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## **"A DIRTY CRAB EATING AWAY AT THE BREAST": THE STIGMA OF CANCER IN POST-SOCIALIST CZECH REPUBLIC**

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*"The word cancer does not form in my mouth  
...I say tumor, that I had a tumor."*

(Věra, age 56)

### **The Stigma of Cancer**

Few diseases in human history have held a stigma as strong and as lasting as that of cancer. Credited to the Greek physician Hippocrates around 400 BC, the term *karkinos* in Greek, or *cancer* in Latin, described the finger-like projections reaching out from a central growth that called to mind the shape of a crab (Cantor 1993). In the late 19<sup>th</sup> and early 20<sup>th</sup> centuries in the United States, as well as in Europe, cancer was thought to be a contagious affliction and a punishment for a terrible deed. Often blamed on weakness of character, patients shamed their families and were blamed for "bringing it on themselves." Patients feared treatment, and the idea that the disease was an act of retribution kept sufferers from discussing their condition with doctors and family members (Harpham and Hoel 1997).

In the midst of socialism the stigma of cancer was prevalent throughout Central and Eastern Europe. Many people felt disgraced by the diagnosis of cancer (Maciejewski et al. 1997) and people in the former Czechoslovakia considered cancer to be a "leprosy-like" disease that could be transmitted through a handshake (*Times of India* 2001). Such misunderstanding was commonplace during socialism, and few patients dared to reveal that they had the disease. Limited access to physicians, poor hospital conditions, and lack of medication caused patients from socialist countries to lose faith in the effectiveness of the biomedical treatments prescribed by their physicians (Maciejewski et al. 1997).

According to sociologist Hana Havelková, during socialism, "social problems were often declared 'solved' and the population partly believed it and partly knew that nothing else could be done from below" (Havelková 1999:

70). The belief that cancer might be contagious gave rise to the perception that cancer, in addition to being a biomedically defined disease, was also a "social problem." As with other "social problems" during this time, the reality of cancer was often ignored. One woman recalled, "During communism it was as if this disease did not exist. We were supposed to be a healthy nation, and cancer, nobody wanted to know about it."

Recent statistics indicate that breast cancer in the Czech Republic continues to be the most frequently diagnosed cancer and the leading cause of death among women with malignant tumor growths (Hodačová 2003; Gatek et al. 2000; Celko 1996). The past 20 years have shown a 75% increase in the number of Czech women diagnosed with breast cancer in a given year (Hodačová 2003). In 1999, over 4,740 new cases were recorded, and for the first time, the incidence of breast cancer in females was higher than that of lung cancer in males (Hodačová 2003). To further compound these alarming statistics, as many as 45% of newly diagnosed breast cancer cases among Czech women are discovered in the later stages of the disease (Gatek et al. 2000; Macháček 1996).

This paper examines the stigma that Czech women were forced to confront following their diagnoses of cancer, and focuses on the various ways it influenced their personal lives. Drawing upon 17 in-depth interviews with Czech women who had been diagnosed and treated for breast cancer at the *Masarykův Onkologické Ústav*, as well as discussions with surgeons, oncologists, and support group organizers, I explore the way stigma affects the terminology used by doctors and patients, the ways women communicate about breast cancer in their everyday lives, the relative lack of interest in support groups, and how this experience shapes women's perceptions of their bodies.

### **Terminology, Doctors, and Cancer Patients**

In her essay *Illness as Metaphor* (1978), Susan Sontag describes how cancer is often regarded as mysterious, evil, a sign of disheveled emotions, or synonymous with death. Sontag argues that people have a natural human tendency to speak symbolically about illness, but that when patients, family, and society communicate about illness using metaphors they are deprived of an honest and truthful means of confronting the reality of their situation. Thus, the illness becomes vulnerable to misconception, and in the case of cancer, is viewed as unconquerable while the patient is demoralized. Sontag writes, "My point is that illness is not a metaphor, and that the most truthful way of being ill – is one more purified of, most resistant to, metaphoric thinking" (Sontag 1978: 3).

Recently, particularly in Western countries, increased understanding of the disease, improved technology, and better awareness have countered the perception that cancer means a slow, unavoidable, and shameful death by showing women that they can live a quality life after a diagnosis of cancer. However, the "universal dread of cancer," though somewhat diminished in the West, reverberates throughout the world (Moore and Butow 2004: 22). When I asked women in my study what they thought of the words *rakovina* (cancer) or *rakovina prsu* (breast cancer), they responded that *rakovina* holds strong negative connotations as "a treacherous and insidious disease," "a harsh and drastic word," "a terminal illness," and "a deadly, incurable disease." Other women felt that cancer means that "you are in terrible trouble," and that a diagnosis equals "death."

The stigma of cancer persists not only in society, but also in the biomedical encounter. During the interviews, women were asked to recall the terminology that their doctors used during diagnosis and treatment. Of the 17 women with whom I spoke, only one woman remembered her doctor using the word *rakovina*. However, women did recall their doctors using a variety of other terms to refer to their illness, including malignant tumor, tumor, carcinoma, bulb, cyst, and "a little finding." While malignant tumor was the

most common diagnosis, an equally large number of women also remembered that their doctor did not "give their disease a name" at all. Women were also asked to recall the terminology they used when they spoke about their breast cancer in their daily lives. Fourteen women mentioned that they consciously chose *not* to use the terms *rakovina* or *rakovina prsu*. Instead, most women used tumor, followed by malignant tumor, carcinoma, oncological illness, "I had breast surgery," "that thing," "it," and "my problem."

Of the women and physicians who were interviewed, the majority in both groups avoided the terms *rakovina* and *rakovina prsu*. The Czech word for cancer (*rakovina*) comes from the root word crab (*rak*)<sup>1</sup>, and for Ana, the word *rakovina* conjures up the image of a "dirty crab eating away at the breast." "At first, I didn't like to speak about it at all, but now after time, I say tumor. I don't like to say cancer." Like Ana, Marie described an aversion to the imagery produced by the term and explained that "the word *rakovina* just sounds like the crab will eat you up with its claws. It is a disgusting creature, and for the individual, the cancer feels like it is disgusting and spreading." As Věra said, "I don't use any word, I still haven't . . . the word cancer does not form in my mouth. I say tumor, that I had a tumor."

Like their American counterparts, Czech doctors take an oath that ethically holds them to do no harm with regard to patient care. In the attempt to do no harm, Czech physicians were adamant about protecting their patients by not fully disclosing a cancer diagnosis that could be psychologically damaging. This is not unique to the Czech Republic. Like the majority of Czech women who recalled their doctors using a range of terms when they were diagnosed, Estape et. al. (1992) found

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<sup>1</sup> The literal translation for *rak* is crawfish. However, *rak* is also the term for the constellation Cancer, as well as the zodiacal sign. The translation for *rakovina* is a malignant tumor, also cancer. For the sake of clarity, *rak* will be translated as crab in this chapter and not its literal definition of crawfish.

that in one Spanish hospital, 38% of patients with a first-time cancer diagnosis were told their cancer was a cyst, node, polyp, wart, or ulcer, and an additional 48% of patients were told they had a tumor.

However, by limiting disclosure and instead using terminology that they deem less truthful and less harmful, physicians in the Czech Republic play an interesting role in perpetuating the stigma of a cancer diagnosis. The majority of Czech doctors I interviewed preferred to describe a patient's cancer using the terms *zhoubny nádor* (malignant tumor), but many simply referred to a woman's cancer as *nádor* (tumor). Throughout my research, physicians repeatedly discouraged me from using terms such as *rakovina* and *rakovina prsu*; I eventually settled on the more neutral term *zhoubny nádor prsu* (malignant tumor of the breast). Many of the physicians felt that explicit terminology might cause anxiety and distress in women and render them unable to participate in the study. Interestingly, both patients and doctors are aware of the ambiguity of the word *nádor* as it is used to describe both malignant (cancerous) and benign (non-cancerous) tumors. Such vague communication about cancer (albeit to protect the patient) has repercussions. The stigma of cancer, fraught with ambiguity and inaccuracy, takes on more power than reality and truth.

### **Communicating About the Illness Experience**

In the Czech Republic, women are struggling to various degrees with the diagnosis of breast cancer. Fourteen of the 17 women reported having psychological problems after their diagnosis, and only one woman sought the help of a psychiatrist for medication. When I asked women how often they thought about the changes that have occurred in their bodies from diagnosis of a cancerous tumor to treatment, 14 women reported that they think about these changes "little" to "not much" of the time. A closer look at these responses reveals that women are actually forcing themselves not to think about their experience. Comments included, "I don't

allow myself to sit and think about it," or "It can't be thought about," or "I try to suppress it."

Although women were able to speak to me about various elements of their experience, nine of the 17 admitted that they avoided discussing their breast cancer beyond a superficial level in their personal lives. The reasons varied widely, but all were centered on the stigma associated with diagnosis. Some women worried they would be physically deformed after the loss of a breast, or labeled as a cancer patient with hair loss after chemotherapy. Others worried that their diagnosis would make them a physical and psychological burden to the family. And some women perceived their diagnoses and treatment as "my problem," and kept it a "secret," choosing to deal with it privately, even within the family environment.

For Ana, the stigma of being marked with the loss of her hair after chemotherapy made it extremely difficult for her to share her experience with others. She was aware that people might suspect something was wrong, but often found herself dealing with her diagnosis and treatment on her own. She was 63 in 1999 when she had a mastectomy. She recalled:

I didn't tell anyone for a long time that I had the surgery. My friends, my co-workers, I didn't tell them. I have to say that I lost all of my hair, even before the surgery, right after the first chemo. My hair fell out, and when I met my co-worker and she looked at me and said "You're coming from the hairdresser?" I said "Yes." She couldn't tell that I had a wig. And for a long time I didn't want to speak with anyone about it. I tried not to go where I would encounter friends. I know that people knew, but no one ever asked me how I was or what was wrong with me.

Ana also communicated very little about the disease at home, despite her struggle with it.

The first time that I went to chemotherapy my husband knew, but not the boys. The second time, I arrived home and my son and his wife were there. I cried because the doctor wrote me a prescription to have a wig and sent me to chemotherapy. I told them that I was softened. How will I walk around? Everyone will be able to tell. And I didn't want anyone to be able to tell.

Later in our interview, Ana said that she was unable to discuss her breast cancer with her husband for fear that he would not be able to handle it. She described the day that she was scheduled to have a mastectomy and sent her husband and son to their vacation home in the country while she traveled to the hospital alone by bus to have a mastectomy. She said, "So my husband's vacation began and I made him take our son to the vacation house. I would meet them there later and then I took a bus to the hospital and my breast was removed. That day it was terrible, the worst."

The same stigma that prevents women and doctors from using the term *rakovina* also affects their ability to communicate openly about their illness in their personal lives. Women like Ana are not as concerned about the way they look wearing a wig during chemotherapy as they are about publicly displaying the physical signs of cancer. One woman noted that she is less judgmental and more sympathetic toward the women she notices who wear wigs in public, "Before I was diagnosed I used to wonder when I saw a woman on the street with a wig or really short hair, 'What happened to her?' Now that I've been through this, I look at these women a little differently. I know what they've been through."

Jaroslava's experience provides another example of the stigma that these women were forced to confront in bearing the physical signs of cancer. Of the women with whom I spoke, Jaroslava stands out because of her lack of inhibition in communicating about her experience with breast cancer. She lived outside of Brno in a small town with her

husband, teenage children, and aging in-laws. In addition to her full-time employment, she was responsible for cooking, cleaning, and caring for everyone who lived in their home. The day that I interviewed Jaroslava was unusually warm, and she answered the door in only a large oversized white T-shirt that was dirty from a morning's work in the garden. She quickly changed while I waited in the kitchen and nonchalantly called over to me, "Do you want to see my scar?" Before I could reply, she entered the kitchen, opened her shirt, and showed me the long scar on the upper portion of her right breast where a lumpectomy had removed her cancerous tumor. Proud of how nicely her scar had healed, she remarked, "Good, yes?"

Jaroslava was 51 when she was diagnosed in 1996. Her narrative differed from those of other women in that she confronted the stigma rather than hiding from it. She described people's reactions to her diagnosis of cancer:

Well, the first moment was terrible. In this country having cancer meant that you're going to die. It means that you are in terrible trouble. 'She has cancer, so she's going to die.' That's what people used to say about me. They kept watching me, expecting me to lose weight. People have the idea that if you have cancer, you'll just keep getting skinnier until you die. But I started to gain weight instead of losing it. I started eating more, thinking, 'Why should I starve?' And the others tried to dissuade me by saying, 'You're only feeding your cancer,' and such nonsense. I thought I needed to make myself strong, so I started eating more instead of dieting and starving, and when people saw me, they said, 'How come you're not losing weight?' and I said, 'Why should I be losing weight?' and they go, 'Because you have cancer,' and I go, 'That's right, I have breast cancer, but that doesn't mean I should die.'

In addition to her candid nature, Jaroslava is exceptional in that her narrative gives voice to

the growing number of women who are compelled to face the societal stigma of cancer. Although these women were not in the majority in my study, my data show that over time women reconsider aspects of their experience and decide that if they had to do it again, they would behave differently. Some say they would push their doctors more for the type of relationship that they desire; others would push harder for more information; and others, like Jaroslava, would address stigma. One woman said, "Now that I have been through this, I think I would be more open with my doctor, and *make* him tell me more."

Sontag's (1977) description of the metaphor of cancer as a "slow, insidious . . . death" continues to hold true nearly 30 years later in the Czech Republic. Amidst the nation's unfolding transition toward membership in the European Union and Westernization, Czechs are forced to reconsider old, socialist ways of thinking as they encounter the new perspectives of democracy and globalization. Women with whom I spoke often found themselves negotiating the stigma of their diagnosis in various ways. For some women, like Ana, the time immediately after diagnosis was more incapacitating than empowering, as she avoided contact with people altogether. Other women, like Jaroslava, chose to address the stigma the moment they encountered it, by confronting it and challenging it directly.

Many of the women I interviewed also described not wanting to be a burden to their families following diagnosis and treatment. This concern was related in part to the fact that after surgery, chemotherapy, and radiation women were more tired and needed help maintaining the home, shopping, and caring for other family members. But it also included the psychological worries of losing a mother, a daughter, or a wife. Like Ana, who felt the need to shelter her husband and children from the details of her experience, Alena K. feared being a burden to her family:

I don't talk about it much, and there's no point in discussing it with strangers. Other people don't want to hear about it, I think, because the

illness scares them. And with my family...I feel that I'd scare them, that I'd burden them with my own problems if I talked to them about it. It's too stressful for them to discuss it. So I've always acted like a completely healthy person around them, as far as the state of my health allowed me. I have a 30 year-old son and a granddaughter, and whenever I had a relapse, they were really scared. So I always made it sound like everything was normal...I mean, my son knew but we didn't talk about it.

Much of what women revealed about how they are dealing with the diagnosis and treatment of breast cancer in their personal lives reflects how their lives were shaped under socialism. Throughout the narratives women described not wanting to burden the family with their illness. In many of the narratives, the societal expectations that shaped women's lives under socialism continued to affect the way many women communicated about their illness in their personal lives; women expressed an underlying sense of obligation and responsibility to shelter the family from their problems.

Under socialism men and women alike were oppressed and expected to work at full-time jobs. But in addition to their employment outside of the home women were also responsible for caring for the family, managing the home, educating the children, and cultivating the family's garden (Šiklová 1997). Perhaps one of the greatest misconceptions about women's lives under socialism is the notion that women's high rates of employment represented their emancipation; but this was not the case, as employment was never a free choice (Havelková 1999). Women were required to manage a full-time career and be in charge of home life, without any modern-day conveniences, in what sociologists have termed the "double burden" (Ferber and Raabe 2003; Šiklová 1997).

Many of the women in my study, regardless of how well or poorly they were dealing with their diagnosis and treatment, felt an obligation to remain strong within the family setting. Under socialism, women used the family as a means to retreat from the oppressiveness of the state, often dissociating themselves from additional party activities by claiming they did not have enough time after working full-time and caring for the children and the home (Havelková 1993a; Wolchik 1998). Caring for the family allowed women to escape the oppression of the socialist regime, and remain central figures in the home environment (Havelková 1996; Nash 2002). Despite the fact that men and women were equally oppressed in their public lives, scholars have often portrayed women as having held more power in the private sphere of the home, particularly over the children and the finances (Čermáková 1995a; Havelková 1993b; Nash 2002). As sociologist Maria Čermáková notes, in the family environment "women's efforts were always devoted to harmony and conciliation" (1995b).

While some Czech women are confronting breast cancer's stigma by refusing to give in to the idea that they are abnormal, sick, or dying, others are facing stigma by means of the empowering metaphors they have chosen to adopt. In his book chronicling the cultural history of cancer in America, Baron Lerner (2001) notes that since the early 1950s, Americans have been declaring a metaphoric as well as a scientific war on cancer. In American "cancer culture," patients and activists have relied upon metaphors of war, battle, and fighting as a means to describe their approach to cancer. Sontag also emphasizes the war-like imagery frequently used in the rhetoric of cancer, with terms such as: "tumor invasion," "fight," "kill," "war," "attack," "radical," and "scans" (1978: 64-66). I have found that Czech women and their physicians do not rely on the symbolic imagery of war when they communicate about cancer. Instead, many women with whom I spoke used the metaphor of the *hrdina* (hero) to describe being protective and strong, while they invoked the metaphor of the *sportovec*

(sportsman or athlete) to convey not making a "big deal" out of their situation.

In Czech, the word *hrdina* (hero) has a dual meaning. In its literary sense, it refers to the protagonist of a story. When women with cancer use the term *hrdina* to describe their behavior, they are referring to their perception of taking a strong and stoic approach to dealing with their diagnosis, rather than an approach that is weak and vulnerable. One woman said,

I told myself that I can't complain in front of him [husband], that I can't tell him about all of my illness, it would make it worse for him, and I saw that my husband was affected worse than me . . . Well, I was stressed out by it, but as I say, I was being a hero, yes? Because I knew it was bothering my husband, not that I will be without a breast, but that it is called cancer, right? And basically, as I say, I was being a hero.

In another example, one woman's identification with the tough and enduring hero is less uplifting. Instead of being worried and seeking help when she suspected that something was wrong with her body, she acted strong and unconcerned and, perhaps, waited too long to seek biomedical treatment. She said, "Now I tell every woman that if they feel anything, not to be a hero and to get examined." In short, she tells other women: "Don't be a hero like me."

In the metaphor of the *sportovec* (sportsman or athlete), or the phrase *brát to sportovně* (take it like a sportsman or an athlete), I see another recurrent theme that women evoked when they described positive ways of dealing with their cancer and rejecting its stigma. The word *sportovec* and the expression *brát to sportovně* literally refer to the characteristics of an athlete. In everyday speech, however, they are often used to convey an attitude of "going with the flow," "taking life as it comes," and not overreacting to a situation. One woman said, "I don't get nervous about the illness, I take it like a sport – as it comes, like I had my appendix out." Another woman

observed that in her family, her children took her cancer "like a sport."

Another interpretation refers to the once-popular *Sokol* movement, which has seen a revival since the end of socialism, under which it was forbidden. Developed in 1862, *Sokol* has played an important role not only in Czech history but also in maintaining national identity and pride. Throughout times of occupation by the Austro-Hungarian Empire, and later by Germany, the *Sokol* movement became a way for Czechs to perpetuate and celebrate their national, cultural, and ethnic identity. Through participation in gatherings and ceremonies in folk costumes and national sports competitions, Czechs reinforced their patriotism. The Czech men and women who were involved in the *Sokol* movement were committed to intellectualism by means of engaging the body and spirit through exercise, art, science, and morality. The underlying motto of the *Sokol* was a dedication to constant evolution toward human perfection in a physical, spiritual, and intellectual sense (Stahlman 1995). Under socialism, participation in the *Sokol* movement was forbidden, but many Czechs continued to live by these life principles.

Hana S. was 52 when she was diagnosed with breast cancer in 1996. Her treatment consisted of mastectomy, radiation, and chemotherapy. She recalled observing her grandmother's "sport-like" approach to her own diagnosis of breast cancer and to her mastectomy at the age of 68 years old. Her grandmother's ability to "take it as it comes" influenced how Hana has dealt with her own diagnosis; however, in her case, in addition to adopting her grandmother's attitude, she made explicit reference to the influence of the *Sokol* philosophy. She recalled:

My grandmother actually survived 24 years, maybe more, 26 I think. When this [cancer] met her, she didn't really know what it was all about. She didn't go through radiation or chemotherapy, just we knew that they took her breast and that she had cancer. And back then the doctor gave her five years and

she had a sport-soul and took it as it came. She didn't understand it [cancer] and was a *Sokol*, she exercised, went to their gatherings when she was young, and even when she took care of my kids, her great-grandchildren she always exercised in the morning. The boys would laugh when grandmother climbed out of bed in her nightgown and started exercising [laugh]. Yes, she had a sport-soul – So I think – She actually died at 94 and I think that if my mother didn't die and there weren't these other problems she would definitely have lived to 100.

As Hana sees it, her grandmother's "sport-soul" approach to "taking it as it came," combined with her commitment to live by the *Sokol* philosophy and maintain her well-being after the removal of her breast, enabled her to live well beyond the few years that her doctors predicted she had left. For Hana, her grandmother's example remains a source of inspiration as she lives with her own diagnosis of breast cancer.

### Support Groups in the Czech Republic

In the Czech Republic, mental health issues remain highly stigmatized and seeking psychological therapy to cope with daily life issues is not a common practice. Most of the women I interviewed (14 out of 17) mentioned that they had psychological issues following their diagnosis and treatment, ranging from fear of recurrence, to feeling deformed after the loss of their breast, to problems with intimacy. In 2002, more than 50 cancer support centers were actively functioning throughout the Czech Republic; many were grassroots organizations (like *Jantar*, *Mammahelp*, and *Klub Isis*) that emerged after the Revolution, founded by women with personal experience with breast cancer. Yet only three of the 17 women relied upon a support center after their diagnosis.

Most of the women who participated in my research were treated at MOU, which offers an active patient support center, *Klub Diana*, located within the hospital. It provides

services for loss of hair, prostheses fittings, and art therapy. In addition, a support group meets on a regular basis to discuss issues relating to emotional well-being, side effects of treatment, diet, and exercise. However, MOU has great difficulty attracting patients to participate in the support center activities. According to the women in my study, reasons for not participating in *Klub Diana* ranged from practical, to misinformation, to fear.

Many patients who arrive for their scheduled appointment are forced to wait in common areas for two hours or more to see their oncologist, surgeon, or radiation oncologist. While this might seem an ideal opportunity for patients to visit the support center, many patients do not leave these areas for fear that they will forfeit their spot in the "line" of other waiting patients.

Many of the women knew that *Klub Diana* existed, but were misinformed about the range of services it offered. Some women thought it was only for information about prostheses. One woman remarked, "That's for prostheses, right? I don't need them. I still have breasts." Another woman said, "I have heard about it, it's for wigs, right? But, I don't go, I have little time." Other women were simply not interested in participating; Libuše admitted, "I know that such clubs exist, but I didn't go there. I just didn't feel the need to get organized."

Prior to the socialist era the women's movement had a long, rich, feminist history during the interwar period of 1918-1938 (Havelková 1999; Nash 2002). During this time, approximately 60 different women's organizations existed, most under the rubric of the Council of the Czechoslovak Women (Garver 1986). Of the period after socialism, sociologist Hana Havelková (1999: 70) writes:

The Communist Party replaced this rich feminist scene by one single official women's organization called the Union of Czech Women, which was directly subordinated to the party and was to spread party ideology among women. Indirectly, any

activity from below was paralyzed because women were strongly supported and protected by the state so, theoretically, they had no reason to complain. Yet they knew something was wrong with this kind of emancipation, but there were no real mechanisms or contexts for discussion (gatherings were not allowed) which would have made it possible for them to actively change things. For it was the very principle of the totalitarian regime that all social arrangements were imposed from above.

Despite the fact that under socialism women had an "organization," they lacked a real and honest means for addressing important issues that concerned them. When Libuše said that she did not "feel the need to get organized," she was referring specifically to the obligation placed upon women to be a part of state-controlled associations under socialism. For some of the women who did not take advantage of a support group, perhaps membership in such an organization is too reminiscent of a time that Czech women want to put behind them. Author Havelková has documented this sense of distrust; she writes (1999: 70): "After 1989, women often viewed groups that were overtly political or too focused on one's personal affairs with suspicion."

The support group is not a new phenomenon in the Czech Republic. My informal discussions with Czechs who lived under socialism revealed that support groups did exist for individuals who had problems with alcoholism, drugs, and sex. However, these groups were highly stigmatized, and in many cases individuals had no choice but to participate. The stigma of support groups that existed under socialism, combined with the fact that women were obligated to participate in organizations in which they could not speak openly and freely, may explain why the majority of the women I interviewed had no desire to "organize" and participate in the growing number of patient organizations and support groups that have evolved since 1989.



They know that these groups exist, but they are reluctant to join them.

One of the largest barriers to women's use of the support center at MOU was their fear that being surrounded by other patients with similar problems would bring on more depressed feelings. Alena, 48, was a dressmaker prior to her diagnosis. When I asked her if she had participated in a support group, she replied, "I prefer the company of healthy people, because it depressed me to hear about it [cancer]. That's why I haven't tried it yet. Because I'm afraid that in a club like this, it [cancer] is a major topic, and I prefer not to discuss it. It's much better for me not to mention it." Marie not only refused to participate in a support group, but made a point of not interacting with other sick patients. During her chemotherapy treatment, she stayed in a room on the MOU hospital grounds provided for patients who lived too far away to commute every day for their treatments. There she met another patient, and together they avoided interacting with the other sick patients. She said, "We started going for walks, having dinners downtown – we simply acted normal. That was a great advantage, and we made *sure* to avoid the patients who cried. We ran away from those people. We didn't want to get upset." Explaining her reasons for preferring to cope with her illness on her own, she said:

You see, the patients tend to talk about the illness, and focus on the most terrible aspects of it, including who just died, and so on. I didn't want to hear any of that. I thought—I'm still alive and I don't want to stress myself by listening to stories about other patients' problems. Some people welcome that because it makes them see they are not the only people with such a problem. But other people prefer to be alone, like myself. I wasn't afraid to be alone. I wasn't afraid to face myself.

Like Maria C. and Alena, Ana chose not to attend the support group. She feared being exposed to an environment that would revolve

around sad stories of suffering and death, potentially increasing her own anxiety and worries. Like many of the women with whom I spoke, Ana was treated for breast cancer at MOU, with its active support center, *Klub Diana*, located on the third floor of the hospital. When I asked her if she used a support center, she replied:

I don't go to any organization, no. I don't know if we have anything in Brno . . . I don't know. To tell you the truth, when I wait here in the waiting room and some woman starts talking about it, I don't like to talk about it . . . With you yes, because we agreed, but if I meet my old friend from work or maybe the neighbor, or others – of course I exchange a few words with them, but I don't return to the illness [cancer]. If they ask me how I feel, I say "well," and then I talk about something else. That's it – if you understand me. I don't like to talk about what I went through. I'm looking forward. I don't like to look back, if you understand me. And for example if someone tells me, "Wow, she died from it." I really don't like to hear it. For example, my cousin's wife was also met by it [breast cancer] but before me. But she went to the doctor so late that she also had to have surgery and she was here for two years and then it got so bad that she died. When she died, I hadn't had my surgery yet. It bothered me . . . but now I don't let it get to me. As I say, I take it as though I have it behind me. I don't know. Ask me something else.

Although they may not realize it, women like Maria, Alena, and Ana, by avoiding other women who have been diagnosed with breast cancer, contribute to the perpetuation of the societal stigma that cancer patients in the Czech Republic must bear. Through this avoidance, they communicate, not only to women with cancer but to women in general, that support centers and their patients are depressing, focused on death, and must be avoided.

During the tenure of my research, I regularly visited several support centers in Prague and Brno, and made weekly visits to *Mammahelp*, *Jantar*, and *Klub Diana* to observe how these centers function. Based on my experience visiting and participating in seminars and numerous activities, I have found these centers anything but depressing. To the contrary, they struck me as uplifting and progressive environments where women gather to support themselves and each other. In Prague, *Mammahelp* has acquired its own space in the basement of a building where it provides regular seminars for maintaining a healthy body and physical appearance during radiation and chemotherapy. Women may attend weekly sessions on yoga and tai chi, and they frequently gather to make traditional folk crafts that coincide with holiday celebrations. *Jantar* meets bi-weekly in a room at the Prague YMCA, where its members discuss a variety of complicated issues related to returning to work after treatment, maintaining a sense of well-being, and the sexual issues that arise after mastectomy.

*Klub Diana* is located on the third floor in the MOU hospital complex. The area for gathering and obtaining general information consists of a single room, but it contains a growing library with numerous books about various types of cancer and forms of treatment. There is a television for watching videos about cancer, a CD player where patients can listen to music, and a computer with high-speed Internet access for patients who wish to access information and research regarding their cancer. The women who are in charge of the hospital's education outreach program frequently walk through the hospital, handing out brochures that explain the support center, and personally promoting the small, sunny room on the third floor with a beautiful view of Brno. Yet few people visit the center.

My discussions with Czech cancer patients, as well as with healthy men and women, revealed that Czechs in general do talk about their health issues – in fact, such discussions are quite common. Typically they revolve around minor aches, pains, and

inconveniences. One person mentioned, "You can't walk through the village without overhearing discussions about how someone is feeling, particularly among the older people." Notwithstanding the enormous body of research documenting the benefits of narrating about the illness experience (for example, see Kleinman1988; Mattingly and Garro 2000; Pennebaker2002), many of the women I interviewed said that they had difficulty speaking about their diagnosis in their personal lives, and that most often they chose not to do so. At the same time, many of these women remarked that they had increased psychological problems following their diagnoses.

Despite the fact that a number of women said they do not like to communicate about their cancer in their personal lives, and that a number of women did not join a support group for fear of being around other women whose problems might depress them further, we must consider that some women might be suffering from more significant psychological issues. McGarvey et al. (1998) suggest that some patients may also suffer from acute stress disorder following a diagnosis of cancer. Patients may feel depressed or anxious, may try to avoid activities or situations that remind them of the cancer, and may avoid thinking about cancer altogether. Alena's mother, grandmother, and aunt died of breast cancer. She noticed a lump during her shower, saw her doctor immediately, and had a lumpectomy shortly thereafter. This experience left her extremely anxious. She said:

The word cancer gives me the creeps. My mother died of it and I remember the whole process. Anything else but this! I was a bundle of nerves after I was diagnosed and my doctor prescribed me some pills [antidepressants]. I took them for about three weeks, but they didn't help...You don't want to hear much about it [cancer] when you actually suffer from it yourself. It depresses me when I hear someone talk about it or when I read about it. I just don't

like to be reminded, and I avoid being reminded... Whenever I read something negative, it makes me feel bad for days. For that reason, I don't like to collect information on the subject or even talk about it.

For Alena, dealing with depression and anxiety represented her biggest challenge. Later during our interview she said:

Psychologically, I'm hanging by a thread. It's hard to explain the state I'm in sometimes. It's all stress-related. My throat constricts, I feel sick and I begin to sweat whenever I just remember or realize something bad. We have cancer in the family and I remember very well what my mother went through and how she ended up. It's always on my mind and I don't think it can ever be banished from there. I think that's the cause of it all.

She recalled being "scared" the day she received my invitation to participate in this research and worrying that "something had come up again." Because cancer is still equated with death in the Czech Republic, some women may be forced to confront their own mortality after their diagnoses of breast cancer. When women were asked how their experience could have been improved, many remarked that they had psychological problems and could have benefited from psychological intervention. For some of the women, their inability to communicate about the disease in their personal lives may be related to acute stress disorder. While a full examination of acute stress disorder is beyond the scope of this paper, this aspect of the breast cancer experience deserves further study.

### **Perceptions of the Body**

In addition to stigma's effect on cancer terminology, as well as on women's communication about their illness in their personal life, stigma significantly influences women's perceptions of their bodies. Of the women who participated in my study, ten had

received mastectomies and six had received lumpectomies. During our interviews, women were asked if their experiences with diagnosis and treatment had changed how they relate to their bodies. Thirteen of the 17 responded that this experience did, indeed, affect how they regard their bodies, and of these women, only one woman's perceptions reflected a positive change. She was, in fact, the only woman in my study who did not have mastectomy or lumpectomy, and instead underwent chemotherapy and radiation to treat her tumor. She remarked,

I think that, yes, it did. I started to value my body more. Basically, I started to take care of myself more than before. I really – I value my body more and myself as a person more than before. Before I lived in a rush and today I value life more. Really, I think that it affected me positively, even the illness – it brought out a different relationship to life and even to people and – to myself.

The majority of the women, however, experienced more negative changes in their relationship to their bodies. In regard to the six women who had received a lumpectomy, their responses centered on a general frustration with bodily changes such as weight gain from taking tamoxifen and feeling self-conscious about their lumpectomy scars. Overall, the women in my study who had received a lumpectomy seemed to be less affected by the physical changes in their bodies that resulted from treatment. Three of these women offered to, and did, show me their lumpectomy scars in a manner that suggested it was not their most important concern in their experience. The only woman who offered to show me her mastectomy was actually showing me her newly purchased and expensive prosthesis. Instead of the prostheses worn by most Czechs, which consist of a cotton breast pad that is inserted directly into a woman's undergarments, she had a prosthesis made of a silicone gel, formed in the shape of a breast with a nipple. With the help of adhesive strips, it attached directly to her skin.

In addition to struggling psychologically, nine of the 10 women who had received a mastectomy reported feeling significantly more negative toward their bodies after their treatment. Following their diagnoses of breast cancer, the women with whom I spoke confronted the various forms of stigma, fear of dying, and fear of recurrence. Women who underwent the removal of a breast were also forced to endure changes in their bodies that made some feel as though they were no longer female, attractive, or sexually appealing to their partners. Upon the loss of a breast, a woman immediately faces the societal construct of what her body should, but now does not, look like. Many women I interviewed said that after a mastectomy they felt "deformed," "crippled," and "no longer attractive."

One woman told me that her husband died three years after her mastectomy. She related:

Of course it was hard. I lost my breast and then my husband died three years later. After that I had to tell my partners that I didn't have all of my "parts" anymore. I told them early in the relationship when it wasn't very serious. I made sure I told them soon enough to be able to get over it easily if they backed out. I wanted to protect myself. I thought if the guy had a problem with it, he would back out right away and I would be okay with it because we weren't very close yet. I simply have this handicap.

Another woman remarked that she "always tries to hide it, so that it wouldn't be noticeable, that which is missing, right?" Many of the women who had mastectomies remarked that they were unable to look at themselves undressed in front of the mirror, and that when they did stand in front of the mirror, they made sure not to look below their shoulders. Another woman said:

Whenever I take a shower, it feels like I am washing a stranger's body, and I don't look at myself in the mirror. I do look at my head, of course, but not below – although I am working on

looking at my body – something I wasn't able to do for a long time. I had a mental block that was hard to overcome. My daughter once told me, "Mom, you look quite normal!" And I said, "Sure I do! What changes can you see when I'm wearing clothes?"

Historically, stigma "referred to the marks that publicly disgraced the person" (Kleinman 1988: 158), and over the course of time the term became associated with religious affliction and later with symptoms of disease (Goffman 1963). Stigma eventually came to represent a "deformity, blemish, or ugliness" (Kleinman 1988: 158). In his book *The Illness Narratives*, Arthur Kleinman looks at the stigma and shame associated specifically with illness. He writes (1988: 160):

In stigmatized disorders, the stigma can begin with the societal reaction to the condition: that is to say, a person so labeled is shunned, derided, disconfirmed, and degraded by those around him, though usually not by the immediate family. Eventually, the stigmatized person comes to expect such reactions, to anticipate them before they occur or even when they don't occur. By that stage, he has thoroughly internalized the stigma in a deep sense of shame and a spoiled identity.

As with the metaphor of cancer spreading uncontrollably, Kleinman's description of stigma brings to mind a cancerous-like entity – beginning with a reaction from society, proliferating to permeate the psyche of the individual, and finally destroying her sense of identity. Maria's experience closely parallels the progression that Kleinman describes. She was diagnosed and treated in 1992. At the time of our interview, she was 60 years old. Maria remarked that after her surgery,

[It was] terrible, terrible. I didn't want to live. To tell you the truth, I was thinking that I wanted to die. I didn't want to live. I felt like . . . like I wasn't a woman. That everyone can see it. I know that when I went out

into the town, and some people knew that I had surgery, and now I didn't have a breast, I felt that everyone was focusing on that. And I don't think it was in my imagination, I think it was the truth. It bothered me psychologically very much. I used to love to go swimming. The mental blocks, one gets beyond them, but the feeling when I get undressed...I still cannot look at myself. That's how I still feel. Still the psychology plays a big part.

Not only was Marie forced to confront the societal stigma that associates cancer with death, but she was also forced to question her identity as a woman after removal of her breast. One of the most difficult encounters for Marie occurred while she was attending the healing spa (*lázně*) at Karlovy Vary with a group of women who had also had mastectomies. One night during their stay, while listening to a musical performance, the women overheard some male guests saying, "Do not go to them, they do not have breasts." Marie said, "It was such a shock for us, we felt like exotic animals or I don't know what – that they saw us that way. It was really terrible for me."

According to Erving Goffman in his essay on stigma and its effect on identity, early use of the term among the Greeks referred specifically to the bodily marks signifying that an individual was "a blemished person, ritually polluted, to be avoided, especially in public places" (1963: 1). Although among the women Marie's example is by far the strongest in terms of feeling ostracized after the loss of her breast, many women who had mastectomies were sensitive to the stares they received, particularly when it was known among neighbors and acquaintances that they had lost a breast.

In her book *History of the Breast*, Marilyn Yalom writes that in Western cultures breasts are viewed as "sexual ornaments – the crown jewels of femininity" (1997: 3). Throughout history, women's naked bodies have been portrayed in ceramics, sculptures, and

paintings that emphasized the breast as a symbol of eroticism, life giver, fertility, and femininity (Yalom 1997). Yalom notes: "Men have always enjoyed looking at women's nude bodies," and, more recently, they have become a symbol of status (1997: 183).

In her article "*Žena na ulici*" [Women on the Street] (1995), Libora Indruchová studied the imagery of women's bodies and the way in which they have been portrayed in billboard advertisements in the Czech Republic since the end of socialism. She concluded that those advertisements that were aimed at women depicted modern women as fashionable, intelligent, and career-oriented. The advertisements that targeted men, on the other hand, were more sexually explicit and objectified the female body. For example, one billboard advertised that the ad space itself was available for rent. The slogan read: "Look at something – or not," accompanied by a woman's nearly bare buttocks encompassing the entire area (1995: 36). Indruchová argues that in the Czech Republic men typically design and rent the billboard space and that these types of advertisements will attract male attention. Similarly, an advertisement for the first issue of *Penthouse* sold in the Czech Republic after the Revolution in the mid-nineties featured a female on the cover in a seductive pose with little clothing. In contrast, advertisements that targeted women sold household amenities, such as laundry detergent, and pictured women in business suits, pushing infants in shopping carts. The messages in advertisements that reach out to women suggest that they can do it all: work full-time, dress fashionably, care for the family, and manage the home. The advertisements directed at men, on the other hand, portray the female body as an object of pleasure. In them, the Czech woman is sexy, barely dressed, with large breasts and a thin waist.

A recent article in the *Washington Times: United Press International* (November 2003) described lawmakers' reactions after the Czech Minister of Education had breast reduction surgery.

Czech Prime Minister Vladimir Spidla condemned the "unacceptable sexism" of Czech legislators who made jokes about Education Minister Petra Bužková's surgery. The comments came in interviews with the newspaper *Blesk*, which wrote about Bužková's surgery and quoted Vlastimil Tlustý, a member of parliament, as saying that she "lost her two advantages." Another legislator, Michal Kraus, told the paper, "Because I have big hands, I prefer bigger size."

I also observed this attitude from men during my own field research. In an interview with a Czech breast surgeon from Prague, I asked him his opinion on breast self-examination. He responded:

Even good clinicians don't palpate a one-centimeter tumor in a big breast. My opinion is that the breast self-examination is good because the woman thinks about it, gets more information which may eventually lead to a mammogram or ultrasound. If the breasts are very small then she may palpate a tumor that is one or two centimeters, but if she has good – nice – big breasts she can miss a tumor that is three centimeters.

When he said the words "good – nice – big breasts" he emphasized the size by cupping each of his hands.

The stigma of cancer is further compounded by the stigma of not having a normal and symmetrical body. Through television programs, the remarks of statesmen, advertisements, pornographic magazines, and trinkets that hang on rearview mirrors, the imagery that "good – nice – big breasts" are better than smaller breasts which are better than deformed breasts, affects women's perceptions of their own bodies as well as the expectations of their partners.

For the majority of women who face the stigma of a "deformed" body that is missing some of its "parts," negative feelings tend to center on how others – husbands, partners, other women – will perceive women after the

loss of a breast. Based on my observations, I believe that some Czech women fear that their husbands will leave them if they lose a breast. Women with whom I spoke expressed a sense of gratitude that their husbands remained in the relationship after their mastectomies, and they followed these statements of appreciation by telling stories of other women whose husbands left the relationship or were no longer intimate with them even though they stayed married and continued to reside in the same house.

### **What Does It Mean for the Future?**

Despite the fact that a diagnosis of breast cancer is devastating for many women in the Czech Republic, positive elements of the illness experience are beginning to emerge in their narratives. There is a sense that over time, women are more at peace with the fear of their disease and its recurrence, and with the changes in their bodies. Hana said:

In the beginning, I was most bothered by the loss of the breast. I thought I would be worthless. I was scared – I couldn't look at myself in the mirror at all then – but it is five and a half years and now I am used to it and I am not bothered by it any more. Most important is that I am alive. Life is beautiful. I have a grandson, the first one, so it is a lot of joy. He's starting to talk. It is beautiful.

Like Hana, Ana (65) said that she still does not like to talk about her breast cancer. She explained, "I don't like to speak about it, but now after – because I had the surgery in August of 1999, now it will be three years and I take it with humor. I try to take it like a 'sport.' I try not to get nervous, that doesn't help it [cancer]. Instead, I say 'Thanks for every morning.' Yes?"

The fact that the term *rakovina* is frequently used in the media (radio programs, television documentaries, and infomercials) may explain why, over time, some women become comfortable using this terminology. Czech television offers only four channels, which limits the choice of programs but increases the

chance that more people will view a particular program. Věra noted:

There is information all of the time on the television. It is great for us, even for those of us who don't have it [cancer]. But for those of us who are ill, we call one another if we find out that it is on the TV or the radio, I tell the women "Listen to it, maybe we'll find out something good." Everyone wants to find out as much as possible.

Similarly, the number of small grassroots organizations for women is increasing (Šiklová 1997a). These support centers are now beginning to help spread valuable information showing that Czech women can live a quality life after the diagnosis of breast cancer.

The stigma that many Czech women must confront after the diagnosis and treatment of breast cancer is an underlying theme in the discussion of terminology, communication about the disease, and perceptions of the body. For many Czech women the stigma associated with cancer continues to play a significant role in how they struggle with the diagnosis of breast cancer in their personal lives. Women are, however, beginning to challenge the powerful metaphor that cancer means death. By confronting others' perceptions that they will "lose weight and die," seeking a more forthcoming relationship with their physicians, and associating with positive symbols such as *hrdina* and *sportovec*, Czech women are beginning to refuse the stigma of cancer. As the Czech Republic continues to welcome democracy and freedom, Czech women are also embracing education and awareness and confronting stigmatizing beliefs. In doing so, they are transforming perceptions of illness, body, and self.

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