

Mind the Gap! Lay and Medical Perceptions of Risks Associated With the Use of Alternative Treatment and Conventional Medicine

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ABSTRACT

Introduction

Studies of the widespread use of complementary and alternative medicine (CAM) demonstrate that CAM users relate to both subjective, experience-based knowledge and medical knowledge in treatment decisions. The aim of this study was to explore lay and medical risk perceptions associated with CAM and conventional medicine.

Patients and Methods

Twenty-five Norwegian users of CAM who were diagnosed with cancer or multiple sclerosis and 12 of their doctors participated in in-depth interviews in an explorative, qualitative study.

Results

Rather fundamental differences in risk perceptions were revealed that influenced treatment decisions and risk communication in clinical encounters. While the CAM users considered conventional medicine as potentially risky and related this to experiences of severe adverse effects of conventional treatments, they perceived CAM as “natural” and “safe”. Doctors’ risk perceptions were quite the contrary, mainly because of lack of scientific evidence for CAM as safe and beneficial.

Conclusion

For the safety of CAM users, such divergent risk perceptions may have far reaching consequences. CAM users need to be met where they actually position themselves as decision-makers based on their approaches to experiences, knowledge, and science. An awareness of differing lay and medical risk perceptions associated with CAM and conventional medicine both in research, doctor-patient communication, and education of patients and doctors is thus important to optimize patient safety in complex health societies.

Keywords

cancer; complementary and alternative medicine; decision making; doctor-patient communication; multiple sclerosis; Norway; patient safety; risk perceptions

INTRODUCTION

From a biomedical perspective, risk is understood as the objective and evidence-based risk of an adverse outcome when performing any diagnostic or therapeutic procedure [1-2]. Comprehensive research based on this approach to risk provides important knowledge on risks related to conventional treatments. Comparatively, little research has investigated *patients'* individual risk perceptions. This fact can be linked to the established scientific understanding of risk as an objective phenomenon. In recent risk research it has been argued that there exists a significant problem with using “objective” epidemiological risk assessment because risk is reduced to a statistical measure that does not take into account patients' attitudes or risk-taking behaviors [3]. A hermeneutic understanding of risk as a social construct including uncertainty and subjective elements has thus been introduced [3-7]. How risk is understood may have a significant influence on how it is handled, and experts and members of the public may disagree about existing risks because they understand risk differently and have different worldviews, experiences, and education [6-10]. This argumentation may be especially relevant in approaching risks associated with patients' use of complementary and alternative medicine (CAM), as CAM use is often unregulated, based on lay knowledge, and initiated by patients themselves or by unauthorized CAM practitioners [7].

CAM and risk

This study explored risk perceptions among a sample of Norwegian CAM users diagnosed with cancer or multiple sclerosis (MS) and their doctors. The Norwegian Act No. 64 of 27 June 2003 [11] defines CAM as

(...) health related treatment which is practiced outside the established health services and which is not practiced by authorized health personnel. Treatment performed inside the health service or by health personnel is included by the concept alternative medicine when methods that normally are practiced outside the health service are used.

Approximately 50 % of Norwegian cancer and MS patients use CAM [12-13]. Despite the widespread use, studies on risks associated with the use of CAM still remain sparse,

and a need for more research that enables patients to make informed treatment decisions has been emphasized by several authors [14-24]. The existing literature shows that benefits and low risk are associated with some specific CAM treatments used by MS and cancer patients when implemented properly [e.g., 14-16, 19, 25-27], while other treatments are considered unsafe or ineffective [e.g., 14-16, 18]. In general, CAM use has been interpreted as a result of both a positive attitude toward CAM and a somewhat negative attitude toward conventional health care. From the patient perspective, encounters between patients and CAM can produce benefits that induce new health practices [14-17, 19, 28-30]. Patients' negative attitudes toward conventional medicine can be linked to adverse effects of treatments, lack of conventional treatment options, or a lack of trust in conventional care [17-19, 24, 28-30]. CAM users seem to base their treatment decisions on lay constructions of a therapeutic pluralism that includes both scientific, medical knowledge and embodied and experience-based knowledge [7, 17, 28-30]. Thus, there may be unexplored gaps between CAM users' and doctors' perceptions of risk. Such possible differences represent an important and under-investigated aspect of decision-making, communication, and patient safety in contemporary health care.

Aims, risk definition and research questions

The purpose of this study was to explore doctors' and cancer and MS patients' perceptions of risks associated with the use of CAM and conventional medicine based on an approach able to capture different stakeholders' risk experiences and understandings. The study was based on a sociocultural understanding of risk as a situation or event where something of human value is at stake, and where there is uncertainty about the potential for and realization of unwanted, negative consequences of the event. The research questions addressed were:

1. How do CAM users diagnosed with cancer or MS perceive risks associated with conventional medicine and CAM?
2. How do doctors perceive such risks?
3. Are there differences in patients' and doctors' risk perceptions? If so, how can these differences be interpreted?

The study is part of a larger qualitative study of cancer and MS patients' position between conventional medicine and CAM [28-30].

MATERIAL

Participants were selected via the Registry of Exceptional Courses of Disease (hereafter “the Registry”), which includes Scandinavian self-reported positive and negative courses of disease related to the use of CAM [31-32]. In this study, patients with cancer or MS were included because both patient groups are large, and their use of CAM is widespread and considered as potentially risky [12-13, 20-24]. Exceptional cases are deviant cases that can illustrate unusual and typical aspects of a phenomenon and be perceived as illuminative and information-rich [33-35]. The Registry contains information on patients representing different commitment to CAM and various experiences from the use of CAM and conventional medicine. It also contains medical records and contact information for the patients’ doctors and CAM practitioners [31, 35]. Such a sample of CAM users and health care providers is time-consuming and challenging to establish, and the Registry can represent a rather unique possibility for idiographic sampling [36] for qualitative studies on different aspects of CAM as viewed from different stakeholders’ perspectives.

Patients

As of December 31, 2008, 52 cancer patients (41 women, 11 men) and 58 MS patients (39 women, 19 men) were registered. Based on a document analysis of the Registry material on these 110 cases (a questionnaire, medical records, etc.), possible participants were selected. Specific differences with respect to gender or country were not identified. 13 Norwegian cancer patients (12 women, 1 man) and 12 Norwegian MS patients (9 women, 3 men) were included. Inclusion continued until only a small amount of new information was obtained during interviews, and redundancy occurred. The data was then deemed to be saturated [37].

The cancer patients ranged in age from 38 to 84. Seven had a higher education. The mean time since diagnosis was 9.2 years. The diagnoses were breast cancer (7), Hodgkin’s lymphoma (2), prostate cancer (1), and ovarian cancer (1). The last two patients had rare cancer diagnoses that are not listed to avoid identification. Nutritional therapy, spiritual healing, and acupuncture were the CAM modalities most frequently used. Six used conventional and alternative therapies simultaneously through their entire cancer

trajectory, while six discontinued or refused conventional cancer treatment at some stage after surgery. One patient refused all conventional treatment.

The MS patients ranged in age from 39 to 55. Ten had a higher education. The number of years since being diagnosed with MS varied from 6 to 21. The distribution of MS subtypes [38] was: relapsing remitting (3), secondary progressive (6), and primary progressive (3). Acupuncture, nutritional therapy, homeopathy, and spiritual healing were the CAM modalities most frequently used. Three used alternative treatments exclusively.

Doctors

In 2009-2010, 15 doctors (five oncologists, five neurologists, and five general practitioners) who had treated 19 of the 25 patients in the study were invited to participate. All but one oncologist and two neurologists accepted. All participants (6 women, 6 men) had a Western medical education. They ranged in age between 41 and 65, and worked within the Norwegian conventional health care system where they had been practicing for more than 10 years. Two general practitioners were also experienced CAM practitioners.

METHODS

Qualitative interviews

Qualitative interviews were the primary source of information, understood as being interactional, reciprocal, and reflexive processes [39], and directed toward understanding the participants' perspectives of their experiences, perceptions, or situations [40]. The patient interviews focused on personal history, experiences from conventional care, and reasons for and experiences from the use of CAM. They were performed face-to-face by the author and a research assistant, lasted 90-150 minutes, and took place in the patients' homes or at another meeting place chosen by the participant. The doctors were interviewed with the aim of gaining an understanding of their perspectives in general, and not regarding their experiences with patients in the study in particular. The main themes were experiences with patients' CAM use, risk perceptions associated with conventional medicine and CAM, and doctor-patient communication. Six were interviewed in their offices, one in his home, and five by telephone. These interviews lasted between 45 and 90 minutes. All 37 interviews were audio-recorded and transcribed verbatim by a professional transcriptionist.

Analysis

Qualitative content analysis and the systematic classification process of coding and identifying different themes or patterns were used to interpret the data [41]. The patient interviews were intensively read to gain a general understanding of main issues under investigation. They were then re-read and coded in NVivo 8 qualitative software, starting with line-by-line coding of ideas, themes, and concepts, and then developing secondary substantive codes that summarized key concepts across the data [41]. “Patients’ and doctors’ differing risk perceptions” was identified as an important empirical pattern in the patient material. The same procedure as described for the patient interviews was followed when analyzing the interviews with doctors. “Differences in risk perceptions” was highlighted by the participants also in these interviews.

Ethical considerations

The study was conducted according to the rules of the Helsinki Declaration [42]. The Regional Committee for Medical and Health Research Ethics and the Norwegian Data Protection Authority approved the Registry and the research project. The patients gave written consent to participate. The transcriptionist signed a written consent to professional confidentiality. The interviews were conducted with sensitivity to the needs and abilities of each participant [43].

RESULTS

Patients’ risk perceptions

The patients differed in diagnosis, but their perceptions of risk were in general very similar. One difference was that while the cancer patients had been offered a regime of conventional treatments, some of the MS patients had been offered very limited conventional options. The patients had made great efforts to create a knowledge basis for their treatment decisions by reading medical and CAM literature as well as talking to doctors, CAM practitioners, and persons in their social networks about treatment options and experiences.

Conventional treatment was perceived as a considerable health risk by many patients in both disease groups. For the cancer patients, this was often based on their experiences of dramatic, fatal cancer courses and substandard medical care in their families. They expressed that, e.g., “the adverse effects of chemotherapy and radiation were frightening”

and “the treatment entailed so much suffering to no avail.” Several MS patients had themselves experienced severe adverse effects from conventional treatments like β -interferon and cortisone before they decided to use CAM. Conventional treatments were also perceived as potential health risks based on what they had learned from their doctors about adverse effects. They often found it difficult to understand their “personal risk” based on risk statistics presented in clinical encounters. They described personal cost-benefit assessments with regard to conventional treatment and risk. A cancer patient stated, “After reading up on what radiation does to the body, and looking at all the adverse effects versus the benefits when it comes to my diagnosis, I chose to decline.” Some patients were experienced conventional health care providers themselves. They used their professional knowledge combined with knowledge about CAM when they made their risk assessments and treatment decisions. A nurse who had cancer and declined all conventional treatment explained:

I had faith that there are many roads to Rome. Most people having had similar operations experience severe adverse effects. I did not want to poison the body with chemotherapy and radiation. I had good reason [based on knowledge of conventional and alternative treatment options] to believe that I could reach a better goal without the conventional treatment that was offered, and I have reached that goal.

How the patients perceived risks associated with conventional medicine and their experiences from risk communication with doctors strongly influenced their decision to use CAM. Most of them combined conventional and alternative treatment and often used CAM to strengthen their ability to benefit from conventional treatment. Many expressed that the goals of their CAM use were to cope and live better with their disease. In general, they described CAM as “safe”, “natural”, and “without adverse effects”. None described negative effects of CAM use experienced by themselves or their significant others. From the media, they knew about patients who had negative experiences with CAM practitioners, CAM products, and the economic burden of using CAM. They did not identify with these CAM users, however, because they meant that the therapies and

practitioners they themselves had chosen were trustworthy. Many patients stated that they “owed themselves” to try out alternatives to conventional treatment because, as explained by a cancer patient, “at least, it wouldn’t hurt me to try, whereas *not* to try could turn out as a really bad decision when I wanted to live a good life with my cancer and maybe even could get cured”. CAM therapies were often evaluated based on bodily experiences, as a kind of “bodily risk assessment”. CAM represented something “positive” and “harmless” the patients themselves could do to strengthen their health by taking active part in treatment decisions and healing processes.

Doctors’ risk perceptions

The doctors were specialized into different fields of medicine, two of them also in CAM. Despite their different competences, they had a common understanding of risk as the evidence-based risk of an adverse outcome connected to specific treatments and diagnoses. Oncologists had more concerns about CAM and risk than neurologists and general practitioners, based on negative consequences of patients’ CAM use observed in their oncological practice. Those who were also trained in CAM meant that far the most CAM treatments are “safe” and “beneficial”. They were very aware, however, that some CAM treatments and unauthorized CAM practitioners could represent risk to patients, and they had been confronted about the safety of CAM by other doctors who they meant needed more education about CAM and safety to become more open-minded.

The doctors had been trained to relate to statistical risk numbers revealed in biomedical studies in their assessments of clinical treatment options. In general, they perceived conventional medicine to be quality-assured, despite possible adverse effects:

One benefit of working with these cancer patients [patients with lymphoma] is that we know from cancer statistics and clinical trials that their chances to get well if they use [certain conventional cancer treatments] are very good ... Of course, this motivates us as doctors to try to motivate our patients to keep up with the possible adverse effects of the treatments.

The doctors found clinical studies of preparations and treatment regimens to be crucial for patients’ safety. An oncologist explained:

The problem with so many of these CAM preparations is that I don't know what they contain ... What we have tried to do [in two cases where the oncologist thought that interaction between a conventional and a CAM treatment caused the death of the patient] was to notify The Norwegian Pharmacovigilance Advisory Board but they didn't want to hear about it because it [the CAM treatment] wasn't registered as a drug.

Some CAM therapies, e.g., acupuncture, were perceived as uncomplicated, whereas e.g., cancer patients' use of St. John's Wort and certain unconventional clinics were perceived as risky behavior. Several doctors had observed interventions between conventional treatments and CAM products: "I have also seen several patients who have died – probably because they have combined our treatment with other drugs, or only taken other preparations. So it's – it's scary."

The doctors described their risk assessments and risk communication in clinical encounters as heavily influenced by the acuteness and prognoses of the patients' disease. CAM use was not that problematic if the prognoses were positive or if there was no conventional treatment available. The oncologists had experienced dramatic consequences of delay or denial of conventional treatment in favor of CAM use in their practices:

It turns out that the consequences of embracing one of those new age – a new outlook on life, in a way, maybe call it a philosophy of life that makes you believe that the soul can heal almost anything, then you remove yourself really far from ... our kind of medicine. And then it ends up that a lot of them ... don't accept [conventional] treatment. ... Of course, that is the major concern.

Delay or denial of essential conventional cancer or MS treatment was perceived as the overall risk associated with patients' use of CAM. The doctors said they felt frustrated and uncertain when seriously ill patients did not trust medical knowledge and chose to use CAM. They felt very responsible for their patients, who they defined as vulnerable,

not only physically, but also psychologically and economically. The oncologists in particular found it difficult that they sometimes had no choice but to accept what they perceived as risky behavior. One said: “Patients suffer in the name of freedom ... these are grown-ups, you know – in their right mind, and ... then they have the full right to decide their treatment themselves.”

All the doctors expressed the need for scientific risk evaluations of specific CAM therapies. They also meant that more knowledge about risk communication with users of CAM would be very useful in clinical practice, as they had experiences from situations where patients did not seem able to relate to medical information and medical risk perspectives.

DISCUSSION

The analysis revealed rather fundamental differences between patients’ and doctors’ perceived risks, and considerable challenges in risk communication. The patients often perceived potential adverse effects related to the use of conventional medicine as health risks and CAM therapies and products as being generally safe. The doctors perceived conventional treatments as quality-assured through scientific studies and thereby safe, whereas many CAM treatments were perceived as possibly harmful. This discussion will focus on how such differences in lay and medical risk perceptions can be understood, and their possible implications.

Based on a sociocultural understanding of risk, perceptions of risk can be considered as fundamental to the way both lay people and experts organize their social world [2-8, 17]. The empirical patterns revealed in this study suggest that contextual factors, scientific knowledge, individual knowledge and experience, as well as instinctive reactions in stressful situations seem to have explanatory power in understanding different stakeholders’ risk perceptions and risk behavior. Many of the CAM users’ risk perceptions, e.g., their assessments of conventional treatments as holding considerable health risks based on knowledge of the suffering of significant others, can be interpreted as examples of subjective, lay constructions of risk. The doctors’ perceptions are examples of “objective”, scientific risk knowledge. The encounter between patients’ and doctors’ risk perceptions when these are conflicting can be perceived as “risk as politics”, involving power structures and knowledge systems within modern risk societies [44-45].

Particularly in stressful situations, lay people seem to look to their positive and negative feelings as a guide to their evaluation of an activity's risks and benefits [44-46]. People need to understand their personal risk, while they experience that doctors often approach risk very analytically and logically, and reality is encoded in abstract symbols, words, and numbers [2-9, 44-46]. In this study, patients' risk assessments were based on their own and significant others' experiences from suffering in conventional health care as well as to which extent the patients perceived a treatment, whether it was conventional and scientifically evaluated or not, as a potential threat to their health and well-being. Perceived risk, trust, and uncertainty were closely connected in these patients' risk behavior. Cure is often perceived as the main treatment goal by doctors, but several patients perceived coping and well-being in their living with MS or cancer as their most realistic and important treatment goals, and found CAM very useful to reach them. Peters and colleagues describe four kinds of uncertainty that may exist in health care settings and result in patient strategies such as those revealed in this study: uncertainty about the magnitude or severity of possible benefits and risks, the strength of current evidence, how to weigh risks and benefits, and about the likelihood of different outcomes [9].

The use of CAM as a lay health practice can be linked to the politicization of health – returning control of one's health to the individual and control of the health system to the community. The flexible use of various sources of knowledge can afford modern health care users considerable latitude in accepting or rejecting forms of evidence as authoritative and trustworthy [3, 9, 44-47]. Prior [47] points out that lay people are experts by virtue of having experience, but that “experience on its own is rarely sufficient to understand the technical complexities of disease causation, its consequences and its management” [47, p. 53]. Improved patient understanding of actual risk of recurrence or death is required in order for patients to be able to make more informed treatment decisions [9-10, 16, 23-24]. However, although patients in clinical encounters often are expected to understand consequences of treatment decisions being quantified by statistical numbers, they are in many situations not able to or willing to do so [4-5, 44, 46]. Doctors, on their side, often do not take into account the attitudes of patients' risk-taking [3, 9-10], and risk communication becomes very challenging for both parts.

This analysis leaves us with a key question: How can we handle differences in lay and medical understandings of risk, i.e., when “our ancient instincts and our modern scientific analyses clash” [44, p. 21], and consequently, patient safety may be threatened? Based on the results of this study, it seems to be essential to take into consideration in risk research, risk communication, and risk education that risk actually often is perceived differently by patients who are users of CAM and their doctors. The basis for CAM users’ decision-making, including their risk assessments, is often a complex construct of scientific and experience-based knowledge. This is important information that should be acknowledged in clinical encounters.

Methodological aspects

The participants were recruited via the Registry of Exceptional Courses of Disease. The patients had reported “exceptionally positive” courses of cancer and MS related to their use of CAM. No “exceptionally negative” courses of MS and cancer have so far been reported to the Registry. It is likely that patients with negative experiences from the use of CAM will perceive CAM as a health risk, as is the case with negative reports from patients with other diagnoses in the Registry [48-49]. Most studies report positive user experiences from the widespread use of CAM, however [e.g., 13, 17, 19, 28-30], and these CAM users need available and quality-assured risk information.

Tendencies to verify preconceived interpretations of patients’ and doctors’ risk perceptions were expressed and processed [39] through working with a co-researcher from the larger, qualitative study [28-30] and two patients and one doctor who participated. To assess the quality of qualitative studies, we may ask whether the credibility of our claims is supported by sufficient evidence [50]. It is not possible to claim that the results of this study can be generalized to populations of cancer or MS patients or transferred to other diagnostic groups. However, this study, as well as other studies on health consumers’ lay theories, indicate that lay theories are important factors in patients’ decision-making processes [7, 17, 28-30, 45-47] and should be taken into account in both in-depth studies and large-sample, attitude-based surveys of risks associated with conventional medicine and CAM in the future.

CONCLUSION

This study revealed rather fundamental gaps in risk perceptions associated with the use of conventional medicine and CAM among MS and cancer patients and their doctors. These differences strongly influenced risk communication and patients' decision-making. While the patients perceived conventional medicine as potentially risky and CAM as safe, their doctors' perceptions were quite the contrary. CAM use tends to be widespread among MS and cancer patients and in Western populations in general, and divergent risk understandings may have far reaching consequences for CAM users' decision-making and risk communication in clinical encounters. CAM users need to be met where they actually position themselves as decision-makers based on their approaches to experiences, knowledge, and science. Thus, in clinical education and practice, there should be a greater focus on differing risk perceptions and their possible implications for doctor-patient communication and patients' decision-making to strengthen patient safety in complex health societies characterized by uncertainty and therapeutic pluralism.

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