



## Disparities in managing emotions when facing a diagnosis of breast cancer: Results of screening program of couples distress

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### ABSTRACT

**Introduction.** Distress screening is now required for cancer center accreditation. Understanding patient and caregiver stress is critical to successful cancer care. This study examines the perceived emotional impact of breast cancer on both patients and partners.

**Methods.** From March 2011–February 2016, patients and partners undertook an electronic, 48–point distress screen during their first visit at a surgical breast clinic. Distress was measured via self-reported concerns on a five point Likert scale. Respondents were also asked about preferred interventions. The ability of the patient and partner to manage emotions was assessed in relation to education, ethnicity, fatigue, anxiety, and depression using ordered logistic regression.

**Results.** Of the 665 individuals screened, 51.7% (n = 344) were patients, while 48.3% (n = 321) were partners. Patients were more distressed than partners regarding fatigue, anxiety, depression, and worrying about the future (p < 0.005). Only 19.7% of partners requested information with regards to “managing emotions” compared to 46.3% of patients. In the univariate analysis, being a partner was protective (OR 0.49 (95%CI 0.34–0.70, p < 0.000) as was holding an advanced educational degree (OR 0.36 (95%CI 0.14–0.93) p = 0.035). In the multivariate regression, having more education remained protective, while being a partner was no longer protective (OR 0.93 (95%CI 0.62–1.39, p = 0.789). Financial concerns, anxiety, depression, and worrying about the future remained statistically significant. Partners asked for help less than patients (OR 0.28 (95%CI 0.17–0.48), p < 0.000).

**Conclusion.** While partners have similar concerns as patients, they do not seek information or help in managing emotions as often as do patients. Both patient and partners with less education and increased financial distress were likely to report difficulty in managing emotions. This study identifies groups who would benefit from supportive measures even in the absence of a request for help.

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Patient centered cancer care is recognized increasingly as a vital aspect of the delivery of care. Perhaps one of the most important aspect of providing high quality patient care is assessing psychosocial distress.<sup>1</sup> As of 2015, the American College of Surgeons Commission on Cancer has mandated standardized systematic distress screening and referral system for distressed patients as part of cancer center accreditation.<sup>2</sup> Our institution was early to recognize this need and for >10 years has used a validated electronic distress screening in our breast cancer patient population,<sup>3</sup> which has been validated and is now carried out in both patients and their partners.<sup>4,5</sup>

Several studies have demonstrated that patient and partner biopsychosocial distress is often correlated.<sup>6,7</sup> Indeed partners can experience similar if not greater levels of distress than the patients themselves<sup>8,9</sup> with a substantial long-term impact on quality of life and partner well-being.<sup>9</sup> Moreover, some studies have identified interdependence between the psychologic and physical distress in both the partner and the patient with breast cancer.<sup>7</sup> Similar phenomena are also observed amongst patients with other cancers, such as prostate,<sup>9,10</sup> lung, and colorectal.<sup>11</sup> There is growing evidence of enhanced satisfaction scores when both patients and partners are screened for biopsychosocial distress.<sup>5</sup>

Little is known about the global factors associated with distress in surgical populations. A pilot study of breast cancer population conducted by our group identified similar distress levels amongst patients and partners, especially for anxiety and depression; however, no associations were examined during that study. The purpose of this study was to evaluate the perceived emotional impact of a new diagnosis of breast cancer on both patients and partners in addition

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to the determinants associated with requesting information or help.

## Methods

### *Distress screening program*

From January 2011 until January 2016, newly diagnosed patients with breast cancer and their partners were administered an institutional review board-validated, electronic 48-point distress screening program our Institution review board at the time of their first visit in the surgery breast clinic at our National Cancer Institute designated Comprehensive Cancer Center at the City of Hope in Duarte, CA. Patients were contacted prior to the visit to assess their desire to participate in our couples program. To be included, participants had to speak English, and both the patient and the partner had to be present at the initial surgeon visit. They also had to be in a committed romantic relationship. There was no exclusion based on gender or sexual orientation. The distress screening was administered on a portable electronic device to both the patients and partners individually prior to their meeting with a surgeon. For each question, distress was assessed using a 5-point, Likert-type scale ranging from “Do not know” to “Severe or Very severe problem.” If distress was indicated by an answer of “Severe or Very severe problem,” responders were also asked what intervention they would prefer; the options ranged from “None” to “Both Talk and written.” Interventions were provided by a social worker or the treating surgeon for all questions rated as “Severe or Very Severe Problem” both at the time of the initial visit and afterwards if necessary. Deidentified data was transmitted electronically to an honest broker, encrypted, and stored on a secure server.

### *Variables*

For this study, key items of the screening were chosen based on their clinical importance: education status, race/ethnicity, fatigue, sleeping, anxiety, depression, “managing emotions,” and “worry about the future.” The outcome variable of “managing emotions” was chosen after deliberation among the authors. We think that this question best represents a responder’s psychosocial distress, because it encompasses more broad issues of emotional stability and difficulty when facing a new diagnosis of cancer.

### *Statistical analysis*

Patient and partner responses were compared using  $\chi^2$ . Univariate and multivariate ordinal logistic regression for “Managing emotions” was conducted including race/ethnicity, patient or partner status, fatigue, anxiety, depression, and “worrying about the future.” Ordinal logistic regression was chosen given the ordinal aspect of the Likert-type scale.<sup>12</sup> In an ordinal logistic regression, for the outcome variable there is an associated increase in the odds ratio (OR) with each increase in the Likert-scale. The categories included in the analysis were “Prefer not to answer do not know or not a problem” (referent category), and “Mild,” “Moderate,” and “Severe/Very severe.” Univariate and multivariate ordered logistic regression was also conducted for asking information about “managing emotions.” In the multivariate analysis, only variables with an overall  $P < .05$  was included. No variable interaction or colinearity in the multivariate models was identified. For the explanatory variables, the OR reported was the overall OR for that variable. All analyses were performed using Stata software, version 14 (Statacorp, College Station, TX).

### *Missing data*

The items chosen had limited amounts of missing data (<20%). The outcome variable “managing emotions” had 3.8% missing data. The regression analysis excluded patients with missing data as reported by “No response.” A post hoc analysis comparing patients with missing data demonstrated that for those questions answered, there was no statistical difference between the patients included in the multivariable analysis and those excluded.

## Results

Of the 665 responders screened, 51.7% ( $n = 344$ ) were patients, while 48.3% ( $n = 321$ ) were partners. While the most represented ethnic group was white (38.3%), a good proportion of patients were Hispanic (14.9%). When compared to partners, a greater proportion of patients reported greater levels of distress regarding fatigue, anxiety, depression, and “worrying about the future” (Table 1). When looking at “managing emotions” in particular, 35.7% of patients reported moderate to very severe distress compared to 16.1% of partners (Fig 1). Only 18.7% of partners requested information with regard to “managing emotions” versus 45.5% of patients (Fig 2).

### *Univariate and multivariate analysis for “managing emotions”*

In the univariate analysis for “managing emotions,” being a partner was protective (OR 0.49; 95% confidence interval [CI], 0.34–0.70,  $P < .000$ ) as was holding an advanced educational degree (OR 0.36; 95% CI, 0.14–0.93,  $P = .035$ ; Table 2). After correcting for confounders in the multivariate analysis, having more education remained protective, while being a partner was no longer protective (OR 0.93; 95% CI, 0.62–1.39,  $P = .789$ ). Financial concerns, anxiety, depression, and “worrying about the future” remained significantly associated with distress in “managing emotions” (Table 2).

### *Univariate and multivariate analysis for requesting information about “managing emotions”*

Both in the univariate and multivariate analysis, partners asked for information less often than patients (OR 0.28; 95% CI, 0.17–0.48,  $P < .001$ ; Table 3). While financial concerns, anxiety, depression, fatigue, and “worrying about the future” were significantly associated with the desire to obtain information in the univariate analysis, only depression (OR 1.72; 95% CI, 1.25–2.36;  $P < .001$ ) remained significant in the multivariate analysis.

## Discussion

Distress screening is essential to providing adequate cancer care. While the current standards of accrediting bodies focus solely on patient distress, the partner’s psychosocial welfare remains poorly described, and its impact on patient distress is poorly understood. The Centers for Medicare and Medicaid Services has recognized this deficit and is beginning to demand engagement by the caregivers and education as a tenet of appropriate cancer care. The present long-term, prospective study of screening of couples distress indicates that after adjusting for confounders, patients with breast cancer and partners both suffer from difficulty in managing emotions when faced with a new diagnosis of breast cancer. Other factors associated with distress are financial concerns, anxiety, and depression.

Financial concerns for both patients and partners are significantly associated with increased distress. There is mounting evidence

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