from brain dysfunction. In 1859 Briquet in his *Traité clinique et thérapeutique de l'hystérie* defined hysteria for the first time as a discrete syndrome characterized by multiple somatic complaints (Mai & Merskey, 1981). He pointed out that men also suffer from hysteria and refuted the still prevailing notion that the disease was due to a pathology of the uterus. Instead Briquet believed that hysteria was produced by suffering due to environmental stimuli on a susceptible personality causing a pathological lesion in the part of the brain that processes affective sensations and determines emotions (Mai & Merskey, 1981). This prolonged unpleasant sensation supposedly created a pathological state of the brain with the various organs becoming ill through the repetitious noxious stimuli. He described eight categories of symptoms and pointed to social factors and to the importance of emotional stress in its causality. In 1895 Freud in his *Project for a Scientific Psychology* separated symptoms due to *hysteria* as caused indirectly by intrapsychic conflict from those of *neurosis* that are directly caused by excessive nervous activity without psychological mediation (De Gucht & Fischler, 2002). The rise of psychoanalysis overshadowed Briquet's work in the second half of the twentieth century, until it was reintroduced by Purtell and colleagues (1951). It was then further developed as Briquet's syndrome by Perley and Guze (1962); thus becoming the precursor to somatization disorder in the DSM III (APA, 1980). Early in the 20th century Stekel introduced the term *somatization,* referring to a hypothetical process whereby a bodily disorder arises as the expression of a deep-seated neurosis (De Gucht & Fichler, 2002). This notion of somatization was closely related to the concept of conversion and to the theoretical framework used by psychoanalysts: that of unconscious defence mechanisms, and the notion of psychogenic somatic disorders. We see here the emergence of the concept of somatization as a somatic manifestation of psychological distress.

Many authors took this direction, including Bridges and Goldberg (1985) who operationalized the criteria for research in primary care and framed somatization as a somatic presentation of a Diagnostic and Statistical Manual of Mental Disorders 3rd edition (DSM-III) Axis I psychiatric diagnosis. Lipowski (1988) also held this view but alters his definition with time. In 1968 he describes somatization as *the tendency to experience, conceptualize and/or communicate psychological states or contents as bodily sensations, functional changes or somatic metaphors*. Twenty years later it becomes *the tendency to experience and communicate somatic distress and symptoms unaccounted for by pathological findings to attribute them to physical illness and to seek medical help for them.* He further underlines the importance of stressful life events and situations in generating these responses, but mentions that somatizing patients usual deny causal this inferred link between their illness and the presumed source of psychosocial stress.

The other orientation taken by somatization holds the assumption that the presentation of somatic symptoms is the hallmark of somatization, regardless of causality. This is the case of the DSM where somatization disorder was included in one of the seven somatoform disorder along with hypochondriasis and conversion disorder since the third edition (APA, 1980), with its actual definition now including severity, chronicity, symptom counting and symptom group, associated disability and medical consumption. The somatoform disorders are a heterogeneous group of diagnoses introduced to the DSM-III to include patients that had somatic symptoms that accounted for no known medical condition but with too few psychological symptoms to be labelled with an alternate psychiatric diagnosis. This causality of psychological conflict was removed from DSM III to become only a temporal factor in DSM III-R (APA, 1987) and DSM IV (APA, 1995). Also the number of symptoms required for diagnosis of somatization disorder diminished, and the addition of the non-specific category of undifferentiated somatoform disorder was added to DSM-IV, which in clinical practice counts for the most commonly used category.

Currently there are various terms in use, whose definitions overlap without being exactly equivalent. Globally, *functional symptoms* refer to a disturbance of bodily function rather than structure, *somatization* implies a psychological problem expressed somatically, *conversion* refers to a loss of function due to the transformation of a psychological problem and somatoform is a psychiatric diagnostic category of the DSM (Sharpe, 2002). The term *medically unexplained symptom* is now being preferred by physicians as neutral, descriptive, non-pejorative, and considered acceptable for patients and medical specialists alike (Escobar et al., 2002). Practically, this term is used in research settings, and this supposed acceptability of the MUS label has never been examined from either perspective in the clinical encounter. One can only speculate that, although the stigma of the psychiatric connotation of somatization or conversion etiquette is removed, this terminology may itself initiate some distress or anxiety for the patient as well as the clinician.

Certain clusters of symptoms are also grouped under specific syndromes or labels, such as irritable bowel syndrome, fibromyalgia, chronic fatigue syndrome, sick-building syndrome, etc., the accepted reality and success of these labels depending on clinical use, patient acceptance, advocacy group activity, and image such as presented by the media.

The common difficulty of this predicament, regardless of the label used, is the absence of a gold standard confirming or ruling out the diagnosis. The absence of diagnosis for a symptom points to the issues of the limits of the technical abilities of medicine to diagnose all conditions and the myth of modern medicine that all symptoms can be efficiently diagnosed and treated. Under these conditions, it is not surprising that the physician would "psychologize" or attribute the symptom to certain personality traits or psychological states of the patient, conveniently shifting the responsibility on to the patient and neutralizing the threat to his professional competence (Kirmayer et al., 2004).

Prevalence and associated factors

MUS are of primary concern in general medical practice, because of their high prevalence, cost, consumption of medical resources and frequent association with psychiatric comorbidity.

Prevalence rates of MUS vary between studies, but have been estimated as high as 5-10% in the general population (Isaac et al., 1995; Kirmayer et al., 1996), and from 18% to 30% of general medical consultations up to 66% of some speciality clinics (Arnold et al., 2004; Fink et al.,1999; Katon & Walker, 1998; Nimnuan et al., 2001, Van Hemert et al., 1993);. About one patient out of five frequent attenders presents with repeated medically unexplained symptoms in primary or secondary care (Karlsson et al., 1997); (Reid et al., 2002).

Their high cost derives not only from increased health care utilization but also from lost productivity due to the missed work days and from claims for social security benefits (Escobar et al., 1987; Reid et al., 2003). In fact somatizing patients have been shown to have a higher rate of primary care, specialist and emergency care visits, and hospital admissions, more medical procedures, and in general higher inpatient and outpatient costs that non-somatizing patients. These findings are confirmed even after adjustment for depression and anxiety co-morbidity, other major medical co-morbidity, and sociodemographic characteristics (Barsky et al., 2005).

Predictive factors associated with MUS include childhood experience of parental ill-health, childhood abdominal pain, lack of care in childhood and high rates of life events in the period before the onset of the MUS (Craig, Boardman et al., 1993; Craig, Cox et al, 2002; Craig, Drake et al., 1994; Hotopf et al., 2000). Increased rates, or epidemics, of MUS have even been known to occur in circumstances of rapid social change associated with trauma and loss (Van Ommeren et al., 2001). Abuse also seems more frequent in patients suffering from MUS, in particular women with pelvic pain have a history of some form of abuse in a third of the cases (Fry et al., 1997).

Many socio-demographic factors are associated with the presence of MUS, but inconsistencies appear across studies. Female age seems to be constantly associated with MUS (Feder et al., 2001; Nimnuan et al., 2001). This may be because of higher symptom reporting in women (Barsky et al., 2001) or because physicians are more likely to identify women as somatizers (Golding et al., 1991). Most studies report that older age, higher level of disability, lower socioeconomic level, more state benefits and unemployment are associated with patients with MUS (Escobar, 1991; Feder et al., 2001; Katon & Walker, 1998; Reid et al., 2003; Van Hemert et al., 1993). On the contrary, another study in seven medical specialities shows MUS to be positively correlated to younger age, employment, absence of disability and higher educational attainment and negatively to receiving benefits (Nimnuan et al., 2001). The contradictions observed between studies may be explained by many factors including the differences in research settings, the variations in the definitions used for MUS or somatization and the multiplicity of the instruments of measurement.

A meta-analytical review of the relationship between depression, anxiety and MUS showed that there was a significant higher rate of major depression and any anxiety disorder compared to healthy controls and to patients with similar symptoms but of known organic pathology (Henningsen et al. 2003). A 3 year longitudinal study of frequent attenders in secondary care with MUS confirmed a high prevalence of psychiatric comorbidity, associated with high use of health services, and substantial functional impairment (Reid et al., 2003). Although patients with MUS clearly are severely disabled, the relationship to psychiatric disorder appears complex and its causality is multidimensional

Attempts at bigger scale, standardized, worldwide research have been conducted by WHO. A large study focusing on somatic symptoms and psychological distress in multiple primary care settings demonstrated that somatization is a common problem cross-culturally in primary care and is associated everywhere with marked disability (Gureje et al., 1997; Simon et al., 1996). Self reported somatic symptoms scores were strongly correlated with distress scores and with anxiety and depression across all sites. The authors defend that the somatic presentation of psychiatric distress is not a culture-bound syndrome of developing countries but a worldwide phenomena and that separation of the physical and the mental is more consistent with a medical model of reasoning that with the patient's lived experience. A smaller WHO international study on somatoform disorder illustrated the cultural ubiquity of MUS, although clear differences in prevalence rates, type of symptoms presented, attributions and interpretations of symptoms, probably reflecting the differences in beliefs and attitudes about health and illness and in the cultural expression of psychosocial distress, as well as the availability and organization of health care services (Isaac et al., 1995).

Influence of doctor-patient communication

Physicians' attitudes, as well as what they communicate to their patients, have been found to influence MUS prevalence. Positive perception of interaction with patient by physician increased the making of a provisional diagnosis for the symptoms while physicians that evaluated the interaction negatively were more likely to find the symptoms medically unexplained (Nimnuan et al., 2000). As well, receiving more information from their physician appeared to decrease the rate of MUS (Nimnuan et al., 2001). Paradoxically, these patients with medically unexplained symptoms are the ones that physicians often find difficult to manage and a source of high frustration (Lin et al., 1991; Reid et al., 2001). But physicians are rarely aware of the effectiveness of available approaches such as cognitive behavioural therapies and antidepressant medication (Kroenke & Swindle, 2000; McLeod et al., 1997; O'Malley et al., 1999). When a symptom is not supported by medical finding after extensive investigation, doctors tend to lower their estimation of the severity of the symptom, whether they have met the patient or not (Tait & Chibnall, 1997).

Reassurance is a recommended strategy to use with patients suffering from MUS (Kathol, 1997). Unfortunately it has proven insufficient to allay health anxieties, and may even be anxiety provoking when followed by a referral for investigations (Page & Wessely, 2003). Effective reassurance is not an easy task, and may be short-lived, in particular in patients with high levels of anxiety (Lucock et al., 1997). Reassurance that does not modify underlying illness representations when the symptoms are persistent may lead to a cycle of self-perpetrating reassurance-seeking (Neal et al., 2000).

A qualitative study in the UK examining interactions between general practitioners and their patients in situations of MUS revealed that a majority of patients provide explanations, opportunities for explanations, and cues to address emotional and social problems, but that physicians rarely pick up on these (Salmon et al., 2004). Physicians instead tended to normalize symptoms, responding with basic reassurance, benign explanations not addressing their patient's concerns, or no explanation at all (Dowrick et al.,2004). These strategies proved counterproductive as they prompted patients to present further evidence of the importance of their problems by elaborating symptoms, introducing new ones, or referring to external authority. Only when a tangible mechanism absolving them from blame was provided did patients accept some reassurance.

Patients' perceptions of doctors' responses to MUS were of three types: *rejection* or denial the reality of the symptoms; *collusion* or acquiescing to the patient's beliefs; and *empowerment* or legitimizing patients' suffering and providing opportunities for management of problem (Salmon et al., 1999). In a study among chronic pain patients, compared to symptomatic patients with a clear organic cause, patients with MUS were more likely to have been told their pain was "all in the mind," and not surprisingly were more dissatisfied with their physician and his investigation plan (Kouyanou et al., 1998).

One of the barriers to good communication is that physicians and patients have different perspectives on health problems. The physician's perspective is characterized by an emphasis on objective measurements, physicochemical data, mind-body dualism, scientific rationality, disease entities and is centred on the individual patient rather than his community. Although this perspective is not uniform as physicians work with a repertoire of different models and are also influences by their own cultural values and assumptions, the lay perspective, which focuses on *illness*, is nevertheless quite different from *disease*. It includes the subjective physical experience of ill health, the meaning and emotions attached that experience, and the social process by which family, friends and colleagues react to the symptoms (Helman, 2000).

The physician's perspective

Research conducted in the UK among primary care physicians reveals that they unanimously conceptualized MUS as a product of psychological distress and decreased tolerance of benign somatic symptoms. Social problems were cited as a frequent aetiology, together with lack of insight on psychological issues, stigma associated with mental health problems, and personal gain from the sick role (Wileman et al., 2002). Patients were perceived as having control over the events that led to their distress as well as over the clinical encounter, and these physicians expressed feelings of powerlessness, frustration, inadequacy and sometimes resentment towards the patient. At the same time these physicians acknowledged the crucial importance of the doctor-patient relationship and the damaging effect of a poor relationship on the quality of care.

In a Swedish study, the majority of general practitioners also explained symptoms as the result of psychological distress, with contributing factors such as fragility of patients, lack of medical knowledge, unrealistic expectations of medicine, traumatic change in social status, secondary gain from sick leave, paucity of social network, complicated life events and the emphasis on performance in postmodern culture (Woivalin et al., 2004). Here again doctors felt controlled by these patients, and often frustrated, powerless and insecure, although these impressions tended to lessen with experience gained.

The patients' perspective

Patients do not come to the medical practitioner from a explanatory void, but instead often hold a rich perspective on their illness. Many authors have offered classifications for patients' health beliefs. Young described patient beliefs about illness as belonging to internalizing versus externalizing systems (Young, 1976). Internalizing systems focus on the aetiology and processes happening inside the individual, whereas externalizing systems examine the causes arising outside of the individual body, in the larger social or supernatural world. Helman (2000) described four general sites for locating illness aetiology: within the individual, in the natural world, in the social world, and in the supernatural world. He also mentions Chrisman's eight groups of lay aetiologies: debilitation, degeneration, invasion, imbalance, stress, mechanical causes, environmental irritants, and hereditary proneness. Furthermore in a study in the USA focusing on patients diagnosed by their general practitioner as having a chronic disorder with a "*definite psychosomatic component*," he found that these patients had multi-causal explanations for their disorder, linking together the physical, psychological and social aspects of their life (Helman, 1985). These explanations included factors such as their emotions (described as "*pathogens attacking vulnerable organs or systems within the body*"), their own personality, hereditary weaknesses, organs behaving independently from their control, *poor relationships*, and stress. Explanations were based on prototypes of prior personal experience, experience of others, folklore, and information read or seen on television. The interactions between biological, psychological and social were also illustrated in an exploration of conceptual models of psychological distress in an US inner-city low-income multicultural primary care clinic (Karasz et al., 2003). Five categories of patient narratives were found: *biosocial* where the body mediates the relationship between (often traumatic) events in the social world by becoming weak and damaged and thus vulnerable to illness; *psychosocial* where recent stressors and events created symptoms through the mediation of mind and emotions; *psychological* where interior motives and traits caused distress; *situational* where an acute event allegedly provoked short-lived "stress" and "nerves"; and *somatic* narratives where psychological symptoms were conceived of as physiological.

Edward Shorter, in his historical review of psychosomatic illness, illustrates how medical models become incorporated over time in the lay discourse of patients, as they are in frequent contact with health care professionals, and how this modifies their explanations for symptoms as well as their clinical presentation (Shorter, 1992). More recent research in the UK with patients presenting MUS with over 12 months of investigations, found that these patients' accounts could not be categorized using biomedical models and ideas (Peters et al., 1998). Rather patients' explanations were incomplete and unsatisfactory, remained fluid, and they continued to consider alternative explanations. Explanations included concepts of imbalance of bodily processes and humours, influence of external social factors, internal nervous and psychological mechanisms, and disease as an autonomous entity.

A detailed analysis of narratives of patients with MUS from a British neurological clinic found these to be chaotic and difficult to listen to (Nettleton et al., 2004). While patients resisted psychological explanations, their utterances were filed with references to psychological issues. The predicament of the absence of a label for their condition made it harder patients them to make sense of their illness, take action for it, adopt a legitimate sick role, and access support and resources.

Bäärnhielm (2000) explored structures of illness meaning for somatizing Swedish and Turkish women in Sweden. Swedish women had several non-competing explanations and were engaged in an ongoing process of making sense of their distress. Causes of illness diverged among participants but usually involved references to somatic and emotional attributions or both, and included causal and non-causal links with stressful life events. They expressed feeling misunderstood by medical staff, and emphasized their own resources and responsibilities in dealing with their condition and the important role of exercise and contact with nature as health strategies. Turkish women's narratives offered few causal attributions for their symptoms, but were rich with parallels to life events (Baarnhielm & Ekblad, 2000). These women resisted psychiatric attributions and expressed a body-brain split. They relied on health care in Sweden as well as in Turkey, and on family for social support. Relationships with family and belief and trust in their physician were judged important for recovery, but their own capacity to contribute to this recovery was considered low by most women. They put considerable effort into understanding their condition, and were very much influenced by the contents of the clinical encounters rather than the non-medical environment.

Social origins of distress

Wider perspectives on MUS symptoms should also be considered. Many systems of medicine include sociosomatic theories, which locate the origins of distress within the social context, emphasizing for instance how cultural and social pressures shape the symptoms, diagnoses, course of sickness, and illness experience (Kleinman & Becker, 1998). A qualitative study in Montreal with Vietnamese immigrants suffering from MUS, multiple somatic symptoms or high level of emotional distress on the GHQ revealed two predominant culture-related explanatory models for their symptoms (Groleau & Kirmayer, 2004). One linked them to a social predicament involving indignation due to a social injustice that was too threatening to mention directly but that members of their community understood as such. The other was a cultural idiom of distress that related the symptoms to “wind and cold” but that was also associated with other stressful events such as migration experience and adaptation to Canada and past traumas.

Pain has been described as a symbol of resistance to societal pressures and expectancies, a legitimate mode of obtaining recognition in a delegitimizing world, and a form of collective opposition to political authority (Kleinman, 1995). And it has been further argued that somatization may represent a resistance to power and authority, and can be interpreted as a form of social protest (Scheper-Hughes & Lock, 1987). The medical profession then reshapes distress and hostile feelings into symptoms of new diseases in order to gain control over them, leading to medicalization and overproduction of illness. Although these larger perspectives of distress cannot be directly used with the patient in the clinical encounter, they provide useful avenues of reflection for the clinician struggling with the frustration of medically unexplained symptoms.

Tools to elicit patients’ narratives and explanations

Medical anthropology introduced the notion that patient have their own illness explanatory models (Kleinman, 1980). The use of explanatory models by clinicians has been promoted by medical anthropology to decode their patients’ symptoms, take into consideration their view of the disease, and facilitate therapeutic negotiation, as research has shown that dissonant models between clinician and patient constitute an important barrier to health care delivery, effective clinical communication, and compliance (Helman, 2000; Hunt et al., 1989). This approach has also informed the Explanatory Model Illness Catalog (EMIC), a research tool that provides a structured method of eliciting and analyzing illness narratives (Weiss et al., 1992).

The explanatory model perspective assumes that the popular models constructed by patients about their symptoms are logic and rational. But some studies have suggested that explanatory models cover only part of patients’ representations of health and illness behaviours, and patterns of use of health services (Groleau, 1998; Kirmayer et al., 1994; Young, 1981; Young, 1982). Certain health behaviours do not conform with explanatory models because these are not the only knowledge structures people use to interpret their symptoms. Based on his ethnographic fieldwork in Ethiopia and among Ethiopian immigrants in primary care clinics in Israel, Young identified three distinct types of knowledge structures in patients' account of illness: 1) formal and informal models derived from explanatory models based on causal logic; 2) knowledge based on prototypic experiences of self or others, leading to an analogical reasoning through metaphors and images of current symptoms or illness; and 3) *chain complexes* linking experiences metonymically, by evoking the sequences of events leading to the current episode without referring to causality or any kind of logic (Kirmayer et al, 1994). Specific questions will tend to elicit particular knowledge structures, although all three are used in explanations and illness narratives. The McGill Illness Narrative Interview (MINI) is a questionnaire that was designed to elicit these different knowledge structures for any particular symptom (Kirmayer et al., 1996; Young & Kirmayer, 1996).

Limits of actual state of research and objectives of this project

Despite the extensive literature on medically unexplained symptoms in part described above, a certain number of issues regarding this topic remain unclear. Problems of diagnostic categories and criteria, their recognition by physicians, the agreement on the absence of other diagnosis, clarification of the relationship between MUS and correlated factors or with psychiatric morbidity are a few of the issues that need to be further explored.

More importantly, very little has been written from the patient's point of view on illness cognition, social and cultural factors influencing illness behaviour, integration of medical model in his belief system. There are few studies of physician's knowledge of patients' beliefs and models of disease in situations where the clinician cannot provide a clear diagnosis. Most studies have focused on analysis of clinical encounters between physicians and patients with MUS, rarely on patients' or physicians' accounts, and even fewer have compared both perspectives.

The role of the physician is essential in the management of MUS and in limiting unnecessary medical intervention and preventing iatrogenic harm. Developing communication tools and strategies that permit a better comprehension of the patient's world and his or her experience of symptoms is necessary to construct illness meaning with the patient. Only through understanding both patient and physician models and clarifying the discrepancies between these two perspectives will such a goal be met.

The chief objective of this research is to acquire a better knowledge of the illness experience of patients with medically unexplained symptoms through analyses of their narratives. In particular, the aim was to identify the cultural, social and personal factors involved in patients' understanding of their illness, their influence on interactions with the health care system, and their possible contribution to the symptom's chronicity. A richer view of patients' illness experience will improve medical understanding and communication, allowing a more targeted and effective management of the clinical situation.

The main hypothesis of the present study is that in the absence of medical diagnosis, patients have their own explanations for their symptom. Borrowing tools from other disciplines, such as medical anthropology, should allow the interviewer to uncover attributions and meanings undiscovered in the clinical interview. Eliciting loosely structured cognition (prototypes and chain complexes) should permit access to more existing links and associations than those available solely through a focus on causal explanatory models. Physicians' interviews were used to contextualize the patient's narrative and offer insight into physicians' knowledge and understanding of their patient's thinking.

II. METHODOLOGY

This project is a cross-sectional qualitative study of patients suffering from medically unexplained symptoms and of their primary care physician.

Research setting

The research took place at two neighbouring sites: the Herzl Family Practice Clinic (HFPC) of the Sir Mortimer B. Davis-Jewish General Hospital, and the Centre Local de Services Communautaires Côte-des-Neiges (CLSC CDN). These two medical practices are located in the Côte-des-Neiges (CDN) area of Montreal, Canada, which has a multicultural population. According to the 2001 Census, 48% of inhabitants of CDN were born outside of Canada and 43% spoke a mother tongue other than English (Statistics Canada, 2004). Both of these clinics provide general family medicine consultations, including perinatal care, and are part of McGill University's Family Medicine Program. Ethical approval for the study was obtained from the Jewish General Hospital and CLSC Côte-des-Neiges Research and Ethics Committee.

Sample

The study population was the physicians (residents and staff) practicing in these two clinics, and their patients. Because the focus of this research is on patients' explanations for their symptoms and physicians' perceptions of these explanations, the working definition used to recruit patients was "*any current principal somatic complaint reported by patients for which no definite medical diagnosis could be found by physical examination and appropriate investigation,*" with the minimum time frame necessary for investigations being three months (Isaac et al., 1995; Nimnuan et al., 2000; Reid et al., 1999).

Physician informants were defined as the regular primary care giver of the patient informants, and had to have known the patient for at least three months. Because this is a study of everyday clinical practice, the extent of investigations and the decision regarding the presence or absence of diagnosis were left to the participating physician's opinion.

To examine the impact of cultural difference and of familiarity with the health care system on the patients' narrative, two subgroups of patients with MUS were recruited: (i) Canadian born and (ii) recent immigrants. The latter were defined as being born outside of Canada, having entered Canada after age 16, and having immigrated less than 10 years ago. Time measures are often used as proxies for acculturation, but as this is a complex relationship; duration of residence alone is insufficient and age at arrival was considered (Dawson et al.,1996; Salant & Lauderdale, 2003). Although there is no clear consensus in the literature on how to conceptualize culture and how to measure acculturation, these proxy measures were chosen as reasonable and practical alternatives for a preliminary study on a diverse patient population. Patients had to be proficient in French or in English, to allow analysis of the interviews without the added time and expense of interpreters. Patients under 18 were excluded, as were refugee claimants because of the complex relationship between their symptoms and ongoing petitions for refugee status.

Recruitment

Recruitment of patient and physician informants took place between January 2004 and October 2004. Physicians were informed about the study by presentations at the weekly training seminar, signs posted in the clinic, and reminders in their hospital mailboxes.[1] The recruitment was done by the author of this thesis, with collaboration from the on-site co-investigators, and was conducted in the supervision room of the two sites. In both clinics, after seeing the patient, residents report to staff doctors in the supervision room, to discuss the case and agree on treatment and management. The author of this thesis spent an average of

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[1] Physicians were told that the project was an attempt to test an instrument that could eventually be used in the clinic to investigate patients' health beliefs and explanations for their symptoms, and that their interview was designed to contextualize the patient's narrative. [put this in the text as it is important]

3-4 half days a week in the supervision room, listening to cases being presented, informing and reminding the physicians about the study, and recruiting eligible case from both residents and staff doctors. This allowed for additional participation observation of residents and staff doctors interactions and resident-patient interactions through the one-way mirrors.

Physicians notified the author in person, by telephone, note in her mailbox or email when they had followed-up a patient for at least three months after a new complaint without evidence of diagnosis. Once a patient was identified, his or her treating physician asked him or her for permission to give their number to the author, who then telephoned the patient to explain in detail the study procedure and purpose.[2] If the patient agreed, an appointment was made for the interview either at the patient's home or at the researcher's office at the Institute of Community and Family Psychiatry of the Jewish General Hospital, according to patient's preference. Use of French or English was the patient's choice. Physicians were interviewed after their patient, usually in the following week, to ensure that the interviewer, also a physician, was not unduly influenced by the medical perspective. These interviews took place at the physician's or the researcher's office, in French or in English, according to physician preference. Formal consent was obtained in writing from both informants prior to the interview.

Data collection

The patient questionnaire was based on the McGill Illness Narrative Interview (MINI) (Groleau et al., 2006; A. Young & Kirmayer, 1996). This interview is designed to elicit the patient's narratives of the current illness episode, its symptoms, causes and consequences, along with patients' representations and explanations organized cognitively in causal (explanatory model), analogical

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[2] Patients were told that the research project was designed to understand patients' perspective of complex symptoms. They were not overtly told that it was because they had a "medically unexplained symptom", as this could be anxiety provoking and might not be how their physician presented the situation.

(prototype) and metonymical (chain complex) reasoning (Kirmayer et al., 1994; Young, 1981; Young, 1982). In this questionnaire, the latter two are elicited first, as their structure is loose and their connections acausal, to insulate them from the structuring effect of the formal explanatory model.

During the interview, many symptoms were spontaneously brought up by patients. The decision of which symptom to focus on was made by asking "whether there was a symptom for which the doctor could not find a diagnosis or an explanation." If this did not provide a specific symptom, the patient was then asked "which symptom was the most important or the most bothersome for you?" The MINI then focused on these symptoms.

The physician interviews were much shorter and focused on narratives of the patient's illness episode, the putative diagnosis, the physician's awareness of and response to the patient's explanation, the possibility of negotiation around this model, the envisioned evolution or prognosis of the illness, and the use of the MUS label.

Both questionnaires were refined during the interview process. Some unclear questions were modified and others were eliminated as they proved irrelevant. The two final questionnaires can be found in the Appendix.

Patients' medical files were accessed after these two interviews were completed, again to avoid influencing the interviewer's perspective. The data gathered in the medical files includes demographic data and information on the patients' past medical history, physicians' impressions and assessments, tests and consultations requested, etc., permitting contextualisation of the illness episode.

All interviews were tape recorded and then transcribed by the author and three transcribers. Relevant data from the medical files was reported by the author in electronic files for coding and analysis purposes. In order to increase reflexivity, a field journal was held by the author throughout the project to record research process, as well as personal impressions, ideas and thoughts (Pope & Mays, 1995). All names and identifying information from the interviews or medical files was eliminated from the transcripts to ensure confidentiality. Tapes and transcripts are stocked in locked filing cabinets in the research office and tapes will be erased upon completion of the study.

The project was approved by the Research and Ethics Committee of the Jewish General Hospital in Montreal and of the CLSC Côte-des-Neiges.

Data analysis

An in depth analysis of the transcripts and the field journal took place, with an emphasis on it being inductive and data-driven, according to methods of grounded theory analysis (Charmaz, 2002; Ezzy, 2002). An initial reading of all interviews was conducted to identify recurrent themes. These themes were organized into a coding tree which included: 1) identified themes from the patients' and physicians' narratives; 2) *a priori* defined codes, such as patient symptom and knowledge structures (chain complexes, prototypes and explanatory models) (Stern & Kirmayer, 2004). This coding scheme was presented to co-researchers (LJK, DG, AY[3]) for comment and revision. Because of the large amount of data obtained, a decision was made to focus primarily on the topic of *symptom explanations*. The interviews were then coded systematically according to the reorganized coding grid. Coding was facilitated by using the qualitative data analysis software package NVivo2 (QSR International). Problems arising with coding were resolved by discussion with co-researchers (LJK, DG, AY).

Although different types of data were collected through patient and physician interviews, through participant observation, and by reviewing medical files, more weight was given to the analysis of the individual interviews. The other data were used mainly to complement, situate and contextualize the information obtained in these interviews. Also, because of the much longer length and depth of the patient

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[3] Laurence J. Kirmayer, Danielle Groleau, Allan Young, who were the author's advisory committee for this Master's thesis.

interviews, their concurrent analysis and discussion will be more elaborated than that of the physician interviews.

To facilitate understanding and synthesis of the large amount of data, a detailed individual summary of each interview was written, that highlighted its main themes, and contained relevant excerpts. Particular attention was given to patients' symptoms, to the types of explanations present within each knowledge structure, and to issues of outcome, management, and patient-doctor communication. The summaries provided a global view of the interviews of the vast amount of material, while facilitating links back to the main text that allowed maintaining the perspective of the individual narratives.

Each patient-physician dyad was then compared on the basis of these summaries but with constant consultation of the initial transcript. This individual comparison of patient and physician interviews was then complemented with a cross-case analysis of all interview dyads. Four types of information were compared between physicians and patients: 1) patients' perceived unexplained or main symptoms; 2) congruence between patients' and physicians' models of explanation for the symptoms (for general explanations, for the three types of knowledge structure, for expected outcome, and for necessary management); 3) correspondence between each group's perspectives of the other group's models with the actual construct; and 4) rating of the communication and understanding.

Patient-doctor agreement was considered present if more than 80% of the items were congruent, partial if at least one item was present in both narratives, and not present if none were the same.

Because of the sizable quantity of data obtained and the richness of the themes brought up in the interviews, it will be impossible to present the totality of the information gathered in this project. Instead the focus of the analysis will be on overall "explanations" for symptoms and illness and other data pertaining directly to this question.

III. RESULTS AND DISCUSSION

This chapter presents analysis of part of the data obtained in this project, with the main focus being the comparison of symptom meaning and explanations, for patients and their physician. To facilitate reading and avoid redundancy, the results will be presented in three sections with their discussion presented at the end of each section.

The first section, after discussing some recruitment issues, will describe the characteristics of patient and physician informants and the unexplained symptoms that were investigated in depth in the interviews. These descriptive quantitative results offer an overview of the sample from which the data was obtained.

The second part of this results section will present the analysis of interviews with patients. In particular, the focus will be on the types of explanations patients provided for their symptoms, the sources of their knowledge about their illness, and their differential use of the three knowledge structures elicited by the MINI.

In the third part of the results section, physicians' perspectives will be given, including their model of disease for these medically unexplained symptoms as well as their understanding of their patient's perspective.

A final section will compare patient and physician perspectives, identifying the ways in which the physician's knowledge of his patient's model may be incomplete, as well as potential conflicting views of symptoms, their causes, outcomes and management.

1. Participant recruitment and characteristics

Recruitment and participation

Recruitment took place from January 2004 to October 2004. Twenty patients were recruited for the study, of whom four refused, after an initial acceptance.[4] In total 33 interviews took place with 16 patients and 14 physicians.[5] Interview duration averaged 103 minutes (range 60-151 min.) with patients, and 29 minutes (range 13-44 min.) with physicians. Seven patients were interviewed in their home, 9 in an office at the Institute of Community and Family Psychiatry (ICPF) of the Sir Mortimer B. Davis-Jewish General Hospital, an outpatient psychiatric clinic. Two physician interviews took place at the ICFP, the 14 others at the HFPC.

Physician refusal to participate is difficult to estimate, as absence of case referral could also be interpreted as lack of eligible patient in their practice or different labelling of this patient. Nevertheless recruitment was a long and tedious process. Despite frequent reminders by the author and the local co-investigators, physicians stated they did not encounter patients eligible for the study. Staff doctors in particular seemed uncomfortable with the idea of their work being scrutinized, as illustrated by remarks that were made during participant observation.

> I have lots of patients with MUS, but we have already worked out that this is the problem.
>
> Either my patients have a diagnosis or are under investigation. We *(doctors)* don't like it when they have no diagnosis or explanation, so we try to find one. I feel like it is a personal failure or a show of my lack of competence.[6]

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[4] Of the patients that refused to participate, two were recent women immigrants (Russia, Cameroun) and two were Canadian born men.

[5] One patient was interviewed twice due to technical problems and her long list of symptoms, and two physicians provided two patients for the study and were therefore interviewed twice also, albeit about different cases.

[6] These comments were made by two doctors in the teaching room, and are not excerpts from the interviews.

Participants' characteristics

Fourteen patient participants were women and 2 were men. Ages varied from 26 to 77, with a mean age of 44. Ten patients were Canadian-born and 6 patients were recent immigrants, their countries of origin being Peru, Israel, Ethiopia, Bangladesh, Sri Lanka and Afghanistan. There was a wide range of marital status, religious and linguistic backgrounds represented.

Of the 16 patient informants, only 5 were working. 2 patients were students (but "mature" students, having worked many years before the contemporary study period), 2 were retired, 3 were housewives (who had formerly worked and wished to work again), and 4 patients were currently not able to work because of their health problem (1 on disability insurance, the others on medical leave).

Level of education was high, with 7 patient participants holding one or more university degree, 3 having completed high school and 2 years of college or professional school, 3 having completed high school only, and 3 not having finished high school (one unknown). The level of education was particularly high in the recent immigrant group, with 4 out of 6 patients having completed high school. Despite this, the immigrant patients could not validate their foreign training and were not able to work in their field of competence in Canada. Patients' characteristics are detailed in Tables 1 and 2.

Physician sample included 5 staff doctors (with 3 to 20 years experience) and 9 residents (6 first year residents, 3 second year), of which 9 were women and 5 men, aged 24 to 50 (mean age 31), with a mean age of 31 (range 24 to 50 years). Cultural diversity was also represented in the physician sample, with 3 out of 14 physicians being non-Canadian born, and 6 having at least one foreign-born parent. Four physicians held a university degree other than medicine. More information about the cultural background of the physician participants can be found in Table 3.

Patients' presenting symptoms

Patient informants were highly symptomatic. They mentioned spontaneously between 2 and 18 symptoms each. Although criteria for somatization disorder were not sought out systematically in the interviews, careful review of the patient narratives did not find any patient that met the full criteria for somatization disorder according to the DSM-IV (APA, 1995). This was either because their symptoms started later than age 30 (5/16), or because the number or type of necessary symptoms required was not attained (13/16), although six patients could be identified using the criteria for abridged somatization (Escobar et al., 1998). Patients did not always differentiate between symptoms that had a diagnosis or an explanation and those that did not in their narrative of illness, and it is unclear how aware they were of the lack of a medical explanation.

The MINI interviews focused on 25 symptoms in total, representing between 1 and 3 per patient. These 25 symptoms were chosen because they were considered medically unexplained or very disabling for patients. Nine of these symptoms were *pain* (back, chest, neck, joint, ubiquitous), 4 were *fatigue*, 3 were *genital-urinary complaints* ("burning when urinating", "bladder problem", heavy menstrual bleeding), 2 were *gastro-intestinal complaints* (abdominal pain with diarrhea and vomiting), and 4 were *others* ("feet all the time cold", "can't walk any more", "too hot all the time", "bad reactions to medications").

When comparing these symptoms with the ones mentioned by their physician as the patient's predominant medically unexplained symptom, a concordance of 19/25 symptoms can be found. 13/16 patient-physician dyads agreed on all main symptoms. In one case (CB-07) they agreed on one symptom "bad reactions to medication", but the doctor showed no acknowledgement of the patient's other main symptom "bladder problem", despite probing by the interviewer. In one case (NCB-06) there was a partial concordance, meaning that the doctor could provide 1 symptom of the 3 mentioned by his patient, but ignored the patient's "dizziness" and "pressure in the head". In one case (NCB-03) there was complete absence of concordance. The physician selected the patient because of her multiple symptoms for which explanations were often unsatisfactory. She focuses on "dizziness, lightheadedness" which was the latest symptom presented by the patient for which she could not find a cause. The patient, on the other hand, mentioned "burning when urinating", "lower back pain" and "feeling too hot all the time".

Discussion

The rate of patient participation (75%) in this study was acceptable. Because patients with MUS represent 18% to 30% of general medical consultations (Nimnuan et al., 2001; van Hemert et al., 1993), the lack of signalling of eligible cases by physicians' suggested their great reluctance to participate due to to the uncertain nature of MUS that challenged their professional competence and authority. This was confirmed in discussions that took place between the author and potential physician participants in the supervision room during recruitment and patient observation. This raises questions about physicians' difficulty in accepting the limits of biomedicine and the apparent failure or lack of efficacy of medicine, which will be discussed in the third section in the light of the physician interviews. Physician participant characteristics were consistent with the greater physician population of these clinics.

The finding that patients did not meet criteria for somatization disorder despite their high level of symptomatology was most likely due to the fact that the interview focused on present symptoms, was not designed to elicit specifically these criteria, and did not explore past symptoms or the precise chronology of their onset. Employing an additional questionnaire (such as the Diagnostic Interview Schedule or the Composite International Diagnostic Interview) to systematically assess criteria for the presence of a psychiatric diagnosis, and in particular of somatization disorder, would be a useful measure to consider in a future study to allow for better comparison of results with existing studies, and for an assessment of other psychiatric co-morbidity.

When comparing this sample's results with those from the existing literature, one must bear in mind our particular setting: primary care physicians were freely invited to refer patients to our study. Although this is not an uncommon choice (Bäärnhielm, 2000; Junod Perron & Hudelson, 2006; Peters et al., 1998), it differs from other studies that performed a systematic screening of physicians' consecutive patients for MUS (Stanley et al., 2002; Woloshynowych et al., 1998), or that recruited patients from the community that thought of themselves as having a medically unexplained symptom (Kirmayer et al., 1996).

Compared to the clinic's female patient population (63%), our sample contained an excess of women (14/16). Medically unexplained symptoms are known to be more common among women (Feder et al., 2001; Nimnuan et al., 2001). However, in our study, the very high proportion of women in the present study also reflects the proportion of women in the physician's caseloads, given that the only new patients accepted into their practices are pregnant women.[7]

The low rate of employment, high level of functional impairment and lost productivity from these patients' symptoms are consistent with other research on patients with medically unexplained symptoms (Feder et al., 2001; Reid et al., 2003). The difficulty in these cross-sectional studies is to know whether the lack of work or disability precedes or is a consequence of the medically unexplained symptoms. In our study, among the 11 cases that were not working, symptoms antedated the lack of activity for 9 (82%). For all, the symptoms greatly diminished their ability to work or study. In fact there appear to be complex interrelations between satisfaction or stress in the workplace, onset of symptoms, and decreased ability.

Although some studies find suggests that patients with MUS have received higher levels of education than patients with a medical explanation for their symptoms (Nimnuan et al., 2001), most of the literature describes a lower education level in

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[7] Statistics from the clinic were obtained from the chief physician's assistant for 2004. Available data included age and sex of patients. Their were no records available for employment rate, level of education, nationality and religion.

patients with MUS compare to general clinical populations (Feder et al., 2001). In our study, the inclusion criteria requiring that recent immigrant participants be fluent in French or English may have selected a sample with higher education attainment. The higher education level of our participants also may reflect a selection bias among the physicians who recruited patients they believed would be articulate enough for an in-depth interview, as illustrated by the following comment:

> Also I thought it would be interesting for you to talk to because she is intelligent and educated and has insight to a certain level. (CB-05-D)[8]

The recruitment of immigrant and Canadian-born subgroups of patients was designed to observe the influence of cultural explanations, of their understanding of biomedical culture and their familiarity with the Canadian medical system –or lack thereof- on their illness narratives and explanations. Results show these subgroups are in fact quite heterogeneous in these aspects. The Canadian-born group included two patients whose parents had both immigrated just before their birth (from Italy and Argentina) and who, despite very good understanding of biomedical culture and the Canadian health care system, held cultural explanations for their symptoms that were heavily influenced by their parents' ethnocultural background. Equally, the recent immigrant sub-sample included several patients (Peru, Israel, Afghanistan) whose adherence to modern biomedical theories of disease was the same as for Canadian patients (with one patient even being a physician) although their knowledge of the local health care was scarce. While this calls into question the validity of the two a priori defined subcategories, the sample certainly reflects the heterogeneity of the Canadian population.

The categories of symptoms experienced by these patients are consistent with studies of medically unexplained symptoms in the community and clinic (Isaac et al., 1995; Kroenke & Price, 1993), except for the high number of genital and

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[8] Excerpts are labelled as follows: CB=Canadian-born, NCB=recent immigrant, P=patient informant, D=physician informant, M=interviewer.

urinary complaints than can be explained by the high number of female participants.

Comparison of the symptoms reported by patients and their physician reveals lack of concordance in 6 out of 25 symptoms. Several explanations can be advanced to explain this apparent lack awareness by the physician of his patient's cardinal symptom of concern:

(i) symptom considered normal or minimal,

> I mean I think they're fleeting kind of side effects, (...) I don't really think it gets in the way of her daily life. (...) oh this is a normal body kind of thing. (CB-07-D)

(ii) "drowning" of the symptom in the patient's multiple complaints,

> Every time she comes she has a different complaint, multiple complaints it's hard to pinpoint. (...) she is always complaining of one pain or another (...) She always comes in feeling unwell, and feels that there is something wrong with her. If it's not one thing it's another. (NCB-03-D)

(iii) symptom not fitting with the physician's agenda,

> 'Cause when someone, you know like when patients don't know you know like what their, you know like, you look to retrosternal chest pain, but they really want to talk about their toe that hurts or you know? And we know that well ok well the chest pain is a more significant symptom I want to work on. (CB-04-D)

(iv) physician strategy to handle chronic unexplained symptoms

> M: Ok, does she present any other symptoms?
>
> D: Ahm, huu .. she has a lot of complaints, often, (...) But she comes often, I see her often and and she comes often with symptoms that are unusual, (mhm) that are difficult to explain, ahm... (...) when I have patients that I don't know what's going on, is just to basically keep following it (...) and you know it will will, it will either sort itself out which it has for her I think. So I just keep trundling along with the hope that either one of these days the problem will go away. (CB-06-D)

(v) language barriers interfering in doctor-patient communication,

> Because there is a bit of a language barrier she can't really tell me exactly what's bothering her. (NCB-03-D)

(vi) physician recall bias

> M: Yeah, yeah. Um, her other symptoms were headaches and ?
>
> D: I don't remember frankly. I know headache was a big one ah, you know at times she felt nauseated I think. She had ah, muscle tensions elsewhere or, you know, what we thought were muscle tension, again they went away. I think she, low back pain, but I don't remember exactly. (CB-01-D)

(vii) and last, the influence of patient's presentation of the symptom (or lack therof).

> I stopped talking about it because the doctor never found an infection. (NCB-03-P)

Although one can speculate on why these profoundly debilitating symptoms were not mentioned by the physician, the interview structure did not allow for further exploration of this. In particular, a choice was made during the interviews not to interfere with what the physicians brought up about their patients, in order not to influence unduly their accounts. Nevertheless, the possibility that physicians filter out the parts of the patients' narratives upon which they are unable, or unwilling, to act will be examined further in this research. But first patients' and physicians' explanations for the symptoms will be presented.

2. Patients' explanations for their symptoms

This section will present three perspectives on patients' explanations for their symptoms: i) the etiological categories of explanations put forward by patients; ii) the kinds of expertise upon which patients rely for these explanations; and iii) their differential use of particular knowledge structures in explaining their symptoms. This framework offers different "lenses" to read the data, reflecting its richness and complexity. Differences between the Canadian-born and recent immigrant patients' narratives of illness will be pointed out when they are present.

Types of explanations

Patients' explanations of their symptoms could be grouped in a number of themes related to their perceived causality: *physical, constitutional, transmitted, social, emotional*, and *missed diagnosis*. *Stress* constituted a hybrid category that bridged the physical and the emotional categories.

Despite the fact that patients mentioned medical diagnoses as causes for their symptoms, the choice was not to use these as categories. A closer look at the underlying medical label provided by patients revealed that their views of "diabetes", "depression", "lymphoma", etc. were not always consistent with the conventional biomedical view. Hence, diagnostic terms used by patients were better classified by the implied etiological categories.

Physical

Physical explanations of symptoms appeared in all patient interviews and reflected a common mechanistic view of the body. Many explanations focussed on the care and needs of the body. The body was considered an object with a complex structure that can be maimed or transformed. In these narratives, bodies can be adversely altered by bad posture, physical trauma, too much or poor quality food, excess of weight or overexertion, pregnancies, bad posture, cold and other environmental factors, and by toxic substances (such as smoke).

> M: Ok. .. Et puis Dr J m'a aussi parlé d'une douleur.
>
> P: Ouais.
>
> M: Ouais.
>
> P: C'est ça. Euh, moi euh, en premier moi je pensais que c'tait des séquelles, parce que quand j'ai eu 6 ans je me suis fait frappée par euh une voiture quand j'étais en b'cyclette, et j'ai resté 72h dans le coma. Ok? Ensuite les médecins m'ont faite un tas d'études, ils m'ont dit que j'avais rien. Mais ils l'ont dit à mes parents que peut-être, quand je vais être plus âgée j'aurais une grosse possibilité que j'aie la, l'épilepsie.
>
> M: Uhum.
>
> P: Finalement, j'ai rien eu, mais moi, ouais, moi je pensais que ma, toute ma douleur, c'était les séquelles d'ça. (CB-06-P)

The body also has a balance of chemical or energetic nature that can be disturbed by stress or by medications, and become depleted in different substances (energy, Chi, iron, iodine, potassium).

> P: And ah .. I .. I can't, you know I was talking to someone the other day who is ah shaman, and he'd gone over to China and trained, ended up being trained in acupuncture or Eastern ah..
>
> M: Mhm.
>
> P: And he was talking to me about, I was talking about how I had gone through all these things but I can't seem to build back. (mhm) That, that I've tried to build back my fitness or my energy or my whatever, and I can't seem to re-strengthen. (mhm) Aside from cross-country skiing which I know how to do in a way that seems to work for my body without straining, overly straining causing other problems, but in most other cases, and he said, "OH IT'S YOUR CHI, you need to refill your energy. And you've, it's gone out and you need to, you need to do these, they're certain Chinese exercises that they do to actually try and bring it back in". And I kind of thought, you know, you may be right, because, it's certainly, I feel like it's here! It's in your, stomach area and I know that I've tried to do all these Pilates, and exercises to strengthen the core muscles to posture. (mhm) I can't do it, I absolutely cannot do them. (...) So when he said, "your Chi is exactly there" I thought, Ok, this sounds, you know, sounds like I can conceive of this (yeah) you know.
>
> M: Yeah, it makes sense.
>
> P: It's completely bizarre, but it makes sense. (CB-05-P)

The body is seen as needing regular exercise or it will become deconditioned. Furthermore, if normal body functions—in particular, sleep and elimination of urine and feces, but also sexual intercourse—are not maintained or used according to nature, body parts may shrink, become stretched, tired or deformed. These altered and weakened bodies are then perceived as more susceptible to disease, and ultimately to death.

> P: I've always had a little weakness in the bladder to start with. (mhm) And ahm I think it was from when I was a child, I used to hold it, because I couldn't go to the bathroom anywhere? (mhm) So I think it started from that, but as I said, old wives tales you know. (mhm) Ahm I never went to the bathroom in anybody else's toilet except my own, so I used to hold myself all day, when I got to my mother's door, she'd open the door quick, otherwise I would pee in my pants. (mhm) Because I held myself in all day. And ahm, so that was just a problem. (...)
>
> M: Yeah, so how, do you think that ah this holding in that you did when you were a child-
>
> P: Yes, yes, I'm pretty sure, I'm pretty sure that's what happened yeah.
>
> M: How does it, influence the health problem now, how does it cause it now?
>
> P: Maybe, it was, made my muscles weaker? (CB-07-P)

A common metaphor is that of the body as a machine that can only take so much before it breaks down.

> P: That you know I assume because our body can only handle being, you know being in a bad situation for only so long before other things start to go too. (CB-05-P)

This body machine draws energy from an internal "battery" that can shut down or "short out".

> P: Ah my mother started experiencing a lot of fatigue and pain, at my age.
>
> M: Ok.
>
> P: So maybe there's a hereditary thing there, we women we go, go, go, go, go and then we burn out.
>
> M: Mhm.
>
> P: She is also, thought of everybody else, did everything for everybody. You know she's here there and everywhere ahm, she also sort of, the batteries started going until, it just shut down. (CB-03-P)

Constitutional

While these physical explanations were expressed as something acquired and that could affect anyone, some patients also described themselves as having a special innate sensitivity or a particular individual constitution that made them more susceptible to illness. This constitutional explanation sometimes took the form of a *variant* in body part (fused vertebra, spinal malformation, scoliosis, double womb, having less small blood vessels than the average person), or a more *diffuse* characteristic such as being more vulnerable, fragile, a bit weak, having a high tolerance for pain, a hypersensitivity to medication, a body that is too hot all the time, having been a premature baby, or needing longer than other people to heal. In contrast to physical explanations, constitutional factors were present since birth.

> M: Uhum. D'accord. Pis à votre avis c'est quoi la CAUSE du problème?
>
> P: Une malformation de la colonne vertébrale.
>
> M: De la naissance?
>
> P: Ouais.
>
> M: Ok.
>
> P: Parce que, dans dans toutes les sites ousque j'ai été, c'est, tu NAIS comme ça.
>
> M: Ouais.
>
> P: Ca se développe pas ça. (CB-06-P)

Some patients thought that their body was *specifically sensitive* to certain factors, whether social, emotional or physical, thus explaining why they got sick whereas other people in the same situation did not.

> P: Sometimes I think my mother is right if I had listened to her maybe I didn't have the pain.[9] But sometimes a friend of mine told me that she never rest when she gave birth to his child she drink cold water, she did everything but she's strong she don't have any pain. She's normal.
>
> M: Why do you think something happened to you and not to her?
>
> P: Because of things that we had in common that we didn't do the things that we should do and.

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[9] By this the patient means respecting the cultural Afghan prescriptions of keeping warm, resting, and eating and drinking certain foods for 40 days after giving birth.

> M: But nothing happened to her?
>
> P: No, nothing happened. When I asked her she said "I don't have pain, I don't have anything." Things are normal but I have. That's why sometimes I think maybe it's not true. (yeah. mhm.) To keep your body warm and sometimes I think maybe the the, our body is different, some sensitive and some are not, some are strong.
>
> M: Yours is more sensitive, maybe?
>
> P: Yeah, I think so. I'm not that strong. (NCB-05-P)

Other explanations of specific sensitivity include one's body needing more time than other people to adapt to migration to Canada, being particularly sensitive to lack of exercise, and female gender making one prone to urinary infections and fibromyalgia.

Finally, an idiosyncratic constitutional explanation was offered by one patient (CB-06-P) who explained that she was born with a special "gift", and that her symptoms were a call for an initiation for her to learn to master these premonitions and dreams.

> P : ... un autre médecin[10] à l'hô-, euh à l'hôpital X. qui est euh, il est spécialisé en, en tout qu'est-ce qui est culturel.
>
> M: Uhum.
>
> P: Y y croit beaucoup à, à, à certaines choses que les médecins d'ici, de c't'hôpital ici, ils croient pas
>
> M: Uhum.
>
> P: que ça l'existe.
>
> M: Uhum.
>
> P: Pis lui, qu'est-ce qui d'sait, que, qu'est-ce que j'avais -ça c'est avant que je découvre que j'avais la scoliose- qu'est-ce qui d'sait y disait que c'était mon temps, pour que j'aille .. trouver c'est quoi, comment je pourrais expliquer, mon, ma mission, [dans la vie.
>
> (...)
>
> P : .. y disait que c'était mon temps, parce que y'a certaines choses que moi j-, c'est inexplicable, euh chuis capable de prémonition, j'ai beaucoup de rêves prémonitoires, pis certaines choses comme ça. Pis y disait que c'était mon temps, pis qu'y fallait que j'aille à, à, à

---

[10] The patient presents this as her doctor's explanatory model. The patient was very ambivalent to accept by it, and cautious in presenting indirectly this delicate explanation to the interviewer (who she knew was also a physician). Further in the interview she described how she had in fact actively sought out this possibility.

> l'autre pays, pour étudier, parce que lui y venait du Chili, pis y'a vu beaucoup de cas comme le mien. Pis y disait que c'était mon cas, pis ça se manifestait de cette façon-là, douleur, vomissements. (CB-06-P)

Family transmission

Patients also viewed illness as something that was transmitted within the family, described as "passed on in the family", "running in the family", "comes from my mother", "hereditary thing", "getting something genetically from the family", "taking the bad traits of the family", "family pattern", "being very frequent in the family" and "exchanging (the disease) with mother and sisters".

This concept of transmission of illness rarely stood alone, and usually was linked to a medical diagnosis (diabetes, cardiac problem, colitis, cancer, depression) and to another type of explanation (physical, emotional, stress).

> P: Apparently, the nerves and the stress and that, seems to run in the family, in my biological family.
>
> M: Okay. Mm-mm. Is there anyone else besides your sister?
>
> P: Oh ya, my other sister. I noticed even R [her brother] has been having stomach problems too now. I think it's, he's worried too eh?
>
> M: So you think the sensitivity to stress and, and nerves, runs in the family?
>
> P: Ya, I think so.
>
> M: Ya. Mm-mm.
>
> P: I mean, I'm not *sure*, cause I, I have an aunt who has, um, shingles?
>
> M: Mm-mm.
>
> P: My aunt, and ah, two uncles and my grandmother: colitis. We're doing good, eh? (mhm) Ah, my aunt: heart disease. Um, my uncle: heart disease. My mom died of a heart attack. Ah, actually my mom, they say was sitting on the side of her bed trying to pull down her pants and dropped dead of a heart attack. (mhm) They said it showed, er, such a massive heart attack, so bad that it would be (xxx?) .. But my heart's good.
>
> M: Ya. Good. Good.
>
> P: Every time they check it they say it's good. I'm amazed! That explains why I had a heart attack at 22. And now I'm doing good, my heart's good. I plan on keeping it that way! (CB-08-P)

Even CB-06-P's constitutional explanation of possessing a "gift" of premonition is reinforced by a transmitted characteristic:

> M: Ok. Pis vous, vous pensiez quoi de son explication à ce médecin chilien?
>
> P: J'ai dit, je disais c'était une possibilité. Parce que, qu'est-ce que moi je, c'est très courant dans la famille. (CB-06-P)

Explanations of transmission were submerged by the use of prototypes of family members, in particular of parents. The presence of the feared illness in close family members contributes to the impression of the illness as something that cannot be avoided, almost a sign of bad omen. This concept will be further illustrated when describing the use of prototypes in illness narratives.

Explanations from the mind

Although physical explanations were the most frequent kind mentioned by patients and were present in all narratives, psychological explanations were second in frequency. Patients referred to psychological factors affecting symptoms in several ways.

Firstly, symptoms might be *brought on* by emotions, "thinking too much" or having too many concerns, worries or stresses.

> P: Mm-mm, well as I told you before, I, I tend to worry a lot. So I don't know, maybe it just comes out, in the form of that and other things that I get (laughs). Like headaches, heart burn, you know, stress-related. (CB-01-P)

> M: Why, what is the reason do you think for this pressure *(in her head)*?
>
> P: Sometimes I think that's ahm, connect to my health maybe. Sometimes I say maybe I'm thinking too much. I didn't give my mind a rest. Maybe it's too hard for me to think and then I don't get any solution or something. So I don't know which one. (NCB-06-P)

Interestingly, two patients considered that worries had a *protective* effect on symptoms because they diverted attention from their symptoms; these bodily manifestations were amplified upon the resolution of their worries.

> M: Uhum. Pourquoi est-ce que vous pensez que ces problèmes de santé ils ont commencé à ce moment là, et puis pas à un autre moment?
>
> P: Pourquoi c'est commencé dans ce moment-là?
>
> M: Ce moment précis?
>
> P: (xx?) Je ne sais pas quand, pourquoi que ça commence, hein? Je pense que, avant,
>
> M: Uhum.
>
> P: J'ai pas le temps pour, euh, .. pour regarder avec, avec moi-même.
>
> M: Uhum.
>
> P: Pour dire "oh, j'ai comme ça", parce que j'ai pas le temps. Je fais beaucoup de choses. (NCB-01-P)

Second, similarly to bodily explanations, patients declared having been emotionally *harmed* or *depleted* by the hardships of their life. This could occur through excessive, difficult, or even traumatizing life events that might "block you" or "shock you", "overwhelm you"; there was a predominance of life events involving losses.

> M: Yeah, okay, and is there anything special in your life when these bladder problems became more important?
>
> P: No, no.
>
> M: 3 years ago?
>
> P: No, no, I don't think so, maybe the shock from all this dying and that didn't help you know.
>
> M: He *(her husband)* died 4 years ago?
>
> P: 4 Years ago. The after effects of that can come anyway, you know, cause I work with this *(support group on grieving)* and I know. The ahm, a lot of the ladies have had things that have happened after. (CB-07-P)

Third, *psychological make-up or character* was referred to as an important contributor to symptoms. Again, this involved "character based on prior experiences and traumas", "having a too tight upbringing", but also more generic references to "type of personality", as well as issues related to managing life situations, such as "wanting to control everything and not being able to," "taking things too personally," "lacking perspective to make the right decisions," being overwhelmed by things going on in life," or "having missed certain stages of development".

> M: Okay, why do you think your health problems started at the precise time when it did?
>
> P: I guess it depends on the type of personality I have. If you're a person who is sensitive, who...take things to heart so the disease will affect you more. Uhm it's only personality. Personality and, and in my case environmental because I wasn't born here. You have on top of it you have external stress so I'm a very extraverted person, however, I do take things to heart and ah...I take things too seriously, too personally. So I guess I would be a good candidate to have fibromyalgia I don't know.
>
> M: So you think certain personalities are prone to getting it more than others?
>
> P: Yeah. (NCB-04-P)

Despite the traditional divide between mind and body, it appears in these interviews that both physical and psychological symptoms arose through similar mechanisms: both might be due to a predisposition for illness, and might be subject to aggravation or deterioration by stresses that leads to illness.

A closer look at patients' discourse reveals that they express much ambivalence about possible psychological causes for their symptom. Psychological causality is brought up either because they spontaneously considered it or because their doctor implied it at some point during their interaction. Sometimes patients would consider this possibility, only to reject later in the same interview as a non-cause, as not "something real".

> M: Ouais. C'était vos engourdissements qui étaient insupportables ou c'était le fait d'être toujours confinée à la maison?
>
> P: Les deux.
>
> M: Les deux, hein.
>
> P: Quand on dit que le physique et le mental, les émotions sont intimement reliées là, je perçois beaucoup, personnellement.
>
> (...)
>
> P: Bon. .. J'tais, j'tais pas contente![11] Hahaha! Psychologique j'veux bien croire là, oui j'suis affectée psychologiquement par l' l'abolition

---

[11] Here a doctor suggested to her that her symptoms were "psychological".

> de mon poste, mais physiquement là, j'ai vécu quequ'chose, j'ai vécu là, quequ'chose! Je sais pas c'que c'est, une crise d'angine, je sais pas quoi euh. (CB-10-P)

Psychological cause in the absence of tangible medical proof appeared to threaten the reality of the patient's symptom, and thus undermine the patient's credibility and suffering.

> P: *Something* must be there, it can't just all be in my head, you know? (CB-01-P)

The physical reality of the body experience thus proved to be too overwhelming, and cannot possibly be explained by a psychological process.

Social Factors

Patients referred to social factors and events in a variety of ways. They might contribute to illness by leading to psychological depletion, harm, worries and concerns, and in this case were embedded in a psychological explanation. Or they might exist as independent meanings, originating from the social sphere whether mentioned as part of a chain complex or in an explanatory model.

Overall, examination of social factors and explanations for symptoms revealed that an overwhelming implicit theme in these narratives was the issue of *loss*: loss of spouse, family member or relationship, loss of job, loss of social status, loss of financial means, or other important resources.

The two main sources of social explanations and contributors to illness were the close family circle and the professional world. Issues from the professional world included: "conflicts with colleagues," "excess of work," "getting fired," and "not being able to find a job."

> P: Hein, ça a commencé comme ça. Surplus de travail, conflit, tout là. Alors euh, j'en avais déjà eu dans le passé un ulcère d'estomac, il est revenu. (CB-10-P)

Issues related to the family circle differed for Canadian-born patients and recent immigrants: the former pointed to conflicts with siblings, parents and spouse, and excessive burden from family members' illness or death as contributing to their symptoms,

> M: Ok, ahm so, another way to ask it is, did anything happen to your family or at work or in you social life that caused ah the chest pain?
>
> P: (...) It was always the situation between my abusive sibling and .. actually, it's HER! (chuckles) Point final!
>
> M: Ok.
>
> P: She'll always have problem with, somebody you know, if not me, it's my dad, if it's not my dad, it's my mom you know, and at one point I was always trying to please her, you know like keep her, keep my parents free from her, you know, and I was just harming myself you know. But, and the things like ahm, I think she's the one that actually brought it on to tell you the truth. Cause it started off as a panic attacks so ahm, then it snowballed into the chest pains, you know cause I would stop, stop myself from breathing type of thing you know. So, she brought it on. (CB-04-P)

whereas non Canadian-borns referred primarily to the *absence* of close family as a factor negatively influencing their illness. This may be related to differences in family systems and range of sense of kinship, or to the effects of migration, but this question cannot be resolved in such a small and heterogeneous group.

> M: Did anything happen in your family, at work or your social life that could explain your health problem?
>
> P: Yeah, again ah..coming here, separated from my family, I'm an only child living abroad, uhm.. trying to make a living here, trying to find a job, uhm..that's basically it.[12] (NCB-04-P)

In addition to isolation from family and community and the support these could bring them, difficulties with administration, non-recognition of foreign diplomas and professional experience, and languages are also seen as related or contributing to disease.

> M: Is it *(the illness)* connected to anything else in your life?
>
> P: I don't know maybe I, in my life I think a lot, I'm thinking a lot because me...I'm not a...I didn't study. I don't have any diploma in my file and I'm thinking to do that because it's getting difficult when my children.. I have a lot of things to do and when I'm looking for a job I don't find really I don't find a job. (...) And the language also make

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[12] Further in the interview the same patient mentions "getting good support from family and friends" as one of the keys to managing her symptoms.

> make difficult for me. For example now my son's in Grade 2 and so he's in a private school, Jewish school, and there it's very difficult. They study much, much, much, too much. And I don't know French. When he's studying with all the homework that he bring home I can't help him.
>
> M: It's all in French?
>
> P: French, English, Hebrew. Three languages. So English, I'm trying you know, it's still now it's okay.
>
> M: It's good.
>
> P: Yeah, I'm hoping. But French I can't help him, so I'm worried that you know that he's gonna be very weak in his class and you know because I don't have the chance to help him. I'm thinking on my head how long that that's. (NCB-06-P)

In fact the immigrant group's narratives point to migration difficulties as the overwhelming social cause or contributing factor to illness.

> P: Everything started from that point.
>
> M: It started here?
>
> P: Here in Canada.
>
> M: And you consider that this health problem is related to any event in your life?
>
> P: Yes, to the stress, to Canada. I think. Trying to make a life here I think.
>
> (...)
>
> M: What do you think was the biggest trigger for this disease to come?
>
> P: Canada! (both laughing)
>
> M: The immigration process.
>
> P: Oh yeah, big time!
>
> M: Aha.
>
> P: Big time. ..
>
> M: You think if you had stayed in Israel things would have been different?
>
> P: Maybe, maybe. ... (NCB-04-P)

Lack of money was also commonly associated with illness for both groups. This may be because of the general practical concerns brought on by economic pressures, or more specifically, not being able to afford treatment and thus experiencing a worsening of symptoms. For one patient, this took the form of conflicts with the Quebec automobile insurance agency over salary replacement and health care coverage.

Finally, patients referred to difficulties in the professional and institutional management of disease. This could involve physicians, nurses or paramedical professionals such as physical therapists, but also the greater Quebec medical system, with many patients complaining about the long waiting periods to obtain medical examinations and test results, as well as lack of communication with some physicians, in particular specialists. Although patients rarely complained about their general practitioner, dissatisfaction about other aspects of care was ubiquitous.

> P: I would have needed more help. And help where they knew what to do, where I could explain, I need this, or I need this, empathic help or whatever, that would have been helpful. And understand soft tissue injury how to deal with it appropriately. I didn't start the first osteopath that I saw was maybe after a YEAR, or longer by which time things had a really good chance to SEIZE in the wrong place, and ah so there was a lot of UNDOING work to do (mhm) and ah there wasn't always continuity of care because the first osteopath I finally got to see an osteopath after a long waiting list and then the SAAQ said, "No, she's not a licensed physiotherapist anymore, so you can't, we won't pay for her, so I had to go to somebody else, there was another few months wait, that somebody else was fine, worked well for me, and then was pregnant, went on maternity leave, was replaced by somebody else who WAS OK. (…) So by the time I found this manual therapy it was this year (mhm) you know, it was last fall so, it would have been helpful to have you know the right .. (…) But things that were actually much more helpful, didn't fall into the bureaucratic slot (yeah) so and, and I just I can't stand.
>
> M: So the inadequacy of the system also didn't help?
>
> P: It was very unhelpful! (CB-05-P)

Undiagnosed illness and need for further investigations

Several patients openly stated that there might be an undiagnosed illness responsible for their symptoms. Others mentioned this possibility more covertly by pointing to the need for a particular investigation to prove the presence of an illness. Some patients had clues to what these missed diagnoses might be. Others only felt that there must be *some* medical explanation for their symptom, and put forward the lived reality of their symptom as evidence for this. Reassurance by their doctor that there was "nothing serious" was often insufficient to overcome this conviction, especially when symptoms were persistent or recurring.

> P: Not like before but ah…I think ah…I don't know but I feel not come not….have something inside like hiding yah I feel like that.
>
> M: Okay, yeah.
>
> P: Yah, I feel like that something hide inside they cannot find…I don't know why.
>
> M: Uhuh, Okay. (…)
>
> P: But…but ah…..its still there still I think something my chest pain is still there. Because when I think I have a chest pain.
>
> M: Yeah, okay uhm... What do you think, do you have any idea what is exactly happening inside your body that makes chest pain?
>
> P: Yeh….yah, because I think something inside, something inside me making something like ah.. you know, it burn if you have, even somebody have cancer. It is it become ah...the (spray?) and it become bigger so it get long time to get big enough huh? But you feel but you don't know. Right? When you find it the doctor has find it, nothing to do. Too late.
>
> M: Yeah.
>
> P: Right? Then I think something.. not I answer…but I know I.. because I don't know maybe because it still there.
>
> M: Uhuh.
>
> P: They said normal then I'm happy. Because the doctor knows me and doctor knows everything.
>
> M: Uhuh.
>
> P: They order test report and everything. But it is still pain.
>
> M: So you feel that there's something hiding there you said.
>
> P: Yes. (NCB-02-P)

Unpacking stress

Stress deserves separate mention because it was very often cited by patients as a cause of their symptoms. But stress cannot be taken at face value; it had multiple meanings in patients' narratives. Stress was associated or equated with "worries, tension," "overdoing it physically," "cardiac stress test," "nerves or break down of the nervous system," "the release of a brain hormone that causes anxiety," "keeping you up at night," "lack of sleep," "dealing with a lot of emotional baggage," and "environmental factors." It might be a cause of depression (or caused by it), chest pain or fibromyalgia. It was often equated with or linked to "nerves", nerves often being a consequence of stress, and anchoring the causality a step further in the physicality of the explanation.

> P: So I just presumed it was stress from the two, and stress and nerves from the two idiots[13] I was with.
>
> M: When you, a lot of people mention stress as related to their health problems, but it can mean very different things for very different people. When you say stress, can you, talk more about that, can you elaborate?
>
> P: I like um, .. like I said to X [*her doctor*], ah, like the money problems, the medical problems, worrying about how we're going to pay the rent, how we're gonna eat. Ah? How's R gonna get back and forth to work, all that type of stuff. That's what I consider stress. You know?
>
> (...)
>
> P: And I, and I, like, that I consider stress, if I have too much of it going on, like say if like you normally say, everybody says, we start fighting, whatever, with the money situation and not enough money, well, what are we gonna do and all this and that, and you know, we, it's on everybody's mind, and everybody starting biting each other's heads' off, because, you haven't come out and said it but you're thinking it, and every little thing just kinda gets to ya, like all that's stressful.
>
> M: Mm-mm.
>
> P: And ah, when the stress gets to be too much, it's like the nervous system kicks in, I'm shaky and I, like the lack of sleep, I'm shaky. (mhm) And ah, I've considered, I get, I lost my nerves that's why I'm not sleeping. (mhm) I'm all unnerved, all on edge, and having trouble to sleep. That's what I thought it was.
>
> M: Mm-mm. So this --
>
> P: So maybe that's what's causing the stomach problems you know I thought, the combination of the nerves and the stress!
>
> M: Yea, ok.
>
> P: And I'll say stress, I'll say nerves, and lots of times I'll say one or the other but I mean it in the same context. (CB-08-P)

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[13] She described these two earlier in the interview as alcoholic and abusive partners she was with in the past.

Stress appeared to be a convenient category that enabled patients to bridge the mind-body dualism prevalent in biomedical thought. It provided them with an acceptable link between difficult social events and physically felt symptoms, allowing them to circumvent the uncomfortable psychological explanation.

In comparison with Canadian-born patients, recent immigrants made many fewer references to stress, and none of their narratives referred to the "body shorting out" or to depression; instead, they gave more emphasis to environmental factors such as the noxious effect of Canada's cold climate, the difficulties of life in the city, or poor-quality food.

Death

A theme that seemed to lurk in the background of many narratives was death. Although not an explanation *per se*, death was a recurrent theme in 50% of the narratives. Allusions to death took many forms, although it is rarely referred to directly as a potential outcome.

One patient's narrative (CB-02-P) alternated between a desire for cure and desire for death. He welcomed the researcher into his home by asking "So, are you here to kill me or are you here to cure me?!" He cited spectacular stories of others' cures that he wanted to try, and at the same time produced a narrative that was permeated with thoughts of his death:

> P: My mother died, my father died, my sisters died, how long do I have left?
>
> I'm the only one left, I don't know how long? (...)
>
> Got my thing reserved, (xx?) for a long time you know. My plot! (...)
>
> One day we're going to go up there. (...)
>
> I wanna die now. (...) You only die once. (CB-02-P)

Another patient's transient desire for death was also put bluntly:

> P: You know, where I know what I've gone through in different like surgeries that I've had, I have a very high tolerance to pain. And this, I

> just, like I begged my husband to get me a gun. (Mhm) You know, because when the pain, it's that bad. You know? (CB-09-P)

Other narratives were punctuated by the deaths of others. These deaths, often of close family members, were present in all three knowledge structures, and were part of several types of explanations. Strikingly most of the deaths that patients referred to were rapid, brutal or unnatural deaths.

> P: I don't know, because of certain things that my family's happened like you know Bouchard's diseases, the man-eating, flesh-eating disease it's a big long word. Ah anyways one of our friends had it and wow she went to Lac St. Jean, and she was there went to the party, and went to a wedding, and everything. All the way down there, had a beautiful beginning of here retirement all excited about being retired she ended up 3 days, she just went like a wave in the sea, she just went whew whew whew, she was dying! So it started with a sore throat, and then .. but you wouldn't think something like that would happen to a person that's healthy normal, you know nothing (thought?) so ahm. (CB-07-P)

As illustrated in this example, accounts of abrupt deaths were particularly common in prototypes, revealing a feeling of alarm and concern in patients' words. This observation will be discussed further in the section examining the specific uses of prototypes.

Sources of patients' knowledge of illness

Patients' main cited sources of expertise for the knowledge of their symptoms (besides their own lived experience) were: their physician and other health care professionals; their close entourage; the mass media, books and internet. Not only did patients have several types of competing explanations, but they also drew these explanations from various sources of information, constantly comparing and modifying their own model.

The predominant authority of biomedicine in shaping patients' explanations will be developed, as well as the uses and transformations that patients made of this source of expertise.

Professional authority

All patients gave accounts of explanations of professional health care workers who they had consulted for their illness. This included principally their family doctor and other medical specialists, but also other health care providers such as nurses, physical therapists, psychologists and social workers.

Patients reported that these biomedical health providers gave them mainly plain medical diagnosis labels (fibromyalgia, depression, panic attacks, schizophrenia, etc.). Other explanations included several physical causes (diabetes caused by too much sugar, whiplash injury and herniated disk from automobile accident, trigeminal neuralgia from a nerve “shorting out”, physical de-conditioning, lack of sleep, etc.), and a few psychological reasons (depression coming from too many personal problems, worries and stress causing anxiety, “too much” in her life), but also numerous statements that “nothing could be found” and that “everything was fine.”

Despite specific questioning and probing, few patients admitted having consulted other healers outside the formal biomedical system; the sources of help mentioned included a Canadian shaman trained in China, a Latin American healer, a yoga professor, a manual therapist, and an osteopath. A few of these helpers provided additional explanations such as: “fatigue comes from lack of Chi,” or “symptoms are a calling for an initiation of the patient’s gift,” or “unresolved anger as a source of symptoms.”

Lay entourage

The second most frequent source of explanations were friends and close family members (spouses, parents, siblings, and children), and more rarely other patients. These persons might provide patients with statements or recommendations, and thus participate in modelling the patient’s explanatory process.

> P: Mhm, my husband! (mhm) Sort of, in a way. (aha) He says that, he says when you’re depression it’s an illness (mhm) he said, “you’re sick like you have, like, like you got a physical illness but” he said,

> "your spirit is sick, your spirit is sick, you spirit is infected, and that's causing you to feel pain and fatigue and, (mhm) the anti-depressants are like an antibiotic, treating your infected spirit".
>
> M: What do you think of that explanation?
>
> P: Oh I thought about it, I thought about it. I never really saw that associated, I always associated pain and fatigue with physical. (yeah) I never really associated it with depression until now.
>
> (...)
>
> P: I would think that if you're depressed, you're depressed if you cry a lot, you're depressed if your mental illness has become, cause you're going crazy and snapping things and banging things around (mhm) and throwing the house apart (mhm) and you know.
>
> M: Cause you used to think that?
>
> P: That I, that I connected to mental illness, yeah. (ok) I never, it never really clicked that it's associated with, physical (mhm) just feeling physically like *crap*! (CB-05-P)

Alternatively, others might influence patients by providing embodied examples or prototypes for the patient (see further discussion on prototypes). In the case of verbal explanations by family members, patients often mentioned that they disagreed with them or did not believe them. Nevertheless, they brought them up, either spontaneously or with probing, during the interview, as if they were ready to discard them, but preferred to verify their plausibility again with the interviewer.

Interestingly, three patients did not report any information provided by friends or family, even when probed, and relied solely on the professional sector to explain their symptoms. For the first (NCB-04-P), the delivery of a fibromyalgia diagnosis by a physician she consulted in her home country brought closure to her situation; the diagnosis validated her suffering and gave it a clear identity. For the other two patients with purely biomedical explanations, the narratives did not provide this sense of closure. One patient (CB-05-P, pain and fatigue), claimed the name of her suffering was not an issue: "I don't really care actually! It's not really relevant as far as I'm concerned!". But her total reliance on health care professionals mirrored the isolation she perceives in her social entourage. The irony was that she relied entirely on health care professionals while constantly challenging their authority.

> P: And my experience with the, whatever, what did you call it?, Western Trained Medical Community, which I have never had any reason to mistrust -or have any particular thoughts about- wasn't, *They don't know anything* about soft tissue injury. If it doesn't show up on an X-Ray, it doesn't exist! (CB-05-P)

The last patient (CB-09-P, facial pain) named the two possibilities to which her doctors had narrowed the diagnosis:

> P: The neurologist said, ah tic douloureux, and the um, I guess he's a neurologist, ah Dr. A. he's world renowned for cluster headaches supposedly, but he's at the Montreal Neuro, he says it's cluster headaches and it's very hard to ah, tell the difference between the two. (CB-09-P)

Nevertheless, she continued to hope for an examination or test that would identify the exact name of her disease. Both of these patients' repeatedly blamed flaws in the biomedical system for their lack of satisfying explanation and noted how they had been mishandled and mistreated. In the narratives of these two very dissatisfied and critical patients, the persistence of their symptoms despite the absence of a medical diagnosis might be interpreted as an unconscious way to fail the medical system that had failed them.

Internet and books: clarify and verify

Half of the patients (both Canadian-born and recent immigrants) had consulted the internet regarding their health problem looking for information that could explain their symptoms, clarify their diagnosis, and offer them some treatment avenues. Two patients looked for the same kind of information in popularized medical books.

Half of these attempts resulted in useful information to clarify the diagnosis, treatment options and prognosis.

> P: That I, that I connected to mental illness, yeah. (ok) I never, it never really clicked that it's associated with, physical (mhm) just feeling physically like CRAP!
>
> M: Yeah. That's what you had learnt from the Internet?
>
> P: Yeah, yeah, and from my doctors, (ok), that I you could, you could be feeling physically like *crap* but it's depression.

> M: Mhm, yeah.
>
> P: It's depression that you know, has to be has to be treated like anything else. (CB-03-P)

For other patients, consulting the Internet or published texts allowed for validation of their symptoms as a genuine illness, by finding other patients with the same symptoms who had received a diagnostic label.

> P: Only when I was diagnosed and I went to did some research on the net I ah got hooked on some forums, some medical forums, chats. And I was reading a lot of people's testimonies and I basically saw that this is the story of my life they're telling! The same thing "pain all over, unexplainable pain, recurrent pain, no special reason why. Ah .. they're always being sent to several specialists, all the tests are coming back with an okay result and still, the same thing". (NCB-04-P)

Other patients did not hold these positive views of Internet information. One patient found the testimonies of patients with similar symptoms ridiculous, while another rejected the information found there because it was too threatening (colitis and colon cancer), and several patients were wary of a source of information that could "drive you crazy" and whose accuracy could not be verified. Patients also criticized the fact that a lot of Internet sites were "just looking for money," and lacked helpful information for their problem.

The media: hope and fear

Half of patients referred to the mass media as a source of information about their illness. This included newspapers, television programs (documentaries, reality and talk shows), and radio programs.[14]

Patients reported obtaining, through the media, general information on health and illness including: physiopathology and management of chest pain, allergies, general health recommendations, herbal remedies, etc. But above all, the media provided them with striking individual stories or prototypes of two kinds: spectacular cures that filled patients with hope of illness resolution (e.g. injection of pig pancreas cells curing diabetes, gastric bypass improving the life of severely

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[14] One patient mentioned two media sources.

obese patients, new imagery technique permitting diagnosis and subsequent successful treatment of a patient with facial pain), or alarming examples of negative outcomes that made them fear a similar fate.

> M: And have you ever heard on television or on the radio, or read in a magazine about chest pains, something that's similar to yours?
>
> P: Ah, yea, I've seen some certain things on, on television I've watched also documentaries about bypass surgery and so on and so forth. Ahm I feel like some of the symptoms I fall into, you know, I wouldn't say like all of them but a good majority of them, like an ex-smoker? yes, I'm border line diabetic? Yes. You know. Are you feeling pains in your arms, either arms? Yes I do, off and on, you know. (CB-04-P)
>
> P: Yeah! Yeah, because I see all the time in the TV it's start with small problem and then they get in cancer and then you know and they didn't do the right way own kind this kind of problems. (NCB-06-P)

This raises the possibility that the type of information provided in the media, particularly the sensationalism of current reality shows, actually contributes to identification with a disease for patients who are anxious to find an explanation for their symptoms.

The transformations of biomedicine

Almost all patient explanatory categories about illness were permeated with biomedical concepts. These were not entirely consistent with medical physiopathology, but rather modified versions which fit with the patient's problem, lived experience, and knowledge. This created a *pseudomedical explanation* that incorporated biomedical concepts but differed from the formal medical model.

> P: Oui, que, euh, de hernia, comme ça?
>
> M: Une hernie?
>
> P: Oui.
>
> M: Oui.
>
> P: Aussi, uhum. Parce qu'avant, avant que je ne me (souvienne?), avant, je pense que c'est à cause que la hernia que pense que je, que je. (...) Parce que c'est, euh, quand je commençais à faire les, les exercices comme ça, je prends les, les .. peso? comme ça ?

M: les poids?

P: Oui, euh, les choses qu'on lever..

M: les haltères!

P: Oui, et je les posais ici pour faire, pour améliorer les, et je pense que, quelques mois après, je fais ça, je sens comme ça (la bosse). Mais je pense que la hernie c'est à cause de ..

M: une déchirure?

P: Oui, exact! C'est ça.

M: Ouais. Ok. Donc vous avez pensé à la hernie à cause de l'accident,

P: oui,

M: enfin, à cause des traumatismes à la gymnastique.

P: Oui. (...)

P: Mais oui. Parce que je pense que si c'est (enlevé le haut?), on pourrait (xx?) comment se dit? ça explose?

M: Ca peut exploser?

P: Ca pouvait exploser, ou si venait quelque organe nobles?

M: Comme toucher des organes nobles?

P: Oui. Uhum.

M: Donc vous pensez encore que la hernie c'est possible?

P: Mais oui.

M: Vous en avez parlé avec un de vos médecins?

P: Oui, je l'ai dit, mais elle sent rien! (NCB-01-P)

Here the patient gives an explanation for hernia etiology that is consistent with biomedical knowledge (injury from weight lifting), but describes consequences (explosion/rupture and effect/contamination on/of noble organs) that differ substantially from the conventional medical model (hernia incarceration and gut necrosis) and are closer to what might happen, for example, with appendicitis.

Typically, pseudomedical models involved an amalgamation of different physiopathological models, allowing patients to blend together the diverse models they encountered. In the following excerpt, the patient links together different elements of medical biology to emphasize her certainty of an impending heart attack.

M: Ok. Do where do you think it comes from in your heart, right now?

> P: Somewhere close to my heart, a vein or or, an artery, leading towards my heart yea. (…) I feel that ahm it's like getting blocked or getting hardened, (mhm) and that why it's not, like the blood is not being able to flow properly that's how I feel. (…)
>
> M: Are there any other causes?
>
> P: Aah! No, well, maybe my smoking in the past, could have contributed, but I think-
>
> M: How did that effect?
>
> P: Well, they say that smoking hardens arteries and my dad who used to be a ex-smoker ah, in his lungs, he would spit up blood, aah (…)and they said that his, lungs, ahm, I don't know if they could say that they were almost finished, due to the fact that ahm, I don't know what they're called but like molecule hairs? Ah, you know, everybody has hairs on their lungs that clean out. (…) So, I feel- I've smoked, ah I would say I've smoked at least 10 years so, my dad had quit smoking in his early thirties, (mhm) and his doctor had forced him to quit you know, (mhm) and then at 60 he still had that problem you know. (..) So, that's how I relate it to myself you know I say, you know my hairs and my lungs (laughing) Call them hairs! (laughs) Ah, they clean out, the smoke ok, but I've probably damaged them enough to cause a problem for my heart, because I still don't find that I'm breathing properly I do have sinus problem and I don't feel like I'm getting enough air in, into my body.
>
> M: So you feel that that is also affecting you heart?
>
> P: Yes.
>
> M: Yea, by making it ah.. ?
>
> P: Ah, you know your heart needs like air and ah, well oxygen not air oxygen and ah it helps your heart function properly, and I find that not enough oxygen is getting to my, to my heart. (CB-04-P)

Complex and dynamic versus fixed truth explanations

As a consequence of the numerous types of explanations available, as well as the multiple sources of information they accessed, patients had several competing explanations for their symptoms. The resulting models were quite complex and multifaceted.

> P: And ah a part of me even before now is saying "it's all in you head," you know and a part of me is saying "it's the medication your on if you, cause if you weren't on this medication you didn't have the pain before", you know. (mhm) So it could be a side effect, yea, (yea) you know. Ahm … and ahm the other part of me says "well, NO it's because of your WEIGHT, you know. (CB-04-P)

As well, the explanatory process was dynamic: explanations were discarded, added, or modified according to new knowledge and experience gained by the patient. Although the single interview used in the present study provided only a cross-sectional view of this changing narrative, several patients gave clear examples of its plastic nature.

> M: Mais pour vous, c'est deux choses différentes ce qui est arrivé, cet accident là, et puis le problème maintenant ou est-ce que c'est lié?
>
> P: .. Au début je pensais que c'était lié, à cause que ma douleur de toute le côté droit comme je vous ai dite ça a commencé (côté?). Mais, non.
>
> M: Maintenant pas.
>
> P: Non.
>
> M: Vous ne pensez pas qu'y a une relation
>
> P: Non.
>
> M: que la douleur de maintenant est peut-être causée par l'accident avant?
>
> P: Non. Parce que, ou sinon ça aurait apparu dans le MRI que le neurologue il m'aurait, il m', il m'a faite. (CB-06-P)

In fact, explanations also varied, or were even contradictory, *during* the interview. The following excerpt was obtained only a few paragraphs earlier in the same interview as the previous one, but clearly contradicts it.

> P: C'est ça. Euh, moi euh, en premier moi je pensais que c'tait des séquelles, parce que quand j'ai eu 6 ans je me suis fait frappée par euh une voiture quand j'étais en b'cyclette, et j'ai resté 72h dans le coma. Ok? Ensuite les médecins m'ont faite un tas d'études, ils m'ont dit que j'avais rien. Mais ils l'ont dit à mes parents que peut-être, quand je vais être plus âgée j'aurais une grosse possibilité que j'aie la, l'épilepsie.
>
> M: Uhum.
>
> P: Finalement, j'ai rien eu, mais moi, ouais, moi je pensais que ma, toute ma douleur, c'était les séquelles d'ça.
>
> M: Ok. (CB-06-P)

The same patient also entertained the possibility that her symptoms were a call for initiation or a “gift” that she had, with premonitions about peoples and events. She brought up this possibility as suggested by a cultural psychiatrist she was consulting, and went back and forth between adhering to it and rejecting it.

The same phenomenon occurred with another patient (NCB-05-P) who, during the interview, played with the idea that her joint pains came from her not following traditional Persian recommendations for self-care after the birth of her first child. Here her own ambivalence as a physician towards non-scientific cultural explanations interacted with her efforts to judge the openness of the interviewer (a physician, but also, at the time, a very obviously pregnant woman) to this kind of thinking. Once the interviewer gave some examples of traditional recommendations from her own culture regarding peripartum care, the patient informant spontaneously admitted more acceptance of her cultural model. These dynamics point to the negotiated nature of illness explanations, which are influenced by the interview context and the need to reconcile different knowledge systems, identities, and allegiances.

In contrast to the dynamic nature of most explanations (or networks of explanations), two patients had explanations that appeared to be immutable, or *fixed-truth explanations*. The first one is CB-07-P who has the following explanation for her symptom of "not tolerating pills":

> P: Okay, and I know that years ago Dr. B. who was at hospital X when I was there. Ah, he gave me a test, for all the allergies, and I'm allergic to a lot of the things. I actually turned orange from one the medications he was giving me. (...) And he said, "oh J. you're going to have a problem when you get older because you're allergic to all, (you better be) healthy when you get older because you're allergic to almost everything". (CB-07-P)

It is almost as if the doctor's words were taken as a kind of spell or a curse, and have functioned as a self-fulfilling prophecy. The impact of this fixed-explanation is such that her current family doctor is sending her off for allergy testing, although he remains entirely unconvinced of the value of this potential explanation.

The other patient with a fixed-truth explanation (CB-10-P) complained of "circulation problems" described as "numbness and tingling" in her extremities when she was forced to stay immobile, which eventually reached her head and impaired her ability to think and concentrate. If she was not able to stop what she was doing to "move" immediately, she believed that these "circulation problems" would lead to a cerebral blood clot. She related this vulnerability to her childhood, when her mother forbade her to leave the house to go outside and play with her friends. She described "not living a normal life," with her mother being overly controlling of all her activities until she eventually left home. She remembered feeling her current symptoms for the first time at age three when she was forced by her mother to stay and play on the balcony. Years later she consulted a physician who told her that her symptoms were linked to her sedentary lifestyle. He advised her to exercise three times a week and her symptoms improved. She felt that he had finally found the right cause for her symptoms, although they persisted.

The common point between these two persistent explanations is that for both patients the explanations are clearly grounded in medical authority. In one case (CB-07-P), the physicians' statement became a self-fulfilling prophecy. In the second example (CB-10-P), it was not clear whether she re-examined her childhood retrospectively through the lens of the explanation given by the physician, or if that explanation just fit well with her own initial explanation. In any event, the physician's explanation gave professional authority to an account that made her mother responsible for her suffering. For both patients, subsequent medical opinions were discounted, and further illness episodes only added to their conviction. For both these patients, the medical expertise they draw their explanations from provides it with a certitude that cannot be contested, even by their current physicians.

Differential use of knowledge structures by patients

Chain complexes, prototypes and explanatory models were elicited specifically by the MINI, but were also brought up spontaneously by patients at other times during the interview, with all patients offering all three knowledge structures throughout their narrative. All three knowledge structures contributed to the explanations described in the first part of this section, but each had specificities of use, structure and function that will be described here.

Chain complexes

Chain complexes are sequences of events that patients linked by contiguity to their symptom experiences without any explicit causal link. Chain complexes were widely used by patients, with a clear dominance of events drawn from their social life, in particular family, relationship and work issues. Striking features of these chain complexes are the frequency with which they refer to *loss* (divorce, death of child, death of parent, loss of job, loss of status, etc.) as well as to situations of *excess* (of weight, work, stress, illness, family responsibilities, etc), which may or may not appear in explicit explanatory models.

Many initial chain complexes become part of an explanatory model later in the interview. Interestingly chain complexes from one category of explanation may be transformed into another category when they are included in an explanatory model later in the interview. Indeed the dominant "social" chain complexes often were elaborated as psychological or physical explanatory models, in addition to social explanatory models. The following case of CB-03-P (pain and fatigue) offers an illustration of this point.

At the beginning of the interview she produced the following chain complexes of social events (work and family) contiguously related to her symptom:

> M: Ok, so tell me a bit about your problem.
>
> P: Ok, ahm I've been, like I said I've been experiencing a lot of pain. I would say, the past 5 years
>
> M: Ok.
>
> P: You know over the 5 years it's gotten worse (mhm) ahm I used to do a lot of physical work (mhm) I was a nurse's aide for 10 years (ok) at the, at the hospital actually, ahm I ah at one point I was working at my nurses aide job one the weekends (mhm) and ah I was working at X (restaurant) during the week to make ends meet. (Mhm) I was a single mother at the time, my daughter was too young to work so, I had to make ends meet (mhm) work where I could, so I did basically what I could (mhm). (...) And ahm, after some point I resigned from

> the restaurant. I just wanted to concentrate working at the hospital (mhm) because I started suffering from migraine headaches. (ok) Severe migraines. Ahm, later on to believe that I developed high blood pressure that ah came later. (coughs) Excuse me. Ahm, ah at some point intermittently I got married, (mhm) again (mhm) and ah during the course of my second marriage, my husband had developed Hepatitis C (…) In the mean time, I had worked 2 jobs. (…) It's a lot, and in between those times ahm, my father had, was diagnosed with cancer. Ahm, at present this is his 3rd reoccurrence and so he has Non-Hodgkin's Lymphoma. (Mhm) Ahm my mother, my mother basically hasn't left the house in 5 years. She's ahm, she became severely depressed and ahm basically she's a shut-in, she doesn't go anywhere. (Mhm) (…) Ahm, in between those times too ahm, my daughter also ahm suffered from teenage adolescent depression. I'm sort of going back and forth here (yeah) and ahm I was you know, I was dealing with that. Dealing with my father's illness, dealing with my husband, with his Hepatitis C, there was, there was a lot to deal with (mhm) and it came to a point now I just, I wanted to stop, but I, I just couldn't. (CB-03-P)

The respondents' notions of cause here can be inferred, but it is only later in the interview when these chain complexes are explicitly incorporated into a psychological explanatory model:

> P: We've all had to, we've all had to learn to say when (yeah) and that's something that this whole family basically has had (mhm) and still has a problem, not knowing when to say when.
>
> M: Well, it's hard because you look like, you seem like a very nice person that you, that really wants to help and ah give things a try and so on and --
>
> P: I'm still, I'm still that way, (yeah) but I'm learning my limits, I'm respecting my limits after all this time of, of emotionally struggling it finally hit me that the people that care about me don't think less of me (mhm) because I'm not going out there and making the money and you know I'm beginning to realize now that it is more than just going out and making money. (CB-03-P)

The same chain of events also is incorporated into a physical explanatory model:

> M: Ok. Why do you think that your symptoms started at a precise time when they did?
>
> P: Mmmm … (clears throat) ahm, I would say because ahm, I was overworked, overworked physically .. (yeah) overworked physically and ahm, dealing with a lot of emotional baggage at the same time. (Yeah) In between my ahm, in between my young adult life and my, and approaching my middle ages, (mhm) there's a lot. (CB-03-P)

Again, these physical and psychological explanations mingle and include stress as a common denominator.

> M: Yeah, you explain very well that, the fatigue, (mhm) how, how it works. Have you ever thought about how about what happens inside your body that provokes the pain?
>
> P: … Ahm, I think, I think between the stress, and over-worrying, it probably causes something like, it probably causes something chemical to go off. (mhm) That's what I thing, what it probably is, if this is depression which I'm sure, you know, 95% sure that it is. (mhm) I think that I overdo it (mhm) when I worry too much about something, or I, emotionally, (mhm) or I overdo something, physically, I think it causes my ahm body chemistry to, to fritz out.
>
> M: To?
>
> P: To go on the fritz. (yeah) My body which is means also, I mean there's also too that depression is a chemical imbalance as well.
> (CB-03-P)

Finally, she also considered an explanation of disease as transmitted hereditarily.

> P: So maybe there's a hereditary thing there, we women we go, go, go, go, go and then we burn out. (CB-03-P)

Other chain complexes stood alone and were not incorporated into a causal model. This is of crucial importance, because an exclusive focus in research or clinical interviews on causal explanations will miss important non-causal events that patients strongly link to the symptom. For instance, in the following patient's narrative of joint pains and fatigue (NCB-05-P), she reveals several chain complexes:

> M: Apart from your pain is there anything else going on in your life at the time? (coughing)
>
> P: Well at first, not something serious but, when I came here just like, (*kid banging things together in the background*) at the beginning, I had studied medicine. When I came here I had to study the language for .. and then not one I had to learn two! And then I had to work to get my career back, and I was married, and I got pregnant, and I had my son. And I suffered too much during my pregnancy, because it was it was like nobody else, it was full of nausea, vomiting, stomach pain and I stopped the living like mmm .. you know?
>
> M: It was a very tough pregnancy.

> P: (…) And after that I had C-section, and, at the time I was living with my in-laws, my father-in-law and my mother-in-law. They were old and I had to take care of them. Even though I had lots of problems, but I was not able to leave them, you know, they were old and they.. especially in my country it's ah the old person is like you know something you have to take care of them, you have to respect them.
>
> M: Mhm.
>
> P: And after that I was pregnant with my other son and when I went to the clinic for some tests because I have some pain in my stomach and some…I was uncomfortable like you know like it was nausea and heartburn. I went in the tests and they said "you are pregnant." And my first son was 8 months. Everything start again. [baby crying]
>
> M: That's tough.
>
> P: Yeah, yeah. The vomiting, the nausea, the pain again and I was kinda depressed because it was just too much to handle for me. And especially nobody can take care of me, just my husband, but he had to work. He had to went out, and my family was away from me, and I had to take care of the other people that were dependant on me. And everything makes me kind of depressed. But it's life it has downs and ups and what do you do about it?
>
> M: Yeah. Mhm. (…) So when all of these started it was a very difficult time for you?
>
> P: Yes of course!
>
> M: A lot of stressors and a lot of work.
>
> P: Yeah! And I know, I'm not able to do anything about my career and, because of the children, because of the…
>
> M: Of the in-laws?
>
> P: Yeah, the in-laws and because I don't have time to study, I don't have time to learn the language. To go out and have some time. And ah that's why I can't like…I'm not able to do the things that I want, and ah…
>
> M: It's very frustrating.
>
> P: Yeah! I was frustrated. (NCB-05-P)

Here she clearly admits to feeling depressed, overwhelmed by the quantity of responsibilities, and very lonely without the support of her family, as well as discouraged by the difficulties of immigration (two languages, non-recognition of her foreign medical diploma). But these meaningful issues that she linked in time to her symptoms are completely absent from her explanatory models, which are "not respecting cultural postpartum prescriptions" and "her body being more sensitive than others to this." In fact, she explicitly rejected causality based on these life events.

> M: Do you consider, do you think that your health problem it's related to something in your life?
>
> P: No, I don't think so because, because I don't have that much problems in my life. I was happy with my husband and the children. But as I told you it bothered me that I was at home and ah I didn't to anything about the study, medicine... (NCB-05-P)

She also openly dismissed psychological causation for her symptoms although this was suggested by physicians she consulted.

> P: When I went to the doctor some of them told me "it's ah it's ah, not ah physical pain. Maybe it's ah..."
>
> M: Psychological like that?
>
> P: Yeah, yeah maybe but or "maybe you think that you have pain" but I don't think it's that because I feel it every single moment.
>
> M: Yeah, you feel it in your body
>
> P: Yeah! (NCB-05-P)

Prototypes

Prototypes are analogical models of illness based on experiences of oneself or others that patients refer to when speaking about symptoms. This analogical reasoning was present in all narratives, with most patients offering several prototypes for their illness experience. As described early, in these narratives of medically unexplained symptoms, patients referred mainly to prototypes of i) their own prior illnesses, ii) illness of very close family members, or iii) acquaintances and people featured in the mass media.

Prototypes were a major source of information for patients, and usually were supportive of their explanatory models, as was the case for chain complexes.

> P: Ahm .. I just don't go to far from the toilet, I drink perfect water, I don't have too much caffeine or too much coke or. I notice that if I take 7-up or Coke, I have a weaker bladder, cause the caffeine eh?
>
> M: Mhm, so you connect with the caffeine.
>
> P: Yeah, well I know that if I take a Diet 7-Up or, a Coke outside, right away the next night I know, and even when I was looking after

> children I gave them a Coke or 7-Up they'd pee the bed at night, so it's definitely something connected with the caffeine yeah, yeah, yeah. (CB-07-P)

Prototypes based on family members' illnesses were used to support explanatory models of transmitted illness. Other prototypes lent weight to the possibility of a missed diagnosis, or illustrated the patient's pseudomedical explanation, or other explanatory model. Patients sometimes mentioned prototypes of illnesses experiences that they had considered as relevant, despite the fact that they had come to reject these. For example, one patient with fatigue and pain (NCB-04-P) had a friend with multiple sclerosis and considered that diagnosis until medical testing excluded it. Another patient with back pain (CB-01-P) compared her symptoms with her own prior depression, as if she was testing the relevance of this similarity with the interviewer, to finally conclude that they were different illnesses.

Invoking current prototypes sometimes appeared to be an oblique or indirect way to communicate sensitive information to the interviewer. For instance, patients' own prototypes of illness often indicated their past mishandling by health care professionals and underscored the need to take their symptoms seriously.

> P: Yeah, it happens all the time but here doctor gave me when my daughter born when that time I have a very bad urine infection in the hospital and I was crying I had a urine infection. Doctor said "I don't see anything wrong." So you know I suffered that is my I cannot forget it was a horrible time and that urine infection is dangerous when I go for peepee I just scream just as I can you know. I cannot peepee. And there is stitches in the because she was a forceps baby and I cannot tolerate. My husband tried with me I cried and he can't because it's horrible and "call doctor I have a urine infection." Doctor said "I will let me see." After five days she called me "yes, you have urine infection." But I suffered five days I feel when I think I cannot, accept. (NCB-03-P)

> P: Funnily, when I had my first pregnancy I was like on my side and ya, I was rocking, but my second, I, I didn't take to the epidural. I had a caesarean without freezing (*lowers and slows voice*) which HURT.
>
> M: Hmm-mm. Mmm!
>
> P: The doctor made a mistake, the anaesthesias had um, had a resident there, and basically she was French, ands he didn't speak, you know she didn't understand and she said to me, "can you feel

> your legs?" cause I had an emergency C-section, and I said, "ya, I can feel my legs," and she told my doctor to go ahead. So the doctor started cutting and I started screaming and she said, once they started cutting, they couldn't stop because of blood clotting or something, and they tried knocking me out and I wouldn't go out, and at the end, thank god the baby was fine, and at the end, the anaesthesias said to my husband, he says "you know, it's like baseball, sometimes you hit and sometimes you miss." So, I mean, I've gone through that without a freezing, I can tolerate pain
>
> M: Mmm, you've had some bad experiences with pain.
>
> P: Ya, ya, and I can tolerate pain. (CB-09-P)

Furthermore, with these prototype accounts of their own prior illnesses, patients referred to their own strengths and abilities to face and improve their condition.

> P: I don't know, you know, sometimes, I was always told like, um, growing up like I had a skiing accident when I was much younger, you know.
>
> M: A skiing accident?
>
> P: Ya, and I had to have some surgery and whatever and the doctor said to me "oh you'll never walk again and this and that" and I think it depends on your mindset, like my mother said "if you're gonna listen to the doctors, you'll never walk, just get up and walk." You know. And I DID, you know, she, ya it took time, a little bit every day but you know, I went skiing after that and I do everything I wanted to do, and if I would have listened to these guys, I might still have been in bed you know like 20 years later, and a lot of it depends on your mindset too, and that's why when I'm in a lot of pain I'll talk to, you know you try to talk yourself through it, and say okay, I'm gonna get through it, I'm gonna get through it, it's gonna last a few more minutes or whatever and I, find that helps too, so you know. I'm not into, ya I talk to myself, so call me crazy but it helps you know, when you're in that much pain, it helps. (CB-09-P)

Another striking aspect of prototypes was that they were often highly *dramatic* accounts of relatives or friends who had suffered a brutal or unexpected death (6/16), or of people suffering from the same symptoms who were diagnosed with a serious medical problem (6/16). Altogether 10/16 narratives contained a dramatic prototype, with two of these holding both prototypes of abrupt death and grave disease, and five in which multiple negative accounts were reported.

> P: Ahm there is heart and lung problems in my father's side of the family. (…)
>
> M: Do you consider that this chest pain is, is somewhat connected or related to something in your life?

> P: I think so. I think so. My father had bypass surgery, ahm in '98, ahm he actually was pronounced clinically dead for about 5 minutes. (mhmm) His mother died of a major heart attack, ahm, the reason why she passed away was ah the lining of her heart cracked, and that's how she passed away.
>
> (...)
>
> P: Exactly, and ah my father lost a cousin ah to ahm bypass surgery also not due to that, but trying to save his life, he didn't make it. So, and my father had an angina attack in '94, before that, and then '98, he actually had passed all the stress test an a week later he kept saying his chest was burning, and he ended up ah, we ended up bring him to the hospital and he ended up staying for a month.
>
> (...)
>
> P: My dad was at this weight when he had his ah he was getting, when he had his major heart attack and that's why they rushed him for a bypass. And ahm, he was at this weight but he was sixty, we're 2004, he was 60 years old, or 62 years old when he had it done you know.
>
> M: And how old are you?
>
> P: I'm 36.
>
> M: Ok.
>
> P: I'm 36.
>
> M: But still you're concerned because he had a negative stress test[15] and he was overweight and he had chest pain
>
> P: Right!
>
> M: So you're, this is a ringing-
>
> P: In my head right! (a bell) Things I found it, because of my weight my dad used to be a heavy smoker, ok, he used to work in the mines in Germany, it doesn't help either ahm, my dad has very bad lungs also, and even when I was a child running in the gym, I could not do the turn of the gym without losing my breath and having to stop because it was so painful. You know, so I see myself headed in that direction. (CB-04-P)

These dramatic prototypes underscored the message that "anything can happen." In the absence of definite diagnosis, these patients could not minimize or discard a symptom deemed banal by their physicians, as their stories showed it might well be the sign of a serious disease that could lead to death. Two-thirds of these spectacular prototypical illnesses or deaths had to do with a specific condition or

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[15] The patient had a stress test done for her chest pain that was negative; she was also overweight and an ex-smoker.

symptom (heart attack, cancer, chest pain, paralysis, etc.), whereas the remaining third pointed more generally to bad health or vulnerability to death.

> P: I can feel my body which is weird because when I had this here in the stomach I realized that when it stopped it went down, and it went into my intestines and it was gone so whatever it was, it had to be something other than .. you know?
>
> M: It must have been something.
>
> P: Yeah, it must been a bug of some sort, one of the ladies at the camp died after supper up there (mhm), and she was 82. Never thought of her having anything we never even, I never even though of it cause she was buried 2 days later, ahm we came home on Thursday, she was buried on the Saturday, we never, 82 years old we just figured she had a weak heart and she had had a *pontage*, since she had the, you know, so could be anything, but could it be that she had it too! A lot of diseases if you're weak, and I, it can make you weaker, it can take you along quickly, because she ate the same supper as I did, and a lot of the people at the camp, there was one cabin that had 7 people in it, and they all had diarrhea and soreness and all the symptoms of this thing. (CB-07-P)

These dramatic prototypes of adverse outcome gave a sense of impending doom to the patients' narrative, picturing grave illness or death as unavoidable, as if the course of disease was unalterable.

> P: Ahm, so, for me all the symptoms are leading somewhere. (mhm) Now right now it's maybe because I'm younger, and eventually it will lead to the fact that I will have a heart attack, if I don't do something about it, you know.
>
> (...)
>
> M: Ok. Do you think there's a way to avoid the heart attack if it will come, or do you think it's in-inevi?
>
> P: Inevitable?
>
> M: Yea.
>
> P: Ahm, I think there is a way, cause my father had lost quite a bit of weight before he had his bypass, from '94 he had lost a good 60 pounds he had put 10 pounds back on because ah he was losing muscle so they told him to increase his diet
>
> M: Mhm.
>
> P: .. I find that if I would lose weight, and exercise ah maybe not a daily but ah 4 to 5 times a week in the sense of going for a walk and bike riding ah, not necessarily doing weights and so on and so forth, ah I probably couldn't avoid it, but that eventuality when I'm older in my father's age or a little bit older, that it might happen.

> M: Yeah. So, it would protect you for a certain time, but you're not sure for how long?
>
> P: Exactly. (CB-04-P)

These dramatic prototypes supported the magnitude of patients' concern surrounding a medically banal symptom and their subsequent use of the medical system, justifying what physicians may consider exaggerated anxiety. They emphasize how important it is for them that doctors believe in the seriousness of their symptoms and act upon them.

A few narratives described positive prototypes of others' illnesses (4/16), with three patients mentioning dramatic cure of other patients, mostly remote acquaintances or people they heard about through the media. Again, however, they were used to justify the continuous use of the medical system and the search for a definite diagnosis and treatment. They also conveyed information about what patients believed should be done to help them, and in some circumstances indirectly pointed to their own doctor's failure to cure their symptoms. For instance, in the media prototype identified by one patient (CB-09-P), the illness was diagnosed and cured by doctors in another city who used a new medical imaging technique. On discovering this account, she was willing to "fly out there to try this machine," but the doctors there had told her that she was not a good candidate for it. This patient denied her blaming her doctors for her persistent ailments, despite the fact that her narrative was filled with her own stories of medical mishandlings and mistakes. She continued to hope for a miracle drug that her doctors had not yet been able to find.

> P: I don't blame anybody, because I mean they've tried all the drugs, I mean if they can't even pinpoint what it is.. it's hard to help, you know. So, I'm not blaming anybody, I just wish they'd come up with a miracle drug that can take the pain away or, you know. (CB-09-P)

Explanatory models

Explanatory models provide causal explanations of illness[16]. These may be more or less developed. In their most rudimentary form, explanatory models simply cited a cause or name a medical diagnosis without developing the underlying causal process or mechanism. However, patients' uses of medical names as causal explanations could prove deceptive, as the underlying mechanism or explanation they had in mind may differ markedly from the biomedical meaning of the term.

> P: Ahm, I started taking high blood pressure pills. (Mhm) They told me I would never have diabetes. From the high blood pressure pills, the diabetic came. (...) I'm taking one in the morning and half at night. (mhm) And ahm I seem to be able to tolerate that, but most pills I don't tolerate, most pills I have trouble with. I had (name of pill) and it cause my sciatic nerve. (CB-07-P)

More elaborated explanatory models provided explicit, detailed mechanisms for symptoms. For instance, one patient (CB-04-P) gave a very elaborate multi-factorial explanation for her chest pain. She believed that she was heading towards a heart attack because of her family predisposition: her grandmother died of a heart attack and her father almost did and had to endure bypass surgery. She stated that her pain came from a region near her heart, from a vein or an artery leading to heart that was getting blocked or hardened, preventing the blood from flowing properly. Her weight was related to this because her heart could not withstand or 'keep up with' her weight. Furthermore, her past smoking could have contributed to hardening her arteries, and must have damaged the "hairs" that clean out the lungs, causing a problem for her heart because she was not breathing properly and, therefore, not getting enough air and oxygen into her body and to her heart. Stress at work also was related to this problem by making her out of breath and making her heart beat faster, thus contributing to tiring her heart.

Explanatory models may include causal information about aetiology, mechanism and timing of illness, both at the onset of symptoms or through the course of illness, as well as the transformation of these with time and according to experiences of medical referrals, exams, and treatments received. Patients'

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[16] The content of the explanatory models and the sources of expertise for them have already been presented in the first part of this section; the focus here is specifically about the uses of explanatory models.

accounts also contained causal discourse about the consequences and outcomes of their illness, and factors aggravating or improving their symptoms. In addition, patients may present explanatory models of other people, and their own explanatory models of other conditions they have experienced. These different aspects of explanatory models are elicited by specific questions in the MINI. Information supplementing or elaborating the core explanation was thus brought by the interview protocol, but was also offered spontaneously by patients during the interview.

Not only were patients' models of illness elaborate, but they may also proved dynamic, plastic, and even contradictory. For example, despite her complex explanation of a possibly impending heart attack, the patient in the interview excerpted above (CB-04-P) also entertained the possibility that her chest pain was related to psychological factors.

> P: It is, and I'm afraid that I might be bringing it on!
>
> M: By talking about it, or by thinking about it?
>
> P: By thinking it. (Mmhm) By thinking it, cause I usually don't talk about it, the only one I talk about it is my sister, my married sister and I've told her you know, and she goes "you're crazy" (…) I just, like, I want to find out, you know. Is it really in my head or is it, is it my head that's bringing it on, I don't think it is, like right now, I don't think it is, you know, cause I'm just like talking about something, I don't think this is because I'm being stressed over it, or I'm nervous, because I don't feel like I'm nervous, you know (mhm). But I'd want to figure out how it is, yea, for my own, setting myself down you know, that it's not necessarily cause of the history in my family, that I'm headed that way. (CB-04-P)

This same patient ultimately entertained the possibility, much later in the interview, that the chest pain might be a side effect of the medication she was taking (antidepressant, anti-diabetic medication, and birth control pill). These multiple coexisting causes do not appear to be conflicting for patients, but rather seem to exist as parallel models.

Finally, while explaining the causes of one symptom, patients spontaneously produced explanatory models about other symptoms or illnesses that they suffered from, as well as explanatory models about general causes of ill or good health, further elaborating their understanding of health, illness, and the mechanisms of the body.

Although both groups' prototypes were similar in terms of the sources as well as in their uses, the Canadian patients produced slightly more explanatory models, while recent immigrant patients' narratives contained more chain complexes. This difference in use of knowledge structures may be due to some immigrants' lack of mastery of English or French. This linguistic difference complicated our analysis in understanding whether or not a causal link existed between the event and the symptom. It is likely that in a clinical setting also, these patients' accounts of symptoms will be more loosely connected in terms of causality, which might have serious consequences on their physicians' understanding of their predicament.

In fact, with both group of patients it sometimes proved difficult to understand whether a causal relationship to the symptom was present or not, that is, whether the patient's utterance contained a chain complex or an explanatory model. This is a limitation of the interview method, which carefully avoided influencing patients' talk and so did not pursue clarification of ambiguous statements.

In any case, the different knowledge structures all contributed to meaning making for patients, suggesting that it is essential for physicians to try to elicit the different accounts to clarify the patient's perspective, as illustrated by the following example.

> M: Mhm. What do you think could be that 5% you know that something that hasn't been diagnosed, have you though about what illnesses it could be?
>
> P: Ahm.
>
> M: Has it gone through your mind?
>
> P: Oh, I know I was tested for Hepatitis C, (ok), (xx). Everything seems to be ah ok in that area. (aha) Ahm, I am on, I am on treatment for high blood pressure, which is controlled, but ah the ah, the fatigue sometimes, that I have, and the body aches, it ah, it, it could be ahm, I've had in the past ahm, they call it ahm "bundle branch block" which sometimes my heart, ah skips a beat!

> M: Yeah.
>
> P: And a lot of times I do feel, sometimes I do feel occasional where I suddenly get dizzy (mhm) and I feel the occasional palpitation.
>
> M: Ok. So, do you feel that could be one of the things that has been missed or not diagnosed?
>
> P: Maybe, maybe, maybe, I don't know!
>
> M: Is there anything else?
>
> P: Ahm, I don't know, she says, I don't know if ahm, I'm it could be maybe my potassium may be a little low because I'm on diuretics. (mhm) I mean not maybe enough, but I'm on diuretics and blood pressure medication, (mhm) so my potassium could be a little low I don't remember if she sent me for potassium ahm blood test or not (mhnm) but my potassium could be a little on the low side (aha) that could that could be 2 of the physical things.
>
> M: Yeah. Ok, anything else?
>
> P: Mm, nothing, yeah, nothing I can really think of off hand here.
>
> M: Ok.
>
> M: Ok... And do you know anyone else that has health problem is pain and fatigue that is similar to yours?
>
> P: Ahm, my dad!
>
> M: Yeah?
>
> P: My dad and he ahm, he has Hodgkin's Lymphoma.
>
> M: Mhm ok.
>
> P: It's still scary, it's still scary, in the back of my mind I'm still afraid that, I have, I could have it or I could get it or I might have it too.
>
> M: Mhm.
>
> P: But that's a can-, that's probably a cancer phobic you know, on my part. (CB-03-P)

Only in discussing the prototype of her father's illness does she disclose her fear of having Hodgkin's lymphoma. This illustrates well the necessity of eliciting different knowledge structures, in order to improve access to the patient's salient illness representations.

Discussion

Examination of patient interviews reveals that patients do not have a single explanation for their symptom. Rather they draw on a mosaic of different models, which may form a coherent aggregate or may coexist in apparent contradiction. Apart from rare exceptions, these explanations are not fixed truths, but rather play a dynamic role in constructing illness narratives. The patient rarely has a definite model for the perceived symptoms but is in constant search of one. Explanations are constantly confronted, weighed, verified or discarded against the experiences of self and others, as well as a wide range of external sources of authority. Use of the MINI to sequentially elicit specific knowledge structures helped to reveal these different patient explanations for illness and the richness, complexity and fluidity of the patient's model.

Categories of explanations

Illness explanations put forward by patients were located in all four sites (individual, natural, social and supernatural) described by Helman (2000), but most often resided in the interaction between these worlds. The supernatural world was only mentioned twice (CB-06-P's "symptoms as a call for an initiation to her gift" and NCB-03-P's vague "bad luck"), which was lower than expected, particularly in the recent immigrant group. Indeed a study in psychiatric setting in the UK showed this type of attribution to be frequent in immigrant populations (McCabe & Priebe, 2004). A possible explanation for this may be patients' reluctance to divulge such explanations, as the interviewer was known to be a physician, and therefore likely to be perceived as adhering to a more "scientific" worldview.

In our study, we found many of the different etiological axes or categories of explanations described in prior studies of illness explanations both in similar and different clinical settings, including the three predominant sources of explanations cited (the body, the mind and society) (Helman, 1985; Helman, 2000; Karasz et al., 2003). Furthermore, our results demonstrated both the multiplicity of illness attributions and the complex and continual interaction between these different origins of illness causation. An illustration of this would be the case of one patient (CB-04-P) who, after describing in detail her perception of the biological mechanism through which her heart produces chest pain that is leading toward a heart attack, points to her elder sister and her long-term psychological abuse as the main cause of her chest pain:

> I think she's *(her elder sister)* the one that actually brought it on to tell you the truth. Cause it started off as a panic attacks so ahm, then it snowballed into the chest pains, you know cause I would stop, stop myself from breathing type of thing you know. So, she brought it on. (CB-04-P)

We can also observe in this example the coexistence and interaction of *internalizing* and *externalizing* systems as described by Young (1976).

Other salient features of our results included patients' overwhelming use of mechanical explanations that fit well with the "plumbing" model of the body, but especially with the modern[17] metaphor of the body as a machine energized by a central battery or requiring "fuel" (Helman, 2000). Patients' references to nerves and their descriptions of "a nerve shorting out" and "batteries shutting down" are reminiscent of the popular attributions of the now out-of-fashion diagnosis of neurasthenia. Kleinman (1988) argues that neurasthenia has not disappeared as a phenomenon but rather has been recast under other medical labels, such as chronic fatigue syndrome, somatization, depressive and anxiety disorder, while patients' complaints have transformed into "stress syndromes".

Bridges over mind-body dualism

Indeed, stress was a predominant aetiology invoked by patients in this study, as already demonstrated in prior research (Helman, 1985; Peters et al., 1998; Salmon et al., 2004; Woloshynowych et al., 1998). A striking aspect of the construct of stress in patients' narratives was that it bridged distinct categories of explanations (physical and psychological, but also social and environmental), and served to transcend the conceptual divide between mind and body. By invoking stress, patients were able to express social and emotional difficulties, without explicitly

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[17] The metaphor of the body, or of man, as a machine, can in fact be traced back to the 17th century and Descartes who, in his *Méditations Métaphysiques* (1641), not only separated it from the mind, but compared its mechanism to that of a clock.

acknowledging psychological causation and risking the moral blame that accompanies psychological illness (Kirmayer, 1988). Thus, stress serves as an effective *idiom of distress*, expressing the individual's plight in an indirect and acceptable manner, preserving and protecting the self from stigma or opprobrium (Nichter, 1981).

The use of "stress" or other polysemous concepts such as "nerves" or "balance" provided patients with a socially acceptable way to make links between difficult social events, negative emotions, and physically felt symptoms, and allowed them to circumvent uncomfortable psychological explanations, which would undermine the credibility of their symptoms. This choice of idioms may be related to narrative strategies described elsewhere that patients make use of to reduce the likelihood of being categorised as "psychological cases", and to convince others that their pain is real and physical rather than imagined (Karasz et al., 2003; May et al., 2000; Werner & Malterud, 2003).

When they did mention psychological factors, patients' models of pathogenesis bore a marked resemblance to that of their physical explanations. The vocabulary used was ambiguous, suggesting that mind and body have similarities in needs and functioning. For instance, both the body and the psyche can be "harmed" or "depleted" by stressful, traumatic or other negative events, and both need to be "given some rest" to recover. "Psychological factors" can be likened to the "constitutional" category, and some psychological factors appear to be hereditary. The notion of balance also is applied to physical or emotional processes, with either excess or deficiency leading to illness. The parallels in metaphors relating to mind and body and the intermixing of references in patients' accounts suggest that patients may not distinguish clearly between mind and their body. Indeed although they did not speak explicitly of the self, it seems that some notions of the self as a psychophysical "entity" bridged the traditional Cartesian mind-body dualism. Similarly, in a primary care clinic in the UK Skelton found that that both patients and physicians use physical idioms to speak of the psychological, and that patients consider their body the container of the self (Skelton et al., 2002).

In our study, another important metaphor was that of *balance*, which cut across the different categories of explanation. It was referred to directly when patients refer to the chemical or energetic balance of the body, but also influenced discourse on more broadly, particular through the notions of *excess* and of *loss*. Excess was expressed as too much of something (sugar, stress, tension, family conflicts, weight, etc.), whereas loss categorized many situations (loss of status, home or job, death of a child, divorce, etc.). Balance was also used both by Canadian-born and recent immigrant patients, although excess was predominant in the Canadian-born. Imbalance between elements or forces within the body is a common explanation for illness in many great medical traditions, including various forms of humoral medicine, Ayurveda and traditional Chinese medicine. Although, with the exception of the patient from Bangladesh, no patient drew from these traditions, balance versus imbalance of different aspects of the body is a concept that can also found both in folk models of illness such as demonstrated in the UK by Helman (1978), but also in many biomedical theories of physiopathology as well (endocrinology, metabolism, etc.). Data from this research pointed to imbalance as a popular image to express a negatively altered state both of mind and body.

Illness expertise

Patients draw on a wide variety of sources to help them explain their symptoms: physicians and other healers, friends and family, mass media, books, and the internet. These can be divided into three sectors as described by Kleinman (1980): the *popular sector* (family, friends, colleagues, acquaintances, other patients); the *professional sector* (physicians, nurses, pharmacist, dentist, physiotherapist, psychologist, social worker); and the *folk sector* (shaman, healer, osteopath, yoga teacher, manual therapist). “Pseudomedical” explanations, or patients’ transformations of biomedical explanations through confrontation with their own experience and knowledge and that of others, can thus be related to small-scale “popularization” of scientific health concepts (Kleinman, 1980).

Our findings are consistent with other studies that demonstrate the paramount role of friends and family in providing information along with additional emotional and social support, especially in life-threatening illness such as cancer (Budtz & Witt, 2002; Carlsson, 2000; Silliman et al., 1998). Although they were set in different clinical settings (cancer patients, geriatrics) or places (USA, Sweden, Denmark) than our research, these studies found that patients obtain additional information from the newspapers, television programs, brochures and leaflets, and less so through the radio, books or internet.

In our study biomedical discourse appeared to be by far the most important source of explanations for patients. This is not surprising as medical discourse holds powerful authority both because of the weight of its social institutions and because of the desire of patients to obtain an expert interpretation of their symptoms in order to find a cure and to receive legitimization (Kirmayer, 1994). Additionally one must remember that the interviewer being a physician might have prevented patients from greatly challenging medical explanations. Nevertheless patients transformed the biomedical information received according to their lived experience and that of close friends and relatives, their understanding of body physiology, and their initial explanations. The resultant "pseudomedical" explanations were "ethnomechanical" explanations, or physical conceptions of the body and its function that are adapted from medical information to fit their own systems of knowledge, and that "serve the purpose" of their condition (Mabeck & Olesen, 1997). Other authors have described how patients may emphasize the primacy and authority of their sensory experience over the indirect knowledge of their physician (Peters et al., 1998). In our study this was the case for some patients who presented their sensory experience as evidence that a "real" disease existed and should be identified, but who also used it to transform, verify and appropriate for themselves the biomedical explanation. Kirmayer (1994) argues that not only do bodily experience and its interpretation modify the nature and the course of illness, but they are also transformed through the authority of the practitioner's diagnosis.

It is surprising that only three patients referred to non-biomedical practitioners or practices, particularly in light of the large and growing market and increasing use of alternative therapies of all sorts in the Western world (Barnes et al., 2004; Tindle et al., 2005). Possible explanations for this lack of mention of complementary and alternative medicines include: a) selection bias due to the use of a clinical sample, as alternative medicine and conventional medicine appear to attract different users (Blais et al, 1997); b) reluctance of patients to share information with the physician-interviewer, which might be even stronger in the case of recent immigrants who may wish to appear "modern and educated" and to distance themselves from traditional practices; and c) that some folk remedies and practices are so much part of life and taken for granted that they are not considered distinct systems of medicine, as for example the selection of adequate food in the case of hot and cold balance. This could explain, for instance, why one patient (NCB-03-P) said there was no great tradition "like Chinese medicine" in her home country (Bangladesh), despite the local widespread use of Ayurvedic medicine.

This description made by patients of their sources of expertise probably underestimated the complexity and diversity of the real situation. Patients did not explicitly acknowledge all sources of information, especially those they had appropriated as their own. For instance, patients mentioned consulting many practitioners, without explicitly stating the explanations received. As well, there probably was a substantial amount of knowledge that patients' received passively through television programs, newspapers, casual talk about health and illness with friends and family that they were unaware of. Nevertheless, the multiplicity of patients' sources of understanding and their modification of the initial model suggest that making meaning of symptoms is a dynamic and incomplete process. Even during the research interview patients questioned the interviewer for confirmation of their model and probed for her own interpretation of their symptoms.[18] The fact that the interviewer was a physician was for many patients

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[18] The interviewer responded to this by telling the patient she would answer their questions at the end of the interview, in order not to bias their story.

an incentive to participate, and some openly stated that they decided to participate in the interview in the hope that the doctor would identify the reason for their symptoms.

Knowledge structures

The different types of knowledge structures used in the narratives served multiple cognitive and rhetorical functions. Chain complexes seemed to support explanatory models, situate the symptoms in a life trajectory, or point to some psychosocial issue that could be referred to causally, but that the patient linked to his symptoms. Prototypes also supported explanatory models by giving case examples of similar situations. But the most frequent use of prototypes was to convey something specific to the interviewer. The message given by a prototype might serve to justify patient concerns, legitimate behaviours (in particular health seeking behaviour), or indirectly criticize the medical system. This was particularly apparent in *dramatic* prototypes that presented stories of people suffering from the same condition who had suffered a brutal death. Their function as a bad omen gave the patient's condition a sort of irreversibility or inevitability, and lent weight to what physicians might consider exaggerated concerns about symptoms. Prototypes had an emotional power for patients, which they attempted to convey to their physicians. The salience of these prototypes might explain in part why reassurance is ineffective in the long term (Dowrick et al., 2004). These dramatic prototypes may be related to hypochondriasis and specific illness fears which are known to overlap with MUS (Escobar et al., 1998). Other account of past events provided patients a way to talk about their dissatisfaction with the medical system or aspects of their social situation (family, migration, etc.) that they did not feel able to act upon. This type of illness narrative is related to the notion of symptoms as a mean of resistance and social protest (Kleinman, 1995; Scheper-Hugues & Lock, 1987). Finally explanatory models appeared to be more of an "official" explanation, either one that was validated by physicians in the case of fixed truth explanations, or the outcome of multiple sources of information and expertise that were amalgamated as well as possible into several types of explanations.

In some cases, it was very difficult, or a matter of arbitrary interpretation, to understand whether or not a chain complex (or a prototype) was part of an explanatory model This difficulty was due partly to the methodology, which aimed at minimizing influence on the interviewee and avoiding artificial causality, but also was due to the dynamic nature of meaning making. Patients continuously reassessed and reconstructed the facts around their symptoms. The interview itself probably contributed to this refashioning of illness explanations.

Stern and Kirmayer (2004) attempted to operationalize a coding scheme for Young's three knowledge structures and found that they needed to add an intermediary category: *generalized chain complex*, when a repeating pattern of factors contiguous with the symptom repeated itself. In our study, however, it was felt that these occurrences could either be labelled as chain complexes or if they referred to prior experiences, as prototypes. Nevertheless, both studies confirmed the frequent presence of knowledge structures other than explanatory models to talk about and make sense of physical symptoms.

Complexity and change

The multiplicity of different explanations, their contradictions, the patient's search for legitimization by different sources of expertise, and the quest for closure are consistent with the findings of Williams and Healy (2001) in a study among new referrals to a community mental health clinic in the UK. These authors question the concept of explanatory model, and criticize the use of health beliefs to predict subsequent behaviour, in particular because the strength of a health belief may not be associated with stability in time. They propose the concept of "*explanatory map*" of health beliefs rather than explanatory model, meaning by this a "map of possibilities, which provide the framework for the ongoing process of making sense and seeking meaning (...) characterized by movement and uncertainty."

(Williams & Healy, 2001, p.473). The coexistence of conflicting views of illness could also be seen in a study of Filipino and American health attributions (Edman & Kameoka, 1997). A review of qualitative research of reports of adults with chronic illness also emphasized the dynamism of patients experience of illness and their "ever changing perspectives about the disease that enable people to make sense of their experience" in ways that reflect their needs and personal situations (Paterson, 2001).

Good argues that in most illnesses the narrator is "typically in the middle of a story (...) which changes as events unfold" (Good, 1994, p.144). As this occurs, both the present and the past are re-read according to the new perspective, an indispensable strategy for coherent meaning-making. In the case of MUS, there is no clear-cut diagnosis that would restrict this process and give a fixed sense of closure, and patients are free to continuously reinterpret their bodily sensations and modify their narrative accordingly. This may lead some physicians to label their patients "inconsistent" or "incoherent," instead of recognizing their difficulty in making sense of their predicament, and accepting the complexity of their narrative.

The next section will explore how physicians make sense of medically unexplained symptoms and what they know of their patients' understanding of their predicament.

3. Physicians' explanations for their patients' symptoms

Categories of explanations

Physician interviews revealed that, just as their patients, they too did not have a single explanation for their patient's symptom, but instead entertained several causes and contributing factors whether concomitantly or sequentially throughout their management of the case. Physicians typically first put forward explanations in terms of *biomedical diagnoses* (somatic, psychiatric, and psychosomatic), But when probed by the interviewer they also presented explanations in terms of *social factors, psychological processes,* and *lifestyle issues*. These included underlying notions the patients' responsibility for their illness, which ranged from the contribution of personality traits to completely blaming the patient for the illness, or even doubting the reality of symptoms. Only one physician admitted to not having an explanation for his patient's symptom.

These categories are not mutually exclusive, and the majority of physicians entertained explanations from several of these categories in the interview. In fact, there seemed to be a normative management plan which first eliminated somatic diagnoses (in particular life threatening ones), then considered psychiatric diagnoses, and finally moved on to psychosocial factors as causes or contributors to disease.

Biomedical diagnoses

All physicians provided at least one biomedical diagnosis that they had considered for the patients symptoms, and these labels were mostly offered to the interviewer without subsequent explanations (as she was also a doctor, it was considered common ground). A wide range of *somatic disorders* were mentioned (diabetes, hypothyroidism, cardiac ischemia, allergies, ulcerative colitis, cancer, etc.) and largely dismissed because of the negative findings of the physical examinations, laboratory tests, and referrals to medical specialists.

The *psychiatric diagnoses* that were considered by 12/16 of physicians included generally depression and anxiety but also panic attacks, PTSD, dysthymia, adjustment disorder, psychosis and unspecified "psychiatric problems". Some physicians (9/16) used labels that were *psychosomatic* or situated between medicine and psychiatry, namely fibromyalgia, chronic pain, somatization, "psychosomatic" and functional symptoms (irritable bowel syndrome). The ambivalent status these diagnostic labels have in the medical literature was also reflected in the physicians' discourse. For example, they used these labels sometimes as a valid diagnosis, other times as a cover-up for a psychiatric diagnosis or as a convenient label for multiple symptoms or complicated cases.

> D: I took her word with fibromyalgia and haven't really explored that very much with her. So a lot of the times she's talk about small complaints here and there and we'll just put it in the pocket of fibromyalgia and put it away for both of us. It seems that she's comfortable with that too so I haven't really investigated it very much and a lot of the complaints that she make just sort of well that's fibromyalgia. (NCB-04-D)

Despite investigations, 2/16 physicians remained worried that there might be a medical condition that they had missed or not yet uncovered. Half of physicians (8/16) either still considered that physical causes for the patient's symptoms were possible even though they had an alternate psychiatric diagnosis or psychosocial explanation, or simply kept their eyes open for new elements that would indicate the need for further referral.

The psychosocial label

All physicians linked some degree of psychosocial factors to the patient's presenting problem. Investigation of these "psychosocial factors" reveals that they include internal psychological factors and external social components that are detailed below.

Physicians generally had limited knowledge of their patients' so-called psychosocial factors, and 3/16 physicians used this idiom as a blanket term to explain symptoms without being able to be specific about these aspects of their patients' lives.

> Like I said I don't really know exactly what the psychosocial issues are. It's just me hypothesizing that there is something else going on, because for her to think constantly about her death when she's a young, healthy woman I don't know what motivated her to start behaving like this but it's suspicious that it started with some event probably, in her country. As far as I know there were no major problems in Canada and that her family life is good here, so.. It's just a suspicion I don't really have any clear ah .. (NCB-03-D)

Ignorance of these aspects came from absence of investigation, allegedly because of lack of time in the consultation, or because time was spent investigating somatic symptoms, or for no special reasons at all. But sometimes this psychosocial label was maintained although prior probing had not revealed a significant explanation.

> D: And I tried to see in her life if she had a boyfriend, if she has anything stress related that (might at all?) could all start at the same time but I couldn't find anything. She said "I'm happy". She didn't have depressive symptoms, she didn't have any uhm she wasn't too anxious when I asked her the questions. And her family is not in town, out of town, but she seems to be having a good relationship with them, talking to them on the phone. Boyfriend wise I think she doesn't have any and she wasn't sexually active, so I couldn't find anything that triggered all of that, but they did start at one moment. And I'm supposed to see her again to try to do a genogram, and try to see if I can just talk to her more to see if (I can find?) something, okay. (...)
>
> M: Uhm, for you which, what do you think is the most likely explanation?
>
> D: Uhm, If her celiac disease test is negative I think there must be some psychosocial thing underlying this or some psychological problem or psychosomatic. That's what I am thinking like even from the beginning that was my gut feeling but I had to ah investigate. That's what I think what we are heading towards. (NCB-01-D)

The other remarkable feature of these explanations is that physicians were unsure of the direction of causality. Not only do diverse psychosocial stresses influence symptoms and their presentation, but symptoms also have stressful effects on work, relationships, and emotions.

Psychological explanations

Psychological explanations were a predominant explanatory category brought up by physicians (11/16), and were presented as factors considered *internal* to the patient. These explanations referred to many different processes: negative emotions bringing on the symptoms; notions of secondary gain; elements of the patient's personality; unresolved trauma or conflict; and attitude towards life and adversity. These psychosocial factors were essential contributors to the psychiatric diagnosis, and because of their quality of being internal to the patient they tended to impute a degree of patient responsibility.

Negative emotions included anger, dissatisfaction with elements of one's life, stress, anxiety, worrying, sadness, and "suffering inside," either as direct cause or through the patient's management of these emotions.

> D: I don't think she's ever really, really dealt with her real anger issues.
>
> M: Which diagnosis do you *think* is where it is now?
>
> D: I think at this point it's unexpressed anger, and there, there's people she wants to punch in the head and she's just using a lot of muscle tension not to do it! (CB-05-D)

Management issues related to these emotions ranged from lack of insight to notions of secondary gain. Secondary gain was frequently brought up by physicians, with the opinion that the patient could be more or less conscious of the advantages conveyed by the symptom, which were expressed mainly in couple, family, or professional dynamics.

> M: How do you think the chest pain affects her life?
>
> D: ... Ahm.. I think she uses it as an excuse to not do things. She's the kind of person who is lazy, (...) Ahm.. and I think that she probably not consciously but she milks it for what it is, in other words, like she has this pain or she feels weak or she's tired, short of breath "Oh now I gotta sit on the couch I can't do anything". (CB-04-D)

Other management issues referred to more cognitive processes, such as "not knowing how to filter out symptoms", "being too much in tune with her body", and "being more sensitive to her body because she had the symptoms before".

The contribution of elements of the patient's personality ranged from participating in the symptom to being the principal cause of the symptom, the patient's "raison d'être."

> D: Yes..I think that there are certain elements of her personality, which...(sigh) I mean, okay, here, here's the you know the chicken and the egg question you know, but people who have chronic pain I find, I mean, well I, I have a lot of patients with chronic pain, they all sort of have certain qualities that sort of seem the same, in many ways, I don't know if it's caused (laughing) by the pain or precedes the pain. But..I do question if there is some sort of... (CB-09-D)

Physicians also referred to patients' past unresolved issues, such as (unidentified) traumatic event in the patient's past or unresolved issues with the patient's mother.

The striking feature of physicians' psychological explanations for their patients' MUS is that they expressed the possibility of patient's responsibility or choice, as a contributor to their symptoms.

> You know so she's, and I think a part of her is that she's anxious about all of these things that she's feeling and doesn't have the judgment to say, "oh no, this is you know, I can tell this is the little thing in my earlobe, it should, you know it's not worth bringing it up to the doctor". (...) I just don't think that she has, she filters well what to ask and what not to ask! (CB-04-D)
>
> I mean sometimes, she really just, she had a little symptom one day for like two seconds, she has to say it. (CB-01-D)

Social explanations

Social factors were cited by more than half of physicians (9/16), and either as cause of symptoms or as contributors to the problem. They were framed as factors *external* to the patient, and therefore as beyond the patient's ability to control them. The main source of social explanations was the close family circle (conflicts in relationships with spouse, parent or sibling, illness of family member, stressful events within the close family, too much work because of having a large family) or its absence (being a single mother, divorce, death of family member). To a lesser extent, the professional sphere also was a locus of social explanations (pressure at work, job problem, loss of job, not being able to get a job). The following excerpt was extracted from the interview of the physician of a patient presenting with chronic fatigue and pain and who was the caregiver to her daughter, a mother suffering from depression, her father with lymphoma, and her husband with hepatitis C. Her relationship with her husband was strained, as were their financial resources.

> D: And also knowing that also there's a lot going on in her family right now both with her father and her daughter and her husband, (mhm) ahm. Those issues, I'm aware of and working on to an extent although, she does most of the work, I believe also contributing to her fatigue.
>
> (...)
>
> M: Ok. How do you imagine her prognosis to be?
>
> D: I think, as you said she's such a remarkable woman. Ahm, in light of everything going on with her family, she's ah , it's hard to say in that, that she has a lot of family stresses right now. Ah some only stand to get worse, which I think will be very difficult on her. (mhm) That makes me concerned. Ah some of the stresses that may be contributing to her depression and her general ah physical state, come from her relationship. (CB-03-D)

Factors related to immigration were often mentioned by physicians as causes or contributors to their non-Canadian born patients' symptoms (absence of community, isolation from close family, racism, instability of status in Canada and unrecognized foreign qualifications). The following example comes from the physician of a Jewish Ethiopian immigrant patient, in which she not only recognizes the social and economic determinants of her patient's health, but also her powerlessness to act upon them.

> M: If you have to select one explanation which one would it be?
>
> D: I think the most likely thing is she's just a bit lost. I mean, I don't think she knows yet that she's a bit lost in a Canadian cultural context. I don't think, I think they've got two small children they're trying to manage on his very meagre salary. They don't fit in I think that's probably the, ultimately what the issue is, and then the normal things have been able to have access to the children's grandparents, the community it's just not there so I think I mean I think that's it's when she's not lonely per se but she's there she's not I still feel like they're settled in to their life here. (...)
>
> M: You think psychosocial factors may have played a role in her presentation?

> D: Yes! (both laughing) I think absolutely I mean I think it's fairly for me I think it's fairly clear I mean if I can write a prescription in giving her two plane tickets to fly two family members here and trip back to visit her family once a year she probably would have a skinny chart because I could get her you know the things that she needs are the things that I can't give her which is a sense that she is still connected to the people that she's connected to. (NCB-06-D)

Other social explanations mentioned occasionally by physicians included lack of financial means, and difficult negotiations with auto insurance company.

Lifestyle issues

A minority of physicians (3/16) reported lifestyle physical causes or contributing factors for the patients' symptoms (fatigue, interscapular back pain and gastro-intestinal symptoms). As is the case for the psychological explanations, these raise the possibility of patient accountability and the spectre of blame.

Lifestyle factors cited by physicians included: de-conditioning from lack of exercise, diet, drinking too much coffee, working nightshifts and exertion. These lifestyle issues were usually contributing factors and not the main cause for the symptoms, and were considered as part of the physician's differential diagnosis, as illustrated below.

> M: Yeah. What diagnostic hypothesis or explanations did you consider for these problems?
>
> D: Um, with the history, I can't remember her previous surgical history, I, I'm talking about my differentials at the time. Um, she, like the thought, with the thought of the nightshifts and she was drinking a lot of coffee, and her, her diet was, she had difficulty eating with some nausea as well, I mean, she's in a lot of stress at work, pressure at work. There was always the thought of, there's some sort of kind of alternating, causation diarrhea or is this irritable bowel, but then you have think you know there's something more dangerous lurking in the background, is there, I can't remember her family history, if there is bowel there or um, she didn't give me a history of any sort of malabsorption disease or anything. I mean where I'd pick up this is celiac, is it, you know is there something else there going on. But the weird thing is it would be, well later on I found out as I kind of got to know her, as I actually gave her some time off, that that symptoms resolved kind of away from work, away from the night shift, so that made it less likely to be a, a kind of like, a celiac or a gluten or any sort of malabsorption disease.

> M: Mm-mm.
>
> D: (…) Those were the main things that sort if popped into my head. Stress and then diet-wise, what she, what she was eating and all the coffee and not really eating, it's hard to tell, I would have said that would have affected her, her bowels as well. (CB-08-D)

Absence of explanation

Two physicians, a junior resident and a staff doctor, openly admitted that they did not know the cause for their patients' symptoms, even though at a later point in the interview they considered psychosocial factors as the main causal explanation of the patient's symptoms. The lack of palpable medical evidence, and the absence of a reasonable mechanism ensuing from it, were of overriding concern for both of them.

> M: What do you think she came away with?
>
> D: Aha.
>
> M: With those explanations?
>
> D: Well, um, that much I'm not sure. I never really got a good feeling for what she thought about the idea of, um, and actually to be honest with you the, with the diagnosis of query fibromyalgia. I'm really not sure, I really gave her a good explanation because I personally don't have a terribly explanation to give her.
>
> M: Mm-mm.
>
> D: Because I don't even have a, a, have a physiology I can really explain. (CB-08-D)

Complex and dynamic explanations

Doctors' models did not rely exclusively on one category, but combined elements of several. The interviews revealed that throughout the management of the case several possibilities were examined and discarded (which is physicians' usual process of diagnosis), but also that their present vision of the patient's predicament included multiple causes and meanings. An example from one physician (CB-05-D) is presented in Table 4 of the appendix to illustrate the polysemy of the physician's model. In this respect, the process of physicians' and patients' reasoning had similarities in terms of multiplicity and plasticity although their content might differ greatly.

Knowledge structures

In these complex explanations, physicians mainly used causal reasoning with a few chain complexes and rare prototypes. There seemed to be a tendency to use the chain complexes and prototypes more often when they reported their patients' explanations, and less often when they stated their own explanations. But the brevity of the physician interview and the questionnaire design did not allow for specific elicitation of each knowledge structure, or of a detailed narrative of the case from the physician. Therefore, these findings are tentative and would require further exploration with a different study design.

Doubt, disbelief, and suspicion

Several physicians (5/16) expressed a sense of doubt about the reality of their patients' symptoms.

> D: And, as a new resident, it didn't bother me at the start but as I got more experience I was always the thought, the worry that your patient is taking you for a little bit of a ride. (Mm-mm) Just asking for time off when you're not sure if they need it or not. (Mm-mm) And especially with this patient with the symptoms that, you know it's, it's hard to say. She has so many symptoms and it's, it's hard to say what, how much is, not, not really true. I'm not saying they're not, they're fake, like she's faking. But there's always the thought you know, is she faking? Oh, I don't know, it's, it's something you hate to think about with your patients, but it's, you know it's reality in it's own little mind.
>
> M: It's doubt?
>
> D: It's doubt! Ad um, and I, I mean it's easy at the start when, it's very much easy when you've all this empathy for your patient, but they'd also do things such as (...) [*physician gives example of patient constantly coming in with disability forms to fill in and how much it frustrated him*]. So I can't verify, it's very tough but I can, but I mean I could see postdated times where it was sent, you know a month ago, but I get it, you know three weeks after it's been sent and so, it's, it's, you know, you don't like the idea of being, like you hate to think about it, but it's something, you know it's, you know anybody else will hate the idea of somebody taking you for a ride. (CB-08-D)

The degree of doubt varied and went from dubiousness about compliance to medications to more open mistrust including fear of drug abuse from the prescribed pain killers to frank disbelief and suspicion of malingering and faking the symptoms, as shown in the following examples.

> D: You know, as things got more and more complicated, (sigh) you know it was like she would be able to go cross-country skiing with her friends for the weekend, but the she would be bedridden the whole week. (...) Oh I think she's quite, well she says she would like to not be in pain. I don't think this pain is inhibiting her from doing exact, exactly what she really wants to do. You know!
>
> M: Yeah.
>
> D: You know, she's always going, "Oh well I went *hiking*, and then I went *biking* and then I was just, couldn't move for three weeks!", for, it's like (chuckles) oky-doky then. (CB-05-D)

"We, the doctors..."

One last striking feature of physicians discourse was the habitual use of the plural "we" to talk about their practice and the decisions they had made for the patients.

> But, we set out , she really, she's had a lot of medications! She, so the neurologist saw her, and then after that every time somebody would suggest something, we would pursue it. (...) We tried to send her, when we started she also had this severe nausea and vomiting so we wondered if it there was something going on from a G.I. point of view that it's to do and connect with the body pain but I mean we sent her also to G.I. to be investigated, they found nothing. (CB-06-D)

In some cases this use might be justified by the presence of other colleagues (supervisor, nurse, other specialist) in the management of the patient, but most often the plural was employed even though the physician was the sole agent in charge of the patient, sometimes even when the physician was clearly speaking of the one-on-one clinical interaction of the consultation.

Discussion

In the absence of a clear diagnosis and physiopathological explanation for their patients' symptoms, physicians relied on a hierarchy of explanations that went from biomedical, to psychiatric nosology and psychological problems, to social and lifestyle issues. Many of these explanations implied some degree of patient responsibility, and might lead to doubt, mistrust or blame of the patient.

During the research process, one of the staff physicians insisted that residents in training were sensitized to social and cultural aspects of patient management, and were encouraged to take in consideration the patient's agenda. In the research interviews, it appeared that physicians did, in fact, search for social clues and patients' current concerns. But in the majority of cases, these were processed in an "either-or" manner: an initial exclusion of biomedical diagnosis followed by a turn of the gaze to psychological and social issues, thus mirroring still prevailing Western postulates in biomedical culture, such as the division between body and mind, and the primacy of the individual over social and political forces (Scheper-Hughes & Lock, 1987; Gordon, 1988; Kirmayer, 1988).

Furthermore, attention to the social sphere was mainly focused on the micro-social elements of the patient's lifeworld (couple, family and professional issues), with the exception of one doctor who mentioned the larger issue of isolation and marginalisation of her migrant patient in Canadian society. Macro-social issues such as inequalities, poverty, racism, were almost completely ignored. Several explanations for this may be considered. One is that the sensitization that the physicians received to social and cultural aspects of patients' lives was presented generically, without much specificity to what should be included under that heading. As well, recognizing the patient's disadvantaged social condition requires that doctors acknowledge their own privileged position, which they may be unwilling to do. Finally, the Canadian political context of official multiculturalism may create a blind spot due to the assumption that the policies supporting cultural diversity guarantee equality for all and the absence of racism in Canadian society. The presence of 5 first- or second-generation immigrants among the physician informants did not increase the mention of issues of racism or disparity. Again, this may reflect the myth of Canada as a harmonious multicultural society and consequent reluctance to admit to having experienced difficulties in intercultural clinical work.

Physicians' focus on psychological and lifestyle issues, and on patient agency in the management of their symptoms is consistent with the behavioural and cognitive perspective of chronic pain and functional symptoms (acquired conditioning, misattributions, avoidance, etc), for which educational interventions and cognitive and behavioural therapies are recommended (Janca et al., 2006; Richardson & Engel, 2004). Physicians in this study often referred to the notion of "secondary gain" but, as Allaz (2003) has described, this was not as "a reference to concepts of adaptation and unconscious benefits, but instead this notion… [was] confounded in practice with the common sense of the word, and associated with the idea of profit and profiteer". A study of chronic pain patients in Switzerland, found that the use of certain pejorative labels for such patients was an indicator of a tension in the doctor-patient relationship (Allaz et al., 1998), such as physicians minimizing the consequences surrounding the apparition of the symptoms, lack of recognition by physicians of psychiatric co-morbidity, insufficient information given to the patient because of communication problems, or lack of congruence between patient and physician models.

With MUS, the tension is firstly around the absence of a diagnosis, which disturbs the well-oiled machinery of biomedicine. During their medical education, physicians are taught how to identify symptoms that will allow them to provide a diagnosis and choose an appropriate treatment. In the case of unexplained symptoms, especially when the patient continues to consult because of the persistence of the symptoms, the absence of diagnosis may be seen as a professional *failure* by the physician, as some informants readily acknowledged. However, MUS not only challenge the competence and credibility of individual physicians, but may also undermine the rationality and authority of the whole institution of biomedicine, ad hence its power explain and control illness (Kirmayer, 1988). This potential threat was evident in our study both by the physicians' reluctance to participate in our study and by the defence mechanisms they employed of transferring the responsibility for the inexplicability of illness onto the patient. Ingrained in our physicians' explanations was the notion of there being "real versus unreal" diseases: a formal medical diagnosis would bestow an unquestionable legitimacy on the patient's symptoms; the absence of this validating label made symptoms appear suspicious and patients' motives questionable. In extreme cases, patients were blamed for their causing or aggravating their condition.

The collective “we” employed by doctors to talk about their practice might be interpreted as another measure to justify and maintain their traditional biomedical practice. Although one could argue that medicine is a team effort which may explain the choice of this pronoun, it is also likely that the use of the collective enhanced the physician’s individual power and authority and made them less vulnerable while managing patient problems for which they could not offer a diagnosis and treatment plan. It also made their failure more impersonal by transferring it to the collective.

Finally, in these physician narratives, we observe the persistence and pervasiveness of certain assumptions in Western medicine described by Gordon (Gordon, 1988). Particularly salient for our study, are the ideas of the body as a representation of nature, distinct from the self, and illness as a universal natural phenomenon separate from society, spirituality and morality. The objective findings take precedence over the subjective meaning of illness for the individual, and the reality of illness is proportional to its degree of physical traces, whether on the body or in laboratory or other exams. Illnesses caused by emotions are not considered entirely “real”, and medical “truth” thus requires a valid physiopathological explanation.

4. Comparing the perspectives of patients and their physicians

This section will confront and compare, individually and collectively, the narratives of patients with those of physicians to examine points of convergence or divergence. First, we compare physician and patient models for the symptoms. Then attention will be given to how each protagonist perceives the understanding of the other, and whether this perspective is congruent with the actual explanations employed by the other. Finally, these results will be correlated to patients' and physicians' evaluation of the effectiveness of clinical communication. A detailed summary of results can be found in Tables 5 and 6.

Congruence of patient and physician models

Divergence and intersection

Both patients and physicians held multiple, coexisting, and dynamic explanations for MUS. Nevertheless, for the most part, there was only partial congruence between their models. In fact, comparison of these multiple explanations revealed a curious combination of divergence of principal explanations and substantial intersection between secondary explications. Common ground between doctors and patients included the use of physical explanations (bad positioning, car accident, fatigue from postpartum and caring for infant) lifestyle issues (lack of sleep from working nightshifts, medical or psychiatric diagnosis (diabetes, irritable bowel syndrome, cervical spine injury, and depression), psychosocial events (divorce, family conflict, illness or death of close relationship). Divergent physician explanations include the notion of secondary gain, patients' lack of judgement regarding the importance of their symptoms, notions of chronicity, somatization or secondary gain, and the fear of a missed diagnosis. Psychiatric diagnosis (depression, anxiety, panic attacks) and psychological factors (stress, type of personality, isolation and absence of support, trauma) constituted common ground in a number of interviews, but also belonged exclusively to physicians' diverging models in other interviews. Most of the discordant patient explanations involved their main hypothesis for their symptom, and again included many different categories of explanations: scoliosis; having a nerve cut during a biopsy; a family schema of women doing too much and burning out, disease passed on by mother; one's body being more sensitive to illness; not respecting cultural prescriptions for postpartum; unhealthy life in a Western city; poor circulation from being too immobile as a child; possessing a spiritual gift that required an initiation; having a heart condition that would lead to a heart attack; the after-effect of an accident in childhood; a missed diagnosis; or poor medical management of a traumatic injury.

Knowledge structures

A specific look at knowledge structures reveals that for the most part physicians did not mention chain complexes in their presentation of their model of disease for the patient's symptoms, although they were asked in the interview how and when the symptoms started and what was happening for the patient at that time. Only one physician raised precisely the same issues as the patient (dissatisfying job and romantic relationship), presenting them as metonymically linked to the patient's symptom. In cases of partial agreement, physicians tended to provide incomplete versions of the patient's chain complexes, but most often linked them to a causal explanation. Frequently, physicians were aware of important elements of the patients' chain complexes (leaving the family house, couple conflict, having a double womb, etc.), but they did not appear to associate them with the symptoms.

Prototypes of self and others were a rich part of patients' models and an important source of expertise for them. In contrast, they were not a component of physicians' narratives of their patient's symptoms, with the sole exception of investigating the family history to look for family predisposition or possible genetic transmission of disease such as myocardial infarct or colon cancer.

As for causal explanations, with the exception of 1 case of perfect agreement, 6 cases differed between patients and physicians, and 9 showed partial congruence.

As a rule, patients expressed more explanatory models than physicians for a single symptom. Interestingly, in the only case where explanatory models coincided, the patient's model (fibromyalgia) was one whose existence is widely recognized (although still controversial) in biomedicine, and which was conveyed by the patient to the physician. This physician did not challenge the diagnosis made by a colleague in another clinic, but instead was so convinced that he never re-examined the patient to verify the presence of diagnostic criteria. In most cases of partial concordance, physician explanatory models did not include the principal patient explanatory models. Physicians provided an overwhelming number of psychiatric, psychosocial and psychological explanations compared to patients, whereas patients tended to express difficulties more in terms of more acceptable ambiguous idioms such as stress, nerves and tension.

Outcome

In terms of outcome, there were 9 cases of disagreement, 5 cases of partial agreement and 2 cases of full agreement. Physicians were divided equally between a vision of the patients' symptoms as being chronic and a more optimistic prognosis of improvement or disappearance of symptoms and resilience of patients. Only one physician viewed the patient's condition as likely to worsen and also as holding the potential to develop new symptoms. Three patients vacillated between expecting outcomes of persistence and improvement of symptoms, whereas half of the patients viewed their symptoms as likely to improve; most of the time this positive expectation was predicated on finding an effective therapeutic intervention (bypass surgery, a miracle drug, etc.). Five patients feared a dramatically negative view of symptom outcome (destruction of kidneys, death, cancer, heart attack), and 2 did not know what to expect. It was common for patients to hold competing and contradictory views of their prognosis.

Management

For half of the physicians, optimal management of these cases included referral for psychotherapy and antidepressant medication which most viewed as difficult to obtain and to have the patient accept. The vast majority of physicians recommended communication strategies such as assuring the patient of the provision of continuity of care, taking more time to listen; reassurance, providing information, believing the patient, accepting the absence of diagnosis, working on functioning and lifestyle issues, etc. A few physicians proposed non-specific symptomatic treatments, whereas some still felt that there might be a need for additional examinations or specialist referrals. In contrast, half of the patients put forward the necessity to continue investigations, fearing a missed diagnosis or just hoping for evidence of a clear cause for their symptoms. Other therapeutic possibilities they wished to try included: massage therapy, osteopathy, herbal treatment, prayer, discontinuation of possibly harmful medication, and "miraculous cure". Five patients mentioned strategies such as controlling their stress, becoming more active, working on lifestyle issues, and just tolerating symptoms. Two patients did not know what more could be done, especially because "everything has already been done."

A notable finding is that agreement between patient and physician on the cause of symptoms did not guarantee agreement on prognosis or necessary treatment, nor was disagreement in one domain always followed by disagreement in another. For instance, in one case (NCB-04) where patient and physician agree on the explanatory model of fibromyalgia and on the contribution of psychosocial factors to the symptomatology, they disagreed on the prognosis. The physician had quite a pessimistic view.

> D: I think she eventually gonna hit, ah..it's gonna, she's grumbled along for two years so I think she can grumble along for a long time. She'll tolerate grumbling along you know like if she hasn't blown a gasket in two years but I think eventually she'll probably break up with her boyfriend (...) ah..they will break-up and she will go back to X [*her home country*] and will feel bitter about the whole experience.
>
> M: Uhuh and how do you think that will affect her clinical presentation?

> D: Yeah well, I think that she'll probably have a lot more presenting complaints around that time. (...) Like a bad comparison: "the cement has been set right now". She's really in a holding pattern and there's not much that's gonna change. I don't think there's any end. But with some change in her psychosocial situation maybe that might be an opportunity for her to re-address the diagnosis that she has, or the way that she looks at the world that may contribute to the problem that she's gotten herself into. (NCB-04-D)

But the patient had a different take on the outcome of her illness.

> P: Finally, when we found it they were relieved it's not something terminal. It's, you can live with it, it's doable. But you have to handle it, to learn to handle it, and that's it. So it was a relief. So now every time I have some pain I say "okay, fine." (...) Ah,..I'm going to live without stress or at least if I would be able to manage my level of stress I think it will dim, it will diminish ah. ...
>
> M: So the key to the future is managing stress?
>
> P: Uhuh, yeah.
>
> M: That's the key to it. How are you go on doing that?
>
> P: You have to have a psychologist. (both laugh) (...) And good support from your family and friends. (NCB-04-P)

The inverse was also true, for instance in the case of CB-10, where patient and doctor explanations were dramatically different (the physician's model was that the patient was somatizing and needed psychotherapy to solve her psychological issues, while the patient rejected psychological explanation and believed that her blood did not circulate well because she did not move around enough as a child), they nevertheless both agreed that the symptoms were not likely to get much better.

Physicians' perspectives of their patients' models

Physician knowledge of their patient's models was incomplete and fragmented. Seven doctors stated that their patients did not have an explanation for their symptoms and, in 6 cases, believed that the patients were still searching for the source of their illness. A look at these patients' narratives reveals that, in fact, all 7 patients had one or several models of explanation, but all were still hoping for a tangible biomedical label. Of these 7 patients, 2 were recent immigrants whereas 5 were Canadian-born.

Eight physicians had partial knowledge of their patients' models, but for the most part they ignored the main explanation held by their patient. Five physicians showed complete absence of coincidence: 2 of these hold the wrong model and 3 erroneously believed that their patient did not have an explanation for his symptoms. Of the 5 patients implicated, 3 were recent immigrants. One of these physicians recognized that the language barrier kept her from "getting the whole picture" (NCB-06-D), whereas one stated that culture was not a problem because his origins were similar to that of the patient. In fact, only 3 doctors could provide an accurate account of their patient's elaborate explanatory model for their main symptom (CB-07-D, CB-10-D, and NCB-04-D). It is noteworthy that for all of these cases the explanatory models had either been validated or initiated by a medical doctor, and in two cases they had existed for several decades.

A closer look at knowledge structures reveals that only one physician cited a chain complex as accurately belonging to her patient's model. This chain complex, i.e. the symptoms having started after the patient's mother's breast cancer, was in fact also present in the physician's model, but as part of a larger psychological explanatory model for the patient's symptoms. Physicians' narratives included many more important circumstances mentioned by patients as part of chain complexes, but without considering that their patient might actually link them to the symptoms. Physicians' knowledge of their patients' analogical reasoning was also limited and inaccurate. Six physicians referred to possible patient prototypes, namely: mother's breast cancer; mother's fibromyalgia; relative's death from a similar problem; own prototype of depression; own experience of abdominal pain being believed by physicians and sent home only to come back with a ruptured appendicitis; and prior bad secondary effects of medications). Of these prototypes, only the last two were referred to in the patient narratives. Reference to mother's breast cancer or to the patient's own depression did not appear at all in the patient interview, whereas other prototypes were inexact, such as the mother of CB-03-P who was a prototype for the patient for depression but not for fibromyalgia. The striking dramatic prototypes disclosed by patients were not acknowledged by physicians as part of their patient's model.

One exception is a physician who considered the mother's death as a possible patient prototype, only to later reject it.

> M: I wanted to go back, you said at some point that "someone in the family had something like it"?
>
> D: Yeah, he -- someone in the family had died of heart problems in his family. And his mother had died but it was a lung infection or it's a lung problem. He said it wasn't the heart so ah, it could have been anything really he didn't really know, pneumonia, it could even be cancer it could have been you know (outside from that that didn't happen?). My main goal was to get ah family history and see if he had a positive cardiac family history. And you know at the back of my mind I was wondering if, does he think that he will die from the same thing caused his mother to die from? That, but ah I did not get that feeling either. I did not get the feeling that he was too concerned about the chest pain, it troubled him, but I don't think he really concerned "am I going to die from this?".
>
> M: Okay and he didn't express maybe it was the same kind of illness that his mom--
>
> D: No, no. (NCB-02-D)

This contrasts with the patient's reliance on his mother's prototype, his belief that his chest pain "comes from her" and that when he gets old he will be like his mother and die from the same problem as she did.

The physicians' perception of patients' explanatory models included medical diagnoses (heart attack, depression, fibromyalgia, anaemia, breast cancer, allergy, and asthma), physical reasons (muscle pull, pinched nerve related problem, working nightshifts, postpartum fatigue, something damaged in her head, and "a permanent delicacy of her system as a sequel of an automobile accident") and psychosocial factors (work and stress, relationship, tired because of the kids, and unspecified "psychosocial factors"). In fact, almost all of the physicians' perceptions of their patients' models fell within the categories found in their own explanations for the symptoms. These categories neglect a number of other explanatory models held by patients, including *transmitted*, *constitutional*, *social* or *pseudomedical*. Finally, only two physicians believed that their patient was not reassured that they had been able to exclude a serious illness, although in fact half of the patients continued to have this concern.

Physicians' estimation of patients' acceptance or rejection of psychological or psychosocial issues was markedly inaccurate. Two of the 3 physicians who believed that their patients actively rejected psychosocial causes or contributors to their illness were incorrect, while only 2 of the 5 who held that their patient accepted psychosocial causes or factors were right.

Physicians generally were aware of their incomplete knowledge of their patients' models. One physician recognized her ignorance of it, while 5 physicians recognised that they had only limited access to it and were "not getting the whole picture." More surprisingly, a few physicians were reluctant to explore the patient's model.

> For someone like this you need to accept, uh, that they have a problem but you can not uh, but its kind of a double edged sword because the more you accept, their explanations for everything, the harder it is to treat them, because you are not taking a firm stand and saying "I think that these could be the real reasons why this is happening". Not like, not the way I'm doing, sort of sugar coating going around the corner. (CB-10-D)

These physicians did not wish to obtain the patient's model, stating they believe they would then have to adopt it, and it would make it more difficult to treat the patient. Others felt that embracing the patient's model would be unethical, as if not telling them the truth about their condition. The position of these physicians contrasts with half of the group of doctors who appeared to actively work with the patient's model.

> M: And how do you think she explained her illness before consulting you?
>
> D: Oh, that question, [speaking simultaneously with interviewer] that, that, that's too hard...
>
> M: How do you think she explains the persistence of her symptoms now?
>
> D: I think she explains it in terms of muscle spasm and ah a persistent delicacy of her system, which has a tendency to go into spasm whenever she over reaches herself.
>
> M: Do you think she links it back to the accident?
>
> D: Yes! Oh yea, she definitely sees this as an, as a ongoing thing.
>
> M: And, how did you explain the persistence of her symptoms?

> D: I, I bought into that explanatory model, I said that, you know, it's, what else am I going to say? You know, I have as I said broached the subject of anger and secondary gain (mhm) and she just...
>
> M: Doesn't listen?
>
> D: She doesn't want to respond.
>
> M: So she presented you with the, the explanatory model of spasm and delicacy?
>
> D: And I'm ok with that, cause it will work. (CB-05-D)

"Working with the patient model" seems in fact to cover heterogeneous strategies and practices that include: reformulating the patient's words; negotiating the explanatory model for the symptoms; using the patient label for the illness; validating patient symptoms and referring to specialist according to patient's wish; and accepting the patient model.

Finally, a last obstacle to physicians gaining knowledge of their patients' models was that they did not always share their model easily or obviously. In this study, 7 patients declared that they had shared their model completely, 5 partially, and 4 not at all. But even among those who did express their view, they often did so obliquely and timidly.

> M: Did you tell the doctor about, these explanations about, you know, did you tell her either that you thought there was an infection, or did you tell her that maybe being too hot had something to do with it?
>
> P: No, I tell her, I, my urine burns too much, I feel maybe it's same infection, because I suffered long time from urine infection.
>
> M: Mm-mm, okay.
>
> P: All the time I tell doctor I suffer long time. Suffering, I'm suffering long time. Maybe, I'm not seeing infection. Doctor say, let me see. (Uh-huh) But then she said, okay if you have any infection I will call you. But I, I don't receive any call. (NCB-03-P)

Patients might present their hypothesis as coming from another source of expertise, or they might allude to a previously diagnosed illness, but they rarely insisted if their doctor did not pick up these clues or if they rejected them. For instance, patient CB-06-P presented to her family doctor the hypothesis that her symptoms might be a calling because she has a healing gift and needed to be initiated, as the model presented to her by a consultant cultural psychiatrist. She reported that her doctor criticized the psychiatrist and proposed to refer her elsewhere. Other patients reported that they tried to share their model but the doctor did not have time to listen or disconfirmed it with a negative diagnostic test.

Patients' knowledge of their physicians' models

Patients demonstrated better knowledge of their physicians' models than vice versa, as they were able to report the physician's perspective accurately in 5 cases and partially in 8. Patients were quite aware of the psychiatric or psychological component of their physician's model of disease, and cited this as their physician's main explanation in half the cases, even though several (3) actively rejected this as a possibility. In fact, patients reported that their physicians' models included psychiatric and medical diagnoses (anxiety, depression, panic attacks, "being cuckoo", fibromyalgia, diabetes, trigeminal neuralgia, allergy, irritable bowel syndrome, anaemia, herniated disk), exclusion of other medical diagnosis (urinary infection, cancer, colitis, "everything is fine"), physical causes (fatigue, de-conditioning, musculoskeletal pain, "high reactivity of the body following a car accident"), and psychosocial factors ("a lot having happened," "her problems are causing this," "it's psychological"). Only one patient stated she did not know her physician's model. No patient mentioned that their doctor might be worried about a missed diagnosis, although this was a subject of concern mentioned individually both by physicians and by patients.

Patients' perceptions of physicians' models for their illness tend to oversimplify and be incomplete.

> M: Uhuh, what did your doctor say was the reason for your weakness?
>
> P: She don't know.
>
> M: She don't know.

> P: (laughing) That's why she said "that I have to have a social worker somebody to talk to me you know about it, and maybe she think I may maybe I have some problem that's caused me this feeling. Because she did the check-up so she said "she doesn't have answer."
>
> M: Before you said "it's problems in your life or?"
>
> P: Maybe it's too much, maybe in a way she knows, she knows my boys and then they are very strong boys and with this boys how could you rest? But now it's not the same they are big they do things by themselves almost.
>
> M: Did she tell you that she thought it was maybe problems?
>
> P: Yeah, "maybe it's too much for you, maybe it's difficulty, life difficulty in outside." I don't get, my life is not straight maybe?
> (NCB-06-P)

While the actual disease model of the physician is more complex and contains more diagnostic hypothesis.

> D: There is no medical reason for her complaints. She could be depressed but she didn't really feel depressed. I mean she classically didn't fit the symptoms of depression and ahm, so it was just she fell in this crack. (…)
>
> M: Besides depression that you mentioned earlier did you what other diagnostic hypothesis or explanations?
>
> D: Well she did some tests to the hypothyroid that was one of them. She doesn't seem to be, I've wondered about some adjustment disorder. I mean, it's a, she's a fallen into an odd category as an Ethiopian-Jew. So they don't quite, so they don't quite fit in because they're Jewish and yet because of the colour of their skin, I sometime find that they're not treated the same way as different complexion individual. (…) So I have wondered whether or not there was just this sense of being very isolated, whether it was just adjustment reaction. And hypothyroidism I checked, she had some problems with her sugars, but again nothing specific. Nothing really that would explain. I don't know, I can't remember if I did liver functions when I was looking to look for liver abnormality, but again nothing, nothing that organically explain it. Nothing about … (long pause) Again you would say is this normal family development, normal life cycle stuff, and again it doesn't feel that way. She doesn't express being terrifically lonely, she seems to be getting out and meeting people and doing some things. There's nothing specific that I could count with my finger on.
>
> M: If you have to select one explanation which one would it be?
>
> D: I think the most likely thing is she's just a bit lost. I mean, I don't think she knows yet that she's a bit lost in a Canadian cultural context. (NCB-06-D)

Communication issues between patients and physicians

Physicians' perspective

Physicians separated issues of relationship and issues of communication. All physicians considered communication with their patients to be good; although 9 mentioned that it could be further improved, no physician gave it a poor rating. Despite this positive evaluation of communication, many physicians had negative feelings about the relationship with their patient. The patient with MUS was often perceived as a different kind of patient, more "challenging", "difficult", or "demanding". Physicians expressed feelings of frustration, annoyance, anger, apprehension, anxiety and stress towards these patients, the abundance of their symptoms, the lack of solutions physicians had to offer them, and the dilemmas raised by their innumerable requests to address social problems. But physicians also found strategies to improve their management of these challenging situations. Many physicians stated that through building a long-time relationship with their patients and obtaining better knowledge of their character and lifeworld, they had gained acceptance of some of these difficulties in communication and relationship.

> M: How do you feel about this patient?
>
> D: She's a mixture! Ah, if I didn't know her, and I didn't know her family (mhm) she would be the kind of patient who, when you see one or two of them in your afternoon schedule you know it's going to be a hard afternoon. (mhm) For a variety of reasons, they're emotionally more demanding (mhm), they take up more time (mhm) and they put you behind and that makes everything else sort of awkward and, and that's a hard, those are facts. The fact is I know her, (mhm) and I, as you saw when you meet her, she's really, she's a remarkable woman (mhm) I also have a lot of admiration for her, (mhm) she is honest in ways that I find striking, she has resilience that's remarkable, and has been able to pull herself through things, she has a family I know, and so, it, I have had the chance with her to develop what I think of as the physician-patient relationship where we, I know her, I know her family and I enjoy our visits. (Mhm.) Even though they're probably among one of the more difficult ones that I have. (CB-03-D)

For other physicians, this process included recognition of their own therapeutic limits, changing their role from diagnostician to caregiver.

> D: She's not difficult to deal with I mean once you sort of realize that you're in this holding pattern and that that you're going to be doing this it's like a dance and you know you're gonna have to do it for however long and usually with patients like this it seems like sometimes it's 2, 3, 4 years. (...) And if you both agree that this is just, you know, it will come, you'll have this conversation, you'll deal with it and you'll both breathe, and you'll come back in three months or six months do the same thing all over again. (NCB-06-D)

The physicians' management strategies included shifting the focus from curing the symptoms to listening to the patient.

> D: Maybe at the beginning, ah, I thought that he actually would get rid of all these soreness and ah. And of course you know, if we could do that (chuckles) he will be thrilled! But by now I think that that's not exactly what he's looking for. I mean it's sad to say, maybe he has given up on that .. But even though every time he comes, and he has a list, and goes through his symptoms. So I think what he wants me really right now, is just to listen to him and to realize that he's going through all these... You know, to realize that you know, ahm. Ok because you know, there is a conception that, you know, there is a perception that "if I, if I don't talk about this maybe my doctor will forget or will think that, you know, I'm all fine right now". And ah, you know, he wants to remind me each time that, you know, "listen I'm going through this even though..." Like we've gone every time "soreness of the chest, soreness of the abdomen" but every time he mentions it. (CB-02-D)

Patients seemed to have an ambivalent view of communication with their physicians. When asked specifically, only one patient judged the communication with his physician to be poor and all the other patients assessed it as good, with 7 patients believing it could still make some progress. Nevertheless, they punctuated their narrative with anecdotes where they did not feel heard or believed or taken into consideration by different physicians and even stories of medical errors or prior bad management.

> P: Sometimes, I mean, you know, I know you're a doctor and they're doctors, but you're human. And you know, they make mistakes and whatever. And sometimes you as the patient or the mother, like, you know if there's something wrong with your child, you know because you're the mother. And you've gotta put your foot down. You know, and that's when like they told me "go home and stay in bed" and I refused. And at the end they told me it was a good thing I refused cause I would of lost her too [*the baby*]! You know, sometimes you have to be a little bit stubborn, you know? (...)Yep, sometimes you're

> feeling something, you know it before, you know, the doctors! Medicine is a science, right, they've still got a lot to learn. (CB-09-P)

Patients' perspectives

As a general rule patients were openly quite critical of the institutions of medicine (clinics, hospitals, or the Quebec medical system) or of specialists they were briefly referred to, but they were reluctant to openly complain about their primary care physician and instead tended to blame structural elements for which the physician is not responsible (lack of time available, little experience of young doctor, stress and competition within the hospital) or even themselves (not explaining well, not speaking good enough French or English).

> P: And it's not her, it's not her incompetence, nothing like that. I mean she's a resident, she's learning. And ahm maybe sometimes I may not be expressing myself, maybe I'm I'm not expressing myself to her totally in a way that maybe, I don't realize. I could be telling her things maybe too, without telling her too, it could be a little bit my fault as well, you know. (CB-03-D)

Agreement

The majority of patient-physician dyads agreed in their rating of the quality communication, with 2 exceptions: in one case the patient thought the communication was poor, and in another case the physician was unsettled by her impression that important issues were not being discussed. Even when there was weak congruence between patient and physician models or little understanding by physicians of their patient models, both still rated the communication as good. For example, patient CB-04-P had a very elaborate model for her chest pain. She believed there was an artery or vein leading to the heart that was blocked or hardened. Her weight was putting too much effort on the heart which could not withstand it. Her smoking contributed to this by hardening her arteries and by killing hairs in the lungs that helped one to breathe, so she was not breathing properly. As a result, she was not getting enough oxygen to her heart for it to function properly. Furthermore, when she was stressed at work she got out of breath and her heart beat faster, which tired it. She believed this would lead her to have a heart attack at age 38. But her physician had another view of her model.

> D: Ah, I think that if she knows that it's, she knows the cause of it, if she knows that it's not her heart, her heart is OK I think, just knowing that will decrease the anxiety, and when she does have this pain, it will probably be shorter lived than if she didn't know what the cause of it was. (...)
>
> M: What do you think she has as an explanation?
>
> D: She probably thought it was her heart. (Mhm) Chest Pains
>
> M: Ok! And, so what do think she believes it is now? What do you think she came away with?
>
> D: I think she came away with, it's not her heart and whatever it is, it not something that's serious, (mhm) ahm, like life threatening serious. (yeah) Ahm .. and I think that she's reassured by that, and I also think that,.. I think that I made a bigger deal out of it than she did. (CB-04-D)

Despite this, both view the communication positively, especially the patient.

> M: Ok, and how do you feel with that communication with Dr. S. the understanding?
>
> P: Ahm, I understand very well what she understands and I can ask her anything and she explains it in details so, I'm very, very comfortable with her.
>
> M: Good.
>
> P: I told her, if she ever leaves, tell me where she goes! (CB-04-P)

Culture

The question of cultural difference as possibly constituting an additional barrier to mutual understanding was also examined in the research interview. Patients minimized this difference, with only one patient recognizing culture as an obstacle, 2 focusing on language difficulties, and 3 denying that this constituted a problem at all. In contrast, physicians were more likely to acknowledge cultural differences. In one case, the patient and the physician both agreed that being from a similar culture (India and Sri Lanka) facilitated their mutual understanding. Two more physicians recognized cultural difference as relevant, although one remained vague about the specific meaning of culture.

> M: Do you feel like there's a cultural barrier that prevents better communication or that makes it more difficult for you to understand her?
>
> D: Yeah, yeah I think there must be, there must be a component that ah ... cause like sometimes when I ask her some questions like depressive questions or anxiety questions and she was looking at me like I was weird. Like "Why are you asking these questions and so uhm .. I'm sure there is. (NCB-01-D)

While the other clearly recognized that he had negative stereotypes concerning the culture of his patient.

> D: And also she's X *(nationality)* and I also have transcultural sort of issues I say she's X, and thorny and she's a Y [*nickname for nationality*], and also, okay that's her culture and that's her way, and I'm not gonna rock the boat one way or the other, that's how she interacts. (...)
>
> M: You feel that the cultural difference was a barrier between you and her?
>
> D: For sure in that I have very strong opinion I spent a lot of time in X and I have very strong feelings about X, not cultural things but I have a very clear idea in my mind what X are like so that definitely caused a problem it always cause I have a number of a few X patients and with every X patient it's very hard for me not to immediately culturally stereotype them.
>
> M: So what's your cultural stereotype of X? (both laugh)
>
> D: Pushy, uh loud, uh tough, uhm....not very.. ah gracious....very ah not really into subtlety you know and you know I just had I just got a new X patient who's not at all like that but it took me the whole visit before I was able to grab my head around that fact, you know. Uhm..so for her I'm sure that I was you know I may not treated her with as much sensitivity because I have thought about her as an X. (NCB-04-D)

The other physicians reformulated the perceived difference in terms of language, socio-economic level, and prejudice experienced due to being a visible minority. But in general culture received as little attention from physicians as from patients, as illustrated below.

> M: Did you feel that uhm the culture differences are a barrier?
>
> D: I don't think that the culture difference is a barrier. I think that if you are, if you understand the culture is an *asset*. But I think if you *don't* understand the culture -because the way we are trained is to *not* make assumptions, you know, certain things that you know- we would not miss anything. But you know of the smaller type

> problems, *that* you know, maybe we would not pick those up. (NCB-02-D)

Discussion

Despite the fact that current medical training emphasizes communication skills, with a special focus on the paramount importance of taking the patient's perspective into account throughout the case management, physicians still appear to lack insight into their patients' beliefs and concerns (Silverman et al., 2005). In our study, physicians clearly demonstrated a lack of knowledge of their patients' understanding of their symptoms. The categories of explanations that physician considered that their patients' might hold were similar to their own biomedical and psychosomatic models, with cultural and social explanations almost inexistent. Most physicians minimized the extent to which patients held an explanation for their symptoms, underestimated the complexity of patients' models, and ignored the possibility that patients were using non-causal types of reasoning. In this respect, physicians seemed to be confined in their reasoning by the limits of biomedicine with its exclusively causal logic. Some physicians also appeared to restrict their acceptance of patient meanings for symptoms when the source of authority lay outside of medicine and were unwilling to explore their patients' models, perhaps because they feared that, in the absence of tangible evidence, their biomedical explanation would be challenged. But for the most part, physicians' lack of awareness of their patients' explanations for symptoms appeared to be related to a lack of ability to access these models rather than a lack of interest. Indeed, a focus group study of general practitioners (GP) in the UK found that doctors were eager to find explanations that would help in their understanding of patients with MUS, but also felt untrained and stressed not knowing how to handle situations where it was obvious that symptoms were produced by life circumstances (Woivalin et al., 2004). In another study in the UK, interviews with primary care physicians revealed that they did not find the patient-centred model helpful in the management of MUS patients (Wileman et al., 2002). In our research, even if physicians were to attempt to elicit their patient's explanatory model, a further difficulty would arise because these models are continuously shifting, integrating new information, and transforming themselves. Thus physicians lack a conceptual framework for eliciting salient features of the patient's complex and dynamic explanatory construct.

The overlap between patient and physician narratives in terms of models of illness shows that there is a substantial amount of common ground for discussion. Comparison of patients and physicians perspectives on outcome and management reveal the same pattern of partial overlap and distinctive viewpoints. Most strikingly, a number of patients feared a terrible prognosis, whereas physicians were divided between status quo and improvement. And whereas half of patients believed in the need for further investigations and half believed in the possibility of improvement conditional on a major therapeutic intervention, physicians on the other hand recommended modest changes in communication strategies rather than further testing or referral. These results are consistent with the studies based on physician interviews, which claim that patients with MUS pressure their GP's for somatic interventions (Hartz et al., 2000; Reid et al., 2001; Steinmetz & Tabenkin, 2001). Ring and colleagues (2004), however, demonstrated through the analysis of audio recorded consultations that it was the GP's themselves that prescribed somatic intervention in response to the intensity of the suffering expressed by their patients. Our methodology unfortunately does not allow us to know whether our GPs actually did limit their investigations or not when in practice.

Physicians found these patients difficult, frustrating and challenging (Lin et al., 1991; Steinmetz & Tabenkin, 2001). But they also managed to find strategies to come to terms with their negative emotions, in particular through the creation of a long-term relationship and a focus on the care of whole families. Despite frequent non-congruence between physician and patient models of illness, a majority of patients considered the communication with their physician to be at least partially satisfactory. It may be that continuity of care, physician engagement and recognition of symptoms and suffering played an important role in maintaining good communication despite misunderstanding or lack of awareness of the patient's point of view. It may also be that physicians' opinions are only one source of meaning for patients, and that non-congruence of models was accepted as a limitation of biomedicine. Importantly, the fact that the interviewer was also a physician may have led patients to censure their criticism of their physician, thus resorting to anecdotes as an indirect expression of their discontent.

Cultural differences were given little attention by physicians. When mentioned, culture was always located in the patient, despite the fact that 3 physicians were born outside of Canada and an additional 4 had at least one parent who was not born in Canadian born. The only physician who mentions his non-Canadian cultural background did it because he was of the same origin as his patient and he believed this played a role in improving their communication. Nevertheless, this physician reiterated the general attitude of a "culture of no-culture" that exists in biomedicine (Taylor, 2003).

One possible hypothesis for this lack of focus on cultural difference it that "otherness" of the MUS patient is such that it overwhelms other differences. Indeed, the course of illness of MUS deviates from norms learned by physicians in their study of pathophysiology. Illness behaviour of patients with MUS diverges from the "official paradigm of body representation" (Le Breton, 1995).

> D: Um and, also knowing her, and I mean she is in her, mid-thirties from what I remember, but ah, she comes to see me, you know, every month or every two months, you know very often for someone her age. (CB-01-D)
>
> D: I think she, I find that she's also the type of patient who will talk to you about every, (...) She will always come up with something "oh, my ear!" or, "I have this thing on my ear!" You know, so she's anxious about all of these things that she's feeling and doesn't have the judgment to say, "oh no, this is you know, I can tell this is the little thing in my earlobe, it should, you know it's not worth bringing it up to the doctor". (CB-04-D)

One consequence of patients' deviation from normative illness behaviour is that physicians questioned the validity and legitimacy of the patients' complaints. This opens the door to physician's doubt or blame, as alluded to in the physician interviews. Therefore, the absence of diagnosis and its consequences are far more problematic for physicians than the cultural difference.

IV. CONCLUSION

This study was designed to understand patients' illness experience and their primary care physician's interpretations of symptoms, in the absence of a medical diagnosis. This last section will briefly summarize its main findings, followed by the clinical implications suggested by our data, and propositions for future research.

Our sample of 16 patients suffering from MUS was predominantly feminine, and came from very diverse ethnocultural backgrounds. Patients were highly symptomatic and their narratives revealed that symptoms were explained through complex, creative, multiple, and dynamic networks of meaning. The body was compared to a machine that maintained a delicate chemical and energetic balance driven by an internal battery that may short out. This elaborate structure was characterized by a potential for transformation, injury and depletion, the need to maintain natural bodily functions, and potential aggravating role of constitutional factors (such as innate vulnerability or variant in body part) or family transmission of illness. Symptoms were also brought on by emotions and thoughts, including emotional harm or depletion from the hardships of life, for which certain personalities may have been predisposed. Other contributors to the process of illness included social factors such as professional and family issues, the difficulties related to migration, lack of money, and non-optimal management of their illness by the health institutions. Further remarkable features of these patient interviews included the high number of losses experienced in their lives, and the difficulty of maintaining a balanced life due to excesses of all kinds.

Explanations seemed to bridge concepts of mind and body, with both becoming ill through similar mechanisms. There was coexistence, contradiction and ambivalence between psychological and physical causes in narratives, and multiple uses of ambiguous expressions such as *nerves, stress,* and *tension* to explain symptoms. These provided convenient idioms of distress that avoided a stigmatising psychological label, and the concurrent threat to their credibility and to the legitimacy of their suffering. Fear of an undiagnosed disease was present both overtly and covertly, and reassurance by physicians proved insufficient. Death was alluded to, both as a fear and as a conclusion for their anguish.

Patients depended mainly on health care professionals' expertise and on accounts of family and friends, and to a lesser extent on the mass media, books, internet, and non-biomedical healers. Multiple sources of information were referred to, with biomedical authority being predominant, albeit transformed according to patients' experience and knowledge. Their explanation processes were dynamic, with the presence of several competing explanations for their symptoms that were constantly being confronted, weighed, and discarded according to the information obtained. This dynamic process of revision showed how symptoms could be linked to major psychosocial issues during the interview. Some initially obtained chain complexes often supported the explanatory model later in the interview. Other free-floating chain complexes allowed patients to point to difficult psychosocial issues or life events whose direct causality they resisted. Besides backing up the explanatory model, patients' prototypes seemed to offer a strategy to convey important messages to the listener with emotional power. Abrupt deaths or startling illness episodes experienced by others appeared to be especially striking for patients and conducive to prototype formation, which served as indirect justification to their health concerns or their requests of the medical system. Patients generally presented several explanatory models of diverse complexity than ran in parallel, could be contradictory, and were often dynamic, incomplete, and still awaiting further information.

Our patients' general practitioners were fairly representative of the clinic physician population, and also showed a high degree of diversity of ethnocultural background. Their own explanations for their patients' symptoms also were plural, with a predominance of biomedical, psychiatric and psychosomatic diagnosis. Psychosocial factors were often referred to, although specifics of what this label included were scarce or even absent. Psychological processes, such as negative emotions, secondary gain, cognitive misinterpretations, etc., were considered elements that were *internal* to the patient and implied some degree of patient responsibility for his illness. Social factors were perceived as *external*, or imposed upon the patient and therefore free of any kind of blame. They included mainly their patients' individual family, professional and migration issues, but neglected their larger social, political or cultural context. A final theme present in physicians' narratives was their doubt of the patient and disbelief of the reality and consequences of the symptoms, which may occur in response to the powerlessness and frustration the physicians felt in these situations of MUS and to the inconsistencies of their patient's narrative.

Both physicians and patients held multiple and dynamic hypothesis for MUS, but their comparison showed substantial intersection of common ground explanations (including physical, lifestyle, social, medical and even psychological explanations). Nevertheless most of patients' main explanations for their symptoms diverged from and were discordant with those of their physician. Patients presented a wider range of explanations with less division between somatic and psychological causality, that were supported by contiguously linked events, and that came from multiple sources of expertise. In comparison, physicians' explanations focused on exclusion of somatic medical diagnoses, mentioned an overwhelming amount of psychiatric or psychological explanations, and sometimes implied patient responsibility and disbelief of their physical suffering.

Physicians were also interviewed on their grasp of their patient's model. Only three doctors could provide an accurate model, with other accounts being incomplete, fragmented, or non-existent. Patients' prototypes of illness were never considered by physicians, despite their salience for the patience. Physicians' estimation of their patient's acceptance or rejection of psychosocial issues was completely inaccurate. Physicians were rarely aware of the extent of their ignorance.

Our two informant groups' perspectives of outcomes and managements also diverged substantially. Physicians considered the prognosis either chronic or prone to improvement, and their management plan included various communication strategies, symptomatic treatment, antidepressants, and referral to psychotherapy. Patients on the other hand expected to improve, with a smaller proportion of patients that considered a dramatically negative prognosis (death, disability, severe illness). They believed that relief would come from further investigations and treatment proposals by their physician, and from complementary and alternative therapies.

Despite these divergences between models, physicians and patients agreed on their rating of communication which they judged good, with a potential for improvement. Physicians expressed many negative emotions towards encounters with their patient (anger, anxiety, annoyance, etc.), but also had acquired strategies to gain acceptance of these challenging situations, mainly through recognition and acceptance of their limits as practitioners. Although patients did not openly criticize their physicians, they expressed their frustration with medical institutions and their structural constraints, and provided prototypes of prior bad medical management of self and others.

Medically unexplained symptoms represent a clinical predicament that is uncomfortable both for physicians and for patients. Because MUS reside at the limits of biomedical knowledge, technology and epistemology, they threaten clinicians' authority and medicine's myth of infallible diagnosis and cure, but also patients' credibility and the legitimacy of their suffering. Engel (1977) pointed out the interrelations between the individual's biological, psychological and social. His *biopsychosocial* model is now a widely recognized model of practice that has been taught in medical school for several decades (Silverman et al., 2005), and is recommended by experts as a key element of formal training about somatization (Goldberg et al., 1992). In spite of this, general practitioners in our study used the biopsychosocial model as a three step reasoning tool (*bio,* then *psycho,* then *social*) rather than holistically, thus illustrating the persistence of the Western mind and body dualism. Physicians resisted the threat to their professional competence by raising doubt about presence or the intensity of patients' symptoms, by using the collective while speaking of their individual medical practice, and by imputing symptoms to internal psychological motives of patients.

Analysis of chain complexes and prototypes revealed important issues of patient narratives that would not be apparent from an exclusive focus on causal explanations and chronological accounts of illness, which are the expected components of a classic medical interview. Elderkin-Thompson and colleagues (1998) analyzed interviews between GPs and patients with medically unexplained symptoms without somatization, with somatization, and with somatization and co-morbid PTSD. These three groups showed progressive deterioration in narrative quality with increasing difficulty maintaining a chronological frame for their narrative; events and symptoms became juxtaposed without explicit linguistic relationship to one another. Furthermore these authors also found that somatizers forced verbal expressions to convey explicit historical narratives and implicit affective messages, because of their inhibition of non-verbal behaviour, with a dramatic effect. These findings raise several issues: i) what is the link between chain complexes and dramatic prototypes, and the diagnosis of somatization?, ii) what kind of narratives would patients from our study produce in medical encounters? To convince the listener, a narrative must show internal consistency, coherence, fit familiar patterns, and have rhetorical quality (Kirmayer, 1994). A certain number of the characteristics of our patients' narratives (multiple and contradictory explanations, narration of issues or events without any obvious causal link with symptoms, rejection of emotional causality despite multiple psychosocial difficulties, etc.) may appear incoherent, confused, or incongruous to their physician, and contribute to doubt, frustration, and disbelief.

The importance of listening to these discordant elements of the patient's narrative, and to the added richness they provide, should be advocated in the clinic to enhance meaning making in the clinical encounter. Whether patients were consciously aware of their explanatory models beforehand, or the setting of the interview led them to construct it cannot be established. What is evident from this research is that allowing a space for patients to develop their narrative will produce explanations and other significant meanings for their unexplained symptoms.

The research interview used in this study, the McGill Illness Narrative Interview (MINI) allowed access to some of the richness and complexity of patients' thinking about their symptoms. The MINI shows that clinicians should give attention to the circumstances surrounding the appearance of symptoms and to the non-causal links made by patients when narrating their illness, as they often point to important social circumstances in the patient's life. Prototypes also should systematically be elicited, in particular to identify *dramatic* prototypes, as these sustain patients' anxiety about having serious diagnoses or poor outcomes, and render reassurance ineffective. Enquiries should be made about explanations given to patients by members of their entourage, in particular the family, in order to comprehend the multiple sources of expertise form which patients draw their models. Finally, the transformative quality of patient models should be acknowledged. Thus the MINI offers a promising clinical tool that allows the physician's faced with unexplained symptoms to explore the meaning of the patient's physical distress and suffering. In the context of this exploration, patient and physician may co-construct new meaning to allow for better adaptation and outcomes for patients with persistent medically unexplained symptoms.

Limitations

Some important limitations to this study must be noted here. The fact that the interviewer was herself a physician might have created a desirability bias with patients, limited their utterances to what they believed a physician would want to hear, censured explanations that would make them appear superstitious or uneducated, and restricted their criticism of their GP. Efforts were made to reduce this by clearly stating that the purpose of the study was to "understand the patients' own perspective", and that "there were no wrong answers", by putting the interviewer at ease, by rendering explicit the interviewer's lack of ties to the clinic, and by probing several times for additional explanations. This last technique proved useful, as it often elicited more non-medical explanations in the later part of the interview.

The professional status of the interviewer may also have influenced the physician informants, leading them to emphasize medical explanations, to the exclusion of recounting patients' idiosyncratic narratives including chain complexes and prototypes. Again, the interviewer was aware of this possibility and tried to minimize physicians' auto-censure by insisting on her interest in the patient's model and their own perspectives on it. She also chose to conduct research in two clinics where she had no prior or future clinical activity or professional ties. Secondly, because of the limit time available for interviewing physician informants, their interviews were much shorter than those of patient's, and it was not possible to systematically explore either the doctors' knowledge structures or their comprehension of patient's knowledge through specific probes. The decision not to probe the physicians with information gleaned from the patient interviews was a deliberate choice intended to avoid biasing the physician interview by suggesting answers.

Clearly the richness and complexity of the patient's explanations may have been partially co-constructed in the very process of the research interview. But the interviewer was very careful not to suggest any answers to the patient, to remain neutral and not offer any judgment of the patient's proffered explanation. Despite this caution, probing and inviting patients to develop their explanations in more detail probably acted as some kind of validation. This process of co-construction of experience is unavoidable in any process of narration. Indeed, subsequently to sharing their narrative, most patients spontaneously declared that they felt relieved and appeased, with their story making more sense to them. This therapeutic effect of eliciting illness narrative has been noted in previous research with the MINI (Groleau & Kirmayer, 2004). Other studies have demonstrated that, in the process of interviews, participants gain new views of themselves or of their situations (Charmaz, 2002). Narration of emotionally painful or traumatic experiences in a way that constructs a coherent story has been shown to improve physical and psychological health (Pennebaker, 1993; Pennebaker & Seagal, 1999).

Although the study was originally designed to compare the experiences of Canadian-born and immigrant patients, it proved impossible to reach any conclusions about the impact of culture or migration on the experience and clinical management of MUS. Several issues undermined this aspect of the study. The general difficulty to recruit patients, related to the already mentioned physician reluctance to participate, was complicated by the restrictive inclusion criteria for the recent immigrant group. Many immigrant patients who suffered from MUS and spoke fluent French or English appeared to be long-time immigrants and had to be turned down. Furthermore, both the recent immigrant group and the Canadian-born group were very heterogeneous in terms of their familiarity with biomedicine and exposure to non-Canadian cultures. Despite these caveats, it did appear that, for recent immigrants, migratory factors and difficulties in the host country, such as isolation, lack of family and community support, or absence of recognition of foreign diplomas, constituted a major source of stress and a salient part of their illness models.

The small number of participants and the narrative-based methodology of this study may limit generalisation and reproducibility of results. Certainly, because of the element of co-construction and because of the dynamic aspect of the patient narrative, it would be technically impossible to reproduce its exact content with another interviewer or at a different time. But more than the specific content of the illness narratives, the chief value of this study is to demonstrate the complexity and richness of the patient model, the multiplicity of sources of knowledge they draw on, and the value of the MINI in eliciting these models. The study also suggests the inadequacy of traditional clinical interviews and the weaknesses of the biopsychosocial model, as currently taught to primary care physicians, for obtaining an accurate perspective of the patients' personal, social and cultural meanings for their illness, at least in situations of MUS.

Over the past decade there have been increasingly frequent calls for a more "narrative-based medicine" to complement the disease-oriented paradigm, in order to improve a series of outcomes as well as to satisfy the basic human need for expression (Greenhalgh & Hurwitz, 1998; Haidet & Paterniti, 2003). Despite this movement within medicine, strong resistances to eliciting patients' models remain — not to mention the structural and institutional barriers of cost and time. Thus the dogma that biomedical theory provides the only clinical reality still prevails and it is "especially difficult for medical and psychiatric professionals .to juxtapose their diagnostic and treatment formulations with those of their patients" (Kleinman, 1980). The difficulty of the task is that it calls for the integration of opposing practices: How to strip the patient's story of all subjectivity and distil it into a few elements that allow identification of a diagnosis, and yet maintain the patient's representations and lived experience of illness?

A study based on analysis of audio taped consultations combined with semi-structured interviews with British GPs found that physicians combined two ways of knowing the patient: a deductive mode of reasoning based on facts that lead to framing the patient as a case, and an inductive mode drawing on contextual interpretations of these facts, and focused on the patient as an actor in a social circle (Fairhurst & May, 2001). This second type of knowledge was associated with continued long-term care of the patient, with a sense of connection to the patient, with physician satisfaction, and with an increased capacity of physicians to predict outcomes. These results show that it would be useful in GP training to develop strategies to improve inductive reasoning. Because it elicits the patient's narrative and meaning for his illness in a jointly constructed way, the MINI provides an interesting tool to teach in clinical training. This hypothesis would need to be tested in further clinical research.

Results from this study shows that the absence of medical explanation for these symptoms is not a question of patients –or physicians- lacking potential explanations of their own. Most patients could provide several complex models of illness for their symptoms; in fact, they had a wider range of explanations that did their physicians. Instead, the fundamental issue was the difficulty that patients and physicians had in finding a satisfactory common ground and a negotiated meaning. In this context, the MINI appears to offer an interesting tool that can be used in primary care research, but also in the clinic as a way for physicians to gain a better understanding of their patients' illness explanations and experience (Groleau et al., 2006).

Our research raises several further questions to be explored in future studies. Although in our study interviews of patients and physicians allow us to partially contextualize each narrative, it would be useful to confront these accounts with audio or video taped consultations, to observe how meaning actually is created or negotiated in the clinical consultation and how it compares with what patients and physicians report in individual interviews. Future research should also focus on using the MINI in situations where symptoms can be readily explained by the biomedical paradigm, in order to examine more closely how less ambiguous biomedical information and other sources of authority find their place in patients' models. And the dynamic transformations of patient models over time also offer an important topic of enquiry, with implications for our understanding of the nature of chronic somatic symptoms and the development of effective clinical interventions. Finally, because of the important overlap and co-morbidity of MUS with psychiatric diagnosis, and because of the influence of emotional distress and trauma on the quality of the narrative, conducting a parallel diagnostic interview to test for criteria of depression, somatization, hypochondriasis, PTSD, and general anxiety disorder would enhance the discussion of narratives of MUS.

The value of these results, lies not with the precise contents of the explanations identified (which may differ with patients of other social and cultural background, age, etc), but with the understanding they provide of patients' process of making sense of their symptoms. This dynamic process and the multiplicity of sources that patients draw from are not only keys to better understanding of the patient, but also point to ways to improve clinical management by the physician. If illness understanding is plastic, there is space for "negotiation of meaning" in which physicians work collaboratively with patients to make sense of their symptoms, despite the absence of a clear medical diagnosis. This requires that doctors share power in the consultation, recognize that biomedicine cannot provide all the answers, and take into account the patient's expertise. This might allow a change of paradigm from medically unexplained symptoms to *multiply explained symptoms*.

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TABLES AND APPENDIX

Table 1 : Patient sample demographic information

Patients	Age	Gender	Marital status	Education	Job
CB-01-P	35	F	Single, lives with mom, no kids	11+2+3	specialized education technician
CB-02-P	77	M	Married, 3 kids, 7 grandchildren	?	retired (managed taxi station)
CB-03-P	46	F	Married twice, 1 daughter	up to grade 11	Orderly, now on sick leave
CB-04-P	36	F	Single, no kids, lives with sister	11	insurance broker
CB-05-P	46	F	Divorced, 1 son	11+4+2	independent conference interpreter
CB-06-P	26	F	Single, no kids, lives with parents	up to grade 11	none
CB-07-P	65	F	Widowed 2 yrs ago, 5 kids alive (1 dead)	11 + secretarial school	Retired, volunteers with handicapped youths
CB-08-P	47	F	Single, 2 sons (27&29), 2 grandchildren	up to grade 9	unemployed, former courier sorter
CB-09-P	43	F	Married, 1 daughter alive (1 dead)	11+2	winder, now housewife
CB-10-P	48	F	Divorced, no kids	12+2+6+3	librarian, now student
NCB-01-P	42	F	Single, no kids.	H.S. +++++	Lawyer, now student
NCB-02-P	48	M	Married, two kids (son 18, daughter 16)	< high school	cook
NCB-03-P	38	F	Married, 2 daughters (14 &8)	10+2	Former airline stewardess, now housewife
NCB-04-P	34	F	Boyfriend, no kids, lives with roommate	12+4+4	unemployed
NCB-05-P	32	F	Married, 3 sons (7, 5, 18 mo)	9+6	Medical doctor, now housewife
NCB-06-P	35	F	Married, 2 sons	10	Works helping old people

Table 2: Patient sample background information

Patients	Born	Mother tongue	Religion	Ethnic group (self-defined)	Background info
CB-01-P	Canada	English	Jewish	Canadian, Jewish	
CB-02-P	Canada	English	Jewish	Jewish	Father immigrated from England
CB-03-P	Canada	English	Jewish	Jewish	
CB-04-P	Canada	English and Italian	Catholic	Italian Canadian	Both parents immigrated from Sicily
CB-05-P	Canada	English	Jewish	Jewish, English, 1st generation Canadian	English (1st generation)
CB-06-P	Canada	Spanish	Catholic (non-practicing)	-	Father from Argentina, mom of Spanish origin, born in Paraguay but moved young to Argentina, sister and brother born in Argentina, then family moved to Canada.
CB-07-P	Canada	English and French	Anglican	Scottish, English, Irish and German	Scottish, English, Irish and German ancestors
CB-08-P	Canada	English	Baptist	Irish, Scotch and Newfie	Ireland, Scotland, England and Newfoundland ancestors (adoptive and biological parents have same background)
CB-09-P	Canada	English	Jewish (non religious)	Canadian	Catholic husband
CB-10-P	Canada	French	Catholic (non-practicing)	Quebecoise	Lived most of her life in Sept-Iles
NCB-01-P	Peru	Spanish	Catholic	-	2 years in Canada (came as student)
NCB-02-P	Sri Lanka	Singhalese	Buddhist	Singhalese	4 years in Canada(came as refugee)
NCB-03-P	Bangladesh	Bengali	Muslim	Bengali	9 years in Canada(came as refugee)
NCB-04-P	Israel	Hebrew	Jewish (secular)	Israeli	9 years in Canada (came as student)
NCB-05-P	Afghanistan	Persian	Muslim	Afghan, Muslim	8 years in Canada (left because of war, was in Germany for a year and a half before Canada)
NCB-06-P	Ethiopia	Amaharic	Jewish	Canadian, Jewish	7 years in Canada (got pregnant while visiting in-laws in Canada, applied for immigration)

Table 3: Physician sample background information

Physicians	Ethnic group (self-defined)	Mother tongue	Religion	Background
CB-01-D	Persian	Persian	Muslim (non-practicing)	Born in Iran, studied in France and USA, came to Canada at age 23 for medical school
CB-02-D	Same as **CB-01-D**			
CB-03-D	Mutt (Protestant of Anglo-Irish descent)	English	Christian	Born in England, medical school in the US, residency in Canada
CB-04-D	Jewish	French /English	Jewish	Mother from Morocco, father Anglophone Canadian, Canadian born, all schools at McGill
CB-05-D	Ashkenazi Jew	English	Jewish	Canadian-born
CB-06-D	Caucasian, English Canadian	English	Christian	Canadian-born, did all her schooling and training in Canada
CB-07-D	Jewish	English	Jewish	Canadian-born, all schooling in Canada
CB-08-D	Chinese	English	None	Chinese origin, born in Canada, schooling in Ontario.
CB-09-D	Jewish	English	Jewish	Canadian-born, Bachelor's and Master's in Boston, rest of schooling in Canada
CB-10-D	Hindu	English	Hindu	Canadian-born, all of schooling and training in Canada (Montreal)
NCB-01-D	Montrealer	French	Christian	Canadian-born, father Egyptian, mother Syrian, grew-up in Montreal
NCB-02-D	?	English, but Hindi spoken at home	Hindu	Parents from India, born in Malaysia, came to Canada at age 4, lived in Kenya from age 10 to 13 (international schools), all medical training in Canada
NCB-03-D	Jewish & Canadian	English	Jewish	Born and raised in Canada, ancestors from all over Europe, one rotation in Israel.
NCB-04-D	Anglophone Jewish Montrealer	English	Jewish	Born and raised in Canada, schooling and medical training as well
NCB-05-D	Same as **CB-04-D**			
NCB-06-D	White anglo-saxon protestant	English	Anglican	Born in Canada, Welsh and English grandparents

Table 4: Example of the polysemy of physicians' explanations

Doctor's explanations	Excerpts
External trauma	D: Ok so she came to me ahm, right after she had a **car accident**, and it was a MINOR, she was like on the highway and there was like a minor rear-ender she said, she was just bumped (mhm). She came in a lot of pain, very, very stiff, and I diagnosed it as a **whiplash type injury**,
Medical diagnosis	and she continues to have exhaustion, severe, severe exhaustion anytime she did anything she would end up bedridden and at a certain
Psychiatric diagnosis **Psychological** **Psychosocial**	point, we entertained the issue of **depression**, and, and ahm .. (...)All the time I was very aware she's getting a lot of **secondary gain** out of this! (Mhm) Ahm because of her **difficult relationship with her husband** who's one of my former residents to put it in a, weird, a weird
Social **Emotional**	thing, and ahm **and her stresses of being a single mom**, and **her just unresolved anger** that she still has from **her divorce,** (...)
Medical diagnosis	At the very beginning I, I thought it was a it like a, a **whiplash injury** and indeed that's what we've been treated it like all the way along. Ahm I did worry that there was some **undiagnosed C-spine fracture**, and I think I investigated her. (...)
Psychiatric diagnosis	and then, ahm then we entered into the phase where we were treating it as a **chronic pain** with **depression,** sort of over ride, (...) D: **I think at this point it's unexpressed anger, and there, there's people she wants to punch in the head and she's just using a lot of muscle tension not to do it**
Psychological	(...) **She's very, very rigid, (mhm) in her thinking, and so she's become quite rigid in her neck as well.** So that's my, that's my analysis of this.. (Your explanation), that's my explanation.
Psychological	(...) **Ahm, I think she's quite lonely (mhm) .. ahm I think being in pain gives her a reason to lie in bed for the weekend ...** (mhm) especially the weekends when (name of son) is with his father (sigh) ...
Psychological/ secondary gain	**It means that she doesn't work as much as, as she, she could work if she was healthy 100 percent, .. which means she remains financially depend on (Name of husband), which maintains some kind of relationship with him.**
Secondary gain	(...)You know, **if she was ABLE, you know on that psychodynamic level which happens to be a little understanding of where she was, and if she was able to give it all up, if she fell in love, her pain would go away in 2 days! ...** M: Mhm, you think even now, after many years?
Psychological	D: Even now after many years. **I think if she really found that adoration that she had as a bride (mhm), she would blossom.** (mhm) .. You know, but it was kind of weird, it was a weird adoration that she had, if she was idealized and I don't think she was ever really seen as a, as a real person one way or the other. ... you know, so ... M: Hard fall from grace. D: Hard fall from grace, you know, going, **going from the queen of the universe to being the bitch whore of Babylon, it's not an easy thing** (mhm).

Table 5: Congruence of patients' and physicians' own explanations for the symptoms

Agreement:*	Yes	No	Partial
Chain complex	1 (1/0)	8 (5/3)	7 (4/3)
Prototype	0	14 (8/6)	2 (2/0)
Explanatory model	1	6 (3/3)	9 (7/2)
Outcome	2 (2/0)	9 (6/3)	5 (2/3)
Management	0	13 (8/5)	3 (2/1)

*Results are expressed in absolute totals followed by totals for each group (Canadian born/recent immigrants)

Table 6: Congruence between patients' and physicians' perspective of the other's model

Agreement:*	Yes	No	Partial
Physician's perspective of the patient's model	2 (1/1)	5 (2/3)	9 (7/2)
Patient's perspective of the physician's model	5 (3/2)	3 (1/2)	8 (6/2)

*Results are expressed in absolute totals followed by totals for each group (Canadian born/recent immigrants)

APPENDIX A: Patient Questionnaire

1. Tell me about your health problem (H.P.).
2. How did it start? What did you do?
3. What happened afterwards? What was done about your H.P.?
4. What was happening at that time in your life (when it started)?

5. Do you consider that your health problem is somehow connected or related to something in your life? To some events? In what way?

6. In the past, have you ever had a H.P. that you consider similar to your actual H.P.? What happened to you? How was it similar or different from your actual H.P.?
7. Do you know anyone else who had a H.P. similar to yours? What happened to that person? How do you consider your H.P. to be similar or different to his/hers?
8. Have you ever seen, read or heard on television, radio, in a magazine, or in a book of a person who had a H.P. like yours? What happened to him/her? How is your H.P. similar or different?

9. What do you call your condition in your own words? Do you have a label that describes it? (For instance if you are talking about your health problem with friends how do you call it?)
9.b) (if recent immigrant) In your country, how is this kind of health problem called? In your language?

10. What do you think caused your H.P.? What do you think is causing it now? Do you think there are other possible causes? Which one is the most important?
11. Why do you think your H.P. started at the precise time it did?
12. What happened inside your body that could explain your illness and the feelings that you experienced?
13. Did anything happen in your family, at work or in your social life that could explain your H.P.? In what way?

14. Did anyone else have an explanation for your H.P.?
15. Have your learned anything about your H.P. from the internet?
16. Have you learned anything from the television, the radio or the newspapers?
16.b) In your country is there a common explanation for your health problem?

17. What problems has the H.P. caused in your life?
18. How do you think your H.P. is going to evolve?
19. What do you think would help/should be done to help you?

20. What did the doctor say was the problem/diagnosis?
21. Did you tell the doctor about your explanation for your H.P.?
22. What kind of treatment did you expect? What did you receive?
23. How do you feel is the understanding/communication between you and your doctor? (If recent immigrant) Do you feel that the cultural difference with your doctor makes communication more difficult? In what way?
24. Did you go see another doctor? Or another healer?

24. Do you see your health problem any differently after this interview?
25. Is there anything you would like to add?
26. Do you have any questions?

General info:

Age, marital status, children, profession, number of school years, language, religion, ethnic group (self defined), Canadian-born/non-Canadian born, length of stay in Canada.

APPENDIX B: Physician questionnaire

1. Tell me about your patient's presenting complaint?

2. What other symptoms did he present or did you elicit? (probes) How did it start? When? What happened? What was done?

3. What diagnostic hypothesis or explanations did you consider? Which did you select? Why?

4. What is you treatment or management plan?

5. What do you believe the patient expects/wants?

6 How do you imagine the development of this problem?

7. How did/does the illness affect the patient's life?

8. How do you think the patient explained his illness before consulting you?

9. How did you explain his symptom to him/her?

10. What do you think the patient came away with? Did he accept your perspective?

11. Did you try and incorporate the patient's model in your explanations? How? Why not?

12. Do you think psychosocial factors may have played a role in this patient's presentation? To what extent? Did you share this with your patient? (clarify model and see if presented to patient)

13. How do you feel about this patient?

14. How do you find the understanding/communication between you and your patient?

(15. What would help? Do you believe there is anything that could improve these?)

16. Do you feel that cultural difference was a barrier with this patient? In what way?

17. What label do you use for this kind of situation with colleagues? With patients?

18. Do you ever use the term "medically unexplained symptom"? Do you find it helpful?

19. Is there a special reason for which you chose to identify this patient for my study?

General personal info:

Age, years of training, marital status, children, language, religion, ethnic group (self-defined), Canadian-born or other country of birth, time spent in Canada, place of medical school and postgraduate training.

APPENDIX C: Research compliance certificates