

2015

Complementary Alternative Medicine: Awareness and Perceptions of Health Care Providers Who Provide Systemic Lupus Care

Carmen Ionie Bartley
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Walden University

College of Health Sciences

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Walden University
2015

Abstract

Complementary Alternative Medicine: Awareness and Perceptions of Health Care

Providers Who Provide Systemic Lupus Care

by

Carmen Ionie Bartley

MSN/IH, University of Phoenix, 2006

BSN, St. Joseph's College, 1996

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

May 2015

Abstract

The purpose of this study was to explore healthcare providers' awareness and perceptions of complementary and alternative medicine (CAM) use in providing systemic lupus erythematosus (SLE) care. This phenomenological study was built upon existing research indicating SLE patients' need to foster better communication about CAM use.

Participants were recruited from the Long Island Rheumatological Clinic in the State of New York. Individual in-depth semistructured interviews were conducted to explore the awareness and perceptions of a purposive sample of 10 healthcare providers who care for patients with SLE. Transcripts were analyzed, and categorical themes were developed.

Guided by the use of the shared decision-making model and self-efficacy theory, 5 themes emerged: varied knowledge and experiences with CAM varied, participants' personal experience and perceived effectiveness led to patient guidance and advice, perceived benefits of CAM use, participants as patient advocates, and initiatives for further research. Study findings revealed that the knowledge, attitudes, and beliefs of health care providers regarding the use of CAM shed light on the importance of health promotion to guide future research, both within and beyond CAM. Strategies are recommended to increase awareness and understanding of CAM use through proper education and advocacy. This research may lead to positive social change in that providers may use the information in this research to break down barriers to communication between patients and professionals regarding CAM usage.

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Dedication

This work is dedicated to my daughter, Danielle, whose presence in my life has brought me enormous joy and a deep sense of purpose. You have inspired me to be a positive role model. Thanks for being patient and understanding, and for putting up with me through the entire journey from start to finish. My hope is that you pursue your dreams and follow them to the highest peak possible, no matter how hard or difficult the journey.

To Leslie, my husband, even though you have not grasped the magnitude of the journey I undertook, you have helped me navigate a world that was challenging for me by encouraging the qualities in me that would help me accomplish this task.

I dedicate this dissertation to my parents, the late Daphne Rebecca Bartley and my only remaining parent, Elvis Bartley, who at an early age instilled in me the purpose and value of education. Thanks for the great support in my education. This educational journey is a true blessing, and God be praised.

To my siblings, I also dedicate this dissertation to you. I know through your unspoken words you had my back. For that, I want to say thanks for the sometimes simple questions asked: How it is going, and where are you now? Have you heard back from your chair yet? It meant a lot and reconfirmed that strength is in numbers.

Although this success was achieved by me, it was not completed in isolation, and I will be forever grateful for those who have provided me with the support I needed along the journey. Your constant prayers and encouragement gave the assurance that the task at hand was conceivable.

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Chapter 1: Introduction to the Study

Background

The use of complementary and alternative medicine (CAM) as a healthcare treatment modality for chronic diseases has been accepted in many branches of conventional medicine (Barnes, Bloom, & Nahin, 2008; Bishop, Yardley, & Lewith, 2007; Ho, Jones, & Gan, 2009; Mehta, Gardiner, Phillips, & McCarthy, 2008; Rosenberg et al., 2008). However, there is a scarcity of studies that examine CAM use in the treatment of systemic lupus erythematosus (SLE). The purpose of this qualitative phenomenological study was to explore the awareness and perceptions of rheumatologist healthcare providers of CAM in providing SLE care.

In 1993, the *New England Journal of Medicine* published the first formal national study documenting the use of unconventional therapies by adults in the United States (Eisenberg et al., 1993). The landmark study was undertaken with the awareness that the medical community could no longer ignore the growing number of Americans turning to therapies that were not part of conventional Western medicine. The study also demonstrated that CAM users constituted a much larger population segment than the researchers had assumed. A subsequent study disclosed, that from 1990 to 1997 the use of CAM became increasingly prevalent (Eisenberg et al., 1998). In October 1998, the National Institutes of Health (NIH) created the National Center for Complementary and Alternative Medicine (NCCAM), dedicated to conducting scientifically rigorous study of complementary and alternative therapies, training CAM researchers, and disseminating information to professionals and the general public (NCCAM, 2009).

CAM embodies diversity, as conventional medicine does, and should not be seen as homogeneous but heterogeneous (Bishop, Yardley, & Lewith, 2007). Individuals managing chronic health conditions are consistently found to have high rates of CAM use (Barnes, Bloom, & Nahin, 2008; Ho, Jones, & Gan, 2009; Mehta, Gardiner, Phillips, & McCarthy, 2008; Rosenberg et al., 2008). The potential role of CAM has been recognized as an important resource in public health settings (Burke et al., 2005).

Many individuals with SLE have used CAM for treating specific symptoms as well as managing their general health (Alvarez-Nemegyei & Bautista-Botello, 2009; Goh et al., 2003; Leong et al., 2003; Moore et al., 2000). Unmet needs related to physical symptoms, activities of daily living, and psychological and social support are a persistent problem for people with SLE (Danoff-Burg & Friedberg, 2009; Moses et al., 2008). Various types of CAM therapies have the capacity to meet those needs, directly or indirectly (Danoff-Burg & Friedberg, 2009).

As CAM has gained popularity with the general public, health care professionals have gradually become more accepting of CAM therapies. Medical students express interest in learning more about CAM (Nedrow et al., 2007). Nurses perceive the integration of CAM into professional practice as highly compatible with the holistic philosophy of nursing (King, Pettigrew & Reed, 2000; Rojas-Cooley & Grant, 2006; Tracy et al., 2005). Growing numbers of nurses and other conventional health care professionals are exploring CAM therapies for their own use as well as for their patients (Dayhew et al., 2009; Lindquist, Tracy, Savik, & Watanuki, 2005). At the same time,

many physicians try to discourage their patients from using CAM due to questions about the safety and efficacy of the treatments (Milden & Stotolis, 2004).

Research suggests that negative or skeptical attitudes on the part of health care professionals do not discourage patients from using CAM; they simply discourage them from disclosing their CAM use (Shelley, Sussman, Williams, Segal, & Crabtree, 2009). Most patients with health conditions use CAM in combination with conventional medical treatments, but do not reveal their CAM use to their providers (Eisenberg et al., 1993; Eisenberg et al., 1998; Mehta et al., 2008; Saydah & Eberhardt, 2006). Paradoxically, lack of communication about CAM use, rather than CAM use per se, can have harmful effects (Murtaza, Singh, Dimitrov, & Soni, 2001). For example, herbal and nutritional supplements—which are extremely popular—can contain substances that aggravate disease symptoms or have adverse effects when taken together with certain medications. In the present state of Western medicine, CAM use for individuals with chronic conditions can be a double-edged sword. Properly integrated into a therapeutic regimen, CAM therapies can produce benefits including pain management, symptom reduction, stress reduction, higher energy, and enhanced quality of life (Shirato, 2005). On the other hand, certain CAM therapies can have negative consequences of which the patient may be unaware. Medical and nursing professionals acknowledge their own lack of knowledge and information about CAM (Murtaza et al., 2001).

CAM has attained a prominent place in oncology research and practice (Rojas-Cooley & Grant, 2006; Wang & Yates, 2006). Individuals with rheumatologic conditions are probable consumers of CAM (Mehta et al., 2008; Saydah & Eberhardt, 2006), but

have received less attention. There appears to be no research on CAM focused on health professionals who work with patients with SLE. This study involved the use of phenomenological qualitative research to explore the attitudes, beliefs, knowledge, and professional practices regarding CAM of physicians and nurses who work with patients with SLE. Understanding health care providers' knowledge, perceptions and practices can be useful for breaking down barriers to communication between patients and professionals. Designing nursing, medical education, and continuing education programs for physicians, nurses, and other healthcare professionals who are interested in knowing more about CAM and possibly pursuing an integrative treatment approach will contribute to evidence-base for CAM.

Problem Statement

There has been an elevated trend of CAM use among patients who have lost trust and patience in conventional medicine (Astin, 1998; Barnes et al., 2004; Danoff-Burg & Friedberg, 2009), and studies have revealed the additional benefits of CAM in the treatment of many illnesses (Artus et al., 2007; Rojas-Cooley & Grant, 2006; Rosenberg et al., 2008). As a result, efforts have been made to provide safe guidelines for patients and medical practitioners regarding CAM use (Lindquist et al., 2005). While there has been an increase in CAM use and CAM provider visits, physicians and nurses who seek to integrate CAM into the delivery of their health care only focus on the physical symptoms associated with a disease (Astin, 1998; Barnes et al., 2004; Burke et al., 2005; Eisenberg et al., 1998; Keith et al., 2005). One limitation of the conventional medical

treatment of SLE, for example, is its tendency to neglect quality of life (QOL) issues (Danoff-Burg & Friedberg, 2009; Moses et al., 2008; Yen, Neville, & Fortin, 1999).

Although research studies have explored the integration of CAM into conventional medical practice (Astin, 1998; Barnes et al., 2004; Barnes et al., 2008; Eisenberg et al., 1998; Ernst & Ferrer, 2009; Keith et al., 2005), very few medical practices have actually incorporated CAM into their practices. The reasons why so few doctors and nurses integrate CAM use into their practice are not well understood (Berry, 2007; Saydah & Eberhardt, 2006; Shelley et al., 2009). SLE patients are among those patients who turn to CAM because they are not satisfied with the care they receive from conventional health care professionals (Danoff-Burg & Friedberg, 2009). In this study, I explored the perceptions, knowledge, and practices of doctors and nurses treating SLE patients about integrating CAM into conventional healthcare.

Nature of the Study

This research project was a qualitative, phenomenological exploration of attitudes, knowledge, and practices related to integrating CAM into conventional healthcare through the perceptions and experiences of a sample of 10 healthcare providers who regularly provide care to patients with SLE. Phenomenology is based on the description and elaboration of the human experience (Leedy & Ormrod, 2005). The phenomenological approach was used in this study to understand the human experience and intentions of SLE healthcare providers. Qualitative research methods are frequently used to examine topics on which there is not a lot of knowledge or to enable researchers to gain new insights into a given phenomenon, develop new concepts or theoretical

perspectives about the phenomenon, or reveal problems within that phenomenon (Leedy & Ormrod, 2005). Semistructured interviews and open-ended questions were used to gather information from participants.

Research Questions

The following research questions guided the study:

RQ1: What is the level of knowledge regarding CAM therapies among health care providers working with SLE?

RQ2: What experiences have these health care providers had with CAM therapies?

RQ3: What barriers have these health care providers experienced in communicating with their patients about CAM use?

RQ4: What are health care providers' beliefs about integrating CAM into treatment for their patients with SLE?

RQ5: What are these health care providers' perceptions of (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative treatment?

Purpose of the Study

The purpose of this qualitative phenomenological study was to gather the perceptions of healthcare professionals, to gain insight into the understanding of the knowledge, beliefs, and experiences of physicians and nurses regarding CAM use and their relationship to the integration of CAM, into treatment for patients with SLE. Ten healthcare providers who regularly provide care to patients with SLE in the Long Island

Osteoporosis and Arthritis Center in the State of New York were recruited through a snowballing sampling technique. The inclusion criteria included those physicians and nurses who (a) had themselves practiced CAM on patients for at least a year and (b) regularly provided care to patients with SLE using CAM or other treatments.

Most CAM modalities lack clinical evidence, but are nonetheless, popular with patients, such as iridology or Vega machines as diagnostic tools (Phelps & Hased, 2010). As Yen et al. (1999) observed, patients and practitioners often have discordant perceptions, so knowledge of both sets of perceptions is essential for optimum patient care. This study was focused on the perceptions, knowledge, and experiences of health care professionals who work directly with patients living with SLE.

Conceptual Framework

Embodied in the conceptual framework for this qualitative study are two models or theories: the shared decision-making model (SDM) and self-efficacy theory. SDM is an important paradigm in clinical health care that indicates that decision making is a shared process involving the decisions of clinicians (physicians and nurses), patients, and often others (e.g., family, friends, and coworkers). The patients in this process (a) understood the seriousness of the disease to be prevented; (b) understood the preventive service, including the risk, benefits, alternatives, and uncertainties; (c) had weighed their values regarding the potential benefits and harms associated with the service; and (d) had engaged in decision making, thereby enhancing their confidence about participating in their own health care (Kaplan, 2004). The SDM model advocates the involvement of patients in their healthcare needs. Kon (2010) stated, “In patient/agent-driven decision

making (akin to strict autonomy), the physician presents all options and the patient makes his/her own choice. The physician provides expert knowledge only and makes no recommendations” (p. 1). The American Medical Association, the American College of Critical Care, and the American Academy of Pediatrics all advocate shared decision making (Murray et al., 2007; Shields et al., 2007).

Self-efficacy theory, developed by Bandura (1995), indicates that “efficacy beliefs” play a large role in influencing how people think, feel, motivate themselves, and behave. Efficacy beliefs develop from four main resources: mastery experiences, vicarious experiences, social persuasion, and physiological and emotional states (Bandura, 1982). Further, self-efficacy influences all phases of personal change, which include the decision to change a health habit, whether people have the motivation and determination necessary to succeed, if they decide to make a change, and the degree to which a person maintains any changes he or she has made (Bandura, 1986).

The SDM and the theory of self-efficacy were used as the framework of the study. The SDM encompasses the principles of autonomy and beneficence. Physicians and nurses have a moral duty (beneficence) to deliver health care for the well-being of patients. Using SDM and self-efficacy theory, I investigated the importance of collaborative decision making by healthcare professionals and patients in the integration of CAM to SLE treatment plans. Using the SDM model and self-efficacy theory, I developed interview questions concerning participants’ experiences in, involving patients and other healthcare professionals in the management of SLE treatment modalities, their

belief system about the efficacy of CAM for patients with SLE, and factors that facilitate and hinder the decision-making process regarding the use of CAM.

Operational Definitions

The following terms were defined for the purpose of this study:

Alternative therapies: The term used when therapies included under the CAM umbrella are used instead of conventional medicine (NCCAM, 2007).

Biologically based therapies: CAM therapies involving the ingestion of natural substances such as foods, herbs, vitamins, and minerals (NCCAM, 2007).

Chronic Condition: is an illness lasting more than 3 months (Horswell et al., 2008).

Complementary and alternative medicine (CAM): “A group of diverse medical and health care systems, practices, and products that are not generally considered to be part of conventional medicine” (NCCAM, 2007, para. 2). Examples of CAM include alternative medical systems, mind-body medicine, biologically based therapies, manipulative and body-based methods, and energy therapies.

Complementary therapies: The term used to denote therapies included under the CAM umbrella that are used in conjunction with conventional medicine (NCCAM, 2007)

Conventional medicine: “Medicine as practiced by holders of MD [medical doctor] or DO [doctor of osteopathy] degrees and by their allied health professionals such as physical therapists, psychologists, and registered nurses” (NCCAM, 2007, para. 2).

Energy therapies: CAM therapies that fall into two types: *biofield* therapies and *bioelectromagnetic-based therapies*. Biofield therapies are based on energy fields that are

presumed to exist within and surrounding the human body, although there is currently no scientific evidence of such fields. Techniques such as Reiki, qi gong, and therapeutic touch rely on the application of pressure and/or on placing the hands in or through the energy fields to promote healing. Bioelectromagnetic-based therapies involve unconventional applications of electromagnetic fields (NCCAM, 2007).

Integrative medicine: Disease and illness treatments that synthesize conventional medical treatments with CAM therapies (Ben-Ary, Frenkel, & Hermoni, 2006).

Manipulative and body-based therapies: CAM therapies including practices such as massage and chiropractic or osteopathic manipulation (NCCAM, 2007).

Mind-body medicine: CAM therapies such as meditation, prayer, guided imagery, yoga, relaxation, mental healing, and creative arts therapies (such as dance, music, or art); mind-body medicine also includes several strategies that have been integrated into mainstream medical practice such as cognitive behavioral therapy (CBT) and patient support groups (NCCAM, 2007).

Systemic lupus erythematosus: A chronic autoimmune condition that causes the immune system to attack the body's own health cells and tissues as if they were foreign invaders such as viruses or bacteria (Tretheway, 2004).

Whole medical systems: Alternative Eastern and Western medical systems that are grounded in complete systems of theory and practice. Eastern systems include traditional Chinese medicine and Ayurveda. Western systems include naturopathic medicine and homeopathic medicine (NCCAM, 2007).

Assumptions, Limitations, and Delimitations

According to Creswell (2003), in every research study there are assumptions, limitations, and delimitations, which are critical to a viable research proposal.

Assumptions

The basic foundations of any proposal are the assumptions, which, according to Leedy and Ormand (2005), are “what the researchers take for granted” (p. 62). This study involved three assumptions. The first assumption related to the interpretation of data, which was based on the participants’ understanding and use of pertinent terms of the topic studied. The assumption was that participants had some knowledge of the language relevant to the research topic. The second assumption was that the participants saw merit in this study and responded to the questions honestly and candidly. Third, it was assumed that the interview questions examined by the expert panel elicited appropriate responses.

Limitations

By nature, qualitative research is limited to a small number of participants. The responses of 10 health professionals could not be presumed to represent all health professionals. In addition, the information garnered was limited to a small sample from a specific practice setting of physicians and nurses, which limits the generalizability of findings to other populations. The results of the study therefore are only applicable to the population with demographic characteristics similar to those of the sample population and the medical environment where CAM has been integrated. An additional limitation was that the study would attract health professionals who were particularly interested in or had superior knowledge and experience of CAM. As such, a possible limitation was

that participation in the study might be skewed toward health professionals who were aware of and interested in CAM. Those who lacked interest, knowledge, or experience with CAM might not be inclined to participate. Another limitation was that the self-reporting data could not be independently verified, because I relied on what the participants had to say.

Delimitations

According to Creswell (2007), delimitations are restrictions that researchers impose to narrow the scope of a study. The scope of this study was delimited to health care providers who cared for systemic lupus patients in the state of New York. The study was also delimited to attitude toward, knowledge of, and practice of CAM as perceived and experienced by healthcare professionals. The study was restricted to the analysis of information that was collected at a single point in time. The transferability of the results of the study therefore was restricted to the perceptions, knowledge, and practices of physicians and nurses who had experiences in integrating CAM in the treatment of patients with SLE.

Significance of the Study

SLE is a chronic disease with complex and unpredictable symptoms that affect virtually all facets of patients' lives. Individuals with chronic diseases are among the top consumers of CAM. In particular, individuals with conditions that do not have cohesive and satisfactory treatments are most inclined to seek out alternative therapies (Coulehan, 1999). No prior study had examined the knowledge, beliefs, and experiences related to CAM among health care professionals who provide care for patients with SLE. This

study addressed the knowledge gap by focusing specifically on health care professionals who worked with this patient population. Second, the study illuminated the role of communication, which was critical to patients' relationships with healthcare providers. Good communication enhances the collaborative relationship for quality healthcare for SLE. Third, this study serves as a springboard for future research with patients and health professionals. The study also disclosed areas that both facilitate and impede the integration of CAM into lupus treatment, as well as areas for improvement. In addition, the number of participants was small, and the results were not expected to be representative of the majority population. The information gained from this study is useful for charting a future direction for professional education, research, and practice related to the integration of CAM into SLE treatment.

Summary and Study Organization

This phenomenological study explored the knowledge, beliefs, and experiences related to CAM of nurses and physicians who care for patients with SLE. Chapter 1 presents the background of the study, problem statement, purpose and research questions, theoretical perspectives, operational definitions, assumptions, limitations, delimitations and the significance of the study. Chapter 2 contains a review of relevant literature covering the nature of CAM, the use of CAM, health care professionals' perceptions of CAM, the research design used for this study, and the disease manifestations and treatments of SLE, including CAM use and quality-of-life issues. Chapter 3 addresses specifics of the study methodology, including the rationale for employing the qualitative research design and the phenomenological approach. Chapter 4 contains the results from

the data and findings of the study. Chapter 5 concludes the study with a discussion of the key findings, in the light of the research literature and theoretical framework of the study, and their implications for health education, health promotion, and future research.

Chapter 2: Literature Review

The purpose of this chapter is to provide a general overview of the research study regarding CAM awareness and perceptions of physicians and nurses who provide systemic lupus care. This chapter includes a review of relevant literature covering the nature of CAM, use of CAM, health care professionals' perceptions of CAM, the research design for this study, and the disease manifestations and treatments of SLE, including CAM use and quality-of-life issues. A review of the literature was conducted to gain an understanding of relevant topics directly related to studies of physicians' and nurses' awareness and perceptions of CAM as a treatment modality of systemic lupus.

Gaps in Literature

Most SLE patients use complementary therapies in conjunction with conventional medicine but do not disclose their CAM use to their health care providers (Eisenberg et al., 1993; Eisenberg et al., 1997; Mehta et al., 2008; Saydah & Eberhardt, 2006; Shelley, Sussman, Williams, Segal, & Crabtree, 2009). A specific issue raised by this trend is that the preference for herbal and other nutritional supplements, which rank high among CAM users, could produce unintended consequences. For example, herbal nutritional supplements may contain high levels of estrogenic substances that can aggravate lupus activity (Moore et al., 2000). Therefore, positive communication between patients and clinicians is essential to minimizing the disease burden and enhancing the quality of life of individuals living with SLE (Danoff-Burg & Friedberg, 2009; Leong et al., 2010; Moses, Wiggers, & Nicholas, 2008; Thetheway, 2004; Yen, Neville, & Fortin, 1999).

Education for health care professionals is also essential for an integrative approach to patient care (Ben-Arye et al., 2006; Dayhew, Wilkinson, & Simpson, 2009; Fearon, 2003; Kemper, Gardiner, Gobble, & Woods, 2006; Nedrow et al., 2007; Xu & Levine, 2008). A common finding in research with health care professionals is that many do not feel that they have sufficient knowledge to recommend complementary therapies to their patients, but interest in learning more about CAM is typically high. Nurses tend to view the integration of CAM into professional practice as especially congruent with the holistic philosophy of nursing (King, Pettigrew, & Reed, 2000; Rojas-Cooley & Grant, 2006; Tracy et al., 2005). Increasing numbers of nurses and other conventional health care professionals are exploring CAM therapies for their own use as well as for their patients (Dayhew et al., 2009; Lindquist, Tracy, Savik, & Watanuki, 2005). However, those CAM practitioners limitedly disclose their experiences regarding alternative treatment modalities. An investigation of the knowledge and experiences of physicians and nurses may provide information regarding ways of integrating CAM into conventional healthcare.

Search Strategies

The literature presented in this review was drawn from PubMed and the following EBSCO databases: Academic Search Premier, MasterFILE Premier, PsycINFO, PsycARTICLES, and MEDLINE. Keywords used either individually or in conjunction included *complementary, alternative, allopathic, integrative, medicine, systemic lupus erythematosus (SLE), treatments, therapies, management, chronic disease, health,*

professionals, practitioners, nurses, physicians, attitudes, knowledge, and beliefs. The article inclusion dates were January 2001 to December 2011.

Conceptual Framework

In this study, I used the shared decision-making model (SDM) process (President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998) and self-efficacy theory (Bandura, 1982). SDM encompasses the principles of autonomy and beneficence. Physicians and nurses have a moral duty to deliver health care that promotes the well-being of patients. The SDM model allows a joint decision process that is shared between the patient and the provider.

Rojas-Cooley and Grant (2006) made several recommendations for nurses that are consistent with the principles of SDM. First, nurses should become familiar with different CAM therapies so that they can confidently and easily talk about them with patients. Second, it is essential to create trusting relationships that promote open and honest dialogue. Third, nurses have the responsibility of educating patients about the potential benefits and risks of combining CAM with conventional medical treatments. Finally, Rojas-Cooley and Grant saw nurses as catalysts in bringing up patients' interests and use of CAM with other members of interdisciplinary healthcare teams. With the exception of the third principle, these recommendations apply to doctors as well as nurses (Rojas-Cooley & Grant, 2006).

CAM practitioners are more likely to use SDM than allopathic physicians are. According to the SDM, the clinician's role is to help the patient select the best treatment option(s) for optimum health and well-being. Describing the model as "true informed

consent,” Yen et al. (1999), who advocated the use of SDM, consider it the physician’s responsibility to initiate discussion on all the available treatment options, including the risks and benefits of each option “so that the patient may weigh each option ... against the others” (Yen et al., 1999, p. 665). In fact, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requires health care providers to query their patients about their use of CAM (Lindquist et al., 2005), but according to patients, few clinicians actually do so (Saydah & Eberhardt, 2006). Patients are wary of bringing up the subject of CAM on the premise that the clinician will probably not approve, and they feel that the clinician is the one who should be initiating any discussion of alternative therapies (Berry, 2007; Shelley et al., 2009). Surveys of medical providers suggest that patients’ apprehension is not without merit. Many physicians say they discourage CAM use due to uncertainty about the safety and efficacy of the therapies and despite expressing interest in CAM, an overwhelming majority indicated the preference to rely exclusively on conventional biomedical therapies (Milden & Stokols, 2004). This puts physicians at odds with the body of evidence since the first studies of Eisenberg et al. (1993, 1998) indicated, an escalating use of CAM by the U.S. public in general and adults with chronic diseases in particular.

Bandura’s concept of self-efficacy was used in this study to examine the belief system of healthcare providers regarding CAM use and their relationship to the integration of CAM into treatment for patients with SLE. According to Bandura (2001), self-efficacy is based on an individual’s thoughts surrounding success and the best approach to accomplish a task. The level of self-efficacy determines how people think

and behave, based on their skill and the challenge level. This is viewed as a key mechanism, which reflects the task performance and thought process of the tasks.

Bandura (2001) also discussed self-efficacy in reference to a personal action or form of control. Individuals with high levels of self-efficacy have a quick response rate to challenges and maintain commitment to achievement. This leads to increased health, achievement, and development (Luszczynska, Guttierrez-Dona, & Schwarzer, 2005). High levels of self-efficacy set the belief that one will perform well, which in turn leads to taking on challenging tasks. People with low self-efficacy can attribute their shortcomings to underdeveloped planning and high stress levels. This also causes difficulty with focusing and responding to failure. According to Luszczynska et al. (2005), positive encouragement increases self-efficacy, whereas negative encouragement decreases self-efficacy. Bandura (1986) originally coined self-efficacy as a discernment about a person's capability, which was later conceptualized as an individual's feeling that he or she has the ability to exert physical dominance over a set of skills needed to complete a particular task. The self-efficacy theory of Bandura (1982) indicates that people are capable of organizing and executing courses of action required managing various situations (Bandura, 1995).

Scope of Complementary and Alternative Medicine

The term *complementary and alternative medicine* covers a broad spectrum of therapies such as mind-body medicine, biologically based practices, and energy medicines. With the burgeoning popularity of CAM, the line between conventional and alternative medicine is increasingly blurred (Dayhew et al., 2009; Factor-Litvak,

Cushman, Kronenberg, Wade, & Kalmuss, 2001; Lindquist et al., 2005; Tracy et al., 2005). Many therapies traditionally labeled *alternative* are in great public demand and have become integrated into mainstream medical practice.

Although the umbrella term *CAM* is commonly used, *complementary* and *alternative* have distinct meanings (NCCAM, 2007). Therapies are complementary when used in conjunction with conventional medicine, such as acupuncture in addition to the usual medications for pain. Alternative therapies are those that are used instead of conventional treatment—for example, using a special diet and supplements to treat SLE instead of traditional medication such as prednisone.

The various therapies included in the definition of CAM are grouped into four broad classifications, with recognition that there is a degree of overlap among the categories (NCCAM, 2007).

Mind-body medicine includes several strategies that have been integrated into mainstream medical practice, such as cognitive behavioral therapy (CBT) and patient support groups (NCCAM, 2007). Mind-body therapies such as music, meditation, spirituality, and prayer have been so thoroughly integrated into pain management that they are routinely recommended for patients with chronic pain (Greco et al., 2004). Mind-body therapies are not used alone, but are combined with lifestyle interventions such as exercise and movement. Mind-body therapy approaches involve patients in their treatment modality. Studies have shown that treatment is more effective when patients participate in their own recovery (Lloyd, 2001; Montgomery, 2001). Other forms of

mind-body therapy include visualization and guided imagery, yoga, relaxation, mental healing, and creative arts therapies (such as dance or art).

Biologically based therapies refer to natural substances that are typically ingested, such as foods, herbs, vitamins, and minerals. *Manipulative and body-based practices* include massage and chiropractic or osteopathic manipulation. The final category, *energy therapies*, has two types: *biofield therapies* and *bioelectromagnetic-based therapies* (NCCAM, 2007). Biofield therapies are based on energy fields that are presumed to exist within and surrounding the human body, although their existence is not yet experimentally proven. Techniques such as Reiki, qi gong, and therapeutic touch rely on the application of pressure and/or on placing the hands in or through the energy fields to promote healing. Bioelectromagnetic-based therapies involve unconventional applications of electromagnetic fields such as pulsed fields and magnetic fields to assuage pain.

In addition to these four types, NCCAM research includes whole medical systems that are grounded in complete systems of theory and practice. These systems have evolved in both Eastern and Western cultures. Eastern systems include *traditional Chinese medicine*, which is based on the view that health is a balance in the body of two forces called *yin* and *yang*, and *Ayurveda*, which is a system from India emphasizing balance among body, mind, and spirit. Western systems include naturopathic medicine, which uses nutrition, herbs, manipulation of the body, and exercise to help the body naturally heal itself, and homeopathic medicine, which uses very small doses of substances to trigger the body to heal.

Mainstreaming CAM in Academic Institutions

The NCCAM also recognizes *integrative medicine*, which synthesizes conventional medical treatments with CAM therapies that show evidence of being safe and effective (NCCAM, 2007). Ben-Arye et al. (2006), members of the Complementary and Traditional Medicine Unit in the Department of Family Medicine at the Rappaport Faculty of Medicine at The Technion in Haifa, Israel, are staunch advocates of integrative medicine. Since 2000, their innovative program has offered comprehensive education in CAM for family practice residents and specialists. The aim of the program is to “provide family physicians with skills to become gatekeepers, coordinators, and case managers for the growing number of CAM users in their practice” (p. 82). Over the 12-week course of study, participants are taught to integrate CAM into individual patient treatment plans. Evaluation in this study was based on four dimensions relevant to the incorporation of CAM into patient care: biopsychosocial, disease-related concerns, patient-oriented concerns, and patient-CAM practitioner alliance. In designing the care plan, the participants sought out online resources on the safety and effectiveness of CAM therapies and engaged in phone or electronic consultations with expert practitioners in the fields of traditional Chinese medicine, homeopathic medicine, mind-body medicine and guided imagery, anthroposophical medicine, reflexology, Reiki, arts therapies, or the Feldenkreis method (Ben-Arye et al., 2006). Preliminary evaluation of the course revealed significant improvements in the participants’ CAM scores and high satisfaction with the course. Five of the six treatment plans elicited positive responses from the patients, who expressed willingness to consider the therapies recommended by the physician. Indeed, many

patients would like to have their physicians initiate a discussion of CAM (Coulehan, 1999; Shelley et al., 2009).

In the United States, the NIH provided grants to 15 allopathic academic health centers for the purpose of developing CAM curricula during the academic year 2004-2005 (Nedrow et al., 2007). The Oregon Health & Science University (OHSU) in collaboration with Oregon College of Oriental Medicine (OCOM), National College of Natural Medicine (NCCM), and Western States Chiropractic College (WSSC) received one of the NIH grants. Together, the four schools formed the Oregon Collaborative for Complementary and Integrative Medicine (OCCIM). The OCCIM created a survey that was used for examining the characteristics and attitude of enrolling students, as well as to track changes in their attitudes toward CAM while enrolled in CAM literacy in the 4-year curriculum. While the literature did not expound on the other health centers, the OCCIM was successful in the integrative approach. The OCCIM is presented as an example of a successful lateral integration approach (Nedrow et al., 2007).

In a study comparing the attitudes toward CAM of Oregon students in the fields of allopathic medicine, Oriental medicine, and chiropractic or naturopathy with those of students in allopathic medicine from the University of Nebraska College of Medicine (UNCOM), Nedrow et al. (2007) found overall high levels of enthusiasm for learning about CAM in both groups. However, the Oriental medicine and naturopathy students expressed the most positive attitudes toward CAM. In terms of personal use, three-quarters of the students in both programs had experience with massage, two-thirds used nutritional supplements, and more than half had experience with movement therapies.

Although the Nebraska medical students were the least familiar with CAM, they were most inclined to turn to prayer (51%) for healing purposes because they were more confident in the effectiveness of prayer for healing than the OSHU students were (Nedrow et al., 2007).

As a group, women in this study were more favorable toward CAM than their male peers (Nedrow et al., 2007). The positive predisposition of women toward CAM is reflected in general population studies (Barnes et al., 2008; Eisenberg et al., 1998; Factor-Litvak et al., 2001; Upchurch et al., 2007). Nedrow et al. (2007) noted that prior studies of medical students and clinicians had also found women to be especially interested in CAM. They proposed that the increasing proportion of women as medical faculty and students may result in greater attention to CAM as part of the allopathic medical curriculum in the future, along with increasing integration of CAM into medical care.

At the same time, Nedrow et al. (2007) pointed out that a dearth of medical faculty members trained in CAM stands as an obstacle to more extensive integration of CAM into allopathic medical education. Furthermore, skepticism toward the effectiveness of CAM is an additional barrier despite the growing interest in CAM. The desire for evidence of safety and efficacy is a consistent factor in conventional health care providers' acceptance of CAM. According to Hsiao et al. (2005), a lack of consensus among providers regarding the definition and practice of integrative medicine has impeded efforts to evaluate the effects of converging models of care on patient care quality and outcomes.

Hsiao et al. (2005) developed a 30-item survey (IM-30) to assess clinicians' attitudes toward integrative medicine on five key dimensions: *openness, readiness to refer, and learning from alternate paradigms, patient-centered care, and safety of integration*. A study of 202 clinicians demonstrated the validity and reliability of the IM-30. An important feature of the IM-30 is that it is equally applicable for conventional and CAM practitioners. The instrument was self-administered and was used to provide a measurement of clinicians' orientation towards integrative medicine. The findings supported the IM-30 because it captured not only the constructs integral to the orientation of the clinicians toward IM, but other dimensions such as practitioners' education, openness, and patient-centered care (Hsiao et al., 2005).

Historical Background and Current Trends

Nearly two decades ago, Eisenberg et al. (1993) published a landmark study documenting the extensive use of unconventional therapies by adults in the United States. This study marked the first formal recognition by the medical community that Americans were turning to therapies that were not part of conventional Western medical treatment and in much greater numbers than had been assumed. A subsequent study showed that from 1990 to 1997, the use of CAM further increased (Eisenberg et al., 1998). In October 1998, the National Institutes of Health (NIH) established the National Center for Complementary and Alternative Medicine (NCCAM) whose designated mission is to conduct scientifically rigorous exploration of complementary and alternative therapies, train CAM researchers, and disseminate authoritative information to professionals and the general public (NCCAM, 2007).

Before the 1990s, the use of CAM was thought to be limited to individuals with cancer and other life-threatening conditions (Eisenberg et al., 1993), even though homeopathy was the principal form of medicine practiced in the United States a century ago, and acupuncture has been a central treatment modality of Chinese medicine for centuries (Eisenberg et al., 1993). However, in the 1990s, CAM began to occupy a more prominent place in medical research and practice for oncology (Rojas-Cooley & Grant, 2006; Wang & Yates, 2006), and is increasingly popular across population groups, for managing multiple chronic conditions (Artus, Croft, & Lewis, 2007; Barnes, Bloom, & Nahin, 2008; Burke & Upchurch, 2006; Eisenberg et al., 1993, 1997; Ho, Jones, & Gan, 2009; Mehta, Gardiner, Phillips, & McCarthy, 2008; Rosenberg et al., 2008; Saydah & Eberhardt, 2006; Spence, Thompson, & Barron, 2005; Upchurch et al., 2007; Witt, Ludke, Mengler, & Willich, 2008). This includes many people with SLE, who turn to CAM for treating specific symptoms as well as managing their overall health (Alvarez-Nemegyei & Bautista-Botello, 2009; Goh, et al, 2003; Leong, Pong, & Chan, 2003; Moore et al. 2000).

CAM Use in the United States

When they undertook their pioneering study, Eisenberg et al. (1993) did not anticipate the powerful presence of CAM in American health care. Roughly one in three adults used some form of CAM in 1990. Furthermore, the estimated number of visits to CAM practitioners in 1990 surpassed the number of visits to all primary care physicians, and out-of-pocket expenses for CAM therapies were comparable to out-of-pocket

expenses for hospitalizations nationwide. Most respondents reported using CAM for a chronic health condition.

Among respondents who utilized CAM for a serious health condition, the vast majority (83%) also relied on conventional medicine (Eisenberg et al., 1993). However, 72% of those seeing a conventional health care provider did not tell that practitioner about their CAM use. Using data from the 2002 National Health Interview Survey (NHIS), Saydah and Eberhardt (2006) noted that scarcely more than one-quarter of adults with chronic diseases using CAM informed their health care provider. Disclosure was highest for individuals with arthritis, but that figure did not exceed 30%. Thus, over the course of 2002, the proportion of Americans managing chronic conditions who discussed their CAM use with their health care provider remained low when compared to those without chronic disease.

During the 1990s, the utilization of CAM in the United States continued to escalate (Eisenberg et al., 1998). Overall, CAM use ranged from 32% to 54% among different socio-demographic groups. CAM use was more prevalent among individuals with higher education and among those with higher incomes. The effect of income is not surprising given the high out-of-pocket expenses. Notable increases were observed for the use of herbal medicine, massage, megavitamins, self-help groups, folk remedies, energy therapies, and homeopathy.

Between 1990 and 1997 overall CAM use rose by 65%. There were significant increases in the proportion of individuals turning to CAM for back problems, allergies, arthritis, and digestive problems. As Eisenberg et al. (1998) pointed out, the 1997 study

revealed both a higher prevalence and a higher frequency of CAM use compared to the 1990 study. The National Health Interview Survey (NHIS) was conducted in 2002 and 2007, and Upchurch et al. (2007) analyzed data from it on CAM use among women in 2002. The nationally representative sample included data from 17,295 women.

Approximately 40% of the women reported using some type of CAM. Biologically based therapies (23.8%) and mind-body therapies (20.9%) were the most popular practices.

Biologically based therapies also ranked as the predominant form of CAM among women in New York City (Factor-Litvak et al., 2001). There were few differences between women who chose different forms of CAM with the exception of prayer, which was analyzed separately (Upchurch et al., 2007). Slightly more than half of the respondents used prayer for health reasons (52.7%); with African Americans representing the largest segment of women who turned to prayer (71.6%). Prayer is a personal way of achieving divine connection. Taylor (2003) describes it as the mechanism for petitioning an omnipotent divinity to grant healing, which frequently sustains coping and brings comfort.

Upchurch et al. (2007) found that CAM utilization was higher among women who were dealing with a medical condition. Fewer than 6% of the women reported using CAM for arthritis, fibromyalgia, gout, or lupus (which was all grouped together). For the sample in general, the main reasons for using CAM were the idea that it would be helpful combined with conventional therapy (54.4%), interest in trying CAM (51.5%), conventional treatment alone was not helpful (28.7%), recommendation by a conventional health care professional (27.4%), or the excessive expense of conventional

treatment (28.7%). Among the New York City women, more than one-third (37.5%) who were using CAM for a specific health condition rated their therapy as very effective, and 46% rated their therapy as somewhat effective (Factor-Litvak et al., 2001). Yoga, meditation and spirituality earned the highest ratings, followed by herbal medicines and teas.

Spirituality is an individualistic and self-determined, inner sense of something greater than oneself. Spirituality helps people to cope with their feelings and change their attitudes toward themselves and their relationships. Spirituality reflects the presence of a relationship with a higher power or being that affects the way we live (Fry, 2003). In explaining the concept of spirituality Dyer (2003) noted:

Spirituality is very similar to health. Everyone has health. For some their health is excellent and for others it is poor, yet you cannot escape having it at some level or another. The same is true for spirituality. Every single human being is a spiritual being. We all have spirit (p. 36).

To Delgado (2005), spirituality as a concept involves faith, making meaning, the transcendence of oneself and connecting with others resulting in a sense of inner peace and well-being. To Gallagher, Rocco, and Landorf (2007), spirituality means activities in which one engages to deepen the relationship to the sacred. The sacred is “a transcendent being within or separate from a religious tradition, higher power, community, or some other entity beyond the individual self” (p. 458).

Upchurch et al. (2007) described the NHIS as a “useful starting point” (p. 112) for more extensive exploration of CAM. The researchers envisioned the expansion of the

health care system to encompass CAM as a mechanism for employing an integrative approach to improve the health of the public, to offer more culturally competent health services, and to extend the scope of health programs and interventions.

While earlier studies documented the prevalent use of CAM among all segments of U.S. society, the 2007 NHIS, which was based on the 2002 survey, examined the trends in the use of CAM (Barnes et al., 2008). Both the 2002 and 2007 surveys included the use of CAM among children and adults. The 2007 survey results showed that 38% of adults and 12% of children were using some type of CAM. With the 38% of adult CAM users, women tended to use CAM more often than men (Kronenberg et al., 2006). The 2007 results showed an increasing trend of women CAM users, from approximately 4.9% in 2002 to 10.2% in 2007 (Saydah & Eberhardt, 2006). The research findings of Upchurch et al. (2007) support the prevalence of CAM use among women, which was roughly 27% of the total participants in the study.

Biologically-based therapies were the most commonly used by adults (Barnes et al., 2008). The most popular natural supplements were fish oil/omega 3, glucosamine, echinacea, and flaxseed. Ginseng and combination herbal supplements were also prevalent. Between 2002 and 2007 there were significant boosts in the use of deep breathing techniques, meditation, massage, and yoga. A notable trend is that each successive survey includes an expanded list of CAM therapies.

One trend that has remained steady over time is that back pain is the overriding condition for which consumers seek CAM therapies (Barnes et al., 2008). In descending order, the health conditions underlying CAM used in 2007 were: back pain (17.1%), neck

pain (5.9%), joint pain (5.2%), arthritis (3.5%), anxiety (2.8%), cholesterol (2.1%), head or chest cold (2.0%), other musculoskeletal problems (1.8%), severe headache or migraine (1.6%), and insomnia (1.4%). The most striking distinction between 2002 and 2007 was the steep drop in CAM use for colds, which ranked second to back pain in 2002. The use of CAM for colds in 2002 was 9.5% and drop by 2.0% in 2007.

While results of NHIS survey in 2002 and 2007 can be compared, the structure of these surveys was not identical for both years. According to the 2002 NHIS, anxiety and depression were grouped together whereas in 2007 the CAM for these health conditions was treated separately. As such, comparative results of CAM use for anxiety and depression dropped from 6% in 2002 to fewer than 5% in 2007. The 2007 NHIS included the first analysis of CAM expenditures since the 1997 survey (Eisenberg et al., 1998). According to NHIS data, Americans made more than 300 million visits to CAM practitioners and spent \$33.9 billion in out of pocket expenses for CAM services and products (Nahin et al., 2009). The findings highlighted the tremendous impact of CAM on the U.S. health care landscape.

CAM Use for Chronic Conditions

Saydah and Eberhardt (2006) investigated CAM use by respondents with chronic diseases in the 2002 NHIS. A total of 31,044 responses were included in the analysis. CAM use was highest among adults with arthritis, with close to 60% reporting some use of CAM. Next in descending order were individuals with lung disease, have cancers, and have two or more chronic conditions (55%), cardiovascular disease (46.4%), and diabetes (41.4%). With the exception of diabetes, the presence of a chronic disease increased the

probability that respondents would be more open to alternative therapies (Saydah & Eberhardt, 2006). However, results of Saydah and Eberhardt's study also found that CAM use is prevalent regardless of health status.

Patients' Reluctance to Discuss Their CAM Use With Their Physician

Saydah and Eberhardt (2006) were alarmed that less than 30% of the adult CAM users with chronic diseases discussed this use with their health care providers. They were concerned because they believed that managing chronic diseases often involves multiple drug regimens and conventional medications can have adverse interactions with biologically based CAM. The implications that Saydah and Eberhardt shared regarding the type of relationship the CAM users had with their clinicians showed that public health practitioners must advocate good patient-clinician relationships (Kon, 2010). This relationship should have open communication between patient and clinician in order to maximize the therapeutic benefits of combined treatments for patients with chronic disease (Kon, 2010).

Types/Conditions of Individuals Who Are Drawn to CAM Use

CAM use is extremely common among individuals who experience chronic pain (Ho et al., 2009). Patients with rheumatologic conditions are likely to be consumers of CAM (Mehta et al., 2008; Saydah & Eberhardt, 2006). Between 42% (Mehta et al. (2008) and 59.6% (Saydah & Eberhardt, 2006) rheumatologic patients are CAM users. Artus et al. (2007) also examined the use of CAM and conventional therapies among primary care patients with chronic musculoskeletal pain in North Staffordshire, England. The mixed methods study included face-to-face interviews, survey questionnaires, and medical

records. A total of 138 patients were interviewed of whom 116 (84%) had used at least one form of CAM over the past year. Roughly two-thirds were using CAM at the time of the study. The vast majority (80%) had used conventional therapies for their pain and 69% relied on a combination of CAM and conventional treatments.

In contrast to most studies, Artus et al. (2007) found that women were not more likely than men to use CAM. However, women were more inclined to use conventional treatments resulting in higher usage of combined conventional and CAM therapies (Artus et al., 2007). The most popular types of CAM were glucosamine (38%) and fish oil (35%), similar to the 2007 NHIS findings (Barnes et al., 2008). In terms of helpfulness, the most highly rated therapies were osteopathy, relaxation, aromatherapy, and evening primrose (Artus et al., 2007). The most prevalent path to CAM use was recommendation by a friend or relative (47%). More than half of the participants said their main reason for using at least one of their CAM therapies was *"I like to try anything that may work."* The overwhelming majority of respondents (87%) said they would continue to use CAM therapy in the future .

Rosenberg et al. (2008) conducted a similar study to that of Artus et al. (2007) with primary care patients drawn from 12 academic medical centers in the U.S. A total of 463 patients with chronic, nonmalignant pain verbally completed the SF-36v2 Health Survey and the Pain Self-Efficacy Questionnaire (PSEQ) and were queried on their attitudes toward conventional and CAM treatments and their experiences with CAM. The researchers also assessed the participants' pain severity.

In the study by Rosenberg et al. (2008), slightly more than half of the participants (52%) used some form of CAM to relieve pain. Of this group, 54% reported that CAM therapy helped ease their pain and 14% said their chosen therapy alleviated their pain entirely. Vitamin and mineral supplements (33%) were the most popular forms of CAM, followed by herbal supplements or teas (15%) and massage (15%). Other therapies included chiropractic (9%), garlic preparations (9%), and meditation or yoga (7%). Aromatherapy and evening primrose, rated highly by the British patients (Artus et al., 2007) were used by a scant 5% and 2%, respectively of the American patients (Rosenberg et al., 2008).

Despite the high proportion of patients who reported some or complete pain relief from their CAM therapy, most expressed a preference for conventional treatment over CAM (Rosenberg et al., 2008). However, the question was posed by asking participants which one they would choose if they could only use one form of treatment. Most participants stated they preferred traditional therapies for pain. Participants with higher educational attainment were significantly more satisfied with their care. In fact, half of the participants described their conventional medical care as very good or excellent and satisfaction was higher among the CAM consumers. Rosenberg et al. proposed that individuals who chose to explore CAM may have a preference for autonomy and a sense of control over their health. The desire to feel in control of one's health is common among CAM users (Bishop et al., 2007).

Two studies, one based in Germany and Switzerland (Witt et al., 2008) and the other from the U.K. (Spence et al., 2005), found that individuals with a variety of chronic

diseases enjoyed significant and sustained improvements with homeopathic treatment.

The patients observed by Spence et al. (2005) had all been referred by primary care physicians or specialists and many had received specialist medical treatment. Out of 6,544 patients, 70.7% reported positive health benefits over a 6-year period and slightly more than half described their health status as better or much better.

The study conducted by Witt et al. (2008) involved 2,722 adults and 819 children drawn from 103 primary care practice settings in Germany and Switzerland. Over eight years, the participants experienced significant improvements in health status and physical and mental QOL. Children, females, and individuals who had more severe symptoms at the onset of the study experienced the greatest benefits. Witt et al. noted that the participants were free to use any treatments they chose; thus the positive results could not be ascribed entirely to the use of homeopathic medicine.

Factors Affecting CAM Use

Bishop et al. (2007) explored the beliefs underpinning the use of CAM through an extensive research review. A total of 94 articles were included, spanning the years from 1995 to 2005. The analysis focused on four prominent themes: 1) control and active participation, 2) health status, 3) holism and natural treatment, and 4) general philosophies (unconventionality and spirituality). There was some support for the theory that individuals who used CAM desired a sense of control over their health (Bishop et al., 2007). In general, CAM users strived to be actively involved in health care decisions and favored active coping strategies. They tended to embrace a holistic philosophy favoring natural or non-toxic approaches to health and fusing mind, body, and spirit. They also

recognized the importance of lifestyle and psychosocial factors in overall health and well-being. The beliefs held true regardless of the participants' illness, socio-demographic characteristics and health status.

Nevertheless, researchers using multivariate analysis revealed different pathways to CAM utilization that distinguished different user groups (Bishop et al., 2007). Invoking previous research by Furnham and colleagues (1996), Bishop et al. outlined three possible types of CAM users. The first, which they call *Principalists*, strongly believe in the power of CAM. The second group is users who turned to CAM out of frustration with conventional medicine. The third group, *opportunists*, was made up of individuals “who shop around” (p. 862).

According to Bishop et al. (2007), the soaring popularity of CAM demands better understanding of why people choose CAM therapies and how their beliefs influence their decisions. Both CAM and conventional health practitioners can apply this understanding toward enhancing their relationships with their patients and cultivating an integrative approach to treatment.

Quality-of-Life Issues

Panopalis et al. (2005) observed that most quality of life (QOL) research with individuals with SLE is cross-sectional, which may result in an inaccurate portrayal of living with a condition characterized by episodes of flare-ups and remissions. According to the researchers, the only prior longitudinal studies of SLE were small and limited to patients recruited from a single medical center. The TRINATION (a union of three countries, the U.S, Canada and the U.K) study offers the opportunity of monitoring the

physical and psychological well-being of a large multinational sample of patients over an extended time period.

The TRINATION study of SLE was comprised of consecutive patients from three different countries with SLE visiting physicians at six tertiary care centers in: Johns Hopkins University School of Medicine, Baltimore and the University of Pittsburgh in the U.S.; Montreal General Hospital and Hospital Notre-Dame, Montreal in Canada; and University College Hospital, London and Queen Elizabeth Hospital, Birmingham in the U.K. (Moore et al., 2000; Panopalis et al., 2005). Consecutive patients were included in a study in the order that they were identified as eligible by the researchers and they were not selected in any particular way that might influence the results of the study. All patients meeting at least four of the revised criteria for SLE delineated by the ACR were invited to enroll in the extensive project, a comparative study encompassing health status, health resources utilization, effects on productivity, and satisfaction. Enrollment took place between July 1995 and July 1997.

An array of instruments was used for the study (Moore et al., 2000). These included: the Revised Systemic Lupus Activity Measure (SLAM-R) along with a visual analogue scale (VAS) to assess disease activity; the Systemic Lupus International Collaborating Clinics (SLICC)/ACR Damage Index to assess disease damage; the Interpersonal Support Evaluation List (ISEL); the Medical Outcomes Study (MOS) Short Form 36 (SF-36); the MOS Patient Satisfaction Questionnaire (version IV); and the Stanford Health Assessment Questionnaire to examine the use of conventional health resources. CAM use was explored via a set of 16 questions. CAM therapies were

excluded from the analysis of the direct costs, which was derived from the cost of each health care service across countries calculated in 1997 Canadian dollars. Indirect costs were calculated in terms of lost productivity.

The QOL study was based on responses provided by 715 TRINATION participants who completed the SF-36 each year over a four-year span (Panopalis et al., 2005). There were no clinically significant differences within the three countries in terms of demographic profiles, disease characteristics, and direct costs. Not surprisingly, the health expenditures of the U.S. patients exceeded the costs of their counterparts in Canada and the U.K. Despite this, there were no differences in accumulated disease damage among participants in the three countries. Hierarchical modeling was used to evaluate yearly changes in mental and physical well-being captured by the Physical and Mental Component Summary (PCS and MCS) scores on the SF-36. The analyses showed that QOL was quite stable over time for participants in all three countries. Similarly, there were no substantial differences between countries.

Panopalis et al. (2005) acknowledged that, given the rapidly changing disease course and the design of the SF-36, which only covers well-being for the previous month, the annual assessment might not have sufficiently reflected the experience of individuals with SLE. They also noted that as a generic instrument, the SF-36 does not address specific features of the SLE such as appearance or infertility that can impact QOL. The most striking finding was the disparity between the QOL of the TRINATION participants and the QOL of the general populations of their respective countries. For the Canadian patients, the mean baseline scores on the PCS and MCS were 40.6 and 46.0, respectively.

Contrast those scores with the mean general population scores for Canadians of similar demographic features (women aged 35-44): 51.5 on the PCS and 50.2 on the MCS. Similarly, the U.S. participants had mean PCS and MCS scores of 37.4 and 45.0, respectively, contrasted with 51.4 and 48.8 for the general population. For the British participants, the PCS and MCS scores of 36.6 and 43.4 contrast with 52.4 and 48.3 for the general population. The study results showed that the quality of life in patients with SLE remained stable over the four-year period.

As further evidence of the burden of chronic illness, the SF-36 scores of the TRINATION participants from the three countries were comparable to individuals living with arthritis, congestive heart failure, or diabetes (Panopalis et al., 2005). In view of the challenges involved in managing SLE, it is not unexpected that individuals with SLE would have unmet needs. The issue of unmet needs in this population was examined by researchers in the U.S. (Danoff-Burg & Friedberg, 2009) and Australia (Moses et al., 2008).

Danoff-Burg and Friedberg (2009) drew their participants from the membership of the Long Island/Queens Affiliate of the Lupus Alliance of America. Their recruitment drew 112 participants, nearly all female (95%). The average respondent was roughly 50 years old, had initially experienced symptoms of SLE at age 30 and was diagnosed about eight years later. At the time of the study, one-quarter of the respondents were working full-time, 28.6% worked part-time, 22.4% were receiving disability benefits, 14.3% were retired, 5.4% were unemployed, and 3.6% were students. Close to two-thirds (61%) were married or living with a partner. Ethnically, the respondents were 75.9% White, 11.6%

African American, 5.4% Latina (o), 2.7% Asian or Pacific Islander, 1.8% Native American, and 2.7% multiracial.

The instrument used was a version of the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ) used by Moses et al. (2008) and adapted by Danoff-Burg and Friedberg (2009) to be more specific to the situation of individuals with SLE in the U.S. Designed to assess the need for help in various life dimensions over the past six months, the SLENQ is scored according to a 5-point scale. Ranging from 1 to 5, the choices were: *not applicable, already satisfied, low need, moderate need, and high need*. The dimensions captured by the SLENQ are: physical symptoms, activities of daily living (ADL), psychological/ existential, social support, health services, health information, and employment/financial.

All the participants reported at least one area of unmet needs (Danoff-Burg & Friedberg, 2009). Tiredness, a symptom of physical need was the overwhelming concern, with more than 90% reporting some need for help in that area. After tiredness, the most prevalent physical issues were pain (80.4%), poor sleep (75%), and feeling worse after being physically active (70.5%). Daily living needs were also prevalent, reported by 90% of the participants, with just over two-thirds expressing moderate to high need levels (Danoff-Burg & Friedberg, 2009). Most of the difficulty reported by 67.0% - 72.3% of the respondent was concentrated in sensory areas such as eye sensitivity to bright light, avoiding exposure to sunlight, and dealing with temperature extremes, less than half the participants (38.4% - 45.5%) rated these problems as moderate to high (Danoff-Burg &

Friedberg, 2009). Difficulties with everyday activities such as reading, writing, speaking, shopping, and driving were less common.

The overwhelming majority of respondents (91.1%) reported some degree of unmet psychological or existential needs and slightly more than three-quarters appraised their needs as moderate to high (Danoff-Burg & Friedberg, 2009). Depression was also a prominent concern, expressed by 70.5% of the participants. Panopalis et al. (2005) noted that the effects of SLE on appearance could affect QOL. This was definitely the case for the individuals surveyed by Danoff-Burg and Friedberg (2009).

Roughly three quarters of the respondents reported needs in the areas of social support, health services, and health information (Danoff-Burg & Friedberg, 2009). The most common concern in the social domain was the ability to be involved in social activities (59.8%). More than 40% of the participants expressed concerns about maintaining friendship and about changes in their sexual relationships. In terms of health services, 56.3% desired the opportunity to talk with someone who shared or understood their experience and 38.4% were uncertain about when to see a doctor upon experiencing changes in symptoms. Continuity of care and the time spent with clinicians were issues for 45% of the participants. Notably, roughly 30% of the lupus respondents cited the need for support in exploring CAM therapies as an unmet needs area.

Danoff-Burg and Friedberg (2009) reported that people with high unmet needs requiring information from medical staff regarding CAM therapy side effects ranged from 17% to 29% for support in exploring the use of CAM. At the same time, about three-quarters of the respondents expressed some degree of health information needs. The

most prevalent unmet need in the area of finances was dealing with costs related to managing SLE, cited by slightly more than half the participants (Danoff-Burg & Friedberg, 2009).

The overarching conclusion is that individuals with SLE have a plethora of psychosocial concerns that are not being addressed. Danoff-Burg and Friedberg (2009) note that there is currently no accepted type of self-management program for SLE. Clinical trials provide evidence of the benefits of physical exercise (Tench et al., 2003) and stress reduction techniques (Greco et al., 2004). According to Danoff-Burg & Friedberg (2009), communication between patients with SLE and health care professionals is essential for addressing the prevalence of unmet needs. The researchers emphasize that effective communication is bidirectional. That is, patients must be able to convey their personal needs and health care providers must be attuned to those needs. They concluded that, “The ability of the patient to communicate unmet needs in both the physical and psychosocial domains can be facilitated by practitioners who are willing to inquire about them with sensitivity” (p. 12). A substantial segment of participants desired support from clinicians in discovering CAM therapies (Danoff-Burg & Friedberg 2009).

Moses et al. (2008) assessed the extent and variability of unmet care needs over time of 233 members of the Lupus Association of New South Wales using a 97-item SLE needs questionnaire (SLENQ) on two occasions six months apart. The gender composition and marital status of the participants was similar to the American study by Danoff-Burg and Friedberg (2009). Moses et al. (2008) also assessed the medications taken by the participants. In descending order, the most common medications were

corticosteroids, hydroxychloroquine, and NSAIDS, with small numbers of participants using azathioprine or cyclophosphamide or no treatment.

Moses et al. (2008) found that the vast majority of participants, 94% at time one and 95% at time two, reported at least one unmet need. Moses et al. used the complete SLENQ consisting of 97 items; there were no needs reductions for 82 of the items between the two points of data collection. Of the 15 items that showed some improvement, the reductions in needs ranged from 4% to 6%. Some 37% of the participants enjoyed a decrease in unmet needs. However there was no change in needs for 45% of the participants and 18% reported an increase in unmet needs. The overall decline in unmet needs reached statistical significance, but revealed abundant room for improvement. In fact, Moses et al. described their findings as evidence of “an unacceptable persistence of care needs not being met” (p. 867).

While there is relationship between reductions in unmet needs and reductions in disease symptoms, the results is not statistically significant (Moses et al., 2008). Slightly more than half of the participants (52%) who reported improvements in symptoms also showed a decrease in their overall needs. Analogous to Danoff-Burg and Friedberg (2009), Moses et al. (2008) emphasized that clinicians need to be sensitive and attentive to their patients’ individual needs. Gustafson (1991) observed that there is the possibility “that needs exist for which there are no services at all” (p. 326). While this may be true, Moses et al. stressed that health care professionals “have a duty of care to respond to patients’ expressed need for care, either through treatment, referral, provision of self-

management advice, or as a minimum, through the provision of reassurance and coping strategies” (p. 874).

Patient-Clinician Relationships

Moses et al. (2008) and Danoff-Burg and Friedberg (2009) concurred that sensitivity to patients’ unique concerns is essential to meeting the QOL needs of individuals with SLE. Yen et al. (1999) pointed out that SLE is defined by subjective symptoms such as fatigue and pain that are perceived by the patient, but not visible to the clinician and by disease indicators that may be imperceptible to the patient, but detectable to the clinician. The difference between the subjective and objective manifestations of SLE can result in *discordance* between the assessments of the patient and the clinician.

Yen et al. (1999) deliberately chose the term *discordance* rather than *discrepancy* or *disagreement*. According to Yen et al (1999), “discordance implies that the patient and the physician assess the disease differently” (p. 661). More important, the term discordant is nonjudgmental, also implying that neither assessment is right or wrong. “Discrepancy” on the other hand, implies that only one of the two opinions is correct and “disagreement” suggests a conflict of some type. There is no uniform definition of discordance and no standard for measuring evaluating discordance. Nonetheless, there is a sizable body of research documenting differences in the perspectives of patients and clinicians that present barriers to optimum care.

Discordance can appear at any time during interactions between patients and health care providers (Yen et al., 1999). Points of discordance include the consultation, when the physician may be narrowly focused on disease diagnosis and treatment while

the patient is concerned with the physical and psychosocial effects of SLE on her life; the diagnosis, due to the subjective and objective nature of disease signs and symptoms; the patient's education which can result in discordance based on the method of delivery; and treatment outcomes which often elicit an agreement between physicians and patients.

Interestingly, an illustration of the importance of providing information to patients so it is comprehensible and the treatment is justified. It is reported that people seek out CAM because of "a need for personal control in healthcare decisions, a desire for philosophical congruence of treatments with worldview and values, and dissatisfaction with conventional treatments" (Saydah & Eberhardt, 2006, p. 805). Leong et al. (2010) observed the face of discordance: patients with SLE may abandon conventional medical treatment for alternative therapies. One of the top seven reasons reported by patients was "Because the explanation of my illness that I was given by my complementary practitioner made sense to me" (Vincent & Furnham, 1996, p. 38). CAM practitioners are more likely than allopathic physicians to employ shared decision-making, the model of medical practice advocated by Yen et al. (1999). According to the shared decision-making model, the physician's role is to assist the patient in choosing the best treatment option(s) for optimum health and well-being. Describing the model as "true informed consent," Yen et al. deem it the responsibility of the physician to initiate discussion on all the available treatment options, including the risks and benefits of each option "so that the patient may weigh each option against the others" (p. 665). That includes the option not to use any treatment.

Yen et al. (1999) essentially advocate a holistic model of health in which the patient's sense of well-being is paramount. They deem this especially important for chronic diseases such as SLE that require ongoing management. The authors called for future research to illuminate areas of discordance and thereby improve the relationship between patients and their physicians and by extension, the patients' QOL and satisfaction with care.

Leong et al. (2010) investigated discordance among patients with SLE and physicians in Singapore. The patients were part of a larger project that began in 2002 (Leong et al., 2010). All patients met the ACR revised criteria for SLE and received care at a single medical center. The SLAM-R and a VAS were utilized for the study along with the SLE quality of life questionnaire (SLEQOL), the SLE Disease Activity Index (SLEDAI), the SF-36, the Rheumatology Attitudes Index (RAI), and the Systemic Lupus International Collaborating Clinic/ACR Damage Index (SDI). Patients who were diagnosed with SLE less than three years before the study were assessed every four months while those who had a longer disease course were assessed annually. The sample consisted of 491 women and 43 men with a mean age of about 43 years. The mean age of onset was 31.5 years, similar to the participants surveyed by Danoff-Burg and Friedberg (2009).

Yen et al. (1999) noted that many studies reported high VAS correlations between patients and physicians but there were still perceptual differences. Leong et al. (2010) attributed the high degree of concordance between patients and physicians regarding lupus activity reported in earlier studies to inappropriate reliance on Pearson's

correlation. In their study, there was a substantial degree of discordance. Certain factors contributed to higher appraisals of disease activity by patients or physicians. The patients tended to perceive the disease as more active than the physicians when they felt their general health was poor. The difficulty in carrying groceries and the presences of hypertension, urinary sediments, and low platelet counts indicated positive discordance (Leong et al. 2010). In contrast, the physicians rated the disease as more active in the presence of higher SLAM-R scores, proteinuria, hemolysis, photosensitivity, tiredness, casturia, when patients were taking azathioprine or cyclophosphamide, or reported that they became ill more easily than other patients.

Leong et al. (2010) noted that their findings were similar to research from Canada including a study undertaken by Yen and his colleagues (1999). Leong et al. outlined strategies for addressing each area on which the assessments of the patients and physicians diverged. Communication and sensitivity were central to each one. For QOL issues, for example, being sensitive to patients' complaints and inquiring about specific health issues can help to reduce the physical and psychosocial burden of SLE. In contrast, several of the disease activity factors assessed as more serious by the physicians that were identified through laboratory tests may not translate into symptoms experienced by the patient. Therefore, it is up to the physician to explain the meaning of the test findings in language that is meaningful to the patient. With respect to the drugs, the shared decision making model proposed by Yen et al. (1999) offers a useful tool for facilitating adherence, or alternately, exploring the possibility of other treatment options.

It is interesting that the physicians gave more importance to photosensitivity and tiredness than the patients (Leong et al., 2010). Leong et al. suggested that the physicians might have overestimated the degree of distress these conditions caused their patients. However, Danoff-Burg and Friedberg (2009) found tiredness to be a pervasive complaint by patients and photosensitivity was also a cause of distress. The quantitative analysis carried out by Leong et al. (2010) was not designed to capture differences in perceptions between individual patients. Leong et al. differed from Yen et al. (1999) in that they gave more weight to the clinicians' evaluations. Nevertheless, both authors agreed that it was important for clinicians to engage in communication with patients, clarify clinical issues, and be sensitive to each patient's concerns.

Systemic Lupus Erythematosus

SLE is a chronic autoimmune disease that manifests in multiple systems of the body (Godfrey, 2006; Patavino & Brady, 2001; Trethewey, 2004). Most cases of lupus affect women of reproductive age. In fact, 90% of individuals with lupus are women. African American women are three times as likely as Caucasian women to be affected, and the disease is also more prevalent in Latina, Asian, and Native American women than White women (Godfrey, 2006). Each case is highly individual and the disease course is unpredictable and marked by flare-ups and remissions. The most common physical manifestations include painful or inflamed joints, renal complications, and skin rash. The term *lupus* comes from the Latin for "wolf," named by the 13th century physician Rogerius who compared the facial lesions accompanying the disease to the bite of a wolf (Hochberg, 2003).

Diagnosis and Etiology of Systemic Lupus Erythematosus

The American College of Rheumatology (ACR) demarcated diagnostic criteria for SLE based on the presence of 4 of 11 signs. The criteria are divided into: *skin criteria* (butterfly rash on the nose and cheeks, discoid rash typically on sun-exposed areas, photosensitivity, and oral ulcerations); *systemic criteria* (arthritis, serositis, kidney disorders, and neurologic disorders, typically psychosis or seizures with no other explanation); and *laboratory criteria* (blood abnormalities, immunologic disturbance, and a positive anti-nuclear antibody [ANA] test).

Current understanding of the etiology of SLE is based on the idea of “environmental factors acting on a genetically prone individual during an undetermined time period resulting in autoimmunity and finally surpassing that individual’s disease threshold” (Jonsen, Bengtsson, Nived, and Truedsson, & Sturfelt, 2007, pp. 613-614). Possible environmental factors include viruses, hormones, smoking, alcohol consumption, pesticides, organic solvents, silica, heavy metals, aromatic amines, and ultraviolet light. Saturated fats and alfalfa sprouts have also been implicated as factors involved in the development of SLE. Yet despite the plethora of factors suggested, there is no precise understanding of specific interactions in disease development.

The focus on physical symptoms neglects the QOL issues affecting individuals with SLE (Danoff-Burg & Friedberg, 2009; Moses et al., 2008; Yen et al., 1999). Roughly 40% of patients with SLE leave their jobs within four years of diagnosis and those who choose to continue working often have to make numerous modifications to accommodate their illness (Trethewey, 2004). Fatigue is a particularly insidious effect

(Danoff-Burg & Friedberg, 2009). SLE is the fourth major cause of disability in women, and raises the risk of cardiovascular disease 5 to 10 times, especially for younger women (Godfrey, 2006).

Conventional Medical Treatments of SLE

SLE is a complicated chronic illness that is poorly understood and is often inadequately treated when using conventional western medical approaches (Coulehan, 1999). Treatment was revolutionized with the discovery of adrenocorticotrophic hormone and cortisone treatment in the 1940s, and corticosteroids remain the first line of treatment (Hochberg, 2003). Ironically, the effectiveness of corticosteroids and immunosuppressive drugs in treating SLE actually had a counterproductive effect in that it reduced interest in testing novel or alternative treatments (Mok, 2006). Biologically based therapies such as DHEA which is a natural steroid hormone produced from cholesterol by the adrenal glands are gradually making inroads into mainstream treatment of SLE (Mok, 2006; Patavino & Brady, 2001; Ruiz-Irastorza et al., 2001).

In addition to corticosteroids (such as prednisone) and immunosuppressive agents, antimalarial drugs are also used to treat disease manifestations (Patavino & Brady, 2001). Nonsteroidal anti-inflammatory drugs (NSAIDS) are often prescribed to boost the effects of the corticosteroids. Cytotoxic drugs such as cyclophosphamide, azathioprine, or methotrexate are also prescribed with the aim of decreasing the steroid dosage.

These powerful drugs carry the risk of adverse side effects (Patavino & Brady, 2001). Even NSAIDS can cause gastrointestinal problems and moderate doses of prednisone heighten the risk of serious infections (Ruiz-Irastorza et al., 2009).

Antimalarials, on the other hand, protect against major infections. A number of novel therapies have been introduced into the treatment with the threefold objective of intensifying therapeutic efficacy, reducing conventional treatment side effects and decreasing the frequency of disease flares, and ideally extending remission (Mok, 2006). These novel treatments have been undergoing rigorous clinical trials.

Natural Medicine and Nutritional Therapies of SLE

Patavino and Brady (2001) reviewed research on the use of natural medicine and nutritional therapy as treatments for SLE. Although the mechanism is not fully understood, DHEA is thought to affect SLE via its androgenic properties. Patients with SLE tend to have low DHEA levels and studies have shown promising effects on disease activity. It is noteworthy that fish oils (omega-3 fatty acids) were found to decrease SLE symptoms in mice. Fish oils are popular with CAM consumers, particularly those living with chronic conditions (Artus et al., 2007; Barnes et al., 2008; Saydah & Eberhardt, 2006). Fish oils and antioxidants have both been found to reduce inflammation, improve immune functioning, and reduce the risk of cardiovascular and kidney disease (Patavino & Brady, 2001).

The Chinese medicine herb *Tripterygium wilfordi* Hook F (TwHG) is one of the most extensively studied herbs for treating SLE (Patavino & Brady, 2001). One study reported that TwHG alleviated symptoms of fatigue, arthralgia, and fever and normalized the results of laboratory tests. Participants taking TwHG reduced their need for prednisone by half. Other Chinese herbs have been tested on mice with the prospect that they can reduce prednisone dosage. These include *Atractylodes ovata*, *Ligustrum lucidum*,

Angelica sinensis, *Cordyceps sinensis*, and *Codanopsis pilosula*. Findings from the tests revealed that *C. sinensis* proved to be effective in controlling the anti dsDNA and prolonging the life span of the affected mice (Patavino & Brady, 2001).

CAM Use by Patients With SLE

As part of the TRINATION study, the researchers explored the utilization of CAM therapies (Moore et al., 2000). The study of CAM was based on 707 patients with SLE from three countries. Relaxation and massage were the most popular therapies for participants in all three countries, used by more than 21% of the sample collectively. Self-help groups were more popular in Canada and the U.S. (10.9% and 9.2%, respectively) than in the U.K. (4.7%). Canadians (7.9%) had the highest usage of folk remedies (treatments that are not clinically based, but rely on experience and knowledge, and are handed down from generation to generation) compared to the U.S. (3.7%) and British (1.9%) participants. On the other hand, spiritual healing was more than twice as prevalent in the U.S. (14.6%) than Canada (7%) or the U.K. (6.6%).

Results from the TRINATION study revealed that, CAM consumers across all three countries tended to be younger, more educated, and had a shorter duration since diagnosis than non-users of CAM (Moore et al., 2000). Other demographics such as sexual orientation, race, disease activities, and social support did not reveal any differences from users and nonusers of CAM. However, the CAM consumers self-assessed their health as lower than nonusers and were less satisfied with their medical care. Moore et al. noted that the difference in satisfaction was slight although statistically significant. The study did not explore whether dissatisfaction with conventional medical

care might have led some patients to seek alternative therapies. Furthermore, patients who used CAM also made greater use of conventional medical services.

Ho, Jones, and Gan (2009) examined the usage of CAM among ethnic groups. Ho et al. was specifically interested in the characteristics of users and use of CAM for chronic pain control among ethnic groups. Using interview questionnaire, 92 patients from pain clinic participated in a structured interview. The authors found that 81% of the participants are already CAM users. However, the study failed to demonstrate the relationship between race or ethnicity and CAM use. The study found that ethnicity was not a significant variable that determines CAM utilization.

Leong et al. (2003) explored the factors that influenced Chinese patients with SLE. The sample consisted of 192 SLE patients who were getting regular treatment from their physicians employed at an outpatient center in Singapore. Using the typology of CAM consumers by Bishop et al. (2007), Leong et al. found that users fell into two basic groups: those who used CAM specifically to treat their medical condition, and those who used CAM for cultural or general health reasons. Native Chinese speakers tended to be greater users of CAM, illustrating the influence of cultural heritage on CAM use. However, the study by Ho et al. (2009) and Leong et al. that links CAM use to ethnicity was disputed by Goh et al. (2003).

Goh et al. (2003) investigated the use of various CAM therapies in a sample of 132 SLE patients in Malaysia, primarily Chinese women. Surprisingly, only a fairly small proportion of patients were using CAM (15.2%). Of that group, more than half (56.7%) were using nutritional supplements. Traditional herbal remedies were the most commonly

used, followed by vitamin C, calcium, vitamin E, vitamin B complex, Spirulina, evening primrose oil, fish oil, and multivitamins. Other supplements included vitamin D, iron, protein powder, cod liver oil, Pharmaton (multivitamins and ginseng), folic acid, garlic pills, goat's milk, magnesium, and vitamin A. Although half of the 15.2% of patients had been taking supplements before seeing a physician, 30% had received information on them from a physician before using them. Relatives, friends, pharmacists, the Internet, and the media served as additional sources of information on CAM.

According to Goh et al. (2003), three-quarters of the SLE patients who used CAM therapies felt their condition had improved as a result and 80% used the therapies on an ongoing basis. The main reasons for stopping were perceived ineffectiveness, a preference for conventional Western medicine, or pregnancy. While noting that supplements such as vitamins, minerals, fish oil, fatty acids, and DHEA have therapeutic effects for patients with SLE, Goh et al. (2003) reiterated the same point as Moore et al. (2000), namely that without consulting a physician there is a question of the safety of some nutritional supplements.

Alvarez-Nemegyei and Bautista-Botello (2009) examined CAM use and health status in 192 patients (94% female) receiving care at a rheumatology center in Yucatan, Mexico. The SF-36 and SLICC/ACR were used to assess quality of life and disease damage. More than half the patients (53.6%) were using some form of CAM although only two patients used their therapy as an alternative to conventional medical treatment. As in most studies, biologically based therapies were the most prevalent form of CAM, used by 81% of CAM consumers. The TRINATION study is a notable exception to that

pattern (Moore et al., 2000). Mind-body therapies were used by 13% of the sample and only a few participants used energy medicine or manipulation and body based practices (Alvarez-Nemegyei & Bautista-Botello, 2009). Close to one-third of the participants had tried several types of CAM therapies since their disease diagnosis.

As a group, the CAM users had higher cumulative disease damage and reported more physical pain (Alvarez-Nemegyei & Bautista-Botello, 2009). The CAM users in the TRINATION study also reported more bodily pain (Moore et al., 2000). However, the TRINATION CAM users did not have more disease damage. Noting the difference in CAM preferences between the participants in the TRINATION and their own study, Alvarez-Nemegyei and Bautista-Botello (2009) raised the issue of whether unregulated herbal and food supplements might have compromised the therapeutic effects of conventional medication or had toxic effects. Although the researchers specifically mentioned poor quality control in Mexico, the quality and composition of supplements sold in the U.S. can vary considerably as well (Moore et al., 2000).

Clinical Trials

Noting that there was minimal research into the benefits of physical exercise for reducing fatigue among patients with SLE, Tench et al. (2003) conducted a randomized clinical trial of a 12-week graded aerobic exercise program. The participants assigned to the exercise group were asked to exercise on their own at least three times weekly according to guidelines for aerobic activity. Participants in one comparison group engaged in relaxation sessions three times per week and the remaining group engaged in

their usual physical activity with specific instructions not to engage in additional exercise. A total of 93 participants comprised the full sample.

After 12 weeks, roughly half of the participants in the exercise group (49%) appraised their condition as “much” or “very much” better versus 28% of the relaxation group and 16% of the comparison group (Tench et al., 2003). The overarching finding was that the aerobic exercise regimen resulted in significant improvements in the participants’ self-assessment. Although the impact on fatigue *per se* was not as strong as the researchers anticipated, the instrument used to assess fatigue might not have been sufficiently sensitive. Only a few participants continued to exercise after the program because the gains they experienced from the program were not sustained. However, the benefits of exercise were illustrated by the continued reductions in fatigue enjoyed by the participants who were still exercising at the 3-month follow-up.

The exercise program did not produce gains in aerobic fitness, possibly because it was fairly easy. Tench et al. (2003) proposed that a more intensive or frequent program would probably result in greater benefits. While the study affirmed that aerobic exercise is safe and has therapeutic benefits for individuals with SLE, it also highlighted the need for a structured, supervised program with motivational strategies to keep participants engaged.

Greco et al. (2004) explored the benefits of a stress reduction program on the psychological and physical well-being and pain management of individuals with SLE who experienced physical pain. The sample was comprised of 92 patients randomly assigned to either a biofeedback CBT intervention (BF/CBT), a symptom-monitoring

support (SMS) program or a usual medical care condition. The BF/CBT intervention was a multifaceted, standardized 6-session protocol consisting of auditory electromyographic biofeedback from the trapezius region, progressive muscle relaxation, and CBT pain and stress management techniques. The SMS protocol involved discussing symptoms and other aspects of the disease with a therapist who listened empathetically, but refrained from offering suggestions for behavior change combined with daily symptom monitoring.

Compared to the participants in the SMS program or the usual care group, the BF/CBT participants enjoyed significantly greater improvements on a number of measures (Greco et al., 2004); these included reductions in pain, improved physical and psychological functioning, enhanced self-efficacy for symptom management, sustaining involvement in personally valued activities, and global self-assessment. Greco et al. noted that comparable improvements had been reported in prior research examining similar interventions with patients with other rheumatic conditions. This was the first study documenting the benefits of the BF/CBT program for patients with SLE.

Attitudes, Knowledge, and CAM Use of Health Care Professionals

Nurses

Rojas-Cooley and Grant (2006) explored oncology nurses' interest and knowledge of CAM along with their experiences with patients who inquired about CAM therapies. The sample consisted of 850 nurses drawn from the registry of the Oncology Nursing Society (ONS) in Pittsburgh, Pennsylvania. All the participants were direct patient care providers who completed the Nurse Complementary and Alternative Medicine Knowledge and Attitude Survey. The participants had ample experience in

patient care, but few had encounters with patients who brought up the topic of CAM. This is actually not surprising given that most patients are hesitant to initiate discussions of CAM (Shelley et al., 2009). Among patients who did ask about CAM, the most common inquiries were about prayer, megavitamins, special diets, massage, herbs, relaxation techniques, chiropractic, meditation, imagery, music therapy, and yoga. Other CAM therapies were rarely mentioned.

Patients' queries about and reported use of prayer far exceeded any other form of therapy (Rojas-Cooley & Grant, 2006). Rather than being unique to cancer patients, the strong reliance on prayer reflected a general U.S. population trend (Upchurch et al., 2007). Massage, relaxation, and megavitamins were also commonly used (Rojas-Cooley & Grant, 2006). According to Rojas-Cooley and Grant (2006), the pattern suggests that patients are probably most comfortable discussing therapies they feel are accepted by nurses, but reticent about bringing up more unusual therapies.

The nurses varied in the degree they were interested in learning about specific CAM modalities (Rojas-Cooley & Grant, 2006), but showed a general degree of interest in gaining more knowledge of CAM, so they could discuss different therapies such as special diet, relaxation, herbs and prayer with their patients and provide them with accurate information. Some nurses expressed interest in training to practice certain CAM therapies such as naturopathic medicine, Ayurvedic medicine, and traditional Chinese medicine with books, professional journals, and patients mentioned as the main sources of information. Rojas-Cooley and Grant proposed that turning to patients for information

on CAM could be symbolic of an open relationship built on mutual trust or else difficulty finding reliable materials on CAM.

Countering the numerous accounts of poor patient-clinician communication regarding CAM use, Coulehan (1999) stated, “it is surprising what patients will tell you if they feel that you’re not only willing to listen, but also interested” (p. 1468). He noted that he learned a great deal about CAM from his patients who included individuals with chronic or progressive diseases including AIDS, cancer, and degenerative neurological disorders, or with conditions such as chronic fatigue syndrome that are inadequately understood and treated by conventional medicine.

Nursing students often turn to informal sources and the popular media for information on CAM. Rojas-Cooley and Grant (2006) declared that, “As health care providers’ beliefs about integrating CAM into treatment for their patients with SLEs, nurses need to assist patients in making evidence-based decisions for the use of CAM therapies; therefore, without exception, nurses must be properly educated in CAM therapies” (p. 586).

Ben-Arye et al. (2006) tested the recommendations of Rojas-Cooley and Grant (2006) in their program that provided CAM education for family practice residents and specialists. Ben-Arye et al. noted that the recommendation of Rojas-Cooley and Grant (2006) were strongly aligned with the principles of integrative medicine. Rojas-Cooley and Grant’s first recommendation cited that nurses should become familiar with different CAM therapies, so they can confidently and easily discuss them with patients. The second recommendation, which is the creation of trusting relationships that promote open

and honest communication, is also related to the CAM education program by Ben-Arye et al. Third, nurses have the responsibility of educating patients about the potential benefits and risks of combining CAM with conventional medical treatments. Finally, Rojas-Cooley and Grant envision nurses as catalysts in bringing up patients' interests and use of CAM with other members of interdisciplinary health care teams. Using these recommendations, Rojas-Cooley and Grant asserted that the use of CAM on oncology patients is also applicable to patients with chronic illnesses. Saydah and Eberhardt (2006) also reported that CAM use is common and is more likely to be used by those with chronic diseases.

Tracy et al. (2005) investigated the use of CAM in professional practice in a sample of 726 critical care nurses. Virtually all the nurses used at least one form of CAM in practice; in fact, the median number of therapies utilized was nine. The most common modalities were among the most mainstream, namely diet (94.2%), exercise (92.7%), relaxation techniques (79.9%), and spirituality or prayer (73.1%). The least common therapies (<5%) were tai chi, Native American medicine, traditional Chinese medicine, and qi gong. More than half of the nurses (55%) had been approached by patients and their families with requests for the 4 most popular therapies along with massage and counseling.

Presented with a list of 28 CAM therapies, the nurses were asked to assess their perceived legitimacy (Tracy et al., 2005). Most of the therapies were considered legitimate and, for therapies with which the respondents were unfamiliar, they were more inclined to respond that they did not know rather than dismiss the therapy as not

legitimate. This overall tendency suggests that the nurses were open to more information about the prospective benefits of the various therapies. The overwhelming majority of respondents (>90%) were willing or eager to integrate CAM into their professional practice. Most desired more information and greater availability of CAM therapies in their practice settings for nurses as well as patients. Despite their enthusiasm, the nurses desired more scientific evidence of the safety and effectiveness of CAM therapies (Tracy et al., 2005). Addressing this issue through ongoing research is a central facet of the mission of the NCCAM (NCCAM, 2007).

Lindquist et al. (2005) examined regional influences on the use of CAM by critical care nurses. Regional differences routinely emerged in studies of CAM utilization (Artus et al., 2007; Barnes et al., 2008; Nedrow et al., 2007). The sample of 726 respondents represented a random sample of critical care nurses from all 50 states (Lindquist et al., 2005). In general, the nurses expressed similar attitudes toward CAM regardless of geographic location. Most were positive toward CAM and were eager to have CAM therapies more available for their patients and their own and their colleagues' use. However, there were some significant regional differences in the utilization of CAM for personal care. Nurses in the Northeast and Midwest used fewer CAM therapies than their peers in the West, Southwest, and Southeast. Massage, diet, exercise, music, counseling, and prayer were the most common forms of CAM for professional practice and self-care. Lindquist et al. (2005) are among the nurse researchers who regard these therapies as essentially mainstream (Rojas-Cooley & Grant, 2006; Tracy et al., 2005).

Physicians

Milden and Stokols (2004) explored the attitudes and practices related to CAM use by 51 physicians practicing in California. Among the participants in the small sample, 76% said they inquired about their patients' use of CAM. Although the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requires health care providers to ask their patients about CAM utilization (Lindquist et al., 2005), patient accounts indicated that this was not typically carried out (Saydah & Eberhardt, 2006). Close to two-thirds of the physicians (61%) said they discouraged CAM use because they were uncertain about the safety and efficacy of the therapies and 80% said they preferred exclusive reliance on conventional biomedical therapies (Milden & Stokols, 2004). Patients were typically wary of a clinician's disapproval (Shelley et al., 2009); the responses of the California physicians suggest their apprehension is not unwarranted.

The responses suggested the physicians were not opposed to CAM (Milden & Stokols, 2004). In fact, they were generally open to CAM therapies, but wanted to see more clinical trials and have more information resources and education in support of CAM practices. More than one-third of the physicians were willing to seek out online resources on CAM in conventional medical websites and even more (42%) were willing to search online databases such as PUBMED and MEDLINE. There was a significant relationship between the respondents' use of technology and positive attitudes toward using CAM. The physicians who expressed the most favorable attitudes toward CAM were also most likely to express intentions to use CAM practices.

Martz et al. (2006) conducted a series of structured interviews with 21 physicians practicing in a small rural community in the Southeast to determine what types of patients they would refer for CAM or health behavior therapies if they were available. They were unanimous in endorsing referral for patients who smoked, had mental health problems, and required exercise, diet, or weight management techniques. Primary care physicians were more apt than specialists to say they would refer patients for weight management, nonmedical pain management, physical therapy, herbal supplements, and pastoral counseling. Physicians who personally used physical therapy, herbal supplements, or pastoral counseling were most inclined to refer patients for the same therapies.

In contrast to the skepticism observed by Milden and Stokols (2004), Stange, Amhof, and Moebus (2008) found much more positive attitudes toward CAM in a sample of 516 German physicians representing 13 fields of medicine. Half the physicians (51%) said they were in favor of CAM and 26% of those said they favored CAM strongly. CAM practices often prescribed included physical therapy (71%), phytomedicine a special category of plant drugs, for example *Goldenseal -Hydrastis canadensis*) (67%), exercise (63%), nutrition and diet (62%), massage (61%), and relaxation techniques (55%). In effect, their responses largely parallel those of nurses in their endorsement of therapies that could be regarded as mainstream.

At the same time, the German physicians were also inclined to prescribe practices that are less common in the U.S. (Stange et al., 2008). These included homeopathy (38%), acupuncture (37%), and traditional Chinese medicine (18%). The study of Witt et al. (2008) suggests that homeopathy is accepted into routine care in Germany. Primary

care physicians were significantly more predisposed to use CAM than were specialists (Stange et al., 2008). Martz et al. (2006) suggest the primary care physicians might encounter more demand from their patients for CAM therapies. In addition, the nature of primary care may make physicians more open to the bio-psycho-social-spiritual care paradigm.

Stange et al. (2008) observed some distinctions regarding specific modes of therapy but overall the differences were minimal. Neither gender nor age affected the physicians' attitudes toward CAM. Among the California physicians, the oldest respondents who had been in practice the longest time expressed the strongest opposition toward CAM (Milden & Stokols, 2004).

Patient-Clinician Communication

Shelley et al. (2009) undertook a multifaceted qualitative exploration of patient-clinician communication about traditional (indigenous) medicine and complementary alternative medicine TM/CAM in a sample of 114 patients, 19 primary care providers, and 41 clinic staff members in Southwestern Native American and Hispanic communities in the Southwest where traditional and CAM practices are commonplace. Three major themes emerged from the analysis: acceptance and nonjudgmental attitudes, initiation of communication, and concerns related to safety and efficacy.

Regardless of whether they used the therapies generally or for a specific condition, the patients were clear in stating that the clinician should initiate discussion of CAM or the conversation would not take place (Shelley et al., 2009). The patients did not expect their conventional health care providers to be experts on CAM, but they felt that

initiating in a nonjudgmental manner would signify openness toward CAM, and thus, overcome their apprehension (often due to previous negative experiences). Ironically, some clinicians construed the limited communication on the subject to mean that CAM use was minimal. Many clinicians were genuinely concerned about the safety and efficacy of some therapies and were afraid they might compromise the effects of conventional treatments. Others expressed similar skepticism, but felt that open discussions were the best way to deal with the issue. For many clinicians time constraints presented a barrier to engaging their patients in discussions about CAM. Shelley et al. (2009) emphasized that clinicians need not be experts on CAM, but they should initiate communication and be candid about their limited knowledge. In general, patients prefer honesty, openness, a nonjudgmental attitude, and willingness to listen on the part of health care providers. To Shelley et al. and the patients they surveyed, training in communication skills is more important than education on CAM.

Qualitative Methods

Qualitative research is a method that elicits understanding of the phenomenon by generating meanings from the experiences, perceptions, and feelings of an individual or group of individuals (Flick, Kvale, & Angrosino, 2007). Qualitative research is appropriate to use when the intention of the researcher is to garner an understanding of a paradigm in which little is known about the problem or variables prior to the study (Creswell, 2005). According to Bogdan and Biklen (2006), qualitative research is used to understand how people make and live their lives. Qualitative research allows researchers to investigate the interpretations and meanings of the participants' actual settings

(Seidman, 2006).

Research in qualitative methodology includes the following types: biography, case study, ethnography, grounded theory, and phenomenology. According to Flick et al. (2007), a biography focuses on the life of an individual without any focus on a particular phenomenon. A case study method explores a specific topic and individuals are studied in their natural settings (Yin, 2009). In a case study, researchers gain in-depth understanding of real life phenomenon by collecting data within encompassed, important, contextual conditions (Maxwell, 2005). Meanwhile, ethnography is a method that describes and interprets a cultural or social group or system (Creswell, 2009). Grounded theory is a systematic approach of generating theories in an attempt to describe phenomena (Seidman, 2006). According to Creswell (2009), when the interest of the study is to understand phenomena by collecting information regarding the experiences of participants in the study, phenomenology is more appropriate than biography, grounded theory, ethnography, and case study (Creswell, 2009).

Phenomenology is a qualitative research design and is used to explore the experience of individuals from their perspectives (Moustakas 1994, van Manen 1990). This means that deep information and perception in the human sphere are gathered via participants' observations, discussions, or interviews. Elliot (2005) supported that the most appropriate method to achieve data validity and reliability in the target population frame is the semi-structured interview (Elliott, 2005). Phenomenological research is rooted in the philosophical works of Husserl and Heidegger. Husserl (1987) referred to essence as the true meaning of things. In phenomenological research, researchers have an

opportunity to examine a phenomenon through individuals who have experienced that phenomenon (Drew & Hewitt, 2006; van Manen, 1990). A phenomenological approach is appropriate when a researcher does not know nor has no existing instruments or measures available for the intended study population (Armour, Rivaux, & Bell, 2009).

The focus of this qualitative phenomenological study is on the awareness and perceptions of physicians and nurses of CAM use as a treatment modality in SLE care. Chapter 3 will provide a more detailed account of the qualitative design which will be used for this study. This phenomenological study will use the SDM model and the theory of Bandura. A more detailed description of these concepts and how these concepts are used in the present study will be presented in the subsequent section.

Operational Use of SDM Model and Theory of Bandura

The shared decision-making model served as a guiding framework in the analysis of the responses of the health care providers, particularly the joint decision process of the patient and provider in the treatment of SLE. Using the SDM model, I identified the activities of healthcare professionals that empowered patients around their options for healthcare needs. The model guided me in tracking the learning process of patients, in understanding the gravity of their diseases and the available healthcare services, alternatives, risks, and benefits surrounding their decisions. Within this framework, I determined the relationship dynamics of healthcare service providers and patients in the treatment plan of SLE.

Bandura's self-efficacy theory, on the other hand, was important in analyzing the influence of health practitioners on patients and vice versa in the integration of CAM in

the SLE treatment plan. With self-efficacy theory, I analyzed the personal values and beliefs of healthcare providers and patients, which influenced their options for the treatment plan. In the study, I posit that patients and healthcare providers have sets of values and beliefs that they wish to follow and implement in their daily interaction with other people. The theory was used as an analytical framework of the study in tracking the attitudinal and behavioral changes that occur between healthcare providers and patients. Both the SDM model and the self-efficacy theory were used to guide the development of the interview questionnaire and the analysis of the responses of the participants.

Alternative Methodologies

Although a qualitative approach was chosen as the research method, Trochim and Donnelly (2007) noted that two other approaches, quantitative and mixed methods, were appropriate for research studies. According to Creswell (2003), the quantitative approach employed measurement strategies to develop knowledge based on cause and effect. The quantitative method was not chosen because the research question was not seeking to measure relationships, but to explore meaning making the quantitative method inappropriate for this study. The mixed methods approach focuses on collecting, analyzing, and mixing both quantitative and qualitative data in a study. The main purpose of the mixed methods approach was combining quantitative and qualitative to provide better understanding of the research problem than either approach alone (Creswell, 2003).

As per Creswell (2003), the research question determined the research design. The qualitative approach was chosen as the best approach based upon the central research

question for this study. Thus, the phenomenological approach was applied (Moustakas, 1994), and was chosen as the best approach for the research question in this study.

In terms of the use of other qualitative methods for this study, case studies, grounded theory, ethnography, and narratives were considered. Case studies, according to Stake (2005), are investigations of cases as a “bounded system” focusing the case or an issue. Case study provides an in-depth study of the system from different sources allowing the researcher to converge the data to illuminate the case. The phenomenological approach was a better fit because the researcher is not seeking to explore a case or multiple cases. A grounded-theory approach was not a fit because the researcher is not interested in generating analytical schema of a phenomenon to generate theory.

Ethnography is qualitative research approach which involves the study of humans focusing on their beliefs, values and behaviors while interacting with their natural environment (LeCompte & Schensul, 2010). This study did not contain components of culture among healthcare providers. Therefore, the ethnography approach was not chosen. In the phenomenological approach, according to Husserl (1987) the purpose is to describe rather than explain perspectives. The phenomenological approach allowed me to bring to the forefront the perceptions of individuals.

According to Clandinin and Connelly (2000), the narrative approach in qualitative research focuses on studying individuals through the collection of their stories. The narrative approach bears some similarity to that of the phenomenological approach in that both capture the experiences and perceptions of the participants in the study. The

difference between the narrative approach and the phenomenological approach is the method of obtaining information. The participant in the narrative approach presents information as spoken or written words (Creswell, 2007). The phenomenological approach allowed the researcher to explore and allowed participants to express their individual perceptions. It was the phenomenological approach that allowed the researcher the potential to generate rich and viable data to produce significant research outcome.

Summary

Since the pioneer study of Eisenberg et al. (1993), surveys have consistently documented escalating use of CAM in the U.S. (Barnes et al., 2008; Eisenberg et al., 1998; Nahin et al., 2009). Although the surging interest in CAM is a global phenomenon that affects all population groups, CAM use is highest among individuals with chronic diseases and especially those who experience chronic pain (Artus et al., 2007; Rosenberg et al., 2008; Saydah & Eberhardt, 2006). Individuals with SLE are included in the growing ranks of those who are turning to CAM (Groh et al., 2003; Moore et al., 2000; Patavino & Brady, 2001).

Clinical trials have demonstrated the effectiveness of exercise and stress reduction techniques for reducing fatigue and pain, and enhancing the physical and psychological well-being of individuals with SLE (Greco et al., 2003; Tench et al., 2003). These therapies are often considered mainstream, as is DHEA for the treatment of SLE (Mok, 2006; Patavino & Brady, 2001). Nurses tend to view the line between conventional and CAM therapies as increasingly fluid and many use CAM therapies to personally endorse their use for their patients (Lindquist et al., 2005; Rojas-Cooley & Grant, 2006; Tracy et

al., 2005). At the same time, most acknowledge a need for more education regarding the use of CAM. German physicians tend to be highly favorable toward CAM (Stange et al., 2008), while the overall view of CAM by U.S. physicians is a high level of skepticism (Milden & Stokols, 2004). Communication between patients and health care providers remains a persistent obstacle to the effective integration of CAM into conventional medical care (Saydah & Eberhardt, 2006; Shelley et al., 2009).

SLE continues to be a difficult disease to manage due to the limited knowledge of its etiology. Thus, treatment modalities have proven to be challenging for healthcare providers. Despite the safety concerns regarding CAM use, the number of people with SLE who have embarked on the use of CAM therapies has increased. CAM use frequency in patients with SLE has been reported as consistently high (Alvarez-Nemegyei, & Bautista-Botello, 2009). Understanding that every patient response to treatment is unique will lead to better coordination of care between people living with SLE, nurses, and physicians regarding CAM use. Further detail relative to the qualitative research methodology was provided in Chapter 3.

Chapter 3: Methodology

Introduction

The purpose of this study was to explore the attitudes toward, perceptions of, and experiences of CAM use of physicians and nurses who regularly provide care to patients with SLE. The focus of this study was gaining insight and understanding of the knowledge, beliefs, and experiences of physicians and nurses regarding CAM use and their relationship to the integration of CAM into treatment for patients with SLE. This chapter contains descriptions of the methodology of the research study, the research design, and the instrument used. The chapter also includes a discussion on why the phenomenological research design was used. The chapter offers a discussion of the sample population, the sampling plan and procedure, data collection, and data analysis. Information regarding the participants recruited for the study, as well as how data were collected from them is included. The chapter concludes with a summary highlighting the key points.

Research Design

In this study, I used a phenomenological approach to examine the knowledge, beliefs, and experiences of physicians and nurses regarding CAM use and their relationship to the integration of CAM into treatment for patients with SLE. Qualitative research is appropriate to use when the intention of the researcher is to garner an understanding of a paradigm in which little is known about the problem or variables prior to the study (Creswell, 2005). According to Onwuegbuzie and Leech (2007), qualitative researchers are interested in capturing “lived experiences” (p. 238) of individuals who

have first-hand information regarding a phenomenon. Qualitative research is used to understand how people make decisions and live their lives (Bogdan & Biklen, 2006). Qualitative research allowed me to investigate interpretations and meanings in the participants' actual settings (Seidman, 2006).

Phenomenological research is essential in understanding the collective meaning of the experiences of an individual or group of individuals (Moustakas, 1994). The approach was appropriate in generating meanings of events based on participants answering questions to describe and understand the phenomena from their points of view (Leedy & Ormrod, 2001). Phenomenological research allows for understanding, exploring, and interpreting social issues from participants' lived experiences and the development of new concepts or theoretical perspectives about the phenomena to be studied (Leedy & Ormrod, 2001).

Research Questions

The following research questions guided the study:

RQ1: What is the level of knowledge regarding CAM therapies among health care providers working with SLE?

RQ2: What experiences have these health care providers had with CAM therapies?

RQ3: What barriers have these health care providers experienced in communicating with their patients about CAM use?

RQ4: What are health care providers' beliefs about integrating CAM into treatment for their patients with SLE?

RQ5: What are these health care providers' perceptions of (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative treatment?

Role of Researcher

There were two roles that I intended to fill in completing this study. First, I intended to separate my personal and professional affiliation with the participants and their clinic, respectively. The separation of myself as the researcher from the participants as well as from the organization included in the study was necessary in ensuring that potential biases were prevented. In addition, as a practitioner of CAM, I intended to separate my personal views, judgment, and experiences in the collection and the analysis of my data.

Second, in my role as a researcher, I needed to process and complete all the requirements to gain access to the participants. I invited those health care providers who regularly provided care to patients with SLE and had been practicing CAM for at least a year in Long Island Rheumatological Clinic in the State of New York to participate. I was also responsible for the preparation of invitation materials for the participants. Moreover, I developed informed consent forms to ensure ethical treatment of participants who agreed to participate in the study. I ensured that participants' confidentiality was protected at all times. I conducted all necessary data analyses to answer the research questions for this study.

Recruitment of Participants

Qualitative research normally involves small sample sizes, as compared to quantitative research, which normally relies on larger sample sizes. Creswell (2005) recommended that the size of a qualitative sample range from 1 to 25 participants, and Polkinghorne (2005) suggested that qualitative research include sample sizes of 5 to 25 participants. According to Patton (2002), “Sample size depends on what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, and what can be done with available time and resources” (p. 244). The phenomenological approach can accommodate sample sizes from 5 to 25 or more participants. However, most qualitative studies tend to use between 10 and 20 participants (Creswell, 2005; Patton, 2005; Polkinghorne, 2005).

For the purpose of this study, a total of 10 participants were recruited. Specifically, the sample included five physicians and five nurses who regularly provided care to patients with SLE in the Long Island Osteoporosis and Arthritis Center in the State of New York. The inclusion criteria included those physicians and nurses who (a) themselves had practiced CAM on patients for at least a year and (b) regularly provided care to patients with SLE using CAM or other treatments. All physicians and nurses in the clinic who had knowledge of CAM had an equal chance of participation in the study, regardless of whether they were currently using CAM, as long as they had previously used CAM on patients for at least a year in their clinical practice. Therefore, the possibility that there were participants who were inactive in the use of CAM to treat SLE was expected.

A snowballing sampling approach was used to recruit qualified participants. Creswell (2005) defined *snowball sampling* as a technique in locating participants who have the information needed for a study. In this study, I started by recruiting one nurse and one physician, and had them suggest other physicians and nurses who might qualify to participate in the study. The recruitment of participants ended when the required number of 10 participants was reached.

I verified the personal information of the participants who were suggested by the participants of the study. When a potential participant qualified to participate in the study, a letter of invitation was delivered personally to the potential participant (Appendix B). The letter of invitation contained the study's purpose and the procedure to participate in the study. When participants decided to participate, they were asked to contact me to schedule an interview. However, regardless of participation in the study, all potential participants were asked to recommend a health care provider whom they thought met the study criteria. I proceeded to recruit the potential participants recommended by the first participants. This process was followed such that the required number of participants was reached. It was also through recommendations from other participants that a physician's assistant was recruited to complete the minimum number of participants in this study.

Data Collection

When the potential participants agreed to participate, specified interview times were set to meet and speak privately so that the information was confidential. The venue of the interview therefore depended on the comfort of the participants and where information could be kept private and confidential. Before the interview, the study was

explained, including the procedures to protect the participants' confidentiality, the audio recording procedures, and the consent form. Each participant was asked to review the consent form and given an opportunity to ask questions. The consent forms were signed and placed in a secure folder. Consent forms included such personal information as name of participant, phone number, and email address (see Appendix D). These consent forms have been kept confidential and will be stored in my home office in a secured file cabinet for 7 years.

After the consents were signed, the audio-recorded interviews proceeded. Individual interviews were conducted to explore the awareness and perceptions of the physicians and nurses who care for patients with SLE. I began the interview by starting a social conversation to help create a relaxed atmosphere (Moustakas, 1994). By creating a relaxed atmosphere, a rapport developed and enabled the participant and the researcher to feel comfortable before answering questions. Once a comfortable level had been reached, the interview questions began. In a hermeneutic phenomenological study, interviews and field notes are used for data collection. The interviews with the participants encouraged them to describe the phenomena in their own words. The interview questions were open-ended to allow the participants to express their experiences and feelings. The interviews were scheduled to last up to 45 minutes, with an additional 15 minutes to accommodate clarifications from either the participant or the researcher.

Instrument

I used an interview guide (Appendix A), reviewed by a panel of experts for clarity of words and alignment of interview questions to the goal of the study. The results of the expert panel review were then integrated into the instrument. After IRB approval, the instrument was then pilot-tested with two individuals who represented the study participants.

Pilot study. The pilot test ensured the content validity of the instrument, the main objective being to determine the appropriateness of the questions as evaluated by the representatives of the study population. The recruitment of the representatives for pilot testing followed the snowballing sampling technique. I recruited one nurse and one physician who had the qualification to represent the sample population of the study. The data from these representatives were excluded from the analysis.

The results of the pilot testing process were consolidated for presentation to the panel of experts. The changes recommended by the pilot-test representatives and the panel of experts were considered in revising the instrument that was used in the actual interviews. The process ensured that possible misrepresentations were eliminated and interview questions were clear and appropriate for the research questions.

In the first part of the interview (see Appendix A), questions regarding the profile of the participants were asked. In the second part of the interview, questions were asked regarding the: (a) level of knowledge regarding CAM therapies, (b) perceptions in communicating with patients about CAM, and (c) beliefs about integrating CAM into treatment of patients. All audio-tapes were transcribed by the researcher and the transcripts were emailed to participants to review them for accuracy. Once all the information met the approval of each participant, the analysis of the individual participant's data began.

Data Analysis

The structured interview questions were based on the research questions of the study. The interviews were conducted face-to-face, recorded, and transcribed to ensure accuracy and verifiability. Creswell (2005) suggested that content analysis categorizes and synthesizes qualitative text data. From the categorization and synthesis of data, themes are expected to emerge.

Neuman (2003) described the process of data analysis as a means to search for patterns to explain the goal of the studied phenomena. For the present study, the responses of participants in the structured interviews were used in determining the patterns that can explain the phenomena. In this study, I used an open-coding system to analyze participants' narrative responses line-by-line, phrase-by-phrase and word-by-word (Creswell, 2003).

Moustakas' (1994) method of phenomenological analysis was used to analyze the responses from the interviews. Moustakas' four-step process of analysis involved the use

of research epoche, phenomenological reduction, imaginative variation, and the synthesis of meanings and essences. These steps allowed the development of a composite description of meaning and the essence of the experiences of the participants.

Epoche is the process of setting aside one's bias and prejudgments to capture the intended meanings that the interviewees wanted to tell the researcher (Moustakas, 1994). This stage was important because the interpretation of data needed to be objective. The beliefs that I held were set aside while interpreting the data.

The second step involves the process of reduction (Moustakas, 1994). Reduction is the process of situating the responses of the participants within an existing knowledge framework, which is the literature. Through reduction, every unique idea that each individual communicated during the interview will be given a name or code. The use of imaginative variation is the third step in Moustakas' (1994) method of analysis. In this stage, I created themes based on ideas that were similar. The codes that emerged across participants will be arranged into themes.

The last step of Moustakas' (1994) method of phenomenological analysis is the synthesis of meanings and essences (Moustakas, 1994). In this stage of the analysis, the themes were used to create a narrative that represents the experience of the entire sample. Findings are presented in chapter 4.

The constant reflection of the data is an important part of this study. I utilized NVivo 10 (QSR International) to track and analyze the data; I reviewed all transcripts to note my personal analysis and biases (Creswell, 2009). In conclusion, the data were analyzed to develop themes to illustrate/explain/show the attitudes, perceptions, and

experiences of CAM use of healthcare providers who regularly provide care to patients with SLE.

Issues of Trustworthiness

Credibility

The participants of the study ensured the credibility of the study. The process of generating credible results required me to provide the transcriptions of the audio-recorded interviews for review of the participants. The transcripts were emailed or handed over to the participants. They were asked to review for accurateness and clarifications of their responses. The intention of the review was to ensure that inaudible words were properly corrected.

Transferability

The study was limited to the knowledge, attitude, and practice of integrating CAM in the treatment for patients with SLE as perceived by physicians and nurses in Long Island, New York. The results of the study, therefore, can only be applied in healthcare environment and professionals that have similar characteristics. Transferability of the study was confined within the scope and limitations of the study.

Dependability

I intended to provide the need to understand the integration of CAM in the treatment of patients with SLE within the context of health care providers who had the knowledge and experiences of CAM application in Long Island, New York. The study design and instrument used in the present study cannot be replicated in other healthcare

setting because the context of the other environment may not be similar to the current environment of the participants included in the study.

Confirmability

In this study, I intended to review the data results with the findings of the past research. The process determined whether recent findings were related or confirmed from other research findings. The process also ensured that distortion or outliers observation are recorded, defined, and discussed within the context of the present study.

Ethical Considerations

I was responsible for the ethical issues and data collection procedures to achieve the purpose of the study. As such, I ensured that before implementing any mechanism to gain permission or contact participants, an approval from Walden University's Institutional Review Board (IRB) was secured. Gaining the trust and support of research participants was critical to informed and ethical academic inquiry in phenomenological research (Marshall & Rossman, 1995; Walker, 2007). I contacted each participating health care provider to discuss the study and the requirements of the participants during the study.

A letter of invitation was handed to the participants during the initial meeting. During the meeting, I personally discussed the objective of the study and other information that was stipulated in the consent form. A consent form containing the purpose of the study, the confidentiality clause, and their rights as participants of the study was provided once the participants verbally agreed to participate in the study. I

explained that participation in the study was voluntary and participants could withdraw from the study at any time.

In maintaining the ethical procedure in the collection of data that involves human subject, I conducted the interview in a private and comfortable venue. The participants were asked for their preferred venue. I reminded the participants that the venue must provide them with appropriate comfort and privacy. I also reminded them that the interview would be audio-recorded.

Confidentiality of protected information was maintained according to the research ethical standards. As such, data was collected and recorded in such a manner that subjects were not identified directly or through identifiers linked to the subjects. The process required me to assign numerical codes to all participants involved in the study. These codes were used to associate the responses to specific participant. All paper and electronic copies of the transcript, data analysis, and audio-recorded materials were secured in a locked repository and are maintained for seven years after the conclusion of the research. These documents and materials will either be shredded or burned after the required time of research.

Summary

Chapter 3 presented the methodology used for the qualitative phenomenology study. The discussions in this chapter provided insight on the direction of the study and the choice of methodology. The chapter also included discussions on population, sample, data collection and data analysis of the research according to the research process. Chapter 4 presented the results of the analyses as related to the research questions.

Chapter 4: Data Analysis and Results

Introduction

In Chapter 4, the findings of the study in relation to the research questions are reported. The purpose of this qualitative phenomenological study was to gain insight and understanding of the knowledge, beliefs, and experiences of physicians and nurses regarding the use of complementary alternative medicine and their relationship to the integration of CAM into treatment for patients with systemic lupus erythematosus. This study was conducted to further explore the experiences of medical practitioners regarding CAM. I used a phenomenological approach as determined by Moustakas (1994), as the focus was the lived experiences of the participants. A total of 10 face-to-face interviews, all audio-recorded and composed of open-ended questions, were conducted with registered nurses, a physician assistant, and medical doctors who cared for patients with SLE. The purpose of the data collection was to address the following research questions.

RQ1: What is the level of knowledge regarding CAM therapies among health care providers working with SLE?

RQ2: What experiences have these health care providers had with CAM therapies?

RQ3: What barriers have these health care providers experienced in communicating with their patients about CAM use?

RQ4: What are health care providers' beliefs about integrating CAM into treatment for their patients with SLE?

RQ5: What are these health care providers' perceptions of (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative treatment?

Pilot Test

The data collection instrument (Appendix A) was pilot tested with two individuals, one physician and one nurse, who represented the study participants. The interviews took place after I received approvals from the Walden University Academic Board and Institutional Review Board from the participating organization. The pilot interviews were conducted to determine whether there were any obstacles or pitfalls that might impact the data collection. The pilot test participants did not recommend changes to the question content and language selection. Thus, there was no need for any changes in the question design, wording, or instructions. Creswell (2008) stated that in a qualitative study, ensuring that the instrument provides the opportunity to elicit adequate and thorough information from the participants is important. The interview questions asked reflected what they were intended to reflect; thus, no revision of the instrument was needed in the study. Information obtained from the pilot study was not used in the analysis.

Setting

The interviews for the study were conducted face-to-face with the medical practitioners. Interview scheduling depended on the availability and the most convenient time and setting for the respondents. Participants were interviewed in the setting of their choice. Three participants were interviewed in a reserved room in the library, which was

conducive to thoughtful responses. One participant chose a quiet area in a park; when asked why she had selected a park, she reported that she loved being outdoors and that she was better able to think there. The other participants were interviewed in their personal offices at work. No personal or unforeseen circumstances occurred to disturb the interview process.

Demographics

The participants of the study were four physicians, one physician assistant, and five nurses who cared for patients with SLE, whom I recruited from the Long Island Osteoporosis and Arthritis Center in the state of New York. These health care providers had 5 to more than 30 years of experience of care for participants with SLE. All participants held New York licenses in their health care practices and had direct contact with patients.

The demographics of the participants can be found in Table 1. The participants were assigned with individual designated code numbers to protect their identities, as agreed upon in the informed consent signed by both the medical practitioners and myself before the interviews started.

Table 1

Basic Demographics of the Participants

	Profession	Number of years in service to patients with SLE
Participant 1	Registered nurse practitioner attending SLE patients	15 years
Participant 2	Registered nurse working with SLE patients	20 years
Participant 3	Registered nurse working with SLE patients	10 years
Participant 4	Medical doctor specializing in rheumatology	30 years
Participant 5	Registered nurse working with SLE patients	30 years
Participant 6	Medical doctor practicing preventive and nutritional family medicine (specializes in traditional and complementary medicine)	30 years
Participant 7	Medical doctor specializing in the use of natural remedies for the treatment and prevention of chronic disease	21 years
Participant 8	Physician assistant specializing in rheumatology	15 years
Participant 9	Registered nurse working with chronic disease including SLE	5 years
Participant 10	Medical doctor specializing in integrative health in chronic disease	32 years

Data Collection

Data collection began once the Walden IRB reviewed and approved my data collection instrument, data collection methods, storage and security protocols, and treatment of human subjects prior to data collection (Walden University IRB approval # 04-22-13-0074686). Ten participants who met the inclusion criteria and agreed to participate were questioned to ensure that they were licensed professionals in their scope of practice. The study was explained, including the procedures in place to protect the participants' confidentiality, the audio recording procedures, and the consent form. The consent forms (see Appendix D) were signed and placed in a secure folder, which have been kept confidential and have been stored in my home office in a secured file cabinet; they will be retained for 7 years. Specified interview times and places were set up at the convenience of the participants. Participants were asked to choose a convenient date and time for the interview, as well as a location that was private, quiet, and not distracting (i.e., conducive to conversation; see Table 2). Before the interview, each participant was asked to review and sign the consent form and was given an opportunity to ask questions. After the consents were signed, the audio-recorded interviews proceeded. Interview questions were based on the research questions addressed in the study.

Table 2

Participant Contact Details (2013)

Participant	Date responded	Date qualified	Date interviewed	Interview length	Transcript approved
P-1	July 15	July 15	July 17	12 :30	July 18
P-2	July 15	July 15	July 17	20:15	July 18
P-3	July 17	July 18	July 18	15:13	July 19
P-4	July 19	July 19	July 20	10:08	July 20
P-5	July 22	July 22	July 23	15:30	July 24
P-6	July 25	July 25	July 26	13:31	July 27
P-7	August 2	August 2	August 3	17:45	August 4
P-8	August 5	August 6	August 6	23:30	August 7
P-9	August 8	August 8	August 9	14:03	August 10
P-10	August 8	August 8	August 10	13:21	August 11

Note. Lengths of interviews stated in minutes and seconds.

Data Analysis

The Process

To determine the themes, an open-coding system was employed to analyze participants' narrative responses line-by-line, phrase-by-phrase and word-by-word (Creswell, 2003). NVivo 10 by QSR International, a computer-assisted software program, was used to code and categorize the large amount of text and identify recurring themes. The transcripts were viewed and approved by participants who confirmed that interpretations drawn from the transcription were acceptable and in accordance with the information provided. Moussakas' (1994) four steps to phenomenological analysis are: (a) epoche; (b) phenomenological reduction; (c) imaginative variation; and (d) the synthesis of meanings and essences.

The first step known as the "epoche" was the process wherein the researcher sets aside bias and predispositions to acquire the meanings that the interviewees or

participants of the study wanted to convey to the researcher (Moustakas, 1994). The second step, the “process of reduction”, is the stage wherein the researcher assigns names or codes to every distinctive thought that each participant shared and communicated (Moustakas, 1994). Key words, phrases and statements directly related to the phenomenon under study were identified as a way for coding. The third step, which was the “imaginative variation”, is the process where themes are formed based on the codes from the interview transcripts. The perceptions and experiences as well as the themes created were based on common ideas across participants, and then were grouped and clustered together in order to form one universal thought; this was done per research question as seen in Table 3 (Moustakas, 1994). Lastly, the final step of Moustakas’ (1994) method of phenomenological analysis was the “synthesis of meanings and essences” which is the "intuitive integration of the fundamental textural and structural descriptions into a unified statement of the essences of the experiences of the phenomenon as a whole" (Moustakas, 1994, p. 100). In this step, I made sense of the themes identified, and their properties. Inferences were made and the meanings derived from the data were constructed to identify the relationships between the themes identified.

Table 3

Codes From Participants' Interviews

Question	Code	# of responses
1	Knowledgeable and well-rounded with CAM	5
1	Very little knowledge of CAM	2
1	Moderate level knowledge of CAM	3
2	I learned CAM as part of my studies	5
2	I learned CAM from family and friends	3
2	I learned CAM from my patients	2
3	Had treatment as a patient with an alternative medical system	4
3	Consulting and using a CAM practitioner for myself	3
3	No personal experience with CAM	3
4	My belief in CAM has helped me in treating my patients	6
4	I do not believe in CAM	2
4	I believe patient should have the choice	2
5	Provide information to the patient in order to facilitate their decision	6
5	Treatments often offer a chance to take control, feel better, and decrease uncomfortable symptoms	2
5	Provide more conclusive evidence on result	4
5	Enhanced patient and provider communication	5
5	Provides fresh perspective on healing	3
6	Patients are part of the decision making process	7
6	Patients do not discuss CAM	3
7a	I explore what research is available about this treatment's safety	6
7a	I explore the therapy myself and provide information to the patient	2
7a	I do not believe that there is enough evidence to support CAM	2

Emerging Themes

Grouping the codes in clusters of similar responses allowed the development of themes (see Table 4).

Table 4

Themes

Theme	Codes associated
Knowledge and experiences with CAM varied	Knowledgeable and well-rounded with CAM Moderate level Very little knowledge of CAM I learn CAM as part of my studies I learn CAM from form family and friends I learn CAM from my patients
Personal experience, perceived effectiveness lead to patient guidance and advice	Had treatment as a patient with an alternative medical system Consulting and using a CAM practitioner for myself My belief in CAM has helped me in treating my patients I believe patients should have the choice
Participants perceived benefits to CAM use	Health benefit, evidence for efficacy, patient demand, and holistic care Lack of clear patient benefit Many fad products that are out there Very few have expressed the desire to use CAM to treat their SLE symptoms
Participants as patient advocates	I explore the therapy myself and provide information to the patient I explore what research is available about this treatment's safety Provide information to the patient in order to facilitate their decision Patients are part of the decision-making process Patients do not discuss CAM Treatments often offer a chance to take control, feel better, and decrease uncomfortable symptoms I do not believe that there is enough evidence to support CAM
Initiative for further research	Provide more conclusive results Provides fresh perspective on healing Enhanced patient and provider communication

Five main themes were determined from the data analysis, as shown in Table 3. These themes, formed by coding responses into clusters and categorizing according to the highest number of responses of the participants, were as follows.

Theme 1. Knowledge and experiences with CAM varied. Participants were asked to identify their level of knowledge and experience regarding CAM. The level of knowledge and experiences of the healthcare providers regarding CAM therapies varied. Respondents reported a range of knowledge and experiences from very high to very little knowledge. As shown in Table 2, five participants were knowledgeable and well-rounded with CAM, three participants had a moderate level of CAM knowledge, and two participants had very little knowledge of CAM. The theme relates to all of the participants whose knowledge and experience varied. Some participants had strong knowledge, competence, and ability to impart and explain the use of CAM therapies to their patients.

Participant # 2 shared:

I believe that I am very knowledgeable and well-rounded in CAM therapies which were the focus of my master's degree. I have been practicing CAM from a young age. I never delved into it much until I got sick and refused traditional medicine and turned to CAM for healing. My master's degree is in nursing with a specialization in alternative medicine with a focus on the many alternative treatments out there.

Participant # 4 also shared having a high level of knowledge:

I have lived CAM all my life and have advanced training in academic studies.

Participant # 6 stated:

I believe that I am very knowledgeable in CAM therapies with over 30 years of experience in holistic/preventive/complementary and conventional medicine.

Participant # 7 explained his CAM experience,

I am very knowledgeable and well-rounded while specializing in the use of natural remedies for the treatment and prevention of disease in CAM therapies. My parents taught me the importance of CAM while a young girl.

Participant # 10 who has been attending to SLE patients over 32 years stated,

I am a practicing physician in integrative medicine. I offer natural remedies to help with the reverse and prevention of various illnesses and diseases to my patients, because they are looking for treatment that leaves no lasting side effects, and they are part of the decision in their health solutions.

Comments from two of the participants indicated that they had very little knowledge about CAM therapies, and thus, could not explain or discuss CAM with their patients. The experience pertains to the belief of the participants that their level of knowledge and expertise with regard to CAM therapies is not enough to explain even the basics to their patients.

Participant # 1 stated that, although he knows a little about CAM, he added,

I don't know enough to explain therapies to a patient.

Participant # 8 simply stated that he has "Very little knowledge of CAM." Participant # 9 reported no personal use of CAM. She practices conventional medicine and found it difficult to alternate between both. Finally, three of the respondents said that they had a

moderate level of understanding based on information from their friends, families, and personal experiences with CAM therapies. The experience pertains to the balanced, but limited level of knowledge of the participants with regard to CAM therapies.

Participant # 5 added:

My knowledge level is moderate. I learned about CAM therapies from a few seminars that I have attended due to curiosity.

Overall, for the thematic label of the practitioners' knowledge and experiences with CAM, there were three levels noted: (a) knowledgeable and well-rounded with CAM; (b) moderate level [of knowledge]; and (c) very little knowledge of CAM.

Theme 2. Personal experience and perceived effectiveness lead to patient guidance and advice. This theme relates to the participants' experience regarding CAM as an effective alternative. Forty percent of respondents themselves have had a personal treatment using an alternative medical system and have integrated the practices of CAM into their life because they found it to be effective. In addition, approximately 30% considered CAM effective and considered it necessary that patients be informed and discussed CAM use with them, based on their personal knowledge of the perceived effectiveness of these therapies for specific conditions.

The participants shared the following.

Participant # 3 explained:

Approximately 2 years ago, I was told by an emergency room physician that my white count was extremely low. I decided to change my diet, and sought treatment with a comprehensive medical center that utilized an alternative approach to care.

A complete lifestyle change coupled with exercise and other therapies was recommended thereby improving my health.

Participant # 4 shared:

My personal use of CAM is that it fits into my way of life/philosophy and is a practice that I have engaged in from a young man. As matter of fact in my office, I have a chart of all the herbs with their use and side effects.

Participant # 6, an educator and advocate of CAM, explained:

When I was in medical school in the mid 1970's, I knew that something was missing when I raised my hand in class one day and begun discussing vitamin C and other lifestyle, dietary, and nutritional techniques to treat disease as an alternative to just suppressing the symptoms with drugs; and got seriously ridiculed and criticized. I live and breathe CAM. It is who I am.

Three respondents said that they had received treatment as patients using an alternative medical system by consulting other CAM practitioners to learn more about the treatment. This perception pertains to the experiences of the participants about CAM from consulting other CAM practitioners to gain more knowledge about the field being discussed.

Participant # 2 stated:

My personal experience is that of consulting and using a CAM practitioner for myself. The CAM practitioners consulted included massage therapist, chiropractor, and homeopath. I find that there is great benefit from consulting with the different type of CAM professional. My experience with SLE is based on

traditional medicine. However, if my patient is interested in using CAM, I would not deter them because I have experienced the benefits from CAM in my own life. Meanwhile, 30% of participants had no experience with CAM therapies.

Theme 3. Perceived benefits of CAM use. The third theme suggests that there are benefits to using CAM. Sixty percent of participants reported that CAM appealed to their beliefs and values about health. CAM also offers them the opportunity to take control of their lives and feel better. This was because the respondents had full belief in the benefits of CAM treatments and did not state any hindrances in communicating CAM to their patients. The theme was deduced from experiences of six participants who had full belief in the benefits of CAM treatment based on health benefits, and evidence of efficacy.

Participant # 4 stated:

Most of my patients are open regarding CAM usage. They would request combining CAM with Conventional medicine. Factors that facilitate my decision to recommend or use CAM are patient honesty with what they are taking. Another factor is that patient brings as much information as they can to their doctor visit.

Supporting the third theme developed was four of the six participants who also believed that CAM provided a more conclusive result to a patient's condition. Participant # 1 simply stated that:

CAM provides more conclusive results to patients' condition and that patients tend to be more satisfied.

Participant # 6 shared the benefits on why CAM should be considered by patients,

Factors facilitating my decisions to use or recommend CAM are disease reversal, patient reaching maximum health, patients taking the time and effort to learn and understanding how their body functions, and what it really needs to survive and thrive!

Participant # 7 stated,

Factors facilitating my decisions to use or recommend CAM include my years of experience with CAM, the concept of wellness and the relationship between the minds, body and spirit and the reduction in stress, improve well-being, prevent illness, avoid or minimize side effects and symptoms for conventional medicine.

Theme 4. Participants as patient advocates. The fourth theme that emerged from the study was the health care providers' beliefs about integrating CAM into treatment for their patients with SLE. The participants believed that: integrating CAM into treatment for their patients with SLE should require cooperation and collaboration between the two parties. The fourth theme, which relates to the belief of the medical practitioners that in order to properly integrate CAM into treatment for their patients, there is a great need for cooperation from both parties especially for further research, and at the same time the decision of the patients after. They also provided information to patients so that they can make and be a part of the decision making process. Sixty percent of the participants stated they explored the safety of the treatment modality before making recommendation to patient while 40% of the participants explored the therapy themselves before providing the information to patients.

Participants 10 stated,

My role is to encourage and support patients in their efforts to take personal responsibility of their own health. If the patient is knowledgeable about the therapy intended to use, I will explore the therapy myself and provide information to the patient in order to facilitate their decision.

Participant # 9

I evaluate the efficacy of the therapy by exploring the research that is out there and the particular therapy that I am engaging in. I also looked at the clinical trials on the therapy as well before recommending therapy to my patient.

Participant # 8 said,

There are many different levels of evidence and it is important to understand the relative strength and weaknesses of each. I also conduct rigorous research which is essential to know whether a treatment helps SLE condition does nothing or worsens it.

Participant # 2 said,

If the patient is an informed consumer, I would also find out what scientific studies have been done on the safety and effectiveness of the complementary product or practice that interests the patient. I am open if they are willing to discuss the information with me before making a decision.

Participant # 8 simply and straightforwardly stated that: “No, my patients do not discuss CAM and I do not use CAM myself.”

Theme 5. There should be an initiative for further research. The theme emerged related to the fifth research question of the study which was the healthcare

providers' beliefs about the perceptions of: (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative treatment. It was known that the participants believe that there should be an initiative for further research and tests from the medical practitioners and other stakeholders about CAM as a therapy to prove and ensure the patients about CAM's safety and treatment.

Overall, 75 % of the participants believed that there should be an initiative for further research. Further research pertains to tests from the medical practitioners and other stakeholders about CAM as a therapy to prove and ensure the patients about CAM's safety and treatment.

Participant # 1 stated,

As a medical practitioner, I believe that I have the responsibility to further research, and explore CAM in order to help in increasing the standards of the therapy, and thus, improve its reputation in the field of medicine.

Participant # 2 shared,

With future initiative for future research the trend will be the integrating of CAM into conventional medicine will be the major tool for health promotion and disease prevention.

Participant # 9 stated,

For CAM to be accepted, future research is needed to provide more conclusive results.

Participant # 4 stated,

Future research will help to foster patient-centered communication resulting in agreement between patient and provider. Patient–center communication will reduce misunderstanding and enhance the quality of patient provider relationships.

Discrepant Cases

I established inclusion criteria in the recruitment of the participants of the study. The inclusion criteria included those healthcare providers who: (a) themselves practiced CAM on patients for at least a year, and (b) regularly provided care to patients with SLE using CAM or other treatments. Furthermore, it was important that participants have knowledge and that regular provisions of health care using CAM does not necessarily account their current experiences. These criteria had become the sources of the discrepant cases found in the analysis of the data. In the criteria, I did not qualitatively define the level of CAM knowledge required in a participant. As such, three health care providers (one physician and two nurses) claimed very low educational knowledge of CAM. The three participants learned about CAM from patients who used them. Although, they did not support the information they willingly shared the information garnered from some patients with other patients who were interested in CAM. They also had no personal use of CAM. All three health care providers believed and subscribed to the conventional model. They saw no need to evaluate the efficacy of CAM use. They believed that there was a lack of convincing evidence that CAM use was effective, safe and affordable. Yet, they were open to communicate with patients who saw the benefits of CAM.

Evidence of Trustworthiness

Trustworthiness

Lincoln and Guba (1985) suggested that trustworthiness is established when findings reflect the true meaning described by the participants. For this qualitative phenomenological study, I created validity and reliability through the characteristics of credibility, transferability, confirmability, and dependability. Face-to-face interviews were recorded and transcribed verbatim. Participants were asked to approve the transcriptions as true prior to use. To prove trustworthiness, the transcripts are kept securely as required by the research protocol in accordance with privacy.

Credibility (Internal Validity)

Credibility is the confidence one has in the truth of the findings. Credibility in qualitative work is associated with internal validity (Bryman, 2004). Lincoln and Guba (1985) ensures that the data speaks to the findings reported. Credibility embodies three methods, member checking, triangulation and negative case analysis. Two of these methods were used in this study. My method of data collection was interviews, which was time consuming. The interviews with the ten participants were not interrupted and did not end abruptly to avoid miscommunication and unclear responses. Based on the questions asked, participants conveyed their ideas and thoughts during the interview process (Patton, 2002). Furthermore, member checks were performed with all 10 participants to ensure the accuracy of the transcripts. Participants confirmed that interpretations drawn from the transcribed data were acceptable and were in accordance with their personal beliefs. This added rigor and congruency to the study. Negative case

analysis involved reexamining each case to ascertain if the emerging themes were applicable to the study. This was achieved with the rich, thick description regarding the setting, subjects, and procedures of the participants and their experiences and thoughts on CAM.

Transferability (External Validity)

Transferability is the extent to which other researchers can apply the findings of the study to other settings, populations or contexts (Polit & Beck, 2012). Transferability may be possible because of the careful tracking and reporting of the research activities and processes. Transferability is achieved when the results are meaningful to individuals not involved in the study. I have provided information that can be used by other researchers to determine if my findings are applicable to a new situation (Lincoln & Guba, 1985).

Confirmability

Confirmability is the concept of how well the inquiry's findings are supported by the data collected (Polit & Beck, 2012). During the data collection process, I maintained objectivity by ensuring that the way in which information garnered was accurate, reliable unbiased, and could be confirmed by another researcher (Lincoln & Guba, 1985).

Marshall and Rossman (2011), drawing on Lincoln and Guba (1985), suggested that the study findings should reflect participants and the inquiry and not on falsification from the bias and prejudices of the researcher. Confirmability was achieved by ensuring that my thoughts did not influence the thoughts and experiences of the participants. The collected interviews were coded, analyzed, evaluated, and reported to allow another researcher to

follow the research model logically and determine how the conclusions were obtained. Interview transcripts were organized and analyzed with the support of NVivo 10 computer software to ensure the accuracy, validity, and reliability of the study results. Participants' responses were analyzed using the same process. Verbatim responses were represented in the findings with no exclusion of responses.

Dependability (Validity)

Dependability as stated by Lincoln and Guba (1985) is the stability and consistency of the data collection overtime. The criteria established to recruit participants and steps used for data collection were the same for each participant. The method used could be replicated even though the responses would vary if the study was repeated. Participants were allowed to choose their location for the interview which varied by participant. Findings from the data collection were analyzed several times with the same results. This was done to ensure accuracy of the results. Dependability was achieved through detailed research processes which included defining the research problem, data collection and analysis.

Results

Connection to Research Questions

One of the most important aspects of the research design is the research question. The research questions indicate what needs to be learned and understood. The research questions, according to Maxwell (2005), help to focus the study, and provide guidance on how to conduct the study and communicate the goals of the research. Open-ended questions regarding personal beliefs and experiences regarding CAM allowed

respondents to directly provide responses. The interview questions were designed to explore the views, experiences, beliefs and motivations of participants regarding CAM and to garner responses that provided an improved understanding of factors that influenced CAM use. The data added to the body of knowledge on the subject of health care workers and CAM integration into traditional medicine arena.

Research Question 1

For the first research question regarding the level of knowledge of physicians and nurses regarding CAM, results indicated that participants' knowledge varied on a range from high to very low. Some were highly knowledgeable and well-rounded while others had no knowledge. This was reflected by the first theme, knowledge and experiences with CAM varied.

Research Question 2

The second research question addressed the experiences that healthcare providers had with CAM therapies. Most of the participants had personal experience with CAM use. For some CAM was a part of their daily lives. Others had consulted CAM practitioners to learn more about treatment they hoped to use for themselves.

Additionally, there were participants who had no experience with CAM and were strong advocates for conventional medicine. Theme 2 addressed personal experience and perceived effectiveness, which can lead to patient guidance and advice as they relate to research question 2.

Research Question 3

The third research question related to the barriers that healthcare providers experienced in communicating with their patients about CAM use. Barriers included patients' hesitation in disclosing CAM use and lack of interest and desire to use CAM. Few participants saw no clear patient benefits from CAM and advocated for the acceptance of conventional medicine instead of CAM. Other participants saw health benefits of CAM and patient demands for CAM usage. In theme 3, some participants saw themselves as health care providers' beliefs about integrating CAM into treatment for their patients with SLEs which allowed them to provide information to patients to aid in their decision-making process.

Research Question 4

Question four assessed health care providers' beliefs about integrating CAM into treatment for their patients with SLE. The results revealed that most participants believed that integrating CAM into treatment for their patients with SLE should be based on its effectiveness to the patients' health and the observed improvements based on the CAM treatment and use. Others believed that the decision to use CAM should be based on patient provider dialog.

Research Question 5

The theme initiative for further research addressed question 5 which focused on health care providers beliefs about perceptions of (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative treatment. Some believe there should an initiative for

further research while others believe that there is not enough evidence to support the use of CAM and that science based medicine is the only validated and tested treatment for SLE.

Summary

I discussed in Chapter 4 the qualitative phenomenological analysis from the data collected from the ten participants who were health care providers with experience in caring for patients with Systemic Lupus. I carefully examined and analyzed participants' awareness and perceptions of CAM and its relation to the usage and benefits obtained. I also presented the sample description of the participants, the research methodology employed, the four steps to phenomenological analysis as suggested by Moustakas (1994), and the overall results of the study with the clustered and themes again based from the interviews. I was able to develop five main themes all central to the five research questions of the study. The findings all adhered to the medical practitioners' perceptions on CAM and its possible use.

In chapter 5, I will present more information on the data collection and analysis. I will elaborate further on the results of the study which will include the research findings interpretations of the result, limitations to the study, recommendation for future research and implications for social change as well as the conclusion to the study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative phenomenological study was to gain insight and understanding of the knowledge, beliefs, and experiences of healthcare professionals regarding CAM use and their relationship to the integration of CAM into treatment for patients with SLE. The nature of the study was qualitative and explorative, and a phenomenological strategy using face-to-face interviews was employed to examine the experiences of participants as they related to CAM. The previous chapter presented results and an analysis of in-depth interviews of 10 health care professionals who were recruited using a snowballing sampling approach (Creswell, 2005). Five themes that emerged from the participants' responses were also presented. Chapter 5 contains a brief summary of the findings pertaining to the research questions. The focus of this chapter is a discussion of the meaning of the results and their implications. This chapter concludes with a discussion of the limitations of the study and recommendations for future research to expand the scope of the study.

Key Findings

Interview questions were developed to explore the participants' feelings and experiences and to garner responses from health care providers who worked in the Long Island Osteoporosis and Arthritis Center in New York State. A total of five themes emerged from the responses of the participants. The themes I created displayed that the majority of participants were knowledgeable of and experienced with CAM because of personal experience. The perceived effectiveness of CAM use appealed to the

participants' beliefs and values about health and helped the participants guide patients and provide advice on CAM treatments. Some of the participants also saw themselves as health advocates and suggested that integrating CAM treatments into conventional medical practices involved the cooperation and collaboration of the medical professional and the patient. The last theme highlighted the need for further research and tests from medical practitioners and other stakeholders to ensure the safety of CAM treatments.

Interpretation of the Findings

In this study, I addressed five research questions:

RQ1: What is the level of knowledge regarding CAM therapies among health care providers working with SLE?

RQ2: What experiences have these health care providers had with CAM therapies?

RQ3: What barriers have these health care providers experienced in communicating with their patients about CAM use?

RQ4: What are health care providers' beliefs about integrating CAM into treatment for their patients with SLE?

RQ5: What are these health care providers' perceptions of (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative treatment?

In order to answer these research questions, I used a qualitative, phenomenological approach involving semistructured interviews and open-ended questions. A sample of 10 health care providers who regularly provided care to patients

with SLE were recruited from the Long Island Osteoporosis and Arthritis Center in the state of New York using a snowball sampling technique. All medical practitioners had 5 to more than 30 years of experience of caring for patients with SLE. The interviews were analyzed using Moustakas's (1994) method of phenomenological analysis, with the assistance of NVivo 10, and followed the shared decision-making model (SDM) and self-efficacy theory as the theoretical frameworks. With the use of both frameworks, the importance of the collaborative decision making of healthcare professionals and patients in the integration of CAM into the SLE treatment plan was investigated.

In this study, the concept of SDM was evaluated in the context of the participants' knowledge and perceived willingness of the patients to share their knowledge and experience concerning the use of CAM. It was noted in this study that the participants had varying levels of knowledge and that CAM use was not openly discussed between health practitioners and patients. The patients who believed in and practiced CAM only discussed their use and knowledge of CAM with practitioners who had openly expressed their support, experience, and knowledge of CAM. The health practitioners who had limited knowledge and had learned about their patients' use of CAM often consulted practitioners and colleagues whom they knew had expertise on CAM. In this regard, the application of the SDM model in the context of the results of the study is limited to practitioners and patients who shared similar knowledge, experience, and interest in alternative medicine. The SDM model that advocates the involvement of patients in meeting their healthcare needs can only be observed in a healthcare environment that integrates CAM as part of healthcare policies and programs.

Self-efficacy theory in this study was demonstrated among knowledgeable and experienced participants. This is consistent with Bandura's (1995) postulation that mastery of experiences, vicarious experiences, social persuasion, and physiological and emotional states are the indications of health practitioners' efficacy beliefs on CAM. It is to be noted that those health practitioners with limited or no knowledge of CAM were not able to persuade and educate patients concerning the use of alternative medicine. However, health practitioners with limited knowledge expressed their willingness to learn about and practice CAM.

The results of the study contribute to the field in that, I analyzed the knowledge, beliefs, and experiences of various healthcare professionals on the use of a nontraditional treatment method for SLE that has been relatively understudied in existing literature. Most of the participants interviewed, believed that they were knowledgeable and experienced in recommending the use of CAM for their patients with SLE. The themes generated from the responses may be used to determine the merits of pursuing CAM integration in professional education, research, and practice in the treatment of SLE in order to support patients' decisions to consider using CAM in their SLE treatments.

Results in Relation to the Literature

In this study, five themes were developed related to the knowledge, beliefs, and experiences of nurses, medical doctors, and a physician assistant concerning the use of CAM with patients with SLE. In this section, I discuss each of the themes and how these findings enrich the current literature by focusing specifically on health care professionals who work with patients with SLE. I also show how the ideas from the themes contribute

to other topics, such as the importance of better communication between the healthcare professional and the patient, as well as the current level of knowledge of healthcare professionals on CAM. Additionally, the responses of the participants provide information on the level of education that healthcare providers have on CAM treatments.

For the first theme, half of the participants had adequate knowledge and information on CAM use due to advanced education and training. Some participants obtained masters' degrees in nursing specifically focused on CAM, and others received advanced training in CAM during their academic studies. The pursuance of advanced education may be explained by the finding of Nedrow et al. (2007) that the United States provided grants to 15 allopathic academic health centers with the sole purpose of developing CAM curricula. The additional funding may be an indication that the United States government is open to providing more support to CAM treatment research or that interest in CAM use is increasing in the medical community. Besides attending academic institutions, the participants may also opt to join programs centered on CAM education. Ben-Arye et al. (2006), an advocate of integrative medicine, provided an example of a good CAM-centered program that offers comprehensive CAM education for family practice residents and specialists. The program entailed seeking online resources and engaging in phone or electronic consultations with various CAM practitioners. The nursing students in Rojas-Cooley and Grant's (2006) study, meanwhile, turned to informal sources and popular media for information on CAM, and one-third of the physicians in Milden and Stokols's (2004) work sought out online resources on CAM on conventional medicine websites and online databases such as PUBMED and MEDLINE.

On the other hand, some of the participants in my study mentioned gaining experience instead of attending education or programs to achieve knowledge on CAM. Some participants had over 30 years of experience in dealing with CAM through their profession or because they were exposed to CAM therapies when they were young. Rojas-Cooley and Grant similarly discovered that oncology nurses in Pennsylvania reported having ample experience in CAM patient care and showed a general degree of interest in gaining more knowledge on CAM. Additionally, most of the 726 critical care nurses in a study by Tracy et al. (2005) used at least one form of CAM in practice.

Several participants claimed that they had a moderate level of understanding of CAM therapies and this information was gained mostly from family, friends, or personal experiences given the rising prominence of CAM. This moderate level of understanding may significantly play a large role in influencing self-concept of CAM treatment and that gaining experiences from the CAM treatment would result to self-persuasion. The source of the understanding was similar to the findings of Artus et al. (2007) who noted that the decision to use CAM mostly came from recommendations by a friend or a relative. In the light of this finding, it was evident that self-efficacy theory of Bandura (1985, 1986) could potentially be used in understanding the dynamic relationship of friends and relatives in influencing medical practitioners concerning the use of CAM. Other participants, who may not have been receiving influential persuasions from friends and relatives, noted that they did not have enough knowledge and training in CAM therapies to be able to provide qualified explanations of even the basics to their patients.

I explained how the second theme revealed that the experiences of the participants on CAM therapies varied such as having personal experiences, obtaining information from second hand sources, or having no experience at all. Four participants revealed that they have had personal treatments using an alternative medical system and have integrated CAM into their lifestyle because they found it to be effective through a perceived improvement in their health. Several of the participants talked about their experiences with CAM therapies and how it has changed their health condition. Using the analytical framework of Bandura's (1986) self-efficacy, the positive experiences with CAM convinced the participants to continue practicing CAM therapies with their patients. Martz et al. (2006) found in their research that physicians who personally used physical therapy, herbal supplements, or pastoral counselling were more inclined to refer patients to the same therapies. In Germany, Stange et al. (2008) learned that physicians were more inclined to prescribe practices that are less common to the United States. Besides personal CAM use, three participants obtained their knowledge of CAM from second hand sources such as consulting other CAM practitioners to gain more knowledge on the field. Information online is also important with Mildren and Stokols (2004) concluding that a positive correlation exists between the use of technology and positive attitudes towards CAM.

The third theme identified the barriers that are prohibiting patients from discussing CAM use with health care practitioners based on the latter's perspectives. One barrier mentioned by the participants was the lack of communication between the physician and the patient as a problem to address in CAM use, similar to the findings of

Eisenberg et al. (1993), Eisenberg et al. (1998), Mehta et al. (2008), Saydah & Eberhardt (2006), and Shelley et al. (2009). The study of Rojas-Cooley and Grant (2006) showed that nurses had ample experience in patient care, but had limited encounters with patients asking about CAM.

Communication between patients with SLE and health care professionals is essential in addressing the prevalence of unmet needs which include tiredness, pain, poor sleep, and feeling worse after being physically active (Danoff-Burg & Friedberg, 2009). A more trusting relationship between the healthcare professional and the patient is necessary to determine the appropriate treatment with which the patient is agreeable. Therefore, proper communication between the patient and physician may make patients more comfortable in disclosing that the patient is also undergoing CAM treatments. The disclosure is important because CAM treatments may have adverse effects if used in conjunction with conventional treatments. However, the results of this study contradicted existing research by showing that the majority of the participants fully believed in the benefits of CAM treatment and did not experience any barriers in communicating CAM to their patients. Shelley et al. (2009) found that most patients hesitate in initiating discussions of CAM, while Rojas-Cooley and Grant (2006) discovered that nurses had limited encounters with patients who brought up the topic of CAM. In this study, the participants shared what drove them to share CAM with their patients such as various health benefits, disease reversal, evidences of efficacy, patient demand, and holistic care similar to the findings of Yen et al. (1999), Tretheway (2004), Moses et al. (2008), Danoff-Burg and Friedberg (2009), and Leong et al. (2010). The proper communication

of integrating CAM in SLE treatment by the healthcare practitioner may have given the patients the opportunity to research and understand their own bodily functions to know what treatment is beneficial for them.

Another potential barrier was the lack of clear patient benefits as a hindrance in communicating CAM use to their patients. Nedrow et al. (2007) also supported the lack of clear benefits as a barrier. These participants argued that CAM lacks scientific evidence that makes it a viable option for patients. Hsiao et al. (2005) explained that a lack of consensus among providers regarding the very definition and practice of integrative medicine impeded efforts to evaluate its effects. One participant in my study then cited numerous fad products that tend to taint the reputation of CAM.

Besides barriers from healthcare providers, the participants also felt the patients created a potential barrier because participants noticed the lack of interest and desire from patients on CAM use. Based on the participants' experiences, very few patients expressed their desire to use CAM to treat their condition which makes it difficult for medical practitioners to discuss this alternative with them. For example, Rosenberg et al. (2008) saw that most patients preferred conventional treatments over CAM while Saydah and Eberhardt (2006) found that less than 30% of adult CAM users with chronic diseases discussed their use with their health care providers. Berry (2007) and Shelley et al. (2009) helped explain why patients are cautious in bringing up the subject of CAM by revealing that the clinician will probably not approve of the treatment and the patients felt that the discussion should be initiated by the physician. This presents a circular reference problem where both the patient and the physician are expecting the other one to initiate the

conversation on CAM use. Conversely, the apparent lack of interest on CAM use is contrary to current literature where 42% (Mehta et al., 2008) and 59.6% (Saydah & Eberhardt, 2006) of rheumatologic patients are CAM users. In addition, Artus et al. (2007) reported that roughly two-thirds of the population in their study used CAM while in the research by Rosenberg et al. (2008), 52% used CAM to relieve pain.

In addition to effective communication, the findings also showed the fourth theme or that healthcare professionals are advocating CAM to patients. To address the fourth research question, the participants believed that collaboration and closer cooperation between the physician and the patient is necessary before CAM can be integrated into the treatment of patients with SLE. Building on the basic tenets of SDM, the decision making process is an integral part of the overall treatment and it is important for healthcare providers to properly guide their patients in making the best decision for the patients' treatment. Yen et al. (1999) further noted that, according to SDM, clinicians' roles include helping patients select the best treatment option for their optimum health and well-being. Patients that do use CAM would appreciate the guidance because CAM users feel the desire to be in control of their own health (Bishop et al., 2007). Rojas-Cooley and Grant (2006) provided several suggestions to foster a joint decision process which are similar to the responses of the participants in this study. For example, medical practitioners should provide all the necessary support to help patients make a decision on the kind of treatment they would like to have. This entails obtaining all the necessary knowledge, training, research and experience of CAM use and sharing this information with their patients. Practitioners should also show full cooperation and responsibility

during the integration process of CAM with SLE patients if this is the direction that patients choose to go.

Despite the positive view on CAM use from most of the participants, two participants were more cautious about CAM use, due to lack of compelling proof of its benefits. The participants argued that integration should only be done after enough evidence of CAM effectiveness is provided. In fact, these participants felt that integrative treatment would be based on their own willingness and determination, which could only be cultivated if they experienced the benefits of CAM use for themselves. Conversely, one participant shared that integrative treatment would not be possible if both the patient and the physician were not interested in pursuing other alternative treatments.

The last theme was related to the perceptions of the participants on the need for further research on integrative treatment. A majority of the participants believed that further research and testing on CAM as a therapy is needed to prove its effectiveness and ensure participants that it is a beneficial and safe treatment that could be trusted. Currently, studies such as those by Spence et al. (2005) and Witt et al. (2008) have provided evidence of significant and sustained improvements with homeopathic treatment. As medical practitioners, the participants felt the burden of furthering the research and development of CAM use in order to help increase the standards of the therapy and improve its reputation in the field of medicine. Exploring the various aspects of CAM use could improve the perceptions of many stakeholders on its effectiveness. Kon (2010) suggested that information should also be responsibly disseminated to patients for them to understand the risks and benefits involved in undertaking CAM

treatments. Therefore, health care practitioners should advocate good patient-clinician relationships in order to maximize the therapeutic benefits of combined treatments for patients (Kon, 2010).

On the other hand, other participants remained adamant that there is not enough evidence to support CAM therapy and that conventional medicine is currently the only option that is sufficiently validated and tested similar to the findings of Milden and Stokols (2004). However, only a minority in the current study reported this as opposed to a majority of the population tested by Milden and Stokols (2004).

Limitations of the Study

Trustworthiness in studies is established when the findings reflect the true meaning described by the participants (Lincoln & Guba, 1985). In order to confirm trustworthiness, I transcribed each interview, requested that the participants review the transcript, and then ensured that the transcripts were securely kept to allow future researchers to review the results and analysis of the study. Further, evidences of trustworthiness may be obtained by assessing the study's methodology and data collection and analysis procedures in terms of credibility, transferability, dependability, and confirmability.

Credibility is the confidence that one has in the truth of the findings (Bryman, 2004). The study relied on the self-reported knowledge, beliefs, and experiences of the participants and had no way of independently verifying their statements despite ensuring that the participants were not interrupted during the interviews to avoid miscommunication and unclear responses. Two of the three methods in determining

credibility, as discussed by Patton (2002) were utilized in this study. First, I performed member checks with all ten participants to ensure the accuracy of the transcripts with participants confirming that interpretations drawn from the transcribed data were acceptable and were in accordance with their personal beliefs. Second, I did negative case analysis involving discussing some responses that appear to contradict the general findings of the study. Additionally, each case was reexamined to ascertain if the emerging themes were applicable to the study through a detailed description on the setting, subjects, and procedures of the participants and their experiences and thoughts on CAM.

Transferability is the extent to which other researchers can apply the findings of the study to other settings, populations or contexts (Polit & Beck, 2012). By nature, qualitative research is limited to a small number of participants so the participants I included are those who were interested in or have superior knowledge in CAM. The participants also came from a specific practice setting and were not representative of the entire population. Therefore, transferability of the results is limited because the responses could not be used to explain the knowledge, beliefs, and experiences of all healthcare professionals. Additionally, I may not easily apply the results to other sample populations that were not included in the study. However, given the time period in doing the study, the resources of the researcher, and the relatively small group of healthcare professionals knowledgeable in CAM, a small population was appropriate to generate important findings on the topic.

Dependability is the stability and consistency of the data collection over time (Lincoln & Guba, 1985). Different participants may provide similar or conflicting responses to the same questions in the study so it is important that the data collection procedure remains uniform throughout the study. In order to achieve dependability, I explained the research process with as much detail as possible to allow other researchers to try and replicate the study. Additionally, the criteria I used to recruit participants and the steps for data collection were the same for each participant making the procedures easy to replicate. I also analyzed the findings numerous times and arrived at the same results to ensure accuracy.

The final aspect in determining trustworthiness was the confirmability of the results, or the concept of how well the inquiry's findings are supported by the data collected (Polit & Beck, 2012). Despite ensuring that my thoughts did not influence the thoughts and experiences of the participants, the analysis of the results still showed how I understood and synthesized the responses of the participants. However, my coding of the verbatim responses, the transcription process, and the confirmation of the participants of the results of the study increased the likelihood that the analysis revealed the true intent of the data.

Recommendations for Further Research

The scope of the study has been purposely restricted given my resources. Future researchers may choose to widen the scope of the study, use a different research method or change the composition of participants to contribute to the wealth of knowledge on CAM use. At this point, I would like to recommend the following extensions or topics:

1. Obtain quantitative findings on the level of understanding and attitudes on CAM among healthcare professionals. A possible instrument may build on the 30-item survey done by Hsiao et al. (2005) to assess a clinician's attitudes toward integrative medicine based on openness, readiness to refer, learning from alternate paradigms, patient-centered care, and safety of integration. This would help better understand the current level of CAM knowledge of healthcare professionals and can be used to gauge the depth of needed research and development of CAM therapies, especially since most participants recommended conducting further research and tests to ensure the CAM treatment's safety. These findings may also help determine the best media or methods needed to improve the overall level of understanding of medical practitioners on CAM use.
2. Determine the factors on why patients with SLE decide to use CAM therapies using a variety of methodological approaches. Patients have the ultimate decision on what treatments they would like to use. Although the current literature provided several factors on why patients decide to use CAM, none specifically target people with SLE. It might be helpful to determine the factors behind making the switch from conventional medicine to CAM through qualitative, quantitative, or a mixed methods approaches. These factors can be studied closely by healthcare professionals and hospital management to create strategies and therapies specifically tailored for people with SLE that could influence patients' decisions on whether to pursue CAM

therapies.

3. Extend the study to include the benefits of CAM therapies on various ailments.

The main drive for pursuing this study was the lack of literature exploring the effects of CAM therapies or integrative therapies on patients with SLE. It would be meaningful to include the effects of CAM therapies or integrative therapies on various ailments to provide an overall indication of its effectiveness.

Implications for Positive Social Change

Positive social change refers to a researcher's ability to create and apply ideas, strategies, and actions for the improvement of others, the community and society (Walden University Student Handbook, 2012). The increase in CAM use among the respondents hints that health care providers are becoming more open and informed about CAM usage in order to provide the best service to their patients. This change in behavior towards an appreciation of CAM demands that health care providers understand CAM therapies so that comprehensive medical care can be provided. Findings from this study may be used to influence strategies to increase CAM usage thereby leading to positive social change by increasing the number of treatment options for patients. Eisenberg et al. (1993) published a landmark study documenting the extensive use of unconventional therapies by adults in the U.S. which marked the first formal recognition by the medical community that Americans were turning to therapies that were not part of conventional western medical treatment. Prior to this recognition, patients were limited to conventional treatment which was comprised of drugs or surgeries to treat medical conditions (Turnock, 2004). Today, patients have choices

which now include CAM therapies. Findings from this study may be used by health care organizations and researchers to validate their ideas regarding CAM usage among health care providers.

Based on the themes generated from the interviews, I have deduced that the main drawback to a wider use and acceptance of CAM therapy as a treatment method for various chronic ailments is a lack of scientific evidence of its benefits and effectiveness. As a fairly understudied topic, further inquiry by medical stakeholders into sufficient scientifically-proven evidence to back up their claims on the benefits of CAM use is valuable for patients, medical practitioners and the medical field. Through proper education, training, and research on CAM use, medical practitioners are able to widen the availability of treatments for their patients and will be able to recommend the most appropriate treatment method for patients. Continuous research and advanced education may also help patients become more accepting of CAM, and may empower patients to ultimately decide on whether they want to integrate or solely use CAM therapies in their treatments. The medical field also benefits through the added knowledge provided by researchers on whether these types of treatments are recommended for certain conditions. Even if CAM may be seen as unsuccessful in treating certain illnesses, the discourse and interchange of ideas in further research may open up new areas or topics that may create a positive or more efficient and effective impact on current conventional treatments.

Communication and cooperation between the patient and the attending physician or nurse are important in the relationship building process to determine the best treatment for the patient. Since medical practitioners are in a position of power as compared to the

patient, the discussion on alternative treatments to help the patient decide the best treatment should come from clinicians. If health care providers neglect to discuss alternative options with patients, either because they are not knowledgeable about them or because patients are not interested in discussing CAM can result in a reduction in medical choice.

In turn, health care professionals should have the necessary knowledge and training to impart to patients to aid them in making a decision. This will make it easier for patients to speak out regarding their concerns and would make it easier for them to discuss CAM use with their doctors. The physician-patient dialogue in a closer and more trusting relationship is an advantage for the physician because it allows a fuller and better understanding of the patient's condition. Similarly, the patient benefits because they are able to freely discuss the range of treatments available. The impact of positive social change from this study can motivate healthcare providers in promoting CAM discussion with patients.

Expanding the findings from this research through additional research may increase CAM discussion and usage could be used to make predictions across other demographic area. These behavior patterns understood can foster strategic programs and initiatives to facilitate educational and promotional programs which can increase patient satisfaction.

Conclusion

The use of CAM has increasingly become popular in the United States over the past decade as an alternative treatment for chronic conditions. Several studies document

the benefits of CAM therapies on patients' quality of life and overall health (Barnes et al., 2008; Bishop et al., 2007; Ho et al., 2009; Mehta, et al., 2008; Rosenberg et al., 2008). However, there is little research on its effects on patients with SLE, or providers' views on its effects with SLE. In this study, I utilized a qualitative phenomenological research method to explore the knowledge, beliefs, and experiences of health care providers on CAM use as a treatment for patients with SLE. The semi-structured interviews using open-ended questions on five nurses, four medical doctors and one physician assistant revealed five main themes. First, the participants were generally knowledgeable on CAM therapies, since they received advanced training or education on CAM use. Next, most participants experienced CAM through personal treatment which had a positive effect on their overall health. A majority of the participants then stated that they had full belief in the benefits of CAM treatment and had no trouble communicating this with their patients. In the fourth theme, the integration of CAM therapy with conventional medicine was considered to be best based on cooperation between the patient and the medical practitioner, to help patients choose the best treatment for their health. Finally, the last theme was a recommendation for further research and tests from the medical industry and other stakeholders on CAM as a therapy to increase awareness and trust of the treatment.

Strategies were recommended to increase awareness and understanding of CAM use through proper education and advocacies. Hospitals should also aim to improve patient-clinician communication and cooperation in the medical industry. Further research is recommended to explore the understanding of CAM among the general medical practitioner's population using quantitative data, determine the factors why

patients use CAM therapies, and an extension of the study to include the benefits of CAM for various ailments.

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Appendix A: Qualitative Research Instrument

Walden University

Researcher: Carmen Bartley

Thank you for considering participation in this dissertation project. This research involves interviewing 10 people. The research is being conducted to address the following questions:

What was the level of knowledge of physicians and nurses regarding CAM therapies?

1. What experiences did these doctors and nurses had with CAM therapies?
2. What barriers have physicians and nurses experienced in communicating with their patients about CAM use?
3. What were physicians' and nurses' beliefs about integrating CAM into treatment for their patients with SLE?
4. What were physicians' and nurses' beliefs about perceptions of (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative ?

Introduction:

1. What is your name?
2. What do you do for living?
3. How long have you been attending patients with SLE?

Questions:

1. What is your level of knowledge regarding CAM therapies?
2. Where did you learn CAM therapies?
3. Please describe your experiences with CAM application?
 - a. Please describe your personal use of CAM.
 - b. Please describe the use of CAM with your patients.

4. How was your belief with CAM able to assist you in treating your patients with SLE?
5. If you have professional experience with SLE, how do you determine whether to use or recommend CAM?
6. Do you involve your patients with SLE in your decisions to use CAM?
7. If you use or recommend CAM for SLE, do you evaluate the efficacy of the CAM among your patients?
 - a. If so, please describe the process.
 - b. If no, why is that so?
8. What factors hinder or facilitate your decision to use or recommend CAM?
9. What are your perceptions of the use of integrated medicine in community SLE health services?
10. What are your perceptions of hospitals and/or clinics that integrate CAM into patients' treatment?
 - a. Describe how they developed their programs.
 - b. What assistance, if any, did they ask from you?
11. What are your perceptions of how integrated treatment is regarded by: (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers?

Appendix B: Letter of Invitation

Title: Complementary Alternative Medicine: Awareness and Perceptions of Physicians and Nurses Who Provide Systemic Lupus Care.

My name is Carmen Bartley and I am a graduate student in the School of Public Health at Walden University in Minneapolis.

I am conducting a research to gather the perceptions of healthcare professionals and to gain insight and understanding of the knowledge, beliefs, and experiences of physicians and nurses regarding CAM use and their relationship to the integration of CAM into treatment for patients with SLE.

If you decide to participate, an interview would be arranged at a time and place of your convenience. The interview would last about 45 to 60 minutes. If you agree to participate your responses to the questions will be kept confidential. Each interview will be assigned a number code to help ensure that personal identifiers are not revealed during the analysis and write up of findings.

There is no compensation for participating in this study. However, your participation will be a valuable addition to our research and findings could lead to greater public understanding

If you are willing to participate, please suggest a day and time that suits you and I'll do my best to be available. If you have any questions please do not hesitate to ask.

Thanks

Carmen Bartley

Appendix C: Participant Information

Walden University Research – Dissertation

Thank you for considering participation in this dissertation project. This research involves interviewing 10 people. The research is being conducted to address the following questions:

1. What was the level of knowledge of physicians and nurses regarding CAM therapies?
2. What experiences did these doctors and nurses had with CAM therapies?
3. What barriers have physicians and nurses experienced in communicating with their patients about CAM use?
4. What were physicians' and nurses' beliefs about integrating CAM into treatment for their patients with SLE?
5. What were physicians' and nurses' beliefs about perceptions of (a) insurance companies, (b) medical hospitals, (c) other private practice physicians/nurses, and (d) alternative medicine providers regarding integrative

Please note the following information:

- x This is a completely voluntary question-and-answer process that will take approximately 30-60 minutes to complete.
- x The interview will be conducted in person.
- x Interviews will be digitally recorded and those recordings will be transcribed verbatim. You can review this transcript if desired.
- x Your responses will be kept confidential and all materials related to this study will be kept in a secure location.
- x Your personal and health information privacy will be maintained by identifying you in the research literature with an alphanumeric code rather than using your name. Participants will be identified with the designation P-1, 2, 3, 4, 5, 6, 7, 8, 9, and 10.
- x Following your participant interview and prior to publication of this dissertation research, you will have the opportunity to review your responses for accuracy.
- x Following your interview and prior to publication of this dissertation research, the researcher may have additional clarifying questions regarding your original response

Appendix D: Informed Consent Form

Complementary Alternative Medicine: Awareness and Perceptions of Physicians and Nurses Who Provide Systemic Lupus Care

Dear Participant:

You are invited to participate in a research study that will attempt to gain insight and understanding of the knowledge, beliefs, and experiences of physicians and nurses regarding CAM use and their relationship to the integration of CAM into treatment for patients with SLE.

This study is being conducted by a researcher named Carmen I. Bartley who is a doctoral student at Walden University. The following information is provided in order to help you make an informed decision whether or not you would like to participate. If you have any questions please do not hesitate to ask. You are eligible to participate in this study because you were recommended by CAM users; you have practice CAM for at least a year and regularly provide care to patients with SLE.

Project: Complementary alternative medicine: Awareness and perceptions of physicians and nurses who provide Systemic Lupus care

Purpose of the Project: This study will explore the attitudes, perceptions and experiences of CAM use of physicians and nurses who provide care to patients with SLE.

Procedures: You will be asked to participate in an interview which will allow the primary investigator to observe and take notes. If you agree to be in this study, you will be asked to: Complete a demographic form that will take approximately 5 minutes to fill out, allow audio-taping of responses to interview questions (interview scheduled to last 45 minutes to 1 hours), provide in-depth responses to interview questions (the timeframe will vary depending upon your willingness to share your experiences), and review the transcript of your interview for accuracy of your experiences.

Risks and/or Discomforts: There are no known risks or discomforts associated with this research.

Benefits: The information gained from this study could be useful for charting a future direction for professional education, research, and practice related to the integration of CAM into SLE treatment.

Confidentiality: Any information you provide will be kept confidential. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study. Audio tapes will only be used to transcribe interview. Once the

interview is transcribed, the audio tapes, interview transcripts, and the xeroxed copies of the documents you provide will be stored in the researcher's home office and locked in a secured vault for seven years.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher [redacted]. If you want to talk privately about your rights as a participant, you can call [redacted]-- the Walden University representative who can discuss this with you--by phone at [redacted] .

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, and returning this form with the words "I consent," I understand that I am agreeing to the terms described above.

Printed Name of Participant

Date of consent

Participant's Written or Electronic* Signature

Researcher's Written or Electronic* Signature
