Illness Experience of Chinese Immigrants with Chronic Fatigue and Weakness

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
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ABSTRACT

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Chronic fatigue and weakness are common complaints afflicting patients seeking relief from physicians world-wide. People of Chinese decent comprise the largest visible minority and fastest growing language group in Canada (Statistics Canada, 1996). Traditional Chinese health beliefs and practices are vastly different from the biomedical model on which the Canadian health care system is based. **Purpose:** To clarify the illness experience of Chinese immigrants suffering from chronic fatigue and weakness and to determine its practical clinical significance. **Theoretical Framework:** Kleinman's (1980) Explanatory Model of Illness, Goffman (1963) and Kleinman and colleagues' (1995) theories on stigma. **Method:** Ethnographic study with a quantitative component. 50 Chinese patients referred by their family physicians were interviewed using the EMIC (Explanatory Model Interview Catalogue) a semistructured instrument, for studying illness experience (Weiss, 1997). **Results:** The impact of migration is a dominant theme in most patients’ narratives of their health problems. Patients reported multiple symptoms, predominantly somatic. Due to the “unknown nature” of their illness and the inability to live up to the Chinese ethos of hard work and family glory, participants felt stigmatized not just for themselves but for their families. Avoid disclosure was their preferred strategy for minimizing the pain of perceived stigma. Social and contextual issues, such as interpersonal conflict and underemployment were the most prominent perceived causes of their fatigue. Informants sought help from multiple sources for their illness, with the majority relying on self-help, family, and friends. Despite limited efficacy of treatment from Western physicians, participants were satisfied with doctors who were supportive and showed interest in their concerns. Practitioners of traditional Chinese
medicine were regarded as healers who could “get to the root” of their illness, but financial constraints deterred help-seeking from this group of caregivers. Conclusion: Findings of this study indicate the complexity of patients’ explanatory models of illness. The practical significance of illness experience and its impact on stigma, help-seeking, course and outcome should be studied further in the context of the Canadian multicultural mosaic. Clinicians need to pay attention to adjustment issues confronting immigrant patients who suffer from an ill-defined chronic illness, as well as other disorders.
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ILLNESS EXPERIENCE OF CHINESE IMMIGRANTS WITH
CHRONIC FATIGUE AND WEAKNESS

Chapter I

THE PROBLEM

Functional disorders of chronic fatigue (CF) and weakness, which are associated with the
diagnosis of chronic fatigue syndrome (CFS) and neurasthenia, cause tremendous suffering to
patients and their families. CFS is a persistent, often debilitating disorder of unknown cause
characterized by fatigue, pain and cognitive disorders. Neurasthenia, similarly, denotes a
constellation of symptoms including lassitude, poor concentration, headache and sleep
disturbance (Lee, S., 1998). While extensive information dealing with the illness experience of
patients suffering from CF has been gathered, relatively little is known about patients from
specific ethnocultural groups. Studies conducted rarely examine the cultural origins of their
subjects and non-English speaking patients are usually excluded from research protocols.
Culture, however, has a profound influence on people’s health belief system, illness management
and help-seeking behaviour (Kleinman, 1980). Frequently, the attitudes of ethnic minorities
towards illness are different from the values embodied in the health care system of the host
society; this situation can lead to ineffective treatment and dissatisfaction both on the part of the
clients and health care providers (Anderson, 1986; Chan, F., Lam, Wong, Leung, & Fang, 1988;
O’Neil, 1989; van der Stuyft, De Muynck, Schillemans, & Timmerman, 1989; Eisenbruch &
Handelman, 1990). According to Statistics Canada, the 1996 census reported that roughly 11.2%
of all Canadians and 15.8% of Ontarians consider themselves to be members of a visible
minority group. In the Greater Toronto Area, where this study was conducted, visible minorities
account for about 31.6% of the population of 4.2 million. The Chinese population has a 150 year
presence and history in Canada, including the most recent influx of immigrants which contribute to make the Chinese the largest visible minority group in Canada and Toronto (Statistics Canada, 1996). Furthermore, the Chinese are known to have a health belief system and a value system that are distinct from that of the larger Canadian society.

"If you wish to help a community improve its health, you must learn to think like the people of that community" (Paul, 1955, p. 1). The goal of this study is to present to health care workers a clinical ethnography of Chinese immigrants who suffer from CF and weakness. This study will provide a better understanding of the illness experience of this group of patients, and more specifically will aid health care workers in (1) gaining a better appreciation of how Chinese patients cope with an illness that is not well defined and (2) improving their ability in the promotion of culturally sensitive and appropriate care for patients from the culturally diverse Canadian mosaic.

This is an ethnographic study with a quantitative component. Its primary focus is on how culture shapes the illness experiences of the Chinese immigrants. However, it is imperative to understand how their experiences intersect with their status as an ethnic minority and the Canadian (Western) health care system which may be vastly different from the one they are familiar with. To that end, background information and a literature review on medically unexplained CF and CFS, traditional Chinese philosophy, and, health beliefs in relation to CF are presented. Kleinman’s (1980) Explanatory Model of Illness, which was developed through extensive research with the Chinese population in China and Taiwan, is the theoretical framework used to guide this study. Profound stigma has been imposed by the Chinese population on illnesses with poorly understood etiology and is the current issue with CF and weakness. Therefore, the conceptualizations of stigma by Goffman (1963), and by Kleinman and co-workers (1995) were employed to complement Kleinman’s (1980) Explanatory Model of
Illness. Data were collected by means of a cultural epidemiological instrument for use in clinical or field setting - the Explanatory Model Interview Catalogue (EMIC) - a semi-structured interview schedule developed with reference to Kleinman’s (1980) Explanatory Model of Illness (Weiss, 1997). A Chinese immigrant sample was selected, so that an ethnic minority perspective could be elicited. Both qualitative and quantitative data analysis methods were used to help interpret the rich data set generated through the EMIC.

This thesis consists of seven chapters. This first chapter presents the problem and objectives of this study. The second chapter describes the background of the topics pertinent to the study, namely, CF and CFS and cultural factors pertaining to the Chinese population and stigma. The third chapter presents the theoretical framework and a review of the literature of the study. The fourth chapter outlines the methodology of this study. The fifth chapter presents the results of the study with reference to the research questions and objectives of the study. The sixth chapter discusses research findings in relation to other research as well as Chinese culture and philosophy. A discussion of methodological issues is also included. The concluding chapter discusses the implications of the results and provides recommendations.
Chapter II

BACKGROUND AND SIGNIFICANCE

This chapter presents the background and significance of the study and is divided into six major sections. The first two sections provide the historic and current overviews of CF and CFS. In the third section, the relationship between CF and neurasthenia is described. The fourth and the fifth sections address cultural factors and the impact of migration on patients. In the last section, the traditional Chinese concepts of health and illness are explored. Finally, the objectives of this study are outlined.

Historic Overview of Chronic Fatigue and Chronic Fatigue Syndrome

Historically, medically unexplained CF and its related symptoms have been called neurasthenia, neuromyasthenia, myalgic encephalomyelitis, atypical poliomyelitis, post-viral syndrome, chronic mononucleosis-like syndrome, chronic Epstein-Barr virus syndrome, Icelandic disease, Royal Free Epidemic and the 'yuppie flu' (Abbey & Garfinkel, 1991; Time Magazine, 1987; Wessely, 1990). Reports of CF date back to 1869 when an American neurologist, George Beard, reported the first cases which he labelled neurasthenia in the Boston Medical and Surgical Journal (Yan, H., 1989).

Conceptual and Methodological Issues

CFS has been attributed to a variety of causes including chronic brucellosis, chronic candidiasis, and allergies. Although some immunological abnormalities are detectable in a minority of patients suffering from fatigue, the significance of this is uncertain, as the immune abnormalities do not exist in all patients or correlate with the patients’ clinical status (Lindh, Samuelson, Hedlund, Evengard, Lindquist, & Ehrnst, 1996; Salit, Abbey, Moldofsky, Ichise, & Garfinkel, 1991). Surveys of fatigue among ambulatory care patients suggested that the Epstein-
Barr virus is only rarely responsible for CFS; other studies reported that almost 90% of the healthy adult population have circulating Epstein-Barr virus, and that not all patients meeting the criteria of CFS have a history of elevated Epstein-Barr virus level (Buchwald, Sullivan, & Komaroff, 1987; Kroenke, Wood, Mangelsdorff, Meier, & Powell, 1988; Straus, 1991). Laboratory tests are of limited usefulness in the diagnosis of the syndrome (Buchwald, Wener, Pearlman, & Kith, 1997b; Komaroff, 1993; Kroenke et al., 1988). A prospective cohort study in primary care of 1,199 patients with symptomatic infections showed no evidence that common infective episodes are related to the onset of CF or CFS (Wessely, Chalder, Hirsch, Pawilkowska, Wallace, & Wright, 1995).

In order to improve the comparability and reproducibility of research and to provide a rational basis for evaluating patients with medically undetermined CF, the United States Centers for Disease Control (CDC) developed a working case definition for this complex of symptoms which they termed Chronic Fatigue Syndrome (CFS). Under this definition, patients suffering from CFS experience severe, persistent, and unexplained fatigue in combination with other complaints, such as muscle and joint pain, headache, sore throat, fever, weakness, dizziness, concentration difficulties and memory loss. This definition describes the signs and symptoms of the syndrome, and excludes any chronic or active physical or psychiatric illnesses that can produce chronic fatigue (Holmes, Kaplan, Gantz, Komaroff, Schonberger, Straus, Jones, Dubois, & Brus, 1988). Psychiatric conditions, such as major depression, panic disorder and somatization have been found to be common in patients suffering from CFS, at a frequency five times greater than in the general population (Manu, Lane, & Matthews, 1993; Schulberg, Saul, & McClelland, 1985).

To date, the pathogenesis of CFS remains unclear. Different diagnostic criteria also produce different prevalence rates, further complicating the task of identifying the issues. Some
researchers have argued that different conditions, rather than a defined disease entity, are being grouped together under the label of CFS (Holmes, 1991; Sharpe, Archard, Banatvala, Borysiewicz, Clare, et al., 1991). Despite extensive research there is no definitive diagnostic test or effective treatment for this syndrome (Wessely et al., 1995); interventions are only directed at the relief of specific symptoms and maintenance of the patient's level of functioning (Buchwald, 1996).

**Definition of Chronic Fatigue and Chronic Fatigue Syndrome**

The complexities associated with the diagnosis and study of CFS prove the need for a comprehensive and systematic evaluation of the problem. The International Chronic Fatigue Syndrome Study Group proposed guidelines for the clinical evaluation and study of CFS and other illnesses associated with unexplained CF (Fukuda, Straus, Hickie, Sharpe, Dobbins, Komaroff, & the International Chronic Fatigue Syndrome Study Group, 1994). These guidelines provide specific parameters to allow differentiation of CFS from other fatigue-related illnesses, as well as an integrated approach to the study of “persons with this condition and other fatiguing illnesses” (p.953). Psychiatric disorders, such as anxiety disorders and less severe forms of depression, were recognized as being highly prevalent in patients with CFS and, therefore, were not used as a basis for exclusion (Appendix A, p.237).

Medically unexplained CF is defined as “self-reported, persistent or relapsing fatigue lasting six or more consecutive months” (Fukuda et al., 1994, p.954) and its sufferer is not a patient of any active or chronic medical or psychological illness including substance abuse. CFS, as a subset of unexplained CF, is defined as “clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset” (p.956). It is not the result of ongoing exertion nor can it be relieved by rest, and it renders the sufferer with a substantial decrease in the level of functioning. Four or more of the following symptoms persist over a 6-month period as
constituting the clinical profile of CFS: muscle and joint pain, headache, sore throat, fever, weakness, dizziness, concentration difficulties, and memory loss, (Fukuda et al., 1994). The present study incorporated these guidelines in formulating the criteria for the selection of its subjects, including both CF and CFS patients.

**Prevalence of Chronic Fatigue and Chronic Fatigue Syndrome**

Fatigue is the chief complaint of at least 5% of patients in primary care and is responsible for over 10 million visits to physicians every year in the United States (The National Ambulatory Medical Care Survey, 1978). Studies have estimated the prevalence of fatigue in general medical practice to be 21% to 47% (Buchwald et al., 1987; Jerrit, 1981; Kroenke et al., 1988; Sugarman & Berg, 1984).

In a survey of a community sample of 13,538 people, 23% reported having experienced the symptom of persistent fatigue sometime during their lives; for 59% of this group, fatigue was unexplained by medical causes (Price, North, Wessely, & Fraser, 1992). Another survey, sampling 18,571, found a lifetime prevalence of fatigue of 24.4% in the general population with medically unexplained CF (Walker, Katon, & Jemelka, 1993). A survey of a random sample of 4,000 members of a US health maintenance organization reported the prevalence of CF as ranging from 1,775 to 6,321 cases per 100,000 (Buchwald, Umali, P., Umali, J., Kith, Pearlman, & Komaroff, 1995).

Researchers have also found that women have a risk ratio that is 1.5 times greater than men, and that only one out of every 400 episodes of fatigue or tiredness experienced by young women is brought to the attention of a physician (Banks, Beresford, Morrell, Walker, & Watkins, 1975;
Chen, M., 1986). This suggests that the symptom of fatigue may be much more prevalent than is reflected in studies of general practice.

While medically unexplained CF is relatively common in primary care, debilitating cases of CFS, as defined by the CDC criteria, have been found to be quite rare both in the general public and in medical outpatients. However, criteria from American, British and Australian case definitions all generate different prevalence rates (3 to 10 per 1,000) of the syndrome (Bates, Schmitt, Buchwald, Ware, Lee, Thoyer, Kornish, & Komaroff, 1993; Gunn, Connell, & Randall, 1993; Price et al., 1992). An estimated crude point prevalence of CFS ranging from 75 to 267 cases per 100,000 has also been reported (Buchwald et al., 1995). About 30,000 Canadians are said to suffer from the illness (Bouw, 1998).

**Social and Financial Impact**

Although there is little agreement on the prevalence of CF and CFS, the social and financial impact from both are significant. Patients with fatigue have a significantly higher utilization of health care services than patients without current episodes of fatigue (Walker et al., 1993). This contributes to a serious strain on scarce health care resources. Annual charges for ambulatory medical care averaged US$356 for patients who are suffering from fatigue compared to US$126 for patients who are not suffering from fatigue, with hospital admissions twice as common for fatigue patients. More than US$300 million in annual medical care costs were incurred by patients suffering from fatigue in the United States (Morrison, 1980; Nelson, Kirk, McHugo, Douglass, Ohler, Wasson, & Zubkoff, 1987; Valdini, Steinhardt, Valicenti, & Jaffe, 1988). A British study also reported an overall prevalence of fatigue of 1.3 per 1,000 patients, with almost half requiring significant or excessive amounts of time from their general practitioners (Ho-Yen & McNamara, 1991).
In the US, the mean number of health care visits per year has been reported to be 21 for CFS patients, 38% of whom are disabled by their illness (Buchwald & Garrity, 1994). An Australian study was conducted to estimate the economic impact of CFS on the individual, the government, and the community. It was found that, with a prevalence of 37.1 cases per 100,000 people of a total general population of 16,956,800, that CFS generated an annual cost of at least $59 million Australian (Lloyd & Pender, 1992).

The prognosis for CF and CFS patients has not been encouraging, with only 3% of the patients reporting complete recovery, and 17% to 35% reporting improvement (Clark, Katon, Russo, Kith, Sintay, & Buchwald, 1995; Vercoulen, Swanink, Fennis, Galama, van der Meer, & Bleijenbery, 1996). Buchwald and co-workers (1996) reported that patients with CF and CFS have marked impairment in functional status. They tended to be severely disabled, particularly in role functioning, social functioning and vitality.

In a case controlled study comparing two groups of 64 primary care patients with and without CF, Cope and co-workers (1996) reported that CF patients experienced significantly more physical and psychological distress than their “without CF” counterparts. Almost 86% claimed that fatigue interfered with their social activities, 75% with their work performance, and 67.2% said that they had stopped one or more activities because of fatigue.

Disruptions in employment were reported by Yeomans and Conway (1991). Only 13% of their sample were able to maintain full-time employment, and 47% had become unemployed because of CFS. A 10-year follow-up of 23 patients in Australia found that 7 patients still suffered from the illness. Although 16 of them were able to return to a premorbid level of activity, all of them suffered a length of disability, from one to eight years (Levine, Snow, Ranum, Paul, & Holmes, 1997). The social and financial impact due to human suffering and loss in productivity are yet to be calculated.
Neurasthenia

CFS has been suggested by some to be "an old wine in a new bottle," that it is actually neurasthenia renamed for the 1980's (Abbey & Garfinkel, 1991; Greenberg, 1990; McSherry, 1993; Wessley, 1990). A British study reported that the World Health Organization's International Classification of Diseases, Tenth Edition's (ICD-10) definition of neurasthenia identifies almost all (97%) of their subjects with the CDC's definition of CFS (Farmer, Jones, Hillier, Llewelyn, Borysiewicz, & Smith, 1995). However, neurasthenia is not recognized by the American Psychiatric Association as a diagnosis. In 1979 it was excluded from the publication of the American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III). Neurasthenia remains listed in the ICD-10 (World Health Organization, 1992), and is widely used in many Asian countries (Altshuler, Xida, Haiging, et al., 1988; Chang, 1987; Cheung, F., 1989; Lin, T., 1989; Yan, H., 1989).

Despite its Western roots, neurasthenia is a diagnosis well accepted by physicians, patients and the general public in China, Hong Kong, and Taiwan (Cheung, F., 1989; Lin, T., 1989; Rin & Huang, 1989; Zhang, M., 1989, Zhong, 1992). Rin and Huang (1989) reported that even practitioners of traditional Chinese medicine have adopted this term and use it frequently. Neurasthenia is conceived in traditional Chinese medicine as a decrease in vital energy (qi) caused by harmful factors in the physical and social environment, as well as by the patient's bodily constitution. These factors affect the functioning of the five internal organ systems which, in turn, cause a deficiency of qi, and lower bodily resistance (Chinese-English Terminology of Traditional Chinese Medicine, 1983 cited in Kleinman, 1986). Furthermore, neurasthenia is often described in conjunction with the concept of shen kuei (kidney weakness), which is characterized by weakness, fatigue, insomnia, anxiety and hypochondria (Lin, T., 1985).
Cheung (1989) noted that in the popular books on neurasthenia in Hong Kong, weakness, fatigue, insufficiency of qi or blood, poor appetite, backache and weak limbs, difficulties in thinking and memory, were all cited as major symptoms of neurasthenia. The recommended treatment was tonics indicated for symptoms of "weakness." Treatment modalities with resemblance to treatments for neurasthenia in the George Beard era (1869) aimed at restoring depleted nerve force and bolstering the body’s natural healing processes, including rest, special diets, and medicine that would stimulate the body and rid it of toxic substances (Stea & Fried, 1993). Chinese newspapers in Canada abound with health columns that discuss etiologies and treatments for neurasthenia (Lau, 1996). "Stasis of liver qi" and the stress associated with being a new immigrant are often cited as causes of neurasthenia (Tam, 1995).

The concept of neurasthenia shares similar features with the concepts of vitalism (qi) and weakness (xu) in traditional Chinese medicine. The Chinese term, shen-jing shuai-ruo (shen-jing means neurological and shuai-ruo means weakness), conveys the same vague idea of organic pathology that the term neurasthenia connotes in English. The patient would suffer from non-specific signs and symptoms associated with the weakness of the neurological system, resulting in a general weakness in the body (Kleinman & Mendelsohn, 1978; Lee, S., 1998). A longitudinal community study, conducted in Switzerland of fifty-one 20-year-old neurasthencic patients, reported that over a 10-year-period half of them continued to exhibit the disorder at an averaged duration of 4 years (Merikangan & Angst, 1994).

As expressed in the Chinese language, symptoms associated with neurasthenia resemble many ailments in traditional Chinese medicine. For example, the main symptoms of neurasthenia - fatigue and weakness - share the same clinical features of xu (deficiency or weakness) in traditional Chinese medicine; other symptoms, such as insomnia, poor concentration and poor memory correspond to the main symptoms of shen kuei (kidney weakness) in traditional Chinese
medicine (Zhang, M., 1989). In fact, it has also been argued that neurasthenia has remained a popular diagnosis in the Chinese community because of the non-stigmatizing nature of the term. It carries the connotation of weakness due to overwork, thus allowing the patient and his or her family to be free of psychiatric labels that suggest insanity. Chinese practitioners may tend to imply that neurasthenia and CF have a benign prognosis, and in a clinical setting this framework may improve the rapport between practitioners and patients and enhance the effectiveness of therapeutic relationships (Cheung, F. & Lau, 1982; Rin & Huang 1989; Zhang, M., 1989). Therefore, in Chinese culture, patients with CF and weakness may experience less stigma than their Western counterparts (Yeh, 1992). A study of neurasthenic patients in China reports that, like most patients in non-Western cultures, Chinese patients tend to have a somatic orientation for their illness when psychological complaints are stigmatized (Kleinman, 1982). As a result, treatments targeting somatic symptoms are usually sought by Chinese patients who suffer from neurasthenia (Lin, T., 1989). Thus, it is important to explore perceived stigma and how it exerts its effects on patients’ help-seeking behaviours.

Cultural Factors

Culture influences the way patients view health, health care and how they present, explain and deal with their illnesses (Harwood, 1981; Kleinman, Eisenberg, & Good, 1978; Pachter, 1987). Cultural health beliefs may be so powerful as to influence mortality rates. Phillips and co-workers (1993) reviewed death certificates of 28,169 Chinese and 412,632 White Americans and found that the Chinese group died 1.3 to 4.9 years earlier than their American counterparts if they had a combination of disease and birth year which Chinese astrology and medicine consider ill-fated. The number of lives lost is directly proportional to how strongly the group is attached to Chinese traditions. Chinese astrology and medicine consider a person’s fate is influenced by year of birth
which is associated with one of the following five phases: metal (years ending in 0 or 1), water (years ending in 2 or 3), wood (years ending in 4 or 5), fire (years ending in 6 or 7), and earth (years ending in 8 or 9). It is believed that a person born in a particular year is more affected than others by the element associated with that year. Since the astrology predictions hold most strongly for the most traditional Chinese, these researchers concluded that their findings result at least partly from psychosomatic processes.

Health care outcomes, such as compliance and satisfaction with care, are directly related to how closely patients’ perceptions of their health problem resemble those of their caregivers’ (Kleinman, 1980). Caregivers’ lack of cultural sensitivity or racial bias in treatment recommendations may compromise the quality of care and possibly lead to misdiagnosis in ethnic minority patients (Lewis-Fernandez & Kleinman, 1995).

A difference in the prevalence of fatigue among cultural groups was found by Cathebras and co-workers (1992); these researchers reported a higher rate of fatigue among French-Canadians compared to their English speaking counterparts. A community epidemiologic survey of 1,747 Chinese Americans in California showed a 12-month prevalence rate of neurasthenia at 3.66% (Zheng, Lin, Takeuchi, Kurasaki, Wang, & Cheung, 1997). Lee, S. and co-workers (2000) in their study of 100 primary care patients with chronic fatigue in Hong Kong reported a CFS prevalence rate of 3%. However, most of the research subjects in CF and CFS studies are White, and prevalence rates are found to be higher for the White population than for the non-Whites (Buchwald, Pearlman, Kith, Katon, & Schmaling, 1997a; Gunn et al., 1993; Komaroff, 1993; Kroenke et al., 1988; Lutgendorf, Klimas, Antoni, Brickman, & Fletcher, 1995; Mawle, Nisenbaum, Dobbins, Gary, Stewart, Reyes, Steele, Schmid, & Reeves, 1997; Ware, 1993). It is not certain whether this difference is a reflection of an actual racial difference in prevalence, an under-representation of non-Whites in the selected sample, or differing health care utilization
patterns of non-Whites compared to Whites. Buchwald and co-workers (1995) conducted a survey on the prevalence of CF and found that over 10% of the patients were unable to participate because they did not speak English.

Impact of Migration

“Immigration represents an interruption and frustration of natural life expectancies, with all the related anxieties and potential damage to self-concept” (Suh, 1980, p. 207). Research conducted over the past six decades indicates that migration and the resulting confrontation with an unfamiliar culture are stressful life events that can affect a migrant’s psychological well-being (Mirdal, 1984). The ethnic configuration of Canada has diversified over recent years as a result of immigration. Statistics Canada (1996) indicated that this country is now home to over 100 different cultural groups. Although Eastern and Northern Europe was the main source of immigration during the post World War II era, forty-eight percent of Canada’s immigrants today are of Asian origin. Adjusting to a society with a vastly different value system than one’s own and the difficulty of learning English for a tonal language speaker, may pose tremendous stress on immigrants from Asian countries (Nicassio, Solomon, Guest, & McCullough, 1986). The greater dissimilarity between culture of origin and culture of destination, the greater the difficulty for the newcomer in adjusting to his/her new environment. Values embedded in the host country’s social and governmental agencies, such as the health care system, may lead to confusion and ambiguity for some immigrants from cultures that are very different from their host country (Westermeyer, 1989).

The worry of an uncertain future due to the transfer of Hong Kong to Communist China has fuelled waves of migration from Hong Kong in the past decade (Holroyd & Mackenzie, 1995). Avoiding political uncertainty in their place of origin, obtaining a better quality of life, and
attaining better educational opportunities and upward social mobility for their children, have been cited as main reasons for migration by Chinese immigrants (Wong, L. & Ng, 1998). Canada is, by far, the most desirable destination for these immigrants. According to the 1996 census (Statistics Canada, 1996), Chinese is the third most-common language spoken in Canada after English and French. Over 40% of the Chinese in Canada reside in Toronto and the Greater Toronto Area.

The Chinese have been immigrating to Canada since 1858 and the pattern of migration has largely been shaped by the political, social and economic conditions of both countries (Li, P., 1992). Unlike the immigrants of the 19th century, who were mainly railway workers from rural China, Chinese immigrants today are mainly from Hong Kong, China, Taiwan and Vietnam and include people from all walks of life - from the highly professional to manual labourers (Statistics Canada, 1996). Because of the current economic hardships and the fact that their overseas credentials are often not recognized in Canada, many bread-winners feel obligated to retain their employment in their countries of origin, while their families stay in Canada in order to fulfill the requirements for Canadian citizenship (Kendall, 1989). Results from the pilot study of this research indicated that subjects' immigration experience affected the way they perceived and coped with their illness. The impact of migration on these “single” or “astronaut” families in a foreign land is yet to be assessed. This study was cognizant of the issues related to the immigration experience of the subjects, as they were all first generation immigrants.

**Traditional Chinese Concepts of Health and Illness**

In Western medicine, the primary explanatory model of illness focuses on abnormalities in the structure and function of body organs and systems. As one of the oldest civilizations in the world, the Chinese civilization has a deeply rooted philosophical, value and health belief system
that is vastly different from the West (Kleinman, 1980). Thus, Chinese patients who suffer from CF and weakness may have very different perceptions and illness experiences compared to their Western counterparts who are familiar with the Western biomedical illness model. A brief overview of Chinese philosophical and religious teachings, history and the development of traditional Chinese medicine, its theoretical concepts, especially those focusing on fatigue and weakness, is presented below. This background information can provide an explanation for the responses and help-seeking behaviours of Chinese patients with CF and their families.

**Chinese Philosophical and Religious Teachings**

Confucianism, Taoism and Buddhism are the three major philosophical and religious teachings that have guided Chinese moral and ethical considerations for centuries. The impact of these beliefs on the Chinese people can still be felt in various Chinese communities around the world. To a great extent, these three major philosophies overlap and most Chinese have internalized these teachings during the course of their upbringing. Traditional Chinese medicine is based on the principles of Taoism, and therefore sets the framework for Chinese patients' perceptions of their symptoms, the causes of these symptoms and directions of their help-seeking behaviour. Confucianism has had the greatest impact on Chinese society and has influenced the practice of medicine for the past two thousand years. Brief descriptions of each philosophy lay the foundation for a discussion of Chinese medical history and help to put into perspective the illness experience of the Chinese immigrants studied here.

**Confucianism**

Confucianism is concerned with the proper way of conducting a person's social life. Since the First Han Dynasty (200 BC), the Chinese emperors respected only Confucianism and rejected
all other schools of philosophy. Thus, Confucianism became the dominant ideology informing the minds of Chinese people, structuring their society, and becoming a vital component of the Chinese culture (Qui, 1988). Through theoretical and structural imperatives to develop a relation-oriented self, that is not only, "socially responsive and dependent but also capable of asserting a self-directed role in constructing a social world" (p. 30), Confucian values exerted the most pervasive influence in the shaping of Chinese character and behaviour (King & Bond, 1985).

Confucianism sets the rules and regulations for social interaction, stressing reciprocity and loyalty, benevolence and righteousness, self-respect, self-reliance, self-control, and face-saving. Reciprocity means that one treats others as one would like to be treated. Loyalty is the unquestioning allegiance and total subordination to one's superiors and elders. Reciprocity and loyalty are the foundations on which is built the authoritarianism, filial piety and the closely-knit family structure of the Chinese. Benevolence is an awareness of others: one should treat others in a kind-hearted manner. To act righteously requires one to do what is appropriate according to benevolence. In the building of character, the exertion of restraint over emotions and an avoidance of extremes demonstrate self-respect and self-reliance. Face-saving, keeping an honourable family name, is a behavioural duty expected by both the family and community (Yang, C., 1967).

In the Confucian tradition, people exist in relationship to others. In such a family oriented state, where the central unit of society is the family not the individual, authority is autocratic and hierarchical. Confucius stresses five cardinal relationships (those between sovereign and subject, father and son, elder brother and younger brother, husband and wife, and friend and friend) and defines rules of correct behaviour in terms of rights and responsibilities within each relationship (Analects, 1938). Paternalism demands that a woman be obedient to her father when single, to her husband after marriage, and to her son in old age (Song, 1985).
Three of the five cardinal relationships pertain to the family with parents having the highest authority (Bond & Hwang, 1993). The principle of filial piety states: “The body with its hair and skin is received from parents; do not cause it harm” (Hsiao Ching, 1908, p.16). One is indebted to one’s parents for one’s being and is responsible to the well-being of one’s body. Status and authority in the Chinese family are not only based on filial piety, but also on age and the principle of kinship proximity. Family members are arranged into a hierarchic order by age, both, according to generation and chronological age (King & Bond, 1985). Familial hierarchy determines responsibilities and obligations to others in the family.

Confucian philosophy strongly advocates the virtue of sacrificing individual needs for the good of the group (Bond & Hwang, 1993). Self-cultivation and self-discipline are the pillars of social identity and moral behaviour. The keys to survival, peace and happiness are harmony, interdependence and loyalty to family (Xingwu, 1991). Because the family rather than the individual is the basic unit of society, the individual’s actions are not his own and are, in fact, considered to be representative of the family, past, present and future. It is a serious criticism to be told, “There is a lack of virtue in your past eight generations of ancestors” (Hsu, J., 1985). Thus, honour or stigma is not an individual but rather a family matter.

Face (lien in Chinese) is an important Confucian teaching that has a profound impact on the daily life of the Chinese people. Hu (1944) defined face in the Chinese culture as “the confidence of society in the integrity of ego’s moral character, the loss of which makes it impossible for him to function properly within the community. Lien is both a social sanction for enforcing moral standards and an internalized sanction” (p. 45) [cited in Ho, D., 1976]. Although the concept of face has long been recognized as a human universal by prominent scholars such as Goffman (1955) and Ho (1976), the degree of concern is much higher for the Chinese than other cultures (Redding & Wong, 1993). “A man needs a face like a tree needs bark” is still a common saying
today and illustrates its importance. In contrast to the Western concept of face, which is oriented towards the individual, the Chinese concept of face is more concerned with the family (King & Bond, 1985). Children are taught at a young age that, “Family shame should not spread outside,” and the father is responsible for any face-losing incurred by his children because “(Children being) fed but not taught (discipline) is the fault of the father.”

Over time, Confucius’ rigidly defined behavioural codes of social relationship were reinforced through tradition and custom and the Chinese people became enmeshed in the Confucian doctrines. More than ever, after over two thousand years, Confucian philosophy continues to be a potent force in shaping Chinese social behaviour. Chinese values and norms contrast sharply with the North American culture which value competitiveness, independence and change (Arensberg & Niehoff, 1975; Song, 1985). These differences may render the Chinese immigrant at odds with the Canadian value system.

**Taoism**

*Tao* is the truth, the way of nature. *Tao* manifests itself in the change of night to day, the recurrence of seasons and the decay and growth that governs the universe. Taoism advocates the adherence to the way of nature in order to achieve harmony with the universe or macrocosm. “The principle of *Yin* and *Yang* is the basis of the universe…. Heaven was created by an accumulation of *Yang*; the Earth was created by an accumulation of *Yin*” (Veith, 1967, p. 15). *Yin* is the feminine quality - cold, shady, passive and *Yang* is masculine - hot, bright and active. These two opposite, yet complementary, forces grow from and with each other. Everything in the universe is believed to originate from them. The movement of the *Yin* and *Yang* forces forms the vital energy - 'qi' - in the universe. *Qi* (vital energy) is the foundation of life and the motivating force for all organs to function properly, and it can be classified into *Yin* and *Yang* with the
former having a conservation and maintenance function and the later a defence and protective function (Zhang, E., 1990). Man, who is part of the universe, a microcosm, is also governed by nature's two opposing forces and owes his life and health to the harmony and balance of natural forces. Following Tao and achieving harmony with Yin and Yang, man can attain good health and long life (Zhang, E., 1991).

Taoism promotes non-action, detachment from the world and a harmonious personal life in relation to cosmological, natural and social environments (Lin, K. M., 1981). Taoist views of nature emphasize cyclical changes; for example, the cycle of birth and death and belief in spirits. Taoism advocates the search for the optimal way for an individual to live a harmonious personal life in relation to cosmological and natural spheres (Hsu, T. S., 1934).

Taoist teaching provided the fundamental principles of traditional Chinese medicine. Illnesses are explained in terms of the balance of the Yin and Yang forces. Fatigue and weakness are symptoms resembling illnesses that resulted from a deficiency of the Yang force. Due to the mode of diagnosis being benign or relatively social connotation free, patients may readily accept an explanation of their illness in Taoist terms to avoid being stigmatized as lazy (resulting from not able to work) or mentally ill (resulting from lack of an organic medical diagnosis).

**Buddhism**

Buddhism, a religion originating in India, stresses the temporary nature and emptiness of life. Reincarnation and the cause and effect of one's deeds are core beliefs. It is vital to accumulate good deeds in order to reach a higher state of being in the next life (Chen-Louie, 1983). Suffering is considered to be the direct effect of bad deed(s) committed either in one's past, or in a previous life or lives. Bad deeds committed by one's ancestors may also be the cause
of suffering. Unless this (or these) bad deed(s) are being “worked cut” by doing good deeds during one's own lifetime, the suffering is likely to continue in the next life (Qui, 1991).

Suffering from a medically unexplained illness such as CF could be perceived by others as a punishment of bad deeds committed by oneself or one’s ancestors, thus rendering upon the individual and their family the stigma of moral corruption. Both individual and family efforts in working out bad deeds and performing good deeds, including offerings in Buddhist temples to enlist help of a greater power to overcome karma, may be considered as appropriate ways in restoring one’s health.

**History of Traditional Chinese Medicine**

The history of traditional Chinese medicine is an integral part of China’s five-thousand-year-old documented history. Like Chinese culture, it has constantly been influenced by religious, philosophical, environmental, and political changes over the centuries. Chinese history recorded that a great farmer by the name of Shen Ning (literally translated into the God of agriculture) tasted different herbs in 2698 BC and this is believed to be the beginning of traditional Chinese medicine. He taught the people about the art of healing, and personally tested the properties of up to 70 medicinal herbs daily. Based on this self-experimentation and then tests on his patients, he wrote prescriptions to treat illnesses. In his old age, he composed *Pen-Tsao Ching* (Book of Herbs) in four volumes to keep a record of the herbal prescriptions for various illnesses (Wang & Wu, 1973).

The Chou dynasty, 722 BC, is one of the most glorious periods in Chinese history. Literature, art, religion, philosophy, government and all the necessary elements for civilisation flourished and reached a high degree of development. This period is called the Age of Philosophy in Chinese history. The study of medicine at that time was dominated by the
scholastic subtleties of visionary philosophers: Lao Tzu - founder of Taoism, Confucius - founder of Confucianism, and many others. Various speculations on the theory and causation of diseases were proposed, but the principle of *Yin* and *Yang* based on Taoism and its theory of cosmogony was by far the most influential in Chinese medical history (Morse, 1978).

The principle of *Yin* and *Yang*, which formed the foundation of the theoretical and therapeutic practices of traditional Chinese medicine, was well illustrated in one of the oldest works of Chinese medical literature - *The Yellow Emperor's Classic of Internal Medicine* (Veith, 1967). Even today this work dominates the thinking of traditional Chinese medicine practitioners and lay people (Wu, 1982). The Yellow Emperor (2696-2598 BC) was one of China's most famous legendary rulers. *The Yellow Emperor's Classic*, which consists of 18 volumes, is estimated to have been written around 3 BC by several prominent physicians over a long period of time, and was antedated to the time of the Yellow Emperor to enhance its value (Veith, 1967; Chan, S., 1981).

Due to Confucian teaching in the *Filial Classic*, that the body is a sacred inheritance from one's parents and therefore not to be mutilated in any way, dissection of the human body was seldom practised by ancient Chinese physicians (Veith, 1967; Wang & Wu, 1973). Ancient drawings of human anatomy were usually a by-product of acts of cruelty and curiosity of an emperor's misrule, especially during the Shen Dynasty (1800-1122 BC) and the Later Han Dynasty (206 BC- AD 100).

During the First Han Dynasty (2nd Century, BC), Confucianism was established as the political orthodoxy of the Chinese state. Thus, medical writings were entirely philosophical (Porket, 1976). Chang Chung-Ching (AD 196-220), later known as the Hippocrates of China, inaugurated a new era in Chinese medicine. Diseases were studied more from a clinical standpoint, with emphasis being laid on the physical signs, symptoms and course of an illness,
the methods of treatment, and the action of drugs. Chang Chung-Ching was the author of ten medical books with topics ranging from typhoid fever remedies to prescriptions for women's diseases. Ingredients of traditional Chinese medicine include not only herbs but also insects, animal parts, and even stones (Sivin, 1987). Around the same period as Chang Chung-Ching, another physician, Hua T'o (circa 190), was well known as a very skilful surgeon. He discovered the use of anaesthetics through acupuncture by first trying them on himself, then on his family. Even today, he is often worshipped as the God of Surgery; “An alive again Hua T'o” is a compliment Chinese would bestow on a brilliant physician.

The practice of traditional Chinese medicine has continued to the present day, without major changes, since the writing of the Yellow Emperor’s Classic of Internal Medicine, and the death of Chang Chung-Ching and Hua T'o. The standard methods of diagnosis relied solely on observation, auscultation (with the physician’s senses only, rather than the use of any instrument), interrogation, and palpation. Treatments were primarily herbs used internally or externally, acupuncture and massage (Liu, 1974; Unschuld, 1985; Veith, 1967). This lack of progress in Chinese medicine over a period of more than 2,000 years is largely the result of the veneration of age and tradition, embodied in Confucian teaching. Anything old and traditional was respected and anything new was never considered better than the old (Pak, 1977). Physicians looked backwards, drawing on their basic texts for knowledge and allowed knowledge to accumulate through their experience treating patients. They relied on time-tested medicine, rather than trying to accelerate this process through artificial situations, such as clinical trials in Western medicine (Christakis, 1992).

Traditional Chinese medicine received a major blow in the early nineteenth century when China’s door was forced open by Western countries (Latourette, 1929). Medical missionaries from Western countries first arrived in China in 1834, introducing Western medicine to China
The dying Ching Dynasty suddenly realized that China was not the centre of the world, as the Chinese were led to believe for 4,000 years. The old empire was actually quite behind in the areas of defence, industry and science. With the founding of the Republic of China in 1912, all the old traditions of China were forsaken and radical changes (westernization) occurred in every walk of life. Western medicine was adopted as the only official medicine for China by the new government. Traditional medicine was deemed as unscientific by Western-trained Chinese physicians. There were numerous attempts on the part of a number of the leaders in the National Medical Association in 1929 and the Chinese Medical Association in 1949 to ban traditional Chinese medicine practitioners, but these were met with strong resistance from traditional medicine groups and users (Wu, 1959; Yip, 1983). However, despite its loss in status in the professional community, traditional medicine is still favoured by most people in China (Holden, 1964).

Because of the lack of Western-trained physicians and insufficient medical resources for a large population, the total abandonment of Chinese traditional medicine was impossible. After the Communists took over in 1949 and established the People’s Republic of China, the movement to combine traditional and Western medicine began with unprecedented support from the government (Lee, R., 1980; Li, C., 1975). As for nationalist Taiwan, Western medicine is still the only official health care system, and traditional Chinese medicine is kept as a subordinate system. Nevertheless, the steady demand for traditional Chinese medicine and the promotion of the World Health Organization to integrate both systems led to the recent examination of the possibility of integrating both systems in Taiwan (Chi, 1994). Pluralism in health beliefs and practices has become normative in Chinese perspectives on illness (Kleinman, 1980) and this approach has been commonplace in most Chinese communities where traditional and Western medicine are both available.
The Evolution of Traditional Chinese Medicine

Philosophical Framework

Just as Confucianism dictated the social structure, Taoism informed the development of traditional Chinese medicine. Traditional Chinese health beliefs and practices have continued to the present day without major changes since the writing of the *Yellow Emperor’s Classic of Internal Medicine*. With major influences from Taoism, this Classic provided a theoretical framework for the interpretation and treatment for illnesses (Veith, 1967). Traditional Chinese medicine is holistic and focuses mainly on function rather than structure. “Disease is rarely localized but generally affects the entire human being” (Veith 1975, p. 665).

In traditional Chinese medicine, *qi* (vital energy) and blood are two important concepts within the theory of *Yin* and *Yang*. *Qi* is the energy extracted from food ingested and air inhaled. It circulates through the *Ching-lo* system (the meridian tracts) to provide vital energy to all parts of the body and is regarded as the motivating force for all organs to function properly (Zhang, E., 1990). Blood is the solvent of *qi* and it brings nutrients to different parts of the body by circulation. *Qi* is the ‘controller’ of blood and the two are not separable; *qi* improves the function of blood and aids in the proper circulation of blood (Qin, 1992). Blood is regarded as the more substantive form of the *qi* circulation (Lin, T., 1989), while *qi* can only be detected through its functions (Qin, 1992). Deficiency of blood will not produce *qi*, and *vice versa* (Zhang, E., 1990).

The mind-body dichotomy is a product of Western culture and is not pervasive in Chinese culture (Kuo & Hopkins Kavanagh, 1994). Unlike Western medicine, traditional Chinese medicine does not differentiate physiological from psychological functions and organs are not viewed in a strictly anatomical sense. Organs are considered as anatomic-physiological-psychological systems that constitute the total existence of an individual as a biopsychosocial system (Lin, K. M., 1981). The internal organs in traditional Chinese medicine have the same
names as in Western medicine but are not viewed as having the same composition and function (Porkert, 1974). Internal organs are viewed as centres for both psychological and physical functions; thus, emotional disturbances are closely associated with dysfunction of organs (Xu, 1987). The heart, kidneys and lungs are of special importance in the regulation of both physical and psychological functions. The heart holds shen (spirit or mind) which governs all psychological functions. The kidneys are the reservoir of ching (essence or the purified, concentrated qi) which play a vital role in reproduction and growth, and the lungs are involved in the formation of qi (Lin, K. M., 1981; Yam, 1997). Each of the five major emotions is purported to be located in a specific internal organ: happiness in the heart, desire in the kidneys, worry in the lungs, anger in the liver, and fear in the spleen. Any imbalance of emotions would disturb the function of the parallel organ, and a dysfunctional organ explains an emotional imbalance (Kuo & Hopkins Kavanagh, 1994).

**Etiology of Illness**

In general, illness, or the imbalance of Yin and Yang, can be the result of one or more of the following three main causes: external, internal and neither external nor internal. External refers to environmental factors, such as poor living conditions, climate changes and invasion by the six licentious elements (Liuoyin) - wind, cold, heat, dampness, aridity and fire (the presence of these elements are not restricted to the external environment but embedded in many foods). Internal refers to physical factors, both hereditary and congenital, and experiences involving disharmony in social activities or extremes in the seven emotions (qiqing) - joy (xi), anger (mu), worry (si), grief (bei), sadness (you), fear (kong), shock (jing). Neither external nor internal refers to injuries and poisoning (Chen, 1986; Veith, 1967; Yam, 1997).

Any of the above causes can lead to a pattern of disharmony or imbalance of Yin and Yang. When Yin and Yang are unbalanced for prolonged periods of time or in an extreme manner the
resulting transformations may be quite drastic. An extreme disharmony means that the deficiency of one force cannot continue to support the excess of the other force to allow the formation of qi. The resulting change may be a rebalancing, or, if that is not possible, either the transformation into opposites or the cessation of existence. For example, when a patient has a very high fever with much perspiration (considered to be an excess of Yang or fire), the patient may be in danger of suddenly going into shock (an extreme Yin or cold condition). This is because it is believed that Yang cannot continue to exist in such an extreme relationship to Yin without some transformation occurring. Either a rebalancing must take place with medical intervention or a radical transformation, i.e. shock, will occur. If a rebalancing is not accomplished, Yin and Yang will separate and existence will cease - i.e. death (Veith, 1967; Zhang, E., 1991).

**Symptom and Diagnosis**

Symptoms of the dysfunction of Yin and Yang, the circulation of qi in particular, are organized and recognized according to the meridian system which serves as a base for the diagnosis and treatment of illnesses (Lin, K. M., 1981). The standard methods of diagnosis relied solely on observation, auscultation (with the physician’s senses only, without the use of any instrument), interrogation, and palpation (Yan, B., 1991). The interrogation and proper interpretation of patients’ explanations and the expressions of their symptoms play an important role in the diagnosis of their illness. Since traditional Chinese medicine and the Chinese language’s expression of illness are characterized by concepts of visceral organs, patients frequently describe their problems in terms of organs, even when it may be emotional in nature. Among the commonly used expressions are “injured heart,” meaning sadness; “insufficiency of kidney function,” asthenic condition or psychosexual problems; “elevated liver fire,” agitation and tension; “loss of gallbladder,” cowardly feeling; “opening of spleen,” relaxing feeling (Tseng, 1973). Effective caregivers
familiarize themselves with the true meaning of these expressions, rather than taking them at face value.

**Treatment**

The pattern of disharmony - the deficiency or excesses of *Yin* and *Yang* - provides the framework for treatment, which attempts to restore harmony or balance to the individual (Wu, J. & Chen, 1993; Zhang, E., 1991). The *Yin* and *Yang* theory has broad application into the daily life of Chinese health maintenance where herbs and foods are classified and extremes of emotions are avoided (Lin, T., 1989). All treatments are aimed at restoring the human body to harmony and balance, as opposed to correcting specific pathological changes (Lin, K. M., 1981). Major types of treatment include herbs used internally or externally, acupuncture, *moxa* (application of burning herbs over acupuncture points rather than use of a needle) and *qi-kung* (massage, exercise, and transfer of *qi* from therapist to patient). Depending on the nature of illness, these treatments can be used alone or in combination with others. With the help of family or friends, self-medication or the use of other treatment modalities is common practice among the Chinese. This usually takes place with or without assistance from trained practitioners (Qin, 1992; Yan, B., 1991; Zhang, E., 1990). In addition, none of these treatments are regulated by the Canadian government; none, except acupuncture (if administered by an Ontario licensed physician who has added acupuncture to their Western medical knowledge), is covered by government health insurance.

**Fatigue and Weakness in Traditional Chinese Medicine**

Fatigue and weakness are the symptoms of the *xu* (deficiency) of *qi* and blood, or the imbalance of the *Yin* and *Yang* forces. A lack in *Yang* would especially deprive the body of the positive energy it requires and further weaken it. Deficiency of *qi* would lead to the functional
decline of the organs which could be caused by overstraining or aging, irregular eating habits, prolonged consumption of cold drinks or foods, extremes in emotions, overthinking, excessive sexual activities and chronic illness, resulting in the symptoms of listlessness, lassitude, fatigue and weakness (Yan, B., 1991; Zhang, E., 1990). Among the organs, the kidneys, are responsible for the preservation of qi and essence. Excessive sexual activity and prolonged illness can lead to the impairment of the reinforcing and astringent functions of the kidneys and, in turn, the deficiency of qi. Malfunction of the kidneys would lead to impotence, infertility, growth retardation, lack of strength, fatigue and weakness (Yam, 1997).

A deficiency of blood would lead to fatigue, vertigo, and insomnia which can be a result of overstraining one’s body and mind through overwork, “overthinking” (Zhang, E., 1991, p. 328) and worrying, overstrain of organs through over eating and irregular diet, or the deficiency in the Yang force due to over indulgence in sexual activities by the male (Zhang, E., 1991).

Based on the traditional Chinese medicinal interpretation of the cause of fatigue and weakness, and the influence of traditional Chinese medicine on the Chinese, it is postulated in this study that Chinese patients who suffer from CF and weakness may adopt some of the traditional interpretations of their condition.

**Summarizing Conclusion**

A review of the development of CF and CFS, cultural factors, impact of migration, and traditional Chinese values and beliefs revealed the potential influences of these issues on the illness experience of immigrant Chinese patients. Research has shown that health professionals who understand local interpretations of the cause, course and treatment of illnesses have better communication with their patients and increased compliance by them. They are also better able to build alliances with the communities they serve (Weiss, 1988). With the influence of both
traditional and Western health belief systems, it is anticipated that Chinese immigrants may hold health beliefs and practices of both systems, and, in turn, may seek help for their ailments from both traditional Chinese and Western health practitioners simultaneously. Not only may this render them at odds with the Canadian health care system, but, adjusting to a new environment with different cultural values and languages, may also pose tremendous stress on this group of patients. Certain illnesses leave patients and their families with unbearable stigma. Understanding the health beliefs, meanings of illness, stigma and help-seeking behaviour of this population could enhance the health care worker's ability to provide culturally sensitive and appropriate care to this large group of new Canadians. An appreciation of patients' needs with respect to how they perceive and define symptoms will also enable health care planners and educators to design health programs that are culturally congruent and meaningful to their clients of Chinese origin and the multicultural community as a whole.

**Research Objectives**

The objectives of this study were to explore in Chinese immigrants with CF and weakness:

1. The patterns of distress (symptoms), stigma, perceived cause(s) and help-seeking behaviour.

2. The influence and impact of Chinese cultural concepts on the patterns of distress, stigma, perceived causes and help-seeking behaviour.

3. The impact of migration on perceived cause(s), stigma and help-seeking behaviour.

4. The interrelationships among their patterns of distress, stigma, perceived cause and help-seeking behaviour.
Chapter III

THEORETICAL FRAMEWORK AND REVIEW OF THE LITERATURE

The clinical features associated with medically unexplained CF and CFS, such as severe and persistent fatigue, muscle and joint pain, headache, sore throat, fever, weakness, dizziness, concentration difficulties, and memory loss, are largely subjective (Holmes et al., 1988). If health care workers are to understand and help patients with their suffering, they will need to attend to this subjective illness experience. The work of Kleinman (1980), Goffman (1963) and Kleinman and co-workers (1995) on the explanatory model of illness, and on stigma were chosen as the theoretical framework for this study because they take into account the cultural context of research participants' subjective illness experience. This is particularly relevant in this study in which all participants are first generation Chinese immigrants to Canada. The theoretical framework and selected variables in the EMIC (Weiss, 1997) - an instrument based on Kleinman's (1980) explanatory model of illness - also served as a guide for the literature review of this study.

Theoretical Framework

The theoretical framework of this study is grounded in Kleinman’s (1980) Explanatory Model of Illness - a model developed from extensive research with the Chinese population over a decade. The work of Goffman (1963), and Kleinman and co-workers (1995) on individual stigma/family stigma also contributed to the theoretical framework directing this research. To be consistent with the tenet of qualitative research which aims at discovery, the theoretical framework serves as an inquiry guide rather than an exclusionary structure.
Eliciting patients’ explanatory models of illness is a means of analyzing their understanding of their condition, and can serve as a base to teach clinicians to elicit the “native’s point of view” during their clinical work (Kleinman et al., 1978). Kleinman (1980) defines explanatory model as the meaning people attribute to their illness as they try to explain it. Explanatory models contain explanations of any or all of the following aspects of an illness episode: (1) etiology; (2) time and mode of onset of symptoms, (3) pathophysiology, (4) course of sickness, and (5) treatment of illness episodes (Kleinman, 1978). The cultural construction of illness produces different interpretations of the causes of illnesses, which influence the presentation of symptoms and the help-seeking behaviours of patients and families (Kleinman, 1980).

To obtain help for their illness, Kleinman (1978) purports that patients and families often must deal with the three social arenas of the health care systems: the popular, the professional and the folk. The popular arena is comprised mainly of the family context of sickness and care, as well as social and community networks. Most illnesses are managed in this arena as are the decisions regarding treatment choices. The mass media of the Canadian Chinese community, play a significant role in this arena in the distribution of health related information to their community. The professional arena consists of professional scientific medicine. The folk arena consists of non-professional healing specialists. Traditional Chinese medicine practitioners in Canada constitute this arena. Their practice is often part of the indigenous culture and well accepted within the community (see section on Traditional Chinese Concepts of Health and Illness, p.16)

Kleinman (1980) maintains that the health care system is an integral part of all cultures, and that illness is articulated as a cultural idiom in all three arenas of the health care system. Cultures establish systematic relationships among beliefs of disease causation, the experience of
symptoms, specific patterns of illness behaviour, decisions concerning help-seeking, actual therapeutic practices, and evaluations of therapeutic outcomes. The ideologies of all three arenas contribute to the patients’ general beliefs about sickness and health care in different social and cultural systems. General health beliefs, therefore, exist independent of and prior to a given episode of sickness; explanatory models, although influenced by these beliefs, are specific responses to a particular illness episode (Kleinman, 1978).

A patient’s explanatory model is partly conscious and partly unconscious. It is based on a cognitive system that directs reasoning along certain lines. In responding to an illness episode, the individual integrates views from the health ideologies of the popular, professional and folk arenas. Therefore, a patient’s explanatory model contains the often changing, ambiguous, tacit meanings of their illness, shaped by the nature of the illness, its impact on the sick person and family, and beliefs, norms and interests that constitute the day-to-day world of the sick person in his particular social situation. Illness is situated in both a cultural and social context (Kleinman, 1980, 1988). As demonstrated in the findings of the pilot study of the current research, the adaptation to Canadian life as an immigrant influences the participants’ illness experience. Therefore, the impact of migration was included in the theoretical framework of this study.

**Individual and Family Stigma**

Goffman (1963) notes that the Greeks, “originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier.” Stigma is inherent in a relationship between the ‘normal’ and the substandard ‘other’ (p.1). From a sociological perspective, Goffman (1963) formulated the concept of stigma as a psychological alteration which produces a “spoiled identity” and he outlines the subtleties of how this process proceeds. He focuses his attention on the idea of shared or transferred stigma, which affects not just the individual, but also his/her family.
Goffman (1963) defined a person who is stigmatized as:

“possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind - in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma” (p. 2-3).

It is not the attribute, per se, that is a stigma, but the “definition of the situation” or the social perception of the attribute which deems it a stigma. Stigma must be seen in terms of what Goffman (1963) calls “language of relationships,” that is, in the social context.

Goffman (1963) suggested that there are three types of stigma: (1) physical stigma of deformity, (2) “tribal stigma of race, nation, and religion,” and (3) “blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour” (p.4). The effect of these stigmata are the same; they interfere with what otherwise might have been a normal social relationship, because of their “undesired differentness from what we had anticipated” (p.5). “By definition, of course, we believe the person with a stigma is not quite human” (p.6). Sufferers of CF and weakness within the Chinese culture fit well into this typology since there is stigma associated with the perceived lack of self-discipline and laziness attributed to moral weakness, and being an immigrant and visible minority who runs the risk of having his/her ethnic group labelled as lazy or being a burden to society.

Kleinman and colleagues’ (1995) research on epilepsy in China has shed new light on the concept of stigma, especially in Chinese communities. Instead of viewing it as a psychological alteration of ‘spoiled identity,’ this reformulation of stigma is embedded in social and cultural processes. These researchers contend that stigma is an individual moral category in the West but
that moral blame is not applied to the Chinese patient alone. It extends to the entire family in the Chinese context. They argue that since the individual is culturally constructed as a relational-self, the indigenous Chinese model of stigma is "a sociosomatic one that frames intersubjective delegitimation, not spoiled identity, as the central process" (p.1328).

Since the person is constructed as a relational-self in the Chinese culture, delegitimation of the person and the family can affect the whole family's chances of marriage, livelihood, and all aspects of social life. Over the long-term, patient and family are delegitimatized, regarded as morally bankrupt, and viewed as capable of bankrupting others. The ruins of social relations can lead to ruined lives. Renqing, favour, the affect central to social exchange, can neither be given nor received. To lose face, to be unable to allocate renqing, to experience delegitimation means that the patients and their families are ostracized (Kleinman et al., 1995).

**Responses to Stigma**

Goffman (1963) maintains that stigmatized individuals share many problems and utilize common strategies to overcome these problems. He discusses three options open to them to avoid interacting with "normals" in situations in which they are at a disadvantage. One option to avoid derogation is to associate only with those who possess the same stigma, or to associate only with those "normals" who are sympathetic to their problems, and for whom the stigma is of no consequence. Another option is for the stigmatized individual to hide his stigmatized identity, i.e. to pass for "normal" (the extent to which this is possible depends on the nature of the stigma). A third option is to "manage" the "audience" by playing on the meanings that "normals" give to his condition (p.9). For example, by agreeing with "normals" that one's fatigue is the result of hard work.

One of the key cultural values of the Chinese is that of avoiding "shame" or "loss of face." From a very early age, Chinese behaviours are moulded by what it is believed people will view as
"good" rather than what the individual believes to be "right." One is expected to act in a way that brings glory and respect to one's family, clan and country (Kendall, 1989). Chinese people have a tradition of bearing hardships and withstanding hard work. They tend to have a close knit family and social system, and a strong sense of interdependence (Xu, 1987). The Chinese consider leisure time a luxury and remaining idle a cardinal sin (Kendall, 1989). Thus, fatigue may be perceived as weakness in one's character or as laziness, which could reflect badly on the family.

Concluding Comments

For the purpose of this study, there are merits in both Goffman's (1963) and Kleinman and colleagues' (1995) conceptualizations of stigma. Both Goffman (1963) and Kleinman and colleagues (1995), address the social dimension of stigma, though the latter emphasize a more indigenous view of stigma pertaining to the Chinese culture. Chinese patients who suffer from CF and weakness fit well into the three types of stigma proposed by Goffman (1963). Unlike the Christian teaching that stresses individual responsibility to bring glory to God, the ultimate responsibilities for a Chinese, based on the four steps outlined in Confucius' teaching, are (1) improving oneself, (2) looking after one's family, (3) serving one's country and (4) bringing peace to the world. Thus, bringing glory to one's family and kinship is fundamental to other virtues. Delegitimation of family and the social network is, therefore, the biggest assault the person can experience. This research incorporated both Goffman's (1963) and Kleinman and colleagues' (1995) views of stigma as a guide to study subjects' perceived stigma.

Review of the Literature

The theoretical framework described above and selected variables in the EMIC (Weiss, 1997), an instrument developed based on Kleinman's (1980) Explanatory Model of Illness, served as an organizing framework for the literature review of this study. Both the Kleinman
(1980) and the Weiss (1997) frameworks were developed from research with patients in Eastern cultures. Kleinman's (1980) model consolidated his extensive research and clinical experience for over a decade with Chinese patients in Taiwan, China, and the US. The EMIC (Weiss, 1997) was the product of comprehensive studies in South Asia, with an adaptation for researching the Chinese population developed by a group of experts in the Chinese culture. Therefore, the Kleinman (1980) Model and the EMIC (Weiss, 1997) are most suited to serve as an organizing framework for the literature review of this study. The major headings chosen were: patterns of distress, stigma, perceived cause, and help-seeking behaviour.

Research in CF has largely focused on its etiology, prevalence, the psychological characteristics of its sufferers, its relationship with other medical and psychiatric illnesses, and its diagnostic and treatment modalities. Almost all subjects in these studies are Caucasians from North America or Europe. Only a few studies have investigated variables such as the patterns of distress, stigma, perceived causes and help-seeking behaviour of patients suffering from CF. No previous research was found concerning the problems to be addressed in this study in the Chinese immigrant population. Therefore, for the purpose of this study, research that explores the patterns of distress, stigma, perceived causes, and help-seeking behaviour of non-Chinese patients suffering from CF and weakness (including studies of CFS and neurasthenia) and studies that explore the Chinese experience with other illnesses were reviewed.

Dwelling amongst members of the same ethnic minority group can buffer direct prejudice from the larger community through social support. Nevertheless, the experiences of being a member of an immigrant and cultural minority group can produce adverse effects on one's mental health (Halpern, 1993). Despite the strong presence of Chinese immigrants in the Greater Toronto Area, results from this study's pilot test of 10 patients indicated that their experiences as new immigrants played an important role in how they perceived and coped with their illness.
Research on the impact of migration was included in the literature review of the present study, in as much as it is an integral feature of their social context.

**Patterns of Distress**

A review of the literature, which follows showed that patients with CF and weakness suffer from multiple symptoms of physical and psychosocial distress. Those patients who reported more medically unexplained physical distress were found to be more likely to have current or lifetime psychiatric disorders.

A qualitative study on neurasthenia was conducted by Arthur and Joan Kleinman (1982; 1985a) at Changsha, the People’s Republic of China, shortly after the conclusion of the Cultural Revolution (1966-1976). One hundred patients with a diagnosis of neurasthenia (52 men, 48 women) were interviewed at their first visit to a psychiatric out-patient clinic. Patients’ narrative accounts of their illness experiences and explanatory models of illness (including cause, course, treatment and anticipated consequences) were elicited with a semi-structured questionnaire, called the Illness Narrative Interview. A mean number of 6.8 complaints were reported by each patient, of which 5 were somatic, and 1.8 was psychological. Seventy-eight percent of the patients held that their disorder was wholly or partially organic and only 22% regarded their illness as wholly or partially psychological. Most of the subjects ascribed the cause of their illness to the terror, oppression and loss they had experienced during the Cultural Revolution. Symptoms were expressed through the symbolic nature of bodily complaints, and the central cultural metaphor of ‘qi’. The Cultural Revolution was perceived to have caused a deprivation of this vital energy to the social fabric as a whole. Somatic symptoms, such as pain, were considered to be both in the body and in strained relationships in families and the workplace. Since traditional Chinese medicine attributes health to the harmonious balance
between macrocosmic environment and the microcosm of the body, symptoms such as dizziness and malaise were interpreted as a disturbance of this balance by these neurasthenic patients - a symbol of their alienation from their bodies, their social contexts and the political process.

This study articulated the indigenous view of the Chinese patients through their narratives. However, questions may be raised about the validity of the data because of the following: (1) the political climate at the time of the study. The study was conducted shortly after the Cultural Revolution, in which millions were persecuted because they held politically incorrect ideologies. Research participants might have limited their revelations to the researchers to what they considered to be politically safe. (2) The perceived role of Kleinman and his colleague by the Chinese at the research site. The researchers were foreigners from the US who came to an impoverished part of China, which had once benefited from the US, especially in medical care (Holden, 1964). The US, at that time, was perceived to be the world’s most capitalist country, long held as the enemy of the communist ideal state. Based on the high degree of co-operation the Kleinmans obtained from their Chinese research collaborators, one could speculate that they were perceived by the Chinese more as saviours who could rescue them from their sufferings, like their predecessors at the turn of the century, than as researchers, which is an unfamiliar role in many underdeveloped parts of the world.

In a study of the psychiatric morbidity and ethnography of subjects with CF and weakness in Hong Kong, Yu (1994) interviewed 100 (75 female) Chinese outpatients with medically unexplained fatigue in a primary care setting. She reported that 72 of them claimed that they suffered from neurasthenia. None of her subjects called their problem CFS, and nearly all of them stated that they had never heard of CFS before. Insomnia (20%), somatic pains (20%) and headache (16%) were the most frequently cited symptoms. Fatigue was an infrequent complaint and not usually thought of as a medical problem. In fact only 5 patients reported fatigue and only
2 patients indicated weakness as their most troubling symptom. Those subjects who did not cite fatigue as one of the most troubling symptoms believed that it might reasonably be expected in a busy city such as Hong Kong, where the determined acquisition of financial security and power through the application of hard work was normative. When asked, they usually identified fatigue as the consequence of insomnia or pain, rather than as a primary problem. Fifty percent of the patients attributed their fatigue to a physical cause, 32% identified a psychological cause and 18% to an interpersonal or social reason. Subjects’ perceived stigma associated with their CF and weakness or help-seeking behaviour were not assessed. Subjects of this study were outpatients of a government funded hospital where free medical care was provided; these patients were mainly from a lower socio-economic neighbourhood and were less educated than the general population in Hong Kong. Thus, findings from this study may not be generalizable to other Chinese communities, but can serve as a reference for the present study, in which all subjects were born in China, Hong Kong or Southeast Asia.

Research with largely Caucasian CF subjects shows that difficulty with sleep is one of the most disturbing symptoms. Farmer and colleagues (1995) found that 79% of the 100 CFS patients they studied suffered from sleep disorder. Moldofsky (1989) reported that patients with CF were awake more than twice as long as controls and took more than twice as long as controls to fall asleep. A case-control study of 12 patients with CF and 12 healthy controls conducted by Morriss and co-workers (1993) showed that the majority (7) with CF had sleep disorders, which might have contributed to their daytime fatigue. Krupp and colleagues (1993) studied 72 CF patients and found that they had much more sleep disturbances compared to patients with multiple sclerosis and healthy controls. CF patients slept more lightly and felt drowsy upon awakening. However, differences in measurement methods in these studies affect the actual severity of observed sleep difficulties and limit comparability of findings.
Studies have also showed that CF patients with medically unexplained physical symptoms are vulnerable to psychiatric disorders. Wessely and co-workers (1996) compared 214 CF patients with their “non-fatigued” counterparts in a primary care setting. These researchers assessed relationships among psychological symptoms, past and current psychiatric disorder, functional impairment, somatic symptoms and CF, using instruments such as the Fatigue Questionnaire, General Health Questionnaire, Chronic Fatigue Syndrome Checklist, Revised Clinical Interview Schedule, and Somatic Symptom Checklist. The subjects were also asked about previous episodes of possible psychiatric disorder and treatment. The researchers reported that patients with CF were at greater risk for psychiatric disorders, mainly depression (60% versus 19%). Amongst CF patients, there was a linear relationship between somatic and psychological symptoms ($r=0.34$, $n=185$, $p<0.001$).

In an earlier study by Katon and Russo (1992), 285 CF patients were assessed with the National Institute of Mental Health Diagnostic Interview Schedule and four self-rating questionnaires assessing psychological distress, functional disability, and the tendency to amplify symptoms. This study also found that patients with the highest number of medically unexplained physical symptoms had an exceptionally high rate of current and lifetime psychiatric disorders. Both of these studies employed well validated instruments, but the experience and the impact of their illness on the lives of the subjects were not assessed.

A study was conducted by Buchwald and co-workers (1997a) in a CF referral clinic to determine the efficacy of the General Health Questionnaire (GHQ), to detect psychological distress. Two hundred and eighty-one (95% Caucasian) CF patients with a psychiatric illness of duration between 6 months and 39 years (mean=5.2) were screened using the self-report GHQ and a structured psychiatric interview. It was found that 35% of these patients had a current psychiatric disorder and 82% had a lifetime psychiatric disorder. A longer illness duration was
associated with a greater severity of fatigue and a shorter length of illness was associated with greater psychological distress. The researchers postulated that patients had developed strategies over time to cope with the psychological distress associated with their CF. They reported that the GHQ showed excellent internal consistency with an alpha coefficient of 0.93. The GHQ achieved the best sensitivity (0.69-0.76) and specificity (0.51-0.62) for current psychiatric diagnosis using a threshold score of 12; indicating that patients scoring <12 are less likely to have a psychiatric disorder. These researchers concluded that the GHQ is a quick and inexpensive tool to assess psychiatric disorders among patients with CF. However, the applicability of GHQ to different cultural or language groups has not been established, and how much the findings from this study can be generalized to CF patients who are non-Caucasian American is yet to be determined. Furthermore, measures such as the GHQ do assess psychological distress, but they do not reveal the qualitative nature of the patient’s experience.

There is an abundance of literature which addresses the symptoms of CF. However, most studies have not explored the meaning of such symptoms to the patients or how these symptoms affect their lives, particularly, in patients who are immigrants.

**Stigma**

A review of the literature pertaining to the Chinese perception of illness-related stigma showed that mental illness, rather than physical illness, dominated the literature. Mental illness carries a tremendous stigma in different Chinese communities. In mainland China, people are reluctant to discuss their feelings and reveal mood symptoms to others because mental disorders are still highly stigmatized (Young & Xiao, 1993; Xu, 1987). Pearson and Phillips (1994) purported that there is little community tolerance for mentally ill people in China, and that such patients and their families are heavily stigmatized. This stigma particularly affects the life
chances of young unmarried people, and families often go to great lengths to hide the illness. Compared to the American general public, American Chinese immigrants have been reported to be particularly negative in their attitudes toward people with mental disorders (Chan, F. et al., 1988). To date, the causes of CF lack a concrete physiological explanation; one may speculate that Chinese CF patients are prone to the kind of perceived stigma endured by their counterparts who suffer from mental illnesses.

In a study of depressed Chinese patients in general practice in Hong Kong, Cheung, F. and colleagues (1980-1981) noted that a majority of patients complained primarily of somatic symptoms. The researchers suggest that Chinese patients conceal their feelings because of the powerful social stigma that attaches to mental illness in their culture. Physical symptoms are substituted for depressive symptoms, so as to be less stigmatizing and therefore more tolerable. However, when directly asked, these patients often admitted to the presence of affective symptoms. These researchers maintain that for most working class Chinese who are used to more concrete modes of expression, conceptualization at the psychic level may seem too abstract. They contend that there is no systematic data to support the alleged Chinese tendency for somatization, as suggested by Kleinman (1977).

Epilepsy is a condition which is stigmatized and its etiology remains controversial in China. Kleinman and co-workers (1995) studied 80 patients suffering from epilepsy in China. A semi-structured interview schedule was used to elicit the experiences of illness and treatment, as well as the impact of the illness on the patient and family. Perceived causes of epilepsy reported by patients and their families included: heredity, head injury, being possessed by demons, geomancy, poverty, overwork and fright. These perceived causes carry implications about the moral status of the family, and thus contribute to the tremendous stigma attached to the illness. The burden of epilepsy on the emotional, financial and familial, marital and interpersonal
relationships is severe. Stigma (affecting both the patient and family) and shame, associated with loss of moral status and low self-esteem, were wide-spread among those who participated in the research. Because of the fear that their entire family would be disgraced, family members often concealed the diagnosis, dropped out of treatment and hid their epileptic members at home. Although the researchers contended that the findings of this study could be applied to other chronic conditions, they should be applied to CF with caution, as epilepsy may be a far more “visible” illness than CF. More study is needed to examine the role of stigma in the illness experience of patients with a poorly defined illness such as CF.

Studies reviewed thus far suggest that the impact of stigma on patients’ illness experience is severe with illnesses that lack a somatic etiology. However, the influence of a culturally defined concept such as stigma on how patients perceive fatigue or seek help is not well researched, especially with the Chinese immigrant population.

**Perceived Cause**

Although most patients with CF and weakness hold pluralistic views and multiple attributions of their illness, as demonstrated in the studies of Kleinman and co-workers (1982, 1985a) and Yu (1994), they still tend to attribute their illness to a physical cause, and to minimize the role of psychosocial factors in their illness.

**Physical**

Both quantitative and qualitative research reviewed indicated that most subjects, predominantly White and American, attribute the cause of their CF to a physical cause.

Lane and co-workers (1991) compared 60 general medicine patients to a control group of 60 CFS patients with a chief complaint of chronic fatigue using the Diagnostic Interview Schedule, version III-A. They found that CFS patients were more likely than controls to be diagnosed with
a somatization disorder and to attribute their illness to physical causes, such as viral and yeast infections, and hormonal imbalances. All participants in this study were mainstream Americans, and the causes they reported were consistent with those prevalent in North American mass media (Bouw, 1998; The Globe & Mail, 1998, Time Magazine, 1987). The extent to which the mass media shaped these patients' perceived causes were not assessed. Whether patients from ethnocultural minority groups share these views has yet to be researched.

In a postal questionnaire survey of 208 hospital out-patients with post-viral fatigue syndrome, with a return rate of 84%, Ray and co-workers (1992) examined the relationship between symptoms and patients’ perceptions of their illness. Participants in this survey were “invited” to describe their illness experience. A majority of the subjects associated the onset of their illness with an infection or stress (84%). Only 3% perceived their illness to have a psychological cause, while 54% reported that the cause of their illness was physical. Patients with a high level of fatigue reported greater levels of disability and severity of symptoms. The researchers concluded that primarily fatigue, and to a lesser extent somatic symptoms and cognitive difficulties, play an important role in determining the perceived severity of the illness. However, there were some limitations to the validity of this study. Participants had to be able to read and write English, and because it was a mail survey, participants were left to interpret the questions on their own or to solicit assistance from others beyond the investigators’ control.

Another survey of 243 American patients by the Dartmouth COOP Project (Nelson et al., 1987), a primary care research network, reported that 65% of those who reported fatigue as their chief complaint indicated a physical cause, 23% psychological and 12% a work-related cause. Patients who did not present their fatigue as the chief complaint cited psychological problems more frequently as the cause of this symptom. When compared with an age/sex matched patient group, fatigue patients were more often found to have multiple physical complaints, difficulties
in many areas of living and a higher health care utilization rate than their non-fatigue counterparts. A prospective study by members of the Dartmouth COOP Project (Kirk, Douglass, Nelson, Jaffe, Lopez, Ohler, Blanchard, Chapman, McHugo, & Stone, 1990) also found that half of the 71 patients who completed their study, attributed their fatigue to a physical cause while the rest attributed it to psychological factors.

Another questionnaire survey of 611 primary care patients (444 female, 167 male) found that the majority (over 50%) of the subjects considered physical ill health to be the cause of their fatigue and that these subjects also had higher total fatigue scores than those who attributed family, social, or emotional difficulties or poor sleep to be the cause of their fatigue (David, Pelosi, MacDonald, Stephens, Ledge, Rathbone & Mann, 1990). All studies reviewed above, except the one by Ray and co-workers (1992), did not solicit participants’ opinion as to the cause of their illness in their own words; thus, the qualitative nature of their perception was not unveiled.

A qualitative study was conducted by Clements and co-workers (1997) to investigate patients’ beliefs about their CF. Patients were asked open-ended questions about the cause and course of their illness. Almost all (64 out of 66) patients believed their illness was caused by physical factors, mainly non-specific viral infections; 45% of them cited physical factors as the sole cause of their fatigue and the remainder reported a combination of physical, social and lifestyle issues. Physical and social stresses accounted for 36% of the combinations. Although citing stress as playing a role in their illness, patients in this study believed that the cause of their illness was not “psychological.” The majority of the patients (70%) claimed that they had identified the cause of their illness through their illness experience and reading; only 30% cited information from health care professionals. Reduction of activity was the coping strategy employed by most patients (76%). Clements and colleagues concluded that stress-induced illness
is commonly seen as blameless, whereas labelling an illness as psychogenic may raise doubts about both the reality of the illness and even the character of the sufferer [cited in Ware, 1992]. Whether such values are universally embraced, however, is highly questionable, especially among patients from culturally diverse North America.

**Psychosocial**

In contrast to reports in which subjects attributed their CF to a predominant physical cause, in the following studies most subjects attributed their illness to a psychosocial cause. Patients with psychosocial attributions reported less fatigue than their “physical cause” counterparts.

In a British community survey, 116 out of 15,283 general practice patients indicated that they were suffering from CF (Chalder, Power, & Wessely, 1996). Thirty-eight patients attributed their fatigue to a physical cause of myalgic encephalomyelitis. These 38 patients were matched randomly to a group of 40 patients who attributed their fatigue to psychological factors and another group of 38 who attributed their fatigue to social factors. Their levels of fatigue, psychological distress, symptoms, style of attribution and levels of disability were compared. Those citing a social attribution (such as excessive work pressures) were less fatigued, experienced less symptoms and were less handicapped in regard to their work, home, social and private leisure activities than the other two groups, and appeared to be most protected from distressing symptoms. The researchers concluded that patients who attributed their fatigue to social reasons, such as “excessive work pressures” expected themselves to be fatigued and claimed to know the cause of their fatigue. Hence, these patients were less anxious and depressed than the psychological cause group, and felt more accepted by others, especially their physicians, than the physical cause group.

Although psychosocial perceived causes could be considered as the primary instigator of CF, Ware (1992, 1993) purported that a “biopsychosocial” one best captured the patients’ chain
of thought in explaining their fatigue. Ware (1992; 1993) conducted a qualitative study of 50 patients (80% female, 92% White) who suffered from CFS in the United States. Negative life events, chronic life difficulties (e.g. illness in the family, marital problems), a family history of psychiatric problem(s) and an abusive childhood were cited by subjects as events leading to the onset of their illness. Almost half of the subjects identified stress as the most probable cause of their fatigue. Stress (the feeling of being overwhelmed by commitments, loss, loneliness and isolation or fears of displeasing others) was blamed for igniting a chain reaction which led to a “cause of their CF.” This “biopsychosocial” perceived cause postulated that the immune system was weakened by stress, resulting in a viral infection which constituted the symptoms of CF. Fifty-four percent of the subjects reported a “biopsychosocial” cause of their CF, and only 26% attributed their illness to a physical cause of viral infection. The sample under investigation was English speaking, with a minimal amount of ethnic diversity. Nevertheless, Ware’s (1992; 1993) research provides a useful comparison to the present study as they elicited the subjective illness experience of their subjects.

As immigrants, Chinese patients in the current study may be confronted by many social issues in their adjustment to the host country, as well as the stigma associated with suffering from a medically unexplained illness. Based on the findings of this study, it may be asked whether patients who articulate their fatigue to social causes, would be protected from distressing symptoms?

**Help-Seeking Behaviour**

Patients’ perceived causes of their illness have been recognized as an important determinant of their help-seeking behaviour (Cheung, F., Lee, & Chan, 1983; Kleinman, 1982). The existence of several distinct therapeutic systems is a common feature of health care in developing countries. Traditional medicine is often perceived as more, or at least no less, effective than Western
medicine (Christakis, Ware, & Kleinman, 1994; Lee, R., 1980). In most Asian countries, both traditional and Western forms of health care systems are often available to those who seek help. Multiple usage of both systems is common among Chinese patients depending on their perception of the nature of their illness (Ho, Lun, & Ng, 1984; Koo, 1987). It has been reported that 60% of a sample of Southeast Asian immigrants in the US used traditional health practices before turning to Western medicine when they were ill (Buchwald, Panwala, & Hooton, 1992). However, despite the growing literature on folk practices cross-culturally, there is little published material on traditional healing in Canadian ethnic communities (Beiser, Gill, & Edwards, 1993).

Ying (1990) explored the opinions of 40 US Chinese female immigrants on major depression. Subjects were non-patients and they were presented with a vignette of a clinical case which met the DSM-III diagnostic criteria of major depression. These women were then asked questions which were adapted from Kleinman (1980), to elicit an explanatory model of major depression. Results indicated that 57.5% conceptualized the problem in the vignette as psychologically based. A majority of them suggested the cause of the problem that the subject of the vignette was experiencing was due to their migration. Thirty-three percent (33%) suggested a physical cause to the problem. Those who provided a psychological cause, because of stigma associated with such an attribution, opted to turn to themselves, family or friends rather than seek help from Western medicine, while those who provided a physical conceptualization were more likely to seek Western professional medical attention. Although the subjects of this study were not actual patients and their actual help-seeking behaviour might differ from speculation based on a vignette, these findings may nevertheless reflect the general thinking of the Chinese population.

Anderson and co-workers (1991, 1992) conducted a comparative ethnographic study to investigate the experience of chronic illness of first generation Chinese immigrant women in
Canada and their Euro-Canadian counterparts. Two to three in-depth interviews were conducted with 30 women, 15 Chinese and 15 Euro-Canadian. Major difficulties were identified in the Chinese immigrant group’s help-seeking experience. Health professionals’ disregard of the obstacles presented by the circumstances of the patients’ everyday life, language barriers and lack of trained medical interpreters in most health care facilities were cited as major problems. Also exacerbating the immigrant women’s difficulties in living with a chronic illness, was their migration experience. These included being without a familiar social support system, the comfort and confidence of living in one’s own culture and the ability to speak freely in their own language. This study illustrates the unique experience of Chinese immigrant women who are managing a chronic illness in an unfamiliar land with a vastly different social environment than their own.

Lee, L. (1992) surveyed a community sample of 100 Australian Chinese to elicit their methods of illness prevention and treatment. Of the 42 subjects who returned their survey (26 female, 16 male), 63% of female and 60% of male subjects indicated that they used Chinese traditional medicine. Sixty-seven percent of all subjects used both Chinese and Western treatments. Since not all participants of this study were patients suffering from an illness or CF, their responses may not represent what they would actually do should they become patients. However, these subjects’ pluralistic approach to help-seeking is consistent with other reports on Chinese help-seeking behaviour (Kleinman, 1980; Cheung, F., 1989).

Another survey which compared Chinese immigrants’ experience with primary health care and their health behaviour to their British counterparts was conducted by Watt and co-workers (1993) in England. Anonymous questionnaires were hand delivered by the researchers and explained in the language of the respondents. Eighty Chinese immigrants (either from China or Hong Kong) and 73 “White” respondents, all employed in the catering industry participated.
Completed surveys were returned in pre-paid envelopes. The most likely action when unwell was to consult a general practitioner, which was reported by 84% of the Chinese compared to 65% of the “White” respondents. The “White” respondents also sought help from other allied health workers such as pharmacists and nurses. Even when there were no traditional Chinese medicine practitioners available in the area they resided, two Chinese respondents indicated that they would seek help from traditional Chinese medicine practitioners. Difficulty in being understood by their family doctor was reported by 71% of the Chinese compared to 33% by the “Whites,” and almost the same proportion (73% Chinese, 35% “Whites”) reported that they were having difficulty in understanding what their doctor was telling them. More than half (57%) of the Chinese needed to use an interpreter to communicate with their caregiver. The researchers concluded that the language barrier denied the Chinese full benefit from the British health service which was only provided in English. The Chinese respondents’ poor knowledge of the function and availability of other health care workers and their cultural preference to consult doctors, because of their perceived higher status than other health care workers, rendered them sub-optimal health service use. Since 90% of the Chinese immigrants in England are in the catering industry, the researchers claim that results from this study have applications for health care of Chinese in other parts of England. The homogeneous nature of the occupation of the Chinese immigrants in England limits this study’s generalizability to their counterparts in other Western countries such as Canada, where Chinese immigrants are employed in all walks of life. Although indicated by the researchers as important, Chinese cultural and health beliefs were not addressed in this study.

To assess the health practices and help-seeking behaviours of Chinese residing in the City of Toronto, Yuan and co-workers (1998) surveyed 720 (52.9% female and 47.1% male) members of the Chinese general public. Only 8% of the participants were Canadian born; most were born in
China (59%) and migrated to Canada more than 20 years ago (83.6%). The majority (90%) reported that during the year prior to the survey they had used the services of a general practitioner of Western medicine, and 21.4% had seen a traditional Chinese medicine practitioner. For those participants who only spoke Chinese, 52.3% reported that the language barrier hindered them in accessing health care. This was the first health survey of this magnitude in the City of Toronto, although the researchers acknowledged that the exclusion of the mental health issue was one of the limitations of the survey. Other limitations of the study include that recruitment of subjects was restricted to the City of Toronto where most Chinese residents who came to Canada prior to 1980, established themselves. The recent wave of Chinese immigrants, who mainly reside in the Greater Toronto Area, were not included proportionally.

In summary, research indicates that Chinese immigrants are receptive to Western medicine, but their success in help-seeking and receiving good quality of care is often hampered by the language barrier between them and their care providers.

**Psychosocial Impact of Migration and Minority Status**

Despite inevitable stresses, the migration process does not necessarily threaten the psychosocial well being of the migrants. It is when additional risk factors combine with the stress of migration that the mental health of migrants becomes a concern (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988a). The intensity of the negative psychosocial impact on the migrants often depends on the amount of adjustment they must make to survive. The more alike the source and host communities are in culture, social structure, language, and racial composition, the less stressful it will be for the migrant to adapt (Verdonk, 1979). Greater cultural dissimilarity between culture of origin and culture of destination is a pathogenic factor that threatens migrants’ mental health (Westermeyer, 1989). Minority status
refers to “social position that is less than that ascribed to members of another group” (Kavanagh & Kennedy, 1992, p. 16). Respect is usually withheld from this group as a result of limited status, power, and/or wealth. Although the Ontario Human Rights’ Code (1993), prohibits any discrimination on the grounds of race or ethnic origin, there is no shortage of reports of racism against ethnic minority (The Toronto Star, 1999). For those immigrants who enjoyed being part of the majority in their home country, being reduced to a minority status and subjected to racism may render them feeling disoriented and resentful. Chinese immigrants who participated in this study were confronted with the stress associated with their migration to a culture vastly different than their own, being reduced to a minority status as well as having to cope with an ill-defined illness of CF and weakness. The combination of these two factors renders their mental health at risk.

An extensive literature review on migrant mental health conducted by the Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees (1988b) reported that unemployment and underemployment affect the mental health of male immigrants more severely than their female counterparts. English proficiency is positively associated with personal well-being, while education is negatively associated with adjustment. Perceived racism and lack of acceptance by the larger society had negative effects on the migrants’ ability to adapt. Although the presence of extended family enables the migrant to cope better with the stress associated with daily living, it also leaves one more prone to familial and intergenerational conflicts. Overly optimistic expectations of their future also raise difficulties for the migrants in adapting to life in their new homeland. Residence in an “ethnic enclave,” which allows migrants to have a sense of belonging and support, was found to enhance their mental health. The Task Force concluded that migrants whose status remains constant and whose familial, communal and societal support are intact in the host country, are at much lower mental health risk than those migrants who lack
these elements. This review provided a comprehensive overview of issues related to post-migration mental health of migrants. However, the findings are dated, as such a comprehensive review has not been repeated for over a decade.

In order to understand the culture-specific employment and socio-emotional needs of Chinese male immigrants, Wong, S. (1997) surveyed a convenience sample of 547 Chinese male immigrants between the ages of 25 to 50 in “local malls” known to have a large Chinese clientele in the Greater Toronto Area. Compared to the national unemployment rate of 9%, 26.9% of those interviewed were unemployed. They cited systematic barriers such as their overseas credentials not being recognized, the requirement of Canadian working experience, and their lack of English proficiency as major hindrances to obtaining gainful employment. Those who were employed indicated that they were not able to make use of their education and skills, because their overseas credentials and work experiences were not recognized, and because of their difficulties with the English language. Those who managed to get their credential recognized reported obstacles in acquiring the needed Canadian experience, to land any kind of professional job. Most of them were underemployed and in unskilled laborious jobs. “Work” and “financial” problems were cited as major sources of stresses in their lives. The instrument of this survey was not validated, the methodology far from rigorous, and the location of the survey (popular Chinese malls cater to Chinese shoppers from the same neighbourhood) was hardly conducive to the generation of confidential and private data, such as one’s financial and emotional status. However, this survey provided a bird’s eye view of some of the hardships encountered by Chinese male immigrants.

A study of two generations of Chinese immigrants in Britain (first generation who were non-British born n=43, second generation who were British born n=27) found that there was a significant correlation between proficiency in English and psychological symptoms (r=0.29, p<0.01), and depression (r=0.23, p<0.05) among these subjects. Proficiency in English was
significantly correlated with occupational prestige ($r=0.46$, $p<0.001$) with the less proficient individuals more likely to be employed in the Chinese catering occupations, unemployed or housewives (Furnham & Li, 1993). These findings suggest that subjects who were immigrants were socially and psychologically disadvantaged because of their language proficiency. Since participants in the present study were all first generation immigrants to Canada, Furnham and Li’s (1993) finding serves as a reference.

Sham and Jackson (1994) reported that the British national unemployment rate was 24% for Asian immigrants and 8.5% for Whites. In order to explore the impact of unemployment on the psychological well-being of British Asians, these researchers compared 71 unemployed and 68 employed, semi-skilled or unskilled South Asian men who were between 18 and 55 years of age. Subjects’ psychological well-being was assessed using the General Health Questionnaire, Zung Anxiety and Depression Scales, Employment Commitment Scale, Locus of Control and Self-esteem Scales. The unemployed group was found to have lower levels of psychological well-being and self-esteem than those employed. Length of unemployment was inversely proportional to psychological well-being, suggesting that the longer one was unemployed the worse the psychological well-being. Since this study did not assess the pre-migration employment or educational status of the subjects, the impact of migration on their employment status cannot be determined. Furthermore, neither of the “standardized psychological questionnaires” used in this study were tested for validity or reliability in the South Asian population, nor was the generalizability of the findings from this study to other ethnocultural group established.

Ethnic communities usually are able to provide emotional support by reinforcing their immigrant members’ sense of identity and self-worth, and providing opportunity for friendship. However, Lock (1990) also cautions that ethnic communities are not “natural” units, that migrants can be subjected to exploitation, especially as a work force by their “own kind”.
Summary

The literature reviewed suggests that patients' symptoms are often presented in the manner most acceptable within the confines of their culture and, that perceived causes of illness are culturally and socially determined. Although some research has indicated that CF patients tend to have perceived the cause of their illness to be physically based, other studies present different and even contrasting findings. With the priority of social harmony in the Chinese culture, stigma, which also extends to the family, is a major concern affecting all facets of a patient's illness experience. Like patients with epilepsy in China (Kleinman et al., 1995), Chinese immigrants who suffer from an illness which is poorly understood, are prone to be stigmatized in their own ethnic community. Studies of help-seeking behaviour of Chinese immigrants indicate that they tend to use traditional Chinese medicine or both traditional Chinese and Western medicine concurrently to deal with their illness. They tend to be more receptive to Western medicine if they perceive their illness to be physically based. However, lack of proficiency in English and feeling not understood by health care workers create significant difficulties for Chinese immigrants seeking help. The process of migration entails a sense of loss and the need to adapt to the new country. Factors such as the disparity between the home and host countries in culture, language, and social systems, and the drop in social and economic status put the migrant at a psychosocial disadvantage in adjusting to a new life. The studies discussed above clarify some of the issues related to CF and weakness, as well as the illness experience of the Chinese immigrant population. However, none of the studies adequately addresses the cultural component of CF or investigates the illness experience of Chinese immigrants with CF and weakness. Good (1994) sums up this dilemma nicely:
The literature on illness representations is voluminous— in history, literary studies, the social sciences, and the medical humanities, whether analyzed as beliefs or cultural models or illness narratives or mystified social relations. But detailed, ethnographic accounts of illness experience, or a well wrought theoretical vocabulary for the study of illness as human experience, are largely absent (p.117).

In order to better understand and serve the increasingly strong presence of the immigrant patient population in the Canadian health care system, it is best to solicit the immigrant patients' point of view. Therefore, this study is aimed at the gap in the literature related to the illness experience of Chinese immigrants who suffer from CF and how they perceive and manage their illness.
Chapter IV

METHODOLOGY

In this chapter, the methodology of this study is illustrated in five sections. The first section is an overview of the study design. In the second and third sections, the sample and site of the study are described. The data management plan is outlined in the fourth section, and the last section addresses the protection of subjects' rights.

Study Design

The goal of qualitative research is to provide an account of a culture from the inside (Hammersley, 1992), and in the present context to gain access to the health beliefs and practices of a culture (Robertson & Boyle, 1984). Quantitative methodology was used to examine the occurrence, distribution and frequency of data, and to explore relationships between variables (Leininger, 1985). The ties between quantitative and qualitative methods reflect a recognition that diseases are more than biological, and that subjective experience influences the outcomes of illness (Agar, 1996). Using both methodological approaches pursue simultaneously the goals of cultural validity and research reliability (Lewis-Fernandez & Kleinman, 1995). It also serves as a vehicle to cross-reference and validate both qualitative and quantitative data, and to unravel the complex relationship between meaning and action.

"Ethnographic research is often a necessary first step for generating culturally informed hypotheses that are appropriate for testing with the quantitative methods of analytic epidemiology" (Weiss, 1988, p. 7). Ethnography, which is concerned with the context of discovery and interpretations of cultural phenomena, aims to produce a detailed narrative account of what actually happens in a given social system or process (Atkinson & Hammersley, 1994; Robertson & Boyle, 1984). This is the qualitative method chosen to generate descriptive data and
to elicit the meaning and context of the illness experience of Chinese immigrants with CF and weakness. Through participants’ direct accounts and narratives, ethnography allows the researcher to understand the situation from the participants’ perspective, to capture rich data, discover patterns, to see ways in which somatic symptoms fit cultural codes or idioms of distress, and how new meaning may be improvised through metaphors grounded in bodily experience (Kleinman, 1986; Leininger, 1991).

A non-experimental descriptive design was the quantitative method of choice for this study. Numeric summaries and descriptions of data, as well as the delineation of relationships among variables were explored using statistical tools. These results were then used to elaborate meaning of categories and associations, and determine the congruence of findings from the content analysis of qualitative data.

**Sample**

Family physicians practising in the Greater Toronto Area (GTA) or those who are known to have a large Chinese patient population were contacted to refer patients to this study. Prior to undertaking the current study, the investigator had a very close professional working relation with members of the Chinatown Physicians’ Journal Club throughout her eight-year-tenure as the co-ordinator of a health service catered to the Chinese Community. The availability of subjects and these physicians’ willingness to refer subjects were assessed. Thirty physicians wrote support letters for this study, and the investigator was invited to present the study proposal to over 50 Club members at one of their regular meetings. After the presentation, the president of the Club took the liberty to solicit support from other member physicians on the investigator’s behalf citing the potential contribution of this study in the understanding of migrant health. All those attended the presentation agreed to refer subjects should any of their patients meet the
study criteria. As the pre-test indicated the need of expanding the recruitment of subjects to the GTA, the co-operation of these physicians was sought. They recommended over 70 of their colleague, who were practising in the GTA, to the investigator to communicate for the purpose of the study. A total of 125 physicians were contacted and they all agreed to refer subjects; 45 actually referred, of whom one referred 3 and three others each referred 2 subjects. All except 3 (these 3 were Caucasians and friends of the Chinese-speaking physicians) referring physicians were first generation Chinese immigrants graduated from Canadian medical schools.

Most Chinese patients in Toronto consult family physicians when they encounter health problems (Yuan et al., 1998). The rationale for recruiting subjects in such a large geographic area was to include patients from all socio-economic classes and diversity, such as clan, age, origin and time of immigration. A convenience sample of 50 subjects was drawn through referrals from family physicians. The subjects who met the following criteria, as determined by their family physicians, were selected for the sample:

Inclusion Criteria

1. Criterion “A” of the International Classification of Disease (ICD-10) of neurasthenia: “Either persistent and distressing complaints of increased fatigue after mental effort, or persistent and distressing complaints of bodily weakness and exhaustion after minimal effort”.

2. Above symptoms of prominent fatigue or weakness of at least 6 months’ duration.

3. Adult men and women aged 18-65 with at least 6 years of education.

4. Self identification of Chinese ethnicity and have immigrated to Canada after age 5 from China, Hong Kong, Taiwan, Vietnam or Southeast Asia.

Exclusion Criteria

1. Any medical disease that accounts for their symptoms, based on professional judgement and findings from physical examination, laboratory investigations, or other diagnostic procedures deemed clinically appropriate by their referring physicians.
2. History of schizophrenia, delusional disorders, bipolar disorders, or dementia.

3. Alcohol or other substance abuse or dependence.

Site of Study

The GTA was selected as the site of the study, as it contains the highest concentration of Chinese people outside of Asia. There are four Chinatowns or Chinese shopping centres in the GTA characterized by the many shops selling Chinese medicinal material. In many of these shops there is a practitioner of traditional Chinese medicine. In addition, there are five major Chinese language newspapers, with an equal number of weekly journals published in Toronto; nearly every one of them has Chinese medicinal advertisements and also special columns discussing the nature and use of Chinese medicine. The Canadian government, with a policy of multiculturalism, has been receptive to the practice of traditional Chinese medicine; acupuncture is well accepted by and integrated into the major health care system. Chinese herbalists (usually called Chung-i or Chinese medicine doctors within the Chinese community) are free to advertise their services through the Chinese mass media. Like many of their counterparts all over the world, herbalists are not regulated and their training often varies from years of formal training in an educational institution to informal apprenticeships in Asia (Lee, R., 1980). Therefore, the standard of their services vary; patients often rely on recommendations of family and friends who have sought help from Chinese herbalists when they decided to see one.

This study was conducted in a hospital located at the heart of the oldest and largest Chinatown in Greater Toronto. The hospital offers health educational programs in Chinese which attract large numbers of the Chinese general public from the GTA. All interviews took place in a private and quiet area at the hospital.
Data Management Plan

Data collection and analysis are not neutral activities, rather they are shaped by, and in turn, shape the theoretical framework of a study (Driscoll & McFarland, 1989). The theoretical framework of this study was used to guide the data management plan of the study.

Aamodt (1982) purports that the ethnographer derives cultural data from abstractions of what people do and what people say they do. In this process the researcher/ethnographer becomes an active participant in data collection and data analysis. Analysis of data is focused on generating categories and discovering the relationships between these categories. These fundamental tenets of ethnography were employed throughout this study.

Data Collection

Data collection involved in-depth face-to-face semi-structured interviews with participants, in an attempt to describe and understand the illness or topic of interest from the participant’s perspective. Upon the referral of the subject by his/her family physician, the investigator telephoned the potential subject to discuss and explain the goals and nature of the project. The subject was also encouraged to ask questions pertaining to the project. An appointment was then made to conduct the interview. The purpose of the interview was to achieve an understanding of how the participants perceive and interpret certain aspects of their life and the world around them; informants were probed beyond their initial answers, and additional questions were asked based on their answers (Herman & Bentley, 1992). Prior to the interview, the nature of the study was again explained to the participant and any concerns he/she might have were discussed. The participant was also informed that he/she was free to stop the interview at any time. Written consent was obtained prior to the interview (Appendix B, p. 238).
Instrumentation

Data were collected using the Explanatory Model Interview Catalogue (EMIC) - a semi-structured interview schedule for clinical ethnographic assessment (Channabasavanna, Raguram, Weiss, Parvathavardhini, & Thriveni, 1993; Weiss, 1997; Weiss, Doongaji, Siddhartha, Wypij, Pathare, Batawdekar, Bhave, Sheth, & Fernandes, 1992) (Appendix C, p.239). Despite its usefulness in providing a guide for research in the understanding and comparing of illness experiences, Kleinman’s (1980) model lacks operational precision which makes systematic comparisons difficult (Weiss, 1997). The Explanatory Model Interview Catalogue (EMIC) was developed based on the conceptualization of Kleinman’s (1980) Explanatory Model of Illness to provide a method to assess and compare explanatory models, illness experience and outcome of treatment within and across groups. Recognizing that both qualitative and quantitative methods have limitations in exploring illness experiences and the impact of these experiences on patients’ lives, the EMIC combines both approaches to facilitate an in-depth study of the indigenous concepts of illness and patterns of help-seeking (Weiss, Sharma, Gaur, Sharma, Desai, & Doongaji, 1986; Weiss, 1997).

The EMIC provides clinical ethnographic insights and a means for comparing cross-cultural studies as well as studying intracultural diversity. It enables researchers to operationalize and compare explanatory models of local experience of illnesses (Choprapawon, Chunsutiwat, Kachondham, & Weiss, 1991). Responses generated from the EMIC produce a data set for both quantitative and qualitative analysis of the local experience of illness (Weiss, Desai, Jadhav, Gupta, Channabasavanna, Doongaji, & Behere, 1988). Guided ethnographic interviews of the EMIC produce a qualitative data set of rich descriptive information. Structured sections of the interviews result in a quantitative data set that provides information concerning the distribution
pattern of major variables. This combined data set can then be integrated to allow a systematic way to evaluate cultural models of illness, and analyze relationships between cultural context and outcomes of practical clinical significance (Channabasavanna et al., 1993).

This instrument offers a framework for studying illness experience; different versions of the EMIC have been developed based on this framework (Weiss, 1997). The current version was developed by a team of international bilingual and bicultural experts specifically for Chinese patients who suffer from CF and weakness. It operationalizes Kleinman’s (1980) Explanatory Model of Illness to allow a systematic elicitation of the following aspects of the Model: (1) demographic background, (2) patterns of distress (including stigma), (3) perceived causes, (4) help-seeking and treatment, (5) general illness beliefs, and (6) significant life events. These six aspects of Kleinman’s Model (1980) form corresponding sections of the EMIC; each section covers a defined group of variables with quantifiable categorical ratings and is supplemented by extensive qualitative prose elaboration (Channabasavanna et al., 1993).

“Patterns of distress” refer to the full range of problems resulting from the patient’s condition. These problems include: experience of symptoms, social and economic difficulties, and stigma. In this section the personal illness experience as perceived by the patient was assessed. Since stigma creates tremendous distress, and often impacts on patients’ help-seeking behaviour in coping with chronic physical and mental illnesses, specific questions pertaining to stigma have been included in the patterns of distress section of the EMIC (Weiss, 1997). These questions emphasise the social experience of illness, thereby incorporating Goffman’s (1963) views on stigma (Raguram, Weiss, Channabasavanna, & Devins, 1996). “Perceived causes,” which may influence how a patient seeks help, refers to the patient’s interpretation of the reasons and situations that have bought his/her illness about. Help-seeking behaviours are all the forms of assistance the patient sought to alleviate the suffering resulting from his/her illness. These
include information that enables the patient to perform self-care, family, friends and various kinds of health caregivers available to the patient.

The section on "general illness beliefs" inquires into the patient's generalized ideas about other illnesses, apart from the current problems that are affecting the patient, and their own and their families' opinions about the management of these illnesses. Epilepsy, depression and schizophrenia - illnesses that are stigmatized and poorly understood in Chinese culture - were chosen by a team of clinicians and researchers who are experts of the Chinese culture to be included in this section of the EMIC (Weiss, 1997). Data obtained in this section provide a backdrop against which explanatory models of CF can be interpreted. The section on "significant life events" elicits incidents that have occurred prior to and after the onset of the patient's illness. Data obtained from this section were incorporated into the data set for analysis. The impact of these events was assessed.

Narrative accounts from all sections of the EMIC were studied qualitatively to identify recurrent social and cultural themes concerning patterns of distress, stigma, perceived causes, help-seeking behaviours and their interrelationships. These interrelationships were further explored and substantiated through quantitative analysis. Pearson r was employed to examine the relationships among these variables. To allow grouping of similar themes into one variable, total stigma scores and summary scores of patterns of distress, perceived cause, and help-seeking behaviours, instead of individual scores, were used for analysis.

Structure of the EMIC The EMIC begins with an empowering introduction, whereby informants are given the reassurance that what they have to say is important and relevant. Short vignettes and metaphors are also used to help subjects understand the purpose of each section and reinforce the learner role of the interviewer. The following is extracted from the introduction to the section on perceived causes:
"Each of us may explain something that happens in various ways. For example, if their television suddenly went blank, some people might immediately think it was a picture tube or something inside their set. They might also consider whether the antennae had broken or whether the station stopped broadcasting. It might occur to them that they should have been maintaining or servicing the set more regularly, or perhaps they just weren't meant to see the next program. Similarly, people have different ideas about what hurts them or makes them sick. We would like to understand your own ideas about this problem, even if they are different from ideas of your friends, family or your doctors."

After introducing each section with an effort to keep the informant at ease as much as possible in a hospital setting, each section of the EMIC begins the inquiry with an open-ended question which aims to solicit a spontaneous response from the informant. For example, in the section on perceived cause, an open-ended question: "What do you think is the cause of this problem?" would be asked to start the section. Screening queries are used to help informants to organize their thoughts and address particular areas of interest. Prose elaboration is also utilized in these queries to help in understanding the relationships or associations, if any, among categories. Each section concludes with a summary query to help clarify and validate the informant's ideas. Summary queries, especially in the section on perceived cause, can help the researcher to have a better understanding of how an informant's explanatory model may change over time. The semi-structured interview is structured to cover a full agenda, but enables a trained interviewer to proceed with patients with different response styles. Not all questions are necessarily asked of each informant. It may only take one question to stimulate substantive details of the informant's experience (Weiss, 1997).

**Ethnographic Interview**

The posture of the ethnographic interview, which can best be described as conversations with a purpose, was employed throughout the EMIC. Agar and MacDonald (1995) purport that
an ethnographic interview typically involves two people, the ignorant interviewer and the knowing interviewee. During the interview, the interviewer mostly listens and the interviewee mostly talks. However, the ethnographer does not start out intellectually “empty-handed,” but rather, the interview schedule should be based on the knowledge of cultural patterns and native language, so that the information obtained is relevant and is based on shared understandings between the interviewer and informant (Robertson & Boyle, 1984).

The interviewer conveys to the interviewee that what he/she has to say is important and the use of his/her every day or native language is imperative (Marshall & Rossman, 1989; Schatzman & Strauss, 1973; Spradley, 1979; Wilson, 1989). The investigator conducted all interviews of this study in a language of the subject’s choice: Cantonese, Mandarin (the two most widely spoken dialects of the Chinese language) or English.

Establishing rapport is very important in a lengthy interview such as the one that was required by this study. Rapport implies a harmonious, trusting, positive relationship, but does not require friendship or intimacy (Spradley, 1979). The researcher made a continuous effort to develop and maintain rapport with the respondents. The researcher began the rapport building process by first engaging the respondent in casual conversation at the beginning of the interview, then telling the respondent the researcher’s role in the process and that the conversation between the respondent and the researcher would be kept in strict confidence. The respondent was assured that should a break or termination from the interview be required, his/her wish would be respected.

The investigator’s background, appearance, experience and manner may affect the responses of the informants and the investigator’s interpretation of the data. This investigator is a female health care worker who was born in China. In the early 1960’s, at the age of 7, she escaped to Hong Kong with her grandmother as a refugee to be reunited with her parents. After completing
her secondary education in an American missionary school in colonial Hong Kong, she migrated to Canada where she obtained her post-secondary education and subsequently worked in large teaching hospitals in Toronto. For the first ten years in Canada, with all her family members living in Hong Kong, the investigator shared accommodations and socialized with mainly Canadians from the larger society. The investigator speaks Cantonese, Mandarin, and three other Chinese dialects in addition to English. With this cultural background, the investigator is able to relate to the Chinese and the larger Canadian cultures at ease. However, due to her professional training in Western health care and this study was conducted in a hospital environment, the investigator was very conscious about her subjectivity and potential Euro-centric interpretation of the data. In order to affirm that the correct interpretations of the data were made, the investigator verified her understanding of their narratives with the informants during and at the end of each section of the interview.

Although the EMIC guide was adhered to throughout the interview, since it was designed to be generative, a great deal of personal narrative came forward from respondents. These narratives enriched the data and led to a “thick description,” a thorough description of the context in which the inquiry was concerned (Crabtree, 1992). Interviews lasted from 45 minutes to 4 hours and the average interview length was one and a half hours. Over half of the interview were over 2 hours, and one (#28) took a total 4 hours broken into 3 different days. Another respondent (#38) returned to the hospital twice to complete her interview lasted a total of 3 hours. All subjects required 15 to 30-minute breaks during the interview because of fatigue and concentration difficulties. Accompanied by the interviewer, they took short walks outside the interview area or had some juice or tea while resting in the interview room. Despite the intensity of their fatigue, all were eager to share their experience with the interviewer. They all revealed that the interview provided them with the first opportunity to tell their “stories” to someone (the interviewer) who
shown genuine interest in what they had endured since the onset of their illness. Furthermore, the repeated reassurance of confidentiality allowed the respondents to express themselves comfortably.

All interviews were recorded with the subject’s permission, and those transcripts in Chinese (all except 3) were translated into English for data entry and analysis. The investigator translated all transcripts referencing the glossaries of translated Chinese term into English by Kleinman (1980) and Lin, K. M. (1981) to maintain consistence and accuracy of the translation. For terms that were expressed in Cantonese and not included in the above glossaries, the investigator would translate the terms in the language of the participants who used the terms. For example, Mo Ching Shen is the Cantonese expression of “lack of vitality”.

Validity and Reliability

Validity

For the quantitative component of this study, validity refers to the degree to which a measurement represents the actual phenomenon being measured (Hammersley, 1987). To ensure validity, an adaptation of the EMIC especially suited to the study of Chinese patients with CF and weakness, was used for this study. It was developed, translated and back-translated by a team of bi-cultural researchers from China, Hong Kong, Taiwan, US and Canada at two separate collaborators’ meetings in 1992 and 1993 to ensure accuracy (Brislin, 1970). The questions and coding options of this version of the EMIC had also been tested and validated by pilot tests done in Hong Kong, China, Taiwan and Los Angeles. Content validity had also been established by a panel of researchers from China, Hong Kong and Taiwan (Weiss, personal communication, 1995).
Validity in qualitative research is "the gaining of knowledge and understanding of the true nature, essence, meanings, attributes, and characteristics of a particular phenomenon" (Leininger, 1985, p. 68). Although the researcher is very much a part of the instrument for qualitative research, which brings bias to data collection, Lincoln and Guba (1985) argue that human instrumentation can actually enhance validity through improved responsiveness, adaptability, holistic emphasis, knowledge, and, opportunities for clarification and exploration of atypical responses. Sharing of insights, consultation with members of the thesis committee, and reviewing the first 14 transcripts and their coding with Dr. M. Weiss provided additional checks on validity. The following qualitative validity has been established for this study:

1. Descriptive validity, which is the accurate presentation of participants' narratives (Maxwell, 1992), was enhanced by the utilization of data from the following multiple sources: transcripts and observations from ethnographic interviews, quantitative findings and field notes.

2. Interpretive validity, which is "a matter of inference from the words and actions of participants in the situations studied," was assured by conducting the interviews in the "participants' own language," "rely as much as possible on their own words and concepts," (Maxwell, 1992, p.289-290), and continuous verification of the investigator's understanding of the data with the participants throughout the interview.

3. Criterion-related validity is "the establishment of the existence and nature of the phenomenon with its meanings, attributes, and contextual features" (Leininger, 1985, p.68). The delineation of the phenomenon: being an immigrant with CF and weakness involves the suffering of multiple symptoms, searching for meanings and attributions of these symptoms and trying to survive contextual and social adversaries in a new land, reflected the establishment of this validity.
4. Construct validity which "focuses on identifying and knowing the nature, essence, and underlying attributes of the phenomenon under study" (p.68) has also been attained as participants' shared similar distress and experiences with subjects in other CF and immigrant issue focused research (Leininger, 1985).

5. Concurrent validity refers to the congruency and syntactical relationships of findings with respect to subjective, inferential, intuitive, objective (empirical), and other quality factors under consideration (Leininger. 1985). Detailed content analysis of participants' narratives and cross-reference to the quantitative data of this study demonstrated the attainment of this validity.

**Reliability**

Hammersley (1987) defined reliability as the ability of a study to generate consistent information of the same phenomenon given the same circumstances. The EMIC has been used in many different cultural settings for assessing various medical and psychological disorders (Channabasavanna et al. 1993; Weiss et al., 1988; Weiss et al., 1992; Weiss, 1997) and it has demonstrated good interrater reliability. Kappa statistics were performed on selected key items of the EMIC (Channabasavanna et al., 1993). For 19 items (included: most troubling symptoms, belief in efficacy of doctors, self-esteem, body, mind and social effects, summary of these effects, body, mind, social, environmental and magico-religious sources of illness, summary of these sources, most troubling perceived cause, perceived cause of madness, first help-seeking, acknowledging family help, satisfaction with this clinic and mind/body relationship), Kappa scores ranged from 0.32 to 0.91. Only one score was below 0.5, indicating interrater agreement was in the fair to excellent range of kappa values. The overall summary Kappa for all key items was 0.75 indicating excellent reliability of the EMIC (Channabasavanna et al., 1993).
To enhance reliability for this study, the investigator was given extensive training by Dr. M. Weiss in the proper administration of the EMIC along with training on effective qualitative research skills and techniques. This training included: (1) one-to-one discussions with Dr. Weiss, (2) viewing of videotaped interview demonstrations by Dr. Weiss, (3) listening to audio taped interviews by researchers at another research site, (4) observing actual interviews by Dr. Weiss, (5) conducting interviews under the direct supervision of Dr. Weiss and comparing data ratings with Dr. Weiss, (6) reviewing of completed interviews from pretests of this study with Dr. Weiss, and (7) participating at a one week collaborators’ working conference, with representatives from Hong Kong, Taiwan, China, India, Korea, Los Angeles, Boston and Toronto, to complete the development and validation of the EMIC for this study. Dr. Weiss also imparted extra training during the development of the specific EMIC’s for three other studies at The Toronto Hospital. The investigator’s ability in obtaining valid data with the EMIC had been assessed and assured by Dr. Weiss (Weiss, personal communication, 1995).

Reliability in qualitative study is the identification and documentation of recurrent, accurate, consistent or inconsistent features, as patterns, themes, values, and experiences in similar or different contexts. The phenomena under study consistently reveal meaningful and accurate truths about particular phenomena (Leininger, 1985). Two types of reliability pertaining to content analysis are pertinent to the current study. They are stability and accuracy (Weber, 1990).

1. Stability is the extent the results of content classification are consistent over time. Stability can be determined when the same content is coded more than once by the same coder. The same person (investigator) did all the coding of narratives referencing the EMIC codes and reviewing coding strategies with Dr. Weiss enhanced stability of the findings.

2. Accuracy refers to the extent the classification of text of findings corresponds to a standard.
The EMIC (Weiss, 1997) provided extensive pre-coded categories, thus decreased the amount of free-form coding needed and enhanced reliability.

The reliability of the data was also enhanced by having verbatim accounts of what participants said, detailed field notes of their behaviour throughout the interview, having the same person (investigator) conducted all interviews and in the same location (LeCompte & Goetz, 1982).

**Field Notes**

Field notes enhance the contextualization of data obtained and the data analysis process (Fischer, 1994), and improved the validity and reliability of this study. Field notes were taken during and after each interview. They documented non-verbal observations such as the tone of voice, gesture, posture and facial expressions of the respondent, and, the investigator’s thoughts and problems. Four types of notes were written including: observational notes, theoretical notes, methodological notes, and personal notes (Schatzman & Strauss, 1973).

Observational notes consisted of all events experienced through watching and interviewing, such as postures, behaviours, tone of voice and expressions (Schatzman & Strauss, 1973; Wilson, 1989). Theoretical notes were interpretations, inferences, and conjectures derived from the observational notes. Methodological notes consisted of instructions to oneself (the researcher), critiques of tactics, and ideas about methodological approaches (Schatzman & Strauss, 1973). Personal notes were written to describe how the researcher’s age, sex, culture, status, role and even appearance might be influencing the data collection and analysis. Feelings, both positive and negative, during the interview were also recorded. Personal notes add valuable context and trustworthiness to observational and theoretical notations (Kirk & Miller, 1990; Spradley, 1979). These notes were inserted into the text of the transcribed interviews and incorporated into the
data to inform the interpretation of findings by providing a context to the verbal data obtained. For example, observational notes would provide the information that the participant was crying when she was illustrating how difficult it was for her to care for her family when suffering from CF.

**Data Analysis**

Both qualitative and quantitative data were checked for completeness before entering into their respective computer programs for analysis. NUD*IST, a free-form prose-oriented database, was used to assist the analysis of qualitative data. Quantitative data were entered into a data entry program written in DataEase, a database management software program which incorporates appropriate range and logic checks to minimize data entry errors. After quantitative data were entered, the same data were entered again and the "double entry" feature of DataEase was used to detect any discrepancies from the initial entry. All errors were corrected, once any discrepancies were detected. These data were then imported into SPSS for MS Windows Release 6.1 for statistical analysis.

**Qualitative Data Analysis**

Analysis of the ethnographic data involves explicit interpretation of the meanings and functions of human actions in verbal descriptions and explanations; as well as rebuilding and presenting the processed data set in a thematic or conceptually relevant whole (Knafl & Webster, 1988). Quantitative and statistical analysis usually play a subordinate role in this endeavour (Atkinson & Hammersley, 1994). Data analysis began after the first interview and ran concurrently with data collection. As soon as an interview was completed, qualitative data were translated, transcribed and analyzed immediately. This preserved the integrity of the data which
might otherwise be jeopardized by difficulty in recollection due to time lapse, and also identified emerging ideas that could be checked or tested in other interviews (Marshall & Rossman, 1989; Miles & Huberman, 1984).

Each section of the EMIC consists of several descriptive categories with predetermined codes for data analysis (Weiss, 1997). After data were inputted into the NUD*IST program, they were coded using the descriptive categories and coding schemes of the EMIC. If specific data did not belong to any categories of the EMIC, free-form coding judgements were made, and new categories and codes were developed. All qualitative data, including observational data obtained during each interview were analyzed using content and thematic analyses.

**Content Analysis**  Content analysis is the isolation, counting, and interpretation of themes, issues, and recurring features of the data (Denzin & Lincoln, 1994). The following steps, proposed by Singleton and colleagues (1993), were used as a guide for content analysis: (1) defining a set of content categories, (2) sampling data described by the categories, (3) quantifying the categories by frequency of occurrence, and (4) relating category frequencies to one another or to other variables. All qualitative data were analyzed, sentence by sentence, to facilitate proper content categorization. Ideas were reduced to numbers or an enumeration of specific variables. Analysis summaries were written on each subcategory. These summaries were used to describe the content of each major category.

**Thematic analysis**  Themes are the manifest generalized statements by informants about beliefs, attitudes, values, or sentiments (Luborsky, 1994). The following steps proposed by Leininger (1985), were employed in thematic analysis: (1) identifying patterns (or pieces of patterns) from informants’ narratives and researcher’s observations, (2) aggregating related data into meaningful units according to similarities, (3) identifying subthemes and their relationship
to the larger themes, (4) synthesizing of small themes into a comprehensive view of the data, and, (5) formulating theme statements to test or reaffirm phenomena.

Themes were delineated within and across categories of data to facilitate the extraction of meaning from the data set. The raw data of this study were analyzed; components or fragments of ideas and experiences were brought together to form meaningful units or categories. Broad topics for the findings, such as perceived cause and help-seeking behaviour, were described in major categories; subcategories, such as physical cause and traditional health practitioners, were developed to reflect narrower topical areas within the major categories. The coded data in these major and subcategories were reconstructed into a thematic whole. Relevant quotations from interviews were employed to illustrate the themes and the impact that informants' illness had on their lives.

**Quantitative Data Analysis**

Descriptive statistics were performed for all quantitative data, such as for the demographic data, frequency of a particular symptom, stigma, perceived cause and help-seeking behaviour categories. Nominal, ordinal and interval data were also obtained from the demographic questions. Interval data were extracted from the patterns of distress, stigma, perceived cause and help-seeking behaviour sections of the EMIC.

Responses to spontaneous, screening and summary questions from each section of the EMIC were tabulated. Based on related meanings, responses were collapsed into summary groupings. For instance, the category of psychological perceived cause was formed by collapsing perceived causes of mind-thoughts-worry (refers to concerns and experience of negative emotions), familial upbringing (refers to how one was brought up) and personality attributes (refers to nature of one's character) (Weiss, 1997).
The significance of each category was rated using a relative weighting system. Scores were assigned based on the importance of a particular response as perceived by the informant. For example, if the informant specified a particular cause of his/her problem as being the most important, a maximum score of 5 was assigned. If the informant responded without prompting to an initial open-ended question, a score of 4 was given. A score of 3 was given to a response that was obtained through a specific question. "Possible" attributions or "first" attributions to the informant's problem were assigned scores of 2 and 1 respectively. Total values for each perceived cause can range from 0 (if the cause were not mentioned at all) to 10 [by adding the following values: mentioned initially (value of 4), most important (value of 5), and first (value of 1)] (Weiss, 1997). Details of computation of grouped patterns of distress scores are described in Appendix D (p.291), clustered perceived cause scores in Appendix E (p.295) and prominence scores of help-seeking in Appendix F (p.299).

A section of the EMIC explores issues related to stigma, including concerns about disclosure of illness and social rejection of self and family, and the impact on self esteem (Raguram et al, 1996). In this study, these concerns were assessed by asking 12 different questions, and a summary indicator of stigma was calculated based on responses to these questions. The response to each question was coded on a scale from 0 to 3, where a higher numeric value indicated greater stigma. Stigma scores that could range from 0 to 36, were obtained by adding responses from all 12 questions. Reliability of this stigma scale was established by assessing its internal consistency using Cronbach's alpha. Details of computation of these scores are described in Appendix G (p.304).

Each of these categories represented variables that were components of the informant's explanatory model. All categories were summarized and further analyzed by using descriptive and inferential statistical techniques. Scatterplots were done to identify linear relationships
between different variables. Differences between two independent groups were examined using t-test to examine relationships between nominal and interval data, such as gender, marital status, religion, place of emigration, place of birth, years of education, years of migration and major variables in the EMIC. Analysis of variance (ANOVA) was used to examine within group and between group differences for variables with interval data in the sections of (a) patterns of distress, (b) perceived causes and (c) help-seeking behaviour. For significant ANOVA’s, a post-hoc comparison test, Tukey’s Honestly Significant Difference, was used to determine the source of the difference (Norman & Streiner, 1994). Levene’s tests were performed to confirm homogeneity of variance (Norusis, 1993).

The Pearson correlation was used to examine the relationships among variables with interval data within and between sections. Due to theExploratory nature of this study, an alpha level of 0.05 was used to determine the statistical significance of the correlation coefficient obtained (Norman & Streiner, 1994). These results were then used to determine their congruence with the findings from the content analysis of qualitative data.

**Advantages of Integrating Quantitative and Qualitative Methods**

Integrating quantitative and qualitative methods in data analysis gives the researcher a much clearer picture of the data. Using both methods concurrently allows a two-way reference of patterns of data obtained from each method. Thus, quantitative data are enriched by qualitative data and *vice versa*. For example, sections of the interview that address particular components of the explanatory model (e.g., kidney weakness as a cause of one’s CF and weakness) or themes of social context (e.g. engage in physical labour as a result of being a new immigrant contributes to one’s CF and weakness) yield categorical ratings of quantifiable explanatory model variables and
qualitative narratives suitable for thematic coding by topic. A tabulation of quantitative data, such as the percentage of subjects who refer kidney weakness as a cause, may then be clarified with prose accounts that clarify the meaning and experience behind the percentages reported in quantitative data. The perceived cause of kidney weakness will then be understood from the patient’s perspective (e.g., why he thinks it is a cause, how it works to affect his body and other aspects of life). Should the theme of ‘overwork’ be recurring in the qualitative data, the researcher can easily refer back to the quantitative data set to identify how many individuals cite overwork as a cause. Subcategories can also be created to delineate how many people attribute their overwork to ‘not adjusting to physical labour as a new immigrant’. Furthermore, cross-tabulations of quantitative categorical data can also enable the researcher “to identify patients from cells with many responses, and for whom prose detail is likely to clarify the meaning of a strong association. On the other hand, examining the prose from a cell with a small number of responses may clarify the nature of exceptions to the typical pattern, from which there may also be much to learn” (Weiss, 1997).

Pretest

A pretest of the EMIC was conducted using a sample of ten subjects who met the sample selection criteria. The pretest was used to determine the adequacy of the procedure for assessing the subjects and the clarity and ease of administration of the EMIC. The pretest provided an opportunity for detecting any gross inadequacies or unforeseen problems before the actual data collection began. The length of time required to recruit the 10 subjects for the pretest helped confirm the decision to extend the recruitment of subjects to the Greater Toronto Area, and not restrict it to the City of Toronto, as large numbers of Chinese had moved to the suburbs of
Toronto. Physicians who had a large composition of Chinese immigrants in their practice were recruited to refer their patients to the study.

Despite their extreme fatigue, all 10 subjects completed the interviews which took one and a half to three hours with one to three short breaks in between. Results of the interviews were analyzed. All of the subjects found the questions comprehensible and appreciated the opportunity to “do a self-analysis of their illness.” Since no major difficulties were encountered in the pretest, no alteration in the interview schedule or the EMIC was required. Findings from these 10 subjects were included in the final study sample of 50 subjects.

**Protection of Subject Rights**

All subjects were assured of anonymity. Each subject was assigned a code number. Subjects’ code numbers and data were kept in a locked file accessed only by the investigator for confidentiality. To ensure as much privacy as possible for the subjects, the interviews took place in a room within the hospital, away from the hospital’s heavy traffic areas. Only the investigator had the security code to access the data on computer. Only group statistics have been reported and no individual subject has been identified from reported results. Permission to conduct this study was obtained from the Office of Research Administration at the University of Toronto.

**Risks and Benefits**

There was no known risk to participants. It was not anticipated that the information asked would jeopardize the emotional well being of the participants and they answered questions willingly. Where participants were experiencing extreme fatigue or discomfort, the interview was paused to allow for a rest period. Participants were encouraged to discuss their requests for referrals with their family doctor rather than with the interviewer. The ethnographer is not an
interventionist; her role was to observe and record (Srivastava, 1991). There was no immediate benefit for the subjects other than having an opportunity to verbalize their feelings and illness experiences. All 10 subjects in the pretest stated that they enjoyed the opportunity to share their experience with the researcher, as many of them felt that they had not been heard by others. The investigator anticipates that the knowledge gained will assist health care workers in providing culturally sensitive and appropriate care to Chinese patients suffering from CF.

Summary

The methodology of this study has been outlined with reference to the literature in order to accurately describe the study design, sample selection and data management plan. Data collection using the EMIC as an instrument has been explained in detail. Validity and reliability of the instrument, as well as in qualitative research were addressed. Finally, strategies in protecting study participants’ rights were proposed.
Chapter V

RESULTS

The goal of this study is to provide a better understanding to health caregivers of the illness experience of Chinese immigrants who suffer from CF and weakness. The objectives of this study are (a) to elicit Chinese patients' patterns of distress, stigma, perceived cause(s) and help-seeking behaviour. This chapter is divided into five major sections. The first section describes the characteristics of the participants. In the second section, descriptive qualitative and quantitative findings are presented with reference to the first three objectives of this study depicted in Chapter II (p.30). Thematic categories delineated from the analysis of data related to the patterns of distress, stigma, perceived cause and help-seeking experience of participants, as well as the influence of Chinese cultural concepts and migration on their illness experience are described. The third section addresses the research questions which explore the relationships of individual variables as outlined in the fourth research objective (p.30). In the fourth section, participant’s general illness beliefs which provided a backdrop to their explanatory model of illness are introduced. Finally, two brief case vignettes are presented in the last section of this chapter to illustrate the lived illness experience of two participants.

Characteristics of Sample

All 50 participants, 28 (56%) women and 22 (44%) men, were first generation Chinese immigrants to Canada. Their mean age was 40.44 years (standard deviation 10.74, range 20 - 64); 80% were between 20 to 50 years of age. Participants’ mean age at immigration to Canada was 30.94 years (standard deviation 10.17, range 15 - 52), with 82% younger than age 40. The average number of years living in Canada was 9.5 years (standard deviation 6.31, range 1 - 23), with 64% less than 10 years. All of them completed at least 6 years of education, 60% (30) achieved post-secondary level and 6 had graduate degrees, mostly from their places of origin. Their average personal monthly income was $875, with 18 (36%) of them claiming that they
were either living on savings or were supported by their families. Their average total monthly household income was $2453, with 3 (6%) conveying that they had no income but had to rely on their savings. The majority (58%) was married, while 24% were single, 12% separated or divorced, and 6% widowed. As for occupation, almost half (46%) were unemployed, 16% were students (post secondary or graduate), 14% were professionals or owners of small businesses, and 6% were clerical workers or laborers respectively. Slightly more than one-third (36%) of the participants had no religious affiliation, while 28% were Protestant, 22% worshipped Chinese gods and ancestors, 10% Buddhist, and 4% Catholic. Although half of the interviewees (50%) were born in China, immigrants from Hong Kong comprised 54% of the total (some participants originally from China immigrated to Hong Kong many years ago). The demographic data are indicated in Table 1.
Table 1
Demographics of Study Participants (n = 50)

<table>
<thead>
<tr>
<th></th>
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<th>Median</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
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<td>15</td>
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</tr>
<tr>
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<td>$1102</td>
<td>$0</td>
<td>$3500</td>
</tr>
<tr>
<td>Total Household Income (Monthly)</td>
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<td>$1824</td>
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</tr>
<tr>
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<td></td>
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</tr>
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<tr>
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<td></td>
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<tr>
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<tr>
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<td></td>
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<tr>
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<td>Other</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Mainland China</td>
<td>17</td>
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<td>Other</td>
<td>6</td>
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</table>
Descriptive Qualitative and Quantitative Findings

Rich qualitative data were generated from participants' narratives of the lived experiences of their illness. They told stories of shattered dreams and ambition, loss of status and opportunities, and threats to family honour, all of which were part of the experience of suffering from CF. Although each patient unveiled a unique experience, the impact of migration was the overriding theme in all interviews. Their narratives were grouped into the following major categories: (1) patterns of distress, (2) stigma, (3) perceived cause, and (4) help-seeking behaviour. Many themes emerged from the participants' narratives of their illness experience and their lives as immigrants. There was considerable overlap across these themes and all the themes within a category are interconnected. Relevant quotations from face-to-face interviews are used to illustrate the themes and convey their concrete significance for the lives of the participants. Descriptive statistics are employed to present the quantitative data, which help summarize the qualitative findings.

Patterns of Distress

All 50 participants described the onset of their distress as gradual. Forty-eight (96%) of them had considered their fatigue as a health problem for two years or less. They reported 4 to 12 symptoms with the majority (72%) suffering from 6 to 8 symptoms. Fatigue was identified by 17 (34%) participants as the symptom that brought them to the awareness that they had a health problem, while 14 (28%) cited somatic symptoms and 12 (24%) sleep disturbances. Twenty-three (46%) perceived their problems as very serious and 20 (40%) as moderately serious.

Despite the overlapping and interconnectedness of themes within the major category of patterns of distress, narratives in this category can roughly be grouped into three sub-categories of somatic, psychological and social distress. Somatic distress, illustrated in both physical and
traditional Chinese medicine terms, was reported by all the participants. Amongst the numerous symptoms of somatic distress reported, fatigue and weakness, as expected, were the most frequently reported symptoms and had the greatest impact on participants’ lives. Psychological distress was alleged to a lesser extent. Within the category of social distress, stigma and difficulties with social relationships were explored. Stigma was indicated to be their sole social distress. Social relations played a significant role in participants’ perceived cause of their illness (see findings presented under heading of perceived cause), but were not considered a major distress to participants.

**Somatic Distress**

Analyses of open-ended questions on somatic distress revealed three general symptom complexes that were particularly salient for the participants: (1) fatigue and/or weakness, (2) sleep disturbances and somatic discomfort, such as pain, and gastrointestinal discomfort and (3) dizziness. Participants’ narratives moved from their description of somatic distress to difficult situations that confronted them on a daily basis, as immigrants. Fatigue and weakness made the participants feel helpless in fulfilling their obligations to their families, and threatened their survival in what was a recession-battered Canadian economy.

The following are descriptions of the salience and explanation of the three symptom complexes:

(A) Fatigue and weakness are the most distressing symptoms,
(B) Sleep disturbance is both a distress and a source of fatigue,
(C) Somatic discomfort is incorporated as part of one’s life.

**A: Fatigue and weakness are the most distressing symptoms**

This theme emerges from the qualitative data of all 50 participants. There is a strong sense of losing control of one’s body. A participant (#23) conveyed, “there is this constant feeling of
tiredness and even sleeping more doesn't help." "Fatigue," "tiredness," "exhaustion," "lack of energy," "no strength," "xu ruo" (deficient and weak), and "mo ching shen" (no vitality) were terms used inter-changeably to describe their feelings of fatigue and weakness. The disabling nature of their fatigue, not only prevented them from functioning at their normal level, but also transformed the simplest daily activities into difficult and even overwhelming tasks. Some had difficulties even in climbing stairs in their own homes, while others, such as a 56-year-old female participant, who claimed not having sick leave during her 20-year employment at a bank, expressed that their fatigue and weakness had turned normal simple tasks into insurmountable challenges. The following remarks were made by this employee:

I cannot take it any more. It is not because I am facing a work problem (as a teller) or anything like that, just ordinary work, right? I just feel that I cannot stand it anymore. So ruo (weak). So ruo (weak). (#37)

Some participants illustrated the severity of their fatigue and weakness by comparing them to a feeling of dying or being "dead", as they did not even want to move their limbs.

Tired to the point that I only lay down, but could not fall asleep. Tired to the point that I did not want to move my arms and legs. I lay there as if I were dead. (#38)

**B: Sleep disturbance is both a distress and a source of fatigue**

Forty-three (86%) out of 50 participants indicated that they suffered from various degrees of sleep disturbances. Insomnia and subsequent difficulty waking up in the morning were reported by 28 (56%) participants. The majority of them were feeling extremely frustrated and helpless as they "tossed and turned" in bed for hours, feeling exhausted but not able to fall asleep. Some even said that they actually felt anxious as the night went by; worrying that it was going to be another long, long sleepless night. They blamed insomnia for their fatigue and "feeling drowsy during the day."

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1 The number following each quote identifies the specific participant.
Fifteen (15) participants reported that sleepiness and the desire to sleep all the time affected their activities of daily living, especially work performance, and in some cases, sleepiness might even have endangered their lives. Some stated that they had a difficult time getting up in the morning. Even if they managed to leave their bed, they would have an urge to sleep throughout the day. Those who were still in the work force, felt so sleepy that they had no motivation to work. Most of them spent all their spare time sleeping and this affected their self esteem and interpersonal relationships. For those who worked with machinery or had to drive on their jobs, their sleep disturbances subjected them to the risk of injury and life threatening situations. A 38-year-old male industrial engineer illustrated:

_I had 3 consecutive car accidents within a 4-week period. On one occasion, I fell asleep when I was driving; it was in the afternoon.... I used to have insomnia and hated to go to bed, but now I want to sleep.... I can sleep 16 to 17 hours at a time._ (#39)

C: **Somatic discomfort is incorporated as part of one’s life**

Almost all the participants suffered from a certain amount of somatic discomfort. They revealed that they had learned to live with multiple somatic symptoms and accepted them as part of life. Forty-one (82%) of them suffered from pain or headaches. Common symptoms included: Pain (27/50 or 54%), mainly joint and muscle pains; headache (14/50 or 28%); GI discomfort (10/50 or 20%) varying from diarrhea, abdominal pain, stomachache, bloating, poor appetite and dry mouth; dizziness (9/50 or 18%); cold symptoms (4/50 or 8%); sexual dysfunction (3/50 or 6%). Most participants suffered from a combination of these symptoms which, they claimed, developed gradually after they immigrated to Canada. Many reported that these symptoms intensified with their fatigue. Some said that they felt as if they had never recovered from a severe cold winter years ago, and that they were having a prolonged flu without the sneezing and coughing. The narrative below is representative of the somatic distress suffered by most participants:
I feel very tired, and have joint pain and experience mo ching shen (lack of vitality). Every night I cannot fall asleep. (#47)

**Psychological Distress**

Functional impairment (especially social and personal functioning), depression and cognitive impairment were the most common forms of psychological distress the participants reported.

Three interrelated themes in this category were identified:

(A) Impairment in social functioning and feeling depressed hinder fulfillment of family obligations and personal goals,

(B) Cognitive impairment hampers self confidence, particularly with regard to social and occupational roles,

(C) Living in a foreign land produces feelings of anxiety.

**A: Impairment in social functioning and feeling depressed hinder fulfillment of family obligations and personal goals**

Twenty-nine (58%) participants reported symptoms of functional impairments (social and personal functioning), and 25 (50%) reported symptoms of depression. These individuals stated that they suffered tremendous psychological distress, because they were losing interest in doing things they used to enjoy and avoiding social functions. Consequently, they were unable to fulfill obligations to their elderly parents and/or young children. Those who were parents felt frustrated and ashamed as they were too listless to play or spend time with their children. Those who were children felt very "inadequate" and guilty as they not only did not have the stamina to pay respect or care for their elderly parents as dictated by the Chinese culture, but rather they required the assistance of their parents to cope with their illness. The patients' suffering was compounded by their loved ones who failed to understand or accept their illness. As this 34-year-old receptionist who lives with her parents illustrated her feeling of frustration and helplessness when her mother would talk to herself but made sure whatever she said was within the patient's earshot:
My mother would say (to herself), "I have never seen anyone as lazy as her (the patient). After eating rice (dinner), she would go to sleep just like a pig. It is ridiculous, after eating rice then to go to sleep. I have never seen anyone like her, then get up to wash dishes, have a shower then back to sleep again. Don't know what she is doing." She (mother) thinks that I am ridiculous, but I do not want to be like that either. Honestly, I don't want to.... I am not happy with my mother's comment. I am honestly not lazy, I am not a lazy person. (#40)

Some felt depressed and "nan-kuo" (sad, miserable) because the goals they had set for themselves probably could never be achieved and their dreams of settling comfortably in a new land could never come true, their hopes dashed and dreams broken. For instance, a 47-year-old mother, who escaped from mainland China to Hong Kong at the age of 13 and thought that she had finally found a permanent home in Canada for herself and her family, alleged:

I feel depressed. I have studied English for a long time. In my mind, I hope that I can learn fluent English here (Canada) and can speak and understand others in English. Now it seems that I cannot achieve this. (#44)

This participant felt that without the blessing of English proficiency, she could never fully participate in the Canadian society, or communicate with her two daughters who were "losing their Chinese." She remarked that her fatigue had robbed her of her hope of a new life in Canada.

B: Cognitive impairment hampers self confidence, particularly with regard to social and occupational roles

Cognitive impairment was reported by 19 (38%) participants. Inability to concentrate and poor memory were the symptoms of psychological distress that the participants had to contend with on a daily basis. Their self esteem was severely eroded; some even lost confidence in themselves. Their activities of daily living were affected; some had to give up driving, because they were not able to concentrate when behind the wheel and on the road. Others could not even prepare a meal because they might forget to turn on the rice cooker or complete the cooking
process. Lack of concentration also made learning difficult for the participants. Poor memory could also be a frightening experience, as illustrated by a 53-year-old sewing machine operator, who was dismissed "due to lack of concentration and falling asleep several times at work":

Sometimes I forget how to write my address when others ask me to do so. I have poor memory. I keep forgetting when I try to do something. I have to devote time to recalling what I want to do all the time. I have to go back to the original spot to figure out what I wanted to do. When I go out, I always forget to bring my keys. I have to go back to the house to get all the things I forgot.... Sometimes, when I am walking on the street, I forget which way I should go. (#47)

Lack of concentration and poor memory created tremendous concern for the participants as many feared that even if their energy level improved and fatigue eliminated, they would not be able to hold on to a job with their cognitive impairment, and in turn, their ability to support themselves and their family.

C: Living in a foreign land produces feelings of anxiety

Anxiety symptoms were reported by 18 (36%) participants. They attributed their anxiety to the decrease in their level of functioning as a result of their illness and maladjustment to Canadian life. Many felt anxious as they envisioned their future. They dreaded possible permanent unemployment should their illness not improve. Unfamiliarity with the Canadian social protocol and lack of English proficiency also made these individuals feel anxious in their interaction with the larger society. Most participants sought help from Chinese-speaking sources if at all possible; many became anxious when they needed to communicate in the English language. Such as applying for sickness benefits or going to see a medical specialist who is non Chinese-speaking. As revealed by a 40-year-old, male, factory worker who immigrated to Canada from China 7 years ago:
I became very anxious. Even with little stress. My heart beats faster. For example, talking with a stranger, seeking help from others in Canada, due to language barriers (I feel very anxious). (#49)

Social Distress

Stigma associated with fatigue is the main theme in the category of social distress. Thirty six (72%) participants claimed that stigma constituted part of their distress in coping with their illness. Participants did not considered difficulty with social relationships to be a social distress, but alleged social discord as a major cause of their problems. Specific questions pertaining to stigma have been included in the patterns of distress section of the EMIC to elicit patients’ distress in coping with their illness (Weiss, 1997). Findings on stigma will be presented under a subsequent heading entitled stigma.

Numeric Summary of Patterns of Distress

Table 2 below shows the mean scores of individual symptoms that constituted the participants’ patterns of distress. The possible range of scores of both the grouped and individual patterns of distress are from 0 to 5. The scores of the participants ranged from 0 to 5 indicating high level of distress to no distress. As illustrated in the qualitative findings, somatic distress, especially fatigue and weakness, played an important role in the participants’ suffering.
Table 2

Patterns of Distress Individual Scores

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Maximum</th>
<th>Minimum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>2.60</td>
<td>1.07</td>
<td>5.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Weakness</td>
<td>1.76</td>
<td>0.96</td>
<td>4.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Sleep</td>
<td>1.72</td>
<td>0.57</td>
<td>3.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Somatic</td>
<td>1.42</td>
<td>1.36</td>
<td>5.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Stigma</td>
<td>1.10</td>
<td>0.81</td>
<td>2.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Functional Impairment</td>
<td>0.94</td>
<td>0.98</td>
<td>4.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Hypochondriasis</td>
<td>0.92</td>
<td>0.94</td>
<td>2.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Depression</td>
<td>0.74</td>
<td>0.83</td>
<td>2.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Cognitive Impairment</td>
<td>0.70</td>
<td>0.95</td>
<td>3.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.66</td>
<td>1.06</td>
<td>4.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Amotivation</td>
<td>0.46</td>
<td>0.81</td>
<td>2.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Lonely</td>
<td>0.18</td>
<td>0.60</td>
<td>3.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Social Relation</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Other</td>
<td>1.52</td>
<td>0.76</td>
<td>2.00</td>
<td>0.00</td>
</tr>
</tbody>
</table>

These individual symptoms were categorized into grouped patterns of distress scores. Figure 2 depicts the grouped patterns of distress mean scores. The participants suffered from a combination of symptoms. Somatic distress was responsible for the major part of the participants' suffering, followed by psychological and social distress.
Most Troubling Aspect of Problem

The participants were asked to identify the one most troubling aspect of their problems. Forty-two (84%) out of 50 who responded were able to pinpoint what troubled them the most: 32 (64%) cited somatic, 6 (12%) psychological and only 4 (8%) social (all cited stigma). The remaining 8 (16%) claimed that a combination of somatic, psychological and social disruptions constituted the most troubling aspects of their problems.
Name of the Problem

The following were names the participants gave to their problem of chronic fatigue and weakness. Only two participants called their problem Chronic Fatigue Syndrome and only one Yuppie Flu. These three patients explained that they found their symptoms to match what they learnt about Chronic Fatigue Syndrome from the mass media. Six declined to give a name as they felt that only doctors were qualified to name an illness. Table 3 shows the names patients used to depict their problem.

Table 3

<table>
<thead>
<tr>
<th>Name</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>13</td>
</tr>
<tr>
<td>Shenjing Shuairuo (Neurasthenia)</td>
<td>10</td>
</tr>
<tr>
<td>&quot;Mo Ching Shen&quot; (no vitality)</td>
<td>5</td>
</tr>
<tr>
<td>Shen-kuej (kidney weakness, degeneration)</td>
<td>2</td>
</tr>
<tr>
<td>Chronic Fatigue Syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Headache</td>
<td>2</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
</tr>
<tr>
<td>Viral Infection</td>
<td>1</td>
</tr>
<tr>
<td>Back and shoulder pain</td>
<td>1</td>
</tr>
<tr>
<td>Back injury</td>
<td>1</td>
</tr>
<tr>
<td>Discomfort in heart</td>
<td>1</td>
</tr>
<tr>
<td>Insomnia</td>
<td>1</td>
</tr>
<tr>
<td>Yuppie Flu</td>
<td>1</td>
</tr>
<tr>
<td>Vexation</td>
<td>1</td>
</tr>
<tr>
<td>Mental breakdown</td>
<td>1</td>
</tr>
<tr>
<td>No Name given</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
</tr>
</tbody>
</table>
Five major themes are identified through thematic analysis from the qualitative data obtained on stigma. These themes are:

(A) Avoid disclosure if at all possible,

(B) Others’ knowledge of one’s illness would affect one’s chance of getting married or one’s marriage,

(C) Family preferred concealing patient’s condition,

(D) Feeling ashamed and inferior, and

(E) Fear of negative effects on the family.

**A: Avoid disclosure if at all possible**

Thirty-five (70%) informants indicated that they would avoid letting others know about their fatigue. Those who did not live with their families said they would keep it from them. Fourteen (14/35) participants felt that since there was no practical gain from telling others, “other people could not help anyway,” it would not be necessary to disclose their fatigue. Another reason for keeping their condition secret was the feeling that other people would not understand their problems. Some (9/35) participants felt that even their family members and physicians did not understand their problems and thus it was futile to tell them. They also feared that if told, they would be labeled as “lazy” rather than having a health problem. A 24-year-old male university student from Hong Kong explained:

*Not just ordinary people, even doctors do not recognize it as a problem. Ordinary people would think I am lazy and use this as an excuse not to work... I do not want to explain to them since they will not understand.... They will not look down on me but think that I am lazy instead.... Basically, how should I say it, she (mother) will keep others from knowing the bad things in the family. She does not accept my problem as an illness. She does not (understand me). She would think that I am lazy and use this (illness) as an excuse. (#18)*
Fourteen (14/35) participants reported that there were certain people they would wish not to
tell about their fatigue. They were afraid of adverse effects such as: (1) the truth might jeopardize
their jobs or might hinder them from landing a job, (2) other people might dislike those who had
problems, (3) they would feel “worthless” if their conditions became known, and (4) the
disclosure would make their family worried. These individuals also commented that it was “a
cultural thing” not to tell others about one’s failure or disgrace. They added that culturally,
Chinese people did not wash their dirty linen in public. Such sentiment became more intense
when they thought their illnesses might be linked to mental illness. People to avoid from
disclosure included co-workers, employers and old friends. For instance, a 47-year-old housewife
from Hong Kong, did not even want the nurse (who is Chinese) in her doctor’s office to learn of
her illness for fear of stigma associated with mental illness. She stated:

*Yes, of course, I do not want others to know about my problem. I seldom tell others of my
problem. I recently told my husband about my problem. But he does not agree with me. I want to
tell Dr. W. (about my conditions and ask him) to refer me to a psychiatrist. My husband thinks
that I do not need to see one. This is a Chinese thing. For the Chinese, they think that it is not a
good thing to have mental illness. It is a taboo amongst the Chinese.... Most Chinese do not like
others to know. It is not just me, but all Chinese. The Chinese are afraid of mental disorders and
think they (who suffer mental illness) are terrible. The person who goes to see a psychiatrist will
be regarded as useless. (#44)*

**B: Others’ knowledge of one’s illness would affect one’s chance of getting married or one’s**

**marriage**

Thirty (60%) participants felt that their illness would jeopardize their chance of getting
married if they were looking for a mate, and 26 (52%) said that their married life would be
affected. These individuals saw themselves as a burden to their spouses, and others, especially
women, felt ashamed of not being able to assume their responsibilities in meeting the day to day
needs of their families. Some participants (11/30) considered themselves suffering from poor
health and speculated that their chance of finding a mate was diminished, because in general,
people prefer to marry someone healthy. The following quote by a 41-year-old woman captured this sentiment:

*If people know, it will affect my chance of marriage. The potential partner would probably mind. It is not a matter of discrimination. It is reality. Everybody is very realistic these days. Exchange places, it does not matter if it is man or woman. If you are looking for a partner and the partner is like this, you would probably think twice.* (#48)

**C: Family preferred concealing patient’s condition**

More than half of the participants (26) remarked that their families felt strongly that their problem should be kept inside the family, in some cases even more so than the patients. They felt that it was a cultural (Chinese) thing that people wanted to keep things to the family. Lack of a concrete physiological explanation of patients’ chronic fatigue, fear of being linked to a mentally ill person and a common Chinese belief, mentioned by some participants: “*Family shame should not spread outside*” might have hindered family members from disclosing patients’ illnesses. A 42-year-old man from China explained:

*I do not mind others knowing about my problems, but my wife does not want other people to know. I may meet someone who has the same condition and he may be cured by taking some medication or being treated by a good doctor. I do not mind telling people. My wife thinks differently. She thinks this is not something you should feel proud of.... She thinks that others may think less of me if they know my problem.* (#22)

**D: Feeling ashamed and inferior**

Suffering from fatigue had a major impact on some participants’ self esteem. Fourteen felt ashamed, 13 thought less of themselves and 7 also felt looked down on by others. They were no longer able to do things that they used to do, “*achieve what others can*” or fulfill family obligations. Feelings of being “useless,” “a failure,” and “losing face” intensified their suffering. Twelve (equal numbers of male and female) participants reported that due to lack of understanding of their illnesses, they had been mistakenly considered by others (especially co-
workers) as being lazy and as a result, they had lost face. Thoughts of being looked down upon by others rendered in the informants feelings of shame and resentment. The subjects also noticed that others had avoided them since they had the illness. A 40-year-old man from Hong Kong resented this avoidance, particularly from his cousin whom he had helped prior to his illness:

Yes, my cousin used to be quite close to me and I helped him to find a job when he first came to Canada. But as soon as he had found out about my problems, he tried to avoid me. He (cousin) would not even come to our house for a visit. (#8)

**E: Negative effects on the family**

Twelve participants (24%) said that others knowing their illness would create problem for their families. Ten (20%) were concerned that their families would be despised by others or their family members’ chances of marriage would be jeopardized as a result of their illness. A 52-year-old man from China felt that his daughter would probably marry a Chinese-Canadian who might be more acculturated into the Canadian culture than an immigrant from China, because more Westernized Chinese-Canadians might be more accepting of his condition:

It may affect my daughter a little bit. I think she will marry a Chinese-Canadian one day, because when someone sees that her father is working as a manual labourer, with illness of fatigue and low social status, you know, they may look down on her. (#20)

**Stigma Scores**

The possible individual stigma scores range from 0 indicating no stigma to 3 indicating highest stigma in each category. The total stigma score is computed by adding the individual scores for a total of 12 categories; the range of the total stigma score is 0 to 36. Table 4 and Figure 2 below show the individual stigma scores and total stigma score from the quantitative data on stigma. These scores summarize the personal experience of stigma illustrated by the qualitative data presented.
The criterion for judging the acceptability of a scale’s internal consistency is a Cronbach coefficient alpha of 0.70 (Frank-Stromborg, 1992). The stigma scale demonstrated good internal consistency with a Cronbach coefficient alpha of 0.814. The mean total stigma score is 14.52, with a standard deviation of 8.44, sum of 726, minimum score of 0 and maximum score of 35. Indicating that most subjects were suffering from a moderate level of stigma. Figure 2 shows the distribution of total stigma scores of all the participants. Most feel they experience a fair amount of stigma as a result of their illness. With the highest score being 36, one participant (a 45-year-old unemployed machine operator, who was a teacher in China) has a score of 35 indicating a high level of perceived stigma suffered by the individual.
Coping Strategies to Minimize Stigma

Coping strategies to minimize the impact of stigma experienced were formulated by the participants. These were mainly self-directed. Strategies included: avoiding people and keeping to themselves, attributing their misfortune to fate, and normalization. Most informants seemed to think that normalization was the only strategy that would help them to keep their jobs in today’s grim employment reality. A 46-year-old man from Hong Kong expressed:

*I don’t want people to know. I want to pretend, especially at work, that there is nothing wrong with me, but my look of fatigue gives me away.... I have this illness I don’t want to have it in the open to let all my co-workers know. That is why even when I was really suffering at work, to the point that I didn’t even want to move, I still kept on working.* (#15)
Perceived Cause

Participants were asked to speculate about the cause of their illness. Culture and their migration experience were believed to have precipitated their illness in many cases, although most participants reported that in fact, there were multiple contributing factors for their fatigue. This was illustrated by the following quote from a 38-year-old university educated male industrial engineer of Hong Kong descent:

_There are multiple factors put together. It may be related to fate, cause and effect. The cause can be my past, my family relationship, educational background, lifestyle, personality, and why my brother’s wife liked Toronto so much that my family moved here. All and all, "I would not be like this, if I was not stuck in Toronto."_  

Eight interrelated themes can be identified from the participants' narratives as causes of their perceived problem. Although the participants were never directly asked about the impact of migration on their illness, some of them gave accounts of their illness experience being shaped by their experiences as immigrants in a foreign land. The impact of migration was reported as one of the major causes of their illness. Many were grieving for their losses - quite a few could not find similar jobs in Canada, while a good number regretted having sold their properties in Hong Kong since the value of property there had incredibly increased 200% after their departure. Their financial difficulties in Canada resulted from downward social mobility, underemployment and unemployment, compounded with increased expenses stemming from the cost of treatments that are not covered by health insurance. A substantial number of the participants were unable to work and had to rely on savings they brought with them at the time of migration. Although they might still be able to put food on the table, they were worried when they thought of their grim future, and the slim chance for them to return to their old selves prior

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2 "*" indicates patient’s actual words in English.
to migration. The common theme of the impact of migration infiltrated and influenced many of
the other themes on the perceived cause, as illustrated below:

(A) Social factors as the most significant perceived cause,

(B) Overwork and adjustment to physically demanding work exhaust one’s body,

(C) Psychological factors contribute to fatigue,

(D) Medical and physical causes - learning the cause from the mass media,

(E) Traditional/cultural explanations - one’s body in disharmony,

(F) Congenital or hereditary factors - getting the illness from birth,

(G) Magical and supernatural forces that are beyond one’s control,

(H) Being exposed to environmental pollution.

**A: Social factors as the most significant perceived cause**

Forty-seven participants (94%) attributed the cause of their fatigue to social issues. Coping with the challenges of an “astronaut” family, difficulties encountered in interpersonal and familial relationships after migration, coming to terms with underemployment or unemployment, being victimized by racial discrimination especially at the workplace are the sub-themes of this theme.

**a: Coping with the challenges of an “astronaut” family**

Participants cited coping in a new social milieu as an immigrant, especially without the support of their spouse, as the major cause of their fatigue. Lack of employment opportunities due to Canadian economic downturn in recent years led to the creation of “astronaut” families, in which one spouse (mostly men) works in Asia to support his family in Canada and flies back and forth to see his family a few times a year; the other spouse (mostly women)
solely carry the burden of caring for young children and elderly parents or parents-in-law in their newly adopted home - Canada. As explained by a 41-year-old mother of two who previously worked as a secretary in Hong Kong, life as a "single mother" in a new land posed great challenges, requiring her to look after her children and manage the household all on her own without any support from her spouse.

*I think its (illness) onset has connection with the fact that my husband and I are living in 2 different countries (husband works in Hong Kong). Besides, my son's health problem also makes me very anxious, and other family members (mother- and brother-in-law) are not communicating with me. Moreover, I feel my life is very monotonous and boring.* (#33)

Other immigrants were left behind in Canada to fulfill the immigration residency requirement, while their spouses returned to their places of origin to continue to pursue their careers. These subjects often found that such long-distance relationships created tremendous difficulties for their marriage and negatively affected their health. A 32-year-old secretary, who was previously employed as a marketing executive in Hong Kong, expressed:

*He (husband, an engineer) has gone back to Hong Kong (owing to lack of employment opportunity in Canada) for a year and a half now. We are separated due to employment problems, but not because of incompatibilities. It is hard to say how it would turn out, because he is there and I am here. There is uncertainty (about our marriage). This has major effects on my problem.* (#16)

**b: Difficulties encountered in interpersonal and familial relationships after migration**

Interpersonal conflicts and tension developed amongst extended family members. In their home country, they usually did not live in the same household or have close contacts with each other. However, they had to live under the same roof in Canada for mutual support, due to unfamiliarity with the new environment. The resulting tension was especially serious for patients from Hong Kong and Guangzhou where space is at a premium, and they were accustomed to living in a nuclear family unit prior to migration. These participants resented
having to share a house or an apartment with members of their extended families after coming to Canada. To the Chinese, the term ‘family’ includes both members of their immediate and extended families and such definition extends beyond the Western concept of a nuclear family unit. Participants felt obligated to live with members of their extended families because space was no longer in short supply. However, they found it extremely difficult to cope with conflicts arising from the day-to-day discord and lack of privacy. Subjects reported difficulty in expressing displeasure to senior family members since they feared this might be interpreted as a disrespectful gesture. A 36-year-old factory worker, who was on sick leave at the time of interview, attributed her illness to family disharmony. She conveyed:

*Three years ago when my sister’s family first came (to Canada) from China, they lived with us. There were conflicts between my mother-in-law and my sister. I was very upset by the situation, but didn’t dare to say anything. I began to experience discomfort in my heart at that time. My husband told me it was because I kept everything to myself and that led to my problem. I think he is right. The emotional upset during those 9 months probably did something to me. (#5)*

Difficulties in adjusting to Canadian life and changes in familial roles were reported as other causes of marital problems, which in turn was perceived to have an impact on the participants’ health and fatigue. The following quote is from a 38-year-old former fashion designer who was very frustrated by her husband’s inability to reestablish his garment manufacturing business in Canada.

*I’ve had lots of arguments with my husband for these 3 years after we came to Canada. We have lots of problems. We even thought of getting a divorce….. We paid a big price for immigration. We had fewer problems when we were in Hong Kong. In Canada, our marital relationship has deteriorated. (#38)*

**c: Coming to terms with underemployment or unemployment**

Many also suffered from downward social mobility due to underemployment or unemployment. They felt demoralized and attributed their illness to an inability to launch a
challenging job and wastage of their skills. A 44-year-old female jewelry salesclerk from Hong Kong, was very resentful that she could no longer resume her career as a successful jewelry merchandizer in Canada. She felt that her fatigue was caused by her change of lifestyle in Canada where her dreams were shattered and potential could not be developed.

*My lifestyle was forced to change after coming to Canada. This is not what I had in mind before I came here. I find that I have to make major changes to adjust, I can put up with the severe climate, but absence of a challenging job is the most difficult thing to adjust to.* (#14)

d: Being victimized by racial discrimination especially at the workplace

Racism, especially discrimination in the workplace, was also perceived as a major contributing factor to their illness. A considerable number of participants felt that preferential treatment was given to their co-workers who were from the major culture. They believed that they were often given the hardest tasks, and were targeted and even blamed for mistakes made by other workers. Their inability to defend or express themselves fluently in English compounded their problem and compelled them to suffer in silence. They said that supervisors, who did not appreciate how difficult it is to learn a new language as an adult, often blamed them for what they thought was reluctance to learn English. Some participants found it very frustrating that they had tried their best to learn English after a day's hard work, but did not seem to be able to retain the English they learnt. A 42-year-old factory worker considered racism and interpersonal conflicts as important causes for his fatigue. He said:

*There are racism and personal conflicts in the factory. I have worked for 4 years in the factory.... I think it is more than overwork. I think discrimination (racism) is the most important cause.... I am not happy working there, because the foreman always wants to find fault with me. It may be because my English is not good enough. I don't know what they think about me.... I think that poor English is a reason for discrimination; people think that we do not want to learn English. They want to increase my workload but with less pay.* (#22)

A 53-year-old female unemployed sewing machine operator also alleged:
"I am discriminated in the factory since I do not speak English. They blame me for others' mistakes. I cannot defend myself because I do not speak English. I feel very miserable in Canada because I cannot speak English. (#47)"

B: Overwork and adjustment to physically demanding work exhaust one's body

Forty-two out of 50 (84%) participants felt that overwork was the cause of their fatigue. Lack of a support system in Canada, change from a sedentary position to a labour intensive job as a result of non-accreditation of their overseas credentials, limited English proficiency and hard work to support extended family members in their homeland were reported as causes for their fatigue. Many found the “Canadian lifestyle” of juggling a full time job, childcare and housework extremely demanding. This was especially so among female participants from Hong Kong who had maids do household chores prior to migration; some of them remarked that they did not even know where to begin. This problem became worse if they were members of an “astronaut” family and had to perform “a man’s work” of shoveling the snow or mowing the lawn. As illustrated by a 43-year-old mother of three young children:

"We have no relatives or friends in Toronto. It is just the two of us coping with all the childcare. Yes, all the hard work and lack of sleep over an extended period of time have exhausted me and weakened my body. (#9)"

Others recounted a long history and cumulative effect of overwork on their bodies over the years. Their narratives reflected the political and social developments of China that greatly affected or even uprooted their lives. Many felt that they were in an exodus all their lives - started by their parents - searching for the promised-land where they could find political and social security. Trying to resettle in a new land was a repeated experience for all the participants who were born in China, later emigrated to Hong Kong and eventually immigrated
to Canada. Perhaps the only difference this time was that they became the leaders of the second exodus. A 46-year-old male recalled:

*I think feeling tired has a lot to do with me working night shift since I came to Canada.... When we (patient and family) went to Hong Kong (from Mainland China) in the 50's, our living conditions were very poor. Shek Kep Mei (a government housing project for refugees and new immigrants from China after the Communists took over China in 1949) was a slum. My mother had to carry soil at construction sites for $2 something a day. After that, she worked as a sewing machine operator, so even I knew how to operate a sewing machine. I had to work when I was 9 years old. She would rent a sewing machine home, she went to work in the morning and returned home at 6 or 7 in the evening. We didn't have electricity and only used oil lamps, and we sewed with that light. Life was hard in Hong Kong at that time. My sister was about 11 to 12 years old and she had to work as a child labourer on an assembly line in a factory. I sewed at home, the complicated items would be sewed by her (mother) and I would sew the simple ones. I would sew straight lines of a pocket, and I would do that as soon as I came home from school. That might have some effects on my fatigue now, because even at such a young age I had already overworked.* (#15)

Many participants, especially those from China, felt that they had overworked themselves to meet expectations and demands from relatives. A lot of resentment was directed at their demanding relatives who still held the belief that Canada was a "gold mountain" for anyone to dig, and that whomever had the opportunity to dig it was obligated to share the good fortune with their loved ones who were left behind in the home country. Despite feeling treated unfairly, the participants did not feel able to forsake this obligation, and they felt that they had to work hard to meet their relatives' demands. As time passed, they believed that the additional hard work took a toll and caused their fatigue. A 50-year-old engineer from Shanghai voiced her frustration:

*They (brother and sister-in-law) do not know how hard life is in Canada. They think we have gone to the Gold Mountain (Some Chinese people call North America by this name due to the gold rush at the turn of the century), and that all we have to do is to pick up the gold wherever we go. In fact, we have to work very hard. Often we work till midnight or 2 o'clock in the morning. They won't understand this. They keep demanding things. They want this and that. They want us to pay for long distance calls. Endless demands. Finally, I cannot take it anymore. This might have been the cause of my problem.* (#25)
C: Psychological factors contribute to fatigue

A psychological cause was reported by 47 (94%) of the participants who stated that they were living with a tremendous amount of stress. They stated that this stress was primarily from trying to survive in a new land, having language problems and having lost the familiarity and security of living in their home country. Living with shattered dreams, some put enormous pressure on themselves to succeed in the new country. Their self-esteem and confidence plummeted as they recalled their “glorious days” prior to migration and now saw their former subordinates in their homeland take over their previous positions. The plunge in their financial and social status rendered them feeling helpless and hopeless, because they could not return to their place of origin, due to skyrocketing house prices or the inability to reclaim their previous jobs or seniority in employment. Moreover, they feared that going back would cause them to be looked down on by others and to lose the ability to acquire citizenship status in Canada. Many felt guilty and wondered if they had made the right decision to come to Canada. They considered stress and their inability to cope with it as the cause of their problem. A 28-year-old mother of two daughters, aged 3 and 5, from China recounted a story of being abandoned by her abusive husband one and a half years prior to the interview.

_I guess it is because of all the stress I have had ever since I came to Canada. I used to lead a very sheltered and protected life when I was in China. I was single then. But ever since I was in Canada, I have had to face lots of misfortune in life by myself especially after my separation from my husband._ (#3)

Others regarded their personality as the contributing factor to their illness such as: having a negative outlook on life, worrying over trivial things, becoming anxious easily and possessing a rigid personality. A 40-year-old factory worker from China, who considered himself as suffering from neurasthenia, explained:

_My personality is that I do not adjust easily, so the most important cause is immigration to Canada. Also, there is pressure from learning English. I cannot pick it (English) up.... In Canada, I get nervous easily. This causes neurasthenia._ (#49)
**D: Medical and physical causes - learning the cause from the mass media**

Perceived causes of a Western medical or physical nature were mentioned by 37 (74%) of the participants. It is surprising to note that their conception of Western medicine was similar to that of their ancestors when Western medicine was first introduced to China more than a century ago. They felt that Western medication was only effective in treating acute illnesses, but might have a negative effect on their health in the long run. Information from the mass media on Chronic Fatigue Syndrome also influenced their perception of the causes of their illness. Some attributed their illness to acquiring the Epstein-Barr virus. This sentiment was expressed by a 56-year-old female bank teller and male owner of a fast food restaurant of the same age:

*Since I had an operation, hysterectomy, I have not been sleeping well, maybe that resulted in my fatigue several years later. (#37)*

*I think my cold causes the deterioration of my body. It is caused by the virus. (#43)*

**E: Traditional and cultural explanations - one's body in disharmony**

Forty-five participants (90%), described the cause of their illness in traditional Chinese medical terms. They claimed that they formulated this cause by monitoring their own body sensations and associating these sensations with what they had learnt about traditional Chinese medicine when they were growing up. They also consulted family and friends, and obtained a diagnosis of their current illness by practitioners of traditional Chinese medicine. Cultural health beliefs were reflected in the participants' use of terminology and in the perceived causes of their illness. The following were common traditional Chinese medicine terms which the participants used to describe the causes of their illness: "M-kau huet" (not enough blood), "xu" (deficiency), "feng hon" (wind, cold), "xu ruo" (deficient and weak), "xu hon" (deficient and
cold), "shuai" (degeneration), "shen xu" (kidney weakness), "shen kuei" (kidney deficiency), "Ching Lock (channels and collaterals) imbalance", "lack of qi," "Yin Yang imbalance," "Mo Ching Shen" (no vitality). Many blamed themselves for not observing rituals outlined by traditional Chinese medicine in maintaining good health, such as a 44-year-old woman with four children ranging from age 8 to 16, who expressed:

*I did not take precautions after my pregnancies. For example, I came in contact with water a lot and I didn’t rest as I should have. I had to do all the housework within a month after I gave birth, there was no one to help me. I’m sure if I did all the right things that month, I would be a lot healthier. Such as avoided water, heavy lifting and work, avoided cold foods.* (#1)

Several interviewees, especially those who called their problem neurasthenia, attributed their problem to shen xu or kidney weakness which is a sign of aging or deterioration of one’s body due to overwork or lack of nutrients. Others used shen kuei or kidney deficiency, which is related to excessive sexual activity to account for their problem. A 32-year-old male whose wife was living in China at the time of the interview illustrated:

"M-kau huet" (not enough blood) in my heart is probably the major cause (of my problem). Neurasthenia is certainly related to shen xu (kidney weakness). According to the principles of Chinese medicine, kidney is the source of Ching lick (vital energy). If a person is energetic, for sure, the person’s kidneys are strong. Also, when people are approaching their thirties or forties, when they start to grow old, the first organ to become weak is the kidney. (#24)

**F: Congenital or hereditary factor - getting the illness from birth**

Half of the participants (25) felt that they were prone to fatigue and weakness because they were born weak or not as strong as others. They attributed their illness to lack of nutrition as a child or before they were born, while others thought that since members of their immediate family, such as mother or sister, suffered from neurasthenia or kidney problem, they must have inherited it. Some felt frustrated rather than relieved when they were told by Western medicine practitioners that their kidneys were healthy. Such worry and confusion
were indicated in the account of a 28-year-old, computer science graduate from a Canadian university:

*I suspect that my waist (pointing to lower back) problem is due to my kidneys. A long time ago, when I was still in my home town, someone told me, in a long distance call, that my sister had kidney disease. I think if the disease is hereditary. I may also suffer from it.* (#42)

**G: Magical or supernatural forces that are beyond one's control**

A cause that was related to interpersonal difficulty was found amongst more than half of the participants (29 or 58%) with references to sorcery, bewitchment and spirit attack. Some interviewees held the belief that one could fall ill merely by the envy, hatred and ill-will of another person who wanted one to die, suffer or fail. Others attributed causation of their illness to ancestral or their own wrongdoing in past or present lives. Moreover, some participants felt that supernatural forces were responsible for their illness, such as being put under a "Kong-Tau" (a curse), in a period of bad luck in one's destiny cycle, or having bad feng shui (geomancy), which can occur if one's ancestors' tombs are dug in the wrong places or one's house faces the wrong direction. A 44-year-old very fashionably dressed jewelry saleslady, stated that after she had moved out of her old house which had bad feng shui, she felt less tired, her son's academic performance had greatly improved, and her husband and she fought less over the phone (her husband, based in Hong Kong is involved in China trade, and the family gathers together twice a year). The following is what she said about her house:

*I think the feng shui of my old house was very bad, because the garage blocked the entrance and that implies there is no way out. Furthermore, the number was 110, an unlucky number sounding like everyday is zero.* (#14)
H: Being exposed to environmental pollution

Environmental pollution and sick building syndrome were cited as causes of their problem by 29 (58%) of the participants. A 56-year-old father of two (#43) had tremendous guilt for bringing a discarded but comparatively new vacuum cleaner home, because he and his family all suffered from upper respiratory distress and fatigue after inhaling dirt and feathers from the vacuum cleaner. His wife and children recovered quickly, but his 90-year-old mother-in-law did not recover till she went back to Hong Kong for three months. However, the patient’s symptoms persisted even after he had thrown the vacuum cleaner out for almost a year. He stated that his fatigue had affected his ability to work and his sexual performance. Although his wife had been very understanding, he was worried that his fatigue might eventually affect their marital relationship if it did not improve. Another participant, a 31-year-old machine operator from China, considered that his fatigue was caused by the poor air quality at work. He alleged:

There are chemicals at work, especially in the area I work. Every place is closed and there is no fresh air. All the glass doors are shut tight.... I think definitely pollution is a cause. All the pollution and dirt in our environment are bad for our health. (#29)

Perceived Cause: Prominence Rankings

Quantitative data from the perceived cause section of the EMIC showed that the participants (all except #27 who could not indicate which cause was the most important) reported the following as the one most important cause of their fatigue: social (34%), mainly interpersonal conflicts, overwork (12%), psychological (10%), medical or physical (10%), congenital or hereditary (6%), environmental or personal hygiene (6%), traditional (Chinese) or imbalance of Yin and Yang forces (4%), magico-religious (4%). Although most participants
alluded to the influence of migration on the above-mentioned causes, in the category of others (12%), all participants cited the impact of migration directly as the cause of their fatigue. Issues related to the impact of migration included: changing from being part of a major culture to being part of an ethnic minority, racism, learning to live in a multicultural society and getting along with diverse cultural groups in the workplace, underemployment or unemployment, drop in social status, language difficulties, unfamiliarity with social and health systems, and adjustment to severe cold climate. Table 5 below depicts the mean scores of 12 clustered categories of perceived causes of the 50 participants. The possible range of the score is 0 to 10, and the range of scores reported by participants is 0 to 10. All perceived causes, except social, are in the lower half of the range.

Table 5

<table>
<thead>
<tr>
<th>Clustered Category</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
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<tbody>
<tr>
<td>Social</td>
<td>5.26</td>
<td>3.07</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Work/Weakness/Nerves</td>
<td>3.72</td>
<td>2.52</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Psychological</td>
<td>3.70</td>
<td>2.15</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Medical/Physical</td>
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<td>2.78</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Traditional (Chinese)</td>
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<td>1.45</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Congenital/Hereditary</td>
<td>1.70</td>
<td>2.26</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Magic/Relig/Supernatural</td>
<td>1.68</td>
<td>1.94</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Ingestion</td>
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<td>1.62</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Toxicity/Sanitation/Hygiene</td>
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<td>1.62</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Victim/Abuse</td>
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<td>1.05</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Sex</td>
<td>0.16</td>
<td>0.58</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Other (Impact of Migration)</td>
<td>2.62</td>
<td>2.97</td>
<td>0</td>
<td>10</td>
</tr>
</tbody>
</table>
Help-Seeking Behaviour

The participants' ways to obtain their diagnosis and effective treatment characterized their help-seeking behaviour. Other than their family doctors, all participants sought help from different practitioners and sources. They were often given alternative diagnoses or told that there was nothing wrong with their health. Such 'medical' advice made them feel discouraged, frustrated and disenchanted with their caregivers. One interviewee (#28) claimed that he had sought help from at least 10 Western doctors and many alternative medicine practitioners. Little improvement in their illness and the quest for a cure accounted for this persistent help-seeking behaviour. Traditional Chinese medicine practised by Chung-i (literally translated as Chinese doctor) was the most preferred alternative treatment sought. Those who had not sought help from practitioners of traditional Chinese medicine stated that actually they would like to see a Chung-i, but they could not afford it as these practitioners' consultation fees were not covered by health insurance. All respondents engaged in some form of self-help or sought help from their families and/or friends to a certain extent. They found that families and friends could be very helpful if they accepted that the patients were ill. However, they added to the patients' suffering by insisting that they behave "normally" and meet commitments to their families. In general, most participants were not satisfied with the help they acquired. The following themes emerged from the category of help-seeking behaviour:

(A) Effective or not, family doctors have done their best to help,
(B) Traditional Chinese medicine may be effective but is too expensive as an ongoing treatment,
(C) Western medicine cannot get to the roots of the problem,
(D) Self-help sometimes works; family and friends can be helpful if they accept there is an illness,
(E) For peace of mind, seek help from supernatural sources,
(F) Mental health practitioners - can they help?
**A: Effective or not, family doctors have done their best to help**

Most participants did not have high hopes of a cure from their family doctors, because the majority of them had seen a number of physicians to no avail. Others felt that their family doctors "can only help me temporarily or just treat the symptoms because only Chung-i can get to the root of things." (#10, a 21-year-old university student majoring in one of the health sciences) Although they knew that their family doctors were willing to help, they felt that the doctors had very little understanding of their illness. However, they did feel that it was important to be assessed and monitored by their family doctors using modern Western medical technology to rule out any major illnesses. Some patients, like a 46-year-old male postal worker, who was a graduate from one of the universities in Hong Kong, were disappointed that just ordinary diagnostic tests rather than more sophisticated ones were prescribed:

_I think that ordinary tests cannot detect my problem. I may need some very special and in-depth tests to find out my problem, but I have never had those yet._ (#27)

**Satisfaction with Care**  
In spite of their fatigue and other distress not being relieved, most patients still had great regard for their family doctors. Since most participants had sought help from various sources to no avail, their expectations of their doctors were relatively low. A willingness to spend time listening and talking, and taking them seriously were considered as major reasons for choosing a particular physician as their family doctor. Reassuring patients that "this (the illness) might be related to immigration to Canada" (#49) gave them hope because they could accept their illness as temporary and believe they would get better once they adjusted to Canadian life. Giving words of encouragement, taking a holistic approach and addressing patients’ and family members’ concerns beyond the patients’ physical distress were looked upon as "exceptional for a doctor to do" (#8) and were key elements in the satisfaction with care. A 30-year-old Canadian trained engineer who is studying for his second degree in
commerce due to an inability to land a job in his field, summed up the sentiment of most participants who were satisfied with their family doctors' care:

I am happy with him since he explains things in detail to me.... I am satisfied with him. I don't expect him to help me with my current problem, because I have seen many doctors before and none of them could help in this matter, so he should not be an exception. (#36)

No concrete diagnosis given, "taking too much blood (for tests)," "no medications given" and feeling that they were not being heard were reasons rendered by the participants for dissatisfaction with care. For Chinese patients, from a tradition in which physicians' standard methods of diagnosis rely solely on observation, interrogation, palpation and auscultation with the physicians' senses only, the heavy dependence of Western trained physicians on modern technology diminished these patients' confidence in the doctors' judgment. Still embracing their forefathers' misconception of Western medicine, some patients who went to a Western trained physician for a quick fix, felt cheated when they were told that their illness was "all in their mind." It was unthinkable to them that no medicine was prescribed. Although most laboratory tests, such as urinalysis, were acceptable, many participants were reluctant to have repeated blood tests, because they believed that even a small sample of blood would drain their positive energy (yang force), and further weaken their bodies. A 56-year-old business man alleged:

He (doctor) relies heavily on laboratory tests and does not diagnose. No matter what you tell him, he thinks that I worry too much and it is in my mind. The most he would do is to tell me to have some x-rays and laboratory tests done, and the results are always fine. This is one of the reliable ways to detect diseases, but it does not work for my cold.... I do not invent this illness or the symptoms myself; it does not come from the mind. He should realize that my complaint is real. If doctors say everything is from the mind, then the patient will have nothing to say. If this illness turns out to be something serious, he may blame the patient for seeing him too late. A lot of doctors are like this, and I don't think he is the only one. (#43)

Some participants felt that their physicians were not understanding or sympathetic to their situation. They felt that doctors failed to realize that: (1) the patients' illness was just one of
many things that they had to cope with, (2) patients had to work to earn their wages, as most of them did not have sickness benefits such as sick leave, and (3) it is very difficult to find a job in today’s economic climate, even for local Canadians. Thus, many patients felt frustrated when the physicians told them to take time off work to rest. It was almost like telling the poor to eat cake when they had no bread. A 45-year-old former high school teacher from China, who worked as a machine operator in a factory, complained:

*I had told my doctor that my boss did not understand me, and that created a lot of stress for me. He (doctor) said, "you should just quit your job." Did he not know that I have responsibilities? If I do not work, where will I get an income? (#31)*

For others, being told that “there is nothing wrong” by their family doctor gave them no comfort but robbed them of the support and concern of their once sympathetic love ones. A 36-year-old factory worker from China alleged:

*I’m tired all the time, so I end up sleeping a lot. When my husband comes home from work, he always says, “Why are you sleeping all the time? The doctor says there is nothing wrong, so why are you tired all the time?” (#5)*

**B: Traditional Chinese medicine may be effective but is too expensive as an ongoing treatment**

Traditional Chinese medicine was by far the most utilized alternative treatment. Other modes of alternative medicine such as naturopath, Shiatsu, aroma therapy, radionic therapy, massage therapy were only used by two respondents (#16 and #28). The majority of the interviewees (42 or 84%) had sought help from traditional Chinese medicine practitioners and those who had not (8 or 16%) were planning to see one in the future. Although not all participants could obtain a diagnosis from their traditional Chinese medicine practitioners, the
following were diagnoses given to some of the participants by their traditional Chinese medicine practitioners:

*Flow of my blood is not very smooth.* (#4)

*Don't have enough blood in my heart.* (#5)

*I don't have enough "qi" (vital energy), so I'm yin and cold.* (#9)

*I don't have enough "qi" and my Yin Yang balance is off.* (#10)

*My spleen had degenerated.* (#12)

*My kidneys are "xu ruo" (deficient and weak).* (#13)

*He (Traditional Chinese medicine practitioners) felt that I did not have enough blood and I had wet heat and wet toxin (too much unsupported yang forces).* (#16)

*Imbalance inside all my internal organs, "shen k'uei" (kidney deficiency). "Ching Lock" (channels and collaterals) being "xu ruo" (deficient and weak).* (#19)

Treatments given by traditional Chinese medicine practitioners as recounted by the participants included: medicinal herbal teas and massage to rebalance the yin yang forces, acupuncture and acupressure to open meridians, cupping to suck out excessive yin force.

**Satisfaction with Care**

Traditional Chinese medicine practitioners were considered to be people who understood the terminology the participants used to explain their illness, and who could get to the roots of their problem in spite of requiring a longer treatment period. However, skepticism developed toward them because they did not employ investigation equipment, and did not have the medical qualifying examinations that are associated with a high standard of care. Since their services are not covered by OHIP, the financial burden arising from such help

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3 These diagnoses should be interpreted in the context of traditional Chinese medicine, but not their literal meaning in Western medicine.
deterred a considerable number of participants from seeing or continuing to consult traditional Chinese medicine practitioners or herbalists, the name generally used by the Canadian public (a misleading term as apart from using herbs, they also include ingredients such as animal parts and minerals in their prescriptions). Nevertheless, due to their desperation to find a cure and based on recommendation of family and friends, some interviewees felt obligated to give traditional Chinese medicine practitioners a try. Their opinions towards traditional Chinese medicine practitioners are summed up by the remarks of the following two participants, a 24-year-old male university student (#18) and a 41-year-old housewife who is a student of English as a second language (#48).

_I am afraid of Chung-i (traditional Chinese medical doctor, herbalist), since there is no qualifying examination. This does not mean I do not believe in the basic principles of Chinese herbal medicine or traditional Chinese treatment methods. It is that they are not like Western doctors who are regulated by rules within a comprehensive system, have to sit for qualifying examinations and whose license will be suspended if they do something wrong. I am afraid that anyone can practice medicine, all "Cheung Three" and "Lee Four" (just about anyone) can practice medicine. There is no way to differentiate how qualified he is; is he a Hua T'o (a famous physician in Chinese history) or just someone who cheats for a living?_ (#18)

_Western doctors do not talk about xu (deficiency) or ruo (weakness) of the body that kind of thing, only Chung-i (traditional Chinese doctor, herbalist) talks like this. Although I do not trust Chung-i (traditional Chinese doctor, herbalist), I have to give it a try._ (#48)

**C: Western medicine cannot get to the roots of the problem**

In addition to seeing their family doctors, all 50 participants had sought help from other physicians of Western medicine (such doctors are called Sai-i in the Chinese language). Some were looking for a second opinion from another family doctor; others were hoping that specialists, who were perceived as having more skills than family doctors, would be able to help them. Neurologists, rheumatologists, internists, gynecologists, nephrologists (Some male patients told their family doctors that they had a kidney problem and insisted on such a
referral) and family physicians were among the Western doctors consulted by the interviewees. When their hope for a cure was shattered, they tended to voice their dissatisfaction with this group of practitioners more readily than toward their family doctors. Perhaps, they had a higher expectation of the specialists, or they were afraid to be too critical of their family doctors, knowing that they were the referring doctors of this study. Some patients, like a 64-year-old man from China who was laid off from his job as a cook, were very disappointed that Western doctors did not prescribe potent oral medication or injections as they expected:

_I have seen 3 different doctors, they didn't tell me anything specific. I found them very conservative in their treatment. No injection was given. All of them said that there was nothing wrong with me._ (#13)

**Satisfaction with Care** Not spending enough time listening or examining the patient, not answering or giving very short answers to their questions, delivering mixed or conflicting messages were the major complaints about this group of Western medicine practitioners. Those who had to wait for a long time for their appointment, were particularly disappointed when they were left with the same or more questions unanswered. Their last hope for a cure from Western medicine seemed to them to have vanished. Many were also very frustrated when these doctors, most of whom were Chinese, did not comprehend the terminology of traditional Chinese medicine which the participants used to explain their symptoms, and did not clarify or admit that they did not understand. Some participants, like a 45-year-old university commerce graduate from China who had just been laid off as a machine operator, resigned to the view that one should not expect Western doctors to understand any concepts from traditional Chinese medicine:

_Different doctors said different things, some even said entirely different things that made you wonder whom to believe.... I know middle aged people may have kidney "shuai" (degeneration), so I asked the doctor if I had kidney "shuai" (degeneration), but he said no. And it was not spleen. "shuai" (degeneration) neither. Of course, Sai-i (Western doctors) do not know those terms._ (#31)
The inability of the practitioner to assign a diagnosis often implied to them that the problem might be psychological. The patients were resentful about an actual referral to a mental health worker or even about the suggestion of such a referral. In addition, they often felt angry about the practitioners’ failure to admit their inability to treat their illness. The following is how a 43-year-old man, former university student in psychology and law, who is now working as an astrologist, felt about Western doctors:

*In the Western world, Sai-i, that is how they are trained in school: when your problem does not fit in the current medical knowledge, they will send you to a psychiatrist. They (Western medicine) don’t teach their doctors to be humble, they won’t admit that their medical knowledge is inadequate and they have not had the knowledge needed to treat this illness. Even it is the truth, they would not admit to it, they would say this is your fault. This is how I feel.* (#28)

Many participants compared Western and traditional Chinese medicine practitioners, without this being solicited. They felt that Western doctors treat patients according to their symptoms, "If I have foot pain, they will just treat the foot pain although the source of the problem is somewhere else…. They treat your head if you have a headache, and your foot if you have foot pain" (#19), while traditional Chinese medicine practitioners treat them holistically by returning their bodies back to balance. The following is the explanation given by a 45-year-old male machine operator from China on why he went to both Western and traditional Chinese medicine practitioners:

*I go to him (Western doctor), because he can do lab tests and blood tests. Chung-i (traditional Chinese medicine practitioners, herbalists) cannot do those things…. They (Western doctors), in general, would not say "you are shuai" (degenerating). Really, they do not even know if you are tired, because this (fatigue) is something you can feel but other people cannot see…. After I read a few of those Chung-i reports, I feel that they make a lot of sense. As for the Sai-i (Western doctor), they stop right here, and they tell me that I am okay, but you still feel unwell. Then, you sense that these people (Western doctors) may not believe what you have told them. You should do this and that, but they never consider that your "Ching-Shen" (vitality) is poor…. Sai-i does not give you medicine, even if he wants to help you, he would say "what can I give you? Antibiotics?" There is not any part of you that has an infection.*
Medication to stop the pain? There is not much pain to stop. There is no way to help. Chung-i would say that my "ching-lock" (channels and collaterals) are not open (block) or balanced. If my "ching-lock" are open, I should be okay. (#31)

D: Self-help sometimes works; family and friends can be helpful if they accept there is an illness

All participants engaged in self-help to a certain extent; they felt that they had to try their best to help themselves in the course of seeking help. Unfortunately, none of the treatments they obtained could lift them from their fatigue and consequently, they felt they had to rely on self-help strategies. Their self-help practices can be grouped as follows:

Foods and remedies  Drinking soups or teas prepared with different kinds of herbs and remedies were the most common self-help practices. Chicken, pork liver and pork brain, beef and turtles were favourite foods and soup stocks. Chinese medications that could strengthen "yang" (male energy) or improve kidney weakness, such as "essence of deer tail (deer penis)," "tong-sum" and "hou-gay-tze" were popular choices. Some participants claimed that they felt better after they had taken these foods and remedies. Vitamin B, which was considered as a vitamin that could strengthen one's body, was also very popular among the participants.

Self psychotherapy  Trying not to think about one's current situation and future events too often, attempting not to demand too much from oneself, having a good long cry alone and relaxing by watching Chinese comedy videos and listening to pleasant music were the strategies almost all participants used to cope with their stress.

Becoming knowledgeable  Almost all the participants read extensively on the topic of fatigue to obtain as much information about their illness as possible. Their resources included books, magazines and newspapers in both English and Chinese published locally or at their place of origin. Most of them also took advantage of information provided by the electronic mass media on the topics of fatigue, CFS and neurasthenia. They often watched the two Chinese TV channels and listened to the five Chinese radio stations while programs on new medical developments and health issues were presented.
**Changing lifestyle** The following changes in lifestyles were reported by most participants: (1) changed eating habits including eating more vegetables and less meat; (2) quit smoking and avoided alcohol; (3) planned and divided activities setting regular schedule for daily routine such as meals and exercises, (4) relaxed as often as possible and engaged in various types of non-strenuous exercises, such as Qi-Kung and Tai Chi, (5) listened to music. Two participants (# 33 and # 39), a 41-year-old woman whose husband is in Hong Kong and a 38-year-old man who is an industrial engineer turned fashion designer, concluded that there was only one way to facilitate the recovery of their illness: to go back to Hong Kong or move out of Toronto. They claimed that they actually felt better as they started the process of planning to leave Toronto.

**Seeking social support** Talking to family members, close friends and joining self-help groups for new immigrants at community centres were the most common sources of social support the participants sought.

**Seeking spiritual help** Some participants said that they became more spiritual after the onset of their illness. Those who were Christians, went to church to pray and read the Bible more often. Those who were Buddhists or believers in traditional Chinese religions went to Buddhist or Taoist temples to worship their gods and ask for blessings; they tended to take a fatalistic view of their illness, by attributing it to fate and believing that all they could do was just to weather things out. Some even rearranged the furniture in their houses to improve feng shui.

**Family and friends** Feeling supported and understood by family and friends was considered very important in helping the participants to cope with their illness. Conversely, lack of support, understanding or acceptance on the part of family and friends made some participants feel betrayed or helpless. Trying to strengthen the patients' yang force by giving them tonics and food prepared with Chinese medicinal herbs was the most common form of
help their families and close friends bestowed on the participants. Tangible materials or services, such as prepared food or remedies, baby-sitting or rides were perceived as gestures of caring and appreciated much more by the participants than verbal support or advice.

Some participants, who had sponsored relatives to come to Canada, were resentful about the latter’s lack of support. They felt that their relatives at least should help them financially, if they could not offer other assistance, since their illness had put them in financial difficulty. Those interviewees, who felt misunderstood or who were accused of being lazy or pretending to have an illness by their loved ones (as they were told by their physicians that there was nothing wrong with them), experienced more distress. As illustrated by a 46-year-old married man from Hong Kong:

She (wife) does not understand me and said that “you think I am not tired?” She thinks that I am pretending that I am sick, because if I am sick, then I don’t have to do certain things…. One day, I was stir-frying beef, the hand that held the spatula got so tired that it was unbelievable, so after I finished that dish, I just left the frying pan in the sink and went for a rest. My wife said that there was no reason that I did that, she thought that I was lazy. Of course, for a normal person he should not feel tired after he just finished stir-frying beef, but I really felt tired and that was why I wanted to rest. But that was how she felt about me (lazy). Even when I went shopping, carrying a few bags of grocery and walked to the car, it might be a one minute walk, after a few steps, I would feel very tired and then she would say that I was just pretending. (#15)

E: For peace of mind: seek help from supernatural sources

Faith healers, Christian ministers, feng shui and Kong-Tau masters (someone who is capable of planting an illness or laying a curse on another person and is able to tell if one is under Kong-Tau) were consulted by 35 (70%) participants. They claimed that they did not believe their illness could be cured by these non-medical people, but they usually would feel better knowing that they had tried every means. A 27-year-old engineer from Hong Kong stated: “A Christian minister prayed for me and ordered the devil to leave my body. (#8)
Exhausted by caring for her 17-year-old schizophrenic son all on her own (her husband worked in China), a 47-year-old woman from Hong Kong “hired a feng shui (geomancy) specialist to rearrange the furniture” (#21) in her house, so that the health of her family members would be improved.

**F: Mental health practitioners - can they help?**

Fifteen (30%) participants had sought help from mental health practitioners, mainly psychiatrists. Most participants did not think mental health practitioners could offer any help for their problem as they felt their distress was primarily physical and they were not mentally ill. Those who were referred felt that this was because their family doctors did not know how to treat them, and because they thought that they were referred to mental health practitioners when they were not able to find a physical cause. Some interviewees wanted to see a mental health professional, but were discouraged from doing so by family members, for fear of stigma affecting the patients and their family members. There was a sentiment expressed by these patients that consulting a psychiatrist was equivalent to declaring a family member insane. Ten participants who had seen mental health practitioners were given different explanations of the causes of their problem, mainly surrounding their social situation and personality:

*He (psychiatrist) told me that there was nothing wrong with me and it was just because of my family (problem), my adjustment to immigration. (#8)*

*He said that I was pessimistic, it was not depression. (#17)*

**Satisfaction with Care** In general, those participants who sought help from mental health workers had very different experiences and opinions about their care. Some appreciated the time their psychiatrists took to help them. "I think that the psychiatrist (Dr. Y.) is the most
helpful although he cannot solve my problem. He tried to analyze it with me, but he was not able to help me.” (#17) While others felt that more time should be given to them, like the following 34-year-old female receptionist, who expressed:

He spent very little time talking to me, just about 10 to 20 minutes talking about my problems. He prescribed medications (sleeping pills) to me, asked me to let things go and told me not to be so tense, but try to relax. (#40)

Help-Seeking Behaviour: Prominence Rankings

Quantitative data from the help-seeking section of the EMIC showed that their family physicians, traditional Chinese medicine and Western medicine practitioners were the main sources and most satisfying forms of help for the participants. Table 6 below depicts the prominence scores of the 8 clustered categories of causes perceived by the 50 participants. The possible range of the score is from 0 to 17. The range of scores reported by the participants was 0 to 17. As shown in the mean scores, all scores were in the lower one third of the range indicating a relatively low level of satisfaction with care from the patients’ perspective.

Table 6

Prominence Rankings of Clustered Categories of Help-Seeking Behaviour

<table>
<thead>
<tr>
<th>Clustered Category</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral Physician (Family Doctor)</td>
<td>5.34</td>
<td>2.19</td>
<td>2.00</td>
<td>9.00</td>
</tr>
<tr>
<td>Traditional Chinese Medicine</td>
<td>4.16</td>
<td>4.21</td>
<td>0.00</td>
<td>17.00</td>
</tr>
<tr>
<td>General Health (Western Medicine)</td>
<td>4.10</td>
<td>1.98</td>
<td>2.00</td>
<td>11.00</td>
</tr>
<tr>
<td>Self/Lay Help</td>
<td>3.14</td>
<td>2.68</td>
<td>0.00</td>
<td>9.00</td>
</tr>
<tr>
<td>Spiritual</td>
<td>2.40</td>
<td>2.05</td>
<td>0.00</td>
<td>8.00</td>
</tr>
<tr>
<td>Mental Health</td>
<td>1.02</td>
<td>1.94</td>
<td>0.00</td>
<td>9.00</td>
</tr>
<tr>
<td>Alternative Treatment</td>
<td>0.76</td>
<td>2.39</td>
<td>0.00</td>
<td>12.00</td>
</tr>
<tr>
<td>Other</td>
<td>1.06</td>
<td>2.08</td>
<td>0.00</td>
<td>8.00</td>
</tr>
</tbody>
</table>
Interrelationships of Patterns of Distress, Stigma, Perceived Cause and Help-Seeking Behaviour

This study examines the interrelationships among patterns of distress (symptoms), stigma, perceived cause and help-seeking behaviour. To determine whether demographic data of the participants had an influence on the major variables of patterns of distress, stigma, perceived cause and help-seeking behaviour, t tests, ANOVA and Pearson r were employed. Post hoc comparisons, using the Tukey-HSD test, were made after an ANOVA had resulted in a significant F test to determine which means were significantly different from each other.

With significance level set at 0.05, no significant association was found among demographic data or between demographic data and grouped patterns of distress scores. There were significant differences found between stigma and place of migration, using the Tukey-HSD test. Those from China were found to have higher stigma scores than their Hong Kong and Southeast Asia counterparts ($F_{2, 47} = 3.29, p = 0.046$). There were also significant differences for places of birth and the perceived cause of victim/abuse. Participants, who were born in Hong Kong were more prone to have a perceived cause as victim/abuse more so than their counterparts whose birth places were China or Southeast Asia ($F_{2, 47} = 7.62, p = 0.0014$).

Although it was not strongly correlated, correlation coefficients of age and perceived cause indicated that age was positively correlated with a perceived cause that was medical ($r = 0.3813, p = 0.006$) and negatively to one that was socially based ($r = -0.3108, p = 0.028$). This suggests that older were more likely than younger participants to attribute the cause of their fatigue to medical factor the reverse was true for social causes. Length of time in Canada ($r = 0.4006, p = 0.004$) and years of education ($r = 0.3023, p = 0.033$) were positively correlated to seeking help from mental health practitioners, indicating that higher level of acculturation and better education may have motivated participants to have better acceptance of mental health practitioners as caregivers.
Grouped scores of the variables of patterns of distress, stigma, perceived causes and help-seeking behaviour were used in the examination of their relationships. Results of their Correlation Coefficients (Pearson r) are presented in Tables 7 to 10. Statistically significant results are “bolded” for easy review.

Table 7

Correlation Coefficients (Pearson r) of Patterns of Distress and Perceived Cause

<table>
<thead>
<tr>
<th>Perceived Cause</th>
<th>Somatic</th>
<th>Psychological</th>
<th>Social</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>-0.24</td>
<td>0.29*</td>
<td>0.09</td>
<td>-0.25</td>
</tr>
<tr>
<td>Physical</td>
<td>0.09</td>
<td>0.014</td>
<td>-0.20</td>
<td>-0.08</td>
</tr>
<tr>
<td>Traditional</td>
<td>0.10</td>
<td>-0.06</td>
<td>-0.09</td>
<td>-0.22</td>
</tr>
<tr>
<td>Over Work</td>
<td>0.13</td>
<td>-0.22</td>
<td>-0.45</td>
<td>0.06</td>
</tr>
<tr>
<td>Ingestion</td>
<td>0.04</td>
<td>-0.22</td>
<td>0.04</td>
<td>-0.07</td>
</tr>
<tr>
<td>Environment</td>
<td>0.04</td>
<td>-0.22</td>
<td>0.04</td>
<td>-0.07</td>
</tr>
<tr>
<td>Social</td>
<td>-0.04</td>
<td>0.13</td>
<td>0.16</td>
<td>0.14</td>
</tr>
<tr>
<td>Abuse</td>
<td>0.03</td>
<td>0.16</td>
<td>-0.12</td>
<td>0.08</td>
</tr>
<tr>
<td>Religious</td>
<td>0.05</td>
<td>-0.06</td>
<td>-0.21</td>
<td>0.18</td>
</tr>
<tr>
<td>Hereditary</td>
<td>0.16</td>
<td>0.04</td>
<td>0.07</td>
<td>0.06</td>
</tr>
<tr>
<td>Sex</td>
<td>0.29*</td>
<td>-0.18</td>
<td>-0.03</td>
<td>0.00</td>
</tr>
<tr>
<td>Other</td>
<td>0.12</td>
<td>-0.07</td>
<td>0.08</td>
<td>0.21</td>
</tr>
</tbody>
</table>

*p<0.05

As indicated in Table 7, very few variables were systematically correlated to each other. None of the variables of patterns of distress of a social nature were related to perceived cause. Only two statistically significant correlations were found between patterns of distress and perceived cause variables. Statistically significant positive relationships were found between the participants’ somatic distress and sexual activity as a perceived cause; psychological distress and a perceived cause that is psychologically based.
Table 8

Correlation Coefficients (Pearson r) of Patterns of Distress and Help-Seeking Behaviour

<table>
<thead>
<tr>
<th>Patterns of Distress</th>
<th>Help-Seeking Behaviour</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Refer Physician</td>
<td>Western Medicine</td>
<td>Self/Lay Help</td>
<td>Chinese Medicine</td>
<td>Mental Health</td>
<td>Alternate Treatment</td>
</tr>
<tr>
<td>Somatic</td>
<td>-0.24</td>
<td>-0.21</td>
<td>0.17</td>
<td>-0.09</td>
<td>-0.01</td>
<td>0.01</td>
</tr>
<tr>
<td>Psychological</td>
<td>-0.15</td>
<td>0.25</td>
<td>-0.05</td>
<td>0.13</td>
<td>0.13</td>
<td>0.11</td>
</tr>
<tr>
<td>Social</td>
<td>0.06</td>
<td>0.35*</td>
<td>-0.08</td>
<td>-0.20</td>
<td>0.15</td>
<td>-0.18</td>
</tr>
<tr>
<td>Other</td>
<td>-0.22</td>
<td>0.12</td>
<td>0.12</td>
<td>-0.12</td>
<td>0.04</td>
<td>0.11</td>
</tr>
</tbody>
</table>

*p<0.05  **p<0.01

As depicted in Table 8, very few variables were systematically correlated to each other. None of the variables of patterns of distress of a psychological nature were related to participants' help-seeking behaviour. Only two statistically significant correlations were found between the patterns of distress and help-seeking behaviour variables. Social distress (all cited stigma) and help-seeking from Western medicine practitioners was found to be positively correlated. A statistically significant negative correlation was found between somatic distress and seeking help from a spiritual source.
Table 9

Correlation Coefficients (Pearson r) of Stigma, Perceived Cause, Patterns of Distress and Help-Seeking Behaviour

<table>
<thead>
<tr>
<th>Perceived Cause</th>
<th>( r = )</th>
<th>Patterns of Distress</th>
<th>( r = )</th>
<th>Help-Seeking Behaviour</th>
<th>( r = )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>-0.16</td>
<td>Somatic</td>
<td>-0.02</td>
<td>Refer Physician</td>
<td>-0.16</td>
</tr>
<tr>
<td>Physical</td>
<td>0.10</td>
<td>Psychological</td>
<td>-0.14</td>
<td>Western Medicine</td>
<td>-0.03</td>
</tr>
<tr>
<td>Traditional</td>
<td>0.02</td>
<td>Social</td>
<td>0.22</td>
<td>Self/Lay Help</td>
<td>-0.15</td>
</tr>
<tr>
<td>Over Work</td>
<td>0.23</td>
<td>Other</td>
<td>0.20</td>
<td>Chinese Medicine</td>
<td>-0.16</td>
</tr>
<tr>
<td>Ingestion</td>
<td>0.16</td>
<td></td>
<td></td>
<td>Mental Health</td>
<td>0.15</td>
</tr>
<tr>
<td>Environment</td>
<td>0.16</td>
<td></td>
<td></td>
<td>Alternative Treatment</td>
<td>-0.02</td>
</tr>
<tr>
<td>Social</td>
<td>-0.01</td>
<td></td>
<td></td>
<td>Spiritual</td>
<td>-0.08</td>
</tr>
<tr>
<td>Abuse</td>
<td>0.30*</td>
<td></td>
<td></td>
<td>Other</td>
<td>0.18</td>
</tr>
<tr>
<td>Religious</td>
<td>-0.10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hereditary</td>
<td>0.18</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>0.32*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>-0.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*\( p < 0.05 \)

Table 9 above again shows that very few variables were systematically correlated to each other. None of the variables of patterns of distress or help-seeking behaviour were correlated with stigma. Only two statistically significant correlations were found between stigma and perceived cause variables. They are: stigma and perceived cause of being a victim of abuse; stigma and sexual activity as a perceived cause.
Table 10

Correlation Coefficients (Pearson r) of Perceived Cause and Help-Seeking Behaviour

<table>
<thead>
<tr>
<th>Perceived Cause</th>
<th>Referral Physician</th>
<th>Western Medicine</th>
<th>Self/ Lay Help</th>
<th>Chinese Medicine</th>
<th>Mental Health</th>
<th>Alternate Treatment</th>
<th>Spiritual</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>0.23</td>
<td>0.26</td>
<td>-0.19</td>
<td>-0.04</td>
<td>-0.06</td>
<td>-0.06</td>
<td>-0.01</td>
<td>-0.00</td>
</tr>
<tr>
<td>Physical</td>
<td>0.06</td>
<td>-0.01</td>
<td>-0.14</td>
<td>-0.01</td>
<td>-0.15</td>
<td>-0.22</td>
<td>0.11</td>
<td>-0.02</td>
</tr>
<tr>
<td>Traditional</td>
<td>-0.16</td>
<td>-0.15</td>
<td>0.04</td>
<td>0.18</td>
<td>-0.005</td>
<td>0.06</td>
<td>0.25</td>
<td>-0.00</td>
</tr>
<tr>
<td>Over Work</td>
<td>-0.11</td>
<td>0.002</td>
<td>0.01</td>
<td>0.14</td>
<td>0.009</td>
<td>0.04</td>
<td>-0.19</td>
<td>-0.09</td>
</tr>
<tr>
<td>Ingestion</td>
<td>-0.14</td>
<td>0.04</td>
<td>-0.02</td>
<td>-0.30*</td>
<td>0.03</td>
<td>-0.09</td>
<td>-0.08</td>
<td>0.03</td>
</tr>
<tr>
<td>Environment</td>
<td>-0.14</td>
<td>0.04</td>
<td>-0.02</td>
<td>-0.30*</td>
<td>0.03</td>
<td>-0.09</td>
<td>-0.07</td>
<td>0.03</td>
</tr>
<tr>
<td>Social</td>
<td>0.11</td>
<td>0.11</td>
<td>0.35*</td>
<td>-0.11</td>
<td>0.19</td>
<td>0.33*</td>
<td>0.20</td>
<td>-0.14</td>
</tr>
<tr>
<td>Abuse</td>
<td>-0.18</td>
<td>0.17</td>
<td>-0.00</td>
<td>-0.12</td>
<td>0.09</td>
<td>-0.002</td>
<td>-0.19</td>
<td>0.06</td>
</tr>
<tr>
<td>Religious</td>
<td>0.11</td>
<td>0.06</td>
<td>0.11</td>
<td>-0.02</td>
<td>-0.05</td>
<td>-0.02</td>
<td>0.17</td>
<td>0.10</td>
</tr>
<tr>
<td>Hereditary</td>
<td>-0.33*</td>
<td>0.31*</td>
<td>-0.01</td>
<td>-0.07</td>
<td>0.36**</td>
<td>0.04</td>
<td>-0.22</td>
<td>0.04</td>
</tr>
<tr>
<td>Sex</td>
<td>-0.14</td>
<td>-0.14</td>
<td>0.21</td>
<td>-0.21</td>
<td>0.09</td>
<td>-0.09</td>
<td>-0.31*</td>
<td>-0.14</td>
</tr>
<tr>
<td>Other</td>
<td>-0.11</td>
<td>-0.15</td>
<td>-0.16</td>
<td>0.01</td>
<td>-0.24</td>
<td>-0.02</td>
<td>-0.18</td>
<td>0.04</td>
</tr>
</tbody>
</table>

*p<0.05 **p<0.01

As indicated in Table 10, very few variables were systematically correlated between perceived cause and help-seeking behaviour. None of the variables of perceived cause of psychological, physical, based on traditional Chinese medicine, over work, abuse, religious and other were correlated with each other. Perceived cause of social nature was found to be positively correlated with self-help, and help-seeking from practitioners of alternative treatment. Heredity as a perceived cause was positively correlated with help-seeking from practitioners of Western medicine and mental health practitioners, but negatively correlated with help-seeking from their referral physicians. There were also statistically significant negative relationships between sexual activity as a perceived cause and help-seeking from a spiritual source; ingestion and environmental factors as perceived causes and help-seeking from traditional Chinese medicine practitioners.
General Illness Beliefs

The section on "general illness beliefs" of the EMIC (Weiss, 1997) inquires about the participant’s generalized ideas and opinions towards epilepsy, depression and schizophrenia - illnesses that are poorly understood and stigmatized in the Chinese culture, and their speculation about those ideas held by other people in their community. Their own opinions and their family’s thoughts with regard to how these three illnesses should be treated were also solicited. Data obtained in this section provided a backdrop against which explanatory models of CF can be interpreted (see Appendix H, p.306).

Brief Case Vignettes

Participants claimed that their illness had a major impact on many aspects of their life, including their level of physical functioning, job or study performance, psychological well being and self esteem, interpersonal relationships, underemployment and unemployment. Their distress from CF was exacerbated by other competing challenges, such as the stresses from dealing with (1) a relative lack of understanding from family members, caregivers, friends and bosses, (2) cultural role conflicts and (3) negotiating differences in values and beliefs in Canada.

To provide a context and to portray the persons behind the quotations, themes and statistics presented, the following are two brief case vignettes that offer narratives relating to the suffering from fatigue:

Case 1: #32

Mr. S. was a 52-year-old biochemist who immigrated to Canada from China seven years prior to the interview. He was married and living with his wife and her parents. He claimed that he had been suffering from fatigue, pain in his lower back and shoulders for the past few years. Mr. S. felt that his health problem was the result of (1) the nature of his body being very "xu ruo"
(weak and deficient) from birth, (2) his conflicts with his wife and in-laws, (3) overwork as he had to care for his wife who suffered from schizophrenia, (4) being taken advantage of by his colleagues at work because of racial discrimination, and (5) frustration of being underemployed and constant threat of unemployment.

Mr. S. expressed that he was not living the life that he expected when he first arrived in Toronto full of optimism. Instead, he was leading the disillusioned life of many foreign-trained professionals whose credentials and work experiences were not recognized. Prior to his immigration to Canada, he had worked as a researcher in a prestigious research institute in Beijing, China. His former colleagues who remained in China or who migrated to the United States, had become scientists or research associates. However, he was unable to attain such achievements in Canada, as his credentials were not accepted. At the time of interview, he was working as a laboratory technician "assisting other people's research" and constantly living in fear that his co-workers, who were Canadians by birth, would blame him for their errors, knowing that he had difficulty in defending himself in English. Mr. S. attributed his fatigue to long working hours including evenings and racial discrimination in the workplace.

Another major source of fatigue was the energy required to care for his schizophrenic wife and the constant conflicts with her and her parents about the management of her illness. Mr. S. felt that his in-laws concurred with their daughter that she was not ill and thus had "no need" for medication, because they did not want to be associated with the stigma of having a mentally ill daughter. Of course, their advice would be detrimental to her health.

For fear of being despised by others, Mr. S. did not tell any of his friends or co-workers about his illness. He was a Christian and he knew that he could obtain emotional support by asking people in his church to pray for him. However, he did not "want my own and family
problems to become known to everybody," he decided to keep them to himself (he had the highest total stigma score among all the participants 35/36).

He had attempted to help himself by reading health-related books and eating special foods prepared with Chinese remedies. He also sought help for his problem from multiple sources but to no avail. After being found falling asleep at work by one of his co-workers, he wondered how long he could pretend that there was nothing wrong with his energy. He was extremely worried about his and his family's livelihood should he not be able to continue to work due to his fatigue, or should he be dismissed as a result of his substandard performance at work.

Case 2: # 30

Mrs. C. was a 53-year-old unemployed teacher who lived with her husband and two daughters in Toronto. She immigrated to Canada with her family five years ago due to the political uncertainty of Hong Kong, after its return to Chinese sovereignty. Mrs. C. claimed that she was suffering from CFS, a diagnosis not given by her doctor but one she had learned about from reading a newspaper. She said that all her symptoms fitted the description of CFS. "I am tired to the point that I don't use the term, 'tired' but I would use the word, 'exhausted' to describe my condition," stated Mrs. C.

In spite of having a college education and work experience as an English teacher in Hong Kong for more than a decade, Mrs. C. was confronted with the grim reality of not being able to land a similar job in Toronto. Unlike her, her husband was fortunate to be able to continue in his profession and worked as a Mathematics teacher in a high school. As the only bread winner, he was responsible for defraying all the day-to-day expenses of the household, but the family savings were dwindling. Although they were not living in abject poverty, they were presently leading a much humbler existence in comparison with their former luxury and comforts in Hong
Kong. CF shattered Mrs. C’s dream of improving their living standard. Prior to coming to Canada, Mrs. C. prided herself on being a liberated career woman, a pioneer among Chinese women of her era. She pulled her weight, including financially, in the family and always had maids in the house to take care of the household chores. After immigration to Canada, she felt that her self-esteem had diminished, and her confidence plummeted. Although she was an experienced English teacher, she had difficulty understanding the English spoken by Canadians and her own soft-spoken English was not comprehended. She lost hope and confidence in being able to find a comparable job as an English teacher in Canada. Mrs. C. ascribed her present state of health to the effects of immigration to Canada. She attributed much of her fatigue to overwork as she was not used to doing household chores or engaging in physical labour. Her initial exhilaration of coming to a safe haven, Canada, was unfortunately followed by years of disillusionment both for herself and her family.

Like Mr. S. in the previous case vignette, Mrs. C. ascribed her fatigue to social and contextual problems resulting from the adjustment to a new life in Canada. In spite of her wish to return to Hong Kong permanently which she believed would “cure” her, she knew that she had to stay in Canada for her family’s sake. Mrs. C. sought help from multiple sources to reduce the distress she was experiencing - including participating in the current study which her family doctor had told her that she would benefit from just talking about her illness.

**Summary**

Study findings have been presented in relation to the theoretical framework and research questions. In addition to fatigue and weakness, informants suffered from mainly somatic and some psychological distress. Due to the “unknown nature” of their illness and the inability to live up to their cultural values of hard work, participants felt stigmatized both for themselves and
their families. They blamed their migration to Canada as the instigator of their illness, and indicated that social disharmony and overwork were the most prominent perceived causes of their fatigue. Informants sought help from multiple sources. Western physicians' lack of understanding of patients' social milieu and cultural health beliefs rendered participants feeling dissatisfied. Traditional Chinese medicine practitioners were regarded as being “able to get to the root of the illness,” but financial constraints deterred help-seeking from this group of caregivers. The lived experience of suffering from CF was illustrated through the presentation of two case vignettes.

Following the interviews, several participants commented on what they described as a therapeutic effect. They commented that it helped put their problems into a context, define its boundaries, explore its possible meanings and implications, forge new connections, and give them an opportunity to express themselves to someone at length about their current situation.

Although these cases are not ‘representative’ in any statistical sense, they portray and represent important aspects of illness experience of Chinese patients with CF. They are powerful, albeit idiosyncratic, illustrations of this group of patients in my study.

The concept of CFS was completely foreign to most participants. The majority was not sure what it was and what they were suffering from. Most of their explanatory models were mainly sociosomatic in nature. This is distinctively different from those subscribed to by many CFS patients described in the literature reviewed, who typically would attribute their illness to a physical cause.
Chapter VI

DISCUSSION

The intent of this study was to present a clinical ethnography of Chinese immigrants with CF and weakness to health care workers to give them a better understanding of the illness experience of this group of patients. Results of this study show that participants' illness experiences were shaped by the social and cultural context of being first generation immigrants in a foreign land. The findings provide insight into the illness experience of first generation Chinese Canadians, specifically with respect to health beliefs, meaning, coping and social impact of CF and weakness on their lives.

The discussion of the results of this study is divided into four main sections addressing: the descriptive data, interrelationships among the major categories and, finally, the limitations of the study.

The bulk of this chapter is comprised by the first section dealing with the descriptive qualitative and quantitative data. It is organized around the four major categories of this study, patterns of distress, stigma, perceived cause and help-seeking behaviour. For each of these categories the discussion begins with an overview of the findings and then references the theoretical framework, Chinese culture and beliefs, the participants' General Illness Beliefs (Appendix H, p.306) as garnered from this research, and related research and descriptive literature as appropriate.
Patterns of Distress

All participants of this study cited the onset of their fatigue as gradual, and said it took them almost a year to realize that they needed to seek help. Gradual onset cases of CF have been linked to a greater number of stressful life events and illnesses in the year prior to illness onset compared to their sudden onset counterparts (Mawle, 1997). This observation is confirmed in the present study, as most of them had encountered different challenging life events associated with their experience as immigrants.

The vast majority of the informants also considered their illness to be serious; all of whom were living with a compromised level of functioning, and almost half of them not working. This finding is in concert with Petrie, Moss-Morris and Weinman’s (1995) results of a survey of 282 CFS sufferers who also found that those who perceived their condition as “catastrophic” (serious) showed greater disability in terms of their sleep and rest, social communication, and recreational activities.

Lock (1993) suggested that symptoms often function as a medium of communication, whether or not they are so intended by the patient. As the informants’ narratives unfolded, the progression of their suffering as victims of CF and as newcomers to a foreign land, they revealed multiple distresses. Similar to Chinese neurasthenia patients in Kleinman’s study (1982), the majority of them reported an average of 7 symptoms. Of the 50 participants, 84% who were able to pinpoint the most troubling aspect of their problem, 74% alleged somatic distress; non-somatic distress was much downplayed by most of the informants. A combination of somatic, psychological and social distress was alleged by only 19% of the respondents as most troubling. This is in keeping with Kleinman’s (1982) report that the majority (78%) of Chinese neurasthenic patients held their illness as “organic.”
In a study of 131 female CF patients and their husbands, Goodwin (1997) suggests that women who are better educated have fewer symptoms. It is speculated that women with higher education levels have jobs and interests that are less physically taxing, resulting in physically limiting symptoms being less problematic. Education also provides women with a broader scope of coping abilities, social support, and other resources. However, findings of the current study show that gender, educational level, marital status, or length of marriage, statistically do not have an impact on the symptoms experienced by the participants. Goodwin’s (1997) study is quantitative and does not have an Asian sample, making it difficult to compare the rationale behind these subjects’ responses.

**Somatic Distress**

**Overview of Findings**

The majority of the participants claimed that fatigue and symptoms of a physical nature were intrusive and negatively affected their daily life. Their fatigue is further aggravated by sleep disturbance which at times even endangered their lives, such as falling asleep when operating a vehicle or machinery. Other than fatigue and sleep disturbance, a constellation of somatic symptoms none of which was found to have an organic etiology, were reported by the informants. These discomforts included pain, gastrointestinal discomfort, dizziness, cold symptoms and sexual dysfunction. Most claimed that these distresses developed gradually after they immigrated to Canada. Three interrelated themes were delineated in the category of somatic distress, and each will be explored under the heading of “discussion of findings” below:

(A) Fatigue and weakness are the most distressing symptoms,
(B) Sleep disturbance is both a distress and a source of fatigue,
(C) Somatic discomfort is incorporated as part of one’s life.
Discussion of Findings

A: Fatigue and weakness are the most distressing symptoms

All informants alleged that fatigue and weakness were their most distressing symptoms, that negatively affected all aspects of their activities of daily living. This contrasts to Yu’s (1994) study, in which only 7% of her patients cited fatigue and weakness as their most troubling symptoms. As stated earlier, subjects in her study expected their lifestyle to cause them fatigue; fatigue was generally identified as the consequence of insomnia or pain, rather than a primary problem. Informants of the current study probably were more willing to present fatigue and weakness as symptoms, since these are distresses often portrayed in the Chinese Canadian mass media. Also, as former sedentary workers forced into physically laborious jobs due to migration, they might have believed that fatigue is more acceptable as a symptom. Furthermore, the selection criteria of “either persistent and distressing complaints of increased fatigue after mental effort, or persistent and distressing complaints of bodily weakness and exhaustion after minimal effort,” might have introduced a bias towards referral of subjects who presented fatigue as their most distressing symptom rather than as one of their distresses.

B: Sleep disturbance is both a distress and a source of fatigue

Almost all (86%) the patients in this study reported that sleep disturbance was one of their most distressing symptoms. Studies of largely Caucasian CF subjects with medically unexplained physical symptoms also showed that sleep disturbance is one of the most problematic symptoms (Farmer et al., 1995; Krupp et al., 1993; Moldofsky, 1989; Morriss et al., 1993). However, despite the participants’ persistent sleep disturbance, no referral to specialists or other treatment was offered, and sleeping pills were prescribed only sporadically. Being new
immigrants, informants were unaware of the availability of such services, thus forcing them to live with intense suffering without help.

**C: Somatic discomfort is incorporated as part of one's life**

All participants revealed that they had learned to accept multiple somatic distress as part of life with over half complaining of pain or headaches, 20% gastrointestinal discomfort and cold symptoms, dizziness or sexual dysfunction for the other. Since none of the symptoms was found to have an organic base, no treatment was given by their physicians. Their symptoms were presented in both traditional Chinese and Western medical terminology reflecting the influence of these two traditions in participants’ explanatory models of illness. As cultural idioms, somatic symptoms express discomfort and distress in ways that are intelligible within the individual's social milieu but may have different meanings to outsiders, including their physicians. The meanings expressed through these idioms are often fragmentary, tentative, and even contradictory (Kirmayer & Young, 1998), especially when two relatively distinct paradigms (traditional Chinese and Western) were employed interchangeably.

In Western medical paradigm, symptoms without an organic base are regarded as somatization “with the assumption that its real meaning is an underlying affective disturbance” (Kleinman, 1982). Somatization has been found to be common in CF patients in the larger culture (Manu et al., 1993). Somatization is defined as “the presentation of physical symptoms in the absence of organic pathology or the application of physical complaints accompanying organic absence beyond what can be accounted for by physiology” (Katon, Kleinman, & Rosen, 1982). The term somatization implies that mental processes are causing somatic symptoms and is, hence, essentially dualistic - a concept inherent in the Western cultural ideology of the person (Kirmayer & Young, 1998).
Although its prevalence and specific features vary considerably across cultures, the process of focusing on, amplifying, and clinically presenting somatic distress are universal and somatic symptoms are the most common clinical expression of emotional distress world-wide (Isaac, Janca, & Orley, 1996). Nonetheless, research suggests that somatization is more common in non-Western countries (Sue & Sue, 1990). With over 70% of all mankind belonging to non-Western cultures (Triandis, 1995), somatization exerts a much greater impact on patients from other cultures than Western. It has been speculated that, the high rate of somatization amongst Asians is because they are socialized to express their symptoms of emotional distress in ways that are appropriate or acceptable to others in their culture, yet are viewed by Western practitioners as somatization (Brislin, 1993).

Somatization is more highly elaborated among Chinese than Caucasian North American (Kleinman, 1980). Kleinman and Good (1985b) reported a higher frequency of somatic complaints by Asian depressive patients, including Chinese, than European Americans.

Traditionally, Chinese hold a holistic view of the mind and body (Cheung, F. & Lau, 1982). Since Chinese do not devote separate attention to mental and physical illnesses, emotions are considered to play a role in the etiology of both types of illnesses (Lin, K. M., 1981). Gaw (1993) asserts that somatization is prominent in Chinese Americans, because of the close correspondences between emotions and body organs in Chinese traditional medicine, so that expression of physical complaints is more socially acceptable than emotional complaints.

It has also been argued that in a sociocentric culture, such as the Chinese that emphasizes the relational self rather than an individual self (Hsu, F., 1971; King & Bond, 1985), physical symptoms which are culturally sanctioned will be more common than psychological ones (Kleinman & Kleinman, 1986). Thus, somatization of psychological problems may be an adaptive coping mechanism as it mobilizes social support from the family and the community,
provides relief from routine responsibilities (Lin, E., Carter, & Kleinman, 1985), and reconfigures family relationships and other social roles (Kirmayer & Young, 1998). Somatization also allows displacement of psychic conflicts that in themselves are not acceptable (Kleinman, 1986), and avoids the stigma or shame associated with reporting psychological problems (Xu, 1987). This mechanism may explain some of the physical symptoms reported by participants in this study.

Kleinman (1980) alleges that the socialization process in the Chinese culture teaches its people to suppress dysphoric emotions, and when these emotions are experienced, to channel them into a somatic idiom of communication. He reveals:

I often have felt exasperated and helpless trying to get Chinese patients to talk about a specific dysphoric affect. Patients who have told me they are feeling depressed or anxious or frightened, for example, seemingly cannot go beyond naming the feeling.... They appear to lack the more refined terminology for what they are feeling (p.141).

Cheung, F. and co-workers (1981) counter that the Chinese cognitive style of communicating inward feelings in outward somatic terms rather than unconscious denial is the rationale behind somatic labelling of illnesses. In their study of Chinese with depression, they reported that when asked directly these patients were able to recognize and admit psychological symptoms of depression. Cheung, F. (1985) argues that in Chinese the very language of affect is in somatic terms, which may create a misconception that Chinese patients are more likely to somatize. Depression or sadness is xin yu “pressure on the heart,” frustration and irritation is qi ding “blocking of air,” psychosexual difficulty is shen kuei “kidney weakness,” and rage is gan huo, “fire in the liver.” Kleinman and Kleinman (1986) concur that perhaps with its highly “somatized language” the Chinese language has “a cultural code of bodily metaphors of psychological problems” (p.54-55).
The current findings are in agreement with those of Cheung, F. and co-workers (1981). Despite multiple somatic symptoms reported by informants, most showed no hesitation in presenting mood symptoms such as feeling depressed and anxious when asked specifically if they were suffering from other distress than somatic. This is in contrast to the conception that Chinese patients are unable to reveal their psychological distress (Young & Xiao, 1993).

Psychological Distress

Overview of Findings

In comparison to somatic distress, psychological difficulties played a much lesser role in the participants' patterns of distress. However, over half (58%) reported impairments in social or personal functioning, and half reported depression. As a result, informants' ability in meeting personal and family commitments was compromised. Lack of concentration and impaired memory turned activities, such as the operation of machinery and driving a vehicle, into life threatening situations, and, learning English into an insurmountable task. They felt anxious over the prognosis of their illness and their chance of survival in Canada without the command of the Canadian social protocol or official languages. Three main themes were identified from the findings:

(A) Impairment in social functioning and feeling depressed hinder fulfilment of family obligations and personal goals,

(B) Cognitive impairment hampers self-confidence, particularly with regard to social and occupational roles,

(C) Living in a foreign land produces feelings of anxiety.
Discussion of Findings

A: Impairment in social functioning and feeling depressed hinder fulfilment of family obligations and personal goals

Most of the respondents felt depressed and did not have the motivation to pursue and excel in their career or assume their familial responsibilities. Even with obvious symptoms of depression, none of the informants had ever been diagnosed with depression. This is in keeping with reports in primary care of the larger culture: despite symptoms of depression being found in 56% of the patients with CF, no diagnoses were ever made (Kroenke et al., 1988).

Moreover, lack of English proficiency has also been found to relate to higher depression and paranoia rates amongst migrants (Westermeyer, 1989). Since English proficiency was limited for most participants of this study, they may have been at increased risk for depression. The severity of patients' depressed mood has also been alleged to have a direct impact on their cognitive functioning (Wearden & Appleby, 1997) - a finding this study shares and is discussed in theme (B) below:

B: Cognitive impairment hampers self-confidence, particularly with regard to social and occupational roles

Cognitive impairment, reported by 38% of participants in this study, is one of their most disturbing symptoms, and a major factor affecting their level of functioning and employment. These findings are in concert with most other research, in which cognitive dysfunction, such as poor concentration and memory, are common amongst patients with CF (Joyce, Blumenthal, & Wessely, 1996; Komaroff & Buchwald, 1991; Marshall, Forstot, Callies, Peterson, & Schenck, 1997; McDonald, Cope, & David, 1993).

This cognitive impairment may be subjective rather than objective. Kane and colleagues (1997) reported that, when comparing 17 CFS patients to 17 healthy controls, CFS patients had
significantly higher levels of somatization and depression, but no difference in their cognitive functioning. However, the small sample size in this study limits the validity of the findings.

C: Living in a foreign land produces feelings of anxiety

Many informants attributed their anxiety to a lack of English proficiency, which compromised their abilities to register important information from relevant visual, auditory channels to communicate verbally, and consequently, their sense of confidence. For many immigrants, learning English is a major problem, and requires them to devote time which could otherwise be spent to earning a living (Lock, 1990). For those who came to Canada in their late teens or as adults, the need to support themselves denied them opportunities to learn English. Even for those who were fortunate enough to be able to enrol in ESL (English as a second language) courses as adult learners, learning a new language turned out to be far more difficult than they had anticipated. Grinberg and Grinberg (1984) state:

When learning a new language, an adult learns vocabulary and grammar in a rational manner; but not the accent, intonation, and rhythm, that is the 'music' of the language, can only be imitated and incorporated through identification with the speaker of the language (p. 30).

Depending on their age, immigrants may never be able to truly express themselves in the language of the host country. Some may feel alienated to their surroundings, and disguised when using the new language, “as though they had lost the language which they feel to be authentically theirs” (Grinberg & Grinberg, 1984, p. 30). Since language is the key to a new culture, language proficiency thus determines, to a large extent, the success of the adaptation process of immigrants; accordingly, they are socially and psychologically disadvantaged (Furnham & Li 1993).
Name of the Problem

Overview of Findings

For most informants the condition was not an entity, but rather a collection of symptoms. Amongst those (88%) who named their problem, more than half (57%) gave a CF related name, such as Fatigue, Neurasthenia, CFS and Yuppie Flu. Names expressed in traditional Chinese medicine, such as Mo Ching Shen (no vitality) and Shen Kuei (kidney weakness), were given by over 18% of the respondents.

Discussion of Findings

Every culture has specific systems for labelling illness and disease states (Waxler, 1981). Inclusiveness is the expectation that certain symptoms, behaviours, and treatments will correspond to the given culture’s definition of illness. Cultural styles of expressing distress are influenced not only by cultural beliefs and practices, but also by familiarity with health care systems and pathways to care (Kirmayer & Young, 1998).

Yu (1994) reported, in her study in Hong Kong, that 72% of patients with CF and weakness called their problem neurasthenia, none called it CFS, and nearly all stated that they had never heard of CFS before. Fatigue was not considered by them to be a medical problem, since it was expected in a busy city such as Hong Kong. More participants (13 or 26%) of the current study named their problem fatigue (highest frequency of names given), in tune with the mass media in Canada.

None of the 100 neurasthenic study participants in Kleinman’s (1982) study in China named their illness in traditional Chinese medical terms. These researchers speculated that in the biomedical setting of the study, patients were hesitant to give names in the terminology of traditional Chinese medicine. This is less so in the current study, in which 18% of the
participants named their illness using the traditional Chinese medical terms, although the study took place in a Canadian hospital. Perhaps, out of respect for Kleinman as a Caucasian and a physician of Western medicine, his subjects were reluctant to use traditional Chinese medical terms with him. Because the interviewer in the present study is an ethnic Chinese, who speaks their language, they might have believed she could understand traditional Chinese medical terminology. However, the vast majority (82%) did not name their illness in traditional Chinese medical terms. Since all subjects were referred by family physicians, this might have exerted some influence on their responses. Possibly, if patients were recruited from traditional Chinese medicine practitioners and interviews were conducted in a non-Western medical setting, they might be more conducive to affirmation of traditional Chinese medical concepts. It may also be that knowledge of an entity is different from experience of an entity. Personal symptoms are not translated into cultural categories as one might expect from knowledge of the framework. This may demonstrate that just because the categories exist, they are not necessarily appealing.

**Stigma**

**Overview of Findings**

Informants believed that it was best not to disclose their illness for the following reasons: (1) there was no practical gain from telling others, (2) the lack of understanding of CF by others, including one’s family members and physicians, and (3) the risk of being labelled as “lazy” by others. Many conceded that it was a “cultural thing” for Chinese people to keep things to themselves or within the family. Perceived ramifications of disclosure included: jeopardizing existing and potential prospects for career and marriage, creating concerns for family members, and running the risk of being labelled mentally ill. Participants also revealed that their families would
prefer to conceal their illness for similar reasons. Since they were no longer capable of fulfilling family obligations, they thought less of themselves, felt that they had lost face and were thus despised by others. They were preoccupied with the stigma associated with their illness which they thought would affect them and their family members.

The following themes evolved from the findings of stigma:

(A) Avoid disclosure if at all possible,

(B) Others’ knowledge of one’s illness would affect one’s chance of getting married or one’s marriage,

(C) Family preferred concealing patient’s condition,

(D) Feeling ashamed and inferior, and

(E) Fear of negative effects on the family.

**Discussion of Findings**

**A: Avoid disclosure if at all possible**

Chinese immigrants in this study were reluctant to share information about their illness with others, because of “shame” about their fatigue and their need to save face. Despite living in the same city, some had yet to share their distress with extended family members. This secrecy may be related to the attitude amongst Chinese that expressing one’s feelings overtly is regarded as an admission of weakness in one’s character, as well as an assault on social harmony (Cheung, F., 1982).

Avoidance of disclosure might also be a personal coping strategy of minimization and denial of their symptoms - a psychological mechanism that is perhaps complementary to the social process. Feelings of vulnerability, powerlessness and marginality in the labour force were major deterrents to any open discussion of one’s illness. Their sentiment is in keeping with Yang’s
(1993) conviction that as a people the Chinese are very practical-minded. However, the strong feelings of perceived stigma revealed by the informants as the interview proceeded, suggested that practicality may be the rationalization that caused them to avoid disclosure of their problem. They might have felt safer with disclosing to the interviewer that they had lost their working ability, since this would not in anyway jeopardize their employment or chance of employment.

Respondents felt that, culturally, Chinese prefer keeping things to themselves or in the family; this attitude was reflected in their view towards epilepsy, depression and schizophrenia (Appendix H. General Illness Beliefs, p.306). The majority of them asserted that patients would keep others from knowing that they were inflicted with these illnesses. This attitude became even more intense with any suggestion, especially by a physician, that their fatigue might be linked to mental illnesses. Knowing that Western medicine classifies most illnesses as either physical or psychological, being denied a concrete physical diagnosis by their physicians left respondents feeling stigmatized and assuming their physicians might be alluding to a psychological cause. Tsai and co-workers (1981) suggest that the fear of stigma and Chinese beliefs, which associate mental illness with the patients and their families’ failure to meet cultural moral standards, may lead patients to avoid seeking help from mental health professionals.

Participants of this study experienced tremendous frustration because they were no longer able to function at their former level due to their CF and weakness. The “abomination of the body” (Goffman, 1963, p.4) left them feeling helpless and threatened their livelihood in today’s harsh Canadian economy. People who were closest to them doubted their personal integrity and character. Individuals who, throughout their lives, had prided themselves on being more industrious than others were now being labelled as lazy by their love ones. This label rendered them as “yee lau gee” i.e. second class citizens within their own culture. As a visible minority, Chinese patients are also susceptible to the “tribal stigma of race” (Goffman, 1963, p.4). These
CF patients experienced the “double jeopardy” of not being accepted by their own people or by main stream Canadian culture.

B: Others’ knowledge of one’s illness would affect one’s chance of getting married or one’s marriage

In the Chinese culture, the person is construed as a relational-self, therefore, delegitimation of the person and the family can affect the whole family’s chance of marriage (Kleinman et al., 1995). Similar to their opinions towards patients suffering from epilepsy, depression and schizophrenia (Appendix H. General Illness Beliefs, p.306), most of the respondents who were married felt that fatigue had an impact on their marriage. Those who were single, believed that fatigue diminished their chance of getting married. However, the underlying reasons for the perceived negative impact of these ailments differed. They believed that the hereditary and unpredictable nature of epilepsy, the gloomy atmosphere created by the presence of a depressed person, and the potential eruption of violent behaviour associated with schizophrenia would reduce these patients’ chances of getting married, or maintaining a marriage. Fatigue implies the inability to earn a living, while other illnesses, such as epilepsy, depression or schizophrenia put the sufferers and their kinships’ integrity and good name in jeopardy.

Participants considered themselves to be a burden to their spouses, and felt ashamed of not being able to fulfill their daily responsibilities in their family. Single informants saw themselves as incapable of taking on any of the obligations of marriage, thus deeming themselves as excluded from the marriage pool. These feelings have roots in the Confucian teaching that obligations come with each interpersonal relationship. “The exchange of obligations is a matter of Confucian duty and the expression of such duty serves to stabilize the family unit which is the framework for all relationships” (Redding & Wong, 1993, p. 287). Failing to engage in such an exchange, limits one
from forming new interpersonal relationships and, subsequently, one’s contribution to the growth of the family.

C: Family preferred concealing patient’s condition

The majority of informants indicated that their family preferred strongly that their condition be concealed, in some cases, more so than the patients. Being denied a diagnosis, and being aware of the dichotomous classification of illnesses as physical or mental in Western medicine, participants lived in constant fear of being labelled mentally ill. They feared that anger would be directed at them by family members, and they considered themselves to be innocent victims who had to shoulder the burden of stigma. They believed that the repugnance of being related to a mentally ill person might prompt family members to conceal the patients’ illness. This sentiment was echoed in their views towards others who suffered from epilepsy, depression and particularly schizophrenia (Appendix H. General Illness Beliefs, p.306).

In their description of the complex dynamics of shame and guilt in the families of mentally ill Chinese patients, Lin, T. and Lin, M. (1981) alleged that the stigma attached to mental illness may have originated from the family’s fear of exposure to criticism and disgrace. Since mental illness “implies character flaws in an ancestor and thus shame is imputed to the whole family” (Puchett, 1993, p.311), it carries a particular stigma amongst Chinese both in China and in immigrant communities in Western societies (Chan, F. et al., 1988; Pearson & Phillips, 1994). Lacking a concrete physiological diagnosis, participants of this study were sensitive to any suggestion that they may be suffering from mental illness to avoid implicating their family members.

The idea of keeping things in the family has strong ties to “face-work” in the Chinese culture. Face-work is a “frontstage behaviour” which one deliberately performs in front of those outside one’s family - the basic social unit; “backstage behaviour” is the true behaviour which one can reveal only to those within the family unit (Bond & Hwang, 1993). Goffman (1955) defines “face”
as "the positive social value a person effectively claims for himself by the line others assume he has taken during a particular contact. Face is an image of self delineated in terms of approved social attribute" (p. 213). One loses face as a result of one’s inability to measure up to expectations in social performance. Loss or gain of face is based on sets of criteria or standards which vary both cross-culturally and over time within a single culture (Ho, 1976). Redding and Wong (1994) purport that although face is a human universal, the degree of concern is much greater for the Chinese than for others. For the Chinese, face (or lien in Chinese) is moral worth and contains the idea of being a decent person; losing face is a serious matter which potentially affects one’s ability to function effectively in society (Ho, 1976). For informants who hoped to attain a much better future for themselves and their children by migration, falling short of expectations established by their community left them feeling as if they had lost face, as they were no longer able to achieve their career goals or attain a better standard of living for their families.

D: Feeling ashamed and inferior

As Schepers-Hughes and Lock (1986) note, the social production of stigma creates a second affliction in addition to the original condition. In this regard, suffering of the CF patients was intensified by not only thinking less of themselves because of the deterioration of their level of functioning, but also by the perception that they were despised by others. They felt shame and lost "face." The majority of respondents also indicated that people who suffered from epilepsy, depression and schizophrenia would feel ashamed if others knew of their illnesses, because, in the Chinese culture, anything that is less than favourable reflects badly not just on the individual, but on the family (Appendix H. General Illness Beliefs, p.306).

Rooted in Confucianism, Chinese culture has been described as shame oriented (Chu, 1973). Through Confucianism’s emphasis on social norms and reference to ideals as models of behaviour, shame is defined in terms of an interpersonal orientation in which behaviours are compared to
social ideals. Confucian teaching places special emphasis on hard work and disapproval of idleness. The particular circumstances of life, especially the surrounding elements of unfamiliarity and insecurity that affect immigrants, lead to the development of a strong work ethic (Redding & Wong, 1993). Being regarded as "lazy" renders one vulnerable to rejection by the social network. Therefore, there is a strong tendency to conform to the general ethics of hard work amongst overseas Chinese, such as participants of this study. It seemed that informants felt that it was "normal" for others to despise them as lazy if they were not working hard, in spite of the fact that they might have a health-related reason for this perceived laziness.

Ever since becoming ill, some (7) informants felt that even relatives they had helped in the past started to avoid them and excluded them from social activities. They resented this avoidance, perhaps because of their unfulfilled expectation of *jen* (benevolence) or mutual support and reciprocity of favours (*renqing*). *Jen*, a central Confucian maxim, is considered as one of the most central virtues of the Chinese people (King & Bond, 1985). Being avoided by someone who owes one a *renqing* intensifies this feeling of losing face and being stigmatized.

**E: Fear of negative effects on the family**

Kleinman and colleagues (1995) contend that in the West, stigma is a personal moral category but that in the Chinese context moral blame extends to the entire family. Patients in this study concurred with Kleinman and colleagues' (1995) view that stigma associated with their illness is not limited to themselves but extends to their families. Informants were concerned that others would look down on them and their families as a result of their illnesses. In concert with Goffman's (1963) idea of shared stigma, participants who were living with or close to their parents were concerned about their parents' feelings of self doubt, anger and embarrassment. They believed that their parents condemned themselves for not fulfilling their responsibility to
their kinship and ancestors, because they failed to bring up industrious descendants. Respondents who are parents were frustrated in their inability to set a good example as hard working people for their children. This way of thinking is in keeping with the family or social orientation of the Chinese (Yang, 1993).

Comparing Americans and Chinese, Yang (1993) argues that instead of being trained to function independently of the family network, the Chinese are brought up to remain an integral part of their families throughout their lives. A self orientation in the West is more common than a Chinese social orientation. Confucian teaching dictates that the family rather than the individual is the basic unit of society, the individual’s actions are not his own and are in fact considered to be representative of the family, past, present and future (Hsu, J., 1985). Thus, honour or stigma is not an individual but rather a family matter. A person’s face can be lost or gained as a result of the behaviour of someone to whom he is closely related, even that of one’s ancestors. An individual’s face and the good name of his family (chia sheng) are inseparable in traditional Chinese society. A son’s misconduct is often taken to be a reflection of his father’s failure to educate the younger generation properly. Both father and son are guilty of not fulfilling filial piety in having brought disgrace to the family and hence to the ancestors (Ho, 1976).

The lack of a medical diagnosis was interpreted by some as suggesting mental illness. The family with a mentally ill member is often excluded from the marital pool (Kleinman, 1977; Lin, K. M., 1981; Sue & Morishima, 1982). This fear was well depicted in respondents’ opinions towards family members of patients with epilepsy and schizophrenia, where close to half of them stated that it would be difficult for relatives of these patients to marry. Why 66% of the participants claimed that depression would not pose a problem for the sufferer’s relatives is not clear and requires further investigation (Appendix H. General Illness Beliefs, p.306).
Strategies to Minimize Stigma

Overview of Findings

Avoiding people and keeping to themselves, attributing their illness to fate, and normalization were coping strategies employed to combat stigma. These strategies, especially normalization, were considered useful in maintaining employment.

Discussion of Findings

Informants utilized mainly self-directed strategies to cope with their perceived stigma. The Confucian tradition of self-discipline may have an influence on the tendency to resort to oneself, rather than seek help from others in times of distress (Cheung, F., 1993). Striving for normalcy seemed to be the only strategy that would help the patients to keep their jobs. This is similar to Goffman’s (1963) suggestion that to avoid stigma is “to pass” (p. 9), that is, to pretend one is normal.

Yang (1993) suggests that, in general, Chinese identify themselves with the expectations of the society or groups to which they belong. They uphold social norms to avoid feelings of shame and guilt, and the threat of group ostracism against those who deviate from norms. Normalization might have allowed informants to maintain the Chinese social norms of being hard working and able to maintain harmonious relationships, which in turn, may have minimized their feelings of shame and guilt.

Perceived Cause

Overview of Findings

Participants varied widely in how they interpreted their illness. However, they all went through a similar process of assigning causes or finding meanings behind their illness. This process involved critically reviewing the circumstances leading up to their fatigue, drawing on
their past illness experiences and health beliefs, and subsequently conjuring up a wide range of explanations and causes for their CF.

Several themes evolved from narratives of the respondents. As each interview progressed, it became clear that macro forces, such as the political uncertainty in their homeland and the economic downturn of their newly adopted country, converged to affect individual lives. A common theme was the impact of migration which uprooted them from their heritage, society, and lifestyle. Fatigue was viewed by some as the result of stress induced by life changes brought on by migration. Not unlike their Caucasian counterparts in other CF research, participants of the current study held multiple explanations simultaneously and without an apparent feeling of contradiction.

Social problems, such as lack of social support, interpersonal conflicts, financial difficulties resulting from lack of employment opportunities, and racism were alleged by most participants to be the major causes of their illness. Many of them believed that their fatigue was caused by exhaustion resulting from overwork, the majority (58%) of whom were sedentary workers not accustomed to physical labour. Out of necessity (such as having to meet living expenses and provide financial support to family members in their home countries) and because of their limited English proficiency, they were forced to take on low-level service and factory jobs often incongruent with their pre-migration work experience and education. Differences in culture, language, social milieu, and value system between their native and adopted homelands became visual triggers which evoked feelings of nostalgia and loss, drawing the interviewees into an oscillating pattern between past memories of joyful moments and mournful junctures and the present. Many also blamed their personality for not being able to let go and get on with their new lives in Canada.
Those who cited a medical or physical cause for their illness, said they learned about it from the mass media. Most of the patients who framed their perceived causes in traditional Chinese medicine concepts and their alleged negligence with regard to cultural health practices, formulated these concepts by paying attention to their own bodily sensations and by consulting knowledgeable people in traditional Chinese medicine. Inheriting a weak body or being deprived of nutrition since birth were cited as congenital or hereditary factors that had contributed to their fatigue. Being bewitched by supernatural forces and punished for bad deeds committed in one’s previous life were considered to be causes beyond one’s control. Those who reported environmental hypersensitivity as a cause had been exposed to adverse chemicals.

The following themes were identified from the narratives:

(A) Social factors as the most significant perceived cause,
(B) Overwork and adjustment to physically demanding work exhaust one’s body,
(C) Psychological factors contribute to fatigue,
(D) Medical and physical causes - learning the cause from the mass media,
(E) Traditional and cultural explanations - one’s body in disharmony,
(F) Congenital or hereditary factors - getting the illness from birth,
(G) Magical and supernatural forces that are beyond one’s control,
(H) Being exposed to environmental pollution.

**Discussion of Findings**

“Meaning and knowledge are always in reference to a world constituted in human experience, formulated and apprehended through symbolic forms and distinctive interpretative practices.” (Good, 1994, p. 177) In this way, informants’ perceived causes of their illness were articulated in their unique social and cultural terms. Like their counterparts in Yu’s (1994) study,
participants in the current study cited multiple causes for their illness without apparent feeling of contradiction. Kirmayer, Young, & Robbins (1994) hold that non-Western cultures seem to allow people to hold quite disparate or logically inconsistent views about different domains of knowledge and belief without insisting that they be reconciled. Pluralism has always been commonplace in Chinese perspectives on illness (Kleinman, 1980), so the multiple causes perceived by the informants is in concert with their culture.

A substantial proportion (34%) of the informants of this study ascribed the most important cause of their illness to social issues, such as family conflicts and workplace discrimination. Physical (10%) and psychological (10%) causes played much lesser roles. This is in contrast to their counterparts in Yu’s (1994) study, in which 50% ascribed their illness to a physical cause, 32 % identified a psychological cause and 18% to an interpersonal or social reason. Yu’s (1994) subjects were out-patients of a government funded hospital where free medical care was provided; these patients were mainly from a lower socio-economic neighbourhood and were less educated than the general population in Hong Kong. Perhaps, it would be considered inappropriate for this group of patients to present their problems in anything but physical terms in a charitable medical care facility. In the present study, physical illness might have been discounted since all passed through a thorough medical examination in order to come to Canada, and no medical cause had been found for their fatigue.

Participants in the current study were all immigrants and thus had to contend with issues related to migration on a daily basis. Identifying social difficulties as the causes of their fatigue might seem to be logical and acceptable in this context. Furthermore, unlike Yu’s (1994) subjects who were less educated than the Hong Kong general public, most of the informants of the current study had a post secondary education which allowed them a much wider use of words to present their opinions. Cheung, F. (1985) maintains that although there is an abundance of words
illustrating abstract feelings in the Chinese language, affect is mostly expressed in somatic terms. Therefore, people who are less educated do not have access to the vocabularies needed to express their views. A determination of whether the differences in these findings are due to the nature of the place of treatment or educational level are beyond the scope of this study. Research with a matched sample would allow the exploration of the influence of these variables.

A: Social factors as the most significant perceived cause

Research in CF has shown that patients (predominately Caucasians of Western culture) are inclined to seek a physical cause for illness, even when supportive evidence cannot be found by their physicians. They also tend to resist a psychological explanation for illness (Clements et al., 1997; David et al., 1990; Kirk et al., 1990; Lane et al., 1991; Nelson et al., 1987; Ray et al., 1992; Yu, 1994). Ware (1992, 1993) reported that even for those patients who favoured a psychosocial cause of their fatigue, they framed it as “biopsychosocial” involving the immune system being weakened by stress and resulting in a viral infection that produced the symptoms of CFS.

Unlike their counterparts in the larger culture, Chinese patients in this study attributed their illness to the impact of migration which precipitated contextual difficulties in their immediate social environment. These difficulties included: unemployment and underemployment, perceived racism and lack of acceptance by the larger society, familial and inter-generational conflicts and unable to fully participate in the larger Canadian society due to limited English proficiency. Although 64% of the respondents also attributed social problems to be a cause of schizophrenia (Appendix H. General Illness Belief, p.306), they emphasized that social difficulties that led to schizophrenia differed from those that caused their fatigue. They claimed that sudden tragic personal or financial losses brought about schizophrenia, while tenacious perpetual obstacles,
such as those contextual difficulties they had encountered, caused their fatigue. Similar difficulties had also been reported to have a negative effect on the psychological well being of immigrants (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988b; Furnham & Li, 1993; Wong, 1997). As new immigrants and visible minority group members, participants in this study share these problems with their fellow newcomers.

Four sub-themes: (a) coping with the challenges of an “astronaut” family, (b) difficulties encountered in interpersonal and familial relationships after migration, (c) coming to terms with underemployment or unemployment, and (d) being victimized by racial discrimination especially at the workplace, are among the themes of social context.

a: Coping with the challenges of an “astronaut” family

Higher earnings and employment status in their place of origin enabled those men who returned to their place of origin to fulfil their obligations to maintain a comparable living standard for their families in Canada and their own social status, and to minimize the losses incurred due to immigration to Canada. With the departure of these spouses, “astronaut families” were created, and changes were brought to the family power structure with women willing or unwillingly being subjected to major transformations in their traditional roles. For the first time in their lives, many female informants had to make decisions for themselves and their families in the absence of their husbands who were working overseas. Some had a taste of Western freedom by earning a pay cheque but still had to live within cultural protocols that dictated that childcare and housework were her responsibilities.

The Canadian Western culture that encourages autonomy and individualism is in direct contrast to the collectivist culture of the Chinese. Cultures with a collective or interdependent concept of the person may give less importance to internal psychological factors in explaining
events, emphasizing instead their social circumstances (Triandis, 1995). The uneven pace of acculturation of members of the same family became apparent, leading to family conflicts and disruptions that most informants had never anticipated prior to their migration.

b: Difficulties encountered in interpersonal and familial relationships after migration

Social discord has been found to be common amongst CF patients. Komaroff and Buchwald (1991) reported that 33% of the American CFS patients they studied had strained relationships with family, friends, and co-workers. The majority of the Chinese neurasthenic patients in Kleinman & Kleinman's (1982, 1985) study also indirectly attributed their illness to strained relationships in the family and the workplace. Like their counterparts in Kleinman and Kleinman's (1982, 1985) study, participants in this study perceived the major cause of their fatigue as difficulties in interpersonal conflicts and problems resulting from their immigration to Canada.

Fabrega (1991) supposes that in traditional Chinese medicine there is no ontological notion of disease. Diagnosis of illness is based on symptom clusters or syndromes that reflect imbalances in bodily systems that are also aligned with aspects of larger social and ecological systems. The holism of Chinese medicine does not develop psychology as a separate realm of discourse. Instead, in conformity with the Confucian ethos, attention is paid to disharmony in relationships as a potent cause of illness. As Kleinman (1988) suggests, cultural values and social relations shape the experience of the body and illness and situate suffering in local moral worlds. Therefore, there are cultural and social reasons for informants to frame their sufferings and social difficulties in cultural and social terms.

c: Coming to terms with underemployment or unemployment

Most of the informants were under the age of 50, had a post secondary education, immigrated to Canada at the prime of their lives, and had promising career opportunities prior to
migration. However, at the time of their interview, almost half (46%) of them were unemployed. Those who were fortunate enough to be employed often experience a significant downward shift in occupational status in Canada. This is in keeping with the findings of a community survey of 547 Chinese male immigrants from Southeast Asia, which indicated that underemployment and unemployment were major problems (Wong, 1997). With informants’ deteriorating energy levels, they experienced increasing difficulties in obtaining and keeping unskilled jobs, which were also disappearing from the Canadian economy. CF patients in the larger society also experience disruptions in employment; Yeomans and Conway (1991) reported that only 13% of their subjects were able to maintain full-time employment, and 47% became unemployed because of CFS.

Given that the poverty line is a monthly personal income of $1367.00 (Statistics Canada, 1996), the majority of (38 or 76%) of respondents was living in poverty. Financial pressures created a significant level of distress for these patients. CF patients in the larger society similarly experience financial constraints. In a descriptive study of 110 CFS patients in the US, Anderson and Ferrans (1997) reported that marriages became strained because of inability to work. A fair number (27%) also indicated that they had no economic choice but to push themselves to work despite worsening symptoms. They were particularly concerned about their long-term financial needs given that most were in their prime wage-earning years. Instead of building a future, they were expending their savings (Anderson & Ferrans, 1997). For participants in this study, the stress associated with failing to land a job commensurate with the position or social status held previously in the home country, and coping with dwindling financial reserves was alleged to be a major cause of fatigue.

With its merit system, the Canadian immigration policy encourages professionals to immigrate to Canada, and many well educated and skilled people particularly from Third World
countries are attracted to come. Unfortunately, most of these immigrants are not fully informed that stringent requirements may disqualify their credentials, and they will not be permitted to practise their professions in Canada (Basran & Zong, 1998). The Access Report (1989) by the Ontario Government concludes that unfair and arbitrary barriers to employment for immigrants are significant. These barriers stem mainly from immigrants' academic credentials and their work experience being devalued or simply not recognized by Canadian employers.

Other migrants also share this predicament. Relating experiences of Australian immigrants of Chinese and Indian backgrounds, Rogler (1994) notes that institutional and bureaucratic barriers often keep them from exercising their professional qualifications. They are often occupationally downgraded and must undertake employment that is qualitatively below what they have been educated to do.

**d. Being victimized by racial discrimination**

Though most of the respondents were grateful for being spared the strains of political uncertainty by migrating to Canada, most still regarded themselves as outsiders struggling for a sense of belonging in their adopted homeland.

Multiculturalism is a Canadian invention, a new phenomena to most newcomers from homogenous cultures. In fact, Canadians actually have the most experience in the world with this concept. However, one of the major adjustments of the participants was dealing with racial prejudice and discrimination. The experience of becoming a member of a minority instead of a part of the majority in one's homeland was threatening. Despite "knowing the odds" prior to their departure, racial prejudice and overt discrimination created distressing and disorienting experiences, shared by their Latino counterparts in the US (Espin, 1987). Since their families' livelihoods depended on their employment income, respondents' distress became particularly acute when they were involved in inter-racial conflicts at the workplace. The stress was
intensified by the knowledge that they did not have the liberty to resign or risk dismissal if they filed a complaint.

Most male informants suffered a loss of status and a feeling of no longer being in charge. Men who had prestigious professional positions in their homeland found themselves doing menial work and became dependent on employed wives to support them and the family. They became burdens on their spouses who already were under tremendous stress from coping with a new culture, particularly in the workplace.

The fact that Chinese immigrants in Western nations are racially visible and cannot blend in as easily as Caucasian immigrants from Europe places them in a special category of immigrants who are more apt to experience discrimination and feelings of being different. In addition, their traditional Chinese culture diverges in many ways from the Western cultures of their host societies, a factor which may create intense challenges to their acculturation into Canadian society.

Separation from loved ones, interpersonal conflicts, racial discrimination, and under- or unemployment, were life strains considered by the participants to be primary causes of their CF and weakness, bypassing the psychological or emotional responses to these stresses. Life strains have also been reported by others as associated with the onset of CF. Dobbins and co-workers (1995) conducted a case-control study of 20 CFS patients and 20 matched controls (predominantly white middle-aged, female) and found that patients with CFS reported significantly more stressful life events, in the 5 years prior to the onset of their illness, than their controls. These events included job (80% vs. 30%) and health problems (45% vs. 5%), and death of a love one (45% vs. 15%). There are similarities in the stressful life events reported by Dobbins and co-workers’ (1995) subjects and informants of the current study. The nature of events was very much a reflection of the social and contextual circumstances of these patients.
B: Overwork and adjustment to physically demanding work exhaust one's body

Participants expanded their definition of long-held Confucian maxims on status, success, honour and shame by passing all their hopes and dreams for a better life on to their children. They swallowed their pride and took on much lower status and laborious jobs to support themselves and their families. They (88%) blamed overwork, especially physically exhausting work as a major cause of their fatigue. In traditional Chinese medicine, overwork can lead to the deficiency of blood which results in fatigue (Zhang, E., 1991). “When the force of Yang is exhausted under the pressure of overwork and weariness, then the essence (of the body) is cut short, the openings of the body are obstructed and the secretions are retained. This causes sickness in the summer and distress” (Veith, 1972, pp. 106-107) [Cited in Wu, 1982].

C: Psychological factors contribute to fatigue

In Clements and colleagues' (1997) qualitative study of 66 CF patients, they found that these patients tended to attribute the cause of their illness as physical or stress-related and to avoid labelling it as psychogenic. This may be because a psychological cause may raise doubts about both the reality of the illness and the character of the sufferer. This is in concert with Ware’s (1992) view that moralistic prejudices imply that a personal weakness or inferiority is present in the sufferer of illnesses that are psychological.

Contrary to Clements and colleagues’ (1997) and Ware’s (1992) reports, a substantial number of informants in this study considered psychological factors as one of the causes of their fatigue. Traditional Chinese medicine asserts that deficiency of blood leads to fatigue, as a result of “over thinking” and worrying (Zhang, 1991, p.328); respondents felt that since they had been worrying and constantly thinking about their future, fatigue would be expected to result. The ubiquity of grieving for the past and the stress of coping with present circumstances result in a
feeling of helplessness and hopelessness, because they felt that they could not return to their place of origin or succeed in Canada.

A positive association between migration and psychiatric disorder has been reported as early as the 1930's (Odegaard, 1932) [cited in Shepherd, Cooper, Brown, & Kalton, 1981]. Even though, none of the participants were diagnosed with a psychiatric disorder, with the stress of immigration, they may be at higher risk than their non-migrant counterparts.

D: Medical and physical causes - learning the cause from the mass media

The majority of informants were told by their physicians that their illness did not have a medical or physical cause. Those who cited a medical or physical cause, claimed to have learned it from the mass media. This is contrary to findings of most CF research in which most of their subjects (predominantly white and American) attributed a physical cause to their CF (Clements et al., 1997; David et al., 1990; Kirk et al., 1990; Lane et al., 1991; Nelson et al., 1987; Ray et al., 1992). Even in Yu’s (1994) study, the majority of her Chinese patients also ascribed their illness to a physical cause.

Holding a belief that the illness is due to a physical cause is strongly associated with poor prognosis (Joyce, Hotopf, & Wessely, 1997; Wessely, 1994). With physical cause playing a minor role, participants might have a much better chance of improvement than their counterparts in other studies. A longitudinal study, which allows the monitoring of the patient’s illness experience overtime, could shed some light on the relationship between prognosis and perceived causes for this group of patients.

E: Traditional and cultural explanations - one’s body in disharmony

Good (1994) states that people reason about illness, and that culture provides the logic of that reasoning. In congruence with traditional Chinese medical concepts, informants ascribed their fatigue to the imbalance of the Yin and Yang forces. One of the major symptoms, as well as
perceived causes of their fatigue, was difficulty in their sleeping pattern. According to traditional Chinese medicine, somnolence is often seen amongst patients who are deficient in the Yang force, while insomnia is common amongst those who lack blood in the heart (not to be interpreted literally), who are over-worried, have deficiency of qi in both the heart and spleen and imbalance of “heart fire” and “kidney water” (Kaptchuk, 1983; Yam, 1997).

Some female participants blamed their CF and weakness on their failure to follow cultural health protocols after childbirth years ago. Within the context of traditional Chinese medical theory, pregnancy and childbirth leave the woman in a state of imbalance much like that of an illness. Since a woman’s joints are considered to be “opened up” after giving birth, she faces the danger of cold wind entering her joints creating weakness and pains. The postpartum period is considered dangerous because the woman is in a state of an excess of yin force (Pillsbury, 1978). According to traditional Chinese cultural health protocol, all women are required to be confined to the house for one month after childbirth, with a specially balanced diet and modified puerperal behaviour. She must avoid cold foods, cold winds, and cold water. This is call “zuo yeuzi” or “sitting in” for the month. (Cheung, N., 1997). Ways to remedy the situation are either to have another birth to correct the imbalance by doing another zuo yeuzi the correct way, or to take proper Chinese herbal medicine to regain balance. Since most of the female participants who cited childbirth as a cause, felt that they were either too old or could not afford to have another child, they pursued traditional Chinese medical help instead.

**F: Congenital or hereditary factors - getting the illness from birth**

Some informants recalled, that their parents were “sickly” when they were growing up, and they thought that they might have inherited a weak body from their parents. However, they were careful not to lay the blame on their parents directly, because of filial piety or bringing stigma to the kinship. Confucian teaching states that “our bodies, skin and hair come
from our ancestors” (Qui, 1988). Should they have labelled their illness as a hereditary one, they would risk dishonouring or stigmatizing their kinship. This sentiment was reflected when their opinions about the cause of epilepsy were sought (Appendix H. General Illness Beliefs, p.306). The majority (66%) of the respondents of this study did not hesitate to allege hereditary (58%) and congenital (8%) factors as primary causes of the illness. This may be because heredity as a cause of epilepsy is well accepted within the Chinese culture. Since they were not victims of epilepsy, attributing heredity as a cause of epilepsy would not implicate them or their family members. Furthermore, epilepsy is a more visible illness than CF and, therefore, more difficult to disguise.

G: Magical and supernatural forces that are beyond one’s control

Participants’ narratives demonstrated that their views included selected beliefs and practices from different philosophies and religions. Many of the practices associated with the various philosophical doctrines were intricately woven into the fabric of their lives. Some participants who claimed to be devoted Christians would adopt a cause proposed by Taoist priests that they were affected by restless spirits, while others blamed bad feng shui as the cause.

Supernatural forces seem to play an important role in the Chinese psyche. Phillips and co-workers (1993) found that Chinese died almost 5 years earlier than White Americans if they had a combination of disease and birth year which Chinese astrology and medicine deemed ill-fated. Chinese astrology and medicine consider a person’s fate as influenced by his/her year of birth.

Buddhist teaching regards suffering as the direct effect of bad deed(s) committed either in one’s past, or in a previous life or lives or by one’s ancestors (Qui, 1991). Participants who were Buddhist resigned themselves to fate, and that their affliction with fatigue was the result of bad deeds.
H: Being exposed to environmental pollution

Some respondents speculated that their CF and weakness were related to their exposure to environmental pollution, such as inhalation of allergens or from sick building syndrome. They acknowledged that they learned these terms from the mass media. They compared the symptoms described in the mass media with those they were experiencing, then came to the conclusion that hypersensitivity to environmental pollution might be one of the causes of their illness. Environmental hypersensitivity refers to a chronic debilitating condition that results from inability to tolerate various foods and environmental substances. The existence of such a condition is dismissed by most in the medical profession (Government of Ontario, 1985), and some equate it with somatization (Stewart & Raskin, 1986; Stewart, 1987). Participants who solicited consensus for such a cause from their physicians felt ridiculed as none of their physicians accepted it as a cause of illness.

Help-Seeking Behaviour

“Illnesses are experiences of devalued changes in states of being and in social function; diseases, in the scientific paradigm of modern medicine, are abnormalities in the structure and function of body organs and systems” (Eisenberg, 1977). In their pursuit of a cure, respondents were struggling to accept the judgement of their physicians that they were not confronted by an acute disease, but rather a chronic illness. Unfortunately, despite extensive research there is no definitive diagnostic test or effective treatment for CF; interventions are only directed at the relief of symptoms and maintenance of the patient’s level of functioning (Buchwald, 1996; Wessely et al., 1995). It was the ill-defined nature of their illness that led most of the participants into their long and difficult journey of help-seeking.
Findings from this study show that participants utilized the three social arenas of the health care systems: popular, professional and folk concurrently (Kleinman, 1978). However, there was limited flow of information about individual patients from one health practitioner to another (except those between the family doctor and the referring specialist in Western medicine). Thus, patients started afresh each time they presented their health history to a new health practitioner.

Similar to their place of origin, in Toronto's Chinatowns practitioners of both Western and traditional Chinese medicines practice side-by-side. These services were utilized concurrently by participants without any feelings of contradiction, because both treatment modalities were perceived as providing unique and complementary care. This finding is consistent with previous studies conducted in China (Kleinman, 1980), Hong Kong (Cheung, F., 1989) and other Chinese immigrant communities (Lee, L., 1992), that Chinese tend to employ a pluralistic approach to health care, in particular, utilizing Western and traditional Chinese medicines simultaneously.

**Overview of Findings**

In terms of a cure, most participants had very low expectations of their family doctors. They expressed their gratitude to this group of caregivers for their willingness to listen and for the ongoing monitoring of their conditions. Almost all informants considered traditional Chinese medicine practitioners as their only hope of getting to the root of their illness, they were deterred by the expenses incurred by their treatments. Respondents preferred Western physicians of Chinese background, trusting that they would share their cultural health beliefs. However, since these health care professionals were educated in the Western biomedical model, most did not share their explanatory models or expectations of treatment in relation to their health beliefs. Some physicians admitted to their lack of knowledge of traditional Chinese health beliefs while others dismissed the patient’s questions, reducing them to feeling ignorant and old-fashioned.
All participants engaged in some degree of self-help. They paced themselves, exercised and kept themselves informed by reading literature related to their illness, and turned to family and friends for help. Some resorted to supernatural sources for help to achieve a peace of mind. A minority of participants saw mental health workers reluctantly in fear of the potential stigma associated with being diagnosed as mentally ill.

The following are major themes identified from the interviews:

(A) Effective or not, family doctors have done their best to help,
(B) Traditional Chinese medicine may be effective but is too expensive as an ongoing treatment,
(C) Western medicine cannot get to the roots of the problem,
(D) Self-help works sometimes; family and friends can be helpful if they accept there is an illness,
(E) For peace of mind, seek help from supernatural sources,
(F) Mental health practitioners - can they help?

**Discussion of Findings**

**A: Effective or not, family doctors have done their best to help**

Family physicians and other practitioners of Western medicine constitute the professional arena of the health care system (Kleinman, 1980). Participants seemed to be motivated by two major concerns as they accessed services from this arena. First, they sought help in order to find a solution to their problem and hoped that a diagnosis would lead to an effective treatment. Secondly, they hoped that their distress would be socially validated and made comprehensible in some way, both for themselves and others. When asked the kinds of help they would suggest for victims of epilepsy, the majority of informants also recommended that due to the unpredictable nature of epilepsy (Appendix H. General Illness Beliefs, p.306) the patients should consult
family doctors so that they would benefit from being diagnosed using sophisticated Western medical technology.

Since its introduction to the Chinese at the turn of the century, Western medicine has become their new standard of truth. It has transformed the subjective experience of illness into visible anatomic lesions or shadows on x-ray films and scans, and numbers in laboratory reports. A diagnosis given by a Western medicine practitioner enables patients to make clear to others that they have a genuine medical problem and provides a name that they can use to organize the mechanism and explanation of their distress. However, much of the practice of Western medicine to date, such as highly sophisticated diagnostic technology, seems to be driven by unrealistic efforts to eliminate uncertainty and to maintain control, although this way, on occasion, be merely illusory. It has also created unrealistic expectations and set the stage for subsequent blame and resentment (Quill & Suchman, 1993).

General practitioners are the entry points to the professional arena of the Ontario health care system. The general practitioners who were designated by the informants as their family doctors were not the only general practitioner they consulted for their illness. Nevertheless, they were the ones with whom the patients had the longest affiliation and highest satisfaction. In general, family doctors have the advantage of direct access to the medical history and social background of their patients. Often their assessment is based on professional contact with the patient extending back over a protracted period (Shepherd, Cooper, Brown, & Kalton, 1981).

Denz-Penhey and Murdoch (1993) surveyed 83 general practitioners in New Zealand and found that 90.2% of those surveyed accepted CFS as a valid diagnosis. These researchers concluded that the controversy of CFS as a valid diagnosis has receded among this group of physicians. This finding is in direct contrast to the practice of the referring physicians of this
study. Although all participants met the selection criteria for this study, only 2 were diagnosed with CFS and most were not given this diagnosis by their physicians.

Most of the informants were pleased with their family doctor's care. This is in contrast to a report in which 92% (N=397) of the patients in general medicine were satisfied with their physician, while only 75% (N=609) of patients with CFS expressed general satisfaction with their medical care. CF patients who expected a cure from their doctor were more dissatisfied, since they were not being cured (Twemlow, Bradshaw, Coyne, & Lerma, 1997). Ward and co-workers (1996), based on their chart review of 425 primary care patients who complained of CF, found that physicians were lax in mental and physical examinations, history taking and ordering laboratory tests, and only 9.9% mentioned CF in the patients' health records. These researchers concluded that because of the non-specific nature of CF, practitioners did not focus on this complaint, and documentation for CF was often incomplete or absent.

Many informants resented the hesitation their family doctors demonstrated in referring them to other physicians. This is in keeping with other research findings that general practitioners manage 98% of patients who present with fatigue, and refer less than 2% to specialists (Ridsdale, Evans, Jerrett, Mandalia, Osler, & Vora, 1993). Respondents felt that their physicians were particularly cautious about a referral to a psychiatrist. This observation concurs with findings reported by Shepherd and colleagues (1981). In comparing two separate random samples of 149 and 75 British family doctors, these researchers discovered that the most frequently cited reason for not referring patients to a psychiatrist was the stigma associated with mental illness. The objection raised by the patient or his/her family may turn on an unwillingness to accept the suggestion that a psychiatrist should see him/her. Furthermore, the family doctor may refrain from making the referral anticipating the patient's refusal, and his/her belief that the stigma
resulting from seeing a psychiatrist may be detrimental to the patient (Shepherd, Cooper, Brown, Kalton, 1981).

Physicians’ hesitancy in referring CF patients to mental health professionals may be justified by findings of a qualitative study conducted by Ax and co-workers (1997) with 2 samples of 9 (one with 6 females and another 8 females) patients suffering from CFS. These researchers found that psychological or psychiatric referrals were unwelcome by these patients, even though most (16) felt unsupported by their family doctors. Lack of information and emotional support from their physicians was given as the reason for opting for alternative treatment by these subjects.

Informants were particularly resentful about their physicians’ continuous reassurance that they were in good health, while they were suffering from multiple symptoms. To “put pressure on people to think positively and to inhibit manifestations of their distress is self serving on the part of health professionals who deal with suffering.” (Lazarus, 1983, p.132) Asking patients to look at the bright side offered little consolation to them as they continued to search for meaning for their illness. Hence, they sought help from other sources, and they felt a need to exhaust every possible avenue to reaffirm their hope for a cure.

Despite a sense of skepticism regarding the care they received, all patients appreciated words of encouragement and concern from their family doctors, as these behaviours implied care and concern for their well being.

**B: Traditional Chinese medicine may be effective but is too expensive as an ongoing treatment**

Often it is suggested that physicians of Western medicine treat acute illnesses, while patients with chronic illnesses for which Western treatment has failed go to traditional healers (Lock, 1980). Traditional Chinese medicine logically was the most utilized alternative medicine
by the participants. In spite of its increasing popularity in the larger Canadian society, traditional Chinese medicine is essentially confined to the Chinese Canadian community. This is due to its practitioners’ lack of English proficiency and a theoretical base that is largely foreign to those who are non-Chinese. Therefore, even though traditional Chinese medicine as it is practised in mainland China fits Kleinman’s (1980) description of the professional arena of the health care system, it can only be considered as a part of the folk arena in Canada.

Most respondents sought help from traditional Chinese medicine practitioners because they feel more comfortable with caregivers who understand their beliefs and speak their language of health. In other words, because traditional Chinese medicine theories and methods are closely linked to the Chinese common culture, practitioners can take into account the whole person, not simply the diseased organ of the body which is the focus of their Western medicine counterparts. Moreover, being first generation immigrants themselves, traditional Chinese medicine practitioners are able to relate to this group of patients from a personal perspective.

Lack of information and emotional support from their physicians has been cited as a reason for opting for alternative treatment by CF patients in the larger culture (Ax et al., 1997). Unregulated traditional Chinese medicine is considered one type of unconventional medicine in Canada, along with naturopathy and aromatic therapy. Eisenberg and co-workers (1993) conducted a national survey of 1539 adults to explore the utilization of unconventional medicine in the US. They discovered that 34% of their respondents used unconventional therapy, most of them non-Blacks age 25 to 49, with above national average education and income. For those with serious medical conditions, 83% also sought treatment from medical doctors. Extrapolating from the US population, the amount spent on unconventional medicine ($425 million) is higher than that spent on primary care ($388 million) by $37 million. Despite unconventional medicine’s
popularity in North America, all but two college educated respondents of the current study utilized other forms of unconventional medicine than traditional Chinese medicine.

All participants were given traditional Chinese herbal remedies in various degrees, and only some received other forms of treatment. The following is a description of treatments participants obtained from traditional Chinese medicine practitioners:

1. Traditional Chinese herbal remedies were widely used. These remedies require synthesis and balance among numerous ingredients to be effective; thus the expertise of a traditional Chinese medicine practitioner is often solicited.

2. Acupuncture is the implantation of thin needles to different depths at a variety of meridian points gathered in connected arrays, according to a sophisticated physiological theory, on the surface of the human body.

3. Moxibustion is the burning of the herb Artemisia vulgaris on the top of an acupuncture needle, so that the heat is conducted to the body through the needle.

4. Acupressure is a gentle form of stimulation of meridian points by means of pressure, using the thumbs, fingers, or hands.

5. Shiatsu is a type of body work originating in Japan. It has roots in Japanese and Chinese acupuncture and massage. It involves meridian point stimulation and a variety of other techniques that involve stretching and rotating of body parts, and use of the thumbs, hands, elbows, and knees of the practitioner on the client’s body (Beal, 1992).

C: Western medicine cannot get to the roots of the problem

Most of the participants in this study went to Western physicians first for help because these professionals’ services are covered by the Ontario Health Insurance Plan (OHIP), and because these patients also wanted to be diagnosed utilizing modern technology. Their impression toward Western medicine has changed little in comparison to the days when Western medicine first
came to China - that of a "quick fix" (Holden, 1964). The practice of Western medicine has been to rely on objective diagnostic data, medical technology and the belief that diseases and illnesses are treated to allow a sense of control in the provision of care. This approach implicitly denies the lived experience of suffering from an illness and the inherent uncertainty in the actual practice of medicine (Quill & Suchman, 1993).

Even though Western professionals were identified as a source of support, they were also alleged to be a cause of frustration. A high degree of dissatisfaction with the medical care received by 15 CFS patients from the larger culture has also been reported by others (Yeomans & Conway, 1991). Their dissatisfaction prompted 47% of them to use alternative therapies, such as homeopathy and herbal medicines. In the current study, participants had unfavourable evaluations of the therapeutic outcomes of the Western physicians they had consulted. They might have felt comfortable expressing their view, knowing that these physicians had no links to the interviewer, and no access to the information from the interviews. Participants' dissatisfaction mainly stemmed from these physicians' failure to (1) deliver a "quick fix" despite numerous diagnostic tests, (2) accept the social reality and suffering associated with their clients' illness, (3) address cultural and linguistic disparities vis-à-vis their patients.

Mind-body dualism permeates much of the medical and popular cultures in the Western world (Kleinman, Brodwin, Good, B., & Good, M., 1992). In this view, the human body is viewed as a machine which the physician is equipped to repair. The manner in which Western medicine was introduced and spread in China reinforces this kind of expectation of Western medical practitioners by the Chinese. Moreover, medical treatment, with a somatic orientation, may relieve the patient's family of the psychological burden of shame, guilt, and stigma (Lin, T. & Lin, M., 1981). For most Chinese patients, physicians are expected to make decisions and give instructions. Failing to do this, they are viewed as weak and incompetent (Hsu, J., 1985). Not
being given a “concrete” diagnosis or effective treatment to alleviate their symptoms reinforced these sentiments. When an informant’s search for quick relief among Western medicine practitioners failed, disappointment and disenchantment ensued.

Participants’ suffering and feelings of self-worth were often deeply affected by the consistent disaffirmation of their illness by the health care workers they encountered. When their diagnostic tests were negative, these patients accepted the “scientific” findings that they might not have an organic problem and started looking for other explanations of their distress. Social problems associated with their immigration to Canada seemed to be the least stigmatizing and most legitimate explanation for their illness.

Although medical discourse claims to exclude the social context, medical encounters can never be free of influence from the social structure to which caregivers and their clients belong (Waitzkin, 1989). In spite of sharing the same cultural background, there is social disparity between the physicians’ mostly upper middle class and the participants’ predominately lower middle class lifestyles. The physicians described in the present study seemed unable to appreciate the social issues confronting their clients. Like informants in Anderson’s (1991, 1992) study, health professionals’ disregard of the obstacles presented by the circumstances of the patient’s everyday life was also cited by participants in the current study. Physicians who gave advice without giving consideration to the day-to-day struggle and suffering of their immigrant patients (such as “if you are too tired to continue working, just rest at home”), only left the patients feeling more frustrated and in despair.

Good (1994) observes that physicians and their patients categorize signs and symptoms of illness differently. Each organizes them into concepts and ascribes significance into a fashion appropriate to the sanctioned language of their own communities and existential concerns. Since categories and life worlds differ between patients and physicians, medical conversations are
filled with interruptions, misinterpretations, and failures of understanding. Findings of the current study concur with Good's (1994) observation. Being fully aware of these differences and striving to minimize the odds of being misunderstood, participants sought help from Western physicians of Chinese descent. Speaking the same native tongue, they hoped that these physicians would be able to appreciate their distress and concerns, but they were soon disillusioned. Even though most patients were able to communicate in Chinese with their physicians, they still felt that they were not being understood because of different health beliefs. Most of these physicians were unable to comprehend the terminology and concepts of traditional Chinese medicine in which their patients framed the explanation of their illness.

Kleinman (1980) purported that Western medicine practitioners communicate in the language of biomedical health concepts, while patients hold blended concepts from the popular (lay) and traditional health systems. Thus, the informants' dissatisfaction evolved from the perception that their physicians being Chinese themselves did not attempt to understand them despite expectations that their common cultural background should enable them to do so. Despite speaking the same language, communication barriers existed between the physicians and the informants because of differences in health paradigms. Western medicine has its roots in the mind-body dichotomy which is a product of Western culture and is in distinct contrast to the holistic approach of traditional Chinese medicine.

Chinese patients may believe that an imbalance of emotions would disturb the function of the parallel organ, and a dysfunctional organ leads to an emotional imbalance (Kuo & Hopkins Kavanagh, 1994). The internal organs in traditional Chinese medicine, have the same names as in Western medicine, but may not share the same postulated composition, function and location (Porkert, 1974). Thus, a complaint of kidney weakness, for example, may not indicate a
functional or organic disorder of the kidney as in Western medicine. This can be extremely confusing to physicians who are not familiar with concepts of traditional Chinese medicine.

Ots (1990) asserted that Western physicians of Chinese descent have lost contact with their own medical tradition. Due to the continued prevailing belief in “scientism” in China, there is a tendency for these physicians to be extremely reliant upon a biomedical point of view and almost totally disregard the biopsychosocial mode of viewing disease and illness. From the respondents’ perspective, their physicians had been divorced from their native culture.

All informants of this study were able to communicate with their family physicians directly. Those who were referred to non-Chinese speaking specialists encountered both language and cultural barriers. Like subjects in Watt and co-workers’ (1993) study of Chinese immigrants’ experience with health care in Britain, and Yuan and colleagues’ (1998) survey of the Chinese general public in Toronto, participants of the current study also experienced language barriers in communicating with their physicians. Interpreter services are often not available and consequently patients were left feeling frustrated and disappointed when they were unable to communicate with their caregivers after waiting weeks if not months for their appointment.

**D: Self-help sometimes works; family and friends can be helpful if they accept there is an illness**

It has been reported that between 70% to 90% of health care received by various ethnic groups are provided within the domain of family, social network, and members of the community (Kleinman, Eisenberg, & Good, 1978). This domain constitutes the popular arena of the health care system in which most illnesses are managed and decisions regarding treatment choices are made (Kleinman, 1980). Self care, which all participants of this study made use of to various degrees is an integral part of the popular arena. With daily radio broadcasting and newspaper columns on various health topics, the burgeoning Chinese mass media play an
important role in fuelling the activities of this arena. Many participants claimed that they obtained their most up-to-date information on CFS and health maintenance through the mass media which informed them and allowed them to take care of themselves while most physicians told them that nothing could be done.

Clements and colleagues (1997) reported that reduction of activity was the coping strategy employed by 76% of the 66 CF patients in their study. Moreover, self care such as organizing their day into rest and active periods, taking vitamins and minerals, and being on special diets were common practices of CF patients in the larger culture (Ax et al., 1997). Participants of the current study also adopted many of these practices with cultural modifications. Traditional Chinese medicine ascribes somnolence, energy deficiency, weakness, lack of motivation and not wanting to speak as symptoms of Yin illnesses. Tonics that can strengthen the Yin and Yang forces as well as qi and blood are the usual treatment prescribed (Yam, 1997). Consumption of dietary prescriptions which combine food and herbs, self-medication and the use of traditional treatment modalities, with or without the help of family and friends, are also common practices among the Chinese in health maintenance (Koo, 1984; Qin, 1992; Yan, B., 1991; Zhang, E., 1990); thus, self-help was a normative response of drawing on one’s cultural reservoir in times of need.

The high prevalence of self care among the participants may be due to the fact that Chinese are less likely to recognize personal problems as being important enough to require the assistance of health professionals (Tracey, Leong, & Glidden, 1986). Furthermore, interviewees’ limited knowledge of the availability of health and social agencies may have increased their reliance on self care.

From their interviews of a subset of 22 CF patients, in a study of 110 subjects from the larger culture, Anderson and Ferrans (1997) found social support was diminished due to the
dwindling capacity to enlist help and maintain social ties, apathetic responses from their social networks, inaccurate perceptions of their illness by the community at large, and the inability to plan activity due to distressing symptoms. Respondents of the current study reported similar problems. In Chinese families, caring is communicated through actions rather than words and concern is demonstrated through taking care of other’s physical needs (Bond & Hwang, 1993). When family members were told that there was “nothing wrong” with the patients, they started to withdraw their support for activities of daily living, such as cooking and cleaning. Participants were then left to struggle on their own with resulting resentment.

E: For peace of mind, seek help from supernatural sources

Out of desperation due to lack of improvement in their condition, several interviewees sought help from supernatural sources, such as faith healers and Chien-wan masters. In the context of this study, these caregivers belong to the folk arena of Kleinman’s Explanatory Model of Illness (1980). Taoist faith healers had been reported to have successfully cured a man who had sought help from multiple Western medical doctors and Chung-i’s with no relief for his problem of “feeling sleepy all day” (Sing Tao Daily, 1997).

Several participants who claimed to be Christians and church-goers also sought help from Taoist faith healers or had their family members act on their behalf. This might be frowned upon by Christians from other cultures. As the first of the ten commandments states “Thou shall have no other gods before Me” (Exodus 20:3). However, these participants did not see any contradiction in their behaviour, as they felt they were just trying to do their best to help themselves. The same attitude seems to apply to their help-seeking from both Western physicians and traditional Chinese medicine practitioners. Patients that have a different view of their illness from their physicians should not be seen as simply having lack of information or being superstitious. Their behaviour may be an indication of their desperation for a cure (Good, 1994).
One of the participants, Mr. L. (#15), a 46-year-old Christian from Hong Kong who was working as a subway supervisor, had sought help from a Chien-wan master to find the cause of his fatigue. Chien-wan is a special kind of divination derived from Buddhist belief of the existence of hell. The divination specialist (soul caller), usually a middle-aged woman, travels to hell for her client(s) to meet with his/her relative. When supposedly possessed by the spirit of this relative, she dialogues with and gives advice to her client(s) on behalf of the relative (Lin, K. M., 1981). The Chien-wan master employed by Mr. L. established her credibility and gained his trust by giving him information he believed that no one knew but himself.

Participants who were Buddhist gave offerings and worshipped in Buddhist temples, hoping to have their health restored. To halt the continuation of suffering, Buddhism promotes the performance of good deeds during one's lifetime to “work out” bad deeds committed by oneself or one's ancestors (Qui, 1991). Bestowing offerings to temples are considered one of the ways to “work out” or pay for one's bad deeds.

**F: Mental health practitioners - can they help?**

Informants expressed hesitation to seek help or accept a referral to see a mental health practitioner. Perhaps, this was because they did not associate their illness with a serious mental illness, or because mental illness is highly stigmatized amongst Chinese. In Chinese culture, tremendous stigma attaches to major mental illnesses as defined in Western medicine, especially those that characterized by extreme emotions or psychotic symptoms (Kleinman, 1980). Such features are associated with the patient’s inability to control or cope with profoundly disturbing affects and to maintain harmonious social relations, thus implying a personal and familial failure in living up to the cultural protocol of self-discipline and resulting in face-losing (Hu, 1944). Psychotic symptoms are considered to be caused by being possessed by evil spirits, punishment of bad deeds committed by the patient or family, and heredity. People with these symptoms are
often cared for at home by the family; help from spiritual sources are sought; Western mental health professionals would be consulted as last resort (Kleinman, 1980). Minor psychiatric problems are often framed as medical illness which allows the patient to assume a legitimate sick role without stigma (Kleinman, 1977). This attitude was revealed in the informants' opinions about how schizophrenic patients should be treated (Appendix H. General Illness Beliefs, p.306). The majority of the interviewees regarded schizophrenia as a serious mental illness and that when beyond the family's ability to keep the patient at home, a mental health professional's help should be sought. In traditional Chinese medicine, psychological or emotional disorders, as defined in Western medicine, have never been regarded as a legitimate domain. Thus treatment of emotional disorders is not considered a chung-i's (traditional Chinese medicine practitioner) responsibility (Zhang, M., 1989).

In Hong Kong, most mentally ill patients with somatic symptoms seek help from general practitioners rather than psychiatrists. In order to avoid the stigma of being labelled “mentally ill,” these patients would refuse to use psychiatric services even though they are referred by their general practitioners (Chiu & Rimon, 1987). This kind of bias is shared by Chinese immigrants worldwide. Somatization accounts for 35% of all illness visits made by Asian migrants in primary care. Instead of seeing mental health practitioners, migrants may seek medical attention for physical problems relating to their psychological states (Lin, E., Carter, & Kleinman, 1985). The following have been proposed as reasons that deter immigrants from seeking help from mental health workers:

1. Cultural conceptions of mental disorder play a major role in determining the extent to which migrants access mental health services. “Minor” disorders such as depression and adjustments, triggered by bereavement or divorce, regarded by many Canadians as legitimate
reasons to consult a mental health practitioner, are accepted by people from traditional cultures as a normal part of life not justifying professional help (Nguyen, 1984).

2. Having limited language proficiency and knowledge of the Western concepts of psychotherapy, immigrants usually turn to familiar forms of health care, such as folk medicine or traditional medical facilities to deal with their emotional problems (Brislin, 1993; Ying & Miller, 1992).

3. Lack of information about existing mental health services and a tendency favour self-help to deal with problems were reported as possible reasons for the under-utilization of mental health services by Chinatown residents in San Francisco (Loo et al., 1989).

4. Chinese resist professional mental health care because they are socialized to keep personal problems in the family and to avoid talking to outsiders about their private life, particularly about issues related to emotions (Lin, T., 1983). Indeed, family oriented stigma amongst the Chinese is one of the biggest obstacles in the provision of optimal mental health care to Chinese communities all over the world (Lin, K. M., 1981).

Despite the lack of effective treatment for CF to date, favourable results have been reported amongst patients who had undergone cognitive behaviour therapy. Butler and Chalder (1990) reported that the majority (22/27) of CF patients demonstrated a significant improvement in their fatigue, mood and functional impairment, following cognitive behaviour therapy. Sharpe and co-workers (1996) also found that 73% (22/30) of patients who received cognitive behaviour therapy, especially designed for patients with CFS, had a much higher level of functioning compared to 27% (8/30) of their counterparts who received only medical care. These researchers claimed that this form of cognitive behaviour therapy, focused on helping patients to re-appraise their illness beliefs, increase activities and solve social problems, enhanced the rehabilitation of patients with CFS.
On the other hand, Lloyd and co-workers (1993) found in a double-blind placebo-controlled trial of 90 patients with CFS that there was no benefit from cognitive behaviour therapy. They attributed the positive results of Butler and Chalder's (1990) study to selection bias and lack of a control group in the study. Although benefit from cognitive behaviour therapy may be possible, none of the participants had received or been referred to this therapy.

Interrelationships between Patterns of Distress, Stigma, Perceived Cause

and Help-Seeking Behaviour

Kleinman (1980) maintains that all three arenas of the health care system: professional, popular and folk, articulate illness as a culturally defined experience. They establish systematic relationships among the experience of symptoms, beliefs of disease causation, specific patterns of illness behaviour, decisions concerning help-seeking, and evaluations of therapeutic outcomes. In this section, variables that showed a statistical relationship will be discussed.

Patterns of Distress and Perceived Cause

The cultural construction of illness produces different interpretations of the causes of illness and the presentation of symptoms (Kleinman, 1980). Findings of this study supported this claim to certain extent. A statistically significant positive relationship was found between the participants' somatic distress and sexual activity as a perceived cause. This is in keeping with the traditional Chinese health belief that excessive sexual activities lead to the exhaustion of ching (essence, sperm) which is produced in the kidney. Thus shen kuei (kidney weakness), in turn, led to loss of yang (positive energy). Fatigue is an indication of deficiency of yang which will eventually precipitate a yin-yang imbalance (Zhang, E., 1991).
A positive correlation was also identified between psychological distress and a perceived cause that is psychologically based. Despite the lack of differentiation between physical and psychological illnesses in traditional Chinese medicine, respondents were able to express some of their symptoms in psychological terms and attribute them to a psychological etiology. It is apparent that these respondents were familiar with how distress is expressed in Western medicine, where physical and psychological symptoms are often classified separately. They had also demonstrated that they felt comfortable enough presenting these symptoms in a hospital setting where the current study took place. With a history of more than a century in China, Western medicine has become an integral part of the Chinese health care system. Based on knowledge of this model, some participants attributed psychological distress to a psychological cause. Furthermore, the "distress" and the "cause" may not be well-differentiated for some patients with reference to psychological or emotional issues; their responses could be biased by this lack of differentiation.

Chalder and co-workers (1996) contend that patients who attribute their fatigue to social reasons have less distressing symptoms and enjoy a higher level of functioning than those who consider the cause of their fatigue to be physical or psychological. Such a protection is not shared by subjects of the current study, as there was no correlation between a social perceived cause and any variables in the category of patterns of distress. Qualitative findings of the current study indicate that most of the participants ascribed their illness to social causes, and the majority of them also suffered tremendous somatic distress. The results of this study refute those of Chalder and co-workers (1996), and suggest that it is not the same for Chinese patients.

**Patterns of Distress and Help-Seeking Behaviour**

A statistically significant negative relationship was identified between somatic distress and seeking help from spiritual source. Subjects of this study understood their somatic distress as
the manifestation of imbalances or malfunctioning of their bodies. They avoided spiritual help, perhaps because they believed it would not provide symptom relief.

**Stigma and Perceived Cause**

A positive correlation was identified between stigma and being a victim of abuse as a perceived cause. Participants who reported such a perceived cause suffered abuses in the forms of domestic violence or racism. Being a victim of these kinds of social adversities attests to a disharmony in one’s interpersonal relationships and casts doubt on one’s moral integrity as a well disciplined person. A Confucian maxim judges one a failure if one falls short of being a decent person who is incapable of maintaining harmonious relationships with others (Ho, 1976). Due to the powerful stigma attached to being a victim of such abuses, none of the participants who suffered from domestic violence or racism revealed their anguish to others or filed any formal complaints. This lack of action is in concert with data from a recent community survey conducted in the GTA which showed that although the majority of those interviewed claimed racism as one of the major problems they had encountered since migrating to Canada, none had brought the issue to the attention of appropriate authorities (Wong, 1997). Avoiding confrontation and maintaining harmony appears to be a common strategy employed by Chinese immigrants in coping with adverse situations.

Another positive correlation was found between stigma and sexual activity as a perceived cause. Ho (1993) claims that “anxiety over sex was high” amongst Chinese and traditionally Chinese have regarded sexual activities, such as masturbation, as shameful. Sexual activities that are deemed inappropriate or shameful have direct implications for a person’s and his/her family’s moral status. Sexual overactivity evinces one’s defiance to filial piety because according to Confucius’ teaching, one should be ashamed if one does any harm to one’s body which is endowed by one’s ancestors.
Stigma and Help-Seeking Behaviour

Although there was no correlation between the total stigma score and participants’ help-seeking behaviour, a positive correlation between social distress (all cited stigma) and help-seeking from Western medicine practitioners was identified. This is consistent with qualitative findings of the study. Respondents who experienced social distress in the form of stigma preferred seeing Western physicians, probably they were hoping that a concrete medical diagnosis would provide a scientific physical basis for their distress, and in turn, diminish the stigma of a psychological cause.

Perceived Cause and Help-Seeking Behaviour

Cognitive processes have been recognized as important correlates of illness and help-seeking experience. They may also shape the perceived cause of one’s problems (Cheung, F. et al., 1983; Kleinman, 1980, 1982). Qualitative findings of this study also showed that participants’ perceptions of their social status as immigrants influenced how they enlisted help.

A strong correlation was identified between a perceived cause that is socially based and self-help and help-seeking from family and friends. This suggested that a socially based perceived cause influenced subjects’ decision to try to help themselves or to turn to family and friends for help. This is in keeping with how Chinese people consider that social issues, such as family conflicts and coping with impacts of migration, should be handled within one’s social network, rather than seek professional assistance. The role of a social worker in the resolution of social discords is foreign to most, as such a role is uncommon in Asia (Pearson & Phillips, 1994). Furthermore, the provision of conflict resolution or financial assistance is not considered to be the job of physicians (Western or traditional Chinese medicine practitioners). This may have prompted subjects to draw on the limited resources for self-help and help from family and friends. Perceived cause of social nature was also found to be positively correlated with help-
seeking from practitioners of alternative treatment. However, only two participants who were university educated and paid closed attention to the mass media on treatments of CFS sought help from this source.

Hereditry as a perceived cause and help-seeking from Western physicians were found to be positively correlated. This relationship is also reflected in the subjects' opinions toward epilepsy victims, with the majority (58%) of the informants reporting epilepsy as a hereditary illness where sufferers would receive the best help from Western physicians (52%) (Appendix H. General Illness Beliefs, p.306). As illustrated in the perceived cause section of this chapter, respondents felt that they might have inherited a "weak body" from their ancestors and seeing a Western physician, especially a specialist might help rule out such a possibility.

A positive correlation was also found between heredity as a perceived cause and help-seeking from mental health practitioners. Some participants had close relatives who had sought help from mental health professionals for neurasthenia and this might have helped them to make the decision to consult one. Moreover, the lack of a "concrete" physiological base to their illness or satisfactory treatment outcomes from other health services might have led informants to give mental health workers a try. However, a negative correlation was found between heredity and help-seeking from referring physician. Perhaps, participants felt that their family physicians might not have the in-depth knowledge a specialist would have to deal with a hereditary illness.

A negative correlation was identified between the perceived cause of sexual activity and help-seeking from a spiritual source. As discussed earlier, sexual activity carries a moral implication to a person and his/her family. Hence, it would be unlikely for the individual to bring sexual issues out into the open to seek help from temples or churches.
There were statistically significant negative relationships between perceived causes of ingestion and environmental factors and help-seeking from traditional Chinese medicine practitioners. Qualitative findings suggest that illness etiologies of ingestion of contaminated foods and environmental factors are relatively new concepts, which informants learned from the popular arena of the health care system, in particular the mass media. Although traditional Chinese medicine does address the role external elements play in illness causality, issues such as environmental hypersensitivity are largely perceived to be a Western phenomenon and are at odds with traditional Chinese medical concepts.

Limitations of the Study

The greatest limitation of this study is its lack of generalizability. Since all participants are Chinese immigrants from the Greater Toronto Area, it is apparent that the findings of this study may not be applicable to other Chinese Canadian immigrants, other ethnic groups in Canada or the Chinese people in general. “Perception and subjectivity or ‘bias’ are essential data and a crucial part of the knowledge generated by qualitative research. Local context and the human story, of which each individual and community story is a reflection, are primary goals of qualitative research, and not ‘generalizability’.” (Miller & Crabtree, 1994, P. 348). This study provides an unique appreciation and understanding of the Chinese CF patients’ illness experience despite limited generalizability.

Other limitations of the study include:

1. The small number of participants may have reduced the power to demonstrate a significant effect between variables (Kramer & Thiemann, 1987).
2. The investigator did not control for extraneous variables, such as social class and level of acculturation of the participants, which could affect their responses.

3. Although subjects appeared to be very willing in sharing their experiences with the investigator, they might not have given full explanations for their actions. "Subjects are seldom able to give full explanations of their actions or intentions; all they can offer are accounts about what they did and why" (Denzin & Lincoln, 1994, p.12). Furthermore, informants might not be able to give the best illustrations of their illness experience, as all of them were suffering from fatigue.

4. Interpretation of the data may be influenced by the investigator's knowledge and experience with the Chinese Canadian Community. Despite conscious efforts (such as continuous self reflection and heightened awareness) to keep potential investigator bias to the minimum, it may not be possible to disregard all preconceived ideas.

5. The study was limited to one culture. Valid cross-cultural comparisons cannot be made until the study is replicated in another culture. Nevertheless, because most of the participants were deeply influenced by the traditional Chinese culture, the findings in this study may prove to be valuable for health care workers caring for patients with traditional Chinese health beliefs.

6. This study obtained its sample from referrals by participants' family doctors; thus it was a convenience sample and might suffer from selection bias. Those respondents who agreed to participate probably were more outgoing, familiar with the research process and had a positive experience with the referring physician. For participants whose relationships with their family doctors were less than favourable, in spite of reassurance of confidentiality, they might still downplay their dissatisfaction towards the referring physician to avoid having their negative comments revealed to their doctors.
Summary

Results of this study have been discussed with reference to the traditional Chinese culture values, the theoretical framework, literature review and relevant research, and participants' "General Illness Beliefs" (Appendix, H. p.306). Interrelationships of patterns of distress, stigma, perceived cause and help-seeking behaviour were discussed based on correlations identified between these variables. Limitations of the study were also addressed.
Chapter VII

IMPLICATIONS FOR THEORY, RESEARCH AND PRACTICE

Results of this study have implications for theory, research and practice in the area of migrant health. Qualitative findings provide a glimpse of the lived experience and a partial understanding of the issues that confronted Chinese immigrants who suffer from CF and weakness. However, the nonprobability sampling method and the relatively small sample size limit the generalizability and representativeness of the quantitative data.

Theory

Kleinman’s (1980) Explanatory Model of Illness, as well as Goffman’s (1963) and Kleinman and colleagues’ (1995) theories on individual stigma and family stigma provided a useful theoretical framework for this research. Through patients’ personal accounts of their illness experiences, the present study has demonstrated the applicability of these theories in directing clinical practice and in generating further investigations in immigrant health issues.

The theoretical framework of this study proposes relationships among patients’ patterns of distress, stigma, perceived cause and help-seeking experiences. Through the Explanatory Model of Illness, Kleinman (1980) formulated a cultural construction of illness which asserts that illness is culturally shaped in the sense that how one perceives and copes with an illness is based on the explanation and meaning one ascribes to the illness. This cultural construction of illness produces different interpretations of the causes of illnesses that influence the presentations of symptoms and help-seeking behaviours of patients and families. Citing contextual difficulties in
their social milieu resulting from migration as the most important cause of their fatigue, the participants presented a contextual construction of illness, with a cultural one as the backdrop. Despite symptoms and etiology of their CF expressed in cultural medical terms, current contextual problems in their immediate environment were alleged as the instigator of their illness process. This contextual construction of illness refers to patients’ day-to-day confrontations with irresolvable social issues, such as inability to fully participate in the larger society due to lack of English proficiency and familiarity with Canadian society, interpersonal conflicts at home and workplace, racism, financial difficulties, under- and unemployment. In fact, immigration was a watershed for the participants’ careers, lifestyles and social milieu, and as a result, it may have been inevitable for them to compare their past with their present. Consequently, most of them became disillusioned and dissatisfied. Kleinman’s (1980) cultural construction of illness failed to address the immediate contextual issues that confront immigrant patients; issues they must contend in addition to coping with their illness.

Help-seeking in each of the three social arenas of the health care system (namely the popular, the professional and the folk) (Kleinman, 1980) reflects patients’ conceptualizations, organizations and interpretations of their illness experience. Yet, findings in this study showed that the nature of patients’ symptoms was more important than their perceived causes in shaping their help-seeking behaviour. Regardless of their perceived cause, the respondents first sought help from Western physicians in order to relieve distressing symptoms and obtain a legitimate diagnosis. Historically, Western physicians have been perceived by the Chinese people as being able to deliver quick relief from symptoms and to provide an indisputable scientific basis for illness. Consequently, they could avoid the stigma of being considered lazy or mentally ill.

As suggested in the theoretical framework, every informant of this study utilized all three arenas concurrently and interchangeably. However, the proportion of usage of each arena in
managing their CF was determined more by contextual issues, rather than by perceived causes, as proposed by Kleinman (1980). Important contextual circumstances included affordability and accessibility of caregivers, availability of supportive families and friends, their own help-seeking experiences in past illnesses (including those of their families and friends), as well as from information in the mass media. The contextual circumstances rather than cultural health beliefs seemed to have a more profound influence on patients’ help-seeking behaviours. Although the vast majority of respondents believed that only traditional Chinese medicine practitioners could get to the root of their problems, financial constraint was the primary deterrent inhibiting them from obtaining help from this group of caregivers. Thus, all respondents sought help from Western physicians and only those who were financially well off went to see practitioners of traditional Chinese medicine. This reflected the contextual reality of the participants which required them to conserve their limited resources, rather than to practise their cultural health beliefs.

Study findings also concurred with Goffman (1963) that stigma reflects the social context. The participants experienced personal stigma but were also concerned that they might have inflicted “tribal stigma of race” (p.4) on all Chinese Canadians. Since hard work is an espoused value in the Chinese culture, the respondents feared that their CF and weakness would lead to the stereotyping of all Chinese by other Canadians as being lazy and reluctant to work for a living. The impact of “tribal stigma,” which is more relevant to multicultural North America, was not addressed by Kleinman and colleagues (1995), who developed their theory based on a homogeneous Chinese population. Nevertheless, the results of this study confirmed Kleinman and colleagues’ (1995) view of stigma in the Chinese context as a moral blame which is not applied to the patient alone, but perhaps even more profoundly to the family. Most of the participants were more worried about the repercussions (compromising family members’ chances
of marriage, social relations and family honour) that their "medically unfounded" illness would have on their families than on their own well-being. Avoiding disclosure, which is one of the stigma coping strategies identified by Goffman (1963), was most commonly utilized by the informants. This strategy is in concert with the Chinese saying that "family shame should not be spread outside." Use of this strategy implied the high level of stigma associated with their illness and affecting their families.

**Revised Theoretical Framework**

According to the findings of this study, a revised theoretical framework for Chinese immigrant health is proposed. This framework incorporates work by Kleinman (1980), Goffman (1963), and Kleinman and co-workers (1995) with the following modifications: Stigma is part and parcel of the suffering of a medically ill-defined illness. Moreover, stigma reflects a moral blame that is not only applied to the immigrant patients and their families, but also to their ethnic community and to people of the same ancestry. Symptoms may be presented and understood in cultural terms, but perceived causes and help-seeking behaviours may take on a contextual construction that reflects patients' immediate sources of distress in their social milieu and the accessibility of health services. Patients will first seek help from health care workers whom they perceive to be most capable of alleviating their symptoms within their financial means. Thus, it can be said that perceived cause is over-ridden by practical considerations.

It is noted that help-seeking behaviour is more influenced by the structure of the local health care system, availability of care providers and affordability of their services, than perceived causes. Patients who considered *yin-yang* imbalance as the cause of their illness, would opt for the "free" Western medical services instead of the costly but culturally congruent traditional Chinese medicine. This practice might be attributed to the Chinese cognitive style of dialectical
thinking which seeks to achieve compromise between extremes and acceptance of contradiction when one is presented with two conflicting perspectives (Peng & Nisbett, 1999). In their study to delineate cultural differences of dialectics and reasoning about contradiction between Chinese and American university students, Peng and Nisbett (1999) reported that when two apparently contradictory propositions were presented, Chinese participants were more accepting of both propositions, while their American counterparts polarized their views. These researchers suggest that the tendency toward dialecticism of the Chinese may be seen as part of a general system of thought in which attention is directed toward the environment, and complexity and contradiction are therefore salient. A dialectical approach enabled participants of the current study to tolerate and even appreciate contradiction. Such cultural value was reflected in their help-seeking decision making. They strove to seek the best help for their health within their financial means.

In his recent work, Kleinman (1995) expressed reservations about the usefulness of the cultural construction of illness and has turned his focus to the global issues of social suffering, rather than the distress associated with illness experience (Weiss, 1999).

Today, I am uncomfortable with the style and even the preoccupations of “models,” ethnocultural or other, which imply too much formalism, specificity, and authorial certainty, but models were definitely in my mind in the 1970s (Kleinman, 1995, p. 7).

Notwithstanding Kleinman’s (1995) repudiation, his Illness Explanatory Model’s focus on patients’ illness experience allows it to maintain “its continuity and currency” (Weiss, 1999, p.13). With local adaptation and modification, the fundamental tenets of the Explanatory Model of Illness (Kleinman, 1980) continues to play an influential role in application in clinical practice and research.
Research

The increasingly diverse Canadian multicultural mosaic prompts the need to study cultural differences in illness experience as a matter of urgent practical importance. Findings in this study point out important considerations for future investigations, including:

1) Replicate the current study with different population

Findings of this study reflect the illness experiences of Chinese immigrants with CF and weakness in Metropolitan Toronto. They need to be replicated in different settings and with ethnocultural groups to compare explanatory models of CF. In this way, the illness experience of patients in various communities who suffer from chronic illness which is medically not well defined can be delineated.

2) Integrate qualitative and quantitative methods to validate cultural issues

Integrating qualitative and descriptive quantitative methods in this study has proven to be beneficial in the cross-referencing of data. To understand illness experience, for instance, recurring themes generated from the qualitative findings, such as a perceived cause that is socially based, were substantiated by the high frequency of responses in the quantitative data. Furthermore, participants’ narratives, which illustrated repeatedly their strong conviction about the impact of social issues on their illness, reinforced the quantitative results of the variable of perceived social causes. Hence, integrating qualitative and quantitative approaches allow cross-referencing and validation of findings. This study proved the EMIC to be a useful semi-structured instrument to elicit both quantitative and qualitative data. Nevertheless, new open-ended questions pertaining to immigration issues should be developed and added to the current version for study populations that involve immigrants.
(3) Conduct longitudinal study to monitor illness experience over time

The literature reviewed indicated that research in CF and migrant health is unanimously cross-sectional (including this study). Longitudinal investigations are needed to better understand the patients’ illness experience over time, and the progress of immigrant patients’ help-seeking preferences. Findings of this study revealed the important role played by the family in the illness experience. The family’s perspective of the patient’s premorbid condition and the impact the patient’s illness on the family over time should be investigated. Results from longitudinal inquiries may also assist health care workers in determining the types of interventions needed to support these patients as they are coping with their illness and with integration into a new culture.

(4) Perform outcome evaluation of health and social programmes to improve quality of services for immigrants

Health program planning without consideration of the patients’ illness experience is unlikely to be useful or to serve the interests of the immigrant patient population. Research is required to solicit input from culturally diverse patient groups in the planning and evaluation of health services.

This is compatible with the present trend in health outcome research to combine the perspectives of health professionals and patients. Future research should be designed to involve both patients and their caregivers, to identify discrepancies in expectations and to undertake remedial measures to improve patient care. Health providers’ knowledge of and attitudes toward health practices of diverse cultural groups also need to be examined. Non-Western immigrants’ opinions of Western health care should also be investigated to gain the users’ perspective.
Practice

The majority of the participants indicated that most of the Western medicine practitioners they had consulted were not effective in treating their illness, mainly because of the disparity between their health beliefs and social status, and those of the physicians. Therefore, it is important for the clinician to recognize that each individual, including caregivers and patients, sees the world through his/her own cultural lens. Caregivers must be cognisant of the cultural and professional biases they bring into the client-therapist relationship. Transcultural health care issues should be a required component of health care workers' continuing education. Practitioners must treat each patient as an individual with unique needs, which may or may not be related to their cultural roots, including values, beliefs and traditions. No cultural heritage will wholly explain how any given individual will think and act, but it can help health care workers anticipate and understand how and why patients make certain decisions (Groce & Zola, 1993).

The impact of migration infiltrates every facet of patients' illness experiences. Stress associated with the adjustment to Canadian life and living with a "medically not-well-defined" illness needs to be recognized. Respondents complained that their physicians did not take them seriously which compounded their suffering. Practitioners must appreciate that subjective symptoms such as fatigue and weakness are an ongoing impingement on the patients' daily lives even when there are no clinical findings. Due to the "unknown nature" of the illness, and the cultural value of hard work and family glory, stigma is a major concern to many patients. In the Chinese culture, "face" is important in the maintenance of social respectability, public family image and self-esteem. These immigrants were particularly aware of the impact of their actions on their families' "face," given that they perceived themselves as reflections of their families and cultural groups rather than as autonomous individuals. Assurance of confidentiality is, therefore,
crucial to the therapeutic relationship with these clients.

Based on the results of this study, recommendations and implications for clinical practice are presented below under the following headings: (1) communication, (2) assessment, (3) intervention, (4) social support, and (5) advocacy.

(1) Communication

Findings of the current study indicated that communication barriers can still develop between patients and care providers, even when the latter share similar linguistic and cultural backgrounds. Differences in nosology and principles in their respective health care systems, social status, levels of education and acculturation, posed challenges to clinician-client communication. The communication barrier is even greater when patients and practitioners do not share the same culture or language. The lack of professional cultural interpreters to bridge the communication gap renders both parties feeling frustrated and dissatisfied with Western health care.

Health care workers should consider patients’ suffering in a cultural and social context, and be aware that for patients in many parts of the world and amongst different ethnocultural groups, there is no sharp distinction between somatic and psychological symptoms. Diagnostic categories that combine somatic and psychological symptoms are popular in many countries (Weiss, Raguram, & Channabasavanna, 1995). Like participants of this study, symptoms may be articulated interchangeably in physical, psychological, cultural and social terms. As the biomedical viewpoint is both culture specific and value-laden, care providers need to move away from the current ethnocentric Western framework and recognize that the clinical reality is culturally constructed and pluralistic (Kleinman et al., 1978).

Kirmayer (1984) cautions that therapists’ preoccupation with specific words of affect may
be problematic in their communication with clients. Patients who do not express their feelings in affective terms, but use somatic idioms instead, should not be regarded as incapable of describing their psychological distress. In the present study, the participants’ expressions of predominantly somatic symptoms were consistent with traditional Chinese medical nosology, rather than with clinical categories of Western medicine. The meaning and symbolic value of symptoms, even sharing the same names, may be culturally specific and are not necessarily interchangeable between cultures (Kleinman et al., 1978). Somatic idioms (or physical metaphors) of narration should be understood as a cry for help in a specific cultural context. Health professionals working in a multicultural setting must make an extra effort to understand their patients’ explanations of illness and what these expressions may mean to the clients. For example, “shen kuei” (kidney deficiency or weakness) may carry drastically different connotations to the clients and practitioners. Without clarification of such a “foreign” concept from the patients or the literature, health professionals’ ability to provide quality care will be compromised and patient satisfaction jeopardised.

Participants may have attributed the cause of their fatigue to social and familial conflicts resulting from migration because they perceived these causes as socially acceptable to others as they were immigrants. Perhaps, they felt comfortable using these issues as an entry point to deal with other personal problems. In order to facilitate communication, caregivers should first address the patients’ immediate concerns associated with adjustment to Canadian life and changes in family dynamics. They should also be prepared to consider other issues, of course.

Most of the Chinese patients in this study held a paternalistic concept of their physicians. They expected their physicians to exercise professional expertise by prescribing medications and treatment, without the patient having to ask. To maintain harmony, the majority of individuals “moved on” to other physicians and alternative therapies, rather than voice their dissatisfaction.
Employing culturally sensitive communication skills would help elicit the concerns of this group of patients.

(2) Assessment

Overcoming cultural and linguistic barriers is prerequisite to a thorough assessment. An investigation and understanding of values, beliefs, and norms of clientele from diverse cultures can afford considerable insight and understanding to the clinician’s practice. A qualitative understanding of illness experience will enhance the development of effective, culturally relevant therapies that acknowledge and work with patients’ explanatory models (Kareem & Littlewood, 1992). Obtaining information about a client’s heritage and taking the time to learn about the relationship between clients’ beliefs and their respective interpretation of illness would allow the formulation of meaningful therapeutic measures. Caregivers who do not explore beyond general questions about the patient’s distress will not know about the various factors that impact on their patient’s illness experience.

Eliciting the patient’s explanatory model of illness and acknowledging values, beliefs, and fears should be the first steps to assessment. A migration-specific health assessment tool that includes an evaluation of the patient’s physical, psychological, cultural, social and migration history could be developed and implemented. This tool could start with a systematic physical and psychological appraisal to identify the principal factors that precipitated illness, including physiological disorders, misinterpretation of bodily sensations, mood abnormalities, ineffective coping behaviours, and social stresses (Mayou & Sharpe, 1997). The cultural and social components of the assessment solicit the patients’ cultural and social perceived causes of their illnesses, and their help-seeking experiences. Interpersonal and occupational problems as well as the family’s understanding of their illness should also be delineated and addressed. A migration
history that elicits the patient’s reasons for migration, sequence of events during migration, their pre-migration sociocultural and socio-economic backgrounds, help-seeking behaviours, and mode of access to the health care system in the country of origin, would provide the needed background to their current explanatory model of illness.

Patients’ accounts of distresses should be accepted and acknowledged as genuine expressions of their suffering and the reality of the complaint should not be disputed. A tolerant approach to benign therapies is also advisable to maintain rapport (Matthews, Manu, & Lane, 1991). To provide culturally sensitive care, practitioners can acknowledge the reality of patients’ symptoms and distress and impaired functioning, without necessarily agreeing with them about the cause. Health care providers need to invite patients to share their explanation of illness with the assurances that their beliefs will not be judged or dismissed as inaccurate representations (Gesler, 1991). For example, while practitioners may be quick to correct a patient who describes his/her fatigue as the result of “bad feng shui,” such behaviour ignores the patient’s emotional and metaphorical context of illness etiology. It is important for caregivers not to argue with patients regarding the explanation of their illness even if there are good reasons to believe that the patients’ interpretation may not be consistent with scientific principles. If the patients’ unscientific beliefs lead to their rejection of needed medical treatment, the consequences of such an action must be explained in detail to the patients to allow an informed decision to be made. With the patients’ permission, their family members should also be involved in the decision making process. Expert opinions on treatment refusal from a medical ethicist, knowledgeable in cultural health behaviours, should also be sought. Clinicians should not undermine patients’ coherent explanations of illness that have provided them with a foundation for coping and self-care. The patients’ beliefs should be acknowledged, addressed, and accepted as legitimate topics for discussion.
Paying close attention to cultural and social meanings of symptoms and illness will allow clinicians to make a more accurate assessment of culturally diverse patients and to devise interventions that respect them and effectively mobilize their personal, family and community resources (Kirmayer et al., 1994). Interviewing patients alone and with their family members would help to obtain information from different perspectives, thus facilitating the formulation of a comprehensive and workable treatment plan for the patients.

(3) Interventions

Culturally sensitive interventions must not simply take patients’ complaints or concerns at face value but should involve an appreciation of their social implications. Effective treatment also requires consideration of the impact of migration and gender on patients’ illness experience. Health care workers should focus not just on the patient’s physical complaint but should take a more holistic approach. In view of their pluralistic help-seeking behaviour, caregivers need to tolerate contradictions or complementary views of Chinese patients in the explanations of their illness and in their help-seeking behaviour. Professional explanations of their illness should be introduced slowly without discounting patients’ folk beliefs. Indeed, such an approach should be taken with all patients.

To be of benefit to patients, medical care needs to take their social context into consideration. Health education materials should be modified to incorporate prevailing Western health concepts, principles of traditional Chinese medicine, and information from the mass media. Discussion with patients about the meanings of fatigue, their past experience with fatigue, and their current expectations about its progress should be essential components of any patient education programme in the management of fatigue. Subsequently, practical strategies that assist this group of previously active patients in coping with activities of daily living should be
explored. Patients should be encouraged to monitor their energy levels and to schedule arduous tasks to be accomplished if there are times in the day in when energy levels increase (Wood, Magnello, & Sharpe, 1992).

A health team should take a multidisciplinary approach that incorporates community resources and health expertise to meet the multifaceted needs of the CF patient. Patients should be referred to appropriate members of the health team when their needs are beyond the scope of the particular caregiver.

Participants of this study alleged that lack of co-ordination and liaison between caregivers created confusion and frustration for them. A line of communication between health care providers should be established to avoid duplication of services and contradictions in the recommendations for care. In many cases, the only communication is between the family doctor and the referring specialist, with no communication among other caregivers. In the present study, the vast majority of participants did not tell their physicians that they were seeing other practitioners for fear of offending them or being perceived as having a lack of confidence in their physicians' ability to treat their illness. On the other hand, traditional Chinese practitioners expected the participants to have a Western physician as their family doctor, and often asked the patient to have certain laboratory tests done to rule out other illnesses, such as diabetes or hypothyroidism. There should be more effort for collaboration amongst patients' caregivers. Since the majority of the respondents had trusting relationships with their family doctors, perhaps with adequate compensation from the Ontario Health Insurance Plan (OHIP) for their time and efforts, this group of practitioners should take on the role of a care co-ordinator, to avoid fragmentation of patient care.

Most informants of the current study, felt that only patients, who suffered from major mental illness such as schizophrenia needed to be treated by mental health professionals. This
misconception, which may apply to Chinese immigrants in general, deterred informants from enlisting help from this group of practitioners. Community education in the area of mental health is urgently needed to allow a better understanding of the roles of mental health workers in Canada. Health professionals need to work with community agencies to educate the immigrant population about the roles of mental health practitioners and potential mental health issues confronting all immigrant communities. Because of this belief and because of the stigma associated with mental illness, general practitioners with in-depth knowledge of the Chinese perception of mental illness and who enjoy a trusting relationship with their patients and families are ideal to provide holistic care. Mental health services should also be delivered in conjunction with other services, such as employment assistance, education and integration to the larger society.

(4) Social support

Since all informants received help from their family and friends, health care workers should capitalize on these natural modes of support and provide assistance and resources to this system. Health care workers should also take a non-judgmental approach, and review their patients on a regular basis to assess the efficacy or any harmful effects of self care.

In view of the pragmatic approach to treatment of the Chinese (Lin, T. & Lin, M., 1981), clinicians need to assure that a sense of accomplishment has been achieved after each patient-clinician encounter. Should medical intervention not be required as part of the treatment, other tangible aid, such as referrals to appropriate community agencies should be offered, where social and instrumental (e.g., employment) support are provided. Although patients gained some temporary comfort from their physicians that “everything is fine from the tests,” services from other members of the health care team should be activated to address patients’ concerns.
As indicated by the informants' experience with community social services, caregivers should ensure that these linkages are desirable and easily accessible to the patients. Through community and social agencies, immigrant patients will be able to acquire the necessary survival skills for their new lives in Canada. They can be taught "Canadian" day-to-day living skills such as snow shovelling and meal preparation (such as shopping for a week's food and proper refrigeration rather than the common practice of daily grocery shopping in their places of origin). Language can be used as a powerful resource in boosting self-esteem. Fostering English proficiency has been found to reduce the impact of acculturation stressors (Nicassio et al., 1986). Special ESL (English as a second language) classes designed for people with poor memory would be beneficial for this group of patients. They also need to be informed of Canadian cultural and social protocols, be equipped with concrete problem solving skills and guided in how to handle issues of day-to-day living, such as improving employment status, fostering favourable working conditions and combating racism.

Traditional values of close family ties and harmony can encourage the hiding of problems in the home, such as domestic violence and racism. Due to the absence of extended family support and mediation in the event of familial conflict, community social services' roles should be promoted in family conflict resolution. Since the vast majority of participants relied heavily on the Chinese mass media for information, utilization of these services should also be encouraged through this channel.

(5) Advocacy

Findings of this study demonstrated that patients who are immigrants, particularly those with a poorly defined illness such as CF, are in a very vulnerable position for mental health problems. Their highly stressful lives are compounded with their limited ability and knowledge
to obtain support. In order to provide equitable and compassionate health care to this group of patients, who are confronting multiple health risks, all health care providers should take upon themselves the role of patient advocates.

We should first examine how our future health care providers are being educated. As Canada becomes increasingly multicultural, intercultural and interracial education needs to be an integral component of curriculum for health care professional (Committee for Intercultural and Interracial Education in Professional Schools, 1994). Impact of culture on illness experience should be a required component of continuing education for front line health care workers.

Informants of this study expressed their frustration and disappointment at not being able to communicate with non-Chinese speaking health care providers. Professional cultural interpreters are not available in most health organizations in Ontario (Ministry of Culture and Citizenship, 1999). Front-line health care workers should lobby health organization administrators to allocate resources to have professional health interpreters be included as an integral part of the health care team, particularly, in parts of Canada that have a high concentration of non-English speaking immigrant populations.

The Canadian Government should advise potential immigrants of ways to get their credentials recognized, and the reality of not being recognized in some professions to prevent false hope and despair. Anti-racism policies and strict enforcement should be in place to minimize discrimination and inequality in employment.

Through the school system and the mass media, the general Canadian public should also be informed of the obstacles confronting new immigrants. It is pivotal for Canadians to understand, like their forefathers, that these newcomers need to be with their own people to achieve a sense of security rather than having their behaviour interpreted that they are not willing to acculturare into the Canadian culture.
Conclusion

This ethnographic study with a quantitative component is the first exploration of the illness experience of CF and weakness of Canadian Chinese immigrants. Its primary focus is on how culture shapes the illness experience of Chinese immigrants. The Explanatory Model Interview Catalogue (EMIC) (Weiss, 1997), a semistructured instrument, was adapted and used to elicit the rich experience of this group of patients.

Kleinman (1980), Goffman (1963), and Kleinman and co-workers (1995) contributed to the theoretical basis that directed this study. Based on the findings of this study, modifications and revisions of their theoretical framework are proposed. This new framework, which takes into consideration the powerful impact of current day-to-day contextual adversities, such as interpersonal conflicts, racism, underemployment and unemployment, on the illness experience of first generation immigrants, calls for a contextual construction instead of cultural construction of illness as proposed by Kleinman (1980).

The theme of the impact of migration transcends the narratives of all participants. These patients endured multiple symptoms and presented their discomfort using predominately somatic and traditional Chinese medical terms. Although integral to their pattern of distress, psychological symptoms were minimized by participants. Being a victim of a “medically not well defined” illness and an immigrant in a foreign land imposed tremendous stress on these individuals. The fear implied by mental illnesses without an organic diagnosis was associated with a sense of failure about not living up to one’s obligations, as defined by the Chinese ethos of hard work. Study participants felt stigmatized, not just for themselves but for their families, the Canadian Chinese community and the Chinese people as a whole.

Consistent with findings reported in the literature, informants of this study sought help from
multiple sources to cope with their illness. Being understanding and willing to listen to their concerns were qualities identified in caring physicians. A statistically significant correlation was found between socially based perceived causes and self-help and help-seeking from family and friends. This is congruent with traditional Chinese norms that individuals with social difficulties are expected to turn to family and close friends for assistance.

Findings of this study attest to the complexity of patients’ explanatory models of illness. In future research and education of health care workers, the relationships between patients’ explanatory models of illness and their illness experiences in the Canadian multicultural mosaic will need to be addressed. Clinicians need to pay special attention in caring for this group of patients, especially, the patient’s suffering associated with a medically not well defined illness, in addition to all the challenges confronting immigrants.
REFERENCES


Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees (1988a). After the Door has been Open: Mental Health Issues Affecting Immigrants and Refugees in Canada. Health and Welfare Canada.


I. Clinically evaluate cases of prolonged or chronic fatigue by:
A. History and physical examination:
B. Mental status examination (abnormalities require appropriate psychiatric, psychologic, or neurologic examination);
C. Tests (abnormal results that strongly suggest an exclusionary condition must be resolved):
   1. Screening lab tests: CBC, ESR, ALT, total protein, albumin, globulin, alkaline phosphatase, Ca, PO4, glucose, BUN, electrolytes, creatinine, TSH, and UA
   2. Additional tests as clinically indicated to exclude other diagnoses.

II. Classify case as either chronic fatigue syndrome or idiopathic chronic fatigue if fatigue persists or relapses for 26 months.

A. Classify as chronic fatigue syndrome if:
   a. Criteria for severity of fatigue are met, and
   b. Four or more of the following symptoms are concurrently present for 26 months:
      1) impaired memory or concentration, 2) sore throat,
      3) tender cervical or axillary lymph nodes,
      4) muscle pain, 5) multi-joint pain, 6) new headaches,
      7) unremitting sleep, and 8) post-exertion malaise.

B. Classify as idiopathic chronic fatigue if fatigue severity or symptom criteria for chronic fatigue syndrome are not met.

III. Subgroup research cases by the presence or absence of the following essential parameters:
A. Comorbid conditions (psychiatric conditions must be documented by use of an instrument);
B. Current level of fatigue (measured by a scale);
C. Duration of fatigue;
D. Current level of physical function (measured by an instrument).

Sub-group research cases further as needed by optional parameters such as epidemiologic or laboratory features of interest.
APPENDIX B: Consent Form

Subject’s Name: ___________________________  Pt. Study No. ____________

Project Title: CULTURAL STUDY OF ILLNESS

We are asking you to participate in a study of the meaning of illness. If you agree to an interview with the project staff, we will ask about your ideas about illness, how you get help and other questions about your life. The length of these interviews usually ranges from 1 1/2 to 4 hours, although this one could be a little longer or a little shorter.

Doctors use their knowledge to help patients. This knowledge comes from experience treating patients and from research. Participation in this research study is not required for you to get the help and treatment you came here for, and you may leave the study at any time without any effect on your treatment.

Potential Risks: During the interview it is possible, though not likely, that you may find it upsetting to talk about some of the issues we ask about. You may stop the interview at any time or refuse to answer any question.

Expected Benefits: Understanding how illness affects people like you, and how you understand your problems may help clinicians to help people who come to them for help more effectively. You may also feel better after the interview from discussing concerns that are not usually spoken about in the clinic.

Statement of Confidentiality: What we talk about will remain confidential, and we will not identify you as a participant in this study.

Investigator’s Statement: I have fully explained to the subject the nature and purpose of the procedures described above and such risks as are involved in its performance. I have asked the subject if he or she has any further questions, and I have answered these questions to the best of my ability. I have also offered a copy of this form to the subject to read and keep.

__________________________
Investigator’s Signature

Subject’s Statement: I understand what has been requested in connection with my participation in this study, and I agree to participate. I also understand that I may withdraw this consent at any time without any effect on the quality of my treatment.

__________________________
Subject’s Signature

Date: ______________
# EXPLANATORY MODEL INTERVIEW CATALOGUE

## THE EMIC

**FOR DISORDERS OF FATIGUE AND WEAKNESS AMONG CHINESE AND AMERICANS**

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| Center for the Study of Culture and Medicine     | Mental Health Institute   |
| Department of Social Medicine                    | Hunan Medical College     |
| Harvard University, Boston                        | Changsha, China           |

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**Mitchell Weiss, M.D., Ph.D.**  
Clarke Institute  
University of Toronto  
250 College Street  
Toronto, Ontario M5T 1R8  
CANADA

March 15, 1994
EMIC: FATIGUE AND WEAKNESS

March 15, 1994

DATE: @
TIME BEGIN: @:

CENTER:

(1-UCLA 2-MS 3-UC 4-TCH 5-UCB 6-S sack 7-SK 8-MHAN 9-JAPAN 10-KOREA) * 

1. PATIENT STUDY NUMBER: * 2. CLINIC ID NUMBER: *

3. PATIENT NAME: 

4. SEX: (1-Male 2-Female) * 

5. AGE: (Years) *

6. RELIGION OF ORIGIN: 

(0=Unsuretn 1=Prot 2=Cath 3=Jew 4=Hindu 5=Islam 6=Tao 7=Mix Trad ChIn 8=Agnostic/Atheist 9=Other) * 

(Narrative) 

7. ETHNIC BACKGROUND: "How would you describe your ethnic background?"

(1=Afro/Amer 2=Hispanic 3=Asian/Pac 4=Near Ind 5=Caucasian 6=Han Chinese 7=Other/Mixed) *

7.1. PLACE OF BIRTH 

(1=USA 2=Taiwan 3=Mainland China 4=E. Korea 5=Other) *

Specify: 

7.2. IF ELSEWHERE: AGE OF MIGRATION: (Years) (#) 

8. LOCAL
ADDRESS OF PATIENT: 

City: State: Zip: 
Telephone(s): 

8.1. Permanent or Temporary? (1=Principal 2=Other) *

8.2. Urban, Suburban, Town, or Rural? (1=Urban 2=Suburban 3=Town 4=Rural) *

9. SECOND ADDRESS: 

City: State: Zip: 
Telephone(s): 

9.1. Permanent or Temporary? (1=Principal 2=Other) *

9.2. Urban, Suburban, Town, or Rural? (1=Urban 2=Suburban
10. CONTACT PERSON: 10.1. NAME:__________________________________________

10.2. Relationship:________________________________________ (Referral Code) *____

10.3. Address: ___________________________________________________________

City:________________ State:____ Zip:_____

Telephone(s):__________________________

11. TYPE OF HOME: "How would you describe the place where you live?"

(1=Homeless 2=Rented In 3=Pub Housing 4=Rented Apt
5=Owned Flat (Condo) 6=Rented House 7=Owned House 8=Other) *____

____________________________________________________________________

12. MARITAL STATUS: 12.1. "Are you married?"

If so: "Are you staying with your spouse?"

(1=Single 2=Married 3=Separated/Divorced
4=Widowed 5=Remarried 6=Cohabitation 7=Other) *____

____________________________________________________________________

12.2. HOW LONG MARRIED/COHABITING: If currently (or ever)
married: "How long have you been (were you) married?"

(Teams) (#)____

12.3. IF ENDED (DEATH/SEP/DIVORCE) HOW LONG: ______________________

(Teams) #____

12.4. LIVING CHILDREN (Biological and Other): If ever married:
"How many children do you have, and how old are they?"

(A) Sons: Ages ___________________________ Living (#)____
(B) Daughters: Ages ___________________________ Living (#)____

12.5. LIVING SIBLINGS (Biological and Other): "How many brothers and
sisters?"

(A) Brothers: Ages ___________________________ Living (#)____
(B) Sisters: Ages ___________________________ Living (#)____

13. EDUCATION:

(Code: 0=Some 1=Some Primary 2=CompI Primary 3=Some Sec
4=HS Dip 5=Some Coll/Foot Sec 6=Coll Degree
7=Some Postgrad 8=Postgrad Master's 9=Postgrad Doctorate)

Details: _____________________________________________________________ *____

____________________________________________________________________

Years of Education: #____
14. OCCUPATION

(1st: 0=Uncertain 1=Professional 2=Manager/Admin
3=Business 4=Clerical 5=Skilled Labor 6=Arts/Crafts, Tailor,
Semi-Skilled Labor 7=Vendor Sales 8=Service (Driver etc.)
9=Unskilled Labor 10=Farmer 11=Housework 12=Student 13=Disabled
14=Unemployed 15=Retired 16=Never Employed 17=Deceased 18=Other)

14.1. PERSONAL OCCUPATION:

IF UNEMPLOYED, RETIRED OR DISABLED: Prior Occupation: ____________

14.2. SPOUSE'S OCCUPATION:

IF UNEMPLOYED, RETIRED, DISABLED OR DECEASED: Prior Occupation: ____________

14.3. PARENT/ORHER CHILDHOOD PROVIDER

(IF Multiple, note in prose but record highest level):

IF UNEMPLOYED, RETIRED, DISABLED, DECEASED: Prior Occupation: ____________

Specify (Fa=Father Mo=Mother Ot=Other): ____________

15. INCOME:

15.1. PERSONAL MONTHLY INCOME $__________

15.2. WELFARE/SUPPORT $__________

15.3. SPOUSE'S INCOME $__________

15.4. ADDITIONAL HOUSEHOLD INCOME $__________

__________________________________________________________ TOTAL $__________
**PERSONAL EXPERIENCE OF ILLNESS: PATTERNS OF DISTRESS**

"I will be asking you questions about the problem that led you to seek help. Later, I will ask about what has been helpful for it in the past and what you feel might now be helpful. While doctors have special ways of understanding illness, people like yourself also have their own ideas, which may be different from what the doctors think. It will help us to help people with problems like yours by understanding how you think about your problem, the ways you believe you might get help for it, and what you do about it."

16. **PROSE ACCOUNT OF PROBLEM**  "What is the problem for which you sought help? Please tell us about it."

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

Code symptoms reported after initial open-ended query:

Code: 0-Not Mentioned 1-Mentioned 2-Emphasis (all that apply)

1. ___ Fatigue 2. ___ Weakness 3. ___ Somatic Sxs 4. ___ Hypochondriacal Sxs
   5. ___ Depress Sxs 6. ___ Loneliness 7. ___ Anxiety Sxs 8. ___ Sleep Disturb
   9. ___ Functional Impairment 10. ___ Cognitive Impairment 11. ___ Social Relations
   12. ___ Stigma 13. ___ Amotivational Sxs 14. ___ Not Troubled 15. ___ Other
   16. ___ Cannot Say

16.1. "How has this (have these) problem(s) affected or changed your life?"

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________
16.2. If subject does not emphasize mood or anxiety symptoms, then continue the inquiry with the following probe:

"Along with these problems, have you been feeling sad or anxious?"

__________________________

__________________________

__________________________

16.3. If subject does not emphasize somatic complaints, then continue the inquiry with the following probe:

"Along with these problems, do you have any aches, pains or other physical troubles?"

__________________________

__________________________

__________________________

Code additional symptoms reported after probes:

Codes: 0=Not Mentioned 1=Mentioned 2=Emphasis (all that apply)

1. __ Fatigue
2. __ Weakness
3. __ Somatic Sxs
4. __ Hypochondriacal Sxs
5. __ Depress Sxs
6. __ Loneliness
7. __ Anxiety Sxs
8. __ Sleep Disturb
9. __ Functional Impairment
10. __ Cognitive Impairment
11. __ Social Relations
12. __ Stigma
13. __ Amotivational Sxs
14. __ Not Troubled
15. __ Other
16. __ Cannot Say

17. ONSET: "When did you first notice the condition and recognize it as a problem?"

(Months Ago) __________

(Narrative) __________________________________________

__________________________

__________________________

__________________________
17.1. "When you first became aware of the problem, what was it that you noticed first? What was it that first troubled you?"

<p>| | |</p>
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Fatigue</td>
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<tr>
<td>2.</td>
<td>Weakness</td>
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<tr>
<td>3.</td>
<td>Somatic Sxs</td>
</tr>
<tr>
<td>4.</td>
<td>Hypochondriacal Sxs</td>
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<td>5.</td>
<td>Depress Sxs</td>
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<td>6.</td>
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<td>8.</td>
<td>Sleep Disturb</td>
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<td>9.</td>
<td>Functional Impairment</td>
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<td>10.</td>
<td>Cognitive Impairment</td>
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(Narrative)………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………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20. DISTINGUISHING MIND AND BODY: "Are the effects of this problem on mind and body distinct from one another, or are mind and body the same? (By mind I mean thinking, feelings, and emotions.)"

______________________________

______________________________

______________________________

(1=Distinct 2=Same 3=Uncertain) *

21. PERCEIVED SERIOUSNESS: "Is your problem serious? (How serious? Moderately or very serious?)"

______________________________

(1=Not Serious 2=Mild Serious 3=Very Serious 4=Uncertain) *

(Narrative)______________________________

______________________________

22. MOST TROUBLING: "What is most troubling about your problem?"

1. Fatigue 9. Functional Impairment
5. Depress Sxs 13. Amotivational Sxs
7. Anxiety Sxs 15. Other
8. Sleep Disturb 16. Cannot Say *

Narrative______________________________

______________________________

23. WORSE, CONSTANT IMPROVED OVER TIME: "Would you say your condition has become worse, improved or stayed about the same over time?"

______________________________

(1=Worse 2=Constant 3=Fluctuating 4=Improved 5=Uncertain) *

(Narrative)______________________________

______________________________
24. ANTICIPATED OUTCOME.

24.1. WITH TREATMENT: "What do you expect to happen as a result of this problem with treatment?"

(Code Best Outcome) *

(Narrative)________________________________________

24.2. WITHOUT TREATMENT: "What do you expect to happen as a result of this problem without treatment?"

(Code Worst Outcome) *

(Narrative)________________________________________

25. WHETHER DOCTORS CAN HELP (MEDICAL PROBLEM): "Is your problem the kind of problem doctors can help with?"

(1=Yes 2=No 3=Possibly 4=Uncertain) *

25.1. If not YES: "How is your problem different from problems doctors help with?"

(Narrative)________________________________________

26. EFFECTS ON HOUSEHOLD INCOME: "Has your problem reduced the income of your household, either because you or someone else cannot work and earn as much?"

(1=Same 2=Reduced 3=May Decrease if not improved 4=Decrease Resolving 5=Other 6=Uncertain) *

(Narrative)________________________________________

27. KEEP OTHERS FROM KNOWING IF POSSIBLE: "If possible, would you prefer to keep people from knowing about this problem?"

(Yes=1 No=2 Possibly=3 Uncertain=4) *

(Narrative)________________________________________
28. **WOULD LIKE SOMEONE TO KNOW**: "On the other hand, is there anyone in particular whom you would like to know about it?"

(Yes=1 No=2 Possibly=3 Uncertain=4) *_____

(Narrative)________________________________________

29. **THINK LESS OF YOURSELF**: "Do you think less of yourself because of this problem?"

(Yes=1 No=2 Possibly=3 Uncertain=4) *_____

(Narrative)________________________________________

30. **SHAMED OR EMBARRASSED/LOSS OF FACE**: "Have you ever been made to feel ashamed or embarrassed (loss of face) because of your problem?"

(Yes=1 No=2 Possibly=3 Uncertain=4) *_____

(Narrative)________________________________________

31. **OTHERS WOULD THINK LESS OF YOU**: "If they knew about it, would your neighbors, colleagues or others in your community think less of you because of this problem?"

(Yes=1 No=2 Possibly=3 Uncertain=4) *_____

(Narrative)________________________________________

32. **OTHERS HAVE AVOIDED YOU**: "Do you feel others have avoided you because of your problem?"

(Yes=1 No=2 Possibly=3 Uncertain=4) *_____

(Narrative)________________________________________
33. OTHERS MIGHT REFUSE TO VISIT: "Would some people refuse to visit your home because of this condition?"

(Yes=1 No=2 Possibly=3 Uncertain=4) * _____

(Narrative)________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

34. OTHERS WOULD THINK LESS OF THE PATIENT'S FAMILY: "If they knew about it, would your neighbors, colleagues or others in your community think less of the family because of this problem?"

(Yes=1 No=2 Possibly=3 Uncertain=4) * _____

(Narrative)________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

35. PROBLEMS FOR THE FAMILY: "If others were to find out about your problem, might it cause problems for your family?"

(Yes=1 No=2 Possibly=3 Uncertain=4) * _____

(Narrative)________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

36. FAMILY CONCERN ABOUT DISCLOSURE: "Would your family prefer to keep others from finding out about your condition?"

(Yes=1 No=2 Possibly=3 Uncertain=4) * _____

(Narrative)________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
37. MARRIAGE:

37.1. PROBLEM GETTING MARRIED.

**If Unmarried:** "If people knew about it, might this problem make it more difficult to marry?"

**If Married:** "Suppose you were not married. If people knew about this problem, would it be more difficult to get married?"

(Yes=1 No=2 Possibly=3 Uncertain=4) *_____

(Narrative)__________________________________________

____________________________________________________________________

37.2. PROBLEM IN ONGOING MARRIAGE: "Might this condition cause problems in your marriage (if you were married)?"

(Yes=1 No=2 Possibly=3 Uncertain=4) +_____

(Narrative)__________________________________________

____________________________________________________________________

37.3. PROBLEM FOR RELATIVE TO MARRY: "Could this problem make it more difficult for someone in your family to marry?"

(Yes=1 No=2 Possibly=3 Uncertain=4) +_____

(Narrative)__________________________________________

____________________________________________________________________
PREVIOUS CAUSES

"Each of us may explain something that happens in various ways. For example, if their television suddenly went blank, some people might immediately think it was a picture tube or something inside their set. They might also consider whether the antenna had broken or whether the station stopped broadcasting. It might occur to them that they should have been maintaining or servicing the set more regularly, or perhaps they just weren't meant to see the next program. Similarly, people have different ideas about what hurts them or makes them sick. We would like to understand your own ideas about this problem, even if they are different from ideas of your friends, family or your doctors."

Provide further examples if necessary.

38. "What do you think is the cause of this problem?"

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<th>Code</th>
<th>Cause</th>
<th>Description</th>
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<tr>
<td>00</td>
<td>Can't Specify-No Idea</td>
<td></td>
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<tr>
<td>01</td>
<td>Food-Water</td>
<td></td>
</tr>
<tr>
<td>02</td>
<td>Nutrition-Diet/Energy</td>
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<td>03</td>
<td>Alcohol</td>
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<td>04</td>
<td>Smoking</td>
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<td>05</td>
<td>Substance Abuse</td>
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<td>06</td>
<td>Prescribed-OTC Medicine</td>
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<td>07</td>
<td>Injury-Accident-Infection</td>
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<td>08</td>
<td>Overwork-Exhaustion</td>
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<td>09</td>
<td>Prior Illness</td>
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<td>10</td>
<td>Immune Deficit-Genetic</td>
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<td>11</td>
<td>Virus-Germ-Infection</td>
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<td>Red Blood-Red Person</td>
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<td>Red Blood-Previous Life</td>
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<td>Reproduction</td>
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<td>46</td>
<td>Birth-Child in Body</td>
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<td>47</td>
<td>Climate: Heat-Cold Etc.</td>
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<tr>
<td>48</td>
<td>Vital Energy (VE)</td>
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<td>Yin-Yang Imbalance</td>
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<td>5th Elemental-Genes Label</td>
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<td>52</td>
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<td>53</td>
<td>Astrology</td>
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<td>54</td>
<td>Fetus-Child-Name</td>
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<tr>
<td>55</td>
<td>Other (Specify)</td>
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</tbody>
</table>

39. CAUSE BY MIND, BODY, SOCIAL OR OTHER "Do you feel this problem that brings you here comes mainly from your body, your mind or your relations with people?"
A. Problem Mainly Comes from Body

B. Problem Mainly Comes from Mind (Thinking, Feeling, Emotions)

C. Problem Mainly Comes from Social Relations

D. Personal Activities, Behavior, Lifestyle

40. SCREENING PERCEIVED CAUSES

"People often have many different ways of explaining problems like yours. I am going to ask you about a number of these explanations. Do you think any one or several of these, which I will list, might have caused the problem?"

40.1. "Do you believe your problem is caused by anything related to food or water, poor nutrition, alcohol, smoking or drugs?"

1) Food-Water

2) Nutrition-Malnutrition

3) Alcohol

4) Smoking

5) Abused Drug

6) Prescribed/OTC Med

40.2. "Do you believe your problem is caused by overwork, some prior illness or problem with your immune system; could it be a virus or infection, kidney weakness or some other physical (or pregnancy-related) problem?"

7) Injury, Accident
9) Prior Illness
10) Immune Dysfct/Allergy
11) Virus-Germs-Infection
12) Kidney Weakness
13) General Weakness
14) Anat-Physical-Biochem
15) Nerves
16) Pregnancy-Related

40.3. "Do you believe it is caused by contamination from an environmental toxin or some other kind of pollution or contact?"

S-A-I-L-E

17) Envrn Toxin-Pollution

40.4. "Do you believe it is caused by stress among your social relations, perhaps a family illness, the death of someone close to you?"

(Pause for Response) "Do you think it is due to a financial problem, family conflict or other problems at home?"

(Pause for Response) "Could it be problems at work or concern about your job?"
40.5. "Do you believe it is the result of physical or sexual abuse when you were a child, or the result of violence more recently?"

26) Childhood Abuse

27) Victim of Violence

40.6. "Do you believe your problem is caused by magic (sorcery or geomancy)? Could it be the result of demons, deities, ghosts, or ancestral spirits?"

28) Sorcery

29) Demons - Deities

PC CODES: S=Definite C=Possible D=Not Cause E=Unclear F=Concept Unknown A=Yes B=No C=7
Impression: (See Code) P=Dependent D=Independent R=Related L=References: If L=D or L=R, PC Code Reference Number
40.7. "Do you think you might have brought this problem on yourself, perhaps because you didn't take good enough care of yourself, or because you did something bad, (either in this life or a previous life)?"

40.8. "Do you believe your problem is caused by your mind, thoughts or your personality, perhaps because you are the kind of person who worries too much?"
40.9. "Do you believe your problem is caused by something passed on in your family, a hereditary factor, or something from birth? Do you think it results from your upbringing?"

38) Heredity
39) Familial Upbringing
40) Congen Not Heredity

40.10. "Do you believe your problem is caused by germs, dirt, not keeping yourself clean enough or contact with an infected person?"

41) Sanitation
42) Personal Hygiene

40.11. "Do you believe your problem is caused by sexual relations of any kind, (loss of semen) or masturbation?"

43) Sexual Experience

PC CODES: S-Definite; C=Possible; D=Not Cause; E=Unclear; F=Concept Unknown; A=Artifact; Y=Yes; N=No; C=?

Instructions: See Codes. Description: D=Dependent; R=Related; I=Independent; CR=Code Reference; L=Low or L=Right, PC Code Reference Number
40.12. "Do you believe your problem is caused by too much or too little heat or cold in your body, or because it gets hot or cold outside as the seasons change?"

- A - I - L - GE

46) Heat-Cold / Body _______ _______

47) Heat-Cold / Climatic _______ _______

40.13. "Do you believe your problem is caused by the fundamental source of vital energy in the body (qi). Could it be due to an imbalance of yin/yang or some other humoral or constitutional imbalance?"

- A - I - L - GE

48) Vital Energy (Qi) _______ _______

49) Yin-Yang Imbalance _______ _______

50) Other Humoral or Constitutional Imbal _______ _______

PC CODES. B = Definite C = Possibly D = Not Cause E = Unclear F = Concept Unknown A = Yes B = No C =？

Legend: (See Codes) L = Inverse D = Dependent R = Related I = Independent CR: Code Reference: If L=D or L=R, PC Code
40.14. "Do you believe your problem may be a result of fate, the Will of God, or bad stars?"

51) Fate

52) Will of God

53) Astrology

54) Fate/God-Stars Nonspc

40.15. "Do you believe your problem is caused by something else?"

55) Other

41. FIRST PERCEIVED CAUSE: "Which of these causes that you have mentioned, or perhaps something else, was the one that you thought of first when you became aware of your problem?"

(FC Code) *_____
42. CHANGED MIND ABOUT CAUSE

42.1. "Since your problem began, have you changed your mind about what you think may have caused it?"  

(1=Yes 2=No 3=Possibly 4=Uncertain) *___

(Narrative) __________________________________________________________________________

If so:

(A) "What did you think caused it previously, but not now?"

PREVIOUS BELIEFS LESS NOW:  (00=FC Code) *____  (*)  (*)
Specify: __________________________________________________________________________

(B) "What do you now think causes it, but did not consider so much previously?"

CURRENT BELIEFS LESS BEFORE:  (00=FC Code) *____  (*)  (*)
Specify: __________________________________________________________________________

43. MOST IMPORTANT PERCEIVED CAUSE: "Which of these causes that you have mentioned (or perhaps something else) is the most important cause of your problem?"

(00=FC Code) *____

PC CODES: B=Benefit  C=Caused  D=Not Cause  E=Unclear  F=Concept Unknown  A=Arbitrary  A=Yes B=No C=?
44. FAMILY PERCEIVED CAUSES: "How do others in your family explain this problem? What do they think is the cause?"

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>0 - Not Mentioned</th>
<th>1 - Mentioned</th>
<th>2 - Emphasized (All That Apply)</th>
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<tbody>
<tr>
<td>99</td>
<td>Cannot Specify-No Idea</td>
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<tr>
<td>1</td>
<td>Fund-Holder</td>
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<td>2</td>
<td>Nutrition-Waeminutrition</td>
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<td>3</td>
<td>Alcohol</td>
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<td>Smoking</td>
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<td>5</td>
<td>Abused Drug</td>
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<td>6</td>
<td>Prescribed-OTC Medicine</td>
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<td>7</td>
<td>Injury-Accident-Surgery</td>
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<td>8</td>
<td>Overwork-Insolation</td>
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<td>9</td>
<td>Prior Illness</td>
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<td>10</td>
<td>Immune System-Allergy</td>
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<td>11</td>
<td>Virus-Genus-Infection</td>
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<td>12</td>
<td>Kidney Weakness</td>
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<td>13</td>
<td>Weakness</td>
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<td>14</td>
<td>Anatomical-Phys-Biochem</td>
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<td>23</td>
<td>Other Fac-Inty Problem</td>
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<td>Other Supernatural</td>
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<td>Poor Health Habits</td>
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<td>Red Dead Previous Life</td>
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<td>Blind-Thought-Tenets</td>
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<td>Sexual Experiences</td>
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<td>Same Loss</td>
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<td>Head-Cold in Body</td>
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<td>Astrology</td>
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<td>Fate-Old-Stare Mempepe</td>
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<td>55</td>
<td>Other (Specify)</td>
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</table>
PREFERENCES FOR HELP SEEKING AND TREATMENT

45. SOCIAL SUPPORTS AND HELP PROVIDED

45.1. FAMILY

(A) "Does your family realize how serious this problem is?"

(1=Yes  2=No  3=Mixed/Possibly  4=Uncertain  5=Unaware of Prob) *_____

(Narrative)________________________________________________________________________

____________________________________________________________________________________

If family is unaware of problem, skip B and C. and code "5" for both

(B) "Overall, has your family provided support or helped you with your current problem?"

(1=Yes  2=No  3=Mixed/Possibly  4=Uncertain  5=Unaware of Prob) *_____

(Narrative)________________________________________________________________________

____________________________________________________________________________________

(C) "Do you feel your family could have done more to help with this problem?"

(1=Yes  2=No  3=Mixed/Possibly  4=Uncertain  5=Unaware of Prob) *_____

(Narrative)________________________________________________________________________

____________________________________________________________________________________

45.2. FRIENDS, COLLEAGUES, EMPLOYER

(A) "What about your friends, colleagues or employer? Do they realize how serious it is?"

(1=Yes  2=No  3=Mixed/Possibly  4=Uncertain  5=Unaware of Prob) *_____

(Narrative)________________________________________________________________________

____________________________________________________________________________________
If friends, colleagues, and employer are unaware of problem, skip B and C, and code "5" for both

(B) "Overall, have your friends, colleagues and employer provided support or helped you with your current problem?"

(1=Yes 2=No 3=Mixed/Possibly 4=Uncertain 5=Unaware of Prob) *

(Narrative)

(C) "Do you feel they could have done more to help with this problem?"

(1=Yes 2=No 3=Mixed/Possibly 4=Uncertain 5=Unaware of Prob) *

(Narrative)

45.3. HEALTH PROFESSIONALS

(A) "Do the doctors or other health professionals you may have seen realize how serious this problem is?"

(1=Yes 2=No 3=Mixed/Possibly 4=Uncertain 5=Mixed 6=None Seen) *

(Narrative)

If health professionals are unaware of problem, skip B and C, and code "5" for both

(B) "Have they provided support or helped you with your current problem?"

(1=Yes 2=No 3=Mixed/Possibly 4=Uncertain 5=Unaware of Prob) *

(Narrative)
(C) "Do you feel they could have done more to be helpful?"

(Narrative)__________________________________________

____________________________________________________

____________________________________________________

46. OTHER HELP SEEKING

"We realize that you have come to a doctor for help, but many people also get help from various other sources, and they also do things to help themselves. This is certainly understandable, and not something you should be embarrassed about discussing with us. We would like to know your ideas about other kinds of help for this problem. Perhaps you have used or might consider other doctors or healers, a chiropractor (or traditional Chinese massage), herbalist, faith healer, or just someone in your family or community who is wise and knows what to do."

46.1. FAST HELP SEEKING FOR THIS PROBLEM: "What other kinds of help have you tried for this problem?"

____________________________________________________

____________________________________________________

____________________________________________________

____________________________________________________

____________________________________________________

Code 0= Never Used  1= Used But Not Past Year  2=Used In Past Year

99  Cannot Say  14  Nutritionist
1  Self Care  15  Herbal-Trad'1 Healer-TCM
2  Help at Home  16  Acupuncture
3  Friends-Relatives Outside  17  Qi-Gong Etc.
4  Drug Store-Pharmacy  18  Faith Healer
5  General Hosp-Public Clinic  19  Astrology-Palmist Etc
6  HMD  20  Healing Temple-Church
7  Private Doctor-Primary Care  21  Meditation-Prayer
8  Homeopathic  22  This Clinic (Referral Clinic)
9  Referral Specialist  23  Doctor (Nonspecific)
10  Mental Health Professional  24  Massage
11  Chiropractor (Amer or Chin)  25  Other (Specify)
12  Stress Management  26  None
13  Health Education
46.2. **TELL ME FOR THIS PROBLEM: "What else have you done for yourself to deal with this problem?"

<table>
<thead>
<tr>
<th>REASON FOR NOT-HELPFUL</th>
<th>(1)</th>
<th>(2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise</td>
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<td>Diet</td>
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<td>Other</td>
<td></td>
<td></td>
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<tr>
<td>Meds or other treatments</td>
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</table>

47. **CORE MEASURES SERVICES AND CLIENT PREFERENCES:**

"Please consider carefully each of the following sources of help and let us know if you have used any of them, either in addition to or instead of the help you are getting from the doctor or clinic. Please also keep in mind that you may have tried any of these for any other problems that may have troubled you or your family, if not this problem.

- Column 1: "Have you ever made use of ... for this problem?"
- Column 2: "If so, was it useful?"
- Column 3: "Have you ever made use of ... for another problem?"

- (1) Sought help from persons inside the family
- (2) Sought help from persons outside the family
- (3) Possibly helpful
- (4) Definitely helpful
- (5) Definitely not helpful
<table>
<thead>
<tr>
<th>(2) Druggist or Pharmacist</th>
<th>[NOTE: Consultation, not just purchase]</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(3) Gen hosp/Pub Hlth Clin</td>
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<tr>
<td>(4) HMO, Pvt (Pri Care) Dr</td>
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<td>(5) Mental Health Professional</td>
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<td>(6) Other Referral Specialist</td>
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<tr>
<td>(7) Chiropractor</td>
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<td>THIS PROBLEM</td>
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<td>TRIED FOR THIS</td>
<td>USEFUL WHEN TRIED</td>
<td>EVER TRIED FOR ANOTHER P/R</td>
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<td>(1=Yes 2=No)</td>
<td>(1=Yes 2=No 3=Possibly-Mixed 4=Uncertain 5=Not Tried)</td>
<td>(1=Yes 2=No)</td>
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<tr>
<td>(6)</td>
<td>Stress Management</td>
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<td>(9)</td>
<td>Nutritionist</td>
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<tr>
<td>(10)</td>
<td>Herbal/Trad Chin Med (Healer or Herbs Only)</td>
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<tr>
<td>(11)</td>
<td>Faith Healer</td>
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<td>(12)</td>
<td>Healing temple/Church</td>
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<td>(13)</td>
<td>Meditation, Prayer, Qi Gong</td>
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<td>(14)</td>
<td>Other? (Specify)</td>
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</table>
48. **CURRENT PREFERENCE FOR MOST USEFUL HELP**  "Apart from this clinic (or referral clinic), what do you now think would be most useful?"

(Help Seeking Code, not TC) * ______

(Narrative) ________________________________


49. **FIRST HELP SEEKING**

49.1. "What was the first help you sought to relieve this problem outside the home other than from friends or family?"

**TYPE**

(Help Seeking Code) * ______

(Narrative) ________________________________


Inquire about further details of first help seeking outside the home only if different from this clinic (or referral clinic). Otherwise continue with "THIS CLINIC" (451, Page 35) or "MOST IMPORTANT HELP SEEKING" (450, Page 32).

(A) "What was the main reason that led you to decide to get help from this place you went to first, rather than some other place?"


Code: 0=Not Mentioned 1=Mentioned 2=Emphasis (one only)

1. ___ Cost  5. ___ Spiritual Power
2. ___ Convenience  6. ___ Professional Referral
3. ___ Past Experience  7. ___ Other
4. ___ Reputation (Popular)  8. ___ Uncertain

(B) **WHO REFERRED** "Who suggested that you got help there?"

(Referral Code) * ______
(C) WHO ACCOMPANIED "Who accompanied you?"

(Narrative) ________________________________________________________________
______________________________________________________________

49.2. "When did you first get help there? How many times did you go and for how long?"

(A) FIRST USE: \__________________________\  Months Ago: \(#\)____

(B) FOLLOW UP: \__________________________\  No. of visits: \#____

\_______________________________________________________________________
\_______________________________________________________________________

and over how many months: \(#\)____

(Narrative) ________________________________________________________________

49.3. "How much did you spend for treatment and medicines for the help and medicines prescribed there?"

(A) COST OF TREATMENT AND MEDICINES \_______________________________________________________________________

(B) PERCEIVED COST "Was it a strain on yours or your family's finances to pay this much money? Did you not have enough money for something else as a result?"

Code: 0-No Charge 1-No Strain 2-Some Strain 3-Considerable Strain 4-Cannot Specify 5-Cost Unknown

Total Cost: \#____

(Narrative) ________________________________________________________________

_______________________________________________________________________

49.4. FHS TREATMENT: "What sort of treatment did you get? Did they give you anything, or do anything else to help you?"

Probe without mentioning specific treatments.

_______________________________________________________________________

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<th>Code</th>
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<td>0</td>
<td>Not Mentioned</td>
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<tr>
<td>1</td>
<td>Antidepressants</td>
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<td>2</td>
<td>Other Oral or Topical Med</td>
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<td>3</td>
<td>Injection</td>
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<td>Other Psycho-Counseling</td>
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<td>Stress Management</td>
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<td>Massage</td>
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<td>Herbal-Traditional</td>
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<td>14</td>
<td>Ritual</td>
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<td>15</td>
<td>Hospital Admission</td>
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</table>

If subject mentions more than one of the above, inquire:

(A) "Which of these do you feel was most important?"

(Ex Code) *

49.5. "What did this person whom you first went to for help tell you about your problem? By what name did he (or she) call it?"

**FHS EXPLANATION OF PROBLEM:**

(0=Can't Say 1=Unknown 2=CFS 3=Chp Epit/Barr 4=Fibromyalgia 5=CFS and Fibromyalgia 6=Chronic Fatigue Imm Dysfct Synd (CFIDS) 7=Viral Inf 8=Kidney Dr 9=Depression 10=Other 11=No Name Given) *

________________________

________________________

________________________

(A) "What does this mean to you?"

________________________

________________________

________________________

49.6. "Were you satisfied with the help you received there?"

**SATISFACTION WITH FHS**

(1=Yes 2=No 3=Mixed 4=Uncertain) *

(Narrative) ____________________________

________________________

________________________

________________________
50. **MOST IMPORTANT HELP SEEKING TYPE**

"Among all the sources of help you consulted before you came here (or the clinic site referring you to the study), which one of them do you consider the most important? Perhaps you consider this particular person or place most important because you think about it the most, because you spent the most money or time there, because of the spiritual power, because of your faith in that place or person, or for some other reason?"

Record "Most Important Help Seeking" (MIBS) by CODE number, as above, for a professional help provider. If it is the same as "Primary Help Seeking," code "FHS". If subject cannot identify MIBS, indicate "Cannot Specify" by "CS".

(Narrative)______________________________

__________________________________________________________________________

50.1. **REASON MOST IMPORTANT** "How is it you consider this one the most important?"

(Narrative)______________________________

__________________________________________________________________________

__________________________________________________________________________

Code: 0=Not Mentioned 1=Mentioned 2=Emphasis (one only)

1. ___ Most Disappointing
2. ___ Money Spent
3. ___ Best Result
4. ___ Spiritual Power
5. ___ Reputation
6. ___ FHS ONLY
7. ___ Other
8. ___ Uncertain

**CONTINUE IF MIBS DIFFERENT FROM FHS. OTHERWISE SKIP TO TG (REFERRAL CLIN).**

(A) "What was the main reason that led you to decide to get this help?"

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

1. ___ Cost
2. ___ Convenience
3. ___ Past Experience
4. ___ Reputation (Popular)
5. ___ Spiritual Power
6. ___ Professional Referral
7. ___ Other
8. ___ Uncertain
(B) **WHO REFERRED** "Who suggested that you got help there?"

(Narrative) ____________________________________________

(Referral Code) *__

(C) **WHO ACCOMPANIED** "Who accompanied you?"

(Narrative) ____________________________________________

(Referral Code) *__

50.2. "When did you first get help there? How many times did you go and for how long?"

(A) **FIRST USE:**

   Months Ago: (#)___

(B) **FOLLOW UP:**

   No. of visits: #__
   and over how many months: (#)___

(Narrative) ____________________________________________

50.3. "How much did you spend for treatment and medicines for the help and medicines prescribed there?"

(A) **COST OF TREATMENT AND MEDICINES**

   Total Cost: #___

(Narrative) ____________________________________________

(B) **PERCEIVED COST** "Was it a strain on yours or your family's finances to pay this much money? Did you not have enough money for something else as a result?"

   Code: 0-No Charge 1-No Strain 2-Some Strain 3-Considerable Strain 4-Cannot Specify 5-Cost Unknown

   Total Cost: __________

(Narrative) ____________________________________________
(a) What does this mean to you?

(b) Which of these do you feel was most important?

The subjects were asked which of the above factors they felt to be most important. The factors included:

- Physical appearance
- Health
- Social interaction
- Financial stability
- Emotional support
- Family
- Education
- Employment
- Personal growth
- Religious beliefs
- Personal values
- Political affiliation
- Cultural background
- Environmental factors
- Community involvement
- Personal health

(c) Which part of treatment did you feel was most important?

(d) How do you feel about your current treatment?

(e) What changes would you like to see in your treatment?

(f) How would you rate your current treatment?

(g) What do you think could be improved?

(h) What is your overall impression of your treatment?

(i) Would you recommend this treatment to others?
50.6. **SATISFACTION WITH MHS**  "Were you satisfied with the help you received there?"  
(1=Yes 2=No 3=Mixed 4=Uncertain) * 
(Narrative) 

51. **THIS CLINIC (TC) OR REFERRAL CLINIC**

51.1. **DESCRIBE TC OR REFERRAL CLINIC:**

51.2. **REFERRAL CLINIC LAST VISIT - THIS PROBLEM**  "When was the last time you were here (or referral clinic) for this problem?"
(Months Age) * 

51.3. (A) **REASON FOR CHOICE**  "How was it decided that you came here (or referral clinic) when you first came for this problem?"

1. Cost 
2. Convenience 
3. Past Experience 
4. Reputation (Popular) 
5. Spiritual Power 
6. Professional Referral 
7. Other 
8. Uncertain 

(B) **WHO REFERRED**  "Whose idea was it that you should come here (or referral clinic) at first?"
(Referral Code) * 
(Narrative) 

(C) **WHO ACCOMPANIED**  "Who accompanied you?"
(Referral Code) * 
(Narrative)
51.4. "When did you first get help here (or at referral clinic), how many times did you go and for how long?"

(A) FIRST USE: Months Ago: (\$)____

(B) FOLLOW UP: No. of visits: \$

and over how many months: (\$)____

(Narrative)________________________________________________________

51.5. (A) COST OF TREATMENT AND MEDICINES "How much did it cost here (or referral clinic) for treatment and medicines?"

Total Cost: \$

(Narrative)________________________________________________________

(B) PERCEIVED COST "Is it a strain on yours or your family's finances to pay this much money? Might you not have enough money for something else as a result?"

Code: 0=No Charge 1=No Strain 2=Some Strain 3=Considerable Strain 4=Cannot Specify 5=Cost Unknown

Total Cost: **____

(Narrative)________________________________________________________

51.6. TC (REFERRAL CLINIC) TREATMENT: "Since you have come, what did they actually do for you here?"

Probes without mentioning specific treatments.

(Narrative)________________________________________________________

Code: 0=Not Mentioned 1=Mentioned
If subject mentions more than one of the above, inquire:

(A) "Which of these do you feel was most important?"

(Ex Code) *______

51.7. TC (REFERRAL CLINIC) EXPLANATION OF PROBLEM "What did the doctors here (or referral clinic) tell you about your problem? By what name did they call it?"

(0=Can't Say 1=Neurasthen 2=CFS 3=Chronic Fatigue Synd 4=Fibromyalgia
5=CFS and Fibromyalgia 6=Chronic Fatigue Imm Dyst Synd (CFIDS)
7=Viral Inf 8=Kidney Ur 9=Depression 10=Other) *______

if name was given, inquire about its meaning. If no name was given, inquire about subject's response to getting no information.

51.8. SATISFIED WITH TC (OR REFERRAL CLINIC) "Are you satisfied with the help you received?"

(1=Yes 2=No 3=Mixed 4=Uncertain 5=Not Yet Treated) *______

(A) MEDICINES DESIRED NOT RECEIVED

If treated: "Would you have liked any other kind of treatment that might be more powerful than what they gave you?"

If not yet treated: "Is there anything in particular that you would like as a part of your treatment?"

(0=Some 60=Specify It) *______

(Narrative) ____________________________________________
(B) MEDICINES RECEIVED NOT DESIRED

If Treated: "Did they do anything here (or referral clinic) you didn't like?"

If not yet treated: "Is there anything in particular that you would not like as part of your treatment?"

(0=No; #=Specify Tx) *

(Narrative)

GENERAL ILLNESS BELIEFS

52. GENERAL ILLNESS BELIEFS AND PRACTICES

"We have asked you many questions about the problem that brought you here (or referral clinic). We would also like to know what you think about some other kinds of problems, whether or not they have troubled you or your family directly."

52.1. (A) CAUSE OF EPILEPSY (Seizures or Fits) (See PC Code Sheet)

"What do you think is the cause of EPILEPSY (Seizures or Fits)?"

COM'TY

PERSONAL

PERSONAL

(+) (+)

(+) (+)

(B) PERSONAL STIGMA

Code: Y=Yes; N=No; P=Possible; U=Uncertain

(1) OTHERS KNOWING WOULD CAUSE PROBLEMS "If others were to know someone having EPILEPSY (Seizures or Fits), is it likely to cause problems for this person?"

(2) MOST PEOPLE WOULD BE ASHAMED OF IT "Would someone with epilepsy feel ashamed of this condition?"

(3) PROBLEM TO MARRY "Would most people be concerned if someone who has EPILEPSY (Seizures or Fits) were to marry into their family? What about you?"
(4) WOULD NOT VISIT HOME "Would most people refuse to visit the home of this person? What about you?"

Others Subject

* * *

(C) FAMILY STIGMA OF EPILEPSY (Seizures or Fits)

Code: 1=Yes 2=No 3=Possibly 4=Uncertain

(1) AVOID DISCLOSURE OF RELATIVE "Would most people with a relative who has EPILEPSY (Seizures or Fits) prefer to keep others from knowing about it if they could?"

* *

(2) REFLECTS POORLY ON THE FAMILY "If someone has EPILEPSY (Seizures or Fits) and others come to know about it, is it likely to cause problems for the family? Will it reflect poorly on the family?"

* *

(3) DIFFICULT FOR RELATIVES TO MARRY "Would this make it difficult for relatives of this person to marry?"

* *

(D) BEST HELP FOR EPILEPSY (Seizures or Fits) "If this were a problem for you or your family, what help of any kind do you think would be useful? Have you or your family ever made use of it? (Would you consider a someone other than a doctor?)"

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<th>Family Pr Use</th>
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52.2. (A) CAUSE OF EMOTIONAL PROBLEMS LIKE DEPRESSION (See PC Code Sheet)

"What do you think is the cause of EMOTIONAL PROBLEMS LIKE DEPRESSION?"

COM'TY PERSONAL

*___ *___

*___ *___

*___ *___

(B) PERSONAL STIGMA

Code: 1=Yes 2=No 3=Possibly 4=Uncertain

(1) OTHERS KNOWING WOULD CAUSE PROBLEMS "If others were to know about someone having EMOTIONAL PROBLEMS LIKE DEPRESSION, is it likely to cause problems for this person?" *___

(2) MOST PEOPLE WOULD BE ASHAMED OF IT "Would someone with EMOTIONAL PROBLEMS LIKE DEPRESSION feel ashamed of this condition?" *___

(3) PROBLEM TO MARRY "Would most people be concerned if someone who has EMOTIONAL PROBLEMS LIKE DEPRESSION were to marry into their family? What about you?" *___ *___

(4) WOULD NOT VISIT HOME "Would most people refuse to visit the home of this person? What about you?" *___ *___

(C) FAMILY STIGMA OF EMOTIONAL PROBLEMS LIKE DEPRESSION

(1) AVOID DISCLOSURE OF RELATIVE "Would most people with a relative who has EMOTIONAL PROBLEMS LIKE DEPRESSION prefer to keep others from knowing about it if they could?" *___
(2) REFLECTS POORLY ON THE FAMILY "If someone has EMOTIONAL PROBLEMS LIKE DEPRESSION and others come to know about it, is it likely to cause problems for the family? Will it reflect poorly on the family?"

(3) DIFFICULT FOR RELATIVES TO MARRY "Would this make it difficult for relatives of this person to marry?"

(D) BEST HELP FOR EMOTIONAL PROBLEMS LIKE DEPRESSION "If this were a problem for you or your family, what help of any kind do you think would be useful? Have you or your family ever made use of it? (Would you consider a someone other than a doctor?)"

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52.3. (A) CAUSE OF SCHIZOPHRENIA (OR MADNESS) (See PC Code Sheet)

"What do you think is the cause of SCHIZOPHRENIA (OR MADNESS)?"

<p>| COM'TY NOT |</p>
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(B) PERSONAL STIGMA

(1) OTHERS KNOWING WOULD CAUSE PROBLEMS "If others were to know that someone one had SCHIZOPHRENIA (OR MADNESS), even though that person has been treated and is not okay, is their knowing likely to cause problems for this person?"
(2) **MOST PEOPLE WOULD BE ASHAMED OF IT**  "Would someone with schizophrenia (or madness) who is now okay feel ashamed of this condition?"  

(3) **PROBLEM TO MARRY**  "Would most people be concerned if someone who once had SCHIZOPHRENIA (OR MADNESS) were to marry into their family? What about you?"

(4) **WOULD NOT VISIT HOME**  "Would most people refuse to visit the home of this person? What about you?"

---

**FAMILY STIGMA OF SCHIZOPHRENIA (OR MADNESS)**

Code: 1-Yes 2-No 3-Possibly 4-Uncertain

(1) **AVOID DISCLOSURE OF RELATIVE**  "If they could, would most people prefer to keep it from others if someone in their family had SCHIZOPHRENIA (OR MADNESS)?"  

(2) **REFLECTS POORLY ON THE FAMILY**  "If someone has SCHIZOPHRENIA (OR MADNESS) and others come to know about it, is it likely to cause problems for the family? Will it reflect poorly on the family?"

(3) **DIFFICULT FOR RELATIVES TO MARRY**  "Would this make it difficult for relatives of this person to marry?"
(D) **BEST HELP FOR SCHIZOPHRENIA (OR MADNESS)** "If this were a problem for you or your family, what help of any kind do you think would be useful? Have you or your family ever made use of it? (Would you consider someone other than a doctor?)"

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53. **MIND/BODY RELATIONSHIP**

53.1. **NATURE OF MIND/BODY RELATIONSHIP** "Are mind (heart) and body the same or different? (Are thinking, feeling and emotions the same or different from the body?)"

(1=Same 2=Unrelated 3=Related 4=Unknown Whether Related
5=Incomprehensible Question 6=Uncertain) *___

53.2. **MIND OR BODY OVER THE OTHER** "Does mind (heart; thinking, feeling or emotions) control the body, or does the body control the mind?"

(1=Mind Over Body 2=Body Over Mind 3=Equal 4=Uncertain) *___
54. **PERSONAL ATTRIBUTES ACCORDING TO SUBJECT**

54.1. **SENSITIVE PERSON** "Would you describe yourself now or ever as an especially sensitive person? More so than most people?"

*If so:* "What do you mean by that?" *(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative)________________________________________________________________________

________________________________________________________________________

54.2. **PERFECTIONISTIC** "Would you describe yourself now or ever as the kind of person who feels it is important that things be done well, be done right?"

*If so:* "Is that especially important to you?" *(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative)________________________________________________________________________

________________________________________________________________________

54.3. **SELF SACRIFICING** "Would you describe yourself now or ever as someone who puts other's needs before your own?"

*If so:* "More so than most people?" *(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative)________________________________________________________________________

________________________________________________________________________

54.4. **ESPECIALLY VALUES HARD WORK** "Would you describe yourself now or ever as someone who believes in hard work? More so than others?"

*If so:* "What do you mean by that?" *(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative)________________________________________________________________________

________________________________________________________________________
56.5. LIKES TO BE BUSY WITH A LOT TO DO. "Would you describe yourself now or ever as the kind of person who prefers always to be busy, to have lots of things to do? More so than most people?"

IF NO: "What do you mean by that?" (1=Yes 2=No 3=Possibly 4=Uncertain) *___

(Narrative) ________________________________________________

56.6. EXCESSIVE WORRIER. "Do you consider yourself someone who worries too much? Do you worry about things going on in your family, at work, or in the world? Do you typically worry excessively about making decisions? More so than most people?"

IF NO: "What do you mean by that?" (1=Yes 2=No 3=Possibly 4=Uncertain) *___

(Narrative) ________________________________________________

56.7. CONCERN ABOUT EMBARRASSING OTHERS/CAUSING LOSS OF FACE. "Do you worry frequently that you might be upsetting others? Embarrassing (causing loss of face), offending, or making them uncomfortable? Are you more concerned about this than most people?"

IF NO: "What do you mean by that?" (1=Yes 2=No 3=Possibly 4=Uncertain) *___

(Narrative) ________________________________________________

56.8. INTROVERTED OR 'BOTTLED UP'. "Do you have difficulty expressing your feelings? Do you bottle them up too much? More so than others?"

IF NO: "What do you mean by that?" (1=Yes 2=No 3=Possibly 4=Uncertain) *___

(Narrative) ________________________________________________
### 56. What changes have you seen in your life?

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**57. Have you seen any changes in your daily routine?**

- [ ] Yes
- [ ] No

**If yes, please specify:**

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### 58. Have you seen any changes in your family?

- [ ] Yes
- [ ] No

**If yes, please specify:**

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### 59. Have you seen any changes in your health?

- [ ] Yes
- [ ] No

**If yes, please specify:**

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**Quarantine:

[Date: Home test: 12/15/2020]

---

**Note:**

- [ ] If you have any questions or concerns, please contact your healthcare provider.
- [ ] Remember to practice social distancing and continue following public health guidelines.
56.2. "Do you feel this/these is/are related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) * 

(Narrative) ____________________________________________

57. SCREENING SPECIFIC LIFE EVENTS:
"Have you had any experience with the following:"

Code Significant Events Only. If multiple, code most recent and specify others in narrative.

57.1. PERSONAL SERIOUS ILLNESS
"Personally experienced serious (other) illness?"

(A) (1=No 2=Yes/Before 3=Yes/After 4=Yes/Both 5=Yes/Uncertain) * 

(B) Onset: (Years Ago) $ 

(C) Endpoint: (6=Months duration; P=Ongoing to Present) $ 

(D) If so: "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) * 

(Narrative) ____________________________________________

57.2. DEATH OR SERIOUS ILLNESS OF CLOSE FRIEND/RELATIVE
"Death or serious illness in a relative or close friend?"

(A) (1=No 2=Yes/Before 3=Yes/After 4=Yes/Both 5=Yes/Uncertain) * 

(B) Onset: (Years Ago) $ 

(C) Endpoint: (6=Months duration; P=Ongoing to Present) $ 

(D) If so: "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) * 

(Narrative) ____________________________________________
57.3. **JOB LOSS**
"Losing your job just before or any time after your problem began?"

(A) (0=No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/Uncertain) * __________

(B) (Years Ago) $ __________

(C) **If so:** "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) * __________

(Narrative) ____________________________________________

57.4. **MAJOR SCHOOL FAILURE**
"Dropping out of school or failing in a major exam?"

(A) (0=No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/Uncertain) * __________

(B) (Years Ago) $ __________

(C) **If so:** "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) * __________

(Narrative) ____________________________________________

57.5. **SERIOUS FINANCIAL PROBLEMS**
"Serious financial problems?"

(A) (0=No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/Uncertain) * __________

(B) **Onset:** (Years Ago) $ __________

(C) **Endpoint:** (0-Months duration; 1=Onset to Present) $ __________

(D) **If so:** "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) * __________

(Narrative) ____________________________________________
57.6. PROBLEMS WITH MARRIAGE OR ROMANCE

Divorce or serious problems with marriage or romance?*

(A) (O=No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/ Uncertain) *

(B) Onset:

(Years Age) $\

(C) Endpoint:

(#Months duration; F=Ongoing to Present) $\

(D) If so: "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative) __________________________________________________________________________

57.7. PROBLEMS WITH IN-LAWS

Major disagreements with your in-laws?*

(A) (O=No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/ Uncertain) *

(B) Onset:

(Years Age) $\

(C) Endpoint:

(#Months duration; F=Ongoing to Present) $\

(D) If so: "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative) __________________________________________________________________________

57.8. OVERWHELMED BY CHILD CARETAKING OR FAMILY RESPONSIBILITIES

"Have you ever been overwhelmed by the burden of child care or other family responsibilities?"

(A) (O=No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/ Uncertain) *

(B) Onset:

(Years Age) $\

(C) Endpoint:

(#Months duration; F=Ongoing to Present) $\

(D) If so: "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) *
57.9. **SERIOUS CONFLICT WITH FAMILY, FRIENDS OR OTHERS** "Any serious conflicts with other family, friends or anyone else?"

(A) (0-No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/Uncertain) *_____

(B) **Onset:**

(C) **Endpoint:**

(D) **If so:** "Do you feel this might have been related to your problem?"

(E0=Yes 2=No 3=Possibly 4=Uncertain) *_____

57.10. **LEGAL DISPUTES OR OTHER LEGAL PROBLEMS** "Involvement in any legal disputes or other legal problem?"

(A) (0-No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/Uncertain) *_____

(B) **Onset:**

(C) **Endpoint:**

(D) **If so:** "Do you feel this might have been related to your problem?"

(E0=Yes 2=No 3=Possibly 4=Uncertain) *_____

57.11. **VICTIM OF VIOLENCE: PHYSICAL/SEXUAL ABUSE OR CRIME** "Victim of violence, such as physical or sexual abuse, or a crime?"

(A) (0-No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/Uncertain) *_____

(B) **Onset:**

(C) **Endpoint:**

(D) **If so:** "Do you feel this might have been related to your problem?"
(D) **If so:** "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative) ____________________________________________

_____________________________________________________

57.12. **POLITICAL PROBLEMS** "Taken part in significant political events or experienced any political troubles?"

(A) 

(0=No 1=Yes/Before 2=Yes/After 3=Yes/Both 4=Yes/Uncertain) *

(B) **Onset:**

(Years Ago) *

(C) **Endpoint:**

(0=Months duration; P=Ongoing to Present) *

(D) **If so:** "Do you feel this might have been related to your problem?"

(1=Yes 2=No 3=Possibly 4=Uncertain) *

(Narrative) ____________________________________________

_____________________________________________________

_____________________________________________________

58. **MOST SEVERE LIFE EVENT** "Among all of these events, or perhaps something else, which do you consider most severe?"

0. None (Code "1" if no others)
1. Personal Illness
2. Family Illness/Grief/Recovery
3. Job Loss
4. School Failure
5. Financial Problem
6. Marital Prob/Emancipation
7. Serious Prob In-Law
8. Family/Child Care
9. Interspers Conflict
10. Legal Problem
11. Violence
12. Poltistical
13. Other
14. Cannot Say

(Narrative) ____________________________________________

_____________________________________________________

_____________________________________________________

59. "How might someone who knows you well have described you before this problem began, compared with now?"
60. **TIME INTERVIEW ENDS:**

**CODE AFTER INTERVIEW:**

61. Based on impressions of the entire interview, rate subject's report of the following symptoms.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Code: 0=Not Mentioned 1=Mentioned 2=Emphasis (all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>*</td>
</tr>
<tr>
<td>Weakness</td>
<td>**</td>
</tr>
<tr>
<td>Somatic Sxs</td>
<td>**</td>
</tr>
<tr>
<td>Hypochon Sxs</td>
<td>**</td>
</tr>
<tr>
<td>Depress Sxs</td>
<td>**</td>
</tr>
<tr>
<td>Lonesiness</td>
<td>**</td>
</tr>
<tr>
<td>Anxiety Sxs</td>
<td>**</td>
</tr>
<tr>
<td>Sleep Disturb</td>
<td>**</td>
</tr>
<tr>
<td>Functional Impairment</td>
<td>**</td>
</tr>
<tr>
<td>Cognitive Impairment</td>
<td>**</td>
</tr>
<tr>
<td>Social Relations</td>
<td>**</td>
</tr>
<tr>
<td>Stigma</td>
<td>**</td>
</tr>
<tr>
<td>Amotivational Sxs</td>
<td>**</td>
</tr>
<tr>
<td>Not Troubled</td>
<td>**</td>
</tr>
<tr>
<td>Other</td>
<td>**</td>
</tr>
<tr>
<td>Cannot Say</td>
<td>**</td>
</tr>
</tbody>
</table>

62. **INTERVIEW LANGUAGE:**

Code: 1=English 2=Chinese-Mandarin 3=Chinese-Hsin-Pin 4=Chinese-Contones 5=Other (Specify)

63. **INTERVIEWER/DATE:** ________________

64. **CLINICAL DIAGNOSIS (Based on Referral Data)**

64.1. **G.P. Diagnosis:** __________________________________________

Clinical Comments: __________________________________________

________________________________________

________________________________________

65. **INTERVIEW DATE(S):**

(1) __________

(2) __________

66. **DATE DATA REVIEWED AND COMPLETED:** __________

**ADDITIONAL COMMENTS**

________________________________________

________________________________________
APPENDIX D: Patterns of Distress - Computation of Prominence Rankings as Analysis Variables and Data Reduction

Individual Scores

Computation of Analysis Variables: Interval Scale of Prominence Rankings

The Patterns of Distress section of the EMIC enquires into the personal experience of illness. It begins the inquiry with an open-ended question followed by screening questions about various somatic, psychological, social and other distresses, and concludes with a summary question. Each of the responses is rated according to the subject’s (1) mode of reporting, whether it is spontaneous or probed, and (2) designation of importance to the response, if the symptom is emphasized or just mentioned. To conclude the section, the subject is asked to identify the first and the one most troubling symptom experienced. Rankings of these responses are added to obtain a score for each of the individual symptom categories (prominence ranking variables). The range of score is from 0 to 5, with 0 indicating the distress is not mentioned to 5 the highest distress. The prominence ranking of each individual variable is derived additively from three contributions. If the symptom is:

<table>
<thead>
<tr>
<th>Contribution</th>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>Mentioned spontaneously (EMIC#16) or after probing (EMIC #16.2-16.3)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Otherwise</td>
<td>0</td>
</tr>
<tr>
<td>(2)</td>
<td>Reported as first symptom noticed (EMIC #17)</td>
<td>1</td>
</tr>
<tr>
<td>(3)</td>
<td>Reported as the most troubling symptom (EMIC #22)</td>
<td>2</td>
</tr>
</tbody>
</table>

For example, if Mr. A reported spontaneously that fatigue was the problem for which he sought help, he gets a contribution of 2 to the ranking. Mr. A., after probing, mentioned that he was having a problem falling asleep (contributing 1). He later also said that fatigue was the first symptom he noticed (contributing 1), and it was the most troubling symptom of all (contributing
2). Adding all the contributions, 2+1+2=5, Mr. A gets the highest ranking possible for the individual variable of fatigue. For the individual variable of sleep disturbance he only gets a ranking of 1, because he had already indicated fatigue as the first and most troubling symptom. Thus, there is no further contribution to the ranking of sleep disturbance.

**Data Reduction**

Due to the large number of variables which resulted in a small number of responses in each cell, data reduction was conducted to classify variables with related meanings into grouped variables for quantitative analyses and hypothesis testing. The sixteen individual variables were sorted into four logical groupings to form four, grouped pattern of distress variables: PD-Somatic, PD-Psychological, PD-Social and PD-Other. For instance, the grouped variable PD-Somatic is made up of the first 4 and # 8 of the patterns of distress individual scores: Fatigue, Weakness, Somatic Symptoms, Hypochondriacal Symptoms, and Sleep Disturbance. The following table depicts the classifications of the grouped variables of patterns of distress:
<table>
<thead>
<tr>
<th>Grouped Variables #</th>
<th>Grouped Variables</th>
<th>Patterns of Distress # in EMIC</th>
<th>Individual Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Somatic</td>
<td>1</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
<td>Weakness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3</td>
<td>Somatic Symptoms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4</td>
<td>Hypochondriacal Symptoms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8</td>
<td>Sleep Disturbance</td>
</tr>
<tr>
<td>2</td>
<td>Psychological</td>
<td>5</td>
<td>Depress Symptoms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6</td>
<td>Loneliness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7</td>
<td>Anxiety Symptoms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9</td>
<td>Functional Impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10</td>
<td>Cognitive Impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13</td>
<td>Amotivational Symptoms</td>
</tr>
<tr>
<td>3</td>
<td>Social</td>
<td>11</td>
<td>Social Relations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12</td>
<td>Stigma</td>
</tr>
<tr>
<td>4</td>
<td>Other</td>
<td>14</td>
<td>Not Troubled</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15</td>
<td>Other</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16</td>
<td>Cannot Say</td>
</tr>
</tbody>
</table>

**Grouped Scores**

**Construction of Interval Scale of Prominence Rankings**

As showed in the data reduction section above, the four grouped variables are formed by grouping individual variables with similar meanings. The following is the procedure to obtain the grouped patterns of distress score (interval scale of prominence rankings):

(1) Take the highest contribution among the individual variables within each grouped variable, in response to open-ended questions (EMIC#16), as the contribution for the grouped variable.

(2) Take the highest contribution among the individual variables within each grouped variable, in response to probing question (EMIC #16.2-16.3), as the contribution for the grouped variable.

(3) Take the individual variable which is indicated as the first (EMIC#17) noticed, and also the most troubling symptom (EMIC#22) as the ones for the grouped variable.

For instance, if Mr. A reported fatigue spontaneously as the problem for which he sought help, he gets a contribution of 2 to the somatic grouped variable score. Since fatigue is one of the individual variables in the somatic grouped variable and 2 is the highest contribution, the somatic grouped variable gets this contribution. Even though he has a score of 1 for sleep disturbance...
which is also one of the individual variables in the grouped variable, being a lower number than 2, it is disregarded. The somatic grouped variable also gets contributions from fatigue being the first symptom he noticed (contributing 1), and the most troubling symptom (contributing 2). Furthermore, the contribution of a probing response is added only if no other symptom in the grouped variable is rated spontaneous or most important. Adding all the contributions, 2+1+2=5, Mr. A gets the highest score possible for the somatic grouped variable.

APPENDIX E: Perceived Cause - Computation of Prominence Rankings as Analysis Variables and Data Reduction

Individual Scores

Computation of Analysis Variables: Interval Scale of Prominence Rankings

The Perceived Cause section of the EMIC enquires into the patients' personal ideas of the attributions that resulted in their illness. This section begins the inquiry with an open-ended question followed by 55 screening questions of different perceived causes, and concludes with a summary question. Each of the responses is rated according to the subject's (1) mode of reporting, whether it is spontaneous or probed, and (2) designation of importance to the response, if the perceived cause is reported as "definite" or as "possible." To conclude the section, the subject is asked to identify the first and the one most important perceived cause. Rankings of these responses are added to obtain a score for each of the individual perceived cause categories (prominence ranking variables). The range of score is from 0 to 10, with 0 indicating not reported as a perceived cause to 10 a perceived cause with the highest importance. The prominence ranking of each individual perceived cause categories is derived additively from three contributions. If the perceived cause is:

<table>
<thead>
<tr>
<th>Contribution</th>
<th>Details</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>Reported spontaneously as a cause to open-ended question (EMIC#38)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Reported as a &quot;definite&quot; cause after probing (EMIC #40)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Reported as a &quot;possible&quot; cause after probing (EMIC #40)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Not mentioned</td>
<td>0</td>
</tr>
<tr>
<td>(2)</td>
<td>Reported as first perceived cause (EMIC #41)</td>
<td>1</td>
</tr>
<tr>
<td>(3)</td>
<td>Reported as the most important perceived cause (EMIC#43)</td>
<td>5</td>
</tr>
</tbody>
</table>
For example, if Mr. A reported spontaneously that malnutrition was the cause of his problem, he gets a contribution of 4 to the ranking. Mr. A., after probing, mentioned that his smoking is definitely a cause also (contributing 3). He later reported that malnutrition was the cause he first thought of (contributing 1), and it was the most important cause of all (contributing 5). Adding all the contributions, 4+1+5=10, Mr. A gets the highest ranking possible for the individual category of malnutrition. For the individual category of smoking he only gets a ranking of 3, because he had indicated malnutrition as the first and most important cause. Thus, there is no further contribution from this category to the ranking.

**Data Reduction**

Due to the large number of variables which resulted in a small number of responses in each cell, data reduction was conducted to classify variables with related meanings into grouped variables for quantitative analyses and hypothesis testing. The summary scores of 55 individual perceived cause categories were sorted into 12 logical groupings to form 12 new clustered categories: PC-Ingestion, PC-Work/Weakness/Nerves, PC-Medical/Physical, PC-Toxicity/Sanitation/Hygiene, PC-Social, PC-Victim/Abuse, PC-Magic/Relig/Supernatural, PC-Psychological, PC-Congenital/Hereditary, PC-Sex, PC-Traditional (Chinese) and PC-Other. For instance, the clustered category PC-Ingestion is made up of the summary scores of the first 6 perceived cause individual categories: Food/Water, Nutrition/Malnutrition, Alcohol, Smoking, Abused Drug, and Prescribed/Over the Counter Medication. The following table depicts the groupings of the clustered categories of perceived cause:
<table>
<thead>
<tr>
<th>Cluster Category#</th>
<th>Clustered Category</th>
<th>PC # in EMIC</th>
<th>Individual Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ingestion</td>
<td>1</td>
<td>Food/Water</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
<td>Nutrition/Malnutrition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3</td>
<td>Alcohol</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4</td>
<td>Smoking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5</td>
<td>Abused Drug</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6</td>
<td>Prescribed/OTC Med</td>
</tr>
<tr>
<td>2</td>
<td>Work/Weakness/Nerves</td>
<td>8</td>
<td>Overwork-Exertion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13</td>
<td>Weakness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15</td>
<td>Nerves</td>
</tr>
<tr>
<td>3</td>
<td>Medical/Physical</td>
<td>7</td>
<td>Injury/Accident/Surgery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9</td>
<td>Prior Illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10</td>
<td>Immune Dysfct/Allergy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11</td>
<td>Virus/Germs/Infection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14</td>
<td>Anatomic/Phy/Biochem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16</td>
<td>Pregnancy Related</td>
</tr>
<tr>
<td>4</td>
<td>Toxicity/Sanitation/Hygiene</td>
<td>17</td>
<td>Envir/Toxin/ Pollution</td>
</tr>
<tr>
<td></td>
<td></td>
<td>33</td>
<td>Poor Health Habits</td>
</tr>
<tr>
<td></td>
<td></td>
<td>41</td>
<td>Sanitation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>42</td>
<td>Personal Hygiene</td>
</tr>
<tr>
<td>5</td>
<td>Social</td>
<td>18</td>
<td>Financial Problem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>19</td>
<td>Failed Romance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20</td>
<td>Marital Problem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21</td>
<td>Family Illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>22</td>
<td>Work Problem/ Employ</td>
</tr>
<tr>
<td></td>
<td></td>
<td>23</td>
<td>Family/Interpers Problem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24</td>
<td>Bereavement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>25</td>
<td>Stress/Loss/Shock</td>
</tr>
<tr>
<td>6</td>
<td>Victim/Abuse</td>
<td>26</td>
<td>Childhood Abuse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>27</td>
<td>Victim of Violence</td>
</tr>
<tr>
<td>7</td>
<td>Magic/Relig/Supernatural</td>
<td>28</td>
<td>Sorcery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>29</td>
<td>Demons/Ghosts/Deities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30</td>
<td>Ancestral Spirits</td>
</tr>
<tr>
<td></td>
<td></td>
<td>31</td>
<td>Geomancy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>32</td>
<td>Other Supernatural</td>
</tr>
<tr>
<td></td>
<td></td>
<td>34</td>
<td>Bad Deed/Bad Person</td>
</tr>
<tr>
<td></td>
<td></td>
<td>35</td>
<td>Bad Deed Previous Life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>51</td>
<td>Fate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>52</td>
<td>Will-of-God</td>
</tr>
<tr>
<td></td>
<td></td>
<td>53</td>
<td>Astrology</td>
</tr>
<tr>
<td></td>
<td></td>
<td>54</td>
<td>Fate/God/Stars Nonspec</td>
</tr>
<tr>
<td></td>
<td></td>
<td>36</td>
<td>Mind/Thoughts/Worry</td>
</tr>
<tr>
<td></td>
<td></td>
<td>37</td>
<td>Personality</td>
</tr>
<tr>
<td></td>
<td></td>
<td>39</td>
<td>Familial Upbringing</td>
</tr>
<tr>
<td>8</td>
<td>Psychological</td>
<td>38</td>
<td>Heredity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>40</td>
<td>Congenital, Not Heredity</td>
</tr>
<tr>
<td>9</td>
<td>Congenital/Hereditary</td>
<td>43</td>
<td>Sexual Experience</td>
</tr>
<tr>
<td></td>
<td></td>
<td>45</td>
<td>Masturbation</td>
</tr>
<tr>
<td>10</td>
<td>Sex</td>
<td>46</td>
<td>Kidney Weakness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>47</td>
<td>Semen Loss</td>
</tr>
<tr>
<td></td>
<td></td>
<td>48</td>
<td>Heat-Cold in Body</td>
</tr>
<tr>
<td></td>
<td></td>
<td>49</td>
<td>Climate: Heat-Cold Etc.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50</td>
<td>Vital Energy (Qi)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>51</td>
<td>Yin-Yang Imbalance</td>
</tr>
<tr>
<td>11</td>
<td>Traditional (Chinese)</td>
<td>52</td>
<td>Oth Humoral/Const Imbal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>53</td>
<td>Other (Specify)</td>
</tr>
<tr>
<td>12</td>
<td>Others</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55</td>
<td></td>
</tr>
</tbody>
</table>
Clustered Scores

Construction of Interval Scale of Prominence Rankings

As showed in the data reduction section above, the 12 clustered categories are formed by grouping individual categories with related meanings. The following is the procedure to obtain the clustered perceived cause score (interval scale of prominence rankings):

1. Take the highest contribution among the individual categories within each clustered category, in response to open-ended questions (EMIC#38), as the contribution for the clustered category.

2. Take the highest contribution among the individual categories within each clustered category, in response to probing question (EMIC #40), as the contribution for the clustered category.

3. Take the individual category which is indicated as the first (EMIC #41) noticed, and also the most important (EMIC #43) as the ones for the clustered category.

For instance, Mr. A reported malnutrition spontaneously with emphasis as the problem for which he sought help. Since malnutrition is one of the individual category in the ingestion clustered category and 4 is the highest contribution, the ingestion clustered category gets this contribution. Even though he has a score of 3 for smoking which is also one of the individual categories in the clustered category, being a lower number than 4 it is disregarded. Furthermore, the contribution of a probing response is added only if no other perceived cause in the clustered category is rated spontaneous or most important. The ingestion clustered category also gets contributions from malnutrition being the first perceived cause (contributing 1), and the most important (contributing 5). Adding all the contributions, 4+1+5=10, Mr. A gets the highest score possible for the ingestion clustered category.

APPENDIX F: Help-Seeking Behaviour- Computation of Prominence Rankings as Analysis Variables and Data Reduction

Individual Scores

Computation of Analysis Variables: Interval Scale of Prominence Rankings

The Help-Seeking Behaviour section of the EMIC enquires into the subjects’ personal experience of help-seeking for their illness. This section begins the inquiry with an open-ended question followed by 26 screening questions of different source of help-seeking, and concludes with a summary question. Each of the responses is rated according to the subject’s (1) mode of reporting, whether it is spontaneous or probed, (2) current preference and satisfaction with help, and (3) designation of importance to the response, if the help is reported as “yes, useful”, “possibly useful”, “uncertain”, or “not useful”. To conclude the section, the subject is asked to identify the first and the one most important source of help. Rankings of these responses are added to obtain a score for each of the individual help-seeking categories (prominence ranking variables). The range of score is from 0 to 17, with 0, indicating a source of help not mentioned, to 17, a source of help with the highest importance. The prominence ranking of each individual help-seeking categories is derived additively from the following four contributions:
1. Mentioning spontaneously (item #46.1) or from screening (#47), considering expression of usefulness as follows:

<table>
<thead>
<tr>
<th>Tried</th>
<th>Useful</th>
<th>Code Contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>1=yes</td>
<td>1=yes</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>3=possibly</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>4=uncertain</td>
<td>3</td>
</tr>
<tr>
<td>2=no but</td>
<td>2=no</td>
<td>2</td>
</tr>
<tr>
<td>yes for &quot;another&quot;</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>2=not tried</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>for this or other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Current preference as for most useful (#48)

   Category mentioned

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4 if yes,</td>
<td></td>
</tr>
<tr>
<td>0 if no</td>
<td></td>
</tr>
</tbody>
</table>

3. First help seeking (#49)

   item mentioned (#49.1)
   and (#49.6) 1=yes satisfied
   3= mixed
   4= Uncertain
   2= No
   item not mentioned

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

4. Most Important help-seeking (#50)

   item mentioned (#50)
   and (#50.6) 1=yes satisfied
   3= mixed
   4= Uncertain
   2= No
   item not mentioned

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

For example, if Mr. A reported spontaneously that a Chinese herbalist was the source of help he had tried and found useful, he gets a contribution of 5 to the ranking. He also indicated that his "current" preference for help-seeking was also this practitioner, because he found him most useful (contributing 4). However, after probing, Mr. A., mentioned that he had tried a faith healer as well, but he is not certain about usefulness (contributing 3). He later reported that the traditional Chinese herbalist was the one he first sought help from and satisfied with (contributing 4), and the most important and satisfying source of help (contributing 4). Adding
all the contributions, \( 5+4+4+4=17 \), Mr. A gets the highest ranking possible for the individual category of herbalist/traditional healer. For the individual category of faith healer, he only gets a ranking of 3, because he had indicated the Chinese herbalist as his current preference, first and most important source of help. Thus, there is no further contribution from this category to the ranking.

**Data Reduction**

Due to the large number of variables which resulted in a small number of responses in each cell, data reduction was conducted to classify variables with related meanings into grouped variables for quantitative analyses and hypothesis testing. These summary scores of 26 individual help-seeking categories were sorted into 8 logical groupings to form the new clustered categories: hs-self/lay help, hs-western medicine, hs-mental health, hs-alternative treatment, hs-traditional Chinese medicine, hs-spiritual, hs-other, hs-referring physician (family doctor). For example, the clustered category hs-self/lay help is made up of the summary scores of the first 3 help-seeking individual categories: hs-self care, hs-help at home, hs-friends-relatives. The following table depicts the groupings of the clustered categories of help-seeking behaviour:
### Clustered Scores

**Construction of Interval Scale of Prominence Rankings**

As showed in the data reduction section above, the 8 clustered categories are formed by grouping individual categories with related meanings. The following is the procedure to obtain the clustered perceived cause score (interval scale of prominence rankings):

1. Take the highest contribution among the individual categories within each clustered category, in response to open-ended questions (EMIC#47), as the contribution for the clustered category.

2. Take the highest contribution among the individual categories within each clustered category, in response to the question of current preference as for most useful (EMIC #48), as the contribution for the clustered category.

3. Take the individual category which is indicated as the first help-seeking and most satisfied (EMIC #49) as the ones for the clustered category.

4. Take the individual category which is indicated as the most important and most satisfied (EMIC #50) as the ones for the clustered category.

<table>
<thead>
<tr>
<th>Clustered Category #</th>
<th>Clustered Category</th>
<th>HS # in EMIC</th>
<th>Individual Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Self/Lay Help</td>
<td>1</td>
<td>Self Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
<td>Help at Home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3</td>
<td>Friends-Relatives</td>
</tr>
<tr>
<td>2</td>
<td>General Health (western medicine)</td>
<td>4</td>
<td>Drug Store-Pharmacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5</td>
<td>General Hosp-Public Clinic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6</td>
<td>HMO</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7</td>
<td>Private Doctor-Primary Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9</td>
<td>Referral Specialist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13</td>
<td>Health Education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>23</td>
<td>Doctor (Nonspecific)</td>
</tr>
<tr>
<td>3</td>
<td>Mental Health</td>
<td>10</td>
<td>Mental Health Professional</td>
</tr>
<tr>
<td>4</td>
<td>Alternative Treatment</td>
<td>12</td>
<td>Stress Management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24</td>
<td>Massage</td>
</tr>
<tr>
<td>5</td>
<td>Traditional Chinese Medicine</td>
<td>8</td>
<td>Homeopathic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11</td>
<td>Chiropractor (Chinese)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>14</td>
<td>Nutritionist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15</td>
<td>Herbal-Trad'l Healer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16</td>
<td>Acupuncture</td>
</tr>
<tr>
<td></td>
<td></td>
<td>17</td>
<td>Qi-Gong</td>
</tr>
<tr>
<td>6</td>
<td>Spiritual</td>
<td>18</td>
<td>Faith Healer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>19</td>
<td>Astrology-Palmist</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20</td>
<td>Healing Temple-Church</td>
</tr>
<tr>
<td></td>
<td></td>
<td>21</td>
<td>Meditation-Prayer</td>
</tr>
<tr>
<td>7</td>
<td>Other</td>
<td>25</td>
<td>Other (Specify)</td>
</tr>
<tr>
<td>8</td>
<td>Referring physician</td>
<td>22</td>
<td>This Clinic</td>
</tr>
</tbody>
</table>
For example, Mr. A reported spontaneously that a Chinese herbalist was the source of help he had tried and found useful. Since herbalist is one of the individual category in the traditional Chinese medicine clustered category and 5 is the highest contribution, the traditional Chinese medicine clustered category gets this contribution. He also indicated that his “current” preference for help-seeking was also this herbalist, because he found the practitioner most useful (contributing 4). Again, the traditional Chinese medicine clustered category gets this contribution of 4. However, after probing, Mr. A., mentioned that he had tried a faith healer as well, but he is not certain about usefulness (contributing 3). Since the individual category of faith healer is part of the clustered category of spiritual, the clustered category of spiritual gets the contribution of 3. He later reported that the herbalist was the one he first sought help from and satisfied with (contributing 4), and was also the most important and satisfying source of help (contributing 4). Adding all the contributions, 5+4+4+4=17, Mr. A gets the highest ranking possible for the clustered category of traditional Chinese medicine. For the clustered category of spiritual, he only gets a ranking of 3, because he had indicated a variable in the traditional Chinese medicine clustered category as the current preference, first and most important source of help. Furthermore, the contribution of a probing response is added only if no other help-seeking in the clustered category is rated spontaneous or most important. Thus, there is no further contribution from the clustered category of spiritual to the ranking.

APPENDIX G: Computation of Self-Perceived Stigma Score

There are twelve questions in the EMIC pertaining to self perceived stigma. These questions enquire concerns about disclosure of illness, diminished self-esteem, social rejections of self and family, especially with regard to negative influence on self and family’s marriages. These questions, each represented a stigma variable, are rated on a 4-point scale (3=yes, 2=possible, 1=uncertain, 0=no). As showed in the table below, based on the subject’s response to each of these variables, the higher numeric values indicated greater stigma. These scores are then combined additively to form a stigma scale. The total score of stigma is the sum of stigma item 1 to stigma item 12. Scores on the scale range from 0 to a possible maximum of 36. Internal consistency of the stigma scale for this has been verified with a Cronbach alpha of 0.814.

<table>
<thead>
<tr>
<th>Stigma#</th>
<th>Variable</th>
<th>Question # in EMIC</th>
<th>EMIC Entry</th>
<th>Score Contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Avoid Disclosure</td>
<td>27</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Self-Esteem</td>
<td>29</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>Shame</td>
<td>30</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>Others think less</td>
<td>31</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>5</td>
<td>Others avoid you</td>
<td>32</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>Others refuse to visit</td>
<td>33</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>7</td>
<td>Others think less of family</td>
<td>34</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>Problems for family</td>
<td>35</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>Family concern about disclosure</td>
<td>36</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>10</td>
<td>Problem to get married</td>
<td>37.1</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>Problem in ongoing marriage</td>
<td>37.2</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
<tr>
<td>12</td>
<td>Problem for relative to marry</td>
<td>37.3</td>
<td>1=Yes</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3=Possibly</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4=Uncertain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2=No</td>
<td>0</td>
</tr>
</tbody>
</table>
**Epilepsy**

**Perceived Cause**

The majority (29 or 58%) of the participants cited heredity as the cause of epilepsy, 22% (11) physical causes such as neurological problems, viral infection and injury; 8% (4) blamed a congenital problem, for example a pregnant woman would render her unborn child susceptible to epilepsy if she ate mutton during her course of pregnancy; 6% (3) alleged social stresses (unpleasant life events) 4% (2) reported psychological distress (over worries), and one participant (2%) attributed his fatigue to “ruo” (weakness). They felt that most people in the community would share their opinion, only “some uneducated” people would consider the person suffering from epilepsy as being possessed by demons or ghosts.

The following is the view towards epilepsy of a 43-year-old female participant, who was a graduate of a prominent US university and former school teacher from Hong Kong:

*It is a genetic illness. My sister-in-law has epilepsy, and my husband’s niece, his brother’s daughter has epilepsy.... This gene is inherited from my father-in-law. My sister-in-law has epilepsy and she has several episodes of seizures before.... This niece also has it. Other people would not think it is heredity, they would say that it was being processed by devil or due to bad deed from previous generation that affected their children. Epilepsy is not an ordinary illness. The person would have seizures and secretion from the mouth. It was a scary scene. (#19)*

**Stigma**

Ninety percent (90% or 45) of the participants indicated that if others were to know about someone having epilepsy, it would cause problems for this person and even his/her family, 4% (2) said possibly and only 6% (3) reported no. Sixty-six percent (66% or 33) claimed that the person having epilepsy would feel ashamed of having it, 12% (6) said possibly and only 22% (11) reported no.
A 52-year-old laboratory technician from China told of the case of his uncle’s son who has epilepsy:

*Not only he (cousin) himself finds it very embarrassing, he is having difficulties in making friends or finding a job, difficulties in every respect. His family is very bothered by this too.* (#32)

Having epilepsy meant not only major impact on the patients’ but also their “blood-related” relatives’ chances of getting married. Therefore, “*before marriage it is important to investigate that the relatives of the person does indeed not have epilepsy*” (#3, a 28-year-old mother of two), and some would “*object if my daughter is going to marry a person with epilepsy*” (#50, a 42-year-old mother of three). Seventy eight percent (78% or 39) of the participants said that they would be concerned if someone who has epilepsy were to marry into their family, 10% (5) indicated possibly and only 12% (6) said no. Eighty percent (80% or 40) of the participants suggested that most people would be concerned if someone who had epilepsy were to marry into their family, 12% (6) reported possibly, 6% (3) uncertain and only one participant (2%) said no.

A 52-year-old former university professor from Shanghai voiced the sentiment of the majority and explained the potential social impact of epilepsy on its victim and family:

*It is embarrassing and shameful for the family. People will look down on the family. Especially in China when people know this person has epilepsy in the family history, they tend to avoid that person, let alone get married with that person. It is impossible. No, not even to socialize with this person. In China, it is almost a taboo. It is the kind of (people who have the) illness everybody would keep a distance from, because when it (seizure) happens, it is uncontrollable. It is very difficult for the family. Also, if people have better options, they will not choose a person with epilepsy to marry.* (#20)

This feeling was echoed by a substantial number of participants as 46% (23) reported that should others know about an individual’s epilepsy. It would be difficult for relatives of this person to marry; 20% (10) noted possibly, and just 34% (17) said no, this was not true.

Respondents purported that victims of epilepsy usually formulate strategies to combat the stigma associated with the illness. A 40-year-old factory worker from China revealed:
I know of a person, a boy, he had to marry someone from far away. His wife did not know about this at the time of marriage. After the marriage, she had no choice. They even had two children. (#49)

The majority (78% or 39) of participants would not refuse to visit the home of a person with epilepsy, one (2%) said possibly, 9 (18%) would refuse and one (2%) individual was not certain. Although visiting the home of an epileptic usually did not pose a problem for most informants, and most recognized that “epilepsy is not an infectious disease,” they would proceed with caution:

I would still go to his house, but I will not say anything that can excite him, because I heard that epilepsy can be triggered by any kind of excitement (or stress). Therefore, cannot talk to him anything that is excitable. You can be friend still. (#15)

The majority (62% or 31) also felt that most people would not refuse to visit the epilepsy patient’s home, 3 (6%) said possibly most people would not refuse, 5 (10%) said that most people would refuse and one (2%) individual was not certain.

A large proportion (82% or 41) of the participants revealed that most people with a relative who has epilepsy would prefer to keep others from knowing about it if they could, 10% (5) reported possibly, and only 8% (4) said no because they felt that other people could not help the patient if they did not know about it. Some felt that to avoid disclosure is the “general attitude of most Chinese” (#38) and that “you do have to mind the face of the person with epilepsy” (#47), especially the nature of the illness allows them to hide it from others. A 56-year-old business man who had a sister with epilepsy explained:

People will try their best not to let others know. No one wants to be sick, she looks normal most of the time, and it just happened suddenly, she can’t help it and it (seizures) doesn’t act up all the time. If it (seizures) happens all the time and has to lie in bed all the time, then you can’t keep others from knowing about it. When it (seizures) doesn’t act up, she is a normal person, so there is no point to tell others about it. (#43)
One of the major reasons for wanting to keep the illness from others was because having epilepsy would reflect poorly on the family. This sentiment was shared by a substantial number of participants; 42% of them (21) reported that if someone had epilepsy and others came to know about, that it would reflect poorly on the family, 26% (13) suggested possibly, and 32% (16) said no, it would not. The following is a quote from a 46-year-old married man from Hong Kong. He explained how epilepsy was considered shameful not only to the patients but also to their family members, and described the Chinese cultural proscriptions against sharing such information with others:

*We, Chinese, would prefer nobody knows about it. As the saying goes, "Family shame do not go spreading outside." Even things that are not very shameful, we still don't want people to know. If other people knew, it would distress the family. Even if the neighbours know, some people have "long tongues" [like to gossip], they will tell others that this person has epilepsy, or even pointing fingers when they see the person. It would also affect the chance of marriage of his family, because it is hereditary.* (#15)

**Help-Seeking Behaviour**

Due to the unpredictable nature of epilepsy, some respondents felt that the immediate action at the time of a seizure is to “*(hurry) to find some green vegetable and put it into his mouth*” (#20, a 52-year-old former university professor from China). Family physicians were the help of choice by 52% (16 suggested patient’s own family doctor and 10 said any general practitioners would do) of the participants to treat epilepsy, self-help and help from family and friends were suggested by 22% (11), other Western medicine specialists, such as neurologists, were recommended by 20% (10), traditional Chinese medicine practitioners were suggested by 6% (3) of the informants.

The reason why most respondents preferred seeking help from Western medicine was captured by a 43-year-old former nursing teacher from Hong Kong:
Chung-i (traditional Chinese medicine doctor, herbalist) lack concrete investigation equipment and there is no standard of their practice. They are not covered by OHIP so I would take the person to see a Western doctor, a specialist. (#19)

One of the three participants who mandated seeing a traditional Chinese medicine practitioner, also proposed other measures probably reflected opinions of older and less educated Chinese individuals. A 64-year-old unemployed cook who immigrated from China suggested:

Go see a Chung-i (traditional Chinese medicine doctor, herbalist) and seek help from a knowledgeable person like an elder who probably will suggest to eat the gallbladder of a fox or a bear. If you have money, you can make the fox skin into a coat and wear it. It can get rid of the wind from one's body. (#13)

**Depression**

**Perceived Cause**

The majority (27 or 54%) of the participants cited psychological problems, such as worry, boredom and personality, as causes of depression, 36% (18) reported causes of social nature (such as personal or financial losses, bereavement, interpersonal conflicts and impact of migration), 4% (2) suggested weakness and 3 others thought it was caused by a physical problem such as postpartum hormonal imbalance, heredity, and fate respectively. Thirty two percent (32% or 16) refused to speculate about what other people in the community would consider as the cause of depression. Those who responded professed that other people in the community shared their point of view.

The opinion of a 47-year-old mother who resigned from her factory job to care for her 20-year-old schizophrenic son represents the thoughts of those participants who claimed a psychological cause to depression:

*These people (those with depression) usually have an introvert personality type and worry a lot. People who cannot handle pressure and cannot let things go. (#21)*
Respondents who reported a social cause to depression told tales of acquaintances who experienced the negative impact of migration. A 46-year-old man illustrated the misfortune of a friend who suffered from depression:

I have a friend who has depression. Her husband was employed in Hong Kong. After he brought his wife and children to Canada, he was not able to find work in Canada. The husband returned to Hong Kong and left the wife here. They had bought a house, a townhouse. He left his wife and children here and returned to Hong Kong by himself. His wife was not able to find work either and relied on him to send money from Hong Kong. His wife rented out the basement of the house to two students. His wife had to cook for the two students as well. Of course, she charged them for the meals, but the husband was not very understanding to the wife. The wife often wondered why the family had to live that way and not living together, and that led to her depression. (#15)

Stigma

The majority (60% or 30) of the participants said that if others were to know about someone having depression, it would cause problem for this person, 12% (6) reported possibly, 2% (1) uncertain and 26% (13) said no, it would not cause a problem. Lack of understanding of the illness by the general public was cited as one of the reasons that would cause problems. A 53-year-old female unemployed sewing machine operator speculated:

It will bring some discrimination to that person. Others may misinterpret depression as being crazy, people get mixed up and think that you had psychiatric illness. (#47)

This comment also reflects most participants' attitude towards depression: unlike schizophrenia, depression is considered an emotional distress not a serious psychiatric illness.

A little less than one third (32% or 16) of the interviewees indicated affirmatively that the person who suffers from depression would feel ashamed should their condition be known by others, and 24% (12) speculated that it was possible that one would feel ashamed. Forty percent (40% or 20) expressed that the person having depression would not feel ashamed of having this
condition while 4% (2) stated that they were not certain. One way to cope with this situation was to keep others from knowing about the problem to avoid psychological "bad effects" on the depressed person "when others are gossiping about this" (#34, a 30-year-old secretary).

More than half (58% or 29) of the participants said that they would be concerned if someone who had depression were to marry into their family, 26% (13) reported possibly and only 16% (8) said no, it would not cause them concern. The majority (60% or 30) also suggested that most people would be concerned if someone who has depression were to marry into their family, 28% indicated (14) that this was possibly so, 2% (1) uncertain and 5 participants (10%) reported no, there would be no concern. The feeling of not wanting to be married to a person with depression evolved from the concern about this person's ability to fulfill his/her marital obligations. A 52-year-old former university professor from China explained:

People would wonder how this person with depression would be able to work as a normal person and support the family. If I want to do this, she feels depressed and if I want to do that, the person would be depressed as well. If I want to have sex, this person might not want to do it. All these might lead to a lot of problems in the marriage. (#20)

The majority (74% or 37) of the participants would not mind visiting the home of a person with depression, 5 (10%) stated that most likely they would not refuse, and 8 (16%) confirmed that they would refuse to visit the home of a person with depression. The majority (66% or 33) also felt that most people would not refuse to visit the depressed person's home, 7 (14%) conjectured that possibly most people would not refuse, 9 (18%) held that most people would refuse and one (2%) individual was uncertain. Although most felt that people would not mind visiting the home of a depressed person, they had the following explanation for people who preferred not to visit, as a 47-year-old female former receptionist at a family doctor's office expressed:
No one should think less of him unless he cannot control himself and is very abnormal. In this case, most Chinese will not visit him. The enthusiastic people may still visit him and will not think less of him. For others who do not know him, they will not visit him. (#44)

The majority (64% or 32) of the participants said that most people with a depressed relative preferred to keep others from knowing about the illness if they could, 18% (9) indicated possibly, and 18% (9) answered no, it did not concern them if others knew. Over a third (34% or 17) concurred that if someone has depression and others come to know about it it would reflect poorly on the family, 24% (12) suggested possibly, 40% (20) reported no that would not be true, and one (2%) was uncertain. Like most other interviewees, a 38-year-old female former fashion design teacher from Hong Kong felt that this kind of thinking is central to the Chinese culture:

Since Chinese are very conservative and try to keep others from knowing their family shame. Chinese have this kind of thinking. (#38)

Only 22% (11) confirmed that if others were to know about an individual’s depression that it would make it difficult for relatives of this person to get married. Twelve percent (12% or 6) stated that this was possible. The majority (66% or 33) felt that it should not have an effect, because as immigrants most patients did not have people from the same community living close enough to learn about their illness. A 40-year-old man from China clarified:

It would not be a problem in Canada but it will cause problems to the family in China since people live close by. In Canada, you do not even know your neighbours so it does not matter. (#49)

Help-Seeking Behaviour
Most of the participants (54% or 27) suggested that family members should care for the patient with depression. Mental health professionals were the choice of help of 16% (8), while 10% (5) chose general practitioners, 8% (4) self-care, help from relatives and friends were suggested by 6% (3), 2% (1) recommended group therapy, 2% (1) indicated that “nothing can help”, and 2% (1) could not tell what would be helpful. The following two quotations captured the opinions of most interviewees:

*I think that the family has to help the person for as long as they can manage at home, but if they can't manage any longer, the first thing they should do is send the person to a Western doctor.*  
(#1, 44-year-old widow, mother of four)

*Communicate with the family. (Seek help from) Doctors, psychologist, psychiatrist (in this order). Only when one gets to be suicidal or harmful to others, then one should see a doctor. But the family should provide support at first.*  
(#12, 44-year-old single male, psychology graduate from an Ontario university and working as a clerk at a post office.)

**Schizophrenia**

**Perceived Cause**

The majority (32 or 64%) of the participants attributed social problems (major personal or financial losses, tragic life events and interpersonal conflicts) as the causes of schizophrenia, or “wires stuck” as most participants would refer to it in Chinese colloquial language. Heredity was reported by 26% (13). Causes of psychological nature such as personality and worry were suggested by 6% (3) of informants. One claimed that it is congenital and another thought it was caused by a physical problem such as a biochemical abnormality in the brain. While 18% (9) refused to speculate what other people in their community would consider as the cause of schizophrenia, most felt that other people shared their opinions.
Many participants emphasized that schizophrenia was caused by serious social matters and not just minor events. A 46-year-old man who was working as a subway supervisor illustrated:

Schizophrenia is usually due to sudden changes, such as in 1987, the stock market crashed, someone who had invested, say he traded margins, that might involved (loss of) millions of dollars and it was no way out for him. He might have a few hundred thousand dollars and he could mortgage his house, it was no way he could pay his debt. Might be at that moment he could suffer a nervous breakdown, then lead to schizophrenia. (#15)

Stigma

The majority (78% or 39) of the participants affirmed that if others were to know about someone having schizophrenia, it would cause problem for this person, 8% (4) suggested possibly, and 14% (7) reported no, that it would not. The same man cited above explained why it would cause problems for the victim of schizophrenia:

I think the person would suffer great distress if people knew, because it is madness. As a victim, he would suffer a lot of discrimination. Because being a schizophrenic, even parents with young children in kindergarten would say (to their children) "don't get close to this person because he is mad." People would have nothing to do with him, and absolutely not marry him. Even if you say that I am too conservative, I would never associate with him. (#15)

Many respondents agreed that even were the person to recover from schizophrenia they would still be treated differently: “In Chinese society, if a person was mad before, other people would be scared of him. What if this person becomes aggressive again?” (#32, 52-year-old unemployed biochemist from China). A former schizophrenic would not be trusted again by others as explained by this 28-year-old business man who had studied computer science in an Ontario university:

He may be crazy again although he is cured. Just like a car, once it has broken down, you would wonder if it would be worse should it break down again. (#42)

The majority (60% or 30) indicated that the person who was suffering from schizophrenia would feel ashamed of having this condition, equal numbers (20% or 10) of informants reported
no or possibly. Many of them blamed the Chinese culture for the high level of shame experienced by schizophrenic patients and families even the patient recovered from the illness.

As explained by a 27-year-old unemployed engineer from Hong Kong:

*People would accept someone who had his leg broken and healed but people would not accept someone who had schizophrenia and recovered. I do not know why, I guess it is just Chinese tradition. I tend to think that way too.* (#8)

A 53-year-old unemployed sewing machine operator from China echoed the thoughts of most participants that other people knowing about the illness would subject the patient and family to lose face.

*The family will let others know unless they are very close. Avoid outsiders knowing about this because the family will lose face if they do.* (#47)

A large proportion (80% or 40) of the participants claimed that they would be concerned if someone who had schizophrenia were to marry into their family, 12% (6) reported no, it would not be a problem, and 8% (4) suggested possibly. An overwhelming majority (84% or 42) of the participants agreed that most people would be concerned if someone who had schizophrenia were to marry into their family, 8% (4) purported possibly, 3 (6%) participants said no and one was (2%) uncertain. Again, most informants blamed the Chinese culture for the stigma attached to schizophrenia, as understood by a 27-year-old unemployed engineer from Hong Kong:

*People would not want to marry into such a family neither and I guess Chinese tradition tells us not to have anything to do with these people.* (#8)

For those who considered the cause of schizophrenia as the result of heredity (26% or 13 of the participants), they claimed that schizophrenia would affect the family for three generations. Therefore, if one contemplated marriage, one must trace back three generations of one’s potential spouse to ensure that schizophrenia was not in this person’s family history. A 53-year-old former English teacher from Hong Kong explained:
Since it is hereditary. It is possible, according to Chinese beliefs, one can inherit the illness for three generations. (#30)

Most (62% or 31) of the participant would not refuse to visit the home of a person with schizophrenia, 4 (8%) most possibly they would not refuse, and 15 (30%) would refuse. Commenting that other people in their community were not as open minded as they were, only 48% (24) respondents considered most people would not refuse to visit the home of a schizophrenic patient, 8% (4) suggested that possibly most people would not refuse, and 44% (22) speculated that most people would refuse because of the unpredictable nature of the illness, where the patient would become aggressive without warning (#20). A 27-year-old female university graduate from China who worked as a secretary at a computer store confided that understanding the illness allowed her to visit her friend who suffered from schizophrenia without fear:

_I have a friend who has schizophrenia. It is a troublesome illness. I understand the suffering she has gone through. Other people are afraid of her but I still visit her._ (#7)

Another woman recounted a horrific experience she had with schizophrenia, and confessed that she would never get physically close to anyone with the illness:

_One of my older relatives had schizophrenia and he was in the newspaper. I was still young at that time. He killed 8 people in his family. I am terrified with this kind of illness._ (#30)

Almost all participants (94% or 47) confirmed that most people with a relative who had schizophrenia preferred to keep others from knowing about it if they could, 4% (2) said possibly, and only one (2%) reported no, people would not keep this quiet. The following comment of a 42-year-old male welder from China captured the opinion of most participants, that of having other people know about their illness would create more suffering for the patient:
I will not let people know because this may create more pressure on the patient. He does not want to have this disease and have others look down at him. (#22)

The majority of interviewees (64% or 32) also reported that if someone had schizophrenia and others came to know about it, it would reflect poorly on the family, 16% (8) speculated that this was possible, and 20% (10) said no. A 38-year-old female former fashion design teacher explained:

Since others will gossip that so and so’s son or daughter is “wire-stuck” (crazy), and the family would be distressed and feel the pressure. (#38)

Almost half of the informants (46% or 23) said that should others know about an individual’s schizophrenia, it would make it difficult for relatives of this person to get married, 14% (7) said possibly; this is especially so for participants who felt the cause of schizophrenia was heredity “It will affect the chance of marriage of relatives since this illness is hereditary” (#45, a 49-year-old sewing machine operator from China). Close to half of the participants (40% or 20) suggested that it would not make it difficult for relatives of this person to get married, because the illness was related to the occurrence of tragic events beyond the victim’s control.

Help-Seeking Behaviour

Most of the participants (40% or 20) felt that mental health professionals’ help should be sought, while 30% (15) demanded that family members or relatives should care for the person who suffer from schizophrenia. General practitioners were the choice of help for 28% (14) of the informants, and one of them suggested a neurologist should see the patient. A 27-year-old unemployed engineer summarized the views of most participants with regard to helping the patient suffering from schizophrenia as follows:
The family should know what his problems are. They should support him and help him solve his problems. Take him to a doctor so that he can get medication. I think public education about what the illness is, is also very important. That's the only way to help get these people (patients) accepted into society. (# 8)

**Comparison of the Participants’ Views on Epilepsy, Depression and Schizophrenia**

The table below depicts a comparison of quantitative responses of the participants’ views on epilepsy, depression and schizophrenia. The first row indicates their opinions on perceived causes, rows 2 to 10 on stigma, and the last row on help-seeking behaviour.

**Perceived Cause**

The participants attributed different perceived causes to epilepsy, depression and schizophrenia. However, some of them pointed out that these illnesses were caused by some common factors. For example, epilepsy (58% of the participants) and schizophrenia (26%) were considered to result from heredity, while schizophrenia (64%) and depression (18%) were regarded to be caused by social difficulties. Over half (53%) of the respondents cited a psychological cause for depression, but only a number of interviewees felt that psychological problems contributed to epilepsy (4%) or schizophrenia (6%).

**Stigma**

The majority of the informants felt that for patients suffering from one of the three illnesses, if other people learnt of their illnesses, this would create problems and would make them feel ashamed; especially in epilepsy (a relatively more visible illness) accounting for 90% and 66%, in schizophrenia 78% and 60%, and depression 60% and 32%. They also considered that schizophrenic patients (80%) would encounter more problems in getting married, in comparison with epileptic (78%) and depressive patients (58%). Moreover, they stated that people in their community would share their opinions (schizophrenia, 84%, epilepsy, 80%, depression, 60%) in this regard. As for home visits, most of the participants would visit the homes of these patients,
particularly those of the epileptic (78%) and depressive (74%) patients, while the willingness to call on schizophrenic patients (62%) was slightly less. Besides, they indicated that people in their community generally would share their view, but would be comparatively less willing than they to go to these patients' homes (depressive, 66%, epileptic 62%), particularly those of the schizophrenic patients (48%). The participants felt strongly that patients with schizophrenia (94%) or epilepsy (83%) would avoid disclosure of their illnesses, while the avoidance of depressive patients would be of a lesser degree (64%). As for the effects of the illness on the family, the majority of the respondents (64%) alleged that schizophrenia would reflect poorly on the family, but less than half (42%) felt that epilepsy or depression (34%) would have the same effect. Furthermore, a substantial number (40%) even said that depressive patients would not reflect poorly on their families. As the effects on relatives' marriage are concerned, slightly less than half (both 46%) claimed that with an epileptic or a schizophrenic patient at home, it would be difficult for the relatives to get married, but 66% maintained that patients suffering from depression would not affect their relatives' chance of marriage.

**Help-Seeking Behaviour**

More than half (52%) of the participants asserted that epileptic patients should seek help from family physicians, while the percentage for schizophrenic patients was 28 and that for depressive patients was 10. The majority expressed that the depressives (68%) would turn to families and friends for help, but a smaller number felt that schizophrenic (30%) or epileptic (22%) patients would do so. Mental health professionals were cited by a fair number of the participants as the help of choice for schizophrenia (40%) and depression (18%), but none of the participants suggested that epileptic patients should seek help from this source.
## Quantitative Findings of Participants' General Illness Beliefs on Epilepsy, Depression and Schizophrenia.

<table>
<thead>
<tr>
<th>Epilepsy</th>
<th>Depression</th>
<th>Schizophrenia</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Personal perceived cause Heredity</td>
<td>29 (58%)</td>
<td>Social 32 (64%)</td>
</tr>
<tr>
<td>Physical</td>
<td>22 (44%)</td>
<td>Heredity 13 (26%)</td>
</tr>
<tr>
<td>Congenital</td>
<td>4 (8%)</td>
<td>Psychological 3 (6%)</td>
</tr>
<tr>
<td>Social</td>
<td>3 (6%)</td>
<td>Congenital 1 (2%)</td>
</tr>
<tr>
<td>Psychological</td>
<td>2 (4%)</td>
<td>Physical 1 (2%)</td>
</tr>
<tr>
<td>Weakness</td>
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</tr>
<tr>
<td>Yes</td>
<td>45 (90%)</td>
<td>Yes 39 (78%)</td>
</tr>
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<td>2 (4%)</td>
<td>Possibly 4 (8%)</td>
</tr>
<tr>
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<td>3 (6%)</td>
<td>No 7 (14%)</td>
</tr>
<tr>
<td>2. Would cause problems if others know Yes</td>
<td>33 (66%)</td>
<td>Yes 30 (60%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>6 (12%)</td>
<td>Possibly 6 (12%)</td>
</tr>
<tr>
<td>No</td>
<td>11 (22%)</td>
<td>No 13 (26%)</td>
</tr>
<tr>
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<td>2 (4%)</td>
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</tr>
<tr>
<td>Yes</td>
<td>39 (78%)</td>
<td>Yes 40 (80%)</td>
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<tr>
<td>Possibly</td>
<td>5 (10%)</td>
<td>Possibly 4 (8%)</td>
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<tr>
<td>No</td>
<td>6 (12%)</td>
<td>No 6 (12%)</td>
</tr>
<tr>
<td>3. Would feel ashamed if others know Yes</td>
<td>33 (66%)</td>
<td>Yes 30 (60%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>6 (12%)</td>
<td>Possibly 12 (24%)</td>
</tr>
<tr>
<td>No</td>
<td>11 (22%)</td>
<td>No 20 (40%)</td>
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<td>2 (4%)</td>
<td>Uncertain 2 (4%)</td>
</tr>
<tr>
<td>Yes</td>
<td>39 (78%)</td>
<td>Yes 42 (84%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>5 (10%)</td>
<td>Possibly 4 (8%)</td>
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<tr>
<td>No</td>
<td>6 (12%)</td>
<td>No 3 (6%)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>3 (6%)</td>
<td>Uncertain 1 (2%)</td>
</tr>
<tr>
<td>4. Problem in getting married (subject’s opinion) Yes</td>
<td>40 (80%)</td>
<td>Yes 31 (62%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>6 (12%)</td>
<td>Possibly 4 (8%)</td>
</tr>
<tr>
<td>No</td>
<td>1 (2%)</td>
<td>No 15 (30%)</td>
</tr>
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<td>3 (6%)</td>
<td></td>
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<tr>
<td>Yes</td>
<td>39 (78%)</td>
<td>Yes 24 (48%)</td>
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<tr>
<td>Possibly</td>
<td>1 (2%)</td>
<td>Possibly 4 (8%)</td>
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<tr>
<td>No</td>
<td>9 (18%)</td>
<td>No 22 (44%)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>1 (2%)</td>
<td></td>
</tr>
<tr>
<td>5. Problem in getting married (other people’s opinion) Yes</td>
<td>41 (83%)</td>
<td>Yes 47 (94%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>5 (10%)</td>
<td>Possibly 2 (4%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (8%)</td>
<td>No 1 (2%)</td>
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</tr>
<tr>
<td>Yes</td>
<td>41 (83%)</td>
<td>Yes 32 (64%)</td>
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<tr>
<td>Possibly</td>
<td>5 (10%)</td>
<td>Possibly 8 (16%)</td>
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<tr>
<td>No</td>
<td>4 (8%)</td>
<td>No 10 (20%)</td>
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<td>1 (2%)</td>
<td></td>
</tr>
<tr>
<td>6. Would visit home of patient (subject’s opinion) Yes</td>
<td>42 (84%)</td>
<td>Yes 24 (48%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>13 (26%)</td>
<td>Possibly 4 (8%)</td>
</tr>
<tr>
<td>No</td>
<td>16 (32%)</td>
<td>No 22 (44%)</td>
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<td>Yes</td>
<td>43 (86%)</td>
<td>Yes 47 (94%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>5 (10%)</td>
<td>Possibly 2 (4%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (8%)</td>
<td>No 1 (2%)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>1 (2%)</td>
<td></td>
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<tr>
<td>7. Would visit home of patient (other people’s opinion) Yes</td>
<td>33 (66%)</td>
<td>Yes 32 (64%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>3 (6%)</td>
<td>Possibly 8 (16%)</td>
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<tr>
<td>No</td>
<td>5 (10%)</td>
<td>No 10 (20%)</td>
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<td>1 (2%)</td>
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<tr>
<td>Yes</td>
<td>32 (64%)</td>
<td>Yes 23 (46%)</td>
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<tr>
<td>Possibly</td>
<td>9 (18%)</td>
<td>Possibly 7 (14%)</td>
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<tr>
<td>No</td>
<td>9 (18%)</td>
<td>No 20 (40%)</td>
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<tr>
<td>8. Avoid disclosure Yes</td>
<td>21 (42%)</td>
<td>Yes 32 (64%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>13 (26%)</td>
<td>Possibly 8 (16%)</td>
</tr>
<tr>
<td>No</td>
<td>16 (32%)</td>
<td>No 10 (20%)</td>
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<tr>
<td>Uncertain</td>
<td>1 (2%)</td>
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</tr>
<tr>
<td>Yes</td>
<td>23 (46%)</td>
<td>Yes 23 (46%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>10 (20%)</td>
<td>Possibly 7 (14%)</td>
</tr>
<tr>
<td>No</td>
<td>17 (34%)</td>
<td>No 20 (40%)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>1 (2%)</td>
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</tr>
<tr>
<td>9. Reflects poorly on family Yes</td>
<td>34 (68%)</td>
<td>Mental Health 20 (40%)</td>
</tr>
<tr>
<td>Possibly</td>
<td>11 (22%)</td>
<td>Fam/friends 15 (30%)</td>
</tr>
<tr>
<td>No</td>
<td>10 (20%)</td>
<td>Family MD 14 (28%)</td>
</tr>
<tr>
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<td>3 (6%)</td>
<td>Specialist 1 (2%)</td>
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<tr>
<td>10. Difficult for relatives to marry Yes</td>
<td>33 (66%)</td>
<td>Yes 23 (46%)</td>
</tr>
<tr>
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<td>6 (12%)</td>
<td>Possibly 7 (14%)</td>
</tr>
<tr>
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<td>33 (66%)</td>
<td>No 20 (40%)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>1 (2%)</td>
<td></td>
</tr>
<tr>
<td>11. Best help Family MD 26 (52%) Fam/friends 11 (22%) Specialist 10 (20%) Trad Chinese 3 (6%)</td>
<td>Family MD 5 (10%)</td>
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