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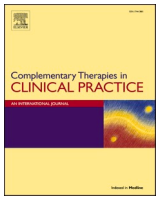

Communication and information about complementary medicine in a Dutch oncology setting: Interviewing patients and providers on their experiences and needs

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ABSTRACT

Background: Complementary medicine such as yoga, massage and art therapy has become increasingly popular among patients with cancer. However, the topic remains under-discussed during oncology consultations: patients seem hesitant to disclose complementary medicine use, and healthcare providers lack resources to discuss complementary medicine. This study aims to gain an understanding of how to improve communication and information provision in oncological settings about complementary medicine by assessing the experiences and needs of patients and healthcare providers.
Materials and methods: Semi-structured interviews were conducted with 17 patients with cancer and 13 oncology healthcare providers recruited from two general hospitals and one breast cancer center in the Netherlands. Nine (former) patients with breast cancer collaborated with the research team as 'co-researchers'. Reflexive thematic analysis was used.
Results: The main themes identified were barriers to patient-provider communication about complementary medicine (e.g. lack of time and knowledge among healthcare providers, negative attitudes toward complementary medicine), facilitators of communication (e.g. openness of healthcare providers, complementary medicine as a routine topic) and information provision needs (e.g. easy access to information, the hospital being involved in providing information).
Conclusion: Patients with cancer and healthcare providers report issues with the current approach to discussing complementary medicine and are of the opinion that complementary medicine should be a routine topic in oncology consultations. Future studies should focus on effective methods for standardizing complementary medicine discussions into oncology care and making reliable information available for patients and healthcare providers.

1. Introduction

In oncology, approximately 51 % of patients use complementary medicine [1]. Examples of complementary medicine are dietary supplements, yoga, massage or art therapy. In contrast to alternative medicine, which is used *in place of* conventional therapies, complementary medicine is used *together with* conventional medicine [2]. Patients with cancer use complementary medicine to relieve symptoms of the disease, side effects of treatment or to influence their general health [1]. Although complementary medicine is generally safe to use, some

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complementary medicines such as herbs can interact with chemotherapeutic agents [3]. The approach of using complementary medicine together with conventional medicine in a coordinated way is referred to as 'integrative medicine' [2]. Examples of clinical recommendations for integrative oncology are mindfulness-based interventions to relieve anxiety or depression or acupuncture for aromatase inhibitor-related joint pain [4,5]. The integration of complementary medicine in oncology care (i.e. integrative oncology) is highly variable between countries [6]. In the Netherlands, the services provided by complementary medicine practitioners are mainly in the private sector. A previous survey among oncology healthcare providers in the Netherlands showed that implementing activities related to complementary medicine into the healthcare programme is the exception rather than the rule [7].

Despite the high prevalence of complementary medicine use among patients with cancer, previous research has shown that this topic is not frequently discussed during oncology consultations [8,9]. Between 20 % and 77 % of patients with cancer do not disclose their use of complementary medicine to their healthcare providers [10]. Patient non-disclosure appears to be influenced by the nature of patient-provider communication, such as the healthcare provider failing to ask or fear of disapproval [10,11]. In previous studies, oncology healthcare providers stated they had limited time for discussing complementary medicine and lacked the knowledge to provide patients with information about complementary medicine [9,12,13]. The lack of communication about complementary medicine in oncology care can result in patients being exposed to misinformation on the Internet, as a previous study showed that online information about complementary medicine often contains unfounded claims [14]. 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. There has not been an in-depth assessment of communication and information provision about complementary medicine in Dutch oncology care.

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. Combining the perspectives of patients and healthcare providers will let us gain an understanding of how to improve patient-provider communication and information provision about complementary medicine. The results can be used in a follow-up study as input for the development of tools to support the conversation about complementary medicine during oncology consultations.

2. Materials and Methods

In this qualitative interview study, 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. Reflexive thematic analysis, a valid and widely used method for the analysis of interview data, was used [15,16]. To increase the 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 [17]. This study is part of a larger mixed-methods research project into communication about complementary medicine entitled 'COMMON' [18]. This study was exempted from formal approval under the Dutch Medical Research Involving Human Subjects Act by the Arnhem-Nijmegen Medical Ethics Committee, protocol code 2020–6917, August 17, 2020.

2.1. Participant recruitment

A combination of purposive and convenience sampling was used. Two general hospitals and one breast cancer center in different regions of the Netherlands agreed to recruit patients and healthcare providers. The participating hospitals were at various stages of development of initiatives for implementing complementary medicine in oncology care. At the time of data collection, Hospital A had been providing integrative medicine consultations to patients with cancer for some time. Patients with questions about complementary medicine that cannot be answered by their healthcare provider due to lack of time or knowledge can be referred to these consultations with a clinician specializing in complementary medicine. Hospital B had recently begun offering such consultations to interested patients, while Hospital C was in the process of setting up similar consultations for its patients. A study coordinator was appointed in each hospital. In hospital A, the study coordinator worked as trial coordinator at a general oncology department. In hospital B and C, the study coordinators were nurse practitioners of patients with breast cancer.

2.1.1. Patients

The patient inclusion criteria were 1) being actively treated for cancer or treated a maximum of 6 months ago, 2) aged ≥18 and 3) with a sufficient command of Dutch. The two nurse practitioners working at breast cancer clinics approached patients with breast cancer during checkup visits. The study coordinators were specifically asked to recruit not only female but also male breast cancer patients. The trial coordinator instructed oncologists and nurse practitioners who worked at the same oncology department to recruit patients face-to-face during checkup visits. The trial coordinator was asked to ensure recruitment of patients who varied in terms of sex and cancer type. The study coordinators provided patients with a study information letter (see Supplementary File 1). If patients were interested in participating and gave verbal consent to share their contact details, the study coordinators shared their contact details with the researcher (MM, female, M.Sc., researcher in training, field of Communication in Healthcare). The researcher contacted the potential participants by phone or e-mail and patients were given the opportunity to ask questions.

2.1.2. Healthcare providers

Healthcare providers were eligible to participate if they were 1) a nurse, nurse practitioner or physician, and 2) mainly treating patients with cancer. The study coordinators were asked to approach colleagues at their departments and give them a study information letter (see Supplementary File 1). If healthcare providers were interested in participating and gave verbal consent for sharing their contact details, the study coordinators shared their contact details with the researcher (MM). The researcher contacted the potential participant by phone or e-mail and healthcare providers were given the opportunity to ask questions.

2.2. Interview guide

For the semi-structured interviews, an interview guide (Supplementary File 2) 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 the expertise of the research team. The interview guide was supplemented and improved, based on feedback from the co-researchers. The final version of the interview guide covers three main topics: 1) experiences with communication about complementary medicine, 2) experiences with providing information about complementary medicine, and 3) the needs of participants in terms of the tools for supporting the conversation (both existing and yet to be developed). Given that it could not be assumed that participants would know the definition of complementary medicine, the first interview question was "How would you define complementary medicine?". If the definition given by the participant deviated significantly from that of complementary medicine as defined by the National Center for Complementary and Integrative Health (NCCIH) [2],

the researcher explained what constitutes complementary medicine before continuing the interview.

2.3. Data collection

The interviews took place between September 2021 and March 2022. Because of COVID-19 restrictions during that time, participants were allowed to indicate whether they preferred an online interview (via Zoom or Microsoft Teams) or a face-to-face interview at home. Preceding each interview, participants were asked to sign an online informed consent form and background characteristics were also collected through an online form. Participants were interviewed in Dutch by a researcher (MM or MB, female, M.Sc., psychologist) and a co-researcher. Participants had no prior acquaintance with the researchers and co-researchers who interviewed them. The co-researchers received an online training session on how to conduct interviews with healthcare providers and fellow patients, organised by an independent consultancy office with expertise in the co-creation of healthcare products and processes involving various stakeholders (IKONE [19]).

The researcher led the interview, and the co-researcher could ask the interviewee additional or in-depth questions at any time. The semi-structured interviews were audio-recorded. The audio recording of each interview was transcribed verbatim and the transcript was verified by the participant. After data saturation was reached (i.e. new data only ever repeated had already been expressed) 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 co-researchers were asked to share their experiences of co-interviewing with each other and the research team during an online evaluative session.

2.4. Data analysis

The transcripts were analysed using reflexive thematic analysis as described by Braun and Clarke [15]. This method involves an iterative process of coding and theme generation, ultimately producing a set of analytic themes that encapsulate patterns of meaning across the dataset. Using MAXQDA 2022 software, one researcher (MM) initially read and coded the entire dataset, allowing for an inductive approach where codes emerged directly from the data without preconceived theories [20]. The interview data from patients and healthcare providers were analysed as separate samples. To enhance the credibility of the findings, a second researcher (LV, female, PhD, experienced researcher, field of Communication in Healthcare) independently coded two transcripts. These initial codes were then discussed in detail with the main coder (MM) to resolve any discrepancies, refine the coding scheme, and ensure consistency in the application of codes across the dataset. This collaborative process led to the optimization of the coding scheme. Subsequently, MM identified thematic areas by grouping the codes, using the themes from the interview guide as framework for this process. To ensure the dependability and confirmability of the analysis, a conceptual coding scheme and thematic map were developed and then presented to the research team (SvD, female, PhD, experienced researcher and professor, field of Communication in Healthcare; JN, female, PhD, experienced researcher, field of Communication in Healthcare; ATB, female, MD, PhD, clinical oncologist; MB, LV) for feedback. During this meeting, the team reached a consensus on the final themes after a thorough review of the thematic map and the relationships between themes, ensuring that the themes accurately reflected the data. Given the significant overlap in the themes identified from the patient and healthcare provider datasets and to enhance the clarity and readability of the findings, the decision was made to merge the themes from both groups. Using the finalized coding scheme and thematic map, MM recoded all transcripts to ensure consistency and accuracy of the analysis. The final thematic map was further validated through an online session where co-researchers provided their interpretations and insights. To support the transferability of the results, representative quotes were selected from the transcripts to illustrate each theme, with translation from Dutch to English by a professional translation office to preserve the original meanings and context.

3. Results

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

3.1. Barriers to patient-provider communication about complementary medicine

When patients and healthcare providers were asked about their experiences of communication about complementary medicine during oncology consultations, two barriers kept recurring: 1) the lack of resources (both time and knowledge) among healthcare providers, and 2) negative attitudes towards complementary medicine.

Table 1
Participant characteristics.

Healthcare providers (n = 13)	N
Age	
Mean (SD), range	47 (11), 22-62
Sex	
Female	9
Male	4
Profession	
Nurse practitioner	5
Oncological surgeon	4
Nurse	2
Urologist	1
Oncologist	1
Years of experience in current profession	
Mean (SD), range	11 (7), 0.5–27
Recruited from	
Hospital A	6
Hospital B	4
Hospital C	3
Patients (n=17)	
Age	
Mean (SD), range	57 (10), 38-71
Sex	
Female	14
Male	3
Education (highest)[a]	
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
Recruited from	
Hospital A	6
Hospital B	6
Hospital C	5

[a] Classified according to the International Standard Classification of Education Fields of Training and Education (ISCED-F) 2013 [21]. Note: SD = standard deviation.

Table 2
Themes and subthemes extracted from the interviews and the main codes.

Themes	Subthemes	Main codes
1. Barriers to patient-provider communication about CM	• Lack of time and knowledge among HCPs for discussing CM with patients	• Lack of time • Lack of knowledge • (Lack of) education about CM • Expertise in CM
	• Negative attitudes toward CM at the HCP and hospital levels	• Scepticism • Alternative medicine • Patient assertiveness
2. Facilitators of patient-provider communication about CM	• Openness of HCPs to discuss CM with patients	• Open attitude • HCP's attention/ respect for patient's needs • Shift in attitude
	• CM embedded as a routine topic during oncology consultations, with initiation by the HCP	• Awareness of CM • Introduction (routine or not) • CM terminology • Initiation of topic • Preference for a specific HCP • Timing of discussion
3. Needs for information about CM	• Easily accessible overview of effective, safe and affordable CM options for patients with cancer	• Reliability of information (or not) • Safety of CM • Evidence/ effectiveness of CM • Costs of CM • Experiences of other patients
	• Involvement of the hospital in providing information about CM to patients	• Patients feeling on their own • Online information • Inclusivity when providing information • Interactive use of information

Note: CM = complementary medicine, HCP(s) = healthcare provider(s).

3.1.1. Lack of time and knowledge among healthcare providers

Both patients and healthcare providers stated there was not enough time to discuss complementary medicine during oncology consultations. Patients said they felt rushed during consultations, which left no scope to talk about complementary medicine. According to the patients and healthcare providers interviewed, nurses or nurse practitioners have more time reserved for patients than physicians, which facilitates communication about complementary medicine. When patients asked their healthcare provider about complementary medicine, they frequently observed gaps in their healthcare provider's knowledge. For instance, one patient described asking an oncologist whether supplements could be used alongside chemotherapy:

> "You're the specialist – what do you think about it? I got no answer then, which made me feel uncomfortable. I know she can't be expected to know everything, sure, but I do assume that if you're a specialist you should be thoroughly aware of what can and can't be done together with the drugs you're administering to me." (Patient 12)

A lack of knowledge of the healthcare provider seems to demotivate patients to talk about complementary medicine, as illustrated by the following quote from a patient who was asked whether she had discussed her complementary medicine use with her (conventional) doctors:

> "But I did keep suggesting it [Chinese herbal medicine] 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.

> "I don't expect my surgeon to know what kind of herbal tea I should take to help me sleep. […] People should stick to what they know." (Patient 5)

Many interviewed healthcare providers evaluated their knowledge about complementary medicine as insufficient, even among those who pursued education in the field of complementary medicine (e.g. basic courses or e-learning). Several healthcare providers interviewed evaluated their knowledge of complementary medicine as being insufficient. Some healthcare providers mentioned a need for more education about complementary medicine, whereas others felt that education or searching for information about complementary medicine was beyond their scope or too time-consuming:

> "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)

If healthcare providers were unable to support patients with questions about complementary medicine, they often sought assistance from colleagues with greater expertise:

> "If it's about very specific medication or something like that, or the medicines the patient wants to use, then I send them to the integrative medicine outpatient clinic, if I've any doubts. They simply know that kind of stuff better than I do." (Medical doctor 2)

3.1.2. Negative attitudes toward complementary medicine at the healthcare provider and hospital levels

When asked about their experiences with discussing complementary medicine during oncology consultations, the majority of patients interviewed were confronted with a negative attitude on the part of their healthcare provider:

> "Well, I kind of got the feeling that it was a bit of nonsense, to be honest. She wrote it down in my file, but yeah, gave very little, actually no response, so to speak." (Patient 14)

> "Well, actually, when I brought it up, I was made to feel like I was wrong" (Patient 5)

Some patients felt that their healthcare providers 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. When a patient was asked whether they perceived their healthcare provider as open to discuss complementary medicine, they responded:

> "No. I would expect them to think along with me to minimize the side effects." (Patient 16)

Although most of the patients interviewed 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 healthcare providers interviewed assessed themselves as having a negative attitude to complementary medicine, although some had the idea that colleagues might dismiss complementary medicine as nonsense.

"I know a lot of colleagues across the country who really think [about complementary medicine], what nonsense, they also believe it's quite pointless that we offer lifestyle consultations, while I think it will significantly contribute to recovery and is truly valuable." (Medical doctor 6)

It seems that negative attitudes expressed by colleagues can affect the behaviour of healthcare providers when discussing complementary medicine with patients, as for instance in the experience of a nurse practitioner who wanted to avoid going against a colleague:

"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 [patients] exactly the opposite." (Nurse practitioner 4)

Other healthcare providers interviewed described worries and resistance among the hospital board when trying to launch initiatives considering complementary medicine. For example, a nurse described that they have an external network of complementary medicine practitioners to refer patients to, but the hospital board did not want them to offer complementary medicine to patients in the hospital:

"Yeah, but internally – and I think that's a shame; it's also rather what our management are afraid of. They say it's fine to get involved, but you mustn't start giving it [complementary medicine] yourselves, actually applying it." (Nurse practitioner 1)

"When we'd started [doing consultations] … There was a lot of resistance too, of course, because people thought – well – that it's all a bit of quackery, isn't it? That's what comes to mind when you talk about acupuncture and mindfulness. The first day we put that in the newspaper or somewhere in a newsletter, several reflexologists wanted to join our team. That made the board of directors a bit nervous." (Medical doctor 1)

Some of the healthcare providers interviewed emphasised the importance of making a clear distinction between complementary medicine (i.e. alongside conventional treatment) and alternative medicine (i.e. instead of conventional treatment), to reassure the sceptics.

3.2. Facilitators of patient-provider communication about complementary medicine

The interviews revealed several facilitators of communication about complementary medicine that were related mainly to openness towards complementary medicine on the part of healthcare providers and routine introduction of the topic during consultations by healthcare providers.

3.2.1. Openness of healthcare providers

Patients and healthcare providers agreed that healthcare providers' openness to discussing complementary medicine during consultations is important. Patients desired to feel listened to when discussing complementary medicine with their healthcare provider, with attention being paid to the underlying needs of patients. When patients were asked what they expect from their healthcare provider in discussing complementary medicine, they stated for example:

"It's all about a way of listening, paying attention and seeing what a patient needs." (Patient 3)

"Well … that you also take a good look at what the patient actually needs." (Patient 13)

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 healthcare providers interviewed 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 could improve the patient-provider relationship or patients' trust in the general treatment process. It seems that healthcare providers explicitly expressing openness to complementary medicine can lower the threshold for patients to talk about it:

"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)

When asked about their experiences with discussing complementary medicine, several patients shared positive experiences:

"In our conversation, it was mentioned that the results, for example with acupuncture and cancer, are very positive. So that was mentioned to me. […] I thought that was really nice because then they don't dismiss it. You don't have to do it secretly either, so to speak. I've never had that feeling." (Patient 11)

"Acupuncture really helped me as well, so I didn't have to use any other medication in the end. And I mentioned that too. They are quite open about it, you know. And one nurse is different from the other, but I was always able to discuss it very well." (Patient 3)

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)

3.2.2. Routine discussion about complementary medicine initiated by the healthcare provider

The patients and healthcare providers interviewed stated that whether complementary medicine is discussed or not depends on the healthcare provider. Some of the healthcare providers interviewed said that they always consult patients about using complementary medicine,

while others said that they did not. A few of the healthcare providers interviewed highlighted the fact that patients do not always understand what the term 'complementary medicine' implies. Both patients and healthcare providers felt that healthcare providers often pose general questions about what patients are "doing themselves" alongside anticancer treatment or only ask questions about specific components of complementary medicine, such as lifestyle or supplements.

In most cases, the topic of complementary medicine was introduced on the initiative of the patient. Some of the patients interviewed felt retrospectively that they had missed out on potentially 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)

Almost all the patients and healthcare providers interviewed advocated embedding complementary medicine as a routine topic during oncology consultations, to ensure that all patients are at least aware of the existence of complementary medicine. Healthcare providers should be the initiators of this discussion and should put out feelers as to whether patient is interested in or needs 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, making the subject of complementary medicine more appropriate with them. Physicians seem to focus more on medical issues, treatment plans and patient safety. However, a large proportion of the participants argued that the type of healthcare provider who discusses complementary medicine is not important. Other factors such as the quality of the patient-provider relationship, the contact frequency or the healthcare provider's knowledge and time are reported by patients as affecting their preference for which healthcare provider they want to discuss complementary medicine with.

Between and within the patient and healthcare provider samples in this study, there was no agreement on the appropriate timing of a conversation about complementary medicine. However, immediately after diagnosis does not seem to be the ideal moment because patients are already overloaded with information at that point. However, one patient noted that this topic needs to be addressed at least early enough to avoid adverse interactions with anticancer treatment. Given that patient's 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)

3.3. Needs for information about complementary medicine

The Internet is a source of information about complementary medicine that is widely used by both 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.

3.3.1. Easily accessible information about effective, safe and 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 information about the safety of complementary medicine use in conjunction with anticancer treatment; about the evidence for its effectiveness, costs and reimbursement; and about other patients' experiences with complementary medicine. Some patients did not feel a need for information about the effectiveness or costs of complementary medicine.

Easy access to information about complementary medicine is crucial according to both the patients and the healthcare providers interviewed. Several healthcare providers mentioned the need for information about complementary medicine to be clustered in a single place instead of being scattered across national and international websites and databases. Healthcare providers preferred accessing information about complementary medicine online, either through a website or a mobile application. Patients and healthcare providers thought that information about complementary medicine intended for patients should be available not exclusively online but also on paper to include less digitally proficient patients. Some healthcare providers added that it was important to provide audio or visual information about complementary medicine to patients with low literacy or language barriers.

3.3.2. Involvement of the hospital in providing information about complementary medicine

Patients stated that their needs for information about complementary medicine are often not met by their 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 by patients as consuming time and energy, especially when exacerbated by symptoms caused by the disease or its treatment. Information about complementary medicine obtained from the Internet or from acquaintances is often contradictory, is overwhelming in its sheer quantity or questionable in terms of its reliability. Patients therefore envisioned a role for the hospital in providing information about complementary medicine, such as providing leaflets or a 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, involving 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)

The healthcare providers interviewed frequently stated that they would like to use complementary medicine information support tools in their interactions with patients, for instance for looking at it together during consultations. Some of the healthcare providers interviewed stressed that discussing complementary medicine during consultations should be leading and that information support tools should only be used alongside this discussion.

4. 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, both patients and healthcare providers identified similar barriers and facilitators with communication about complementary medicine and expressed the same need for better information provision on the topic. Barriers identified in previous studies such as scepticism and a lack of time and knowledge on the part of healthcare providers [9,12], seem still relevant. The results point to the need for open, routine communication about complementary medicine initiated by healthcare providers, and for clustering information about complementary medicine in a single place, with an important role for the hospital in disseminating the information.

The results showed varying experiences of patients with communication about complementary medicine in Dutch oncology care. The majority of patients had a negative experience with discussing complementary medicine with their healthcare provider. However, most of the healthcare providers interviewed perceived themselves and colleagues as being open towards complementary medicine, which was also found in a previous study among oncology healthcare providers in the Netherlands [7]. Notably, sceptical attitudes were mainly acknowledged in colleagues but not in themselves. The discrepancy between patients' and healthcare providers' perception of the healthcare providers' openness or scepticism towards complementary medicine might be explained by differences in communication style, in which healthcare providers are unaware of their own verbal or nonverbal expressions of scepticism when discussing complementary medicine with patients. The power imbalance between patients and healthcare providers might lead patients to perceive a lack of enthusiasm or cautiousness from healthcare providers as scepticism, especially if they feel vulnerable or dependent on the provider's approval. However, some of the patients and healthcare providers interviewed have noticed a shift towards more openness towards complementary medicine over recent years. The authors of a previous study conducted in the United States also reported a trend towards more positive attitudes to complementary medicine [22]. Another study showed that increased awareness and knowledge about complementary medicine among healthcare providers can lead to more positive attitudes [13]. Considering the high rates of complementary medicine use among patients with cancer [1], open discussion about the topic has a certain synergy to patient-centred medicine (i.e. healthcare providers addressing patient needs) [23].

The healthcare providers interviewed acknowledged they did not have the time and knowledge to discuss complementary medicine adequately with patients. The participants felt that healthcare providers are inclined to adopt a 'reactive style' to communicating about complementary medicine, i.e. the topic is only addressed when brought up by a patient. Previous literature also shows that patients are the main initiators of discussions about complementary medicine [8,9]. Both the patients and healthcare providers interviewed expressed the need for healthcare providers to adopt a more active style of communication about complementary medicine by embedding it as a routine discussion, to be initiated by the healthcare provider. Some of the participants interviewed thought that discussing complementary medicine was an activity better suited to nurses. According to them, nurses have more consultation time and a broader overview of patients compared to physicians. 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 much knowledge of the topic [13].

Despite two of the three hospitals providing complementary medicine consultations to patients with cancer at the time of data collection, the results of the current study show that most patients with cancer felt that information provision about complementary medicine was inadequate. Perhaps the complementary medicine consultations are not sufficiently brought to the attention of patients, or not all healthcare providers were well aware of the possibility to refer patients with questions about complementary medicine to these consultations. A lack of support from healthcare providers - whether real or perceived - may not only affect the patient-provider relationship [24] but could also compromise patient safety, for instance when healthcare providers remain unaware of patients using complementary medicine that interacts with anticancer treatment [3]. Especially given that approximately half of all patients with cancer use complementary medicine [1], it is important that the provision of information about this improves. The patients interviewed wanted to receive information about effective, safe and affordable complementary medicine, preferably from the hospital where they are being treated. Patients mentioned several options for information provision by the hospital, such as handing out leaflets or putting information about complementary medicine on the hospital website. According to some patients, if information was provided by the hospital, it could lower the threshold for patients to introduce the topic to their healthcare provider. Outside the hospital, it is conceivable that national cancer patient associations or online information platforms for patients could provide reliable, clustered information about complementary medicine. If reliable information about complementary medicine is made easily accessible, patients with cancer may become able to take an active role in discussing the topic with their healthcare provider. This is especially important as it cannot currently be assumed that complementary medicine will be addressed on the initiative of the healthcare provider.

Because of the lack of time and knowledge, most healthcare providers will need support when discussing complementary medicine. Education about complementary medicine is generally not part of medical or nursing school curriculums, although several educational programmes on complementary medicine for oncology healthcare providers are available [25,26]. However, not all healthcare providers have sufficient time or personal interest to pursue education in this field. Part of the solution is to refer patients to colleagues who do have such expertise and who provide consultations for patients who have questions about complementary medicine. Nonetheless, such experts will not be available in every hospital. To ensure that basic information about complementary medicine is accessible to all healthcare providers, the healthcare providers interviewed wanted an online overview of effective, safe and affordable complementary medicine, e.g. summaries of clinical recommendations from integrative oncology guidelines by the Society of Integrative Oncology (SIO) [4,5]. However, information about efficacy and safety is not available for all types of complementary medicine because grant funding for complementary medicine research is limited in Western countries, which leads to shortcomings in the

evidence for complementary therapies.

4.1. 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 the study's validity and relevance. The co-researchers actively collaborated with the researchers in establishing the interview guide, conducting interviews and interpreting the results. The presence of co-researchers at the interviews led to richer interview data due to the addition of questions from another perspective, namely that of healthcare users with their own experiential knowledge. On the other hand, the presence of co-researchers during the interviews could also have amplified socially desirable answers to the interview questions, especially in healthcare providers.

The three oncology departments from which participants were recruited had already established or were in the process of establishing initiatives about complementary medicine. They can be considered as early adopters, i.e. using new interventions before the majority. This probably led to selection bias, in which most of the healthcare providers interviewed were open to complementary medicine to some extent. In addition, most of the healthcare providers interviewed were female. Female healthcare providers have been found to be more likely to initiate discussions about complementary medicine [27] and to express positive attitudes towards complementary medicine compared to male healthcare providers [7]. The patient sample had a higher proportion of breast cancer patients because recruitment was primarily conducted through breast cancer clinics. Furthermore, female patients with high education levels were overrepresented. According to previous systematic reviews, this is a profile that is representative of complementary medicine users [1,28]. Most of the patients included in our sample were familiar with the use of complementary medicine. The selection bias above described increases the likelihood of patients and healthcare providers expressing opinions about barriers, facilitators and solutions for communicating and providing information about complementary medicine during an interview. Because the healthcare providers included had more positive attitudes towards complementary medicine than average, certain needs and experiences related to communication and information provision may not have been fully represented. The needs and experiences of participants recruited from hospitals without initiatives for complementary medicine may differ from those of participants recruited from hospitals that offer complementary medicine consultations, for instance. Selection bias can compromise the reliability of the results and it is important to take this into account when interpreting and generalising the study findings. Nonetheless, it is likely that the need for improved communication and information provision expressed by the patients interviewed can be generalised for the Dutch oncology setting as a whole.

5. Conclusion

This study showed that patients in oncology care are often dissatisfied with communication and information provision about complementary medicine. Patients experienced scepticism, a lack of knowledge and time when discussing the topic with healthcare providers. Both patients and healthcare providers felt that complementary medicine should be routinely discussed during oncology consultations, and initiated by the healthcare provider. There is a substantial need for improved access to reliable information on complementary medicine among patients and healthcare providers. Patients prefer their hospital to be involved in providing such information. Future research could explore how a standardized approach to integrating discussions about complementary medicine into oncology care practices can be developed and implemented. Additionally, it is important to investigate the most effective methods for making reliable information about complementary medicine accessible to patients and healthcare providers, such as implementing hospital-based information resources.

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CRediT authorship contribution statement

Marit Mentink: Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Project administration, Investigation, Formal analysis, Data curation. **Liesbeth van Vliet:** Writing – review & editing, Validation, Methodology, Formal analysis, Conceptualization. **Martine Busch:** Writing – review & editing, Methodology, Investigation, Formal analysis, Conceptualization. **Anja Timmer-Bonte:** Writing – review & editing, Supervision, Formal analysis. **Janneke Noordman:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Sandra van Dulmen:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Formal analysis.

Declaration of competing interest

The authors declare that they have no conflicts of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ctcp.2024.101916.

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