Distress During Radiation Therapy

Assessment among patients with breast or prostate cancer

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BACKGROUND: Distress is regarded as the sixth vital sign in cancer care, but few studies describe distress in patients undergoing radiation therapy.

OBJECTIVES: The purpose of this study was to assess distress levels among patients with breast or prostate cancer undergoing radiation therapy and investigate which problems contribute to patients’ distress levels.

METHODS: A retrospective medical record review was conducted for 217 patients with breast or prostate cancer at a midwestern community cancer center. Demographic data, distress scores, and problems or concerns from the patient-completed Distress Thermometer and associated Problem List were collected. Descriptive and bivariate statistics were calculated.

FINDINGS: The average distress of patients with breast cancer was significantly higher than that of patients with prostate cancer, and patients with breast cancer reported more problems than those with prostate cancer.

KEYWORDS
radiation therapy; distress; medical record review; breast cancer; prostate cancer

DIGITAL OBJECT IDENTIFIER
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ONE IMPORTANT CONCERN AMONG THOSE DIAGNOSED WITH CANCER IS DISTRESS, which is acknowledged as the sixth vital sign in cancer care (Bultz & Carlson, 2005, 2006). Distress in patients with cancer is defined as “a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (National Comprehensive Cancer Network [NCCN], 2016, p. 7). Assessing for distress among people with cancer is important to allow for prompt symptom management, with the expectation of improvement in quality of life. Distress has been acknowledged as a significant factor in cancer care by NCCN (n.d.), a nonprofit alliance of 26 cancer centers throughout the United States that develops and maintains evidence-based clinical practice guidelines supporting best practices in managing patients with cancer.

About 37%–62% of people with cancer report clinically significant distress (Carlson, Groff, Maciejewski, & Bultz, 2010; Graves et al., 2007; Johnson, Gold, & Wyche, 2010; Shimizu et al., 2010; Steinberg et al., 2009). Distress is reported in people with varied cancer diagnoses who undergo a variety of treatment modalities, including surgery, chemotherapy, hormonal therapy, immunotherapy, and radiation therapy (Dabrowski et al., 2007; Fulcher & Gosselin-Acomb, 2007; Johnson et al., 2010; Mergenthaler et al., 2011; Steinberg et al., 2009; Yamagishi, Morita, Miyashita, & Kimura, 2009). Given the high prevalence of distress among this population, the NCCN (2016) recommends distress screening for all patients at their initial visit and across the care continuum, particularly when a change occurs in disease status.

Despite the prevalence of distress and the acknowledged importance of distress screening in people with cancer, sparse research exists that describes distress in patients undergoing radiation therapy. This study explored distress in patients with breast cancer or prostate cancer because these were the top two cancer sites treated in a community radiation therapy clinic, representing 30% and 17% of its patients, respectively. Therefore, this study investigated the distress levels of patients with breast or prostate cancer who were undergoing radiation therapy and investigated which problems were contributing to patients’ distress levels.
BACKGROUND

Researchers conducting large-scale studies of mood problems in patients with cancer confirmed that distress, depression, and anxiety are common complaints (Herschbach et al., 2008; Mitchell, Baker-Glenn, Granger, & Symonds, 2010; Mitchell, Hussain, Grainger, & Symonds, 2011). Despite efforts to highlight the need for psychological screening, these mood problems are often under-recognized by busy cancer care professionals and negatively affect patients’ quality of life (Ransom, Jacobsen, & Booth-Jones, 2006). Existing psychological guidelines endorse early recognition measures, such as routine screening for distress of all patients with cancer (NCCN, n.d., 2016).

The Distress Thermometer (DT) and its associated Problem List (PL) were created for use throughout care in an effort to assist with early detection of and interventions for distress among patients with cancer. Researchers in many countries have demonstrated the feasibility, acceptability, and usefulness of the DT and PL in patients with different types of cancers (Dabrowski et al., 2007; Fulcher & Gosselin-Acomb, 2007; Grassi et al., 2013; Hegel et al., 2008; Mergenthaler et al., 2011). Fulcher and Gosselin-Acomb (2007) specifically found that use of the DT and PL allowed for prompt follow-up, education, and referrals to address identified problems.

Mergenthaler et al. (2011) screened 1,446 outpatients with cancer and discovered that the most prevalent problems reported by these patients with cancer were fatigue (49%), pain (44%), impaired mobility (41%), and sleep disturbances (41%). In addition, Hegel et al. (2008) examined distress and psychiatric syndromes in patients with breast cancer, finding a high prevalence of distress and major depression, anxiety, and associated impaired function. In another study, Hegel et al. (2006) found the DT to be useful in detecting depression in patients with breast cancer. Ploos van Amstel et al. (2013) used the DT and PL to identify distress in patients with breast cancer, as well as problems with fatigue, muscle strength, and physical fitness, but did not differentiate by treatment modalities. Chambers, Zajdlewicz, Youlden, Holland, and Dunn (2014) demonstrated the ability of the DT to detect cancer-specific distress, anxiety, and depressive symptoms in patients with prostate cancer across different treatment modalities.

Although distress is studied in a variety of patients with cancer, little information is available specifically for patients with cancer receiving radiation therapy. In studies, researchers often include patients with a variety of types of cancers and treatment modalities; these patients are typically receiving more than one treatment modality. Therefore, the purpose of this study is to assess the level of distress of patients with breast cancer or prostate cancer receiving radiation therapy, identify which problems were contributing to distress levels, and correlate distress with demographic variables.

METHODS

This study is a retrospective medical record review of patients with breast or prostate cancer who presented to the radiation oncology department at the Community Cancer Center (CCC) in Normal, Illinois, from January 1, 2012, through March 31, 2012. The CCC is a joint venture between two midwestern community hospitals that provides services from experienced oncology professionals. In the radiation oncology department, a DT and PL are completed at each visit (i.e., the initial consultation, weekly on-treatment visits, and follow-up visits). Institutional review board approval was obtained from both hospitals and from Illinois State University.

PROCEDURES

The research team used a standard data abstraction tool, and a detailed procedure manual was developed. The data abstraction process was piloted, and initial orientation to the procedures was completed with two members of the research team to establish inter-rater reliability.

Medical records were abstracted for demographics (age, gender, marital status, and ethnicity), type of cancer, cancer stage, treatment status, comorbidities, distress score, and associated problems. The abstracted medical records were from patients aged 18 years or older with breast or prostate cancer who presented to the radiation therapy department. Microsoft Access® database forms were used to collect all necessary variables.

INSTRUMENTS

The DT is a single-item visual analog instrument that uses an 11-point scale to measure the amount of distress patients with cancer have experienced in the past week (Roth et al., 1998). Respondents self-report their level of distress from 0 (no distress) to 10 (extreme distress) (Jacobsen et al., 2005). Mitchell et al. (2011) categorized distress scores as mild (4–5), moderate (6–7), and severe (8 or greater). Researchers have demonstrated the DT has good sensitivity and specificity, as well as that it is significantly correlated with the Hospital Anxiety and Depression

“Women with breast cancer in this study had significantly higher Distress Thermometer scores than did men with prostate cancer.”
Scale (Akizuki, Yamawaki, Akechi, Nakano, & Uchitomi, 2005) and the Brief Symptom Inventory 18 (Graves et al., 2007; Roth et al., 1998). The DT has been shown to have good sensitivity and adequate specificity in patients with prostate cancer (Chambers et al., 2014). Ploos van Amstel et al. (2013) reported good internal reliability of the DT (Cronbach alpha of 0.9) in patients with breast cancer.

On the PL, respondents identify problems or concerns grouped into six categories (practical, family or social, emotional, spiritual or religious, informational, physical); these are selected by checking corresponding “yes” or “no” boxes (NCCN, n.d., 2016). The PL in this study was modified by the CCC with permission from NCCN to include questions about the following: housing and accommodations, worry about children, frustration and anger, applying for disability benefits, medication coverage, wigs and prostheses, feelings of being a burden to others, feelings of being alone, meaning and purpose of life, challenges to faith, and changes in appearance, nutrition, and weight. A total of 48 problems were included in six categories on the PL. In addition, respondents could indicate if they wanted to receive help for any identified problems, which problems were the most distressing, and the best time for additional contact.

Statistical Analysis
The statistical analysis was performed using SPSS®, version 22.0. The descriptive statistics were computed to characterize the distress scores and visits. Problem totals were computed by creating sum scores for the number of items patients indicated on the PL. Distress scores were categorized as little to none (0–3), mild (3.1–5), moderate (5.1–7), and severe (7.1–10). Bivariate relationships using t tests, Pearson correlation coefficients, and analysis of variance were used to correlate distress measures with patient factors (selected demographic variables and diagnosis).

Results
Medical records were reviewed of 217 patients with breast or prostate cancer presenting for radiation therapy consultation, treatment, or follow-up. The mean age of the total sample was 65.71 years (SD = 12.19), compared to 60.99 years (SD = 12.62) for patients with breast cancer and 70.4 years (SD = 8.2) for patients with prostate cancer. All disease stages were represented by the patients with breast cancer (stage 0 [n = 13, 10%]; stage I [n = 52, 40%], stage II [n = 42, 32%], stage III [n = 17, 13%], stage IV [n = 6, 5%]). Of the patients with prostate cancer, 21 were classified as low risk, 43 as intermediate risk, and 23 as high risk. In addition, all patients with breast cancer were women, and all patients with prostate cancer were men. Table 1 offers additional demographic details for the total sample, as well for patients with breast or prostate cancer. No significant differences existed between the distress score and cancer stage for patients with breast cancer (F [4, 123] = 1.091, p = 0.364) or distress score and prostate risk assessment for patients with prostate cancer (F [2, 81] = 0.851, p = 0.431).

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>TOTAL SAMPLE (N = 217)</th>
<th>BREAST (n = 130)</th>
<th>PROSTATE (n = 87)</th>
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<tbody>
<tr>
<td>Ethnicity</td>
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</tr>
<tr>
<td>Caucasian</td>
<td>207 95</td>
<td>126 97</td>
<td>81 93</td>
</tr>
<tr>
<td>African American</td>
<td>8 4</td>
<td>4 3</td>
<td>4 5</td>
</tr>
<tr>
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<td>1 1</td>
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<tr>
<td>Unknown</td>
<td>1 1</td>
<td>- -</td>
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<tr>
<td>Living arrangements</td>
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<tr>
<td>Alone</td>
<td>49 23</td>
<td>32 25</td>
<td>17 20</td>
</tr>
<tr>
<td>With family</td>
<td>10 5</td>
<td>7 5</td>
<td>3 3</td>
</tr>
<tr>
<td>With friends</td>
<td>2 1</td>
<td>1 1</td>
<td>1 1</td>
</tr>
<tr>
<td>With spouse</td>
<td>131 60</td>
<td>72 55</td>
<td>59 68</td>
</tr>
<tr>
<td>Other</td>
<td>6 3</td>
<td>2 2</td>
<td>4 5</td>
</tr>
<tr>
<td>Unknown</td>
<td>19 9</td>
<td>16 12</td>
<td>3 3</td>
</tr>
<tr>
<td>Marital status</td>
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<td></td>
<td></td>
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<tr>
<td>Married</td>
<td>143 66</td>
<td>81 62</td>
<td>62 71</td>
</tr>
<tr>
<td>Divorced</td>
<td>28 13</td>
<td>19 15</td>
<td>9 10</td>
</tr>
<tr>
<td>Widowed</td>
<td>28 13</td>
<td>19 15</td>
<td>9 10</td>
</tr>
<tr>
<td>Single</td>
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<td>9 7</td>
<td>7 8</td>
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<tr>
<td>Separated</td>
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<td>2 2</td>
<td>- -</td>
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<tr>
<td>Religion</td>
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<td></td>
<td></td>
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<tr>
<td>Stated preference</td>
<td>165 76</td>
<td>103 79</td>
<td>62 71</td>
</tr>
<tr>
<td>No preference</td>
<td>48 22</td>
<td>24 19</td>
<td>24 28</td>
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<tr>
<td>Unknown</td>
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<td>3 2</td>
<td>1 1</td>
</tr>
<tr>
<td>Treatment status</td>
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<td></td>
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<tr>
<td>Complete</td>
<td>152 70</td>
<td>88 68</td>
<td>64 74</td>
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<tr>
<td>Ongoing</td>
<td>55 25</td>
<td>37 28</td>
<td>18 21</td>
</tr>
<tr>
<td>Consultation</td>
<td>10 5</td>
<td>5 4</td>
<td>5 6</td>
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</table>

Note. Because of rounding, percentages may not total 100.
TABLE 2.
MEAN SCORES OF DISTRESS AND PROBLEM GROUP BY CANCER TYPE

<table>
<thead>
<tr>
<th>CHARACTERISTIC</th>
<th>TOTAL SAMPLE (N = 217)</th>
<th>BREAST (n = 130)</th>
<th>PROSTATE (n = 87)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>DT score</td>
<td>2</td>
<td>2.48</td>
<td>3.37</td>
<td>&lt; 0.000</td>
</tr>
<tr>
<td>Total number of problems</td>
<td>4.28</td>
<td>4.87</td>
<td>3.37</td>
<td>&gt; 0.053</td>
</tr>
<tr>
<td>Practical</td>
<td>0.76</td>
<td>0.9</td>
<td>0.54</td>
<td>&lt; 0.044</td>
</tr>
<tr>
<td>Family or social</td>
<td>0.54</td>
<td>0.6</td>
<td>0.45</td>
<td>&gt; 0.205</td>
</tr>
<tr>
<td>Emotional</td>
<td>0.86</td>
<td>0.97</td>
<td>0.7</td>
<td>&gt; 0.201</td>
</tr>
<tr>
<td>Spiritual or religious</td>
<td>0.11</td>
<td>0.12</td>
<td>0.08</td>
<td>&gt; 0.413</td>
</tr>
<tr>
<td>Informational</td>
<td>0.23</td>
<td>0.26</td>
<td>0.18</td>
<td>&gt; 0.324</td>
</tr>
<tr>
<td>Physical</td>
<td>2.04</td>
<td>2.25</td>
<td>1.71</td>
<td>&gt; 0.194</td>
</tr>
</tbody>
</table>

DT—Distress Thermometer
Note. The DT measures patients’ self-reported level of distress experienced in the past week on a scale of 0 (no distress) to 10 (extreme distress).
Note. A total of 48 problems were included in six categories (practical, family or social, emotional, spiritual or religious, informational, and physical) on the Problem List. Means indicate the average number of problems selected in each of the six categories.
Note. Bolded p values indicate that patients with breast cancer had significantly higher DT scores and experienced significantly more practical problems.

Distress Thermometer Scores and Problem List
A total of 1,108 DT and PL instruments from patients with breast or prostate cancer were reviewed. The number of patient visits ranged from 1–16, averaging 5.27 (SD = 3.92) visits. No significant difference was noted between the number of visits for patients with breast cancer or patients with prostate cancer (F[1, 215] = 0.19, p = 0.665). Patients reported DT scores throughout the entire range of the scale (0–10). The most reported DT score was 0 (n = 343, 31%), and the least reported DT score was 10 (n = 2, 0.2%). The average DT score was 2 (SD = 2). DT scores indicated that 72% (n = 156) of patients experienced little to no distress, 19% (n = 41) experienced mild distress, 6% (n = 13) experienced moderate distress, and 1% (n = 2) experienced severe distress. When comparing DT scores by type of cancer, the average distress of patients with breast cancer (X = 2.39, SD = 1.94) was statistically higher (p < 0.001) than that of patients with prostate cancer (X = 1.5, SD = 1.8) (t[210] = 3.36, p = 0.001).

Each time a patient indicated a concern on the PL, this information was recorded. For example, if a patient indicated on a single visit that he was concerned about pain, but did not indicate it was a concern on any other visit, pain was included in his list of concerns. The mean number of problems was 4.28 (SD = 5.43) for patients with breast or prostate cancer. Patients with breast cancer were most concerned about fatigue (29%, n = 37), worry about family and friends (24%, n = 31), weight (24%, n = 31), fears and worries (21%, n = 27), and pain (20%, n = 26). Patients with prostate cancer were most concerned about fatigue (n = 20), sleep (n = 19), pain (n = 15), worry about children (n = 14), and family health issues (n = 13). Only 6% of all patients documented anxiety or depression concerns.

In all problem groups (see Table 2), patients with breast cancer reported more problems than patients with prostate cancer. No significant correlations were observed among age, gender, and problems in patients with breast or prostate cancer. A significant correlation was noted between the average DT score and the total PL score (r = 0.5, p < 0.001), indicating that respondents who reported more issues on the PL had higher DT scores.

Discussion
In this study of patients with breast or prostate cancer undergoing radiation therapy, the levels of distress were assessed and the most concerning problems were ascertained using the DT and PL. The findings demonstrated that women with breast cancer reported significantly higher distress scores and more problems on the PL than did men with prostate cancer.

Unlike the numerous DT and PL studies that have captured many cancer types, this study focused on patients with breast cancer or prostate cancer undergoing radiation therapy. In this study, the overall average DT score was 2, which is lower than other researchers have reported. A reason for this low average may be because other researchers have investigated various types of cancer, including cases in which chemotherapy and radiation therapy are administered concurrently. Multimodality treatment is common in cancer care and can contribute to increased side effects, potentially increasing distress scores. For example, Baken and Woolley (2011)
reported that the average DT score was 2.9 in a sample from a regional cancer treatment database that included patients with a variety of cancer types and treatments across the cancer continuum. In other studies examined, the reported average DT scores ranged from 2.2 (Fulcher & Gosselin-Acomb, 2007) to 4.7 (Mergenthaler et al., 2011). Just one study had a median DT score of 2 (range of 0–9) (van Dooren et al., 2009). However, this study included only women who are at risk for developing breast cancer; therefore, a lower DT score may be expected.

Similar to the literature, women with breast cancer in this study had significantly higher DT scores than did men with prostate cancer. Bawwens, Baillon, Distelmans, and Theuns (2009), in a study of 538 patients (consisting of 60% women, 37% of whom were patients with breast cancer) from an ambulatory outpatient oncology clinic, demonstrated that women exhibited statistically significantly higher levels of distress than men. Calderón et al. (2014) reported that women in general tended to show more distress than men. Similarly, Miller et al. (2012), in a sample of breast cancer survivors of mixed cancer types, including patients with breast cancer and patients with prostate cancer, also found that the female participants had documented higher DT scores.

In this study, fatigue, pain, fears and worries, and sleep were the most commonly reported problems. These results are similar to other studies in which patients have reported the most common problems as fatigue, ranging from 36% (Dabrowski et al., 2007) to 57% (Ploos van Amstel et al., 2013); sleep problems, ranging from 33% (Dabrowski et al., 2007) to 41% (Mergenthaler et al., 2011); and concerns with pain ranging from 32% (Dabrowski et al., 2007) to 44% (Mergenthaler et al., 2011). Mosher and DuHamel (2012) found, in a sample of 90 women with stage IV breast cancer, that poor sleep quality was the most reported problem. Comparisons of the PL among the various studies are difficult because researchers often customize this instrument to fit their individual environments.

When the individual PL components were categorized, emotional problems and physical problems were most often reported. In a sample of 166 outpatients with cancer, Calderón et al. (2014) found that 80% of the participants reported emotional problems, whereas 54% reported physical problems. Researchers have also demonstrated a significant correlation between DT score and the number of problems identified on the PL (Mergenthaler et al., 2011; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008), adding evidence to the notion that the higher the DT score, the more problems the patient experiences.

In addition to assessing distress scores and problems, this study gathered information on comorbidities. Hypertension was the most identified comorbidity, with more patients with prostate cancer reporting hypertension than patients with breast cancer. The finding of lower overall distress scores in this study may be related to the fact that only 6% of the patients had documented anxiety or depression.

IMPLICATIONS FOR PRACTICE

- Note that the Distress Thermometer and associated Problem List may be appropriate for initial screening for patients undergoing radiation therapy.
- Understand that women with breast cancer undergoing radiation therapy may need follow-up for distress-related concerns and problems.
- Recognize that common problems reported by patients with breast cancer and undergoing radiation therapy include fatigue, pain, fears and worries, and sleep.

Limitations

Several limitations to this study exist. This was a retrospective medical record review of self-reported DS and PL instrument data. Self-report relies on the participants honestly documenting their distress and identifying all their problems. This study had a homogeneous sample, with 95% of the population identifying as Caucasian; therefore, the generalizability of this study is limited.

Conclusion

The DT with its associated PL is a vehicle for assessing distress in patients with cancer. Healthcare professionals may use this instrument to screen for distress in patients, which is a recommendation from NCCN. However, individual follow-up is necessary and should be patient-specific. These findings support that healthcare professionals can anticipate higher distress and more associated problems and concerns in women undergoing radiation therapy for breast cancer than in men undergoing radiation therapy for prostate cancer. Specific interventions for the most common problems of fatigue, pain, fears and worries, and sleep should be readily available.

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