

SUPPORTING CHINESE-SPEAKING CANCER PATIENTS TO MAKE SAFE AND
INFORMED COMPLEMENTARY MEDICINE (CAM) DECISIONS

by

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Abstract

Clinical observation indicated that there were a substantial number of Chinese-speaking cancer patients receiving care at the British Columbia Cancer Agency (BCCA) located in Vancouver, where the second largest Chinese Canadian population resides. CAM has been popular among Chinese-speaking cancer patients around the world, but little research has been done to examine the prevalence of CAM use in these patients in Canada. It was found that almost half of these patients used CAM and their preferred choice of CAM therapy was biological-based therapy that included natural health products (NHPs) and traditional Chinese medicine (TCM). The use of CAM is controversial because of its potential to interact with conventional cancer treatment and other medications. Due to a lack of culturally relevant CAM information and decision support intervention, many Chinese-speaking patients were using CAM without adequate support. This type of support is urgently needed to help these patients to make safe and informed CAM decisions. Knowledge about their CAM decision-making experiences and the types of CAM information and decision supports needs are required to create such interventions.

A sequential multi-method research design was used for this study, which occurred in two phases: a quantitative secondary data analysis and qualitative semi-structured interviews. In this study, we found that more than 65% of the Chinese-speaking cancer patients surveyed reported to have used CAM since their diagnoses, and the prevalence of its use was significantly higher than that used by the mainstream cancer population. There were two types of CAM decision-making experience: Spontaneous and deliberate. The spontaneous decision makers relied heavily on their peers to help with decision making, whereas the deliberate decision makers gathered information from multiple sources and selected the CAM therapies that were safe and fitted their cultural health beliefs and their previous CAM use experience. In addition,

the group of patients also had unique CAM information and decisions supports needs. All this newly gained knowledge would contribute to the development of future interventions to help these patients to make safe and informed CAM decisions.

Preface

This thesis project was approved by the University of British Columbia (UBC) Behavioural Research Ethics Board (BREB). The Certificate Number of the ethics certificate obtained was H10-01780.

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List of Abbreviations

| <u>Full Name</u> | <u>Acronyms and abbreviations</u> |
|------------------------------------------------------------|-----------------------------------|
| British Columbia | BC |
| British Columbia Cancer Registry | BCCR |
| Behavioural Research Ethics Board | BREB |
| Complementary and Alternative Medicine | CAM |
| Complementary Medicine Education and Outcomes | CAMEO |
| Health Information-Seeking Behaviours | HISB |
| National Centre for Complementary and Alternative Medicine | NCCAM |
| Natural Health Product | NHP |
| Oncology Health Care Provider | OHCP |
| Traditional Chinese Medicine | TCM |
| University of British Columbia | UBC |
| United States | US |
| Vancouver Centre of the British Columbia Cancer Agency | VC-BCCA |

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Dedication

I would like to dedicate this thesis to all the study participants whose contributions were essential in making this thesis possible. I would also like to dedicate this thesis to my husband, Kenneth Wong, who supported me every step of the way.

Introduction

Recent studies have shown that the use of complementary and alternative medicine (CAM) is prevalent in the general public in North America. In the United States (US), the rate of use ranged from 27% to 45% (Arcury et al., 2006; Brett & Keenan, 2007; Graham et al., 2005; Nguyen, Davis, Kaptchuk, & Phillips, 2011). In people suffering from cancer in the US, the CAM use rate could reach as high as 86.1% (Greenlee et al., 2009). In Canada, the prevalence of reported CAM use among cancer patients was between 42% and 91% (Boon et al., 2000; Boon, Olatunde, & Zick, 2007; Helpman et al., 2011; McKay, Bentley, & Grimshaw, 2005; Rakovitch et al., 2005; Sewitch, Yaffe, Maisonneuve, Prchal, & Ciampi, 2011; Tough, Johnston, Verhoef, Arthur, & Bryant, 2002; Trinkaus et al., 2011; Vyas et al., 2010). However, little is known about the prevalence of CAM use among cancer patients with Chinese heritage in Canada. To date, one quantitative study has focused on this topic (Ferro et al., 2007). Forty-seven percent of the 230 patients surveyed reported using TCM or CAM at the time of the study. Another qualitative study found that all 14 of the study participants were using CAM with conventional cancer treatment (Chiu, Balneaves, Barroetavena, Doll, & Leis, 2006).

The preference in CAM choices was found to be a function of ethnicity (Lee, Lin, Wrench, Adler, & Eisenberg, 2000; Shumay, Maskarinec, Kakai, & Gotay, 2001), wherein patients with Chinese heritage were more likely to use herbal remedies when compared to patients with other ethnic backgrounds. Although CAM may provide some benefits to support cancer patients, because of a lack of strong scientific evidence to prove the efficacy of many CAM therapies (Ernst, Cohen, & Stone, 2004) and concerns regarding potential for harm (Gerber, Scholz, Reimer, Briese, & Janni, 2006; Lesperance et al, 2002; Marcus & Grollman, 2002), its use is controversial.

In the last decade, the majority of Chinese immigrants to Canada had settled in either the Greater Toronto area or the Greater Vancouver area, where the Vancouver Centre (VC) of the BCCA is located (Statistics Canada, 2007). As ethnicity is not recorded in the British Columbia Cancer Registry (BCCR) or in the BCCA record (Yavari, Barroetavena, Hislop, and Bajdik, 2010), the actual number of cancer patients with Chinese heritage attending VC-BCCA can only be estimated. Yavari et al. (2010) recently conducted a study to compare the treatment received by breast cancer patients in British Columbia (BC) in three ethnic groups: Chinese, South Asian, and Iranian. Of the 3009 cases analyzed, 65% were of Chinese ethnic background (n=1958). Between 2007 and 2008, the total number of requests for Chinese language interpreters was approximately 4500, or 75% of the total requests for interpreters (Kwong, Mackenzie, & Barroetavena, 2009). These statistics indicate that there were a high number of Chinese-speaking cancer patients receiving care at VC-BCCA. Currently, the prevalence of CAM use and the related decision-making process in this population are not well studied. It is unclear whether these patients are making informed decisions around CAM. Further research and exploration of these issues is needed in order to create appropriate and culturally relevant interventions to support these patients in making safe and informed decisions around CAM use.

Background

Overview of prevalence of CAM in general cancer populations. In Europe, the prevalence of CAM use varies widely by region, ranging from 21.7% to 87.2% (Amin et al., 2010; Avci, Koç, & Sağlam, 2011; Chang, Brodie, Choong, Sweeney, & Kerin, 2011; Corner et al., 2009; Inglin et al., 2008; Malak, Karayurt, Demir, & Yümer, 2009; Molassiotis et al., 2006; Nagel, Hoyer, & Katenkamp, 2004; Newsom-Davis et al., 2009; Pedersen, Christensen, Jensen,

& Zachariae, 2009). The most commonly used CAM therapies reported were herbal medicine treatments and prayers (Avci et al., 2012; Malak et al., 2009).

In North America, CAM use is slightly more prevalent than in Europe, with a rate ranging from 30% to 91% (Boon et al., 2000; Boon et al., 2007; Fouladbakhsh, Stommel, Given, & Given, 2005; Greenlee et al., 2009; Helpman et al., 2011; McKay et al., 2005; Rakovitch et al., 2005; Sewitch et al., 2011; Tough et al., 2002; Trinkaus et al., 2011; Vyas et al., 2010). The most commonly used CAM therapies reported were biological-based therapy, including different supplements and herbal medicine, and mind-body therapy such as prayers and meditation (Boon et al., 2007; Fouladbakhsh et al., 2005; Goldstein, Lee, Ballard-Barbash, & Brown, 2008; Greenlee et al., 2009; Mao, Farrar, Xie, Bowman, & Armstrong, 2007; Naing et al., 2011; Sewitch, et al., 2011; Trinkaus et al., 2011; Vyas et al., 2010; Wyatt, Sikorskii, Wills, & Su, 2010).

Overview of prevalence of CAM in Chinese cancer populations. CAM use has historically been most popular in Asian countries. In Singapore, where 74.1% of citizens are of Chinese heritage (Department of Statistics Singapore, 2010), the CAM prevalence rate reported in recent studies ranged from 55% to 67.8% (Chow et al., 2010; Lim, Ng, & Loh, 2010; Shih, Chiang, & Chan, 2009). The commonly used CAM therapies in the Singaporean adult cancer population were TCM, bird nest, and special diets (Shih et al., 2009).

In China and Taiwan, 93.4% to 98.1% of the cancer patients had used CAM (Chen et al., 2008; Cui et al., 2004; Teng et al., 2010; Yang, Chien, & Tai, 2008). The most commonly used CAM therapies reported in this population were natural health products, traditional Chinese herbal medicine, physical activities, and prayers (Chen et al., 2008; Cui et al., 2004; Teng et al., 2010; Yang et al., 2008).

Chinese-speaking cancer patients residing in the Greater Vancouver area continued to use CAM after immigrating to Canada. As mentioned previously, 47% of 230 patients used TCM or some form of CAM therapy at the time of the survey; the most popular therapies were herbal remedies, vitamin and minerals, and prayers (Ferro et al., 2007). These patients frequently used TCM concurrently with conventional cancer treatments (Chiu et al., 2006). Patients reported difficulty in finding reliable CAM information and trustworthy CAM practitioners. Their CAM decisions were made based on anecdotal evidence from trusted others within their social network and information from lay literature in the local media (Chiu et al., 2006). In addition, there was a lack of communication between patients and their oncology health care providers (OHCP) around CAM issues, with a lack of CAM information and decision support. Their decision-making process was not explored in depth in this study. More research studies are required to explore current trends in CAM use as well as the decision-making experience in this population.

Overview of CAM information and decision-support needs research. Despite the popularity of CAM use, limited research studies have been done to explore and describe the information and decision-support needs around CAM among cancer patients. Studies determined that people living with cancer desire information about the safety and efficacy of CAM therapies (Eng, Monkman, Verhoef, Ramsum, & Bradbury, 2001; Verhoef, Trojan, Armitage, Carlson, & Hilsden, 2009). Although OHCP and conventional cancer centers were the preferred sources of information, relatively few patients actually obtained CAM information from these sources (Verhoef et al., 2009). Instead, patients often used information obtained from the Internet, health newsletters, books, and their social network. The information obtained from these sources was at times conflicting, and the amount of information could be overwhelming (Verhoef et al., 2009).

Also, the information was not necessarily specific to cancer and could be outdated (Eng et al., 2001). Patients often experienced difficulties during the information-seeking process.

Little is known about the type of information and decision-support needs in CAM required by Chinese-speaking cancer patients. One study that researched Chinese immigrants living in Seattle, US and Vancouver, Canada focused on the sources of health information used among these populations (Woodall et al., 2009). The most commonly used sources included Chinese-language newspapers, Chinese-language television stations, friends, and doctors and nurses. Vancouver residents were significantly more likely to report getting health information from Chinese-language television stations, newspapers, and radio. However, these participants were not cancer patients and the sources used may be different than those used by cancer patients. In another study, Chinese-speaking cancer patients also reported using these information sources except for doctors and nurses (Chiu et al., 2006). Woodall et al.'s (2009) study focused on general health information, not CAM information. Currently, it is still unclear what kind of CAM information and decision-making support would be most helpful for the decision-making processes of Chinese cancer patients. More research to investigate these needs is needed.

Overview of CAM decision making. CAM decision making has not been studied extensively. There are only four studies currently available that explore and describe the CAM decision-making process in the North American cancer population. These studies are briefly described in the following paragraphs in this section.

Shumay et al. (2001) conducted a qualitative study with 14 cancer patients with multiethnic backgrounds to examine their reasons for declining part or all of recommended conventional cancer treatments and choosing to use CAM therapies. The choices of CAM

selected were different among ethnic groups. The researchers also found that the participants had strong beliefs about the damaging effects of conventional cancer treatment on the body, and also questioned these treatments' efficacy in curing their cancer. Some participants decided to decline conventional cancer treatment after the discovery of CAM, believing that CAM was more effective and less harmful to the body. As a result, they used CAM exclusively for their cancer treatment.

Boon, Brown, Gavin, and Westlake (2003) explored prostate cancer patients' perceptions, feelings, ideas, and experiences in making decisions around CAM use. The results of five focus groups conducted with 29 prostate cancer patients indicated that the decision making about CAM appeared to depend on both fixed (i.e. disease characteristics, demographic characteristics, and medical history) and flexible (i.e. perceptions about the need for control or action) decision factors. The researchers concluded that the participants in this study appeared to be pushed into CAM use due to negative experiences with the conventional health care system rather than pulled into CAM by perceptions about its safety or congruence with their beliefs about health and illness.

White and Verhoef (2006) examined the role of spirituality in the decision to decline conventional prostate cancer treatment and instead use CAM. After interviewing 29 prostate cancer patients, they found that the men's spirituality had provided a means of coping with the cancer diagnoses and the decision-making process. Cancer was seen as a messenger or a teacher that led these men to explore the meaning of life. These patients' spirituality helped them to transform the meaning of a life-threatening illness into a healing experience. They also incorporated spiritual imagery and metaphor into treatment decision making and their cancer care. White and Verhoef (2006) commented that spirituality may play an important role in the

treatment decision making. Health care providers need to address patients' concerns about the potential conflict between conventional cancer treatment and patients' spiritual beliefs and practices.

Truant and Bottorff (1999) conducted a qualitative research study with 16 breast cancer patients in Vancouver, Canada regarding their decision-making processes in using CAM. The motivation behind these women's CAM use was to achieve a sense of control over a disease full of uncertainty, and in doing so, maintain a sense of hope (Truant & Bottorff, 1999). This study identified three interconnected sequential phases within the decision-making process around CAM: (1) getting something in place: covering all bases, (2) hand-picking CAM that fit: getting a personalized regimen in place, and (3) living with the security of CAM therapies: fine-tuning a regimen to live with. Women with breast cancer rarely spoke with their OHCP about their CAM use, but instead relied on trusted others within their social network for information and decision support.

Balneaves, Truant, Kelly, Verhoef, and Davidson (2007) examined the CAM decision-making process in women with early-stage breast cancer in Vancouver, Canada. All women in this study aimed to survive the cancer and improve their well-being in their cancer journey. When they were considering CAM, their knowledge and beliefs about conventional cancer treatment and CAM influenced their decisions. Once they had identified potential CAM therapies, they progressed into a complex and confusing process to search for information and evaluate the credibility of the information. They were faced with contradicting information and recommendations about the safety and values of CAM. In addition, due to lack of support in CAM decision making within the context of conventional medicine, these women tried to select CAM therapies that fitted their knowledge and beliefs by engaging in one of three different

decision-making processes: (1) taking a step at a time in choosing CAM therapies, (2) playing it safe in regards to making CAM decisions, and (3) bringing it all together in using both CAM and conventional cancer treatments.

In summary, many cancer patients were felt anxious following their cancer diagnosis and began to consider CAM as part of their cancer treatment at an early stage. Depending on their clinical situation, patients' selection criteria for CAM and influencing factors for its use varied. The search for and evaluation of CAM information proved to be a complex and confusing process during these patients' cancer experience (Balneaves et al., 2007; Truant & Bottorff, 1999). However, participants received little or no support from their OHCP in the search for CAM information or in making decisions about CAM use. Instead, they relied on their friends and families within their social networks to help with their decision making. More support from their OHCP when searching for information and making decisions would help ensure cancer patients were making informed decisions around CAM.

As mentioned previously, a large number of Chinese cancer patients are receiving care in Vancouver, BC. Previous research has shown that almost half (47%) of them used TCM or CAM. Currently, Chiu et al.'s (2006) study is the only qualitative study that specifically considers the decision-making process from a socio-cultural perspective in Chinese-speaking cancer patients. This study interviewed 14 male and female Chinese-speaking cancer patients with a variety of cancer diagnoses in an urban center in BC. All participants were found to be using TCM concurrently with conventional cancer treatments. The decision-making process in this population was found to be non-linear and comprised of four distinct phases: (1) fitting with the cultural belief framework/lifestyle, (2) seeking information and clarification, (3) evaluating the effectiveness of CAM use, and (4) balancing the cost and benefits of CAM use. Chiu et al.'s

(2006) study provided foundational knowledge about these patients' decision-making processes, but did not study them in depth. More research studies are needed in culturally diverse populations to provide a basis for developing culturally appropriate services.

Conceptual Issues

Defining CAM therapies. CAM is defined as a group of diverse medical and health care systems, practices, and products that are not generally considered to be part of conventional medicine (National Centre for Complementary and Alternative Medicine [NCCAM], 2012).

According to this definition, CAM is grouped into five different categories: biological-based therapy, mind-body based therapy, manipulative and body-based therapy, energy therapy, and whole medical systems (NCCAM, 2012). Each category is described and illustrated with examples in the following paragraph.

Biological-based therapy includes items such as herbal medicine or botanicals and vitamins and minerals. They are often called natural health products and are commonly sold over the counter in health food stores and even pharmacies. Mind-body based therapy uses the mind to affect physical functioning and promote health. Some examples of this type of therapy include meditation, deep-breathing exercises, and hypnotherapy. Manipulative and body-based practices focus on the manipulation of the structure and the system of the body. Chiropractics and massage therapy are examples of this kind of therapy. Energy therapy involves the manipulation of various energy fields to affect health. Acupuncture, Reiki, and healing touch are examples of such practices. Whole medical systems are based on theories and practices that are completely different from conventional or Western medicine. These systems are found in different cultures and have evolved over time. TCM and Ayurvedic medicine are examples of ancient whole

medical systems. More modern examples of this type of CAM include homeopathy and naturopathy (NCCAM, 2012).

Difficulties in conceptualizing CAM. The definition of CAM varied across different studies resulting in variation in the measurement parameters and CAM categorizations in these studies (Ernest & Cassileth, 1998; Fouladbakhsh et al., 2005). In addition, historical and cultural influences may impact the conceptualization of CAM, especially in cultural groups (Chiu et al., 2006; Fønnebø, Verhoef, & Paterson, 2007). Cancer patients with Chinese heritage, who had integrated TCM into their daily life, did not consider it to be a CAM therapy (Chiu et al., 2006). TCM and conventional medicine were both equally valued in a Chinese society, but TCM was used for slow-progressing chronic diseases whereas conventional medicine was considered more appropriate for urgent acute illnesses (Lam, 2001). Due to these reasons, the prevalence and categorization of CAM varied among studies.

Why study Chinese Cancer Patients at VC-BCCA?

Large numbers of Chinese patients at VC-BCCA. Between 2001 and 2010, Canada has welcomed about 2.5 million immigrants (Citizenship and Immigration Canada, 2011). Of this number, a total of 201,901 were Chinese-speaking immigrants, which is 8% of the total immigration population between 2001 and 2010 (Citizenship and Immigration Canada, 2011). The majority of Chinese-speaking immigrants settled in the Greater Toronto and Greater Vancouver areas (Statistics Canada, 2007).

Significant numbers of Chinese-speaking cancer patients have received care at the VC-BCCA (Yavari et al., 2010). However, the exact number of cancer patients with Chinese heritage is unknown, because information about patients' ethnicity is not recorded in the BCCA

or the BCCR. The methodology in classifying ethnicity was by recognizing typical last names that Chinese people had. As a result, the total number of Chinese-speaking cancer patients may be underestimated.

CAM use is controversial and often hidden. Currently, there is a lack of assessment of CAM use among cancer patients (Balneaves et al., 2007, Chiu et al., 2006; Truant & Bottorff, 1999). Verhoef, Boon, and Page (2008) argued that OHCP needed to assess whether their patients were using CAM and understand the rationale behind the use, presenting the following reasons. First, there is the possibility of adverse events directly associated with CAM use. Tam et al. (2011) also found significant discrepancies between the values of certain ingredients in NHP and the information listed on the product labels. Second, CAM products may interact with conventional medicine, and the harms and benefits of CAM may be misattributed to conventional treatment and may complicate treatment regimens (Verhoef et al., 2008). Third, patients using CAM may delay using conventional treatment. Finally, knowing the reasons behind patients' CAM use may provide important information about beliefs, values, expectations, and hopes on the part of the patient and will facilitate building rapport that may enhance the delivery of patient-centered cancer care. Due to the above reasons, it is imperative to assess for patients' CAM use, especially in the oncology setting.

Timing is appropriate to study this population. A research program, called Complementary Medicine Education and Outcomes (CAMEO), now exists at the VC-BCCA to focus on developing CAM information and decision support for cancer patients. CAMEO is a joint research program between BCCA and the School of Nursing (SON) at the University of British Columbia (UBC). The program aims to (1) support people with cancer and their significant others in making CAM decisions, (2) strengthen health professionals' knowledge and

clinical decision-support skills related to CAM, and (3) facilitate the development of new CAM research. Using the most current evidence-based CAM information as its foundation, CAMEO creates and delivers a series of CAM education courses and lecture, published documents to patients and OHCP, and also provided individualized information and decision-support interventions to patients within the conventional cancer care setting.

These interventions are only available in English, and Chinese-speaking cancer patients who are not proficient in the English language cannot benefit from them. Based on the results of a CAMEO environmental scan at the VC-BCCA, there is a lack of culturally appropriate CAM information, support services, and resources available on site. Drawing from clinical experience, the writer observed that Chinese-speaking patients frequently had CAM questions about using herbal products, TCM, and specific diet therapy to help them recover from their cancer and its treatments' side effects at a monthly support group meeting. Due to the lack of research knowledge around CAM information and decision-support needs in this cultural group, it is difficult to create culturally appropriate interventions for these patients. Research studies are needed to gather these types of information.

Research Purpose

The purpose of this study is to describe the prevalence of CAM use and to understand the CAM information and decision-support needs in Chinese-speaking cancer patients residing in the Greater Vancouver area in BC, Canada. Based on the foundational knowledge gained from this study, we aim to develop a series of CAM education and decision-support interventions to help these patients make safe and informed decisions around CAM use.

Research questions:

1. What is the current prevalence of CAM use by Chinese-speaking cancer patients receiving care at the VC-BCCA?
2. What are the information and decision-support needs related to CAM of Chinese-speaking cancer patients receiving care at the VC-BCCA?
3. What demographic characteristics are associated with CAM use and the information and decision-support needs of Chinese-speaking cancer patients receiving care at the VC-BCCA?
4. What are the differences between Chinese-speaking and non-Chinese-speaking cancer patients receiving care at the VC-BCCA in terms of the prevalence of CAM use and the information and decision-support needs related to CAM?
5. What are the CAM decision-making experiences of Chinese-speaking cancer patients receiving active treatment and supportive cancer care (i.e. pain and symptom management and emotional support) at the VC-BCCA?

Summary

In this chapter, the rates of CAM use in the general population and in the cancer population around the world were described. Research studies cited indicated that a high number of cancer patients with Chinese heritage used CAM. In Canada, many of these patients incorporated CAM into their cancer treatment regimens, but, similar to non-Chinese-speaking cancer patients, they experienced difficulties in searching for CAM information, leading to barriers within the decision-making process. Currently, there is a lack of culturally relevant support to help Chinese-speaking cancer patients obtain reliable CAM information and make

safe and informed CAM decisions. More research is urgently needed to assess these patients' CAM information and decision-support needs. Ultimately, the knowledge gained will be used as the foundation to create culturally appropriate interventions within the context of conventional medicine.

Chapter One: Literature Review

This thesis aims to identify and describe the current trend of CAM use in the Chinese-speaking cancer patients residing in the Greater Vancouver area in BC, Canada. In addition, these patients' decision-making process around CAM use and their related information and decision-support needs are of interest in this thesis study.

This chapter first describes the current prevalence of CAM use in the general population in North America to allow for comparison with the one in the North American cancer population. It is followed by a description of the current trend of CAM use, including the prevalence and types of CAM use, and predictive factors for CAM use in the cancer population around the world. Current knowledge in cancer patients' CAM information and decision supports needs, health information preferences, and CAM decision-making process will also be discussed. This chapter concludes with a description of the Andersen's Behavioural Model of Health Services Utilization, and a discussion of how it connects different predictive factors to explain CAM use.

Current State of CAM Use in the North American General Population

CAM has been gaining popularity in the US (Su & Li, 2011). Recent large population studies revealed that the prevalence of CAM use in the US ranged from 27% to 45% (Arcury et al., 2006; Brett & Keenan, 2007; Graham et al., 2005; Nguyen et al., 2011). In Canada, William, Kitchen, and Eby (2005) reported that more than 1.2 million adults aged 18 or older living in the Province of Ontario had consulted a CAM practitioner in 2005. Similar findings were seen from another study using data from a national cross-sectional survey study (N=400,055). In this study, 12.4% of Canadians had visited a CAM practitioner in the year they were surveyed (Metcalf, Williams, McChesney, Patten, & Jetté, 2010). The rate was significantly higher in people

suffering from chronic diseases (Metcalf et al., 2010; William et al., 2005). People with poor health status and unmet health care needs associated with chronic disease were also more likely to see a CAM practitioner (William et al., 2005).

Asian Americans and Asian Canadians had significantly higher prevalence in CAM use (Arcury et al., 2006; Hsiao et al., 2006; Roth & Kobayashi, 2008). Research studies also found that Chinese Americans and Chinese Canadians were more likely to use CAM compared to other ethnic groups residing in North America (Hsiao et al., 2006; Roth & Kobayashi, 2008). The types of CAM therapies used were also found to be associated with ethnicity (Quan, Lai, Johnson, Verhoef, & Musto, 2008). Chinese Canadians were more likely to use herbal medicine than Caucasian Canadians, but less likely to use massage or chiropractic care. If people with Chinese heritage and people living with chronic illnesses tend to use CAM more frequently, then people with Chinese heritage who have been diagnosed with a chronic illness such as cancer may be highly likely to use CAM. In order to confirm this assumption, it is important to review current literature on the prevalence of CAM use, the types of CAM use, factors influencing CAM use, and the decision-making process in cancer populations.

Current State of CAM Use in Cancer Populations

In the past decade, a growing number of studies have analyzed the trend of CAM use internationally. Research studies found the extent of CAM use varied among different countries (Fønnebø et al., 2007). A recent meta-analysis involving 152 studies from 18 countries estimated the average prevalence of CAM use was approximately 40% (Horneber et al., 2011). This analysis also suggested there was an increasing trend in using CAM among cancer patients, from an estimated 25% in the 1970s and 1980s to approximately 50% after 2000. Since 2000, research

studies have continued to document the extent of CAM use among cancer patients around the world. The prevalence ranged from 22% to 98.1%.

The broad range within the prevalence of CAM use may be attributed to the differences in the measurement parameters and CAM classifications used among the studies (Ernest & Cassileth, 1998; Fouladbakhsh et al., 2005), the extensive international differences in CAM regulations, and the historical and cultural influences on the people in different nations (Fønnebo et al., 2007). In this section, the prevalence of CAM use and relating factors in different parts of the world will be described.

Asia. In Asia, CAM use has been most prevalent in China and Taiwan where the range of prevalence of CAM use among people living with cancer was reported to be from 93.4% to 98.1% (Chen et al., 2008; Cui et al., 2004; Teng et al., 2010; Yang et al., 2008). Cui et al. (2004) and Chen et al. (2008) conducted two large survey studies involving more than 6,000 women with breast cancer in China, and found that the prevalence of CAM use over the years stayed at 98% and 97%, respectively. These findings suggested CAM has been commonly used in the Chinese breast cancer population over time. No research study was found that investigated the prevalence of CAM use in Chinese cancer survivors with specific types of cancer other than breast cancer. However, other studies that involved Chinese cancer survivors with different types of cancer also reached a similar conclusion (Teng et al., 2010; Yang et al., 2008). As a result, CAM was popular among Chinese people living with various types of cancer.

The most commonly used CAM therapies reported in this population were natural health products, traditional Chinese herbal medicine, physical activities, and prayers (Chen et al., 2008; Cui et al., 2004; Teng et al., 2010; Yang et al., 2008). Chinese cancer patients who were younger, had higher income and education levels, and married tended to be more likely to use

CAM (Chen et al., 2008; Cui et al., 2004). The patients using CAM had the following goals: to improve the body's natural ability to prevent metastasis or recurrence of the cancer, to boost the immune system, to improve quality of life, and to treat cancer (Chen et al., 2008; Cui et al., 2004; Teng et al., 2010; Yang et al., 2008).

Studies regarding CAM use prevalence were also frequently conducted in Singapore, a country located off the southern tip of the Malay Peninsula in Asia (Central Intelligence Agency [CIA], N.D.), in which 74.1% of its citizens have Chinese heritage (Department of Statistics Singapore, 2010). The CAM prevalence rate reported in recent studies ranged from 55% to 67.8% (Chow et al., 2010; Lim, Ng, & Loh, 2010; Shih et al., 2009). Common predictors of CAM use included ethnicity (Chinese), gender (female), age (< 65 years), higher education, and previous CAM use experience (Chow et al., 2010; Lim et al., 2010; Shih et al., 2009).

The commonly used CAM therapies were TCM, bird nest, and special diets in the Singaporean adult cancer population (Shih et al., 2009). The reason for use was not the focus of the studies; as a result, such information was not reported (Chow et al., 2010; Lim et al., 2010; Shih et al., 2009).

Compared to China and Taiwan, CAM use was not as popular in Singapore (Chen et al., 2008; Chow et al., 2010; Cui et al., 2004; Lim et al., 2010; Shih et al., 2009; Teng et al., 2010; Yang et al., 2008). However, findings from the Singapore studies indicated that Chinese ethnicity was one predictor for CAM use (Chow et al., 2010; Shih et al., 2009), which implied that Chinese cultural influences had an impact on the patient's decision to use CAM.

Europe. Turkey is a country located between Asia and Europe. Studies conducted in Turkey indicated that there was a decrease in CAM use from 87.2% (Malak et al., 2009) in 2009 to 58.9% in 2011 (Avci et al., 2011). Although this may be the case, the sample size in Avci et

al.'s (2011) study was five times larger (N=281) than in Malak et al.'s (2009) study (N=55). The larger the sample, the more likely it is to reflect the whole population (Field, 2009), and thus the findings from Avci et al.'s (2011) study were better able to accurately infer the CAM use prevalence in the cancer population in Turkey.

The most commonly used CAM therapies reported were herbal medicine treatments and prayers (Avci et al., 2012; Malak et al., 2009). The factors associated with use were a poor prognosis or advanced disease (Avci et al., 2012). Demographic variables, such as age, gender, marital status, location of residence, education and financial status, were not found to be statistically significant (Malak et al., 2009). These patients' goals were to mitigate the effects of cancer, to prevent recurrence, to increase blood values, and to feel psychologically relieved (Malak et al., 2009).

In European countries west of Turkey, the prevalence of CAM use reported in recent studies ranged from 21.7% to 40% (Amin et al., 2010; Chang et al., 2011; Corner et al., 2009; Inglin et al., 2008; Molassiotis et al., 2006; Nagel et al., 2004; Newsom-Davis et al., 2009; Pedersen et al., 2009). The use of CAM therapies was less prevalent in cancer patients living in these European countries. Within the European cancer population, women with breast cancer reported the highest rate in CAM use. Pedersen et al. (2009) conducted a quantitative survey study in Germany involving 3,343 women with breast cancer, and found that 40.1% had used one or more types of CAM since the time of diagnosis. Another quantitative survey study done in Scotland found that 36.4% of 360 breast cancer patients reported CAM use before diagnosis, and 33.1% continued using CAM following their cancer diagnosis (McLay, Stewart, George, Rore, & Heys, 2011). Nagel et al. (2004) examined 263 breast cancer survivors' prevalence of CAM use three years after their initial diagnosis and found the rate remained at 36%. Based on

the findings in these studies, CAM was determined to be more prevalent among women with breast cancer in Europe (McLay et al., 2011; Nagel et al., 2004; Pedersen et al., 2009).

The types of CAM therapies used varied greatly in different countries. For example, the most commonly used CAM therapies in Ireland were spiritual practices and laying on of hands (Amin et al., 2010). However, in another study involving cancer patients in four European countries not including Ireland, the most popular CAM therapies were biological-based therapies such as herbal medicine, medicinal tea, and vitamins and minerals (Molassiotis et al., 2006). The difference in preferred CAM may be attributed to the differences in the measurement parameters and CAM classifications used between the studies (Ernest & Cassileth, 1998; Fouladbakhsh et al., 2005), the extensive international differences in CAM regulations, and the historical and cultural influences on people in different nations (Fønnebø et al., 2007).

Factors associated with CAM use were found to be varied among different studies. However, the most common demographic variables associated with CAM use were age, gender, and education level (Amin et al., 2010; Chang et al., 2011; Corner et al., 2009; Inglin et al., 2008; Molassiotis et al., 2006; Nagel et al., 2004; Newsom-Davis et al., 2009; Pedersen et al., 2009). In particular, younger women (less than 65 years old) with post-secondary education were more likely to use CAM. The main reasons recorded for using CAM therapy were to counteract the ill effects of cancer and its treatment and to improve body's ability to fight cancer (Amin et al., 2010; Inglin et al., 2008; Molassiotis et al., 2006; Newsom-Davis et al., 2009).

US. In the US, the prevalence of CAM use was higher than reported in Europe, but lower than reported in China and Taiwan. The prevalence of CAM use in the US ranged from 30% (Fouladbakhsh et al., 2005) to 86.1% (Greenlee et al., 2009).

Studies found an upward trend in CAM use among cancer patients in the US.

Fouladbakhsh et al. (2005) found that among 986 breast, colon, and prostate cancer patients surveyed, 30% had used at least one form of CAM. In the following year, Mao et al. (2006) reported that 40% of 1,904 cancer patients surveyed had used CAM. Two years later, Goldstein et al. (2008) reported the prevalence of CAM use among participants living with cancer was 57.8%. The findings in these studies pointed to the fact that CAM had been gaining in popularity in the US cancer population. As a result, the National Cancer Institute (NCI) has spent approximately \$120 million annually on different CAM-related research projects on cancer prevention, treatment, symptom or side-effect management, and epidemiology in recent years (Jia, 2012). The goals of CAM use were rarely reported in the studies. The most popular CAM therapies used in the US were biological-based therapy including different supplements and herbal medicine, and mind-body therapy such as prayers and meditation (Fouladbakhsh et al., 2005; Goldstein et al., 2008; Greenlee et al., 2009; Mao et al., 2007; Naing et al., 2011; Wyatt et al., 2010).

Depending on the type and stage of cancer studied, the factors associated with CAM use varied widely. In a study exploring CAM use in advanced cancer patients, CAM use was not significantly associated with race, age, level of education, employment, or income level, but instead female gender (Naing et al., 2011). In another study that involved people living with different types of cancer, race (Caucasian), age (middle age), gender (female), cancer diagnosis, and education level (high) were predictive factors for CAM use (Fouladbakhsh & Stommel, 2010). In other studies describing CAM use in breast cancer patients, one found that patients who were middle aged (age: 59 to 69), had higher education and income, and were post-menopausal were more likely to use CAM (Greenlee et al., 2009). However, Wyatt et al. (2010)

found that higher education and lower quality of life were the only associating factors in this cancer population. Depending on the focus of the study and the sample characteristics, the factors associated with CAM use may vary.

Canada. In Canada, studies exploring the extent of CAM use among people with various types of cancer resulted in a wide range of prevalence from 42% to 91% (Boon et al., 2000; Boon et al., 2007; Helpman et al., 2011; McKay et al.; Rakovitch et al., 2005; Sewitch et al., 2011; Tough et al., 2002; Trinkaus et al., 2011; Vyas et al., 2010).

Numerous studies have been conducted to assess CAM use prevalence and related issues in different cancer populations. CAM has become popular over time in the breast cancer patient population in Ontario, Canada (Boon et al., 2007). In 1998, 66.7% of 557 women with breast cancer surveyed in Ontario reported having used CAM at some time in their lives (Boon et al., 2000). The rate increased to 81.9% (N=877) when a similar survey was done in 2005 (Boon et al., 2007). However, the findings from another study conducted in the same year in Montreal, Quebec, reported that only 43% of 251 breast cancer survivors had used CAM (Rakovitch et al., 2005). This regional variation in CAM consumption may be attributed to the differences in provincial health insurance (Millar, 1997).

The prevalence rates in other cancer populations in Canada have also been investigated and are described in this paragraph from the highest rate to the lowest rate. Sewitch and colleagues (2011) found that among 100 cancer patients surveyed in Montreal, 86% had used at least one type of CAM therapy in the past month, and 91% had used CAM in the past 12 months. The prevalence of CAM use among 123 advanced cancer patients was also found to be high at 85%, and 42% of them were using CAM with curative intent (Trinkaus et al., 2011). Recent studies of gynecological patients showed that CAM therapy was less popular among this patient

population (Helpman et al., 2011; McKay et al., 2005). McKay et al. (2005) found that 76.3% of 152 gynecological patients surveyed in 2005 reported having used CAM, but this rate was found to have decreased to 52% in a similar study in 2011 (Helpman et al., 2011). People diagnosed with head and neck cancer have also been studied in recent years, and their prevalence of CAM use was reported at 42%, which was the lowest among different cancer diagnoses (Vyas et al., 2010). In Canada, at least 40% of people living with cancer had used CAM, and the extent of its use was significant.

According to some studies, the most commonly reported CAM therapy was biological-based therapy (Boon et al., 2007; Sewitch, et al., 2011; Trinkaus et al., 2011; Vyas et al., 2010). Other studies reported mind-body based therapy as the most frequently used (McKay et al., 2005; Tough et al., 2002).

The goals of use varied depending on the cancer population studied, and they included improving physical well-being, boosting the immune system, improving quality of life, relieving symptoms, curing cancer, and preventing recurrence (Boon et al., 2000; Helpman et al., 2011; McKay et al., 2005; Trinkaus et al., 2011; Vyas et al., 2010).

Factors associated with CAM use were found to vary in Canadian studies. Rakovitch et al. (2005) found that younger women with breast cancer who had higher education levels, full-time employment, and private insurance, and who perceived a higher risk of cancer recurrence or death were more likely to use CAM. In another study regarding women with breast cancer, it was found that support group attendance was the only factor associated with CAM use (Boon et al., 2000). The writer speculates that the diversity in the most popular types of CAM use, reasons for use, and factors associated with use may be attributed to the different clinical situations associated with their cancer diagnoses among the study samples.

Ethnocultural groups in the US and Canada. Limited research has been conducted to examine the use of CAM in diverse ethnocultural groups among cancer patients and the general population in North America. Chiu et al. (2006) identified several factors that led to this limitation of research. First, ethnicity was not the focus of this type of study, and the majority of the study participants identified themselves as either North American or European descent. Second, the lack of culturally appropriate and sensitive conceptualization of CAM and the specific exclusion of traditional healing practices in surveys of CAM use may have underestimated CAM use in diverse ethnocultural groups. Lastly, language restrictions, with most surveys being distributed in English language only, may have compromised the validity of the survey method. This limitation would also restrict members of other ethnocultural groups from participating in the survey, and prevent accurate comparisons of CAM use among ethnocultural groups.

Three North American quantitative research studies have been identified that explored the prevalence of CAM use in cancer patients among different ethnocultural groups in the past decade (Lee et al., 2000; Shumay et al. 2001; Ferro et al., 2007). Shumay et al. (2001) investigated the prevalence of CAM use and its relation to quality of life among cancer patients from diverse ethnic backgrounds in the State of Hawaii, US. Surveys in English language were mailed to 2,452 patients diagnosed with invasive cancer, and 1,168 surveys (47.6%) were returned. The results showed that approximately 25% of the respondents reported using at least one CAM therapy since cancer diagnosis. The highest prevalence was seen in Filipino and Caucasian patients, followed by Native Hawaiians and Chinese. Japanese had the lowest rate of CAM use. An important finding identified in this study was the ethnic differences in CAM use

and choices, which supported the study's hypothesis that CAM use may be related to the ancestry and cultural heritage of cancer patients.

This study was a large-scale population study conducted in an ethnically diverse setting. However, this study was published 12 years ago and may not reflect the current picture of CAM use. In addition, the response rate of this study was less than 50%. This was possibly related to the language restriction of the survey, which could have excluded patients who were not proficient in English language, thus resulting in an underestimated prevalence of CAM use in ethnic groups (Chiu et al., 2006). Also, the 21 CAM choices offered in the survey were selected based on previous studies, and did not include any whole medical system of care deeply rooted in patients' cultural heritage (e.g., TCM, Japanese Kampo) except Hawaiian healing. The exclusion may underestimate the prevalence of this CAM therapy use in specific ethnic groups. To address these potential exclusions, the survey in our study was translated into Chinese language and included all categories of CAM therapy as defined by NCCAM.

Lee et al. (2000) conducted a study in San Francisco, California to examine the types and prevalence of conventional treatments and CAM therapies used by women diagnosed with breast cancer in four ethnic groups: Latino, Caucasian, Black, and Chinese. Using a researcher-developed questionnaire as a guide, they interviewed 379 breast cancer patients over the phone in English, Chinese, or Spanish. The questionnaire included questions on demographics, social support, general attitude towards life, history of smoking, alcohol consumption, exercise habits, support groups attended or counseling received, and pregnancy and health history. The questionnaires also gathered information about conventional breast cancer therapies and alternative therapies used.

In this study, approximately half of the women had used at least one type of alternative therapy and approximately one third had used at least two types. Women who had higher education or income levels, were younger, had private insurance, and had been exercising or attending a support group were more likely to use alternative therapies. Ethnicity was not found to be one of the predictive factors in CAM use. However, similar to the findings in Shumay et al. (2001), this study also detected ethnic differences in the choice of CAM therapy. Chinese women were twice as likely as women of the other three ethnicities to use herbal therapies, but they were less likely to use dietary and mental therapies. Black women were less likely to use dietary and physical therapies, while Latino women were more likely to use mental, physical, and herbal therapies. In addition, they also found that factors associated with using any alternative therapies differed by ethnicity. Belonging to community groups, attending support groups, engaging in exercise, or having a higher income were found to be statistically significant factors for Black, Chinese, Latino, and Caucasian women, respectively. Cultural influences within each ethnicity may affect patients' CAM selection, but the writer believes that the different factors associated with CAM use in each ethnicity may reflect the type of influence most valued in that ethnic group. For instance, both Black and Chinese women may value the opinion of their social peers in their community or support groups, but Latino women who valued self-care may use other therapies to improve or maintain their health.

This study's sample size (N=379) included 82 women with Chinese heritage. However, it was published 12 years ago and may not reflect the current picture of CAM use in different ethnic groups. Also, the 13 CAM therapies included in the survey were selected based on previous research studies. Again, the limitation in CAM choices on the survey and exclusion of traditional healing practices may underestimate the prevalence of CAM use in diverse

ethnocultural groups (Chiu et al., 2006) in Lee et al.'s (2000) study. As mentioned previously, our survey included whole systems of healing and other CAM categories as defined by NCCAM (2012).

The third study was conducted by Ferro et al. (2007) to survey 230 newly diagnosed Chinese-speaking cancer patients receiving care at the BCCA regarding their use of TCM and other CAM therapies. The goal of the study was to assess the impact of acculturation on the prevalence of TCM and other CAM therapies in this patient population. In this study, acculturation was defined as assimilation into the dominant culture and was measured by patients' place of birth (Canada vs. outside of Canada), survey language (English vs. Chinese), and language spoken at home (official language vs. unofficial language). Of the 230 respondents, 47% had used TCM or CAM, and the most popular therapies were herbal remedies, vitamin and minerals, and prayers. Prior TCM/CAM use, having received conventional medicine, and being less acculturated were three factors associated with TCM/CAM use. No other demographic variables were found to be significantly associated with CAM use. Ferro et al. (2007) argued that patients who were less acculturated might have a stronger belief in TCM or CAM therapies.

This is the most current study focusing on the prevalence of CAM use in a Chinese-speaking population in North America. The study involved a large sample size of 230 adult Chinese cancer patients admitted to BCCA. The survey was provided in both simplified Chinese written language and English to facilitate involvement in the study by patients whose main language was Chinese, and those whose main language was English but understood Chinese language.

Ferro et al. (2007) had listed only ten TCM and CAM therapies on the survey, and this may result in an underestimation of the prevalence of CAM use in this population due to lack of

CAM selection options on the survey. These therapy options were selected based on the findings from one previous qualitative study (Chiu et al., 2006), which involved 14 Chinese-speaking cancer patients receiving care from the same vicinity as those in Ferro et al.'s (2007) study. These ten items were the most commonly used TCM and CAM therapies found in that study (Chiu et al., 2006). Although Ferro et al. (2007) had included an "other" category to include CAM therapy not listed on the survey, only the five most commonly used CAM therapies were reported, and it was unclear if any participant had selected the "other" category. Since these items were selected from one qualitative study with 14 patients from a selection of 14 items, the narrow range of TCM and CAM therapies options may compromise the validity of the survey method. It is imperative for the survey used in our study to provide a comprehensive list of CAM therapies.

In summary, limited research studies have been done in recent years to examine CAM use among different ethnic groups in North America. The prevalence of CAM use in studies with people living with cancer in different ethnic groups in North America varied from 25% to 47%. Almost half of the Chinese-speaking cancer patients use TCM or CAM therapies (Ferro et al., 2007). The prevalence of CAM use and the preference of CAM therapies were found to be influenced by ethnicity (Lee et al., 2000; Shumay et al., 2001).

CAM Information and Decision Support Needs

Few research studies have been done to examine cancer patients' needs for CAM information and decision support (Eng et al., 2001; Verhoef et al., 2009). The findings reported in these research studies indicated that cancer patients wanted information around safety and efficacy of CAM therapies (Eng et al., 2001; Verhoef et al., 2009). Although OHCP and

conventional cancer centers were the most preferred information sources, cancer patients often used information obtained from the Internet, health newsletters, books, and their social networks, and relatively few patients obtained information from the OHCP or conventional cancer centers (Verhoef et al., 2009). Patients faced an overwhelming amount of information, at times conflicting, from the Internet, health newsletters, books, and their social networks, causing frustration and confusion (Verhoef et al., 2009). Also, the information may not be specific to cancer and could be outdated (Eng et al., 2001). These studies did not focus on the types of support required by cancer patients during decision making. More research is needed to explore this type of need, as patients often experience difficulties during the information-seeking process.

No research has been conducted to investigate the needs of Chinese-speaking cancer patients. Woodall et al. (2009) looked at the health information sources used by Chinese immigrants living in the Pacific Northwest (Seattle, Washington, US and Vancouver, BC, Canada). They found that the most commonly used information sources included Chinese-language newspapers, Chinese-language television stations, friends, and doctors and nurses. Vancouver residents were significantly more likely to report getting health information from Chinese-language television stations, newspapers, and radio. However, the participants were not cancer patients and the information sought was not CAM related. More research is needed to investigate Chinese-speaking cancer patients' CAM information and decision-support needs.

Health information-seeking behavior in cancer patients. A recent research study found variations in health information-seeking behavior s (HISB) based on cancer patients' preferred roles in decision making (Lambert, Loiselle, & Macdonald, 2009a; Lambert, Loiselle, & Macdonald, 2009b). The five HISB patterns identified were (1) intense information seeking - a keen interest in detailed cancer information, (2) complementary information seeking - the

process of getting adequate cancer information, (3) fortuitous information seeking - the search for cancer information mainly from others diagnosed with cancer, (4) minimal information seeking - a limited interest in cancer information, and (5) guarded information seeking - the avoidance of some cancer information.

According to Lambert et al. (2009a), the core variable that emerged and appeared to explain the variation in HISB among participants was, “Playing my part and taking care of myself” (p. 15, 2009a). Based on the participants’ interpretation of their current clinical situation, they selected aspects of their situation that were most important to them, and began to select the roles (i.e. active or passive role in treatment decision making) they wanted to play in their illness experience, and then took necessary actions (e.g., seeking information) to take care of themselves.

Types of HISB. The participants who engaged in the intense information-seeking process preferred to be actively involved with the treatment decision making. The health information sought was scientific-based from multiple sources, and was evaluated using logical reasoning to reach the best cancer treatment options (Lambert et al., 2009a). The participants who preferred the complementary information-seeking approach took a passive role in their treatment decision making. Their information-seeking goal was to reach a comfortable level of knowledge about their cancer, and these patients often restricted the amount of information to a search of a few summarizing sources (e.g., books) focusing on practical information that was useful for the current clinical situation.

The participants who exhibited the fortuitous information-seeking behaviour did not intentionally search for health information (Lambert et al., 2009a). Instead, they took an experiential approach in gathering information when they interacted with others diagnosed with

cancer. Verbal information from fellow cancer survivors was highly valued, and patients used it to compare their situations with others. The outcome of this type of information seeking was encouragement if the participants found their situations to be on the right track or better than others.

The participants with minimal information-seeking behavior took a passive approach in searching for health information, and relied on their OHCP to provide them with the necessary health information to deal with the issues at hand (Lambert et al., 2009b). This type of behavior precluded them from engaging in decision making around treatment, and allowed the OHCP to take over their care. The participants expressed that they needed “to go with the flow (p. 32, 2009b) and accept the situation. The outcome of this type of HISB was a sense of contentment and acceptance.

In guarded information seeking, patients often ignored health information to prevent emotional upheaval. They trusted their OHCP and delegated any treatment decision making to them. The motivations behind this approach appeared to be a tremendous amount of anxiety and fear felt after the cancer diagnosis. Often, the participants engaged in guarded information seeking were hesitant to pursue their interest in seeking cancer information because of the risk of encountering undesirable cancer information. Similar to the participants with minimal information-seeking behavior, these guarded information seekers also relied on their OHCP for cancer information, because information from this source often dispelled fears and provided reassurance. The outcome of taking this approach was maintaining good morale in their cancer experience.

This study provided an in-depth knowledge about the variation in HISB among cancer patients. Their preferred role in treatment decision making and their clinical situation dictated

their approach to HISB. Although this theory was not about CAM information-seeking behavior, the knowledge gained from this study may provide insight into the CAM information-seeking behavior in cancer population to explain variations in behavior.

This study was limited in several ways. The participants in this study were diagnosed with one of three cancers: breast, prostate, or colorectal. Since cancer patients with other types of cancer diagnosis were not involved, these findings may not be applicable to them. In addition, as the majority of the participants were Caucasian, the findings may not be as relevant to Chinese-speaking patients.

CAM Decision Making

The number of qualitative research studies that explore the CAM decision-making process in people living with cancer is limited. Six studies within the last 13 years focused on this topic (Balneaves et al., 2007; Boon et al., 2003; Chiu et al., 2006; Shumay et al., 2001; Truant & Bottorff, 1999; White & Verhoef, 2006). Only one of these six studies specifically targeted Chinese-speaking cancer patients. In this section, these research studies are described in detail to illustrate the current knowledge about CAM decision making in the cancer population.

Shumay et al. (2001) conducted a qualitative study to examine cancer patients' reasons for declining all or part of recommended conventional cancer treatment and choosing to use CAM therapies. In this study, 14 multiethnic participants with a wide range of cancer diagnoses were recruited from a population-based tumor registry in the State of Hawaii, US. All participants used three or more types of CAM, and the most preferred CAM therapies were biological-based therapies (e.g. herbal and nutritional supplements).

The participants had strong beliefs that conventional cancer treatment could damage their bodies; as a result, they declined all or part of the recommended conventional cancer treatment to protect their body from harm (Shumay et al., 2001). In addition, they questioned the efficacy of these treatments in managing their cancer. Some participants decided to take an alternative approach in CAM use due to unsatisfactory or alienating relationships with their conventional OHCP. Others reported that they made the decision simply because they had discovered CAM, and in general, they believed CAM was more effective and less harmful alternative to conventional cancer treatments.

The purpose of this study was to explore the reasons in declining all or part of the recommended conventional cancer treatments in multiethnic adults diagnosed with cancer. It did not examine the process of decision making. However, the findings shed light on cancer survivors' beliefs regarding conventional cancer treatment and CAM and their reasons for declining conventional treatments. The participants in this study were of multiple ethnic backgrounds. Although the study may have included participants with Chinese heritage, they were not the majority of the study participants; as a result, the findings may not be applicable to Chinese-speaking cancer patients. More current studies involving the exploration and description of CAM decision-making process in oncology patients with Chinese heritage are needed.

Boon et al. (2003) explored prostate cancer patients' perceptions, feeling, ideas, and experiences in making decisions around CAM use. A focus group was used to gather data from 29 prostate cancer patients, who had been diagnosed for an average of 39 months prior to participating in the study. The group's mean age was 65 years old, and more than three-quarters of them were married with a level of education higher than high school and an annual income of

more than \$60,000. More than 80% of the men identified their ethnic background as being North American or European.

Boon et al. (2003) found that feelings of fear related to the prostate cancer diagnosis and the perceived loss of control were at the center of the decision-making process for both conventional treatment and CAM. Two major decision-making factors that influenced these patients' decisions around the type of treatment were identified as being fixed and flexible. These factors either pulled them into exploring CAM due to its attractive qualities or pushed them into seeking CAM due to dissatisfaction with conventional cancer care (Furnham & Smith, 1988).

Fixed decision factors are those that the patient cannot change, such as age, comorbid conditions, and disease status. Age and comorbid conditions (e.g., heart disease) often limited their treatment options within the context of conventional medicine (Boon et al., 2003). Older men living with a chronic condition were often recommended to take a watchful waiting approach in dealing with their cancer. For many men, this treatment recommendation pushed them to seek CAM in order to gain a sense of control. With regard to disease status, a more advanced disease, which was indicated by a high Gleason score or Prostate Specific Antigen (PSA) level, or disease recurrence after conventional cancer treatment also pushed these men to explore CAM.

Flexible decision factors are those that the patient has the ability to change, which include their perceptions of conventional and CAM treatments (Boon et al., 2003). These perceptions can be powerful, but may change over time. For example, conventional cancer treatments were considered too aggressive and radical for some patients to consider, which pushed them into exploring CAM. In addition, the significant side effects (i.e. impotence and incontinence)

generally associated with conventional treatments also impacted their decision to use CAM as a means of coping with side effects.

Another flexible factor was a belief in the efficacy of CAM rooted in their personal as well as their families and friends' experiences with CAM (Boon et al., 2003). In addition, some men chose CAM specifically because it was congruent with their beliefs about health and disease. Experiences with CAM and conventional medicine practitioners often shaped their decisions on which treatment paradigm to use for their cancer. A negative experience with a practitioner from one paradigm would often push the men to seek medical care from the other paradigm to cope with their cancer.

In contrast, the main reason to decline CAM was an absence of what the men perceived as reliable information about the CAM option being considered (Boon et al., 2003). Safety issues with regard to potential adverse reactions and interactions with conventional medicine also had an impact on these men's choice to not use CAM.

Boon et al.'s (2003) research findings provided a thorough understanding of the factors influencing prostate cancer patients' treatment decisions. However, the focus of our study is Chinese-speaking cancer patients, and the majority of the participants in Boon et al.'s (2003) study self-identified as North American and European, which make the applicability of the findings to Chinese cancer patients questionable due to cultural differences.

White and Verhoef (2006) also conducted a study trying to understand the treatment decision-making process in prostate cancer patients. In particular, they examined the role of spirituality in the decision to decline conventional prostate cancer treatment for CAM. Based on Cunningham's (2005) description of spirituality, it is defined as the personal experience, or

search for experience, of connection to some higher power, transcending the material, which typically conveys a sense of meaning or purpose in life.

After interviewing 29 prostate cancer patients who declined conventional cancer treatment, the following themes related to the role of spirituality in cancer management emerged: beliefs about Western medicine, the role of spirituality beliefs in treatment decision making, and the impact of cancer on spirituality.

Beliefs about Western medicine. Participants appeared to place more importance on psychological factors as a cause for cancer (White & Verhoef, 2006). They attributed psychological influences such as life stressors, negative emotional patterns, and an inability to heal from the past as major contributors to their illnesses. As such, the philosophies behind conventional medicine tend to focus on treating the tumor instead of the whole person conflicted with their beliefs around healing. After being diagnosed with cancer, some participants wanted to focus on healing within the broader context of their lives, while their cancer specialists were only focusing on curing the disease. As a result, these participants decided to forgo conventional treatments.

The role of spirituality beliefs in treatment decision making. Influenced by their spirituality, these men interpreted the meaning of their cancer diagnosis as part of their life journey (White & Verhoef, 2006). They often referred to cancer as a “teacher” or “messenger” (p. 119), and exploring the meaning of cancer became part of the healing journey. Their spirituality appeared to help them transform the meaning of a life-threatening diagnosis into a healing experience. Many participants agreed that conventional cancer treatment would interfere with their ability to heal and declined these treatments. As these men tended to focus on healing instead of curing, they preferred healing treatment options in the context of mind, body, and

spirit. As a result, they sought help with spiritual healers or teachers and intensified their use of spiritual practices such as prayers, meditation, guided imagery, and visualization.

The use of spiritual imagery and metaphor. Despite differences among religious beliefs and spiritual practices, most participants identified with the idea of a divine energy that existed within a person and others. They believed that loving oneself and others was important, as were spiritual practices were supportive of that. Gratitude emerged as an important part of spirituality that helped them to cope with cancer.

Many embarked on a personal journey using spiritual practices such as prayer, meditation, guided imagery, and visualization as a means of arriving at a treatment decision (White & Verhoef, 2006). One participant encountered a labyrinth during a spiritual retreat before he made his treatment decision. As he walked into the labyrinth, he saw his prostate was weeping as it commented that it was being besieged from within and from without. The participant's interpretation was that the prostate was besieged by the cancer from within and by conventional cancer treatment from without. He consequently declined the treatment recommended by his cancer specialist.

The impact of cancer on spirituality. The cancer influenced these men's spirituality in several ways. First, it intensified their commitment to spiritual practice and strengthened their connections with their spiritual communities. Also, they perceived their cancer as a "gift" or "blessing" (p. 121), and this perception led them to a better appreciation of the meaning of life and an ability to integrate the cancer into their spiritual journey.

White and Verhoef (2006) explored the meaning of spirituality in men living with prostate cancer and described the ways this meaning had influenced the men's decisions in declining conventional cancer treatment. The information showed that spirituality is an important

consideration in treatment decision making; however, the study only focused on mind-body therapies in CAM and their impact on prostate cancer patients declining conventional medical treatment. It was unclear whether these participants used other types of CAM therapies for their cancer in addition to spirituality. Also, the ethnicity of the participants was not reported in the study, and the findings may not be applicable to cancer patients with Chinese heritage.

Truant and Bottorff (1999) conducted a qualitative research study using grounded theory to examine the process by which women with breast cancer make decisions related to CAM use. Open-ended interviews were conducted with 16 women diagnosed with various stages of breast cancer in Vancouver, BC, Canada, who had received conventional cancer treatment and also used a wide variety of CAM.

The motivation for these women's CAM use was to achieve a sense of control over a disease full of uncertainty, and in doing so, also maintain a sense of hope (Truant & Bottorff, 1999). The goals of use included attempting to control the spread of cancer cells, managing side effects from treatments, promoting a feeling of well being, boosting the immune system, and preventing or delaying any recurrence.

Using constant comparative method to analyze the data, Truant and Bottorff (1999) found three interconnected sequential phases within the decision-making process around CAM: (1) getting something in place: covering all bases, (2) hand-picking CAM that fit: getting a personalized regimen in place, and (3) living with the security of CAM therapies: fine-tuning a regimen to live with.

Getting something in place: covering all bases. This phase began at the diagnosis or recurrence of breast cancer and ended before breast cancer surgery. Women with breast cancer were overwhelmed with the diagnosis, and started to explore CAM options hoping to control the

progression of the disease. The decisions were made quickly without doing thorough research, and were influenced by their past experience in CAM use or by advice from trusted others. The implementation of CAM therapies gave the women a sense that the likelihood of curing the cancer would increase.

Hand-picking CAM that fit: getting a personalized regimen in place. This phase began after the women with breast cancer had had surgery to remove the cancer and continued until the completion of adjuvant conventional cancer treatment (i.e. chemotherapy, radiation therapy). The women felt a sense of relief knowing that the cancer had been removed from their bodies. As a result, they were able to spend more time thoroughly researching CAM therapies to find ones that fit their beliefs about health and illness. Many would match their perceived cause of cancer with a CAM therapy. For example, one woman believed that her cancer was caused by stress; as a result, her chosen CAM therapy regimen leaned toward mind-body therapy to help with relaxation.

The process of searching for CAM information was found to be relatively complex (Truant & Bottorff, 1999). The most commonly used information included written material from lay literature and advice from trusted others and CAM practitioners. Women with breast cancer rarely consulted their conventional OHCP for CAM information; in fact, very few disclosed their use of CAM due to the level of CAM information overload, a lack of energy within these women, the OHCP's knowledge of and attitude towards CAM, and the OHCP's pattern of interaction with the women.

The goals of using CAM in this phase were much broader than the last phase. Women with breast cancer did not believe CAM therapy could cure their cancer, but saw it as capable of supporting the potential benefits of conventional cancer treatments as well as alleviating the side

effects. They used CAM to control the spread of cancer cells, manage side effects from treatments, promote a feeling of well being, boost their immune systems, and prevent or delay any cancer recurrence.

Women with breast cancer also evaluated their previous CAM choice and made modifications to their regimen in this stage. All women evaluated the CAM therapy based on the fit between the CAM therapy and their perceived disease status, and the assessment of benefits versus harms. The CAM therapies initiated in the last phase were either continued or discontinued. New therapies were added to the regimen to be tried out for a period of time. Women evaluated and modified the regimen based on three criteria: the degree of effort to use the therapy, the cost of the therapy, and the severity of side effects. The outcomes of this phase were an increased sense of personal control, maintenance of hope, and a sense of healing.

Living with the security of CAM therapies: fine-tuning a regimen to live with. This phase began after the completion of the adjuvant conventional cancer therapy and could last indefinitely. In this phase, women believed that their cancer was controlled by the conventional cancer treatment and the CAM therapies. They also believed that the CAM therapies were benefiting them based on their own evaluation criteria. As time progressed, women may have reduced the frequency and/or dosage of CAM use, but would continue to maintain a core CAM regimen. Further modifications to their CAM regimen occurred usually in response to added life stressors, such as another illness or emotional stress. Women may increase the frequency and/or dosage of their CAM therapies, or re-establish a previous CAM regimen that had worked for them. The major stressors in these women were being diagnosed with cancer recurrence or moved to palliative status; as a result, they may revisit the last phase to carefully select CAM

therapies to help them cope with these stressors. The outcomes of this phase were that women were able to sustain a sense of control, maintain hope, and decrease uncertainty.

This study illustrated the three sequential phases of a CAM decision-making process in women with breast cancer. The main motivation of CAM use was to maintain a sense of control over a disease that was full of uncertainty, despite the fact that this sense of control may be just an illusion (Truant & Bottorff, 1999). The findings also revealed that few women received CAM information or decision support from their OHCP. Instead, the women were information gatherers and decision-makers in the midst of dealing with cancer and its treatment.

Balneaves et al. (2007) examined the CAM decision-making process in women with early-stage breast cancer in Vancouver, BC, Canada. All women in this study aimed to survive the cancer and improve their well being in their cancer journey. When they were initially considering CAM, their decisions were influenced by their knowledge and beliefs about conventional cancer treatment and CAM. Their goals of CAM use were to maximize treatment benefits, increase a sense of control and autonomy, and decrease the chance of recurrence. Once they had identified potential CAM therapies, they progressed into a complex and confusing process of searching for and evaluating the credibility of the information. They were faced with contradicting information and recommendations about the safety and values of CAM. In addition, due to lack of support in CAM decision making within the conventional medicine context, these women tried to select CAM therapies that fit their knowledge and beliefs by engaging in three different decision-making processes: (1) taking a step at a time in choosing CAM therapies, (2) playing it safe in regards to making CAM decisions, and (3) bringing it all together in using both CAM and conventional cancer treatments.

Taking a step at a time in choosing CAM therapies. Women who took the approach of a step at a time in making CAM decisions expressed high anxiety and conflict, the result of encountering unexpected barriers in incorporating CAM into their cancer treatment regimen to improve their overall well being and decrease the risk of recurrence (Balneaves et al., 2007). There was also a lack of clear recommendations from the OHCP related to their current conventional cancer treatment. Women invested significant amounts of time and energy on their own in searching for CAM information from a wide range of sources, which resulted in a substantial amount of information, causing more uncertainty and anxiety. They often delayed their CAM decision making until a later time, when they had more energy to review the options. Some would incorporate less invasive and less controversial CAM therapies, such as meditation and massage therapy, into their treatment regimens. Once they had completed their conventional cancer treatments, they would then reinvestigate their CAM options and consider incorporating a wider range of CAM therapies to improve their overall well-being.

Playing it safe in regards to making CAM decisions. Women who engaged in this decision-making process were less committed to including CAM as part of their cancer treatment in comparison with the women in the previous decision-making approach (Balneaves et al., 2007). They had little CAM use experience and were skeptical about the claimed benefits of CAM. They viewed their cancer as a serious illness and worried about the potential interactions between natural health products and conventional cancer treatment. In addition, they were concerned about the potential adverse risks of the natural health products had to the disease (i.e. the potential risk of phytoestrogen aggravating breast cancer with estrogen-receptor positive status). As a result, they would only incorporate CAM therapies that had minimal conflict with conventional treatment, such as meditation and acupuncture.

In terms of information used during decision making, these women relied mainly on scientific evidence and searched information from research studies in medical journals. These women were well supported by their social network in making decisions and in gathering and evaluating CAM information. They also limited the number of CAM therapies they searched for information on, and avoided the types of information sources that would overwhelm them during the information gathering and evaluating process. As a result, these women experienced minimal anxiety and conflict when making decisions about CAM.

Bringing it all together in using both CAM and conventional cancer treatments.

Women, who took this decision-making approach, preferred cancer treatment regimens that were tailored to help improve their overall well-being, instead of only focusing on their cancer. These women had experience in using CAM and were committed to incorporating CAM into the cancer experience. They saw their cancer as serious but manageable with conventional medical treatment. However, they also viewed including CAM therapies as a necessary part of their treatment regimen to optimize their physical, psychological, and spiritual health, as well as to alleviate side effects from conventional cancer treatments. These women limited their search for CAM information and depended on trusted individuals within their social networks to help them evaluate the CAM information and make decisions. They were confident decision-makers, and often relied on intuition to select a wide range of CAM therapies that made sense to them. At the end of their adjuvant cancer treatment, women in this group expressed satisfaction with their CAM choices and intended to continue with the current CAM regimen or expand to include more CAM therapies in the future.

In the above two studies, both Truant and Bottorff (1999) and Balneaves et al. (2007) focused on examining the CAM decision-making process in women at different stages of breast

cancer. Although these studies substantially contributed to the understanding of this process, the knowledge gained in this study was mainly from non-Chinese-speaking cancer patients. These studies may not have captured the unique cultural aspects of CAM decision making in the Chinese cancer population. As a result, the applicability of the information in this study to the target population was limited. Moreover, this study targeted women with breast cancer, producing results that could only be applied to this population, but not women with other cancers or male cancer patients. Lastly, these studies have been published for some time, newer research studies that explore the decision-making process are needed to reflect current picture of CAM decision making.

Currently, Chiu et al.'s (2006) study is the only qualitative study that specifically looked at the decision-making process from a socio-cultural perspective in Chinese-speaking cancer patients. This study was conducted in an urban center in BC, where 14 male and female Chinese-speaking cancer patients with a variety of cancer diagnoses were interviewed. All except one participant had been born outside of Canada, and the average time since their immigration was 12.3 years.

In general, the participants conceptualized CAM as non-Western medicine, non-conventional medicine or health care that was not covered by provincial medical insurance (Chiu et al., 2006). Variations in the understanding of CAM were evident among the participants. Many were aware of this term, but did not know what therapies were considered to be CAM. Others were able to produce a list of therapies associated with this term. Some considered TCM a type of CAM therapy, but others, who had integrated TCM into their daily lives, were reluctant to categorize it as CAM.

The goals of their CAM use included regulating and strengthening the body in a holistic manner, compensating for the shortfalls of conventional cancer treatment in symptom management, and hoping for a cure. The participants were also motivated to use CAM due to previous experience with CAM and the encouragement received from others.

All participants in this study used TCM concurrently with conventional cancer treatments (Chiu et al., 2006). Within the TCM treatment modality, herbal medicine was the most prevalent treatment method followed by Qi-Gong, Tai Chi, and diet therapy. The preferences in TCM may be associated with the concept of acculturation. Acculturation is defined as a process of change in cultural features that occurs as a result of continued contact between two or more groups (Redfield, Linton, & Herskovits, 1936). Although it is usually a two-way process, one aspect of acculturation is cultural assimilation, which involves the adaptation of the cultural features of the larger group by the minority group.

Ferro et al. (2007) conducted a quantitative study examining the prevalence and predictive factors of CAM use in 230 newly diagnosed Chinese-speaking cancer patients receiving cancer care from the same vicinity as Chiu et al.'s (2006) study. They found that these patients, who were less acculturated to Western society, were more likely to select TCM as part of their CAM regimen.

Using a naturalistic, descriptive study design that integrated semi-structural ethnographic interviewing and qualitative data analysis, the decision-making process in this population was found to be non-linear and comprised four distinct phases: (1) fitting with the cultural belief framework/lifestyle, (2) seeking information and clarification, (3) evaluating the effectiveness of CAM use, and (4) balancing the cost and benefits of CAM use. In the following paragraphs, these phases will be described.

Fitting with the cultural belief framework/lifestyle. In the fitting with cultural belief framework/lifestyle phase, Chiu et al. (2006) found that Chinese-speaking cancer patients tended to choose CAM therapies that fitted their cultural health beliefs and lifestyle (i.e. TCM). From a Chinese cultural perspective, an imbalance between the two internal forces (i.e. the Yin [cold] force and the Yang [Hot] force) disrupted normal body functions causing illness such as cancer (Xu, Towers, Li, & Collet, 2006). In order to cure the disease, different treatment methods within the TCM modality (e.g., diet therapy, herbal medicine, acupuncture, and acupressure) were used to counteract the excess force in order to restore balance. It was believed that once balance was achieved, the body would return to health (Xu, Towers, Li, & Collet, 2006).

Conventional medicine was well respected and trusted in this population for treating acute and life-threatening illnesses or conditions (e.g., cancer); however, the side effects from conventional treatments were interpreted as being too aggressive, causing an imbalance (Chiu et al., 2006). Consuming Chinese herbal medicine that counteracted the excess force was seen as a necessary step to ensure complete recovery (Bell & Lee, 2009; Chiu et al., 2006; Chui, Donoghue, & Chenoweth, 2005). Based on these cultural beliefs, Chinese-speaking cancer patients supported the integration of conventional medicine and TCM to cure cancer and support healing (Bell & Lee, 2009; Chiu et al., 2006).

Seeking information and clarification. In the seeking information and clarification phase, Chinese-speaking patients reported having difficulties locating a credible and trustworthy CAM practitioner (Chiu et al., 2006). They also reported a lack of information and decision support from the OHCP. They rarely engaged in a meaningful dialogue with their OHCP, and the few participants who reported having had conversations around CAM with their OHCP found the quality of the dialogue to be highly directive but not informative. As a result, these

participants consulted with trusted people in their social networks for CAM information and clarification. They valued anecdotal evidence from their friends, families, or fellow cancer survivors, and relied on it to make CAM therapy decisions. In addition, CAM information from lay literature and local Chinese-language media also became main sources of information.

This study presented two important points for further exploration. First, the reason(s) behind the communication gap between the participants and their OHCP was unknown. Was this communication hindered by language barriers or by a conflict in cultural beliefs between the patients and the OHCP? The answer to this question will help to bridge this communication gap, and ultimately, allow OHCP to support cancer patients to make safe and informed decisions. Second, the participants were often faced with difficulties when searching for CAM information, but the types of difficulties encountered are not well understood. They could be related to a lack of culturally appropriate CAM information source or participants' lack of knowledge in how to find credible information. Until there is a clear understanding of their needs in the information-searching process, it is difficult create support services to address these needs. These questions will be addressed in our research study.

Evaluating the effectiveness of CAM use. In the evaluating the effectiveness of CAM use phase, Chinese-speaking patients evaluated their CAM therapies through different means. Some monitored themselves for new and abnormal symptoms after adopting a new CAM therapy. Other required their family's approval of their CAM therapy choice. Relying on family approval as an evaluation criterion indicated the social influence of family was an important element in the CAM decision-making process.

Family values are the cornerstone of Chinese culture and have a major impact on treatment decisions (Simpson, 2003). Based on the most influential philosophies within Chinese

culture, Confucianism emphasizes maintaining harmony through respecting and following the rules assigned to each role within a social system (i.e. family, society) (Liu, 2003). The social influence of family on CAM decision making is not well understood. Would participants forego their CAM therapy if their family disapproves of the choice? In our study, we will explore and describe the impact of families or trusted others within the participants' social networks.

Balancing cost and benefits. Chiu et al. (2006) found that the Chinese-speaking cancer patients often discontinued CAM therapies due to financial burden. This phase also belonged to the evaluating process of CAM use and could be amalgamated with the previous phase. CAM therapies were not covered by the provincial medical insurance, and participants had to pay out of their pocket to purchase CAM products or services. Many participants were unable to work due to the physical and psychological demands of cancer and its treatment, and their financial resources were limited. Often, Chiu et al. (2006) found that the substantial cost for using CAM in participants' cancer experience was the reason for discontinuing CAM use. However, the writer suspects that there may be other pragmatic issues that led to the discontinuation of CAM therapies. Also, Chiu et al. (2006) only described how financial constraint had dissuaded participants from continuing with their CAM regimen, but the process of how participants balanced the cost with the benefits was not described in the study. In our study, the process to evaluate the CAM therapies will be addressed to further examine the reasons behind the decisions to continue or discontinue a CAM therapy.

Common Problems in the Decision-Making Process

After reviewing all the studies about the CAM decision-making process in people living with cancer, some commonalities in their experiences emerged (Balneaves et al., 2007; Chiu et

al., 2006; Truant & Bottorff, 1999). Foremost, regardless of their ethnicities or cultural backgrounds, all participants reported having difficulties searching for and evaluating CAM information. Second, cancer patients rarely communicated with their OHCP regarding their CAM use. Third, they also reported that there was a lack of information and decision support around CAM within the conventional medicine context. Fourth, many relied on trusted others in their social network to provide these types of support. These problems need to be addressed in order to support all cancer patients in making safe and informed decisions around CAM.

Influential Factors in CAM Use Decisions

Personal factors. Various personal factors were reported in previous research studies as predictors of CAM use. However, depending on the characteristics of the study samples, these factors varied among studies. In non-Chinese-speaking cancer patients, age, gender, and education and income levels were the most common personal factors reported to be associated with CAM use (Amin et al., 2010; Chang et al., 2011; Corner et al., 2009; Greenlee et al., 2009; Inglin et al., 2008; Molassiotis et al., 2006; Nagel et al., 2004; Naing et al., 2011; Newsom-Davis et al., 2009; Pedersen et al., 2009; Rakovitch et al., 2005; Wyatt et al., 2010). These factors were also found to be associated with CAM use in cancer patients with Chinese heritage among various studies (Chen et al., 2008; Chow et al., 2010; Cui et al., 2004; Ferro et al., 2007; Lee et al., 2010; Lim et al., 2010; Shih et al., 2009). In addition, studies involving multiethnic groups reported ethnicity (Chinese) as a predictive factor in CAM use (Chow et al., 2010; Shih et al., 2009).

Social factors. According to previous research studies on CAM decision making, both Chinese-speaking and non-Chinese-speaking cancer patients relied on their social networks to

gather and evaluate CAM information (Balneaves et al., 2007; Chiu et al., 2006; Truant & Bottorff, 1999). They valued the advice and recommendations of their social networks and often included them in the decision-making process. Chiu et al. (2006) also reported that Chinese-speaking cancer patients considered the opinion or approval of their family as an important criterion in determining the effectiveness of the CAM therapy used. The writer believes that family or significant others play an important role in making important decisions around health treatment.

Cultural factors. Cultural factors are influential in selecting CAM therapies and deciding on the actual implementation of CAM in ethnocultural groups. Both Lee et al. (2000) and Shumay et al. (2001) reported that ethnicity was found to have influenced the prevalence of CAM use and the preference of CAM therapies among multiethnic participants in their studies. The language, values, ideas, beliefs, and symbols within the culture of an ethnic group directly affect how the members assign meaning, experience their environment, react to stressors, and treat bodily dysfunction and illness (Ferro et al., 2007). As mentioned previously, Chinese-speaking cancer patients ascribed meanings to the causes of cancer and the side effects from the treatment through a cultural lens (Chiu et al., 2006). These patients may be less acculturated into Western society and were found to be more likely to use TCM as part of their health regimen (Ferro et al., 2007). As a result, many decided to integrate TCM with their cancer treatment.

Conceptual Model

Andersen's Behavioural Model of Health Services Utilization. In this chapter, studies documenting factors impacting the decision to use CAM were reviewed in detail. The disparate findings around the factors influencing CAM use need to be examined in accordance with a

consistent theoretical framework to provide a clear understanding of how these factors apply to the CAM decision-making process (Fouladbakhsh et al., 2005).

Andersen's Behavioural Model of Health Services Utilization (Andersen, 1995; Andersen & Newman, 1973) provides a framework that illustrates health services use as a function of (1) predisposing variables, (2) enabling variables, and (3) need or health status variables.

Andersen's (1995) definitions of predisposing variables, enabling variables, and need or health status variables are as follows. Predisposing variables are the conditions or factors that predispose a person to use health services. Such variables identified in this model include gender, age, education, ethnicity, and marital status. Enabling factors recognized in this model are the conditions or factors that allow or impede the use of health services or resources. These factors are personal, family, and community resources (e.g., income, family support or caregiver presence, geographic location, established relationship with health care provider, and health insurance status). Need or health status variables involve both evaluated and perceived needs for health services. Evaluated needs refer to objective measurable indicators of health status, such as diagnostic reports, symptom severity measure, or treatment received. Perceived needs are the individual's perception of health status and illness state.

Andersen's (1995) model was created to explain how different variables affected the utilization of conventional medicine. However, Brown, Barner, Bohman, and Richards (2009), Fouladbakhsh et al. (2005), and Ferro et al. (2007) used this model to guide their analysis of which of the variables from this model were associated with CAM utilization.

Ferro et al. (2007) applied the Andersen model to their study. The independent variables used in their study to predict CAM use included certain predisposing variables (i.e. demographic variables such as age, sex, marital status, education level; and cultural variables such as survey

language, place of birth, parental place of birth, language spoken at home, and household composition), enabling variables (i.e. household income and prior experience in TCM/CAM use), and needs and health status (i.e. the type of cancer, conventional cancer care received, and disease duration) (Ferro & Leis, 2006). Among these variables, they found that having prior experience with TCM/CAM use, having received conventional treatment, and being less acculturated were associated with TCM/CAM use.

Fouladbakhsh et al. (2005) aimed to determine the predictors of CAM use among 968 patients with lung, breast, colon, or prostate cancer. Secondary data analysis of two panel studies of patients with cancer and their caregivers was done using binary logistic regression. The study was guided by the Andersen's model (1995), and included predisposing variables, enabling variables, and needs or health status variables as the independent variables in this study. The dependent variable was CAM use. The results from the secondary data analysis indicated that gender (female), marital status (separated or divorced), cancer stage, cancer treatment received (surgery and chemotherapy), and number of severe symptoms were predictive of CAM use.

In another study, Brown et al. (2009) surveyed 4,256 African American adults in Austin, Texas, US to investigate which Andersen's model variables were associated with CAM use in this population. The participants in this study were not cancer patients. The predisposing variables associated with CAM use were found to be age (middle-aged to older), level of education (high), and gender (female). The only enabling factor was the region (south). The study also found that numerous needs or health status variables (i.e. higher numbers of comorbidities or physician visits, better health status, prescription and over-the-counter medication use, frequent exercise, and have having activities of daily living limitations) were associated with CAM use.

Andersen's Behavioural Model of Health Services Utilization provides a consistent theoretical framework that connects different variables to explain CAM-seeking behavior. The significant predictive variables associated with CAM use could be used as prompts by OHCP to assess for CAM use in their patients and open a dialogue to discuss issues related to such use.

Conclusion

In this chapter, the current literature regarding CAM use in the general population and cancer population is reviewed. Research studies specifically looking at the trend of CAM use and decision-making processes among Chinese-speaking cancer patients were very limited. Currently, there is only one qualitative study that describes the decision-making process in this population. Similar to their non-Chinese-speaking counterparts, these patients experienced difficulties in searching for and evaluating information around CAM. Also, there was a communication gap with OHCP and a lack of information and decision support around CAM within the context of conventional medicine. The reasons behind these issues are not well understood. Patients made their decisions independently or with the assistance of people in their social networks, adding more burdens during their cancer journey. This thesis study will provide more information about the information and decision-support needs of Chinese-speaking cancer patients, and the knowledge gained will help support these patients during their decision-making process around CAM use.

Chapter Two: Methods and Procedures

Although CAM is not part of the mainstream medical system in North America, many Chinese-speaking cancer patients living in Canada have integrated CAM, such as TCM, into their lives to treat ailments or maintain health (Lai & Chappell, 2007; Roth & Kobayashi, 2008; Quan et al., 2008). Based on the findings of an environmental scan conducted by CAMEO program, there is a lack of culturally-appropriate education programs and resources addressing CAM use in relation to cancer care for Chinese cancer patients at the VC-BCCA. It is challenging to create such programs and resources because little is known about Chinese-speaking cancer patients' information and decision support needs around CAM decision making. Gaining an understanding of their preferred choices of CAM and their experiences of making CAM decisions will inform OHCP of any knowledge gaps and unique needs in this cultural population related to making safe and informed decisions about CAM.

Purpose

The purpose of this research study is to describe the prevalence of CAM use, the information and decision support needs, and the experience of making CAM decisions in Chinese-speaking cancer patients receiving care at the VC-BCCA. In this chapter, the specific research questions that are guiding this study will be presented, followed by a detailed discussion of the study methods, including the procedures used, sample, recruitment, data collection, and analyses.

Research Questions

1. What is the *current* prevalence of CAM use by Chinese-speaking cancer patients receiving care at the VC-BCCA?

2. What are the information and decision support needs related to CAM of Chinese-speaking cancer patients receiving care at the VC-BCCA?
3. What demographic characteristics are associated with CAM use and the information and decision support needs of Chinese-speaking cancer patients receiving care at the VC-BCCA?
4. What are the differences between Chinese-speaking and non-Chinese-speaking cancer patients receiving care at the VC-BCCA in terms of the prevalence of CAM use and the information and decision support needs related to CAM?
5. What are the CAM decision-making experiences of Chinese-speaking cancer patients receiving active treatment and supportive cancer care, such as pain and symptom management and emotional support, at the VC-BCCA?

Methods

A sequential multi-method research design was selected for this study, which occurred over two phases – first quantitative, then qualitative. Multi-method research design allows for triangulated measurement to explore the phenomenon of interest from different methodological viewpoints (Polit & Beck, 2004). In this study, the quantitative and qualitative components were carried out in a sequential manner to allow the interview data to clarify any unanswered questions identified in the survey study. The findings from one type of method can always be enriched when combined with the findings gathered by another research method (Brewer & Hunter, 1989). Burns and Grove (2003) commented that quantitative descriptive surveys generate a broad spectrum of situational knowledge in a quick and efficient manner. As well, there is less opportunity for bias since the questions are presented in a consistent manner to all

study participants. However, a questionnaire does not allow the study participants to elaborate on their answers or clarify the questions. By adding a qualitative research component into the study, it allows the investigator to probe participants' experiences and generate an in-depth, more complete understanding of the phenomena. A multi-method research design, therefore, allows quantitative and qualitative design methods to complement each other, resulting in data that is often considered to be richer and more valid (Polit & Beck, 2004).

In this study, the first four research questions were answered in phase 1 by doing a secondary analysis using data gathered in a descriptive cross-sectional survey study, which was conducted by the CAMEO research team in 2008. The last research question was addressed in phase 2 of the study by conducting qualitative semi-structured interviews with Chinese-speaking cancer patients with CAM decision-making experience, and a focus group was carried out after the preliminary qualitative data analysis to verify the findings.

Phase 1: quantitative secondary data analysis. In this section, the CAMEO needs assessment survey study is first described in details to illustrate the goals of the study, the recruitment strategies and sample characteristics, as well we data collection procedures and data analysis strategies. This is followed by a thorough description of the procedures involved in the secondary data analysis. Information regarding the purpose of the analysis, the sample characteristics of the Chinese-speaking cancer patients involved in the study, the details of the study variables used, and the data analysis strategies are revealed.

The CAMEO needs assessment survey. This phase of the study was part of a larger needs assessment survey conducted by the CAMEO research team that aimed to address the information and decision support needs related to CAM in cancer patients at the VC-BCCA.

Previous qualitative research conducted by Balneaves and colleagues suggested that the most significant information needs of cancer patients in Canada included: Understanding the types of CAM treatment available; the risks and benefits of CAM treatments; access to comprehensive and credible information resources on specific CAM topics; guidance on how to evaluate information about CAM; and how to make appropriate CAM-related decision (Balneaves et al., 2007; Balneaves, Weeks, & Seely, 2008; Oneschuk, Balneaves, Verhoef, & Boon, 2007; Verhoef, Balneaves, Boon, & Vroegindewey, 2005). Based on their foundational work, a 21-item survey was developed by the CAMEO research team to assess VC-BCCA cancer patients' current use of CAM, their CAM information, education, and decision support needs, as well as key demographic characteristics. The survey was available in English and Chinese. A full description of the survey will be provided below when the secondary data analysis is described in more detail.

Purpose of the CAMEO needs assessment survey. The purpose of the CAMEO needs assessment survey was to assess the prevalence of CAM use and of the CAM information and decision support needs of patients living with cancer at the VC-BCCA. The overall goal of this project was to: a) Provide direction to the CAMEO research program to develop targeted information and decision support interventions to effectively address cancer patients' unmet information and decision support needs related to CAM; b) Raise awareness among the interprofessional health care team as to the potential need for such education and decision support interventions related to CAM, thereby, promoting referrals to CAMEO by health professionals at the VC-BCCA; and c) Provide a baseline measure of information and decision support needs of patients from which to evaluate the long-term impact of the CAMEO program.

Sample and recruitment. The needs assessment survey was administered on November 4th and 5th in 2008 by the CAMEO research team at the VC-BCCA. UBC Behavioural Research Ethics Board (BREB) granted ethics approval to carry out this study (H08-02097). Any consenting adult (at least 18 years old) patient who spoke and read English, or who spoke Cantonese or Mandarin and/or read the Chinese written language who presented at the VC - BCCA for cancer treatment and supportive cancer care were approached by a CAMEO research team member and invited to take part in the brief survey. Patients who were incapacitated due to their disease or treatment and were unable to complete the survey independently or with the assistance of a CAMEO research team member were not asked to complete the survey. All patients were reassured that their participation in the survey was voluntary and their decision to complete or not complete the survey would not jeopardize the care received. Patients were also reassured that the information they provided would be kept confidential and anonymous, and a patient identification number was placed on each survey to protect anonymity.

A total of convenience sample of 410 adult cancer patients, who spoke and read English or Chinese, was recruited for this study. Among the total sample, 52 of the study participants completed the Chinese version of the survey, and 13 patients indicated that their main spoken language was Chinese but completed the English version of the survey. These 65 patients whose main language was Chinese were grouped together as the Chinese-speaking cancer patient sample, which was used to compare with the rest of the sample to address research question 4.

Data collection procedures. The CAMEO team verified patient eligibility to participate in this study before providing them with a copy of the survey. Those patients who were comfortable completing the survey while they were waiting for care (or receiving care for selected in-patient and ambulatory chemotherapy patients) were provided with a letter of

explanation and the brief 2-page survey that assessed their current use of CAM, their CAM information, and decision support needs, and key demographic and disease characteristics (i.e., age, gender, type of cancer, type of conventional treatment). Those patients requesting or needing time to consider the request to complete the survey were provided with a stamped, self-addressed envelope, a letter of invitation, and the survey to review and complete at their leisure and mail to the CAMEO research program. Consent was implied by the completion and return of the survey. All patients approached were given a sticker with the CAMEO logo to wear during the duration of their visit at the VC-BCCA to reduce the chance of approaching the same individual more than once.

Data analysis. All the survey data was entered into the Statistical Package for the Social Sciences (SPSS) quantitative data analysis program. The data was randomly checked for data entry accuracy and all identified errors were corrected. There was one survey that was missing too much data and was eliminated from the analysis. Data analysis was conducted that included both descriptive statistics that described the sample, their CAM use, and their information and decision support needs related to CAM. In addition, inferential statistics, in particular Chi-square tests, were conducted to examine the associations among demographic and disease characteristics and CAM use and information and decision support needs, and to examine the differences in CAM use and information and decision support needs between Chinese-speaking and non-Chinese cancer patients.

Secondary data analysis. The purpose of the secondary data analysis was to assess the prevalence of CAM use and the information and decision support needs of Chinese-speaking cancer patients at the VC-BCCA. In addition, we examined the associations among demographics characteristics and CAM information and decision supports needs. Lastly, we also

tried to identify the unique information and decision support needs in this population by comparing their data with the non-Chinese-speaking cancer patient at the VC-BCCA.

Sample. The sample for the secondary data analysis included all patients who completed the survey. However, the data from the 65 Chinese-speaking cancer patients, who chose to complete the Chinese version of the needs assessment survey and those who completed the English version of the survey but indicated that their main spoken language was Chinese, were extracted to perform analysis to answer research question 1 to 3. Their data were then compared with the data from the 345 non-Chinese-speaking patients to address research question 4.

In this study, patients who completed the Chinese version of the survey and the ones who completed the English version but self-identified their main spoken language as Chinese were referred to as Chinese-speaking cancer patient.

Study variables. The needs assessment survey from which the data for the secondary data analysis was drawn was comprised of 21 items that examined the following key themes: CAM use (current and considering); experience of CAM-related support at the VC-BCCA; CAM information and decision support needs; and demographic and disease information (see Appendix A). All the variables used in the survey were investigator-developed. The majority of variables were either categorical (i.e., nominal) or were ordinal. Ordinal variables, for the purpose of inferential analyses, were collapsed into dichotomous variables. Detailed descriptions of the variables included in the survey study are described in the following paragraphs.

The four categorical variables that measured CAM use included: 1) CAM used since diagnosis; 2) CAM being considered at the time of the survey; 3) types of CAM therapies used; and 4) types of CAM therapies considered at the time of the survey. CAM used since diagnosis and being considered at the time of survey completion were dichotomous variables to understand

whether patient had used CAM since being diagnosed with cancer or were currently considering using a CAM therapy. The survey also elicited the kinds of CAM therapies patients were using or considering. Type of CAM therapies used or being considered were nominal variables that allowed patients to select specific CAM therapies from seven categories: Biological-based therapy, energy therapy, manipulative or body-based therapy, mind-body therapy, alternative medical systems, other types of complementary therapies, and supportive care services. In order to capture the specific types of CAM therapies used or being considered, space was allotted to allow patients to provide a qualitative description of the types of CAM therapies.

The survey also included seven variables that captured participants' experiences in discussing and disclosing CAM at VC-BCCA. Using a "yes/no" response option, patients were first asked "Has a health care provider at the BC Cancer Agency spoken to you about complementary therapies?" Patients who were answered "yes" were then asked to identify from a list of OHCPs at the VC-BCCA who had spoken to them about CAM (e.g., medical oncologist, radiation oncologist, oncology nurse, radiation therapist, dietitian, pharmacist, social worker, librarian, and others). They were also asked if they felt comfortable talking to OHCPs at the VC-BCCA about CAM using an ordinal scale ranging from "Yes, completely", "Yes, somewhat", and "No". Using the same ordinal response scale, patients were asked if OHCPs at the VC-BCCA listened to what they had to say about complementary therapies. It is important to note that the skip question pattern was not always understood.

All patients, regardless of whether they responded "yes" or "no" to the question about if an OHCP from the VC-BCCA had spoken to them about CAM, were asked if a OHCP from the VC-BCCA had put them in touch with another OHCP or program (e.g., CAMEO program). Patients could respond to this questions about referral by answering "yes", "no", or "I did require

information about complementary therapies”. All participants were also asked if they received enough information about CAM from the VC-BCCA and they get enough support in making decisions about CAM (response options: “Yes, completely”, “Yes, somewhat”, “No”, or “I did not require any information/support in making decisions complementary therapies”)

The CAM information and decision support required by Chinese-speaking cancer patients was assessed using two variables. First, patients were asked to select from an established list of information needs specific to CAM all those that they had experienced since being diagnosed with cancer (see Appendix A). An open-response option was provided to allow patients to add information needs that were not included in the list and the option “I have no questions about complementary therapies” was also available. Similarly, patients were asked to select from an established list of information and decision support services those that they would find helpful in making decisions about CAM. An open-response option, as well as an option that indicated no CAM-related support services were needed by the participants, were included in this variable. A final dichotomous variable was used to assess if patient would participate in a CAM education program, if it was available at the VC-BCCA. Patients who were not interested in attending a CAM education program were asked to provide the reasons for not attending.

Information about patients’ demographic and disease characteristics were also collected to gain an understanding of the patients’ background. Variables in this section include date of birth, gender, and main language, date of cancer diagnosis, type of cancer, and type of conventional cancer treatment received and about to receive. Main language was proxy for identifying Chinese-speaking participants. These variables were used to explore the associations between demographic characteristics and CAM use, type of CAM information needs, and type of preferred CAM information and decision support.

Data analysis. Descriptive statistics were used to describe the sample and the key variables assessed in the survey. The key variables include the prevalence of CAM use, interest in CAM and patients' information and decision support needs related to CAM. Frequency distributions with percentages were calculated on all key variables to address research questions 1 and 2.

For research questions 3 and 4, Pearson chi-square tests were used to investigate whether distributions of categorical variables differ from one another (Polit, 1996). In particular, Pearson chi-square was used to examine if any demographic characteristics were associated with CAM use and the information and decision support needs of Chinese-speaking cancer patients receiving care at the VC-BCCA. The same statistical test was used to explore the differences between Chinese-speaking and non-Chinese-speaking cancer patients receiving care at the VC-BCCA in terms of the prevalence of CAM use and the information and decision support needs related to CAM. Statistical significance was achieved when p-values were less than 0.05. A 95% confidence interval was also calculated around point estimates (i.e., frequencies) to show the range of possible effect size. The Holm-Bonferroni correction factor was applied to adjust the p-value and confidence interval for multiple tests. In order to perform the Holm-Bonferroni correction method (Holm, 1979), the p-values from the multiple tests were organized from the smallest one to the largest one. Then the smallest p-value was being compared to the adjusted p-value, which was α/k ($\alpha=0.05$ and k =total number of tests). If it was less than the adjusted p-value, then this assumption was rejected. The second smallest p-value became the smallest p-value, and was then compared to the adjusted p-value. However, since we had rejected the last assumption, the adjusted p-value was calculated by $\alpha/k-1$ ($\alpha=0.05$ and k =total number of tests done). If the smallest p-value was less than the adjusted p-value, then this assumption was gain

rejected. With an additional assumption being rejected, the adjusted p-value was recalculated by α/k -the number of assumption rejected. This comparison continued until the assumption with the smallest p-values could not be rejected, and then the remaining of assumption could not be rejected. Since the data was nominal or ordinal in nature, and given the small sample size, regression or analysis of variance could not be performed.

Ethical considerations. Ethics application was submitted to UBC BREB and ethics approval was received (H10-01780) for this research study. There was no known risk in participating in this study; however, it was acknowledged that some participants could experience certain emotions, such as anxiety, when talking about their cancer experience. The investigator paid special attention to patients' well being and attempted to not burden them physically and psychologically. During the interviews and the focus group session, the investigator assessed for any signs of physical or emotional distress in the participants on a regular basis. When the participants exhibited any signs of distress or verbalized feeling distressed, the investigator would stop the interview and assessed to see if they were able to continue with the interview or focus group. If they were unable to continue, the interview would either be rescheduled or cancelled depending on participants' preference. Referrals to patient and family counseling at the VC-BCCA were also available, if required. With regards to benefit of participating in the study, all patients who consented to be interviewed received a \$20 honorarium to compensate for their time and transportation expenses. Moreover, some participants potentially found it beneficial to speak about their cancer experiences.

Phase 2: qualitative semi-structured interviews. The purpose of the qualitative interview was to gain an in-depth understanding of the Chinese-speaking cancer patients' CAM decision-making experiences. The information collected during this phase complemented the

findings from the surveys. Recruitment for this phase began after completing data analysis of the cross-sectional survey data. Qualitative semi-structured interviews were conducted based on the interpretive descriptive approach (Thorne, Reimer Kirkham, & Macdonald-Emes, 1997). A focus group was completed following initial data analysis to confirm the findings and interpretation of the interviews and enhance the rigor of this phase of the research. Interpretive description is an inductive analytical approach designed to create ways of understanding clinical phenomena that yield practical applications (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). This qualitative approach goes well with the purposes of this study as it describes, in the patients' own words, their CAM decision-making experiences, as well as patients' needs related to CAM decisions. Ultimately, this knowledge will be used to raise the awareness of the information and supportive needs specific to CAM that are unique to Chinese-speaking cancer patients, and will inform the development of culturally appropriate educational and supportive services in the clinical setting.

Sample and Sampling. In this study, Chinese-speaking cancer patients were recruited using theoretical sampling. In interpretive description, theoretical sampling is used to gain a representative sample of people who have had experience with the phenomenon of interest and are willing to share rich and dense description of their experiences (Streubert Speziale & Carpenter, 2003). The sample size suggested for different types of qualitative research approaches varies from 6 to 50 participants (Bertaux, 1981; Creswell, 1998; Morse, 1994). According to Bertaux (1981), the smallest acceptable sample is 15 participants in any type of qualitative study. Based on previous research exploring the decision-making process of cancer patients (Balneaves et al., 2007), it was anticipated that 20 participants would be sufficient. During the interviews, five family members had accompanied the participants to the interviews.

Due to the strong influence of their families on the Chinese-speaking cancer patients' decisions on cancer management (Bell & Lee 2009; Chiu et al., 2006; Pang, Jordan-Marsh, Silverstein, & Cody, 2003; Simpson, 2003), we accepted them to be part of the interviews as well. Data collection was discontinued when data was saturated and no new information arose from the interviews (Siegale, 2002).

The inclusion criteria included adult (age 18 or above) Chinese-speaking cancer patients, who were diagnosed with cancer for less than five years, were receiving treatments or supportive care at the VC-BCCA, were born outside of Canada, and were either using or considering using CAM. We were targeting patients who had a higher probability of using CAM. As a result, we initially only included patients who had been living in Canada for less than ten years based on the assumption that these individuals would have less time to assimilate into the Canadian culture, and would be adhering to their cultural health beliefs and practices from their countries of origin. We also limited the types of the cancer diagnoses to include only the most frequently diagnosed gender-neutral cancer in people with Chinese ancestries living in North America. These cancer types included head and neck cancer, lung cancer, gastrointestinal cancer (Luo, Birkett, Ugnat, & Mao, 2004; McCracken et al., 2007). However, the limitations related to length of Canadian residency and type of cancer diagnosis hindered the recruitment process. Ethics amendments were made and approval received to include Chinese-speaking cancer patients with any length of residency in Canada and all types of cancer diagnoses.

Recruitment procedures. Participant recruitment was done via information on the CAMEO webpage, which is embedded within the BCCA website, and recruitment posters and flyers placed in public areas throughout the VC-BCCA. Presentations regarding this research study were also given to OHCP groups within the VC-BCCA to facilitate recruitment and letter

of invitations and flyers were available for OHCPs to give to patients. For Chinese-speaking patients who were interested in participating in the interview, OHCPs were asked to obtain permission from them for the investigator to contact them within a week. Alternatively, patients also contacted the investigator directly via the contact information provided on the posters or flyers. All patients were ensured that their participation was voluntary and they could withdraw at anytime.

Data collection procedures. Patients participated in a 1-hour interview, and were also invited to participate in a one-hour focus group to validate the research findings. Interviews were arranged at a time convenient to the patient and was conducted either in the CAMEO office located near the VC-BCCA or in the patient's home. Interviews were conducted in either Mandarin or Cantonese after patients reviewed and signed the consent forms. All interviews were tape recorded, and field notes were taken to document important contextual information about the interviews. At the end of the interview, participants were reminded that they would receive an invitation to participate in a focus group interview.

Interview guide. The interview guide was developed based on the principles of the interpretive description approach that new knowledge should be built on the foundation of existing knowledge (Thorne et al., 1997). Previous research on CAM decision making in cancer patients had found that common challenges encountered by cancer patient during this process were knowledge deficit in CAM, lack of support in finding and evaluating CAM information, informational conflict, as well as lack of support in decision making (Balneaves et al., 2007; Balneaves et al., 2008; Evans et al., 2007; Legare et al., 2007; Shumay et al., 2001). The interview guide were developed based on these previous research findings and the preliminary secondary data analysis results to explore the decision-making process in Chinese-speaking

cancer patients living in Greater Vancouver, BC, Canada. The questions in the interview guides asked about important elements within the decision-making process, which included the goals and motivation behind the use, the types and sources of their CAM information, the experience around communicating with OHCPs around CAM issues, the information-evaluating process, the selection process of the CAM therapies, the evaluation of the CAM efficacy, and the CAM information and decision support needs. (See Appendix B).

Data analysis. The interviews were translated and transcribed into English by a professional transcriptionist who is proficient in both Chinese and English languages. Important words and phrases that were difficult to translate were retained in Chinese to maintain meaning. The transcripts were reviewed by the investigator (M. Wong), who is proficient in both Chinese and English language, to verify their accuracy and to prevent biases. All transcripts and field notes were entered and stored into a password protected and data encrypted qualitative software program, NVivo.

In the interpretive description approach, constant comparative analysis process is used to develop ways to understand human phenomena within the context in which they are experienced (Thorne, 2000). Constant comparative analysis takes one piece of data and compares it with all others that may be similar or different in order to develop conceptualizations of possible relations among an assortment of data (Glaser & Strauss, 1967). This approach was complemented by theoretical sampling, which allowed new research subjects to be selected who were able to provide insight into new themes or directions identified in the data analysis.

According to leading interpretive descriptive theorists, during data analysis, investigators must refrain from premature and excessive coding in order to apprehend the overall picture presented in the data (Thorne et al., 1997). Premature coding can sacrifice the deeper and more

meaningful analytic interpretations. In interpretive description, nurse researchers are required to know individual cases intimately in order to abstract relevant common themes within these individual cases, and produce special knowledge that can be applied back to these cases. Based on these principles, the investigator recorded field notes from participant observation during and immediately after the interview. Also, the investigator had read the transcripts several times before coding. An audit trail was kept during the coding process to record the analytic reasoning process. The investigator also sought guidance from her advisors to ensure the accuracy of the coding process.

Rigor. To ensure rigor, Thorne et al. (1997) suggested keeping a trail of the development of abstractions from the data to ensure the analytic directions are defensible. As mentioned earlier, an audit trail was kept for this purpose. Thorne et al. (1997) also suggested researchers bring the beginning conceptualizations back to individual research participant for their critical considerations to see “what does not fit”. This was done through a focus group. This strategy provided an opportunity to challenge the emerging findings and to refine theoretical linkages among concepts. At the end, it is hoped that the conceptualizations are grounded in the data and representative of participants’ realities.

Ethical considerations. All transcripts and field notes were entered and stored into a password protected and data encrypted qualitative software program. All study documents that included participants’ data, for example interview transcripts, completed questionnaires, and investigator’s notes, are being kept in a locked filing cabinet within the CAMEO research office. CAMEO is a research program associated with the UBC School of Nursing and is located near the VC-BCCA in the Fairmont Medical Building in Vancouver, BC. Computer files are password protected. Confidential information was not collected or exchanged via e-mail. After

the study, all data will be stored for seven years in either a locked room in the CAMEO research office or in Dr. Lynda Balneaves' office at the UBC School of Nursing. All data will be destroyed after this period.

Conclusion

The CAM decision-making process in Chinese-speaking cancer patients is not well understood. Multimethod research, including a quantitative descriptive survey and qualitative semi-structured interviews, were used in this study to understand this phenomenon. Basic descriptive and inferential statistical analyses were done to summarize, describe, and compare the data. Significant findings from the quantitative phase of this study were used to inform the development of the interview guide. The interviews provided in-depth knowledge of Chinese-speaking patients' experiences of making CAM decisions while living with cancer. In addition, their information and supportive needs related to CAM were identified, which will ultimately help educate OHCP regarding this population's unique needs and inform future development of education and supportive services that are culturally-sensitive.

Chapter Three: Secondary Data Analysis Results

This secondary data analysis focused on survey data collected from Chinese-speaking cancer patients who received cancer care at the VC–BCCA. Chinese-speaking cancer patients are referred to as participants throughout this chapter, except when they are being compared to the non-Chinese-speaking cancer patients, and then they will be referred to as Chinese-speaking cancer patients.

In this chapter, demographics and disease characteristics of the sample will be first described, followed by the prevalence of CAM use as well as the type of CAM therapies reported being used by the participants. Participants' experiences around CAM communication with OHCP and receiving support in CAM decision making at the VC-BCCA will also be discussed. The types of information needs and CAM decision-support services participants found most helpful will be examined. Lastly, the significant findings found on the associations between key demographic variables (i.e. age, gender, and Chinese-language ability) and the prevalence of CAM use, CAM information and decision support needs will be reported.

Descriptive Statistics

Demographics. In total, 65 participants had identified their main language was Chinese in the larger CAMEO needs assessment study. Almost half of the sample indicated that their main dialect was Cantonese (47.7%) and 16.9% indicated their main dialect was Mandarin. Five participants (7.7%), who indicated their main language was English and completed the English survey but identified themselves as being able to speak or understand Chinese language, were included in the sample. The remaining 18 participants (27.7%) indicated their main language was Chinese but did not specify the dialect used. There were more women than men who participated

in the survey (67.7% vs. 30.8%), with an average age of 59.3 years. (See Table 1 for more detailed demographic information.)

The top four cancer diagnoses in this sample were breast (33.9%), nasopharyngeal (18.5%), lung (18.5%), and colorectal cancer (10.7%). Almost half of the sample (47.7%) had been diagnosed with cancer for less than 12 months. The types of conventional cancer treatments received were chemotherapy, radiation therapy, surgery, and hormone therapy. (See Table 1 for specific disease and treatment information.)

Current prevalence of CAM use. Sixty-six percent ($\pm 11.5\%$) of the sample reported using CAM since their cancer diagnoses. Also, about fifty-four percent ($\pm 12.1\%$) of these participants also indicated that they were considering using other CAM therapies. Of the 20 participants who reported not using CAM since their diagnosis, 30% ($\pm 11.1\%$) of these individuals reported that they were considering using CAM sometime in the future. The most popular type of CAM used by the participants was biological-based CAM therapies ($52.3 \pm 12.1\%$). Biological-based therapies included herbs, vitamins, and minerals, many of which are sold over the counter as dietary supplements (NCCAM, 2012). The second most frequently used CAM were whole systems of care ($36.9 \pm 11.7\%$), which are defined as a complete system of theories and practices evolved over time in different cultures and apart from conventional or Western medicine (NCCAM, 2012).

Table 1.**Demographic and Disease Characteristics of the Sample (n=65)**

| Characteristics | Frequency (%) |
|---------------------------------------------|---------------|
| Gender | |
| Male | 20(30.8) |
| Female | 44(67.7) |
| Transgendered | 0(0.0) |
| Missing | 1(1.5) |
| Main language | |
| Cantonese | 31(47.7) |
| Mandarin | 11(16.9) |
| Other dialect(dialect not specified) | 18(27.7) |
| English but understand Chinese language | 5(7.7) |
| Missing | 0(0.0) |
| Age^a | |
| < 60 years | 32(49.2) |
| 60+ years | 30(46.2) |
| Missing | 3(4.6) |
| Type of cancer | |
| Breast | 22(33.9) |
| Lung | 12(18.5) |
| Nasopharyngeal | 12(18.5) |
| Colorectal | 8(10.7) |
| Genitourinary | 4(6.2) |
| Gynecological | 3(4.6) |
| Other types of cancer | 4(6.2) |
| Missing | 0(0.0) |
| Time since diagnosis | |
| Less than 12 months | 31(47.7) |
| More than 12 months | 34(52.3) |
| Missing | 0(0.0) |
| Type of cancer treatment^b | |
| Surgery | 42(64.4) |
| Chemotherapy | 49(75.4) |
| Radiation therapy | 44(67.7) |
| Hormone therapy | 11(16.9) |
| Other type of treatment | 0(0.0) |
| Missing | 0(0.0) |

Note ^a The mean age was 59.3 years. ^b Some participants had more than one type of treatment; therefore, the total of the type of treatments received is more than 65.

Some examples of whole systems of cares include South Asian Ayurvedic medicine, homeopathic medicine, and naturopathic medicine. Among the participants, traditional Chinese medicine was the preferred whole system of care (see Table 3). Mind-body ($23.1 \pm 10.2\%$) and energy-based therapies ($23.1 \pm 10.2\%$) rounded out the top four types of CAM therapies that were used by participants. Mind-body based therapy, such as meditation and some forms of yoga, uses the mind to influence physical functioning in order to promote health. Energy-based therapy involves manipulation of both veritable and putative energy fields to affect health (NCCAM, 2012). Some examples include qi-gong, reiki, and electromagnetic field therapy.

Body-based therapies, which employ manipulation of body structures and systems to promote health and healing, were the least frequently used CAM therapy reported by participants ($18.5 \pm 9.4\%$). See Table 3 for a comprehensive list of individual CAM therapies that were reported by participants.

CAM communication and decision support. In the survey, the participants' perception of CAM communication and decision support at the VC-BCCA was also assessed. Although two-thirds of participants had used CAM therapies since their diagnoses, only $18.5\% (\pm 9.4\%)$ ($n = 12$) reported that their OHCP at the VC-BCCA had spoken to them about CAM therapy use. However, of the 29 participants who responded to the question regarding whether they felt their HCP had listened to their queries about CAM, the majority ($65.5\% \pm 17.3\%$) felt they were listened to "somewhat" or "completely". Similarly, almost all of these 29 participants ($92.9\% \pm 9.3\%$) felt somewhat or completely comfortable talking about CAM with their HCPs. The HCPs that were reported to have spoken to participants about CAM in the clinical setting included medical oncologists ($20 \pm 12.2\%$), radiation oncologists ($10.8 \pm 9.5\%$) and nurses ($7.7 \pm 8.2\%$) (See Table 3 for further details).

Table 2:**Specific CAM Therapies (n=43)**

| CAM Therapies | Frequency (% \pm 95% CI) |
|-------------------------------------------------------|----------------------------|
| Biological-Based Therapies | |
| Non-specific vitamins/minerals | 15 (34.1 \pm 14.2%) |
| Non-specific herbal therapies | 9 (20.5 \pm 12.1%) |
| Mushrooms (e.g., Reishi, <i>Coriolus versicolor</i>) | 6 (13.6 \pm 10.2%) |
| Chinese herbs | 2 (4.6 \pm 6.3%) |
| Others | 8 (18.2 \pm 11.5%) |
| Energy-based Therapies | |
| Acupuncture | 3 (6.8 \pm 7.5%) |
| Magnetic Therapy | 2 (4.6 \pm 6.3%) |
| Qigong | 2 (4.6 \pm 6.3%) |
| Reiki | 1 (2.3 \pm 4.5%) |
| Therapeutic Touch | 1 (2.3 \pm 4.5%) |
| Body-based Therapies | |
| Massage Therapy | 7 (15.9 \pm 10.9%) |
| Physiotherapy | 1 (2.3 \pm 4.5%) |
| Yoga | 1 (2.3 \pm 4.5%) |
| Exercise | 1 (2.3 \pm 4.5%) |
| Tai Chi | 1 (2.3 \pm 4.5%) |
| Mind-body based Therapies | |
| Meditation | 5 (11.4 \pm 9.5%) |
| Support Group | 5 (11.4 \pm 9.5%) |
| Relaxation | 2 (4.6 \pm 6.3%) |
| Others | 3 (6.8 \pm 7.5%) |
| Whole System Therapies | |
| Traditional Chinese Medicine | 13 (29.6 \pm 13.6%) |
| Naturopathic Medicine | 4 (9.1 \pm 9.5%) |
| Other Therapies | |
| Special Diet | 5 (11.4 \pm 9.5%) |
| Cleansing | 1 (2.3 \pm 4.5%) |

Note. Total frequencies does not equal to 100%, because some participants used more than one type of CAM therapy.

Table 3:**Health Care Provider Communication about CAM (n=65)**

| Type of Health Care Provider | Frequency (% \pm 95% CI) |
|-------------------------------------|----------------------------------------------|
| Medical oncologist ^a | 13 (20 \pm 9.7%) |
| Radiation oncologist | 7 (10.8 \pm 7.5%) |
| Nurse | 5 (7.7 \pm 6.4%) |
| Radiation therapist | 4 (6.2 \pm 5.9%) |
| Dietitian | 2 (3.1 \pm 4.2%) |
| Pharmacist | 3 (4.6 \pm 5.1%) |
| Social worker | 5 (7.7 \pm 6.4%) |
| Librarian | 2 (3.1 \pm 4.2%) |

^a One participant answered this question that had initially indicated on question 5 that they had NOT been spoken to about CAM by an HCP

With regards to the perceived support that participants received related to their CAM decisions, only 6.2% (\pm 5.9%) (n = 4) reported receiving referrals to other HCPs or programs that provided information about CAM, with 10.8% (\pm 7.5%) (n = 7) reporting that they did not perceive themselves as needing any information about CAM. Less than a third (28.0 \pm 10.9%) reported that they had received enough information about CAM, and only 23.0% (\pm 10.2%) felt that they had received enough decision-making support from their HCPs (see Table 4 for further details).

Table 4:**CAM Information and Decision Support Received (n=65)**

| CAM Support Received | Frequency (% ± 95% CI) |
|-----------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|
| Did a health care provider at the BCCA put you in touch with a health care provider or program that could help you get information about CAM? | |
| Yes | 4 (6.2 ± 5.9%) |
| No | 49 (75.4 ± 10.5%) |
| I did not require information about CAM | 7 (10.8 ± 7.5%) |
| Missing | 5 (7.7 ± 6.5%) |
| Did you get enough information about CAM from the BCCA? | |
| Yes, completely | 2 (3.1 ± 4.2%) |
| Yes, somewhat | 16 (24.6 ± 10.5%) |
| No | 37 (56.9 ± 12.0%) |
| Missing | 4 (6.2 ± 5.9%) |
| I did not require any information about CAM | 6 (9.2 ± 7.0%) |
| Did you get enough support in making decisions about CAM from the BCCA? | |
| Yes, completely | 2 (3.1 ± 4.2%) |
| Yes, somewhat | 13 (20.0 ± 9.7%) |
| No | 39 (60.0 ± 11.9%) |
| Missing | 7 (10.8 ± 7.5%) |
| I did not require support in making decisions about CAM | 4 (6.2 ± 5.9%) |

CAM information and decision support needs. In terms of CAM information needs, 78.5% ($\pm 10.0\%$) of the participants indicated they had questions about using CAM therapies. Many reported requiring additional information on finding a CAM practitioner ($52.3 \pm 12.1\%$), knowing the types of CAM therapies were available at the VC-BCCA ($43.1 \pm 12.0\%$), and communicating with HCP regarding CAM ($40.0\% \pm 11.9\%$). See Table 5 for more detailed data regarding the CAM information needs held by participants.

Table 5:**Participants' CAM Information Needs (n=65)**

| CAM Information Needs | Frequencies (% \pm 95% CI) |
|--------------------------------------------------------------------------------|------------------------------------------------|
| How to choose a CAM HCP? | 34(52.3 \pm 12.1%) |
| What CAM are available at the BCCA? | 28(43.1 \pm 12.0%) |
| How to talk to a HCP about CAM? | 26(40.0 \pm 11.9%) |
| When is it safe to use CAM? | 21(32.3 \pm 11.4%) |
| How to find trustworthy CAM information? | 21(32.3 \pm 11.4%) |
| What CAM is helpful? | 19(29.9 \pm 11.1%) |
| What CAM can be used safely in combination with conventional cancer treatment? | 19(29.9 \pm 11.1%) |
| I have no question about CAM. | 9(13.8 \pm 8.4%) |
| Missing | 9(13.8 \pm 8.4%) |

Note. The total number of CAM information needs exceeds 65 because participants chose more than one CAM information need on the list.

Regarding participants' CAM decision support needs, 89.2% (\pm 7.5%) indicated that 1) counseling sessions from a health care provider about using CAM therapies, 2) education sessions on making decisions about CAM therapies, 3) a workbook on helping participants to make decisions about CAM therapies, 4) an information booklet on how to make decisions about CAM therapies, 5) a website on how to make decisions about CAM therapies, and 6) access to BC Cancer Agency library resources about CAM to be helpful. The most preferred CAM support services were having access to CAM information in the VC-BCCA library (60 \pm 11.9%), followed by a website on CAM decision making (43.1 \pm 12.0%), a workbook on CAM decision

making (43.1% \pm 12.0%), and a CAM education session (43.1% \pm 12.0%). See Table 6 for detailed information regarding participants' decision support needs.

Table 6:

Participants' Decision Support Needs (n=65)

| CAM Decision Support Needs | Frequencies (% \pm 95% CI) |
|----------------------------------------------------------------------------------|------------------------------------------------|
| 1:1 CAM Counseling with a HCP | 18(27.7 \pm 10.9%) |
| CAM Education Session | 28(43.1 \pm 12.0%) |
| Workbook on CAM decision making | 28(43.1 \pm 12.0%) |
| Information booklet on CAM decision Making | 25(38.5 \pm 11.8%) |
| Website on CAM decision making | 28(43.1 \pm 12.0%) |
| Access to CAM information at the BCCA library | 39(60.0 \pm 11.9%) |
| I would <u>NOT</u> find any of these education/decision support services helpful | 3(4.6 \pm 5.1%) |
| Missing | 5(7.7 \pm 6.5%) |

Note. The total does not equal to 100%, because the participants selected more than one of the CAM decision support services.

Associations between Demographic Characteristics and CAM Use

On the CAMEO needs assessment survey, demographic information was collected to gain an understanding of participants' background. Previous research studies on Chinese-speaking cancer patients had found that age, gender, education, and marital status were associated with CAM use (Chen et al., 2008; Chow et al., 2010; Cui et al., 2004; Lim, Ng, & Loh, 2010). On the CAMEO need assessment survey, only information on participants' age and gender were requested. Chi-square tests were used to explore the associations between gender

and prevalence of CAM use as well as between age and prevalence of CAM use. Participants' gender was dichotomized into male and female (with no participants identifying themselves as transgendered). Age was also divided into two groups, using the participants' median age of 60 years as a cut-off point (i.e., < 60 years of age and 60+ years of age). Holm-Bonferroni method was used to prevent a type 1 error as a result of conducting multiple comparisons. P-value was reduced from 0.05 to 0.025 by dividing $0.05/2$ (α /number of tests).

Gender was found to be significantly associated with CAM use ($X^2= 5.921$, $p=0.015$). Men ($89.5 \pm 7.5\%$) are more likely to use CAM than women ($58.1 \pm 12\%$). Age was not found to be significantly associated with CAM use, with 69.4% of participants less than 60 using CAM compared to 64.0% of those 60 years or older ($X^2 = .198$, $p=.656$).

Demographic Characteristics and CAM Support Needs

CAM information needs. Age and gender were also tested for any association with CAM information needs. On the survey, the participants were asked to select from eight response options about the types of CAM information needs they had since diagnosis, and an open-ended question was included at the end to allow for any additional information need not listed in the question. These options included 1) What CAM therapies are available at the BCCA?, 2) What CAM therapies are helpful for people with cancer?, 3) What CAM therapies can be used safely in combination with medical cancer treatments (e.g. surgery, chemotherapy, radiation, hormone therapy)?, 4) When is it safe to use CAM therapies after being diagnosed with cancer?, 5) How do I talk with my health care providers (e.g. doctors, nurses) at the BCCA about CAM therapies?, 6) How do I choose a health care provider that offers CAM therapies?, 7) Where do I

find trustworthy information about CAM therapies?, 8) I have had no questions about using CAM therapies?, and 9) Other-Please list all other questions you have had about CAM therapies.

The first seven types of information needs listed above was the focus of the analysis, and no participant reported any additional information need. Chi-square tests were repeated seven times to determine the association between types of CAM information needs and age. The same tests were performed another seven times to investigate any association between CAM information needs and gender. Holm-Bonferroni method was used to adjust the p-value to prevent Type 1 error as a result of multiple comparisons (see Methods section for description).

Before using the Holm-Bonferroni method to correct the p-value, there were two significant associations found between age and the type of CAM information required in making CAM decisions. Participants who were younger than 60 years of age were more likely to require information on the type of CAM therapies that could be used in combination with conventional cancer treatments than participants 60 and older ($79.4 \pm 9.8\%$ vs. $50.0 \pm 12.2\%$; $X^2=5.05$, $p=0.025$). Also, younger participants were more likely than older participants to want to know when it would be safe to use CAM after being diagnosed with cancer ($76.5 \pm 10.3\%$ vs. $45 \pm 12.1\%$; $X^2=5.47$, $p=0.019$).

After the p-values for each association were ordered from smallest to largest and the step-wise adjustments of the p-values were conducted, both initially significant associations were rejected. As such, there were no significant associations among the different types of CAM information needs and the demographic factors of gender and age.

CAM decision support needs. Chi-square tests were used to explore for the associations between age and gender and the type of CAM decision support required by participants. The participants were to select all the respond option that they found helpful from the six types of

CAM decision support services options listed in the question. These options were 1) Counseling sessions from a health care provider about using CAM therapies, 2) Education sessions on making decisions about CAM therapies, 3) A workbook that would help me to make decisions about CAM therapies, 4) An information booklet on how to make decisions about CAM therapies, 5) A website on how to make decisions about CAM therapies, and 6) Access to BCCA library resources about CAM therapies. Additional two respond options allowed participants to indicate that they would not find the aforementioned decision support services helpful and to add in additional CAM decision support needs.

Since the analysis was focusing on the six options and no participant had added any additional CAM decision support services needs, Chi-square tests were performed 12 times to explore the associations between age and gender and the type of CAM decision support required by participants. .Holm-Bonferroni method was used to adjust the p-value to prevent Type 1 error.

Before the adjustments, there were several significant associations found between the two demographic variables and types of CAM decision support services needs. Compared to participants 60 years or older, participants who were younger than 60 years of age preferred a website on CAM decision making ($30.4 \pm 11.2\%$ vs. $71.4 \pm 11.0\%$; $X^2=10.073$, $p=0.006$) and a CAM information booklet on CAM decision making ($36.4 \pm 11.7\%$ vs. $74.3 \pm 10.6\%$; $X^2=8.071$, $p=0.004$). Compared to male participants, female participants were more likely to perceive a CAM education session ($31.3 \pm 11.3\%$ vs. $62.8 \pm 11.8\%$, $X^2=4.674$, $p=0.031$) to be helpful and a CAM information booklet on decision making (25.0 ± 10.5 vs. $72.1 \pm 10.9\%$; $X^2=10.717$, $p=0.001$).

After the p-values for each association were ordered from smallest to largest and the step-wise adjustments of the p-values were conducted, only two associations remained statistically

significant: 1) the association between gender and the preference for a CAM information booklet; and 2) the association between age and the preference for an information booklet. Women who were under the age of 60 were more likely to prefer an information booklet as a decision support tool than those who were older than 60 years old. There was no other significant association between age and gender and participants' decision support needs.

Comparison between Chinese-speaking and Non-Chinese-Speaking Participants' CAM Use

Chi-square tests were used to test for differences between the Chinese-speaking and the non-Chinese-speaking cancer patients in terms of their prevalence of CAM use and their CAM information and decision support needs. Foremost, Chinese-speaking patients were more likely to use CAM than non-Chinese speaking participants ($68.3 \pm 4.5\%$ vs. $47.8 \pm 4.8\%$, $X^2=8.8$, $p=0.003$) (Note: slight discrepancy in prevalence of CAM use is a result of missing data being omitted from the chi-square analysis).

CAM information needs. Chinese-speaking cancer patients reported different CAM information needs than non-Chinese speaking cancer patients. Due to the number of information needs assessed in this analysis, a total of seven Chi-square tests were performed. The Holm-Bonferroni correction factor was applied to adjust the p-value to prevent Type 1 error due to multiple comparisons.

Before the adjustment, there were six significant associations among CAM information needs and Chinese language ability. Compared to non-Chinese-speaking cancer patients, Chinese-speaking cancer patients were more likely to find the following information helpful: Where to find trustworthy information about CAM ($38.1 \pm 4.7\%$ vs. $62.5 \pm 4.7\%$, $X^2=11.426$, $p=0.001$), how to talk with my HCP at the BCCA about CAM ($24.5 \pm 4.2\%$ vs. $53.6 \pm 4.8\%$,

$X^2=19.161$, $p=0.000$), when is it safe to use CAM after being diagnosed with cancer ($42.3 \pm 4.8\%$ vs. $62.5 \pm 4.7\%$, $X^2=7.697$, $p=0.006$), what CAM can be used in combination with medical cancer treatments ($45.8 \pm 4.8\%$ vs. $66.1 \pm 4.6\%$, $X^2= 7.697$, $p=0.006$), what CAM therapies are helpful for people with cancer ($47.9 \pm 4.8\%$ vs. $66.1 \pm 4.6\%$, $X^2=6.186$, $p=0.013$), and how to choose a health care provider that offers CAM ($24.5 \pm 4.2\%$ vs. $39.3 \pm 4.7\%$, $X^2=5.224$, $p=0.022$). There was no significant association between Chinese-speaking and non-Chinese speaking patients with regards to requiring information about which CAM therapies were available at the VC-BCCA (50.0% vs. 31.9% ; $X^2 = 2.76$, $p = .097$).

After the p-values for each association were ordered from smallest to largest and the step-wise adjustments of the p-values were conducted, all significant associations identified above remained significant. Compared to non-Chinese speaking cancer patients, Chinese cancer patients were more likely to perceive themselves to have a broad range of information needs related to CAM.

CAM decision support needs. We also used Chi-square tests to examine the differences between Chinese-speaking and non-Chinese-speaking cancer patients in terms of their CAM decision support needs. Due to the number of CAM decision support needs assessed, Chi-square tests were performed six times to investigate difference between the two language groups. Holm-Bonferroni method was used to adjust the p-value to prevent Type 1 errors due to multiple comparisons.

Before the p-value adjustment, there was one significant result found. Compared to non-Chinese-speaking cancer patients, Chinese-speaking cancer patients were more likely to find counseling sessions from a HCP about CAM to be helpful in their CAM decision-making process ($50.5 \pm 4.8\%$ vs. $71.2 \pm 4.4\%$, $X^2=8.426$, $p=0.004$). Even after the adjustment, this

remained a significant finding. No significant differences were found between the remaining decision support needs of Chinese-speaking and non-Chinese speaking cancer patients (see Table 7).

Table 7:

Decision Support Needs between Chinese and Non-Chinese Speaking Cancer Patients (n=410)

| CAM Decision Support Needs | Chi-square Values (p-values) |
|-----------------------------------------------|------------------------------|
| 1:1 CAM Counselling with a HCP | 8.426(0.004) |
| CAM Education Session | 0.739(0.390) |
| Workbook on CAM decision making | 0.749(0.387) |
| Information booklet on CAM decision Making | 0.142(0.707) |
| Website on CAM decision making | 4.923(0.085) |
| Access to CAM information at the BCCA library | 2.654(0.103) |

Conclusion

In conclusion, Chinese-speaking cancer patients were more likely to use CAM since their diagnoses compared to non-Chinese-speaking cancer patients. Male participants were more likely than female participants to use CAM in this ethnocultural group. In addition, Chinese speaking cancer patients were more likely to have information needs about CAM and prefer a counseling session with a HCP than non-Chinese speaking cancer patients. However, there was a communication gap between HCPs and Chinese-speaking patients regarding CAM use, and a lack of CAM information and decision support available for these patients. Since their most preferred CAM therapies were biological-based therapy and traditional Chinese medicine, there could be potential for interacting with their conventional cancer treatment. These findings from

this study have provided some ideas about the frequencies around their CAM use and additional related issues, and the next chapter will provide more in-depth information around their experiences in CAM decision making.

Chapter Four: Qualitative Data Analysis

One of the goals of this study is to understand Chinese-speaking cancer patients' decision-making experience around CAM. Between October 2010 and March 2011, 15 Chinese-speaking cancer patients and 5 of their significant others were recruited and interviewed in the second phase of this study. Purposive sampling was used in the hopes of recruiting a sample that had some diversities (e.g. age, gender, place of birth within their country of origin, tumor type, stages of disease, and length of time in Canada); however, the majority of the participants recruited were from the southeast part of China. Four participants validated the research findings at a post-interview focus group in August 2011.

This chapter will report findings from the interviews about the participants' CAM decision-making experiences. Participants' demographic information and the context in which they sought CAM will first be described, followed by a discussion regarding their reasons for using CAM at different phases along the cancer trajectory, and the types of CAM therapies used. Two distinct types of CAM decision-making experience will be described, and participants' CAM information-seeking and therapy selection experiences will be discussed in relation to each. This chapter will conclude with a description of the participants' methods of evaluation of the selected CAM therapies.

Cancer Experience: Context and Demographics

Demographics. In this phase of the study, we recruited 15 Chinese-speaking cancer patients to share their experiences of the CAM decision-making experience. Five significant others accompanied the patients to the interviews and were invited to participate as well.

However, the main focus remained on the patients' experiences, with the significant others' perspectives providing additional insights and confirmation of the patients' narratives.

Using purposeful sampling, we recruited participants with diverse demographic characteristics. There were 8 male and 12 female participants, with an average age of 55 years (range from 34 to 81 year). Regarding their main language spoken at home, the majority (n=17) spoke Cantonese, with three participants identifying Mandarin as their main language. Their main language reflects the fact that the majority of participants originated from the province of Guangdong in southeast China, where Cantonese is the regional dialect. All participants emigrated from China, with the majority originating from Hong Kong. The length of stay in Canada ranged from 1.5 to 40 years, with an average of 17 years. The top four most prevalent cancers were breast, colorectal, liver, and lymphoma (See Table 1)

Context for seeking CAM. The participants in this study informed us that they began to consider incorporating CAM into their cancer care immediately after diagnosis. Their actions seemed to be triggered by limited understanding of their current clinical situation as affirmed by one participant's comments that "we did not understanding what was happening and were feeling very lost" (ID 17). Many participants described themselves as feeling "anxious" when they were first diagnosed with this life-threatening illness. One female participant with inoperable cancer shared that "like many cancer patients, I was very worried about my illness and became pessimistic about my future. I worried that I would die very soon" (ID 4). Other than fear of dying, the participants also expressed fear about the uncertainty of their future. A young participant diagnosed with an acute type of blood cancer described his feelings as follows:

Yes, we don't know what to expect most of the time....I was hospitalized immediately after being diagnosed with cancer and had absolutely no knowledge about the impending recommended medical procedures. Although we were given some brochures about the

procedures, we just didn't know what to expect... I think it is the fear of unknown, you just don't know what's going to happen... maybe it is a fear of suffering... not knowing if you would suffer... not the fear of death. Death is not the scariest thing but the uncertainty ahead of you makes you feel uncomfortable. (ID 9)

Fear and anxiety led many participants to talk to trusted individuals in their social network for reassurance during this uncertain time. They also turned to fellow cancer survivors to gain support and advice about how to cope with cancer and navigate their treatment.

Some participants were told by fellow cancer survivors that “the treatments are very difficult” (ID 17) and “have many side effects” (ID 16). This heightened the anxiety of many participants and led them to look for alternatives that would make their cancer journey less arduous. For example, one man, who was diagnosed with sarcoma, shared that while he was waiting for his conventional treatment to begin and “wished that there was something I could do to help myself in this situation” (ID 20). The potential of not surviving the disease and the anticipation of suffering from the impending treatments drove many participants to seek CAM therapies that would increase their chance of survival and help them manage the negative side effects of conventional cancer treatment. For other participants, the decision to use CAM increased their sense of control, particularly during the initial waiting period before conventional treatments were available. For instance, one elderly participant shared the following:

Once I was referred to the cancer agency, I had another CT scan, bone marrow biopsy and other blood tests. Anyway, I had to be tested all over again, and there was a waiting period to have all these tests done. I could not do the tests right away. I started the process in September, and when I was referred to the cancer agency, it was November... I waited two months and still was not given the treatments yet. I was very worried. It felt like I could just wait and wait and wait, so I read about bee propolis in the newspaper. My friends also recommended it to me. I decided to give it a try. (ID 11).

Reasons for CAM Use

The overarching reason participants reported for their using CAM was to “stay well” throughout the cancer journey, from diagnosis to survivorship, and for some, palliative care. Staying well had multiple meanings to the participants. For some, it meant staying as physically fit as possible for the body to fight against cancer and be able to tolerate the side effects of conventional cancer treatment. For others, staying well was a psychological construct that meant being calm and composed while facing a life-threatening illness.

The reasons for seeking CAM, however, shifted across the cancer journey. At diagnosis, the main reason expressed by participants for using CAM was to exert a certain degree of control over the cancer, while they were waiting for further diagnostic tests or the start of conventional cancer treatment. As one participant shared:

Well, from the time of my diagnosis to the time of treatment, in that period of time, I have used a thing called Xango juice... Ehhh, antioxidant is actually, without formal research support but through friends' recommendation, and also in Xango's information session, we know about this [antioxidant] for a long time. At that time, we did not know when I would receive the official treatment, so I hoped that there would be something I could help myself... Therefore, I chose to use Xango juice. (ID 20)

For some participants, control over cancer was thought to be achieved by using CAM therapies that would improve the body's innate ability to fight the disease. For example, some participants began to take an herbal supplement called Yun Zhi (*Coriolus Versicolor*) at diagnosis to boost the immune system. Other participants believed cancer could be controlled by changing their lifestyles or their exposure to toxins in the environment. For example, one male participant drastically changed his lifestyle in the hopes of “optimiz[ing] my genetic potential to fight cancer” (ID 2). This male participant had become a vegetarian since his diagnosis and ate only organic food and cooked with filtered water to prevent additional environmental toxins (e.g.

pesticides) from entering his body. His wife, who was also present at the interview, was fully supportive of these changes. These specific reasons for using CAM appeared to mirror the participants' beliefs related to the cause of their cancer.

During conventional cancer treatment, the reason for using CAM shifted to controlling treatment side effects to maintain quality of life and ensuring the course of treatment could be completed. After checking for potential interaction risk with his oncologist, one male participant with locally advanced cancer used Yun Zhi (*Coriolus Versicolor*) and dried Goji berries during his concurrent chemotherapy and radiation to ease the side effects. He described “chemotherapy and radiation therapy are tough treatments. I have been through them twice. I am interested in anything that can reduce the side effects and improve patients' quality of life” (ID 16). Another male participant diagnosed with sarcoma consistently experienced low white blood cell count after receiving chemotherapy. As a result, his oncologist had to delay his treatment until his white blood cell count had returned to a safe level. He decided to incorporate TCM diet therapy to “help replenish my white blood cells in a faster manner” (ID 20) to prevent any further delay in completing his chemotherapy cycles.

Only one female participant with advanced cancer looked beyond side effect management with regards to the reason for using CAM during conventional treatment. Instead, her focus was on enhancing the cancer fighting effects of the chemotherapy agent she was taking. She shared that “my cancer drug stabilizes my cancer but has not reduced it as fast as I had hoped” (ID 19). Consequently, she decided to take a seaweed supplement to enhance effect of her conventional cancer treatment.

During conventional treatment, control continued to be an important reason for using CAM. The focus of the control, however, shifted away from controlling cancer to reducing the

side effects of conventional treatment and maintaining overall quality of life. The goal was to complete conventional treatment, which was described as “their one and only hope for cure” (ID 16).

Chinese-speaking cancer patients continued to use CAM after completing their conventional cancer treatment. Depending on their treatment outcomes, the reasons for using CAM varied. For those who had completed treatments and their cancer was either cured or in remission, CAM was used to help the body to recover from the conventional cancer treatments and to prevent recurrence. For those participants who progressed to palliative status, their reasons for using CAM were to improve quality of life and their life expectancy. In the following paragraphs, the reasons given by the non-palliative participants will first be revealed, and then followed by those described by terminally ill participants.

During the post-treatment period, participants wanted to “become a healthy individual again” (ID 3) and return to a normal life. However, some continued to suffer from treatment side effects, such as peripheral neuropathy, fatigue, menopausal symptoms, and depression, which caused much psychological distress. As one breast cancer survivor described:

After completing all the treatments, I thought I should be on my way to live a normal life...However, my body was always tired, and I was sad all the time and often raised questions about life, like, why should I stay alive? What was the meaning of my existence? When would the cancer come back? This fear greatly impacted my will to live...I felt kind of depressed (ID 5).

To help her cope with these feelings and side effects, she began practicing a meditative form of yoga, which she found “helps me to calm down” (ID 5).

Participants also used CAM, especially TCM, to help the body to recover from the conventional cancer treatment side effects. Many participants held similar beliefs about TCM, including that it could “restore the body” (ID 20), “strengthen body’s immunity” (ID 1, 7), and

“revitalize and maintain health” (ID 13). In addition, many participants believed that chemotherapy was “very hot (ID 18)” and “can weaken the spleen meridian and impair blood circulation (ID 4)”, leading to multiple side effects. In order to resolve these side effects, one participant with colorectal cancer shared that one must drink special herbal soup to rid the “fire from the chemotherapy” (ID 18). The need for detoxification following conventional cancer treatment was also commonly discussed by participants. Many believed that TCM was needed to detoxify the body from the accumulated toxins from the chemotherapy and radiation treatments and restore balance. For some participants who believed in the TCM concepts of energy flow and meridian systems, CAM therapies were necessary to, “strengthen the spleen and stomach meridians to improve the digestive function” (ID 4).

Preventing metastasis or recurrence was also another reason for some participants to use CAM at this phase of the cancer trajectory. Disease recurrence was often a preoccupying worry among the participants. One male participant with a young family shared that “I started to take Goji berries after the completing my cancer treatment, because she [his wife] read it somewhere that it can prevent cancer from spreading to other parts of the body” (ID 16). Another young female participant who had a familial form of breast cancer believed that “my mother had had cancer only in one side of her breast and I think TCM has protected her other breast. I did not take TCM like she did, and I had cancer in both breasts” (ID 13). These comments highlight the perception among participants that TCM has a protective effect against cancer from migrating to other parts of the body.

For participants who had moved into the palliative stage, their reasons for using CAM were mainly to improve quality of life and to maintain hope. For example, one participant, who had not responded to either standard cancer treatment or an investigative drug, continued to use

TCM diet therapy “not to cure the cancer, but to achieve a stronger immunity (ID 6)” that would help him maintain an optimal level of health. Another participant who lived alone and was diagnosed with terminal colorectal cancer used TCM diet therapy “to improve my energy level so that I can look after myself” (ID 18).

Although there was no cure for their cancer, these participants continued to search for CAM therapies in the hope of extending their lives and improving their quality of life. As shared by one participant with an inoperable tumor, “I have to survive...doctors told me there was nothing more that can be done, so I tried my best to seek other remedies” (ID 4). For these participants, CAM therapies offered hope in the face of limited treatment options.

In summary, Chinese-speaking cancer patients used CAM for a variety of reasons, which shifted as they moved through the cancer journey and their disease status changed. At diagnosis, CAM was used to control the growth of tumors. As the participants moved into the treatment stage, their reason for using CAM had changed to controlling the side effects of the conventional cancer treatments in hope of completing the treatment without delay. As treatment had completed, the participants used CAM to help with the recovery process as they returned to live a normal life. For some who had progressed to the palliative stage, CAM therapies served as a means to maintain quality of life and hope. In this patient population, CAM was not used to replace conventional medicine, but truly to complement it to achieve the best treatment outcomes.

CAM Therapies Used

Regarding the types of CAM, various patterns of CAM use emerged at different stages along the cancer trajectory, and appeared to be related to the reasons for their use. These patterns will be described from (1) at the time of diagnosis, (2) during treatment, and (3) after treatment.

At diagnosis, the majority of the participants had shared that they felt anxious about the diagnoses. Many participants began to incorporate CAM to control and treat their cancer before the beginning of conventional cancer treatments, and NHPs were the main CAM choices to achieve these goals. As one participant described:

I finally found a tumor in the liver, sized of 4.8cm in diameter after a sequence of tests....so it's pretty big. I didn't believe that I had cancer at that stage because I didn't have any symptoms except maybe a little bit of indigestion. I returned for more tests after a month and the results showed that the tumor had grown in size. At that point, my family and I became panic and I thought about the Cancer Trio supplements again and decided to resume taking them. I understood that they were not medicines and could not possibly cure my problem, but I thought since they helped with cancer prevention before, they should also help strengthen my qi [The vital energy described in TCM theory]. (ID 2)

Besides consuming NHPs, he also drastically changed his diet and only consumed filtered water and organic produce. Another participant informed us that, before the beginning of her conventional cancer treatment, she took herbal medicine prescribed by a TCM practitioner and drank fresh vegetable fruit juice to detoxify her body and improve her immunity. Taking NHPs, herbal medicine, and change of diet were implemented to control the cancer at this stage.

During the treatment stage, many participants wanted to alleviate the side effects to improve quality of life and to ensure the body could tolerate the full course of treatment without delay. However, due to the risks of interaction with their conventional cancer treatments, many participants simplified their CAM regimen during the treatment phase. Biological-based CAM therapy was the most common type of therapy to be eliminated to prevent complications at this stage. For instance, one young participant diagnosed with sarcoma was consuming mangosteen juice to “reduce oxidative damage” (ID 20). After speaking with a pharmacist at VC-BCCA, he learned that it may interact with his chemotherapy, and hence, he stopped using it immediately before treatment. However, some may continue to use TCM herbal medicine without informing

their OHCPs. Many participants continued to use less controversial items such as using special diet (e.g. vegetarian diet), qi-gong exercise, and attending support group through the treatment phase.

After completing treatment, many participants restarted the CAM therapies stopped before treatment or incorporated additional types of CAM therapies into their care plans. NHPs, TCM herbal medicine, and lifestyle change were used to alleviate treatment side effects, prevent recurrence, and maintain quality of life and hope. For example, one participant, who suffered from fatigue, poor appetite, and severe peripheral neuropathy from her chemotherapy, restarted Yun Zhi supplements to help alleviating these side effects. Other CAM therapies were also included in their care routine to minimize the chance of recurrence. For example, TCM herbal formula, either prescribed by the TCM practitioners or purchased over the counter at a local herbal store, was used to “detoxify and restore my body” (ID 20).

Lifestyle changes (e.g. healthy diet and exercise) had also been incorporated from diagnosis and continued through the cancer journey. One participant shared her perspective on using CAM post-treatment:

With regard to the post-treatment, patients want to know what to eat in order to avoid recurrence. For those who have been forsaken by their doctors and were informed that no further conventional treatment would help, they still have to live and eat as usual during their remaining days...it is still something to do with dietary choices. In any case, making the right dietary choice is very important for cancer patients. Doing exercise is another important part as it promotes blood circulation for the entire body especially for those who have completed chemotherapy and radiation. They have to bear lots of side effects. Exercising regularly allows one to gradually recover. (ID 4)

Many participants felt weak after the treatments, and began to use body-based therapy (e.g. qi-gong) to strengthen their bodies. As one participant shared that:

...besides diet, many Chinese also believe in Qi Gong exercise (Bart Tuen Kam) and many friends suggested other physical exercises for strengthening my body. I have

started practicing Bart Tuen Kam exercise at home because I found it easy, and it's almost like a stretching exercise with some strengthening moves. (ID 9)

Other participants incorporated mind-body therapy (e.g. relaxation class, Kundalini yoga) into their care regime to cope with the psychological effects from the treatment. One participant described:

There were still some emotional stress I was experiencing...I think that chemotherapies have long-term extensive impact on patients...it's not like I will be fully recovered right away...most people may not be aware of this. I am still facing lots of emotional issues and decided to join the relaxation class every Thursday here [VC-BCCA]. I found the class very helpful and had positive effects on my thinking so I won't think of negative matters. It also calmed my mind and my inner self. (ID 3)

As for the ones who had progressed to the palliative stage, they often adopted CAM therapies, primarily biological-based therapies, which claimed to have curative effect against cancer. For example, one participant who had locally advanced cancer used goji berry extract as a measure to prevent metastasis. Another participant with terminal GI cancer consumed asparagus paste daily in hope to cure his cancer, he shared that:

I have read on the internet about asparagus being able to strengthen the immunity. Some people said this can even cure cancer but not particularly liver cancer, my cancer is of liver primary...Everybody has to die...but I am unfortunate and will probably die relatively soon. However I would still try out any effective diet or other solutions suggested by doctors....trying my best to extend my life and improve the quality of life. (ID 1)

In summary, Chinese-speaking cancer patients used a variety of CAM therapies in their cancer journey. High numbers of CAM therapies, especially NHPs, were used at diagnosis, but the majority of the participants eliminated biological-based CAM therapy before beginning their conventional cancer treatment to avoid NHPs-drug interaction. However, they would continue to use less controversial CAM therapies during the treatment stage to minimize side effects for maintaining quality of life and completing conventional cancer treatments without delay. Once

treatment was completed, then they reincorporated the CAM therapies that were helpful to them in the past in the recovery process. For the terminally ill participants, biological-based therapies were used in hope to maintain quality of life as well as hope for cure.

Decision-Making Experience

There were two types of decision-making experiences found in this study: spontaneous and deliberate. The participants who engaged in spontaneous decision making appeared to highly value anecdotal evidence from trusted individuals in their social network and relied on this type of evidence to make their decisions about CAM. These participants expressed a high level of anxiety, and described both emotional and physical side effects following conventional cancer treatments. Because of all these side effects, the participants perceived themselves to have limited access to information sources other than their social network. One participant who had suffered from multiple side effects shared that:

When I finished all treatments, my next step was to go for CAM... I actually didn't have too much energy and enthusiasm to invest in searching for CAM. I relied much on my gut feeling to choose the kind of CAM. I don't like it when I am overwhelmed with too much information that gives me obstacle to nail down on a decision and I can get confused. (ID 5)

Another elderly participant who lived alone described her decision-making experience:

When people said it was good, I followed and took it [Lecithin]. I have been taking it since then...I don't have enough energy [to look for additional information] since I am 81 years old already and suffered from many side effects from my treatment (ID12).

In essence, the participants prized others' positive experience, and use it as the only criterion for making CAM decisions.

The participants who described a deliberate decision-making experience also consulted with their social network to learn about the kinds of CAM therapies that could be beneficial. The

purpose of this peer consultation was to narrow down the number of CAM therapies to be considered as part of their cancer care. These recommendations, however, were not sufficient. Before arriving at a decision, these participants would search for additional information about the recommended therapies from additional information sources and assess the credibility of the information based on their knowledge and beliefs around CAM. One participant who used the deliberate approach shared the following:

Although we trusted their advices, I still wanted verify their information. Therefore, I searched for more background information. During the searching process, I stumbled upon many medical research studies conducted in the Hong Kong University or Hong Kong Chinese University on the effects of Yun Zhi and another drug; I forgot the other drug's name, in alleviating the cancer treatment side effects in about 50 cancer patients. The results showed that these two drugs could significantly decrease the treatment side effects compared to the patients in the control group, especially in vomiting. I read many articles that stated the same findings, so I believed that it would be helpful...I still chose research papers published by doctors. I think these types of information were more credible, because they were not funded by any company selling certain products, so their opinions should not be bias. It should be more trustworthy (ID 17).

Another participant shared that:

I think we have to process all the information, think thoroughly and then make decision on the CAM therapies or remedies that are most suitable for ourselves. We should not just take others' suggestions and follow without giving careful consideration (ID 4).

In this particular sample, the participants favoring this option tended to be better educated, have more stable disease, and have higher energy levels than those who were less deliberative in their choices." They desired unbiased information from trusted sources instead of simply taking others' advices in their decision making. They also had access to other information sources (e.g. access to a computer or transportation to bookstore or library). As a result, their approach to decision making about CAM therapy revealed a more deliberative approach.

Seeking CAM information. In this section, the participants' experience in seeking CAM information is described in details to illustrate their reasons for choosing specific information

sources, their preferred types of information, the perceived characteristics of trustworthy information, and the challenges they encountered in the process.

Sources of CAM information and reasons for choosing these sources. During the information-seeking process, the participants generally were searching from different sources and in different formats for information to support them through all phases of their cancer journey. All participants using either type of decision making styles used verbal and written CAM information. The main verbal information sources were friends, families, and fellow cancer survivors from their social network. Regarding written information, the participants mainly relied on books, the Internet, and some investigated published research studies.

Due to their poor health status, spontaneous decision makers needed to find an effective CAM therapy to ease their anxiety while waiting for treatment or to help them manage their bothersome side effects during and after conventional cancer treatments. One participant with breast cancer who suffered from severe neurological side effects from chemotherapy shared: “it doesn’t really matter whether this supplement is poisonous or not, I still think it is worth trying as long as it can help me to have my life back and live as who I was” (ID 5). These individuals lacked the energy to search and read additional information. As a result, they preferred anecdotal evidence given by the trusted individuals within their social network.

The deliberate decision makers also consulted their social network, but the purpose was to narrow down the potential CAM therapy options. They preferred to search for more information, from diverse sources, to learn about recommended therapies, and used their knowledge and previous experience of CAM use to evaluate the credibility of the information regarding efficacy. Many participants shared that they obtained information mainly from books, websites on the Internet, and research studies. A few participants also acquired CAM

information from local Chinese language newspapers, television and radio programs. The knowledge gained from the search empowered them. One participant with advanced lung cancer believed that “when there is no knowledge, there is no power. Knowledge is power” (ID 19). These participants appreciated additional information to support their learning about the CAM therapies under consideration, and to help them with their decision-making process.

Information preferences. Regarding the preferred information, the participants favored four types of information. The first type was related to the efficacy of CAM information. Many participants wanted to know what types of CAM therapies were effective in managing the cancer symptoms and side effects. For example, one participant commented that:

I would like to learn from other patients’ experience in battling cancer and I want to know how they did it: What kind of exercise they did? How they managed emotional well-being? What kind of supplements they took for stress management, sleep quality improvement as I found it hard to fall asleep. (ID 2)

These CAM therapies did not need to be commonly used by Chinese people. In fact, information on any CAM therapy that may be beneficial to their conditions would be appreciated. Only one participant mentioned that she wanted information on the potential side effects of the CAM therapies. The second type of information was about the kind of food and diet beneficial in improving immunity “to fight the cancer and tolerate the drugs” (ID 4). Improving immunity was an important issue and was associated with better quality of life from diagnosis to survivorship. The third type of information preferred was about mind-body therapies for helping with easing emotional distress and strengthening the body. The participants expressed wanting information and demonstration on the following specific mind-body therapies: Tai chi, qi-gong, and yoga. They believed these therapies were helpful to strengthen the body during recovery and to relax the mind. The fourth type of information required by the participants was a list of local TCM

practitioners with experience in treating cancer. Many participants believed that, because cancer was a serious illness, they needed to be treated by health care providers with specialized knowledge in this field. This belief also applied in selecting a TCM practitioner. One participant compared finding a reliable TCM practitioner with finding “a good Feng Shui Master”: “There are many out there, but only a few are good” (ID 20). Many participants expressed that they were unable to verify the TCM practitioner’s clinical experience in treating cancer. This was an important piece of information they needed to find a reliable TCM practitioner.

Characteristics of trustworthy/credible information. The participants’ interpretation of credible CAM information was also explored in the interviews. Many participants were uncertain about what constituted credible and trustworthy CAM information. For the spontaneous decision makers, the anecdotal stories from trusted individuals, especially people who had experienced cancer, was sufficient evidence. For example, a participant, who was confined to home due to his advanced stage gastrointestinal (GI) cancer, was seriously considering a special diet because it helped a fellow cancer survivor to control his illness:

My friend had metastatic GI cancer to the liver. He told me about his special diet. At the time of diagnosis, his physician told him that there was no further treatment for him and initially gave him six months to live. He insisted staying on his diet and is still here with us after three years. He has also found out that his tumors in his GI tract and liver have shrunk... I will try it if my next scan result shows that my asparagus therapy is ineffective (ID 1).

Such miraculous stories shared by fellow cancer survivors served as a living proof regarding the safety and efficacy of CAM therapies they were considering.

The deliberate decision makers preferred information written by authors with medical training, because they believed they were unbiased and trustworthy. They also evaluated the credibility of CAM information they gathered based on specific characteristics they valued. For

example, information was considered credible if it was “up-to-date” (ID 19), and “scientific” (ID 4) or “evidence-based” (ID 16). They believed that credible CAM information should come from objective and unbiased empirical data from current research studies. The statistical data provided a sense of how effective a CAM therapy was, and this type of information helped them to decide on choosing a CAM therapy. However, if the research studies were outdated, then the information did not reflect the latest findings making the information not credible.

Challenges/Facilitators. In both types of decision-making styles, the participants rarely spoke with the OHCP about their CAM use. A few participants who did have a conversation with their OHCP only asked about potential interactions between NHPs and their conventional cancer treatments. They shared that they did not think the OHCP had training, interest, or trust in CAM therapy. Also, there was limited time during the consultation with physicians, making it difficult for them to ask questions about CAM therapies beyond potential interaction risk. One male participant with advance cancer shared his experience in consulting his OHCP:

Well, I didn't know how to ask...my English is not good too. Most of the time there was an interpreter but mostly doctors were too busy. Doctors talked to me and discussed about my conditions and medications and left no time for me to ask question about CAM. Sometimes, the doctor even didn't show up and I was seen by the doctor's assistants. I remember that I have talked to them about CAM. They asked me how I felt after my chemotherapy. I told them I felt great, I ate asparagus but I didn't go into details. I felt that they didn't care too much about what we ate...it's up to the patients' choices. I have consulted with couple doctors if it's good for me to take Reishi supplement. Doctors asked me in return what was Reishi ...they were not sure what it was even when I gave the complete English name to them. Doctors said it's entirely up to me if I wanted to take that. Doctors said if I thought that Reishi was good for me then I could take it. I felt that I couldn't get definite suggestion from doctors on this (ID 1).

As was the case for this participant, these patients did not believe that they had received enough information and decision support from their OHCP. Instead, the spontaneous decision makers

sought this support from their social network, and the deliberate decision makers expanded the scope of their search to include the sources mentioned above.

The information seeking process was challenging for both types of decision makers. Foremost, the participants experienced difficulties in distinguishing the credibility of the different information sources they consulted. For example, a homebound participant's quest for CAM information proved to be an arduous one. Many of his friends emailed various links to CAM therapy websites, but he believed "the information from the Internet is not evidence-based. Most of the information comes from unknown sources or based on only one person's experience. I usually don't follow what is recommended on the Internet because they are not reliable" (ID 9). Second, differentiating credible from not credible information was also challenging and described as being a "guessing game...and sort of experimental" (ID 9). Third, current available CAM information sources were mainly in English language and lacked information regarding CAM therapies commonly used by Chinese people (e.g. TCM herbs). The lack of a culturally appropriate CAM information source added an additional challenge in this process. For example, a participant with breast cancer who had followed the web links found on her cancer treatment center website had the following experience:

These websites are not related to any commonly used remedies by Chinese people in any way. Most of these websites are only in English and some older Chinese cancer patients do not use computer to access websites. Also, there is no websites in Chinese language being recommended and I would check out related websites, from one link to another. So far, I haven't come across any website that provides much reliable information. To some extent, I think it's better not to read the information because they are just overwhelming, especially the websites that sell natural health products...I just don't know which one I should browse as each company promotes their own products; they would not say that their products are not good but promoted them as effective for sure (ID 3).

Such challenges confirmed for the spontaneous decision makers that further deliberation and information seeking was unlikely to be helpful. The deliberate decision makers who had done additional searching often found this process laborious and confusing.

The participants of both decision making types sought CAM advice from CAM practitioners and health care providers outside of the oncology setting. In addition to prescribing TCM treatments to the participants, TCM practitioners also provided information about incorporating specific food and herbs into the participants' diet as part of a self-care regimen during the recovery process. Some participants sought information about CAM from health care professionals outside of the oncology setting who were Chinese and fluent in Chinese language. These health professionals were often identified after attending general health information seminars organized by local Chinese community organizations (e.g. Canadian Chinese Christian Mission) and visits with their general practitioners or dentists. These professionals were perceived to be knowledgeable about CAM therapies and had the ability to answer questions about CAM in the participants' native language. Also, as one explained, the participants felt that "I have more confidence with people who have medical knowledge" (ID 19). These health professionals appeared to be the facilitators during the CAM information-seeking process.

Selecting CAM therapy. There seemed a distinct difference in the CAM selection experience between the spontaneous and deliberate decision makers. In general, the decision-making style remained the same among the participants; however, some spontaneous decision makers indicated that they might switch to become deliberate decision makers if their physical and psychological condition improved. The deliberate decision makers did not change, however, and become spontaneous decision makers, because they had strong support from their families, and sometimes friends, to help with information gathering and decision making.

Spontaneous decision-making experience. The participants who engaged in spontaneous decision making were usually homebound due to their poor physical conditions, and had limited access to information other than from their social network or cancer survivors encountered during cancer treatments. They made CAM decision swiftly based on anecdotal evidence, as one participant described:

To me, if someone actually has tried it, then I feel it is more trustworthy. Like my friend, she has been seeing her TCM doctor, and she seems to be doing well. Because she is doing well, that's why I also go to see her TCM doctor in Chinatown. (ID 15)

Fellow cancer survivors' positive experience led the participants to choose the same CAM therapy or to seek medical care from the same CAM practitioner. A participant shared her thoughts about hearing another breast cancer survivor's encouraging CAM use experience:

A friend of my friend was diagnosed with breast cancer...well it was a mass in the breast detected by mammogram at the beginning. Her doctor suggested to her to surgically remove the breast, but she refused, because she found out that she was pregnant at that time. She sought help from her TCM practitioner and was given some TCM herb...I wasn't sure what particular herbs were in her formula. Her mass eventually disappeared and she had her baby afterward and is now doing well. I don't know much detail about this case since I heard her story from my friend...I don't really know that patient. However this is encouraging to know, especially for young patients who don't prefer to have their breasts removed (ID 13).

The participants who engaged in the spontaneous decision making often reported hearing positive CAM use experience from their social network. They may not be able to verify the credibility of these stories; however, it was encouraging enough for them to make the decision and try the CAM therapies.

Deliberate decision-making experience. In contrast to the spontaneous decision makers, the participants who adopted the deliberate decision-making style took a methodical approach in selecting the CAM therapies. For example, a participant shared that:

We did more research ourselves and compared the information...Yes I listened to my friends. When my friends told me that something [CAM therapy] was good, I would keep that in mind...of course not all suggestion was good, so I had to read more information. Like the Yun Zhi, I am now feeling better about it. (ID 7)

The goal was to select safe and effective CAM therapy to improve their conditions. These participants consulted their social network for information about CAM to narrow down the number of choices. To ensure the CAM therapy was safe, they verified the information provided by their friends and families with the one obtained from other aforementioned sources to ensure there was no conflicting evidence. For example, a participant shared that:

TCM doctor told me it was okay to take the TCM herbs while receiving radiation. However, the people at the cancer agency told me not to take any TCM herbs, because they did not know the ingredients in the herbal formula, and was unsure if it would cancel the effect of the radiation treatment. So, to be safe, I stopped taking the TCM herbs once I began the radiation treatment. (ID 15)

While they were checking for congruency of the information about the CAM therapy, they also avoided choosing any controversial CAM therapy that may cause harm to their bodies.

For example, a participant with hormone-sensitive breast cancer shared her experience:

The topic about soymilk...it's very controversial. Many doctors said that drinking soymilk regularly can help maintain hormonal balance and reduce the risk of getting breast cancer. However, I have also learned that many other doctors opposed the idea of drinking soy milk even though soy contains mainly phytoestrogen which they think it could be detrimental to our health. This is the biggest controversy that I have come across and I tried to stay away from those things that are controversial. (ID 14)

Avoiding potential interaction between the CAM therapy and the conventional cancer treatment was also important among deliberate decision makers. One participant described that:

My main concern is drug interaction. I have asked my doctor about TCM when I was hospitalized for bone marrow transplant as an in-patient but I don't quite remember the exact details of our discussion. Generally, my doctor did not recommend I use any other kind of medicine because of the concern about drug interaction (ID 9).

The deliberate decision makers eliminated the potential CAM therapy if (1) there was conflicting evidence about its efficacy; or (2) it was controversial and may aggravate their cancer or their condition; or (3) it may interact with their conventional cancer treatment.

Before the participants adopted the CAM therapy, they also compared the information about the CAM therapy with their beliefs about health and healing, and their experiences in using CAM. Many deliberate decision makers trusted the effects of TCM due to its long history and their previous positive experience in using this type of treatment method. TCM was thought to be able to eliminate the root cause of the disease by balancing the two opposing forces (i.e. Yin/cold vs. Yang/hot) and preventing the recurrence of cancer. They also believed that TCM was needed to eliminate the toxin from the conventional cancer treatments, and helped the body to restore the balance of the two forces and improve the energy flow by unblocking the meridians. One participant explained such a belief:

Perhaps we have been drinking soup [TCM diet therapy] for many years, and our digestive system is used to having soup, so the soup helps with detoxifying the body especially after chemotherapy. Many people do not know chemotherapy is very "hot" to the body. After chemotherapy, your face becomes flush and lips become redder, and cancer patients should not have flush cheek and such red lips. These are caused by the "fire" in chemotherapy, and the soup will decrease the "fire"... Yes, the soup will help decrease the fire gradually. The chemotherapy kills so many red blood cells; a cancer patient's face should not be flushed. This is caused by the "fire" according to TCM theory. Once the fire is eliminated, you would feel better. (ID 19)

Some participants also preferred natural remedies to chemicals, because they believed it was difficult to eliminate chemicals from the body. The accumulated chemicals caused the body

to become toxic. Hence, they preferred to use remedies made with natural ingredients such as NHPs and TCM herbal medicine. As one participant described that:

I am currently taking Yunzhi supplements which are considered as a natural medicine. I chose to practice yoga because it is a very natural therapy that supports my body and strengthen my immunity. Natural therapy is always my first choice of CAM. I would prefer not having to take any medicine [chemical] orally. (ID 5)

In summary, the deliberate decision makers took a systematic approach in eliminating questionable CAM therapies, and only selected those that fitted their beliefs about health and healing and their experience in CAM use. At the end, they selected CAM therapies they believed to be safe and effective.

Evaluation. After the participants tried the CAM therapies for some time, they evaluated the effectiveness of the CAM therapies. There were two types of CAM evaluation: subjective measure and objective measure. Regardless of their decision- making experience, most participants mainly used subjective measure in their evaluation. For example, after using the CAM therapies, some participants felt that they had more energy. Others noticed improvements in appetite, quality of sleep, cognitive function, and functions of elimination. A few participants combined the objective and subjective to evaluate the efficacy of the CAM therapies. One participant, who tried a NHP, believed that:

I should see a difference in my tumor size and tumor marker in two months. I also want to monitor how I feel after taking this for two months. These are the only ways I know if it is good for me. Otherwise, there is no other way I can monitor its efficacy. (ID 19)

Following positive results from the use of CAM therapy, the participants would continue to use the same therapies. However, when the results were not as good as they expected, they would stop using the CAM therapy and return to searching for more therapy. For example, one participant tried a vegetable soup recommended by her friends for two months, but she “did not

feel any different from the soup...no good or bad effects” (ID 3). She, consequently, stopped using it. Another participant stopped taking Reishi mushroom because the ultrasound test indicated that “the mass in my mammary glands kept getting bigger despite taking Reishi supplement” (ID 13). When one CAM therapy was stopped, the participants returned to searching for other CAM therapies “until I found the right one” (ID 3).

Pragmatic issues also influenced some participants’ decisions whether or not to continue with a CAM therapy current. For example, a participant stopped taking Reishi mushroom, because “authentic Japanese red reishi mushroom was too expensive” (ID 13). Another participant stopped seeing her TCM practitioner in Chinatown to instead go to one closer to home. She commented that “[the TCM practitioner in Chinatown] was good, but he was too far away. If the TCM practitioner [close to home] did not work, then I would go back to the one in Chinatown” (ID 15).

In summary, participants evaluated the benefits of CAM therapies based on their physical responses through subjective and sometimes objective measures. Depending on their responses, they either continued or discontinued the CAM therapy. Pragmatic issues were also a determining factor in this decision to continue a CAM therapy. When the results were not as effective as expected, they continued to search for new ones. This was a continuous process until they found the ones that were effective and safe.

Conclusion

In conclusion, Chinese-speaking cancer patients began considering CAM at the time of diagnosis for the purpose of fighting their cancers. The reasons for use and the specific CAM therapies changed depending on their stage along the disease trajectory. Depending on the type of decision-making experience they had, the types of information sought and the sources used for

information were also different. Based on their decision-making style, they either tried the CAM therapies suggested by the social network, or went through a laborious information search to make the decisions using their own judgments. When the therapies worked well, the participants would continue with them. However, when the therapies were not as effective as was hoped, the participants would discontinue the therapy and search for other CAM therapies until the right therapy was found. Making decisions around CAM use was challenging due to lack of support for this cultural population in CAM information seeking and decision making.

Conclusion

As expected, the Chinese-speaking cancer patients in this study revealed a high rate of CAM use. Despite the popularity of CAM use in this population, their unique needs for CAM information and decision-making support are not being addressed in the context of conventional cancer care. In this chapter, we will discuss the distinctive findings related to patients' CAM use and decision-making experiences resulting from both quantitative and qualitative data, and compare these findings with previous research to discover any similarities and differences. We will consider the strengths and limitations of the study, and also explore means to improve the current situation to better assist Chinese-speaking cancer patients in making CAM decisions.

CAM Use in Chinese-Speaking Cancer Patients

Prevalence of CAM use in Chinese-speaking cancer patients. In this study, 66% of the Chinese-speaking participants reported using at least one type of CAM since their cancer diagnosis, and 65% of those individuals were also considering using additional CAM therapies. The remaining 34% of the participants, who were not using CAM, expressed an interest in possibly using CAM in the future. This prevalence is substantially higher than was reported in previous research conducted within the same clinical setting, specifically a 2007 study found that 47% of Chinese-speaking cancer patients were using CAM (Ferro et al., 2007). This result suggests the possibility that Chinese-speaking cancer patients' interest in using CAM during their cancer journey may have increased in the past five years and/or may reflect a growing awareness of CAM within the Chinese community in the greater Vancouver area.

Half of the sample in this study consisted of patients who had been diagnosed within the past year; the other half were diagnosed more than a year ago. The prevalence of CAM use with this sample variation suggests that CAM use is prevalent throughout the disease trajectory, from

diagnosis into survivorship. This is supported by the qualitative data in which participants shared their use of CAM not only to control and treat the cancer before beginning conventional cancer treatment, but also to alleviate side effects during treatment, to support the recovery process after treatment, and to prevent recurrence during survivorship.

This evident interest in CAM use throughout the cancer trajectory highlights the importance of assessing and documenting patients' CAM use, as well as their related information and decision-making support needs, at multiple points throughout the course of their disease. This assessment may be particularly relevant at specific milestones, such as diagnosis, beginning and end of treatment, and recurrence.

Types of CAM therapies used. Similar to previous research studies' findings on Chinese-speaking cancer patients, the most popular CAM therapies reported in this study were biological-based therapies and whole systems of care, particularly TCM (Chen et al., 2008; Chiu et al., 2006; Cui et al., 2004; Ferro et al., 2007; Teng et al., 2010; Yang et al., 2008). The popularity of biological-based therapies may reflect current trends in the general cancer population in North America, where NHPs are among the most commonly used CAM therapies (Boon et al., 2007; Fouladbakhsh et al., 2005; Goldstein et al., 2008; Greenlee et al., 2009; Mao et al., 2007; Naing et al., 2011; Sewitch, et al., 2011; Trinkaus et al., 2011; Vyas et al., 2010; Wyatt et al., 2010). NHPs are readily accessible through over-the-counter sources (e.g., health food stores, pharmacies) and are advertised widely in the Chinese community through local Chinese-language newspapers and other media sources. This availability may have contributed to this trend of using NHPs to treat cancer among Chinese-speaking cancer patients.

TCM was also found to be one of the most popular CAM therapies in previous studies in this cultural population (Chiu et al., 2006 & Ferro et al., 2007). Ferro et al. (2007) found that

Chinese-speaking cancer patients who were less acculturated were more likely to use TCM than patients who reported higher acculturation. In their study, the participants identified as less acculturated were born outside of Canada, able to read Chinese to complete the Chinese language survey, and spoke Chinese at home. In our study, data regarding the participants' place of birth or year of immigration to Canada were not collected. As a result, it was difficult to determine the degree of acculturation in our sample and its potential effect on the type of CAM therapies used. The high use of TCM within this sample may reflect less acculturation within Canadian society, but it may also reflect other factors, such as participants' care experiences in their country of origin or their health care beliefs and preferences. For example, the interview data suggests that participants held specific cultural beliefs about health and healing that led them to use TCM in their cancer journey. They believed that TCM has detoxifying and restorative effects, which are crucial to support the body to fully recover from conventional cancer treatment side effects, to improve quality of life, and to prevent recurrence. These beliefs may have led them to choose TCM over other CAM therapies.

Safety concerns. The use of highly concentrated NHPs and TCM herbal medicine during cancer treatment does raise some concerns from a safety perspective. Some literature has suggested that NHPs, including herbal remedies, may cause harm due to potential interactions with conventional cancer treatments (Verhoef et al., 2008). Despite the recent regulations through Health Canada's Natural Health Product Directorate, some NHPs may still be contaminated by foreign substances, including pharmaceutical drugs, or may not be of the quality or quantity indicated on the label. Beyond physical risks posed by NHPs, the costs associated with using these types of CAM therapies may be exorbitant for some patients and their families. Despite these risks, and the lack of strong scientific evidence to prove the efficacy

of NHPs, many patients continue to use them at high rates (Ernst, Cohen, & Stone, 2004). CAM information and decision-making support is therefore needed to help cancer patients make safe and informed CAM use decisions.

It is important to note that the patients who participated in our study did not limit their CAM use to only NHPs or traditional therapies arising from TCM. According to both the quantitative and qualitative data, the participants used a variety of CAM therapies beyond TCM, including therapies not commonly reported by Chinese-speaking people. For example, many participants practiced yoga, participated in meditation and relaxation classes, and took NHPs that are popular in North America (e.g., mangosteen juice and lecithin). This may illustrate a form of acculturation within the Canadian cancer community, in which Chinese-speaking cancer patients are exposed to a wider variety of CAM therapies, including those now being offered within conventional cancer care settings. The power of a social network, especially support groups, in translating knowledge about CAM among people living with cancer, cannot be underestimated.

Factors Associated with CAM Use

Only one demographic variable, gender, was found to be associated with CAM use. Male Chinese-speaking cancer patients were found to be significantly more likely to report using CAM compared to female patients. This finding is in contrast to the literature, which has shown female Chinese-speaking cancer patients to be more likely to use CAM than their male counterparts (Chow et al., 2010; Lim et al., 2010; Shih et al., 2009). This difference may be attributable to the cultural role that women play within the traditional Chinese family. Our qualitative data suggests that the wives who participated in the interviews were very involved in the decision-making process and supported their husbands' use of CAM therapies. For example, the wives who played a traditional role within the family prepared herbal medicine and

incorporated special diet therapies to ease side effects from conventional cancer treatment and support the recovery process, in order to support their husbands through the cancer journey. In contrast, the female cancer patients who participated in our study did not report this type of practical support during their cancer experience. This may mean that female cancer patients may require additional support in making decisions about CAM and incorporating supportive CAM therapies into their care regimen. In addition, it is important to assess family role structure in relation to providing food-related guidance.

Despite previous research that suggests younger cancer patients are more likely to use CAM than older patients (Chow et al., 2010; Lim et al., 2010; Shih et al., 2009), age was not found to be associated with CAM use in our study. In other words, CAM use was commonly reported across all age groups. The use of CAM across all generations may be related to the pervasive cultural beliefs around health and healing that are shared within families and the Chinese community and the strong influence of these patients' social networks. For example, the cultural belief that illness, such as cancer, is caused by an imbalance between two internal forces (i.e. the Yin [cold] force and the Yang [hot] force) is widely held within the Chinese community (Xu et al., 2006). Both younger and older participants in our study expressed a similar belief: that TCM would restore balance to their body and aid in recovery, as well as prevent recurrence. Moreover, participants in our study also perceived conventional cancer treatments as "too aggressive" and a contributing factor to a greater imbalance within the body. This finding echoes previous research findings that Chinese-speaking cancer patients consumed TCM herbal medicine to counteract the excess force of chemotherapy and radiation to ensure their complete recovery (Bell & Lee, 2009; Chiu et al., 2006; Chui et al., 2005).

From the qualitative data, patients' social networks were a prominent factor in their decisions related to CAM therapies. All participants we interviewed described consulting with their peers for suggestions about which CAM therapies were seen as beneficial. Many participants, especially the spontaneous decision-makers, relied on suggestions from their peers and tried a variety of CAM therapies throughout their cancer journey as a result. This finding is similar to that from Chiu et al.'s study (2006), where Chinese-speaking cancer patients depended heavily on their peers for CAM information and help with choosing appropriate CAM therapies. The significant role of the social network in Chinese-speaking cancer patients' decisions about CAM highlights a possible avenue for intervention. Developing evidence-based information resources about CAM that target both patients and their social networks may enable patients to make better-informed decisions about CAM.

Patient-OHCP Communication about CAM

Currently, there seems to be gaps in communication about CAM use between Chinese-speaking cancer patients and their OHCPs. In this study, less than 20% of participants reported being spoken to about CAM in clinical consultations. This finding echoes the results from Chiu et al. (2006), who found Chinese-speaking cancer patients rarely had a meaningful conversation with their OHCP about CAM. From our interview data, the participants did not think the OHCP had the necessary training, interest, or belief in CAM therapies to have a productive and meaningful conversation about CAM. Also, time during the consultation with the OHCP was limited, making it difficult for participants to ask questions beyond those related to conventional cancer treatment. Interestingly, of those patients who did speak with an OHCP about CAM, the majority reported feeling listened to and almost all felt comfortable talking about CAM. This finding suggests that Chinese-speaking cancer patients and OHCP can engage in consultations

about CAM in a manner that is perceived to be positive and supportive. However, the lack of initiative from physicians and other OHCPs to begin the conversation about CAM, as well as assumptions held by Chinese-speaking cancer patients about the futility of discussing CAM with OHCPs, have prevented these important consultations. Education for both OHCPs and patients is required to dispel these barriers and highlight the importance of discussion about and disclosure of CAM use during OHCP-patient interactions. In particular, having physicians and other OHCPs initiate the conversation about CAM may dispel patients' misconceptions about OHCPs' level of interest in and knowledge about CAM, as well as reinforce the importance of talking about CAM use.

The practice guideline published by the Society of Integrative Oncology (SIO) recommends that OHCPs inquire about CAM use as a routine part of the initial evaluation of cancer patients (Deng et al., 2009). In addition, the NCCAM also encourages patients and their health care providers to talk openly about their health care practices, including CAM use, to ensure safe and coordinated patient care. Frequent and comprehensive assessment of patients' CAM use and demonstrated interest by their OHCPs can ensure that patients are fully informed and make appropriate and safe decisions around CAM.

CAM Information and Decision-Support Needs

CAM information needs. In our survey, 78.5% of the participants reported having CAM information needs, but only a third of them received sufficient CAM information and less than a quarter of them reported having received adequate decision support. The data indicated that Chinese-speaking cancer patients were using CAM without adequate information and decision support, which raises substantial concerns about the safety and level of information used in their CAM decisions.

The most common information need, according to more than half of the participants, was how to find a CAM practitioner who was “good” in the sense of being qualified and specialized in treating cancer patients. Based on the interview data, many participants specifically encountered difficulty when choosing a CAM practitioner who was trained in TCM and had experience in treating cancer. They believed that cancer was a serious illness, and that a trustworthy TCM practitioner must possess specialized knowledge and clinical experience in this field. Compared with previous research on CAM information needs among cancer patients (e.g., Eng et al., 2001; Verhoef et al., 2009), this seems to be a unique and not previously reported need.

More than 40% of the Chinese-speaking cancer patients reported needing information about the types of CAM therapies available at the VC-BCCA. However, according to the CAMEO environmental scan (Balneaves, Truant, Verhoef, Porcino, & Ross, 2008), the majority of CAM therapies and information sources at the VC-BCCA (with the exception of the CAMEO research program and the Cantonese-language support group) are in English only. This lack of culturally appropriate CAM information and decision-support resources not only makes it difficult for patients with limited English-language proficiency to access these services, but also makes it difficult for OHCPs to make appropriate and helpful referrals to help Chinese-speaking cancer patients with their CAM questions.

In the survey, 40% of the Chinese-speaking participants reported they required knowledge regarding how to communicate with OHCPs about CAM use. The qualitative interviews included little discussion about why participants wanted help, and in what way, with their communication about CAM with their OHCPs. Anecdotally, patients highly value the advice of conventional health professionals and desire their insights about the efficacy and safety

of CAM therapies. However, patients who have attended the CAMEO program have shared their concerns about damaging their relationship with their OHCP by talking about CAM with them. Although additional research could further explore this issue, it appears that coaching strategies may be needed to help Chinese-speaking cancer patients broach the subject of CAM use with an OHCP, identify important questions related to CAM use, and select the types of information (e.g. NHP monograph) to bring to a consultation with an OHCP. Such training could possibly occur individually, with families, or in a group setting.

Younger patients and safety around CAM use. The results indicated a trend towards younger participants being more likely to require information about combining CAM therapies with conventional cancer treatments and about safety issues related to CAM. Based on our clinical experience, younger patients are more likely to be prescribed more aggressive treatments than older patients, because they are physically stronger and thus better able to tolerate treatment of curative intent. Our qualitative data indicated that these participants were most worried about the impact of side effects, and the resultant possibility of a delay in their conventional cancer treatment. Therefore, they were more likely to combine CAM therapies with conventional cancer treatment to alleviate the side effects. In addition, younger participants may be more aware of the potential harmful effects of some CAM therapies learned from a variety of information sources. These participants felt that safety was an important consideration when selecting and using a CAM therapy. In our interview data, the deliberate decision-makers, only one of whom was over the age of 60, considered safety to be an important criterion when selecting CAM therapies. Knowledge about safety issues related to CAM use (i.e. how to safely combine CAM therapy with conventional cancer treatment for symptom management) needs to be translated to patients of all ages in a group setting early in the disease trajectory, ideally before beginning conventional

cancer treatment. Additional individualized information around safety may be offered to younger patients, who require additional information to help with their CAM decision-making process in a one-to-one setting.

CAM decision-support needs. Almost all the participants indicated that at least one type of CAM decision-support services presented on the survey had been found to be helpful. Almost all of the participants also indicated that they were interested in receiving some type of decision support. However, Chinese-speaking cancer patients favored information provision services that could be accessed independently, and the three most preferred services were having access to CAM information in the VC-BCCA library, a website or a workbook on CAM decision making, and CAM education sessions.

Counseling sessions from OHCPs for using CAM therapies received limited interest, which may reflect previous negative interaction experiences with OHCPs. According to Chiu et al. (2006), participants indicated that conversations with OHCPs about CAM use were highly directive and uninformative. Our qualitative data showed that having a feeling of control over their cancer was one of the participants' main reasons for using CAM, and thus, they may prefer to have the power to make CAM decisions instead of being told what to do. In addition, our participants assumed the OHCP lacked the necessary training, interest, or belief in CAM therapies to have a productive and meaningful conversation about using CAM. Compounded with language barriers, counseling sessions with an English-speaking OHCP about using CAM may not be appealing to these patients. CAM decision-support services focused on providing evidence-based CAM information that patients can access independently will be helpful for their CAM decision-making process. Counseling sessions with Chinese-speaking OHCPs who coach, not direct, patients to make CAM decisions may also be a viable option in this process.

Factors influencing CAM decision-support needs. In this study, younger women were found to prefer a booklet-type resource about CAM decision making. This suggests that it is important to assess the preferred decision-support service to ensure needs are being met. Age and gender were not found to have any other impact on participants' preferences for other CAM decision-support services in our data. A coherent CAM education program in multiple formats (e.g., in-person program, web-based program, group education session) could be developed for this population. Based on the interview data about participants' most desired CAM information needs, which included types of effective CAM therapies, food and diet information, demonstrations of specific mind-body based therapies, and a list of qualified TCM practitioners), a comprehensive support services program (e.g., group education, individual counseling, web-based information database, and information booklet) is a feasible way to translate CAM knowledge and provide decision support to these patients.

Findings Unique to Chinese-Speaking Cancer Patients

Higher reported prevalence of CAM use in Chinese-speaking cancer patients.

Chinese-speaking cancer patients reported a higher prevalence of CAM use compared to their non-Chinese-speaking counterparts. This result was similar to that found in studies conducted in Singapore, where Chinese ethnicity was found to be one of the predictors of CAM use (Chow et al., 2010; Lim et al., 2010; Shih et al., 2009). Our results also echoed the findings from Chinese and Taiwanese studies, where almost all Chinese-speaking cancer patients used CAM therapies (Chen et al., 2008; Cui et al., 2004; Teng et al., 2010; Yang et al., 2008). The high interest in CAM, especially TCM, shown by cancer patients with Chinese heritage may be related to the aforementioned unique cultural beliefs in health and healing and their preferred health care

practices. Therefore, it is particularly important that OHCPs initiate conversations with Chinese-speaking cancer patients about their CAM use, and assess their use on a regular basis.

Chinese-speaking cancer patients were more likely to have questions about CAM, and these questions encompassed the following concerns: where to find trustworthy information about CAM, how to talk with my OHCP at the VC-BCCA about CAM, when is it safe to use CAM after being diagnosed with cancer, what CAM can be used in combination with medical cancer treatments, what CAM therapies are helpful for people with cancer, and how to choose a health care provider that offers CAM.

As per the findings from our study, it seems that Chinese-speaking cancer patients' information needs are not being addressed in the conventional health care setting. They may not be able to access the services and resources currently available in the community or on the Internet due to a language barrier, culturally irrelevant information, and lack of awareness of the existence of the resources. A comprehensive information program is urgently needed in this population. This information may be best provided to these patients through individual counseling sessions, an option selected by almost three-quarters of the sample as a helpful CAM decision-support service. This type of supportive service would require OHCPs to have appropriate language skills and an awareness of Chinese culture. Currently, the CAMEO program is piloting this type of decision-support service in the Chinese language on a research basis.

Chinese-Speaking Cancer Patients' CAM Decision-Making Experience

Chinese-speaking cancer patients were found to use two types of decision-making experiences: spontaneous and deliberate. The participants who had the former type of experience

made their decisions mainly based on advice from their social networks (i.e. friends, family, and fellow cancer survivors), an approach similar to the Chinese-speaking cancer patients in Chiu et al.'s (2006) study. This type of health information-seeking behavior was similar to the fortuitous information seeker behavior in which patients took an experiential approach to gathering information from their social networks, especially those who had personal cancer experience (Lambert et al., 2009a; Lambert et al., 2009b). However, the participants' purpose in engaging in this type of behavior was different in our study. The fortuitous health information seekers used the information gathered to assess whether they were on the right track when comparing their progress or results with other cancer survivors in similar situations (Lambert et al., 2009a). Conversely, in our study, the spontaneous decision-makers wanted to discover an effective CAM therapy that could help control their cancer before beginning conventional cancer treatments or help alleviate the side effects from treatment. This objective requires OHCPs to begin assessing CAM use and providing CAM information and decision support early in the disease trajectory. In addition, access to symptom management resources is also essential to ensure patients' symptoms and side effects are well managed, ideally with 24-hour translation services available for those who are not proficient in the English language.

Participants who had deliberate decision-making experiences used a methodical approach to select CAM therapies. These participants searched for CAM information from multiple sources after consulting with their peers to narrow down the number of CAM therapies under consideration. This type of health information-seeking behavior resembled the intense decision-making behavior demonstrated in another study, in which cancer patients sought information from multiple sources and determined the best options through logical reasoning (Lambert et al., 2009a). The deliberate decision-makers chose uncontroversial CAM therapies that were without

conflicting evidence and did not interact with conventional cancer treatment. In addition, similar to Chiu et al.'s (2006) finding among Chinese-speaking cancer patients, the deliberate decision-makers also favored CAM therapies that fit with their cultural beliefs and health and healing as well as their lifestyle. The deliberate decision-makers' rationale of incorporating CAM into conventional medicine was similar to that of women with breast cancer who engaged in the behavior of "bringing it all together in using both CAM and conventional cancer treatments" (Balneaves et al., 2007). Both the breast cancer patients and our deliberate decision-makers believed that cancer was serious but treatable with conventional medical treatment, and that CAM was a necessary part of their care regimen to optimize their health and alleviate side effects. However, in terms of the selection process, the women with breast cancer relied on their intuition, whereas the deliberate decision-makers used a methodical approach, as described above. It may be that Chinese-speaking cancer patients who prefer this type of decision-making would benefit from receiving evidence-based CAM information and coaching in decision-making around CAM use, especially those patients planning to incorporate CAM throughout their cancer journey.

Overall, the results about Chinese-speaking cancer patients' information and decision-support needs could form the foundation of culturally relevant CAM education and decision-support programs offered in a variety of formats for this patient population. These programs would provide knowledge from the most current evidence about the safety and efficacy of different CAM therapies in a culturally relevant manner and assist patients in making safe and informed decisions around CAM use in their cancer journey.

Implications

Chinese-speaking cancer patients seem more likely than their English-speaking counterparts to use CAM, especially NHPs and TCM, throughout their cancer journey for a variety of reasons. It is important for OHCPs to initiate conversations about these patients' CAM use, and continue to assess and document the use of these therapies to ensure patients are using CAM in a safe manner. Current resources include the Time to Talk educational campaign organized by the NCCAM, a subsidiary of the National Institutes of Health (NIH) in the US. This campaign encourages open discussions between patients and their OHCPs around CAM. This campaign provides free clinical tools to facilitate discussions between the two parties. OHCPs are encouraged to enroll in CAM education programs to maintain or enhance a continuing competency in CAM knowledge in order to support patients in their search for CAM information and their decisions about CAM use. Currently, there are online education programs available for OHCPs in different disciplines. These education programs can be taken at any time or location convenient to the OHCP. Examples of these programs include the CAM issues in undergraduate medical education project (CAM UME Project) and the Oncology Nursing Society's CAM and cancer education program. These courses are both online courses targeting CAM education for different health disciplines. The CAMEO program in BC has also developed a pilot CAM education program for all health disciplines, and intends to develop a nursing curriculum on CAM for undergraduate registered nurses. These education programs are an excellent resource for OHCPs who provide CAM information and decision support for patients.

Currently, Chinese-speaking cancer patients' CAM information and decision-support needs are not being addressed within the context of conventional cancer care, and thus, they are using CAM without adequate support from their OHCPs. A culturally relevant information and

decision-support program that addresses their unique needs is urgently needed (e.g., How to find a qualified TCM practitioner). Such a program would be best offered in a variety of formats to promote uptake by Chinese-speaking cancer patients of all age groups and genders. Moreover, as patients' social networks have a strong influence on their CAM decision making, these programs should be available to patients and their support persons.

Strengths and Limitations

This study has provided information on the current trends of CAM use in Chinese-speaking cancer patients residing in the greater Vancouver area. We have explored and described the communication barriers around CAM between these patients and their OHCPs, and the results of this study will hopefully help promote effective communication between the two parties. In addition, we have also presented the CAM information and decision-support needs unique to this patient population for future education and support program development. However, there are limitations in this study. The majority of the patients and family members participating in the interviews were from the province of Guangdong situated in southeast China. The cultural beliefs about health and healing and care practices revealed in this study may be unique to that area, and the results of the study may only reflect the decision-making experiences of Chinese-speaking cancer patients originating from this area. The findings in this study may not be applicable to patients with Chinese heritage from elsewhere in the world. Also, since most of the participants were female, more research is needed to specifically examine the decision-making experiences of male Chinese-speaking cancer patients as well as those from other areas.

Conclusion

Chinese-speaking cancer patients have a higher prevalence of CAM use when compared to a non-Chinese-speaking population. These patients use CAM therapies throughout their cancer journey for a variety of reasons. Currently, this population has many unmet information and decision-support needs. A culturally relevant CAM education and decision-support program is urgently needed to ensure these patients are making safe and informed CAM decisions throughout the cancer journey.

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Appendices

Appendix A



Complementary Therapies Survey – Patients

The purpose of this survey is to understand cancer patients' information needs related to complementary therapies at the Vancouver Centre of the BC Cancer Agency. Complementary therapies refer to therapies that are not typically recommended by your medical doctor or other conventional health care providers, and include, for example, vitamin supplements, herbal therapies, relaxation therapy, naturopathic medicine, and traditional Chinese medicine.

1. Have you used any complementary therapies since you were diagnosed with cancer?

Yes (If Yes, please go to Question 2)

No (If No, please go to Question 3)

2. Please check and list in the space provided all complementary therapies you have used since being diagnosed with cancer:

Biologically-based therapy (e.g., vitamins, minerals or herbal therapy)

Energy therapy (e.g., reiki, therapeutic touch, magnet therapy, qi gong)

Manipulative or body-based therapy (e.g., chiropractic medicine, massage therapy)

Mind-body therapy (e.g., meditation, hypnosis, guided imagery, art therapy)

Alternative medical systems (e.g., naturopathy, traditional Chinese medicine, ayurveda)

Other types of complementary therapies (e.g., special diets, cleansing programs)

Supportive care services (e.g., support groups, Patient and Family Counseling)

3. At this time, are you considering using any complementary therapy?

Yes (If Yes, please go to Question 4)

No (If No, please go to Question 5)

4. Please check and list in the space provided **all** complementary therapies you are considering using at this time:

Biologically-based therapy (e.g., vitamins, minerals or herbal remedy)

Energy therapy (e.g., reiki, therapeutic touch, magnet therapy, qi gong)

Manipulative or body-based therapy (e.g., chiropractic medicine, massage therapy)

Mind-body therapy (e.g., meditation, hypnosis, guided imagery, art therapy)

Alternative Medical Systems (e.g., naturopathy, traditional Chinese medicine, ayurveda)

Other types of complementary therapies (e.g., special diets, cleansing programs)

Supportive care services (e.g., support groups, Patient and Family Counseling)

5. Has a health care provider at the BC Cancer Agency spoken to you about complementary therapies?

Yes (If Yes, please go to Question 6)

No (If No, please go to Question 9)

6. **Please check all** health care providers at the BC Cancer Agency who have spoken to you about complementary therapies:

- Medical oncologist
 - Radiation oncologist
 - Nurse
 - Radiation therapist
 - Dietitian
 - Pharmacist
 - Social worker
 - Librarian
 - Other (please specify):
-

7. Did you feel comfortable talking to health care providers at the BC Cancer Agency about complementary therapies?

- Yes, completely
- Yes, somewhat
- No

8. Did health care providers at the BC Cancer Agency listen to what you had to say about complementary therapies?

- Yes, completely
- Yes, somewhat
- No

9. Did a health care provider at the BC Cancer Agency put you in touch with a health care provider or program (e.g., family physician, CAMEO program) that could help you get information about complementary therapies?

- Yes
- No
- I did not require any information about complementary therapies

10. Did you get enough information about complementary therapies from the BC Cancer Agency?

- Yes, completely
- Yes, somewhat
- No
- I did not require any information about complementary therapies

11. Did you get enough support in making decisions about complementary therapies from the BC Cancer Agency?

- Yes, completely
- Yes, somewhat
- No
- I did not require any support in making decisions about complementary therapies

12. Have you had any of the following questions about complementary therapies since you were diagnosed? **Please check all that apply:**

- What complementary therapies are available at the BC Cancer Agency?
- What complementary therapies are helpful for people with cancer?
- What complementary therapies can be used safely in combination with medical cancer treatments (e.g., surgery, chemotherapy, radiation, hormone therapy)?
- When is it safe to use complementary therapies after being diagnosed with cancer?
- How do I talk with my health care providers (e.g., doctors, nurses) at the BC Cancer Agency about complementary therapies?
- How do I choose a health care provider that offers complementary therapies?
- Where do I find trustworthy information about complementary therapies?
- I have had NO questions about using complementary therapies
- Other – **Please list all** other questions you have had about complementary therapies:

13. What information or services would you find helpful? **Please check all that apply.**
- Counseling sessions from a health care provider about using complementary therapies
 - Education sessions on making decisions about complementary therapies
 - A workbook that would help me to make decisions about complementary therapies
 - An information booklet on how to make decisions about complementary therapies
 - A website on how to make decisions about complementary therapies
 - Access to BC Cancer Agency library resources about complementary
 - I would NOT find any of these education/decision support services helpful
 - Other – **Please list** other programs or services about complementary therapies that you would find helpful:

14. Would you use a complementary therapy education program if it was available?
- Yes (If **YES**, please go to Question 16)
 - No (If **NO**, please go to Question 15)

15. Please tell us in the space provided, why you would not use a CAM education program/service if it was available:

16. When were you born
(Day/Month/Year)? _____

17. What gender are you?

Male

Female

Transgendered

18. What language do you speak most often? _____

19. When were you diagnosed with cancer? (Day/Month/Year)? _____

20. What type of cancer do you have? _____

21. Please check off all medical cancer treatment(s) you have received/are receiving for cancer:

Surgery

Chemotherapy

Radiation

Hormone therapy

Other (please specify):

Thank you very much for completing the survey. If you have any questions, please contact the CAMEO Program by email at cameo@bccancer.bc.ca or by telephone at 604-707-5900, local 2882

Appendix B

Interview Guide

Script: Thank you for participating in this interview. This interview will last about an hour and will be taped-recorded. There is no right or wrong answer to the questions. We are interested to learn about your experience. As we talk, I will be writing down notes as well. All the information you provided will be kept confidential. All data are reported as group data and your identity will be anonymous.

Background questions:

1. Tell me about your complementary medicine (CAM) use...

Questions related to their experience in CAM decision making:

2. What was it like to make your decision about CAM? Tell me about your experience in making decisions about CAM therapies? What was difficult? What was easy?
3. Thinking back, what was happening when you decided to use CAM? What were you thinking about at the time?
4. What were you hoping the CAM would do for you? (To identify their goals for using CAM)
5. Where did you find CAM information to help you make the decision?
 - a. What kinds of information are important to you? What sources did you trust? (To assess their information sources and to identify what is considered to be reliable sources. Are the source different from those identified in previous research i.e. internet, lay print, social network?)
6. Who did you talk to about your CAM decision?

- a. Who did you talk to the BCCA regarding your CAM question? How did they help you/not help you to make decisions? (To assess who help them to make decision [Social])
 - b. What was it like for you when you were considering whether or not to discuss your CAM decisions with your oncologist? Other BCCA health care team members?
 - c. Who did you decide NOT to talk to about your CAM decision?
7. What would have been helpful for you when making your decision about CAM therapies?
8. If you have to make a CAM decision again, what kind of support do you think should be in place to help you? (To assess the supports needed to facilitate safe and informed decision making in CAM)
 - a. How should people at the BCCA help you with your CAM decisions?
 - b. What resources should be in place to help you make CAM decisions?
9. What would it look like if you had everything you needed to make good decisions about CAM?
10. We are considering developing CAM education programs and resources for Chinese Canadians with Cancer at the BCCA. What advice would you have for us to develop and deliver these programs and resources?