Changing Cancer Care: The Role of Patient Perspectives

Listening and Responding Requires a Culture Change

Chair: Sanchia Aranda
Deborah Dudgeon (CPAC), Esther Green (CCO), Sean Molloy (CCO)

Session code: PS.4.390-1
Screening for Distress

- Driver to achieve person-centred care
- Part of cancer program accreditation standards
- Point of entry followed by assessment, intervention &/or referral
# Screening for Distress

**Edmonton Symptom Assessment System:**

<table>
<thead>
<tr>
<th>Please circle the number that best describes:</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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<tbody>
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<td>No pain</td>
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<td>Not nauseated</td>
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<td>Not depressed</td>
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<td>Not anxious</td>
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<td>Not drowsy</td>
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<td>Best appetite</td>
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<td>Best feeling of wellbeing</td>
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<tr>
<td>No shortness of breath</td>
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<tr>
<td>Other problem</td>
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</tbody>
</table>

**Canadian Problem Checklist:**

Please check all of the following items that have been a concern or problem for you in the past week including today:

**Emotional:**
- Fears/Worries
- Sadness
- Frustration/Anger
- Changes in appearance
- Intimacy/Sexuality

**Spiritual:**
- Spiritual and/or religious concerns
- Faith

**Practical:**
- Work/School
- Finances
- Getting to and from appointments
- Accommodation

**Informational:**
- Understanding my illness and/or treatment
- Talking with the health care team
- Making treatment decisions
- Knowing about available resources

**Social/Family:**
- Feeling a burden to others
- Worry about family/friends
- Feeling alone

**Physical:**
- Concentration/memory
- Sleep
- Weight
Screening for Distress

Cancer Journey Portfolio

Screening for Distress, the 6th Vital Sign: A Guide to Implementing Best Practices in Person-Centred Care

September 2012

Melbourne - December 4th, 2014
Program Implementation

Below is a model which may be of assistance when establishing a Screening for Distress program. The following flowchart has been adapted from the Healthcare Association of New York State Breast Cancer Demonstration Project (HANYS BCDP).

1. Gather information
   - Build your rationale (quality of care, social, economical, political impacts)
   - Identify key stakeholders

2. Lay the Groundwork
   - Seek stakeholder input and enlist support
   - Reiterate impacts (patient centered, social, economical, political) of the program, and confirm your goals and uptake

3A. Evaluate Potential Obstacles
   - Evaluate potential obstacles to implementation, brainstorm for solutions

3B. Plan
   - Determine program scope, description, supporting tools, cost, and implementation

3C. Examine Current care
   - Collect baseline data for needs assessment and evaluation

4. Implement Program

5. Assess program implementation process and effectiveness.

6. Report the process and outcomes of your implementation
Outcomes of Treatment

- Lab, Imaging
- Physical Exam
- Clinician-graded symptoms
- QOL & Patient Reported Outcomes

Perceived value

Increasing Patient Recognition

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Balance of Discussion (Power)
The Ontario Cancer Symptom Management Collaborative (OCSMC)
A Hierarchy of Improvement Aims

1. 90% target population screened for symptom severity (ESAS)

- Patient screened with ESAS at initial contact and each subsequent contact
- More comprehensive assessment of pain, dyspnea, depression, anxiety or nausea if severity score is 4 or higher

HOW?

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A Person Centered Approach to Symptom Management

1. Patient self screens electronically for symptoms
2. Clinician discusses the ESAS with the patient
3. Manage symptoms using evidence based guidelines

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ISAAC Tracks Symptoms Over Time

Histogram

This is an example of the print-out, also called a histogram.

It shows that the patient has completed their symptom assessment several times at one hospital site.

It allows clinicians to view the patient’s symptom ratings over time, and this information will be available to the health care team as part of their comprehensive assessment.

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Structure to Support OSCMC

14 symptom management improvement leads aligned with Regional Cancer Programs

Regional Accountability Agreements with Symptom Management Deliverables

Provincial Support for Regional Improvement Initiatives

Dedicated Funding

IT Support – ISAAC Platform (Provincial Symptom Management Electronic Record)

Focus on Data for Use in Performance Management and Quality Improvement

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Balance of Discussion (Power)
To Achieve Screening Aims

- Examination of roles, reorganization of workflow & responsibilities, change booking times
- Involvement & education of all team members
- Engagement of clinical champions – “pull”
- Development of Symptom Guides & algorithms
Evidenced Based Tools to Guide Care

Cancer Care Ontario’s
Symptom Management Guides-to-Practice: Pain

Preamble

Cancer Care Ontario’s Symptom Management Collaborative
An initiative of Cancer Care Ontario, the Ontario Cancer Symptom Management Collaborative (OCSCM) was undertaken as a joint initiative of the Palliative Care, Psychosocial Oncology and Nursing Oncology Programs. The overall goal of the OCSCM is to promote a model of care emphasizing earlier identification, communication and documentation of symptoms, optimal symptom management and coordinated patient care.

The OCSCM employs common assessment and care management tools, including the Edmonton Symptom Assessment System (ESAS) screening tool to allow patients to routinely report on any symptoms they are experiencing. Symptom Management Guides-to-Practice were developed to assist health care professionals in the assessment and appropriate management of a patient’s cancer-related symptoms. In addition to the symptom-specific Guides-to-Practice, multidisciplinary Pocket Guides and Algorithms were created. Additionally, for a comprehensive management plan for patients with advanced disease, please refer to the Palliative Care Collaborative Care Plans.

Objective

The objective of this initiative was to produce Guides-to-Practice for management of patients with cancer-related symptoms. These documents are clinical tools designed to support healthcare providers in providing appropriate patient care and are not intended to serve as standards of care.

Target Population

The target population consists of adult patients who require symptom management related to cancer. It is outside the scope of these Guides-to-Practice to address the management of patients experiencing acute adverse effects secondary to treatment or radiation therapy. Please refer to the Program of Evidence-Based Care for guidelines related to these topics.
Over 61% of all Regional Cancer Centre (RCC) patients in Ontario are now being screened monthly (over 27,000 patients and 38,000 ESAS screens per month)

- All 14 RCCs offer electronic symptom assessment
- 23 partner hospitals now use ISAAC kiosks for symptom screening
- 10 hospitals have integrated ISAAC with their electronic health records (EHR)
- Over 1.6 million ESAS screens have been performed since the introduction of ISAAC

Goal: Every Ontario cancer patient has the ability to electronically assess their symptoms
Evaluation Dimension – Clinical Outcomes

- Provincial screening volumes have steadily increased since electronic screening was implemented in 2007
- As of **July 2014**, 60.1% of patients are screened each month, representing over 28,000 patients and 40,000 symptom screens
- Over 2.5 million symptom screens currently in the Provincial database
- Over 600,000 patient ECOG submitted (patient reported functional status)
- 372,000 patients registered in the symptom management database (size of New Orleans or London, ON)
### Evaluation Dimension – User Experience

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
<th>Comparison 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>92% (85%)</td>
<td>Thought ESAS was important to complete as it helps health care providers know how they are feeling</td>
<td></td>
</tr>
<tr>
<td>89% (62% - 2007)</td>
<td>Agreed that their physical symptoms have been controlled to a comfortable level</td>
<td>62% - 2007</td>
</tr>
<tr>
<td>86% (61% - 2007)</td>
<td>Agreed that their health care providers took into consideration ESAS symptom ratings in developing a care plan</td>
<td>61% - 2007</td>
</tr>
<tr>
<td>83%</td>
<td>Agreed that their care team responded to their feelings of anxiety or depression</td>
<td></td>
</tr>
<tr>
<td>62%</td>
<td>Indicated that their healthcare team talked with them about their ESAS symptom rating</td>
<td></td>
</tr>
</tbody>
</table>

Survey of 3,660 patients from 14 Regional Cancer Centres in 2014
Attitudes of Cancer Care Professionals Towards Symptom Screening and Management

<table>
<thead>
<tr>
<th></th>
<th>Percent Positive Responses</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The ESAS helps patients report their symptoms</strong></td>
<td></td>
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</tr>
<tr>
<td>Physicians</td>
<td>65.6%</td>
<td>59.9%</td>
<td>71.4%</td>
</tr>
<tr>
<td>Nurses</td>
<td>72.9%</td>
<td>68.3%</td>
<td>77.4%</td>
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<tr>
<td>Radiation Therapy Staff</td>
<td>78.3%</td>
<td>73.1%</td>
<td>83.5%</td>
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<tr>
<td>Psychosocial Oncology Staff</td>
<td>87.0%</td>
<td>80.8%</td>
<td>93.1%</td>
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<tr>
<td><strong>The ESAS serves as a useful starting point to assess patients’ symptoms</strong></td>
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<tr>
<td>Physicians</td>
<td>64.9%</td>
<td>59.1%</td>
<td>70.7%</td>
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<tr>
<td>Nurses</td>
<td>84.5%</td>
<td>80.8%</td>
<td>86.2%</td>
</tr>
<tr>
<td>Radiation Therapy Staff</td>
<td>80.7%</td>
<td>44.5%</td>
<td>88.2%</td>
</tr>
<tr>
<td>Psychosocial Oncology Staff</td>
<td>93.9%</td>
<td>89.5%</td>
<td>98.3%</td>
</tr>
<tr>
<td><strong>The ESAS improves symptom screening</strong></td>
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<tr>
<td>Physicians</td>
<td>59.5%</td>
<td>53.8%</td>
<td>65.5%</td>
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<tr>
<td>Nurses</td>
<td>64.5%</td>
<td>59.6%</td>
<td>69.5%</td>
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<tr>
<td>Radiation Therapy Staff</td>
<td>63.1%</td>
<td>57.1%</td>
<td>69.2%</td>
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<tr>
<td>Psychosocial Oncology Staff</td>
<td>85.2%</td>
<td>78.7%</td>
<td>91.7%</td>
</tr>
<tr>
<td><strong>The ESAS enables me to better manage my patients’ symptoms</strong></td>
<td></td>
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</tr>
<tr>
<td>Physicians</td>
<td>43.5%</td>
<td>37.5%</td>
<td>49.5%</td>
</tr>
<tr>
<td>Nurses</td>
<td>51.5%</td>
<td>46.4%</td>
<td>56.7%</td>
</tr>
<tr>
<td>Radiation Therapy Staff</td>
<td>37.7%</td>
<td>31.6%</td>
<td>43.8%</td>
</tr>
<tr>
<td>Psychosocial Oncology Staff</td>
<td>52.2%</td>
<td>43.0%</td>
<td>61.3%</td>
</tr>
</tbody>
</table>
The Symptom Management Summit

Design Thinking Approach

- Summit on Symptom Management brought together 180 administrative and clinical leaders with patients and family members from across Ontario.
- Process leveraged “design thinking” to develop quality improvement plans for each of the 14 Regional Cancer Centres.

1. Data driven ideation – results from the provincial attitudes to symptom management study was used to frame conversations.
2. Engage key administrative and clinical leaders from each region to ensure success.
3. Patient driven change by involving patients as full participants in each improvement team.
4. Build actionable QI plans for each region by the end of the day.
Symptom Management Summit Strategic Priorities

Melbourne - December 4th, 2014

Pivotal Challenges

A) Migrate from a Disease-Centered Care Model to a Person-Centred Care Model

- Increase the number of patients screened for symptoms before the start of their visit
- Increase clinician response to and use of patient-provided outcome data
- Define appropriate models of care for symptom management

B) Ensure a consistently excellent ISAAC experience to enable better care

- Create a standard entry point to the ISAAC system from all locations
- Ensure universal accessibility to ISAAC through mobile access
- Integrate ISAAC with hospital and community EMR systems

C) Ensure patients are empowered and engaged in their care

- Engage patient and family advisors in decision making at all levels
- Support patient education resources to improve symptom management
- Improve measurement of symptoms and treatment effects through new patient reported outcome measures

Objectives
Listening & Responding Requires a Culture Change