Health-related quality of life of patients with neuroendocrine tumor compared to the United States general population

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BACKGROUND

• Health-related quality of life (HRQOL) can be disrupted in patients with malignancies
• A recent Norwegian study has shown that patients with neuroendocrine tumor (NET) have significantly reduced HRQOL compared to the general Norwegian population

OBJECTIVE

To evaluate the HRQOL burden of patients with NET compared to the general United States population

METHODS

• Individuals with NET were invited via email to participate in an online anonymous survey
• Data collected:
  • Demographic and disease-related questions
  • RAND-36 health survey
  • PROMIS-29 health index
  • Both standardized measures of HRQOL (RAND-36, PROMIS-29) have US general population normative values available for comparison
• Norm-based scores were calculated for all subscales, such that a score of 50 represents the mean of the general population (standard deviation=10) and evaluated using one-sample t tests
• On the anxiety, depression, fatigue, pain interference, and sleep disturbance subscales of the PROMIS, higher scores (+50) represent worse outcome
• On the physical functioning and social role subscales of the PROMIS and all RAND-36 scales, lower scores (<50) represent worse outcome
• Clinically important difference is approximately 2.5 – 5 points (or 0.25 to 0.50 standard deviation units) on T score metrics such as these
• HRQOL scores of 3 subgroups were compared to the general population using t-tests:
  • Patients with no tumor currently present (e.g., been surgically removed) — no current NET
  • Patients with tumor that has not been surgically removed or has come back after surgery — current NET, but without carcinoid syndrome
  • Patients with current NET and carcinoid syndrome

RESULTS

• Demographic and clinical characteristics of the sample are described in Table 1
• HRQOL scores in patients with NET are significantly worse than the general US population (all p < 0.01; Figures 1 and 2)
• Patients with no current NET had scores similar to the general population or better; patients with current NET but without carcinoid syndrome reported much worse HRQOL (Figures 3 and 4) particularly in the areas of fatigue, general health, & role limitations-physical
• Patients with current NET and carcinoid syndrome reported HRQOL that is comparable to individuals with anxiety, depression, diabetes, or arthritis, but is worse than a mixed cancer population (patients/survivors) or individuals with hypertension (Table 2)

Table 1. Demographic and clinical characteristics of sample (N=663)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Male %</th>
<th>White %</th>
<th>Hispanic %</th>
<th>Median age</th>
<th>Median years since diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumor type</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carcinoid</td>
<td>53.6</td>
<td>81.1</td>
<td>2.9</td>
<td>50-55</td>
<td>4 (range: 0-34)</td>
</tr>
<tr>
<td>Islet cell</td>
<td>62</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not sure what</td>
<td>65</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NET currently present</td>
<td>44.3</td>
<td>68%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PROMIS-29 spread to part of body other than lymph nodes</td>
<td>30.9</td>
<td>47%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2. PROMIS scores relative to other chronic diseases

<table>
<thead>
<tr>
<th>All (n=663)</th>
<th>No current NET (n=328)</th>
<th>NET, no carcinoid syndrome (n=115)</th>
<th>NET + carcinoid syndrome (n=328)</th>
<th>Cancer</th>
<th>Hypertension</th>
<th>Anxiety</th>
<th>Depression</th>
<th>Diabetes</th>
<th>Arthritis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Function</td>
<td>45.0</td>
<td>51.5</td>
<td>47.2</td>
<td>43.1</td>
<td>47.4</td>
<td>45.0</td>
<td>44.5</td>
<td>44.2</td>
<td>42.7</td>
</tr>
<tr>
<td>Social Role</td>
<td>46.4</td>
<td>53.1</td>
<td>47.8</td>
<td>44.6</td>
<td>50.7</td>
<td>48.6</td>
<td>46.0</td>
<td>45.8</td>
<td>48.1</td>
</tr>
<tr>
<td>Anxiet</td>
<td>54.3</td>
<td>51.3</td>
<td>53.0</td>
<td>55.0</td>
<td>48.6</td>
<td>50.3</td>
<td>57.6</td>
<td>56.2</td>
<td>51.3</td>
</tr>
<tr>
<td>Depression</td>
<td>51.7</td>
<td>48.0</td>
<td>50.2</td>
<td>52.7</td>
<td>48.5</td>
<td>50.4</td>
<td>56.8</td>
<td>56.8</td>
<td>51.6</td>
</tr>
<tr>
<td>Fatigue</td>
<td>54.7</td>
<td>47.9</td>
<td>51.8</td>
<td>56.8</td>
<td>49.3</td>
<td>51.6</td>
<td>57.5</td>
<td>57.3</td>
<td>53.5</td>
</tr>
<tr>
<td>Pain Interference</td>
<td>52.3</td>
<td>46.8</td>
<td>49.6</td>
<td>54.0</td>
<td>50.6</td>
<td>52.9</td>
<td>56.2</td>
<td>56.1</td>
<td>54.7</td>
</tr>
</tbody>
</table>

Notes: general US population score = 50, lower scores on Physical Function and Social Role indicate worse HRQOL; Sleep Disturbance scores not available in comparison groups; subgroup sizes do not sum to total since some participants did not provide information on current presence of NET or carcinoid syndrome; chronic diseases “Have you ever been told by a doctor that you have...? asked of n=21,133 in PROMIS calibration sample

CONCLUSIONS

• Patients with NET reported worse HRQOL outcomes compared to the general population on all subscales of the RAND-36 and PROMIS-29
• HRQOL burden is primarily due to the presence of carcinoid syndrome in over half of the sample, as this subgroup reported the greatest burden
• Symptom management and/or psychosocial interventions are needed to ease the HRQOL burden experienced by patients with NETs
• A limitation of this study is that it is a cross-sectional, observational survey of a non-randomized sample
• Further studies of treatment impact on HRQOL are warranted

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