

Addressing Unmet Information Needs: Results of a Clinician-Led Consultation Service About Complementary and Alternative Medicine for Cancer Patients and Their Relatives

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Abstract

Purpose. To report on a telephone consultation service with cancer patients and their relatives about complementary and alternative medicine (CAM) between 1999 and 2011. **Methods.** We offered a Germany-wide, free-of-charge telephone consultation service about CAM led by oncology clinicians from a comprehensive cancer center. The consultations followed a patient-centered approach with the aim to provide guidance and evidence-based information. Sociodemographic, disease-related data as well as information about the consultations' content were collected in a standardized manner, and feedback questionnaires were sent out immediately after the consultations. **Results.** Overall, 5269 callers from all over Germany used the service (57% patients, 43% relatives). The “big 4” cancer types (breast, gastrointestinal, prostate, and lung) accounted for 55% of all calls. In 67% of calls, patients had just received the diagnosis or commenced anticancer therapy; 69% of patients had advanced or metastatic diseases. More than half of the callers (55%) had vague concerns like “*what else can I do?*” rather than specific questions related to CAM. The consultations covered a broad spectrum of issues from CAM therapies to cancer treatment and measures supportive of health, nutrition, and psychosocial support. Callers highly valued the service. **Conclusions.** Consulting about CAM addresses important unmet needs from cancer patients and their relatives. It provides clinicians with the opportunity to engage in open and supportive dialogues about evidence-based CAM to help with symptom management, psychological support, and individual self-care. Consulting about CAM cannot be separated from consulting about conventional care and should be provided from the beginning of the cancer journey.

Keywords

information-seeking, communication, patient education, family involvement, unmet needs, consultation service, complementary therapies, supportive care

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Introduction

Complementary and alternative medicine (CAM) encompasses supportive measures of various kinds used to supplement conventional cancer treatment as well as diverse

healing practices aimed at preventing or affecting tumor growth.¹ In the past 2 decades, we have seen a steady increase in the interest of cancer patients in CAM,² with

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current usage rates up to 87%.³ Whereas certain CAM modalities have the ability to control treatment- and disease-related symptoms and to improve the quality of life, others may pose risk to some individuals, particularly during active cancer treatment when the risk of interactions is increased.⁴

When faced with a cancer diagnosis, patients are interested to learn not only about conventional treatment options, but also about therapies from the domain of CAM.⁵⁻⁷ Information-seeking, as a coping strategy, helps them understand their options, gives them a sense of hope and control, and could improve communication with family members.⁸⁻¹¹ In this process, patients often get frustrated about the diverging information and contradictory messages about the evidence of CAM, and their efforts do not mitigate feelings of uncertainty and fear but lead to a new and even greater burden.^{12,13} It is, therefore, not surprising that cancer patients want physicians to be their primary point of contact for information and guidance about CAM.¹⁴⁻¹⁶

This clear position notwithstanding, discussions of CAM are relatively rare in the oncology encounter for reasons coming from both sides¹⁷⁻²⁰ Patients refrain from asking questions because they feel that doctors are not receptive or because of fear of being considered difficult and of receiving worse care.²¹⁻²⁴ On the other side, clinicians often do not perceive themselves equipped to provide the necessary information (lack of training in knowledge and communication about CAM),²⁵⁻²⁷ are skeptical about safety and efficacy, or are insensitive to patients' informational, cultural, and emotional needs.^{28,29} Given only the fact that CAM use may lead to a delay of conventional treatments³⁰ or may interfere with them and thus affect patients' well-being and chances of survival, the lack of communication is a serious problem.

To allow systematic research and information about CAM in the setting of a comprehensive cancer center, we established a work group called Biologic Cancer Therapy (BCT) in the early 1990s. In addition to its research activities, the BCT took on the task of representing German Cancer Aid as a point of contact for patients and caregivers who had questions about CAM.

The BCT's oncology clinicians did not offer CAM treatments but restricted consultations to information and guidance. Hence, the contacts resembled encounters in which counseling and coordination of care dominates. The communication about CAM was based on the guidelines for clinicians that were published at that time (adapted from Holland et al³¹):

- evaluate the reasons for the interest in CAM and assess if they reflect needs that are not met within conventional care;
- encourage questions, listen actively, and take related concerns seriously;

- provide balanced information about limitations, interactions with other treatments, risks, and potential benefits of CAM to patients and their families; and
- encourage open discussion and avoid making moral judgments.

With the increasing awareness of the BCT, the number of contacts rose markedly, with inquiries coming not only from the clinic and its large catchment area but from all over Germany. Hence, callers were offered the opportunity to consult also over the telephone since 1999, and consultations had to be managed systematically.

The purpose of this article is to report on all telephone consultations with cancer patients or their relatives routinely held between 1999 and 2011 along with the results from a nested feedback survey. We were in particular interested in learning who used the service, at which points of the cancer continuum the need for advice arose, which were the points of inquiry, and to what kind of informational needs they were related.

Methods

Telephone Consultation Service

Individuals could contact the BCT 4 hours per day, 5 days per week. Callers did not need a medical referral or anything similar. Trained receptionists managed all the contacts to the BCT and the related paper work.

When callers requested a consultation, the receptionists sought their consent to document and analyze their personal data, informed them that the consultations were free of charge because of the sponsorship of German Cancer Aid, and arranged an appointment. Because many callers had an urgent need for information, appointments for telephone consultations were arranged as quickly as possible: often on the same day, but no later than within the next 1 to 2 work days. That precluded a pre-post comparison but gave us the opportunity to learn about the information needs in rather unaltered conditions.

Documentation of Consultations

The receptionists indicated on a paper-based documentation form, which complied with standards for medical record documentation, whether the caller was a patient or a caregiver, and asked for personal data. They also indicated whether a caller asked about a particular CAM, whether the query was open in its phrasing and did not refer directly to a specific CAM, or whether the question had to do with conventional cancer treatment. Whenever possible in terms of timing, the callers sent medical documentation before the consultation.

During or after each consultation, all clinicians supplemented the information on the form by filling in the fields

about the diagnosis, staging, therapeutic situation, and current treatments; the intention of the oncological treatment as they assessed it; and any other topics discussed during the consultation. They also added their own notes about the content and course of the consultations. The receptionists entered all data from the documentation forms verbatim in a programmed database (MS Access).

Consultation Concept

Drawing on its clinical background and the experiences acquired during its research activities around CAM at that time,³² the BCT developed an evidence-based approach for the consultations. The aim was to understand the callers' reasons for encounter and to provide them with information adapted to their needs and wishes, integrating both the individual clinical expertise and external evidence.³³ The communication during the consultations resembled in its core the patient-centered clinical interviewing, in which consultants weave to and fro between the patients and their agenda, bringing them together to give a shared understanding, which then allows for explanations and further planning.³⁴

Staff and Support

Six oncology clinicians from our department (referred to as *consultants* hereafter) worked part-time for the BCT and took part in the consultation service for different time periods (2-5 years). The consultants had different levels of specialty training in internal medicine, oncology, hematology, and palliative care and had completed advanced clinical communication skills trainings. All consultants became acquainted with the concept by a collegial training. Regular team sessions among consultants were used to share experience and ideas to find ways of addressing issues in the consultation context and to foster experiential learning. All consultants participated not only in continuous medical education about clinical nutrition, mind-body therapies, and phytotherapy but took also part in the BCT's activities around systematically reviewing the evidence of CAM in cancer.

Data Collection

The data for this article came from all telephone consultations with cancer patients or caregivers between November 1999 and February 2011 on first contact. The consultants had completely filled in 5269 documentation sheets during or immediately after phone consultations. A total of 95 documentations were incomplete and were not included in the analysis. Also, data from on-site consultations (n = 412) were not included.

Data for this study came furthermore from feedback forms that were sent to each caller from January 2003 to January 2008 immediately after the telephone consultation

(n = 3373). The main reason why feedback forms were sent only during that time period was that the BCT had more resources during that time period because of expanded funding for German Cancer Aid.

Standardized Documentations

The information included the kind of caller, age and sex of the caller, and other variables (*a* to *h*) indicated in the forms, as follows:

- (a) How callers came to the BCT: referrals (helplines, health professionals, etc), media (electronic, print), or other (tips from other patients, etc).
- (b) Callers' proximity to the BCT: regional (only postcodes starting with 9), national, and foreign country (calls from outside Germany).
- (c) Type of malignancy (categorized according to site or type).
- (d) Treatment situation: if the patients were in a period of planning or decision making about or prior to the beginning of treatment, it was categorized as "before start of treatment"; if the cancer had progressed so far that anti-tumor treatment was no longer possible or indicated, it was summarized under ("no invasive treatment").
- (e) The intent of oncological treatment: the consultants assessed the intent based on the available medical information.
- (f) Points of inquiry and topics of discussion: to code the points of inquiry and topics of discussions, the consultants generated an extensive list and regularly updated it as consultations were held. The list included more than 150 items, which were grouped into 14 domains. Seven of these domains covered topics related to specific CAM and were derived from the classification of the Office of Cancer Complementary and Alternative Medicine (OCCAM) of the US National Cancer Institute (NCI) (see Table 1). The other 7 domains covered topics that went beyond CAM (see Table 2). The latter domains emerged gradually during the team discussions. In doing so, the operational definitions for allocating the items of the list to the individual domains were repeatedly discussed until there was consensus. The domain "General inquiry" was coded if callers expressed their inquiry as a general question (eg, "What else can I do?") that did not relate to a specific CAM.
- (g) Duration of the consultation (<30 minutes, 30-60 minutes, >60 minutes).

Feedback Survey

We used a self-constructed questionnaire with 7 quantitative items. Some items were answered on a 5-point rating scale (how the consultation was perceived) and others

Table 1. Domains Used to Classify the Topics Related to Specific CAM That Were Mentioned on Contact With the Consultation Service or Topics Related to Specific CAM Discussed During the Consultations.

Domains	Examples
Alternative medical systems	Acupuncture, Ayurvedic medicine, Hildegard medicine, homeopathy, traditional Chinese medicine, Kampo medicine
Manual and body-based methods	Chiropractic, therapeutic massage, osteopathy, kinesiology, reflexology
Mind-body interventions	Meditation, hypnosis, art therapy, imagery, relaxation therapy, music therapy, yoga, tai chi/qi gong, yoga, mindfulness-based stress reduction
Other CAM treatments	Technical treatments (hyperthermia, galvanotherapy, electrochemotherapy), noninvestigational immunotherapies (vaccination, oncolytic viruses, dendritic cells), fever therapy, IPT (insulin-potential therapy)
Pharmacological and biological treatments	Herbs and herbal extracts (<i>Artemisia</i> , <i>Boswellia</i> , <i>Cannabis</i> , <i>Echinacea</i> , <i>Ginseng</i> , St Johns wort, <i>Uncaria</i> , <i>Viscum</i> , etc), tissue extracts (shark cartilage, thymus extracts, snake/spider venom, etc), certain drugs (Essiac, factor af2, Flor Essence, laetrile, melatonin, NeyTumorin, PC-SPES, etc), medicinal mushrooms (<i>Agaricus</i> , <i>Grifola</i> , <i>Lentinus</i> , etc)
Spiritual and energy therapies	Reiki, therapeutic touch, spiritual healing, electromagnetic fields, Biofield therapies
Supplements and special diets	Vitamins, minerals, trace elements, dietary supplements (carnitine, coenzyme Q10, glutathione, proteolytic enzymes, omega-3 fatty acids), special diets (Budwig, Breuss, Gerson, ketogenic, macrobiotic, etc)

Abbreviations: CAM, complementary and alternative medicine.

Table 2. Domains Used to Classify Topics Other Than Specific CAM That Were Discussed During the Consultations and Description of Related Issues.

Domains	Description
Cancer treatment	Issues related to cancer therapies (surgery, chemotherapy, radiation therapy, hormonal therapy, targeted therapy, investigational therapy), supportive therapy, palliative care, and cancer rehabilitation
Contact and referral	Qualified points of contact and addresses, hospitals, physicians, second opinions, rehabilitation centers, specialist departments, support groups
Emotional support	Need of the caller to talk about the cancer experience, psychological, and interpersonal issues; assistance in coping with burdens, negative feelings, and thoughts; encouragement, active listening, and reassurance
Nutrition and metabolism	Issues related to diets rich in macronutrients and micronutrients, the relevance of specific ingredients, the risks of poor nutrition, dealing with specific diets, and the function of the metabolism and GI tract
Physical activity and exercise	Issues related to the physiological effects of exercise and training, selecting the right kind of exercise and training in the respective therapeutic situations, coping with impairments caused by the disease or its treatment
Principles of EbM	Interpreting the findings of research, validity and significance of different kinds of studies (interventional studies, observational studies, case studies, preclinical studies) as the foundation for taking decisions, especially with regard to risks and benefits of CAM
Social support	Social and practical needs of cancer patients and their families, access to support groups, opportunities to use one's own experiences to help others, and participation in social situations; insurance coverage

Abbreviations: CAM, complementary and alternative medicine; GI, gastrointestinal; EbM, evidence-based medicine.

with 2 to 4 predefined responses (see Table 6). The respondents could add their comments in free text to all items.

Of 3373 feedback questionnaires, 979 (29%) were completed and returned. Comparison between responders to the survey and the entire sample of callers showed slight differences in gender, age, caller's level of proximity, and type of caller: more female (69%) than male (31%) callers ($P < .05$), patients (63%) than relatives/friends (37%, $P < .001$), callers who lived more than 100 km away from the BCT (73%, $P < .001$), and older callers (mean age 57 years, $P < .001$) responded to the questionnaire.

Analyses

Before analyses were done, any identifying characteristics were replaced using pseudonymization techniques complying with data protection regulations. We used frequencies and percentages to describe the proportion of categorical variables and means and their SDs to describe continuous variables. We performed χ^2 tests to determine significant differences between categorical variables. Adjusted residuals were assessed if significance was reached at the $P = .05$ level to determine which categories contributed to the

significance. If adjusted residuals were more than 2.0 or less than -2.0 , this was reported and discussed. We used Mann-Whitney U tests for continuous variables. All statistics were analyzed in R (version 3.2.1 for Windows).

Compliance With Ethical Standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Verbal informed consent was obtained from all individual participants included in the study.

The consultation service complied with the code of medical ethics of the German Medical Association. The project was approved by the institutional review board of the Klinikum Nuernberg.

Results

Diagnosed cancer patients represented 57% of callers to the BCT ($n = 3009$), and family members or friends of cancer patients (called *caregivers* hereafter) represented 43% ($n = 2260$). The characteristics of the sample of callers are summarized in Table 3.

The “big 4” cancer types (breast, gastrointestinal, prostate, and lung) accounted for 55% of all calls ($n = 2907$). Breast cancer patients or their caregivers were the largest group of callers (24%, $n = 1273$). In more than two-thirds of calls (69%, $n = 3613$) the afflicted patients had cancers that were in advanced or metastatic stages for which there were no curative treatment options. In 67% of calls ($n = 3529$), patients had just received the diagnosis or had commenced anticancer therapy (eg, chemotherapy). The average call duration was 33 minutes, with 43% of calls being 30 minutes or less, and 5% lasted more than 60 minutes.

Points of Inquiry

In all, 55% of all callers ($n = 2890$) did not inquire about a specific CAM but rather asked how to deal with the situation and tried to find out whether CAM interventions might be helpful or beneficial. Only a third of callers ($n = 1785$) asked for a consultation about a specific CAM. Here, the most common queries involving CAM came from the domain “Pharmacological and biological treatments” ($n = 792$). Also, 11% ($n = 594$) inquired about topics related to conventional cancer treatment. The points of inquiry mentioned on first contact to the BCT are summarized in Table 4

Topics of Discussion

The topics of discussion covered a broad spectrum of issues and belonged on average to 3 to 4 of the domains

listed in Tables 1 and 2 (mean = 3.5; SD = 1.6). In 3458 consultations (66%, Table 5), the topics dealt with conventional therapies, including supportive and palliative care, anticancer treatment, or rehabilitation (“Cancer treatment” in Table 2). The second most widespread topic ($n = 2849$, 54%) was content involving the domain of “Pharmacological and biological treatments.” In a little more than one-third of the consultations ($n = 2054$, 39%), the discussion focused on subjects such as how to apply data about clinical efficacy and safety to individual clinical decisions related to CAM (“Principles of EBM”). More than a quarter of the consultations ($n = 1440$, 27%) dealt with issues like encouragement, active listening, and reassurance, categorized as “Emotional support” (see Table 2).

The numbers of domains from which topics were discussed were greater among callers who had asked a general question (mean = 3.7; SD = 1.6) as compared with callers who expressed their inquiry with relation to a specific CAM (mean = 3.3; SD = 1.5).

Differences Between Patients and Caregivers Calling

The differences between the characteristics of patients and caregivers are shown in Table 3. If relatives or friends called, the patients for whom they cared were more frequently in treatment situations without curative intent or even without any oncological treatment options. Conversations with patients lasted slightly longer on an average than with caregivers. There were only minor differences among the domains that patients or their caregivers inquired about (Table 4). The domains from which topics were discussed during the consultations varied: the consultants spoke, if patients called, more frequently about supplements and special diets and Mind-body interventions, and—with regard to domains that did not directly relate to CAM—and about nutrition and metabolism and physical activity and exercise (Table 5).

Feedback Survey Responses

The results of the feedback survey suggest that the consultations satisfied the expectations of most of the callers (Table 6). Around one-fifth of them stated that they had expected something else but still experienced the consultation as positive. In more than 9 of 10 consultations, the callers’ concerns and questions were answered, and an equally high number regarded the consultations as informative, clarifying, supportive, or helpful. The fact that the consultation was conducted by phone was not a problem for the majority of callers, although a third of them stated that it would have been helpful to have an additional discussion in person (Table 6).

Table 3. Characteristics of Callers Who Used the Telephone Service of the Consultation Service (n = 5269).

Variable Level	Total, n (%)		Patients, n (%)		Caregivers, n (%)		P Values
Gender							.04
Female	3439	(65)	1929	(64)	1510	(67)	
Male	1830	(35)	1080	(36)	750	(33)	
Age							<.001
Mean (SD)	55	(13)	56	(12)	49	(15)	
Proximity							<.001
National	3296	(639)	1732	(58)	1564	(69) ^a	
Regional	1696	(32)	1127	(37)	569	(25) ^b	
Foreign country	131	(2)	66	(2)	65	(3)	
Contact/Referral							<.001
Cancer helplines	1638	(31)	871	(29)	767	(34) ^a	
Electronic media	1019	(19)	495	(16)	524	(23) ^a	
Print media	892	(17)	562	(19)	330	(15) ^b	
Unknown/Did not remember	812	(15)	464	(15)	348	(15)	
Health professionals	630	(12)	440	(15)	190	(8) ^b	
Patient groups	184	(3)	106	(4)	78	(3)	
Relatives/Friends	94	(2)	71	(2)	23	(1)	
Type of malignancy							<.001
Breast cancer	1273	(24)	945	(31)	328	(15) ^a	
Gastrointestinal tract cancer	860	(16)	384	(13)	476	(21) ^b	
Leukemia and lymphoma	737	(14)	473	(16)	264	(12) ^a	
Gynecological and urological cancer	548	(10)	326	(11)	222	(10)	
Prostate cancer	397	(8)	294	(10)	103	(5) ^a	
Lung cancer	377	(7)	139	(5)	238	(11) ^b	
Pancreatic and hepatobiliary cancer	344	(7)	128	(4)	216	(10) ^b	
Brain and other nervous system cancer	195	(4)	49	(2)	146	(6) ^b	
Sarcoma	168	(3)	66	(2)	102	(5) ^b	
Head and neck cancer	134	(3)	70	(2)	64	(3)	
Skin cancer	125	(2)	76	(3)	49	(2)	
Cancer of unknown primary	89	(2)	46	(2)	43	(2)	
Other cancer	22	(<1)	13	(<1)	9	(<1)	
Oncological treatment situation							<.001
Ongoing treatment	2063	(39)	1210	(40)	853	(38)	
Before start of treatment	1466	(28)	854	(28)	612	(27)	
Treatment finished	782	(15)	498	(17)	284	(13) ^b	
No invasive treatment	626	(12)	243	(8)	383	(17) ^a	
Wait and see	197	(4)	141	(5)	56	(2) ^b	
Treatment refused	127	(2)	63	(2)	64	(3)	
Intent of oncological treatment							<.001
Palliative	3613	(69)	1786	(59)	1837	(81) ^a	
Curative	1656	(31)	1223	(41)	433	(19) ^b	
Duration of consultations							<.001
<30	2247	(43)	1165	(39)	1082	(48) ^a	
30-60	2663	(51)	1592	(53)	1071	(47) ^b	
>60	271	(5)	208	(7)	63	(3) ^b	

^aFrequency was significantly higher than expected (adjusted residuals > 2).

^bFrequency was significantly lower than expected (adjusted residuals < -2).

Discussion

In this study of more than 5000 telephone consultations, we found that the interest in CAM was related to many

informational needs and was especially high if patients had just received the diagnosis, be it the initial one or that of a recurrence, or were about to commence treatment. We also found that the majority of callers—no matter whether

Table 4. Domains That Callers Inquired About on First Contact With the Consultation Service (n = 5269).

	Total, n (%)		Patients, n (%)		Caregivers, n (%)		P Value
General inquiry	2890	(55)	1614	(54)	1276	(56)	<.001
Inquiry about a specific CAM ^a	1785	(34)	1018	(34)	767	(34)	
Pharmacological and biological treatments	792	(44) ^b	445	(44)	347	(45)	
Supplements and special diets	514	(29)	314	(31)	200	(26)	
Other CAM treatments	382	(21)	202	(20)	180	(23)	
Spiritual and energy therapies	47	(3)	28	(3)	19	(2)	
Alternative medical systems	50	(3)	29	(3)	21	(3)	
Inquiry related to conventional cancer treatment	594	(11)	377	(13)	217	(10) ^c	

Abbreviations: CAM, complementary and alternative medicine.

^aSee Table 1, which shows the domains used to classify the inquired-about topics related to CAM.

^bProportion of the number of inquiries "related to a specific CAM" (44% \pm 792/1785).

^cFrequency was significantly lower than expected (adjusted residuals < -2).

Table 5. Frequency of Domains^a of Which Topics Were Discussed During the Consultations, Indicated by Type of Caller.

Domains	Total		Patients		Caregivers		P Values
	n	(%)	n	(%)	n	(%)	
Domains of topics beyond CAM							<.001
Cancer treatment	3458	(66)	1948	(65)	1510	(67) ^b	
Principles of EbM	2054	(39)	1199	(40)	855	(38)	
Nutrition and metabolism	1792	(34)	1135	(38)	657	(29) ^c	
Emotional support	1440	(27)	713	(24)	727	(32) ^b	
Physical activity and exercise	1034	(20)	765	(25)	269	(12) ^c	
Contact and referral	735	(14)	429	(14)	306	(13)	
Social support	574	(11)	348	(12)	226	(10)	
Domains of topics related to specific CAM							<.001
Pharmacological and biologic treatments	2849	(54)	1659	(55)	1190	(53)	
Supplements and special diets	1799	(34)	1184	(39)	615	(27) ^c	
Other CAM treatments	1349	(26)	740	(25)	609	(27)	
Mind-body interventions	573	(11)	458	(15)	115	(5) ^c	
Alternative medical systems	343	(7)	226	(8)	117	(5)	
Spiritual and energy therapies	164	(3)	104	(3)	60	(3)	
Manual and body-based methods	37	(1)	34	(1)	3	(<1)	

Abbreviations: CAM, complementary and alternative medicine; EbM, evidence-based medicine.

^aPercentages will exceed 100% because consultants could code more than 1 domain.

^bFrequency was significantly higher than expected (adjusted residuals > 2).

^cFrequency was significantly lower than expected (adjusted residuals < -2).

patients or their relatives—expressed their leading concerns in open questions such as, “*What else can I do?*” or “*What else could be done?*” In the pursuit of patient-centered care, increasing awareness of those needs may have important implications for effective communication during the phase around diagnosis and start of anticancer therapy.

Our findings contribute to a growing body of literature documenting that the need not only for general information, but also for topics such as symptom management, diet, nutrition, and CAM is highest around diagnosis for both cancer patients and their caregivers.³⁵⁻³⁷ They also substantiate findings of researchers from Canada who have shown that immediately after the diagnosis of

cancer, a process of seeking and evaluating information regarding risks and benefits of a wide range of therapies is set off.³⁸⁻⁴⁰ In this process, patients did not sharply discern between conventional and CAM therapies.³⁹ They were rather searching for a more general road map for treatment options⁴¹ and were proactive in an attempt to organize the situation, so that they had several choices available to them, to increase their perceived chances of success.³⁸ This corresponds with findings that there is no need for expert knowledge of CAM treatments to give patients a basic framework for evaluating their use.⁴²

The number and diversity of the topics that were dealt with in our consultations fit the results of a recent study

Table 6. Feedback Survey Items and Summarized Data From All Respondents (n = 979).

Item, Possible Responses	Patients, ^a n (%)	Caregivers, n (%)	P Values
The consultation met my expectations			.84
Yes	451 (76)	263 (74)	
It was different from what I expected, but positive	91 (15)	57 (16)	
No	52 (9)	34 (10)	
The questions I had were answered			.04
Yes	498 (85)	320 (90)	
Several were, but not all	51 (9)	24 (7)	
No	40 (7)	12 (3)	
The consultation was perceived as			<.01
Informative ^b	519 (85) ^c	334 (92)	
Clarifying	484 (79)	300 (82)	
Supportive	451 (73)	283 (78)	
Helpful	490 (80)	307 (84)	
The consultation influenced subsequent treatment or behavior			<.001
Yes	402 (69)	224 (65)	
No	119 (31)	119 (35)	
The aspect of consultation via the telephone was			.66
Difficult	22 (4)	12 (3)	
Unusual but positive	158 (28)	98 (28)	
Helpful	116 (21)	83 (24)	
Of no importance	270 (48)	156 (45)	
Having a personal consultation as well			.76
Would have been helpful	188 (34)	112 (32)	
Was not needed	218 (40)	146 (42)	
Uncertain	146 (26)	91 (26)	

^aNumber of responding patients: n = 614; number of responding caregivers: n = 365.

^bOn a rating scale from 1 (*very much*) to 5 (*not at all*).

^cNumber/percentage of respondents who scored 1 or 2.

from Germany, which showed how numerous the requirements for information are and that the perceived deficits of information are highest in the domain of every day needs such as measures supportive of health, nutrition, CAM therapies, and psychosocial support.⁴³ The fact that the most commonly discussed CAM in our consultations belonged to the domain “Pharmacological and biological treatments” is in accordance with the findings of several reviews.^{44,45} The frequency with which we talked about conventional treatment options in our consultations shows that not every question about CAM deserves an answer out of the realm of CAM. A state-of-the-art medical consultation about CAM always has to take into account the various conventional treatment options, be it with regard to supportive and palliative care, anticancer treatment, or rehabilitation.

Our results that many caregivers sought advice about treatment options from CAM for their partners or friends reminded us that cancer is a problem that involves the patient’s family and social networks. Patients appreciate and value the involvement of family members and their informational support.⁴⁶ The results of a qualitative study

showed that the involvement with CAM allows caregivers to advise about therapy options and provide an opportunity to “do something for the cancer patient.”⁴⁷ A recent survey found that the endorsement of CAM use by family members strongly influenced patient expectations and hopes.⁴⁸

Finally, we were somewhat surprised that most of the callers perceived our approach to consult about CAM as helpful, because we did not hesitate in the individual consultations to unequivocally highlight where risks of CAM were unknown and their benefits uncertain. These positive responses are in accordance with studies that showed higher satisfaction of patients after doctor visits that had included CAM discussions¹⁹ and after being given the opportunity to consult doctors by telephone.^{49,50} We acknowledge that there is evidence that not only the topics of a consultation, but also its perceived duration is a determinant of patient satisfaction.^{51,52}

Limitations

Although our study population included a large number of patients and caregivers, it could be that people with higher

levels of engagement in their own health or the care of another person were more likely to ask for a consultation. Our study relied on the consultants' documentations, which are inherently influenced by differences in communication styles and prioritizing of issues. However, we tried to adjust our consulting techniques, skills, knowledge, and personal awareness by means of regular peer consulting.

We limited the analysis to telephone consultations because we felt that these were different from those held on-site for 2 main reasons: the patients were usually referred for consultation from colleagues, and thus, the vast majority of on-site consultations were with inpatients or outpatients of our clinic who knew our team.

A limitation of the feedback survey analysis was that only one-third of callers completed the survey. Finally, we could not rule out that the feedback results were biased because callers answered in a way that seemed more favorable to the consultants. However, virtually all consultations were single telephone contacts, no patients treated at our department were included, and all respondents answered the survey at home.

Practice Implications

Our results underline previous findings that patient-centered communication about CAM provides the opportunity to engage in an open and supportive dialogue with patients.⁵³ We agree with these authors and believe that there are 5 important implications of the current study:

- An independent consultation service about CAM provides the opportunity to revisit the patients' informational needs and adapt advice and guidance to their current situations and preferences.
- It provides the opportunity to advise about evidence-based CAM to help with symptom management, psychological support, and individual self-care.
- Including family in consultation and education on CAM could help achieve realistic patient expectations about risks and benefits, and avoid potential adverse effects or rejections of conventional treatment.
- Consulting about CAM cannot be separated from consulting about conventional care, and consultants should be educated on prevalent CAM and have practical therapeutic experience in oncological care.
- Expert knowledge about specific CAM treatments is not a prerequisite to have meaningful discussions with patients and to help them negotiate CAM treatment decisions.

However, any approach that aims to provide evidence-based information about CAM in a patient-centered way

has to deal with the delicate balance between fostering hope without creating unrealistic expectations of clinical benefits.⁵⁴

Conclusion

The BCT's experiences with a physician-led consultation service about CAM raise awareness about the extent of related unmet needs of cancer patients and their caregivers. They also suggest that the topic of CAM offers caregivers an important opportunity to be involved in exploring and advising their afflicted relatives or friends about therapy options.

With the guidelines in mind that were available at the time we started the service,³¹ our team of oncology clinicians was able to have open communications about CAM with cancer patients and their relatives that the majority of them perceived as helpful. To our knowledge, this is the first study to examine telephone consultations about CAM between physicians, patients, and their caregivers. Our approach to communicate about CAM helped us understand the point within the cancer illness trajectory when patients seek information or an active role in their health care. It also revealed that many inquiries about CAM are intertwined with needs relating to the entirety of the cancer experience. Hence, a professional consultation about CAM is adapted to the individual situation, includes balanced information about risks and benefits, takes into account conventional treatment options, and keeps in mind that supportive care includes taking care of emotional, social, spiritual, and practical needs.

Although the time we needed for our consultation went beyond the average 8 minutes of contacts in practices, we hope that our results encourage clinicians to be open for discussions about CAM with their patients, so that they may help them make safe and informed decisions.

Our data have been used in the ongoing collaborative research project KOKON (<http://www.kompetenznetz-kokon.de>) for the development of information and training programs for clinicians^{26,52} and of a multicenter consultation service about CAM at comprehensive cancer centers with physicians coming from different medical specialties (publication in preparation).

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Authors' Note

MH, GVA, HK, and JB were involved in the conception and design of the study. MH, GVA, and HK participated as consultants in the study. GVA and MH monitored the data acquisition. FF and MH analysed and interpreted the data. MH drafted the manuscript and all authors revised the draft critically for important critical content at several stages. All authors approved the final version and confirmed to meet ICMJE criteria for authorship.


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