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Coming to Grips with Breast Cancer: The Spouse's Experience with His Wife's First Six Months

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Abstract

This study examines the experiences of 48 spouses of wives newly diagnosed with local or regional breast cancer. Their reported experiences were organized into the core construct of Coming to Grips reflected by four domains: (1) Feeling nailed by the breast cancer; (2) Changing us; (3) Taking care of me; and (4) Making things work. Prior studies have underestimated the extent to which the assumptive world and day-to-day lives of spouses are shattered by the diagnosis of breast cancer and the work they do to guess how to be supportive to their wives. Interventions are needed which directly assist spouses add to their ways of managing the intrusion of their wife's breast cancer in their lives.

Keywords

Breast cancer; Spouse; Qualitative analysis; Impact on family; Spouses

INTRODUCTION

In 2009, an estimated 192,280 women will be diagnosed with invasive breast cancer and an additional 62,280 women had *in situ* disease (American Cancer Society, 2009). Although the magnitude of women affected is alarming, equally significant are the ramifications of the illness for the spouse. Breast cancer is a couple's illness, not a disease of the wife's breast (Lewis, Fletcher, Cochrane, & Fann, 2008).

Distress (anxiety, depressed mood, physical symptoms) in spouses of women with early stage breast cancer has been demonstrated in studies using standardized questionnaires as well as interviews in the U.S. and other countries. Significantly elevated levels of distress are known to occur up to 3 years post diagnosis and in some studies spousal distress exceeds that of the diagnosed woman (Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003; Foy & Rose, 2001; Langer, Abrams, & Syrjala, 2003).

In the first known longitudinal study, Northouse's team documented that the spouse's level of distress was similar to the level of morbidity in their wives [Brief Symptom Inventory--BSI] and remained higher than normal levels at 3 days, 30 days, and 18 months (Northouse & Swain, 1987). In another seminal study of spouses whose wives had undergone a mastectomy, Wellisch's team reported that spouses experienced disruptions in their sleep, eating, and ability to work that they attributed to their wife's breast cancer (Wellisch, Jamison, & Pasnau, 1978).

Spouses are known to have concerns about their wife's fatigue and other debilitating symptoms; sexual intimacy; the illness' unpredictable nature, including fear of recurrence and uncertainty of outcomes; and personal and household disruptions (Ben-Zur, Gilbar, & Lev, 2001; Chekryn, 1984; Hilton, 1993; Hilton 1993a; Hilton, 1994; Hilton, 1994b; Hilton, Crawford, & Tarko, 2000; Hoskins, 1995; Lethborg, Kissane, & Burns, 2003; Lewis, Fletcher, et al., 2008; Longman, Braden, & Mishel, 1996; Longman, Braden, & Mishel, 1997; Mast, 1998; Nelson, 1996; Northouse, 1992; Northouse, 1994; Northouse, 1995; Northouse, 1996; Northouse & Swain, 1987; Skerrett, 2003; B. L. Walker, 1997; Walker & Eremin, 1996; Wellisch, et al., 1978).

There are six qualitative studies of spouses' reported concerns about their wife's breast cancer but the majority of these studies involve spouses of women diagnosed 1.5-2.5 years prior or are limited to very specific experiences, e.g., the spouse's response to the surgical scar (Hilton, et al., 2000; Lethborg, et al., 2003; Northouse, 1989; Sabo, Brown, & Smith, 1986; Samms, 1999; Zahlis & Shands, 1991). When we turn to studies relevant to the initial diagnostic and treatment period, only 3 interview studies included spouses of wives diagnosed an average of 13 or fewer months (Lethborg, et al.; Northouse; Zahlis & Shands). This means that we have a very limited understanding of spouses' experience during the initial period of diagnosis and treatment. A summary of results from these 3 qualitative studies follows (Table 1).

Spouses described feelings of shock and disbelief (Lethborg, et al., 2003; Zahlis & Shands, 1991); helplessness (Lethborg, et al.); fear and sadness (Lethborg, et al.; Zahlis & Shands). They reported worrying about the extent of disease (Lethborg, et al.), cancer recurrence (Northouse, 1989; Zahlis & Shands), what the future might bring (Lethborg, et al.; Zahlis & Shands) and their wives' survival (Northouse; Zahlis & Shands). A few spouses reported feeling guilty about not being able to do more to help their wives (Zahlis & Shands) or were self-critical about their own inability to support her (Zahlis & Shands). In addition, to describing their emotional response to the breast cancer, some described a physical response as well (Lethborg, et al.; Zahlis & Shands).

Spouses talked about their difficulty in waiting for test results and waiting for surgery to be over (Northouse, 1989; Zahlis & Shands, 1991). They found it hard to watch their wives struggle or be in distress (Lethborg, et al., 2003; Zahlis & Shands). Spouses reported a range of reactions when they viewed the surgical site. For some, it was "no big deal." For others the physical disfigurement was shocking (Northouse; Zahlis & Shands). Some men felt their own feelings went unacknowledged by their wives and others (Lethborg, et al). Men felt their wives believed they were getting on with their life – that the illness had not impacted them. They felt that their own distress went unrecognized.

Men reported the breast cancer impacted their relationship with their wives (Zahlis & Shands, 1991). For some, the breast cancer magnified already existing problems (Zahlis & Shands). Some worried that their wives would not be able to accept the breast loss (Northouse, 1989; Zahlis & Shands).

Men talked about what they did to support their wives. On a practical level, many said they changed their work schedules (Northouse, 1989), did more child care (Northouse; Zahlis & Shands, 1991) and assumed management of the household (Northouse; Zahlis & Shands). They worked to meet their wives' emotional needs (Lethborg, et al., 2003) by being a sounding board, consoling her (Zahlis & Shands), assuring her that changes to her body had not altered their relationship, and by not allowing her to feel sorry for herself (Lethborg, et al.). They also talked about taking care of her physically and about needing to be strong for her (Zahlis & Shands).

Some men felt supported by others (Northouse, 1989) while others talked about feeling isolated and having insufficient support (Lethborg, et al., 2003). A few men talked about not knowing how to handle people who were non-supportive (Zahlis & Shands, 1991).

Across all three studies, spouses described what they did to cope with the breast cancer, including devising strategies, avoiding their own feelings and avoiding thinking about it (Lethborg, et al., 2003; Zahlis & Shands, 1991) and keeping busy (Zahlis & Shands). They worked to stay focused on the positive (Lethborg, et al.; Zahlis & Shands), drew from their religious beliefs (Northouse, 1989), and trusted in God (Zahlis & Shands). For some, their wives' positive attitude helped them (Northouse). Spouses talked about taking control (Lethborg, et al.) by becoming educated about breast cancer (Northouse; Zahlis & Shands) and by helping make decisions about surgery and treatment (Zahlis & Shands). Spouses described taking things day by day and trying to make the most out of life (Lethborg, et al.).

These three studies provide an important beginning description of the spouse's early experience with his wife's recently diagnosed breast cancer. But only one of the studies included spouses who were interviewed during the initial months of diagnosis and treatment (Northouse, 1989). The other two studies relied on spouses' retrospective recall of the early days of the experience (Lethborg, et al., 2003; Zahlis & Shands, 1991). What is still needed is a study to examine spouses' experience during the acute initial period of diagnosis and treatment of their wives' breast cancer. The purpose of the current study is to more fully describe, in spouses' own words, their experience with their wives' newly diagnosed early stage breast cancer, focusing explicitly on the first six months of diagnosis and treatment.

METHODS

Participants

Spouses were eligible for inclusion in the current study if their wife were diagnosed within the past six months with early stage breast cancer (Stage 0-2) and couples were married. The study sample was a subsample of spouses who were accrued into a larger randomized trial whose goal was to help couples better manage the impact of the wife's cancer. The larger clinical trial was a 2-group randomized control study (Lewis & Fletcher, under review, 2009). Spouses' wives were receiving treatment for their cancer at the time of spouses' participation in the interview study. Data for the current study were obtained prior to intervening with the couples.

Spouses were largely Caucasian (87%), ranged in age from 31 years to 68 years (Mean = 44 yrs, SD 6.31). Eighty-seven percent had completed at least some college. The majority of men were in long-term marriages (mean = 16 years, range 3 years -32 years) and had children living at home (Mean = 2 children) at the time of their wife's diagnosis. At the time of the interview, spouses were 4 months from their wife's diagnosis of breast cancer (Mean = 129 days, SD 47.53; range 40 days-225 days). Sixty percent of the wives were treated with breast conserving surgery (lumpectomy/nodal dissection) and 40% with non-conserving breast surgery. Fifty-six percent of the wives were receiving chemotherapy and 27% were having radiation therapy at the time of spouses' interviews.

Procedure

Confidential face-to-face interviews were conducted in the homes of spouses by a Master's educated clinician. The interview consisted of four open-ended questions:

1. What parts of your daily life have changed since your wife was diagnosed with breast cancer?
2. What kinds of things have been particularly difficult for you?

3. What things have you felt unprepared for?
4. Is there anything else we should know about what this experience is like for you?

Interviews lasted 20 to 45 minutes and were audio-tape recorded. (Variation occurred in the length of each interview, depending on the amount of time each spouse spent responding to the questions. All spouses were asked the same questions.) The tapes were transcribed by a professional transcriptionist and verified 100% for accuracy against the audio-recordings.

Data Analysis

Following transcription and verification for accuracy, transcripts were read and down loaded into Atlas.ti version 5.0. Transcribed text was reviewed line by line to identify any aspect of the spouses' experience – positive or negative. Those data were then grouped when the data shared a common property. Groupings were organized into categories and the categories were defined. Participants' words, not imposed words by the study authors, were used to label the categories. As coding continued, additional spouses' quotes were coded using the category definitions. Alternatively, a new category was created if the unit of data to be coded did not fit the previous categories.

Categories were continually examined for similarity and overlap for the duration of the coding process. Similar categories were merged in an effort to further organize the data. During the entire process of coding, categories were refined and examined to ensure they were mutually exclusive. No verbatim data from spouses appeared under more than one category.

Initial coding resulted in 28 categories which were eventually re-organized into 16 categories (Table 2). This was done by asking the question, "Does this category share a property that is common to another category?" (This constitutes an example of constant comparative analysis.) Reorganization created a more parsimonious representation of the data. Through this process of condensation for parsimony, definitions of the categories were refined to represent the new category while still maintaining distinction between the remaining categories.

Categories were then organized into higher order groups, called domains. (See Figure 1 for an example of coding.) Categories within a domain represented different dimensions of the domain. Domain labels were chosen to best capture the manifest meaning of the categories. Finally, each of the domains was defined. The core construct was identified after the final set of domains and definitions were generated. By organizing the categories into domains, we increased the density of the spouses' reported descriptions of their experiences.

The trustworthiness of study results was tracked through formal peer debriefing; by maintaining an audit trail; and by requiring 100% consensus between the peer debriefer and the primary coder. The peer debriefer reviewed initial categories and related verbatim statements from spouses. This review included three analyses: (1) a comparison between all categories, including an examination of distinctions between categories for their uniqueness and non-overlapping characteristics; (2) a comparison between each category and the adequacy of fit between the verbatim quote within each category; and (3) a comparison of each verbatim quote with all the other categories in order to verify the correctness of fit of each verbatim with its placement within the designated category. Whenever possible, the peer debriefer recommended ways to increase the parsimony of the evolving categories while still maintaining distinctions between categories.

RESULTS

Four domains were identified: Feeling nailed by the breast cancer; Changing us; Taking care of me; and Making things works. A description of the domains and the categories follows, including illustrative quotes from spouses.

Domain 1: Feeling Nailed by the Breast Cancer

Spouses viewed the breast cancer diagnosis as unexpected, sudden, and emotionally overwhelming. They felt helpless to save themselves or their wives from what was happening. Every aspect of their daily lives and function was impacted, including job performance and social times with friends. They struggled to understand why such a thing would happen. This domain included three categories: Being struck by lightning, Feeling life change, and Wondering why God would single her out.

Being struck by lightning—Spouses described their responses to their wife's breast cancer diagnosis as: shock, rage, devastation, sadness, fright, grief, worry, and guilt. "...when I found out she had it. I mean, I think I bawled for 2 days." They felt unprepared for the diagnosis and completely ignorant about its treatment. They found it difficult to accept the cancer and grieved the loss of her breast. "I think it's like saying good-bye to a friend...Just to have something cut off and saying, 'Well, that's the way it goes.'"

They were shocked at how quickly things happened following the diagnosis. They were stunned at the physical effects surgery and treatment had on their wives. They described feeling stressed emotionally and physically. Some of the men said they lost sleep, lost hair, and felt aged by the breast cancer. As a result, they worried about their own health.

Some spouses felt angry with their wife's physician. They experienced her doctor as patronizing, uncaring or disregarding of them. "Kind of felt like we were just cars being run into a shop and back out the other end, personally. To the doctor, it seemed like it was no biggie. You know, just another car in the garage."

Spouses felt guilt at their own inability to protect their wife from what was happening or felt they were not doing enough to support her. "I feel as though I'm not necessarily, I'm not doing the job that I'm here to do, to help her and protect her....You have that initial sensation of, she has distress, therefore I'm not doing something right here. What am I failing to do?"

Spouses experienced an array of worries about the cancer and what it might mean for their wife's physical and mental health, her future health, their children, and their children's risk for breast cancer. They worried that the cancer would not be cured or that it would recur some time in the future. They wondered if the correct treatment decisions were being made. Many spouses thought about their wives' potential death and the changes it would bring for them, as well as managing being a single parent. "Dealing with the possibility that she may not survive this has changed my life....my emotional life...I've considered life without her and it's not a pleasant prospect."

Men described feeling "powerless" when it came to helping their wife. They experienced the breast cancer as an uncontrolled situation and as something they could not change. It bothered them to see her in pain and sick from treatment. "The hardest times I have is when (my wife's) upset about something....I can't do anything about it. All I can do is try to hold her hand and get her through it. But it gives me a real sense of inadequacy that I can't help her." As much as they may have wanted to change things for her or to trade places with her, there was nothing in their minds that they could do or say to protect her from her struggle with the breast cancer.

Feeling life change—Spouses talked about changes that had taken place in their daily schedules and routines that they attributed to the breast cancer. Life had become more hectic. “For the last 6 months...it’s been like one thing after another - surgery, to chemotherapy, to, you know, so it’s been pretty much of a constant thing.”

They felt they needed to be ready to respond, at any time of day or night, to take her to medical appointments or to respond to her emotional needs. “I guess sometimes I feel like I’m on call... twenty-four hours.” Men altered their working schedules to make time to be with their wives but worried about the impact of their absences on their work. It was also a challenge to keep their mind focused on work. “I go to work and think about her 8 hours a day, come home.” It was difficult to experience feeling pulled in two different directions - home and work responsibilities - and this sometimes left them feeling irritable and frustrated and less patient with others in the workplace. Some men found co-workers to be understanding and encouraging of their absences from work, while others needed to stay on the job to secure their job and benefits.

Spouses described themselves as not being able to take on more than they were already doing, physically, or emotionally. They were exhausted from caring for her, taking care of the family, experiencing pressure from others to do things differently, going to work, and lacking sleep from being up with their wife during the night.

Wondering why God would single her out—Some spouses wondered why their wife got cancer, given that she took care of herself. “She doesn’t take aspirin, she doesn’t drink to excess, she does nothing that you would think, so. You know, it happened for some reason, we just haven’t figured it out.” They struggled to understand and accept why something like this would happen to a good person. “...the suffering that they have to go through, I guess, is the thing that you don’t understand.” And from another man, “I want to say God picked her to have cancer. But that’s not right. I mean...it’s such a mystery. No, He wouldn’t choose that for anybody.”

Domain 2: Changing Us

The breast cancer altered the couple’s relationship. For some spouses, the experience brought them closer together and they approached the breast cancer as a team. For other spouses, and at other times, the breast cancer challenged their relationship as a couple in new ways and created friction between them. The breast cancer also altered and challenged their parenting. This domain consisted of three categories: Bringing us closer together; Making our relationship more difficult; Affecting us as parents.

Bringing us closer together—Some spouses reported that the illness had strengthened their relationship. Together, they worked through the breast cancer. “I don’t see this as her crisis or my crisis; it’s something that we deal with together, as a team.” Another man said, “In some ways, it’s (the breast cancer) sparked a little more life there that we needed to wake up to. So that’s been good.” Some spouses reported that they spent time as a couple talking about the breast cancer and they worked to keep the communication open between them. “The changes in our communication have been for the better. It’s (the cancer) been a common foe that the two of us have had a chance to spend a lot of time talking about and feeling out each other’s feelings.”

Making our relationship more difficult—For some spouses, the breast cancer was felt to negatively impact their relationship, including challenging their communication as a couple. They cited multiple sources of difficulty in talking with their wife about her breast cancer. These included: her not wanting to talk about it; finding talking was difficult due to the gravity

of the situation; and feeling talking did not necessarily get them anywhere. “We have gotten to the point of not arguing, but...becoming so depressed talking about it, that we just have to stop, you know?”

Not only did the cancer impact their communication, many spouses claimed the cancer negatively affected their physical relationship. Men attributed the changes in their intimate relationship and sex life to: their wife’s changed physical appearance, including her being bald; side effects from her treatment; her surgical scar and tubes; her reticence to show him her scar or breast; her self-consciousness about how she looked; his ambivalence in wanting to see her breast; his own concerns about being physically responsive to her; her lack of sensation in her affected breast; and his awareness that she was sore from the surgery and his fear he would hurt her.

Spouses described being unprepared for the emotional toll the breast cancer took on their wife. Part of dealing with his wife’s emotions was dealing with her fears about how he would respond to changes to her body from the cancer treatment. Spouses struggled to convince their wife that her physical scars and loss of breast did not change their feelings toward their wife and that they found her just as attractive as they ever had. In trying to reassure her, there was a danger of communicating it so their wife took their reassurance the wrong way. “It was very difficult for me to find the right words to communicate that (my feelings about the mastectomy) without seeming to say, ‘Don’t worry about it. Don’t trouble your little head about it....It will be okay.’”

Dealing with their wife’s emotions was a challenge as spouses tried to anticipate or soothe her feelings or attempted to reason her out of them. They never knew how she would be feeling next or what might upset her. They found her depression, worry, fears, and feelings of hopelessness particularly difficult. “I realize the release is good for anyone to cry. And talk. But, sometimes it gets so bad it scares me, for her.” Spouses worked to build their wife up emotionally, sometimes with discouraging results. “You can’t turn a light switch on her emotions, on and off.”

Spouses talked about the friction that sometimes developed in their relationship about the breast cancer. One cause was their differing views about the cancer. Men attributed this to their having different philosophies about how to best deal with the breast cancer. They differed with their wives in the extent to which they asked questions about treatment, wanted to talk to others about the cancer, or explore the emotional side of the experience.

Men attributed another source of friction between them to the continuing strain of living with breast cancer. They sometimes were less patient with each other which led to arguing and fighting. Sometimes spouses became impatient with their wives’ symptoms. “I want her to be okay. And she’s not okay....I do get frustrated....” Some men reported their wife felt they were not doing enough or the right things to support them.

Affecting us as parents—Spouses described the challenges of trying to parent their children about the breast cancer. For some, it was very difficult to know what to say to their children about the breast cancer and they worked to say things in a non-threatening way. Other men said that nothing was hidden from the kids and that they were told everything. They sometimes reminded their kids to help their mother or give her a hug. Spouses described themselves as not doing their best parenting because of a lack of time and energy. Some men found they spent less time with their kids, spent less time together as a family, and spent less time together doing fun things. “...So much of the time we’re kind of pushing them (the children) off, trying to get them to...do things independently, so that we can deal with the cancer and everything about it.”

Domain 3: Taking Care of Me

Spouses' experiences in getting support varied greatly. While some men appreciated and sought help from others, others chose not to talk about what was happening. Some reported receiving support from others, while others claimed they were abandoned by friends. Some men took time for themselves, while others did not. Three categories describe this domain: Being supported; Taking personal time for me; Keeping it inside.

Being supported—Some spouses described not keeping the cancer secret, but asked for help from others. They were surprised by the number of people (friends and family members) who proffered support. Being offered support by others had been, for some, the one positive aspect of their experience with their wife's breast cancer. Several men claimed that a friend had been there to listen to them and their concerns about their wife's breast cancer. A few spouses shared that they openly talked about their wife's breast cancer with friends and people at work. In some cases, they said it was helpful for them to do so.

A few spouses were amazed how friends and family stayed away from them. "The weird thing that has happened is that a lot of friends...don't ever come by. Won't stop by. Never have. Just disappeared." They suspected that others did not want to deal with them or did not know how to respond to them.

Taking personal time for me—Men who talked about taking time for themselves fell into two groups: those who described taking personal time for themselves and those who said they did little or nothing for themselves. A few men described ways they took a break from the breast cancer, including going to a sports event, taking time to be alone, having a beer, or just taking a deep breath and reassuring themselves. "I spend more time, kind of taking a deep breath, going, 'Ahhhhh, this won't last forever.'"

A few men admitted to taking little or no time for themselves. Even though they might be encouraged by others to do so, it was uncomfortable to be away from her or to take down time when there was so much to be done.

Keeping it inside—Some men described not talking about the breast cancer with others. They did not want to dump on others or felt others would not understand. Even when friends asked how they were doing, men reported that they said little about how they were feeling. "I had a lot of friends stop by and see how I was doing and I really, I didn't talk to them a whole lot about how I was feeling."

Spouses swallowed their feelings rather than share them with their wife or others, sometimes to avoid conflict. "I have to spend a certain amount of time kind of stifling what would be an outward reaction when (my wife) kind of just throws it at me....And when I say, throws it at me, just, you know, 'This is how I'm feeling.'" Sometimes spouses felt they needed to protect others, such as children or parents, from worrying about them, and at other times to protect his wife's feelings. "...I had that feeling where I needed to put and show strength all the time when she was really down to help keep her up. And there were times that I didn't feel like that, but... and I couldn't say anything."

Domain 4: Making Things Work

Spouses used a variety of methods to get through the breast cancer. These included: taking on increased household responsibilities, working to understand and support their wife, finding ways to take an active role in their wife's treatment, and adopting attitudes they believed would help them and their wife get through the breast cancer. Seven categories are contained in this domain: Taking the load; Being sensitive to what she's going through; Mapping out a game

plan; Being positive; Not dwelling on the cancer; Hoping for the best; Doing what you have to do to live with it.

Taking the load—Men described taking over many of the child-rearing and household tasks as well as taking care of their wife. They also coordinated activities within the household. Men asked their wife what they could do to help. A few men were surprised by how much they had to take on. Some men felt the amount they had to do was a challenge while others were happy to be busy and felt good about contributing to their wife's comfort.

Spouses found they needed to be their wife's caretaker. They took care of her physically or made sure she was taken care of if they were unavailable. They helped with her after-care from surgery and made sure she exercised her arm and helped her manage her symptoms. They tried to protect her health.

Being sensitive to what she's going through—Spouses struggled to help their wife deal with the emotional side of cancer. Men empathized with their wife's feelings. They asked her how they could support her and tried different things to try to help her feel better. Spouses made a greater effort to be sensitive to their wife, including paying attention to her moods and making a conscious effort to listen to her. They worked to help her feel better when she was feeling badly about the loss of her breast and discouraged about how she looked. They tried to help her feel less scared about her cancer and possible cancer recurrence. They encouraged her when she was feeling fearful or discouraged. They worked to get to the root of her depression. "And it's been hard for me to determine whether she's really depressed about something, sometimes, or not. And, so I've done some prodding. And I've tried to do some by saying, 'What's the matter? Could you tell me if there's anything wrong?' I'd like to get into her depression. I'd like to find out what's causing it and see if we could work on that." "I'd like to find out if there's anything I can do to help her with it (her depression). If there's something I can do." They said they sometimes felt limited in being able to help her, given they were not in her position and did not know exactly how it felt.

Mapping out a game plan—Spouses described various strategies they used to help plan their wife's medical care. Strategies included: talking as a couple and talking to others; exploring options; seeking to understand all the information; and finding the best doctor - someone with whom they were both comfortable. Spouses spent time studying statistics, protocols, and treatment options. They questioned the doctors in an effort to understand the disease, its treatment and prevention, and to gain insight into their situation. "As far as...reading and absorbing the stacks of information we have on breast cancer, that's the kind of thing that I feel like I'm responsible for."

They noted that they would have felt badly if they had failed to consider all possible options or had not secured the best care. In some cases, the game plan meant leaving it up to the doctors to make the decisions or supporting their wife's decision. Some men felt that the final decision was best left to their wife because it was her body and she needed to do what was right for her.

Being positive—Men refused to accept that their wife's breast cancer would turn out badly. They placed a high value on optimism and worked to maintain it in themselves. "...You catch yourself getting the negative side, maybe sometimes, steering that way, so you have to correct yourself and get on the right track." They believed that her attitude and feelings were important components of her recovery from breast cancer and that their own optimism could, in turn, strengthen her and lead to a more positive outcome. "So she has to have the right attitude, feelings about the situation. So how does that come about? Well, um, you don't want to introduce any bad feelings. Or cause them to come."

Not dwelling on the cancer—Spouses shared that they intentionally worked to not think about or talk about the cancer or allow it to bother them because it was something they could not change. This included choosing: not to look at her scar; not wanting information; or not going with her to her doctor's appointments. Men said they did not necessarily want to discuss the breast cancer with their wife. "...hopefully, I think, if we don't talk about it, you know, it will go away." They did not want to spend more time on gloom and doom. It was easier to think of the breast cancer as finished. "I guess my way of coping is to pretend that it hasn't happened, in a way. And that the disease is gone."

Hoping for the best—Some spouses held on to thoughts of a favorable outcome of the cancer - that it would not be serious, that the cancer would be over, that it would not return, and that everything would turn out well for their wife. "I'm just hoping that everybody does what they're supposed to do and everything works out fine." "You just hope, you know, you're going the right way and get doing the right things." "So, I just pray and hope that everything's going to be okay, you know?"

Doing what you have to do to live with it—Men described their efforts to dig in, make the needed adjustments to accommodate to the breast cancer and to move through it – whatever that took. Men described their attitude of doing what had to be done and what could be done, when something like breast cancer occurred. "It's pretty straight forward. She got sick. We did what we had to do to get her as well as we could." They said the breast cancer was something they could not run away from, but needed to face. It forced them to put their time to the best use... "to maximize everything you can do." Spouses focused on taking it a day at a time. "So we just, like I said, one day at a time. We're on the twelve step program."

Sometimes spouses needed to shut down their own emotions in the process - to get through it. "I almost feel like I've built this wall, automatically inside me, that says, 'This is what you do and this is how you're going to deal with it, no matter what it takes. And that's the way it is.'" Some men applied their problem-solving abilities to dealing with the breast cancer. "You try something different until you find out what works. You know, it's just a matter of making things work."

DISCUSSION

There is substantial evidence that the breast cancer was not only the wife's medical diagnosis, but the spouse's illness as well. Every aspect of his temporal and cosmological life was affected, including how unprepared he felt about the diagnosis, the rapidity of changes that happened to him and to them as a couple, how he spent his day, how he struggled to make things work, how he took on increasing amounts, as well as the quality of their time together as a couple. Even when some spouses were able to identify positive benefits from their experience with the illness, spouses were overwhelmed, devastated, and unprepared to handle what was happening to themselves, to their wife, and to their relationship as a couple. Earlier studies' findings were both corroborated and further elaborated in the current study's results, including a fuller description of the depth and scope of spouses' distress in the early months of diagnosis and treatment. This substantial distress deserves early attention by clinicians.

For the most part, spouses dealt with their emotional response to her breast cancer on their own, including shutting down their own feelings and emotions. Some kept their feelings to themselves when little support was offered to them by others. Some kept feelings to themselves because they did not want to burden their wives. Even their wives did not always want their spouses to talk about the cancer or to talk about the cancer with others.

Disagreement existed for couples on how to frame the breast cancer and how to talk or not talk about the breast cancer. Even intimacy, which might have offered spouses some relief from their isolation, was fraught with difficulty. Being alone with their own feelings is consistent with results reported by others (Hilton, et al., 2000; Holmberg, Scott, Alexy, & Fife, 2001; Lethborg, et al., 2003; Skerrett, 1998).

Men were frustrated and sometimes frightened by the level of emotion that was expressed by their wives. In the face of their own emotional response to the breast cancer, men encouraged, cheered, and listened to their wife's worries and fears. They struggled to do and say things they hoped would lift their wives' spirits and help them feel less distressed or depressed. But helping her feel better was not always possible or permanent, adding to spouses' feelings of failing to protect their wife from the breast cancer and its impact on her.

They worked to keep themselves thinking positively even as their wives expressed fears. They did not know what to do, what to say, or how to let her know that she was more to him than her breasts. They walked a fine line between assuring her that her breasts were not important, and trivializing the impact of her breast changes or loss

To further add to the pressure of helping their wives manage the wives' negative thinking, some men believed that to the extent their wife experienced positive or negative thoughts, it affected the outcome of her illness and eventual survival. Others have cited similar findings (Hilton, et al., 2000; Lethborg, et al., 2003; Samms, 1999; Zahlis & Shands, 1991).

Spouses worked at ways they could take some control of the impact of the breast cancer on their own lives. In addition to assuming more of the work load in managing the couple's daily life at home, spouses described creating a systematic way to help their wife make decisions about treatment and care. Beyond that, they mostly hoped, thought positively, pretended it was over, or just put their heads down and did what was necessary without thinking about what could happen next. Prior research by others has reported the use of similar strategies by partners to deal with the breast cancer (Lethborg, et al., 2003; Samms, 1999; Zahlis & Shands, 1991).

LIMITATIONS

Study results are limited to spouses in long-term marriages who were mostly Caucasian and were within six months of their wives' initial diagnosis with early stage breast cancer. Results are also limited to spouses who were willing to participate in a larger clinical trial; we do not know if men who agreed to participate in the clinical trial are a unique population of men.

CLINICAL IMPLICATIONS

To the extent that these data adequately depict the experience of other spouses, both clinicians and scientists need to develop and test interventions to assist spouses with the distress caused in the first months of diagnosis and treatment for their wife's breast cancer. Spouses are not background or context but are themselves directly and deleteriously affected by her illness. They deserve and need attention. Although men have said they want counseling services and need to talk, men in the current study reported not using or seeking out such services (Hilton, et al., 2000).

There are multiple ways men can access existing support and help in what they are going through that do not include face-to-face counseling. Men can be linked to telephone peer support services through such organizations as Men Against Breast Cancer (www.menagainstbreastcancer.org), Strength for Caring (strengthforcaring.org) or through Network of Strength (www.networkofstrength.org). In addition, a few websites offer online support groups (www.thewellnesscommunity.org; cancercare.org), for example.

Specially written material for men whose partner has breast cancer are also available from the following organizations: The Komen Foundation (www.komen.org) *What's Happening to the Woman I love?*; Breast Cancer Awareness and Support (www.networkofstrength.org) *When the Woman you Love has Breast Cancer*; and Men Against Breast Cancer (www.menagainstbreastcancer.org) *For the Women we Love*.

In addition, for spouses who need help in care-giving, managing things around the home, and/or childcare, two websites assist in helping to organize friends and neighbors who want to help (www.lotsahelpinghands.com and www.sharethecare.org).

More programs and services need to be created which are attractive to men and target their needs. The entree for men most likely to be successful may be linking them to actions to help their wives, not just themselves. See recent results of a pilot intervention that attempted to do just that (Lewis, Cochrane, et al., 2008).

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Category Mapping out a game plan	Category Being positive	Category Do what you have to do
Verbatim “We talked to the doctors about when and what the urgency was or what it wasn't. And what we could do. And looked at what business things I had to do.”	Verbatim “I think if you can be stronger and be more positive for her, you know, and be more supportive, hopefully, you know through your mind, things will get stronger and more positive.”	Verbatim “Don't be a male chauvinist. You know, that has (pause) there's no part for that in this type of atmosphere when there is cancer or some type of illness. You know, do what you have to do to get the job done, you know.”

Figure 1.
Sample Coding Scheme: The Domain Taking the Load

TABLE 1

Qualitative Studies Describing Spouses' Response to their Wife's Breast Cancer

Authors	Sample size	Timing of Interview	Interview Questions	Patient Surgery and Treatment
Lethborg, Kissane, & Burns (2003)	8 (7 husbands and one female partner/friend)	Average time = 9 months since diagnosis	(1) What was it like to support someone through diagnosis and treatment; (2) what thoughts do you have the treatment process; (3) what does the future look like; (4) why you were chosen to be a support person and what did you do that was supportive?	100% completed chemotherapy; (no surgery type or radiation treatment information)
Northouse (1989)	50 partners	Three days and 30 days post mastectomy	(1) Describe (your) greatest concerns about the illness; (2) describe (your) reaction to seeing the mastectomy site; (3) identify which phase of illness (within 1 st 30 days) was most stressful; (4) identify factors that helped (you) to cope?	84% had modified radical mastectomy 32% had chemotherapy 8% had radiation
Zahlis & Shands (1991)	67 partners	Mean time since diagnosis = 395 days	(1) What parts of your daily life have changed since your wife's diagnosis? (2) What things have been particularly difficult; (3) what things did you feel unprepared for as a result of your wife's breast cancer?	60 % had mastectomy 40 % had lumpectomy (No treatment information given)

TABLE 2

Coming to Grips with Breast Cancer Domains and Categories Including Percentage of Men Reporting

Domains	Categories	Men Reporting
Feeling Nailed by the Breast Cancer	Being struck by lightning	94%
	Feeling life change	71%
	Wondering why God would single her out	16%
Changing us	Bringing us closer together	54%
	Making our relationship more difficult	69%
	Affecting us as parents	29%
Taking Care of me	Being supported	33%
	Taking personal time for me	10%
	Keeping it inside	23%
Making Things Work	Taking the load	56%
	Being sensitive to what she's going through	50%
	Mapping out a game plan	48%
	Being positive	40%
	Not dwelling on the cancer	40%
	Hoping for the best	54%
	Doing what you have to do to live with it	21%