UNDERSTANDING THE USE AND DISCLOSURE OF NATURAL
PRODUCTS BY CANCER PATIENTS

BY

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ABSTRACT

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Background: Although cancer patients frequently use natural products (NP) to complement conventional oncology treatments and often do not disclose NP use to their healthcare providers, NP use initiated after diagnosis and the biopsychosocial determinants of NP use and disclosure have not been investigated. **Purpose:** The study purpose was to determine prevalence, patterns, and disclosure of NP use by cancer patients, and apply the Self-Regulation Model (SRM) to understand these behaviors. **Methods:** Analysis of a sub-set of the data from a cross-sectional survey of 1,226 cancer patients at a NCI–designated comprehensive cancer center within a 12-month period. Descriptive statistics were used for patterns of NP use and disclosure. Survey results were assigned to categories within the SRM and sequential

bivariate correlations were performed through the model's dual-arm structure. **Results:** Among patients with a cancer diagnosis (64.6% female, 87% white, 72.8% married, 75.3% age 50+), 74.1% reported current use of 1 or more NP and 28.2% (n=346) indicated they initiated NP use after being diagnosed with cancer. Female sex ($\chi 2$=20.00, p<.001) and higher level of education ($\chi 2$=22.41, p=.004) were significantly associated with current NP use. Of the 28.2% (n=346) who initiated NP use post-diagnosis, 55.8% listed one or more NP among the top five CAM therapies that provided the most benefit. Green tea (EGCG, pills)(n=65), multivitamin/mineral (n=56), and selenium (n=18) were most commonly reported to be most beneficial. SRM Illness Representations (IR) dimensions Consequences (r_s =.176, p=.014) and Desire to Avoid Suffering (r_s =.157, p=.030) were very weakly positively correlated with the coping strategy of Continuation of NP Use. Consequences (r_s =.214, p=.003) and Cure/Control (r_s =.226, p=.002) positively correlated with disclosure of NP use. Negative (scared, afraid) (r_s =-.435, p<.001) and Neutral (r_s =-.548, p<.001) emotional IR dimensions and Disclosure were negatively correlated. Disclosure and Illness Outcomes (Treatment and Cancer Status) (r_s =-.173, p=.016) were negatively correlated. **Conclusions:** NP use, post diagnosis initiation of use, and belief of benefit, were high among cancer patients surveyed. Multiple aspects of the SRM were found to be predictive of NP use and disclosure.

Chapter I

INTRODUCTION AND BACKGROUND

Context and Background of the Problem

The use patterns of natural products by cancer patients are not fully elucidated, the factors that motivate and sustain natural product use among cancer patients are not well known, and the disclosure patterns of natural product use to healthcare providers and the influencers of disclosure are not well understood. These gaps in knowledge are problematic due to the high use of natural products among cancer patients and the low disclosure rates to healthcare providers. The non-utilization of conventional medical treatment (Downey, Tyree, Huebner, & Lafferty, 2010; Pisani, Pagán, Lackan, & Richardson, 2012) and delays in conventional care (Ayers & Kronenfeld, 2012; Tom Xu & Farrell, 2007) have been associated with high use of complementary and alternative medicine, including natural products.

In addition, potential adverse interactions between natural products and conventional cancer treatments (Abebe, 2002; Sparreboom, Cox, Acharya, & Figg, 2004) may be worse due to lack of disclosure to healthcare providers. An improved understanding of these topics by oncology health care

providers will result in enhancements in the healthcare provided to those diagnosed with cancer and potentially to augmentation of their health and health outcomes.

The data for this study was derived from a cross-sectional survey of Complementary and Alternative Medicine (CAM) use by adults who sought care at the Cancer Institute of New Jersey (CINJ) during a 12 month period (Perlman et al., 2013). In 2013, Perlman et al. reported patterns of CAM use by this population at the level of broad categories (special diet, psychotherapy, movement/physical therapy, spirituality, mind/body, and natural products). This was an important study due to its large sample size (N=1,226), number of cancer types included (N=26) and it being conducted at CINJ, one of only 41 National Cancer Institute-designated comprehensive cancer centers in the United States. In addition, post diagnosis initiation of CAM therapies and independent predictors of use of individual CAM therapies had not been explored in previous studies. Younger age and female sex were found to be significantly associated with current CAM use. The initiation of CAM use after cancer diagnosis was found to be associated with female sex, younger age, and divorced/separated/single marital status vs. married (Perlman et al., 2013). Building off of Perlman et al.'s innovative work, which focused on the use of CAM after diagnosis, this study analyzed and described critical aspects of the survey that have not been investigated.

This study constituted an in-depth analysis of the patterns of natural product use and disclosure of natural product use to health care providers among cancer patients seen during a 12-month period at the CINJ. Previous studies have found associations between education level, race, and gender with natural product use (Adams & Jewell, 2007; Chang, Brodie, Choong, Sweeney, & Kerin, 2011; Ferrucci, McCorkle, Smith, Stein, & Cartmel, 2009; Velicer & Ulrich, 2008). It also evaluated the application of Leventhal's Self-Regulation Model (Leventhal et al., 1997; Leventhal, Nerenz, & Purse, 1984) to better understand health beliefs and behaviors among cancer patients seen at the CINJ during that time period.

The specific health beliefs that were investigated included the participant's beliefs as to how a natural product worked (i.e. mechanism), how effective they believed it was, whether they believed it caused any negative effects, and the perceived or anticipated response to disclosure of natural product use to a participant's oncologist. The behaviors related to those beliefs that were studied include patterns of natural product use and patterns of disclosure of natural product use to a participant's CINJ oncologist.

The results and conclusions of this research will be disseminated to healthcare providers, and it therefore has the potential to better the lives of cancer patients through improvements in their care. This would come as a result of a more accurate understanding of the patterns of natural product use, motivators of disclosure and a theory-based understanding of cancer

patients' health beliefs and behaviors specific to natural product use. This study makes an important contribution to the field as it enhances our understanding of this topic and can be applied to future research. It also could be of great benefit to clinicians and their patients as it would result in improved provider-patient communication and patient care that is based on empirical evidence.

Natural Product Use in the General US Population

As seen in Figure 1, natural products at 17.9% are the most commonly used category of Complementary and Alternative Medicine (CAM) in the United States (Peregoy, Clarke, Jones, Stussman, & Nahin, 2014).
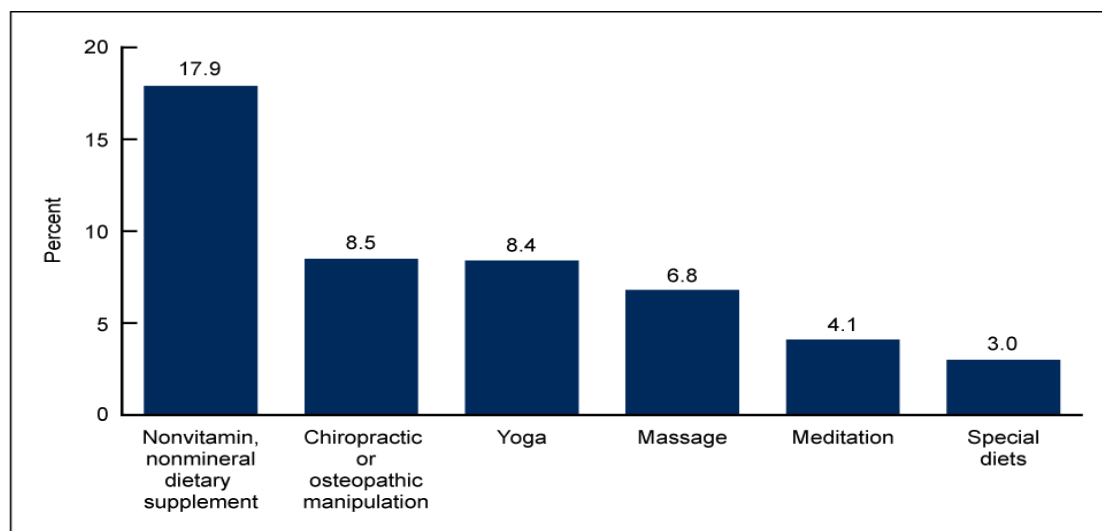
NOTE: Not all complementary health approaches are presented in this figure.
SOURCE: CDC/NCHS, National Health Interview Survey, 2012.

Figure 1. Percentage of adults who used complementary health approaches in the past 12 months, by type of approach: United States, 2012.
Note. Adapted from CDC/NCHS, National Health Interview Survey, 2012.

A US government sponsored survey of a nationally representative sample of U.S. adults conducted in 2007 and 2012 found that a total of 17.7% of adults reported use of nonvitamin, nonmineral natural products in the past 12 months (P. M. Barnes, Bloom, & Nahin, 2008; Clarke, Black, Stussman, Barnes, & Nahin, 2015). When vitamin and mineral dietary supplements are included, usage numbers are even higher in both adults (54%) and children (39% 1-3 years old, 43% 4-8 y, 29% 9-13 y, 26% 14-18 y) (Bailey et al., 2011).

Of the 17.7% of U.S. adults who in 2007 reported use of nonvitamin, nonmineral natural products, the most commonly reported natural product consumed was fish oil/omega-3/DHA (see Figure 2). Fish oil products have been reported to be utilized for the treatment of a wide array of common diseases and conditions including cancer, heart disease, and asthma. This is due in part to the fact that fish oils are rich in omega-3 fatty acids, principally docosahexaenoic acid (DHA) and eicosapentaenoic acid (EPA). Omega-3 fatty acids are precursors to prostaglandins, thromboxanes, and leukotrienes. These compounds regulate important physiological changes in the body including vasoconstriction and inflammation. At 19.9%, glucosamine was the second most commonly reported natural product used among US adults (P. M. Barnes et al., 2008). Utilization of glucosamine has mainly been attributed to those using it for the treatment of osteoarthritis. The scientific support for the use of glucosamine in the treatment of osteoarthritis is based on the fact

that glucosamine is a constituent of glycosaminoglycans and proteoglycans, which themselves are part of cartilage in the joints. Numerous clinical studies, lasting up to 3 years, have found glucosamine to be at least somewhat effective in the treatment of osteoarthritis by decreasing pain and improving range of motion (Drovanti, Bignamini, & Rovati, 1980; McAlindon, LaValley, Gulin, & Felson, 2000; Poolsup, Suthisisang, Channark, & Kittikulsuth, 2005; Reginster, 2007; Towheed et al., 2005). Echinacea, whose consumption peaks during flu season due to its reported use in prevention and treatment of communicable diseases via improvements in the immune system, was the third most commonly reported natural product used by US adults (Figure 2) (P. M. Barnes, Bloom, B., Nahin, R. L., 2008). Currently, the scientific evidence in support of the use of Echinacea for infectious diseases such the common cold is limited. For example, clinical trials and meta-analyses have found Echinacea can modestly reduce the severity and duration of common cold symptoms by 10% to 30%, but these reduction levels may not be clinically meaningful (Barrett, Vohmann, & Calabrese, 1999; Brinkeborn, Shah, & Degenring, 1999; Lindenmuth & Lindenmuth, 2000).
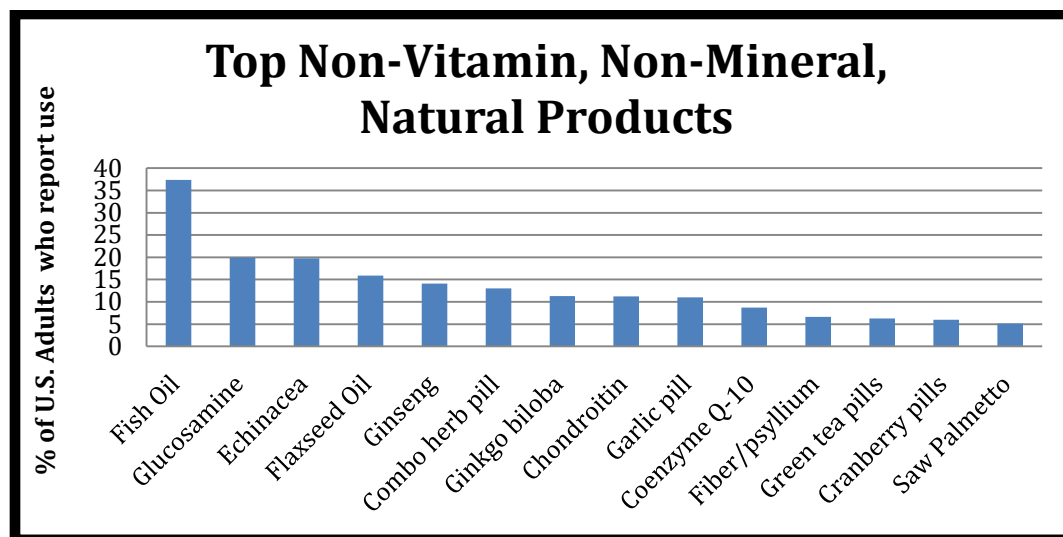
Figure 2. Most Commonly Used Natural Products Among U.S. Adults. Note. Data from Barnes, P. M., Bloom, B., Nahin, R. L. (2008). Complementary and Alternative Medicine Use Among Adults and Children: United States, 2007. *National Health Statistics Reports* (12), 1-23.

The frequently reported reasons for the use of these and the other most commonly used natural products among US adults are listed in Table 1. It is worth noting that heart disease and cancer, which are the leading causes of death in the United States, are among the most commonly reported reasons for the use of a number of natural products consumed by US adults. Natural product usage for heart disease and cancer spans across dietary oils, herbs, enzymes and botanicals. Other chronic health concerns including arthritis and digestive function are also commonly reported reasons for the utilization of natural products.

Table 1

Reasons for Natural Product Use Among U.S. Adults

Natural Product	Common Reasons for Use in US Adults
Fish Oil	Heart Disease, Asthma, Cancer, Cognitive Function, Inflammation
Glucosamine	Arthritis
Echinacea	Immune Function
Flaxseed Oil	Heart Disease, Inflammation, Digestive Function
Ginseng	Stimulant, Immune Function, Stress
Combo herb pill	Various uses
Ginkgo biloba	Cognitive Function
Chondroitin	Arthritis
Garlic pill	Heart Disease, Cancer
Coenzyme Q-10	Heart Disease, Cancer
Fiber/psyllium	Digestive Function
Green tea pills	Heart Disease, Cancer, Weight Loss
Cranberry pills	Bladder Function, UTIs
Saw Palmetto	Prostate

Note. Information from Wheaton, A. G., Blanck, H. M., Gizlice, Z., & Reyes, M. (2005). Medicinal herb use in a population-based survey of adults: prevalence and frequency of use, reasons for use, and use among their children. *Annals of epidemiology, 15*(9), 678-685.

Natural Products Industry

With a large proportion of the US population using natural products, the manufacturing and sales of such products is substantial. According to the trade publication The Nutrition Business Journal, the US nutrition industry had total consumer sales of $115 billion in 2010 (Rea, 2010). Dietary supplements

(defined as vitamins, minerals, herbs, meal supplements, sports nutrition

supplements, and specialty supplements) accounted for $28.1 billion of those

sales, an increase of 4.4% from the previous year and a 25% increase since

2007 (Rea, 2010). Within US dietary supplement sales in 2010 (see Figure 3),

vitamins accounted for the largest portion of sales at 34% and minerals the

smallest at 8% (Rea, 2010).
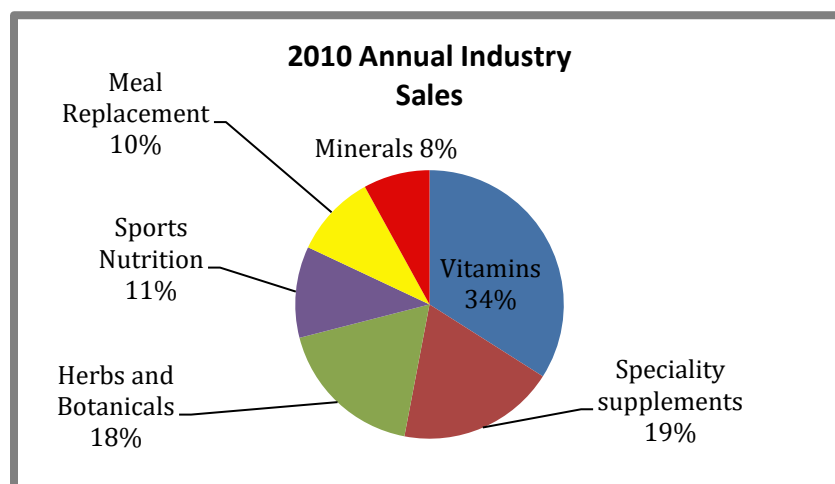
Figure 3. 2010 Annual Dietary Supplement Sales.
Note. Data from Rea, P. (2010). NBJ Supplement Business Report. *2011 NBJ Nutrition Industry Research Reports.* Retrieved 09/21/2011, 2011

Natural Product Use Among Cancer Patients and Survivors

Natural products are also some of the most commonly used forms of

CAM by cancer patients (Anderson & Taylor, 2012). Use rates, shown in

Table 2, for a wide array of natural products have been found to be at parity

or higher among those diagnosed with cancer compared to the general US

population (P. M. Barnes et al., 2008).

Table 2

Natural Product Use by Cancer Patients and General US Population

Natural Product	Cancer Patients (% Usage)	General Population (% Usage)
Vitamin & Minerals		
Calcium	**34**	23
Folate	**5**	4
Vitamin B Complex	**9**	8
Vitamin C	**19**	18
Vitamin E	**15**	9
Multivitamin	83	**84**
Herbs & Other Supp.		
Chondroitin	**14**	12
Coenzyme Q10	**12**	9
Fish Oil	**44**	38
Flaxseed Oil	16	16
Garlic pills	**16**	11
Echinacea	11	**18**
Ginseng	7	**12**
Soy/Isoflavones	3	**5**

Note. Data from Anderson, J. G., & Taylor, A. G. (2012). Use of complementary therapies for cancer symptom management: results of the 2007 national health interview survey. *The Journal of Alternative and Complementary Medicine, 18*(3), 235-241.

These substantial rates of reported use among those diagnosed with cancer increase the potential for drug-nutrient interactions, which raise concerns regarding both efficacy and safety (Chang et al., 2011; McCune et al., 2004). For example, beta-carotene has been shown to reduce the effects of 5-fluorouracil by lessening its inhibition of thymidylate synthase, which has

been demonstrated to be an effective target for down regulating tumor progression (Longley, Harkin, & Johnston, 2003; Seifter, Rettura, Padawer, & Levenson, 1984). As such, this may result in the need for a higher dose of 5-flurouracil to obtain the desired effect. Beta-carotene has also been found to increase the apoptotic effects of cyclophosphamide (Seifter et al., 1984). This could be beneficial if the beta-carotene use is known and can be properly adjusted for, otherwise this interaction may carry safety risks that are currently unknown. The antioxidant N-acetylcysteine (NAC) has also been found to interact with chemotherapeutics through its inhibition of the cytotoxic activity of cisplatin in two separate *in vitro* studies (Miyajima et al., 1999; Roller & Weller, 1997). It is important to note, though, that these were *in vitro* findings, meaning they were done at the cellular level outside the whole organism. Additional research needs to be done to test these findings *in vivo*, first in animal models and then, if warranted, in humans.

High rates of use of natural products (80%) have been reported by cancer patients while undergoing radiation therapy (Yates et al., 2005). This may be of concern, as for instance Vitamin E supplementation has been associated with an increased risk of recurrence of primary cancers after radiation treatment (Bairati et al., 2005; Bairati et al., 2006). Additionally, the reports of contamination of natural products with heavy metals (i.e. lead, mercury and arsenic), allergens (i.e. mold and fungi), and adulteration with prescription drugs are other areas of concern. For example, the herbal

formula PC-SPES was found to contain warfarin, diethylstilbestrol, and other

substances(Guns, Goldenberg, & Brown, 2002; White, 2002). This raises the

risk of toxicity of the natural products themselves and through interactions

with conventional cancer treatments (Biloba, 1999; Drew & Myers, 1997;

Ernst, 2002; Hitokoto, Morozumi, Wauke, Sakai, & Kurata, 1978; Saper,

Kales, Paquin, & et al., 2004).

In the U.S., natural products are regulated by the FDA, and under

current regulations manufacturers and distributors of natural products are not

required to prove efficacy or safety before they are sold to consumers

(Umhau, Garg, & Woodward, 2012). Conversely, manufacturers of natural

products are not allowed to make any claims that such products can be used

to treat, prevent, or cure a specific disease or condition. They are allowed to

make three types of claims: health claims, structure/function claims, and

nutrient content claims. Each type of claim has different requirements that

apply (Umhau et al., 2012). Also, under the FDA's Good Manufacturing

Practices (GMPs) each manufacturer is allowed to determine their own quality

standards and the analytical tests used to evaluate the quality of their

products (Denham, 2011). Numerous independent analyses have found

problems with the identity, strength, and purity of natural products (Gershwin

et al., 2010), which would likely lead to variability of action.

This study addresses a number of important areas in which the

research is currently limited. For example, some studies that have reported

on natural product use among cancer patients are limited to those who reported a cancer diagnosis at any point in their lives and who may not have received conventional cancer treatment for some time (P. M. Barnes et al., 2008; Velicer & Ulrich, 2008). This study evaluated data from participants who sought care at a comprehensive cancer center during a 12-month period. In contrast to other studies in the literature, it consisted of cancer patients who were currently receiving cancer related care and allowed for characterization of natural use patterns relative to diagnosis. This enabled the evaluation of the usage and disclosure patterns for a large and diverse cancer patient population. It included participants whose cancer status spanned the full spectrum of cancer care, including those who were receiving chemotherapy, radiation, were enrolled in clinical trials, and/or were cancer-free.

While many studies of natural product use among cancer patients have been limited to one cancer type (Barqawi, Gamito, O'Donnell, & Crawford, 2004; Mireille Bright-Gbebry et al., 2011; Westerlund et al., 2011; Wiygul et al., 2005), the survey used in this study included a wide array of 26 different cancer types. In addition, when natural product use among cancer patients has been reported, it has often been limited to general or broad category (e.g. vitamins, herbs) natural product use (Chang et al., 2011; A. Molassiotis et al., 2005; Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000; Yates et al., 2005). In contrast this study provided an in-depth analysis of use patterns for individual natural products use by individual cancer patients and as a

group, with a broad spectrum of types of cancer, and in relation to their

cancer treatment and diagnosis. It investigated associations between the use

of individual natural products and demographics, socioeconomic status,

cancer factors (e.g. cancer type, conventional treatment), participant

disclosure, and perceived efficacy.

Another limitation of previous studies has been small sample sizes.

The survey used for this study was sent to a random sample of a patient

database that contained all the patients seen at the Cancer Institute of New

Jersey (CINJ) for cancer, treatment, screening, and prevention during a 12-

month period (2,777 patients with 1,755 usable surveys returned), making it

the largest sample used for a study of this kind. It is important to note that the

CINJ is one of only forty-one comprehensive cancer centers nationwide. To

receive this designation by the National Cancer Institute (NCI) at the National

Institutes of Health (NIH) a cancer center must "...demonstrate reasonable

depth and breadth of research in each of three major areas: laboratory,

clinical, and population-based research, as well as substantial

transdisciplinary research that bridges these scientific areas. In addition, a

comprehensive center must also demonstrate professional and public

education and outreach capabilities, including the dissemination of clinical

and public health advances in the communities it serves" (Institute, 2012).

Thus, using the CINJ as the collection site for this research resulted in a more

comprehensive sample population compared to the majority of the current literature, improving the study's generalizability.

Disclosure of Natural Product Use (General US population)

Disclosure of all CAM use by the general US population to conventional healthcare providers has been estimated to range between 12% and 90% (Shim, Schneider, & Curlin, 2014), while disclosure of natural product use was estimated to be at 33% in 2002 and 45% in 2007 (Wu, Wang, & Kennedy, 2011). It has been found that better access to healthcare and having a diagnosis of a specific medical condition are associated with higher rates of disclosure of CAM use by the general US population. In addition, minorities have been found to be less likely to disclose CAM use compared to whites (Shim et al., 2014).

Disclosure of Natural Product Use By Cancer Patients

As noted previously, natural products are the most common form of CAM used by cancer patients. A study using a nationally representative sample of those diagnosed with cancer found 76% reported using vitamins and minerals and 32% reported using herbal therapies (Anderson & Taylor, 2012). Yet research has found that only between 25% and 50% of cancer patients disclose any CAM use to their doctors (Adler & Fosket, 1999; Kappauf et al., 2000; Salmenperä, Suominen, Lauri, & Puukka, 2001). Cancer patients report being hesitant to disclose their CAM use to their physicians out

of fear that they will be characterized as "fringe, ungrateful, unrealistic, or gullible," and that they believe that the decision to use CAM is a personal one, and does not need input from their physician (Pappas & Perlman, 2002). Additionally, if a patient believes that CAM therapies are not harmful and that they are irrelevant to conventional cancer treatment they are also less likely to disclose them (Pappas & Perlman, 2002).

This lack of disclosure combined with high rates of use by cancer patients is problematic because it may compromise the efficacy of conventional cancer treatment and raises safety concerns as stipulated previously. Additionally, the potential benefits of natural products in the treatment of cancer and/or the management of symptoms may also be lost by the limiting of clinical evidence that would have otherwise been documented.

This study further investigated this important issue and went beyond previous research by investigating factors that motivated disclosure of individual natural products used by cancer patients to their oncologist. Improvements in provider-patient communication has the potential to raise the quality of patient care by increasing healthcare providers' awareness of their patients' natural product usage and motivations for such use.

Self-Regulation Model

Health behavior theories aim to explain the process by which individuals come to take action (or lack thereof) with regards to their health.

For example, the Transactional Model postulates that an individual develops a means to cope with a stressor, which can arise from the internal and external environment, through a two-level appraisal of the stressor (Rimer & Glanz, 2005). The primary level of appraisal evaluates the significance of the stressor or health threat. Appraisal at the secondary level evaluates the controllability of the stressor and a person's coping resources (Rimer & Glanz, 2005). The Health Belief Model posits that health-related behaviors are determined by four core factors: 1) perceived susceptibility, 2) perceived severity, 3) perceived benefits, and 4) perceived barriers (Glanz, Rimer, & Viswanath, 2008). Finally, the Theory of Planned Behavior/Reasoned Action suggests that an individual's behavior is set by their intention to carry out a behavior and that their intention is a function of their attitude about the behavior and guided by the external environment.

The Self Regulation Model (SRM), shown in Figure 4, is an improvement over these models, because it incorporates the essential components of feedback, motivations, and goals. In addition, the SRM takes into account emotional processes. The SRM emphasizes the dynamic nature of health behaviors, and incorporates both the cognitive and emotional representations that manifest when an individual is faced with a health threat. The SRM was applied via analyses of survey questions on the perceived efficacy and disclosure of natural products written-in by the study participants. The various dimensions of the SRM will be explained in detail in Chapter 2.

The procedures use in the mapping of survey questions to the SRM model

will be detailed in Chapter 3.
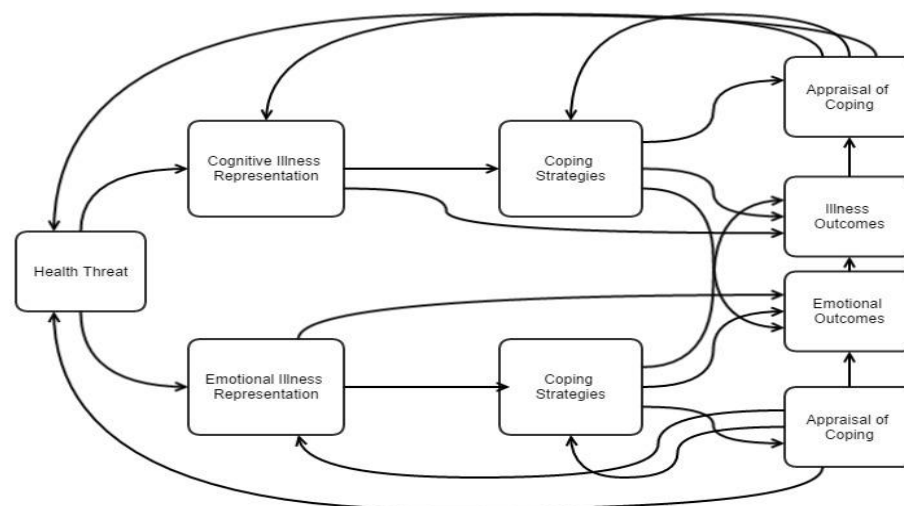
Figure 4. Author's Rendition of Self-Regulation Model.

Problem Statement and Goals

This dissertation characterized and analyzed for the first time a sub-set

of the data from a groundbreaking cross-sectional survey that included 1,226

cancer patients at a comprehensive cancer center among the 1,755 usable

surveys (Perlman et al., 2013). It explored the use, disclosure, and

motivations for the use of natural products among a large cancer patient

population while they were seeking care. The problem statements of this

research are as follows:

1. How cancer patient characteristics (demographics & cancer factors) are associated with use of natural products and why cancer patients are using natural products has not been fully explored.

2. The patterns of how cancer patient characteristics (demographics & cancer factors) are associated with disclosure of natural product use to healthcare providers and the perceived/anticipated provider responses to the disclosure of natural product use to a patient's oncologist are not well understood.

These are problems due to the high use of natural products among cancer patients combined with low disclosure rates. In addition, the issue of the efficacy of conventional cancer treatment being compromised, the potential benefits of natural products may be lost, and interactions between natural products and conventional cancer treatment may be a safety risk.

Research Questions, Hypotheses and Aims

The first aim of this research was to determine the prevalence and patterns (e.g. timing, types) of natural product use by cancer patients seen at the Cancer Institute of New Jersey (CINJ) within a 12-month period and to apply the Self-Regulation Model to better understand why cancer patients use natural products. The second aim of this research was to identify patterns of disclosure of natural product use to healthcare providers and the covariates of

that disclosure among CINJ patients. The two research questions of this study are as follows.

Within a cohort of cancer patients who sought care at CINJ:

1. How is the use of natural products associated with patient characteristics (demographics & cancer factors) and what patterns of motivations of use will be found by applying the Self-Regulation Model to understand patient beliefs about the perceived efficacy and side effects of natural products?

2. How is the disclosure of natural product use to healthcare providers associated with patient characteristics (demographics & cancer factors) and the perceived/anticipated provider responses to the disclosure of natural product use to a patient's CINJ oncologist?

The two hypotheses that were tested are as follows:

1. We hypothesized that the frequency and timing (pre- and post-diagnosis) of initiation of natural product use will be associated with age, cancer type, and potentially other patient characteristics (demographics & cancer factors) and that applying the Self-Regulation Model to the perceived efficacy of natural products used will result in a greater understanding of the differences in the patterns of natural product use by this cancer patient population.

2. We hypothesized that the frequency that natural product use is

   disclosed to a patient's CINJ oncologist will be associated with age,

   cancer type, and potentially other patient characteristics

   (demographics & cancer factors) and the perceived/anticipated

   provider responses to the disclosure of natural product use to a

   patient's CINJ oncologist.

Significance/Need for Study

This study resulted in a more thorough understanding of natural

product use throughout the full-spectrum of cancer care by those who sought

treatment during a 12-month period at the Cancer Institute of New Jersey. It

identified key patterns of frequency and timing of natural product use and

then explained these patterns by evaluating the application of the Self-

Regulation Model to interpret natural product use among cancer patients. The

results of this study provide greater insight into the motivators and sustainers

of natural product use by cancer patients. It is important to have an accurate

understanding of the use of natural products among cancer patients for

researchers and clinicians to address issues surrounding drug-nutrient

interactions, disclosure, compliance and decision-making by cancer patients

and by their health care providers.

The outcomes of this study may be valuable for researchers at CINJ

and nationwide, as it will likely add to their understanding of the topic and they

may apply the findings to their future work. It may also be valuable to

clinicians at CINJ and nationwide, as it may be used to improve patient care

procedures based upon a better understanding of natural product use,

disclosure and motivations for use of natural products. Cancer patients may

receive better evidence-based medical care relating to this topic from their

healthcare providers and may themselves be better informed.

Chapter II

REVIEW OF THE LITERATURE

Introduction

A review of the literature was done to find research that had been

published relating to Complementary and Alternative Medicine (CAM) and

natural product use in the general US population and among cancer patients,

disclosure of CAM and natural product use in the general US population and

among cancer patients, and the application of the Self Regulation Model

(SRM) to health beliefs and behaviors. The organizing framework for this

review is a progression from CAM use in the general US and cancer

populations, moving on to natural product use in the US in general, then

among cancer populations as a whole, and then by individual cancer type for

the most common cancer types. Next, the disclosure of CAM use by the

general US population and then disclosure specifically of natural product use

by the general US and cancer patient populations. Finally, the SRM and the

application of the SRM are reviewed. The topical areas included are CAM

use, natural product use, disclosure of natural product use and the SRM. The

problems areas addressed are that the use of natural products by cancer patients is not fully elucidated and the motivations for use and disclosure of use are poorly understood.

Sources, Search Strategies, and Selection Criteria

A systematic search of the literature relevant to this dissertation was conducted within the following databases: OVID Medline 1950 - present, PsychINFO 1806 - present, the Health Cumulative Index to Nursing and Allied Health Literature (CINAHL) 1981 - present, Psychosocial Instruments 1985 – present, and dissertation abstracts 2007 - present. Each was utilized to search for relevant literature. Independent searches using the following terms were carried out: complementary and alternative medicine use, natural product use, dietary supplement use, herbal supplement use, vitamin use, mineral use, disclosure, self-regulation theory, self-regulation model, common sense model, cancer diagnosis, cancer survivors, cancer patients, motivators and sustainers.

Searches were limited to studies of adults (18 years and older) and those written in the English language. Only those articles available electronically through the Rutgers libraries or for free via an interlibrary loan request were included. This will be expanded for the full dissertation. Articles were also found through a manual search of the references of articles that has already been identified. Primary research was given preference over

secondary research, such as review articles. The 91 most notable and relevant articles yielded from these search criteria were included in this literature review.

Complementary and Alternative Medicine Use in the United States

According to the National Center for Complementary and Integrative Health (NCCIH) website, formerly National Center for Complementary and Alternative Medicine (NCCAM), Complementary and Alternative Medicine (CAM) is defined as "...a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. ("Complementary, Alternative, or Integrative Health: What's In a Name?," 2014)."

In the US the use of CAM has been on the rise for decades. Eisenberg et al. greatly improved the awareness of the substantial utilization and increases in the frequency of CAM use in the United States, first with their seminal work "Unconventional Medicine in the United States -- Prevalence, Costs, and Patterns of Use" published in 1993 (D. M. Eisenberg et al., 1993), and then with their follow up study published 5 years later (David M Eisenberg et al., 1998). This work would go on to have a major impact on the field resulting in multiple papers being published utilizing subsets of this data.

The National Health Interview Survey (NHIS) is conducted by the Center for Disease Control and Prevention (CDC). It is one of the nation's

largest in-person household health surveys. Since 2002, a supplement to investigate CAM use has been included in the NHIS every 5 years. Utilizing data from the 2007 NHIS CAM supplement, Barnes et al. concluded that 38.3% of U.S. adults ages 18 years and older reported using at least one form of CAM within the past 12 months (P. M. Barnes, Bloom, B., Nahin, R. L., 2008). This was up 2.3% from 2002 when 36% of adults were found to have used some form of CAM therapy within the past 12 months (P. M. Barnes, Powell-Griner, E., McFann, K., Nahin, R.L., 2004). In addition, Barnes et al. reported that the most commonly used therapies in 2007 were nonvitamin, nonmineral, natural products at 17.7% and deep breathing exercises at 12.7% (P. M. Barnes et al., 2008). They also found that American Indians or Alaska Natives (50.3%) and Whites (43.1%) were more likely to use CAM therapies compared to Asians (39.9%) or Blacks (25.5%) in 2007 (P. M. Barnes et al., 2008).

The greatest strength of the 2008 publication by Barnes et al. was that its data was collected from a nationally representative sample (29,266 households) of both U.S. adults and children, which supports external validity for the United States. The data (sourced from the National Health Interview Survey) was collected by randomly selecting one adult and one child (aged 0-17 years) per randomly selected household. Information was self-reported for the selected adult, which may have resulted in recall error. Verifying responses with another source of information (e.g. medical records) or an

objective measure of exposure are ways to address this, but are not practical for a survey of this size and scope. Information on the selected child was collected from an adult, usually the child's parent. This may have resulted in incorrect data due to lack of knowledge of the child's CAM use by the reporting adult, but also may have yielded more accurate results as children may not be capable of correctly answering the survey questions. Proxy responses were accepted for adults who were not present at the time of the interview. This may have introduced additional recall error.

A total of 36 types of CAM therapies used in the United States were included per the definition of CAM used in the report. While comprehensive, this resulted in the exclusion of folk medicine practices and faith healing. A total of 45 nonvitamin, nonmineral natural products were included in the survey questions, which again was comprehensive, but not exhaustive. The reference period for the nonvitamin, nonmineral natural products section of the survey was 30 days, which was an improvement from the previously used 12-month time period, but may have still introduced recall error. Conversely, it is long enough to enable capture of use that is occasional or less than daily. The study used a cross-sectional design, which limits the ability to evaluate changes in use by the individuals surveyed over time. As stated previously, the NHIS is currently scheduled to repeat the CAM supplement every 5 years, which allows for comparisons between similar samples over time, but not changes within each of the samples.

A data brief published in April of 2014 used data from the most recent CAM supplement from the 2012 NHIS survey (Peregoy et al., 2014). Its focus was on the regional variations in CAM use by US adults, but it did include limited information about the most commonly used CAM therapies nationally. Interestingly, it reported nonvitamin, nonmineral dietary supplements as the most commonly used form of CAM at 17.9%, up slightly from the 2007 numbers (17.7%), but this change may have been within the margin of error. Deep breathing exercises, which were the second most common form of CAM (12.7%) in the report by Barnes et al. using the 2007 data, was not included in the data brief as a standalone therapy, but included as an aspect of yoga. It is worth noting that the definitions for what constituted a nonvitamin, nonmineral natural product were not the same, limiting comparisons between the data. The full report of the 2012 dataset is due out in 2016 by Barnes et al., which will enable a better comparison between the 2007 and 2012 data (Barnes, personal communication).

CAM use in the United States is widespread and becoming more prevalent (P. M. Barnes et al., 2008; Clarke et al., 2015; Kessler et al., 2001; Su & Li, 2011). Natural products are the most common form of CAM used by Americans by a large margin (Figure 1) (Clarke et al., 2015). With such a substantial portion of the US population utilizing natural product it is imperative that we understand why people are choosing to natural products. Previous research has been limited to descriptions of patterns of natural

product use. While this research also reports on natural product use, it went beyond this important first step, and investigated why natural product users decided to use natural product use by applying the Self-Regulation Model to understand the biopsychosocial drivers of natural product use. It focused on the use of natural products among cancer patients and the differences between this population and the general US population.

CAM Use Among Cancer Patients and Survivors

An important point of difference of CAM use among cancer patients and survivors and the general US population is that they have been found to be more likely to use CAM therapies compared to the general public (Fouladbakhsh & Stommel, 2008). These differences may in part be due to those who have been diagnosed with cancer wanting a greater sense of control over their health due to the potential fatal impacts of cancer (Astin, 1998).

Natural Product Use

Natural products are defined by the National Institutes of Health (NIH) National Center for Complementary and Integrative Health (NCCIH) as, "...a large and diverse group of substances from a variety of sources. They are produced by marine organisms, bacteria, fungi, and plants. The term encompasses complex extracts from these producers, but also the isolated compounds derived from those extracts. It also includes vitamins, minerals

and probiotics." ("Natural Products Research-Information for Researchers,"
2014).

Natural Product Use in the General US Population

As noted previously, using data from the most recent NHIS, Peregoy et
al. reported 17.9% of US adults used nonvitamin, nonmineral natural products
in 2012 (Peregoy et al., 2014) This was more than double all other
complementary health approaches (Figure 1).

Natural Product Use Among Cancer Patients and Survivors

A study utilizing the 2007 NHIS dataset found that natural products
were among the most common forms of Complementary and Alternative
Medicine (CAM) used by those diagnosed with cancer in the United States
(Anderson & Taylor, 2012). Among a subset of adults (aged 18 years and
older) survey respondents (n=1785), who self-reported a previous cancer
diagnosis, 77% reported using vitamins and minerals within the past 12
months (Anderson & Taylor, 2012). For this same group 32% reported use of
herbal therapies within the past 12 months (Anderson & Taylor, 2012).

The most commonly used vitamins and minerals in this nationally
representative sample among those who self-reported being diagnosed with
cancer were multivitamin (83%), calcium (34%), vitamin C (19%), vitamin E
(15%), vitamin B complex (9%), and folate (5%)(Anderson & Taylor, 2012).

For this same group, the most commonly used nonvitamin, nonmineral

natural products were fish oil (44%), glucosamine (26%), flaxseed oil (16%),

garlic pills (16%), chondroitin (14%), and coenzyme Q10 (12%) (Anderson &

Taylor, 2012).

A systematic review of 32 studies published between 1999 and 2006

found vitamin and mineral supplement use was widespread among patients

with cancer and long-term cancer survivors (Velicer & Ulrich, 2008). Studies

that combined cancer sites found 64% to 81% of cancer survivors reported

use of any vitamin or mineral supplements (Velicer & Ulrich, 2008). Use was

reported to have been initiated after diagnosis by 14% to 32% of cancer

survivors, with use rates differing by cancer type (Velicer & Ulrich, 2008).

Studies included in the review by Velicer et al. were limited to those published

between 1999 and 2006 to allow for improved comparisons. Only studies

which included quantitative estimates of vitamin and mineral use that was

separate from broader natural product use were included. Studies which

included cancer patients who were at high nutritional risk (e.g. weight loss,

wasting, and malnutrition) were not included to avoid considering supplement

use that was a result of medical supervision. Similarly, those studies who

used random and convenience sampling methodologies were included, but

designs which oversampled CAM users were avoided, on the basis that CAM

users would be more likely to use vitamin and mineral supplements.

Comparisons between studies was limited due to variations in the definition of

vitamin and mineral use, the duration of time used for measuring use and a lack of age-adjusted use among most studies. Most studies were at risk for self-selection bias based upon the methods used for sampling.

Having a higher level of education is a factor that has been found to consistently be associated with higher vitamin and mineral supplement use among those diagnosed with cancer (Velicer & Ulrich, 2008). For example, a study by Ferrucci et al. found that compared to those with some high school education or less, cancer survivors with a high school diploma were 2.77 times (95% CI = 1.55-4.96) more likely to report using natural products, and those with a graduate school or professional degree were 5.44 times (95% CI = 2.98-9.93) more likely to report use (Ferrucci et al., 2009). Race has also been associated with natural product use among cancer survivors, with non-whites be less likely than whites to report use (Ferrucci et al., 2009). Results have been mixed as to whether women are more likely than men to initiation of natural product and/or CAM use after being diagnosed with cancer (Adams & Jewell, 2007; Chang et al., 2011; Perlman et al., 2013).

Several studies have investigated whether receiving a cancer diagnosis is associated with changes in natural product use. A study of 100 adult cancer patients found that use of high-dose vitamin/antioxidants (p = .0002) and herbal/botanical products (p = .013) increased after cancer diagnosis (Sparber et al., 2000). Garland et al. attempted to investigate the

impacts of natural products use on "benefit finding" (Garland et al., 2013).

The "benefit finding" instrument used assessed the perception of life benefits

after a cancer diagnosis (Tomich, Helgeson, & Nowak Vache, 2005).

Participants using herbs ($p = .007$) and vitamins ($p = .03$) recorded higher

benefit finding compared to participants not using such therapies (Garland et

al., 2013).

Health status has also been found to be a factor, with cancer survivors

reporting a less than excellent health status found to be three to four times

more likely to use natural products (M. F. Miller et al., 2008). In addition,

cancer survivors who reported being physically active and consuming five or

more servings of fruits and vegetables each day were found to be significantly

more likely to use natural products (M. F. Miller et al., 2008). Similarly, those

who had never smoked cigarettes or had quit smoking were significantly more

likely than those who currently smoked to report use of natural products (M.

F. Miller et al., 2008). Interestingly, the use of other forms of CAM have been

found to be associated with natural product use, with provider-based CAM

therapies and mind-body therapies having been found to be positively

associated with natural product usage (M. F. Miller et al., 2008).

A study by Greenlee at el. compared the use of natural products by

10,857 cancer survivors to cancer-free controls. After adjusting for age,

gender, education, and race, they found that the natural products with the

strongest positive associations were: cranberry pills with bladder cancer OR = 3.44 (95% CI = 1.86, 6.35); soy with prostate cancer 1.99 (1.38, 2.87), ovarian cancer 2.19, (1.41, 3.40), vitamin D with thyroid cancer 1.66 (1.21, 2.28) and melatonin with cervical cancer 1.86 (1.19, 2.90) (H. Greenlee, White, Patterson, & Kristal, 2004).

Use of natural products among those diagnosed with cancer has consistently be found to be higher compared to the general U.S. population (Anderson & Taylor, 2012; Ball, Kertesz, & Moyer-Mileur, 2005; Patricia M Barnes, Bloom, Nahin, & Statistics, 2008). The previously referenced 2007 NHIS survey found higher use of vitamins and mineral (76.67% and 64.02%, p < .001) and herbal therapies (32.14% and 24.11%, p < .001) by a subset of adult respondents, who self-reported being diagnosed with cancer, compared to the general U.S. population (Anderson & Taylor, 2012). Among the vitamins and minerals most commonly used by those reporting a cancer diagnosis, higher rates of use were found for Calcium (33.70% and 22.65%), Folate (5.17% and 3.78%), Vitamin B complex (9.35% and 8.02%), Vitamin C (19.12% and 17.87%), Vitamin E (14.57% and 8.53%). Multivitamin use was found to be slightly lower in those diagnosed with cancer compared to the general population (82.75% and 84.09%) (Anderson & Taylor, 2012).

Among the most commonly utilized herbs and other supplements, use was found to be higher in those diagnosed with cancer for Chondroitin

(13.81% and 11.89%), Coenzyme Q10 (11.76% and 9.35%), Fish Oil
(44.38% and 38.33%), Flaxseed oil (15.79 and 15.74%) and Garlic pills
(15.72% and 11.23%), but lower in the use of Echinacea (11.31% and
17.95%), Ginseng (7.33% and 12.45%) and Soy/Isoflavones (2.87% and
5.08%) (Anderson & Taylor, 2012).

Although medical marijuana is derived from the cannabis plant it is
considered a drug by the FDA. It was classified as a Schedule I drug under
the Controlled Substances Act passed by Congress in 1970. Drugs also
classified as Schedule I include heroin, LSD and methaqualone. As such it is
not typically included in surveys of natural product use among cancer patients
and was not included in this study.

Those diagnosed with cancer have been found to commonly use
natural products, typically at rates higher than the general US population.
Previous research has found that patterns of use differs. With such
widespread use of natural products occurring in this population an improved
understanding as to why cancer patients (across the spectrum of care) are
using natural products is needed.

Natural Product Use by Cancer Type

Cancer is a term used for a numbers of diseases, which share the
common characteristic of uncontrolled cellular division. A common way that
cancer is further defined is by the location in the body where abnormal cells

that divide without control are first identified. This results in a patient typically

being told they have "breast cancer" or "lung cancer" by their healthcare

providers. The diagnosis, prognosis, symptoms and treatment of cancer all

vary by this location differentiation. As such, previous investigations of natural

product use by cancer patients have found notable differences in the patterns

of use by cancer type.

Natural Product Use (Breast Cancer)

Natural product use has been found to be highest among patients with

breast cancer, compared to people with other types of cancer, with 67% to

87% reporting use of any vitamin or minerals and 57% to 62% reporting multi-

vitamin use (Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000;

Ganz et al., 2002; Lengacher, 2002). The women that were included in a

review of nine studies by Greenlee et al. ranged from those currently

undergoing treatment to those 9 years after cancer diagnosis. One study

comparing breast cancer survivors and cancer-free controls found that the

cancer survivors were 11% to 20% more likely to use multivitamins, vitamin E,

vitamin B6, or calcium, after adjusting for age, race and education level (H.

Greenlee, White, E., Patterson, R. E., & Kristal, A. R., 2004).

Prevalent use among breast cancer survivors for both Vitamin D (37%)

and antioxidants(30%) has been found (P. Miller et al., 2008). The use of

"megavitamins" was investigated in three studies and use among breast

cancer patients was found to range from 8% to 25% (M. M. Lee, Lin, Wrensch, Adler, & Eisenberg, 2000; VandeCreek, 1999). It is important to note though, that two of the three studies lacked clear definitions for the term "megavitamins" making comparisons difficult. Two studies that reported changes in natural product use after breast cancer diagnosis found increases in use ranging from 8% to 32% (Burstein, Gelber, Guadagnoli, & Weeks, 1999; Lengacher, 2002). The factors that have been found to be associated with natural product use among breast cancer patients include younger age, higher education, greater physical activity and psychosocial factors (dissatisfaction, depression) (Velicer & Ulrich, 2008). Older breast cancer survivors who had higher intakes of "Fruit" (OR=1.12, 95% CI=1.01, 1.23), "Whole Grain" (OR=1.14, 95% CI=1.04, 1.25), and "Oil" (OR=1.10, 95% CI=1.01, 1.11) were found to be significantly more likely to take supplements, while those with higher intakes of "Meat and Beans"(OR=0.81, 95% CI=0.71, 0.93) were found to be significantly less likely (P. Miller et al., 2008).

When looking specifically at herbal supplement use, Bright-Gberby et al. found that among 998 breast cancer survivors, 39% had used one or more herbal supplements at least 3 days per week over the two year period of March 1997 to March 1999 (Mireille Bright-Gbebry et al., 2011). The most commonly reported herbal supplements were garlic (21%), gingko biloba (12%), echinacea (9%), ginseng (8%) and goldenseal (5%) (Mireille Bright-Gbebry et al., 2011). In a similar study of 371 long-term (10 years post-

diagnosis) breast cancer survivors 59% were found to use herbals, with echinacea (29%), herbal tea (21%), gingko biloba (19%), ginseng (13%), and St. Johns wort (13%) being the most commonly used (Carpenter, Ganz, & Bernstein, 2009).

Natural Product Use (Prostate Cancer)

Reported vitamin and mineral use among prostate cancer survivors ranges from 26% to 48% (Chan et al., 2005; Westerlund et al., 2011; Wilkinson et al., 2002; Wiygul et al., 2005). In three studies reporting megavitamin use among those diagnosed with prostate cancer it was found that use ranged from 4% to 24% (Jones, Metz, Devine, Hahn, & Whittington, 2002; Kao & Devine, 2000; M. M. Lee, Chang, Jacobs, & Wrensch, 2002). Higher education, higher income, but not race and age were found to be associated with natural product use among prostate cancer patients (Kao & Devine, 2000; Wilkinson et al., 2002). Use of herbal medicines among prostate cancer patients has been found to range between 10% to 21% (Barqawi et al., 2004; F. L. Bishop et al., 2011). The herbs most commonly reported to be used by prostate cancer patients are saw palmetto, green tea, garlic, echinacea, ginkgo biloba, and ginseng (Barqawi et al., 2004; F. L. Bishop et al., 2011).

Natural Product Use (Colorectal Cancer)

Utilization of vitamin and mineral supplements was found to occur among 49% of colorectal cancer survivors, while multivitamin use was found to range from 38% to 42% (Sandler et al., 2001; Satia et al., 2004). Supplement use was found to be higher among female colorectal cancer survivors compared to their male counterparts (Sandler et al., 2001; Satia et al., 2004). The use of herbal supplements by colorectal cancer patients has been found to range from 37% to 48% (Alexander Molassiotis et al., 2005). A review of CAM use by colorectal cancer patients found a six fold increase in herbal supplement use after diagnosis (Sewitch & Rajput, 2010). Colorectal cancer patients reported that their rational for use was "to promote general health and well-being" (Sewitch & Rajput, 2010).

Natural Product Use (Lung Cancer)

Only a few studies have looked at natural product use among lung cancer patients and survivors. One study of 178 lung cancer survivors found that 60% reported use of any vitamins or minerals. Multivitamin use ranged from 49% to 55% among patients with small cell or non-small cell lung cancer in two small studies (Jatoi, Williams, Nichols, et al., 2005; Jatoi, Williams, Marks, et al., 2005). The few studies that have investigated herbal supplement use among lung cancer patients found use ranged from 9% to

48% (Molassiotis et al., 2006). A threefold increase in use was found post-diagnosis and the reported motivations for use included pain, difficulty breathing, fatigue, sleeping problems and concentration (Joos, 2011; Ritchie, 2007).

Investigations of individual cancer types have found wide variations in how natural products are used by cancer patients and why cancer patients report they are using natural products. A study that used a cohort of cancer patients from a comprehensive cancer center including a wide array of cancer types was warranted to fill in the current gaps in knowledge of these important subjects. This study investigated both how natural product use and disclosure of use differs by cancer type and why those differences occur. It applied the Self-Regulation Model (SRM) to understand how differences in a patient's cognitive and emotional representations of their cancer, including their cancer type, are associated with patterns of natural product use, disclosure of natural product use to healthcare providers and disease outcomes. What was learned from this work can be applied by healthcare providers to improve patient safety and the effectiveness of the treatment that patients receive. It could also be used to identify areas that require further inquiry.

Natural Product Use Trends

As detailed previously, use of CAM among the general US population and among those diagnosed with cancer is common and use has been found

to be increasing. The utilization of natural products by the general US population has increased nearly 9-fold in the past 20 years up from an estimated ~2% in 1990 (P. M. Barnes et al., 2008; David M Eisenberg et al., 1998). Similarly, a recent systematic review found a 2-fold increase in CAM use globally among cancer patients in the past 40 years (Horneber et al., 2012), and a comparison of natural product use by breast cancer survivors between 1998 and 2005 found significant increases ($p > .01$) for multiple types of natural products (e.g. herbal remedies, Essiac) (Boon, Olatunde, & Zick, 2007).

Natural product use among cancer patients is widespread and increasing. An investigation to improve the understanding of the patterns of natural product use in terms of frequency and timing was needed. It is important for the safety of patients and the effectiveness of their care that we know how patterns of natural product use are influenced by their beliefs regarding natural product use and the disclosure of natural product use to their healthcare providers. This research applied the Self-Regulation Model (SRM) to better understand the beliefs that underpin a cancer patient's behaviors regarding natural product use and disclosure of natural product use.

Disclosure of Natural Product Use

Disclosure of the use of natural products by patients to their physicians has consistently been found to be low, with only 28% to 53% of patients reporting to have shared their use with their doctors (David M Eisenberg et al., 2001; Rausch et al., 2011; Swarup, Barrett, & Jazieh, 2006). Patients have indicated a number of barriers to open communication regarding use, including anticipated negative responses or ambivalence from physicians and a physician's emphasis on scientific evidence, which is set against their expectation of support and non-judgment from their doctors (Tasaki, Maskarinec, Shumay, Tatsumura, & Kakai, 2002; Verhoef, White, & Doll, 1999). These views are supported by studies that have found that the majority (60%) of patients received a negative response from physicians regarding natural product use and 35% of attempts by patients to discuss CAM use were ignored by oncologists (Schofield, Juraskova, & Butow, 2003; Swarup et al., 2006). Patients need to believe that they will receive constructive feedback from their physicians on the efficacy and safety of CAM use (Pappas & Perlman, 2002).

Cancer patients who do discuss their use of biological-based CAM with their oncologists reported higher levels of satisfaction with their consultation compared to those who did not ($p = .027$) (Oh et al., 2010). Being married or

living with a partner, younger age, higher level of education, receiving

chemotherapy and radiation after surgery, and higher family income have

been associated with disclosure of CAM use among cancer patients

(Ashikaga, Bosompra, O'Brien, & Nelson, 2002; Saxe et al., 2008). Patients

who perceive their oncologist as open-minded, respectful and willing to listen

are more likely to disclose their CAM use (Adler & Fosket, 1999).

 A substantial portion of cancer patients has been found to not disclose

their natural product use to healthcare providers. This lack of disclosure

creates issues regarding patient safety and may result in comprised patient

care. We needed an improved understanding of the how patient

characteristics are covariates of disclosure and why patients are deciding to

disclose or not disclose their natural product use to healthcare providers. This

study used a cohort of cancer patients from a comprehensive cancer center

that included a wide array of cancer types to more fully elucidate which

patient characteristics are predictive of disclosure and why patients are

deciding to disclosure or not disclose. It applied the SRM to understand how a

patient's cognitive and emotional representations of their illness are

associated with the decision to disclose or not disclose their natural product

use to their oncologist and how this coping strategy is associated with

outcomes of their illness.

Efficacy & Safety Issues

The prevalent use of natural products by cancer patients raises a number of issues around efficacy and safety, especially among those actively undergoing conventional cancer treatments. For example, Yates et al. found that 80% of cancer patients reported using natural products while undergoing radiation therapy (Yates et al., 2005). Study participants were recruited from seventeen sites around the United States, this strengthened external validity, but may have created a sample that is not representative of the general US population. Patients who were on tamoxifen alone were excluded from participation, which limited analysis of this important population. Inclusion criteria also required subjects to be able to read and write in English, which may have limited inclusion of minority populations. Important participation numbers were not reported, such as the number of people who were deemed eligible and the number of people assessed for eligibility. The study's cross-sectional retrospective design limited results compared to a prospective longitudinal design. Participants were sent a survey to complete, which may have increased recall error and self-selection bias. The survey was comprehensive in its measurement of demographic and medical information and natural product use.

These findings raise safety concerns, as interactions between chemotherapy drugs and natural products have been documented (Chang et al., 2011; McCune et al., 2004; Richardson et al., 2000). Plasma levels of the

active metabolites of the chemotherapy agents irinotecan, imatinib mesylate, and docetaxel have been found to be reduced by St. John's wort (Hypericum perforatum) (Frye, Fitzgerald, Lagattuta, Hruska, & Egorin, 2004; Komoroski, Parise, Egorin, Strom, & Venkataramanan, 2005; Lundahl, Hedeland, Bondesson, Knutson, & Lennernäs, 2009; Smith et al., 2004).

Herbs including garlic (Allium sativum), ginkgo (Ginkgo biloba), echinacea (Echinacea purpurea), ginseng (Panax ginseng) and kava (Piper methysticum) have been cited as having potential pharmacokinetic interactions with anticancer drugs (Sparreboom et al., 2004). This is due to their potential to modulate the activity of drug transporter P-glycoprotein and/or drug-metabolizing enzymes (e.g. cytochrome P450 isozymes). Hydrazine sulfate has been found to be used by cancer patients in the treatment of loss of appetite and weight loss (Chlebowski et al., 1987). Its use has been associated with serious adverse effects including coma, seizure, hepatotoxicity and death (Black & Hussain, 2000; Hainer, Tsai, Komura, & Chiu, 2000).

Shiitake mushrooms, which contain beta glucans, stimulate the immune system and may cause tumor cell death (Miyazaki et al., 1995; Okamura et al., 1986). Potential side effects of shiitake mushrooms include rash, abdominal discomfort and eosinophilia (Levy et al., 1998). Apricot kernel or amygdalin use among cancer patients has been increasing even through it

is likely ineffective in the treatment of cancer (Moertel et al., 1982). Side

effects include liver damage, low blood pressure, fever, coma and death

(Newall, Anderson, & Phillipson, 1996). Use of natural products and lack of

disclosure among those diagnosed with cancer is also of concern in clinical

research with 34% of patients in phase I trials reporting use (Hlubocky,

Ratain, Wen, & Daugherty, 2007). This may impact the accuracy of data from

early-phase cancer trials.

The widespread use of natural products by those diagnosed with

cancer has been shown to be problematic in terms of drug-nutrient

interactions, side effects of their use, and as a potential confounder in cancer

clinical trials. These serious safety and efficacy issues are indicative of the

importance of research into both how natural products are being used by

cancer patients and why they are deciding to use natural products and

disclose or not disclose their use to their oncologists. This research resulted

in an improved understanding of how cancer patients are using natural

products, why they are deciding to use natural products and disclose or not

disclose their use to their healthcare providers. The results can be used in

clinical practice to improve patient-provider communication and by

researchers to know which areas warrant more investigation.

Self-Regulation Model

The current literature provides some basic understanding of the patterns of natural product use among those diagnosed with cancer in the United States. There is however limited information explaining why those diagnosed with cancer are utilizing natural products in these aforementioned patterns and why they are deciding to disclose or not disclose their natural product use to their healthcare providers. This research applied the Self-Regulation Model (SRM) to gain insight into a cancer patient's beliefs, which guide their natural product use and disclosure decisions. The following sections provide a detailed explanation of the SRM and how it has previously been applied to understand health behaviors.

Levanthal's Self Regulation Model (SRM) (Figure 5), also known as the Common Sense Model, hypothesizes that individuals will create cognitive and emotional representations of their illness (Leventhal, Meyer, & Nerenz, 1980).
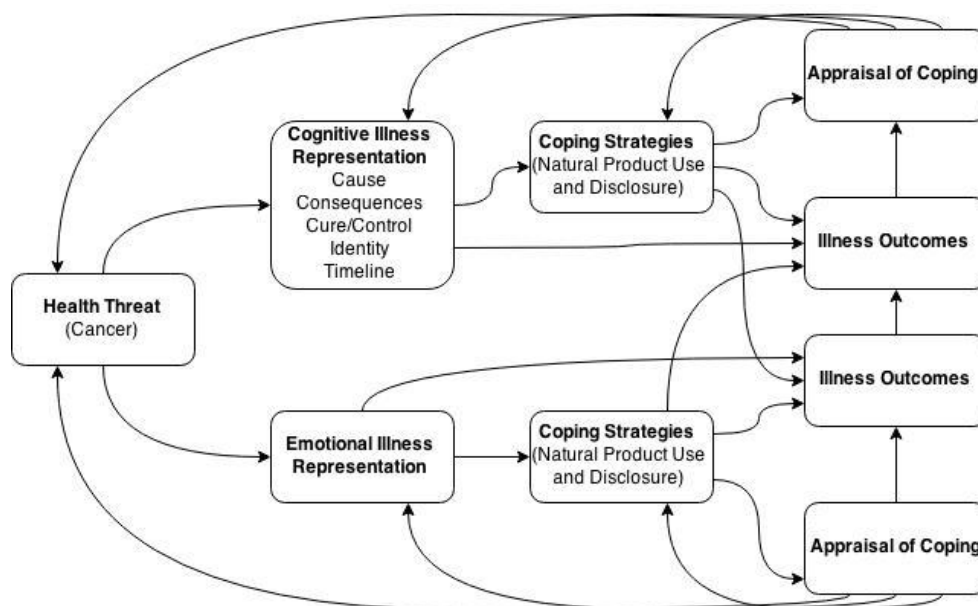
Figure 5. Author's Rendition of Self-Regulation Model as Applied in Proposed Research

These illness representations are a person's own implicit, common sense beliefs about their illness (health threat) (G. D. Bishop & Converse, 1986). They are based on the information sources available to them and are developed in order to make sense of and manage (both cognitively and emotionally) a health threat. These sources of information can be both concrete and abstract in nature (Leventhal et al., 1980). It is through the interpretation of this information that the individual begins the process of developing an illness management protocol and engages in a coping strategy (Leventhal et al., 1984).

Illness representations are driven by three sources of information. First, a general resource of common information that the individual has acquired from previous cultural knowledge and social communication pertaining to the illness (health threat). Second, information received from those perceived by the individual to be significant others in their external social environment, such as a spouse or physician. Third, the individual takes into account the somatic or symptomatic information that they currently experience based on both current perceptions and on previous direct experiences with the illness (Leventhal et al., 1980; Leventhal et al., 1984). It is important to note that the individual's current experience of the illness also includes their knowledge of how effective previous methods of coping were (Diefenbach & Leventhal, 1996).

The individual uses information from all of these sources to form a representation of their illness through a two-level procedure. The process of creating a representation by the linking of abstract and concrete sources of information is a symmetrical one. The mind does not create constructs from nothing, thus, symptoms require labels and a label must have indicators (symptoms). This linking of symptoms with diagnosis is theorized to be done automatically and intuitively. The illness representation is a result of the perception and interpretation of the different sources of information through schematic (perceptual and concrete) and conceptual (abstract and prepositional) procedures (Leventhal, 1990). It vital that the theoretical basis

of the SRM is well understood for it to be properly applied in health sciences research.

Qualitative research into the cognitive content of illness representations has resulted in them being ordered into five dimensions: identity, cause, timeline, consequences and cure/control (Meyer, Leventhal, & Gutmann, 1985). Identity refers to statements about the illness label (e.g. "I think I have cancer") and about the label's symptoms. Cause refers to the factors that the individual believes are responsible for causing their illness or disease. These factors include biological causes (e.g. germs, genetics, and immune function (Heijmans & de Ridder, 1998)), environmental causes (e.g. chemical and pollution), emotional causes (e.g. anxiety and depression (Moss-Morris, Petrie, & Weinman, 1996)) and psychological causes (personality type and mental outlook (Moss-Morris et al., 2002)). Overlap exists between individual items that are used to evaluate the causal dimensions.

The timeline dimension refers to one's perceptions about the course of the illness or disease (e.g. "My cancer is acute") and its symptoms (e.g. "The pain is episodic"). Consequences refers to the individual's beliefs about the impact the illness will have on their quality of life and ability to function (e.g. "My cancer keeps me from playing sports"). The more recently added cure/control dimension is comprised of the individual's beliefs regarding

whether strategies exists that are able to cure or control the illness (e.g. "If I do chemotherapy it will cure my cancer") (Lau, Bernard, & Hartman, 1989). Emotional representations refer to an individual's assessment of the emotional impact of the illness, which can be major drivers of emotional outcomes.

Processing of cognitive and emotional representations are done simultaneously or in parallel. Research has found significant intercorrelations among the model's dimensions. For example, identity has been found to be strongly and negatively related to cure/control and positively related to timeline (chronic) and consequences (seriousness) of the illness. In the proposed research identity will be defined as primary cancer type and categorized by virulence. Those cancer types categorized as highly virulent (e.g. pancreatic cancer) are expected to be negatively related to cure/control and positively related to consequences (seriousness). In the SRM, illness representations are explicitly connected to coping strategies (Leventhal et al., 1980). In this research the patient's decision to continue natural product use or not and the decision to disclose natural product use to their oncologist or not were the coping strategies that were explored. Illness representations function as a filter and provide an interpretive framework for available information about the illness. It is theorized that the relationship is causal, with the illness representations exacting an effect on coping strategies in direct proportion to the level of severity that is perceived. For example, research has

demonstrated that the cure/control and identity dimensions were significantly correlated with seeking social support, behavioral disengagement and active coping (Moss-Morris et al., 1996). This relationship was investigated in this research within the context of natural product use and the SRM. In another study, identity, timeline and consequences were found to have a positive relationship with emotion-focused and passive coping behaviors including denial, venting emotions, avoidance and cognitive reappraisal (Heijmans, 1999; Rutter & Rutter, 2002). Such correlations must be interpreted with caution as they may be spurious or confounded by measurement artifacts and more research should be done to test these findings.

Illness representations are linked to illness outcomes (i.e. physical and psychological modifications) through their causal relationship with coping strategies, which impact health outcomes (Leventhal et al., 1980). That is to say, that coping acts as a mediator of the effect that illness representations have on illness outcomes (Baron & Kenny, 1986). For example, a study of patients with Addison's disease found that patients who viewed their disease as a serious condition and who considered their illness as uncontrollable were found to engage in more passive coping and reported higher levels of physical disability compared to those who believed the opposite (Heijmans, 1999). It is important for a mediation relationship such as this one to demonstrate that the independent variable (illness representations) is related to the dependent variable (illness outcomes). Studies on a number of different

illnesses have found associations between illness representations and illness

outcomes (Heijmans & de Ridder, 1998; Lacroix, 1991; Scharloo et al., 1998).

This indicates the importance of properly understanding why those diagnosed

with cancer are utilizing natural products, as it may affect the outcomes of

their cancer. Additionally, the beliefs which underpin why cancer patients use

natural products may also affect their decision to disclose their natural

product use to their oncologists or not. Examples of this relationship has been

found in studies of patients with chronic illnesses (chronic fatigue syndrome,

rheumatoid arthritis, chronic obstructive lung disease, and psoriasis), with

illness representations of a strong illness identity, chronic timeline and serious

consequences being found to have negative associations with social role and

physical functioning (Scharloo et al., 1998). In addition, Rutter and Rutter

found that active coping strategies mediated the effect of perceptions of

control on health satisfaction levels in patients with irritable bowel syndrome

(Rutter & Rutter, 2002). The performance of the coping behavior/ strategy on

the illness outcome is appraised by the individual which results in a re-

evaluation of the health threat. As such, the Self Regulation Model is dynamic

in nature, with new information from both internal and external sources being

constantly integrated.

Numerous descriptive and intervention studies have utilized the SRM

to investigate health threats and health behaviors. The SRM has been utilized

extensively in health care to bring better understanding of decision making.

For example, using the SRM, an assessment of the cognitive and emotional determinants of health care utilization by middle-aged and older adults, found that care seekers reported more symptoms than age, gender and health status matched controls (Cameron, Leventhal, & Leventhal, 1993). Importantly, care seekers did not report more symptoms than did matched controls with new symptoms. The authors concluded that the presence of atypical symptoms alone were not sufficient to induce care seeking. As such, care seeking was seen to be a result of well formed illness representations, a perceived inability to cope with the health threat, life stress and advisement to seek care (Cameron et al., 1993). A study of patients with breast cancer used the SRM to examine the relationship between illness representations and coping strategies and the perceived health of patients (Rozema, Völlink, & Lechner, 2009). After controlling for external variables, regression analysis showed that the illness representations consequences and identity explained 57% of variance in physical health and treatment control, whereas emotional illness representation and treatment control explained 47% of variance in mental health (Rozema et al., 2009).

Relevance of the Literature Review to the Proposed Study

The literature included in this review provides a solid foundation for the dissertation research that was conducted. We know from previous research that use of natural products by those diagnosed with cancer is widespread

and often at greater rates than the general US population. Additionally, it has been found that natural product use among cancer patients has been increasing over time. Disclosure of natural product use to healthcare providers is low and poses serious efficacy and safety issues. Finally, we know that the Self-Regulation Model is a well-established theoretical model that has been applied extensively to understand health beliefs and behaviors.

Our knowledge of natural product use among those diagnosed with cancer in the U.S. is far from complete. As such, more research was needed to more fully elucidate differences in use of natural products among the diverse populations of people who have been diagnosed with a variety of cancers. Although a growing body of evidence on the use of CAM modalities in general among those diagnosed with cancer is now becoming available, very little research has been done looking directly at the patterns of and reasons for use of natural products among those with a cancer diagnosis, particularly down to the level of individual natural products, the relationship of initiation of use to diagnosis, and sources of advisement. This research examined the prevalence and patterns of natural product use among CINJ patients diagnosed with cancer relative to these variables. Drawing on data from a previously completed survey, it investigated motivational predictors of natural product use in general and for individual natural products. In addition, it evaluated the perceived efficacy and anticipated response of disclosure of natural product use among a diverse cancer patient population. The Self-

Regulation Model was applied to better understand participants' health beliefs and the decision-making process participants utilized for natural product use related behaviors.

Furthermore, as demonstrated in the literature above, we needed a better understanding of why patients are not disclosing the use of natural products to their oncologists/physicians and how provider-patient communication can be improved. The aim of this research was to determine the prevalence and patterns (e.g. timing, types) of natural product use by CINJ patients and apply the Self-Regulation Model to better understand why cancer patients are using natural products and identify patterns of disclosure of natural product use to healthcare providers.

Chapter III

METHODS

Paradigm and Research Design

The specific research design that was utilized for this dissertation was

a retrospective, cross-sectional design. This research included unique

analyses of an existing SPSS database created from the responses to a

cross-sectional survey. It reported the data in much greater detail, in

particular within the areas of natural product use and disclosure of natural

product use to healthcare providers. For the first time, the Self-Regulation

Model (SRM) was applied to the data to understand how cancer patients are

utilizing natural products and why they are using natural products.

Participants were cancer patients who were seen at CINJ during a 12-month

period. Relevant questionnaire information includes demographics (sex, race,

marital status, education level, age, and income), disease factors (cancer

type, cancer status), treatment factors, natural product factors, disclosure of

natural product use, and perceived provider response to disclosure information.

Instrumentation

The survey instrument utilized for this study was adapted and modified from a tool that had been used and validated with patients at a comprehensive cancer center (Richardson et al., 2000). As reported by Perlman et al. (Perlman et al., 2013), the survey instrument was updated to include current commonly used natural products and modified to enable the application of the SRM to better understand the biopsychosocial drivers of natural product use throughout the full spectrum of cancer care. The survey contained sections for the collection of demographic and cancer information.

This study utilized the write-in responses regarding individual natural products: green tea, multivitamin/mineral, and selenium (based on sample size available) for application of the SRM. Cancer information collected includes tumor type, cancer stage/status, time since diagnosis, and current cancer treatment. As the SRM relies on an individual's perceptions, self-report was utilized to gather cancer information, rather than objective medical data (e.g. medical charts).

The survey (write-ins responses only) also contained sections on reasons for natural product use, the participant's perceived benefits of natural products they reported using, and the participant's decision-making process

for disclosing natural product use. The sections on reasons for natural product use, the participant's perceived benefits of natural products they reported using, and the participant's decision-making process for disclosing natural product use were available in the existing data only for natural products that participants wrote-in as ones that they found to be most effective. Thus, the analysis of the contribution that the SRM provides in understanding natural product use was limited to a subset of the data.

No previous scale had been established to evaluate a patient's perceived efficacy of the natural products they used. In light of this fact, the authors of the initial study reported that a 11-item scale was created based on a review of both qualitative and quantitative studies on the reasons for natural product use throughout the continuum of cancer care (Perlman et al., 2013). A 5-point Likert scale, ranging from "not at all" to "completely", was used to evaluate each item for perceived effectiveness using commonly indicated reasons for natural product use that had been pre-coded.

Similarly, no scale existed to evaluate reasons a patient chose to disclose or not disclose their natural product use to their healthcare providers. To address this problem, Perlman et al. reported they conducted a review of the available literature to investigate what was currently known about this subject (Perlman et al., 2013). Based on this review, a scale was created that consisted of two subscales. The first subscale was to be used if a participant

indicated they had disclosed their natural product use to their CINJ

oncologist. The questions were used to investigate what the oncologist's

response was. Each of the questions used a 5-point Likert scale ("not at all"

to "completely"). The questions were:

- *encouraged me to continue using?*

- *encouraged me to stop using?*

- *warned me of the risks?*

- *referred me to another practitioner?*

- *was neutral about me using?*

The other was to be used if they chose to not disclose their natural product

use to their CINJ oncologist. The questioned were used to investigate why the

respondent chose not to disclose. Each of the questions used a 5-point Likert

scale ("not at all" to "completely"). The questions of this subscale were:

- *he or she never asked about?*

- *I did not think he/she would understand about?*

- *I thought he/she would discourage or disapprove of?*

- *I did not think it was important for my oncologist to know about?*

- *my oncologist might not continue to be my provider?*

- *I am unsure if therapy is/are beneficial?*

Additionally, this study conducted analyses to investigate associations between demographic variables (sex, race, marital status, education level, age, and income) and natural product use. Analyses we done for both current natural product use and for natural product use initiated post-diagnosis. For evaluation of each natural product used, participants were asked to report if they had ever heard of the natural product, if they had ever used the natural product, if they were currently using the natural product, and if they initiated use of the natural product after receiving a cancer diagnosis. These questions were used to investigate how familiar cancer patients were with various natural products, how frequently they used the various natural products, and how frequently they initiated use of the various natural products after they received a diagnosis of cancer.

Variables and Operational Definitions

The Self-Regulation Model was applied to understand why those diagnosed with cancer continued to use or did not continue to use natural products. This investigation used a sequential analysis based on the structural progression of the SRM (Table 3), and variables that operationalize the SRM theoretical constructs were created post-hoc from the existing questions in the data set. Additionally, the SRM was applied to understand why those diagnosed with cancer chose to disclose or not disclose natural

product use and what the outcomes were. That investigation utilized the same sequential analysis format.

Table 3

Continuation of Natural Product Use & Disclosure of Natural Product Use

Independent	Dependent
Illness Representation (Cognitive and Emotional)	Coping Strategy
Coping Strategy	Illness Outcomes
Illness Outcomes	Appraisal of Coping Strategy

Nearly all aspects of the Self-Regulation Model (SRM), shown in Table 4 & 5, were included in the investigation of why participants chose to continue or not to continue natural product use that was initiated after receiving a cancer diagnosis and the decision to disclose or not disclose natural product use. The cause dimension was not included, as it is not accurately represented by any of the survey questions. Specific natural products that were investigated were limited to those natural products participants chose to write-in as ones which they found to be among the top five therapies they felt provided the most benefit and whose numbers are large enough to support analysis.

Continuation of Natural Product Use

Cognitive illness representation. The various dimensions of the participant's cognitive illness representation of their cancer were defined by the following survey questions with its number in the CINJ Survey indicated in brackets.

- Identity - Primary cancer type (22)

- Timeline - Time elapsed since initial cancer diagnosis (21)

- Consequences - Help you live longer? (16-20_C02), Relieve symptoms of cancer? (16-20_C03), Relieve side effects of chemotherapy treatment? (16-20_C04), Relieve side effects of radiation treatment? (16-20_C05), Relieve side effects of hormonal treatment? (16-20_C06)

- Cure/Control - Have more control over your cancer care? (16-20_C09), Help you live longer? (16-20_C02), Relieve symptoms of cancer? (16-20_C03), Treat your cancer? (16-20_C01), Prevent your cancer from recurring? (16-20_C10), Improve your quality of life? (16-20_C08)

Coping strategy. For the investigation of why cancer patients are using natural products, the coping strategy variable was defined as the behavior of the continuation of natural product use or not (16-20_B04).

Illness outcomes. The illness outcomes aspect of the SRM was categorized as the participant's cancer status (recurred/metastasized or cancer free) (23, 24) and their treatment status (active or none) (25).

Appraisal of coping. Finally, within the cognitive arm of the SRM, a participant's appraisal of the employed coping strategy was evaluated using the survey questions, Improve your quality of life? (16-20_C08), Relieve symptoms and side effects? (16-20_C03), Help you live longer? (16-20_C02), Treat your cancer? (16-20_C01), Prevent your cancer from recurring? (16-20_C10), and Was this therapy the most beneficial to you? (16-20_A).

Emotional illness representation. For the emotional illness representation, the emotions of fear and a desire to avoid suffering were investigated. The emotion of fear was evaluated using the survey questions, Help you live longer? (16-20_C02), Improve your quality of life? (16-20_C08), Prevent your cancer from recurring? (16-20_C10), and Have more control over your cancer care? (16-20_C09). Whereas, survey questions, Relieve symptoms of cancer? (16-20_C03), Relieve side effects of chemotherapy treatment? (16-20_C04), Relieve side effects of radiation treatment? (16-20_C05), and Relieve side effects of hormonal treatment? (16-20_C06) were used to represent a desire to avoid suffering.

Coping strategy, illness outcomes and appraisal of coping (emotional illness representation arm of SRM). The same survey questions used to define the coping strategy, illness outcomes and appraisal of coping dimensions for the cognitive illness representation arm of the SRM were also used for the emotional illness representation arm (Table 4). As with the cognitive representation arm of the SRM, the investigation of the emotional illness representation aspect of the SRM utilized a respondent's behavior of continued natural product use or lack thereof as the applied coping strategy. Additionally, the illness outcomes and appraisal of the applied coping strategy were defined the same as with the cognitive arm of the SRM and utilized the questions listed in those sections above.

Table 4

Analysis of Natural Product Use

Cognitive Illness Representation		Coping Strategies	Illness Outcomes	Appraisal of Coping
Cognitive Dimensions	*Corresponding Survey Questions Representing Dimensions of Self-Regulation Model*			
Identity	Primary Cancer Type (22)	Continued NP use or not (16-20_B04)	Cancer Status (Recurred/Metastasized, Cancer Free) (23, 24) Treatment Status (Active, None) (25)	1. Improve your quality of life? (16-20_C08) 2. Relieve symptoms and side effects? (16-20_C03) 3. Help you live longer? (16-20_C02) 4. Treat your cancer? (16-20_C01) 5. Prevent your cancer from recurring? (16-20_C10) 6. Was this therapy the most beneficial to you? (16-20_A)
Timeline	Time elapsed since initial cancer diagnosis (21)			
Consequences	1. Help you live longer? (16-20_C02) 2. Relieve symptoms of cancer? (16-20_C03) 3. Relieve side effects of chemotherapy treatment? (16-20_C04) 4. Relieve side effects of radiation treatment? (16-20_C05) 5. Relieve side effects of hormonal treatment? (16-20_C06)			
Cure/Control	1. Have more control over your cancer care? (16-20_C09) 2. Help you live longer? (16-20_C02) 3. Relieve symptoms of cancer? (16-20_C03) 4. Treat your cancer? (16-20_C01) 5. Prevent your cancer from recurring? (16-20_C10) 6. Improve your quality of life? (16-20_C08)			

Emotional Illness Representation		Coping Strategies	Illness Outcomes	Appraisal of Coping
Emotional IR	*Corresponding Survey Questions Representing Dimensions of Self-Regulation Model*			
Fear	1. Help you live longer? (16-20_C02) 2. Improve your quality of life? (16-20_C08) 3. Prevent your cancer from recurring? (16-20_C10) 4. Have more control over your cancer care? (16-20_C09)	Continued NP use or not (16-20_B04)	Cancer Status (Recurred/Metastasized, Cancer Free) (23, 24) Treatment Status (Active, None) (25)	1. Improve your quality of life? (16-20_C08) 2. Relieve symptoms and side effects? (16-20_C03) 3. Help you live longer? (16-20_C02) 4. Treat your cancer? (16-20_C01) 5. Prevent your cancer from recurring? (16-20_C10) 6. Was this therapy the most beneficial to you? (16-20_A)
Desire to avoid suffering	1. Relieve symptoms of cancer? (16-20_C03) 2. Relieve side effects of chemotherapy treatment? (16-20_C04) 3. Relieve side effects of radiation treatment? (16-20_C05) 4. Relieve side effects of hormonal treatment? (16-20_C06)			

Disclosure of Natural Product Use

The structural approach for the investigation of why those diagnosed with cancer chose to disclosure their natural product use to their oncologist was similar to the natural product use investigation described previously.

Cognitive illness representation and appraisal of coping. As shown in Table 5, survey questions representing the cognitive dimensions of the illness representation and the appraisal of coping were the same as with the analysis of natural product use (see Table 4).

Coping strategy. The coping strategy that was examined for the cognitive arm of the SRM was the decision/behavior of disclosing or not disclosing nature product use to a participant's CINJ oncologist (16-20_D).

Illness outcomes. The illness outcome variables were cancer status (23, 24) and treatment status (25).

Emotional illness representation. The emotional illness representation was defined as either a negative emotional state (i.e., scared, afraid) or a non-negative emotional state. Survey questions, "he or she never asked about? (16-20_D06), "I did not think it was important for my oncologist to know about?" (16-20_D09) and "I am unsure if NP is beneficial" (16-20_D11) were used to represent the non-negative emotional state. With questions, "I did not think he/she would understand about NP?" (16-20_D07), "My oncologist might not continue to be my provider (16-20_D10)" and "I

thought he/she would discourage or disapprove of NP? 16-20_D08)" being used for the negative emotional state.

      Coping strategy (emotional arm of SRM). The decision/behavior of disclosing or not disclosing natural product use (16-20_D) was used as a coping strategy for the emotional arm of the SRM, with treatment status (23, 24) and cancer status (25) being the two variables used to represent the illness outcome dimension of the SRM.

Table 5

Analysis of Disclosure of Natural Product Use

Cognitive Illness Representation		Coping Strategies	Outcomes	Appraisal of Coping
Cognitive Dimensions	*Corresponding Survey Questions Representing Dimensions of Self-Regulation Model*			
Identity	Primary Cancer Type (22)	Disclosure – Yes or No (16-20_D)	Cancer Status (Recurred/Metastasized, Cancer Free) (23, 24) Treatment Status (Active, None) (25)	• Improve your quality of life? (16-20_C08) • Relieve symptoms and side effects? (16-20_C03) • Help you live longer? (16-20_C02) • Treat your cancer? (16-20_C01) • Prevent your cancer from recurring? (16-20_C10) • Was this therapy the most beneficial to you? (16-20_A)
Timeline	Time elapsed since initial cancer diagnosis (21)			
Consequences	1. Help you live longer? (16-20_C02) 2. Relieve symptoms of cancer? (16-20_C03) 3. Relieve side effects of chemotherapy treatment? (16-20_C04) 4. Relieve side effects of radiation treatment? (16-20_C05) 5. Relieve side effects of hormonal treatment? (16-20_C06)			
Cure/Control	1. Have more control over your cancer care? (16-20_C09) 2. Help you live longer? (16-20_C02) 3. Relieve symptoms of cancer? (16-20_C03) 4. Treat your cancer? (16-20_C01) 5. Prevent your cancer from recurring? (16-20_C10) 6. Improve your quality of life? (16-20_C08)			
Emotional Illness Representation			**Outcomes**	**Appraisal of Coping**
Emotional IR				
Non-negative (neutral)	1. He or she never asked about? (16-20_D06) 2. I did not think it was important for my oncologist to know about? (16-20_D09) 3. I am unsure if NP is beneficial (16-20_D11)	Disclosure – Yes or No (16-20_D)	Cancer Status (Recurred/Metastasized, Cancer Free) (23, 24) Treatment Status (Active, None) (25)	• Improve your quality of life? (16-20_C08) • Relieve symptoms and side effects? (16-20_C03) • Help you live longer? (16-20_C02) • Treat your cancer? (16-20_C01) • Prevent your cancer from recurring? (16-20_C10) • Was this therapy the most beneficial to you? (16-20_A)
Negative (scared, afraid)	1. I did not think he/she would understand about NP? (16-20_D07) 2. My oncologist might not continue to be my provider (16-20_D10) 3. I thought he/she would discourage or disapprove of NP? 16-20_D08)			

Self-Regulation Model Construct Development and Computation

Substantial cleaning, recoding and new variable creation was required to prepare the existing data for analysis. The details of how all of the variables representing each of the Self-Regulation Model dimensions that were analyzed as part of this study were developed and computed are contained in Appendix A.

Natural Product Use and Demographic Variables

Previous studies have found associations between education level, race, and gender, and natural product use (Adams & Jewell, 2007; Chang et al., 2011; Ferrucci et al., 2009; Velicer & Ulrich, 2008). As such, the relationships between natural products used (dependent variable) and the following independent demographic variables (sex, race, marital status, level of education, age and income) were also investigated in this research (Table 6).

Table 6

Study Variables for Natural Products Used

Primary Dependent Variables	
1.	Natural Products Used
Independent Study Variables	
Demographics	
1.	Sex
2.	Race and Ethnicity
3.	Marital Status
4.	Level of Education
5.	Age
6.	Income

Subjects

A potential participant list (n = 2,777) was randomly generated from a patient database (n = 9,062) that included all patients, 18 years and older, who were seen at CINJ for cancer screening, treatment and prevention during a 12-month period. A sample of 33% of the patient database was used, as it would provide adequate power to detect an effect size of 0.10 at 80% power with alpha being set at 0.05 with an expected response rate of 50%. The actual response rate was 57% based on a total of 1,755 usable surveys being returned, of which 1,226 who indicated a cancer diagnosis, were used in this study. All respondents received a $10 voucher to a local restaurant. Children were not included as their CAM use, including natural products, may have been selected by their parents/guardians. All participants were required to be able to read and write in English to be included in the study. Participants first received a study packet that included a survey, cover letter (IRB-approved

consent document) and a self-addressed stamped envelope for participants to use to return the completed survey. To improve response rates, a reminder postcard was mailed out 2 weeks later. A second identical study packet was sent 1 month later to all those who did not respond to the first study packet.

Data Analysis Plan

Natural product use and demographic variables. The descriptive statistics (number and percentage) for sex, age, race, marital status, level of education, and income were analyzed and reported. These analyses were conducted for all current natural product and natural product use initiated after diagnosis. Chi-squared analyses were conducted to investigate which independent variables predict current natural product use. "Are you currently using?", for all natural product use combined vs. demographics. Similarly, for natural product use that was initiated after diagnosis "Did you start using only after your cancer diagnosis?", for all natural product use combined vs. demographics.

The application of the Self-Regulation Model (SRM) in the analyses of natural product use and disclosure of natural product use, was done through sequences of bivariate analyses. The rationale for this structure was based on how the SRM is organized. It progresses sequentially from illness

representations to coping strategies to illness outcomes to appraisal of coping simultaneously through its dual-arm structure.

Analysis of natural product use. Sequential bivariate analyses were carried out to investigate if illness representations predicted coping strategy, if coping strategy predicted illness outcomes and if illness outcomes predicted how the coping strategy is appraised. Based upon the non-normal distributions of the data, Spearman's rho was used.

Analysis of disclosure of natural product use. Sequential bivariate analyses were done to investigate if illness representations predicted coping strategy, if coping strategy predicted illness outcomes and if illness outcomes predicted how the coping strategy is appraised.

Methodological Assumptions and Limitations

There are several methodological assumptions that were made in the design of this study. The first was the belief that participants understood the survey questions and answered them correctly. It was also assumed that all respondents answered the survey questions honestly. Additionally, the current dataset was assumed to accurately represent the original surveys that were returned by the participants. Finally, it was assumed that the SRM was

an appropriate framework to understand the health beliefs and behaviors of this cancer patient population.

The main methodological limitation of this study was that it was retrospective. It was known *a priori* that the data available for the aforementioned analyses was not what would have been collected if the SRM were to be evaluated prospectively. Additionally, the study included only a single study site. The fact that the site was a comprehensive cancer center, which included a wide array of cancer types, and the large sample size helps to mitigate this limitation. Data was limited to those who self-selected to participate. The level of nonresponse bias, while of concern, did not pose a serious threat to the study's validity. The response rate was 57%, which was higher than expected (50%) and higher than the response rate for a similar study (51%) that was completed at a different NCI-designated comprehensive cancer center (Richardson et al., 2000). Only those who could read and write in the English language were included in the study, which may limit its application to those who are not literate in English. This is of limited concern as the literacy rate in the United States has been estimated to be approximately 99%. It is worth noting, however, that a nationwide study by the US Department of Education, published in 1993, found that 21% to 23% of US adults demonstrated English literacy skills at the lowest level of proficiency (Kirsch, 1993). Finally, preliminary analysis found the sample to

be predominately white, potentially limiting the application of this study's

findings to non-whites (Perlman et al., 2013).

Chapter IV

Results and Findings

Introduction

Data from the CINJ survey was analyzed according to the plan detailed

in Chapter III. The results of the analyses investigating natural product use

are reported in Section 1, followed in Section 2 by outcomes relating to the

disclosure of natural product use. Within Section 1, the findings of data

analyses done on association of natural product use with demographic

variables are reported first. This is followed by the findings of the sequential

bivariate analyses applying the SRM, with analyses being reported via

progression through the SRM as it is structured.

Section 1 Natural Product Use

Question 1. How is the use of natural products associated with patient

characteristics (e.g. demographics & cancer factors) and what patterns of

motivations of use will be found by applying the Self-Regulation Model (SRM)

to understand patient beliefs about the perceived efficacy and side effects of natural products?

Hypothesis 1. The frequency and timing (pre- and post-diagnosis) of initiation of natural product use will be associated with age, cancer type, and potentially other patient characteristics (demographics & cancer factors) and that applying the Self-Regulation Model to the perceived efficacy of natural products used will result in a greater understanding of the differences in the patterns of natural product use by this cancer patient population.

Demographics and natural product use. A total of 1,226 survey respondents indicated a cancer diagnosis and were analyzed for this study. Among participants who reported a cancer diagnosis, 74.1% (n=909) indicated they were currently using at least one natural product, and 28.2% (n=346) indicated they initiated natural product use after being diagnosed with cancer. The majority of participants were female (64.6%), white (87%), married (72.8%), and age 50 or older (75.3%). Sex (χ^2 = 20.00, P <.001) and level of education (χ^2 = 22.41, P = .004) were significantly associated with current natural product use in the total sample who used natural products. None of the demographic variables that were analyzed were found to be significantly associated with natural product use initiated after cancer diagnosis as detailed in Table 7.

Table 7

Current NP Use and NP Use Initiated After Diagnosis, by Demographic

Characteristic

Characteristics	Total with Cancer Diagnosis (%)	Current NP use (column %)	Current NP use % of total in timing category	NP Use Initiated After Diagnosis (column %)	NP use initiated after diagnosis % of total in timing category
Sex					
Male	434 (35.4)	289 (31.8)	66.6	111 (32.1)	25.6
Female	792 (64.6)	620 (68.2)	78.3	235 (67.9)	29.7
Total	1226 (100)	909 (100)	74.1	346 (100)	28.2
*P**		**<.001**		.128	
Race/Ethnicity					
White	1055 (87)	790 (87.9)	74.9	288 (85.2)	27.3
Hispanic	51 (4.2)	33 (3.7)	64.7	17 (5.0)	33.3
African American	56 (4.6)	42 (4.7)	75	19 (5.6)	33.9
Asian	49 (4)	34 (3.8)	69.4	13 (3.8)	26.5
American Indian	2 (0.2)	0 (0)	0	1 (0.3)	50
Total	1213 (100)	899 (100)	74.1	338 (100)	29.9
P		.159		.327	
Age, years					
18-29	34 (2.8)	23 (2.5)	67.6	10 (2.9)	29.4
30-39	79 (6.4)	55 (6.1)	69.6	24 (6.9)	30.4

40-49	189 (15.4)	128 (14.1)	67.7	63 (18.2)	33.3
50-59	291 (23.7)	236 (26.0)	81.1	89 (25.7)	30.6
60-69	297 (24.2)	216 (23.8)	72.2	79 (22.8)	26.6
70-79	250 (20.4)	185 (20.4)	74	60 (17.3)	24
80-92	86 (7)	63 (7.0)	73.3	21 (6.1)	24.4
Total	1226 (100)	906 (100)	73.9	346 (100)	28.2
P		.051		.315	
Marital status					
Married/with partner	890 (72.8)	642 (72.5)	72.1	247 (73.3)	27.8
Divorced/separated	108 (8.8)	72 (8.1)	66.7	24 (7.1)	22.2
Widowed	142 (11.6)	116 (13.1)	81.7	38 (11.3)	26.8
Single/never married	80 (6.5)	54 (6.1)	67.5	27 (8.0)	33.8
Other	3 (0.2)	2 (0.2)	66.7	1 (0.30	33.3
Total	1223 (100)	886 (100)	72.4	337 (100)	27.6
P		.177		.513	
Education					
Some high school/graduate	345 (28.3)	246 (27.2)	71.3	96 (28.0)	27.8
Tech. school/assoc. degree	126 (10.2)	95 (10.5)	75.4	34 (9.9)	27.0
Some college/bachelors	494 (40.2)	365 (40.4)	73.9	135 (39.4)	27.3
Graduate degree	249 (20.3)	198 (21.9)	79.5	78 (22.7)	31.3
Total	1217 (100)	904 (100)	74.3	343 (100)	28.2

P		**.004**		.991	
Income, $					
12,500-19,999	244 (21.1)	159 (18.4)	65.2	68 (20.6)	27.9
20,000-59,999	309 (26.7)	242 (27.9)	78.3	85 (25.8)	27.5
60,000-99,000	183 (15.8)	137 (15.8)	74.9	57 (17.3)	31.1
100,000 or more	146 (12.6)	113 (13.0)	77.4	39 (11.8)	26.7
Don't know/ prefer not to say	276 (23.8)	215 (24.8)	77.9	81 (24.5)	29.3
Total	1158 (100)	866 (100)	74.8	330 (100)	28.5
P		.056		.571	

Note. NP= Natural Product *All significance values based on χ^2 test of independence.

Cancer Type and natural product use. A total of 1153 participants reported their primary cancer type. The most common types of cancer among those participants who reported a cancer diagnosis were Breast (34.4%), Other (15.4%), Hematologic (13.9%), Skin (melanoma) (13.1%), and Gynecologic (7.5%). Breast cancer (38.0%) remained the most common type of cancer among participants who reported current natural product use, followed by Other (15.0%), Skin (melanoma) (13.4%), Hematologic (12.2%), and Gynecologic (7.1%). For those participants who initiated natural product use after receiving a cancer diagnosis, Breast cancer was the most common type of cancer at 41.9%. This was followed

by Hematologic (13.4%), Gynecologic (10.6%), Other (8.8%), and Prostate (7.4%). Breast cancer, analyzed as breast cancer versus all other cancer types, was found to be associated with both current (x^2 = 8.17, P = .004) and post-diagnosis initiated natural product use (x^2 = 6.67, P = .010). Skin (melanoma) cancer was found to be significantly associated with natural product use initiated after receiving a cancer diagnosis (x^2 = 8.98, P = .003). The cancer type Other was also found to be associated with natural product use that was started after a patient was diagnosed with cancer (x^2 = 8.95, P = .003) (Table 8).

Table 8

Current NP Use and NP Use Initiated After Diagnosis, by Cancer Type

Cancer type	Total with Cancer Diagnosis (%)	Current NP use (%)	Current NP use % of total in category	NP Use Initiated After Diagnosis (%)	NP use initiated after diagnosis % of total in category
Skin (melanoma)	151 (13.1)	87 (13.4)	57.6	15 (6.9)	9.9
P		.707		**.003**	
Prostate	80 (6.9)	39 (6.0)	48.8	16 (7.4)	20.0
P		.164		.780	
Breast	397 (34.4)	246 (38.0)	62.0	91 (41.9)	22.9

P		**.004**		**.010**	
Lung	43 (3.7)	21 (3.2)	48.8	13 (6.0)	30.2
P		.321		.051	
Hematologic	160 (13.9)	79 (12.2)	49.4	29 (13.4)	18.1
P		.061		.808	
Colorectal	59 (5.1)	33 (5.1)	56.0	11 (5.1)	18.6
P		.966		.972	
Gynecologic	86 (7.5)	46 (7.1)	53.5	23 (10.6)	26.7
P		.598		.051	
Other	177 (15.4)	97 (15.0)	54.8	19 (8.8)	10.7
P		.683		**.003**	
Total	1153 (100)	648 (100)	56.2	217 (100)	18.8

Note. NP= Natural Product *All significance values based on χ^2 test of independence. Coded as cancer type versus all other cancer types.

Natural product use (SRM-subset). Of the 346 respondents who indicated they initiated natural product use after being diagnosed with cancer, 55.8% (n=193) reported (responses written-in) one or more natural products as among the top five Complementary and Alternative Medicine (CAM) therapies they found provided the most benefit. Data from these participants was used in the analysis applying the Self-Regulation Model (SRM). This subset was used because this was a new behavior initiated after cancer diagnosis, and data was available to analyze relative to their beliefs about this use. Spearman's rank correlation

coefficients were conducted to analyze the relationship between demographic variables, the continuation of natural product use and disclosure of natural product use. Additionally, nonparametric tests were done based on the distribution of the data. None of the demographic variables that were analyzed were found to be significantly associated with continuation of natural product use or disclosure of natural product use (Tables 9 & 10). As such, these demographic variables are unlikely to be confounding variables in the SRM analysis, and therefore were not corrected for in those analyses.

Table 9

Continued NP use (SRM), by Demographic Characteristic

Characteristics	SRM - Cont. NP Use	%
Sex		
Male	67	34.7
Female	126	65.3
Total	193	
*P**	.451	
Race		
White	164	85
Hispanic	4	2.1
African American	14	7.3
Asian	9	4.7
American Indian	2	1.0

Total	193	
P	.659	
Age, years		
18-29	9	4.7
30-39	13	6.7
40-49	46	23.8
50-59	58	30.1
60-69	35	18.1
70-79	25	13
80-92	7	3.6
Total	193	
P	.464	
Marital status		
Married/with partner	154	79.8
Divorced/separated	8	4.1
Widowed	11	5.7
Single/never married	19	9.8
Other	1	.5
Total	193	
P	.927	
Education		
Some high school/graduate	35	18.1
Tech. school/assoc. degree	23	11.9
Some college/bachelors	89	46.1
Graduate degree	46	23.8
Total	193	
P	.200	
Income, $		

12,500-19,999	41	21.2
20,000-59,999	57	29.5
60,000-99,000	31	16.1
100,000 or more	18	9.3
Don't know/pefer not to say	46	23.8
Total	193	
P	.596	

Note. NP= Natural Product SRM= Self-Regulation Model
All significance values based on χ^2 test of independence.

Table 10

Disclosure of NP use (SRM), by Demographic Characteristic

Characteristics	SRM - Disclosure of NP Use	%
Sex		
Male	66	34.7
Female	126	65.3
Total	193	
*P**	.083	
Race		
White	164	85
Hispanic	4	2.1
African American	14	7.3
Asian	9	4.7
American Indian	2	1.0
Total	193	

P	.164	
Age, years		
18-29	9	4.7
30-39	13	6.7
40-49	46	23.8
50-59	58	30.1
60-69	35	18.1
70-79	25	13
80-92	7	3.6
Total	193	
P	.952	
Marital status		
Married/with partner	154	79.8
Divorced/separated	8	4.1
Widowed	11	5.7
Single/never married	19	9.8
Other	1	.5
Total	193	
P	.667	
Education		
Some high school/graduate	35	18.1
Tech. school/assoc. degree	23	11.9
Some college/bachelors	89	46.1
Graduate degree	46	23.8
Total	193	
P	.482	
Income, $		
12,500-19,999	41	21.2

20,000-59,999	57	29.5
60,000-99,000	31	16.1
100,000 or more	18	9.3
Don't know/pefer not to say	46	23.8
Total	193	
P	.624	

Note. NP= Natural Product SRM= Self-Regulation Model
All significance values based on χ^2 test of independence.

Descriptive Statistics were performed for all of Self-Regulation

Model dimensions analyzed in this research (Table 11). Median, Range,

Minimum and Maximum were reported due to the non-normal distribution

of the data. A detailed explanation of how each variable was created and

computed is located in Appendix A.

Table 11

Descriptive Statistics of Self-Regulation Model Dimensions

Self-Regulation Model Dimensions	(N=193)			
	Median	Range	Min.	Max.
Illness Representations Cognitive Dimensions				
Identity (Cancer Type)				
Breast	0	1	0	1
Prostate	0	1	0	1
Other	0	1	0	1

Timeline	44	182	6	188
Consequences	2	20	0	20
Cure/Control	5	30	0	30
Illness Representations Emotional Dimensions				
(Natural Product Use)				
Fear	4	20	0	20
Desire to avoid suffering	1	20	0	20
Illness Representations Emotional Dimensions				
(Disclosure)				
Non-negative (neutral)	0	14	0	14
Negative (scared, afraid)	0	15	0	15
Coping Strategy				
Natural Product Use	25	100	0	100
Disclosure	40	100	0	100
Illness Outcome				
Cancer Status	2	6	-3	3
Treatment Status	0	5	-4	1
Appraisal of Coping Strategy	5	26	0	26

Self-regulation model and natural product use. A series of two-tailed Spearman's rank correlation coefficients (Spearman's rho) were conducted. Analyses progressed from Illness Representation (IR) through

Appraisal of Coping, based on the organizational structure of the SRM as depicted in Table 4 in Chapter III. The Identity dimension within the cognitive IR was defined as the primary type of cancer with which a participant reported being diagnosed. Survey respondents were provided a list of 27 primary cancer types (e.g. stomach, kidney, lung and other) from which to select. Based on the cancer type selection rate, breast and prostate cancer were analyzed individually and all other cancer types were combined for analysis.

Cognitive illness representations. Correlations between illness representations and continued NP use were analyzed using Spearman's rho and are reported in Table 10. No significant correlation was found between the cognitive IR dimensions of Timeline (r_s=-.072, p=.408) and Identity (breast r_s=.089, p=.217), (prostate r_s=-.057, p=.315), (other r_s=-.020, p=.783) and the coping strategy of continuation of natural product (NP) use. A very weak positive correlation was found between the cognitive IR dimension Consequences (r_s=.176, p=.014), but not Cure/Control (r_s=.136, p=.059) and the coping strategy of continuation of NP use.

Emotional illness representations. The emotional IR dimensions that were analyzed included "Fear" and "Desire to avoid suffering". "Desire to avoid suffering" was found to have a very weak positive correlation with

the coping strategy of continuation of NP use (r_s=.157, p=.030). The correlation between "Fear" (r_s=.109, p=.132) and the coping strategy of continuation of NP use was found not to be significant.

Individual natural products. The most commonly used individual natural products among write-ins identified as one of the top five most helpful CAM modalities were green tea (EGCG, pills)(n=65), multivitamins/mineral (MVM)(n=56) and selenium (n=18). None of the correlations between continued natural product use and any dimensions of the IR were found to be significantly associated for green tea, MVM or selenium.

Table 12

Spearman Coefficients for the Relationship Between Illness Representations

and Continuation of NP use

Self-Regulation Model	Continuation of NP use (N=193)	
Illness Representations Cognitive Dimensions	Spearman Correlation	
Identity (Cancer Type)		
Breast	.089	(p=.217)

Prostate	-.057	(p=.430)
Other	-.020	(p=.783)
Timeline	-.072	(p=.408)
Consequences	**.176**	**(p=.014)**[a]
Cure/Control	.136	(p=.059)
Illness Representations Emotional Dimensions		
Fear	.109	(p=.132)
Desire to avoid suffering	**.157**	**(p=.030)**[a]

Note. NP=Natural Product, [a] Correlation is significant at the 0.05 level (2-tailed)

Illness outcomes. Progressing through the SRM, the relationship between the coping strategy of continuation of NP use and a patient's illness outcome was analyzed. A patient's illness outcome was defined as their responses to questions regarding their cancer status (recurred, metastasized, cancer free) and treatment status (chemotherapy, radiation, none) (Table 11). When analyzed individually, both aspects of the patient's illness outcome were found to not be correlated with a continuation of natural product use (cancer status r_s=.039, p=.587) (treatment status r_s=-.085, p=.238). When combined into a patient's illness outcome they were also not found to correlate with continuation of NP use (r_s=-.011, p=.878).

Table 13

Spearman Coefficients for the Relationship Between Illness Outcome and Continuation of NP use

Self-Regulation Model	Continuation of NP use (N=193)	
	Spearman Correlation	
Cancer Status	.039	(p=.587)[a]
Treatment Status	-.085	(p=.238)[a]
Illness Outcome	-.011	(p=.878)[a]
(Cancer+Treatment Status)		

Note. NP=Natural Product [a]2-tailed

Appraisal of coping. Finally, within the SRM analysis of natural product use, the relationship between a patient's reported illness outcome and their appraisal of the coping strategy they employed was investigated. Cancer Status (r_s=-.061, p=.397) and Treatment Status (r_s=-.080, p=.270) were both found to not be significantly correlated with a patient's appraisal of their coping strategy (Table 12). The survey participant's reported illness outcome was also found to not be significantly correlated with their appraisal of the applied coping strategy of continuation of NP use (r_s=-.073, p=.311).

Table 14

Spearman Coefficients for the Relationship Between Illness Outcome and Appraisal of Coping for Continuation of NP use

Self-Regulation Model	Appraisal of Coping (N=193)	
	Spearman Correlation	
Cancer Status	-.061	(p=.397)[a]
Treatment Status	-.080	(p=.270)[a]
Illness Outcome	-.073	(p=.311)[a]
(Cancer+Treatment Status)		

Note. NP=Natural Product [a]2-tailed

All of the relationships of the Self-Regulation Model investigated as part of this study for the coping strategy of continuation of natural product use are depicted in Figure 6. Those relationships that were found to be significant are bolded and in blue.
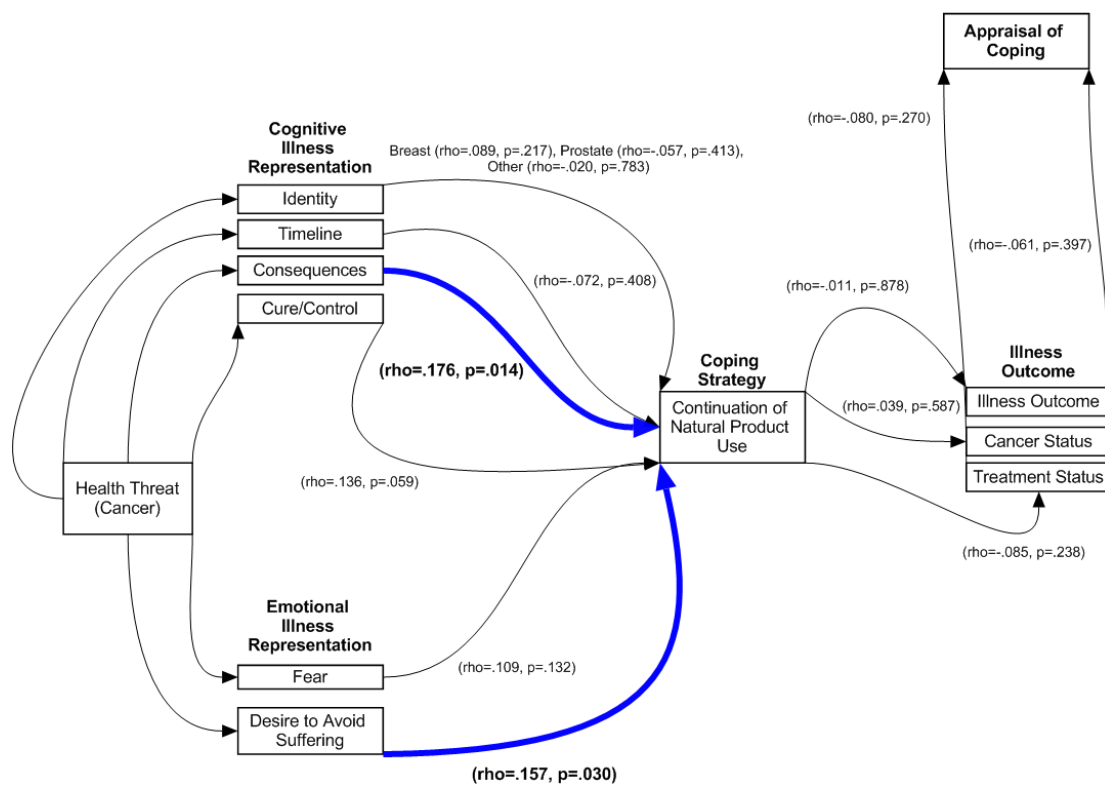
Figure 6. Schematic Representation of Self-Regulation Model Analysis for Continuation of Natural Product Use Coping Strategy

Section 2 Disclosure of Natural Product Use

Question 2. Is the disclosure of natural product use to a patient's CINJ oncologist associated with patient characteristics (e.g. demographics & cancer factors) and the perceived/anticipated provider responses to the disclosure of natural product use to a patient's CINJ oncologist?

Hypothesis 2. The frequency that natural product use is disclosed will be associated with age, cancer type, and potentially other patient characteristics (demographics & cancer factors) and the perceived/anticipated provider responses to the disclosure of natural product use to a patient's CINJ oncologist.

As with the analysis of natural product use, a series of two-tailed Spearman' rho correlation coefficients were conducted to determine relationships. This analysis was designed to test if cognitive and emotional illness representations, as defined by the SRM, predict disclosure of natural product use, if disclosure of natural product use predicted illness outcomes, and if illness outcomes predicted a participant's appraisal of the coping strategy employed (disclosure of natural product use or not).

Cognitive illness representations. When the Identity dimension of the cognitive IR was used, no correlation was found between it and the decision to disclose natural product use (breast r_s=-.061, p=.401) (prostate r_s=.066, p=.363) (other r_s=.016, p=.829). The cognitive IR dimension of Timeline, which was defined as time since diagnosis with primary cancer type, was also found to not correlate with the behavior of natural product disclosure (r_s=.082, p=.346). The cognitive IR dimensions of Consequences (r_s=.214, p=.003) and Cure/Control (r_s=.226, p=.002) were both found to have weak positive correlations with disclosure of natural product use.

Emotional illness representations. For the investigation of disclosure of natural product use, the emotional IR was defined as "non-negative" (neutral) and "negative" (scared, afraid) dimensions. When the correlation between disclosure of natural product use and the negative dimension of the emotional IR was tested, they were found to have a moderately negative relationship (r_s=-.435, p<.001). The non-negative dimension was found to have a moderately negative relationship with the decision to not disclose natural product use (r_s=-.548, p<.001) (Table 13).

Individual natural products. Disclosure of the use of green tea (EGCG, pills) and the investigated emotional dimensions of the IR, non-negative (neutral) (r_s=-.536, p<.001) and negative (scared, afraid) (r_s=-

.438, p<.001), were both found to have moderately negative relationships. No cognitive dimensions of the IR, namely Consequences and Cure/Control, were found to be significantly associated with disclosure of green tea use. Among users of multivitamins/mineral natural products the cognitive Illness Representation dimensions of Consequences (r_s=.312, p=.019), Cure/Control (r_s=.272, p=.043), Identity (prostate)(r_s=-.307, p=.021) were found to be weakly positively associated with disclosure. Additionally, the non-negative (neutral) (r_s=-.412, p=.002) emotional dimension of the Illness Representation was found to have a moderately negative relationship with disclosure. Finally, among selenium users, disclosure of selenium use was found to have a strong and moderately positive relationship with the cognitive dimension of the IR Consequences (r_s=.646, p=.004) and Cure/Control (r_s=.568, p=.014). The emotional dimensions of non-negative (neutral) (r_s=.983, p<.001) and negative (scared, afraid) (r_s=-.718, p=.001) were found to have very strong and strong negative associations with disclosure of selenium use.

Table 15

Spearman Coefficients for the Relationship between Illness

Representations and Disclosure of NP use

Self-Regulation Model	Disclosure of NP use (N=193)	
Illness Representations Cognitive Dimensions	Spearman Correlation	
Identity (Cancer Type)		
Breast	-.061	(p=.401)
Prostate	.066	(p=.363)
Other	.016	(p=.829)
Timeline	.082	(p=.346)
Consequences	**.214**	**(p=.003)[a]**
Cure/Control	**.226**	**(p=.002)[a]**
Illness Representations Emotional Dimensions		
Non-negative (neutral)	**-.548**	**(**p<.001**)[b]**
Negative (scared, afraid)	**-.435**	**(**p<.001**)[b]**

Note. NP=Natural Product [a]Correlation is significant at the 0.05 level
(2-tailed).
[b]Correlation is significant at the 0.01 level (2-tailed).

Illness outcomes. The relationship between the coping strategy of

disclosure of natural product use and a patient's illness outcome was

found to be very weakly negatively correlated (r_s=-.173, p=.016). When

each aspect of the illness outcome was analyzed individually, cancer

status– (r_s=.149, p=.038) was found to have a very weak negative

correlation with disclosure of natural product use, but treatment status,

(r_s=-.131, p=.070) did not (Table 14). Among the top 3 individual natural

products (green tea (EGCG, pills), multivitamins/minerals and selenium)

no significant relationships were found between disclosure of use and

illness outcomes.

Table 16

Spearman Coefficients for the Relationship between Illness Outcome and

Disclosure of NP use

Self-Regulation Model	Coping Strategy Disclosure of NP use (N=193)	
	Spearman Correlation	
Cancer Status	**-.149**	**(p=.038)[a]**
Treatment Status	-.131	(p=.070)
Illness Outcome	**-.173**	**(p=.016)[a]**
(Cancer+Treatment Status)		

Note. NP=Natural Product [a]Correlation is significant at the 0.05 level (2-tailed).

Appraisal of coping. The final analysis performed was for Illness

Outcome and Appraisal of Coping dimensions of the SRM. This was

represented by the same questions for both the investigation of NP use

and the disclosure of NP use, because we determined that those

questions appropriately mapped to the SRM in both these ways. As such,

the results of the investigation into the relationship between illness

outcome and appraisal of coping for disclosure of natural product use is

the same as reported for natural product use; no significant relationship

(Table 15).

Table 17

Spearman Coefficients for the Relationship between Illness Outcome and

Appraisal of Coping for Disclosure of NP use

Self-Regulation Model	Appraisal of Coping (N=193)	
	Spearman's Correlation	
Cancer Status	-.018	(p=.800)[a]
Treatment Status	-.068	(p=.344)[a]
Illness Outcome	-.043	(p=.551)[a]
(Cancer+Treatment Status)		

Note. NP=Natural Product [a]2-tailed

All of the relationships of the Self-Regulation Model investigated as part of this study for the coping strategy of disclosure of natural product use are depicted in Figure 7. Those relationships that were found to be significant are bolded and in blue. Arrow thickness denotes the relative strength of relationship between the dimensions.
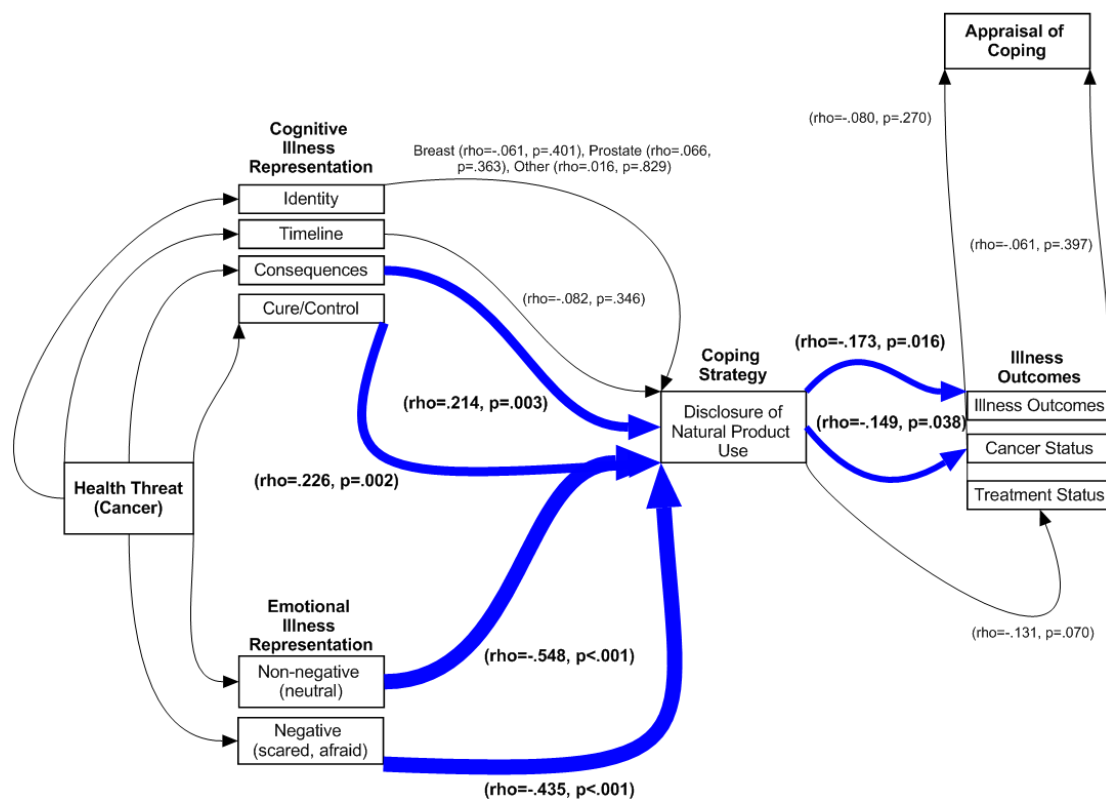
Figure 7. Schematic Representation of Self-Regulation Model Analysis for Disclosure of Natural Product Use Coping Strategy

Chapter V

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

Key Relationships, Patterns, and Themes

   Natural product use. The first aim of this research was to

determine the prevalence and patterns of natural product (NP) use by

cancer patients at the Cancer Institute of New Jersey (CINJ) within a 12-

month period, and to apply the Self-Regulation Model to better understand

why cancer patients are using natural products.

   Natural product use and patient characteristics

Sex/Gender. The majority (64.6%) of the 1,226 people who responded to

the survey, indicated that they had received a cancer diagnosis, and were

therefore included in this study, were female (Table 7). Females also

accounted for the majority of those reporting current NP use, with more

than two thirds (68.2%) of those who reported current NP use being

female. This was not just due to the greater total number of females, but

also to a higher percentage of females (74.1%) than males (25.9% of the

males responding with a cancer diagnosis) who reported currently using at

least one natural product. Therefore, current NP use was significantly

associated with sex (χ^2 = 20.00, P = <.001). In contrast, initiation of NP use

after diagnosis was not significantly associated with sex/gender (χ^2 = 2.33,

P = .128). While more females reported that they initiated NP use after

receiving a cancer diagnosis (n=235) vs. males (n=111), the percentages

of the totals in each category/gender (female 29.9%, male 25.6%) were

not significantly different than individuals who did not initiate after

diagnosis (Table 7).

We hypothesized that patient characteristics (which included sex)

would potentially be associated with frequency and time of initiation of

natural product use. This was based upon previous research that had

found sex to be associated with natural product use. For example,

(Patterson et al., 2003), found females were 2.2 times more likely to take

new natural products after receiving a cancer diagnosis (P <.01)

compared to males. When Perlman et al. analyzed this data at the level of

all CAM use they found sex (χ^2 = 16.80, P = <.001) to be associated with

initiation of CAM therapy after cancer diagnosis (Perlman et al., 2013). It is

not clear why sex was found to be strongly associated with current natural

product use, but this relationship was not maintained with natural product use that was initiated after diagnosis. This may have been due to fact that current use rates for both sexes were rather high, meaning that those individuals who would likely be motivated to use natural products post-diagnosis were already using them pre-diagnosis.

Race and Ethnicity. The Office of Management and Budget (OMB) requires all federal agencies to include a minimum of five race categories (White, Black or African American, American Indian or Alaska Native, Asian and Native American or Other Pacific Islander) and a minimum of two ethnicities (Hispanic or Latino, and Not Hispanic or Latino) (CDC, 2014). For this study we asked a single question about a participant's racial and ethnic identity that had eleven race categories and one ethnic category, Hispanic/Latino.

Among the participants (n= 1213) who completed the question on race, the vast majority identified themselves as White (87%). Whites were probably overrepresented in this sample, with the most recent census data estimating 62.1% of Americans identify as White, not Hispanic or Latino (Census, 2014). A total of (n=51) 4.2% of participants identified as Hispanic. The category of White was not broken out as White, not Hispanic or Latino and White, Hispanic or Latino. Due to this fact, we do not know how many participants who identified as White were Latino or

identified as both categories. The largest racial minority in this population

were those who identified as African Americans at 4.6% of those who

reported a cancer diagnosis. Nationally, the most recent census data

estimated that 13.2% of Americans identify as African Americans (Census,

2014). Among those participants who reported a cancer diagnosis 4.6%

identified as African American. The percentage was nearly the same for

those participants who reported currently using natural products and

identified as African American at 4.7%. Among those who reported natural

product use initiated after cancer diagnosed, the percentage was slightly

higher for participants who identified as African American (5.6%). These

differences did not result in race being associated with either current NP

use (χ^2 = 13.09, P = .159) or NP use initiated after diagnosis (χ^2 = 10.30, P

= .327).

We hypothesized that patient characteristics including race would

potentially be associated with frequency and time of initiation of natural

product use. This was based upon previous research that found race to be

associated with natural product use, with nonwhites being found to be

nearly half (0.59, 95% CI = 0.38-0.90) as likely to report using natural

products as whites (Ferrucci et al., 2009). When (Perlman et al., 2013)

looked at race among all CAM use in this survey they found that race was

not associated with either current CAM use (P = .285) or CAM use

initiated after cancer diagnosis (P = .357).

In our research, race and ethnicity were not found to be associated with current natural product use or natural product use initiated post-diagnosis among our study subjects. This difference may have been due to our sample being overwhelming white (88%) and underrepresenting racial minorities. The number of racial or ethnic minority participants may not have been large enough to provide adequate power to reach a significant difference for the statistical analyses we conducted or it may not have been representative of the survey or local populations. Interestingly, we found high rates of current natural product use across nearly all racial groups. These findings may have been due to the unique cultural traditions regarding natural product use practiced by racial and ethnic groups local to the geographical area studied. Previous studies have found that culture-specific knowledge about illness and a strong adherence to traditional health beliefs influences complementary and alternative medicine use (Chua & Furnham, 2008; G. B. Lee, Charn, Chew, & Ng, 2004; Read et al., 2014). Those groups whose cultural traditions make them more likely to utilize natural products may have been more likely to self-select to participate in the study.

The CINJ sample population may not be fully representative of the target population. There may have been self-selection bias, as those who were utilizing natural products may have been more likely to respond to the survey compared to those who were not. The high education and

income rates in this sample population may also not be representative of racial and ethnic minority rates in the general population. In addition, the sample population may not be representative of the local population due to the rates of cancer in that area (Howlader et al., 2014).

Age. For analysis of age, the following age groups were created: 18-29 years old (YO), 30-39 YO, 40-49 YO, 50-59 YO, 60-69 YO, 70-79 YO, and 80-92 YO. Among those participants who reported a cancer diagnosis, over three quarters (75.3%) were 50 years old or older. The largest age group, at nearly a quarter (24.2%) of those who indicated a cancer diagnosis, were between the ages of 60 to 69 years old. We found that 26.0% of patients 50-59 YO reported currently using natural products, while they only represented 23.7% of those patients who reported a cancer diagnosis. This difference was not large enough for current natural product use by age group to reach significance (χ^2 = 14.04, P = .051).

For use of natural products initiated after diagnosis 18.2% of those patients aged 40-49 years old reported use, while representing 15.2% of those who reported a cancer diagnosis. Conversely, those patients aged 70-79 YO made up 20.4% of all patients reporting a cancer diagnosis, but only 17.3% reported initiating natural product use after diagnosis. As with current natural product use, these differences were not large enough for

age to be found to be significant for natural product use started post-diagnosis (χ^2 = 8.20, P = .315).

As with other patient characteristics, we hypothesized that age would potentially be associated with frequency and time of initiation of natural product use. This hypothesis was based upon previous research that found that younger age was associated with natural product use (Velicer & Ulrich, 2008). For all CAM use (Perlman et al., 2013) found that younger age was associated with current CAM use (P = <.001) and CAM use initiated after diagnosis (P = <.001). In our study, we did not find that age was associated with current NP use or NP use that was started after a patient received a cancer diagnosis, though age and current NP use did approach significance (P = .051). This result may have been due to such a large proportion of participants of all age groups reporting current NP use (73.9%) and NP use started post-diagnosis (28.2%).

Our results for age may have also be due to differences occurring in other demographic variables. For example, we found that current natural product use was associated with sex. Females tend to live longer than males, which may have resulted in the older age groups being comprised of more females. This population was also highly educated, with current natural product use being associated with level of education. Older people tend to have higher levels of education. This may have been

a factor in why age was not found to be associated with natural product use.

Marital status. Nearly three quarters (72.8%) of participants who reported a cancer diagnosis indicated that they were married or with a partner. This distribution was maintained among those reporting current NP use (72.5%) and NP use initiated after diagnosis (73.3%). As such, marital status was not found to be associated with current NP use (χ^2 = 10.21, P = .177) or NP use initiated after receiving a cancer diagnosis (χ^2 = 6.23, P = .513) (Table 7).

We hypothesized that marital status would potentially be associated with frequency and time of initiation of natural product use. We based this hypothesis on previous research that had found that marital status was associated with CAM use among those diagnosed with cancer (M. Bright-Gbebry et al., 2011; Kang et al., 2012). (Perlman et al., 2013) did not find that marital status was associated with current CAM use (P = .335), they did find it was associated with CAM use initiated post-diagnosis (P = .013). When examining CAM use was limited to only NP use, as we did in this study, marital status was not found to be associated with either current NP use or NP use initiated post-diagnosis.

The rates of current NP use were higher for all marital status categories in our study (Married/with partner 72.1%, Divorced/separated

66.7%, Widowed 81.7%, and Single/never married 67.5%) compared to previous research (Married/living as married 40.1%, Single 14.4%, and Divorced/separated/widowed 42.6%) (Mireille Bright-Gbebry et al., 2011). Using the Perlman et al. study as a comparison, for all CAM use, 42.1% of those married reported initiating CAM use after receiving a cancer diagnosis, compared to 48.2% of non-married participants. In comparison, for NP use, 27.8% of married participants reported post-diagnosis initiated NP use and 27.6% of non-married uses reported initiating NP use after receiving a cancer diagnosis. This smaller difference in NP use initiated post-diagnosis may have been due to the ease of use of natural products relative to other forms of CAM. Natural products are highly accessible, low in cost, and can easily be given to cancer patients by others.

Education. The majority (70.9%) of participants who reported a cancer diagnosis had education beyond high school, with 72.8% of those who reported currently using natural products having a more than a high school degree. The largest percentage difference occurred among those who reported having a graduate degree, 80% of whom reported currently using natural products. As such, education was found to be associated with current NP use ($\chi^2 = 22.41$, P = .004). The graduate level education group also had the largest proportion (31.3%) who reported that they initiated NP use after receiving a cancer diagnosis. However, this did not result in

education being associated with post-diagnosis initiated NP use (χ^2 = 1.61, P = .991).

We hypothesized that education would potentially be associated with frequency and time of initiation of natural product use. We made this hypothesis based on previous research that found higher education to be associated with NP use (Adams & Jewell, 2007; Chang et al., 2011; Ferrucci et al., 2009; Kao & Devine, 2000; Velicer & Ulrich, 2008; Wilkinson et al., 2002). For example, (Ferrucci et al., 2009) found that compared to those with some high school education or less, cancer survivors with a high school diploma were 2.77 times (95% CI = 1.55-4.96) more likely to report using natural products, and those with a graduate school or professional degree were 5.44 times (95% CI = 2.98-9.93) more likely to report use. (Perlman et al., 2013) found that in this cancer patient population higher education was not associated with either current CAM use (P = .804) or CAM use initiated post-diagnosis (P = .682).

The lack of association between level of education and NP use initiated after diagnosis may have been a result of the large proportion of our population reporting levels of education beyond a high school level. In this population 81.9% of participants reporting a cancer diagnosis had education beyond high school, whereas in the study by (Ferrucci et al., 2009) only 67.8% had education above a high school diploma. With such a large proportion of our sample population reporting levels of education

beyond a high school level education, we were limited in our ability to

make meaningful comparisons in terms of education level and natural

product use.

Income. Reported incomes were broken into the following categories for

analysis: $12,500 to $19,999, $20,000 to $59,999, $60,000 to $99,000,

and $100,000 or more. Participants could also choose to report that they

did not know their income or preferred not to say. Among those patients

who reported a cancer diagnosis, the single largest income category

(26.7%) reported an income of $20,000 to $60,000. This was followed by

the large proportion (23.8%) of respondents who indicated they either did

not know their income or preferred not to say what it was. A substantial

proportion (12.6%) reported incomes of $100,000 or more. When asked

about current natural product use, 27.9% of the $20,000 to $60,000

income group and 13.0% of those reporting incomes of $100,000 or more

reported currently using natural products. Conversely, for the 21.1% of

participants with a cancer diagnosis who indicated income between

$12,500 and $19,999 a year, only 18.4% of this income group reported

currently using natural products. As such, income was nearly significant

for current NP use (χ^2 = 32.19, P = .056).

A larger proportion of those participants who reported incomes of

$60,000 to $99,000 indicated initiating natural product use after diagnosis

(17.3%) compared to the proportion in that income group who indicated they had received a cancer diagnosis (15.8%). This was not the case with the $100,000 or more income group, which made up 12.6% of those who reported a cancer diagnosis, but only 11.8% who reported initiating natural product use after receiving a cancer diagnosis. Across all income levels, higher income was not found to be associated with NP use that was started after a participant received a cancer diagnosis (χ^2 = 19.22, P = .571).

We had hypothesized that higher incomes would potentially be associated with frequency and time of initiation of natural product use. This was based upon previous research that had found higher income to be associated with natural product use by cancer patients (Kao & Devine, 2000; Wilkinson et al., 2002). When (Perlman et al., 2013) looked at income and CAM use in this population, they did not find higher income to be associated with either current CAM use (P = .167) or CAM use started after cancer diagnosis (P = .716).

In our study we did not find higher income to be associated with either current NP use or NP initiated post-diagnosis, although current NP did approach significance. Our findings may have been due to the fact that although those patients in the lower income groups have less income to be used for healthcare expenditures they may likely choose to use

complementary therapies due to conventional medical treatments being cost prohibitive relative to CAM therapies. This could have been due to higher rates of no or low quality health insurance among those with lower incomes and high out of pocket expenses associated with conventional medical care among those with higher quality insurance coverage. We also had one in four participants report that they either did not know their income or chose not to disclose it. Therefore, any conclusions that may be drawn regarding the relationships between income and natural product use in this population are somewhat limited.

Cancer Type. Due to the small cell sizes of multiple types of cancer, certain cancer types were combined for analysis. The 28 cancer type categories were combined to represent the most prevalent types of cancer in the United States (Siegel, Miller, & Jemal, 2015). These cancer types were: prostate, breast, lung, skin (melanoma), hematologic (leukemia, Hodgkin and non-Hodgkin lymphomas), colorectal, gynecologic (cervical, vaginal, ovarian, and uterine), and "other".

The most common types of cancer among those participants who reported a cancer diagnosis were Breast (34.4%), Other (15.4%), Hematologic (13.9%), Skin (melanoma) (13.1%), and Gynecologic (7.5%). Breast cancer (38.0%) remained the most common type of cancer among participants who reported current natural product use, followed by Other (15.0%), Skin (melanoma) (13.4%), Hematologic (12.2%), and

Gynecologic (7.1%). For those participants who initiated natural product use after receiving a cancer diagnosis, Breast cancer was the most common type of cancer at 41.9%. This was followed by Hematologic (13.4%), Gynecologic (10.6%). Other (8.8%), and Prostate (7.4%). We had hypothesized that cancer type would be associated with frequency and time of initiation of natural product use. We based this hypothesis upon existing research that had found differences in use of natural products by cancer type (Velicer & Ulrich, 2008).

Breast cancer was found to be associated with both current ($\chi^2 = 8.17$, P = .004) and post-diagnosis initiated natural product use ($\chi^2 = 6.67$, P = .010). This finding may have been influenced by other demographic factors, namely sex, as breast cancer is typically found in females. Skin (melanoma) cancer was found to be significantly associated with natural product use initiated after receiving a cancer diagnosis ($\chi^2 = 8.98$, P = .003). Melanoma accounts for only 2% of skin cancers, but is associated with most of its deaths (Cancer, 2015). Despite the lethality of melanoma, we currently lack good scientific evidence for the use of natural products in its treatment (Medicines, 2015). This may explain the lower than expected use rates post diagnosis.

The cancer type Other was found to be associated with natural product use that was started after a patient was diagnosed with cancer ($\chi^2 = 8.95$, P = .003). This category was a composite 17 different cancer

types. This may indicate that patients with a wide array of different types of cancer may be initiating natural product after receiving a cancer diagnosis. This may be significant in the development of improved awareness of natural product use among healthcare providers. Future studies may want to investigate populations with large enough numbers of participants for each of these cancers, so they can be analyzed individually.

Individual natural product use. Green tea (EGCG, pills) (n=144) was the most commonly reported natural product to be initiated after diagnosis at 13.7% of respondents. This may have been due to green tea usage having been found to be associated with reduced risk for a large number of cancers, including endometrial, ovarian, bladder, esophageal, pancreatic, breast, colorectal, gastric, lung, oral, and prostate cancer (Inoue et al., 1998; Ji et al., 1997; Jian, Xie, Lee, & Binns, 2004; Kakuta et al., 2009; Kuriyama et al., 2006; Mitscher et al., 1997; Seely, Mills, Wu, Verma, & Guyatt, 2005; Tang, Li, Qiu, Zhou, & Ma, 2009; Tsao et al., 2009; Zhang, Binns, & Lee, 2002) as well as reduced recurrence of cancer (Inoue et al., 2001; Nakachi et al., 1998; Ogunleye, Xue, & Michels, 2010; Seely et al., 2005). This rate of use may indicate that patients are aware of the scientific evidence regarding green tea, as coverage of

complementary and alternative medicine by the news media has been found to be increasing (Bonevski, Wilson, & Henry, 2008).

Multivitamins/minerals (10.3%) was the second most commonly post-diagnosis initiated natural product, followed by Vitamin C (8.3%), Vitamin E (8.2%), and Selenium (5.4%). In comparison, in a study of 356 people diagnosed with breast, prostate or colon cancer, Multivitamins (29.2%), Vitamin E (28.1%), Calcium (17.0%), Vitamin C (14.6%), and Garlic (9.4%) were the most commonly initiated natural products after diagnosis (Patterson et al., 2003). In our study at least one natural product was initiated post-diagnosis by 13.6% of participants. This was on the lower end of the 14% to 32% that has been seen in other studies (Velicer & Ulrich, 2008). In comparison current usage (74.1%) was just above the average of what had been found in previous research (64% to 81%) (Velicer & Ulrich, 2008). With such a large proportion of participants reporting current use of natural products in our study, fewer participants had the capacity to initiate use after cancer diagnosis. Post diagnosis use rates of individual natural products were lower compared to other studies. As such, the individual natural product use rates were in alignment with the overall post cancer diagnosis natural product use rates being on the lower end of what has been found previously. The differences in which individual products were found to be most commonly used may be a result of the timing of when a study is conducted. Positive or negative

information about a particular natural product that is widely disseminated in the media may result in increases and decreases in use.

Self-Regulation Model and Natural Product Use

The Self-Regulation Model (SRM) has previously been applied to other disease-specific patient populations to understand various health behaviors, but never to investigate natural product use or disclosure of natural product use among cancer patients. The Illness Perception Questionnaire (IPQ) is commonly used in SRM research and has been adapted for numerous diseases and conditions, but not specifically for cancer. The SRM has been used to understand other health behaviors in previous investigations of individual cancer types (e.g. breast, prostate), but to our knowledge it has not been previously utilized with a comprehensive cancer population. The second part of the first hypothesis of this study was that applying the Self-Regulation Model to the perceived efficacy of natural products used will result in a greater understanding of the differences in the patterns of natural product use by this cancer patient population.

For the SRM analysis, a subset of the larger data base was created that included only those subjects who indicated a natural product as the one of the top five write-in options (n=193). For each dimension of the Self Regulation Model, survey questions were selected to be mapped to

that dimension based on how well each survey question represented that dimension as it is defined by the literature. The cognitive illness representation dimensions that had been defined in the literature were: Identity, Cause, Timeline, Consequence and Cure/Control. The Coping Strategies, Illness Outcomes and Appraisal of Coping had been defined as well. Emotional dimensions of the illness representation had not been defined, so definitions were created that were relevant to cancer and to the survey. Mapping was done for all aspects of the SRM with the exception of the Cause dimension of the cognitive illness representation, as it was determined that no questions within the survey were well matched to it.

The results of this investigation indicated for the first time that a patient's cognitive perceptions of the Consequences (r_s=.176, p=.014) of their cancer may affect a patient's behavior of continued natural product use. The Consequences dimension of the illness representation (IR) encompasses a patient's beliefs about the impact their cancer will have on their quality of life and ability to function (e.g. "My cancer will shorten my lifespan" or "I will experience symptoms from the cancer and/or side effects from the treatment of it").

Based on the results of this study and the mapping of the questions to the SRM, we theorize that the more severe the consequences of a patient's cancer are perceived to be, the more likely they are to actively

cope by continuing to use natural products. The results also indicate that the emotional dimension of the IR may be a factor in the behavior of natural product use by cancer patients. The aspect of the emotional dimension of the IR that was defined as a "desire to avoid suffering" was a composite of the survey questions "Relieve symptoms of cancer? (16-20_C03)", "Relieve side effects of chemotherapy treatment? (16-20_C04)", "Relieve side effects of radiation treatment? (16-20_C05)" and "Relieve side effects of hormonal treatment? (16-20_C06)?". This emotional IR dimension was found to be modestly positively (r_s=.157, p=.030) associated with natural product use. Interestingly, the emotional dimension of the IR that was defined as Fear was not associated with continuation of natural product use. The questions used to define the Fear dimension were "Help you live longer? (16-20_C02)", "Improve your quality of life? (16-20_C08)", "Prevent your cancer from recurring? (16-20_C10)", and "Have more control over your cancer care? (16-20_C09)". The wording of some of these questions (e.g. improve quality of life (16-20_C08), have more control (16-20_C09)) is comparatively more nebulous than the questions used in the Desire To Avoid Suffering dimension, which may have resulted in a weaker emotional connection. It may be that the suffering associated with the symptoms of cancer and the side effects of chemotherapy, radiation and hormonal treatment and the desire to avoid it

involves relatively strong and unique emotions that significantly impact a person's coping behaviors.

In conclusion, the results of our analysis supports the utility of the Self-Regulation (SRM) in understanding the factors that influence a patient's behaviors of adherence to natural product use and disclosure of natural product use. Through the use of SRM we are able to move beyond simply reporting what natural products cancer patients are using and how often they are disclosing their natural product to why they are engaging in those behaviors. We are able to investigate the cognitive and emotional factors that underlie a cancer patient's motivation to adopt and/or continue natural product use. The SRM is an improvement over other models of health behaviors because it emphasizes the dynamic nature of health behaviors, and incorporates both the cognitive and emotional representations that manifest when an individual is faced with a health threat. Additionally, the SRM encompasses the essential component of feedback, through the appraisal of coping dimension. The design of the current study limited the investigation of this important aspect of the SRM. Future research should build off of what we have learned with this study to investigate how the appraisal of the coping strategy of natural product use influences illness representations, coping strategies and in turn illness outcomes.

Disclosure of Natural Product Use

The second aim of this research was to identify patterns of disclosure of natural product use to healthcare providers and the covariates of that disclosure among CINJ patients.

Disclosure and patient characteristics. The investigations into disclosure of natural product by cancer patients to their CINJ oncologist was done using the subset of subjects who indicated a natural product as the one of the top five write-in options (n=193). Age was not found to be associated with disclosure of natural product use ($\chi^2 = 1.98$, P = .922). Additionally, when disclosure by those 70 years old (YO) (n = 32) or older was compared to participants 30 to 39 YO (n = 12) and 40 to 49 years old (n = 41), neither younger age group ($\chi^2 = 0.14$, P = .711) ($\chi^2 = 0.71$, P = .401) was found to be associated with disclosure of natural product use initiated post diagnosis.

SRM and disclosure of natural product use. When the SRM was applied to investigate the biopsychosocial underpinnings of natural product use disclosure behaviors, the results suggested a weak positive association between some of the cognitive dimensions and moderate to borderline strong negative association between lack of disclosure and emotional aspects of a patient's illness representation. Specifically, the Consequences (r_s=.214, p=.003) dimension of the IR was found to have a

weak positive relationship with the decision of a cancer patient to disclose their natural product use to their CINJ oncologist. According to our mapping of the questions onto the SRM, this connection may indicate that if a patient perceives their cancer as having severe consequences, they are more likely to disclose their natural product use to conventional healthcare providers. It is important to note that this was a weak relationship and thus additional research must be done to determine if this finding can be replicated in other samples.

Additionally, the Cure/Control cognitive dimension of the IR was also found to have a weak positive association with disclosure. In this context, the Cure/Control dimension is comprised of a patient's beliefs regarding whether strategies exist that are able to cure or control the illness. Thus, the more that a patient indicated that they perceived a natural product improved their quality of life, treated their cancer, and provided them more control over their cancer care, the more likely they were to disclose their natural product use to their oncologist.

The emotional illness representation for the investigation of disclosure of natural product use was defined as "non-negative" (neutral) and "negative" (scared, afraid) dimensions. The non-negative (neutral) emotional IR dimension was comprised of questions regarding disclosure that did not contain language that conveyed negative emotions specific to

a patient's CINJ oncologist (He or she never asked about? (16-20_D06), I did not think it was important for my oncologist to know about? (16-20_D09), I am unsure if NP is beneficial (16-20_D11)). This was in contrast to the negative (scared afraid) emotional IR dimension that was made up of questions that were based upon negative emotions specific to a patient's beliefs regarding their CINJ oncologist (I did not think he/she would understand about NP? (16-20_D07), My oncologist might not continue to be my provider (16-20_D10), I thought he/she would discourage or disapprove of NP? 16-20_D08)). Interestingly, both the negative (r_s=-.435, p<.001) and non-negative (r_s=-.548, p<.001) dimensions were found to have moderately negative associations with disclosure of natural product use. This indicates that emotions that relate to a patient's beliefs regarding their oncologist and emotions that more broadly relate to their natural product use are both important factors in a patient's disclosure behaviors.

In previous studies, patients have indicated anticipated negative responses, ambivalence from physicians, a physician's emphasis on scientific evidence, and patient's expectations of support and non-judgment from their doctors, as barriers to open communication regarding CAM use (Tasaki et al., 2002; Verhoef et al., 1999). In our study, patients who reported strong emotions about potentially losing a provider, anticipated disapproval from a provider, and/or indifference of a provider

to their natural product use were more likely not to disclose their use to their oncologist. These findings should be used in the improvement of provider-patient communication with the goal of increasing patient disclosure rates.

When the coping strategy of disclosure of natural product use was compared to a patient's illness outcome we found that disclosure was very weakly negatively correlated (r_s=-.173, p=.016) to a patient's overall illness outcome. The illness outcome was defined as a patient's self-reported cancer status and treatment status. When cancer status and treatment status were analyzed individually cancer status cancer status (r_s = -.149, p=.038), but not treatment status (r_s = -.131, p=.070) was found to be very weakly negatively associated with disclosure of natural product use. These associations are very weak, so any inferences made about them should be done cautiously, but they may indicate that a patient's cancer status (e.g. recurred, metastasized or cancer free) may be a factor in the behavior of not disclosing natural product use to one's oncologist, with lack of disclosure being linked to worse cancer outcomes.

We hypothesized that the frequency of disclosure of natural product use by cancer patients would be associated with various patient characteristics and the perceived/anticipated provider responses to the disclosure of natural product use to a patient's CINJ oncologist. This

hypothesis was based upon previous investigations into the disclosure of natural product use by patients to their physicians, that has consistently found low rates of disclosure, with only 28% to 53% of patients reporting to have shared their use with their doctors (David M Eisenberg et al., 2001; Rausch et al., 2011; Swarup et al., 2006). Patients have indicated a number of barriers to open communication regarding natural product use. These include anticipated negative responses and/or ambivalence from physicians. These negative expectations are set against their desire of support and non-judgment from their doctors (Tasaki et al., 2002; Verhoef et al., 1999). The findings of our study support these factors as being involved in the process of determining the behavior of a cancer patient not disclosing their natural product use to their oncologist. Moreover, we linked the disclosure of natural product use and relevant beliefs in a cancer patient population within the context of the theoretical framework of the Self-Regulation Model.

Conclusions and Implications

Multiple studies have reported on the prevalent use of natural products by cancer patients and have investigated important issues regarding drug-nutrient interactions, side effects of natural product use, and as a potential confounder in cancer clinical trials (P. M. Barnes, Bloom, B., Nahin, R. L., 2008; Chang et al., 2011; Frye et al., 2004;

Hlubocky et al., 2007; Komoroski et al., 2005; Lundahl et al., 2009;

McCune et al., 2004; Richardson et al., 2000; Sparreboom et al., 2004).

This widespread use is occurring while only 25% and 50% of cancer

patients are reporting disclosure of any CAM use to their doctors (Adler &

Fosket, 1999; Kappauf et al., 2000; Salmenperä et al., 2001).

To our knowledge no previous studies have focused on the

biopsychosocial basis for why patients are using natural products after

receiving a cancer diagnosis, or why they are often choosing to not

disclose their natural product use to their oncologists. This study aimed to

apply the Self-Regulation Model to understand the cognitive and

emotional dimensions that influence natural product use behaviors.

Additionally, we aimed to understand how a patient's coping strategy, in

terms of behaviors regarding natural product use and disclosure of natural

product use, related to their illness outcomes and appraisal of their

employed coping strategy.

The results of this study indicate that the coping behaviors of

natural product use and the disclosure of natural product use are

influenced by both cognitive and emotional dimensions of a patient's

illness representation (IR) of their cancer diagnosis. Specifically, the

cognitive illness representation dimension Consequences and emotional

dimension Desire to Avoid Suffering were significantly positively correlated

with continuation of natural product use that was initiated after a patient received a cancer diagnosis.

The Consequences dimension of the illness representation (IR) encompasses a patient's beliefs about the impact their cancer will have on their quality of life and ability to function (e.g. "My cancer will shorten my lifespan" or "I will experience symptoms from the cancer and/or side effects from the treatment of it"). We therefore theorize that the more severe the consequences of a patient's cancer are perceived to be, the more likely they are to actively cope by continuing to use natural products. The emotional dimension Desire to Avoid Suffering was comprised of questions specific to the negative emotions associated with cancer symptoms and the side effects of cancer treatment (radiation, chemotherapy, and hormonal treatment). Therefore, the more serious the cancer symptoms and side effects a patient experiences the more likely they are to continue using natural products.

With disclosure of natural product use, the cognitive IR dimensions Consequences and Cure/Control were significantly positively correlated with disclosure of natural product use. That is to say, that the stronger the perceived Consequences of the cancer (e.g. shorten lifespan, symptoms from the cancer, side effects from the cancer treatment) and perceived Cure/Control of the cancer (e.g. control of cancer care, prevent recurrence, quality of life improvement) the more likely a patient was to

disclose their natural product use to their CINJ oncologist. The emotional

dimensions of Non-Negative (neutral) and Negative (scared, afraid) were

significantly negatively correlated with disclosure of natural product use.

Meaning that the stronger a patient reported non-negative (neutral) (e.g.

oncologist didn't ask, not important for oncologist to know, unsure about

NP benefit) and negative emotions (scared, afraid) (e.g. oncologist would

not understand, oncologist would not approve, may not continue with

oncologist) the more likely they were to not disclose their natural product

use to their CINJ oncologist.

This study demonstrated how a theoretical model of health

behaviors and coping mechanisms, the Self-Regulation Model, can be

appropriately used to improve our understanding of the behaviors of

natural product use and disclosure of natural product use in cancer

patients. The findings of this study indicate the importance of healthcare

providers taking into account a patient's cognitive and emotional

perceptions when communicating with them regarding natural product

use. Taking these findings into account, healthcare providers should

inquire with their patients about their natural product use. Providers

inquires should occur in a manner that is non-judgmental and respects

their patient's beliefs and emotions regarding their healthcare decisions.

Additionally, we provide further evidence that sex and level of education

predict current use of natural products by cancer patients and that natural

product use initiated post diagnosis varied by cancer type (i.e. breast &

skin) (Table 7).

Limitations

This study was limited by its retrospective design and the survey

questions that were mapped to the SRM not being fully optimized for this

purpose. This limitation could be improved through the use of a

prospective design that utilized SRM tailored questions and/or validated

tools for understanding patient illness perceptions based on the SRM,

namely the Illness Perception Questionnaire (IPQ). The IPQ has been

extensively studied and has been found to be valid for use across

numerous illnesses and languages (Brink, Alsen, & Cliffordson, 2011;

Cavelti et al., 2012; Chen, Tsai, & Lee, 2008; Chilcot, Norton, Wellsted, &

Farrington, 2012; Giannousi, Manaras, Georgoulias, & Samonis, 2010;

Hallegraeff, van der Schans, Krijnen, & de Greef, 2013; Hvidberg, Jensen,

Pedersen, Aro, & Vedsted, 2014; Pertl, Hevey, Donohoe, & Collier, 2012).

However, the IPQ has not been specifically adapted for use with

individuals with cancer.

Additionally, the study was conducted at a single study site. This

limitation was partially mitigated by the fact that the study site was a

comprehensive cancer center, which included a wide array of cancer

types from a large sample. Beyond this, expanding future investigations to

multiple study sites would help improve generalizability. Finally, the cross-sectional design of the study limited the ability to track patients over time and monitor changes in natural product use, disclosure of natural product use, illnesses representations and outcomes. To do so, a longitudinal design would be required.

The expected response rate of this study was 50%. Thus, a strength of this study was the higher than expected response rate of 57%. Furthermore, this response rate was higher than the response rate of a similar published study (51%) that was completed at a different NCI-designated comprehensive cancer center (Richardson et al., 2000).

Generalizations

This study indicates that sex and level of education are associated with natural product use by this fairly large cohort of patients with a variety of cancers. However, neither of these variables were found to be associated with initiation of natural product use after diagnosis. This may have been due to the high rates of use in the sample population. It was the first study to apply the Self-Regulation Model to investigate the biopsychosocial underpinnings of the behaviors of natural product use and disclosure of natural product use by cancer patients. The Self-Regulation Model illness representation dimensions of Consequences, Fear, and Desire to Avoid Suffering have a weak positive relationship with

continuation of natural product use. The cognitive IR dimensions (Consequences, Cure/Control) have a weak positive association with disclosure of natural product use. The emotional IR dimensions of "Non-Negative" (neutral) and "Negative" (scared, afraid) have a moderately strong negative association with disclosure of natural product use. This suggests that use of natural products by cancer patients and the disclosure of their use to healthcare providers is influenced by both cognitive and emotional perceptions they have regarding their natural product use and decisions to disclosure their use to their providers. Additionally, it suggests that emotions relating to a patient's perceptions of their oncologists lack of understanding, support of, and interest in knowing about their patient's natural product use may play a role in their disclosure behaviors.

Unanswered Questions and Recommendations

This study contributed valuable evidence to the existing body of knowledge on important areas of cancer patient care. A few important questions remain unanswered. Among these is why emotional dimensions of a patient's illness representation are more strongly associated with their decision to disclose compared to cognitive dimensions. The relationship between illness representations and coping strategies is theorized to be causal, with the illness representations exacting an effect on coping

strategies in direct proportion to the level of severity that is perceived

(Leventhal et al., 1980). This research provides a starting point with

multiple IR dimensions (e.g. Consequences and Desire to Avoid Suffering)

having been found to be associated with NP use. Much more work must

be done to investigate this proposed cause-effect relationship between a

cancer patient's illness representations and their use of natural products

and the proportionality of it. Additionally, due to the data that was used for

the SRM analysis not being normally distributed, we were unable to

investigate the more complex relationships that exist within the SRM,

namely the relationship between the IR and illness outcomes. It is

theorized that a coping strategy, such as natural product use, acts as a

mediator of the effect that illness representations have on illness

outcomes (Baron & Kenny, 1986). We investigated some of the

relationships between the cancer patient's illness representations and two

coping strategies they engaged in, natural product use and disclosure of

natural product use. It was beyond the scope of this study to investigate if

a patient's illness representations affect the outcomes of their cancer

through their indirect relationship with their coping strategies.

This research was cross-sectional in design; thus it was only able

to explore relationships within the SRM at one moment of time. As the

SRM is dynamic in function, future research would benefit from

investigating how aspects of the SRM (illness representations, coping,

outcomes) change over time. Additional research must be conducted to confirm or refute the validity of this relationship between a patient's illness representations and their illness outcomes as they exist within the Self-Regulation Model. We recommend that an instrument specific to cancer be developed and validated. It would be comprised of questions uniquely designed for use with cancer patients and well suited for each aspect of the Self-Regulation Model. A cancer specific Illness Perception Questionnaire (IPQ) could be a starting point to achieving this.

Summary

Natural product (NP) use by this large surveyed population with a cancer diagnosis was high. Nearly three out of four respondents reported currently using one or more NPs, and three out of ten initiated NP use after receiving a cancer diagnosis. This research also found that female sex and higher level of education were associated with current NP use. No specific demographic variables were found to be associated with NP use that was initiated after a person received a cancer diagnosis, with high prevalence of use being found across demographic groups. The majority of people who initiated CAM use after diagnosis indicated at least one NP

as among the top five therapies they found to be most beneficial. Green tea (EGCG, pills), multivitamins/mineral, and selenium were the most common NPs these cancer patients found to provide the most benefit.

This first ever investigation utilizing the Self-Regulation Model of health behavior (SRM) (Leventhal et al., 1997; Leventhal et al., 1980; Leventhal et al., 1984) to understand the biopsychosocial basis of NP use and disclosure of NP use by cancer patients found differences in multiple cognitive and emotional dimensions of a person's illness representation, including the perceived consequences of their cancer, the desire to avoid the suffering associated with their cancer, and the level of perceived control they had over their cancer. These differences in illness representation were associated with variations in the health behaviors or coping strategies that were employed. Additionally, an individual's expectations of how their oncologist would respond to their disclosure of NP use strongly affected the disclosure of NP use (complete, partial, or non-disclosure). It would be worthwhile for healthcare providers to be aware of our findings for several reasons. For example, healthcare providers would benefit from knowing that people who believe their cancer is more severe and have a stronger emotional desire to avoid suffering are more likely to continue the NP use they started after being diagnosed with cancer. Additionally, individuals who believe their cancer is more severe, and individuals that believe they have more control over their cancer, are

more likely to disclose their NP use. Conversely, it would be useful for

healthcare providers to know that those cancer patients who have strong

negative emotions pertaining to what they anticipate their oncologist's

response to their disclosure will be, are less likely to disclose their use. A

lower likelihood of disclosure was also found to occur among people who

have strong negative emotions associated with their NP use generally.

This included the emotions pertaining to believing that is was not

important for their oncologist to know about their NP use and a high level

of uncertainty as to whether their NP use was beneficial. We also found

that a person's lack of disclosure of their NP use to their oncologist was

associated with worse cancer status (metastasized or recurred vs. cancer

free). This valuable information could be used by healthcare providers to

raise the quality of patient care by improving provider-patient

communication. Our results indicate that healthcare providers who initiate

an open, non-judgemental, dialogue with patients regarding their NP use

will likely be better informed of their patients NP use. Providers would do

well to emphasize to patients and their families why disclosing their NP

use is important for their care to be of the highest quality possible.

Patients and families members would gain from providers informing them

about how NPs can interact with conventional cancer therapies (e.g.

chemotherapy, radiation), potentially making conventional treatments less

effective and causing more harm. Additionally, those diagnosed with

cancer would benefit from receiving education about the quality issues (e.g. contamination, adulteration) that may potentially exist with the NPs they are using. Healthcare provider initiated conversations about these issues are most useful when they occur in a manner which is non-judgmental and respects a patient's individual beliefs and personal healthcare decisions. The findings of this study could also increase healthcare providers' awareness of their patients' potential NP usage and motivations for such use. This research also demonstrates, for the first time, the utility of the SRM for investigating and beginning to understand the behaviors of NP use and disclosure of NP use by people diagnosed with cancer. Thereby supporting the use of the SRM by researchers in future studies of these important topics.

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Appendix A

Self-Regulation Model Construct Development and Computation

Illness Representation (Cognitive Dimensions)

- **Identity** - This dimension used one survey item to assess how a patient identified their cancer diagnosis. Question 22 of the survey had 27 primary cancer types that could be selected and one option for a participant to write in their cancer type if it was not present. For analysis primary cancer type variable was recoded into three new variables of #1 breast cancer (1), all other cancers (0), #2 prostate cancer (1) all other cancers (0), and #3 all other cancer (1), and prostate and breast cancer (0).

- **Timeline** - This dimension used one survey item to assess a patient's perceptions about the course of their illness. Question 21 asked for the date of initial diagnosis. For analysis these dates were recoded into months since diagnosis.

- **Consequences** - This dimension used five survey items to assess a patient's beliefs about the impact the illness will have on their quality of life and ability to function. The questions that were mapped to this dimension were: Help you live longer? (16-20_C02), Relieve symptoms of cancer? (16-20_C03), Relieve side effects of chemotherapy treatment? (16-20_C04), Relieve side effects of radiation treatment? (16-20_C05), and Relieve side effects of hormonal treatment? (16-20_C06). Each of these questions was coded 0 through 5 for Not applicable, Not at all, a little bit, somewhat, quite a bit, and completely. Each of these questions could have been answered 0 to 5 times depending on the number of natural products a cancer patient wrote-in as one of the top five CAM therapies they found to be the most effective. The value of this variable was the combined sum of the included survey questions divided by the number of write-in therapies out of five that were natural products.

- **Cure/Control** - This dimension used six survey items to assess a patient's beliefs regarding whether strategies exists that are able to cure or control the illness. The questions that were mapped to this dimension were: Have more control over your cancer care? (16-20_C09), Help you live longer? (16-20_C02), Relieve symptoms of

cancer? (16-20_C03), Treat your cancer? (16-20_C01), Prevent

your cancer from recurring? (16-20_C10), and Improve your quality

of life? (16-20_C08). Each of these questions was coded 0 through

5 for Not applicable, Not at all, a little bit, somewhat, quite a bit, and

completely. Each of these questions could have been answered 0

to 5 times depending on the number of natural products a cancer

patient wrote-in as one of the top five CAM therapies they found to

be the most effective. The value of this variable was the combined

sum of the included survey questions divided by the number of

write-in therapies out of five that were natural products.

Illness Representation (Emotional Dimensions)

- **Fear (Natural Product Use)** - This dimension used four survey

  items to assess the distressing emotion aroused by the patient's

  perception of a threat to their health (cancer). The questions that

  were mapped to this dimension were: Help you live longer? (16-

  20_C02), Improve your quality of life? (16-20_C08), Prevent your

  cancer from recurring? (16-20_C10), and Have more control over

  your cancer care? (16-20_C09). Each of these questions was

  coded 0 through 5 for Not applicable, Not at all, a little bit,

  somewhat, quite a bit, and completely. Each of these questions

could have been answered 0 to 5 times depending on the number

of natural products a cancer patient wrote-in as one of the top five

CAM therapies they found to be the most effective. The value of

this variable was the combined sum of the included survey

questions divided by the number of write-in therapies out of five that

were natural products.

- **Desire to avoid suffering (Natural Product Use)** - This dimension

  used four survey items to assess the emotion/desire to avoid

  feeling pain or distress aroused by the patient's perception of a

  threat to their health (cancer). The questions that were mapped to

  this dimension were: Relieve symptoms of cancer? (16-20_C03),

  Relieve side effects of chemotherapy treatment? (16-20_C04),

  Relieve side effects of radiation treatment? (16-20_C05), and

  Relieve side effects of hormonal treatment? (16-20_C06). Each of

  these questions was coded 0 through 5 for Not applicable, Not at

  all, a little bit, somewhat, quite a bit, and completely. Each of these

  questions could have been answered 0 to 5 times depending on the

  number of natural products a cancer patient wrote-in as one of the

  top five CAM therapies they found to be the most effective. The

  value of this variable was the combined sum of the included survey

questions divided by the number of write-in therapies out of five that were natural products.

- **Non-negative (neutral) (Disclosure)** - This dimension used three survey items to assess the non-negative or neutral emotions aroused by the patient's perception of a threat to their health (cancer). The questions that were mapped to this dimension were: He or she never asked about? (16-20_D06), I did not think it was important for my oncologist to know about? (16-20_D09), and I am unsure if NP is beneficial (16-20_D11). Each of these questions was coded 0 through 5 for Not applicable, Not at all, a little bit, somewhat, quite a bit, and completely. Each of these questions could have been answered 0 to 5 times depending on the number of natural products a cancer patient wrote-in as one of the top five CAM therapies they found to be the most effective. The value of this variable was the combined sum of the included survey questions divided by the number of write-in therapies out of five that were natural products.

- **Negative (scared, afraid) (Disclosure)** - This dimension used three survey items to assess the negative emotions characterized as being scared and/or afraid aroused by the patient's perception of

a threat to their health (cancer). The questions that were mapped to this dimension were: I did not think he/she would understand about NP? (16-20_D07), My oncologist might not continue to be my provider (16-20_D10), and I thought he/she would discourage or disapprove of NP? 16-20_D08). Each of these questions was coded 0 through 5 for Not applicable, Not at all, a little bit, somewhat, quite a bit, and completely. Each of these questions could have been answered 0 to 5 times depending on the number of natural products a cancer patient wrote-in as one of the top five CAM therapies they found to be the most effective. The value of this variable was the combined sum of the included survey questions divided by the number of write-in therapies out of five that were natural products.

Coping Strategy

- **Continuation of Natural Product Use** - This dimension used one survey item to assess continuation of natural product use that was initiated after a patient received a cancer diagnosis. The question that was mapped to this dimension was: Are you currently still using? (16-20_B04). This question was coded 0 for No and 1 for Yes. This question could have been answered 0 to 5 times

depending on the number of natural products a cancer patient
wrote-in as one of the top five CAM therapies they found to be the
most effective. The value of this variable was the number of natural
products reported to have been continued divided by the number of
natural products written in as one of the top five therapies,
multiplied by 100. This number could range from 0 to 100
representing 0% to 100% continuation of natural product use. For
example, a cancer patient could have reported 5 natural products
as their top five therapies and reported that they continued 4 out of
5 (4/5=0.8x100) or 80% continuation of natural product use.

- **Disclosure of Natural Product Use -** This dimension used one
  survey item to assess disclosure of natural product use that was
  initiated after a patient received a cancer diagnosis. The question
  that was mapped to this dimension was: Did you mention you were
  using the natural product to your oncologist at CINJ? (16-20_D).
  This question was coded 0 for No and 1 for Yes. This question
  could have been answered 0 to 5 times depending on the number
  of natural products a cancer patient wrote-in as one of the top five
  CAM therapies they found to be the most effective. The value of
  this variable was the number of natural products reported to have
  been disclosed divided by the number of natural products written in

as one of the top five therapies, multiplied by 100. This number

could range from 0 to 100 representing 0% to 100% disclosure of

natural product use. For example, a cancer patient could have

reported 5 natural products as their top five therapies and reported

that they disclosed 4 out of 5 (4/5=0.8x100) or 80% disclosure of

natural product use.

Illness Outcome

- **Cancer Status** - This aspect of the illness outcomes used three

  survey questions to assess the status of a patient's cancer. The

  questions that were mapped to this aspect of the illness dimension

  were: Has your cancer recurred? (23), Has your metastasized?

  (24), and Are you cancer free now? (25). Questions 23 and 24 were

  coded -1 for Yes and 1 for No and 0 for I don't know. Question 25

  was coded 1 for Yes, -1 for No and 0 for I don't know. The value of

  this variable was the sum of these three questions.

- **Treatment Status -** This aspect of the illness outcomes used one

  survey question to assess the status of a patient's treatment. The

  questions that was mapped to this aspect of the illness dimension

  was: Are you currently receiving any treatment for your cancer?

(Mark all that apply). A selection of Chemotherapy, Radiation, Surgery, Research study/Clinical Trial were each coded as -1. A selection of None was coded as 0. The value of this variable was the sum of all of the possible treatment status options.

- **Illness Outcome** - The Cancer Status variable and the Treatment Status variable were added together to create the Illness Outcome variable.

Appraisal of Coping Strategy

- **Appraisal of Coping Strategy** - This dimension used six survey items to assess the patient's appraisal of the coping strategies investigated in this study, those being continuation of natural product use or not and disclosure of natural product use or not. The questions that were mapped to this dimension were: Improve your quality of life? (16-20_C08), Relieve symptoms and side effects? (16-20_C03), Help you live longer? (16-20_C02), Treat your cancer? (16-20_C01), Prevent your cancer from recurring? (16-20_C10), and Was this therapy the most beneficial to you? (16-20_A). All but one of these questions was coded 0 through 5 for Not applicable, Not at all, a little bit, somewhat, quite a bit, and completely. The question, Was this therapy the most beneficial to

you? (16-20_A), was coded as 1 for Yes and 0 for No. Each of

these questions could have been answered 0 to 5 times depending

on the number of natural products a cancer patient wrote-in as one

of the top five CAM therapies they found to be the most effective.

The value of this variable was the combined sum of the included

survey questions divided by the number of write-in therapies out of

five that were natural products.

Appendix A

The Cancer Institute of New Jersey™

A Study of the Prevalence of Complementary and Alternative Medicine Use and Disclosure to Healthcare Providers in a Comprehensive Cancer Center

DIRECTIONS: Some patients use complementary or alternative therapies to treat cancer or to cope with issues related to cancer. We are interested in learning more about your use of complementary/alternative therapies. Please answer all of the following questions by filling in the appropriate boxes.

Please provide the following information:

1. What is your gender?

☐ Male
☐ Female

2. Are you: (Mark one or more to indicate what race you consider yourself)

☐ Hispanic/ Latino
☐ White
☐ Black/ African American
☐ American Indian/ Alaska Native
☐ Native Hawaiian
☐ Asian Indian
☐ Chinese
☐ Japanese
☐ Filipino
☐ Korean
☐ Vietnamese
☐ Other Asian
☐ Something else (Please specify) _____

3. Which of the following best describes you?

☐ Married
☐ Divorced
☐ Widowed
☐ Separated
☐ Single/ Never married
☐ Not married but living with partner
☐ Other (Please specify) _____

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4. What is the highest grade or level of education you completed?

☐ Some high school
☐ High school diploma, GED, or equivalent
☐ Technical school
☐ Associate degree
☐ Some college
☐ Bachelors degree
☐ Masters degree
☐ Doctoral degree

5. What is your date of birth?

_____ / _____ / _____

6. Have you ever received a cancer diagnosis?

YES NO
☐   ☐

If NO, complete columns A, B and C for Questions 7-14 then skip to question 27.

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Please answer each of the following questions by marking the circle Y for YES or N for NO.

	A Have you ever heard of?	B Have you ever used?	C Are you currently using?	D Did you start using only after your cancer diagnosis?

7. Special Diet:

	A	B	C	D
Lacto-Ovo Vegetarian (no meat)	Y N	Y N	Y N	Y N
Vegan (no meat, dairy, eggs)	Y N	Y N	Y N	Y N
Macrobiotic	Y N	Y N	Y N	Y N
Gerson's Diet Treatment	Y N	Y N	Y N	Y N
Other special diet (low fat, Low carbohydrate) (Please specify): ___	Y N	Y N	Y N	Y N

8. Psychotherapy:

	A	B	C	D
Social Worker	Y N	Y N	Y N	Y N
Psychologist	Y N	Y N	Y N	Y N
Psychiatrist	Y N	Y N	Y N	Y N
Support Group	Y N	Y N	Y N	Y N
Other psychotherapy (Please specify): ___	Y N	Y N	Y N	Y N

9. Movement/Physical Therapy:

	A	B	C	D
Exercise	Y N	Y N	Y N	Y N
Yoga	Y N	Y N	Y N	Y N
Tai chi	Y N	Y N	Y N	Y N
Chi Gong	Y N	Y N	Y N	Y N
Chiropractic/Osteopathic	Y N	Y N	Y N	Y N
Massage	Y N	Y N	Y N	Y N
Other Movement/Physical Therapy (Please specify): ___	Y N	Y N	Y N	Y N

10. Mind/Body

	A	B	C	D
Imagery/visualization	Y N	Y N	Y N	Y N
Hypnosis	Y N	Y N	Y N	Y N
Meditation	Y N	Y N	Y N	Y N
Biofeedback	Y N	Y N	Y N	Y N
Massage Therapy	Y N	Y N	Y N	Y N
Reiki	Y N	Y N	Y N	Y N
Energy Healing/Therapeutic touch	Y N	Y N	Y N	Y N
Journaling	Y N	Y N	Y N	Y N
Music Therapy	Y N	Y N	Y N	Y N
Other Mind/Body Therapy (Please specify): ___	Y N	Y N	Y N	Y N

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	A Have you ever heard of?	B Have you ever used?	C Are you currently using?	D Did you start using only after your cancer diagnosis?

11. Spiritual Practices

	A	B	C	D
Prayer (by *you*)	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Prayer/spiritual healing (by *others*)	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Other Spiritual Practices (Please specify): _____	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N

12. Dietary Supplements

	A	B	C	D
Multivitamins/mineral	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Vitamin E	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Vitamin C	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Soy supplement (isoflavones, pills)	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Echinacea	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Garlic (pill form)	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Selenium	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Saw Palmetto	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Green tea (EGCG, pills)	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Coenzyme Q10	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
St. John's Wort	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Melatonin	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Essiac	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Mistletoe (Iscador)	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Milk Thistle	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
PC SPES	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Laetrile	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Shark cartilage	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Bovine Cartilage (Catrix)	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Other Dietary Supplements (Please specify): _____	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N

13. Other Therapies:

	A	B	C	D
Homeopathy	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Ayurvedic remedies	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Bioelectricmagnetic therapies	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Acupuncture	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N
Folk Remedies (Please specify): _____	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N

14. Other :

	A	B	C	D
Other: (Please specify): _____	☐Y ☐N	☐Y ☐N	☐Y ☐N	☐Y ☐N

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15. For questions 16 through 20 on the following pages, please list the therapies that you indicated in *Column D* that you had *started using only after your cancer diagnosis.*

- *If you used more than 5 therapies please choose the five that you feel provided the most benefit.*

- *Place a star (*) next to the therapy you feel was the most beneficial to you.*

1. _____

2. _____

3. _____

4. _____

5. _____

- *If you did not list any therapies above please skip to question 21.*

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16. For the therapy that you wrote in Blank # 1 _____

When did you stop using the therapy #1?

	YES	NO
Before your cancer treatment began?		
During cancer treatment?		
After completing cancer treatment?		
Are you currently still using #1?		

If you used the therapy listed in #1 for the following, how did it work?

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Treat your cancer?						
Help you live longer?						
Relieve symptoms of cancer?						
Relieve side effects of chemotherapy treatment?						
Relieve side effects of radiation treatment?						
Relieve side effects of hormonal treatment?						
Improve your immune system?						
Improve your quality of life?						
Have more control over your cancer care?						
Prevent your cancer from recurring?						
Reasons not related to your cancer?						
Other reasons (please list)_____						

Did you mention that you were using the therapy listed in #1 to your oncologist at CINJ?

	YES	NO

If YES, how did your oncologist at CINJ respond? (Mark all that apply)

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Encouraged me to continue using #1?						
Encouraged me to stop using #1?						
Warned me of the risks of #1?						
Encouraged me to continue using #1?						
Was neutral about me using #1?						

If NO, what are your reasons for not telling your oncologist at CINJ about using #1? (Mark all that apply)

He or she never asked about #1?

I did not think he/she would understand about #1?

I though he/she would discourage or disapprove of #1?

I did not think it was important for my oncologist to know about #1?

My oncologist might not continue to be my provider?

I am unsure if #1 is/are beneficial?

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Did you mention that you were using the therapy listed in # to:		
	YES	NO
Your primary care physician?		
Your oncologist (not at CINJ)?		
Your nurse practitioner (APN) at CINJ?		
Your treatment nurse at CINJ?		
Your registered dietitian at CINJ?		
Your pharmacist at CINJ?		
Someone else at CINJ?		
(please list) _____		

Did you experience any negative effects of #?

Not at all   a little bit   somewhat   quite a bit   completely

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17. For the therapy that you wrote in Blank # 2 _____

When did you start using the therapy #2?

	YES	NO
Before your cancer treatment began?		
During cancer treatment?		
After completing cancer treatment?		
Are you currently still using #2?		

If you used the therapy listed in #2 for the following, how did it work?

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Treat your cancer?						
Help you live longer?						
Relieve symptoms of cancer?						
Relieve side effects of chemotherapy treatment?						
Relieve side effects of radiation treatment?						
Relieve side effects of hormonal treatment?						
Improve your immune system?						
Improve your quality of life?						
Have more control over your cancer care?						
Prevent your cancer from recurring?						
Reasons not related to your cancer?						
Other reasons (please list)						

Did you mention that you were using the therapy listed in #2 to your oncologist at CINJ?

	YES	NO

If YES, how did your oncologist at CINJ respond? (Mark all that apply)

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Encouraged me to continue using #2?						
Encouraged me to stop using #2?						
Warned me of the risks of #2?						
Encouraged me to continue using #2?						
Was neutral about me using #2?						

If NO, what are your reasons for not telling your oncologist at CINJ about using #2? (Mark all that apply)

He or she never asked about #2?
I did not think he/she would understand about #2?
I though he/she would discourage or disapprove of #2?
I did not think it was important for my oncologist to know about #2?
My oncologist might not continue to be my provider?
I am unsure if #2 is/are beneficial?

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Did you mention that you were using the therapy listed in 42 to:

	YES	NO
Your primary care physician?		
Your oncologist (not at CINJ)?		
Your nurse practitioner (APN) at CINJ?		
Your treatment nurse at CINJ?		
Your registered dietitian at CINJ?		
Your pharmacist at CINJ?		
Someone else at CINJ?		

(please list) _____

Did you experience any negative effects of 42?

Not at all   a little bit   somewhat   quite a bit   completely

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18. For the therapy that you wrote in Blank # 3 _____

When did you start using the therapy #3?

	YES	NO
Before your cancer treatment began?		
During cancer treatment?		
After completing cancer treatment?		
Are you currently still using #3?		

If you used the therapy listed in #3 for the following, how did it work?

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Treat your cancer?						
Help you live longer?						
Relieve symptoms of cancer?						
Relieve side effects of chemotherapy treatment?						
Relieve side effects of radiation treatment?						
Relieve side effects of hormonal treatment?						
Improve your immune system?						
Improve your quality of life?						
Have more control over your cancer care?						
Prevent your cancer from recurring?						
Reasons not related to your cancer?						
Other reasons (please list) _____						

Did you mention that you were using the therapy listed in #3 to your oncologist at CINJ?

	YES	NO

If YES, how did your oncologist at CINJ respond? (Mark all that apply)

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Encouraged me to continue using #3?						
Encouraged me to stop using #3?						
Warned me of the risks of #3?						
Encouraged me to continue using #3?						
Was neutral about me using #3?						

If NO, what are your reasons for not telling your oncologist at CINJ about using #3? (Mark all that apply)

He or she never asked about #3?
I did not think he/she would understand about #3?
I though he/she would discourage or disapprove of #3?
I did not think it was important for my oncologist to know about #3?
My oncologist might not continue to be my provider?
I am unsure if #3 is/are beneficial?

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Did you mention that you were using the therapy listed in #5 to:

	YES	NO
Your primary care physician?		
Your oncologist (not at CINJ)?		
Your nurse practitioner (APN) at CINJ?		
Your treatment nurse at CINJ?		
Your registered dietitian at CINJ?		
Your pharmacist at CINJ?		
Someone else at CINJ?		
(please list) _____		

Did you experience any negative effects of #5?

Not at all   a little bit   somewhat   quite a bit   completely

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19. For the therapy that you wrote in Blank # 4 _____

When did you start using the therapy #4?

	YES	NO
Before your cancer treatment began?		
During cancer treatment?		
After completing cancer treatment?		
Are you currently still using #4?		

If you used the therapy listed in #4 for the following, how did it work?

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Treat your cancer?						
Help you live longer?						
Relieve symptoms of cancer?						
Relieve side effects of chemotherapy treatment?						
Relieve side effects of radiation treatment?						
Relieve side effects of hormonal treatment?						
Improve your immune system?						
Improve your quality of life?						
Have more control over your cancer care?						
Prevent your cancer from recurring?						
Reasons not related to your cancer?						
Other reasons (please list)_____						

Did you mention that you were using the therapy listed in #5 to your oncologist at CINJ?

	YES	NO

If YES, how did your oncologist at CINJ respond? (Mark all that apply)

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Encouraged me to continue using #4?						
Encouraged me to stop using #4?						
Warned me of the risks of #4?						
Encouraged me to continue using #4?						
Was neutral about me using #4?						

If NO, what are your reasons for not telling your oncologist at CINJ about using #4? (Mark all that apply)

He or she never asked about #4?
I did not think he/she would understand about #4?
I though he/she would discourage or disapprove of #4?
I did not think it was important for my oncologist to know about #4?
My oncologist might not continue to be my provider?
I am unsure if #4 is/are beneficial?

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Did you mention that you were using the therapy listed in #4 to:		
	YES	**NO**
Your primary care physician?		
Your oncologist (not at CINJ)?		
Your nurse practitioner (APN) at CINJ?		
Your treatment nurse at CINJ?		
Your registered dietitian at CINJ?		
Your pharmacist at CINJ?		
Someone else at CINJ?		
(please list) _____		

Did you experience any negative effects of #4?				
Not at all	a little bit	somewhat	quite a bit	completely

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20. For the therapy that you wrote in Blank # 5 _____

When did you start using the therapy #5?

	YES	NO
Before your cancer treatment began?		
During cancer treatment?		
After completing cancer treatment?		
Are you currently still using #5?		

If you used the therapy listed in #5 for the following, how did it work?

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Treat your cancer?						
Help you live longer?						
Relieve symptoms of cancer?						
Relieve side effects of chemotherapy treatment?						
Relieve side effects of radiation treatment?						
Relieve side effects of hormonal treatment?						
Improve your immune system?						
Improve your quality of life?						
Have more control over your cancer care?						
Prevent your cancer from recurring?						
Reasons not related to your cancer?						
Other reasons (please list)_____						

Did you mention that you were using the therapy listed in #5 to your oncologist at CINJ?

	YES	NO

If YES, how did your oncologist at CINJ respond? (Mark all that apply)

	Not at all	a little bit	somewhat	quite a bit	completely	not applicable
Encouraged me to continue using #5?						
Encouraged me to stop using #5?						
Warned me of the risks of #5?						
Encouraged me to continue using #5?						
Was neutral about me using #5?						

If NO, what are your reasons for not telling your oncologist at CINJ about using #5? (Mark all that apply)

He or she never asked about #5?
I did not think he/she would understand about #5?
I though he/she would discourage or disapprove of #5?
I did not think it was important for my oncologist to know about #5?
My oncologist might not continue to be my provider?
I am unsure if #5 is/are beneficial?

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Did you mention that you were using the therapy listed in #5 to:

	YES	NO
Your primary care physician?		
Your oncologist (not at CINJ)?		
Your nurse practitioner (APN) at CINJ?		
Your treatment nurse at CINJ?		
Your registered dietitian at CINJ?		
Your pharmacist at CINJ?		
Someone else at CINJ?		
(please list) _____		

Did you experience any negative effects of #5?

Not at all   a little bit   somewhat   quite a bit   completely

21. What was the date of your initial diagnosis of cancer?

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22. Where is your primary cancer? (Mark all that apply)

	YES	NO		YES	NO
Anus			Ovary		
Bladder			Pancreas		
Bone			Penis		
Brain/spinal cord			Prostate		
Breast			Skin (Melanoma)		
Cervix/vagina			Skin (Non-melanoma)		
Colon/rectal			Stomach		
Esophagus			Soft tissue (muscle, fat, etc.)		
Head/neck			Testicle		
Kidney			Thyroid		
Leukemia			Unknown Primary		
Liver/Bile duct			Uterus		
Lung			Other (specify below)		
Lymphoma (Hodgkin's)					
Lymphoma (Non-Hodgkin's)					

	YES	NO	I DON'T KNOW
23. Has the cancer recurred?			
24. Has the cancer metastasized?			
25. Are you free of cancer now?			

26. Are you currently receiving any treatment for your cancer? (Mark all that apply)

☐ Chemotherapy
☐ Radiation
☐ Surgery
☐ Research study/ Clinical Trial
☐ None
☐ Other _____

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27. Has anyone ever advised you on which complementary/alternative therapies to use?

	YES	NO
Family/friend		
Cancer patient		
Doctor		
Oncology Nurse		
Primary Care Nurse		
Social worker/Psychologist		
Alternative Medicine Practitioner		
Books/magazines/newsletter		
Internet		
Nutritionist/Registered dietitian		
Other: (please specify)_____		

Reminder, all of the information obtained will be kept strictly confidential.
28. For classification purposes only, what was your total yearly household income before taxes in 2004?

☐ $12,500 - $19,000
☐ $19,000 - $19,999
☐ $20,000 - $39,999
☐ $40,000 - $59,999
☐ $60,000 - $79,999
☐ $80,000 – $99,000
☐ $100,000 or more
☐ Don't know
☐ Prefer not to say

Thank you for taking the time to complete this survey.