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Factors underlying the use of non-conventional medicine and forgoing biomedical treatment among patients with cancer – Recommendations for doctor-patient communication

Short title: Forgoing biomedical treatment among patients with cancer – Recommendations for doctor-patient communication

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Abstract:

The use of Complementary and Alternative Medicine (CAM) is increasing and a considerable number of patients forgo biomedicine, employing these non-conventional modalities as an alternative to orthodox cancer treatment. CAM use and motivations vary according to how and to what ends it is being used. Values, such as a preference for “natural” cures and lay theories of illness causation play a pivotal role in choice of therapy. These, in turn, affect and are affected by the manner in which the patient encounters and interprets information. CAM use may signify a point of tension in the doctor-patient relationship, as both parties are frequently reluctant to discuss the issue, albeit non-conventional modalities may pose threats to patient safety and thus warrant open communication. Extensive research in this particular area of medical communication is scarce, even more so concerning patients who forgo biomedical treatment completely. The following contains practical recommendations for communicating with patients at risk of declining conventional cancer treatment.

INTRODUCTION

The use of non-conventional diagnostic and treatment methods, that is, Complementary and Alternative Medicine (CAM), is increasing throughout the Western world ¹. Studies suggest CAM use is highest among middle-aged, wealthy, well-educated, Caucasian females suffering from breast cancer ¹⁻⁵. Reasons for using CAM in cancer include aiming to cure or inhibit the exacerbation of the disease and alleviating side-effects of conventional treatment ⁶. Non-conventional modalities can be employed in conjunction with biomedicine (complementary treatment) or instead of it (alternative treatment); the latter implies forgoing conventional cancer treatment. Albeit most patients consider non-conventional approaches as augmenting therapies, a growing number of individuals employ CAM to the exclusion of biomedicine. After a brief overview of the definition and prevalence of CAM, the following narrative review discusses motivations underlying the use of CAM modalities in cancer and factors behind forgoing conventional treatment. Finally, some specific recommendations for doctor-patient communication are disclosed and contextualized within the relevant literature.

DEFINING COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

CAM is most frequently defined as “non-conventional medicine”: modalities that do not comprise part of conventional medicine in a given country’s healthcare system. Yet, for the purposes of research and well-rounded understanding, it does not suffice to rely on just this. What is considered “conventional” can differ greatly depending on specific attributes of a healthcare system, as well as cultural, socioeconomic, and political factors. In a definition developed for the Cochrane Collaboration, CAM is described as “A broad domain of healing resources that encompasses all health systems, modalities, and practices and their

accompanying theories and beliefs, other than those intrinsic to the politically dominant health systems of a particular society or culture in a given historical period”⁷. This directs attention to the fact that CAM modalities are usually not only a product or service, but are embedded in a larger cultural system with specific values and practices. Furthermore, it is implied in the definition, that biomedicine is not always the dominant medical system of a country; in fact, according to 2005 WHO data, 80% of the world population relies on traditional, folk remedies as their primary source of healthcare⁸.

PREVALENCE IN CAM USE

Meta-analyses on the prevalence of CAM use are rare because such figures are not easily comparable on an international scale. A systematic review from 2012 revealed that the 12-month prevalence of CAM use in the general population varied from 9.8–76%¹. The high variance in the available prevalence estimates of CAM use limits the scope of conclusions that can be drawn. The variability of this is due to e.g. differing operationalizations, recall bias, and insufficient representation of countries in the study samples⁹. For example, making the distinction between complementary and alternative CAM use in operationalization is an important one, not only in terms of prevalence but also regarding patient motivations underlying its use. Non-conventional medicine is most frequently employed in tandem with biomedicine; while alternative use is less common, but still high, as this figure may reach 30% of all CAM users^{3,10}.

The majority of CAM users (69.4%) seem to exhibit a preference for one CAM modality, although employing several modalities is not uncommon either⁹. Those who select spiritual healing and acupuncture are more frequently reported to be alternative users compared to other CAM modalities (14.9% and 12.1%

respectively)⁹. CAM is most commonly used to treat chronic diseases and its usage is high among cancer patients^{9,11}. A systematic review and a meta-analysis revealed that CAM use among cancer patients has increased from an estimated 25% in the 1970s and 1980s to 49% after 2000¹², particularly among those with breast cancer (prevalence rate $\geq 40\%$)^{13–17}. Cancer patients in Europe seem to have higher odds of referring to mind-body practices compared to those with no health problems⁹. CAM use among cancer survivors is significantly higher than among cancer patients (66.5%, of which 43.3% employed CAM during the past year)¹⁸.

COMPLEXITY IN HOW CAM IS EMPLOYED

Understanding motivations underlying CAM use requires a level of complexity that accounts for differences in complementary versus alternative use vis-à-vis the specific illness and its clinical characteristics. For example, Astin showed that dissatisfaction and distrust in biomedicine (as a whole or with a specific provider) was a significant predictor of the alternative, but not the complementary use of non-conventional medicine. In alternative use, psychological constructs such as holistic thinking and spirituality were predictive¹⁰, although the few other studies examining this show varying results¹⁹. Furthermore, attitudes and behavior might differ a great deal, as there are a number of patients who would prefer to avoid pharmaceuticals, but due to their condition, are forced to adhere to conventional treatment. The illness in question is also essential to consider, e.g.: using acupuncture as an alternative to biomedicine in treating migraines or tendinitis is a different issue than treating appendicitis or cancer with solely acupuncture. Additionally, decision-making is time-sensitive and context-dependent²⁰; strategies may differ

in various stages of one particular illness or at the onset of a new symptom. Also, decisions (as well as their subsequent appraisal) regarding comorbidities may have a strong influence on each other ¹⁰.

Some authors argue that CAM users should be differentiated based on their level of commitment to CAM use, which is strongly associated with how much they identify with the sociocultural and behavioral environment of the CAM modality ²¹. Others would group CAM users based on their underlying motivations into the following three categories: CAM use stemming from worldview (principle-based), stemming from dissatisfaction with conventional medicine (frustration-based), and those just “shopping around” or using CAM out of curiosity (opportunistic use) ²². Making such distinctions can be a useful analytic tool, while keeping in mind that these typological lines may be blurred and categories may overlap (e.g. opportunistic use may frequently be prompted by some kind of dissatisfaction).

FACTORS UNDERLYING CAM USE

Patient motivations in CAM use are addressed by several hypotheses. The market niche hypothesis asserts that CAM appeals to patients in areas where biomedicine is perceived to be lacking: patient-centered care and the attribution of meaning to suffering ^{23–25}. Boon et al. take another approach by grouping aspects into “fixed decision factors” that the patient cannot change (e.g. demographic characteristics, comorbid conditions, disease status) and “flexible decision factors” (e.g. patient perceptions of conventional and CAM treatments, psychological needs) ²⁶. The Push and Pull dichotomy states factors can be grouped into the categories of “push factors” repelling patients from biomedicine (e.g. ineffective cure for their illness or severe side-effects) and “pull factors” drawing patients toward CAM ²⁷. The most prominent pull factor is “philosophical congruence” ²⁸, which occurs when a patient believes they have identified their own cultural

values in the sociocultural environment of a CAM modality. As CAM is often embedded in a distinct worldview, such congruence may occur in a wide variety of ways with an assorted constellation of values and attitudes.

According to a number of studies, the effects of values or beliefs eclipse patient dissatisfaction in motivations underlying CAM use ^{1,2,10,29}. Values that have been linked to increased CAM use include a preference for more control and empowerment in the illness experience ^{2,24,30,31} and in the practitioner-patient relationship ^{2,32,33}, as well as a marked need for social support ^{3,32}.

Many studies explore the correlations among CAM use and psychological constructs such as positive thinking ², optimism ^{34,35}, self-efficacy and agency ^{36,37}, as well as holistic thinking ^{38,39}. Yet such constructs differ in how they are defined and measured, suggesting that studies' use of identical construct labels does not necessarily imply that they are measuring the same phenomenon ⁴⁰. Thus, explaining CAM use in this manner may not provide the most accurate picture of patient motivations.

CAM has also been examined in correlation with Modern Health Worries (MHW) ⁴¹, beliefs concerning the perceived detrimental effects on health posed by modern, technological advances and devices, as well as urbanization. Items in the scale relate to environmental pollution, toxic interventions, radiation, and food additives. CAM use exhibits a positive correlation with MHW ⁴², as well as Medical Conspiracy Theories ⁴³ and somatosensory amplification ⁴⁴.

International studies have found that CAM users tend to retain a preference for the "natural", often defined as "clean", "healthy", and "not man-made" ^{36,45,46}. The "natural" may also be linked to dietary choices, such as consuming "organic" and "unprocessed" food that does not contain "toxins" or additives. Natural therapies are conceptualized as harmless and drawing on the body's "self-healing" mechanisms;

these therapies are usually equated with herbal, folk or traditional medicine ⁴⁷. With a preference for the natural in mind, pharmaceuticals may be seen as “chemicals” to be avoided ^{45,48}.

A widespread etiology among CAM users is the accumulation of “toxins” or “chemicals” in the body, which is conceptualized as an inevitable part of modern, urbanized life ⁴⁵. In fact, 15 out of 24 studies discussed in a systematic review of lay etiologies in breast cancer found that patients believed there was a connection between exposure to environmental toxins and their diagnosis ⁴⁹. A practice congruent with this etiology is “detoxification” via various diets and cleansing processes with the aim of regaining health and boosting the immune system. Siahpush argues that these attitudes may have a metaphoric element as well: if the body is seen as “part of nature”, it can be “polluted” similarly to environmental pollution ²⁹.

Several studies have found that the use of “natural products”, like vitamins and herbs, is prevalent among cancer patients (for example, 64-81% in the USA ⁵⁰, 32% in Japan ⁵¹, 43% in Germany ⁵²). Qualitative studies, such as Arthur et al.’s conducted with 23 cancer patients², emphasize lay associations between the “natural” and the “benign”, other studies highlight connections to perceived safety⁵³. Chemotherapy and radiation therapy, on the other hand, are frequently seen by cancer patients as “toxic” and hazardous ^{2,54}. Again, it is worthwhile noting that the construct of “natural” may differ among studies, some may only consider herbal products to be natural, while others also include e.g. massage and relaxation in this category.

Furthermore, studies have shown that lay psychosocial etiologies are strong predictors of CAM use ^{32,38}, which implies that the patient adheres to a (largely) unidirectional causality between “soul” or “mind” and body. In this worldview, psychosocial phenomena are believed to cause somatic illnesses, and congruently, healing is also accredited to psychological changes ^{29,47,55}. Psychologization is dominant in the

broader healthcare market of Western countries with many patients conceptualizing healing as the transformation of the Self through illness or “personal growth” ^{25,36,37,56,57}. Consequently, this etiology may cause the patient to see pharmaceuticals and biomedical procedures as inadequate treatment for somatic ailments that are “in reality” caused by psychosocial problems ^{25,47}.

A substantial portion of cancer patients attribute their illness to psychosocial factors. A systematic review on breast cancer patients reports that in 21 out of 24 studies psychosocial factors were among the most popular attributions ⁴⁹. Studies conducted with, for example, cervical cancer ⁵⁸ and lung cancer patients ⁵⁹ also confirm this, but attributions may differ widely based on sociodemographic and clinical variables. Furthermore, beliefs regarding the meaning or causality of illness may change in an individual over time. Additionally, a large number of cancer patients view their disease as a punishment for their own shortcomings, failings. Many studies investigate the adaptiveness of self-blame with ambiguous results, as self-blame can be adaptive via re-establishing the patient’s belief in a controllable environment, but it can also be maladaptive, leading to feelings of guilt, anxiety, depressive states, and increased self-stigmatization ^{49,59}.

DYSFUNCTIONAL CAM USE

Thus, for analytic purposes, CAM can be seen as embedded in a larger cultural system and retaining a sociocultural environment with specific values and practices. Non-conventional modalities may be employed in tandem with biomedicine as a complementary therapy, but can also serve as alternative treatments. The decision to employ non-conventional medicine is generally recursive in the patient journey, and it is time and context dependent. Although the complementary use of CAM is more common, patients may often

employ non-conventional medicine to the exclusion of biomedicine. Alternative use does not always pose a threat to patient safety, and its frequency is well illustrated by the fact that patients regularly attempt to treat most of their complaints and mild illnesses with home remedies or some form of self-healing ⁶⁰. Yet if patients refuse to undergo or elect to discontinue conventional therapy when faced with life-threatening disease, the exclusive use of CAM endangers the individual and can be referred to as “dysfunctional CAM use” ⁶¹.

Patients with cancer may employ CAM as a complementary therapy to inhibit the exacerbation of the disease, alleviate side-effects of conventional treatment, boost their immune system, gain a sense of control in their therapeutic process or experience increased social support through the sociocultural environment of a CAM modality ^{6,32}. Acting in accordance with a preference for “natural cures” or a lay theory of illness causation (e.g. attributing cancer development to psychosocial factors) may lead the patient to forgo conventional therapy if they see therapeutic choices as mutually exclusive. The decision to employ CAM (and in what way) depends on a myriad of factors, such as the ones discussed above. Another vital element in the decision-making process is the relationship between the cancer patient and their treating physician(s), which is crucially determined by doctor-patient communication. Communication is especially important if the cancer patient is at risk of declining conventional therapy; furthermore, poor communication can greatly contribute to their decision to forgo treatment ^{47,62}. Despite its pivotal importance, extensive research in this particular area of medical communication is scarce. Authors such as Frenkel et al. ^{63,64}, Verhoef & White ^{20,62}, Winslow & Shapiro ⁶⁵, Ge et al. ⁶⁶, Tenner et al. ⁶⁷ and Zörgő & Olivas ⁴⁷ have outlined specific recommendations based on empirical research. These are detailed below and contextualized within relevant literature.

RECOMMENDATIONS FOR DOCTOR-PATIENT COMMUNICATION

Talking about conventional therapy

Leave time after diagnosis

At the point of diagnosis, the patient is “run-over”, overwhelmed by information; as Koehler et al. put it: “the patient’s identity as a whole is altered by the global loss of their former references and orientation points”⁶⁸. The experience of hearing a diagnosis can denote a mental traumatization that requires emotional and intellectual processing. In their qualitative study with 31 cancer patients refusing one or more conventional therapy, Verhoef & White detail the accounts of patients being offered treatments “closely intertwined with the shock of diagnosis”, leading them to feel pressured into immediately complying with the conventional therapy⁶². There is evidence to suggest that the prospective assessment of a treatment, through anticipatory mechanisms and expectancy, can affect the experience of the therapy and its side-effects: low preference for a treatment mid-intervention can be associated with a lower quality of life, as well as worse nausea/vomiting and cancer symptoms^{69,70}. Thus, if a patient feels pressured into complying with a therapy, it may negatively influence future adherence, side-effect intensity, and treatment experience.

Do not employ “scare tactics”

Appeals to fear, messages aimed at changing behavior by creating anxiety, are widely used in health communication and public health initiatives. Yet, an article investigating 60 years of fear appeal research concludes that experimental evidence argues against the use of threatening health information⁷¹. The

patient perspective seems to correlate with this: using “scare tactics”, such as “If you don’t accept this therapy, you will be dead within a year”, tends to invoke resentment and diminishes trust in the doctor-patient relationship ⁶².

Be clear about side-effects

Side-effects exerting a negative impact on the patient’s physical, social, or emotional functioning may lead the patient to discontinue their therapy ⁷². In a qualitative study, Zörgő & Olivas found that patients often terminated their radiation or chemotherapy because they experienced novel somatic sensations, which they either felt could not report to their doctor (due to the perceived nature of the doctor-patient relationship) or tried to report them but were unable to (dismissed by the doctor as a moot topic). The authors also describe how patients who are asymptomatic at the onset of treatment may experience side-effects for the first time and interpret the sensations as therapeutic inefficacy or iatrogenic effect ⁴⁷. It is hence crucial to maintain a discussion about (both expected and unexpected) side-effects throughout the therapeutic process.

Talking about CAM

(Non-)disclosure of CAM use

Patients using CAM frequently do not inform their physician about the employed complementary therapy. Prevalence of non-disclosure varies greatly depending on country, illness, and prognosis, but studies indicate that 40-77% of CAM users keep this information from their treating physician ^{4,73–76}. According to a meta-analysis, CAM use in cancer ranged between 11-95%, while 20-77% of patients did not inform their physician

about the employed modalities⁷⁷, even though studies suggest physicians retain a strong interest in knowing whether their patient is using non-conventional approaches^{65,78}. Fostering a mere desire to talk about CAM may not suffice: for example, one study conducted with over 300 physicians in the USA found that although 84% wanted to know more about CAM, only 8% asked their patients about their CAM use, 17% never asked, while 52% asked their patients less than half of the time⁶⁵.

Initiate the conversation

From the patient's point of view, the prevailing reason behind non-disclosure is that they are afraid of the physician's reaction, their condemnation, or the patient believes the doctor is indifferent to their use of CAM. Other justifications of non-disclosure include: the doctor did not inquire about it, there was insufficient time to discuss it, or the physician would be incompetent in the subject^{4,37,47,75,77,79}. Whether the patient initiates or participates in such conversations depends on a variety of factors including: the level of trust in the doctor-patient relationship, effective communication strategies, societal and subcultural appraisal of the employed CAM modality, relationship between biomedicine and CAM in the particular healthcare system⁸⁰. Due to the fact that so many factors determine whether a patient discloses their CAM use or not, it is advised that the physician initiates the conversation and sporadically returns to this issue throughout the treatment trajectory.

Failing to discuss CAM use can pose dangers to patient safety through complementary substances adversely interacting with or hindering the efficacy of conventional treatment. Another issue is exemplified via a study conducted by Adler among breast cancer patients, 72% of whom employed a CAM modality. Only 54% of CAM users informed their treating physician about the non-conventional approaches, yet 94%

regularly discussed their conventional therapy and test results with their CAM practitioner⁸¹. This directs attention to the importance of establishing and cultivating trust in the doctor-patient relationship in order to maintain an unhindered flow of crucial health-related information and increase patient safety.

Ask about reasons for declining treatment

If the patient divulges that they are considering declining the conventional therapy, delving deeper into their rationale can be useful. The mere act of asking to know more about the patient's decision-making process and practicing active listening strengthens the therapeutic bond⁸². At this point, there is no need to agree or disagree with what the patient discloses. Active listening (listening and expressing attentiveness in a verbal and/or non-verbal manner) and the expression of empathy are essential in good communication, which in turn, translates into better adherence⁸³⁻⁸⁵. Opening a discussion about the advantages and disadvantages of each therapeutic option is also an excellent way to explore the patient's underlying preferences, assumptions, and fears.

Do not condemn the patient's decisions

According to cognitive dissonance theory, people select information congruent with their existing beliefs, because incongruence (i.e. dissonance) can lead to significant mental and physical discomfort^{86,87}. The information physicians provide the patient concerning both conventional and non-conventional therapies may be in dissonance with the knowledge and beliefs the patient already holds. Even from a trusted source, novel information aimed to change beliefs or behavior may achieve the exact opposite to its intention: it

may strengthen existing beliefs; this is referred to as the backfire (aka the boomerang effect) ^{88–91}. This has been well-observed with e.g. political convictions ⁹², conspiracy theories ⁹³, and vaccine hesitancy ⁹⁴.

In a situation where the physician retains a negative opinion on CAM and the patient is considering the exclusive use of non-conventional medicine, if the former states their opinion upfront, it may achieve pushing the patient more towards dysfunctional CAM use. CAM modalities serve certain psychological (e.g.: agency, social support) and physical needs (e.g.: side-effect alleviation, pain management), which the patient may feel are vital for their quality of life and survival. As discussed earlier, CAM use is frequently congruent with existing beliefs and attitudes; depending on the intensity with which the individual identifies with CAM, and (inadvertently) directing a negative comment at a stronghold of consonance may be interpreted by the patient as the physician “rejecting” them personally ⁴⁷. Thus, it is advised to take on a dialogic, rather than a didactic stance when talking about non-conventional medicine. Furthermore, such a dialogic approach may assist the conventional treatment by revealing clinically relevant information about side-effects, decreasing the chances of the patient employing therapies that interact negatively, and building rapport.

Offer counseling

Lay theories of illness causation and consequent therapy choice are influenced greatly by how individuals in the patient’s social network dealt with cancer ⁴⁹. Many patients decline treatment because they have lost a loved one who received solely orthodox cancer treatment and thus see the recommended therapy as ineffective or high-risk. A counselling session with an oncologist may help patients explore differences between their diagnosis and treatment plan compared to that of their family member or friend who died of

cancer⁶². To provide patients with additional aid, especially around the point of diagnosis, they can be referred to psychosocial support services.

Addressing information-seeking behavior

The lure of the internet

The patient normally has several sources of information at their disposal, such as physicians, family, friends, peers, and the internet. Illness behavior and therapy choice are governed to a large extent by how patients encounter novel information, judge its trustworthiness, and interpret its content^{95,96}. The majority of citizens in Western countries have internet access (81% in USA⁹⁷, 89% in EU⁹⁸), and a substantial proportion of those individuals perform searches concerning healthcare issues, especially symptoms and illnesses (USA: 72%⁹⁹). According to data from 2011, 26% of the US population had followed another person's illness experience in the past 12 months, 16% is a member of an online patient group⁹⁹. These groups are usually found on social media, which in itself is a prominent source of information for many; in the US alone, 81% of the population is registered on such a webpage⁹⁹.

In a milieu of profuse and polycentric information production extending into the healthcare sector also, patients not only gravitate towards do-it-yourself internet searches, but are often forced to be what Kelner calls "smart consumers"¹⁰⁰, orienting themselves among (oftentimes contradictory) healthcare information. These changing sociocultural and behavioral tendencies are also manifest in new patient roles and identities, such as the e-patient: equipped, enabled, empowered, engaged with their own therapeutic process¹⁰¹.

Filter bubbles

Albeit patients retain a marked need for performing internet searches, the concept and effects of a world wide web based on “relevance” is lessor known to them. Not only are various advertisements tailored to the individual’s preferences, but identical searches yield vastly different search results for users ¹⁰². Seeing as most internet users only browse the first page(s) of the search results, the order of presented content is pivotal. Due to the fact that the patient is most likely not aware of the notion of relevance, or does not know how to access the filters governing their query results, they do not perceive what Pariser calls the “filter bubble” around them, creating a self-reinforcing informational environment ¹⁰². Practically speaking, during everyday internet activity, the patient who previously searched for a CAM product (perhaps merely out of curiosity) will see advertisements for similar products (herbs, supplements, crystals, etc.). An individual interested in psychology, for example, who is suddenly diagnosed with an illness, may see more search results promoting “holistic cures” or CAM modalities focused on psychosocial aspects of illness. To the naïve user, these results appear to be the most popular webpages “objectively” the most relevant to their query. Filter bubbles can be considered a manifestation of the confirmation bias, i.e. the tendency to search for, interpret, favor, and recall information that affirms one’s prior assumptions ¹⁰³.

Echo chambers

Another manifestation of the confirmation bias is the echo chamber, whereby individuals make conscious (or subconscious) decisions to only subscribe to (sources of) information that are congruent with their own beliefs. For example, a study in 2016 scrutinized 376 million Facebook users’ relationship to 900 news portals and found that individuals searched for information that supported their opinion, ignoring conflicting

portals¹⁰⁴. The same filtering of information may occur regarding print and other media, as well as interpersonal relationships. These enclosures of information may create homogeneous cognitive stimuli, lead to self-reinforcing loops and informational determinism, which have a strong effect on decision-making in healthcare contexts as well. Regarding therapy choice, the patient will prefer the treatment congruent with their worldview^{60,100}, which in turn is largely defined by the individual's informational, sociocultural, and behavioral environment.

Advocate "smart searches"

Due to the present informational landscape, patients will most likely encounter information – both online and offline – that is congruent with their established worldview. Informational determinism can reaffirm convictions that lead to other biases and self-isolating behavior. On the other hand, the abundance of available information and the potential heterogeneity of content may cause mental fatigue and confusion²⁶. Notwithstanding, patients wanting to seek out information may have advantages as well; optimally, with more information they can make better-informed decisions, satisfy a need for cognitive closure and feel more secure about treatment choices²⁶. The outcomes of such searches rely on many factors, notably media literacy and health literacy.

Advising the patient against seeking information can be detrimental to the doctor-patient relationship as it might convey that the doctor does not trust the patient as a party in decision-making. In the process of informed decision making, the patient obtains information from the clinician and other sources also, then ideally this information is coupled with decision counselling to help patients understand potential risks, benefits, and uncertainties of clinical options¹⁰⁵. To aid the patient, they can be given tips on

finding trustworthy information, such as specific, medically reliable webpages and tools. Several, cancer-related decision aids exist for comprehensively comparing therapies and calculating risk.¹⁰⁵ Furthermore, patient critical thinking can be boosted by tips like 1) cross-check facts you find on the internet or opinions you hear about, 2) be conscious of the keywords you use to search for information (avoid suggestive phrasing, e.g.: disadvantages of X therapy). Additionally, it is important to inform patients about filter bubbles and the potential effects they have on searches. Countermeasures can be suggested, such as: use more than one search engine, use more than one computer and/or download a cache cleaner application to your PC – these will limit the effects of previous searches on new search results.

Addressing the patient's theories of illness causation

Meaning-making in illness

Illness frequently induces a loss of control¹⁰⁶, which may trigger a strong need for ascribing meaning to the illness experience in order to increase perceived control². Albeit this may aid disease management or even boost resilience³⁷, it can also lead to postponing help-seeking via meaning-making and the normalization of symptoms¹⁰⁷. In the patient journey, choices of therapy may be significantly influenced by the sociocultural aspects of CAM, namely, distinct worldviews and etiologies providing possible avenues of illness interpretation^{23,29,48}. Patients feeling dissatisfied with their diagnosis, prognosis, or aspects of medical communication (e.g. receiving “insufficient” information on their illness or experiencing a lack of empathy) may be especially prone to searching for novel interpretations regarding their disease and illness experience

Concepts of health and illness comprise a unified system with other, non-healthcare concepts and are in strong interaction with notions in the social network of the patient ¹⁰⁸. This conceptual framework and related attitudes are significant, as they influence the interpretation of symptoms, health and illness behavior, self-care, help-seeking, appraisal of sources of information, adherence, and coping ^{108–110}. Lay etiologies usually connote a distilled version of the patient's worldview and patients will tend to select a treatment that is congruent with their theory of illness causation ^{60,111}.

Listening to lay theories of illness causation

Creating a shared understanding about the cause and state of the disease, as well as its prognosis and management, is at the crux of doctor-patient communication ¹¹². The more complete the mutual understanding, the greater the chances of good cooperation. An effective way to enhance understanding and build trust is asking questions, probing the patient's views ¹¹². Schofield et al. analyzed 314 initial consultations between cancer patients and oncologists; references to CAM were made in 91 of these. Of 156 separate mentions of CAM, the vast majority were initiated by the patient; 101 instances were statements, 11 were questions directed to the patient, and in 44 instances, the doctor completely ignored the topic brought up by the patient ¹¹³. These results illustrate a hesitance in physicians to discuss the topic of CAM and to create room for questions and listening, rather than making statements. This type of communication may not be effective in reaching pivotal issues in illness attribution, CAM use, and interpersonal trust.

Addressing mutual exclusivity

Avoid dichotomous thinking

As discussed earlier, a patient may employ CAM for different purposes (alleviating side-effects, pain management, boosting quality of life, etc.), exhibit varying motivations (acting in congruence with attitudes or preferences, enhancing agency or control, etc.), and use CAM in two very distinct ways (as a complementary therapy or an alternative to biomedicine). These purposes, motivations, and types of use may change throughout the patient journey, as pertinent decisions are made continuously. Furthermore, these factors only become meaningful when weighed against the type of disease, prognosis, and available conventional treatments. CAM use can be dysfunctional if it endangers patient safety, for example, because non-conventional medicine is being employed as an alternative treatment for a life-threatening illness. This situation may occur if the patient and/or the doctor considers biomedicine and non-conventional medicine as mutually exclusive ⁴⁷. Such dichotomous thinking limits available treatment options and hinders the patient and physician reaching a consensus if treatment preferences differ.

Aim for integration and cooperation

Integrative medicine is gaining ground, especially in oncology ¹¹⁴; albeit, many physicians may feel uncomfortable discussing CAM or ill-equipped in advising patients on this topic (c.f. ¹¹⁵). The level of integration (in theory or practice) can differ greatly among individual physicians, hospitals, and healthcare systems; and logically, integration is not always preferred with every CAM modality/product regarding every disease. Healthcare professionals who employ CAM themselves are generally more likely to discuss or

recommend CAM to their patients^{65,115}. Bearing in mind that mutual exclusivity hinders communication and limits therapeutic options, aiming for some level of integration is a more productive strategy. At the very least, a cancer patient leaning toward the exclusive use of CAM can be reminded that various therapies may be used in tandem. In this context, this is a reasonable claim even for a physician who does not feel comfortable recommending CAM. Another strategy for low-level integration may be to unearth the (psychosocial and clinical) needs of the patient who is leaning towards dysfunctional CAM use and invite the patient to explore alternative (conventional and non-conventional) strategies for meeting those needs. Higher levels of integration can be achieved through cooperation with CAM specialists who are involved in the patient's care. Merely communicating with each other in such a situation, maintaining an unimpeded flow of information, increases patient safety. Finally, integrative medicine is a viable option for oncologists interested in combining non-conventional and conventional treatment methods within their practice.

Leave the door open

If the patient has made the decision to forgo conventional cancer therapy, encourage the patient to stay in contact to maintain ongoing follow-ups and have an opportunity to change their mind about their treatment choice⁶². In a qualitative study, Boon et al. expound several examples of prostate cancer patients feeling rejected and left to their own devices after making a decision to decline one or more biomedical treatments²⁶. If all contact is severed with a patient, the chances of them reconsidering their decision decreases and several issues in patient safety may arise.

(insert Panel 1 here – see end of manuscript)

Panel 1: Recommendations for Communicating with Patients at Risk of Forgoing Conventional Cancer
Treatment

Conclusions

CAM may denote a point of tension in the doctor-patient relationship, as both parties frequently have reservations about discussing non-conventional modality use. Most cancer patients who employ CAM do so in tandem with biomedicine; although less frequent, such usage may pose risks to patient safety via causing adverse interactions or hindering the efficacy of conventional treatment. There is a considerable number of patients who forgo biomedical treatment in order to exclusively employ non-conventional therapies; if this occurs when faced with life-threatening illness, it can be considered dysfunctional CAM use. Inadequate doctor-patient communication may lead to diminished trust and an impeded flow of information. These spur patient non-disclosure regarding CAM use and the autonomous modification of conventional treatment regimens or trajectories. In order to strengthen the doctor-patient relationship and ensure patient safety, further research is needed to explore and expound recommendations for medical communication in this area.

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WAIT, ASK, LISTEN	
Leave time after diagnosis	<ul style="list-style-type: none"> -Before talking about treatment options, allow the patient some time to absorb the diagnosis and adjust -If treatment is offered too soon, the patient may feel pressured to accept and this may have a negative effect on treatment experience and adherence
Listen to the patient's theories of illness causation	<ul style="list-style-type: none"> -The patient will gravitate towards treatments that are congruent with their lay etiology -Establish trust through listening; no need to agree or disagree with the patient, just acknowledge their perspective
Initiate the conversation about CAM	<ul style="list-style-type: none"> -Both patients and doctors may be reluctant to discuss CAM use, the treating physician should initiate the conversation and inquire regularly -Patient safety depends on the physician knowing about complementary therapies
Ask about reasons for declining treatment	<ul style="list-style-type: none"> -Dig deeper into reasons for declining biomedical treatment; do not dismiss patient rationale -Active listening and the expression of empathy are essential in good communication, which in turn, translates into better adherence
INFORM	
Do not employ "scare tactics"	<ul style="list-style-type: none"> -Avoid statements such as "If you don't accept this therapy, you will be dead within a year." -Appeals to fear are largely ineffective and diminish trust in the doctor-patient relationship
Be clear about side-effects	<ul style="list-style-type: none"> -Inform the patient about the side-effects of conventional treatment, and be ready to discuss them as they arise -This is crucial, as patients asymptomatic at the beginning of conventional treatment might attribute side-effects to the treatment being "ineffective" or "noxious"
Offer counseling	<ul style="list-style-type: none"> -Many patients decline treatment because they have lost a loved one who received solely orthodox cancer therapy and thus see the recommended treatment as ineffective or high-risk -Offer patients counseling to help them explore the differences between their diagnosis and treatment plan compared to that of their loved one
Advocate "smart searches"	<ul style="list-style-type: none"> -In most cases, the patient will perform searches on the internet and try to gather information on treatment options and outcomes -Encourage seeking information, but warn the patient about filter bubbles and biases; help them to be critical with information they encounter and find trustworthy sources of information
INTEGRATE AND COOPERATE	
Aim for integration	<ul style="list-style-type: none"> -Regardless of what level of integration a physician is comfortable with, it is productive to avoid dichotomous thinking concerning conventional and non-conventional medicine because it limits therapeutic options and hinders communication -If the patient considers biomedicine and non-conventional medicine as mutually exclusive, reinforce that various therapies may be used in tandem
Do not condemn the patient's decisions	<ul style="list-style-type: none"> -If the patient is still deciding, do not condemn CAM, as this strong negative opinion may beget the patient's condemnation toward biomedicine -While in the process of decision-making or even after a choice has been made, do not condemn the patient's decision or threaten to refuse future treatment; identify and acknowledge the clinical/psychological needs the patient is trying to meet with CAM
Leave the door open	<ul style="list-style-type: none"> -If the patient has made the decision to forgo conventional therapy, encourage the patient to stay in contact to maintain ongoing follow-ups and have an opportunity to change their mind about treatment
Aim for cooperation	<ul style="list-style-type: none"> -Be open to communicating with CAM providers who are involved in the patient's care; this will boost trust in the doctor-patient relationship -Emphasize that an unimpeded flow of information is necessary for the patient's safety