

How to Find an Alternative: A Typology of Cancer Patients' Information Behavior With Regard to Complementary and Alternative Medicine

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Abstract

To participate in a shared decision making process, cancer patients need to gain an adequate understanding of their illness and the options for treatment. Complementary and alternative medicine (CAM) holds particular challenges for them. Due to a lack of evidence-based information, it is often difficult for doctors to guide patients in this field. Patients are hence frequently compelled to gather and evaluate information on CAM on their own, making their information behavior crucial to reach informed decisions. We therefore examine what types of information behavior cancer patients apply with regard to CAM. In this, we drew from literature on general and cancer-specific information behavior for our theoretical framework for analysis. In semi-structured interviews, we asked 50 cancer patients about their information behavior with regard to initiating factors, information needs, information strategies, selection, use and evaluation of information sources, and consequences of their information behavior. On this basis, we derived a qualitative typology of cancer patients' information behavior with regard to CAM based on the categories analyzed. We discuss how different types of information behavior may influence patients' empowerment in the decision making process and outline implications for CAM-related health communication to improve informed decision making.

Keywords: information behavior, patients, cancer, complementary and alternative medicine, qualitative typology

The common ideal of a shared decision making process – in which patients become more involved and that is supposed to lead to better treatment decisions, higher therapy compliance and more effective outcomes (Rimer, Briss, Zeller, Chan & Woolf, 2004) – requires patients to gain an adequate understanding of medical information of their illness and the options for treatment. However, patients usually have little to no prior expertise in these fields (Schiavo, 2014). One area that holds particular challenges for them is *complementary and alternative medicine (CAM)* in oncology. CAM is a “term for medical products and practices that are not part of standard medical care” and refers to treatments that are used with or instead of standard therapies (National Cancer Institute, 2015), such as acupuncture or homeopathy. On average, 35.9 per cent of cancer patients in Europe use CAM (Molassiotis et al., 2005). Nevertheless, due to a lack of evidence-based information, it is often difficult for doctors to guide

patients in this field (Dooley, Lee & Marriott, 2004), which is why many oncologists foster a “culture of ‘pervasive silence’ and ‘professional disinterest’” (Evans et al., 2007, p. 2). Accordingly, patients can rarely rely on doctors as their information source (Molassiotis et al., 2005), but instead need to gather and evaluate information on CAM themselves, e.g. through different media or from interpersonal sources. How patients deal with information on CAM therefore determines their ability to make informed decisions in this field of medical uncertainty. This makes it necessary to identify different types of information behavior that may help understand how patients deal with information on CAM and how informed decision making may be improved. We thus ask: *What types of information behavior do cancer patients apply with regard to CAM?* To answer this question, we empirically construct a typology of information behavior with regard to CAM that is informed by previous literature on (cancer-related) information

behavior and builds on semi-structured interviews with cancer patients. Based on this typology, we draw conclusions for adequate health communication in the context of medical uncertainty, as well as directions for future research.

Literature Review

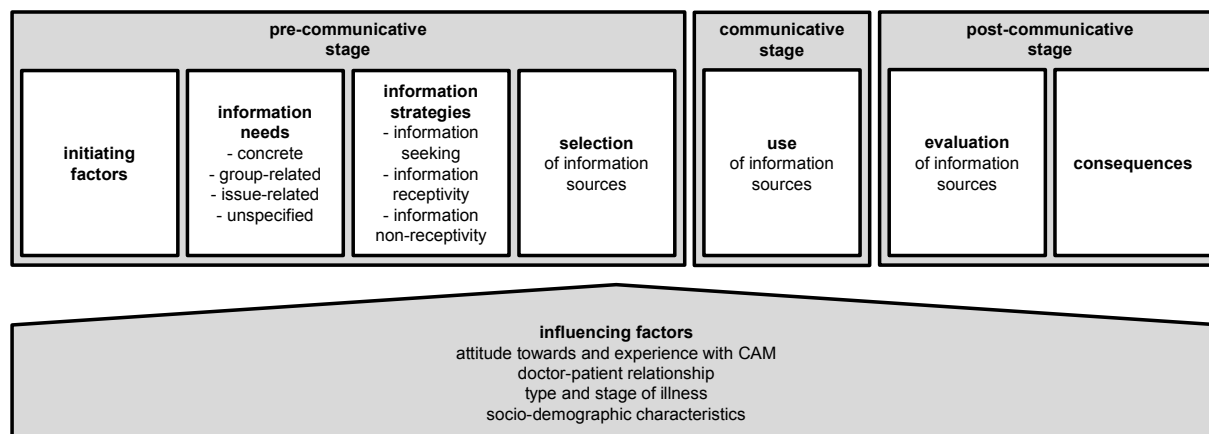
Information behavior may be understood as “the totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use” (Wilson, 2000, p. 49; comp. Case, 2002). *Illness-related information behavior* then focuses on information on a particular illness and its treatment. It can be understood as adaptation to extrinsic uncertainties (Atkin, 1973) and knowledge gaps (Dervin, 1989) caused by the disease and is “one of the primary functional coping strategies that individuals have at their disposal” (Johnson, Meischke, Grau & Johnson, 1992, p. 186).

Even though there is only a small number of studies on cancer patients’ information behavior with regard to CAM (e.g. Broom & Tovey, 2008; Verhoef, Mulkins, Carlson, Hilsden & Kania, 2007; Verhoef, Trojan, Armitage, Carlson & Hilsden, 2009), there is an extensive body of research on (cancer-related) information behavior in health communication (e.g. Johnson, 1997; Johnson, Andrews & Allard, 2001; Johnson & Meischke, 1991). Most of these studies, however, focus on active *information seeking behavior* (Marton & Choo, 2012), leaving aside passive aspects, such as unintentionally coming into contact with or trying to avoid information. Furthermore, existing studies on

cancer-related information behavior mainly focus on isolated dimensions (e.g. information needs or sources; Finney Rutten, Arora, Bakos, Aziz & Rowland, 2005; Maddock, Lewis, Ahmad & Sullivan, 2011) rather than refer to overarching theoretical frameworks.

To better understand the complex entity of information behavior, we therefore synthesize a theoretical model for our analysis that follows a *communication perspective* (see Figure 1). It is structured along the established differentiation of communicative behavior into a *pre-communicative*, a *communicative* and a *post-communicative stage* (Levy & Windahl, 1985). The dimensions of the model are drawn from existing theoretical frameworks (Galarce, Ramanadhan & Viswanath, 2011) and empirical studies. At the pre-communicative stage, there are certain (internal or external) *initiating factors* for patients that result in particular *information needs* (e.g. Maddock et al., 2011; Tariman, Doorenbos, Schepp, Singhal & Berry, 2014). Patients then apply specific *information strategies* (e.g. Atkin, 1973; Czaja, Manfredi & Price, 2003; Evans et al., 2007; Wilson & Walsh, 1996) to fulfill these needs, in the process *selecting* certain media or interpersonal information sources (Broom & Tovey, 2008; LaCoursiere, Tish Knobf & McCorkle, 2005). At the communicative stage, patients then actually *use* this information (e.g. Mayer et al., 2007; Verhoef et al., 2009). Finally, at the post-communicative stage, they *evaluate* the information and sources used (e.g. Verhoef et al., 2007) and draw *consequences* with respect to the information received and future information behavior (e.g. Czaja et al., 2003; Evans et al., 2010).

Figure 1 Model of information behavior



(Source: Own figure)

We outline the state of research on each dimension regarding the information behavior of cancer patients, where possible with respect to CAM.

Pre-communicative Stage

Initiating factors

Despite a substantial body of literature on cancer patients' information needs (e.g. Tariman et al., 2014; Verhoef et al., 2009), little is known about the factors that initiate particular needs. We consider *internal factors*, e.g. self-efficacy, and *external factors*, such as suggestions from doctors, relatives, or other patients as well as media reports.

Information needs

In empirical studies on the information behavior of cancer patients, different types of information needs are usually listed simply by theme. For a more structured approach, we here adopt a general model of information needs from Hasebrink and Domeyer (2010) (comp. van der Rijt, 1998). It differentiates four levels of information needs with respect to increasing problem specificity regarding the situation and persons affected: *Unspecified needs* exist when a person does not look for concrete information, but rather monitors his/her environment for information that may potentially be or become relevant to him/her. They may include needs for general information on the field of CAM in the context of cancer (e.g. to get an overview or monitor new developments). *Issue-related needs* describe active orientations with regard to specific issues to gather advanced expertise in these areas. They include needs for information on certain aspects of CAM in general (e.g. side-effects of CAM) or on specific CAM treatments (e.g. mistletoe). *Group-related needs* are directed towards information from and about people from relevant (peer) groups. They consist of needs for information on relevant groups in the context of CAM and cancer (e.g. experiences of other patients). *Concrete needs for problem solving* finally emerge in specific situations in which individualized information is required. They relate to information needs on concrete aspects of a certain CAM treatment in a specific situation (e.g. on the side-effects of a certain CAM treatment in a particular stage of illness).

Empirical studies show that cancer patients have a very broad range of information needs, ranging from unspecified information (e.g. general information on CAM in the context of cancer) to issue-related information (e.g. on specific treatment options) to group-related information (e.g. on support groups), and concrete information (e.g. on side-effects of specific

treatments) (Maddock et al., 2011; Tariman et al., 2014; Verhoef et al., 2007, 2009).

Information strategies

While most work on information behavior focuses on how people actively search for certain information (Case, 2002), we may identify at least three kinds of information strategies (Atkin, 1973; Wilson & Walsh, 1996): 1) *Information seeking* relates to active, usually need-driven behavior to search for certain information. It can be further specified into *active search*, "where an individual actively seeks out information" (Wilson & Walsh, 1996, p. 21), and *ongoing search*, "where active searching has already established the basic framework of ideas, [...] but where occasional continuing search is carried out to update or expand one's framework" (Wilson & Walsh, 1996, p. 21). 2) *Information receptivity* refers to a passive behavior where people do not look for particular information, but rather come into contact with it. It can be further specified into *passive search*, which "signifies those occasions when one type of search (or other behavior) results in the acquisition of information that happens to be relevant to the individual" (Wilson & Walsh, 1996, p. 21), and *passive attention*, "such as listening to the radio or watching television programs, where there may be no information-seeking intended, but where information acquisition may take place nevertheless" (Wilson & Walsh, 1996, p. 21). 3) *Information non-receptivity* finally comprises kinds of behavior that people apply when they do not want to come into contact with information. It can be specified into *information yielding*, where people try to yield certain information, but do not take efforts to avoid it when they are confronted with it, *information ignoring*, where people do not pay any attention to certain information, despite being confronted with it, and *information avoidance*, where people undertake efforts not to come into contact with certain information (Atkin, 1973, p. 238). Most studies on the information behavior of cancer patients focus solely on information seeking aspects (Czaja et al., 2003; Evans et al., 2007; Johnson, 1997; Mayer et al., 2007; Verhoef et al., 2007, 2009).

Selection of information sources

Selecting information sources is a crucial aspect of information behavior in an area of limited medical evidence. Since it is particularly difficult to select online information sources on CAM, cancer patients tend to be rather critical and highly selective and make source credibility an essential aspect of their selection (e.g. by searching for institutionally affiliated sites; Broom & Tovey, 2008; LaCoursiere et al., 2005).

Communicative Stage

Use of information sources

While cancer patients generally prefer information from their doctors, many of them use additional information sources (Mayer et al., 2007). With regard to CAM treatments, however, their use of information sources differs (Molassiotis et al., 2005): friends (56.5%) and family (29.1%) are referred to as the most common sources of information on CAM, followed by the media (28.4%). Patients' physicians (18.6%) and CAM practitioners (12.9%) play a minor role (though physicians and conventional care centers are highlighted as the most desired sources of CAM-related information; Verhoef et al., 2009).

Post-communicative Stage

Evaluation of information sources

In their evaluation of CAM-related information sources, cancer patients express "frustration about the overwhelming amount of available information and [find] it difficult to identify reliable information" (Verhoef et al. 2007, p. 345). Besides reliability (e.g. in supporting them to arrive at a treatment decision; Verhoef et al., 2007), cancer patients consider evidence an important aspect in evaluating information sources (Verhoef et al., 2009). Evaluations differ depending on patients' experiences with CAM (Verhoef et al., 2007).

Consequences

While cancer patients tend to have high information needs during the treatment of their disease (Ernst, Schröder, Schwarz & Brähler, 2009), and their information behavior may also result in increased medical knowledge (Evans et al., 2010), their wish to actually participate in treatment decisions is less pronounced (Ernst et al., 2009), but rather variable (Degner et al., 1997). The wish for information and the wish to participate in medical decisions are therefore not equivalent (Czaja et al., 2003).

Method

Data Collection

Data was gathered within an interdisciplinary research network on CAM in oncological contexts. In semi-structured interviews, we asked 50 cancer patients about their information behavior regarding the dimensions of the theoretical model. On average, interviews took $M = 43.5$ minutes ($SD = 16.8$ minutes).

Sample

37 women and 13 men at an average age of 60 years (range: 34 to 83 years; $SD = 12.1$ years) were

interviewed. About half of them were diagnosed with breast cancer ($n = 27$) and seven with prostate cancer. Other patients suffered from a broad range of other cancer types. Most interviewees were in follow-up care ($n = 32$), 14 were still receiving treatments and four patients stated they had completed therapy as well as aftercare.

Data Analysis

Interview transcripts were anonymized and coded with deductive and inductive codes using qualitative analysis software (*MAXQDA 11*). We aggregated single cases (patients) to multidimensional patterns sharing similar characteristics of information behavior (i.e. types) in four prototypical steps (Kuckartz, 2010): first, we defined a set of criteria to differentiate and cluster individual cases. These primary criteria are based on the pre-communicative and communicative dimensions of the proposed theoretical model of information behavior. We focused on information needs and strategies (as central categories reflected in most research on information behavior that offer a compromise between reducing complexity and being highly informative) before considering other dimensions. Post-communicative dimensions from the theoretical model were used as secondary criteria to characterize types in more detail. Secondly, we created a tabular one-page summary for each case along the theoretical dimensions by retrieving and aggregating relevant codings. Case summaries were grouped in an iterative process by a team of four researchers with respect to the primary criteria, until a satisfying clustering of all cases was reached. Cases subsumed under a resulting polythetic (or "natural") type did not have to be identical with regard to all relevant criteria, but are characterized by a high internal homogeneity and a high external heterogeneity (Kuckartz, 2012). Thirdly, we created type summaries by describing all groups with respect to both constituting and descriptive criteria and chose appropriate group names. Finally, we compared all case summaries to all type summaries to check for adequate grouping.

Results

Based on our analysis, we identified nine different types of information behavior among the patients interviewed (see Table 1). We characterize each type by giving a *summary* of its overarching features and outlining shared *characteristics* of the respective patients, and then discuss the *implications for health communication* to adequately anticipate the information behavior of the individual type.

Table 1 Typology of cancer patients' information behavior with regard to CAM.

Type of information behavior	1) Generally Interested Non-users	2) Active Multipliers	3) Critically Steadily Interested Patients	4) Conversation-oriented Information Seekers	5) Generally Interested CAM-users	6) Doctor-focused Patients	7) Well-informed Patients During the Acute Phase	8) Concrete Occasional Seekers	9) Information Seekers During Rehabilitation
Number of patients (n)	6	2	5	4	19	3	4	4	3
Pre-communicative stage									
<i>initiating factors</i>									
personal contact (non-professional), e.g. other cancer patients, friends and family	x	x	x		x			x	
personal contact (professional), e.g. doctors or alternative practitioners					x	x	x	x	
“professional” contact with other patients		x							x
reduce side-effects of standard therapy		x	x	x			x		
general trust in alternative methods					x				
wish to become more active, support body, prevent relapses			x				x		x
contact during rehabilitation				x					
disappointment with standard therapy					x				
prior knowledge of CAM									x
search for alternatives					x				
<i>information needs</i>									
concrete						x		x	x
group-related						x			x
issue-related	x	x	x	x	x	x	x	x	x
unspecified		x			x	x	x		
<i>information strategies</i>									
<i>information seeking: ongoing search</i>		x	x		x				
<i>information seeking: active search</i>		x	x	x	x	x	x	x	x
<i>information receptivity: passive search</i>	x		x	x		x	x		x
<i>information receptivity: passive attention</i>	x		x		x	x		x	
<i>information non-receptivity: info. yielding</i>							x		
<i>information non-receptivity: info. ignoring</i>									x
<i>information non-receptivity: info. avoidance</i>							x		
<i>selection of information sources</i>									
based on trustworthiness		x							x
based on evidence, reliability, independence, plausibility			x					x	
based on professional trust in doctors						x	x		
Communicative stage									
<i>use of information sources</i>									
internet		x	x	x	x	x	x	x	x
general printed media (e.g. books)	x				x	x	x	x	x
patient and medical journals	x	x		x	x		x		x
information material		x			x		x		x
TV								x	
oral presentations	x				x		x		
talks with doctors	x			x		x			x
talks with friends and family	x			x		x			x
talks with other patients (e.g. support groups)		x		x	x				

Generally Interested Non-users (n = 6)

Summary. Generally Interested Non-users are rather open-minded regarding CAM, but usually do not use it because they strongly trust in standard methods.

Characteristics. These patients got in contact with CAM because of their own diagnosis or through other cancer patients who already had experiences with CAM. They have issue-related needs including a general interest in CAM as alternative therapies, especially their advantages and disadvantages: "Well, I found the topic fascinating, [...] because I honestly know way too little about it." (female, 52 years) Therefore, they search passively and pay attention to CAM in media and personal interactions. Media sources are mostly printed material such as patient magazines, brochures, daily newspapers or books. Rather common for this type is also listening to oral presentations about CAM and talking about it with doctors, friends and family. Nevertheless, interviewed patients mention neither evaluating the information obtained nor the consequences of their information behavior.

Implications for health communication. Generally Interested Non-users have an interest in CAM but are not very active in gathering information on the topic. Health communication should therefore proactively provide these patients with overview information on CAM using rather general media formats (e.g. television broadcasts) to facilitate informed decision making.

Active Multipliers (n = 2)

Summary. Working for a cancer patient organization or support group encourages Active Multipliers to constantly monitor and seek a range of information on CAM.

Characteristics. Negative side-effects of standard therapies induced these patients to search for alternative methods. Their friends suggested certain CAM therapies. Their "professional" contact with other patients in support groups requires broad knowledge to be able to share information on CAM. They hence have unspecified and issue-related needs, especially regarding new therapies (e.g. mentioned by other patients in support group sessions). To meet these needs, they search the internet, patient and medical journals as well as information material from trustworthy organizations (e.g. cancer associations) or medical books. Parts of this ongoing search are also discussions with and input from support group clients. Active Multipliers are very sensitive to the quality of CAM-related information and critically reflect on new information. Due to their professional interest and experience, they know about the difficulties in distinguishing "good" from "bad" information and put together an information repertoire that fits their individual

quality requirements. If they still have questions on a certain CAM method, they also ask their doctors for explanations: "I have certain information sources to gain information on this topic. If I do not understand certain aspects, I consult local doctors and complement their information to teach it to others in an adequate way." (male, 63 years)

Critically Steadily Interested Patients (n = 5)

Summary. Critically Steadily Interested Patients have high information needs right after they are diagnosed and maintain the high level throughout their illness. In this, they critically reflect information on CAM.

Characteristics. These patients came into contact with CAM in a personal context (e.g. through their own or their relatives' prior experiences). They want to use CAM to become active by strengthening their immune system or restoring balance and well-being, and apply CAM complementarily to standard care to reduce the side-effects of standard treatments. These patients share an issue-related need for information on specific CAM treatments such as mistletoe and its application. They search for information to meet their high information needs on an active and ongoing basis, and also passively search for or are attentive to CAM-related information. These patients typically use a broad range of information, including a multitude of websites. In this, they critically reflect the information with regard to evidence, reliability and independence. Critically Steadily Interested Patients are very thoughtful in their evaluation of the broad range of mediated information. They typically highlight a small set of sources they rate positively, while critically reflecting other sources with regard to both positive (e.g. well-structured factual information, written by doctors) as well as negative aspects (e.g. not understandable for lay persons, commercial interests): "So, I think I read a lot about it [...]. Regarding some points, well, I often encounter advertisements and then I consider, I am not so sure what to think about this." (female, 43 years) These patients typically consult their doctors after finding information on a specific CAM treatment that might be relevant for them.

Implications for health communication. Critically Steadily Interested Patients already show a high ability to make informed decisions. Health communication measures may additionally support them by providing evidence-based and rather detailed information on CAM.

Conversation-oriented Information Seekers (n = 4)

Summary. Conversation-oriented Information Seekers usually obtain information in personal interactions.

Characteristics. These patients mostly want to ease the negative side-effects of applied standard therapies and seek alternative methods. They often came into contact with CAM during rehabilitation. They have issue-related information needs, especially on existing kinds of CAM methods and their effects. Conversation-oriented Information Seekers actively search the internet or read magazines and also passively search for information in personal conversations, e.g. when discussing new information on CAM with their doctors or talking with relatives or other cancer patients: "Well, this originated from the people you got to know. [...] We exchanged information and then you asked your doctor." (male, 76 years) Contact with other patients can also be mediated, e.g. via an online forum. These patients sometimes read or hear contrary information on CAM that confuses them. Some of them do not feel well informed about CAM. Nevertheless, they also take media reporting on particular CAM methods as an occasion to give them a try.

Implications for health communication. Conversation-oriented Information Seekers mostly rely on interpersonal information sources. Health communication should aim to make these patients sensitive to the quality of different information sources, support them by providing criteria to evaluate the gathered information, and encourage them to contact their doctors in case of uncertainties.

Generally Interested CAM-users (n = 19)

Summary. Generally Interested CAM-users are very interested in CAM and use a broad repertoire of sources to acquire information on different aspects of it.

Characteristics. Many patients in this group generally trust alternative methods and/or came across CAM through recommendations from their doctors, alternative practitioners or other cancer patients. Some of them are also disappointed by standard methods and are looking for alternatives. They are hence interested in a general overview of CAM (unspecified needs) and information on the advantages and disadvantages of certain methods (issue-related needs). Usually, these patients search for information on an active and ongoing basis. They also passively absorb information on CAM from their environment. These patients accordingly use a broad variety of media and personal sources: online sources include *Wikipedia*, internet platforms on CAM, *YouTube* (e.g. instructions for yoga practices) and online communities. They also read patient magazines, information material and books on CAM in general or on particular therapies. Some of them also visit conferences and presentations. Several patients are members of a support group and/or communicate with other patients

via *Facebook*. Generally interested CAM-users are sometimes overwhelmed and irritated by contradictory and complex information on CAM that is, to some extent, hard to understand. Even patient magazines are not always perceived as easy to comprehend. Still, these patients are inspired by media coverage on CAM, discuss it with others or even try new CAM methods they hear about in the media.

Implications for health communication. Health communication should make Generally Interested CAM-users aware of criteria to evaluate the broad range of information sources they use. Since they apply CAM treatments, they should be encouraged to discuss CAM with their doctors and contact them in case of uncertainties, and at least to let them know about the methods they use to prevent unhealthy interactions.

Doctor-focused Patients (n = 3)

Summary. Doctor-focused Patients concentrate on their doctors when it comes to CAM and their information behavior is closely oriented towards their doctors' recommendations.

Characteristics. These patients came into contact with CAM when their doctors recommended it: "My oncologist said [...] I should take this. Since then, I apply it in addition to my other treatments." (female, 70 years) While they passively search for CAM-related information (e.g. in talks) and are passively attentive to information on CAM during their general media use (e.g. when reading newspapers), these patients also actively search for CAM-related information and, in this, mostly refer to doctors as information sources (either via personal consultations or via websites of doctor associations). For Doctor-focused Patients, mediated information on CAM plays a minor role. They highlight that some mediated information is hardly useful to patients and that too much information may rather overwhelm than help them. After considering information from doctors (and sometimes also media), they apply selected CAM treatments: "I simply relied on the doctor, what he said or recommended." (female, 70 years)

Implications for health communication. Since Doctor-focused Patients strongly rely on their medical experts, health communication measures should make doctors aware of the interest that patients have in CAM treatments and of the relevance of fostering their competency for doctor-patient communication in this field.

Well-informed Patients During the Acute Phase (n = 4)

Summary. Patients of this group actively and intensely look for comprehensive information on CAM during the acute phase of their illness. Afterwards, their

information needs decline and they become rather non-receptive to CAM-related information.

Characteristics. The information behavior of these patients is usually initiated by health practitioners recommending CAM to them. They want to become active and to support their body and use CAM as a complement to standard care to reduce side-effects, such as headaches. During the acute phase of their illness, they are in need of a broad range of information. They look for information on CAM in general (unspecified needs) as well as for information on specific CAM treatments (issue-related needs). Therefore, they usually actively and intensely search for comprehensive information on particular treatments, and also passively search for CAM-related information in a variety of sources. While using a range of different media channels (including online resources (e.g. discussion boards) and offline resources (e.g. presentations)), all patients also refer to print material such as books, information leaflets or patient magazines. After the acute phase of their illness, information needs decline substantially and patients become rather non-receptive to CAM-related information. Some of them yield new information (because they have become more used to their situation), while others even try to avoid it (to prevent confusion): "While in the beginning I thought that I really had to inform myself about everything, after a couple of years I became more sober-minded or calm." (female, 57 years) Patients in this group evaluate media information on a differentiated level with respect to its credibility and usefulness. They prefer information from sources in which doctors are involved (e.g. information material from cancer organizations or patient magazines edited by doctors). Based on intense searches, these well-informed patients knowingly select and apply particular CAM treatments.

Implications for health communication. Well-informed Patients During the Acute Phase have high information needs in one stage of their illness and treatment but very low information needs in others. Health communication measures should consider these changes and anticipate and point out what information is relevant at which stage of illness and treatment.

Concrete Occasional Seekers (n = 4)

Summary. Concrete Occasional Seekers generally show rather passive information behavior. However, when they encounter information that is potentially relevant to them, they look further for concrete CAM-related information.

Characteristics. These patients came into contact with CAM in a personal context, e.g. because relatives used CAM during cancer treatment or doctors pointed them towards CAM. They typically have issue-

related and rather concrete information needs to solve specific problems, such as answering detailed questions, particularly on their individual situation, or clarifying certain CAM-related terms. These patients are typically only passively attentive to CAM-related information, such as to recommendations, and limit their active searches to concrete information they need in a specific and individual situation: "So, I really only read on the internet if I want to know something very specific." (female, 72 years) Besides being attentive to CAM-related information on TV broadcasts, these patients use the internet to conduct searches for specific information. They pay attention to plausibility and evidence and try to avoid non-credible sources of information. They evaluate mediated information on CAM rather negatively, in that it is not very useful to patients or might even become a mental burden. Their information behavior does not increase their use of CAM, but they state either that mediated information had no influence on their decision to use CAM, or that they even refrained from using CAM treatments after reading information on it.

Implications for health communication. Since Concrete Occasional Seekers show high information needs regarding specific aspects during particular periods of time, health communication should foster their competency to find rather specific information (e.g. by giving overviews on promising search strategies) and make them aware of quality criteria to evaluate information they find.

Information Seekers During Rehabilitation (n = 3)

Summary. Information Seekers During Rehabilitation already have some knowledge about CAM when they receive their diagnosis, so they do not have high information needs during the acute phase of their illness. However, during rehabilitation they develop a growing need for information and actively and passively search for it.

Characteristics. These patients hold a job in health care and therefore already had some prior knowledge on CAM. They typically turn to CAM in order to become active (e.g. reduce stress) and to prevent themselves from relapses. When diagnosed, Information Seekers During Rehabilitation were rather non-receptive to additional CAM-related information: They were either so convinced of a particular CAM treatment that they did not feel the need for further information, or they were too overwhelmed by the diagnosis to develop information needs, and therefore ignored CAM-related information. In rehabilitation, these patients developed information needs with regard to particular CAM treatments in general (issue-related needs), providers of certain CAM treatments (group-related) or particular aspects of certain CAM treatments such as mode of operation and

different kinds of mistletoe (concrete needs for problem solving). They then actively sought information about particular treatment options and respective providers (either in personal conversations with relatives, acquaintances or doctors, or on the internet), and passively sought CAM-related information in personal talks. They primarily use printed information material (such as books, information leaflets and patient magazines). Their internet use is rather restricted and focused on concrete tasks. These patients are critical in their evaluation of information sources and state that mediated information is often difficult to understand, not balanced or even contradictory. They tend to have a small set of sources for mediated information on CAM that they consider credible, such as websites and information leaflets of cancer associations. In the conducted interviews, patients of this group hardly reflected the consequences of their information behavior (e.g. on treatment decisions).

Implications for health communication. Health communication measures should proactively provide these patients with CAM-related information during rehabilitation, especially regarding CAM options that support fast recovery from cancer treatment itself. Communication measures should also stress the importance of telling their doctors about applied methods to prevent unhealthy interactions of treatments.

Discussion

In this paper, we developed a qualitative typology of CAM-related information behavior that presents different patterns of how cancer patients deal with information in an area of medical uncertainty.

For our *theoretical background*, we combined different dimensions of existing theoretical frameworks and empirical studies on cancer-related information behavior. Results show that these aspects are well-suited to qualitatively describe and structure illness-related information behavior. The explorative qualitative approach also revealed several aspects that proved to be particularly relevant and should be further investigated in future studies: For some groups of patients, the *temporal dimension* of their information behavior was essential. They showed a particular information behavior in a certain stage of their illness and its treatment (e.g. Well-informed Patients During the Acute Phase, Information Seekers During Rehabilitation) or in specific situations (Concrete Occasional Seekers). Subsequent studies might therefore focus on particular information-related actions in specific situations rather than describing the information behavior of different patients as a whole. Furthermore, the general *repertoire of information sources* a patient uses before his/her diagnosis seems to play a crucial part in selecting

illness-related information sources (e.g. due to evaluations concerning trustworthiness). To reduce complexity, we did not consider *intervening aspects* in our analysis (e.g. personal attitude towards CAM, doctor-patient relationship). In addition to these factors, information behavior may also depend on the *cultural system* in which it takes place, as well as on the *health system* of the individual country.

From a *methodological perspective*, the derived typology can function as a link between hermeneutic procedures focusing on understanding a single case and statistical procedures aiming at correlations (Kuckartz, 2012). It reduces complexity and facilitates health communication practitioners in drawing conclusions. The typology does not, however, allow for representative statements as our sample was limited to 50 self-selected patients. Self-selection might also be the reason why many patients reported a high interest in CAM and used a broad variety of media channels to retrieve information on CAM.

Conclusion

This study showed that there are different ways in which cancer patients deal with CAM-related information. The derived typology of CAM-related information behavior may inform adequate health communication measures to improve informed decision making in this field of medical uncertainty. Patients of each type of information behavior may be addressed by specific communicative measures. On a more general level, overarching key points for health communication in the context of CAM can be identified based on the type-specific implications derived:

Fostering information competencies of patients. Several types of information behavior are characterized by using a broad repertoire of information sources and by uncertainties in evaluating the multi-faceted information gathered. It is therefore necessary to foster patients' competencies in searching for qualitatively good information, e.g. by providing information seeking strategies to find rather specific information. Health communication may also help patients to evaluate information from different (media and interpersonal) sources by making patients sensitive for the quality of different sources and can provide quality criteria and seals that assist in evaluating information (e.g. HON Code). Fostering patients' information competencies is particularly important since our results show that information sources play an important role in encouraging patients to gather information on CAM and sometimes also to apply certain CAM treatments (even without consulting their doctors).

Strengthening interaction between patients and doctors. In line with existing research (e.g. Molassiotis et

al., 2005), our results show that there are several types of patients who hesitate to talk about CAM with their doctors but rather decide on their own what treatment to use (often due to a perceived lack of knowledge or support from their doctors). Health communication should encourage patients to discuss CAM with their doctors, to contact them in case of uncertainties and to at least tell them what CAM methods they are using to prevent unhealthy interactions of treatments.

Fostering communication competencies of medical experts. Acknowledging patients' interest in CAM requires doctors to "become well versed in the methods of obtaining information in this area and the quality of the available information sources" (Dooley et al., 2004, p. 118). Increasing the "awareness by medical practitioners of the need to ask their patients about CAM" (Dooley et al., 2004, p. 117) may prevent misuse of CAM due to a lack of communication. It is hence necessary to foster doctors' competencies in interacting with and guiding patients in this area of medical uncertainty, e.g. by offering courses on communication about CAM. Furthermore, health communication measures could provide information for medical professionals who are not yet experts as regards CAM, but need to find adequate and evidence-based information they can then pass on to their patients. This proves particularly important for patients who largely depend on their doctors to gather information on and make treatment decisions with regard to CAM. This holds true for patients who prefer doctors as their most trusted source of information (Doctor-focused Patients), but also for patients who would otherwise avoid looking for respective information (e.g. because they feel overwhelmed by media information on CAM) and therefore depend on information that is directed towards medical practitioners who can then pass it on to them.

Proactively providing information. Since some types of patients do not actively search for CAM-related information but are interested in the topic once they know about it, it is important to proactively provide them with information on CAM. Here, initial information may be on a rather general level so patients get a first overview on the topic and may then decide whether they want to gather more information on specific aspects, thereby fostering their autonomy. In proactively providing information on CAM, health communication measures have to consider the different ways in which patients inform themselves and get in contact with medical

information (e.g. by providing information via different media channels and also in talks with medical practitioners).

Providing information at different levels of complexity. Our typology implies that patients have needs for information at different levels of complexity. Health communication measures should therefore also provide information on CAM at different levels of complexity, e.g. via an online information platform. This way, offering various text versions might be an option to provide Generally Interested CAM Users with overview information, while providing others, such as Concrete Occasional Seekers, with very specific information on certain CAM treatments and contact information of approved health practitioners.

Considering different stages of illness and treatment. Our results show that CAM-related information needs of several types of patients vary depending on the different stages of their illness and its treatment, especially because some CAM treatments may become relevant only in specific phases. Accordingly, health communication measures should anticipate what kind of information is relevant and should be provided at which stage.

Providing structural support for patients' exchange. Different types of patients either actively engage in providing other patients with information (Active Multipliers) or make use of other patients' experiences as they decide whether or not to apply CAM. Health communication measures may provide structures that facilitate patients' sharing of information, e.g. by encouraging to host and participate in (offline or online) support groups in which they can share and receive other patients' experiences. At the same time, health communication has to make patients aware of the potentials and possible risks of this kind of information, e.g. by raising their awareness on how to evaluate interpersonal information by other patients or by establishing moderated forums that are supervised by medical experts.

Acknowledging the growing importance of CAM in the context of cancer, we thus encourage further research to extend and quantify this typology. Representative data about patients' information behavior would be beneficial in developing or improving health communication measures for cancer patients in this field of medical uncertainty.

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