Communication about Complementary Medicine in Oncology



Marit D.C. Mentink

RADBOUD UNIVERSITY PRESS

Radboud Dissertation Series

Communication about Complementary Medicine in Oncology

Marit D.C. Mentink

Financial support for this thesis was provided by Dutch Cancer Society (grant number 12566). The research presented in this thesis was conducted at Nivel, Netherlands Institute for Health Services Research, Utrecht, The Netherlands. Nivel participates in the Netherlands School of Public Health and Care Research (CaRe), which is acknowledged by the Royal Netherlands Academy of Arts and Sciences (KNAW).

Author: Marit Dianna Corina Mentink

Title: Communication about Complementary Medicine in Oncology

Radboud Dissertations Series

ISSN: 2950-2772 (Online); 2950-2780 (Print)

Published by RADBOUD UNIVERSITY PRESS Postbus 9100, 6500 HA Nijmegen, The Netherlands www.radbouduniversitypress.nl

Design: Proefschrift AIO | Annelies Lips

Cover: Guntra Laivacuma, Marit Mentink, Ruben de Roo

Printing: DPN Rikken/Pumbo

ISBN: 9789493296862

DOI: 10.54195/9789493296862

Free download at: www.boekenbestellen.nl/radboud-university-press/dissertations

© 2024 Marit Dianna Corina Mentink

RADBOUD UNIVERSITY PRESS

This is an Open Access book published under the terms of Creative Commons Attribution-Noncommercial-NoDerivatives International license (CC BY-NC-ND 4.0). This license allows reusers to copy and distribute the material in any medium or format in unadapted form only, for noncommercial purposes only, and only so long as attribution is given to the creator, see http://creativecommons.org/licenses/by-nc-nd/4.0/.

Communication about Complementary Medicine in Oncology

Proefschrift ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen

op gezag van de rector magnificus prof. dr. J.M. Sanders,
volgens besluit van het college voor promoties
in het openbaar te verdedigen op
maandag 4 november 2024
om 12.30 uur precies

door

Marit Dianna Corina Mentink geboren op 28 juli 1993 te Zwolle

Promotor:

Prof. dr. A.M. van Dulmen

Copromotoren:

Dr. J. Noordman (Nivel)

Dr. J.N.H. Timmer-Bonte

Manuscriptcommissie:

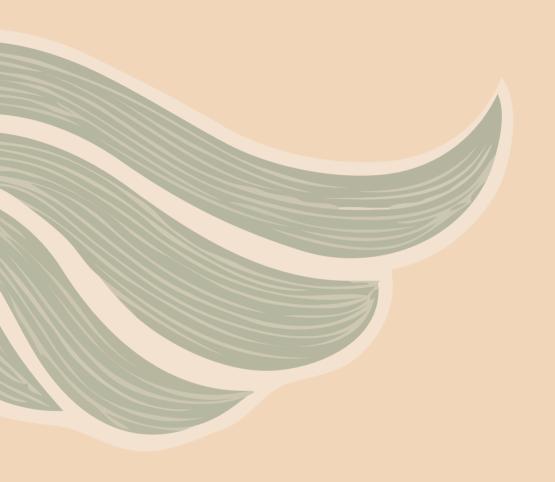
Prof. dr. Y.M.P. Engels

Prof. dr. E.M.A. Smets (Amsterdam UMC)

Prof. dr. V.C.G. Tjan-Heijnen (Maastricht UMC+)

TABLE OF CONTENTS

Chap	pter I	General introduction	7	
Chaj	pter II	Towards an open and effective dialogue on complementary medicine in oncology: protocol of patient participatory study 'COMMON'	17	
Chapter III		How is complementary medicine discussed in oncology? Observing real-life communication between clinicians and patients with advanced cancer		
Chapter IV		Communication and information about complementary medicine in oncology: experiences and needs of patients and healthcare providers		
Chapter V		Interprofessional contact with conventional healthcare providers in oncology: a survey among complementary medicine practitioners		
Chaj	pter VI	The effects of complementary therapies on patient-reported outcomes: an overview of recent systematic reviews in oncology	111	
Chapter VII		Fostering the conversation about complementary medicine in oncology consultations: development and evaluation of communication tools for patients		
Chap	pter VIII	Summary and general discussion	181	
Appe	endices		197	
I.	Summar	y in Dutch (Nederlandse samenvatting)	198	
II.	Evaluatio	on by the co-researchers	201	
		n data management		
IV. List of pu		publications		
V. Portfolio		0		
VI. Curriculi				
VII. Acknowl		ledgements (Dankwoord)		



CHAPTER I GENERAL INTRODUCTION

COMPLEMENTARY MEDICINE

The World Health Organization (WHO) states that complementary medicine is an important and underestimated source in the prevention and management of chronic disease [1]. The current challenges posed to the healthcare system, such as aging and rising costs, have led to increased popularity of complementary medicine [1]. Complementary medicine refers to practices, products or health systems that are used alongside standard medical care [2]. Examples of complementary medicine practices are mind-body therapies (e.g., meditation or yoga) or manipulative therapies (e.g., massage or chiropractic therapy). Complementary medicine products can consist of vitamins, supplements, botanicals, special foods or diets. Examples of health systems include Traditional Chinese, ayurvedic or naturopathic medicine. The integration of safe and effective complementary medicine practices into conventional healthcare is often referred to as "integrative medicine" [2]. Integrative medicine is characterized by patient-centredness and a holistic view that addresses mental, physical and spiritual health. When complementary medicine is used in place of standard medical care, it is referred to as "alternative medicine". Only 0.01% of patients with cancer were found to use alternative medicine to treat or cure their cancer [3]. Although patients have the right to refrain from conventional treatment, alternative medicine is often surrounded by fraudulent practices, and misleading information and thus may impair patient safety [4]. This thesis focuses on complementary medicine used alongside standard medical care, and not on alternative medicine.

Complementary medicine use in patients with cancer

Cancer disease and its treatment often impose serious burdens, such as fatigue, nausea and pain, which affect a person's quality of life. The alleviation of such adverse effects is one of the most important reasons for the use of complementary medicine by patients with cancer [2]. In addition, the use of complementary medicine can give patients with cancer a sense of control over their own health. Approximately half of the patients with cancer in Western countries use complementary medicine alongside standard anticancer treatment [3]. The demographic factors associated with increased complementary medicine use in patients with cancer are being female, having a higher education level, being younger and having a higher income [3, 5]. Patients with breast cancer seem to be the predominant users of complementary medicine among cancer patient populations [5]. Biologically-based complementary medicine, such as herbs, vitamins and special foods or diets, followed by mind-body medicine is most commonly used among patients with breast cancer [5].

Safety and effectiveness

Some complementary medicine practices are quite thoroughly studied and found to be safe and effective for use by patients with cancer. The Society of Integrative Oncology (SIO) has published four evidence-based guidelines for the incorporation of complementary therapies into conventional oncology clinical practice [6-9]. Examples of recommendations in these guidelines are the use of acupuncture to relieve pain [6] and the use of mindfulness-based interventions to manage anxiety and depressive symptoms in patients with cancer [8]. However, the use of complementary medicine can also have harmful effects or interfere with standard anticancer treatment. For instance, St. John's wort, an herbal preparation frequently used to improve sleep or mood, can alter the effects of chemotherapy or cause adverse effects such as dizziness or diarrhoea [10]. Apparently, 'natural means safe' does not always seem to hold true [11].

TALKING ABOUT COMPLEMENTARY MEDICINE IN ONCOLOGY

There are three important reasons why complementary medicine should be a topic of discussion in oncology. First, to ensure that all patients with cancer are aware of the existence of safe and effective complementary therapies. This will avoid unnecessary suffering from symptoms that could have been prevented or alleviated by evidence-based complementary medicine recommended in international guidelines [6-9]. Second, to avoid adverse or interaction effects from complementary medicine use because not all complementary medicine is safe to use for patients with cancer [10, 11]. Third, to enhance patient-centredness in cancer care. Historically, medicine was mainly physician-oriented. The contemporary movement towards patient-centred care takes into account the goals, preferences and values of individual patients [12]. Effective communication, the cornerstone of patient-centred medicine, can be reinforced by healthcare providers gathering clinical and contextual information about a patient, encouraging patient involvement in decision-making and ensuring that a patient's needs are met [13]. Thus, communication about complementary medicine use can enhance the delivery of effective, safe and patient-centred cancer care.

Patient-provider communication

In a substantial proportion of oncology consultations, the topic of complementary medicine use is not discussed [14, 15]. Patients with cancer seem hesitant to disclose complementary medicine use to their healthcare provider, with reported nondisclosure rates as high as 77% [16-18]. Reasons for nondisclosure are disapproval,

disinterest or inability to help by the healthcare provider, or patient's unawareness of the relevance of discussing complementary medicine [17]. If the topic of complementary medicine is discussed, this is often on the initiation of patients [14, 19, 20]. Patients with cancer express the need for guidance and trusted sources about complementary medicine [15]. Their information and decision-making needs with regard to complementary medicine do not seem to be met by healthcare providers. This places patients with cancer at risk for exposure to online misleading information about complementary medicine [21].

Less than 20% of healthcare providers in oncology feel knowledgeable about complementary medicine [15]. They often do not feel confident in discussing the topic with patients [19, 22, 23]. The multitude of complementary therapies and rapid increase in publications make it difficult for healthcare providers to stay up-to-date on the topic [24]. In addition, healthcare providers have varying opinions and attitudes towards complementary medicine [20, 22]. For instance, some oncologists believe that complementary medicine does not belong in conventional healthcare or discredited complementary medicine because of a (perceived) lack of scientific evidence [20]. Other oncologists do talk about complementary medicine with their patients to foster openness about reasons for complementary medicine use, patient burden of symptoms or side-effects or protection from health and financial risks associated with complementary medicine use.

A longer visit duration, more patient engagement, less clinician verbal dominance and patient-centred communication seem to increase the chances of a discussion about complementary medicine during a consultation [14]. Consultations in which complementary medicine is discussed are associated with increased visit satisfaction among both patients and healthcare providers [14].

Interprofessional communication

To optimize multidisciplinary cancer care, it is important for healthcare providers and complementary medicine practitioners to communicate about mutual patients. Such interprofessional communication can prevent the disappearance of valuable medical information in the metaphorical "Bermuda Triangle" between patients, healthcare providers and complementary medicine practitioners [25]. However, interprofessional communication between healthcare providers in oncology and complementary medicine practitioners is rare and seems to be impacted by factors such as medical dominance, role clarity and education [25, 26].

COMPLEMENTARY MEDICINE FOR CANCER PATIENTS IN THE NETHERLANDS

In the Netherlands, patients with cancer often make use of psychosocial services, dietetics and physical therapy alongside their conventional treatment. These types of care can be considered part of conventional medicine, although they are not or are only partially reimbursed by healthcare insurers. Complementary medicine practices such as acupuncture or yoga seem less integrated into cancer care. The services provided by complementary medicine practitioners take place mainly in the private sector. Some types of complementary medicine, such as acupuncture, chiropractic, herbal medicine, homeopathic medicine, naturopathy and osteopathy, are reimbursed in supplementary healthcare insurance packages. The Netherlands has no national policy on complementary medicine [1], although herbal medicine is regulated under the Medicine Law (Geneesmiddelenwet).

The only information available on complementary medicine use among patients with cancer in the Netherlands stems from two surveys administered among members of cancer patient societies in 2018. The first survey was conducted among 750 members of the Dutch Breast Cancer Society and showed that 65% of the patients used complementary medicine [27]. The most commonly used were dietary supplements, herbal or homeopathic medicine, mindfulness and relaxation exercises. A survey among 229 members of the Hematon Foundation, a Dutch patient advocacy group for patients with blood cancers, indicated that 43% of the participants used complementary medicine [28]. In total, 29% of patients with breast cancer and 38% of patients with blood cancers did not discuss complementary medicine use with their healthcare provider.

THESIS OUTLINE

In this thesis, we aimed to explore and strengthen communication about complementary medicine in oncology to ensure safe, effective and patient-centred cancer care. The main research questions addressed are as follows:

- How is complementary medicine discussed in oncology care in the Netherlands and what are the barriers to and facilitators of communication experienced by patients, healthcare providers and complementary medicine practitioners?
- Which complementary therapies are effective and safe for patients with cancer?
- How can patients with cancer be supported in discussing complementary medicine with their healthcare provider?

Chapter II outlines the study protocol that was drafted prior to the execution of the five studies described in this thesis. The studies have a participatory design in which the researchers collaborate with a group of patient experts as 'co-researchers'. To enhance communication about safe and effective complementary medicine during oncology consultations, we first need to gain insight into actual conversations about this topic in oncology practice. In **Chapter III**, we report whether, by whom and how the topic of complementary medicine was discussed in audio-recorded real-life consultations between patients with cancer and their healthcare providers. Although international research has shown that patients with cancer and oncology healthcare providers experience barriers to communication about complementary medicine, such a needs assessment in the Netherlands is lacking. Chapter IV therefore assesses the experiences and needs of patients with cancer and healthcare providers in the Netherlands considering communication and information provision about complementary medicine. Semi-structured interviews with patients, physicians and nurses provided insight into their underlying patterns and feelings towards discussing complementary medicine. The integration of their perspectives revealed a clear need for support in communication about complementary medicine in oncology care. For healthcare providers, it is important to gain insight into which therapies are effective and safe for patients with cancer. Chapter V embarks on the topic of interprofessional contact from the perspective of complementary medicine practitioners. An online survey was distributed among complementary medicine practitioners in the Netherlands. The survey contained questions about experiences with interprofessional contact and about the importance attached to patient disclosure of complementary medicine use to their healthcare providers. Chapter VI provides an overview of the effects of twelve different complementary therapies on several patient-reported outcomes. This overview summarizes the quality and

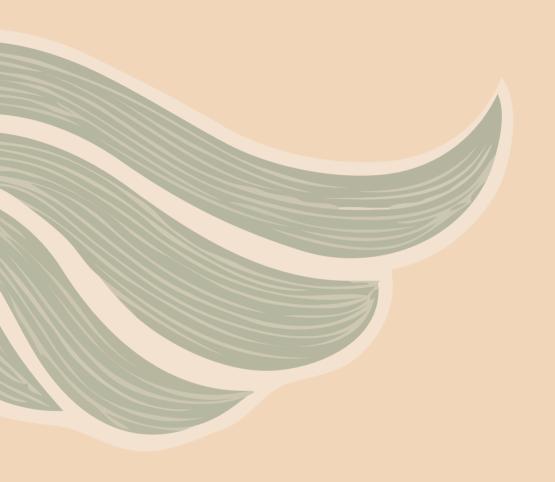
results of one-hundred systematic reviews published over the last decade. This can support healthcare providers in discussing complementary medicine with their patients. In Chapter VII, we describe the evaluation of two tools that intended to guide patients in introducing and discussing the topic of complementary medicine during oncology consultations. The first tool consists of a question prompt sheet, and the second tool is a slideshow that visually presents to patients with cancer why it is important to discuss complementary medicine use with their healthcare providers. In addition to strengthening patient-provider communication, it is important to consider interprofessional contact between healthcare providers and complementary medicine practitioners. In Chapter VIII, the findings are summarized. This final chapter also contains a general discussion of the findings. A summary in Dutch is included in **Appendix I**. In **Appendix II**, we provide a summary of the experiences of eight (former) patients with cancer who throughout the research project collaborated with the researchers as 'co-researchers'. A dual rationale underlies the involvement of co-researchers actively contributing to research processes. First, because patients are affected by the implementation of research knowledge in healthcare, they have the right to exert influence [29]. "Nothing about us, without us" is a slogan frequently used in this context. Second, working with individuals who have first-hand experience regarding their health, healthcare and contextual determinants, has the potential to contribute to more adequate research knowledge. By being healthcare users themselves, patients have a unique 'insider' perspective and can more easily interpret data [30].

REFERENCES

- World Health Organization (WHO), WHO global report on traditional and complementary medicine 2019.
 2019: World Health Organization.
- National Cancer Institute (NCI), Complementary and Alternative Medicine 2023 [cited 15 Feb 2024; Available from: https://www.cancer.gov/about-cancer/treatment/cam.
- 3. Keene, M.R., et al., Complementary and alternative medicine use in cancer: A systematic review. Complementary therapies in clinical practice, 2019. **35**: p. 33-47.
- Raposo, V.L., Complementary and alternative medicine, medical liability and the proper standard of care. Complementary Therapies in Clinical Practice, 2019. 35: p. 183-188.
- 5. Wanchai, A., J.M. Armer, and B.R. Stewart, Complementary and alternative medicine use among women with breast cancer: a systematic review. Clinical journal of oncology nursing, 2010. 14(4).
- Mao, J.J., et al., Integrative medicine for pain management in oncology: society for integrative oncology-ASCO guideline. Journal of Clinical Oncology, 2022. 40(34): p. 3998-4024.
- 7. Greenlee, H., et al., Clinical practice guidelines on the evidence-based use of integrative therapies during and after breast cancer treatment. CA: a cancer journal for clinicians, 2017. **67**(3): p. 194-232.
- 8. Carlson, L.E., et al., Integrative oncology care of symptoms of anxiety and depression in adults with cancer: Society for Integrative Oncology-ASCO Guideline. Journal of Clinical Oncology, 2023. 41(28): p. 4562-4591.
- Deng, G.E., et al., Complementary therapies and integrative medicine in lung cancer: diagnosis and management of lung cancer: American College of Chest Physicians evidence-based clinical practice guidelines. Chest, 2013. 143(5): p. e420S-e436S.
- de Wit, L., S. Jeurissen, and W. Chen, Risk assessment of herbal preparations containing St John's wort. 2021.
- National Center for Complementary and Integrative Health (NCCIH). Natural Doesn't Necessarily Mean Safer, or Better. 2024 [cited 15 Feb 2024; Available from: https://www.nccih.nih.gov/health/know-science/natural-doesnt-mean-better.
- 12. Laine, C. and F. Davidoff, Patient-centered medicine: a professional evolution. Jama, 1996. 275(2): p. 152-156.
- Makoul, G., et al., Reinforcing the humanity in healthcare: The Glasgow Consensus Statement on effective communication in clinical encounters. Patient Education and Counseling, 2024. 122: p. 108158.
- 14. Roter, D.L., et al., Communication predictors and consequences of Complementary and Alternative Medicine (CAM) discussions in oncology visits. Patient education and counseling, 2016. 99(9): p. 1519-1525.
- King, N., et al., Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. Integrative cancer therapies, 2015. 14(6): p. 515-524.
- 16. Rausch, S.M., et al., Complementary and alternative medicine: use and disclosure in radiation oncology community practice. Supportive Care in cancer, 2011. 19: p. 521-529.
- 17. Davis, E.L., et al., Cancer patient disclosure and patient-doctor communication of complementary and alternative medicine use: a systematic review. The oncologist, 2012. 17(11): p. 1475-1481.
- 18. Oh, B., et al., Patient-doctor communication: use of complementary and alternative medicine by adult patients with cancer. Journal of the Society for Integrative Oncology, 2010. 8(2).
- 19. Lee, R.T., et al., National survey of US oncologists' knowledge, attitudes, and practice patterns regarding herb and supplement use by patients with cancer. Journal of Clinical Oncology, 2014. **32**(36): p. 4095.

1

- 20. Corina, G., H. Christine, and G. Klein, Oncologists' experiences of discussing complementary and alternative treatment options with their cancer patients. A qualitative analysis. Supportive Care in Cancer, 2016. 24: p. 3857-3862.
- 21. Bianchini, C., et al., Avoiding misleading information: a study of complementary medicine online information for cancer patients. Library & Information Science Research, 2019. 41(1): p. 67-77.
- 22. Chang, H.Y. and H.L. Chang, A review of nurses' knowledge, attitudes, and ability to communicate the risks and benefits of complementary and alternative medicine. Journal of clinical nursing, 2015. **24**(11-12): p. 1466-1478.
- 23. Jones, E., et al., Exploring the use of complementary and alternative medicine in cancer patients. Integrative cancer therapies, 2019. **18**: p. 1534735419846986.
- 24. Ng, J.Y., Insight into the characteristics of research published in traditional, complementary, alternative, and integrative medicine journals: a bibliometric analysis. BMC Complementary Medicine and Therapies, 2021. 21(1): p. 1-31.
- Schiff, E., et al., Bridging the physician and CAM practitioner communication gap: suggested framework for communication between physicians and CAM practitioners based on a cross professional survey from Israel. Patient education and counseling, 2011. 85(2): p. 188-193.
- 26. Nguyen, J., et al., Conventional and complementary medicine health care practitioners' perspectives on interprofessional communication: A qualitative rapid review. Medicina, 2019. 55(10): p. 650.
- 27. Borstkanker Vereniging Nederland (BVN), 65 procent van de borstkanker patienten maakt(e) gebruik van complementaire zorg 2018 [cited 4 March 2024; Available from: https://www.borstkanker.nl/nieuws/65 -van-de-borstkankerpatienten-maakte-gebruik-van-complementaire-zorg.
- 28. Hematon. *Grote groep patienten maakt gebruik van complementaire zorg*. 2018 [cited 4 March 2024; Available from: https://www.hematon.nl/nieuwsberichten/grote+groep+patienten+maakt+gebruik +van+complementaire+zorg.
- 29. Malterud, K. and K.T. Elvbakken, *Patients participating as co-researchers in health research: a systematic review of outcomes and experiences*. Scandinavian journal of public health, 2020. **48**(6): p. 617-628.
- 30. Liu, P., S. Currie, and J. Adamyk-Simpson, What are the most important dimensions of quality for addiction and mental health services from the perspective of its users? Patient Experience Journal, 2018. 5(1): p. 106-114.



CHAPTER II

Towards an open and effective dialogue on complementary medicine in oncology. Protocol of patient participatory study 'COMMON'.

Marit Mentink, Janneke Noordman, Martine Busch, Liesbeth van Vliet, Johanna (Anja) Timmer-Bonte, Sandra van Dulmen

> BMJ Open. 2021 Oct 20; 11(10): e053005. doi: 10.1136/bmjopen-2021-053005. PMID: 34670766.

ABSTRACT

Introduction

Approximately half of patients with cancer use some form of complementary medicine alongside conventional cancer treatment. The topic of complementary medicine often remains undiscussed in consultations between patients with cancer and their healthcare providers. This results in increased risks for adverse or interaction effects and decreased access to the benefits of evidence-based complementary medicine for patients with cancer. This paper describes the design of patient participatory study titled 'COMMON' that aims to explore and enhance open and effective communication about complementary medicine in oncology. The study is carried out in collaboration with 12 (former) patients with breast cancer as coresearchers.

Methods and analysis

The study complies with the six steps of the intervention mapping framework. Three non-academic hospitals recruit participants (patients with cancer, oncology healthcare providers and managers) for interviews about the organisation, experiences and needs regarding complementary medicine. To assess communication about complementary medicine, recorded oncology consultations are analysed. For an overview of evidence-based complementary medicine available to patients with cancer, a review of reviews is conducted on the evidence on cancer patient-reported outcomes of complementary medicine frequently used by patients with cancer, supplemented with an online search and survey among organisations and persons providing complementary medicine to patients with cancer. Together, these steps generate input for the development of a toolbox that supports an open and effective discussion on complementary medicine in oncology. In a pilot study, acceptability and usability of the toolbox are assessed among patients with cancer and oncology healthcare providers. Dissemination of the toolbox is covered by the commitment of stakeholder parties.

Ethics and dissemination

The Medical Ethics Committee Arnhem-Nijmegen declared the study was exempted from formal approval under the Dutch Medical Research Involving Human Subjects Act. The results will be disseminated through open-access, peer-reviewed publications, stakeholder-reporting and presentations at relevant conferences.

INTRODUCTION

The use of complementary medicine among patients with cancer has become increasingly common over the last decades [1]. Nowadays, approximately half of all oncology patients use complementary medicine alongside conventional cancer treatment [1-3]. However, the topic of complementary medicine remains undiscussed in the majority of oncology consultations [4-6].

Complementary medicine in oncology entails health approaches that are not typically part of conventional cancer treatments, but are used to complement them [7, 8]. This contrasts with alternative medicine replacing conventional cancer treatment. Together, they are often referred to as CAM (Complementary and Alternative Medicine). The current study focuses solely on complementary medicine and adopts a broad definition, encompassing all approaches that complement biomedical treatment of the oncological disease and that aim to contribute to the physical, mental or social well-being of the patient. The definition includes approaches that were previously considered complementary, but are now regularly incorporated in conventional supportive care (eg, exercise and psychological therapies).

Complementary medicine approaches frequently used by patients with cancer in Western countries are mind-body therapies, massage, nutrition counselling and acupuncture [9]. Patients with cancer state several reasons for using complementary medicine, such as improving physical and emotional well-being, quality of life or reducing side-effects from conventional treatment [10]. In the field of conventional medicine, the added value of complementary medicine is still hotly debated. Complementary medicine is a heterogeneous field and for many approaches neither effectiveness nor safety have been sufficiently proven. Some supplements or herbs can have adverse effects or interact with conventional cancer treatment [11, 12]. On the other hand, a growing body of evidence shows that particular types of complementary medicine can be efficacious and safe to use for patients with cancer, such as acupressure for reducing chemotherapy-induced nausea and vomiting [13]. A few complementary medicine approaches receive recommendation in oncology guidelines [14], implying sufficient evidence.

However, 20%-77% of the patients with cancer do not disclose their use of complementary medicine to conventional healthcare providers [15]. In 2017, the Dutch Breast Cancer Association administered a survey among 750 members showing that 65% of the patients use complementary medicine. Of those patients, 29% did not discuss their complementary medicine use with their healthcare provider [16]. A

similar survey among 229 Dutch patients with haematological cancer reported that 43% of the respondents use complementary medicine, of which 38% did not discuss this with their healthcare provider [17]. The main reasons for nondisclosure stated by patients with cancer are related to healthcare providers' disapproval, disinterest, lack of inquiry or inability to provide information [15]. Conventional healthcare providers often feel uncomfortable discussing complementary medicine due to limited education and knowledge on the topic [3, 18]. In view of the frequent use of complementary medicine among patients with cancer, not discussing the topic in oncology is problematic. It increases risks for patients' exposure to misleading information, adverse effects due to inappropriate use and interactions with conventional cancer treatment [12, 19]. Additionally, some patients may remain devoid of evidence-based complementary medicine that could potentially support them.

It is well known that effective communication, the cornerstone of patient-centred care, can positively influence physical and psychosocial aspects of a patients' health [20-22]. An effective discussion about complementary medicine consists of exchanging adequate information, responding to emotional needs and managing uncertainty of patients [19]. Furthermore, the healthcare provider can play a significant role in informed decision-making about complementary medicine use. In an open dialogue on the topic, both benefits and risks or the lack of evidence thereof, can be acknowledged [23]. Open communication about complementary medicine fosters mutual trust between patients and healthcare providers and encourages patients to discuss their (interest in) complementary medicine use. Both patients and clinicians are found to report higher satisfaction with the oncology consultation when complementary medicine was discussed [6].

It seems evident that communication about complementary medicine decreases risks and potentially maximises positive outcomes for patients with cancer. In some countries, tools have been developed to support oncology healthcare providers in discussing complementary medicine, such as educational courses or decision aids [24-27]. A recent study reported on a complementary therapy education seminar for patients with cancer in Canada [28]. These supporting tools cannot simply be generalised across countries, given differences in language, culture and healthcare systems. To the best of our knowledge, there are no nationwide tools available for healthcare providers or patients with cancer and there is no scientific literature reporting on communication about complementary medicine in oncology in the Netherlands.

Aim

This paper describes the design of this study titled COMMON, in which patients participate as coresearchers. The study aims to explore communication about complementary medicine in oncology and to enhance an open and effective dialogue on the topic by the development of a toolbox for patients with cancer and oncology healthcare providers. This project seeks to answer the following research questions:

- 1. What organisational and process factors hinder or contribute to communication and implementation of complementary medicine in oncology?
- 2. How is complementary medicine currently being discussed in consultations between healthcare providers and patients with cancer?
- 3. What are the experiences, needs and expectations regarding communication about and access to complementary medicine in patients with (breast) cancer and oncology healthcare providers?
- 4. What is the evidence on patient-reported outcomes on complementary medicine frequently used by patients with (breast) cancer?
- 5. What is the acceptability and usability of the developed toolbox?

METHODS AND ANALYSIS

Setting and participants

This patient participatory multicentre study is conducted in the Netherlands. Three non-academic hospitals with an oncology department have committed to recruite participants for the study. We deliberately selected hospitals that differ in the extent to which they implemented initiatives regarding complementary medicine in standard oncology care. This contributes to the diversity of the study participants and provides opportunities to learn from fellow hospitals' experiences. The study specifically focuses on patients with breast cancer, the most commonly diagnosed cancer in women worldwide [29]. Patients with breast cancer are found to be the most frequent users of complementary medicine compared with patients with other cancers [30, 31]. In total six categories of study participants are included (see table 1).

Table 1. Participant categories

Participant category	Recruitment	Data collection	Expected numbers
Patients with (breast) cancer	Participating hospitals	Interviews about needs	16-20
		Pilot study toolbox	90
Healthcare providers	Participating hospitals	Interviews about organisation	6-9
		Interviews about needs	16-20
		Pilot study toolbox	30
Healthcare managers	Participating hospitals	Interviews about organisation	6-9
Complementary medicine providers	Researchers from Nivel	Online survey	Unknown
Patients with advanced breast cancer and their oncologist	Secondary analysis	Observation of consultations	45 patients and 12 oncologists
Patients with cancer and their healthcare provider	Secondary analysis	Observation of consultations	26 patients and 16 healthcare providers

The first three participant categories are recruited by a designated nurse coordinator in each participating hospital:

- 1. Patients with (breast) cancer, currently or during the last 6 months in active treatment, older than 18 years of age, Dutch-speaking.
- 2. Healthcare providers working with patients with cancer, such as oncologists and oncology nurses.
- 3. Healthcare managers responsible for or connected to an oncology department. The nurse coordinator in the hospital informs eligible participants about study aims and methods and provides them with a participant information letter. When a participant is interested in participating, the nurse coordinator asks for consent to share their contact details with the researcher team. Before study data collection, written informed consent is obtained.

The fourth category of participants is recruited by the research team from Nivel:

4. Persons and organisations providing complementary medicine to patients with cancer, recruited through professional organisations, stakeholder parties and researchers' networks.

Data derived from two observational studies in 2018 is used for secondary analysis. Two categories of participants were recruited from different hospitals in the Netherlands:

- 5. Patients with incurable breast cancer, female, >18 years of age, with sufficient command of Dutch language, scheduled for a test-result consultation. Patients were approached by the participating hospital via phone and when interested by the research team. Information was sent by post. Written informed consent was obtained preceding the consultation [32].
- 6. Patients with incurable cancer, >18 years of age, with sufficient command of Dutch, with limited health literacy (based on a vocational level education or lower and/or screening questions for health literacy and/or clinician's views). Patients were approached by the hospital/research team by phone and when interested met by the research team, prior to the consultation when written consent was obtained [33].

Patient and public involvement

Before submission, this research protocol was reviewed by the Patient Advocacy Group (PAG), a joint initiative of the Breast Cancer Research Group (BOOG) and National Breast Cancer Society (BVN) in the Netherlands. Furthermore, several other stakeholder parties in the Netherlands (Dutch Nursing Society (V&VN), Netherlands Comprehensive Cancer Organisation (IKNL) and the online information platform for Dutch patients with cancer (Kanker.nl) are involved since the beginning of the study to provide feedback on interim findings and advise on dissemination of results and output of the study.

Patients as coresearchers

For the cancer system to become more responsive to the needs of patients, involvement of patients with cancer in research is vital. As healthcare users with their own experiential knowledge, they can more easily extract relevant themes or interpret experiences from fellow-patients. This unique patient perspective enhances the relevance of the research findings [34]. Therefore, coresearchers prominently participate in the current study. We aim to recruit twelve Dutch-speaking patients aged at least 18 years that are diagnosed with breast cancer in the last 2 years with a fairly stable health and emotional situation. The recruitment of the coresearchers is performed by the nurse coordinator of each involved hospital and by means of an online advertisement on the website of the BVN.

In research, patients can provide input by means of (1) consultation, where patients are seen as objects of research (2) collaboration, where researchers and patients work in a partnership and make joint decisions (3) control, where patients have complete decision-making power [35]. In this study, patients acting as coresearchers collaborate with the researchers. They are involved in formulating interview questions, conducting interviews, interpreting the research findings and designing the toolbox. To ensure the privacy of study participants, the coresearchers sign a confidentiality agreement. Two important conditions for participatory research were yielded by a previous multiple case study [36]: a good working environment and good collaboration. These conditions can be achieved by the organisation of training sessions, availability of the researcher, (financial) appreciation and a clear division of roles. In the current study, an introductory meeting and three half-day training sessions are organised at the start of the project to prepare the coresearchers for their role. A follow-up training is provided after 1 year, next to several evaluation moments during the study. One of the researchers (MM) is continuously available as contact person and keeps the coresearchers up to date by means of a quarterly newsletter. We aim to create an open, safe working environment in which coresearchers feel free to ask questions and discuss their needs. The coresearchers are reimbursed for their participation. The nature of participation as a coresearcher is voluntary and withdrawal is possible at any time.

Data collection and analysis

The data collection takes place during the period 2020–2024 (see figure 1). For development of the toolbox, the six steps of the intervention mapping (IM) framework are followed: (1) assessing the needs of the target group, (2) specifying the problem and its determinants into change objectives, (3) selecting theoretical intervention methods and practical applications for change, (4) designing and developing the intervention, (5) implementing the intervention and (6) evaluating the intervention [37] (see figure 2). The IM framework supports health promotion programme planners in systematically developing an evidence-based intervention. Several effective interventions in oncology have been developed using the IM framework [38].

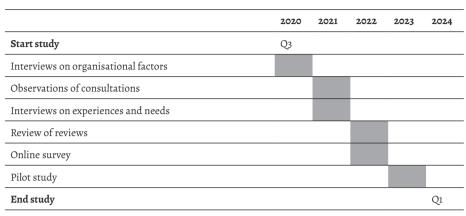


Figure 1. Time frame of the study titled 'COMMON'.

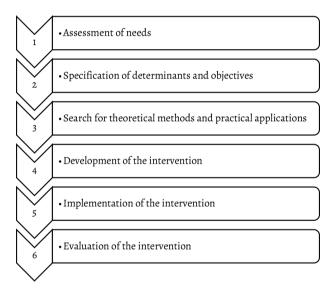


Figure 2. The six steps of the intervention mapping framework.

Step 1: needs assessment

In this first step, the needs of the target group regarding communication and access to complementary medicine are assessed to specify the goals for the intervention. The needs assessment of this study consists of interviewing healthcare managers and healthcare providers in oncology and observing previously recorded consultations [32, 33] between patients with cancer and healthcare providers.

Interviews on organisational factors

By means of semistructured interviews with healthcare managers and healthcare providers working in oncology, insight is sought in the organisational factors that hinder or facilitate communication and implementation of complementary medicine in oncology (research question 1). The interview guide will be developed in close collaboration with the coresearchers. Data saturation [39] is expected to be achieved after interviewing 2-3 healthcare managers and 2-3 healthcare providers in each participating hospital (12-18 interviews in total). Each interview is conducted by one of the researchers together with a coresearcher, preceded by a one-on-one meeting to prepare the coresearcher for the interview. The interviews have a planned duration of 45 min and are held at a time and location convenient for the interviewees (online interviews are an option given COVID-19 restrictions). With permission of the participants, the interviews are audiorecorded. The recordings are transcribed verbatim and coded thematically using MAXQDA. For the analysis of the interview data, we make use of a framework on implementation of innovations in healthcare [40] and an indicative method for identifying, analysing and reporting patterns within data [41].

Observation of consultations

By secondary analysis of recorded consultations from two previous observational studies, we observe how complementary medicine is currently discussed in oncology consultations between patients and healthcare providers (research question 2). In the first study, consultations of 45 patients with incurable breast cancer and 12 oncologists in two hospitals were audio-recorded between August and December 2018. Postconsultation, the participants completed a self-created questionnaire on sociodemographic and disease characteristics [32, 42, 43]. Given the fact that curative treatment was not a topic of discussion, complementary medicine is expected to be discussed relatively often, like previously found in an Australian study [5]. In the second study, consultations between 26 patients with incurable cancer and 16 healthcare providers (medical specialists and nurses) were videorecorded between April and October 2018. Preconsultation, background characteristics were assessed by the research team.

An observation scheme to code communication about complementary medicine during the consultations will be developed based on insights from literature on categorisations of complementary medicine and guidelines on grading of complementary medicine interventions [44-46]. Using the observation scheme, one observer codes all recordings. For inter-rater agreement, a second observer independently codes 10% of the recordings and discrepancies will be discussed among the observers until consensus is reached. Descriptive statistics (Stata V.14.0) are employed for analysing the data.

Interviews on experiences and needs

We investigate experiences and needs (eg, timing in treatment programme) regarding communication about and access to complementary medicine by conducting semistructured interviews with patients with breast cancer and healthcare providers (research question 3). Interview questions are formulated in close collaboration with the coresearchers. The recommendations of Francis *et al* [47] for sample size in qualitative studies are followed. The initial analysis sample consists of 16 interviews with patients with breast cancer and the same number of healthcare providers. The stopping criterion is three consecutive interviews without additional emerging themes in each of the two groups. The interviews last approximately 45 min and are held at a time and location convenient for the interviewes (online interviews are a possibility given COVID-19 restrictions). The interviews are conducted by one of the researchers together with one coresearcher. After permission, the interviews are audiorecorded. The audiorecordings are transcribed verbatim and then thematically coded using MAXQDA.

Steps 2 and 3: specifying determinants, objectives, theoretical methods and practical application

The goal of step 2 is specifying what or who changes as a result of the toolbox. By analysing the input from the needs assessment in step 1, behavioural and environmental determinants that are changeable are translated into a list of intervention objectives. In step 3, we seek theory-based methods and practical applications to change the determinants of behaviour and environment to meet the intervention objectives. The stakeholder's parties will be involved in the selection of strategies. The main criterion is the possibility to integrate the toolbox in daily clinical practice without interfering in conventional cancer treatment.

Step 4: development of the intervention

The goal of this step is to develop the toolbox supporting patients with cancer and oncology healthcare providers in discussing complementary medicine. The coresearchers are involved in designing the structure and lay-out of the toolbox. The content is based on the information gathered in steps 1–3. The toolbox will at least consist of a communication guideline to support patients and healthcare providers in discussing complementary medicine, supplemented with a list of available evidence-based complementary medicine frequently used by patients with cancer in the Netherlands. This list will be based on a review of systematic reviews on the evidence of complementary medicine on patient-reported outcomes and an online survey among persons and organisations providing complementary medicine.

Review of reviews

A review of reviews is conducted on the evidence on patient-reported outcomes (eg. quality of life, coping skills, general well-being, perceived psychological and physical symptoms) of complementary medicine that is frequently used by patients with cancer (research question 4). The search on review studies is initially developed in PubMed/ MEDLINE and adapted to other databases such as Cochrane library, PsycINFO, CINAHL and Embase. For this search, we make use of medical subject heading terms and/or keywords frequently used in literature on complementary medicine. The search is limited to systematic reviews and meta-analyses published after 2000, written in English. Two researchers will independently screen titles and abstracts. Subsequently, a full-text screening is conducted by two researchers. In case of inconsistencies between the two researchers, consensus will be reached by discussion. If necessary, a third researcher can be involved. For inclusion in the review of reviews, articles should meet the criteria of having a methods section that describes a search strategy and an a priori approach to synthesising the data. Then, methodological quality is assessed by means of quality criteria adapted from the Quality of Reporting of Meta-analyses (QUOROM) [48] and the Assessment of Multiple Systematic Reviews (AMSTAR) [49]. A comprehensive, detailed protocol of the review of reviews will be registered in PROSPERO.

Online survey

To gain an overview on what types of evidence-based complementary medicine are currently available in the Netherlands, an online search accompanied by an online survey is performed among persons and organisations providing complementary medicine approaches that are widely used by patients with cancer (research question 4). Survey questions are formulated in close collaboration with the coresearchers, but minimally covers what kind of complementary medicine is being offered, to whom, with what goal and what the outcomes are.

Step 5: implementation of the intervention

Planning the implementation of the toolbox begins as soon as the needs assessment has been performed and is continuously revisited during the study by the involvement of coresearchers and the stakeholder parties.

Pilot study

Following the development of the toolbox, we conduct a pilot study for which 90 patients with cancer (half of them complementary medicine users) and 30 oncology healthcare providers are recruited from the three hospitals. If relevant, informal caregivers are also recruited. As recommended by the Medical Research Council guidance [50], the exact selection of instruments and dimensions evaluated in the pilot study will be adjusted to the eventual design of the toolbox. The toolbox will be at least assessed on acceptability, usability, layout and transparency using descriptive statistics. The coresearchers are involved in the design of the pilot study. No risks are expected to be associated with participation in the pilot study, because the toolbox will not interfere with conventional cancer treatment.

The results of the pilot study are used to optimise the toolbox before shifting to the phase where it is made publicly available. We plan to organise an invitational conference to guarantee proper use and uptake of the toolbox and to report on its development and evaluation. Dissemination in the intended population is covered by the commitment of the stakeholder parties. Naturally, the content of the toolbox changes as new insights into effectiveness and safety of complementary medicine becomes available. To ensure continuation of the intervention, budget is reserved for biennial updates of the toolbox for at least 4 years after dissemination.

Step 6: evaluation of the intervention

As described in step 5, a preliminary evaluation of the toolbox by means of a pilot study will take place. In the future, we intend to recruit funding for an additional, larger trial to measure the impact of the toolbox on aspects of communication about complementary medicine (eg, initiation, satisfaction) between healthcare providers and patients with cancer. A description of the trial design for an effect evaluation of the toolbox is beyond the scope of the current protocol paper that describes the development of the toolbox.

IN CONCLUSION

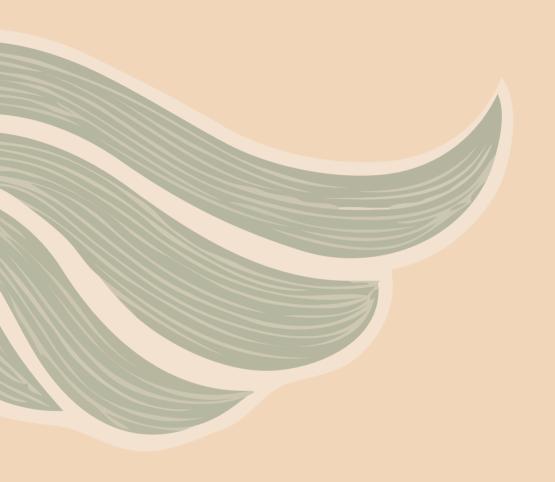
To the best of our knowledge, this is the first patient participatory study that aims to explore and enhance communication about complementary medicine in oncology. Despite the frequent use of complementary medicine among patients with cancer, the topic often remains undiscussed in consultation with the healthcare provider [4-6]. This results in risks for adverse or interaction effects and decreases access to evidencebased complementary medicine for patients with cancer. To date, it is unknown to what extent complementary medicine is discussed and implemented in oncology in the Netherlands and what the experiences and needs of patients with cancer and oncology healthcare providers are in this area. This study will fill these information gaps by conducting interviews, observations, a survey and a review of reviews on complementary medicine in oncology. Perspectives of patients with cancer, oncology healthcare providers, healthcare managers and complementary medicine providers are included. The collected data are used for the systematic development [37] of an unique toolbox supporting the dialogue on complementary medicine in oncology. Preceded by a pilot-test, the toolbox is disseminated with the support of national stakeholders to the intended population: patients with cancer and oncology healthcare providers. The toolbox aims to provide (1) tips and tricks on how to conduct an open and effective discussion about the use of complementary medicine in oncology and (2) evidencebased complementary medicine interventions which patients with cancer can use safely alongside their conventional cancer treatment. Thereby, we want to minimise the risks and maximise the benefits of evidence-based complementary medicine for patients with cancer.

REFERENCES

- 1. Horneber M, Bueschel G, Dennert G, et al. How many cancer patients use complementary and alternative medicine: a systematic review and metaanalysis. *Integr Cancer Ther* 2012;11(3):187-203.
- Keene MR, Heslop IM, Sabesan SS, et al. Complementary and alternative medicine use in cancer: A systematic review. Complement Ther Clin Pract 2019;35:33-47.
- King N, Balneaves LG, Levin GT, et al. Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. *Integr Cancer Ther* 2015;14(6):515-24.
- 4. Juraskova I, Hegedus L, Butow P, et al. Discussing complementary therapy use with early-stage breast cancer patients: exploring the communication gap. *Integ Cancer Ther* 2010;9(2):168-76.
- 5. Schofield PE, Juraskova I, Butow PN. How oncologists discuss complementary therapy use with their patients: an audio-tape audit. *Support Care Cancer* 2003;11(6):348-55.
- Roter DL, Yost KJ, O'Byrne T, et al. Communication predictors and consequences of Complementary and Alternative Medicine (CAM) discussions in oncology visits. Patient Educ Couns 2016;99(9):1519-25.
- 7. West HJ. Complementary and alternative medicine in cancer care. JAMA Oncol 2018;4(1):139.
- 8. National Center for Complementary and Integrative Health. Complementary, Alternative, or Integrative Health: What's In a Name?, 2018. Available: https://www.nccih.nih.gov/health/complementary-alternative-or-integrative-health-whats-in-a-name [Accessed 21 January 2021].
- Seely D, Weeks L, Young S. A systematic review of integrative oncology programs. Curr Oncol 2012;19(6):e436-61.
- O'Callaghan, V. Patients' perceptions of complementary and alternative medicine. Cancer Forum 2011;35(1):44-47.
- Ambrosone CB, Zirpoli GR, Hutson AD, et al. Dietary supplement use during chemotherapy and survival outcomes of patients with breast cancer enrolled in a cooperative group clinical trial (SWOG So221). J Clin Oncol 2020;38(8):804-14.
- 12. Lee RT, Kwon N, Wu J, et al. Prevalence of potential interactions of medications, including herbs and supplements, before, during, and after chemotherapy in patients with breast and prostate cancer. Cancer Published Online First: 1 February 2021. doi: 10.1002/cncr.33324
- 13. Dibble SL, Luce J, Cooper BA, et al. Acupressure for chemotherapy-induced nausea and vomiting: a randomized clinical trial. *Oncol Nurs Forum* 2007;34(4):813-20.
- Lyman GH, Greenlee H, Bohlke K, et al. Integrative therapies during and after breast cancer treatment: ASCO endorsement of the SIO clinical practice guideline. J Clin Oncol 2018;36(25):2647-55.
- Davis EL, Oh B, Butow PN, et al. Cancer patient disclosure and patient-doctor communication of complementary and alternative medicine use: a systematic review. Oncologist 2012;17(11):1475-81.
- 16. Borstkanker Vereniging Nederland. Maak(te) jij gebruik van 'complementaire zorg'?, 2017. Available: https://bforce.nl/maakte-jij-gebruik-van-complementaire-zorg [Accessed 21 January 2021].
- 17. Hematon. Grote groep patiënten maakt gebruikt van complementaire zorg, 2018. Available: https://www.hematon.nl/nieuwsberichten/grote+groep+patienten+maakt+gebruik+van +complementaire+zorg [Accessed 1 March 2021].
- Winslow LC, Shapiro H. Physicians want education about complementary and alternative medicine to enhance communication with their patients. Arch Intern Med 2002;162(10):1176-81.
- 19. Frenkel M, Ben-Arye E, Cohen L. Communication in cancer care: discussing complementary and alternative medicine. *Integr Cancer Ther* 2010;9(2):177-85.

- 20. Stewart MA. Effective physician-patient communication and health outcomes: a review. *CMAJ* 1995;152(9):1423-33.
- 21. Street Jr RL, Makoul G, Arora NK, et al. How Does Communication Heal? Pathways Linking Clinician-Patient Communication to Health Outcomes. *Patient Educ Couns* 2009;74(3):295-301.
- 22. Epstein RM, Street Jr RL. Patient-centered communication in cancer care: promoting healing and reducing suffering. Bethesda, MD: National Institutes of Health 2007: 1-17.
- 23. Evans M, Shaw A, Thompson EA, et al. Decisions to use complementary and alternative medicine (CAM) by male cancer patients: information-seeking roles and types of evidence used. *BMC Complement Altern Med* 2007;7:25.
- Balneaves LG, Truant TL, Verhoef MJ, et al. The Complementary Medicine Education and Outcomes (CAMEO) program: a foundation for patient and health professional education and decision support programs. Patient Educ Couns 2012;89(3):461-66.
- 25. Ben-Arye E, Frenkel M, Bar-Sela G, et al. Teaching complementary medicine at an academic oncology department. *J Cancer Educ* 2008;23(1):46-50.
- 26. Witt CM, Helmer SM, Schofield P, et al. Training oncology physicians to advise their patients on complementary and integrative medicine: An implementation study for a manual-guided consultation. Cancer 2020;126(13):3031-41.
- 27. Chong W-Q, Mogro MJ, Arsad A, et al. Use of decision aid to improve informed decision-making and communication with physicians on the use of oral complementary and alternative medicine (CAM) among cancer patients on chemotherapy treatment: a randomised controlled trial. Suppor Care Cancer Published Online First: 14 November 2020. doi: 10.1007/s00520-020-05872-5
- 28. Allen Searson N, Balneaves LG, Thorne SE, et al. The Effect of a Complementary Therapy Education Seminar on Support Persons of Individuals with Cancer. *J Altern Complement Med* 2021;27(4):365-72.
- 29. Bray F, Ferlay J, Soerjomataram I, et al. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin 2018;68(6):394-424.
- 30. Velicer CM, Ulrich CM. Vitamin and mineral supplement use among US adults after cancer diagnosis: a systematic review. *J Clin Oncol* 2008;26(4):665-73.
- 31. Morris KT, Johnson N, Homer L, et al. A comparison of complementary therapy use between breast cancer patients and patients with other primary tumor sites. *Am J Surg* 2000;179(5):407-11.
- 32. Van Vliet LM, Francke AL, Meijers MC, et al. The Use of Expectancy and Empathy When Communicating With Patients With Advanced Breast Cancer; an Observational Study of Clinician—Patient Consultations. Front Psychiatry 2019;10:464.
- 33. Noordman J, Schulze L, Roodbeen R, et al. Instrumental and affective communication with patients with limited health literacy in the palliative phase of cancer or COPD. *BMC Palliat Care* 2020;19(1):152.
- 34. Wright D, Corner J, Hopkinson J, et al. Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda. *Health Expect* 2006;9(1):3-12.
- 35. INVOLVE. Briefing note seven: Approaches to public involvement in research, 2012. Available: http://www.invo.org.uk/posttyperesource/[Accessed 19 Nov 2020].
- Scheffelaar A, Bos N, de Jong M, et al. Lessons learned from participatory research to enhance client participation in long-term care research: a multiple case study. Res Involv Engagem 2020;6:27.
- 37. Bartholomew L, Parcel G, Kok G, et al. Planning health promotion program: an intervention mapping approach. San Francisco, CA: Jossey-Bass 2011.
- 38. Lamort-Bouché M, Sarnin P, Kok G, et al. Interventions developed with the Intervention Mapping protocol in the field of cancer: a systematic review. *Psychooncology* 2018;27(4):1138-49.

- 39. Given LM. 100 questions (and answers) about qualitative research. Thousand Oaks, CA: SAGE Publications 2015.
- 40. Herzlinger RE. Why innovation in health care is so hard. Harv Bus Rev 2006;84(5):58-66.
- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101.
- 42. Westendorp J, Stouthard J, Meijers MC, et al. The power of clinician-expressed empathy to increase information recall in advanced breast cancer care: an observational study in clinical care, exploring the mediating role of anxiety. Patient Educ Couns Published Online First: 22 October 2020. doi: 10.1016/j.pec.2020.10.025
- 43. Hoffstädt H, Stouthard J, Meijers MC, et al. Patients' and Clinicians' Perceptions of Clinician-Expressed Empathy in Advanced Cancer Consultations and Associations with Patient Outcomes. Palliat Med Rep 2020;1(1):76-83.
- 44. Deng GE, Rausch SM, Jones LW, et al. Complementary therapies and integrative medicine in lung cancer: diagnosis and management of lung cancer: American College of Chest Physicians evidencebased clinical practice guidelines. Chest 2013;143(5):e420S-e36S.
- 45. Greenlee H, DuPont-Reyes MJ, Balneaves LG, et al. Clinical practice guidelines on the evidencebased use of integrative therapies during and after breast cancer treatment. CA Cancer J Clin 2017;67(3):194-232.
- 46. Deng GE, Frenkel M, Cohen L, et al. Evidence-based clinical practice guidelines for integrative oncology: complementary therapies and botanicals. J Soc Integr Oncol 2009;7(3):85-120.
- Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health* 2010;25(10):1229-45.
- 48. Moher D, Cook D, Eastwood S, et al. Improving the quality of reports of meta-analyses of randomized controlled trials: the QUOROM Statement. Rev Esp Salud Publica 2000;74(2):107-18.
- 49. Shea BJ, Grimshaw JM, Wells GA, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. BMC Med Res Methodol 2007;7(1):10.
- 50. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. Int J Nurs Stud 2013;50(5):587-92.



CHAPTER III

How is Complementary Medicine Discussed in Oncology? Observing Reallife Communication between Clinicians and Patients with Advanced Cancer

Marit Mentink, Liesbeth van Vliet, Johanna (Anja) Timmer-Bonte, Janneke Noordman, Sandra van Dulmen

> Patient Educ Couns 2022; 105(11):3235-3241. doi: 10.1016/j.pec.2022.08.007. PMID: 35989202

ABSTRACT

Objective

This study aims to examine the structure of communication about complementary medicine (CM) between patients with cancer and clinicians during oncology consultations.

Methods

Previously, consultations between 29 clinicians and 80 patients with advanced cancer were recorded in six hospitals in the Netherlands. The present study considers a secondary analysis. References to CM during the consultation were coded using a self-developed observational coding scheme.

Results

At least one reference to CM was observed in 35 out of 80 consultations (44%), with a total of 73 references. In most cases, CM was initially referred to by patients. Clinicians often did not elaborate on the subject of CM. Relevant aspects related to CM (e.g., safety, effectiveness) were infrequently discussed. Both patients and clinicians showed predominantly neutral to positive attitudes towards CM.

Conclusions

This study shows that patients are still the main initiators of discussions about CM and the topic is not consistently discussed in daily oncology practice.

Practice implications

If exploration of patients' interest in CM or its use became routine in oncology practice, it may relieve patients of the burden of introducing the topic, decrease potential risks of CM use and increase access to evidence-based CM for all patients with cancer.

INTRODUCTION

Almost half of all patients with cancer use complementary medicine (CM) [1, 2], especially in advanced disease stages [3, 4]. CM refers to interventions outside conventional medical care but delivered alongside it [5], such as mind-body therapies, natural products and lifestyle alterations. Some CM modalities can interact with anti-cancer treatment, for instance antioxidant supplements with chemotherapy [6]. Other CM modalities have been proved safe and effective for symptom management in patients with cancer, such as acupuncture for cancer pain and chemotherapy-induced peripheral neuropathy [7, 8] or meditation and yoga to reduce anxiety [9, 10]. Evidence-based CM practices are now recommended in oncology guidelines [11, 12], or have even become integrated into conventional oncology care programs (i.e. integrative oncology [13, 14]).

Patients' interest in CM or its use were found to be infrequently discussed during oncology consultations and both patients and clinicians perceive barriers against doing so. In previous studies, discussions about CM were noted in 11% -34% of oncology consultations, mainly initiated by patients [15-19]. Only up to 16% of patients with cancer say that they consulted their clinician for information about CM [20] and in this respect, patients' information and decision-making needs are often not met [21]. Up to 77% of patients with cancer do not even disclose CM use to their clinician [22]. Reasons given by patients for not disclosing CM use include clinicians' lack of inquiry, anticipated disapproval or inability to provide information [22]. Although there are discrepancies in the attitudes of clinicians towards CM, previous studies showed that the limited education and knowledge cause reluctance and discomfort in discussing CM with patients [21, 23].

When the topic of CM remains undiscussed during oncology consultations, clinicians remain unaware of potential harmful interactions and less assertive patients remain uninformed about potentially supporting, evidence-based CM. Despite the importance of discussing patient CM use in oncology, in-depth analyses of actual conversations about CM between clinicians and patients with cancer are scarce. However, insights into the content and structure of these conversations are useful for developing tools to assist patients and clinicians in discussing CM. As far as we are aware, this study is the first in a European country aiming to examine how CM is discussed during oncology consultations by observing how the topic is introduced, how often and by whom, what aspects related to CM are discussed, and what the attitudes of patients and clinicians towards CM use are.

MATERIALS AND METHODS

Study design

The present study considers a secondary analysis of audio/video recordings of consultations between patients with advanced cancer and clinicians, recently collected in six hospitals as part of two previous studies [24, 25]. The main purpose of the previous studies were: 1) to examine Shared Decision Making (SDM) between patients with advanced cancer and clinicians in practice, and assess clinicians' perspectives on their own SDM [24]; 2) to provide insight into how often and how clinicians use expectancy-and empathy expressions in consultations with patients with advanced cancer [25]. In the current study, transcriptions of the recorded consultations were coded with a self-developed observational coding scheme for communication about CM. This study is part of a larger mixed-methods research project titled 'COMMON', aiming 1) to explore communication about CM in oncology and 2) to enhance communication about CM by developing and implementing a toolbox for patients with cancer and clinicians [26].

Participants and procedure

Inclusion criteria of the two previous studies

The first previous study consisted of 45 test result consultations that were audiorecorded in two hospitals (one general and one specialized cancer hospital) in the Netherlands in 2018. Patients' eligibility criteria were 1) advanced, incurable breast cancer, 2) age \geq 18, 3) sufficient command of Dutch, and 4) cognitively able to provide consent and complete a questionnaire. Eligible patients were contacted by the hospital and, if interested, phoned by the research team. Written informed consent and patient characteristics were obtained preceding the consultation [25].

The second previous study consisted of 59 new or follow-up consultations that were audio or video-recorded in four hospitals (three academic hospitals and one general) in the Netherlands between 2018 and 2021. Patients' eligibility criteria were 1) palliative phase of cancer or COPD, 2) age \geq 18, 3) command of Dutch, and 4) low level of health literacy based on education level and screening questions [27]. Eligible patients were phoned by the hospital or research team and, if interested, met by the research team preceding the consultation to obtain written informed consent and patient characteristics [24].

Inclusion criteria of the current study

The consultations recorded in the two previous studies were included in the current study provided they 1) were recorded in an oncology, radiology or pulmonary

department and 2) involve patients diagnosed with cancer. The consultations recorded in a specialized palliative care department were excluded, since they were expected to be not representative of oncology consultations in terms of communication patterns, length and type of clinician (Fig. 1).

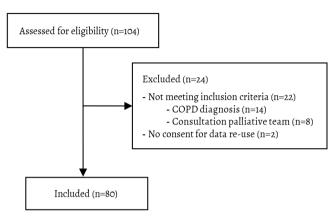


Figure 1. Inclusion of consultations in the current study

Measures and analysis

In this study, complementary medicine (CM) is defined as approaches outside conventional biomedical cancer treatment, used in addition with the aim of improving a patient's physical, mental or social well-being. This definition includes supportive therapies (e.g., physical therapy, psychological support) and lifestyle changes (e.g., nutrition, exercise). It was decided to exclude the following types of care, since they are either part of conventional care or are simple self-care aids: 1) vitamins and supplements recommended by national guidelines [28-30] and available on prescription by conventional clinicians (e.g. vitamin D for bone fractures), 2) general medical advice regarding nutrition (e.g., drinking enough water when having diarrhea), and 3) common self-care aids without medical claims (e.g., creams, foot baths).

A coding scheme with 16 items was developed for coding communication about CM during the consultations (see Table 2). This scheme was partially based on an existing coding scheme on aspects of patient-clinician communication about CM [15, 16] and supplemented with additional items of our interest (e.g. reimbursement of CM, observed patient and clinician attitudes towards CM) based on a content analysis of some of the recordings and research team expertise (M.M., L.v.V., A.T.-B., J.N. and S.v.D.). One researcher listened to all recorded consultations and fragments of conversations referring to CM were transcribed. The topic codes covered how CM was introduced and by whom, what aspects relating to CM were mentioned (e.g., safety, evidence base, costs) and how patients and clinicians verbalized their attitude towards CM (positive, negative, neutral). The coding scheme was pilot-tested by two observers (M.M. and L.v.V.) on a subsample of 3 transcripts of recordings in which CM was discussed at least once. In between coding of each recording, findings were discussed and items were refined or deleted. The second observer (L.v.V.) independently coded a random 10% of the transcripts in which CM was discussed at least once (n = 4, nine instances of CM discussions) with an average inter-rater agreement of 90%, indicating an excellent level of agreement. Discrepancies between the two observers were discussed until consensus was reached. The main observer (M.M.) coded all transcripts of consultations with references to CM (where a type of CM was mentioned more than once in the same consultation, this was coded as one instance). Two weeks after initial coding, the main observer (M.M.) recoded a random 10% of the transcripts in which CM was discussed for intra-rater purposes (n = 4, six instances of CM discussions). Average intra-rater agreement was 97%.

Stata 14.0 was used for descriptive data analyses. The STROBE guidelines [31] were used for reporting the results. To illustrate the findings, quotes obtained from the coded transcripts were used and translated from Dutch to English. The quotes were used as exemplars to supports the results of the observational coding. The co-researchers collaborated with the research team in the categorization of the referenced types of CM.

RESULTS

Table 1. Participant background characteristics

Clinician characteristics	n = 29	
Sex		
Female	19	
Male	10	
Profession ^a		
Medical oncologist	13	
Radiation oncologist	9	
Pulmonologist	6	
Nurse practitioner	1	

Table 1. Continued

Patient characteristics	n = 80
Age	
Mean (sd)	61 (12.5)
Range	31-89
missing	n = 10
Sex	
Female	59
Male	21
Highest education ^b	
Low	34
Intermediate	24
High	17
missing	5
Type of cancer	
Breast	44
Lung	15
missing	21

^a 3 out of 9 radiation oncologists and 3 out of 6 pulmonologists were residents

Table 2. Quantitative description of results of analyzed conversations about complementary medicine (CM) in oncology consultations

CM modalities discussed ^a	Category	n=73	%
Nutritional	Specific diets or foods	13	18
	Dietary counseling	8	11
	Vitamins, herbs, supplements (oral)	7	10
Physical	Exercise or activation	15	21
	Physical therapy	13	18
	Massage	2	3
	Acupuncture	1	1
Psychological	Psychological support	4	5
Other	General health or lifestyle ^b	5	7
	Cutaneous application with medical claim	4	5
	Oncological revalidation program	1	1
Coding scheme themes	Items		
1. Who introduced CM?	Patient	45	62
	Clinician	22	30
	Companion	6	8
2. How is CM introduced?	Statement	42	58
	Question	20	27
	Answer to indirect question	11	15

^b classified according to ISCED-F 2013 [32]

Table 2. Continued

Coding scheme themes	Items		
3. First response of clinician to CM	Statement	23	32
	Topic disregarded	19	26
	Question	9	12
	N/A, clinician initiated	22	30
4. Safety or risks of CM discussed	Yes	10	14
5. Scientific evidence of CM discussed	Yes	6	8
6. Costs of CM discussed	Yes	3	4
7. Purpose of CM use discussed	Yes	52	71
8. Alternative options for CM discussed	Yes	17	23
9. Information sources about CM discussed	Yes	1	1
10. Clinician contact with CM provider	Yes	3	4
11. Patient quit conventional treatment	Yes	1	1
12. Clinician encouraged patient choice	Yes	4	5
13. Attitude of clinician towards CM	Encouraging	28	38
	Neutral	26	36
	Discouraging	3	4
	Topic disregarded	16	22
14. Attitude of patient towards CM	Positive	33	45
	Neutral	30	41
	Negative	5	7
	Indistinct	5	7
15. Patient already used CM	Yes	53	73
16. Discussion changed patient's CM use	Yes	5	7

^a National Center for Complementary and Integrative Health (NCCIH) classification [33]

Overview

Consultations between 29 clinicians and 80 patients with advanced cancer were included for coding in the current study. Background characteristics of clinicians and patients are provided in Table 1. Each clinician saw on average 2–3 patients (SD = 2.08; range = 1-8). In 86% of the consultations, a companion was present. Most consultations concerned follow-ups, except for two initial consultations. The average consultation duration was 20.24 min (SD = 9.95; range = 4.43-53.47).

References to CM

In 35 out of 80 consultations (44%), there was at least one reference to CM. In these 35 consultations, 73 references to CM were observed with a mean of 2 per consultation (SD = 1.22; range = 1-6). As shown in Table 2, the most commonly mentioned CM

^b general healthy lifestyle or stopping alcohol/smoking

modalities were exercise/activation, specific diets/foods, and physical therapy. In more than half of the occasions, the topic of CM was initiated by patients.

How is CM introduced?

Initial references to CM were mainly incorporated into statements or questions. When a patient introduced the topic by a statement, it was often about using CM or visiting a CM provider:

Patient: "I guess I should say I've also started [product], which I got at [drugstore]. And it's, well, a medicine or – you know – a preparation that purifies the liver."

Patient: "She's an oncology physical therapist. She massaged it [the shoulder] but I had a lot more pain after that."

When patients introduced the topic of CM through a question, they often asked for advice about the potential benefits or risks of particular types of CM:

Patient: "Can I do physio fitness and stuff like that in the meantime?"

When clinicians introduced the topic of CM, it was mainly about nutritional advice or questions related to lifestyle:

Clinician: "It's better to eat solid foods too, though – not just smoothies. I can get the dietician to contact you again if you want."

Clinician: "And the smoking: how's that going?"

Clinicians were not seen to ask questions about a patient's interest in CM in general or their use of it: the topic was always introduced by mentioning specific CM modalities directly.

Clinician's response to introduction of CM

The clinicians' most common response to the introduction of the topic of CM was a statement to answer a question asked by the patient or to positively reinforce CM use (e.g. "very good"). In 19 out of 51 instances where a patient introduced the topic of CM, the clinician disregarded the topic. In most of those cases, the patient just made a statement about CM use in passing. Clinicians always responded to direct questions about CM asked by patients. The 'disregarding' action was coded when the clinician only expanded on the health complaint related to CM use, moved on to another topic

or merely responded with "yes, yes". Only in a minority of the instances, the clinician responded to the introduction of CM with a question. In these instances, clinicians asked for clarification or information about the type of CM:

Clinician: "Not one I know. What's [supplement]?"

Mentioned aspects that are related to CM

Safety, effectiveness and costs of CM

The safety of a CM modality was mentioned in a small minority of the conversations and was only twice highlighted by a clinician. In most instances, patients directly asked their clinician for reassurance that it was safe to use a particular CM modality in their situation:

Patient: "But it's not, like, an amount [of a calcium supplement] that you'd say shouldn't he added?"

In the following example, a clinician reassures a patient that lymph drainage is safe:

Clinician: "Well, you know, the fact that we've now seen a shadow like this by your hip means that some of the cancer was left behind and has spread [...] And lymph drainage there, well, it will have no influence on that."

Comments about scientific evidence for effectiveness were rare and all observed in the context of nutritional interventions, such as herbs, supplements and specific foods. When discussed, it was mainly patients asking the clinician about evidence for a specific type of CM, to which clinicians responded that scientific evidence was limited (only laboratory) or absent:

Clinician: "Well, certain food products can definitely affect it [cancer]. (...) But it's not yet very clear yet, or very easy to prove scientifically."

Clinician: "Studies have been done in laboratories with very high doses of turmeric that inhibit some tumor cells, especially some kinds of blood cancer and lymphoma. Whether it really does... I wouldn't dare say one way or the other, but it can't hurt either."

Overall, aspects related to costs were only observed in three conversations about CM and all revolved around health insurance reimbursement of CM.

Purpose and alternative options for CM use

The purpose or goal of CM use was mentioned in most of the discussions, for example:

Patient: "I'm also noticing that my muscles are getting weaker (...), so I just try to keep going swimming twice a week."

Clinician: "Then it's about how to deal with uncertainty. Sure, I can tell you about that from a medical perspective, but I'm not a psychologist and that's who you might actually need for that."

In the majority of these cases, the purpose of CM was to manage specific physical or psychological symptoms (non-curative). However, it was generally unclear whether the symptoms were related to the cancer diagnosis or treatment, or to pre-existing or co-existing conditions.

Alternatives for the type of CM discussed were mentioned in a quarter of the cases, mostly suggested by the clinician. These alternatives were other complementary modalities or conventional treatments (e.g., prescribing pain killers or nausea suppressants, or changing anti-cancer treatment doses).

Contact with CM provider, information source and alternative treatment

It was rarely observed that a clinician suggested to refer to, or to contact, a CM provider. **On** one occasion, an information source was mentioned by a patient who received information from a friend about a specific form of exercise. One time, it appeared from the conversation that a patient had ended conventional treatment and received alternative treatment in a clinic outside the Netherlands. The clinician seemed already aware and asked some in-depth questions about the alternative treatment without expressing an explicitly discouraging or encouraging attitude.

Patient choice

Patient choice in deciding whether or not to use CM was emphasized by the clinician in four instances, for example:

Clinician: "Yes, you can do that [supplement your nutrition]. And it's a good thing too, that you see that and feel it and want it yourself."

Clinician: Whatever you're comfortable with [...]. We can cancel it if you'd rather [appointment with the physical therapist]."

Clinician attitude towards CM

Overall, clinicians verbalized either an encouraging or neutral attitude towards the discussed type of CM. Clinicians mainly encouraged CM modalities related to nutritional (specific foods, dietary counseling) and physical interventions (exercise, physical therapy). An encouraging attitude was expressed by means of cheerful words about CM use (e.g., "good" or "beautiful") or by explicit recommendations:

Clinician: "Keep exercising, that keeps your fitness level up and it's important for the overall physical condition."

Three times, CM use was actively discouraged by the clinician for the following reasons: long wait list, lack of safety, or lack of evidence. An example of the latter:

Clinician: "Well, it often doesn't work in humans, so I don't recommend it [sodium bicarbonate]."

Patient attitude towards CM

The patients' verbalized attitudes towards the CM mentioned were predominantly positive or neutral. An example of a patient referencing CM neutrally, without being overtly positive or negative about its use, is:

Patient: "Maybe I can go to a masseur who can massage it [the back pain] away. Isn't that an option?"

Only a few patients expressed a negative attitude towards CM, by means of doubts, drawbacks or objections to using CM. For instance:

Patient: "Yeah. And the food [organic diet] is, like, very limited."

Patients' use of CM

In a majority of the observed conversations about CM, it appeared that the patient already used the type of CM referred to. In five instances, the patient explicitly mentioned an intention to change CM use as a result of the conversation, such as decreasing, stopping or starting the use of CM. For instance, after a clinician told a patient using milk thistle that using that herb can lead to abnormal liver values, the patient stated:

Patient: Right, then I'll stop.

In the remaining instances, it was not clear from the conversation whether it led to a change in patient CM use.

Table 3 summarizes the results of the qualitative analysis of the observed conversations about CM.

Table 3. Qualitative description of results of analyzed conversations about complementary medicine (CM) in oncology consultations

Theme	Patient	Clinician
Introduction of the topic of CM	Patients introduced the topic of CM in most cases Patients introduced the topic by making statements or asking questions about CM	 Clinicians introduced mainly lifestyle-related CM modalities, such as nutrition or exercise Clinicians often disregarded statements about CM made by patients, but not questions
Safety and effectiveness of CM	Patients mainly initiated the discussion of aspects related to safety or scientific evidence	Clinicians provided information about scientific evidence mainly in the context of nutritional interventions
Costs of CM	• Rarely discussed, all about health insurance reimbursement	
Purpose of CM	The purpose of CM use was mentioned in most instances, mainly by patients	
Alternative options for CM		Clinicians suggested alternative options for CM, such as adding or changing conventional treatment
Contact with CM provider		Clinicians rarely suggested referral to or contact with a CM provider
Information source	On one occasion, a patient mentioned receiving information about CM from a friend	
Alternative treatment	On one occasion, a patient mentioned ending conventional treatment	
Patient choice		Clinicians seldom explicitly emphasized patient choice in using CM
Attitude towards CM use	Patients mainly verbalized a positive or neutral attitude	Clinicians mainly verbalized an encouraging or neutral attitude Clinicians seldom discouraged CM use
Patient use of CM	• Patients mentioned in most cases that they already used CM	

DISCUSSION

This study examined how CM is discussed during real-life oncology consultations in the Netherlands. Discussions about CM were mostly patient-initiated and the clinician often did not expand on the topic. This resulted in a minimal information exchange about aspects related to CM, such as safety and effectiveness. A predominantly neutral to positive attitude towards the type of CM discussed was observed in both patients and clinicians.

In the current study, references to CM were observed in a relatively high number (45%) of oncology consultations, compared to other studies involving patients with cancer (11%-34%) [15-19]. This high number might be explained by the study sample consisting of patients with cancer in the palliative phase of the disease, with an overrepresentation of female patients. Advanced disease stage and being female are both found to be positively associated with CM use in patients with cancer [2-4]. In addition, patients with breast cancer and lower-educated patients were overrepresented in the study sample. However, previous studies repeatedly showed a negative association between lower educational levels and CM use and no association between breast cancer and CM use [2].

Another factor contributing to the high number of observed references to CM in the current study, could have been the relative high number of references to lifestyle interventions (e.g., exercise, diet) and supportive interventions (e.g., physical therapy and psychological support). These CM modalities are not always included in the definition of CM. For instance, diet and exercise are in some studies included in the definition of CM [15], but excluded in others [11]. Physical therapy is seen as part of conventional medicine, but patients in the current sample stated that their physical therapists used techniques usually incorporated in the definition of CM, such as massage, acupressure and dry needling. What is considered conventional or complementary medicine can thus overlap and shift due to emerging scientific evidence or changing healthcare policy. For instance, programs for integrative oncology (i.e., combining conventional medicine with evidence-based CM [13]) are upcoming in conventional healthcare [14].

The results showed that communication about CM is mainly initiated by patients, which is consistent with findings from previous studies [15-19]. This fits within the reluctance and discomfort reported by clinicians in communicating about CM [21, 23]. However, as we only observed a single consultation per patient, it might be possible that the clinician inquired about patient CM use in previous (or future) consultations.

Furthermore, most clinicians included in the current study were physicians. Potentially, CM use was discussed with another clinician, such as the nurse. The topic of CM is far more often addressed in nursing literature, although nurses were not found to be more likely than physicians to initiate a conversation about CM or to feel more comfortable in doing so [35].

Comparably to what previous studies showed [15, 16, 18], clinicians seldom responded to the introduction of the topic by patients or companions with a question and often did not respond at all. As a result, some of the consultations observed included no more than one statement by the patient or companion about CM without further elaboration on the topic. When patients introduced the topic by means of a question, they always received a response from the clinician. This finding implies that patients should be advised to ask direct questions about CM instead of solely mentioning it in passing to their clinician.

Although there is potential for interaction effects between anti-cancer therapy and particular CM modalities, such as supplements and herbs [6, 36], the majority of CM modalities discussed in the current study could be considered generally safe to use for patients with cancer. This potentially explains why important aspects related to CM, such as safety and effectiveness, were less frequently discussed than expected based on previous studies [15, 16]. Additionally, the observed discussions on safety or effectiveness were mainly initiated by patients. A lack of education and knowledge about CM often reported by clinicians [21, 23] might explain why they do not proactively raise aspects such as safety or effectiveness.

The large proportion of generally safe CM modalities discussed in the current study might also explain why clinicians discouraged patients' CM use less than expected based on previous study results [15, 16, 18]. In general, clinicians seemed to be encouraging or neutral in their verbalized attitude towards CM use. However, a positive clinician attitude towards CM does not necessarily correlate with clinical practice behaviors towards CM (e.g. referral or prescription) as was shown in a literature review [37].

Strengths, limitations and future studies

This study is, to our best knowledge, the first to observe real-life CM discussions in oncology in a European country. To complement self-reporting studies, it is important to observe the content and structure of actual communication between patients and clinicians. The observation scheme developed and used in the current study showed promising rates of inter-rater and intra-rater reliability, but needs further assessment on psychometric qualities, such as validity, and transferability to other medical disciplines.

The consultations observed are likely to reflect true communication about CM as participants were blind to this secondary analysis. The likelihood of discussions about CM to arise during the consultations might have been influenced by the fact that most of the analyzed data considered follow-up visits in which test-results were shared with patients. For future research, it would be interesting to study the impact of consultation content on the likelihood of discussions about CM. Since the consultations had already been recorded, it was not possible to observe nonverbal communication or administer self-reported questionnaires. Future studies could obtain self-reported data about patient needs, expectations, and satisfaction with regard to CM discussions. For instance, previous research has shown that communication about CM is associated with higher visit satisfaction reported by patients and clinicians [17]. In addition, it would be interesting to study the influence of communication about CM on patient(-reported) health outcomes.

The lack of consensus on a definition of CM impacts the generalizability of studies in this field. The line between conventional and complementary medicine is unclear, shifting, and subject to intercultural variation. It therefore seems sensible to assess all health approaches used by patients with cancer and aiming to contribute to physical, mental, or social well-being equally alongside biomedical treatment of the disease.

Practice implications

The results of the current study show that patients are still the main initiators of discussions about CM. When the introduction of CM is left up to patients and not consistently discussed in oncology practice, less assertive patients will remain unaware of evidence-based CM options for symptom management and clinicians cannot monitor potential interactions between CM use and anti-cancer treatment. To provide safe and patient-centered cancer care, it is important for clinicians to be open and attentive to the topic of CM. This means that clinicians do not only respond when patients ask direct questions about CM, but also when the topic is mentioned in passing. However, proactively asking about patient interest in and usage of CM is preferred given the large number of patients with cancer who use CM [1, 2], the high rate of patient nondisclosure of CM use [22], the potential risks [6, 36] and the evidence base for some types of CM [11, 12]. A recently published clinical practice guideline [34] provides useful recommendations and example questions for oncology clinicians to ask when addressing patient CM use. In addition, to improve communication about

relevant aspects of CM, such as counseling on safety and effectiveness, oncology clinicians will benefit from more education about CM. Although educational programs about CM for oncology clinicians have been developed and evaluated [38, 39], they are not incorporated as standard in medical education.

CONCLUSION

It is important that both patients and clinicians feel comfortable discussing the topic of CM in oncology, given the widespread use and the potential benefits and risks related to it. When it becomes routine practice in oncology to explore patients' interest in and usage of CM, this will minimize the potential risks and maximize the benefits of CM use for patients with cancer. Future studies should investigate the needs and expectations of clinicians and patients with cancer in regard to discussing CM.

REFERENCES

- Horneber M, Bueschel G, Dennert G, Less D, Ritter E, Zwahlen M. How Many Cancer Patients Use Complementary and Alternative Medicine: A Systematic Review and Metaanalysis. Integr Cancer Ther 2012;11:187-203.
- 2. Keene MR, Heslop IM, Sabesan SS, Glass BD. Complementary and alternative medicine use in cancer: A systematic review. Complement Ther Clin Pract 2019;35:33-47.
- Paltiel O, Avitzour M, Peretz T, Cherny N, Kaduri L, Pfeffer R, et al. Determinants of the use of complementary therapies by patients with cancer. J Clin Oncol 2001;19:2439-48.
- 4. Tautz E, Momm F, Hasenburg A, Guethlin C. Use of complementary and alternative medicine in breast cancer patients and their experiences: a cross-sectional study. Eur J Cancer 2012;48:3133-39.
- 5. West HJ. Complementary and alternative medicine in cancer care. JAMA Oncol 2018;4:139-39.
- Ambrosone CB, Zirpoli GR, Hutson AD, McCann WE, McCann SE, Barlow WE, et al. Dietary supplement use during chemotherapy and survival outcomes of patients with breast cancer enrolled in a cooperative group clinical trial (SWOG S0221). J Clin Oncol 2020;38:804-14.
- 7. Huang C-C, Ho T-J, Ho H-Y, Chen P-Y, Tu C-H, Huang Y-C, et al. Acupuncture Relieved Chemotherapy-Induced Peripheral Neuropathy in Patients with Breast Cancer: A Pilot Randomized Sham-Controlled Trial. J Clin Med 2021:10:3694.
- 8. He Y, Guo X, May BH, Zhang AL, Liu Y, Lu C, et al. Clinical evidence for association of acupuncture and acupressure with improved cancer pain: a systematic review and meta-analysis. JAMA Oncol 2020;6:271-78.
- 9. Lin K-Y, Hu Y-T, Chang K-J, Lin H-F, Tsauo J-Y. Effects of yoga on psychological health, quality of life, and physical health of patients with cancer: a meta-analysis. Evid Based Complement Alternat Med 2011;2011:659876.
- 10. Würtzen H, Dalton SO, Elsass P, Sumbundu AD, Steding-Jensen M, Karlsen RV, et al. Mindfulness significantly reduces self-reported levels of anxiety and depression: results of a randomised controlled trial among 336 Danish women treated for stage I–III breast cancer. Eur J Cancer 2013;49:1365-73.
- Lyman GH, Greenlee H, Bohlke K, Bao T, DeMichele AM, Deng GE, et al. Integrative therapies during and after breast cancer treatment: ASCO endorsement of the SIO clinical practice guideline. J Clin Oncol 2018;36:2647-55.
- Deng GE, Rausch SM, Jones LW, Gulati A, Kumar NB, Greenlee H, et al. Complementary therapies
 and integrative medicine in lung cancer: diagnosis and management of lung cancer: American
 College of Chest Physicians evidence-based clinical practice guidelines. Chest 2013;143:e420S-e36S.
- 13. Witt CM, Balneaves LG, Cardoso MJ, Cohen L, Greenlee H, Johnstone P, et al. A comprehensive definition for integrative oncology. J Natl Cancer Inst Monogr 2017;52:3-8.
- 14. Yun H, Sun L, Mao JJ. Growth of integrative medicine at leading cancer centers between 2009 and 2016: a systematic analysis of NCI-designated comprehensive cancer center websites. J Natl Cancer Inst Monogr 2017;52:29-32.
- Juraskova I, Hegedus L, Butow P, Smith A, Schofield P. Discussing complementary therapy use with early-stage breast cancer patients: exploring the communication gap. Integr Cancer Ther 2010;9:168-76.
- 16. Schofield PE, Juraskova I, Butow PN. How oncologists discuss complementary therapy use with their patients: an audio-tape audit. Support Care Cancer 2003;11:348-55.

- 17. Roter DL, Yost KJ, O'Byrne T, Branda M, Leppin A, Kimball B, et al. Communication predictors and consequences of Complementary and Alternative Medicine (CAM) discussions in oncology visits. Patient Educ Couns 2016;99:1519-25.
- 18. Koenig CJ, Ho EY, Trupin L, Dohan D. An exploratory typology of provider responses that encourage and discourage conversation about complementary and integrative medicine during routine oncology visits. Patient Educ Couns 2015;98:857-63.
- Tilburt J, Yost KJ, Lenz HJ, Zúñiga ML, O'Byrne T, Branda ME, et al. A Multicenter Comparison of Complementary and Alternative Medicine (CAM) Discussions in Oncology Care: The Role of Time, Patient-Centeredness, and Practice Context. Oncologist 2019;24:e1180.
- 20. Truant TL, Porcino AJ, Ross BC, Wong ME, Hilario CT. Complementary and alternative medicine (CAM) use in advanced cancer: a systematic review. J Support Oncol 2013;11:105-13.
- King N, Balneaves LG, Levin GT, Nguyen T, Nation JG, Card C, et al. Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. Integr Cancer Ther 2015;14:515-24.
- Davis EL, Oh B, Butow PN, Mullan BA, Clarke S. Cancer patient disclosure and patientdoctor communication of complementary and alternative medicine use: a systematic review. Oncologist 2012;17:1475.
- 23. Lee RT, Barbo A, Lopez G, Melhem-Bertrandt A, Lin H, Olopade OI, et al. National survey of US oncologists' knowledge, attitudes, and practice patterns regarding herb and supplement use by patients with cancer. J Clin Oncol 2014;32:4095.
- Roodbeen RT, Noordman J, Boland G, van Dulmen S. Shared Decision Making in Practice and the Perspectives of Health Care Professionals on Video-Recorded Consultations With Patients With Low Health Literacy in the Palliative Phase of Their Disease. MDM Policy Pract 2021;6:23814683211023472.
- 25. Van Vliet LM, Francke AL, Meijers MC, Westendorp J, Hoffstädt H, Evers AW, et al. The Use of Expectancy and Empathy When Communicating With Patients With Advanced Breast Cancer; an Observational Study of Clinician–Patient Consultations. Front Psychiatry 2019;10:464.
- Mentink M, Noordman J, Busch M, van Vliet L, Timmer-Bonte JA, van Dulmen S. Towards an open and effective dialogue on complementary medicine in oncology: protocol of patient participatory study 'COMMON'. BMJ Open 2021;11:e053005.
- 27. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. Fam Med 2004;36:588-94.
- 28. Nederlands Huisartsen Genootschap. NHG-behandelrichtlijnen, https://richtlijnen.nhg.org/#tab--nhgbehandelrichtlijnen/; 2021 [accessed 6 September 2021].
- Federatie Medisch Specialisten. Richtlijnendatabase, https://richtlijnendatabase.nl/; 2021 [accessed 6 September 2021].
- 30. Gezondheidsraad. Adviezen, https://www.gezondheidsraad.nl/; 2021 [accessed 6 September 2021].
- von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol 2008;61:344-49.
- 32. UNESCO International Standard Classification of Education Fields of Education and Training 2013 (ISCED-F 2013): Detailed Field Descriptions, UNESCO Institute for Statistics, Montreal, QC, 2015.

- National Center for Complementary and Integrative Health. Complementary, Alternative, or Integrative Health: What's In a Name?, https://www.nccih.nih.gov/health/complementaryalternative-or-integrative-health-whats-in-a-name/; 2021 [accessed 21 January 2021].
- 34. Balneaves LG, Watling CZ, Hayward EN, Ross B, Taylor-Brown J, Porcino A, et al. Addressing complementary and alternative medicine use among individuals with cancer: an integrative review and clinical practice guideline. J Natl Cancer Inst 2022;114:25-37.
- 35. Hann D, Baker F, Denniston M. Oncology professionals' communication with cancer patients about complementary therapy: a survey. Complement Ther Med 2003;11:184-90.
- 36. Lee RT, Kwon N, Wu J, To C, To S, Szmulewitz R, et al. Prevalence of potential interactions of medications, including herbs and supplements, before, during, and after chemotherapy in patients with breast and prostate cancer. Cancer 2021;127:1827-35.
- 37. Sewitch MJ, Cepoiu M, Rigillo N, Sproule D. A literature review of health care professional attitudes toward complementary and alternative medicine. Complement Health Pract Rev 2008;13:139-54.
- 38. Rogge AA, Helmer SM, King R, Canella C, Icke K, Pach D, et al. Effects of training oncology physicians advising patients on complementary and integrative therapies on patient-reported outcomes: A multicenter, cluster-randomized trial. Cancer 2021;127:2683-92.
- 39. Hayward EN, Watling CZ, Balneaves LG. A pre-post evaluation of oncology healthcare providers' knowledge, attitudes, and practices following the implementation of a complementary medicine practice guideline. Support Care Cancer 2021;29:1-9.

SUPPLEMENTARY MATERIALS

Supplementary material 1: Observational Coding Scheme

o. Type of complementary medicine discussed

1. Who initiated the conversation about complementary medicine?

- 1. Patient
- 2. Companion
- 3. Healthcare provider (question 3 code '4')

Indicate who initially started about the type of CM during the consultation.

If applicable, write down the sentence(s) from which this is apparent and who stated them:

2. How was the topic of CM introduced?

- 1. Statement or cue about CM
- 2. Direct question about CM
- 3. Answer to an indirect question

Indicate how the type of CM was introduced. This is the first sentence where the type of CM was mentioned, so do not code the sentence that preceded it.

Statement or cue – a statement is made about CM, e.g. P: "I was at the homeopath and he said..."

Direct question – a direct question is asked about CM, e.g. P: "how do you feel about using [CM]", "I heard about [CM]. What should I do with that?" or H: "Do you ever use [CM]?"

Answer to an indirect question – an answer is given to a question that did not specifically address the type of CM discussed, e.g. P: "I often feel tired" H: "have you tried [CM]?" or H: "do you use anything for that?" P: "Yes, I use [CM]"

If applicable, write down the sentence(s) from which this is apparent and who stated them:

3. What is the healthcare provider's initial response to complementary medicine being introduced?

- 1. Statement
- 2. Topic neglected
- 3. Question
- 4. Does not apply; healthcare provider introduced topic

Indicate the first response of the healthcare provider after the type of complementary medicine is mentioned.

Statement – the healthcare provider comments on the type of complementary medicine, e.g., "You shouldn't do that" or "that's fine to use". If the healthcare provider responds to the complaint for which CM is used and not to CM itself, score 2.

Topic neglected – the healthcare provider does not explicitly address the discussed type of complementary medicine by asking a question or making a statement, says nothing or only said "hm-hm" or "Yes". However, if the healthcare provider says "yes, yes" while listening and then expands on CM without another topic intervening, score 1 or 3.

Question – the healthcare provider asks a question about the type of complementary medicine, e.g., "What is that?" or "How often do you use that?"

If applicable, write down the sentence(s) from which this is apparent and who stated them:

4. Is consideration given to safety/potential risks of using the type of CM discussed?

- 1. Yes
- 2. No

Indicate whether any risks of the type of CM are discussed, such as possible side effects or interaction effects with conventional anti-cancer treatment, e.g. "[CM] can be dangerous in combination with chemotherapy" or "Beware of using too much [CM]". If it is mentioned that there are no risks and CM is safe to use, also score 1.

If applicable, write down the sentence(s) from which this is apparent and who stated them:

5. Is scientific (evidence-based) information about effectiveness of the type of CM discussed?

- 1. Yes
- 2. No

Indicate whether scientific information or evidence about effectiveness or working mechanism of the type of CM is mentioned, Examples: "Research has shown that [CM] can inhibit some tumor cells" or "That effect has not been proved."

If applicable, write down the sentence(s) from which this is apparent and who stated them:

6. Are costs or reimbursements of the type of CM discussed?

- 1. Yes
- 2. No or not applicable

Indicate whether the costs or health insurance reimbursement of CM are discussed.

If applicable, write down the sentence(s) from which this is apparent and who stated them:

7. Has the purpose of complementary medicine use been discussed?

- 1. Yes
- 2. No

If applicable, write down the sentence(s) from which this is apparent and who stated them:

Indicate whether it appears from the conversation what complementary medicine (CM) is used for e.g. a particular complaint.

Yes – e.g., if the topic of complementary medicine follows a discussion about a particular complaint to which it is obviously linked. It is not necessary that it is literally said: the purpose of [CM] is...

No – e.g., if CM is mentioned indirectly and it is not clear what the aim of its use is or for which health complaint it is used.

8. Are alternate options discussed for the type of CM as a result of the discussion?

- 1. Yes
- 2. No

Indicate whether, as a result of the discussion about CM, alternate options for the type of CM are being discussed and by whom. These can also be conventional options. Examples: "It's better to use [alternate option] than [CM]" or "We can also try [alternate option]"

If applicable, write down the sentence(s) from which this is apparent and who stated them:

9. Are internal or external information sources about the type of CM mentioned in the conversation?

- 1. Yes
- 2. No

Indicate whether information sources about the type of CM are discussed during the consultation, such as websites, articles, acquaintances, folders, (complementary) healthcare providers. Example: H: "You can check out this website for more information about [CM]" Examples: P: "A friend told me about [CM]" or "I read an article about [CM]"

If applicable, write down the sentence(s) from which this is apparent and who stated them:

10. Is a referral to (or contact with) a CM provider offered the healthcare provider or requested by the patient?

- 1. Yes
- 2. No or not applicable

If applicable, write down the sentence(s) from which this is apparent and who stated them:

11. Is CM used as an alternative to conventional anti-cancer treatment?

- 1. Yes
- 2. No

Indicate whether CM was suggested or used instead of conventional anti-cancer treatment.

If applicable, write down the sentence(s) from which this is apparent and who stated them:

12. Does the healthcare provider explicitly encourage the patient's choice?

- 1. Yes
- 2. No or unclear

Indicate whether patient choice in CM use is encouraged.

Yes – Healthcare provider uses words such as "You can decide that yourself" or "I'll leave the choice up to you" or "If you like that" or "Do you want that?"

No or unclear – healthcare provider makes the choice about CM use: "You really shouldn't do that" or no words are used that emphasize that the patient can make a choice to use CM.

If applicable, write down the sentence(s) from which this is apparent and who stated them:

13. What is the healthcare provider's attitude towards the type of CM discussed?

- 1. Encouraging
- 2. Discouraging
- 3. Neutral
- 4. Healthcare provider did not respond to CM

Indicate the attitude of the healthcare provider towards the type of CM discussed.

Encouraging – healthcare provider highlights benefits of CM through positive words. Examples: "That's very good", positive outcome expectations "That can help a lot" or encouragement of CM use "Try [CM]" or actively facilitating CM "Shall I ask [CM provider] to contact you?"

Discouraging – healthcare provider highlights the drawbacks of CM, such as "There is no proven effect", negative outcome expectations "I don't think that helps" or advises against CM use.

Neutral – healthcare provider highlights advantages and disadvantages of CM without expressing a clear preference about whether or not to use CM or healthcare provider agrees with the patient without expressing an opinion about CM himself.

Healthcare provider did not respond to CM – healthcare provider did not respond to CM (question 6, score 4), but only the complaint, for example.

If applicable, write down the sentence(s) from which this is apparent and who stated them:

14. What is the patient's attitude towards the type of CM discussed?

- 1. Positive
- 2. Negative
- 3. Neutral
- 4. Patient did not respond to CM

Indicate the patient's attitude towards the discussed type of CM.

Positive – patient highlights the benefits of CM use and uses positive words such as "I like going to my psychologist" or expects a positive effect from CM use "I eat very healthily" or expresses the wish to (continue to) use CM: "Can I still exercise?" or "I do that every day to stay healthy" **Negative** – patient highlights disadvantages of CM or expresses the preference to not use CM: "I don't like that"

Neutral – patient does not express an obvious preference or opinion about CM or its use such as "Okay that's fine" or indirectly mentions a form of CM: "I'm going to the physio" or "The dietician has told me to gain weight" or the patient highlights both pros as cons of CM use.

The patient did not discuss CM – healthcare provider or relative mentioned CM, but the patient did not specifically address this: "yes" or "hm hm".

If applicable, write down the sentence(s) from which this is apparent and who stated them:

15. Did the patient already used the type of complementary medicine discussed?

- 1. Yes
- 2. No or not clear

Indicate whether the discussed type of CM has already been used by the patient at the time of consultation

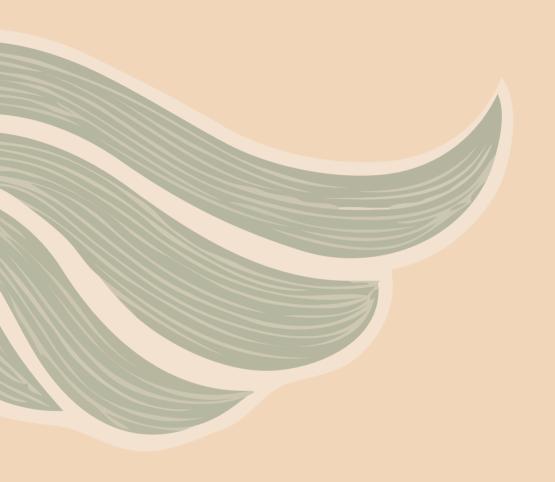
If applicable, write down the sentence(s) from which this is apparent and who stated them:

16. Has the patient's (intended) CM use changed as a result of the conversation?

- 1. Yes
- 2. No or not clear

Indicate whether the conversation about CM has led to a change in the patient's actual or intended CM use. If CM use was not suggested by the patient, but they mentioned that they decided to use it based on recommendation of the healthcare provider, code 'Yes'

If applicable, write down the sentence(s) from which this is apparent and who stated them:



CHAPTER IV

Communication and information provision about complementary medicine in oncology: experiences and needs of patients and healthcare providers

Marit Mentink, Liesbeth van Vliet, Martine Busch, Anja Timmer-Bonte, Janneke Noordman, Sandra van Dulmen

Submitted

ABSTRACT

Background and purpose

Complementary medicine, such as yoga, massage and art therapy, has become increasingly popular among patients with cancer. However, the topic remains underdiscussed during oncology consultations. Patients seem hesitant to disclose complementary medicine use, and healthcare providers lack the resources to discuss complementary medicine. This study assesses the needs of patients with cancer and healthcare providers in oncology considering communication and information about complementary medicine.

Materials and methods

Semi-structured interviews were conducted with 17 patients with cancer and 13 oncology healthcare providers recruited from three nonacademic hospitals in the Netherlands. Nine (former) patients with breast cancer collaborated with the research team as 'co-researchers'. Reflexive thematic analysis was used for the analysis of the interview data. The themes extracted from interviews of patients and healthcare providers overlapped and were therefore integrated.

Results

Negative attitudes and lack of time and knowledge among healthcare providers were identified as barriers to communication about complementary medicine during oncology consultations. Both patients and healthcare providers expressed the need for an open, proactive style of communication and information provision about complementary medicine in oncology care, whereby the topic of complementary medicine gets routinely discussed.

Conclusion

This study showed the need for tools to support patients and healthcare providers in communicating and providing information about complementary medicine. Reliable information, clustered in one place, that is easily accessible to patients and healthcare providers is warranted. Hospitals are preferably involved in the dissemination of reliable information about complementary medicine.

INTRODUCTION

In oncology, approximately 51% of patients use complementary medicine [1]. Examples of complementary medicine are dietary supplements, yoga, massage or art therapy. Complementary medicine is used together with conventional medicine and should not be confused with alternative medicine, that is used in place of conventional therapies [2]. Patients with cancer use complementary medicine to relieve symptoms from the disease, side effects of treatment or to influence their general health [1]. Examples of such interventions include mindfulness-based interventions for anxiety or depression or acupuncture for aromatase inhibitor-related joint pain [3, 4]. Although the use of complementary medicine is generally safe, some complementary medicine can interact with chemotherapeutic agents, such as herbs [5].

Despite the high prevalence of complementary medicine use among patients with cancer, previous research has shown that this topic is infrequently discussed during oncology consultations [6, 7]. Between 20% and 77% of patients with cancer do not disclose their complementary medicine use to their healthcare provider [8]. Patient nondisclosure appears to be influenced by the nature of patient-provider communication, such as lack of inquiry by the healthcare provider or fear of disapproval [8, 9]. In previous studies, oncology healthcare providers reported limited time to discuss complementary medicine and a lack of knowledge to provide patients with information about complementary medicine [7, 10, 11]. The gap between the fields of complementary and conventional medicine implies that patients are left on their own when using or being interested in complementary medicine. A previous study showed that online information about complementary medicine often contains unfounded claims [12]. Given the widespread use of complementary medicine among patients with cancer, open patient-provider communication and access to reliable information about complementary medicine are essential for the delivery of safe, person-centred cancer care.

Studies focusing on communication and providing information about complementary medicine in an oncology setting are scarce and often include either patients, physicians or nurses [10, 13]. Since most studies make use of a survey design [7, 14], it is not possible to ask additional questions to participants or to expose their underlying feelings, patterns and needs. To our best knowledge, an in-depth assessment of the needs of patients and healthcare providers considering communication and information provision about complementary medicine in oncology care is lacking.

The current study assesses the experiences and needs of patients and healthcare providers regarding communication and information provision about complementary medicine in an oncology setting. By combining the perspectives of patients and healthcare providers, we aim to gain insight into how to improve patient-provider communication and information provision about complementary medicine. The results will serve as input for the development of tools to support the conversation about complementary medicine during oncology consultations in a follow-up study.

MATERIALS AND METHODS

Semi-structured interviews were conducted to investigate the experiences and needs of healthcare providers and patients with cancer regarding communication and information provision about complementary medicine. To increase internal validity and relevance of the study, nine (former) patients with breast cancer collaborated with the research team as 'co-researchers'. The consolidated criteria for reporting qualitative research (COREQ) were used as guidance for describing the study [15]. This study is part of a larger mixed-methods research project about communication about complementary medicine titled 'COMMON' [16].

Participants and recruitment

The patient inclusion criteria were 1) in active treatment for cancer, or maximum 6 months ago, 2) aged \geq 18 years, and 3) sufficient command of Dutch. Healthcare providers were eligible to participate when they were mainly treating patients with cancer. Three non-academic hospitals in different regions of the Netherlands agreed to recruit participants. The hospitals were in different stages of development of initiatives regarding the implementation of complementary medicine in oncology care. Hospitals A and B offer patients interested in complementary medicine a consultation with a clinician with expertise about complementary medicine. Hospital C was in the process of establishing such a consultation for patients at the time of data collection. A combination of purposive and convenience sampling was used. A study coordinator was appointed in each hospital who face-to-face approached eligible participants. If participants were interested in participation, the study coordinator shared their contact details with the researcher (MM, female, M.Sc.), who contacted the potential participants by telephone or e-mail.

Interview guide

For the semi-structured interviews, an interview guide (Supplemental file 1) was developed in close collaboration with the co-researchers. First, the research team

proposed relevant themes for the interview guide based on previous literature and expertise of the research team. Then the interview guide was supplemented and improved based on feedback of the co-researchers. The final version of the interview guide involves three main topics: 1) experiences with communication about complementary medicine, 2) experiences with information provision about complementary medicine, and 3) the needs of participants considering the (to be developed) conversation-supporting tools. Given that comprehension of the definition of complementary medicine among participants could not be assumed, the first interview question was: How would you define complementary medicine?. If the definition provided by the participant deviated significantly from that of complementary medicine as defined by NCCIH [2], the researcher explained what constitutes complementary medicine before continuing the interview.

Data collection

The interviews took place between September 2021 and March 2022. Because of COVID-19 restrictions during that time, participants could indicate their preference for an online interview (via Zoom or Microsoft Teams) or face-to-face interview at home. Preceding each interview, participants provided online informed consent and background characteristics were collected through an online form. Participants were interviewed in Dutch by a researcher (MM or MB, female, M.Sc.) and a co-researcher. Participants had no prior knowledge of the researchers that interviewed them. The co-researchers received an online training session on how to conduct interviews with healthcare providers and fellow patients organized by an independent consultancy office (IKONE). The researcher led the interview, and the co-researcher could pose additional or in-depth questions to the interviewee at any time. The semi-structured interviews were audio-recorded. The audio-recording of each interview was transcribed verbatim and the transcript was authorized by the participant. After data saturation was reached according to the researcher (MM), two more participants in each category (patients and healthcare providers) were interviewed. Upon finishing the data collection, the audio-recordings of the interviews were deleted. The coresearchers were invited to share their experiences with co-interviewing with each other and the research team during an online evaluative session.

Data analysis

Transcripts were analyzed using reflexive thematic analysis as described by Braun and Clarke [17]. Using MAXQDA 2022 software, transcripts were coded by one researcher (MM). A combination of coding techniques was used. The entire dataset was read and coded (i.e., inductive content analysis) and a detailed account of themes relevant to the research question was subsequently provided (i.e., deductive content analysis). To increase the reliability of the results, a second researcher (LV, female, PhD) coded two transcripts, and the results were discussed with the main coder (MM), after which the coding scheme was optimized and presented to the research team (SvD, female, PhD; JN, female, PhD; ATB, female, MD, PhD; MB). After the feedback was received during this session, all transcripts were coded again by the researcher (MM). Initially, the interview data of patients and healthcare providers were analyzed as separate samples. However, due to the large overlap in the themes extracted from the samples and to increase the readability of the results, it was decided to merge the themes from patients and healthcare providers. The co-researchers were asked for their interpretation of the findings in an online session. To illustrate the findings, quotes obtained from the transcripts were used and translated from Dutch to English by a translation office.

RESULTS

Seventeen patients with cancer and thirteen healthcare providers were interviewed (Table 1). The average interview duration was 27 minutes (SD=9, range=9-44). Three main themes and six subthemes were extracted from the interview data of patients and healthcare providers (Table 2).

Table 1. Participant characteristics

Healthcare providers (n=13)	
Age	
Mean (SD), range	47 (11), 22-62
Sex	
Female	9
Male	4
Profession	
Physician	6
Nurse practitioner	5
Nurse	2
Years of experience in current profession	
Mean (SD), range	11 (7), 0.5-27
Patients (n=17)	
Age	
Mean (SD), range	57 (10), 38-71
Sex	
Female	14
Male	3

Table 1. Continued

Patients (n=17)	
Highest education ¹	
Low	1
Intermediate	5
High	11
Type of cancer	
Breast	12
Lung	4
Bladder	1
Time since diagnosis (in months)	
Mean (SD), range	15 (13), 2-48
In active anticancer treatment	
Yes	15
No (<6 months)	2
Complementary medicine user	
Yes	13
No	4

¹ classified according to ISCED-F 2013 [18]

Table 2. Extracted (sub)themes from interviews about experiences and needs related to communication and information provision about complementary medicine (CM) with patients and healthcare providers (HCPs)

Themes	Subthemes
Barriers to patient-provider communication about CM	 Lack of time and knowledge among HCPs to discuss CM with patients Negative attitudes toward CM at the HCP and hospital levels
2. Facilitators of patient-provider communication about CM	 Openness of HCPs to discuss CM with patients CM embedded as routine topic during oncology consultations, by initiation of the HCP
3. Needs for information about CM	 Easily accessible oversight of effective, safe and affordable CM options for patients with cancer Involvement of hospital in information provision about CM to patients

Barriers to patient-provider communication about complementary medicine

When patients and healthcare providers were asked about their experiences with communicating about complementary medicine during oncology consultations, two barriers were recurrent: 1) the lack of resources of time and knowledge among healthcare providers and 2) the occurrence of negative attitudes toward complementary medicine.

Lack of time and knowledge among healthcare providers

Both patients and healthcare providers reported they lack time to discuss the topic of complementary medicine during oncology consultations. Patients mentioned feeling rushed during consultations, which left no space to talk about complementary medicine. According to patients and healthcare providers, nurses or nurse practitioners have more time reserved for patients than physicians, which facilitates communication about complementary medicine. When patients did ask questions about complementary medicine to their healthcare provider, they often noticed a lack of knowledge of their healthcare provider. This lack of knowledge could lead to nondisclosure of complementary medicine use among patients:

"But I did keep suggesting it to the doctor. And it was always the same tune: 'I don't know.' [...] There came a point where I didn't speak to the doctor about it anymore." (Patient 15)

However, not all patients expected their healthcare providers to be knowledgeable about complementary medicine and felt that this topic was beyond the expertise of healthcare providers working in conventional care.

Many interviewed healthcare providers evaluated their knowledge about complementary medicine as insufficient, although some pursued education in the field of complementary medicine (e.g., basic courses, e-learning). Some healthcare providers mentioned the need for (more) education about complementary medicine, while others felt that education or searching for information about complementary medicine was beyond their scope or too time-consuming. If healthcare providers were unable to support patients with questions about complementary medicine, they often enlisted the support of colleagues with more expertise:

"Sure, it's really interesting to learn more about that [complementary medicine], but getting properly trained in it does take a great deal of time [...] The need for training isn't so great, or at any rate it doesn't outweigh the need for someone who's got expertise in it." (Nurse practitioner 4)

Negative attitudes toward complementary medicine at healthcare provider and hospital levels

When discussing complementary medicine during oncology consultations, many patients were confronted with a negative attitude by their healthcare provider, for instance expressed by acting annoyed or being nonresponsive or unsupportive of complementary medicine use. Some patients experienced that their healthcare

provider explicitly stated that they did not want to talk about complementary medicine. Other patients felt that their healthcare provider was not open to discussing the subject. Although most of the interviewed patients did not feel anxious about introducing the topic of complementary medicine to their healthcare provider, some patients and healthcare providers stressed that not all patients are likely to be assertive enough:

"I don't mind sticking my oar in and mentioning it [complementary medicine], but I think that a lot of people need to be pushed into it a bit, partly because there's such a taboo about the subject." (Patient 5)

"With some specialists you need to be pretty assertive as a patient to bring it [complementary medicine] up, and sometimes they just wave it away." (Nurse practitioner 1)

None of the interviewed healthcare providers evaluated themselves as having a negative attitude toward complementary medicine, although some made mention of colleagues dismissing complementary medicine as nonsense. It seems that negative attitudes expressed by colleagues can impact the behavior of healthcare providers when discussing complementary medicine with patients:

"You're working with an oncologist, with a doctor who may have their own very firm opinions about it [complementary medicine], and so you don't want to say or advise exactly the opposite." (Nurse practitioner 4)

Other healthcare providers described fear and resistance among the hospital board when trying to launch initiatives considering complementary medicine. Some healthcare providers emphasized the importance of making a clear distinction between complementary (e.g., alongside conventional treatment) and alternative medicine (e.g. instead of conventional treatment) to reassure sceptics.

Facilitators of patient-provider communication about complementary medicine

The interviews exposed several facilitators of communication about complementary medicine that were related mainly to openness toward complementary medicine by healthcare providers and a routine introduction of the topic during consultations by healthcare providers.

Openness of healthcare providers

Patients and healthcare providers agreed on the importance of openness of healthcare providers to discussing the topic of complementary medicine during oncology consultations. Patients wanted to feel listened to when discussing complementary medicine with their healthcare provider, whereby attention should be given to the underlying need of patients. Several patients expressed the need to feel respected and understood in their decisions about complementary medicine use, regardless of the opinion of a healthcare provider about its use.

All the interviewed healthcare providers perceived themselves and most of their colleagues as open to communication about complementary medicine with patients. Some healthcare providers believed that an open attitude towards complementary medicine can improve the patient-provider relationship or patients' trust in the general treatment process. It seems that by healthcare providers explicitly expressing openness toward complementary medicine the threshold for patients to talk about complementary medicine can be lowered:

"I think that if you're a specialist, you do in fact need to be open to these things [complementary medicine] and should invite people to talk about it. Because otherwise they're not going to talk about it and will just go ahead anyway. [...] I mean, if you give your judgement straight away, they don't feel there's any scope for discussion." (Physician 2)

"My oncologist said to me – and I thought it was very good of him – that I've got the diagnosis now and there'll be hundreds of people with tips and advice. He told me I should listen and write down the things that I thought might be right for me, and then come back rather than spending entire days on the internet looking things up. Because you hear so many stories. He said, then we can look together at what suits you and what we can do to help you. [...] Well, I thought that was really nice because they're not just being dismissive. You don't have to do it on the sly, as it were – I've never had that feeling." (Patient 11)

Although patients shared varying experiences with the degree of openness of their healthcare providers toward discussing complementary medicine, some patients and healthcare providers noticed a shift toward more positive attitudes regarding complementary medicine in recent years:

"I do reckon the trend is improving, though. That's because I've been involved with it for years now, so I can also see that it's getting better. That more attention is already being paid to it [complementary medicine]." (Patient 3)

"It's completely different to how it was years ago, when you kept it [complementary medicine] strictly at arm's length, right? Because back then in the consulting rooms it was always, 'Well, no, you shouldn't start on that' and 'We don't know anything about that'." (Nurse practitioner 4)

Routine discussion about complementary medicine initiated by the healthcare provider

The interviewed patients and healthcare providers stated that whether complementary medicine is discussed depends on the healthcare provider. Some interviewed healthcare providers said that they always assess patient complementary medicine use, while other healthcare providers do not. A few healthcare providers highlighted that patients do not always understand what the term 'complementary medicine' implies. Both patients and healthcare providers experienced that healthcare providers often pose general questions about what patients are "doing themselves" alongside anticancer treatment or only about specific components of complementary medicine, such as lifestyle or supplements.

In most cases, complementary medicine seems to be discussed on initiative of the patient. Some interviewed patients retrospectively felt that they missed potential helpful complementary medicine because the topic was not introduced by their healthcare provider:

"But it [complementary medicine] could have been discussed much earlier and it'd have been much more useful to me then. [...] And then I also wondered why I hadn't been told that." (Patient 16)

To ensure that each patient is at least aware of the existence of complementary medicine, almost all patients and healthcare providers advocated that complementary medicine should be embedded as a routine topic during oncology consultations. Healthcare providers should be the initiators of this discussion and probe patient interest or need for complementary medicine:

"Well, I think it'd be really nice if that [complementary medicine] was simply one of the things that was always discussed. [...] And alright, if there's no need for it, that can be made clear - or if there are no questions. But it should at least be mentioned at some point." (Patient 13)

"Well, what I really ought to do – and that's my plan for the near future, of course – is make it one of the standard questions: are you using complementary therapies or would you like to, and do you want information about that?" (Physician 4)

Some patients preferred to discuss complementary medicine with a specific type of healthcare provider, such as their nurse, oncologist or general practitioner. According to several patients and healthcare providers, nurses or nurse practitioners have a more comprehensive overview of patients, where the subject of complementary medicine is more appropriate. Physicians seem to focus more on medical issues, treatment plans and patient safety. However, a large proportion of patients and healthcare providers argued that the type of healthcare provider is not important but that other factors are. For instance, the patient-provider relationship, contact frequency or healthcare provider knowledge and time. Several healthcare providers were of the opinion that, regardless of being a nurse or physician, all healthcare providers should be open to discussing complementary medicine.

Between and within patient and healthcare provider samples, there was no agreement on an appropriate timing of a conversation about complementary medicine. However, immediately after diagnosis does not seem to be the ideal timing because patients are already overloaded with information at that time. However, a patient noted that this topic needs to be addressed at least in a timely manner to avoid adverse interactions with anticancer treatment. Given that patient needs for complementary medicine can constantly change depending on the phase of disease and treatment, interest should be monitored:

"I think that complementary medicine is actually something you should keep talking about throughout a course of treatment, for instance." (Nurse 2)

Needs for information about complementary medicine

The Internet is a source of information about complementary medicine widely used by patients and healthcare providers, although the information is perceived as scattered and not always reliable. Several patients and healthcare providers expressed the need for easy access to reliable, clustered information about complementary medicine and the involvement of the hospital in providing information.

Easily accessible information about effective, safe, affordable complementary medicine Most patients and healthcare providers described the need for a clear, concise overview of complementary medicine options for patients with cancer structured according to different domains of complementary medicine and according to symptoms or side-effects:

"You're then looking for things like 'fatigue' or 'neuropathy', or 'exercise or 'physiotherapy'... so there are different avenues of approach every time. [...] For example searching because of a side effect, or the relaxation aspect, or because of a question." (Patient 13)

"So it's really about starting from the questions that can arise and the symptoms that are present, keeping it very clear and simply using comprehensible language too." (Nurse practitioner 4)

In addition, patients and healthcare providers wanted to be informed about the safety of complementary medicine use in conjunction with anticancer treatment; about the evidence for its effectiveness, costs and reimbursement; and about the experiences with complementary medicine from other patients. Some patients did not have a need for information about the effectiveness or costs of complementary medicine.

Easy access to information about complementary medicine is crucial according to the interviewed patients and healthcare providers. Several healthcare providers mentioned the need for information about complementary medicine to be clustered in one place instead of being scattered among (inter)national websites and databases. healthcare providers preferred to access information about complementary medicine online through a website or an app. Patients and healthcare providers reasoned that information about complementary medicine intended for patients should not be exclusively available online but also on paper to include less digitally proficient patients. Some healthcare providers added the importance of providing auditive or visual information about complementary medicine to patients with low literacy or language barriers.

Involvement of hospital in providing information about complementary medicine

Patients reported that their needs for information about complementary medicine are often unmet by the healthcare provider in the hospital, which makes patients feel on their own in the search for information about complementary medicine:

"Well, I do think I'd like it if the healthcare provider brought the subject up. [...] Because I sometimes get the feeling at the moment that I have to find everything out myself." (Patient 15) Searching for information is perceived as energy- and time-consuming by patients, especially when confronted with complaints due to the disease or its treatment. Information about complementary medicine retrieved from the Internet or from acquaintances often contradicts, is overwhelming in its amount or of questionable reliability. Therefore, patients envisioned a role for the hospital in providing information about complementary medicine, such as providing a leaflet or website with information or offering consultations with an in-house expert on complementary medicine or referring to regional complementary medicine practitioners. According to patients and healthcare providers, the involvement of the hospital increases the reliability of the information and creates an opening for patient-provider communication about complementary medicine:

"Lots of websites are unreliable, so if the hospital puts it all together you'll have a reliable website that's genuinely useful to you. [...] You know, that the information has been checked and an expert has looked it through. The hospital should take the first steps to point you in the right direction." (Patient 1)

"Yes, I think so: if a hospital is open to the idea and puts information on the website there, I think that people will go there and start clicking to find out whether this thing or that might be right for them. Which might perhaps make them feel a bit more encouraged to start that kind of discussion with a case manager or a doctor." (Patient 7)

"A few pages on our hospital's website, for instance – that alone would feel like something reliable, as it were. If something sensible is said there." (Nurse practitioner 4)

Healthcare providers frequently mentioned that they would like to use complementary medicine information support tools in interaction with patients, for instance, by looking at it together during consultations. Some healthcare providers stressed that discussing complementary medicine during consultations should be leading and that information support tools should only be used alongside this discussion.

DISCUSSION

This study assessed the experiences and needs of patients and healthcare providers regarding communication and information provision about complementary medicine in an oncology setting in the Netherlands. Strikingly, patients and healthcare providers

expressed similar experiences regarding barriers to and facilitators of communication about complementary medicine and aligned needs given the improvement in the provision of information about complementary medicine. The results point to the need for open, routine communication about the topic of complementary medicine initiated by healthcare providers and for clustering information about complementary medicine in one place, with an important role for the hospital in information dissemination.

The results showed varying experiences of patients with communication about complementary medicine in oncology care. Barriers identified in previous studies, such as skepticism and a lack of time and knowledge of healthcare providers [7, 10], seem still relevant and contributing to the non-disclosure of complementary medicine use among patients. The interviewed healthcare providers acknowledged the lack of time and knowledge to adequately discuss complementary medicine with patients. Notably, a skeptical attitude was mainly recognized in some colleagues but not in themselves. The study results indicated that healthcare providers are inclined to adopt a 'reactive style' toward communicating about complementary medicine, i.e., the topic is addressed only when brought up by a patient. Indeed, previous literature shows that patients are the main initiators of discussions about complementary medicine [6, 7]. Both patients and healthcare providers in this study expressed the need for healthcare providers to adopt a more active style of communication about complementary medicine. The participants advocated for a routine discussion about complementary medicine on initiation of a healthcare provider. This will ensure that all patients become aware of the benefits and risks of complementary medicine use during anticancer treatment, regardless of patient assertiveness in introducing the topic themselves.

Previous studies showed that being female and having a high education level are predictors for complementary medicine use among patients with cancer [1, 19]. Therefore, healthcare providers should ensure to discuss the topic also with male patients and lower-educated patients. In addition, attention should be paid to patients' understanding of the concept of complementary medicine. According to some interviewed healthcare providers, clarifying the difference between complementary and alternative medicine is crucial for diminishing taboo surrounding complementary medicine among healthcare providers. In addition, a previous study showed that increased awareness and knowledge about complementary medicine among healthcare providers can contribute to more positive attitudes [11].

Some interviewed participants were of the opinion that discussing the topic of complementary medicine better suits nurses. Nurses, compared to physicians, seem to have more consultation time and a broader overview of patients. It is unclear

whether nurses are more likely to discuss complementary medicine with patients, but previous studies showed that nurses in cancer care are generally positive and supportive towards complementary medicine despite not necessarily having adequate knowledge on the topic [11]. However, assigning the responsibility for discussing complementary medicine to a specific type of healthcare provider, such as a nurse, might not be the appropriate approach. The participants of the current study advocated for a collective responsibility among healthcare providers to openly and actively discuss the topic of complementary medicine.

Given the lack of time and knowledge, most healthcare providers will need support when discussing complementary medicine. The healthcare providers that were interviewed expressed a great need for an overview of the effectiveness, safety and affordability of complementary medicine. This information should be clustered in a place that is easy to access for both healthcare providers and patients, so it can also be used interactively during consultations. The interviewed patients currently experienced difficulties in navigating through the online landscape that provides them with an overwhelming amount of information about complementary medicine, which is often contradictory or unreliable [12]. Without the support of their healthcare provider, patients felt alone in their search for information about complementary medicine. This lack of support may not only affect the patient-provider relationship but also could compromise patient safety, for instance when healthcare providers remain unaware of patients using complementary medicine that interacts with anticancer treatment [5].

The study results highlight the importance of prioritizing the improvement of information provision about complementary medicine in oncology. Patients with cancer desire to receive information about effective, safe and affordable complementary medicine from the hospital where they are being treated. Handing out a leaflet or placing information about complementary medicine on the hospital website could lower the threshold for patients to introduce the topic to their healthcare provider. Beyond the hospital, it is conceivable that national cancer patient associations or information platforms for patients provide reliable, clustered information about complementary medicine. When reliable information about complementary medicine is made easily accessible, patients with cancer can be empowered to take an active role in discussing the topic with their healthcare provider. This is especially important since it can currently not be assumed that complementary medicine is addressed on initiation of the healthcare provider. Future studies should also prioritize the development of tools that support patients and healthcare providers in discussing complementary medicine during oncology consultations.

Strengths and limitations

The current study combined the perspectives of patients with cancer, physicians and nurses on communication and information provision about complementary medicine. Their experiences and needs were extracted from in-depth interviews. The involvement of nine (former) patients with breast cancer as co-researchers increased study validity and relevance. The co-researchers actively collaborated with the researchers in establishing the interview guide, conducting interviews and interpreting the results.

The three hospitals from which participants were recruited, could be considered early adapters since initiatives considering complementary medicine were already established or in progress in the oncology department. This probably led to selection bias, in which most interviewed healthcare were open to complementary medicine to a greater or lesser extent. In addition, most interviewed healthcare providers were female. Female healthcare providers are found to be more likely to initiate discussions about complementary medicine [20] and to express positive attitudes towards complementary medicine compared to male healthcare providers [21]. In the patient sample, female breast cancer patients with a high education level were overrepresented. This is a profile representative of complementary medicine users according to previous systematic reviews [1, 19]. Accordingly, most included patients were familiar with the use of complementary medicine. The above described selection bias increases the likelihood of patients and healthcare providers expressing an opinion about barriers, facilitators and solutions for communicating and providing information about complementary medicine during an interview. When the included healthcare providers had above average positive attitudes towards complementary medicine, it is possible that certain barriers for communication and information provision about complementary medicine have not surfaced. Different needs could emerge when participants were recruited from a hospital without initiatives regarding complementary medicine. Selection bias can compromise the reliability of the results and it is important to take into account when interpreting and generalizing the study findings. Nonetheless, it is likely that the need for improved communication and information provision expressed by the interviewed patients is generalizable. Especially given that half of the patients with cancer uses complementary medicine [1], with on top of that, an unknown number of patients with cancer is interested in complementary medicine.

CONCLUSIONS

This study showed that patients are often dissatisfied with communication about complementary medicine in conventional oncology care due to prevailing skepticism and a lack of knowledge and time among healthcare providers. A more active style of healthcare provider communication about complementary medicine during oncology consultations is warranted. Patients and healthcare providers are in great need for reliable information about complementary medicine, that is easily accessible in one place (e.g., website, leaflet). The hospital is preferably involved in information provision about complementary medicine. Given that the emergence of the topic of complementary medicine during oncology consultations is inevitable, meeting patient and healthcare provider demands for communication and information provision about complementary medicine is essential for the delivery of safe, personcentred cancer care. Future studies should develop tools to support communication and information provision about complementary medicine.

REFERENCES

- Keene, M.R., et al., Complementary and alternative medicine use in cancer: A systematic review. 1 Complementary therapies in clinical practice, 2019. 35: p. 33-47.
- National Center for Complementary and Integrative Health. Complementary, 2. Alternative, or Integrative Health: What's In a Name? 2018 21 January 2021]; Available from: https://www.nccih.nih.gov/health/complementary-alternative-or-integrative-healthwhats-in-a-name.
- Mao, J.J., et al., Integrative medicine for pain management in oncology: society for integrative oncology-ASCO guideline. Journal of Clinical Oncology, 2022. 40(34): p. 3998-4024.
- Carlson, L.E., et al., Integrative Oncology Care of Symptoms of Anxiety and Depression in Adults With 4. Cancer: Society for Integrative Oncology-ASCO Guideline. Journal of Clinical Oncology, 2023: p. JCO. 23.00857.
- Fasinu, P.S. and G.K. Rapp, Herbal interaction with chemotherapeutic drugs—a focus on clinically significant findings. Frontiers in oncology, 2019. 9: p. 1356.
- Mentink, M.D., et al., How is complementary medicine discussed in oncology? Observing real-life communication between clinicians and patients with advanced cancer. Patient Education and Counseling, 2022. **105**(11): p. 3235-3241.
- King, N., et al., Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. Integrative cancer therapies, 2015. 14(6): p. 515-524.
- Davis, E.L., et al., Cancer patient disclosure and patient-doctor communication of complementary and alternative medicine use: a systematic review. The oncologist, 2012. 17(11): p. 1475.
- Foley, H., et al., Disclosure of complementary medicine use to medical providers: a systematic review and meta-analysis. Scientific reports, 2019. 9(1): p. 1573.
- Balneaves, L.G. and C.Z. Watling, "Part of the Conversation": A Qualitative Study of Oncology Healthcare Professionals' Experiences of Integrating Standardized Assessment and Documentation of Complementary Medicine. Integrative Cancer Therapies, 2022. 21: p. 15347354221077229.
- Keene, M.R., et al., Knowledge, attitudes and practices of health professionals toward complementary and alternative medicine in cancer care-a systematic review. Journal of Communication in Healthcare, 2020. 13(3): p. 205-218.
- 12. Bianchini, C., et al., Avoiding misleading information: a study of complementary medicine online information for cancer patients. Library & Information Science Research, 2019. 41(1): p. 67-77.
- 13. Corina, G., H. Christine, and G. Klein, Oncologists' experiences of discussing complementary and alternative treatment options with their cancer patients. A qualitative analysis. Supportive Care in Cancer, 2016. 24: p. 3857-3862.
- 14. Ge, J., et al., Patient-physician communication about complementary and alternative medicine in a radiation oncology setting. International Journal of Radiation Oncology Biology Physics, 2013. 85(1): p. e1-e6.
- Tong, A., P. Sainsbury, and J. Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International journal for quality in health care, 2007. 19(6): p. 349-357.
- Mentink, M., et al., Towards an open and effective dialogue on complementary medicine in oncology: protocol of patient participatory study 'COMMON'. BMJ open, 2021. 11(10): p. e053005.
- Clarke, V. and V. Braun, Thematic analysis: a practical guide. Thematic Analysis, 2021: p. 1-100.
- Statistics, U.I.f., International Standard Classification of Education Fields of Education and Training 2013 (ISCED-F 2013): Detailed Field Descriptions. 2015, UNESCO Institute for Statistics Montreal, QC.

- Guillaud, A., et al., Predictive factors of complementary and alternative medicine use in the general population in Europe: A systematic review. Complementary therapies in medicine, 2019. 42: p. 347-354.
- 20. Aveni, E., et al., Healthcare professionals' sources of knowledge of complementary medicine in an academic center. PLoS One, 2017. 12(9): p. e0184979.
- Schouten, A.E., et al., Perspectives and Attitudes of Dutch Healthcare Professionals Regarding the Integration
 of Complementary Medicine in Oncology. Integrative Cancer Therapies, 2023. 22: p. 15347354231164650

SUPPLEMENTARY MATERIALS

Supplementary material 1: Interview guide patients

Complementary medicine (CM)

- If you had to describe CM in one sentence, what would it be?
- Have you ever used any form of CM?

Communication about CM

- Has the subject of CM been discussed with you in the hospital where you are (have been) receiving treatment?
 - o If yes, who was the initiator? What was the trigger? What was the goal of the discussion?
 - o Were your expectations of the conversation met? Were you able to ask questions? How were they responded to? Did you receive answers/information?
 - o At what stage of treatment did you feel the need to discuss CM?
 - o If no, why was it not discussed? Would you like to discuss CM options with your health care provider?
- Do you think it is important for CM to be a topic of conversation at the hospital? Or that your health care provider knows about your CM use?
- With which health care provider would you prefer to discuss CM? Who should bring it up?
- What do you expect from the health care provider in a conversation about CM? E.g., attitude, role, type of information.
- What information about CM do you think is important to discuss? E.g., safety, reimbursement, providers.
- Would you like the health care provider at the hospital to refer you to a CM provider? Or another health care provider (e.g., family doctor)?
- Did you feel there were things that could be improved when discussing CM? Did you miss anything?
- What might help you discuss CM with your health care provider? When do you feel invited to have a conversation about CM?

Information provision about CM

- Have you searched for information about CM or CM providers? If yes, what kind of information? Where do you search/find information?
- What kind of information do you find important or do you need to decide whether to use CM? E.g., safety, efficacy, providers.

- When searching for information, did you experience difficulties or missed things?
- What could help you find information about CM?

Tools

- What do you think is important in a tool? What information should it contain?
- How would you like to access information? E.g., internet, leaflet, letter.
- Do you have any ideas on how we can help healthcare providers make CM more discussable with patients? E.g., information letters, websites, communication guide.

Supplementary material 2: Interview guide healthcare providers

Communication about CM

- Is the topic of CM discussed during consultations with patients? Do you ever get questions from patients?
 - o If yes, who initiated it? What triggered it? What was the goal for you?
 - o If no, what caused it not to be discussed? Would you like to talk to patients about CM? Do you think this is important?
- Do you have an idea of what patients expect from you when discussing CM? Can you meet those expectations?
- What role would you like to have regarding CM use of patients? E.g., inform, advise, monitor, refer, no role.
- With which regular health care provider do you feel the conversation about CM is best suited? At what stage of patient treatment?
- Do you think CM should be discussed with every patient? Who should initiate it?
- What aspects of CM do you think are important to discuss with patients? E.g., options, risks, evidence, reimbursements.
- Are you currently missing anything to adequately discuss CM with patients?
 - o What is the culture of hospital (department) regarding CM?
- What might help you in discussing CM with patients?
 - o Are there differences in what supports the discussion about CM with patients who already have knowledge/experience of CM and patients who do not?

Do you ever refer patients to CM providers?

- o If yes, how do you determine to which providers?
- o If no, would you like to? Why or why not?

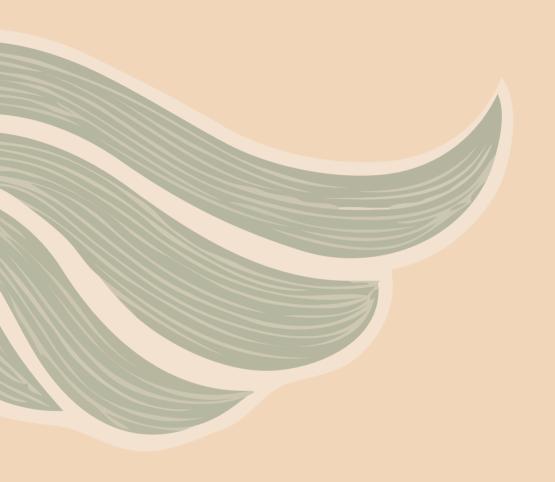
Information about CM

- Do you feel you have sufficient knowledge about CM to discuss the topic with patients?
 - o If yes, how was this knowledge acquired?

- Do you search for information about CM?
 - o If yes, what kind of information? Where do you look for find information?
- What is the importance of effectiveness and safety of CM to you? What are important outcomes? What is "sufficient" evidence?
- Do you ever experience difficulties when searching for information about CM or miss something?
- What might help you find information about CM?

Tools

- Are there any tools currently available to you to support a discussion about CM with patients? Or to acquire information about CM?
- What information should a tool contain?
- How would you prefer to access a tool? E.g., online, patient file, pocket card, mouse pad?
- What would make sure that a tool is usable by all health care providers?
- What should be the purpose of a tool?
- Do you have any ideas about tools we could develop to support patients in discussing CM or finding reliable information about CM?



CHAPTER V

Interprofessional contact with conventional healthcare providers in oncology: a survey among complementary medicine practitioners

Marit Mentink, Julia Jansen, Janneke Noordman, Liesbeth van Vliet, Martine Busch, Sandra van Dulmen

> BMC Complementary Medicine and Therapies 2024; 24(1), 285. doi: 10.1186/s12906-024-04563-6. PMID: 39061012

ABSTRACT

Background

Half of all patients with cancer use complementary medicine. Given the benefits and risks associated with complementary medicine use, contact between complementary medicine practitioners and conventional healthcare providers (oncologists, nurses) is important for monitoring the health and well-being of mutual patients with cancer. Research on occurrence of such interprofessional contact is scarce. This study aims to describe complementary medicine practitioners' experiences with contact with conventional healthcare providers about mutual patients with cancer and the importance they attach to patient disclosure of complementary medicine use to their conventional healthcare provider. Predictors for interprofessional contact are explored.

Methods

An online survey was administered among complementary medicine practitioners who treat patients with cancer or cancer survivors and who are member of a professional association in the Netherlands.

Results

The survey was completed by 1481 complementary medicine practitioners. Forty percent of the participants reported to have contact with conventional healthcare providers of patients with cancer. Only 13% of the complementary medicine practitioners experienced conventional healthcare providers as open to communication with them. An explorative logistic regression showed that openness of conventional healthcare providers as experienced by complementary medicine practitioners was the most important predictor for the occurrence of interprofessional contact (OR=8.12, 95% CI 5.12-12.86, p<.001). Most complementary medicine practitioners (82%) considered it important that patients disclose complementary medicine use to their conventional healthcare provider and 49% of the participants always motivates their patients to do so.

Conclusions

Interprofessional contact with conventional healthcare providers in oncology occurs but is not routine for most complementary medicine practitioners. More than one-third of the surveyed complementary medicine practitioners experienced conventional healthcare providers as not open to communication with them. The openness of conventional healthcare providers as experienced by complementary practitioners is an important predictor for interprofessional contact to take

place. Most complementary practitioners acknowledge the importance of patient disclosure of complementary medicine use to their conventional healthcare provider. Open communication about the topic of complementary medicine use between complementary practitioners, conventional healthcare providers and patients prevents overlooking relevant medical information and facilitates optimal monitoring of health and safety of patients with cancer.

BACKGROUND

Approximately half of all patients with cancer use complementary medicine (CM) (1). CM is a healthcare approach that is being used alongside conventional cancer treatment and includes many therapies, such as massage, acupuncture and nutritional supplements (2). CM can benefit the quality of life of patients with cancer, for instance acupuncture can be used for cancer pain management (3) and mindfulness-based interventions for depression and anxiety during cancer treatment (4). However, CM can also pose a risk to patients with cancer, for example when herbs and supplements interact with chemotherapy (5).

Given the potential benefits and risks for patients with cancer that use CM, communication between individuals providing CM (CM practitioners) and conventional healthcare providers (HCPs) is important for monitoring the health and safety of patients with cancer. However, there seem to be several barriers to such interprofessional contact. Generally, CM practitioners are located outside the hospital and often work independently of conventional HCPs such as oncologists and nurses. Other barriers described in two previous studies were unfamiliarity with each other's medical system, language barriers due to distinct terminology (6), medical dominance of conventional HCPs and the lack of role clarity (7). There are no guidelines available on interprofessional communication about CM between CM practitioners and conventional HCPs.

A previous study showed that physicians and CM practitioners regarded communication with each other as important, although only 7% of physicians and 18% of CM practitioners reported previously having such interprofessional contact (6). Importantly, only one previous study was conducted in an oncology setting and assessed actions to improve communication between CM practitioners and conventional HCPs in oncology, such as being trained in the other field, using common medical terminology and being located in the same practice (8). To the best of our knowledge, no further studies have been conducted on contact between CM practitioners and conventional HCPs about mutual patients with cancer.

Additionally, previous research shows that many patients with cancer do not disclose their CM use to their conventional HCP for reasons such as lack of inquiry or anticipated disapproval (9). The potential role of CM practitioners in motivating disclosure of CM use by patients to their conventional HCPs remains unclear.

This study therefore aims to assess CM practitioners' experiences with interprofessional contact with conventional HCPs about mutual patients with cancer and the importance they attach to patient disclosure of CM use to their conventional HCP. Potential predictors for interprofessional contact will be explored.

METHODS

An online survey was administered among complementary medicine (CM) practitioners in the Netherlands. This study is part of a larger mixed-method research project titled 'COMMON' (10).

Participants and sampling

CM practitioners were eligible for participation if they 1) currently treated patients with cancer or cancer survivors and 2) were members of a professional association for CM practitioners. Membership in a professional association is an important quality criterion for CM practitioners in the Netherlands (11). To recruit participants, a combination of convenience and purposive sampling was used. Eight professional associations of CM practitioners were directly approached with the request to distribute a link to the online version of the survey among their members. One association did not respond to the request, seven associations agreed with distributing the survey link (see Additional file 1, Table A1). The largest participating association (n=8858) was the Register for Complementary Medicine (RBCZ), an umbrella quality register for complementary medicine practitioners in the Netherlands. In addition, RBCZ requested 24 attached professional associations to distribute the link among their members (e.g. Dutch associations for naturopathy, psychology, homeopathy, shiatsu and reflexology). In response to the distributed survey link, two professional organizations approached us with the request to distribute the survey link among their members (i.e. snowball sampling). The average response rate among the seven actively approached professional associations was 9%.

The number of members at time of survey administration of members attached to other associations is unknown, so a response rate could not be calculated.

Materials and measures

The survey was designed by the research team. First, the researchers (SvD, JJ, MB) defined important themes in a brainstorm session and subsequently created a first draft of the survey. This draft was piloted in a group of coresearchers, consisting of nine (former) patients with cancer. The improvements based on this pilot consisted of the addition of answer options for three survey questions and minor adjustments in sentencing to improve comprehensibility of the questions or answer options. The final survey consisted of 17 items, including both open-ended and closed questions (see Additional file 2 for full survey). The first 10 items consisted of background characteristics of CM practitioners, such as demographics and the type of CM they provide to patients with cancer. To assess CM practitioner experiences with interprofessional contact, four items were included (e.g. contact frequency with conventional HCPs, experienced openness of conventional HCPs to communication). Two items consider the importance attached to patient disclosure about CM use. Last, a question about referral of patients with cancer to the CM practitioner was included. A link was created to direct participants to an online version of the survey. When For statistical analysis, SPSS version 27 was used.

Data collection and analysis

When opening the survey link, participants were first provided with information about the study, for instance about data use and expected time for survey completion (10-15 minutes). Participants were then asked to sign an online informed consent form and background characteristics were collected. If participants indicated that they did not treat patients with cancer or cancer survivors, they were thanked for their participation and excluded from the rest of the survey. The link to the online survey remained open for 2 months (Aug-Sep 2022). In the first week of September 2022, the approached participating professional organizations sent a reminder to their members about the survey.

After finishing data collection, one researcher (MM) recoded the answers to open questions into relevant categories using qualitative analysis. Because of the large amount of categories for type of cancer of visiting patients, type of CM modality provided and type of symptom treated, only the five most common categories were reported in the Results section. Question 11 ("When you provide therapy to patients who have/had cancer, in general how often do you have contact with doctors or nurses who treat the patient?") was recoded into three categories. The first category ('no') consisted of participants who indicated that they never communicated with conventional HCPs about their mutual patients with cancer. The second category ('yes') comprised participants who indicated communicating with conventional HCPs during patient treatment, independent of the frequency of communication. Answers that did not fit into these two categories (e.g. contact only through patients) were categorized as 'other'. It was decided to exclude question 17 ("How do patients who have/had cancer get to visit you?") from analysis because its answer categories were not mutually exclusive and the word 'referral' was not clearly defined in the answer options.

Descriptive statistics were used to present the data on background characteristics, experiences of CM practitioners with interprofessional contact and the importance they attach to patient disclosure of CM use. To explore factors that predict contact between CM practitioners and conventional HCPs, a logistic regression analysis (two-sided, p<0.05) was performed in consultation with a statistician. The dependent variable 'interprofessional contact' (Q11) was recoded into a binary variable (yes/no) by excluding the 'other' category. Of the available variables, six seemed relevant and appropriate as predictor. The predictor 'sex' (Q2) was also recoded into a binary variable (male/female) by removing the category 'other', which consisted of only four participants. For each predictor, the largest category was used as a reference.

RESULTS

In total, 1961 participants gave informed consent for participation, of which 17 participants were excluded because they were not members of a professional association (see Figure 1) and 458 participants because they indicated that they did not treat patients with cancer or cancer survivors. Eventually, 1486 participants were included.

Most participating CM practitioners were female (82%), with a mean age of 56.9 years (SD=8.1) (see Table 1). Years of experience treating patients with cancer ranged from 0 to 45 years, with a mean of 11.4 years (SD=8.5). On average, CM practitioners reported being visited by 3 to 4 patients with cancer per month.

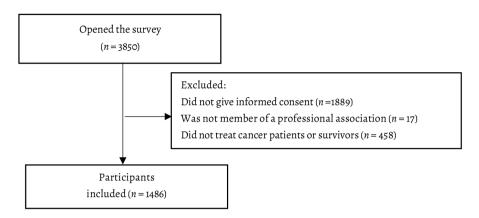


Figure 1. Flowchart exclusion criteria survey response

Experiences with interprofessional communication

Half of the surveyed CM practitioners indicated that they do not have contact with conventional HCPs (see Table 2). Forty percent of the participants had occasional or frequent contact with conventional HCPs of patients with cancer. CM practitioners who gave other answers for instance indicated that contact with the conventional HCP only takes place through the patient. More than one-third of the CM practitioners (35%) did not experience conventional HCPs to be open to interprofessional communication.

If CM practitioners communicated with conventional HCPs, this was most frequently by phone (36%). CM practitioners reached out to conventional HCPs to report the treatment plan (27%) or treatment progress (32%). This was sometimes preceded by a referral from a conventional HCP, as appeared from the answers to this open-ended question. In many cases, respondents mentioned that they do not receive a response from the conventional HCP to their report. In other cases (21%), interprofessional communication between CM practitioners and conventional HCPs consisted of joint coordination, for instance by discussing contraindications for CM use.

Importance of patient disclosure of CM use

The majority (82%) of the CM practitioners indicated that they consider it important that patients disclose their CM use to their conventional HCP and that approximately half of the CM practitioners always motivate their patients to do so. CM practitioners who gave other answers frequently mentioned that patients were anxious to disclose CM use to their conventional HCP.

Table 1. Background characteristics of surveyed complementary medicine practitioners (n=1486)

Variable	No. (%)
Sex	
Male	255 (17%)
Female	1219 (82%)
Other	4 (0%)
missing	8 (1%)
Age in years	
Mean (SD)	56.9 (8.1)
Range	26-84
missing	17 (1%)
Education level ^a	
Low	0 (0%)
Intermediate	6 (0%)
High	1454 (98%)
missing	26 (2%)
Mean years of experience with treating	
cancer patients	
Mean (SD)	11.4 (8.5)
Range	0-45
missing	46 (3%)
Mean monthly number of cancer patient visiting	
Mean (SD)	3.5 (6.9)
Range	0-124
missing	90 (6%)
Five most common cancer types of patients visiting	
CM practitioners b	
Breast	692 (47%)
Colorectal	414 (28%)
Blood	296 (20%)
Lung	250 (17%)
Prostate	192 (13%)
Five most provided complementary therapies by	
CM practitioners ^b	
Massage therapy	479 (32%)
Lifestyle counselling	439 (30%)
Relaxation exercises	418 (28%)
Dietary counselling	340 (29%)
Acupuncture	310 (21%)
Five most treated cancer patient symptoms by	<u> </u>
CM practitioners b	
Fatigue	1240 (83%)
Anxiety	1012 (68%)
Sleeping problems	944 (64%)
Depression	874 (59%)
Concentration problems	684 (46%)

Percentages may add to less or more than 100% due to rounding

^a Classified according to CBS 2017 (14)

^b Participants could choose multiple answer options. See Additional file 1 for a comprehensive overview.

Variable						No. missing (%)
Do you communicate with conventional HCPs of patients with cancer?	ıtional HCPs of patients witl	ı cancer?				
Yes	No	Other a				
591 (40%)	743 (50%)	133 (9%)				(%1) 61
If yes, which method do you use f	for communication with conventional HCP? (n=591)	entional HCP? (n=591)				
Phone	E-mail	Letter	Electronic medical record	Face to face	Other ^b	
212 (36%)	116 (20%)	96 (16%)	26 (4%)	20 (3%)	114 (19%)	7 (1%)
If yes, what is the subject of comn	munication with conventional HCP (n=591)	!] HCP (n=591)				
To report progress or evaluation of complementary treatment	To report complementary treatment plan	To align conventional and complementary treatment	To ask for or share patient information	Other °		
187 (32%)	158 (27%)	126 (21%)	86 (15%)	83 (14%)		55 (9%)
How do you experience conventional HCPs' openness to communication about patients with cancer?	onal HCPs' openness to comr	nunication about patients wit	h cancer?			
Most clinicians are not open	Most clinicians are open	No opinion	Other ^d			
525 (35%)	193 (13%)	427 (29%)	327 (22%)			14 (1%)
How important do you think it is that patients discuss CM use with their conventional HCP?	that patients discuss CM use	with their conventional HCP				
Very important	Quite important	Little important	Not important	No opinion		
887 (60%)	328 (22%)	101 (7%)	26 (2%)	103 (2%)		41 (3%)

•	τ	3
	ď	
	2	5
	-	4
	2	
	-	-
	+	٠
	-	
	7	Ξ
(:	J
	_	
	_	:
	c	٧
	•	١
	<u> </u>	2
	-	٦
۰	÷	5
	ď	ú
1	2	4
٠	•	

Variable				No. missing (%)
How often do you motivate pati	atients to discuss their CM	ients to discuss their CM use with their conventional HCP?	HCP?	
Always	Sometimes	Never	Other °	
730 (49%)	401 (27%)	134 (9%)	189 (13%)	32 (2%)

Percentages may add to less or more than 100% due to rounding

^a E.g. contact through patient

 $^{\text{b}}\,E.g.$ via a secured digital environment or using multiple methods

 $^{\circ}\,E.g.$ relevant information depending on situation

 $^{\rm d}$ E.g. situation-dependent (patient, symptoms, HCP)

E.g. patients' own decision, patients are anxious to disclose CM use, lack of openness conventional HCP, situation-dependent

Predictors of interprofessional contact

The explorative, multivariate logistic regression model shows three significant predictors of interprofessional communication with conventional HCPs as reported by CM practitioners (see Table 3). CM practitioners with more years of experience in treating patients with cancer were significantly more likely to have contact with conventional HCPs (OR=1.05, 95% CI 1.04-1.06, p<.001), although the effect was small. Compared to CM practitioners who experience conventional HCPs as not being open to communication with them, CM practitioners who experience conventional HCPs as open to communication are significantly more likely to have interprofessional contact (OR=8.12, 95% CI 5.12-12.86, p<.001). This also applies to CM practitioners who gave other answers (e.g. experienced openness of HCPs is situation-dependent), who are more likely to communicate with conventional HCPs compared to CM practitioners who experience conventional HCPs as not open (OR=2.54, 95% CI 1.82-3.54, p<.001). CM practitioners who have no opinion on the experienced openness of HCPs are significantly less likely to have interprofessional contact with conventional HCPs compared to CM practitioners who experience HCPs as not open to interprofessional communication (OR=0.66, 95% CI 0.47-0.92, p<.05). CM practitioners who consider patient disclosure of CM use to their conventional HCP quite or little important are less likely to have contact with conventional HCPs of the patient compared to CM practitioners who consider patient disclosure of CM use very important (OR=0.70, 95%CI 0.51-0.96, p<.01/OR=0.39, 95%CI 0.23-0.68, p<.001).

Table 3. Multivariate logistic regression predictors for interprofessional contact (IPC) (n=1186)

Predictor	В	S.E.	OR	95% CI
Sex (female)	-0.29	0.18	0.75	0.53-1.05
Age	0.02	0.01	1.02	1.00-1.04
Years of experience with cancer patients	0.05***	0.01	1.05	1.04-1.06
Monthly number of cancer patients visiting	0.03	0.02	1.03	1.00-1.06
Experienced openness of conventional HCP to IPC (Most HCP are not open to IPC)				
Most HCP are open to IPC (1)	2.09***	0.24	8.12	5.12-12.86
No opinion (2)	-0.42*	0.17	0.66	0.47-0.92
Other (3)	0.93***	0.17	2.54	1.82-3.54
Perceived importance of patient disclosure of CM use (Very important)				
Quite important (1)	-0.36*	0.16	0.70	0.51-0.96
Little important (2)	-0.94***	0.28	0.39	0.23-0.68

Table 3. Continued

Predictor	В	S.E.	OR	95% CI
Not important (3)	-0.88	0.52	0.41	0.15-1.15
No opinion (4)	-0.39	0.30	0.68	0.38-1.21
Constant	-1.84	0.54		

Note: R²=0.28 (Nagelkerke). Model χ 2 =276.59, p<.001. *p<0.05, **p<0.01, ***p<0.001

DISCUSSION

This study examined the experiences of CM practitioners with contact with conventional HCPs in oncology and the importance CM practitioners attach to patient disclosure of CM use to their conventional HCP. Potential predictors for interprofessional contact were explored. In total, 40% of the surveyed CM practitioners (n=1486) indicated that they occasionally or frequently have contact with conventional HCPs of patients with cancer. The emergence of interprofessional contact seems to be mainly predicted by the extent to which CM practitioners experience conventional HCPs to be open to interprofessional communication. Most CM practitioners (82%) consider it important that patients with cancer disclose CM use to their conventional HCP and motivate their patients to disclose CM use.

In a previous survey, 18% of CM practitioners reported to have previously communicated with conventional HCPs (6). The surveyed CM practitioners in the current study reported a much higher prevalence of previous contact with conventional HCPs, which might be explained by the frequent use (51%) of CM by patients with cancer (1). The study results indicate that the CM practitioner is mostly the initiator of contact by reporting the treatment plan or treatment progress. The study of Schiff et al (6) showed that most physicians and CM practitioners feel that the CM practitioner should initiate interprofessional communication.

Only a minority of the surveyed CM practitioners experienced conventional HCPs to be open to communication with them. This perceived lack of openness is in line with the reported skepticism towards and lack of knowledge on complementary medicine among conventional HCPs in oncology (13, 14). However, since conventional HCPs were not surveyed in the current study, our findings do not reflect the actual openness of conventional HCPs to communication with CM practitioners. Previous studies showed that conventional HCPs find interprofessional communication less important (6) and are less supportive of opportunities to improve interprofessional

communication when compared to CM practitioners (8). Nurses were more supportive than medical doctors (8), implying that nurses could play a pivotal role in bridging the communication gap between conventional HCPs and CM practitioners.

A notable finding is that almost one-third of the surveyed CM practitioners reported having no opinion on their experience of openness of conventional HCPs to communication. Additionally, it was shown that these CM practitioners were significantly less likely to have contact with conventional HCPs compared to CM practitioners who experienced conventional HCPs as not open to communication. This could imply that these CM practitioners did not consider interprofessional communication relevant. The relevance of interprofessional contact between CM practitioners and conventional HCPs is situation dependent, e.g. in the case of cancer survivors who have completed treatment. Another possibility is that CM practitioners who indicated to have no opinion on the openness of conventional HCPs, have treated few cancer patients yet, making them unable to properly evaluate this topic. Indeed, the results showed that years of experience in treating patients of the CM practitioner was significantly associated with communication with conventional HCPs.

The role of CM practitioners in the patient disclosure of CM use to their HCP is an understudied topic in existing literature. The present study shows that a large majority of CM practitioners attach importance to patient disclosure of CM use and motivate their patients to discuss CM use with their conventional HCPs. The importance a CM practitioner attaches to patient disclosure of CM use to their conventional HCP can reflect how relevant they consider it that the conventional HCP is informed. Indeed, the results of this study showed that perceived importance of patient disclosure of CM use predicts whether a CM provider has contact with conventional HCPs.

CM practitioners highlighting the importance and encouraging a patient to discuss CM use could facilitate patient disclosure of CM use, which is reportedly hindered by a lack of inquiry by the healthcare provider, anticipation of disapproval by the healthcare provider or the perception that disclosing CM use is not relevant or patient's (9, 15). In the current study, experience with patients being anxious to disclose CM use to their conventional HCP was also reported in open-ended questions by the surveyed CM practitioners.

The specific situations in which contact between CM practitioners and conventional HCPs is relevant should be explored in a follow-up study. Nonetheless, it is important for HCPs to be aware of patient CM use since it can provide valuable medical information about the patient and their (unsolved) complaints. In addition, complementary medicine use may indicate dissatisfaction with conventional care [1]. Patients are often given the responsibility of informing the conventional HCP on their CM use. It is questionable whether patients should bear this responsibility, especially when it concerns the safety of combining CM with conventional anticancer treatment. For optimal monitoring of the health and safety of patients with cancer, there should be open communication about CM use between all parties involved: conventional HCPs, CM practitioners and the patient. This will prevent the disappearance of valuable medical information in the metaphorical "Bermuda Triangle" between the three parties (6).

Strengths and limitations

This study is, to the best of our knowledge, the first to describe CM practitioners' experiences with contact with conventional HCPs in oncology. To overcome sampling bias and include different types of CM practitioners, we approached an umbrella quality register. Although the average response rate among members of actively approached professional organizations was low (9%), the total sample size is large enough to outline the experiences of CM practitioners with interprofessional contact. The 9% response rate might have resulted in bias, for instance complementary medicine practitioners more willing to communicate with conventional healthcare providers responded, resulting in an overestimation of interprofessional contact. Furthermore, some types of CM practitioners are overrepresented in the sample, such as acupuncturists, because their professional associations were directly approached for survey distribution. In addition, most participants were females with a high education level. Whether this is representative of the population of CM practitioners in the Netherlands is not clear because sufficient oversight is lacking. In a comparable survey conducted in an oncology setting in Norway, the CM practitioners visited by patients with cancer were also predominantly female (8). The sex of a CM practitioner was no significant predictor for contact with conventional HCPs.

Some limitations are associated with the survey. The fact that proportionately many participants chose the 'other' category for multiple-choice questions could indicate that the existing answer options were not sufficient. Respondents who answered in the 'other' categories often mentioned that they could not provide an unequivocal answer to the question posed because it was situation dependent. For example, experienced openness varies by HCP, or the relevance of interprofessional contact varies by patient. In addition, it was possible to proceed with the next question without answering the previous question, resulting in missing values.

Future studies

The current study only highlighted the perspective of CM practitioners on interprofessional contact. Future research should focus on the needs and desired roles of conventional HCPs and patients in the process of interprofessional contact. It is unclear how patients feel about their intermediary role between CM practitioners and HCPs. Given that interprofessional communication is often a nonroutinized, unstructured process, the appropriate method, frequency and content of communication should be further explored. For instance, it could be explored amongst conventional healthcare providers what type of information about complementary medicine use of their patients is of relevance, such as indication, content or outcomes of treatment by the complementary medicine practitioner. In addition, the factors that determine the openness of HCPs as experienced by CM practitioners could be investigated more in depth, for example by means of interviews.

CONCLUSIONS

To conclude, interprofessional contact with conventional HCPs occurs but is not a standard routine for most CM practitioners. More than one-third of the surveyed CM practitioners experienced conventional HCPs as not open to communication with them. The openness of conventional HCPs as experienced by CM practitioners appeared to significantly determine whether interprofessional contact occurs. Most CM practitioners considered patient disclosure of CM use to their conventional HCP to be important. Open communication about the topic of CM use between CM practitioners, conventional HCPs and patients prevents overlooking relevant medical information and facilitates optimal monitoring of the health condition and safety of patients with cancer.

REFERENCES

- Keene MR, Heslop IM, Sabesan SS, Glass BD. Complementary and alternative medicine use in cancer: A systematic review. Complement Ther Clin Pract. 2019;35:33-47.
- National Center for Complementary and Integrative Health (NCCIH). Complementary, Alternative
 or Integrative Health: What's In a Name? https://www.nccih.nih.gov/health/complementaryalternative-or-integrative-healthwhats-in-a-name 2021. Accessed 28 May 2024.
- Mao JJ, Ismaila N, Bao T, Barton D, Ben-Arye E, Garland EL, et al. Integrative Medicine for Pain Management in Oncology: Society for Integrative Oncology–ASCO Guideline. J Clin Oncol. 2022;40:3998-4024.
- Carlson LE, Ismaila N, Addington EL, Asher GN, Atreya C, Balneaves LG, et al. Integrative Oncology
 Care of Symptoms of Anxiety and Depression in Adults With Cancer: Society for Integrative
 Oncology—ASCO Guideline. J Clin Oncol. 2023;41:4562-4591.
- Lee RT, Kwon N, Wu J, To C, To S, Szmulewitz R, et al. Prevalence of potential interactions of medications, including herbs and supplements, before, during, and after chemotherapy in patients with breast and prostate cancer. Cancer. 2021;127:1827-1835.
- Schiff E, Frenkel M, Shilo M, Levy M, Schachter L, Freifeld Y, et al. Bridging the physician and CAM practitioner communication gap: suggested framework for communication between physicians and CAM practitioners based on a cross professional survey from Israel. Patient Educ Couns. 2011;85:188-93.
- 7. Nguyen J, Smith L, Hunter J, Harnett JE. Conventional and complementary medicine health care practitioners' perspectives on interprofessional communication: A qualitative rapid review. Medicina. 2019;55:650.
- 8. Stub T, Quandt SA, Arcury TA, Sandberg JC, Kristoffersen AE. Complementary and conventional providers in cancer care: experience of communication with patients and steps to improve communication with other providers. BMC Complement Altern Med. 2017;17:1-14.
- Davis EL, Oh B, Butow PN, Mullan BA, Clarke S. Cancer patient disclosure and patientdoctor communication of complementary and alternative medicine use: a systematic review. Oncologist. 2012;17:1475.
- Mentink MD, van Vliet LM, Timmer-Bonte JAN, Noordman J, van Dulmen S. How is complementary
 medicine discussed in oncology? Observing real-life communication between clinicians and
 patients with advanced cancer. Patient Educ Couns. 2022;105:3235-41.
- 11. Consortium voor Integrale Zorg en Gezondheid (CIZG): Uitgangspunten en zorgvuldigheidseisen. https://cizg.nl/over-ons/ (2022). Accessed 6 November 2023.
- 12. Centraal Bureau voor de Statistiek (CBS). Opleiding. https://www.cbs.nl/nl-nl/nieuws/2017/50/lager-opgeleiden-minder-gezond-en-tevreden/opleiding 2017. Accessed 6 November 2023.
- 13. King N, Balneaves LG, Levin GT, Nguyen T, Nation JG, Card C, et al. Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. Integr Cancer Ther. 2015;14:515–24.
- 14. Balneaves LG, Watling CZ. Part of the conversation: a qualitative study of Oncology Healthcare professionals' experiences of integrating standardized Assessment and Documentation of Complementary Medicine. Integr Cancer Ther. 2022;21:15347354221077229.
- 15. Jermini M, Dubois J, Rodondi P-Y, Zaman K, Buclin T, Csajka C, et al. Complementary medicine use during cancer treatment and potential herb-drug interactions from a cross-sectional study in an academic centre. Sci Rep. 2019;9:5078

SUPPLEMENTARY MATERIALS

Supplementary material 1: Comprehensive overview of CM practitioners background characteristics

Table A1. Professional associations that distributed the survey link and response rates

Original name in Dutch (abbreviation)	English translation	No. of members	Response rate (%) ^a
Register Beroepsbeoefenaren Complementaire Zorg (RBCZ)	Register for Complementary Medicine Professionals	8858	2% (n=182) ^b
Artsen Vereniging Integrale Geneeskunde (AVIG)	Physicians Association Integrative Medicine	255	7% (n=18)
Nederlandse Vereniging voor Acupunctuur (NVA)	Dutch Association for Acupuncture	1080	16% (n=169)
Nederlandse Artsen Acupunctuur Vereniging (NAAV)	Dutch Physicians Acupuncture Association	122	5% (n=6)
Wetenschappelijke Artsen Vereniging voor Acupunctuur Nederland (WAVAN)	Scientific Doctors' Association for Acupuncture the Netherlands	58	12% (n=7)
Netwerk Massage bij Kanker	Network Massage for Cancer	110	4% (n=4)
Nederlandse Vereniging voor Traditionele Chinese Geneeskunde (Zhong)	Dutch Association for Traditional Chinese Medicine	840	15% (n=54)

Note: participants can be member of more than one professional association

Table A2. Answers Q7: Which types of cancer did patients who visit you have/had? (N=1486)

Answer	n
Specific type(s) of cancer (see Figure A2)	1106
Diverse types of cancer	216
Other ^a	12
Missing	152

^a E.g. 'metastized cancer', 'cancer survivors' or 'irrelevant'

^a Numbers include CM practitioners that indicated to not treat cancer patients

 $^{^{\}mathrm{b}}$ 1125 participants reported membership of one of the 24 professional associations attached to the umbrella register

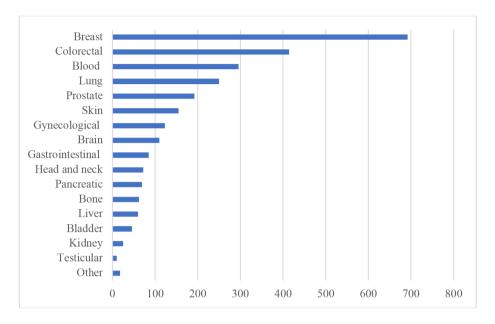


Figure A2. Number of CM practitioners reporting cancer type of patients they are visited by (n=1106). Note: participants could report multiple answer options

Table A3. Number of CM practitioners reporting complementary therapy provided to patients with cancer (N=1482)

Complementary therapy	N
Manipulative and body-based therapies (total)	1227
Massage	479
Acupuncture	310
Shiatsu	73
Lymph drainage	62
Haptotherapy	46
Craniosacral therapy	39
Kinesiology	38
Fascia or triggerpoint therapy	27
Osteopathy	12
Other manual therapies	10
Mind-body therapies (total)	1019
Relaxation exercises	418
Mindfulness	297
Hypnotherapy	142
Yoga	51
Art therapy	49
Music therapy	21
Body stress release	17
Breathing exercises	17
Qigong	15
Other mind-body interventions	11
•	
Lifestyle therapies (total)	984
Lifestyle counseling	439
Dietary counseling	340
Exercise or movement advice	205
Psychological therapies (total)	444
Psychotherapy	203
Body-focused psychotherapy	68
Psychosocial therapy	67
Coaching or counseling	58
Systemic therapy	48
Biological-based therapies (total)	342
Supplements, herbs, plants	277
Aromatherapy	65
Energy therapies (total)	135
Energetic therapy	57
Therapeutic or healing touch	56
Bioresonance	22
Whole medical systems (total)	123
Homeopathy	86
Antroposofic medicine	11
Naturopathy	8
Mesology	7
Ayurveda	6
Other medical systems	5

Note: participants can provide multiple complementary therapies

Table A3. Number of complementary practitioners reporting to treat symptom (n=1481)

Symptom	N
Fatigue ¹	1240
Anxiety	1012
Sleeping problems	944
Depression	874
Concentration problems	684
Neuropathy	657
Psychosocial problems	622
Coping problems	542
Headache	526
Nausea	519
Stool problems	516
Muscle pain	515
Joint pain	453
Lack of appetite	383
Dyspnea	363
Vomiting	233
Drowsiness	188
Swallowing	184
Other ²	291

¹ Merged with 'lack of energy' category due to magnitude of overlap (79%)

² Mainly symptoms related to (physical) pain and psychological symptoms (emotions, mental health, mood).

Supplementary material 2: Survey

1.	What	İS	your	age?

..... Years

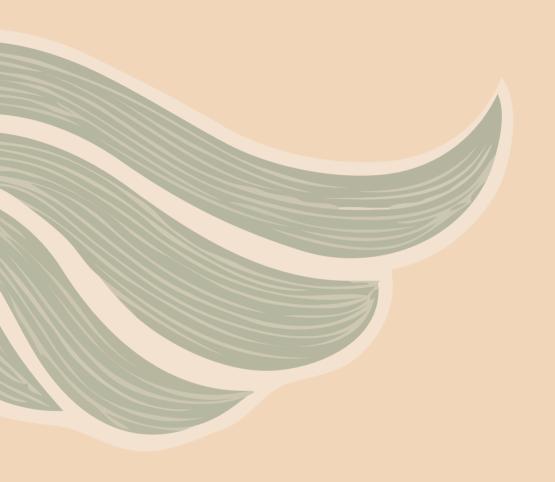
- 2. What is your sex?
 - o Male
 - o Female
 - o Other
- 3. What is your education?
- 4. Of which professional association are you a member?
- 5. Do you see patients who have/had cancer?
 - o Yes
 - o No (End of survey)
- 6. We would like to know which therapy you offer to patients who have/had cancer. In addition, we would like to know if you followed additional education for oncology.
 - o Aroma care
 - o Acupuncture
 - o Art therapy
 - o Movement therapy
 - o Dietary advice
 - o Haptotherapy
 - o Hypnotherapy
 - o Lifestyle advice
 - o Massage

- o Mindfulness
- o Music therapy
- o Edema therapy
- o Relaxation exercises
- o Osteopathy
- o Therapeutic touch
- o Nutritional supplements
- o Yoga
- o Other, namely.....
- 7. Which type(s) of cancer did patients who visit you have/had?

o Face to faceo Other, namely.....

O. 44 III	ch complaint(s) of patients who hav	e/had ca	nncer do you treat?
0	Anxiety complaints	0	Nausea
0	Shortness of breath	0	Neuropathy
0	Vomiting	0	Problems with bowel movement
0	Problems with concentration	0	Psychosocial problems
0	Coping	0	Sleeping problems
0	Depression complaints	0	Swallowing problems
0	Lack of appetite	0	Drowsiness
0	Lack of energy	0	Muscle pain
0	Joint pain	0	Fatigue
0	Headache	0	Other, namely
ave	en you provide therapy to patients	who ha	
	ragely have contact with convention treat or treated the patient? Never		ve/had cancer, how often do you hcare providers (doctor or nurse)
0	Never Once at the beginning of complement	nal healt entary tr	hcare providers (doctor or nurse)
o o o	Never Once at the beginning of complem Once during complementary treats	n al healt entary tr nent	hcare providers (doctor or nurse)
0 0	Never Once at the beginning of complementary treatments Multiple times during complementary	nal healt entary tr nent cary trea	hcare providers (doctor or nurse)
0 0 0	Never Once at the beginning of complem Once during complementary treats Multiple times during complementary treats	nal healt entary tr nent cary trea	hcare providers (doctor or nurse)
0 0 0	Never Once at the beginning of complementary treatments Multiple times during complementary	nal healt entary tr nent cary trea	hcare providers (doctor or nurse)
0 0 0 0 0	Never Once at the beginning of complem Once during complementary treats Multiple times during complement At the end of complementary treat Other, namely	entary tr nent ary trea ment you uso	cheare providers (doctor or nurse) reatment tment e when communicating with a
0 0 0 0 0	Never Once at the beginning of complementary treatments Once during complementary treatments Multiple times during complementary treatments At the end of complementary treatments Other, namely	entary tr nent ary trea ment you uso	cheare providers (doctor or nurse) reatment tment e when communicating with a
0 0 0 0 0	Never Once at the beginning of complementary treatments of the beginning of complementary treatments. Multiple times during complementary treatments of the end of complementary treatments. Other, namely ich communication method do eventional healthcare provider who be Electronical medical record	entary tr nent ary trea ment you uso	cheare providers (doctor or nurse) reatment tment e when communicating with a
0 0 0 0 0 0	Never Once at the beginning of complementary treatments Once during complementary treatments Multiple times during complementary treatments At the end of complementary treatments Other, namely	entary tr nent ary trea ment you uso	cheare providers (doctor or nurse) reatment tment e when communicating with a

- 13. What do you discuss with a conventional healthcare provider who treat or treated the patient?
- 14. How do you experience the openness of conventional healthcare providers (doctors and nurses) who treat or treated patients with cancer towards communication about complementary medicine with you?
 - o Most doctors/nurses are open for communication
 - o Most doctors/nurses are not open for communication
 - o No opinion
 - o Other, namely.....
- 15. How important do you think it is that your patients that have/had cancer and visit your practice, discuss their complementary medicine use with conventional healthcare providers (doctors and nurses)?
 - o Not important
 - o Little bit important
 - o Important
 - o Very important
 - o No opinion
- 16. How often do you motivate patients who have/had cancer and visit your practice, to discuss their complementary medicine use with conventional healthcare providers (doctors and nurses)?
 - o Always
 - o Sometimes
 - o Not at all
 - o Other, namely.....
- 17. How do patients who have/had cancer and visit your practice get to visit you?
 - o These patients are (almost) always referred to me by an HCP
 - o There patients are (almost) never referred to me
 - o These patients are (almost) always referred to me by an HCP or get to me without referral
 - o Other, namely.....



CHAPTER VI

The Effects of Complementary Therapies on Patient-Reported Outcomes: An Overview of Recent Systematic Reviews in Oncology

Marit Mentink, Daniëlle Verbeek, Janneke Noordman, Anja Timmer-Bonte, Ines von Rosenstiel, Sandra van Dulmen

Cancers 2023; 15(18):4513. doi: 10.3390/cancers15184513. PMID: 37760483.

ABSTRACT

Many patients with cancer make use of complementary medicine alongside conventional medicine, but clinicians in oncology often lack the knowledge to adequately advise patients on the evidence base for complementary therapies. This study aims to provide an overview of recently published systematic reviews that assess the effects of complementary therapies on patient-reported health outcomes in patients with cancer. Systematic reviews, including a meta-analysis of at least two randomized controlled trials, were identified from the PubMed. Embase, Cochrane Library, CINAHL and PsycINFO databases. The methodological quality was assessed with AMSTAR 2. One-hundred systematic reviews were included. The results suggest that several complementary therapies can improve health outcomes reported by patients with cancer, such as acupuncture to relieve pain, music interventions to reduce anxiety and yoga to improve cancer-related fatigue. The side-effects related to complementary therapy use are generally mild. The results remain inconclusive for some intervention-outcome combinations. Many of the included systematic reviews insufficiently assessed the causes and impact of bias in their interpretation of the results. This overview of systematic reviews can support clinicians in counselling their patients on this topic and provide directions for future research and clinical practice guidelines in the field of complementary medicine.

INTRODUCTION

Complementary medicine refers to a variety of healthcare interventions not typically part of conventional medical care, but used alongside it. It constitutes of a broad range of modalities, such as mind-body therapies, acupuncture and massage therapy. Complementary medicine use increases when an individual is diagnosed with cancer [1,2]. On average 51 percent of all patients with cancer use complementary medicine [3]. Research shows a variety of motivations for patients with cancer to use complementary medicine, such as treating side-effects of therapy or improving general health [3,4]. In addition, COVID-19-related anxiety and fear seems to have resulted in more complementary medicine use among patients with cancer [5].

Despite the frequent use of complementary medicine by patients with cancer, clinical resources to inform healthcare providers about complementary medicine are scarce. Healthcare providers report limited knowledge about the evidence and potential risks to support complementary medicine use in cancer care [4]. In addition, patients express the need for reliable information about what complementary therapies are helpful when diagnosed with cancer [4]. They often perceive healthcare providers as uninformed or uninterested in complementary medicine [4,6,7], contributing to prevalent non-disclosure of complementary medicine use in patient-provider interactions [8]. Both patient and clinician visit satisfaction was found to increase in consultations in which complementary medicine was discussed [9].

Considering the multitude of complementary therapies and the rapid increase in biomedical publications, it is almost impossible for healthcare providers to keep up with up-to-date evidence on the topic. Existing overviews of systematic reviews for complementary therapies in patients with cancer often focus on one specific intervention [10], specific outcome measures [11] or specific cancer patient populations [12]. The current study aims to provide a comprehensive overview of up-to-date evidence on the effects of complementary therapies on physical, psychological and general patient-reported health outcomes in patients with cancer. Such an overview can facilitate clinical decision-making and support patientprovider communication about complementary medicine.

MATERIALS AND METHODS

A review of systematic reviews was performed by using the Cochrane Handbook for Systematic Reviews of Interventions [13]. The protocol is registered on PROSPERO (CRD42022321732). This review is part of a larger mixed methods research project titled 'COMMON' [14].

Search strategy

We systematically searched the PubMed, Embase, Cochrane Library, CINAHL and PsycINFO databases for systematic reviews with a meta-analysis of randomized controlled trials (RCTs) that assess the effect of a complementary therapy on patient-reported outcome measures (PROMs) in patients with cancer. The following main search terms were used: "neoplasm", "cancer", "tumor" AND "integrative medicine", "integrative oncology", "complementary therapies", "complementary medicine", "complementary and alternative medicine" AND "systematic review", "meta-analysis" (see Supplementary Materials S1 for a full list of the search terms). The PubMed search term was adapted for use with other bibliographic databases.

We included studies published from 1 January 2018 through to 20 April 2022 in the English language. Initially, we searched for records published between 2000 and 20 April 2022, but we decided to narrow the search window due to the large amount of publications for full text screening that were left after the title/abstract screening (n = 735). The cutoff point for the year 2018 is based on a comparable overview of systematic reviews published till January 2018 [15]. However, the current review of reviews should not be interpreted as a formal update, because the aforementioned review included only four outcome measures (quality of life, overall survival, pain and depression) and the cur-rent review included all patient-reported health outcomes.

Study selection

The study selection for this review of reviews was conducted according to the PICOS (population, intervention, control, outcomes, study design) framework:

Population: Adults (>18 years) with cancer or cancer survivors. Excluded were systematic reviews that included a population broader than only patients with cancer (except when patients with cancer were separately analyzed).

Intervention: Individual complementary therapies provided alongside conventional cancer treatment or after conventional cancer treatment listed under the MeSH term 'Complementary Therapies' in PubMed. Excluded were systematic reviews reporting on: (1) intervention groups (e.g., mind-body therapies) or combined interventions (e.g., acupuncture + yoga) that were not analyzed separately; (2) interventions that were used as alternative, curative therapy (instead of conventional cancer treatment); (3) interventions that are often part of conventional oncology care in Western

countries (e.g., psychosocial support, physical therapy, nutritional advice); (4) nonprovided therapies (e.g., self-care, exercise, nutrition); (5) separate ingestible or injectable compounds (e.g., herbs, supplements).

Control: Any control group (e.g., usual care, placebo, no treatment, active control).

Outcomes: The effect on patient-reported outcomes (PROMs) considering subjective physical health (e.g., pain, fatigue), psychological health (e.g., depression, anxiety) or general health (e.g., quality of life). Excluded were systematic reviews exclusively reporting on objective health outcome measures (e.g., heart rate, survival rate) or grouped outcomes (e.g., psychological symptoms).

Study design: Systematic reviews published between January 2018 and 20 April 2022 in the English language, including a meta-analysis of at least two RCTs per eligible intervention-outcome combination and reporting effect sizes. Excluded were systematic reviews: (1) including only descriptive, qualitative or case studies as primary studies; (2) providing only a qualitative synthesis of RCTs.

Data selection

After removal of the duplicates from the combined search results across the databases, all the titles and abstracts were screened in Covidence against the in- and exclusion criteria by two independent reviewers (MM and DV). The full texts of possible eligible studies were retrieved and screened by the same two reviewers (MM and DV). At both stages, disagreements over eligibility were resolved by consensus or by the involvement of the research team (SvD, JN, ATB). During full text screening, it was noticed that the definitions of complementary therapies appeared heterogeneous. Therefore, the reviewers paid additional attention to assessing whether the intervention description of the primary studies included in the systematic review fit our eligibility criteria.

Data extraction

The data relevant for the purpose of this review were extracted from the systematic reviews by one reviewer (MM) in a data extraction table in Microsoft Word (see Table S1). The following data were collected and summarized:

1. Descriptive characteristics of the systematic reviews and the included primary studies (author, year, aim, participants, intervention, comparator, outcomes, outcome measures, number of primary studies (RCTs), number of participants in the RCTs).

2. Quantitative outcome data (meta-analysis effect sizes of the eligible outcome-intervention combinations) and the overall conclusion.

In some cases, only part of the systematic review complied with our in- and exclusion criteria on population, intervention, outcome or study design (e.g., a systematic review includes both patient-reported and objective health outcomes). When the complying part of the systematic review (e.g., the patient-reported outcome measures) was separately analyzed, only this part of the data was extracted from the systematic review. If more than one outcome measure was used for a patient-reported outcome (e.g., fatigue status and fatigue score), all outcome measures were extracted but only the outcome measure with the most underlying RCTs was reported in the results section.

Data synthesis

Given the high heterogeneity in the population, intervention, comparators and outcomes, among the included systematic reviews, pooled meta-analyses were deemed impossible. Therefore, we provide a descriptive synthesis of the quantitative outcome data (meta-analysis) per complementary therapy.

Quality appraisal

Two reviewers (JN, MvG) appraised the methodological quality of the included systematic reviews according to the seven critical domains of AMSTAR 2 (a measurement tool to assess systematic reviews) [16] (see Table S2). Disagreements were resolved by the involvement of a third reviewer (MM).

RESULTS

Study characteristics

After full text screening for eligibility, 100 systematic reviews were included in the overview (Figure 1). A detailed overview of the included studies and extracted data can be found in Table S1.

Of the total 100 included systematic reviews, 51 focused on a patient population with various primary cancer diagnoses, 33 focused on patients with breast cancer and 7 on patients with lung cancer. The remaining systematic reviews focused on patients with colorectal, rectal, liver, ovarian or pancreatic cancer, or leukemia. The three most frequently analyzed complementary therapies were herbal medicine, acupuncture and yoga. A description of the complementary therapies can be found

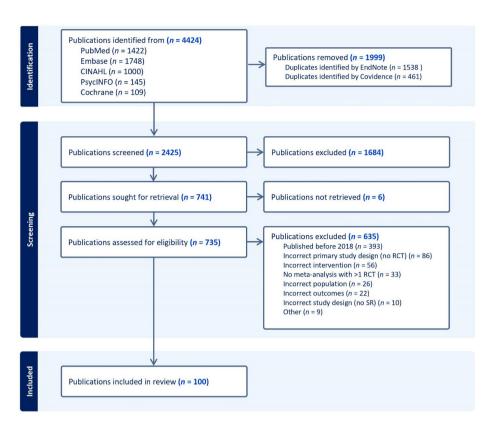


Figure 1. PRISMA flow chart of the identification of included publications.

Methodological quality

As shown in Figure 2, only half of the systematic reviews included an explicit statement that the methods were established prior to conducting the review and the review protocol was registered or published (item 2). Most included systematic reviews used a satisfactory search strategy, but scored only a Partial Yes because they did not incorporate at least one of the following sources in their search strategy: reference lists, study registries, grey literature or did not consult experts in the field (item 4). Only four systematic reviews provided a list of excluded studies with justifications for their exclusion (item 7). In all but two cases, the risk of bias for individual studies included in the review was assessed (item 9). Although most authors justified combining data and used appropriate weighted techniques to combine study results, the causes for heterogeneity (if present) were not (properly) investigated in several systematic reviews (item 11). In the majority of the systematic reviews, the authors did not account for the risk of bias in individual studies, when interpreting the results in the discussion section (item 13). In almost all the systematic reviews, statistical tests were used for publication bias. However, a discussion on the impact of publication bias on the results was regularly missing (item 15). None of the included systematic reviews scored 'Yes' on the seven domains of AMSTAR 2. Only five systematic reviews (partially) met six out of the seven criteria and fourteen systematic reviews (partially) met five out of the seven criteria. The scores on the seven critical domains of AMSTAR 2 for each included systematic review can be found in Table S2.

Table 1. Description of included complementary therapies.

Complementary therapy (nr. of included meta-analyses)	Definition
Herbal medicine (26)	A type of medicine that uses roots, stems, leaves, flowers, or seeds of plants [15] (we did not include meta-analyses assessing the effectivity of individual herbs)
Acupuncture (23)	The technique of inserting thin needles through the skin at specific points on the body (including electroacupuncture in which pulses of weak electrical current are sent through acupuncture needles into acupuncture points in the skin) [15]
Yoga (15)	An ancient system of practices used to balance the mind and body through exercise, meditation (focusing thoughts), and control of breathing and emotions [15]
Mindfulness-based stress reduction (7)	A moment-to-moment awareness of one's experience without judgment and as a state and not a trait [16] (we included only mindfulness-based stress reduction (MBSR), a structured group program of mindfulness training [17])
Acupressure (7)	The application of pressure or localized massage to specific sites on the body [15] (including ear acupressure in which seeds or pellets are taped on auricular acupoints)
Tai Chi (6)	One of the martial arts and also a form of meditative exercise using methodically slow circular stretching movements and positions of body balance [16]
Music interventions (5)	A type of therapy that uses music to help improve a person's overall health and well-being [15] (we included passive and active listening music interventions)
Manual therapy (5)	A type of therapy in which the therapist moves or manipulates one or more parts of the patient's body [15]
Qigong (4)	An ancient Chinese system of postures, exercises, breathing techniques, and meditations designed to improve and enhance the body's Qi (e.g. vital energy) [16]
Moxibustion (4)	A type of heat therapy in which an herb is burned on or above the skin to warm and stimulate an acupuncture point or affected area [15]
Relaxation therapy (2)	Treatment to improve one's health condition by using techniques that can reduce physiological stress, psychological stress or both [16]
Art therapy (1)	Treatment that uses the making of art and the response to art to improve one's physical, mental, and emotional well-being [15]

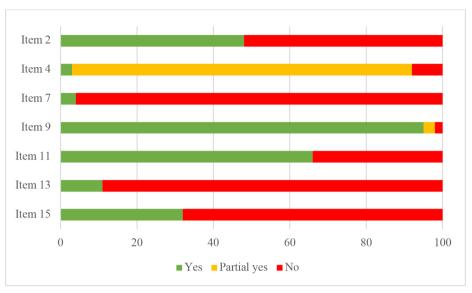


Figure 2. Quality assessment of systematic reviews by the seven critical domains of AMSTAR 2 [14].

Efficacy of complementary therapies

The meta-analysis results for the 12 included complementary therapies are shown in Table 2 through to 10 and are described in the text. To maintain the readability of the tables, the patient-reported outcomes with only a few included meta-analyses are not displayed in the tables but in **bold text**.

Acupuncture

Acupuncture seems to have the capacity to alleviate several physical symptoms in patients with cancer (see Table 2). Significant reductions in cancer pain, including aromatase inhibitor-induced arthralgia (AIA) [22,23] and lymphedema pain [24], post-mastectomy pain [25] and neuropathy pain [19,26] were reported in the included meta-analyses.

Peripheral neuropathy symptoms measured with the FACT-NTX (Functional Assessment of Cancer Therapy-Neurotoxicity) subscale seem to be significantly relieved in cancer patients receiving acupuncture [19,26]. However, this effect was not significant in a meta-analysis including only breast cancer patients [27]. When neuropathy symptoms were measured with a variety of instruments in patients with breast cancer, a significant decrease in the symptoms was reported [23].

The side effects of three-step analgesics, such as nausea, vomiting, constipation and dizziness, were significantly reduced in patients using acupuncture compared to using only three-step analgesic drugs [17]. In patients with breast cancer, the beneficial effects of acupuncture on gastrointestinal symptoms were reported when RCTs mainly conducted in China were meta-analyzed [23]. No significant effect was reported in a meta-analysis with RCTs originating mainly from Western countries [28].

The meta-analysis results on the effect of acupuncture on hot flash frequency in patients with breast cancer were inconsistent. In one case, a significant effect was reported during acupuncture treatment but not at post-treatment or follow-up [29]. Some meta-analyses indicated a significant reduction in hot flash severity [30] or hot flash scores [27], but not hot flash frequency. A meta-analysis [31], which primary studies entirely overlap with two smaller meta-analyses [28,32], shows a significant negative effect of acupuncture on the incidence of menopausal symptoms measured with the Kupperman index.

Regarding sleep disturbance and quality of life, different measurement instruments were used across the meta-analyses and the results are inconclusive.

Considering psychological patient-reported outcomes, no significant effects were reported in meta-analyses assessing the effect of acupuncture on **anxiety**, **depression** and **cognitive function** [27,30,33]. One meta-analysis of two RCTs reports a significant negative effect of acupuncture on anxiety in patients with breast cancer, but in a pooled analysis of only high-quality articles the effect was not significant [27].

Xerostomia (dry mouth) symptoms were significantly relieved in patients receiving acupuncture, according to a meta-analysis of two RCTs [34].

The **functional status**, measured with the Karnofsky Performance Scale (KPS), was significantly improved in the acupuncture combined with opioids group, compared to opioids alone, in a meta-analysis including four RCTs [35].

Furthermore, acupuncture may be effective for improving the quality of life in patients with colorectal cancer by improving **abdominal pain**, **stool score**, **defecation dysfunction**, **sexual dysfunction** and **self-feelings** [36].

Acupressure

As shown in Table 3, acupressure seems to be effective for the amelioration of physical symptoms in patients with cancer, such as pain (remission rate) [45] and gastrointestinal symptoms, such as nausea, vomiting, constipation and diarrhea [46–48]. No significant effects of acupressure were reported on **headache** and **abdominal distension** [46].

 Table 2.
 Summary of meta-analysis results for effect of Acupuncture per outcome (numbers indicate amount of RCTs in meta-analysis).

Author and year	Population	Pain	Neuropathy	Gastrointestinal	Fatigue	Hot flash	Menopausal	Sleep	Ouality of life
`	4			symptoms	0	frequency	symptoms	disturbance	` '
Chan 2021 [23]	Breast	4*1	2*	*9					*6
Chien 2020 [31]	Breast					4	*5		
Gao 2021 [24]	Breast	2*							
Jang 2020 -2 [32]	Breast					3	3		
Kannan 2022 [25]	Breast	2*							
Li 2021 -1 [30]	Breast	3*2			4*2	3		2	
Liu 2020 [37]	Breast					3			
Liu 2021 [22]	Breast	3*1							
Wang 2018 [29]	Breast					3*3			
Yuanqing 2020 [28]	Breast	*\		ζ.	*4	7*	3		88
Zhang 2021 [27]	Breast	*4	2		·9	4		*4	2*
Zhu 2021 [33]	Breast	*4						2	
Chien 2019 [26]	Mixed	3*	*4						
Dai 2021 [38]	Mixed	7*							
Dong 2021 [39]	Mixed	12*							
He 2020 [40]	Mixed	7*							
Hou 2020 [35]	Mixed	18*							
Jang 2020 -1 [41]	Mixed				*4				

Table 2. Continued

Author and year	Population	Pain	Neuropathy	Pain Neuropathy Gastrointestinal Fatigue symptoms	Fatigue	Hot flash frequency	Hot flash Menopausal frequency symptoms	Sleep disturbance	Sleep Quality of life disturbance
Jin 2020 [19]	Mixed	*4	3*						
Li 2021 -2 [17]	Mixed	18*							
Lin 2019 [42]	Mixed								3
Tan 2021 [43]	Mixed				2				
Zhang 2018 [44]	Mixed				*\scrip*				

^{*} asterisk = significant effect; no asterisk = no significant effect. ¹ Outcome 'aromatase inhibitor-induced arthralgia (AIA). ² Significant effect when compared with waitlist control or usual treatment, nonsignificant when compared with sham acupuncture. 3 Significant effect during treatment, but not posttreatment or at follow-up.

 Table 3. Summary of meta-analysis results for effect of Acupressure per outcome (numbers indicate amount of RCTs in meta-analysis).

Author and year	Population	Pain	Fatigue	Sleep quality	Sleep quality Nausea and Constipation vomiting	Constipation	Diarrhea	Quality of life
Chen 2018 [47] ²	Leukemia					3*		2^*
Jing 2018 [48] ^a	Leukemia					3*		2*
Chen 2021 [46] ^a	Mixed		2*		*01	·9	2*	
Hsieh 2021 [49]	Mixed		14*					
Mai 2022 [45]	Mixed	11*		7*				*8
Tan 2021 [43]	Mixed		2					
Wang 2021 [50] ²	Mixed			*9				

^{*} asterisk = significant effect; no asterisk = no significant effect, ^a Auricular acupressure.

Moxibustion

According to the four included meta-analyses, moxibustion can significantly reduce physical symptoms in patients with cancer, such as fatigue [51] (see Table 4). Except for inappetence and abdominal pain, significant effects on the amelioration of gastrointestinal symptoms, such as nausea and vomiting, constipation, diarrhea and abdominal distension, were reported for patients using moxibustion [52,53]. Compared to pneumatic circulation, moxibustion was found to be significantly effective for reducing lymphedema swelling in breast cancer patients [24].

Herbal Medicine

The effect of herbal medicine on gastrointestinal symptoms is often meta-analyzed (see Table 5). The included meta-analyses showed significant negative effects of herbal medicine on the incidence of nausea and vomiting and diarrhea [54-62]. Inappetence was significantly relieved in patients with primary liver cancer using Chinese medicinal formulas [57]. In patients with colorectal cancer, anorexia, constipation and abdominal pain were not found to be significantly alleviated by the use of traditional herbal medicines, but abdominal distension was [55]. No significant effect of Chinese herbal medicine (CHM) was reported on constipation experienced by patients with breast cancer [54].

In addition, herbal medicine is frequently used to treat skin-related problems in patients with cancer. For instance, Chinese herbal medicine seemed to exhibit clinical effectiveness on the treatment of epidermal growth factor receptor (EGFR) inhibitorinduced skin rash in patients with cancer [63], among which were patients with lung cancer [60]. A meta-analysis including two RCTs showed a significant reduction of chemotherapy-associated alopecia in breast cancer patients using Chinese herbal medicine [54]. In patients with pancreatic cancer receiving gemcitabine or docetaxelbased chemotherapy, traditional medicine preparations did not significantly reduce the incidence of hair loss [64]. A meta-analysis including 21 RCTs showed that the addition of herbal medicine to fluoropyrimidines therapy was associated with a statistically significant decrease in all-grade hand-foot syndrome, measured with three different grading scales [65]. However, this negative effect of herbal medicine was not significant in a meta-analysis in which all-grade hand-foot syndrome was measured with the National Cancer Institute (NCI) criteria [66].

Table 4. Summary of meta-analysis results for effect of Moxibustion per outcome (numbers indicate amount of RCTs in meta-analysis).

Author and year	Population	Fatigue	Nausea and vomiting	Constipation	Diarrhoea	Lymphedema (swelling)	Functional status	Quality of life
Gao 2021 [24]	Breast					3*		
Ma 2019 [51]	Mixed	10*						*6
Yao 2022 [52]	Mixed		24*	7*	7**		*9	2*
Zhang 2018 [53]	Mixed		7*				*4	ж *

 $^{^*}$ asterisk = significant effect; no asterisk = no significant effect.

 Table 5. Summary of meta-analysis results for effect of Herbal medicine per outcome (numbers indicate amount of RCTs in meta-analysis).

Author and year	Population	Gastrointestinal Diarrhea Nausea and Sleep symptoms vomiting quality	Diarrhea	Nausea and vomiting	Sleep quality	Fatigue	Pain	Neuropathy	Neuropathy Functional Quality of status life	Quality of life
Bai 2022 [69]	Breast	5*								12*
Li 2020 [54]	Breast		*4	28*1						
Li 2021 [68]	Breast						3*		*4	*4
Shi 2021 [70]	Breast	*6							*9	
Chen 2021 [55]	Colorectal	20*2	13*	17*						
Liu 2019 [66]	Colorectal							*6		
Li 2020 [56]	Gastric			*8					*4	
She 2021 [57]	Liver			7*					11^*	
Chen 2020 [71]	Lung	14*							*6	
Jin 2021 [58]	Lung			*\^						

6

ರ
Б
2
Ξ.
Ιţ
10
\tilde{C}
٠.
N
ŀ
Р
g
Н

Author and year	Population	Gastrointestinal symptoms	Diarrhea	Diarrhea Nausea and vomiting	Sleep quality	Fatigue	Pain	Neuropathy Functional status	Functional status	Quality of life
Kwon 2021 [72]	Lung								5*	2*
Lu 2021 [62]	Lung		8*						2*	
Wang 2020 [73]	Lung								*4	
Yang 2020 [59]	Lung		3*	*6						,*\
Zhang 2018 [60]	Lung		15*	3*		3*			28*	
Chen 2019 [63]	Mixed									
Deng 2018 [65]	Mixed								*8	*4
Huang 2020 [74]	Mixed					8*3			*4	
Li 2019 [75]	Mixed							15*		
Lin 2019 [42]	Mixed									*4
Wang 2021 [76]	Mixed						14*			7*
Wu 2019 [77]	Mixed	2							*4	
Yoon 2021 [78]	Mixed				*9					
Zhao 2020 [79]	Mixed					10*				
Wang 2019 [61]	Ovarian		2	7*				3	*6	*~
Hu 2022 [64]	Pancreatic	,*\scrip*		īΛ					*4	*6

* asterisk = significant effect; no asterisk = no significant effect; ¹Nausea and vomiting (toxicity grade III-IV) was significantly reduced, but nausea and vomiting (toxicity grade o-II) was significantly aggravated in experimental group receiving herbal medicine; Only significant in subgroup of RCTs without double blind design, Outcome 'fatigue status'. A nonsignificant, negative effect was reported for outcome 'fatigue score'

Oral mucositis seemed to be significantly alleviated by the use of traditional herbal medicine in patients with colorectal cancer treated with fluoropyrimidine-based chemo-therapy [55]. In a meta-analysis including 7 RCTs, CHM appeared to alleviate **depressive symptoms** in cancer patients, either compared with no treatment, antidepressants or psychological treatment [67]. **Menopausal symptoms**, such as hot flashes, depression and irritability, were found to be significantly relieved by the use of CHM in patients with breast cancer treated with endocrine therapy [68].

Mindfulness-Based Stress Reduction (MBSR)

MBSR is mainly used for the treatment of psychological symptoms in patients with cancer (see Table 6). Significant effects of MBSR on the amelioration of depression were reported [80–82]. According to three meta-analyses, anxiety was significantly relieved by MBSR [80–83]. In patients with breast cancer, the meta-analysis results on the effect of MBSR on anxiety and sleep quality were inconclusive [80,81]. A significant effect on pain relief and improvement of the quality of life were reported in a meta-analysis of MBSR in a mixed cancer patient population [82]. In patients with breast cancer receiving MBSR, no significant effects were reported on the outcomes for pain and quality of life [80].

Music Interventions

Music interventions can be used to relieve a variety of symptoms in patients with cancer, especially psychological symptoms such as depression, anxiety, low mood and distress (see Table 7). For instance, two meta-analyses reported significant effects of music interventions for the relief of depression [87,88]. In addition, significant effects were reported for music interventions on the improvement of cancer pain [88-90], sleep quality [87], fatigue [91] and quality of life [87,88].

 Table 6. Summary of meta-analysis results for effect of MBSR per outcome (numbers indicate amount of RCTs in meta-analysis).

Author and year Population	Population	Anxiety	Depression	Stress	Fatigue	Sleep quality	Pain	Quality of life
Chang 2021 [80] Breast	Breast	3	*9	3	*4	5	Ŋ	4
Schell 2019 [81] Breast	Breast	,*9	,9		×*.	* 4		
He 2020 [84]	Mixed				%℃			
Lin 2022 [82]	Mixed	14*	12*		*8		*4	7*
Suh 2021 [85]	Mixed					9* 1		
Xie 2020 [86]	Mixed				14*			
Xunlin 2020 [83] Mixed	Mixed	*6						

^{* =} asterisk significant effect; no asterisk = no significant effect; 'Only significant increase in sleep quality when compared to usual care control, mixed results when compared to active control.

 Table 7. Summary of meta-analysis results for effect of Music interventions per outcome (numbers indicate amount of RCTs in meta-analysis).

Author and year Population	Population	Depression	Anxiety	Mood	Distress	Pain	Sleep quality	Fatigue	Anxiety Mood Distress Pain Sleep quality Fatigue Functional status Quality of life	Quality of life
Bro 2018 [89] Mixed	Mixed	2	*6	*4	2	*6		3		2
Li 2020 [88]	Mixed	*9	*9			*5				10*
Qi 2021 [91]	Mixed							*8		
Yang 2021 [87] Mixed	Mixed	14*	8 1				*4		3*	7*
Yangöz 2019 [90] Mixed	Mixed					*9				

^{* =} asterisk significant effect; no asterisk = no significant effect; 'Large, significant effect of music intervention on anxiety measured with Hamilton Anxiety Rating Scale (HAM-A), but not significant when measured with Self-Rating Anxiety Scale (SAS).

			1				
Author and year Population	Population	Fatigue	Anxiety	Depression	Sleep quality	Pain	Quality of life
Liu 2021 [92]	Breast	2*					
Liu 2020 [97]	Breast	2 1		3	2		2*
Luo 2020 [93]	Breast	3*	2*			*4	*^
Cai 2022 [96]	Mixed		2*	4			
Ni 2019 [94]	Mixed	3*			3*		8 * 2
Song 2018 [95]	Mixed	6*3					

* = asterisk significant effect; no asterisk = no significant effect; 'Compared to conventional supportive care. Significant decrease in fatigue when Tai Chi was used as adjunct to conventional care.; 2 Outcome measure 'physical functioning'. Psychological functioning also medium significant effect. Social functioning not significant; 3 Measured post-intervention. At 3 month follow-up, no significant effect of Tai Chi on fatigue.

Table 9. Summary of meta-analysis results for effect of Qigong per outcome (numbers indicate amount of RCTs in meta-analysis).

Author and year Population	Population	Fatigue	Sleep quality	Quality of life
Kuo 2021 [98]	Mixed	5 **	2*	3*
Lin 2019 [42]	Mixed			3
Wang 2021 [99] Mixed	Mixed	*4		
Yin 2020 [100]	Mixed	13*1		

* = asterisk significant effect; no asterisk = no significant effect; 1 Qigong compared to usual care/waitlist control. No significant effect when compared with Western exercise/treatment control.

Tai Chi

The results of the included meta-analyses indicated that Tai Chi can decrease cancerrelated fatigue [92-95] (see Table 8). Considering the psychological symptoms, a meta-analysis of two RCTs showed that Tai Chi can alleviate anxiety [93,96]. There was no evidence that Tai Chi decreases the symptoms of depression [96,97]. Sleep quality was found to be improved by Tai Chi in one meta-analysis including RCTs with different cancer types [94], but a non-significant positive effect was reported for patients with breast cancer [97]. A significant positive effect was found for Tai Chi on quality of life [93,94,97].

Qigong

Qigong seems a promising intervention for the relief of cancer-related fatigue [98-100] (see Table 9). Sleep quality was significantly improved by Qigong according to a meta-analysis of two RCTs [98]. One meta-analysis showed a significant positive effect of Qigong exercise on quality of life [98], whilst a metaanalysis including different RCTs showed a non-significant positive trend [42].

Yoga

The effect of yoga on cancer-related fatigue is often meta-analyzed and the results show a significant decrease in fatigue [92,101-107] (see Table 10). In addition, yoga seems effective for the management of psychological symptoms in patients with cancer, such as anxiety, depressive symptoms and stress [101,104,107-109]. A significant reduction in sleep disturbance in the yoga intervention group was reported [104,107,110]. However, a meta-analysis including seven RCTs showed that yoga did not significantly improve sleep quality measured with the Pittsburgh Sleep Quality Index (PSQI) in patients with breast cancer [111]. In a meta-analysis including two RCTs the effect of Yoga on cognitive impairment was studied, but did not report a significant effect [112].

 Table 10.
 Summary of meta-analysis results for effect of Yoga per outcome (numbers indicate amount of RCTs in meta-analysis).

	`		,					
Author and year	Population	Fatigue	Anxiety	Depression	Stress	Sleep disturbance	Pain	Quality of life
Coutiño 2019 [108]	Breast			×*S				
Dong 2019 [102]	Breast	18*						
El-Hashimi 2019 [113]	Breast							8
Hsueh 2021 [104]	Breast	14*	* 8	12*	*4	5*	× 5	5*1
Liu 2021 [92]	Breast	13*						
O'Neill 2020 [106]	Breast	18*2						10*2
Wang 2020 [111]	Breast					7 3		
Yi 2021 [107]	Breast	4 * 4	×*^	*9		2* 4		3*
Armer 2020 [101]	Mixed	29*2		12*2				17
Danon 2021 [114]	Mixed						7	
Gonzalez 2021 [109]	Mixed		15*	25**				
Haussmann 2022 [103] Mixed	Mixed	24*						
Jihong 2021 [105]	Mixed	11*						
Lin 2019 [42]	Mixed							7
Tang 2019 [110]	Mixed					13 *		

well-being was not significant; 2 Only significant effect when compared to active control group; 3 Outcome measure 'sleep quality'; 4 Measured post-intervention. No * asterisk = significant effect; no asterisk = no significant effect; Functional, emotional and social well-being were significantly improved by yoga. Effect on physical significant effect when measured at medium of long term follow up.

Art Therapy

In one meta-analysis including two RCTs on expressive writing, a significant negative effect of expressive writing on depressive symptoms was reported in patients with breast cancer [108] (see Table S1).

Manual Therapy

Two meta-analyses assessed the effect of manual lymphatic drainage (MLD) in breast cancer patients with lymphedema and vielded contradictory results: the first meta-analysis included three RCTs and showed a significant negative effect on lymphedema pain [115]. The second meta-analysis included two RCTs, of which one overlapped with the first meta-analysis, and showed a non-significant negative effect of MLD on pain [116].

A meta-analysis among patients with breast cancer revealed a significant negative effect of manual therapy (e.g., massage, myofascial release) on chronic musculoskeletal pain [117]. A significant effect of myofascial release on the relief of post-mastectomy pain was reported in a meta-analysis including two RCTs [25].

Manual therapies did not seem to have a significant positive effect on quality of life [42,115,117].

Relaxation Therapy

One meta-analysis [118] evaluated the effect of the combined practice of progressive muscle release and guided imagery in patients with breast cancer. Significant effects were reported on the improvement of the quality of life (two RCTs) and the amelioration of stress (five RCTs), anxiety (five RCTs), depression (five RCTs) and nausea and vomiting (two RCTs).

One meta-analysis [119] reported that hypnosis before general anesthesia for breast cancer surgery could significantly reduce anxiety (six RCTs) and post-operative pain (seven RCTs), but not post-operative nausea and vomiting in patients with breast cancer undergoing minor surgery.

Safety of Complementary Therapies

The majority of the included systematic reviews (60 out of 100) reported on the incidence or absence of adverse events related to complementary therapy use. Reported adverse events were generally mild, such as bruising related to acupuncture treatment [23], cramps related to yoga practice [102] or a skin allergy related to herbal medicine use [75]. In the included systematic reviews on herbal medicine, potential herb-drug interactions were not systematically reported. Only a few included systematic reviews included an explicit statement about the interaction effects [54,63,64,72], such as insufficient documentation and monitoring of traditional medicine preparations by clinicians and the lack of (pharmacokinetic) studies on herb-drug interactions.

In many cases, the group of patients receiving anti-cancer treatment combined with a complementary therapy experienced less adverse reactions from anti-cancer treatment compared to the control group receiving only anti-cancer treatment (for example: [35,64,67,74]). In two instances, a significant deteriorating effect of a complementary therapy on a patient-reported outcome was reported. First, in the group of breast cancer patients receiving herbal medicine and chemotherapy, the frequency of non-severe (grade o-II) nausea and vomiting was significantly increased compared to patients receiving only chemotherapy [54]. Nonetheless, severe nausea and vomiting (grade III-IV) frequency was significantly alleviated in the experimental group. Second, sleep quality measured with the Pittsburgh Sleep Quality Index (PSQI) was significantly less improved in the intervention group receiving MBSR compared to the active control (i.e., psychoeducation or stress management techniques) [85]. When compared to usual care, MBSR significantly improved sleep quality.

DISCUSSION

This study aimed to summarize the evidence on complementary therapies on patient-reported health outcomes in patients with cancer. This resulted in an overview of one hundred recently published meta-analyses, which described the effects of twelve different complementary therapies on several health outcomes reported by patients with cancer. To the best of our knowledge, such a comprehensive overview of the systematic reviews on this topic is not available yet.

According to the results from this overview of systematic reviews, some complementary therapies can ameliorate physical and psychological symptoms caused by cancer itself or its treatment and, importantly, improve the quality of life as reported by patients with cancer. Side effects from complementary therapies barely occurred, and if they occurred, they were generally mild. Despite diversity in the methodological quality of the included meta-analyses, the selected complementary therapies show beneficial effects on patient-reported health outcomes. For instance, the included meta-analyses show the efficacy of acupuncture and related therapies to relieve cancer pain in different subgroups of patients and yoga to improve cancer-related fatigue. The use of acupuncture for pain management was also recommended in a recently

published clinical practice guideline on integrative medicine in oncology [120]. The results from the current overview seem consistent with several other existing clinical recommendations, such as music interventions to reduce anxiety [121], acupuncture to relieve neuropathy symptoms [120,122] or yoga to improve quality of life [123].

For some intervention-outcome combinations, the results were inconclusive. This is probably due to variations in the systematic review's eligibility criteria on the study population, intervention (delivery), comparators or outcome measures that are inherent in such a comprehensive overview of systematic reviews. It was beyond the scope of this study to analyze the differences within an intervention. For instance, the enormous amount of different botanical compounds used in herbal medicine can easily lead to inconclusive results on the same patient-reported outcome. Variations in the measurement instruments used for the same patient-reported outcome between meta-analyses may also lead to inconclusive results.

Only a few systematic reviews met most of the criteria, as defined in the seven critical domains of AMSTAR 2 [16]. However, not all criteria equally compromise the research process quality. For instance, a lack of protocol registration does not mean that the protocol is significantly violated without justification, or the absence of a list of missing studies does not mean that there is no proper justification for exclusion. An important criterion often violated by the systematic review's authors, is accounting for the impact of the risk of bias (including publication bias) in the interpretation and discussion of the results. In addition, the causes of heterogeneity among combined primary study results were not (properly) investigated in several included metaanalyses. When authors do not take into account these factors when interpreting the meta-analysis results, there is an increased risk of drawing distorted conclusions about the effect of complementary therapies. In almost all the systematic reviews, the authors raised their concerns about the quality of the underlying primary studies and the need for randomized clinical trials with larger sample sizes. When interpreting the results from individual meta-analyses, it is important to consider that the nature of complementary therapies makes it difficult to conduct double-blinded trials. The lack of double blinding makes it more likely to show an advantage of complementary therapy due to a placebo effect or response bias, especially in patient-reported outcome measures.

Limitations

When interpreting the results section, it is important to take the following limitations into account. First, the RCTs of the included meta-analyses often (partially or entirely) overlap because we did not control for the duplication of primary studies. Thus, the

amount of included meta-analyses has no value. Second, the meta-analyses effect sizes were not comparable because of heterogeneity in the effect size type and the interpretation of the effect sizes was dependent on the study parameters and clinical outcomes. However, the effect sizes for each included meta-analysis can be found in Table S1. Third, because of the broad scope of this overview of systematic reviews, we did not differentiate between the patient populations (e.g., active treatment or survivor), intervention delivery (e.g., intensity and duration), comparators and outcomes (e.g., different instruments and measurement moments). However, if the meta-analysis outcomes were significantly affected by one of these factors the information was generally extracted and reported in the current paper.

Lastly, it is possible that relevant meta-analyses for particular complementary therapies, outcomes or in specific cancer populations are missing due to the narrowing of our search window (January 2018–April 2022). For example, two systematic reviews published before 2018 showed beneficial effects of massage therapy on pain in cancer patients [124,125], whilst in the current review only a few systematic reviews on manual therapies were included (e.g., lymphatic drainage, myofascial release). Nonetheless, the included meta-analyses most likely will cover the majority of relevant primary studies on complementary therapies.

Applications

Given the lack of knowledge on complementary therapies reported by clinicians, this up-to-date overview of the evidence can support them in counselling patients with cancer on the topic by describing the effect of complementary therapies on a range of outcomes relevant for patients with cancer. A complicating factor is that evidence on the efficacy of some complementary therapies is inconclusive. As proposed in the ethical framework by Cohen et al. [126], clinicians can tolerate the use of complementary therapies for which evidence is inconclusive, but safety is supported by evidence as long as caution is provided and effectiveness is closely monitored. This way, patient beliefs and decisions about complementary therapy use can be respected in a safe manner. The recently published clinical practice guideline by Balneaves and colleagues [127] provides further recommendations for oncology healthcare providers for addressing complementary medicine use among patients with cancer. For instance, by supporting patients to make evidence-informed decisions on complementary medicine use by ensuring that the patient understands the potential benefits and risks related to this use.

The evidence presented in this study was not pooled and not graded, which means that it was not possible to make explicit clinical recommendations. However, the

results can provide leads for updating clinical recommendations. For instance, the included meta-analyses indicated that yoga can relieve fatigue among patients with breast cancer. In the last update to the clinical practice guideline on integrative therapies for breast cancer patients [121], there was insufficient evidence to form a clinical recommendation on this intervention-outcome combination.

Future studies

The results from the current study can indicate directions for future research in the field of complementary medicine, since this overview clarifies which complementary therapy, outcome measure and in which population little research has been conducted. For example, the included meta-analyses included only two RCTs indicating a positive effect of Tai Chi on anxiety, which is an intervention-outcome combination that should be further explored. Some complementary therapies, such as yoga and Qigong, did not significantly improve patient-reported outcomes when compared to the active control (e.g., regular exercise) [100,101,106]. Non-inferiority trials are recommended.

Many of the described complementary therapies in this overview have their roots in traditional Chinese medicine. A large proportion of the primary studies have been conducted in Chinese clinical research samples. For future research, it would be interesting to investigate to what extent the results are applicable to other populations, such as patients from Western countries.

The safety of complementary therapy use was not assessed in several included systematic reviews, despite its relevance for clinical decision-making [126]. The lack of adverse event reporting in RCTs and SRs affects the reliability of the safety judgment for complementary therapies. Therefore, it is important that future studies always report on (the absence of) adverse events that occur during complementary therapy use and also take into account possible interaction effects with anti-cancer treatment, especially for herbal medicine.

In the included meta-analyses in the current study, it was reported a few times that the effect of a complementary therapy on a patient-reported outcome was only significant during or immediately post-intervention. This finding indicates that the effect of complementary therapies, such as acupuncture and yoga, diminishes once you stop using it. For future research, longer follow-ups are recommended to provide more insight into effect duration, which is valuable information for patients. In addition, longer follow-ups can provide more information about the long-term safety of complementary therapy use.

CONCLUSIONS

This study provides an overview of the recently published systematic reviews that assess the effects of complementary therapies on physical, psychological and general patient-reported health outcomes in patients with cancer. The results suggest that several complementary therapies can have an effect on the improvement of symptoms or side effects from treatment reported by patients with cancer. For example, the included meta-analyses show the effectiveness of acupuncture to relieve pain, yoga to improve fatigue and music interventions to reduce anxiety. Importantly, complementary therapy use in general seems to improve the quality of life for patients with cancer. The side effects related to complementary therapy use are generally mild. For some intervention-outcome combinations, the results remain inconclusive. Rigorous randomized clinical trials on the effect of complementary therapies are warranted. In many of the included systematic reviews, the causes and impact of bias were insufficiently assessed in the interpretation of the results. Nonetheless, this up-to-date overview of the evidence on complementary therapies could support clinicians in counselling their patients on this topic and could provide directions for future research and clinical practice guidelines.

REFERENCES

- Kemppainen, L.M.; Kemppainen, T.T.; Reippainen, J.A.; Salmenniemi, S.T.; Vuolanto, P.H. Use 1 of complementary and alternative medicine in Europe: Health-related and sociodemographic determinants. Scand J Public Health 2018, 46, 448-455.
- Kim, D.; Sung, S.H.; Shin, S.; Park, M. The effect of cancer on traditional, complementary and alternative medicine utilization in Korea: a fixed effect analysis using Korea Health Panel data. BMC Complement Med 2022, 22, 137.
- Keene, M.R.; Heslop, I.M.; Sabesan, S.S.; Glass, B.D. Complementary and alternative medicine use 3. in cancer: A systematic review. Complement Ther Clin Pract 2019, 35, 33-47.
- King, N.; Balneaves, L.G.; Levin, G.T.; Nguyen, T.; Nation, J.G.; Card, C.; Truant, T.; Carlson, L.E. 4. Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. Integr Cancer Ther 2015, 14, 515-524.
- Uslu-Sahan, F.; Yesilcınar, I.; Kurt, G.; Hancer, E.; Guvenc, G. Effects of COVID-19 fear and anxiety on attitudes towards complementary and alternative medicine use in women with gynecological cancer during the COVID-19 pandemic. J Integr Med 2023, 4, 377-384.
- Huebner, J.; Muenstedt, K.; Prott, F.J.; Stoll, C.; Micke, O.; Buentzel, J.; Muecke, R.; Senf, B. Online survey of patients with breast cancer on complementary and alternative medicine. Breast Care 2014, 9,60-63.
- Davis, E.L.; Oh, B.; Butow, P.N.; Mullan, B.A.; Clarke, S. Cancer patient disclosure and patientdoctor communication of complementary and alternative medicine use: a systematic review. Oncologist 2012, 17, 1475.
- Foley, H.; Steel, A.; Cramer, H.; Wardle, J.; Adams, J. Disclosure of complementary medicine use to medical providers: a systematic review and meta-analysis. Sci Rep 2019, 9, 1573.
- Roter, D.L.; Yost, K.J.; O'Byrne, T.; Branda, M.; Leppin, A.; Kimball, B.; Fernandez, C.; Jatoi, A.; 9. Kumbamu, A.; Montori, V. Communication predictors and consequences of Complementary and Alternative Medicine (CAM) discussions in oncology visits. Patient Educ Couns 2016, 99, 1519-1525.
- 10. Mazzocco, K.; Milani, A.; Ciccarelli, C.; Marzorati, C.; Pravettoni, G. Evidence for Choosing Qigong as an Integrated Intervention in Cancer Care: An Umbrella Review. Cancers 2023, 15, 1176.
- Belloni, S.; Bonucci, M.; Arrigoni, C.; Dellafiore, F.; Caruso, R. A Systematic Review of Systematic Reviews and a Pooled Meta-Analysis on Complementary and Integrative Medicine for Improving Cancer-Related Fatigue. Clin Ther 2022.
- Sun, H.; Gong, T.-T.; Xia, Y.; Wen, Z.-Y.; Zhao, L.-G.; Zhao, Y.-H.; Wu, Q.-J. Diet and ovarian cancer risk: an umbrella review of systematic reviews and meta-analyses of cohort studies. Clin Nutr 2021, 40, 1682-1690.
- Higgins, J.P.; Thomas, J.; Chandler, J.; Cumpston, M.; Li, T.; Page, M.J.; Welch, V.A. Cochrane handbook for systematic reviews of interventions; John Wiley & Sons: 2019.
- Mentink, M.; Noordman, J.; Busch, M.; van Vliet, L.; Timmer-Bonte, J.A.; van Dulmen, S. Towards an open and effective dialogue on complementary medicine in oncology: protocol of patient participatory study 'COMMON'. BMJ Open 2021, 11, e053005.
- Lee S.M.; Choi H.C.; Hyun M.K. An Overview of Systematic Reviews: Complementary Therapies for Cancer Patients. Integr Cancer Ther 2019, 18, 1534735419890029.
- 16. Shea, B.J.; Reeves, B.C.; Wells, G.; Thuku, M.; Hamel, C.; Moran, J.; Moher, D.; Tugwell, P.; Welch, V.; Kristjansson, E. AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. BMJ 2017, 358.

- National Cancer Institute. Dictionary of Cancer Terms. Available online: https://www.cancer.gov/search/results?swKeyword=acupuncture (accessed on 08/05/2023).
- Medicine, N.L.o. Medical Subject Headings (MeSH). Available online: https://www.ncbi.nlm.nih. gov/mesh/ (accessed on 08/05/2023).
- 19. Kabat-Zinn, J.; Hanh, T.N. Full catastrophe living: Using the wisdom of your body and mind to face stress, pain, and illness; Delta: 2009.
- Liu, X.; Lu, J.; Wang, G.; Chen, X.; Xv, H.; Huang, J.; Xue, M.; Tang, J. Acupuncture for arthralgia induced by aromatase inhibitors in patients with breast cancer: a systematic review and meta-analysis. *Integr Cancer Ther* 2021, 20, 1534735420980811.
- Chan, Y.-T.; Wang, N.; Tam, C.-W.; Tan, H.-Y.; Lu, Y.; So, T.-h.; Chau-Leung Yu, E.; Lao, L.; Feng, Y. Systematic Review with Meta-Analysis: Effectiveness and Safety of Acupuncture as Adjuvant Therapy for Side Effects Management in Drug Therapy-Receiving Breast Cancer Patients. Evid Based Complement Alternat Med 2021, 2021.
- 22. Gao, Y.; Ma, T.; Han, M.; Yu, M.; Wang, X.; Lv, Y.; Wang, X. Effects of Acupuncture and Moxibustion on Breast Cancer-Related Lymphedema: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. *Integr Cancer Ther* **2021**, 20, 15347354211044107.
- 23. Kannan, P.; Lam, H.Y.; Ma, T.K.; Lo, C.N.; Mui, T.Y.; Tang, W.Y. Efficacy of physical therapy interventions on quality of life and upper quadrant pain severity in women with post-mastectomy pain syndrome: a systematic review and meta-analysis. Qual Life Res 2022, 31, 951-973.
- Chien, T.-J.; Liu, C.-Y.; Fang, C.-J.; Kuo, C.-Y. The efficacy of acupuncture in chemotherapyinduced peripheral neuropathy: systematic review and meta-analysis. *Integr Cancer Ther* 2019, 18,1534735419886662.
- 25. Jin, Y.; Wang, Y.; Zhang, J.; Xiao, X.; Zhang, Q. Efficacy and safety of acupuncture against chemotherapy-induced peripheral neuropathy: a systematic review and meta-analysis. *Evid Based Complement Alternat Med* **2020**, 2020.
- 26. Zhang, Y.; Sun, Y.; Li, D.; Liu, X.; Fang, C.; Yang, C.; Luo, T.; Lu, H.; Li, H.; Zhang, H. Acupuncture for breast cancer: A systematic review and meta-analysis of patient-reported outcomes. *Front Oncol* **2021**, 11, 646315.
- 27. Li, D.-h.; Su, Y.-f.; Fan, H.-f.; Guo, N.; Sun, C.-x. Acupuncture combined with three-step analgesic drug therapy for treatment of cancer pain: a systematic review and meta-analysis of randomised clinical trials. Evid Based Complement Alternat Med 2021, 2021, 1-12.
- 28. Yuanqing, P.; Yong, T.; Haiqian, L.; Gen, C.; Shen, X.; Dong, J.; Qi, C.; Miaomiao, Q. Acupuncture for Hormone Therapy—Related Side Effects in Breast Cancer Patients: A GRADE-Assessed Systematic Review and Updated Meta-Analysis. *Integr Cancer Ther* 2020, 19, 1534735420940394.
- 29. Wang, X.-P.; Zhang, D.-J.; Wei, X.-D.; Wang, J.-P.; Zhang, D.-Z. Acupuncture for the relief of hot flashes in breast cancer patients: A systematic review and meta-analysis of randomized controlled trials and observational studies. *J Cancer Res Ther* **2018**, *14*, S600-S608.
- 30. Li, H.; Schlaeger, J.M.; Jang, M.K.; Lin, Y.; Park, C.; Liu, T.; Sun, M.; Doorenbos, A.Z. Acupuncture improves multiple treatment-related symptoms in breast cancer survivors: A systematic review and meta-analysis. *J Altern Complement Med* **2021**, *27*, 1084-1097.
- 31. Chien, T.-J.; Liu, C.-Y.; Fang, C.-J.; Kuo, C.-Y. The maintenance effect of acupuncture on breast cancer-related menopause symptoms: a systematic review. *Climacteric* **2020**, *23*, 130-139.
- 32. Jang, S.; Ko, Y.; Sasaki, Y.; Park, S.; Jo, J.; Kang, N.-H.; Yoo, E.-S.; Park, N.-C.; hee Cho, S.; Jang, H. Acupuncture as an adjuvant therapy for management of treatment-related symptoms in breast cancer patients: systematic review and meta-analysis (PRISMA-compliant). *Medicine* 2020, 99.

- 33. Zhu, X.-Y.; Li, Z.; Chen, C.; Feng, R.-L.; Cheng, B.-R.; Liu, R.-Y.; Wang, R.-T.; Xu, L.; Wang, Y.; Tao, X. Physical therapies for psychosomatic symptoms and quality of life induced by aromatase inhibitors in breast cancer patients: a systematic review and meta-analysis. Front Oncol 2021, 4703.
- 34. Ni, X.; Tian, T.; Chen, D.; Liu, L.; Li, X.; Li, F.; Liang, F.; Zhao, L. Acupuncture for radiationinduced xerostomia in cancer patients: a systematic review and meta-analysis. Integr Cancer Ther 2020, 19, 1534735420980825.
- 35. Hou, X.-B.; Chen, D.-D. Effectiveness and safety of acupuncture on cancer pain: a meta-analysis. TMR Integr Med 2020, 4, e20018.
- 36. Xu, G.; Lei, H.; Zhou, Y.; Huang, L.; Tian, H.; Zhou, Z.; Zhao, L.; Liang, F. Acupuncture for Quality of Life of Patients with Defecation Dysfunction after Sphincter Preserving Surgery for Rectal Cancer: A Systematic Review. Evid Based Complement Alternat Med 2021, 2021.
- 37. Liu, J.; Nie, G.; Li, Y.; Wen, Z.; Lu, L.; Xie, L.; Cao, D.; Lai, Y.; Yang, H. Nonhormonal hot flash management for breast cancer survivors: a systematic review and network meta-analysis. Evid Based Complement Alternat Med 2020, 2020.
- 38. Dai, L.; Liu, Y.; Ji, G.; Xu, Y. Acupuncture and derived therapies for pain in palliative cancer management: systematic review and meta-analysis based on single-arm and controlled trials. J Palliat Med 2021, 24, 1078-1099.
- 39. Dong, B.; Lin, L.; Chen, Q.; Qi, Y.; Wang, F.; Qian, K.; Tian, L. Wrist-ankle acupuncture has a positive effect on cancer pain: a meta-analysis. BMC complement med 2021, 21, 1-10.
- 40. He, Y.; Guo, X.; May, B.H.; Zhang, A.L.; Liu, Y.; Lu, C.; Mao, J.J.; Xue, C.C.; Zhang, H. Clinical evidence for association of acupuncture and acupressure with improved cancer pain: a systematic review and meta-analysis. JAMA Oncol 2020, 6, 271-278.
- 41. Jang, A.; Brown, C.; Lamoury, G.; Morgia, M.; Boyle, F.; Marr, I.; Clarke, S.; Back, M.; Oh, B. The effects of acupuncture on cancer-related fatigue: updated systematic review and meta-analysis. Integr Cancer Ther 2020, 19, 1534735420949679.
- 42. Lin, W.-F.; Zhong, M.-F.; Zhou, Q.-H.; Zhang, Y.-R.; Wang, H.; Zhao, Z.-H.; Cheng, B.-B.; Ling, C.-Q. Efficacy of complementary and integrative medicine on health-related quality of life in cancer patients: a systematic review and meta-analysis. Cancer Manag Res 2019, 11, 6663.
- 43. Tan, J.-Y.B.; Wang, T.; Kirshbaum, M.N.; Zhao, I.; Eliseeva, S.; Polotan, M.J.; Yao, L.-Q.; Huang, H.-Q.; Zheng, S.-L. Acupoint stimulation for cancer-related fatigue: A quantitative synthesis of randomised controlled trials. Complement Ther Clin Pract 2021, 45, 101490.
- 44. Zhang, Y.; Lin, L.; Li, H.; Hu, Y.; Tian, L. Effects of acupuncture on cancer-related fatigue: a metaanalysis. Support Care Cancer 2018, 26, 415-425.
- 45. Mai, Q.; Li, X.; Yang, D.; Zhang, X.; Peng, K.; Hao, Y. Effects of acupressure on cancer-related pain management: A systematic review and meta-analysis of randomized controlled trials. Eur J Integr Med **2022**, 102120.
- 46. Chen, L.; Wu, X.; Chen, X.; Zhou, C. Efficacy of auricular acupressure in prevention and treatment of chemotherapy-induced nausea and vomiting in patients with cancer: a systematic review and meta-analysis. Evid Based Complement Alternat Med 2021, 2021, 1-11.
- 47. Chen, C.-Y.; Lin, X.-X.; Wang, X. Efficacy of non-invasive auricular acupressure for treating constipation in leukemia patients undergoing chemotherapy: a systematic review. Complement Med Res 2018, 25, 406-412.
- 48. Jing, X.; Liu, J.; Wang, C.; Ji, M.; Chen, X.; Mei, Y.; rong Zhu, Q. Auricular acupressure is an alternative in treating constipation in leukemia patients undergoing chemotherapy: A systematic review and meta-analysis. Complement Ther Clin Pract 2018, 31, 282-289.

- Hsieh, S.-H.; Wu, C.-R.; Romadlon, D.S.; Hasan, F.; Chen, P.-Y.; Chiu, H.-Y. The effect of acupressure on relieving cancer-related fatigue: a systematic review and meta-analysis of randomized controlled trials. Cancer Nurs 2021, 44, E578-E588.
- Wang, Y.; Zhang, J.; Jin, Y.; Zhang, Q. Auricular acupressure therapy for patients with cancer with sleep disturbance: a systematic review and meta-analysis. Evid Based Complement Alternat Med 2021, 2021.
- Ma, H.-L.; Lou, L.-F.; Sun, Z.-H.; Lv, B.-L.; Yang, B. The effectiveness of moxibustion for cancerrelated fatigue: An updated systematic review and meta-analysis. Eur J Integr Med 2019, 30, 100960.
- 52. Yao, Z.; Xu, Z.; Xu, T.; Liu, X.; Xu, S.; Wan, C.; Zhou, X. Moxibustion for alleviating chemotherapyinduced gastrointestinal adverse effects: a systematic review of randomized controlled trials. Complement Ther Clin Pract 2022, 101527.
- Zhang, H.W.; Lin, Z.X.; Cheung, F.; Cho, W.C.S.; Tang, J.L. Moxibustion for alleviating side effects
 of chemotherapy or radiotherapy in people with cancer. Cochrane Database of Systematic Reviews 2018.
- 54. Li, S.; So, T.-h.; Tang, G.; Tan, H.-Y.; Wang, N.; Ng, B.F.L.; Chan, C.K.W.; Yu, E.C.-L.; Feng, Y. Chinese herbal medicine for reducing chemotherapy-associated side-effects in breast cancer patients: a systematic review and meta-analysis. *Front Oncol* **2020**, 10, 599073.
- 55. Chen, Y.; Cheng, C.-s.; Tan, H.-Y.; Tam, C.W.; Wang, N.; Feng, Y. Efficacy of Herbal Medicines Intervention for Colorectal Cancer Patients With Chemotherapy-Induced Gastrointestinal Toxicity—a Systematic Review and Meta-Analysis. Front Oncol 2021, 11, 629132.
- Li, Y.; Sui, X.; Su, Z.; Yu, C.; Shi, X.; Johnson, N.L.; Chu, F.; Li, Y.; Li, K.; Ding, X. Meta-analysis
 of paclitaxel-based chemotherapy combined with traditional Chinese medicines for gastric cancer
 treatment. Front Pharmacol 2020, 11, 132.
- 57. She, Y.; Huang, Q.; Ye, Z.; Hu, Y.; Wu, M.; Qin, K.; Wei, A.; Yang, X.; Liu, Y.; Zhang, C. the therapeutic principle of combined strengthening Qi and eliminating pathogens in treating middle-advanced primary liver cancer: a systematic review and meta-analysis. Front Pharmacol 2021, 2783.
- 58. Jin, H.; Park, S.B.; Yoon, J.-H.; Lee, J.Y.; Kim, E.H.; Yoon, S.W. Traditional herbal medicine combined with first-line platinum-based chemotherapy for advanced non-small-cell lung cancer: A PRISMA-compliant systematic review and meta-analysis. Medicine 2021, 100.
- Yang, J.; Zhu, X.; Yuan, P.; Liu, J.; Wang, B.; Wang, G. Efficacy of traditional Chinese Medicine combined with chemotherapy in patients with non-small cell lung cancer (NSCLC): a meta-analysis of randomized clinical trials. Support Care Cancer 2020, 28, 3571-3579.
- 60. Zhang, X.-W.; Liu, W.; Jiang, H.-L.; Mao, B. Chinese herbal medicine for advanced non-small-cell lung cancer: a systematic review and meta-analysis. *Am J Chin Med* **2018**, 46, 923-952.
- 61. Wang, R.; Sun, Q.; Wang, F.; Liu, Y.; Li, X.; Chen, T.; Wu, X.; Tang, H.; Zhou, M.; Zhang, S. Efficacy and safety of Chinese herbal medicine on ovarian cancer after reduction surgery and adjuvant chemotherapy: a systematic review and meta-analysis. Front Oncol 2019, 9, 730.
- 62. Lu, Y.; Sun, C.; Jiao, L.; Liu, Y.; Gong, Y.; Xu, L. Chinese herbal medicine combined with first-generation EGFR-TKIs in treatment of advanced non-small cell lung cancer with EGFR sensitizing mutation: a systematic review and meta-analysis. Front Pharmacol 2021, 12, 698371.
- 63. Chen, Z.-Q.; Li, Z.-Y.; Yang, C.-Z.; Lin, R.-T.; Lin, L.-Z.; Sun, L.-L. Chinese herbal medicine for epidermal growth factor receptor inhibitor-induced skin rash in patients with malignancy: An updated meta-analysis of 23 randomized controlled trials. *Complement Ther Med* 2019, 47, 102167.
- 64. Hu, J.; Jiang, J.; Liu, R.; Cheng, M.; Zhu, G.; He, S.; Shi, B.; Zhao, Y.; He, Z.; Yu, H. Clinical efficacy and safety of traditional medicine preparations combined with chemotherapy for advanced pancreatic cancer: A systematic review and meta-analysis. Front Oncol 2022, 12.
- Deng, B.; Sun, W. Herbal medicine for hand-foot syndrome induced by fluoropyrimidines: A systematic review and meta-analysis. Phytother Res 2018, 32, 1211-1228.

- 66. Liu, Y.; May, B.H.; Zhang, A.L.; Guo, X.; Lu, C.; Xue, C.C.; Zhang, H. Integrative herbal medicine for chemotherapy-induced peripheral neuropathy and hand-foot syndrome in colorectal cancer: a systematic review and meta-analysis. Integr Cancer Ther 2019, 18, 1534735418817833.
- 67. Li, M.; Chen, Z.; Liu, Z.; Zhang, N.; Liu, I.; Wang, H.; Wang, W.; Liang, Y.; Chen, J.; Liu, Z. Twelve Chinese herbal preparations for the treatment of depression or depressive symptoms in cancer patients: a systematic review and meta-analysis of randomized controlled trials. BMC Complement Altern Med 2019, 19, 1-16.
- 68. Li, L.; Wang, R.; Zhang, A.; Wang, L.; Ge, Q.; Liu, Y.; Chen, T.; Wang, C.C.; Leung, P.C.; Sun, Q. Evidence on efficacy and safety of Chinese medicines combined western medicines treatment for breast cancer with endocrine therapy. Front Oncol 2021, 11, 661925.
- 69. Bai, X.; Ta, N.; Gong, G.-H.; Zhang, B.; Wei, C.-X. Effects of integrated Chinese traditional medicine and conventional western medicine on the quality of life of breast cancer patients: a systematic review and meta-analysis. Evid Based Complement Alternat Med 2022, 2022.
- 70. Shi, G.; Yu, D.; Wu, J.; Liu, Y.; Huang, R.; Zhang, C.S. A systematic review and meta-analysis of traditional Chinese medicine with chemotherapy in breast cancer. Gland Surg 2021, 10, 1744.
- Chen, S.; Bao, Y.; Xu, J.; Zhang, X.; He, S.; Zhang, Z.; Qi, R.; Jiang, J.; Liu, R.; Guo, Q. Efficacy and safety of TCM combined with chemotherapy for SCLC: a systematic review and meta-analysis. J Cancer Res Clin Oncol 2020, 146, 2913-2935.
- Kwon, C.Y.; Lee, B.; Kong, M.; Lee, S.H.; Jung, H.J.; Kim, K.I.; Lee, B.J. Effectiveness and safety of herbal medicine for cancer-related fatigue in lung cancer survivors: A systematic review and metaanalysis. Phytother Res 2021, 35, 751-770.
- 73. Wang, L.-C.; Chang, Y.-Y.; Lee, I.-C.; Kuo, H.-C.; Tsai, M.-Y. Systematic review and meta-analysis of Chinese herbal medicine as adjuvant treatment in advanced non-small cell lung cancer patients. Complement Ther Med 2020, 52, 102472.
- Huang, Z.; Zhang, Q.; Fan, Y.; Zhou, J.; Liang, M.; Deng, X.; Liang, J. Effect of traditional Chinese medicine injection on cancer-related fatigue: A meta-analysis based on existing evidence. Evid Based Complement Alternat Med 2020, 2020.
- Li, Z.; Jin, H.; Yan, Q.; Sun, L.; Wasan, H.S.; Shen, M.; Ruan, S. The method of activating blood and dredging collaterals for reducing chemotherapy-induced peripheral neuropathy: a systematic review and meta-analysis. Evid Based Complement Alternat Med 2019, 2019.
- 76. Wang, Y.-h.; Chang, J.-y.; Feng, L. Effect of oral Chinese medicine combined with Western medicine on cancer pain: a meta-analysis. Chin J Integr Med 2021, 27, 713-720.
- Wu, J.; Liu, Y.; Fang, C.; Zhao, L.; Lin, L.; Lu, L. Traditional Chinese medicine preparation combined therapy may improve chemotherapy efficacy: a systematic review and meta-analysis. Evid Based Complement Alternat Med 2019, 2019.
- 78. Yoon, J.-H.; Kim, E.H.; Park, S.B.; Lee, J.Y.; Yoon, S.W. Traditional herbal medicine for insomnia in patients with cancer: a systematic review and meta-analysis. Front Pharmacol 2021, 12, 753140.
- 79. Yueyang, Z.; Sumei, W.; Jinhua, L.; Yushu, Z.; Wanyin, W.; Hann, S.S. Effectiveness and safety of traditional Chinese medical therapy for cancer-related fatigue: A systematic review and Metaanalysis of randomized controlled trials. J Tradit Chin Med 2020, 40, 738.
- 80. Chang, Y.-C.; Yeh, T.-L.; Chang, Y.-M.; Hu, W.-Y. Short-term effects of randomized mindfulnessbased intervention in female breast cancer survivors: a systematic review and meta-analysis. Cancer Nurs 2021, 44, E703-E714.
- 81. Schell, L.K.; Monsef, I.; Wöckel, A.; Skoetz, N. Mindfulness-based stress reduction for women diagnosed with breast cancer. Cochrane Database of Systematic Reviews 2019.

- 82. Lin, L.-Y.; Lin, L.-H.; Tzeng, G.-L.; Huang, Y.-H.; Tai, J.-F.; Chen, Y.-L.; Wu, C.-J.; Chen, P.-H.; Lin, P.-C.; Hung, P.-L. Effects of mindfulness-based therapy for cancer patients: A systematic review and meta-analysis. J Clin Psychol Med Settings 2022, 29, 432-445.
- 83. Xunlin, N.; Lau, Y.; Klainin-Yobas, P. The effectiveness of mindfulness-based interventions among cancer patients and survivors: a systematic review and meta-analysis. *Support Care Cancer* 2020, 28, 1563-1578.
- 84. He, J.; Hou, J.-h.; Qi, J.; Zhang, T.; Wang, Y.-l.; Qian, M. Mindfulness ased stress reduction interventions for cancer related fatigue: a meta-analysis and systematic review. *J Natl Med Assoc* 2020, 112, 387-394.
- 85. Suh, H.-W.; Jeong, H.Y.; Hong, S.; Kim, J.W.; Yoon, S.W.; Lee, J.Y.; Chung, S.-Y. The mindfulness-based stress reduction program for improving sleep quality in cancer survivors: a systematic review and meta-analysis. *Complement Ther Med* 2021, 57, 102667.
- 86. Xie, C.; Dong, B.; Wang, L.; Jing, X.; Wu, Y.; Lin, L.; Tian, L. Mindfulness-based stress reduction can alleviate cancer-related fatigue: a meta-analysis. *J Psychosom Res* **2020**, *130*, 109916.
- 87. Yang, T.; Wang, S.; Wang, R.; Wei, Y.; Kang, Y.; Liu, Y.; Zhang, C. Effectiveness of five-element music therapy in cancer patients: A systematic review and meta-analysis. *Complement Ther Clin Pract* **2021**, 44, 101416.
- 88. Li, Y.; Xing, X.; Shi, X.; Yan, P.; Chen, Y.; Li, M.; Zhang, W.; Li, X.; Yang, K. The effectiveness of music therapy for patients with cancer: A systematic review and meta-analysis. *J Adv Nurs* 2020, 76, 1111-1123.
- 89. Bro, M.L.; Jespersen, K.V.; Hansen, J.B.; Vuust, P.; Abildgaard, N.; Gram, J.; Johansen, C. Kind of blue: A systematic review and meta-analysis of music interventions in cancer treatment. *Psycho-Oncol* 2018, 27, 386-400.
- 90. Qi, Y.; Lin, L.; Dong, B.; Xu, E.; Bao, Z.; Qi, J.; Chen, X.; Tian, L. Music interventions can alleviate cancer-related fatigue: a metaanalysis. Support Care Cancer 2021, 29, 3461-3470.
- 91. Yangöz, Ş.T.; Özer, Z. The effect of music intervention on patients with cancer-related pain: A systematic review and meta-analysis of randomized controlled trials. *J Adv Nurs* **2019**, *75*, 3362-3373.
- 92. Liu, C.; Qin, M.; Zheng, X.; Chen, R.; Zhu, J. A meta-analysis: intervention effect of mind-body exercise on relieving cancer-related fatigue in breast cancer patients. *Evid Based Complement Alternat Med* 2021, 2021.
- 93. Luo, X.-C.; Liu, J.; Fu, J.; Yin, H.-Y.; Shen, L.; Liu, M.-L.; Lan, L.; Ying, J.; Qiao, X.-L.; Tang, C.-Z. Effect of Tai Chi Chuan in breast cancer patients: a systematic review and meta-analysis. Front Oncol 2020, 10, 607.
- 94. Ni, X.; Chan, R.J.; Yates, P.; Hu, W.; Huang, X.; Lou, Y. The effects of Tai Chi on quality of life of cancer survivors: a systematic review and meta-analysis. Support Care Cancer 2019, 27, 3701-3716.
- 95. Song, S.; Yu, J.; Ruan, Y.; Liu, X.; Xiu, L.; Yue, X. Ameliorative effects of Tai Chi on cancer-related fatigue: a meta-analysis of randomized controlled trials. *Support Care Cancer* **2018**, 26, 2091-2102.
- 96. Cai, Q.; Cai, S.-b.; Chen, J.-k.; Bai, X.-H.; Jing, C.-X.; Zhang, X.; Li, J.-Q. Tai Chi for anxiety and depression symptoms in cancer, stroke, heart failure, and chronic obstructive pulmonary disease: A systematic review and meta-analysis. Complement Ther Clin Pract 2022, 46, 101510.
- 97. Liu, L.; Tan, H.; Yu, S.; Yin, H.; Baxter, G.D. The effectiveness of tai chi in breast cancer patients: A systematic review and meta-analysis. *Complement Ther Clin Pract* **2020**, *38*, 101078.
- 98. Kuo, C.-C.; Wang, C.-C.; Chang, W.-L.; Liao, T.-C.; Chen, P.-E.; Tung, T.-H. Clinical effects of Baduanjin Qigong exercise on cancer patients: a systematic review and meta-analysis on randomized controlled trials. *Evid Based Complement Alternat Med* **2021**, 2021, 1-10.

- 99. Wang, R.; Huang, X.; Wu, Y.; Sun, D. Efficacy of qigong exercise for treatment of fatigue: a systematic review and meta-analysis. Front Med 2021, 8, 684058.
- 100. Yin, J.; Tang, L.; Dishman, R.K. The efficacy of Oigong practice for cancer-related fatigue: A systematic review and meta-analysis of randomized controlled trials. Ment Health Phys Act 2020, 19, 100347.
- 101. Armer, J.S.; Lutgendorf, S.K. The impact of yoga on fatigue in cancer survivorship: a meta-analysis. JNCI Cancer Spectr 2020, 4, pkz098.
- 102. Dong, B.; Xie, C.; Jing, X.; Lin, L.; Tian, L. Yoga has a solid effect on cancer-related fatigue in patients with breast cancer: a meta-analysis. Breast Cancer Res Treat 2019, 177, 5-16.
- 103. Haussmann, A.; Schmidt, M.E.; Illmann, M.L.; Schröter, M.; Hielscher, T.; Cramer, H.; Maatouk, I.; Horneber, M.; Steindorf, K. Meta-analysis of randomized controlled trials on yoga, psychosocial, and mindfulness-based interventions for cancer-related fatigue: what intervention characteristics are related to higher efficacy? Cancers 2022, 14, 2016.
- 104. Hsueh, E.-J.; Loh, E.-W.; Lin, J.J.-A.; Tam, K.-W. Effects of yoga on improving quality of life in patients with breast cancer: a meta-analysis of randomized controlled trials. Breast Cancer 2021,
- 105. Song, J. The effectiveness of yoga on cancer-related fatigue: a systematic review and meta-analysis. Oncol Nurs Forum 2021, 48, 207-228.
- 106. O'Neill, M.; Samaroo, D.; Lopez, C.; Tomlinson, G.; Santa Mina, D.; Sabiston, C.; Culos-Reed, N.; Alibhai, S.M. The effect of yoga interventions on cancer-related fatigue and quality of life for women with breast cancer: a systematic review and meta-analysis of randomized controlled trials. Integr Cancer Ther 2020, 19, 1534735420959882.
- 107. Yi, L.-J.; Tian, X.; Jin, Y.-F.; Luo, M.-J.; Jimenez-Herrera, M.F. Effects of yoga on health-related quality, physical health and psychological health in women with breast cancer receiving chemotherapy: a systematic review and meta-analysis. Ann Palliat Med 2021, 10, 1961-1975.
- 108. Coutiño-Escamilla, L.; Piña-Pozas, M.; Garces, A.T.; Gamboa-Loira, B.; López-Carrillo, L. Nonpharmacological therapies for depressive symptoms in breast cancer patients: Systematic review and meta-analysis of randomized clinical trials. The Breast 2019, 44, 135-143.
- 109. Gonzalez, M.; Pascoe, M.C.; Yang, G.; de Manincor, M.; Grant, S.; Lacey, J.; Firth, J.; Sarris, J. Yoga for depression and anxiety symptoms in people with cancer: a systematic review and metaanalysis. Psycho-Oncol 2021, 30, 1196-1208.
- 110. Tang, M.-F.; Chiu, H.-Y.; Xu, X.; Kwok, J.Y.; Cheung, D.S.T.; Chen, C.-Y.; Lin, C.-C. Walking is more effective than yoga at reducing sleep disturbance in cancer patients: A systematic review and metaanalysis of randomized controlled trials. Sleep Med Rev 2019, 47, 1-8.
- 111. Wang, W.-L.; Chen, K.-H.; Pan, Y.-C.; Yang, S.-N.; Chan, Y.-Y. The effect of yoga on sleep quality and insomnia in women with sleep problems: a systematic review and meta-analysis. BMC Psychiatry 2020, 20, 1-19.
- 112. Zeng, Y.; Dong, J.; Huang, M.; Zhang, J.-e.; Zhang, X.; Xie, M.; Wefel, J.S. Nonpharmacological interventions for cancer-related cognitive impairment in adult cancer patients: a network metaanalysis. Int J Nurs Stud 2020, 104, 103514.
- 113. El-Hashimi, D.; Gorey, K.M. Yoga-specific enhancement of quality of life among women with breast cancer: systematic review and exploratory meta-analysis of randomized controlled trials. J Evid Based Integr Med **2019**, 24, 2515690X19828325.
- 114. Danon, N.; Al-Gobari, M.; Burnand, B.; Rodondi, P.Y. Are mind-body therapies effective for relieving cancer-related pain in adults? A systematic review and meta-analysis. Psycho-Oncol 2022, 31, 345-371.

- 115. Lin, Y.; Yang, Y.; Zhang, X.; Li, W.; Li, H.; Mu, D. Manual lymphatic drainage for breast cancerrelated lymphedema: a systematic review and meta-analysis of randomized controlled trials. Clin Breast Cancer 2022.
- 116. Qiao, J.; Yang, L.-n.; Kong, Y.-h.; Huang, X.; Li, Y.; Bai, D.-q. Effect of Manual Lymphatic Drainage on Breast Cancer-Related Postmastectomy Lymphedema: A Meta-analysis of Randomized Controlled Trials. Cancer Nurs 2023, 46, 159-166.
- 117. da Silva, F.P.; Moreira, G.M.; Zomkowski, K.; de Noronha, M.A.; Sperandio, F.F. Manual therapy as treatment for chronic musculoskeletal pain in female breast cancer survivors: a systematic review and meta-analysis. J Manipulative Physiol Ther 2019, 42, 503-513.
- 118. Sinha, M.K.; Barman, A.; Goyal, M.; Patra, S. Progressive muscle relaxation and guided imagery in breast cancer: a systematic review and meta-analysis of randomised controlled trials. *Indian J Palliat Care* 2021, 27, 336.
- 119. Zeng, J.; Wang, L.; Cai, Q.; Wu, J.; Zhou, C. Effect of hypnosis before general anesthesia on postoperative outcomes in patients undergoing minor surgery for breast cancer: a systematic review and meta-analysis. Gland Surg 2022, 11, 588.
- 120. Mao, J.J.; Ismaila, N.; Bao, T.; Barton, D.; Ben-Arye, E.; Garland, E.L.; Greenlee, H.; Leblanc, T.; Lee, R.T.; Lopez, A.M. Integrative Medicine for Pain Management in Oncology: Society for Integrative Oncology–ASCO Guideline. J Clin Oncol 2022, 40, 3998-4024.
- 121. Greenlee, H.; DuPont-Reyes, M.J.; Balneaves, L.G.; Carlson, L.E.; Cohen, M.R.; Deng, G.; Johnson, J.A.; Mumber, M.; Seely, D.; Zick, S.M. Clinical practice guidelines on the evidence-based use of integrative therapies during and after breast cancer treatment. *CA: Cancer J Clin* **2017**, *67*, 194-232.
- 122. Deng, G.E.; Rausch, S.M.; Jones, L.W.; Gulati, A.; Kumar, N.B.; Greenlee, H.; Pietanza, M.C.; Cassileth, B.R. Complementary therapies and integrative medicine in lung cancer: diagnosis and management of lung cancer: American College of Chest Physicians evidence-based clinical practice guidelines. *Chest* 2013, 143, e420S-e436S.
- 123. Lyman, G.H.; Greenlee, H.; Bohlke, K.; Bao, T.; DeMichele, A.M.; Deng, G.E.; Fouladbakhsh, J.M.; Gil, B.; Hershman, D.L.; Mansfield, S. Integrative therapies during and after breast cancer treatment: ASCO endorsement of the SIO clinical practice guideline. *J Clin Oncol* 2018, 36, 2647-2655.
- 124. Boyd, C.; Crawford, C.; Paat, C.F.; Price, A.; Xenakis, L.; Zhang, W.; Evidence for Massage Therapy Working Group Buckenmaier Chester III MD, C.B.P.R., LMT Cambron Jerrilyn DC, PhD Deery Christopher LMT Schwartz Jan MA, BCTMB Werner Ruth BCTMB Whitridge Pete BA, LMT. The impact of massage therapy on function in pain populations—A systematic review and meta-analysis of randomized controlled trials: Part II, cancer pain populations. *Pain Med* 2016, 17, 1553-1568.
- 125. Lee, S.-H.; Kim, J.-Y.; Yeo, S.; Kim, S.-H.; Lim, S. Meta-analysis of massage therapy on cancer pain. Integr Cancer Ther 2015, 14, 297-304.
- 126. Cohen, M.H.; Eisenberg, D.M. Potential physician malpractice liability associated with complementary and integrative medical therapies. *Ann Intern Med* 2002, 136, 596-603.
- 127. Balneaves, L. G.; Watling, C. Z.; Hayward, E. N.; Ross, B., Taylor-Brown; J., Porcino, A.; Truant, T. L. Addressing complementary and alternative medicine use among individuals with cancer: an integrative review and clinical practice guideline. J Natl Cancer Inst 2022, 114, 25-37.

SUPPLEMENTARY MATERIALS

Supplementary material 1: Search term PubMed

("neoplasms "[MeSH Terms] OR neoplasm*[tiab] OR cancer*[tiab] OR tumor*[tiab] OR tumour*[tiab] OR carcinoma*[tiab]) AND ("integrative medicine"[MeSH Terms] OR integrative medicine[tiab] OR integrative oncol*[tiab] OR "complementary therapies"[MeSH Terms] OR complementary therap*[tiab] OR complementary medicine[tiab] OR complementary modalit*[tiab] OR complementary and alternative medicine[tiab] OR CAM[tiab] OR CIM[tiab] OR Acupuncture[tiab] OR Electroacupuncture[tiab] OR Meridian*[tiab] OR Moxibustion[tiab] OR Anthroposoph*[tiab] OR Auriculotherap*[tiab] OR Cupping Therap*[tiab] OR Diffuse Noxious Inhibitory Control[tiab] OR Dry Needling[tiab] OR Holistic Health[tiab] OR Holistic Therap*[tiab] OR Holistic Medicine[tiab] OR Bioresonance Therap*[tiab] OR Homeopathy[tiab] OR Horticultural Therap*[tiab] Gardening Therap*[tiab] OR Traditional Medicine[tiab] OR Home Remed*[tiab] OR Traditional Chinese Medicine[tiab] OR Ayurvedic Medicine[tiab] OR Ayurveda[tiab] OR Oriental Medicine[tiab] OR Mesotherap*[tiab] OR mind body medicine[tiab] OR mind body therap*[tiab] OR Aromatherap*[tiab] OR Biofeedback[tiab] OR Neurofeedback[tiab] OR Breathing Exercise*[tiab] OR Oigong[tiab] OR Hypnosis[tiab] OR Hypnotherap*[tiab] OR Suggestion[tiab] OR Autogenic Training*[tiab] OR Imagery[tiab] OR Guided Imagery[tiab] OR Laughter Therap*[tiab] OR Meditation[tiab] OR Mental Healing*[tiab] OR Mindfulness[tiab] OR Mindfulness based stress reduction[tiab] OR MBSR[tiab] OR Psychodrama[tiab] OR Role Playing[tiab] OR Tai Ji[tiab] OR Tai Chi[tiab] OR Therapeutic Touch[tiab] OR Yoga[tiab] OR Musculoskeletal Manipulation*[tiab] OR Manipulative Therap*[tiab] OR Manipulation Therap*[tiab] OR Manual Therap*[tiab] OR Reflexology[tiab] OR Kinesiology[tiab] OR Chiropractic Manipulation*[tiab] OR Chiropractic Adjustment*[tiab] OR Osteopathic Manipulati*[tiab] OR Acupressure[tiab] OR Shiatsu[tiab] OR Massage*[tiab] OR Massage Therap*[tiab] OR Zone Therap*[tiab] OR Manual Lymphatic Drainage[tiab] OR Manual Lymph Drainage[tiab] OR Myofascial Release Therap*[tiab] OR Naturopath*[tiab] OR Naturopathic Medicine[tiab] OR Phytotherap*[tiab] OR Herb Medicine[tiab] OR Herbal therap*[tiab] OR Herbal Medicine[tiab] OR Aromatherap*[tiab] OR Reflexotherap*[tiab] OR Reflex therap*[tiab] OR Sensory Art Therap*[tiab] OR Acoustic Stimulation[tiab] OR Auditory Stimulation[tiab] OR Art Therap*[tiab] OR Color Therap*[tiab] OR Dance Therap*[tiab] OR Music Therap*[tiab] OR Play Therap*[tiab] OR Spiritual Therap*[tiab] OR Faith Healing[tiab] OR Meditation[tiab] OR Relaxation[tiab] OR Mental Healing[tiab] OR Therapeutic Touch[tiab] OR Energetic Medicine[tiab] OR Touch therap*[tiab] OR Reiki[tiab] OR Yoga[tiab]) AND ((systematic* [ti] AND review [ti]) OR Systematic overview* [ti] OR Cochrane review* [ti] OR systemic review* [ti] OR scoping review [ti] OR scoping literature review [ti] OR mapping review [ti] OR Umbrella review* [ti] OR (review of reviews [ti] OR overview of reviews [ti]) OR meta-review [ti] OR (integrative review [ti] OR integrated review [ti] OR integrative overview [ti] OR meta-synthesis [ti] OR metasynthesis [ti] OR quantitative review [ti] OR quantitative synthesis [ti] OR research synthesis [ti] OR meta-ethnography [ti]) OR Systematic literature search [ti] OR Systematic literature research [ti] OR meta-analyses [ti] OR meta-analyses [ti] OR meta-analysis [ti] OR meta-analysis [ti] OR meta-analytic review [ti] OR meta-analytical review [ti] OR meta-analysis [pt] OR ((search* [tiab] OR medline [tiab] OR pubmed [tiab] OR embase [tiab] OR Cochrane [tiab] OR scopus [tiab] or web of science [tiab] OR sources of information [tiab] OR data sources [tiab] OR following databases [tiab]) AND (study selection [tiab] OR selection criteria [tiab] OR eligibility criteria [tiab] OR inclusion criteria [tiab] OR exclusion criteria [tiab])) OR systematic review [pt]) NOT (letter [pt] OR editorial [pt] OR comment [pt] OR case reports [pt] OR historical article [pt] OR report [ti] OR protocol [ti] OR protocols [ti] OR withdrawn [ti] OR retraction of publication [pt] OR retraction of publication as topic [mesh] OR retracted publication [pt] OR reply [ti] OR published erratum [pt]) AND (english[Language]) AND ("2018/01/01"[Date -Publication]: "2022/04/20" [Date - Publication])

Supplementary material 2: Data extraction table

Due to size of file: available online (doi: 10.3390/cancers15184513)

Supplementary material 3: Quality appraisal

The seven critical domains of the AMSTAR 2 Key Item 2—Did the report of the review contain an explicit statement that the review Yes methods were established prior to the conduct of the review and did the report Partial yes justify any significant deviations from the protocol? **Item 4**—Did the review authors use a comprehensive literature search strategy? No Item 7—Did the review authors provide a list of excluded studies and justify the exclusions? **Item 9**—Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review? **Item 11**—If meta-analysis was performed, did the review authors use appropriate methods for statistical combination of results? Item 13—Did the review authors account for RoB in primary studies when interpreting/discussing the results of the review? **Item 15**—If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?

Table S3. AMSTAR 2 scoring for each included systematic review

First author, year	Item 2	Item 4	Item 7	Item 9	Item 11	Item 13	Item 15
Armer 2020	•	•	•	•	•	•	•
Bai 2022	•	•	•	•	•	•	•
Bro 2018	•	•	•	•	•	•	•
Cai 2022	•	•	•	•	•	•	•
Chan 2021	•	•	•	•	•	•	•
Chang 2021	•	•	•	•	•	•	•
Chen 2018	•	•	•	•	•	•	•
Chen 2019	•	•	•	•	•	•	•
Chen 2020	•	•	•	•	•	•	•
Chen 2021-1	•	•	•	•	•	•	•
Chen 2021-2	•	•	•	•	•	•	•
Chien 2019	•	•	•	•	•	•	•
Chien 2020	•	•	•	•	•	•	•
Coutiño-Escamilla 2019	•	•	•	•	•	•	•
Dai 2021	•	•	•	•	•	•	•
Danon 2022	•	•	•	•	•	•	•
Deng 2018	•	•	•	•	•	•	•

Table S3. Continued

First author, year	Item 2	Item 4	Item 7	Item 9	Item 11	Item 13	Item 15
Dong 2019	•	•	•	•	•	•	•
Dong 2021	•	•	•	•	•	•	•
El-Hashimi 2019	•	•	•	•	•	•	•
Gao 2021	•	•	•	•	•	•	•
Gonzalez 2021	•	•	•	•	•	•	•
Haussmann 2022	•	•	•	•	•	•	•
Jin 2021	•	•	•	•	•	•	•
He 2020-1	•	•	•	•	•	•	•
He 2020-2	•	•	•	•	•	•	•
Hou 2020	•	•	•	•	•	•	•
Hsieh 2021	•	•	•	•	•	•	•
Hsueh 2021	•	•	•	•	•	•	•
Hu 2022	•	•	•	•	•	•	•
Huang 2020	•	•	•	•	•	•	•
Jang 2020-1	•	•	•	•	•	•	•
Jang 2020-2	•	•	•	•	•	•	•
Jihong 2021	•	•	•	•	•	•	•
Jin 2020	•	•	•	•	•	•	•
Jing 2018	•	•	•	•	•	•	•
Kannan 2022	•	•	•	•	•	•	•
Kuo 2021	•	•	•	•	•	•	•
Kwon 2021	•	•	•	•	•	•	•
Li 2019-1	•	•	•	•	•	•	•
Li 2019-2	•	•	•	•	•	•	•
Li 2020-1	•	•	•	•	•	•	•
Li 2020-2	•	•	•	•	•	•	•
Li 2020-3	•	•	•	•	•	•	•
Li 2021-1	•	•	•	•	•	•	•
Li 2021-2	•	•	•	•	•	•	•
Li 2021	•	•	•	•	•	•	•
Lin 2019	•	•	•	•	•	•	•

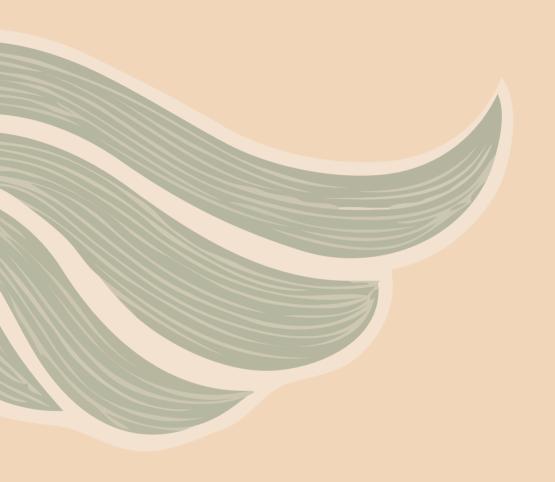
Table S3. Continued

First author, year	Item 2	Item 4	Item 7	Item 9	Item 11	Item 13	Item 15
Lin 2022-1	•	•	•	•	•	•	•
Lin 2022-2	•	•	•	•	•	•	•
Liu 2019	•	•	•	•	•	•	•
Liu 2020-1	•	•	•	•	•	•	•
Liu 2020-2	•	•	•	•	•	•	•
Liu 2021-1	•	•	•	•	•	•	•
Liu 2021-2	•	•	•	•	•	•	•
Lu 2021	•	•	•	•	•	•	•
Luo 2020	•	•	•	•	•	•	•
Ma 2019	•	•	•	•	•	•	•
Mai 2022	•	•	•	•	•	•	•
Ni 2019	•	•	•	•	•	•	•
Ni 2020	•	•	•	•	•	•	•
O'Neill 2020	•	•	•	•	•	•	•
PinheirodaSilva 2019	•	•	•	•	•	•	•
Qi 2021	•	•	•	•	•	•	•
Qiao 2022	•	•	•	•	•	•	•
Schell 2019	•	•	•	•	•	•	•
She 2021	•	•	•	•	•	•	•
Shi 2021	•	•	•	•	•	•	•
Sinha 2021	•	•	•	•	•	•	•
Song 2018	•	•	•	•	•	•	•
Suh 2021	•	•	•	•	•	•	•
Tan 2021	•	•	•	•	•	•	•
Tang 2019	•	•	•	•	•	•	•
Wang 2018	•	•	•	•	•	•	•
Wang 2019	•	•	•	•	•	•	•
Wang 2020-1	•	•	•	•	•	•	•
Wang 2020-2	•	•	•	•	•	•	•
Wang 2021-1	•	•	•	•	•	•	•
Wang 2021-2	•	•	•	•	•	•	•

Table S3. Continued

First author, year	Item 2	Item 4	Item 7	Item 9	Item 11	Item 13	Item 15
Wang 2021-3	•	•	•	•	•	•	•
Wu 2019	•	•	•	•	•	•	•
Xie 2020	•	•	•	•	•	•	•
Xu 2021	•	•	•	•	•	•	•
Xunlin 2020	•	•	•	•	•	•	•
Yang 2020	•	•	•	•	•	•	•
Yang 2021	•	•	•	•	•	•	•
YangözŞ 2019	•	•	•	•	•	•	•
Yao 2022	•	•	•	•	•	•	•
Yi 2021	•	•	•	•	•	•	•
Yin 2020	•	•	•	•	•	•	•
Yoon 2021	•	•	•	•	•	•	•
Yuanqing 2020	•	•	•	•	•	•	•
Zeng 2020	•	•	•	•	•	•	•
Zeng 2022	•	•	•	•	•	•	•
Zhang 2018-1	•	•	•	•	•	•	•
Zhang 2018-2	•	•	•	•	•	•	•
Zhang 2018-3	•	•	•	•	•	•	•
Zhang 2021	•	•	•	•	•	•	•
Zhao 2020	•	•	•	•	•	•	•
Zhu 2021	•	•	•	•	•	•	•

The effects of complementary therapies on patient reported outcomes \mid 151



CHAPTER VII

Fostering the conversation about complementary medicine: acceptability and usefulness of two communication-supporting tools for patients with cancer

Marit Mentink, Janneke Noordman, Anja Timmer-Bonte, Martine Busch, Sandra van Dulmen

Submitted

ABSTRACT

Objective

To describe the development and evaluation of two communication tools to support patients with cancer when discussing complementary medicine with oncology healthcare providers.

Methods

Two tools were developed, a question prompt sheet and a slideshow with visual information. Nine (former) patients with breast cancer were involved in the development of the tools and evaluation questionnaire. In a 15-item online questionnaire, the tools were evaluated by patients with cancer on acceptability, perceived usefulness and intention to use. Participants were recruited by three hospitals in the Netherlands, a patient panel and the Dutch Breast Cancer Society.

Results

In total, 144 participants completed the questionnaire. The content and layout of the tools were generally found to be acceptable. Items regarding exercise and diet were suggested to be added to the question prompt sheet. Approximately half of the participants perceived the tools as useful. The other half of the participants felt no need to use the tools because they were able to discuss complementary medicine with their healthcare provider anyway or were not interested in (a conversation about) complementary medicine use. The developed tools were considered especially useful for fellow patients.

Conclusions

The tools were generally accepted by the participants, although they demanded minor alterations or additions. Approximately half of the participants felt no need to use the tools, which could have influenced the study results. For targeted use of the tools, patient characteristics associated with the need for extra support in discussing complementary medicine should be assessed.

BACKGROUND

Complementary medicine refers to non-mainstream approaches used together with conventional medicine, such as massage therapy, mindfulness or dietary supplements¹. The incorporation of complementary medicine alongside conventional cancer treatments has become increasingly prevalent among patients seeking to manage symptoms and side effects, enhance overall well-being and exert a degree of control over their health². Complementary medicine offers promising advantages for symptom relief, such as acupuncture to reduce chemotherapy-induced nausea and vomiting in breast cancer patients or mindfulness-based interventions for patients with depression symptoms during or after cancer treatment ³⁻⁵. Nonetheless, complementary medicine also presents inherent risks that demand careful consideration, such as interactions with conventional treatments ⁶. For the delivery of effective and safe cancer care, patient-provider communication about complementary medicine is pivotal.

Patients with cancer are not always aware of the importance of disclosing complementary medicine use ⁷. Additionally, they often feel hesitant to disclose complementary medicine use to their healthcare provider for reasons such as fear of disapproval or expected lack of time or knowledge by the healthcare provider ⁸. A systematic review showed that nondisclosure rates of complementary medicine ranged from 22% to 77% among patients with cancer ⁹. Nonetheless, patients are the main initiators of discussions about complementary medicine during oncology consultations ¹⁰, ¹¹. Healthcare providers experience a lack of knowledge and confidence in adequately addressing complementary medicine during oncology consultations ¹². Less than 20% of healthcare providers in oncology feel knowledgeable about complementary medicine ¹³.

The barriers experienced by patients and healthcare providers lead to a gap in patient-provider communication about complementary medicine. Given the potential benefits and risks of complementary medicine, it is important to address this gap in communication to encourage safe and informed choices about its utilization among patients with cancer. Although several communication-supporting tools are available for patients with cancer in the Netherlands ¹⁴⁻¹⁶, to the best of our knowledge, there are no tools supporting patients in discussing complementary medicine.

Therefore, two communication-supporting tools were developed for patients to guide them in introducing and discussing the topic of complementary medicine during oncology consultations. This study describes the development of these tools and aims to evaluate the acceptability, perceived usefulness and the intention to use these tools among patients with cancer.

METHODS

A patient-participatory study design was used for the development and evaluation of two communication-supporting tools for patients with cancer. Nine co-researchers, consisting of (former) patients with breast cancer, collaborated with the research team throughout the study. The communication-supporting tools are the final products of a larger mixed-method research project focused on communication about complementary medicine in oncology titled 'COMMON' ¹⁷.

Development of the communication-supporting tools

The intervention mapping (IM) framework was used for the development of the communication-supporting tools ¹⁸. Prior to designing the tools, the needs of patients with cancer were assessed (Figure 1). First, audio-recorded consultations between patients with cancer and healthcare providers were analyzed ¹⁰. If complementary medicine was discussed during the consultation, the section was coded with a self-developed observation scheme. Next, the experiences and needs of patients with communication about complementary medicine were assessed by conducting semi-structured interviews. Subsequently, an online session was organized in which the results of the previously mentioned studies were presented and the attendees were invited to brainstorm about the tool contents. The session was attended by the research team, eight co-researchers and members of several stakeholder parties: 1) the National Breast Cancer Society (BVN); 2) the Dutch Nursing Society (V&VN); 3) the Netherlands Comprehensive Cancer Organization (IKNL); and 4) an online information platform for Dutch patients with cancer (Kanker.nl).

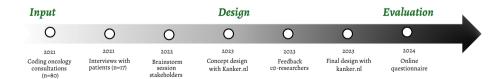


Figure 1. Steps in the development of the communication-supporting tools

A few key barriers to communication about complementary medicine emerged, for instance, that not all patients with cancer are aware of the existence of complementary medicine or the importance of discussing complementary medicine use with their

healthcare providers. In addition, not all patients with cancer are assertive enough to introduce the topic of complementary medicine to their healthcare provider. Furthermore, it is important for communication-supporting tools to be inclusive, e.g., using visual information to include lower-literate patients. The results clearly indicated the need among patients with cancer for support in conversations about complementary medicine. Therefore, two tools were developed:

- A question prompt sheet (OPS) that aims to stimulate and guide conversations 1) about complementary medicine by providing a set of question prompts to patients with cancer. The QPS includes prompts for different situations in which patients may find themselves, such as being interested in complementary medicine, already using complementary medicine or in need of further information about complementary medicine. For instance, "I am being treated by an acupuncturist. Can I continue this during cancer treatment?" or "Does my hospital offer complementary medicine? If so, what is offered?".
- A slideshow that aims to highlight the importance of discussing complementary 2) medicine with visual support. The slideshow also contains a few examples extracted from the QPS on how to introduce the subject of complementary medicine to the healthcare provider.

For the design of the content and layout of the communication-supporting tools, the research team collaborated with an editor and visual designer from Kanker.nl. This website already provides information about the effects of complementary medicine for patients with cancer. Subsequently, the concept tools were presented to the coresearchers, who provided further feedback before the QPS and slideshow were finalized. It is our intention that the final version of the communication-supporting tools becomes publicly available on the website of Kanker.nl.

Online questionnaire

An online questionnaire was developed by the researchers (SvD, JN, MM) to evaluate the tools. The initial version was piloted among four co-researchers, which led to the addition of response options and the rephrasing of a few questions. The final version consisted of 15 items (Supplement 1) that assessed the background characteristics of the participants (e.g., age, sex, education, type of cancer, treatment phase) and their acceptability, perceived usefulness and intention to use the tools. The majority of the questions was adapted from previous studies that evaluated comparable communication-supporting tools among patients with cancer 16,19.

Acceptability

Acceptability refers to the extent to which users consider a healthcare intervention appropriate based on anticipated or experienced cognitive and emotional responses to the intervention ²⁰. In this study, acceptability is measured by the following:

- The first impression of the tool by selecting a maximum of three words best describing their feelings. Nine answer options were already provided (e.g., appealing, boring, confusing, inviting). Participants could add other feelings in an open answer category.
- The degree to which the tool was assessed as clear, helpful, comprehensive, professional, informative, reliable, simple, reassuring, or emotional on a 5-point scale.
- The attractiveness of the tool and appropriateness of the provided examples in the tool were scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).

Perceived usefulness

Perceived usefulness is a term extracted from the Technology Acceptance Model (TAM) ²¹ and can be defined as the degree to which a user sees the added value of a product. In this study, perceived usefulness is measured by the following:

- Eight statements about the perceived usefulness of the tool for patient-provider communication about complementary medicine; the educational value of the tool; and the perceived usefulness of the tools for other patients or relatives. The statements are scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).
- The compilation of the top three most useful questions (QPS only), including an open-ended category where participants could describe which questions were missing.

Intention to use

- The participants were asked about their intention to use the tool on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).
- Using a yes/no question, participants were asked whether they would use the QPS, including an open-ended category where participants could describe why they did not intend to use the QPS.

Participants and recruitment

The eligibility criteria for participation in the evaluation questionnaire were 1) 18 years or older, 2) Dutch-speaking, and 3) currently or during the last 6 months in treatment for cancer. The aim was to include at least 90 participants. Oncology departments of three non-academic hospitals in the Netherlands were involved in the recruitment of participants. In each hospital, a study coordinator was appointed who ensured the distribution of a flyer with a call for study participation among patients visiting the clinic. The flyer included a link and OR code that led to the online questionnaire. The call for study participation was also distributed online by the National Breast Cancer Society (BVN). In addition, patients with cancer who were members of a panel (n=819) were e-mailed with a request for study participation. This panel is part of Kanker.nl.

Data collection

Participants were able to participate in the evaluation study between mid-November 2023 and mid-January 2024. When opening the link to the questionnaire, participants were first presented with study information and were asked to sign an online informed consent form. Subsequently, background information was collected. To increase study validity, a video with a duration of 1:39 minutes was presented to participants, during which the concept of complementary medicine was explained. Examples of complementary medicine used in the video were mindfulness, yoga, massage, music therapy and acupuncture. The video was already publicly available on the website of Kanker.nl. Next, the QPS and slideshow were presented, with accompanying questions to evaluate each of the two tools.

Statistical analysis

Stata version 16.1 was used to calculate descriptive statistics of background characteristics and evaluation measures. Open coding was used to analyze comments on open questions.

RESULTS

In total, 144 participants completed the questionnaire. Background characteristics are presented in Table 1.

Table 1. Background characteristics of participants (n=144)

Variable	No.	(%)
Sex		
Male	54	(36%)
Female	90	(63%)
Age in years		
Mean (SD)	58 ((12.2)
Range	27	7-83
Education level according to ISCED 2011 ²²		
Low	13	(9%)
Medium	47	(33%)
High	84	(58%)
Type of cancer (multiple answers possible)		
Breast	62	(43%)
Urological	30	(21%)
Gastrointestinal	18	(13%)
Skin	14	(10%)
Blood or lymph	12	(8%)
Gynecological	8	(6%)
Lung	8	(6%)
Head or neck	6	(4%)
Other	4	(3%)
Treatment status		
In active treatment	82	(57%)
Post treatment (≥6 months)	41	(28%)
Other ^a	21	(15%)
Current complementary medicine (CM) user		
Yes, CM use discussed with HCP ^b	34	(24%)
Yes, CM use not discussed with HCP	19	(13%)
No, but interested in CM or former user	61	(42%)
No, not interested in CM	30	(21%)
Recruited through		
Patient panel	92	(64%)
Hospital	27	(19%)
Breast cancer society	25	(17%)

The percentages may add to less or more than 100% due to rounding

^a E.g., awaiting treatment, regular check-ups, wait-and-see, palliative treatment

^b Healthcare provider

Evaluation of the question prompt sheet (QPS)

Acceptability

At first impression, the QPS was mostly described as clear (71%), professional (33%) or inviting (33%) by the participants. Upon further inspection, ≥70% of the participants rated the QPS as clear, easy, helpful or professional. The QPS was described as not educational by 14% of the participants and as incomplete by 10% of the participants. As presented in Figure 2, approximately half of the participants (53%) found the QPS appealing and a majority of the participants (71%) perceived the examples in the QPS as appropriate.

Perceived usefulness

Figure 2 shows that the majority of the participants (66%) felt that the QPS could help them discuss complementary medicine with their healthcare provider by giving them a sense of control over the conversation (53%), learning more about the topic (48%) or diminishing fear of discussing complementary medicine (33%). Most participants (83%) found the QPS useful for fellow patients with cancer.

One-third of the participants (29%) found all question prompts useful. Two prompts were rated as most useful: 1) whether complementary medicine can be used for existing side effects (37%) and 2) whether complementary medicine can be used for potential symptoms (29%). Participants rated the question prompt about where to find reliable complementary medicine practitioners as least useful (6%). In total, 7 out of 144 participants (5%) regarded none of the question prompts useful. Sixteen participants (11%) missed question prompts in the QPS, such as questions prompts about nutrition and exercise or about experiences of fellow patients with complementary medicine.

Intention to use

Approximately half of the participants (48%) indicated they would use the QPS (Figure 2). In total 47% of the participants felt no need to use the QPS. An additional yes/no question about the intention to use the QPS showed that 53% of participants would use the QPS and 47% of participants would not. Among participants without the intention to use the QPS, the most common reasons provided were: 1) ability to discuss complementary medicine without support, 2) not interested in discussing complementary medicine with their healthcare provider (e.g., sufficiently informed themselves, lack of time or knowledge by healthcare provider) and 3) not interested in complementary medicine. Four participants mentioned reasons inherent to the layout or content of the QPS, such as 'too crowded' or missing examples of nutrition and exercise.

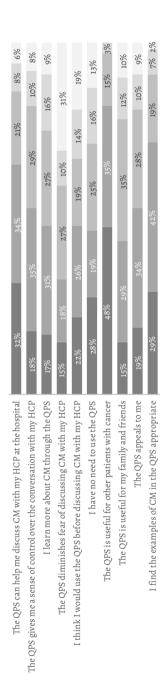


Figure 2. Acceptability and perceived usefulness of the question prompt sheet (QPS) for discussing complementary medicine (CM) with a healthcare provider (HCP) according to patients with cancer (n=144)

Strongly disagree

Disagree

■ Neutral

■ Agree

■ Strongly agree

	%					4%				
%11	8% 3%	16%			13%	4	13%	%11	%91	agree
%8			79%	79%	12%	78%	14%	%11%		Strongly disagree
	24%	18%			1		14		18%	Stro
27%			12%	20%	\0			35%		gree
		797			32%	767	34%	35		■ Disa
ı	36%		28%	22%					37%	eutral
33%				.,	17%			%		Ž
ı		78%	%61	%61			24%	25%	%	Agree
	767			15	797	39%		ı	15%	ree
21%		12%	15%	13%	2		15%	18%	14%	■ Strongly agree ■ Agree ■ Neutral ■ Disagree
The slideshow can help me discuss CM with my HCP at the hospital	The slideshow gives me a sense of control over the conversation with my HCP	I learn more about CM through the slideshow	The slideshow diminishes fear of discussing CM with my HCP	I think I would use the slideshow before discussing CM with my HCP	I have no need to use the slideshow	The slideshow is useful for other patients with cancer	The slideshow is useful for my family and friends	The slideshow appeals to me	I find the examples of CM in the slideshow appropriate	■ Str

Figure 3. Acceptability and perceived usefulness of the slideshow for discussing complementary medicine (CM) with a healthcare provider (HCP) according to patients with cancer (n=144)

Evaluation of the slideshow

Acceptability

At first impression, the participants described the slideshow mostly as clear (67%), professional (30%) or inviting (26%). After taking a closer look, ≥70% of the participants perceived the slideshow to be clear, easy, reliable and professional. In total, 43% of participants indicated finding the slideshow appealing and 29% found the examples of complementary medicine used in the slideshow appropriate. Twenty-percent of the participants felt that the slideshow was incomplete, and 15% of participants indicated that the slideshow was slow and/or not educational.

Perceived usefulness

Figure 3 shows that approximately half of the participants (54%) regarded the slideshow as helpful for discussing complementary medicine with their healthcare provider. In total, 65% of the participants indicated that the slideshow could provide them with a sense of control over the conversation with their healthcare provider. A minority of the participants felt that the slideshow taught them something about complementary medicine (40%) or diminished fear of discussing the topic (34%). Most participants (68%) perceived the slideshow as useful for other patients.

Intention to use

Thirty-two percent of participants intended to use the slideshow (Figure 3). In total, 43% of participants felt that there was no need to use the slideshow.

DISCUSSION

The evaluation of the tools indicated that participants were neutral to positive in their acceptance of the QPS and the slideshow. The tools were identified as clear, easy and reliable by most participants. Some areas of improvement in the tool content emerged, such as the desire to incorporate question prompts about diet and exercise in the QPS. Approximately half of the participants perceived the tools as useful for themselves, although the other half of the participants had no intention to use the QPS or slideshow. Several patients felt that they could adequately discuss the topic of complementary medicine without support. The tools were considered especially useful for fellow patients.

The main reason participants did not intend to use the QPS was their ability to discuss the topic of complementary medicine without the support of a tool. The

overrepresentation of higher educated participants in the current study might account for this decreased need for the use of these tools. In a previous study, it was shown that patients with higher education levels are more inclined to disclose complementary medicine use to their oncologist 23. Patients with a higher education level may be more assertive in patient-provider communication than patients with a lower education level are. As noted in a previous study 24, patients can evolve from three communication states during oncology consultations: 1) overwhelmed and passive; 2) proactive and self-motivated and 3) proficient and empowered. The communication-supporting tools are especially useful for patients to transfer from the first to the second state, i.e. from contributing little to the conversation to preparing their consultations to fulfill certain goals. The patients in the current sample were probably already in a proactive or proficient state of communication, given that the majority was member of a patient panel or society. Future research should explore which patient characteristics are associated with the need for extra support in discussing complementary medicine, to ensure targeted dissemination of the communication-supporting tools.

Some participants did not wish to discuss the topic of complementary medicine use with their healthcare provider because they felt sufficiently informed about the topic or perceived their healthcare provider to lack knowledge or time to discuss the topic. These results indicate that awareness about the importance of patients discussing complementary medicine use with healthcare providers should increase to avoid complementary medicine to harm patients during conventional treatment ⁶. In fact, the developed slideshow aimed to portray the importance of discussing complementary medicine in a visual way (important to note: participants were not presented the slideshow until after providing a reason for non-intention to use the QPS).

Part of the participants indicated that they were not interested in complementary medicine use and thus had no intention to use the QPS. In the study sample, non-users of complementary medicine were overrepresented, although many of these non-users were former users or were interested in complementary medicine. Nonetheless, the overrepresentation of non-users could have contributed to the relatively high number of neutral responses to the questions involving a Likert scale, given that non-users have less of an opinion about the tools.

To evaluate the effectiveness of the communication-supporting tools in a clinical setting, this study could be succeeded by a randomized trial. For instance, characteristics of the discussion about complementary medicine, or consultation

satisfaction could be compared between those who used a communicationsupporting tool to prepare a conversation about complementary medicine and those who did not.

Study limitations

The developed communication-supporting tools were intended for use in the generic population of patients with cancer. However, the results showed that many of the included participants in the current study did not feel the need to use the tools. It would have been appropriate to assess which patient characteristics are associated with the need for support in communication about complementary medicine, prior to recruitment of participants for evaluation. For instance, previous research showed that patients with lower education and male patients have lower disclosure rates of complementary medicine 23.

The currently used method of convenience sampling can lead to selection bias. For instance, patients with lower education levels appeared to be underrepresented. For instance, it is conceivable that predominantly assertive or experienced patients acted on the call for study participation distributed by the patient panel and the Dutch Breast Cancer Society. Furthermore, the hospitals from which participants were recruited already launched initiatives in the field of integrating complementary medicine into oncology care, which could have led to the recruitment of participants who were better informed about complementary medicine or who were experiencing fewer barriers to discuss complementary medicine with their healthcare provider. In addition, by collecting data online, patients who were not digitally proficient were inadvertently excluded from study participation.

Clinical implications

In clinical oncology, choice of treatment and patient information are individually tailored. Patients selecting personally relevant questions from a QPS can enhance tailored communication during oncology consultations. The results of this study showed that the QPS and slideshow seemed particularly valuable to patients who are unaware of the importance of discussing complementary medicine with their healthcare provider or to patients who experience barriers to talking about the topic with their healthcare provider. For patients with cancer uninterested in complementary medicine, the tools can at best raise awareness about the existence and potential benefits and risks of complementary medicine, and the importance of discussing complementary medicine use with their healthcare provider.

The responsibility for discussing the topic of complementary medicine use during oncology consultations should not lie solely with patients. Given that communication is reciprocal, healthcare providers also play an important role. Healthcare providers should be aware that some patients perceive them as lacking knowledge and time to adequately discuss complementary medicine. In addition, a reason for nondisclosure of complementary medicine among patients is non-inquiry by the healthcare provider 7. Therefore, it is important that healthcare providers adopt an active role in initiating the subject of complementary medicine, especially towards patients who are known to have decreased complementary medicine use disclosure rates, such as patients with lower education and male patients 23. To reinforce knowledge and confidence among healthcare providers, in future research we aim to develop tools that support healthcare providers in discussing complementary medicine.

CONCLUSIONS

The question prompt sheet and slideshow were generally accepted by the participants, although the participants demanded minor alterations or additions to the content of the tools. Approximately half of the participants felt no need for the use of the tools, which has probably influenced the results of this evaluation study. For targeted use of the tools, it would be valuable to assess which patient characteristics are associated with a need for support in discussing complementary medicine.

REFERENCES

- National Center for Complementary and Integrative Health (NCCIH). Complementary, Alternative or Integrative Health: What's In a Name? [Cited 2024 Feb 9]. Available from: https://www.nccih.nih.gov/health/complementary-alternative-or-integrative-health-whats-in-a-name
- 2. Keene MR, Heslop IM, Sabesan SS, Glass BD. Complementary and alternative medicine use in cancer: A systematic review. Complement Ther Clin Pract 2019; 35:33-47.
- 3. Mao JJ, Ismaila N, Bao T, et al. Integrative medicine for pain management in oncology: society for integrative oncology—ASCO guideline. J Clin Oncol 2022; 40:3998-4024.
- 4. Greenlee H, DuPont-Reyes MJ, Balneaves LG, et al. Clinical practice guidelines on the evidence-based use of integrative therapies during and after breast cancer treatment. CA Cancer J Clin 2017; 67:194-232.
- Carlson LE, Ismaila N, Addington EL, et al. Integrative oncology care of symptoms of anxiety and depression in adults with cancer: Society for Integrative Oncology–ASCO Guideline. J Clin Oncol 2023; 41:4562-4591.
- 6. Lam CS, Koon HK, Ma CT, et al. Real-world data on herb-drug interactions in oncology: A scoping review of pharmacoepidemiological studies. Phytomedicine 2022; 103:154247.
- Akeeb AA, King SM, Olaku O, White JD. Communication between cancer patients and physicians about complementary and alternative medicine: A systematic review. J Integr Complement Med 2023; 29:80-98.
- 8. Foley H, Steel A, Cramer H, Wardle J, Adams J. Disclosure of complementary medicine use to medical providers: a systematic review and meta-analysis. Sci Rep 2019; 9:1573.
- Davis EL, Oh B, Butow PN, Mullan BA, Clarke S. Cancer patient disclosure and patient-doctor communication of complementary and alternative medicine use: a systematic review. Oncologist 2012; 17:1475-1481.
- Mentink MD, van Vliet LM, Timmer-Bonte JAN, Noordman J, van Dulmen S. How is complementary
 medicine discussed in oncology? Observing real-life communication between clinicians and
 patients with advanced cancer. Patient Educ Couns 2022; 105:3235-3241.
- 11. Tilburt J, Yost KJ, Lenz HJ, et al. A Multicenter Comparison of Complementary and Alternative Medicine (CAM) Discussions in Oncology Care: The Role of Time, Patient-Centeredness, and Practice Context. Oncologist 2019; 24:e1180-e1189.
- Balneaves LG, Watling CZ, Hayward EN, et al. Addressing complementary and alternative medicine use among individuals with cancer: an integrative review and clinical practice guideline. J Natl Cancer Inst 2022; 114:25-37.
- King N, Balneaves LG, Levin GT, et al. Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. Integr Cancer Ther 2015; 14:515-524.
- 14. Kanker.nl. Gesprekshulp bij kanker [Cited 2024 Jan 12]. Available from: https://www.kanker.nl/gesprekshulp
- 15. Nederlandse Federatie Kankerpatiëntenorganisaties (NFK). Gesprekskaart: Vragen over leven en dood als je niet meer beter wordt [Cited 2024 Jan 12]. Available from: https://nfk.nl/media/1/200922-Gesprekskaart-Digitaal.pdf
- 16. Driesenaar JA, van Dulmen S, van Weert JC, Noordman J. Patients' evaluation of a preparatory online communication tool for older patients with cancer preceding chemotherapy. Cancer Nurs 2020; 43:E71-E78.

- Mentink M, Noordman J, Busch M, van Vliet L, Timmer-Bonte JA, van Dulmen S. Towards an open and effective dialogue on complementary medicine in oncology: protocol of patient participatory study 'COMMON'. BMJ Open 2021; 11:e053005.
- 18. Bartholomew LK, Parcel GS, Kok G, et al. Planning health promotion programs: An intervention mapping approach. John Wiley & Sons; 2006.
- 19. Noordman J, Driesenaar JA, van Bruinessen IR, Portielje J, van Dulmen S. Evaluation and implementation of ListeningTime; a web-based preparatory communication tool for elderly cancer patients and their healthcare providers. JMIR Cancer 2019; 5:e11556.
- Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. BMC Health Serv Res 2017; 17:1-13.
- 21. Marangunić N, Granić A. Technology acceptance model: a literature review from 1986 to 2013. Universal Access Inf 2015; 14:81-95.
- 22. UNESCO Institute for Statistics. International standard classification of education: ISCED 2011. Comp Soc Res 2012; 30.
- 23. Wortmann JK, Bremer A, Eich H, et al. Use of complementary and alternative medicine by patients with cancer: a cross-sectional study at different points of cancer care. Med Oncol 2016; 33:1-11.
- 24. van Bruinessen IR, van Weel-Baumgarten EM, Gouw H, Zijlstra JM, Albada A, van Dulmen S. Barriers and facilitators to effective communication experienced by patients with malignant lymphoma at all stages after diagnosis. *Psychooncology* 2013; 22:2807-2814.

SUPPLEMENTARY MATERIALS

Supplementary material 1: Communication-supporting tools

Question Prompt Sheet (QPS)

Gesprekshulp



In gesprek met je arts of verpleegkundige over complementaire zorg (aanvullende zorg)

Complementaire zorg kan je misschien helpen om je lichamelijk of geestelijk beter te voelen, tijdens of na je behandeling. Deze zorg kun je aanvullend op de reguliere zorg krijgen. Goed om te weten

Gebruik deze gesprekshulp voor en tijdens een gesprek met je arts of verpleegkundige. Zo kun je je goed voorbereiden en heb je je vragen op een rijtje. De vragen zijn voorbeelden. Je kunt ze altijd aanpassen of eigen vragen toevoegen.

Hier	heb ik last van							
	Angst en spanning							
	Somberheid, depressie en stemmingswisselingen, vermoeidheid							
	Misselijkheid en overgeven							
	Pijn							
	Vermoeidheid, slaapproblemen							
	Opvliegers							
	Anders, namelijk							
1/	haddan an assadan and da assa							
Voor	beelden van complementaire zorg							
	Acupunctuur		Muziektherapie					
	Aromazorg		Ontspanningsoefeningen					
	Beeldende therapie		Therapeutic Touch					
	Haptotherapie		Vaktherapie					
	Homeopathie		Voedingssupplementen					
	Hypnotherapie		Yoga					
	Massage		Anders, namelijk					
	Medicinale cannabis							



Gesprekshulp complementaire zorg





Vragen die je kunt stellen aan je arts of verpleegkundige

Meer informatie vind je op kanker. nl/complementairezord



Gesprekshulp complementaire zorg





Vragen die je kunt stellen aan je arts of verpleegkundige

Als je erover nadenkt om complementaire zorg te gaan gebruiken
Ik wil misschien
Kan dat kwaad?
Ik wil misschien gaan doen. [vul soort complementaire zorg in, bijvoorbeeld mindfulness of massagetherapie]
Kan dat kwaad?
Als je meer informatie en ondersteuning wil op het gebied van complementaire zorg
Bij wie in dit ziekenhuis kan ik terecht voor meer informatie en/of ondersteuning over complementaire zorg?
Biedt mijn ziekenhuis zelf ook complementaire zorg aan? Zo ja, wat dan?
Vergoedt mijn zorgverzekeraar ? [vul de soort complementaire zorg in]
Als ik zelf informatie wil zoeken over, wat zijn dan betrouwbare bronnen? [vul de soort complementaire zorg in]
Waar vind ik een betrouwbare
Staat jouw vraag niet tussen? Schrijf dan hier je vraag.
State Journ Frang Hot tussen. Selling and Hell Journal

Meer informatie vind je op kanker. nl/complementairezorg

Bedenk voor jezelf welke 2 of 3 vragen je in ieder geval wilt stellen.





















Of hebben invloed op je



Zeg bijvoorbeeld:

Ik slaap slecht. Mag ik cannabis gebruiken?

Of zeg:

Ik wil acupunctuur proberen tegen pijn. Is dat een goed idee?

In de gesprekshulp complementaire zorg vind je meer voorbeeldvragen.

kanker.nl/complementaire-zorg



Supplementary material 2: Evaluation questionnaire communication tools oncology

1. What is your age (in years)?
2. What is your sex?
o Male
o Female
o Other
3. What is the highest education you completed?
o Primary/elementary school
o Primary or preparatory vocational education (such as LTS, LEAO, LHNO, VMBO)
o Pre-vocational secondary education (such as MAVO, (M)ULO, VMBO-t)
o Secondary vocational education. (such as MTS, MEAO)
o Senior general secondary or pre-university education (such as HAVO, VWO, HBS, MMS)
o Higher professional education (such as HBO, HTS, HEAO, HBO-V)
o University education
o Other, namely
4. What type of cancer do you have or have had (multiple answers are possible)?
o Breast cancer (mammary carcinoma)
o Lung cancer
o Stomach, liver or colon cancer, including esophageal cancer, rectal cancer, pancreatic cancer (gastroenterological tumor)
o Gynecological cancer (e.g., cervical cancer, ovarian cancer)
o Blood or lymph node cancer (e.g., (non)-Hodgkin's disease, leukemia)
o Urological cancer (e.g., kidney, prostate, bladder cancer)
o Skin cancer (e.g., melanoma)
o Other type of cancer, namely
5. Which situation applies to you?
o I am awaiting treatment (period between diagnosis and treatment)
o I am currently being treated for cancer
o I have completed cancer treatment in its entirety
o Other, namely

Complementary medicine

Complementary medicine literally means supplemental care. It adds something to regular anti-cancer treatment, such as chemotherapy or radiation. Complementary medicine can help with symptoms and recovery. Some examples of complementary medicine include: acupuncture, mindfulness, vitamin supplements, yoga. Complementary medicine is not the same as alternative medicine that replaces regular treatment.

Below is a video explaining what complementary medicine is.

VIDEO HERE

6. Are you currently using complementary medicine?

- Yes, I am currently using complementary medicine
 - o If yes, do you discuss this use of complementary medicine with your doctor or nurse at the hospital?
- Yes
- No, because....
- No, but I have used complementary medicine in the past (for instance before you were diagnosed with cancer)
- No, but I have interest or need
- No, I have no interest or need

Below is a link to the conversation aid. This is a tool that patients can use to discuss complementary medicine with their health care provider. Click on the link to view the conversation aid. Then you can answer the questions about the conversation aid.

QPS HERE

7. What is your first impression of the conversation aid?

Choose the word that best represents your feelings, or type in your own word. Maximum of 3 answers possible.

- o Clear
- o Professional
- o Crowded
- o Attractive
- o Boring
- o Confusing
- o Reliable
- o Gloomy
- o Inviting
- o Fill in a word of your own:....

8. Please indicate the extent to which you agree or disagree with the statements below. We would like to have your opinion. There are no right or wrong answers.

	Totally disagree				Totally agree
The QPS can help me discuss complementary medicine with my healthcare provider at the hospital	-	-	-	-	-
2. I learn more about complementary medicine through the QPS	-	-	-	-	-
3. I have no need to use the QPS	-	-	-	-	-
4. I find the examples of complementary medicine in the QPS appropriate	-	-	-	-	-
5. The QPS gives me a sense of control over the conversation with my healthcare provider	-	-	-	-	-
6. I think I would use the QPS before discussing complementary medicine with my healthcare provider	-	-	-	-	-
7. The QPS diminishes fear of discussing complementary medicine with my healthcare provider	-	-	-	-	-
8. The QPS appeals to me	-	-	-	-	-
9. The QPS is useful for my family and friends	-	-	-	-	-
10. The QPS is useful for other patients with cancer	-	-	-	-	-

9. The conversation aid is...

On each line, click the circle closest to your opinion.

Clear	0	0	0	0	0	0	Unclear
Useful	0	0	0	0	0	0	Not useful
Complete	0	0	0	0	0	0	Incomplete
Amateuristic	0	0	0	0	0	0	Professional
Educational	0	0	0	0	0	0	Not educational
Reliable	0	0	0	0	0	0	Unreliable
Difficult	0	0	0	0	0	0	Simple
Reassuring	0	0	0	0	0	0	Distressing
Emotional	0	0	0	0	0	0	Not emotional

10. Would you use the conversation aid to discuss complementary medicine with your health care provider?

- Yes
- No, because....

11. Which questions from the conversation aid, repeated below, do you find most useful? Choose up to 3.

- I do not find any of the questions useful.
- I suffer from [fill in what symptoms you have, e.g., fatigue, pain, hot flashes]. Is there anything we can do about this, perhaps with complementary medicine?
- Suppose I get side effects from treatment. Is there anything that can be done without medication? For example, with some type of complementary medicine?
- I use [fill in type of complementary medicine, e.g. dietary supplements, cannabis or essential oils]. Can I continue this during cancer treatment?
- I do [insert type of complementary care, e.g. yoga, Tai Chi]. Can I continue this during cancer treatment?
- I am under the treatment of a [insert type of complementary practitioner, e.g. acupuncturist, naturopath, haptotherapist]. Can I continue this during cancer treatment?
- I may want to use [insert type of complementary medicine, for example, acupuncture or herbal products]. Can that hurt?
- I may want to do [fill in type of complementary medicine, for example, mindfulness or massage therapy]. Can that be harmful?
- Who in this hospital can I go to for more information and/or support about complementary medicine?

- Does this hospital itself offer complementary medicine? If so, what is offered?
- Does my health insurance company reimburse? [insert type of complementary medicine]
- If I want to search information about myself, what are reliable sources? [insert type of complementary medicine]
- Where can I find a reliable? [fill in the type of complementary medicine practitioner you are looking for, e.g. haptotherapist]
- I find all the questions useful

12. Are you missing any questions in the conversation aid that you would like to ask your health care provider about complementary medicine?

- Yes, namely.....
- No

o Clear

Below is a slideshow about discussing complementary medicine with health care providers in the hospital. After watching the slideshow, please answer the questions.

SLIDESHOW HERE

13. What is your first impression of the slideshow?

Choose the word that best represents your feeling, or type in your own word. Maximum of 3 answers possible.

o Professional
o Crowded
o Attractive
o Boring
o Confusing
o Reliable
o Gloomy
o Inviting
o Fill in a word of your own:

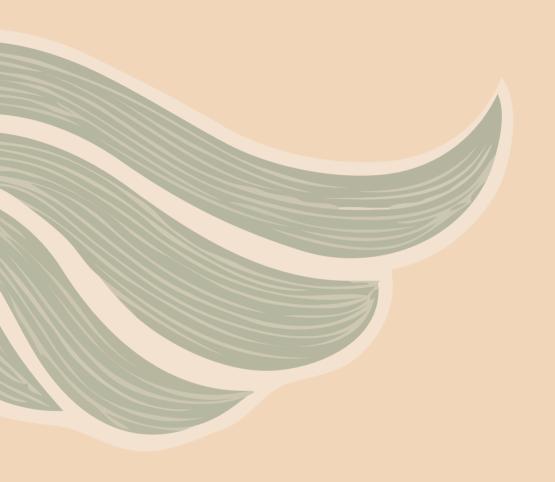
14. Please indicate the extent to which you agree or disagree with the statements below. We would like to have your opinion. There are no right or wrong answers.

	Totally disagree				Totally agree
The slideshow can help me discuss complementary medicine with my healthcare provider at the hospital	-	-	-	-	-
I learn more about complementary medicine through the slideshow	-	-	-	-	-
3. I have no need to use the slideshow	-	-	-	-	-
4. I find the examples of complementary medicine in the slideshow appropriate	-	-	-	-	-
5. The slideshow gives me a sense of control over the conversation with my healthcare provider	-	-	-	-	-
I think I would use the slideshow before discussing complementary medicine with my healthcare provider	-	-	-	-	-
7. The slideshow diminishes fear of discussing complementary medicine with my healthcare provider	-	-	-	-	-
8. The slideshow appeals to me	-	-	-	-	-
9. The slideshow is useful for my family and friends	-	-	-	-	-
10. The slideshow is useful for other patients with cancer	-	-	-	-	-

15. The conversation aid is...

On each line, click the circle closest to your opinion.

Clear	0	0	0	0	0	0	Unclear
Useful	0	0	0	0	0	0	Not useful
Complete	0	0	0	0	0	0	Incomplete
Amateuristic	0	0	0	0	0	0	Professional
Fast	0	0	0	0	0	0	Slow
Reliable	0	0	0	0	0	0	Unreliable
Difficult	0	0	0	0	0	0	Simple
Reassuring	0	0	0	0	0	0	Distressing
Emotional	0	0	0	0	0	0	Not emotional



CHAPTER VIII

SUMMARY AND GENERAL DISCUSSION

SUMMARY OF FINDINGS

The studies described in this thesis focused on the multifaceted subject of communication about complementary medicine in oncology care. Below, the most important findings are summarized and structured by the three main research questions we sought to answer.

1. How is complementary medicine discussed in oncology care in the Netherlands and what are the barriers to and facilitators of communication experienced by patients, healthcare providers and complementary medicine practitioners?

Actual conversations about complementary medicine between patients and healthcare providers were examined by observing and coding 80 audio-recordings of oncology consultations conducted in six different hospitals in the Netherlands (Chapter III). Complementary medicine was referenced in 44% of the consultations and these references primarily considered lifestyle-related modalities (e.g., exercise, diet). The topic of complementary medicine was, in most instances (62%), introduced by patients. Patients who did ask a specific question about complementary medicine always received a response from their healthcare provider. When patients did not ask a specific question but solely mentioned complementary medicine, healthcare providers rarely further elaborated on the topic. Important aspects of complementary medicine, such as safety and effectiveness, were seldom touched upon during the consultations. Both patients and healthcare providers verbalized neutral to positive attitudes towards the referenced complementary medicine modalities.

To analyse experiences and needs regarding communication about complementary medicine, semi-structured interviews were conducted with 17 patients and 13 healthcare providers recruited from three hospitals in the Netherlands (**Chapter IV**). The results showed that effective conversations about complementary medicine are hindered by barriers such as lack of knowledge and time constraints among healthcare providers. Healthcare providers acknowledge that scepticism towards complementary medicine prevails among colleagues and hospital boards. Patients felt discouraged from disclosing complementary medicine use when their healthcare provider was dismissed or uninterested about the topic. According to the participants, patients are sometimes unaware of the existence of complementary medicine or not assertive enough to discuss it with their healthcare provider. Although some healthcare providers said to routinely consult their patients on complementary medicine, the topic was not structurally embedded in oncology consultations. Both patients and healthcare providers are warranted for an open communication environment in

which the topic of complementary medicine is routinely introduced by the healthcare provider. Additionally, patients and healthcare providers expressed the need for easily accessible, reliable information about complementary medicine. Information provision for patients should be inclusive, for instance, by combining information online and on paper to include less digitally proficient patients or combining textual and visual information to include lower-literate patients. Patients preferred that their hospital is involved in providing information about complementary medicine.

The current thesis also sheds light on the interprofessional dynamics between complementary medicine practitioners and conventional healthcare providers in oncology (Chapter V). An online survey among 1481 complementary medicine practitioners in the Netherlands showed that 40% of practitioners had previously communicated with the conventional healthcare provider of a mutual patient with cancer. However, only 13% of the complementary medicine practitioners perceived healthcare providers as open to communication with them. Such perceived openness was significantly predictive of the occurrence of interprofessional communication. Most complementary medicine practitioners (82%) recognized the importance of patients disclosing complementary medicine use to their conventional healthcare provider, and 49% actively encouraged their patients to do so.

2. Which complementary therapies are effective and safe for patients with cancer?

To answer this research question, one-hundred systematic reviews on the effects of complementary therapies on cancer patient-reported outcomes were assessed (Chapter VI). Twelve different complementary therapies, such as herbal medicine, acupuncture and yoga, were included. Although evidence for several therapy-outcome combinations remains inconclusive, the results indicate that some complementary therapies have the potential to improve patient-reported outcomes. Examples include acupuncture to relieve pain, music interventions to reduce anxiety and yoga to improve cancer-related fatigue. Side-effects associated with complementary therapy use, such as bruising related to acupuncture treatment or cramps related to yoga practice, were generally mild. Forty out of 100 included systematic reviews did not report on safety. Additionally, several of the included systematic reviews inadequately assessed the causes and impact of bias in their interpretation of the results.

3. How can patients with cancer be supported in discussing complementary medicine with their healthcare provider?

As described in Chapter IV, a few key barriers emerged for patients to discuss complementary medicine with their healthcare provider. For example, not all patients with cancer are aware of the existence of complementary medicine or the importance of discussing its use with their healthcare provider. In addition, not all patients with cancer are assertive enough to introduce the topic of complementary medicine to their healthcare provider, especially when faced with scepticism. To include lower-literate patients, visual information should complement textual information. With this knowledge, we developed two tools to support patients with cancer in communication about complementary medicine: a question prompt sheet and a slideshow (Chapter VII). The question prompt sheet aims to stimulate and guide conversations about complementary medicine by providing a set of question prompts to patients for different situations in which they may find themselves. The second tool consists of a slideshow that visually presents patients with the relevance of discussing complementary medicine use with their healthcare provider. The tools were evaluated by means of an online 15-item questionnaire that was completed by 144 patients with cancer. The tools were generally well received by the participants. The content and layout of the tools were perceived as acceptable, and approximately half of the participants found the tool useful. The other half of the participants had no intention to use the tools. The most frequently mentioned reasons for not using the tool were 1) being able to discuss complementary medicine without support, 2) not being interested in complementary medicine, or 3) not wanting to discuss the topic with their healthcare provider. The participants considered the tools especially useful for fellow patients.

GENERAL DISCUSSION

Reflection on the results

In line with previous studies [1, 2], our results showed that communication about complementary medicine during oncology consultations often hinges on patient initiation rather than on proactive inquiry by healthcare providers [3]. Consequently, communication about complementary medicine is often non-systematic and its occurrence heavily depends on consultation circumstances, such as patient assertiveness or healthcare providers' affinity with the subject. Some healthcare providers believe that is not their responsibility to discuss complementary medicine because they solely want to focus on conventional medicine. The discussion of whether healthcare providers are responsible for consulting patients on complementary medicine is ongoing in the international literature [4]. A survey among 159 oncology healthcare providers in the Netherlands showed that 69% felt that they should routinely inquire about patients' use of complementary medicine [5]. This opinion was shared by the patients and healthcare providers we interviewed [6]. To provide safe and effective patient-centred cancer care, patients should be informed on all evidencebased options for symptom relief, either conventional or complementary. In addition, healthcare providers should ensure having complete medical background information of patients. This includes patients' complementary medicine use, especially since some types of complementary medicine can have adverse effects or interact with conventional anticancer treatment [7, 8]. Interprofessional communication with complementary medicine practitioners can contribute to the completeness of medical background information [9].

Healthcare providers were more inclined to elaborate on complementary medicine when patients were asking them specific questions [3]. This implies that patients should be encouraged to ask questions to foster communication about complementary medicine in oncology consultations. However, patients often experience hesitancy in discussing complementary medicine with their healthcare provider or are unaware of the importance of such a discussion. To address these barriers and empower patients to introduce the topic of complementary medicine to their healthcare providers, two communication-supporting tools were developed. The evaluation of these tools, a question prompt sheet and slideshow, indicated that they are probably most useful for a group of patients specifically in need of communication support [10]. The characteristics of this subpopulation are currently unknown, although a previous study indicated that a higher level of education was associated with increased complementary medicine disclosure rates in patients with cancer [11].

To close the communication gap about complementary medicine in oncology, it is important that healthcare providers also receive support. Consistent with the results of previous studies [12-14], we found that healthcare providers often lack the knowledge and time to effectively communicate about complementary medicine [6]. Educational interventions are found to improve healthcare providers' knowledge about complementary medicine and confidence in discussing the topic with patients [15, 16]. When healthcare providers received education on complementary medicine, patient satisfaction also increased [17]. By contributing to more positive healthcare providers' attitudes, awareness and knowledge about complementary medicine can address scepticism towards complementary medicine [18]. Our results indicated that the taboo towards complementary medicine among healthcare providers has declined over recent years [6]. A previous study also showed that healthcare providers' attitudes towards complementary medicine became more positive [19]. In the realm of patient-centred medicine, healthcare providers are increasingly willing to address patient needs.

Given restrictions in time and differences in personal interest among healthcare providers, it is unrealistic to think that all could become experts in complementary medicine. Therefore, some hospitals that participated in our study installed a complementary medicine expert [6]. This expert in the shape of a nurse, medical doctor, pharmacist or dietician, acts as a resource for oncology healthcare providers and supports patients in so-called *integrative medicine consultations*. Integrative medicine consultations are a fine example of patient-centred care and the occurrence of such consultations in cancer care has increased in recent years [20]. Integrative medicine consultations not only decrease distress in patients with cancer, but also provide patients with the opportunity to obtain reliable information about complementary medicine and empower them to be more involved in managing their care [21]. This promising phenomenon also meets patients' need for receiving reliable information about complementary medicine from the hospital in which they are treated [6]. Nonetheless, integrative medicine consultations are the exception rather than the rule. In the Netherlands, there are a few pioneering hospitals offering such consultations.

According to our results, the provision of information about complementary medicine for patients is still inadequate [6]. Due to the lack of information provided by hospitals, patients often need to rely on the internet as an information source, which appears to contain contradictory and unreliable information about complementary medicine [6, 22]. Nevertheless, the internet can play an important role in providing reliable information about complementary medicine when information is made accessible on the websites of respectable institutions with wide access. In the Netherlands, since 2022 information about effectiveness and

safety of complementary medicine interventions has become available on Kanker. nl, a large, online information platform for patients with cancer. Creating awareness of the existence of such reliable information sources among healthcare providers and patients is important. However, such information provision cannot replace a conversation about complementary medicine between patients and healthcare providers. The two tools we developed to support such conversations are therefore valuable additions to the platform of kanker.nl [10].

Although our overview of systematic reviews indicated that some complementary therapies have shown potential in improving patient-reported outcomes and quality of life [23], rigorous randomized clinical trials with long-term follow-up are warranted to provide a more robust evidence-base. Increased knowledge on the effectiveness and safety of complementary medicine interventions can facilitate patient-provider communication about the topic and reimbursement by healthcare insurers. Academic and funding parties have a role in balancing research on the effectiveness of curative or life-extending interventions, and preventive or qualityof-life enhancing interventions. Given the wide variety of symptoms and side-effects experienced by many patients with cancer, research on the effectiveness and safety of interventions that decrease symptom severity has the potential to improve the quality of life of a large number of patients. In addition, given the aging population and accompanying rising healthcare costs, cost-effective interventions with preventive or self-management characteristics will become increasingly important [24].

Methodological reflections

This thesis encompasses a wide range of data collection methods to assess the perspectives of patients with cancer, healthcare providers and complementary medicine practitioners. Throughout this participatory research project, nine coresearchers actively collaborated with the researchers in the study. For instance, the co-researchers were involved in establishing the interview guides, interviewing patients and healthcare providers, interpreting study results and developing communication-supporting tools for patients. We felt that the addition of the perspective of co-researchers led to richer data and more accurate interpretations of the study results, increasing the relevance of the findings. There are several important things we can learn from this experience. First, it is important to build a strong foundation in which researchers and co-researchers get to know each other and co-researchers feel properly prepared for their role by means of expectation management, clear role division and appropriate training. Second, researchers should adopt an individualized approach towards each co-researcher by taking notice of their barriers to participation. Co-researcher capacity can be decreased by fatigue

and other (residual) symptoms from disease or treatment, or by obligations related to work or care for others. Third, we perceived it difficult to involve co-researchers during periods of data analysis. The provision of frequent updates through newsletters or actual meetings may be helpful in this regard. Finally, we involved the co-researchers from the start of the study. For future studies, we recommend involving co-researchers at an earlier stage so that they can also provide input on study design, such as outcomes and strategies for recruitment.

Two overarching methodological limitations are important to consider when interpreting and generalizing the findings presented in this thesis. The first limitation is the influence of selection and nonresponse bias on participant samples. For the data collected in the different studies, we used a combination of convenience and purposive sampling. This recruitment strategy led to the overrepresentation of female patients with breast-cancer and a high education level, which is the typical profile of a complementary medicine user within oncology populations [25]. Individuals who participate in research can have different characteristics and thus perspectives compared to individuals choosing not to participate (i.e., nonresponse bias) or those who are not reached (i.e., selection bias) [26]. Possibly, patients and healthcare providers with a more critical attitude towards complementary medicine were inadvertently excluded from participation in our studies because we recruited mainly from patient organizations and hospitals who are pioneering in the field of complementary medicine. When the experiences or needs of these healthcare providers and patients are missed, this decreases the generalizability of the results.

The second overarching limitation is inconsistent use of terminology. The lack of consensus on a definition of complementary medicine impacts the generalizability of studies in this field. Complementary medicine consists of a heterogeneous group of modalities that are used alongside standard medical care, but are not part of standard medical care. The exact complementary practices and products included in this definition are inconsistent. For instance, complementary medicine is sometimes used as an umbrella term covering various lifestyle or self-help interventions, such as exercise, diets and vitamin supplements. To further complicate matters, some practices previously considered 'unconventional' eventually become integrated into standard medical care. For example, psychosocial support has been integrated into conventional oncology care since a few decades [27]. Within the growing field of integrative oncology, some complementary practices have become part of standard oncology care. However, the structure and implementation of integrative oncology are highly variable across countries [28]. The terminology in the scientific literature is also subject to change. The most commonly used term was "complementary and

alternative medicine", but currently, the term tends to include aspects of integration such as "complementary and integrative health" [29]. To avoid inconsistency, we continuously used the term "complementary medicine" throughout our studies. Furthermore, we paid extra attention to defining complementary medicine as applicable to the study in question in each methods section. Prior to data collection from participants, we always defined complementary medicine.

Future research opportunities

The next step in pursuance of this thesis would be to explore whether and in what way patients with cancer can benefit from the use of communication-supporting tools. For instance, whether the use of tools increases the occurrence of communication about complementary medicine, improves the quality of communication or enhances patients' confidence (for example, see [30]). For effective implementation of these tools, patient characteristics associated with the need for support in communication about complementary medicine should be explored. Barriers to and facilitators of tool implementation could also be assessed.

Although not elaborated on in this thesis, as part of the current research project, we also designed a tool for healthcare providers. This online tool provides healthcare providers with the opportunity to search for available evidence of complementary therapy-outcome combinations. The information about the evidence that was subsequently presented is derived from four international guidelines published by the Society of Integrative Oncology [31-34]. The usefulness of the tool is currently being evaluated among healthcare providers working in oncology in the Netherlands.

Patients reported that a negative attitude expressed by their healthcare provider was an important barrier to talking about complementary medicine [6]. The impact of verbal communication by a healthcare provider on patient disclosure of complementary medicine has already been assessed in a previous study [1]. Future studies could therefore focus on the observation of healthcare providers' nonverbal communication during oncology consultations, such as eye contact or facial expressions, and its potential effects on the occurrence and quality of communication about complementary medicine.

A striking gap in the literature is the lack of information on frequently used types of complementary medicine by patients with cancer. There is only one systematic review addressing this topic in patients with breast cancer [25]. A survey conducted in the Netherlands showed that biologically-based medicine (e.g. dietary supplements, herbs) and mind-body medicine (e.g. mindfulness, relaxation, yoga) are most

commonly used by 750 members of the Dutch Breast Cancer Society [35]. Future studies should provide insight into the most commonly used types of complementary medicine in populations other than patients with breast cancer. More knowledge on frequently used types of complementary medicine is valuable for healthcare providers because it allows them to focus more when inquiring patients about complementary medicine use or when increasing their knowledge about complementary medicine.

Implications and recommendations for clinical practice

The findings of this thesis have significant implications for practice. The four most important recommendations for clinical oncology are discussed below:

1. Routinize proactive, effective counselling on complementary medicine

Both patients and healthcare providers desire the embedding of proactive counselling on complementary medicine in oncology consultations [6]. This implies a shared responsibility for engaging in conversations about complementary medicine among patients and healthcare providers. To implement routine discussions about complementary medicine, health informatics may play a significant role [13]. For instance, the inclusion of standardized questions about patients' complementary medicine needs and use in existing electronic patient reporting systems, enabling mutual sharing of information about patients' complementary medicine use between healthcare providers or the creation of avenues for patients with cancer to self-report complementary medicine. When discussing complementary medicine, it is important for healthcare providers to realize that most patients are not familiar with the term 'complementary medicine'. To ensure patient understanding, healthcare providers should cite concrete examples of complementary medicine. Further recommendations for effective communication about complementary medicine can be found in a recently published clinical practice guideline for oncology healthcare providers [36]. In this guideline, healthcare providers are recommended to: 1) address the topic of complementary medicine across the disease trajectory, 2) acknowledge patient beliefs, values and preferences, 3) document and monitor complementary medicine use, and 4) explore risk factors and needs. Many of these recommendations draw on basic communication skills expected from healthcare providers, such as inquiring about selfmanagement behaviour and patient needs in a nonjudgmental manner [13].

2. Address scepticism towards complementary medicine among healthcare providers

Although the role of complementary medicine is becoming more recognized in oncology care, scepticism towards complementary medicine seems to prevail at

the individual, institutional and societal level [6]. Healthcare providers should be reflective of their attitude and aware of the influence of their attitude on patient disclosure of complementary medicine use. To encourage patients to talk about complementary medicine use, an open and supportive communication environment must be created [6]. To diminish the taboo on complementary medicine, we can learn from the normalization of other taboo subjects in oncology such as intimacy, fertility and substance abuse. Effective cancer care regarding these subjects is supported by taking a risk-reduction approach, inviting two-way communication and facilitating referral to appropriate resources [37]. Although regulation can facilitate normalization of a subject, standardized policies or procedures for complementary medicine are currently lacking in the Netherlands [24]. By developing and sharing (inter)nationally available evidence-based scientific knowledge, the Consortium for Integrated Care and Health (CIZG) aims to contribute to the sustainable and responsible integration of complementary medicine in the Netherlands [38]. According to some healthcare providers we interviewed, scepticism toward complementary medicine can be decreased by clearly distinguishing between alternative medicine and complementary medicine [6]. Alternative medicine that is used instead of conventional medicine is often surrounded by misleading information and fraudulent practices that can impair patient safety [39]. Nonetheless, a healthy dose of scepticism can be useful for healthcare providers when interpreting the results of studies on complementary therapies. For instance, our overview of systematic reviews showed that randomized clinical trials on complementary medicine often lack safety reporting and that the impact of bias on systematic review results remains frequently unassessed [23].

3. Improve the provision of information about complementary medicine for patients

Because of the constraints experienced when searching for information about complementary medicine on the internet, patients prefer to receive information from the hospital in which they receive treatment [6]. To provide adequate information about complementary medicine to patients, knowledge among healthcare providers needs to be improved. Several effective educational programs on complementary and integrative medicine have been developed for healthcare providers in oncology [15, 16, 40]. In addition to formal education, there are other tools available to support healthcare providers who receive questions about complementary medicine from patients. Examples of such tools include international databases of natural medicine or herbs [41, 42] and international guidelines published by the Society of Integrative Oncology [31-34]. Another useful tool for clinical practice is the ethical framework by Cohen et al. [43], which supports healthcare providers in deciding whether complementary medicine use should be recommended, tolerated or discouraged based on evidence on efficacy and safety. The implementation of integrative oncology consultations by healthcare providers with expertise in complementary medicine can address barriers of lacking time and knowledge among healthcare providers [6]. Although face-to-face conversations with healthcare providers should always be leading, hospitals are encouraged to publish basic information about complementary medicine on their website. Alternatively, patients can be referred to existing, reliable information platforms (for example, *kanker.nl* in the Netherlands). To include less digitally proficient patients, information leaflets on complementary medicine that combine textual and visual information can be presented to patients in waiting areas and consultation rooms

4. Promote interprofessional communication between conventional healthcare providers and complementary medicine practitioners

Interprofessional communication between healthcare providers and complementary medicine practitioners remains limited, despite its importance for the completeness of medical information and for clear role divisions in multidisciplinary patient care. An important facilitator of interprofessional communication about mutual patients with cancer is the openness of healthcare providers [9]. Efforts to promote interprofessional communication should focus on raising awareness of its importance among the involved parties and creating (digital) pathways for interprofessional communication.

In conclusion

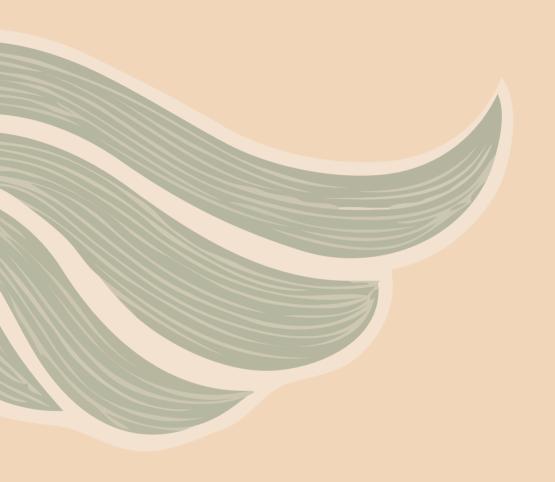
A growing number of patients with cancer use complementary medicine. Due to the lack of routine communication about this topic in oncology care, opportunities to enhance the safety, effectiveness and patient-centredness of cancer care are missed. The findings presented in this thesis contribute to a deeper understanding of the challenges and opportunities inherent in communication about complementary medicine during cancer treatment. Patients, healthcare providers, healthcare institutions and complementary medicine practitioners can play a role in closing the communication gap.

REFERENCES

- Roter, D.L., et al., Communication predictors and consequences of Complementary and Alternative Medicine 1 (CAM) discussions in oncology visits. Patient education and counseling, 2016. 99(9): p. 1519-1525.
- Koenig, C.J., et al., An exploratory typology of provider responses that encourage and discourage conversation 2. about complementary and integrative medicine during routine oncology visits. Patient education and counseling, 2015. 98(7): p. 857-863.
- Mentink, M.D., et al., How is complementary medicine discussed in oncology? Observing real-life 3. communication between clinicians and patients with advanced cancer. Patient Education and Counseling, 2022. 105(11): p. 3235-3241.
- Verhoef, M., H. Boon, and S. Page, Talking to cancer patients about complementary therapies: is it the 4. physician's responsibility? Current Oncology, 2008. 15(s2): p. 88-93.
- Schouten, A.E., et al., Perspectives and Attitudes of Dutch Healthcare Professionals Regarding the Integration 5. of Complementary Medicine in Oncology. Integrative Cancer Therapies, 2023. 22: p. 15347354231164650.
- Mentink, M.; Busch, M.; Timmer-Bonte, A.; Noordman, J.; van Dulmen, S., Communication and information provision about complementary medicine in oncology: experiences and needs of patients and healthcare providers. Submitted, 2024.
- de Wit, L., S. Jeurissen, and W. Chen, Risk assessment of herbal preparations containing St John's wort. 2021.
- 8. National Center of Complementary and Integrative Health (NCCIH), Natural Doesn't Necessarily Mean Safer, or Better. 2024 [cited 15 Feb 2024; Available from: https://www.nccih.nih.gov/ health/know-science/natural-doesnt-mean-better.
- Mentink, M., Jansen, J., Noordman, J., van Vliet, L., Busch, M., & van Dulmen, S., Interprofessional contact with conventional healthcare providers in oncology: a survey among complementary medicine practitioners. BMC Complementary Medicine and Therapies, 2024. 24(1), p. 285.
- Mentink, M.; Timmer-Bonte, A.; Busch, M.; van Dulmen, S., Fostering the conversation about 10. complementary medicine: acceptability and usefulness of two communication-supporting tools for patients with cancer. Submitted, 2024.
- Davis, E.L., et al., Cancer patient disclosure and patient-doctor communication of complementary and alternative medicine use: a systematic review. The oncologist, 2012. 17(11): p. 1475-1481.
- King, N., et al., Surveys of cancer patients and cancer health care providers regarding complementary therapy use, communication, and information needs. Integrative cancer therapies, 2015. 14(6): p. 515-524.
- Balneaves, L.G. and C.Z. Watling, "Part of the Conversation": A Qualitative Study of Oncology Healthcare 13. Professionals' Experiences of Integrating Standardized Assessment and Documentation of Complementary Medicine. Integrative Cancer Therapies, 2022. 21: p. 15347354221077229.
- Jones, E., et al., Exploring the use of complementary and alternative medicine in cancer patients. Integrative cancer therapies, 2019. 18: p. 1534735419846986.
- Blödt, S., et al., A consultation training program for physicians for communication about complementary medicine with breast cancer patients: a prospective, multi-center, cluster-randomized, mixed-method pilot study. BMC cancer, 2016. 16: p. 1-8.
- Hayward, E.N., C.Z. Watling, and L.G. Balneaves, A pre-post evaluation of oncology healthcare providers' knowledge, attitudes, and practices following the implementation of a complementary medicine practice guideline. Supportive Care in Cancer, 2021. 29(12): p. 7487-7495.
- Rogge, A.A., et al., Effects of training oncology physicians advising patients on complementary and integrative therapies on patient-reported outcomes: A multicenter, cluster-randomized trial. Cancer, 2021. 127(15): p. 2683-2692.

- 18. Keene, M.R., et al., Knowledge, attitudes and practices of health professionals toward complementary and alternative medicine in cancer care-a systematic review. Journal of Communication in Healthcare, 2020. 13(3): p. 205-218.
- Wahner-Roedler, D.L., et al., Physicians' attitudes toward complementary and alternative medicine and their knowledge of specific therapies: 8-year follow-up at an academic medical center. Complementary therapies in clinical practice, 2014. 20(1): p. 54-60.
- 20. Yun, H., L. Sun, and J.J. Mao, Growth of integrative medicine at leading cancer centers between 2009 and 2016: a systematic analysis of NCI-designated comprehensive cancer center websites. Journal of the National Cancer Institute Monographs, 2017. 2017(52): p. lgx004.
- Frenkel, M., et al., Integrative medicine consultation service in a comprehensive cancer center: findings and outcomes. Integrative cancer therapies, 2010. 9(3): p. 276-283.
- Bianchini, C., et al., Avoiding misleading information: a study of complementary medicine online information for cancer patients. Library & Information Science Research, 2019. 41(1): p. 67-77.
- Mentink, M., et al., The Effects of Complementary Therapies on Patient-Reported Outcomes: An Overview of Recent Systematic Reviews in Oncology. Cancers, 2023. 15(18): p. 4513.
- 24. World Health Organization (WHO), WHO global report on traditional and complementary medicine 2019. 2019: World Health Organization.
- Wanchai, A., J.M. Armer, and B.R. Stewart, Complementary and alternative medicine use among women with breast cancer: a systematic review. Clinical journal of oncology nursing, 2010. 14(4).
- Sedgwick, P., Questionnaire surveys: sources of bias. Bmj, 2013. 347. 26.
- 27. Holland, J.C., History of psycho-oncology: overcoming attitudinal and conceptual barriers. Psychosomatic medicine, 2002. 64(2): p. 206-221.
- 28. Semeniuk, G., et al., Integrative Oncology and the Clinical Care Network: Challenges and Opportunities. Journal of Clinical Medicine, 2023. 12(12): p. 3946.
- National Center for Complementary and Integrative Health (NCCIH), Complementary, Alternative or Integrative Health: What's In a Name? 2021 Feb 9, 2024]; Available from: https://www.nccih.nih.gov/ health/complementary-alternative
 - -or-integrative-health-whats-in-a-name.
- 30. van Bruinessen, I.R., et al., An integrated process and outcome evaluation of a web-based communication tool for patients with malignant lymphoma: randomized controlled trial. Journal of medical Internet research, 2016. 18(7): p. e206.
- Mao, J.J., et al., Integrative medicine for pain management in oncology: society for integrative oncology-ASCO guideline. Journal of Clinical Oncology, 2022. 40(34): p. 3998-4024.
- 32. Greenlee, H., et al., Clinical practice guidelines on the evidence-based use of integrative therapies during and after breast cancer treatment. CA: a cancer journal for clinicians, 2017. 67(3): p. 194-232.
- 33. Carlson, L.E., et al., Integrative oncology care of symptoms of anxiety and depression in adults with cancer: Society for Integrative Oncology-ASCO Guideline. Journal of Clinical Oncology, 2023. 41(28): p. 4562-4591.
- 34. Deng, G.E., et al., Complementary therapies and integrative medicine in lung cancer: diagnosis and management of lung cancer: American College of Chest Physicians evidence-based clinical practice guidelines. Chest, 2013. 143(5): p. e420S-e436S.
- 35. Borstkanker Vereniging Nederland (BVN), 65 procent van de borstkanker patienten maakt(e) gebruik van complementaire zorg 2018 [cited 4 March 2024; Available from: https://www.borstkanker.nl/ nieuws/65-van-de-borstkankerpatienten-maakte-gebruik-van-complementaire-zorg.

- 36. Balneaves, L.G., et al., Addressing complementary and alternative medicine use among individuals with cancer: an integrative review and clinical practice guideline. JNCI: Journal of the National Cancer Institute, 2022. 114(1): p. 25-37.
- 37. Perez, G.K., et al., Taboo topics in adolescent and young adult oncology: strategies for managing challenging but important conversations central to adolescent and young adult cancer survivorship. American Society of Clinical Oncology Educational Book, 2020. 40: p. e171-e185.
- 38. Consortium voor Integrale Zorg en Gezondheid (CIZG), Our vision. 2024 9 May 2024]; Available from: https://cizg.nl/over-ons/.
- Raposo, V.L., Complementary and alternative medicine, medical liability and the proper standard of care. Complementary Therapies in Clinical Practice, 2019. 35: p. 183-188.
- 40. Helmer, S.M., et al., Effects of blended learning training for oncology physicians to advise their patients about complementary and integrative therapies: results from the multicenter cluster-randomized KOKON-KTO trial. BMC cancer, 2023. 23(1): p. 836.
- Memorial Sloan Kettering Cancer Center, About Herbs. 2024. Available from: https://www.mskcc.org/ cancer-care/diagnosis-treatment/symptom-management/integrative-medicine/herbs
- 42. Therapeutic Research Center, Natural Medicines. 2024. Available from: https://naturalmedicines. therapeuticresearch.com/
- 43. Cohen, M.H. and D.M. Eisenberg, Potential physician malpractice liability associated with complementary and integrative medical therapies. Annals of internal medicine, 2002. 136(8): p. 596-603.



APPENDICES

- I. Summary in Dutch (Nederlandse samenvatting)
- II. Evaluation by the co-researchers
- III. Research data management
- IV. List of publications
- V. PhD Portfolio
- VI. Curriculum Vitae
- VII. Acknowledgements (Dankwoord)

I. SUMMARY IN DUTCH (NEDERLANDSE SAMENVATTING)

De onderzoeken die we beschrijven in dit proefschrift zijn gericht op het onderwerp communicatie over complementaire zorg in de oncologie. Hieronder vat ik de belangrijkste bevindingen samen aan de hand van de drie onderzoeksvragen die we wilden beantwoorden:

1. Hoe wordt complementaire zorg besproken in de oncologische zorg in Nederland en wat zijn de belemmerende en bevorderende factoren voor communicatie die worden ervaren door patiënten, oncologische zorgverleners en complementaire behandelaars?

We onderzochten daadwerkelijke gesprekken over complementaire zorg tussen patiënten en zorgverleners door het observeren en coderen van 80 audio-opnames van oncologische consulten in zes verschillende ziekenhuizen in Nederland (Hoofdstuk III). In 44% van deze consulten werd er gesproken over complementaire zorg, meestal met betrekking tot leefstijl-gerelateerde interventies (bijv. beweging, voeding). Het onderwerp complementaire zorg werd in de meeste gevallen (62%) aangekaart door patiënten. Patiënten die aan hun zorgverlener een specifieke vraag stelden over complementaire zorg, kregen altijd een antwoord van hun zorgverlener. Als patiënten geen specifieke vraag stelden, maar het onderwerp alleen (terloops) benoemden, gingen zorgverleners er zelden verder op in. Belangrijke aspecten van complementaire zorg, zoals veiligheid en effectiviteit, kwamen tijdens de consulten weinig aan bod. Zowel patiënten als zorgverleners lieten zich neutraal tot positief uit over de besproken vormen van complementaire zorg.

Om de ervaringen en behoeften met betrekking tot communicatie over complementaire zorg te onderzoeken, interviewden we 17 patiënten en 13 zorgverleners uit drie ziekenhuizen in Nederland (Hoofdstuk IV). De resultaten lieten zien dat effectieve gesprekken over complementaire zorg belemmerd worden door tijdsdruk en een gebrek aan kennis bij zorgverleners. Zorgverleners erkenden dat er ten opzichte van complementaire zorg scepsis heerst onder collega's en het ziekenhuisbestuur. Patiënten voelden zich ontmoedigd om complementaire zorg te bespreken als de zorgverlener het onderwerp afwees of er niet in geïnteresseerd was. Volgens de geïnterviewde patiënten en zorgverleners zijn niet alle patiënten zich bewust van het bestaan van complementaire zorg en zijn ze niet allen assertief genoeg om het onderwerp aan te kaarten bij hun zorgverlener. Hoewel sommige zorgverleners vertelden dat ze complementair zorggebruik altijd uitvragen bij patiënten, is het onderwerp niet structureel ingebed in oncologische consulten. Zowel de geïnterviewde patiënt-

en als zorgverleners waren voorstander van een open communicatieomgeving waarin het onderwerp complementaire zorg routinematig wordt geïntroduceerd door de zorgverlener. Daarnaast gaven patiënten en zorgverleners aan de behoefte te hebben aan gemakkelijk toegankelijke, betrouwbare informatie over complementaire zorg. Voor patiënten moet erop gelet worden dat de informatie inclusief is, bijvoorbeeld door het combineren van online en papieren informatie om minder digitaal vaardige patiënten te bereiken, of door het combineren van tekstuele met visuele informatie om laaggeletterde patiënten te bereiken. De geïnterviewde patiënten gaven aan dat ze graag zouden zien dat hun ziekenhuis betrokken is bij het verstrekken van informatie over complementaire zorg.

In dit proefschrift hebben we ook aandacht besteed aan de dynamiek tussen complementaire behandelaars en oncologische zorgverleners (Hoofdstuk V). Uit een online vragenlijst ingevuld door 1481 complementair behandelaars in Nederland bleek dat 40% wel eens had gecommuniceerd met een oncologisch zorgverlener van een patiënt met kanker. Slechts 13% van de complementair behandelaars had het gevoel dat oncologisch zorgverleners open stonden interprofessionele communicatie. De mate waarin complementair behandelaars ervoeren dat oncologisch zorgverleners open staan voor communicatie, was significant voorspellend voor het ontstaan van interprofessionele communicatie. De meeste complementair behandelaars (82%) vonden het belangrijk dat patiënten het gebruik van complementaire zorg meldden aan hun oncologisch zorgverlener en 49% van de complementair behandelaars moedigde hun patiënten ook actief aan om dit te doen.

2. Welke complementaire zorg is effectief en veilig voor patiënten met kanker?

Om deze onderzoeksvraag te beantwoorden, beoordeelden we honderd systematische reviews die rapporteerden over het effect van een complementaire therapie op patiëntgerapporteerde uitkomstmaten (Hoofdstuk VI). Twaalf verschillende complementaire therapieën werden geïncludeerd, zoals kruidengeneeskunde, acupunctuur en yoga. Hoewel het bewijs voor meerdere therapie-uitkomstcombinaties niet overtuigend was, laten de resultaten wel zien dat sommige complementaire therapieën de potentie hebben om patiënt-gerapporteerde uitkomsten te verbeteren. Voorbeelden zijn acupunctuur om pijn te verlichten, muziekinterventies om angst te verminderen en yoga om kanker-gerelateerde vermoeidheid te verbeteren. Gerapporteerde bijwerkingen van het gebruik van complementaire therapieën waren over het algemeen mild, zoals blauwe plekken door acupunctuur of spierkramp door yoga. Veertig van de 100 geïncludeerde systematische reviews rapporteerden helemaal niet over veiligheid. Bovendien heeft een groot deel van de geïncludeerde systematische

reviews bij de interpretatie van de resultaten onvoldoende beschreven wat de oorzaken en gevolgen zijn van bias (vertekening van resultaten).

3. Hoe kunnen patiënten met kanker worden ondersteund bij het bespreken van complementaire zorg met hun oncologisch zorgverlener?

Zoals beschreven in hoofdstuk IV, kwamen er een paar belangrijke belemmerende factoren naar voren die patiënten kunnen ervaren bij het bespreken van complementaire zorg. Zo zijn niet alle patiënten met kanker zich bewust van het bestaan van complementaire zorg of het belang van het bespreken van complementair zorggebruik met de zorgverlener. Daarnaast zijn niet alle patiënten met kanker assertief genoeg om het onderwerp te introduceren, vooral wanneer ze geconfronteerd worden met een sceptische zorgverlener. Om ook laaggeletterde patiënten te ondersteunen bij het bespreken van complementaire zorg, is het belangrijk om visuele met tekstuele informatie te combineren. Met deze kennis hebben we twee hulpmiddelen ontwikkeld om patiënten met kanker te ondersteunen in de communicatie over complementaire zorg; een gesprekshulp en een slideshow (Hoofdstuk VII). De gesprekshulp heeft als doel om gesprekken over complementaire zorg te stimuleren en richting te geven door patiënten te voorzien van een reeks voorbeeldvragen die ze kunnen stellen aan hun zorgverlener. De slideshow laat patiënten op een visuele manier zien waarom het belangrijk is om complementair zorggebruik te bespreken met de zorgverlener. De twee hulpmiddelen werden geëvalueerd aan de hand van een online vragenlijst van 15 items die werd ingevuld door 144 patiënten met kanker. De hulpmiddelen werden over het algemeen goed ontvangen door de deelnemers. De inhoud en de lay-out werden als aanvaardbaar ervaren en ongeveer de helft van de deelnemers vond de hulpmiddelen nuttig. De andere helft van de deelnemers was niet van plan om de hulpmiddelen te gaan gebruiken. De meest genoemde redenen hiervoor waren 1) in staat zijn om complementaire zorg te bespreken zonder ondersteuning, 2) niet geïnteresseerd zijn in complementaire zorg, of 3) het onderwerp complementaire zorg niet willen bespreken met de zorgverlener. Een groot deel van de deelnemers vond de hulpmiddelen vooral nuttig voor medepatiënten.

II. EVALUATION BY THE CO-RESEARCHERS

Background

The group of co-researchers consisted of nine (former) patients with breast cancer. The co-researchers actively contributed to the current participatory research project, for instance by developing interview guides and by co-interviewing and interpreting study results. At the end of the research project, the co-researchers were asked to complete an online questionnaire in which they were asked to reflect on their experiences as coresearchers (see Figure 1). Eight out of nine co-researchers responded. Their answers are summarized below and illustrated by some translated quotes.

- How did you experience being a co-researcher within the research project?
- 2. Did you feel well enough prepared for your tasks as a co-researcher? How did you feel about the training sessions?
- 3. How did you experience the collaboration with the researchers?
- 4. Did you feel you had a say or could make a difference?
- 5. What did you learn from your role as a co-researcher?
- 6. Did you prefer online contact moments or face-to-face meetings?
- 7. Was the financial compensation for the hours sufficient?
- 8. Are there things we can do better when working with co-researchers in the future?
- 9. Would you accept an invitation to be co-researcher in the future? Why or why not?
- 10. Would you recommend other people to become co-researcher? Why or why not?

Figure 1. Evaluation questionnaire for co-researchers

Summary of answers on evaluation questions by the co-researchers

The co-researchers generally experienced their participation as valuable, pleasant and educational. Their role as co-researcher was supporting during (or shortly after) a time of severe illness:

"Being a co-researcher gave a positive flow to something very negative. [...] It also dragged me a bit through a very difficult time. For a moment I was not just sick!" (Co-researcher 1)

"I had a lot of support from it, [...] I felt appreciated and heard." (Co-researcher 2)

"Being co-researcher benefited my recovery by being able to make my experience useful. It put me back in life with both feet." (Co-researcher 3)

The co-researchers felt sufficiently prepared for their role and perceived the organized training sessions as educational. The co-researchers were satisfied with the guidance received from the researchers. Overall, collaboration with the researchers was experienced as pleasant and inspirational:

"Above all, I found the collaboration to be based on connection. Working together towards the set "goal". Complementing each other is an important aspect." (Co-researcher 3)

The co-researchers learned from their experiences, for instance about the importance of combining different perspectives and how to ask good questions during interviews. The co-researchers felt that their voices were heard and that they could make impact, especially with regard to developing the interview guides and conducting interviews:

"My interview questions as a former patient were sometimes on a different terrain than those of the researchers." (Co-researcher 3)

Some co-researchers found it difficult to stay objective or neutral in their role:

"Remaining neutral while being emotionally very involved." (Co-researcher 1)

Although co-interviewing while being ill was experienced as intense by some co-researchers, others perceived the intensity of participation to be too low. One co-researcher would have liked to provide more substantial input into the content of the study and suggested a more active form of participation as a co-researcher. Some co-researchers felt that engagement in the study could be improved by providing more frequent updates on the study or by meeting more often.

The co-researchers were divided in their preferences for online or face-to-face participation¹. Some co-researchers preferred online meetings, because of (travel) time constraints or illness-related factors. Others preferred meeting each other face-to-face. Alternation of online and face-to-face sessions was also appreciated by some of the co-researchers. Financial compensation for participation was perceived as sufficient by all co-researchers, but was unnecessary for some.

All eight co-researchers would accept a future invitation to participate as co-researcher, as long as the research topic was of interest. Additionally, all co-researchers stated that they would encourage other patients to participate as co-researcher.

The research project started during the COVID-19 pandemic, necessitating mainly online meetings.

A

III. RESEARCH DATA MANAGEMENT

Ethics and privacy

This thesis is based on the results of human studies or existing data from published papers, which were conducted in accordance with the principles of the Declaration of Helsinki. The Medical Ethics Committee Radboud CMO, Nijmegen, the Netherlands exempted these studies from formal approval under the Dutch Medical Research Involving Human Subjects Act (Radboud CMO dossier number: 2020-6917). Informed consent was obtained from participants to collect and process their data for this research project; also, consent was obtained for sharing the (pseudonymized) data after research. Transcriptions of audio and video files do not contain privacy sensitive information.

Data collection and storage

For chapter III and VI, existing data were used. The audio- and video recordings used in chapter III were previously collected and stored with permission for data-re-use. The published literature reported on in chapter VI, was extracted from online bibliographical databases (e.g., PubMed). Data for chapter IV was collected by means of interviews. Data for chapter V and VII were collected through online surveys. Pseudonymized data were stored and analyzed in a project folder (P:\COM\COM-049) at Nivel that is accessible only to project members working at Nivel. After project completion, data is archived for a minimum of 10 years.

Data sharing

All studies are published open access. Only metadata and de-identified aggregated data will be published, so it is not traceable to individual respondents. Data were made reusable by adding sufficient documentation (e.g., research protocol, logbook, codebook). Data can be found at nivel.nl, which is a repository at OpenDOAR. Due to data characteristics, access is restricted and upon request. Request for access will be checked by a steering committee. Privacy sensitive data will not be shared.

IV. LIST OF PUBLICATIONS

In this thesis

Mentink, M., Noordman, J., van Vliet, L., Busch, M., van Dulmen, S. (2024). Interprofessional contact with conventional healthcare providers in oncology: a survey among complementary medicine practitioners. BMC Complementary Medicine and Therapies, 24(1), 285.

Mentink, M., Verbeek, D., Noordman, J., Timmer-Bonte, A., von Rosenstiel, I., & van Dulmen, S. (2023). The Effects of Complementary Therapies on Patient-Reported Outcomes: An Overview of Recent Systematic Reviews in Oncology. Cancers, 15(18), 4513.

Mentink, M. D., van Vliet, L. M., Timmer-Bonte, J. A. N., Noordman, J., & van Dulmen, S. (2022). How is complementary medicine discussed in oncology? Observing real-life communication between clinicians and patients with advanced cancer. Patient Education and Counseling, 105(11), 3235-3241.

Mentink, M., Noordman, J., Busch, M., van Vliet, L., Timmer-Bonte, J. A., & van Dulmen, S. (2021). Towards an open and effective dialogue on complementary medicine in oncology: protocol of patient participatory study 'COMMON'. BMJ open, 11(10), e053005.

Not in this thesis

Schouten, A. E., **Mentink, M. D.**, Timmer-Bonte, J. A. N., Noordman, J., & van Dulmen, S. (2023). Perspectives and attitudes of Dutch healthcare professionals regarding the integration of complementary medicine in oncology. Integrative Cancer Therapies, 22, 15347354231164650.

Mora, D. C., Kristoffersen, A. E., Overvåg, G., Jong, M. C., **Mentink, M.**, Liu, J., & Stub, T. (2022). Safety of Complementary and Alternative Medicine (CAM) treatment among children and young adults who suffer from adverse effects of conventional cancer treatment: A systematic review. Integrative Cancer Therapies, 21, 15347354221105563.

Van der Zwaan, K. F., **Mentink, M. D.**, Jacobs, M., Roos, R. A., & De Bot, S. T. (2022). Huntington's disease influences employment before and during clinical manifestation: A systematic review. Parkinsonism & Related Disorders, 96, 100-108.

Submitted

Mentink, M., Vliet, van., Busch, M., Timmer-Bonte, A., Noordman, J., van Dulmen, S., Communication and information provision about complementary medicine in oncology: experiences and needs of patients and healthcare providers.

Mentink, M., Noordman, J., Timmer-Bonte, A., Busch, M., van Dulmen, S., Fostering the conversation about complementary medicine: acceptability and usefulness of two communication-supporting tools for patients with cancer.

Noordam, D., **Mentink, M.**, van Kippersluis, A., Noordman, J., Busch, M., Timmer-Bonte, J., van Dulmen, S., Facilitators and barriers for integrating complementary medicine into oncology care: Perspectives of healthcare providers and managers.

V. PhD PORTFOLIO

Department:Primary and Community CarePhD period:15/07/2020 - 15/04/2024PhD Supervisor(s):Prof. dr. A.M. van Dulmen

PhD Co-supervisor(s): dr. J. Noordman, dr. J.N.H. Timmer-Bonte

Courses Breast cancer (2020) STATA (2020) RIHS - Introduction course for PhD candidates (2020) Workshop Kwaliteit (2020) Persoonlijke effectiviteit (2020) Energiemanagement tijdens thuiswerken (2020) Qualitative Research Methods and Analysis (2021) Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) Grant Writing: creating a compelling narrative for your proposal (2024)	2.00 8.00 15.00 3.00 8.00 2.00 60.00 18.00 1.00 2.00 2.00 30.00 4.00
 STATA (2020) RIHS - Introduction course for PhD candidates (2020) Workshop Kwaliteit (2020) Persoonlijke effectiviteit (2020) Energiemanagement tijdens thuiswerken (2020) Qualitative Research Methods and Analysis (2021) Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	8.00 15.00 3.00 8.00 2.00 84.00 60.00 18.00 1.00 2.00 2.00 30.00 4.00
 RIHS - Introduction course for PhD candidates (2020) Workshop Kwaliteit (2020) Persoonlijke effectiviteit (2020) Energiemanagement tijdens thuiswerken (2020) Qualitative Research Methods and Analysis (2021) Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	15.00 3.00 8.00 2.00 84.00 60.00 18.00 1.00 2.00 2.00 30.00 4.00
 Workshop Kwaliteit (2020) Persoonlijke effectiviteit (2020) Energiemanagement tijdens thuiswerken (2020) Qualitative Research Methods and Analysis (2021) Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	3.00 8.00 2.00 84.00 60.00 18.00 1.00 2.00 2.00 30.00 4.00
 Persoonlijke effectiviteit (2020) Energiemanagement tijdens thuiswerken (2020) Qualitative Research Methods and Analysis (2021) Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	8.00 2.00 84.00 60.00 18.00 1.00 2.00 2.00 30.00 4.00
 Energiemanagement tijdens thuiswerken (2020) Qualitative Research Methods and Analysis (2021) Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	2.00 84.00 60.00 18.00 1.00 2.00 2.00 30.00 4.00
 Qualitative Research Methods and Analysis (2021) Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	84.00 60.00 18.00 1.00 2.00 2.00 30.00 4.00
 Academic writing (2021) Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	60.00 18.00 1.00 2.00 2.00 30.00 4.00
 Observational coding (2021) How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	18.00 1.00 2.00 2.00 30.00 4.00
 How to write a rebuttal (2021) Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	1.00 2.00 2.00 30.00 4.00
 Interviewen voor co-onderzoekers (2021) Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	2.00 2.00 30.00 4.00
 Waarden-vol onderzoek (2021) Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	2.00 30.00 4.00
 Presenting in English (2021) EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	30.00 4.00
 EBROK recertification (2022) Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	4.00
 Boost your academic writing skills (2022) Scientific integrity (2022) ChatGPT workshop (2023) 	
Scientific integrity (2022)ChatGPT workshop (2023)	1.00
ChatGPT workshop (2023)	
	20.00
Grant Writing: creating a compelling narrative for your proposal (2024)	3.00
	70.00
Seminars	
Socratisch gesprek (2020) - attendence	2.00
• Social media (2020) – attendance	1.00
• Amsterdam Center for Health Communication digital symposium (2020) - attendence	5.00
Integrative Oncology (2021) – attendance	2.00
Conferences	
• International Conference on Communication in Healthcare (2021) - attendence	16.00
• CaRe days (2021) – oral presentation	16.00
• Consortium voor Integrale Zorg en Gezondheid congres (2021) - attendence	8.00
• European Conference on Health Communication (2021) – attendance	10.00
• 2nd World Congress on Integrative Medicine and Health (2023) – poster presentation	24.00
Other	
• Peer to peer meeting (2020)	1.00
• KWF researchers meeting (2022)	8.00
Board member staff association Nivel (2023)	75.00
• Peer review (2023)	8.00
Presentation about COMMON study for VWS (2024)	1.00
Teaching activities	
Supervision of internships / other	
Supervision master thesis (2021)	50.00
Supervision master thesis (2022)	50.00
Supervision master thesis (2023)	25.00
Total	

\mathbf{A}

VI. CURRICULUM VITAE

Marit Dianna Corina Mentink was born on July 28, 1993, in Zwolle, the Netherlands. After completing secondary school, she began her studies at Utrecht University in 2014, where she earned bachelor's degrees in Sociology and Psychology. In 2017, she graduated cum laude with a master's degree in Neuropsychology. For her master's thesis, she studied verbal fluency in glioma patients at Erasmus Medical Center in Rotterdam. Her clinical internship was at the Department of Neurology at Leiden University Medical Center (LUMC), where she was subsequently offered a position as a neuropsychologist and study coordinator. Realizing her passion for research, Marit continued her role as study coordinator at LUMC while also taking on the position of language area coordinator at the European Huntington's Disease Network in 2018. In this role, she managed clinical study sites in the Netherlands and Belgium. In July 2020, she began her PhD research at Nivel, the Netherlands Institute for Health Services Research, in Utrecht. She was an external PhD candidate at the Department of Primary and Community Care at Radboud University Medical Center in Nijmegen. Currently, Marit works as a researcher at Isala Hospital in Zwolle, focusing on a trial that studies the effectiveness of early, routine provision of mindfulness-based cognitive therapy (MBCT) on psychological distress in patients with cancer.

VII. ACKNOWLEDGEMENTS (DANKWOORD)

Het afronden van dit proefschrift markeert het einde van een leerzame periode in mijn leven. Dit werk zou niet tot stand zijn gekomen zonder de steun en begeleiding van mijn promotieteam:

Allereerst wil ik mijn promotor, prof. dr. Sandra van Dulmen, bedanken. Jou schat aan kennis en ervaring zijn heel waardevol voor mij geweest. Naast je aandacht voor de kwaliteit van het onderzoek, had je ook altijd oog voor mij als persoon. Ik had mij geen fijnere promotor kunnen wensen.

Mijn oprechte dank gaat ook uit naar mijn co-promotoren, dr. Janneke Noordman en dr. Anja Timmer-Bonte. Janneke, bedankt voor jou continue inzet en bijdragen aan het onderzoek. Naast co-promotor ben je een ontzettend attente collega. Anja, jou kritische blik en perspectief als oncoloog hebben dit proefschrift naar een hoger niveau getild. Dank je wel voor het vervullen van de rol als co-promotor.

Naast mijn promotieteam, zijn er nog vele anderen die op verschillende manieren een onmisbare bijdrage hebben geleverd aan dit proefschrift:

Co-onderzoekers, jullie ervaringen als patiënt en jullie passie om je in te zetten voor complementaire zorg hebben mij enorm gemotiveerd bij de uitvoering van het onderzoek. Dankzij jullie openheid, betrokkenheid en inzet is dit werk zoveel rijker en betekenisvoller geworden. Duizendmaal dank!

Martine, het is prachtig om te zien hoe jij je met volle inzet beweegt in het complementaire zorgveld. Jouw kennis en netwerk waren van onschatbare waarde voor dit onderzoek. Daarnaast ben je ook gewoon een erg fijn mens om mee samen te werken. Dank je wel!

Liesbeth, jou inzichten en expertise hebben het onderzoek verrijkt en hielpen mij altijd weer op weg. Bedankt!

Danielle, jouw scherpe blik heeft de kwaliteit van de overview of systematic reviews aanzienlijk verhoogd. Bedankt daarvoor! Ik denk met plezier terug aan de keren dat we samen stonden te hupsen voor de camera om ons bloed te laten stromen tijdens al het zittende werk.

Ines, ik bewonder jou activisme op het gebied van integrative medicine in Nederland. Gesprekken met jou en jouw presentaties waren altijd bijzonder inspirerend voor mij.

Stagiaires Angelique, Aniek en Julia, het was een genoegen om jullie te mogen begeleiden. Bedankt voor de fijne samenwerking en jullie bijdragen aan het onderzoek.

Zonder deelnemers geen onderzoek. Mijn speciale dank gaat uit naar de patiënten met kanker, oncologisch zorgverleners en complementair behandelaars die aan dit onderzoek hebben deelgenomen.

Daarnaast wil ik de drie deelnemende ziekenhuizen, het Alexander Monro te Bilthoven. Rijnstate te Arnhem, Maxima Medisch Centrum te Eindhoven, en in het bijzonder de studiecoördinatoren aldaar, bedanken voor hun medewerking aan het onderzoek.

Ik heb ook veel mogen leren van de samenwerking met afgevaardigden van andere partijen, zoals kanker.nl, Integraal Kankercentrum Nederland (IKNL), Beroepsvereniging Verzorgen & Verpleegkundigen (V&VN) en Borstkanker Vereniging Nederland (BVN). Dank!

Graag wil ik de leescommissie, bestaande uit prof. dr. Yvonne Engels, prof. dr. Ellen Smets en prof. dr. Vivianne Tjan-Heijnen, bedanken voor het zorgvuldig lezen en beoordelen van mijn proefschrift.

Collega's van het Nivel, jullie wil ik bedanken voor de gezelligheid op kantoor. Désanne, hoewel we nooit intensief hebben samengewerkt, was je een heel fijn teamlid. Roland, als enige kamergenoot die van begin tot eind is gebleven, ben ik je dankbaar voor het altiid verbreken van de oorverdovende stilte in kamer 3.12. PVbestuursgenoten, wat hebben we een leuke tijd gehad tijdens de personeelsuitjes en het organiseren daarvan! Ik denk met plezier terug aan de silent disco tijdens de Nivel kerstborrel en de bungee jump in het klimbos.

Het grootste support systeem bevindt zich voor mij buiten het werk. Lieve familie, schoonfamilie, vrienden, buren die vrienden zijn worden, bedankt voor alle fijne momenten die we samen beleven. Een aantal mensen wil ik in het bijzonder benoemen:

Lieve Willeke, wat is het fijn om een vriendin te hebben die op meerdere vlakken hetzelfde pad bewandelt. Onze samenwerkdagen waren een welkome afwisseling in het eenzame bestaan als promovendus. Als kers op de taart zijn wij elkaars paranimf. Ik hoop dat we de komende jaren nog kilometers zullen zwemmen in de kletsbaan en nog liters koffie zullen drinken terwijl onze kindjes samen spelen.

Lot, mijn liefste zusje. Je weet niet half hoe veel onze hechte band voor mij betekent. Deze zal ik nooit voor lief nemen. Ik kan mij geen betere paranimf wensen dan jij. Love you! Bob, ik ben blij dat jij en Lotte elkaar hebben leren kennen. Bedankt voor je oneindige enthousiasme, zelfs als het over mijn werk gaat!

Lieve mam, pap & Marian. Het is niet vanzelfsprekend om twee plekken buiten je eigen huis te hebben waarvan je weet dat je er te alle tijde terecht kunt. Vanaf de basisschool, tot aan de universiteit, tot aan het schrijven van dit proefschrift, jullie hebben mij op alle vlakken onvoorwaardelijk ondersteund. Ik heb hierbij nooit enige prestatiedruk gevoeld en daar ben ik ontzettend dankbaar voor. Dit proefschrift draag ik aan jullie op.

Lieve Ruub, je bent niet alleen mijn verloofde maar ook mijn trouwe "collega" naast wie ik verreweg de meeste werkuren heb doorgebracht bij de totstandkoming van dit proefschrift. Eerst aan de keukentafel in ons appartementje in Utrecht, nu in ons thuiskantoor in Zwolle. Jij bent al 14 jaar mijn stabiele factor. Dank je wel voor je onvoorwaardelijke liefde voor mij en voor Floris. Ik hou van jou.

Mijn allerliefste Flo, het grootste geluk in mijn leven dat ben jij.

Marit







