

Understanding Older Women's Experience of Being Diagnosed with Breast Cancer

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ABSTRACT: This study describes the experience of being diagnosed with early stage breast cancer for women age 65 and older. This qualitative study used content analysis to analyze twenty interviews of older women with early stage breast cancer. A variety of positive and negative factors influence the experience of being diagnosed with breast cancer. These factors include: their initial reactions, interactions with their respective medical teams, family support, religion, education, and misinformation. Nurses can use the information from this study to help make diagnosis more positive by educating older women about breast cancer and treatment, encouraging them to develop an optimistic attitude, practicing open communication, and suggesting the older woman use religious practices that she finds comforting.

KEYWORDS: nursing, breast cancer, older women, diagnosis, care

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INTRODUCTION

The purpose of this research is to describe the experience of being diagnosed with early stage breast cancer in women age 65 and older. Women who have a positive experience upon being diagnosed with breast cancer have a better experience with symptoms and treatment (Boehmke & Dickerson, 2006), in contrast to younger women, who report more distress at the time of diagnosis with breast cancer than older women (Kenefick, 2006). However, because most research in breast cancer focuses on younger women, the experience of diagnosis is unknown for older women. Increasing knowledge of the experience of diagnosis in older women will help identify the needs and concerns of this population so care can improve. This knowledge will help make the transition into cancer treatment smoother and less distressful for the patient.

BACKGROUND

It is estimated that 230,480 women were newly diagnosed with breast cancer in 2011 (American Cancer Society, 2011). Of these diagnoses more than forty percent occurred in women age 65 and older (National Cancer Institute, 2010). By the year 2030, one in five people in the United States will be 65 and older (U.S. Census Bureau, 2008). It is expected that the increasing age of the U.S. population will result in an increase in older women being diagnosed with breast cancer. Unfortunately, there is little information about the experiences of older women newly diagnosed with breast cancer. This deficit of information may lead to the inability of healthcare providers to properly care for these older women and their needs.

METHODS

This study is a secondary analysis of interview data collected for a study that used grounded theory to explore how older women integrated breast cancer into their lives with other challenges of aging (Loerzel, 2011). This current study uses qualitative content analysis to describe the experience of being diagnosed with early stage breast cancer in older women. Transcripts from these interviews were obtained from the principal investigator of the parent study. All transcripts from the parent study were used. These transcripts, in Microsoft Word™ files, were sent to this student researcher via a confidential email and were not shared with any third party. The files were

stored on the student researcher's computer, which is password protected. The transcripts were not printed at any time.

Sample

Data consisted of twenty de-identified interviews with women, age 65 and older, who were diagnosed with early stage breast cancer within the past year. Each transcript was between ten and twenty pages long. At the beginning of each interview, each participant was asked to share how she was diagnosed. While the focus of the original interviews was not on diagnosis itself, the topic of diagnosis was a way to begin communication and to prepare the participant for the rest of the conversation. Additionally, women often referred to their diagnoses throughout the interview.

Institutional review board approval was not sought because there were no human participants in this secondary analysis. Under 45 CFR 46.102(f), subjects are not considered human if the private information obtained was collected from a previous research project and the investigator cannot easily determine the identity of the individuals (Office for Human Research Protections, 2008).

Data Analysis

Data were analyzed using the following process: (a) the data were read to gain an in-depth familiarity of the content; (b) initial impressions of the data were discussed with the primary investigator; (c) the transcripts were re-read and coded using language closely reflecting what was found in the transcripts; (d) codes were placed in groups according to themes that emerged when there were numerous similar codes; (e) codes and themes were checked for consistency with the principal investigator, who agreed with the codes.

FINDINGS

Demographics

The mean age of the participants was 73 years old. Most of the women (80%) were Caucasian. Nineteen of the 20 women reported English as their primary language. All were high school graduates; 65% of them were college graduates. Thirteen women were Protestant, five were Catholic, one was Jewish, and one identified herself as

having no religion. Most of the women were married (55%) or widowed (30%). Seventy percent of the women lived with at least one other person and were community-dwelling. Seventeen of the women were retired, while the other three worked part-time, full-time, or never worked. Half of the women reported their incomes to be higher than \$30,000. For treatment, eighteen of the women received lumpectomies and two received mastectomies. Seventy-five percent of the women did not receive chemotherapy. Seventy-five percent of the women received radiation.

The Experience of Being Diagnosed with Early Stage Breast Cancer

This study reveals that a variety of positive and negative factors shape the experience of being diagnosed. These factors include: the patient's initial reaction, her interactions with her medical team, family support, religion, education, and misinformation.

A majority of the women found their cancers through a routine screening mammogram. Others felt a lump on their breasts while performing routine daily activities. A few were diagnosed after having breast exams from their doctors. Most of the women had no family history of breast cancer.

Initial Reactions

Most women reported initial surprise at a diagnosis of breast cancer. One frequently-stated reason by the women for their surprise was that they had previously been in good health. One woman stated, "I was scared, shocked. I really didn't think it would be me. I just was healthy, never been sick." Although a family history of breast cancer increases a woman's risk for developing breast cancer (American Cancer Society, 2010), both women with and without a family history of breast cancer were surprised. One woman whose mother died of breast cancer stated, "I thought I beat this." Only two women were not surprised at their diagnoses because of their family histories of breast cancer.

Despite initial shock, most older women seemed to easily accept their breast cancer diagnoses. Many had an attitude of "taking things as they come."

Comments typical of these women included:

"And [I] just kind of roll with the punches, you know. There's things you can do, there's things you can do something about and there's things that you—um—have to let take its course."

"I just considered it a bump in the road."

"It was positive - after the initial shock - it all became a very positive experience for me."

At least one woman saw cancer as a challenge:

"I'm gonna control you - you are not gonna control me."

Medical Teams

The medical teams influenced the older women's experience with being diagnosed with breast cancer. Some women experienced a positive attitude from their medical team, while some women believed their caregivers lacked empathy. Some women believed they had an open communication line with their medical team, while others felt that they could have used more communication.

Attitude

An overwhelming majority of the women state that their medical team had a positive impact on their experiences of breast cancer diagnoses. The upbeat and reassuring attitude of the medical teams were especially critical in the women's perception of their diagnoses. One woman described her doctor's reassurance after diagnosis and her reaction to his words. He told her: "But the good news [is], we can take care of it." She stated she "felt better immediately." Similarly, another woman was grateful for her medical team's kindness: "He was young and they were all very positive. I didn't walk in there and they were 'oh, you've got cancer.'" Because the medical teams did not demonstrate worry about the diagnosis, many women were similarly undisturbed and felt able to reassure their own families. When trying to ease a family member's concern about possibly dying of breast cancer, one woman cited her doctor's opinion: "All the tests are coming back fine, the doctors are very positive about this, we caught it really early." The woman believed that she did not have as much stress related to her cancer due to her doctor's optimistic opinion.

As a whole, women believed that the medical teams were supportive and kind. However, some women encountered staff members who lacked empathy. These encounters made the women feel like the staff members didn't care about them. One woman described a nurse's poor behavior and believed "some [nurses], you just know are there because they have to." She felt that these nurses, while they completed the necessary tasks, did not care about her. Another woman who had expressed her pain during a diagnostic procedure reported the technician quieted her in response to her pain, which made the woman feel as though the technician did not understand what she was going through. This lack of empathy made her feel unaccepted by the technician. While the few women who experienced these unpleasant encounters were able to get past them, they were still detrimental to their experiences with breast cancer diagnoses.

Communication

Open communication lines between the women and their medical teams were also influential in creating a positive experience in being diagnosed with breast cancer. The women felt more comfortable when they understood the disease as well as their treatment options. One woman says she appreciated "how much time they took with me, you know, to explain things and answer questions." In addition, open communication lines between the medical teams and the women enabled the women to develop trust. This trust in the medical teams also lessened the stress of diagnosis. One example of such trust comes from a woman who said, "I've always been one to have confidence in the doctors and everybody. I don't worry about it. Let them do their job." Because this woman trusted her medical team, she felt less stressed.

Conversely, lack of communication with the medical teams often created stress for these women as they tried to adjust to their diagnoses. One woman had a delayed diagnosis because of miscommunication. She stated that her doctor "swears that he told me that he found a lump. And I swear that [he didn't] tell me that he found a lump." The woman's perceived miscommunication caused an increased worry level, as the participant was left to ponder whether this delay would eventually alter her outcome.

Family Support

Support from family positively influenced the diagnosis of breast cancer in older women. Family members, although worried, provided emotional support and optimism for many of the women. One woman described her family's reaction to her diagnosis: They were "supportive but shocked, but very, very supportive." She also stated that she "feel[s] sorry for women that are doing it alone cause it would be real hard, you know, to do that by yourself." When asked if the diagnosis scared her, another woman responded: "Oh sure. And I think that particularly somebody who doesn't have a husband living in or a family person would be horrendously fearful because it is not polite to tell people how frightened you are." Being able to talk about fears with a family member helped these older women process their diagnoses better. Optimism from family also lessened distress. One woman described the attitude of her family: "They were behind me, you know, encouraging me, that you're gonna be fine."

Although most women gained strength from their family members, a number of women could have benefited from more familial support. One woman whose family lived nearby expected them to offer more support, but, as she stated: "They didn't come around as much as I thought they would come around." She was disappointed in the failure of her family members to provide support. Her feelings about the lack of support from her family was detrimental to her overall experience with her diagnosis.

Religion

Many women gained strength at diagnosis from their religion. They reported gaining strength from participating in religious rituals, prayer, and a relationship with God. Religious rituals, such as anointing and communion, gave women peace with their diagnoses. One woman, who was Baptist, became anointed after receiving her diagnosis. All the members of her immediate family had been anointed during an illness or before a surgery: she believed that the ritual helped them survive. After the ritual, she stated that she "knew then, right then, that I was going to be okay. And I was."

Some women thanked God for an early diagnosis, and some gained strength or peace from God. A common belief was the recognition that; although they were powerless to control the disease, the women strongly believed God was in control and trusted him. One

woman's statement illustrates this conviction: "Whatever I'm going through I thought, well, my hand, my life is in God's hand. I mean, if this is my time, well, nothing I can do." Another woman had a similar trust in God: "I said okay, God, um, you're sending me to this oncologist. I'm in your hands... you open the door to the ones you want me to go to and you close the doors to the ones you don't want me to go to. And it works."

Women also gained comfort from prayer. Some women stated that they prayed more often after their breast cancer diagnosis. One woman stated that prayer gave her "a peace and a calm that, you know, that you've asked for God's help. And you are having help from a higher power." Another woman gained a similar peace from prayer. She stated: "Why worry when you can pray?" Several women also gained comfort from knowing that other people were praying for them. One woman appreciated how many people she knew "put [her] on the prayer list at their churches, or their synagogues, or their mosques, you know." These prayers comforted her because she knew she had support from many people.

Education

While most women did not specifically mention being educated about breast cancer, some women discussed how lack of education about breast cancer added to their concern about the disease. In addition, some women wished for better communication with their doctors. For example, many women did not fully understand their breast cancer diagnosis. They knew that they had breast cancer because their doctors told them so, but they did not fully comprehend what such diagnoses meant. One woman did not understand the stages of breast cancer: "I mean, I knew that it, it existed, but I didn't know, you know, the stages, and so forth." This woman was educated later when she was given a brochure from the makers of Arimidex, a drug for treating breast cancer, and she shared this education with her friends: "They hadn't seen the different stages and really, really enjoyed [learning] more about breast cancer." In another instance, a woman asked the interviewer how the doctors knew she had breast cancer rather than another cancer that had spread to her breast. After the interviewer explained the process of how breast cancer is diagnosed, she felt much better. The participant stated: "They are so knowledgeable that they think that you are as knowledgeable. Just like they never, they said it was breast cancer, but they never explained to me like you just did about the cells are actually cells and that, it's not that I have the cancer

someplace else and it's spread to the breast. Um, which makes me feel much better."

Several women believed that nurses and doctors presume that the other party has explained something to the patient, leaving gaps in information for the patient. These gaps in information may be detrimental, especially to older women with breast cancer who, according to one woman, "are not real computer literate." Another woman advises medical professionals: "Don't assume we know what's going on." One woman wishes that she had been educated by medical professionals about breast cancer even before her diagnosis "because you don't have to wait until you yourself had cancer, then all of a sudden, 'Oh boy, I have to know this information and all that business that happens to me.'" This woman believes that prior education would have made her diagnosis less overwhelming.

Misinformation

Several misperceptions related to the cause of breast cancer were detrimental to the experience of a diagnosis of breast cancer. These misperceptions varied greatly and were based on life experiences. Two women believed their breast cancer was caused by environmental factors at work. One woman felt a "bat infestation" caused her cancer because many of her co-workers were diagnosed with cancer. Another woman felt there was "something in the water," since several of her colleagues at work had also been recently diagnosed with breast cancer. Another woman believed if she hadn't eaten so much meat and exercised more that "maybe [she wouldn't] even have [had] to go through this experience." Another woman believed that she "caught" cancer because she had spent a lot of time volunteering with cancer patients prior to diagnosis. These misperceptions caused the women to feel that they were partly responsible for developing cancer; this guilt was detrimental to their diagnosis.

DISCUSSION

This current study shows that many older women, regardless of family history, were initially shocked when diagnosed with breast cancer. In a comparative study, Boehmke & Dickerson (2006) state that younger women and people with no family history of breast cancer are more shocked at their diagnosis than older women. Most of the women in the current study do not have a family history of breast cancer. The findings of the current study indicate that diagnosis can be surprising for older

women and its impact should not be discounted in this population. Boemke & Dickerson (2006) also found that the emotional distress of women diagnosed with breast cancer is profound. This current study concludes that the amount of distress a woman experiences upon diagnosis is determined by a variety of factors.

In the current study, the medical teams had a largely positive effect on older women diagnosed with breast cancer. These women appreciated the optimism of the medical staff, which made the actual diagnosis less scary. This appreciation for optimism is consistent with findings of Wright, Holcombe, and Salmon (2004); women with breast cancer, diagnosed at various stages, want to be “left on a positive note” during communication with their doctors. Another finding by Wright, Holcombe, and Salmon (2004) is that women appreciate and value open communication lines with the medical staff, including explanations and answering questions. Wright et al. (2004) also found that some patients “did not want to be given as much information as possible” and that some patients complained of being “over-informed.” The difference in opinion on this matter may be due to the fact that this current study only includes women diagnosed with early stage breast cancer, whereas the study by Wright, Holcombe, and Salmon (2004) included women who had been diagnosed at various stages. Women diagnosed with early stage breast cancer may want more information about their prognosis because an early prognosis is generally good. In addition, the trust that many women had in their doctors is consistent with the study by Wright et al. (2004), which states that the primary concern of women with breast cancer is to trust the expertise of the doctor. Another finding in the current study is that religion plays an important role in an older woman’s diagnosis of breast cancer. Religion often gave women strength to deal with their diagnosis. Trust in God also allowed women to be at peace with their diagnosis. The feeling of trusting God is consistent with a study by Feher and Maly (1999), which focused on religious and spiritual coping strategies among older women within the first six months of breast cancer diagnosis. Feher and Maly (1999, p. 408) state that “Religious and spiritual faith provided respondents with the emotional support necessary to deal with their breast cancer.” Feher and Maly (1999) also state that religion provided women with social support during their diagnosis. These findings are consistent with the current study: many women found comfort in the knowledge that they were being prayed for by other people.

Family support also positively influenced the process of being diagnosed with breast cancer in older women. Most women believed their family was supportive and that family members played a positive role in diagnosis. This finding is supported by Maly, Yoshiko, Leake, and Silliman (2004) who report that women over 55 who have been diagnosed with breast cancer whose family members are supportive have better mental health. However, that study did not specifically focus on diagnosis. This current study shows that some women are not educated about breast cancer, and some have a knowledge deficit at diagnosis. Although these women were diagnosed with early stage breast cancer, not all of them understand what early stage means. This lack of knowledge can cause undue stress because they may believe their situation is more dire than it actually is. This study also shows that women want more education about breast cancer. It is not known if misinformation worsened the experience of a diagnosis of breast cancer. However, it is possible that misinformation indeed caused undue stress on women who were diagnosed with breast cancer. Two women falsely believed that their environment (i.e., something in the water, bat infestation) or lifestyle (i.e., eating too much meat, spending time with cancer patients) may have caused their breast cancers. The notion that they may have caused their own breast cancers could potentially cause guilt, which may worsen the diagnosis experience.

Implications

Several implications for education, practice and research exist. Older women need to receive education about their risk factors for breast cancer, including advanced age and a family history of breast cancer. The nurse has a duty to educate older women about breast cancer risk, as well as to answer any questions the older woman may have. Such information may reduce the stress and shock that the older woman faces when she is diagnosed with breast cancer. This study also revealed that some women want more education related to their diagnoses, including more information about the stage of their cancers. Women with early stage breast cancer have a generally positive prognosis, and so an explanation about staging may help older women recognize that cancer may not be as life-threatening as they imagined. Because open communication between the medical staff and the patient was valued by older women with breast cancer, staff members should make every effort to provide explanations and answer questions. The nurse should encourage the patient to ask any questions that she may

have and explain answers thoroughly. The nurse should also consider re-explaining in layman's terms what the doctor has already said to promote understanding. Because older women with early stage breast cancer generally have a good prognosis, the medical staff should make a strong effort to exhibit an optimistic and encouraging disposition. It is important for the older woman to be reminded that her breast cancer is treatable so that she can maintain a positive outlook.

Because religion provided so much strength for these women, older women with breast cancer should be encouraged to use any religious practices that give them comfort. Nurses can encourage the woman newly diagnosed with breast cancer to continue those religious or spiritual practices in which she finds comfort. This research only describes the experience of diagnosis in older women with early stage breast cancer. It may be useful for researchers to examine older women with more advanced stages of breast cancer or older women with different diagnoses to get a clearer picture of how a diagnosis of breast cancer affects older women. In addition, many misperceptions about breast cancer were revealed in this study. Further research should be conducted to address misperceptions that older women may have related to the cause of their breast cancer and possibly to educate older women about breast cancer by using media that is more accessible to them.

CONCLUSION

The purpose of this research was to describe the experience of being diagnosed with early stage breast cancer in women age 65 and older. A variety of factors influence this experience. Most older women diagnosed with early stage breast cancer are initially shocked at their diagnosis, even if they have increased risk factors. The medical team's optimistic attitude increases the woman's optimism, and the medical team's willingness to communicate promoted trust. Many women gained emotional support from their family members, while some felt they needed more support. They also gained strength and peace with their diagnosis from their religion. Some women would have benefited from more education related to their breast cancer, and some women had misperceptions about the causes of their cancer. Understanding the experience of a diagnosis of early stage breast cancer in women age 65 and older will enable health care professionals to make this event as positive as possible.

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