

Worry about recurrence in a multi-ethnic population of breast cancer survivors and their partners

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Abstract

Purpose The objectives of this study are to describe racial/ethnic differences and clinical/treatment correlates of worry about recurrence and examine modifiable factors in the health care experience to reduce worry among breast cancer survivors, partners, and pairs.

Methods Women with non-metastatic breast cancer identified by the Detroit and Los Angeles SEER registries between 6/05 and 2/07 were surveyed at 9 months and 4 years. Latina and Black women were oversampled. Partners were surveyed at time 2. Worry about recurrence was regressed on sociodemographics, clinical/treatment, and modifiable factors (e.g., emotional support received by providers) among survivors, partners, and pairs.

Results The final sample included 510 pairs. Partners reported more worry about recurrence than survivors. Compared to Whites, Latinas(os) were more likely to report worry and Blacks were less likely to report worry (all $p < 0.05$). Partners of survivors who received chemotherapy reported more worry (OR = 2.47 [1.45, 4.22]). Among modifiable factors, survivors and pairs who received more emotional support

from providers were less likely to report worry than those survivors and pairs who did not receive such support (OR = 0.56 [0.32, 0.97]) and (OR = 0.45 [0.23, 0.85]), respectively.

Conclusions Early identification of survivors and partners who are reporting considerable worry about recurrence can lead to targeted culturally sensitive interventions to avoid poorer outcomes. Interventions focused on health care providers offering information on risk and emotional support to survivors and partners is warranted.

Keywords Worry about recurrence · Survivors and partners · Breast cancer

Introduction

Helping families cope with cancer and manage continuing concerns in survivorship has been identified as a priority for delivering quality cancer care. Women with breast cancer rank worry or fear about recurrence (hereafter referred to as worry) among their most pressing concerns in survivorship [1–4], and studies have found that partners and/or family caregivers report even more worry than survivors [5, 6]. There is a growing recognition that couples react to the diagnosis of cancer as an “emotional system,” mutually influencing each other’s worry [5, 7, 8], suggesting that the survivor-partner pair must be viewed as the most appropriate “unit of care” [9]. Assessment and greater focus on worry is essential for survivors and partners given its documented impact on quality of life (QOL) [1, 2, 10]. Similarly, when a partner’s worry goes unrecognized, it can impact the entire family’s QOL, including the survivor [5, 8, 11].

Several studies have identified factors associated with worry, especially age [4, 12]. However, most studies have focused on survivor worry early in survivorship, and have been limited by relatively small, clinic-based samples. These studies have found

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Black women worry less while Latinas worry more than Whites [13]. When acculturation has been measured across health outcomes for cancer survivors, Latinas with low acculturation experience more worry [12]. An important area of research is to identify disparities in worry across racial/ethnic groups, and further, to determine if similar factors influence worry among partners and pairs. Survivor comorbidities and symptoms may contribute to greater worry [5] while the findings are mixed on the association between treatment course and worry [3, 14]. The extent to which the treatment course of survivors influences partner worry has not been explored in depth.

Few studies have examined whether modifiable factors in the health care experience (e.g., information around risk of recurrence, emotional support from providers) influence persistent worry among survivors, partners or pairs. Receipt of emotional support has been shown to be important to survivor outcomes, however, most studies have focused on emotional support received from family and friends [15]. How often survivors or partners receive emotional support from providers remains unclear, as both oncologists and primary care providers perceive that they provide the majority of emotional support [16]. The amount survivors and partners worry could be enhanced if their “perceived risk” of cancer recurrence is higher than the “actual risk.” Cancer care and primary care health care teams have opportunities to discuss risk, assess worry, and provide emotional support in an effort to manage considerable worry among survivors and partners.

By better understanding modifiable factors that make survivors, partners, and pairs more vulnerable to persistent worry, high-risk populations can be identified and targeted, and interventions tailored to these specific components affecting risk. To address these gaps, we used a large multi-ethnic population-based sample of women with breast cancer and their partners to (1) describe the racial/ethnic differences and clinical and treatment correlates of worry among breast cancer survivors, their partners, and survivor-partner pairs 4 years following breast cancer diagnosis and, (2) assess the association of potentially modifiable factors (receipt of emotional support from providers and, receipt of information about risk of recurrence) on worry about recurrence.

Methods

Study population and data collection

The study population included breast cancer survivors and their partners. We initially identified women with breast cancer in Los Angeles (LA), California and Detroit, Michigan. Eligible participants were women 20–79 years old, diagnosed with ductal carcinoma in situ or invasive breast cancer from June 2005 through February 2007, and reported to the National Cancer Institute’s Surveillance, Epidemiology, and

End Results (SEER) registry. Asian women in LA were excluded because of enrollment in other studies. Black and Latina women were oversampled in LA to ensure sufficient representation of racial/ethnic minorities. A total of 3252 women were surveyed at about 9 months after diagnosis (time 1) and 2290 (73.1 %) completed the survey. Time 1 respondents were surveyed again 4 years after diagnosis (time 2) and 1536 (67.7 %) completed the survey. Details of the time 1 and time 2 surveys have been previously published [10, 17].

For the partner survey, 774 women who reported being married/living with partner at time 1 and 2 were asked to give a survey packet to their partners from October 2010 to February 2012. The partner packet included an introductory letter, survey, \$10 cash gift, and a return envelope. All materials were in English and Spanish if the respective survivors had Spanish surnames. A modified Dillman method [18] was used to encourage response. Of 774 potential eligible partners, 517 (67 %) completed the survey. Details of the partner survey have been previously published [19]. Our final sample included 510 pairs of survivors and their respective partners. We refer to our study subjects as survivors, partners, and pairs.

All study protocols were approved by the institutional review boards of the University of Michigan in Ann Arbor, the University of Southern California, and Wayne State University.

Measures

A modified stress and appraisal conceptual framework based on Lazarus and used by Northouse provided guidance for our research [20]. The framework includes antecedent factors (personal factors and illness-related factors of survivors and/or their partners), proximal outcomes (e.g., appraisal factors and coping factors of survivors and/or their partners), and the distal outcome (i.e., level of worry about recurrence 4 years after diagnosis) for survivors, their partners, and the pairs. All survivor measures were assessed at time 2 (approximately 4 years after breast cancer diagnosis) unless indicated otherwise.

Dependent variables

For survivors, worry was measured as the mean of three items (i.e., worry about cancer coming back in the same breast, in the other breast, and to other parts of my body) on a 5-point Likert-type scale (“not at all” to “a lot”). The mean score was 2.3 (SD = 1.0, min = 1, max = 5), with a Cronbach’s alpha of 0.87. The worry scale has been used in previous publications (10, 12), and is highly correlated in expected directions with quality of life measures. *For partners*, worry was measured by “how often they worry about the possibility that their spouse or partner’s breast cancer might recur” on a 5-point Likert-type scale (“not at all” to “a lot”). The mean score was 2.5

(SD = 1.1, min = 1, max = 5). For purposes of analyses, worry was dichotomized as follows: *for survivors and partners*, those with mean scores for worry ≥ 3 were considered as “worriers”; otherwise, considered “non-worriers.” *For pairs*, to be considered as “worriers,” both the survivor and partner had to be “worriers.” If either the survivor or the partner was not a “worrier,” the pair was considered a non-worrying pair.

Independent variables

For survivors and partners, personal factors included age (<50, $50 \leq 65$, and ≥ 65 years), education (high school education or less, some college education or more). Race was assessed as White, Black/African American, American Indian or Alaska Native, Asian or Pacific Islander, or other; and, ethnicity (yes/no for Hispanic/Latino) in order to subsequently categorize into non-Hispanic White, non-Hispanic Black, and Latinos. The Short Acculturation Scale for Hispanics (SASH) [21] assessed their preferences for English or Spanish in four different social contexts, as has been done in previous work [22, 23]. Responses to the four items were averaged and then dichotomized into lower acculturation (≤ 4) and higher acculturation (> 4) to survivors and partners, subsequently referred to as Latino-low and Latino-high. Current health was measured on a 5-point scale from “poor” to “excellent,” and then dichotomized into “excellent/very good/good” vs. “fair/poor.” Number of comorbidities was categorized into “none” vs “ ≥ 1 ” using the Charlson comorbidity index [24]. *For survivors*, at time 1, clinical factors included tumor stage, surgery, radiation (yes/no), and chemotherapy (yes/no). *Survivors and partners* were asked if they received enough information on the risk of recurrence from the doctors or the staff (yes/no). For the pair, both survivor and partner had to indicate “yes” to receiving enough information. Receipt of emotional support from health care providers was measured on a scale from 1 to 5 (“none” to “a lot”). We categorized partners and survivors as having received sufficient emotional support if the score was ≥ 3 . *For pairs*, to be designated as having received emotional support, both survivor and partner needed to have a score ≥ 3 .

Statistical methods

We first compared the 264 survivors who were partnered but whose partners did not return their surveys to the 510 survivors whose partners did complete the survey. The primary analyses to address the research questions was based on the 510 survivor surveys with their corresponding partner surveys. We calculated summary statistics for variables on survivors and partners included in our analytical sample. To compare distributions of variables between survivors and their partners, we used Stuart-Maxwell tests to account for the correlation between survivors and their partners. We described

the percent of survivors and partners who worried at 4 years in each subgroup defined by personal factors, illness-related factors, and proximal outcomes. We then used unadjusted logistic regression to estimate whether there was an association between worry by survivors (partners) and each characteristic.

Two separate logistic regression models were fit, without and with proximal outcomes, for level of survivor, partner or pair worry. We fit two additional logistic regression models: One added partners’ worry into the survivor model and the other added survivor worry into the partner worry model while retaining all other factors. Race/ethnicity, education, and age had a small amount of missing data (between 0.1 and 8 %). We imputed missing values by assigning them to the partner’s response if available based on high concordance observed in these variables within pairs. All analyses were conducted using R package, version 3.1.1 (Vienna, Austria).

Results

Compared to non-responders, partners who did respond were significantly more likely to have spouses (survivors) who were White, older, had some college education or higher and were less likely to have spouses who were Latino-low or had received chemotherapy, (all $p < 0.05$). Table 1 presents the sample characteristics of survivors and their partners 4 years after diagnosis. Survivors and partners were similar on most characteristics, except survivors were significantly younger than their partners (e.g., 31.0 vs 43.5 % being 65 or over). Among survivors, 59.8, 12.9, 13.9, and 12.2 % were White, Black, Latino-high and Latino-low; and 63.5, 25.1, and 10.0 % had lumpectomy, unilateral mastectomy and bilateral mastectomy. In addition, partners were significantly more likely to report receiving enough information about the risk of recurrence than survivors (71.1 vs. 64.7 %, $p = 0.003$), but less likely to report receiving sufficient emotional support from providers (45.7 vs. 75.0 %, $p < 0.001$). Finally, partners were significantly more likely to report worry about recurrence at 4 years after diagnosis than the survivors (42.3 vs. 27.2 %, $p < 0.001$).

Table 2 shows the percentage of survivors (partners) who reported worry within each subgroup defined by survivor (partner) characteristics. *For survivors*, the likelihood of worry was significantly higher among those with younger age, lower education levels, or worse health status. Worry also differed significantly among racial/ethnic groups. Latinas-low were most likely to express worry (50 %), compared with 36.5 % for Latinas-high, 27.1 % for Whites, and 14.0 % for Blacks. *For partners*, the likelihood of worry was significantly more likely among those who were less educated or had worse health themselves. Similar to survivors, partners worry differed among racial/ethnic groups. Latino partners reported the highest percentages of worry, with 67.2 and 66.7 % for

Table 1 Characteristics of 510 breast cancer survivors and their partners 4 years after diagnosis

	Survivor N ^a (% ^a)	Partner N ^a (% ^a)	Paired P value
Total:	510 (100)	510 (100)	
Antecedent factors			
Personal factors			
Race			0.086
Non-Hispanic White	305 (59.8)	313 (61.4)	
Non-Hispanic Black	66 (12.9)	68 (13.3)	
Latino (higher acculturation)	71 (13.9)	56 (11.0)	
Latino (lower acculturation)	62 (12.2)	67 (13.1)	
Age			<0.001
Under 50	89 (17.5)	70 (13.7)	
50–65	263 (51.6)	218 (42.7)	
65 and over	158 (31.0)	222 (43.5)	
Education			0.510
High school diploma or less	163 (32.0)	156 (30.6)	
Some college or more	347 (68.0)	354 (69.4)	
Illness-related factors			
Current health			0.437
Good or better	436 (85.5)	424 (83.1)	
Fair or worse	65 (12.7)	72 (14.1)	
Comorbidities (at time 2)			0.136
0	122 (23.9)	104 (20.4)	
1 or more	388 (76.1)	406 (79.6)	
Stage			–
Stage 0	125 (24.5)	–	
Stage 1–2	338 (66.3)	–	
Stage 3	46 (9.0)	–	
Surgery type			–
Lumpectomy	324 (63.5)	–	
Unilateral mastectomy	128 (25.1)	–	
Bilateral mastectomy	51 (10.0)	–	
Radiation therapy			–
Yes	363 (71.1)	–	
No	135 (26.4)	–	
Chemotherapy			–
Yes	229 (44.9)	–	
No	271 (53.1)	–	
Proximal outcomes			
Enough info about risk of recurrence			0.003
Yes	330 (64.7)	363 (71.1)	
No	171 (33.5)	131 (25.7)	
Health care provider emotional support			<0.001
None/a little	120 (23.5)	263 (51.5)	
Some/quite a bit/a lot	383 (75.0)	233 (45.7)	
Distal outcomes			
Worry about recurrence			<0.001
No (not at all/a little)	342 (67.0)	252 (49.4)	
Yes (some/quite a bit/a lot)	139 (27.2)	216 (42.3)	

^a N(%) values do not add up to 510(100 %) due to missing values

Table 2 Percent of survivors and their partners reporting worry about recurrence, by characteristic

Characteristic	Survivors who worry <i>N</i> (%)	Partners who worry <i>N</i> (%)
Overall	132 (29.3)	212 (47.1)
Personal factors		
Race		
Non-Hispanic White	74 (27.1)**	124 (44.3)**
Non-Hispanic Black	8 (14.0)	16 (27.1)
Latino (higher acculturation)	23 (36.5)	32 (66.7)
Latino (lower acculturation)	26 (50.0)	39 (67.2)
Age in years		
Under 50	30 (38.5)*	32 (51.6)
50–65	75 (31.0)	99 (50.0)
65 and over	27 (20.8)	81 (42.6)
Education		
High school diploma or less	51 (36.7)*	69 (51.5)**
Some college or more	81 (26.0)	143 (45.2)
Illness-related factors ^a		
Current health		
Good or better	102 (26.4)**	178 (47.0)**
Fair or worse	27 (49.0)	31 (50.0)
Comorbidities at time 2		
0	28 (25.5)	37 (39.3)
1 or more	104 (30.6)	175 (49.1)
Stage		
Stage 0	25 (22.9)	45 (41.3)
Stage 1–2	97 (32.4)	143 (47.8)
Stage 3	9 (22.0)	24 (58.5)
Surgery type		
Lumpectomy	93 (31.6)	133 (45.2)
Unilateral mastectomy	31 (28.1)	60 (54.5)
Bilateral mastectomy	6 (14.6)	17 (41.5)
Radiation therapy		
Yes	98 (30.0)	154 (47.2)
No	29 (25.6)	54 (47.7)
Chemotherapy		
Yes	64 (31.3)	115 (56.3)**
No	64 (27.0)	95 (40.0)

* and ** indicate that there is a significant association between worry about recurrence and the characteristic based on unadjusted logistic regression with * for $p < 0.05$ and ** for $p < 0.01$. For example, out of 273 non-Hispanic Whites, 74(27.1 %) reported worry. Total = 450 pairs of survivors and their partners who have responded on questions about their worry about recurrence

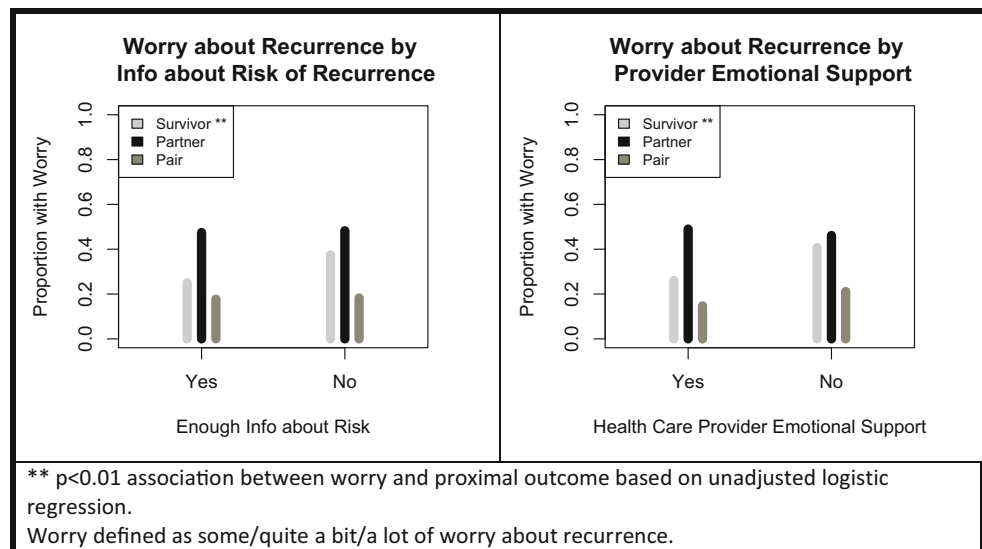
^a Stage, surgery type, radiation, and chemotherapy are survivor's characteristics

low and high acculturation groups, respectively, compared with 44.3 % for Whites and 27.1 % for Black partners. The likelihood of reported worry was similar among survivors irrespective of whether they received chemotherapy. However, partners of survivors who received chemotherapy were more likely to report worry than the partners of those who did not (56.3 vs. 40.0 %, $p < 0.001$). No other factors

were significantly associated with worry for either survivors or partners.

Figure 1 displays the proportion of worrying survivors/partners/pairs within groups defined by receipt of information about risk of recurrence and receipt of emotional support from providers. The percentages of reported worry were consistently higher among the partners than the survivors. *For survivors,*

Fig. 1 Survivor, partner, and pair worry about recurrence by information received about risk and emotional support by providers



without covariate adjustment, higher likelihood of worry was significantly associated with not having received enough information about the risk of recurrence (OR [95 % CI] = 1.82 [1.18, 2.78]) or not having emotional support from providers (OR [95 % CI] = 1.96 [1.23, 2.78]). For either their partners or the pairs, the likelihood of worry was not associated with either of these outcomes.

Table 3 presents the results from multivariable models for worry by survivors, partners and pairs. For survivors, with personal and illness-related factors in model 1, race/ethnicity, age, and current health status were found to be significantly associated with worry. Compared with Whites, Latinas-low were significantly more likely to report worry (OR [95 % CI] = 2.22 [1.01, 4.85]) while Blacks were less likely (OR [95 % CI] = 0.40 [0.16, 0.97]). Survivors with worse health were significantly more likely to report worry than their counterparts (OR [95 % CI] = 2.31 [1.13, 4.69]). In model 2, when proximal outcomes were added to model 1, the previous factors remained significant. Additionally, survivors who received sufficient emotional support from providers were less likely to worry than those who did not receive such support (OR [95 % CI] = 0.56 [0.32, 0.97]).

For partners, model 3 in Table 3 shows that Latinos were significantly more likely to report worry than Whites (OR [95 % CI] = 3.02 [1.41, 6.47] for low acculturation and 2.67 [1.31, 5.45] for high acculturation); while Blacks were less likely to report worry than Whites (OR [95% CI] = 0.54 [0.27, 1.06]). Partners with any comorbidity were more likely to report worry than those without (OR [95% CI] = 2.13 [1.24, 3.68]). Partners of survivors who had received chemotherapy were also more likely to report worry than their counterparts (OR [95% CI] = 2.47 [1.45, 4.22]). With proximal outcomes added, model 4 demonstrates the same significant factors associated with worry.

For pairs, model 5 in Table 3 demonstrates that Latinos were more likely to report worry than Whites (i.e., OR [95% CI] = 2.17 [0.95, 4.98] for Latinos-low, and OR [95% CI] = 1.97 [0.98, 3.97] for Latinos-high). In contrast, Blacks were less likely to report worry than Whites (OR [95%CI] = 0.23[0.54, 1.04]). Furthermore, pairs with worse survivor health status were more likely to report worry than those who did not (OR [95% CI] = 2.89 [1.36, 6.15]). Pairs who reported they received sufficient emotional support from providers were less likely to report worry than those who did not receive such support (OR [95%CI] = 0.45 [0.23, 0.85]). When we repeated the analyses using the personal factors, illness-related factors and proximal outcomes of the partners as well as the cancer stage and treatment factors of the survivors, we found the same significant factors associated with worry about recurrence by the pairs.

Finally, while not shown in Table 3, when we added partner worry to the survivor model, we found that partner worry was significantly associated with survivor worry (OR[95 % CI] = 2.12 [1.29, 3.51]). Similarly, survivor worry was significantly associated with partner worry when added to the partner model (OR [95 % CI] = 2.05 [1.23, 3.40]).

Discussion

Our findings provide further support for the importance of viewing cancer as a family experience, where survivors and partners are both affected, and each affects the others' worry and emotional response well into survivorship [5, 7, 11, 25, 26]. Partners reported more worry than survivors, possibly because they perceive less control, and receive less support than the survivor [5, 6]. In approximately 18 % of pairs, both survivor and partner were worried about recurrence at 4 years, making

Table 3 Multivariable logistic modeling of survivor/partner worry at 4 years

Survivor/partner characteristic	Survivor worry		Partner worry		Pair worry ^b	
	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6
	OR	OR	OR	OR	OR	OR
Antecedent factors						
<i>Personal factors</i>						
Race						
Non-Hispanic White (ref)	*	*	**	**	*	**
Non-Hispanic Black	0.40	0.40	0.54	0.53	0.23	0.24
Latino (higher acculturation)	1.62	1.63	2.67	3.05	1.97	2.43
Latino (lower acculturation)	2.22	1.85	3.02	2.96	2.17	1.95
Age						
Under 50 (ref)	*	*				
50–65	0.44	0.45	1.15	1.17	0.74	0.67
65 and over	0.31	0.36	1.02	1.16	0.48	0.52
Education						
High school diploma or less (ref)						
Some college or more	0.94	0.99	1.03	0.98	0.644	0.60
<i>Illness-related factors^a</i>						
Current health						
Good or better (ref)	*	*			**	*
Fair or worse	2.31	2.23	1.03	1.10	2.89	2.58
Comorbidities (at time 2)						
0 (ref)			**	*		
1 or more	1.33	1.16	2.13	1.95	0.82	0.93
Stage						
Stage 0 (ref)						
Stage 1–2	1.54	1.64	0.64	0.57	1.26	1.03
Stage 3	0.65	0.73	0.52	0.42	0.51	0.35
Surgery type						
Lumpectomy (ref)						
Unilateral mastectomy	0.64	0.64	1.11	1.10	1.35	1.29
Bilateral mastectomy	0.31	0.30	0.88	0.83	0.75	0.78
Radiation therapy						
No (ref)						
Yes	0.90	0.99	0.94	1.02	1.18	1.41
Chemotherapy						
No (ref)			**	**		
Yes	0.87	0.90	2.47	2.77	1.23	1.76
Proximal outcomes						
Enough info about risk of recurrence						
No (ref)						
Yes	–	0.65	–	0.80	–	1.22
Emotional support from health care						
None/a little (ref)		*				*
Some/quite a bit/a lot	–	0.56	–	0.85	–	0.45

* and ** indicate that there is a significant association between worry about recurrence and the characteristic based on adjusted logistic regression with * for $p < 0.05$ and ** for $p < 0.01$. Italicized items denote characteristics that are significant compared to the reference category for characteristics that are significant overall with $p < 0.05$

^a Stage, surgery type, radiation, and chemotherapy are survivor's characteristics

^b Using antecedent and illness-related factors of survivors

them particularly vulnerable to the negative consequences of worry on behavior and emotional well-being [5, 10].

In this large diverse population-based sample of survivors and their partners, we found that Latinas/os were most vulnerable to worry. Possible explanations for the racial/ethnic differences include differences in the perceptions of the likelihood or consequences of cancer, cultural, and contextual differences in coping with cancer [27], variation in willingness to report worry, and/or structural and language barriers in the health care

system. In previous studies, Black survivors report fewer concerns and higher emotional well-being than Whites [14]. In contrast, cultural factors such as cancer stigma, shame, and secrecy are often expressed by Latina survivors [28] and may contribute to worry. In terms of coping strategies among older adults, African Americans are most likely to rely on religious coping [29], and recent studies have shown that fatalism is often expressed by Latinos, irrespective of level of acculturation [30, 31]. Finally, low acculturated Latinas may be

unfamiliar with the US health system and vulnerable to language barriers in patient-physician communication, particularly if discussing emotional issues through interpreters [28, 32, 33].

Consistent with previous studies [5, 11, 12], younger survivors and partners reported more worry. Younger couples facing cancer have more competing demands and fewer peers facing life-threatening illnesses [17]. Greater attention to symptom and comorbidity management may result in less worry, since studies show those who perceive their symptoms are well managed perceive less worry [12]. Survivors and partners with comorbid diseases are likely to have regular contact with their primary care provider (PCP), creating opportunities for PCPs to provide support and manage worry for these individuals [34]. PCPs are well positioned to provide emotional support as they play a more diverse role including preventive services, treatment of comorbidities, and psychosocial care [35], and cancer patients seem open to PCPs assuming more responsibilities in follow-up care [36].

While survivors' worry did not differ by treatment, partners whose spouse had chemotherapy were over twice as likely to report worry. Partners may need more information on the benefits of chemotherapy in reducing risk of recurrence to offset the visible side effects common to chemotherapy. Previous studies have identified added responsibilities, concerns, and unmet information needs of partners of patients receiving chemotherapy [37, 38], and partners have expressed feelings of helplessness and being marginalized by the health care system in getting their information needs addressed [38].

This study explored whether modifiable factors related to the health care experience might be associated with worry by survivors, partners, or pairs. Among the two factors considered, the amount of emotional support received from providers was significantly related to worry among survivors and pairs. Most studies have focused on emotional support received by family or friends [11, 39] but our results suggest that support from providers should not be overlooked. In a recent study, only about one-third of cancer patients recalled a discussion about the emotional impact of cancer with their health care professionals [40]. Our findings indicate there may be unmet need for emotional support from providers that could be directed at both survivors and partners.

Although this study did not find that receipt of sufficient information on risk of recurrence was a significant correlate of worry, previous studies suggest that survivors desire more information about recurrence than is generally provided [23]. Furthermore, survivors and partners may not understand the risk information that is communicated by physicians, particularly when English is not their first language [19, 23]. Greater resources should be devoted to language support services for survivors and partners, when needed, to increase the likelihood that what is being discussed in the clinical encounter is understood by both individuals.

Early intervention and/or referrals when necessary would likely alleviate persistent worry by survivors and partners. Interventions focused on psychoeducation, skill building, mindfulness training, finding meaning, and benefit have shown promise with survivors [5, 30, 41] but need to be evaluated with partners and pairs. Support programs developed and led by professionals familiar with cultural norms is an important direction for clinical intervention. In addition, expanding the services provided by both oncologists and primary care providers focused on reducing worry and anxiety among partners and survivors would be helpful [42]. Other directions include referral to social support services, culturally sensitive navigation programs, and consistent use of trained interpreters [33].

Limitations

This study was a cross-sectional examination of worry about recurrence among survivors, partners, and pairs 4 years after cancer diagnosis. Future research should examine worry longitudinally. While our measure of worry did not include the duration, frequency, and impact of distress on impairment, it is correlated in expected directions with quality of life measures [3, 12]. Most measures were self-reported and may be subject to recall bias given the time delay between treatment and survey completion. We achieved good survey response rates for both survivors and partners, but acknowledge the possibility that non-response could present a source of bias in our findings. One of the strengths of this study was that it was guided by a stress/appraisal framework [20]; the field would benefit from further testing of the theoretical underpinnings of worry about recurrence [5, 7, 43]. Another major strength of the study was the relatively large population-based sample with sufficient numbers of Latinos to examine acculturation. However, the US Hispanic population is diverse, so generalizability is limited to Latinos in our geographic location.

Conclusions

Our results underscore the need to consider survivors and partners as pairs and intervene with the couple as an emotional and interdependent unit to provide quality cancer care [7, 9]. We must focus on identifying pairs that are most vulnerable to persistent worry and target interventions to avoid the likelihood of poorer outcomes [10, 25, 43]. Future studies must include more racial, cultural and socioeconomic diversity, and broaden the definition of partners to include more same-sex couples. Theory-based interventions need to be developed and evaluated for survivors and partners that are culturally and linguistically tailored [30, 34]. Greater attention to modifiable risk factors to manage worry such as providers offering more

emotional support is warranted. Interventions directed at cancer care and primary care providers are needed to raise their confidence in presenting risk of recurrence and managing worry in survivors and partners [44]. With survivorship care plans, there comes an opportunity to increase the support of patients and partners by improving communication between providers and with patients and partners about worry. [45]. Unfortunately, current SCP templates do not systematically contain this information. Given the scarcity of resources, interventions will need to be innovative, and incorporate technology as another vehicle to provide information and support [25, 41].

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Compliance with ethical standards

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Conflict of interest The authors declare that they have no conflict of interest.

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