

Breast Cancer: A Personal and Professional Crisis

My own experience with a diagnosis and treatment of breast cancer has given new meaning to my capacity for change and reshaped my professional role as group facilitator and teacher

by
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I thought I was an expert in working with women diagnosed with breast cancer. Not a modest statement, but I have been doing it for almost 20 years. This narrative about my experience with breast cancer describes a journey which affected me personally and professionally.

I am a single, 51-year-old woman with three grown children. Social work was the career choice I made as an undergraduate and continued on through graduate school. I have been employed full time in the field since my youngest child was a baby and have struggled with such typical issues of balancing family with career responsibilities. Proud of my accomplishments, I enjoy this stage of my life as it gives me more time to focus on my own personal interests. I have had many different social work positions since my first post-MSW job on the oncology unit of an acute hospital but continue to work part time with women diagnosed with breast cancer.

Frequently I wonder what drew me to work with cancer patients. It is a difficult question. It is a population clearly in need of social work services on many levels: the overwhelming sense of loss; pain and suffering; body image issues; financial issues. Cancer's impact on an individual and a family has been addressed *ad*

infinitum. I do know that my work with cancer patients has been satisfying and meaningful, even though I have had my share of "burn-out," wondering if it is time to move on. Those are the times I catch myself using "pat" phrases, responding too quickly, not listening or tuning in. Yet I really want to continue. Often I am able to recognize my feelings, re-focus, and continue to find satisfaction in the work I do. The feedback from clients that I have made a difference in their lives makes me feel valued and important.

Most women diagnosed with breast cancer react to the news with considerable shock. This is the most predominant feeling, despite the fact that the national incidence of breast cancer has increased to 1 in 8 women, and information about detection, early cure, and new treatments is constantly in the news. Women often say to me, "I always knew it could happen to me; I just never really believed that it would." Listening to women struggle with making decisions about surgery and treatment, I wondered what I would do. Would I opt for a mastectomy? Could I cope with the possibility of recurrence? How would I handle the loss of my breast? I don't think any female social worker can work with this population without having these thoughts. Have I ever wondered that I might be



diagnosed with breast cancer? Absolutely! Have I ever thought it would happen to me? No. I have a lot of experience counseling individuals diagnosed with all types of cancer, from the initial pre-diagnosis period to hospitalization and surgery, treatment, and the post treatment fear of recurrence.

My Personal Experience

A year ago, I was diagnosed with breast cancer. The diagnosis was made following a mammogram that showed "micro-calcifications," and a surgical biopsy which confirmed the malignancy. The mammogram, which I normally have once a year, was done six months late. I was "too busy" to get around to it (an indication of my naiveté and denial that breast cancer was something that I might have to deal with). My personal physician is the physician with whom I work, and whose women patients I counsel both individually and in a group. The physician's nurse specialist is also a close personal friend. I knew that she would receive the results of the biopsy before I did. We discussed how she should handle this difficult position or, more accurately, how I wanted her to handle it.

I knew all too well how this is normally handled in the office. Following a biopsy which is positive for malignancy, women are scheduled for a follow-up visit, with the tactful suggestion they bring someone with them to the appointment. At the appointment, they

are ushered into a well-decorated conference room. The surgeon and the nurse (my close friend) then tell the patient the results of the biopsy and discuss options for treatment.

Obviously, calling me into the office in this manner without sharing the news on the phone would not work for me. Instantly I would know the news was not good. I told my friend, "Just call me and tell me in a straight-forward manner." Later I wondered how she felt about my request. How did she feel about having to be the person to tell me I had cancer? Anxiously I waited. I called the day the results were expected, and there was no news. By the next day, my anxiety was at an all-time high, and I was avoiding another phone call to the physician's office. One of my colleagues at work encouraged me to get it over with and make the call. I closed the door of my office and called. My friend was straight-forward and to the point. "The results are what we were suspicious of. The biopsy was positive for malignancy. Even though it is a very early cancer, it is the more aggressive type. The doctor needs to talk to you about further surgery or treatment." I sat and cried. "You knew it was likely," she softly replied. I responded, "I know. I guess I didn't really believe it."

My cancer experience is not unlike the experiences of the women I have worked with over the years. And, I realize I am not the first woman to be diagnosed with the same illness as her/his clients. The experience of dealing on a personal

level with a crisis that one has been such an expert on professionally is complicated. As with many women, my initial reaction to the diagnosis was shock, followed by periods of denial and a "blunting of feelings." Is this kind of reaction unusual for me? Not really. My therapist reminds me that I am much more skilled at tuning into others' feelings than I am at recognizing my own.

I opted for a mastectomy after researching all of my options and had two weeks before my surgery. I wanted to use the time to deal with my feelings in preparation for my surgery. This is what I focus on with those women I meet prior to their surgery. If they can express their feelings, they seem to approach their surgery with the reassurance that their feelings are normal. What I actually did was to avoid my feelings as much as possible! I spent the time with my partner, who was concerned about my emotional state and I think decided that his job was to keep me as busy. His concern and attention were reassuring and comforting. We shopped. We saw every newly released high-action movie we could. We talked a lot, but not about my diagnosis or upcoming surgery. I felt he was watching over me, and he seemed to be my buffer against the outside world. I would check in with myself. I wondered what I was feeling and found I wasn't feeling much.

As I awaited the mastectomy, I began to feel a "heaviness" that was with me all the time. I did all my normal activi-

ties with the constant awareness that something within me had changed. In groups of people I wondered if I looked "different." I wavered between wanting to tell everyone, "Hey, I've got cancer," and avoiding people—wanting to be alone. The tears, the anger, and the upset came later.

I have had my share of caring professionals, and those oblivious to the impact their callousness has on persons who just received the news that they have a life-threatening disease. Extremely angry at some of them, I wondered if I was overreacting or displacing my anger. Early on, when I went to the hospital for my pre-operative lab work, I filled out the paper work and was asked to have a seat. The receptionist then called out across the room, "What kind of surgery did you say you were having?" I was appalled. I quickly went up to the desk and whispered, "I am scheduled for a mastectomy." I did not share with her the horror I felt—exposing to all in the waiting area this very personal information.

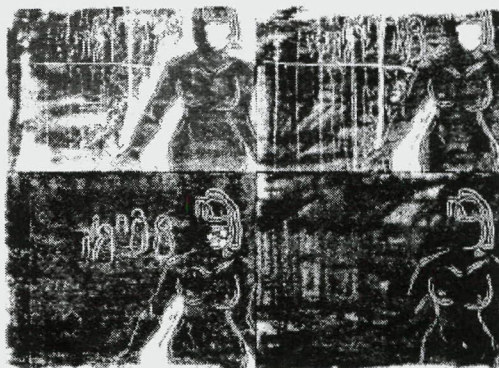
While awaiting surgery, I often felt and acted helpless, and sometimes passive, which is unusual for me. I consider myself assertive and I was surprised with some of my reactions. I would go to the doctor's appointments and "forget" to ask important questions. Or, the doctor would make decisions that upset me, and I would say nothing. It is ironic because I practice assertiveness and encourage it in the women I counsel. I began to realize how diffi-

cult assertiveness is when one is feeling vulnerable, helpless, and powerless.

Fortunately, I do practice what I preach—eventually. After enough of such encounters with medical staff, I absolutely forced myself to schedule another appointment "just to talk." During one visit with the plastic surgeon who was doing the reconstruction of my breast, the nurse asked me to browse through a copy of *Playboy*, and to choose the model who had breasts that I wanted the surgeon to strive for. I felt as if I was given a catalog of clothing to look at and pick from. But, this was my body! I just wanted to look normal again, and wondered if this was even possible. I felt humiliated and depressed. I had heard similar stories from women who described some of their doctors as detached and insensitive. Here I was after my mastectomy and in the middle of reconstruction, losing a breast due to a life-threatening disease, and being treated casually by the doctor, as if this was a cosmetic procedure I had asked for. Hadn't this doctor learned anything from me as a professional? After choosing, I said nothing, left the appointment, went home, and cried.

I have professionally worked with these doctors, and they have excellent reputations for their medical skills and their

relationships with their patients. I was surprised at my passivity with them: I have had no difficulty advocating for my clients. After much encouragement from friends, I met with the plastic surgeon and told him my feelings. The doctor's reaction surprised me. A kind and considerate man, he listened carefully. He then asked me if I thought I might be projecting my anger related to my diagnosis to the incident with the magazine. After all, he said, none of his other patients had ever reacted negatively to



looking through the magazine. I was angry. Did he really know anything about psychological defenses? He did give me some food for thought, though. I told him he could be partially correct but that I did indeed find the experience upsetting and wanted him to know about it. I hadn't been aware of how angry I was about my diagnosis of cancer; maybe this was a safe place to allow the anger to surface. I left the appointment still depressed, but at least I stopped "obsessing" about the incident. I was glad that I had the meeting. I could see firsthand the benefit of confronting the issue for myself, but also saw that I was in an important position professionally to share how I felt with my doctors in order to sensitize them to how other women might feel in similar situations.

Facilitating the Breast Cancer Support Group

I run a monthly support group for such women, and my first challenge professionally was whether or not to share my diagnosis in the group and, if so, how much. My biggest concern was deciding what was appropriate and helpful; and about my own feelings and reactions. Would I be able to keep the focus outside of myself? It was clear to me that to not tell them would be dishonest. I was a patient in the same office as many of these women, and very likely they would learn of my diagnosis anyway. If this were to happen, I feared this would damage the trust and closeness that had been established. Conversely, I knew that at some level, sharing my experience might benefit some of the women and add credibility to my knowledge about the emotional aspects of breast cancer.

To keep my feelings from interfering with the group's process, I needed to be aware of what those feelings were. I never realized how difficult this could be! I found it hard to focus on my feelings when my general reaction to the crisis was shock and denial. Before facilitating the first support group, I had several therapy sessions focused mostly on my anxiety about the next group session. At that first meeting, I shared the news of my diagnosis with the other women. I began the group and stated that I had something personal to tell them. "After having a routine mammogram, I had a biopsy that is positive for

a malignancy, and am scheduled for a mastectomy in two weeks. As I spoke, I focused on the group and their reactions. The members expressed shock at my news. "I just can't believe that this has happened to you of all people." Their response was disconcerting; why would they be surprised when this diagnosis can happen to anyone, and in fact happened to them? It caught me off guard, and I struggled with an answer. "It was a shock to me as it was to many of you when you were diagnosed," I responded. Later, when I had a chance to think more clinically about their reaction, it made more sense to me. I was their group leader, there to help them with their crises, not to have my own. In their eyes, I was "immune" to cancer! I realized that I missed an opportunity to explore this with them—to help them express their feelings. They were very interested in my experience, and it was difficult to refocus the group away from me. First they asked many factual questions, which was a relief to me. It was so much easier to talk about facts than to answer questions about my emotional state. I was afraid that if I focused too much on my emotions, I would lose control and cry. Eventually, one member asked (mirroring my own words to them in the past!), "So, how are you holding up?" I have known this particular woman for a long time. She is a ten-year breast cancer survivor and has been in one of my

groups since her original diagnosis. She is cancer free and active in the national breast cancer organization that sponsors our support group. She comes to the groups to comfort other women and to receive support for herself. I felt awkward, but shared a little more about how I felt on an emotional level. "I am feeling somewhat numb, depressed at times, much like you have described," I stated. They nodded in agreement. I felt a warmth and closeness to these



women that I hadn't felt before. I realized after the meeting that the challenge would be to maintain my role as facilitator without becoming a group member. How

would I do this after receiving such welcome support from women who had been there already? I needed to be careful not to use the group to "work" on my issues. It was clear to me that this was the appropriate boundary. If I were to "work" on my issues, I would no longer be the facilitator.

My mastectomy and reconstructive surgeries completed, I continue to facilitate the support group, and talk about my experience. I talk about my feelings related to my appearance, how painful some of the procedures have been, and how the whole experience has been such an intrusion in my life. Just recently I talked about feelings about the one-year anniversary of my diagnosis and initial surgery. I have often told the group that the most meaningful support comes from oth-

ers who experience a similar event. The mere presence of these women in the group gives me support. I have watched the women struggle with many crises—they have been able to cope and it reassures me. Some of the women have had recurrence. Some of their relationships have ended. They have lost jobs. These are scary stories, and yet they find the strength to deal with their fears and losses and continue to lead meaningful and productive lives.

Many of the women have become much more assertive and proactive in their care. One woman I have worked with for several years began with a lot of anxiety. Since her original diagnosis, she has had many rounds of treatment to deal with a number of recurrences. Emotionally, she is almost unrecognizable today compared to the woman I first met. She developed a solid support system that she relies on; she is assertive and makes her own decisions around her treatment. She is a positive role model for the group and for me.

I try to help the women develop strategies to deal with their fear and now see for myself that some of these work! Fear is such a normal part of this experience, and it is helpful to acknowledge it and talk about it. However, I can see that accepting fear as a normal reaction is easier said than done. When some of the women have shared their fears with their friends and family, the response has often been, "I know you are going to be fine," or, "you need to have a positive attitude; being negative may just make you become ill

again." As a result, many women have been resistant to discussing their fears. In the group, I try to reframe this. I might ask, "What are you most afraid of?" One of the most common answers is, "I'm afraid the cancer will come back." The threat of recurrence is a real one and has happened to several group members. The discussion about recurrence is painful, but most women tell me they feel much better after the discussion. I feel more genuine in my responses. In the past, I might have said something such as, "Many women diagnosed with cancer have shared with me" Now, some of my statements begin with, "I find myself feeling... similar to what many women have shared with me." I am much more patient and understand that coping with cancer is an on-going process. Grieving the loss of a breast, dealing with a new body image, coping with the pain of surgery is very difficult. The grieving process is not accomplished smoothly; feelings surface and disappear in no logical formation. I have known this on a theoretical level, but never so personally.

Teaching At the University

My experience with breast cancer has also had a major impact on my current full-time position as a field coordinator in both the MSW and BASW programs. My responsibilities include teaching small seminars focused on helping students integrate social work

theory into their field practice experience. Although the seminar is unstructured in the sense that students function as a group and it is focused on students' issues and concerns, there are several topics that I do cover in depth. Of these topics, self-awareness, self-disclosure, counter transference, and setting appropriate boundaries are among the most critical. As the facilitator, I realize that I am a role model for the students (positively and negatively). I need to model appropriate behavior, and practicing what I teach is important. I have found that one of the earliest challenges for students is self-awareness—to be able to identify one's own feelings. Students seem to have the most difficulty in identifying their own feelings as opposed to those of their clients. I have observed this as students struggle with the dreaded "process-recordings." Many students confuse feelings with thoughts. They discuss their views on the interviewing process, or they focus on what the client was feeling during the interview. When asked directly, "What were you feeling during the interview?" many students respond, "I don't know," or, "I wasn't feeling anything." I admit, I find this very frustrating! I believe that my cancer experience has taught me just how difficult it can be to "get in touch with one's feelings."

My initial diagnosis of breast cancer and surgeries have occurred during university sessions, and I missed several class sessions. Because the surgeries were planned ahead of time, the

students knew that I would not be in class. But, what was I to share with them? Normally, I disclose little about my personal life with students, again trying to be a positive role model and to share what I think will be a good learning experience. If I am to miss a seminar, I normally share just that, and no more. Was this an opportunity to model appropriate self-disclosure? I had several weeks to struggle with this issue, and decided to give some details of my upcoming surgery. I came to this decision because I thought it might be difficult to keep this a secret and that the way I told them might provide important learning for the students.

Briefly I told them about what was happening to me and let them know in general how I was doing. The students were incredibly empathic. They wanted to know how I was feeling. Some of the students talked about people they knew who had a similar experience and had done quite well. They tried to be very reassuring. I told them that I would continue to let them know how I was doing but would not generally talk a lot about the experience. This was the boundary I set. Was this boundary too rigid? I never really explored with my students their feelings and reactions to my diagnosis. I have no idea if my experience resulted in feelings of fear or reminded them of similar personal experiences. This might have been a meaningful discussion to have but one that I did not initiate and hence, another opportunity missed. Throughout the semes-

ter, students continued to ask how I was, but respected my privacy. They continued to write wonderful notes of encouragement and support.



Reshaping My Thoughts: New Questions and Challenges

The morning I turned 50 I woke up tearful. I continued to sob throughout the day. Was I crying because of my age? I wasn't aware of being particularly depressed about turning 50. I was, however, in the middle of my reconstruction. I was uncomfortable; I hated the way I looked. It had been a rough several months for me physically, and I realized I was depressed and angry. Was I finally reacting and having a good cry? As I review my cancer experience, I realize several things. It is embarrassing to admit that as a professional in the social work field and one who has focused on the emotional experience of breast cancer, I initially believed that I would handle this experience somehow better than the women I had worked with, that because of my knowledge of what to expect, I would cope "better." I also expected the physicians that I worked with professionally and who became my personal phy-

sicians to treat me deferentially as a colleague with more respect and patience. It is not that I thought I deserved better treatment, but that surely they would remember some of what I had shared with them about treating women with respect and dignity. The reality was that I struggled as most women do and that I was treated by my physicians as any other woman. It has been an important humbling learning experience for me, one which I hope will continue to enhance my skills with clients and students.

I have set some rather definite boundaries in my professional roles. Were these boundaries too rigid? I realize that at times I set them with my own comfort in mind, rather than what would be most beneficial for my clients or for my students. I have tried to be less rigid in my support group by sharing more of myself. In some ways, my role has become blurred. I am the facilitator and a group member at times. I wonder if this dual role is appropriate. I have no answer at this point but will continue to struggle with setting boundaries and expect that I will continue to find this difficult. In my role with students, I understand more keenly that learning is a process and that self awareness, self-disclosure, and setting boundaries are difficult concepts to put into practice. I am more humble and patient. I realize that even the very experienced social worker can find that practicing appropriate social work skills is an incredible challenge. □

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