

Information and Training Needs Regarding Complementary and Alternative Medicine: A Cross-sectional Study of Cancer Care Providers in Germany

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Abstract

Background: Among cancer care providers (CCPs), lack of knowledge constitutes an important barrier to the discussion of complementary and alternative medicine (CAM) use with patients. This study assessed CCPs' needs and preferences regarding CAM information and training (I&T). **Methods:** An online survey was completed by 209 general practitioners, 437 medical specialists, 159 oncology nurses and medical assistants, and 244 psychologists and social workers engaged in cancer care. Latent class analysis (LCA) was used to identify subgroups of individuals with distinct preference patterns regarding I&T content. **Results:** CCPs prefer CAM I&T to be provided as lectures, information platforms on the internet, workshops, and e-mail newsletters. Concerning subject matters, many CCPs considered CAM therapy options for the treatment of a variety of cancer disease- and therapy-related symptoms to be very important (75%-72% of the sample); the same applies to an "overview of different CAM therapies" (74%). LCA identified 5 latent classes (LCs) of CCPs. All of them attached considerable importance to "medical indication," "potential side effects," and "tips for usage." LCs differed, however, in terms of overall importance ratings, the perceived importance of "patients' reasons" for using specific CAM therapies, "case examples," and "scientific evidence." Notably, the 5 LCs were clearly present in all 4 occupational groups. **Conclusions:** CAM I&T should provide CCPs with an overview of different CAM therapies and show how CAM might help in treating symptoms cancer patients frequently demonstrate (eg, fatigue). Moreover, I&T programs should be flexible and take into account that individual information needs vary even within the same occupational group.

Keywords

complementary and alternative medicine, information needs, training, continuing education, cancer care providers, cancer care

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Introduction

According to a meta-analysis, as many as 41% of cancer patients use complementary and alternative medicine (CAM) therapies, and the prevalence of CAM use appears to be increasing.¹ Many cancer patients wish to know more about CAM^{2,3} but rely primarily on friends, family members, and the media for information.⁴ Patient-doctor discussions on CAM are crucial for a number of reasons⁵ but rarely take place.⁶ Many cancer patients do not disclose their CAM use to cancer care providers (CCPs)⁶⁻⁹ either because it does not occur to them to do so, or they believe that their CAM use has no influence on their conventional cancer treatment, and/or because they expect physicians to have a negative attitude toward CAM and to be unable to help.^{7,8}

Likewise, CAM use is rarely proactively addressed by CCPs. According to a recent US survey, oncologists had discussed herbs and supplements with an average of 41% of their cancer patients over the previous 12 months, and only 26% of these discussions were initiated by the oncologists themselves.¹⁰ A main barrier would appear to be a lack of knowledge: Two out of 3 oncologists in this sample indicated that they did not know enough to be able to answer

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patients' questions properly, and 59% reported not having received any education on the topic. In both the US study and a survey of hospital doctors and general practitioners (GPs) in New Zealand,¹¹ self-perceived knowledge was found to be a significant predictor of readiness to proactively discuss CAM use with patients. Hence, physicians and other CCPs should have access to reliable information and training (I&T) on CAM.¹¹

The purpose of the present study was to assess CCPs' needs for further I&T on CAM. Our focus was on the 4 main occupational groups involved in cancer care in Germany: medical specialists in oncology (MSs), oncology nurses and medical assistants (ONs/MAs), GPs, and psychologists and social (education) workers engaged in psycho-oncology care and social medicine (POs/SWs). We first aimed to examine what CAM therapies and potential fields of application for CAM (ie, treatment of specific cancer and cancer therapy-related symptoms) are of greatest importance and should be covered by information materials and training programs for CCPs. Second, using latent class analysis (LCA), we investigated whether subgroups of CCPs exist that show distinct preference patterns with regard to specific I&T content (eg, mechanisms of actions, evidence from studies regarding efficacy, potential side effects, tips for use) and how prevalent subgroups demonstrating the identified specific preference patterns are in each of the 4 occupational groups. Third, we determined CCPs' preferences with regard to the form CAM I&T should take.

Methods

An online survey was used to investigate CAM I&T needs among CCPs from all main areas of cancer care in Germany (see below). The study was conducted as part of the KOKON competence network for CAM in oncology, which was funded by the German Cancer Aid association from 2012 to 2015. The Head of the Institutional Review Board of the University Hospital Frankfurt/Main decided on the basis of the professional code of conduct of the Medical Association of the Federal State of Hessen/Germany (§ 15 BO hess. Ärzte) that specific ethical approval was not required for this investigation.

The items on the questionnaire were based on the results of semistructured interviews with 63 individuals from the 4 targeted occupational groups. To ensure a common, broad understanding of the term *CAM* among all survey participants, the questionnaire began with an item block gauging the importance of 25 different CAM therapies as potential subjects for CAM I&T. Next, the importance of 13 possible fields of application for CAM—that is, specific cancer disease- and therapy-related symptoms—were to be rated in the same manner. Further topics were how often and in what situations CAM information needs emerge and how

participants have sourced information on CAM in the past. We also asked about experiences with existing sources of information, the perceived importance of specific I&T content on CAM, previous participation in training courses on CAM, preferences regarding the forms I&T should take, personal information (sociodemographic data, professional education, current occupation), and professional experience in oncology care and with patients using CAM as well as attitudes toward CAM.

Cognitive interviews with a GP, a MS, and an ON were used to test preliminary versions of the questionnaire for comprehensibility, and a programmed online version was piloted by a physician, a psycho-oncologist, and an ON.

Recruitment of Participants and Definition of the Analytical Sample

Our aim was to survey members of the 4 above-mentioned occupational groups that work in inpatient and outpatient oncology care, oncology rehabilitation centers, and counseling centers for cancer patients throughout Germany. From July 2013 to August 2014, we contacted scientific medical societies, German Cancer Society working groups, professional associations, educational institutions, and other national institutions. With only few exceptions, these societies and institutions forwarded the study information letter and the invitation to participate to their members.

A total of 1257 individuals completed the online questionnaire between September 2013 and August 2014. A subsample of 128 participants did not have current working experience with cancer patients and were, therefore, excluded. Of the remaining 1129 survey participants, 80 individuals did not belong to any of the 4 targeted occupational groups; thus, the final analytical sample size was $n = 1049$.

Statistical Analyses

CCPs' preferences with respect to the subject matter and the different ways of providing CAM I&T were studied by means of descriptive statistics using SAS version 9.3. To investigate whether subgroups of individuals exist that show distinct preference patterns with regard to the I&T content, we performed latent class (LC) modeling¹² using CCPs' importance ratings (on a 4-point Likert scale ranging from "very important" to "not at all important") for 9 specific items. These were the medical indication for the CAM therapy in question, patients' reasons for using it, case examples, summary of evidence from studies, appraisal of evidence from studies, study references, mechanisms of action, potential side effects, and tips for use. The exact wordings of the 9 items are given in Supplementary File 1 (supplementary material available at <http://ict.sagepub.com/supplemental>). By means of the SAS procedure LCA,¹²

Table 1. Sociodemographic Characteristics and Experience of Working With Cancer Patients, Perceived Importance of Being Well-Informed About CAM Therapies, Attitude Toward CAM Use in Oncology, and Confidence in Discussing CAM, for the Total Sample of Cancer Care Providers (for the 4 Occupational Groups and the Total Sample).

	General Practitioners	Medical Specialists	Oncology Nurses and Medical Assistants	Psychologists, Social (Education) Workers	Total Sample
Number of individuals (n)	209	437	159	244	1049
Age (years), mean (SD)	53 (8)	50 (9)	45 (8)	48 (9)	49 (9)
Gender, percentage of women	55	50	91	87	66
Number of federal states (out of the total of 16 in Germany)	16	16	16	15	16
Years of experience in working with cancer patients, mean (SD)	20 (9)	18 (9)	15 (8)	11 (7)	16 (9)
Proportion of cancer patients among all his/her patients, ^a percentage very large or large ^b	14	61	84	77	59
Proportion of his/her cancer patients interested in CAM, ^c percentage very large or large ^b	66	44	36	42	47
Perceived importance of being well-informed about CAM, ^d percentage strongly agree ^e	70	55	57	49	57
Positive attitude toward CAM use in cancer care, ^f percentage strongly agree ^e	79	48	62	51	57
Confidence in discussing CAM, ^g percentage strongly agree ^e (percentage somewhat agree ^h)	31 (70)	12 (40)	09 (36)	03 (32)	13 (35)

Abbreviation: CAM, complementary and alternative medicine.

^aThe wording of the item was, "Over the last two years, what proportion of your patients were cancer patients?" (n = 1047 valid answers).

^bPercentage of participants choosing "very large" or "large" on a 5-point Likert scale ranging from "very large" to "very small."

^cThe wording of the item was, "How large do you rate the proportion of cancer patients interested in CAM and/or using CAM among all cancer patients you dealt with in your daily professional life within the last two years?" (n = 1044 valid answers).

^dThe wording of the item was, "Being well-informed about CAM therapies is important in my daily work." (n = 1043 valid answers).

^ePercentage of participants choosing "I strongly agree" on a 4-point Likert scale ranging from "I strongly agree" to "I strongly disagree".

^fThe wording of the item was, "Basically I have a positive attitude towards CAM in oncology." (n = 1035 valid answers).

^gThe wording of the item was, "I feel confident when discussing CAM therapies with cancer patients." (n = 1036 valid answers).

^hPercentage of participants choosing "I agree" on a 4-point Likert scale ranging from "I strongly agree" to "I strongly disagree."

we used the EM algorithm¹³ to estimate maximum likelihood parameters for models with 1 to 6 LCs. For each model, 100 different start value sets were used to avoid the issue of local maxima. Model selection—that is, the decision on the number of LCs (latent subgroups of individuals)—was based on the Bayesian Information Criterion.¹⁴ To characterize the LCs in the selected model, we provide a figure that depicts the expected values of the identified LCs for the 9 indicators. This figure shows the preference patterns and displays the probabilistic class sizes—that is, the a priori probabilities of LC membership, which were directly estimated by the model. A short description of the LC model and an explanation of how the expected values in the figure were calculated from the model parameter estimates are provided in Supplementary File 2. To allow the frequency distributions of the identified LCs to be compared across the 4 occupational groups, individuals were allocated to the different LCs according to the

maximum posterior probability rule—that is, they were assigned to the class to which the probability that they belonged was highest.

Results

A description of the sample in terms of sociodemographic and occupational characteristics, perceived importance of being well-informed with regard to CAM therapies, attitude toward CAM, and confidence in discussing CAM with cancer patients is provided in Table 1. Among the 4 occupational groups, MSs make up the largest group (n = 437), but even the smallest group (ONs/MAs) contains n = 159 participants. Participants in each group come from at least 15 of the 16 German federal states, and members of all 4 groups also have considerable experience of working with cancer patients. GPs have the greatest experience of working with them (mean = 20 years; SD = 9), and 77% of POs/

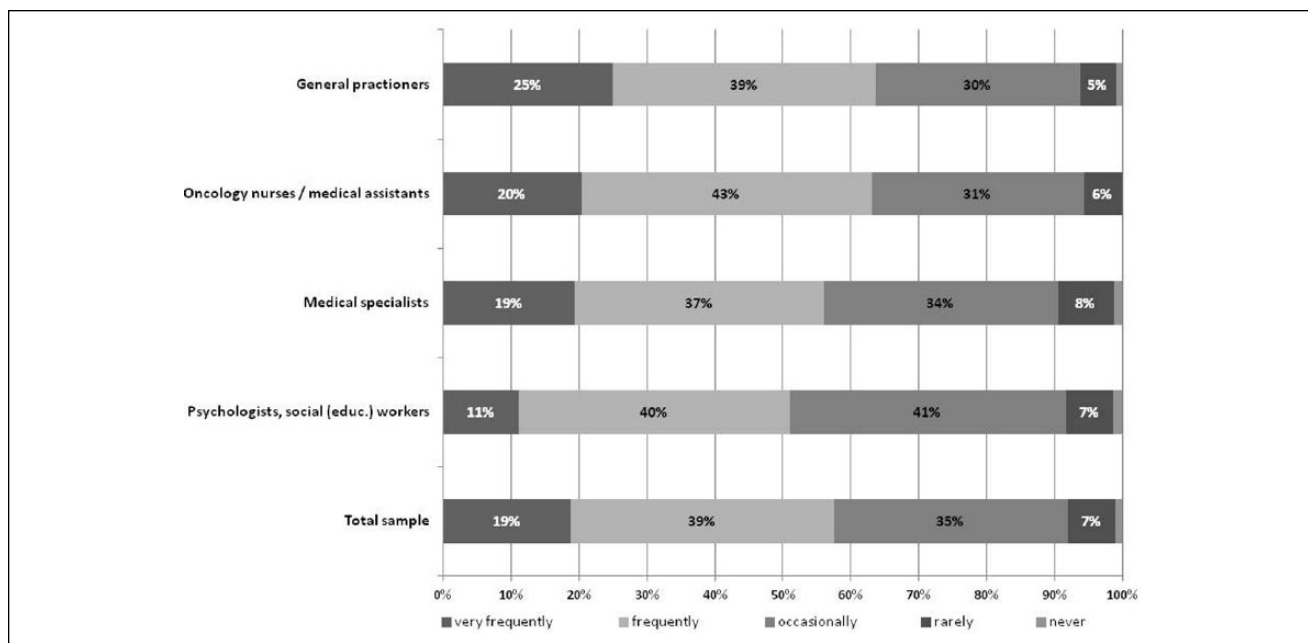


Figure 1. Frequency of information needs regarding complementary and alternative medicine (CAM) therapies by occupational group and overall. The wording of the item was, “How often do you need to gather information on CAM therapies for cancer patients in your daily professional life?” (n = 1042 valid answers).

SWs said that cancer patients make up a very large or large share of their patients. The share of individuals who consider a very large or large proportion of their cancer patients to be interested in CAM varies considerably between the 4 groups (range = 36%-66%) and is highest among GPs and lowest among ONs/MAs. More than half the survey participants strongly agree that being well-informed with respect to CAM is important for their daily work. This proportion is especially large among GPs and lowest among POs/SWs. Confidence in discussing CAM with cancer patients was low in all 4 occupational groups, with GPs being the most confident.

Information and Training Needs

All 4 groups report frequently needing further information on CAM in their daily working lives (see Figure 1). In the total sample, the proportion of individuals with “very frequent” or “frequent” information needs amounts to 58%. When “occasional” information needs are included, the proportion rises to as much as 92%.

With regard to the subject matters to be included in information materials and training programs on CAM, an “overview of CAM therapies for cancer patients” was rated to be “very important” by nearly 74% of the total sample (range across the 4 occupational subsamples: 70%-84%). In contrast, “very important” ratings with regard to information on the 25 named individual CAM therapies ranged from 5% (Bach flower remedies) to 55% (relaxation

techniques/ meditation) in the total sample. Furthermore, the 4 occupational groups do not vary much as regards the 5 CAM therapies they consider most important. In the total sample, these are (1) relaxation techniques/meditation (55% “very important” ratings; range across the 4 occupations: 51%-62%), (2) herbal drugs (44%; range: 40%-55%), (3) nutritional supplements, vitamins and trace elements (39%; range: 36%-46%), (4) homoeopathy (39%; range: 29%-61%), and (5) mistletoe therapy (39%; range: 31%-54%). Many ONs/MAs also regard it as very important that I&T includes information on compresses (45%) and aromatherapy (41%), whereas POs/SWs regard visualization (52%) as very important as well (see upper part of table in Supplementary File 3). With regard to the subject matter of I&T, survey participants were also asked to rate the importance of 13 potential fields of application for CAM therapies, all of which were disease- or therapy-related symptoms cancer patients are known to often exhibit. A large majority of survey participants thought that every one of the fields of application was a “very important” topic for CAM I&T. In the total sample, the 5 most important application areas were (1) fatigue (75%; range across the 4 occupational groups: 72%-80%), (2) tumor-related pain (73%; range: 69%-87%), (3) psychological afflictions such as anxiety or depression (72%; range: 66%-81%), (4) nausea and vomiting (68%; range: 62%-89%), and (5) lack of appetite and changes in sense of taste (64%; range: 54%-83%). In addition, GPs and ONs/MAs considered mucosal inflammations to be very important (GPs: 68%; ONs/MAs: 84%). A large

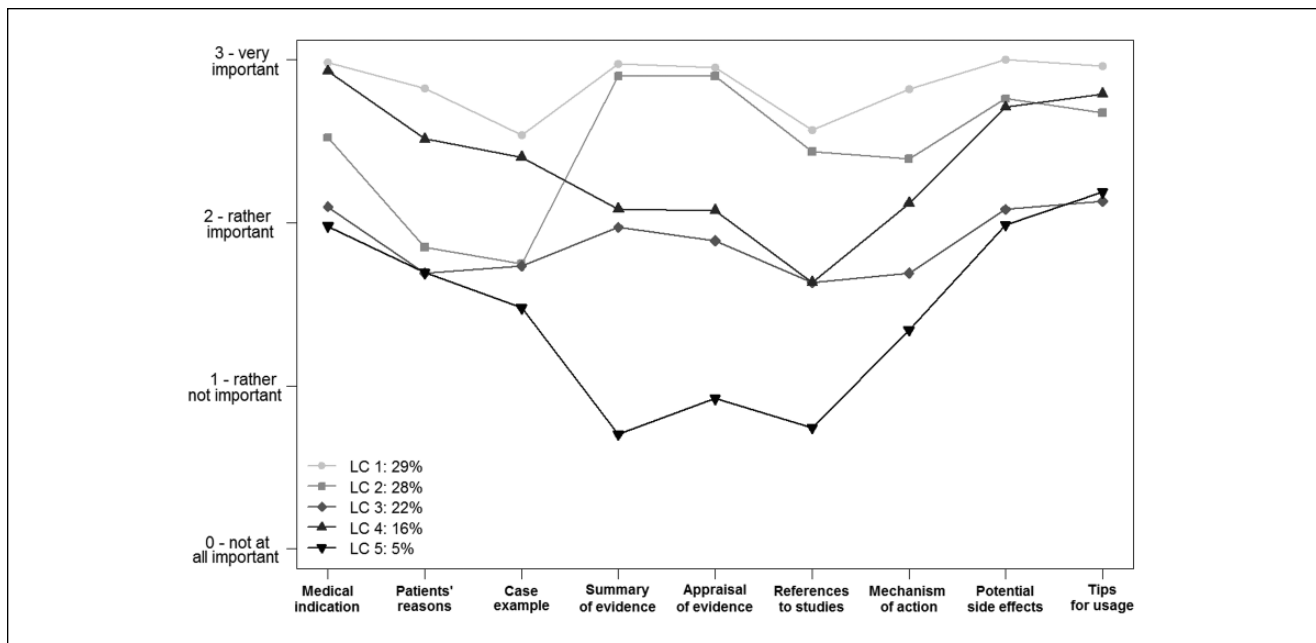


Figure 2. Five latent subgroups of cancer care providers with different preference patterns regarding content of complementary and alternative medicine information and training. Based on their answer patterns for the 9 manifest indicator variables, 5 latent classes (LCs; subgroups) could be identified. The figure depicts the expected values of the 5 LCs on each of the 9 indicators, which had been answered on a 4-point Likert-type scale using the 4 labels shown on the y-axis. (For an explanation on how the expected values have been calculated based on LC parameter estimates, see Supplementary File 2). The 5 LCs can be characterized as follows: LC 1, “very interested in all content”; LC 2, “especially interested in evidence from studies”; LC 3, “moderately interested in all content”; LC 4, “especially interested in medical indication”; and LC 5, “moderately interested in patients’ reasons and in case examples.”

proportion of participating POs/SWs (72%) considered cognitive impairment very important as well (see lower part of table in Supplementary File 3).

Latent Subgroups of Individuals With Distinct Preference Patterns Regarding Content of CAM I&T

When using LC analysis to assess the importance ratings ascribed by participants to 9 items that CAM I&T could potentially focus on, 5 distinct LCs (subgroups) were identified. The preference patterns characterizing these 5 LCs can be seen in Figure 2. All LCs attached considerable importance to “medical indication,” “tips for usage,” and “potential side effects.” They differed, however, in terms of mean overall importance ratings as well as in the perceived importance of “scientific evidence” on one hand and “patients’ reasons” (for CAM use) and “case examples” on the other. Individuals belonging to the largest LC ($\pi_1 = 29\%$) are likely to consider each of the 9 items “very important” and can hence be characterized as “very interested in all content.” Those belonging to the third largest LC ($\pi_3 = 22\%$) tend to rate all 9 items as “rather important” and may thus be labeled “moderately interested in all content.” Whereas the second largest LC ($\pi_2 = 28\%$) can be characterized as “especially interested in scientific

evidence,” the fourth largest LC ($\pi_4 = 16\%$) appears to be “particularly interested in medical indication.” The fifth and smallest LC ($\pi_5 = 5\%$) can be characterized as “moderately interested in patients’ reasons and case examples.”

As demonstrated in Figure 3, each of the 5 latent subgroups is present within each of the 4 occupational groups. LC 1 (“very interested in all content”) is the most frequently occurring latent subgroup among ONs/MAs (38%) as well as among POs/SWs (31%). It is also often observed among MSs (31%). In this group, however, LC 2 (“especially interested in scientific evidence”) is slightly larger (35%). In contrast, LC 3 (“moderately interested in all content”) constitutes the largest latent subgroup among GPs.

How Should Information on CAM Be Presented and What Form Should Training Programs Take?

When asked how they would prefer information on CAM to be provided, CCPs most frequently chose “information platforms on the internet” (67% of the total sample), “lectures on specific CAM-related topics” (62%), and “regular e-mail newsletters” (62%). Furthermore, publications in scientific journals are highly regarded by MSs as well as by ONs/MAs, whereas many GPs favor the opportunity to contact experts. (For further details regarding preferred sources

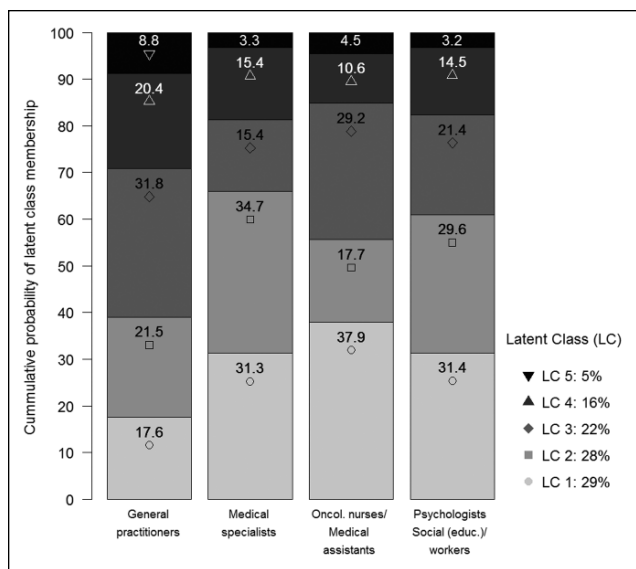


Figure 3. Latent class membership by occupational group: The 5 latent classes can be characterized as seen in Figure 2.

of information see upper part of table in Supplementary File 4). Survey participants were also asked what functions they would like to see if a new information platform was developed for the internet. The 2 most popular functions were “keyword search for specific disease-related symptoms” (81%) and “keyword search for specific CAM therapies” (75%).

With regard to training programs, “lectures (eg, as part of a conference)” (72%) were preferred to other forms of education, followed by “face-to-face workshops” (63%) in second and “continuing education courses that are accessible at all times on the internet” (45%) in third place (see lower part of table in Supplementary File 4 for further details regarding preferred types of training).

Discussion

The 4 occupational groups participating in the German nationwide survey prefer CAM I&T to be provided in the form of lectures, information platforms on the internet, face-to-face workshops, and e-mail newsletters. All 4 groups considered the most important subjects to be an “overview of different CAM therapies for cancer patients” and a variety of disease- and therapy-related symptoms as potential application areas of CAM in oncology (especially “fatigue,” “tumor-related pain,” and “psychological afflictions”). The 3 CAM therapies that participants thought it was most important that CAM I&T focus on were “relaxation techniques/ meditation,” “herbal drugs,” and “nutritional supplements/vitamins/trace elements.” When examining the ratings given by CCPs for 9 items relating to the content of I&T for particular CAM therapies, it was possible to identify 5 LCs with distinct preference

patterns. These 5 latent subgroups not only differed in their mean overall importance ratings but also in the importance attached to specific content such as “scientific evidence” on one hand and to “patients’ reasons” and “case examples” on the other. Interestingly, all 5 latent subgroups were found to be present in each occupational group, which means that there is substantial heterogeneity not only between but also within the 4 occupations.

Even though we took great care to include CCPs from all main areas of cancer care in Germany, one of the limitations of this study relates to convenience sampling. Moreover, the questionnaire took participants about 20 minutes to fill in, which may have been a barrier for those who are not especially interested in CAM. It is, therefore, uncertain to what extent noteworthy characteristics of survey participants, such as the high importance they attached to being well-informed about CAM and their very frequent information needs, can be transferred to the total population of CCPs in Germany. Acknowledging that future users of CAM I&T will probably be those who are interested in CAM, the present findings can nonetheless be considered suitable for helping in the development of demand-based information materials and training programs. Strengths of this study concern the careful, mixed-methods-based development of the questionnaire and the focus on CCPs’ actual needs and preferences with regard to the content and type of CAM I&T. The present findings thus fill a gap left by previous studies investigating CCPs’ knowledge, attitudes, and practices with regard to CAM^{10,11,15-27} rather than specific CAM I&T needs. Furthermore, our sample of CCPs from all over Germany was large enough to conduct subgroup analyses. This enabled us to gain insights into the specific needs and preferences of 4 occupational groups. By applying LC analysis to investigate interindividual heterogeneity independently of predefined, known characteristics, it was also possible to identify 5 latent subgroups of CCPs with differing needs with respect to the content of CAM I&T.

Based on these findings, we would recommend the development of CAM I&T for CCPs that first presents a general overview of different CAM therapies used by cancer patients. More specific I&T programs should then provide information on CAM therapy options for symptoms associated with cancer disease and antitumor therapy—for example, for fatigue, tumor-related pain, and psychological afflictions. Alternatively, they could focus on specific CAM therapies such as relaxation techniques or phytotherapy. CAM I&T should, of course, also take the specific needs and preferences of the targeted occupational groups into account. A small group of GPs (about 9%) clearly preferred case reports over learning about studies in the field (LC5). We consider it necessary to inform all health care personnel who are skeptical about scientific studies (irrespective of their preferences) of study results in order to enable them to give their patients the chance to make informed decisions.

Nonetheless, CAM I&T for CCPs should be flexible enough to consider participants' interests independently of their occupation. This especially applies to "scientific evidence," "patients' reasons," and "case examples," to which varying degrees of importance were attached, depending on latent subgroup membership, whereas information on "medical indication," "tips for usage," and "potential side effects" should always be provided.

It may, however, not be enough to enhance CCPs' knowledge of CAM. To allow for the development of trust and openness between patients and CCPs, a reluctance to discuss CAM therapies must be overcome.^{7,28} It is, therefore, also important to train CCPs in initiating a sensible discussion on CAM by asking the "right" questions.²⁹ As an example, a recent study by Ben-Arye et al²⁹ found that the disclosure rate of dietary supplement (DS) use in cancer patients can be increased by naming DS options and by using DS-related keywords such as "teas" and "infusions." Likewise, the "how" in communicating treatment options should not be neglected but rather trained in workshops on CAM. Such training programs could follow the guidance provided by the model of Frenkel et al⁵ on effective patient-doctor communication on CAM.

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