Original article

Annals of Oncology 16: 655–663, 2005 doi:10.1093/annonc/mdi110 Pulished online 3 February 2005

Use of complementary and alternative medicine in cancer patients: a European survey

A. Molassiotis¹*, P. Fernadez-Ortega², D. Pud³, G. Ozden⁴, J. A. Scott⁵, V. Panteli⁶, A. Margulies⁷,

M. Browall⁸, M. Magri⁹, S. Selvekerova¹⁰, E. Madsen¹¹, L. Milovics¹², I. Bruyns¹³,

G. Gudmundsdottir¹⁴, S. Hummerston¹⁵, A. M.-A. Ahmad¹, N. Platin¹⁶, N. Kearney⁵

& E. Patiraki¹⁷

¹School of Nursing, University of Manchester, Manchester, UK; ²Institut Català Oncologia ICO, Barcelona, Spain; ³Faculty of Social Welfare and Health Studies, University of Haifa, Haifa, Israel; ⁴Gazi University Hospital, Ankara, Turkey; ⁵Department of Nursing and Midwifery, University of Stirling, Stirling, UK; ⁶Greek Oncology Nursing Society and Ag. Anargiri Hospital, Athens, Greece; ⁷Zurich University Hospital, Poliklinik Onkologie, Zurich, Switzerland; ⁸Sahlgrenska University Hospital, Gothenburg, Sweden; ⁹Università degli Studi di Milano-Istituto Nazionale Tumori, Milan, Italy; ¹⁰Masaryk Memorial Cancer Institute, Brno, Czech Republic; ¹¹Oncology Department, Aarhus University Hospital, Aarhus, Denmark; ¹²Department of Education, Institute for Oncology and Radiology, Belgrade, Serbia and Montenegro; ¹³Belgian Society of Oncology Nursing, Brussels, Belgium; ¹⁴Department of Oncology, Lanspitali, Reykjavik, Iceland; ¹⁵Department of Oncology, City Hospital, Nottingham, UK; ¹⁶School of Health Sciences, Koc University, Istanbul, Turkey; ¹⁷Greek Oncology Nursing Society and Department of Nursing, University of Athens, Athens, Greece

Received 17 June 2004; revised 5 November 2004; accepted 15 November 2004

Background: The aim of this study was to explore the use of complementary and alternative medicine (CAM) in cancer patients across a number of European countries.

Methods: A descriptive survey design was developed. Fourteen countries participated in the study and data was collected through a descriptive questionnaire from 956 patients.

Results: Data suggest that CAM is popular among cancer patients with 35.9% using some form of CAM (range among countries 14.8% to 73.1%). A heterogeneous group of 58 therapies were identified as being used. Herbal medicines and remedies were the most commonly used CAM therapies, together with homeopathy, vitamins/minerals, medicinal teas, spiritual therapies and relaxation techniques. Herbal medicine use tripled from use before diagnosis to use since diagnosis with cancer. Multivariate analysis suggested that the profile of the CAM user was that of younger people, female and with higher educational level. The source of information was mainly from friends/family and the media, while physicians and nurses played a small part in providing CAM-related information. The majority used CAM to increase the body's ability to fight cancer or improve physical and emotional well-being, and many seemed to have benefited from using CAM (even though the benefits were not necessarily related to the initial reason for using CAM). Some 4.4% of patients, however, reported side-effects, mostly transient.

Conclusions: It is imperative that health professionals explore the use of CAM with their cancer patients, educate them about potentially beneficial therapies in light of the limited available evidence of effectiveness, and work towards an integrated model of health-care provision.

Key words: alternative medicine, complementary medicine, Europe, herbs, homeopathy, spiritual healing, vitamins

Introduction

Complementary and alternative medicine (CAM) has been defined as 'any diagnosis, treatment or prevention that complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual framework of medicine' [1, 2].

The use of CAM has increased steadily over the past 15 years or so, and undoubtedly it has gained medical, economic and sociological importance [3]. However, little is known about the use of CAM in cancer patients specifically. This is especially true in the context of Europe, as the bulk of the literature comes from the USA.

A survey conducted in 33 countries, yielding a meagre 83 responses mainly from oncologists, indicated the existence of a large and heterogeneous group of CAM therapies or remedies used to treat cancer in both developed and developing countries [4]. A literature review suggested that the use of CAM among

^{*}Correspondence to: Dr A. Molassiotis, University of Manchester, School of Nursing, Coupland III, Coupland Street, Manchester M13 9PL, UK. Tel: +44-161-275-5337; Fax: +44-161-275-7566; E-mail: alex.molassiotis@manchester.ac.uk

cancer patients is common, with a prevalence rate across studies of 31.4% (range 7% to 64%) [3]. The latter review included 26 surveys from 13 countries carried out from 1977 to January 1998. However, more recent studies suggest that the use of CAM is considerably higher, with some studies reporting rates of 70.2% in a sample of 356 colon, breast and prostate cancer patients [5], and 83.3% in an outpatient sample of 453 patients [6]. Depending on the instrument used to collect the data, the particular population under study, the sample size and the CAM definition used, studies report rates from 37% to 87% [7–11]. In paediatric patients rates are equally high, ranging from 32.7% in the UK [12] to 84% in the USA [13].

The most popular therapies seem to be dietary treatments, herbalism, homeopathy, hypnotherapy and imagery/visualisation [2]. Spiritual therapies, prayer as a therapy, massage, shark cartilage, green tea, support groups and non-traditional diets are also commonly reported in the literature [6, 9, 11, 14, 15]. Improvements in physical and psychosocial well-being and increasing hope are the main reasons cancer patients turn to CAM [11], although dissatisfaction with some aspects of conventional health care, poor doctor—patient relationship, accessibility, perceived effectiveness and desperation may also be key motivating factors [16].

CAM includes a wide range of therapies. The National Center for Complementary and Alternative Medicine in the USA classifies CAM therapies into five categories [17]:

- (i) alternative medical systems, such as traditional Chinese medicine or Ayurveda;
- (ii) mind-body interventions, such as meditation, prayer, healing or support groups;
- (iii) biologically based therapies, such as herbs, dietary supplements or vitamins;
- (iv) manipulation and body-based methods, such as massage, chiropractic or osteopathy; and
- (v) energy therapies (i.e. biofield therapies such as Qi Gong and Reiki or bioelectromagnetic-based therapies such as magnetic fields).

The aim of the present study was to assess the use of complementary and alternative therapies across a number of European countries, using the same measurement tool and same definition of CAM.

Patients and methods

Patients and settings

A cross-sectional descriptive survey design was used to collect data through a questionnaire about CAM therapies. Eighteen National Oncology Nursing Societies, all members of the European Oncology Nursing Society, were approached for possible collaboration. Of the 18 societies, 15 agreed to participate, although one withdrew later on. A key person from each society was selected, based on interest and/or experience in CAM. Each person had to translate the questionnaire into their own country's language, apply to the ethics committee in each hospital involved in the study and collect the data. In certain countries the questionnaire had to be altered slightly, as some of the 25 ethics committees where the study was assessed requested changes (i.e. in Switzerland collecting data on income levels was not recommended to be included as a variable).

Also, in most cases, researchers did not have access to patients' medical records. Data collected from each country were returned to one of the investigators and then data were coded for analysis. On many occasions, data had to be translated back to English, especially qualitative comments patients made on the questionnaire.

Data were collected in the outpatient clinics of a number of hospitals over several random days. On the selected days, all patients attending a given clinic were approached for possible inclusion in the study. In most countries data were collected from more than one hospital, and in five countries there were hospitals included from large cities as well as rural units. Both metastatic and non-metastatic cancer patients were included from cancer centres, oncology units of general hospitals, day units, radiotherapy units and hospices.

All participating patients received information about the study and in most countries those volunteering to participate signed a consent form. However, in a small number of countries (i.e. England) a written consent form was not necessary, and completing the questionnaire implied that patients volunteered for the study. Patients were included if they met the following inclusion criteria: they were adult patients of either gender with a diagnosis of cancer; aware of their diagnosis; able to understand the questions; free from any condition that would make completing the questionnaire inappropriate or overburdening for the patients; and they were willing to participate in the study.

In several countries, especially the Mediterranean and Eastern European ones, data collection proved to be difficult, as a substantial number of patients did not meet one of the inclusion criteria, namely that of being aware of their diagnosis.

Procedures

The questionnaire was anonymous and was handed out to the patients after they received information about the study, agreed to participate and signed the consent form. Patients completed the questionnaire while they were waiting at the outpatient clinic to be seen by their physician or during therapy. On completion, patients either put the questionnaire in a box or handed it to the local researcher. Owing to the multinational nature of the study, it was not possible to assess the number or characteristics of those declining to participate.

The questionnaire

The questionnaire used was based on the one developed by Swisher et al. [11]. However, the questionnaire was modified for the purposes of the present study and some new items were added (for example, personal spending on CAM and frequency of CAM use) and some others were modified to reflect European culture (for example, items on ethnic background and financial status). There were 27 items in total. These included demographic data (age, gender, occupation, education, household income, marital status, number of people living in the household and ethnicity), clinical data (site of primary cancer, standard treatments received previously and current standard treatment) and questions about CAM use.

If patients reported no past or current use of CAM after completing the sociodemographic and clinical section of the questionnaire, they were asked to choose an answer from a list of possible reasons for not using CAM. After that, patients were thanked for their contribution and asked to stop completing the questionnaire at that stage. If patients reported past or current use of CAM, they were asked to continue. The rest of the questions asked were:

Which CAM therapy patients used before the diagnosis of cancer, since
the diagnosis of cancer or currently. 'Since diagnosis' was defined as
any time from the moment a diagnosis of cancer was made until the
present time, and 'currently' was defined as actually using a CAM

therapy at the present time. This was done from a list of 26 possible therapies, with space to add other therapies if appropriate. Examples of therapies listed were spiritual therapies, herbs, animal extracts, osteopathy, chiropractic, mega-vitamins, aromatherapy, Qi Gong, acupuncture and others.

- Types of CAM practitioners consulted before the diagnosis of cancer, since the diagnosis of cancer or currently.
- Method of use of the reported therapy (i.e. by mouth, injection or enema).
- Frequency of use of reported therapy.
- · Reasons for using CAM therapies.
- Benefits experienced by the use of CAM.
- Ill effects or side-effects from using the reported CAM therapy.
- Expenditure on CAM.
- Satisfaction and perceived effectiveness (on a 0-7 scale with higher scores indicating higher levels of satisfaction or perceived effectiveness).
- Sources of information about CAM therapies.

Data analysis

Data were analysed using the Statistical Package for Social Sciences (SPSS) programme. Descriptive statistics were calculated with all variables to summarise the data. Differences in sociodemographic characteristics between CAM users and non-users were assessed using the χ^2 -test. Spearman correlation coefficients were also calculated between CAM use and other variables of interest. Finally, multivariate analysis was used to assess which variables predicted CAM use.

Results

Participating countries

Fourteen countries completed the study, providing a total of 956 patient-completed questionnaires for evaluation. Table 1

Table 1. Participating countries, number of patients per country (in descending order) and frequency of CAM use

Country	n	%	CAM use	CAM non-use
·			$[n\ (\%)]$	[n (%)]
Spain	115	12	34 (29.8)	81 (70.2)
Israel	111	11.6	36 (32.4)	75 (67.6)
Turkey	100	10.5	37 (37)	63 (63)
Scotland	93	9.7	27 (29)	66 (71)
Greece	81	8.5	12 (14.8)	69 (85.2)
Switzerland	72	7.5	35 (48.6)	37 (51.4)
Sweden	59	6.2	18 (30.5)	41 (69.5)
Italy	52	5.4	38 (73.1)	14 (26.9)
Czech Republic	51	5.3	30 (58.8)	21 (39.2)
Serbia	50	5.2	16 (32)	34 (68)
Denmark	50	5.2	18 (36)	32 (64)
Belgium	45	4.7	18 (40)	27 (60)
Iceland	43	4.5	13 (30.2)	30 (69.8)
England	34	3.6	10 (29.4)	24 (70.6)

CAM, complementary and alternative medicine.

shows the countries and the number of questionnaires returned from each country.

Sociodemographic and clinical characteristics of the sample

A total of 591 (61.8%) female and 365 (38.2%) male patients participated in the study. Their mean age was 55.68 years [range 17–91; standard deviation (SD) 12.78]. The most frequent diagnosis included breast (n=282; 30.8%), colorectal (n=148; 16.1%) and lung (n=111, 12.1%) cancer. Most participants (n=703; 74%) were married. The vast majority (98.5%) were of white ethnic background. Most were earning <20 000 Euros annually (72.5%). Most (n=767; 82%) were currently receiving standard treatment. More details are shown in Table 2.

Use of CAM

Past or current CAM use was reported by 35.9% (n = 342) of the total patient population. CAM use ranged from 14.8% to 73.1% (see Table 1). Use of CAM ranged from 1 month up to 18 years in some cases (mean 27 months). In most countries, around one-third of patients were using some form of CAM, with only Switzerland, the Czech Republic and Italy showing high levels of CAM use and Greece showing very low levels of use (Table 1). It was interesting to see that CAM use was lower before the diagnosis of cancer, increased by at least 30% since diagnosis and current use stabilised at a little higher (8%) than the CAM use before diagnosis. Thirty-eight different therapies had been used before the diagnosis, 46 since diagnosis (10 were new types never used before by the patients) and 39 types of therapies were currently used. In total, 58 different CAM therapies were reported. Table 3 shows the frequency of use of different CAM therapies before diagnosis, since diagnosis and currently.

There were significant differences in CAM use among the different cancer diagnostic groups of the sample. The highest prevalence rate of CAM use was in pancreatic, liver, bone/ spinal and brain cancer patients, followed by breast, stomach, gynaecological and genitourinary cancers. The lowest rates of CAM use were observed in lung and head and neck cancer patients (Table 4).

Patients who paid for CAM privately were also asked to report how much, on average, they spent on such therapies or remedies. Patients were spending an average of €123/month, and the maximum reported amount was €4140/month. However, less than half the patients using CAM actually paid for such therapies or remedies (*n* = 188/342), as most of the remedies used were easily available without a charge (i.e. by collecting herbs themselves or by relatives collecting herbs from the mountain or given by friends).

The five most frequently used broad categories of therapies were similar across most countries. Herbs were the most commonly used CAM therapy in 13 out of 14 countries and they were the number one CAM therapy in nine countries (Turkey, Israel, Serbia, Czech Republic, Denmark, Italy, Switzerland,

Table 2. Sociodemographic and clinical characteristics of the sample^a

nGender Female 591 61.8 Male 365 38.2 Education level Illiterate 3 0.3 Primary education 290 30.6 Secondary education (high school) 375 39.5 College/University education 164 17.3 Postgraduate education 72 7.6 Professional/technical schools 44 4.6 Occupation Retired 254 27.9 Educational profession 45 4.9 Managerial profession 69 7.6 Housewife 13.8 126 Manual worker 257 28.2 Clerical staff 7.1 65 5 Health professional 46 Engineering 25 27 Unemployed 24 2.6 Marital status 98 10.3 Single Married 703 74 Divorced/separated/widowed 70/10/69 7.4/1.1/7.3 Ethnicity 932 98.5 Caucasian 5 Black 0.5 Asian 10 1 Annual income (in €) <10000 324 44.9 $10\,001 - 20\,000$ 199 27.6 20001 - 3000092 12.7 30 001 - 40 000 46 6.4 >40 000 61 8.4 Primary cancer Breast cancer 282 30.8 Colorectal cancer 16.1 148 Lung cancer 111 12.1 75 8.2 Head and neck cancer 72 7.9 Gynaecological cancers Haematological cancers 69 7.6 Genitourinary cancers 40 4.4 3.4 Stomach cancer 31 30 Prostate cancer 3.3 Bone/spine cancers 22 2.4 Pancreatic cancer 16 1.7

Table 2. (Continued)

	n	%
Liver cancer	9	1
Malignant melanoma	8	0.9
Brain tumors	4	0.4
Past treatment received $(n=713)$		
Surgery alone	120	16.8
Chemotherapy	106	14.9
Radiotherapy	41	5.8
Surgery and chemotherapy	155	21.7
Chemotherapy and radiotherapy	68	9.5
Surgery, chemotherapy and radiation	159	22.3
Other combinations	16	8.8
Currently receiving treatment ($n = 767$; 82.	1%)	
Surgery alone	8	1.1
Chemotherapy	597	78.8
Radiotherapy	35	4.6
Surgery and chemotherapy	20	2.6
Chemotherapy and radiotherapy	43	5.7
Surgery, chemotherapy and radiation	16	2.1
Other combinations	39	5.2

^aNot all frequencies add up to 956 subjects, as there were missing data.

Spain and Greece) and in the top five in all countries but Sweden. Homeopathy was the most commonly used CAM therapy in Belgium and in the top five in six other countries (Turkey, Czech Republic, Sweden, Italy, Spain and Greece). Medicinal teas were also in the list of the five most frequently used CAM therapies (seven countries), as were vitamins/minerals (nine countries). Most herbs were specific to each country (i.e. mistletoe in Switzerland, olive leaf paste in Greece, nettle leaves/tea in Turkey, aloe vera in Serbia and Spain or Ovosan in the Czech Republic). Israel, Denmark, Italy, Spain, Greece and Iceland featured strongly in relation to spiritual therapies.

The types of herbs or biological ingestibles used by participants were also assessed, as we asked participants to write down the names of herbs/remedies used. Herbs and other biological ingestibles used included green tea, essiac tincture, Chinese herbs, sage tablets, Echinacea, cod liver oil, fresh juice and vegetables, vitamin E, glucosamine, chamomile, peppermint, selenium, mistletoe/Iscador, yeast extract, multivitamins, Ayurveda herbs, vitamin C, soya drinks, dry thyme, dry nettle, nettle tea, nettle or nettle seeds mixed with honey, ginseng, mulberry molasses, shark cartilage, fish oil, gingko biloba, milk thistle, minerals (i.e. Zn, Ca, Mg), aloe vera (orally and externally used), papaya tea, beet and carrot juice, paste from olive leaves, a mixture of aloe-honey-rhaki and wine, and angelica herb. Most herbs were used to treat the cancer, although no participant specified for which specific condition they were using which method.

Table 3. Complementary and alternative medicine therapies used before the diagnosis of cancer, since diagnosis and currently

	Before diagnosis		Since diagnosis		Currently	
	n	%	\overline{n}	%	\overline{n}	%
Alternative medical systems: homeopathy	59	6.2	58	6.1	36	3.8
Alternative medical systems: acupuncture	37	3.9	29	3	18	1.9
Alternative medical systems: Ayurveda	2	0.2	5	0.5	4	0.4
Alternative medical systems: naturopathy	5	0.5	7	0.7	4	0.4
Biologically based therapies/ alternative medical systems: herbs	57	5.9	149	15.2	118	12.1
Biologically based therapies: medicinal teas	25	2.6	51	5.3	43	4.5
Biologically based therapies: vitamins/minerals	26	2.7	50	5.2	49	5.1
Biologically based therapies: other dietary supplements	15	1.6	34	3.5	19	1.9
Biologically based therapies: other	20	2.1	18	1.8	13	1.3
Mind-body interventions: spiritual therapies and healing	31	3.2	52	5.4	30	3.1
Mind-body interventions: relaxation therapy	18	1.9	44	4.6	35	3.7
Mind-body interventions: visualisation	10	1	28	2.9	22	2.3
Mind-body interventions: other	30	3.1	57	5.9	40	4.2
Energy therapies	31	3.2	20	2.1	14	1.5
Manipulative and body-based methods: massage	43	4.5	37	3.9	22	2.3
Other manipulative and body-based methods	55	5.7	34	3.6	18	1.9

Alternative medical systems: homeopathy, Chinese herbal medicine and acupuncture, Ayurveda, naturopathy.

Biologically based therapies: **herbs**, dietary supplements (**animal extracts**, coenzyme Q10), **vitamins/minerals**, **medicinal teas**, diets (**juicing**, macrobiotic diet, fasting therapy), **aromatherapy**, oxygen therapy, Bach flowers, cannabis smoking, bioresonance therapy, Iscador injections.

Mind-body interventions: spiritual therapies and healing, relaxation, visualisation, hypnotherapy, psychic therapies, curandero, support groups, yoga, art therapy, autogenic training, Alexander technique, anthroposophic medicine, bio-orgonomy.

Energy therapies: Tai Chi, Qi Gong, electromagnetic therapy, Reiki, Shiatsu, energy healing.

Manipulative and body-based methods: **massage**, chiropractic, **osteopathy**, drainage therapy/lymphatic massage, **reflexology**, zone therapy.

Numbers and words shown in bold represent most frequent single CAM therapies used.

Patients tended to be satisfied with the use of CAM and they also felt the particular therapy used was effective. The mean satisfaction score was 5.27 (SD 1.52), where a score of 7 indicated the most satisfied. Similarly, the mean score for perceived effectiveness was 5.04 (SD 1.52).

Table 4. Frequency of CAM use by cancer diagnostic group (in descending order)

Diagnostic group	% of CAM use			
Pancreatic cancer	56.3			
Liver cancer	55.6			
Bone/spinal cancer	54.5			
Brain cancer	50			
Breast cancer	44.7			
Stomach cancer	41.9			
Gynaecological cancers	40.3			
Genitourinary cancers	40			
Colorectal cancer	32.7			
Prostate cancer	30			
Haematological cancers	26.5			
Melanoma	25			
Lung cancer	23.6			
Head and neck cancer	22.7			

CAM, complementary and alternative medicine.

Frequency of use

Thirty-three different types of CAM practitioners were consulted. Seven patients (6.3%) received CAM therapy through their general practitioner/family doctor. Most patients who were visiting a CAM practitioner (n=111) did so less than once a month (34.2%), once a week (24.3%) or once a month (22.5%). Some 8.1% of patients visited a CAM practitioner once a month and 8.1% of patients visited a CAM practitioner 2-3 times a week. Furthermore, 2.7% visited a practitioner almost daily.

Reasons for using CAM and perceived benefits from its use

Most patients were using CAM as they wanted to increase their body's ability to fight the disease (50.7%), improve physical well-being (40.6%) or improve emotional well-being (35.2%) (Table 5). However, there were some differences in the reasons for using CAM therapies and the experienced benefit from them. In more detail, although the primary reason stated for using CAM was to increase the ability to fight the cancer, only 22.4% found CAM of benefit (P<0.001). Additionally, it is interesting to note that 42.5% found CAM to be helpful in improving emotional well-being, although this was only identified as a reason for use in 35.3% of the sample (P<0.01). Only 31 patients (3.2%) found the CAM therapy/therapies they used were not of benefit at all.

Sources of information about CAM

Patients were asked to note where they had learnt about the CAM therapy they used/were using. Friends were the most common source of information (56.5%), followed by family (29.1%) and the media (28.4%). Other sources of information

Table 5. Reasons for using CAM and perceived benefits

Reasons for using CAM			Benefits experienced	
	n	%	\overline{n}	%
To directly fight the disease with alternative therapy/decrease tumor	55	16.4	13	3.9*
To increase the body's ability to fight the cancer	170	50.7	75	22.4*
To improve physical well-being	136	40.6	152	45.4
To improve emotional well-being, provide hope and increase optimism	118	35.2	143	42.8
To counteract ill effects from the tumor or medical treatments	83	24.8	76	22.6
'Might help, can't hurt'	77	23.1	-	-
Desire to do everything possible to fight the disease	76	22.6	-	-
Requested by physician	3	0.9	-	-

CAM, complementary and alternative medicine.

included patient's physician (18.6%), CAM practitioners (12.9%), the Internet (9.3%), their nurses (3%), religious groups (2.4%), personal knowledge (1.8%) and other patients who used CAM (1.5%).

Side-effects

Fourteen patients (4.4%) reported side-effects from the CAM therapy they had used. Most seemed to be transient side-effects and they were all related to ingesting herbs or minerals. Responses were obtained from seven countries. These side-effects included stomach aches (one incident with thyme and nettle tea, one with vitamin C, and one with aloe); gastric upset and nausea from using nettle tea (one report); itching [one incident with nettle leaves, one with selenium tablets and one with Iscador (mistletoe)]; headaches and migraine (one incident, unspecified herbs); diarrhoea (one incident, unspecified herbs); and poor renal status/accumulation of body acid (one incident with vitamin C).

Multivariate analysis

Spearman correlation coefficients showed that the use of CAM was associated with younger age $(r_s=0.18;\ P<0.001)$, female gender $(r_s=0.14;\ P<0.001)$, higher education level $(r_s=0.15;\ P<0.001)$, higher annual income $(r_s=0.08;\ P=0.025)$ and previous standard treatment $(r_s=0.12;\ P<0.001)$, although these correlations were weak. These were also the variables that differed significantly between the users and non-users of CAM $(\chi^2$ -tests). Additionally, occupation was also different between users and non-users (P=0.008). A multivariate model of sociodemographic and clinical characteristics showed that three variables were the strongest predictors of CAM use: younger age, female gender and higher educational level (P<0.001). However, the model could only explain 26% of the variance in the use of CAM.

Why patients do not use CAM

Patients who were not using CAM were asked to note why they did not do so. The majority (n=236; 43.4%) reported that they were happy with the conventional treatment they received/were receiving. Also, 34.7% (n=189) reported that they never thought of CAM and 15.1% (n=82) that they did not believe in CAM. Other reasons included discouragement from family (n=12; 2.2%), lack of information about CAM (n=11; 2%), and inability to pay for CAM (n=9; 1.7%). Five patients (0.9%) noted that they were interested in CAM but they had not decided to use any as yet.

Discussion

The current study constitutes one of the largest surveys to date on the use of CAM in cancer patients, and is the only European-wide survey available. As such, it provides initial evidence of the extent of the use of CAM therapies, types, reasons behind use or non-use, perceived benefits, expenditure, and commonly observed side-effects. It has shown that although Europe consists of a diverse cultural population, CAM use has more similarities than differences across Europe. It is shown that the most popular CAM therapy in cancer patients is the use of medicinal herbs or remedies, although the variety of herbs used differed by country.

More than one-third (35.9%) of the cancer patients reported using some form of CAM, with little variation across countries. This is an increase of the average mean CAM use from that reported in a review of 29 studies covering 20 years [3]. Similar to the study by Ernst and Cassileth [3], there was great variability in the use of CAM, and this may partly be the result of the patient's understanding of what CAM is. A standardised protocol was used in the current study to minimise such biases, and the definition used was as broad and inclusive as possible. The variability probably also reflects adjunctive use of CAM, as the sample was derived exclusively from health-care settings.

Nevertheless, CAM use is considerably lower in the present study than surveys reporting results from US samples. US studies demonstrate a much higher use of CAM, which is often well above 40% [6, 8, 9, 15]. This could indicate that the concept of a more holistic approach to medicine or the use of an integrated model of health-care provision is lagging in Europe compared with the USA. North Americans may also be using CAM more frequently due to the wider influence that ethnic groups may have had on Western (scientific) medical philosophy, and the realisation that some of the CAM therapies may be beneficial to patients and possibly cost-effective. Furthermore, Kessler et al. [18] also suggest that the trend in the use of CAM in the USA may be a result of a secular trend that began about half a century ago, which nevertheless highlights the increasing patient demand for such therapies. However, the limited available data on the effectiveness of various CAM therapies also highlights the necessity to be selective and careful (but open minded) about CAM therapies.

^{*}P<0.001.

The country with the highest CAM use was Italy, but as the source of data was from a palliative care unit these results may not be accurate. An observation of the study was that participants from palliative care facilities tended to use CAM more often, but the mixed settings in most of the countries participating in the study did not allow us to validate this observation. Furthermore, another observation was that CAM use was higher in cities, but when samples from rural hospitals within the same country were added, it decreased the overall number of users. This was especially true in Greece and Spain, where such data were available. Hence, use of CAM therapies may also be related to the availability of such therapies in a given geographical setting. The lowest frequency of CAM use was observed in Greece, and this may reflect the lack of availability of many CAM therapies, high compliance with conventional medical treatments, cultural norms or concealing use of CAM in order to avoid any conflict of opinion with the health-care team. Indeed, before completing the study questionnaire, many participants from a number of countries in the study did mention that they did not want their healthcare team to know about their use of CAM.

A large number (n = 58) of heterogeneous CAM therapies was reported. Confirming earlier reports, herbals and medicinal teas, vitamins and minerals, spiritual therapies, homeopathy, and relaxation techniques were the CAM therapies used more often in this current sample [7-11]. These did not differ substantially among all the countries involved in the study. Perhaps reflecting cultural preferences, availability and national legislation from country to country, differences were observed in the less frequently used CAM therapies. Based on the CAM classification by the National Center for Complementary and Alternative Medicine [17], most patients were using biologically based therapies. This highlights the attractiveness for patients of 'natural' therapies and remedies, but also suggests that patients may be at risk of side-effects or, as most patients were currently receiving treatment, interactions with conventional medicines. Several good reviews of such side-effects have been presented in the literature (e.g. Niggemann and Gruber [19]). The role of CAM in affecting (positively or negatively) the outcomes of pharmaceutical clinical trials in cancer care is also an issue that needs attention, as many patients involved in trials will also be using CAM therapies.

Patients typically used more than one CAM therapy together. This fact alone makes research into the effectiveness of CAM using traditional trial designs complicated. It was also interesting to see that only a small number of patients used support groups. This was 0.3% before the diagnosis of cancer (reflecting presence of other chronic conditions), increasing to 1.8% at some point since the diagnosis of cancer and only 1.4% using support groups currently. This is considerably lower than rates reported in past psychosocial literature [20, 21], perhaps highlighting the lack of availability of support groups in many countries in Europe. However, past research on support groups comes mainly from America, with data commonly collected from breast cancer patients and

specialist clinics, so the higher rates reported may not be generalisable to all cancer patients. Further, as can be seen in Table 3, the overall use of energy therapies (often used for 'wellness' rather than specific illnesses) and manipulative methods were decreased after the diagnosis of cancer (with the exception of electromagnetic therapy and massage).

Herbal medicines were by far the most commonly used therapy, escalating in use from 5.3% before the diagnosis of cancer to 13.9% (an almost three-fold increase) after the diagnosis of cancer. A wide range of herbs were recorded as being used. These differed from country to country, probably based on specific ethnopharmacological information and tradition, as well as availability. For example, among others, Turkey reported most commonly the use of nettle leaves/teas, as well as thyme, often mixed with other compounds; Scotland reported more often the use of green tea; Switzerland used mistletoe more often (a particularly popular herb in Germanspeaking countries); the Czech Republic used Ovosan (a locally produced tablet combining a number of herbs), selenium, ginseng, gingko biloba and Echinacea; Sweden reported the use of blood salts and ginseng; Serbia and Spain reported more often the use of aloe vera; Greece reported the use of a paste made from olive leaves; Iceland reported the use of lupine extracts (angelica) and green tea; and Israel and England reported the use of multivitamins.

It was interesting to see the wide variation in the prevalence rates of CAM use among different diagnostic groups. Despite suggestions from the literature that breast cancer patients are more likely to use CAM compared with other cancer patients [22], the present study showed that pancreatic, liver, bone and brain cancer patients used CAM therapies significantly more often than any other cancer patient group. All four of these diagnostic categories are characterised by poor prognosis and a rapid physical decline, often with metastasis present, and such patients may have little hope from conventional treatments, turning to CAM as an additional intervention to improve their lives. The role of CAM not only in increasing hope and optimism, but also in improving quality of life and managing symptoms, especially in terminal illness, may be important, but relevant data in cancer patients is almost nonexistent to date. However, some of the results in this subgroup analysis should be viewed with caution, as only a small number of patients participated from some of the diagnostic categories. Also, a longitudinal design could have given more accurate information about variation of CAM use along the patient's disease experience.

Patients seem to be satisfied with the use of CAM, even if they do not see any obvious benefit from it. A wide range of reasons contribute to the use of CAM, and perhaps the concept of 'hope' is fundamental in each one of these reasons. More than two-thirds of the patients used CAM therapies to directly fight the cancer or to increase the body's ability to fight cancer, but eventually they found little benefit for this. However, those who used CAM to improve physical and emotional well-being seemed to have benefited from CAM. These findings coincide with findings from the USA [11]. It is interesting

to see that <1% of the patients used CAM following the recommendation of their physician, perhaps reflecting the disapproval of CAM therapies by the medical community or the lack of information to the medical community about available and effective CAM therapies. Examples of such information include the consistently positive results with acupuncture in the management of chemotherapy-related nausea and vomiting [23]; the positive effects of self-hypnosis, massage or acupuncture in pain relief in cancer patients [24]; the relief of dyspnoea with acupuncture, acupressure or relaxation/breathing techniques [24]; the positive short-term benefits of massage and aromatherapy massage on psychological well-being [25]; and the promising results from the use of mistletoe in relation to survival, management of side-effects or quality of life in cancer patients [26]. Also, <4% used CAM to directly fight the disease (i.e. as an alternative cancer treatment) and the overwhelming majority used CAM to complement their cancer treatment or help them cope with the treatment and/or its side-effects. As many of the therapies used are 'complementary' in nature (such as aromatherapy, massage, relaxation, reflexology and others), we may not need to prove their effectiveness before using them, as patients are demanding such therapies, they are low-risk therapies and patients feel good after their use. Such therapies may have a great role to play, especially in the palliative care setting, where the goal is not cure but rather improvement in quality of life. Patient satisfaction can be an appropriate end point outcome for evaluation rather than clinical outcome studies in this setting.

A wide variety of sources of information were used before patients selected a given therapy. Friends and family or word of mouth seemed to be the most important sources of information. This may be problematic, as what is effective for one patient may not be for another, even with the same symptoms. Also, the media was shown to be a common source of information, and this may again be problematic, as the media often sensationalises patient stories without balancing the information presented. The role of physicians as sources of information was quite low, with only 18.6% actually providing information to patients. This number is even lower among nurses: only 3% of nurses were identified as the main source of information for patients. Health professionals need to be able to provide information about CAM to their patients, although the knowledge deficit is acknowledged. The Internet is another commonly used source of information, but the commercial nature of many relevant websites (especially in relation to herbs) and the lack of quality assessment of the information posted on the web may be sources of misinformation [27].

Findings should be evaluated in light of the limitations of the study. The European-wide nature of the study was difficult to conduct, and it was difficult to maintain consistency, because of its international breadth and specific requests from various ethics committees or hospital boards. As we did not have access to medical records, we could not ascertain whether there was metastatic disease or not and other, more sensitive clinical data. There is also an overlap between the users of CAM 'since diagnosis' and 'currently'. Based on the selected design of the study, made simple and anonymous to fulfil recruitment criteria in all the countries involved, it was difficult to track patients who refused participation (albeit recruitment rates of >90% were achieved in the majority of the cases, based on individual researchers' comments). Finally, as the samples were taken from different settings, patterns of use may reflect different rates because of the setting rather than the countries concerned.

Irrespective of what health professionals believe about CAM and how dismissive of CAM they may be, it is evident that patients are using, and will continue to use, CAM therapies. Hence, from a professional point of view, health-care staff need to be aware of such use of CAM and to be able to educate patients appropriately. This will probably necessitate the rethinking of the provision of medical and health-care education, broaden our understanding of the concept of medicine and help us work towards integrating into mainstream healthcare services those CAM therapies for which evidence of effectiveness exists. This debate has already been discussed elsewhere (i.e. Owen et al. [28]). At the same time, there will be a need for considerable increase in the funding for CAM research. Currently only the National Center for Complementary and Alternative Medicine, National Institutes of Health in the USA provides substantial funds for such research, and other organisations and countries would need to follow their example. In the UK, research funding for CAM has increased over the years but, until recently, this was still only $\sim 0.31\%$ of all funding available for medical research, suggesting that funding is low [29]. The need to increase the evidence base of CAM therapies, using methodologies that are appropriate and sensitive to CAM, cannot be overemphasised. This is also important from an economic point of view, as the use of CAM is a multibillion Euro business, and as shown in this study, some patients pay large sums out of their pockets to receive such interventions. In the USA, where such data are available, the use of CAM is conservatively estimated to cost patients US\$27 billion (for the year 1997) [30]. In Europe it is the second biggest growth industry [31]. Finally, appropriate legislation and regulation of CAM therapies in Europe is also necessary. While many countries have developed their own regulation and legislation [32], there are wide variations in such laws across Europe. Since it would appear that CAM is here to stay, the European Community needs to consider broader policies, common laws and a rationalisation of the available legislation.

Acknowledgements

We would like to acknowledge and thank the following people for their direct contribution to this work: Jose Sanfrancisco Andrés, Hospital Donostia, Donostia, Spain; Emi Chirveches, Hospital General de Vic, Barcelona, Spain; Maria Luz Hospital, Hospital Miguel Server, Zaragoza, Spain; José María Izquierdo, Hospital Dr J. Trueta, Gerona, Spain; Justa Rodríguez Orduña, Htal Universitario, Granada, Spain; Paz Zabaleta, Instituto Oncológico de Guipúzcoa, Guipúzcoa,

Spain; Sole García, Hospital Carlos Haya, Malaga, Spain; Javier Gómez, Hospital General de Alicante, Alicante, Spain; Elisa Holgado, Hospital General Universitario de Valencia, Valencia, Spain; Concha Vallejo, Hospital Xeral de Lugo, Lugo, Spain; Amelia de León, Hospital Clínico Universitario, Salamanca, Spain; Concha Vila, Hospital Clínico San Carlos, Madrid, Spain; Aliza Yaffe, Israel Cancer Association, Israel; Sara Ben-Ami, Israeli Oncology Nursing Society, Tel Aviv, Israel; Amira Morag, Tel-Hashomer, Israel; Eti Kaner, Beer Sheva, Israel; Figen Kava Bay, Gazi University Hospital, Ankara, Turkey; Gaye Paterson, Morven Miller, University of Stirling, Stirling, Scotland; Liz MacMillan, Lesley Newlands, Susan Davidson, Lynette McGeever and Jennifer Wilson, Falkirk Royal Infirmary, Falkirk, Scotland; Bridget Johnston, Strathcarron Hospice, Denny, Scotland; Vaso Spiropoulou and Anna Papadimitriou, 'METAXA' Oncology Hospital, Athens, Greece; Eleftheria Tzamakou, University Hospital of Ioannina, Ioannina, Greece; Konstantina Papadopoulou, University of Athens, Greece; Christel Böhme, Kantonsspital St Gallen, St Gallen, Switzerland; Emmie Okkinga, Inselspital Bern, Bern, Switzerland; Cécile Matt and Evelyn Barata-Salgueiro, Universitätsspital Zürich, Zürich, Switzerland; Mariangela Luppolo, Azienda Ospedaliera FBF Milano, Italy; Marco Gialli, Ospedale Riuniti di Bergamo, Italy; Asciolla Valentina, Polo Universitario San Paolo, Italy; Sara Bianchi, Istituto Nazionale Tumori, Italy; Simona Pizzi, Ospedale Buzzi I.C.P. Milano, Italy; Jana Haicmanova, Masaryk Memorial Cancer Institute, Brno, Czech Republic; Lena Andersen, Aarhus University Hospital, Aarhus, Denmark.

References

- Ernst E, Resch KL, Mills S et al. Complementary medicine a definition. Br J Gen Pract 1995: 45: 506.
- Ernst E. Complementary cancer treatments: Hope or hazard? Clin Oncol 1995; 7: 259–263.
- Ernst E, Cassileth BR. The prevalence of complementary/alternative medicine in cancer. A systematic review. Cancer 1998; 83: 777–782.
- Cassileth BR, Schraub S, Robinson E, Vickers A. Alternative medicine use worldwide. Cancer 2001; 91: 1390–1393.
- Patterson RE, Neuhouser ML, Hedderson MM et al. Types of alternative medicine used by patients with breast, colon, or prostate cancer: predictors, motives, and costs. J Altern Complement Med 2002; 8: 477–485.
- Richardson MA, Sanders T, Palmer JL et al. Complementary/alternative medicine use in a comprehensive cancer center and the implications for oncology. J Clin Oncol 2000; 18: 2505–2514.
- Oneschuk D, Fennell L, Hanson J, Bruera E. The use of complementary medications by cancer patients attending an outpatient pain and symptom clinic. J Palliat Care 1998; 14: 21–26.
- Jordan ML, Delunas LR. Quality of life and patterns of nontraditional therapy use by patients with cancer. Oncol Nurs Forum 2001; 28: 1107–1113.
- 9. Bernstein BJ, Grasso T. Prevalence of complementary and alternative medicine use in cancer patients. Oncology 2001; 15: 1267–1272.
- Sparber A, Bauer L, Curt G et al. Use of complementary medicine by adult patients participating in cancer clinical trials. Oncol Nurs Forum 2000; 27: 623-630.

- Swisher EM, Cohn DE, Goff BA et al. Use of complementary and alternative medicine among women with gynecologic cancers. Gynecol Oncol 2002; 84: 363–367.
- Molassiotis A, Cubbin D. Thinking outside the box. Eur J Oncol Nurs 2004: 8: 50–60.
- Kelly KM, Jacobson JS, Kennedy DD et al. Use of unconventional therapies by children with cancer at an urban medical center. J Pediatr Hematol Oncol 2000; 22: 412–416.
- von Gruenigen VE, White LJ, Kirven MS et al. A comparison of complementary and alternative medicine use by gynecology and gynecologic oncology patients. Int J Gynecol Cancer 2001; 11: 205–209.
- Bennett M, Lengacher C. Use of complementary therapies in a rural cancer population. Oncol Nurs Forum 1999; 26: 1287–1294.
- Ernst E. The role of complementary and alternative medicine. Br Med J 2000; 321: 1133–1135.
- National Center for Complementary and Alternative Medicine. Available on-line at: http://nccam.nih.gov/health/whatiscam/ (17 June 2004, date last accessed).
- Kessler RC, Davis RB, Foster DF et al. Long-term trends in the use of complementary and alternative medical therapies in the United States. Ann Intern Med 2001; 135: 262–268.
- Niggemann B, Gruber C. Side-effects of complementary and alternative medicine. Allergy 2003; 58: 707–716.
- Bui LL, Last L, Bradley H et al. Interest and participation in support groups programs among patients with colorectal cancer. Cancer Nurs 2002; 25: 150–157.
- Eakin EG, Strycker LA. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: Patient and provider perspectives. Psychooncology 2001; 10: 103-113.
- Morris KT, Johnson N, Homer L, Walts D. A comparison of complementary therapy use between breast cancer patients and patients with other primary tumors. Am J Surg 2000; 179: 407–411.
- Shen J, Wenger N, Glaspy J et al. Electroacupuncture for control of myeloablative chemotherapy-induced emesis: A randomized controlled trial. J Am Med Assoc 2000; 284: 2755–2761.
- 24. Pan CX, Morrison RS, Ness J et al. Complementary and alternative medicine in the management of pain, dyspnea, and nausea and vomiting near the end of life. A systematic review. J Pain Symptom Manage 2000; 20: 374–387.
- Fellowes D, Barnes K, Wilkinson S. Aromatherapy and massage for symptom relief in patients with cancer. Cochrane Database Syst Rev 2004: CD002287
- Kienle GS, Berrino F, Bussing A et al. Mistletoe in cancer a systematic review on controlled clinical trials. Eur J Med Res 2003; 8: 109–119.
- Molassiotis A, Xu, M. Quality and safety issues of web-based information about herbal medicines in the treatment of cancer. Complement Ther Med (in Press).
- Owen DK, Lewith G, Stephens CR. Can doctors respond to patients' increasing interest in complementary and alternative medicine? Br Med J 2001; 322: 154–157.
- Wider B, Ernst E. CAM research funding in the UK: surveys of medical charities in 1999 and 2002. Complement Ther Med 2003; 11: 165–167.
- Eisenberg DM, Davis RB, Ettner SL et al. Trends in alternative medicine use in the United States, 1990-1997: results of a follow-up national survey. J Am Med Assoc 1998; 280: 1569-1575.
- Reilly D. Comments on complementary and alternative medicine in Europe. J Altern Complement Med 2001; 7 (Suppl 1): S23–S31.
- Fisher P, Ward A. Medicine in Europe: Complementary medicine in Europe. Br Med J 1994; 309: 107–111.