

Doctor–patient communication and cancer patients’ choice of alternative therapies as supplement or alternative to conventional care

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ABSTRACT

Cancer patients’ use of complementary and alternative medicine (CAM) is widespread, despite the fact that clinical studies validating the efficacy of CAM remain sparse. The purpose of this study was to explore possible connections between cancer patients’ communication experiences with doctors and the decision to use CAM either as supplement or alternative to conventional treatment (CT). The Regional Committee for Medical and Health Research Ethics and the Norwegian Data Inspectorate approved the study. From a group of 52 cancer patients with self-reported positive experiences from use of CAM, 13 were selected for qualitative interviews. Six used CAM as supplement, and seven as alternative to CT, periodically or permanent. Communication experiences with 46 doctors were described. The analysis revealed three connections between doctor-patient communication and patients’ treatment decisions: a) negative communication experiences *because of* the use of CAM; b) negative communication experiences *resulted in* the decision to use CAM, and in some cases to decline CT; and c) positive

communication experiences led to the decision to use CAM as supplement, not alternative to CT. The patients, including the decliners of CT, wanted to discuss treatment decisions in well-functioning interpersonal processes with supportive doctors. In doctors' practices and education of doctors, a greater awareness of potential positive and negative outcomes of doctor-patient communication that concern CAM issues could be of importance. More research is needed to safeguard CAM users' treatment decisions and their relationship to conventional health care.

INTRODUCTION

Doctor-patient communication involves interaction between individuals in non-equal positions, is often non-voluntary, is emotionally laden, concerns issues of vital importance, and requires close cooperation (1). The quality of doctor-patient communication can be critical in developing patient satisfaction, compliance, and positive health outcomes (1-6). If the focus of the 21st-century health care system is to be the patient, the value of the doctor-patient relationship must be promoted (7). Patients, doctors and health authorities are facing a complex landscape of changing and competing health care paradigms. One implication is that many patients choose to use complementary and alternative medicine (CAM) as supplement or alternative to conventional treatment (CT), although clinical studies validating the efficacy of CAM remain sparse (8). This article focuses on doctor-patient communication with regard to 13

Norwegian cancer patients' decisions to use alternative therapies instead of or in combination with conventional cancer care. The Cochrane Collaboration defines CAM 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 system of a particular society or culture in a given historical period. (9:693)

The Norwegian Act No. 64 of 27 June 2003 relating to the alternative treatment of disease, illness, etc. (10) defines CAM as treatment performed outside the health service and not practiced by authorised health personnel. The CAM concept includes both treatments used as alternatives and supplements to CT. In this article, the terms “complementary medicine” (CM) when referring to CAM used as supplement, and “alternative treatment” (AT) when referring to CAM used as alternative to CT are used. When referring to other studies, the concept CAM is used because these studies do not focus on the distinction between CM and AT (11).

The use of CAM is widespread, and has been estimated to be 50% among Norwegian cancer patients (12-13). Patients' use of CAM has been interpreted as a result of both a positive attitude towards CAM and a somewhat negative attitude towards conventional health care. The orientation towards CAM can be seen as a development of control and self-management of cancer, as well as facilitating “holistic” treatment, hope, and well-being (14-18). Many doctors and patients find it challenging to communicate about CAM

(19-20). CAM users run the risk of being considered as deviant and noncompliant because they by their treatment decisions make themselves different from the majority of patients and challenge the rationality of medical advice (21-22). Trostle (23) claims that labelling of patients who take care of themselves in their own way as noncompliant, implies not being interested in analysing and trying to understand the reasons for patients' ways of relating to the illness situation. Thus, from a public health perspective, it is important to establish more knowledge about patients' reasons for and experiences from the use of CAM (24, 25). This implies a need for further research on doctor-patient communication and treatment decisions from a CAM user perspective.

Several studies have been published about CAM and decision-making (15, 16, 18, 25, 26). A few of these mention a connection between negative communication experiences and the decision to decline CT (25-26). Still, there is a lack of studies which specifically explore possible connections between doctor-patient communication and patients' choice of CAM as supplement or alternative to CT. Studies reporting the outcomes of patients who decline CT in favour of alternative therapies are also lacking. A recent study of clinical outcomes of 61 decliners revealed that failure to comply with CT led to increased risk of cancer progression and/or death (8). Thus, the distinction between CM and AT is important to explore both to ensure patient safety and extend our knowledge of decision-making in the CAM field. In the material from a larger explorative and not yet published study of various patient groups' reasons for and experiences from the use of CAM, the cancer patients in particular brought up this distinction in CAM use with regard to their experiences with doctor-patient communication. The purpose of this study is to analyse

this phenomenon to contribute empirically based hypotheses for further research. The research questions addressed were:

1. How have cancer patients who chose to use CAM as supplement or alternative to CT experienced doctor-patient communication?
2. Did doctor-patient communication influence these patients' treatment decisions? If yes: How and why?

MATERIAL

The patients were selected from the Registry of Exceptional Courses of Disease (hereafter "the Registry"), which includes self-reported positive and negative "exceptional" cases after the use of CAM (27). Deviant cases can illustrate unusual and typical aspects of a phenomenon of interest (28, 29). The Registry contains patients with experiences from the use of various CAM therapies used as supplement or alternative to CT, and represents a quite unique possibility for idiographic sampling (30) for in-depth studies that can generate hypotheses of patients' complex reasons for, and experiences from, the use of CM or AT.

Sampling and Participants

As of December 31, 2008, 52 patients (41 women, 11 men) were registered with various cancer diagnoses. All of them reported "exceptionally positive" experiences from use of CM or AT (43 versus 9). Breast cancer and malignant melanoma were the largest groups. Based on a document analysis (31) of the Registry material of the 52 cases (questionnaires, medical records, etc.), patients were strategically selected to obtain variation, especially in which CAM modalities used, experiences from conventional health care, and from CAM used as supplement or alternative to CT. Nine patients were

first included. After a preliminary analysis where empirical patterns including those explored in this study were identified, inclusion continued until only a small amount of new information was obtained in additional interviews, and data seemed to be saturated (32). Four more patients were included during this process.

Characteristics

The patients (12 women, 1 man) ranged in age from 38 to 84. Seven had a higher education. The mean time since diagnosis was 9.2 years. Their diagnoses were breast cancer (7), Hodgkin's lymphoma (2), prostate cancer (1), and ovarian cancer (1). The last two patients had rare cancer diagnoses which are not listed to avoid identification.

Nutritional therapy, spiritual healing, and acupuncture were the CAM modalities most frequently used. Six of the included patients used CM through their entire cancer trajectory and six discontinued or refused CT at some stage after surgery. One patient refused all CT.

METHODS

An inductive, qualitative approach was chosen. Qualitative research can provide descriptions of the individual and unique aspects of experiences of illness such as meaning and intentionality (33), and can generate important hypotheses of patients' complex reasons for, and experiences from, the use of CM and/or AT. The aim was to transfer knowledge as working hypotheses which can be a valuable contribution to further research on topics of which we have little previous knowledge (34). In-depth interviews were used as the primary source of information, understood as being interactional, reciprocal, and reflexive processes (35). They were performed face-to-face and directed toward understanding the patients' perspectives on their lives, experiences,

or situations as expressed in their own words (36). Main interview themes were: personal history, receiving the diagnosis, being a patient in conventional health care, reasons for and experiences from the choice and use of CM or AT, patients' personal efforts, and the reasons for defining the disease course as "exceptionally positive". Each interview lasted between 90 and 150 minutes and took place in the participants' homes or another meeting place the interviewee was comfortable with. The interviews were audio-taped and transcribed verbatim by a professional transcriptionist. The citations from the interviews were translated from Norwegian to English and back to Norwegian by professional translators.

ANALYSIS

The interviews were intensively read as a whole to gain a general understanding of the participants' reasons for, and experiences from, the use of CAM. Then they were re-read and coded in NVivo 8 (37), starting with line-by-line coding of ideas, themes, and concepts, followed by the development of secondary substantive codes that summarised key concepts across the text data. During this process of establishing an understanding of the meaning of the participants' decisions to use CM or AT, connections between doctor-patient communication and treatment decisions were identified as an empirical pattern that deserved further consideration. The coding decisions, categories and conclusions were discussed with two patients, researchers, and a person working for a cancer organisation to ensure validity (35). The citations from interviews are approved by the patients.

Ethical Considerations

The study was conducted according to the rules of the Helsinki Declaration of 2002 (38). The Regional Committee for Medical and Health Research Ethics and the Norwegian Data Inspectorate approved the Registry and the research project. The patients gave written consent to participate. The transcriptionist signed a written consent to professional confidentiality.

RESULTS

Communication experiences with 46 doctors were described. Other doctors involved in the treatment of the patients than those described in terms of doctor-patient communication were not included in the analysis. The patients experienced positive communication with 19 doctors (4 oncologists, 2 surgeons, 7 general practitioners, 6 doctors offering CM), and negative communication with 27 (17 oncologists, 2 surgeons, 6 general practitioners, 2 doctors offering CM). During the empirical analysis, two main categories of communication behavior were constructed, *traditional* and *supportive*. A traditional communication behavior can be defined in line with Hall and colleagues' definition of an instrumental communication behavior: "... technically based skills used in problem solving, which compose the base of "expertness" for which the physician is consulted" (39, p. 400). A supportive communication behavior has been described in the literature as affective, socio-emotional, interactional, and with a focus on patients in the context of their psychological and social circumstances (3, 40).

Traditional Communication Behavior

A traditional communication behavior was characterised by focus on the tumor, medical language, and negative response to patients' use of CM. The patients were not comfortable with the passive patient position in their experience doctors with a traditional

communication behavior perceived as a premise. Several patients chose to decline CT after negative communication experiences with such doctors.

Supportive Communication Behavior

The communication with supportive doctors was characterised as equal and opening up for discussions about benefits and risk with regard to both CT, CM, and AT. The doctors with a supportive communication behavior often expressed scepticism toward the patients' choice of CM or AT, but still respected these choices. The patients emphasised the well-functioning communication with these doctors as invaluable in critical periods and an important reason for not declining CT after challenging experiences with doctors with a traditional communication behavior.

Connections

Three connections between experiences with doctor-patient communication and treatment decisions with regard to use of CM or AT were identified in the patients' descriptions:

- Negative communication experiences *resulted in* the decision to use CM or AT
- Negative communication experiences *because of* the patients' use of CM or AT
- Positive communication experiences led to the decision to use CM, not AT

Negative communication experiences resulted in the decision to use CM or AT

Several patients were not using CM from the start of their cancer course, but chose to do so because they wanted a supplement to conventional care after meetings with doctors with a traditional communication behavior. A young woman said:

There was a paradox in this whole thing. To be put on chemotherapy, suffer through it, and then hear the oncologist say that “No, we don’t think it will help.” And she laughed scornfully at my trying to tell my body that chemotherapy was helping ... she took away from me absolutely all hope in this world ... For me it was so important to think that I was a part of this, that I was a part of my healing process, not leaving my body to others ...

The patients expressed the need to be an active part of treatment decisions and treatment processes in order to cope with and survive their cancer. They actively searched for alternative practitioners to relate to. The young woman chose to visit an acknowledged spiritual healer abroad. In retrospect she thought that the meetings with him and the strength she gained from taking control of her body and her treatment decisions were of vital importance for the healing of her cancer.

Negative communication experiences because of the patients’ use of CM or AT

All except two patients originally wanted to use CAM as supplement, not alternative to CT. They wanted to discuss and safeguard treatment decisions with their doctors, but experienced what they perceived as a distinct negative response from doctors with a traditional communication behavior:

I told what I did myself – with [a mistletoe-preparation] and food supplements.

He answered: “You may very well do that, but nothing that you do yourself

makes any difference for the development of your cancer. It will run its course no matter what.” ... I could not relate to a doctor with an attitude like that.

Many of the patients requested a change of doctor based on such experiences. In a letter to the hospital one of them wrote:

... I have worked as a nurse for many years – been part of the conventional health care system. Now I feel like I’m put on the side-line, having to fight in two “battlefields” at the same time, against the conventional health care system and the cancer ... I’m afraid our next meeting will not allow the time or possibility for discussing anything but medical/technical themes. I am afraid of being seen as difficult and making incessant complaints, afraid not to get a chance to express myself and have real inter-human contact.

Five of the patients became users of AT instead of CM after meetings with doctors with a traditional communication behavior. One woman wanted to “walk the natural path” after surgery, but still wanted to have check-ups at the hospital:

The oncologist screamed at me: “You’re going to die and you will get multiple metastases! And alternative treatment will cost you all your money!” Then she got up with a loud bang from the chair – and ran out ... I was really scared ... Then the oncologist came back – she had written this paper and signed it – and I didn’t understand half of it, because it was written in Latin. But she said that from now

on you have to take full responsibility for your own life, we disclaim all responsibility.

The patients expressed expectations to the doctor-patient relationship that doctors with a traditional communication behavior did not fulfill:

I feel that I haven't been met with the respect and understanding that a patient is entitled to. Rather, I feel that I have been perceived as “strange“ and difficult because of my personal views on life, death, and alternative treatment. ... I think that in our enlightened society the doctors should be more open to combining conventional and alternative treatment methods. The medical knowledge is actually not unique. Rather, each patient is unique.

Positive communication experiences led to the decision to use CM, not AT

After meetings with doctors with a traditional communication behavior, nearly all of the patients looked for alternative practitioners as well as supportive doctors to relate to. Six of the patients found combined alternative and medical knowledge in doctors also offering alternative therapies, while five found doctors they considered as supportive within conventional health care. Supportive doctor-patient communication influenced their decision to use CM instead of AT:

When I chose my doctor, I chose the one who communicated something positive to me. So I went regularly to my surgeon ... I mentioned to him that I had visited

healer [X], something he was not very happy about. But he listened when I talked about how important this spiritual healer and my personal efforts and hope were for me.

In general, the patients looked for doctors who were able to communicate based on an understanding of the importance of patients' own efforts in treatment processes:

... [The anthroposophical doctor] said: "There is a lot we can do here." And that word "we" stayed in my mind ... here we were a team.

The patients expressed clear preferences:

I expect collaboration and respect for the way I see my illness, and to be involved in the treatment decisions ... one has to choose those doctors who dare include the patient ... it would be so much easier if doctors were inspired to include the patients' own efforts and use of alternative treatment together with what they know ... there are many doctors who are far-sighted and open-minded ... the patients want supportive doctors!

Many concluded that doctors with a supportive communication behavior were of vital importance for the "best cases" of cancer they had experienced: "This doctor gave me the ability to choose the best from two systems."

DISCUSSION

Roter and Hall (41) describe four forms of doctor–patient relationship: default, paternalistic, consumerist, and mutualistic. In this study, doctors with a traditional communication behavior act as if the patients are passive and the relationship paternalistic. Mutuality is characterised by a sharing of decision-making, like in the patients’ relationship with supportive doctors. The traditional paternalistic approach to doctor-patient communication is being challenged by new health care users who take an active role and include CAM as possible treatment options. Many cancer patients express the need to be an active part of treatment decisions and treatment processes in order to cope with and survive their cancer. These patients want doctors to focus on both the biomedical and psycho-social aspects of their illnesses. From a patient perspective, health care professionals can practise patient centred cancer care by focusing on subjective aspects that seem to affect patients’ quality of life, such as psychosocial considerations, personal opinions and shared decision making in therapeutic processes (3, 5, 15, 17, 40, 41). Medical evidence is essential, but so is an understanding of what ultimately influences ill persons’ quality of life (6, 17, 23), e.g. in situations where they decide to decline CT. Many patients highly value the focus on holistic health and on well-being rather than illness that they experience as users of various CAM therapies (18, 20). However, doctors are central to patients’ treatment decisions including their engagement with CAM (2). The results in this study reveal that even patients with “exceptionally positive” experiences from the use of CM or AT do not wish to make treatment decisions by themselves, but rather together with supportive doctors. These findings are in line with another study among Norwegian cancer patients (43).

Patients tend to adhere more to recommended treatments when the communication is satisfactory (40). In cases where failing doctor-patient communication is followed by a decision to decline CT, this can put patients at considerable risk. A present study exploring clinical outcomes in cancer patients who chose CAM as primary treatment, revealed associations to disease progression and increased risk of recurrence and death (8). In less extreme cases, failing communication may withdraw patients from telling their doctors about their CAM use (21, 22), followed by a possible risk of interaction between conventional cancer treatment and CAM products (44). Doctors should recognise the potential of their role in supporting patients in treatment discussions including discussion of CAM issues. Instead of focusing on noncompliant patient behavior, the focus should be on the way the patients experience and explain their illnesses and treatment decisions. Educational training of doctors focusing on the benefits of a supportive approach to patients can facilitate patient-centred conventional cancer care and serve as a basis for reviewing both positive and negative CAM outcomes (7, 17, 18, 23, 45-47).

Methodological Aspects

It has been argued that the Registry can represent a unique source of idiographic sampling for explorative studies (27, 30). The logic of extreme group sampling is that extreme cases can be information-rich cases because, by being unusual, they can illuminate both the unusual and the typical (28, 29). Patients with “exceptionally positive” experiences from the use of CM or AT may report more negative experiences with doctors and CT than CAM users in general. However, when these patients report that they want to relate to doctors in their decision-making, this deviant sample may be

considered as an argument for an increased reliability of the tentative results presented here.

A qualitative approach was chosen to develop knowledge about an unexplored issue. Tendencies to verify preconceived interpretations were expressed and processed through working with two patients, other researchers and a person working for a cancer organisation. In assessing the quality of qualitative studies, we may ask whether the credibility of our claims is supported by sufficient evidence (48). Some evidence of an association between doctor-patient communication and patient health outcomes in cancer care have been established in quantitative studies (2, 4). This study contributes with hypotheses of outcomes of doctor-patient communication that need to be further explored in various research designs, focusing on e.g. the prevalence of cancer patients choosing to decline CT based on negative communication experiences.

CONCLUSION

Cancer patients who have experienced “exceptionally positive” results from the use of CM or AT are still searching for supportive doctors in order to safeguard and optimise their treatment decisions. From these patients’ perspective, traditional communication behavior can potentially lead to mistrust in conventional health care and health-related risky behavior such as denial of CT. In doctors’ practices and education of doctors, a greater awareness of the potential positive and negative outcomes of doctor-patient communication that concern CAM issues could be of importance. These tentative conclusions should be further investigated to develop and safeguard doctor-patient communication with regard to cancer patients’ choice and use of CAM.

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