Use of complementary and alternative medicine by patients with hematological diseases: experience at a university hospital in northeast Mexico

José Carlos Jaime-Pérez Adrián Chapa-Rodríguez Marisol Rodríguez-Martínez Perla Rocío Colunga-Pedraza Luis Javier Marfil-Rivera David Gómez-Almaguer

Department of Hematology, Internal Medicine Division, Hospital Universitario "Dr. José Eleuterio González", Facultad de Medicina, Universidad Autónoma de Nuevo León – UANL, Monterrey, Mexico **Background:** Complementary and alternative medicine includes a diverse group of medical and healthcare systems, practices and products not considered part of conventional medicine. Although there is information on unconventional practices in oncological diseases, specific data regarding the use of complementary and alternative medicine by hematology patients is scarce.

Objective: The aim of this study is to document the prevalence of this modality of unconventional therapy in patients with malignant and benign hematological diseases, particularly children with acute lymphoblastic leukemia.

Methods: An observational study of adult patients and guardians of children with malignant or benign hematological diseases was carried out by applying a structured questionnaire detailing the use and results of the most prevalent complementary and alternative medicine practices.

Results: One hundred and twenty patients were included; 104 had malignant and 16 had benign hematological diseases. The use of complementary and alternative medicine was greater in benign diseases but the difference was not statistically significant (64.7% versus 41.7%; p-value = 0.08). Patients and guardians with high school or college educations used these alternative practices more than patients with less schooling (60.7% versus 54.7%; p-value = 0.032). The use of folk remedies was most prevalent followed by herbal preparations and spiritual healing. Sixty-four percent of patients that used these unconventional practices reported improvement in their symptoms and increased capacity to perform daily activities.

Conclusion: No significant difference was documented between patients with malignant or benign hematological diseases using these alternative practices. The majority of complementary and alternative medicine users reported improvement of the disease or chemotherapy-related symptoms.

Keywords: Complementary therapies; Herbal medicine; Medicine, traditional; Hematologic diseases

Introduction

Complementary and Alternative Medicine (CAM) consists of the use of any medical system, practice or products not considered a medical therapy by conventional western medicine as practiced by healthcare professionals holding a medical degree. The underlying rationale for many of these therapies is based on a form of magical thinking derived from imagined anatomical analogies; this takes the form of anatomical correspondences where the body part – the eye in iridology or the ear in auricular acupuncture – is treated as a microcosm representing the whole body, but can also involve correspondences with the treatment itself such as some herbal medicines or other natural phenomena, as in acupuncture. The most common CAM used by patients include homeopathy, herbal medicine, acupuncture, folk remedies, nutritional therapies, shiatsu, iridology, shaman rituals, and yoga.

The reported incidence of CAM use by oncology patients in industrialized countries ranges from 25% to 84%. (1) Studies from Iran, Israel, Jordan, and Turkey reported a high prevalence of CAM use, especially herbal medicine, along with spiritual practices in both pediatric and adult patients diagnosed with breast, hemato-oncological, gynecological and other cancers. (3) The high cost of conventional therapy, restricted access to medical care, and dissatisfaction either of the bedside manners of the doctor or the outcome of treatment, are some of the most common reasons that patients give for using CAM. (4) The use of diverse CAM treatments by hemato-oncologic patients satisfies an important psychological urge. When a patient is diagnosed with a lifethreatening disease, a feeling of hopelessness and loss of control over his or her life develops. (5) Therefore, CAM therapy can be seen by patients as a way of regaining control in decision-making related to the treatment of their disease, giving them the

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Corresponding author:

José Carlos Jaime-Pérez
Department of Hematology, Internal
Medicine Division, Hospital Universitario
"Dr. José Eleuterio González",
Facultad de Medicina, Universidad
Autónoma de Nuevo León – UANL
Av Madero y Gonzalitos S/N, Colonia Mitras
Centro
64460 – Nuevo Leon, Monterrey, México
Phone: 1257-2905 y 06
carjaime@hotmail.com

www.rbhh.org or www.scielo.br/rbhh

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feeling that they can influence their current and future health status. (6)

CAM use by oncology patients, as well as the isolated use of various CAM methods, has been previously reported.^(7,8) Most of the patients that use CAM do so without the physician being aware or without the physician's consent due to fear of being criticized and the perception that their doctor will disapprove or minimize CAM as a co-adjuvant therapy.⁽⁹⁾ There is a lack of information regarding the use of CAM by patients with hematological diseases.

Objective

The aim of this study was to document the prevalence of this modality of unconventional therapy in patients with malignant and benign hematological diseases currently on conventional treatment. Additionally, their opinions on the severity and chronicity of their hematological disease were documented as was their perception of the improvement of symptoms using CAM.

Methods

An observational, cross-sectional and descriptive study was conducted from February 1st 2009 to July 31st 2009 by applying an *ad hoc* questionnaire during interviews of all adult patients and parents or guardians of children diagnosed with malignant or benign hematological diseases that consented to participate. At the time of the study, patients enrolled were receiving conventional treatment according to their disease in the Hematology Department of the *Hospital Universitário "Dr. José Eleuterio González"* of the *Facultad de Medicina*, *Universidad Autónoma de Nuevo León* - UANL. Incomplete questionnaires were excluded. Interviews were conducted by a specially trained healthcare worker.

Questions regarding the use of different CAM modalities (acupuncture, folk remedies, shaman spiritual healing, homeopathic medicine, iridology and others) were answered on a 'yes' or 'no' basis. If the answer was positive, the duration of use of CAM in months was recorded and whether the patient (or guardians) perceived any improvement in symptoms. Asthenia, adynamia, anorexia, depression and limitation in daily activities are the most commonly reported symptoms. Additionally, perception regarding disease severity (mild, moderate, serious and very serious) and the duration of the disease (chronic or not) were documented. Information regarding years of schooling was gathered for adult patients as this group was responsible for taking decisions regarding CAM. Finally we asked if the patient was currently using any type of CAM and if the disease limited the patient's daily activities and/or led to days off work or school. Family income was documented by a social worker. Univariate analysis estimating frequencies, central tendencies according to the distribution of variables and bivariate analysis using the χ^2 test were carried out.

Results

One hundred and thirty-one patients were interviewed, 11 (8%) patients were excluded as their questionnaires were incomplete and thus 120 (92%) participated in this study; 104 with malignant hematological diseases and 16 with benign diseases. Diagnoses by age group are shown in Table 1 and documented CAM is presented in Table 2. The distribution of responses to the questionnaire is shown in Table 3.

Fifty-six percent of the patients had been sick for more than one year at the time of the interview. Forty-five percent of all patients reported that they had tried CAM (Table 2) including homeopathy, herbal remedies, acupuncture, folk remedies, shaman rituals and iridology. Folk remedies were the most commonly used (38%) whereas the most efficient were herbal remedies with 71% of the patients that used this CAM reporting an overall improvement in their health.

Table 1 - Hematological diagnosis by age group of the 120 participating hematological patients

Malignant diseases ($n = 104$)					
Diagnosis	Gender M/F	Age - median years	Adults n (%)	Children n (%)	
Acute lymphoblastic leukemia	29/22	10	20 19.2	31 81.6	
Acute myeloid leukemia	4/3	67	7 6.7		
Chronic lymphoblastic leukemia	0/1	65	1 1.0		
Chronic myeloid leukemia	4/3	61	6 5.8	1 2.6	
Myelodysplastic syndrome	1/1	74	2 1.9		
Hodgkin's lymphoma	5/3	26	7 6.7	1 2.6	
Non-Hodgkin's lymphoma	10/9	52	14 13.5	5 13.2	
Multiple myeloma	3/2	62	5 4.8		
Essential thrombocytosis	0/2	58	2 1.9		
Polycythemia vera	1/0	59	1 1.0		
Myelofibrosis	0/1	62	1 1.0		

Benign diseases (n = 16)

Diagnosis	Gender M/F	Age - median years	Adults n (%)	Children n (%)
Autoimmune hemolytic anemia	1/3	1/3	3 21.4	1 50.0
Aplastic anemia;	0/2	0/2	1 7.1	1 50.0
Idiopathic thrombocytopenic purpura	3/5	3/5	8 57.1	
Hemophilia	0/1	0/1	1 7.1	
Paroxysmal nocturnal hemoglobinuria	1/0	1/0	1 7.1	

Table 2 - Modalities of complementary and alternative medicine (CAM) and its perceived efficacy

CAM therapy	n (%)	Perceived improvement n (%)	p-value
Homeopathy	4 (3)	1 (25)	0.642
Herbal remedies	15 (12)	10 (67)	0.358
Acupuncture	2(2)	-	0.890
Folk remedies	38 (32)	26 (68)	0.241
Shaman's rituals	5 (4)	2 (50)	0.067
Iridology	2 (2)	-	0.082

Table 3 - Answers to complementary and alternative medicine (CAM) use questionnaires by patients with benign (n = 16) and malignant (n = 104) hematological diseases

	Malignant disease n (%)	p -value	Benign disease n (%)	p-value
Gender				
Female	47 (45.2)	0.283	11 (68.8)	0.182
Male	57 (54.8)	0.031	5 (31.2)	0.071
Have you used CAM?				
Yes	44 (42.3)	0.170	10 (62.5)	0.032
No	60 (57.7)	0.253	6 (37.5)	0.130
What is your highest education level? (adult patient only)				
Incomplete elementary school	3 (4.6)	0.224	0 (0)	0.512
Elementary school	20 (30.3)	0.961	5 (35.7)	0.271
Junior high school	15 (22.7)	0.087	4 (28.6)	0.380
High school	13 (19.7)	0.043	2 (14.3)	0.067
College	15 (22.7)	0.032	3 (21.4)	0.030
Do you believe you will be cured?				
Yes	92 (88.5)	0.020	13 (81.3)	0.081
No	3 (2.9)	0.190	2 (12.5)	0.582
Do not know	9 (8.7)	0.489	1 (6.3)	0.621
Do you think your disease is chronic?				
Yes	22 (21.2)	0.321	8 (50.0)	0.288
No	61 (58.7)	0.020	5 (31.3)	0.083
Do not know	21 (20.2)	0.153	3 (18.8)	0.642
How long have you had this disease?				
0 to 6 months	22 (21.2)	0.810	4 (25.0)	0.672
7 to 12 months	26 (25.0)	0.879	1 (6.3)	0.547
1 to 3 years	34 (32.7)	0.320	3 (18.8)	0.860
> 3 years	22 (21.2)	0.145	8 (50.0)	0.730
How serious do you think the disease is?				
No answer	3 (2.9)	0.270	0 (0)	0.170
Mild	20 (19.2)	0.387	1 (6.3)	0.473
Moderate	16 (15.4)	0.459	5 (31.3)	0.012
Serious	39 (37.5)	0.080	6 (37.5)	0.124
Very serious	26 (25.0)	0.060	4 (25.0)	0.360
Do you miss days off school or work?				
Does not apply	14 (13.5)	0.671	1 (6.3)	0.280
Yes	57 (54.8)	0.060	3 (18.8)	0.340
No	33 (31.7)	0.470	12 (75.0)	0.062
Do you have limitations to perform daily activities?				
No answer	3 (2.9)	0.823	0 (0)	0.230
Yes	53 (51.0)	0.058	6 (37.5)	0.170
No	48 (46.2)	0.320	10 (62.5)	0.930

In the malignant group, men more frequently used some type of CAM compared to women (54.8% vs. 45.2%; p-value = 0.031); the median age was 29 years old (range: 1-89 years). Thirty percent of adult patients in this group had only attended elementary school, 19.7% high school and 22.7% held a college degree; 4.6% had not finished elementary school. The average family monthly income was US\$500.00. Adult patients were divided in two groups according to their schooling: less than high school (basic education) and high school and college education. Patients with basic education

used less CAM than those with more years of schooling (54.7% vs. 60.7%; p-value = 0.032).

The prevalence of CAM use by patients with benign hematological diseases was higher than patients with malignant pathologies but this difference was not statistically significant (41.7% vs. 64.7%; p-value = 0.08). Of these, 68.8% of patients were female and 31.2% were male; half had had the disease for more than three years. Most of the adult patients of this group had only studied elementary school. A total of 81.3% of all patients thought their disease was curable

and did not see it as a chronic pathology. More than 88% of those with malignant hematological diseases believed that their disease was curable and 58.7% of them or their guardians did not think that the illness was chronic.

Thirty percent of patients with malignant hematological diseases used more than one CAM method, 95% of them believed that they would be cured (p-value = 0.001) and 66% did not think of their disease as chronic (p-value < 0.05). These results were similar to patients that did not use CAM (86% and 53%, respectively; p-value = 0.27).

With respect to the perception of illness severity, 37.5% of both malignant and benign groups thought that their diseases were serious and 25% of patients in each group perceived them as very serious. Sixty-nine percent of the patients with malignant hematological diseases who perceived their disease as serious or very serious used CAM, compared to 31% in this same group who did not perceive their disease in that way (p-value = 0.04).

About half of the patients (52%) with malignant hematological diseases reported limitations to perform daily activities and 55% missed work or school sometimes. On the other hand, 65% of those with benign hematological diseases did not report having such limitations and 71% did not miss work or school (p-value > 0.05). Patients who perceived their disease as serious or very serious frequently missed work or school (p-value = 0.003 and p-value = 0.048, respectively) and those who perceived their disease as very serious reported more limitations to perform daily activities (p-value = 0.007). In the group with benign hematological diseases, there was no difference between the patient's perception of the severity of disease and missing work or school (p-value = 0.39) or on limitations to perform daily activities (p-value = 0.62). Most of the patients that used some kind of CAM missed work or school more frequently than those who did not use alternative therapies (60% vs. 23%; p-value < 0.05); this, however, was not related to the severity of the disease.

The vast majority of patients with malignant hematological diseases who used some modality of CAM tried folk remedies (91%) recommended by their family or friends, followed by herbal remedies (33%). Sixty-four percent of all CAM users reported improvements in their disease or chemotherapy-related symptoms (Table 2). The most commonly reported symptoms are asthenia, adynamia, anorexia, abdominal pain, nausea, dizziness, fatigue, headache and depression. Sixty percent of the patients with malignant hematological diseases did not use any kind of CAM.

As 51% of the study group (31 children and 20 adults) had acute lymphoblastic leukemia (ALL), this was the most frequent malignant diagnosis with non-Hodgkin's lymphoma being the second commonest malignant disease (5 children and 14 adults – Table 1). About half of the children with ALL (16 patients) received some form of CAM treatment compared to 12 adults; there was no statistical difference between these groups (p-value = 0.41).

For the benign group, the most common diagnosis among adults was idiopathic thrombocytopenic purpura (57.1%) followed by autoimmune hemolytic anemia (21.4%), whereas in children autoimmune hemolytic anemia and aplastic anemia were the only two benign diseases observed.

Discussion

The use of CAM reflects a need to seek different manners to alleviate the suffering caused by severe diseases as well as some of the chemotherapy-related symptoms such as nausea, vomiting, pain, anxiety and fatigue. This need motivates the patient's quest for therapies congruent with his/her beliefs.⁽¹⁰⁾ Several studies have stated that cancer patients use CAM therapies more frequently,⁽¹¹⁾ especially those who had suffered their disease for a longer period of time and those for whom conventional medical treatment has failed.^(5,12)

Patients with malignant hematological diseases also have complications related to the chemotherapeutic regimen; it would be reasonable to believe that some patients may improve with different modalities of CAM.^(7-9,13) In a study addressing this issue in patients with different chronic diseases, 86% of those with oncology diagnoses used herbal remedies and perceived this modality as effective.⁽¹⁴⁾ The perception of the effectiveness of CAM by patients suffering from hematological diseases has not been previously documented. The use of CAM by the patients in this study, both with malignant or benign hematological diseases, appears to be related to the patients' or their guardians' perception of the severity or chronicity of the disease, probably reflecting a uniform cultural phenomenon in this population.

We found that 41.7% of the study group used CAM; this was more common for those individuals in the benign disease group (62.5%) than those with malignant diseases (42.3%; p-value = 0.032). These results are similar to outcomes reported for Japanese, Canadian and Turkish hemato-oncologic patients (44.6%, 49.0% and 47.0%, respectively), (15-17) but less than outcomes in the USA, which are reported as high as 83.3%. (1)

Previous studies in industrialized countries show that being female, of high socioeconomic status and of high education level are factors associated with the use of CAM. (6,18,19)

Our results differ as the prevalence of CAM use in malignant diseases was higher in men than in women. There was a direct relationship between the number of years schooling and the use of CAM; patients who studied longer, more frequently resorted to CAM modalities; thus the data of the current study agrees with other published studies. (1) The association between socioeconomic status and the use of CAM is controversial. (18-20) The vast majority of patients attending our hospital belong to the low socioeconomic group and most of them did not use CAM; those who did,

did not suspend or substitute the prescribed conventional chemotherapy.

A prevalence of 39.4% was reported in a recent large cohort study that assessed CAM use in pediatric cancer survivors, with 46% using more than one therapy. (21)

To the best of our knowledge, the use of CAM in a group of patients with hematological diseases has not been reported previously. Parental perception of the severity and chronicity of children's disease probably explains the similarities in the patterns of the use of CAM by adult patients.

We found a statistically significant difference in relation to the use of CAM and perception of severity between the malignant and benign groups. Although the majority of our patients using CAM reported improvement in the disease or in their treatment-related symptoms, this was not reflected on days missed from work or school, which was similar for both groups.

The expectations of the oncology patient that turns to CAM are that this modality will help to improve symptoms, enhance quality of life and well-being, provide a feeling of control regarding the progression of the disease, and even offer a cure. (11) This agrees with our results, as practically all of our patients believed that they would be cured and more than half with malignant or benign diseases did not think that theirs was a chronic condition.

CAM modalities have the potential of improving the quality of life directly or with a placebo effect. There have been reports that show that, apart from receiving psychological help,⁽⁸⁾ patients taking some form of CAM tend to be more optimistic and do not contemplate death as a possibility.⁽¹⁾

Nevertheless the use of CAM therapies may result in harmful drug interactions and convey a risk to patients and clinical trials as this will affect the results if the patient is enrolled in one. Possible dangerous side effects of some herbal remedies may affect the liver function which is already threatened by chemotherapeutic agents; they can also cause severe myelosuppression, hemostatic defects and impairment of renal function. (12) There have been reports that the pharmacokinetics of agents such as imatinib are affected and the plasma levels of irinotecan are decreased with the use of some natural health products. (22) Physicians must take time to ask patients about the use of CAM and have sufficient knowledge on these therapies to explain about possible interactions with the patients' conventional therapy to assure their wellbeing.

Our results contrast with other studies regarding the use of CAM in two important aspects: most CAM users were men and folk remedies were the most common type of CAM chosen by patients diagnosed with hematological diseases. However the results of this study agree to the fact that the higher the education level, the greater the use of CAM.

The present study was carried out at a regional reference hematology center, on a single ethnic population, probably depicting more accurately the regional cultural

behavior on CAM use; in contrast to other studies dealing with CAM utilization, we focused only on patients with hematological diseases and the study was carried out while patients were receiving treatment. It is important to recognize that patients with hematological diseases recur to CAM as a way to improve their quality of life and to feel directly involved in the decision-making regarding their disease and future. Also, some CAM modalities can adversely affect pharmacokinetics of chemotherapeutic agents, potentially affecting treatment outcome. In consequence, physicians should acknowledge that CAM use by hematological patients is frequent and offers some benefits, in order to advise and help them to receive the highest standard of care available.

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- xxx -