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Illness Management Strategies among Chinese Immigrants

Living with Arthritis

by

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ABSTRACT

The purpose of this exploratory study was to generate a substantive theory regarding illness management among Chinese immigrants living with arthritis. Purposive sampling was used to select 19 Chinese immigrants for in-depth interviews. This information was supplemented by data collected from 7 participants in mainland China.

The data were analyzed according to the following steps (1) transcribing interview materials, (2) developing codes, categories and themes, and (3) theoretical coding.

The results of this study describe factors which directly/indirectly impacted on illness management strategies. The illness management usually started with using self-care remedies, followed by consulting Western physicians, consulting Chinese doctors, and then returning to Western medicine. Factors directly impacting on illness management strategies are: arthritic symptoms, beliefs about Western/Chinese medicine based on treatment experience, barriers to using Western/Chinese medicine, and external factors. Factors indirectly impacting on illness management strategies are: beliefs about Western/Chinese medicine, beliefs about combining Western and Chinese medicine, and beliefs about arthritis.

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CHAPTER 1

INTRODUCTION

I. STATEMENT OF THE PROBLEM

A. Initial premise

Chinese immigrants have specific beliefs about illness management strategies for their chronic diseases. In general, they believe that Chinese medicine is a holistic approach towards health which teaches that good health is a state of spiritual and physical harmony with nature (Spector, 1996). Traditional treatments treat the cause of disease, therefore, they lead to permanent cures or long-term remissions and are effective in the management of many chronic diseases (Chi, 1994). In contrast, Western medicine tends to focus on subsystems such as the organs, cells or genes and does not treat the human body as a whole (Chi, 1994). The strengths of Western medicine consist of surgical abilities and eradicating infectious disease, but it is not as effective in the management of chronic disease (Yang, Lin, & Lawson, 1991). In Canada and the United States, many Chinese immigrants with chronic diseases are dissatisfied with the care received from Western practitioners. They prefer to use Chinese medicine when dealing with symptoms of chronic illnesses (Elfert, Anderson, & Lai, 1991; Spector, 1996).

Chinese immigrants with musculoskeletal problems (mainly arthritis) are more likely to use Chinese medicine than those with different kind of chronic diseases. They are hesitant to see Western physicians, or follow their recommendations (X. Y. Cheng, B. H.

Ma, J. H. Yang, & S. M. Edworthy, personal communication, December, 1996). However, little is known about Chinese immigrants' beliefs regarding arthritis and its management. Therefore, the purpose of this study is to assess management strategies among Chinese immigrants living with arthritis.

B. Immigrant situation

Because little literature is available, the researcher discussed this subject with several experts (Chinese healers, Chinese physicians, a Western specialist) in Calgary. These experts reported that most Chinese immigrants believe that arthritis is better treated by traditional Chinese medicine than with Western biomedical treatment. They make a personal diagnosis and begin their own management long before consulting a physician (B. X. Ma & S. Y. Cheng, personal communication, December, 1996).

According to information obtained from five Chinese healers in Calgary, arthritis is one of the most frequent illnesses treated in their clinics. Patients with arthritis who were treated at these clinics often are in a serious condition. Initially, they had most often seen a Western doctor since the cost was covered by health care. When they believe that Western medicine is not effective, they then go to a Chinese doctor (X. B. Huang, Y. L. Zheng, J. Lee, & S. Y. Chen, personal communication, December, 1996).

One Western physician reported that Chinese immigrants' beliefs regarding arthritis are interesting and difficult to understand; for example, why rheumatoid arthritis means "Wind and Wet Arthritis" in Chinese, why Chinese immigrants with arthritis are usually hesitant to see Western physicians until their condition becomes critical, or, why

they do not follow through with Western physicians' advice (S. M. Edworthy, personal communication, 1995).

C. Mainland situation

Some Chinese healers practicing in Canada indicated that patients in mainland China, whose arthritic condition is mild, might first consult relatives or friends, or care for themselves with aspirin or heat treatment. Later, when their disease worsens, they might experiment further with other self-care remedies. Patients with severe arthritis then look at either Chinese or Western medical care for diagnosis and treatment (B. X. Ma & S. Y. Chen, personal communication, December, 1996).

Many mainland patients with arthritis choose traditional Chinese treatments such as natural herbs, acupuncture and massage as their dominant treatment; they also believe that Chinese medicines for external application are effective for arthritis. A small proportion of patients use Western medicine for pain relief. However, if their condition becomes serious, they frequently turn to Chinese medicine (J. H. Yang & Z. H. Ma, personal communication, December, 1996).

D. Gap in existing knowledge

For the one Canadian case-study that could be located (Dyck, 1992), a description was given about an arthritic Chinese immigrant woman's acquisition and use of health care knowledge. Some studies have been done on illness management of Chinese-Canadians living with diabetes and asthma, and a few studies on Chinese immigrants' perspectives

regarding mental illness (see detailed description in Chapter 2). However, there is no comprehensive study that identifies the key components of general management of arthritis by Chinese immigrants. There is also no theoretical framework regarding management strategies of any chronic disease by Chinese immigrants.

II. RESEARCH OBJECTIVES

The purpose of this exploratory study is to generate a substantive theory regarding illness management among Chinese immigrants in Canada living with arthritis. The central research question was, “How do Chinese immigrants suffering from arthritis manage their illness?” The specific aims of this study were:

- (1) to identify and describe illness management strategies and their impact in Chinese immigrants living with arthritis.
- (2) to identify and describe factors which contribute to Chinese immigrants’ illness management strategies.
- (3) to develop a theoretical model explaining how illness management strategies are linked to contextual conditions among Chinese immigrants living with arthritis.

In September, 1997, the researcher visited Harbin, China, which presented an opportunity to collect background information as supporting or comparative data for the study of immigrants. At that time, initial interviews with immigrants had been completed and categories created. Preliminary analysis showed that most interviewees’ attitudes toward health or illness were not influenced to a large degree by the dominant culture

(possibly because they arrived in Canada as adults, some quite elderly). The researcher believed therefore, that collecting background information regarding arthritis management and factors impacting management strategies from their country of origin could be helpful for interpreting immigrants' beliefs or behaviors and understanding the meanings attached to their beliefs. This became a fourth aim of the study.

III. SIGNIFICANCE OF THE STUDY

This study is significant in four potential ways. *First*, Chinese immigrants are the largest ethnic group of Asian-Americans in North America (Louie, 1985). *Second*, arthritis is a common disease in this population. In the Canadian general population, the overall prevalence of OA and RA were 18% (Badley, 1995) and 1 to 2% (Wilske & Yocum, 1996). Although the prevalence of OA and RA in the Chinese immigrants population has been found to be lower than in the Caucasian population (Lau, Symmons, & Croft, 1996; Wigley et al., 1994) (no statistical evidence), arthritis is still very common among Canadian Chinese immigrants (S. Y. Chen, X. B. Huang, B. H. Ma, & J. H. Yang, personal communication, 1995) and therefore, it is important to know how they manage arthritis.

Second, this study intends to develop a substantive theory which will contribute to knowledge in an area where important variables and relationships are largely unknown; and no theories exist that can explain how and why Chinese immigrants use different management strategies.

Third, the results of this study may have significance for clinical practice. To offer culturally appropriate and sensitive care, health professionals should be aware of important characteristics among Chinese immigrants, and their beliefs regarding illness and its management. This information should eventually bring about improved health care delivery for Chinese immigrants.

Finally, although this is a small, preliminary qualitative study which is designed to provide a basic understanding of this research area, it may also provide useful information for policy development. For example, this study may provide information regarding Chinese immigrants' barriers to using Chinese/Western medicine. Knowledge about these barriers could help policy developers in planning appropriate health care strategies for Chinese immigrants.

IV. DEFINITION OF KEY TERMS

Three important key terms were used in this study. These are management, belief, and contextual conditions.

A. Management

The term management was defined as a variety of actions/interactions people take in response to their illness. These responses are usually in terms of people's beliefs or personal concerns about dealing as well as possible with chronic illness, as opposed to following the standards established by professionals. 'Management' involves choosing and

using self-care remedies and conventional/unconventional treatments for relieving symptoms rather than reducing emotional stress.

B. Belief

Belief was defined as “the ‘truth’ of a subjective reality that influences biopsychosocial-spiritual structure and functioning” (Wright, Watson, & Bell, 1996, p. 41). Beliefs shape people’s experience, perceptions and interpretations regarding their illness. In this study, the researcher will be most interested in uncovering *beliefs about illness, management strategies, and health professionals*.

C. Contextual conditions

Contextual conditions represent a set of conditions (internal and external factors) which impact on illness management strategies.

CHAPTER 2

LITERATURE REVIEW

A literature review was conducted for the following purposes: The first purpose was to **enhance theoretical sensitivity**. The literature can help researchers to become sensitive as to what to look for in their data and to assist in generating the questions to ask the respondents during data collection or the analysis process. However, care should be taken not to become too dependent on data. The second purpose of the literature review was to **direct theoretical sampling**. The literature can give researchers ideas about where they might go to uncover phenomena important to the development of theory, thereby, enabling them to add variation to the study. The third purpose was to review the literature to **validate and elaborate categories**. This occurs by referencing the literature in appropriate places to support the validity and accuracy of the findings (Strauss & Corbin, 1990). This purpose will be elaborated in the discussion chapter.

The following literature review is organized into five sections: *first*, illness management in Chinese immigrants with arthritis; *second*, illness management in Chinese immigrants with chronic diseases; *third*, results from studies of Chinese patients living in mainland China, Taiwan and Hong Kong; *fourth*, use of Chinese medicine in North America by the general population, and *fifth*, conceptual frameworks regarding illness management.

I. ILLNESS MANAGEMENT IN CHINESE IMMIGRANTS WITH ARTHRITIS

Only one immigrant study was found which describes illness management among Chinese immigrants living with arthritis (Dyck, 1992). This case study provided a general picture of how a Chinese immigrant woman living with rheumatoid arthritis (RA) managed her illness. This information specifically influenced the researcher's thinking in developing guiding questions and theoretical sampling, e.g., beliefs were only a small part of this study (possibly due to the fact that the subject was a poorly educated, elderly woman). This study indicated the need to explore beliefs about the illness and its management. Therefore, care was taken to select participants who were able to verbalize their beliefs.

A. Management process

This case study described how a 61-year-old Chinese-Canadian woman with rheumatoid arthritis used different types of health care services and how she managed her illness. The management process was as follows:

At first she visited her Western family doctor for treatment. The doctor gave her medication to take, but it did not really help. Next, the family physician referred her to a Western specialist in rheumatic diseases. The specialist adjusted her medication and referred her to occupational therapy for an orthotic fitting because a wedge which was made for her shoe caused her to experience further pain and swelling in her foot (Dyck, 1992). Finally, she seemed to accept the prospect of ongoing discomfort with her arthritis as she aged. She stated: "There is not too much we could do about the arthritis. It's also what the specialist told me. The specialist said that while I am taking the medication, now

since it is not hurting me, then it is the best that he could do, and that is the best I can expect. Because you cannot really cure arthritis.” (Dyck, 1992, p. 698).

Finally, she visited a traditional Chinese physician and found that visit to be successful. She described the treatment provided and its outcome: “He (the Chinese physician) put some herbs there and wrapped it up for me. I had to go to his place to get it changed every few days. I had that done two or three times. My knee was all right My knee is still a bit swollen, but it is not hurting me anymore.” (Dyck, 1992, p. 699).

B. Self-care remedies

After the prescribed Western medications did not provide effective relief, she tried additional techniques at home when her feet hurt, such as massaging with a traditional Chinese ointment obtained in Chinatown. Also, she tried soaking her feet in hot water and bath salts (Dyck, 1992).

C. Social interaction

Social interaction for the woman in this case study occurred primarily with her family and with other Chinese-Canadians in her workplace.

Her son always accompanied her to the Western clinic. He acted as a translator throughout the visit. “He also answered some questions posed to his mother by the occupational therapist without consulting her.the subject depended on her son for interpretation of the therapist’s questions and explanations” (Dyck, 1992, p. 700).

From other Chinese-Canadians in her workplace, she had learned of some self management remedies.

D. Worry about job loss

The woman worked in a food processing plant 7 to 10 hours a day, sometimes 6 days a week. Although this work was bad for her health, her job remained very important to her. She said: "I do need some spending money for myself. I would really like to work until I can work no longer" (Dyck, 1992, p. 701). The ability of the study participant to move to better jobs was limited by language and educational barriers (Dyck, 1992).

E. Beliefs about arthritis

The subject regarded arthritis as a common condition, arising from old age and working in damp conditions.

II. ILLNESS MANAGEMENT IN CHINESE IMMIGRANTS WITH CHRONIC DISEASES

Since little research has been done on how Chinese immigrants with arthritis manage their illness, studies dealing with Chinese immigrants with other chronic diseases have been reviewed as well. Some studies about illness management among Chinese immigrants with diabetes and asthma, and some reporting on the general status of illness management among Chinese immigrants, were found to be relevant to this study because they provide supportive or comparative information for the research subject.

A. Management process

A case study done by Elfert, Anderson, and Lai (1991) showed Chinese immigrant parents' negative perceptions of the Western medical care received by their asthmatic child in Canada. The child (born in Canada) had been treated by Western physicians. However, the family was troubled by the medical care he received. Also, when the child was in the hospital, they were upset that he was given ice water. When they were told that the child was already taking the adult dose of medication, their reaction was this: He is already on an adult dose; if he gets worse he might die. Then the father phoned his mother for advice, and she sent him Chinese medicine from Hong Kong. The family spent large amounts of money on a variety of Chinese medicines because they believed that Chinese medicine can cure asthma. They continued to use both Chinese and Western therapies, in hopes of a cure (Elfert, Anderson, & Lai, 1991).

For some chronic diseases, such as diabetes, which depend on Western medicine (insulin), many Chinese immigrants use Chinese medicine as a supplementary treatment. According to the findings of qualitative study done by Anderson and her assistants (1991, 1995), on Chinese immigrant women with diabetes, most used a combination of Western medicine and Chinese herbal medicine (Anderson, 1991; Anderson et al., 1995). These women believed that remedies like ginseng were useful in the management of diabetes. The herbs they used were viewed as "tonics" or dietary supplements (e.g., pig's pancreas soup, pearl barley) to give strength. However, although they believed that traditional remedies were useful in the management of diabetes, and had used or were using them,

none used these remedies to replace conventional Western treatments. Moreover, most of the women discontinued, or said they would discontinue, taking these remedies if directed to do so by their physicians. At the time the study was conducted, all the women were using conventional Western treatments (either insulin or oral hypoglycemic medication) (Anderson, Blue, & Lau, 1991; Anderson et al., 1995).

A survey study conducted in Vancouver shows that Chinese immigrants suffering from rheumatologic diseases, fatigue, and stress were more likely to start using traditional Chinese medicine than those with other types of chronic diseases after repeated visits to their family physicians (Wong et al., 1998).

According to immigrant studies conducted in California (Spector, 1996), which has a large Chinese population, many Chinese immigrants with chronic illnesses prefer traditional forms of Chinese medicine and seek help from Chinatown “physicians” who treat them with traditional herbs, acupuncture, etc. Often, the residents of Chinatowns do not seek help from the Western system at all. Others use Chinese methods in conjunction with Western methods of health care (Spector, 1996).

Chinese immigrants often purchase herbs and other patent Chinese medicines in herbal dispensaries; this is also a place where they can compare notes. Because there is no law governing herbal prescriptions, a prescription can be renewed many times. Some herbal formulas of proven efficacy are shared among friends and relatives (Chen-Louie, 1983). With these treatment options, patients with chronic disease usually do not seek medical care from Western or Chinese physicians unless they cannot reduce the symptoms by lay diagnoses and Chinese “prescriptions” (Chen-Louie, 1983).

B. Beliefs about Chinese/Western medicine

Most Chinese immigrants believe that Western medicine is like taking out the stem but not the roots. Chinese medical cures are more like digging up the roots, so that once you remove the root there will not be any more problems (Elfert, Anderson, & Lai, 1991). According to many Chinese immigrants, acute illnesses and those requiring surgery, e.g., appendicitis and gallstones, are best treated by Western medicine. Chinese medicine is usually used to treat conditions with prolonged symptoms (Lai & Yue, 1990). The Chinese also value the wholeness of the body and thus they may avoid surgery because it is a form of mutilation; surgery is resorted to only if all other treatments fail (Lai & Yue, 1990).

C. Barriers to using Western medicine

Chinese immigrants experience many barriers when accessing Western medicine. These barriers make Chinese immigrants hesitant to see a Western doctor (Anderson, Blue, Holbrook, & Ng, 1993; Elfert et al., 1991; Louie, 1985). The following main barriers were identified.

1. Language barriers and lack of knowledge

Language problems and limited education prevent Chinese immigrants from understanding the importance of medical intervention and the nature of the health care system. Research shows that in many cases, they had difficulty gaining access to health

care facilities, learned little from health professionals, and had few resources to help them understand their condition (Anderson, 1993).

These complex issues which add to the burden of living with a chronic illness are not always recognized by health professionals, whose interactions with immigrants often do not involve exploring the social context of the patient's illness. In seeking explanations for immigrants' seeming non-compliance, health professionals may pay little attention to the mediating circumstances of their lives: their working conditions, economic situation or lack of access to health care resources. They may not realize that for many Chinese immigrants, the Western health care system can be perplexing, inconvenient, and appear culturally inappropriate (Hoang, 1985).

Fluency in English was also found to be associated with medication usage, diet management, and appropriate management of blood testing in Chinese immigrant women with diabetes. Also, women with a high degree of knowledge about the disease reported better management practices than women with a poorer level of knowledge (Anderson et al., 1995).

2. Economic status

Some studies show that a high proportion of Chinese immigrants suffer economic hardship (Elfert et al., 1991) because most Chinese immigrant women hold blue collar jobs (Anderson, 1986).

Chinese immigrant women with diabetes had difficulty in visiting a doctor or managing their diet, because the fear of losing their jobs leads them to keep their diabetes

a secret from coworkers and employers. Many Chinese immigrant women who work outside of the home have reservations about disclosing diabetes to coworkers and employers (Anderson, Blue, & Lau, 1991; Anderson, Blue, Holbrook, & Ng, 1993).

D. Social relations

Recent studies on Chinese immigrants' health care utilization suggest that the family plays an important role in how and when Chinese immigrants seek formal health care (Elfert et al., 1991; Dyck, 1992; Leclerc, Jensen & Biddlecom, 1994). In addition, relatives provide information and advice which individuals use to make health care decisions (Leclerc et al., 1994).

III. RESULTS FROM STUDIES OF CHINESE PATIENTS LIVING IN MAINLAND CHINA, TAIWAN AND HONG KONG

This section includes studies regarding illness management and traditional health/illness beliefs among Chinese who are living in mainland China, Taiwan, or Hong Kong.

A. Treatment choice

In Taiwan, Kang, Chen and Chou (1993, 1996) conducted two surveys to investigate the different factors influencing patients' choice of traditional Chinese medicine and/or modern Western medicine. The patients were selected from the outpatient departments of 13 teaching hospitals accepting reimbursement from the Labor Medical

Insurance Plan. Patients who suffered from musculoskeletal problems, respiratory diseases, sense organ problems or skin disorders were most likely to visit traditional Chinese medicine clinics (Kang, Lee, Chen, & Chou, 1993); patients who suffered from endocrine or metabolic diseases were more likely to visit Western medicine clinics (Kang, Chen, & Chou, 1996).

Chiu, C. S. Chen, T. H. Chen, & Ho (1990) found in a recent survey that when the respondents did not know the type of disease they had, 15% would choose Chinese medicine for treatment (Chiu, C. S. Chen, T. H. Chen, & Ho, 1990). The proportion of respondents choosing Chinese medicine would increase to 41% if they had skeletal problems (Chi, 1994).

B. General beliefs about Western/Chinese medicine

With immigrants, Chinese people in their homeland believe that Western medicine is like taking out the stem but not the roots (Elfert et al., 1991). They believe that traditional Chinese healers look more at the functions and balance in the body and see causes of disease in weaknesses, deficiencies, or redundancies of energy (Elfert et al., 1991).

In a national survey in Taiwan about perception of different medical systems, 78% of respondents considered the modern Western medicine treatments as working faster than Chinese medicine. However, even though the majority of these respondents (79%) regarded Chinese medicine as slower to take effect, they perceived Chinese medicine to be more effective than modern Western medicine in treating the cause of diseases. As for

pharmaceuticals, 77% of respondents felt that the side-effects of modern Western medicine are greater than that of Chinese medicine, while 82% believe that Chinese medicine has no side-effects (Chiu et al., 1990). This perception was also found among residents of Hong Kong (Lee, 1978). The main disadvantage of Chinese medicine, according to the respondents, was inconvenience (i.e., too troublesome to prepare medicinal herbs) (Chi, 1994).

Another national survey in Taiwan also compared the perceived effectiveness of Chinese medicine and modern Western medicine in treating chronic disease. While 42% of respondents considered the former to be more effective, 43% of them considered the two systems to have the same effectiveness. Chronic illnesses associated with joint pain or vascular insufficiency were illnesses most frequently treated by Chinese medicine (Chi, 1994).

C. Traditional health beliefs

The Chinese concepts of health and illness are based on the *Yin* and *Yang*: energies or forces that determine the dynamic nature of the universe. *Yin* stores the vital strength of life, while *Yang* protects the body from outside forces. A healthy body has a balance of both; an imbalance of either *Yin* or *Yang* will result in illness. Therefore, to diagnose imbalance and restore balance, a variety of traditional therapeutic techniques are used by the Chinese. Generally, Chinese herbs, acupuncture and moxibustion are believed to have eight categories of functions, which increase, decrease, or neutralize the imbalances of the *Yin-Yang* energies (Louie, 1985; Masi, 1988).

Illness is not only a result of an imbalance of *Yin* and *Yang*, but also the presence of *wind* or *poison*, or *weakness* and *low resistance*. It is believed by Chinese that joint pain can be caused by the *wind* (Chen-Louie, 1983).

In Chinese philosophy, the external force is called *chi* and is considered to be the basic “energy” of the universe. It is believed that disruption of *chi* can upset the harmonious balance of the *Yin* and *Yang* and lead to illness. Loss of blood results in loss of *chi* and can result in either illness or further deterioration of someone already ill (Masi, 1988).

The body is composed of five solid organs (*ts'ang*), which collect and store secretions, and five hollow organs (*fu*), which excrete. The heart and liver are regarded as the noble organs. The head is the storage chamber for knowledge, the back is the home of the chest, the loins store the kidneys, the knees store the muscles, and the bones store the marrow (Spector, 1996).

IV. USE OF CHINESE MEDICINE IN NORTH AMERICA BY THE GENERAL POPULATION

There is an increasing awareness of the use of complementary medicine by patients in North America. A 1992 nation wide population survey in the United States reported that 34% of adults had used at least one complementary therapy in the past year (Eisenberg et al., 1993). A population survey in Canada reported that 22% of the population used one or more unconventional medicines during a six month period in 1993 (Berger, 1993).

According to the 1994-1995 National Population Health Survey in Canada, the age adjusted rates for use of the three leading alternative medicine were 2% for massage therapy, 2% for homeopathy and 1% for acupuncture (Millar, 1997). The 1991 National Survey in U.S. show that the prevalence of use of acupuncture and herbal medicine are about 1% and 3% (Eisenberg et al., 1993).

A 1991 survey in California reported the following major reasons for visiting an acupuncturist by Americans. The largest number reported that they were dissatisfied with Western medical treatment (55.7%), 11.9% came under pressure from friends or relatives, 9.2% reported that they used Chinese medicine as a last resort, and 7% reported that they were attracted by a treatment philosophy that was traditional, holistic or drugless (Anderson, 1991).

The majority of these patients made their decisions without professional input (91%). Only 1.0% came on the recommendation of a medical doctor (Anderson, 1991).

Musculoskeletal problems comprised one-third of the principal reasons for using Chinese medicine. It is equally striking that one-third of all patients had problems that were largely psychiatric or psychosomatic in nature. The rest one-third can be described as general medical problems (Anderson, 1991).

In conclusion, there are not many studies which focus on how and why Western people use Chinese medicine. Anderson's study shows that (1) as with the Chinese, musculoskeletal problems (include OA and RA) are the principal reasons for American people using Chinese medicine and, (2) that although many patients in North America use

Chinese medicine, physicians still lack awareness of the usefulness of it and usually do not recommend that their patients use it.

V. FRAMEWORKS REGARDING ILLNESS MANAGEMENT

Because there are no conceptual frameworks of illness behavior that apply to Chinese immigrants living with arthritis/chronic diseases, the researcher also reviewed existing general theories of health-related behavior to assess if they could explain illness management in Chinese immigrants.

A. Cognition models and social cognition models

Fourteen promising general behavioral theories that have had the biggest impact on health-related behavioral (health behavior, illness behavior, and sick role behavior) were reviewed. These models were divided into cognition models and social cognition models .

Cognition Models examine the predictors and precursors to health behaviors. They are derived from subjective expected utility theory (Ogden, 1996). Cognition Models such as the **Health Belief Model** (Rosenstock, 1990) and **Protection Motivation Theory** (Rogers, 1975; 1983; 1985) describe behavior as a result of rational information processing and emphasize individual cognitions, not the social context of those cognitions (Ogden, 1996). According to the **Health Belief Model**, if an individual takes action to prevent a disease, two main factors involved are: (1) the disease must be perceived as one having severe or serious consequences, and (2) the individual must believe that the

recommended action will be effective in reducing the perceived health threat (Rosenstock, 1990).

Social Cognition Models not only examine factors which predict behavior and/or behavioral intentions but also they examine why individuals fail to maintain a behavior to which they are committed (Ogden, 1996). These models, for example, **The Health Action Process Approach** (Schwarzer, 1992) and **An Illness Behavior Model** (McHugh & Vallis, 1986), attempt to place the individual within the context both of other people and the broader social world. **The Health Action Process Approach** specifies self-efficacy, outcome expectancies and a subset of social outcome expectancies, and threat appraisal as factors determining whether or not to carry out a behavior. **The Illness Behavior Model** (McHugh & Vallis, 1986) includes four areas which influence illness behavior (1) symptoms; (2) the cognitive processes whereby bodily symptoms are interpreted; (3) the context of individuals' emotional states and concurrent environmental events; and (4) the ethnocultural influences that pervade all facets of human behavior.

There are a number of theories which emphasize the influence of cultural factors on help-seeking behavior (Good, B. & Good, M, 1981; Kleinman, 1980; Toumishey, 1993). According to Toumishey's help-seeking behavior model, help-seeking behaviors are essentially culturally determined. There are three major components which are common to all cultures: culture, values and beliefs, and intercultural communication. Culture is the dominant factor which underlies health values, beliefs and behavior, the etiology of disease and illness and the interpretation of these phenomena (Toumishey, 1993).

B. Relevance of stated theories to research purpose

None of the conceptual frameworks reviewed were fully applicable for the purpose of this research. *First*, most of the theories and models were designed to identify the factors underlying utilization of Western medicine by Caucasians, whereas the major purpose of this study was to explain what management strategies Chinese immigrants use and, how and why they use them. In addition, interactions between different management strategies is of importance.

Second, although some theories, e.g., Toumishey's help-seeking behavior model (Toumishey, 1993), emphasized the importance of cultural factors in illness behavior, they were not fully useful in explaining how and why cultural factors play a role in the management strategies people with different backgrounds use. In addition, these models were designed with a strong purpose of optimizing patient care by encouraging Western health practitioners to educate themselves as to the types of cultural beliefs common to their patient population. The researcher did not wish to be constrained by this type of model because it would limit the depth and breadth of the framework to be developed.

VI. CONCLUSION

In this chapter, background knowledge about illness management in Chinese immigrants with arthritis/chronic diseases, and frameworks regarding illness management were reviewed. Due to the fact that none of the theories seemed fully appropriate for the researcher's purpose, study objectives were selected to develop a substantive theory

regarding illness management strategies among Chinese immigrants living with arthritis.

Although the researcher did not want to start with existing theories or variables (categories), some components of the existing models show up over and over in the literature and thus appear to be significant (e.g., perceived seriousness of disease X). These components stimulated the researcher to generate some questions for the interviews, to see whether or not they apply to Chinese immigrants.

Following description of the model, more literature will be reviewed in chapter 5 (Discussion) as a source of data to verify and elaborate categories (Chenitz & Swanson, 1986). The review will be specific and focused. Some components of the informal, substantive model will also be compared with the components of existing formal behavior models. Then the developed theory will be presented in the context of other work.

CHAPTER 3

STUDY METHODS

The information in this chapter describes the study design, study participants, data collection, data analysis, data quality, and ethical issues.

I. STUDY DESIGN

This study uses a qualitative approach with the purpose of developing a substantive grounded theory about illness management strategies among Chinese immigrants living with arthritis. Qualitative data consist of information collected in the course of a study that is in narrative (nonnumerical) form, such as the format of an unstructured interview (Polit & Hungler, 1991). Qualitative analysis consists of the organization and interpretation of non-numerical observations for the purpose of discovering important variables and underlying patterns of relationships (Polit & Hungler, 1991). According to Mays and Pope (1995), qualitative research is a way of developing concepts to deal with social phenomena in natural (rather than experimental) settings. This emphasizes the meanings, experiences, and views of all the participants (May & Pope, 1995). Qualitative studies are concerned with answering questions such as, what is X and how and why does it vary with different circumstances. The strengths of qualitative methods are that they generate rich, detailed, and valid process data which leave the study participants' perspectives intact. Qualitative methods also provide contextual

understanding of health behavior by exploring complex phenomena not amenable to an analysis by quantitative research (Steckler, McLeroy, Goodman, Bird, & McCormick, 1992).

This study used a qualitative method to explore the conditions which influence the relevant phenomenon, i.e., illness management. The specific qualitative approach used in this study is grounded theory. This approach is a method that links analysis with data collection and uses a systematically applied set of methods to generate an inductive theory about a substantive area (Glaser, 1992). The grounded theory approach was chosen as opposed to other qualitative methods because its purpose is to discover underlying social forces that shape human behavior (Liehr & Marcus, 1994). Grounded theory is a powerful way to develop a rationale to explain everyday reality. Therefore, grounded theory is appropriate given the researcher's purpose to identify underlying factors that shape immigrants' illness management.

II. THE STUDY SAMPLE

A. Selection criteria for participants

Participants for this study were 19 Chinese immigrants with medically diagnosed and/or self-reported osteoarthritis/rheumatoid arthritis (OA/RA), who consented to participate in this study. In general, these patients with OA/RA were diagnosed by Western or Western-trained physicians. Chinese medical practitioners diagnose patients with arthritis symptoms as *flaccid paralysis*, indicating that symptoms (which are similar in OA/RA) are caused by cold and damp environments.

The reasons for choosing patients with OA and RA for the study is that these two types of arthritis represent, by far, the most common form of arthritic affliction in the general population. In addition, these two groups tend to use different illness management strategies (B. H. Ma & J. H. Yang, personal communication, December, 1996).

B. Sampling

A combination of purposive and snowball sampling techniques were used for this study. Purposive sampling is based on the beliefs that a researcher's knowledge about the population can be used to subjectively choose the cases to be included in the sample (Polit & Hungler, 1995). The purpose of using this sampling type was to select the widest possible variety of respondents (e.g., samples were collected from Western specialists, traditional Chinese healers, Chinese churches, and some Long Term Care Facilities. See detail in section C: Recruitment). Snowball sampling is based on asking individuals initially selected in the sample to identify and refer other people who meet the eligibility criteria (Polit & Hungler, 1995). The researcher believed that it would be difficult to select patients only through professional contacts (such as Chinese healers), because many arthritic Chinese immigrants do not necessarily use any medical services; therefore the use of snowball sampling was included as well.

In order to maximize variations in disease status, *The Dimensions of Health Outcomes: The Health Assessment Questionnaire, Disability and Pain Scales* (Fries, Spitz, & Young, 1982) were used to assess both RA and OA patients' degree of disability and pain after each interview. The disability scales include 8 component sets (dressing,

arising, eating, walking, hygiene, reach, grip, activities). The scoring system was based upon the highest abnormal response in each component. Patients who scored between 0 to 0.7, 0.8 to 1.2 and higher than 1.3 on the Index of Disability were defined as mild, fairly serious, or serious respectively. The pain scale runs from 0 to 100. 0 means no pain, 100 being the most intense pain experienced. The HAQ disability and pain scales are widely used to measure both RA and OA patients' disability index. They are presently available for use in clinical practice and clinical trials (Fries et al., 1982).

In the initial immigrant interviews, the researcher was interested in uncovering as many potentially relevant categories as possible (Strauss & Corbin, 1990). Later, the concentration was on development, density, and saturation of categories; therefore the researcher gathered data systematically on each category. During the data collection and analysis process, theoretical saturation became the criterion in determining when to stop searching for new participants. Theoretical saturation means, "until: (1) no new or relevant data seem to emerge regarding a category; (2) the category development is dense, insofar as all of the paradigm elements are accounted for, along with variation and process; (3) the relationships between categories are well established and validated" (Strauss & Corbin, 1990, p.188).

C. Recruitment

First, a letter and a consent form (see appendices 1 & 2) which included a self-addressed, stamped envelope, were circulated by eight Chinese healers to possible participants, describing the research, the voluntary nature of their participation and their

rights as research subjects. The letter was written in both Chinese and English. When using snowball sampling, the first participants identified and referred others with arthritis. The recruitment letter was then circulated by these early participants.

After having completed the initial immigrant interviews and created categories, the letter was circulated by two Western physicians who have Chinese patients, four Chinese healers, a Chinese church official, and a coordinator of the Bethany Care Center, Calgary to potential participants, for the purpose of achieving maximum variation of sampling.

After the initial interviews, the researcher recognized that most of the early respondents did not have a serious condition, and since severity of disease may be very influential on patients' beliefs and management strategies, it became essential to search out those with a severe condition. In later sampling, the researcher specified to those who circulated the consent letters a need for patients believed to have a serious condition.

Also, after the initial interviews, the researcher recognized that a few patients were unable to verbalize their beliefs well. Because information on beliefs is a major interest of this study, the researcher explained to those who circulated the consent letters that she needed patients who could express their feelings and experiences clearly (which usually equates to the ability to explain beliefs).

The researcher contacted each patient by phone after receiving the consent letter or phone call indicating that they were willing to participate in the study. In dealing with later respondents, she talked with them for a longer time (than had been done with initial respondents) about their symptoms and feelings/experiences regarding medication they

had used. During a 10 minute conversation, the researcher obtained a basic idea about the participants' ability to verbalize about their illness and feelings.

Most of the later respondents met the selection criteria and were able to explain their beliefs and feelings. Only one elderly lady was not very suitable for an interview because she did not have clear enunciation. However, the researcher decided to interview her anyway because (1) she has a long experience with arthritis. Therefore, it was possible to obtain useful information about management strategies and (2) her daughter understands her speaking style and could translate during the interview. Therefore, the researcher believed that she would be able to obtain relatively accurate information regarding management strategies although the accuracy of the description of beliefs might be influenced because of translation.

III. DATA COLLECTION

A. Interview structure

Each of the 19 respondents was asked to participate in an in-depth, open-ended interview. The average length of the interview was estimated to be one hour. All interviews were conducted in Chinese, except one, because the respondent was a second generation Chinese Canadian unable to speak Chinese, and so, English was used. All interviews were audio-taped. One audiotape was used for each interview. Interview locations were determined by the participants.

An interview guide was developed at the onset and included questions which examine how Chinese immigrants with arthritis manage their illness and what the

important factors are which influence the management of their illness. The guiding questions were as follows:

- 1 Can you tell me about your symptoms?
- 2 What did you do when the symptoms started?
- 3 Of the things that you have tried, which do you believe are helpful/non-helpful?
- 4 How do you believe that you acquired arthritis?
- 5 How is your daily life affected by arthritis?
- 6 Tell me your feelings about Western medicine and Chinese medicine.
- 7 Do you believe that your particular type of arthritis can be improved by either Chinese treatment or Western medicine?
- 8 How have your family members, relatives or friends helped you in the daily management of your illness?
- 9 What difficulties have you had in managing your disease?
- 10 If you could design/create the ideal treatment strategy for your condition, what would it be?

In order to describe the participants and to enhance maximum variation, the interview also included socio-demographic characteristics including age, language, education, occupation, marital status, immigrants' place of origin, length of time in Canada, and disease status. Then the researcher reviewed these characteristics and checked whether in fact maximum variation was obtained.

B. Interview strategy

A conversational tone was set for the interview. The order and phrasing of the questions remained flexible. Through guiding questions, the respondents were encouraged to answer all questions freely and to ask questions as desired. They were assured that there were no “right” or “wrong” answers (Chenitz & Swanson, 1986). During the interviews, the researcher was cautious to avoid introducing concepts if the respondents had not previously introduced them.

Probes were used to encourage the respondents to tell more of their experience or provide further description. Four types of probes were used during the interviews: “chronology (... and then?; when was that?), detail (tell me more about that; that is very interesting;), clarification (I do not quite understand; earlier you said...), and explanation (Why?; how come?)” (Schatzman & Strauss, 1973, p. 74).

A general statement was sometimes used to give the respondent assurance that his or her concerns were reasonable and were the concerns of others as well, without tending to be leading. For example, “Some people express concerns about..... What are your concerns in this area?” (Chenitz & Swanson, 1986).

The *Funnel/inverted funnel* approach was used when the informants gave little information answering the guide questions. “In the funnel approach, the interviewer starts with a general question, and follows up with more specific questions.” (Chenitz & Swanson, 1986, p. 74). For example, when the researcher asked the informants a fairly specific question such as: “How have your family members, relatives or friends helped you in the daily management of your illness?”, many of them answered in a very simple way

such as, “I decided to do everything myself” or “my family member/friends do not really care about my situation”. In order to obtain more detailed information, the researcher always discussed the patients’ daily life first (e.g., social activities). After obtaining a general picture of the informants’ daily life, the researcher followed with more specific questions relating to the external factors which influenced the informants’ illness management.

When patients were unable to express their feelings related to a general question such as beliefs about Chinese/Western medicine, the interviewer used the inverted funnel approach which started with specific questions and followed with more general questions (Chenitz & Swanson, 1986). For example, the researcher asked about the informants’ personal experience with Chinese/Western doctors when they lived in mainland China, then asked about their experiences in Canada. In this way, the informants’ train of thought led to a more general verbalization about Western and Chinese medicine/physicians.

IV. DATA ANALYSIS

Generally speaking, all transcription and analysis was first done in Chinese. Then, the researcher translated the data into English and entered it into the computer. Quality of the translation was checked by three Chinese colleagues (see the details in section VI). The reason for first analyzing, then translating, was because all the transcriptions are in Chinese and using Chinese is more natural and convenient for the researcher during the thinking process. Also, analyzing first can make later translations more accurate as to the Chinese meaning.

A. Transcribing interview materials

After each interview, the researcher listened to the tapes and transcribed verbatim what each patient said. During the manual process for each respondent's file, many conceptual headings were developed. Then all relevant materials relating to the concepts/topics were inserted into the file. This retrieval process was long and arduous, but from the researcher's view point, absolutely necessary.

According to Strauss, the actual transcribing could be **selective**. The very first interviews could be entirely transcribed and analyzed before going on to the next interviews. Later, only materials relating to the evolving theory need to be transcribed (Strauss & Corbin, 1990). The researcher decided to transcribe all interview materials for the following reasons: (1) difficulty in making a decision to transcribe only as much as is needed; and (2) inexperience in using grounded theory method to conduct a study.

B. Revising interview questions

By reviewing the transcribed verbatim reports and thinking about the probes after every interview, the researcher listed concepts that were relevant to the subject of research. Then, new questions or rephrasing of questions were constructed in order to obtain fuller information, or to make the interviewee more comfortable.

C. Developing codes and categories

After each interview was entirely transcribed, open coding was conducted. Open coding is the part of the analysis that pertains specifically to the naming and categorizing of phenomena through close examination of data (Strauss & Corbin, 1990).

The analyst broke the data down into bits and pieces by reading the data line by line and paragraph by paragraph, looking for an event or idea. Each event or idea was then coded as a concept¹ or abstraction of the data (Chenitz & Swanson, 1986). For instance, statements such as “Usually I am unable to squat down and stretch my arms,” or “It is also difficult to flex my index finger and thumb”, were coded as **activity limitation**, although the words **activity limitation** had not been used by any respondents. Statements such as “The major reason I believe that I got RA is because I lived in a place that was damp and dark for many years,” or “I did not take adequate care of myself after I gave birth to a child. This is the reason I believe that I got RA,” were coded as **contributory factors of arthritis**. Then subheadings such as “catching a cold”, “inadequate post-natal care,” were coded directly under **contributory factors of arthritis**.

The researcher’s study purpose was to develop a theory, thus identifying abstract categories² was necessary. Important concepts that emerged from the data formed the basis for a category system. The process of grouping concepts that seem to pertain to the same phenomena is called categorizing (Strauss & Corbin, 1990).

¹ *Concepts*: Conceptual labels placed on discrete happenings, events, and other instances of phenomena (Strauss & Corbin, 1990, p. 61).

² *Category*: A classification of concepts. This classification is discovered when concepts are compared one against another and appear to pertain to a similar phenomenon. Thus the concepts are grouped together under a higher order, more abstract concept called a category (Strauss & Corbin, 1990, p. 61)

Some concepts emerged under a more abstract concept and were then grouped to form a category. For example, concepts such as **activity limitation**, **intensity**, or **duration** belong to the broader concept **symptoms**, thus **symptoms** as a category was created.

One of the fundamental features of the grounded theory approach is that data collection and data analysis occur simultaneously. A procedure referred to as *constant comparison* was used to analyze interviews (Polit & Hungler, 1995). As analysis proceeded, the categories which emerged from the data were constantly compared with data obtained earlier in the data collection. The existing categories were therefore continuously expanded or merged and new categories developed.

D. Themes

“Themes often develop within categories of data (i.e., within categories of the coding scheme used for indexing materials) but sometimes cut across them.” (Polit & Hungler, 1995, p. 527).

Common themes emerged within categories and became clear during the analysis process. Themes were not identified as important until they emerged three or four times. By discovering commonalities across subjects (searching themes), the researcher began to recognize relationships within the data.

Those themes were used to describe each category and subcategory. Some of the themes became names of subcategories or headings of descriptions, while others were placed under subcategories and became the content that described the subcategories. For

example, the theme, **excessive dependence on diagnostic tools**, was placed under the subcategory, **lack of trust in Western physicians**. These themes formed the basis for establishing relationships within the data.

Then the researcher evaluated whether or not the themes were an accurate representation of the perspectives of those interviewed. A second reading of the narrative materials was done to see if the materials matched the themes. Some themes were refined since they were incongruent with the materials.

E. Theoretical coding

After categories were created by open coding, theoretical coding was conducted by making connections between categories and their subcategories. That means arranging categories around core category: illness management strategies.

Grounded theory links categories in a set of relationships denoting causal conditions, phenomenon, context, intervening conditions, action/interactional strategies, and consequences (Strauss & Corbin, 1990). The definition of terms is as follows:

Causal Conditions: Events, incidents, happenings that lead to the occurrence or development of a phenomenon.

Phenomenon: The central idea, event, happening, incident about which a set of actions or interactions are directed at managing, handling, or to which the set of actions is related.

Context: The specific set of properties that pertain to a phenomenon; that is, the locations of events or incidents pertaining to a phenomenon along a dimensional range. Context

represents the particular set of conditions within which the action/interactional strategies are taken.

Intervening Conditions: The broad structural conditions bearing on action/interactional strategies that pertain to a phenomenon. They facilitate or constrain the strategies taken within a specific context.

Action/Interaction: Strategies devised to manage, handle, carry out, respond to a phenomenon under a specific set of perceived conditions.

Consequences: Outcomes or results of action and interaction (Strauss & Corbin, 1990, p. 96).

The researcher did not follow Strauss's conditions (*context* and *intervening conditions*) rigorously because *first*, "context" is defined as a set of very specific properties (locations or events) that pertain to a phenomenon. As a result, only one category (i.e., symptoms) which emerged from this study was denoted as "context".

Second, the "intervening conditions" were defined as "broad structural conditions". "Broad structural conditions" is too general a concept for analyzing and differentiating the factors which had different degrees of impact on the management strategies which emerged from this study.

Therefore, the researcher changed Strauss's conditions to two basic types of influential factors: *Factors directly impacting on illness management* and *Factors indirectly impacting on illness management*. Factors which directly impact on illness management such as cost, affect action/interaction intensely. Factors which indirectly

impact on illness management, such as general beliefs about Western medicine, refer to the conditions within which illness management takes place in the larger sense.

Because “arthritic symptoms” in the present study are the central event relating to actions/interactions, the researcher used the component “arthritic symptoms” instead of Strauss’ components “causal conditions” and “phenomenon”. In addition, the term “impact” was used instead of “consequences”, in order to facilitate understanding.

Many different categories which were identified during open coding, were systematically rearranged in order to make connections between categories. As a result, some categories pertained to arthritic symptoms while others referred to factors directly/indirectly impacting on illness management. Still other categories denoted action strategies used to manage, handle, or respond to symptoms. Finally, some categories referred to the impact of action/interaction.

Statements regarding theoretical relationships under varying contextual conditions were ultimately developed by laying out the theory narratively and diagrammatically. Such statements were then checked against each interview to determine whether or not they fit.

F. Field notes

In order to keep an account of the developing theory, the researcher has completed approximately 400 pages of handwritten Chinese field notes done during the interview time or immediately after the interview. These notes are descriptive and analytical.

Descriptive notes include the researcher’s personal experiences, perceptions, impressions and thoughts of the interview through watching and listening. Non-verbal

cues, such as facial expressions, or a speaking manner used by the respondents were also noted. These non-verbal cues stimulated the researcher to probe until the matter was clarified.

Analytical notes clearly stated the conditions before actions taken by immigrants. The notes arranged every transcribed interview into a manageable format. The data were sorted out into certain categories, extended and merged existing categories, and developed new categories by using a constant comparative method.

Analytical notes also include emerging themes or relationships, the deriving process of hypotheses, and how the hypotheses were compared, verified, modified, or changed as new data come in.

V. DATA COLLECTION FROM MAINLAND CHINA

In September, 1997, the researcher visited Harbin, China, which presented an opportunity to collect background information as comparative data for the immigrant study. For example, learning how mainland Chinese with arthritis manage their illness, and what relevant variables are which influence their management strategies. Through the office of a rheumatologist, a vice-president of the Medical University, Harbin, and a cadre (someone in charge of a residents' committee), the researcher was able to interview seven patients with either mild, fairly serious, or serious RA or OA.

The interview structure, guiding questions, interview strategy and data analysis were similar to that done in Calgary. The researcher analyzed the data obtained from the

mainland China patients separately from the data obtained from the Canadian immigrants, using the same coding strategies.

The themes which emerged from mainland China stimulated the researcher to develop new themes from the immigrant data which were later tested in the immigrants' interviews. The themes also inspired the researcher to further identify subcategories of categories developed from the immigrant data, and caused a re-thinking of the immigrants' specific conditions. The information was integrated into categories developed from immigrants' data, as a section of supporting background information or comparison.

VI. DATA QUALITY

Lincoln and Guba (1985), proposed four criteria for assessing the "trustworthiness" of qualitative research. These four criteria are: confirmability, dependability, credibility, and transferability (Lincoln & Guba, 1985).

A. Confirmability(objectivity)

Guba and Lincoln suggest that confirmability be the criterion of neutrality in qualitative research. This refers to the findings themselves, not to the subjective or objective stance of the researcher (Sandelowski, 1986).

The researcher's responses to address issues related to confirmability were: (1) findings were supported by individual quotes; (2) transcripts and preliminary findings were reviewed by the researcher's supervisor and two experts in order to check the research process, to check how and why the hypotheses were formulated and supported, to check

the preliminary categories developed from open coding, and to check the shift from open coding to theoretical coding; (3) three experts were asked to review and code some transcripts of interviews. Then the researcher checked the coding against the established codes. Their codes were very similar to the established codes; and (4) the researcher will retain the tapes, transcripts, field notes, preliminary findings, conclusions, and final report for possible re-analysis.

B. Dependability

Guba and Lincoln proposed that the dependability criterion relates to the consistency of qualitative findings. Guba used the term 'auditable' to describe the situation in which another researcher can clearly follow the decision trail used by the investigator in the study (Krefting, 1991).

In order to address this issue, (1) the researcher used the same basic interview guide for all interviews. The interview guide is a consistent foundation for the interviews; and (2) the researcher conducted a code-recode procedure from some important informants' data (participants who provided sufficient representative data). This procedural step made coded information consistent. Obviously, the coding by the three experts contributed to consistency as well.

C. Credibility

Credibility, the truth value of a qualitative investigation, generally resides in the discovery of human phenomena or experiences as they are lived and perceived by subjects,

rather than in the verification of a priori conceptions of those experiences (Sandelowski, 1986). “When a qualitative study presents such accurate descriptions or interpretations of human experience that people who also share that experience immediately recognize the descriptions, it is credible” (Krefting, 1991, p. 221).

The researcher’s responses to address issues related to credibility were: (1) *Conducting a member check*. At the end of the analysis, the researcher sent a summary of the findings, in Chinese, to five informants with different disease status to see if they regard the findings as a reasonable account of their experience (Mays & Pope, 1995). After two weeks, the researcher phoned those participants to encourage them to offer suggestions that might support or contradict this analysis. All reported the findings are an accurate account of their experience. Although some did not have specific experience regarding some findings, they believed that the findings were generally reasonable. Because all five informants agreed with the results, the researcher felt that she did not need to send summary findings to every informant interviewed; (2) *Having transcripts reviewed by experts* (see section A, responses 2 & 3); (3) *Considering language issues*. The researcher considered Chinese expressions and communication styles, as well as culturally specific understandings when she interpreted and translated the data. Also, in order to make sure the researcher’s translations into English reflect the Chinese meaning, two Chinese colleagues (both of whom have Ph.D. degrees issued in Canada) were asked to check two interviews (#2 and #4) which had been entirely translated verbatim. They commented that the researcher’s translation was at a very good to excellent level and put this in writing. Another Chinese colleague was asked to translate some paragraphs of the

transcripts from Chinese to English. Then these translations were also compared with the researcher's. The outcome of his translation was very similar to that of the researcher; and (4) *Revising the interview guide*. When necessary, the interview guide was revised before each interview in order to make the interviewee more comfortable and, because new concepts emerged from the previous data, revising the interview guide is anticipated in qualitative research.

D. Transferability/fittingness

Guba proposed an alternative perspective on applicability in qualitative research by referring transferability, or fittingness, as the criterion against which applicability of qualitative data is assessed (Krafting, 1991). Research meets this criterion when the findings fit into other contexts that are determined by the degree of similarity between the two contexts (Krafting, 1991).

Lincoln and Guba presented that it is not the qualitative researcher's job to provide an index of transferability; it is his responsibility to provide sufficient descriptive data to allow transferability judgments to be made by other researchers (Krafting, 1991)

The researcher's major responses to address issues related to transferability are: (1) during data collection and analysis, the researcher made significant effort to determine if the beliefs, behaviors, and observed events are typical or atypical of the lives of the informants; (2) the researcher provided background information about informants, and (3) the researcher provided background information from mainland China in order to increase

the understanding of information obtained from the Chinese immigrants. These three activities will allow others to assess how transferable the findings are.

VII. ETHICAL ISSUES

The researcher considered these ethical issues: *First*, participation in this study was entirely voluntary. A letter (plus a consent form) that described the purpose of the study and what they would be asked to do if they decided to be part of the study, and assured confidentiality, was distributed to potential Chinese immigrants. Interviews were only conducted after the researcher obtained consent from the participants. In mainland China, the researcher also obtained consent from the patients before the interview. The rheumatologist introduced some patients to the researcher in the wards of the hospital. After reading the distributed letters, all of the patients signed the consent form. *Second*, in order to protect the confidentiality of interviewees, the information will not identify the respondents in anything the researcher writes about the study (e.g., the sources of quotations are not provided). *Third*, even though the individuals agreed to participate, they had the freedom to change their minds or to withdraw from the research at any time. *Fourth*, participants received a summary of the research results at the end of the study. *Fifth*, when the individuals had questions regarding the research or their participation, the researcher answered their questions. *Finally*, tapes and transcripts are kept in a locked cabinet.

Ethical approval of this study was obtained from the Conjoint Health Research Ethics Board of the University of Calgary prior to proceeding with the study.

CHAPTER 4

RESULTS

In this chapter, first, a description of the study samples, and a list of emergent categories/subcategories which came from open coding will be presented. Then a detailed description of these categories/subcategories will be presented in systematic order.

I. DESCRIPTION OF THE STUDY SAMPLES

The first interview was held in Calgary, on May, 21, 1997. By the end of November, 1997, a total of 16 Chinese immigrant women and three men had been interviewed, with ages ranging from 20 to 85, and with different types and severity of arthritis. Their length of stay in Canada ranged from 2 years to 25 years. Only one is a second generation Chinese Canadian.

The seven mainland Chinese participants (five women and two men) were interviewed in China, between September 12th and 26th, 1997. They had more serious conditions than the immigrants.

Theoretical saturation occurred at the end of the 15th immigrant interview. In order to validate the interview data and focus on some key questions more in-depth, the researcher purposely interviewed four more eligible respondents who were willing to participate. The researcher also re-interviewed the first respondent because the questions

developed in the later interview stage changed and she was an articulate and agreeable respondent.

Demographic data were collected from the 19 immigrants and 7 mainland patients on age, sex, language spoken, education, employment status, marital status, country of immigrants' origin, and disease status. Table 1 and 2 present this information.

Table 1. Demographic characteristics of study participants

AGE	# Immigrants	# Mainland Patients
<30	1	0
30-39	2	2
40-49	7	1
50-59	0	2
60-69	3	1
>70	6	1

SEX	# Immigrants	# Mainland Patients
Female	16	5
Male	3	2

LANGUAGE	# Immigrants	# Mainland Patients
Chinese only	9	7
Chinese and English	9	0
English only	1	0

EDUCATION	# Immigrants	# Mainland Patients
<Junior high school	3	1
Junior high school	4	1
High school	1	1
College	3	2
University	5	2
>University	3	0

EMPLOYMENT STATUS	# Immigrants	# Mainland Patients
Homemaker	14	4
Student	1	0
Health related	1	1
Computer Programmer	1	0
Industrial worker	2	1
Government official	0	1

MARITAL STATUS	# Immigrants	# Mainland Patients
Married	11	7
Divorced	2	0
Widowed	4	0
Single	2	0

COUNTRY OF ORIGIN	# Immigrants	# Mainland Patients
Mainland China	8	7
Taiwan	3	N.A.
Hong Kong	5	N.A.
Vietnam	3	N.A.

Table 2. Disease status of immigrants and mainland patients

IMMIGRANTS' DISABILITY STATUS			
	OA ¹	RA ²	AS ³
Mild (HAQ ⁴ : 0-0.7)	7	1	0
Fairly serious (HAQ: 0.8-1.2)	3	4	0
Serious (HAQ: >1.3)	1	2	1

¹ OA: osteoarthritis

² RA: rheumatoid arthritis

³ AS: ankylosing spondylitis (a kind of RA)

⁴ The Dimensions of Health Outcomes: The Health Assessment Questionnaire, Disability and Pain scales.

MAINLAND PATIENTS' DISABILITY STATUS			
	OA	RA	(AS)
Mild (HAQ: 0-0.7)	0	1	0
Fairly serious (HAQ: 0.8-1.2)	0	2	0
Serious (HAQ: >1.3)	1	1	2

IMMIGRANTS' PAIN SCALE SCORES					
	0-20	30-40	50-60	70-80	90-100
Arthritic flare-up	0	0	4	6	9
In a normal condition	5	8	6	0	0

MAINLAND PATIENTS' PAIN SCALE SCORES					
	0-20	30-40	50-60	70-80	90-100
Arthritic flare-up	0	0	1	2	4
In a normal condition	0	2	4	1	0

The three participants with AS were also assessed with the HAQ scales because AS is regarded as being under the wing of RA.

In a normal condition, most of the patients' pain scores are below 60. Patients with a serious condition usually rank around 50-60 with some degree of swelling, stiffness, and visual signs of arthritis. Patients with a mild condition usually have no symptoms. *During an arthritic flare-up*, most of the patients' pain scores are above 60. Some patients with serious conditions rank between 90-100 with swelling, stiffness, and visual signs (off color, deformed joints, walk with a limp, etc.).

These results show that maximum variation was achieved to a major degree in the sampled group, as demographics and disease status varied.

Due to the fact that the consent letter was circulated by Chinese healers, Western physicians, etc., it is not known how many patients were requested to participate and how many refused to participate or were not interested in the study.

II. EMERGENCE OF CATEGORIES AND SUBCATEGORIES FROM OPEN

CODING

Twelve categories and their subcategories emerged after the open coding process, and 33 themes emerged within the categories. These themes were used to describe each category and subcategory. Some of the themes became names of subcategories, or headings of descriptions. Table 3 lists the categories, major subcategories and descriptions.

Table 3. Emergence of categories, subcategories, and descriptions

Emergence of Categories, Subcategories, and Descriptions		
CATEGORIES	SUBCATEGORIES	DESCRIPTIONS
Arthritic Symptoms	Mild condition	-HAQ scale
	Fairly serious condition	-Pain scale
	Serious condition	-Activity limitation -Location -Duration -Variation
Beliefs about arthritis	Perceived contributory factors of arthritis	-Being chronically cold. -Inadequate post-natal care. -Aging, etc.
	Perceived seriousness of arthritis	-Belief that arms or legs are less important. -Beliefs about arthritic pain. -Arthritis does not influence life span.
	Activities perceived to be improving on arthritic condition	-Keeping warm. -Doing exercise. -Reducing stress. -Changing bad life habits. -Improving a negative mind-set.
External factors	Friendship support	-Information about: -Family doctor. -Specialist. -Chinese healer.
	Family support	-Choosing specialists. -Making medical appointments.
Beliefs about Western Medicine (W.M.)	Advantages of W.M.	-Scientific methods. -Surgery is helpful.
	Ill effects of W.M.	-Causes are ignored. -Not effective for chronic diseases.

Emergence of Categories, Subcategories, and Descriptions		
CATEGORIES	SUBCATEGORIES	DESCRIPTIONS
Beliefs about W.M. based on treatment experience	Ineffectiveness of W.M for arthritis.	<ul style="list-style-type: none"> -Cause of RA is unknown. -Lack of specific treatment for arthritis. -Side effects. -Short-term efficacy. -Unnecessary surgery.
	Lack of trust in Western physicians	<ul style="list-style-type: none"> -Excessive dependence on diagnostic tools. -Do not pay attention to patients' explanations. -Prefer more positive, dialectical explanations by physicians.
Perceived barriers to using W.M.	Lack of knowledge about W.M.	<ul style="list-style-type: none"> -Language problems. -Do not know the name and function of medication. -Lack information about Western doctors.
	Cost Worry about job loss	
Beliefs about Chinese medicine (C.M)	Advantages of C.M.	<ul style="list-style-type: none"> -Effective for chronic diseases. -Treats causes. -No side effects.
	Disadvantages of C.M.	<ul style="list-style-type: none"> -Curative effects are delayed. -Inconvenient.
Beliefs about C.M. based on treatment experience	<ul style="list-style-type: none"> - Placing hopes in excellent Chinese doctors -Obscure treatment methods of C.M. 	<ul style="list-style-type: none"> -Reputation -Experience -Specific training -Methods of diagnosis -Secret recipes -Concoctions -Enigmatic interpretation

Emergence of Categories, Subcategories, and Descriptions		
CATEGORIES	SUBCATEGORIES	DESCRIPTIONS
Perceived barriers to using C.M.	Cost	-For immigrants who came from mainland China & Vietnam. -For immigrants who came from Hong Kong & Taiwan.
	Lack of excellent Chinese doctors	-Superficial knowledge. -Passive activities.
Beliefs about Combining W.M. and C.M.	Off-set each other's deficiencies. Examining illness from various angles.	
Illness management strategies	Self-care remedies	-Self-care remedies before treatment. -Self-care remedies as a supplementary treatment.
	Consulting Western physicians	-Reasons for consulting Western physicians. -Compliance with Western physicians' recommendations.
	Consulting Chinese doctors	-Short time usage. -Long periods of treatment.
	Combination	-Anti-inflammatory drugs & herbal medicine. -Acupuncture, massage, & aspirin. -Triterygium wilfordii Hook F & Apo-Naproxen. -Physiotherapy & acupuncture. -Acupuncture & analgesics.

Emergence of Categories, Subcategories, and Descriptions		
CATEGORIES	SUBCATEGORIES	DESCRIPTIONS
Outcomes of strategies	Effectiveness of Self-care remedies	<ul style="list-style-type: none"> - Exercise: feeling much better but not cured. - Keep warm methods: improved symptoms. - Chinese plasters: short-term efficacy.
	Effectiveness of Western medicine	<ul style="list-style-type: none"> -Analgesics: short-term efficacy; side effects. - Injection: short-term efficacy; strong side effects. -Anti-inflammatory drugs & Indomethacin: alleviates symptoms; side effects. -Methotrexate or Cortisone: improved symptoms; strong side effects. -Physiotherapy: temporary effects or alleviates symptoms; no side effects.
	Effectiveness of Chinese medicine	<ul style="list-style-type: none"> -Acupuncture: alleviates symptoms; no side effects. -Massage: alleviates symptoms; no side effects. -Natural herbs: not effective.
	Effectiveness of Combination	<ul style="list-style-type: none"> -Successful treatment results

III. DELINEATION OF CATEGORIES AND THEIR SUBCATEGORIES

All categories/subcategories which were identified during open coding, were then systematically rearranged in order to identify relationships between categories and their subcategories (theoretical coding). This section describes each category and their

subcategories in the following order: *First*, arthritic symptoms which directly lead to illness management strategies. *Second*, factors indirectly impacting on illness management strategies. These are: beliefs about Western medicine, beliefs about Chinese medicine, beliefs about the combination of Western and Chinese medicine, and beliefs about arthritis. *Third*, an emerging common illness management process will be presented, namely from self-care remedies, to consulting Western physicians, to consulting Chinese doctors, to combining Western and Chinese medicine, to returning to Western medicine and the impact of these management strategies. *Fourth*, factors directly impacting on these behaviors will be presented in combination with these management strategies in order to show their impact. These are beliefs about Western medicine based on treatment experience, beliefs about Chinese medicine based on treatment experience, perceived barriers to using Western medicine, perceived barriers to using Chinese medicine, and external factors.

The information obtained from mainland China was integrated into categories developed from immigrants' data, as comparative data to the immigrant study.

A. Arthritic symptoms

Difference in severity of arthritic symptoms is the most direct factor which leads to different types of illness management strategies. Three subcategories regarding severity emerged after using the HAQ scales to assess both RA (AS) and OA patients' disease condition. They are: mild, fairly serious, and serious.

1. Mild condition

Most of the OA patients had a mild condition. Their daily life was little affected by arthritis since their arthritic flare-ups were infrequent (several times a year). Their symptoms might be serious during arthritic flare-ups but did not bother them on a daily basis. Their symptoms usually worsened in cold and wet weather; they usually had arthritic symptoms in their knees or elbows (one or two joints).

The following quotes present the typical arthritic symptoms of patients with a mild condition:

“My left knee hurts if I use it. If I just lie down and do not do anything, I just feel a little bit uncomfortable, a tingling sensation, and the muscle around the knee is tired but not painful. The pain is worse when I go up and down the stairs. When the weather is rainy and cold, my knee pain occurs.” (*Hu*)¹

“The arthritic flare-up is likely to happen before the weather changes. My knee pain continues until the weather clears. During the worst arthritic flare-ups, I walked with a limp and had a hard time coming down stairs. Sometimes, I fall on my knees suddenly.” (*Wei*)

2. Fairly serious condition

For patients with a fairly serious condition, daily life and work were affected by arthritis. Their symptoms (pain, swelling, stiffness, deformity) were constant and they had to use some type of treatment continuously. They usually had some degree of activity limitation, e.g., unable to flex hands, squat down, or go up and down stairs. They usually

¹ The names used are fictions.

had arthritic symptoms in several joints of their body. Some RA patients reported that their symptoms worsened in the morning and evening and were better in the daytime.

The following quotes present the typical arthritic symptoms of patients with a fairly serious condition:

“The pain and swelling of my hands is continuous. It is difficult to flex my hands in the morning. The pain is better in the daytime and worsens in the evening. The pain reminds me at night if I forget to take my medicine. Since coming to Canada, the worst attacks of my arthritis also cause severe stiffness and pain in the back of my neck.” (*Lia*)

“The pain and swelling on my elbows, hands, wrists, shoulders, knees, and anklebones are continuous. Usually I am unable to squat down and stretch my arms. It is also difficult to flex my index finger and thumb. The knee pain is serious when I come downstairs but is much better (still uncomfortable) when I sit down or walk on flat ground. I had walked with a limp until I went abroad in 1988..... The palm of my hands and the under side of my feet are hot during the night.” (*H*)

3. Serious condition

For patients with a serious condition, daily life and work are totally affected by arthritis. Two patients had very limited mobility which rendered them unable to take care of themselves. They had to depend on medical treatment continuously. Their symptoms (pain, swelling, stiffness, deformity) usually appeared in many joints of the body.

The following quotes present the typical arthritic symptoms of patients with a serious condition:

“It is difficult for me to flex any finger and my wrists. I have deformed joints on my hands, knees, and feet. I am unable to stretch my arms and knees. Almost every place, every joint feels sore and stiff. The pain and stiffness are continuous. With every arthritic flare-up, my husband helps me to get up from bed, dress, and brush my teeth. I could not even chew during that time.” (*Wan*)

B. Beliefs about Western medicine

Most immigrants have similar ideas about Western medicine, regardless of sex, age, seriousness of their condition, type of condition, or level of education. They believe that Western medicine uses a scientific treatment methodology and has advanced equipment for diagnosis and treatments. Surgery is considered both safe and helpful. However, they believe that Western medicine is not very effective in the management of chronic disease such as arthritis, asthma, etc. because it only deals with symptoms, while the causes of the disease are ignored.

“Western medicine can quickly solve clinical symptoms. The equipment for treatment and diagnosis are advanced. Blood tests, urine tests, X rays, etc. are effective. However, Western medicine is not effective for chronic diseases such as arthritis and asthma. Western doctors mainly pay attention to symptoms. They do not seem to care about the different causes of symptoms. As a result, RA patients with different causes of disease receive the same treatment.” (*H*)

“Western medicine sometimes digs a hole to fill another hole. It does not have a universal treatment approach. Just as with environmental protection; many years ago, people built a nuclear-electric industry in this area and believed that it was good. Now they recognize that it has damaged the regular pattern of nature. The way of thinking of Western medicine is just like that. It is concerned only with the partial and the immediate. Western physicians only treat the part of your body which has symptoms and do not pay much attention to how this part will influence your whole body. I believe that as scientific research becomes more complicated, Western medicine will need a more universal way of thinking.” (*Wei*)

Mainland patients hold very similar general beliefs about Western medicine as the immigrants.

C. Beliefs about Chinese medicine

Two subcategories of beliefs about Chinese medicine emerged from the data. They were advantages and disadvantages of Chinese medicine.

1. Advantages of Chinese medicine

Most immigrants interviewed have similar ideas about Chinese medicine, regardless of sex, age, seriousness of their condition, type of condition, or level of education. They believe that Chinese medicine is more effective than Western medicine in the management of chronic disease. Since Chinese medicine has a long-lasting effect, it is good for permanent cures or long-term remissions. They mentioned that Chinese medicine is very effective in the management of chronic diseases such as osteoarthritis, rheumatoid diseases, gastric diseases, spondylitis, hypertension, respiratory diseases such as asthma, neurosis and neurasthenia which are related to the nervous system, dermatosis, dysmenorrhoea, spleen disease, and liver disease. They believe in Chinese medicine's holistic approach towards health and that Chinese medicine is natural and has no side effects. In addition, they believe that although the curative effects of Chinese medicine are delayed, it will treat the cause of the disease.

The following quotes express this general view:

“Practitioners of Chinese medicine treat symptoms and the roots of disease at the same time; e.g., if a Chinese doctor believes that a patient's RA is closely related to a deficiency in the kidneys, he will treat the patient's kidneys at the same time as he treats the patient's RA.” (*H*)

“I believe that Chinese medicine is beneficial for general health. It is a tonic which is especially good for the kidneys and good for energy.” (*Lia*)

2. Disadvantages of Chinese medicine

The most common beliefs about the ill effects of Chinese medicine are that the curative effects of Chinese medicine are delayed, and preparation of medicinal herbs is inconvenient.

“The curative effects of Chinese medicine are so slow. It does not have an effect right away. It comes slowly. Therefore, it is not good for acute diseases.”(*Le*)

“.....it is too troublesome to prepare medicinal herbs.” (*Di, Wo*)

3. Comparative data from mainland China

Mainland patients hold similar general beliefs about Chinese medicine as the immigrants. They also believe that Chinese medicine is beneficial for general health, and by taking out the root of disease results in permanent cures or long-term remissions.

“I believe that Chinese medicine is a very traditional, therapeutic and health protection method. It can finally take out the root of the disease. Therefore, it is good for chronic diseases. In ancient times, we did not have Western medicine, and Chinese medicine cured many people’s diseases.” (*Zho*)

As with immigrants, the most common beliefs about the ill effects of Chinese medicine are that the curative effects of Chinese medicine are delayed, and the treatments are inconvenient.

“It is very difficult to persist in taking the concoction of medicinal ingredients with a very bad taste. I believe that Chinese medicine can treat my RA. However, it takes a long time.” (*Zho*)

D. Beliefs about combining Western and Chinese medicine

Most of the immigrants were familiar with the combination of Western medicine and Chinese medicine and feel that it is a shortcoming to use only one system.

1. Off-setting each other's deficiencies

Six immigrants' ideal treatment strategy would be the combination of Chinese and Western medicine. The following quotes express this belief.

"My ideal treatment for arthritis is: Western doctor for diagnosis, Chinese doctor for treatments. People's illnesses are very complex. We should examine the matter from various angles, even though it is hard to understand it completely. A combination of Chinese and Western medicine is better than using only one system; they can make up for each other's deficiencies; for arthritis, I believe that Chinese medicine should play a major role. Physiotherapy can be used as a supplementary treatment." (*Li*)

"I believe that Chinese medicine is more effective for arthritis than Western medicine. However, since Chinese medicine treats disease very slowly, we do need Western medicine which can relieve pain, otherwise patients will suffer pain during the long treatment period." (*Ln*)

2. Comparative data from mainland China

Patients in mainland China are also very familiar with the combination of Western and Chinese medicine. They believe that the combination is better than using only one system, although some people believe more in Western medicine and others more in Chinese medicine. The following quotes express the general view:

"I believe that combining Western and Chinese medicine is the best treatment strategy for my situation. Because my RA has febrile symptoms, I cannot use antibiotics for a long time and should use Chinese medicine as

an antipyretic. Also, because RA is a chronic disease, patients usually cannot sleep well, so we should use Chinese medicine as a tonic to benefit the nervous system.” (*Bin*)

“The ideal physician should have learned both Western and Chinese medicine, like Dr. Zhang (the Rheumatologist who is Vice President of Harbin Medical University), who is an excellent Western-style rheumatologist but who studied Chinese medicine for many years and can prescribe Chinese medicine.” (*Bin*)

E. Beliefs about arthritis

Three subcategories of beliefs about arthritis emerged from the data. There were perceived contributory factors of arthritis, perceived seriousness of arthritis, and factors perceived to improve arthritis. Management strategies were influenced by these beliefs.

1. Perceived contributory factors of arthritis

a. Being chronically cold

Most of the immigrants with OA or RA interviewed perceived that being chronically cold and getting wet are contributory factors of arthritis. The following quotes express the general view:

“The major reason I believe that I acquired RA is because I lived in a place that was damp and dark for many years. Also, when I was young, I always took cold baths in the summer.” (*Lia*).

b. Inadequate post-natal care

There are also many immigrants who believe that inadequate post-natal care and gynecopathy are contributory factors of arthritis (cause or worsen arthritis). *H* reported:

“I did not take adequate care of myself after I gave birth to a child. This is the reason I believe that I acquired RA.”

c. Other beliefs

There are many other perceived contributory factors of arthritis which emerged from the data, but they were not mentioned as frequently. These are heredity, depression, sports injury, introvert and relatively negative personality, excessive physical labor, inadequate care after an injury, aging, too much stress from work and family, and catching a ghost at her father's funeral (unexplained eruption of the disease).

2. Perceived seriousness of arthritis

The majority of the immigrants interviewed believed that arthritis is not a serious disease, and they tended to ignore their arthritic symptoms until their condition became much worse. Only patients with serious conditions paid much attention to their disease; most of the others will ignore their disease if their symptoms are stable.

Major reasons for not recognizing the seriousness of arthritis are beliefs that arms and legs are less important, and beliefs about arthritic pain (complaining about arthritic pain is undignified).

a. Belief that arms and legs are less important

Chinese immigrants, regardless of the seriousness of their condition, sex, or age, did not attach much importance to diseases which do not relate to their important internal

organs. To them, arms and legs are less important. The following quotes express the general view:

“I believe that Chinese people pay a lot of attention to their feelings. They do not really care what other people think about them. Diseases related to internal organs always cause bad feelings which directly influence eating and sleeping, and even influence the life span. Diseases of the arms and legs make others feel sorry for you. Even if you lose a hand, once you get used to it and if you do not care what others think, it does not influence your health or your life span.” (*Li*)

“If I get an internal disease such as gastritis or hepatitis, I will take it very seriously since those diseases will influence my health and life. A person’s body is just like a car. I will pay much more attention to the engine than the tires. Usually diseases of arms or legs do not cause serious effects on life style.” (*Zha*)

b. Beliefs about arthritic pain

Chinese patients are reluctant to voice complaints about arthritic pain. They believe that complaining about arthritic pain is undignified, because arthritis pain is not severe according to the culture. If a person complains about his or her arthritic pain a lot, other people (even relatives) may think that he or she is faking.

Lu is in a fairly serious state. She has very serious pain in every joint of her right leg. With every arthritic flare-up, she absolutely cannot move for at least two weeks. However, she reported:

“If you complain too much about arthritic pain, people will think that you are a hypochondriac. Even my husband believes that I exaggerate my pain because he thinks that arthritic pain is not so serious.”

Ji is in a serious state. Her hip and leg pain began when she was 18. Even though she was a favorite with her parents, her illness was ignored for many years.

“Whenever I complained of pain to my mom, she said that I exaggerated my pain so that I could cut classes. She said that my pain was caused by my imagination, and that in fact I did not have any disease.”

c. Other reasons for not recognizing the seriousness of arthritis

Many immigrants believe that arthritis is just an aging problem. They consider arthritis as a common disease which does not influence life-span, and is unable to have serious effects. Therefore, they do not worry about their quality of life in the future.

3. Activities perceived to be improving on arthritic condition

Immigrants believe that keeping warm, resting, reducing stress, changing bad life habits, learning how to improve a negative mind-set, exercise, etc. are contributory factors in improving their condition.

They especially believe that low-impact exercise is good for any kind of arthritis. People with a serious or fairly serious condition believe even more strongly in exercise.

“Exercise can keep my joints nimble. Luckily, I liked sport activities when I was young, otherwise my condition would be worse.” (*H*, a RA patient with a fairly serious condition).

“My joints have serious problems and I must make my muscles more powerful to support my joints. Exercise can strengthen the muscle..... Water exercise is a very good exercise for any kind of arthritis.” (*Wan*, a RA patient with a serious condition)

Wo and *Ji* are also RA patients with serious conditions. *Wo* believes that Tai-Chi and Chi-Gong are very good for her arthritis. *Ji* believes that exercise is more effective than medication, and that without exercises, the medication would not help her very much.

4. Comparative data from mainland China

Just as with immigrants, most of the patients in mainland China believe that their arthritis is caused by being chronically cold and being wet. They also shared beliefs about contributing factors such as heredity, depression, excessive physical labor, aging, introvert and relatively negative personality.

New information which emerged from the mainland data is that some mainland patients believe that lack of nutrition and calcium may also be contributory factors in getting arthritis.

Also, similar to the Chinese immigrants in Calgary, all the patients interviewed in mainland China believe that arthritis is not a serious disease. The major reasons are very similar to those mentioned by Chinese immigrants.

Many believe that arthritis is a common disease which does not have serious effects. Arms or legs are not considered important. Even some patients with a serious condition did not recognize that arthritis is a serious disease.

“Unlike heart disease, arthritis is not a dangerous disease which can influence the life-span.” (*Man*)

“I just knew that RA is difficult to treat, but did not know that it caused such serious effects for me”. (*Bin* with a serious condition)

Some believe that there is no effective Western treatment for arthritis:

“I always think that it can be improved by taking good care of myself. I do not see a doctor frequently since I believe that they do not have effective treatment for my disease”. (*Zho*)

“When you go to hospital, they only can relieve your symptoms but cannot cure your arthritis. I believe that most of the Chinese with arthritis have similar thought as I do.”(*Fo*)

Mainland patients also feel embarrassed to voice complaints about arthritic pain due to cultural restrictions.

“If I recuperate, somebody will say, See! He stays at home only because of leg pain.”(*Fo*)

F. Self-care remedies

Beliefs about arthritis (perceived contributory factors of arthritis, perceived seriousness of arthritis, and activities perceived to be effective in improving arthritic conditions) influence the type of self-care remedies chosen. To keep warm and exercise are two major types of self-care management strategies for Chinese immigrants with arthritis. Respondents with mild symptoms, which are not continuous, usually only use self-care remedies, or do nothing. Even some patients with a fairly serious or serious condition continue to use self-care remedies while they are taking medication.

1. Self-care remedies before treatment

When the symptoms started, nine immigrants used self-care remedies for a period of time (some used them for a very long time) before they consulted a Western or a Chinese doctor. Because most of the patients believe that their arthritis is caused by being

chronically cold and wet, their self-care activities usually focus on keeping warm and staying out of the wind. Strategies to keep warm include using hot water bottles, electrotherapy machines, wearing thick, cotton-padded trousers, being exposed to the sun, and using Chinese medicine for external application. Before *H* consulted a physician, she reported:

“Every winter, my mom made very thick, cotton-padded trousers for me. Sometimes, I applied a hot-water bottle to my knee or elbow when I felt uncomfortable. I also used pieces of leather wrapped round my knees in very cold weather.”

Chinese plasters, or Chinese medicine for external application, are the most commonly used self-care remedies (the major function of these external applications is to draw out cold or wet). For example, After *Ya*’s right elbow was sprained, she applied ‘Panacea of bone’, ‘Tung oil’ and Chinese plasters on her elbow. *Ho* and *Lu* also applied a Chinese plaster and some Chinese medicine for external application when their pain was not very intense.

Cupping is also a commonly used self-care remedy (the function of cupping is to draw out cold, wet and pus). *Lia* consulted a physician 15 years after her knee pain occurred. Before being diagnosed with RA, she just used cupping and some plasters for pain relief because the pain was not serious,

If their self-care remedies were effective, immigrants did not consult a doctor. *Li* said:

“I never see a physician. Whenever I feel knee pain, I apply a hot water bottle to my knees (or elbow). It is always effective.”

2. Self-care remedies as a supplementary treatment.

Some immigrants continue to use the self-care remedies mentioned above for many years while they are taking medication.

Because many patients believe that low-impact exercise is good for all types of arthritis, they engage in different kinds of exercises (swimming exercise programs, range of motion, walking, step machines, Tai-Chi, Chi-Gong, turn a health ball, or freestanding exercise). Immigrants with a serious or fairly serious condition tend to do more exercise than these with mild conditions. The following examples concern patients with a fairly serious or serious condition:

“I believe that exercise is very good for my RA. When I took sick leave in 1992, I joined a water exercise program twice a week. Because the exercise made me feel better, I went to the program whenever I was on sick leave. I also joined a RA program at the Children’s Hospital. They gave me knowledge about RA and exercise. Sometimes I also do a range of motions at home.” (*Wan*)

“I did Tai-Chi and Chi-Gong for many years when my condition was stable.” (*Wo*)

Some patients believe that special foods have an effect on their RA:

“When I eat less red meat, I feel less pain. My specialist said that my feeling is not unusual. I had not eaten red meat and only eaten fruit, vegetable, chicken breast meat and fish for a long time. However, I do not abstain from red meat right now because I am not sure whether abstaining from red meat really can reduce pain. My good feeling was probably not because of this reason.” (*Wan*)

“I tried a Naturopath. He developed a special diet for me. I thought maybe that dairy products were not good for me, so I stopped drinking milk. It seemed to help. In June, my pain was gone. My stiffness was also less than before. I am taking some things from a health store (Elderberry consentrese, kyolic, Royal jelly, etc.). I think they help, but I do not know which ones exactly because I took a lot of things.....” (*Le*)

3. Comparative data from mainland China

Mainland patients use self-care remedies more actively than do immigrants. They use more over-the-counter medication as part of their self-care. There are many drugstores where people have a choice of buying any kind of Western medicine, Chinese medicine, health food, medical appliances, or self-care apparatus without a physicians' prescription. Immigrants in Canada usually cannot buy Western medicine without a physician's prescription. The Chinese drug stores in Canada are also limited and there are far fewer Chinese therapy choices than in mainland China. In mainland China, the most commonly used self-care remedies are Chinese medicines including Chinese plasters, balls of Chinese medicine, Chinese medicinal liquor, *Tripterygium wilfordii* Hook F, cupping, and Western medicine such as Voltaren, Piroxicam, Brufen, Aspirin, calcium, even Prednisone. Some also use self-care apparatuses (e.g., a small magnet hammer with which to touch every acupuncture point).

Activities to keep warm and Chi-Gong are also important self-care remedies. Three people have studied Chi-Gong for more than one year. However, few mentioned the importance of low-impact exercise except for two patients (*Fo, Zhe*) who have serious conditions. They have to follow a physician's recommendation to exercise daily otherwise their spines will become very stiff.

G. Impact of self-care remedies

1. Immigrant data

Self-care remedies such as Chinese medication for external application, hot water bottles, cotton-padded trousers, and cupping usually relieve patients' pain temporarily. Sometimes they play an important role for patients with mild conditions. For example, *Wei* has used Chinese plasters for more than ten years. They played an important role during his arthritic flare-ups. *Li* has had arthritis for more than 20 years and has never seen a physician. Whenever she feels knee pain, she applies a hot water bottle to her knees. It is always effective.

Low impact exercise is seemingly the most effective self-care method for Chinese immigrants with arthritis. As mentioned above, immigrants with serious or fairly serious conditions value exercise more and do more of it. *Wan*, who has serious RA, reported that she felt more energetic after she did range of motion exercises and the water exercise program. *Ji*, who has serious AS, reported that exercise is more effective than medication. She feels that without exercise, the medication would not help her very much. *Wo*, a patient with serious RA, reported that Tai-Chi and Chi-Gong are very helpful. *H*, *Le*, and *Lan* are patients with a fairly serious condition. They said,

“Tai-Chi is very good since before, if I dropped something, I could not pick it up. Now it is difficult but I can pick things up. I also can dress myself.” (*Le*)

“Before doing knee bends and squat down 300 times in the morning and 300 times at night, I could not squat down, now I can, no problem.” (*Lan*)

2. Comparative data from mainland China

Mainland patients value Chi-Gong more than exercise. Three people mentioned that they have studied Chi-Gong for more than one year and reported that it is helpful. The two patients with serious AS reported that exercise is very helpful (both of them have to follow their physicians' recommendations to exercise every day).

Self-care apparatuses are also considered effective by mainland patients. *Pu* uses a small magnet hammer to touch every acupuncture point 100 times daily. She reported that it is effective. *Man* is using a masseur; she reported that this therapy reduces her symptoms.

Mainland patients also reported that Chinese plasters, cupping, and keeping warm are activities which are effective for patients whose symptoms are not very serious.

H. External factors

Before discussing the immigrants' use of medical treatments (i.e., consulting either Western or Chinese doctors), external factors which directly influence the immigrants' treatment choice will be discussed.

External factors are defined as external influences on illness management strategies. Major external factors which are significant in this study include support of family and friends, knowledge about Western medicine, and cost of treatment. Factors such as "knowledge about Western medicine", or "cost" are included in the categories "barriers to using Western medicine" and "barriers to using Chinese medicine", because they each only directly influence one or the other category.

When immigrants first seek medical treatment, friends' suggestions and family members' help are major social factors which help determine their treatment choice. Friends' suggestions and successful/unsuccessful experiences are the most influential factors.

1. Friendship support

In the immigrant data, friends' suggestions and successful/unsuccessful experiences are important for many Chinese immigrants' treatment choices, regardless of age, sex, or level of education. They usually obtained information from their friends about family doctors or Chinese healers. Sometimes they believed their friends' suggestions more than their family members; for example, because *Lu*'s friends said that one Chinese healer is a very good orthopedist, she went to see him for a massage and hid this from her husband (her husband does not believe in Chinese medicine). Sometimes they even believe their friends' suggestions more than their specialists. For example, *Hu*, a university student, did not follow her physician's suggestion to do physiotherapy since her friend said that this does not help at all.

Immigrants, especially the elderly, reported that they need friends, otherwise they will feel very lonely. Therefore, many have rich and varied social activities for the purpose of making friends. *Lia*, for instance, goes to the Calgary Chinese Elderly Citizens' Association to talk, sing, and do volunteer work every Friday. She also goes to the Chinese Friendship Group which meets at the Chinese Cultural Center. *Ce* is an elderly woman who likes the Cantonese Opera. She participates in a musical group in Chinatown

three times a week. *Di* is an elderly man who has a lot of friends. Every day he goes to the Chinese seniors' building for Mahjong. He goes to restaurants with his friends on the weekend; information about treatment is mostly obtained during these social activities.

2. Family support

When immigrants have little or no social support from friends, their family members help to choose a specialist or family doctor who can speak Chinese with them, make medical appointments and drive them to these appointments. These patients usually had some degree of activity limitations, which left them unable to engage in social activities.

In comparison to patients who mainly depended on their family member's help, patients who tended to follow friends' suggestions dealt with their illness more actively and were more likely to use Chinese medicine. Their friends' experiences with Chinese medicine were the most direct and trustworthy information for them.

3. Comparative data from mainland China

For patients in mainland China, there are more external factors which influence a patient's management strategies. Advertisements, large amounts of written information available from drugstores or book stores, and a large amount of information from their friends are major external factors which influence their management strategies. People follow advertisements and friends' suggestions to find famous Chinese doctors, buy Chinese medicines and Chinese health foods.

For example, people are given much information about new drugs or new medical appliances from salesmen when they get into these stores. They can also buy any kind of medical book either for the layman or a specialist (both for Chinese and Western medicine) from book stores. People can also buy many traditional prescriptions which have been approved by the Government.

Even inpatients can get information from salesmen. As *Bin* reported:

“Now, wherever you are hospitalized, salesmen go to your room to sell books related to your disease. I got “Clinic Immunity about RA”, and the magazine “Family Doctor” from them.

Generally speaking, mainland patients’ management strategies are strongly influenced by external factors. Even though a patient may have strong beliefs about illness and Chinese/Western medicine, it is hard to avoid being influenced by these outside influences. For example, a mainland patient who strongly believes in Western medicine (he is a Western physician) readily placed trust in advertisements about Chinese medicine, the use of which later caused disastrous results for him.

Compared to mainland patients, immigrants’ management strategies are less influenced by external factors. Many of them have no Canadian friends whom they can talk to. Immigrants are often unable to receive treatment information from their homeland, and even if they could, such treatment is unavailable. Therefore, their management strategies are neither strongly influenced by the dominant culture nor influenced by homeland information.

I. Consulting Western physicians

1. Reasons for consulting Western physicians

If self-care remedies are not effective, or if these remedies cease to be effective after awhile, or if their condition becomes worse, immigrants generally turn to medical treatment to mitigate their symptoms. They usually consult a Western physician first, due to convenience, the fast curative effects of medicine, and coverage by the health care system. They would not normally start with Chinese medicine. 16 immigrants used, or are using Western medicine now. The following examples express similar reasons for using Western medicine:

“After I used ‘Panacea of bone’, ‘Tung oil’ and Chinese plasters for about one month, my skin festered and I had severe elbow pain. Then, I went to see my family doctor.” (*Ya*)

H consulted a physician and started medical treatment five years after she had a red, swollen knee along with severe pain. The reason *Ho* consulted the physician is because she was unable to walk due to severe pain in her hip joints. *Chi* went to see her family doctor when her hand became deformed. *Ji* did not pay much attention to her severe hip and leg pain for many years until very bad arthritic flare-up in 1995.

2. Compliance with Western physicians’ recommendations

Many immigrants with a mild or fairly serious condition do not follow the Western physician’s recommendations or just use the medication for a short time. RA patients, especially those with serious conditions, follow physicians’ recommendations better since, without medication, they have more intense pain and swelling.

Most immigrants with a mild or fairly serious condition were prescribed **Analgesics** for pain relief. However, most of them did not completely follow their physicians' recommendations to take analgesics due to the side effects or the short term efficacy of the medication. The following quotes express their aversion to analgesics:

"You just do not know how painful my stomach is after taking analgesics. The pain sometimes lasts a whole day even though I take analgesics after a meal. Therefore, I only take them when I am unable to tolerate my severe pain." (*Ya*)

"Analgesics are just like crude opium, I felt much better after taking them. However, my stomach and head were so uncomfortable. I believe that it will damage my health. Also, the pain returned if I stopped taking them. Now I have stopped using analgesics." (*Qi*)

Many immigrants are also treated by **Physiotherapy, Electrotherapy, and Infrared treatment**. Most of them reported that physiotherapy is effective.

"I received physiotherapy during every sick leave. Before physiotherapy, I could not raise my feet. After physiotherapy, my feet could lift a 9 lb. sandbag." (*Wan*)

When *H* feels uncomfortable, she sometimes uses physiotherapy and infrared treatment. They improved her symptoms. *Ya* also believes that physiotherapy is helpful. *Lia* and *Zha* stopped physiotherapy due to its short-term efficacy.

Some patients with a fairly serious condition were treated by **injection (Myochrysine, Cortisone)**. Although it is effective, it is only temporary and some are worried about its side effects.

".....because my skin peeled and I got spots all over my body, I believe it (injection of Myochrysine) is poisonous..... I decided to stop treatment and have not visited Dr. C. since 1995." (*Lia*)

"My family doctor transferred me to Dr. C. three years ago. He gave me about three injections. It just relieved my pain temporarily. Because I

believe that injections are not good for my health, I stopped using them.”
(*Chi*)

A few patients were treated by **Cortisone (tablet)**; but because they were worried about the strong side effects, they stopped using it when they had another choice.

“I have not taken Cortisone and only have used Apo-Naproxen since 1995. Cortisone can relieve my pain temporarily but the side effects were a stomach ache, an uncomfortable liver and bones which break easily.” (*Lia*)

Yan stopped using Cortisone injections because she believes that they will damage her nerves.

Some patients were suggested to have **surgery** by their specialists. But because the specialist explained to the patients that surgery is not a permanent solution, they refused to have it. *Ce* reported:

“Dr. C. (her specialist) suggested that I have surgery. He told me that surgery costs a lot of money. He also said that surgery is not a permanent solution. After four to five years, I would have to undergo it again. I was so unhappy with this information. I refused to have surgery and have not visited Dr. C. since.”

Patients with serious or fairly serious RA are treated by **Anti-inflammatory drugs**, including **Relafen** and **Plaquenil**; **Cancer Palliative drugs (Methotrexate)**; **Nonsteroidal Anti-inflammatory Drugs (Indomethacin)**; and **Corticosteroid (Cortisone)**. Patients with serious conditions are dependent on these medications which can control their symptoms. Only patients who experienced very strong side effects stopped using them.

“I have followed my specialist’s recommendations for many years; if I stop it (Methotrexate) and wait until it goes out from my blood, my condition will be critical. It happened once, so I cannot give it up.” (*Wan*)

Ji and *Chi* have followed their specialist's recommendations and have taken Anti-inflammatory drugs (Relafen), Indomethacin, Mucosal Protective Agent (Cytotec), and Cortisone for many years.

Because *Le* had a strong allergic reaction to Anti-inflammatory drugs (Relafen), she stopped using it.

One OA patient with a serious condition is treated with Opioid Analgesic (Morphine). She is completely following her physician's recommendations to take Morphine twice a day, otherwise she cannot tolerate the severe hip pain.

Five patients followed Western physicians' recommendations well. Four are RA patients with serious conditions. They have to use Western medicine to control their symptoms otherwise their condition would be critical. 11 patients did not completely follow the Western physicians' recommendations. They have a mild or fairly serious condition. They indicated that they can get symptomatic relief from some alternative methods such as acupuncture, massage, etc., and do not need to depend on Western medicine.

Western medicine is very important for RA patients with serious conditions in order to control their symptoms. For patients with a mild or fairly serious condition, the importance of Western medicine is less because they believe that the side effects will probably cause more serious problem than the arthritis itself. Those patients are very likely to stop Western medicine due to its side effects.

3. Comparative data from mainland China

Generally speaking, mainland Chinese patients usually go to an assigned hospital first if they have health care insurance. After being diagnosed by a physician (usually a Western physician), most of them receive Western treatment or a combination of Western and Chinese medicine.

Patients in an early stage of the illness were usually treated by **Antibiotic (Penicillin)**, and **Corticosteroid (Dexamethasone)** (intravenous drip). Most of them used these drugs for a long time. For example:

“The nurse dripped Penicillin and Dexamethasone for me whenever I felt uncomfortable. They relieved my pain.this situation lasted 3-4 years.”
(*Fo*)

“After I was diagnosed with RA, the doctor injected Dexamethasone and Penicillin into me for more than 10 years (about 100 days a year).” (*Zhe*)

The most commonly used oral medications are **Aspirin**, and **Anti-inflammatory drugs (Voltaren)**. After they were told by their physicians that they can use them, they buy them from drug stores and use them whenever they feel pain. They then do not go to see physicians until those medications are no longer effective for them.

Block therapy is also a very commonly used treatment.

There are also various kinds of **Physiotherapy** in mainland China and **Infrared treatment**. Patients usually use them for a long time (several months), much longer than do immigrants.

For patients with fairly serious or serious conditions, the most commonly used medications are **Indomethacin, Methotrexate, Corticosteroid (Prednisone), and Immunoregulatory Capsules**, plus **Vitamins and Calcium**.

Five patients interviewed in mainland China are inpatients in the hospital attached to the Medical University, Harbin. Currently, they are mainly being treated by Western medicine, with some Chinese medicine as a supplementary treatment; the other two are using self-care remedies.

J. Impact of Western medicine

1. Immigrant data

Generally speaking, none of the immigrants with OA or RA reported that their arthritis was cured or much improved with Western medicine. Many immigrants reported the short-term efficacy and upsetting side effects of **Analgesics**. They only use them when they are unable to tolerate the pain. Some immigrants who received injections of **Myochrysine** and **Cortisone** reported that the side effects of injections are usually stronger than those of analgesics. Therefore, most of the immigrants only received injections a few times and then never used them again.

RA patients reported that **Anti-inflammatory** drugs can control their symptoms to a certain extent but that they suffer side effects in varying degrees. Patients with serious conditions reported that **Anti-inflammatory** drugs, **Indomethacin, Methotrexate, or Cortisone** control their symptoms but that the side effects of these medications are fairly

strong, especially of Methotrexate and Cortisone. Immigrants always try to stop Cortisone or to reduce the doses. They only use Cortisone when they have no other choice.

Many patients with RA or OA reported that **Physiotherapy** improved their symptoms without any side effects. Although some stopped using physiotherapy due to its short-term efficacy or cost, physiotherapy is the only Western treatment about which immigrants have relatively positive opinions.

2. Comparative data from mainland China

Mainland patients reported that **Penicillin** and **Dexamethasone** (intravenous drip) can only relieve pain temporarily.

Aspirin and **Voltaren** can also relieve symptoms temporarily. Mainland patients reported that when they first used them, they were always effective. However, after taking them for a long time, they cease to be effective. Voltaren is seemingly the most effective one.

Patients reported that they usually get 2-3 weeks pain relief after every use of **Block therapy**.

Just as with the immigrants, mainland Chinese patients reported that **Physiotherapy** can improve their symptoms and that there are no side effects. They usually use it for a long time (several months), much longer than do immigrants. Therefore, it appears logical to conclude that immigrants with arthritis might use physiotherapy in Canada more often if it were completely covered by health care insurance.

Patients reported that **Indomethacin, Methotrexate, Immunoregulatory Capsules, and Prednisone** can also control their conditions, but that the side effects are strong, especially Prednisone. They believe that the side effects of Immunoregulatory capsules are fewer than taking Prednisone and that they have the same effectiveness. However, Immunoregulatory capsules are much more expensive than Prednisone.

K. Beliefs about Western medicine based on treatment experience

The above categories presented how immigrants consulted Western physicians and the impact of Western medicine. In this section, belief factors impacting directly on using Western medicine will be discussed.

When immigrants talked about their beliefs about Western medicine, based on their treatment experience in Canada, their attitude became aggressive when compared to their general beliefs about Western medicine. No one interviewed believed that their arthritis can be cured or much improved with Western medicine because they have little confidence in the Western medication prescribed. Although most of the patients with fairly serious and serious conditions depend on Western medicine and it does control their symptoms, they realize that this is not a cure. Also, many lack trust in Western physicians' treatment skills, and do not like their cold manners. The above beliefs directly and powerfully influenced their ensuing behaviors such as discontinuing medication, or using them for a short time only, or turning to Chinese medicine.

1. Ineffectiveness of Western medicine for arthritis

a. Lack of knowledge about the cause of RA

Immigrants, especially RA patients, believe that it is impossible for Western medicine to cure their arthritis because Western physicians do not know the cause of arthritis. Some RA patients with a serious condition reported:

“Western medicine is absolutely necessary since it can control the patients’ critical symptoms and give them a stable health status for treatment. However, it is impossible for Western medicine to cure my RA since they do not know the cause of RA. They only know that my immune system is compromised, but the reason why is unknown.” (*Wan*)

“Western physicians do not understand my disease completely. They can only control my symptoms to a certain extent. I believe in Western medicine but I do not believe they can cure my disease. I have already adapted myself to the disease and have recognized that the rest of my life will be afflicted by it.” (*Ji*)

b. Lack of specific treatments for arthritis

Immigrants believe that they will get the same or very similar treatments from any Western doctor. Patients with mild or fairly serious conditions (mainly OA) believe that when using a Western doctor, he just gives you Analgesics, so why bother going to see a doctor. Patients with a fairly serious or serious condition (mainly RA) commonly use Anti-Inflammatory drugs or Corticosteroid. Some of them who joined an RA program or arthritis class said that others in the class had very similar experiences with Western medicine.

“There are 11 people in my arthritis class. They are all taking Anti-Inflammatory drugs just like me; and they have all got problems because of the pills.” (*Le*)

“I do not place my hopes on Western medicine because it does not have any special treatment for OA except Analgesics.”(*Ho*)

c. Temporary effects of treatment

Patients got temporary pain relief from Western medications with different degrees of side effects. With results no better than that, they have little confidence in Western medicine. They are disappointed that their symptoms return quickly if they stop the medication.

d. Side effects

Immigrants sometimes hold extreme views about the side effects of Western medicine (Analgesics, Anti-inflammatory drugs, Methotrexate, Cortisone, etc.). They are especially deeply concerned with Cortisone. They use Cortisone only when they have no choice. Many reported their negative feelings toward using Western medicine:

“I refused to take Methotrexate for half a year since it has strong side effects. It is toxic. I am also unsatisfied with the side effects of Anti-inflammatory drugs and Methotrexate. They are not good for my stomach, kidneys and liver although I have medicine for stomach sickness.” (*Wan*)

e. Unnecessary surgery

Some immigrants believe that surgery is unnecessary for arthritis. They refused their specialists' recommendation to have surgery. *H*, who is a Chinese healer, reported:

“I believe that Western doctors do many unnecessary operations on patients whose disease really does not require surgery. As a result, since surgery destroys the patients' main and collateral channels, acupuncture will not be very effective for them.”

2. Lack of trust in Western physicians

Nine immigrants whom interviewed, reported their lack of trust in Western physicians. Common reasons are (1) excessive dependence on diagnostic tools, (2) do not pay attention to patients' explanations, and (3) prefer more positive, dialectical explanations by physicians.

a. Excessive dependence on diagnostic tools

Chinese immigrants believe that physicians in Canada are excessively dependent on lab results and lack necessary clinical experience which causes them to mis-diagnose and which results in delayed treatment. This is the most important reason which underlies patients lack of trust in Western physicians. The following quotes express the general view.

"Western physicians' diagnoses are too conservative. Their diagnoses and treatment are excessively dependent upon lab results and they lack necessary clinical experience. If lab results fail to show your problem, you cannot get any treatment. For example, I have kidney disease, but since the lab result could not show the exact problem of my disease, my specialist therefore has not prescribed any medication for me for many years." (*Wan*)

"I went to emergency three times in Canada due to a serious stomachache. The physicians did many tests on me but could not find anything abnormal. Physicians here never have any idea about the patient's disease if lab results fail to show a particular problem. This does not make sense! A physician's role is to identify the patient's problem. If their conclusions are only based on lab results, they do not need to be trained for so many years." (*Zha*)

Chinese people believe that a physician's clinical experience is the most important aspect of his training. Without clinical experience, they believe that many diseases (especially common diseases such as pneumonia and chronic appendicitis) will be misdiagnosed. The following quotes express the general view about physicians' clinical experience.

"I believe that physicians' experience is the most important thing. You can use the same principle for computers but not for human beings. Different people have different physiological characteristics, so they will have different symptoms even though they have same disease. Only a physician with rich experience, and not a dogmatist, can treat different cases of illness successfully." (*Zha*)

"My family doctor is absolutely a quack and does not have any necessary clinical experience. I got pneumonia in February. He treated me for the flu for six weeks until I coughed up blood." (*Lu*)

If the lab result fails to show a particular problem, Chinese patients hope that physicians can explain their situation to them.

"I prefer that a doctor who voices his hunches and opinions to me. I also prefer that he use medication very conservatively. Due to an inconclusive lab result, I did not receive treatment and now I am in constant pain." (*Zha*).

Chinese immigrants concluded that the reason Western physicians are excessively dependent on lab results is because the system restricts physicians' talents and causes them to worry about whether the patient will sue them. As a result, they are not worried whether a patient's treatment will be delayed. *Ya* and *Li* spoke in a very angry manner:

"I have a strong aversion to such physicians. Many Chinese physicians in Canada also have acquired this habit." (*Ya*)

"Western physicians' intuitiveness is seemingly suppressed by something, maybe the system. Their treatment approach does not have any individual

content..... The purpose of their work is based on the medical principle that they do not cause harm.”(Li)

b. Do not pay attention to patients’ explanations

Another important issue is that physicians do not pay attention to patients’ experiences and explanations. This is another important reason which causes Chinese immigrants to have a dislike of Western physicians. The following quotes express the general view.

“My specialist absolutely did not pay any attention to my feelings. I explained my symptoms to him many times but he just did not believe me. Because he believed that there was no physical basis for my symptoms, he suggested that I consult a psychologist. It is absurd.” (Li)

“I believe that a patient’s illness experience is very important for a physician’s diagnosis. Unlike Chinese doctors who trace back the patients’ medical history for several months, Western physicians’ diagnosis is only based on the lab result on the day you visit him. They never ask about the patient’s past illness experience.” (Zha)

Even though some immigrants have a family doctor or specialist who is Chinese, they still think that these physicians practice very differently from physicians in China. They are likely to stop visiting these doctors in order to show their dissatisfaction. Some seem to dislike Chinese physicians more than Western physicians, because some Chinese doctors, with a Western education, treat their patients in an arrogant and condescending manner.

c. Prefer more positive, dialectical explanations by physicians

Western physicians' indifferent manner and scientific explanations of the limitations of the medication also cause patients to lose hope. Unlike Chinese doctors who care whether their explanations will reassure patients' mental states, Western physicians generally do not pay much attention to patients' feelings. They simply tell them that the reason for RA is still unknown and the medication for RA has dangerous side effects, or tell them that their RA cannot be improved any further. Some patients reported that their specialists gave them information that was too technical and presented it in a very blunt manner.

"My specialist told me that the reason for RA is still unknown. He said that Methotrexate can control my symptoms, but this is not a cure. The medication may damage my liver. He suggested that I do regular cutsections of liver tissues for microscopic examination. He also warned me that if I refuse Methotrexate, my condition will become critical.....I made great efforts to free my mind of misgivings of the strong side effects of Methotrexate. I thought and thought.....finally, I straightened out my thinking. I believed that it is better for me to have a short and sweet life than a long life with limited mobility." (*Wan*)

"When I was diagnosed by a specialist in 1982, my specialist told me that my RA cannot be improved any further. As I age, I will be seriously afflicted by the disease. She talked with me in a very objective manner. She said that the most important thing for me is how I can manage my life better from now on. She said that we physicians are not God, we have limitations. This research area just started about 20 years ago. There are many problems waiting to be resolved."(*Ji*)

Many immigrants preferred more positive explanations from physicians. The following quotes express this general view.

"I prefer a more positive explanation from doctors. If the doctor explains the negative things such as the strong side effect of medication, and the serious disease status to me very frankly, it will depress me which can worsen my condition. I believe that patients' (especially female) emotional

feelings are very important for their health. Medical science should not ignore the fact that it is facing a human being with emotions and feelings. I just do not know why Canada has so many psychologists while physicians treat patients like inanimate objects. They forget that they are facing an organic entity with thoughts and emotions. They do not care whether explanations will lighten patients' mental states, their only concern is to impart facts and relieve themselves of the patient's psychological welfare." (Li)

"If a patient's condition is serious, too frank an explanation will absolutely cause him to lose hope. It is also possible to cause the patient to stop treatment because he believes that the treatment will not really improve his condition." (Zha)

3. Comparative data from mainland China

This section presents mainland patients' beliefs about Western medicine based on their treatment experiences.

a. Side effects

Mainland patients' negative attitudes towards Prednisone or Cortisone seem stronger than the attitudes of immigrants in Calgary. One woman stubbornly insisted on reducing Prednisone during her rapid deforming process. This resulted in severe deformity of her hands and feet. She recognized later that if she had not reduced her drug intake, Prednisone could have controlled the deformity and her condition would not be so terrible now. She said, "Now I recognize that the terrible result of not using Prednisone is much worse than the side effects of taking it". No immigrants in a similar situation have refused hormones although they know the side effects.

The following quote expresses the general worries about Prednisone.

“I am afraid of hormones since they can cause osteoporosis. People can die from serious osteoporosis. I am only 50 years old now, I do not want to use hormone treatment even though it can reduce pain and swelling effectively. If I was over 65, I might take hormones, because by that time, I will not care if I die after taking hormones for 3-5 years.” (*Zho*)

b. Surgery

Similar to immigrants, some mainland patients do not believe in the benefits of surgery. They also believe that surgery is unnecessary for arthritis.

“I am also afraid of surgery since it is not 100% safe. Otherwise, why before surgery, do doctor always tell you about the possible accidents of surgery? I can not imagine that I would have such bad luck.” (*Zho*)

“I am afraid of surgery. I believe that I can not endure it. I will only do it out of absolute necessity.” (*Bin*)

c. Fair-minded attitudes towards Western medicine/physicians

Unlike many immigrants who hold extreme views towards Western medicine/physicians, mainland patients have an open attitude towards Western medicine and physicians.

“I believe that Western medicine is absolutely necessary. It has a rapid, positive effect. It really equates with the word ‘humanitarianism’.” (*Pu*)

“Western medicine plays a major role in treating my disease. It can control and alleviate my symptoms. I can get up and walk after I take Western medicine. My blood test also becomes normal after I take it. However, I do not believe that Western medicine can cure my RA. If I stop medication, my symptoms will return.” (*Bin*)

No mainland patients interviewed reported their lack of trust in Western physicians.

L. Perceived barriers to using Western medicine

Immigrants perceived many barriers to accessing Western medicine. The major barriers are (1) they lack knowledge about Western medicine (due to language problems, etc.), (2) cost, and (3) worry about job loss.

1. Immigrant data

a. Lack of knowledge about Western medicine

Unlike the patients interviewed in mainland China, who know clearly about the functions and the advantages and disadvantages of Western medicine they use, more than half of the immigrants interviewed in Calgary do not know the name and function of the medication they use. They believe that the Western medicine they are taking is probably an analgesic. Some of them never ask their doctor what disease they have. Some even do not know there are arthritis specialists in Canada.

Language barrier is a reason why many immigrants do not make positive efforts (i.e., to seek help) toward dealing with their disease. Patients who cannot speak English very well find it very hard to get the information they need from their Western doctors or elsewhere. Due to language problems, some immigrant women cannot access a doctor because their husbands have no time to go with them. Also, for many other diseases, they prefer to use Chinese medicine that already prepared by a pharmacy and which they brought from mainland China, or can buy in Chinatown.

Even though about half the immigrants interviewed can read English, most of them reported that they do not feel like reading the material because reading requires great

effort. Therefore, they did not search out any information related to their illness. Only two people who speak English well paid attention to the information regarding their illness. They discussed their condition with their specialists actively, and searched for information on the Internet. The rest of them did not search for any information related to their illness.

b. Cost

One immigrant stopped physiotherapy because of the cost. *Ya* only uses physiotherapy eight times a year since she can only get eight free treatments per year. She now is recuperating at home while waiting for another free physiotherapy treatment.

c. Worry about job loss

A few people delayed treatment because they worried about their work record. For example, *Ya* is in a fairly serious state. Her elbow pain forced her to quit a job which she believes was the most important thing in her life. She feels that because she ignored her illness and returned to work whenever she felt better, her acute tennis elbow became chronic arthritis.

“I did not know that (tennis elbow) could cause such serious problems for me, and it became a chronic disease. I just thought that it is not good for me to go home on sick leave.”

2. Comparative data from mainland China

Mainland patients' barriers to using Western medicine in China are different from those of immigrants in Canada. Obviously, language is not a problem. Because of the

payment system, mainland patients face economic barriers in gaining access to health care services. Working people can get a certain percent of costs reimbursed from their workplace. However, they can only use one assigned hospital for treatment (in mainland China, hospitals usually have both a Western and a Chinese medical department). Patients do not get reimbursed if they go to other hospitals or use different treatments without transfer permission from the assigned hospital. The use of the health care system is largely dependent on a patient's economic status, and not the physician's recommendations, because only a few workplaces can reimburse more than 60% of a treatment's cost to patients. Physicians have much less authority than before when patients could get large amounts reimbursed from health care insurance. This situation also increases patients' involvement in their care:

“After you give money to the hospital, a doctor prescribes medicines for you. Then, the nurse brings all of your medicines to your ward in the hospital and lets you take care of them. The nurse also tells you how to take them. When you need an intravenous drip, the nurse will come to your room to get your medication and administer it twice a day.” (*Zhe*)

“Whenever I go to see my specialist, he just sits, holds a pen and asks me which medication I want to use. Whenever the hospital gets new medication for RA, I ask him to prescribe it for me.” (*Pu*)

The payment system does not cause passive attitudes towards treatments among patients. On the other hand, they may choose to continue or stop treatment more actively because they do not want to waste money for an ineffective treatment. When they believe that the treatment is not useful for them, they are very persistent in getting their physicians to transfer them to another hospital.

Mainland patients also worried about their work record. They reported that they do not want to take sick leave for a long time or visit a doctor during working time.

M. Consulting Chinese doctors

When immigrants' disease status is relatively stable, or they feel discouraged about Western medicine, many use some kinds of Chinese medicine.

Only three people have never used Chinese medicine. 16 people used, or are using, some kinds of Chinese medicine. Acupuncture, natural herbs and massage are the most commonly used treatment methods. However, most of them have used Chinese medicine for only a short time. Only four people have used Chinese medicine for a relatively long period.

1. Immigrant data

a. Short time usage

Due to the cost or ineffectiveness, many immigrants used Chinese medicine for just a short time, despite the fact that several of them have been sick for a long time. The following examples express their experiences.

Wan is a RA patient with a serious condition. She has mainly depended on Western medicine for many years. She tried Chinese medicine many times when her disease status was relatively stable. However, the treatment periods were always short.

“In 1992, a friend of mine introduced me to a Chinese healer in Calgary. He did acupuncture on me about ten times. He also gave me Chinese herbs. Because they were not effective, I stopped using them and returned to my specialist.”

“In Dec. 1994, when I went back to Taiwan, I consulted a Chinese healer. He gave me Chinese medicine powder. After I took a few doses of that medicine, my heart palpitations seemed to become faster, so I stopped it.”

“In 1995, I went back to Taiwan again. I consulted another Chinese healer. He gave me natural herbs. I took about ten doses but stopped it since the effectiveness was not obvious.” (at that time, Methotrexate and Anti-inflammatory drugs could control her symptoms).

When her condition became much worse by the end of 1995 and Methotrexate and anti-inflammatory drugs had steadily ceased to be effective, she reported:

“I was so disappointed with those medicines. A friend of mine introduced me to a Chinese healer in Calgary who had cured him. The healer gave me medicine for external application and natural herbs and told me to stop Methotrexate and anti-inflammatory drugs. I followed his requests and decided to try these medicines for one month. They were not effective, so I stopped using them.”

Due to the strong side effects of analgesics, *Ya* stopped using them and consulted a Chinese healer. However, she only used the Chinese medicine for 3 days.

“I was surprised that the natural herbs are so expensive, \$60 only for 3 days. However, I would feel embarrassed if I did not buy the medication because I had been treated by him already. The medicine was not effective.”

Lu was much improved by the short time usage of Chinese medicine. However, she stopped using it because she could not afford the cost.

“Dr. Ce was amazing. I got a miraculous effect after his treatment. He only massaged me once. My severe arthritic pain was gone for one and half years (before his treatment, I had an arthritic flare-up every month). Dr. Ce said that if I can receive his massage for one more month, my disease can be completely cured. However, I did not have any money.”

b. Long periods of treatment

Only four people's treatment periods have been relatively long. Three of these finally obtained successful treatment results.

"When my family doctor could not diagnose my disease, I went to see a Chinese doctor. I had acupuncture for about one year. It diminished my inflammation and stopped my pain. I felt so good. This is the best treatment I have received. However, acupuncture is expensive. \$38 dollars each time. I could not afford it any more." (*Chi*)

When *Ce*'s specialist suggested that she have surgery, she turned away from him, and then she visited several Chinese healers.

"Someone in a Chinese drug store introduced me to Dr. *Ce*, he massaged me about a hundred times. He almost cured my OA. I wish I could continue the treatment if I could only afford the cost. Do you know whether the Government can help us?"

H is a Chinese healer in Calgary. She opened a Chinese clinic after she emigrated to Canada. She has basically used Chinese medicine for about 40 years for her RA. She tried many kinds of Chinese medicine. Most of them were not effective at all. She keeps practicing on herself and finally found the specific acupuncture points for her symptoms. Acupuncture treatment keeps her illness status stable. She said:

"The most effective treatment is acupuncture. Now my husband uses acupuncture on me when I feel uncomfortable. My condition is continuously improving."

One reported her unsuccessful treatment results.

"He prescribed natural herbs for me. I took about 60 doses but the effectiveness was not obvious. I stopped taking it." (*Wo*)

"I also used acupuncture six or seven years ago about 40 times. I stopped using it because it was not effective." (*Wo*)

2. Comparative data from mainland China

For mainland patients, if the treatment is not effective, some assigned hospitals will transfer patients to another hospital. Most of the patients will use their own knowledge and information to choose various treatments available, including Chinese medicine, self-care remedies, etc.

All of the participants used many kinds of Chinese treatment and treatment times are usually much longer than that of immigrants in Calgary who use Chinese medicine. This applies to patients with arthritis who live in mainland China, regardless of sex, age, seriousness of the condition, type of condition, level of education, belief in Chinese medicine, or having/not having health care insurance.

Some patients are basically dependent on Chinese medicine. Following is a typical treatment process by a mainland patient (*Zho*) who tried Chinese medicine many times.

“In 1989, I was treated by a well-known Chinese doctor in the RA research institute in Harbin. He gave me Chinese medicine in powder form. It is a secret prescription from his older generation. I took it for three months. The pain and swelling of my hand joints were almost gone. My feet symptoms had also improved. However, the side effect was diarrhea; I could not stand it and stopped taking that medicine.

In 1990, the pain in my hands returned; I went to see the same doctor and received a three months supply of medicine again. My hand pain improved but I had to stop the medicine because of severe diarrhea.

Then, my friend introduced me to another Chinese doctor because my condition was so bad. I was unable to walk at that time. The doctor administered acupuncture more than 10 days. It was not effective.

When my condition became much worse in 1997, I again consulted a Chinese doctor in a Chinese medical college. He gave me more than 30 doses of Chinese herbs. Those drugs were not very efficacious.

Through reading an advertisement, I found another well-known Chinese doctor in a RA research center. He used a system of Chinese medicine (natural herbs, Chinese medicinal tablets and balls, Chinese medicinal capsules, and Chinese medicinal liquor) for me. He also compounded a new herb medicine for me. At the same time, he used some Western medicine as a supplementary treatment such as Xiong Xian Tai (Western medicine which can enhance the immune system), an intravenous calcium gluconate, Dexamethasone drip, etc. These medicines were effective. After two months of taking these medicines, the swollen joints of my feet were reduced, but then my hands began to swell. Therefore, I stopped the treatment and decided to go to the hospital attached to the medical university in Harbin.”

The above example showed that Chinese doctors sometimes used Western medicine as a supplementary treatment. Patients’ symptoms can be relieved by these Western medicines and so they can continue to follow the Chinese treatment for a long time.

Unlike immigrants who only use Chinese medicine when their condition is relatively stable, mainland patients also use Chinese medicine when their condition is very critical.

“At that time, my condition worsened. All my body joints were hot, very painful, and swollen. I also had a high fever. I was almost paralyzed at that time. Then, I found a well-known Chinese doctor in a RA research center (she received a very similar treatment as that of *Zho*. As mentioned above, *Zho* was also treated by this doctor). I was treated by Dr. Wu for one year. I felt much better. I could walk up and down stairs at a very slow speed. My feet and hands were not deformed at that time. However, my blood test and rheumatic factors showed that my condition was not improved with these medicines. Therefore, I decided to stop his treatment.” (*Bin*)

N. Impact of Chinese medicine

Acupuncture and massage are often the most effective traditional treatments for immigrants with arthritis, not natural herbs. None of the immigrants interviewed mentioned that they had obtained improvement from natural herbs although some of them have taken many doses.

1. Effectiveness of short time usage

Of the 12 patients who used Chinese medicine for a short time, some reported that they obtained successful treatment results from acupuncture and massage without any side effects, although their disease may not be cured.

“When my symptoms occurred in an acute way, I quickly consulted a Chinese healer. My symptoms were gone after the fifth time I used acupuncture. She (a Chinese healer) suggested that I use more in order to strengthen the effect, so I doubled the treatment.”(*Ln*)

“Dr. Ce is massaging me. Also, he gave me Chinese medicine which can build up the function of kidneys and strengthen bones and muscles. My condition has been much improved by these treatments.” (*Lan*)

More immigrants reported that they did not get obvious treatment results from the Chinese medicine. However, because they only used the treatment for a short time period, and the curative effects of Chinese medicine were delayed, it is not necessarily true that the treatments were ineffective.

2. Effectiveness of long treatment periods

For patients who have used Chinese medicine for a long time, most of them (3 out of 4) got effective treatment results from acupuncture and massage without any side effects. Only one had unsuccessful treatment results.

In conclusion, all of the immigrants who obtained successful treatment results from Chinese medicine are patients with a mild or fairly serious condition. Nobody with a serious condition obtained improvement with Chinese medicine.

3. Comparative data from mainland China

The mainland patients reported that their conditions were much improved by Chinese treatment in which natural herbs played a major role. They also reported that acupuncture and massage had only a temporary effect. In addition, not only patients with mild conditions obtained successful treatment results, some with serious conditions also got much improvement from Chinese medicine.

O. Beliefs about Chinese medicine based on treatment experience

Beliefs about Chinese medicine based on treatment experience, showed that immigrants have a more deeply rooted positive attitude about Chinese medicine, when compared to their general beliefs about Chinese medicine. These beliefs impel them to keep trying Chinese medicine whenever they have a chance.

Most of the immigrants (15 out of 19) believed that their disease could be cured or much improved by Chinese medicine. Even those who had unsuccessful experiences with

Chinese medicine, or people who depend on Western medicine which does control their symptoms, still have faith in Chinese medicine. The major reasons for retaining faith in Chinese medicine are as follows:

1. Placing hopes in excellent Chinese doctors

Some immigrants believe that only an excellent practitioner of traditional Chinese medicine can make Chinese medicine highly effective (not just effective). The excellence of a doctor includes his/her reputation and experience.

“I probably will go back to mainland China for two months next year. Hopefully, I can find an excellent, old, Chinese doctor. Probably my arthritis can be improved with acupuncture. Sometimes acupuncture is very effective. However, it depends on the doctors. When I had gastrospasms in China, I had a very successful treatment result from one doctor who used acupuncture on me. However, only he could do that. The treatment results were not effective at all when others did acupuncture on me.” (*Ya*)

“Next week, I will go back to China for a few months. I will see a famous Chinese doctor first. Before I go to see him, I will investigate to see whether he is worthy of the name.” (*Lu*)

Some immigrants attribute the ineffectiveness of Chinese medicine to the fact that they did not find a highly trained Chinese doctor. They still keep trying Chinese medicine in the hope that someday they can find an excellent Chinese doctor who can cure their disease.

“I tried Chinese medicine several times and I did not have the good luck to get any remission. Probably someday an excellent Chinese healer will create a miracle so my arthritis can be treated by him.” (*Wan*)

“I do not know why Chinese herbal medicine was not effective for me. It should have been effective if the doctor in China filled an appropriate prescription for my symptoms.” (*H*)

Immigrants believe that unlike Western physicians who have received the same training, Chinese doctors' training and knowledge is not identical. *Li* said:

"I believe that even for same disease, different Chinese doctors will use their own special treatment methods. Therefore, the fact that doctor A cannot treat your disease does not mean that doctor B also cannot. Even dying people still hope that someday they can find an excellent Chinese doctor who can cure their illness. Such hope plays a positive role during a patient's management process, especially for patients with chronic disease since it makes them feel optimistic."

2. Obscure treatment methods of Chinese medicine

Immigrants believe that Chinese treatment methods are obscure because of the philosophical theory of Chinese medicine. They are not clear about what the treatment really is. When a Chinese doctor makes up a prescription of natural herbs for a patient, the composition of the medication does not have a name and it is specific for every patient (i.e., patients with the same disease will be prescribed different medications, depending on their personal health status). Immigrants consider Chinese medicine's enigmatic treatment methods to be a sign of their usefulness. The following quotes express their thoughts about the unfathomable characteristics of Chinese medicine:

"The basic concept of Chinese medicine is extremely enigmatic and hard to understand. It is very abstract and is perceived through the senses, e.g., *Yin* and *Yang*, lacking in vital energy, etc. However, even the treatment methods are enigmatic, I admit that they are effective, especially acupuncture.....sometimes I think that Chinese medicine may be in the preceding stage of Western medicine. That is why I believe Chinese medicine can perform miracles. It is just impossible to explain and understand completely." (*Wei*)

"Traditional Chinese medical methods have not been approved by modern Western medical science; e.g., main and collateral channels are actual things which are activated by Chi and blood. However, what is Chi? The

interpretation of Chi by Chinese medical sources is obscure and not concrete. Traditional Chinese medicine also has not been approved by Western medical science because it cannot be validated by scientific instruments such as an electronic microscope.”(H)

“I believe that the complexity of Chinese medicine fits the complexity of life. Western medicine has a thorough understanding about life based on genetics. Chinese medicine has a thorough understanding about life based on main and collateral channels and passages through which vital energy circulates. I believe in the theory of Chinese medicine although it is too difficult for me to totally understand.” (Li)

3. No side effects

Almost all of the immigrants believe that Chinese medicine has no side effects. This phenomenon is also considered a contributing factor as to why patients retain faith in Chinese medicine.

4. Comparative data from mainland China

Similar to their immigrant counterparts in Calgary, most of the mainland patients whom I interviewed retained faith in Chinese medicine. They also believed that an excellent practitioner of traditional Chinese medicine can make Chinese medicine highly effective. They paid much more attention to looking for doctors with a very good reputation. Although some of these patients were unsuccessful with Chinese medicine, they attributed the ineffectiveness to the fact that they did not find a good Chinese doctor. They still keep trying Chinese medicine in the hope that someday they can find an excellent Chinese doctor who can cure their disease. The following quotes express the general view of patients who were unsuccessful using Chinese medicine :

“The Chinese doctor who prescribed medicine for me does not have high levels of success in training because he did not study Chinese medicine intensively. Therefore, it is sweeping and unfair to say that Chinese medicine is not good, just because he did not concentrate on Chinese medicine. Only an excellent practitioner of Chinese medicine can make Chinese medicine very effective.” (Fo)

“All Chinese doctors I visited with have a very good reputation The effectiveness of these Chinese medicines was not obvious. However, I will not miss the chance if I can meet another excellent Chinese doctor. I hope a miracle will happen to me.” (Bin)

Chinese medicine’s enigmatic and various treatment methods, also help mainland patients keep a gleam of hope in finding an excellent, traditional Chinese doctor. The following quotes express their ideas about the enigmatic characteristics of Chinese medicine:

“Secret recipes (from the older generation) of Chinese medicine are based on a wealth of accumulated experience. During treatment, Chinese doctors continuously add something or drop something depending on the patient’s situation. Therefore, even though two Chinese doctors use the same secret recipe, doctor A may cure the patient but doctor B may not.” (Fu)

“Chinese medicine is difficult to learn. For example, even the four methods of diagnosis (observation, auscultation and olfaction, interrogation, pulse feeling and palpation) are very difficult to learn. Many practitioners of traditional Chinese medicine have learned the methods of diagnosis over many years but are still confused by the principles.” (Fu)

Most of the mainland patients interviewed also believe that Chinese medicine has no side effects; only one patient mentioned an opinion about potential side effects of Chinese medicine.

“One treatment strategy of Chinese medicine is to ‘use poison as an antidote for poison’. Scorpion, centipede, and snake venom can endanger health if the doctor cannot match the prescription to the illness”.

P. Perceived barriers to using Chinese medicine

The major barriers to using Chinese medicine are cost and a lack of excellent Chinese doctors. A few participants also believe that massage is a dangerous treatment.

1. Immigrant data

a. Cost

The major barrier for using Chinese medicine by immigrants who came from mainland China and Vietnam is the cost, especially for mainland Chinese immigrants. Currently, for 8 of the 16 immigrants who stopped using Chinese medicine, 6 of them stopped using Chinese medicine due to cost.

Both *Ya* and *Lu* only tried Chinese medicine once in Canada and were worried by the high cost of it. They believe that they are unable to use it unless they find a good job. They went to every Chinese clinic in Chinatown to ask the diagnosis price, acupuncture price, etc. They strongly hope that they will be able to afford it eventually.

Lia , *Chi* and *Li* also experienced economic barriers in gaining access to Chinese medicine.

“I am financially dependent upon my daughter and she is not wealthy. I do want to use Chinese medicine but I cannot afford the extra cost of it.”
(*Lia*)

Some said that if health insurance would cover the cost, they would not only use it for arthritis but also as a tonic to build up their health.

b. Lack of excellent Chinese doctors

Some immigrants believe that unlike Chinese doctors in mainland China who receive a good medical education and have rich clinical experience, many Chinese healers in Canada have relatively superficial knowledge of Chinese medicine. This barrier also directly prevented them from using Chinese medicine. For example:

“It is very difficult to use Chinese medicine in Canada. Maybe in mainland China, my arthritis can be treated successfully with Chinese medicine. Many Chinese healers in Canada have only a superficial knowledge of Chinese medicine. They just want to promote the sale of their medication. They just want your money! They really do not focus on how the patients can be cured. I do not trust them. Who knows whether they are real Chinese doctors.” (*Ya*)

“In Canada, many Chinese doctors switch to medicine, a field they were not originally trained for. This results in a lack of credibility which is why many Chinese people in Canada treat Chinese medicine only as a tonic to build up health, not as a treatment for disease. Also, the development of Chinese medicine in Canada is restricted due to the fact that the Western health care system does not cover the cost of using Chinese medicine. A Chinese doctor with excellent treatment skills will become marginalized because he is living in Canada, and does not have opportunities for further advances.” (*Li*)

Chinese healers in Canada usually work in a fairly passive way. Officially, they are only allowed to practice acupuncture. Some do not want to prescribe natural herbs to patients because they worry that Canadian patients will sue them (personal communication with some Chinese healers in Calgary). Therefore, it is unlikely that they will use secret recipes or specific treatments developed by themselves. They are also unlikely to do further research regarding concoctions of medicinal ingredients in Canada. Treatments they use in Canada are generally based on very common principles of Chinese medicine. These medical concoctions are not specific enough for the patients.

c. Massage: a dangerous treatment

Three immigrants believe that the most dangerous treatment in Chinese medicine is massage. They believe that with massage it is possible to cause disastrous effects such as disability or death. This worry is based on experiences of other Chinese immigrants.

“My friend’s knee was injured and he went to see a Chinese healer for massage. He got a very unsuccessful treatment result and had his kneecaps surgically replaced. Therefore, I believe that without X ray, massage is a very dangerous treatment.” (*Wan*)

“Since there are many important acupoints on the waist and stomach, I only dare to use massage on my arms or legs.” (*Ya*)

2. Comparative data from mainland China

Mainland patients’ barriers to using Chinese medicine are fewer than using Western medicine because traditional treatment is usually cheaper than Western treatment.

Some people mentioned that it is also difficult to find an excellent Chinese doctor in mainland China because there are too many advertisements about famous Chinese doctors and many of them are not true. As *Zho* reported:

“The major problem is that I cannot find an excellent Chinese doctor. Through TV, newspapers and radio, you can get many advertisements for Chinese clinics. However, if you follow these, you just cannot get any improvement. Sometimes the technical equipment and conditions in these Chinese clinics are very bad, the medication is very expensive, and the doctors are professionally hostile. You just cannot trust them.”

Q. Combination of Western and Chinese medicine

Six immigrants used, or are using a combination of Western and Chinese treatment in Calgary without their physicians' recommendations.

Wei is using injections from her specialist and is also using massage and natural herbs from a Chinese healer. *Chi* is using Anti-inflammatory drugs to control her pain and is also using herbal medicine. *H* is using the combination of acupuncture, massage, Aspirin and exercise. *Lia* is using the combination of *Tritergium wilfordii* Hook F (Chinese medicine) and Apo-Naproxen. *Ln* was using acupuncture and some Analgesics during her treatment period. *Ya* used Physiotherapy and acupuncture at the same time for her elbow.

As mentioned above, All seven patients in mainland China have experienced using a combination of Chinese and Western medicine. Three of these patients reported that they received very successful treatment results from a combination of Western/Chinese medicine. Nobody reported any unsuccessful experience with the combination method.

R. Return to Western medicine

When Chinese medicine was not effective, both immigrants and mainland patients returned to Western medicine. This was especially true of patients with serious conditions; otherwise, their conditions would become critical.

For immigrants with a serious condition who depend on Western medicine, even if they have faith in Chinese medicine, they usually do not dare to try it again, since they are afraid of severe attacks of arthritis caused by stopping Western medicine.

“The Chinese healer gave me natural herbs and told me to stop Methotrexate and anti-inflammatory drugs. I suffered the worst attacks of my arthritis which caused severe pain and swelling over my whole body. Finally I could not even open my lower jaw. I could not move and could not sleep.....”(Wan)

However, mainland patients with a serious condition still plan to try Chinese medicine again. They only completely depend on Western medicine when they are in a very desperate state. Although the mainland patients interviewed were inpatients then, all of them were only in hospital for a period of 20 days. When their condition becomes a little better, some reported that they will change their treatment to Chinese medicine. Some also reported that they will stop Western medicine as soon as they find an excellent Chinese doctor. For example:

Zho was hospitalized in the hospital attached to the Harbin medical university and is being treated with Methotrexate, Voltaren, Vitamin E, Calcium, and Dexamethasone. Although Western medicine can control her symptoms, she plans to try a very dangerous Chinese treatment after hospitalization:

“I heard from somebody that there is a sanatorium in DaLian (a Northeast city). One Chinese doctor is using a special treatment for RA patients. It is a very painful treatment which lasts for one week. Patients will get many big blisters on their whole body. I heard that many patients were cured with this treatment. I am collecting information now, I may go to there after I get out of hospital.”

S. Summary

In this section, a detailed description of the emergent categories and subcategories was presented. Demographic variables, such as age, sex, marital status, and education did

not impact on beliefs and management strategies. However, some variables such as immigrants' country of origin, type of disease, and the severity of disease carry some impact (see detailed description in Chapter 5).

Further description about interactions between categories/subcategories, and the development of a theoretical model for illness management strategies, among Chinese immigrants living with arthritis, will be described in chapter 5.

CHAPTER 5

DISCUSSION

The discussion chapter first presents an overview of the relationships between categories and subcategories (major findings). Then the development of a theoretical model will be presented. Finally, comparison of the findings with existing knowledge, the strengths, significance and limitations of the study, implications of the study, and suggestions for future research will be presented.

I. OVERVIEW OF MAJOR FINDINGS

This section will describe relationships between categories and subcategories. Then, the model for illness management strategies among Chinese immigrants living with arthritis will be presented.

A. Relationships between categories

1. Arthritic symptoms: factors impacting directly on illness management (FD)

Symptoms are the central event from which actions/interactions originate. The severity of arthritic pain and swelling leads directly to different management strategies. Under conditions of an initial onset or mild conditions, immigrants usually use self-care remedies. Only a few patients with acute attacks use Western/Chinese treatment directly.

Patients with fairly serious conditions usually have to use some types of medical treatment. However, most do not fully comply with either Western or Chinese physicians' recommendations. Many change treatments frequently (from Western to Chinese medicine or the other way around) based on their beliefs and symptoms.

Patients with serious conditions depend mainly on Western medicine because they perceive that Western medicine is able to control their symptoms immediately. They usually follow physicians' recommendations well.

2. General beliefs about Western medicine: factors impacting indirectly on illness management (FID)

Immigrants reported their general beliefs about Western medicine in an open-minded manner. The belief that Western medicine cannot cure or has only temporary effects for chronic diseases influences their management strategies. However, this belief does not keep them from using Western medicine.

3. General beliefs about Chinese medicine (FID)

The general beliefs, that Chinese medicine treats the cause of the disease, and is effective for chronic diseases, help immigrants retain faith in Chinese medicine. Despite this, consulting Western physicians is the first step in seeking medical treatment. Chinese immigrants usually use Chinese medicine only when they are dissatisfied with Western medicine.

4. General beliefs about combining Western and Chinese medicine

(FID)

Due to the fact that immigrants are familiar with a combination of Western and Chinese medicine, and believe that the combination is better than using only one system, they frequently use a combination of treatments without their Western physicians' knowledge.

5. General beliefs about arthritis (FID)

The majority of the immigrants interviewed perceived that being chronically cold and getting wet are contributory factors of arthritis. Because they believed that arms and legs are less important than internal organs, they tended to ignore their arthritic symptoms until their condition became much worse. These beliefs are major contributory factors for arthritic immigrants' passive attitudes towards dealing with their illness. These beliefs also determine the types of self-care remedies chosen (e.g., keeping warm and exercise).

6. Illness management strategies and their impact

There are four core management strategies for the purpose of controlling arthritic symptoms: self-care remedies, consulting Western physicians, consulting traditional Chinese doctors, and using a combination of Chinese and Western medicine.

a. Self-care remedies

Self-care remedies are taken in response to early symptoms, or as a supplementary method during the treatment process. The effectiveness of self-care remedies makes immigrants continue to use them and not seek medical treatment, while the ineffectiveness of self-care leads most of the immigrants to use Western medicine.

b. Consulting Western physicians

Consulting Western physicians is done in response to the ineffectiveness of self-care remedies, an acute onset, or a fairly serious condition. This is the first stage of medical treatment sought by immigrants due to the convenience, fast curative effects of Western medicine, and coverage by the health care system.

Temporary relief and bad side effects from Western medicine cause most immigrants to seek help from Chinese medicine. Side effects sometimes cause other symptoms in their body, but do not worsen their arthritic symptoms.

c. Consulting Chinese doctors

Chinese doctors are often consulted in response to the ineffectiveness of Western medicine. However, many immigrants used Chinese medicine for just a short time. The outcomes of Chinese medicine were either effective or ineffective, no one reported temporary effects or side effects from Chinese medicine.

d. A return to Western medicine

A return to Western medicine is often taken in response to the ineffectiveness of Chinese medicine. For patients with mild or fairly serious condition, when their conditions become stable using Western medicine, many continue to try Chinese medicine. Patients with serious conditions appear unwilling to try it again, although they retain faith in Chinese medicine.

e. Combination of Chinese and Western medicine

Using the combination of Chinese and Western medicine does not seem to be immediately linked to the stages of disease or the management process. Chinese immigrants use both in a very natural manner because they are familiar with the idea of combining both systems.

7. Beliefs about Western medicine based on treatment experience (FD)

After receiving Western treatment, many immigrants (especially those with mild or fairly serious conditions) developed negative feelings towards both the treatment and the physicians. This is reportedly due to the side effects of Western medicine and Western physicians' indifferent manner (i.e., do not pay attention to patients' explanations, too technical and blunt interpretation, and excessive dependence on diagnostic tools). These beliefs and feelings powerfully influence their ensuing behaviors such as stopping the use of Western medicine, using it for a short time only, or turning to Chinese medicine.

8. Beliefs about Chinese medicine based on treatment experience (FD)

Beliefs about Chinese medicine based on treatment experience, showed that immigrants have a deeply rooted positive attitude about Chinese medicine. These beliefs impel them to keep trying Chinese medicine whenever they have a chance. Even though many have had ineffective experiences using Chinese medicine, this neither causes them to lose hope in Chinese medicine, nor is it the major reason which causes them to stop Chinese medical treatment. The major reasons for retaining faith in Chinese medicine are: (1) Chinese immigrants believe that an excellent Chinese doctor can bring about miracles; and (2) they consider Chinese medicine's enigmatic treatment methods to be a sign of their usefulness.

9. Barriers to using Western medicine (FD)

Perceived barriers of using Western medicine include three major subcategories (1) lack of knowledge about Western medicine, (2) cost, and (3) worry about job loss. Lack of knowledge about Western medicine (including language problems) causes passive attitudes towards using Western medicine in the beginning, but they are not very influential during the treatment process. The cost of treatment and worry about job loss have a very limited influence on their behavior.

In conclusion, concrete barriers to using Western medicine are less influential than perceived lack of confidence in Western medicine and lack of trust in Western physicians.

10. Barriers to using Chinese medicine (FD)

Perceived barriers to using Chinese medicine include two major subcategories (1) cost and (2) lack of excellent Chinese doctors. The perceived barriers to using Chinese medicine are more influential in affecting behaviors than perceived barriers to using Western medicine, especially the cost. These barriers powerfully influence the immigrants to stop using Chinese medicine, or use it for a short time only, despite their belief in Chinese medicine.

11. External factors (FD)

Friends' suggestions and family members' help influence Chinese immigrants' behavior in managing an illness. Friends' suggestions and previous successful/unsuccessful experiences are the most influential factors.

B. Model development

Based on the relationships between the categories and their subcategories presented above, a model for illness management strategies among Chinese immigrants living with arthritis was developed grounded in the data collected in the interviews. The model is presented in Figure 1.

Figure 1. Model for illness management strategies among Chinese immigrants living with chronic Osteoarthritis or Rheumatoid arthritis

II. COMPARISON OF THE FINDINGS WITH EXISTING KNOWLEDGE

This section is organized into two sections: (1) Comparison of relationships identified in the model to descriptive information from the literature, and (2) Comparison of the resulting model with existing models of illness management.

A. Comparison of relationships identified in the model to descriptive information from the literature

In this section, literature which is specific to, and directed at relationships identified in this study is reviewed in order to verify and elaborate on these findings.

1. Beliefs about Western/Chinese medicine impact on illness management strategies

Several other studies validated the major finding of this study which are that both immigrants and mainland patients believe that Western medicine is like taking out the stem but not the roots. Western medicine is believed to be good for surgery and to be more effective in acute diseases, but not as effective in the management of chronic diseases (Yang, Lin, & Lawson, 1991). Chinese medical cures are usually used to treat conditions with prolonged symptoms, which is like digging up the roots (Elfert et al., 1991; Lai & Yue, 1990).

2. Chinese immigrants believe that the combination of Western/ Chinese medicine is the ideal treatment for arthritis

This phenomenon is congruent with the changes in health care in China and Taiwan, in which political values emphasize the use of both traditional and Western medicine (Chi, 1994). In mainland China, since the 1950's, the Chinese Government began to promote the idea of combining Chinese and Western medicine. Almost every hospital has a Chinese, as well as a Western, medical department. Also, in an official, traditional Chinese medical hospital, most of the Chinese doctors use diagnostic methods and therapies similar to these used by Western physicians. Current practitioners of Chinese medicine who graduate from a Chinese medical institute have also been trained in Western medicine; and many physicians trained in Western medicine take one or two year courses to learn Chinese medicine in mainland China (C. J. Fu, Y. B. Huang, F. Z. Zhou, & P. Zhang, personal communication, September, 1997).

As with mainland China, the government in Taiwan focuses on combining traditional Chinese medicine with Western medicine. Students in the China Medical College's Department of Chinese Medicine are trained in the same modern Western medicine curriculum as all other Western medicine students (Wu & Hu, 1980).

3. Immigrants' beliefs about arthritis impact on their illness management strategies

One study found that immigrant women attributed their arthritis to the damp, cold conditions of their workplace (Dyck, 1992). Another review found that the postpartum

period is considered dangerous by Chinese because the woman is more susceptible to cold weather than normal because in confinement their joints are very loose and thus are easily affected by wind, damp and cold. Often, she is warned that if she does not take care she may suffer long-term consequences such as rheumatism or enduring pain in her limbs. To avoid this possibility she must avoid cold foods and stay inside to avoid cold winds. This common practice is called “sitting for the month.” (Lai & Yue, 1990). Although mainland patients did not mention inadequate post-natal care as a cause of arthritis, most likely they share this belief with immigrants.

Although no literature deals with the belief that arms and legs are less important, many studies mention that the Chinese view their ten internal organs as central to their physiological and psychological well-being (there are five important solid organs: liver, heart, spleen, lungs, and kidney and five hollow organs: gallbladder, stomach, large intestine, small intestine, and bladder) (Hoang, 1985; Lai & Yue, 1990; Masi, 1988; Spector, 1991). These ten organs have a complex relationship which maintains the balance and harmony of the body. Diseases are caused by an upset in the balance and harmony of the body. In addition to these ten internal organs, they believe that the back is the home of the chest, the loins store the kidneys, the knees store the muscles, and the bones store marrow (Spector, 1996), but these functions are secondary to good health.

4. Friends' suggestions and successful/unsuccessful experiences are important factors which determine Chinese immigrants' treatment choices.

According to many traditional immigrant studies, family plays an important role in how and when individuals seek formal health care (Leclerc et al., 1994). However, in this study, only a few immigrants interviewed mentioned that their family members' suggestions were important in helping with their treatment choice. Immigrants with arthritis usually talk with their friends more than they talk with their family, this could be because most of these patients are not employed. Their husbands, daughters or sons are usually less informed than the patients because they are pre-occupied with their own work or study commitments. They do not have a lot of time to take care of their arthritic family members and they may not take it seriously.

5. Side effects of medication and physicians' manner affect immigrants' illness behavior

Some literature regarding Chinese patients' worries about side effects was also found. According to Lai and Yue (1990), Chinese believe in "all things in moderation". Thus, they think that taking medicine over an extended period of time will weaken their bodies. Often they feel that Western medicine is too potent for them because of their small bodies and they may reduce dosages to a quantity they believe suitable, e.g., an elderly Chinese with diabetes may reduce his insulin because it is "foreign" and he thinks it

jeopardizes his health. It is crucial for health professionals to give patients specific and clear instructions about medications (Lai & Yue, 1990).

Although some literature mentioned immigrants' complaints about Western physicians (Anderson, 1991), no literature mentioned such strong criticism towards Western physicians as did the immigrants interviewed.

Lai and Yue (1990) also reported that Chinese patients associate symptomatic relief with the doctor's skill rather than the effectiveness of the medicine. It is not uncommon for patients to attribute cures to the doctor, not the medicine. Therefore, it is understandable that disliking Western physicians' approach becomes an important barrier for immigrants in accessing Western medicine.

In conclusion, Chinese people value and trust a physician with rich clinical experience. They believe that a physician's clinical experience is the most important aspect of his training. Therefore, they do not trust physicians who are very young or who have just graduated. Without clinical experience, they believe that many diseases (especially common diseases such as pneumonia and chronic appendicitis) will be mis-diagnosed.

6. Chinese immigrants retain faith in Chinese medicine

There was no literature which mentioned that immigrants/mainland patients do not lose hope in Chinese medicine even if it is not effective; nor any research which mentioned that placing hopes in excellent Chinese doctors and enigmatic treatment methods are contributory factors for patients retaining their faith in Chinese medicine.

7. Role of beliefs

Wright et al. suggested that beliefs can be good or bad for one's health. Some beliefs are more useful than others in coping with illness. To uncover the beliefs that are useful and those that are not, a simple dichotomy of beliefs was provided: *constraining beliefs* versus *facilitative beliefs*.

"*Constraining beliefs* perpetuate problems and restrict options for alternative solutions to problems. *Facilitative beliefs* increase opinions for solutions to problems" (Wright, Watson, & Bell, 1996, p. 42).

Constraining beliefs and facilitative beliefs are not very useful for this study because immigrants tend to use two contrasting management strategies: Chinese medicine vs. Western medicine. As a result, one belief has two functions. A facilitating belief for one type of medicine (e.g., Chinese medicine) is automatically a constraining belief for the other type of medicine (i.e., Western medicine) and vice versa. Therefore, classifying beliefs into constraining beliefs and facilitative beliefs would complicate things and make it difficult to explain findings.

Instead of classifying beliefs based on their usefulness for one's health (constraining beliefs and facilitative beliefs), this study classifies two types of beliefs based on their degrees of impact on illness management strategies. These are *general beliefs* and *beliefs based on treatment experience*.

B. Comparison of the resulting model with existing models of illness management

In this section, two key components of this informal, substantive model which are considered to be important and new, were compared with the existing formal models of illness management.

1. Different types of illness management strategies

This model explains how and why Chinese immigrants use different management strategies (i.e., self-care remedies, Western medicine, Chinese medicine, and the combination of Western and Chinese medicine), and the interactions between management strategies. This model is different from most of the existing behavior models which were designed to identify the factors underlying utilization of Western medicine.

2. Beliefs about Western/Chinese medicine based on treatment experience

The present model highlights immigrants' beliefs about Western/Chinese medicine based on their treatment experience, because these beliefs are very specific, important and influential, regarding their management strategies.

Many existing health-related behavior models developed belief components with which to explain illness behavior. For example, The Health Belief Model assumes that individuals choose their specific actions based on the perceived benefit of taking a particular action (Rosenstock, 1990). The Theory of Planned Behavior states that both

beliefs about the outcome of a particular behavior, and a positive or negative evaluation of the behavior, compose attitudes towards a behavior (Ajzen, 1985). However, these beliefs are patients' assumptions about the treatment outcomes before the actual behavior is taken, not beliefs relating directly to the actual received treatment.

Some illness behavior models concentrate on the illness experience in every stage of medical care and help-seeking behavior. However, they are usually concerned with concrete items such as successful/unsuccessful communication and interaction between the patients and the practitioner which influence the individual's decision, etc. (Wolinsky, 1980). Few models specify beliefs based on treatment experience which then influences their following management strategies.

III. STRENGTHS AND LIMITATIONS

A. Strengths

1. The theory

This is a culturally sensitive model because it contributes new and unique information regarding Chinese immigrants' beliefs about Chinese/Western medicine and Chinese/Western physicians and possibly other health professionals. The cultural factors identified are helpful for providing culturally sensitive care which can lead to greater satisfaction and well-being for Chinese immigrants. The model can provide potential guidelines for further professional action when they are evaluated and tested cautiously in future research.

2. Methodological quality

The strengths of methodological quality include expert reviews, data from mainland China, positive feedback from participants, and maximum variation.

a. Expert reviews

The transcripts of interview and categories of the model were reviewed and coded by three experts. They commented that these categories delineated a large body of information regarding illness behavior, especially the beliefs regarding Chinese immigrants' illness management strategies; and also, that the transference from open coding to theoretical coding was very well done. In addition, the experts' codes were very similar to the established codes.

b. Data from mainland China

This study benefited from the additional information collected in mainland China. This ethnic background information became the supporting or comparative basis which increased understanding of information obtained from the Chinese immigrants.

c. Positive feedback from participants

The findings received very positive and encouraging feedback from the five patients who were sent a two-page summary of the findings (three women and two men with different disease status and different beliefs towards Western/Chinese medicine). All reported the findings as an accurate account of their experience.

d. Maximum variation

The subjects participating in this study showed a wide range of age, sex, education, occupation, country of origin and disease status. These results show that maximum variation was achieved to a major degree. A total number of 19 immigrants and 7 mainland patients were interviewed. These subjects represent a relatively large number in terms of qualitative studies of this nature.

B. Limitations

In this section, two types of limitations will be described: (1) limitations of the study (the actual existing limitations inherent in this study) and (2) limitations of the design (potential limitations with qualitative research).

1. Limitations of the study

Two limitations were identified in this study. *First*, this study was only able to recruit three men, and none of them had serious RA. However, this limitation was minimized by: (1) these three men provided sufficient representative data to allow transferability judgments to be made by other researchers; and (2) the researcher provided background information about men with serious RA in mainland China. This information supported the conclusion of this immigrant study that gender does not impact on beliefs and management strategies. *Second*, two self-reported osteoarthritis patients were interviewed who did not have a physician's diagnosis. However, the researcher reduced

the effect of the limitation by talking with an OA specialist about their symptoms. Based on the specialist's conclusion, these patients' symptoms fit the osteoarthritis criteria.

2. Limitations of the design

a. Generalizability

In a qualitative research, the relatively small number of participants and purposive sampling limit the generalizability of the results. However, unlike quantitative research where random sampling is important for generalization, the purpose of this qualitative study was to learn about a specific phenomena (illness management among Chinese immigrants with arthritis) in natural settings, and to develop concepts to deal with this phenomena by emphasizing the meanings, experiences, and views of the participants (Mays & Pope, 1995), rather than rigorously testing research hypotheses.

b. Subject recall bias

The validity of the data may be limited because of the possibility of subject recall bias. Subjects may be unwilling to give information or be unable to express their feelings or previous experiences. In this study, the researcher minimized this bias by setting a conversational tone for the interview. All participants were quite at ease and showed a desire to explain their feelings. The funnel/inverted funnel approach was also used to arouse the informants' train of thought.

c. Researcher bias

In grounded theory research, researcher bias is always a potential problem since theoretical sensitivity of the researcher plays a very important role in the data analysis and theory development in the study. It is possible that a researcher unintentionally uses his or her feelings, curiosity, hunches, and intuition to explore and understand the setting. As a result, one researcher may arrive at results quite different from another or from data collected by a different method (Dooley, 1990).

In order to minimize researcher bias, the researcher maintained an attitude of skepticism toward any categories or hypotheses arising from the research, by validating them repeatedly with the data themselves. She also periodically stepped back and ask herself: What is really going on here? Does what I think I see fit the reality of the data? (Strauss & Corbin, 1990).

IV. IMPLICATIONS

A. Implication for theory development

By providing a flow chart which describes how Chinese immigrants generally manage their arthritis, this study suggests a unique direction for studying management strategies among people who have their own healing system, and who therefore tend to use different management strategies.

B. Implications for patients

The present study demonstrated that Chinese immigrants with arthritis have passive attitudes towards dealing with their illness. They do not seek medical treatment until their conditions become critical. Chinese immigrants should be encouraged to participate in dealing with their illness and take more responsibility for their illness as mainland patients do. In order to overcome barriers in using the health care system in Canada, they should make more effort to learn about the Western health care system. They need to overcome preconceived ideas towards Western medicine, learn about the good aspects of Western medicine/physicians, and learn how to deal with Western physicians. They also should learn how to find information related to their illness.

If they can speak English, they should not look for Chinese speaking specialists, because Chinese specialists usually have too many patients (e.g., There is only one Chinese speaking rheumatologist in Calgary. He reported that he treats more than 100 patients a week, most of them Chinese). Chinese specialists might treat their patients in an arrogant and condescending manner as reported by respondents because they are in such demand.

C. Implications for health professionals

The findings show that professionals should be aware of several important characteristics among Chinese immigrants. For example, physicians should be aware of the importance of developing skills in intercultural communication, in order to take more responsibility in providing culturally appropriate and sensitive care for immigrants with different backgrounds. When dealing with Chinese immigrants, even if the lab results fail

to show the problem, they should still offer an explanation about the possible disease and the function of any medication being prescribed. Without clear statements and explanations, Chinese immigrants feel that the physicians are not qualified and have little confidence in them. Also, physicians should pay more attention to their Chinese patients experiences and explanation about their illness.

For Chinese immigrants who are hospitalized or long term care center residents, nurses are central to quality care. They also need to be informed of Chinese immigrants' beliefs and feelings about their illness and treatment. For example, in order to avoid Chinese immigrants' misunderstandings and disappointments, nurses should be guarded in their speech when explaining the real limits of the medication to them. In addition, a nurse may need to acknowledge each person as a unique individual and take time to listen and respond sympathetically, because Chinese immigrants have very negative feelings towards professionals who have an indifferent manner.

D. Implications for the health care system

The findings showed that Chinese immigrants with arthritis prefer to use Chinese medicine and that Chinese medicine is effective for many of them. Their major barrier to using Chinese medicine is that they do not get reimbursed; if Chinese medicine could be part of the Canadian health care payment system, specifically in the area of arthritis, perhaps Chinese immigrants would seek more traditional Chinese treatments and manage their arthritis more successfully.

E. Implications for medical education

Education to raise awareness of cultural factors in immigrant populations regarding their health is very important. Students in the health professions should be knowledgeable about cultural beliefs related to health and illness among people of diverse cultures. They should be informed about the influence of cultural beliefs and barriers to help-seeking behavior by immigrants, so they can successfully incorporate this knowledge into clinical practice.

V. SUGGESTIONS FOR FUTURE RESEARCH

A. Validating and testing the model

This study is only a preliminary theory. Future investigations are needed with other groups to validate, refine and test these findings. Some components in the present model specifically require further investigation because they are new and little information is available. The researcher suggests that the following groups should be investigated.

First, a similar Chinese immigrant population with arthritis should be investigated. *Second*, the beliefs and behaviors of Chinese immigrants with different chronic diseases should be investigated. This information can add variations to the present model. *Third*, findings should also be investigated with different ethnic groups who have their own healing methods (e.g., Asian-Canadians, native people), to see if they have similar/different belief systems and behavior patterns from those of the Chinese immigrants.

Only a quantitative study can test findings with sufficient and appropriate sampling, then produce factual and reliable outcome data that are generalizable to a large

population. It is suggested that an instrument be developed based on the model to test the validity and reliability of the knowledge about the beliefs and management strategies, through quantitative, hypothesis-testing research designs.

In addition, in order to increase the understanding and knowledge about a long-term chronic disease such as arthritis, the temporal relationship developed from this study needs to be further validated and refined. This could be accomplished by a longitudinal study in which each subject serves as his or her own control. Also, by following the same subjects over a period of time, the researcher would be able to assess changes in the variables of interest over time.

Longitudinal research is suggested for assessing the management process provided in this study. Although this study did not indicate a changing pattern in beliefs at different disease stages, information from a longitudinal study would also be useful in making more specific causal judgment about how beliefs relate to management strategies.

As mentioned before, most demographic variables do not impact on beliefs and management strategies; only three demographic variables (i.e., country of origin, type of disease, the severity of disease) seem to carry some impact. Therefore, in addition to validate and test the major findings presented in Chapter 5, section I (overview of relationships), hypotheses which related to above three demographic variables are also suggested to be tested in future research in large-scale, controlled investigations.

1. Country of origin

There are three major differences in illness management between patients that originated in different countries:

- (1) In comparison to immigrants who came from Hong Kong or Taiwan, immigrants who came from mainland China are more likely not to follow physicians' recommendations.
- (2) the major barrier toward using Chinese medicine by immigrants from mainland China and Vietnam is the cost of treatment, especially those from mainland China.
- (3) In comparison to immigrants who came from Hong Kong or Taiwan, immigrants who came from mainland China are more likely to complain about the treatment skills of Chinese healers in Canada.

The researcher suggests the following explanations regarding the above hypotheses. *First*, in mainland China, there are many more people per physician than in Hong Kong or Taiwan. Because of the inconvenience of visiting doctors, mainland patients become relatively knowledgeable and independent about their health care and illness. They use self-care remedies based on self diagnosis for many common diseases. As they are fairly well informed, they frequently doubt the correctness of physicians' recommendations, and do not always follow physicians' recommendation. *Second*, in mainland China, the treatment skills of Chinese healers are at a much higher level than those in Hong Kong and Taiwan. Therefore, mainland patients are critical of Chinese healers in Calgary because most of them came from Hong Kong. *Third*, due to political circumstances, mainland patients' financial conditions are much worse than those in Hong Kong and Taiwan.

2. Type of disease

There are four seeming differences in illness management between OA and RA patients:

- (1) RA patients, especially those with a fairly serious or serious condition, are more deeply concerned about the side effects of Western medicine than OA patients.
- (2) RA patients, especially those with a fairly serious or serious condition, believe more strongly that their arthritis cannot be cured or much improved with Western medicine than do OA patients. However, they have a more accepting attitude towards Western medicine than OA patients.
- (3) RA patients, especially those with a serious condition, have fewer negative feelings towards Western physicians than OA patients.
- (4) RA patients, especially those with a serious condition, tend to follow physicians' recommendations better than OA patients.

In comparison to OA patients, RA patients have more treatment experiences with Western medicine because their symptoms are constant and they have to use some type of treatment continuously (mainly Western medicine). By being in frequent contact with Western physicians, they were able to feel more positive towards them. RA patients worry more about prescribed medication than OA patients because the medications for RA patients usually have stronger side effects than those for OA patients. However, they have a more compliant attitude towards medication than OA patients because they depend on them, and cannot stop using them.

In this study, RA patients have more severe conditions than OA patients. Therefore, the impact of different disease types may also depend on the severity of the disease.

3. Severity of disease

There are four seeming differences in illness management between Chinese immigrants with a different severity of arthritis:

- (1) Immigrants with a serious or fairly serious condition tend to do more exercise than those with mild conditions.
- (2) Immigrants with a serious or fairly serious condition tend to use self-care remedies as a supplementary treatment while they are taking medication.
- (3) In comparison to immigrants with a severe condition, immigrants with a mild or fairly serious condition are more likely to obtain successful treatment effects from Chinese medicine.
- (4) Only patients with a serious condition appear unwilling to try Chinese medicine again after receiving unsuccessful treatment from Chinese healers.

There are factors which may influence the effectiveness of Chinese medicine. For example, many immigrants only use Chinese medicine for a short time and, many Chinese healers in Calgary may have only a superficial knowledge of Chinese medicine.

B. Final reflections

This preliminary model was developed to provide a basis for studying the management of arthritis. Although is not a study of general illness management, it could also be applicable to other studies such as asthma or hypertension, after being validated with further research. It is assumed that for these diseases, many Chinese believe in Chinese medicine. For these diseases, Chinese medical theory is believed to be well developed and there are various treatments available. On the other hand, for these diseases, Western medicine is believed by the Chinese to be not especially effective.

Therefore, this model does not easily apply to study diseases which mainly depend on Western medicine, such as diabetes; for which Western medicine is very effective. This is not to say that beliefs are not important in management strategies, but that the options are fewer and more clear in the treatment choice.

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APPENDIX 1

關於患關節炎的中國移民如何對待自己疾病的調查研究

卡城大學社會健康科學系的張進進女士(碩士研究生)正在對卡城患有關節炎中國移民的疾病治療及自我保健情況進行調查研究。張女士準備和大約20個有關節炎症狀的病人和被醫生診斷為有風濕性關節炎或骨關節炎的病人分別面談一次(每人大約需要45分鐘)。面談的內容大致如下：談談關節炎對您生活的影響以及您是如何根據病情配合醫生的治療和如何進行自我保健的情況。如果您允許的話，這次面談可能會被錄音以供分析時用。面談的時間、地點以及用何種語言進行面談(國語、粵語或英語)均由您來決定。

您所提供的資料將被嚴守秘密。在張女士的論文中不會披露資料提供者您的名字及任何情況。當此項研究結束後，您將會收到一份概括扼要的研究結果報告。

雖然您不會從該項研究中獲取直接的利益，但是對於加拿大醫療保健提供者來說，了解您，一個患有關節炎的中國移民的病程體驗和所採取的治療、保健措施是非常重要的。您所提供的資料很可能會對加拿大醫療保健制度的改進產生一定的作用。所以張女士和她的導師 M. J. Verhoef 教授都非常希望您能夠熱心地參加此項研究。

如果您願意參加此項研究的話，請將同意書簽字後放入同封已付過郵資的信封中寄出。張女士會和您聯係並約定面談時間。

如果您有不明白的問題，可直接電話詢問張女士或她的導師 M.J. Verhoef 教授。她們的電話號碼是：

張進進：(403)220-7368 (辦公室)

(403)241-9210 (家)

Dr. M. J. Verhoef: (403) 220-7813 (辦公室)

如果您還想詢問有關參加者權利的問題，請和卡城大學醫學系醫學倫理辦公室聯係。電話：220-7990。

APPENDIX 1

How Chinese immigrants with arthritis deal with their disease

Ms. Jinjin Zhang, a graduate student in the Department of Community Health Sciences, Faculty of Medicine, University of Calgary, is conducting a research project on how Chinese immigrants with arthritis deal with their illness. Jinjin plans to collect information on this topic by interviewing about 20 Chinese patients who have rheumatic/osteoarthritic complaints or are diagnosed with rheumatoid arthritis or osteoarthritis by physicians. The interview will take approximately 45 minutes and will be audio-taped with your permission. The interview will be at a place of your choice and in the language of your choice (Chinese or English). The type of questions she wants to discuss with you are your experiences with arthritis, your beliefs about the management of your arthritis, and what you have done to deal with arthritis.

The information you share with Ms. Jinjin Zhang will be kept confidential and it will not be possible to identify you in anything Jinjin writes about her study. At the end of the study, you will receive a summary of the results.

While it is not expected that you will receive any immediate direct benefits from this study, the knowledge gained about the health belief system as related to illness management among Chinese immigrants living with arthritis, is important for health care providers. Also, the results of this study may lead to recommendations for the western health care providers. Therefore, your cooperation is much appreciated.

Taking part in the study is entirely voluntary. If you are willing to participate in this study, please return the enclosed consent letter to Ms. Jinjin Zhang. She will contact you to make an appointment for an interview.

If you have any questions about the study, please call Jinjin Zhang (220-7368(O), 241- 9210 (H)) or her supervisor Dr. M. J. Verhoef (220-7813).

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, at 220-7990.

APPENDIX 2

同意書

張進進女士：

我已收到您的研究課題簡介並願意參加此項研究。您可以和我直接聯係。

我的名字是：_____，

電話號碼：_____，

地址：_____。

簽名

日期

(您簽字以後，請將它放入同封已付過郵資的信封中寄出)。

Letter of consent

Dear Jinjin Zhang:

I have received information regarding your study and am interested in participating in this study. My name is _____.

You may contact me at (address) _____.

(telephone number) _____.

Signature

Date

(When you have signed this letter, please put it in the prepaid envelope and return it).

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