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# 'All I can do is help': Transition experiences of male spouse caregivers of women with breast cancer

by Kelly Struthers Montford, Wendy Duggleby, Ceinwen Cumming, Roanne Thomas, Cheryl Nekolaichuk, Sunita Ghosh and Katia Tonkin

## ABSTRACT

*The transition experience of male spouses of women with breast cancer is largely unknown. Ninety-one open-ended surveys of male spouses were analyzed using thematic analysis to understand the transition experience of this population when their partners were diagnosed and treated for breast cancer. While 10 participants indicated they experienced no changes, the majority experienced changes to their roles and relationships, their mental health, and their share of household work. Spouses took on a supportive role. They adjusted to the changes they faced by proactively becoming aware of their situation, fostering a positive approach, and being actively involved in their partners' experiences. Implications for nurses entail recognizing the role of the spouse, as well as facilitating access to reliable information and support networks.*

**Key words:** male spouse caregivers, breast cancer, transition, caregiving

## INTRODUCTION

The majority of care for women with breast cancer is provided by their spouse (American, Cancer, & Society, 2010; Canadian Cancer Society, 2013). This care can encompass physical caregiving, emotional support, and responsibility for a greater amount of household duties. Patients have improved outcomes when their spouses are supportive; support provided by friends and family do not compensate for an unsupportive partnership (Wagner, Tanmoy Das, Bigatti, & Storniolo, 2011).

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How men cope with the significant changes (transitions) they experience, as caregivers, can influence their ability to provide this unique form of support for their spouse with breast cancer (Duggleby, Bally, Cooper, Doell, & Thomas, 2012; Duggleby, Swindle, Peacock, & Ghosh, 2011; Zalis & Lewis, 2010) and their quality of life (Duggleby et al., 2015).

Transitions are processes of incorporating new realities into a person's life (Meleis, & Sawyer, 2010). There are several theories and conceptual models of transitions developed from diverse populations, yet previous research has not focused on male spouses of women with breast cancer (stages 1-3). For example, Duggleby et al.'s (2011) conceptual model of transitions for caregivers of persons with dementia and resulting toolkit intervention have been shown to positively influence the quality of life of caregivers (Duggleby, Swindle, Peacock, & Ghosh, 2011). In this case, caregivers transitioned by acknowledging their situation, connecting with others, reframing their 'normal,' and incorporating the major changes they experienced into their everyday lives.

Even though the existing literature does not approach the male caregiving experience from a transitions theory perspective, men caring for their spouses with breast cancer have described changes to their relationship, roles, and responsibilities (Northouse, 1989; Zalis & Lewis, 2010). They often take on additional household activities and provide care for their partner. Participants have described these changes in both positive and negative terms. However, it is unclear how male spouses have dealt with these changes. A more nuanced understanding of their transition experience is necessary to develop strategies to support male spouses of women with breast cancer. How men cope with, and adjust to, the changes associated with their partner's diagnosis can impact their personal health, as well as their ability to care for and support their spouse (Duggleby et al., 2012; Duggleby et al., 2011).

## PURPOSE AND OBJECTIVES

The purpose of this study was to explore the transition experience of male spouses of women with breast cancer (stages 1-3) via an analysis of qualitative data from a mixed method study that has been reported elsewhere (Duggleby et al., 2015). The specific objectives were to describe: a) the types of transitions experienced, b) how male spouses dealt with these transitions, and c) the factors that influenced their ability to cope with the transitions.

## RESEARCH DESIGN AND METHODS

Applied thematic analysis as described by (Guest, MacQueen, & Namey, 2012) was used to address the study purpose. This approach has been used to identify themes from qualitative data by combining elements from the most useful and appropriate elements from grounded theory and phenomenology in studies in applied settings (Guest et al., 2012). Qualitative data were collected using open-ended written survey questions.

### Accrual of Participants and Setting

As part of a larger mixed-methods study (Duggleby et al., 2015), a staff member at the Alberta Cancer Registry mailed survey packages to women diagnosed with breast cancer and their male spouses. The purpose of the larger study was to examine factors related to the quality of life of these spouses. A sample size of 600 women had been determined for the larger study and was randomly selected through the Alberta Cancer Registry database.

The survey package included demographic forms for both the women with breast cancer and their male spouses, surveys, and an open-ended Transition Survey. Eligibility requirements for participating in the Transitions Survey were male partners who were living with and had a legal relationship with women diagnosed with breast cancer (stages 1-3), 18 years of age or older, and fluency in English.

The qualitative data from the Transitions Survey are reported in this article. This study received ethical approval from the Alberta Cancer Research Ethics Board.

## DATA COLLECTION INSTRUMENT

The open-ended Transition Survey asked the males to write their responses to the following five questions:

1. Please tell us about the biggest changes you have experienced in caring for your family member.
2. How did you deal with the changes?
3. What do you think had an influence on the changes?
4. Was there anything you think could have helped?
5. Is there anything else you would like to mention?

These written survey questions have been used successfully in two other studies of transitions (Duggleby et al., 2010; Duggleby et al., 2011).

### Participants

Ninety-one male spouses completed Transitions Surveys. The mean age of male participants was 60.9 years of age (s.d.=12.13), while the mean age of their spouses was 58.39

years (s.d.=11.52); couples had been married an average of 30.92 years (s.d.=14.97). The female participants had been diagnosed with breast cancer an average of 33.1 months (s.d.=58.11) and 32.2% of female participants were undergoing treatment during the study. The majority of male spouses were Caucasian (n=74, 85%), religious, (n=57, 85.10%), and had an average of 14.11 years (s.d.=3.68) of education; 14.9% (n=13) were visible minorities. Most were employed (n=55, 60.40%), many were retired (n=35, 38.50%), and one participant was unemployed.

### Data analysis

The written responses to the open-ended survey questions were transcribed verbatim, and then coded and analysed. NVivo version 10 was used to organize and manage the data. Slightly more than 10 percent (n=10) of the transcripts were randomly selected and checked for transcription accuracy. All those that were checked were 100% accurate.

Thematic analysis was used to understand the transitions experienced by male spouses of women with breast cancer (Guest et al., 2012). The qualitative data from the open-ended surveys were read and reread as a whole with a focus on transitions. Data were grouped and coded according to their similarities, and then categorized into themes. When possible, the participants' words were used to define and describe the themes. Statements were further grouped into sub-themes to account for variation within themes. This allowed for an analysis of patterns within the data, and of relationships across themes. In consultation with the research team, a PhD trainee coded and analyzed the survey responses. A log was kept to catalogue analytic decisions and rationales.

## FINDINGS

### Context

The participants' experiences were interpreted within the physical and psycho-social context of their partners' experiences. For example, one spouse reported that one of the biggest changes he experienced was the "mood swings during therapy" that his partner experienced. Another wrote: "the biggest thing was the side effects of the chemo therapy. Wife is and will remain somewhat disabled—cannot walk for any distance. No walking the dog, travel limited, etc." Others said that their wives' decreased physical abilities impacted them as well: "She has gone from an independent and active lifestyle to one in which she is sedentary and dependent. This leads me to be more sedentary and to spend time driving her around, etc." Treatment side effects, such as mood swings, hot flashes, and "chemo-brain," were also cited

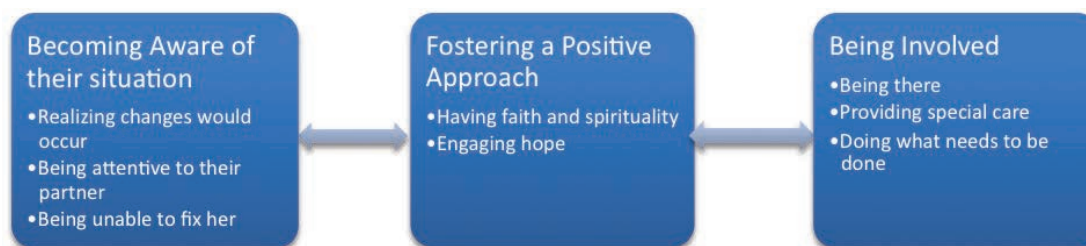


Figure 1: Transition experience of the male spouses  
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as changes that couples experienced together: *“Chemo brain... the inability to have a conversation or remember her past conversations is incredibly frustrating and probably the biggest change...”* Thus, within the context of women’s illness experiences, the male participants shared transitions. The participants acknowledged changes to their lives in multiple ways. For example, they experienced changes in their psychological health, their roles and their relationships.

**Changes to psychological health.** As a result of their partner’s diagnosis, some male spouses experienced distress, feelings of sadness, uncertainty, worry, and fear. For example, a participant reported that he felt *“down in the dumps.”* For some, this was a new experience: *“Dealing with periods of sadness and fear have been difficult. Neither of us is used to it.”* Some participants also adjusted to being continually uncertain. One participant wrote that one of the biggest changes was, *“Living with the uncertainty associated with cancer. Will the disease recur? Has it been cleared up?”* They worried about their wives’ condition and health, their children, and they experienced *“fear of her death.”* Another participant felt guilty for considering himself, specifically *“about feeling selfish about how this was affecting my life.”*

**Changes in roles and relationships.** These changes included taking on more household activities, changes in their sex life due to surgeries and side effects, and becoming a caregiver. One participant noted: *“It is hard to cuddle at bed time when my wife is pouring sweat.”* While another said: *“The decrease in my sex life can take a toll some weeks. It was not very frequent before, but is really nonexistent now.”*

The participants reported that they faced time management constraints, and decreased personal time, e.g., *“I had to do more or take on more responsibilities at home/family/children. It was challenging to fulfill family obligations when [my] spouse is sidelined with the effects of chemo. At times it was overwhelming.”* Equal sharing of household chores prior to their partner’s diagnosis might have off-set the experience of major lifestyle changes for some, e.g., *“No major changes. We have always shared tasks, i.e., (cooking, cleaning...)”*

**No change.** Ten participants (11%) reported experiencing few or no changes to their lives: *“There have really been no changes. My wife is a very strong-willed person”* or *“Small changes, she takes care of herself.”* Some male partners of women with breast cancer may also have relied solely on what they ascertained from their own observations, e.g., *“Although my wife had cancer, she does not need a caregiver. She seems just as fine now as she did before she got cancer.”*

### Transitions

The analysis of the participants’ transition experiences revealed these could be described within three overarching processes: being aware of their situation, fostering a positive approach, and being involved. These processes (discussed first) are not linear, but are co-occurring and interrelated. The processes also inform and are shaped by facilitators (discussed second).

### Becoming Aware of Their Situation

Becoming aware of their situation was an important part of dealing with the changes they experienced. This involved, *“realizing change would occur,” “being attentive to my partner,”* and accepting their *“inability to fix her.”*

**Realizing change would occur.** Part of the transition experience for our participants entailed realizing that some change would occur. For example, *“understanding from [the cancer clinic] that things were going to change.”*

**Being attentive to their partner.** Men also became aware by being attentive to their partners, *“being aware of her worries and fear”* and asking, *“what I can do to help her... talk with her more.”*

**Being unable to fix her.** Another process participants underwent was a realization that they could not change their partner’s diagnosis, distress, or changes in her physical and mental health. One participant described how he had to *“accept [...] the disease.”* Another participant explained that he felt *“helplessness [in] not being able to ‘fix’ her.”*

### Fostering a positive approach

Participants described the importance of fostering a positive approach in order to help their partners. Male spouses supported their partners by following their lead to engage in a positive approach. For example *“Just kept pushing myself to stay positive and she inspired me by trying to be consistently positive.”* Components of their positive approaches included having faith and spirituality, and using strategies to engage hope.

**Having faith and spirituality.** Participants explained that faith, prayer, and their trust in a divine power were resources upon which they relied. One participant wrote, *“committed [the] situation to God and prayed”*. Faith helped them cope, *“The belief in Jesus Christ and the promise of his salvation has had a calming effect on us.”* Spiritual resources also shaped how male spouses provided care. One participant said that his *“spiritual perspective to put others first”* shaped how he dealt with the changes he faced.

**Engaging hope.** Hope for participants was the possibility of a positive outcome. Participants mentioned the likelihood of a positive outcome: *“...was ok with it [partner’s breast cancer], knowing that things were going to get better.”* Participants also chose to focus their attention on the potential for a positive outcome. One participant noted the need to trust in what medical professionals had told him: *“focus on the odds (in [their] favour), focus on the need to stay positive for [his] wife and kids.”*

### Being Involved

Being involved with their partners’ experience consisted of *“being there,”* providing *“special care,”* and *“doing what needs to be done.”* The extent to which a participant was able to be involved differed among couples and entailed a process of negotiation. For example, some women with breast cancer prevented their spouses from being involved in ways their

husbands wanted, “I wanted to help more than I was allowed to... It was very frustrating at time[s] when attempting to extend kindness or helpful hand and being refused.”

**Being there.** Many male spouses understood part of their caregiving role as “being there when I was needed.” Flexible work schedules and understanding employers allowed caregivers to “be around more.” For example, one participant stated that his “employer was very supportive... my schedule (work) was around my wife’s tough times,” which allowed him to be “there with my wife at every step.” Retirement also helped caregivers to easily adapt to their situations “easily...[as they had] lots of free time.” Others, conversely, were prevented from being there for their spouses because of geographical constraints. One participant noted that it was “very draining to try and help long distance.”

**Providing special care.** Male spouses provided special care to their partners. One participant mentioned learning new skills in order to care for his partner, “The caring for her wound and draining her tubes, recording the drained fluids and watching for changes in her body temperature was a new learning experience, which I accepted willingly.” Others managed the side effects of treatment: “I had to keep track of medications, temperatures, etc., on a daily basis. It was a problem to keep her hydrated.” In addition to treatment-specific care requirements, they also helped their wives with activities of daily living: “[I] helped her shower and helped cook and clean.”

**Doing what needs to be done.** Male caregivers often deferred to their wives about which tasks to assume. Many described this as “do[ing] what needs to be done” or “just do what is needed.” This indicates an approach that is focused on dealing with immediate requirements. As stated by one participant, “I tried to focus on the immediate and not look too far ahead into the future.”

### Transition Facilitators

The transition processes described by our participants were facilitated by communication with their spouses and trusted experts, access to reliable information, support networks, and the availability of socio-economic resources (e.g., supportive workplaces, increased time provided by retirement).

**Communication.** Communication between spouses and with health care providers facilitated much of the transition experiences for male spouse caregivers of their partners with breast cancer. One participant noted that he had “[o]pen discussion with my wife daily.” This type of communication with his spouse helped him to acknowledge the illness, engage a positive approach, and be actively involved. Conversely, poor communication resulted in undefined roles: “Communication would have helped. My wife had a tendency to do things on her own, therefore I did not always know what to expect or do.”

Communication with health care providers was also seen as important: “Knowledge and experience of the medical professionals was great. Open discussions with staff.” However, another male spouse caregiver whose partner was diagnosed with a mental illness and breast cancer found communication with health

care providers difficult: “I wish I knew how to communicate with the doctors in a way that they would listen to the person that lives with the sick one.”

**Reliable information.** Access to reliable information helped spouses during their partner’s illness: “online information and meetings with the terrific people in the health care system.” Participants did not always appreciate the information they were given by health care professionals, however. One participant stated: “Though doctors provided a lot of information that prepared one for the treatments (surgery, chemotherapy and radiation) the ‘we know this helps x women in 20 but we don’t know which ones—before or after chemotherapy’ was a huge disappointment and difficult to deal with.” Participants also accessed online information, but some were frustrated and stated the need for trusted information sources: “a list of recommended internet information sources, and a list of ones to stay away from. There is a huge amount of bad information out there that is just frightening.” There was also a desire for specific information regarding lifestyle changes couples could make: “I would have liked a more specific program for post-recovery health, diet, lifestyle changes...I’m not feeling we are doing enough to prevent a second diagnosis, which is my biggest concern.”

**Support networks and resources.** Active support networks helped these caregivers manage their situations. Mutual exchange of support and appreciation between spouses bolstered a male participant’s ability to persevere, “my spouse telling me her appreciation and support of my efforts. My kids also encouraging me through the transition.” Friends and family supported couples, as did some employers. One participant wrote, “Work spared me time off when required, friends and family helped with kids where possible, etc.” Socio-economic resources such as the ability to hire outside help and the flexibility of retirement helped them care for their partners.

Male spouse caregivers also accessed services from health care centres and counsellors, as a means of coping. In seeking support from counselling services they were able to remain actively involved in their partner’s illness. One participant “took stress leave and went for counselling. Attended almost all the free sessions that the [cancer centre] provided.” Others described not being able to access the support they needed. For example, one participant wrote that, “it would have helped to have a support group to discuss your feelings you were having and the different stages of treatment had different effects on your daily routines.”

## DISCUSSION

The study findings indicated that the participants’ transition experience consisted of three main processes: becoming aware of their situation, fostering a positive approach, and being involved. The emotional and physical changes experienced by their wives, because of breast cancer, catalyzed changes in our participants’ roles, responsibilities, relationships with their wives, and resulted in closer relationships for some. These changes are similar to changes previously reported for male spouse caregivers. Closer relationships with partners have been reported by other study populations as positive changes

(Bigatti, Brown, Steiner, & Miller, 2011; Levy, 2011; Wagner et al., 2011; Zahlis & Lewis, 2010), while male spouses have also felt strained and burdened by caregiving, resulting in distress, uncertainty, and isolation (Bigatti et al., 2011; Hilton, Crawford, & Tarko, 2000; Lethborg, Kissane, & Burns, 2003; Wagner et al., 2011; Zahlis & Lewis, 2010). It should be noted that a small number (10) of participants described having experienced no changes, even though they simultaneously described how they dealt with changes and what influenced these changes. As a result, we are unable to determine whether they experienced changes or did not report that they had done so.

**Becoming aware of their situation.** Participants became aware of their situation by recognizing the changes associated with their partners' diagnosis. They were able to assume a caregiver role when they realized that they were unable to reverse her diagnosis or prevent her suffering. This is consistent with the study of Lethborg and colleagues (2003) that showed a role change from partner to carer and protector upon diagnosis and treatment, with a return to partner at treatment completion. Being unable to "fix" their partner with cancer has also been described in a study of family caregivers of persons with advanced cancer (Duggleby et al., 2012). Becoming aware of their situation has been reported in studies focused on transition in other populations (Duggleby et al., 2010; Duggleby et al., 2011).

**Fostering a positive approach.** Participants cultivated a positive approach in partnership with their wife. Faith and spiritual resources were subcomponents of this process, as were strategies that engaged hope. The participants' ability to foster a positive way of coping centred upon their spouses' approach to their illness. This is consistent with previous research showing that the patient's attitude toward the illness strongly influences the caregiver's attitude (Hilton et al., 2000; Zahlis & Lewis, 2010). Although the illness experience and the caregiving experience are specific to the individuals concerned, they are also interrelated (Zahlis & Lewis, 2010). Consistent with findings reported in Duggleby et al. (2012), hope was a resource that male spouses of women with breast cancer engaged in their daily lives. Hope helped our participants cope with the changes and challenges they faced (Duggleby et al., 2012).

**Being involved.** Active involvement entailed "being there" physically and emotionally for their partners, and by providing special care. Spouses also did what was needed, an approach premised on their belief that their wife's illness was temporary, and that they could persevere until an eventual return to normal.

**Facilitators.** The transition facilitators of communication with spouses and trusted experts, reliable information, and support networks and resources are similar to those reported in Duggleby et al. (2010) in a study of the transition experience of caregivers for persons with advanced cancer. However, our data suggest that employment networks are important sources of support in helping male spouses provide care and support to their partners. While this is consistent with previous findings about this population (Hilton et al., 2000; Zahlis & Lewis, 2010), this resource was not discussed in previous transitions research and could be explained by this study's focus on male spouses.

Consistent with previous literature, some participants sought the support of counsellors. Others said that support groups might have helped, but that they did not seek out support because they were too consumed with managing their daily lives (Hilton et al., 2000). A desire to not appear weak had been reported as preventing some male spouses from accessing resources (Hilton et al., 2000).

Communication with their spouses and with their spouse's health care providers helped male spouses to acknowledge their situation, foster a positive approach, and be actively involved. Previous studies have demonstrated the benefits of positive communication, such as helping couples cope with their situation, strengthening their relationship, (Hilton et al., 2000) and allowing male spouses to understand their partner's experience (Lethborg et al., 2003). Research findings show that some spouses choose to focus only on the positive in order to avoid addressing their own turmoil (Hilton et al., 2000; Lethborg et al., 2003). In this instance, support networks where male caregivers can openly discuss what they are going through, and "unload" on someone other than the patient, are of notable value (Lethborg et al., 2003). When patients did not communicate their needs or communicate with their husbands, some participants understood blocked communication as blocking them from caregiving for their spouses.

The availability of quality information is a facilitator that provides reassurance to male spouses and allows them to prepare for the future. Lack of information caused feelings of uncertainty and worry, which is consistent with previous research that identifies seeking information as a response to feelings of powerlessness (Zahlis & Lewis, 2010). Lack of information also is related to communication with trusted experts and resources. Future research should examine the best way to enhance the facilitators that help male spouses deal with the transitions they experience.

## LIMITATIONS

There are several study limitations related to the methodology and sample. For example, data were collected through a mailed survey of open-ended written questions rather than in-person interviews. Hence, there was no opportunity to probe for more in-depth information or clarification. Although the findings add to our existing knowledge, a study with in-depth face-to-face qualitative interviews would assist in further understanding transition experiences.

The sample for the larger study was a randomly selected sample of women. However, the male respondent participation depended upon the women inviting them to participate. This could have resulted in participation by males who reflected supportive and caring relationships. Males who were fundamentally not supportive of their wives may not have been asked to participate or may have declined.

The demographics of the participants can also be considered a limitation. Participants were generally older adults, had a high socio-economic status, and had few personal health problems. Future research could explore the transition experience with participants of lower socio-economic status or those with pre-existing chronic conditions.

## CONCLUSIONS

Although there are limitations to this study, the findings add further confirmation to the understanding of changes male partners experience and make a contribution to our understanding of their transition experience. The work also provides a foundation for future research.

The transition experience includes being aware of their situation, fostering a positive approach, and being actively involved. Transitions are facilitated by communication with spouses and trusted experts, access to reliable information, and access to support networks and resources. Future research could explore the relationship between those who note “no changes” to their lives as a result of their spouse’s diagnosis, and how they experience transition processes, as compared to other male spouses.

## INTERPRETATIONS FOR NURSING PRACTICE

The study has several implications for nursing practice. The findings increase the awareness about the types of transitions or changes experienced by male spouses. Nurses can share information about these experiences with male spouses

through public awareness and psycho-educational programs for women with breast cancer and their spouses, as a means of validating their own experience.

Nurses may need to acknowledge that some male spouses may not perceive any changes in their lives when their partners are diagnosed with breast cancer. As well, not all women want to share their cancer experience with their spouses, which can lead to communication barriers and relationship conflicts. Supportive therapy groups or individualized counselling specifically for male spouses may help validate their experiences and normalize the range of emotions they may be feeling. Nurses can facilitate access to reliable information and assist male spouses in developing a supportive network to help them deal with their transitions. As well, because of the complex transitions experienced by male spouses and their diverse approach to dealing with them, the study findings underscore the need to tailor programs that meet the unique needs of spouses of women with breast cancer.

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