

# Yearly report to Ekhagastiftelsen for 2021

Application number: 2020-76

## Project title

Development of an evidence-based decision aid on Complementary and Alternative Medicine (CAM) for parents of children with cancer

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## Background

### *Aim*

The aim of this study is to develop, implement, and validate an evidence-based decision aid on CAM use for supportive care in childhood cancer in Norway. We hypothesize that this decision aid will be helpful for parents and health care professionals in their decision-making and discussion of CAM use and will contribute to patient safety.

### *Method and theory*

The study design is a mixed-methods approach and will be guided by the criteria of decision aid development as outlined by the International Patient Decision Aid Standards (IPDAS) (1). The study will be designed in four phases. In Phase 1, the needs of parents in Norway will be identified in a broader sample through a survey among members of the Norwegian Children's Cancer Society. In Phase 2, a systematic review and, if possible, a meta-analysis will be performed on the efficacy/effectiveness and safety of CAM modalities for supportive care in children with cancer. In addition, in-depth interviews will be performed to map the clinical experiences of pediatric oncologists. In Phase 3, the decision aid will be developed using the seven-step GRADE method. Phase 4 will comprise field-testing and evaluation of the decision aid.

### **Achievements and partial results (2001)**

To map parents' needs, our study team is currently conducting a survey among members of the Children's Cancer Society (phase 1). So far, 116 participants have completed the questionnaire, and preliminary results show that massage therapy (18%), psychotherapy (14%), physiotherapy (9%), acupuncture (8%), and healing (6%) are the top five most popular CAM modalities. The top five mostly used biological remedies are multivitamins (76%), vitamin D (54%), Omega 3 (31%), vitamin C (22%), and turmeric and garlic (15%). We will close the data collection at the end of this year (2021).

In line with IPDAS' phase 2, we have conducted a systematic review and meta-analysis of randomized controlled trials (RCT) and a systematic review of observational studies (2, 3). The review of RCTs demonstrated the acceptance and beneficial effects of CAM such as acupuncture, hypnosis, yoga, art and music therapy to manage cancer-related symptoms such as anxiety, vomiting and nausea, to improve functional mobility, and physical activity levels. Based on data from the observational study, these modalities were considered safe. Both papers have been submitted and are now in a review process at the BMC Complementary Therapies and Medicine, a level 2 journal according to the Norwegian system.

Our research team is currently performing in-depth interviews with pediatric oncology experts (nurses and doctors) and CAM providers. So far, we have interviewed 11 health care providers in Norway and the USA/Canada: pediatric oncology doctors (n=3); CAM providers (two acupuncturists, one healer, and one music therapist (n=4)); pediatric oncology nurses (n=3), and one play therapist (n=1). The plan is to include a total of 20 participants and complete the data collection before end of the year 2021. These achievements are in line with the timeline of the study.

### **Aims and plan for 2022**

The aim for next year (2022) is to develop the decision aid. First, our team will analyze the data and draft a paper based on data collected among members of The Children's Cancer Society. Secondly, we will analyze the data and draft a paper based on the qualitative interviews with health care providers. These papers will be published in international peer-review journals. Information gathered from these studies constitutes the basic information in the decision aid. To avoid double publication of information, we will include information already available at <https://cam-cancer.org/en> NAFKAM's *nettleksikon* (online dictionary).

### **References**

1. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. International Patient Decision Aids Standards (IPDAS) Collaboration. *BMJ*. 2006;Aug 26;333(7565):417.
2. Mora DC, Kristoffersen AE, Overvåg G, Jong MC, Mentink M, Liu JP, et al. Complementary and alternative medicine (CAM) modalities used to treat adverse effects of anti-cancer treatment among children: A systematic review and meta-analysis of randomized control trials. *BMC Complementary Medicine and Therapies*. 2021;Submitted for publication.
3. Mora DC, Overvåg G, Jong MC, Kristoffersen AE, Stavleu DC, Liu JP, et al. Safety of Complementary and Alternative Medicine (CAM) modalities among children with cancer who suffer from adverse effects of conventional cancer treatment: A systematic review of observational and qualitative studies. *BMC Complementary Medicine and Therapies*. 2021;Submitted for publication.