

THE EFFECT OF AN EDUCATION SEMINAR ON SUPPORT PERSONS OF  
INDIVIDUALS WITH CANCER ON KNOWLEDGE AND DECISION MAKING  
RELATED TO COMPLEMENTARY AND ALTERNATIVE MEDICINE

by

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## **ABSTRACT**

Complementary and alternative medicine (CAM) use is prevalent among cancer patients; thus, patients require information about the efficacy and safety of these therapies. Some cancer patients struggle to make informed decisions, highlighting the need for education and decisional support. Patients often look to support persons for assistance in treatment decision making; recognizing the social context of decision making, a patient education seminar focused on CAM therapies was developed to include support persons.

This study examines the effect of an education seminar for adult cancer patients and their support persons on support persons' use of CAM, knowledge about CAM and CAM decision making, CAM information-seeking behaviour, and decision-making experience pertaining to CAM. This research idea was developed following a number of projects completed as part of the Complementary Medicine Education and Outcomes (CAMEO) research program. The data presented for the first time in this thesis were collected from support persons as part of an initial study of the CAMEO research program. Surveys completed before and after the education seminar were used to examine the impact of the education seminar on support persons. Six measurement scales comprised the baseline and follow-up surveys: a CAM use survey, a CAM knowledge scale, two decisional outcomes scales (i.e., decision self-efficacy and decision conflict), a distress scale, and a demographic form. The conceptual frameworks providing the foundation for the CAMEO program, as well as data collection and analysis, were the Shared Decision Making and Ottawa Decision Support Framework. The Supportive Care Framework informed how decision support interventions were developed and offered by the CAMEO program, including the patient and support person education intervention.

There was no significant difference in support persons' CAM use following the seminar. After the seminar, most people continued to find information about CAM using the Internet; however, there was a significant increase in the use of the CAMEO website. In addition, significant increases in support persons' CAM knowledge were observed, as well as improved confidence in four key areas of CAM decision making. A significant decrease in support persons' decisional conflict was also found. No significant changes in decision-making distress were found.

## **LAY SUMMARY**

Complementary and alternative medicine (CAM) use is common among cancer patients, but the safety and effectiveness of many CAM therapies is not well understood. Some patients struggle to make informed decisions and may seek help from family and friends in making treatment decisions, including those related to CAM. An education seminar was developed for patients and their support persons to provide information about CAM use by individuals living with cancer and how to make safe and informed decisions. Following the seminar, this study assessed changes in support persons' CAM knowledge and behaviour, particularly regarding how treatment decisions about CAM are made, using baseline and follow-up surveys. Outcomes showed significant improvement in support persons' knowledge and decision making, and a decrease in decisional conflict. Future implications include acknowledging support persons as a necessary component of the decision-making process and using strategies to engage support persons in CAM education.

## **PREFACE**

The work presented in this thesis was developed following completion of the CAMEO research program at the BC Cancer Agency. The CAMEO research program was conducted by Dr. Lynda Balneaves (thesis co-supervisor) and her colleagues, Ms. Truant and Dr. Verhoef.

The secondary data analysis conducted by the author, Ms. Nancy Allen Searson, used data that were gathered from cancer patients' support persons as part of an education seminar about CAM use, knowledge and decision support needs, and communication needs of patients as identified in the CAMEO CAM Blitz, the University of British Columbia Behavioural Research Ethics Board application H08-02097.

Ms. Allen Searson received the support persons' database and was responsible for developing key research questions, cleaning and analyzing the data, and synthesizing the findings with the existing literature. The chapters of this thesis are the author's original, unpublished work.

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## **LIST OF ABBREVIATIONS**

BCCA	British Columbia Cancer Agency
CAM	Complementary and Alternative Medicine
CAMEO	Complementary Medicine Education and Outcomes
HCP	Healthcare Professional
NCCIH	National Center for Complementary and Integrative Health
NHP	Natural Health Products
NNHPD	Natural and Non-prescription Health Products Directorate
ODSF	Ottawa Decision Support Framework
SCF	Supportive Care Framework
SDM	Shared Decision Making
UBC	University of British Columbia
VC-BCCA	Vancouver Centre of the British Columbia Cancer Agency
WHO	World Health Organization

## GLOSSARY

**Alternative medicine.** Alternative medicine is treatment used in place of conventional medicine (NCCIH, 2016).

**Complementary medicine.** Complementary medicine refers to therapies and practices that are used in conjunction with conventional medicine (NCCIH, 2016).

**Conventional cancer medicine and treatments.** Conventional cancer medicine and treatments focus on inhibiting the ability of cancer to grow and spread (Canadian Cancer Society, 2014).

**Healthcare professional (HCP).** For this thesis, HCPs are identified as those persons providing treatment and care to patients in either a conventional or CAM context.

**Integrative health care.** More recently, the term integrative health care has become popular within both research and clinical communities. It is defined as health care that applies conventional and CAM therapies in a harmonized, evidence-informed manner (Boon, Verhoef, O'Hara, Findlay & Majid, 2004; NCCIH, 2016). The goal of integrative health care is to provide comprehensive, patient-centered care that is safe and evidence based. The journey of integrative health care is individual, with a patient-centred focus so that the patient's needs are emphasized, not those of the HCP (Weeks et al., 2013).

**Support persons.** In this thesis, support persons are defined as those individuals that patients identify as accompanying them during their cancer journey. Their support, which can be physical, emotional, relational, informational, and/or spiritual, is crucial for patients, as the support persons help advocate and support the patient during each stage of the cancer experience, from diagnosis to survivorship, and for some, to end-of-life. Support persons can include spouses, family members, friends, fellow cancer patients, and patient advocates.

## ACKNOWLEDGEMENTS

This journey began in 2009. This thesis has had many drafts, required data cleaning and more data cleaning into all hours of the night, and spanned two pregnancies and maternity leaves and family time. At times, it would seem I had to learn everything from scratch. While I would have preferred on some points of this journey to be able to wiggle my nose like Samantha from “Bewitched” and have everything complete in a twitch, the experience I have had and lessons I have learned from completing this thesis have been invaluable, on both an academic and personal level. This thesis would not have been possible without the unwavering support of my thesis committee, friends, and family.

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It seems serendipitous that I would complete this thesis in 2017, as you were both born on the 17<sup>th</sup> of different months. This journey began for me before either of you were on this earth. This road was long, hard, and detoured; you were my inspiration to complete. I took my time to finish because when you asked, "Mommy, will you play with us?" I did blessedly say, "Yes." I want you to know you can achieve anything you put your mind to. An education may have its difficulties to attain, but it is a very easy thing to carry around.  
I love you both... with all my heart.

## CHAPTER 1 – INTRODUCTION

### Background Information

Cancer as a disease has a significant impact on society, causing many individuals to experience chronic disability that limits their ability to work and care for their families. The Canadian Cancer Society's Advisory Committee on Cancer Statistics (2017) estimated 202,400 new cases of cancer were diagnosed in 2016, with lung, breast, colorectal, and prostate cancers representing 51.0% of all new cases. Statistics Canada (2012) reported cancer as the leading cause of death in Canada, with approximately 78,800 deaths or 30.0% of all deaths. Each day, 555 individuals are newly diagnosed with cancer and 216 die from cancer in Canada (Statistics Canada, 2012). Cancer affects Canadians of all ages and genders, but individuals 50 years and older are more likely to be affected and a slightly higher percentage of men than women are diagnosed each year (Advisory Committee on Cancer Statistics, 2017). There have been, however, substantial advances in conventional cancer treatments, with approximately 63% of diagnosed patients surviving for at least five years after their initial diagnosis (Advisory Committee on Cancer Statistics, 2017).

In recent years, there has been growing emphasis on prevention and the active role individuals can take in preventing cancer. In particular, there is persuasive evidence that lifestyle, including diet and exercise, is a prominent factor in preventing cancer (Canadian Cancer Society, 2017). Complementary therapies have been the subject of increasing interest for their potential role in preventing cancer and also in supporting individuals who are coping with the side effects of conventional cancer treatment. Historically, evidence supporting the effectiveness of complementary and alternative medicine (CAM) has been limited, but in the past 20 years, there has been an expanding body of research that supports the use of CAM

alongside conventional cancer care (Deng et al., 2009; Deng et al., 2013; Greenlee et al., 2014; Greenlee et al., 2017).

The definition of CAM that is used most frequently comes from the National Center for Complementary and Integrative Health (NCCIH) in the United States: “[CAM is] a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine” (2016). NCCIH (2016) further divides CAM into five categories: biologic (e.g., diet); mind-body medicine (e.g., yoga, meditation); body-based (e.g., chiropractic, massage); energy (e.g., acupuncture); and whole medical systems (e.g., traditional Chinese medicine).

Within the general population in Canada, a recent national survey indicated over three-quarters of Canadians had used some form of CAM in their lifetime (Esmail, 2017). The majority of CAM users were between the ages of 25 and 44 years and prevalence was found to increase with higher education and income levels (Esmail, 2017). Women were also found to be more likely to report CAM use than men (Schernhammer, Haidinger, Waldhor & Vutuc, 2009). The most prevalent CAM therapy used by Canadians within their lifetime was massage therapy, followed by chiropractic treatments and yoga (Esmail, 2017). Natural health products (NHPs), including vitamins and herbal therapies, were the most prevalent CAM reported in the previous 1997 survey; however, the use of NHPs in Canada has since declined (Esmail, 2017).

CAM use is very common among individuals living with cancer. After receiving a cancer diagnosis, many patients seek information about all possible treatment options, including conventional and CAM therapies. It is estimated that between 9% and 88% of all cancer patients use some form of CAM during their treatment (Horneber et al., 2012). Cancer patients report using CAM therapies for the following reasons: minimizing the side effects of

conventional cancer treatment, enhancing the therapeutic effect of conventional cancer treatment, and increasing quality of life and survivorship (Leggett, Koczwara & Miller, 2015).

It is often difficult for cancer patients to determine the credibility of information about CAM readily available through the Internet and social media and to safely integrate it with their conventional cancer treatments. While some CAM therapies are well researched and have been shown to have positive outcomes when used alongside conventional treatments (e.g., acupuncture, meditation, massage therapy), other CAM therapies may pose a risk, such as negatively interacting with conventional cancer treatments (e.g., NHPs) (Beijnen & Schellens, 2004; Meijerman, Beijnen & Schellens, 2006). Of further concern, many cancer patients do not discuss CAM use with their conventional HCPs, despite needing support in making informed decisions regarding the efficacy of CAM therapies and how to safely integrate these with their conventional treatment. It is imperative that HCPs be aware of patients' CAM use to ensure comprehensive and safe oncology care (Verhoef, Boon & Page, 2008).

The decision-making process surrounding CAM use is individual and complex, with demographics, social factors, disease-related factors, and cultural norms all influencing CAM decisions (Weeks, Balneaves, Paterson & Verhoef, 2014). It is important to recognize that cancer patients do not make treatment decisions independently or in isolation; instead, decision making typically occurs in a shared and social context that involves family members and other support persons (Öhlén, Balneaves, Bottorff & Brazier, 2006). As such, education and decision support programs are needed that include both cancer patients and their support persons.

To assist HCPs, cancer patients, and their support persons to safely navigate the use of CAM, the Complementary Medicine Education and Outcomes (CAMEO) research program was established in conjunction with the University of British Columbia (UBC) and British Columbia Cancer Agency (BCCA).<sup>1</sup> The CAMEO research program was developed in 2008 with the following main objectives: 1) To understand the best ways to support cancer patients and their support persons when making decisions about CAM; 2) To evaluate HCPs' current knowledge and ability to support patients and support persons; and 3) To assist in the development of new cancer and CAM research. The overarching goal of the CAMEO research program was to ensure that all cancer patients at the BCCA were assessed for CAM use and provided appropriate education and decision support (Balneaves et al., 2012).

In a patient needs assessment conducted by the CAMEO research team at the Vancouver Centre of the BCCA in 2008, 75% of participants indicated that they would attend an in-person CAM education seminar, if available at the BCCA. To address this interest and need, a patient education seminar was developed and offered numerous times to patients and support persons over a four-year period at the BCCA.

### **Purpose of the Study**

The purpose of this study, which was a secondary data analysis, was to examine the effect of an education seminar for adult cancer patients and their support persons on the support persons' use of CAM, knowledge about CAM and CAM decision making, and decision-making experience as it pertains to CAM.

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<sup>1</sup> BCCA is the provincial comprehensive cancer agency in BC for cancer treatment and cancer research. It comprises six regional centres as well as community oncology programs throughout BC. (<http://www.bccancer.bc.ca/about/who-we-are>).

## **Research Questions**

The following questions directed data analysis for this study:

- What was the effect of a CAM education seminar on support persons' use of CAM?
- What was the effect of a CAM education seminar on support persons' knowledge of CAM and CAM decision making?
- What was the effect of a CAM education seminar on support persons' CAM information-seeking behaviour?
- What was the effect of a CAM education seminar on support persons' CAM decision-making experience?

## **Outline of the Thesis**

The chapters of this thesis are organized as follows: Chapter 2 provides a review of the literature related to the major concepts underlying the thesis; Chapter 3 outlines the research methodology undertaken during the primary study and the subsequent secondary data analysis; Chapter 4 provides the results of the data analysis; and Chapter 5 discusses the secondary data analysis findings in the context of the current literature and provides recommendations for future research and decision support services related to CAM use in the context of cancer care.

## **Definitions**

**Alternative medicine.** Alternative medicine is treatment used in place of conventional medicine (NCCIH, 2016).

**Complementary medicine.** Complementary medicine refers to therapies and practices that are used in conjunction with conventional medicine (NCCIH, 2016).

**Conventional cancer medicine and treatments.** Conventional cancer medicine and treatments focus on inhibiting the ability of cancer to grow and spread (Canadian Cancer Society, 2014).

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**Support persons.** In this thesis, support persons are defined as those individuals that patients identify as accompanying them during their cancer journey. Their support, which can be physical, emotional, relational, informational, and/or spiritual, is crucial for patients as the support persons help advocate and support the patient during each stage of the cancer experience, from diagnosis to survivorship, and for some, to end-of-life. Support persons can include spouses, family members, friends, fellow cancer patients, and patient advocates.

### **Conceptual Framework**

Shared Decision Making (SDM) (Charles, Gafni & Whelan, 1997) and the Ottawa Decision Support Framework (ODSF) (O'Connor, 2006) were two decision-making conceptual frameworks that provided the foundation for the CAMEO research program as well as informed the data collection and analysis used in this thesis. The Supportive Care Framework (SCF) (Fitch, 2008) also informed how decision support interventions were

developed and offered by the CAMEO research program, including the patient and support person education intervention.

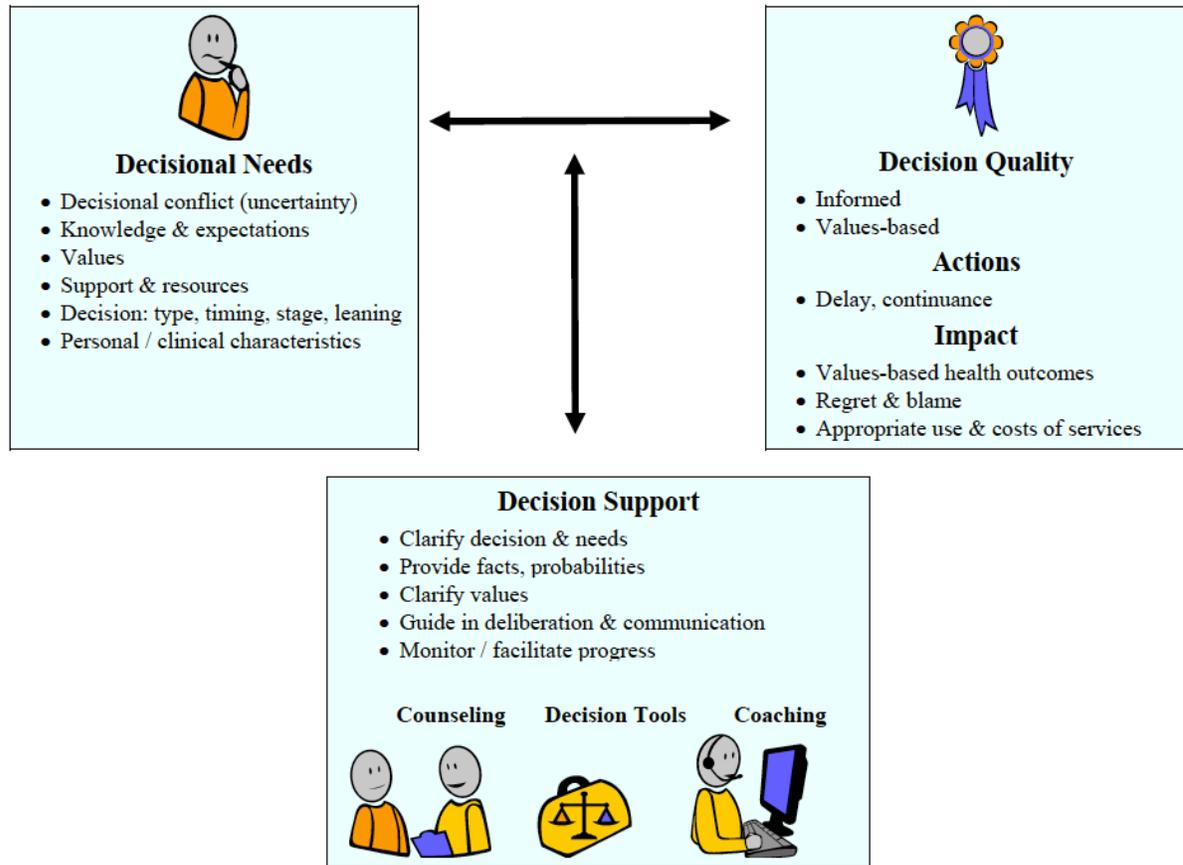
**Shared decision making (SDM).** This is the primary theoretical concept that informed the CAMEO research program and this thesis. SDM was introduced in the early 1980s to counteract what was perceived to be a paternalistic healthcare system in which the “doctor knows best” and the patient had a minimal role in treatment decisions (van Nistelrooij, Visse, Spekkink & de Lange, 2017). SDM is considered an essential element of patient-centered care and informed decision making (Godolphin, 2009) and is a partnership between patients and HCPs in terms of understanding and acknowledging the beliefs and values embedded in the process of making a collaborative healthcare decision (Charles, Gafni & Whelan, 1997, 2000; Jull, Stacey, Giles & Boyer, 2012). SDM allows for patients to make fully informed and supported decisions with their physician without interference from external sources and ensures their own perspective is a part of the process (van Nistelrooij et al., 2017).

SDM encourages the development of trust between patients and HCPs and requires patients to be informed and understand the various treatment options and possible consequences prior to giving their consent for treatment (Charles, Gafni & Whelan, 1999). Before the advent of SDM and patient-centred care, patients often passively consented to treatments recommended by their healthcare team without meaningful involvement in their treatment plan or without their beliefs and values being considered (Charles et al., 1997, 2000; Jull et al., 2012). SDM establishes a relationship between the HCP and the patient by reviewing the patient’s preferences regarding receiving information about a healthcare decision, including the quantity and format of information, as well as identifying the patient’s desired involvement in the SDM process (Godolphin, 2009). SDM is seen as a method to

decrease the power and information asymmetry between the HCP and patient by increasing the patient's autonomy and control over decisions regarding treatment (Charles et al., 1997, 2000; Jull et al., 2012).

**Ottawa decision support framework (ODSF).** The purpose of the ODSF, which is based firmly on the concept of SDM, is to assist individuals, families, and HCPs in making informed treatment decisions through the use of various decisional tools (refer to Figure 1). The decisional aids developed by the ODSF differ from patient education programs as they primarily focus on the benefits and risks of various treatment options (O'Connor et al., 1998) and help individuals identify their decisional needs, values, beliefs, and choices related to healthcare decisions (O'Connor, 2006). The ODSF suggests improving the quality of a patient's decision making will directly correlate to improved patient outcomes (Légaré, O'Connor, Graham, Wells & Tremblay, 2006). Furthermore, research has shown that individuals who are supported in their decisions report increased decisional quality and health outcomes and, as a result, experience less regret regarding their decision making (O'Connor, 2006).

**Figure 1 Ottawa Decision Support Framework**



(O'Connor, 2006)

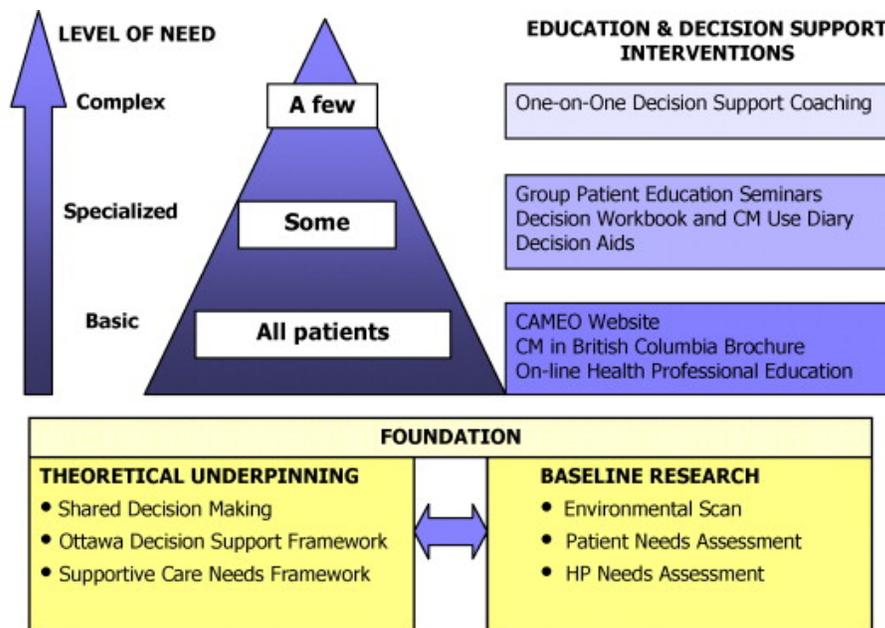
**Supportive care framework (SCF).** This framework originated in 1994 and was developed by Canadian nursing scholar, Dr. Margaret Fitch. The SCF was designed to assist oncology HCPs and healthcare teams in understanding and planning for the information, support, and healthcare needs of cancer patients (Fitch, 2008). The SCF draws on the concepts of cognitive appraisal, coping, and adaptation in considering how care should be provided to individuals living with cancer (Fitch, 2008). It further suggests that all people with cancer have basic needs that can be dealt with, providing they have access to information and supportive HCPs; however, as a patient's needs and illness complexity increase, the strategies to address those needs must also change. As a framework, the SCF

can be used to inform healthcare research, for program planning, or as an organizational tool to assist with patient education needs (Fitch, 2008).

### **CAMEO Research Program and Theoretical Underpinning**

The CAMEO research program used the SDM and the ODSF to inform how decisional support strategies, including patient and HCP education seminars and one-on-one decision coaching, were developed in a manner that was patient-centred and addressed the complexity of CAM use in the context of cancer (Balneaves et al., 2012). The SCF was used to triage patients based on the complexity of their information and decision support needs as well as develop decision support strategies in a hierarchical manner with regards to degree of intervention and resources required (see Figure 2). Figure 2 highlights the different levels of interventions used by the CAMEO research program.

**Figure 2 Levels of Interventions Used by the CAMEO Research Program**



CM - Complementary medicine  
HP - Health professional

(Balneaves et al., 2012)

## **Relationship Between CAMEO Research Program and Thesis Study**

The idea for this thesis was developed following completion of the CAMEO research program at the BCCA. The data used in this secondary data analysis were collected from cancer patients' support persons during the initial CAMEO research program, conducted by Dr. Lynda Balneaves and colleagues (Ms. Truant and Dr. Verhoef), and had yet to be analyzed. Ms. Allen Searson was provided with the support persons' database and was responsible for developing key research questions, cleaning and analyzing the data, and synthesizing the findings with the existing literature as partial fulfillment of her Master of Science in Nursing.

## **Conclusion**

CAM use is prevalent in the general population and among cancer patients. Whether using CAM concurrently with conventional cancer treatment or exclusively during cancer treatment, patients require information about the efficacy and safety of these therapies. Some cancer patients struggle to make informed decisions, highlighting the need for education and decisional support. Patients often look to support persons for assistance in treatment decision making; recognizing the social context of decision making, a patient education seminar focused on CAM therapies was developed that included both cancer patients and their support persons. The aim of this thesis is to explore the impact of this education seminar on support persons' own CAM use, their sources of CAM information, and their CAM knowledge and decision experience. The next chapter will provide an overview of the literature focused on CAM use in the context of general population, cancer population, and the social nature of treatment decision making.

## **CHAPTER 2 – REVIEW OF THE LITERATURE**

Interest in CAM use has grown substantially over the past decade and is expected to continue to increase in many countries around the world (WHO, 2013). Dr. Margaret Chan, Director-General of the World Health Organization (WHO), stated, “The two systems of traditional and Western medicine need not clash. Within the context of primary health care, they can blend together in a beneficial harmony, using the best features of each system, and compensating for certain weaknesses in each” (2013, p. 37). This review of the literature will provide a brief overview of the history of CAM, as well as CAM use across general and cancer patient populations. The literature review will also delve into the risks of CAM use as well as the attitudes of HCPs toward CAM use and give a brief overview of integrative oncology centres in North America. The process through which patients make treatment decisions and the role of support persons in patients’ treatment decision-making process will also be explored.

### **History of CAM**

Many CAM therapies have arisen from traditional medicines, whose philosophical underpinnings do not always align with conventional medicine, creating scepticism regarding their efficacy and safety (Deng, 2008). In 1992, CAM use in the context of cancer was referred to as “scientifically unproven treatments of cancer or cancer remedies” (Lerner & Kennedy, p. 181); since then, CAM terminology has evolved. Many people use the terms “complementary” and “alternative” interchangeably when referring to CAM therapies; however, it is important to recognize there is a difference between these two categories of therapies. The majority of people use conventional treatments alongside non-conventional therapies; alternative medicine without the concurrent use of conventional treatment is quite

rare and, therefore, most CAM use is considered complementary (NCCIH, 2016). As well, it is important to recognize that time, geographical location, and culture can influence how CAM is defined and which therapies and practices are considered to fall under the CAM rubric (Boon, Brown, Gavin, Kennard & Stewart, 1999; Hornberner et al., 2012). As a consequence, the boundary between conventional medicine and CAM is often blurred (Dayhew, Wilkinson & Simpson, 2009) and may shift over time and communities.

Historically, many CAM therapies were among the first medical treatments used to heal people. For example, Ayurvedic medicine dates back over 5,000 years (Garodia, Ichikawa, Malani, Sethi & Aggarwal, 2007; Gogtay, Bhatt, Dalvi & Kshirsagar, 2002) and traditional Chinese medicine dates back more than 2,500 years (NCCIH, 2013). Traditional healers and medicine are included under the rubric of CAM and often employ healing knowledge and techniques passed down from generation to generation (WHO, 2013). In Canada, with its diverse, multicultural population, it is important to recognize that many ethnocultural communities, including the Indigenous community, may not consider their traditional therapies to be complementary or alternative, but a reflection of their culture or an important part of their primary health care (Balneaves, Weeks & Seely, 2008).

### **Use of CAM in the General Population**

CAM use is increasing at a rapid pace throughout the world (WHO, 2013), with various reasons for its use. People who lean toward a more holistic health perspective are often more inclined to use CAM (Barnes, Bloom, Nahin, 2008). CAM use can also be ingrained in cultural history (Jang, Kang & Kim, 2017; Ock et al., 2009; Siti et al., 2009; Yamashita, Tsukayama & Sugishita, 2002); for example, CAM use is very prevalent in Asian and South Asian countries, where two of the oldest whole medical systems originated (i.e., traditional Chinese medicine and Ayurvedic medicine) (Kang et al., 2012; Lee, 2001; Shih,

Chiang & Chan, 2009). Similarly, cultural and historical influences can affect the use of CAM in places where medical systems are well established (WHO, 2013). Demographically, international studies of higher income countries show middle-aged women living in metropolitan centres, with higher education, social status, and personal income, and living with a chronic illness, tend to be more prevalent users of CAM (Molassiotis et al., 2005; Pedersen, Christensen, Jensen & Zachariae, 2009; Schernhammer, Haidinger, Waldhor & Vutuc, 2009).

In Canada, the use of CAM is very prominent. Between 1997 and 2016, the Fraser Institute commissioned three national surveys of CAM use in Canada (1997, 2006, and 2016). In 2016, 79.0% of Canadians reported using CAM sometime in their lives compared to 74.0% in 2006 and 73.0% in 1997 (Esmail, 2017). In 2016, Canadians living in British Columbia had the highest prevalence of CAM use, with over 89.0% reporting use in their lifetime (similar to the 1997 and 2006 survey results) (Esmail, 2017). Over the last two decades, the use of massage, acupuncture, chiropractic care, osteopathy, and naturopathy has expanded (Esmail, 2017). Herbal therapies, which were in the top five most commonly used therapies in the 1997 and 2006 surveys, were supplanted by yoga in the 2016 survey (Esmail, 2016). The other most commonly used CAM therapies in 2016 were massage, chiropractic care, relaxation techniques, and acupuncture (Esmail, 2017).

In the United States, the National Health Interview Survey used data from three studies that were conducted by the Center for Disease Control and Prevention's (CDC) National Center for Health Statistics in 2002, 2007, and 2012 (Barnes, Powell-Griner, McFann & Nahin, 2004; Barnes, Bloom & Nahin, 2008; Clarke, Black, Stussman, Barnes & Nahin, 2015). During this 10-year time span, reported CAM use ranged from 32.3% in 2002, 35.5% in 2007 and 34.0% in 2012 (Clarke et al., 2015). NHPs have been the most commonly

used CAM therapies in the United States over the past 10 years, with deep breathing being the second most commonly used CAM (Clarke et al., 2015). Yoga, tai chi, and qigong use increased at each time period, with yoga being the most common of the three therapies.

Accessibility and availability are other factors that can influence CAM use (WHO, 2013). In many developing countries, traditional healers, traditional practices, and herbal medicines are the primary form of health care and, at times, the only type of health care available (Chibwana, Mathanga, Chinkhumba & Campbell, 2009; WHO, 2013). For example, in Africa, with a ratio of 1:500 traditional healers to residents compared to 1:40,000 medical doctors to residents, the high prevalence of CAM use can be attributed to CAM being more readily available and accessible (WHO, 2013). Similarly, in Trinidad and Tobago, the lack of access to conventional medicine has resulted in home remedies being more frequently used (Bahall & Legall, 2017).

The use of conventional medicine or CAM can also be dependent on socioeconomic factors (Harris, Cooper, Relton & Thomas, 2012). In North America, where the conventional healthcare system is well established, CAM is typically a complement to conventional care (WHO, 2013) and is used more predominantly for health promotion and illness prevention than for treating serious illnesses (Eisenberg et al., 1998). In contrast, on continents such as Africa, conventional medicine is very expensive for the majority of the population. As such, many individuals rely upon CAM as their primary form of health care (WHO, 2013).

### **Use of CAM in Chronic Diseases**

In individuals with chronic diseases such as HIV/AIDS, arthritis, and renal failure, CAM use is very prevalent and is often used to manage symptoms and side effects that are not well controlled by conventional treatments. For example, in the United States, it is estimated that up to 78% of patients with HIV/AIDS use some form of CAM (Littlewood &

Vanable, 2014), with the goal of improving their general health and increasing their chances of survival (Abou-Rizk, Alameddine & Naja, 2016). These patients have also expressed the belief that CAM therapies are more natural compared to conventional anti-retroviral treatments (Abou-Rizk et al., 2016). Interestingly, the researchers in this study found that over half of the participants were unaware of potential interactions that could occur when CAM and pharmaceutical drugs were used concurrently (Abou-Rizk et al., 2016).

For patients with arthritis, up to 90% have reported using some form of CAM (Efthimiou, Kukar & MacKenzie, 2010; Taibi & Bourguignon, 2003). In one study of patients with arthritis receiving specialist care, 90.5% reported having tried at least one CAM therapy for arthritis symptoms (Callahan et al., 2009). In this population, CAM use has been framed by patients as a way of taking control of their health care, with CAM therapies being perceived as having limited risk (Efthimiou et al., 2010).

For patients with renal failure undergoing hemodialysis, a recent study found that 63.1% of patients used one or more CAM therapies after starting hemodialysis (Ceyhan, Goris, Dogan & Korkut Bayindir, 2017). The patients chose CAM therapies primarily to decrease the side effects and symptoms associated with that treatment (Ceyhan, Goris, Dogan & Korkut Bayindir, 2017).

### **Use of CAM in Cancer Care**

An international review found between 9% and 88% of cancer patients use CAM at some point during their cancer journey (Horneber et al., 2012). The review spanned 30 years and noted an increase of CAM use after the year 2000 (Horneber et al., 2012). For some cancer patients, CAM is regarded as natural, non-toxic, and less harmful than conventional medicine (Boon et al., 1999; Hermann & von Richter, 2012; Oh et al., 2010). Other patients have described CAM therapies as being on the same spectrum as conventional medicine, to

be used concurrently to support them through the treatment experience (Balneaves, Kristjanson & Tataryn, 1999).

After receiving a cancer diagnosis, many patients educate themselves regarding all therapies, conventional and otherwise, that may be able to treat their cancer or complement their care (Balneaves et al., 2008; Richardson, Masse, Nanny & Sanders, 2004). Patients with cancer and other serious illnesses tend to have a “leave no stone unturned” mentality and, therefore, are prime candidates to use CAM therapies (Ernst & Cassileth, 1998). While some patients with cancer use CAM therapies only from diagnosis to end of conventional treatment, others continue to use these therapies well into survivorship or when cancer recurs and becomes terminal. Patients’ CAM use often begins prior to their cancer diagnosis (Roberts et al., 2005), with some cancer patients having used CAM for other chronic ailments (Corner et al., 2009; Smith, Clavarino, Long & Steadman, 2014). For others, cultural influences may determine whether they used CAM prior to and following their cancer diagnosis (Ock et al., 2009; Siti et al., 2009; Yamashita et al., 2002). CAM use fits into the way of life and personal philosophy of many patients (Shorofi & Arbon, 2017).

### **Cancer Patients’ Reasons for Using CAM**

Cancer patients use CAM for a variety of reasons (Balneaves et al., 2008; Smith et al., 2014). It is well documented that cancer patients use CAM therapies as a means of decreasing the side effects associated with conventional treatments (Arslan & Ozdemir, 2015; Corner et al., 2009; Molassiotis et al., 2005; Ryan et al., 2012; Shen et al., 2002; Smith et al., 2014), especially when conventional treatments aimed at reducing side effects are ineffective (Corner et al., 2009). While not an exhaustive list, side effects that may be the target of CAM use include pain, peripheral neuropathy, fatigue, nausea and vomiting, sleeplessness, insomnia, and pruritus (Arslan & Ozdemir, 2015; Greenlee et al., 2017; Ryan

et al., 2012; Smith et al., 2014). For example, there is growing interest in the possible role and efficacy of acupuncture in reducing the side effects related to conventional cancer treatment, such as xerostomia, fatigue, and nausea and vomiting (Asadpour, Meng, Kessel & Combs, 2016).

Cancer patients also use CAM to improve and enhance their overall quality of life, which includes physical, psychological, social, and spiritual wellbeing (Bahall, 2017; Balneaves et al., 2007; King et al., 2015; Lin, Hu, Chang, Lin & Tsauo, 2011; Singh & Chaturvedi, 2015; Wilkinson et al., 2008). Other patients have reported using CAM therapies to decrease their anxiety, depression, and pain brought about by cancer, thereby increasing their quality of life (Jang et al., 2017; Singh & Chaturvedi, 2015). A diagnosis of cancer may encourage patients to improve their overall health as treatment morbidity can be greatly reduced by participating in activities such as exercise and weight control (Jones & Demark-Wahnefried, 2006). Similarly, many CAM therapies, such as yoga, meditation, and massage, may be incorporated as part of a healthier lifestyle (Dayhew et al., 2009; Jones & Demark-Wahnefried, 2006; Lin et al., 2011).

Cancer patients have also reported using CAM to enhance their conventional treatment (Arthur et al., 2012; Balneaves et al., 2007; Balneaves et al., 2008; Corner et al., 2009). For example, patients have reported taking antioxidants to boost their immunity during conventional cancer treatments (Block et al., 2008; Greenlee, Hershman & Jacobson, 2009; Smith et al., 2014; Wilkinson et al., 2008).

The use of CAM therapies has also been found to give some cancer patients hope in the face of a challenging diagnosis and treatment trajectory (King et al., 2015; Richardson, Masse, Nanny & Sanders, 2004). Patients use CAM in hope of a cure and to provide them with peace of mind that they have done everything possible to enhance their chances of

survival (Arthur et al., 2012; Boon et al., 1999; Molassiotis et al., 2005; Richardson et al., 2004; Verhoef, Balneaves, Boon & Vroegindewey, 2005). Sometimes, hope does encourage cancer patients to consider CAM, especially when faced with limited conventional treatment options.

Other cancer patients use CAM because they feel their needs are not being fully met by conventional HCPs (Verhoef, Boon & Page, 2008). By some individuals, compared to HCPs, CAM providers are considered to provide better treatment explanations, be more engaged listeners, and be more compassionate (Citrin, Bloom, Grutsch, Mortensen & Lis, 2012; Esmail, 2017). In Canada, 47% of participants reported their CAM practitioners spent more time with them compared to their conventional HCPs (Esmail, 2017). For many patients, conventional medicine is seen as only part of the solution with regard to treatment, and they may use CAM as way to complete the package (Arthur et al., 2012). Other cancer patients have shared the belief that CAM addresses what they perceive to be gaps in conventional medicine, including a lack of attention to holism and the importance of the mind-body connection during the cancer journey (Arthur et al., 2012; Balneaves et al., 2007).

At the beginning of the cancer journey, there is a wealth of information that patients must absorb and retain in order to make treatment decisions, which may overwhelm some patients (Balneaves et al., 2007; Citrin et al., 2012). In this environment, some individuals have used the decision-making process surrounding CAM as a way of regaining a sense of control (Arslan & Ozdemir, 2015; Balneaves et al., 2007; Corner et al., 2009; Truant & Bottorff, 1999; Wilkinson et al., 2008), as CAM therapies are often selected and decided upon independently by patients. Frequently in conventional care, patients have few treatment options and may experience a limited role in the treatment decision-making process (Corner et al., 2009). As CAM use is outside the sphere of conventional care, patients are typically

able to take a more active and autonomous role in decisions about these therapies (Balneaves et al., 2008; King et al., 2015; Verhoef et al., 2005).

Lastly, if patients have had a difficult experience with conventional medicine or a practitioner, or if their treatment options in conventional medicine are limited, they will sometimes look to CAM as an alternative (Boon et al., 1999; Boon, Brown, Gavin & Westlake, 2003; Citrin et al., 2012). Dr. Heather Boon from the University of Toronto categorized the reasons underlying CAM use as either being a “push” or a “pull” (Boon et al., 2003). A push toward CAM resulted from patients’ dissatisfaction with conventional medicine whereas a pull towards CAM came from the perception that CAM use was more natural and, therefore, less toxic compared to conventional treatment (Boon et al., 2003).

### **Risks of CAM Use**

Despite the perception held by some individuals that CAM therapies are safer than conventional medicine, some CAM therapies may pose a risk to patients’ health and safety (WHO, 2013). CAM therapies, such as NHPs, may be particularly problematic when used concurrently with conventional treatment as negative drug-supplement interactions may occur (Alsanad, Howard & Williamson, 2016; Hermann & von Richter, 2012; Sparreboom, Cox, Acharya & Figg, 2004). Specifically, within the context of cancer, there has been concern that select NHPs may either reduce the efficacy of chemotherapy agents, leading to potential treatment failure, or increase the therapeutic effect of medication to a toxic level (Smith et al., 2014). These concerns are supported by research that has demonstrated select herbal supplements (i.e., St. John’s wort, echinacea, and garlic) can inhibit enzymes in the liver that metabolize and break down cancer drugs or the transporters that carry the drugs across cell membranes (Mathijssen, Verweij, de Bruijn, Loos & Sparreboom, 2002). Other herbal remedies and dietary supplements are contraindicated with surgery due to their anti-

platelet effect, which could increase bleeding duration (Andersen, Sweet, Zhou & Standish, 2015; Ben-Arye et al., 2016). Further, the use of high dose antioxidants (e.g., vitamin E) is controversial as there is early research that some antioxidants may protect not only healthy cells during adjuvant cancer treatment, but also cancerous cells (Lawenda et al., 2008), increasing the risk of recurrence.

As mentioned, a common assumption among cancer patients is that CAM therapies are natural and, thus, pose limited risk (Stub et al., 2016; Wilkinson et al., 2008). However, there have been numerous case studies in which CAM therapies have resulted in significant harm. One example is black salve, which has been purported to be a natural, non-toxic treatment for skin cancers; instead, it contains numerous chemicals, including highly corrosive zinc chloride (Croaker, King, Pyne, Anoopkumar-Dukie & Liu, 2017). There has also been concern that some NHPs, many of which are unregulated if manufactured outside of Canada, may contain prescription drugs not listed on the label and have toxic levels of other substances, such as mercury, cadmium, lead, arsenic, and aluminum (Genuis, Schwalfenberg, Siy & Rodushkin, 2012; Smith et al., 2014).

Another potential risk of CAM use is cancer patients declining all conventional medicine; instead, using CAM as their sole treatment method (Citrin et al., 2012; Verhoef, Rose, White & Balneaves, 2008). While the percentage of patients declining conventional treatment is small (i.e., 3-6%), it is still significant (Verhoef et al., 2008). Patients may elect to use alternative therapies for several reasons, including believing in holistic healing, wanting an active role in treatment decisions and their health, fearing the potential side effects of conventional cancer treatments, and perceiving conventional cancer treatments to be high risk with little chance of success (Citrin et al., 2012; Verhoef et al., 2008). Poor communication and a negative experience with a conventional HCP have also been found to

be associated with a patients' decision to use CAM exclusively (Citrin et al., 2012; Verhoef et al., 2008). Such avoidance of or delays in seeking conventional treatment may significantly negatively impact cancer patients' overall survival rates (Johnson, Park, Gross & Yu, 2017; Verhoef et al., 2008).

### **Oncology Healthcare Professionals' Attitudes Toward CAM Use**

Healthcare professionals' attitudes toward CAM use have been historically negative (Broom & Adams, 2009; Dayhew et al., 2009). Factors that can influence HCPs' attitudes toward CAM include limited education and knowledge about CAM, personal philosophy and experience, and the limited evidence of efficacy and safety associated with many CAM therapies (Broom & Adams, 2009; King et al., 2015; Rojas-Cooley & Grant, 2006; Shorofi & Arbon, 2017; Truant, Balneaves & Fitch, 2015).

The extent and depth of CAM knowledge and education in conventional healthcare settings and education programs is varied and, sometimes, very limited (Avino, 2011; Broom & Adams, 2009; King et al., 2015; Zanini et al., 2008), leaving many HCPs feeling ill-equipped to assist their patients in making informed decisions about CAM use (Broom & Adams, 2009; Christina, Abigail & Cuthbertson, 2016; Cooley & Grant, 2005; King et al., 2015). HCPs are often ambivalent towards patients' CAM use (Rojas-Cooley & Grant, 2006) and many may discourage patients from using CAM therapies due to the perceived potential for negative interactions with conventional treatments and the lack of evidence regarding efficacy (Broom & Adams, 2009; King et al., 2015).

More recently, there has been a shift toward more positive attitudes regarding CAM use within the conventional HCP community (Dayhew et al., 2009; Shorofi & Arbon, 2017). Early research indicates that some HCPs perceive CAM as a way to improve the quality of care available to patients and to ultimately improve patients' overall quality of life (Hall,

Leach, Brosnan & Collins, 2017). In fact, a recent article found HCPs perceive integrative medicine to be the future of medicine and the combination of CAM and conventional treatments as superior to conventional treatment alone (Bahall & Legall, 2017).

As CAM use expands in the general population, many HCPs are also using CAM for self-care. International studies show between 60-96% of HCPs use CAM in their personal lives (Jong, Lundqvist & Jong, 2015; Kim, Lee & Lee, 2016; Shorofi & Arbon, 2017). These personal experiences with CAM therapies may positively influence HCPs' attitudes toward CAM (Rojas-Cooley & Grant, 2006; Shorofi & Arbon, 2017) and possibly make them more open to discussions with patients.

### **Disclosure of CAM Use**

It is imperative cancer patients discuss their CAM use with HCPs as non-disclosure can be potentially harmful (Balneaves et al., 2008). When patients do not disclose their CAM use, HCP do not have all the health information necessary to ensure patients make an informed choice regarding treatment options (Hall et al., 2017). It is estimated that between 40 to 77% of cancer patients do not discuss their use of CAM with their conventional HCPs (Balneaves et al., 2012; Rojas-Cooley & Grant, 2006; Verhoef et al., 2008). Patients decide to not disclose CAM use to conventional HCPs for various reasons, including the HCP failing to ask about CAM use, a belief the HCP has negative or ambivalent attitudes toward CAM, anticipating dismissal of their questions regarding CAM therapies by the HCP, and thinking CAM use is not related to their conventional cancer care and, therefore, is not a concern for the conventional HCPs (Balneaves et al., 2012; Davis, Oh, Butow, Mullan & Clarke, 2012; Farooqui et al., 2012; Richardson et al., 2004; Robinson & McGrail, 2004; Rojas-Cooley & Grant, 2006; Tasaki, Maskarinec, Shumay, Tatsumura & Kakai, 2002; Verhoef et al., 2008).

From the perspective of oncology HCPs, some do not discuss CAM therapies with patients because they perceive CAM as not their responsibility, there is insufficient evidence to support the use of CAM, and there is insufficient time during consultations to discuss CAM with patients (Balneaves et al., 2012; King et al., 2015). Research has also shown there is a direct correlation between HCPs' personal knowledge of CAM and discussing CAM use with patients (Hessig, Arcand & Frost, 2004; Jong et al., 2015; Kim et al., 2016; Rojas-Cooley & Grant, 2006), and many HCP readily admit their knowledge surrounding CAM use is lacking (King et al., 2015). Furthermore, in one study from Alberta, up to 70% of oncology HCPs did not feel prepared to monitor patients' CAM use nor did they know where to find credible resources about CAM (King et al., 2015). However, in this study, 90% of oncology HCPs were interested in receiving CAM training (King et al., 2015); as such, educating HCPs may provide them with the knowledge and skills necessary to open a dialogue with cancer patients about the potential benefits and risks of CAM use (Hessig et al., 2004).

As CAM use increases within the general population and within specific health conditions, there is an urgent need for patient and HCP education programs focused on CAM. With many patients choosing not to share their CAM use with members of their healthcare team, concerns exist regarding how well informed they are about their CAM decisions. Education is needed at both a patient- and HCP-level to encourage unbiased and informed conversations about CAM in the context of cancer care.

### **Integrative Oncology Programs in North America**

As interest in CAM has expanded in cancer populations, and the evidence has grown related to the safety and efficacy of many CAM therapies, there has been a movement towards the integration of CAM into conventional cancer care. In 2012, Seely, Weeks and Young reviewed the purpose, structure, and activities of 29 international integrative oncology

programs. All of the programs reviewed emphasized the importance of complementary supportive care versus alternative care and approximately half of the programs reported providing care to both patients and support persons. Many of these programs are connected to major academic institutions or clinical agencies and offer not only clinical services, but also conduct cutting-edge CAM research.

**Integrative oncology federal agencies.** Several federal agencies have been established in the United States and Canada to focus on research, education, and for some, regulation of CAM. The following section provides a brief overview of some of these programs.

***Natural and Non-prescription Health Products Directorate.*** The Natural and Non-prescription Health Products Directorate (NNHPD) is the regulatory authority for NHPs in Canada and is a part of the Health Products and Food Branch of Health Canada. The role of the NNHPD is to ensure Canadians have access to safe, effective, and high-quality NHPs by assessing all products prior to their sale within Canada (Government of Canada, 2015). Consumers and clinicians are able to access an NHP ingredients database, therapy monographs, and basic information about NHPs through the NNHPD website (Government of Canada, 2015).

***Office of Cancer Complementary and Alternative Medicine.*** In the United States' National Cancer Institute (NCI), an Office of Cancer Complementary and Alternative Medicine (OCCAM) was established in 1998. OCCAM's role is to encourage collaborations between cancer researchers and CAM practitioners through workshops, lectures, and conferences. Also, the OCCAM identifies gaps in cancer and CAM research and provides targeted funding (National Cancer Institute, 2016). Therapy monographs (called PDQs®) are also available for patients that summarize the latest evidence on a variety of CAM therapies.

Until recently, OCCAM hosted a monthly public lecture series that discussed the role of CAM therapies in cancer care.

***National Center for Complementary and Integrative Health.*** The National Center for Complementary and Integrative Health (NCCIH) is a government-led agency within the United States' Department of Health and Human Services. It functions mainly as a research institute, with its mission being “to define, through rigorous scientific investigation, the usefulness and safety of complementary and alternative medicine interventions and their roles in improving health and health care” (NCCIH, 2017). The NCCIH website has evidence-based resources and links to other CAM information sources for patients. There is an online continuing education section, which features video lectures about CAM research and various CAM therapies. However, there are no resources to assist patients with treatment decision making.

**Integrative oncology centres – United States.** Three leading integrative oncology centres in the United States are briefly described below.

***Memorial Sloan Kettering Cancer Center.*** Memorial Sloan Kettering Cancer Center (MSKCC) is a leading cancer care organization in New York City, with other locations in Long Island, New Jersey, and Westchester. MSKCC's integrative medicine service, now called the Bendheim Integrative Medicine Centre, focuses on managing symptoms and complementing conventional treatments with the goal of encouraging healing and maintaining wellbeing. The program has a wide range of evidence-based CAM therapies available for all MSKCC patients (Deng, 2008) such as meditation, acupuncture, music therapy, yoga, and nutrition and fitness classes. Recognizing the stress experienced by support persons, MSKCC also offers counseling services for support persons to assist in their self-care management so they are able to maximize their ability to care for the patient.

MSKCC has been a leader in developing reliable information, with a strong emphasis on educating patients, support persons, and the public about CAM therapies (Memorial Sloan Kettering Cancer Center (a), n.d.). For example, an online library is available that includes written references, webcasts, and videos about health and wellness. MSKCC also offers in-person education classes and support groups and virtual, online programs that enable patients to participate in interactive programs from their homes. Further, MSKCC has a public database called “About Herbs, Botanicals & Other Products”, which provides up-to-date, evidence-based information about specific herbs and dietary supplements (Memorial Sloan Kettering Cancer Center (b), n.d.).

***MD Anderson Cancer Center.*** MD Anderson Cancer Center is a leading cancer organization at the University of Texas, with an additional site at Banner MD Anderson in Arizona. The goal of the Integrative Medicine Center at both sites is to improve patients’ physical and psychological wellbeing as well as help them cope with the stress and anxiety associated with a cancer diagnosis and treatment. Available educational resources include a regular newsletter and an online audio and video library of mind-body therapies. Patients have access to oncology massage, acupuncture, yoga, and integrative physicians. Meditation and music therapy are also available in-person as well as online (MD Anderson Cancer Center, 2017).

***Leonard P. Zakim Center.*** The goal of the Leonard P. Zakim Center for Integrative Therapies and Healthy Living at the Dana-Farber Cancer Institute in Boston, Massachusetts is to increase knowledge surrounding the efficacy of CAM use through evidence-based research. The Zakim Center is also committed to improving patients’ quality of life by integrating evidence-based CAM therapies with conventional cancer treatments. Group education programs are regularly held to encourage patients to be active participants in their

care and all patients, family members, and caregivers are invited to attend lectures and educational seminars to become more informed about CAM and conventional cancer treatments (Dana-Farber Cancer Institute, 2017).

**Integrative oncology centres – Canada.** Five leading integrative oncology centres in Canada are briefly described below.

***Tom Baker Cancer Centre (TBCC).*** The TBCC is located in Calgary, Alberta and is an integrative oncology program that aims to treat the whole person – body, mind and spirit – using evidence-based CAM therapies in conjunction with conventional medicine. TBCC has monthly integrative education seminars for patients and family members that discuss integrative medicine and various evidence-based CAM therapies and how they are used in practice. Potential interactions between CAM therapies and conventional medicine are also discussed. On the TBCC website, there is a section that has links to evidence-based resources, including other integrative cancer centres in North America (Tom Baker Cancer Centre, 2017).

***Ottawa Integrative Cancer Care (OICC).*** The OICC is a cancer care, education, and research facility located in Ottawa, Ontario. It was established to provide integrative cancer care and improve quality of life for those living with cancer. The OICC employs regulated CAM HCPs to provide therapies aimed at increasing quality of life and decreasing side effects linked to conventional treatments. The OICC is committed to empowering cancer patients with education on self-care practices that support health. Similarly, the OICC also educates those wishing to take steps to prevent cancer. As well as providing care, the OICC conducts clinical research through a collaborative network with local academic and conventional care facilities. The OICC believes health care should be individualized and aims

to develop CAM regimens that do not interfere with nor negatively impact conventional treatments (<http://www.oicc.ca/en/>).

***The Healing and Cancer Foundation.*** Founded in 2007, the Healing and Cancer Foundation is based out of Dalhousie University in Halifax, Nova Scotia and is staffed by an oncologist and psychotherapist. The purpose of the program is to help patients receive the best care possible from the conventional medical system while empowering the self through the mind, body, and spirit. This program aims to provide patients and families with an integrative approach, using science, spiritual traditions, and personal inherent wisdom. The Healing and Cancer Foundation provides free teachings to an international audience through education videos, webcasts, and documentaries, with a focus on mind-body CAM therapies, such as meditation, yoga, and relaxation (<http://healingandcancer.org/>).

***InspireHealth.*** InspireHealth is an organization located in three cities in British Columbia: Vancouver, Victoria, and Kelowna. The purpose of the organization is to provide supportive care for cancer patients and their support persons under the guidance of HCPs. InspireHealth applies the person-based model of care where the person plays a very important role in his or her own health and wellbeing. The organization promotes lifestyle changes that may enhance quality of life, increase survival rates, and decrease cancer recurrence rates. InspireHealth also researches the efficacy and cost associated with supportive cancer care (<https://www.inspirehealth.ca>).

***CAMEO research program.*** In conjunction with the University of British Columbia and the Vancouver Centre of the British Columbia Cancer Agency (VC-BCCA), under the direction of Dr. Lynda Balneaves (Principal Investigator), Ms. Tracy Truant and Dr. Marja Verhoef (Co-Investigators), the CAMEO research program opened its doors in 2008 and was active at VC-BCCA until 2013. The CAMEO research program was committed to increasing

the quality of conventional cancer care related to CAM by creating an open and unbiased environment that was supported by evidence related to CAM therapies. The CAMEO research program's goals included supporting cancer patients in making evidence-informed decisions about CAM, evaluating and improving HCPs' knowledge and support skills related to CAM, and facilitating new CAM and cancer research (Balneaves et al., 2012; CAMEO Program, n.d.). While the focus of most integrative oncology programs has been providing CAM therapies to patients living with cancer, the CAMEO research program uniquely focused on the development and evaluation of a variety of knowledge translation interventions, including education and decision support programs on CAM for patients, support persons, and HCPs (Balneaves et al., 2012). The CAMEO research program attempted to fill a gap in not only providing evidence-based information about CAM to patients and their support persons but also providing decision support to help them navigate this material in a way that considers the evidence while acknowledging their beliefs and values. Although no longer a physical entity, CAMEO continues to maintain an online presence with courses for cancer patients and oncology HCPs as well as links to reputable sites for the public.

The education and decision support interventions developed by CAMEO were informed by SDM and previous research conducted by the research team on the CAM information and decision support needs of people living with cancer and their support persons. These interventions included in-person and online patient and HCP education programs on CAM, one-on-one counseling for patients with complex decision-making needs, written and educational material on CAM decision making, and decision aids ([cameoprogram.org](http://cameoprogram.org)). The CAMEO research program also collaborated with the TBCC to develop education material for their HCPs. CAMEO filled a gap for support persons; while

many of the integrative health programs in North America included support persons in their education programs, most of the centres did not have the aim of providing decisional support services to patients and their support persons.

After reviewing the various integrative oncology centres and programs, with the exception of the CAMEO research program, a gap exists in how cancer patients and their family members and caregivers are supported in making evidence-informed treatment decisions regarding CAM. While many of the integrative oncology programs offer therapy monographs and links to evidence-based resources, patients and support persons can be easily overwhelmed by the amount of information available and, thus, be unable to apply this knowledge to their treatment decision. Interactive education resources that focus specifically on how to make safe and informed treatment decisions about CAM are lacking. Instead, existing integrative oncology programs provide static education focused on specific therapies, making patients responsible for identifying which therapy would best meet their needs and not cause harm. The development and evaluation of decision support education is needed to determine the impact of such interventions on both patients and support persons.

### **Cancer Patients' CAM Decision-Making Process**

Decision making is a complex and individualized process for cancer patients that occurs at various time points in the cancer journey and proceeds through a series of distinct phases (Balneaves et al., 2007; Reyna, Nelson, Han & Pignone, 2015; Weeks et al., 2014). In an integrative review of 35 studies focusing on CAM decision making, Weeks et al. (2014) divided the decision-making processes into three phases: early, mid, and late.

The early phase of decision making begins immediately after diagnosis or a recurrence of cancer (Weeks et al., 2014). This phase involves gathering information and evaluating various CAM therapies and the benefits and risks associated with each (Weeks et

al., 2014). The speed at which an individual moves through this phase of decision making is dependent on their previous experience with CAM (Weeks et al., 2014). Those who have used CAM therapies in the past tend to be less conflicted and overwhelmed with the available information (Weeks et al., 2014). In contrast, those with less experience with CAM tend to need more time to find information and evaluate the possible role of CAM therapies in their cancer journey (Weeks et al., 2014).

The next stage of the decision-making process is the mid phase, which has been framed as the maintenance phase of decision making (Weeks et al., 2014). This phase is focused on finding CAM therapies that fit cancer patients' needs and beliefs while supporting and maintaining their overall wellbeing and health (Weeks et al., 2014). Patients typically move into this phase of decision making after experiencing something positive in their cancer journey, for example, the psychological acceptance of their cancer diagnosis or completion of conventional treatment (Weeks et al., 2014).

The last phase of CAM decision making is called the late phase (Weeks et al., 2014). In this phase, patients and support persons are gathering and evaluating information about CAM again, but with less urgency than the early phase as the late phase occurs at the end of treatment when patients either move into survivorship or palliative care (Weeks et al., 2014).

### **Conflict in Decision Making**

In a study by Balneaves et al. (2007), the authors addressed the decision-making needs of women with breast cancer and developed the "Bridging the Gap" model, which described how the women navigated decision making within conventional medicine and CAM. It was found patients frequently experienced conflict during the decision-making process and three styles were identified that capture how patients navigate conflict:

1) “Taking it one step at a time”; 2) “Playing it safe”; 3) “Bringing it all together” (p. 979-980).

Patients classified as “taking it one step at a time” were overwhelmed by the amount of information about CAM they uncovered, and required time to contemplate their treatment decisions (Balneaves et al., 2007). These patients experienced high anxiety resulting from the conflict they experienced when trying to implement CAM therapies as part of their cancer care (Balneaves et al., 2007). As a consequence of this conflict, patients decided to postpone their use of CAM therapies until they had more time investigate the possible benefits and risks (Balneaves et al., 2007).

The second style of decision making, “playing it safe,” was seen in patients with limited CAM experience and a high level of trust in conventional medicine (Balneaves et al., 2007). These patients had less experience with CAM, were doubtful of the benefits of CAM, and concerned with the associated risks (Balneaves et al., 2007). As a result, the women in this group avoided CAM practitioners and stayed within the realm of conventional medicine, only considering CAM therapy that could be used safely alongside their conventional medicine (Balneaves et al., 2007).

In the third decision-making style, “bringing it all together”, patients were able to successfully merge their CAM and conventional medicine decisions (Balneaves et al., 2007). These patients reported an extensive history of CAM use and wanted to treat cancer in a way that would address their whole being (Balneaves et al., 2007). These patients were confident decision makers who relied on their intuition, trusted sources of information, and a personal network of support persons and HCPs (Balneaves et al., 2007).

## **Health-Information Seeking Behaviour**

Seeking health information has been identified as a key coping strategy used by patients to mentally adjust to their illness and to promote personal health (Lambert & Loiselle, 2007). Information seeking occurs across all phases of decision making and has a definitive pattern during each phase (Weeks et al., 2014). Lambert and Loiselle (2007) analyzed various studies from 1984 to 2003 to understand how and why the general public and people with illnesses seek health information, as well as from where individuals attempt to obtain such information, the particular types of information preferred, and how the information will be used in a particular health setting (Lambert & Loiselle, 2007). The review found that many people sought information to help them cope with health threats whereas other individuals avoided information and were passive in their information-seeking behaviour (Lambert & Loiselle, 2007). Across the studies, Lambert and Loiselle (2007) found that information varied in terms of specificity and sought from a combination of personal (e.g., family, friends) and impersonal (e.g., Internet, books) sources. From their analysis of literature, the authors also found HCPs were desired sources when seeking medical facts, potentially due to the belief that HCPs can provide unbiased and reliable information (Lambert & Loiselle, 2007). Overall, it was perceived that health-information seeking behaviour is beneficial to many individuals by allowing them to participate in the decision making surrounding their medical care (Lambert & Loiselle, 2007). However, at times, patients reported being too fatigued to cope with the amount of information they found and they relied on support persons to assist them in their search and understanding.

In a qualitative study of 34 male cancer patients using CAM, Evans et al. (2007) found patients were either proactively seeking or passively receiving information. The degree of involvement in information seeking was dependent on a patient's type and stage of cancer

(Evans et al., 2007). In those men who took a proactive approach, individuals who had common cancers were more likely to actively seek information on supportive CAM therapies while those who had rare or more advanced cancers were more likely to look for evidence on curative CAM therapies (Evans et al., 2007). Passive recipients of information were evenly divided between those who had used CAM therapies prior to their cancer diagnosis and those who were new to using CAM therapies (Evans et al., 2007). These individuals tended to use the CAM therapies they first encountered during their cancer journey. Overall, men in this study relied predominately on personal information sources, especially women (i.e., wives and daughters), and traditional sources, such as books and magazines (Evans et al., 2007).

### **Role of the Support Person in the CAM Decision-Making Process**

An important piece of the decision-making puzzle concerns who assists patients in making treatment decisions. Personal autonomy is a traditional and individualistic approach that assumes people are able to make decisions based on their own knowledge and values (Bell & Balneaves, 2015; Walter & Ross, 2014). In a paternalistic model of care in which physicians make decisions on the patient's behalf, personal autonomy allows patients to receive information from their physician and jointly make decisions regarding care (Walter & Ross, 2014). The newer concept of relational autonomy, however, includes a support person in the decision-making process. Relational autonomy shifts the focus away from the individual, instead acknowledging a person's social, political, and emotional context as well the importance of meaningful relationships and social situations (Bell & Balneaves, 2015; Sherwin & Winsby, 2011; Walter & Ross, 2014). Relational autonomy acknowledges the major role others such as family members, friends, and peers have in decision making (Walter & Ross, 2014).

Not surprisingly, when patients are gathering information about cancer treatment modalities, CAM or conventional, their decisions are not made in isolation (Sherwin & Winsby, 2011; van Nistelrooij et al., 2017). Patients are part of a larger social network, including support persons who provide emotional support during the cancer journey and assist the patient in making sense of information and reaching treatment decisions (Öhlén et al., 2006; Sherwin & Winsby, 2011; Smith et al., 2014; van Nistelrooij et al., 2017). Some support persons' involvement in the decision-making process is at the request of the patient. For other support persons, their involvement is self-initiated as a way to offer support to the patient during their cancer experience (Öhlén et al., 2006). Support person involvement in the decision-making process can be influenced by the relationship between the patient and the support person and the demographics of the patient and support person (e.g., gender, culture, and age) (Boehmer & Clark, 2001; Laidsaar-Powell et al., 2016; Öhlén et al., 2006).

Overall, there has been limited research on the role of the support person in treatment decision making in conventional and CAM cancer care. In an early article, Hilton (1994) described the family decision-making processes about conventional treatment in the context of breast cancer, identifying four types of family decision making: “1) Deferring to the physician; 2) Minimal exploration; 3) Joint engagement; and 4) Extensive examination” (p. 10). In deferring to the physician, patient involvement in treatment decisions was relatively passive as they preferred to be told what to do by their physician and the support person was not involved in the process (Hilton, 1994). In minimal exploration, both the patient and support person remained quite passive in their involvement in treatment decisions, which were generally physician-directed (Hilton, 1994). Unlike the previous decision-making processes that were quite passive in terms of seeking additional information, in the joint engagement process, patients were moderately active in seeking information and the support

persons were involved in treatment decisions (Hilton, 1994). In the final process, extensive examination, information-seeking behavior was extensive and support persons were very engaged in the decision (Hilton, 1994). These last two processes involved more complex diagnoses and decision making, and often involved younger and more educated patients and support persons (Hilton, 1994).

Laidsaar-Powell et al. (2016) identified four phases of family involvement in cancer patients' decision making: pre-consultation preparation, information exchange, deliberation, and decision. The pre-consultation preparation involved the selection of an oncologist and treatment centre as well as researching and discussing the disease and potential treatment options (Laidsaar-Powell et al., 2016). The information exchange phase included information assistance for the patient (e.g., note taking at physician consultations, recalling information presented by HCP) and for the HCP (e.g., providing the patient's medical information) (Laidsaar-Powell et al., 2016). The information exchange phase occurred both within and outside of consultations to assist patients with interpreting and understanding information about their cancer treatments (Laidsaar-Powell et al., 2016). The deliberation phase was considered to be beneficial for most patients and included the support persons acting as a sounding board and supporting the patient's wishes about treatment (Laidsaar-Powell et al., 2016). A post-decision deliberation phase allowed for reevaluation and analysis of previous decisions to reassure the patient that the correct decision has been made. In this phase, the family member offered support by listening (Laidsaar-Powell et al., 2016). In the final decision phase, Laidsaar-Powell et al. (2016) identified four levels of family involvement: 1) No family involvement; 2) Family involvement through proximal actions; 3) Shared patient and family influence; 4) Controlling family influence. When there is no family involvement, the physician and patient make the decisions regarding care. When a family member

contributes to a decision through proximal actions, the family member typically wants to help the patient sort through information and be a sounding board; however, the family member does not want to influence the patient's decision. In the shared family influence phase, it is a joint decision made by the family member and the patient. The final level involves the family member as the dominant and controlling decision maker (Laidsaar-Powell et al., 2016), which sometimes occurs due to the support person and patient's personalities and, at other times, because the patient is too fatigued or sick to make their own decisions.

In the only article focused on the role of the support person in CAM decision making, Öhlén et al. (2006) found four ways that support persons were involved in patients' CAM decision making: 1) Creating a safe place for the patient to make a decision; 2) "Becoming a team" for collaborative decision making; 3) "Moving the patient toward a decision"; 4) "Making the decision for the patient" (p. 1628). The first type of decisional involvement had the support person creating a safe place for the patient to make a decision by becoming an active listener and unbiased resource and respecting that the patient is capable of making a good decision and will do so on a private journey uninfluenced by others (Öhlén et al., 2006). The second type of decisional involvement, collaborative decision making, required the patient and the support person to become a team and work together to make a CAM decision (Öhlén et al., 2006). The third type of decisional involvement focused on moving the patient toward a decision, with the support persons encouraging the patient to make a CAM decision by either using the support person's preferred therapy or not using any CAM therapy (Öhlén et al., 2006). In the last type of decisional involvement, the support person made the decision for the patient, often without the patient's consent (Öhlén et al., 2006), based on the support person's own beliefs and knowledge. This paternalistic form of decisional involvement often creates conflict between the patient and support person (Öhlén et al., 2006).

In examining the limited body of research on the role of the support person in the treatment decision-making process, it is apparent that many support persons play a key role in finding, evaluating, and discussing information about treatment options with patients. As such, it is integral that not only patients, but their family members, friends, and peers be engaged in education about both conventional and CAM therapies and acknowledged as being part of the treatment decision-making process.

### **Conclusion**

CAM therapies are viewed by many individuals living with cancer as being an important part of their cancer care, enhancing the effects of conventional medicine and improving their overall quality of life. Thus, it is not surprising that many patients seek information and support in making safe and informed decisions about CAM therapies during their illness experience. People living with cancer, however, do not make treatment decisions in isolation. Family members, friends, and other support persons take on myriad roles in the treatment decision-making process, including seeking health information, evaluating the available evidence, and being a sounding board for patients. As such, both patients and support persons require assistance in finding credible, evidence-based information about CAM to enable them to make well-informed treatment decisions that reflect the values and beliefs of the patient. This thesis is focused on the role of the support person in the CAM decision-making process and the impact of an education program on key decisional outcomes.

## **CHAPTER 3 – METHODOLOGY**

### **Study Design**

A pre-post survey design was used in this secondary data analysis to examine the effect of an education seminar for adult cancer patients and their support persons on the support persons' use of CAM, their knowledge about CAM and CAM decision making, their information-seeking behaviour and decision-making outcomes. The support person's CAM knowledge was the primary outcome for this thesis. Secondary outcomes included CAM use and those that assessed the decision-making experience (i.e., decision conflict, decision self-efficacy, and distress).

### **Recruitment and Sampling**

The initial method of recruitment for the study from which the data were drawn for the analysis involved inviting patients who previously contacted the CAMEO research program for support and indicated their desire to be contacted about future research studies. The patients who contacted the CAMEO research program came from four regional cancer centres associated with the BCCA and located throughout the Canadian province of British Columbia. An invitation letter was mailed to those who expressed interest in participating in the CAM education seminar, encouraging them to contact the CAMEO program director if they were interested in taking part in the study. The next phase of recruitment began one week after the initial recruitment phase. General recruitment occurred via the CAMEO research program website, which displayed a description of the study and information about how to register. The general recruitment phase also involved the use of study postcards, which were placed in the waiting room areas in the largest regional cancer centre of the

BCCA, the VC-BCCA, and distributed to HCPs at VC-BCCA to give to patients inquiring about CAM.

Patients who expressed interest in the patient education seminar were asked if they had a support person who would also like to attend the seminar. Both patients and support persons were given consent forms (as shown in Appendix 1) that described the study's purpose and procedures. The consent forms were to be completed by both patients and support persons prior to attending the education seminar.

### **Inclusion Criteria**

The inclusion criteria for support persons participating in the primary study included being a support person who was 18 years or older and had the ability to read and speak English and give written consent to participate. It is important to note that patients who attended the CAMEO patient education seminar with their support persons were within five years of an initial diagnosis of cancer or recurrence of cancer. Support persons were defined by the patients and included family members, spouses, friends, partners, and peers.

### **Exclusion Criteria**

The exclusion criteria for participants in the primary study included individuals who did not speak or read English, were under the age of 18 years, and were unable to provide consent.

### **Intervention**

The patients and support persons participated in a four-hour education seminar at one of the four BCCA regional cancer centres. The education seminar was informed by a 2008 survey of patients receiving care at VC-BCCA. Patients who participated in this survey reported having significant information needs related to CAM, including the efficacy of CAM therapies, the safety of using CAM during the cancer journey, and how to safely

integrate CAM with conventional cancer treatment. Patients indicated they would be willing to access a variety of education and decision support services, including an in-person education seminar, if made available at the BCCA.

The CAMEO research program education seminar had a number of components. The purpose of the education seminar was to provide information that would assist in decision making regarding CAM use, rather than focusing on specific CAM therapies. Participants were introduced to strategies to make informed decisions about CAM therapies and the importance of discussing these therapies with their HCP. General information on CAM therapies was based on the Society of Integrative Oncology Guidelines for cancer patients<sup>2</sup> (Deng et al., 2007). Drawing on the Society of Integrative Oncology Guidelines, potential risks and benefits of various types of CAM therapies (i.e., NHPs, mind-body therapies, body-based therapies, energy therapies, and whole systems) were discussed. The education seminar also reviewed the SCOPED Framework,<sup>3</sup> a decision tool developed by Dr. Jeffery Belkora that has been used with cancer populations to support informed treatment decision making in clinical cancer settings as well as online (Belkora, 2016; Yao et al., 2017).

Participants were given links to evidence-based websites to support them in making future CAM decisions. A CAM use diary was also given to all participants to help them monitor their use of CAM over time, including dose and frequency, side effects (including possible interactions with conventional medicine), and patient-reported outcomes of CAM

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<sup>2</sup> Society of Integrative Oncology Guidelines were among the first published evidence-based guidelines in the field of integrative oncology. The guidelines summarized and rated the existing evidence on various CAM therapies using rigorous systematic literature reviews, as well as considering the potential risks versus benefits, and the practicality and value of offering a therapy within a cancer care setting (<https://integrativeonc.org/integrative-oncology-guidelines>).

<sup>3</sup> SCOPED is an acronym for Situation, Choices, Objectives, People, Evaluation, and Decision.

use. The aim of the information documented in the diaries was to help patients determine if their treatment goals were being met, and facilitate discussions with HCPs about CAM use. To wrap up the education seminar, participants were provided credible, evidence-based information on specific CAM therapies that, prior to the seminar, they had identified as being interested in learning more about.

Across the four provincial cancer centres, a total of 12 education seminars were held over a 3-year time period. An effort was made to ensure the information and education material provided was consistent in content and presentation in all of the seminars, with the exception of the questions raised by participants about specific CAM therapies. Patients and support persons were encouraged to ask questions about any aspect of CAM. The CAMEO research team facilitated the education seminars, drawing on the experience of three registered nurses who had each worked in the oncology field for over 10 years and had some research experience, a PhD-prepared nurse scientist with expertise in CAM, and a former CAM practitioner who was also the CAMEO research program project director. Participants were provided with a 30-minute break with refreshments and access to a quiet room with yoga mats.

### **Data Collection**

**Baseline survey.** Initially in the primary study, the baseline survey was given to patients and support persons to complete in-person just before the start of the education seminar at the BCCA regional site. Some participants, however, needed a substantial amount of time to complete the baseline survey. This was especially the case with participants who used numerous NHPs and wanted to accurately document the name of the product and dose on the survey. As a result, the initial protocol was revised and the baseline survey was

emailed or mailed to participants one week prior to the education seminar for them to complete at home and return either via email or by bringing a hard copy to the seminar.

The language in the patients' and support persons' baseline surveys varied slightly to reflect the patient's or support person's perspective. Two additional items were added to the support persons' survey to differentiate their CAM information needs from those of patients (refer to Appendix 2 for a copy of the baseline survey).

**Follow-up survey.** One month after the education seminar, patients and support persons received a follow-up survey with an addressed stamped return envelope. The support persons' post-education seminar survey was almost identical to the initial baseline survey but with altered language to reflect the passage of time and the impact of the education seminar on their knowledge and CAM use behaviour (refer to Appendix 3 for a copy of the follow-up survey). Also included in the follow-up package was an evaluation form to gain insight regarding participants' satisfaction with the education seminar. To increase the response rate, reminder emails and/or phone calls occurred at two- and four-week intervals after the initial distribution of the follow-up survey.

### **Data Collection Instruments**

Six measurement scales were integrated into the baseline and follow-up surveys used in the primary study: a CAM use survey, a CAM information-seeking behaviour survey, a CAM knowledge scale, two decisional outcomes scales (i.e., decision self-efficacy and decisional conflict), and a distress scale (refer to Appendices 2 and 3 for these measurement scales). The baseline survey also included a demographic form.

**Complementary therapy use survey.** The Complementary Therapy Use Survey was developed by the CAMEO research team based on a previous survey developed by Balneaves et al. (1999) and informed by other CAM surveys (Balneaves et al., 2012). This survey

included 18 closed-ended items that assessed support persons' use of various CAM therapies and practitioners using a "yes" or "no" response. An open-ended question was included to capture any CAM therapies or practitioners not listed.

**Seeking information about complementary therapies scale.** The second scale assessed how participants sought information about CAM. It was divided into four sections, with each section containing close-ended items with a dichotomous response format (yes/no) and an open-ended item that allowed participants to identify additional options. The first section consisted of 10 items that assessed where support persons had looked for CAM information over the past month. The next section comprised 10 items that assessed which HCPs at BCCA were consulted by support persons about CAM. The third section included six items that assessed which community HCPs were consulted by support persons about CAM. The last section of this survey asked support persons to identify which websites they had used within the last month from a list of eight evidence-based CAM websites, a general search engine, and an open-ended item for additional websites.

**CAM knowledge scale.** The CAMEO research team developed the CAM Knowledge Scale, which assessed support persons' understanding of the content reviewed in the education seminars during the primary study. This included knowledge about CAM therapies and how to make informed decisions about CAM. The CAM Knowledge Scale consisted of 10 items with a Likert-type response scale (0 being "not at all knowledgeable" and 4 being "very knowledgeable"). The CAM Knowledge Scale was an investigator-developed instrument that was used for the first time in the primary study. To test the reliability of the scale, a Cronbach's alpha was calculated, which is a common measure of internal consistency (Field, 2013). Assessing the scale's reliability is important because if a different result is

found every time an instrument is used, it is impossible for the results of that scale to be considered valid.

**Decision self-efficacy scale.** This scale was originally derived from Bandura's concept of self-efficacy (1977), and was developed by Dr. Annette O'Connor to capture the social properties of the decision-making process (O'Connor, 1995 [modified 2002]). In addition, the Decision Self-Efficacy Scale measures the impact of decision aids on patients' decision making and assess an individual's confidence in their ability to make decisions (Bunn & O'Connor, 1996; Cranney et al., 2002; O'Connor, 1995 [modified 2002]). Prior research has supported this tool's internal consistency, with a Cronbach's alpha of .89 (Bunn & O'Connor, 1996).

For the purpose of this primary study, the Decision Self-Efficacy scale was slightly modified to reflect support persons' confidence in their ability to support a patient in making CAM decisions. The scale comprised 11 items and a 0 to 4 response scale, with 0 being "not at all confident" and 4 being "very confident." An open-ended question was included following the scale to identify a specific CAM decision that the support person and patient were thinking about that day. In the follow-up survey, participants were asked to reflect on this specific CAM therapy decision and indicate at what stage of the decision-making process they were with regards to making the decision. This latter outcome was not analyzed in this thesis.

**Decisional conflict scale.** This scale was originally derived from the decisional conflict construct by Janis and Mann (1977), but was further developed by Dr. Annette O'Connor to measure the cognitive process involved in decision making (Bunn & O'Connor, 1996). Decisional conflict has been defined as the uncertainty that is experienced in response to a particular sequence of events (Bunn & O'Connor, 1996; LeBlanc, Kenny, O'Connor &

Légaré, 2009; O'Connor, 1995 [modified 2002]). Decisional conflict increases when people are concerned about making an ineffective decision, feel uninformed or unsupported, have personal values that are unclear, or are faced with decisions that are high risk (Bunn & O'Connor, 1996; LeBlanc et al., 2009; O'Connor, 1995 [modified 2002]). High decisional conflict is linked to higher distress (Bunn & O'Connor, 1996; LeBlanc et al., 2009; O'Connor, 1995 [modified 2002]), and it can cause people to delay a decision out of concern about making the wrong choice.

The Decisional Conflict Scale was developed initially because there was an absence of tools to assess the effectiveness of decisional aids and has continued to be used in decision support research to measure the efficacy of interventions (O'Connor, 1995 [modified 2002]). The scale measures personal opinions related to the uncertainty of taking a specific course of action (e.g., making a decision) (O'Connor, 1995 [modified 2002]). Factors that contribute to decisional conflict but can be changed include feeling uninformed, personal ambiguity in values and beliefs while attempting to make a decision, and feeling unsupported in decision making (O'Connor, 1995 [modified 2002]). Patients who feel more supported, informed, and guided in their decision making have been found to report less stress and be more satisfied with their choices (Bunn & O'Connor, 1996; LeBlanc et al., 2009; O'Connor, 1995 [modified 2002]).

The low literacy version of the Decisional Conflict Scale, used in the primary study, comprised 10 items with three response categories (i.e., 0 - "yes," 2 - "unsure" and 4 - "no"). The low literacy version has been tested with a group of men eligible for prostate screening and had a reliability alpha coefficient of .80 (Linder et al., 2011).

**Distress scale.** This scale was based on other visual analogue scales of distress that have been widely used in Canada as a screening tool for cancer patients' levels of distress

during their cancer journey (Vodermaier, Linden & Siu, 2009). This one-item scale was modified in the primary CAMEO study to assess support persons' level of distress related to supporting the person living with cancer in making CAM decisions. Participants were asked to rate their distress from 1-10, with 1 being "no distress at all" to 10 being "extreme distress."

**Demographics form.** Developed by the CAMEO research team, this survey assessed key demographic information from support persons and also the patient's disease characteristics.

### **Ethics**

Ethical approval for the primary study (the CAMEO research program) was received from UBC and the BCCA (H09-01382). Refer to Appendix 4 for the ethics application, approved in 2009. Confidentiality was maintained throughout the study by removing all identifying information from study material and creating identification codes for each participant. Only research team members had access to the file linking identification codes to participants' identifying information and this information was stored in a password-protected electronic file on a firewalled server within the UBC School of Nursing. Participants were made aware they were free to withdraw from the study at any time and were free to leave the education seminar if at any time they were uncomfortable or no longer wished to participate. The participants were also informed that their participation or decision not to participate in the study would not affect their care at the BCCA.

### **Statistical Analysis**

**Missing data and imputation.** As with any research, the data needed to be carefully reviewed prior to analysis. Some inconsistencies were identified in the data entry when initial

descriptive statistics were conducted. As a result, many of the surveys had to be checked against the entered data and many surveys had to be re-entered.

Given the length of the survey, it was not surprising that some of the participants did not fully complete both the baseline and follow-up surveys. To address the issue of missing data while attempting to maintain the sample size needed to permit inferential statistics, it was decided that on any scales where participants answered less than 15% of the items, their data would be deleted from that particular section in either the baseline or follow-up survey (Polit & Beck, 2010). Imputation of the data was considered; however, it was decided that this was beyond the scope of this Master's thesis.

**Psychometric testing.** Psychometric testing evaluates the validity and reliability of an instrument. In this secondary analysis, psychometric testing was undertaken on the CAM Knowledge Scale and focused on reliability. With regards to validity, the CAM Knowledge Scale was developed based on qualitative research conducted by the principal investigator of the CAMEO research program (Dr. Balneaves) and was reviewed for face validity by experts in the CAM field.

The reliability of the CAM Knowledge Scale was assessed using Cronbach's alpha. Cronbach's alpha can range from 0 to 1, with results closer to 1 indicating a higher internal consistency; .70 is traditionally set as a criterion for reliability (Field, 2013). In the study, the baseline and follow-up CAM Knowledge Scale demonstrated high internal consistency, with Cronbach's alpha scores of .89 and .93, respectively. Inter-item correlations were conducted to determine the internal consistency of the scale. According to Field (2013), all inter-item correlations should be positively scored between .3 and .5 to demonstrate internal reliability of a scale. There were two items on the baseline survey that had a negative inter-item correlation of -.008 ("Which health professionals at the BCCA to talk to when making

decisions about complementary therapies” and “Which complementary therapies I have to pay for out of my own pocket”), which may be a reflection of the small sample size in this study. Given the strong inter-item correlations along other scale items and the desire to preserve the integrity of the scale, the decision was made to retain both items.

**Descriptive statistics.** Descriptive statistics were used in this secondary data analysis to summarize the key study variables assessed in the baseline and follow-up surveys.

Descriptive statistics allow researchers to summarize the characteristics of the sample and key study outcomes in a convenient, easily read manner (Polit & Beck, 2010). Descriptive statistics employed in this study included means, standard deviations, and correlations. The mean is the sum of all the scores divided by the number of scores and is typically referred to as the average (Polit & Beck, 2010). This statistic was used to summarize the average baseline and follow-up responses of participants across key study variables, including the number of CAM therapies used, self-efficacy in decision making, decisional conflict, and distress. The standard deviation is a descriptive statistic to analyze the average extent of deviation of values from the mean; every score is used to calculate the value (Polit & Beck, 2010). This statistic was used to determine the degree of variability in the data and were calculated to accompany each mean score.

**Inferential statistics.** Several inferential statistical tests were undertaken in order to answer the main research questions related to the effect of the education seminar on support persons’ CAM use, knowledge, information-seeking behavior, and decisional outcomes. Inferential statistics attempt to reach conclusions beyond viewing the initial data (Polit & Beck, 2010).

**Paired t-test.** This test was used to analyze if support persons experienced a significant difference on study outcomes (ordinal or ratio-level variables) that were assessed

on the baseline and follow-up surveys following participation in the education seminar. A paired t-test was conducted as participants acted as their own control. The paired t-test was used on the data derived from the CAM Knowledge, Decision Self-Efficacy and the Decisional Conflict scales.

As there is limited research on support persons and CAM education, secondary data analysis was conducted on every item across study instruments; to avoid the risk of a Type 1 error, the Bonferroni Correction Method was conservatively applied. The Bonferroni Correction Method is an adjustment made to the p-value and was used in conducting the paired t-tests to counteract the potential for Type 1 errors (false positive result) due to conducting multiple comparisons using a single data set. Using a correction increases confidence that any significant study findings identified are true and not by chance (Field, 2013). The Bonferroni Correction Method was calculated by dividing the level of significance set for each analysis (set at  $p = .05$  for this study) by the number of comparisons (i.e., items per scale). For example, in the Complementary Therapy Use analysis, there were 19 items on the scale, so the Bonferroni Correction Method was  $.05/19 = .0026$ . As such, a comparison was considered significant if the associated p-value was less than .0026.

***McNemar test.*** This inferential statistical test is used for nominal-level data and when comparing two related, dichotomous groups (Polit & Beck, 2010). It was used specifically in this secondary data analysis to compare participants' baseline and follow-up scores on the Complementary Therapy Use and Seeking Information About Complementary Therapies scales (Field, 2013). Significance was set at  $p\text{-value} < .05$ .

***Wilcoxon signed test.*** This non-parametric inferential statistic is used to compare two related samples on a single sample (Polit & Beck, 2010). In this secondary data analysis, the Wilcoxon signed test was used to compare the baseline and follow-up surveys with regards to

the CAM Knowledge, Decision Self-Efficacy, and Decisional Conflict scales. Significance was set at  $p\text{-value} < .05$ .

### **Conclusion**

A pre-post study design was used to examine the impact of attending an educational seminar, focused on the safe use of CAM in the context of cancer, on people living with cancer and their support persons. A secondary data analysis was conducted that used descriptive and inferential statistics to examine the effect of the education seminar on support persons' CAM knowledge, as well as use of CAM and decisional outcomes. The following chapter will present the results of this secondary data analysis.

## CHAPTER 4 – RESULTS AND FINDINGS

### Characteristics of Support Persons

A total of 62 support persons participated in the CAMEO education seminar. The majority were between 50 and 69 years old, with a mean age of 56.6 years. There was almost an equal split between male and female participants (46.8% and 51.6%, respectively), with the majority of support persons being spouses of the patients who took part in the education seminar. The sample was well educated, with 69.3% reporting some level of university education. Just over 88.0% of the sample spoke English as their primary language at home. While the most common cancer diagnosis experienced by the patient was breast cancer (22.6%), a wide diversity of diagnoses was represented. Table 1 provides additional socio-demographic characteristics of the sample.

**Table 1 Characteristics of Study Participants (N=62)**

Characteristics	Frequency
Age (years)	Mean = 56.6
Less than 30	1 (1.6%)
30-49	16 (25.8%)
50-69	34 (51.6%)
70-89	11 (17.7%)
Gender	
Male	29 (46.8%)
Female	32 (51.6%)
Transgender	1 (1.6%)
Language spoken most often	
English	55 (88.7%)
Chinese	6 (9.7%)
Ukrainian	1 (1.6%)

Characteristics	Frequency
<b>Education</b>	
Some high school	2 (3.2%)
High school diploma	4 (6.5%)
Some college / trade school	5 (8.1%)
College / trade school diploma	8 (12.9%)
Some university	10 (16.1%)
Undergraduate degree	22 (35.5%)
Graduate degree (Master's, PhD)	11 (17.7%)
<b>Relationship to cancer patient<sup>a</sup></b>	
Spouse / partner	43 (69.4%)
Parent	7 (11.3%)
Sibling	4 (6.5%)
Friend	3 (4.8%)
Other	4 (6.5%)
<b>Patient's type of cancer</b>	
Breast	14 (22.6%)
Prostate	5 (8.1%)
Lung	9 (14.5%)
Colorectal	9 (14.5%)
Gynecological	6 (9.7%)
Gastrointestinal	2 (3.2%)
Head and neck	2 (3.2%)
Blood cancers	6 (9.7%)
Skin	3 (4.8%)
Other	6 (9.7%)

<sup>a</sup>N=61 in this category, because of missing data.

## Use of CAM by Support Persons

The four most frequently reported CAM therapies used by support persons at both baseline and follow-up were vitamin and mineral supplements, herbal therapies, other dietary supplements, and special foods or diets, as shown in Table 2. Following application of the Bonferroni Correction Factor, no significant differences between baseline and follow-up with regard to CAM use were reported among the support persons. Meditation, however, did approach significance (p-value = .004).

Table 3 summarizes the total number of CAM therapies used by support persons at baseline and follow-up. There was no significant change in number of CAM therapies used following the education seminar.

Table 4 illustrates the mean number of CAM therapies that were currently being used at baseline and follow-up. Support persons reported using an average of 3.7 CAM therapies at baseline, and 4.3 therapies at follow-up, suggesting a slight increase in CAM use following the education seminar. This difference, however, was not significant (p-value = .26).

**Table 2 Comparison of CAM Use at Baseline and Follow-up (N=61)**

CAM therapies	Baseline	Follow-up	p-value
Vitamin and mineral supplements	42 (68.9%)	42 (68.9%)	1.000
Herbal supplements	18 (29.5%)	13 (21.3%)	.302
Other dietary supplements	26 (42.6%)	29 (47.5%)	.549
Special foods / diets	28 (45.9%)	32 (52.5%)	.541
Massage therapy	17 (27.9%)	16 (26.2%)	1.000
Acupuncture	8 (13.1%)	5 (8.2%)	.453
Chiropractic medicine	9 (14.8%)	12 (19.7%)	.375
Naturopathic medicine	5 (8.2%)	12 (19.7%)	.109

CAM therapies	Baseline	Follow-up	p-value
Homeopathic medicine	5 (7.8%)	7 (11.5%)	.727
Traditional Chinese medicine	7 (11.5%)	10 (16.4%)	.508
Qigong	7 (11.5%)	7 (11.5%)	1.000
Reiki	7 (11.5%)	8 (13.1%)	1.000
Yoga	8 (13.1%)	12 (19.7%)	.344
Relaxation therapy	11 (18.0%)	14 (23.0%)	.549
Therapeutic / healing touch	9 (14.8%)	7 (11.5%)	.774
Meditation	10 (16.4%)	23 (37.7%)	.004
Guided imagery	4 (6.6%)	7 (11.5%)	.508
Art therapy	4 (6.6%)	6 (9.8%)	.687
Other CAM therapy	6 (9.8%)	5 (7.8%)	1.000

*Note.* McNemar's Test (Bonferroni Correction Factor, p-value <.0026).

**Table 3 Total Number of CAM Therapies Used at Baseline and Follow-up (N=61)**

Total number of CAM used	Baseline (SD)	Follow-up (SD)
0	11 (18.0%)	11 (18.0%)
1-3	25 (41.0%)	20 (33.0%)
4-6	15 (25.0%)	18 (30.0%)
7+	10 (16.0%)	12 (20.0%)

**Table 4 Difference in CAM Use Before and After Education Seminar (N=61)**

Mean number of CAM therapies used		Mean difference (SD)	95% confidence interval of the difference		t	Sig (2-tailed) p-value
Baseline (SD)	Follow-up (SD)		Lower	Upper		
3.71 (3.42)	4.30 (3.97)	0.59 (4.08)	-1.64	0.46	-1.13	.26

## Sources of CAM Information

Table 5 summarizes where support persons sought information about CAM on behalf of their patients. The primary source of information was the Internet, which was used by 61.0% and 72.0% of the sample at baseline and follow-up, respectively. Family members, friends, and books were also popular sources of CAM information at both time points. No significant difference was found in CAM information sources accessed before and after the education seminar.

**Table 5 Sources of CAM Information (N=59)**

Sources of information	Baseline	Follow-up	p-value
Healthcare professional	24 (40.7%)	20 (33.9%)	.557
Family member and/or friends	31 (52.5%)	26 (44.1%)	.442
Internet	36 (61.0%)	43 (72.9%)	.189
Books	28 (47.5%)	32 (54.2%)	.424
Magazines	22 (37.3%)	16 (27.1%)	.180
Media sources	26 (44.1%)	19 (32.2%)	.143
Scientific journals	11 (18.6%)	11 (18.6%)	1.000
Canadian Cancer Society	22 (37.3%)	23 (39.0%)	1.000
Social support groups	11 (18.6%)	9 (15.3%)	.754
Health food stores	17 (28.8%)	15 (25.4%)	.791
Other	2 (3.4%)	2 (3.4%)	1.000

*Note.* McNemar's Test (Bonferroni Correction Factor, p-value <.0045).

Table 6 summarizes the type of HCPs that support persons used as sources of CAM information both at the BCCA and in the community. At the BCCA, medical oncologists

were the HCPs most frequently consulted about CAM at baseline (37.5%) and follow-up (26.8%). In the community, family physicians were the most popular HCP to seek CAM information from at both baseline (27.3%) and follow-up (29.1%). Support persons also consulted CAM practitioners, including naturopathic physicians and traditional Chinese medicine doctors but at rates lower than conventional HCPs. No significant difference was found between baseline and follow-up regarding which HCPs were used as a source of CAM information.

**Table 6 Healthcare Professionals Used as CAM Information Source**

Healthcare professional	Baseline	Follow-up	p-value
BC Cancer Agency (N=58) <sup>a</sup>			
Medical oncologist	21 (37.5%)	15 (26.8%)	.286
Radiation oncologist	9 (16.1%)	5 (8.9%)	.219
Surgeon	6 (10.7%)	2 (3.6%)	.063
Radiation therapist	6 (10.7%)	2 (3.6%)	.219
Social worker / counselor	6 (10.7%)	5 (8.9%)	1.000
Librarian	3 (5.4%)	2 (3.6%)	1.000
Nurse	10 (17.9%)	10 (17.9%)	1.000
Pharmacist	5 (8.9%)	4 (7.1%)	1.000
Dietitian	4 (7.1%)	3 (5.4%)	1.000
CAMEO staff member	8 (14.3%)	7 (12.5%)	1.000
Other	1 (1.8%)	1 (1.8%)	1.000

Healthcare professional	Baseline	Follow-up	p-value
Community (N=55) <sup>b</sup>			
Family physician	15 (27.3%)	16 (29.1%)	1.000
Pharmacist	11 (20.0%)	8 (14.5%)	.508
Nutritionist / dietitian	6 (10.9%)	2 (3.6%)	.219
Naturopathic physician	10 (18.2%)	5 (9.1%)	.180
Traditional Chinese medicine doctor	8 (14.5%)	8 (14.5%)	1.000
Chiropractor	6 (10.9%)	4 (7.3%)	.625
Other	5 (9.1%)	2 (3.6%)	.375

<sup>a</sup>McNemar's Test (Bonferroni Correction Factor, p-value <.0045).

<sup>b</sup>McNemar's Test (Bonferroni Correction Factor, p-value <.0071).

Websites that support persons used as CAM information resources were also assessed and are presented in Table 7. In the baseline survey, close to 29% of support persons used the CAMEO research program webpage on the BCCA website as their primary source of information. In the follow-up survey, a significantly greater proportion of support persons reported using the CAMEO research program webpage (52.5%; p-value = .004). The Complementary and Alternative Cancer Therapies webpage of the BCCA website was the second most used website for support persons at both baseline (22.0%) and follow-up (32.2%). Memorial Sloan Kettering Cancer Center and Canadian Cancer Society both showed substantial but not significant increase between baseline and follow-up. Over half the sample, however, used general search engines (e.g., Google) both before (54.2%) and after (57.6%) the education seminar to find information about CAM.

**Table 7 Sources of Information - Websites (N=59)**

Websites	Baseline	Follow-up	p-value
CAMEO research program website (BCCA)	17 (28.8%)	31 (52.5%)	.004
Complementary & alternative cancer therapies section of the BCCA website	13 (22.0%)	19 (32.2%)	.286
Natural Standard database	4 (6.8%)	7 (11.9%)	.453
Natural Medicines Comprehensive database	7 (11.9%)	5 (8.5%)	.754
National Centre on Complementary & Alternative Medicine website <sup>a</sup>	4 (6.8%)	8 (13.6%)	.388
Memorial Sloan Kettering Cancer Center's Herbs, Botanicals and other products website <sup>b</sup>	5 (8.5%)	15 (25.4%)	.021
Canadian Cancer Society	10 (16.9%)	16 (27.1%)	.210
MD Anderson Cancer Center	5 (8.5%)	6 (10.2%)	1.000
General search engine (e.g., Google, Yahoo)	32 (54.2%)	34 (57.6%)	.824
Other	2 (3.4%)	1 (1.7%)	1.000

*Note.* McNemar's Test (Bonferroni Correction Factor, p-value <.005).

<sup>a</sup>Website is now National Center for Complementary and Integrative Health.

<sup>b</sup>Website is now MSKCC About Herbs, Botanicals and Other Products.

### **CAM and CAM Decision Making Knowledge**

Table 8 summarizes mean item scores on the CAM knowledge scale before and after the education seminar. Highly significant differences were found between the baseline and follow-up surveys on all items (p-value = .000), with participants demonstrating increased knowledge about CAM and CAM decision making. Table 9 shows the mean total CAM knowledge also increased significantly, from 9.20 at baseline to 22.12 at follow-up (p-value = .000).

**Table 8 CAM and CAM Decision Making Knowledge Questions (N=51)**

Knowledge questions	Baseline mean (SD)	Follow-up mean (SD)	p-value
Where to find evidence about safety and usefulness of CAM	1.24 (1.09)	2.51 (0.93)	.000
Which health professionals at BCCA to talk to regarding decision making	0.69 (0.93)	2.12 (1.19)	.000
Possible risks and benefits about CAM	1.08 (1.07)	2.24 (0.89)	.000
When is it safe to use NHP during cancer treatment	1.12 (1.14)	2.16 (0.97)	.000
How are complementary HCP regulated in BC	0.43 (0.76)	1.84 (1.01)	.000
What questions to ask when selecting a complementary HCP	0.88 (0.95)	2.33 (0.97)	.000
Which complementary therapies have to be paid for	1.10 (1.24)	2.35 (1.11)	.000
Type of research studies should be looked at to help with decision making about CAM	0.94 (1.10)	2.27 (1.08)	.000
Which complementary therapies may be helpful in managing side effects from conventional cancer treatment	0.92 (0.85)	2.27 (0.92)	.000
How to assess whether or not a CAM is helping	0.80 (0.96)	2.02 (1.05)	.000

*Note.* Wilcoxon Signed Two Related Paired Test (Bonferroni Correction Factor, p-value <.005).

**Table 9 CAM Knowledge Total and Difference (N=51)**

Mean knowledge			95% confidence interval of the difference		t	Sig (2-tailed) p-value
Baseline (SD)	Follow-up (SD)	Difference (SD)	Lower	Upper		
9.20 (7.20)	22.12 (7.83)	-12.92 (8.52)	-15.32	-10.52	-10.82	.000

### Decision Making Self-Efficacy

Table 10 summarizes the baseline and follow-up data for support persons' perceived self-efficacy in CAM decision making. Significant differences were found on four of the self-

efficacy items, including being able to “get the facts” about CAM choices and the related risks and benefits, as well as understanding information about CAM to be able to support the person living with cancer make a decision. Using the ODSF scoring, the mean self-efficacy in decision making at baseline was 56.87 and 68.63 at follow-up, reflecting a significant difference (p-value of .002), as shown in Table 11.

**Table 10 Decision Making Self-Efficacy (N=46)**

Self-efficacy items	Baseline mean (SD)	Follow-up mean (SD)	p-value
Get the facts about the complementary therapy choices available	1.93 (1.27)	2.72 (0.91)	.000
Get the facts about the benefits of each choice	1.80 (1.28)	2.70 (0.96)	.000
Get the facts about the risks and side effects of each choice	1.80 (1.26)	2.57 (1.00)	.001
Understand the information enough to be able to support the person living with cancer to make a choice	2.11 (1.23)	2.80 (1.00)	.003
Ask questions without feeling dumb	2.76 (1.25)	3.07 (1.08)	.114
Express my concerns about each choice	2.57 (1.09)	2.78 (1.05)	.213
Ask for advice	2.96 (0.87)	2.80 (1.15)	.499
Figure out what therapy best suits the person living with cancer	1.87 (1.28)	2.35 (0.99)	.021
Help him or her handle unwanted pressure from others while making a choice	2.28 (1.17)	2.74 (1.10)	.012
Support him or her in letting the healthcare team know what’s best for them	2.30 (1.15)	2.78 (0.96)	.018
Support him or her in delaying the decision if they feel they need more time	2.63 (1.16)	2.89 (0.95)	.139

*Note.* Wilcoxon Signed Two Related Paired Test (Bonferroni Correction Factor, p-value <.0045).

**Table 11 Decision Making Self-Efficacy Total and Difference (N=46)**

Mean decision making self-efficacy (ODSF score)			95% confidence interval of the difference		t	Sig (2- tailed) p-value
Baseline (SD)	Follow-up (SD)	Difference (SD)	Lower	Upper		
56.87 (23.09)	68.63 (21.24)	-11.76 (24.28)	-18.97	-4.55	-3.29	.002

**Decisional Conflict**

Table 12 summarizes the baseline and follow-up data on decisional conflict reported by support persons. With the exception of two items—“having enough support from others” and “choosing without pressure from others”—all items demonstrated a significant reduction in decisional conflict following the education seminar.

Table 13 outlines the mean total decisional conflict scores at baseline and follow-up (59.82 and 24.40, respectively) using the ODSF total scores, where 0 equates to no decisional conflict and 100 equates to highest decisional conflict. A significant reduction in total decisional conflict was observed from baseline to follow-up (p-value = .000).

**Table 12 Decisional Conflict (N=27)**

Decision conflict item	Baseline mean (SD)	Follow-up mean (SD)	p-value
Do you know which options are available to you?	2.44 (1.40)	0.37 (0.79)	.000
Do you know the benefit of each option?	2.59 (1.35)	0.89 (1.12)	.000
Do you know the risks and side effects of each option?	2.81 (1.39)	1.04 (1.29)	.000
Are you clear about which benefits matter most to you?	2.22 (1.78)	0.74 (1.26)	.002
Are you clear about which risks and side effects matter most to you?	2.22 (1.70)	1.04 (1.40)	.002

Decision conflict item	Baseline mean (SD)	Follow-up mean (SD)	p-value
Do you have enough support from others to make a choice?	2.07 (1.52)	1.48 (1.72)	.059
Are you choosing without pressure from others?	1.04 (1.51)	0.67 (1.36)	.308
Do you have enough advice to make a choice?	2.89 (1.28)	1.19 (1.39)	.000
Are you clear about the best choice for you?	2.89 (1.28)	1.41 (1.45)	.002
Do you feel sure about what to choose?	2.74 (1.38)	1.41 (1.45)	.002

*Note.* Wilcoxon Signed Two Related Paired Test (Bonferroni Correction Factor, p-value <.005).

**Table 13 Decisional Conflict Mean (N=27)**

Mean decisional conflict ODSF scores			95% confidence interval of the difference		t	Sig (2-tailed) p-value
Baseline (SD)	Follow-up (SD)	Difference (SD)	Lower	Upper		
59.82 (24.40)	25.56 (25.62)	34.26 (26.52)	23.77	44.75	6.71	.000

### **Distress Related to CAM Decision Making**

Table 14 illustrates the distress levels experienced by support persons related to CAM decision making. There was no significant difference in mean distress reported at baseline versus follow-up.

**Table 14 Distress Related to CAM Decision Making (N=34)**

Mean distress			95% confidence interval of the difference		t	Sig (2-tailed) p-value
Baseline (SD)	Follow-up (SD)	Difference (SD)	Lower	Upper		
5.44 (2.96)	5.06 (3.03)	0.38 (3.71)	-0.91	1.68	0.60	.55

## Survey Completion

Table 15 summarizes the percentages of support persons out of a total sample size of 62 that completed the various measurement scales across both the baseline and follow-up surveys. There was a noted lack of complete data in the decisional conflict and distress scales.

**Table 15 Completion of Scales on Both Baseline and Follow-up Surveys**

Scales	Completed baseline and follow-up surveys	
	N	%
CAM use	61	98.0
Sources of CAM information	59	95.0
HCP used as CAM information source (BCCA)	58	94.0
HCP used as CAM information source (community)	55	89.0
Sources of information (websites)	59	95.0
CAM and CAM decision-making knowledge	51	82.0
Decision making self-efficacy	46	74.0
Decisional conflict	27	44.0
Distress	34	55.0

## Conclusion

The most common support person that participated in the education seminar was a spouse or partner to a cancer patient. There was no significant increase in support persons' use of CAM therapies following the education seminar; however, the use of meditation did approach significance. Most people found CAM information using the Internet, but there was a significant increase of people using the CAMEO website to find information after the education seminar. Search engines, such as Google, continued to be popular sources of CAM

information despite recommendations provided during the education seminar to be cautious in using such information sources. Knowledge of CAM and CAM decision making was found to have significantly improved following the education seminar and support persons' confidence in their own CAM decision making significantly increased on four items associated with obtaining and understanding CAM information. With regards to decisional conflict, a significant decrease in conflict was reported following the education seminar; however, more than half of the support persons failed to complete the survey on decisional conflict. There was no significant change in distress reported by support persons as a result of attending the education seminar.

## CHAPTER 5 – DISCUSSION AND CLINICAL IMPLICATIONS

This thesis is one of the first studies of its kind to explore the social context of cancer patients' decisions about CAM therapies. As explored in this thesis, cancer treatment decision making is a relational process that involves support persons, who may include but are not limited to family, friends, and HCPs. The findings of this secondary data analysis provide insight into the impact of engaging support persons in patient education seminars on their knowledge about CAM and treatment decision making, their confidence in supporting cancer patients in making CAM decisions, and their decisional conflict and distress associated with involvement in patients' decision-making process. Support persons' personal use of CAM therapies was also assessed. Such knowledge will inform future education programs focused on CAM use within cancer care and highlight the important role that support persons play in cancer patients' treatment decisions, including those regarding CAM therapies and practitioners.

This discussion will examine in greater depth the study findings and how they relate to previous research as well as future implications for practice, research, and education. Study limitations will also be described.

### **Discussion of Study Findings**

**CAM use by support persons.** The secondary data analysis examined whether attendance at an education seminar on CAM for cancer patients would change support persons' use of CAM therapies. While the survey did not inquire if the support persons had been diagnosed with cancer themselves, their use of CAM is reflective of the national average in Canada, with over 79.0% of the general population reporting the use of at least one CAM therapy in the previous year (Esmail, 2017). Support persons' use of CAM did not

change as a result of taking part in the education seminar; however, the increased use of meditation did approach significance. This increase may have been a result of the persuasive evidence presented during the seminar on the physical and emotional benefits of maintaining a regular meditation practice, particularly in the context of cancer. A recent review of mind-body interventions in cancer care reported that meditation not only promotes a non-judgemental attitude in life, but also decreases stress, anxiety, and depression and increases overall quality of life (Carlson et al., 2017). Educating both patients and their support persons about the purpose of meditation and the potential benefits, as well as the misperceptions associated with this mind-body therapy, may increase the use of meditation (Russell et al., 2017). The non-significant increase in meditation use seen in this study is also reflective of the growing interest in relaxation and mind-body therapies seen in the Canadian population over the last two decades (Esmail, 2017). It is important to note that the small sample size in this study may have caused a Type II analysis error in which the increased use of meditation did not reach significance.

The support persons' reasons for using CAM were not assessed in this study; however, it has been documented that many individuals use CAM therapies not only for chronic ailments but also to maintain wellness, prevent future illnesses, and increase future health and vitality (Esmail, 2017). Support persons of cancer patients may use the cancer diagnosis of their loved ones as a teachable and motivational moment to examine their own health and wellbeing and undertake therapies to address any deficiencies in their own lives (Humpel, Magee & Jones, 2007). Research has also shown that family members often alter their lifestyle behaviours (e.g., diet, exercise, sun exposure, smoking cessation) to demonstrate support for loved ones during their cancer experience and to encourage patients to make similar lifestyle changes (Balneaves et al., 2014; Humpel et al., 2007). As such,

patients' use of CAM may influence support persons and vice versa. CAM use may also be framed as a family experience, reflecting long-standing cultural and health beliefs, or a reflection of the predominance of CAM use in general society. Future research could investigate the relational context of CAM use within families and communities, exploring the impact of culture, health beliefs, social norms, and previous health behaviour on CAM decisions both within and beyond the cancer journey.

**Knowledge about CAM and CAM decision making.** Support persons in this study had a low baseline knowledge about CAM risks and benefits, how to safely use CAM in the context of cancer treatment, and how to make a good decision. Overall, the education seminar was successful in increasing support persons' knowledge about CAM and how to make informed and safe CAM decisions. All the criteria in this section were found significant but there is room for improvement in increasing the knowledge base of support persons. In the future it is important to facilitate continuing education and to engage support persons in education material related to cancer.

**Sources of CAM information.** In examining support persons' information-seeking behaviour about CAM therapies, a variety of information sources were accessed. Internet, family members, and conventional HCPs were identified as being the most common sources of information used by support persons in this study both pre- and post-education seminar. These findings are similar to previous research among the general public as well as cancer patients in terms of where individuals find conventional and CAM information (Arif & Ghezzi, 2017; Holmes, Bishop & Calman, 2017; Oh et al., 2010). For example, in a small study of 11 breast cancer survivors, the Internet was identified as being their primary source of information about CAM therapies (Holmes et al., 2017). Similarly, in a study about male cancer patients, the Internet was named as a primary source of information for the

participants when searching for information about specific CAM (Evans et al., 2007).

Research suggests patients use the Internet to be more engaged and involved in their health care and also to look for additional or alternative treatment options (Holmes, Bishop & Calman, 2017; Lee, Gray & Lewis, 2010; Lee, Hoti, Hughes & Emmerton, 2015).

In our study, despite attending an education seminar presenting a variety of current, evidence-based online resources, including the CAMEO research program website, support persons continued to use general search engines to access websites containing information that may be based on anecdotal and non-empirical evidence or that may not be updated on a regular basis (e.g., the BCCA website on alternative and complementary therapies [<http://www.bccancer.bc.ca/health-info/coping-with-cancer/complementary-alternative-therapies>]). While there are a growing number of credible websites related to CAM therapies, much of the information about CAM on the Internet may be biased and used for marketing purposes (Kim, Lee & Nam, 2009). For example, when CAM therapies are searched for on Google, commercial websites tend to be more visible than government or non-profit agency websites (Arif & Ghezzi, 2017). By using such websites, patients and support persons may make treatment decisions based on poor quality information, leading to safety issues and increased conflict in their decision-making process (Anderson & Klemm, 2008; Kim, Lee & Nam, 2009; Mazzocut et al., 2016; Weber, Derrico, Yoon & Sherwill-Navarro, 2010). In a Korean study that analyzed the quality and content of 119 CAM websites, the authors found some of the websites provided commercialized information and encouraged patients to avoid conventional medicine entirely and not adhere to HCPs' advice (Kim, Lee & Nam, 2009). A recent Italian study uncovered large numbers of patients who do not communicate with their HCPs about their CAM use; instead engaging in informal conversations online (e.g., Facebook) (Mazzocut et al., 2016).

The use of the Internet as a primary source of information about CAM highlights the importance of coaching cancer patients and their support persons on how to identify reliable, trustworthy, and credible information about CAM therapies online (Puts et al., 2017). Puts et al. (2017) also found family members wanted additional written material about recommended treatments, and both patients and family members wished for more clarification about medical terms. The numerous sources of CAM information used by support persons in our study suggest that any future education on CAM should use different modalities to address an individual's preference for written, electronic, and face-to-face communication and information.

NCCIH has attempted to address patients' and support persons' information needs related to CAM through the development of a self-guided webpage that provides instruction on how to search for and identify credible and evidence-based sources of CAM information on the Internet and through social media (<https://nccih.nih.gov/health/webresources>). Patients and support persons must be able to identify information resources about CAM that may be biased, intended for marketing purposes, or are based on questionable evidence. Introducing patients and support persons to programs such as Health on Net (<https://www.healthonnet.org>), a certification program used to identify credible and safe health information on the Internet, may be a useful first step.

Comparable to our study findings, researchers in Australia found conventional HCPs to be one of the most common sources of CAM therapy information for cancer patients (Oh et al., 2010). Unfortunately, as identified in a meta-synthesis of 15 articles, a lack of training and education on CAM therapies inhibits many HCPs from providing balanced information about CAM to patients and families (Hall, Leach, Brosnan & Collins, 2017). This gap in knowledge highlights the need for CAM education for physicians, nurses, and other

conventional HCPs at the undergraduate and continuing education levels. To address this gap, the Academic Consortium for Integrative Health Education was developed in 1999, with the goal to “advance integrative medicine and health through academic institutions and health systems” (<https://www.imconsortium.org>) by supporting academic leaders and students, circulating evidence-based research, information, and education curriculums, and informing healthcare policies (<https://www.imconsortium.org/about/about-us.cfm>). The Academic Consortium for Integrative Health Education has 69 institutional members in North America and has developed a range of education programs targeting undergraduate and post-graduate HCPs. For example, since 1994, the University of Arizona has offered a 2-year distance education fellowship for physicians that focuses on the whole person and preventive medicine and provides training in nutrition, botanicals and dietary supplements, mind-body medicine, and other integrative approaches (<http://integrativemedicine.arizona.edu/education/fellowship/#curriculum>).

In Canada, the Canadian Academic Consortium for Integrative Health Education has recently formed to address CAM and integrative health education at the undergraduate, graduate, and post-graduate levels within medical, pharmacy, and nursing programs across the country. The CAMEO research program also developed an online education program for oncology HCPs that provides basic information about CAM use in cancer care ([www.cameoprogram.org](http://www.cameoprogram.org)).

**CAM and CAM decision making.** The underlying assumption of the CAMEO research program was that CAM decisions occur within a social network and cancer patients share the decision-making experience with important people in their lives, including family members, friends, and trusted healthcare providers. Researchers have found family and friends’ personal stories and recommendations about CAM therapies are often patients’ first

introduction to CAM (Caspi, Koithan & Criddle, 2004; Evans et al., 2007). Offering CAM therapy recommendations is one way support persons demonstrate their concern and try to help their loved ones. Öhlén et al. (2006) found, however, support persons' assistance with CAM decisions can also be a source of tension and conflict for patients, as patients have reported being overwhelmed with information about conventional medicine and CAM, particularly during stressful times in their cancer journey (e.g., newly diagnosed, recurrence), and are strongly encouraged to use therapies that do not fit with their beliefs and preferences (Evans, Sharp & Shaw, 2012; Öhlén et al., 2006; Thorne, Oliffe & Stajduhar, 2013).

Thus, the goal of including support persons in the CAMEO research program education seminar was to ensure that both patients and support persons were “on the same page” regarding how to make informed treatment decisions about CAM, the importance of using evidence-based information, and the possible benefits and risks associated with CAM use. The objective of facilitating a shared understanding of CAM and related evidence was to decrease decisional conflict for both patients and support persons. Future research that compares patients' and support persons' beliefs, knowledge, and preferences related to CAM and the conflict and distress experienced in the decision-making process would allow this hypothesis to be explored.

**Decision making self-efficacy.** The four items on the Decision Making Self-Efficacy Scale that support persons significantly improved on following attendance at the education seminar—get the facts about the CAM choices available, get the facts about benefits of each choice, get the facts about risks and side effects of each choice, and understand the information well enough to be able to support the person living with cancer to make a choice—were among the items that scored the lowest at baseline. This significant change may have been reflective of the fact that support persons felt unprepared or lacked

confidence in being able to find and understand trustworthy information about CAM therapies before attending the seminar. The CAMEO research program education seminar provided support persons not only with the skills required to identify credible sources of CAM information, but also the questions that they should ask before selecting CAM therapies and practitioners. The remaining decisional self-efficacy items scored high both before and after the education seminar, suggesting support persons already felt confident in these aspects of treatment decision making (e.g., ask questions without feeling dumb, ask for advice, express concerns about each choice). As over half of the sample reported having either an undergraduate or graduate degree, they may already have had the skills and knowledge required to be confident in their ability to ask questions and express concerns about their loved one's health care. In addition, it is important to note that the support persons who attended the education seminar were individuals who were interested in seeking more knowledge about CAM therapies; therefore, their overall self-efficacy related to treatment decisions was already well established.

**Decisional conflict.** Previous research has framed support persons as being motivators of CAM use rather than individuals who assist patients with the decision-making process (Öhlén et al., 2006). As has been discussed in this thesis, support persons are an important part of cancer patients' social network – family members, close friends and neighbours provide physical, emotional, informational, and decisional support to individuals undergoing cancer treatment and moving into survivorship. However, conflict can occur between support persons and loved ones during the treatment decision-making process (Öhlén et al., 2006). Support persons have expressed concerns regarding CAM decisions being made without evidence-based information, with some support persons becoming more proactive in the patient's decision making in an attempt to protect the patient from making

poor decisions. This can sometimes lead to conflict in the relationship (Öhlén et al., 2006). Conflict can also arise when support persons and patients hold contradictory beliefs about which treatment options, including CAM therapies, should be used by the patient during the cancer journey (Öhlén et al., 2006). Conflict particularly arises when support persons are unsupportive of CAM use (Öhlén et al., 2006). It is interesting to note that some support persons will at times avoid sharing their viewpoints on CAM therapies to maintain the relationship and demonstrate respect for the patient's autonomy (Öhlén et al., 2006). Conflict and tensions between participants was not examined in this study as the support persons were supportive participants and wanted to learn alongside their loved ones, therefore, the education seminar focused on making people more confident and less conflicted about their CAM decisions.

In the qualitative study conducted by Balneaves et al. (2007) of the CAM decision-making process of women living with breast cancer, participants were found to experience anxiety and frustration, especially when faced with conflicting information about CAM therapies. The authors identified three key types of decisional conflict experienced by breast cancer patients: paradigm, information, and role (Balneaves et al., 2007). Paradigm conflict occurred when the breast cancer patients struggled to bring together the different worlds of CAM and conventional medicine and were faced with conflicting beliefs about CAM therapies and whole person care (Balneaves et al., 2007). Information conflict was experienced when patients were overwhelmed with information, often contradictory, about CAM and conventional treatment options (Balneaves et al., 2007). Lastly, patients in Balneaves et al.'s (2007) study experienced role conflict when they attempted to juggle the various new roles in their lives including cancer patient, information gatherer, and liaison between practitioners and decision maker. Support persons could potentially reduce these

types of conflict experienced by their loved one by first understanding that these various decisional conflicts occur, and secondly, by becoming involved in the decision-making process as described by Öhlén et al. (2006). It will be important to explore in future qualitative research whether support persons also experience the same decisional conflicts when they engage with patients in the CAM decision-making process.

Although we did not explore support persons' experience of conflict in the decision-making process, we did find they reported significantly less decision conflict related to their loved one's CAM decisions following participation in the education seminar. Given the items on the Decision Conflict Scale that were statistically significant (refer to Table 12), it appears that support persons experienced less information conflict related to understanding the appropriate treatment options, risks, benefits, and side effects associated with each option. One of the key principles of the CAMEO research program was for support persons to be as educated as patients about CAM therapies to decrease decisional conflict within families or larger social networks and to ensure support persons provided people living with cancer with decisional support that does not cause harm or undue distress to the patient. The education seminar was successful in decreasing information-based conflict for the support persons, which may subsequently alleviate some of the conflict experienced by patients by virtue of their shared understanding of CAM. It is beneficial to reduce decisional conflict as doing so improves an individual's wellbeing and decision making, thereby reducing decisional regret, emotional distress, and anxiety (O'Connor, 1995). Future research could investigate how allowing the involvement of support persons in patient education seminars impacts the conflict experienced by cancer patients related to the treatment decision-making process.

Despite the education seminar being targeted at cancer patients, it may have also affected support persons' decision making about CAM therapies and practitioners. Given that

one in three Canadians are likely to experience cancer in their lifetime, it is likely that many support persons may have also been cancer patients, or may be diagnosed in the future. The seminar may have provided them with valuable information to manage any current or future CAM decisions they may experience.

**Decisional distress.** The cancer journey has been identified as unlike any other illness trajectory where many decisions are made during the beginning stages of diagnosis, when emotions run high and information content can be overwhelming (Thorne, Oliffe & Stajduhar, 2012). In the past, it was not well recognized that the patient's cancer journey had a major impact on the wellbeing of support persons; however, recent research has shown support persons experience emotional distress and can become overwhelmed (Northouse, Katapodi, Schafenacker & Weiss, 2012). A recent literature review found support persons experience hidden morbidities such as depression, anxiety, and distress, particularly among spouses (Li & Loke, 2013). Support persons experience poor physical health and functioning (Li & Loke, 2013). Social morbidity also occurs in this population and impacts the marital relationships and level of social support received from external supports (Li & Loke, 2013). Across these three types of morbidities, women are typically more affected than men (Li & Loke, 2013). Female support persons are more likely to be distressed than male support persons, likely due to the fact that women may spend more time giving care while receiving less external social support (Hagedoorn, Sanderman, Bolks, Tuinstra & Coyne, 2008; Northouse, Mood, Templin, Mellon & George, 2000; Northouse et al., 2012).

In our study, regarding their engagement in the patient's CAM decision, support persons scored a mean of 5.44 at baseline and 5.06 at follow-up, which is basically in the middle of the distress scale. One possible explanation for this result is support persons did not feel they had as much at stake compared to patients regarding the CAM decision-making

process and, hence, experienced only moderate distress. Alternatively, it is possible that the one-item scale, which has been typically used to measure an individual's general distress, was not nuanced enough to capture the anxiety associated with supporting a patient in making treatment decisions.

### **Limitations of the Study and Recommendations for Future Research**

There are limitations to this thesis. Foremost, as a secondary data analysis, the student was limited with regards to what research questions she could ask and what data was available for the secondary data analysis. Also, as mentioned in Chapter 3, numerous data entry errors were identified during review of the initial dataset, which required the student to re-enter significant portions of the data. However, we are confident that the dataset used in the analysis was accurate as a result of these actions.

Further, the inclusion of patients and support persons in the education seminars who were at different stages of the cancer journey may have resulted in a sample with differing needs related to CAM knowledge and decision support. They may have also been experiencing different levels of conflict and distress associated with their treatment decisions. This variability may have confounded the study results and reduced our ability to identify significant findings.

Regarding the use of CAM by support persons, a one-month time period between baseline and follow-up may not have been sufficient to identify differences in CAM use behaviour that may have emerged and been present in a longer period of observation. Wait times to see a CAM practitioner may have hindered CAM usage even if a support person was motivated. Similarly, the education seminar most likely gave support persons information they can use in the future, but the support persons' focus the during the time of the study

would primarily be on the patient, therefore, it was reasonable that no significant differences were found between baseline and follow-up assessment of support persons' CAM use.

Due to the nature of self-reported data, social desirability may have influenced participants' responses, meaning participants may not have answered authentically but were influenced by a desire to please the people administering the survey. This limitation could have been avoided by having the survey administered by someone who was not associated with the education seminar.

On the decisional conflict and distress scales, there was a considerable reduction in survey participation, with only 44% and 55% of the sample completing both surveys, respectively, in what was already a small sample size (N = 62). As mentioned previously, the survey was long and response fatigue or participant burden may have prevented many support persons from completing all the survey items. In addition, due to the focus of the decisional conflict and distress scales on the turmoil and anxiety associated with making important treatment decisions, these scales may not have been perceived as being as relevant to support persons as they were to the patients who were enacting and affected by the decision. Large amounts of missing data and a small sample size affected our ability to make generalizations to a larger population of support persons. In future research, qualitative interviews may provide more insights about how support persons understand such questions and whether the scales are, in fact, relevant to them.

### **Implications for Practice**

The CAMEO research program education seminar was developed for patients and support persons who had shown interest in learning more about CAM. The attendance at the education seminar indicated support persons' desire to be proactive in their loved ones' cancer journeys. Most likely, the support persons already had some insight into CAM and

looked to the education seminar as a place to receive more information and to have their existing questions about CAM therapies answered from a conventional, evidence-based perspective.

Going forward, it will be important for clinicians to recognize the vital role that support persons may play in cancer patients' CAM decisions and to strategize ways to engage them in the decision-making process while still honouring the patient's autonomy. One way may be to ensure patients, support persons, and HCPs are all on the "same page" by expanding shared decision making at the bedside to include the support person.

Acknowledging the support person and their information and decision support needs alongside those of the patient will allow the conflict and distress experienced by the support person to be addressed and not interfere with the patient's decision. The patient's autonomy can also be respected by acknowledging differing opinions and learning to use evidence to overcome conflicting views. Further, it may be helpful to assess where support persons are getting their information about CAM and how their personal values and beliefs may create conflict with the patient's CAM decisions and to offer education and support to mitigate conflict.

Assessing support persons' emotional distress is also an important practice for clinicians engaged in shared decision making. Northouse et al. (2012) designed a series of four questions, called "TASK", to assess caregivers' level of distress: 1) Have the tools to provide optimal care; 2) Are able to juggle multiple responsibilities; 3) Engage in self-care to maintain their health; 4) Are able to keep their spirits up as they deal with the stress associated with caregiving" (p. 242). This informal clinician-designed questionnaire can be incorporated into family assessments or used independently to assess support persons' overall distress. Other formal measurement scales such as the Distress Thermometer (National Comprehensive Cancer Network, 2003) and Kessler Psychological Distress Test (Mewton et

al., 2016) that have been validated in cancer patients and other populations may also be valuable clinically to assess distress in support persons (Northouse et al., 2012). The Canadian Association of Psychosocial Oncology is working toward having emotional distress become the “sixth vital sign” (<https://www.copingwithcancer.ca/about-capo/>). Attending to both patients’ and support persons’ distress, whether it is related to treatment decision making or other aspects of the cancer journey, is important and ensures support persons are able to stay healthy and continue to care for their loved one (Northouse et al., 2012).

### **Implications for Education**

It is important in future education programming to tailor the information and the nature of the intervention to support persons (O’Connor, Jacobsen & Stacey, 2002). In addition, acknowledging the potential impact of age, gender, education level, and ethnicity on information preference and learning styles will be essential in the development of future education strategies for CAM (O’Connor, Jacobsen, Stacey, 2002).

How support persons prefer to receive information about CAM and other therapy options is an important education consideration. The support persons in our study suggested a multimodal approach (e.g., written, online, in-person) would best meet their needs related to CAM therapies. The CAMEO research program currently has an online course for patients and HCPs (<http://www.cameoprogram.org>); in the future, the education modules could be adapted to fit the needs and decision-making role of support persons. As study participants used a variety of information sources, a booklet for support persons about specific treatments and how to support cancer patients in the treatment decision-making process may be beneficial for those who prefer written formats. For support persons who favour face-to-face consultations, group seminars like the one analyzed in this thesis or one-on-one counseling would be appropriate. As educators, it is important we understand how to better relate to the

support persons' needs, thereby assisting support persons in navigating their role so they can tend to their patients without contributing to an already distressing situation.

## **Conclusion**

The goal of this secondary analysis was to examine the effect of an education program for adult cancer patients and their support persons on the support persons' use of CAM, knowledge about CAM and CAM decision making, and related decisional outcomes. This research confirms CAM decisions are not made in isolation and support persons are an integral part of the decision-making process for many cancer patients. Education seminar attendance helped increase support persons' knowledge about CAM and how to make an informed decision, and their confidence in their ability to support patients' treatment decisions while decreasing their associated decisional conflict, particularly in relation to understanding the risks and benefits of a CAM therapy option. These findings highlight the importance of engaging patients and support persons in shared decision making related to CAM and developing education strategies that meet the needs of both patients and support persons.

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## APPENDICES

### Appendix 1 – Consent Form



**BC Cancer Agency**  
CARE & RESEARCH



### CONSENT FORM

**Title of Study:**  
**Complementary Medicine & Cancer:**  
**Laying the Foundation for Making “Good” Decisions**

**Principal Investigator:**

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Associate Professor, School of Nursing, University of British Columbia  
Principal Investigator, CAMEO Program, BCCA

**Co-Investigators:**

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Professor, Department of Community Health Sciences,  
University of Calgary, Co-Investigator, CAMEO Program

The “Complementary Medicine & Cancer: Laying the Foundation for Making “Good” Decisions” patient education workshop has been developed by the Complementary Medicine Education and Outcomes (CAMEO) Program, which is a UBC research program situated at the BC Cancer Agency-Vancouver Center (BCCA-VC).

**Purpose:**

The purpose of the workshop is to determine the effectiveness of a group educational intervention in assisting patients and patient support persons in developing the knowledge and skills needed to make decisions based on both evidence and their values about whether or not to use complementary medicine (CAM) in their cancer care. The information gathered from this workshop will be used to develop and improve future CAM education programs.

**Study Procedures:**

If you choose to take part in the workshop, up to two weeks before the workshop you will be asked to identify your top three learning needs. This information will be used to develop the workshop content, though not all questions may be addressed. All participants will attend a 4-hour workshop at the BCCA-VC. The topics to be covered include an introduction to CAM, how to search for and evaluate information about CAM, and how to make decisions about CAM that are based on your values and the evidence.

The workshop includes several refreshment breaks and uses different teaching methods (lecture, demonstration, case study examples, and opportunity for asking questions). A separate room will be available where people can go and rest at any time that they feel they need it, with refreshments.

Each person attending the workshop—patient or support person—will be asked to complete a baseline questionnaire before the workshop. We are offering several ways to complete that questionnaire: you have been provided a digital copy of the questionnaire and a link to that questionnaire on-line. We would ask that you do the questionnaire on-line, or you may fill out the digital copy and email it back, print it out and complete it ahead of time and bring it with you to the workshop, or request us to mail you a hard copy. You may also come at 8:30 on the morning of the workshop and fill in a provided copy of the questionnaire then.

At two points during, and at the end of the seminar you will be asked to complete a brief evaluation form. One month following the workshop, you will be contacted to fill out a final questionnaire and final evaluation form similar to the ones you have previously filled out. The questionnaires are focused on your CAM knowledge, your current CAM use, how you feel about your decision, and any symptoms you may have, and some demographic information. The evaluation forms ask about your opinions of various components of the workshop.

**Risk and Potential Benefits**

By taking part in this study you will benefit by learning about the evidence related to CAM in the context of cancer, sources of credible information regarding CAM, choosing a CAM practitioner, and decision-making. Participants will also receive a Decision-Making Toolkit for their own use. Your decision to take part in this study will in no way impact your care at the BC Cancer Agency. There are no known risks related to taking part in this study.

**Confidentiality**

We will keep your name and information you provide strictly confidential. We will not use your name in research reports, and all data that is reported will be grouped data that will not identify you. You will be given a numerical identification number, which will be used to identify you in the database. The file linking your name, contact information, and identification number will be stored in a separate, password protected computer file. Any hard copies of study information will be stored in a locked file cabinet and the computer files will be password protected and stored on a secured network server at the BCCA. Only the research staff directly involved in the data collection and analysis will have access to the information. The data from this study might be used in future research that is part of the CAMEO Program, but only if approved by the appropriate university committees. The information collected in this study may be used for teaching purposes without revealing any information that would identify you.

## Consent

Your participation in this study is entirely voluntary and you may withdraw from the study at any time by contacting the CAMEO research team. Your signature indicates that you consent to participate in this study. A hard or electronic copy of the consent form will be forwarded to you for your records.

If you have any questions or require information with respect to this study, you may contact Dr. Lynda Balneaves at 604-707-5900 ext. 2883 or by e-mail at [lynda.balneaves@nursing.ubc.ca](mailto:lynda.balneaves@nursing.ubc.ca) if you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line at the UBC Office of Research Services at 604-822-8598.

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*I have read the above information and I have had a chance to ask any questions about the study and my involvement. I understand what I have to do and what will happen if I take part in the study. I freely choose to take part in this study and I have a copy of the consent form.*

---

Please Print Name

---

Signature of Participant

---

Signature of Witness

---

Date

-----

Would you be willing to be contacted in the future for other studies related to cancer and complementary medicine?

- Yes, I would like to receive information about future studies.
- No, I would not like to receive information about future studies.

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Signature of Participant

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Date

## Appendix 2 – Baseline Survey

# CAMEO

Complementary Medicine Education & Outcomes Program

### CAMEO Support Person Education Survey – Baseline

**The purpose of this survey** is to understand your use of and knowledge about complementary therapies, as well as how you are supporting your person living with cancer regarding decision-making activities related to complementary therapies.

**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.

**In 4 weeks you will be asked** to complete a similar survey to measure any changes as a result of attending today's education seminar.

#### **PART 1 - Complementary Therapy Use**

This section asks about your use of complementary therapies and the use since diagnosis by the person living with cancer whom you are supporting. Please check off all appropriate therapies.

**B** Are **you** using, or **the person you are supporting** using, any of the following CAM therapies? **Please check all that apply.**

<b>Complementary Therapies</b>	<b>Yes</b>	<b>No</b>
Vitamin and mineral supplements (e.g., Vitamin C, D, B)		
Herbal supplements (e.g., Essiac, Saw Palmetto)		
Other dietary supplements (e.g., Omega 3-6, coenzyme Q10)		
Special foods and/or diets (e.g., Green tea, mushrooms)		
Massage therapy		
Acupuncture		
Chiropractic medicine		
Naturopathic medicine		
Homeopathic medicine		
Traditional Chinese medicine		
Qi Gong		
Reiki		

<b>Complementary Therapies</b>	<b>Yes</b>	<b>No</b>
Yoga		
Relaxation therapy		
Therapeutic and/or healing touch		
Meditation		
Guided imagery		
Art therapy		
Other (please specify):		

### **PART 2 - Seeking Information about Complementary Therapies**

Family members and friends often help cancer patients in making decisions about complementary therapies. The following section asks about where you received information about complementary therapies. Please answer “yes” or “no” for each item.

- C** Have you used any of the following sources of information about complementary therapies in the past month? **Please check all that apply.**

<b>Sources of Information</b>	<b>Yes</b>	<b>No</b>
Health care professional		
Family member and/or friends		
Internet		
Books		
Magazines (e.g., Chatelaine, Common Ground)		
Media sources (e.g., television show, newspaper)		
Scientific journals		
Canadian Cancer Society (e.g., booklet, information line, volunteers)		
Social support group		
Health food stores		
Other (please specify):		

**D** Have you spoken with any of the following health care providers at the BC Cancer Agency about complementary therapies? **Please check all that apply.**

<b>Health Care Provider(s)</b>	<b>Yes</b>	<b>No</b>
Medical oncologist		
Radiation oncologist		
Surgeon		
Radiation therapist		
Social worker/counselor		
Librarian		
Nurse		
Pharmacist		
Dietitian		
CAMEO staff member		
Other (please specify):		

**E** Have you spoken with any of the following health care providers outside of the BC Cancer Agency about complementary therapies? **Please check all that apply.**

<b>Health Care Provider</b>	<b>Yes</b>	<b>No</b>
Family physician		
Pharmacist		
Nutritionist/dietitian		
Naturopathic physician		
Traditional Chinese medicine physician		
Chiropractor		
Other (please specify):		

- F** Have you visited any of the following websites in the past month to learn more about complementary therapies? **Please check all that apply.**

<b>Website</b>	<b>Yes</b>	<b>No</b>
CAMEO Program section of the BC Cancer Agency website		
Complementary & Alternative Cancer Therapies section of the BCCA website (previously known as the Unconventional Therapies section)		
Natural Standard database		
Natural Medicines Comprehensive database		
National Centre on Complementary & Alternative Medicine (NCCAM) website		
Memorial Sloan Kettering Cancer Center's Herbs, Botanicals, and Other Products website		
Canadian Cancer Society		
MD Anderson Cancer Center		
General search engine (e.g., Google, Yahoo, MSN)		
Other (please specify):		

### **PART 3 - Knowledge Questions**

This section asks you about your level of knowledge related to complementary therapies and making decisions about complementary therapies. **Please select one response**, (0 to 4, with 0 being "Not at all knowledgeable" and 4 being "Very knowledgeable") for each item.

- G** With regards to complementary therapies, **how knowledgeable do you feel about:**

<b>I feel knowledgeable about:</b>	<b>Not at all</b>	<b>A little</b>	<b>Some-what</b>	<b>Moderately</b>	<b>Very</b>
Where to find the most recent evidence about the safety and usefulness of complementary therapies.	0	1	2	3	4

I feel knowledgeable about:	Not at all	A little	Some-what	Moderately	Very
Which health professionals at the BC Cancer Agency to talk to when making decisions about complementary therapies.	0	1	2	3	4
The possible risks and benefits of the complementary therapies I am interested in.	0	1	2	3	4
When it is considered safe to use natural health products (e.g., vitamins, herbal therapies) during cancer treatment.	0	1	2	3	4
How complementary health care providers are regulated in British Columbia.	0	1	2	3	4
What questions to ask when selecting a complementary health care provider.	0	1	2	3	4
Which complementary therapies I have to pay for out of my own pocket.	0	1	2	3	4
What type of research studies I should pay attention to when making decisions about complementary therapies.	0	1	2	3	4
Which complementary therapies may be helpful in managing side effects from my conventional cancer treatments.	0	1	2	3	4
How to assess whether or not a complementary therapy is helping.	0	1	2	3	4

#### **PART 4 - Making Decisions about Complementary Therapies**

The following section asks you about making decisions about complementary therapies and how confident you and the person living with cancer whom you are supporting feel about making such decisions.

- H** Below are listed some areas of knowledge involved in making informed decisions about complementary therapies. Please show how confident you feel in supporting the person living with cancer in doing these things by circling a number from 0 (not at all confident) to 4 (very confident) for each item listed below:

Supporting the person living with cancer, I feel confident that I can:	Not at all	A little	Some-what	Moderately	Very
Get the facts about the complementary therapy choices available.	0	1	2	3	4
Get the facts about the benefits of each choice.	0	1	2	3	4
Get the facts about the risks and side effects of each choice.	0	1	2	3	4
Understand the information enough to be able to support the person living with cancer to make a choice.	0	1	2	3	4
Ask questions without feeling dumb.	0	1	2	3	4
Express my concerns about each choice.	0	1	2	3	4
Ask for advice.	0	1	2	3	4
Figure out what therapy best suits the person living with cancer.	0	1	2	3	4
Help him or her handle unwanted pressure from others while making a choice.	0	1	2	3	4
Support him or her in letting the health care team know what's best for them.	0	1	2	3	4
Support him or her in delaying the decision if they feel they need more time.	0	1	2	3	4

**I** Identify one complementary therapy decision you and the person living with cancer are thinking about today:

---

**J** Considering this decision, how far along with the decision are you and the person with cancer whom you are supporting? **Please check the one response that best applies to you today.**

- I am not part of making this decision (If checked, please go to **Part 5, next page**)
- I have not yet thought about the options
- I am considering the options
- I am close to making a choice
- I have already made a choice
- I have already made a choice, but am reconsidering my options

**K** Considering the complementary therapy option you and the person living with cancer are thinking about, please answer the following questions by **checking 0 – “Yes”, 2 – “Unsure”, or 4 – “No”** for each item listed below:

Items	0 Yes	2 Unsure	4 No
Do you know which options are available to you?			
Do you know the benefit of each option?			
Do you know the risks and side effects of each option?			
Are you clear about which benefits matter most to you?			
Are you clear about which risks and side effects matter most to you?			
Do you have enough support from others to make a choice?			
Are you choosing without pressure from others?			
Do you have enough advice to make a choice?			
Are you clear about the best choice for you?			
Do you feel sure about what to choose?			

**L** On a scale of **1 to 10** where 1 is no distress at all and 10 is extreme distress, **please select** the number (1-10) that best describes how much distress you have been experiencing **related to supporting the person living with cancer in making a CAM decision(s)**.

<b>No Distress at All</b>					<b>Extreme Distress</b>				
1	2	3	4	5	6	7	8	9	10



**R** What type of cancer is the person living with cancer whom you are supporting diagnosed with or at risk for?

- Breast
  - Prostate
  - Lung
  - Colorectal
  - Gynecological (e.g., cervical)
  - Gastrointestinal (e.g., stomach, esophageal)
  - CNS (e.g., brain)
  - Head and neck
  - Blood cancers (e.g., leukemia, lymphoma)
  - Skin
  - Other (please specify):
- 

**S** Please check off all medical cancer treatment(s) the person living with cancer whom you are supporting has received/is receiving for cancer:

- Surgery
  - Chemotherapy
  - Radiation
  - Anti-hormone therapy
  - Genetic counseling
  - Other (please specify):
-

T What is your relationship to the person living with cancer (at risk for cancer) whom you are supporting?

Spouse / partner

Parent

Sibling (brother or sister)

Aunt or uncle

Cousin

Friend

Other (please specify): \_\_\_\_\_

**Thank you very much.**

**If you have any questions, please speak with one of the CAMEO Program investigators, or contact the CAMEO Program.**

### Appendix 3 – Follow-up Survey

# CAMEO

Complementary Medicine Education & Outcomes Program

## CAMEO Support Person Education Survey – Follow-up

**The purpose of this survey** is to understand your use of and knowledge about complementary therapies, as well as how you are supporting your person living with cancer regarding decision-making activities related to complementary therapies.

**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.

### PART 1 - Complementary Therapy Use

This section asks about your use of complementary therapies and the use since diagnosis by the person living with cancer whom you are supporting. Please check off all appropriate therapies.

**B** Since attending the CAMEO Workshop on Complementary Therapies on [DATE], have **you continued, started, or stopped using** any of the following complementary therapies? **Please check all that apply.**

<b>Complementary Therapies</b>	<b>Yes</b>	<b>No</b>
Vitamin and mineral supplements (e.g., Vitamin C, D, B)		
Herbal supplements (e.g., Essiac, Saw Palmetto)		
Other dietary supplements (e.g., Omega 3-6, coenzyme Q10)		
Special foods and/or diets (e.g., Green tea, mushrooms)		
Massage therapy		
Acupuncture		
Chiropractic medicine		
Naturopathic medicine		
Homeopathic medicine		
Traditional Chinese medicine		
Qi Gong		
Reiki		

<b>Complementary Therapies</b>	<b>Yes</b>	<b>No</b>
Yoga		
Relaxation therapy		
Therapeutic and/or healing touch		
Meditation		
Guided imagery		
Art therapy		
Other (please specify):		

**C** Since attending the CAMEO Workshop on Complementary Therapies on [DATE], has **the patient you are supporting continued, started, or stopped using** any of the following complementary therapies? **Please check all that apply.**

<b>Complementary Therapies</b>	<b>Yes</b>	<b>No</b>
Vitamin and mineral supplements (e.g., Vitamin C, D, B)		
Herbal supplements (e.g., Essiac, Saw Palmetto)		
Other dietary supplements (e.g., Omega 3-6, coenzyme Q10)		
Special foods and/or diets (e.g., Green tea, mushrooms)		
Massage therapy		
Acupuncture		
Chiropractic medicine		
Naturopathic medicine		
Homeopathic medicine		
Traditional Chinese medicine		
Qi Gong		
Reiki		
Yoga		
Relaxation therapy		
Therapeutic and/or healing touch		
Meditation		
Guided imagery		
Art therapy		
Other (please specify):		

## PART 2 - Seeking Information about Complementary Therapies

Family members and friends often help cancer patients in making decisions about complementary therapies by helping them get information about these therapies. The following section asks about where you received information about complementary therapies. Please answer “yes” or “no” for each item.

- D** Since attending the CAMEO Workshop on Complementary Therapies on [DATE], have **you** used any of the following sources of information about complementary therapies? **Please check all that apply.**

Sources of Information	Yes	No
Health care professional		
Family member and/or friends		
Internet		
Books		
Magazines (e.g., Chatelaine, Common Ground)		
Media sources (e.g., television show, newspaper)		
Scientific journals		
Canadian Cancer Society (e.g., booklet, information line, volunteers)		
Social support group		
Health food stores		
Other (please specify):		

- E** Since attending the CAMEO Workshop on Complementary Therapies on [DATE], have **you** spoken with any of the following health care providers at the BC Cancer Agency about complementary therapies? **Please check all that apply.**

Health Care Provider(s)	Yes	No
Medical oncologist		
Radiation oncologist		
Surgeon		
Radiation therapist		
Social worker/counselor		
Librarian		

Health Care Provider(s)	Yes	No
Nurse		
Pharmacist		
Dietitian		
CAMEO staff member		
Other (please specify):		

F Since attending the CAMEO Workshop on Complementary Therapies on [DATE], have **you** spoken with any of the following health care providers **outside** of the BC Cancer Agency about complementary therapies? **Please check all that apply.**

Health Care Provider	Yes	No
Family physician		
Pharmacist		
Nutritionist/dietitian		
Naturopathic physician		
Traditional Chinese medicine physician		
Chiropractor		
Other (please specify):		

G Since attending the CAMEO Workshop on Complementary Therapies on [DATE], have **you** visited any of the following websites to learn more about complementary therapies? **Please check all that apply.**

Website	Yes	No
CAMEO Program section of the BC Cancer Agency website		
Complementary & Alternative Cancer Therapies section of the BCCA website (previously known as the Unconventional Therapies section)		
Natural Standard database		
Natural Medicines Comprehensive database		
National Centre on Complementary & Alternative Medicine (NCCAM) website		
Memorial Sloan Kettering Cancer Center's Herbs, Botanicals, and Other Products website		
Canadian Cancer Society		
MD Anderson Cancer Center		
General search engine (e.g., Google, Yahoo, MSN)		
Other (please specify):		

### PART 3 - Knowledge Questions

This section asks you about your level of knowledge related to complementary therapies and making decisions about complementary therapies. **Please select one response**, (0 to 4, with 0 being "Not at all knowledgeable" and 4 being "Very knowledgeable") for each

H With regards to complementary therapies, **how knowledgeable do you feel about:**

I feel knowledgeable about:	Not at all	A little	Some -what	Moderately	Very
Where to find the most recent evidence about the safety and usefulness of complementary therapies.	0	1	2	3	4
Which health professionals at the BC Cancer Agency to talk to when making decisions about complementary therapies.	0	1	2	3	4
The possible risks and benefits of the complementary therapies I am interested in.	0	1	2	3	4
When it is considered safe to use natural health products (e.g., vitamins, herbal therapies) during cancer treatment.	0	1	2	3	4
How complementary health care providers are regulated in British Columbia.	0	1	2	3	4
What questions to ask when selecting a complementary health care provider.	0	1	2	3	4
Which complementary therapies I have to pay for out of my own pocket.	0	1	2	3	4
What type of research studies I should pay attention to when making decisions about complementary therapies.	0	1	2	3	4
Which complementary therapies may be helpful in managing side effects from my conventional cancer treatments.	0	1	2	3	4
How to assess whether or not a complementary therapy is helping.	0	1	2	3	4

#### **PART 4 - Making Decisions about Complementary Therapies**

The following section asks you about making decisions about complementary therapies and how confident you and the person living with cancer whom you are supporting feel about making such decisions.

- I Below are listed some areas of knowledge involved in making informed decisions about complementary therapies. Please show how confident you feel in supporting the person living with cancer in doing these things by circling a number from 0 (not at all confident) to 4 (very confident) for each item listed below:

<b>Supporting the person living with cancer, I feel confident that I can:</b>	<b>Not at all</b>	<b>A little</b>	<b>Some-what</b>	<b>Moderately</b>	<b>Very</b>
Get the facts about the complementary therapy choices available.	0	1	2	3	4
Get the facts about the benefits of each choice.	0	1	2	3	4
Get the facts about the risks and side effects of each choice.	0	1	2	3	4
Understand the information enough to be able to support the person living with cancer to make a choice.	0	1	2	3	4
Ask questions without feeling dumb.	0	1	2	3	4
Express my concerns about each choice.	0	1	2	3	4
Ask for advice.	0	1	2	3	4
Figure out what therapy best suits the person living with cancer.	0	1	2	3	4
Help him or her handle unwanted pressure from others while making a choice.	0	1	2	3	4
Support him or her in letting the health care team know what's best for them.	0	1	2	3	4
Support him or her in delaying the decision if they feel they need more time.	0	1	2	3	4

One month ago, you and the person living with cancer whom you are supporting were considering the following question/decision:

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**J** Considering this decision, how far along with the decision are you and the person with cancer whom you are supporting **now**? **Please check the response that best applies to you today.**

- I am not part of making this decision (If checked, please go to **Part 5, next page**)
- We have not yet thought about the options
- We are considering the options
- We are close to making a choice
- We have already made a choice
- We have already made a choice, but are reconsidering our options

**K** Considering the complementary therapy option you and the person living with cancer are thinking about, please answer the following questions by **checking 0 – “Yes”, 2 – “Unsure”, or 4 – “No”** for each item listed below:

Items	0 Yes	2 Unsure	4 No
Do you know which options are available to you?			
Do you know the benefit of each option?			
Do you know the risks and side effects of each option?			
Are you clear about which benefits matter most to you?			
Are you clear about which risks and side effects matter most to you?			
Do you have enough support from others to make a choice?			
Are you choosing without pressure from others?			
Do you have enough advice to make a choice?			
Are you clear about the best choice for you?			
Do you feel sure about what to choose?			

- L** On a scale of 1 to 10 where 1 is no distress at all and 10 is extreme distress, please select the number (1-10) that best describes how much distress you have been experiencing related to supporting the person living with cancer in addressing the above CAM question/decision.

No Distress at All					Extreme Distress				
1	2	3	4	5	6	7	8	9	10

**Thank you very much!**

Please return this survey and the Workshop evaluation in the provided return envelope. If you have any questions, please contact the CAMEO Program by email at [cameo@bccancer.bc.ca](mailto:cameo@bccancer.bc.ca) or by telephone at 604-707-5960.