Highlights

- 14 Regional Cancer Centres, 14 Community Care Access Centres and their contracted nursing providers participated
- Over 50 Regional Improvement Teams were created
- All regions are using a web based tool to enter information and identify progress toward the improvement aims
- At seven hospital sites patients can enter their own symptom scores at a kiosk or through the Internet (“ISAAC”)
- As a province, we are about half-way to reaching the goal of 90% symptom screening for lung cancer patients.
- In less than one year, there has been more than a 20-fold increase in screening with the Palliative Performance Scale within the Regional Cancer Centre palliative clinics and adoption in the community sector has been even greater.
- 85% of respondents to a patient satisfaction survey thought ESAS was important to complete as it helps providers know how they are feeling.

Quotes from PPCIP participants

“The project highlighted the whole journey that patients take, which has formerly received little attention.”

PPCIP Improvement Team member

“The stars aligned and a lot of factors contributed to the success of the PPCIP-palliative care now gets discussed at senior leadership meetings- We need to maintain that focus.”

Palliative Care Physician

“I often forget to tell the doctor and nurse how I’m feeling, so this is great.”

(in reference to using ESAS)

Cancer Patient
Introduction

The following report provides an overview of the first year of the highly successful Provincial Palliative Care Integration Project (PPCIP). It includes information on the structure as well as the results and highlights some of the key learnings which could be applied to other larger quality improvement efforts. The project was able to achieve these results due in large part to the strong desire of the participants to create system-wide change in Palliative Care.

It is often said that change takes time, however through the use of a quality improvement collaborative approach you can in a short order make profound change that has the capacity for lasting results. Across Ontario cancer patients are now being routinely screened for common symptoms and data is being collected to help make decisions focused on improving patient care at both a clinical and system level. This report provides the highlights of the project’s results to date but this is clearly just the beginning!

Background

Over the past few years it has become evident that challenges exist in the system that provides palliative and end-of-life care services for patients across the province. Gaps exist in the quality of care, including how patients’ symptoms are assessed and managed, where care is accessed and the seamlessness with which care is delivered as patients move between hospital and home.

In order to begin to address these problems, in 2004 Cancer Care Ontario (CCO) identified Palliative Care as a strategic priority, and followed this up with activities such as: appointing a provincial Head of Palliative Care; providing financial support for regional Palliative Care Physician Leads; and developing a Palliative Care Strategy designed to define and address goals for system wide improvement in palliative care service provision. In 2006, CCO working with the provincial End-of-Life Care Networks decided to build on the successful local initiative in the South East Local Health Integration Network (LHIN) as a foundational first step toward meeting the strategy’s goals and objectives.

“It was reassuring to discover that others around the province were experiencing the same issues.”
The PPCIP was modeled after the South East LHIN project that was created to improve the quality of palliative care services by supporting collaboration and service integration across care sectors. It focused on the implementation of common tools for symptom screening and assessment, symptom management and collaborative care planning for cancer patients who require palliative care services. Prior to submission of a proposal to the Ministry of Health and Long-Term Care - Ontario Health Performance Initiative (OHPI), CCO and the End-of-Life Care Networks approached the regional partners about their interest and commitment to participate in the PPCIP. Initially it was anticipated that four to six regions would likely be interested, however the response was overwhelming as all 14 regions provided written expressions of interest and support for the project.

With partial funding provided by the Ministry of Health and Long-Term Care - Ontario Health Performance Initiative (OHPI), CCO launched the Provincial Palliative Care Integration Project (PPCIP) in late 2006. The fundamental goal of the PPCIP has been to promote efficient, high-quality palliative care delivery to patients and their families through the dissemination and utilization of evidence-based practices and through collaboration and service integration across the continuum of care. The project has been a partnership between the Regional Cancer Centres; Community Care Access Centres; End-of-Life Care Networks and Palliative Care Physician Leads.

The PPCIP included the implementation of a set of common validated tools to improve symptom screening and assessment; symptom control; and coordinated palliative support; use of an established model for quality improvement (QI); and provincially established improvement aims. Systems already in place at CCO to support improvements in Palliative Care, to lead and manage projects, and to collect, analyze and report data were enhanced by the introduction of a model for improvement which helped to make the large system improvements possible through small, incremental changes in each region.
Organizing for Improvement

This project has been implemented in every region of the province; has crossed hospital and home care boundaries; has included clinicians in all disciplines; moved between private and public providers and has as well increased patients’ control of their own symptom screening. The involved organizations all voluntarily agreed to be part of the collaboration and put resources, time and energy to the project including learning about and implementing the Institute for Healthcare Improvement’s Model for Improvement. The PPCIP was designed with both a central project support structure housed at CCO and a regional structure for each participating region. The roles of the team members in the central project team included: the creation of provincial project plans and project management as well as the provision of tools, and expert coaching and guidance for the regions. The central team also carried out project progress reporting, provincial data analysis, and program evaluation.

Each region received funds to support the hiring of a Regional Improvement Coordinator (RIC). Their role has been to support the implementation of the project in their regions with a primary focus on coaching and leading the quality improvement methodology. Each region has a Regional Steering Committee, which has been accountable for overall planning and coordination within the region. Accountability for this project in the regions has rested with the Regional Vice Presidents (RVPs) of CCO and clinical leadership has been provided by the Palliative Care Physician Leads in the regions with support from the Provincial Palliative Care Head. Regional Improvement Teams have been carrying out the work necessary for process improvements in the target areas in each region.

In addition to using a quality improvement framework and approach the PPCIP included a formal evaluation of the impact of the project. The evaluation was designed to track performance in the achievement of improvement aims and the impact of the collaborative implementation strategies on improving care processes.

“Having a dedicated RIC coordinator was an exceptional model”
Common Tools

The project included the implementation of a set of common tools to improve:

1. Symptom Screening and Assessment:
   • *Edmonton Symptom Assessment System (ESAS)*
2. Symptom Control:
   • *Symptom Management Guidelines (SMGs)*
3. Coordinated Palliative Support:
   • *Palliative Performance Scale (PPS)*
   • *Collaborative Care Plans (CCPs)*

Included in the objectives of the PPCIP was the implementation of technological tools for screening and monitoring of symptoms. CCO developed software known as the Interactive Symptom Assessment and Collection (ISAAC). ISAAC was built to allow patients to enter their ESAS scores directly at a touchscreen kiosk at the clinic or from home via the internet. The system maintains a database of demographic data, as well as the nine symptom scores contained in ESAS and the PPS score from each contact. Each patient record is associated with their Health Card Number, enabling symptom severity and functional status tracking over time and across health care settings. The system also provides the ability for clinicians to be notified by e-mail when a patient’s symptom score exceeds certain parameters, thus providing a mechanism for appropriate steps to be taken to improve symptom control or for referrals or consults.

Sites that do not have the kiosk or internet version of ISAAC, patient symptom screening data is recorded on a paper version of the ESAS tool and then the scores are manually entered into ISAAC or onto an excel file and uploaded into ISAAC.

Provincial Improvement Aims

The Model for Improvement begins with an identification of an improvement aim or aims, measures to detect process improvement and identification of changes that can be made towards these improvements. Rapid cycles of Plan-Do-Study-Act (PDSA) are then undertaken to implement and test change in the system process.
Although the ultimate aim is to implement the program with all cancer patients, a target population was initially chosen to break the work into manageable pieces.

The target population was:
- all lung cancer and palliative care clinic patients in Regional Cancer Centres, and
- all palliative care cancer patients in the home setting

A common provincial set of improvement aims was developed to guide the work of the regional improvement teams.

To improve care for cancer patients

1. 90% of target population are screened for symptom severity (ESAS)
2. 90% of target population’s symptoms are controlled. (SMGs)
3. 90% of target population have functional status assessed (PPS) and coordinated palliative care support provided (CCPs).

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

Patient screened with ESAS at initial contact and each subsequent contact

More comprehensive pain assessment if severity score is 4 or higher

More comprehensive dyspnea assessment if severity score is 4 or higher
2. 90% of target population’s symptoms are controlled. (SMGs)

- Symptom severity of pain and dyspnea will be 6 or lower within 72 hours of initial contact and 4 or lower on subsequent contact
- Patients will be satisfied with their level of comfort related to pain and dyspnea
- Depression score of 5 or higher will result in further assessment and/or referral to psychosocial resources within 72 hours

3. 90% of target population will have functional status assessed (PPS) and coordinated palliative care support provided (CCPs).

- 80% will be asked about goals for care and/or preferences for place of care
- 80% clinic patients with PPS scores 60 and below referred to home care and/or palliative care services within 72 hours
- 90% of patients with PPS 60 or less will have appropriate CCP initiated and documented

Cancer Care Ontario
Provincial Palliative Care Integration Project Report- Executive Summary
Key Results:

Symptom Screening and Assessment:

- Two regions surpassed the 90% mark in terms of the percent of the lung cancer population being screened in October 2007. (see graph below)

- Over 53% of lung cancer patients at the cancer centres and 29% of palliative home care cancer patients were screened with Edmonton Symptom Assessment System (ESAS) in October 2007.

- A total of 4,643 cancer patients completed ESAS in October 2007 and the total number of ESAS assessments has risen to over 10,000 per month.

- Regions with palliative care clinics report that ESAS screening is consistently between 70% and 90% of patients.

- 85% of respondents to a patient satisfaction survey thought ESAS was important to complete as it helps providers know how they are feeling.

- 70% of patients indicated they preferred the Kiosk/Internet version of ESAS over the paper-based tool and 15% indicated no preference, therefore 85% of patients were willing participants to the use of kiosk/internet technology.

- The ESAS histograms provide clinicians with a snapshot that summarizes the patient’s experience with various symptoms and “carries their history over time”.

- Over 70% of audited charts had a documented pain assessment and over 60% had completed a dyspnea assessment when symptom scores were in the moderate to severe range.
Symptom Control:

- 61% agreed that their providers took into consideration ESAS symptom ratings in developing a care plan.
- 62% of patients have indicated that their pain and other symptoms have been controlled to a comfortable level.
- 85% of patients have indicated that they have “never” or “rarely” had to wait to get a change in their pain or symptom medication.
- The province is about half way to the 90% goal of appropriate assessment or referral for patients experiencing depression.
- Among those patients who provided frequent enough ESAS scores to measure symptom improvement, 69% saw their pain scores reduced within 72 hours.
**Coordinated Palliative Support:**

- In less than one year, there has been more than a 20-fold increase in screening with PPS within the RCC clinics. Adoption in the CCAC sector has been even greater.

The benefits of the project beyond the individual patient outcomes and as perceived by the participants include such things as: improved system integration, “speaking with one language”, and collaboration among providers.

**Key Learnings:**

1) **Keep Improvement Aims Simple & Clear**
   - The improvement aims of a quality improvement initiative need to be simple, clear and easy to communicate.
   - The improvement aims for this project were designed to be easily measurable, but we learned they did not easily communicate the intent to the clinicians and front-line workers at the individual centres.

2) **Use the Right Words**
   - Use of the word “Palliative” introduced an automatic bias into the project. Often taken to mean “end-of-life”, the palliative label limited our ability to expand the use of the tools into certain clinical areas.

3) **Common tools mean shared meaning**
   - There is clear benefit to using common tools across sectors and disciplines.
   - Common language is a strong driver of integration since the way to describe patient symptoms is common to everyone giving care—regardless of the sector or discipline.

“Finally we are all speaking the same language”
4) **Trust the Local Process**
   - In this project, we set the provincial aims but didn’t direct how they would be carried out at the local level. Initially we were concerned that we were providing too much direction and standardization but we learned that the regions were able to apply the expectations and the model within their local context.
   - Our role was to provide the opportunity and the support, and we trusted the regions to re-engineer the implementation to create local success.

5) **Be Ready for the Pull**
   - CCO has been receiving requests from acute care hospitals, Family Health Teams, other provinces and other jurisdictions for access to the ISAAC software.
   - We didn’t anticipate how desirable the clinical application and ongoing ability to measure and monitor palliative care would be to others outside the original scope of the project. This has prompted us to work and plan differently for an unanticipated spread.

6) **Balance your need for provincial data with need to get quality improvement started**
   - It was very important to have data that could be reported across the province but we learned that at best, it is only a proxy for how well the improvement is embedded into practice.
   - There is valuable information in the stories, learnings and feedback from the local level.
   - Getting data to report is important but it should not be gathered at the expense of getting the local improvements off the ground.

7) **Champions, Champions, Champions.**
   - Having a dedicated resource and champion in the Regional Improvement Coordinators was one of the most important factors in the success of this initiative.
   - Leadership at the local level across all sectors and disciplines was also critical to success.
   - Sustainability is enhanced when expectations for performance are formally embedded in the role of the leaders (e.g. Regional Vice Presidents at the cancer centres).
Looking Forward:

Quality improvement is clearly a journey that continues over time, not a one-time destination and it is this central understanding, which has guided the efforts of the members of the PPCIP. CCO will continue to lead and facilitate further growth and sustainability over time and will begin reporting publicly on the data on the use of ESAS across the province. In the future CCO will have the ability to assess the impact of the project on longer-term outcomes such as reduction of emergency room visits and reduction in acute care hospital stays by using the data sets gathered as part of the PPCIP and this will provide a greater understanding of the impact of a quality improvement initiative on critical system outcomes.

The goals set for the next three years by CCO include continuing the spread of the improvement aims to other cancer patient populations, beyond lung cancer, and to other care sites. Patient access to ISAAC will be expanded beyond the current seven cancer centres and the processes required to enable patients to access ISAAC at home will be targeted.

The work of the initial project has now grown into a new improvement effort—The Ontario Cancer Symptom Management Collaborative. This collaborative builds on the initial work of the PPCIP and aims to spread existing knowledge to other settings, foster sharing of successes and challenges and seek the engagement of multiple partners in the system. The name brings with it a particular focus on improving the engagement of all team members in improved symptom management at all phases of the patient journey.

For more information go to: www.cancercare.on.ca