Cancer Care Ontario

Recommendations for the Delivery of Psychosocial Oncology Services in Ontario

Ontario
Cancer Care Ontario

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As the government's principal cancer advisor, Cancer Care Ontario equips health professionals, organizations and policy-makers with the most up-to-date cancer knowledge and tools to prevent cancer and deliver high-quality patient care. We do this by collecting and analyzing data about cancer services and combining it with evidence and research that is shared with the healthcare community in the form of guidelines and standards. We also monitor and measure the performance of the cancer system, and oversee a funding and governance model that ties funding to performance, making healthcare providers more accountable and ensuring value for investments in the system.

Cancer Care Ontario actively engages people with cancer and their families in the design, delivery and evaluation of Ontario's cancer system, and works to improve the performance of Ontario's cancer system by driving quality, accountability, innovation and value while ensuring a positive patient experience.

Provincial Psychosocial Oncology Program

The provincial Psychosocial Oncology Program (PSO) at Cancer Care Ontario is dedicated to improving the awareness of, access to and quality of specialized services that support the social, psychological, emotional, spiritual, quality of life and functional needs of patients and their families through the cancer care continuum.

Foreword

As a psychiatrist and psychosocial professional who has worked for more than 20 years with patients and families affected by cancer, I have seen both the psychosocial impact of the disease as well as the tremendous improvements in quality of life offered by high-quality psychosocial oncology (PSO) services.

While we have ample evidence demonstrating the benefits that PSO services can provide in managing the emotional, spiritual, functional, practical, nutritional and rehabilitative challenges associated with cancer, patients and families continue to face significant barriers in finding and accessing these services in Ontario. Across the province there are marked variations in the delivery and availability of PSO services. Patients often do not know how or where to find help, while healthcare providers struggle to connect them with appropriate supports.

Confusion about what PSO is and a lack of a cohesive identity and understanding about the essential elements required for a well-defined PSO program have contributed to this fragmented and vulnerable system of care delivery. This document aims to address these issues and provide recommendations around PSO service delivery across Ontario's Regional Cancer Programs.

My hope is that as these recommendations are adopted, we will see improved access to consistently high-quality care for all Ontarians, regardless of where they live in the province.

DR. MARK KATZ

Provincial Head, Psychosocial Oncology Program,
2015-2017 Cancer Care Ontario

If you want to make Ontario's cancer system better for patients then you have to ask the people who have themselves faced all the physical and emotional ups and down that cancer entails. Consulting patients and their families is particularly important when it comes to developing recommendations for the delivery of PSO services. We are the ones who have, as the result of cancer, struggled with anxiety, depression and brain fog, faced employment and financial challenges, and had to come to terms with our post-treatment realities. We are also the ones who have felt confused and alone as we tried to navigate the system to get the help we need.

On behalf of the Patient and Family Advisors who were engaged and contributed to the Recommendations for the Delivery of PSO Services in Ontario, I would like to thank Cancer Care Ontario and the provincial PSO Program for their commitment and leadership in this area. Working together, we will improve access to PSO services for patients and their families across Ontario.

JOANNE M.

Patient and Family Advisor,
Chair of the PSO PFA Committee

Executive Summary

RECOMMENDATIONS FOR THE DELIVERY OF PSYCHOSOCIAL ONCOLOGY SERVICES IN ONTARIO

one

ORGANIZATION, STRUCTURE AND PHILOSOPHY OF THE PSO PROGRAM

1.1 Psychosocial Oncology is reflected as a distinct program within the internal organizational structures of all Regional Cancer Programs in order to enhance cohesion and communicate a consistent identity; an external program name change is not necessary.

1.2 All patients and providers within the Regional Cancer Program will actively be made aware of appropriate and available psychosocial supports within the Regional Cancer Program and the community to ensure timely and appropriate referral to specialty PSO services.

1.3 In all Regional Cancer Programs, PSO services are offered and available to patients and families throughout the cancer care continuum (from prevention and cancer screening through onset of symptoms, diagnosis and treatment, to survivorship or recurrence and end-of life-care).

1.4 Regional Cancer Programs ensure that PSO services are delivered in the language that the patient feels most comfortable using and in a way that respects cultural diversity and varying levels of health literacy.

1.5 All Regional Cancer Programs use a consistent methodology in data collection and reporting, as set out by Cancer Care Ontario's PSO Program.

two

SCREENING FOR PSO CARE

2.1 Regional Cancer Programs continue to consistently use symptom screening tools as a component of the screen for PSO needs.

2.2 All sites develop an inter-professional approach for responding to clinically significant screening for all issues and/or elevated symptom screen scores. Teams consider secondary assessment tools for elevated scores.

2.3 Symptom screens be addressed routinely at clinic visits; the symptom scores should be acknowledged followed by assessment, interventions and referral to another healthcare provider when necessary.
A conversation between patient and frontline provider is essential before referral to specialized PSO providers occur to ensure that the intervention required is within the scope of the specialized PSO provider and to maximize the availability of PSO resources.

three

ACCESS TO PSO CARE

3.1 Regional Cancer Programs ensure cancer patients have access to timely PSO interventions, according to Cancer Care Ontario's target wait times.

3.2 Patients experiencing emotional, psychological, cognitive and/or spiritual distress have access to psychiatrists, social workers, psychologists, and/or spiritual care providers.

3.3 Patients experiencing physical, functional, rehabilitative, and/or nutritional concerns have access to occupational therapists, physiotherapists, registered dietitians and/or speech language pathologists.

3.4 Regional Cancer Programs ensure continuity of care for all patients, regardless of where they receive their cancer treatment.

3.5 Regional Cancer Programs are encouraged to work collaboratively with stakeholders for provision of PSO services for a shared model of care. Patients be provided with the opportunity to be referred to the Regional Cancer Program where services are not available in the community.

four

SPECIALIZED PSO SERVICES FOR PATIENTS AND FAMILIES

4.1 Regional Cancer Programs ensure patients and families have access to individual, family and group PSO care from an inter-professional team of specialized providers to cover a full range of services.

five

QUALITY IMPROVEMENT THROUGH CLINICAL TRAINING, SUPPORT AND RESEARCH

5.1 Regional Cancer Programs provide the opportunities and necessary infrastructure for teaching and training students of the specialized PSO disciplines, as well as front-line providers in the principles and practices of PSO.

5.2 Opportunities be provided for frontline staff in accessing the expertise and support services offered by specialized PSO providers.

5.3 Opportunities be provided for peer supervision, and knowledge sharing activities such as participation in inter-disciplinary case conferences and communities of practice.

5.4 Regional Cancer Programs support specialized PSO providers in enhancing their clinical skills and competence through continued education.

5.5 Specialized PSO Providers complement their clinical practice with evidence-based PSO guidelines.

5.6 PSO programs be involved in quality-improvement projects, as well as collaborative, inter-professional, multi-centre research.

5.7 Regional Cancer Programs participate in the measurement of PSO services outcomes as a means of ongoing quality improvement.

5.8 Regional Cancer Programs ensure Patient and Family Advisors are engaged in the planning and evaluation of PSO services.

> Regional Cancer Programs ensure patients and families have access to individual, family and group PSO care from an inter-professional team of specialized providers to cover a full range of services.

About the Report

One of the goals identified in the Ontario Cancer Plan IV is the delivery of responsive and respectful care, optimizing individuals' quality of life across the cancer care continuum.

The Ontario Cancer Plan IV, released by Cancer Care Ontario in 2015(1), is a road map for how Cancer Care Ontario, the Regional Cancer Programs, our many partners and the Ministry of Health and Long-Term Care will work together to continue to improve the performance of the cancer system in this province.

One of the goals identified in the Ontario Cancer Plan IV is the delivery of responsive and respectful care, optimizing individuals' quality of life across the cancer care continuum. This goal is supported by the strategic objective to expand and integrate access to palliative, psychosocial and rehabilitation services to improve quality of life and patient experience in cancer programs and the community. This document, Recommendations for the Delivery of Psychosocial Oncology Services in Ontario, is an important step towards meeting this objective.

The 2017 Annual Report released by the Office of the Auditor General of Ontario also highlighted insufficient and inconsistent PSO services for cancer patients(2). While services and interventions have been shown to be effective in meeting the needs of cancer patients and their families, confusion over what PSO is and what it isn't, and significant variability in the delivery of these services across Ontario - from who provides them, to where they are available and even what they are called - can impede patients' access to the services they need. The Auditor General's Report recommends that Cancer Care Ontario, together with hospitals, develop and implement a long-term strategy to finance and expand PSO services available to cancer patients, and establish provincial standards for the delivery of PSO services in Ontario(2). The service delivery recommendations in this report reflect patient needs while specifically addressing the delivery of PSO services in the Ontario context.

Recommendations in this report were built upon a foundation of person-centred care principles(3) and core values, as well as existing models of care across the Canadian context(3-5). Some of the recommendations are novel and move beyond existing literature or guidelines.

OUR GOAL WITH THIS REPORT IS:

- To ensure the range of necessary PSO services are provided consistently and in a timely fashion to all cancer patients and their families in Ontario who require them.

OUR OBJECTIVES ARE:

- To promote a consistent identity for PSO;
- To provide recommendations around the components of service and providers of service for high-quality and equitable PSO services within a Regional Cancer Program; and
- To articulate the relationships and important linkages between PSO and other programs and services within Regional Cancer Programs that provide or support psychosocial care.

TARGET AUDIENCE

The primary target audiences for this report are clinicians and administrators from the Regional Cancer Programs and Cancer Care Ontario. The secondary audiences are patients and families, community-based organizations, and provincial and federal organizations.

This recommendation report provides a comprehensive overview and articulates the need for necessary PSO services across Ontario. It is intended to foster further discussions and consultation within Regional Cancer Programs about the "how" to improve PSO service delivery to patients and their families. The recommendations can be used as a starting point for conversations about unique challenges and innovative ways for local implementation.

This document was developed by Cancer Care Ontario's PSO program in collaboration with an extensive group of stakeholders, with the knowledge and expertise to advise on the benefits and challenges of providing timely, integrated, high-quality PSO services to patients and their families. The inter-professional stakeholders offered insights from their diverse areas of expertise, including psychiatry, nursing, primary care, social work, spiritual care, nutrition, physiotherapy, speech language pathology and community care. Cancer Care Ontario's Regional PSO Leads, PSO experts and Patient and Family Advisors from across the country were also consulted.

This recommendation report provides a comprehensive overview and articulates the need for necessary PSO services across Ontario

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Psychosocial Oncology Definition and Guiding Principles

Introduction

With this report, we demonstrate the need to expand, standardize and integrate access to Psychosocial Oncology (PSO) services in this province. We offer recommendations for developing and consistently offering high-quality PSO services: the components that should be included, the providers who should be involved, and the important links within the Regional Cancer Programs required to ensure equitable access. This report was developed in consultation with specialized PSO providers, nurses, community providers as well as patients and families.

What is Psychosocial Oncology?

Cancer Care Ontario has endorsed the definition of psychosocial oncology from the Canadian Association of Psychosocial Oncology as follows: a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life, and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer(4).

Guiding Principles: Person-Centred Care

The following Person-Centred Care dimensions, as published in the Cancer Care Ontario Person-Centred Care Guideline(3), have been used to guide the development of the service delivery recommendations.

1. KNOWING THE PATIENT AS AN INDIVIDUAL.

Treat the person, and not just the disease. Patients value healthcare professionals acknowledging their individuality and the unique way in which they experience a condition. Recognizing the holistic aspect to care is fundamental to person-centred care delivery.

2. PROVIDING ESSENTIAL REQUIREMENTS OF CARE TO ENSURE A POSITIVE PATIENT EXPERIENCE.

Ensure consistent support for patient needs that fall beyond the treatment scope of their specific health condition(s). Person-centred care requires that patients feel respected, that patient concerns are listened to and addressed, that various aspects of patient care (i.e., nutrition, pain) are appropriately managed, that patients are provided support to maintain independence, and that all of the above is done with patient consent.

3. TAILORING HEALTHCARE SERVICE FOR EACH PATIENT.

Tailor the healthcare system to meet the unique needs, preferences, and circumstances of the individual. Care should be as personalized and individualized as possible.

4. PROMOTING CONTINUITY OF CARE AND RELATIONSHIPS.

Continuity and consistency of care, and establishing trusting, reliable relationships with healthcare professionals are key to a positive patient experience and to receiving effective care. Open and systematic sharing of information between professionals and across healthcare boundaries supports high-quality, person-centred care.

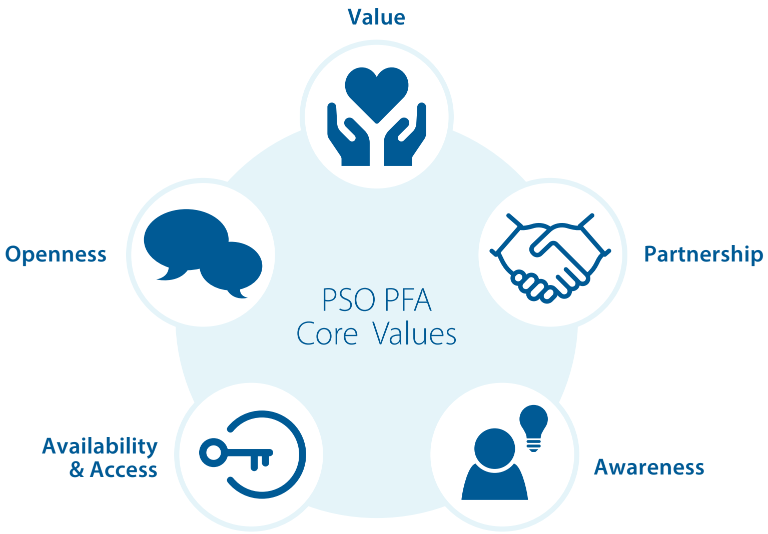
5. ENABLING PATIENTS TO ACTIVELY PARTICIPATE IN THEIR CARE.

Promote a positive outcome of person-centred care, to ensure patients are enabled to be active participants in their own healthcare, by involving them in creating and managing their health strategy and the use of services. Four key areas that encourage self-management and self-care include: communication, information, shared decision making, and education programs.

PSO Patient and Family Advisors Core Values

In addition, the values and perspectives from the PSO Program's Patient and Family Advisors were incorporated in the document. Their core values highlight the importance of awareness and availability of and access to PSO resources and services (see Figure 1).

Figure 1: PSO Patient and Family Advisors: Core Values



Value:
Demonstrate value of PSO services by lending the patient and caregiver voice.

Partnership:
Work in partnership with Cancer Care Ontario, regional partners, patients and caregivers.

Awareness:
Increase awareness about the importance, needs and values of PSO services.

Availability & Access:
Advocate for greater availability and access to PSO resources and services for patients and caregivers.

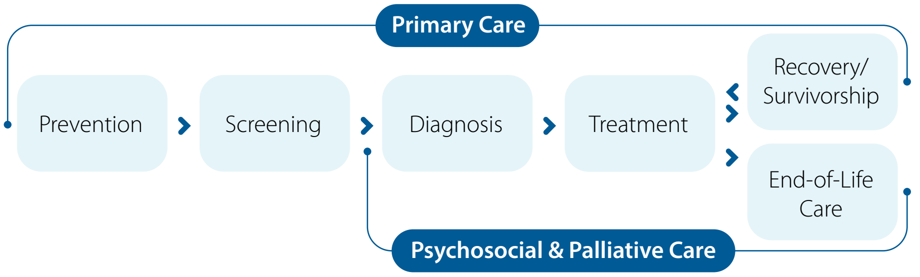
Openness:
Encourage more open and meaningful discussions on PSO services between providers, patients and caregivers.

Building the Case: Why is Psychosocial Oncology Care Important?

Cancer's Psychosocial Impact

Despite significant progress in cancer care in recent years, a diagnosis of cancer continues to place a tremendous burden on individuals, caregivers and the healthcare system. As survival rates improve, the prevalence is rising, meaning that more Ontarians than ever before are living with cancer.

Figure 2: Cancer Care Continuum



CANCER IN ONTARIO[6]

It is expected that one in every two Ontarians will develop cancer in their lifetime.

- In 2018, an estimated 90,483 cases of cancer are expected to be diagnosed in Ontario.
- An estimated 30,574 people are expected to die from the disease in the same year.
- Five-year relative survival for all cancers combined was 64.7% (for cases diagnosed from 2009-2013).
- At the end of 2013, an estimated 370,713 people living in Ontario had been diagnosed with cancer within the previous 10 years.

The impact of cancer on patients and their families is far reaching. Throughout the cancer care continuum - from screening and diagnosis, through treatment and survivorship or palliative care - many patients will experience concerns with not only their physical health but also their emotional, social, mental health and wellbeing issues (7-9). Throughout the continuum, there are also unique needs associated with the adolescent and young adult and the elderly population (10-13). Their families and caregivers may also be affected by the disease, experiencing emotional and psychological distress, shifting roles, increasing responsibilities, financial burden and caregiver stress (14) (See Table 1 for a summary of patients' and families' psychosocial concerns).

Table 1: Psychosocial concerns of patients with cancer

Category	Concern
Cognitive	- Brain fog - Delirium - Preexisting and worsening cognitive issues (e.g., due to dementia, brain tumours - Capacity (consent to treatment and medical assistance in dying)
Nutritional	- Cachexia, anorexia, end-of-life issues related to nutrition support - Weight loss leading to poor global functioning - Sarcopenia or loss of muscle mass causing functional impairment - Inability to sustain adequate oral intake, necessitating enteral or parenteral nutrition. - Delayed wound healing - Dehydration - Weight changes impacting body image - Lack of education about safe and healthy eating for cancer patients and for health promotion and prevention - Myths around food choices in cancer - Lack of adequate nutrition for reconditioning and rehabilitation
Physical/ Functional/ Rehabilitative	- Pain and symptom control - Impaired energy and physical functioning - Impaired sleep - Deconditioning - Lymphedema management - Speech and swallowing impairment - Adjustments in home or work modifications due to physical limitations - Loss of muscle mass impacting activities of daily living

Table 1: Psychosocial concerns of patients with cancer continued on page 14

More than 40 percent of all cancer patients will develop significant distress at some point during diagnosis, treatment, survivorship, progression of disease, palliation or end of life.

Table 1 (continued): Psychosocial concerns of patients with cancer

Category	Concern
Practical	• Need for community support (e.g., social work, nursing) • Practical needs (e.g., housing, food, disability aid, transportation, functions of daily living, drug reimbursement, daycare) • Rehabilitation issues (e.g., back-to-work difficulties, changes to home routine and set up) • Employment, school or career concerns, advocacy • Cultural or language issues • Caregiver availability
Psychological/ Emotional	• Depression and suicidal ideation • Anxiety (e.g., about treatment, recurrence, uncertainty for the future, family) or exacerbation of pre-existing anxiety disorder. This includes needle phobia or other phobias (e.g., claustrophobia) that could interfere with treatment and recovery • Anticipatory nausea and vomiting • Body image disturbance • Sexual functioning issues and impact on self-esteem • Distress related to mortality and life-threatening illness • Difficulty with getting on with living; adjusting to new normal • Loss of dignity or meaning in one's life • Addiction (e.g., alcohol, nicotine, other substances of abuse)
Social	• Coping and adjustment to altered social roles due to illness • Communication with healthcare providers • Family conflicts and sense of isolation from family members • Relationship disruptions • Discussion of illness with partner and family • Impact of cancer on children • Difficulty in decision-making • Dealing with stigma • Domestic abuse and neglect • Impact of functional changes (e.g., body image, sexuality) on relationships • Impact of anticipatory grief on patient and family • Family distress and caregiver burnout
Spiritual	• Grief/bereavement • Concerns about death and the afterlife • Conflicts or challenged belief systems • Loss of faith • Concerns about the relationship with a deity/God • Isolation from the religious community • Guilt • Hopelessness, demoralization • Conflict between beliefs and recommended treatment • Cultural, religious

Adapted from National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology: Distress Management (15)

Prevalence and Extent of Psychosocial Distress in Cancer

More than 40 percent of all cancer patients will develop significant distress at some point during diagnosis, treatment, survivorship, progression of disease, palliation or end of life(8). One recent study(16) identified high levels of distress in 52 percent of cancer patients over a range of tumour sites. Distress has been called the "sixth vital sign" (17), and persistent severe distress can have negative implications for patients, including reduced health-related quality of life, poor satisfaction with medical care and possibly reduced survival (8, 18). Screening for distress as the 6th vital sign is considered a standard through Accreditation Canada(19).

Examples of distress include issues such as depression, anxiety (including extreme fear of recurrence) and body image disturbance, which may or may not be associated with sexual health problems. These difficulties can contribute to an inability to return to work and relationship problems with family members and friends, in turn leading to feelings of isolation(14, 18, 20). Family members often struggle with anticipatory grief, trying to support the complex physical and psychosocial needs of their loved ones, and the impact of bereavement(21, 22).

Amongst these psychosocial issues, depression is perhaps the most important. Depression is common among people living with cancer. A systematic review showed that the prevalence rates of major depression in adult cancer patients range from 4 to 16 percent among inpatients and outpatients, and as high as 49 percent among patients in palliative care(23). Further evidence shows that patients who are depressed are more likely to be non-adherent with their treatment(24). Recent meta-analyses have estimated the prevalence of clinically significant depression among cancer patients at 8 to 24 percent(25, 26). Suicide is more prevalent in cancer patients than the general population(27) and is most closely associated with clinical depression and uncontrolled pain(28).

Anxiety disorders have been estimated to occur in 18 percent of cancer patients(30), and significant fear of recurrence is seen in 42 percent of cancer survivors(31). Unmet needs have been reported in up to 89 percent of patients, including activities of daily living, psychological, information, psychosocial, physical, spiritual, communication and sexuality domains(32).

Nutrition and Functional Concerns

Thirty to 90 percent of cancer patients are malnourished during the course of their illness(33). Patients with poor nutritional status are more likely to be intolerant of medical treatment, experience heightened toxicity of chemotherapy and/or radiation therapy, have impaired wound healing, experience decreased quality of life, be hospitalized more often and for longer durations, and die sooner(34).

Functional impairment (due to fatigue, weight loss or lymphedema, for example) can present challenges for patients returning to work or to their premorbid levels of functioning and activities(35). In particular, patients with breast, head and neck, or gynecological cancers, can experience negative physical and psychosocial effects related to lymphedema. Approximately 33 percent of breast cancer patients(36), 75 percent of head and neck cancer patients(37), and 18 percent of gynecological cancer patients(38) experience early or late stage lymphedema that adversely affects their function and quality of life. Head and neck cancers and their treatment can also be associated with disturbances in speech, swallowing and eating, and require specialized speech language therapy interventions(39).

Addressing patients' psychosocial needs offer benefits to both the individuals and the healthcare system. Research consistently shows that PSO services reduce patients' suffering and improve quality of life, emotional distress, coping, physical functioning and care experiences.

Benefits of PSO Interventions

Addressing patients' psychosocial needs offer benefits to both the individuals and the healthcare system. Research consistently shows that PSO services reduce patients' suffering and improve quality of life, emotional distress, coping, physical functioning and care experiences(5, 40-45). There is evidence for benefits from specific treatments for depression (including psychotherapeutic, psychopharmacologic and collaborative care treatments(46, 47), anxiety(40) and fear of recurrence(48). Early rehabilitation, such as physical, occupational and speech language therapy interventions can also reduce the risk of surgical morbidity and improve pain, swallowing difficulties, physical functioning and other psychosocial problems among cancer patients(44, 45, 49, 50). Research also supports that nutritional care should be integrated into part of oncology care because of its significant improvement to patients' quality of life(51, 52). A recent systematic review and meta-analysis(53) concluded that various types of psycho-oncologic interventions are associated with small to medium size effects on emotional distress, while highlighting the need for better quality studies in the field. In particular, adequately powered high quality, multisite effectiveness trials are needed to advance the evidence base in PSO(54).

A controversial area of potential benefit from PSO interventions concerns survival. Many studies that have examined the impact of psychosocial intervention on survival have failed to find an association(55, 56), although a recent meta-analysis(57) found evidence that psycho-behavioral interventions of an adequate dose (greater than 30 hours) were associated with prolonged survival in the first two years of follow-up. Another study(58) found significant survival benefits at one to two years follow-up in group but not individual interventions. Preliminary research suggests that improvement in immune system functioning may be a mechanism through which PSO interventions improve survival(59, 60).

Emerging evidence suggests that PSO interventions may be cost effective and have acceptable cost utility(61-64). Integrated collaborative care interventions in depression(65, 66), mindfulness-based stress reduction(67), group therapy for fear of recurrence(68), and rehabilitation(49, 69, 70) have all been shown to demonstrate benefits from a health economics perspective.

Models of PSO Care in the Canadian Context

Over the last 10 years, a number of guidelines have developed models of care for PSO service delivery relevant to the Canadian experience. These models of care have laid the foundation for articulating what psychosocial oncology programs should look like, and what the standards and components of care should be.

Canadian Association Of Psychosocial Oncology: Phases Of Illness Model

A Canadian Association of Psychosocial Oncology (2010) document entitled "Standards of Psychosocial Health Services for Cancer Patients and their Families" articulated the standards of care people with cancer and their families are entitled to(4). Using a phases of illness model, the document laid out six standards of care from prevention through screening and assessment, treatment, palliation, survivorship, and grief/bereavement. The standard of care for treatment, for example, said that patients are entitled to "access to appropriate levels of treatment to meet their needs". These "may include peer or professional led support groups, psycho-education, individual/couple/family counselling or psychotherapy, sex therapy, psychotropic medication and rehabilitation services".

Cancer Care Ontario: Institute of Medicine Domains of Care Model

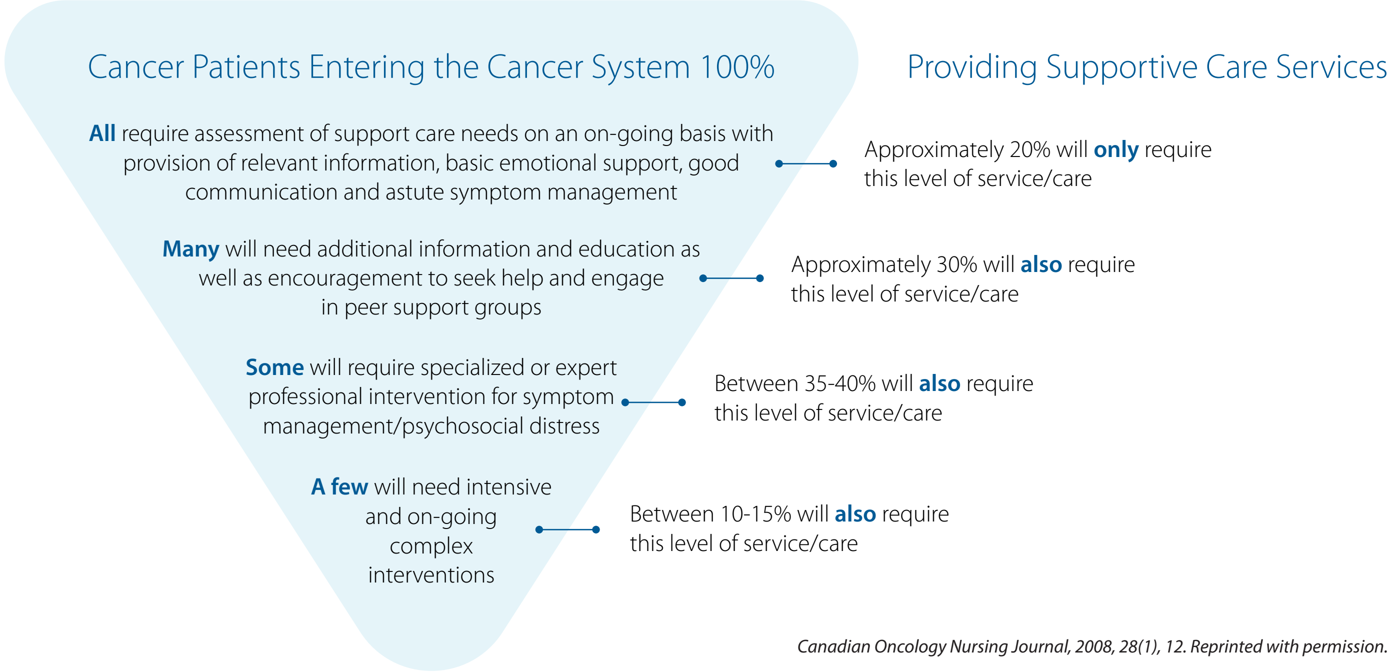
Cancer Care Ontario, in two documents published in 2010(3) and 2012(4) adapted the Institute of Medicine's Domain Framework to the Ontario experience, identifying eight domains of psychosocial care. These included raising awareness; standards of care; healthcare providers; patient and family education; quality oversight and monitoring progress; workforce competencies; standardized nomenclature; and psychosocial research. The standards of care domain that concerns assessment and treatment, articulated the need to facilitate effective communication, identify psychosocial needs, design and implement a psychosocial treatment plan, and systematically monitor, evaluate and readjust the plan. Furthermore with respect to healthcare providers, emphasis was on all healthcare providers, from oncologists to volunteers to specialized psychosocial providers ensuring that patients and families receive the psychosocial standard of care.

CancerControl Alberta: Stepped Care Model

In 2016, CancerControl Alberta released “Supportive Care Framework Report”(71), which proposed a framework based on the Stepped Care Model articulated by Fitch and Davison(72, 73). According to this model (see Figure 3), not every patient requires the same level of PSO service. Patients with the greatest need should receive the most specialized care and see the specialized PSO providers with the most expertise.

According to this model, for optimal outcomes all cancer patients should receive ongoing assessment of their PSO needs, along with basic care information and tools (Level 1). Many patients, approximately 30 percent, will also need individualized information and education, as well as additional support from a psychoeducation program or peer-support group (Level 2). Another 35 to 40 percent of patients will have moderate to severe distress requiring specialized PSO assessment and intervention (Level 3). A few, about 10 to 15 percent of patients, may need complex care from multiple PSO disciplines (Level 4); for example, a patient with head and neck cancer may need symptom management, rehabilitative care (nutrition, speech language pathology), as well as social, emotional and practical support from a variety of PSO professionals.

Figure 3: **Stepped Care Model of Specialized PSO Service Provision(72)**



Cancer Patients Entering the Cancer System 100%

Providing Supportive Care Services

All require assessment of support care needs on an on-going basis with provision of relevant information, basic emotional support, good communication and astute symptom management

Approximately 20% will **only** require this level of service/care

Many will need additional information and education as well as encouragement to seek help and engage in peer support groups

Approximately 30% will **also** require this level of service/care

Some will require specialized or expert professional intervention for symptom management/psychosocial distress

Between 35-40% will **also** require this level of service/care

A few will need intensive and on-going complex interventions

Between 10-15% will **also** require this level of service/care

Canadian Oncology Nursing Journal, 2008, 28(1), 12. Reprinted with permission.

Beyond the Existing Models of Care

All of the models of care mentioned above emphasize the importance of raising awareness of PSO, screening for distress, and equitable access to PSO services. However, these models of care as described in the guidelines do not go far enough in terms of the following areas:

- The promotion of a consistent identity for PSO.
- The role of various providers of care and the range of PSO services were highlighted to a limited degree.
- The full range of expert services that should be expected in a PSO program is not explicitly defined.
- The roles and differences between various specialized PSO providers are not fully articulated.

These are essential components required to develop, protect and expand PSO services across the province. The gaps identified provide opportunities for us to build on existing models of care and develop recommendations for PSO service delivery that promote access to consistent high-quality PSO care to meet the needs of patients and their families in Ontario.

Organization, Structure and Philosophy of the PSO Program

one

> "During my pathway with cancer the first time, I experienced a lot of anxiety and didn't know where or who to talk to. Some days it was hard to get out of bed and face another day… I tried to commit suicide. I needed help. PSO services are so vital to patients and their families. We need them before they become acute or critical – before we are in so much pain that our quality of life is drastically affected."
>
> **- Joanne M., Patient and Family Advisor**

The significant burden that cancer places on all aspects of patients' and families' lives requires a comprehensive range of integrated PSO services. One of the barriers to accessing timely and appropriate care is the variation across the province as to who provides what PSO services and where.

Challenges with PSO Definition and PSO Core Disciplines

Both conceptually and in practice, there has been some confusion over the degree of overlap and differences between PSO and related concepts such as supportive care and palliative care(74-76). There has also been reference to a "psychosocial standard of care"(4), which is supposed to be provided by all providers of services and care, ranging from oncologists to volunteers to specialized PSO providers. A similar distinction has been made between palliative care as an aspect of care provided by many providers and a specialized service.

At Cancer Care Ontario, we conceptualize supportive care to be a broad umbrella term encompassing the symptom screening, effective communication and alliance building, distress management and end-of-life care carried out by frontline oncology providers, the specialized supportive care services of PSO and palliative care, and a range of other services provided both within the cancer treatment facility and in the community (see Figure 4).

There has also been a lack of consensus as to who the PSO providers and core disciplines should include; for example some definitions highlight the core mental health disciplines of psychiatry, psychology, social work and spiritual care only(77).

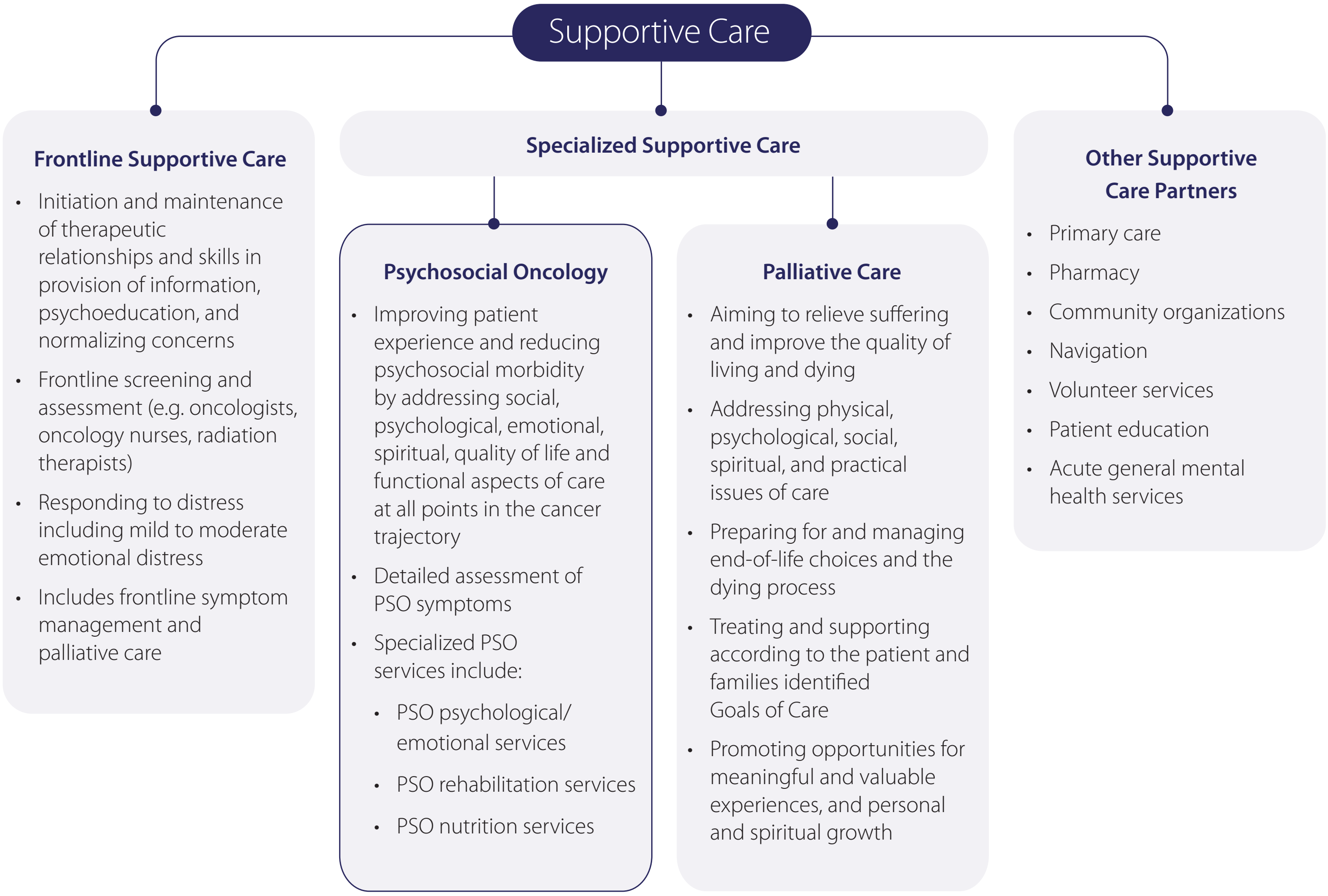
At Cancer Care Ontario, we define eight disciplines as specialized PSO providers, which include psychiatrist, psychologist, social worker, spiritual care provider, occupational therapist, physiotherapist, registered dietitian, and speech language pathologist(78). These professionals have training in being able to provide expert intervention of symptom management/ psychosocial distress.

Across Ontario, clinical nurse specialists or nurse practitioners who have received special training in PSO, and medical psychotherapists and family physicians with special interest and expertise in psychotherapy may also support patients with their PSO needs.

Variation in PSO Program Names

A contributing factor to the challenge is the inconsistency with naming psychosocial oncology programs, with some Regional Cancer Programs identifying their PSO services as "supportive care" or "patient and family support," or offering the services under the umbrella of their palliative care programs. A 2016 survey(79) found that only four out of 14 regional cancer centres use the term "psychosocial" in identifying their PSO programs. This lack of a common identity can result in both healthcare providers and patients being unaware of available supports and can delay referrals to appropriate care. In addition, the lack of a distinct identity can lead to cuts in funding and services. Increased awareness of all supports available will help ensure that patients and families access services when needed.

Figure 4: **Psychosocial oncology: A specialized supportive care service**



Supportive Care

Frontline Supportive Care

- Initiation and maintenance of therapeutic relationships and skills in provision of information, psychoeducation, and normalizing concerns
- Frontline screening and assessment (e.g. oncologists, oncology nurses, radiation therapists)
- Responding to distress including mild to moderate emotional distress
- Includes frontline symptom management and palliative care

Specialized Supportive Care

Psychosocial Oncology

- Improving patient experience and reducing psychosocial morbidity by addressing social, psychological, emotional, spiritual, quality of life and functional aspects of care at all points in the cancer trajectory
- Detailed assessment of PSO symptoms
- Specialized PSO services include:
  - PSO psychological/ emotional services
  - PSO rehabilitation services
  - PSO nutrition services

Palliative Care

- Aiming to relieve suffering and improve the quality of living and dying
- Addressing physical, psychological, social, spiritual, and practical issues of care
- Preparing for and managing end-of-life choices and the dying process
- Treating and supporting according to the patient and families identified Goals of Care
- Promoting opportunities for meaningful and valuable experiences, and personal and spiritual growth

Other Supportive Care Partners

- Primary care
- Pharmacy
- Community organizations
- Navigation
- Volunteer services
- Patient education
- Acute general mental health services

While the external public-facing names of the PSO programs need not change, a commonality in internal organizational structures would enhance cohesion and communicate a consistent identity to other stakeholders such as regional cancer centres and regional administrative leadership. Regional Cancer Programs should structure their PSO services as a distinct program that provides psychosocial resources to meet the needs of cancer patients and families.

Consistency with Data Collection

Variations in program organization and structure also make it difficult to collect and analyze data, as different methodologies and definitions are used across the province. Consistency with high-quality data collection is essential for capacity planning. Measurement-based outcomes need to be developed in order to demonstrate the effectiveness of interventions or areas for quality improvement.

Recommendations

1.1 Psychosocial Oncology is reflected as a distinct program within the internal organizational structures of all Regional Cancer Programs in order to enhance cohesion and communicate a consistent identity; an external program name change is not necessary.

1.2 All patients and providers within the Regional Cancer Program will actively be made aware of appropriate and available psychosocial supports within the Regional Cancer Program and the community to ensure timely and appropriate referral to specialty PSO services.

1.3 In all Regional Cancer Programs, PSO services are offered and available to patients and families throughout the cancer care continuum (from prevention and cancer screening through onset of symptoms, diagnosis and treatment, to survivorship or recurrence and end-of-life care).

1.4 Regional Cancer Programs ensure that PSO services are delivered in the language that the patient feels most comfortable using and in a way that respects cultural diversity and varying levels of health literacy.

1.5 All Regional Cancer Programs use a consistent methodology in data collection and reporting, as set out by Cancer Care Ontario's PSO Program.

Screening for PSO Care

two

> “After my surgery, I really struggled with sadness and fear. I reported these feelings on my symptom screens, but no one ever followed up. My mother happened to see a flyer in the waiting room with information about connecting with a social worker. I made an appointment and she was wonderful, exactly what I needed.
>
> Screening for PSO issues should be treated like any other diagnostic tool, like a CT scan or blood work, with follow-up and referral for services. It can’t just be left to chance.”
>
> **- Kelly Anne B., Patient and Family Advisor**

In consultations with Cancer Care Ontario, patients and families have advocated for early screening and early access to psychosocial resources and providers. The Canadian Association of Psychosocial Oncology also recommends that people at risk for or living with cancer should be assessed throughout the cancer care continuum to determine their needs for psychosocial support, information and education.

In Ontario, patients can assess and monitor their symptoms using the Your Symptoms Matter tool. Patients complete a questionnaire about the severity of their symptoms prior to appointments with their cancer care provider at 14 regional cancer centres and most partner hospitals. The intent of these self-assessments is to initiate a conversation between the patient and the patient’s care team, who can use the information to manage the symptoms more effectively and efficiently. Depending on the results of symptom screening, patient-reported outcomes and clinical assessment, patients may need additional information, support and interventions that may include referrals to specialized PSO providers. Particular items, such as the depression and anxiety, may trigger a referral to the appropriate specialized PSO providers, such as social workers, psychiatrists or psychologists. However, the screening tool is about current levels of distress on the day of assessment and should not be used to trigger referral to a specialized PSO provider before a conversation between the patient and the frontline provider occurs, such as the oncology nurse, radiation therapist, physician or other. Anxiety, for example, may be due to pain, a fear of treatment, or new recurrence anxiety which can often be addressed appropriately by frontline providers. Similarly, loss of appetite may signal issues with insufficient nausea control and not a reason to automatically refer to a dietitian.

Symptom Management Guides to Practice help healthcare professionals assess and appropriately manage patients’ cancer-related symptoms(80). Patient symptom management guides are also available to help people with cancer manage their symptoms using current, evidence-based self-management recommendations. The guides help to validate their symptoms and encourage them to seek help from their healthcare providers to manage them.

Recommendations

2.1 Regional Cancer Programs continue to consistently use symptom screening tools as a component of the screen for PSO needs.

2.2 All sites develop an inter-professional approach for responding to clinically significant screening for all issues and/or elevated symptom screen scores. Teams consider secondary assessment tools for elevated scores.

2.3 Symptom screens be addressed routinely at clinic visits; the symptom scores should be acknowledged followed by assessment, interventions and referral to another healthcare provider when necessary. A conversation between patient and frontline provider is essential before referral to specialized PSO providers occur to ensure that the intervention required is within the scope of the specialized PSO provider and to maximize the availability of PSO resources.

Access to PSO Care

three

> “There needs to be more resources for patients in the survivorship phase of the cancer continuum. As patients, we receive so much care while we are in hospital and receiving treatment. But afterwards, we are cut loose with no support. It feels like we are being left to the wolves.”
>
> **- Melissa G., Patient and Family Advisor**

Many patients have reported facing barriers to accessing psychosocial oncology services. Not only does availability of services vary across the province, but patients (and healthcare providers) are not always aware of services that do exist or how to access them. Race, culture, gender, age, sexual orientation, immigration status and education may result in additional barriers to finding and accessing cancer services.

Connecting Patients to the Care They Need

Ontario’s cancer system is layered and complex, and patients may or may not receive PSO services in the same location where they receive other cancer care.

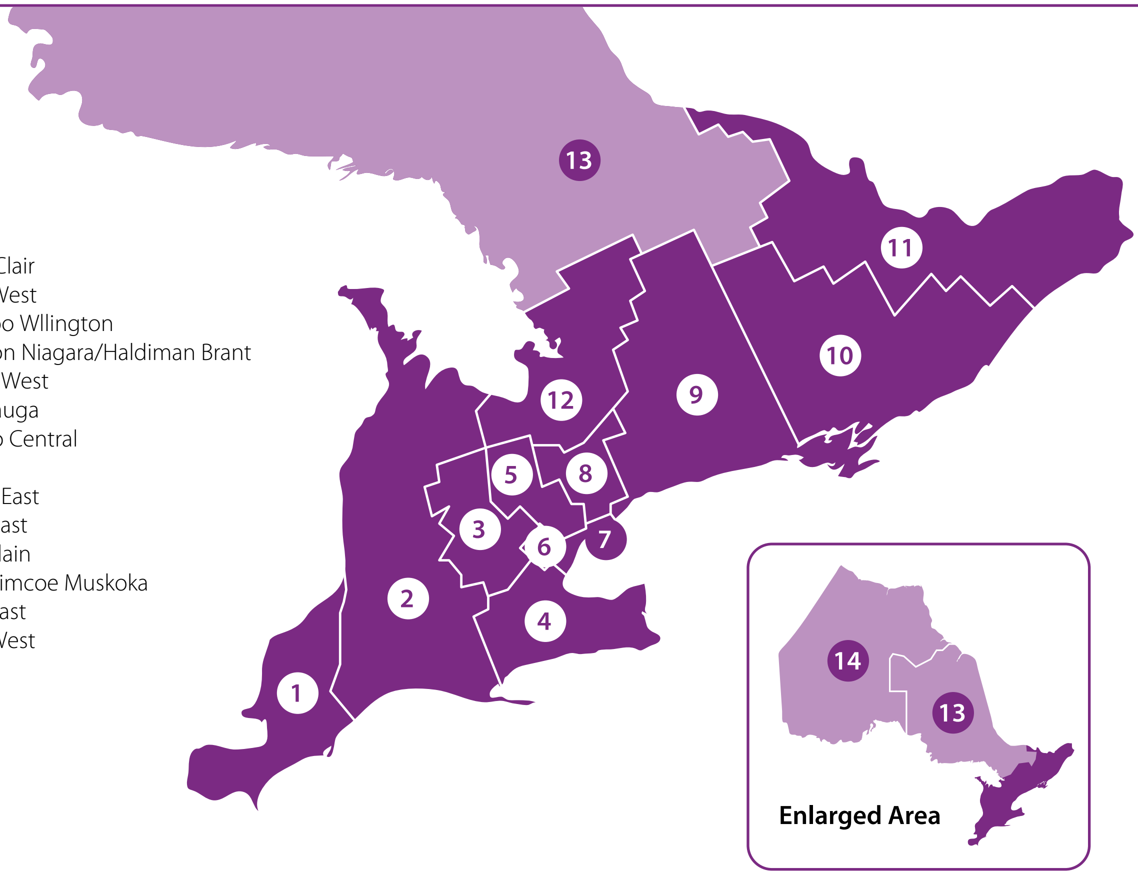
The delivery of cancer care services is organized into Regional Cancer Programs, which are aligned with the province’s 14 LHINs (see Figure 5).

Each Regional Cancer Program consists of a network of healthcare organizations and professionals. Within each Regional Cancer Program is a regional cancer centre, where systemic and radiation therapy consultation, treatment and follow-up is delivered, and its host hospital where surgery, inpatient beds and emergency services are located. Affiliate hospitals and cancer clinics provide systemic therapy and surgery but do not usually offer radiation therapy.

After a cancer diagnosis, patients may receive treatment or other services at a single facility or may be treated in a shared model of care where consultation could occur at one facility with treatment occurring at another location closer to their home. Patients may access services at a variety of locations, such as a regional cancer centre, affiliate hospital, home, hospice and/or satellite clinics (depending on the complexity of care required).

Similarly, patients may access PSO care in a variety of locations, since different hospitals offer different services. Specialized PSO providers may be part of an established, recognizable PSO program (e.g., within a regional cancer centre) or operate as part of a referral network. Regardless, patients should have access to specialized PSO providers no matter where they receive their cancer care or where they live in the province.

Figure 5: Regional Cancer Programs/ Local Health Integrated Networks (LHINs) in Ontario



1. Erie-St Clair
2. South West
3. Waterloo Wllington
4. Hamilton Niagara/Haldiman Brant
5. Central West
6. Mississauga
7. Toronto Central
8. Central
9. Central East
10. South East
11. Champlain
12. North Simcoe Muskoka
13. North East
14. North West

> A 2016 environmental scan found significant variation in the availability of outpatient PSO services and providers at regional cancer centres across the province.

ACCESS VARIES ACROSS ONTARIO (79)

A 2016 environmental scan found significant variation in the availability of outpatient PSO services and providers at regional cancer centres across the province.

At the time of the scan, few regional cancer centres offered programs focusing on cancer and sexual health, mindfulness, cancer related cognitive impairment (e.g., brain fog) or lymphedema. Few regional cancer centres reported having a dedicated psychiatrist (full time or part time), psychologist, dedicated spiritual care provider, speech language pathologist, occupational therapist or physiotherapist. Even fewer regional cancer centres had a medical psychotherapist or mental health nurse on site. Social workers and registered dietitians were the only categories of specialized PSO providers available at all regional cancer centres but their allocation varies geographically.

It is important for all Regional Cancer Programs to provide patients' access to specialized PSO providers either on site or through other models.

There are a variety of models that can be used to address staffing deficiencies in specialized PSO providers. Examples of such models for specialized mental health services are identified in Appendix 1. On site-dedicated specialized PSO providers that are embedded within inter-professional oncology teams (including site specific teams) is the ideal, but other models including nearby and accessible providers in the host hospital, knowledgeable and accessible providers in the community, and distance consultation and follow up via Ontario Telemedicine Network or a similar platform are all preferable to a lack of expert and accessible support.

Regional Cancer Programs should have a system in place to assess patients' PSO needs and refer them to PSO services and providers as required. These referrals may be to specialized PSO providers at the regional cancer centre, at the affiliate hospital or in the community (e.g., to a community mental health clinic, private practitioner with experience in treating patients with cancer, primary care physician, palliative care specialist, or local hospice with trained counsellors). It is very important that affiliate hospital and community services are rapidly accessible and have experience in dealing with needs of cancer patients. The availability of community services may also vary by region. It is recognized that specialized PSO providers in the Regional Cancer Program may be a point of contact for other healthcare professionals in the system who may need to consult on cases and/or be provided with information to provide optimal care to cancer patients and families.

PSO Professionals as Champions for Health Equity

PSO professionals can play central roles within cancer programs to identify needs of vulnerable or under-served populations and solutions to ensure health equity. This role may include focusing on patients with severe and persistent mental health problems or significant physical disabilities, those living in poverty or who are homeless/vulnerably housed, and others who experience barriers to accessing care. Programs may, for example, look to their social work team members to establish strong relationships and partnerships with community organizations and services to ensure that social care needs are also optimally addressed in patient care. Through their understanding of the social determinants of health, social workers and others within the psychosocial oncology team can help the cancer program to work to address practical, emotional and social barriers that prevent individuals from accessing and/or benefiting fully from care(81). Programs should fully utilize the knowledge and skills of PSO providers to champion health equity and identify programmatic opportunities to improve care for all.

Relationship of PSO with other Programs

Through better collaboration among all partners in an inter-professional team, all cancer patients and their families should be able to access timely, appropriate PSO services. This access includes care as close to home as possible, and the availability of culturally appropriate education and information. To improve continuity of care, patients who receive chemotherapy at community hospitals should be able to access specialized PSO services at their regional cancer centre. Likewise, patients who receive specialized cancer treatment at regional cancer centres outside their LHIN should be able to receive PSO care closer to home.

Below are other programs and providers that provide vital supportive care services (see Figure 4 on page 18) but are not typically located within discrete PSO programs.

Frontline oncology providers (including oncologists, surgeons, general practitioner-oncologists, nurses and radiation therapists) play a critical role in providing emotional support, encouragement and hope to patients. They are also involved in screening for and assessing patients' distress (which may be primarily psychological/emotional or secondary to a physical symptom like pain) and providing timely and appropriate referral to specialized PSO services. To improve patients' timely access to care, these providers should be familiar with the range of PSO services and providers available in their setting.

Primary care practitioners: Primary care practitioners, including family doctors and nurse practitioners, can provide emotional support and assessment and management of depression and anxiety for distressed cancer patients.

Acute general mental health services: Programs to support more severely distressed cancer patients who require emergency assessment and/or intervention are typically located in hospitals associated with the regional cancer centre. These acute general mental health services are usually not cancer specific, however.

Palliative care: Regional palliative care networks provide home-based and inpatient hospice-based interventions, including on-call support to people living with advanced cancer. Services also include support to nursing homes and assisted living centres with palliative care patients. Palliative care and PSO services are often linked even if they are not part of a joint program. These connections may include sharing of staff such as social workers, spiritual care providers and dietitians. There may be overlapping services in areas of symptom management, treatment of depression and anxiety, and provision of caregiver support. They also provide support to families in the wake of a patient's death and provide linkages to local bereavement resources. Some palliative care services are accessed through community-based organizations.

Pharmacy: Pharmacists play an important role in helping to identify potential drug interactions between cancer therapeutics and psychopharmacologic treatments. They can also provide important information to patients and families about how to take medications properly, potential side effects and contraindications with any complementary treatments. Located in even small communities, pharmacists offer highly accessible expertise.

Patient education: Patient education specialists, particularly within the Regional Cancer Programs or centres, may collaborate with PSO content experts to develop and deliver face-to-face, written or virtual resources tailored to this patient population (e.g., information about self-management and how to access local PSO resources).

Through better collaboration among all partners in an inter-professional team, all cancer patients and their families should be able to access timely, appropriate PSO services.

Patient navigation: Patient navigators, including Aboriginal and nurse navigators, play an important role in helping patients understand and find their way through the cancer system. Their services include explaining treatment options, answering patients' questions and concerns, coordinating appointments, and directing patients to local resources and support.

Volunteer services: Hospital volunteers can help patients navigate the healthcare system and find other supportive care support. Community-based volunteer organizations often provide services such as peer counselling, programs for family members/caregivers, bereavement support, transportation, meal delivery and complementary therapy activities. Some organizations also provide telephone support or virtual support groups to address the needs of patients in rural or remote areas.

Community-based programs: Community organizations, such as non-governmental organizations and ambulatory hospices, provide important supportive services, including group support programs, individual counselling, programs for family members/caregivers, grief and bereavement support and complementary therapy activities. Many patients and family members prefer to engage these services outside of a cancer centre or hospital, and they should be made aware of local community supports. In some cases, these community organizations may be the primary source of supportive care support. However it is important to recognize that such programming may not be available in remote and rural communities where population density presents a challenge to sustain community programming. Religious and spiritual institutions in the community provide support and address spiritual concerns and bereavement related services.

Virtual PSO programs and services: Patients who cannot access direct PSO care close to home can increasingly connect with services virtually. These virtual programs and services include distance consultation, support through Ontario Telemedicine Network, and virtual support groups (including informal support groups set up by patients and family members). Informational support is available on many websites, such as those hosted by Cancer Care Ontario, regional cancer centres and the Canadian Cancer Society.

Recommendations

3.1 Regional Cancer Programs ensure cancer patients have access to timely PSO interventions, according to Cancer Care Ontario's target wait times.

3.2 Patients experiencing emotional, psychological, cognitive and/or spiritual distress have access to psychiatrists, social workers, psychologists, and/or spiritual care providers.

3.3 Patients experiencing physical, functional, rehabilitative, and/or nutritional concerns have access to occupational therapists, physiotherapists, registered dietitians and/or speech language pathologists.

3.3 Regional Cancer Programs ensure continuity of care for all patients, regardless of where they receive their cancer treatment.

3.4 Regional Cancer Programs are encouraged to work collaboratively with stakeholders for provision of PSO services for a shared model of care. Patients be provided with the opportunity to be referred to the Regional Cancer Program where services are not available in the community.

Specialized PSO Services for Patients and Families

four

> “The new frontier of personalized medicine includes psychosocial care. A routine symptom screening program paired with clarity of role definitions among psychosocial team members is the most efficient way to deliver the right care, to the right patient, at the right time.”
>
> **- Dr. Madeline Li, Psychiatrist, Department of Supportive Care, Princess Margaret Hospital**

The Role of Specialized PSO Providers

While all cancer care providers have a responsibility to ensure that patients and their families receive the psychosocial standard of care, a well-defined PSO program within a Regional Cancer Program should provide patients with access (on site or through referral) to specialized PSO providers from the eight core disciplines(78): psychiatrist, psychologist, social worker, spiritual care provider, occupational therapist, physiotherapist, registered dietitian, and speech language pathologist. For detailed role descriptions of these specialized PSO providers, see Appendix 2.

All of these specialized PSO providers provide direct patient care and also help patients and families connect with appropriate community supports. They also support and promote measureable, evidence-based care for PSO outcomes. Each discipline has specific professional practice standards, competencies and accountabilities with their associated college. In addition, these healthcare professionals provide educational programs to healthcare providers about how to recognize, assess and manage symptoms, as well as programs about staff burnout and wellness. Additional members of a PSO team could include medical psychotherapists and nurses with expertise in mental health, such as clinical nurse specialists or nurse practitioners.

Cancer Care Ontario and the Canadian Association of Psychosocial Oncology have previously developed high-level recommendations for PSO care(4). Table 2: “Recommended services for PSO care in Ontario” builds upon these recommendations by combining them with the consensus of expert opinion from the content reviewers and the most recent literature on PSO services. The table provides specific recommendations around services that should be provided to patients and families in any Regional Cancer Program.

Recommendations

4.1 Regional Cancer Programs ensure patients and families have access to individual, family and group PSO care from an inter-professional team of specialized providers to cover a full range of services.

Table 2: Recommended services for psychosocial oncology care in Ontario

Service	Description of service
Addiction support/ counselling[82]	Access to on site or community-based resources to support the management of nicotine, alcohol and other substances
Capacity assessments and support around treatment decisions/ MAID[83]	Availability of psychiatric/psychological assessments to provide second opinions regarding capacity to accept or refuse treatment, and to request medical assistance in dying (MAID), as well as the provision of emotional support around issues like treatment refusal and MAID
Complex mental healthcare[84]	Identification and care of patients with cancer who have pre-existing and comorbid serious mental health and addiction issues at an early point in their cancer care
Detailed psychosocial assessment[85]	Detailed assessment of patient experience of cancer, including: • understanding of diagnosis and prognosis; • level and type of emotional symptoms experienced; • adaptive and maladaptive coping styles employed; • level and range of social support; • view of their future and existential/spiritual concerns; • physical symptoms contributing to quality of life; • marital/family/financial and work concerns; • active addiction issues; • safety concerns; • mental health and addiction history; • medical history and response to previous illness; • psychiatric/psychological diagnoses, formulation and treatment plan
Expert psychopharmacologic management[86]	• Pharmacological treatment of depression, anxiety, delirium and insomnia in cancer patients • Strategies to address treatment resistance, and recognize and manage neuropsychiatric side effects of cancer drugs and supportive medications like steroids or antiemetics • PSO practitioners should be familiar with evidence-based guidelines and clinical expertise concerning the use of drugs for treatment in cancer patients, as well as knowledge of drug interactions and side effect profiles of psychotropic medications
Expert psychotherapeutic management[87-90]	• Provide individual or group cognitive behavioural therapy, behavioural activation therapy, problem-solving, interpersonal and supportive-expressive therapy • PSO practitioners should be familiar with evidence-based guidelines and clinical experience in providing individual or group psychotherapeutic management to cancer patients, and cancer-specific interventions that have been developed and described in the literature
Financial/disability services counselling[72]	Guidance and support to access financial and disability services (e.g., help with application forms)
Group programs[72, 91]	• Support, psychoeducation or skills-based groups may be specific to the type of cancer, type of patient (e.g., based on age or gender) or phase of the continuum • Groups may focus on behavioural or coping skills, such as mindfulness-based stress reduction, mindfulness-based cognitive therapy and cancer related cognitive impairment • Psychoeducation groups may be led by a healthcare professional or peers at the cancer centre or in the community
Mental health crisis intervention[92]	• Urgent availability of mental/emotional health PSO providers to assess and manage safety issues including suicidal ideation and violence/ aggression; including presence of an emergency response system • Appropriate linkages to emergency and specialized mental health services should be available at all centres that provide cancer care services

Service	Description of service
Nutritional support & education[93-97]	• Detailed clinical nutrition assessment looking at cancer diagnosis, care plan and clinical goals of care, relevant past medical history, medication use, weight history, biochemical data, social history, overall activity and functioning, nutrition impact symptoms and overall oral intake • Development of individualized patient care goals and nutrition care plan • Recommendations for Total Parenteral Nutrition (TPN) formulation, enteral tube feedings, oral nutritional supplementation, symptom management, rehydration and medication review and advice
Patient education material & self-management programming[94-96]	• Access to education tools, coaching and resources in the areas of emotional management, coping with cancer, anxiety, depression and symptom management for patients and families • PSO practitioners should have expertise in health literacy, self-management and patient education competencies in the context of providing psychoeducational support for people with cancer
Psychosocial symptom screening[80]	• Systematic symptom screening for distress and malnutrition at the initiation of the cancer treatment and thereafter at regular intervals in all settings where cancer care is delivered, using established standardized tools (e.g., Edmonton Symptom Assessment System Revised [ESAS-r] or Malnutrition Screening Tool) • Systematic response to screening for identified high scores
Rehabilitation services[98-101]	• Assessment to determine patients' needs regarding physical functioning at home, activities of daily living, lymphedema care, back-to-work support and the corresponding rehabilitation interventions • Assessment and rehabilitation may be provided by an occupational therapist, physiotherapist and/or other specialized PSO providers • Neuropsychological assessment and cognitive rehabilitation for brain tumour patients, and those with cancer associated cognitive disturbances (brain fog) • Structured exercise programs have increasingly been shown to be safe and effective for improving functional outcomes, well-being, and successful return to work in cancer patients
Sexual health assessment and intervention[102]	• Assessment of sexual, body image and relationship problems commonly associated with cancer and cancer treatments, including treatments that impact on hormonal system • Delivery of educational material, resources and linkage to appropriate specialized providers who can deliver relationship and sexual counseling and/or somatic interventions to improve function • These specialized providers may or may not be part of an inter-professional sexual health clinic
Speech Language therapy[103]	Swallowing assessment and management and speech-language therapy should be provided by a Speech-Language Pathologist
Spiritual care[104, 105]	Access to spiritual support (including links to grief and bereavement programs) and to address spiritual concerns for patients and families
Support for families and caregivers[90]	The PSO assessment and services mentioned above for family caregivers and other members (including children) as well as educational material listed below and access to coping groups, and to community based resources

Content of this table reflects expert consensus opinion. It is also informed by the scientific literature (selected references are noted) and previous high-level service delivery framework recommendations.[4, 89]

Quality Improvement Through Clinical Training, Support and Research

five

> “We need to encourage multi-centre research, as the patient populations within individual cancer centres are too small to produce generalizable results. We need to be able to demonstrate that the benefits of these interventions can be delivered in cancer centres across the province.”

- Dr. Gary Rodin, Head, Department of Supportive Care,
Princess Margaret Hospital

Clinical Training and Support

In order to ensure that patients and families receive high-quality PSO care, healthcare providers must be given opportunities to enhance their clinical skills and practice. Regional Cancer Programs can support the development of these skills and high levels of competence by encouraging PSO providers (frontline and specialized providers) to enhance their expertise through seminars, workshops and Inter-professional Psychosocial Oncology Distance Education (offered by providers such as the Canadian Association of Psychosocial Oncology(106); and the de Souza Institute(107)).

Frontline oncology staff may be vulnerable to compassion fatigue and burnout because of the conditions under which they provide care, and may benefit from support programs led by specialized PSO providers to enhance their own coping skills and improve morale (e.g., programs on nursing burnout or mindfulness-based stress reduction). It is important to optimize the utilization of PSO expertise and provide one-on-one consultations, group programs, education and/or advice through various quality initiatives to frontline oncology staff. Research suggests that healthy and supportive work environments are imperative to oncology nurses' health, well-being and satisfaction, as well as improvement in health outcomes for patients and nurses and reduction in healthcare expenditures(108).

PSO Research and Evidence-Based Guidelines

Research is essential in order to advance the knowledge and development of PSO services across the healthcare system. When Regional Cancer Programs create an environment that values and encourages PSO research, not only within the regional cancer centres but also in collaboration with smaller sites across the province, developing such linkages will facilitate the translation of research into clinical practice.

Active involvement in psychosocial research can also help PSO providers keep up to date with the latest evidence, provide opportunities for inter-professional collaboration and encourage students, residents and fellows to participate in academic projects.

> “I think there’s a valuable opportunity in training healthcare providers to maximize their precious time with patients by helping them listen beyond the parameters of their own interventions and the diagnosed problems. Each patient/clinician meeting is a chance to teach or put us at ease and make us a partner in our healing.”
>
> **- Laurence S., Patient and Family Advisor**

Evidence-based PSO guidelines inform best practices and improve patient care, and should be incorporated into clinical practice. Cancer Care Ontario, as well as other professional organizations, such as the Canadian Association of Psychosocial Oncology and Canadian Partnership Against Cancer have developed a number of evidence-based clinical practice guidelines to help ensure that PSO interventions, wherever possible, reflect state of the art clinical research and the recommendation of experts in the field where such research is not available.

Patient and Family Advisors

Clinical education and research are two components of our continuous quality improvement initiatives; consultations with Patient and Family Advisors is another. Patient and Family Advisors are increasingly becoming involved in health system planning at all levels, including within local hospitals, Regional Cancer Programs and Cancer Care Ontario. Patients and families are valued stakeholders who can provide important insight and guidance about their needs and priorities.

Recommendations

5.1 Regional Cancer Programs provide the opportunities and necessary infrastructure for teaching and training students of the specialized PSO disciplines, as well as frontline providers in the principles and practices of PSO.

5.2 Opportunities be provided for frontline staff in accessing the expertise and support services offered by specialized PSO providers.

5.3 Opportunities be provided for peer supervision, and knowledge sharing activities such as participation in inter-disciplinary case conferences and communities of practice.

5.4 Regional Cancer Programs support specialized PSO providers in enhancing their clinical skills and competence through continued education.

5.5 Specialized PSO Providers complement their clinical practices with evidence-based PSO guidelines.

5.6 PSO programs be involved in quality-improvement projects, as well as collaborative, inter-professional, multi-centre research.

5.7 Regional Cancer Programs participate in the measurement of PSO services outcomes as a means of ongoing quality improvement.

5.8 Regional Cancer Programs ensure Patient and Family Advisors are engaged in the planning and evaluation of PSO services.

Acknowledgements

The development of Recommendations for the Delivery of Psychosocial Oncology Services in Ontario was organized by Cancer Care Ontario's Psychosocial Oncology Program and written in consultation with inter-professional content reviewers, regional PSO Leads, and PSO committee members. An expert panel reviewed and approved the recommendations, drawing upon their clinical expertise to assess the overall quality, utility and value of the document. External PSO providers, Patient and Family Advisors, and administrative leaders also offered their feedback.

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CANCER CARE ONTARIO PSO REGIONAL LEADS AND COMMITTEE MEMBERS

Appendix 1:

Models of Specialized Mental Health Service Delivery in Oncology

There are three models of care options for the delivery of specialized mental health PSO services:

1. **On-site dedicated psychiatrist or psychologist.** This model of care involves an on-site psychiatrist and/or psychologist dedicated to provide PSO services in the cancer centre or hospital providing cancer services. This "psycho-oncologist", who has an office full or part time in the regional cancer centre or part of the hospital where the systemic treatment is delivered, is often involved in teaching and supervision, and may be involved in research and administrative leadership.
2. **Off-site but rapidly accessible consultation with or without follow up.** Centres without a dedicated on-site psycho-oncologist must be able to refer patients to a hospital-based or community-based practitioner who has an understanding of oncologic illness, treatment issues and potential interactions between oncologic and psychopharmacologic drugs. A consult-liaison psychiatrist who has experience dealing with the medically ill is the ideal choice, particularly around the use of medication for more complex cases. A rapidly accessible psychologist who does not operate on a private payer model (for example a host hospital based psychologist) could provide psychotherapeutic support. Psychotherapy may also be offered by a psychiatrist depending on their availability.
3. **Collaborative care model.** This model involves:
   - a care manager (usually a nurse or social worker with mental health training) to provide psychotherapeutic interventions like problem solving therapy or behavioral activation directly or through accessible psychotherapists;
   - a psychiatrist (for medication +/- psychotherapy) or psychologist (for psychotherapy) to supervise the case (through face-to-face supervision or distance supervision);
   - a primary care or oncology or palliative care provider to prescribe medications for uncomplicated cases; and,
   - a psychiatrist to provide direct consultation and/or follow up for complex cases (e.g., treatment resistance, complex diagnoses like pre-existing bipolar disorder or schizophrenia).

Collaborative care models often involve manualized intervention (e.g., cognitive behavioural therapy, problem-solving therapy or behavioural activation), measurement-based care and algorithm based interventions.

If PSO services are not available in the hospital where patients receive their cancer care or in their community, efforts should be made to facilitate access as needed. In some cases, technology-assisted services, such as Ontario Telemedicine Network (OTN), may allow assessment, consultation and supervision to be conducted at a distance. E-consultation models that allow for direct email support around complicated cases between front-line practitioners and specialized PSO providers might also be applicable to PSO and streamline the number of direct distance assessments that are required.

Appendix 2:

Role Descriptions of Specialized PSO Providers

1. **Occupational Therapists:** Occupational therapists play an important role in assisting people to maximize their function in the face of cancer-related functional decline. They work collaboratively with people with cancer to enable them to participate in the occupations which give meaning and purpose to their lives, including assessment and intervention in the areas of self-care, productivity and leisure. Occupational therapists conduct environmental assessments, recommend assistive devices and equipment, and teach self-management strategies to help people be as safe and as independent as possible in their day-to-day activities. Occupational therapists are key interdisciplinary team members who can work with people to assist with cancer-related brain fog and cognitive issues, energy conservation techniques, lymphedema management, exercise prescription and return to work planning(44, 109). As part of academic responsibilities, they supervise students and contribute to the learning of other students/ residents doing practicums in cancer centres. They participate in research, expert panels, development of professional standards, present at scientific and professional meetings. College of Occupational Therapists of Ontario: https://www.coto.org/
2. **Physiotherapists:** Physiotherapists play a key role in designing and conducting rehabilitation programs aimed at assisting people to achieve their maximum function for people across the cancer care continuum. Physiotherapists create individualized treatment plans that can include exercise prescription, patient education, provision of gait aids, and hands-on assistance. They are specially trained to make adjustments to treatment plans based on patients' medical status and performance. Along with providing individualized treatment interventions, physiotherapists can assess and treat conditions such as lymphedema (educate on recognition of the condition, self-management and assist with appropriate compression, if needed), axillary web syndrome and provide scar management. They have expertise in exercise, and re-conditioning, respiratory treatment, pain management, sexual health and back to work programs. They also have expertise in musculoskeletal and pulmonary function as it relates to physical activity and mobility. They may conduct pre- and post-treatment assessments to determine any musculoskeletal or pulmonary impairments. They work collaboratively with patients to restore functional mobility, strength, range of motion, and cardiovascular endurance. Some physiotherapists offer relaxation, stress management and mindfulness-based stress reduction programs(110-112). Physiotherapists can make recommendations for home modifications, mobility equipment and general conditioning programs and refer patients to other community programs for home support. As part of academic responsibilities, they supervise students and contribute to the learning of other students/ residents doing practicums in cancer centres. They participate in research, expert panels, and development of professional standards, quality improvement and assurance initiatives, as well as present at scientific and professional meetings. College of Physiotherapists of Ontario: https://www.collegept.org
3. **Psychiatrists:** Psychiatrists are medical practitioners who provide specialty care to cancer patients, and often self-identify as psycho-oncologists or consult-liaison psychiatrists, a sub-specialty dedicated to providing care to medically ill populations. Psychiatrists are experts in the assessment and diagnosis of psychiatric and emotional disorders, including biopsychosocial formulations. They provide the highest level of expertise

in providing psychopharmacologic management, including major depression, anxiety disorders and in particular treatment resistant or difficult to treat populations. They also provide expertise in recognizing when psychiatric symptoms are caused by medical conditions or as a result of treatment protocols, for example oncologic medication that causes mood symptoms such as tamoxifen, steroids or leuprolide. They are also very familiar with drug interactions between psychiatric medications and chemotherapeutic agents. Psychiatrists provide psychotherapeutic treatment directly, and may collaborate with other healthcare professionals who provide this service such as social workers, spiritual care professionals, psychotherapists and nurses. They work collaboratively with other psychiatrists who have been caring for cancer patients with existing complex mental health needs, such as pre-existing disorders like Schizophrenia or Bipolar Disorder. They may also provide second opinion assessments around capacity for treatment refusal and MAID, as well as the support of patients who refuse treatment or ask for assistance in dying. Psychiatrists also provide expertise in risk assessment and management including suicide and aggression.

The College of Physicians and Surgeons of Ontario: http://www.cpso.on.ca/

4. **Psychologists:** Psychologists are scientist-practitioners who obtain competency in one or more of clinical psychology, health psychology, rehabilitation psychology, and neuropsychology. They are experts in the assessment, diagnosis and treatment of mental and emotional disorders and syndromes. They have expertise in psychometric testing, including neuropsychological and psycho-vocational assessments, assessment and management of cancer associated cognitive disturbances (brain fog). In addition to assessment, they are experts in the use of evidence-based psychotherapeutic interventions (e.g., cognitive-behavioral, existential, and interpersonal) for a range of mental, emotional and characterological disturbances (e.g., anxiety, depression, phobia, trauma, eating disorders, addictions, and existential crises) as well as counsel individuals around coping and adjustment to a range of issues across the lifecycle (e.g., illness, loss, life transitions). They are often specially trained to provide behavioral health interventions such as hypnosis, biofeedback, mindfulness-based interventions, and motivational interviewing that can be applied to a range of mental health and addiction problems. Psychologists are involved with training practicum students and residents in clinical psychology. They are trained as researchers as well as clinicians and often conduct psychosocial and quality of life research, and provide leadership and grant writing expertise to research endeavours with inter-professional research teams.

   The College of Psychologists of Ontario: http://www.cpo.on.ca/

5. **Registered Dietitians:** Registered dietitians work as part of the interdisciplinary care team and play a role in caring for cancer patients through the identification, prevention and management of malnutrition, cancer cachexia, nutrient deficiencies and dehydration. Registered dietitians are actively involved in those illness sites and treatment regimens that have a direct effect on nutritional status, such as head and neck, esophageal and gastrointestinal malignancies(113-116). They provide detailed clinical assessments, nutrition diagnosis, and implement, monitor and evaluate evidence-based nutrition care plans. The goals of nutrition intervention are to optimize tolerance to treatments as well as quality of life (See table 2). Registered

dietitians also provide individualized nutrition counseling and/or group education to patients and their families about realistic eating after a cancer diagnosis, as well as reducing risk of cancer recurrence through healthy living. Dietitians may also work with physicians for the delegation of medical directives; for example they may be authorized to order nutrition supplements or therapeutic diets. As experts in oncology nutrition, they supervise dietetic interns and contribute to the learning of other students/residents doing practicums in cancer centres. They promote evidence-based practice through research, participate on expert panels, and present at scientific and professional meetings. They also play a consultative role in helping patients and healthcare professionals: identify evidence-based nutrition resources, address commonly held misconceptions about diet and cancer, and increase understanding of the potential risks and benefits of complementary or alternative diet therapies.
College of Dietitians of Ontario:
https://www.collegeofdietitians.org

6. **Social Workers:** Social workers deliver a wide range of PSO services to patients and families through all phases of the cancer care continuum. They conduct psychosocial assessments, and intervene with distress, including anxiety, depression and suicidal ideation. They have expertise in family and couple assessments, and are often involved in supportive interventions such as helping children adjust when a family member is diagnosed with cancer. They may also provide or facilitate care for patients with mental health concerns who often have unique challenges in accessing and receiving cancer treatments. Social workers can provide therapy or education to patients with concerns related to cancer treatments, such as cognitive changes, fatigue, sexual health, insomnia, caregiver distress and other presenting psychosocial problems. Social workers engage in advanced care planning with patients and families, and provide psychosocial support for terminal illness and end of life care. Social workers support patients who may request assistance in dying and their families, provide therapeutic intervention for anticipatory grief and legacy work, and offer grief and bereavement counselling. They are experts at linking patients with resources and supports in their home and/or community. Social workers design and develop many group modalities such as therapeutic groups, educational groups, and can assist and support community stakeholders interested in developing and sustaining peer led support groups. They assist patients and families with navigating the healthcare system, and offer practical support with housing, transportation and completing financial assistance forms to access disability benefits. In some circumstances, social workers may be asked to support and debrief staff. As part of academic responsibilities, social workers supervise student practicums, are involved in research, present at professional and scientific meetings, and participate in expert panels to advance the standards of PSO in the field. Ontario College of Social Workers and Social Service Workers:
http://www.ocswssw.org/
Association of Oncology Social Work:
http://www.aosw.org/professional-development/scope-of-practice/

7. **Speech Language Pathologists:** Speech language pathologists (SLPs) can help patients manage communication and swallowing issues, whether they are temporary or long- term, as a result of cancer and its treatments which can affect swallowing, voice, speech, and overall quality of life. They are essential members of head and neck cancer programs and they provide interventions for patients with head and neck malignancies who are undergoing or have undergone

surgical interventions, radiation therapy and/or chemotherapy, which can affect the ability to speak and swallow properly. In Ontario, it is recommended that all head and neck programs have a SLP as part of their interdisciplinary team according to head and neck program treatment guidelines(117). SLPs work collaboratively within an interdisciplinary team where delegated medical acts may be instituted, such as the ability to perform tracheoesophageal voice prosthesis (TEP) insertions and prosthetic changes. In addition, SLPs offer expertise in dysphagia management with any disease site group where there is disease or treatment in the chest/abdominal area that can cause physical impedance of bolus flow or discomfort when swallowing (e.g., breast, lung, esophageal). Patients with brain cancer can also benefit from SLP's expertise in the area of speech, language, and communication. SLPs working in oncology frequently perform delegated medical acts. They also create personalized rehabilitation plans, and provide counselling and education to patients and families before and throughout treatment. As part of academic responsibilities, they supervise SLP students and contribute to the learning of other students/residents completing practicums in cancer centres.

They promote evidence based practice through research, participate in expert panels, clinical case conferences, the development of professional standards, and present at scientific and professional meetings.

College of Audiologists and Speech-Language Pathologists of Ontario:
http://caslpo.com/

8. **Spiritual Care Practitioners (Chaplains):** Spiritual care practitioners play a critical role supporting the spiritual health, emotional needs and well-being of patients and their families. They are uniquely trained to provide spiritual care screening, assessment and interventions, and to facilitate spiritual, multi-faith, religious and non-religious cultural practices. They have a particular expertise in the provision of grief, bereavement, and end of life care. As members of an oncology interdisciplinary team they are also uniquely situated to provide education in spiritual care for other health care providers, conduct research and initiate quality improvement projects in spiritual care related to the relief of suffering, quality of life, and quality of care(105). Spiritual care practitioners also provide site supervision for practicum students from affiliated Universities/Colleges and Clinical Pastoral Education programs, affiliated with the Canadian Association for Spiritual Care (CASC). They play a key role identifying and responding to the spiritual health and well-being of the oncology team, facilitating debriefings and reflective practices to mediate the spiritual stressors associated with the provision of care in this context. In Ontario, many spiritual care practitioners are also registered psychotherapists and use skills and expertise from both professions to respond with compassion, empathy and openness to the needs, values and preferences of the individual.

   The Canadian Association of Spiritual Care:
   www.spiritualcare.ca/profession/scope-of-practice/

   College of Registered Psychotherapists of Ontario:
   http://www.crpo.ca/

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