

CLINICAL SERVICES

SUPPORTIVE CARE

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A. INTRODUCTION	2
B. CLINICAL SERVICES	2
1. Goals	2
2. Scope	2
3. Pathway	3
4. Concepts	4
5. Levels	5
6. Settings	6
C. RESOURCES	7
7. Facilities and Equipment	7
8. Human Resources	8
9. Information Management	10
D. MANAGEMENT	11
10. Leadership	11
11. Operating Standards, Guidelines, Policies, Processes and Procedures	12
12. Data-informed Management Decisions	12
E. QUALITY	13
13. Standards, Guidelines and Best Practices	13
14. Performance Monitoring, Reporting and Quality Improvement	17
F. THE FUTURE	19
G. REFERENCES	20

A. INTRODUCTION

Treatment successes have made cancer a condition that requires long-term management in the biomedical, psychological, behavioural and social arenas.^{1,2} In 2012, 14.1 million new cancer cases were diagnosed worldwide and 32.6 million people were living with cancer within five years of diagnosis.³ By 2030, the number of new cancer cases is predicted to increase to 21.7 million, with the number of survivors increasing as well.⁴

Supportive care is a broad term, encompassing multiple services that go beyond meeting a person's need for testing and interventions to treat cancer. Organizations use different and overlapping terminology for these services (e.g., psycho-oncology, psychosocial oncology, survivorship, rehabilitation and palliative care), and configure them in varying ways based on their preferred model of care and local circumstances. Regardless of the terminology and configuration of services, supportive care must be recognized as a distinct and intrinsic part of cancer care.

Supportive care is essential for individuals who are at risk for cancer, living with cancer, living beyond active treatment, or receiving palliative and end-of-life care.⁵ Everyone who experiences cancer – whether as a patient, family or friend – requires supportive care.

This chapter presents the essential elements required to establish a supportive care service as part of a comprehensive system of cancer care.

B. CLINICAL SERVICES

1. GOALS

The goal of supportive care is to meet the needs of cancer patients and their families that go beyond testing and treatment. Supportive care addresses the psychological, emotional, social, economic, physical, practical, spiritual, health promotion and disease prevention, and information needs arising from a cancer diagnosis and subsequent treatment.

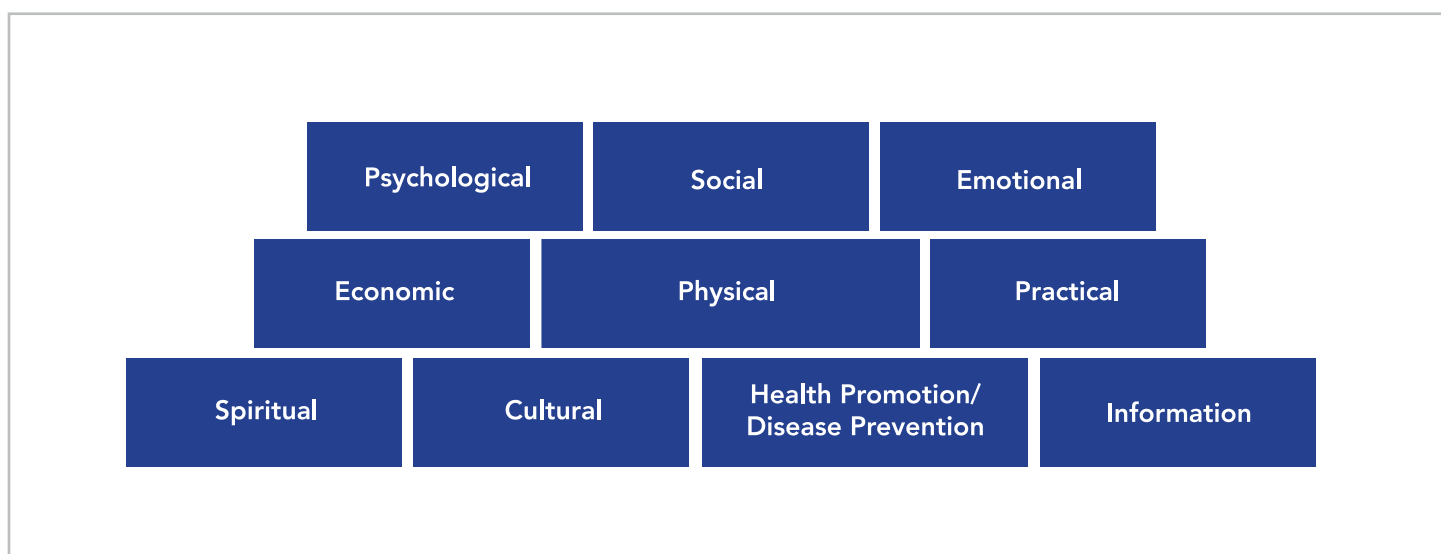
2. SCOPE

People who experience cancer require supportive care to address:⁵⁻⁸

- Psychological and emotional needs (e.g., distress, anxiety, worry, fear, anger or depression due to a cancer diagnosis, treatment outcomes, changes in physical appearance or relationships, financial concerns, difficulties living and coping with cancer, instability due to life transitions and palliative care)
- Social needs arising from changing roles with family and friends, or at school or work
- Economic needs, due to potential loss of employment and income or increased expenses
- Physical needs, such as impaired mobility, communication and cognition issues, sexual health issues, challenges with daily activities, coping with the effects of treatment (e.g., pain, fatigue, weight), and return to work
- Practical needs for assistance, such as help with the activities of daily living, return to work, transportation, child care, shopping or cooking
- Spiritual needs, such as questioning the meaning of life, suffering and death
- Cultural needs, such as access to traditional medicine approaches
- Health promotion and disease prevention needs, such as self-management, physical activity, nutrition and diet, surveillance for cancer recurrence, screening for other cancers, and awareness of health risks and late effects
- Information needs, such as information about their cancer, treatments, available services and coping skills

Mental health issues related to cancer, such as depression and anxiety, contribute to functional impairment in carrying out family, work and other roles, poor adherence to medical treatments, adverse medical outcomes, impaired social functioning, unhealthy behaviours (e.g., smoking, overeating, sedentary lifestyle), and decreased coping abilities.⁹ More than 35 per cent of people with cancer express distress.⁵ Psychosocial interventions are helpful in alleviating distress levels in patients, and may benefit medical outcomes and result in cost savings.¹⁰

Figure 1: The Breadth of Supportive Care



Traditions surrounding health vary widely across cultures. For more information about traditional and complementary medicine in healthcare, please see the World Health Organization's *Traditional Medicine Strategy 2014-2023*.¹¹

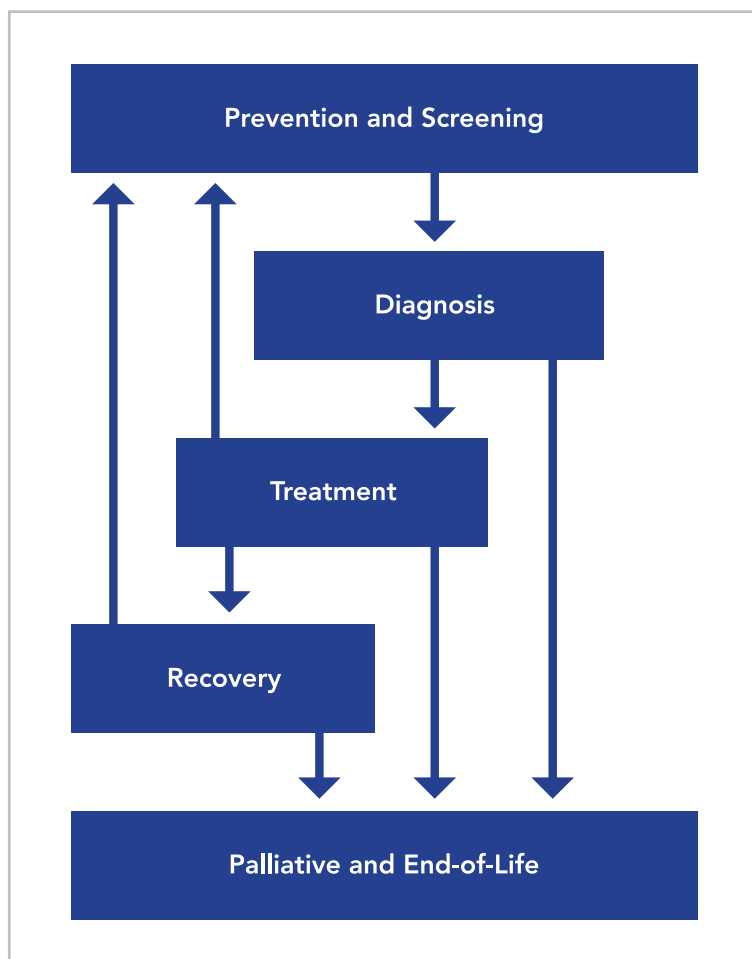
3. PATHWAY

The supportive care pathway is depicted in Figure 2.

At the point of cancer **prevention and screening**, individuals require information about available tests and their side-effects. Those waiting for screening and/or genetic testing, as well as those who come for follow-up screening after cancer treatment, may experience distress and anxiety. Individuals may also experience distress and anxiety during **diagnosis**, while awaiting the results of diagnostic tests and cancer staging or while waiting to see an Oncologist.

Patients who receive a cancer diagnosis require information about their diagnosis and the types of **treatment** and other services available, including their recommended treatments and the side-effects, impacts and expected outcomes of those treatments. Patients and their families may need additional supportive care to deal with the psychosocial distress associated with treatment and **recovery**. Psychosocial issues may include coping with health outcomes, changes in physical appearance and relationships, financial challenges, practical issues relating to work and home, and emotional considerations.⁵

Figure 2: The Supportive Care Pathway



Patients who receive a cancer diagnosis for which there is no treatment or for which treatment is unsuccessful require supportive care to address issues related to **palliative and end-of-life care**. See the *Cancerpedia: Palliative Care* chapter for more information.

Individuals should be assessed for symptoms and distress at every step of the cancer journey.

4. CONCEPTS

Terms for Supportive Care

Cancer centres and other organizations use a variety of terms for supportive care and configure supportive care services in different ways. For example, supportive care programs, departments or portfolios in tertiary cancer centres across Canada may be named: Psychosocial Resources; Rehabilitation Services; Patient and Family Support Services; Psychosocial Oncology; Psychosocial Oncology and Palliative Care; Supportive Care; Supportive Care Services; Patient and Family Counselling; Counselling and Support Services; or Integrated Psychosocial, Supportive and Palliative Care.⁵

Regardless of how services are named and organized, the supportive care service must be recognized as a fundamental part of cancer care. Each cancer patient requires a personalized supportive care plan, and supportive care interventions must be tailored to each patient's personal needs, goals and ways of coping. These factors are influenced by the patient's perception of the situation, socio-economic status, educational background, social supports, culture, religion and geographical location.⁷

Within the broad definition of supportive care, it is useful to examine some additional key concepts and elements of supportive care.

Cancer Survivor

By convention, a survivor is someone who continues to function during and after overcoming a serious hardship or life-threatening disease. A cancer patient is considered to be a survivor from the time of diagnosis until the end-of-life.¹²

Cancer Survivorship

The beginning of cancer survivorship may be the point of diagnosis (especially for patients who cannot be treated), when treatment begins, when the first line of treatment has been completed or when the cancer treatment phase has ended.

Traditionally, the end of cancer survivorship has been regarded as the point at which active cancer treatment is finished or a patient has died. There is now wider recognition that survivorship incorporates the transition from active cancer treatment to post-treatment, including the long-term and late effects of successful treatment.^{6,12}

In their work on survivors of adult cancer following primary treatment, Hewitt et al. (2005) identified four essential components of survivorship care:⁶

1. Prevention of recurrent and new cancers, and of other late effects. Cancer survivors are at risk of late- or long-term effects that depend on the type of cancer, its stage and the cancer therapies used.⁸
2. Surveillance for cancer spread, recurrence or secondary cancers, and assessments of medical and psychosocial late effects.
3. Intervention for the consequences of cancer and its treatment, such as medical problems (e.g., lymphedema, sexual dysfunction), symptoms (e.g., pain, fatigue), the psychological distress of cancer survivors and their families, and concerns related to employment, insurance and disability.
4. Co-ordination between specialists and primary care providers to help ensure that all of the survivor's health needs are met. A cancer patient may have multiple specialists and experience treatment with different therapies in different facilities, as an inpatient and outpatient. The Primary Care Provider must be aware of all treatment and be involved in the patient's follow-up care and health promotion.

Psycho-oncology/Psychosocial Oncology as a Cancer Specialty

Psycho-oncology/psychosocial oncology is a cancer specialty that focuses on the impact of cancer on the whole person. The specialty began developing in the 1970s as the stigma surrounding cancer and mental illness were increasingly being challenged.¹⁴ The terms psycho-oncology and psychosocial oncology appear to be used interchangeably. The vision of the International Psycho-Oncology Society (IPOS) – a professional association with multiple national member organizations – is to foster the science and practice of psychosocial oncology to improve the care of people affected by cancer worldwide.¹⁵

The definition of psycho-oncology/psychosocial oncology may vary by organization. For example, IPOS focuses on the psychological, social, behavioral and spiritual factors that affect tumor progression and the quality of life and survival of cancer patients. The British Psychosocial Oncology Society (BPOS) defines psychosocial oncology as the field of study concerned with the psychological, social and behavioural aspects of cancer, whereas the Canadian Association of Psychosocial Oncology (2010) includes the social, practical, psychological, emotional, spiritual, quality of life and functional aspects of cancer, from prevention through to survivorship and bereavement.^{5,16} Individual cancer centres may include different types of services within a psycho-oncology/psychosocial oncology program.

Rehabilitation

According to the World Health Organization (WHO), “rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.”¹⁷

Although the WHO definition suggests that rehabilitation could encompass all of supportive care, typically rehabilitation services focus on helping people regain or optimize the physical, mental and/or cognitive abilities that have been lost or impaired due to disease, injury or treatment.¹² Rehabilitation during and after cancer treatment helps patients increase their strength, mobility, endurance, balance, functioning, productivity and independence. In addition, rehabilitation before cancer treatments can be used to optimize a patient’s physical and mental condition and improve their physical and emotional outcomes.¹⁸

Although cancer rehabilitation has traditionally been part of cancer management, increased survivorship has seen rehabilitation evolve from simple supportive and palliative care to more complex interventions focused on restoring the integrity of organ structure and function, remediating functional loss, and adapting to the environment to enable full participation in daily activities and life roles.¹

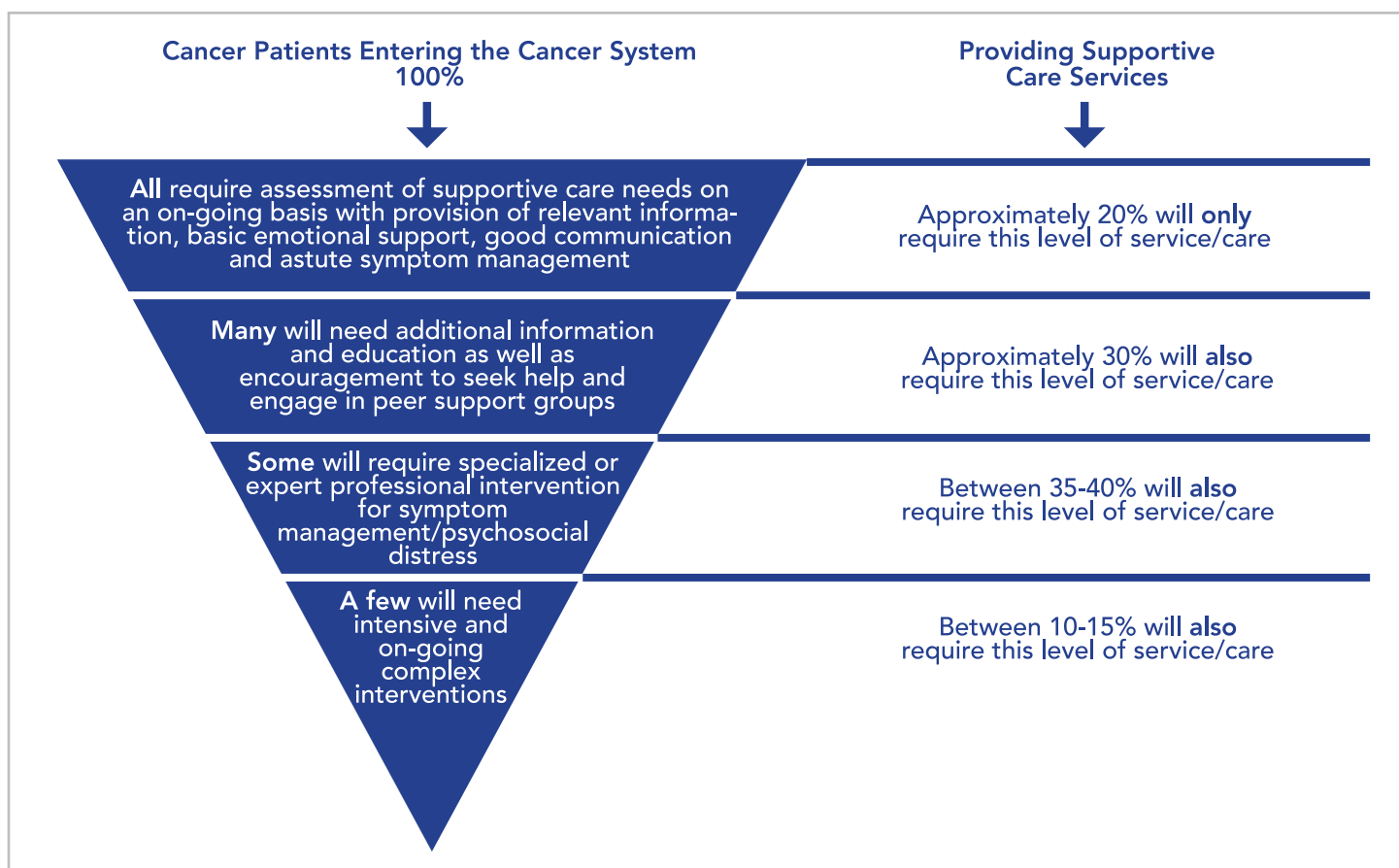
Palliative Care

Palliative care is, “an approach that improves the quality of life of patients and their families, facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹⁹ Palliative care is part of the broad definition of supportive care. See the *Cancerpedia: Palliative Care* chapter for more information.

5. LEVELS

Although individuals affected by cancer should have access to supportive care services from prevention and screening through to palliative care and end-of-life, the proportion of individuals who require these services will vary.⁷ Cancer patients and families are a diverse group with varying needs that shift over time.²⁰

Figure 3 shows that all cancer patients entering the cancer system require an ongoing assessment of their supportive care needs, with the provision of information, basic emotional support, communication and symptom management to support these needs. Approximately 20 per cent of individuals will require only this level of ongoing supportive care. The highest level of supportive care (i.e., intensive and ongoing complex interventions) is required by 10 to 15 per cent of patients.

Figure 3: Range of Supportive Care Needs⁷

Ideally, as a patient moves through his or her cancer journey, the level and types of supportive care required are available.

6. SETTINGS

Supportive cancer care is provided in a number of settings, each of which varies in terms of the services provided.^{5,8}

Cancer Centre

The cancer centre should have a designated supportive care department or program (recognizing that the name of the department or program and mix of services offered may vary by organization). The department must provide a full range of supportive care services, including more specialized and intensive supportive care to meet complex needs and the needs of those who do not respond to simple, established protocols. Depending on the service required, supportive care may be delivered as an inpatient service (e.g., specialized rehabilitation) or an outpatient service. Patients may also be referred to community-based specialists and resources.

Generally, a cancer centre's supportive care professionals have a high degree of training and operate at advanced practice levels. The cancer centre's supportive care team should be recognized as part of the cancer team and provide interprofessional/multidisciplinary supportive care assessments. Co-locating and integrating clinical treatment with supportive care services may improve access to services and care co-ordination.

If the cancer centre plays a larger regional role, it may also establish working and consulting relationships with community hospitals, primary care providers and other community-based organizations. Electronic communications and telehealth may help facilitate these partnerships. The cancer centre may also provide public access to a web-based repository of supportive care information and education. See the *Cancerpedia: Education*, *Cancerpedia: Communication*, and *Cancerpedia: Integrating Hospital and Community* chapters for more information.

Community-Based Hospitals

Community-based hospitals that provide cancer services must provide some supportive care services, but typically offer less breadth and depth of supportive care than a cancer centre. To ensure that patients receive appropriate supportive care, community hospitals should consult with the cancer centre or refer complex patients with specialized needs to the cancer centre, as needed. Community hospitals may also refer patients to community-based services and providers.

The community hospital should have a supportive care department or program that directs and oversees a suite of supportive care services (the name of the department or program and mix of services offered may vary). Formal screening and assessment for supportive care needs should be conducted by professional staff.

Primary Care

All cancer patients interact with primary care providers (i.e., family physicians, general practitioners, nurse practitioners). Generally, the Primary Care Provider should screen for supportive care needs, provide basic supportive care services (e.g., information and supportive counselling to meet basic psychosocial needs), refer patients to community resources as needed, and refer complex patients to more specialized supportive care providers at the cancer centre.

Other Organizations

Many other community-based organizations provide supportive care services to cancer patients and their families, especially by providing information about available resources, education and peer support. These settings may employ staff as well as engage volunteers. See the Cancer Index for a list of national and international organizations involved in cancer treatment, research and support.²¹

C. RESOURCES

Resources include the facilities and equipment, human resource and information management infrastructure required to provide supportive care. The core resource elements required are standard; however, various factors will impact the level and configuration of resources required for a specific cancer centre. For example, increased resources may be needed to support higher patient volumes. Similarly, different types of resources may be needed to support highly-specialized supportive care services.

Generally, cancer centres that provide the full array of cancer treatments have well-developed supportive care services. A cancer centre that is part of a larger healthcare facility may configure its supportive care services to support other clinical programs beyond cancer.

7. FACILITIES AND EQUIPMENT

Facility infrastructure for supportive care in a cancer centre will vary depending on the location and range of services provided within the centre. Generally, the supportive care department requires fully-equipped offices and workspaces for staff. In addition, rooms large enough to allow supportive care teams and professionals to meet with and provide services, education and information to individuals and groups of patients and families are necessary. Space allowances must be made for inpatients on stretchers as well as individuals using mobility devices. Outpatient clinics should include a spacious and inviting reception and waiting area, where patients can wait before appointments, as well as clinic rooms for appointments. The rooms should be large enough for multiple family members to join the patient, if required.

Cancer centres should consider providing an inviting space where cancer survivors can socialize, provide peer support and relax. This space may include exercise facilities and a kitchen for nutritional training. In addition, cancer centres should include one or a few centralized locations where information and patient resource material are available – electronically and in hard copy – about cancer, cancer treatments, and services and supports. Electronic access may include computers with internet access and interactive health portals.

Specialized cancer rehabilitation requires a fully-equipped inpatient short-stay rehabilitation unit (either on- or off-site), along with additional space and equipment to support outpatient rehabilitation programs and clinics. Offices and workspaces are required for staff, as well as meeting space to conduct interprofessional/ multidisciplinary assessments of patients and develop patient care plans.

Considerations for patients that travel long distances for appointments or need to stay close by the cancer centre for a number of days should also be made. One solution is a short-term stay lodge that patients and their family members can use, if required. This can lessen the stress and financial burden of travel for patients and their families.

8. HUMAN RESOURCES

Many individuals with a wide range of education and backgrounds provide supportive care services. All staff of the cancer centre who care for or encounter patients should be educated about supportive care needs and aware of the range of supportive care resources and referral options available. Typically, specialized professionals with advanced education deliver tertiary-level supportive care services, whereas professionals and service providers with less advanced training deliver primary and secondary supportive care. The following human resources are usually part of a cancer centre's supportive care department or program. Supportive care providers work as a team. The types and numbers of providers in a supportive care service will depend on the number of patients served, their supportive care needs, and decisions about which providers to use when a similar service can be provided by more than one group.

Dietitians/nutritionists provide information and practical support related to optimal food selection, nutrition, and menu planning and preparation for patients. Dietitians also provide health promotion and disease prevention advice related to nutrition. Although educational requirements for licensed dietitians vary by jurisdiction, the International Standard for Dietetics Education – developed by the International Confederation of Dietetic Associations (ICDA) in 2004 – identified a bachelor's degree plus at least 500 hours of supervised professional practice as the minimum requirement for dietitian training.²² This standard is aspirational and is used to assess membership applications to the ICDA. In the cancer centre, senior dietitians may have postgraduate degrees in nutrition.

Psychosocial, emotional and mental health practitioners include a number of supportive care professionals:

- **Psychiatrists** have a medical degree, with additional specialty training in psychiatry (i.e., mental, emotional and behavioural disorders). Cancer centre psychiatrists have subspecialty training in psychosocial oncology and provide highly-specialized, intensive and complex supportive care.
- **Psychologists** working in a cancer centre typically have a master's or doctoral degree in psychology. Those with doctoral degrees have additional training (i.e., internship or supervised practice), are licensed, and have subspecialty expertise in areas such as psychosocial oncology or rehabilitation psychology. Typically, psychologists cannot prescribe medications. Doctoral-prepared psychologists provide highly-specialized, intensive and complex supportive care, whereas those who are master's-prepared provide less complex supportive care.
- **Social workers** provide psychosocial and emotional support and information to patients and families, usually from a systemic perspective. In cancer centres, social workers are typically master's-prepared, with additional training in psychosocial oncology. Senior social workers may have a doctoral degree. In addition to helping patients deal with emotional, mental and social issues, social workers may also provide or refer patients to support services, provide financial and job-related advice and assistance, address caregiver needs and counsel on changing roles within social networks.
- **Counsellors and therapists** provide psychosocial and emotional support and information. In cancer centres, these individuals are typically master's-prepared with additional training in specialty areas, such as marriage and family counselling.

Nurses provide a broad range of supportive care, including psychosocial, emotional and physical support, and information. Nurses providing primary and secondary levels of supportive care in a cancer centre typically have, at a minimum, a bachelor's degree in nursing, with additional training in psychosocial oncology. More advanced training is required to provide more specialized supportive care. For example, advanced practice nurses (APNs) and nurse practitioners (NPs) with master's or doctoral degrees in nursing and additional training can provide the following support:

- Nurses with training in mental health can provide mental health support.
- Nurses who are trained in rehabilitation can assist patients with cancer-related disabilities to become more independent, adjust to their environment and have fewer treatment-related complications.
- Nurses with ostomy training can help individuals with ostomies (i.e., tracheostomies, ileostomies, colostomies) by providing pre-operative counselling, post-operative care and education, and follow-up assessment and counselling.

Cancer centres may use nurses with advanced training as cancer nurse co-ordinators or clinical cancer nurses to help the patient navigate the healthcare system, understand their cancer and its treatment, monitor symptoms and anxiety, and address supportive care needs.

Physician assistants (PAs) work with and under the supervision of a Physician. PAs may provide supportive care services, depending on their scope of practice and their level of education and expertise. Historically, PAs were developed and used in the military and are increasingly being used in civilian healthcare. Some jurisdictions in which PAs practice include the United States, some European countries (e.g., United Kingdom, Germany, the Netherlands), some Canadian and Australian provinces and India. PAs may also be known as physician associates, physician extenders, clinical assistants and medical care practitioners.

Prerequisites to becoming a PA, and the necessary education and certification requirements, vary by jurisdiction. The PA scope of practice also varies depending on the jurisdiction, the supervising Physician and the organization. Depending on the jurisdiction, PAs may have bachelor's, master's or doctoral degree, along with a specialization in oncology.²³ Depending on the jurisdiction, PAs with an advanced degree may perform duties similar to APNs.

Expanding the role of advanced practitioners – including nurses and physician assistants – can help optimize care in survivorship programs, especially where there is a shortage of oncologists.²⁴

Recreation therapists provide psychosocial, emotional and physical functioning support through the creative arts (e.g., crafts, music, dance, theatre), sports and leisure activities. These activities enable non-verbal expression and help with relaxation. Depending on the jurisdiction, recreation therapists may have college diplomas, or bachelor's or master's degrees.^{25,26}

Rehabilitation specialists and practitioners include a number of supportive care professionals:

- **Occupational therapists (OTs)** provide physical rehabilitation support, as well as health promotion and disease prevention advice and information in relation to the activities of daily living. OTs assess a patient's functional abilities, their daily activities and the layout of their home, workplace and/or school. OTs may advise on how to accomplish daily activities effectively and safely, conserve energy and improve fine motor skills. Depending on the jurisdiction, OTs may have a bachelor's, master's or doctoral degree along with a specialization in oncology.²⁷ In cancer centres, OTs should have a master's degree, at a minimum.
- **Physiatrists** have a medical degree, with additional specialty training in physical medicine and rehabilitation. Cancer centre physiatrists may have subspecialty training in cancer rehabilitation, and may provide highly-specialized, intensive and complex rehabilitative care (e.g., for musculoskeletal, neurologic or other severe impairments).
- **Physiotherapists/physical therapists (PTs)** provide physical rehabilitation support, as well as health promotion and disease prevention advice and information in relation to a person's mobility and physical activity. PTs assess a person's functional abilities, address issues such as weakness, pain, balance and fatigue, and advise on the effective use of a prosthesis or other assistive devices. Although education requirements for PTs may vary by jurisdiction, the World Confederation for Physical Therapy has set four years of university or university-level courses as the entry level for PTs.²⁸ In the cancer centre, senior PTs may have master's or doctoral degrees in physical therapy.

- **Speech language pathologists (SLPs)** provide physical rehabilitation support and information related to communication (i.e., speech, language, cognition, swallowing, voice and sensory issues, strength and flexibility in the mouth and facial muscles). Depending on the jurisdiction, SLPs may have a bachelor's, master's or doctoral degree. In cancer centres, SLPs should have a master's degree, at a minimum.
- **Vocational therapists/vocational rehabilitation counsellors** provide support and information in relation to employment (i.e. returning to a current job, finding or starting a new job). Vocational therapists assess the functional, psychological, developmental, cognitive and emotional issues that may present barriers to an individual's successful employment. Depending on the jurisdiction, the education of VTs can vary widely.^{29,30}

Spiritual care/counselling specialists provide psychosocial, emotional and spiritual support and information in relation to faith and belief systems. Although the background and education of these individuals may vary, many jurisdictions have programs that set out educational requirements for the profession. For example, the Canadian Association for Spiritual Care certifies specialists in spiritual and religious care and specialists in pastoral counselling.³⁰ The Spiritual Care Association – based in New York and affiliated with the HealthCare Chaplaincy Network – offers Credentialed Chaplain and Board Certified Chaplain programs.³² Healthcare chaplaincy education and practice requirements vary across Europe.³³ Cancer centres should have certified spiritual care/counselling specialists with additional training in psychosocial oncology.

Volunteers provide a wide range of supportive care services that vary depending on their backgrounds, experiences and volunteer training. For example, volunteers may provide social and emotional support to patients (i.e., especially if they have a similar lived experience), help patients navigate the services of the cancer centre, provide information about practical resources and supports, accompany patients and assist patients in completing screening forms. The cancer centre must provide training to ensure that volunteers can perform their tasks effectively.

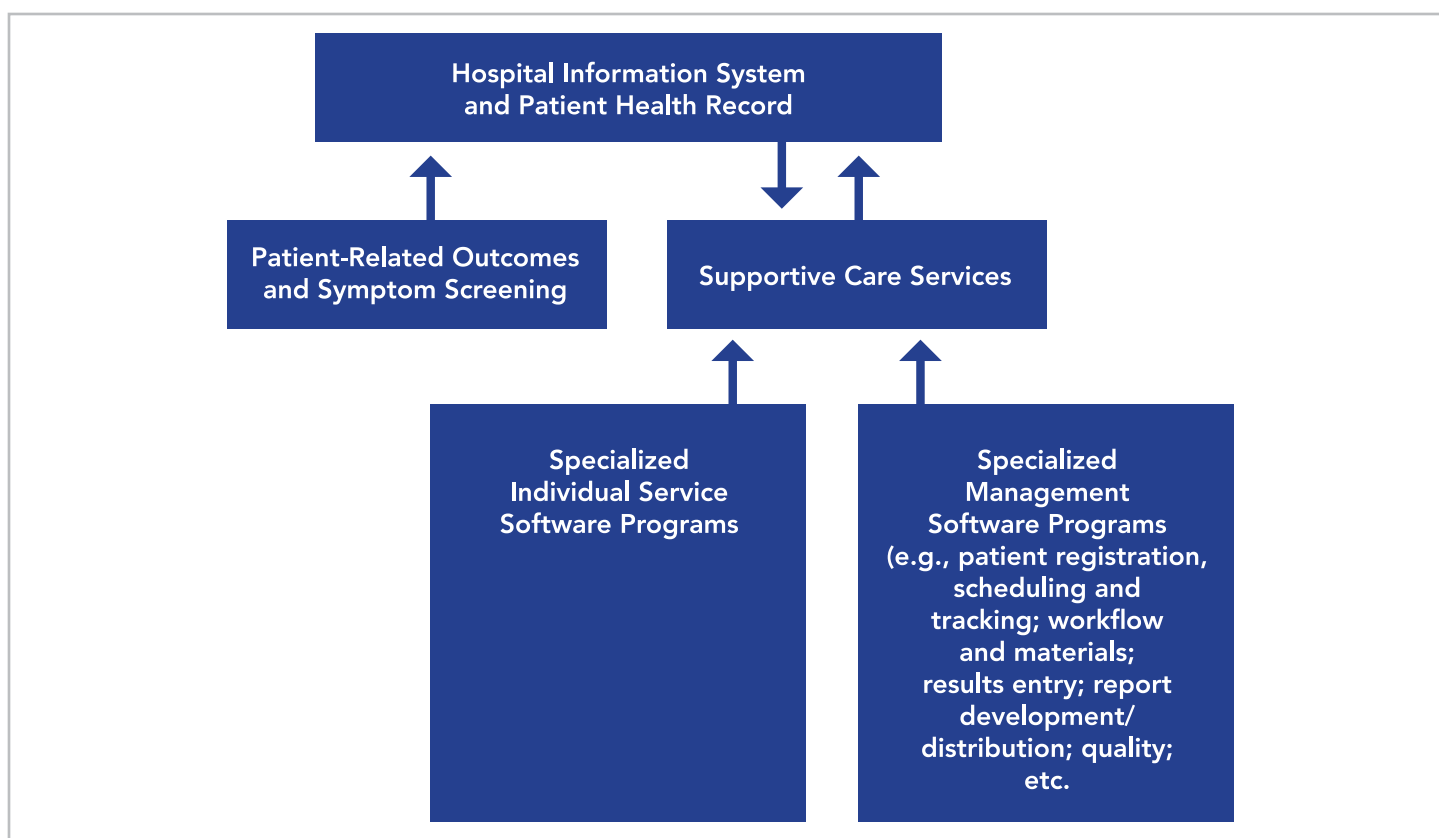
In addition to the human resources providing direct supportive care, the supportive care department or program needs management and administrative staff to support operations. See the *Management* section of this chapter for more information.

9. INFORMATION MANAGEMENT

The cancer centre should have supportive care information systems that capture information relating to symptom assessment and management and a range of supportive care services. The supportive care information systems must connect to the corporate-wide information management (IM) infrastructure, which includes the hospital information system and the patient health record. Ideally, the corporate-wide IM infrastructure and the function-specific supportive care IM infrastructure are electronic and fully integrated. If no electronic system is available, procedures for paper documentation must be developed.

Supportive care uses two main information systems, as illustrated in Figure 4.

Figure 4: Supportive Care IM Infrastructure



Patient-reported outcomes and symptom screening is a computerized system that collects information entered by patients. Patients use a standardized, validated tool to rate the severity of common cancer and treatment symptoms and side-effects (e.g., pain, nausea, anxiety, depression, wellbeing).

Patients complete the screening tool at regular intervals (e.g., before their initial visit, before other clinic visits, if warranted, when their clinical status changes). This information flows into the patient's health record, where it is reviewed by the healthcare team. This process ensures that every member of the healthcare team is aware of, and can track, the symptoms and side-effects experienced by the patient over time. Ideally, the patient health record is electronic and automatically notifies the appropriate team members when symptoms are moderately severe or above, and thus require prompt referral or attention. Automated feedback illustrates the concept of a rapid learning healthcare system, where patients generate the evidence required to receive optimal care.³⁴

There is a two-way link between the **supportive care services** information system and the patient health record. When care needs are identified in the patient health record – either via the patient-reporting outcomes and symptom screening tool or a member of the cancer team – supportive care services are activated. Conversely, when supportive care services are used, they are documented in the patient health record.

Specialized software programs feed into the supportive care services information system, as noted above.

D. MANAGEMENT

10. LEADERSHIP

High-quality supportive care requires the identification of individuals who are accountable for a successful service, as well as committees with key staff who focus on improving the service. The management of the cancer centre's supportive care department or program may be different than the management of a centre's full range of supportive care services.

In terms of managing a **discrete supportive care department or program**, a shared clinical-administrative leadership model should be used. The Clinical Director (or Medical Director or Lead) is accountable for the overall quality and safety of supportive care practices, clinical management and processes, and clinical staff recruitment and performance. The Administrative Director (or Executive Director) is accountable for the effective and efficient management of the service, operational processes, capital issues, financial performance and project management. The clinical-administrative leadership dyad should have a common vision, a unified program and business plan with agreed-upon goals, and a commitment to work together to achieve common objectives in clinical care, education and research. The dyad should also represent the supportive care department or program at the hospital-level and beyond.

Each specific subspecialty area within the supportive care department or program should have an area Clinical Head, with tertiary-level expertise, and an Administrative Director/Manager/Supervisor, working jointly to oversee the operations of their respective area. The Clinical Head should be responsible for the quality and safety of the supportive care practices within the area. The Administrative Director should be responsible for the quality and safety of the area's operational processes.

A Quality Manager/Supervisor should ensure that quality management processes are being implemented and quality issues in supportive care are being addressed.

The membership and size of the core leadership team in the supportive care department or program may increase, depending on the number of specialized areas of service and the role of the cancer centre as a referral centre. For example, if the centre's supportive care service has high internal volumes as well as significant external referrals into the centre, the leadership group may include managers with expertise in areas such as:

- Communications and education, to ensure appropriate linkages with external supportive care providers.
- Finance and business analysis, to enable appropriate overall and case costing.
- Patient flow systems, to support appropriate care pathways for inpatients, outpatients and external referrals.

In terms of managing a **broad range of supportive care services**, a supportive care department or program may request consultations with professionals who are accountable to other departments. This is especially the case if the cancer centre is part of a full-service hospital and its professionals meet the needs of a broad range of hospital patients. Examples include professionals in rehabilitation, psychiatry, nutrition, recreation therapy and spiritual care. Each of these professionals will report to a senior colleague in their respective department.

11. OPERATING STANDARDS, GUIDELINES, POLICIES, PROCEDURES AND PROCESSES

Cancer centres must meet accreditation operating standards and guidelines that have been established by their national accreditation body.³⁵ Many countries have health service accreditation programs, whereas others adopt or adapt the programs of other countries (e.g., Jimenez et al. 2006).³⁶ These accreditation bodies set out operational standards and guidelines to support a safe and effective hospital and may also include explicit requirements for the inclusion of supportive care services, such as rehabilitation, spiritual care, palliative care and end-of-life care. For example:

- Accreditation Canada is an independent, not-for-profit organization that accredits health organizations across the country and includes standards for rehabilitation and hospice, palliative and end-of-life services.³⁷
- The Commission on Cancer provides multidisciplinary accreditation for cancer programs in the United States.³⁸ Cancer Program Standards address areas such as oncology nursing services, psychosocial support services, rehabilitation services, nutrition services, palliative care services and the continuum of care, which includes psychosocial distress screening and survivorship care planning.

Cancer centres adopt or adapt standards of practice for supportive care, and use them to guide the development of policies, processes and procedures. The Institute of Medicine's recommendations for improving the care of cancer patients who are beyond their acute treatment phase and living with cancer have been influential in advancing standards for supportive care.⁶ These standards include, but are not limited to:

- Establishing cancer survivorship as a distinct phase of cancer care
- Delivering appropriate survivorship care
- Giving a patient who has finished their primary cancer treatment a comprehensive care summary and follow-up plan
- Developing evidence-based clinical practice guidelines, assessment tools and screening instruments to manage the late effects of cancer and cancer treatment
- Using quality of survivorship care measures and quality assurance programs to monitor and improve care

For examples of national standards of practice for supportive care services see: Canadian Association of Psychosocial Oncology (2010); Howell et al. (2011); Israel Psycho-Oncology Society (2003); National Comprehensive Cancer Network (2014); National Institute for Clinical Excellence (2004).^{5,8,39-41}

12. DATA-INFORMED MANAGEMENT DECISIONS

Cancer centres need to collect and analyze standard supportive care information to ensure that appropriate supportive care services are available to respond to patient and family needs in a timely manner, and that services are used effectively and efficiently and reflect quality care.

Given that the amount of data collected can be overwhelming, management should develop a minimum data set of clearly defined key indicators to monitor activities and processes. Indicators should be analyzed and management should implement tactics to mitigate risks and make improvements. Improvements can be assessed in various ways. For example, a centre can focus on internal performance improvements, compare performance in relation to external standards or compare performance in relation to external peer group benchmarks.

Table 1 presents a suite of supportive care management indicators that might be considered for a cancer centre's minimum data set, as well as potential management analyses targeted at improving performance. Additional indicators may depend on local circumstances.

Table 1: Examples of Supportive Care Indicators and Management Analysis

Area	Indicators	Management Analysis
Screening of Symptoms and Distress	<ul style="list-style-type: none"> Number of patients screened at the initial visit Number of patients screened at appropriate intervals, consistent with protocols Number of screenings completed successfully 	<ul style="list-style-type: none"> Review screening volumes over time (initial, subsequent, completed), analyze reasons for incomplete screenings and identify improvement tactics
Response to Screening	<ul style="list-style-type: none"> Number of discussions completed in response to screening results Number of screenings indicating increased severity of symptoms/distress consistent with protocols (red flags), and the response or planned follow-up 	<ul style="list-style-type: none"> Monitor and address disparities between number of screenings and follow-up discussions Analyze increase in severity by type of issue and response/service required
Services	<ul style="list-style-type: none"> Number of referrals to supportive care services by type of service Number of patients obtaining a service by type 	<ul style="list-style-type: none"> Track volumes, resource utilization and costs (e.g., financial, human, capital, operating) to identify resource gaps and opportunities for improved effectiveness and efficiency, without compromising access to quality services
Service Flow	<ul style="list-style-type: none"> Times along the service flow (e.g., when screening indicates increased severity to when the issue is discussed with the patient, to when the issue is resolved and/or when a service referral is made to when the service is obtained). 	<ul style="list-style-type: none"> Analysis of delays and blockages in service flow, and improvement tactics Analysis of wait times against wait time targets, and improvement tactics
Supportive Care Quality Practices	<ul style="list-style-type: none"> Compliance with quality standards, policies and procedures 	<ul style="list-style-type: none"> Rate of compliance with quality standards, policies and procedures

E. QUALITY

Quality performance in supportive care is critical given that all individuals who are at risk for cancer, living with cancer, living beyond active treatment and receiving palliative and end-of-life care will require some type of supportive care.⁵ The increased use of standards of practice for supportive care has and will continue to improve quality performance.

13. STANDARDS, GUIDELINES AND BEST PRACTICES

Generally, quality standards, guidelines and best practices are broadly applicable to all of the work provided by supportive care services in a full-service hospital, and are not specific to cancer services. Quality standards, guidelines and best practices used by a cancer centre may originate from different sources, such as international, national and subnational organizations and bodies. Although cancer centres may develop local best practices, these practices should align with the national and subnational standards and guidelines of the jurisdiction in which the cancer centre is located.

Clinical and Practice Guidelines

Standards and guidelines for supportive care are based on evidence or expert consensus. They may be developed by supportive care-specific organizations or by larger health bodies. A number of organizations make available a wide range of cancer-related standards and guidelines, including those for supportive care. See the *Cancerpedia: Clinical Management* chapter for more information.

Professional Human Resources

A quality supportive care service must meet human resource requirements and ensure that all staff meet ongoing quality standards. Healthcare professional groups develop professional care standards and recommended practices for their members, including ongoing competency and continuing education requirements. All supportive care providers must meet their profession-specific standards as set out in legislation, by their regulatory licensing bodies and by the cancer centres in which they work. Professional bodies and associations that develop human resource standards, practices and education for supportive care providers include the following.

Dietitians/nutritionists

- The International Confederation of Dietetic Associations' list of more than 40 national dietetic associations⁴²

Psychosocial, emotional and mental health practitioners

Psychiatrists

- The World Psychiatric Association's list of member societies⁴³ and affiliated associations⁴⁴

Psychologists

- The International Association of Applied Psychology's list of networked international associations and societies of psychology⁴⁵

Social workers

- The International Federation of Social Workers' list of member organizations⁴⁶

Counsellors and therapists

- The Canadian Counselling and Psychotherapy Association's list of provincial, national and international associations⁴⁷

Nurses

- The International Council of Nurses' members list⁴⁸

Physician assistants

- International Academy of Physician Associate Educators' list of international programs⁴⁹

Recreation therapists

- Alberta Therapeutic Recreation Association's list of therapeutic recreation sites of interest⁵⁰

Rehabilitation specialists and practitionersOccupational therapists

- The World Federation of Occupational Therapists' country and organization profiles⁵¹

Physiatrists

- The International Society of Physical Medicine and Rehabilitation's list of national societies⁵²

Physiotherapists/physical therapists

- The World Confederation for Physical Therapy's list of members⁵³

Speech language pathologists

- The American Speech-Language-Hearing Association's list of audiology and speech-language pathology associations outside of the United States⁵⁴

Vocational therapists/vocational rehabilitation counsellors

- Vocational Rehabilitation Association (United Kingdom)²⁹
- Vocational Rehabilitation Association of Canada³⁰

Spiritual care/counselling specialists

- International Council on Pastoral Care and Counselling⁵⁵

Work Practices

To provide an exemplary supportive care service, all cancer centres must follow a number of key quality work practices.

Symptom Assessment and Management

It is widely recognized that all cancer patients must be assessed routinely for symptoms, issues and concerns related to their cancer diagnosis and treatment, including late effects.^{2,6,8,56,57} Consistent with the broad definition of supportive care, a patient's needs may be psychological, emotional, social, economic, physical, practical, spiritual, behavioural or informational. Healthcare providers tend to under-detect the onset of symptoms, as well as their severity and frequency.⁵⁸ As well, side-effects are often de-emphasized in cancer diagnosis and treatment, and clinicians tend to systematically report fewer symptoms of lower severity compared with patient reports.⁵⁹ As a result, the patient (and family, if necessary) should be given the opportunity to self-report their supportive care needs.

Symptom assessment has many benefits. It may be therapeutic and act to validate a patient's concerns. Early detection of symptoms and other issues enables early intervention through patient and family referral to appropriate supportive care services. Screening can help guide care by providing clinicians with patient-reported evidence about the impact and outcomes of care. From a resource perspective, screening can also inform the need for supportive care services and emphasize their value to patients.

Both patients and clinicians find symptom assessment helpful. In one study, 92 per cent of patients found it helpful to use a summary of their self-reported symptoms and functional status to discuss health issues with their clinicians; 87 per cent of patients and 92 per cent of clinicians said they would recommend symptom assessment to other patients.⁵⁸

Assessment tools for distress related to cancer diagnosis and care are quite well developed. This is in response to the fact that the reported incidence of significant distress at all phases of the cancer journey ranges from 35 per cent to 45 per cent in North America.⁵⁶ In addition, emotional distress has been characterized as the sixth vital sign in cancer care (with the other five being temperature, pulse, blood pressure, respiratory rate and pain).⁶⁰

Although symptom assessment tools can focus on one particular area of concern, others include a suite of items to address a range of concerns. Examples of symptom assessment tools are:

- The National Comprehensive Cancer Network's Distress Thermometer and Problem List for Patients, which measures level of distress and includes a checklist of practical, family, emotional, spiritual/religious and physical problems and concerns.⁶¹
- The Edmonton Symptom Assessment System-Revised tool, which measures nine common symptoms experienced by cancer patients (i.e., pain, tiredness, drowsiness, nausea, appetite, shortness of breath, depression, anxiety and well-being).⁶²

Symptom assessment provides valuable information, but requires timely and effective follow-up to be of value to the patient. This follow-up includes a focused assessment and interventions based on evidence-based practice guidelines.⁸ The five components of assessment for distress provide a valuable model for cancer centres:⁵⁶

- Complete a standardized assessment tool
- Open a dialogue and initiate a therapeutic relationship
- Assess risk factors and intensively assess concerns
- Ascertain patient perceptions and negotiate a plan of care
- Provide interventions either directly or by referral, when required

The plan of care and interventions will vary depending on the issues identified, the needs to be met and the model of supportive care within the cancer centre.

All supportive care services within the cancer centre should use the same assessment tools and evidence-based practice guidelines to ensure a consistent approach to care, and for quality auditing. In addition, the cancer centre should incorporate screening and follow-up processes into its patient health records system.

Individualized Supportive Care Plans

Patients with cancer need a supportive care plan as part of their overall cancer treatment plan. There is no agreement on the contents, format or delivery of a supportive care plan, or even what it should be called.⁶²

To illustrate, the Institute of Medicine recommends that a Survivorship Care Plan (SCP) should be developed for each patient who has completed primary cancer treatment.⁶ The SCP should include a comprehensive care summary and follow-up plan for the patient, summarizing critical information needed for the survivor's long-term care, and should be written by the principal healthcare providers who co-ordinated the patient's oncology treatment. Suggested contents of the SCP include:

- Cancer type, treatments received and their potential consequences
- Specific information regarding the timing and content of recommended follow-up
- Recommendations for preventive practices and how to maintain well-being
- Information on legal protections regarding employment and access to health insurance
- The availability of psychosocial services in the community

The Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology adapted the Institute of Medicine recommendation to reflect an SCP that is developed by a designated member of the core team. This SCP should include a standard set of core multi-dimensional elements tailored to the individual's cancer and treatment experience.⁸ The recommended core elements include:

- Cancer type, treatment received and potential adverse late and long-term effects of cancer treatment that must be routinely screened for, monitored and managed on an ongoing basis
- Goal, frequency and timing of follow-up visits, as well as a designating co-ordinator/provider for follow-up care tests and procedures
- Specific procedures or tests for the ongoing surveillance and detection of recurrence, tailored to cancer type and treatment modalities
- The need to report new, persistent symptoms promptly, without waiting for the next scheduled appointment, and the specific provider to notify
- Psychosocial, rehabilitative, supportive care and other healthcare services that are available on-site, in the local community and online
- Education on selecting peer support programs and resources that meet standards for best practice
- Guidance on strategies to reduce the risk of recurrence and maximize well-being (e.g., lifestyle changes related to nutrition, physical activity, smoking cessation)
- Information about employment, financial and legal issues, and counselling services available in the local community

Cancer centres should identify the required elements of the care plan based on the advice of their national and subnational standard-setting bodies, and their local circumstances.

SCPs are widely endorsed and well received.⁶³ For example, a pilot test of an SCP for breast cancer found that 75 per cent of participants who remembered receiving an SCP said it gave them peace of mind and 91 per cent found it useful. Regardless, Salz et al. (2012) found that SCPs do not appear to be widely used. The study showed that only 43 per cent of National Cancer Institute-designated cancer centres provided SCPs to their breast or colorectal cancer survivors, and no centres provided plans that included all components recommended by the Institute of Medicine. SCPs require funding, time and commitment from the cancer centre.⁶³

Seamless Flow of Quality Services

Cancer centres need to enable a seamless flow of supportive care services for patients both within the centre and in the local community. However, this co-ordination is often difficult, given that one patient may have multiple care providers at the cancer centre, receive both inpatient and outpatient care at different locations, and be cared for in the community by their Primary Care Provider.

To ensure a seamless flow of quality services, the cancer centre should make one or more designated healthcare providers responsible for providing the broad range of supportive care follow-up services, working with primary care providers to monitor late and long-term treatment effects, co-ordinating access to interdisciplinary specialists as required, and actively engaging and empowering survivors.⁸

14. PERFORMANCE MONITORING, REPORTING AND QUALITY IMPROVEMENT

International, national and subnational organizations that develop quality standards and requirements for supportive care should inform the cancer centre's overall supportive care quality performance efforts. These organizations should also directly influence quality activities within the supportive care service.

The supportive care service must establish a system for quality and performance management and continuous quality improvement. Quality improvement includes the following.

Establishing a quality framework to guide performance improvement efforts. The framework should include broad domains for performance improvement, such as accessibility, appropriateness, effectiveness, efficiency, patient-centredness, safety, and staff work-life.⁶³ These broad domains should align with the cancer centre's priorities and reflect the particular priorities of the supportive care service. The selection of broad domains may also be influenced by international, national and subnational standard-setting bodies, as well as national or subnational health ministries or organizations that focus on quality in cancer care.

Selecting quality performance indicators within each broad domain. As with the selection of domains, the selection of indicators should align with the cancer centre's objectives, reflect the priorities of the supportive care service and may be influenced by the priorities of external bodies. Clinical and other staff should have confidence in the process used to select indicators, and in the indicators themselves. A wide range of supportive care staff should participate in the selection of the indicators, which need to be clearly defined, measurable and reliable. Indicators should incorporate the use of evidence or benchmarks, and be used to manage and improve the quality of the supportive care service.

Indicator definitions may be adopted or adapted from other reliable sources. Table 2 presents examples of quality performance indicators for supportive care.

Table 2: Examples of Quality Performance Indicators for Supportive Care

Domains	Examples of Quality Performance Indicators
Accessible	<ul style="list-style-type: none"> • Wait times for supportive care services (e.g., from time screening indicates increased severity to when the issue is discussed with the patient to when the issue is resolved and/or when a service referral is made to when the service is obtained) • Equitable and timely access to supportive care expertise (internal and external referrals) • Availability of supportive care services to the population
Appropriate	<ul style="list-style-type: none"> • Use of priority rating scale or red flags referring to urgent need for service • Appropriate number and mix of staff to meet supportive care demands
Effective	<ul style="list-style-type: none"> • Use of evidence-based supportive care services • High-level team performance • Achieve requirements of accreditation bodies
Efficient	<ul style="list-style-type: none"> • Wait times along the flow for service • Time between scheduled appointment and start of service • Total number of patients screened • Efficient use of supportive care resources (actual vs. budget) • Average cost per supportive care unit hour
Patient-Centred	<ul style="list-style-type: none"> • Patient satisfaction levels • Patient education and information
Safety	<ul style="list-style-type: none"> • Staff injuries due to safety breaches • Patient harm due to safety breaches • Percentage of staff meeting continuing education and competency requirements
Staff Work Life	<ul style="list-style-type: none"> • Staff satisfaction • Staff absenteeism • Staff efficiency • Staff turnover • Overtime hours

Establishing an infrastructure to collect data, monitor and report on performance, and target areas for improvement. This infrastructure should include:

- Information management support to collect, analyze and report on indicators. The timing of indicator collection may vary from just-in-time to weekly, monthly, quarterly, semi-annually or annually. Regular access to supportive care data and the ability to develop customized reports are critical to driving improvements. Customized performance reports may focus on certain supportive care services, groups of clinical and other staff, or individual staff.
- A supportive care service quality team – composed of administrative leaders, clinical leaders, managers, quality experts and representatives of partner facilities, as appropriate – with overall accountability for quality and performance improvement. The team should identify indicators and targets in relation to evidence- and consensus-based benchmarks and best practice standards and guidelines, as set by international, national and subnational bodies. The team should also develop action plans that include improvement targets with associated timelines, track improvements, address performance issues and engage other staff in ongoing quality improvement.
- Ongoing training for supportive care staff in quality improvement and patient safety, including best practices, adverse events (i.e. recognize, respond, report, disclose) and human factors. The latter includes factors that can influence people and their behaviour. In the cancer centre, these factors may be environmental, organizational or job factors, or individual characteristics that influence behaviour at work.⁶⁵
- Communication of performance information to promote transparency and drive continuous quality improvement for those working in the supportive care service and – more broadly – everyone in the cancer centre, including commentary on the data, expected plans of action and successes in improving performance.

F. THE FUTURE

The field of supportive care is facing significant increases in demand due to the sheer growth in the incidence and prevalence of cancer. Not only is the number of patients growing, patients now expect to be more actively involved in their care, and have timely access to information and supportive care services. These conditions are shaping the future of supportive care. This section discusses major innovative trends that are transforming supportive care and the impact of these trends on supportive care services.

Advancements in e-Communication Technologies

The ability of patients to access supportive care information online is now commonplace in many jurisdictions. Internet use among cancer patients has increased over the past decade.⁴³ Numerous websites provide access to comprehensive information and tools related to supportive care, including educational material, apps for downloading, blogs and links to support groups. Examples include Cancernet-UK and OncoLink.^{66,67} Cancer centres also usually provide supportive care information on their websites. See the *Cancerpedia: Education* and *Cancerpedia: Communication* chapters for more information. This practice is very beneficial and will continue to grow.

Patients are increasingly using web-based tools and handheld devices to report their symptoms and receive advice. Results from computerized symptom management systems are integrated into in-person visits with clinicians. As well, online platforms for patient-reported outcomes related to chemotherapy based on standard criteria for toxicity monitoring are being utilized.⁵⁹ The increased use of these applications for supportive care will continue to grow over time. The challenge is to determine how these emerging technologies can combine efficiency with patient satisfaction, while remaining economically feasible.²⁴

Although advancement in e-communication technologies are beneficial, it is important to consider that not everyone is able or willing to access information online. For example, some patients may have a low level of familiarity or comfort with technology, or income or language issues may prevent some patients from using technology.

Evolving Human Resource Roles

The patient demand for supportive care providers has human resource implications. It is challenging for cancer centres to employ enough trained supportive care providers to see every patient. Cancer centres should consider various options for bridging this gap. For example, cancer centres may provide basic supportive care training to all staff who interact with patients. This training may include how to recognize signs of distress, when and how to alert the appropriate staff, and the development of compassionate communication skills. Cancer centres can also ensure that supportive care professionals are able to provide care at the highest scope of their practice. This may include allowing more highly-trained professionals to focus on patients who are in crisis or need complex interventions, as well as working with the interprofessional/multidisciplinary team to ensure patients receive the appropriate level of supportive care. Finally, cancer centres can explore new and innovative roles for volunteers.

Evolving Supportive Care Models

Highly-skilled supportive care professionals will increasingly play an active role across the full continuum of cancer care. Supportive care assessments and follow-up will become standard practice from the beginning of the patient's experience with cancer (i.e., prevention, screening, diagnosis) through to treatment, survivorship and end-of-life. Supportive care will also take a more active role as the patient transitions through various stages of their cancer experience.

A related trend is the biopsychosocial model of cancer care, which recognizes the interconnections and interactions between behaviours, cognition, emotions, social factors, beliefs and both physical health and disease. Although the model was first developed more than 40 years ago, its adoption is varied along the cancer care continuum.⁶⁸ Psychological and social factors can influence health and illness, treatment compliance, responses to treatment and pain. For example, depression, anxiety and distress, and lower quality of life are associated with greater pain intensity in cancer patients.⁶⁹ Adherence to long-term therapies are also influenced by many social, economic and personal factors, including patient education and understanding, level of readiness to follow recommendations, anxiety and fear of medication dependence, and psychological stress.¹⁹ Supportive care plays an important role in improving adherence by addressing these issues.

The Impact of Trends

Future trends impact the design, planning and development of supportive care services.

From a physical facilities perspective, additional space may not be required for supportive care if the cancer centre invests significantly in e-communication technologies. Patients may need to be on-site less frequently if they can access supportive care information and report symptoms remotely. Developing these systems and tools, as well as educating patients and staff on their use, will require financial investment.

The evolution of human resource roles must be supported by new training programs. If all staff who interact with cancer patients are to receive basic supportive care skills training, these programs will need to be developed with sufficient time for training provided.

Evolving supportive care models may have staffing implications. If the cancer centre expects their supportive care staff to play a more active role across the full continuum of care and work more closely with their biomedical colleagues, more supportive care staff may be required.

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