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CASE 9

Shifting Culture Between Patients and Health Care Teams to Impact Symptom Screen and Management

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BACKGROUND

Cancer patients often receive a combination of treatments to optimize the fight against cancerous cells. Along with desired outcomes of treatment, healthy tissue is also damaged and symptoms manifest. Patients typically suffer from multiple symptoms that range from mild to severe, which impact their daily functions and quality of life. Thus, an essential part of cancer care is symptom management as it gravely influences patients' quality of life. Palliative care attempts to prevent and treat symptoms caused by the disease and/or the disease's treatment. In 2007, Cancer Care Ontario adopted the Edmonton Symptoms Assessment Screening (ESAS) tool (Barbera et al., 2015). The aim of ESAS is to ensure and improve symptom management.

In July 2012, the percentage of cancer patients who were screened at least once with ESAS was 61.5% at the London Regional Cancer Program (LRCP) (Cancer Care Ontario, 2014). Since that time, the number of patients completing ESAS has declined. In March 2014, the proportion of all cancer patients screened at least once with ESAS was 39%; below the provincial average of 58.4% and substantially under the provincial target of 70% (Cancer Care Ontario, 2014). Accordingly, Cancer Care Ontario placed LRCP on a formalized performance management escalation plan. This plan aimed to investigate reasons for the decline and outline progressive steps to increase the ESAS rate. LRCP created the Symptom Screening and Management Project, which aimed to increase the ESAS completion rate by patients, and address care team members' actions on following up with moderate to severe ESAS scores.

In September 2014, the project was underway but lacked a program manager to take ownership of the program. LRCP appointed Lisa Grey as program manager. Grey was a Regional Program Specialist at South West Regional Cancer Program (SWRCP) and had several years of experience working with health promotion and facilitating similar programs in Windsor, Ontario. She was knowledgeable with ESAS and was able to help facilitate the transition of the tool to other South West centres. Leaders at LRCP felt that she would be a great asset to the team to build buy-in and generate a successful outcome. When Grey joined the project, she noted with concern that the ESAS rate had drastically dropped in the ESAS Usage Reports. Since 2012, the number of patients who had completed ESAS at least once during their cancer journey had reduced to just over 20%. In September 2014, the percentage of all cancer patients who were screened at least once with ESAS was 36%. Grey was determined to strengthen cancer symptom screening and management. As program manager, Grey was in charge of leading the

Symptom Screening and Management Project. Her role was to assess the performance measures, be consistently aware of changes involving ESAS, monitor the percentage of patients completing ESAS, evaluate patient and health care team barriers, supervise and maintain communication among five work streams dedicated to promoting ESAS usage, and investigate options to arrive at high-level recommendations.

AGENCIES

Cancer Care Ontario is an agency of the Government of Ontario that focuses on cancer prevention, screening, care, management, delivery, and access. It provides funding to 14 Regional Cancer Programs across Ontario. The South West Regional Cancer Program oversees local cancer issues and assists health care teams and centres such as the LRCP. Cancer Care Ontario had recently launched the Ontario Cancer Plan IV – a roadmap for how the government and partners across the province would work together to develop and deliver cancer services over the next four years. This Plan was structured around improving the patient experience. By adopting ESAS, Cancer Care Ontario aimed to improve symptom management by encouraging communication between patients and their health care teams to ensure patient-centered care. Doing so involves flagging and discussing moderate to severe symptoms and providing appropriate care in a timely manner.

EDMONTON SYMPTOMS ASSESSMENT SCREENING (ESAS)

ESAS is an interactive validated assessment tool (Chang, Hwang, & Feuerman, 2000). It allows for a self-assessment of patient symptoms on a standardized scale, and is accessible at a private kiosk where patients may be more likely to answer and rate their symptoms honestly. When patients are asked open-ended questions by clinicians, two-thirds of information is lost and patients underreport their experience (Homsi et al., 2006). ESAS screens nine symptoms: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath; brief definitions are included to explain each symptom (see Exhibit 1). This tool helps patients and health care providers by allowing them to track symptom changes during the patient's cancer journey. Ideally, patients complete ESAS after registration and at each patient review and clinical appointment visit. The results are then used by health care providers to conduct a deeper assessment, and to implement clinical measures and interventions into the patient's care plan.

ESAS provides an opportunity to identify symptoms earlier and reduce negative health outcomes through the management of these symptoms. It has been identified that patients with higher symptom scores have a greater chance of using an emergency room (Barbera et al., 2013). ESAS screening is associated with fewer emergency room visits (Barbera et al., 2015). In a population-based cohort study of elderly patients with cancer, one-third of patients who had reported high pain scores had not received a prescription for opioids (Barbera et al., 2012). Additionally, symptom scores may be an indication of death approaching. Symptoms such as fatigue, poor well-being, poor appetite, and drowsiness tend to increase during the last months of life, whereas pain, nausea, anxiety, and scores for depression remain constant (Seow et al., 2011). A survey of patients identified that ESAS is valued and contributes to their care plan (Green, 2012).

DECLINING USE OF ESAS

To discover barriers that contributed to the lack of ESAS use, LRCP conducted surveys and focus groups among both the health care team and patients. The goal of the research was to identify existing attitudes, values, and beliefs about symptom screening and management.

The following were investigated:

- Patient understanding of ESAS
- Patient concern about ESAS
- ESAS accessibility and user friendliness
- ESAS orientation
- Patient-health care team communication about ESAS results and symptom management
- Health care team familiarity with ESAS
- Health care members' roles in relation to ESAS
- Health care team access of screening and management resources and guidelines

BARRIERS

The surveys and focus groups completed by LRCP revealed aspects of team culture and patient culture. The work streams also gave insight to barriers.

Team culture among health care employees has a significant impact on patient use of the tool. Unfortunately, at LRCP, there were many factors that contributed to the breakdown of how staff encouraged and facilitated the use of the tool. For example, at patient registration for appointments, clerks were not asking patients to complete ESAS. Allied staff failed to direct patients to complete the screen when given the opportunity. Volunteers that stand at the kiosks to assist and orient patients to ESAS felt uncomfortable approaching patients because of privacy concerns. These factors all contributed to a lack of consistency in orienting patients to the kiosks. Some health care team members had lost confidence in the use of the tool and did not believe that it improved patient outcomes, and that symptom assessments were being completed during patient appointments regardless of the tool. Other care providers believed they were making use of ESAS, but did not directly refer to the tool when discussing symptoms with patients. The staff at LRCP used paper charting to document assessments. ESAS, however, is generated electronically and requires clinicians to access the ESAS results on a computer. This adds to their workload because in addition to completing the paper chart, they need to find an available computer and log in to view the results. Clinicians felt that accessing ESAS was time-consuming and that it took away from patient interaction.

Patient culture was another barrier that contributed to the decline of ESAS use. First, patients felt a lack of confidentiality when being assisted by volunteers. A lack of confidentiality and privacy was also due to the location of the kiosks in open areas within LRCP. It was reported that the placement of the kiosks on the walls was not accessible, nor user-friendly to patients in wheelchairs or those who wanted to complete ESAS while seated. Furthermore, the term kiosk had been used to reinforce the simplicity of completing ESAS electronically. However, there was an inconsistency with the use of the term and it has also been referred to as a computer. Some older patients were uncomfortable using computers and felt threatened by technology. While ESAS is offered in English and French, the number of languages spoken in London's multicultural community meant that some language barriers were present. There were also misperceptions of what the program was, why the ESAS should be completed, and where the information went. Some patients felt that the hospital was trying to take shortcuts in care and minimize patient-care provider interaction. These misperceptions are a result of insufficient orientation of patients with ESAS and a resulting lack of knowledge about program objectives.

IMPACTING ESAS

In June 2015, the Symptom Screening and Management Project (SSMP) continued, with revised goals:

- Ensure that at least 70% of patients seen at LRCP in a given month would complete ESAS at least once by March 2016.
- Ensure care team members take action to address symptom concerns in 100% of patients who identify moderate to severe symptoms by March 2016.

Project Manager Grey oversaw and ensured communication among five work streams, which included: 1) Process, Nursing, and Respiratory Therapist (RT) Engagement; 2) Patient and Volunteer Promotion and Resource; 3) Leadership Engagement and Accountability; 4) Volunteer and Clerk Engagement; and 5) Physician Engagement.

1. The Process, Nursing, and RT Engagement aims to improve processes related to cancer symptom screening and management in clinics and patient review, as well as define and communicate nurse and RT roles and symptom screening and management expectations.
2. Patient and Volunteer Promotion and Resources support patients and volunteers by creating educational and promotional material.
3. Leadership Engagement and Accountability defines and communicates leadership roles and symptom screening expectations. In addition to building and integrating accountability related to symptom screening and management across all levels, this work stream is responsible for monitoring and communicating program successes and potential areas for improvement over time.
4. Volunteer and Clerk Engagement aims to define and communicate the roles of volunteers and clerks and outline symptom screening expectations. This work stream also focuses on how to orient patients to ESAS.
5. Physician Engagement focuses on defining and communicating physician roles. This work stream also outlines physician symptom screening and management expectations.

The work streams developed a symptom screening and management strategy to build value in ESAS and outline specific tactics to change the health care team and patient culture. The vital behaviours they planned included prompting patients to complete ESAS, encouraging patient-care team discussions about symptom concerns, and empowering care teams to take action when addressing symptoms.

MAKING CHANGES

Grey entered the boardroom just in time for the teleconference with the Promotion and Education work stream. Present at the meeting were Patient Educators Matilda Cage and Veronica Darcy, Publicity and Marketing Specialist Lauren Spades, and Marketing Associate Arianna Spence. In a previous meeting, it was decided that these individuals would create posters and pop-up banners to prompt patients, and a postcard that would be a symptom screening overview for patients to explain why and how to complete ESAS. When these materials were completed, they were given to the steering committee for evaluation. With the steering committee's feedback, Spades and Spence made sure that messaging was clear, the wording reinforced positive messaging, and the colours used were consistent with the SSMP materials (see Exhibit 2: Postcard-Symptom Screening Overview). In this meeting, these materials were approved and team members continued to discuss patient engagement. They collaborated on where to place the posters and pop-up banners in LRCP. It was decided that the banners would be placed at patient entrances, across from the main elevators, at the blood lab, at the patient review, and in appointment rooms (see Exhibit 3: LRCP Map) with the goal of stimulating conversation about ESAS, and reminding patients to complete the screen after registration. They also decided to place wall stripes and decals behind each kiosk to increase

their visual identity in the often crowded waiting room. The meeting concluded and Grey sent out a communication memo to update the other work streams about the pending initiatives.

The collaboration of all work streams continued to develop ways to change patient culture and promote ESAS completion. In an effort to address patient feedback and the lack of understanding about ESAS, the My Care Binder was updated. The My Care Binder is given to patients on their first visit to LRCP. It is an educational resource that includes information on care, support, and services, and is also a place for patients to record and organize information throughout their cancer journey. Updates to the binder include information about what ESAS is and the importance of completing it. Furthermore, information was reorganized on the LHSC website (Symptom Screening page) and more resources were provided, including: symptom screening overview, symptom screening key messages, symptom screening Frequently Asked Questions document, and a symptom screening management video. Another tactic was to add welcome and exit key messages to the kiosks to reinforce reasons for completion. At the initial orientation, volunteers guide patients with the use of the touch screen technology at the kiosks and help them answer questions. At this time, patients also receive a postcard with instructions on how to complete the screen and messages about how the information is used. To address feedback about privacy, a hood was created to shelter the kiosk. This was piloted to see if it would be effective in decreasing privacy concerns and if supported, the hood would be implemented at all kiosks. Lastly, to make the kiosks more accessible, the screen height was made adjustable for patients in wheelchairs or those who wanted to complete it while seated. The combination of these tactics was believed to have highlighted the value of using ESAS on a consistent basis.

NEXT STEPS

With the implementation of patient-focused tactics, LRCP began to see an increase in ESAS use, but Grey knew that in order to see further improvements, there needed to be a greater focus on the internal culture at LRCP. The health care team was a fundamental factor in symptom screening and management. Buy-in was needed from the health care team and from management in order to achieve the project goals. The work streams proposed that the following needed to be addressed:

- Consistent messaging for ESAS
- Identify health care team roles and responsibilities
- Create leadership and communication related to symptom screening and management
- Create resources
- Refresh the health care team on available resources addressing management
- Strengthen patient-health care team communication

Grey had several meetings lined up with each work stream to discuss how to tackle these issues. As she prepared for the upcoming week, Grey knew that supporting symptom screening and management by changing the attitudes and values of the health care team would strengthen the cancer program and positively impact the quality of life for cancer patients at LRCP.

EXHIBIT 1
ESAS

Cancer Care Ontario
Action Cancer Ontario

Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness *(Tiredness = lack of energy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness *(Drowsiness = feeling sleepy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression *(Depression = feeling sad)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety *(Anxiety = feeling nervous)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing *(Wellbeing = how you feel overall)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem *(for example constipation)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name _____

Date _____ Time _____

Completed by (check one):
- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

ESAS-r
Revised: November 2010

Source: Cancer Care Ontario, 2010.

EXHIBIT 2
Postcard – Symptom Screening Overview

You know how you are feeling. We know how to help.

Completing the symptom screen helps you and your health care team to identify symptoms that may be of concern.

Your results are kept confidential and stored in your electronic medical record. Your health care team will review your scores before they meet with you. During your appointment, they will ask about the symptoms you have flagged as a concern to you. Ask about any symptoms of concern that are not part of the symptom screen.

We want to help manage your symptoms to help you feel better. There may be changes we can make to your care plan or other health care team members who can help (e.g., social workers, dietitians).

Completing the symptom screen:

1. Complete at every clinic and patient review appointment after registering – it takes less than five minutes
2. Use a touch screen kiosk located in the clinic and patient review waiting areas
3. Log in with your Ontario Health Card
4. Touch the kiosk screen to enter your answers
5. Rate your symptoms based on how you are feeling at that time

A score of zero means no symptom and ten means worst possible symptom

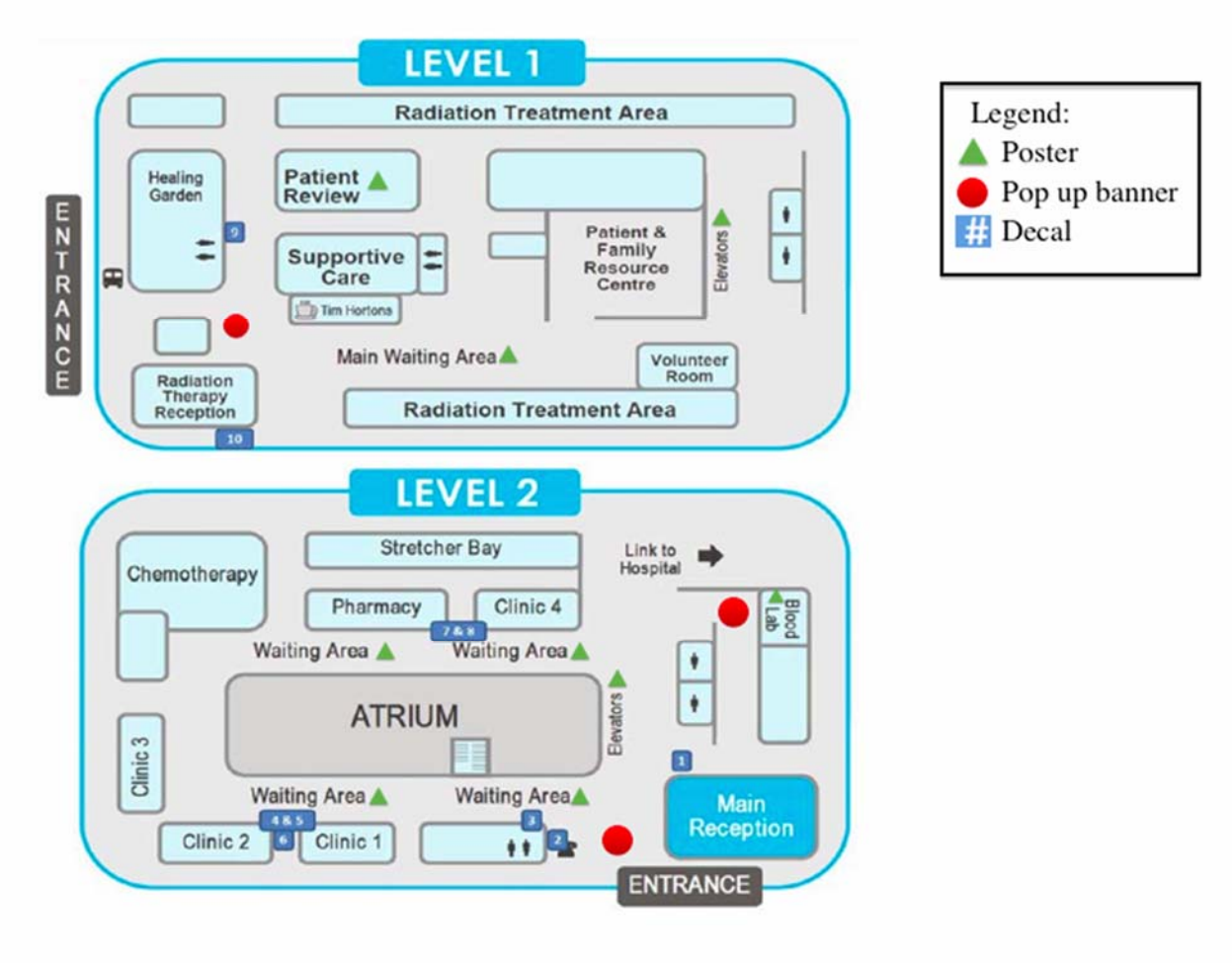
Ask a volunteer for help if needed.

Key terms:

Tiredness = lack of energy or low energy level
Drowsiness = feeling sleepy
Depression = feeling sad
Anxiety = feeling nervous or restless
Well-being = how you feel overall

Source: London Health Sciences Centre, 2015.

EXHIBIT 3
LRCP Map



Source: London Health Science Centre, n.d.

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Schulich MEDICINE & DENTISTRY

INSTRUCTOR GUIDANCE

Shifting Culture Between Patients and Health Care Teams To Impact Symptom Screen and Management

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BACKGROUND

Health Promotion Specialist Lisa Grey is faced with the task of strengthening patient and health care team culture using the Edmonton Symptoms Assessment Screening (ESAS) tool. ESAS is a standardized symptom screening tool used in health care settings across Ontario and is completed by patients at each clinic visit. The tool measures and tracks a patient's symptom severity relating to nine common cancer symptoms. Symptoms are an indication of the progression of cancer and patient health status. ESAS gives an opportunity to identify symptoms earlier on, prevent emergency admission, and manage symptoms such as pain (Barbera et al., 2012; Barbera et al., 2015). The percentage of total cancer patients who were screened at least once with ESAS had declined at the London Regional Cancer Program; screening rates were below the provincial target of 70% and the provincial average of 58.4% (Cancer Care Ontario, 2014). Grey oversees five work streams in an effort to change attitudes and beliefs among patients and health care employees, and highlight the value of using ESAS on a consistent basis.

OBJECTIVES

1. Understand the factors that influence patient and health care team culture.
2. Develop a strategy based on survey and focus group feedback.
3. Analyze and develop applicable health communication methods.
4. Apply a behaviour change model to the case.

DISCUSSION QUESTIONS

1. What are health communication methods and strategies that can be used to improve patient culture relating to participating in symptom screening?
2. What are the advantages and disadvantages of using these methods and strategies?
3. What partnerships are necessary to facilitate health care team (e.g. management, clerks, volunteers, nurses, physicians, and other allied health) culture changes?
4. Identify the key tensions related to the health care team culture.
5. Develop a strategy to address the issues in 'Next Steps' to increase symptom screening and management use among health care teams.

KEYWORDS

Patient culture; health care team culture; symptom screening and management; ESAS.