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German physicians' perceptions and views on complementary medicine in pediatric oncology: a qualitative study

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ABSTRACT


Complementary and alternative medicine (CAM) use in children with cancer has a high prevalence. If (parents of) patients bring up the topic of CAM, pediatric oncologists (POs) face considerable challenges regarding knowledge and professional behavior. In this study, we explore German POs' understanding of CAM and related attitudes as well as challenges and strategies related to CAM discussions by means of semi-structured interviews analyzed according to principles of qualitative thematic analysis with parents of children with cancer. We could conduct 14 interviews prior to theoretical saturation. The interviews had a duration of 15–82 min ($M=30.8$, $SD=18.2$). Professional experience in pediatric oncology was between 0.5 and 26 years ($M=13.8$, $SD=7.6$). Main themes identified were a heterogeneous understanding and evaluation of CAM, partly influenced by personal experiences and individual views on plausibility; the perception that CAM discussions are a possible tool for supporting parents and their children and acknowledgement of limitations regarding implementation of CAM discussions; and uncertainty and different views regarding professional duties and tasks when being confronted with CAM as a PO. Our interdisciplinary interpretation of findings with experts from (pediatric) oncology, psychology, and ethics suggests that there is need for development of a consensus on the minimal professional standards regarding addressing CAM in pediatric oncology.

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Introduction

Complementary and alternative medicine (CAM) use in children with cancer has a high prevalence and is, accordingly, relevant for clinicians working in the field of pediatric oncology.¹⁻³ The term CAM is defined heterogeneously in the literature and covers a range of measures offered by health professionals to improve health but stand, simultaneously, outside the range of options usually offered to patients with cancer as part of the dominating health-care system.⁴ According to international data, the prevalence of CAM use in children with cancer varies from 6% to 91%.⁵ Studies from German-speaking countries indicate that CAM is used by 35% of the children or adolescents with cancer in Germany and up to 53% of the children with cancer in Switzerland.^{3,6} In a survey among parents of children with cancer, Laengler et al.⁶ report that CAM mentioned most frequently were: homeopathy, dietary supplements, and anthroposophic medicine. Nevertheless, discussions about CAM are not a common practice in pediatric oncology.^{7,8} Laengler et al.⁹ showed for Germany that the majority (59.4%) of pediatric oncologists (POs) only raise the issue of CAM if the parents bring up the topic themselves. A study by Roth et al.⁷ indicates that POs are comfortable with some forms of CAM such as massage (74%) and yoga (57%). At the same time, POs have reservations regarding possible negative effects of other types of CAM.⁹

A lack of time for discussions with patients and parents and a lack of knowledge about CAM have been referred to as possible reasons for the discrepancy between the high prevalence of CAM use in children and the low rate of taking up the topic as part of consultations in pediatric oncology.^{7,9} Literature indicates that younger POs with less professional experience⁷⁻⁹ and, in some studies,^{7,8} female doctors seem to have a more positive attitude toward CAM and more often tend to actively bring up the topic of CAM in their consultations. Roth et al.⁷ showed that the experience with CAM as part of professional practice might influence the communication about it or at least influence the desire for further continuing medical education.⁹

If the (parents of) patients bring up the topic of CAM, POs are faced with a broad variety of measures for which limited research on their efficacy and safety exists. Survey research indicates that POs are concerned about the potential harmful adverse effects of CAM therapy such as possible interactions of substances labeled as CAM with conventional therapy.^{7,9} Furthermore, a previous study conducted in Germany indicates that POs who wished to integrate CAM in their conventional therapy particularly are in need of information and further education regarding possible use of CAM for complex clinical problems, such as the treatment of loss of appetite, nausea and vomiting, tumor-related pain, psychological afflictions (anxiety, depression), and fatigue.¹⁰

In Germany, pediatric oncology is a subspecialty of pediatrics which is performed in designated centers mostly at university hospitals. To date, little is known about the motives of German POs regarding raising the topic of CAM (or not doing so) and perceived challenges regarding the issue. Such knowledge is relevant to be able to respond to possible educational needs and provide the support POs in Germany may need regarding discussions about CAM. While some knowledge on motives, experiences, and challenges related to CAM has been generated in other countries,¹¹⁻¹³ these findings cannot necessarily be extrapolated because the understanding of CAM and

options to prescribe CAM measures differ between countries. Therefore, we explored various perceptions and views of German POs about CAM concerning the following aspects:

1. POs' understanding of CAM,
2. perceived benefit or harm related to CAM, and
3. experiences, barriers, and strategies regarding discussions about CAM with parents of children with cancer.

In line with the multidisciplinary methodological approach within the KOKON (Kompetenznetz Komplementärmedizin in der Onkologie) research collaboration which this study is part of,¹⁴ we will discuss the findings from a clinical, psychological, and ethical perspective.

Methods

Participants and sampling

The selection of physicians started with an initial convenience sample of four physicians working in PO from the authors' professional network. All initial four interviewees were participants of a conference of the Society of Pediatric Oncology and Hematology [Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH)]. While all four physicians were personally known to the one of the authors (A.L.), they were all working at different centers distributed among different geographic regions in Germany. Moreover – as far as this was known to this author – the interviewees held differing views regarding the use of CAM. With regard to CAM some but not all study participants have additional specializations (see [Table 1](#)).

Following the analysis of the transcripts of the first interviews, characteristics of the interviewees, which might be relevant for the perspectives of POs on the topic (e.g. gender, age, research, or practical interests related to CAM) were identified. In line with the principles of purposive sampling, we asked the initial interviewees for other possible candidates (snowball sampling) who might fulfill the criteria identified.¹⁵ In addition, POs who participated in training sessions on CAM which had been offered as part of the overall project were approached by the authors and asked whether they would be interested in participating in the study. All participants were informed about the study by the interviewers and gave written informed consent. The study was approved by the local research ethics committee (Ethikkommission der Bayerischen Landesärztekammer No. 17021).

Interviews

Semi-structured interviews were conducted by three of the authors (C.K., P.K., and J.S.). The topic list was based on an interview guide used for a qualitative study with oncologists,¹⁶ and adapted by the authors who have expertise in pediatric oncology, (psycho-)oncology, and medical ethics. While the researchers in the KOKON Consortium held a shared definition of CAM,¹⁷ the starting point for each interview was the

Table 1. Socio-demographic data of the interviewees.

Participants	<i>n</i> (%)
Male	7 (50.0)
Female	7 (50.0)
Age	
30–39	2 (14.0)
40–49	7 (50.0)
>50	5 (35.7)
Hospital	
University	10 (71.4)
Other	4 (28.6)
Professional level	
Resident	7 (50.0)
Consultant	6 (42.9)
Other	1 (7.1)
Additional qualification	
Natural therapies	1 (7.1)
Rehabilitation medicine	1 (7.1)
Palliative medicine	4 (28.6)
Pain therapy	1 (7.1)
Other	2 (14.9)

understanding of CAM as provided by the individual interviewee. Accordingly, all interviews started with an open-ended question on the participant's understanding of CAM. At the end of the interview, the interviewers requested participants to complete a brief socio-demographic questionnaire.

Data analysis

All transcripts were analyzed following the ad verbatim transcription of the audiotaped interviews and a check of data. Each transcript was coded separately by at least two researchers (C.K., J.S., P.K., and E.R.). Codes and subcodes were developed by the researchers based on an initial sample of five interviews compared subsequently. In the case of differences, consensus between coders was sought. Principles of qualitative thematic analysis – namely, the constant comparison of data, open coding, and writing memos – were used to explore participants' perceptions and views regarding CAM in pediatric oncology.¹⁸ The qualitative analysis was performed with the help of the MAXQDA program.¹⁹

In addition to the coding process, a selection of raw data and interpretations from preliminary data analysis was discussed among the author group to elicit suggestions for additional interpretations of data and clarify suggested interpretations. Different from quantitative research in qualitative research, there is no predefined number of participants, but the definitive number will be determined by the researchers in the course of the research. This point is reached when the narratives of the research participants enrolled at the later stages of the study do not contribute new facets regarding the main topics of the interview guide (so-called theoretical saturation). This decision was made jointly by those researchers involved in the analysis of the transcript. All authors primarily analyzing the transcripts (C.K., J.S., and P.K.) were trained in qualitative research methods as part of either their studies (methods module of psychology studies, P.K., C.K.) or postgraduate training in research methods (J.S.).

Results

Fourteen interviews with POs were conducted face-to-face ($N=7$) or via phone ($N=7$). The interviews had a duration of 15–82 min ($M=30.8$, $SD=18.2$). Half of the interviewees were women. Age varied from 33 to 54 years ($M=45.8$, $SD=6.6$). Professional experience in pediatric oncology was between 0.5 and 26 years ($M=13.8$, $SD=7.6$). Table 1 summarizes the socio-demographic data of the interviewees.

POs' understanding of CAM

Given the heterogeneous definitions of CAM, all interviewees were asked about their individual understanding of CAM as a starting point in the interviews. Although interviewees provided a broad range of examples of CAM, there were nonetheless common characteristics in the narratives regarding use of CAM as “complementary treatment” in the sense of “something additional and outside” the regular treatment offered by pediatric oncology.

[...] everything that supplements the classic orthodox medical therapy concepts. (Interview 5)

In addition, “complementary” was seen to have a rather positive connotation, whereas the term “alternative” was depreciated by the interviewees with reference to the risks of non-effectiveness and even harm of measures which were offered instead of established tumor-specific treatment.

[...] i.e. families who completely reject chemotherapy and a – yes, then it is already no longer a complementary but an alternative medical measure. (Interview 10)

Furthermore, a common feature regarding the understanding of CAM was that such measures may have positive effects on symptoms of the disease or side effects of established treatment but not on the cancer itself.

Perceived benefit and harm of CAM

Interviewees described empowerment and control of patients and parents as important beneficial aspects of CAM. These supposed benefits of CAM were combined by some respondents with the notion that established tumor-specific treatment imposes a lot on child and parents and may make them feel “passive.”

Complementary medicine is also part of, that you again take control and this needs to be canalized in the right way. (Interview 11)

Concerning the possible harm of CAM, interviewees distinguished different ways in which this could occur. A first aspect mentioned by several interviewees was the possibility of harm generated by using CAM instead of an established cancer treatment.

[...] is gross nonsense and the child may be massively endangered because he or she is actually under alternative therapy and an effective therapy is to be discontinued. These are more critical situations. (Interview 1)

Second, interviewees referred to the harm of CAM based on the additional burdening of the respective measure.

[...] if injected subcutaneously, it can be torture for the child. (Interview 7)

A third notion of possible harm was related to the possible negative influences of CAM on the effectiveness of the conventional therapy through negative interaction between cancer drugs and substances labeled as CAM.

Sure, if you don't know whether something might not be compatible with therapy. (Interview 2)

As part of their reflections on benefits and harm, POs pointed to the fact that individual judgments regarding the plausibility of the mode of action of a specific CAM as well as their personal and clinical socialization and experiences might influence their evaluation of the benefit or harm of CAM.

Somehow, I can understand them better than if it were now about these bicarbonate therapies that I just mentioned; they are quite suspect to me, and also these, yes, these alternative practitioner methods; I personally cannot do much with them or do nothing at all, and I simply have great doubts about the integrity of these methods. (Interview 8)

Counseling on CAM: rationale, barriers, and strategies

All study participants viewed an openness to discuss CAM-related questions from parents as an adequate professional behavior, not least because they want to prevent their patients from possible harmful effects. Some even advocated a proactive approach to raise the topic, for example, at the beginning of a treatment regime.

But we are, so we're trying to structure this and talk about it because we know that the parents are doing something anyway and we'd rather be involved than have them somehow running parallel. (Interview 4)

As I always try to be open and, above all, in the sense of good patient care, I do not forbid my patient from doing anything that he himself is convinced of. (Interview 6)

However, POs report several barriers regarding discussing CAM. Among the barriers quoted by respondents are uncertainty regarding the evidence of CAM and challenges to acquire knowledge about the effectiveness, risks, costs, and feasibility of specific CAM measures. Furthermore, a lack of time in daily routines was mentioned as a barrier.

But there are a lot of compounds we don't know about, and it's already making us insecure. (Interview 11)

Or there are time constraints. I can't do research for a whole weekend for a 40 euro clinic fee. (Interview 1)

Interviewees cited their willingness to search for information on specific CAM as a strategy to deal with CAM-related queries from parents. In addition, most of the interviewees have had many years of professional experience and could rely on a network of practitioners with expertise in CAM to whom they could refer parents and their patients.

[...] sometimes they bring some drops, pills or other things and we take a photo of the boxes and send it to our pharmacist and then we sometimes advise the families together. That is a real luxury. (Interview 10)

[...] but it's a renowned private practice and when parents say, "That's where we want to go", I can't say it's somewhere; I can say from my experience we already have two families there – have turned to them, have had counselling, they are qualitatively in accordance with the requirements of good medical standards, so to speak. (Interview 11)

In terms of their professional obligations regarding the use of CAM, all interviewees viewed prevention of physical harm for the child as the priority of their professional duties. However, narratives also indicated that the decision how and when to intervene in cases with possible negative effects for children was not straightforward. In addition, some interviewees viewed it as their task to intervene in the case of perceived high financial burdens for parents.

There are a few points that I give to all patients: The first is that they must not ruin themselves financially if they have to pay for it themselves, and the second, it must not harm the children and, above all, it must not hurt the children. (Interview 6)

[...] then 600 to 700 Euros for the family are easily gone for nothing – from my point of view. These are the things where I think I have to intervene and I can't allow that. (Interview 3)

Discussion

This is, to the best of our knowledge, the first qualitative interview study with German POs on their perceptions and views regarding CAM. The main findings are, first, that while there are heterogeneous understandings of CAM, there is a shared acceptance concerning non-harming measures in addition to established treatments and a rejection of CAM if it is used as an alternative to established treatments. Second, interviewees reflect that their evaluation of any possible benefit is influenced by individual views on the plausibility of the mode of action of specific CAM measures. In addition, different types of direct and indirect possible harm of CAM are distinguished. Finally, study participants are open and in favor of discussing the topic of CAM openly with their patients and, at the same time, they acknowledge several individual and systemic limitations, which prevent them from handling the topic satisfactorily in clinical practice.

Understanding and evaluating the benefit and harm of CAM

The POs interviewed in this study located the adequate role of CAM as complementary but not as alternative to the conventional therapy. This distinction is in line with Lorenzo and Markman's²⁰ definition that "alternative treatments are not integrated in conventional medicine. Complementary medicine, however, makes use of non-conventional treatment modalities, [...], in combination with conventional therapies." Regarding possible beneficial effects of CAM, POs consider complementary measures particularly when it comes to treating negative side effects of the conventional cancer treatments or symptoms of the disease.¹⁰ This seems in line with other reports,²¹

which consider CAM a supportive measure particularly in situations when established treatments fail or in palliative situations. With regard to evaluating the benefit or harm of CAM measures, the narratives suggest that factors influencing the respective judgments are personal experience with particular CAM and views on the plausibility of the mode of action. Against this background, it is probable that experiences of parents who discuss a particular CAM with their PO will depend considerably on the personal experience and attitude of the respective physician. It seems important to equip physicians with relevant knowledge and skills for a professional handling of such discussions that should go beyond pure personal views and experiences. However, up to now, there has been a scarcity of respective resources for POs.²²

Discussing CAM in pediatric oncology. Benefits, barriers, and professional role(s)

Respondents provided different rationales for their willingness to engage in CAM discussions. In addition to a functional argument to make sure that children do not take any CAM that might interact negatively with conventional treatment, the discussion of CAM was also perceived as an element to strengthen the relationship with POs and parents. This notion is in line with findings of earlier research that discussing CAM and related topics openly seems to be an important means to close communication gaps between patients, parents, and health providers.^{7,23} Such a function of CAM discussions can be crucial, particularly in situations where conventional treatment is burdensome, in the sense that parents and children trust their POs and respective treatment recommendations given that they know their POs are caring physicians.^{24,25} The lack of knowledge regarding CAM has been pointed out as an important barrier by interviewees, a finding which is supported by survey research.^{10,26} Although the recent national guideline on CAM in oncology in Germany provides a comprehensive resource for information on the current evidence,²⁷ there is a scarcity of research specifically on the clinical context in pediatric oncology.

The POs differed regarding their perceptions of professional roles and duties when engaging in CAM discussions. There was common ground in the group of interviewees that the principle of “do not harm” should be followed, in the sense that physicians should prevent measures that may physically harm the patient. At the same time, the narratives indicate that there is some leeway in the individual interpretations regarding what harm for the child means and, moreover, a considerable challenge to discuss this issue in light of the risk of ending the relationship with the parents. Similarly, the findings indicate that POs take different positions regarding the acceptance or intervention in cases of considerable financial burden due to CAM. Although individual variations regarding initiating or responding to discussions about CAM are not a problem in principle, the findings raise questions whether it is possible to develop a minimal standard of professional behavior in such situations. Such a standard, on the one hand, would need to consider the relevant ethical and legal framework, which differs between countries.¹² Such standards need also to be adaptable to changes regarding the professional framework. In Germany, for example, the German Medical Association has changed its model professional curriculum more recently so that

certificates for additional qualification in homeopathy are no longer mentioned. On the other hand, it would be important to inform such a standard by evidence regarding patients' and parents' preferences as well as outcomes on communication strategies. If such a standard could be identified – for example, as part of a professional consensus project – it may inform future undergraduate and postgraduate curricula and thereby support POs concerning the frequent and, in some cases, challenging requests regarding CAM.²⁸

Limitations

A methodical limitation that must be considered is that the findings cannot be generalized because it is possible that the experiences and views of POs elicited in this explorative study may not cover the whole range. Second, and related to the first point, it is possible that we could only attract physicians who are interested in CAM and, therefore, our narratives do not adequately reflect the views of physicians who oppose CAM or for whom this topic is irrelevant in practice. Another possible source of bias could be the use of snowball sampling since interviewees might have recommended colleagues with similar views on CAM. Finally, the findings are based on perceptions of physicians and should be triangulated with findings derived from other stakeholders (e.g. parents, nurses etc.) as a next step.

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Disclosure statement

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