Awaiting Diagnosis of Breast Cancer: Strategies of Enduring for Preserving Self

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Undergoing the diagnosis of breast cancer is one of the most severe stresses that a woman may experience (Lally, 2010; Lally, Hydeman, Schwert, Henderson, & Edge, 2012; Lebel et al., 2003; Poole & Lyne, 2000; Thorne, Harris, Hislop, & Vestrup, 1999; Woodward & Webb, 2001). Recognizing this, diagnostic centers have worked to reduce this stress by shortening wait times between mammogram, biopsy, and results (Castellanos et al., 2008; López et al., 2009).

However, the intensity and duration of the stress experienced during this period transitions quickly to aversive emotional responses in these women (Blow et al., 2011; Doré, Gallagher, Saintonge, & Hébert, 2012; Thorne et al., 1999). The purpose of this study was to add to the literature by describing women’s emotional responses when facing the possibility of breast cancer and through the construction of a theory to conceptualize strategies for “getting through” the time between finding a breast lump, receiving news of an abnormal mammogram, and hearing biopsy results. Working inductively, the authors linked the derived theory with the mid-range Praxis Theory of Suffering.

Background and Significance

Breast cancer has become a familiar illness through media attention, mass mammography screenings, and the willingness of women to discuss their experiences (Edwards, 2006; Ganz, 2000); however, it remains one of the most feared conditions among women (Blow et al., 2011; Fridfinnsdottir, 1997). Globally, breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death among women (Jemal et al., 2011).

When a breast lump is found by a woman or confirmed by a healthcare provider, it jars the woman from her familiar routine. For example, she must disrobe to be touched by strangers, and later to have her breasts inserted and squeezed in the mammography device, which begins the process of care for those diagnosed with breast cancer. This process is structured with distinct phases related to waiting for appointments and the results (Doré et al., 2012; Poole & Lyne, 2000; Thorne et al., 1999). All women (regardless of the final diagnosis) go through the same prediagnostic waiting,
but each may take different steps, including multiple repeated examinations and procedures (Blow et al., 2011). No such thing as a “simple diagnostic test” exists, some are uncomfortable and others painful; however, waiting for the results causes greater psychological discomfort than the invasive procedures (Flory & Lang, 2011). Women experience a wide range of intense emotions while waiting to receive the results of diagnostic testing, including acute depression and high levels of anxiety (Benedict, Williams, & Baron, 1994; Doré et al., 2012; Fridfinnssdottr, 1997; Lebel et al., 2003; Poole, 1997). For some women, it can be a traumatic experience that perpetuated distress.

Women use a variety of personally chosen strategies to manage the distressing wait, including religious beliefs (Logan, Hackbusch-Pinto, & De Grasse, 2006), family (Ching, Martinson, & Wong, 2009), exercise or physical diversions (Blow et al., 2011), or work (Dragset & Lindström, 2005). Feeling and acting “normal” in a world with changed assumptions require a reframing of self-perspectives and individual beliefs (Ching et al., 2009). Physicians often focus on the cancer diagnosis and treatment of the breast instead of a woman’s emotions. Leydon, Bynoe-Sutherland, and Coleman (2003) reported that this made it difficult for women to communicate their symptoms or concerns. Women with breast cancer considered active listening and provider awareness of their feelings to be enormously helpful (Harris & Templeton, 2001).

How women make their way through this period of waiting reflects individual personalities and situations. This distressing wait experience has been described as clinically significant (Hegel et al., 2006) and comparable to the distress experienced by psychiatric patients (Hewitt, Herdman, & Holland, 2004; Poole et al., 1999). Quantitative studies have considered the strategies used by the women during the diagnostic phase, such as thought suppression or avoidance, as indicators of psychological maladjustment and a poor prognosis, regardless of positive or negative diagnosis (Ando et al., 2011; Donovan-Kicken & Caughlin, 2011; Iwamitsu et al., 2003, 2005a, 2005b).

Methods

Glaserian grounded theory provides methodologic strategies for developing mid-range theory from data. It provides techniques for thinking about data, organizing categories, developing concepts, and developing mid-range theory (Glaser, 1978). Such mid-range theory, developed from data, may be used as a basis for intervention development. Initially, the current study’s authors sought women from clinic referrals and advertisements to interview about their experiences of waiting to receive biopsy results shortly after receiving them. However, during the initial interviews, some women were still waiting for final results, whereas others who responded had previously experienced this process, sometimes many years earlier. Therefore, the length of time between receiving a diagnosis and being interviewed for this study ranged from one month to 14 years. Four individuals who were waiting for final results were re-interviewed after they received their diagnosis. When phenomena are delineated by sequential events and common experiences, most grounded theorists tend to use 30–40 participants to reach saturation.

A total of 37 participants were interviewed, with four participants interviewed twice. The age range was 32–76 years (X = 52.5 years). It was the first biopsy for 29 women, the second biopsy for 2, and 4 reported having more than five biopsies. Eleven women received a positive diagnosis, and 24 received a negative diagnosis for breast cancer (two not known). The amount of time the women had to wait between biopsy and diagnosis differed dramatically; however, the possibility of having cancer remained an emotional crisis for all. Although the length of the time required for the diagnostic experience has been reduced, women continue to fear the possibility of breast cancer (Benedict et al., 1994). Therefore, the emotions expressed have not differed.

Data Collection

Data were collected using unstructured telephone interviews conducted by three research assistants. Four participants were interviewed twice (by the same three research assistants) because they had not received the results of their biopsy at the time of the first interview. Pre-arranged interviews allowed women to find a quiet and private place so they could speak freely. The phone provided intimacy, anonymity, and a way for the authors to record interviews. Verbal consents, along with any questions the women asked about the study, were recorded on a separate audio file. Institutional review board permission was obtained from the University of Alberta and the University of Utah.

After obtaining demographic information, the interviews commenced with open conversation (i.e., “Tell me . . .”). This open-ended strategy enabled participants to tell their story to an attentive interviewer, with minimal interruption. Any questions that arose during the interview were asked by the interviewer at the end of the woman’s story.

Interviewing women after their experience of waiting for diagnosis gave them time to reflect on and make sense of what had happened. Emotional depth and personal meanings were reflected in each woman’s voice and descriptions as they relived their feeling and events as emotional reenactment (Morse, 2002).
Data Analysis

Following the methods of Glaserian grounded theory (Glaser, 1978), the interviews were transcribed, transcription errors were corrected, and the interviews were read. Analysis began with first-level coding by highlighting key phrases in each segment. Analysis proceeded with small groups of researchers asking analytic questions of the data using interpretive coding. Those ideas (coding and memos) were placed directly below the relevant text in capital letters to separate the analysis from the text. Memos remained with interview text so that if text was later placed in a category or subcategory, the memo also was transferred for analysis.

Initially, the authors worked with broad categories according to common content and copied the relevant text (with participant number, page number, and memo) from all interviews into appropriate categories. As these categories expanded, comparison revealed similarities and differences, which were divided into subcategories.

Once the authors understood the course of events, phases were identified and subcategories reanalyzed, interpretively labeled, and described. Processes of constant comparison and memos were used to compare instances within and between categories, and subcategories with subcategories. The authors examined transitions of the process examining the relationships and outcomes. Finally, the core variable, a theme connecting data and unifying the emerging theory, was identified.

In grounded theory, validity and reliability are attended to in the process of theory construction (Meadows & Morse, 2001). As categories form and conjectures are developed, they are confirmed with participants and with other data for consistency. In this way, the theory is constructed. It was clear that the behaviors of suffering described by these women had been described in the Praxis Theory of Suffering (Morse, 2001, 2010). Therefore, at that point in the analysis, the authors’ findings were linked to that explanatory theory. The Praxis Theory of Suffering describes enduring as the response of those who are suffering. Initially, after learning of a loss (or the threat of a loss), emotions are cognitively and behaviorally suppressed, enabling people to go about their daily tasks until they can cognitively grasp the implications of their loss. Once the ramifications of the loss are acknowledged, the person may move into a state of emotional suffering. The Praxis Theory fit these women’s descriptions of their feelings, emotions, and behaviors while waiting for diagnosis, and was used as a theoretical frame that explained their behaviors and provided insight into the stages of waiting.

Findings

Undergoing procedures to diagnose breast cancer is a highly distressing personal experience, dictated by the institutional context of hospitals and clinics, and deeply embedded in the traditions of medical science. The breast cancer diagnostic process is incremental; women receive mammograms (some repeated) and MRI scans, followed by needle biopsies, and perhaps lumpectomies. Sometimes, results were given immediately, but more often were delayed because of chance holidays, physicians’ schedules, and delays in information transfer. During this process, women were dependent on physicians to provide their results.

Throughout the diagnostic process, women continued with daily routines and employment, while controlling their emotions and maintaining normality so as not to upset others. These women tried, with extraordinary effort, to suppress all feelings of distress, thinking they appeared normal. In this context, enduring is a necessary and healthy response that enabled women to live through the experience, and is a behavior that exemplifies the concept of preserving self (Morse, 2012; Morse & Johnson, 1991; Morse & O’Brien, 1995) (see Figure 1).

Facing Cancer: Feeling Stunned

Some women came to the clinic because they felt something unusual in their breast. They immediately recognized these lumps as the possibility of breast cancer, which signified difficult treatments, disfiguring surgery, and the possibility of dying. Women who presented for a routine mammogram did not suspect a breast abnormality until the procedure was repeated two or more times. Sometimes, they were told that something was there; other times, a woman fearfully worried and waited without any information.

And, finally, okay, she took it again. And then she came back . . . and did it over again. And I’m sure it was three times she did it over. So, that was fine. Then, I waited, and then she had me go into another room and they came in, they said that there was something there.

Grappling with the idea: All women grasped the significance of cancer; some had a family history of breast cancer, and all knew of others who had received breast cancer treatments or of people who had died from breast cancer. Implications of an abnormality in their own breast made the women concerned and frightened, yet also incredulous. They sat on “pins and needles” with their “minds racing,” some “freaking out,” whereas others just “sat and prayed.” “Half of my mind said the news isn’t going to be good, and the other half would say, ‘Oh, it’s going to be okay. It’s going to be okay.’”

Some women had an immediate ultrasound or needle biopsy; others spoke to the doctor and made an appointment for these procedures. Eventually, they were allowed to dress, go home, and wait. Women remained
worried, even to the point of panic. Some were crying; others reported that their heart was “racing” with an anxiety attack while preparing for the news. I think you’re so prepared to hear the worst . . . you keep thinking, “What if it is, what if it is? I’d bet it is, I’d bet it is.” And you’re getting—well, if it is, I’ll do this, and I’ll do that, and I’ll do this. You’re always thinking the worst.

Women could not speak of cancer directly, referring to it as “the big C,” “it,” or “you know.” Women forced down their fears and emotions, but thoughts of cancer still surfaced quickly and unexpectedly. These thoughts were immediately and intentionally squelched by “putting the thoughts to the back of their mind” or “setting the thought aside.” Although the women had not received a definite diagnosis, some made up their minds that they either did or did not have cancer. No uncertainty existed in this data.

Some of the women found that telling others helped them come to terms with their situation. “I found the most helpful thing was telling people [because] it made me have to say over and over again, ‘I have cancer.’” Yeah, [because] I, I thought well, there’s no point worrying until I actually know, [because] my husband’s always saying, “Don’t worry until you finally find out something,” you know. But I, deep down inside, I knew that I had cancer.

Telling others about the possibility of having breast cancer was carefully paced and varied with time, place, and relationship. However, women were aware that the possibility that they had cancer would have a rippling effect of distress on immediate and extended family, friends, and work associates. Most immediately told their husbands, who were supportive. Family context also was important; if their mother had had breast cancer, women were not likely to tell her. Others told their sisters or close friends. They delayed telling their children because they did not want to upset them or cause distress.

Bracing for the biopsy: When waiting to be called for the biopsy, women realized that they could not change their situation. They told themselves that it was benign, “‘Just a fibroadenoma’—I thought that the whole time. But the chance that it wasn’t [benign] was, was a torture—was torture.” For the women, waiting was particularly difficult, “Was I worried that it would be cancer? . . . Not outwardly. But I think, you know, even a miniscule percent plays on the back of your mind.” They braced and prepared for the worst by controlling their thoughts and emotions.

The biopsy for some was “not too bad,” but other women were surprised by how many samples were taken and by the strange sensation of having a needle in their breast. Some women recalled the biopsy as deep and painful, and said that their breasts became swollen and bruised. Some worried about the size of the scar. “[The] biopsy procedure I found really horrible. Uh, this cyst, I think, was very deep into my breast, and I found the surgery horrible, horrible, horrible, horrible.” For others, the biopsy itself forewarned them of the seriousness of their disease.

Before going in for the biopsy, I thought there [were] just going to be three [tumors], but afterwards being told that [the doctor] had taken out seven, it was like, “Oh my God!” [laugh]. So yeah, your heart kinda hits the cement floor and goes “Splat!”

Waiting to Hear: Enduring

Wrapping your mind around it: Women could not stop their lives as they managed the idea of cancer; they had responsibilities, expectations from others, and children to care for. Women tried to come to terms with the idea of cancer while normalizing their daily life.
You know, it impacts everything in who you are. It impacts your family, your children, and your work, you know, your personal, everything. I worried what my, my husband would think about if I had to have a mastectomy... What if I lost my hair?... What would the drugs do to my body?

You still have to get up. You still have to get dressed and go to work and feed the kids and take them to school... but yeah, your brain just kinda—I don’t know—kinda starts to shut down a little [laugh], but you kinda go into self-preservation mode.

Women had frequent thoughts about what if they had breast cancer. They assessed the odds for the likelihood of cancer by considering their personal history. If a woman had a strong family history of cancer, she considered herself to be high risk, “It is really rampant in my family. So, of course, that’s the first thing you think about—you know, now it’s my turn.” Those without a family history tended to think they were low risk, “We don’t [have] breast cancer in my family.” “You know, I’ve never worried about getting breast cancer. Like that doesn’t run in my family, you know.” A previous history of abnormal, but benign, examinations allowed women to believe that cancer was not a consideration. Those who convinced themselves they did have cancer began planning for the future. Many women spoke of their fears, including fears of dying, cancer, prolonged illness, and the clouds of future uncertainty.

You know, a lot of self-talk and saying... “You’re just overreacting, get back to reality. It’s not that bad. Lots of women have this and have done it perfectly well, and so what if your hair falls out, you know, you [have] lots of gray anyhow, so...”

Women were anxious to hear the results of their biopsy. One woman explained,

I need an answer so I can make a plan. If, you know, if it’s not cancerous, great! Let’s just move on. If it is cancerous, I need to know so I can plan because not only am I planning for myself, but I need to plan for my family.

Some women barely got through the day. They reported that tears “broke through,” and they had trouble concentrating at work. Nights were worse, with many women reporting difficulties sleeping and nightmares. In the quiet of the night, anxieties would “creep in,” or terror would come “tumbling back.” Others used the quiet of night to reflect. “You lie there and you’re thinking in the dark. It’s really just you. And you have to put your head around it and, and find the best way that you’re going to get through it all.”

**Controlling distress:** The major mechanisms for controlling distress were cognitive. Some placed all thoughts of cancer at the back of their mind so they did not have to think about it.

Just a feeling that stewing isn’t going to help me anyway. Even if it’s the worst possible news. If I... if just sort of sit around worrying, or if I disrupt my whole day with worry, it will absolutely do nothing for me.

Others weighed the odds, “And if it’s not for sure, then you have a 50/50 chance of it being good. Just as well, as there’s a 50/50 chance of being bad. So take the good side.”

Deliberate suppressing of the emotions of fear and distress required considerable physical effort and could not be sustained for long periods without release. Although women appeared to be unemotional in public, they also described moments when their anguish and fears rose to the surface, “Cry. If you do anything else, it’s not going to change anything. The best thing is let it go.”

**Keeping going:** Women made much effort to get through each day by living in the present and using distraction to sequester their internal emotional chaos. They said that they were “keeping a stiff upper lip,” “putting one step ahead of the other,” and “doing one thing at a time.” They kept busy with activities such as running, yoga, exercise, and housework, while keeping their minds occupied with prayer, logical self-talk about the likelihood of cancer, working at paid jobs, and suppressing intrusive thoughts of the possibility of cancer.

One of the ways some of the women attempted to regain a sense of control was to actively seek information about breast cancer. They got books from the library, asked neighbors for opinions, and talked with their nurse to learn what to expect in the future.

I got more books. I read them. I continued to talk to, um... I think really that’s what got me through it all was talking to the cancer nurses and to the cancer survivors. That’s where I got most of my support. Not my family. It was very, very devastating for me... Waiting for results was excruciating.

And you wait at home. And you wait. And you wait. And the phone doesn’t ring... You’re waiting, and you’re waiting and not knowing. And that is very difficult, to wait. And I think I’d have sooner, even if it had been bad news, let’s get it, get the news. Good—okay; bad—let’s deal with it.

Waiting seemed to extend time, adding unnecessary strain.

So, again, every day I come home and your heart just pounds, and you’re so scared to pick up the
Women knew their lives would be substantively changed.

**Hearing Positive Results**

**Confronting your worst fears:** Eventually, the results of the biopsies were available. Some women were actually told on the phone, depending on their physician or their need to travel for the appointment; others were asked to come to the physician’s office and to “bring someone with you.” This information, accompanied by the serious and even a distressed tone of the receptionist, provided a foretelling and time to brace for bad news. The women were told of positive cancer results, sometimes with compassion.

And I could just see by her face right away. So she sat down and took my hand. She gave me a hug and she said they found cancer. . . . And then we sat and talked for about 20 minutes. But, to be quite honest with you, I don’t remember a lot because I think you just, that “C” word flashes and, and it really is true.

Your whole life flashes in front of you of what you’re not going to see. You know, I’m not going to see my sons get married or have children and, and it’s like a split-second feeling. I’ve never had anything, experience like that before. And so she tried to assure me that this was caught very early and . . . she was just going to get me to the best care.

Women reported they were stunned when hearing the news: “It scared the living daylights out of me,” and “Your world just shatters.”

I was scared. Like cancer is a scary word to me. I think it is to anybody, I really do. But cancer’s very scary to me. When I heard; when I heard that word, oh man, I’ll tell you. I just fell apart so bad. I cried for many days, many days after I got the news. I’ll tell you. Many days I cried. I just couldn’t control . . . I just went to pieces.

Sometimes, the diagnosis was given to the women bluntly, along with the treatment plan: “You have cancer. You need your breast removed. You need radiation. You need [chemotherapy].”

She just said . . . “I’m sorry. I’ve got bad news.” Well, right then and there, I broke wide open crying right there. She didn’t really . . . she didn’t really sit down and really talk to me. . . . Well, the state that I was in . . . I cried. I cried for days. I cried for days. I had such a sore stomach from crying, and [I was] sick to my stomach that I didn’t know what to do.

Sometimes, the women were given the news over the phone.

As I say, I prepared everything. I made sure that I had, uh, you know, life insurance and so on and so forth, and my children were looked after. Mentally preparing myself for the end, so to speak. And yeah, so naturally when that came, it sure, it made me weak. I had to sit down, you know. Yeah.

**Continuing enduring:** Women knew their lives would be substantively changed.

It, it’s like your world just shatters, it just shatters. It just, it’s like one minute you’re there, and the next minute you’re just, you’re picking up the pieces and you know that you’ll never ever get it back together the way that it was. It’s like your life just changes in a heartbeat, just on a turn of a dime—forever!

Women who were given a positive diagnosis then moved into emotional suffering and back to enduring through their treatment plan of surgery, chemotherapy, and radiation.

**Hearing Negative Results**

**Releasing from enduring:** Receiving negative results was a different pattern of telling. Braced to hear the worst, the good news took some time to sink in.

[I] was all prepared for the worst, but when it wasn’t it was just, “Hohhh!” You can breathe . . . I think, I’m sure, I was holding my breath when she was talking to me. You can finally breathe and . . . because I should have known all along it was okay. Like, I was sort of mad at myself because I was thinking the worst; almost like, well, you didn’t have to worry for nothing . . . you worried for nothing . . . almost made yourself sick worrying about it, and it was okay. You didn’t have to do all that worrying . . . you’re fine!

Well, he came in the room and he said, “I’ve got good news for you.” And he had a big smile on his face, and he said it was nonmalignant. And he repeated it two, three times. He said it was not cancer.

Women described their feelings when immediately hearing the news, not of relief, but as a physical feeling of weakness, of having to sit down: “My knees just went, oh, I had to sit down. I went, ‘Oh my God! Thank God, thank God!’ You know? It was, it was
amazing news, yeah.” They “broke out in a sweat” or felt “flushed and sweaty,” but shortly after, when realizing the significance of the news, felt joyous, giddy, and humbled, even shedding tears.

And I was sitting there—actually, I was crying. And [my son] came in and he goes, “Mommy, what’s wrong?” Of course, right away he thought, you know, bad news. And I said, “No, no.” I said, “This is happy tears.” And I told him, I said, “Mom’s going to be okay.”

Sharing the good news: The pent-up emotions of enduring were released through feelings of profound relief. The relief was not instantaneous; it was somatic, followed by joyous tears of happiness. Some women actively celebrated the news—for instance, going out and buying a chocolate cake. Women then phoned friends and family to share the good news.

Experiencing the threat of cancer appeared to have changed the women deeply. They were determined to live each day to its fullest, appreciate others, and be grateful for their health.

I feel grateful each day and, and I thank God for, for each day. Um . . . so that . . . when I think back to it, it’s, it’s a reminder of . . . being blessed and [having] another chance and . . . just to try and be the best person that, that I can be.

A few women, however, were concerned about the tentative nature of medical talk. They said the “doctor wants to check me in six months,” and felt they did have cancer, but the doctor had not “found it yet.”

But, so there is, there still is that sense of yeah, well, you know, this is good for now [laughs]. But there’s still that possibility that it may not be, you know, down the road, but that’s remote. And, but it’s, it’s still something to be considered.

Theoretical Development

The overwhelming content of the authors’ interviews was that of emotional distress. The interviews consisted of strategies for suppressing and managing distress so the women could continue with their daily lives. Being distraught, crying, and the posturing of emotional suffering distresses others, incites compassion, and initiates comforting responses. Emotional suffering often is considered a private, undignified behavior, and, therefore, can be inappropriate in the workplace. The suppression of this emotional distress has been described as enduring (Morse, 2001, 2010; Morse & Carter, 1996). Enduring enables an individual to manage extraordinarily stressful situations without being overwhelmed with distressing emotions. Enduring or suppressing distress was essential to the women’s survival as wife, mother, and employee (Morse, 2010).

While enduring, women focused on the present and doing what must be done. They removed the thought of cancer from their mind by focusing on their children and daily tasks. They kept busy, aware that if they thought of cancer, they would lose control and become overwhelmed. When containing the fear of cancer, women described various strategies to put the thought of cancer out of their mind. Enduring required the most effort while waiting to hear results. Sometimes enduring failed when women least expected it; for instance, in the quiet of the night, emotions would break through and overwhelm them.

Throughout the process of waiting for a diagnosis, the strategies for enduring were varied according to the woman’s belief about whether or not she had cancer. If women had no previous history or contact with breast cancer, they seemed to be more successful at enduring. Women with friends or family members with prior histories of cancer endured less successfully and moved quickly into emotional suffering.

In the context of waiting for the results of the biopsy, most women had little choice but to endure. The suppression of their emotions in the process of enduring was an act that enabled essential functioning and included normalizing, rationalizing, and going through the actions to preserve the self.

While examining the function of enduring, it became evident to the current authors that the purpose was protective. These women had no choice but to hold themselves together to continue functioning in their daily roles. Therefore, enduring is a normal cognitive process that is behaviorally visible and recognizable. Enduring must be considered a healthy, but physically demanding, protective response that enables functioning, prevents emotional disintegration, and enables preservation of sense of self. In this study, preserving self was the core variable, enabled by enduring, and formulating a midrange theory, Awaiting Diagnosis: Enduring for Preserving Self.

Discussion

The emotional responses of women waiting to receive a potentially life-threatening breast cancer diagnosis were the responses of enduring as described in the Praxis Theory of Suffering (Morse, 2001, 2010). Suffering is the response to a threat of one’s psychosocial integrity through potential loss, and consists of two major states: enduring and emotional suffering. Although emotional suppression had been previously noted in women undergoing diagnosis for breast cancer, it has been treated as abnormal (Ando et al., 2011; Donovan-Kicken & Caughlin, 2011; Iwamitsu et
Implications for Practice

Women undergoing the diagnosis process related to breast cancer are faced with several simultaneous potential losses, including the loss of valued friends, a spouse, children, a future, and life itself. However, responding in a manner that brings forth feelings of distress in women may result in an emotional disintegration into suffering and loss of self.

Thoughts of life-endangering events are difficult to suppress, and if suppressive coping was perfect, no unwanted thoughts would occur. However, the psychological research suggests attempts to avoid anxiety-producing thoughts may exacerbate a cycle of returning negative thinking (Wenzlaff & Wegner, 2000). Emotional re-education has been recommended to instruct women how to communicate feelings accurately (Iwamitsu et al., 2005b; Reardon & Buck, 1989). However, major depression and, consequently, distress are often unrecognized and untreated (Ando et al., 2011; Fann et al., 2008).

The administration of short self-report instruments has been advocated to determine the level of emotional distress. One instrument, the distress thermometer, is a 10-point scale with all scores above four considered worthy of further attention (National Comprehensive Cancer Network, 2013). Several problems exist with this format. For example, women might consider the self-report too simplistic and not representative of their feelings or experiences (Cohen, 2013). Clinicians know little of what this scale measures, and that the distress thermometer must be compared with qualitative interviews, skilled observational assessment, and the truest gold standard—asking the person how she or he feels (Stewart-Knight, Parry, Abey, & Seymour, 2012).

Nevertheless, the Praxis Theory of Suffering offers a theoretical rationale for women’s emotions (Morse, 2001, 2010). From this theoretical perspective, enduring is a contextual, normal, natural, and even healthy response to a potential threat of an unavoidable loss that will continue until the women are able to cognitively accept the fact that they have (or may have) cancer. Therefore, enduring should be supported by healthcare professionals. Caregivers must maintain a respectful distance from those who are enduring, using silent compassion, refraining from touch and the use of empathic and sympathetic statements. It is not helpful for the person to be moved to emotional suffering; caregivers must affirm patients’ humanness, their intrinsic strength, their right and need to endure.

Women will emotionally suffer when they are able, ready, and the context is appropriate. Rather than considering the lack of emotional display to be abnormal, physicians and nurses must support enduring by refraining from using empathy and comforting touch, to help their patients get through this time. The use of empathy with women who are enduring breaks through their attempts to suppress emotions (Morse et al., 1992; Morse, Bottorff, Anderson, O’Brien, & Solberg, 1992), unintentionally bringing emotional suffering to the fore. However, these women know instinctively that they cannot function if they are emotionally suffering, so the use of empathy at this time results in women increasing their enduring behaviors. For this reason, empathy is not helpful at this time (Morse, 2010), and the transition from enduring to emotional suffering has been microanalytically described elsewhere (Morse, Beres, Spiers, Mayan, & Olson, 2003). Women should not be questioned about their distress, but caregivers should follow the woman’s behavioral cues, communicating with silent compassion and providing respectful and individualized care.

Conclusion

By exploring the emotional responses of women to the diagnostic processes for breast cancer and the impact on their families and daily lives, this study revealed ways that women endured an extremely distressing time. By enduring, they were able to continue with caring for themselves and their families, preserving self as women, mothers, wives, friends, and employees. By linking the new mid-range theory, Awaiting Diagnosis: Enduring for Preserving Self, to
the Praxis Theory of Suffering, the results provide a framework for clinicians, and this framework is transferable to those who are undergoing diagnosis for a potentially life-threatening condition. Using the new mid-range theory, nurses and other clinicians will be able to recognize the behavioral indicators of suffering—patients’ attempts to preserve self—and respond accordingly.

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References


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Journal club programs can help to increase your ability to evaluate literature and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

1. This study included women who were diagnosed with breast cancer and those who had a negative biopsy. All women experienced significant distress. In your experience, would a negative biopsy minimize the trauma experienced by these women and what does this study tell you about fear of breast cancer?
2. Some of the women in this study were many years past their biopsy. How would this influence the conclusions drawn by the researchers?
3. What can nurses do to mitigate this trauma as described by these women?
4. The authors suggest that empathy and touch should be avoided when patients are enduring. Do you agree or disagree and why?
5. What do you think are helpful strategies to assist women who are enduring or emotional suffering during this waiting time?

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