

Characterizing Burden, Role Strains and Psychological Distress of Husbands of Breast Cancer
Patients During Treatment and Beyond

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Husbands play a pivotal role during the periods of treatment and recovery of breast cancer patients. During the course of this potentially life-threatening disease, patients often experience disease-induced disability that causes role limitations. As a result, husbands often take on the tasks that patients can no longer perform, over and above their own social and familial roles, career-related obligations, and new caregiving responsibilities.^{1,2} This new role of caregiver may result in reduced quality of life and psychological distress.³

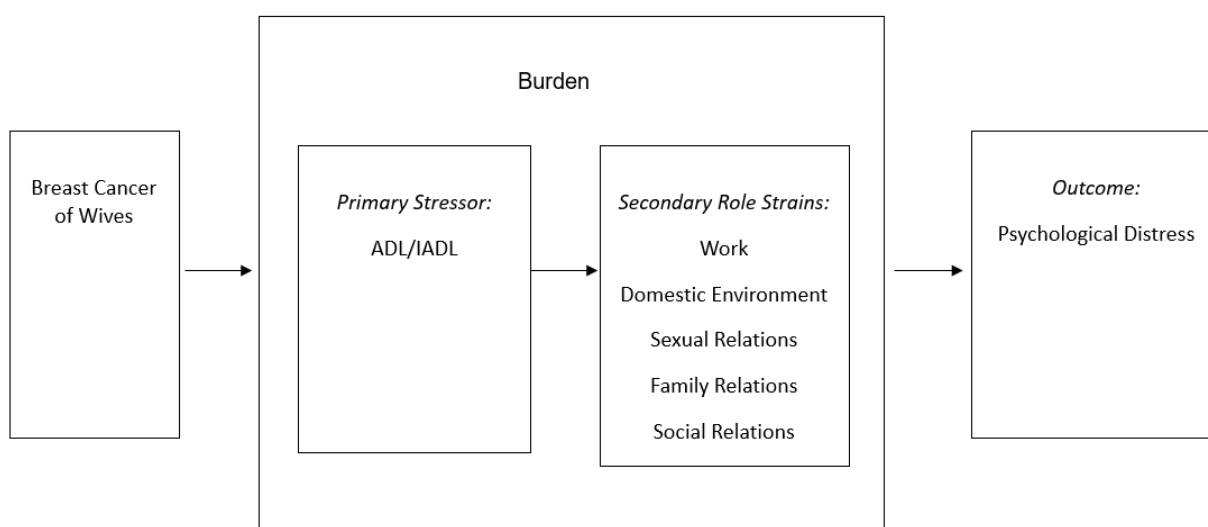
Husbands act as the most frequent providers of support for breast cancer patients;⁴ however, only a small portion of the caregiving literature is devoted to men, leaving a gap in knowledge about the caregiving experience of husbands of women with breast cancer. While caregiving was a role traditionally assumed by females in the past, a growing number of males now provide care. Recent estimates indicate 39% of caregivers are male,⁵ highlighting the importance of bridging this gender gap in the caregiving literature.

Theoretical Foundation

Pearlin's Stress Process Model (see Figure) provides a strong theoretical foundation through which to understand the caregiving experience of husbands of breast cancer patients. This theory suggests that primary stressors and secondary role strains are important predictors of psychological distress.⁶ Primary stressors stem directly from the needs of patients and include both assisting with activities of daily living (ADLs; such as bathing, dressing, feeding), and instrumental activities of daily living (IADLs; such as taking medication, shopping, managing finances). Secondary role strains represent new hardships that arise as a result of primary stressors. The addition of primary stressors, such as new caregiving responsibilities, can spill

over to negatively impact a caregiver's performance in a variety of domains resulting in role strain. Therefore, primary stressors and role strains can lead to caregiver burden. Burden may be defined as a caregiver's perception that his physical health and psychological well-being, social life, and financial status are negatively affected by the patient's illness.⁷

Figure. 1 Pearlin's Stress Process Model Applied to Husbands of Breast Cancer Patients



Primary Stressors: Caregiving Responsibilities

Following a wife's breast cancer diagnosis, husbands must learn to balance new informal caregiving responsibilities with old and new social roles. Caregiving tasks can include assisting with ADLs and IADLs, in addition to maintaining household chores such as cleaning and cooking as well as taking up responsibilities of rearing children. Other time-consuming roles reported by husbands include assisting patients with emotional support, transportation, and monitoring symptoms.^{3,8} Balancing caregiving responsibilities with work is also a great concern,

as the majority of caregivers are employed while caregiving and report that caregiving negatively impacts their work responsibilities.⁵

Secondary Role Strains

Role strains may develop when these new caregiving responsibilities interfere with the performance of the caregiver's ordinary, non-caregiving roles inside and outside the home. These strains may produce perceptions of burden among caregiving husbands.

Meeting the continual and fluctuating needs of patients, in addition to coping with their own psychological reaction to the illness, can be emotionally and physically taxing for husbands.⁹ Additionally, husband's role strain at diagnosis is a significant predictor of his role strain 1-year later.¹⁰ This suggests that husbands with the greatest role strain at the time of diagnosis are not reporting relief over time and may not seek assistance.

Role strains have been correlated among breast cancer patients and husbands in both cross-sectional¹¹ and longitudinal studies,¹² indicating that the strain of partners is inter-related. Perceptions of burden can hinder the husband's ability to provide optimal support for his wife with breast cancer. Patients fare better both physically and emotionally when their spouses are supportive¹³ and other sources of support cannot compensate for the negative effects of a partner relationship that is unhelpful.¹⁴

Positive Aspects of Caregiving

In addition to caregiver burden, it is also important to note that the caregiving experience is not always perceived negatively and can even be appraised as a life-enhancing experience or opportunity for growth. Positive aspects of caregiving can include personal satisfaction, enhanced self-esteem and self-efficacy, gaining greater purpose in life, and forging a closer relationship with the patient.^{15,16} Males are more likely to appraise the caregiving experience as

boosting their self-esteem than females¹⁷ and this enhanced caregiver esteem is associated with reporting less distress.¹⁸

Caregiving and Distress

Research shows that husbands of breast cancer patients report levels of distress comparable to and sometimes even greater than the levels of distress reported by patients.^{11,19-23} Caregiving burden may represent one important predictor of psychological distress among husbands. Distress is highest among husbands whose wives report higher symptom distress¹⁷ and functional impairment,²⁴ which may be the cases where husbands need to provide more assistance, leading to a stronger perception of caregiver burden.²⁵

Few studies have specifically examined which aspects of caregiving, both negative and positive, relate to psychological distress of husbands over the course of breast cancer treatment, which would allow for the development of more targeted interventions. Some researchers have found that subjective appraisals about the stressfulness and benefits of caregiving are more important predictors of caregiver depression than objective stress indicators, such as assistance with ADLs.²⁶

Even fewer studies have examined the relationship of burden and distress over time for husbands of breast cancer patients. One such study found that role strain correlated with emotional distress at six different time-points ranging from 7-10 days after a wife's breast surgery to 1-year later.²⁷ However, the relationship of role strains to distress were examined with cross-sectional analyses rather than longitudinally to determine the predictive value of role strain across time.

Goals of Present Study

While there is a growing body of literature devoted to the adjustment of husbands with breast cancer, current studies do not provide a detailed description of actual caregiving responsibilities performed by husbands (primary stressors), the degree of secondary role strains, or how these two factors change in the first year of survivorship. Therefore, our first goal was to describe the caregiving responsibilities and secondary role strains reported by husbands at the time of diagnosis, and 1-year later, in order to characterize their behavior over time. As a sub-goal, we also analyzed the extent to which husbands reported gaining meaning from their caregiving experience, to examine possible benefits of caregiving during the wife's adjuvant treatment, when caregiving responsibilities were hypothesized to be the greatest.

While Pearlin's Stress Process Model suggests primary stressors and secondary role strain are important predictors of physical and psychological distress,⁶ breast cancer caregiving studies have primarily focused on role strain as an outcome variable, a proxy for psychological adjustment,^{11,28} rather than as a predictor of subsequent distress. Therefore, the second goal of the present study was to investigate caregiver burden and positive aspects of caregiving as predictors of psychological distress both cross-sectionally during treatment and 1-year later.

Methods

Participants

At baseline assessment, 119 husbands accompanying their wives with breast cancer to the infusion clinic at a university cancer center were approached and agreed to participate in this study; no men who were approached at baseline declined participation. Of those who were recruited, 81 (68%) returned completed questionnaires at baseline. One husband dropped out of the study due to divorce and six husbands reported during follow-up phone calls that they were no longer interested in the study. The reasons why the remaining 31 husbands did not return

surveys are unknown. Fifty-eight husbands who completed the first survey indicated they would be interested in further follow-up and were mailed letters and brochures 1-year later inviting them to participate in a second survey. Forty-one of these husbands completed these follow-up surveys, a 71% recruitment rate. We were unable to ascertain the reason for non-return of 17 follow-up questionnaires because of limitations imposed by the institutional review board.

The sample was predominantly Caucasian (97%) with an average age of 50.78 years ($SD = 12.36$). About a half of the participants were college graduates (47.5%), employed full-time (67.5%), and a large proportion of participants (48.7%) earned an annual income over \$70,000. Husbands reported marriage to their wives for an average of 25 years ($SD = 15$). See Table 1 for a more detailed description of demographic characteristics.

Procedure

After receiving approval from appropriate Institutional Review Boards, research assistants approached breast cancer patients and their husbands at the cancer center in chemotherapy infusion clinics. Research assistants explained the purpose of the study to the couple and asked husbands to participate. Husbands were eligible for the study if they were English speaking, at least 18 years of age, and married to a woman undergoing active treatment. Husbands completed informed consent at the infusion clinic and were provided a packet of questionnaires to complete at home and return via mail upon completion.

Research assistants monitored study completion and called husbands who did not return surveys within 2 weeks, during each phase of data collection, and ensured that husbands had received surveys, inquired whether husbands had any further questions, and encouraged husbands to return their surveys promptly. All participants who returned survey packets were

compensated for their time with grocery gift certificates after each assessment. Data were entered and double-checked by trained research assistants.

Measures

Project Questionnaire.

This instrument was developed by project personnel to obtain participant demographic and information on patient's cancer and treatment from the husband. Results are presented in Tables 1 and 2.

Table 1. Husband Demographic Variables

Variables	N = 40
Age	
Mean	53.18
SD	12.77
Years Married	
M	24.86
SD	14.84
Ethnicity	
% Caucasian	97.5
% Asian/Pacific Islander	2.5
Education	
Below college grad	21 (52.5%)
College and beyond	19 (47.5%)
Employment Status	
Employed	27 (67.5%)
Unemployed	1 (2.5%)
Retired	10 (25.0%)
Disabled	1 (2.5%)
Other	1 (2.5%)
Income Level	
\$40,000 and below	6 (15.4%)
\$40,001 – \$70,000	14 (35.9%)
Above \$70,000	19 (48.7%)

Table 2. Patients' Breast Cancer and Treatment Characteristics

	(N = 40)	Duration (mos.) M (SD)	Range
Cancer Stage			
Stage I	7 (18.9%)		
Stage II	11 (29.7%)		
Stage III	10 (27.0%)		
Stage IV	9 (24.3%)		
Treatment Methods			
Chemotherapy	37 (92.5%)	9.42 (17.57)	.25 - 96
Radiation	20 (50%)	2.14 (2.18)	.50 - 10.50
Hormones	16 (40%)	36.62 (39.44)	2 - 150
Type of Surgery			
Lumpectomy	16 (40.0%)		
Mastectomy	24 (60.0%)		

Primary Stressors

The *Illness Impact Form* provided a measure of primary stressors as outlined according to Pearlin's Stress Process Model.⁶ Designed by Gallo and reported in Sexton,²⁹ this instrument measures how much the patient depends on the spouse for ADLs and how much the illness impacts the husband's life. Caregiving responsibilities are assessed with a list of ADLs (eg. dressing, eating, bathing, toileting, and walking inside house) and IADLs (eg. trips outside, organizing appointments, managing finances, taking medication, and shopping). Caregivers are asked how much the patient depends on them for each activity on a 4-point Likert scale (0 = *never*, 1 = *sometimes*, 2 = *most times*, 3 = *always*). Husbands were asked specifically about needs of the wife *because of the breast cancer or its treatment*. Reliability has been reported at α

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= .83.³⁰ In the present study, reliability was estimated at $\alpha = .81$ when completed during adjuvant treatment and $\alpha = .91$ 1-year later.

The *Illness Impact Form* also includes a separate indicator of caregiving burden, which we refer to as *caregiving impact*, and examined for descriptive purposes. The five items on this scale assessed whether or not husbands perceived illness-related changes in activities, roles and responsibilities as worries or problems in general. Again, husbands were asked specifically about needs of the wife *because of the breast cancer or its treatment*.

Secondary Role Strains

The *Psychological Adjustment to Illness Scale (PAIS)*³¹ is a self-report, 46-item measure assessing role strains and the psychological and social adjustment of a spouse to their partner's illness. It includes seven domains, of which 5 were used for the measurement of burden in the present study: vocational, domestic, and social environments as well as sexual and extended family relationships. Reliability coefficients ranged from a high of .87 for domestic environment to a low of .66 for extended family.³¹ In the present sample, reliability ranged from .44 for sexual relationships to .83 for social relationships.

Positive Aspects of Caregiving

Husbands completed the Positive Aspects of Caregiving Scale¹⁵ at Time 1 only, when their wives' were undergoing adjuvant treatment. This instrument was designed to assess positive meaning in caregiving reported by partners of HIV positive gay men and includes 6 items rated on a 4-point Likert scale (1 = *strongly disagree*, 2 = *disagree*, 3 = *agree* 4 = *strongly agree*). The items were revised for use with husbands of women with breast cancer and assessed whether caregiving 1) has helped the husband feel needed, 2) has helped the husband grow as a person, 3) is a way to show love for his partner, 4) has brought him closer to his partner, 5) has

taught him a lot about breast cancer, and 6) has involved him with other groups and organizations. Folkman and colleagues¹⁵ report good reliability for this scale ($\alpha = .72$). The calculated reliability estimate for our husbands of breast cancer patients was $\alpha = .76$.

Psychological Distress

The *Profile of Mood States – Short Form (POMS-SF)*,³² a 30-adjective instrument, assesses the intensity of the 6 mood states from the past week using a 5-point Likert scale (0 = *not at all*; 4 = *extremely*). The total mood disturbance score was as a measure of psychological distress. The validity and sensitivity of this scale has been confirmed in cancer populations.³³ Reliability in the present study at follow-up was strong, $\alpha = .92$.

Data Analysis

Our first goal, describing burden and changes in burden over time, was analyzed through a series of descriptive statistics and two-tailed paired samples *t*-tests. Descriptive statistics were used to describe husband's demographic characteristics, wife's treatment characteristics, and positive appraisals of caregiving at baseline. Descriptive statistics were also calculated for baseline and follow-up caregiver responsibilities, role strains, and psychological distress. Paired-samples *t*-tests were then computed to determine whether caregiving responsibilities, roles strains and distress differed across the two time points. In order to address our second goal, we employed a 2-step process to identify which aspects of baseline burden predicted distress 1-year later. In the first step, we analyzed the bivariate relationships between potential covariates (including husband's age, education, employment, and income and wife's cancer stage and treatment variables), primary stressors, role strains, and positive aspects of caregiving with mood disturbance. In the second step, statistically significant correlates were then entered into a hierarchical regression equation controlling for baseline distress and covariates.

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Results

Equivalence of Baseline and Follow-Up Samples

Because we were interested in changes in burden and distress from active treatment to 1-year later, all analyses were performed for the 41 husbands who returned both assessments. To ensure that husbands' demographic and wives' disease characteristics were not responsible for selective attrition, baseline and follow-up samples were compared on demographic and treatment characteristics. One-way analyses of variance (ANOVAs) and chi-square tests revealed that the sample of husbands who completed follow-up assessments did not differ from the group of men who did not complete follow-up surveys; no statistically significant differences were found in husbands' age, education, employment status, income, ethnicity, chronic health conditions, or years married ($P > .05$). There were also no differences between groups in wife's cancer stage or whether the wife was treated by mastectomy, lumpectomy, chemotherapy or radiation ($P > .05$). One-way ANOVAs revealed there was also no difference in husband's ratings of wife's health, or time undergoing chemotherapy or radiation treatments between samples surveyed at each time ($P > .05$).

Goal 1. Description of Husbands' Burden Over Time

In order to provide the most descriptive picture of caregiver burden possible, we examined individual items of the *Illness Impact Form* during treatment and at 1-year follow-up, to characterize the types of caregiving responsibilities husband's reported and how they changed over time. Below we describe burden in two broad categories, caregiving responsibilities (primary stressors) and caregiver impact. Caregiving responsibilities detail the ADLs and IADLs husbands performed, while caregiver impact assesses perceived changes and worry experienced by the husband as a result of his wife's breast cancer.

Primary Stressors

Baseline *Illness Impact Form* scores ranged from 0 to 20, with a possible range of 0 to 66 ($M = 8.45$, $SD = 4.80$). Follow-up scores ranged from 1 to 33 ($M = 6.21$, $SD = 6.38$). A 2-tailed, paired-samples *t*-test determined there was no significant decrease in overall caregiving responsibility ($P > .05$) from time of treatment 1-year follow-up; however, examination of individual items indicated that many responsibilities which husbands reported assisting with *sometimes* during baseline were rated as tasks they *never* assisted with at follow-up. In order to provide a more thorough description of husband's assistance over time, ratings of individual items of the *Illness Impact Form* at both times are described below.

Caregiving Responsibilities.

Table 3 outlines the degree to which husbands assisted with ADLs and IADLs at baseline and follow-up. In general, husbands reported assisting more with IADLs as opposed to ADLs at both times. At baseline, husbands provided the most ADL assistance with dressing and eating. Husbands reported the highest levels of IADL assistance with shopping and managing medication and finances. At follow-up the most commonly assisted IADLs included managing finances and shopping, while dressing remained the most frequently reported ADL. Two-tailed paired samples *t*-tests comparing specific forms of ADL/IADL assistance from baseline to follow-up revealed that assistance with medication ($t_{34} = 2.23$, $P = .03$) and shopping ($t_{34} = 2.38$, $P = .02$) decreased significantly with time.

Table 3. Activities of Daily Living and Instrumental Activities of Daily Living Performed by Husband.

Items	Frequencies		Items	Frequencies			
	Time 1	Time 2		Time 1	Time 2		
Dressing	Never	65.0%	81.8%	Trips outside	Never	57.5%	78.8%
	Sometimes	35.0%	15.2%		Sometimes	27.5%	9.1%
	Most times	0.0%	0.0%		Most times	12.5%	6.1%
	Always	0.0%	3.0%		Always	2.5%	6.1%
Eating	Never	70.0%	90.9%	Organizing appointments	Never	52.5%	81.8%
	Sometimes	27.5%	6.1%		Sometimes	42.5%	12.1%
	Most times	0.0%	0.0%		Most times	5.0%	6.1%
	Always	2.5%	3.0%		Always	0.0%	0.0%
Bathing	Never	82.5%	84.8%	Managing finances	Never	52.5%	72.7%
	Sometimes	15.0%	12.1%		Sometimes	25.0%	9.1%
	Most times	2.5%	0.0%		Most times	12.5%	12.1%
	Always	0.0%	3.0%		Always	10.0%	6.1%
Toileting	Never	90.0%	93.9%	Taking medicine	Never	60.0%	78.8%
	Sometimes	10.0%	3.0%		Sometimes	32.5%	15.2%
	Most times	0.0%	0.0%		Most times	2.5%	3.0%
	Always	0.0%	3.0%		Always	5.0%	3.0%
Walking inside the house	Never			Shopping	Never	32.5%	72.7%
	Sometimes	92.5%	93.9%		Sometimes	50.0%	12.1%
	Most times	7.5%	3.0%		Most times	12.5%	9.1%
	Always	0.0%	0.0%		Always	5.0%	6.1%
		0.0%	3.0%				
					Time 1	Time 2	
Have you had to make changes in your life because of your wife's BC?				yes = 67.5%	yes = 60.6%		
Have you had to take on new roles and responsibilities because of her BC?				yes = 67.5%	yes = 60.6%		
Have you had to give up activities because of her BC?				yes = 50.0%	yes = 30.3%		
Have you had significant problems due to her BC?				yes = 90.0%	yes = 90.9%		
Do you worry about your wife because of her BC?				yes = 95.0%	yes = 97.0%		

Note: Instructions were: Because of the breast cancer, how often is your partner dependent on you for the following:

Caregiving Impact.

Husbands were also asked to indicate whether or not their wives' breast cancer had impacted various aspects of their lives (see Table 3). The majority of husbands reported having been impacted in various domains, with the highest at both times being worry about the wife's breast cancer. Paired-samples *t*-tests revealed no significant differences in reports of impact over time ($P > .05$).

Secondary Role Strains

Descriptive statistics are provided to characterize role strains of these husbands at both times, while 2-tailed paired samples *t*-tests demonstrate changes in role strain over the two time periods. Total role strain, computed by adding all items from the 5 PAIS subscales, was reported at baseline ($M = 35.32$, $SD = 7.67$, range = 2 – 51 out of a possible 0 to 93) and follow-up ($M = 27.06$, $SD = 14.00$, range = 5 – 63). Total role strain decreased significantly over time ($t_{31} = 2.59$, $P = .01$), however, the range and variability of role strain was greater at follow-up.

For the individual subscales of the PAIS, scores were added and then divided by the number of items on each scale to allow comparisons among subscales, which then ranged from 0 to 3, with higher scores indicating greater role strain. See Table 4 for descriptive statistics for each subscale at both times. Two-tailed paired samples *t*-tests comparing baseline to follow-up subscale scores revealed social relations significantly improved ($t_{34} = 2.68$, $P = .01$), while the domestic environment role strain ($t_{34} = -2.63$, $P = .01$) worsened significantly at 1-year follow-up compared to baseline. There were no significant changes in vocational, sexual or family relations over time ($P > .05$).

Table 4. Time 1 and Time 2 Role Strains (PAIS) and results of paired sample t-tests

Subscales	Time 1		Time 2		<i>t(df)</i>	<i>P</i>
	<i>M</i>	<i>(SD)</i>	<i>M</i>	<i>(SD)</i>		
Vocational Environment (effects on work, school or home activities)	0.60	(0.42)	0.67	(0.47)	<i>t</i> (31) = -.84	0.41
Domestic Environment (effects on family members)	0.39	(0.26)	0.50	(0.35)	<i>t</i> (33) = -2.41	0.02
Social Environment (effects on social and leisure time activities)	0.89	(0.58)	0.61	(0.57)	<i>t</i> (33) = 2.70	0.01
Sexual Relations (effects on quality of sexual functioning)	0.71	(0.55)	0.80	(0.57)	<i>t</i> (32) = -.77	0.45
Extended Family Relations (effects on extended family members)	0.28	(0.39)	0.21	(0.41)	<i>t</i> (33) = 1.03	0.31

Abbreviations: PAIS, Psychological Adjustment to Illness Scale.

Relationships between Primary Stressors and Secondary Role Strains

Correlation analyses were performed among measures of burden. A positive association was found between the total caregiving responsibility score (primary stressor) and total role strains at baseline (Pearson $r = .40$; $P = .01$), indicating the perception of role strain increased with mounting caregiving demands. Examination of role strain subscales indicated that caregiving responsibilities interfered significantly with sexual relations (Pearson $r = .34$; $P = .04$) and the social domain (Pearson $r = .48$; $P < .01$). See Table 5 for correlation coefficients.

Table 5. Correlations Among Study Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1 Burden	♦											
2 Vocation RS	.25	♦										
3 Family RS	.18	.24	♦									
4 Social RS	.48**	.41**	.16	♦								
5 Sexual RS	.34*	.22	.10	.19	♦							
6 <u>Domestic RS</u>	.26	-.12	.40**	.18	.03	♦						
7 Age	-.02	.38*	.15	-.17	.03	-.21	♦					
8 Education	.05	-.06	.15	-.14	.05	-.12	.02	♦				
9 Employment	.07	.38*	.14	.00	-.04	-.10	.28	.03	♦			
10 Income	.06	-.17	-.26	-.11	.17	-.19	-.15	.49**	-.33*	♦		
11 Total RS	.12	.38*	.70**	-.05	.47**	.00	.31	.19	.18	-.13	♦	
12 F/U Mood	.48**	.39*	.32*	.35*	.22	.44**	.11	-.07	.17	-.03	.05	♦

Abbreviations: RS, Role Strain.

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Positive Aspects of Caregiving

Table 6 reports the descriptive statistics for the items of the *Positive Aspects of Caregiving Scale* and demonstrates that husbands, on average, appraised their caregiving as an experience which produced both intrapersonal and interpersonal growth. The total score can range from 6 to 24 and the average score in this sample was 18.95 ($SD = 2.20$). The positive aspects of caregiving score was then correlated with all baseline and follow-up measures of burden, and no significant associations were found ($P > .05$).

Goal 2. Relationship between Burden, Positive Aspects of Caregiving and Psychological Distress

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Psychological Distress – POMS-SF

Total scores on the POMS-SF can range from -20 to 120 with higher scores indicating greater distress. At baseline, POMS-SF mood disturbance scores ranged from -12 to 70 with a mean of 12.63 ($SD = 21.79$), indicating that while average reports of psychological distress were low, there was substantial variation among participants. Reports of distress were comparable at follow-up ($M = 12.28$, $SD = 19.21$, range -9 to 82), and 2-tailed paired samples t -tests revealed no differences between the two time periods ($t_{39} = .13$, $P > .05$).

Predictors of Psychological Distress from the Applied Model

The second objective of this study investigated how well burden experienced during treatment predicted mood disturbance 1-year later. Burden was conceptualized as primary stressors and secondary role strains, according to Pearlin's Stress Process Theory. We were also interested in whether positive perceptions of caregiving during adjuvant treatment, when a wife is most likely to be sick and require assistance, would also predict psychological distress 1-year later. To accomplish this goal, analyses were conducted in two steps. First, baseline caregiving responsibility, role strains, and positive aspects of caregiving, and potential covariates were correlated with follow-up distress. Caregiving responsibilities, positive aspects of caregiving and role strains in vocational, domestic, and social domains at baseline emerged as significant positive correlates of distress 1-year later. Because vocational role strain correlated significantly with age and employment, these potential confounding demographic variables were controlled in the subsequent regression analysis. Refer to Table 5 for correlation coefficients among all variables. Baseline caregiving responsibilities, positive aspects of caregiving, and domestic, vocational, and social role strains were entered into a hierarchical regression equation, controlling baseline distress, income, and age, to test the relative strength of each baseline

predictor of follow-up distress. The results indicated that baseline domestic role strain ($\beta = .35$, $P = .01$) during wife's breast cancer treatment predicted psychological distress 1-year later, even after controlling for demographic characteristics and baseline mood disturbance ($\beta = .51$, $P = .01$; $R^2 \Delta = .17$, $F\Delta(5, 28) = 2.96$, $P = .03$). The addition of caregiving responsibilities and role strains in the second step of the equation explained an additional 12% of variance, over and above the contributions of baseline distress and demographic covariates; the final model accounted for a total of 58% variance.

Discussion

As the population of breast cancer survivors continues to grow and economic hardships dictate more chronic health care be performed by informal caregivers at home, the burden placed on husbands of women with breast cancer will continue to rise. Recent research has estimated the total time associated with caregiving for women with breast cancer during the first 2 years following diagnosis as an average of 6.4 hours per day for 13.6 months, for a total time cost of over \$38,000.³⁴ We aimed to provide a more thorough description of caregiving responsibilities, role strain and benefits of caregiving reported by these husbands and also determine their relationship to psychological distress 1-year later. Most research on cancer caregiving occurs during the diagnostic, treatment or terminal phases of illness, leaving us with limited knowledge about adjustment of patients and husbands after treatment, during normal recovery.³⁵ This study provides an important glimpse into the caregiving responsibilities performed by husbands and the strain which spills into other domains of their lives, both at the time of active treatment and 1-year later.

Husbands reported assistance with a variety of ADLs and IADLs for their wives, with the most frequently reported activities including dressing, eating, shopping, managing medications

and finances. Assistance levels reported for most ADLs remained constant, but this was not surprising as reports of assistance were relatively low. We were surprised, however, by stable reports of assistance with dressing 1-year later. While we expected many husbands to assist their wives with dressing immediately following surgery, we believed this assistance would decrease significantly 1-year or more following surgery. Although we did not inquire about the specific reasons for assistance, these findings may point to cases of lymphedema or other long-term physical limitations associated with the cancer treatment.

Husbands also indicated they adopted new domestic duties that were typically performed by wives before breast cancer. A year later, husbands assisted less with medication management and shopping. However, duties that might be more stereotypically performed by men, such as managing finances, remained a frequent and stable form of assistance.

One of our most important findings was an unexpected one. Because rates of caregiving responsibility were low at baseline, dramatic decreases were not expected; however, reports of impact such as breast cancer worry, added responsibilities, and activities given up since breast cancer diagnosis were strongly endorsed by participants at baseline and expected to decrease with time. Surprisingly, these forms of burden remained unchanged. This finding of persistent impact despite reduction of caregiving responsibilities highlights the complexity of the caregiving role and advocates for a multidimensional assessment of the construct. Hornea et al³⁶ distinguished between several dimensions of caregiving, including objective and subjective burden. Objective burden refers to events and activities associated with the caregiving role, such as ADLs and IADLs, while subjective burden describes the subjective experience of a caregiver. Drawing these distinctions between types of burden proves important, as some studies indicate a stronger association between psychological distress and subjective burden, compared to

objective burden.²⁶ While our study did not thoroughly assess subjective burden, our impact items were endorsed highly and remained stable over time, whereas, assistance with ADLs was low and decreased with time. These reports demonstrate that the long-lasting impact of breast cancer related concerns for husbands do not necessarily end with treatment completion, and what remains may be more related to subjective burden than objective burden. These subjective forms of burden are less apparent and more likely to be concealed by husbands in an effort to reduce the patient's concern, which places an even greater demand on health care professionals to assess and monitor the more subjective experiences related to caregiving. Clinicians and researchers should always examine both objective and subjective forms of burden in order to develop a thorough understanding of the experience of caregivers.

Our findings are consistent with Hoskins et al's²⁷ longitudinal findings, which reported significant associations between PAIS role strains and psychological distress across multiple assessments. We extend their findings by investigating whether early burden and role strains could predict psychological distress 1-year later. We found that baseline caregiver responsibilities and role strains in the domestic, vocational and social domains correlated significantly with later distress and explained variation in psychological adjustment of husbands above and beyond their baseline distress and demographic characteristics. Furthermore, domestic role strain emerged as a particularly noteworthy variable in this study. While initial reports of role strains were low, domestic role strain worsened over time, suggesting that the impact of breast cancer may accumulate gradually for husbands and their wives at home. Domestic role strain was also the strongest predictor of psychological distress over time.

Domestic role strain assesses the husband's perception of the quality of his relationship with the patient and other family members, in addition to measuring how much the patient's

illness has impacted domestic duties, and how other family members have shifted duties to help the husband. There may be many explanations for why husbands experience more role strain with time and why domestic role strain exerts such a strong influence on husbands' psychological health. One possibility is that much of the outside support a couple receives is likely to be directed toward assisting the patient more than the husband, so while her domestic duties are decreasing, his are increasing. Northouse³⁷ reported that husbands perceive less social support than breast cancer patients, which may lead to domestic role strain for husbands. Another possible explanation may be that while outside support is quickly mobilized and strong at the time of diagnosis and during treatment, much of that support may be withdrawn once treatment ends. A third explanation for higher domestic role strain at 1-year could be that domestic and family conflicts are avoided topics during the initial crisis stage of breast cancer diagnosis and treatment. When treatment concludes and normal family life resumes, these avoided topics may resurface and create conflict. Each of these potential explanations warrants further study.

In addition to assessing primary stressors and secondary role strains, this study also investigated positive aspects of caregiving, an often neglected area of focus in many caregiving studies. Husbands in this study endorsed several benefits associated with caregiving, including feeling needed, experiencing growth, and being able to show love for their partner. While recent studies have found that caregiver esteem is associated with decreased stress and increased quality of life among husbands caring for cancer survivors,^{17,18} we found that positive aspects of caregiving was associated with increased distress. Positive aspects of caregiving did not emerge as a significant, independent predictor in the test of our model, however. The disparities between our findings and Kim and colleagues^{17, 18} may be a product of methodological differences

including design (longitudinal versus cross-sectional), time of assessment (active treatment versus survivorship), measurement constructs (positive aspects of caregiving versus caregiving esteem), and types of cancer (breast only versus mixed). The finding that distress was higher for caregivers who perceived caregiving more positively warrants further investigation to determine what this means. One possible explanation could be that those who found the most meaning from caregiving, who enjoyed feeling needed, or who appreciated an increasing bond with their spouse during treatment could have been let down following treatment, as a normal routine resumed and they found they were not needed or could not enjoy as much time with their spouse. Alternatively, those most distressed may be actively pursuing more meaning in an effort to control their distress, unsuccessfully in the long run.

Other researchers have also reported no relationship between perceived benefits of caregiving and psychological distress of caregivers.³⁸ These conflicting findings may lend support to the view that positive aspects of caregiving are more strongly related to positive affect variables, such as happiness, than negative affect variables, such as psychological distress.³⁹ In one study testing this assumption among caregivers of Alzheimer's disease patients, burden was associated with distress, while caregiver satisfaction was associated with positive affect.⁴⁰ We did not measure positive affect, and are thus unable to test this hypothesis in our own study. Future research should try to elucidate these relationships further because positive aspects of caregiving have the potential to serve a protective function among cancer caregivers.

Several treatment implications stem from the present study. Clearly, breast cancer related concerns persist for an extended period of time. These findings are a strong reminder to health care providers that husbands are not automatically relieved of burden and worry when treatment ends, and domestic life does not automatically proceed without strain. When provided the

opportunity to follow-up with breast cancer patients and their husbands, health care providers must remain vigilant to persisting difficulties with adjustment, especially impact and balance of domestic duties with other roles.

The generalizability of these findings must be placed in the context of the methodological limitations of this study, the most significant being the small sample size and convenience sampling. Our sample was homogeneous, composed primarily of white, college educated, middle-aged men. Because breast cancer is more prevalent among older women, our sample is representative of the age of the general population of breast cancer husbands. However, concern regarding the limited ability to generalize the findings to other ethnic groups and husbands from other socioeconomic groups is valid, and too often a research limitation in this area.

Additionally, our sample consisted of husbands who accompanied their wives to treatment. Many husbands do not accompany their wives to clinic due to personal preference or economic limitations which prohibit them from missing work. Therefore, the husbands in our study may be comprised of an unrepresentative group of men who provide high levels of social support and have high economic standing, which means our findings may underestimate the burden and psychological distress of less advantaged populations. Ideally, recruiting from among all husbands of current chemotherapy patients may have resulted in a more representative sample. However, our own experience suggests problems with such methodology as well, namely poor accrual, which may explain why our procedures are commonly used.^{13,41,42} Other authors have noted this limitation when recruiting husbands of breast cancer patients,⁴² but also note that even if samples were recruited through random selection, bias would still exist as a result of self-selection to this type of study.

Despite these limitations, the present study adds significantly to our understanding of burden, positive appraisals of caregiving, and psychological distress among husbands of women with breast cancer. Our descriptive analysis of caregiving responsibilities identified the ADLs and IADLs most frequently reported by husbands and revealed that while these caregiving responsibilities decrease with time, impact remains high. We also describe benefits husbands report associated with caregiving. Additionally, our longitudinal investigation reveals the long-lasting impact of role-strain on psychological adjustment. Health care providers can provide a great assistance to husbands by intervening early when role strains are identified and continuing to monitor such strain and burden throughout survivorship. Importantly, when health care providers assist and support husbands in balancing their competing demands, they may also improve the quality of life of their patients with breast cancer.

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