Using PROMIS tools to assess change in patient’s experience of anxiety, depression, and pain among cancer survivors in a survivorship clinic.

Sarcoma Survivorship Program
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Sarcoma is rare.

- 0.2-0.6 per 100,000 people*
- 2-3% of childhood cancer*
- 800-1000 pediatric cases/yr. in the U.S.**
- Estimated 24-30 cases/yr. in Michigan
- 70% survival rate


Progress in Sarcoma

Therapeutic Advances
Fewer amputations

More Sarcoma Patients Cured
70% of Ewing & Osteosarcoma
50% of Rhabdomyosarcoma

Sarcoma recurrence
Second cancers
Chronic Health Conditions
Heart disease
Hypertension
Type 2 diabetes
Lipid disorders
Renal failure
Anxiety, depression
Suicide
Impact of Sarcoma Treatment

Sarcoma Treatment
chemotherapy, radiation, surgery

Medical issues that **shorten** life
heart failure, hypertension, renal failure, pulmonary insufficiency, depression/suicide, etc.

Medical issues that **affect** quality of life
thyroid disorders, fertility issues, problems of mobility and strength, social problems (employment, marriage)
Cancer Survivorship

- 20,000 children are diagnosed yearly with cancer
- Nearly 70% are cured

Among survivors:
- 2/3 had chronic health problem
- 25% had severe or lethal chronic condition
- 25% had 3 or more chronic health problems

Eligibility

- 18 years or older
- 2 years post-treatment
- No current diagnosis of secondary cancer
- Does not have to have received their cancer treatment at U of M or be a current patient.

Grant Funded
- IRB: HUM00095825
PROs+ Education + Regular Clinic Visits

• Anxiety and Depression is a prominent consequence of cancer treatment*.
  • Fear of Recurrence, reduced physical function, chronic pain.

• Survivorship care includes patient education, diagnosis, and management of chronic conditions- including anxiety and depression.

• Survivorship care should be more than monitoring for recurrence.

What does survivorship care mean to you?

“I don’t want to spend my whole life constantly freaking out that something bad is going to happen to me.”
Questionnaire:
- Health behavior
- Family medical history
- Current medical conditions
- PRO-PROMIS

Clinic Visit
- Comprehensive Exam
- Blood tests
- Imaging

Post-Visit
- Evaluation
- Treatment
- Survivorship Care Plan

There is a paucity of data related to psychiatric illnesses such as depression and anxiety in sarcoma survivors.
Patient Cohort

- 50% of cohort are aged 18-39
- 14 years- mean time between diagnosis and first visit
Positive change in PROMIS measures across domains

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline (T1)</th>
<th>12 months (T2)</th>
<th>24 months (T3)</th>
<th>T-score change</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>T3-T1</td>
</tr>
<tr>
<td></td>
<td>N=67</td>
<td>N=31</td>
<td>N=21</td>
<td></td>
</tr>
<tr>
<td>Global Mental Health v1.2</td>
<td>49.2 (7.9)</td>
<td>52.0 (7.9)</td>
<td>52.8 (5.2)</td>
<td>3.6 (+)</td>
</tr>
<tr>
<td>Global Physical Health v1.2</td>
<td>49.9 (6.3)</td>
<td>52.2 (6.8)</td>
<td>53.5 (6.4)</td>
<td>3.6 (+)</td>
</tr>
<tr>
<td>Pain interference CaBank v1.1*</td>
<td>51.5 (9.3)</td>
<td>48.7 (7.3)</td>
<td>48.0 (9.0)</td>
<td>3.1 (-)</td>
</tr>
<tr>
<td>Anxiety 8a</td>
<td>49.9 (9.6)</td>
<td>45.9 (10.6)</td>
<td>48.1 (8.5)</td>
<td>1.8 (-)</td>
</tr>
<tr>
<td>Depression 8a</td>
<td>47.6 (9.1)</td>
<td>45.8 (8.9)</td>
<td>44.4 (6.2)</td>
<td>3.2 (-)</td>
</tr>
<tr>
<td>Physical Function CaBank v1.1*</td>
<td>48.0 (9.2)</td>
<td>51.6 (8.8)</td>
<td>52.6 (8.7)</td>
<td>4.6 (+)</td>
</tr>
<tr>
<td>Sleep Disturbance 6a</td>
<td>50.1 (8.8)</td>
<td>48.9 (7.8)</td>
<td>47.2 (7.7)</td>
<td>2.9 (-)</td>
</tr>
</tbody>
</table>
Patients report PROMIS measures enhance clinical care and are easy to use

<table>
<thead>
<tr>
<th>Patient Survey Results (n=29)</th>
<th>MEAN / SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall Experiences / Preferences</strong></td>
<td></td>
</tr>
<tr>
<td>• I prefer to complete the health questionnaire electronically.</td>
<td>4.69 / .541</td>
</tr>
<tr>
<td>• I like being able to complete the health questionnaire at my own pace.</td>
<td>4.76 / .577</td>
</tr>
<tr>
<td>• I like being able to complete the health questionnaire in a place I am comfortable.</td>
<td>4.59 / .733</td>
</tr>
<tr>
<td><strong>Ease of Completion</strong></td>
<td></td>
</tr>
<tr>
<td>• Overall, the health questionnaire was easy to complete.</td>
<td>4.43 / .634</td>
</tr>
<tr>
<td>• The health questionnaire was too long.</td>
<td>2.79 / 1.013</td>
</tr>
<tr>
<td><strong>Supportive of Clinical Care</strong></td>
<td></td>
</tr>
<tr>
<td>• The health questionnaire asked me about a wide range of issues.</td>
<td>4.14 / .848</td>
</tr>
<tr>
<td>• My provider asked me about a wide range of health concerns because of the health questionnaire.</td>
<td>4.21 / .917</td>
</tr>
<tr>
<td>• The health questionnaire made me more comfortable talking about my health concerns</td>
<td>4.21 / .619</td>
</tr>
</tbody>
</table>
PROs+ Education + Regular Clinic Visits = Improved Quality of Life?

• Administering multiple PROMIS measures is feasible.

• Patients value PROs in enhancing the clinical experience.

• Patients report a positive change in PROs over time.

• “(Survivorship care) made me say, well, as they are willing to put the effort in, take care of yourself.”

• “I know that even if once a year he is looking at what my blood tests are showing and what is going on with my body, that gives me a high level of comfort.”
Thank you

Questions?

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