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Complementary and Alternative Medicine Use among Long-Term Survivors: A Pilot Study

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Abstract

No published survey has specifically addressed the beliefs, knowledge, and usage of complementary and alternative medicine (CAM) in long-term (5 to 20 years) lymphoma survivors alone. In this pilot project, 95 subjects were randomly selected from a population of 2,475 long-term lymphoma survivors and mailed a questionnaire. The median time from lymphoma diagnosis to completion of the questionnaire was 11 years (range 6-20). Overall, 68% (95% CI: 54-80%) of the long-term lymphoma survivors reported that they have used CAM, a rate higher than the estimated usage rate reported for the general population The most commonly used modalities were chiropractic (39%, 95% CI: 27-53%) and massage therapy (21%, 95% CI: 12-34%). Less than 10% used meditation (5%, 95% CI: 1-15%) and relaxation (7%, 95% CI: 2-17%). In terms of common herbal usage, 5% (95% CI: 1-15%) had used St. John's Wort and 7% (95% CI: 2-17%) had used shark cartilage. While none of the patients reported that CAM usage was directed specifically towards treating their lymphoma, 4% (95% CI: 0-12%) of patients reported that CAM could cure cancer, and 14% (95% CI: 6-26%) reported that CAM could increase their feeling of control over their health. This pilot study suggests that long-term lymphoma survivors appear to use CAM at a rate higher than the general population. The use of potential agents of risk by the survivors and the lack of access to potentially beneficial modalities highlights the need for further study of CAM in this population.

Keywords

complementary medicine; Hodgkin lymphoma; non-Hodgkin lymphoma

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Introduction

Many adult Americans report use of complementary and alternative medicine (CAM). In 2002, NIH-NCCAM conducted a comprehensive survey of the adult U.S. population and their use of CAM [1]. The NIH reported that nearly 40% of American adults had used CAM in the past year. This finding is consistent with several other surveys that have examined the prevalence of CAM [2-6]. Therefore, it appears that CAM usage is common practice of the adult population in our country. In examining which populations are most like to report CAM usage, CAM usage tends to be higher in populations with chronic or serious health conditions [7-12]. This is particularly the case in cancer patients [13-19].. For example, in a study of 453 cancer patients from M.D. Anderson Cancer Center, 57 of whom were lymphoma patients, usage of at least one CAM approach was reported by 83.3% of cancer and lymphoma patients [13]. In another study of 143 cancer survivors, nearly half reported that they had incorporated some form of CAM into their health care [20]. The most common reasons identified for CAM usage included seeking to increase feeling of well-being, improve health maintenance, prevention of recurrence, avoidance of causes of cancer, and taking control of one's health. In addition to herbal, pharmacologic and dietary changes, other types of CAM practices reported by breast cancer survivors included mind-body techniques, bioelectromagnetics, manual healing, alternative medical systems, and yoga-relaxation [21].

Certain cancer populations have received particular attention with regard to CAM usage, including patients with breast cancer [21-26], prostate cancer [27-32], gynecological cancer [33-36], leukemia [37,38], colon cancer [39], non-melanoma skin cancer [40], and head and neck cancer [41]. Although lymphoma patients occasionally have been included in general surveys of cancer patients' usage of CAM [13], no published survey has focused specifically on the use of CAM by this significant segment of the cancer survivorship patient population. A comprehensive review of the literature to date did not find a single published study that focused on the important question of what CAM modalities long-term lymphoma survivors are incorporating into their ongoing health care. We therefore conducted a pilot survey of long-term lymphoma survivors to ascertain their use of CAM and whether their attitudes towards CAM influenced their health care decisions.

Methods

This study was reviewed and approved by the Mayo Foundation Subject Institutional Review Board (IRB). Long-term lymphoma patients were identified using the Mayo Tumor Registry. Eligibility criteria included diagnosis of Hodgkin lymphoma (HL) or non-Hodgkin lymphoma (NHL) from 1984 to1998, surviving five or more years since their diagnosis, age 18 years or older at the time of diagnosis, a U.S. resident, and diagnosed or treated at Mayo Clinic Rochester. From this sampling frame, 2,477 potential patients were identified. From the potential patients currently alive (according to last follow-up in the Tumor Registry), 45 were randomly selected with survival of 5-9 years after diagnosis and 50 were randomly selected with survival of 10 or more years after lymphoma diagnosis. Current addresses for patients and next-of-kin were obtained through Medical Registration Information, Mayo Tumor Registry, and *Accurint*, a search service available through the Mayo Survey Research Center.

A 23-page survey questionnaire packet was developed to survey multiple survivorship issues, including CAM, in this patient population. The definition of CAM provided by the National Center for Complementary and Alternative Medicine (NCCAM) was used to develop the questionnaire. (http://nccam.nih.gov/health/whatiscam/). To assess the face validity of the questionnaire, four patient advocates reviewed the survey questionnaire

packet prior to data collection. The patient advocates were a 49-year old male with a complicated history of follicular lymphoma; a 50-year old male general internist with a history of non-Burkitt NHL; a 72-year old female with a MALT lymphoma of the lung; and a 20-year old college student with a history of HL. All were enthusiastic about the content of the survey, agreed that the major content areas related to CAM usage in cancer survivors were being measured, and reported they did not find the length of survey questionnaire packet too burdensome to complete.

A cover letter describing the study, a study brochure, a consent form and the study questionnaire were mailed to the 95 identified long-term lymphoma survivors in October 2004. If a response was not received within a month, the study team attempted to contact the patients via telephone to provide more information about the study and encourage study participation. Per our IRB's policy, we had permission to contact patients two additional times after the initial mailing (by either mail or phone). We attempted to reach non-responders by telephone using two phone attempts in the daytime, two in the evening and two on a weekend, spread out over eight weeks, before a message was left on an answering machine or with another household member (considered one contact by the IRB). Persons returning a completed questionnaire were reimbursed $25 for their time.

Of the 95 presumed living patients to whom we mailed our questionnaires, six were subsequently found to be deceased, and were therefore excluded, leaving 89 eligible subjects. Of the 89 subjects, we could not obtain a correct address on six (6%) patients, one (1%) patient was too ill to participate, 12 (14%) refused to participate, 14 (17%) did not return a survey, and 56 (62%) returned a completed survey. Thus, of patients whom we could find a (presumed) correct address and were not too ill to complete a survey, we achieved a 68% (56/82) participation rate.

Survey

The completed surveys were reviewed by the study coordinator and the study PI (TMH) for completeness and accuracy. The completion rate for individual instruments within the surveys was greater than 95%.

Forty-four dietary supplements were named, including: algae/spirlina, aloe, barley green, bee pollen, black walnut, cat's claw, chinese herbs, dandelion, DHEA, echinacea, Essiac tea, evening primrose oil, flaxseed, garlic, ginkgo, ginseng, grape seed extract, green tea, Hawaiian herbs, Hawaiian salt, herb mixtures unspecified, herbal tea, horse tail, Hoxsey formula, licorice root, marijuana, mistletoe, mushroom extract tea, noni, orange zest, parsley, pau d'arco, peppermint, red clover, royal jelly, saw palmetto, shark cartilage, shark liver, St. John's Wort, wheat grass, white fish supplement, and yam. Patients were asked if they had previously used or currently used the supplements, and if so, if the use was for cancer or for other health issues.

Complementary therapies including meditation, yoga, acupuncture, etc. were listed, and patients were asked if the use was for cancer or for other health issues. Space was also provided for participants to include therapies that were not included and to provide specifics regarding treatments. The lists of therapies were developed from review of the medical literature and authors' clinical experience. Specifically, patients were asked, "Have you ever tried any of the following alternative therapies? Check all that apply." These included mind/body (meditation, relaxation, yoga), manual healing (acupuncture, chiropractic, massage), alternative medical, traditional Chinese medicine, religious/spiritual, naturopathy, and homeopathy.

The survey had 15 items regarding beliefs of CAM therapies, based on previously published work by Yates and Boon [21,42]. The questionnaire asked the following: “In your opinion, how true are the following statements about complementary/alternative products or therapies for cancer care?” The possible responses were “not at all true, not very true, don’t know, fairly true, and very true.” The statements are listed in Table V. Participants were asked to respond regardless of their use of CAM therapy.

Results

Questionnaire data were available on 56 long-term lymphoma survivors. The median age at diagnosis was 50 years (range: 16-75). The median age at completion of the questionnaire was 62 years (range: 25-85). The median time since diagnosis was 11 years (range: 6-20). The characteristics of the study population are shown in Table I.

With respect to CAM utilization, 68% (95% CI: 54-80%) of patients reported that they have used CAM (Table II). Specifically, 38% (95% CI: 25-51%) of patients reported they have used herbal supplements and 59% (95% CI: 45-72%) of patients reported they have used alternative therapies (Table III). None of the patients reported that CAM usage was directed specifically towards their cancer.

The most commonly used CAM modalities were chiropractic (39%), massage (21%), relaxation therapy (7%), religion/prayer (7%), meditation (5%), yoga (5%), and acupuncture (5%) (Table IV). Overall, usage of herbal supplements was low with green tea, garlic, flax seed, and echinacea being the only herbal supplements used by more than 10% of respondents. In addition, 5% had used St. John’s Wort and 7% had used shark cartilage. The most common herbal supplements and alternative therapies are summarized in Tables 3 and 4, along with corresponding CIs.

Attitudes and knowledge of CAM were assessed (Table V). A majority of patients expressed no knowledge about the use of CAM in cancer care. However, 4% (95% CI: 0-12%) of patients responded that CAM could cure cancer and 4% (95% CI: 0-12%) felt that CAM is perfectly safe. Ten to twenty percent of patients felt that CAM could assist other therapeutic interventions, relieve symptoms, assist the body to heal, increase their quality of life, boost the immune system, or give a feeling of control over the cancer.

Discussion

This pilot study of patients who have survived lymphoma for 5 to 20 years resulted in several important observations. First, lymphoma survivors may use CAM at a rate higher than the general population, and which is similar to the rate of CAM usage found in other cancer populations. Second, there was a general lack of knowledge about CAM. Third, cancer survivors were unaware of potential risks associated with CAM, and, finally, only a small percent of survivors reported using relaxation and meditation, CAM practices that do have evidence of effectiveness.

Long-term lymphoma survivors in this pilot study appear to have a CAM utilization rate higher than that of the general adult population in the United States [1]. This is an expected finding, as most previous studies have suggested that cancer survivors tend to be much higher users of CAM than the general population [13,33,43]. This pilot study was embedded in a larger survivorship survey so patients using CAM were no more likely to reply.

Lack of knowledge of the risks and benefits regarding CAM was also identified in the survey. This lack of information may lead patients to try alternative therapies which could potentially be dangerous or interfere with their conventional therapy. Cancer survivors are

routinely inundated with information promoting a variety of herbs and supplemental products as “anti-cancer therapies’ [44]. Patients often view such dietary supplements as “natural” and therefore, “safe”. Patients frequently incorporate such products in an attempt to “boost immunity” and thus, lymphoma survivors with a prior disease of the immune system, might be especially interested in using such therapies. However, some supplements may have adverse effects, interact with conventional pharmaceuticals or displace more efficacious conventional medicines. In this survey, 7% of patients were using shark cartilage, which at this time does not have sufficient evidence to suggest any benefit in lymphoma treatment. In fact, some studies have suggested a decrease in QOL when shark cartilage was taken [45]. Five percent of the patients were using St. John’s Wort, which has well recognized interactions with a number of pharmaceutical drugs and therefore has potential risks if not identified prospectively. Other CAM interventions have also been associated with toxicities [46-49] and psychosocial side effects [50].

That four percent of patients felt that CAM could cure cancer was of concern, however no patients were using CAM for their cancer. This finding further highlights the need for increased educational opportunities for lymphoma patients regarding CAM. No CAM modality has been shown to effectively cure cancer and, in fact, many CAM therapies do have potentially significant side effects. This suggests the need to improve access to evidence-based information regarding CAM to all patients with lymphoma.

At the same time, failure to incorporate CAM modalities with proven benefits may be an equal cause for concern. Stress, fatigue and anxiety are commonly reported in cancer survivors [51-53]. Fear of recurrence, concerns regarding long-term effects of therapy, and other factors contribute to a heightened stress level in cancer survivors. Yet modalities with good evidence of efficacy in treating stress, specifically relaxation therapy and meditation [54], were only used by 7% and 5% respectively. Thus, patients dealing with the recognized stress present during cancer survivorship who are unaware of the potentially beneficial CAM modalities (e.g. massage, meditation) may be missing an opportunity to improve their quality of life. The relatively large number of patients who are unfamiliar with CAM suggests the need for targeted educational opportunities. Hematologists, oncologists and other health care providers treating lymphoma survivors should be aware of both the high interest in CAM (with 68% of patients reporting CAM usage) as well as the potential knowledge deficit in this regard.

This was a pilot study and, therefore, results are limited by the small sample size and conclusions are only preliminary. The limited numbers of patients also precluded further subset analyses such as patient age, gender, education level, and other variables, and these should be investigated in future larger studies. The study population was also white and based mostly in the Midwest, which may also limit generalizability of the study results. These results reflect CAM use in a population of survivors. As such, the findings cannot necessarily be extrapolated to patients undergoing active disease treatment.

In conclusion, our results indicate that lymphoma long-term survivors appear to use CAM at a rate higher than the general population, which follows the typical pattern of high CAM usage that is found in other cancer populations. There was a general lack of knowledge about forms of CAM, and about potential risks associated with specific types of CAM. Given that many cancer survivors have unmet psychosocial needs, it is possible that, if appropriate, CAM interventions could be a modality to enhance the quality of life of long term lymphoma survivors. These observations suggest the opportunity for future studies of a larger cohort of patients and targeted educational interventions regarding the use of CAM in long-term lymphoma survivors.

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Table I

Characteristics of the Study Population

	All (N=56)	Hodgkin Lymphoma (N=22)	Non-Hodgkin Lymphoma (N=30)
Sex			
Male	29 (52%)	8(36%)	19 (63%)
Female	27 (48%)	14 (64%)	11 (37%)
Age at diagnosis			
<60 years	38 (68%)	22 (100%)	13 (43%)
60+ years	18 (32%)	0 (0%)	17 (57%)
Survival (years)			
Median (Min, Max)	11 (6, 20)	13 (7, 20)	11 (7, 18)
Histology			
HL*	22 (39%)	22 (100%)	
Diffuse	21 (38%)		21 (70%)
Follicular	3 (5%)		3 (10%)
High Grade	1 (2%)		1 (3%)
Peripheral T-Cell	5 (9%)		5 (17%)
Other	4 (7%)		
Marital status			
Single	3 (5%)	0 (0%)	2 (7%)
Married/Cohabitate	47 (85%)	22 (100%)	22 (76%)
Widowed	4 (7%)	0 (0%)	4 (14%)
Divorced	1 (2%)	0 (0%)	1 (3%)
Education			
High school or less	12 (22%)	0 (0%)	12 (41%)
<College graduate	22 (40%)	9 (41%)	10 (34%)
College graduate	21 (38%)	13 (59%)	7 (24%)
Employment status			
Full-time employed	21 (38%)	14 (64%)	5 (17%)
Part-time	13 (24%)	5 (23%)	8 (26%)
Homemaker	5 (9%)	3 (14%)	2 (7%)
Retired	16 (29%)	0 (0%)	14 (48%)

*HL: Hodgkin lymphoma

Table II

Summary of CAM Utilization

	Percent of participants (95% CI)
Any CAM	68% (54-80%)
Any alternative therapy	59% (45-72%)
Any herbal supplement	38% (25-51%)

Table III

Herbal supplements Utilized

Herbal supplement	Percent of participants (95% CI)
Green tea	16% (8-28%)
Garlic	16% (8-28%)
Flaxseed	13% (5-24%)
Echinacea	11% (4-22%)
Aloe	7% (2-17%)
Shark cartilage	7% (2-17%)
Gingko	5% (1-15%)
Grape seed extract	5% (1-15%)
Herbal tea	5% (1-15%)
St. John's Wort	5% (1-15%)

Table IV

Alternative Therapies Utilized

Therapy	Percent of participants (95% CI)
Chiropractic	39% (27-53%)
Massages	21% (12-34%)
Relaxation	7% (2-17%)
Religion/prayer	7% (2-17%)
Meditation	5% (1-15%)
Yoga	5% (1-15%)
Acupuncture	5% (1-15%)

Table V

Beliefs about CAM

Question	Percent who believe (95% CI)
They have side effects.	23% (13-36%)
They will relieve the symptoms.	20% (10-32%)
They will assist other treatments to work.	16% (8-28%)
They give a feeling of control over the cancer.	14% (6-26%)
They assist the body's natural forces to heal.	13% (5-24%)
They will provide a boost to the immune system.	13% (5-24%)
They will increase the quality of life.	11% (4-22%)
They can reduce the chance that conventional medicine will work.	5% (1-15%)
They will cure the cancer.	4% (0-12%)
They are perfectly safe.	4% (0-12%)
They weaken the body's natural reserves.	2% (0-10%)
It is easy to understand how they work.	2% (0-10%)
They will prevent a recurrence of the cancer.	0% (0-6%)
It is the patient's fault if they don't work.	0% (0-6%)