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# Partner Interfering Behaviors Affecting Cancer Quality of Life

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# Partner interfering behaviors affecting cancer quality of life

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## Abstract

**Objective:** Because partners are an important and unpaid resource in cancer care, understanding how destructive, controlling or interfering partner behaviors influence women's cancer care may be particularly relevant for health care providers seeking to provide cancer care and enhance recovery. Using a new measure of partner interfering behaviors in cancer care (PIB-C), we investigated whether women with a recent cancer diagnosis who additionally endorsed any PIB-C would report (a) more symptoms of depression and stress, and (b) lower Functional Assessment of Cancer Therapy (FACT-G) and lower Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-SP) scale scores indicating poorer quality of life (QOL).

**Methods:** Women aged 18–79 included in cancer registries as having an incident, primary, biopsy-confirmed cancer in the past 12 months were eligible for this study. Consenting women completed a phone interview 9–12 months following cancer diagnosis between 2009 and 2015. Interviews provided data to measure outcomes (perceived stress and depressive symptoms, FACIT-SP and FACT-G scores), partner supportive and interfering behaviors, and other potentially confounding factors.

**Results:** Of the 2376 women in a relationship at cancer diagnosis, 14.7% endorsed one or more of 14 PIB-C items. Women endorsing any PIB-C item reported more symptoms of depression and stress and lower FACT-G and FACIT-SP scores than partnered women reporting no PIB-C even when controlling for partner supportive behaviors and lifetime intimate partner violence. Increasing PIB-C scores were also correlated, in a dose–response pattern, with these same outcomes.

**Conclusions:** Partner interfering behaviors during cancer care impact patients' QOL across multiple domains.

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## Introduction

Intimate partner violence (IPV) has been associated with increased symptoms of depression, anxiety and poorer functioning for women undergoing cancer therapy following diagnosis [1]. This relationship held for women experiencing IPV in a current or past relationship and for those experiencing sexual, physical or psychological IPV relative to those never experiencing IPV. That study found that current psychological IPV was most strongly associated with poorer quality of life (QOL) scores [1]. A recent qualitative study of 21 partnered women experiencing both violence and cancer reported that partners' abusive behaviors increased during treatment and, these physical, sexual or psychologically abusive behaviors contributed to delays in [cancer] treatment [2]. Four themes emerged from this qualitative research regarding partners' actions toward women during their cancer care: (a) self-centered focus, (b) continued expectations of cancer patient despite receiving cancer treatment, (c) critical, demanding or 'mean' behaviors and (d) withdrawal of affection. These data suggest that abusive behaviors by a current partner may specifically impact patients' ability to psychologically recover and adjust following both diagnosis of and treatment for cancer.

Mechanistically, how might abusive or specifically interfering partner behaviors influence treatment or recovery among those diagnosed with cancer? Convincing evidence now links chronic stress, depression and cancer progression [3–5]. Stressed individuals are more likely to smoke, excessively consume alcohol and become obese; all three stress responses are associated with chronic inflammation which may influence cancer risk or progression [3]. Thai researchers have recently observed that partner violence had direct effects on lower social support, increased stress, depressive symptoms and cervical cancer ( $p < .01$ ) among 532 women and stress alone mediated the effect of partner violence on cancer. [6] While stress may not cause cancer, stress does influence this disease's process [3,4]. Partner violence has consistently been associated with increased self-perceived stress including symptoms of post-traumatic stress disorder (PTSD) among women with [1] and without cancer [7,8]. Both the well-documented association between partner violence and PTSD as well as meta-analyses documenting stress and depression [9] as important factors in cancer progression provide additional impetus to determine the impact of negative partner behaviors during cancer care and recovery. Partner

interfering behaviors may directly affect cancer care by delaying or sabotaging treatment or recovery plans and impact prognosis through increasing patient stress.

The role of patients' social support has been explored as a potential buffer for the inevitable stress associated with a cancer diagnosis and its treatment. Social support has been found to improve post-treatment physical functioning for cancer patients when measured using validated quality of life measures [10–12]. Intimate partners appear to be the more significant member of patients' social networks in terms of providing needed support [13]. While intimate partners may be crucial members of women's social networks [11,12], partner interactions may be both supportive and unsupportive or directly *aversive* [14,15], yet with the exception of the work by Manne & Schnoll, few have measured unsupportive or interfering partner behaviors that may impact cancer care.

Manne and Schnoll developed the Partner Responses to Cancer Inventory (PRCI) as a measure of both positive and negative spouse responses to patients with cancer. This 45-item measure had four loading factors; two measured unsupportive partner behaviors characterized as criticism or withdrawal and distancing or self-restraint [16]. Investigators have further used the partner unsupportive behaviors measure to determine adaptation in early stage breast cancer patients ( $n=330$ ) and their spouses. Unsupportive partner behaviors were found to positively correlate with patients' increased cancer distress and were mediated by mental and behavioral disengagement [17].

The current study builds on prior research which noted that partner abusive or violent behaviors [1] as well as unsupportive behaviors [17] influence patients' perceptions of their own distress and poorer quality of life. We have chosen to examine specific interfering or controlling behaviors by a partner which may influence a cancer patient's perceived quality of life or indirectly impact receipt of cancer care. Our new measures of partner interfering behaviors in cancer care coupled with a concurrent measure of partner supportive behaviors (PIB-C and PSB-C) were found to have strong psychometric properties [18]. Subscales from factor analysis of the PIB-C revealed themes consistent with qualitative reports from abused women cancer patients: partner focused on self, not patient; partner undermining the seriousness of her cancer, and partner's interference in her cancer care. This scale appears to provide a reliable measure of partner interfering behaviors which may impact cancer care and psychological adaptation following cancer diagnosis and treatment.

The aim of this research was to determine whether, and if so how, partner interfering behaviors in cancer care (PIB-C) were associated with distress and quality of life measures among women recently diagnosed with cancer. We hypothesized that higher PIB-C scores would be associated with (a) more symptoms of depression or stress, and (b) lower cancer-related quality of life as measured by

FACT-G scores. Because partner support has been associated with superior cancer outcomes [19], analyses were adjusted for partner support, lifetime IPV and other relevant demographic and stage at cancer diagnosis and number of comorbid physical conditions at cancer diagnosis. Both supportive and aversive behaviors may occur within the same member and may be *more* harmful than aversive behaviors alone [20].

## Method

### Participant recruitment

Women included in the Kentucky Cancer Registry (KCR) or the North Carolina Central Cancer Registry (NCCR) Rapid Case Ascertainment program as an incident and primary case of cancer were eligible for this study. Recruitment from both state registries was needed to yield the target study size; case recruitment began with KCR in November 2009 through December 2013 and in October 2013 case recruitment began at NCCR with recruitment through January 2015. Only women ages 18–79 at cancer diagnosis who were additionally diagnosed and included in the state registry in the prior 12 months were eligible. Those with a recurrent cancer, a squamous cell skin carcinoma, non-residents of either Kentucky or North Carolina and those unable or willing to provide consent were not eligible for study participation.

The registries allowed slightly different approaches to subject contact. The primary difference was that staff at the Kentucky Registry directly contacted eligible women by mail (with follow up by phone if they did not respond by mail). This direct contact by KCR staff meets with active consent requirements of patients for researchers contact. Contact information for consenting patients was then forwarded to researchers for further explanation of the protocol, opportunity to address questions and participate, if interested. In contrast with KCR, North Carolina Registry staff allowed researchers to directly contact eligible participants. In both registries, physicians were informed that their patients were eligible for this study and were asked if there were any reason why a patient should not be approached (i.e. dementia, death or being too ill to participate). Patients, whose physicians indicated a reason for not contacting, were not contacted.

A letter inviting participation and explaining the study goals was sent to eligible women. This letter additionally provided researcher contact information (name and phone number) on an enclosed card stamped and addressed to research staff if women wished to be interviewed or learn more about this study. Women could also indicate that they did not wish further contact on the same card. Trained research staff at the University of Kentucky Survey Research Center (SRC) called eligible women to

explain the study and answer any questions. The interviewer presented a formal introduction about the study and obtained explicit verbal consent before beginning the interview. Phone interviews were conducted within one year of cancer diagnosis. This study was approved by the Institutional Review Board at the University of Kentucky, protocol number 09-0685-F1V and an NIH Certificate of Confidentiality was granted (MD-09-007). Data was collected by telephone interview with an average duration of 30 min; those completing the interview were offered US \$10.00 incentive for their participation.

## Measures

### Abbreviated partner interfering behaviors in cancer care (PIB-C)

For the current analyses, the 14 PIB-C items (see Table 1) were summed to create a continuous score (overall and by three distinct subscales), and endorsement of items was used to create an ordinal (2 or more PIB-C items, 1 item, or 0 PIB-C item endorsed) and dichotomous (any item endorsed) variable. The 14-item PIB-C had good internal consistency (Cronbach's  $\alpha=0.913$  using Likert response options and  $\alpha=0.840$  for yes no responses). Similarly, when the 12-item PSB-C was reduced to 5 items for these analyses this reduced measure continued to have good internal consistency (Cronbach's  $\alpha=0.838$ ).

Our abbreviated PIB-C, based on the original 20-item measure of PIB-C, was found to have strong internal consistency (Cronbach's  $\alpha=0.936$ ) [18]. Subscales from factor analyses revealed themes consistent with qualitative report from abused women cancer patients [2]: partner focused on self, not patient; partner undermining the seriousness of her cancer, and partner's interference in her cancer care. The six excluded items were: Spouse or partner (a) started more arguments than usual, (b) would not do household chores to help with your recovery, (c) made it difficult for you to get the physical care you needed for recovery, (d) made you feel as though it was your fault you got cancer, (e) reminded you how much your cancer treatment and recovery cost the family financially and (f) let you know how much their life was disrupted by your cancer treatment/recovery. These items were excluded because these were highly correlated (Pearson correlation coefficient  $>0.50$ ) with the first 14 PIB-C items and each excluded item loaded on the three existing subscales. [Researchers may wish to retain excluded item b because 8% of the pilot sample reported this partner behavior and this item most strongly associated with the subscale, partner focusing on self].

Demographic attributes and other potentially confounding factors were obtained directly from women or through data available from cancer registries (see Table 2 legend for response options and measure sources). Cancer registry staff provided data to describe stage at diagnosis; stage was simplify

**Table 1.** Partner interfering behaviors in cancer care (PIB-C): psychometric evaluation

PIB-C Items (abbreviated 14-item measure)*	Agree% (n)	Factor and loadings		
		Partner focused on self	Partner cautious	Partner interfered
1. Partner interfered with your getting a doctor's appointment	0.7 (16)	0.188	0.202	0.643
2. Partner implied you did not deserve medical treatment	0.6 (14)	0.205	0.297	0.342
3. Partner made you feel your medical needs were a burden on the family	3.3 (78)	0.724	0.166	0.144
4. Partner made you feel guilty for needing extra help or care during cancer treatment or recovery	5.0 (118)	0.776	0.176	0.151
5. Partner refused to handle existing or new responsibilities as a result of your cancer treatment	5.0 (120)	0.650	-0.042	0.217
6. Partner created an embarrassing scene at your doctor's office	1.1 (26)	0.125	0.356	0.649
7. Partner criticized your doctor or their medical care	2.5 (59)	0.209	0.717	0.039
8. Partner suggested that your doctor was not capable of providing medical treatment for you	2.0 (48)	0.142	0.757	0.209
9. Partner made you think you did not have a serious medical condition	3.8 (90)	0.718	0.251	0.090
10. Partner 'forgot' to pick up your prescriptions.	1.7 (40)	0.186	-0.186	0.676
11. Partner said no treatment until you got a second opinion.	3.1 (73)	0.098	0.653	0.045
12. Partner complained that you were not focusing on him or your family	3.9 (94)	0.696	0.112	0.185
13. Partner discouraged your talking with others about your cancers.	1.5 (36)	0.412	0.326	0.281
14. Partner did not allow to relax or recover following cancer treatment	3.4 (81)	0.679	0.186	0.120
<b>Psychometrics of scales</b>				
# Items in factor (14 in full scale)	14	7 (Items 3-5, 9, 12-14)	3 (Items 7, 8, 11)	4 (Items 1, 2, 6, 10)
N (%) Endorsing any time in scale (or subscale)	349 (14.7)	262 (11.0)	123 (5.2)	72 (3.0)
Mean score or subscale; (range)	0.37 (0-14)	0.26 (0-7)	0.08 (0-3)	0.04 (0-4)
Cronbach's Alpha by factor	0.840	0.835	0.651	0.560
Variance explained by factor		66.3%	19.5%	14.4%

\*Agree (=1) vs disagree (=0) response options

**Table 2.** Demographic attributes and lifetime violence experience by partner interfering behaviors in cancer care (PIB-C)

All women with a recently diagnosed cancer and in a relationship at diagnosis: n = 2385	Any PIB-C (n = 349)	No PIB-C (n = 2036)	test <sup>a</sup> p value
Age at diagnosis *(Mean ± SE)	53.12 (0.58)	55.94 (0.24)	t -4.53 <.0001
Number of children** (Mean ± SE)	2.09 (0.07)	2.10 (0.03)	t -0.19 NS
PSB-C score **	3.53 (.06)	4.52 (0.03)	t -15.12 <.0001
Private Insurance (vs other including uninsured)**	60.5%	64.3%	$\chi^2_{df}$ 1.91 NS
Monthly income**			30.25 <sub>5</sub> <.0001
<\$1000	13.6%	6.1%	
\$1000-\$1999	20.7%	17.7%	
\$2000-\$2999	15.6%	17.3%	
\$3000-\$3999	11.1%	14.3%	
\$4000-\$4999	13.6%	16.5%	
\$5000+	25.3%	28.2%	
Education level**			19.53 <sub>4</sub> <.0006
< High school (HS) degree	11.4%	6.4%	
HS or graduation equivalency degree	22.7%	31.3%	
Some college or associates degree	18.2%	17.4%	
Bachelor degree	13.4%	14.5%	
Beyond a bachelor's degree	34.4%	30.4%	
Currently married**	75.9%	87.5%	32.78 <sub>1</sub> <.0001
Current smoker**	17.5%	10.1%	16.51 <sub>1</sub> <.0001
Appalachian county of residence (%) relative to non-Appalachian*	28.1%	30.6%	0.85 <sub>1</sub> NS
North Carolina resident (vs Kentucky)	25.8%	23.9%	0.61 <sub>1</sub> NS
Diagnosed with breast cancer *	58.7%	61.1%	0.68 <sub>1</sub> NS
Stage at cancer diagnosis			12.49 <sub>4</sub> .01
0	2.6%	2.2%	
1	52.7%	62.6%	
2	12.3%	9.9%	
3	22.6%	17.4%	
4	9.7%	7.9%	
Number of comorbid conditions			16.38 <sub>5</sub> .006
0	25.7%	20.8%	
1	29.5%	34.9%	
2	22.3%	26.0%	
3	11.6%	11.9%	
4	6.9%	3.9%	
5 or more	4.1%	2.6%	
Lifetime IPV**	69.6%	29.6%	208.31 <sub>1</sub> <.0001
Sexual**	19.8%	7.8%	50.00 <sub>1</sub> <.0001
Physical **	39.3%	19.5%	66.93 <sub>1</sub> <.0001
Psychological**	67.6%	26.8%	225.18 <sub>1</sub> <.0001
Current IPV**	41.3%	5.4%	402.78 <sub>1</sub> <.0001
Sexual**	5.0%	0.8%	29.33 <sub>1</sub> <.0001
Physical **	9.7%	1.8% <sup>b</sup>	48.01 <sub>1</sub> <.0001
Psychological**	40.4%	4.8%	416.12 <sub>1</sub> <.0001

\*Cancer Registry's data.

\*\*Women's interview data.

<sup>1</sup>PSB-C (5 items; 1) partner gone with woman to doctor visits and appointments; 2) partner spend time with woman when she was in the hospital; 3) Partner was involved in woman's medical care; 4) Partner did something unexpected to make the woman 'happy'; 5) Partner willingly made small sacrifices to assist in woman's care or recovery.<sup>2</sup>Current partner (at diagnosis) was perpetrator.

across all cancers stages 0–4 to range from in-situ (coded as stage=0; and primarily breast) to evidence of metastases (stage=4). Data to characterize the number and type of comorbid conditions were obtained during phone interviews; the conditions queried included the following list of self-report of physician-diagnosed physical conditions: high blood pressure, heart disease, diabetes, irritable bowel syndrome, fibromyalgia, stroke or liver disease. The number of comorbid conditions was summed to create an ordinal measure.

Information to describe physical, sexual and psychological IPV was obtained from participants. Detailed measures were described elsewhere [1]. An abbreviated form of the Conflict Tactic Scale [21] was used to measure physical and sexual IPV. The following three items measured physical IPV: [has any partner] (a) shoved, grabbed, pushed, pinched, slapped, shook you or thrown non-dangerous objects at you that was NOT done in a playful manner? (b) hit you with a fist, kicked you, punched you,

bitten you, slapped you hard, thrown you, dragged you, hit you with an object or used any other type of physical aggression like these which could cause injuries and (c) pointed a weapon at you, beat you up, choked you or attempted to strangle you, burned you, used a weapon or other dangerous object on you or used any other physical aggression like these to hurt you? A modified version of the Measure of Psychologically Abusive Behaviors (MPAB) [22] in combination with the Women's Experience with Battering Scale (WEB) [23,24] was used to measure psychological abuse. The following two grouped items from the MPAB were used: has any partner (a) embarrassed you in public on purpose, or yelled or screamed, put you down, called you mean names or treated you as an inferior, (b) used threatening behaviors toward you or harmed or destroyed your personal things of value, harmed pets or threatened to harm family/children or friend to scare you. The following three items from the Women's Experience with Battering Scale (WEB) [23,24] were used to measure psychological abuse: (a) Your spouse/partner makes you feel like you have no control over your life, no power, no protection, (b) you hide the truth about your relationship from others because you are afraid not to and (c) your partner can scare you without laying a hand on you. An indicator variable of lifetime physical, sexual or psychological IPV (ever versus never) was created.

### Measures of distress and QOL outcomes

Women were recruited into the study up to 12 months after their cancer diagnosis; thus, women were asked to recall symptoms since their cancer diagnosis at their phone interview. The following items from the Brief Symptom Inventory [25] were used to measure depressive symptoms: since your cancer diagnosis, has there been a period of at least two straight weeks in which most of the time you (a) were down, depressed or hopeless, (b) experienced very little interest or pleasure in doing things, (c) difficulty sleeping and eating (that was not a result of any medical treatment)?, felt no energy, difficulty concentrating, feelings of worthlessness and (d) were you told by a medical doctor or mental health professional that you were depressed. Response options were yes (=1) or no (=0); the items were summed to yield a symptom score ranging from 0 to 5. [Cronbach's  $\alpha=0.800$ ; 36% no depressive symptoms;  $M=1.76$ ;  $Std\ Dev=1.74$ ;  $Skewness=0.54$ ].

Three of the 4-item Perceived Stress Scale [26,27] were used to measure patients' perceptions of stress during the 2–3 months following diagnosis and in the month prior to the phone interview. The excluded PSS item, how often have you felt 'that things were going your way?', was not asked because it was not specific to challenges and response to cancer care. The three included items were summed and scores ranged from 0 to 12. For stress recalled for the last month before interview, the

psychometric properties were: Cronbach's  $\alpha=0.645$ ; 20.7% no stress;  $M=3.20$ ;  $Std\ Dev=2.62$ ;  $Skewness=0.59$ . The psychometric properties for PSS for this latter time frame were: Cronbach's  $\alpha=0.663$ ; 12.5% no stress;  $M=4.68$ ;  $Std\ Dev=3.02$ ;  $Skewness=0.19$ .

The 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-SP) [28] was used to measure the spiritual well-being in people with cancer. Women were asked to indicate 'how well each of 12 statements described how you've been feeling over the past seven days': Response options were not at all (=0), a little bit, somewhat and a lot (=3). Summed scores ranged from 4 to 36;  $M=31.67$ ,  $Std\ Dev=5.00$ , and skewness of  $-1.58$ . Factor analyses indicated one factor: Cronbach's  $\alpha=0.820$ .

The 27-item Functional Assessment of Cancer Therapy—General cancer questionnaire [29] (FACT—G) was used to measure physical functioning, social/family functioning, emotional functioning and work/life functional status. We used the FACT-G because women with a range of cancers were included in this study and the items covered were generalizable across all cancer sites. The same response options used with the FACIT-Sp were used for FACT-G. Total FACT-G scores ranged from 10 to 81 ( $M=65.60$ ;  $Std\ Dev=12.57$ ;  $Skewness=-1.19$ , The 27 items scale has good internal consistency (Cronbach's  $\alpha=0.908$ ). FACT-G was designed and used to measure four subscales of physical wellbeing items (Cronbach's  $\alpha=0.819$ , Range 0–21,  $M=15.28$ ;  $SD=4.86$ ,  $Skewness=-0.866$ ), social/family well-being (Cronbach's  $\alpha=0.756$ , Range 2–21,  $M=18.69$ ,  $SD=3.18$ ,  $Skewness=-2.08$ ), emotional well-being (Cronbach's  $\alpha=0.752$ , Range 0–18,  $M=13.97$ ;  $SD=3.60$ ,  $Skewness=-0.91$ ) and functional well-being (Cronbach's  $\alpha=0.805$ , Range 0–21,  $M=17.65$ ,  $SD=3.93$ ,  $Skewness=-1.57$ ).

### Statistical analysis

Internal consistency for the abbreviated measures was calculated using Cronbach's  $\alpha$ . Factor analysis with varimax rotation was used to determine thematic PIB-C subscales. Eigenvalues and scree plots determined the optimal number of factors and the associated variance explained (Table 1).

Correlates of PIB-C: Demographic attributes, PSB-C and IPV potentially associated with PIB-C (any item versus no item endorsed) were assessed using either *t*-tests for continuous variables or chi-square tests for categorical variables (Table 2). These bivariate relationships were used to help identify potential covariates to be included in multivariable analyses (Tables 3 and 4).

Correlates of distress and QOL outcomes: These same demographic factors, lifetime IPV and PSB-C scale scores were investigated as correlates (as independent variables) of the distress and QOL outcomes (continuous dependent variables) using analyses of variance.

**Table 3.** Proportion of cancer patients experiencing partner interfering behaviors in cancer care (PIB-C) and symptoms of stress, depression, FACIT-spirituality (Sp) and FACT-general scores and subscales (MANCOVA)

	Categorical PIB-C mean score (std error)* P value comparison			
	No PIB-C N = 2036	ANY PIB-C N = 349	Higher PIB-C N = 176	Lower PIB-C N = 176
<b>Outcomes (N = 2385)</b>				
Distress outcomes				
Perceived Stress Scale: symptoms <sup>1</sup>				
- 2–3 months after cancer diagnosis	4.57 (0.11)	5.54 (0.18) <sup>a</sup>	5.71 (0.25) <sup>b</sup>	5.38 (0.23) <sup>c</sup>
- In month before study interview	3.28 (0.09)	4.38 (0.15) <sup>a</sup>	4.64 (0.21) <sup>b</sup>	4.14 (0.20) <sup>c</sup>
Depressive symptoms since cancer diagnosis <sup>2</sup>	1.76 (0.06)	2.44 (0.10) <sup>a</sup>	2.62 (0.13) <sup>bd</sup>	2.28 (0.13) <sup>c</sup>
QOL outcomes				
FACIT-SP Scale <sup>3</sup>				
FACT-G Scale <sup>4</sup>	30.99 (0.18)	28.72 (0.29) <sup>a</sup>	28.16 (0.41) <sup>bd</sup>	29.23 (0.38) <sup>c</sup>
Subscales <sup>5</sup> Physical	62.75 (0.41)	56.19 (0.66) <sup>a</sup>	54.40 (0.90) <sup>bd</sup>	57.80 (0.86) <sup>c</sup>
Subscales <sup>5</sup> Functional Status	13.26 (0.16)	11.84 (0.26) <sup>a</sup>	11.26 (0.36) <sup>bd</sup>	12.36 (0.34) <sup>c</sup>
Subscales <sup>5</sup> Emotional	17.12 (0.14)	15.60 (0.22) <sup>a</sup>	15.49 (0.30) <sup>b</sup>	15.70 (0.29) <sup>c</sup>
Subscales <sup>5</sup> Social	13.79 (0.13)	12.31 (0.21) <sup>a</sup>	12.00 (0.28) <sup>b</sup>	12.58 (0.27) <sup>c</sup>
18.58 (0.10)	16.45 (0.17) <sup>a</sup>	15.66 (0.23) <sup>bd</sup>	17.16 (0.22) <sup>c</sup>	
<b>Additionally adjusting for treatment received**</b>				
<b>Outcomes (N = 1810)</b>				
Distress outcomes				
Perceived Stress Scale: symptoms <sup>1</sup>				
- 2–3 months after cancer diagnosis	4.82 (0.11)	5.64 (0.20) <sup>a</sup>	5.81 (0.28) <sup>b</sup>	5.49 (0.26) <sup>c</sup>
- In month before study interview	3.35 (0.09)	4.34 (0.17) <sup>a</sup>	4.65 (0.24) <sup>b</sup>	4.07 (0.22) <sup>c</sup>
Depressive symptoms since cancer diagnosis <sup>2</sup>	1.91 (0.06)	2.65 (0.11) <sup>a</sup>	2.86 (0.16) <sup>b</sup>	2.47 (0.15) <sup>c</sup>
QOL outcomes				
FACIT-SP Scale <sup>3</sup>				
FACT-G Scale <sup>4</sup>	31.22 (0.18)	29.02 (0.33) <sup>a</sup>	28.36 (0.45) <sup>bd</sup>	29.62 (0.43) <sup>c</sup>
Subscales <sup>5</sup> Physical	64.67 (0.41)	58.11 (0.74) <sup>a</sup>	55.66 (1.03) <sup>bd</sup>	60.30 (0.98) <sup>c</sup>
Subscales <sup>5</sup> Functional Status	14.84 (0.16)	13.33 (0.30) <sup>a</sup>	12.65 (0.41) <sup>bd</sup>	13.94 (0.39) <sup>c</sup>
Subscales <sup>5</sup> Emotional	17.44 (0.13)	15.83 (0.24) <sup>a</sup>	15.56 (0.34) <sup>b</sup>	16.08 (0.32) <sup>c</sup>
Subscales <sup>5</sup> Social	13.63 (0.13)	12.34 (0.23) <sup>a</sup>	11.89 (0.32) <sup>bd</sup>	12.73 (0.31) <sup>c</sup>
18.76 (0.11)	16.61 (0.19) <sup>a</sup>	15.55 (0.27) <sup>bd</sup>	17.56 (0.25) <sup>c</sup>	

\*Adjusting for age at diagnosis, monthly family income, current smoking status, state of residence, cancer site (breast versus other cancer site), lifetime IPV, PSB score, stage and number of comorbid conditions.

\*\*Additionally adjusting for treatment received (chemotherapy (yes v no), radiation (yes v no) and other non-surgical treatment (yes v no); 96% received surgery). Treatment data only available from Kentucky Cancer Registry.

<sup>a</sup>Comparison of Any versus No PIB-C significant at  $p < .001$ .

<sup>b</sup>Comparison of Higher versus No PIB-C significant at  $p < .001$ .

<sup>c</sup>Comparison of Lower versus No PIB-C significant at  $p < .001$ .

<sup>d</sup>Comparison of Higher versus Lower PIB-C significant at  $p < .05$ .

<sup>1</sup> = Perceived Stress Scale [26,27]: 3 items measured patients' perceptions of their stress during the 2–3 months following cancer diagnosis and 3 items in the month prior to the phone interview.

<sup>2</sup> = Depression symptoms: 5 items from the Brief Symptom Inventory [25].

<sup>3</sup> = FACIT-SP Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale. First 12 items. Response options range from not at all (=0) to very much (=4). Recall frame was past 7 days.

<sup>4</sup> = Functional Assessment of Cancer Therapy – General questionnaire.

<sup>5</sup> = FACT-G Subscales measured physical functioning (7 items), social/family functioning (7 items), emotional functioning (6 items) and functional status (7 items).

Decision making regarding model covariates: Variables associated with both PIB-C and distress or QOL outcomes were operationally defined as confounders and included in subsequent multiple variable modeling. Factors associated with both PIB-C and either distress or QOL outcomes were included in final models as confounders. Because differences in cancer treatment received may explain associations between PIB-C and distress or QOL outcomes additional sensitivity analyses were conducted such that cancer treatment was included in final models. Only cases from the Kentucky Cancer Registry were included in this subanalysis because cancer treatment data was available for only these cases ( $n = 1810$ ).

PIB-C and outcomes: The two specific sets of distress (perceived stress measured for two time periods and depressive symptoms (3 items)) and QOL outcomes (FACIT-Sp and total FACT-G and by four subscales) were correlated with PIB-C as the primary independent variable. Because these two sets of outcomes were correlated within sets and negatively correlated with each other, the associations with PIB-C were conducted using Multivariate Analysis of Co-Variance (MANCOVA) where covariates were defined as variables associated with PIB-C and the distress or QOL outcomes. Two sets of MANCOVA analyses were conducted with the distress

**Table 4.** Partner interfering behaviors in cancer care (PIB-C) total score and subscale and symptoms of stress, depression, FACIT-SP and FACT-G total scores and subscales (MANCOVA)

Outcomes (N = 2385)	PIB-C continuous score and three subscales: $\beta$ estimate (SE)* P value			
	PIB-C total (14 items)	Partner focused on self (7 items)	Partner cautious (3 items)	Partner interfered (4 items)
<b>Distress outcomes</b>				
Perceived Stress Scale: symptoms <sup>1</sup>				
- 2–3 months after cancer diagnosis	0.27 (0.05) <.0001	0.38 (0.07) <.0001	0.51 (0.17) .003	0.47 (0.24) .05
- In month before study interview	0.29 (0.04) <.0001	0.36 (0.06) <.0001	0.78 (0.14) <.0001	0.75 (0.20) .0002
Depressive symptoms since cancer diagnosis <sup>2</sup>	0.18 (0.03) <.0001	0.25 (0.04) <.0001	0.38 (0.09) <.0001	0.38 (0.13) .004
<b>QOL outcomes</b>				
FACIT-SP Scale <sup>3</sup>				
FACT-G Scale <sup>4</sup>	-0.56 (0.08) <.0001	-0.80 (0.12) <.0001	-0.88 (0.28) .001	-1.26 (0.39) .002
Subscales <sup>5</sup> Physical	-1.74 (0.19) <.0001	-2.56 (0.26) <.0001	-2.60 (0.62) <.0001	-3.59 (0.89) <.0001
Subscales <sup>5</sup> Functional Status	-0.40 (0.07) <.0001	-0.57 (0.10) <.0001	-0.59 (0.25) .02	-0.93 (0.35) .008
Subscales <sup>5</sup> Emotional	-0.37 (0.06) <.0001	-0.55 (0.09) <.0001	-0.43 (0.21) .04	-0.80 (0.29) .006
Subscales <sup>5</sup> Social	-0.39 (0.06) <.0001	-0.54 (0.08) <.0001	-0.81 (0.19) <.0001	-0.79 (0.28) .004
Subscales <sup>5</sup> Social	-0.59 (0.05) <.0001	-0.89 (0.07) <.0001	-0.77 (0.16) <.0001	-1.06 (0.23) <.0001
<b>Additionally adjusting for treatment received** outcomes (N = 1810)</b>				
<b>Distress outcomes</b>				
Perceived Stress Scale: symptoms <sup>1</sup>				
- 2–3 months after cancer diagnosis	0.25 (0.06) <.0001	0.37 (0.08) <.0001	0.44 (0.19) .02	0.48 (0.25) .06
- In month before study interview	0.28 (0.05) <.0001	0.32 (0.07) <.0001	0.85 (0.16) <.0001	0.74 (0.21) .0006
Depressive symptoms since cancer diagnosis <sup>2</sup>	0.19 (0.03) <.0001	0.25 (0.04) <.0001	0.42 (0.11) .0001	0.38 (0.14) .007
<b>QOL outcomes</b>				
FACIT-SP Scale <sup>3</sup>				
FACT-G Scale <sup>4</sup>	-0.53 (0.09) <.0001	-0.74 (0.13) <.0001	-1.03 (0.31) .001	-1.06 (0.41) .01
Subscales <sup>5</sup> Physical	-1.79 (0.21) <.0001	-2.62 (0.29) <.0001	-2.82 (0.72) .0001	-3.72 (0.95) <.0001
Subscales <sup>5</sup> Functional Status	-0.41 (0.09) <.0001	-0.63 (0.12) <.0001	-0.47 (0.29) NS	-0.95 (0.38) .01
Subscales <sup>5</sup> Emotional	-0.38 (0.07) <.0001	-0.56 (0.10) <.0001	-0.61 (0.24) .009	-0.76 (0.31) .01
Subscales <sup>5</sup> Social	-0.39 (0.07) <.0001	-0.53 (0.09) <.0001	-0.86 (0.22) .0001	-0.86 (0.30) .004
Subscales <sup>5</sup> Social	-0.60 (0.05) <.0001	-0.90 (0.08) <.0001	-0.88 (0.19) <.0001	-1.14 (0.25) <.0001

\*Adjusting for age at diagnosis, monthly family income, current smoking status, state of residence, cancer site (breast versus other cancer site), lifetime IPV, PSB score, stage and number of comorbid conditions.

\*\*Additionally adjusting for treatment received (chemotherapy (yes v no), radiation (yes v no) and other non-surgical treatment (yes v no); 96% received surgery). Treatment data only available from Kentucky Cancer Registry.

<sup>1</sup>= Perceived Stress Scale [26,27]: 3 items measured patients' perceptions of their stress during the 2–3 months following cancer diagnosis and 3 items in the month prior to the phone interview.

<sup>2</sup>= Depression symptoms: 5 items from the Brief Symptom Inventory [25].

<sup>3</sup>= FACIT-SP Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale. Twelve items. Response options range from not at all (=0) to very much (=4). Recall frame was past 7 days.

<sup>4</sup>=Functional Assessment of Cancer Therapy—General questionnaire.

<sup>5</sup>= FACT-G Subscales measured physical functioning (7 items), social/family functioning (7 items), emotional functioning (6 items) and functional status (7 items).

outcomes included in one model and the QOL outcomes in the second MANCOVA model.

PIB-C scores were analyzed as both continuous (overall and by subscale) and categorical (dichotomous and ordinal) variables. Investigation of categorical variables allows for a comparison based on exposure to partner behaviors; adjusted group mean differences in outcomes scores were presented by PIB-C exposure, higher (PIB-C  $\geq 2$ ) and lower (PIB-C = 1) versus no PIB-C (Table 3). Exposure to behaviors may be more useful to healthcare providers as an indicator of impact to cancer patient's distress or QOL. Additionally, regression estimates for PIB-C scores (overall and by the three subscales) as a continuous variable indicate how changes in partner impact distress and QOL outcomes (Table 4).

All analyses in Tables 3 and 4 were adjusted for potential confounders; sensitivity analyses were conducted with

additional adjustment for cancer treatment received among cases recruited from the Kentucky Cancer Registry. All data were analyzed using Statistical Analysis System, SAS, versions 9.3/4 (SAS Institute; Cary North Carolina).

## Results

### Response rates

From November 2009 to January 2015, the two cancer state cancer registries identified 14 224 eligible (age 18–79) women with an incident and primary cancer. Of these, 3335 completed a phone interview (23.4% response rate). Interview response rates, defined as completing a phone interview, did not differ by registry (KCR: 22.9% (2434/10 623) and NCCR: 25.0% (901/3601)). Within

each state registry, other disposition rates differed somewhat and may be attributable to differences in how frequently researchers were allowed case contact; researchers were allowed one contact for NCCR cases and two with KCR. The physician refusal rate was 3.1% (KCR: 3.5% (372/10623) and NCCR: 1.9% (69/3601), and the case refusal rates was 13.9% (KCR: 16.0% (1700/10 623) and NCCR: 7.6% (275/3601)). The majority 59.6% of women cases could not be contacted by phone or mail (KCR: 57.6% (6117/10 623) and NCCR: 65.4% (2356/3601)).

Given limited access to demographic data on individuals included in the registries yet not consenting to study participation, we could not determine the sociodemographic characteristics of those not consenting. We were able to determine how those not participating differed from those completing a phone interview based on whether women lived in an Appalachian region or not ( $\chi^2 = 2.54^{p=NS}$ ) and by cancer site. Women diagnosed with breast cancer were more likely to participate than women diagnosed with other cancers ( $\chi^2 = 10.65^{p=.001}$ ).

Among the 3335 women completing a phone interview, 931 women were not in an intimate relationship at cancer diagnosis (27.9%) and were excluded because PIB-C items were not asked of those without a partner. Also excluded were women missing demographic factors ( $n=10$ ) or violence experienced ( $n=9$ ). The distribution of cancer sites among the 2385 women included in this analyses was: breast cancer ( $n=1443$ ; 60.7%), female urogenital ( $n=296$ ; 12.5%) colorectal ( $n=164$ ; 6.9%), head, neck, lung ( $n=135$ ; 5.7%), hemopoetic ( $n=102$ ; 4.3%), thyroid ( $n=107$ ; 4.5%), malignant melanoma ( $n=70$ ; 2.9%) and other ( $n=59$ ; 2.5%). Of the 2385 women in a relationship at cancer diagnosis, 14.7% endorsed one or more PIB-C item (see Table 1).

Table 2 presents the unadjusted associations between endorsing at least one PIB-C item and demographic attributes, lifetime and current IPV experienced, and cancer stage and number of comorbid physical conditions at diagnosis. Relative to women endorsing no PIB-C, those reporting at least one PIB-C were younger, had lower PSB-C scores indicating less supportive partners, had less income, less education, were less likely to be currently married, more likely to be a current smoker, more likely to be diagnosed at a later cancer stage and had more comorbid physical conditions. Because PIB-C was designed to measure psychologically interfering behaviors influencing cancer care, we anticipated and observed that women endorsing any PIB-C item were more likely to disclose all forms of current and lifetime IPV but particularly psychological IPV.

Associations with each of the demographic attributes presented in Table 2 were repeated for the five outcomes to determine potential confounding factors. Briefly, increasing age, PSB-C scores, income, education and

current smoking status were inversely correlated with increasing symptoms of stress and depression and positively correlated with increasing FACT-G and FACIT-SP ( $p < .001$ ). Lifetime IPV, increasing cancer stage at diagnosis, and increasing number of comorbid physical conditions were positively correlated with symptoms of stress and depression and inversely correlated with FACT-G and FACIT-SP scores. Based on assessment of potential confounders and (a) PIB-C and (b) outcomes, the final multiple variable models included age (in years), stage (0–4), income (1–6 levels), PSB-C scores (0–5), lifetime IPV (yes v no), current smoking status (yes v no), number of comorbid conditions (0–5), breast cancer (yes v no) and state of cancer registry (NCCR v KCR). The first seven variables were associated with both PIB-C and the outcomes; breast cancer site and state were included as covariates because these were attributes of the study design. Because income, education and current marital status were highly correlated, only income was retained in multivariable models as only income remained significantly associated with the outcomes when education and marital status were included.

The MANCOVA test for model appropriateness including the five correlated outcomes, FACIT-SP and four FACT\_G subscales, and any PIB-C was statistically significant (Wilks's Lambda:  $F(6, 2367) = 24.40$ ;  $p < .0001$ ). Wilks' Lambda for the MANCOVA including the three distress outcomes was also significant ( $p < .0001$ ) and indicated appropriateness of model use.

Endorsing any relative to no PIB-C item was associated with more symptoms of stress in the 2–3 months after cancer diagnosis and in the month before interview, more depressive symptoms since cancer diagnosis and with significantly lower FACIT-Sp and all 4 FACT-G subscale scores which indicated poorer QOL. Evidence of a dose–response pattern of increasing PIB-C items endorsed and greater depressive symptoms and lower FACIT-SP and FACT-G physical and social subscales was observed such that significant differences in these outcomes were associated with two or more PIB-C endorsed relative to only one PIB-C and no PIB-C endorsed. The same patterns were observed for the sensitivity analyses in which cancer treatment was included as a covariate and analyzed only among Kentucky cases which suggests that differences in cancer treatment received do not explain the pattern of PIB-C being associated with distress and lower QOL.

The analyses presented in Table 4 provided an indication of how PIB-C dose, measured as increasing number of partner interfering behaviors, affects distress and QOL. Increasing PIB-C scores were associated with increasing symptoms of stress at both time intervals measured and with increased numbers of depressive symptoms since cancer diagnosis ( $p < .0001$ ). Additionally, increasing PIB-C scores were associated with significantly

lower FACIT-SP and all 4 FACT-G subscales indicating poorer cancer QOL. These same patterns held for all three PIB-C subscales with the 7 item PIB-C of 'Partner focused on self, not patient' subscale being the more important subscale (even with the scales given equal weights for number of items and included in the same model). Sensitivity analyses which included cancer treatment as a covariate in MANCOVA models yielded similar findings.

## Discussion

As hypothesized, higher PIB-C scores (and each subscales) were associated with (a) reporting more symptoms of depression or stress, and (b) having lower cancer-related quality of life as measured with the Functional Assessment of Cancer Therapy (FACT-G) and Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-SP) scales even when additionally controlling for partner support, lifetime IPV, demographic attributes, cancer site, stage and comorbid conditions.

This large cohort of women recently diagnosed with cancer from two state registries represents the first to estimate the frequency of partner interfering behaviors and their impact on a range of cancer outcomes. Our use of the same interview protocol for all participants in both cancer registries and use of outcomes measures with strong psychometric properties limits measurement bias. This new PIB-C measure had strong internal consistency and good face and construct validity [18]. Confounding bias was unlikely to explain these findings because a wide range of individual and relationship factors were evaluated. Our inclusion of all who met the eligibility criteria (age, female and included in the cancer registries as an incident and primary cancer in the prior year) improved the study power and representativeness of our sample. All communications with potential participants described the project as the 'Life stresses, family and partner support and cancer care for women' study to indicate the focus but not exclude those in potentially challenging relationships. Those completing the phone interview may still differ from those who did not on attributes we can and cannot measure (e.g. partner violence or other partner behaviors). We did not find differences in interview completion by State or region yet breast cancer cases were somewhat more likely to complete an interview than those with other cancers. The more likely scenario impacting selection bias may be that a larger proportion of women currently experiencing partner interfering behaviors or IPV are either too ill to be interviewed, refused or could not be contacted (by phone or mail) than women without these experiences. If women with these partner experiences were disproportionately not included AND these women not participating have poorer cancer outcomes, then our resulting measures of association would be biased toward the null; we would have included fewer experiencing

partner interference and poorer cancer outcomes. The cross-sectional nature of data collection is a study limitation. Women were asked to recall partner behaviors potentially impacting cancer in the past 12 months (after cancer diagnosis). This retrospective approach was used because these behaviors could only be measured after cancer diagnosis and during treatment or recovery. Using a prospective assessment of partner behaviors potentially affecting cancer care just after diagnosis, in the first 3 to 6 months following diagnosis and up to 12 months following diagnosis, would provide a more robust PIB-C measure yet would be more burdensome for respondents. From these cross-sectional data we cannot determine directionality of increasing partner interfering behaviors and greater symptoms of stress and depression and lower FACT-G and FACIT-SP scores indicating poorer QOL. These two sets of outcomes may increase partner interfering behaviors. Alternatively, that those who experienced more symptoms of stress or depression may be more likely to report negative partner behaviors.

The significance of this study within the body of research investigating the impact of supportive/unsupportive partner behaviors on health, and specifically oncology outcomes lies in its identification of partner actions *specific to cancer care or recovery*. These interfering partner behaviors are more serious in nature than 'unsupportive' actions yet do not meet the threshold of 'violence' which could be identified in recommended clinical partner violence screening [30]. Prior measures of unsupportive behavior typically have addressed general traits of criticism or withdrawal that may not be related to the patient's experience of cancer, whereas the PIB-C addresses behaviors with considerable consequences for cancer treatment or QOL (e.g. interfering with sleep, not picking up prescriptions). Where resources must be targeted, screening using the PIB-C is likely to identify patients more at risk for poorer outcomes and also to identify areas where intervention might be directed, for example, to services for transportation, in-home help or support persons. Although this measure currently requires passage of time from a patient's diagnosis for that person to be able to report on their partner's actions, future research could identify partner's pre-existing traits or abusive behaviors or that are highly associated with PIB-C. Clinicians could then use this information to appropriately screen and identify those relationships in need of targeted counseling and follow up.

In conclusion, these data suggest that patterns of partners' interfering behaviors are correlated with increased symptoms of distress and poorer cancer-related QOL. Others have argued for incorporating IPV screening within oncology care [31]. Our findings suggest that specific partner interfering behaviors are more common (14.7%) than current IPV (10.7%) and have similar cancer impact [1]. Additional evidence-based research is needed to determine the role of patient screening for problematic

partner behaviors (including abuse) in preventing the potentially dramatic impact of these behaviors on women's cancer care and recovery. The recent Affordable Care Act requirement and ACOG endorsement of domestic violence screening as part of routine care for reproductive aged women is an example of a policy intervention that may be relevant for improving cancer care in oncologic settings [30,31].

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