Engaging Hope: The Experiences of Male Spouses of Women With Breast Cancer

Wendy Duggleby, PhD, RN, AOCN®, Jill Bally, RN, Dan Cooper, MDiv, RQHR, Heather Doell, MN, RN, and Roanne Thomas, PhD

Male spouses comprise a significant portion (30%–40%) of informal caregivers for chronically ill partners (Kramer & Thompson, 2002). Male spouses of women with breast cancer provide physical, as well as psychological, care in response to their partners’ needs (American Cancer Society, 2010; Canadian Cancer Society and National Cancer Institute of Canada, 2010). Several studies report that male spouses of women with breast cancer suffer emotional, psychological, and physical effects, such as poor physical and mental health (Fitch & Allard, 2007; Russell, 2008; Wagner, Bigatti, & Storniolo, 2006). They often experienced stress and frustration at the inability to fix their new-found life circumstances and report being overwhelmed and unprepared for the challenges of caregiving (Zahis & Lewis, 2010). Male spouses also have as many concerns as their partners with breast cancer (Foy & Rose, 2001), with their stress and distress having cumulative and long-lasting effects on their health, which, ultimately, reduces their quality of life (QOL) (Kramer & Thompson, 2002; Wagner et al., 2006).

Hope has been defined as the possibility of a better future in the context of uncertainty (Duggleby et al., 2010) and has been identified as a valuable psychological resource that is beneficial for caregivers of family members with various illnesses (Benzein & Berg, 2005; Bland & Darlington, 2002; Borneman, Stahl, Ferrell, & Smith, 2002; Kylma, Vehvilainen-Julkunen, & Lahdevirta, 2003; Verhaeghe, van Zuuren, Defloor, Duijnstee, & Grypdonck, 2007). Positive physical and mental health outcomes and improved levels of coping are significantly related to hope (Bluvol & Ford-Gilboe, 2004; Duggleby et al., 2007). The research suggests that hope is an important construct that can have positive effects on caregivers, as well as positive benefits for male spouses of women with breast cancer. Studies exploring the hope experience of male spouses of women with breast cancer appear to be nonexistent in the published literature. With new cases of breast cancer affecting as many as 23,200 and 207,090 people in Canada and the United States, respectively (American Cancer Society, 2010; Canadian Cancer Society and National Cancer Institute of Canada, 2010), a clear and comprehensive understanding of the male spouses’ hope experiences is needed to address this knowledge gap. The objective of this study was to explore the hope experience in the male spouse caregiver population. The findings may inform and guide healthcare practice that could help
to alleviate the negative emotional, psychological, and physical effects that male spouses endure as caregivers.

**Background**

Although no reported studies explore the hope experience of male spouses of women with breast cancer, a study exploring the caregiving experience of male spouses discovered the importance of hope (Zahis & Lewis, 2010). Zahis and Lewis (2010) found that 48 male spouses of women with breast cancer described their experience of hope as hoping for the best outcome. Therefore, hope appears to be an important part of the male spouse caregiving experience.

The majority of studies on hope and family members have been qualitative in nature. The few studies measuring hope suggest a relationship between hope and QOL. For example, two studies of hope and family caregivers reported that hope was significantly related to the caregivers’ QOL (Bluvol & Ford-Gilboe, 2004; Irvin & Acton, 1997). The hope of family caregivers of patients with terminal illness has been found to be significantly less than the people they were caring for (Benzein & Berg, 2005).

In a metasynthesis study by Duggleby et al. (2010), the findings of 14 qualitative studies of the hope experience of family caregivers of patients with chronic disease were synthesized with a total sample of 178 participants. The studies focused on informal caregivers for patients with a variety of illnesses, including HIV or AIDS, advanced-stage cancer, mental illness, severe brain injury, sickle cell anemia, dementia, and patients who are comatose. The findings suggested that hope helped caregivers deal with the experience. A strong, overall feeling of hope decreased feelings of loss and grief and improved both physical and psychosocial well-being, as well as feelings of control and coping. The caregivers’ experience of hope was situational, as it was influenced by internal (e.g., spirituality, positive outlook) and external factors (e.g., level of support, relationship with the family member) (Duggleby et al., 2010). Although the metasynthesis study did add to the understanding of hope in family caregivers, the authors concluded that additional research in this area is essential if healthcare professionals are to provide support to family caregivers to foster hope.

As none of the included studies in the metasynthesis explored the hope experience of male spouses of women with breast cancer, whether the findings are applicable to that population is unknown.

Findings such as those outlined here demonstrate the importance of hope for family members who act as informal caregivers. The illness experience of the person they are caring for clearly had an impact on their hope experience. An understanding of the hope experience of male spouses of women with breast cancer is essential for adequately supporting and fostering hope.

**Research Approach**

Using an interpretive, descriptive (Thorne, 2008), qualitative approach, 24 open-ended interviews were conducted with male spouses of women with breast cancer. The aim of this approach was to generate practice-relevant findings that would provide a methodologic framework to meet the specific needs of nursing science (Hunt, 2009). Interpretive description is a useful approach to enhance understanding of the hope experience of male spouses of women with breast cancer. That approach values the perspective of those living the experience and acknowledges the constructed and contextual nature of the human experience (Thorne, 2008).

**Methods**

**Sample**

Women with breast cancer who had a male spouse meeting the inclusion criteria were approached by nurses at a regional hospital’s breast health program and through a coordinator of a provincial breast cancer network. Participants had to be male, living with a woman with breast cancer (any stage), at least 18 years of age, and English speaking. The women were asked if they would share a study brochure with their spouse and if they and their spouse would be willing to have a researcher contact them about the study. If they agreed, a research assistant contacted them. A snowball sampling technique also was used. Study participants provided other male spouses of women with breast cancer with a brochure and, if they were interested, asked them to contact the researchers for more information (using a toll-free phone number or e-mail). A diverse sample was sought to inform the study findings; therefore, researchers were in constant communication with the recruiters requesting diversity in sampling (e.g., age, stage of cancer). Thorne (2008) suggested that researchers should seek diversity in their participants and outlying cases to determine the sample size.

The mean age of the 11 male spouses was 55 years (SD = 13, range = 36–76). They had been married an average of 28 years (SD = 14.9, range = 6–50) and rated their health as good with a mean score of 4 (SD = 0.5) out of a possible 5 (excellent). The men were highly educated, with an average education level of 17 years (SD = 4.1). All were Caucasian, and all but two said their religious preference was Christian. Their female partners had a mean age of 53.2 years (SD = 11.4, range = 34–69) and reported a variety of stages of breast cancer (stage I, II, and III). They represented a diverse group in regard to months since diagnosis, with a range of 1–174 months and with five women still receiving treatment.
Data Collection

After obtaining telephone consents from the women with breast cancer and from their spouses, a demographic form was completed by the male spouses. Written consents were mailed to participants and returned in a prepaid postage envelope, with participants keeping one for themselves. Twenty-two open-ended, tape-recorded telephone interviews were conducted using an interview guide. Although some limitations exist when using telephone interviews, the process is more convenient for the participants (Wilson, Roe, & Wright, 1998), facilitates the development of positive relationships between researchers and participants, and may result in improved quality of data (Musselwhite, Cuff, McGregor, & King, 2007). The items in the interview guide were as follows.

- Tell me about hope.
- What gives you hope?
- What kind of things change (increase or decrease) your hope?
- What can others do to help you have hope?

The questions changed based on the individual’s response. A second interview was conducted for participants to clarify data from the first interview and obtain more in-depth data. Only one participant was unable to complete the second interview because of conflicting schedules. Confirmatory interviews were completed with three participants who appeared to have a deep understanding of their experience. During the confirmatory interview, preliminary study findings were shared and discussed with the participants to confirm the findings as much as possible.

Data Analysis

Demographic information was entered into SPSS®, version 18.0, and analyzed using descriptive statistics. Qualitative data analysis occurred as data were collected. All interviews were transcribed verbatim, coded, and analyzed. Transcripts were checked for congruency with the audiotapes and then entered into QSR®, version 8.0.

Using Thorne’s (2008) interpretive description approach to data analysis, preliminary codes were developed by collecting data with similar properties. As patterns of preliminary codes emerged, categorical groups were noted, and then larger analytic concepts (themes) were developed showing the relationships among patterns. The data were reanalyzed until no new themes could be identified. Constant comparative analysis techniques also were used to ensure that data were examined thoroughly for similarities and differences with all participants.

Scientific Rigor

Thorne (2008) suggested that scientific rigor is achieved through representative credibility and interpretive authority. In the current study, representation credibility was achieved through confirming the interpretation of the event by using direct quotes from study participants to represent themes and interviewing participants more than once. Interpretive authority was achieved by continually checking that the findings reflected the data gathered and keeping an audit trail that detailed the reasoning behind each analytic decision.

Findings

Context

The findings were interpreted in the context of the experience of male spouses of women with breast cancer. The participants described the unexpected and sudden change to their lives and resulting distress that accompanied their partner’s diagnosis of breast cancer. For example, one participant said, “And she says they found a lump and they believe it’s the real thing . . . and it really hit me. That was my lowest point, I think, in my life, really.” Participants also described feeling out of control, saying, “now you’re on a roller coaster,” and another participant stating, “I was entirely powerless. They say it’s a guy thing or a man thing, you want to fix things, you want to put things to right and, of course, I couldn’t do that.” The overarching theme of engaging hope and sub-themes of finding balance, discovering what works, and focusing on the positive were derived in those feelings of helplessness, lack of control, sudden changes, and distress. Although presented separately, the themes were overlapping and interconnected.

Engaging Hope

Hope was tangible and of daily importance to the participants. As one participant said, “Hope is something I live, actually. . . . I think every day you get up in the morning there’s still hope.” The men described their hope as always being there, though they were not always aware of it. The diagnosis of their partners’ breast cancer required them to be more aware of their hope and to engage or activate it to help them deal with this new situation. One participant said, “Engage hope . . . as it [hope] . . . is working for you, so that you are imagining what can be done and then doing it.”

The active, engaged hope was dynamic and changing. One participant said, “There’s all kinds of hope. . . . But hope changes all the time, you define it by that particular instant.” The dynamic and situational nature of hope also was described. “There are ebbs and flows and just because something doesn’t go the way you want it, that’s not a reason to lose hope.” Several participants described their hope for the best outcome. For example, a participant said, “Hoping for the best, but what you are hoping for can change.” Hope was for themselves (hope they could support their partners), as well as
hope for a positive future for their partners and for their family. As one participant said, “I have hope for her and for my family . . . hoping that something good would happen.” Hope gave them courage to support their partners: “Well, hope is to, uh, you know, get my wife through the terrible disease and have her with me for as long as I can.” It gave participants a reason to feel positive about the future: “I guess to me hope means that there is a reason to feel positive.” In addition, hope was the possibility of a positive future in the difficult context of a serious illness: “Hope is about making the best of a bad situation and moving on.”

Finding Balance

To make the best of a bad situation, the participants described the constant, conscious need to balance the positive and negative aspects of their lives. As one participant described, “You are rebalancing at every step. There were times when everything’s goin’ wrong and it challenges your hope and things that you want out of life. Then, all of a sudden, you’ll have long periods where things are going pretty good.” Participants described having to consciously find balance. “Finding that, looking for that balance sort of has to be an act of will. I have to, I have to consciously and very deliberately do that.” Participants had to consciously prevent negative thoughts from overwhelming them at times. “You have to prevent negative thoughts from creeping into your life . . . thoughts that will diminish your hope.” To find balance, participants had to accept the reality that their situation had changed with their partner’s diagnosis. One participant said, “You learn to accept what’s there and work with what you have. The worst thing you can possibly do to not give you hope is to ignore it.”

To find balance, the participants described the importance of looking after themselves.

I find that when I am not, when I have not been looking after myself, you know, taking a break or walking or taking the dog out or whatever, um, then I think, you know, I haven’t been, um, as supportive for [my wife] as I could be. You’ve got to make it happen yourself, you can’t ride on the back of somebody else, and other people aren’t going to look after you; you look after your own self and get on with it.

Activities that helped participants find balance included running, music, and humor. For some participants, their faith and support from others helped them find balance. One participant noted, “Other people have been so supportive and encouraging.” Another commented that “it does give me hope that there are—well, that you know, God watches out for me and for my wife and for my kids.”

Discovering What Works

Participants described trying to find balance and support their partners by “trying to figure out how to work with what you have.” They described wanting to do what works for them and their spouse. “I do what’s working for both of us, really. What’s working for us, and whether it’s right or wrong or mixing things up, I don’t really give a s____, it’s working for us, and it’s working for us.” Supporting their wives often took the form of being present, learning to be open, and listening. One spouse said that he “would say that, in addition to listening and being present with one’s spouse, that next thing a spouse could do would be to try to do some of that background information, try to find out what kind of questions to ask.” Another participant suggested that what worked for him was open communication.

Being open and willing about the degrees of support that can be provided, and some of them will be expressed by my wife, that if I could do this or I could do that, [it] would be very helpful to her because she had wished to do this and this at that time so I can do that, it’s something tangible and that’s right up a man’s alley.

Overall, discovering what works to support their partners and taking action helped the participants to have hope.

Focusing on the Positive

Participants in the study described how they had to focus on the positive in their future to have hope. As one participant said, “Look to the future and get a positive twist on it. You can draw from the past, but you always have to find or focus on whatever’s the good.” For the participants, focusing on the positive at times involved personal learning and growth. For example, one participant explained “finding other possibilities . . . learn and discover about yourself and your relationship and what you can do to make it better.”

Having a positive outlook was important for both the participants and their partners. The wives’ positive outlook and their hope influenced the hope of their male partners. As one participant described, “[My wife] is my hope.” Another described how his wife “continues to [stay positive] and certainly that keeps me staying positive and supportive, and we hope my positivity is part of the support that I provide as well.”

Another participant described how looking for positive possibilities and having hope gave him courage.

Bravery comes from the capacity to imagine, in a sense at the heart’s core, the possibility of things being better. Or even maybe of the fact that life is good. And, even in its limitation, that life is good even in its limitations so that one can have courage or bravery because one can keep striving for that.
Discussion

The active engagement of hope by male spouses of women with breast cancer speaks to the essential nature of hope for the participants. They relied on it every day to help them deal with the challenging nature of their wives’ illness. The constant reliance on hope also has been described by family caregivers of persons with dementia (Duggleby, Williams, Wright, & Bollinger, 2009). Elliott and Oliver (2007) suggested that hope must be active in nature to achieve positive outcomes. The current study’s participants described the positive outcomes of engaging their hope, such as being able to support their wives and finding balance in their lives.

Finding balance also was described in a study of the hope experience of bereaved female caregivers of patients with advanced-stage cancer (Holtslander & Duggleby, 2008). Women who were caregivers of patients with advanced-stage cancer struggled daily to find balance so that negative emotions did not overwhelm them. As in the current study, physical activity, music, and humor helped bereaved female caregivers to maintain their balance. These similar findings suggest that commonalities may exist in the hope experience of family caregivers and the hope experience of male spouses of partners with breast cancer.

The theme of discovering what works, as described by the study participants, included finding ways to support partners by being open, present, listening, and finding information. The participants engaged in a process of discovering ways of working with their spouse to find what would help them deal with the new challenges they were facing, including learning new skills such as being open and listening to their partners. Making a conscious effort to listen and to obtain information also were mentioned in a study of 48 male spouses of women with breast cancer (Zahis & Lewis, 2010). The hope of male spouses is connected to their ability to find ways to support their partners with breast cancer. Discovering what works is a theme not found in other studies of hope, which suggests that differences may exist in the hope experience for male spouses versus other family caregivers. Whether the hope experience is different for men and women is unclear (Gaughler, Anderson, Zarit, & Pearlin, 2004); however, knowledge of gender differences in the caregiving experience is growing (Hayes, Zimmerman, & Boylstein, 2010) and may impact the hope experience. However, more research is needed to determine if gender differences exist in the hope experience.

One aspect of engaging hope was the current participants’ conscious decision to focus on positive future possibilities. The importance of having a positive attitude and having a positive outlook also was found in Zahis and Lewis’s (2010) study of male spouses of women with breast cancer. Similar to the current study, their participants recognized that their positive outlook influenced their spouse and vice versa. Having a positive outlook was an important condition of hope. In a metasynthesis study of the hope experience of family caregivers of persons with chronic disease (Duggleby et al., 2010), in the metasynthesis, internal factors (within the person) influencing hope were found. The internal factors included having a positive outlook, spirituality and faith, and psychological and physical well-being. The participants in the current study also described how spirituality and faith were important aspects of finding balance. Although they did not describe physical and psychological well-being as influencing their hope, they did identify that taking care of themselves was important, which may imply that physical and psychological well-being also influenced their hope.

Factors Influencing the Study

Several factors influencing the study results are related to the participants and to the study design. A participant’s age may have an influence on his hope (Benzein & Berg, 2005; Duggleby & Wright, 2005), and if and how the participants’ wide range of ages influenced the study results is unclear. The study participants also had been married an average of 28 years, and their experience may have differed if they had been married for a shorter length of time. Additional research is needed to determine if that is the case.

The participants were Caucasian and the majority were Christian. Whether or not ethnicity has an influence on hope is unknown; however, participants from different cultures may view their hope differently (Baumann, 2004). Research on the hope experience of male spouses of women with breast cancer from different ethnic groups would be important to develop the concept. In addition, spirituality was identified by the study participants as influencing their hope and is considered to be an attribute of hope (Farran, Herth, & Popovich, 1995).

The spouses of the participants suffered from various stages of breast cancer. Whether stage of disease had an impact on hope is unclear (Felder, 2004). Participants with wives or partners with different stages of cancer were purposively selected to obtain sample diversity. As hope is situational, more research is needed to determine if the stage of breast cancer has an influence on the hope of the male spouse or partner. The study design is exploratory in nature; however, it does provide a foundation for future research.

Conclusions

The study participants emphasized the importance of, and the positive outcomes associated with, hope.
They identified an important aspect of engaging hope as the deliberate decision to focus on positive future possibilities. They suggested that, to cope with the challenges of having a wife with breast cancer, they were required to learn to listen, be open, and be present. An important part of those activities necessitated enhanced knowledge about breast cancer. Future research should explore what knowledge is critical for the male spouses and what is the best way to enhance their knowledge.

The participants described the importance of spirituality and faith, as well as learning to care for themselves, as methods to achieve balance and support their own hope and caregiving abilities. Overall, it seems that male spouses wish to support their wives in ways that are not familiar to them and may need assistance in learning how to care for and relate to their wives in new and unique ways. In addition, male spouses need support in refamiliarizing and in finding new ways to care for themselves.

Implications for Nursing Practice

As strategies to foster hope in men should be tailored to distinctive aspects of the male experience, assessing and aligning activities that are of interest to each male spouse is essential in assisting them to care for themselves. Helpful activities may include running or walking groups, Internet resources, and support groups related to breast cancer. Identifying family and friends who have been supportive and wish to help is essential in assisting men with asking for and organizing help at home with daily living activities. Nurses can help male spouses identify individuals who may help with daily living activities and resources, which provides more family time and energy for the male spouse to support his wife.

Caring for patients with breast cancer is only one part of nursing care. The obligation to care for the entire family, including male spouses, is essential and is an important aspect of maintaining and supporting hope in patients with breast cancer and their spouses. Future research should explore the best ways to engender the hope of male spouses of women with breast cancer.

Wendy Duggleby, PhD, RN, AOCN®, is a professor and Nursing Research Chair of Aging and Quality of Life in the Faculty of Nursing at the University of Alberta in Edmonton; Jill Bally, RN, is an assistant professor in the College of Nursing at the University of Saskatchewan in Saskatoon, Saskatchewan; Dan Cooper, MDIV, RQHR, is a palliative care services clinical practice leader (Spiritual Care), spiritual care educator researcher, and quality improvement and special projects manager at Regina Qu’Appelle Health Region in Regina, Saskatchewan; Heath Doedel, MN, RN, is regional manager of the Saskatchewan Cancer Agency in Saskatoon; and Roanne Thomas, PhD, is an associate professor in the School of Rehabilitation Sciences at the University of Ottawa, all in Canada. Financial support was received from the Canadian Breast Cancer Foundation Pears/NWT Region (#2009-06(2)). Duggleby can be reached at wendy.duggleby@ualberta.ca, with copy to the editor at ONFEditor@ons.org. (Submitted June 2011. Accepted for publication August 26, 2011.)

Digital Object Identifier: 10.1188/12.ONF.400-406

References


Caregivers of women with breast cancer in low-and-middle-income countries experience significant physical and economic burdens. The review aimed to map the evidence of studies that had reported on the experiences of family caregivers of women diagnosed with breast cancer. The current review demonstrated that family members, including male spouses, assumed the caregiving role for women diagnosed with breast cancer. Based on this finding, future research using comparative study designs should be conducted to examine how breast cancer caregiving differs among male and female caregivers. Six hundred surveys were mailed to women with breast cancer (stage 1–3) and their male spouses. A total of 110 surveys were completed. Results: With the use of generalized linear modeling, participating male spouses with higher quality of life scores: (a) were older (P = .01), (b) had higher hope scores (P = .01), (c) had lower feelings of guilt scores (P < .01) (subscale of loss and grief), (d) had higher general self-efficacy scores (P < .01), and (e) had partners with breast cancer with higher quality of life scores (P < .01). Conclusions: Hope, self-efficacy, feel

The aims of this study were: to describe the levels of hope and compare hope scores for these patients with a sample from the general Norwegian population; to describe the relationship between hope and fatigue; and finally to evaluate the effect of demographic and clinical characteristics and fatigue on hope. Method: Hope-Promoting Strategies: Perspectives of Iranian Women with Breast Cancer About the Role of Social Support. International Journal of Cancer Management, Vol. In Press, Issue.

This pertains to all the authors of the piece, their spouses or partners. Yes No. More information *.