

Modes of Embodiment in Breast Cancer Patients Using Complementary and
Alternative Medicine

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Abstract

Abstract

Breast cancer patients are frequent users of complementary and alternative medicine (CAM). They often have complex reasons for, and experiences from, their use of CAM. Bodily experiences are important and almost unexplored elements in CAM use. Our aim was to explore the meaning and importance of bodily experiences among breast cancer patients who were using CAM as a supplement or an alternative to conventional treatment (CT). Our findings based on qualitative interviews with 13 women suggest that bodily experiences were particularly important when positioned outside conventional health care prior to medical diagnosis and as user of CAM as alternative to CT. We introduce three central modes of embodiment related to CAM use: the right to one's body, the body used as a gauge, and the body used as a guide. Patients' positioning between treatment systems should be further explored from a bodily perspective to safeguard and optimize patients' treatment choices.

Keywords

cancer, breast; embodiment/bodily experiences; health care, alternative and complementary; illness and disease, experiences; knowledge construction; safety, patient

The most common cancer worldwide is breast cancer, representing 16% of all cancer diagnoses in women (World Health Organization, 2008). Breast cancer patients experience many physical and psycho-social challenges during their breast cancer continuum (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Bredin, 1999; Carter, 1993; Thomas-MacLean, 2004), and an increasing number of breast cancer patients in Western countries choose to use complementary and alternative medicine (CAM) to strengthen their health and well-being (Boon, Olatunde, & Zick, 2007; Kremser et al., 2008; Lengacher et al., 2002; Molassiotis et al., 2006; Nahleh & Tabbara, 2003). An international review revealed that the prevalence of CAM use varied between 63 % and 83 % among breast cancer patients using at least one type of CAM (Di Gianni et al., 2002). There is, however, a great variation in these rates, depending on the definition of CAM used in each study, the setting of the study and the sample size.

In this article we will describe use of CAM among breast cancer patients in a Norwegian and Danish health care context. In these countries, breast cancer counted for 23% (Cancer Registry of Norway, 2009) and 27.9% (Sundhedsstyrelsen, 2009), respectively, of diagnosed cancer cases in women in 2008. A nationwide Danish study among early stage breast cancer patients revealed that 40.1% had used one or more types of CAM (Pedersen, Christensen, Jensen, & Zachariae, 2009). We have no such Norwegian data on breast cancer, but in general, CAM use among Norwegian cancer patients has been estimated to be about 50%, and on the increase (The Norwegian Cancer Society, 2008). The Cochrane Collaboration (Zollman & Vickers, 1999) 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 (p. 693).

The Norwegian alternative treatment act of illness (The Norwegian alternative treatment act of illness, 2004) defines CAM as health related treatment performed outside of the health service and 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 of the health service are used. No applicable official definition of CAM exists in Denmark, but the situation is quite similar to Norway. CAM in a Danish context can be defined as therapies that go beyond the treatments offered by the state-financed health system (Baarts & Pedersen, 2009). In general, the prevalence of CAM use in Scandinavia is higher among women, individuals with higher education, and people with poor self-reported health (Hanssen et al., 2005). In Denmark, patients with breast and gynecological cancer seem to be more likely to seek CAM treatments than patients with all other types of cancer (Kimby, Launsø, Henningsen, & Langgaard, 2003), and breast cancer patients using CAM seem to be healthier and more likely to have higher socio-economic status than non-users (Pedersen et al., 2009).

Cancer patients choose to use CAM for various reasons such as curing the cancer, minimizing the side-effects of CT, gaining control, dissatisfaction with the health outcomes of CT, or dissatisfaction with doctor-patient communication. Some patients

find the philosophical values of CAM to be of vital importance (Boon, Brown, Gavin, Kennard, & Stewart, 1999; Siahpush, 1998; Verhoef, Balneaves, Boon, & Vroegindewey, 2005). Use of CAM is an area where patient and medical perspectives often diverge (Tovey & Broom, 2007). Patients who choose to use CAM often base their treatment choices on personal experiences and lay knowledge of significant others (Salamonsen et al., 2010; Boon et al., 1999; Broome, 2009a; Thorne, Paterson & Russell, 2003). CAM users are often perceived as non-compliant patients who demand attention from, and change in, the conventional health care system to safeguard and optimize their treatment choices (Salamonsen et al., 2010; Bodeker, Kronenberg & Burford, 2007).

One important and so far almost unexplored aspect of cancer patients' complex use of CAM is the meaning and importance of bodily experiences. Relevant studies among patients with various diseases indicate that focus on bodily awareness, bodily experiences and embodied knowledge are important elements in experienced effects of, and reasons for, the use of CAM (Agdal, 2005; Baarts & Pedersen, 2009; Broom 2009a; O' Connor, 2003; Paterson, Baarts, Launsø, & Verhoef, 2009). O'Connor (2003) has emphasized that it is common for individuals to report that one or another CAM modality is more congruent with their experience of the body than what they have found in CT. Baarts & Pedersen (2009) have argued that CAM per se profoundly disrupts modes of bodily "disappearance", and that the encounter between the patient and CAM can produce a fresh and sustained sense of bodily responsibility that induces new health practices. It has also been argued that the shift in various cultural understandings of the body and how people cope with this diversity deserves to be more thoroughly

investigated, because this might affect patient choices as well as the legitimacy of health authorities (Agdal, 2005).

We have not been able to identify any studies that specifically explore bodily experiences among breast cancer patients using CAM, or any studies where breast cancer patients' choice of CAM as a supplement or an alternative to CT has been in focus. Use of AT can be perceived as a potential health risk from a medical perspective, but we have so far little knowledge about CAM users' personal risk assessments. Thus, we argue that this distinction between CAM used as a supplement versus an alternative to CT is worth exploring in connection to the meaning and importance of bodily experiences. More knowledge about the specific health strategies of CAM users is needed to optimize and safeguard patients' treatment choices in a society with competing health paradigms (Baarts & Pedersen, 2009; Bodeker, Kronenberg, & Burford, 2007; Hughner & Kleine, 2008).

The aim of this article is to explore the meaning and importance of bodily experiences among breast cancer women who have chosen to use CAM as either a supplement or alternative to CT. We use the term "complementary medicine" (CM) when referring to CAM used as a supplement to CT, and the term "alternative treatment" (AT) when referring to CAM used as an alternative to CT. When we refer to other studies, we use the concept CAM because authors usually do not focus on the distinction between patients' use of CM and AT (Low 2001). The research question to be addressed is: What is the importance and meaning of bodily experiences among women diagnosed with breast cancer who are users of either CM or AT?

Data Collection

The Registry of Exceptional Courses of Disease

We selected patients from a registry of patients with self-defined positive experiences from the use of CAM, the Registry of Exceptional Courses of Disease (hereafter referred to as “the Registry”). The Registry includes Norwegian and Danish patient-defined, self-reported positive and negative exceptional courses of disease after the use of CAM (Launsø et al., 2006; Salamonsen et al., 2010). It contains patients with experiences from the use of various therapies and both from the use of CAM as a supplement and alternative to CT. By selecting patients from a registry of self-defined exceptional courses of disease, we limited this study to deviant cases. Such cases can illustrate unusual and typical aspects of a phenomenon and can be perceived as illuminative and information-rich (Patton, 2002; Stake, 1995). One benefit of the self-selected sample the Registry represents is that it contains patients with different forms of use of CAM and commitment to CAM (Balneaves, Bottorff, Bislop, & Herbert, 2006; Kristoffersen, Fønnebø, & Norheim, 2008). Such a sample is time-consuming and challenging to establish. Based on this, we argue that the Registry can be perceived as a suitable and valuable source for strategic sampling and in-depth studies that can generate hypotheses of various and un-explored aspects of patients’ complex reasons for, and experiences from, the use of CM or AT.

Participants

As of December 31, 2008, there were 19 breast cancer patients in the Registry, 9 from Norway and 10 from Denmark. All of them were reporting “exceptionally positive” experiences from the use of CM or AT. During the inclusion process, 15 of these patients were invited to participate, and 13 accepted (7 from Norway and 6 from Denmark).

Inclusion of patients continued until only a small amount of new information was obtained in additional interviews, and data seemed to be saturated (Bryman, 2004). Although saturation is the most commonly used strategy in qualitative research, we realize that saturation cannot really be fully achieved. We carefully monitored when redundancy began to occur in our data.

Ten patients participated in individual in-depth interviews, and three of the Danish patients participated in a focus group interview. The patients in the focus group were chosen based on their common use of an alternative practitioner offering herbal treatment. The 13 patients ranged in age from 41 to 84 years, whereas the number of years since being diagnosed with breast cancer varied from one to 34. Five had a tertiary education, and the patients had been using CM or AT from three to 27 years. The most frequently used CAM modalities in the interview group were nutritional therapy including herbs (nine), followed by acupuncture (four). The mean number of used CAM modalities was 2.6. Four of the 13 patients had decided to decline CT at the starting point of their breast cancer course. The other nine patients had chosen CT from the beginning, and had then supplemented or replaced CT in individual ways.

Methods

We chose qualitative interviews as our main source of information. Qualitative studies can contribute to a deep understanding and thorough knowledge of important issues in health and well-being, especially given a situation in which we have little previous knowledge of our phenomenon of interest (Minichiello, Aroni, Timewell, & Alexander, 1990). A qualitative methodology also made us able to study patients' experiences regarding their use of CM or AT from a contextual perspective. Patients using CAM are

often suffering from chronic and complex illnesses, and the principles of alternative treatment formulated by alternative practitioners in many cases incorporate the patients' subjectivity, everyday life, and general environment. Hence, in addition to quantitative studies, patients' use of CAM need to be studied from the patient perspective, using a qualitative or mixed research design (Launsø & Rieper, 2006).

The Individual Interviews

We understand in-depth interviews as being interactional, reciprocal, and reflexive processes (Kvale, 1996). The individual interviews were performed face-to-face by the first author in Norway and the second author in Denmark. They were directed toward understanding the patients' perspectives on their lives, experiences, or situations as expressed in their own words (Minichiello et al., 1990). The main interview themes were: personal history, receiving the cancer diagnosis, being a patient in conventional health care, interpretation of illness, doctor-patient communication, reasons for, and experiences from, the choice and use of CM and/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 chosen by the interviewee. The interviews were audio-taped and transcribed verbatim by a professional transcriptionist.

The Focus Group Interview

The focus group interview was directed at the same themes as the individual interviews, and the themes were sent to the participants beforehand. In addition to the main themes for the individual interviews, we here wanted to learn more about the participants' experiences with the specific CAM treatment they all had used as a supplement to CT. In

the focus group interview the researchers' knowledge from the individual interviews served as a basis for the conversation. This interview was not used to test tentative findings in the individual interviews (Bloor, Frankland, Thomas, & Robson, 2001), but rather to achieve a concentrated conversation among informants that might never occur in the "real world" (Morgan, 1998). Focus groups are particularly suited to the study of attitudes and experiences found around specific topics (Barbour & Kitzinger, 1999), such as patients' reasons for, and experiences from, the use of CAM. The focus group interview was conducted by the second author and an assistant, was held in a rented space, and lasted for 2.5 hours. An extended report was written from the interview. The fact that we, because of practical circumstances, had to base our analysis on an extended report and not on a full transcription, limited the possibility to explore how the three participants in detail articulated, opposed, and eventually changed their accounts through their interaction (Barbour & Kitzinger, 1999). The extended report was approved by the participants.

Data Analysis

We used an inductive approach, and based our analysis on patients' descriptions of, and reflections on, their experiences related to their choice and use of CAM. Because we here analyze the patients' verbal descriptions, we define "bodily experiences" in terms of the individual's own direct verbal reference to what is phenomenologically presented to her, i.e. what she perceives (Baarts & Pedersen, 2009; Gendlin 1997). Qualitative content analysis was used for the subjective interpretation of the text data through the systematic classification process of coding and identifying different themes or patterns (Hsieh & Shannon, 2005). The text data was coded in NVivo qualitative software (QSR, 2009)

according to the main interview themes and other important empirical themes that emerged. During the interviews, bodily experiences were brought up by the patients as being important for them in their reasons for, and experiences from, their various use of CAM. We therefore analyzed the empirical data of the participants' bodily experiences in connection to their use of CM and/or AT. Furthermore, a theoretical approach to embodiment was applied in the analysis, because we aimed at generating empirically and theoretically based hypotheses for further research.

Ethical Considerations

The Regional Committee for Medical and Health Research Ethics and the Norwegian Data Inspectorate have approved the Registry and the research project. The participants received letters of invitation, including ethical information. Voluntary participation as well as the participants' option of withdrawal at any time was emphasized by the researchers both prior to and during the study. We provided information about the aim of the study and the research procedures. The report from the focus group interview was sent to the participants for their approval. The transcriptionist signed a written consent to professional confidentiality, and personal information that could identify the participants was deleted from the transcripts. No such information has been provided in this article.

Cancer patients can be considered as potentially vulnerable people (McIlfatrick, Sullivan, & McKenna, 2006), and so can "non-compliant" patients who choose treatment options outside the conventional health care system (Robinson & McGrail, 2004). The participants in this project had themselves reported illness experiences to a registry, which was used to recruit them for in-depth interviews. They had all reported positive courses of breast cancer, and all were in good health status when they were interviewed.

In a registry questionnaire, the patients stated that they were motivated to participate by having the opportunity of being listened to and a desire to see other patients benefiting from their experience. We aimed at conducting the interviews with sensitivity to the needs and abilities of each of the participants (Rose, 1994). None of the interviewers had treatment positions within conventional health care or the field of alternative treatment, and we were aware of the distinction between research and therapeutic interviews (McIlfatrick, Sullivan, & McKenna, 2006):

The research interviewer is, first and foremost, an investigator interested in gaining an understanding of a particular phenomenon. Although a researcher may provide information, reassurance and/or emotional support at some time during an interview, the major role is that of scientist (p. 43).

One ethical concern involved legal issues related to Norwegian legislation, affecting, for example, some patients who brought unlicensed medication with them from abroad. The Regional Committee for Medical and Health Research Ethics approved that the participants could be informed that we would not initiate legal proceedings around any cases of possible violation of the law affecting patients' use of drugs or unlicensed medication.

Results

In the analysis, we identified four settings in which the meaning and importance of bodily experiences varied: the everyday context before being diagnosed with breast cancer, the use of conventional treatment (CT), the use of complementary medicine (CM), and the use of alternative treatment (AT). Consequently, the results are presented in these

categories, with a main focus on the women's bodily experiences in relation to the use of CM and/or AT.

Bodily Experiences in the Everyday Context

A bodily experience in an everyday context was of great importance as a prelude to breast cancer being diagnosed among the women in this article. Eleven women expressed that they had bodily experiences which told them that "something was wrong" before they were diagnosed with breast cancer, whereas two women were diagnosed based on a routine mammography. Women in the first group noticed a lump in their breast or under their arm, experienced the breast as "different", or saw something in the mirror. Most of the women were quickly diagnosed within conventional health care based on these bodily experiences.

Two women had to demand additional examinations. One of these was diagnosed after she insisted that she clearly noticed three lumps in her breast. The mammography was negative, but she insisted on first being examined by ultrasound and later having a biopsy. This biopsy showed that the three lumps did exist and were malignant. These women experienced that reliance in and insistence on the correctness of their bodily experiences was a vital prerequisite for the breast cancer to be diagnosed. One of them sensed that she had cancer in the other breast even though the tests were fine:

When I first got cancer in my left breast, I had no sense of anything being wrong. The tumor was discovered at a routine mammography. But then – when the body had experienced cancer in the left breast, I suddenly knew that I had cancer in the right breast even though the tests were fine. Fortunately, my oncologist took me

seriously in spite of the test results. She ordered additional examinations and the new tumor was discovered in an early stage.

In retrospect, this woman considered her trust in her bodily experience and her doctor opening up to an equal and open communication about her experience to be of vital importance both for how her breast cancer disease turned out and for her trust in CT.

Bodily Experiences and the Use of Conventional Treatment

Nine women chose to use CT. Some of them started the treatment immediately after receiving the diagnosis. A woman in her 40's explained:

. . . and then there was no doubt that I was going to get some real treatment at the hospital and chemotherapy and everything – I am not really into – other types of medicine – I have never really had anything to do with herbal medicines and things.

In the interview this woman said that she recommended CT to everyone who asked for her advice: “What I usually say is that if you are offered chemotherapy, just take it. And if you are not offered chemotherapy, then ask to have it.” The women who started to use CT immediately all stated that they relied on conventional treatment based on medical expertise. None of them referred to bodily experiences as important in their choice and use of CT from the beginning. They trusted conventional treatments since these were safeguarded because they had been tried out on other patients' bodies. Later in their breast cancer trajectories, negative experiences from side effects became an element in their choice and use of complementary medicine as a supplement to CT.

The other women in our sample who used CT, chose to do so after some consideration. For one of them, the cancer diagnosis put her in a state of shock and chaos, in which she gave up everything and expected to die. She had always imagined that if she ever would get cancer, “I would go the natural path - and then I was in shock, and I could not do so.” She therefore accepted surgery even though she thought that alternative therapies had the holistic perspective she felt was crucial to treat her illness.

Bodily Experiences and the Use of Complementary Medicine

The women who chose to use CT, decided to use alternative therapies as supplements to CT at various stages of their cancer trajectories. Several started right after surgery. One had never planned to use CT, but felt that she was forced to accept surgery by the doctors at the hospital:

The doctors were all the time confronting me with taking into consideration that I had children and family. It seemed like I should have a bad conscience no matter what. When I commented that the illness was in my body and that what I chose to do did not concern others, it seemed like they thought I was crazy and that I had not realized the seriousness of the situation.

This woman has not visited the hospital or used any conventional therapies after she had surgery several years ago. In the interview she said, however, that she would have accepted check-ups at the hospital after her operation, but she had never been invited to come. This was a surprise to her, because she worked in the conventional health care system herself and knew the hospital routines. After being diagnosed with breast cancer, she collected a lot of information on both conventional and alternative therapies, and then

made her decision about how she wanted to treat her cancer. Her philosophy was that she herself knew what was best for her health and well-being. She believed that she could depend on the signals she sensed from her body and mind, and treat herself with alternative therapies based on her awareness of these signals. If she after all should die from cancer, this was meant to be. Then she would not have to let other control her body and she would not have to suffer from side-effects from chemotherapy and radiation during her last months.

Another woman initially accepted all the conventional treatment she was offered, but started to use alternative therapies as a supplement after her second chemotherapy treatment made her terribly sick. She lost her hair, developed large sores on her scalp, and experienced strong pain in her joints, fatigue, and nausea. Through a family member she came in contact with an alternative practitioner whom she immediately trusted, and started treatment with herbs. She expressed in the focus group interview how she in three days experienced that her well-being increased:

The tiredness was reduced by 80 % and the flu symptoms were almost gone. My scalp was healed and the pain was reduced. The bodily improvements turned my mood, my energy level raised, and I started to think that I could cope with and survive the cancer.

After these bodily experiences this woman intervened in a regulatory manner in the CT she was offered. The doctors recommended her to have surgery, which she decided to postpone because she herself thought that her tumor was too large and that she first needed more chemotherapy and herbs. She postponed the surgery several times until

she sensed by listening to her body that the synergy between chemotherapy and herbs had led to an optimal bodily effect. This woman thought that her bodily experiences and assessments based on her bodily experiences was “the correct foundation on which to make the decision about surgery.” In retrospect she experienced that she was strengthened by her cancer course, because she combined the good elements from two treatment systems based on a personal, bodily-based knowledge.

The other women in the focus group chose to supplement CT with the same herbal treatment because their oncologist recommended it. Taking the herbs, they experienced lesser side effects from the chemotherapy than the doctors had told them to expect. In the focus group interview, these women expressed that through the use of CM they learned to listen to their bodies and take responsibility for their health and well-being based on their bodily experiences. One of them pointed out that it “had been a fantastic relief and support” that she could share her bodily experiences with her doctor because he had initiated her use of the alternative therapy.

Another woman among the CM users said that she fully trusted conventional health care and therefore accepted surgery and several chemotherapy courses. Despite her trust, she discontinued the anti-oestrogen treatment which the doctors recommended her to take for five years. Her argument was that this treatment was part of a standardized program that was not based on her as an individual. She did not like to take a drug that made everything in her body elderly, and she experienced it as being “really bad” to have to take a medicine each day that reminded her of her illness. She read some literature about anti-oestrogen treatment and then decided to discontinue it. The doctors recommended her to continue, “. . . but I didn’t do that. It was my choice.” Even though

this woman accepted almost all the conventional therapies she was offered, she at the same time thought that “. . . now I will do as much as I can myself.” She did not believe in herbal medicines and alternative therapies, but thought that it could not hurt her to try them. She read books about diet, visited a dietician a couple of times and then changed her diet. She exercised, tried acupuncture and chiropractic treatments, ate soy products that were supposed to help her avoid menopause and took ginger to combat the nausea associated with the chemotherapy. This woman claimed in the interview that her use of CM had positive effects on her body in various ways. She did, however, choose not to continue to have mistletoe injections because she experienced that those made her body swell. It was her experience that her choice of discontinuing the anti-oestrogen treatment and combining conventional and alternative therapies strengthened her general physical condition, which she understood as crucial for how well she handled the chemotherapy and how she evaded menopausal symptoms.

An elderly woman we interviewed had fully trusted the conventional health care system during a long life before she was diagnosed with breast cancer. When she wanted to share her positive bodily experiences from the use of shark cartilage and vitamins with her oncologist, she felt that she was met in a very negative manner. She experienced the oncologist as sarcastic and not interested in her positive bodily effects from the use of alternative therapies. In addition, she felt that the oncologist tried to deny the medical test results that she perceived as evidence for her positive effect of CM. She lost trust in the oncologist and she decided to decline conventional treatment and use only alternative treatment if she ever becomes ill with cancer again.

Bodily Experiences and the Use of Alternative Treatment

Soon after being diagnosed, four of the women in our sample decided to decline conventional treatment and use AT. This decision was based on their experiences of dramatic, fatal cancer courses in their close families, medical knowledge about side-effects from conventional cancer therapies, as well as both medical and lay information about therapeutic options. Their common experience was that focusing on bodily experiences and personal efforts, which they all found to be crucial for their cancer treatment, was not accepted within the conventional health care system. One of them was an experienced nurse within the conventional health care herself. Another had to fight for a medical examination based on her bodily experiences for a long period before her breast cancer was medically diagnosed.

Based on their experiences, these women perceived conventional breast cancer treatment as a considerable health risk. They collected a lot of information about treatment options immediately after their diagnosis, and chose to use different alternative therapies and practitioners based on what they found to be best for their bodies. Three of them visited clinics where they learnt to manage their cancer from a therapeutic perspective that included both body and mind. One of these clinics had its own medically educated doctors. The clinic was, however, defined as AT in this article because the Norwegian hospital doctors were fundamentally skeptical to this foreign hospital, the medical skills of these doctors, and the treatment that this clinic offered.

These women all made radical changes in their diet, and several of them also made other vital changes in their personal life. They continually performed self-examination, experienced that their cancer tumors became smaller, and concluded, based on these bodily experiences, that the use of AT had positive effects. Several of them

perceived their cancer as a chronic condition which they controlled by the use of alternative therapies based on their bodily experiences. When these women sensed something they interpreted as a negative cancer development, they adjusted their efforts by the use of diets and other types of AT: “It is about a couple of times a year – it is so little – but when it moves, I kill what is growing, and after a week I do not notice anything.”

For these women, their bodily experiences were of vital importance, and AT was integrated into their daily life. Many of the alternative therapies demanded an extensive personal effort. The therapies was continuously tested based on bodily experiences such as skin which tingled, tumors growing smaller, sores that healed, vomiting that stopped, energy that grew stronger or weaker, the condition of the skin, the hair, and the nails, and the shine in the eyes. Bodily experiences formed the basis for these women’s assessment of the character and activity of their cancer illness, and had a vital influence on their decisions regarding whether, when, and for how long to make an effort in their recovery and well-being.

Using, then Declining Conventional Treatment

Two of the women used CT until they had gone through surgery. One of them felt that she was forced by the doctors to accept surgery, and it was of vital importance to her to take control of the access to her body. After the surgery she used the Internet and a variety of literature as a basis for her choice and use of AT.

The other woman who first used and then declined CT chose to accept surgery because she felt she did not have “sufficient power and courage to say no” to CT during the immediate period after the diagnosis. She had then gone through a personal crisis

with a breakup of her relationship, a limited amount of time with her children, and the loss of a business which she had put her heart and soul into for years. After the surgery, she had an important talk with one of her children and decided to fight to survive her breast cancer. She then checked out many available alternative therapies and read quite a bit of literature. Based on this, she decided to decline chemotherapy and radiation, and use alternative therapies as a supplement to check-ups at the hospital. According to this woman, her oncologist was very upset when she told her about this decision, and wrote a document saying that the hospital had no responsibility for her as long as she insisted on her treatment choices. She felt abandoned by the conventional health care system and was using AT for a period of time.

This woman then tested several alternative therapies (e.g. diet and reflexology) which she experienced as having no effect. In her opinion, these alternative therapies were directed toward the physical body only, and what she needed was therapies that were orientated toward the cause of her breast cancer. In the interview this woman said that she became ill because of a big, emotional shock and the extensive changes that this had led to in her life. For her, the road to healing was therapies that would release emotions: “So I experienced that my approach was to go back to what caused the illness. And then harmonize body and soul and emotions – and then the body would do its own natural healing.” For her, the breast cancer was the introduction to an all-embracing process of learning and change. After declining CT, she was actively using her bodily experiences to check “whether there is a balance between body, soul, and emotions”, and “whether the body’s self-healing powers are working.”

Discussion

Theoretical approach to “embodiment”

We find Thomas Csordas’ approach to bodily experiences and embodiment (Csordas 1990, 1999a, 1999b) relevant for use in a theory-based analysis of modes of embodiment among the breast cancer patients in this study.

Csordas’ approach to embodiment is developed from the perspective of psychological anthropology, and leans strongly in the direction of the phenomenology of Merleau-Ponty (Csordas 1990). This perspective of experience and action is also inspired by social constructivism and semiotic perspectives, and focuses on actor, meaning, and action (Grøn 2004). Csordas (1999b) has emphasized the importance of making a distinction between “body” and “embodiment”:

If embodiment is an existential condition in which the body is the subjective source or intersubjective ground of experience, then studies under the rubric of embodiment are not “about” the body per se. Instead they are about culture and experience insofar as these can be understood from the standpoint of bodily being-in-the-world. (p.143)

Moreover, Csordas (1999a) has argued that embodiment is the existential ground of culture and self:

The central issue is the manner in which the body is an existential condition of life – of course we have bodies, but there are multiple modes of embodiment, and it is the modulations of embodiment that are critical for the understanding of culture (pp. 181-182).

We can say that access to embodiment takes place through action, increased bodily awareness, and a verbalizing of bodily experiences and knowledge. Bodily awareness is here understood as the process through which people give discursive attention to the body in various cultural contexts. The body is perceived as a “body self”, i.e. body and mind are mutually connected in a dialectical relationship (Csordas, 1999a; Thomas-MacLean, 2004).

Modes of Embodiment among Breast Cancer Patients Using Complementary Medicine and Alternative Treatment

The patients in our study were positioned both inside and outside the conventional health care system because of their treatment choices. Within the frame of Csordas’ theory of embodiment, the conventional health care systems in Scandinavian welfare states can be perceived as cultures of health and well-being in relation to Scandinavian CM and AT users’ bodily being-in-the-world. The conventional health care systems in Norway and Denmark are covering most of the expenses of health care for the citizens, as long as the treatments are based on established Western medical knowledge. In general, alternative therapies are paid out of the patients’ own pockets, although some patients receive alternative therapies within the conventional health care system (Fønnebø & Launsø, 2009). Trust in the conventional health care system and health care professionals can be perceived as embodied in many citizens, although these trust relations and the traditional evidence-based culture of health care delivery are being challenged by active “expert” patients in a post-traditional culture of health care (Rowe & Calnan, 2006).

The empirical analysis suggests that bodily experiences and embodied knowledge play different roles according to the positions that these breast cancer women have in

relation to the conventional health care systems in Norway and Denmark. We argue that it can be of relevance to separate between patients using complementary medicine and those using alternative treatment both empirically and theoretically when exploring some issues regarding CAM users, e.g. the meaning and importance of their bodily experiences. The body is a biological, material entity and embodiment is an indeterminate methodological field defined by perceptual experience and by mode of presence and engagement in the world (Csordas, 1999a):

Embodiment is about neither behavior nor essence per se, but about experience and subjectivity, and understanding these in a function of interpreting action in different modes and expression in different idioms (p. 184).

Csordas (1990) has argued that an analysis of perception (the preobjective) and practice grounded in the body leads to collapse of the conventional distinction between subject and object:

This collapse allows us to investigate how cultural objects (including selves) are constituted or objectified, not in the processes of ontogenesis and child socialization, but in the ongoing indeterminacy and flux of adult cultural life (p. 40).

In our analysis we used bodily experiences as a productive starting point for analyzing culture and self, and perceived Scandinavian welfare states as cultures of health and well-being. We knew that medical and patient perspectives on health and well-being often diverge. Modern health care users who choose to use CAM often base their treatment

choices on personal experiences and lay knowledge of significant others, whereas the Scandinavian conventional health care systems are based on medical expert knowledge (Salamonsen et al., 2010; Boon et al., 1999; Broome, 2009a; Thorne, Paterson & Russell, 2003, Tovey & Broom, 2007). Inspired by Csordas' methodological and theoretical approach to embodiment, we identified three central modes of embodiment related to the use of complementary medicine and alternative treatment among the women we interviewed: "the right to one's body", "the body used as a gauge", and "the body used as a guide". Embodiment, in this sense, is a methodological standpoint in which bodily experiences are understood to be the existential ground of culture and self, and therefore a valuable starting point for their analysis (Csordas, 1999a).

The Right to One's Body

All the women we interviewed strongly emphasized the importance of having the rights to their bodies. "The right to one's body" is a central principle in human rights, and can, according to our theoretical standpoint, be perceived as embodied in the women as citizens before they became breast cancer patients. In general, the women expressed that jurisdiction over their bodies implied that they could decide what their bodies should be exposed to or which doctors they would be able to relate to. As patients in the conventional health care system, many of the women had experienced that their right to their body was not in focus, or they felt that their jurisdiction to their bodies was disrespected by conventional doctors and nurses. The users of complementary medicine were particularly referring to "the right to one's body" when they chose which parts of the recommended conventional treatment they wanted to use. Among those who only used alternative therapies, "the right to ones' body" represented an important aspect of

their perspectives on negative experiences within the conventional health care system in the past, followed by their choice to decline CT.

The Body as a Gauge

Trust in conventional health care can be perceived as embodied in many citizens (Rowe & Calnan, 2006). In addition, we have argued that “the right to one’s body” can be perceived as embodied. Many of the patients we interviewed experienced a conflict between their embodied trust in conventional health care and the way they felt their right to their bodies were limited or neglected when they met the conventional health care system as breast cancer patients. The CM users in our sample experienced health personnel’s negative response to their use of CM as one such limitation. They perceived various conventional and alternative treatment options and treatment providers as a tool kit. They picked their tools on a pragmatic basis, without considering the classification of the treatment or treatment provider to be of vital importance.

When the CM users started to use alternative therapies as a supplement to conventional treatment, bodily experiences were perceived as important in testing out various alternative therapies to find a tool that had positive bodily effects. These “test results”, which were carried out by using “the body as a gauge”, were gradually used as a background experience for these women’s evaluation of their bodily effects of CT. They experienced an increased bodily awareness through their use of alternative therapies. Later in the course of breast cancer, “the body as a gauge” was used as a background for discussing bodily effects from CT with their doctors within the conventional health care system. The CM users trusted medical knowledge, but they also found their bodily

experiences relevant to consider with regard to their treatment choices, health and well-being.

The Body as a Guide

AT users in our sample who chose to decline conventional treatment made this decision based on a risk assessment. They based their decisions on their general knowledge of side-effects from various conventional therapies, as well as their embodied knowledge of their own and close relatives' former negative bodily experiences within the conventional health care system. Based on their embodied knowledge from theirs and significant others' bodily experiences with CT, they had a fundamental distrust in the conventional health care system. These women perceived their breast cancer as a result of an imbalance that always potentially exists. At the starting point of their course of breast cancer, they noticed an imbalance in their bodies. These bodily experiences created the background for the medical breast cancer diagnosis. Instead of continuing conventional treatment after being diagnosed, those who used alternative therapies exclusively chose to try various therapies to create a balance in their bodies. These women chose AT because they found that alternative practitioners often shared their perspectives on health and illness, which included the idea of imbalance and that bodily energies and the body's self-healing resources are perceived as vitally important for patients' recovery and well-being.

In contrast to the pragmatic users of complementary medicine, who did not consider the classification of the treatment or treatment provider to be of vital importance and who used "the body as a gauge", the AT users focused on the philosophical values integrated in conventional medicine versus alternative therapies. They wanted to use

treatments where the body was perceived as an experiencing subject. They found the philosophical values of alternative therapies and practitioners to correspond with “the right to one’s body” and their personal perspectives on body, illness and treatment. In these AT users’ perspective, the body holds the authority, and their breast cancer trajectories were perceived as never-ending learning processes with a focus on the relationship between body and mind. They emphasized the importance of the possibility to learn several of the alternative therapies, so these therapies could be integrated in their everyday life. The alternative therapies were constantly evaluated by using “the body as a guide”. By using “the body as a guide”, the AT users experienced themselves as actors in healing processes which included their bodies’ self-healing resources, and they described their focus on bodily awareness as vitally important for their recovery and well-being. Personal experience from the AT users life world, as well as the philosophies and methods of several alternative therapies and therapists, were emphasized as more important and trustworthy than medical expert knowledge.

Lay Knowledge versus Medical (Expert) Knowledge

In this article, we describe patients who have established their own personal knowledge including both medical expert knowledge and lay embodied knowledge based on bodily experiences. Our main hypothesis is that there is a possible connection between the patients’ present positions toward various systems of health care, and the importance and meaning of bodily experiences as seen from their perspective.

From other studies, we know that cancer patients often seem to include lay knowledge as important elements in their treatment choices (Boon et al., 1999, Broom 2009a, Tovey & Broom, 2007). Verhoef and colleagues (2007) found that many cancer

patients did not value scientific evidence as highly as health care providers did, whereas Boon and colleagues (1999) demonstrated that women with breast cancer faced making decisions based on very little objective, scientific evidence. The women were attracted to alternative therapies because of a general belief in “the alternative paradigm”, and they had bad experiences from CT. Broom (2009a) described therapeutic decision making among cancer patients who use CAM as based on a combination of scientific expertise, embodied physicality and social knowledge. Thomas-MacLean (2004) found that breast cancer patients’ reliance on and rejection of medicalized understandings of their condition were based on embodied memories of treatment.

In a study of patients from the Registry, Kruse (2009) revealed how interpretations of causes of illness represented interpretations of the past, the present and the future and how their illnesses were perceived as never-ending learning processes. These interpretations were used by the patients as a framework in respect to their present personal efforts and treatment choices. Such a learning process has been described by Williams (2006) as a re-embodiment involving considerable biographical work.

Kleinman (1981) has pointed out that there will always be a potential gap between lived experience of illness (lay knowledge) and medical models that classify diseases (expert knowledge). A key concern in the sociology of CAM is increased individualization in contemporary cultural practice (Broom 2009a; McClean & Shaw, 2005), described by Giddens (1991) as one of the consequences of late modernity. Laypeople, in their differential engagement with biomedical knowledge, seek to adopt, mimic, critique, or rewrite experts’ positions (McClean & Shaw, 2005). The modern health care users can be perceived as active managers and explorers of therapeutic

options rather than passive recipients of expertise. They search for knowledge that is meaningful in their everyday life with their disease, and often share “the alternative paradigm” (Salamonsen et al., 2010; Boon et al., 1999; Broom 2009a; Launsø & Rieper, 2006; Thorne, Paterson & Russell, 2003). Prior (2003) has discussed the phenomenon of “the knowledgeable patient” and the limits of lay versus medical knowledge. Laypeople can be perceived as experts by virtue of “having experience.” They have valuable knowledge about their bodies, and they often have detailed knowledge of other people as well as themselves and the circumstances in which they live. Prior still emphasizes that experience on its own is rarely sufficient for understanding the technical complexities of disease causation, its consequences or its management (Prior 2003).

Csordas (1990) has argued that a paradigm of embodiment can be elaborated for the study of culture and the self, representing a consistent methodological perspective that encourages reanalysis of existing data and suggests new questions for empirical research. This article describes a cultural context (Scandinavian welfare states) in which the citizens are supposed to trust and receive CT financed by the health authorities (Bergh & Bjørnskov, 2011). At the same time an increasing use of CAM is observed in Scandinavia (Hanssen et al., 2005; Kimby et al., 2003; Molassiotis et al., 2006). 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 (McKenzie & Oliphant, 2010; Rowe & Calnan, 2006). Fox and Ward (2006) have argued that the constellation of health identities around lay experiential models of health and the body can be understood as reflecting the diversity of relationships in a technology-driven, consumer-oriented and media-saturated society. We link this diversity

of relationships to Csordas' theory of embodiment in which he claims that multiple modulations of embodiment are critical for the understanding of culture (Csordas, 1999a), in this case how modern patients relate to various systems of treatment in Scandinavian welfare states.

Walking the Boundaries – Patients and Various Systems of Treatment

CAM use is an area where patient and medical perspectives often diverge (Tovey & Broom, 2007), and the use of CAM in Western countries has been interpreted as both a positive choice toward CAM and a negative choice toward CT (Astin, 1998; Goldstein, 2003; Siahpush, 1998; Truant & Bottorff, 1999; Verhoef & White, 2002). Patients using CM or AT can be perceived as resisting consumers (Fox & Ward, 2006) and boundary walkers, walking the boundaries between various treatment systems (Salamonsen et al., 2010, Broom 2009a).

We find links between the modes of embodiment revealed in our analysis and other studies of modern health care users based on bodily perspectives. Physicians often seem to assume that patients will be able to cognitively distance themselves from their bodies, or disembody (MacLachlan, 2006). From a patient perspective, however, the encounter between the patient and CAM can produce derivative benefits such as a sense of bodily responsibility that induces new health practices (Baarts & Pedersen, 2009). Gale (2010) has discussed the “body work” undertaken by CAM practitioners, based on an idea of “body-talk”. Here, the body is seen as being able to communicate its distress and needs, and the embodied patient is not perceived as a passive recipient of health-care. Lende and Lachiondo (2008:226) have argued in line with this that we need “embodied interventions”.

Although patients we interviewed experienced positive impacts from the use of bodily experiences as a basis for treatment choices and from positive experiences of CAM engagement, it is important to keep safety in mind. Several potential health related risks of use of CM or AT should be considered such as the unregulated nature of various CAM products and CAM practitioners in many countries (World Health Organization, 2002). Studies have focused on e.g., interaction between herbs and pharmaceuticals (Izzo & Ernst, 2009), the refusal of important conventional treatment and delay of medical diagnosis (Malik & Gopalan, 2003), and problematic notions of self-healing and hyperpositivity that involve restrictive notions of self-discipline (Broom 2009b). McClean (2005) has concluded that CAM practices are de-politicising and that they manifest a “blame-the victim” ideology. Kruse (2009) revealed how patients searched for a balance between a destructive self-reproach and a productive sense of responsibility in terms of their illness and their personal efforts.

We perceive Norway and Denmark as cultures of health and well-being with complex, changing, and competing health paradigms (Hughner & Kleine, 2008). In such a situation, we argue that there is a need for a more patient-centered approach (Mead & Bower, 2000) in public health care, which includes patients’ experience-based perspectives on health and well-being. Modern health care users expect doctors to be less dominant during interaction (Wright, Sparks, & O’Hair, 2008), but doctors are still central to patients’ treatment choices and patients tend to adhere more to recommended treatments when they find doctor-patient communication to be equal and open-minded (Arora, 2003; Mocherla, Raman, & Holden, 2011). A patient-centred approach is crucial to optimize patients’ treatment choices and treatment outcomes in modern welfare states,

where complex and growing unofficial health care systems and change in patients' health strategies based on e.g. various modes of embodiment are important elements in the landscape of health care (Baarts & Pedersen, 2009; Bodeker, Kronenberg, & Burford, 2007; Coulter & Ellins, 2007; Håkanson, Sahlberg-Blom, & Ternstedt, 2010).

Methodological Aspects

So far most CAM studies of breast cancer patients have explored whether or not these patients use CAM, or have been designed as effect studies of outcomes of specific CAM modalities. We argue that CAM research needs more theoretical input and mixed and qualitative research designs to develop a deeper understanding of patients' complex reasons for, and experiences from, the use of CAM. Furthermore, we argue that a distinction between CAM used as a supplement versus an alternative to conventional medicine can be relevant for a deeper understanding of some issues, e.g. the meaning and importance of CAM users' bodily experiences. In this study we chose a qualitative design and an inductive and explorative approach to learn more about patients' "exceptionally positive" experiences from their use of CM or AT in a broad perspective.

We have argued that the Registry is a valuable source for in-depth studies of what different patients groups actually find useful in CM or AT, and why. Self-selection of patients with positive experiences from CAM use implies, however, that no representative estimate of breast cancer patients' bodily experiences can be made. It could be argued that self-selection represents a threat to validity, and that a possible selection bias is that patients in our sample are happy and familiar with the concept of sharing positive experiences from the use of CAM. One of the very strengths of

qualitative research, its capacity to discover new explanations, may pose a distinctive problem, given the selection of extreme or deviant cases (Collier & Mahoney, 1996):

However, this distinctive contribution, involving complexification based on extreme cases, may in turn leave case-study and small-N researchers vulnerable to a distinctive form of systematic error that will occur if they overlook the fact that they are working with a truncated sample and proceed to generalize their newly discovered explanations to the full spectrum of cases. This would be a mistake, given that this smaller set of cases is likely to be unrepresentative because of selection bias (p. 71).

In this article our aim was not to make empirical generalizations, but to transfer knowledge as working hypotheses which can be a valuable contribution on unexplored topics (Gobo, 2008). In the analysis of the qualitative interviews, we identified bodily experiences in connection to the use of CM and AT as an important empirical pattern that deserves to be further explored in various research designs. We used Csordas' approach to embodiment as a paradigm in our analysis, as a methodological and theoretical perspective that suggests new questions for empirical research (Csordas, 1990).

Quantitative studies in a random sample of women with breast cancer, as well as qualitative studies among breast cancer patients who have negative or no experiences from the use of CM or AT, may reveal other modes of embodiment among breast cancer patients than those found in the group of patients we studied.

We chose qualitative interviews as our primary source of information because we wanted to study experiences of which we had little previous knowledge, and the patients'

perspectives were the source of new knowledge (Minichiello et al., 1990). The interviews were open-ended, with a broad focus on the many and complex aspects of being a patient between various systems of treatment. As such, the boundary-crossing and sense-making practices of patients need more attention in studies of health and illness (Broom, 2009a). We sought idiographic knowledge (Gobo, 2004) and wanted “thick” descriptions of individual and unique aspects of experiencing illness as meaning and intentionality (Turner & Samson, 1995). We conducted one focus group interview where important themes were explored based on a discussion between the three women in the group. As mentioned, we had to base our analysis of the focus group interview on an extended report and not on a full transcription. This situation limited the possibility to explore how the three participants in detail articulated, opposed, and eventually changed their accounts through their interaction (Barbour & Kitzinger, 1999). We gained extended information, however, from the discussion of experiences in general and from these patients’ perspectives of the meaning and importance of bodily experiences in their evaluation of CT and the alternative therapy from which they all had bodily experiences.

We ensured the internal validity by the three authors reading through the available text data on all the 19 breast cancer patients in the Registry, applying theoretical approaches to our empirical data, and comparing our data and interpretations with previous studies. The results have been presented to closed circles of patient associations, conventional health care providers, alternative practitioners, and researchers within the field of CAM who recognize our empirical findings and the theoretical understanding of our findings. Based on this, we claim that our empirical and theoretical interpretations might have some power as hypotheses. The findings presented in this article are tentative,

however, and our hypotheses need to be further explored, both among breast cancer patients and patients with other diseases who are frequent users of CAM. In a long-term perspective, we think that qualitative research which transfers working hypotheses (Gobo, 2008) on the use of CM and AT can contribute to a more patient-centered model of care (Mead & Bower, 2000) both in the conventional health care system and among alternative practitioners. Todres et al. (2009) have argued that through its illumination of people's perspectives and experiences, qualitative research has contributed a particular type of useful evidence for caring practices, and that qualitative research has the potential to be meaningfully translated into practice in ways that place people as human beings at the center of care.

Conclusion

Our results suggest that the meaning and importance of bodily experiences and embodied knowledge can depend on patients' present position toward the conventional health care system and the field of alternative treatment. Bodily experiences and embodied knowledge were of vital importance to the women in our sample both before medical diagnosis and as AT users using their body as an exclusive guide for their treatment choices. The women using CM related to bodily experiences and embodied knowledge, as well as to medical expertise based on knowledge from effect studies of bodies of unfamiliar others. Bodily experiences and embodied knowledge played an important role for the users of CM in doctor-patient communication regarding their use of conventional treatment. On the basis of these empirical patterns, we introduce three central modes of embodiment in breast cancer patients using CM or AT: the right to one's body, the body used as a gauge and the body used as a guide. Breast cancer patients' and other patient

groups' positioning between various systems of treatment should be further explored from a bodily perspective to obtain more knowledge about lay expertise as it pertains to the experienced benefits and disadvantages of CAM usage.

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