Cancer Care Ontario

Oncology Caregiver Support Framework

Prepared by the Psychosocial Oncology Program

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Ontario

Executive summary

Caregivers of cancer patients frequently require their own psychosocial support as many patients are relying on caregivers[1] for support and care. Given the increasing need to support caregivers, the Patient and Family Advisory Council at Cancer Care Ontario[2], identified caregiver support as a priority.

The Psychosocial Oncology Program conducted a formative evaluation of oncology caregiver support in Ontario. A key outcome of the evaluation is the development of a caregiver support framework in oncology to guide best practice and standard of care.

By adapting the caregiver support framework developed within the Central Local Health Integration Network, the Psychosocial Oncology Program has developed an oncology-specific caregiver support framework. The framework was developed through expert consultation, reviewing the literature, and drawing on expertise and lived experience from a caregiver support working group.

The framework focuses on five components of caregiver support:

1. Caregiver Identification, Recognition, and Inclusion
2. Caregiver Screening and Assessment
3. Caregiver Referral and Pathway
4. Caregiver-specific Education
5. Monitoring and Evaluation of Caregiver Supports

The framework is intended as a best practice guide to support regional planning for caregiver support strategies and to foster more discussion between healthcare providers and caregivers.

Each framework component outlines implementation objectives that can be adopted to improve caregiver support, desired long-term outcomes that can be achieved through the implementation objectives, and overall healthcare system outcomes for caregiver support in Ontario.

Cancer Care Ontario will support the Regional Cancer Programs with framework implementation and continued caregiver engagement.

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[1] Please see the definition of an oncology caregiver on page 5 of this document

[2] In time, the work of Cancer Care Ontario will be taken on by Ontario Health. Ontario Health is a single health agency that will oversee healthcare delivery, improve clinical guidance and support providers to ensure better quality care for patients.

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Introduction

Caregivers of cancer patients frequently require their own psychosocial support throughout the patients’ cancer experience. There is a growing cancer burden, and many patients rely heavily on caregivers for the support they require. This often results in caregivers requiring their own support to cope. Given the increasing need to support oncology caregivers, the Patient and Family Advisory Council at Cancer Care Ontario identified caregiver support as a priority for offering high quality cancer care. As such, in 2017, the Psychosocial Oncology (PSO) Program conducted a formative evaluation of oncology caregiver support in Ontario. Evaluation results showed variability and inconsistency in access to caregiver support services, and identified opportunities to improve support to caregivers. A key outcome from the evaluation is the development of a caregiver support framework to guide best practice and articulate a consistent standard of care for oncology caregivers.

Framework development approach

This framework was adapted from the caregiver support framework developed within the Central Local Health Integration Network (LHIN), which was co-led by the Alzheimer Society of York Region (AS York) and the consulting firm, Collaborative Aging.

1. Expert consultation

The PSO Program consulted with experts at AS York and Collaborative Aging on how to best leverage and adapt the Central LHIN caregiver support framework to an oncology-specific framework. The Central LHIN framework was created using an expert panel, as well as co-design methods to involve caregivers and health professionals in the planning process. Broad consultations in the form of surveys, focus groups and interviews with healthcare providers and caregivers helped to inform the components of the Central LHIN framework, which is a five component logic model format. The five components in the Cancer Care Ontario oncology caregiver support framework were informed by the Central LHIN framework.

2. Literature review

An initial literature scan was conducted to find oncology-specific caregiver support best practices, recommendations, and experience from caregivers and care recipients. Forty-three articles were reviewed, which included evidence from academic and grey literature. Key resources on caregiver support from the Change Foundation, an independent health policy think-tank, were also included. Using the evidence from the literature scan and the Central LHIN framework, a draft framework specific to oncology was created.

3. Working group

A caregiver support working group consisting of specialized PSO providers, patient and family advisors (PFAs), and caregivers was formed to develop the framework through a consensus process. Six working group meetings were held to gain both clinical and lived experience input into the guiding objectives, long-term outcomes, and system outcomes outlined in the framework. Additionally, the working group developed and tailored an oncology-specific definition of a caregiver to guide the overall framework.

Following the working group meetings, the framework was reviewed by Cancer Care Ontario leadership and staff, the working group, and an external review panel. The finalized framework received endorsement from the working group.

Definition of an oncology caregiver

The caregiver support working group developed the following definition of an oncology caregiver:

“A person who takes a caring role without pay in a non-professional capacity, providing one or more of the following: physical, emotional, financial, social, spiritual, and system navigation support, to a person with cancer at any phase of the cancer continuum from suspicion of cancer to survivorship or end of life. Caregivers may be a spouse/partner, family, friends, neighbours, colleagues, and/or anyone identified by the care recipient. Caregivers play a pivotal role in the circle of care and are key partners in healthcare delivery to cancer patients. A person with cancer can have multiple caregivers with distinct roles.”*

*A note on the term “survivorship” used in the definition of a caregiver (1).

We acknowledge that there are limitations to the term “survivorship” as it has many uses and meanings in different contexts. In this document, we define survivorship as the phase of the cancer continuum following diagnosis and primary cancer treatment, prior to recurrence of subsequent cancers or death. The term also encompasses people who may be receiving ongoing adjuvant hormonal therapy and other treatments to manage cancer recurrence or control symptoms.

Supporting oncology caregivers

The value of caregivers in Ontario is significant as they provide unpaid care and reduce pressure on the healthcare system. The Ontario population is aging, and cancer patients may have other active illnesses such as diabetes and dementia, which can make caregiving challenging and complex. However, caregivers are largely unrecognized for their role, and gaps in caregiver support can create additional burdens for both caregivers and care recipients. Caregivers provide support by taking on many new responsibilities to manage patients' treatment and care, which can be overwhelming and stressful (2). If patients are to receive the best care, there is a need to advance support for caregivers as they require optimal physical and emotional wellbeing to fulfill their role as caregivers. Formally recognizing caregivers as a valuable member of the healthcare team, and providing caregiver-specific supports are important steps to maximizing and acknowledging their contributions to the health and wellbeing of Ontarians (3).

Oncology caregiver statistics

There are approximately 3.3 million caregivers in Ontario, 85% (2.8 million) of which do not receive any financial support for their caregiving efforts (4). Ten percent of caregivers in Ontario take care of someone with cancer (4). Caregivers save the healthcare system upwards of $26 billion annually by taking on informal, unpaid caregiving, which the current healthcare system cannot afford to replace (3,5,6). The 2018 Ontario Cancer Statistics Report indicate that over 90,000 new cancer cases were diagnosed in 2018 (7), which means a large number of oncology caregivers exist within the province, although the exact number is unknown.

Caregivers are an integral part of a patient's cancer experience as they take on many responsibilities ranging from physical and emotional support, to technical and logistical tasks such as transportation and assisting with medical treatments (4,8).

In Ontario:

- More than half of caregivers are women
- 76% provide care while balancing employment
- 32% balance employment, caregiving, and raising one or more children under the age of 14

- Almost 50% of oncology caregivers are spending two to nine hours per week providing care, with 36% spending 10 hours or more per week providing care

It is important to note that the above figures were gathered in 2012 and likely underestimate current caregiver statistics in Ontario (4).

Current state of oncology caregiver support in Ontario

Cancer Care Ontario conducted a formative evaluation in the 2017/2018 fiscal year to understand the current state of support provided to caregivers by the Regional Cancer Programs (RCPs) across Ontario. The evaluation had two components: a regional cancer centre current state survey completed by each PSO regional lead, and PFA consultations held by each regional lead.

Overall, the formative evaluation showed significant variation in the availability of caregiver supports, services, and resources offered in RCPs. While all RCPs offer various forms of caregiver support such as counselling services and linkage to oncology-specific community resources, gaps in, and barriers to caregiver supports still exist.

Four key themes were identified by PFAs at consultations held in each of the regional cancer centres (RCCs):

- The need for a clear definition of caregiver
- A clear process to identify and engage caregivers
- Acknowledgment of the caregiver role by the healthcare team
- The need to screen caregivers for distress throughout the cancer continuum

The framework was developed to address caregiver support gaps in the healthcare system, including the themes identified by PFAs during the consultations.

> *"Caregivers take on different personas. My needs as a caregiver and husband are different depending on the role, from the person driving her to-and-from appointments and maintaining continuity between appointments vs. my caregiver needs as her spouse vs. my caregiver needs as a father to my sons whose mother is terminal. The needs of the caregiver are different." – Patient and Family Advisor*

Intent of the framework

This framework was created to serve as a best practice guide for oncology-specific caregiver support. It describes the supports that should be available to caregivers in an oncology setting, and provides guidance on the implementation and operationalization of caregiver support. This framework also encourages healthcare administrators and providers to examine how caregiver support can be implemented, enhanced, and measured in their organizations.

The framework outlines the level of caregiver support service that any person (patient, family member or caregiver) receiving adult oncology services in the RCPs should expect to receive.

This document does not prescribe how organizations and providers should achieve the objectives and outcomes outlined in the framework, rather it establishes a guide for how care should be optimally designed to best support caregivers in an oncology setting.

The five main components in caregiver support are the focus of the framework, but we acknowledge that it does not address all aspects of caregiving. The Change Foundation has resources on other aspects not included in this framework, such as legal and privacy resources for caregivers (9), and caregiver assessment tools (10).

Oncology caregiver support framework

Each framework component includes implementation objectives as well as long-term outcomes. The overall framework includes system outcomes for caregiver support in oncology.

1. Caregiver Identification, Recognition, and Inclusion	2. Caregiver Screening and Assessment	3. Caregiver Referral and Pathway	4. Caregiver-specific Education	5. Monitoring and Evaluation of Caregiver Supports
Implementation Objectives				
• All members of the healthcare team to proactively identify caregivers and document who they are early on in the cancer continuum • Share with the healthcare team who the identified caregivers are throughout the cancer continuum • Recognize caregivers as valued partners in the care recipients' cancer care experience • Recognize that caregivers may need support, deserve the offer of support, and should be encouraged to seek support • Ask caregivers what they need and connect caregivers to services, information, and resources accordingly • Accept caregivers as part of the healthcare team and accept their participation and contribution in the care process	• Screen each caregiver to identify needs as well as caregiver burnout, including through the use of patient reported outcome measures • Establish and maintain routine clinical practice using evidence-based tools to assess caregiver needs • Assess for caregiver needs early on in the cancer continuum with touchpoints throughout and document appropriately • As needed, healthcare team to provide caregivers with separate, individualized, and private advice and attention	• Improve availability of, reduce variability of, and improve equitable access to caregiver support services, resources and information in all care settings across the cancer continuum • Provide caregiver-specific resources and information to address caregivers' needs across the cancer continuum, including linking to caregiver support services • Identify and increase visibility of designated points of contact beyond the primary clinician, who can help caregivers navigate different areas of the cancer continuum for access to caregiver support services, information, and resources	• Provide appropriate caregiver-specific information and education to build capacity for self-advocacy and self-care • Proactively and regularly offer caregivers options to seek culturally relevant and appropriate supports including: financial/legal support, respite care, employment rights, physical/emotional support, family and child support, spiritual support, bereavement support, palliative care support, and any other appropriate caregiver supports early on and throughout the cancer continuum • Regularly check in with caregivers throughout the cancer continuum as their educational needs change to help build their capacity to seek out timely information, and to increase their awareness of various caregiver resources available	• Include caregiver feedback, input, and engagement regarding caregiver support and their caregiver experience • Understand the impact and address continuing gaps in caregiver support services, information or resources in hospitals and in the community • Identify an action plan for addressing gaps in caregiver support

1. Caregiver Identification, Recognition, and Inclusion	2. Caregiver Screening and Assessment	3. Caregiver Referral and Pathway	4. Caregiver-specific Education	5. Monitoring and Evaluation of Caregiver Supports
Long-term outcomes				
• A healthcare delivery culture where caregiver inclusion is common practice and encouraged • Caregivers are recognized and included from suspicion of cancer and throughout the cancer continuum • The healthcare team includes and validates caregivers as an essential component of the care recipient’s cancer continuum and as valued partners in the care delivery process	• The healthcare team refers caregivers to the appropriate caregiver support services, information, and resources • Gaps are identified and addressed in the quality and availability of appropriate caregiver supports, information, and resources that reflect Ontario’s diverse caregiver population	• Streamlined cancer care for both caregivers and care recipients • Increased caregiver and healthcare team awareness of available caregiver support services, information, and resources in the hospital and in the community	• Empowered and prepared caregivers with the educational tools and capacity for self-care and being a caregiver	• A shift in healthcare culture whereby caregiver support is embedded both at the frontline and at the system level, and caregiver self-advocacy and self-care is encouraged throughout the cancer continuum • Supported caregivers who can self-manage, who are more empowered to have a positive caregiving experience, and who are able to take care of their wellbeing in order to best support their care recipients • Continuous quality improvement that drives effective, evidence-based and high quality caregiver support
System outcomes				
A caregiver support system in oncology that: • accepts and welcomes caregivers as key partners in the patient’s care and experience • provides equitable access to streamlined and timely caregiver support services, information, resources, and education throughout caregivers’ cancer experience • leads to healthcare system savings, decreased healthcare provider burnout, and improved patient and caregiver experience				

Implementation objectives

The implementation objectives outlined under each framework component are specific activities and strategies that can be adopted to improve caregiver support in Ontario. Further, these objectives encompass strategies at the individual (caregiver), clinician (healthcare team), and system (cancer centre/hospital and community) level. The objectives also address the caregiver support gaps identified in the formative evaluation.

Long-term outcomes

The long-term outcomes outlined under each framework component are the desired outcomes that could be achieved through the implementation objectives. Key outcome themes include inclusion and awareness of caregivers in the healthcare delivery system, equitable access to caregiver supports, and caregiver empowerment.

System outcomes

The system outcomes are the overall result of the implementation objectives at work over time, creating a culture shift around caregiver support within the healthcare system. As a result, inclusive and welcoming caregiver support within Ontario's cancer system, which emphasizes equitable and timely access to caregiver support, becomes the standard.

Summary and next steps

The framework is intended to support regional planning for caregiver support strategies by setting the foundation for oncology caregiver support in Ontario. The framework is intended as a best practice guide, which organizations can implement based on their unique circumstances, and develop strategies that best meet the needs of the populations they serve.

The framework is also intended to foster more discussion between healthcare providers and caregivers around inclusion of caregivers as essential partners of cancer care. It is our hope that healthcare providers using this framework will champion a culture shift in oncology, leading to greater caregiver support that recognizes caregivers as valued partners in the cancer continuum.

As next steps, Cancer Care Ontario will support the RCPs with framework implementation and with continued caregiver engagement.

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