Cancer-Related Distress and Unmet Needs among Triple Negative Breast Cancer Patients: Findings from the Cancer Experience Registry

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BACKGROUND
Cancer patients and survivors experience distress related to physical, psychological, social, and financial concerns. Individuals diagnosed with triple negative breast cancer (TNBC) may be at increased risk of distress due to the aggressive nature of the illness and high rates of recurrence.

AIMS
The aim of the present study was to describe how TNBC patients characterize cancer-related distress and concerns and identify factors associated with distress.

METHODS
• Cancer Support Community’s Cancer Experience Registry® (CER) is an online research program of surveys examining the physical, emotional, practical, and financial impact of cancer.
• From January 2015 to August 2021, a total of 195 U.S. residents with a history of TNBC took part in the CER and completed CancerSupportSource® (CSS-25), a 25-item validated distress screening tool.
• CSS subscale scores were calculated as the average item rating (0=Not at all; 4=Very seriously) across five key domains:
  (1) Emotional well-being (8 items)
  (2) Symptom burden and impact (8 items)
  (3) Body image and healthy lifestyle (4 items)
  (4) Healthcare team communication (2 items)
  (5) Relationships and intimacy (2 items)

PARTICIPANTS
N=195 individuals with TNBC
Mean ± SD:
Age (years) = 53.1 ± 10.3
Race & Ethnicity:
- Non-Hispanic White: 159 (82%)
- Non-Hispanic Black: 13 (7%)
- Hispanic: 10 (5%)
Household Income:
- <$40,000: 34 (17%)
- $40,000-$59,999: 24 (12%)
- $60,000-$79,999: 14 (7%)
- $80,000-$99,999: 25 (13%)
- $100,000 or above: 57 (29%)

RESULTS
Top Concerns by CSS-25 Subscale: “Moderately” to “Very Seriously” Concerned

<table>
<thead>
<tr>
<th>Concern</th>
<th>Emotional Well-Being</th>
<th>Symptom Burden and Impact</th>
<th>Body Image and Healthy Lifestyle</th>
<th>Healthcare Team Communication</th>
<th>Relationships and Intimacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating and nutrition</td>
<td>52%</td>
<td>54%</td>
<td>55%</td>
<td>52%</td>
<td>54%</td>
</tr>
<tr>
<td>Body image and feelings about how you look</td>
<td>40%</td>
<td>54%</td>
<td>49%</td>
<td>54%</td>
<td>42%</td>
</tr>
<tr>
<td>Recent weight change (gain or loss)</td>
<td>39%</td>
<td>40%</td>
<td>37%</td>
<td>33%</td>
<td>32%</td>
</tr>
<tr>
<td>Worrying about the future and what lies ahead</td>
<td>39%</td>
<td>32%</td>
<td>36%</td>
<td>32%</td>
<td>33%</td>
</tr>
<tr>
<td>Worrying about family, children, and/or friends</td>
<td>35%</td>
<td>30%</td>
<td>27%</td>
<td>30%</td>
<td>32%</td>
</tr>
<tr>
<td>Feeling irritable</td>
<td>32%</td>
<td>27%</td>
<td>23%</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Health insurance or money worries</td>
<td>30%</td>
<td>23%</td>
<td>23%</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Feeling nervous or afraid</td>
<td>37%</td>
<td>32%</td>
<td>27%</td>
<td>30%</td>
<td>28%</td>
</tr>
<tr>
<td>Feeling sad or afraid</td>
<td>35%</td>
<td>30%</td>
<td>27%</td>
<td>29%</td>
<td>27%</td>
</tr>
<tr>
<td>Finding meaning and purpose in life</td>
<td>34%</td>
<td>27%</td>
<td>23%</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Feeling lonely or isolated</td>
<td>32%</td>
<td>23%</td>
<td>23%</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Thinking clearly (e.g., “chemo brain”, “brain fog”)</td>
<td>49%</td>
<td>42%</td>
<td>36%</td>
<td>36%</td>
<td>34%</td>
</tr>
<tr>
<td>Feeling too tired to do the things you need or want to do</td>
<td>40%</td>
<td>37%</td>
<td>32%</td>
<td>32%</td>
<td>31%</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>37%</td>
<td>27%</td>
<td>23%</td>
<td>23%</td>
<td>22%</td>
</tr>
<tr>
<td>Moving around (walking, climbing stairs, lifting, etc.)</td>
<td>34%</td>
<td>27%</td>
<td>23%</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Changes or disruptions in work, school, or home life</td>
<td>30%</td>
<td>24%</td>
<td>21%</td>
<td>22%</td>
<td>21%</td>
</tr>
<tr>
<td>Managing side effects of treatment (nausea, swelling, etc.)</td>
<td>30%</td>
<td>22%</td>
<td>20%</td>
<td>21%</td>
<td>21%</td>
</tr>
<tr>
<td>Pain and/or physical discomfort</td>
<td>31%</td>
<td>24%</td>
<td>21%</td>
<td>22%</td>
<td>21%</td>
</tr>
<tr>
<td>Transportation to treatment and appointments</td>
<td>22%</td>
<td>18%</td>
<td>15%</td>
<td>16%</td>
<td>16%</td>
</tr>
<tr>
<td>Intimacy, sexual function, and fertility</td>
<td>33%</td>
<td>27%</td>
<td>23%</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Problems in your relationship with your spouse/partner</td>
<td>33%</td>
<td>27%</td>
<td>23%</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>Making a treatment decision</td>
<td>31%</td>
<td>25%</td>
<td>21%</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>Communicating with your doctor</td>
<td>32%</td>
<td>26%</td>
<td>22%</td>
<td>23%</td>
<td>22%</td>
</tr>
</tbody>
</table>

CONCLUSIONS AND IMPLICATIONS
• These data demonstrate that individuals with TNBC have persistent needs for psychosocial support and wellness programs.
• For TNBC patients, supportive services may be especially useful for younger cancer patients with metabolic disease and those who may be unemployed due to disability or other reasons.
• Psychosocial support should not only address emotional distress but also persisting concerns around cognitive function and fatigue.

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- Celgene Corporation
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Many individuals with TNBC reported concerns that were physical and future-oriented, highlighting critical areas of unmet need.

57% were concerned about cancer progressing or coming back (recurring).

• Younger age was associated with concerns about body image and healthy lifestyle and relationships.
• Unemployment was associated with higher distress of all types aside from healthcare team communication.
• Time since diagnosis was inversely associated with concerns about emotional well-being, such that distress was higher closer to diagnosis.
• TNBC patients with metastatic disease had significantly higher distress related to symptom burden and healthcare team communication.

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