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Abstract

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Keywords

breast cancer, social support, resources, role function

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ABSTRACT. A woman's ability to navigate her new role as a breast cancer patient can be impacted by the support she has available to her during this time. One form of social support, tangible support, refers to providing support in a physical way that assists an individual in meeting their role responsibilities. The Roy Adaptation Model was used as a framework for conceptualizing the various roles in a woman's life that can be impacted by breast cancer and how the type and extent of tangible support impacts these roles. Through a qualitative open-ended interview, 33 women with breast cancer described their experiences with their illness as it pertains to issues of role function and tangible supports. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2005 by The Haworth Press, Inc. All rights reserved.]*

KEYWORDS. Breast cancer, social support, resources, role function

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INTRODUCTION

Breast cancer is the most common cancer among women who are newly diagnosed (Jemal et al., 2004). As with most cancers, it demands physical and psychological adjustments even in the best of cases (Taylor, Falke, Shoptaw, & Lichtman, 1986). A woman's ability to navigate her new role as a breast cancer patient can be impacted by the support she has available to her during this time.

Tangible Supports

One form of social support, tangible support, refers to providing support in a physical way, for example, helping someone with tasks such as cooking or cleaning. For women with breast cancer this tangible support may also take the form of assistance with self-care, such as bathing, childcare or having someone to take notes at a doctor's appointment. Individuals such as spouse, children, other family members, and friends are key elements in the provision of tangible support (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Bloom, Stewart, Johnston, Banks, & Fobair, 2001). It is believed that the perception of the availability of tangible support is more important than its actual use (Wortman, 1984). Literature on social support and breast cancer often looks at emotional support (communications of compassion, caring, and concern) rather than tangible support (Pistrang & Barker, 1995; Smith, Redman, Burns, & Sagert, 1985; Wortman, 1984). This distinction is important because some patients have reported tangible support to be very helpful and that it helps to buffer some of the stress brought on by having a serious illness (Dakof & Taylor, 1990).

Several researchers suggest that support from family members helps the patient to recover from surgery and illness and that tangible support provided to women with breast cancer from their family is linked to future adjustment (Blanchard, 1995; Borwell, 1996; Bourjolly & Hirschman, 2001; Green, 1986; Northouse, Cracchiolo-Caraway, & Appel, 1991; Schag, 1993). For most women with breast cancer, primary support comes from the family. At the same time, however, new stresses related to the illness can tax this resource. Therefore the patient's need and availability of supports are associated with the patient's ability to function daily and carry out her social roles in society (i.e., care for one's self and fulfill daily roles as a caregiver, housekeeper, employee and community participant).

The tangible support literature examines this type of support primarily using scales and instruments to elicit the information on the type and extent

of support provided. Although useful, these scales do not provide information on the woman's perception of available tangible supports and the impact the amount of support she has or lacks has on her ability to continue to manage her other roles such as being a mother, wife/partner, daughter, or employee, as well as provide tangible support to others as a caregiver.

Theoretical Framework

The Roy Adaptation Model (Roy & Andrews, 1999) was used as a framework for conceptualizing the various roles in a woman's life that can be impacted by breast cancer and how the type and extent of tangible support impacts these roles and the activities within them. According to the Roy Adaptation Model, adaptation to environmental stimuli takes place in three psychosocial modes and one biological mode. The psychosocial modes are: (1) role function, (2) self concept, and (3) interdependence. The role function is concerned with people's performance of roles on the basis of their positions within society. The self-concept mode deals with people's conceptions of their physical and personal selves. The interdependence mode addresses the development and maintenance of satisfying affectional relationships with significant others. The biological mode, also referred to as the physiological mode, is concerned with the basic needs requisite to maintaining the physical and physiological integrity of the human system (Roy & Andrews, 1999).

These four modes are interrelated and a stimulus in one mode may impact or affect another mode or all of the other modes concurrently or sequentially (Andrews & Roy, 1986). Environmental stimuli are categorized as focal, which refers to the stimuli most immediately confronting the person; contextual, which refers to contributing factors in the situation; and residual, which refers to other unknown factors that may influence the situation. When the factors making up residual stimuli become known, they are considered focal or contextual stimuli (Roy & Andrews, 1999). According to this model, outcomes in adaptation in the three psychological modes and one biological mode would be functional status, psychological state, interpersonal relations and immune status, respectively (Tulman, 1990).

Published research on women with breast cancer that has used the Roy Adaptation Model often focuses on participation in group social support and educational interventions (Samarel et al., 1998; Samarel et al., 1999; Samarel, Tulman, & Fawcett, 2002) to assess patient adaptation to their illness. Yet within the context of the role function mode of the Roy Adaptation Model, breast cancer and its treatment, could be

separated out and seen as a focal stimulus affecting a woman's functional status and her performance in activities typically ascribed to various roles she has in society (Roy & Andrews, 1999; Tulman, 1990). Functional status after diagnosis of breast cancer would therefore be defined as the extent to which the woman continues her usual primary (such as self-care), secondary roles (such as household chores, family responsibilities, occupational activities) and tertiary roles (such as community activities, hobbies, religious activities) (Tulman, 1990; Tulman & Fawcett, 1996). Using this conceptualization, and specifically focusing on the domain of role functioning, we were able to see how tangible supports impacted the manner in which women with breast cancer were able to perform in their primary and secondary roles, specifically in the areas of self care and household responsibilities.

METHODS

This pilot study used a qualitative approach, which examined how individuals arrange themselves and their environment in response to changes impacting that environment (Berg, 2001). The strategy of "reflexive interviewing" (Hammersley & Atkinson, 1986; Mischler, 1986), in which participants are encouraged to "tell their own story," and statements are "reflected back" as a continuing set of questions until the topic is saturated (Strauss & Corbin, 1990), was utilized to gather data. This enabled the women to describe their various roles, providers of support and the types of tangible support received during their illness experience.

The interviews were guided by a semi-structured open-ended interview schedule. Where appropriate, additional questions were posed to follow through with unexpected responses. The data collection instrument was created based on a review of the breast cancer literature, informal discussions with doctors, nurses, and social workers at a large Academic Medical Center with a Comprehensive Cancer Center (AMC/CCC), and with patients. The interview schedule included questions regarding social functioning and social support, diagnosis, and medical treatments, as well as patient demographics and characteristics. With the permission of the patient, these data were then cross-referenced with their medical chart to confirm information.

Tangible Supports

Subjects were asked describe any difficulties they had fulfilling their role responsibilities as a result of their breast cancer surgery or treat-

ments (such as self care, household chores, caring for children, caring for other ill family members, working, social or community activities, etc.). For each area in which women identified having difficulties, probe questions were asked to assess what specific tasks or aspects of their roles were affected by breast cancer treatment. The women were then asked to discuss if they received any assistance from family members, friends, or coworkers with the previously mentioned role difficulties and to describe the experience.

Sample

Breast cancer patients were recruited from two Oncology departments at a large AMC/CCC. Women were eligible to be interviewed if they had a diagnosis of breast cancer, were within 24 months subsequent to diagnosis or initial surgery, and, if applicable, had started some form of adjuvant therapy (i.e., radiation or chemotherapy). These criteria were established to ensure that the subjects had at least a minimal amount of experience with dealing with the process of breast cancer treatment and care. Women who met these criteria were asked to participate by either a nurse or an interviewer (KH). Of the women who were asked to participate, all but two women were not available to complete the interview at a later time (33/35; 94%).

Participation in the study was voluntary and written informed consent was obtained, in accordance with the institutions' Committee on Studies Involving Human Beings. With permission from the patient, all interviews were audio taped, or detailed notes were taken and then transferred to tape immediately after the interview. Interviews from this sample of convenience were conducted over a 6-month period of time (May 1998-December 1998).

Data Analysis

Qualitative analysis of open-ended responses was completed by the authors and a third coder using grounded theory techniques (Strauss & Corbin, 1990). Preliminary codes were revised by consensus among the three reviewers, and final codes were applied (Glaser & Strauss, 1967; Pidgeon & Henwood, 1996). All data was entered in to a qualitative data analysis package (NUD*IST4, 1998). Basic frequency counts and descriptive statistics are also presented.

Human Subjects Protection

This survey study was reviewed and approved by the Institutional Review Board of the University of Pennsylvania and the University of Pennsylvania Health System Cancer Center.

RESULTS

Sample Characteristics

The final sample consisted of 33 women. Fifteen women with breast cancer came from the Radiation Oncology Department and 18 women came from the Hematology Oncology Department (see Table 1). Women ranged in age from 38 to 69 years old with a mean age of 51.6 years. The majority of the women were white (24; 73%). Eleven out of 33 women reported having children under the age of 18 living at home. The number of children ranged from one to six with a median of two children in the home. The average number of people living in the household with these women was two (range: 0-7). Over half of the women in this sample indicated they were married. Women had an average of 15 years of education and the majority of the women had an annual household income of \$30,000 or greater (22/30; 73%).

Twenty-six (79%) women were diagnosed with invasive carcinoma of the breast (see Table 1). The majority of women (70%) had early stage breast cancer (Clinical T stage \leq T1). The average number of months from diagnosis when interviewed was 7.9 months (Median = 8 months).

TANGIBLE SUPPORT

All of the women in this sample expressed that they could rely on someone for tangible support to help her deal with the some of the primary and secondary roles (i.e., self care, mother, household cook, etc.), which were impacted by her breast cancer experience. The individuals most often noted as sources of tangible support to these women were immediate family members such as husbands, partners, fiancés, children, siblings, parents, and in-laws. Thirty-two (97%) women noted that they received this type of support from family.

TABLE 1. Characteristics of Women with Breast Cancer (N = 33)

<u>Variables</u>	<u>Mean (sd)(range)</u>
Age (years)	51.6(8.1)(38-69)
	<u>N (%)</u>
Married/Living with Partner	20 (61)
White	24 (73)
Household Income*	
\$0-\$19,999	5 (15)
\$20,000-\$39,999	5 (15)
\$40,000-\$59,999	7 (21)
\$60,000 +	13 (40)
Education	
< 12 years	2 (6)
12 years	6 (18)
12-15 years	8 (24)
16 + years	17 (52)
Employed	21 (64)
Breast Cancer Diagnosis	
Invasive	26 (79)
Non-Invasive	7 (21)
Clinical Tumor Stage (T)	
T ₀ : In Situ	5 (15)
T ₁ : ≤ 2 cm	18 (55)
T ₂ : 2 > and < 5 cm	6 (18)
T ₃ : ≥ 5 cm	4 (12)
Surgical Treatment	
Lumpectomy or Partial Mastectomy	24 (73)
Lumpectomy then Mastectomy	6 (18)
Mastectomy	3 (9)
Adjuvant Therapy	
Nothing	1 (3)
Radiation	9 (27)
Chemotherapy	7 (21)
Both	15 (46)
Both plus Stem Cell	1 (3)

*N = 30, missing data.

Women also cited friends, religion/spirituality, coworkers and other patients' as sources of tangible support to assist them with meeting their role responsibilities. Twenty-two women (67%) indicated that friends provided this type of support. Nineteen women (58%) indicated they found support from God, organized religion, a higher power, or through personal spirituality. Seven women (21%) indicated that they received social support from coworkers or from their employer. Three women (9%) indicated that they found support in their relationships with other

breast cancer patients going through treatment at the same time that they were receiving treatment for their breast cancer. Women identified between 1-4 sources of tangible support (Median = 2).

There were a few women who expressed that although they had people to provide support, those individuals were not always supportive. One woman stated, “. . . my mother is a bigger stress, she thinks she is helping me but she just makes a bigger mess” and another woman stated, “. . . my husband told me he wanted a divorce the day I found out I had cancer.” Women who reported having some “less supportive” people among their providers of support did have other avenues to tangible support, most often noting other family members, friends or coworkers filling the void.

Tangible Support: Family and Friends

Like much previous research, the women in this study expressed that their family and friends provided them with the greatest amount of tangible support in assisting them with their primary and secondary roles (Blanchard, 1995; Borwell, 1996; Bourjolly & Hirschman, 2001; Green, 1986; Northouse et al., 1991; Schag, 1993). Specifically most women indicated their partner or husband and mother were most helpful in providing tangible support to them during the process of their breast cancer diagnosis and treatments. Other women indicated that their children, siblings and/or in-laws provided support in times of need.

ROLE FUNCTION

Most women in this sample indicated that they had some difficulties fulfilling role responsibilities in their life mainly as a result of their initial surgery for their breast cancer, but also as a result of ongoing treatments. For women who indicated some difficulties fulfilling their role responsibilities due to being ill, the support from their family and friends helped them deal with the impact of breast cancer on their everyday life. Women described that they had difficulty with both primary and secondary roles, specifically, self-care, being the caregiver for others in the family, and household responsibilities.

Primary Role: Self-Care

Women's comments regarding self-care varied, but most comments regarding difficulty meeting this primary role were concentrated in the

time period just after their initial surgery. For example, S.H., a white single woman who had a mastectomy stated:

When I came home from the hospital I thought I would be able to take care of myself and that was not the case. I had to have a woman stay with me for two weeks after I came home until I got my strength back and I was able to take care of myself. She did some cooking. My sister-in-law had to give me a couple of baths during that time. So, I did have to rely on other people.

Another woman (M.C.) indicated that after her mastectomy she had her mother come and stay with her to help “look after me,” but that within two weeks she was back to walking four miles a day. She expressed she knew it would take some time to recuperate after the surgery but that it was important to her to continue with her normal routine once her breast healed. Another woman (K.E.) had a similar story, that “only the couple of days after the lumpectomy” did she have some difficulty caring for herself. But she also indicated that “[B]ecause of the fatigue factor, everything is a little more difficult,” but that she did not feel that she was having any trouble caring for herself beyond those instances. Another woman (G.G.), who had moved from her home 2000 miles away to be with her family while she was undergoing treatments for her breast cancer, indicated that she had some self care difficulties in the beginning, after her mastectomy. She stated specifically that her grandchildren would “. . . comb her hair and put her make up on . . .” for her.

Most women in this sample noted that although caring for themselves may have been difficult, they managed their primary role and fulfilled these roles to the best of their ability. But for those who were also caring for others, including children, husbands, or parents, they expressed that needing assistance with these secondary roles was “frustrating.”

Secondary Roles: Caring for Others

About one-third (12/33) of the women in this sample noted issues’ surrounding the secondary role of caretaker for others both for children and ill family members. Their role responsibilities as a caretaker were impacted by their experience with breast cancer. These women expressed frustration with not being able to perform the tasks associated with caring for others, yet many did not want to burden their family

members with the fact that they had breast cancer. Some women indicated that they did not want to worry their family member by telling them about the cancer so they refrained from sharing the diagnosis or they delayed telling their family members about the diagnosis of breast cancer. One woman (I.Y.) who had two children of elementary school age shared that she had some difficulties with following through with tasks like carpooling and getting her children to school. When asked how she dealt with this she stated, “. . . I told my daughter’s friends parents [about the breast cancer] and they started taking her with them sometimes. They would drive her to school once in a while.” She reached out to others for tangible support to meet the needs of her family and her role as mother.

Other women stated they too received tangible support to care for their children or help them care for their children from their mothers who came to stay and who helped provide primary care for the children. And some women indicated they received assistance from neighbors who provided everything from meals to watching the children during or after treatments.

. . . my neighbor has a daughter that is my son’s age so he’d go over there and play and I could rest. And she formed a meal brigade every time I had chemotherapy; the neighbors all pitched in and cooked for me that weekend. So I had lots of food, I had leftovers, that kind of thing. And that helped a lot. (J.O.)

Another woman who had small children had a similar story. She expressed that she received a lot of support from her immediate family, which she found invaluable.

While I didn’t have too much trouble taking care of myself, I did have trouble taking care of my children. During the period when I was in the worse shape my children would go to school and all I had to do was to get up and get them out the door. I could get up and get them ready but I . . . had a hard time walking out to the bus. The walk up that hill would just do me in; I was done for the day. So either my sister, who lives quite near by . . . she’d come up in the morning or my husband would come home from work . . . so he’d either get everything started early in the morning and then come home and the kids would be up or my sister would come up. So, like I said, I had wonderful help. (H.K.)

Of the women who expressed that they were caring for other ill family members, most of the women explained that their husband was ill or a parent was ill. H.P. explained that she was caring for her husband who also had cancer and that she was “more concerned about him because his cancer was diagnosed at a much later stage” than her cancer. K.E. indicated that her father had a stroke while she was having her first course of radiation treatments that she stated was very stressful for her to navigate both the role of daughter and caregiver as well as provide tangible support while needing support. Another women, R.C., explained that her mother came to stay with her while she was going through her surgeries and treatments for her breast cancer but that it was more of a “role reversal.” “She thinks she is caring for me and I am trying to care for her.”

Secondary Roles: Household Activities

The role women most often indicated that they had difficulties with the duties and responsibilities around the house as a result of their treatment for breast cancer. Whether as a result of limitations due to surgery and moving a vacuum cleaner or being too fatigued to fold the laundry or cook a meal, over 67% (22/33) of the women indicated difficulties with this role and completing household chores.

E.J., a 56-year-old, single, African American woman, discussed that she loved to cook and found it was like therapy for her but that since she had started her treatments for breast cancer she had not been able to continue to cook. “I love to cook, I enjoy it, it’s like therapy for me. And I have not been doing that much anymore. It takes so much work, I have to clean up, I don’t want to do that anymore. But, hopefully, I will get back when I get stronger.” E.J. went on to explain that she received tangible support from a friend who came on a regular basis to help out by cooking and cleaning for her. S.L., a 42-year-old, married, white woman, explained she too did not cook much and either her friends brought food in for her and her family or that she went out to eat with her husband and son. She reported that when she was first dealing with the initial role as patient, right after the surgery, that she had to have someone to help her clean the house but that she was eventually able to take that responsibility back and was now able to clean the house again and resume her other role.

P.L., a 57-year-old married white woman, stated that she had difficulty with some household responsibilities during certain times in her illness process. “Everything from the wash, the dishes, cooking any-

thing . . . ” was difficult for P.L. after her surgery and during her treatments. She stated that her children provided tangible support, even coming to live with her in order to help her.

S.H., a single 46-year-old white woman, described feeling incapacitated after her surgery and other treatments and explained that she received tangible support from her family with household chores. “Household chores were kind of left by the wayside, many, many, many times. My brother actually stayed with me for a period of time after the mastectomy so that there would be somebody there and he cooked for me.” T.J. received tangible support from her sister, brother-in-law and her mother with household chores such as vacuuming, cooking meals and dog walking. In regard to household chores for M.S., a married 42-year-old white woman, explained, “I just didn’t do anything (laugh), I didn’t clean, I didn’t cook, I didn’t do laundry. My husband did those things.”

For J.B., a divorced 52-year-old white woman, accepting the impact of having breast cancer on her everyday household chores was expressed in terms of the fatigue associated with the treatments for breast cancer. She stated she was “. . . probably not as energetic about doing it as I used to. I could easily convince myself that it can be done tomorrow that I might not have before, just because I am tired.” And S.P., a married 53-year-old white woman, found humor in the adjustment to her breast cancer and the impact it had on her other responsibilities of household chores. “Oh [laughter] the house is a pigsty! I was able to do some of the housework but not much.”

LIMITATIONS

It is important to note this study does have some limitations that affect the generalizability to the population as a whole. First, the small sample size limits this study’s generalizability. Although this sample is small these results are consistent with what other researchers have reported on women with breast cancer and their use of tangible supports (House, Landis, & Umberson, 1988; Northouse, 1989a; Northouse, 1989b; Reifman, 1995; Rowland & Massie, 1998; Wortman, 1984). Second, All of the women with breast cancer who were interviewed were being treated at a Comprehensive Cancer Center. The women who found their way to this center may not be typical of other women with breast cancer. Similarly, all of these women had the ability to reach a CCC in an urban area indicating that they have access to resources such

as transportation, possibly indicating greater access to tangible supports to assist them in accessing care. And finally, the availability of tangible support may differ for women living in less urban or suburban environments as the women in this study. It is recommended that future research incorporate a more diverse sample of breast cancer patients to assess adaptation.

DISCUSSION

These results indicate that women receive tangible supports from various people in order to deal with the impact of breast cancer on their role functioning. Women in this sample described needing help with their primary and secondary role responsibilities, such as, self-care, caring for others, and household chores.

In this sample, a number of women indicated that their role function as a caregiver was impacted by their illness. This may be a result of women, primarily, between the ages of 40-60 being 'sandwiched' between their children and their parents as caregivers (Raphael & Schlesinger, 1993; Spillman & Pezzin, 2000). Being the caregiver for others already has a level of stress that is part of that responsibility, couple it with the care giving being ill themselves with breast cancer and you compound the stress (Northouse et al., 2002). Further study of women with breast cancer, as well as other cancers, and the impact of also being a caregiver is necessary.

The tangible support reported by this group of women was a factor in their ability to manage their daily roles. Most women confirmed that they had some difficulties meeting some of their other daily role responsibilities as a result of their breast cancer or the treatments associated with the disease at some point during their adaptation to their cancer. Yet the majority of the women in this study were able to utilize their tangible supports in order to better cope with their ability to function and manage both primary and secondary role functions. This has implications for practice.

For clinicians, an assessment of tangible supports available to a patient early in the treatment process could be a worthwhile discussion in order to determine what a breast cancer patient may need to fill the gaps in support and help them to assess role responsibilities as they adapt to their breast cancer. Discussions with patients about who is available to provide tangible support and the type of help these individuals provide can offer a clearer picture of support availability and untapped resources that the patient may need to call upon during their breast cancer

treatments. Other interventions may also be required to help women with breast cancer find ways to manage their everyday needs in ways that are beneficial. Such interventions may include such tangible supports as: transportation, cab vouchers, bus tokens, parking reimbursements, homemaker services, or a visiting nurse. These approaches would be most useful shortly after initial surgery and in the early stages of cancer treatment, the times when functioning is most affected.

Because the literature on tangible supports generally uses quantitative approaches to data collection, a qualitative approach to data collection was taken in this study. This qualitative approach provides a more detailed look at how a woman perceives the availability and impact of tangible supports on her ability to manage her ability to function and meet role responsibilities. The in-depth interviewing approach also provides a rich description of the importance of tangible support in the lives of women undergoing treatment for breast cancer and the way women interpreted their role function in relation to their cancer. This description fills some of the gaps in the literature regarding the impact of tangible supports and role functioning on women with breast cancer.

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