

Integrating Cancer Care Beyond the Hospital and Across the Cancer Pathway: A Patient-Centred Approach

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Abstract

Cancer patients constitute one of the most complex, diverse and growing patient populations in Canada. Like other high-needs patient groups, cancer patients desire a more integrated approach to care delivery that spans organizational and professional boundaries. This article provides an overview of Cancer Care Ontario's experience in fostering a more integrated cancer system, and describes the organization's emerging focus on patient-centred models of integrated care through the whole cancer pathway, from prevention to end-of-life care and survivorship.

Introduction

Patients with multiple co-morbidities, frequent hospitalizations and physical, mental or psychosocial challenges often bear the brunt of fragmented healthcare systems (Hollander and Prince 2008; Kodner and Spreeuwenberg 2002). These complex patients require services from several healthcare providers and organizations that frequently operate in silos. A lack of communication and coordination across professional and organizational boundaries can result in poor quality of care, wasted resources and dissatisfied patients (Enthoven 2009). Complex patients also have a significant impact on healthcare costs, as demonstrated by their health-service utilization patterns. In Ontario, over 80% of annual healthcare expenditures are linked to the healthcare services provided to only 20% of the

population (Wodchis et al. 2012). This group of high-cost, complex patients includes accident/trauma survivors, individuals at the end of their lives and those with one or more chronic illnesses, most notably cancer (Wodchis et al. 2012).

Cancer patients constitute one of the most complex, diverse and growing patient populations in Canada, as a result of higher rates of cancer incidence and improved detection, treatment and survival. Nearly 190,000 new cancer cases are diagnosed annually in Canada, of which approximately 40%, or 74,000 cases, are in Ontario (CSQI 2013). Cancer patients utilize a range of diagnostic, treatment and supportive-care services in different settings delivered by a multitude of professionals, including multiple non-cancer specialists, primary care physicians, nurses, pharmacists, physiotherapists and psychosocial workers. Like other complex patient groups, cancer patients require *integrated care* from medical, nursing and allied-health practitioners across hospital and community settings.

The delivery of integrated care requires coordination and collaboration across various organizations, care settings and professionals to ensure patients receive the right care, in the right place, at the right time. Canadian and international integrated care models (which typically involve case-managed multidisciplinary team care, organized provider networks and financial incentives) have demonstrated a range of positive outcomes. These include reduced emergency department (ED)

visits and nursing home placements, lower institutional costs, higher patient satisfaction and improved health outcomes (Curry and Ham 2010). Another common feature of these models is their focus on the frail elderly and those with chronic diseases. The academic literature suggests that integration initiatives focused on complex patient populations will yield greater quality, efficiency and patient satisfaction when compared with broader, generic approaches to integration (Burns and Pauly 2002; Kodner and Spreeuwenberg 2002; Leutz 1999).

Cancer patients who experience disease progression have particularly complex health and social needs, as they often present with multiple co-morbidities. In Ontario, almost 40% of all deaths are related to cancer, and the percentage of cancer patients who visit an ED during their last two weeks of life or who die in an acute care hospital remains high (43% and 53%, respectively) (CSQI 2013). The early introduction and integration of palliative care into patients' cancer journeys therefore has the potential to improve quality of care and the patient experience, while reducing or maintaining healthcare costs (Barbera and Dudgeon 2010; Klinger et al. 2013; Temel et al. 2010).

This paper summarizes Cancer Care Ontario (CCO)'s integration efforts across the patient journey from prevention to end-of-life care and survivorship and discusses the organization's emerging focus on a patient-centred integrated model of care.

Integrated Cancer Care in Ontario

CCO's integration efforts to date have focused primarily on hospital and provider partnership strategies. These institution- and provider-centred approaches to functional, organizational and clinical integration reflect similar steps taken towards integrated care in various other jurisdictions (Evans et al. 2013).

In the 1990s, Ontario's cancer system had reached a critical point and was under intense pressure to change. As the incidence of cancer continued to grow, the cancer system was fragmented and unable to meet patient demands. In addition, limited information existed about access, quality of care and

outcomes for cancer patients at the provincial and regional levels, making quality improvement on a provincial scale a challenge (Hudson 2001).

In response to growing concerns, CCO worked with the Ministry of Health and Long-Term Care (MOHLTC) and regional partners to plan for system-wide changes in the administration of cancer services. In January 2004, the governance and leadership structures at the ambulatory care Regional Cancer Centres (RCCs), and those of their co-located hospitals, were integrated. On the path towards achieving organizational and functional integration, CCO devolved its operational authority over the RCCs and made their host organizations accountable for delivering cancer services under an overarching CCO-led strategy, the Ontario Cancer Plan. CCO also led provider-level integration by building clinical leadership at the provincial and regional levels to facilitate the development and implementation of shared guidelines for cancer care across organizations and regions. The adoption of Multidisciplinary Cancer Conferences (MCCs) by CCO is one example of how clinical leads champion new evidence-based programmatic initiatives. MCCs are regularly held in cancer programs, where interprofessional oncology teams review individual cases and collectively determine treatment plans. Patients whose cases are reviewed at an MCC are more likely to receive treatment according to clinical guidelines (Forrest et al. 2005). In a study of almost 14,000 women with breast cancer, MCCs improved survival by 11% and reduced variation in survival among hospitals (Kesson et al. 2011). In 2012/2013, 32,000 patients were discussed at MCCs throughout Ontario. In 2008, CCO expanded its clinical leadership model to include primary care and launched the Provincial Primary Care and Cancer Network (PPCCN) (Levitt and Lupea 2009). The initial focus of the network was on increasing the rates of colorectal cancer screening and has since expanded to improving care and the patient experience across the entire cancer pathway from prevention to end-of-life care and survivorship.

Over the past 10 years, evidence has emerged suggesting equivalent outcomes for appropriately selected cancer survivors whose care is transitioned from oncologist-led models to nurse-led models in cancer clinics or primary care-led models in the community (Grunfeld et al. 1999; Grunfeld and Earle 2010; Lewis et al. 2009; Sussman et al. 2012; Wattchow et al. 2006). Primary care providers are often willing to assume followup care with proper guidelines and a clear transition of care for their patients, and are more likely than oncologists to provide preventive interventions directed at non-cancer conditions (Del Giudice et al. 2009; Grunfeld and Earle 2010). Based on these observations, funding was provided in 2012 to support the development and evaluation of models to transition appropriate breast and colorectal cancer survivors from medical oncology-led practice to primary care settings.

LIST OF ACRONYMS

Acronym	Description
CCO	Cancer Care Ontario
ED	Emergency department
RCCs	Regional Cancer Centres
MCCs	Multidisciplinary Cancer Conferences
PPCCN	Provincial Primary Care and Cancer Network
MOHLTC	Ministry of Health and Long-Term Care
CCACs	Community Care Access Centres
ESAS	Edmonton Symptom Assessment System
ORN	Ontario Renal Network

Integrated Patient-Centred Care

Recent literature and evolving patient needs demonstrate that patient centredness and community-based health and social services are the next frontiers for healthcare integration (Evans et al. 2013; Singer et al. 2011). As such, the definition of integration has recently been extended to incorporate not only the concept of coordination, but also the concept of patient centredness (Singer et al. 2011). According to Singer and her colleagues (2011: 113), integrated patient care is:

- coordinated across professionals, facilities and support systems;
- maintained over time and between visits;
- tailored to patients' needs and preferences; and
- based on shared responsibility between the patient and caregivers for optimizing health.

This explicitly patient-centred model of integration targets the well-documented challenges faced by complex patients and their families – and provides the framework for CCO's efforts to improve cancer services integration. The province-wide focus on integrated care, led by the MOHLTC's Transformation Secretariat, provides a supportive and enabling context for CCO's integration initiatives. It offers unique opportunities for collaboration with the work of the MOHLTC's recent initiative for Health Links, which integrate services for high-needs patients.

Beyond Hospitals and into the Community

Integration strategies are becoming an increasingly timely and common element of health-system redesign and reform efforts as populations age, the burden of chronic disease deepens, financial constraints tighten and new technologies and treatments are developed (Tsisis et al. 2012). The academic literature increasingly emphasizes the need to move beyond integrating tertiary-care services to integrating home- and community-based services (Valentijn et al. 2013). Research indicates that health systems that are supported by a strong primary care foundation result in better health outcomes at lower total health-service costs (Starfield et al. 2005). Yet, the largest gaps in quality of care, identified in following text, occur where patients transition from one provider to another (Coleman 2003).

Three key areas of focus for improving integrated care for complex patients have been identified.

Focus 1: Care Transitions

A lack of communication and coordination at transition points contributes to numerous quality and safety problems, including suboptimal chronic disease management, adverse events, medication errors, unnecessary declines in patient health and functional status and preventable hospital readmissions and

costs (Coleman 2003). Therefore, the first area of focus is to improve transitions in care for patients as they move across settings and providers, particularly from the hospital back into the community.

Focus 2: Care Outside Hospitals

Many patients and caregivers prefer the convenience of home- or community-based care, and empirical evidence confirms that several cancer treatments can be safely delivered outside of the hospital (Boothroyd and Lehoux 2004; Luthi et al. 2012). Some services are also more cost effective when delivered in the community or in patient homes rather than in hospital (Boothroyd and Lehoux 2004). The second area of focus is to enable the provision of safe treatment and care outside of hospitals, such as chemotherapy infusions and wound care in community settings or patients' homes.

Focus 3: Palliative Care

The third area of focus is to promote early identification of patients who can benefit from an integrated, interprofessional approach to palliative care. Palliative care refers to services that improve the quality of life of patients who have a serious or life-threatening disease by preventing or treating, as early as possible, the symptoms of the disease and the side-effects of the treatment, in addition to addressing the related psychological, social and spiritual needs of patients and their families (National Cancer Institute 2014). Cancer patients at the end of life have complex health and social needs that, if not adequately addressed, result in poor patient outcomes and experiences, as well as high costs to the system due to inappropriate utilization of acute care services (CSQI 2013). Despite the significant potential benefits of palliative care, patients continue to be referred to palliative care programs in low numbers and late in their cancer journey (Hui et al. 2010). In the remainder of this article, we discuss CCO's approach to integrating palliative care for cancer patients as a central component of CCO's integrated care improvement work.

Early Access to Integrated Palliative Care Services

A common misperception about palliative care is that it is appropriate only at the end of life. In Ontario, 53% of cancer patients died in an acute care hospital in 2009, and 8.3% of these patients were referred to palliative care only in the last two weeks of life (CSQI 2013). Identifying the need for palliative care only at the end of life has significant negative implications for patients, including unnecessary prolonged suffering from pain and other symptoms, a lack of preparedness for the end of life and the inappropriate and unwanted use of acute care services. Early implementation of palliative care, meanwhile, has been proven to provide benefits to both patients and their families, which

include less depression and anxiety, better quality of life, less aggressive treatment and lowered healthcare costs (Temel et al. 2010; Howie and Peppercorn 2013; Zimmerman et al. 2014). A Canadian public survey found 87% believe that a palliative approach to care should be available early on in the course of a disease; and 93% believe palliative care services should be available in the setting of their choice (The Way Forward 2014)

CCO is implementing the INTEGRATE Project, a pilot project that incorporates integrated models of palliative care for early identification of palliative care, assessment and management of patients across settings. Interdisciplinary teams that include primary care, MCC teams and Community Care Access Centres are participating in this pilot. The surprise question, “Would you be surprised if this patient were to die in the next year?” (Free et al. 2006) will be leveraged to promote early identification of patients in the primary care and cancer centre settings. This approach will be tested from 2014 to 2017 in select regions of Ontario. To support these integrated models of palliative care, existing CCO and other evidence-based infrastructure, resources and tools will be utilized, including symptom management guides and validated symptom assessment tools, such as the Edmonton Symptom Assessment System (ESAS). ESAS assesses pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. This approach requires education for all care providers on the appropriate use of the tools and the development of process maps between care providers for information flow.

Conclusion

While great strides have been made in the early detection and treatment of cancer, cancer patients continue to represent one of the most complex, diverse and growing patient populations in Canada. The provincial and regional structures that have been established in Ontario's cancer system in recent years provide a strong foundation for interdisciplinary care, evidence-based practice, continuous quality improvement and performance management. However, much remains to be done to provide truly patient-centred integrated care across the cancer continuum.

Together with existing and new partners, CCO is building on past work to integrate hospital-based services to design a care system that provides integrated care across multiple settings. The current focus on palliative care is aligned with the provincial government's transformation agenda and offers an opportunity to have an impact on growing system costs while improving experience and outcomes for this underserved segment of the population. The Ontario Renal Network is also working with CCO to further advance integrated palliative care for renal patients, leveraging alignment across the organization. It will be possible to achieve high-quality, cost-effective integrated care by looking beyond the four walls of hospitals and into the community, and by integrating palliative care earlier in the

patient journey. Improving services for complex and vulnerable individuals may also contribute to system-wide enhancements in integrated care for all patients by highlighting innovative and successful patient-centred models that can be applied more broadly. **HQ**

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