

KOKON-KTO consultation manual

Authors: Rogge, A.A., Helmer, S.M., Schofield, P., Wastell, M. & Witt, C.M.



The KOKON-KTO consultation guideline was developed for the KOKON-KTO consultation. Use of the guideline is only recommended in the setting of the KOKON-KTO consultation.

KOKON-KTO consultation guideline for a systematic consultation

KOKON-KTO comprises e-learning sessions and one on-site skills training workshop and communicates basic competence in complementary and integrative medicine and a systematic interview method. The guideline is supplemented by a questionnaire for patients and a pocket card for the everyday work of the physician.

What is the objective of the KOKON-KTO consultation? The KOKON-KTO consultation aims to give interested patients the opportunity to receive information and recommendations concerning complementary and integrative medicine and further supportive treatments from their oncology physician. It should be possible to integrate the consultation into the physician's everyday work. The duration of 20 minutes is designed to enable this.

What opportunities does the KOKON-KTO consultation offer? The planned timeframe means that no comprehensive discussion of the topic of complementary and integrative medicine is possible, but rather that the process must be focused. The consultation focusses on information and recommendations regarding evidence-based CIM treatments and general information on physical activity, relaxation and nutrition with the objective of better controlling symptoms, relieving symptoms and improving the quality of life.

How can the KOKON-KTO consultation be personalized? The information and recommendations that are communicated in the consultation can be adapted to suit the individual treatment situation and the previous use of complementary and integrative medicine by the respective patient. We can expect individualization to increase with increased experience in the execution of KOKON-KTO consultations.

Who should be offered a KOKON-KTO consultation? Patients should already be under cancer treatment by the consulting physician in order to be able to integrate the consultation usefully into the overall treatment context. The patients should also be interested in this topic. Other topics that may be hiding behind the desire to use complementary and integrative medicine (e.g. emotional topics such as fear of death or informational topics such as a need for information on the cancer treatment) should already have been discussed in other consultations.

When is a situation not suitable following the KOKON-KTO consultation? The setting that is introduced here is not suitable for patients who are looking for alternatives to the cancer treatment or who would like to know more about the details of selected CIM therapies. It is also not suitable in







order to discover which topic might lie behind the patient's wish to find out about complementary and integrative medicine.

What challenges may be faced in the course of the KOKON-KTO consultation? Different challenges can emerge in the course of the consultation that complicate a systematic consultation or that show that the planned consultation is not appropriate at this time. Challenges that can have an effect on the planned timeframe are discussed in the form of examples in the different elements of the systematic consultation. If emotional topics such as fear of death are broached for the first time during this consultation then this topic should be handled as a priority in a suitable context and the KOKON-KTO consultation should be rescheduled.

Example sentences if another topic needs to be given priority:

"We wanted to talk about complementary medicine today. However I can see that 'Topic XY' seems to be more important right now. I would suggest we discuss complementary medicine another time and talk about 'Topic XY' today.









Sections in the KOKON-KTO consultation guideline

This guideline presents the steps of the KOKON-KTO consultation (figure 1). Aspects of the consultation context (**C**-CONTEXT) are summarized in section **A**, then the 6 steps of the consultation are presented in section **B**. The consultation can be carried out in the order as shown. However, steps 2-5* can also be carried out variably in a different order or may also occur in the consultation several times.

- 1. INFORM
- 2. CAPTURE*
- 3. PRIORITIZE*
- 4. ADVISE*
- 5. DISCUSS*
- 6. CONCRETIZE ADVICE

The guideline ends with information of the monitoring of the consultation (M-MONITOR; Element C).

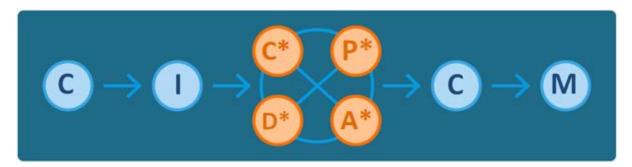


Figure 1: Steps of the KOKON-KTO consultation

A CONTEXT

The consultation should consider the general recommendations for good interaction between physician and patient. The following is a summary of the relevant aspect, which you will already be aware of for the most part:

Ideally, the consultation should be held in a quiet room where you will not be disturbed. If no rooms are free then a private area can be created using curtains or by turning away from other patients and speaking in a calm voice. Move so you are at eye level with your patient. An open body position, facing the patient, signals interest [1-4].

The kind of patient-physician interaction and your posture are important for the course of the consultation. Approach your patient in a communicative manner, showing interest and empathy and without judgment. Respect the cultural and language differences as well as the different value system of the person you are speaking to [3]. Adapt your explanations to the language level of your patient.

In order to keep to the timeframe the consultation is primarily physician-centered, which means that you mainly lead the discussion. However, there are steps in which you are the listener. The guideline makes suggestions for when you could take on a more speaking or more listening role. The medical







recommendations should be communicated as advice and not in a preaching manner. It is important here to pay close attention to the feelings and the level to which your patient is currently open and ready. Open questions are suitable to open the discussion and allow you to speak about knowledge of the current situation and about emotional topics. Closed questions are suitable to clarify understanding [2]. They can signal interest through active listening. Approving nods and exact or paraphrased repetition of what has been said support interested interaction with and an understanding of the specific situation of your patient [1].

If your patient moves away from the actual objective of the consultation but the topic is not a priority or if time becomes short, then closed questions, kept as concrete as possible, can help to re-establish focus. If you interrupt the flow of your patient's speech, then maintain eye contact and address him or her by name. Then briefly summarize what has been said [5]. You can politely inform your patient that they are moving away from the topic and that you cannot go into detail on other topics because of the timeframe of the consultation. If there is an opportunity, you can offer to discuss these topics at the next meetings instead.

B Steps of the KOKON-KTO consultation [3, 6, 7]

1. INFORM

Begin the consultation by informing your patient of the topic of the consultation and that you will have approximately 20 minutes for this discussion. Clarify in particular that complementary and integrative medicine will be discussed in this consultation as a supportive and additional treatment to the cancer treatment. You should also communicate that there are different treatments within complementary and integrative medicine that have different effects and side effects.

Adopt the role of primary speaker in this step. Plan approx. 2 minutes to INFORM.

Example sentences

Reason for the consultation:

"Today I would like to talk to you about complementary medicine and other supportive treatments such as physical activity and relaxation in relation to your cancer treatment."

"Today I would like to discuss with you how you can contribute yourself to promote your recovery and reduce side effects using treatments from the sector of complementary medicine, for example through measures relating to nutrition and physical activity, using herbal remedies or with treatments that contribute to relaxation and the minimization of stress reduction."

Expected duration of the consultation:

"We have approximately 20 minutes for the consultation."

Outline the contents of the consultation and the possible structure:

"I will explain what I understand complementary medicine to be and we can see what experience you have already had with it."

Note on the possible definition of complementary medicine: "Complementary medicine comprises many treatments that are used for cancer treatment and afterwards. It includes whole medical









systems such as traditional Chinese medicine (TCM) but also other treatments such as natural products used as supplements. The effects and side effects of complementary and integrative medicine treatments have been examined to differing extents and for this reason it is important to speak about individual treatments and not complementary medicine as a whole. However, I would like to give you information on nutrition and physical activity and on safe complementary medicine treatments. We can also find out if you are interested in any specific treatments."

CAPTURE

If you would like to personalize the consultation it is important to know your patient's current use of complementary and integrative medicine. To save time it can be helpful to have the patient fill out a questionnaire in advance. We recommend looking at the questionnaire briefly with the patient during the consultation and underlining to the patient your interest in his or her personal situation.

Challenge I: Having the patient name complementary and integrative medicine, treatments in which he or she is interested can be a challenge if you have a lack of knowledge of the treatments. Therefore, we would advise against explicitly enquiring about the patient's wishes. Explicit enquiry can also cost a lot of time and lengthen the consultation considerably.

Challenge II: If you have the feeling that this is a patient for whom the identification of previous use will take a long time within the consultation then you can move directly to the ADVISE section in order to be able to complete the consultation within the planned timeframe.

Challenge III: If you notice that fear of the side effects of the cancer treatment is most prevalent then you may be able to address this usefully during the consultation in reference to complementary medicine and supportive care. However, if the topic is clearly prevalent for the patient then you can also postpone the KOKON-KTO consultation and address only this topic.









Adopt the primary role of listener in this step. Plan approx. 4 minutes to CAPTURE.

Example sentences:

If you have used a questionnaire in advance: "We asked you to fill out a questionnaire in advance. Can we look at that together?"

If you have decided not to use a questionnaire or if the patient has not brought it with them: "It would be helpful for me to know which complementary medicine treatments you have already used or are using, so that I can give you suitable recommendations. Can you tell me about that?"

If treatments have already been used: "I can see you already have experience with complementary medicine. You are currently using >CIM treatment< / you have used >CIM treatment< previously."

If no treatments have yet been used: "I can see that you have not had any experience with complementary medicine before."

If the patient directly expresses the desire to hear about certain CIM treatments: "I am happy to write down "Treatment XY" and then we come back to that later in our discussion."

PRIORITIZE

If there are different CIM topics and you have the feeling that this cannot be realized within the planned duration of 20 minutes then decide on one or several main points for the KOKON-KTO-Consultation. There are two ways to do this:

- a.) The patient named preferences in the CAPTURE step. Prioritize these desires and choose a reasonable number of treatments together with the patient. If you have the opportunity to carry out further consultations then you can also offer to discuss the other treatments at a later date.
- b.) The patient has a general or not yet specified interest in CIM. In this case you can carry out 'internal' prioritization and share your prioritization process with the patient if suitable (e.g. based on frequency / severity of symptoms).

Challenge I: If many symptoms are named or the patient asks about a lot of CIM therapies and if he or she insists that they are all discussed then you can postpone some of them to later consultations. It could be useful to concentrate on the patient's current complaints to an extent. You can also use the KOKON-KTO leaflet from the step 'Concretize advice' and reference the fact that the websites will surely include information on the treatments.

Challenge II: If the patient already has a lot of experience with complementary medicine and seems to be knowledgeable then you can mainly provide information on the treatments for which there is positive evidence.

Challenge III: If the patient is currently receiving a CIM therapies that could interact with the cancer treatment then make a note of this and mention it at the best possible point of the consultation. We recommend first providing information on other, safe opportunities (ADVISE step), before explaining the possible interaction problem and advising against the treatment as necessary.







Adopt the primary role of speaker in this step. Plan approx. 2 minutes to PRIORITIZE.

Example sentences:

If the patient has not expressed any concrete wishes: "I know your treatment situation well and I will incorporate this and your prior experience with complementary medicine into my recommendations."

"There are different complementary medicine therapies that are generally considered to be recommended. I would like to make a recommendation relating to your situation."

If a desire has been expressed, directly or indirectly:

"I think that >SymptomX< bothers you most. Did I understand correctly?"

"It seems to me that you are very interested in >CIM treatment X<. Am I right?"

4. ADVISE

Physical movement and relaxation are recommended for cancer patients in principle. You should therefore give general recommendations on physical activity and relaxation. You can also give recommendations here in relation to nutrition if the situation and time allow. Try to adapt your nutrition recommendations roughly to the treatment and illness situation in order to stay within the timeframe. If you are knowledgeable about nutritional recommendations then a further consultation may be suited to this. However, you can also skip nutritional recommendations if the patient does not actively express interest or if there is an opportunity to refer him or her for a nutrition consultation.

If available and known to you then you can provide evidence-based and symptom-specific complementary medicine recommendations here and talk about effects and possible interaction risks with the patient's cancer treatment in this respect.

Challenge I: If you have symptom-specific recommendations on possible cancer treatment side effects then you should consider whether explaining these side effects that have not yet presented themselves could also have a nocebo effect. It is different if the patient actively mentions possible side effects and you have recommendations in that regard. In this case your recommendations might even reduce nocebo effects.

Challenge II: If you have already addressed the topic of physical activity in a prior consultation then you can cover the implementation into daily life in this consultation and focus on detailed recommendations as necessary. Thus, a flexible approach to the sections of capture, prioritize, advise and discuss could be useful here.









Adopt the role of primary speaker in this step. Plan approx. 5 minutes to ADVISE.

Example sentences:

"Before I address the complementary medicine therapies that you have mentioned again, I would like to inform you about the complementary medicine and other supportive treatments that are generally recommended and for which there are positive scientific findings."

"There are different ways of doing yourself some good besides the cancer treatment. There is particular good scientific evidence that physical activity and relaxation can be very helpful for cancer patients."

Optional:

"I would also be pleased to give your nutrition recommendations for your current situation."

"In your situation of >SymptomX< >CIMtreatmentX< or >CIMtreatmentY< can be beneficial."

5. DISCUSS

Now you should give information, if you have the knowledge, regarding selected complementary medicine therapies (information from the CAPTURE step). Discuss previous use with the patient with regard to the recommendations made beforehand. Address the effectiveness of the CIM therapies, possible side effects, interactions and costs where necessary. It is possible that there will be treatments you recommend but also treatments that you do not recommend (e.g. because of a lack of evidence) but that are still safe. The right thing in this case is to neither recommend nor advise against but rather to accept the use. Then summarize the recommendations again. It is important to show empathy here, not to judge the patient's decisions and to respect them. Be aware that your words can cause both placebo and nocebo effects. Placebo effects (e.g. through a recommendation) are desirable while nocebo effects (e.g. from direct warnings) should be avoided where possible.

Challenge I: It is possible that you would like to advise the patient against a treatment that he or she is currently using because it has a high level of potential interaction with the cancer treatment. It is important here to offer a good alternative and to explain to the patient in an understandable manner why you are advising the change. It would be good to avoid nocebo effects where possible Challenge II: If the patient has requested information in the CAPTURE step on complementary medicine treatments that you are not familiar with then you can tell the patient this and offer a solution for this situation.







Adopt the role of primary speaker in this step. Plan approx. 5 minutes to DISCUSS.

Example sentences:

Recommendation:

"I think this is a good decision."

Accept:

"We don't know very much about this treatment, it doesn't seem to be dangerous and it could help you. However it has not undergone sufficient scientific testing. If you would like to use / try the treatment then I can accept your decision."

Advise against:

"I understand that you (would like to) use >CIM treatmentX< but based on my experience / the scientific findings I would (urgently) advise you against it because....and recommend >TreatmentY< to you in its place, because... or ... I do not support >CIM treatment< because...or ... I do not consider >CIM treatment< to be indicated / useful because ...or ... I am concerned because...."

Unknown treatment:

"Complementary medicine is broad and I know more about the treatments and preparations that have shown positive results in studies. I don't know of any scientific tests with >CIM treatmentX<. I would be pleased to look into it and report back to you at our next consultation."

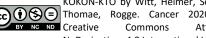
">CIM treatment< might not be paid by the health insurance company and could be associated with a higher financial cost to you."

"I can see that you are preoccupied by the topic >CIM treatmentX<. I would like to offer you a further appointment to approach the topic together so that we have enough time to talk about it."

6. CONCRETIZE ADVICE

Briefly summarize the contents of the consultation in order to eliminate any remaining ambiguities. State concrete advice and offer support for (practical) realization, ideally by giving recommendations for suppliers. If you do not have any concrete advice then give the patient the flyers with important criteria for reputable providers of CIM treatments.









Adopt the role of primary speaker in this step. Plan approx. 2 minutes to CONCRETIZE ADVICE.

Example sentences:

Adopt the role of primary speaker in this section.

"Allow me to briefly summarize our discussion."

"What have I forgotten? Now I would like to discuss possible ways to implement the recommendations." "I would also like to give you a flyer with recommendations on how to find the right provider for >CIM treatmentX<."

"I would also like to give you an information flyer on helpful websites for complementary and integrative treatments for cancer. It lists different website and there is something for every user group, whether you have previous experience or not. The websites have been screened in advance by experts. So you can be sure that they are trustworthy."

"I would like to support you and so it would be good if you could update me on the complementary medicine therapies you undertake in future."

C MONITOR:

Don't forget to document the consultation afterwards and to also record the usage behavior going forwards.









Literature

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