Access to Critical Oncological Support Systems For Newly Diagnosed Breast Cancer Patients

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Introduction

With over 240,000 women in the United States diagnosed with breast cancer every year, public awareness of this disease is at an all time high (www.cancer.org). Successful lobbying efforts by organizations including the American Cancer Society have promoted legislation and brought substantial funding to research (www.opensecrets.org/lobby/clientsum.php?lname=American+Cancer+Society&year=2008). Survival rates have increased because of earlier detection. Yet newly diagnosed patients know little about oncology professionals, support groups, or patient advocates. Many studies now conclude that breast cancer patients make medical decisions with "inadequate and even incorrect information" (Fagerlin et al., 2006). Lack of trust in medical professionals or knowledge about support systems can contribute to poor decisions, stress, and disempowerment (Arora et al., 2007).

Patients without a good support system after diagnosis can easily feel overwhelmed but nevertheless are still required to make important, expensive, life-altering choices. Women must process a large amount of detailed information while still psychologically stunned from being confronted with a chronic, life-threatening disease. Gruman's 2007 study,

based on hundreds of interviews with patients and family, documents the magnitude of adjustments patient face after receiving a cancer diagnosis and the importance of understanding options.

The trauma of a positive diagnosis comes after a woman has already undergone a series of streamlined tests over a period of approximately two weeks. These tests include a mammogram, sonogram or ultrasound, biopsy, and an MRI. Therefore, having undergone several invasive tests, patients are already in a state of heightened anxiety during the testing and the subsequent waiting period before receiving the results.

Women acting alone (or with another who is unknowledgeable) who do not know the standard of care for breast cancer treatment are likely to feel rushed or pressured into quick decisions. New patients, shortly after diagnosis, must decide on methods of surgery and adjuvant therapy, such as radiation, chemotherapy and hormone therapy, based on medical terms and tests results that are technical and difficult to understand. Survivors must also consider long-range decisions such as reconstruction that all require planning.

Women often feel a sense of urgency to undergo surgery as quickly as possible, thus adding additional pressure. Haste may be warranted if the cancer is aggressive, but in non-aggressive cases, being rushed into surgery deprives patients of time to consider a choice of surgeons and type of surgery, a situation that contributes to a feeling of disempowerment. One study of newly diagnosed colorectal cancer patients observed that "a rushed or forced decision seemed to alienate and isolate the participants and inhibited interaction in the reciprocal relationship (i.e. being involved in treatment planning decisions)" (Ramfelt & Lützen, 2005). Another study found that women breast cancer patients often made surgery decisions so quickly that they could not have had adequate time to process the information (Fagerlin et al., 2006). The continuing advancement of

breast cancer research, new tests, types of standard and holistic treatment and clinical studies mean patients have even more choices to consider. Broom's study (2009) claims that patients made medical decisions based on "intuitive or embodied knowledge" that develops within the patient over time and with experience in the medical system.

Overwhelmed or distraught patients who lack support systems to help them process and understand information are less likely to make good decisions or any decisions at all. A patient may relinquish all decision making to her doctor. Ramfelt and Lützen (2005) suggest that a person who has received such a diagnosis would rather count on the "expert knowledge of physicians and nurses and ... has no desire to participate in the decision making." Additionally, physicians with patients who are unwilling or unable to make choices are put in the position of making decisions for the patient, rather than supplying the necessary, neutral information patients need to make the decisions themselves (Gafni, Charles, & Whelan, 1998).

As the experts with the knowledge and information, doctors play an enormously important supportive role. Therefore, when there is an unsatisfactory doctor-patient relationship, the patient experiences not only anxiety from distrusting the person who is supposed to be helping her the most but also an actual fear for her life.

Patients who lack support systems are forced to self advocate, which requires locating sources for information and services. Although such resource information is relatively abundant online and through treatment centers, women recently diagnosed with cancer may not have the physical or mental energy to locate what is needed. For example, several online national breast cancer advocacy groups, such as the Susan B. Komen Foundation, address legal rights and insurance matters. The Patient Advocate Foundation, after a brief monthly acceptance period

(15 minutes), provides reimbursements for cancer related pharmaceutical co-payments. The American Cancer Society Support Services provide bras, prosthetics, and transportation to chemotherapy sessions. In Hudson Valley, New York, an organization of breast cancer survivors called Breast Cancer Options (BCO) goes a step further and reaches out to patients. A BCO Companion/Advocate accompanies the patient to appointments to help her ask appropriate questions and remember information. This is an important function, as there is ample research documenting how high levels of stress and emotion may cause the inability to process and remember information (Fagerlin et. al., 2006).

During the last ten years, extensive research has examined the increased role of self advocacy for patients, particularly regarding cancer care (Fagerlin et al., 2006). The analysis centers on the responsibilities and roles of patient and caregiver, attempting to find the optimal balance between the two. Physicians face the problem of how to convey a large amount of information in a short time to someone in distress while expecting the patient to sort it out and then self advocate. Yet, survivors accomplish this every day, although not every time and with varying degrees of success. Considering the variety of personalities, finding a formula for doctor-patient roles is futile. The critical shortcoming about the recent popularity and research of patient self advocacy is that it begins its assessments once the doctor-patient relationship *has already been established.* Once with a surgeon or doctor, patients are unlikely to seek a second opinion or a better personality match. If patients had more time to make choices regarding health care professionals and cancer centers immediately after diagnosis, however, they could choose physicians with whom they were more comfortable and find a natural equilibrium.

Only by identifying the barriers that women face in receiving critical support—a good doctor-patient relationship, support groups and a patient advocate—can bridges be built or barriers removed. In this study I used

personal interviews to examine the points at which women experienced stress and difficulty with their diagnosis, treatment, and recovery. Also, I explored how the above three critical support systems could have better helped patients through their struggles. Two major themes emerged: the importance of trust in their doctor, and the lack of information about the three support systems. The difficulties of some interviewees are compared with information from interviewees who had positive experiences with doctor selection and support systems. The findings on these issues will be shared with local treatment centers and contribute to the developing role of a patient advocate in Eugene, Oregon. Perhaps through more awareness of the needs of patients made apparent through their own testimony, simple, practical measures may be taken to help to reduce stress and increase optimism for women breast cancer survivors.

Methodology

This is a qualitative study using one-on-one personal interviews of thirteen female breast cancer survivors. All women have been diagnosed and treated for breast cancer within the last seven years in Eugene, Oregon, and nine are still receiving hormone treatment therapy. The interviewees were contacted in person or by phone. They were located through a local support group, professional acquaintances, and at a breast cancer awareness event. The women interviewed ranged in age from 41 to 82. Interviews were individually arranged at each woman's convenience at her home or a restaurant, digitally recorded, and transcribed. Each interview lasted about an hour. The majority of the women were eager to tell their stories. One woman declined because she did not wish to relive the experience. Each subject signed a consent form.

During the interviews, some questions asked women to share how they discovered they had cancer, what chain of events led them to their surgeon and oncologist, and what their subsequent experience was with

their doctors. Other questions had the subjects explore by what means and at what point they began attending a support group, whether the support group was beneficial, and in what way. Still other questions sought to learn what knowledge the women had about patient advocates and where, other than their doctors, they received information. The data was analyzed and sorted by common themes or topics (see interview protocol in Appendix B). The two key themes that arose were the importance of trust in their doctors and the lack of knowledge about both doctors and peer and professional support systems. Three patients with professional medical backgrounds had more knowledge about local doctors and the medical system. Because of this, they did not experience most of the difficulties the others faced.

Key Themes

1. The Importance of Trusting Their Doctors

Having confidence and faith in doctors is a major form of support, and the five patients that were initially happy with their referred doctors felt that they were the "lucky" ones. Women that experienced confidence in their physicians appeared more positive and content with the entire process.

> I got my team through referrals and felt really blessed because every physician I had was just so nice and supportive (Mary, 42, Dec. 2010).

Patients who were happy in the way they were personally treated and confident in the way that the physician approached her treatment or surgery handled the situation with considerably less stress than those who did not. If the physicians maintained the confidence of their patients throughout, then the patients were more likely to feel optimistic about the future, and less likely to second guess treatment decisions.

> I had complete confidence. I felt good (that) I understood I was ready (Nadine, 71, Sept. 2010).

> You don't realize how much you are leaning on and have confidence in that one doctor. Either you click or you don't (Debbie, 68, Dec. 2010).

If doctors did not retain the confidence of patients, the results were sometimes traumatic, as in the case of three patients.

> I ended up in the hospital because he [the doctor] didn't listen to me. It was a mess (Nora, 52, Aug. 2010).

> The doctor called me and said we are going to have to do it over. I was just heartsick. Later he called back and said the pathologist made a mistake so I didn't have to have the second surgery (Sarah, 80, Aug. 2010).

For five patients, unease about the doctor's level of concern and the prescribed mode of treatment led to anxiety that continued throughout the treatment process. The lack of confidence these patients had in their doctors sometimes carried through treatments and continued to affect the way they viewed doctors, the medical profession, and their medical condition and prognosis.

> I felt I wasn't given honest, truthful answers. I was given "standard of care." You have to advocate for yourself because they really don't know (Judy, 64, Aug. 2010).

> I don't trust anybody. I see Dr. X now. I can tolerate him (Nora, 52, Aug. 2010).

> I don't have much confidence in doctors. It makes me wonder if I even had cancer (Sarah, 80, Aug. 2010).

When women were unhappy with their treatment, they expressed frustration and anger to their doctors, and reluctantly self advocated. These patients resented that in the midst of their emotional turmoil, they felt forced to compensate for the inadequacies of the health care system. Patients felt obligated to self advocate because they did not know of any alternative means, such as a patient advocate who could advocate for them.

> The patient should not be the patient's best advocate, and that is what I found to be the case, the patient must be their own defense (Tina, 41, Dec. 2010).

> I got mad and I went to the surgeon's office and I said, "Why is there nothing out here, no pamphlets or nothing telling people where to go [for doctors]?" (Judy, 64, Aug. 2010).

> I called … and said, "I don't want to see him [the oncologist] anymore." It was a nightmare. It was really, really bad (Nora, 52, Aug. 2010).

For these four women, their frustration and anger stemmed from not being heard or validated. They felt no one was in their corner except themselves.

Three women in the study were current or retired nurses. They felt that their profession gave them a distinct advantage over other patients in knowing whom to ask for a referral. They also felt that they probably received more comprehensive information and timely appointments. Overall, these women showed the highest sense of satisfaction about their experience.

> I got to look at my cancer cells under the microscope. Dr. X spent 45 minutes with me on pathology. I had a visual thing to know what I was fighting (Tiffany, 51, Aug. 2010).

> I met with doctors and asked questions and wasn't told what to do (Nadine, 71, Sept. 2010).

None of the nurses worked in oncology. They said their work experience in the medical field did not prepare them mentally or physically for breast cancer treatment.

2. Lack of Knowledge About Support Systems

2a. Lack of knowledge about where to find a doctor

Women going through cancer treatment for the first time most often do not know the order of events during treatment. In the testing stage, a woman will see a different doctor related to each step. By the time of diagnosis, a woman has seen about four different doctors. Because pre-diagnostic steps are usually singular in nature—one ultrasound or one biopsy—patients do not have the time to develop trust with those medical professionals. Therefore, the people who worked to determine whether she has a life altering disease are usually less distinct in her memory because of the number of procedures, the speed with which they were performed, and how little control she had over the process. Patients tend to accept this rapid pre-diagnostic chain of events because of distress and being unfamiliar with what else to do. Questions often went unasked, as the patient often does not know where the expertise of one particular physician ends, and the next begins (Haber et al., 1995, 16). Newly diagnosed patients are generally satisfied to have the current professional person or establishment arrange the next step.

> My surgeon sent a referral to an oncologist (Lauren, 52, Aug. 2010).

> That path was chosen for me (Tina, 41, Dec. 2010).

However, once women receive a positive diagnosis, given the opportunity, they are more discriminating when locating a surgeon or oncologist. Yet, because most women lack knowledge about oncological professionals, they still relied on direct, single referrals from doctor to doctor.

> I didn't have a clue where to go (Dorothy, 75, Aug. 2010).

> I didn't know anybody who had cancer. I didn't know anybody [for a referral]. I felt like I was just being shuffled through (Tina, 41, Dec. 2010).

When this referral came from their general practitioner, the results tended to be positive because the women tended to view the general practitioner as a trusted and familiar source.

> I trusted her [general practitioner] to assign me some doctors … I don't know where I would have gone besides that (Debbie, 68, Dec. 2010).

When the patient did not have an existing, positive relationship with a general practitioner, then the referral came from the last point of contact with a health professional, often from the imaging center. Sometimes this was a smooth transition, but often it was unsatisfactory.

> They were going to pair me up with this young guy [surgeon] … with no experience or minimal experience in that particular area [mastectomy], who specialized in pediatrics (Dorothy, 75, Aug. 2010).

> My GP recommended a doctor who was going on vacation, so I ended up with another (Sheila, 69, Sept. 2010).

Women most often accepted a referral from the last point of contact and took a wait-and-see attitude before making a decision about keeping the doctor or surgeon. Still, patients found it difficult and stressful to

change doctors once one had been established.

2b. Lack of information about support groups

Currently, Eugene, Oregon, has one breast cancer support group led by a health care professional (who is not a survivor) and housed at a local cancer center. The group meets weekly and is loosely structured. All women interviewed except one nurse attended the support group in Eugene, but they began at various points during treatment. The frequency and duration that survivors continue to attend varies widely by individual. One woman undergoing a recurrence began right away. Often, however, there was a significant lag time from the first diagnosis to the first attendance at the support group. Ideally, once a woman is diagnosed, she would be informed by her doctor, nurse, or advocate that a support group is available, that she has the option to go, and that most women find it beneficial to discuss their experience with other women who can empathize. The cancer center where the support group is located displays information on a flyer at the reception counter and includes that information as part of an informational packet women receive after diagnosis. At another cancer center in Eugene, this information is not displayed but is included in the informational packet. Despite seemingly adequate access to this information about the support group, many women do not notice it, do not read the literature, are not told by their doctor until later, and so do not act on it until later. Often, only when the survivors have reached a level of emotional desperation do they make the effort, and usually at the insistence of a spouse, friend, or relative who recognizes their level of stress.

> I never wanted the support group. My boyfriend at the time said, "you really ought to go." [Then later] my emotions were going crazy, and I was alone with no one to talk to (Mary, 42, Dec. 2010).

> My daughter was adamant that I go (Debbie, 68, Dec. 2010).

Unfortunately, the delay in attending a support group can be based on a misunderstanding.

> I thought it was for survivors. I know now that just sounds ridiculous but at the time, the mindset is, no I am not the winner yet (Tina, 41, Dec. 2010).

> I called, and she [facilitator] said I could come anytime (Nadine, 71, Sept. 2010).

A large part of the fear of cancer comes from uncertainty about treatment, side effects, and the possibilities of recurrence. The twelve women who attend the support groups have formed lasting relationships through their shared experience. While most of the women went to the group because of an emotional need, they learned through the discussion about aspects of the disease that they otherwise might not have known. About seven women attend on a regular basis for friendship and emotional support, but several women go only occasionally when they feel the need for support and information. Women who resisted going to a support group ultimately found it beneficial because of what they learned from the other women.

> I didn't realize the information I would get, the support I would get, I mean it is just critical (Dorothy, 75, Aug. 2010).

> I found value in being able to vent, share my frustrations, [and] get some little bit of feedback (Tina, 41, Dec. 2010).

> It [support group] opened up a whole new world for me (Betty, 63, Aug. 2010).

2c. Lack of knowledge about patient advocates as a source of information and support

The general role of a patient advocate includes being available to

answer questions, address personal concerns, and access resources. They may also intervene on the patient's behalf regarding insurance and doctor issues. The history of patient advocates in Eugene has been inconsistent, and most assist only on a part-time basis.

Occasionally women will have access to an advocate affiliated with a certain treatment center, such as an imaging (mammography) center. In that case, the advocate's help does not extend beyond the scope of a specific facility. Therefore, the patients did not know where to turn to get basic questions answered. Often, the peripheral, personal questions that arose between doctor visits left patients wondering where to turn for simple answers. For example, most oncologists are men, and there are questions women have regarding their breasts that they would rather ask a woman.

> You didn't really know who to go to, to get simple questions answered (Betty, 63, Aug. 2010).

Most women felt that the larger questions such as her options for surgery and whether she should have radiation, chemotherapy or hormone therapy were adequately addressed by their doctors. Therefore, supplemental material in brochures and informational books from the cancer center were largely irrelevant to patients, as they were concerned only with the information that had a direct bearing on their particular case. Information packets given by the cancer center often went ignored, and information over the internet was closely screened or mostly avoided, as women wanted to avoid frightening themselves with statistics, photographs, or false information.

> I felt I knew enough (Pamela, 80, Aug. 2010).

> I didn't want it (cancer) to become the center of my world (Debbie, 68, Dec. 2010).

Other doctor-related issues caused additional patient stress. For example, physicians who left their practices caused changes of doctors for patients in the midst of treatment. Finally, several patients expressed dissatisfaction about how they were told about their disease, the time delay of test results, and the overall profound effect that cancer would have on their physical and emotional life.

Discussion

Initially, the broad purpose of this study was to know how patients received information and whether the content was adequate and understandable enough to be translated into action. Given the abundance of information in books and on the internet about this kind of cancer and types of treatment, it was surprising that most women obtained most of their information from their doctor during office visits. The content of the information and the manner in which doctors conveyed it to patients was closely linked with the overall quality of care perceived by patients. The women interviewed felt strongly, both positively and negatively, about their relationships with their doctors and in the personal manner in which they were treated. The quality of those relationships became the primary theme. The level of trust patients placed with their surgeon and oncologist had a significant effect upon how they felt about their outcomes and future prognoses. Therefore, women were more likely to trust a doctor referred through a familiar source or located on their own.

When doctors provided timely information about options on the next phase of treatment, answered questions and concerns, and showed caring compassion, patients expressed trust and relief. However, the more women depended on their doctors for opinions and advice, the more they willingly limited their access to other information. It then followed that the less active a women was in choosing her treatment, the more likely

she was to second guess the procedures afterward. Lally's qualitative study (2009) of eighteen breast cancer patients showed that while most of the women interviewed wanted only "just enough information to satisfy themselves," they also felt that the information was "important, plentiful, readily available and that their needs were met." The difference in overall group satisfaction between Lally's study and this study could be explained not by an optimal doctor-patient relationship or a support group, but by the consistent and active role of an Advanced Oncology Certified Nurse (AOCN) in the Midwestern study, who was available to patients throughout treatment. After the AOCN delivered the diagnosis, she provided the newly diagnosed patient with information about surgery options. The nurse then met with the patient before and after the appointment with the surgeon to assuage any concerns or questions of the patient. The study does not, however, explain how these patients chose their surgeons.

The satisfaction of patients with their physicians was more likely when patients were able to choose their doctors. Rarely, however, did patients have the option to make that choice an issue that became the first of the three sub-themes of this study. A dearth of research exists about how cancer patients build their teams of doctors. Women largely ignore or do not access the significant amount of information online or in written materials. Although the information includes the importance of finding a team, asking physicians questions, and understanding the roles physicians play in a patient's treatment plan, there is no definitive method of how to find a good doctor. Yet patients demonstrated routinely in interviews that the doctor/patient relationship had the strongest bearing on a positive experience. Most frequently a patient is directly referred to a doctor who is within the treatment center's professional network. The process begins when a patient is referred to a physician for a biopsy. She is then continually referred from one doctor or medical center to another without

further discussion with the doctor making the referral. A patient does not know the qualifications of the doctor to whom she has been referred.

Other concerns stem from wondering if the doctor was referred because he was perceived by the referring physician as the best doctor for her, because he is a personal friend of the referring doctor, or because the doctors have established a professional referral system. This dynamic plays a critical role. Unless there is an immediate and distinct personality clash, a patient will most often take a "wait and see" approach toward the doctor and is highly unlikely to get a second opinion. Three women who had doubts about their doctor just hoped that it would work out to their satisfaction. Women who have doubts about their treatment and would like a second opinion or a change of doctors may find a change nearly impossible to make because of fear that her physician will feel doubted or rejected (Haber et al., 1995, 16). Remarkably, none of the interviewees sought second opinions about one of the most important health decisions she will make in her life. Encouragement and support by a medical professional such as a support group leader or patient advocate would be beneficial to the patient. A patient advocate could hear the patient's concerns, and help her obtain a second opinion. A support group could also be an encouraging source for her to get what she needs.

There is only one breast cancer support group in Eugene, Oregon. About one third of the women in this study went to the group immediately, another third when they found out about it, and the last third at the insistence of a friend, family member or spouse. Once having attended, the women found the group beneficial for finding emotional support and obtaining information from other survivors. Information regarding the second sub-theme to emerge from the study—lack of knowledge about support groups—suggests that had survivors known that the group was available to them and how it could help them, they would have attended

earlier in the process. A suggestion coming from a surgeon, oncologist or patient advocate would have carried a great degree of influence.

Although the benefits of support groups has been well researched and documented, the protocol of who may attend and when is still misunderstood. It may seem a minor thing to seek out a support group, and many people seem to assume that, given the availability of information, those who want to go to a support group will actually do so. However, that is often not the case. The interviewees did not know about the local support group or assumed that the support group was only for survivors. Because they were still in treatment, they did not yet see themselves as survivors, an important psychological and emotional distinction. Cancer patients are considered survivors immediately after diagnosis, and they should be made aware of that view. Patient advocates or support group leaders could officially invite the newly diagnosed survivor, making her feel welcome to talk to other women who have gone through the same ordeal.

Patient advocates are medical professionals who are trained to meet the emotional and practical needs of patients. Sarah Lawrence College in New York has been educating such health advocates through their Health Advocacy Masters Program since 1980. On its webpage "Defining the Field," the program lists the responsibilities of an advocate as one who supports the rights of patients, has direct involvement with patients, and works as health information specialist to empower patients. Access to a patient advocate depends upon location. In Eugene, the existence of a patient advocate has been inconsistent; therefore, the absence of someone to answer questions, support and empower patients became the third sub-theme (2c). Often a patient advocate is available only at a specific treatment facility and cannot help the patient beyond the scope of the treatment center. Women also thought it important to be contacted by an advocate

early in the treatment process to be most helpful. One interviewee felt she did not know whom to ask when she needed simple questions answered. Another felt that neither her oncologist nor her nurse would listen to her. One woman delayed getting a prosthetic because she was misinformed of the expense. Most of the women were only vaguely familiar with the role of a patient advocate.

The relevance of the role of a patient advocate for any type of cancer is unique compared with other illnesses. Diagnosis, treatment, recovery, and consistent doctor-patient visits occur over a period of years, not weeks or months. A patient advocate could satisfy all thematic concerns that emerged from this study. The advocate could be trained to educate and support survivors to help find doctors, financial resources, transportation, new drugs and therapies, prosthetics and wigs, and other services. Advocates could lighten the pressures of doctors and nurses, fill in communication gaps, and provide an emotional and practical aid for cancer survivors.

Conclusion

The patients in Eugene, Oregon, are best served by a three-way support system of medical professionals. The first includes a patient's choice of physicians and surgeons. Personal choice of physicians and surgeons increases probability of a good doctor/patient relationship, an element that patients view as vital to their confidence of recovery. The second support system is a breast cancer support group. Currently there is only one such group in Eugene, and evidence from interviews suggests that more are needed to accommodate different ages and group formats. For example, most women appreciated a loose structure of the meetings, but women often meet outside of the group to exchange thoughts and information about doctors and nurses that is not allowed to be shared in the group setting. One woman is planning to start a group for younger women, as

their concerns sometimes differ from those of older women, particularly in the case of reconstruction. The third support system important for survivors is that of a patient advocate. This person could assist in choosing a doctor and making the patient aware of a support group. Additionally, a patient advocate could help with insurance matters, financial resources, and answer the myriad questions that occur between doctor visits.

Further research needs to explore how best to ensure a good doctor/patient match. The practice of automatic referrals can lead to patient distrust. The efficacy of alternative methods of support, such as online groups, should be studied to learn whether they could be a significant part of the patient's support system. The role of a patient advocate in Eugene is currently being developed. This study can assist administrators in better understanding the specific concerns of patients.

When all three systems are used in conjunction with one another, a newly diagnosed breast cancer patient can minimize stress and confusion while shifting her focus to increase her chances of having a supportive and optimistic experience.

Appendix A

My interest in this research stemmed from my personal experience as a breast cancer patient. In December of 2008 I was diagnosed with stage 1B invasive ductal carcinoma. I was confused and bewildered by the process and the amount of information I felt I needed to know to make informed decisions. I felt fortunate I had a close friend who was a local physician and another close friend who was a nurse at a local cancer center. Because of their intervention, I felt confident at the time that I was receiving the best medical attention from a local top surgeon and oncologist. I researched my condition extensively by buying books and in the most convenient way possible by using the internet. Often helpful, sometimes very frightening, it helped me to feel as if I were engaged in the process and able to make intelligent decisions and ask relevant questions. Still, I mostly felt blindsided and overwhelmed. I became very concerned about others who did not have my resources and were not as proactive as myself. I wondered why there was no one in the business of helping people through this medical maze. I later learned about patient advocates and navigators. Much of the fear around cancer comes from uncertainty. The complexity and individual nature of the disease precludes knowing what direction the next treatment step will take. I wanted definitive answers, but there were very few. Even with my personal experience, I had no idea when I asked, "How did you find your doctors?" that I would be opening up such a sensitive and critical topic for all types of women. The survivors in this study were probably more open with me because of our shared background. They also knew what they had gone through and wanted to help other women.

Appendix B-Interview Protocol

- A representative sample of 13 women from Eugene, Oregon, diagnosed within the last 7 years was chosen. Interviews were conducted in their homes or at a restaurant, and lasted about an hour.
- The participants received written information about the study before their informed consent was obtained. All the participants were informed that they could decline participation or withdraw from the interview at any time. Confidentiality was guaranteed throughout. The IRB from the Office of Protection for Human Subjects granted approval.
- The goal of the survey was to determine how newly diagnosed breast cancer patients felt about the critical support systems of their health care system,

specifically health care professionals and support groups. The survey sought answers to such questions as the following: How did you choose your physicians, and how and when did you find and join a support group?

- The data was compared and analyzed with open coding. The interviews were transcribed, and data that related to support systems coded.
- The data was further analyzed around common themes, problems, and concerns. Those that showed a rate of occurrence of over 30% constituted a theme.

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