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Empowering the Cancer Patient or Controlling the Tumor? A Qualitative Study of How Cancer Patients Experience Consultations With Complementary and Alternative Medicine Practitioners and Physicians, Respectively

Aslak Steinsbekk, PhD, MSc, and Laila Launsø, DSc, MSc

Objectives: The authors describe how patients with cancer, who have had consultations with both a conventional physician and a complementary and alternative medicine (CAM) practitioner, experience these consultations. The theoretical background of this study is inspired by a description of 2 models of principles of treatment. In the first model, the instrumental intervention (eg, the medicine) is defined as the causal factor for outcome. In the second model, the patient is defined as the causal factor; the outcomes of the treatment are dependent on the resources of the patient (eg, the body's ability to heal itself) and the impact of the patient's situation. **Methods:** Semistructured, in-depth interviews were conducted with 17 Norwegian cancer patients who had visited both a CAM practitioner and a physician. The patients were recruited from both an oncology department at a university hospital and a newspaper advertisement in the area of Trondheim in central Norway. Methods of data analysis used were open coding, relational coding, and categorizing of themes. **Results:** The cancer patients have experienced 2 different modes of consultations: one characterized by practitioners focusing on controlling the tumor and another characterized by practitioners focusing on the patient. The patients' accounts of these 2 modes of consultation differ in a number of ways: which issues are discussed during the consultation, who is in control of the consultation agenda, what are the patients' perceptions of the practitioners' health and disease understanding (ontology), what are the practitioners' communication skills, and how empowered the patient feels during the consultation. **Conclusions:** Patients in this study ask for a consultation style that conveys a focus on both the disease and the whole patient. The results of this study point to a possible connection between the practitioners' understanding of health and disease and the content and form of the consultations. Future research should test this connection.

Keywords: *complementary therapies; physician-patient relations; communication; neoplasms; patient satisfaction*

Cancer patients who look at the private health care market will be faced with a large variety of providers with different understandings of health. Those who decide to try some form of complementary and alternative medicine (CAM) might be faced with understandings of health, disease, treatment, and consultations that are not commonly found within conventional medicine. This may influence the patients, either by validating their understanding of health and their demands on consultations by health providers or by leading to a change in their previous understandings.

A review of 26 surveys from different countries across the world on the use of CAM among adult cancer patients found the prevalence to be between 7% and 64%, with an average of 31%.¹ In Norway, the cumulative use of CAM among cancer patients 5 years after diagnosis was 45%.² Cancer patients both self-treat with CAM products and visit CAM practitioners. In the United States, 50% of CAM-using cancer patients had visited a CAM practitioner.³

Two case studies from England found that perceived positive aspects of the consultation with a CAM practitioner were related to the caring attitude of the practitioner, the whole-person approach, and the involvement of the patient in the process of care.^{4,5} Surveys and qualitative studies show that many patients value features of CAM such as the potential for extensive consultation time and the continuity of care, attention to the patient's personality and

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personal experience, patient involvement, and making sense of illness and treatment.⁶ These features can lead to an experience of transformation in which patients become more aware of who they are and how they relate to the world.⁷

There is a growing literature on the different aspects of consultations between cancer patients and physicians.⁸ Empirical data indicate that both cancer patients and their relatives prefer a patient-centered approach over one that is more disease focused in the consultation with oncologists.⁹ This is in line with findings that cancer patients receiving palliative treatment want to discuss psychosocial problems more often than physicians practice in follow-up consultations.¹⁰ At the same time, clinicians tend to use closed questions (eg, "Have the tablets helped your pain?"), and they seldom offer the patients an opportunity to initiate discussions.¹¹ These sorts of communication problems are not resolved simply by time and clinical experience among senior doctors working in cancer medicine.¹² A qualitative study found that women with breast cancer valued doctors who were experienced, who could form a relationship with the patient, and who showed respect for the patient.¹³ Similar factors were also found in a study of health care communications with patients having chronic illness, in which courtesy, respect, and engagement were used to name common communication themes requested by patients.¹⁴

The theoretical background of this study is inspired by a description of 2 models of treatment principles (Table 1).^{15,16} In model 1, the instrumental intervention (eg, the medicine) is defined as the main or causal factor for outcome. In model 2, the patient is defined as the causal factor; the result of the treatment is dependent on the resources of the patient (eg, the body's ability to heal itself) and the impact of the patient's situation. Model 2 represents a treatment model that focuses on the interaction between the patient's subjectivity, life situation, and instrumental intervention in the healing process. Model 1 focuses on the intervention itself and the measurement of effect; the effect of the intervention is not perceived to be dependent on the patient's subjectivity and life situation. These different principles of treatment are suggested to have an impact on the form and content of consultations.

We hypothesized that model 2 would be closer to cancer patients' experiences of consultations with CAM practitioners, and model 1 would be related more to experience with physician consultations. This hypothesis is based on research described above^{4,7,11,12} and results showing that cancer patients' motives for seeking out CAM practitioners are characterized by a desire to consult with practitioners with a different

Table 1. Two Different Principles of Treatment

<i>Model 1</i>	<i>Model 2</i>
The intervention is considered determinant for outcomes	Patient/situation is considered determinant for outcomes
The standardization principle	The individualization principle
The objectification principle	The subject-based motivation principle
Treatment may be reduced to a technical measurable intervention	Treatment is a complex relational process that adheres to the situation

understanding of their disease and treatment than those offered within the conventional health care system.^{17,18}

The core research question in this study is, how do cancer patients who have consulted both a CAM practitioner and a physician experience these consultations?

Materials and Methods

The findings presented here are from an exploratory qualitative study consisting of in-depth, face-to-face, semistructured interviews. The regional committee for medical research ethics in Health Region IV approved the study protocol and informed consent.

To ensure that the informants discussed the same themes, a semistructured interview guide was formulated. Based on a literature review and discussions with experienced researchers, the following themes were formulated in the interview guide to operationalize the core research question:

- cancer patients' life situation and history of disease,
- cancer patients' experience with the practitioners' information about treatment,
- cancer patients' expectations related to treatment outcomes,
- cancer patients' experience with and assessment of the quality of the communication and their perception of time related to the consultations, and
- cancer patients' positive and negative experiences with the consultations.

The patients were allowed to introduce and talk about any theme they wanted. The interviewer introduced themes from the interview guide if the informants did not spontaneously talk about them.

Patients were recruited by nurses at the outpatient clinic of an oncology department at the university hospital in central Norway. The nurses handed out information about the study from January to March 2001 to cancer patients they knew or believed had been to a CAM practitioner. In addition, an advertisement was placed in the local newspaper in February 2001. To

Table 2. Details of the 17 Patients Interviewed

Age	Gender	Cancer Site	Years Since Diagnosis	CAM Practitioner Visited
46	Female	Breast	4	Anthroposophic medical doctor, biopath, healer
69	Male	Kidney	8	Homeopath/acupuncturist
69	Female	Breast	20	Anthroposophic medical doctor, healer, homeopath, kinesiologist
53	Male	Non-Hodgkin's lymphoma	10	Acupuncturist, complementary cancer clinic, healer
68	Female	Breast	1	Acupuncturist
60	Male	Prostate	3	Anthroposophic medical doctor
36	Female	Breast	2	Acupuncturist, biopath, complementary cancer clinic
53	Female	Melanoma of skin, Breast, Non-Hodgkin's lymphoma	21	Acupuncturist, aromatherapist, chiropractor, healer, homeopath, reflexologist
58	Female	Lachrymal gland	9	Healer
54	Female	Non-Hodgkin's lymphoma	8	Healer, homeopath
62	Female	Breast	20	Acupuncturist, healer
43	Female	Thyroid gland	14	Healer
65	Female	Breast	4	Healer, homeopath/acupuncturist
60	Female	Colon	8	Homeopath/acupuncturist
61	Female	Colon	2	Healer
49	Male	Acute leukemia	6	Acupuncturist, anthroposophic medical doctor

CAM = complementary and alternative medicine.

participate, the patients had to contact the researcher by phone.

The inclusion criteria were aimed at recruiting cancer patients who (1) had visited both a CAM practitioner and a conventional physician for their cancer, (2) were between 18 and 70 years old, and (3) had received their cancer diagnosis no less than 4 months before enrollment. All those who volunteered by March and who met the inclusion criteria were included. The sample size was based on the saturation principle, whereby data collection continued until no new knowledge was obtained beyond that of the previous interviews.

The interviews lasted between 1 and 2.5 hours and were audiotaped and then transcribed verbatim. The informants chose the location for the interview. Twelve interviews were conducted in the interviewer's office and 5 in the informant's own home.

Methods of data analysis used were open coding, relational coding, and categorizing of themes.¹⁹ The identification of themes and the relationships between these themes were tested by rereading the interviews. To select citations to illustrate the themes, the rules formulated by Kvale (Box 14.4) were used.¹⁹ Citations from the same themes were compared, and those that were the most illustrative and well formulated for each of the themes were selected. The citations were edited into a readable form and translated to English.

Results

Seventeen participants took part; 5 were recruited through the oncology department and 12 from an ad in the local newspaper. Twelve were women and 5 were

men (Table 2). The average time since first diagnosis was 7 years (range, 1-21 years). Sixteen of the participants had been treated with surgery, 9 with chemotherapy, and 7 with radiation. The frequency of consultations with CAM practitioners varied from only once to once a week for 2 years. Six of the patients had visited a CAM practitioner regularly for a longer period.

The numbers and types of physicians visited could not be counted because the informants had visited many different physicians. This is in line with an English study that found that cancer patients with an average period of cancer care of 2 years, 4 months had seen a median of 32 physicians.²⁰ All patients had been to regular follow-up as proposed by their physician/oncologist. A large majority of those physicians with whom the cancer patients had consultations were specialists working in a variety of departments at the university hospital.

The coding procedures resulted in identification of the following 5 main themes characterizing the patients' experience with consultations: (1) focus on the whole patient or the disease, (2) patient or practitioner in control of the agenda, (3) the practitioners' and the patients' understandings of health and disease, (4) the practitioners' communication skills, and (5) empowerment of the patient during the consultation.

Focus on the Whole Patient or the Disease

The informants reported a difference between CAM practitioners and physicians regarding whether the consultation focused on the patients as whole persons or the disease. Consultations with CAM practitioners

were reported as allowing the patients to tell their own story by asking broad questions about the patient's life situation.

Both the healer and the homeopath treated me as a whole person by asking questions about all aspects of me, and also of my work and family. They also look for connections between your complaint and its causes. (Woman, gastrointestinal cancer)

This was in contrast with how the patients viewed the consultations with the physicians; the patients frequently reported consultations during which the physician was most interested in the disease/tumor (see quote below).

Patient or Practitioner in Control of the Agenda

Some patients seem to adapt to what they think the practitioner wants to discuss during the consultation. By doing so, these patients give the practitioner an indirect control of the agenda and thereby the power to define the issues to be discussed during the consultation. The consultation style therefore influences whether it is the patient or the practitioner who is in control of the agenda. The patient feels free to discuss issues that are not raised by the practitioner if the practitioner asks questions that invite the patient to express his or her thoughts and wishes. By asking broad questions (see the quote above), CAM practitioners were reported to let the patient have a larger room for setting the agenda.

I don't ask so many questions because I feel I am there for the disease. If he [the physician] had asked me, "How do you feel now when you have discovered a new tumour?" I would have asked other kinds of questions. (Woman, lymph)

Understandings of Health and Disease

From the patients' perspective, both patients' and the practitioners' understandings of the etiology of cancer influence the consultation. The patients spoke of differences between physicians' and CAM practitioners' concerning view of possible disease causations and important treatment factors. CAM practitioners seemed to include more aspects than physicians, thereby making it easier for the patients to express their thoughts about factors influencing either the cause of the disease or the actions needed to prevent a relapse.

If you have got cancer because of your way of living or eating, then you will have a relapse if you don't change this. Your body will not get back in balance. . . . There is no use in talking about psychological issues during the

consultations, because when they [medical doctors] don't believe in pollution and other physical factors as causes of cancer, they certainly don't believe in psychological causes. (Woman, breast)

I believe in their [CAM practitioners'] theory that the cancer hasn't developed during the night. It has come from psychological trauma and then it lays smoldering in the body. (Woman, breast)

Practitioners' Communication Skills

Lack of communication skills among physicians was a comment raised spontaneously by the informants. To contrast, they talked about their relative satisfaction with CAM practitioners' communication skills.

He [the medical doctor] sits and looks down into his papers. I wish the physician had asked more about "How are you, how are your moods and your family?" Then I would feel that he cared for me. (Woman, head)

Most comments described how the physicians behaved during the consultation. Not taking notes on what the patients discussed was viewed as a form of disrespect for the patient's story and a confirmation that the test results, which were already in the medical record, were the only thing that mattered. The practitioner's body language and care activities were also taken as a signal of whether he or she was interested in the patient.

Empowerment of the Patient During the Consultation

When asked to compare physicians and CAM practitioners, some patients pointed to a difference in how they were cared for and encouraged to remain hopeful and optimistic. In general, CAM practitioners were perceived as focusing more on empowering the patient than the physician. The CAM practitioners' way of empowering the patient in the consultation was to greet the patient in the waiting room, to spend time on comforting the patient, and not talking about the probability of dying from the disease but talking about other patients who had recovered and to some extent acknowledging that miracles can happen. The following citation is an example of how a patient experienced being empowered and disempowered by 2 different physicians:

When I had the relapse, one physician told me this in such a nice way. "It has gone to your lungs," he said, "but it can lie there for many years." I told this to another physician when I was in for control. "Well," he said, "you have it in your blood vessels as well, everyone knows that." "Why do you say that?" I said, "Why can't you let me keep my hope?" (Woman, head)

Length of the consultations was commented on only when patients were questioned directly about the issue. The informants had the experience that the CAM practitioner spent more time with them than the physicians did.

Discussion

The main conclusions from this study are that the informants experienced the consultations with the CAM practitioners, compared to consultations with the physicians, as more focused on them as a whole person with a history and a life outside the disease.

It is important to reassert that this study reports only patients' perceptions of their health consultations. There has been no observational data collected from consultations or interviews with the physicians and the CAM practitioners referred to by the patients. Generalizing the results of this study to other cancer patients' experience and assessment of consultations with physicians and CAM practitioners might be limited due to the sampling strategy, which was based on a self-selection criterion. To reduce the chance of recruiting only the most "pro-CAM" patients, we have chosen not to recruit patients from CAM practices. However, none of the patients were negative to CAM. This could point to the fact that the self-selection method has excluded patients with a negative experience of consultations with CAM practitioners.

By comparing the interviews, we found no systematic differences in the patients' experiences with consultations between those who were recruited at the hospital and those recruited from the newspaper advertisement. The cancer patients could have chosen CAM practitioners because they, in one way or another, disliked the treatment offered by their physicians. However, all of our informants expressed positive attitudes to some of the physicians with whom they had a consultation. None of the informants had discontinued the treatment prescribed by the physicians, and none of the CAM practitioners had given the patients promises of cure as far as the cancer patients could tell. The self-selection strategy might have the consequence that those interviewed represent only those patients who prefer patient-centered consultations.

We have not been able to find other studies comparing cancer patients' experience from consultations with both physicians and CAM practitioners. The results from our study on cancer patients' experience with physician consultations are similar to findings in other studies^{9-11,13,14} and are also similar to findings on noncancer patients' consultations with CAM practitioners.^{4,16,21}

At the time this study was conducted, Norwegian law made it illegal for other than authorized health care personnel to treat cancer (the law was changed in January 2004, and CAM practitioners are now allowed to treat patients with cancer as long as the aim of the treatment is to strengthen the body's self-defense and the immune system). The Norwegian legislation might compel Norwegian CAM practitioners to focus on the person instead of the tumor. But based on findings from studies in other countries with different legislation, it seems more likely that the CAM practitioners' consultation style is influenced by different understandings of health and disease and different principles of treatment compared to that of physicians.^{4,7}

The results of this study and previous studies suggest that the practitioners' understanding of health and disease and their principles of treatment influence the content and form of the consultation. The content of consultations between 2 practitioners who hold the view that the only thing influencing the cancer disease is, respectively, (1) the tumor or (2) the patient and his or her situation is likely to be different. The development of the disease/tumor is best monitored by tests, while knowledge about how the patient feels is best obtained by asking the patient. The practitioner is the expert on the test results and treatment options, but the patient is the expert on his or her body and experiences. A consultation that could convey both these aspects seems desirable and indicates that practitioners should strive to fully integrate a focus on the disease and the whole patient. Future research should test if there is a connection between the practitioner's understanding of health and disease and the content and form of their consultations.

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References

1. Ernst E, Cassileth BR. The prevalence of complementary/alternative medicine in cancer: a systematic review. *Cancer*. 1998;83:777-782.
2. Risberg T, Lund E, Wist E, Kaasa S, Wilsgaard T. Cancer patients use of nonproven therapy: a 5-year follow-up study. *J Clin Oncol*. 1998;16:6-12.
3. Eisenberg DM, Kessler RC, Van Rompay MI, et al. Perceptions about complementary therapies relative to conventional therapies among adults who use both: results from a national survey. *Ann Intern Med*. 2001;135:344-351.
4. Luff D, Thomas KJ. "Getting somewhere," feeling cared for: patients' perspectives on complementary. *Complement Ther Med*. 2000;8:253-259.
5. Mercer SW, Reilly D. A qualitative study of patient's views on the consultation at the Glasgow Homoeopathic Hospital, an

- NHS integrative complementary and orthodox medical care unit. *Patient Educ Couns.* 2004;53(1):13-18.
6. Zollman C, Vickers A. ABC of complementary medicine: complementary medicine and the patient. *BMJ.* 1999;319:1486-1489.
 7. Mulkins AL, Verhoef MJ. Supporting the transformative process: experiences of cancer patients receiving integrative care. *Integr Cancer Ther.* 2004;3:230-237.
 8. Maguire P. Improving communication with cancer patients. *Eur J Cancer.* 1999;35:1415-1422.
 9. Dowsett SM, Saul JL, Butow PN, et al. Communication styles in the cancer consultation: preferences for a patient-centred approach. *Psychooncology.* 2000;9:147-156.
 10. Detmar SB, Muller MJ, Wever LD, Schornagel JH, Aaronson NK. The patient-physician relationship: patient-physician communication during outpatient palliative treatment visits—an observational study. *JAMA.* 2001;285:1351-1357.
 11. Ford S, Fallowfield L, Lewis S. Doctor-patient interactions in oncology. *Soc Sci Med.* 1996;42:1511-1519.
 12. Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a cancer research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet.* 2002;359:650-656.
 13. Wright EB, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ.* 2004;328:864.
 14. Thorne SE, Harris SR, Mahoney K, Con A, McGuinness L. The context of health care communication in chronic illness. *Patient Educ Couns.* 2004;54:299-306.
 15. Launsø L, Gannik DE. The need for revision of medical research designs. In: Gannik DE, Launsø L, eds. *Disease, Knowledge and Society.* Fredriksberg, Germany: Samfundslitteratur; 2000:243-259.
 16. Launsø L. *Det alternative behandlingsområde. Brug og udvikling: rationalitet og paradigmer.* Copenhagen, Denmark: Akademisk Forlag; 1996.
 17. Brendstrup E, Launsø L. Description of a holistic integrated treatment model used by cancer patients & research evaluated: part 1. *Townsend Letter for Doctors & Patients.* 1994;137:1342-1356.
 18. Brendstrup E, Launsø L. Description of a holistic integrated treatment model used by cancer patients & research evaluated: part 2. *Townsend Letter for Doctors & Patients.* 1995;138:54-63.
 19. Kvale S. *InterViews: An Introduction to Qualitative Research Interviewing.* London: Sage; 1996.
 20. Smith SDM. Encounters with doctors: quantity and quality. *Palliat Med.* 1999;13:217-223.
 21. Mercer SW, Reilly D, Watt GC. The importance of empathy in the enablement of patients attending the Glasgow Homoeopathic Hospital. *Br J Gen Pract.* 2002;52:901-905.