the Regional Cancer Center Stockholm Gotland. All physicians chose to be interviewed at their workplaces. An overview of patients' declined and accepted conventional cancer treatment are shown in Table 2, and reported CAM modalities are listed in Table 3. For all patients, at least 1 year had passed since both diagnosis and treatment decline (Table 3).

Table 2. Declined and accepted conventional cancer treatment among the 7 patients. Time since diagnosis and treatment decline in years. To avoid identification of participants, patient identification numbers are different from those presented in Table 3.

	Patient (*n* = 7)	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Declined conventional cancer treatment	Radiotherapy		X			X	X	
	Chemotherapy		X	X		X	X	X
	Hormone therapy	X			X	X		
	Other treatment	X						X
Accepted conventional cancer treatment	Surgery	X			X	X		
	Radiotherapy		X		X			X
	Chemotherapy		X					X
	Hormone therapy							X
	Other treatment		X					X
Time since diagnosis in years		1	6	16	4	3	10	7
Time since treatment decline in years		1	5	≥1[1]	4	3	10	7

[1]Unsure if chemotherapy had been recommended earlier; patient never accepted any chemotherapy.

Table 3. Reported CAM modalities among the 7 patients (categorized according to National Center for Complementary and Integrative Health). To avoid identification of participants, patient identification numbers are different from those presented in Table 2.

Patient (*n* = 7)	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Natural products							
Vitamins and minerals	X	X	X		X	X	X
Dietary supplements[1]				X			
Injections with mistletoe extract	X				X		
Herbal products	X	X	X		X		
Homeopathy						X	
Mind-body approaches							
Meditation				X	X	X	
Personal development				X		X	
Stress management					X	X	
Yoga		X		X			
Acupuncture			X	X			
Physical exercise							X
Qi gong		X					
Therapy sessions		X					
Other approaches							
Changes in diet	X	X		X	X	X	X
Hyperthermia		X			X		
Kinesiology		X	X	X			
Bioresonance			X				
Anthroposophic medicine					X		
Germanic medicine						X	
De-toxification therapies[2]	X	X					
Candida treatment[3]		X					
Oxygen treatment[3]		X					

[1]Dietary supplement was either reported in general terms or as products with constituents other than vitamins, minerals, or herbals (eg, omega-3 oils or probiotics).
[2]De-toxification treatments involving elimination of toxins from bowels, liver, or teeth.
[3]Further specification of what these treatments entailed is missing

Table 4. Categories and codes.

Categories	Codes
Divergent perspectives on treatment choices	Whish for treatment and care addressing illness and health
	Consequences of treatment choices and costs
	Diverging views on treatment choices
	Experiences of CAM and conventional treatment
Roles and power struggles in the patient-physician relationship	Roles in treatment decisions
	Power struggles and pushes toward extreme positions
Paving the way for improved communication in difficult treatment choices	Transparency and interest
	Respect and support

No patient expressed regret for their decision to decline (parts of) conventional treatment. An overview of categories and codes is shown in Table 4

We present our results in the different sections by starting with similarities in data from both patients and physicians followed by identified differences.

Divergent Perspectives on Treatment Choices

Treatment and Care Addressing Illness and Health

All participants expressed the importance of treatments (conventional and CAM) both to combat their cancer and to strengthen their health. Several patients emphasized their desire to take an active stance on their illness and treatment. For some, this included using lifestyle changes and/or CAM and addressing psychological and social aspects of cancer, eg, the role of resolving grief, fear, and conflicts. All patients expressed appreciation for the holistic aspects of care and criticized conventional cancer care for lacking a holistic perspective. Some of the physicians also recognized patients' desire for more holistic care:

> "They [patients] mention that they are more holistic in their… They believe in something other than just mutations, other things that improve their health…" (Male, 30-39, physician)

All physicians described being generally positive toward patients' treatment choices involving the use of mind-body practices. Some considered use of multivitamin/mineral supplements uncontroversial; others dissuaded patients from taking supplements during chemotherapy.

Consequences of Treatment Choices and Costs

Most patients and physicians spoke about the consequences and potential and actual costs involved in declining recommended oncological treatment and using CAM.

Among patients, the consequences of a treatment choice were often viewed in relation to their present state of health. For example, a man offered curative radiotherapy for prostate cancer weighed his current excellent health against the potential side effects and uncertain outcomes of the proposed treatment:

> "I have no symptoms. Do you seriously mean that I should mutilate myself? Just because you say so? When I don't have any symptoms, I have a good love life, no trouble peeing, and so on./…/ And besides, you can't say whether or not it will cure me. 'I have to say,' I told him, 'that's a really bad offer.' " (Male, 70-79, patient)

Several physicians, however, reasoned about the consequences of treatment decline in strictly medical terms: premature death, poorer quality of life, unnecessary suffering, or greater risk of relapse. Some voiced concerns that patients who traveled abroad to access CAM risked losing precious time with family or receiving low-quality healthcare. However, several physicians also expressed equipoise, saying one could never be sure what would be best for an individual patient, especially in palliative situations.

In terms of costs, all participants mentioned economic aspects. Most patients rather neutrally noted that CAM in general is expensive. Some said the cost led them to stop the treatment, while one patient called it an investment in health. In contrast, many of the physicians spoke about unwarranted costs for ineffective therapies, and the immorality of some CAM practitioners making false promises and putting a financial burden on patients. Some physicians, however, also stressed the importance of the patients' hope, and that CAM use often supported hope.

Most patients also described investing time in learning about cancer, conventional treatment, and CAM. For some this involved reading scientific literature, while others participated in courses. With a couple of exceptions, most physicians in this sample acknowledged knowing very little about CAM. A few described this as a problem while most did not. Most patients in this sample explicitly called for increased knowledge about CAM among physicians, and some criticized physicians harshly for their lack of knowledge.

Experiences of CAM and Conventional Treatment

All participants shared both positive and negative experiences related to both CAM and conventional cancer care.

In relation to the choice to decline conventional treatment, several patients emphasized positive experiences of CAM and negative experiences of conventional healthcare. Patients' positive experiences spanned over a continuum of well-being including vitality and a sense of meaningfulness, symptom relief, reduced pain, better sleep, and fewer side effects from conventional treatment. A few patients also mentioned improved outcomes in terms of longer survival than their doctors had told them to expect. One woman who was using multiple CAM products compared perceived positive outcomes of feeling good and strong, having less stomachache, and fewer side-effects to situations when she had not used CAM and experienced more symptoms:

> "I'm feeling so much better from this, and if I don't do all these things [CAM], all those I mentioned, then this medication absolutely do not work, my stomach gets hypersensitive and I have side-effects. But when I do everything right, then I feel really good and really strong." (Woman, 30-39, patient)

Several physicians acknowledged that some of their patients perceived benefits from CAM use and a few mentioned trajectories that were surprisingly positive in relation to the expected course of the disease. However, most physicians focused their discussions about CAM on negative experiences

and adverse consequences, such as lack of effect, side effects, or possible interactions with conventional cancer treatment.

Concerning the choice to decline conventional treatment, many patients referred to previous negative experiences of conventional therapies, such as side effects and troublesome experiences with healthcare professionals. Notably, only one physician reflected on the aspect of patients' previous negative experiences of conventional care presenting a possible reason to decline conventional treatment. Rather, most physicians discussed patients' motives for treatment decline as being related to a general lack of confidence in conventional healthcare.

Diverging Views on Treatment Choices

A majority of both patients and physicians expressed feeling frustration about certain diverging views on treatment choices. Most patients in this sample criticized physicians for being narrow-minded. They implied that physicians lacked curiosity about individual experiences; some attributed this to physicians' lack of knowledge about CAM, while others attributed it to the focus on purely biological explanations for cancer within conventional cancer care. Some physicians mentioned feeling frustrated by patients' explicit projections of them being narrow-minded or servants of the pharmaceutical industry. Some physicians expressed being reluctant to comply with what they sometimes perceived as orders from patients wanting to monitor the results of CAM treatments through unconventional lab tests and x-ray examinations. A few physicians said they found discussions about different treatment choices interesting and stimulating, albeit time-consuming.

While both patients and physicians emphasized the need for research on CAM, some patients questioned the research process and expressed concerns about the economic and structural disadvantages facing the evaluation of CAM, compared with research on conventional cancer treatments. Several patients had the impression that a potent pharmaceutical industry lobbied for its drugs and neglected CAM approaches. One woman specifically linked her decision to decline conventional treatment with her perception of a biased pharmaceutical industry with the primary goal of making money:

> "… to get back to why I made that decision [to decline conventional treatment]... the more I read that wasn't research reports from the pharmaceutical industry, which were biased, but all the other kinds of reports without financial interests but rather seeking the truth, yeah, then I understood that okay, there's a lot of power and money governing the cancer industry…" (Woman, 50-59, patient)

Roles and Power Struggles in the Patient-Physician Relationship

Roles in Treatment Decisions

Although most participating patients and physicians expressed that the final treatment decision falls to the patient, many pointed to difficulties when patients consider declining treatment; when CAM was considered as an alternative, this was even more problematic. For example, some patients described discussions about such decisions with their physician as deeply disturbing: they felt disempowered, with diminishing control of their lives and worth as human beings. While some patients initially expected physicians to be their consultants, some described forsaking this expectation and losing respect during treatment decision-making. One patient who had chosen to decline parts of the recommended conventional treatments and used CAM instead expressed frustration about some physicians' comments on her treatment choice:

> "Then I was completely drained, feeling awful and I remember one physician came into my room, he'd never met me before, he didn't know that much, he'd only read what I had done [CAM] and his first reaction was: 'You should know, that stuff you're doing, there's no statistics showing that it helps, it's useless." And there I lay, totally powerless and he doesn't know what thoughts I have about it." (Woman, 30-39, patient)

The quote above also illustrates some patients' expressed vulnerability, loneliness, and dependency on physicians' expertise. In parallel, some patients emphasized that using CAM required great courage due to the risk of feeling rejected or blamed by conventional care staff. Some physicians described patients' vulnerability in general terms, while others expressed this more specifically as connected to CAM use, eg, that patients may feel ashamed or even blamed by CAM therapists for not successfully completing a CAM regimen in case of lack of effect.

Most of the physicians mentioned the difficulty of imparting knowledge about the natural course of untreated cancer and its consequences in terms of suffering and a shortened life. Some also expressed an understanding of how difficult it could be for patients to grasp at the time of diagnosis when they experienced no or few symptoms.

Some physicians acknowledged the risk of being too pushy but emphasized their responsibility to make sure that patients understand the full implications of their choice.

> "… clearly you have to respect: people make their choices. You just want them to understand, have understood: It's your choice. I can't view it in any other way. You choose a life this short (showing a short distance with her hands) or you could choose this (hands farther apart). Is that really what you want?" (Woman, 50-59, physician)

Power Struggles and Pushes Toward Extreme Positions

Several patients described their encounter with physicians in terms of feeling verbally and non-verbally threatened with consequences unless they pursued cancer treatment. Several felt that physicians abused their power by not respecting patients' values. Some patients even described these situations as causing extreme distress, diminishing their respect for both the individual professional and the healthcare system, resulting in decisions to decline conventional cancer treatment. One man who was inclined toward curative radiation therapy for prostate cancer described how a disrespectful attitude from the physician/healthcare system pushed him to choose to decline conventional treatment:

> "They would have needed a completely different approach, to get me to… even just telling me 'Of course you can think

> it over,' and so on, meeting me halfway, but when I felt them being so darn assertive, something grew inside of me, and I thought goddammit I'll do the exact opposite." (Male, 70-79 patient)

Some physicians described similar situations as extremely challenging in terms of finding a balance between the need to be clear about their treatment recommendation while also having a duty to support a patient and to accept his/her treatment decisions even when this collides with their own recommendations. Such experienced difficulty is reflected in a quote by one physician:

> "It was not, it wasn't that good. I can't feel satisfied with myself. But I don't really know what I would have done either. I have thought about it so much that I almost get a lump in my throat when I think about it. It was difficult. Because I wanted to support her, I saw that she felt very bad…." (Woman, 50-59, physician)

Physicians described that they became defensive when they felt that their expertise was being questioned. One physician described this as adopting an uncomfortable role, a role perceived as too focused and defensive about the recommended treatment and thus, with less focus on supporting the patient. Thus, some situations seem to have triggered power struggles where both patients and physicians may have taken more extreme positions than they initially desired.

Paving the Way for Improved Communication in Difficult Treatment Decisions

Transparency and Interest

Even though several patients described negative reactions from healthcare staff when sharing their experiences around CAM, most wished to discuss CAM with their cancer care professionals. Some emphasized that genuine respect for the patient's experiences was a prerequisite for wanting to share those experiences. Some patients also expressed that it was important to them that their CAM experiences were correctly reported in the medical records.

Despite awareness of patients' frequent negative experiences of discussing CAM with healthcare professionals, several physicians stressed the need to show interest in this use. They also emphasized the importance of patients' transparency regarding the use of CAM both for the sake of mutual trust and to safeguard against interactions and side effects.

> "And I absolutely don't get angry if someone uses cannabis for… if it helps them. But I do get angry if they don't tell me so I don't understand the symptoms or the side-effects. No, that didn't turn out well. Yeah, that's one of the patients I remember where it didn't turn out well. We had a little falling-out./…/ I felt that he hadn't been entirely upfront with me." (Woman, 40-49, physician)

Importantly, however, some physicians mentioned avoiding asking patients about CAM because they lacked knowledge in the field.

Respect and Support

Several patients explained what kind of dialogue they would wish to have with their physicians when discussing treatment options. This included a respectful relationship with sufficient time and where they felt listened to. Their desire for support from healthcare professionals when making choices indicated a preference for shared decision-making. Some patients shared experiences of receiving such support from cancer nurses, CAM, and integrative medicine practitioners. Some physicians wished for better professional support, and an ability to offer patients a wider team of healthcare professionals with competency in CAM.

Discussion

This study highlights patients' and physicians' perspectives when patients decline conventional cancer treatment and consider CAM use. The results indicate tensions in the patient-physician relationship where both parties risk adopting more extreme positions than initially intended. Rather than reinforcing dichotomized attitudes of mistrust toward conventional cancer treatment and beliefs in alternative treatments, the results from this study point to a need for communication that embraces the complexity of these situations including patients' values and previous experiences.

Interestingly the results of this study, focusing on a small percentage of patients choosing CAM as an alternative, reiterates much of the reports from previous research exploring motives for CAM use as a complement to conventional cancer care. For example, patients' preference for care strategies encompassing both illness and health as seen in this study echoes previous research pointing to patients' attraction to CAM and criticism of conventional treatment.[17-20,32] As in previous studies on CAM use, patients in this study desired personal control of their treatment and health.[10] This is in line with current trends in healthcare including cancer care encouraging patients to be informed and active,[33,34] and has been shown to related to better clinical outcomes including survival.[35-39] In contrast to patients' desire to be active in treatment choices, our results suggest that patients did not feel respected when declining oncological treatment and using CAM, also previously shown.[22]

In line with previous research, this study highlights a dissonance between patients' wish to discuss CAM[1,4,40] with cancer care professionals, and professionals' lack of knowledge about CAM.[5,6,8,41] Many cancer patients do not disclose their CAM use to cancer care professionals,[3,4] often due to an assumed lack of knowledge about CAM.[3,40] Some physicians in this study acknowledged such gaps, while others felt no need for more knowledge.

Although disparate perspectives and assumed lack of knowledge play into the conflicts highlighted in this study, the results also indicate inadequate communication and power struggles between patient and physician as decisive factors. This is comprehensible, given reports of substantial discordance between patients and oncologists' regarding prognosis,[42] patients' preference for shared decision-making,[43] and the generally acknowledged need for improved patient-physician communication about life-threatening illness.[44-48] Our results show the importance of acknowledging multiple perspectives to improve these communications. This is confirmed by a scoping review[33] concluding that patient participation requires healthcare professionals to shift from "doing to" to "working with" patients, which includes sharing information, knowledge, and power. While patients declining conventional

treatment and using CAM clearly presented a severe challenge to many physicians in this study, treatment discussions may become easier if physicians can accept patients' reasons as value-driven rather than driven by goals.[22]

Research indicates a great need for information and support functions to help both patients and professionals make well-informed decisions.[5] Our results suggest that patients and cancer care professionals sometimes need support that goes beyond mere information about CAM treatments. When polarization might compromise the therapeutic relationship,[1] one-on-one decision-making coaching[49] may be the most appropriate. Such support must balance evidence-based information with an empathic discussion that respects individual patients' needs, preferences, and values.[50,51] Based on our findings, we suggest implementing general recommendations for how cancer care professionals should address their patients' CAM use and basic education on CAM as a starting point to be prepared for even more challenging situations.[2,5]

While the conflicts highlighted in this study are relatively rare, resolving them is likely to become more urgent as attitudes toward conventional cancer treatment among the general population may change. A US survey on cancer opinions showed that 39% of people believe that cancer can be cured through alternative practices alone.[52] Widespread use of and belief in alternative treatment has prompted medical professionals to replace the term CAM with CIM—complementary and integrative medicine—thus demarcating the use of these treatments as alternatives as a distinct phenomenon.[53,54] The concept of CIM also highlights complementary treatment strategies' compatibility with conventional care principles and paradigms, including evidence-informed treatment recommendations.[55] This is also in line with the definition of evidence-based medicine requiring "integration of the best research evidence with clinical expertise and patients´ unique values and circumstances." [56]

Methodological Considerations

Given limitations in the selection and inclusion of study participants, our findings are unlikely to cover all possible experiences related to patients' declining conventional treatment and using CAM. Especially, data saturation is clearly questionable given the small number of participating patients. Moreover, CAM use may have changed over time since our data collection. Nevertheless, there are striking similarities between our results and previous results[17-22,24,32,40,57] and we argue that our findings raise important new questions and perspectives for today's cancer care around these sparingly researched situations.

The transparent, systematic, framework analysis approach was found particularly appropriate given our multidisciplinary research team combining experience in qualitative methods and various professional backgrounds including oncology, palliative care, oncology nursing, and pharmacy.[27]

Conclusion

The results of this study highlighting both patients' and physicians' experiences of situations when patients decline conventional cancer treatment and consider CAM, exemplify the difficulty of shared decision-making in practice. To achieve shared decision-making in these clinically challenging situations when patients' and physicians' views on the best treatment option deviates the results here point to a need for the embracement of the complexity of these situations bringing attention to patients' values rather than reinforcing dichotomized attitudes of mistrust toward conventional cancer treatment and beliefs in alternative treatments. For this, improved knowledge among physicians about patients' values as well as about CAM is imperative.

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Conflict of Interest

The authors indicated no financial relationships.

Author Contributions

Conception/design: K.W., L.S., J.H.N. Provision of study material or patients: K.W., J.H.N. Collection and/or assembly of data: K.W., J.H.N. Data analysis and interpretation: K.W., J.H.N. Manuscript writing: K.W., L.S., P.F., J.H.N. Final approval of manuscript: All authors.

Data Availability

The data underlying this article cannot be shared publicly due to few study participants and rare conditions (treatment decline). The data will be shared on reasonable request to the corresponding author.

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