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### A systematic review

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## **Open dialogue about complementary and alternative medicine (CAM) integrated in conventional oncology care; characteristics and impact. A systematic review**

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Alternative Medicine; Cancer Communication; Complementary Medicine; Dialogue; Integrative; Oncology; Systematic Review

## Abstract

**OBJECTIVE:** To systematically review evidence on the characteristics, experiences and impact of an open dialogue about complementary and alternative medicine (CAM) integrated in oncology care.

**METHODS:** We searched MEDLINE, EMBASE, AMED, Scopus, ProQuest Dissertations and Thesis, Cochrane Central Register, clinicaltrials.gov, forskningsdatabase.dk and PROSPERO. Two reviewers screened title, abstract and full-text articles. Each study was appraised using the Critical Appraisal Skills Programme (CASP) and synthesized narratively. PROSPERO registration CRD42019112242.

**RESULTS:** We retrieved 4736 articles and included 5; 3 received 9 ½, 1 received 9, and 1 received 5 points on the CASP score. Predominately, the open dialogue was one or two individual, patient-centered, face-to-face consultations led by oncology physicians. In one study, it was a tele-phone consultation and in another it was structured counseling led by pharmacists. Integrated information and recommendations about CAM contributed to high level of satisfaction and improvement in concerns, quality of life and well-being.

**CONCLUSION:** Integration of open dialogue about CAM in oncology care including acknowledging patients' preferences, values, wishes and knowledge, and providing information about CAM expands the opportunities for improving patients' health, quality of life and well-being.

**PRACTICE IMPLICATIONS:** Open dialogue about CAM has potentials, but research on how it specifically helps patients, is needed.

## 1. Introduction

Despite lack of evidence to support the use of complementary and alternative medicine (CAM) as cancer treatment [1-5], increasing rates of patients with cancer use CAM such as **special diets, naturopathy, homeopathy**, vitamins, dietary supplements, **manipulative therapy**, massage, acupuncture, **psychological therapy and many others** [6-11]. **There are several techniques and approaches within CAM, but the common feature is that their effectiveness as cancer treatment is still unproven.** Most patients, however, view CAM as complementary rather than alternative [12] and their main reasons for CAM use are not specifically related to treating the cancer. Instead, they use CAM as an adjunct to conventional medicine in order to boost their immune system, improve quality of life, palliate symptoms of conventional cancer treatment, take control and play an active role in their own health and care and to feel empowered and hopeful [7, 13-17]. Studies show that CAM as an adjunct to conventional oncology care improves patients' quality of life and well-being [18-22], e.g. by reducing side effects such as nausea and vomiting [23, 24], fear, fatigue, depression, and pain [20]. CAM also enhances hope [25], self-care, self-control and empowerment [17, 26]. In that sense, an open dialogue **characterized as a person-centered conversation** between a patient and a health professional **where the health professional in a non-judgmental manner respects the patient's needs, preferences, values, and reasons for using CAM and supports evidence based knowledge about CAM**, is essential in guiding both parties towards the best possible way of improving the patient's quality of life and well-being [27, 28]. In fact, given the potentially harmful interactions between certain types of CAM and conventional oncology medicine [1, 29, 30], it is crucial that health professionals and patients openly discuss the use or wish to use CAM - both in terms of patient safety, quality of life, and well-being [25, 31-34]. Studies suggest that open dialogue

about CAM integrated in oncology visits leads to increased patient engagement, more patient-centered communication. It also improves patient and clinician satisfaction [35] and addresses patient stress and uncertainty, reduces exposure to misleading information, and enhances the patient-physician relationship, which is paramount in delivering high-quality care [36]. Still, it remains unclear how open dialogue about CAM integrated in conventional oncology care affects the health, quality of life and well-being of the patients and how their experience with open dialogue on the issue is unexplored. Open dialogue between patients and health professionals about CAM is not systematically integrated in daily oncology practice [31, 37, 38] and research in the area reports mainly on the impact, effect and patient experience of the combination of conventional biomedicine and CAM [39-41]. Considering that health care interventions should be based on the best available evidence, a deeper knowledge on patient experience with open dialogue on CAM and its effect on health, quality of life, and well-being is warranted. Hence, we systematically reviewed the available evidence on the issue. Our research questions were as follows: When open dialogue about CAM is integrated in conventional oncology care: 1) What are the characteristics of the open dialogue? 2) How do patients experience the open dialogue? and 3) How does the open dialogue affect the health, quality of life, and well-being of the patients?

## 2. Methods

In order to satisfy each of the three questions and get an enhanced insight of how open dialogue integrated in oncology care affects the patients, we conducted a systematic review by systematically reviewing studies with quantitative and/or qualitative designs [42]. The review was registered in the International prospective register of systematic reviews PROSPERO (PROSPERO CRD42019112242) and the protocol remained unchanged while undertaking the

review. We report our findings according to the PRISMA guidelines (Preferred Reporting Items for Systematic Review and Meta-Analysis) [43]

## 2.1 Eligibility criteria

We set out to include studies with a quantitative, qualitative, or mixed method design investigating and/or describing measurable effects and/or patient experience of open dialogue about CAM integrated in oncology care. Eligible studies would report findings on patients aged 18 years or older diagnosed with cancer. Since chemotherapy is a significant determinant of increased CAM use [10, 12, 44] and **some** patients use CAM while undergoing conventional antineoplastic treatment [14] (chemotherapy, immunotherapy, antibody treatment and/or radiotherapy), studies focusing on terminally ill patients and cancer survivors were excluded. A priori, we defined open dialogue about CAM in a broad perspective as a consultation, conversation, communication, discussion or dialogue. Non-specific or multi-faceted behavioral or educational interventions addressing and recognizing patients' usage or wish to use CAM as an adjunct to conventional oncology treatment would also be included. Further, we viewed the open dialogue about CAM as akin to a complex intervention composed of several parts. For example, interventions could consist of one scheduled dialogue about CAM between the patient and the health professional with no further intervention or several dialogues with referral to specific complementary therapy. The dialogue about CAM could also be a part of a broader integrative program but still integrated in conventional oncology care. All studies would have to present outcomes and/or patient experience exclusively related to the open dialogue about CAM.

## 2.2 Search strategy

Inspired by the PICO tool (Population, Intervention, Comparison and Outcomes) [45], a structured search strategy was developed in collaboration with a research librarian at the

University of Southern Denmark using a mixture of medical subject headings (MeSH) and terms related to open dialogue about CAM in an oncology setting. Following the recommendations by the librarian, the C and O of the PICO tool was changed to Co (Context). The search strategy was peer reviewed by a second librarian not otherwise associated with the project. A draft search strategy is presented in Figure 1.

We searched the three largest medical and nursing databases MEDLINE (OVID interface, 1947 onwards), EMBASE (OVID interface, 1980 onwards), and **CINAHL**. The AMED database, Scopus, ProQuest Dissertations and Theses, and the Cochrane Central Register were also searched. Ongoing or recently completed protocols and trials were searched for on ClinicalTrials.gov and forskningsdatabase.dk. PROSPERO was searched for ongoing or recently completed systematic reviews. The search was limited to English, Danish, Swedish, and Norwegian language and human subjects. To ensure literature saturation, we scanned the reference lists of included studies or relevant reviews for additional references. When relevant studies were identified, we checked for additional, relevantly cited and citing articles.

### 2.3 Screening

Search results were uploaded to Covidence (covidence.org). The first and last authors (Mette Stie, MS and Birgitte Nørgaard, BN) independently screened the titles and abstracts yielded by the search against the inclusion criteria. Subsequently, they both reviewed full reports for all titles and abstracts categorized as potentially relevant. Reasons for excluding trials were recorded and disagreement between the reviewers was solved through discussion. Neither of the review authors was blinded to journal articles, study authors or institutions.

## 2.4 Data extraction

Prior to data extraction, MS and BN piloted a standardized data form and few adjustments were made. **To ensure consistent methodology, data extraction was performed by a primary reviewer MS and edited/confirmed by BN.**

For each study included, we extracted study characteristics (author, year, and research design), characteristics of the intervention (type and number of consultations, type of health professional conducting the consultation), patient characteristics (sample size, age and sex distribution), and data collection methods (questionnaires and/or interview). Outcome data related to the reported outcomes and/or patient experience of the intervention were also extracted.

## 2.5 Quality appraisal

Each study selected for inclusion was appraised individually by two authors (MS and BN) using the Critical Appraisal Skills Programme (CASP) [46] checklists in order to determine risk of bias, study quality, transferability and trustworthiness. **CASP checklists were used according to the design of the included studies i.e. the case-control study checklist and the cohort study checklist.** The included studies were read and reread during the appraisal process. The CASP checklist contains 12 questions facilitating rapid evaluation, but it does not provide a scoring system. In order to outline the level of quality of each study, we used the scoring system as described by Butler et al. [47]. For each question in the CASP checklist, the study would receive the following points; 0 (=No), ½ (Can't tell), or 1 (=Yes). The CASP checklist and the scoring system are outlined in Appendix 1. Disagreements about study quality were solved through discussion. It should be noted that we aimed at identifying the level of quality and that no study would be excluded due to low quality.

## 2.6 Data synthesis and interpretation

We synthesized, interpreted, and summarized the extracted data. Due to heterogeneity in designs and outcomes we described the findings narratively and performed descriptive analyses in order to identify the relevant features of the studies. We looked for similarities and differences between the results of the studies and organized them into themes.

## 3. Results

### 3.1 Study selection

After removing duplicates, we identified 4736 studies of which 4697 were excluded on the basis of their title or abstract. Of the 39 remaining studies, 34 were excluded based on their text.

Reasons for exclusion are described in the PRISMA flow diagram, Figure 2. We also identified six potential studies when scanning the reference lists of the included studies. However, none of them met the inclusion criteria. Ultimately, only five studies were eligible.

### 3.2 Study characteristics

Study characteristics of the five included studies are described in Table 1. Two studies originated from the United States [48, 49], two were from Germany [50, 51], and one from Canada [52].

**Although the included studies had different research design (observational [49], cross-sectional [51], longitudinal [50], prospective [48], intervention [52]) and that size of study population differed (n=238 [49], n=75 [51], n=979 [50], n=1832 [48], n=121 [52]), they were all based on quantitative data collected through questionnaires.** In total, the studies report data on 3245 patients, predominantly women (range 51%-100%) and a mean age between 52.5

and 60 years. In all studies except one [52], the intervention was described as an individual or patient centered consultation led by oncology physicians. Only in this study [52] the intervention was described as a routine and structured counseling led by pharmacists. **In three studies [48, 50, 52], the intervention was also described as a consultation including evidence-based information about CAM. In two studies, it remained unclear whether the information about CAM was evidence-based [49, 51].** The patients participated in one or two consultations [48-51]. In four studies the consultation was conducted face-to-face [48, 49, 51, 52] and in one, it was a telephone consultation [50].

### 3.3 Quality appraisal

The appraisals of the methodological quality of the included studies are summarized in Figure 2. Three studies received 9½ points [49, 51, 52], one study received 9 points [48] and one study received 5 points [50]. Although the level of methodologic quality varied, we found that all studies but one [50] addressed a clearly focused issue. Four studies recruited the cohort in an acceptable way [48-51] and three studies measured outcome accurately in order to minimize bias [48, 49, 52]. In general, the authors had not identified or taken into account all confounding factors, but we found the results of each study applicable.

### 3.4 Results

The main **results** related to patient reported outcomes on satisfaction, concerns and well-being are provided in Table 1.

#### 3.4.1 Patient satisfaction

Three studies reported on patient satisfaction with the consultation about CAM [50-52]. Each study presented a very high or high level of satisfaction among the patients. Although the consultations differed slightly **with regard to research design**, all three studies reported that the high level of satisfaction in particular was related to 1) getting information and recommendations about CAM therapies and 2) the fact that consultations about CAM were integrated in the conventional treatment setting. Overall, Hack [51] found **that 25.3% were very satisfied and 46.7% were satisfied with the consultation, and in particular, that the high level of satisfaction (very satisfied 44%, satisfied 42.7%)** was related to the integrative approach with calm and quiet surroundings and atmosphere, which allowed the patients to share their expectations and worries with a physician taking their uncertainties about using CAM seriously. Horneber [50] reported that even though the majority of the patients did not find a consultation by phone problematic, **34 %** stated that an additional discussion in person would have been helpful. Taylor did not examine how surroundings, atmosphere or the face-to-face discussion about CAM affected the patient's satisfaction with the consultation. **However, Taylor found higher patient satisfaction in the intervention group (consultation) compared to the control group with an overall mean score of 4.23 and 3.98, respectively, yet non-significant (p=0.129). Nevertheless, statistical significant differences were found in the two groups (4.06; 3.16, p=0.001) in relation to receiving general information about CAM[52].** Accordingly and consistent with Hornebers study [50], **85% of the included patients perceived the consultation as informative and helpful towards making decisions on whether to use CAM** whereas in the Hack study, **29.3% of the included patients were very satisfied and 46.7% were satisfied** with the individual treatment plan including both conventional and complementary treatment [51]. Still, Horneber found that patients were searching for a more

general road map for treatment options – conventional as well as CAM therapies (**mean 3.7; SD 1.6**) compared to specific advises on CAM therapies (**mean 3.3; SD 1.5**). [50]. Taylor emphasized that it was unclear whether CAM counseling actually impacted the decision to use CAM [52].

**Both Horneber and Hack found that patients were satisfied (positive 28% and helpful 21%, 38.7% very satisfied and 34.7% satisfied, respectively) with the way the consultation about CAM was organized including the fact that it was integrated in conventional care [50, 51].** Horneber found **that in 66% of the consultations**, various problems and thus various treatment options – CAM as well as conventional treatment options - was addressed. Hence, Horneber **found** that not every question about CAM deserves an answer out of the realm of CAM as well as not every question about conventional treatment should be addressed by conventional treatment. [50]. Similarly, **when asking the patients how to improve the integrative consultation**, Hack **found** that consultations about CAM should lead to an individual treatment plan including conventional as well as complementary therapy with the highest level of efficacy and safety for individual patients, regardless of type of treatment [51]. Conversely, in Taylor’s study the consultation about CAM was exclusively about Natural Health Products and did not include a discussion on conventional treatment options, although the consultation was a routine integrated in conventional oncology care [52].

### 3.4.2 Patient reported symptoms, quality of life, concerns, and well-being

Two studies [48, 49] reported how patients’ concerns and well-being was affected by the consultations about CAM. Additionally, Lopez presented the effect of the consultations on patient-reported symptoms and quality of life. In the study by Frenkel et al. the main concern of

the patients at baseline was related to the topic “What else can I do?” and **63%** were in particular looking for reliable information on CAM to integrate in their care. Leading concerns were also related to physical problems (**37%**), improving well-being (**34%**), worries about the future (**28%**), healing (**27%**), regaining balance (**26%**), adapting, and coping (**25%**) [49]. In Lopez’s study, the baseline three main concerns were related to herbs and supplements (**35.2%**), topics within an integrative/holistic approach (**33.9%**), and diet/nutrition (**21.7%**) [48]. Although the main concerns were slightly different, both studies found that consultations about CAM provided information addressing the main concerns of the patients and promoted their well-being. In fact, **with almost a two-point drop (-1.92 and -1.98, p<001) on the MYCaW score**, Frenkel showed clinically significant improvements on patients’ main concerns and well-being after the consultations [49]. **Likewise, Lopez found significant improvement of depression (-0.2, p=0.009), anxiety (-0.7, p=0.001), well-being (-0.3, p=0.004), psychological distress (-0.9, p=0.001), and global distress (sum of pain, fatigue, nausea, depression) (-1.6, p=0.010) [48].** **Frenkel found that the decrease in severity of main concerns was much more dramatic in patients who rated their concerns 5-6 at baseline compared to those who rated their concerns 0-1. The number of patients who reported a high degree of main concerns was reduced by 31% while the number of patients who reported a low degree increased with 13% [49]. Similarly, in Lopez’s study an impact on patient reported symptoms was observed in patients reporting a moderate to high symptom burden at baseline. In particular, the psychosocial symptoms of anxiety and depression were most affected by the consultation about CAM (mean change 2.17; SD 4.43), but these symptoms were not among the patients’ top concerns. However, patients who reported a higher degree of anxiety and psychological distress prior to the initial consultation had a response rate of 70.4% and 56.3%,**

respectively regarding asking for a follow-up consultation. Interestingly, in patients who asked for a follow-up consultation, a small but significantly higher satisfaction with the initial consultation was reported (**9.6 versus 9.4, p=0.012**). According to Lopez, these results suggest that patients are seeking continued counseling and support for CAM treatments in general rather than focusing on the management of a specific symptom [48].

Frenkel's results relied partly on questionnaires including open-ended questions about what the most important aspect of the consultation had been. Patients noted that the benefits of the consultation about CAM included support for daily life, obtaining a positive outlook, and the ability to take a proactive role in their health care and well-being. Addressing concerns and distress in relation to cancer diagnosis and treatment and providing reliable information on CAM therapies seemed to empower the patients to be involved in their own care and provided significant relief [49]. Although Lopez did not present data on what had been the most important aspect of the consultation from the patient's point of view, he found that the improvements in symptoms were clinically meaningful to the patients [48].

#### 4. Discussion and Conclusion

##### 4.1 Discussion

We reviewed and synthesized evidence on 1) the characteristics, 2) patient experiences, and 3) the impact of an open dialogue about CAM integrated in oncology care on patient satisfaction, patient reported symptoms, quality of life, concerns, and well-being. Although researchers suggest the integration of open dialogue about CAM in conventional oncology care to be potentially beneficial [27, 53, 54], we located only five studies exclusively reporting how this

type of consultation affects the patients. No qualitative studies describing patient experiences were identified and thus our research question 2;”How do the patients experience the open dialogue?” cannot be answered. The review did show, however, that patients are very satisfied with the open dialogue about CAM and that their concerns, well-being, symptoms, and quality of life are improved.

The positive outcomes were especially related to the fact that open dialogue about CAM was literally integrated in conventional oncology care. For example, in Hack’s study the importance of integrative approaches being included in conventional treatment settings was emphasized [51]. Frenkel’ s study showed that patients were looking for reliable information on CAM to integrate in their care and that this integration in particular showed measurable, clinically significant improvements of the main concerns and well-being of the patients [49]. Considering that open dialogue about CAM integrated in conventional oncology was an inclusion criterion, the integrative approach was expected to be an important issue. Therefore, in the included studies patient needs and problems were resolved by various treatment options – conventional as well as CAM.

Consequently, open dialogue about CAM integrated in conventional oncology care expanded the opportunities for improving the health, quality of life, and well-being of the patients [53, 55].

However, since open dialogue about CAM is not systematically integrated in conventional oncology care [31, 38, 56], the opportunities for improving patients’ health, quality of life and well-being are not fully exploited. Health professionals’ knowledge about CAM is sparse [57-59] and only few feel comfortable discussing CAM with their patients [53, 59]. Nevertheless, and similar to previous research [55, 60], we found that patients valued discussing CAM with conventional health professionals. **Interestingly, providing evidence-based information about**

**CAM was not emphasized as important in the open dialogue about CAM. Instead, receiving reliable, general and individualized information about CAM was highlighted as important and proved to increase patients' satisfaction. Accordingly, a Cochrane review assessing the effects on decision aids on people facing treatment or screening decisions, including providing information about options and associated benefits/harms and personal values has shown an overall patient satisfaction of 82.5% for the decision aid compared to 80.0% for usual care (no decision aid). Also, the Cochrane review has shown that patients exposed to decision aids report higher satisfaction with their choice of treatment due to lower decisional conflict (mean decrease -9.28 CI95% -12.20 to -6.37) more knowledge and information (mean difference at 13.27, CI95% 11.32;15.23) and less uncertainty about their values (mean decrease -8.81 CI95% -11.99 to -5.63) [61]. This may explain why this current review revealed that receiving reliable, general and individualized information increased satisfaction and allowed patients to be actively involved and empowered in their own care and treatment decisions concerning both conventional and complementary options. Being actively involved in making treatment decisions about CAM increases the sense of control and a feeling of empowerment [55]. Nevertheless, a qualitative study has shown that while making their own choice about CAM to some patients is therapeutic, it can be a burden to others [62]. In accordance with the cornerstones of SDM [63, 64] this highlights that gauging patient values, wishes, and preferences for level of participation in decisions about CAM treatment is equally important as providing the evidence based information on the issue. However, it is not solely a matter of providing scientific knowledge and clarifying preferences and level of participation. Qualitative studies exploring why patients do not communicate about their use of CAM have shown that the focus on scientific evidence by health professionals hinders a successful**

communication about CAM [65]. Also, patients draw on different kinds of knowledge in decisions about CAM as well as conventional treatment [66]. In order to decide about treatment they piece together their intuition, their embodied knowledge, and formalized scientific knowledge [66]. It is not clear whether the open dialogue about CAM in the current review included these different kinds of knowledge. One study [51] showed that patients' high level of satisfaction was especially related to the possibility of extensively sharing their worries and expectations about CAM with a physician taking their uncertainties seriously. Four of the five studies described the open dialogue as "patient-centered", "individual" and "empowering", and similar to other studies [67, 68] this approach addressed the main concerns of the patients and improved their wellbeing and quality of life. Getting reliable information about CAM and conventional treatment was emphasized as very important. In summary, this indicates that combining research knowledge with clinical experience, context data, and patient experiences and preferences will lead to effective patient-centered care as suggested by Rycroft-Malone [69]. Hence, and congruent with Rycroft-Malone, the delivery of effective, evidence based and patient-centered open dialogue about CAM will only be realized **when patients' experiences, values, and beliefs are embraced as an integral part of decisions about CAM use [69]. The question is whether health professionals are prepared to recognize and embrace patients' experiences and how this will affect their perception of their role as professionals.** Are they prepared to realize that being a professional is not solely a matter of being an expert providing evidence based knowledge about conventional treatment and CAM but indeed also of paying sensitive situation-specific attention to the patient as suggested by Delmar [70]?

We found that the open dialogue about CAM affected patients' health, well-being, and quality of life in various ways. For instance, Frenkel found that patients who rated their concerns at the

highest degree benefitted more from the open dialogue compared to patients rating their concerns to a lower degree [49]. Lopez, on the other hand, found that anxiety and depression were the most affected symptoms, although not among the patients' top concerns [48]. It seems that open dialogue about CAM integrated in oncology care generally improves health, well-being and quality of life, but further details on how open dialogue about CAM affects patients need further clarification. Exploring patients' experiences of the open dialogue about CAM is also warranted in order to get an in-depth and more comprehensive understanding of how the open dialogue affects the patient.

This review was limited by the fact that we located only five quantitative studies describing the characteristics of the required CAM subject and no qualitative studies describing patients' experiences of the dialogue.

We synthesized, interpreted and narratively described the extracted data. A meta-analysis may have brought exact estimates but was not chosen for two reasons. First, we aimed to gain enhanced insight into the way open dialogue integrated in oncology care affects the patients rather than looking for exact estimates. Second, the heterogenic definitions of open dialogue about CAM as well as differences in design and outcomes of the included studies did not allow for collapsed analyses.

**Another limitation was that the included studies primarily focused on assessing patient satisfaction and well-being. In fact, none of the included studies explored the actual effect of open dialogue about CAM on health, quality of life, and well-being of the patients. In order to identify an actual effect of the open dialogue about CAM, studies using rigorous designs such as randomized controlled trials, are required. In addition, it is difficult to**

**interpret whether the positive patient reported outcomes were related to the focused discussion about CAM, to the possibility of spending time with a health care provider willing to listen to the patients concerns and provide emotional support or to a combination hereof. However, none of the studies have considered that open dialogue about CAM is a complex intervention which might present methodological difficulties.**

The strengths of this review should also be noted. We followed the PRISMA guidelines [43] ensuring a systematic approach, transparency, accuracy, and completeness of the review. Two authors independently screened and reviewed all titles, abstracts, and full reports, and quality appraisal of the included studies was based on the Critical Appraisal Skills Programme (CASP) [46] ensuring that risks of bias, study quality, transferability, and trustworthiness was identified.

## 4.2 Conclusion

Based on this review, we conclude that open dialogue about CAM integrated in conventional oncology care is typically conducted as one or two scheduled consultations between a physician or a pharmacist and a patient. The open dialogue is primarily based on a patient-centered and individualized approach and a key aspect is the integration into the conventional oncology setting. This entails that the open dialogue is literally open and includes not only health professionals' scientific knowledge about conventional biomedicine and CAM but also patients' needs, preferences, values and knowledge. The openness and combined knowledge will inevitably support the health professional and patient in identifying the best possible way of improving the health, quality of life, and well-being of the patient. We also conclude that health professionals need to acknowledge that scientific evidence is not all that counts in the open discussion about CAM. Patients' intuition and embodied knowledge must be part of the

dialogue. Open dialogue about CAM integrated in conventional oncology care **might** improve patients' health, well-being, and quality of life, but more research on patient experiences of open dialogue about CAM integrated in conventional oncology care as well as details on how patients' health, quality of life and well-being are affected is required.

#### 4.3 Practice Implications

Participating in a scheduled open dialogues about CAM truly integrated in conventional oncology care improves patient satisfaction, health, quality of life, and well-being. By respectfully recognizing patient preferences, values, and knowledge at the same time with providing evidence about conventional medicine and CAM, health professionals have a unique possibility of improving the quality of life and well-being of the patients. Major barriers to successful communication between health professionals and patients about CAM are the indifference or opposition towards CAM use by the professionals, their emphasis on scientific evidence, and the patients' anticipation of a negative response from the professional. This indicates a need for information and education of health professionals about the patients' aim of using CAM and how it may improve their quality of life and well-being. Combined with training in patient-centered communication this could potentially close the communication gap between health professionals and patients when it comes to CAM and lead to improved quality of life and well-being. Developing effective interventions to improve communication about CAM should be an integral part of future research.

This review identified limited and heterogeneous evidence on how open dialogue about CAM affects patients' health, quality of life, and well-being. Further studies using rigorous designs are required. Qualitative studies for in-depth understanding as well as randomized controlled trials

testing interventions are needed in order to gain a comprehensive understanding of how open dialogue about CAM integrated in oncology care may best help the patients.

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### **Declaration of interest**

The authors have no conflicts of interest relevant to this article to disclose.

### **Data availability**

Data in relation to this manuscript are available from the corresponding author upon reasonable request.

### **Protocol registration**

PROSPERO registration CRD42019112242

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## **Appendix A**

Detailed description of the CASP checklist and the scoring system.

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Table 1 Characteristics of included studies

Study	Aim	Research Design	Intervention	Patient Characteristics	Outcomes and Measures	Data Collection	Reported Outcomes
<b>Frenkel 2010</b>	To explore patients' experiences with an integrative medicine consultation.	Intervention B/A No control group	An educational empowering consultation addressing patients' main concerns about CIM use.  Physician led 1-2 consultations	N= 238 Female: 60% Mean age 56 Range age: 21-90	Whether a CIM consultation provided measurable benefits in addressing patients' concerns and whether it reduced patients' distress	Questionnaires Measure Yourself Concerns and Well-being (MYCaW)	Decreased severity of patients' concerns supported patients in obtaining a positive outlook and a proactive role in their health care and well-being
<b>Hack 2018</b>	To assess the success of the consultancy service and the extent of the patients' satisfaction with it.	Cross-sectional	An individual treatment plan is developed in accordance with the patients' needs and wishes. Patients must implement the treatment plan on their own  Led by a naturopathic physician 2 consultations	N=75 Female: 100% Mean age 52.5 Age range: N/A	Patients' satisfaction with the standardized consultancy service for integrative medicine	Questionnaires IMed and standardized patient satisfaction. Telephone-interview	Very high level of satisfaction with the consultancy service, including the individual treatment approaches
<b>Horneber 2018</b>	To learn how telephone consultations about CAM are perceived	Longitudinal	Patient centered telephone consultation  Led by oncology clinicians with medical education about clinical nutrition, mind-body-therapies and phytotherapy 1 consultation	N=979 Female: 69% Patients: 63% Relatives: 37% Mean age: 57 Age range: N/A	User satisfaction with consultation about CAM	Self-constructed questionnaires	Overall, the users were very satisfied with the consultation
<b>Lopez 2017</b>	To assess the effects of integrative oncology (IO) consultations on patient-reported symptoms and quality of life	Intervention B/A With control group	An individual integrative care plan is made at the consultation based on the patients' symptoms and concerns.  Led by physician and advanced practice provider 1 or 2 consultations	N=1832/642 Female: 68.1%/71.1% Mean age: 55.5/57.2 Age range: 18.1-90.1/ 18.8-90.6	Changes in patient-reported symptoms and quality of life after IO consultations	Questionnaires regarding CAM use Measure Yourself Concerns and Well-being (MYCaW) Edmonton Symptom Assessment Scale (ESAS)	Psychosocial symptoms were improved and top concerns addressed satisfactorily.

<b>Taylor 2008</b>	To report the impact of routine counselling on natural health products on cancer patients	Prospective Interventional, controlled B/A Non-randomized	Routine and structured counselling on natural health products  Led by trained pharmacists Number of consultations N/A	N=121/121 Female: 51%/46% Mean age: 60/59,4 Age range:N/A	Patient satisfaction with routine counselling on natural health products	Questionnaire Patient Satisfaction with Cancer Treatment Education (PS-CaTE)	Overall satisfaction with the routine counselling on natural health products. Appropriate in content and increased patients' knowledge
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Table 2 Quality assessment

<b>Item/Study</b>	<b>Frenkel 2010</b>	<b>Hack 2018</b>	<b>Horneber 2018</b>	<b>Lopez 2017</b>	<b>Taylor 2008</b>
<b>Did the study address a clearly focused issue?</b>	Yes	Yes	No	Yes	Yes
<b>Was the cohort recruited in an acceptable way?</b>	Yes	Yes	Yes	Yes	Can't tell
<b>Was the exposure accurately measured to minimize bias</b>	Yes	Can't tell	No	Yes	Yes
<b>Was the outcome accurately measured to minimize bias?</b>	Yes	Yes	No	Yes	Yes
<b>Have the authors identified all important confounding factors?</b>	Can't tell	Can't tell	No	Yes	Can't tell
<b>Have they taken account of the confounding factors in the design and/or analysis?</b>	No	No	No	No	Can't tell
<b>Was the follow-up of subjects complete ?</b>	Can't tell	Yes	Can't tell	No	Can't tell
<b>Was the follow-up of subjects long enough?</b>	Yes	Yes	Can't tell	Can't tell	Can't tell
<b>What are the results of this study? How precise are the results and do you believe the results?</b>	Can't tell	Can't tell	No	Can't tell	Yes
<b>Can the results be applied to the local population?</b>	Yes	Yes	Yes	Yes	Yes
<b>Do the results of this study fit with other available evidence?</b>	Yes	Yes	Yes	Yes	Yes
<b>What are the implications of this study for practice</b>	Yes	Yes	Yes	Yes	Yes
<b>Total score</b>	9 ½ point	9 ½ point	5 point	9 point	9 ½ point

## Appendix 1 Quality assessment and scoring system

Item	Guideline
<b>Question 1: Did the study address a clearly focused issue?</b>	Yes – The study is focused in terms of e.g. population, risk factors, detecting beneficial or harmful effect and the outcomes considered Can't tell – The aim is stated but not focused No- Not stated
<b>Question 2: Was the cohort recruited in an acceptable way?</b>	Yes – The cohort presents a defined population Can't tell – Unclear whether there was something special about the cohort or whether everybody was included who should have been No- Recruitment strategy and/or recruited participants are not described
<b>Question 3: Was the exposure accurately measured to minimize bias?</b>	Yes – All subjects were classified using the same procedure Can't tell – Unclear or not relevant No- Not discussed or inappropriate classification
<b>Question 4: Was the outcome accurately measured to minimize bias?</b>	Yes – The measurements have been validated Can't tell – Unclear whether measurements are validated No- Not described or discussed
<b>Question 5a: Have the authors identified all important confounding factors?</b>	Yes – Authors addresses potential important confounders Can't tell – Unclear or not relevant No- Authors have not addressed potential important confounders
<b>Question 5b: Have they taken account of the confounding factors in the design and/or analysis?</b>	Yes –The design is restricted and/or with adjustment for confounding factors Can't tell – Unclear or not relevant No- Not addressed or discussed
<b>Question 6a: Was the follow up of subjects complete enough?</b>	Yes – Only few subjects are lost to follow up and may NOT have different outcomes than those available for assessment Can't tell –unclear whether persons lost to follow up are different from those who completed follow up No- Not stated
<b>Question 6b: Was the follow up of subjects long enough?</b>	Yes – the follow up is appropriate Can't tell – Follow up period is unclear or not discussed No- Good or bad effects would revealed themselves by time
<b>Question 7-9: What are the results of this study? How precise are the results and do you believe the result?</b>	Yes – Results are explicit and the design makes the results reliable. Can't tell –Results are explicit only, with no

	discussion of the design and methods No- High risk of bias and confounding
<b>Question 10: Can the results be applied to the local population?</b>	Yes –The subjects and the setting covered in this study are similar to our local population and setting Can´t tell – The subject and the setting is unclear or not sufficiently described No- The subjects and the setting covered in this study is different from our population and setting which may cause concern
<b>Question 11: Do the results of this study fit with other available evidence?</b>	Yes Can´t tell No
<b>Question 12: What are the implications of this study for practice?</b>	Yes - The study provides sufficiently robust evidence to recommend changes to clinical practice Can´t tell- Implications are stated only with no discussion of how the findings can be transferred to other populations or contexts No- Not stated
<b>Scoring system:</b>  Yes: 1.0 point Can´t tell: 0.5 point No: 0 point	

Table 1 Characteristics and results of included studies

Study	Aim	Research Design	Intervention	Patient Characteristics	Outcomes and Measures	Data Collection	Reported Outcomes
<b>Frenkel 2010</b>	To explore patients' experiences with an integrative medicine consultation.	<b>Observational intervention study without control group</b>  <b>Time point measure at baseline and 6 and 12 weeks after intervention</b>	An educational empowering consultation addressing patients' main concerns about CIM use.  Physician led 1-2 consultations	N= 238 Female: 60% Mean age 56 Range age: 21-90	Whether a CIM consultation provided measurable benefits in addressing patients' concerns and whether it reduced patients' distress	Questionnaires Measure Yourself Concerns and Well-being (MYCaW). <b>Patients rate their two top concerns and general feeling of well-being on 7-point liker scale</b> <b>Open ended questions about what has been the most important aspect of the consultation</b>	<b>Main concerns: Reliable information on CAM (63%), physical problems (37%), improving well-being (34%), worries about the future (28%), healing (27%), regaining balance (26%), adapting, and coping (25%)</b> <b>Top concern was reduced by 1.92 points (P&lt;.001)</b> <b>Second main concern was reduced by 1.98 points (P&lt;.001)</b> <b>Lack of well-being was reduced by 0.63 points (P&lt;.001)</b>  Decreased severity of patients' concerns supported patients in obtaining a positive outlook and a proactive role in their health care and well-being
<b>Hack 2018</b>	To assess the success of the consultancy service and the extent of the patients' satisfaction with it.	<b>Cross-sectional survey evaluating the intervention, there was no control group</b>  <b>Time point measure at baseline and at the patient's next appointment at the hospital. Thus, follow-up time points differ</b>	An individual treatment plan is developed in accordance with the patients' needs and wishes. Patients must implement the treatment plan on their own  Led by a naturopathic physician 2 consultations	N=75 Female: 100% Mean age 52.5 Age range: N/A	Patients' satisfaction with the standardized consultancy service for integrative medicine	Questionnaires IMed and standardized patient satisfaction on a six-point scale with 1 being very satisfied and 6 being very dissatisfied <b>Telephone- interview asking patients ways of improving the consultation</b>	<b>Satisfaction with consultation, overall:</b> <b>Very satisfied: 25.3%</b> <b>Satisfied: 46.7%</b> <b>Partly satisfies: 21.3%</b> <b>Dissatisfied: 4.0%</b>  Suggestions for improvement was individual treatment plan including CAM and conventional treatment
<b>Horneber 2018</b>	To learn how telephone consultations about CAM are perceived	<b>Research design was not clearly stated, but supposedly it was a longitudinal study evaluating the intervention, but no control group</b>  <b>Time point measure was immediately after the consultation</b>	Patient centered telephone consultation  Led by oncology clinicians with medical education about clinical nutrition, mind-body-therapies and phytotherapy 1 consultation	N=979 Female: 69% Patients: 63% Relatives: 37% Mean age: 57 Age range: N/A	User satisfaction with consultation about CAM	Self-constructed questionnaires with 7 quantitative items. Some items were answered on a 5-point rating scale and some with 2 or 4 predefined responses <b>Registration of topics during the consultation</b>	<b>The consultation was perceived as:</b> <b>-Informative (85%)</b> <b>-Clarifying (79%)</b> <b>-Supportive (73%)</b> <b>-Helpful (80%)</b>  <b>Main topics in consultations:</b> <b>-Cancer treatment in general: 66%</b> <b>Mean 3.7, sd=1.6</b> <b>-Specific CAM: 54%</b> <b>Mean 3.3, sd=1.5</b>

<b>Lopez 2017</b>	To assess the effects of integrative oncology (IO) consultations on patient-reported symptoms and quality of life	<b>Intervention study with control group.</b>  <b>Time point measure at baseline, immediately after the intervention and at follow-up (in average 99.1 days after intervention)</b>	An individual integrative care plan is made at the consultation based on the patients' symptoms and concerns.  Led by physician and advanced practice provider 1 or 2 consultations	N=1832/642 Female: 68.1%/71.1% Mean age: 55.5/57.2 Age range: 18.1-90.1/ 18.8-90.6	Changes in patient-reported symptoms and quality of life after IO consultations	Questionnaires regarding CAM use Measure Yourself Concerns and Well-being (MYCaW) <b>Patients rate their two top concerns and general feeling of well-being on 7-point liker scale</b> Edmonton Symptom Assessment Scale (ESAS) <b>Patients rate ten symptoms on a numeric scale of 0 to 10, 10 being worst.</b>	<b>Main concerns:</b> <b>Herbs &amp;Supplements: 35.2%</b> <b>Integrative/Holistic Approach: 33.9%</b> <b>Diet/Nutrition: 21.7%</b> <b>Pain: 14.0%</b> <b>Overall Health: 13.9%</b> <b>Stress/Anxiety: 12.1%</b> <b>Fatigue: 11.3%</b> <b>Others:&gt;10%</b>  <b>Change in symptoms:</b> <b>Pain: +0.1 (p=0.728)</b> <b>Fatigue: -0.2 (p=0.189)</b> <b>Nausea: 0 (p=0.342)</b> <b>Sleep: -0.2 (p=0.074)</b> <b>Breath -0.1 (p=0.586)</b> <b>Appetite: 0 (p=0.082)</b> <b>Drowsy: -0.1 (p=0.459)</b> <b>Depressed: -0.2 (p=0.009)</b> <b>Anxious: -0.2 (p=0.001)</b> <b>Well-being: -0.3 (p=0.004)</b> <b>Physical distress: -0.5 (p=0.283)</b> <b>Psychological Distress: -0.3 (p=0.001)</b> <b>Global distress: -1.6 (p=0.010)</b>
<b>Taylor 2008</b>	To report the impact of routine counselling on natural health products on cancer patients	<b>Prospective Interventional, Controlled, non-randomized study</b>  <b>Time point measure approximately one month after intervention</b>	Routine and structured counselling on natural health products  Led by trained pharmacists Number of consultations N/A	N=121/121 Female: 51%/46% Mean age: 60/59,4 Age range:N/A	Patient satisfaction with routine counselling on natural health products	Questionnaire Patient Satisfaction with Cancer Treatment Education (PS-CaTE) <b>On a 5-point Likerts scale, (strongly disagree to strongly agree) patients rate their perception of the information given.</b>	<b>Patient satisfaction (control vs. intervention):</b> <b>Overall scale: 3.98 vs. 4.23 (p=0.129)</b> <b>CAM subscale: 3.16 vs. 4.06 (p=0.001)</b> <b>Cancer treatment subscale: 4.12 vs. 4.26 (p= 0.891)</b> <b>Side effects subscale: 4.11 vs. 4.30 (p=0.749)</b> <b>Resources subscale: 4.21 vs. 4.34 (p=0.773)</b>

Figure 1 Search Strategy

<b>P</b>	<b>I</b>	<b>Co</b>
<b>Neoplasms</b> (MEDLINE, CINAHL, EMBASE) <b>Cancer patients</b> ( EMBASE, CINAHL) <b>Malignant  neoplasm</b> (EMBASE) cancer* neoplasm* carcinoma* oncolog malignan* tumo?r tumo?rs tumors tumours melanoma* blastoma* radiotherapy chemotherapy	<b>Communication</b> (MEDLINE, CINAHL,EMBASE) <b>Health communication</b> (MEDLINE) <b>Counseling</b> (MEDLINE, CINAHL,EMBASE <b>Patient counseling</b> (EMBASE) <b>Conversation</b> (CINAHL,EMBASE) <b>Doctor patient relation</b> (EMBASE) <b>Physician-patient-relation</b> (MEDLINE, CINAHL) <b>Nurse patient relation</b> (MEDLINE, CINAHL, EMBASE) Communication Interpersonal communication Health communication Counseling Patient counseling Nursing counseling Conversation Consultation Integrative consultation Dialogue Advic* Doctor patient relation Physician-patient-relation Patient-doctor communication Nurse patient relation Nurse-patient communication	<b>Integrative oncology</b> (MEDLINE, EMBASE) <b>Integrative medicine</b> (MEDLINE, CINAHL, EMBASE) <b>Complementary therapies</b> (MEDLINE) <b>Alternative medicine</b> (EMBASE) <b>Alternative therapies</b> (CINAHL) Integrative <i>adj 3</i> oncology Integrative <i>adj 3</i> medicine Complementary therap* Integrative <i>adj 3</i> care Integrative <i>adj 3</i> cancer care Integrative <i>adj 3</i> approach Integrative <i>adj 3</i> supportive care Integrative <i>adj 3</i> nursing Integrative <i>adj 3</i> therapy Integrative <i>adj 3</i> clinic Integrative <i>adj 3</i> health care Complementary medicine Complementary alternative therap* Complementary health approaches Comprehensive cancer care Complementary and alternative medicine Complementary nursing Supportive cancer care Supportive care Alternative medicine Alternative therap*

The search for “P” Neoplasm is adopted from Zhang X, Zhou L. Cochrane Review: Interventions to enhance return-to-work for cancer patients. Cancer Nursing 2013; 36

Title: Open dialogue about complementary and alternative medicine (CAM) integrated in conventional oncology care; characteristics and impact. A systematic review

Journal: Patient Education and Counseling

### **Author Contributions- based on CRediT**

**Birgitte Nørgaard:** Conceptualization, Methodology, Formal Analysis, Writing – Original Draft, Writing – Review & Editing, Supervision. **Charlotte Delmar:** Conceptualization, Writing – Review & Editing. **Lars Henrik:** Conceptualization, Writing – Review & Editing, Supervision