

**REGAINING CONTROL OVER CANCER: A HEALTH COMMUNICATION  
INITIATIVE DOCUMENTING COMPLEMENTARY AND ALTERNATIVE  
MEDICINE USE AMONG CANCER PATIENTS AND SURVIVORS**

by

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**ABSTRACT**

Cancer is a complex chronic disease that has remained a paramount public health problem for the last 42 years. Systemic treatments, like chemotherapy, or local therapies, like radiation, are often used to treat metastatic cancer. Chemotherapy and radiation can cause a host of physical side effects including fatigue, hair loss, nausea, and vomiting. To combat these side effects of treatment, cancer patients and survivors turn to complementary and alternative medicine (CAM) both during and after cancer treatment, to improve their prognosis, symptoms, and quality of life.

While CAM is often sought for symptom abatement, many patients fail to disclose their CAM use to their healthcare providers, despite the potential for adverse reactions with conventional treatments. To understand issues associated with CAM use, including the nondisclosure patterns, the National Cancer Institute Office of Cancer Complementary and Alternative Medicine's (OCCAM) existing sources of qualitative data were reviewed along with the websites of several national cancer advocacy groups. A literature search on the motivations for CAM use and the barriers and facilitators to patient-provider communication about CAM was conducted to understand the current research on communication about CAM in different healthcare settings.

Under the auspices of OCCAM, the author developed an interactive workbook to encourage patients' participation in their health care by increasing their confidence to talk to

their providers about CAM. The workbook contains different adaptations of health diaries to help patients track their motivations for CAM use, the frequency of their CAM use, and all of their medications, including vitamins, herbs, and dietary supplements. Two rounds of pretesting with cancer survivors and healthcare providers were conducted to determine the usability and functionality of the workbook. The healthcare providers and cancer survivors surveyed believed OCCAM's initiative is an important resource because it empowers patients to help their healthcare providers understand their coping mechanisms during and after cancer care, including their use of CAM. This initiative has public health significance because there are limited patient education resources that encourage patients to talk to their providers about CAM and furthermore, when patients and providers communicate with each other, patients experience more positive health outcomes.

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From January 9, 2012, through November 14, 2012, I participated in the National Cancer Institute's Health Communications Internship Program (HCIP). Typically, the Health Communications Internship Program (HCIP) is a six-month to one-year internship sponsored by the National Cancer Institute (NCI). This internship program provides current graduate students and recent graduates with the opportunity to participate in a health communications or scientific writing internship at one of the offices, centers, or divisions of the National Cancer Institute. Students who participate in the HCIP program develop initiatives that increase the NCI's dissemination of cancer information to the American public. As an HCIP intern, I was placed in the Office of Cancer Complementary and Alternative Medicine (OCCAM) and was specifically assigned to work in the Communications and Outreach Program (COP).

OCCAM is one of the offices that support the overall mission of the National Cancer Institute, "to conduct and support research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients,"<sup>1</sup> by studying the role of complementary and alternative medicine (CAM) in cancer. OCCAM accomplishes these ends through its various programs, including the Office of the Director, the

Communications and Outreach Program, the Case Review and Intramural Science Program, the Extramural Research Program, and the Research Development and Support Program.

During the first month of the internship, I had several meetings with each of the program directors of OCCAM, including the office director, Dr. Jeffrey D. White, to learn about the various projects and tasks conducted within the office. By the end of January, I was provided an explanation of my internship-specific project. I was tasked with developing a patient education resource to not only increase OCCAM's patient education portfolio, but more importantly to increase knowledge about cancer CAM. Both the communication medium and topic were left undefined; however, through the design process, I was asked to determine the best methods of communicating cancer CAM information to patients.

This project would not have been completed without the support of Dr. Jeffrey D. White, Elizabeth Austin, Barbara McMakin, and the rest of OCCAM's staff. I appreciate the confidence and trust you placed in me to take on the role of project lead for this communication initiative. I cannot thank you enough for supporting my growth as a burgeoning public health professional, encouraging my attendance to various lectures, seminars, trainings, and classes, and offering career advice throughout the entire course of my internship.

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## ACRONYMS

The following acronyms are used in this document:

|       |  |
|-------|--|
| AARP  | American Association of Retired Persons                    |
| ACS   | American Cancer Society                                    |
| AOSW  | Association of Oncology Social Work                        |
| CAM   | complementary and alternative medicine                     |
| CARRA | Consumer Advocates in Research and Related Activities      |
| CME   | Continuing Medical Education                               |
| COP   | Communications and Outreach Program                        |
| CPEN  | Cancer Patient Education Network                           |
| FDA   | Food and Drug Administration                               |
| HCIP  | Health Communications Internship Program                   |
| HINTS | Health Informational National Trends Survey                |
| ICCMR | International Congress on Complementary Medicine Research  |
| LLS   | Leukemia and Lymphoma Society                              |
| NCCAM | National Center for Complementary and Alternative Medicine |
| NCI   | National Cancer Institute                                  |
| NHIS  | National Health Interview Survey                           |
| NIH   | National Institutes of Health                              |
| NP    | Nurse Practitioner   |
| OAR   | Office of Advocacy Research                                |

|                  |   |
|------------------|---|
| OBBR             | Office of Biorepositories and Biospecimen Research      |
| OCCAM            | Office of Cancer Complementary and Alternative Medicine |
| OCE              | Office of Communication and Education                   |
| ODS              | Office of Dietary Supplements                           |
| OMB              | Office of Management and Budget                         |
| OMRE             | Office of Market Research and Evaluation                |
| ONC              | Office of the National Coordinator                      |
| ONS              | Oncology Nursing Society                                |
| OTC              | Over-The-Counter Medicine                               |
| PA               | Physician Assistant                                     |
| PRA              | Paperwork Reduction Act                                 |
| PDQ <sup>®</sup> | Physician Data Query                                    |
| RDD              | Random-Digit-Dial                                       |

## 1.0 INTRODUCTION

Cancer is a chronic health problem that has remained a paramount national health priority since 1971, when President Nixon declared “the conquest on cancer” by signing the National Cancer Act of 1971.<sup>2</sup> Forty-two years later, cancer continues to be a devastating disease that affects people of all races, sexes, and ages; cancer is the second leading cause of death of Americans, preceded only by heart disease.<sup>3</sup> National trends indicate that the overall cancer death rates for several of the leading cancer types, (lung, prostate, colorectal, breast (women), ovary, brain, kidney, stomach, oral cavity, larynx (men), leukemia, non-Hodgkin’s lymphoma, myeloma, bladder (women), esophagus (women), and gallbladder (women)) have declined over the past two decades for men and women of all races and ethnicities.<sup>4</sup> However, while the mortality rates and incidences of the aforementioned cancers continue to decline, the incidence of several other cancer types, namely pancreas, liver (men), melanoma (men), and uterus (women) have begun to increase.<sup>4</sup> Even with the death rates of some of the leading types of cancer declining, cancer continues to plague the health of the nation and directly influences healthcare costs. In 2012, it was estimated 1,638,910 new cases of cancer would be diagnosed and 577,190 Americans would die from cancer.<sup>3</sup> In 2010, the national costs for cancer care were \$124 billion dollars and the cancer costs are projected to increase to \$158 billion (in 2010 dollars) by 2020.<sup>5</sup>

An important component in cancer care and a direct contributor to associated medical costs is deciding on the best course of action to combat cancer. Some of the standard



conventional treatments include, but are not limited to, chemotherapy, radiation, surgery, targeted therapy, and stem cell transplants. The choice of therapy is influenced by multiple factors, including but not limited to the stage of diagnosis, cancer site, and patient preference. Each therapy is associated with a set of risks and benefits that patients, their families, and their healthcare providers must openly discuss. Treatment protocol conversations should also include discussions of possible side effects and complications from treatment, such as the physical and mental side effects of chemotherapy and radiation. Frequently observed symptoms during the administration of chemotherapy or radiation include anemia (chemotherapy), diarrhea, fatigue, hair loss, mouth changes, nausea and vomiting, nerve and muscle changes (chemotherapy), skin changes, and increased chance of bruising, bleeding, and infection (chemotherapy).<sup>6,7</sup> Typically, the symptoms that occur in the active phases of treatment are the most severe, however, many late effects of cancer treatments may also persist among cancer survivors, including fatigue, insomnia, neuropathy, and pain.<sup>8</sup>

To combat these side effects, some cancer patients and survivors turn to complementary and alternative medicine (CAM) to lessen the severity of symptoms. The Office of Cancer Complementary and Alternative Medicine (OCCAM) defines complementary and alternative medicine as “any medical system, practice, or product that is not thought of as standard care.”<sup>9</sup> CAM is typically organized into five categories which include alternative medical systems, energy therapies, manipulative and body-based methods, mind-body interventions, and nutritional therapeutics.<sup>9</sup> Examples of modalities within each of the above mentioned CAM categories include homeopathy, qigong (a practice that involves gentle physical movements combined with deep breathing exercises), therapeutic massage, meditation, and vitamins, respectively.<sup>9</sup>

Use of CAM therapies among cancer patients and survivors ranges from 7-64%.<sup>10</sup> The variable rates of CAM use are attributed to a lack of a standard definition of CAM and the differences in patient populations studied and survey methodology. While it is uncertain what the true measure of prevalence of CAM is in the cancer patient population, it has been documented that anywhere between 40% to greater than 60% of cancer patients fail to inform their physicians of their use of CAM.<sup>11,12</sup> Non-disclosure of CAM use is particularly dangerous because of potential for some therapies to decrease medication efficiency and increase toxicity.<sup>13</sup> Additionally, many CAM therapies have not been thoroughly researched so it is unknown how these therapies may interact with conventional treatments or the patients themselves.

To help cancer patients and survivors communicate their use of CAM to their providers, OCCAM developed a patient education workbook entitled, *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips*. This workbook was designed after careful review of the literature, existing sources of qualitative data, and several cancer advocacy groups' websites. Comprised of different adaptations of health diaries, OCCAM's workbook encourages patients and survivors to track the different CAM therapies they use for symptom management. Documenting use and motivations of CAM, enables cancer patients and survivors to be participatory members in their healthcare, and provides them with the necessary skills to engage in conversations about CAM with their provider(s).

This thesis covers the development of the workbook designed for the Office of Cancer Complementary and Alternative Medicine during the course of the author's participation of the Health Communications Internship Program. The thesis outlines the conceptualization, development, and implementation of the workbook. Chapter Two discusses the prevalence of complementary and alternative medicine (CAM) use among cancer patients and survivors, the

motivations for CAM use, and the barriers and facilitators affecting patient-provider communication about CAM. Chapter Two also outlines how the qualitative data reviewed and use of the Health Informational National Trends Survey (HINTS) database contributed to the development of the workbook. Chapter Three describes the methods used during the course of the formative research process and pretesting phases. Chapter Four discusses the accessibility and presentation of CAM information by various national cancer advocacy groups. This chapter also describes the two rounds of pretesting that were conducted with cancer survivors, advocates, caregivers, and healthcare professionals and discusses the implementation of the workbook. Chapter Five analyzes how this workbook enhances patient-provider communication and the public health significance of such a communication campaign. Chapter Six provides a thesis summary and describes the strengths as well as the limitations of *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips*. This chapter also offers recommendations for educational campaigns targeted at healthcare providers to increase awareness and knowledge about CAM.

## 2.0 BACKGROUND

In 1990, the first national survey of alternative medicine use in the U.S. was conducted. Using a random-digit-dial (RDD) telephone survey of non-institutionalized U.S. adults, Eisenberg et al.<sup>14</sup> demonstrated 33.8% of adults used CAM. In 1997, Eisenberg et al.<sup>15</sup> repeated the RDD telephone survey to once again measure the prevalence of CAM among U.S. adults. Between 1990 and 1997, the prevalence rate of CAM use increased from 33.8% to 42.1%.<sup>15</sup> This seven year time period also saw marked changes in the estimated total number of visits to CAM practitioners with 427 million office visits in 1990 and 629 million office visits in 1997.<sup>15</sup> Furthermore, the total number of visits to CAM practitioners in 1997 surpassed the total number of office visits to primary care physicians (386 million).<sup>15</sup> Coupled with increased visits to CAM practitioners in 1997, the out-of-pocket expenditures for CAM therapies also increased between 1990 and 1997, from approximately \$14.6 billion to \$21.2 billion, although Eisenberg et al.<sup>15</sup> argue that the true out-of-pocket costs for 1997 were more likely between \$27.0-\$34.0 billion dollars.

Beginning in 2002, the National Health Interview Survey (NHIS), a representative random household survey of non-institutionalized U.S. adults was used to calculate the prevalence of CAM. The 2002 survey estimated the rate of CAM use among U.S. adults to be 62% when the definition of CAM included prayer; if prayer was excluded the rate was 36%.<sup>16</sup> In the analysis of CAM trends, this was the first instance in which the operationalization of the

CAM definition greatly affected the resulting statistics. The 2007 NHIS is the last available recorded national prevalence data for CAM use. Results from this survey, which did not include prayer for health in the definition of CAM, estimated approximately 38% of U.S. adults had used CAM in the previous 12 months.<sup>17</sup> The 2007 NHIS also revealed that the out-of-pocket expenditures for CAM practitioners, products, classes, and materials increased to \$33.9 billion dollars, which accounted for 1.5% of the total U.S. healthcare expenditures and 11.2% of the total out-of-pocket expenditures.<sup>18</sup> Using the Medical Expenditure Panel Survey to determine the annual expenditures on the most common CAM therapies of credentialed providers, chiropractic care, acupuncture, and massage therapy, Davis et al. estimated U.S. adults spent \$9 billion dollars each year on visits to CAM practitioners for treatment of chronic conditions.<sup>19</sup>

The motivations for CAM use remained unchanged from 1990 through 2007. Adults tended to gravitate to CAM therapies to alleviate a host of chronic ailments, which included back pain, neck pain, arthritis, anxiety, head and chest colds, depression, and headaches.<sup>15,16</sup> The 1997 survey revealed women, those between the ages of 35-49, and individuals with higher education and higher incomes, and individuals with chronic health conditions were more likely to use CAM therapies.<sup>15</sup> A 2010 survey conducted by the American Association for Retired Persons (AARP) and the National Center for Complementary and Alternative Medicine (NCCAM) observed CAM use to be highest among adults age 50-59.<sup>20</sup> This study revealed that CAM use was also high for adults 30-39 (39.6%), 40-49 (40.1%), and 60-69 (41.0%).<sup>20</sup> Among older adults surveyed by AARP and NCCAM, the motivations for CAM use, to alleviate pain, promote wellness, and treat health conditions, remained the same as previously reported, as did the use patterns, with more women than men and those with higher education utilizing CAM.<sup>20</sup>

Although the motivations for CAM use remained relatively unchanged between 1997 and 2007, interest shifted among the different CAM modalities through this 10-year period. In 1997, use of herbal medicine, massage, megavitamins, self-help groups, folk remedies, energy healing, and homeopathy were popular among CAM users.<sup>15</sup> However, from 2002 to 2007, interest in mind-body and manipulative and body-based therapies increased, with adults utilizing acupuncture, deep breathing exercises, massage therapy, meditation, naturopathy and yoga more frequently than in the past.<sup>17</sup> By 2007, the most commonly used CAM therapies were nonvitamin, nonmineral natural products, such as ginkgo biloba, garlic and herbal remedies, deep breathing exercises, meditation, chiropractic or osteopathic manipulation, massage, and yoga.<sup>17</sup>

National trends from 1990 through 2007 demonstrated an increased interest in complementary and alternative medicine, coupled with large out-of-pocket expenditures in efforts to promote wellness and relieve pain. Some of the reasons for increased public interest in CAM included the creation of a marketplace for CAM products and practitioners,<sup>21</sup> the easing of labeling regulations on dietary supplements,<sup>21</sup> the dissemination of CAM information through mass media and the Internet,<sup>16,21</sup> the desire of patients to be actively involved with medical decision making,<sup>16</sup> and dissatisfaction with conventional medicine.<sup>16</sup> While CAM interest remained high among the public between 1990 and 2007, the disclosure of CAM use to healthcare practitioners was low. From 1990-1997, less than 40% of adults who utilized CAM disclosed that use to their healthcare providers.<sup>15</sup> The 2010 survey conducted by AARP and NCCAM also demonstrated that the disclosure rates remained relatively unchanged from 2007, with only 42% of CAM users, aged 50 or older, informing physicians of their use of CAM therapies.<sup>20</sup>

## 2.1 COMPLEMENTARY AND ALTERNATIVE MEDICINE USE IN CANCER

Analysis of the 2002 and 2007 NHIS revealed that individuals with chronic diseases, such as cancer, were more likely to use CAM than the general population.<sup>16,17</sup> In a cross sectional analysis of the 2002 NHIS data, Saydah et al.<sup>22</sup> found adults diagnosed with cancer were 55% more likely to report ever using CAM when compared to adults without chronic diseases, and 43% of adults with cancer reported having used CAM in the past 12 months. The authors suggested that CAM use may be more prevalent among individuals with chronic diseases due to the self-care management a chronic disease diagnosis requires.<sup>22</sup> Mao et al.<sup>23</sup> conducted a separate cross-sectional analysis of the 2002 NHIS data and found a cancer diagnosis was associated with an 11% greater use of CAM when compared to the general population. Comparisons among individuals diagnosed with cancer and individuals with other symptomatic chronic diseases, however, did not reveal differences in the patterns of use of CAM, but cancer patients were more likely to use prayer for health.<sup>23</sup> An RDD survey of Californians with cancer also observed that individuals diagnosed with cancer were more likely to use CAM therapies than were those without cancer.<sup>24</sup>

Among the cancer population, utilization of CAM is quite varied, with different prevalence rates observed for patients in active treatment, i.e. chemotherapy and radiation, versus survivors. The prevalence rates for CAM use among cancer patients range from 10% to greater than 60%.<sup>25</sup> In a systematic review conducted in 1998 of CAM use among cancer patients, Ernst et al.<sup>10</sup> observed the average prevalence rate among studies included in the review to be approximately 31.4%. In a recent systematic review and meta-analysis, Horneber et al.<sup>26</sup> found the current combined prevalence of CAM use by cancer patients, across all studies included in the review, was 40%. Among the countries included in the review, Australia, Canada, all

European countries, Israel, Turkey, New Zealand and the United States, the United States was the highest consumer of CAM.<sup>26</sup> A secondary analysis of the 2002 NHIS estimated 39% of cancer survivors had used CAM at one point in their lives.<sup>27</sup> In their analysis of the 2007 NHIS data, Mao et al.<sup>28</sup> reported 66.5% of cancer survivors indicated they had ever used CAM and 43.4% of survivors had used CAM within the past year. The variability and inconsistency of these prevalence rates is due to a lack of use of a uniform definition of CAM. Without a standardized way of describing CAM, it is hard to establish a true measure of the prevalence of CAM use among cancer patients.

### **2.1.1 Patient Motivations for CAM Use**

While the prevalence rates for CAM use among cancer patients vary, the predictors of CAM use for cancer patients and survivors are similar to those of the general population. These include female gender, higher education, higher socioeconomic status, younger age, Caucasian<sup>27</sup> and a holistic, philosophical orientation toward health.<sup>21,29</sup> Cancer patients and survivors often turn to complementary and alternative medicine for alleviation of undertreated or undiagnosed symptoms at the tumor site, which may include insomnia, fatigue, depressed mood, and anxiety, recurring pain or treatment-related pain, neuropathy, and ongoing psychological distress.<sup>8,28,29</sup> For example, 60-90% of cancer in active treatment report cancer-related fatigue and 30-50% report insomnia, while 33% of survivors develop cancer-related pain even after curative treatment:<sup>8</sup> all of these symptoms threaten the quality of the patients' and survivors' lives.

CAM is often utilized to aid in the management of side effects, as it is often viewed as a less toxic approach to symptom management than conventional treatments, like the administration of chemotherapy or palliative medications.<sup>11,21,28,30-32</sup> Many cancer patients



believe CAM therapies will help boost their immune system<sup>11,21,28,30,33</sup> and may prevent secondary or recurring cancers.<sup>30,33</sup> Patients also utilize CAM therapies because they provide hope<sup>11,21,34</sup> and enhance one's quality of life and well-being.<sup>11,21,28,30,31,33,34</sup> Numerous studies cite one of the primary reasons for CAM use among cancer patients and survivors is to regain a sense of control.<sup>11,12,21,28,31,33-36</sup> Patients may also seek CAM therapies due to dissatisfaction with their physicians<sup>21,23</sup> or a failure of conventional therapies to meet their unique needs.<sup>12,21</sup> In a telephone survey of women under age 50 with stage I to IIIA breast tumors, undergoing their first round of chemotherapy, patients who were dissatisfied with the decision making process at the beginning of chemotherapy and dissatisfied with their providers four months after beginning treatment were more likely to use complementary therapies.<sup>37</sup>

### **2.1.2 Barriers and Facilitators to CAM Discussions**

A desire to regain a sense of control<sup>11,12,21,28,31,33-36</sup> and to participate in treatment decisions<sup>36</sup> often leads cancer patients to begin to use CAM therapies. Cancer patients and survivors use a wide variety of CAM therapies, many of which are self-selected, rather than provider-directed and as a result are often not disclosed to healthcare providers. Richardson et al.<sup>11</sup> found while 68.7% of the cancer patients surveyed (n=435) at a comprehensive cancer center identified using at least one type of CAM therapy, nearly 60.6% did not disclose their CAM use to their providers. Yates et al.<sup>12</sup> observed similar disclosure rates among newly diagnosed cancer patients receiving chemotherapy or radiation who used CAM, as 43% reported not disclosing their CAM use to either their oncologist or primary care physician. A recent cross-sectional survey of radiology patients (n=305) at an urban academic center revealed 43.6% of patients used CAM therapies yet only 12.1% disclosed their use of CAM to their radiation oncologist.<sup>38</sup> This study

found only 21.6% of patients discussed their CAM use with at least one type of physician.<sup>38</sup> Analysis of the 2002 NHIS survey revealed 27.6% of cancer patients reported talking to their physician about CAM use.<sup>22</sup> Among cancer survivors surveyed in the 2007 NHIS survey, 22.7% informed their providers of their use of CAM, while only 14.6% informed their providers of their herb use.<sup>28</sup> While herb supplementation is considered a part of CAM, this is an important finding because it highlights the discrepancy between use of dietary supplementation and disclosure patterns of supplement use to healthcare providers.

One of the primary reasons why patients are often hesitant to discuss their use of CAM with their providers is that they are concerned their physician will react negatively.<sup>12,31,33,35,39</sup> Patients are also fearful their physicians may dismiss their questions,<sup>31,33</sup> or show a lack of interest in discussing CAM.<sup>12,30,35,37</sup> Others may not disclose their use of CAM because of a physician's emphasis on scientific evidence to support treatment decisions.<sup>35,39</sup> Assumptions about a physician's knowledge may also influence disclosure of CAM use, including a patient's belief that his physician may have limited knowledge on the topic<sup>12,30,35</sup> or that CAM is not within the physician's scope of practice.<sup>31</sup> Patient beliefs surrounding CAM use may also govern disclosure patterns. Patients may view CAM therapies as natural and safe alternatives to conventional medicine that do not require physician input.<sup>21,31</sup> Lastly, patients may not inform their physicians of their CAM use because they did not perceive the therapy they were using as CAM,<sup>12</sup> they thought it was irrelevant to the biomedical treatment course,<sup>12,21</sup> or they simply were not asked by physicians about CAM use.<sup>12,31</sup>

Equally responsible for the lack of communication about CAM are healthcare providers, particularly physicians. Physicians may be particularly hesitant to engage in conversations about CAM if they perceive they have a lack of knowledge about the topic.<sup>21,31,40</sup> Many physicians lack

training in CAM<sup>31,41</sup> and display skepticism toward CAM<sup>11,31,39,41</sup> due to the lack of credible and authoritative evidence on the subject.<sup>21,31,39,40</sup> These negative attitudes towards CAM may be the result of a desire to not appear uninformed.<sup>21,40</sup> Physicians may be apprehensive about engaging in a potentially time-consuming conversation, in an already limited interaction.<sup>11,41</sup>

Hann et al.<sup>42</sup> found only 21% of oncologists surveyed initiated conversations about CAM with their patients, despite the fact that 48% of oncologists believed CAM conversations would enhance doctor-patient communications. In a cross-sectional study of physician and patient perceptions about CAM at M.D. Anderson Cancer Center, 80% of physicians believed non-disclosure was due to patient fears of being discouraged or disapproved of by physicians, while 50% of patients attributed nondisclosure of CAM to an uncertainty about the benefits and physicians never asking about CAM use.<sup>41</sup> In this study, 91.7% of physician-patient CAM discussions were sometimes or often/very often initiated by the patients.<sup>41</sup> Analysis of audiotaped consultations of Australian and New Zealand oncologists with 102 early stage breast cancer patients revealed 73% of CAM conversations were initiated by patients.<sup>43</sup> In a similar study of 314 transcribed conversations between Australian oncologists and their patients, 66% of complementary therapy discussions were initiated by patients.<sup>44</sup>

Regardless of who initiates the conversation, CAM conversations are an important component in oncology care as many cancer patients have been shown to utilize CAM therapies as part of their treatment strategies.<sup>10,25-28</sup> To enhance the model of patient-centered care, which recognizes the patients as engaged members in their care, physicians need to strive to understand the motivations for CAM use.<sup>35</sup> Addressing a patient's reasons for CAM use helps to identify that patient's values, explanatory models, lifestyle, health beliefs, and goals for care, and may address

unmet needs in conventional treatment.<sup>12,21,28</sup> Frenkel et al.<sup>35</sup> describe the merits of learning a patient's belief system, arguing physicians need to:

identify patient's beliefs, fears, hopes, and expectations; learn what conventional therapies have been tried, have failed, or have been rejected because of safety, quality of life, cost, or other issues; make sure the patient understands prognostic factors associated with the stage of the disease and also understands the potential benefits of conventional therapy as well as its potential harm; acknowledge the patient's spiritual and religious values and beliefs, including views about the end of life and seek to understand how these impact health care choices; discover what levels of support the patient relies on from family, community, faith community and friends (p290).

With a plethora of information available on the Internet, in books, and in journal articles, informed cancer patients are bound to have questions regarding CAM's safety, efficacy, and potential for interactions with conventional therapies.<sup>21</sup> When approached with CAM questions physicians need to react to CAM interests in a "way that makes their patients feel comfortable and safe to at least disclose what CAM they are using and for what purpose." (p367)<sup>33</sup> Additionally, physicians have both a legal and ethical responsibility to respect a patient's autonomy and to discuss CAM.<sup>31,41</sup> There may be instances where physicians need to exert their paternalism<sup>45</sup> to dissuade patients from using therapies that have proven to be harmful, expensive, useless, and ineffective.<sup>35</sup>

The first step in developing strong patient-provider relationships is to establish open, clear lines of communication. Establishing lines of clear communication can lead to increased patient satisfaction, increased medical decision making, increased quality of life, and improved health outcomes,<sup>21,30,35</sup> while poor communication may result in a loss of self-efficacy and patient autonomy.<sup>35</sup> Tasaki et al.<sup>39</sup> warn physicians who disagree with patients' use of CAM need to respectfully disagree with their patients' decisions, so as not to threaten communication about CAM use. Keeping communication channels open between patients and providers fosters a

trusting and supportive relationship, in which shared decision-making can occur.<sup>30,31,35</sup> Shared decision-making recognizes patients as a participatory members in their care and serves to empower them by providing the knowledge necessary to make good decisions about their care.<sup>35</sup>

There are several ways physicians can create a patient-friendly atmosphere for CAM discussions. The simplest strategy is to ask patients about their CAM use as part of the routine medical history or at important points in the illness trajectory, rather than waiting for patients to disclose this information.<sup>21,46</sup> By initiating the conversation about CAM, physicians demonstrate they are open and receptive to talking about the subject. Another strategy is to develop effective, non-judgmental communication skills.<sup>30,35</sup> Several additional evidence-based guidelines for patient-provider CAM discussions emerged in a systematic review conducted by Schofield et al.<sup>46</sup> Among the listed guidelines were respecting cultural and linguistic diversity and actively listening to patients' concerns, including their emotional state and use of CAM.<sup>46</sup> Lastly, even if physicians do not subscribe to CAM use, they should be prepared to have informed, balanced conversations about the available evidence, including the risks and benefits with their patients.<sup>30,35,46</sup> Physicians should also be prepared to conduct regular follow-ups to monitor for adverse reactions and therapy effectiveness.<sup>30,46</sup>

## 2.2 REVIEW OF EXISTING DATA

### 2.2.1 Information Seeking Behaviors of Cancer Patients

The HINTS database is an NCI database of biennial cross sectional surveys that monitor health communication trends and use patterns among adults 18 years or older. First administered in 2002, HINTS surveys seek to determine population-level estimates of health information-seeking behaviors, associated with cancer communication, patient-provider communication, Internet use, and nutrition and physical activity. Currently there are only three datasets available on information-seeking behaviors, the 2003, 2005, and 2007 datasets, so whenever possible the 2007 dataset was utilized for analysis. The HINTS database is comprised of individual survey questions and their responses related to cancer diagnosis and acquisition of cancer information as well as summary factsheets called *HINTS Briefs*. *HINTS Briefs 10* and *16* were reviewed to understand the information-seeking behaviors and the communication medium preferences of cancer patients and survivors.

HINTS Brief 16: *Trends in Cancer Information Seeking* and several HINTS survey questions were reviewed to learn about the different sources cancer patients use when looking for cancer information. Data collected in 2008 revealed nearly 40% of the American public has searched for cancer information, with 55.3% of the population seeking information via Internet searches, while only 24.9% sought cancer information from healthcare providers.<sup>47</sup> Another HINTS question revealed similar trends with 61% of people reporting use of the Internet in their most recent attempts to learn about health topics, while only 13.9% of respondents sought their healthcare providers for health information.<sup>48</sup> In 2003, the most visited sites and search engines for health information were Google, Mayo Clinic, MSN, WebMD and Yahoo.com.<sup>48</sup> Despite the

high prevalence and easy access of Internet searches, only 18.9% of the 2007 HINTS survey respondents placed trust in the information found through Internet searchers, while 68.2% of respondents placed a lot of trust in information obtained from healthcare providers. Hesse et al.<sup>49</sup> hypothesized these trends correspond to the volume of data found through Internet searches, which often leaves patients confused and seeking the counsel of their healthcare providers to help decipher the information found online.

HINTS Brief 10: *Information Support for Cancer Survivors: Cancer Information Seeking Behaviors* was also reviewed to understand the information-seeking behaviors of cancer survivors, since there are an estimated 12 million cancer survivors in the United States.<sup>3</sup> National trends revealed 63% of cancer survivors search for cancer information, 54% of people with a family history of cancer search for information, and 27% of Americans with no affiliation to cancer diagnoses, whether personal or familiar, report searching for cancer information.<sup>50</sup> These trends highlight a desire of cancer survivors to be informed about their diagnosis and treatment options. The 2005 HINTS survey revealed educational level was a predictor of information-seeking behaviors, with those possessing a high school diploma or post-secondary education more likely to search for cancer information than those individuals without high school diplomas.<sup>50</sup> Similar to the information-seeking behaviors observed among cancer patients and the public, survivors tend to retrieve their cancer information from Internet sources, but ultimately prefer to receive this information from healthcare providers.

However, unlike the general American public or Americans with other illnesses, during the first year of diagnosis, survivors were more likely to go directly to their healthcare providers for additional cancer information.<sup>50</sup> From the second year through the tenth year post diagnosis, survivors resorted to the Internet for their cancer-specific informational needs before consulting

with their healthcare providers.<sup>50</sup> In the eleventh year after diagnosis, survivors once again reverted to seeking information from healthcare providers first.<sup>50</sup> The quality of the information available on the Internet is a primary concern among survivors, which may indicate why survivors turn to healthcare providers for cancer information.<sup>50</sup>

## **2.2.2 Public Comment Responses from Healthcare Providers**

To determine the most salient CAM topics for cancer patients and survivors, OCCAM's existing survey data was reviewed. Between April and May 2009, OCCAM conducted an online survey of healthcare professionals. This exploratory survey was conducted to help OCCAM better understand the informational needs of cancer patients with regard to CAM therapies in order to produce communication materials which reflected topics of interest among patients. Several specific groups of healthcare providers were targeted in the administration of the survey, including members of the Cancer Patient Education Network (CPEN), the Oncology Nursing Society (ONS), and the Association of Oncology Social Work (AOSW), and healthcare providers at NCI-designated Cancer Centers, including MD Anderson Cancer Center, Memorial Sloan Kettering Cancer Center, and the Dana Farber Cancer Institute. The survey was posted to OCCAM's website, which allowed additional healthcare providers to respond.

The survey included 11 questions developed to assess the informational needs of cancer patients with regard to CAM. The survey asked healthcare providers to consider the following issues (NCI Public Comment, unpublished data, 2009):

- Please indicate which of the following organizations or type of institution you are affiliated with (choose all that apply):
- Please choose the role you would primarily identify yourself with from the following:
- Please list common issues, topics, or themes that emerge when discussing CAM with cancer patients.



- Please indicate the main reasons your patients use CAM. (For example, symptom management, cure, prevention of recurrence, other diseases, general health)
- Please list the specific CAM therapies you are asked about most frequently.
- When patients ask about specific CAM therapies, indicate what they are most interested in learning about those therapies (for example, safety, effectiveness, cost, and where to go).
- Please comment about the most common myths or misinformation you encounter about CAM when talking to your patients.
- Please describe the resources your patients use to get information about CAM. If possible, please list specific information such as the name of a particular organization.
- Please comment on specific resources (for example publications, websites, databases) you are sharing with your patients when discussing CAM.
- Please indicate the ways you think media stories about CAM affect cancer patients.
- If NCI were to develop only one cancer CAM resource or service for patients, please describe what you think that resource should be?

132 responses were obtained from healthcare providers scattered throughout the country. All answers were entered into NVivo software, coded independently by two members of the Communications and Outreach Program (COP) staff, and assessed for inter-rater reliability.

For each issue, the top ten responses were analyzed due to their representation of the most common concerns and answers. Several of the themes observed in the literature were echoed in the responses obtained from healthcare providers. One such trend focused on the reasons why patients seek CAM therapies: for symptom management, to prevent recurrence, for general health, to reduce stress and relax, a hope for a cure, for pain management, to reduce side effects of conventional treatments, to augment conventional medicine, to regain control over their diagnosis, and to boost their immune function (NCI Public Comment, unpublished data, 2009). Similar to the trends observed in the literature, a majority of the healthcare providers indicated the primary reason their patients report seeking CAM therapies is for symptom management (NCI Public Comment, unpublished data, 2009).

Reasons for nondisclosure of CAM use observed in the public comment data also mirror those cited in the literature. Several healthcare providers noted patients' hesitation to disclose

CAM use to physicians because of a fear of physician disapproval or a negative response (NCI Public Comment, unpublished data, 2009). When patients initiate conversations with healthcare providers about CAM, they are often interested in learning more about treatment efficacy, the cost and insurance coverage available for CAM therapies, places to seek CAM treatments, safety issues associated with CAM use, and how to find qualified practitioners (NCI Public Comment, unpublished data, 2009). The CAM therapies frequently discussed by patients include acupuncture, supplements and vitamins, herbs and natural supplements, massage, diet and nutrition, yoga, reiki (a Japanese spiritual healing practice, which involves placing ones hands over the patient to improve his/her life force energy), meditation, relaxation and stress management, and guided imagery (NCI Public Comment, unpublished data, 2009).

Trends associated with information retrieval observed in the HINTS database<sup>47,48,50</sup> were identified in the public comment data. Healthcare providers noted their patients' primary source of CAM specific information was the Internet or word of mouth and the secondary source of information was from healthcare providers (NCI Public Comment, unpublished data, 2009). In addition to the websites identified from the 2003 HINTS inquiry,<sup>48</sup> healthcare providers reported their patients seek cancer information from the websites of NCI-designated Cancer Centers, such as MD Anderson Cancer Center, the Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, or Memorial Sloan Kettering Cancer Center, in addition to NCCAM's and NCI's websites (NCI Public Comment, unpublished data, 2009).

When asked what type of resource the NCI should produce to educate patients about CAM, healthcare providers indicated the NCI should develop either a patient-friendly website or a printed resource (NCI Public Comment, unpublished data, 2009). This resource should provide patients with information on a variety of topics including specific CAM modalities, how to find

credentialed practitioners, and use of CAM for side effects (NCI Public Comment, unpublished data, 2009). One healthcare provider described the need for better patient education when it comes to CAM therapies, stating (NCI Public Comment, unpublished data, 2009):

patients would like to be a part of the decision making in their care and as much as possible choose their treatment. Adding complementary therapies allows patients to get the most out of treatments for the best possible results. Many patients are not aware of the potential for interactions among therapies especially dietary supplements and chemotherapy and therefore need the best possible education.

A primary limitation of this data was that it excluded patients from the survey, using healthcare providers as proxy responders to identify patient preferences.

### **2.2.3 Patient Focus Group Transcripts**

Focus group transcripts were also reviewed to determine what topics were important to patients with regard to CAM use. The responses obtained in the focus groups helped to shape *Thinking About Complementary and Alternative Medicine: A Guide for People With Cancer*,<sup>51</sup> a previous patient education resource about CAM produced by the Office of Cancer Complementary and Alternative Medicine, Office of Communications, Office of Education and Special Initiatives, and the National Center for Complementary and Alternative Medicine. In 2002, six, 90-minute focus groups were conducted with 52 cancer patients and their caregivers. The objectives of the focus group were to (NCI and NCCAM, unpublished data, 2003):

- Better understand the circumstances in which cancer patients and caregivers seek out CAM information, including why, how, where, and when to seek it;
- Assess what types of CAM information patients seek and how they evaluate that information, including questions they want answered and how they consider the source, criteria of evidence, legitimacy, and tone;
- Examine patients' challenges in finding and concerns about using CAM information and therapies; and
- Determine promising format and delivery options for new and existing CAM materials, including but not limited to print, Internet and CD-ROM.

An additional six telephone interviews were conducted with patients who had chosen alternative therapies over conventional therapies as a treatment strategy.

Several of the themes identified in the healthcare provider survey emerged in the focus group transcripts, including motivations and disclosure patterns associated with CAM use. Among the participants of the focus group, use of CAM varied throughout the course of diagnosis, with some individuals integrating CAM at the beginning of diagnosis and others waiting until later in the treatment course to first use CAM (NCI and NCCAM, unpublished data, 2003). Regardless of when CAM was used, it was often associated with poor prognosis and quality of life and unsuccessful administration of conventional therapies (NCI and NCCAM, unpublished data, 2003). Of the patients who reported having used CAM therapies, many of their motivations were identical to those observed by the healthcare providers. Patients sought CAM to improve their prognosis, increase their immune system support, improve their quality of life, and lessen side effects. The primary sources for CAM information also reflected the trends observed from the healthcare provider survey and HINTS database; patients often obtained their information on CAM topics from the Internet but preferred to receive this information from their providers.

Patients and caregivers reported a variety of responses from their physicians regarding CAM use. Some patients described having supportive conversations with their physicians about CAM, with some physicians even recommending massage, chiropractic, and acupuncture for symptom relief (NCI and NCCAM, unpublished data, 2003). Other patients noted negative, hostile, or disrespectful responses from their physicians, which threatened or dissolved their patient-physician relationships (NCI and NCCAM, unpublished data, 2003).

In addition to asking about patterns of use, sources of CAM information, and interactions with providers about CAM use, several questions were asked about what type of information patients would want in an education resource. One of the primary items patients wanted was an overview of CAM, the types of therapies it included, information on how to find CAM practitioners, and a list of helpful resources to learn new information about CAM (NCI and NCCAM, unpublished data, 2003). Of the potential ways to receive CAM information, participants stated the ideal way would be in the form of a brochure or booklet from their healthcare provider (NCI and NCCAM, unpublished data, 2003).

Despite a seven-year gap between the administration of the focus group and the request for public comment data from healthcare providers, the trends associated with cancer patient use of CAM remained the same as those reported by healthcare providers. The motivations for CAM use in cancer patients were to improve prognosis, quality of life, and control over cancer. The trends related to the preferred sources of information were also congruent with those found in the HINTS database<sup>47,48,50</sup> and public comment responses (NCI Public Comment, unpublished data, 2009). These three sets of data revealed that the primary source of CAM information is the Internet, although the preferred source of acquiring health information is from healthcare providers.

#### **2.2.4 Patient Education Symposium Transcripts**

Transcripts from the 2010 International Congress on Complementary Medicine Research (ICCMR) symposium, “What are Best Practices in Developing Cancer CAM Patient Education Materials,” were reviewed to provide insight to develop CAM patient education resources. This symposium featured health communication experts from three NCI-designated Cancer Centers,

MD Anderson Cancer Center, Memorial Sloan Kettering Cancer Center, and the Dana Farber Cancer Institute, “to identify the best practices on developing cancer patient education materials on the topic of complementary and alternative medicine (CAM)”(p1).<sup>52</sup> One of the speakers emphasized a key element to always keep in mind when developing patient education resources is that patient education resources should be empowering (National Capitol Captioning, unpublished data, 2010). The other two participants expounded on this point, stating that any initiative undertaken should always strive to present the health information in ways that are easy to understand and encourage the readers to take action (National Capitol Captioning, unpublished data, 2010). Furthermore, they argued, if possible, health communication specialists should always try to keep communication campaigns simple by reducing the number of topics presented in each campaign (National Capitol Captioning, unpublished data, 2010). Additional factors to consider are the overall purpose of the communication campaign, the size of the intended audience, and accessibility of new information (National Capitol Captioning, unpublished data, 2010). The panelists also discussed the importance of speaking with clinical staff about topics of interest as well as searching the literature to identify trends (National Capitol Captioning, unpublished data, 2010).

Other topics discussed during the symposium revolved around the issue of health literacy. To increase the reach of communication initiatives, the panelists suggested communication materials should be written at a 6<sup>th</sup> to 8<sup>th</sup> grade reading level, should not include a lot of acronyms, and should try to reduce medical jargon whenever possible (National Capitol Captioning, unpublished data, 2010). Other ways to increase health literacy include using pictures to convey communication messages or incorporating more white space into the design (National Capitol Captioning, unpublished data, 2010). Another strategy for improving health

literacy is to include patients and their family members or caregivers in the design processes of health communication materials.

A final topic discussed during the symposium was how frequently content should be updated. The choice of communication medium, content, and design of campaigns usually dictates the frequency with which materials need to be updated, whether every year or every three years (National Capitol Captioning, unpublished data, 2010). For example, websites require more frequent updates than print material; however the content of print material needs to withstand the test of time between revisions (National Capitol Captioning, unpublished data, 2010). Several of the topics discussed during the ICCMR symposium, including the frequency of content updates, communication medium selection, and health literacy, helped to lay a foundation of communication development guidelines for the creation of OCCAM's patient education resource.

### 3.0 METHODS

To enhance communication between patients and healthcare providers OCCAM developed a patient education workbook to track use of complementary and alternative medicine, both during and after cancer care. Documenting use of cancer CAM therapies strengthens the model of patient-centered care because it enables greater communication about potentially untreated or undiagnosed cancer-related symptoms and may yield information about patient preferences for a holistic approach to their care. Development of OCCAM's patient education workbook was guided by the information collected from the review of existing sources of data. This process previously discussed in Chapter Two included a review of the Health Information National Trends Survey (HINTS) database factsheets and OCCAM's existing qualitative data. The following section of this thesis will describe how the formative research processes led to the development, pretesting, and implementation of the workbook.

After reviewing OCCAM's available qualitative data, an environmental scan of various cancer advocacy websites was conducted. A total of 18 websites of national cancer organizations and advocacy groups for several of the leading types of cancer were selected for review from a list of 64 cancer organizations that OCCAM had previously catalogued as having at least some form of CAM information. Each website was reviewed to determine what type of information was available about CAM therapies, in what mediums this information was presented (e.g., pdfs, role model stories, webinars, or videos), and accessibility of the CAM information (i.e., how



easy it was to find CAM information on a website). Since the author lacks an extensive CAM background, the environmental scan was performed from the perspective of a patient or his/her family member seeking information about CAM.

During the preliminary development of OCCAM's workbook, initial healthcare provider feedback was obtained from members of the American Society for Clinical Oncologists. Additional feedback was obtained via email outreach from members of NCI's Office of Communications and Education (OCE).

To test the functionality and usability of the workbook, OCCAM conducted two rounds of pretesting. During the first round of pretesting, OCCAM utilized Open Call Testing to collect feedback. Open Call Testing is a form of usability testing or pretesting sponsored by the NCI and conducted through the Office of Market Research and Evaluation (OMRE) to test communication materials. Offered bimonthly, usability testing combines two-to-four communication projects, including brochures, workbooks, websites, videos, and pamphlets into one aggregate project (User Center Designs, Inc., unpublished data, 2012). During usability testing, project designers, web portal managers, and content managers are provided an opportunity to collect qualitative data on their work from members of the general public. Additional feedback strategies employed during the first round of pretesting included an interview with a Medical Oncology Clinical Fellow and two in-services with members of the nursing staff of 3 SE South Hematology/Oncology Day Hospital at the NIH's Clinical Center. Email outreach was also conducted with members of the NIH's Clinical Center Department of Social Work.

The second round of pretesting was comprised entirely of email outreach. The Office of Advocacy Relations' (OAR) Consumer Advocates in Research and Related Activities (CARRA)

program was utilized to acquire contact information for cancer advocates, including survivors, caregivers, and advocates, willing to review OCCAM's workbook. Healthcare provider contact information was obtained internally from OCCAM's Director, Dr. Jeffrey D. White and OCCAM's Case Review and Intramural Science Program Director, Dr. Farah Zia.

## **4.0 RESULTS**

This section describes how the information obtained from the literature review, existing data review and environmental scan were synthesized to develop *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips*. Also detailed in this section are the results of the two rounds of pretesting, including the revisions that were made after each subsequent round of testing. Finally, a description of each of the workbook pages and the rationale for the creation of the overall work are provided.

### **4.1 FORMATIVE RESEARCH RESULTS**

#### **4.1.1 Environment Scan of Cancer Advocacy Websites**

Of the 18 cancer organizations in the sample, several national organizations including the American Cancer Society (ACS), the Leukemia and Lymphoma Society (LLS), the Livestrong Foundation (Livestrong), and Susan G. Komen for the Cure (Komen) were reviewed for their CAM content. Additional specific cancer site advocacy groups' websites were also reviewed including BreastCancer.org, Breast Cancer Action, the Colon Cancer Alliance, the Hirshberg Foundation for Pancreatic Cancer, the Lung Cancer Alliance, the National Brain Tumor Society, the National Ovarian Cancer Coalition, the Prostate Cancer Foundation, and ProstateNet.org.

Other advocacy groups included in the scan included the Alliance of State Pain Initiatives, the Cancer Journey.org, Patient Advocates for the Advanced Cancer Treatment, Patients Against Lymphoma, and the Wings Cancer Foundation. The websites for each of advocacy organizations reviewed are listed in Appendix A.

Comparisons of the national organizations revealed drastic differences in the volume of CAM information available and ease of information retrieval: the ACS, Komen, and LLS websites were much easier to navigate than Livestrong. On the Livestrong website, there was no discernible CAM section, and CAM information was embedded within the body of the text and usually at the bottom of the webpage. For example, on Livestrong's Neuropathy page, examples of complementary therapies, which might alleviate some of the symptoms associated with neuropathy, are presented as a list of therapies, with no description. Additionally, utilizing the search field for "complementary and alternative medicine" yielded no search results. Therefore it was determined the Livestrong Foundation's website was not a good resource for extensive CAM information.

In contrast with the Livestrong Foundation's website, the Susan G. Komen for the Cure (Komen) website was an example of an outstanding resource for CAM information. Not only was all of the CAM information located on a central webpage, but it was also presented in a highly organized way. Anyone seeking CAM information could search for specific topics of interest either by the therapy name or class of therapy. For example, information about acupuncture is found within the master list of CAM therapies, and listed under the Manipulative and Body-Based Practices.

When a CAM topic is selected from the list of 75 available topics, an entire webpage opens that provides a brief background, a list of synonyms for the therapy, and an explanation as

to why the therapy is or is not beneficial. In addition, the scientific evidence indicating the safety and efficacy of a therapy is described for a variety of symptoms and diseases and given a ranking of “A” to “F.” A letter grade of “A” represents strong scientific evidence for the application of use. For example, use of acupuncture to treat chronic pain receives an “A”, while omega-3 supplementation for diabetes receives a “D,” which indicates there is a lack of sufficient scientific evidence to support its use. The CancerJourney.org also provides similar rankings of therapies in terms of their effectiveness for anxiety, fatigue, depression, and nausea and vomiting, but labels the effectiveness for each therapy most helpful, likely to be helpful, and not enough evidence.

Besides offering comprehensive information on various CAM therapies, the Komen website provides information on common topics associated with CAM use, such as safety and efficacy, locating CAM practitioners, finding CAM clinical trials, and questions to ask your providers. A strength of this website is that it provides CAM information in a variety of communication mediums, which include html webpage text, PDFs, videos, podcasts, and interviews with survivors, and booklets, such as *Feel Better During Breast Cancer Treatment: Learn How Integrative and Complementary Therapies Can Help*.

Other breast cancer advocacy sites, such as Breast Cancer Action and BreastCancer.org were also reviewed. Breast Cancer Action is a grassroots education and advocacy organization located in San Francisco and does not contain readily available CAM information on its site. Discussions of CAM are focused in Breast Cancer Action newsletters only. Unlike Breast Cancer Action, BreastCancer.org contains a wealth of CAM information. Some of the resources available on this site include strategies for talking to your doctor about CAM, tips regarding safety and effectiveness, and sheets summarizing a variety of CAM therapies. Each summary

sheet provides an overview of the therapy, expectations for use, practitioner certification requirements, current scientific evidence, and possible complications. These descriptive sheets are available for acupuncture, aromatherapy, chiropractic therapy, guided imagery, hypnosis, journaling, massage, meditation, music therapy, progressive muscle relaxation, reiki, tai chi, and yoga. This site also features quotes from women who have used CAM and found the integration of these therapies helpful as well as comments from healthcare providers citing the validity of including CAM in treatment regimens.

Similar to Komen's and BreastCancer.org's websites, the American Cancer Society's (ACS) website contains a myriad of CAM information. The information available is much more extensive than that on Komen's, but that is to be expected as the American Cancer Society is the largest non-profit volunteer health organization in the United States. For example, there are over 300 CAM modalities fact sheets available for review. Each fact sheet provides the user with an overview of the therapy, a history of the use of the therapy, how it is intended to be used, scientific evidence surrounding the therapy, any complications which may arise as a result of using the therapy, and additional resources for more information. Additional information on the CAM portal of the ACS's website includes an overview of CAM, explanations about dietary supplement safety, and explanations of five different classes of CAM therapies, mind, body and spirit, manual healing and physical touch, herbs, vitamins, and minerals, diet and nutrition, and pharmacological and biological treatments. ACS employs many of the same communication mediums as Komen to disseminate CAM information including pdfs, videos, booklets, survivor interviews, and podcasts. In addition, the American Cancer Society has published a book<sup>53</sup>, *The American Cancer Society Complete Guide to Complementary and Alternative Cancer Therapies*,

*2nd Edition*, to help cancer patients, caregivers, and the public understand the field of CAM as well as therapies classified as CAM.

Most of the websites reviewed were not as thorough as the American Cancer Society in terms of available CAM information and accessibility of this information. In fact, most of the websites featured a brief, basic discussion of CAM. A majority of the information about CAM on these sites is often embedded within website sections dedicated to symptom management and treatment options or located in larger discussions of quality of life issues. For example, the Leukemia and Lymphoma Society (LLS), the National Ovarian Cancer Coalition, and the National Brain Tumor Foundation all provide a description of CAM on their websites, but more thorough explanations of CAM, including an overview of CAM, its major categories, and the associated risks and benefits of CAM use, occur in their patient education resources. These publications included the LLS's thirteen-page booklet about CAM, *Integrative Medicine and Complementary and Alternative Therapies as Part of Blood Cancer Care*, the National Ovarian Cancer Coalition's patient education resource, *Ovarian Cancer Quality of Life Issues*, and the National Brain Tumor Society's publication *The Essential Guide to Brain Tumors*. In contrast, the Prostate Cancer Foundation does not provide a direct description or overview of CAM therapies on its website. Instead it uses its publication, *Nutrition, Exercise and Prostate Cancer*, to discuss the role of exercise and nutrition, including the use of supplements, antioxidants, and phytochemicals in prostate cancer diagnoses.

Other sites like the Colon Cancer Alliance, Hirshberg Foundation for Pancreatic Cancer, the Lung Cancer Alliance, and ProstateNet provide patients with rudimentary explanations of CAM and refer patients to outside resources such as NCCAM's or OCCAM's website for more CAM information. While sites like the Wings Foundation or the CancerJourney.org recommend

specific types of therapies such as nutritional counseling, meditation, yoga, labyrinth walking or massage for pain, they do not provide overarching discussions of CAM. Still other sites such as Patient Advocates for the Advanced Treatment and the Alliance of State Pain Initiatives do not provide any CAM information, whatsoever.

Similar to the analysis of CAM trends, classification of CAM therapies, and definitions applied to CAM, great variability was observed in the content, organization, accessibility, and presentation of CAM information in the small survey of cancer advocacy websites. These inconsistencies may be due to the size and scope of the organizations and the resources each organization has available towards patient education and website maintenance. Organizations like Susan G. Komen for the Cure and the American Cancer Society should have extensive information and patient friendly websites, due to their size, brand recognition, advocacy efforts, and budgets. Other reasons for such differences between websites may include organizational support of CAM therapies, organizational confidence discussing CAM, and marketing of CAM, i.e. as separate tabs on websites or embedded within larger patient education efforts. It is no surprise then, that of the websites surveyed, ACS and Komen provided the best explanations of CAM. These sites not only thoroughly described the categories of CAM and the individual CAM therapies, by providing explanations on the safety, effectiveness, and rationale for use, but they were also easy to navigate.

In addition to reviewing cancer advocacy websites, three NCI-designated Cancer Centers' websites (MD Anderson Cancer Center, Memorial Sloan Kettering Cancer Center, and the Dana Farber Cancer Institute) were also analyzed. These three were chosen because of their national recognition as leading cancer centers. Similar to the presentation of CAM in the various advocacy groups surveyed, each cancer center's patient education department was very different.



For example, the Leonard P. Zakim Center for Integrative Therapies at Dana Farber Cancer Center used a variety of communication modalities to discuss CAM; these included html webpages, PDFs, YouTube videos, and role model stories describing patient's experiences using CAM therapies. This website also details the available therapies Dana Farber Cancer Center offers, which include acupuncture, nutrition services, creative arts, music therapy, qigong, and reiki.

Memorial Sloan Kettering Cancer Center's website provides some information on treatments available at the hospital, acupuncture, exercise, and art therapy, as well as information on current research endeavors and active clinical trials. This site features several videos that explain common concerns associated with CAM use, demonstrate yoga breathing techniques, discuss herbal use during survivorship, and describe the role of therapeutic touch for symptom alleviation. The website also includes an extensive database of evidence-based information for over 200 herbs about the uses, pharmacokinetics, adverse reactions, warnings, and herb-drug interactions. This database is available online and in mobile app format for healthcare providers and patients.

Similar to Memorial Sloan Kettering and Dana Farber's Integrative Medicine websites, MD Anderson Cancer Center provides a wealth of information for patients about complementary therapies and clinical trials. Information on the various CAM therapies is organized by the category of therapy, including but not limited to energy therapies, manipulative and body-based methods, and mind-body approaches. Thorough explanations of both the CAM category as well as the individual therapy are provided. This website contains an extensive list of books, websites, periodicals, government resources, and academic centers which feature either general or cancer-specific CAM information along with ongoing lecture series at MD Anderson. Unlike the

websites of the Dana Farber Cancer Institute or Memorial Sloan Kettering Cancer Center, a small section of the Integrative Medicine resources are dedicated to discussing patient-provider conversations.

#### **4.1.2 Discussing CAM with Healthcare Providers**

Information about the importance of talking to healthcare providers about CAM use was present on all websites that provided an overview of CAM. Most of the sites reviewed featured this information in the form of bulleted lists of tips patients can employ to facilitate CAM conversations. However, the American Cancer Society and Susan G. Komen for the Cure developed specific patient education resources to help guide patients on how to talk to their providers, including sample questions to ask. Instructions to speak with one's healthcare provider were usually preceded by warnings about CAM's potential interactions with prescription medicines and other conventional treatments.

NCCAM designed a communication campaign to specifically address this very issue. The *Time to Talk* campaign educates both patients and providers about the importance of talking to one another about CAM, regardless if the intended use of CAM is preventative or curative. *Time to Talk* provides guidelines for patients, providers, and community members to engage in conversations about CAM use. This campaign features strategies designed to help patients and providers talk about CAM use as well as explanations as to why these conversations are important. The campaign resources also include wallet cards for patients to document their medications, including vitamins, herbs, and dietary supplements; posters and brochures for healthcare providers to promote such conversations; and widgets, which can be placed on other

websites to increase awareness about NCCAM’s campaign and the need to change patient-provider dialogues regarding CAM use.

## **4.2 PRETESTING: ROUND ONE**

### **4.2.1 Preliminary Pretesting Efforts**

Throughout the development of the patient education workbook, OCCAM sought feedback on the design, functionality, and utility of its design at various draft phases. The first pretesting efforts were employed in June 2012 at the American Society of Clinical Oncologists’ annual meeting in the form of public comment requests. Under the Paperwork Reduction Act (PRA) of the Office of Management and Budget (OMB), there is a limit to the number of people who can be surveyed without requiring official clearance and approval. Established in 1995, the PRA seeks to monitor the processes by which information is obtained by or for the government from the public.<sup>54</sup> Per the PRA,<sup>54</sup> “information collection must be cleared by OMB if an agency collections information from ten or more people, regardless of whether the collection is mandatory, voluntary, or required to obtain or retain a benefit during the following circumstances:

- When an agency obtains, causes to be obtained, solicits, or requires the disclosure
- To an agency, third party or the public of information
- By means of identical questions or identical reporting, recordkeeping, or disclosure requirements.

By utilizing public comments, or open-ended, unstructured questions, OMB clearance was not needed in order to solicit feedback from conference attendees.<sup>54</sup>

OCCAM's Office of Communication and Education (OCE) liaison, Shea Buckman Manley, facilitated collection of responses by asking attendees who visited her booth at the conference to respond to the following comments:

- Please describe your experience talking with patients about their complementary and alternative medicine (CAM) use and beliefs (e.g. yoga, vitamins, acupuncture) and whether or not you believe this resource would encourage useful conversations about CAM in your practice.
- Identify whether patients keeping track of their CAM use in these logs may help you enhance their care.
- Identify how you or your office staff would use this resource.

Four physicians, three Medical Doctors (M.D.s) and one Doctor of Osteopathic Medicine (D.O.) provided comments on OCCAM's workbook. Three of the physicians noted the resource would be helpful and that they liked the overall design of the workbook. Two of the workbook pages that resonated with the physicians were the medication list and the provider list because these pages provide useful information for all members of the healthcare team (S.B. Manley, email communication, 2012). Some of the suggestions were to add a section on patient rights and responsibilities, include more spaces to list medications, create more space to list CAM therapies, and provide patients with information about CAM clinical trials (S.B. Manley, email communication, 2012). One physician was concerned about the potential "set-up" and unrealistic expectations to discuss all of the workbook topics within one clinical visit. These initial comments provided an early validation that there was in fact a need for a resource designed to improve communication between patients and providers about CAM.

Additional preliminary feedback endeavors included review of OCCAM's material by two members of OCE's staff. Direct feedback was not provided on the utility of the materials by

the OCE staff; instead, suggestions were provided on how to lower the reading level of the document. One suggestion was to simplify the medical terminology used throughout the document, making such changes as switching the word “medication” to “medicine” on the medicine list (S.B. Manley, email communication, 2012). An additional suggestion was to change the text of the document from the third person to first person to better engage the reader. For example, the questions on *Why I want to use CAM* were changed from “Why are you interested in using complementary or integrative therapies with your cancer treatment?” to “I am interested in using CAM because” (S.B. Manley, email communication, 2012). Other suggestions were to reduce the length of the sentences, simplify the instructions, and reduce the overall amount of text used in the workbook (S.B. Manley, email communication, 2012).

#### **4.2.2 Open Call Testing**

On July 17-18 2012, OCCAM participated in usability testing along with two other offices, the Office of the National Coordinator (ONC) and the Office of Biorepositories and Biospecimen Research (OBBR). Prior to the pretesting sessions, several meetings were held with the OMRE, OCCAM, and OBBR to establish screening criteria, testing goals and objectives, and to develop a moderator’s guide for the pretesting session. Each Open Call Testing session is capped at nine people so as to not require OMB clearance.<sup>54</sup> Due to the sample size restrictions, OMRE facilitated a meeting with OBBR and OCCAM to determine what types of individuals each project required for optimal feedback, and together the two offices established a set of recruitment criteria. ONC was not involved in the initial recruitment meetings due to its late addition to the testing schedule for the month of July. Since the patient education booklet was not targeted to any one particular group, OCCAM was not restrictive with the recruitment

criteria, but instead encouraged a variety of participants with different demographic characteristics. The only criterion OCCAM requested was that some of the participants had some familiarity with CAM therapies, so that time would not be spent explaining CAM. In order to assist with recruitment, OCCAM developed two CAM specific screening questions (see Appendix B 1.1).

User Centered Design, Inc., an independent firm that conducts usability testing for a variety of non-profit, industry, and governmental organizations, including the National Cancer Institute, recruited the study participants (User Center Design, Inc., unpublished data, 2012). Despite sampling restrictions, an even distribution among racial categories was achieved, with three African American participants, three Caucasian participants, and three Caucasian-Hispanics participants (see Appendix C, Table 1). Additionally, a range ages were represented and both men and women were included in the usability testing sessions. The educational level of the participants was fairly high and consistent.

OMRE, OCCAM, OBBR and User Centered Design, Inc. held an additional meeting to draft the moderator's guide for the focus group. Each office was asked to provide its objectives and questions for testing (see Appendix B.1.2). OCCAM's primary objectives for testing were to determine if the material, as written, was understandable; whether patients would utilize a workbook designed to track CAM use, if so, how and which pieces; and whether a patient education resource would help patients discuss complementary and alternative medicine with their doctor. A secondary focus of testing was to determine participant preference for images, color, text, and layout. The final moderator's guide (see Appendix B.1.3) was distributed to each group for review prior to testing, and captured a majority of topics OCCAM was interested in investigating.

Usability testing was conducted over the course of two days. The nine testing sessions were recorded allowing members from OCCAM, OBRR, and ONC to observe the interactions between the moderator and the participant. Each testing session lasted approximately one hour, with 17 minutes allotted for each of the three group's communication products (User Center Inc., unpublished data, 2012). Due to the limited amount of time with each participant, OCCAM selected three workbook pages for review, *Why I want to use CAM* (see, Appendix B, Figures 1 and 2), *My weekly CAM use* (see, Appendix B, Figures 3 and 4), and the cover (see, Appendix B, Figures 5 and 6). Two versions of each tested page were developed with specific criteria to evaluate the design elements and utility. Another set of objectives for usability testing included determining participant preference for completing the workbook pages, with each participant offered the opportunity to fill in the requested information either on printed forms or online versions of each form.

At the start of each testing session the moderator asked participants whether they were familiar with the term complementary and alternative medicine. If a participant was familiar with CAM he was asked to provide examples of specific CAM therapies that he had used. If a participant was not familiar with CAM, he was provided a brief definition as well as a list of examples of CAM therapies that included but were not limited to yoga, meditation, tai chi, supplements, and acupuncture, so that he would have some familiarity with CAM in order to fill out the information in the worksheets. Of the nine total participants, six participants were at least somewhat familiar with CAM.

Next, participants were asked their preference for online versions or printed worksheets. A majority of participants began the testing session using online versions of each document but later switched to paper documents to complete the testing session. Participants were shown either

version A or B during their testing session and asked to provide comments on each workbook page, as prompted by the facilitator. Before the end of each testing session, participants were shown the alternate versions of each document and asked to indicate which they preferred.

Participants were first shown was *Why I want to use CAM* (Appendix B, Figures 1 and 2). Participants were asked to provide their thoughts about the utility of this worksheet. Two of the participants recognized the value of documenting their questions, concerns, and CAM interests prior to visits with their provider(s) to engage in better health conversations. Another participant was concerned with the inherent assumptions underscored on *Why I want to use CAM*: she felt this document assumes the patient is “knowledgeable about CAM.” Several other participants echoed her concerns indicating that it would be helpful to have a list of CAM modalities included in the workbook for reference prior to completing *Why I want to use CAM*.

Additional questions were asked about the two versions, A and B, (Appendix B, Figures 1 and 2) with regard to image selection and text box size and placement since the content of each version was identical. A majority of participants preferred the linear arrangement of version A to that of version B. However, many preferred the images of version B to that of version A because they were more discernible.

Finally, participants were asked whether this workbook would aid discussions of CAM use with their providers. One participant indicated she would have found this resource helpful at the time of diagnosis to help facilitate discussions with her providers. Another participant explained she would be more likely to discuss CAM use with her oncologist than primary care physician because her oncologist supported trial of therapies that make her “feel good.”

The second worksheet participants were asked to review was *My weekly CAM use* (Appendix B, Figures 3 and 4). Two versions of this document were shown to participants;



version A had labeled columns with rows for the days of the week, which allowed only three CAM therapies to be tracked per day, or version B, an unlabeled version, which allowed patients customize the number of CAM therapies they tracked per day. Those participants who were shown version B found the unlabeled version to be confusing, preferring to have both the gridlines and days of the week clearly delineated.

Participants were also asked to comment on the column headings and usefulness of tracking conventional therapies. Most participants felt the column headings were straightforward; however, one participant suggested changing the last column's heading from "how did it make you feel" to "notes." She argued it is impossible to attribute "relief" to any one therapy when "multiple therapies" are used simultaneously. Regardless of the version reviewed, some participants struggled to understand what the term "conventional therapies" referred to; they did not understand that it was synonymous with standard treatments.

Since the content of the two versions, A and B was identical, a majority of the questions about *My weekly CAM use* were centered on its usefulness. Several participants stated they would be more likely to use this document for personal use rather than for sharing the information with their physician. One participant suggested documenting CAM therapies and their effects on symptom management might be useful to obtain "insurance authorization" for certain CAM therapies, since tracking CAM use could demonstrate an improvement of symptoms through use of the particular therapy/ies. Several other participants admitted they would not track their CAM use in such an organized way because they were not as disciplined as they should be. However, most participants stated they would fill out this form if their healthcare provider gave it to them.

Two participants had concerns about tracking CAM use on a weekly basis, particularly when receiving cancer treatments. They stressed during the active phase of treatment, patients are grappling with the emotional, psychological, and physical ramifications of cancer diagnoses and treatments, so tracking CAM use on a weekly basis may be “too taxing” for some patients. Plus some patients may rely on caretakers to “keep track of medications” and act as their advocates because they are simply too ill. A concern was also raised about the amount of time needed to feel the “effect of a treatment” and the restrictions of being able to document only three CAM therapies per day. One participant suggested creating a monthly tracking log instead of a weekly calendar to increase the breadth and scope of CAM therapies captured as well as their effect.

The last workbook page that participants reviewed was the front cover. Two versions of the cover were produced (Appendix B, Figures 5 and 6). Version A of the cover displayed predominantly cool colors and darker images, with the title *Talking about Complementary and Alternative Medicine Use with Your Doctor: A Guide for Cancer Patients*, while version B had warmer colors, images of patient-provider interactions, and the title *A workbook and tips to improve communication with your doctor about complementary and alternative medicine*. Participants were asked to evaluate several aspects of the cover design, including title, use of the term “workbook” versus “guide,” color and image selection, and placement of the OCCAM’s office banner. Study participants did not reach consensus on the title or color preference with five of nine participants preferring the terms “workbook” and “tips” to “guide” and five of nine people favoring an orange banner bar to a blue bar. As for the location of the office banner bar, it was determined it should be a small box placed near the top of the document to inform the reader who produced the work, but should not detract from the workbook title.

As for the number and types of images, some participants felt there were too many images on the orange cover (Appendix B, Figure 6). Participants noted that when viewing health communication materials, they preferred to see healthy, smiling people because they “make people feel positive.” Participants also suggested the selected CAM images on the cover should be of therapies people would recognize. One participant associated the meditation photo featured on version A of the cover with “the darkness of cancer,” while the yoga image on the same cover was correlated with “health” and “exercising.”

When time permitted, participants were also asked to give their opinions about *My complete medicine list* and *Members of my health care team*. The majority of participants felt both forms would be very helpful and appreciated the layout of each document that separated the information into various categories. Of the forms included in the workbook, participants felt *My complete medicine list* would be most helpful in communicating interests with physicians, due to the frequency with which patients are asked about their medication use. Participants liked the separate categories for prescriptions, over-the-counter (OTC), and vitamins, herbs, and dietary supplements because several participants did not consider supplements “as medicine.” The primary complaints about *My complete medicine list* were the size of the cells and not being able to track all of their medications within the allocated spaces. Three participants also discussed how they would be more likely to utilize the provider contact list for personal use, but would be willing to show their providers, if they wished to establish coordinated care plans.

#### **4.2.3 NIH Clinical Center 3 South East South Oncology Nurses**

Pretesting with the healthcare providers coincided with preparations for Open Call Testing. Outreach efforts for the month of July 2012 were primarily concentrated with healthcare

professionals located in the NIH's Clinical Center. The Clinical Center is a world-renowned medical research hospital located at the heart of the NIH's main campus. OCCAM's OCE liaison, Shea Buckman Manley, identified a nurse manager of an oncology unit located within the Clinical Center, 3 SE South Hematology/Oncology Day Hospital (3 SE South), whom she believed would be willing to provide feedback on OCCAM's project. This professional contact had previous experience collaborating with NCI offices on patient education projects. Through email correspondences and an in-person meeting between the author and the nurse manager, strategies were developed to obtain feedback from her nursing staff. It was suggested the author conduct an in-service with the nursing staff of 3 SE South during one of their morning staff meetings.

3 SE South Hematology/Oncology Day Hospital is comprised of 20 to 25 nurses, with a variety of nursing expertise in the public and government sectors. The nurses of 3 SE South monitor the health and safety of oncology patients who are involved in NIH clinical research trials and are often placed under strict protocols for medications.<sup>55</sup> Since the clinical environment of 3 SE South is not reflective of public or private hospital oncology floors, the nursing staff was asked to evaluate OCCAM's workbook as healthcare providers and not as federal Clinical Center employees, since utilization of CAM therapies by 3 SE South's patients is often restricted due to clinical trial protocols.

About one week after meeting with 3 SE South's unit director, the author provided an in-service presentation for eight members of the nursing staff about OCCAM's initiative. During the staff meeting, the author described the purpose of the campaign, presented the two workbook versions, and explained the questions OCCAM wanted to have answered during the review process. Samples of each version of the workbook as well as feedback tracking forms were left

with the nursing staff for a period of two weeks. The feedback tracking forms enabled nursing staff to evaluate each workbook page, making any notes about specific pages while answering the questions regarding utility of the workbook (see Appendix B.1.5 and Figure 7). A second in-service for approximately 10 to 12 nurses was conducted two weeks after the first presentation was held.

From the two in-services conducted with staff members of 3 SE South, six feedback forms were completed. The nursing staff that responded to OCCAM's inquiry had favorable reactions to the workbook. Most nurses believed OCCAM's workbook was a "good resource" that would be "valuable/useful" for patients and caregivers as well as nurses, doctors, social workers, dietitians, pain/palliative care coordinators, and nutritionists. One nurse believed *My complete medicine list*, *Why I want to use CAM*, and *Members of my healthcare team* would be most helpful for patients. Every nurse who provided feedback indicated she thought this resource was helpful and would recommend the workbook patients.

Similar to the patient population, the nurses were asked to evaluate each page of the workbook, paying particular attention to the two versions of the cover, *Why I want to use CAM* and *My weekly CAM use* (Appendix B, Figures 1-6). Since the feedback forms were left with the nurses to fill out at their leisure, comments were obtained for mostly every workbook page. However, unlike the patient population, when comments were rendered the answers provided by the nurses were more succinct because they were written. There were no responses regarding preference for version A or B's cover design, title, or layout. The comments for *Why I want to use CAM* mirrored those of the patient population; the nurses suggested adding a list of CAM therapies prior to this worksheet to assist patients in filling out their motivations for CAM use. Similar to the participant reactions to *My weekly CAM use*, some nurses believed this resource

might be more helpful for patients, than healthcare providers, as they “test out” the effects of different therapies on their symptomology. Many of the nurses conceded that the information was still valuable and important for nurses to know as it connected “actions and results” of use of CAM for symptom relief.

A primary concern with the design of the workbook was the amount of space present in the medication list. Several nurses stressed many cancer patients medication regimens include more prescription medications, in effort to manage both the cancer as well as potential comorbidities than OTCs or vitamins, herbs, and dietary supplements. It was advised to include more spaces for prescription medications and reduce the space for OTC and nutritional supplements. An additional expressed concern was associated with the reading level of OCCAM’s workbook. One nurse suggested creating simpler versions of the workbook pages written at a “6<sup>th</sup> grade reading level.”

#### **4.2.4 NIH Clinical Center Medical Oncology Branch Clinical Fellow**

On July 9, 2012, the author conducted an hour-long interview with a Medical Oncology Branch Clinical Fellow regarding the use and utility of OCCAM’s workbook. During the course of the interview, the medical oncologist was asked the same set of questions as the nursing staff (Appendix B.1.5) and asked to review each workbook page. The Fellow’s overall impressions of the workbook, similar to the nursing staff, were positive. He felt this resource would be very helpful for physicians to acquire additional “information” about patients’ coping mechanisms, which is “generally” not disclosed, including their use of CAM. He stated he would recommend this resource to seasoned and novice CAM users alike as well as patients who “expressed interest” in incorporating CAM into their treatment regimen.

Of the workbook pages, the medication list received the greatest praise from the Oncology Fellow. He believed documentation of all medication would “stimulate dialogue” between patients and providers about the different types of medications used (prescription, OTC, and supplements), medication adherence, side effects, and potential interactions in addition to increasing “awareness” among physicians about the use of supplementation. The Oncology Fellow had a more favorable response to *My weekly CAM use* than the nurses, reiterating “documentation” of patient coping strategies outside of the clinical environment is always “helpful.” He appreciated the “concise and organized” format of *My weekly CAM use*.

In addition to providing positive feedback on the resource, the Fellow gave a lot of constructive criticism during the course of the interview. He expressed concerns, similar to those of the nurses of 3 SE South, about the breadth and health literacy level of the workbook. To improve use and utility of the workbook, he advised creating a simplified version of the workbook so as not to “overwhelm” patients who might not be familiar with CAM and might be experimenting with its use for symptom alleviation or health management. He also suggested that OCCAM should redefine its use of standard of care, providing an anecdotal story a Ukrainian patient who consumed an herbal tea daily, which to him was a standard of care, but greatly interfered with his electrolyte balance. The last suggestion was to include more cautionary language within the booklet about the dangers associated with CAM use, particularly because of the “vulnerability of cancer patients.” Unfortunately, there are many websites and products that prey upon cancer patients’ desire to find additional therapies, medicines, or cures for their cancers by claiming that their products prevent or reduce cancer recurrence or can cure cancer. Extreme caution should always be utilized when purchasing supplements. The Food and Drug Administration (FDA) does not regulate dietary supplements in the same manner as

prescription drugs, requiring proven safety and effectiveness prior to marketing, but they are monitored for adverse effects.

#### **4.2.5 NIH Clinical Center Department of Social Work**

During a cancer diagnosis, there are many different types of healthcare providers with whom patients come in contact, including social workers. A member of the NIH's Department of Social Work provided his critiques of the workbook. Similar to the other healthcare providers contacted, the social worker was provided an electronic copy of the workbook and asked to review both the document and the list of questions (Appendix B.1.5). Nearly all of the questions posed to the social worker were identical to those posed to the nurse and medical oncologist, with the exception of one question that was changed to be more reflective of the field of social work: Identify how and when you would use a resource such as this with your patients. Upon review of the workbook, the social worker believed OCCAM's project would in fact strengthen communication efforts between patients and providers because this workbook facilitates documentation and discussion of CAM use, yielding valuable information for providers about patients' "ability to cope" with their cancer diagnoses.

### **4.3 CHANGES IMPLEMENTED AFTER ROUND ONE OF PRETESTING**

OCCAM's first round of pretesting yielded a wealth of information surrounding the design, functionality, and utility of the workbook. As a result of the testing efforts several changes were made to the workbook pages. Based on the suggestion of several survivors as well as healthcare



providers, a list of CAM therapies was created to be included in the workbook prior to *Why I want to use CAM*. This new workbook page, *Understanding cancer CAM terminology*, provides an explanation of the different CAM descriptors, integrative medicine, complementary medicine, alternative medicine, complementary and alternative medicine, and also provides a list of commonly utilized CAM therapies which include acupuncture, massage, meditation, intravenous vitamin C, and chiropractic care (see Appendix D).

At the suggestion of the Oncology Fellow, a definition of the standard of care was provided on *Why I want to use CAM*. For the purposes of the workbook and CAM therapies, OCCAM defined standard of care as those therapies practiced or observed in Western countries. The question order was also changed on *Why I want to use CAM* to better capture the information most pertinent for healthcare providers. On the revised form, the order of questions two and three was reversed; patients were asked to consider the side effects they wanted to relieve through CAM use and then indicate the specific CAM therapies they would like to try. Lastly, due to survivor preference version A of *Why I want to use CAM* was selected as the final version of the worksheet (see Appendix B, Figure 1). Prior to the second round of pretesting all of the images on version A were replaced with more easily identifiable CAM therapies.

Some of the tips for talking to your provider about CAM were revised. More neutral, non-accusatory language was implemented for some of the tips to prevent alienation of healthcare providers. As suggested by the social worker, an additional tip was included on *Tips for talking to your provider about CAM*, with regard to addressing a potential negative interaction with a provider. This tip reminds patients that obtaining a second opinion is always within their rights. Additionally, all of the tips were reorganized to reflect a logical and temporal flow beginning with preparations for an office visit.

A common concern stated by both healthcare providers and survivors was that there was not enough room to track medications within the medication log. To address this concern, the columns “dose” and “frequency and time(s) of day taken” were collapsed into one column, which created some additional space within each row and column. Within the new dose and time column, examples were provided for each category of dosing amounts and time of day taken. Although the amount of space within each block was still not ideal, the column height and row width were increased as much as possible, to keep information about all types of medications on one sheet of paper. Additionally, a second sheet to track all medications was created to be included within the workbook.

On the weekly CAM use log, nearly everyone surveyed preferred to have the days of the week listed within the first column (see Appendix B, Figure 3). Since the term “conventional therapy” was confusing to some survivors, it was replaced with “standard treatment.” However, the term “conventional” was retained to describe providers elsewhere within the workbook. Additionally, the title of the last column was changed from “how did it make you feel” to “notes.” The examples provided on this page were also changed to reflect an exercise-based CAM therapy, walking, and a nutritional therapy, ginger pills, to provide users with examples of how to document exercise as well as supplementation. Also, because some participants felt documenting CAM therapies on a weekly basis might be too taxing during the active course of cancer treatments, a monthly CAM use log was created. This log contains the same information as the weekly CAM log, date, CAM therapy used, how much or how long, and a notes field, but allows the user to track as few or as many CAM therapies as they use each day or week.

Several changes were made to the glossary as well as the resource page. The glossary was reorganized into medication-related terms and CAM categories. The resource page was

restructured to cluster the NCI-specific resources together and each description of the additional government sources for CAM information was made as simple as possible.

The cover design was also changed for the workbook as a result of pretesting. Due to patient preference, an orange NCI banner bar was placed on the left hand column of the workbook, per the NCI graphic design guidelines. Additionally, a small office banner bar was placed at the top of the cover page. During testing, one patient suggested the number of images on the cover be reduced from six to four. Five images depicting CAM therapies and patient-provider interactions were selected for the cover; these images feature identifiable mainstream CAM therapies as well as images of healthy, smiling people. Because no consensus was reached about use of the terms “workbook” versus “guide,” OCCAM made the final decision to call the resource a workbook because a majority of the pages require some form of patient interaction. Additionally, the phrase *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* was chosen for the title to complement OCCAM’s prior patient education resource, *Thinking About Complementary and Alternative Medicine: A Guide for People With Cancer*.

Other stylistic changes made to the workbook included changing the color palette and header images. The original color palette for the workbook consisted of cool colors. Patients surveyed did not dislike the cool palette, but the palette was changed to reflect the selection of the orange banner bar for the cover. The orange color was pulled throughout the workbook and counterbalanced by a selection of warm and cool colors. The black and white yoga image from the front cover was also incorporated throughout the workbook pages by including it in the header. The original header images included a picture of vegetables, a yoga image, and a picture of multicolored pills. A photo of a tea set replaced the image of the pills.

Lastly, wherever possible the sentence structure and instructions were simplified to increase reading comprehension. Even after restructuring and reducing sentence length, most of the documents included within the workbook have a Flesch-Kincaid Reading Score of 12.0. This is in part because the medical terminology used throughout the workbook does not have simplified versions or descriptors; for example, there are no other terms or ways to describe “chemotherapy.”

## **4.4 PRETESTING: ROUND TWO**

### **4.4.1 Patient Population Feedback**

By September 2012, OCCAM was ready to test a second version of the patient education workbook with patients and providers. OCCAM was unable to perform another round of Open Call Testing because the September session was for Spanish initiatives only. Therefore, OCCAM needed to resort to a different method for surveying cancer patients and survivors. NCI’s Office of Advocacy Research (OAR) manages the Consumer Advocates in Research and Related Activities (CARRA) program, which is comprised of consumer advocates from across the nation who voluntarily provide assistance to NCI in the development of various projects. These members represent the voice of the cancer community in the roles of survivors, caregivers, and advocates.<sup>56</sup> With assistance from Shea Buckman Manley OCCAM contacted OAR to acquire a list of cancer advocates to review OCCAM’s draft material. By using OAR’s CARRA advocates,

OCCAM was able to circumvent OMB clearance requirements via the Paperwork Reduction Act.<sup>54</sup>

“Cold call” emails were sent to each of the 13 identified CARRA advocates. Each respondent was asked to review OCCAM’s workbook and consider the following points of consideration:

- How would a resource that encourages you to talk to your healthcare providers about your CAM use be useful to you?
- Based on your experience, do you think this workbook would be helpful to patients?
- Would you recommend this resource to other people?
- Identify the person or persons within the clinical setting who you think would be most likely to refer you to a reference such as this.
- Describe how keeping track of your CAM use through the forms included in this workbook would help you to talk to your doctor about CAM.
- Describe changes you would suggest to make the resource more useful to you.

Each participant was provided with the same feedback tracking form as the healthcare providers to record their answers (Appendix B, Figure 7). Participants were asked to return their responses within two weeks of receipt of the email.

As in the first round of pretesting, the cancer advocates represented a variety of cancer types, including bladder, breast, lung, brain, and leukemia; and females were overrepresented. Of the 13 advocates contacted, 10 responded. No follow-up efforts were made to contact the three advocates who did not respond to the initial email request because of the voluntary nature of their services. Included among the advocates were representatives of several major cancer advocacy groups, including the American Cancer Society, the Leukemia and Lymphoma Society, Friend for Life Cancer Support Network, the National LGBT Cancer Network, and the Oklahoma Brain Tumor Foundation. The only demographic data requested of each participant was an identification of whether they were a caregiver or survivor. Of the people surveyed, three people identified themselves as cancer survivors and seven classified themselves caregivers. No additional demographic information was collected from the participants.

All 10 participants who reviewed the workbook found it to be useful and would recommend the resource to other people. Several advocates were impressed by the functionality of the workbook, specifically the workbook's encouragement for patients to organize their thoughts about CAM use and their treatment options. When asked to consider whether OCCAM's workbook would enhance communication between providers and patients, all participants felt it would strengthen the fragmented lines of communication in oncology care. Many participants discussed some of the observed patterns of nondisclosure discussed in the literature including a "fear of physician response," a lack of "physician initiation" of CAM conversations, and a lack of "understanding" about the "impact of CAM on treatments." Of the participants who recognized the importance of CAM disclosure to healthcare providers, all felt OCCAM's workbook would empower patients to "feel more comfortable," and "organize their thoughts" to discuss CAM with their "medical team."

Participants were asked to identify the healthcare providers who would be most likely to refer patients to this resource. Providers identified included patient navigators, case managers, social workers, nutritionists, nurses, nurse navigators, nurse practitioners (NP) and physician assistants (PA), oncology nurses, and pharmacists. Of the nine people who responded to this particular question, three people believed some physicians might recommend or guide patients to this resource as well. Even though several different types of clinical and ancillary professionals were named, one advocate was convinced she would not receive this type of resource in the clinical environment due to dismissive reactions of her healthcare providers to use of CAM therapies.

Without having been provided a description of the medium for dissemination, two participants emphasized that the workbook should be available in an electronic format, which

would allow for continual updating. To increase the utility of the workbook, several respondents recommended incorporating the workbook, or select pages from the workbook, into the patient record. Integrating the information from the workbook into the medical record would allow all physicians and nurses to access important patient information. Even without incorporation into a patient's medical records, several participants believed the information captured would still be helpful for healthcare providers because it describes patients' "overarching view of their whole-body treatment regime." Finally, one advocate noted the limited availability of CAM information resources for patients. OCCAM's contribution to the development of patient education resources on CAM serves to "improve understanding" of CAM and emphasizes the necessity of patient-provider conversations about CAM use.

#### **4.4.2 Healthcare Provider Feedback**

The healthcare providers solicited for feedback during the second round of pretesting were professional contacts of OCCAM Director Dr. Jeffrey D. White and Case Review and Intramural Science Program Director, Dr. Farah Zia. Dr. Zia, a medical oncologist who divides her time between OCCAM and the Clinical Center, identified three staff members, two nurse practitioners and a fellow M.D., within her clinical working group to provide feedback. Both nurse practitioners provided feedback; however, the oncologist could not be reached for comments. Three attempts, including email reminders, were sent to the oncologist, but efforts were abandoned after no emails were answered. As in the first round of pretesting, each healthcare practitioner was asked to review both the workbook as well as the list of questions and comments, discussed previously (see Appendix B.1.5 and Figure 7). The two Clinical Center NPs did not have any suggestions for changes to the text or layout of the workbook, and both

believed OCCAM's workbook would be a useful resource for patients. A concern of both of the NPs was the amount of space available to describe medications within the medication list, an issue that had been discussed extensively by both healthcare providers and survivors during the first round of pretesting. Despite the strict protocols for patients seen at the Clinical Center, one of the nurse practitioners noted that patients keeping track of their CAM use in logs would be helpful, particularly in "clinical trials," to monitor patient's CAM use for exclusionary treatments, supplements, or regimens.

While Dr. Zia provided professional contacts within the NIH, Dr. White identified several professional contacts in outside hospital systems, including a NP at Johns Hopkins Kimmel Cancer Center and a medical oncologist who practices at Oncology/Hematology of Loudon and Reston. Overall, the comments from the NP were very supportive of OCCAM's endeavor. The NP emphasized it is "critical" for healthcare provider to learn of all the medications patients taking, including nutritional supplements, to minimize the risks associated with drug interactions. The oncologist merely stated the workbook looked good, without elaborating on any changes that should be made or the utility of the workbook.

In an effort to obtain additional feedback from healthcare providers, Dr. White suggested the author present the project to the NCI Physician Data Query (PDQ)<sup>®</sup> CAM editorial board, which is comprised of experts in the fields of oncology, pharmacology, natural products, drug discovery and development, traditional Chinese medicine, acupuncture, and homeopathy.<sup>57</sup> After the presentation to the editorial board on September 21, 2012, follow-up emails requesting feedback were sent to each of the 18 board members: of the 18 members, four responded. However, two of the respondents were not healthcare providers and therefore, their comments were not utilized; the remaining respondents were a registered dietitian and an integrative



oncologist. While the registered dietitian stated she would recommend OCCAM's workbook to patients, she emphasized she would do so with hesitation because of the potentially dangerous drug interactions with nutritional supplements during the "active" phases of treatment. The integrative oncologist also expressed a hesitation to refer patients to this resource because most of the information that would be derived from use of this workbook was acquired through his interactions with his patients; however, he believed it would be useful for conventional oncologists.

#### **4.5 CHANGES IMPLEMENTED AFTER ROUND TWO OF PRETESTING**

The second round of pretesting did not yield as many edits as the first round of pretesting. Pretesting efforts were stopped once a point of saturation occurred in the comments provided by healthcare providers and survivors. A majority of the changes made to the workbook were concentrated on stylistic elements and included numbering each page of the workbook, identifying and keeping a consistent format throughout the glossary for defining terminology and the associated examples, changing the title of *Understanding cancer CAM terminology* to *Understanding cancer CAM*, and incorporating the use of the term "healthcare providers" versus "doctors" throughout the workbook, including the cover. The only major textual change to the workbook was the incorporation of general CAM education and a statement about potential herb/drug interactions on *Understanding cancer CAM*.

Additional changes included replacing several of the images on the cover and *Why I want to use CAM*. These images depict people from a variety of ethnic backgrounds and ages and also feature a variety of easily identifiable CAM therapies.

## 4.6 SUMMATION OF PRETESTING RESULTS

Through two rounds of testing, OCCAM was able to obtain feedback from 42 individuals of the 88 individuals who were solicited for feedback (see Appendix C, Table 2). These individuals included patients currently undergoing treatment, survivors, caregivers, staff of major cancer advocacy groups, physicians, nurse practitioners, nurses, registered dieticians, and social workers. In total, five contractors or general members of the public were solicited for their feedback, and therefore did not require additional OMB clearance because OCCAM stayed within the parameters of surveying nine or fewer members of the general public. Healthcare providers who work for the federal government and are employed by the NIH's Clinical Center represented a convenience sample for OCCAM's pretesting initiatives (see Appendix C, Table 3). These individuals are overrepresented because they were easier to solicit for their feedback since clearance was not required to speak with federal employees.

## 4.7 WORKBOOK DESIGN

*Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* is an interactive workbook designed to increase patient confidence to discuss CAM use both during and after cancer treatment with their healthcare providers. This workbook consists of informational pages about CAM as well as several documents to track CAM use (see Appendix D). The workbook pages include *How to use this workbook*; *Understanding cancer CAM*; *Why I want to use CAM*; *Tips for talking to your provider about CAM use*; *My monthly*

*CAM use; My complete medicine list; Members of my health care team; Glossary; and Cancer CAM Resources.*

The cover of the workbook features images of several different types of CAM therapies and modalities as well as interactions between patients and healthcare providers. A wide variety of ages and ethnicities are depicted in the selected photos. The cover design features images and color blocks displayed in a grid-like fashion. The combination of the gridlines and the color blocks provides sections of white space for the eye to rest and also reduces the amount of clutter on the cover. During Open Call Testing, participants favored two of the images selected for the cover, the woman in a yoga position and barrels of spices. Another design feature of the cover is the interplay between warm and cool colors, which provides an overall calm appearance for the cover.

*How to use this workbook* is the first page of the workbook and introduces the reader to the content of the booklet and the importance of discussing CAM therapies with healthcare providers. Instructions are provided for both patients and healthcare providers about how to utilize the worksheets included.

*Understanding cancer CAM* provides a list of definitions for commonly used terms to describe CAM, including “complementary medicine,” “alternative medicine,” “complementary and alternative medicine,” and “integrative medicine.” Unfortunately, as previously discussed, there is no standardized way to describe complementary and alternative medicine, and the application of these terms varies between institutions as well, further complicating comprehension of CAM. As an example, the National Cancer Institute uses the term “complementary and alternative medicine” throughout its publications while the M.D. Anderson Cancer Center prefers the term “integrative” in its descriptions and promotion of CAM therapies.

*Understanding cancer CAM* also features common reasons why people seek CAM therapies and a list of CAM therapies.

*Why I want to use CAM* encourages patients to think about their motivations for CAM use, why they want to use CAM, what side effects they want to alleviate through CAM, and what therapies intrigue them. This sheet is meant for patients to complete prior to a doctor's appointment to help organize their thoughts about CAM use. The collaborative Ask 3 campaign of the National Patient Safety Foundation and the American Medical Association was used as a proxy for question development on this document.<sup>58</sup> The Ask 3 initiative encourages patients to discuss three main questions with their provider: 1) What is my main problem? 2) What do I need to do?, and 3) Why is it important for me to do this?<sup>58</sup> Modifications to these questions were made to reflect information that would help oncology and primary care providers understand motivations for CAM use, while maintaining the integrity of the information obtained from these questions. Review of these questions not only empowers patients to speak with their healthcare provider about their CAM use, but also provides an avenue for patients to discuss any symptoms or side effects of treatment that are not being managed through conventional therapies. This sheet can be either handed to the physician to review or used as an aid to guide the conversation.

The next sheet in the booklet, *Tips for talking to your provider about CAM use*, provides patients with guidelines for engaging in CAM conversations with their providers. Eleven tips are presented and organized into three categories to provide guidance and empowerment at various stages of patient-provider interactions. These suggestions involve simple strategies patients can employ prior to and during their consultations with healthcare providers to enhance discussions about both CAM use and their treatment plan. A majority of the tips provided were adapted from

guidelines provided by several advocacy organizations and government resources including the American Cancer Society, the Leukemia and Lymphoma Society, BreastCancer.org, the Canadian Cancer Society, Susan G. Komen for the Cure, NCCAM, the NCI PDQ<sup>®</sup> Cancer Information Summary: Pain, and the NCI PDQ<sup>®</sup> Cancer Information Summary: Communication in Cancer Care. The tips, while rewritten and adapted for CAM-specific use, encourage patients to be proactive, document their concerns and questions, and request additional time, appointments, or resources when necessary.

*My monthly CAM use* asks patients to track their CAM and its effect(s) on symptom abatement over the course of a month, noting the length of time a therapy was performed (e.g., 30 minutes of yoga) or quantity that was used (e.g., 2 cups of green tea). As Schumacher et al.<sup>59</sup> observed, tracking symptoms via health diaries enables patients to observe trends in their own behavior as well as trends in their own symptom management, pain, and symptom alleviation. For healthcare providers, tracking CAM use over the course of a month provides cross-sectional data about the self-care strategies patients employ to manage their care outside of the clinical environment.

*My complete medicine list* asks patients to think about all of the medicines they currently use, including herbs, dietary supplements, and vitamins. OCCAM's medication list was adopted from the American Cancer Society's Medicine List, which encourages patients to keep track of their medicines regardless of class of medication. The ACS Medicine List is not separated into prescription medications, OTC medications, and nutritional supplements. Only a small note, located at the bottom of the sheet, instructs patients to document their supplement use.

Since patients neglect to tell their providers about supplements they use in addition to prescription medications, it was imperative for OCCAM's worksheet to separated medicines into

three categories: prescription; OTC; and herbs, vitamins and dietary supplements. Documentation of all types of medications cancer patients use is particularly important because of the propensity of cancer patients to utilize nutritional supplements and the fact that cancer patients may have comorbidities, for which medication effectiveness may be decreased through use of supplements. For example, Echinacea, an herbal supplement often touted to improve immune function, interferes with the chemotherapy drugs methotrexate and ketoconazole.<sup>53</sup> Another common herbal supplement, ginkgo, is not recommended for people who take aspirin, non-steroidal, anti-inflammatory drugs, such as ibuprofen, or anticoagulants, such as heparin, due to an increased risk of bleeding.<sup>13,53</sup> Vitamin B6 when taken with altretamine, an antineoplastic used to treat ovarian cancer, decreases the drug's effectiveness.<sup>13</sup> Finally, St. John's wort, an herbal supplement often taken to suppress mild to moderate depression, has been shown to interfere with warfarin, (Coumadin), an anticoagulant which is sometimes prescribed for cancer patients who may present a risk of developing of blood clots from their chemotherapeutic treatments or have cardiovascular comorbidities.<sup>13,53</sup>

*Members of my health care team* gives patients a space to organize the contact information for their conventional and complementary providers. This sheet may be valuable for personal use or and can be shared with healthcare providers to foster coordination of care between conventional and complementary providers.

The *Glossary* provides definitions of medicine-related terms used throughout the patient education booklet. In addition, it describes the categories of CAM therapies that governmental organizations use.

Finally, the *Cancer CAM resources* page lists additional resources for patients and healthcare professionals to learn more about CAM therapies. There are no private organizations

supported in this document due to governmental restrictions on private endorsements. However, all of the sites listed provide evidence-based information and include the FDA, Office of Dietary Supplements (ODS), NCCAM, and other NCI resources.

#### **4.8 WORKBOOK RATIONALE**

From the environmental scan that was performed, it was determined any education material created should provide cancer patients with tangible materials to empower them to engage in conversations with their healthcare providers about use of CAM. With so few patient education resources dedicated to fostering effective communication about CAM use, OCCAM pursued the development of a patient education resource surrounding this very topic. Traditionally strategies to engage in CAM conversations with healthcare providers have been characteristically presented as lists, as demonstrated through the environmental scan, and while they highlight the importance of CAM conversations, they do not inherently motivate a patient to initiate such conversations. Increasing a patient's self-efficacy is a central component of the design of the workbook, particularly because one of the reasons cancer patients seek CAM therapies is to regain a sense of control over their cancer diagnosis. This workbook strives to help patients regain a sense of control over their conversations with their doctors and healthcare providers, in an effort to communicate their goals, expectations, and needs associated with the physical, mental, and spiritual aspects of cancer care. A workbook format enables patients to take proactive roles in their health dialogues by organizing and documenting their CAM use, rather than relying on a list of suggested tips for approaching conversations.

Due to the size and scope of the target audience, which includes cancer patients, cancer survivors, caregivers, family members, healthcare providers, and members of the general public, an online communication campaign was chosen as the communication medium. This medium is not only cost-effective, but also has the ability to reach the most members of the target audience. However, a primary limitation of an online campaign is it does not address the digital divide, and therefore ignores an important population that does not have ready access to computers. Another limitation is segmentation of the audience by age, sex, race, or cancer type to create tailored health communication messages is virtually impossible. The ability to create culturally competent material is also restricted. Lastly, the workbook is only available in English, although OCCAM may pursue Spanish translation at a future point. To address the issues of segmentation and cultural competency, a workbook was created for an adult population using neutral language, and every effort was made to select images that represented a diverse group of individuals and ages. Even though it is hypothesized that patients will be more likely to use this resource than healthcare providers, the decision to utilize an online medium does not exclude healthcare providers from using these resources as well.

To further expand the reach of the communication initiative, the patient education material was designed as a compilation of PDFs, which can be downloaded as a complete education workbook or as individual pages. Presenting the communication materials in this manner enables the patient to use the resource pages in a way that will be most beneficial to him. For example, some individuals may find *My complete medicine list* most helpful because they do not view herbs, vitamins, or dietary supplements as medicine, and other people may find downloading the complete booklet more helpful to initiate CAM conversations with their healthcare provider(s).



Several assumptions are inherent in both the design and utilization of this workbook. One assumption is the user possesses a higher degree of health literacy, as there are many complex topics discussed within the booklet, including medication compliance, knowledge of medication side effects, patient-provider communication, and knowledge about the field of CAM. It is recognized that the average health communication material is written at a 10<sup>th</sup> grade reading level, despite the fact that the average American reads at an 8<sup>th</sup> or 9<sup>th</sup> grade level.<sup>60</sup> However, much, if not all, of *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* is written at a 12<sup>th</sup> grade reading level due to the medical terminology used throughout the workbook. There are no simpler terms for most medical treatments used in cancer care including radiation and chemotherapy.

Another inherent assumption in the design of the workbook is that the user is motivated to track symptoms, medications, and CAM use. Lastly, this workbook assumes healthcare providers will want to know about the CAM therapies patients utilize and will be receptive to talking about CAM.

Much of the design of the workbook is built on adaptations of different health diaries and health-related forms for tracking medical information. Several studies discussed the validity of using health diaries for pain management in cancer treatments.<sup>61-65</sup> In a 2011 review article, Allard and colleagues<sup>64</sup> suggested that pain diaries are a promising nursing intervention due to their brevity and high compliance rates, which ranged from 60-85%.<sup>61,63,66</sup> The American Pain Society<sup>67</sup> also recommends the use pain diaries to increase patient involvement in their care. As clinical interventions, health diaries are generally not perceived as invasive or time-consuming by the patients themselves.<sup>63,68</sup> When health diaries are used as clinical interventions, patients are asked to document their symptoms for two to four weeks at different intervals during the day:

however, the length of time of data collection may differ depending on the focus of the intervention.<sup>69</sup>

One of the strengths of using of a health diary is it enables researchers and clinicians to gather a wealth of information from patients<sup>70,71</sup> about symptom management, medication compliance, and other health behaviors outside of the clinical setting.<sup>61,65,68</sup> Health diaries may also provide a way for clinicians to derive real-time information about chemical toxicities<sup>72</sup> and observe fluctuations in pain levels that may occur during and after treatment.<sup>68</sup> It also minimizes recall bias.<sup>68,69,71</sup>

Through the use of health diaries, a tool successfully used in oncology practice to document pain management and patterns,<sup>59,61-66,72</sup> patients are able to record their nutritional supplement use, note different CAM therapies they have tried over the course of a month, and organize contact information for all of their conventional and complementary practitioners. Schumacher et al.<sup>59</sup> argued that pain diaries help patients recognize the extent of their pain, develop proper medication adherence, and notice patterns of pain by tracking behaviors. Through documentation of symptoms and associated coping strategies via health diaries patients enhance their understanding of their disease and treatment<sup>59</sup> and also become more aware of their need for assistance.<sup>65</sup>

#### **4.9 IMPLEMENTATION OF THE WORKBOOK**

As of January 2013, *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* was finalized. Dissemination of this workbook has begun and

promotional strategies to date have used a variety of channels to reach to the intended audiences. Nearly every channel that is being utilized or that will be utilized is Internet-based. Even though multiple websites, listservs, and social media outlets will be employed for promotion, the primary location of the workbook will be on OCCAM's website (<http://cam.cancer.gov>). From OCCAM's website, the user will be able to download the entire workbook or the individual workbook pages as PDF files for free (see Appendix E, Figure 8). Small screenshots along with descriptions of the function and use of each page enable users to easily search for the document that will be most beneficial to them without having to download the entire workbook.

The workbook is also available for download from the NCI Publications Locator, a database that allows users to search for NCI publications by using keywords, titles, or publication number (see Appendix E, Figure 9). The specific search terms associated with OCCAM's workbook include "complementary medicine," "alternative medicine," "integrative medicine," "cancer CAM use," "CAM," "patient-provider communication," "patient education," "communication," "medication list," "cancer treatments," "symptom management," "dietary supplements," and "supplements." The NCI Publications Locator contains several of OCCAM's existing publications for download including *Thinking About Complementary and Alternative Medicine: A Guide for People With Cancer*<sup>51</sup>, *NCI CAM News*, *NCI's Annual Report on Complementary and Alternative Medicine* from fiscal years 2005 through 2010, and several other pamphlets OCCAM has produced.

To date, additional promotional activities have involved email outreach via OCCAM's listserv (see Appendix E, Figure 10). OCCAM's listserv subscribers include healthcare providers; CAM researchers; the general public; members of CPEN; patient education departments of the NCI-designated Cancer Centers; the Consortium for Academic Health

Centers for Integrative Medicine, which is composed of integrative medicine centers or hospitals located in the United States, Canada, and Mexico; and various cancer advocacy organizations. In addition, the Winter 2013 issue of OCCAM's newsletter, *NCI CAM News*, main story discussed the development of OCCAM's initiative, further promoting this resource. Other internal promotion of OCCAM's workbook may be occurring at the NIH's Clinical Center, but the author is not privy to this information.

Future dissemination strategies could include contacting the CARRA advocates and healthcare professionals, who provided feedback on the draft materials, to not only show each person the final version, but also encourage them to share this resource. OCCAM could also choose to contact the patient education departments of various NCI-designated Cancer Centers to encourage integration and promotion of their resource into patient education resources. In their contact with various patient education departments, OCCAM could suggest providers distribute its resource to patients, as many patients cited they'd expect to receive this resource from their doctor.

Other NCI resources that could be used to promote OCCAM's initiative include NCI's Facebook and Twitter accounts. Unlike a lot of the offices, divisions, and centers of the NCI, OCCAM does not have a presence on social media. The use of social media is important in order to increase the outreach and knowledge about OCCAM's patient education resources, since many people use Internet searches and cancer advocacy groups to obtain health information instead of governmental resources. By utilizing social media, OCCAM will not only increase promotion of the workbook, but also increase awareness about its office and the research it supports. On February 5, 2013, OCCAM's workbook was posted to the NCI's main Facebook page (see Appendix E, Figure 11). The same week it was "shared" by six organizations including

the Association of Oncology Social Work, the Oklahoma Health Care Authority, and an insurance agency, Insurance Advisors Agency, Inc. (see Appendix E, Figures 12 and 13).

Another advantage of using social media is the potential to partner with other NIH offices, institutes, and centers, thus further expanding the reach of the campaign. Two NIH offices and centers with similar campaigns are ODS and NCCAM. ODS has produced a mobile app to help people track their dietary supplement use, called My Dietary Supplements or MyDS, while NCCAM encourages patients and providers to talk about CAM use through their *Time to Talk* campaign. ODS and NCCAM have a social media presence and could facilitate increased dissemination of OCCAM's workbook through their Twitter accounts, since their audiences differ from those of OCCAM. Relative to OCCAM, ODS's and NCCAM's target audiences are not as specialized and include people with a variety of chronic diseases, acute illnesses, and healthy members of the general public in addition to healthcare providers and researchers.

The marketing strategies for the patient education workbook target a variety of audiences, including healthcare providers, cancer patients and survivors, caregivers, and members of the general public. Use of multiple methods and channels of dissemination will strengthen the reach of OCCAM's initiative, increasing the likelihood that cancer patients and their healthcare providers will utilize this resource. These promotional strategies may also serve to increase the brand recognition of OCCAM, since OCCAM is often confused with NCCAM or not recognized as an existing office of the NCI.

Evaluation of the patient education workbook will remain a constant challenge for OCCAM because of the medium of the resource. As an Internet-based initiative it will be hard to determine the patterns of use for this document. While web analytics will inform the COP staff how often the resource is downloaded, it will not show what is done with the resource once it is

downloaded. The web analytics also will not be able to decipher artifacts associated with downloading, which include accidental downloads. Additionally, the office is limited in its ability to survey healthcare providers and patients under the guidelines of the Paperwork Reduction Act; any formal surveys to determine how useful the resource is once downloaded would require additional funding, official approval, and clearance.

Even though there are limitations to the feasibility of developing formal evaluation strategies, one strategy OCCAM can employ is to request comments from users. A statement could be placed at the bottom of the webpage featuring the workbook pages voluntarily asking users to email comments or suggestions to COP staff, thus circumventing the guidelines of the Paperwork Reduction Act. While not ideal, this method of obtaining feedback on the validity and usability of OCCAM's patient education resource might provide at least some guidelines as to how effective this communication initiative is to the public and provide OCCAM with ideas to develop additional patient education resources.

## 5.0 DISCUSSION

During the course of any physician-patient interaction, patients and healthcare providers should engage in clear communication with one another and establish and maintain open lines of communication, but this is particularly important when patients are thinking about or actively using complementary and alternative medicine. By developing effective communication with one another, the patient and provider are able to better understand one another's perspectives, and more importantly, the provider is able to recognize some of the patient's unmet needs. These unmet needs may also change throughout the course of treatment, and particularly as patients transition into survivorship. Encouraging communication between patients and providers about CAM use is necessary in order to reduce medical mistakes,<sup>39</sup> increase trust and patient satisfaction of providers,<sup>21,30,35</sup> and increase medication compliance,<sup>21,30,35</sup> all while strengthening the model of patient-centered care. Addressing communication issues between patients and providers is also important as the prevalence of CAM use continues to grow among the cancer patient and survivor communities, in their quest to seek less toxic alternatives to cancer symptom management.<sup>11,21,26,30,31</sup>

This paper does not report on the motivations for CAM use among cancer patients and survivors or describe the disclosure patterns of CAM use. Instead, this paper focuses on the designs used to test the utility of *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips*. It was necessary to review the literature on the

prevalence of CAM use among the general population and the cancer population, the patterns of CAM use, and the barriers and facilitators of CAM conversations in order to develop an understanding of the context of the problem.

A review of the literature coupled with pretesting demonstrated that *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* addresses an identified gap in existing resources for patients and providers. Of the patients and healthcare providers surveyed, nearly every respondent recognized the importance of discussing CAM use. Many participants discussed how their physicians were always asking about what types of medication they were taking. During the course of medical encounters, patients expect their healthcare providers to ask them questions about their medications, symptoms, and behaviors, and OCCAM's workbook enables patients to better prepare for these questions as well as interject their own questions into the health conversations. Both healthcare professionals and patients spoke of the important role of documentation in the context of patient-provider communications. Through the course of testing, patients described how documentation of questions and CAM use would aid them in their conversations with providers, and healthcare providers appreciated any supplemental information patients provide during clinical visits.

Several of the healthcare providers surveyed felt this resource would be helpful for patients who expressed an interest in CAM therapies. Many reiterated the importance of knowing all medications a patient uses, including vitamins, herbs, and dietary supplements. Nutritional supplements are particularly dangerous when not disclosed, because they have an increased potential for drug interactions and toxicity with prescription medication, chemotherapeutic regimens, and radiation treatments. Unlike prescription drugs, nutritional supplements are not required by the FDA to be "approved for their safety and effectiveness before they reach



consumers.”<sup>73</sup> However, they are monitored for adverse effects once on the market. Most healthcare providers identified OCCAM’s initiative as an innovative strategy to aid physicians and patients in discussions about the motivations for CAM use. Comments from the advocates, caregivers, and patient populations echoed the sentiments of the healthcare providers regarding the utility of the workbook; many felt this resource would be useful in their personal records of symptom management and recognized the value of documenting medications and CAM therapies.

A primary objective of OCCAM’s initiative was to increase knowledge about cancer CAM. In addition to educating patients and survivors about the importance of talking to healthcare providers about CAM, OCCAM’s workbook seeks to empower patients and survivors to initiate these conversations. Embedded throughout the entire workbook are reminders about the importance of disclosing CAM use to providers as well as strategies to engage in these conversations. By creating action-oriented tasks, OCCAM’s initiative provides an innovative solution to addressing the miscommunication about CAM. The current medical climate of patient-centered care is based on “effective communication which forms the basis of patient’s understanding of disease and self-management options”(p365).<sup>74</sup> This workbook requires users to interact with not only the workbook pages, but also with their healthcare provider, creating an active two-way conversation about CAM, if the workbook is used as intended. However, even if the workbook is not shared with healthcare providers, it still encourages patients to think about their motivations for CAM use, including symptoms that are not being properly managed through traditional care.

Another goal of OCCAM’s initiative is to impart patients’ preferences for holistic approaches to their health to their healthcare providers. The workbook helps providers learn

patient perceptions about the use of CAM, their preferences for certain CAM therapies, and how patients make decisions about which therapies to use. Understanding these motivations for self-directed CAM or provider-directed CAM is particularly important to establish active and open dialogue between patients and healthcare providers.

One way in which this is accomplished is through the integrated use of health diaries in *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips*. Health diaries are clinical tools that have been used to monitor a variety of conditions and behaviors. Some of the more popular adaptations of health diaries include sleep logs, exercise logs, and food diaries. These clinical interventions have also been prominently used within oncology to track and monitor pain. As clinical interventions, health diaries are generally not perceived as invasive or time-consuming by the patients themselves,<sup>63,68</sup> and they allow clinicians to acquire information about symptom management, medication compliance, and other health behaviors outside of the clinical setting.<sup>61,65,69</sup> Furthermore, they enable patients to increase their understanding of their disease and treatment<sup>59</sup> as well as their need for assistance.<sup>65</sup>

OCCAM's initiative is an important first step in bridging the communication gap between cancer patients and survivors and healthcare providers and is embedded with several important public health principles. The development of OCCAM's workbook was not designed to address any Healthy People 2020 goals specifically, but it was determined that this workbook contributes to the work of at least two of the Healthy People 2020 Health Communication and Health Information Technology goals. Healthy People 2020 is a set of 10-year national objectives designed to improve the health of the nation. These objectives seek to identify and reduce the burden of disease, reduce health disparities and health inequalities, and promote the

health and wellness of the country. The specific Healthy People 2020 objectives<sup>75</sup> that OCCAM's workbook works towards are:

HC/HIT-3: Increase the proportion of persons who report that their healthcare providers always involved them in decisions about their healthcare as much as they wanted.

HC/HIT-4: Increase the proportion of patients whose doctor recommends personalized health information resources to help them manage their health.

OCCAM's workbook facilitates greater participation of patients in health conversations by providing them with resources to feel more supported to initiate CAM conversations with their providers. This is accomplished through the use of pages to document CAM, including motivations for CAM use, frequency and type of CAM used, and all medications used in care management, and informational pages that provide patients with strategies on how to engage in health conversations and sources of additional information. Documentation of CAM, whether self-selected or provider-directed, permits members of the healthcare team to understand patients' beliefs allowing for greater personalization of care plans. This workbook also addresses one of the core functions of public health: to inform, educate, and empower people about health issues.<sup>76</sup>

OCCAM's development of a patient education workbook represents an effort to improve the dialogue between cancer patients, survivors, and healthcare providers about CAM. Future communication campaigns should focus on the development of mobile applications (apps) to track CAM use. Rather than develop a cancer CAM-specific app to track CAM use, communication initiatives should attempt to integrate CAM tracking into already existing medical tracking apps. Integration of medications, questions, and appointments may foster better documentation of behaviors and streamline the information available for both patients and healthcare providers. In an increasingly mobile society, packaging all of this information

together in one location may prove to be extremely useful. These strategies will allow users to access their medication lists and CAM use at any point in time and without having to rely on their memory to bring paper versions of this documented information with them to doctor's appointments. Development of a mobile app to track CAM use may result in greater assessment of CAM use among minorities since 44% of Blacks and Latinos are smartphone users.<sup>77</sup> Additionally, a CAM app may result in greater CAM-tracking behaviors among adults 25-44, as 58% of Americans between the age of 25 to 34 and 44% of adults 35-44 own smartphones.<sup>77</sup> Further research on the development of CAM tracking apps may indicate that the aforementioned groups, younger individuals and minorities, prefer to record their CAM use via mobile apps than on online PDFs or paper tracking forms.

Future research on the patterns of CAM use among cancer patients and survivors should focus on why disclosure rates of CAM use remain so low, despite changing patterns of acceptance and use of CAM therapies by traditional medicine. Additional research is also needed to determine the types of educational resources healthcare providers want to increase their knowledge about CAM. This research should also include strategies to get more healthcare providers to initiate CAM conversations.

Coupled with increased research efforts, greater public awareness campaigns should be created to educate patients and the general public about provider knowledge of CAM therapies. Consumers of CAM need to recognize the evolutionary nature of the field and that it remains impossible for healthcare providers to stay abreast on all of the various remedies, supplements, and therapies. The field of CAM is ever-evolving and there is much work to be done in order to create evidence-based knowledge of the effects of CAM therapies on the body and clinical treatments. What remains imperative throughout this iterative process is the need for active and

open dialogue among patients, conventional healthcare providers, and complementary practitioners.

## 6.0 CONCLUSION

### 6.1 THESIS SUMMARY

Many patients utilize CAM during or after a cancer diagnosis as a way to regain a sense of control over a health condition that makes many cancer patients feel powerless.<sup>11,12,21,28,31,33-36</sup> Other motivations for CAM use include managing side effects,<sup>11,21,28,30-32</sup> preventing secondary or recurring cancers,<sup>30,33</sup> and boosting the immune system<sup>11,21,28,30,33</sup> and enhancing one's quality of life.<sup>11,21,28,30,31,33,34</sup> Often the therapies that are chosen are self-selected and not disclosed to healthcare providers.

Despite a high prevalence of CAM use among cancer patients and survivors, use of these therapies is often not disclosed to healthcare providers. Patients are often fearful of their healthcare providers' reaction to CAM use,<sup>12,31,33,35,39</sup> underestimate a physician's knowledge and comfort discussing CAM,<sup>12,30,35</sup> are unaware that CAM therapies can adversely affect their treatments,<sup>12,21</sup> and are simply not asked by their healthcare providers about CAM use.<sup>12,31</sup> Furthermore, when patients want to discuss CAM, it is often up to them to initiate the conversation.<sup>41,43,44</sup>

*Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* was developed to address the miscommunication between cancer patients and healthcare providers about CAM. Several studies have demonstrated CAM use is high

among cancer patients and survivors.<sup>10,25-28</sup> To develop OCCAM's workbook, several of OCCAM's existing sources of qualitative data were reviewed, including public comment responses and focus group transcripts. Review of these data revealed the major reasons why patients utilize CAM therapies as well as their information-seeking behaviors. An environmental scan was performed of 18 different cancer advocacy groups to determine how CAM is presented and what communication mediums are frequently used. Nearly every website surveyed stressed the importance of disclosing CAM use to one's healthcare provider. Finally, a literature review was conducted to understand the current research on the barriers and facilitators associated with patient-provider communication of CAM.

*Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* was designed to complement OCCAM's existing patient education resource, *Thinking About Complementary and Alternative Medicine: A Guide for People With Cancer*. While the workbook was not designed using any form of theoretical framework, looking at the two resources together, it is apparent these efforts reflect an adaptation of the TransTheoretical Model.<sup>78</sup>

In considering the posited constructs of the TransTheoretical Model, *Thinking About Complementary and Alternative Medicine: A Guide for People With Cancer* provides an overview of CAM including questions to ask doctors about CAM, strategies on how to choose CAM therapies and practitioners, and additional resources for more CAM information and would be appropriate for those in precontemplation or contemplation stage of CAM use. The format of *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips*, however, would be considered appropriate to help patients in the preparation, action, or maintenance stage, who are already familiar with CAM therapies and

those who have integrated CAM into their treatment strategies. Together these resources encourage patients and providers to communicate about complementary and alternative medicine use both during and after cancer treatments and recognize the importance of involving patients as active participants in decisions about their treatment plans in order to increase their self-efficacy.

To help bridge the communication gap between patients and providers, OCCAM developed an interactive patient education workbook designed to document CAM use and to empower patients to engage in CAM conversations with their providers. To the best of OCCAM's knowledge, this is the first interactive CAM workbook for cancer patients and survivors. The 15-page workbook is comprised of informational sheets and health diaries, to encourage patients to record their nutritional supplement use, note different CAM therapies they've tried, and document their motivations for CAM use. The workbook design revolves around the use of health diaries because of the success seen in the use of health diaries in oncology practice to document pain management and patterns.<sup>59,61-65,66,72</sup> Health diaries provide an easy method to capture patient behaviors outside of the clinical environment and have the potential to be integrated into a patient's medical record.

Two rounds of pretesting were conducted among cancer patients, survivors, caregivers, cancer advocates, and healthcare professionals. Pretesting was conducted to evaluate the design of the workbook and to determine the usability and functionality of the workbook. Through each round of pretesting, the workbook was improved based on the suggestions made by healthcare providers and cancer survivors. The overall response to OCCAM's initiative was quite favorable, as most of the survivors and healthcare providers believed OCCAM's workbook would aid conversations about CAM. Of the worksheets included in the workbook, *My complete medicine list* was the most popular sheet among survivors and healthcare providers.



## 6.2 STRENGTHS AND LIMITATIONS

There are several limitations of this project. *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* was designed for a national audience. It is limited in its ability to target the communication messages to any particular group or develop culturally competent messages. Another limitation of the workbook is the communication medium that was chosen. By choosing an online format for its communication initiative, OCCAM does not address the issue of the digital divide. Furthermore, while cancer patients gravitate towards online sources for information, tracking CAM use via OCCAM's workbook requires the user to either download the workbook and fill in the information on one's computer or fill in the information by hand. This increases the burden on the individual to accurately capture his use of CAM therapies and to remember to bring this information with him to his doctors' appointments. A preferable method to track CAM use may be through the use of a mobile app, such as ODS' MyDS app, allowing the user to retrieve this information or add entries at any point in time. Finally, the choice of an online medium, which requires the user to download either the workbook or an individual worksheet from OCCAM's website, renders OCCAM powerless to determine the effect of its initiative.

The data used during the formative research process also present another limitation of the workbook. The focus group transcripts, which were used to understand patient's motivations for CAM use, were collected over 10 years ago. These data may not be reflective of current needs and motivations for CAM use among cancer patients and survivors, particularly as trends associated with CAM use have continued to increase.

The sample sizes obtained for each round of pretesting is also a limitation. Twelve cancer patients and survivors and an additional 30 healthcare providers, advocates, and caregivers were

asked to provide input on OCCAM's workbook. By no means is either sample representative of the populations of cancer survivors, caregivers, or healthcare providers. In fact, the sampling strategy employed to garner feedback was a convenience sample. The trends observed from the two rounds of pretesting indicate OCCAM's workbook might improve CAM conversations, however, without a representative sample of cancer patients, cancer survivors, caregivers, and healthcare provider generalizations cannot be made about the workbooks impact. In order for generalizations to be made, a larger, more representative sample of cancer survivors and healthcare providers would need to be obtained.

Another limitation of OCCAM's pretesting efforts was that key groups of healthcare providers, including pharmacists, could not be identified to provide feedback on the workbook. Among those who were surveyed, healthcare providers at the NIH's Clinical Center were oversampled because surveying federal employees does not require OMB clearance. Additionally, the comments provided by these doctors, nurse practitioners, and social workers may be different from those obtained from healthcare providers working in public or private hospital systems or practices. Patients who are seen or admitted to the NIH Clinical Center are enrolled in clinical trials and must adhere to the guidelines and protocols of the clinical trial, thus reducing their use of CAM therapies.

A final limitation of the workbook is lack of an evaluation plan for dissemination of the workbook. Evaluation is a necessary step in the process of the development of any public health resource, whether it is a program or a patient education resource. Future critiques of OCCAM's workbook will likely require the use of an external evaluation and should be coordinated with NCI-designated Cancer Centers, university hospitals, and physician's offices to determine the effectiveness of the materials.

There are several limitations of this workbook, but there are also several strengths associated in the design of the workbook. Much of the discussion of this thesis has focused on the use of OCCAM's workbook for either cancer patients or survivors, but patients enrolled in palliative treatments, with no hope for a cure, may also find this workbook helpful. These patients may seek CAM as a way to retain a sense of hope<sup>11,21,34</sup> and increase their quality of life<sup>11,21,28,30,31,33,34</sup> when conventional treatments have failed. It should be noted that palliative treatments are not only administered when a cure is not possible, but may also be administered in conjunction with conventional treatments. Therefore, workbook as designed can be used at any stage of a cancer diagnosis, with patients in active treatment, active surveillance, palliative treatment, with no cure, or survivorship able to use this resource to engage in CAM conversations with their providers.

While the focus of this workbook was to improve CAM conversations among those diagnosed with cancer and their healthcare providers, people who have additional chronic diseases, other than cancer, can also utilize this workbook. As previously discussed, adults use CAM to help manage a variety of chronic diseases including neck pain, back pain, arthritis, anxiety, head and chest colds, depression, and headaches.<sup>15-17</sup> In a cross-sectional survey of CAM use among adults with chronic disease, Saydah et al.<sup>22</sup> found individuals diagnosed with arthritis to be the highest CAM consumers. The neutral language embedded within OCCAM's workbook and limited discussions of cancer, allow the workbook to be used by other chronic disease populations. This workbook may foster greater discussion of CAM with healthcare providers, including specialists or general internists. Lastly, the design of the workbook and availability to download individual workbook pages encourages use by members of the general public as well.

Other strengths of OCCAM's initiative include the widespread dissemination to anyone with computer access, the free usage and the capability to download multiple copies of the workbook, and the availability of the workbook to be used by healthcare providers, patients, and members of the general public. OCCAM's workbook also supplements existing CAM resources and highlights the importance of discussing and disclosing CAM use within health conversations. Finally, the design allows for the individual to tailor use of the resource to his/her needs, with the capability of downloading individual worksheets or the entire workbook.

### **6.3 RECOMMENDATIONS**

Prior to or after dissemination, a small pilot test should be conducted with patients in active treatment to assess the design, functionality, and usability of the workbook. Due to governmental sampling limitations and funding constraints, a convenience sample of patients at the NIH Clinical Center is suggested and should include a brief survey in addition to patient documentation of their CAM use. A self-administered or interviewer-administered survey could ask patients to identify how the workbook helped facilitate discussions of CAM use with their providers and probe on what aspects of the workbook were most and least useful.

Other efforts to enhance patient-provider communication about cancer complementary and alternative medicine use should include developing health communication campaigns targeted at healthcare providers. Although *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* was designed for both patients and providers, it is expected that patients will find this resource more helpful than providers. Several of the providers surveyed through the pretesting efforts indicated a need for educational

resources aimed at increasing healthcare providers' knowledge and awareness of the use of CAM therapies. Resources should be designed to help healthcare providers understand the scientific evidence supporting CAM use, patient motivations to use CAM, and establish guidelines for engaging in conversations with patients about CAM.

One possible avenue to increase physician awareness about CAM would be for OCCAM to develop a curriculum of continuing medical education (CME) credits for physicians, in the form of modules, webinars, presentations or journal articles. One possible avenue for this would be to develop a webinar for NCI's Division of Cancer Prevention *Frontiers in Nutrition and Cancer Prevention: Online CME Series*. Developing CME-based courses would likely require partnership with the American Medical Association. Assigning CME credits to health communication materials would create incentives for physicians to learn more about CAM therapies without being coercive. Additionally, designing an educational campaign that incorporates CME credit might also increase the diversity of physicians who participate in the program, thus further increasing awareness about the science behind CAM in addition to increasing the brand recognition of OCCAM.

Another possible initiative would be to create health communication materials that encourage greater communication and coordination of care between primary care physicians and oncologists. As cancer patients enter survivorship, their interaction with their oncologist begins to wane, and the onus of their care shifts to their primary care physician. Survivorship care planning requires clear communications about the "acute and late toxicities of treatment, the ongoing need for cancer surveillance, non-cancer related health maintenance, and the real potential for disease recurrence"(p.2493).<sup>79</sup> However, many primary care physicians lack the training and knowledge to treat the lingering mental, emotional, and physical symptoms of

cancer treatment.<sup>80,81</sup> In addition, the roles of oncologists and primary care physicians in survivorship care are poorly defined.<sup>79</sup> The Survey of Physicians' Attitudes Regarding Care of Cancer Survivors, a nationally representative survey of primary care providers and oncologists' knowledge and attitude about breast and colon survivorship care, revealed 40% of primary care physicians were confident in their ability to detect cancer recurrence, and only 23% of primary care physicians were confident in their the knowledge to treat the late physical effects of cancer.<sup>81</sup>

Development of communication materials to help primary care physicians understand the possible lingering side effects of cancer treatments, such as signs of congestive heart failure, peripheral neuropathy, and decreased cognitive function/mental ability, may aid in the promotion of overall health for cancer survivors.<sup>80,81</sup> In addition to increasing physicians' knowledge of late effects of cancer treatment, these resources should seek to educate primary care physicians on the prevalence of CAM use among survivors and provide recommendations for CAM therapies explicitly for CAM survivors, as primary care physicians will play an integral role in the administration of healthcare to cancer survivors.

Simultaneously, future communication initiatives should strive to reduce the stigma associated with CAM therapies. Many traditional physicians have a negative view of CAM, despite continued trends of increased popularity among the American public.<sup>21,31,40,41</sup> For example, in a survey of physicians in Denver (n=302) more than 50% surveyed were not comfortable talking about CAM and 52% of physicians asked less than half of the time about CAM use.<sup>82</sup> This same survey revealed 60% of doctors wanted to learn more about CAM in order engage in evidence-based conversations with their patients, with a particular interest in dissuading patients from use of harmful or ineffective CAM modalities.<sup>82</sup> Some of the physician

pushback may be derived from a fear of the unknown: practicing physicians relative to current medical students may not have had the opportunity to take electives on CAM to enhance their formal training.<sup>31,41</sup> A 1997 mixed method survey of 117 of the then 125 medical schools in the United States indicated 64% of medical schools had integrated some form of CAM course into their curriculum either as an elective or part of another required course.<sup>83</sup>

One possible way OCCAM could work to reduce the stigma associated with CAM would be to engage in greater collaboration efforts with NCCAM. This may be particularly important since a recent survey of 41 NCI-designated Cancer Centers revealed 46% of their websites referred to NCCAM and only 12% referred to OCCAM.<sup>84</sup> Through a collaboration, NCCAM and OCCAM could work to reduce some of the confusion surrounding the terminology used to describe CAM, i.e. “complementary medicine,” “alternative medicine,” “complementary and alternative medicine,” and “integrative medicine.” One healthcare provider stated, “we see a recurring problem with confusion about the different terminology used by OCCAM...people often do not know or understand the difference between ‘alternative’ and ‘integrative’ therapy” (NCI Public Comment, unpublished data, 2009). As the field of CAM evolves, it may become imperative that NCCAM and OCCAM devise a systematic definition for CAM. Many CAM therapies once considered “alternative” are becoming more mainstream, like acupuncture, and are even integrated into conventional treatment protocols, so it might be suggested the term CAM be replaced with “complementary medicine” or “integrative medicine.”

## 6.4 FINAL THOUGHTS

Designing communication initiatives at the national level presents challenges for selecting images, text, format and other design elements, which will resonate with the greatest number of people, as well as challenges to incorporate cultural sensitivity and relevancy. However, when appropriately designed and tested, these campaigns can address the needs of their intended populations. The development and subsequent testing of OCCAM's workbook revealed this initiative is important for facilitating conversations between patients and providers because no such resource, which asks patients to document CAM use, currently exists.

Use of OCCAM's workbook, whether with or independent of one's healthcare provider, will serve to empower cancer patients and survivors, who in turn will be able to better articulate their symptoms, concerns, needs, and beliefs. Furthermore, use of this workbook may encourage greater information sharing between patients and healthcare providers. As patients become more involved in their healthcare, it will be imperative that healthcare providers help direct patients to reputable sources of information. Since the majority of patients report receiving their healthcare information online, it will be vital that physicians direct patients to .gov, .edu., or .org sites, instead of .com or .net sites.<sup>85</sup> This initiative has public health significance because CAM patient education resources that serve to embolden patients to talk to their providers about CAM use are lacking, despite a continued interest in CAM among cancer patients, survivors, and the general public. OCCAM's initiative is an important first step to informing, educating, and empowering patients to discuss complementary and alternative medicine use with their healthcare providers in order to promote their health, prevent drug-interactions, and help manage treatment-related side effects.



## **APPENDIX A**

### **ENVIRONMENTAL SCAN WEBSITES**

Appendix A contains the URLs for the websites included in the environmental scan. These websites include, but are not limited to:

- The American Cancer Society
- The Leukemia and Lymphoma Society
- The Livestrong Foundation
- Susan G. Komen for the Cure

This appendix includes the general website URLs as well as specific URLs for the patient education resources mentioned in this thesis.

Alliance of State Pain Initiatives: [www.trc.wisc.edu](http://www.trc.wisc.edu)

American Cancer Society: [www.cancer.org](http://www.cancer.org)

Breast Cancer Action: [www.bcaction.org](http://www.bcaction.org)

BreastCancer.org: [www.breastcancer.org](http://www.breastcancer.org)

The CancerJourney.org: [www.thecancerjourney.org](http://www.thecancerjourney.org)

Colon Cancer Alliance: [www.ccalliance.org](http://www.ccalliance.org)

Dana Farber Cancer Institute: [www.dana-farber.org](http://www.dana-farber.org)

Hirshberg Foundation for Pancreatic Cancer: [www.pancreatic.org](http://www.pancreatic.org)

Leukemia and Lymphoma Society: [www.lls.org](http://www.lls.org)

Livestrong Foundation: [www.livestrong.org](http://www.livestrong.org)

Lung Cancer Alliance: [www.lungcanceralliance.org](http://www.lungcanceralliance.org)

MD Anderson Cancer Center: [www.mdanderson.org](http://www.mdanderson.org)

Memorial Sloan-Kettering Cancer Center: [www.mskcc.org](http://www.mskcc.org)

National Brain Tumor Foundation: [www.braintumor.org](http://www.braintumor.org)

National Cancer Institute: [www.cancer.gov](http://www.cancer.gov)

National Center for Complementary and Alternative Medicine: [www.nccam.nih.gov](http://www.nccam.nih.gov)

National Ovarian Cancer Coalition: [www.ovarian.org](http://www.ovarian.org)

National Patient Safety Foundation: [www.npsf.org](http://www.npsf.org)

Patients Advocates for the Advanced Cancer Treatment: [www.paactusa.org](http://www.paactusa.org)

Patients Against Lymphoma: [www.lymphomation.org](http://www.lymphomation.org)

Prostate Cancer Foundation: [www.pcf.org](http://www.pcf.org)

ProstateNet.org: [www.prostatenet.org](http://www.prostatenet.org)

Susan G. Komen for the Cure: [www.komen.org](http://www.komen.org)

Wings Cancer Foundation: [www.wingscancerfoundation.org](http://www.wingscancerfoundation.org)

## **APPENDIX B**

### **OPEN CALL TESTING INFORMATION**

Appendix B contains the versions of the patient education workbook pages, which were tested during Open Call Testing. These pages include:

- Versions 1 and 2 of *Why I want to use CAM*
- Versions 1 and 2 of *My Weekly CAM use*
- Versions 1 and 2 of the cover

Appendix B also contains the screening questions used to recruit participants for Open Call Testing, OCCAM's list of questions to be addressed during Open Call Testing, the finalized moderator's guide, which was used during Open Call Testing, and the feedback tracking forms administered to healthcare providers.

### **B.1.1 Screening Questions**

1. Have you engaged in any of the following activities? Check all that apply.
  - a. Yoga
  - b. Meditation
  - c. Taken vitamin or supplements
  - d. Tai-chi
  - e. Massage
  - f. Acupuncture
  - g. Chiropractic Care
  - h. Following specific diet plan
  - i. Exercise
  - j. Taken dietary supplements (including vitamins or herbal and plant-based products)
  
2. During cancer treatments, what have you tried to alleviate your symptoms?

## **B.1.2 OCCAM's list of questions for pretesting**

Open Call Testing Items to Test:

### **Specific Items to Test with Alternative Versions**

*(MG) = questions included on the Moderator's Guide*

#### **Title Page:**

- (MG) Alternative Titles
- (MG) Word Usage, i.e. guide vs. workbook
- (MG) Pictures
- (MG) Color palettes
- (MG) Size of OCCAM's banner

#### **Understanding cancer CAM interests**

- (MG) Would you use this form? Why or Why not?
- Why do you think this form would be helpful, or why not?
- Would this form help you to organize your thoughts about CAM use?
- (MG) Would this form help you to discuss with your doctor your use of CAM therapies?
- (MG) Layout of pictures: Which format do you prefer? Why?
- (MG) Pictures
- Are the directions clear?
- (MG) Orientation of text boxes
- Is there enough space to write answers to questions regarding CAM use?
- (MG) If you could add one question to this page, what would it be?

#### **Weekly CAM therapy use**

- Would you track the use of CAM therapies?
- Are the examples clear?
- (MG) Is the conventional therapy space at the top of the page helpful?
  - Would you want to track your conventional therapies at all on this form or would you prefer to track conventional therapies on a completely separate form?
- Days of the week listed vs. blank spaces to be filled in by user
- Line weight: thick lines vs. dashed
- Line spacing: is there enough space to write on this form?
- (MG) Would you show this page to your doctor and discuss your weekly CAM use with your healthcare team?
- Would this page facilitate/ make it easier to talk to your doctor about your use of CAM therapies?

- What type of information do you think should go in the last column?
- (MG) Would you suggest changing any of the column titles? Are there other titles/headings that would be more useful?

**General Items to Test**

- (MG) Is this helpful? Would you find this helpful/useful/ beneficial?
- Worth/Usability
- Have you ever used something like this before?
- Do these worksheets help formulate your thoughts?
- Are the headings clear? Do the headings make sense to you? If not, what would you suggest?
- Throughout the workbook are the directions clear?
- Other ideas from patients, what's missing from this workbook?
- What is confusing to you?
- What does this mean to you?
- What would you put down?
- Font size
- Color scheme
- Other recommendations for the workbook
- If your doctor gave you this workbook, would that make you motivated to complete it?
- Would you rather print out the entire workbook or specific pages? Which pages would you be most likely to print out?
- (MG) Would you prefer to fill out these forms online or to print them out and fill in the information by hand?

**Shea's Suggestions:**

- (MG) Would this be something you would use? Would you be more likely to print it off and fill it out or fill it in online?
- (MG) What changes would you recommend?
- What do you expect this to contain based on the title? What does the word tool mean to you? Are there alternate titles that you would recommend based on the contents?
- Are the instructions clear on this page? Is there adequate space for you within the charts? Are there enough spaces for you to fill in all of your healthcare providers/medications/CAM therapies?
- How would you make this chart better?
- Does the order of the sheets make sense to you?
- How would you use these?
- Do you prefer this wording or this wording? Images? Format?
- Do you find any words/phrases confusing?

## B.1.3 Moderator's Guide

Open Call Testing Guide: General Audience  
Session Dates: July 17 & 18, 2012

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### Introduction and preparation for the session

Hi. Thanks so much for making the time to talk to us today. Let me share with you what we will be doing here. As you may know, we work with communications groups within the National Cancer Institute to help them with their web sites and other materials.

We want to understand how people find and use health and cancer information. As we create new sites and materials, we meet with many different people, asking them to try them out and help us improve them. This means that there are no right or wrong answers. The way you can help us the most is to share your reactions with us: if you like something, don't like it, find it easy or find it hard, we want to hear about your experience.

You don't have to answer any of my questions: if you'd rather not talk about something, just say so. And, of course you can stop at any time.

You and I will be working together for about an hour. [Name] will be helping me take notes. And, there are some people listening and observing the session, too.

I think they told you that we will record this session. The recording is primarily to help us take notes, but we might show anonymous clips to people working on these products. Is that all right with you?

On parts of today's session we will be tracking where you are looking on the screen to help us understand how you read the information. To do this, I will need to set up the eye tracker.

|                      |   |
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| Open Call July, 2012 | P |
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### Web and health information use      Patients and Family

I understand you have had a recent experience with cancer? Can you tell me a little bit about that?

Did you use the web to find information that would help you understand this disease better and make decisions?

Have you ever heard of NCI?  Yes  Not sure  No  
If you had to describe NCI to someone, what would you say it is?

Have you ever been to the NCI web site, cancer.gov?  Yes  Not sure  No  
(if yes) Tell me about the last time you were there.



---

**Segment 3: OCCAM Patient Education Material**

1. **[Show booklet hard copy]** The Office of Cancer Complementary and Alternative Medicine has created a booklet to help patients and doctors better communicate with each other about the use of Complementary and Alternative Medicine. This first page talks about what it is and how to use it. Please read it over.
  - a. Are you familiar with the term "Complementary and Alternative Medicine"?
    - i. **If not:** Complementary and Alternative Medicine or CAM is any medical system, practice, or product that is not thought of as standard care. Complementary medicine, in particular, is used along with standard care and can include things such as: Yoga, meditation, tai chi, massage, acupuncture, chiropractic care, exercise, following a specific diet, and taking dietary supplements.
  - b. Have you done anything like this to help alleviate symptoms?
    - i. **If yes** – Is this something you discussed with your doctor or did you do it on your own?
    - ii. **If no** –Perhaps after you learn a little more about it, you might decide that CAM is something you would be interested in.
2. As you read earlier, this booklet has some informational content, as well as several worksheets. We're going to focus on three worksheets in particular.
  - a. **[Show online PDF and hard copy]** This document is going to be available as a PDF online. You can either fill it out on the computer and print it out, or you can print it out and write in it by hand. Do you have a preference for which way you would do it?
3. **[Show Why I want to use CAM]** We'll start with this worksheet. Please take a few minutes to fill this out.  
*[If participant is taking a while, stop them after the first question and have them discuss the rest verbally]*
  - a. What are your overall thoughts about this worksheet?
    - i. How would these questions and your answers be helpful in starting a discussion with your doctor?
    - ii. How would you ask your doctor about CAM? Would you feel comfortable talking to your doctor about this?
    - iii. Are there other questions or additional information that would be helpful to have on this page? (perhaps, examples of words to use in bringing up the subject)
4. **[Show My Weekly CAM Use]** Are you currently doing any CAM activities (and remember that includes even things like exercise, a special diet, and dietary supplements)?
  - a. **If yes** - Please fill this out for last week.
  - b. **If no** – OK, go ahead and fill it out then as if you were. You can make some things up.
  - c. Is this something you would find useful?

- d. Would you show this page to your doctor and discuss your weekly CAM use with your health care team?
  - e. Would you suggest changing any of the column titles? Are there other titles/headings that would be more useful?
  - f. Is the conventional therapy space at the top of the page helpful?
  - g. Would you want to track your conventional therapies at all on this form or would you prefer to track conventional therapies on a completely separate form?
5. **[If there's time: Show Medication List]** Next we have a form to fill out your medications. You don't have to fill out the whole form, though if you feel comfortable filling out one or two you may do so.
- a. Is there enough room to write everything? Are the squares large enough?
  - b. Would you remember all of your medications and the details that are asked here, or would you need to check your medication bottles or ask someone?
6. **[Show alternate cover]** I have an alternate design for the cover. Take a moment to look at it, and then we'll compare the two.
- a. What are your overall thoughts?
  - b. Which one do you prefer?
  - c. Do you have a color preference?
  - d. Do you have a preference on images?
  - e. Which title do you prefer?
7. **[Show alternate Why I want to use CAM worksheet]** These two pages have the same content but a different layout and different images.
- a. Which layout do you prefer? Which images?
8. **[Show alternate My Weekly CAM use worksheet]** Again, these two pages have the same content but a different design.
- a. Which do you prefer?
  - b. Do you have a preference for whether or not to include the days of the week?
  - c. Do you have a preference in the style of the lines?
9. Thinking about everything we've looked at with this booklet, is the booklet something you think you would use? If so, how?
- a. What changes would you recommend? Are there other items which should be included in this document?
  - b. Would you look for and print it out yourself or expect your doctor to give it to you?
  - c. If there were a mobile app that covered the same material would you use it? For example you might be able to track your CAM usage, medications, doctor information, etc.


---

## Wrapup

[General thanks and payment of stipend.](#)


## B.1.4 Draft Versions Tested

**Why I want to use CAM**





Complementary and alternative medicine (CAM) is any medical system, practice, or product that is not thought of as standard care. Before trying any CAM therapies, it is important that you speak with your doctor. Talking to your health care providers about your interest in using CAM therapies will help them better coordinate your cancer care. Try to answer the following questions before your next office visit and remember to discuss your thoughts with members of your health care team.


**I am interested in using CAM because:**



**The specific CAM therapies I might like to try are:**



**The side effects I would like to relieve by using CAM are:**




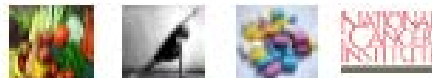
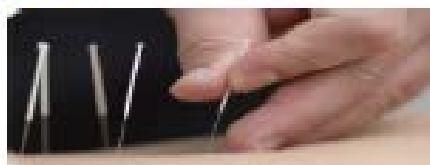


Figure 1: Version A of *Why I want to use CAM*

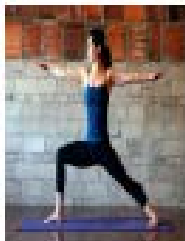
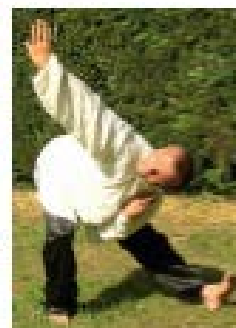
## Why I want to use CAM



Complementary and alternative medicine (CAM) is any medical system, practice, or product that is not thought of as standard care. Before trying any CAM therapies, it is important that you speak with your doctor. Talking to your health care providers about your interest in using CAM therapies will help them better coordinate your cancer care. Try to answer the following questions before your next office visit and remember to discuss your thoughts with members of your health care team.



I am interested in using CAM because:



The specific CAM therapies I might like to try are:

The side effects I would like to relieve by using CAM are:



Figure 2. Version B of *Why I want to use CAM*

## My weekly CAM use



To help you improve communication with your doctor about your use of CAM therapies, try recording the different CAM therapies you have tried and the effects they have had on your symptoms.

What conventional therapies do you have scheduled for this week? \_\_\_\_\_

| Day of Week            | Date       | CAM Therapies      | How Much? or How Long? | How Did It Make you Feel?                              |
|------------------------|------------|--------------------|------------------------|--|
| <i>Example: Monday</i> | <i>8/4</i> | <i>Yoga</i>        | <i>30 minutes</i>      | <i>Decreased anxiety about upcoming treatment</i>      |
| <i>Example: Friday</i> | <i>8/8</i> | <i>Acupuncture</i> | <i>30 minutes</i>      | <i>Relieved nausea and vomiting after chemotherapy</i> |
| Sunday                 |            |                    |                        |  |
|                        |            |                    |                        |  |
|                        |            |                    |                        |  |
| Monday                 |            |                    |                        |  |
|                        |            |                    |                        |  |
|                        |            |                    |                        |  |
| Tuesday                |            |                    |                        |  |
|                        |            |                    |                        |  |
|                        |            |                    |                        |  |
| Wednesday              |            |                    |                        |  |
|                        |            |                    |                        |  |
|                        |            |                    |                        |  |
| Thursday               |            |                    |                        |  |
|                        |            |                    |                        |  |
|                        |            |                    |                        |  |
| Friday                 |            |                    |                        |  |
|                        |            |                    |                        |  |
|                        |            |                    |                        |  |
| Saturday               |            |                    |                        |  |
|                        |            |                    |                        |  |
|                        |            |                    |                        |  |



NIH...Turning discovery into health



Figure 3. Version A of *My weekly CAM use*



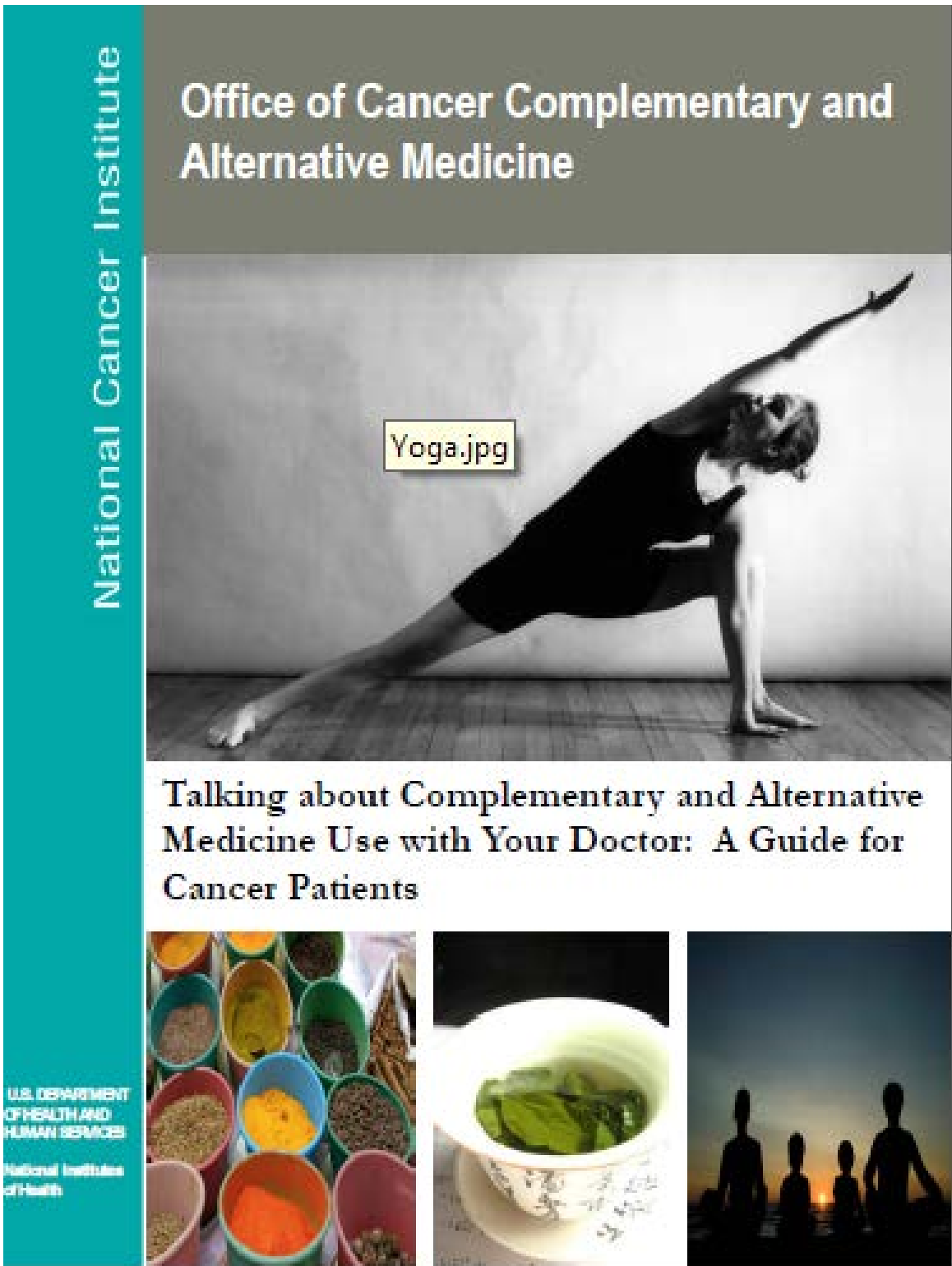


Figure 5. Version A of the workbook cover

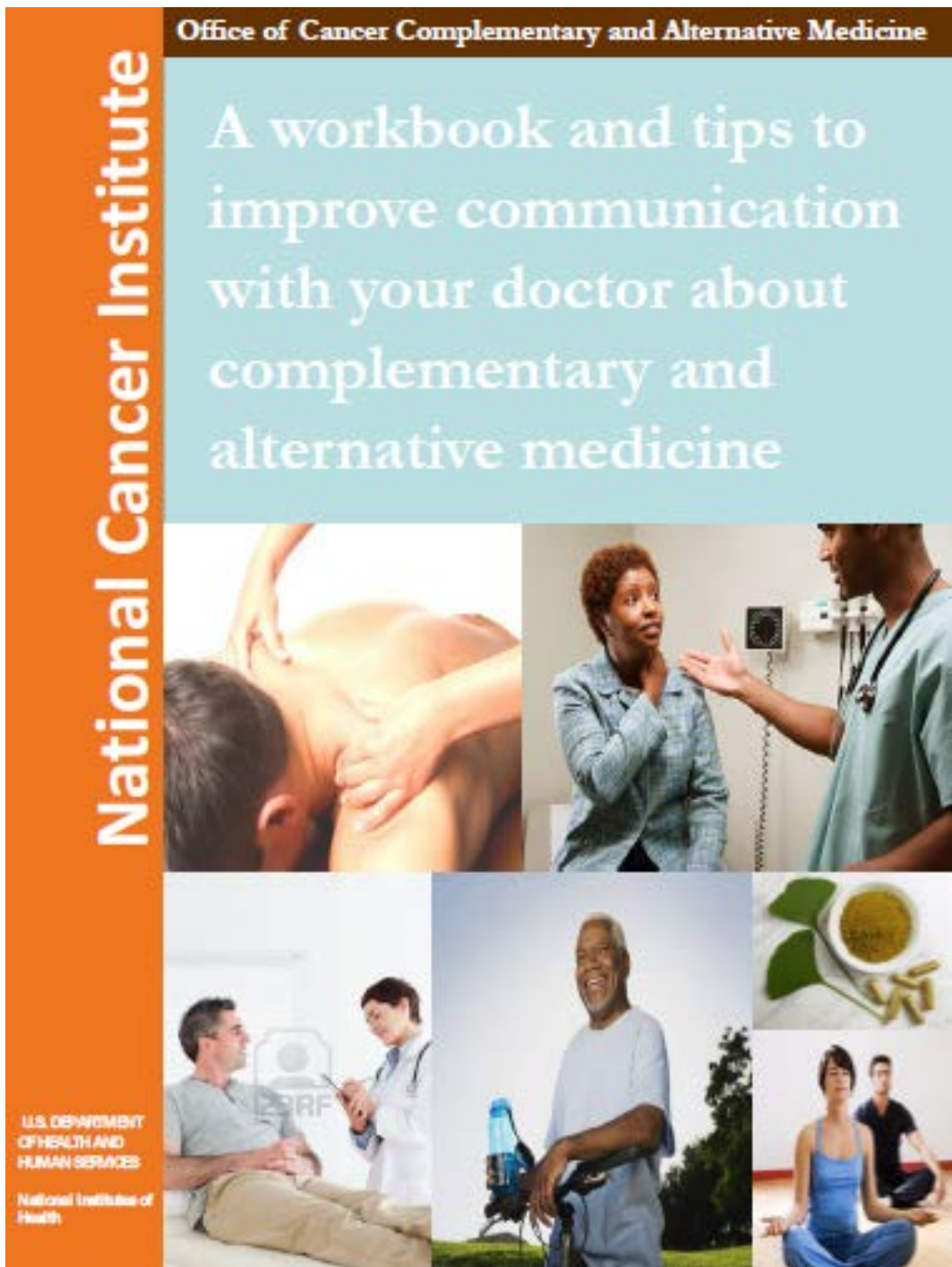


Figure 6. Version B of the workbook cover



## **B.1.5 Healthcare Provider Feedback Tracking Form**

### Healthcare Provider Feedback Form

Federal Employee/ Contractor (circle one) Occupation: \_\_\_\_\_

1. Would you find a resource useful that encourages conversations with your patients about their CAM use and beliefs?
2. Based on your clinical experience, do you think this would be a resource patients would use?
3. Would you recommend a resource such as this to a cancer patient?
4. Identify who you would think is most likely to use this resource in the clinical setting? Are there multiple people?
5. Would patients keeping track of their CAM use in these logs help you enhance their care?
6. Describe changes you would suggest to make the resource more useful in your practice?
7. Is there adequate space to write within the charts?

|                                      |  |
|--------------------------------------|--|
| Instructions                         |  |
| Understanding cancer CAM terminology |  |
| Why I want to use CAM                |  |
| Tips for talking with your provider  |  |
| My Weekly CAM log                    |  |
| My Complete Medication List          |  |
| Members of my healthcare team        |  |
| Glossary                             |  |
| Resources                            |  |

**Figure 7. Feedback tracking form**

## **APPENDIX C**

### **PRETESTING TOTALS**

Appendix C consists of three tables (Tables 1-3) that describe the individuals who were surveyed during OCCAM's pretesting effort. Table 1 illustrates the varied backgrounds of the cancer survivors who participated in Open Call Testing, while Table 2 shows the number of cancer survivors, healthcare providers, cancer advocates, and caregivers who were surveyed in each round of testing. Finally, Table 3 differentiates between federal and non-federal healthcare providers surveyed between round one and two of pretesting.

**Table 1. Open Call Testing Participant Demographics**

| Sex    | Age | Race               | Education                     | Cancer Type                                     | Year of Diagnosis |
|--------|-----|--------------------|-------------------------------|---|-------------------|
| Female | 24  | Caucasian          | College Degree                | Leukemia  | 2010              |
| Male   | 25  | African American   | College Degree                | Hodgkin's Lymphoma                              | 2010              |
| Male   | 42  | African American   | High School                   | Kidney Cancer                                   | 2011              |
| Female | 57  | Caucasian-Hispanic | College Degree                | Breast Cancer                                   | 2010              |
| Female | 58  | Caucasian          | Some College                  | Breast Cancer                                   | 2010              |
| Male   | 63  | African American   | Some College                  | Prostate Cancer                                 | 2011              |
| Female | 65  | Caucasian-Hispanic | College Degree, Some Graduate | Breast Cancer                                   | 2010              |
| Female | 71  | Caucasian-Hispanic | College Degree                | Breast Cancer                                   | 2007              |
| Female | 74  | Caucasian          | Some College                  | Colon Cancer, Bladder Cancer, Melanoma, Sarcoma | 2012              |

**Table 2. Pretesting Totals For Each Round of Testing**

| Classification                              | Number Surveyed | Pretesting Round | Total |
|---|-----------------|------------------|-------|
| Survivor                                    | 9               | 1                | 9     |
| Survivor                                    | 3               | 2                | 3     |
| Healthcare Provider, Caregiver, or Advocate | 15              | 1                | 15    |
| Healthcare Provider, Caregiver, or Advocate | 15              | 2                | 15    |
| Total                                       |                 |                  | 42    |

**Table 3. Distribution and Type of Healthcare Provider Surveyed**

| <b>Healthcare Professional</b> | <b>Number Surveyed</b> | <b>Federal or Non-Federal Affiliation</b> | <b>Total</b> |
|--------------------------------|------------------------|---|--------------|
| Physician (M.D. or D.O.)       | 2                      | Federal                                   | 2            |
| Physician (M.D. or D.O.)       | 6*                     | Non-Federal                               | 6*           |
| Nurse Practitioner (N.P)       | 3                      | Federal                                   | 3            |
| Nurse Practitioner (N.P.)      | 2                      | Non-Federal                               | 2            |
| Nurse (R.N)                    | 5                      | Federal                                   | 5            |
| Social Worker (S.W).           | 1                      | Federal                                   | 1            |
| Registered Dietitian (R.D)     | 1                      | Non-Federal                               | 1            |
| Total Healthcare Providers     |                        |   | 20           |

\*At the American Society of Clinical Oncologist’s Annual Meeting four of six physicians provided voluntary comments, and the remaining two physicians were contacted during the first and second rounds of pretesting.

## **APPENDIX D**

### **TALKING ABOUT COMPLEMENTARY AND ALTERNATIVE MEDICINE WITH HEALTH CARE PROVIDERS: A WORKBOOK AND TIPS**

Appendix D consists of screenshot of final versions of each page included within the patient education booklet, *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips*. The workbook pages have been included to provide the reader with a sample of the health communication material created for the Office of Cancer Complementary and Alternative Medicine of the National Cancer Institute. The workbook may be downloaded via OCCAM's website at [http://cam.cancer.gov/talking\\_about\\_cam.html](http://cam.cancer.gov/talking_about_cam.html).



# Talking about Complementary and Alternative Medicine with Health Care Providers:

## A Workbook and Tips



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

## How to use this workbook



**If you are a patient...** this workbook is designed to help you talk with your health care provider(s) about your complementary and alternative medicine (CAM) use during and after your cancer care. This workbook can be used in its entirety or as individual sheets to best meet your needs and interests.

**If you are a health care provider...** this workbook contains several documents which can be used to help your patients keep track of their medicines, CAM use, and complementary providers. It is intended to help you talk with your patients about their goals, beliefs, symptom management, and use of CAM therapies during and after cancer care.

This workbook contains several worksheets:

- **Why I want to use CAM** encourages you to think about why you are considering using CAM therapies and what specific symptoms you wish to relieve.
- **My monthly CAM use** helps you to keep track of your CAM use over a month to get a sense of how the CAM therapies you've tried have helped manage your cancer-related symptoms.
- **My complete medicine list** allows you to organize in one place all of the medicines you are taking, including prescription medicines, over-the-counter drugs, herbs, dietary supplements, and vitamins.
- **Members of my health care team** provides a place to organize the contact information for everyone involved in your care, including conventional and complementary therapy providers.

Other resources included in this workbook are:

- **Understanding cancer CAM**
- **Tips for talking with your provider about CAM use**
- **Glossary**
- **Cancer CAM resources**



## Understanding cancer CAM



What is the difference between complementary and alternative medicine, complementary medicine, alternative medicine, and integrative medicine?

**Complementary and alternative medicine (CAM)** is any medical system, practice, or product that is not thought of as standard medical care in Western countries.

**Complementary medicine** is used *along with* standard medical care.

**Alternative medicine** is used *in place of* standard medical care.

**Integrative medicine** is an approach that *combines treatments from standard medical care and CAM* for which there is some high-quality evidence of safety and effectiveness.

Other terms may be used to refer to CAM therapies such as “natural,” “holistic,” “home remedies,” or “Eastern medicine.”

Why do people use CAM therapies?

People use CAM therapies for a variety of reasons including:

- To help cope with the side effects of cancer treatments, such as nausea, pain, and fatigue
- To comfort themselves and ease the worries of cancer treatment and related stress
- To feel that they are doing something more to help with their own care
- To try to treat or cure their cancer

Should I be concerned about using nutritional supplements with my standard treatments?

Whenever starting a new routine, whether an exercise program or use of a multivitamin, you should always consult your doctor first. It is important to clearly communicate all medications you take, including dietary supplements, vitamins, and herbals to prevent potential drug interactions. Some supplements may interfere with the effectiveness of chemotherapy, radiation, or prescription medications.



### What are some examples of CAM therapies?

Please note the following is not a complete list of CAM therapies. For more information on cancer CAM therapies, visit <http://cam.cancer.gov>. CAM therapies can also be organized into different categories such as mind-body therapies or exercise therapies. See the Glossary for a list of the different categories of CAM.

|                              |                            |                               |
|------------------------------|----------------------------|-------------------------------|
| Acupuncture                  | Immunoaugmentative therapy | Probiotics                    |
| Antineoplastons              | Intercessory prayer        | Pulsed electromagnetic fields |
| Antioxidants                 | Intravenous Vitamin C      | Qigong                        |
| Aromatherapy                 | Kelley/Gonzalez regimen    | Reflexology                   |
| Art therapy                  | Laetrile                   | Reiki                         |
| Biofeedback                  | Low-dose naltrexone        | Relaxation therapy            |
| Chiropractic                 | Macrobiotic diet           | Selenium                      |
| Coenzyme Q10                 | Magnet therapy             | Soy                           |
| Cognitive-behavioral therapy | Meditation                 | Spiritual healing             |
| Dietary Supplements          | Melatonin                  | Support groups                |
| Exercise                     | Milk Thistle               | T'ai chi                      |
| Gerson therapy               | Mistletoe                  | Tea                           |
| Herbs and herbal extracts    | Multivitamin               | Therapeutic massage           |
| Hydrazine sulfate            | Music therapy              | Vegetarian Diet               |
| Hypnosis                     | Omega-3 fatty acids        | Vitamins                      |
| Imagery                      | Osteopathy                 | Yoga                          |

## Why I want to use CAM



Complementary and alternative medicine (CAM) is any medical system, practice, or product that is not thought of as standard medical care in Western countries. Before trying any CAM therapies, it is important that you speak with your health care providers. Try to answer the following questions before your next office visit. At your visit, remember to discuss your thoughts with members of your health care team.

### I am interested in using CAM because:



### The side effects I would like to relieve by using CAM are:



### The specific CAM therapies I might like to try are:



## Tips for talking to your provider about CAM



Talking to your health care providers about your use of complementary and alternative medicine (CAM) is important. Before each visit, think about what you would like to discuss and use the suggestions below to have more effective conversations with your providers about your CAM use.

### *Preparing for your visit:*

- To maximize the time you have with your health care providers, prepare 1-2 questions before each visit regarding concerns you may have about CAM therapies.
- Sometimes it may be up to you to “start the conversation.” Some easy ways to bring up CAM use with your health care providers would be to say, “I’m looking for your thoughts on how I can include complementary and alternative therapies in my treatment plan” or “I’ve been thinking about ways to make myself feel better, so I’ve started a yoga routine and take a multivitamin daily.”
- You may want to bring along a limited amount of information from trusted sources if you feel it will help you to communicate your CAM interests with your health care providers.

### *During your visit:*

- At each visit, remember to discuss the CAM therapies you are using.
- Inform your health care providers of any additional symptoms you may be experiencing as a result of your treatment, such as cancer-related fatigue.
- It may be helpful to restate your commitment to standard treatments if you think your health care providers are concerned about your use of complementary therapies.
- Ask your health care providers to direct you to additional resources about CAM therapies or providers.
- Don’t be afraid to ask for clarifications if something is unclear or you need additional information.
- If you can’t speak with your doctor about your CAM use, you can also talk to the nurse practitioner (NP), physician assistant (PA), nurse, or other medical staff at your doctor’s office.

### *After your visit:*

- Future appointments may require more time to discuss your concerns with your health care providers — ask the receptionist or appointment coordinator about scheduling longer appointments.
- Remember, obtaining a second opinion is always an option. Second opinions can help strengthen your relationship with your existing doctor, clarify diagnoses, provide different options for treatment, and may even lead you to a doctor who is better suited to address your needs.





## My complete medicine list



Tell your oncologist, specialists, and primary care physician about **all** of the medicines you are taking, including prescriptions and over the counter (OTC) medicines as well as vitamins, herbs, and dietary supplements. This is important because things that seem safe, such as certain supplements or pills, may interfere with your cancer treatment.

### Prescription Medicines

| Name of medicine | Dose and time(s) taken<br>(ex. 200 mg daily at 10AM) | Prescribed by | Reason for medicine | Side effects and notes |
|------------------|--|---------------|---------------------|------------------------|
|                  |  |               |                     |                        |
|                  |  |               |                     |                        |
|                  |  |               |                     |                        |
|                  |  |               |                     |                        |
|                  |  |               |                     |                        |

### Over the Counter (OTC) Medicines

| Name of OTC medicine | Dose and time(s) taken<br>(ex. 1 pill as needed) | Recommended by | Reason for OTC medicine | Side effects and notes |
|----------------------|--|----------------|-------------------------|------------------------|
|                      |  |                |                         |                        |
|                      |  |                |                         |                        |
|                      |  |                |                         |                        |
|                      |  |                |                         |                        |
|                      |  |                |                         |                        |

### Herbs, Vitamins, and Dietary Supplements

| Name of herb, vitamin, or supplement | Dose and time(s) taken<br>(ex. 1000 IU at bedtime) | Recommended by | Reason for supplement | Side effects and notes |
|--------------------------------------|--|----------------|-----------------------|------------------------|
|                                      |  |                |                       |                        |
|                                      |  |                |                       |                        |
|                                      |  |                |                       |                        |
|                                      |  |                |                       |                        |
|                                      |  |                |                       |                        |

| Prescription Medicines |   |               |                     |                        |
|------------------------|---|---------------|---------------------|------------------------|
| Name of medicine       | Dose and time(s) of day taken<br>(ex. 200 mg daily at 10AM) | Prescribed by | Reason for medicine | Side effects and notes |
|                        |   |               |                     |                        |
|                        |   |               |                     |                        |
|                        |   |               |                     |                        |
|                        |   |               |                     |                        |
|                        |   |               |                     |                        |
|                        |   |               |                     |                        |
|                        |   |               |                     |                        |

| Over the Counter (OTC) Medicines |   |                |                         |                        |
|----------------------------------|---|----------------|-------------------------|------------------------|
| Name of OTC medicine             | Dose and time(s) of day taken<br>(ex. 1 pill as needed) | Recommended by | Reason for OTC medicine | Side effects and notes |
|                                  |   |                |                         |                        |
|                                  |   |                |                         |                        |
|                                  |   |                |                         |                        |
|                                  |   |                |                         |                        |
|                                  |   |                |                         |                        |
|                                  |   |                |                         |                        |
|                                  |   |                |                         |                        |
|                                  |   |                |                         |                        |

| Herbs, Vitamins, and Dietary Supplements |   |                |                       |                        |
|--|---|----------------|-----------------------|------------------------|
| Name of herb, vitamin, or supplement     | Dose and time(s) of day taken<br>(ex. 1000 IU at bedtime) | Recommended by | Reason for supplement | Side effects and notes |
|  |   |                |                       |                        |
|  |   |                |                       |                        |
|  |   |                |                       |                        |
|  |   |                |                       |                        |
|  |   |                |                       |                        |
|  |   |                |                       |                        |
|  |   |                |                       |                        |
|  |   |                |                       |                        |





## Members of my health care team



This worksheet is intended to help you keep track of all of your health care providers. Examples of conventional therapy providers include your primary care physician, medical oncologist, nurse practitioner, and pharmacist. Examples of complementary or integrative medicine providers include your massage therapist, nutritionist, acupuncturist, or chiropractor. Sharing the contact information among all of your health care team members may help establish coordinated care.

| Conventional Therapy Health Care Providers:                  |  |
|--|--|
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |

| Complementary/Integrative Therapy Health Care Providers:     |  |
|--|--|
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |

| Conventional Therapy Health Care Providers:                  |  |
|--|--|
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Complementary/Integrative Therapy Health Care Providers:     |  |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |
| Provider Name:   | Provider Name:   |
| Specialty:   | Specialty:   |
| Phone Number:  | Phone Number:  |
| Location:  | Location:  |
| Referred by:<br>(health care provider, friend, family, etc.) | Referred by:<br>(health care provider, friend, family, etc.) |



## Glossary



### Medicine-related terminology

**Conventional medicine:** A system in which medical doctors and other health care professionals (such as nurses, pharmacists, and therapists) treat symptoms and diseases using drugs, radiation, or surgery. Also called allopathic medicine, mainstream medicine, orthodox medicine, Western medicine, and standard treatment.

**Dietary supplement:** A product that is added to the diet. A dietary supplement is taken by mouth, and usually contains one or more dietary ingredients. Also called nutritional supplements.

- Examples: vitamins, minerals, herbs, amino acids, enzymes

**Dose:** The amount of medicine taken, or radiation given, at one time.

- Examples: 800 mg of ibuprofen, 200 cGy (centigray) of radiation

**Health care team:** All of the individuals involved in the management of your care. Team members include, but are not limited to, doctors, nurses, physician assistants, nurse practitioners, pharmacists, physical therapists, occupational therapists, and social workers, as well as acupuncturists, massage therapists, nutritionists, and chiropractors.

**Herbal supplement:** A product made from a plant that is thought to be useful in promoting health. Herbal supplements are taken by mouth and are considered a type of dietary supplement.

- Examples: ginger, milk thistle, turmeric

**Over the counter (OTC) medicine:** A medicine that can be bought without a prescription (doctor's order). Also called nonprescription medicine.

- Examples: aspirin, acetaminophen

**Prescription:** A doctor's order for medicine or another intervention.

**Side effect:** A problem that occurs when treatment affects healthy tissues or organs.

- Examples: fatigue, pain, nausea, vomiting, decreased blood cell counts, hair loss, mouth sores

**Standard medical care:** Treatment that experts agree is appropriate, accepted, and widely used. Also called best practice, standard of care, and standard therapy.

**Vitamin:** A nutrient that the body needs in small amounts to function and stay healthy. Sources of vitamins are plant and animal food products and dietary supplements.

- Examples: vitamin A, vitamin C, vitamin E

## Glossary



### CAM Categories:

**Alternative Medical Systems:** Systems built upon complete systems of theory and practice. Often, these systems have evolved apart from and earlier than the conventional medical approach used in the United States.

- Examples: Homeopathy, Naturopathy, Ayurveda

**Complex Natural Products:** An assortment of plant samples (botanicals), extracts of crude natural substances, and extracts from marine organisms used for healing and treatment of disease.

- Examples: Herbs and herbal extracts

**Energy Therapies:** Therapies that involve the use of energy fields. Two types of energy therapies are biofield therapies and electromagnetic-based therapies.

**Biofield therapy:** A type of energy therapy that is intended to affect energy fields that purportedly surround and penetrate the human body. The existence of such fields has not yet been scientifically proven.

- Example: Reiki

**Electromagnetic-based therapy:** A type of energy therapy that involves the unconventional use of electromagnetic fields.

- Example: Magnet therapy

**Exercise Therapies:** Health-enhancing systems of exercise and movement.

- Example: Yoga

**Manipulative and Body-Based Methods:** Methods based on manipulation and/or movement of one or more parts of the body.

- Example: Massage

**Mind-Body Interventions:** A variety of techniques designed to enhance the mind's capacity to affect bodily functions and symptoms.

- Example: Meditation

**Nutritional Therapeutics:** An assortment of nutrients, non-nutrient bioactive food components, and specific foods or diets used as cancer prevention or treatment strategies.

- Example: Vegetarian Diet

**Pharmacological and Biologic Treatments:** Treatments that include the off-label use of certain prescription drugs, hormones, complex natural products, vaccines, and other biological interventions not yet accepted in mainstream medicine.

- Example: Melatonin

**Spiritual Therapies:** Therapies that focus on deep, often religious, beliefs and feelings, including a person's sense of peace, purpose, connection to others, and beliefs about the meaning of life.

- Example: Intercessory praying

## Cancer CAM resources



Conducting internet searches about cancer CAM therapies results in a wealth of information and can often be overwhelming. The websites included on this page provide credible, reliable, and frequently updated information you can discuss with your health care providers. Remember to talk with your health care providers before beginning any new therapies or treatments.

### National Cancer Institute (NCI)

#### **Thinking About Complementary and Alternative Medicine: A Guide for People with Cancer**

- A free NCI booklet for patients and caregivers that provides guidance on how to choose CAM therapies and practitioners, questions to ask your doctor, and additional CAM resources.
- To order a copy, visit: <https://pubs.cancer.gov/ncipl/detail.aspx?prodid=P042> or call 1-800-4-CANCER (1-800-422-6237) and mention the book title or inventory number (P042).

#### **Office of Cancer Complementary and Alternative Medicine (OCCAM)**

- Oversees NCI's projects in CAM.
- Provides patients with information on specific cancer CAM therapies, tips for talking to health care providers, and frequently asked CAM questions.  
Visit: <http://cam.cancer.gov>

#### **Fact Sheets**

- Provide frequently updated information on a variety of cancer topics including prevention and treatment.  
Visit: <http://www.cancer.gov/cancertopics/factsheet>

#### **Cancer Information Service (CIS)**

- Trained cancer communication professionals provide real-time answers to questions about cancer.
- Provides help finding NCI information and printed materials on the Internet.
- Gives referrals to clinical trials and certain cancer-related services.  
Visit: <http://www.cancer.gov/aboutnci/cis>  
Chat online: [https://livehelp.cancer.gov/app/chat/chat\\_launch](https://livehelp.cancer.gov/app/chat/chat_launch)  
Toll-free: 1-800-4-CANCER (1-800-422-6237)

#### **NCI Clinical Trials**

- Search cancer CAM clinical trials.  
Visit: <http://www.cancer.gov/clinicaltrials/search/results?protocolsearchid=6791991>
- Search all clinical trials.  
Visit: <http://www.clinicaltrials.gov>

#### **NCI Publications Locator**

- An online system for finding, viewing, and ordering NCI reports, publications, and other materials.  
Visit: <https://pubs.cancer.gov/ncipl/home.aspx?s=1>

#### **NCI-Designated Cancer Centers**

- Universities and cancer research centers, located throughout the United States that conduct NCI-supported research and turn promising laboratory discoveries into new treatments for cancer patients.  
Visit: [http://cancercenters.cancer.gov/cancer\\_centers/index.html](http://cancercenters.cancer.gov/cancer_centers/index.html)

#### **Physician Data Query (PDQ®) Information Summaries**

- Regularly updated information on cancer types, screening, treatment, and CAM.  
Visit: <http://www.cancer.gov/cancertopics/pdq>

#### **National Institutes of Health (NIH)**

- Promotes, conducts, and supports scientific research to improve the health of the Nation.  
Visit: <http://www.nih.gov/>

#### **National Center for Complementary and Alternative Medicine (NCCAM)**

- NIH center that supports CAM research and provides information to health providers and the public about CAM for all disease types.  
Visit: <http://nccam.nih.gov>  
Toll-free: 1-888-644-6226 / TTY: 1-866-464-3615

#### **National Library of Medicine**

- **Medline Plus** provides access to reliable health information, including articles, organizations, directories, and answers to health questions.  
Visit: <http://medlineplus.gov>
- **PubMed** is a free and easy-to-use search tool for finding scientific articles.  
Visit: <http://www.ncbi.nlm.nih.gov/PubMed>
- Searches on PubMed can also be narrowed to CAM-specific research.  
Visit: <http://nccam.nih.gov/research/camonpubmed>

#### **Office of Dietary Supplements (ODS)**

- NIH office that provides information about dietary supplements, including background information and ongoing scientific research.  
Visit: <http://ods.od.nih.gov/>
- Access *My Dietary Supplements*, a free mobile application (app) to track dietary and nutritional supplement use.  
Visit: <http://ods.od.nih.gov/HealthInformation/mobile/aboutmyds.aspx>

#### **Food and Drug Administration (FDA)**

- Oversees the safety of drugs and medical devices.  
Visit: <http://www.fda.gov>  
Toll-free: 1-888-INFO-FDA (1-888-463-6332)



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## **APPENDIX E**

### **DISSEMINATION EFFORTS**

Appendix E contains screenshots of OCCAM's promotion of *Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* via OCCAM's website, the NCI Publications Locator, OCCAM's Listserv, and Facebook.





# OCCAM

Office of Cancer Complementary and Alternative Medicine

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- CAM at the NCI
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- Clinical Trials
- Identifying Novel CAM Therapies
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## Health Information

Updated: 01/22/13

- ▶ About CAM
- ▶ For Patients
- ▶ For Health Professionals
- ▶ CAM Therapies: A-Z
- ▶ Research Results
- ▶ Other Government Resources

### Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips



**If you are a patient...** this workbook is designed to help you talk with your health care provider(s) about your complementary and alternative medicine (CAM) use during and after your cancer care. This workbook can be used in its entirety or as individual sheets to best meet your needs and interests.

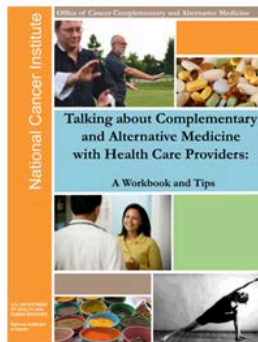
**If you are a health care provider...** this workbook contains several documents which can be used to help your patients keep track of their medicines, CAM use, and complementary providers. It is intended to help you talk with your patients about their goals, beliefs, symptom management, and use of CAM therapies during and after cancer care.

## Downloads

Download the entire workbook:

This 15 page workbook provides a one-stop resource for all your CAM conversation and tracking needs.

- [Download pdf](#)



Download each individual sheet:

Instructions for Use

- [Download pdf](#)



Figure 8. OCCAM's promotion and new webpage for the workbook

**National Cancer Institute** at the National Institutes of Health | [www.cancer.gov](http://www.cancer.gov)

**NCI Publications Locator**  
Your Resource for *free* publications

0 Items in your cart [View Cart](#)  
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Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips



◀ PREVIOUS    NEXT ▶

**Updated Publications (6)**

**FactSheet**

**Psychological Stress and Cancer**

Figure 9. NCI Publications Locator Promotion of OCCAM's workbook



National Cancer Institute



## Talking About Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips

The National Cancer Institute's Office of Cancer Complementary and Alternative Medicine (OCCAM) is pleased to announce a new educational resource, available for both patients and health care providers.

*Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips* was created to help patients and their health care providers have meaningful discussions about complementary and alternative medicine (CAM) use during and after cancer care.

This workbook includes resources for patients interested in trying CAM for the first time and worksheets to record medications, herbs, and supplements they may already be taking.

It also includes tips for talking to health care providers about CAM use and resources for CAM-related information.

Health care providers can encourage their patients to use this workbook to keep track of CAM therapies they are using.

Visit OCCAM's website ([http://cam.cancer.gov/talking\\_about\\_cam.htm](http://cam.cancer.gov/talking_about_cam.htm)) for more information and to download the workbook.

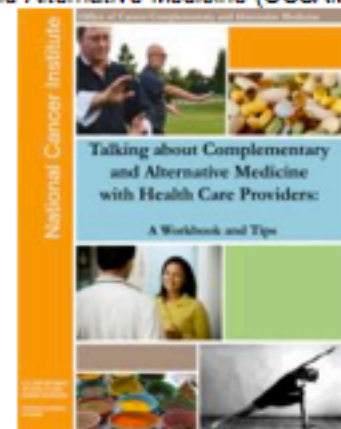


Figure 10. OCCAM's email promotion of the workbook via its listserv

facebook  Search for people, places and things

 **National Cancer Institute** shared a link via Spredfast.  
February 6 

Get tools and tips on how to talk to your health care provider about complementary therapies for cancer care. NCI's newly released Talking About Complementary and Alternative Medicine: A Workbook and Tips is a free resource.<http://1.usa.gov/VIBHaR>

 **Health Information -About CAM - OCCAM**  
[cam.cancer.gov](http://cam.cancer.gov)

If you are a patient... this workbook is designed to help you talk with your health care provider(s) about your complementary and alternative medicine (CAM) use during and after your cancer

Like · Comment · Share  5

 15 people like this.

 **Insurance Advisors Agency, Inc.** Very helpful for our health clients...thank you.  
February 7 at 11:46pm · Like

Figure 11. NCI promotion of OCCAM's workbook via Facebook



**Insurance Advisors Agency, Inc. via National Cancer Institute**

We have seen too many cancer patients in our office. Hopefully this will provide some help in talking with your health care provider.

Like · [Comment](#) · February 7 at 11:48pm · 🌐



**The Medical Mystery Tour via National Cancer Institute**

Good info! Wish we'd known about some of this sooner.

Like · [Comment](#) · February 7 at 11:23pm · 🌐



**OHCA via National Cancer Institute**

Get tools and tips on how to talk to your health care provider about complementary therapies for cancer care. NCI's newly released Talking About Complementary and Alternative Medicine: A Workbook and Tips is a free resource. <http://1.usa.gov/VIBHaR>

Like · [Comment](#) · February 7 at 9:50am · 🌐



**Amigos de los enfermos de cancer de pulmon**

Get tools and tips on how to talk to your health care provider about complementary therapies for cancer care. NCI's newly released Talking About Complementary and Alternative Medicine: A Workbook and Tips is a free resource

Like · [Comment](#) · February 7 at 5:23am · 🌐



**Radiation Therapy via National Cancer Institute**

Get tools and tips on how to talk to your health care provider about complementary therapies for cancer care. NCI's newly released Talking About Complementary and Alternative Medicine: A Workbook and Tips is a free resource. <http://1.usa.gov/VIBHaR>

Like · [Comment](#) · February 6 at 10:51pm · 🌐

Figure 12. Facebook Shares of OCCAM's workbook

**facebook**  Search for people, places and things

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 **Association of Oncology Social Work (AOSW)** shared a link.  
February 5 

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From our friends at NCI

\*\*\*\*\*

The National Cancer Institute's Office of Cancer Complementary and Alternative Medicine (OCCAM) is pleased to announce a new educational resource for your patients.

Talking about Complementary and A...[See More](#)

[http://cam.cancer.gov/talking\\_about\\_cam.htm](http://cam.cancer.gov/talking_about_cam.htm)  
cam.cancer.gov

---

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 Kjirsten Yahr likes this.

Figure 13. AOSW Facebook share of OCCAM's workbook

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