



Individual Advanced Research Opportunities Program

Research Report

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Why are so many Czech Women Dying of Breast Cancer?: Understanding Illness, Detection, and Treatment in the Czech Republic

Topic of Research

Breast cancer can be devastating and fatal for a woman, yet if detected and treated in its early stages, it is curable. In the Czech Republic, breast cancer continues to be the most frequently diagnosed cancer and the leading cause of death among women with malignant tumor growths (Gatek et al. 2000; Celko 1996). As many as 45% of newly diagnosed cases of breast cancer among women in the Czech Republic are discovered in the later stages of the disease, significantly decreasing a woman's chances of survival (Gatek et al. 2000; Machacek 1996). To further compound these statistics, a national screening program for the early detection of breast tumors is not yet available for all women.

Little is known regarding how women living in the Czech Republic are dealing with breast cancer outside of biomedicine. Such information is vital for understanding the cultural, social and behavioral influences that shape the way health is maintained and illness is conceptualized among a group of people. My IREX project proposal outlined several questions that I sought answers to during my year in the Czech Republic, 2001-2002:

- Do Czech women delay seeking medical treatment when they sense something abnormal in their breast or surrounding tissue? If so, why?
- To what extent do folk beliefs about cancer, how it develops, and how it should be treated affect how a woman deals with this disease in her personal life?
- What types of healing strategies do Czech women use in addition to or outside of biomedicine (including folk medicine, complementary and/or alternative therapies) and when and how do they make decisions about the therapies they choose?
- Finally, how do Czech women conceptualize their bodies and femininity in post communist Czech Republic and cope with the changes in their bodies following lumpectomy and/or mastectomy?

Relevance and Contribution to Field

Research in the United States, as well as in other parts of the world, suggests that patients often use alternative and folk therapies to complement their biomedical cancer treatment. Patients do so increasingly, in part because of their growing frustration with biomedicine's ability to treat cancer, a need for psychological support, and a desire for a more active role in their treatment.

Biomedical research and treatment of breast cancer continues to improve in the Czech Republic, and in many cases, is comparable to treatment in the United States. However, a comprehensive study of the prevalence, types, and reasons for folk and alternative therapies used in the Czech Republic has not yet been conducted. Likewise, a thorough examination of the psychological and social aspects of the disease has also been neglected. Social stigma, taboos, where a woman can obtain information about the disease, and who she is able to speak with about her disease are all important factors that not only affect women diagnosed with breast cancer, but also influence and shape other's perceptions of the disease experience. The only study in the Czech Republic to question why Czech women delay in seeking treatment when they suspect breast cancer concluded that fear was the most significant reason for this delay (Machacek 1996).

At the most basic level, my research encouraged women to speak freely about their experience with breast cancer. Many of the women that I interviewed, particularly those outside of large cities like Prague and Brno, were unable to speak about this event in their daily lives and rarely shared their feelings with others. Perhaps even more significant is that these women often lacked a vocabulary for speaking about their experience and referred to their breast cancer simply as "my problem."

Although many of the cancer centers in larger cities offer the most modern and up-to-date therapies, the education and openness about the disease, as well as the resources available for psychological and social support are comparable to how cancer was perceived in the United States 20 to 30 years ago. Not only will

this study give voice to an experience that many women find difficult to speak about, it will also provide much needed information to the biomedical community in need of a more holistic understanding of this experience.

Approach and Research Methodology

For this project I am combining two approaches, those of folkloristics and medical anthropology, to organize and analyze the material related to folk/alternative therapies and illness narratives. My methodology is also a combination of qualitative and quantitative methods, as well as my observations.

Since the revolution in 1989, Western forms of alternative medicine have continued to infiltrate Czech culture and have become increasingly popular: for example, acupuncture, Traditional Chinese medicine, and energy healing are practiced in even small cities. At the same time, traditional forms of healing such as mineral baths, wise women, and healers, known as *lecitele*, are frequently sought out for treating a wide range of ailments. Many of the biomedical practitioners that I spoke with for this research viewed folk/alternative therapies both skeptically and negatively. For my inquiry into the folk and alternative therapies that may be used to treat breast cancer I am relying on Bonnie O'Connor's idea of "vernacular health belief systems" which considers what people *actually* do and believe when they are sick as compared to what they *ought* to do and believe by an official entity such as biomedicine (O'Connor 1995). For example, a large majority of women believed that their breast cancer was caused by bruising their breast. Similarly, many women spent significant amounts of money on Wobenzym, an enzyme, taken several times a day to treat their cancer and lymphedema, but not scientifically proven nor prescribed by their physician.

To complement my investigation of the folk/alternative therapies, I also encouraged my informants to "tell me about their experience." The narrative portion of this research evolves from the idea that when we become ill, one of the most compelling ways that we can communicate this experience is through the story, or *illness narrative*, that we create and tell about this event in our lives. Such narratives are essential to shed light upon how individuals make sense of their illness experience, decide treatment options, obtain control of their experience, and deal with changes in their identity.

For the quantitative portion of this research, I worked with the Masaryk Memorial Cancer Institute, Brno, and my primary advisor Jan Zaloudik, M.D., Ph.D., provided me with a list of 1,000 names of women who had been treated at MOU within the past five years. I first contacted these women by letter explaining my research project. Each letter had a reply card that could be sent back to me if a woman was interested in meeting with me to be interviewed, receive the questionnaire, or both. Pilot tests of the questionnaire were administered from October to January and a final version of the questionnaire was created by the

end of January. Questionnaires were sent out at the beginning of February and I received responses through the middle of July. Of the 1,000 women who were initially contacted, 700 women were interested in receiving the questionnaire and being interviewed. Of the 700 women who were sent a questionnaire, 560 returned a completed questionnaire. The questionnaire included questions concerning demographics, therapies (type, frequency, and use); biomedical treatment; social support; beliefs about cancer; support groups attended; and the amount of time between suspecting a problem in the breast and seeking biomedical treatment.

One of my biggest obstacles with the questionnaire stemmed from the language of cancer, which is highly coded. Czech doctors are startlingly vague when they discuss the diagnosis of cancer with a patient. For example, with the exception of television programs where the term “breast cancer” might be used in an infomercial, doctors and patients often avoid using expressions like “your breast cancer” or “my cancer.” Instead, the disease is more often discussed in vague terms like “tumor,” “tumor of the breast” or simply “my problem” avoiding the word cancer and emphasizing the word tumor which can be either benign or malignant. The root of the word for cancer (*rakovina*) in Czech is the same word for crab (*rak*) and several women relayed disgust at the image of a “dirty crab eating away at the breast.” What ensued was a cycle of doctors avoiding the terminology to protect their patients and patients avoiding the terminology to avoid a worse condition. These women often alluded to the idea that they could survive a “tumor of the breast” but could not survive “breast cancer,” despite that in many instances women knew that they were one and the same.

For the qualitative portion of this research, I rented a car which allowed me to conduct interviews throughout the Czech Republic, including the smaller cities and villages where public transportation was less frequent or not available at all. Twenty of the interviews were conducted with women who were diagnosed and treated for breast cancer within the past five years. While most of the patients came from Moravia, others came from northern and southern Bohemia, as well as Silesia. Most of the women also preferred to be interviewed in their homes, rather than in the hospital setting. These interviews ranged from 1 to 3 hours and will be coded and analyzed in the results section of my research. The remaining twenty interviews were less formal and were conducted to enhance my base of knowledge. These interviews took place with surgeons, oncologists, mammographers, support workers and educators. Each interview was tape-recorded and following the interview, I took notes in a field journal about the setting and my observations.

In Prague, I also worked with two separate grassroots organizations, Mammahelp and Jantar, developed by Jana Drexlerova and Marie Koudelkova, respectively. Both women had been treated for breast cancer and each was inspired to create a support center to help others after diagnosis and treatment.

These centers encouraged women to talk freely about their experience, find information, and provided long-term emotional and psychological support.

Summary of Research Findings and Preliminary Conclusions

Although I am in the midst of statistically analyzing my research, I suspect that the final results will reveal interesting trends. My preliminary findings suggest that the women who participated in my research did not delay seeking treatment to see a healer, as argued by other scholars. In fact, a large majority of the women, who were relatively healthy and between 1-5 years following their treatment, sought medical treatment within a few weeks after detecting something abnormal. My preliminary findings also suggest that while some women did use folk and alternative therapies to supplement their medical treatment, such as going to a healer, using herbs, or changing their diet, the majority of women did not appear to do so.

Many women also felt that their breast cancer was caused by injury to the breast and stress in their lives, which they felt increased significantly after the fall of communism. In general, cancer education outside of the larger cities like Prague and Brno is often nonexistent. Many of the women I interviewed were never taught how to properly do a breast exam and also did not know who they should see if they had a question. These women also felt that prior to 1989 they did not need to be concerned about their health care. They were told when to come in for their yearly exam (*kontrola*), and how to maintain their health. After 1989, many felt that one's health became an individual responsibility and one that they have neglected. Even female doctors that were interviewed described neglecting their own health care due to lack of time and self-discipline.

Likewise, the comparison between the larger cities and smaller towns and villages already suggests differences in availability of resources, information, and the overall experience. Outside of the larger cities like Prague and Brno, taboos and social stigma still exist for many individuals who are diagnosed with this disease. Where a woman can get information about breast cancer prior to and following a diagnosis is unclear and not standard. Despite the organization of support centers, women often felt limited to family members when they needed to discuss problems, fears, and depression following diagnosis and treatment. Many described having a difficult time throughout their treatment, and at the same time insisted that they did not need to speak to anyone.

Finally, following diagnosis and treatment of breast cancer, women are labeled, and even referred to themselves, as "handicapped." Very few women returned to work following their diagnosis regardless of how young they were or how they felt. At the start of a woman's treatment for the disease, the government provides a disability payment that can be continued for the rest of her life. Although I did encounter a few women who absolutely refused to accept this title or payment, they were rare. I will be pursuing this idea further in my dissertation.

Suggestions for future research agendas in your field for the scholarly community.

Social scientists that study breast cancer in the United States often track a large number of patients for several years. This type of long-term qualitative inquiry is ideal to fully understand the complexity of living with cancer. Although my preliminary results do not suggest that women delayed seeking treatment as reported by other scholars, my study was limited to fairly healthy women who had successfully responded to their treatment. Those women who had died or were not healthy and able to participate were not included in this project. A larger study including this set of women is essential as this group may contain a high number of women diagnosed in the later stages of the disease. Likewise, a national assessment of the type, frequency and use of folk and alternative therapies that includes healthy and sick people would also continue to broaden our understanding of Czech health beliefs and practices.

Finally, a larger inquiry into the “handicapped identity” could potentially have significant influence on the number of individuals who are able to return to a normal life after being treated for cancer or other illnesses.

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