



Canadian Association of Psychosocial Oncology
Association Canadienne d'Oncologie Psychosociale

Standards of Psychosocial Health Services for Persons with Cancer and their Families

Approved May 28, 2010

© 2010 Canadian Association of Psychosocial Oncology
www.capo.ca



Canadian Association of Psychosocial Oncology Association Canadienne d'Oncologie Psychosociale

PREAMBLE

The Canadian Association of Psychosocial Oncology (CAPO) published “National Standards for Psychosocial Oncology” in 1999, the first document of its kind worldwide. As with any standards document, and recognizing that practice and priorities in cancer care had evolved significantly over the preceding decade, the CAPO Board of Directors appointed a working group in 2006 to initiate the National Standards revision process to reflect these changes. The Board of Directors determined that the revised Standards should include:

- Standards of care – stated in terms of what people diagnosed with cancer and their family members might expect to receive in relation to their psychosocial health care needs including assessment, evidence based intervention, and access to psychosocial oncology and supportive care services.
- Organizational standards
- Educational standards in the form of competency statements for psychosocial oncology providers.
- Integration of all phases of the cancer control trajectory, including prevention and survivorship

DEFINITIONAL CHALLENGES

The directives of the CAPO Board of Directors suggested a shift in focus from the 1999 National Standards for Psychosocial Oncology, which focused on structure of programs, professional issues, patient and family service, research and program evaluation and professional development, to Standards of Care, which address a person/family centred perspective of care delivery and incorporating organizational and education standards. This shift is consistent with other documents published around the world in the past decade (Adler & Page, 2008; National Breast Cancer Centre and National Cancer Control Initiative, 2003).

Part of the challenge that the committee dealt with was the great variability in the definitions and labels associated with psychosocial oncology and supportive care. These definitional controversies have not been adequately resolved and while we agree with others (Adler & Page, 2008) that the term ‘psychosocial health services’ may best describe the range and variety of both “mental health” sub-specialty and supportive care services, here we attempt to add to the ongoing discussion by offering a slightly different conceptualization that draws on the definitional elements of the 1999 CAPO Standards. The intent is to add clarity to this complex issue with the hope that persons affected by cancer, as well as providers will understand and differentiate the specific roles carried out by professionals and non-professionals. Our intent is to conserve the conceptual framework of ‘psychosocial oncology’ as espoused by the original Standards, while integrating current concepts of multi- and interprofessional models of care delivery, as delineated in the IOM Report “Cancer Care for the Whole Patient” (Adler & Page, 2008).

Several national initiatives that occurred simultaneously with the CAPO standards revision project were influential in informing the present document. These included the development of “A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient” (Howell et al., 2009) and the “National Psychosocial Oncology Education Framework” (Canadian Strategy for Cancer

Control, 2007). The Institute of Medicine (IOM) report “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” (Adler & Page, 2008) outlined that there were a number of psychosocial health care needs that were not being met and highlighted gaps in care delivery to persons affected by cancer. This international resource provided viewpoints that the committee considered in the standards revisions work.

Definitions

We have adopted the following definition of **psychosocial health services**:

Psychosocial health services are psychological, social and spiritual care services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioural, social and spiritual aspects of illness and its consequences so as to promote better health. (Adapted from Adler & Page, 2008, pgs 359-360)¹

Under this umbrella definition of service delivery, we define two distinct areas of psychosocial health services: Psychosocial Oncology and Supportive Care (see Figure 1).

Psychosocial oncology (PSO) is a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional [practical] aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs. Psychosocial Oncology focuses on the emotional distress aspects of cancer care and is particularly concerned with the assessment and treatment of distress (as supported by its identification internationally as the 6th Vital Sign of cancer care) and the management of complex issues. Psychosocial Oncology offers care to persons with cancer who have specific unmet needs related to coping with their illness, emotional distress, changes in relationships and planning for the next phase of their lives (see Figure 2) and is addressed by professionals trained in this sub-specialty (e.g., psychologists, social workers, spiritual care specialists, psychiatrists and psychiatric/mental health advanced practice nurses [APNs]). Psychosocial oncology professionals offer assessment, treatment and follow up that is consistent with Clinical Practice Guidelines published by CAPO.

Supportive Care services address a range of needs, including informational and counselling needs related to the management of symptoms and specific practical or functional issues. A variety of disciplines may be involved in provision of supportive care, such as nursing, medicine, nutrition and rehabilitation services. Supportive Care services address unmet needs of persons with cancer who require information, education, support, financial advice, or other practical advice as described in Figure 2. The third area of the Figure 2 triangle represents an area of overlap between supportive care and psychosocial oncology. All professionals whether generalists or specialists are dedicated to providing whole person cancer care.

¹ The original definition excluded spiritual care as part of the description of psychosocial health services. In Canada, spiritual care is generally included in definitions of psychosocial oncology.

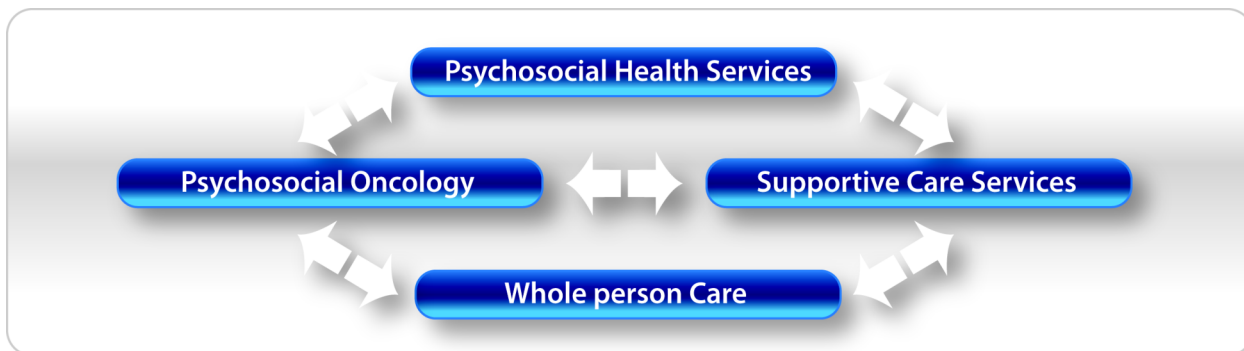


Figure 1 Psychosocial Health Services: Contributions to Whole Person Care

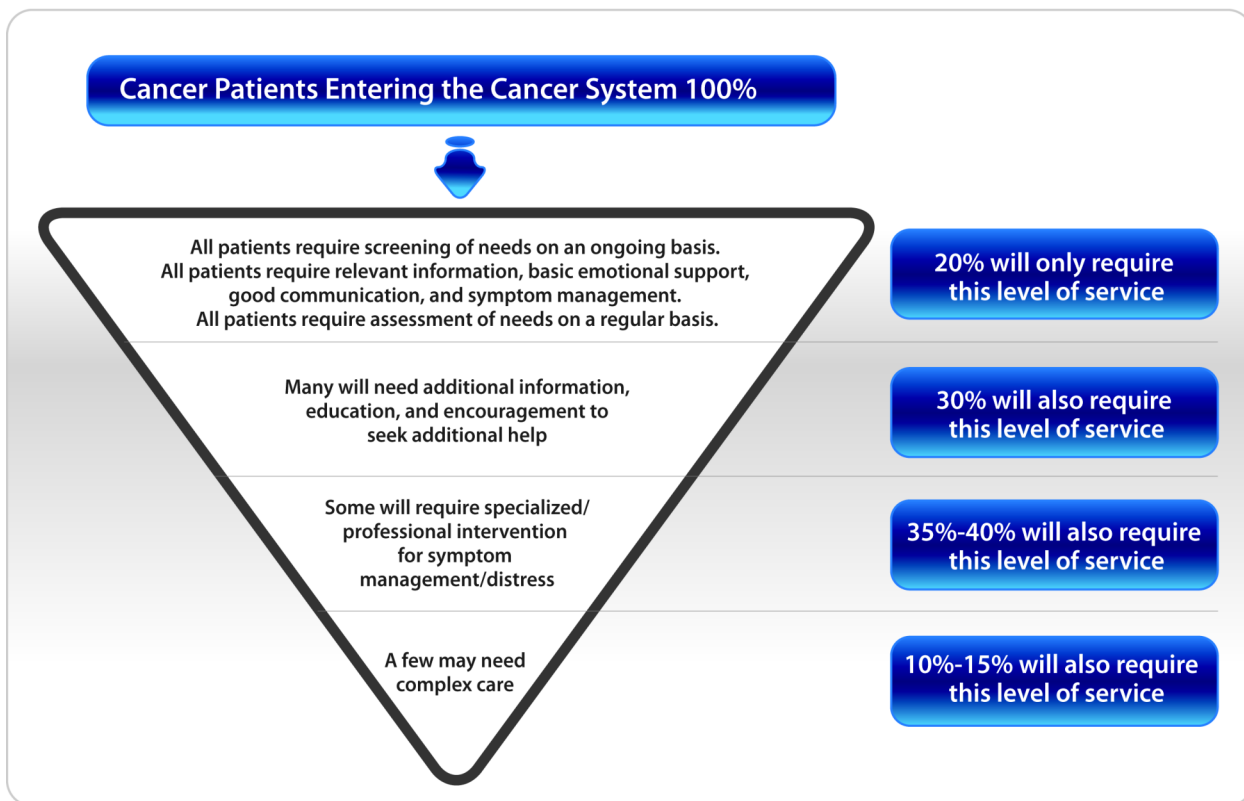


Figure 2 Fitch, Porter & Page, 2008 (adapted with permission)

Figure 2 provides an overview of the psychosocial health service needs of persons affected by cancer. This diagram suggests that between 15-55% of patients may require specialized psychosocial oncology assessment and intervention, while an overlapping 50-75% will require some level of supportive care. This principle applies across the cancer patient trajectory.

Process for Standards Revision

This Standards revision project was initiated in the spring of 2006 with 6 professionals from across Canada representing the major disciplines offering psychosocial care. The CAPO Board of Directors approved a project plan identifying the priorities for updating the document at their November 2006 meeting and the committee commissioned a literature review. That review was completed in February 2007 and the work began in earnest in the spring of 2007. The committee met 9 times between the fall of 2006 and throughout 2007 (see Appendix A for committee membership).

Toward the end of 2007 the committee determined that focused in person meetings were needed to complete the first draft. With the approval of the Board, in early 2008 the committee chairs lobbied several organizations for financial support to complete the work. Support for an in-person meeting was received from the Cancer Journey Action Group of the Canadian Partnership Against Cancer and the meeting was held in February 2009.

Prior to, during and following the February 2009 meeting, detailed feedback was received from Committee members, both verbally and in writing. The Chairs incorporated this feedback and sent the revised document to the CAPO Board of Directors and the Committee for review in August 2009. The committee met twice in the fall of 2009 to discuss the draft and to develop the process for review by CAPO members, other psychosocial oncology practitioners, researchers, educators, cancer agencies, and others. A survey was sent out in November 2009.

Responses were received from 66 individuals and organizations as well as verbal and email feedback. The committee met 3 times in January and February 2010, including an all day meeting in Toronto with 4 committee members in person and 4 via teleconference (February 6th, 2010) to incorporate this feedback into the third draft of the document. Key opinion leaders both within, and externally to, Canada were invited to comment on the third draft. Final comments were incorporated and the CAPO Board of Directors approved the document in April 2010.

Overview of Sections

These Standards are divided into four sections. Section I provides an introduction and key definitions, while Section II defines the scope of these standards and provides tables that present the standards of care in relation to setting. Section III identifies key principles guiding care the development of these standards (incorporated from the 1999 Standards). Section IV provides specific Standards organized under the following headings: IV-A Organization and Structure, IV-B Education Standards, and IV-C Standards of Care. Section IV includes tables that interpret the standards for different levels of care.

SECTION I - INTRODUCTION

The Canadian Association of Psychosocial Oncology (CAPO) is a professional organization and registered charity, established in 1987, to bring together the disciplines that play a major role in the delivery of psychosocial oncology services, research, and education in oncology. The purpose of CAPO is to foster and encourage interprofessional excellence in psychosocial research, education and clinical practice in oncology. The objectives of the association are to educate and disseminate information on all aspects of psychosocial oncology by:

- a) Conducting conferences and workshops educating professionals, health personnel and the public in clinical skills and theoretical concepts in psychosocial oncology;

- b) Preparing and disseminating educational material to the public and health care professionals across Canada on all aspects of psychosocial oncology;
- c) Providing a national network for the exchange of ideas; and
- d) Establishing a library of educational materials concerning all aspects of psychosocial oncology.

The “Standards of Psychosocial Health Services” were developed to assist cancer facilities, administrators, program leaders and professionals in the delivery of psychosocial health services in Canada by providing a basic framework for these services. This initiative came about from the recognition that standards are required to ensure that basic principles are met and quality of care in the domain of psychosocial health services is available to every person affected by cancer across Canada. The standards identify the *minimum* level of care that persons affected by cancer can expect to receive from health professionals.

Psychosocial Health Services include multidisciplinary areas of expertise, including specialists (mental health professionals with a specialty in oncology), and supportive care professionals, described above. Psychosocial oncology specialists are licensed/registered, graduate level professionals who have taken additional training in the field of psychosocial oncology. Psychosocial oncology specialists may include professionals from: medicine, nursing, psychology, social work & spiritual care. Professionals providing supportive care include, for example: nurses, physicians, rehabilitation specialists and registered dietitians.

Psychosocial oncology and supportive care professionals providing psychosocial health services in Canada are guided by discipline specific standards through provincial legislation, regulatory bodies, the accreditation process, or individual facility policies. The CAPO Standards of Psychosocial Health Services have been developed to complement, rather than replace, existing professional standards and guidelines.

People affected by cancer often want to talk with someone else who has lived the cancer experience. Peer support volunteers are non-professionals who play a unique role in providing this type of support. These volunteers are guided by the policies and guidelines of their agencies.

SECTION II – SCOPE OF STANDARDS

Population Addressed by These Standards

Persons requiring psychosocial health services include individuals at risk for cancer, those living with cancer, those living beyond active treatment (survivors), and those receiving palliative and end of life care, including the bereaved. This includes family members and other caregivers.

Assessment of Psychosocial Health Needs

Assessment of psychosocial health care needs is required at all stages of the cancer journey. From a prevention perspective, this may include genetic testing in the presence of potential hereditary factors being uncovered. During this period, the person may experience distress and anxiety. Similarly, during screening and its associated waiting period, individuals may experience anxiety and worry. Often, the most difficult parts of the journey are those periods of waiting. This might be before a confirmed diagnosis of cancer, or, if confirmed, when undergoing tests for staging, waiting for results and/or to see an oncologist.

The literature indicates that the psychosocial distress that the person diagnosed with cancer and his or her family members experience during treatment includes such things as wondering about health outcomes, changes in physical appearance, changes in relationships, financial issues, practical issues, such as workload and roles at home and emotional challenges (Adler & Page, 2008). Equally important are the issues that people face through the transitional periods of palliative care (National Consensus Project for Quality

Palliative Care, 2009) and survivorship (Hewitt, Greenfield, & Stovall, 2005). At each point along the journey, health professionals need to be aware that distress has been identified as the 6th Vital Sign and screening for distress is an essential element of assessing psychosocial health care needs (Bultz & Carlson, 2005, 2006; Howell et al., 2009; Accreditation Canada, 2008; CJAG/CPACC, 2009; Holland & Bultz, 2007). A psychosocial assessment of both the person diagnosed with cancer and their family members is essential in directing individuals to appropriate services and supports (Howell et al., 2009). Where peer support volunteers are involved, they should be trained and supervised in an appropriate fashion.

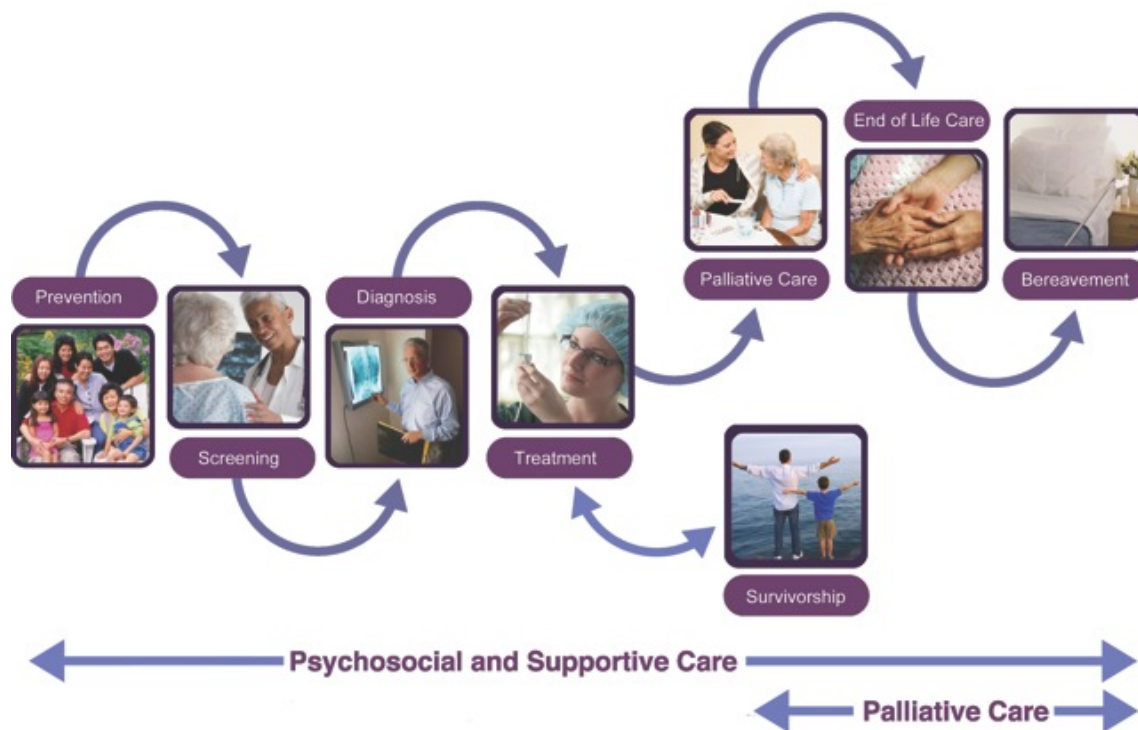


Figure 3

Scope of Service Organizations/Agencies

Psychosocial health services exist in a variety of settings, including hospitals, comprehensive cancer centres, satellite clinics, multipurpose public health clinics, primary care settings and NGO/volunteer agencies in urban and rural communities throughout Canada. These psychosocial oncology standards of care are intended to inform the range of oncology health care settings for persons affected by cancer, including those who are diagnosed with cancer, and their families. They are designed to guide programs, administrators and providers in the development of psychosocial oncology health services.

SECTION III–KEY PRINCIPLES

Principle 1: Person/Family Centred Care

The focus of care in psychosocial oncology/supportive care is the person who is diagnosed with cancer and his or her family, as defined by the person.

Patient-centred care has been defined as an approach that consciously adopts the patient’s perspective about what matters (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). It includes the following elements:

- Respecting the patient’s values, personal dignity, preferences, and needs

- Providing physical comfort and emotional support
- Coordinating and integrating care
- Ensuring information, education, and communication
- Involving family and friends
- Ensuring transition and continuity
- Providing access to care
- Facilitating individuals and families to use their own resources to promote wellbeing.

Similarly, family-centred care ensures the health and well being of the ill person of any age, and their family, by recognizing them as important partners in the assessment, planning, delivery, and evaluation of health care (Adler & Page, 2008; Lewandowski & Tesler, 2003). Therefore, the principles of providing family-centred care include respect for the person and the family, including:

- Culture, values, beliefs, knowledge, perspectives, and choices, and
- Need to participate, collaborate, and communicate in care delivery and decision-making.

Principle 2: Access

Persons affected by cancer are informed of, and have access to, psychosocial oncology and supportive care services as required by the Accreditation Canada standards (www.accreditation-canada.ca).

Patient satisfaction surveys (see e.g. Sadoval, Brown, Sullivan & Green, 2006) have consistently identified that persons affected by cancer are uninformed of psychosocial oncology resources that may assist them in dealing with cancer burdens. Further, those affected by cancer identify that they are least satisfied with how their emotional need are addressed by cancer care systems. Since needs vary at different points in the cancer control continuum (Fitch, Porter, & Page, 2008), those affected by cancer must be educated regularly regarding psychosocial oncology resources that exist in their communities.

Principle 3: Ethical Practice

The psychosocial health services received are guided by ethical principles of autonomy, beneficence, honesty and confidentiality and by professionals' respective codes of ethics.

Principle 4: Respect for Culture/Diversity

Persons affected by cancer receive psychosocial health services that are respectful of, and attend to, cultural and linguistic diversity, gender and sexual orientation for the population they serve.

A recent review (CJAG/CPACCC, 2008) identified that there is little evidence with regard to culturally appropriate interventions for minority and underserved groups. However, it is well acknowledged that various factors influence health disparities in Canada (Public Health Agency of Canada, 2005) and up to 30% of Canadians are to some extent not served or underserved by the health care system (Pierre & Seibel, 2007). Distress levels are likely to be higher in these groups, emphasizing the need for appropriate services. Education and other psychosocial and supportive care interventions should be offered in a culturally appropriate manner that respects needs related to gender, sexual orientation, literacy, and socio-economic variables.

Principle 5: Interprofessional collaboration

Care is provided by health professionals who collaborate effectively with each other on interprofessional teams.

Collaborative person-centred practice is an approach to care that involves “the continuous interaction of two or more professionals or disciplines, organized into a common effort, to solve or explore common issues with the best possible participation” of the ill person. (Herbert, 2005). Martín-Rodríguez and her colleagues (Martín-Rodríguez, Beaulieu, D’Amour, & Ferrada-Videla, 2005) describe four necessary but insufficient elements that need to exist within a team: a willingness to collaborate; good communication; mutual trust and respect. The members of interdisciplinary care teams and communities of practice respect each other’s expertise and knowledge base.

Principle 6: Evidence-based Care

The psychosocial care of persons affected by cancer is informed by evidence/best practice informed by clinical judgement.

Evidence-Based care is a person-centred integration of best research evidence and clinical judgement (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000), which respects the values and preferences of the person. Through a collaborative process, persons affected by cancer develop preferences for both a method of decision-making and for particular care options. The process of informed consent establishes a shared decision for a reasonable course of action. Care decisions and actions occur within the context of regulations, professional standards and legal requirements, as well as within the context of particular clinical settings, available resources, political jurisdictions and in relation to society. Health professionals advocate for improvements in practice in accordance with best research evidence and the definition of evidence-based care. Figure 4 incorporates these elements.

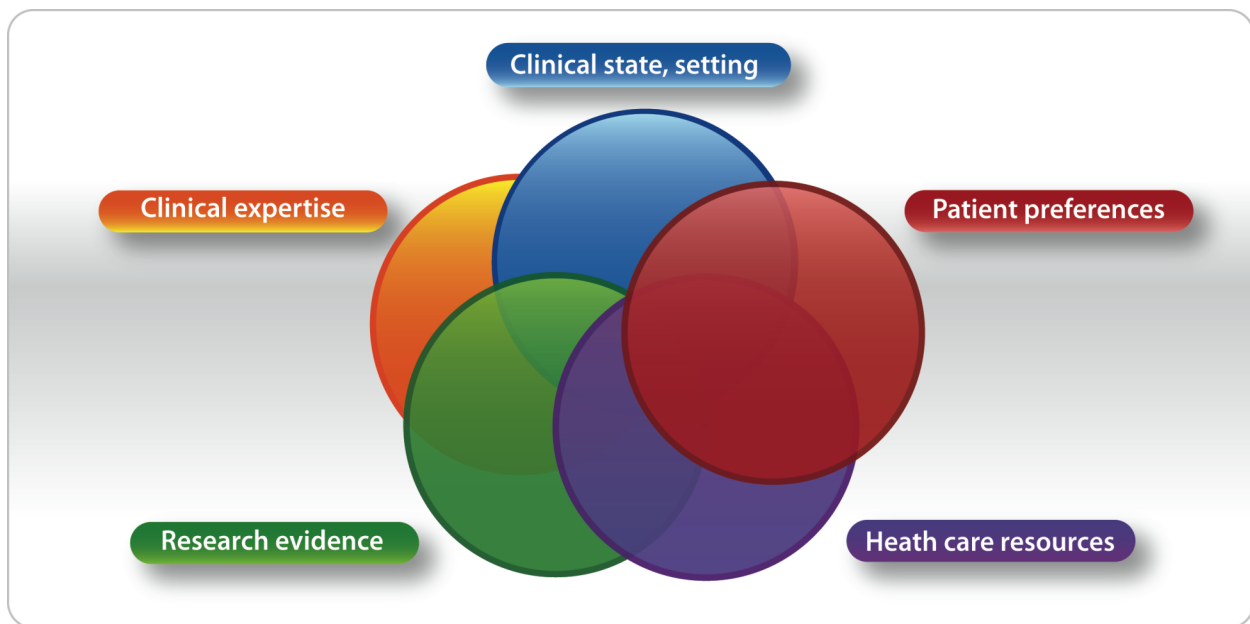


Figure 4

Haynes, R.B., Devereaux, P.J. & Guyatt, G.H., 2002

PRINCIPLE 7: Quality Monitoring and Quality Improvement

Persons with cancer expect that the psychosocial care and services that they access are subject to ongoing quality monitoring and improvement processes. Cancer treatment settings should conduct periodic health record audits to determine if certain expected components of quality psychosocial health care such as screening for distress, assessment of psychosocial health needs, development of plans to address psychosocial health needs and evaluation are being provided (Jacobsen et al., 2009).

SECTION IV A - ORGANIZATION AND STRUCTURE

Tertiary Care Settings

In Canada, cancer control and cancer care service delivery has structures and accountabilities that vary province by province and by territory. The Canadian Association of Provincial Cancer Agencies notes that there has been increased emphasis in recent decades towards developing population based systems of cancer control, as well as geographically distributed services. There has been an increased concentrated and systematic effort at integration to achieve consistent person-centred evidence based care. Most of the provinces have Cancer Acts, which clearly define these responsibilities and those that do not, have other enabling legislation (see www.capca.ca)

In any given province, a cancer centre may be stand-alone, part of a provincial cancer care and research agency, or affiliated with a host hospital, depending on the model established by the province. In cancer centres, multi-disciplinary assessment is provided; treatment plans are established such that individuals may receive surgery, a combination of systemic and radiation treatment, or one modality, depending on the stage

and type of cancer. Equal to the resource requirements for treatment of the disease, psychosocial and supportive care interventions are required to help people manage the many issues that arise throughout their cancer experience from pre-diagnosis, through diagnosis and treatment, and beyond (see Cancer Continuum Figure 4).

There are many studies and reports that have identified the psychosocial and emotional burden faced by those with cancer and their families (Adler & Page, 2008; Ashbury, Findlay, Reynolds, & McKerracher, 1998; Moadel et al., 1999; Richardson, Medina, Brown, & Sitzia, 2007; Sanson-Fisher et al., 2000; Wen & Gustafson, 2004). Overall, it is recognized that more than 35%² of people with cancer express distress and require specialized psychosocial oncology or supportive care interventions to assist them to cope and manage the burden of illness and achieve improvements in quality of life (Carlson, Angen, Cullum, et al., 2004; Carlson & Bultz, 2003a; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001).

Just as there is variation province to province on the structures of cancer care delivery so too is there variation in how these programs and services are grouped together and named. Some examples of the current names of programs, departments, or portfolios in tertiary cancer centres across the country include “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” and “Integrated Psychosocial, Supportive and Palliative Care Program,” among others.

Disciplines within these programs may include combinations of professionals and specialists, such as social workers, psychologists, psychiatrists, advanced practice nurses, clinical counsellors, marriage and family therapists, registered dietitians, rehabilitation specialists (including vocational rehab), spiritual care specialists, and speech language pathologists.

Within this group of services in tertiary centres, there are psychosocial oncology specialists with education, clinical skills, and knowledge in psychotherapy and/or clinical counselling. These include social workers (MSW), psychologists (PhD), and counselling psychologists (Masters or PhD), advanced practice nurses (MN or PhD) with a background in psychiatry/mental health, psychiatrists, and spiritual care specialists (CAPPE certified). Psychosocial oncology specialists provide individual, couple, family and/or group therapy or counselling interventions.

Programs of education and research in psychosocial oncology are essential components of tertiary cancer care centres as is the identification of barriers to effective service delivery, community development and program development.

Community Oncology Program

Community oncology programs provide care closer to home for many of those affected by cancer by providing care planning, systemic therapy (and occasionally radiation therapy) as well as psychosocial and supportive care. The community oncology cancer programs are integral to the cancer system and support

² Various authors report that clinically significant distress, generally defined as affective, anxiety or adjustment disorders, occurs in between 15-50% of people, depending on the instrument and cutoffs used and the specific population assessed. Variations also have been reported in relation to a number of variables, such as age, tumor site, illness trajectory and gender. The average figure reported is often 35%. In this document we use 35% as an approximate figure while recognizing the variability that exists in the literature. See e.g.: Carlson et al., 2004; Carlson & Bultz, 2003a; Pikler & Brown, 2010, Vodermaier, Linden, & Si, 2009, Zabora et al., 2001.

individuals and their family through the cancer experience. Community oncology cancer programs may have some of the psychosocial oncology and supportive care resources described above in tertiary centres. The structure, variety, and availability of these resources may vary depending on human and financial resources of the community oncology program, but access to at least some of these resources is critical. Community oncology cancer programs are often integrated with the tertiary centres, or collaborate closely with them. This relationship can help provide access to psychosocial oncology specialists and supportive care professionals, including access through technology such as tele-health, telephone or online media. Community oncology programs are also active in community development and program development, based on community needs and resources available.

Primary Care Providers

Cancer care begins in the primary care settings more often than not as individuals seek assessment and diagnosis related to symptoms that may be indicative of cancer. Even if someone is first seen in emergency, related to bleeding or obstructions, for example, the treating physician in the hospital will refer the person to primary care. Given the data reported by the Institute for Clinical Evaluative Sciences (Del Giudice, Bondy, Chen, & Maaten, 2006), it is important to recognize that primary care providers (general practitioners, family physicians, nurse practitioners) address psychosocial health care needs of persons affected by cancer across the care continuum.

In some provinces, relationships have been established to support primary care providers to manage the needs of persons affected by cancer. For example, Cancer Care Manitoba (CCMB) established the UPCON, which is a network to unite primary care and oncology. The network is a collaborative partnership between family practice and CCMB to promote and support shared care of those affected by cancer. Similarly there are other networks or similar models to connect primary care practitioners with the cancer systems in provinces across Canada. Some relevant facts provided by ICES:

- In a practice of 2,000 people, an average family physician may have 50 individuals with a history of cancer.
- Family physicians report that cancer care/oncology makes up 24% of their professional activity.
- Compared to pre-diagnosis, individuals see their family physicians 75%-200% more often during the diagnostic phase, 38%–88% more often during active treatment, 15%–50% more often during the follow-up period, and at least 300% more often during the final three months of palliative care.
- Except during active treatment, individuals diagnosed with cancer see their family physician more often than any oncology specialist or other physician.
- Proportion of visits to family doctor for anxiety and depression peak during active treatment.

Therefore, it is imperative that primary care providers understand the range of needs and complexities that persons affected by cancer experience. Primary care providers must assist in meeting psychosocial health care needs and understand the processes to refer to psychosocial oncology specialists for those who require this level of intervention.

Community Based Cancer Agencies

While those affected by cancer require information and interventions from health providers, they also want information and support from peers or people who have had cancer experiences (Matthews, Baker and Spillers, 2004). Persons affected by cancer describe the benefits that are experienced through agencies such

as the Canadian Cancer Society and where peer support programs, information sessions and social networking (Adler & Page, 2008) are offered. Many programs have been developed by community-based agencies to provide information and support to cancer patients and their family members. Psychosocial oncology and supportive care professionals can practice out of community based cancer agencies, where peer support volunteers are often a key component of services. It is important to note that these professionals often provide education and training to peer support volunteers. These agencies provide important services and resources that give those affected by cancer and their families additional choices to select the type of program that best suits their style of learning and ways of coping.

Table 1: Psychosocial Health Services by Programmatic Structure

		Tertiary Cancer Programs	Community Oncology Cancer Program	Community Based Cancer Agency	Primary Care
Psycho-social Health Services	Psycho-social oncology program structure	There is a well-defined psychosocial oncology program within the cancer centre, which includes availability of multi-professional psychosocial oncology specialists who function as an integral part of the clinical cancer care team, and are involved in education, research and community development activities.	A modified psychosocial oncology program is established or referrals are made to community psychosocial oncology specialists or mental health resources. Links to tertiary care centre for direct care, collaborative care, consultation.	Community based agencies have a structure to provide volunteer resources to meet the individual's and his/ her family's needs for support and information.	Referral to appropriate psychosocial oncology or mental health resources in the community and /or tertiary care centre, based on assessment of need.
	Supportive Care Services	Supportive care services are available to address the range of complex care issues.	Supportive care services are available to address the distinct needs of patients	Community based agencies offer supportive care services.	
Level of Psycho-social Oncology Expertise		There are psychosocial oncology specialists available with knowledge and clinical skills to assess and intervene for people who require counselling. It is essential that the range of expertise across the disciplines of social worker, psychologist, psychiatry, spiritual care and nursing at an advanced practice level is available.	There are links to tertiary centres for Psychosocial Oncology.	Volunteers trained in peer helping skills are available.	Primary care practitioners are generally aware of the challenges that cancer presents. They are skilled in providing supportive counselling and/or are aware of and refer to community resources.

SECTION IV B - EDUCATION STANDARDS

Education Standard: Persons affected by cancer are entitled to access to appropriately educated professionals across the health care system.

Background

Persons affected by cancer are entitled to access to an appropriate level of care to address their needs. All persons benefit from supportive care, including assessment and intervention from health professionals, as necessary. Some people will have a higher level of need, with up to 50% requiring care provided by psychosocial oncology specialists (Fitch et al., 2008).

Persons receiving psychosocial health services are entitled to care that is evidence based and guided by best practice guidelines. In order to provide evidence based care in this area, health care professionals must receive formal education in psychosocial oncology. The breadth and depth of that education will vary depending on the role assumed (oncology or supportive care professional or psychosocial oncology specialist). These standards apply to health care professionals in primary care, oncology/supportive care and the psychosocial oncology specialist (Canadian Strategy for Cancer Control, 2007). Volunteers are governed by the policies of their agencies and are included in Table 1 but otherwise are not addressed by these standards.

At the time of preparation of this document, there were no published standards for psychosocial oncology education. A national Canadian focus group study was conducted by CAPO through the Interprofessional Psychosocial Oncology Distance Education (IPODE) project (McLeod, Dumont, White & Curran, 2008). This study identified key areas for psychosocial oncology education.

Education Standard I: The Cancer Experience

Persons affected by cancer require professionals who are educated to understand the cancer experience across the continuum of care.

Rationale

Effective communication, including active listening, expressions of empathy, eliciting and responding to emotional cues and sensitivity to the experience of the person affected by cancer has been shown to improve psychological adjustment, adherence to treatment plans and satisfaction with care (Adler & Page, 2008; Epstein & Street, 2007; Hack, Degner, & Parker, 2005; Helgeson & Cohen, 1996). Anticipatory guidance and coaching at every point along the illness trajectory allows the person affected by cancer to better understand and manage the cancer experience. To effectively communicate and provide competent coaching, it is necessary (though not sufficient) for all providers to develop an understanding of the cancer experience from the perspective of those experiencing cancer, including basic understanding of the pathophysiology, treatment and course of cancers.

Education Standard II: Assessment

Persons affected by cancer require providers that are educated in assessment processes that are appropriate to their scope of practice.

Rationale

Understanding of standardized screening tools and psychosocial assessment frameworks and processes, including the type and timing of assessment and need for referral to specialists is necessary to identify

current psychosocial status, needs and wishes with regard to care, and to develop intervention plans (Howell et al., 2009).

Education Standard III: Therapeutic Relationships

Persons affected by cancer are entitled to professionals who are knowledgeable and skilled in developing, maintaining and terminating therapeutic relationships that are appropriate to the level of care required.

Rationale

Considerable evidence now exists to inform cancer care providers about the value of a therapeutic relationship to the well-being of those affected by cancer (Adler & Page, 2008; Helgeson & Cohen, 1996). At one level, the therapeutic relationship is experienced as care and is not simply a vehicle for something else. It is one potential avenue for continuity of care. Therapeutic relationships are also an essential aspect influencing the success of all forms of counselling and psychotherapy (Hubble, Duncan & Miller, 1999).

Education Standard IV: Therapeutic Intervention

Persons affected by cancer are entitled to professionals who are knowledgeable and skilled in providing therapeutic psychosocial and supportive care interventions for identified needs that are appropriate to the level of care required by those affected by cancer.

Rationale

There is extensive evidence regarding effective interventions for those experiencing a cancer diagnosis (Adler & Page, 2008; Gottlieb & Wachala, 2007; Jacobsen, 2009). Theoretical and practical education is required to gain understanding and skill in implementing interventions. The evidence applies to all providers.

Education Standard V: Self Care

Persons affected by cancer are entitled to professionals who are self-aware, reflective practitioners who are knowledgeable and skilled in taking care of their own needs for support, and in the prevention and management of personal distress.

Rationale

There is good evidence that cancer care takes a toll on health providers, with emotional burden, vicarious trauma, compassion fatigue and burnout as potential occupational hazards. When these outcomes occur, there are significant costs to the health provider and their families. In addition, when personal needs for support and management of distress is inadequate, providers are less able to meet the needs of the people to whom they provide care (Aycock & Boyle, 2009; Kearney, Weininger, Vachon, Harrison, & Mount, 2009).

Education Standard VI: Interprofessional Collaboration

Persons affected by cancer are entitled to providers who are competent in interprofessional collaboration, including recognizing their scope of practice as well as the scope of other providers.

Rationale

Psychosocial health services are provided by many disciplines, with areas of overlap and areas of unique knowledge and skill. Lack of education in interprofessional collaboration can limit effective team communication and access to appropriate care providers. This can result in gaps, fragmentation and duplication of service. Health professionals who are skilled in interprofessional collaboration contribute to seamless and appropriate care (Oandasan et al., 2004).

Table 2: Education Standards by Provider

Standard of Care: Persons affected by cancer are entitled to access to appropriately educated providers across the health care system			
Education Standard	Provider		
	Health Professionals (Psychosocial Oncology (PSO) Specialists)	Health Professionals (PSO Generalists – includes primary care and oncology professionals)	Peer Support Volunteer
The cancer experience	All providers will understand common experiences and responses of persons affected by cancer across the cancer care continuum.		
Assessment	In addition to the others, PSO specialists will be educated to conduct more in-depth psychosocial assessment for diagnosis and intervention planning. Psychosocial oncology specialists require a basic understanding of cancer and its treatment as a foundation for assessment.	Health professionals will be educated to conduct systematic and comprehensive assessments of the psychosocial, spiritual and cultural aspects of the cancer experience.	Volunteers will be educated to informally identify needs, including the need for professional care.
Therapeutic relationships	In addition to the others, PSO specialists will receive more extensive supervision in therapeutic relationships. Typically this will occur during graduate education. If not, opportunities for supervision should be provided as part of clinical practice for a minimum of the first 2 years in psychosocial oncology by a PSO specialist. Ongoing supervision, including peer supervision, is desirable.	Health Professionals will have opportunities to develop theoretical knowledge and skill in the initiation, maintenance and termination of a therapeutic relationship that is respectful of diversity and professional boundaries.	Volunteers will understand and develop skills in peer helping relationships

Education Standard	Provider		
	Health Professionals (Psychosocial Oncology (PSO) Specialists)	Health Professionals (PSO Generalists – includes primary care and oncology professionals)	Peer Support Volunteer
Therapeutic intervention	In addition to the others, PSO specialists manage more complex problems and will have additional theoretical knowledge and clinical supervision in counselling and/or psychotherapy in one or more modalities of intervention (individual, couples, family and group therapy). These skills are developed during graduate level education and require clinical experience with direct supervision in counselling and/or psychotherapy. Those providers who do not have at least 300 hours of clinical supervision during their education program should receive supervision in their clinical setting until that minimum is reached.	In addition to skills in therapeutic relationships, health professionals will have theoretical knowledge and skill in intervening through the provision of information, psycho-education, normalizing concerns, brief interventions to manage anxiety and distress and supporting medical decision-making.	Volunteers will understand and develop skills in peer helping.
Self care	All providers will have opportunities to reflect upon and develop knowledge and skill in self assessment, recognizing one's own emotional limits, need for support, and prevention and management of personal stress or distress. Required for all providers.		
Collaboration	Health professionals and Psychosocial oncology professionals will develop knowledge and skill in interprofessional collaboration, team building, and conflict management. They will be very knowledgeable about their own scope of practice as well as the scope of other providers.	Volunteers will develop skills in communicating with other providers and understand their own and others' role.	

SECTION IV C - STANDARDS OF CARE

Psychosocial health care needs are recognized, monitored, and treated promptly across the cancer control continuum from the time of cancer screening, throughout treatment phases to palliation and end of life care. Those who are affected by cancer, including individuals, family members and treatment teams will be informed that management of distress is an integral part of total health care and provided with appropriate information about psychosocial services in the treatment centre and community (Adler & Page, 2008; Howell et al., 2009)

Standard of Care I: Prevention

People at higher risk for cancer and the general population are entitled to access psychosocial and supportive care as needed to address concerns and fears related to cancer risk or screening, as well as to receive information that: assists them to address primary, secondary and tertiary prevention behaviour and lifestyle change and any challenges or perceived barriers related to following appropriate cancer screening recommendations.

People with inheritable cancer risks or cancers are entitled to receive genetic counselling and testing, which fully integrates psychosocial and supportive care to facilitate informed medical decision making concerning risk reducing options (e.g. prophylactic surgery; chemoprevention).

Rationale

While several comprehensive reviews and long term studies suggest that adverse psychological consequences of cancer screening, risk counselling and genetic testing can be uncommon, there are subgroups of individuals who are at risk for negative psychological outcomes associated with cancer or risk screening or testing. While there remains challenges in the identification and appropriate care of those subgroups that are at increased risk for psychological distress and decreased quality of life or inadequate screening, it is recognized that psychosocial care be an integral component of cancer risk management. In an effort to achieve reductions in cancer related morbidity and mortality, engaging in screening programs and primary, secondary, & tertiary risk reduction strategies is key (Sagar & Lawenda, 2009). Addressing psychological reactions and concerns will potentially maximize opportunities for prevention, early detection, adaptation and enhanced quality of life (Braithwaite, Emery, Walter, 2004; Vadaparampil, Miree, Wilson, & Jacobsen, 2007).

Standard of Care II: Screening and Assessment

People at risk for, or living with, cancer are entitled to psychosocial screening using a standardized approach, and to be assessed at appropriate intervals throughout the cancer continuum across their journey to determine coping and adjustment, information, practical and support needs, level of functioning, including the domains of social, emotional, psychological, cognitive, physical, sexual and spiritual health.

Rationale

As new cancer treatments lead to increased survival rates, the prevalence and impact of symptoms has also increased (Alfano & Rowland, 2006). Increased symptom burden can greatly impair quality of life and may even limit potentially curative therapies. Individuals with cancer and their family members experience significant practical, psychological, social and spiritual concerns. Dimensions of quality of life are often ignored or are not addressed in a consistent manner, based on best evidence for practice (Carlson & Bultz, 2003b; Howell et al., 2009). Increasing diversity in the Canadian population and the complexity of issues

that arise for those affected by cancer, require standard approaches in the realm of social and emotional well being. Estimates of serious psychological distress, that is meeting criteria for DSM IV diagnoses for mood disorder, anxiety or adjustment disorder, varies from 35 to 45% (Carlson & Bultz; Howell et al; Zabora et al., 2001) and significant anxiety or depression symptoms that do not meet full diagnostic criteria for a mood disorder are also common. Psychological factors, such as distress and feelings of vulnerability predict poorer adjustment, result in co-morbidity, and can affect treatment decisions, quality of life and medical outcomes. However, patients may not express challenges or difficulties concerning psychological functioning or reactions. Screening and routine assessment of concerns, strengths, psychological reactions and functioning is useful in identifying needs and preventing distress. Screening and assessment increasingly have become an ethical imperative and the chief route to adequate psychosocial care (Adler & Page; Howell et al). Appropriate screening and triage results in more appropriate management of limited resources in providing those most in need with care and may lead to enhanced cost-effective management of cancer care (Carlson & Bultz, 2003a, 2003b).

Standard of Care III: Treatment

Persons affected by cancer are entitled to access appropriate levels of treatment to address their needs. This may include peer or professional led support groups, psycho-education, individual/couple/family counselling or psychotherapy, sex therapy, psychotropic medication and rehabilitation services.

Rationale

Everyone affected by cancer requires at least a minimum of supportive care. However, approximately one-third of those with cancer suffer from significant psychological distress and concerns and are in need of appropriate psychosocial intervention. The various stages of cancer have their own unique issues and therefore the need for psychosocial and supportive care can vary over time during the course of the cancer journey from the time of diagnosis to end of life care (Fitch et al., 2008). Particular time points where stress and vulnerability for distress is high include: prior to and just after receiving the diagnosis, at transition points (e.g. transition to treatment; at end of treatment), following a recurrence or change in prognosis as well as during end of life (Fitch et al., 2008). The type of intervention and approach required can vary over time, for example, early on in the course of diagnosis and treatment phases there is often a need for educational and coping-oriented interventions. People in survivorship or advanced disease phases may benefit most from specific interventions that focus on particular problems, such as those focused on body image or sexuality (Fitch et al., 2008; Hewitt et al., 2005), or supportive-expressive group counselling approaches (Spiegel et al., 2007). Stress management based techniques are useful across the continuum in promoting self-care and the management of anxiety and uncertainty (Carlson & Bultz, 2008). Various interventions have demonstrated effectiveness in facilitating positive coping, managing anxiety and fear, promoting family and couple communication, facilitating adjustment to body image and intimacy concerns, enhancing social support and promoting clarity in treatment decision making, as well as improving quality of life and (Adler & Page, 2008; NCCN, 2008). There are various evidence-based modalities of psychosocial and supportive treatments including, but not limited to, educational and psycho-educational, cognitive-behavioural, supportive-expressive, mind-body, use of psychotropic medications, peer support, art therapy, internet-based, spiritual, individual, family, couple or group counselling approaches (NCCN, 2008).

Standard of Care IV: Palliation

Persons affected by cancer are entitled to access and timely referral to palliative care that includes psychosocial assessment and intervention.

Rationale

Those affected by cancer are entitled to access and timely referral to palliative care that includes psychosocial assessment and intervention. Access to palliative care includes opportunities for conversation about diagnosis and prognosis, spiritual and existential meaning, end-of-life decision making, advance directives and care planning. The World Health Organization (2007) defines palliative care as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families”.

Palliative care ideally is considered at the time of diagnosis of a life-threatening or debilitating condition and continues through cure, or until death, and into the family’s bereavement period. Palliative care aims to prevent and relieve suffering and to support the best possible quality of life, regardless of the stage of the disease or the need for other therapies (Ferris et al., 2002). “Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making, providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care” (National Consensus Project for Quality Palliative Care, 2009, pg. 6).

Current definitions of palliative care recognize the benefits of palliative approaches early on at the time of a diagnosis of a life-threatening illness (Ferris et al., 2002). Psychological complications of palliative care have received more attention as end of life care has received a greater focus. Greater recognition of the complexity of physical and psychological symptoms and their interactions has led to the recognition of the need for an integrated and interprofessional approach to care in an effort to address such complex issues and interactions. In addition, the literature over recent decades has underlined the importance of social and spiritual/existential concerns when persons with cancer and their families are faced with a life-threatening illness and the ongoing management of symptoms and ethical and psychological challenges that emerge as an individual approaches the end of life (Ferris et al., 2002; Lethborg, Aranda, & Kissane, 2007; National Consensus Project for Quality Palliative Care, 2009). The complexities require team effort in managing challenging family and individual reactions to the prognosis or when making informed medical decisions that involve challenges around the weighing of pros and cons of potential medical treatments. Individuals are living longer with cancer and often palliative care occurs in settings outside of tertiary centres, frequently the home environment. This requires effort in managing the privacy of individuals and transmitting knowledge concerning patient medical care, preferences and values between agencies and in the context of a family dealing with increased feelings of vulnerability or anticipatory grief. Spiritual concerns, personal values and culture all play an important role in the receipt and management of care (Ferris et al., 2002).

Standard of Care V: Survivorship

Individuals with cancer have the right to psychosocial and supportive care that includes availability of professionals to meet needs related to the late- and long-term psychosocial effects of cancer treatment. They are offered a survivorship care plan that summarizes the treatment received to date, follow-up appointment frequency schedule with oncology and primary care, a checklist of relevant late effects of treatment, and a psychosocial resource guide.

Rationale

Cancer survivors report ongoing difficulties in recovery and returning to 'normal' following treatment for this life-altering experience. Survivors of cancer, although hearing that they are 'free of cancer', may still experience fears of recurrence, and may have long-standing issues, such as depression, anxiety, and impairment of cognition (Ganz, 2000; Hewitt et al., 2005). Body image, sexual alterations, and long term functional changes are common, as are relationship and other social role difficulties, return to work concerns, financial challenges, among others (Hewitt et al.) Cancer survivors commonly face these psychosocial concerns and worries (Rowland, 2008), as do their family members (Golant & Haskins, 2008).

Standard of Care VI: Grief/Bereavement

Surviving family members are offered a grief and bereavement care plan prior to the death of their loved one that provides opportunities for assessment of grief and psychosocial functioning for at least twelve months after the death. Identification of those at high risk for complicated grief is a priority. Services may include but are not limited to: individual, couple, family and group grief counselling, educational materials, internet-based forums, and spiritual counselling.

Rationale

Increased communication and comprehension of cancer and its impacts among the public, among health care professionals and among families has led to greater recognition of potential implications of a cancer diagnosis. Cancer as a life-threatening illness brings forth ongoing feelings of loss as a result of quality of life impacts, losses due to treatments and eventual loss of a loved one at various time points across the cancer journey. Individuals with cancer and their family members are confronted with feelings of vulnerability, anticipatory and actual grief, feelings of despair and hopelessness at times as well as in some cases anticipatory reactions concerning family members at risk for cancer (Ferris et al., 2002; National Consensus Project, 2009). Palliative care approaches consider the family the unit of care. Bereavement plans and treatment are an extended aspect of care recognized as an important component of the treatment trajectory, available for at least 12 months following the loss of a loved one (National Consensus Project, 2009). Bereavement programs range from individual to group facilities for both the ill person and his or her family and other support networks and aim to facilitate the grieving process, address spiritual and life value concerns and optimal coping in dealing with a cancer diagnosis and its associated losses.

Table 3: Standards of Care In Relation to Programmatic Structure

Standard	Programmatic Structure			
	Tertiary Cancer Programs	Community Oncology Cancer Program	Community Based Agency	Primary Care
Prevention				Primary care providers provide health counselling related to prevention and screening. They screen for psychosocial functioning and refer to psychosocial oncology specialists or mental health professionals if necessary.
Assessment	There is a comprehensive psychosocial oncology program within the cancer centre with structures and processes for screening and assessment.	There is a modified psychosocial oncology program established, which includes at minimum, structures and processes for screening and referral psychosocial oncology resources.	Clients are informed of available psychosocial oncology resources in their community.	Primary care providers screen for cancer related distress. They are aware and inform their clients of available psychosocial oncology and mental health resources in their community.
Treatment	Provide a range of services, including individual, couple, family and group interventions or develop referral sources in the community.	Provide, at minimum, psycho-educational and supportive counselling. They inform people accessing their services of appropriate programs in their community and facilitate referrals	Volunteers provide peer support programs.	Primary care providers offer information and supportive counselling. They are aware of and facilitate referral to programs and services in their community.

Standard	Programmatic Structure			
	Tertiary Cancer Programs	Community Oncology Cancer Program	Community Based Agency	Primary Care
Survivorship	There are established psychosocial oncology resources to support the person's transition from treatment to survivorship post-treatment, including the development of care plans to manage late or long term emotional and physical effects	Community programs support the survivorship plans to the extent possible and collaborate with the tertiary cancer programs.	Same as above	Same as above
Palliation	Psychosocial oncology and palliative care in tertiary programs work in collaboration recognizing the multi-dimensional aspects of care to support and manage the palliative population	Community programs support the palliative individual and his/her family within community resources.	Same as above	Same as above
Bereavement	There are established bereavement follow-up programs.		Same as above	Same as above

REFERENCES

- Accreditation Canada (2009) www.accreditation-canada.ca.
- Adler, N. E. & Page, E. K. (Eds.). (2008). *Cancer care for the whole patient: Meeting psychosocial health needs*. The National Academies Press: Washington, D.C.
- Ashbury, F. D., Findlay, H., Reynolds, B., & McKerracher, K. (1998). A Canadian survey of cancer patients' experiences: Are their needs being met? *Journal of Pain and Symptom Management*, 16(5), 298-306.
- Aycock, N., & Boyle, D. (2009). Interventions to manage compassion fatigue in oncology nurses. *Clinical Journal of Oncology Nursing*, 13(2), 183-191.
- Braithwaite, D., Emery, J., Walter, A. (2004). Psychological impact of genetic counselling for familial cancer: a systematic review and meta-analysis, *Journal of the National Cancer Institute*, 96, 1675-1682.
- Bultz B. D., Carlson L. E. (2005). Emotional distress: the sixth vital sign in cancer care. *Journal of Clinical Oncology*, 23, 6440-6441.
- Bultz, B.D. & Carlson, L. E. (2006). Emotional Distress: The sixth vital sign - future directions in cancer care. *Psycho-Oncology*, 15, 93-99.
- Cancer Journey Action Group (CJAG)/ Canadian Partnership Against Cancer (CPACC), (2009). *Guide to implementing screening for distress, the 6th vital sign*. Toronto: Author.
- Canadian Strategy for Cancer Control (2007). *National psychosocial oncology education framework*. Toronto: Author.
- Cancer Journey Action Group (CJAG)/ Canadian Partnership Against Cancer (CPACC) (2008). *Providing culturally competent supportive cancer care for underserved populations*. Toronto: Author.
- Carlson, L. E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., et al (2004): High levels of untreated distress and fatigue in cancer patients. *British Journal Cancer*, 90, 2297-2304.
- Carlson L. E., Bultz, B. D. (2003a). Cancer distress screening: Needs, methods and models. *Journal of Psychosomatic Research*, 55, 403-409.
- Carlson L. E., & Bultz, B. D. (2003b). Benefits of psychosocial oncology care: improved quality of life and medical cost offset. *Health Quality of Life Outcomes*. 1(8). Retrieved May 22, 2009 from www.hqlo.com/content/pdf/1477-7525-1-8.pdf.
- Carlson, L. & Bulz. B. (2008). Mind-body interventions in oncology, *Cancer Treatment Options in Oncology*, 9, 127-134.
- Del Giudice, L., Bondy, S. J., Chen, Z., & Maaten, S. (2006) *Physician care of cancer patients. Primary Care Atlas. Chapter 10*. Institute for Clinical Evaluative Sciences (ICES) retrieved July 25, 2009 from http://www.ices.on.ca/file/PC_atlas_chapter10.pdf
- Epstein, R. M., & Street, R. L. (2007). *Patient-centered communication in cancer care: Promoting healing and reducing suffering*. NIH Publication No. 07-6225. Bethesda, MD: National Cancer Institute.
- Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, H., Lamontagne, C., et al. (2002). *A model to guide hospice palliative care: Based on national principles and norms of practice*. Canadian Hospice Palliative Care Association (CHPCA). Retrieved July 22, 2009 from: http://www.chpca.net/resource_doc_library/model_to_guide_hpc/A+Model+to+Guide+Hospice+Palliative+Care+2002-URLUpdate-August2005.pdf.
- Fitch, M. I., Porter, H. B., & Page, B.D. (2008). (Eds.), *Supportive care framework: A foundation for person-centered care*. Pembroke, ON: Pappin Communications.
- Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, T. L. (1993). *Through the patients' eyes: understanding and promoting patient-centered care*. San Francisco: Jossey-Bass.

- Golant, M., & Haskins, N. V. (2008). "Other cancer survivors": The impact on family and caregivers. *Cancer, 14*(6) 420-24.
- Gottlieb, B. H., & Wachala, E. D. (2007). Cancer support groups: A critical review of empirical studies. *Psycho-Oncology, 16*(5), 379-400.
- Hack, T. F., Degner, L. F., & Parker, P. A. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology, 14*, 831-45.
- Haynes, R. B., Devereaux, P. J., & Guyatt, G. H. (2002). Clinical expertise in the era of evidence-based medicine and patient choice. *ACP, 136*, A11-14.
- Helgeson, V. S., & Cohen, S. 1996. Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology 15*(2):135–148.
- Herbert, C. P. (2005). Changing the culture: Interprofessional education for collaborative patient-centred practice in Canada. *Journal of Interprofessional Care, 19*, Suppl. 1, 1-4.
- Hewitt, M., Greenfield, S., & Stovall, E (Eds.) (2005). *From cancer patient to cancer survivor. Lost in translation*. The National Academies Press: Washington, D.C.
- Holland, J. C. & Bultz, B.D. (2007). The NCCN Guideline for Distress Management: Case for making distress the 6th vital sign. *Journal of the National Comprehensive Cancer Network 5*(1), 3-7.
- Howell, D., Currie, S., Mayo, S., Boyle, M., Hack, T., Green, E., et al. (2009). *A Pan-Canadian Clinical Practice Guideline: Psychosocial and Supportive Care of Adults with Cancer, Part I: Psychosocial Health Care Needs Assessment and Screening for Distress*. Toronto: Canadian Association of Psychosocial Oncology.
- Hubble, M. A., Duncan, B. L., & Miller, S. D. (Eds.). (1999). *The heart and soul of change: What works in therapy*. Washington, D.C.: American Psychological Association.
- Jacobsen, P. B. (2009). Promoting evidence-based psychosocial care for cancer patients. *Psycho-Oncology, 18*(1), 6-13.
- Jacobsen, P. B., Shibata, D., Siegel, E. M., Lee, J., Alemany, C. A., Brown, R., et al. (2009). Initial evaluation of quality indicators for psychosocial care of adults with cancer. *Cancer Control, 16*(4), 328-334.
- Kearney, M., Weininger, R., Vachon, M., Harrison, R., & Mount, B. (2009). Self-Care of physicians caring for patients at the end of life. *JAMA, 301*(11), 1155-1164.
- Lethborg, C., Aranda, S., & Kissane, D. (2007). Meaning in adjustment to cancer: A model of care. *Palliative and Supportive Care, 6*, 61–70.
- Lewandowski, L. A. & Tesler, M. D. (2003). *Family centered care: Putting it into action (The SPN/ANA Guide to family-centered care)*. The Society of Pediatric Nurses and the American Academy of Nursing.
- Martín-Rodríguez, L. S., Beaulieu, M. D., D'Amour, D., Ferrada-Videla, M. (2005). The determinants of successful collaboration: A review of theoretical and empirical studies. *Journal of Interprofessional Care, 19*, Suppl. 1, 132-147.
- Matthews, B. A., Baker, F. & Spillers, R. L. (2004). Oncology professionals and patient requests for cancer support services. *Supportive Care in Cancer, 12*(10):731–738.
- Moadel, A., Morgan, C., Fatone, A., Grennan, J., Carter, J., Laruffa, G., et al., (1999). Seeking meaning and hope: Self-reported spiritual and existential needs among an ethnically diverse cancer patient population. *Psycho-Oncology, 8*(5), 378-385.

- National Breast Cancer Centre and National Cancer Control Initiative. (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre: Camperdown, NSW. National Comprehensive Cancer Network (NCCN).
- National Consensus Project for Quality Palliative Care (2009). *Clinical practice guidelines for quality palliative care, 2nd Ed.* Retrieved July 25, 2009 from www.nationalconsensusproject.org.
- Oandasan, I., D'Amour, D., Zwarenstein, M., Barker, K., Purden, M., Beaulieu, M.D., et al. (2004). *Interdisciplinary Education for Collaborative, Patient-Centred Practice: Research & Findings Report*. Ottawa, ON: Health Canada.
- Pikler, V. I. & Brown, C. (2010). Cancer patients' and partners' psychological distress and quality of life: Influence of gender role. *Journal of Psychosocial Oncology*, 28, 43–60, 2010.
- Pierre, N., & Seibel, H. (2007). *The Frontline Health Dialogues, report from the Ottawa roundtable*. Accessed March 2, 2010 from www.cprn.org/documents/49117_EN.pdf.
- Richardson, A., Medina, J., Brown, V., & Sitzia, J. (2007). Patients' needs assessment in cancer care: A review of assessment tools. *Supportive Care in Cancer*, 15(10), 1125-1144.
- Rowland J. H. (2008). What are cancer survivors telling us? *Cancer*, 14(6), 361-68.
- Sackett, D. L., Straus, E. S., Richardson, W. S., Rosenberg, W. M. C. and Haynes, B. (2000). *Evidence-based Medicine: How to Practice and Teach EBM*. London: Churchill Livingstone.
- Sagar, S. M. & Lawenda, B. D. (2009). *The role of integrative oncology in a tertiary prevention survivorship program*. *Preventive Medicine* 49, 93–98.
- Sandoval, G. A., Brown, A. D., Sullivan, T., & Green, E. (2006) Factors that influence cancer patients' overall perceptions of the quality of care. *International Journal for Quality in Health Care*, 18, 266-274.
- Sanson-Fisher, R. W., Girgis, A., Boyes, A., Bonevski, B., Burton, L., Cook, P., et al. (2000). The unmet supportive care needs of patients with cancer. *Cancer*, 88 (1), 226-237.
- Spiegel, D., Butler, L. D., Giese-Davis, J., Koopman, C., Miller, E., DiMiceli, S., et. al. (2007). Effects of supportive-expressive group therapy on survival of patients with metastatic breast cancer: A randomized prospective trial. *Cancer*, 110(5): 1130-8.
- Vadaparampil, S., Miree, C. Wilson, C. and Jacobsen, P. (2007). Psychosocial and behavioral impact of genetic counselling and testing. *Breast Disease*, 27, 97-108.
- Vodermaier, A., Linden, Wolfgang & Siu, Christopher (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. *Journal of the National Cancer Institute*, 101, 1464 – 1488.
- Wen, K..Y., & Gustafson, D. H. (2004). Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes*, 2, 11.
- Zabora, J., Brintzenhofesoc, K., Curbow, B., Hooker, C., Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psychooncology* 10, 19-28.

APPENDIX A

Standards Revision Project Committee Members (2006-2010)

- Michael Boyle (2006-07)
- Mary Elliott (2007)
- Mary Jane Esplen (2006-10)
- Esther Green (Co-Chair) (2006-10)
- Tom Hack (2006-2007; 2009-10)
- Debbie McLeod (Co-Chair) (2006-10)

Myrna Tracy (2006-Feb10)
Zeev Rosberger (2006-10)
Sheila Damore Petingola (2009-10)
Steve Simpson (2009-10)
Jill Taylor Brown (2009-10)

Attendees at the February 26th, 2009 meeting in Toronto

Shelley Currie
Sheila Damore Petingola
Mary Jane Esplen
Esther Green (Co-Chair)
Tom Hack
Debbie McLeod (Co-Chair)
Steve Simpson
Jill Taylor Brown
Myrna Tracy
Zeev Rosberger

Attendees February 6th, 2010 (2nd Full day meeting)

Sheila Damore Petingola
Mary Jane Esplen
Esther Green (Co-Chair)
Tom Hack
Debbie McLeod (Co-Chair)
Steve Simpson
Jill Taylor Brown
Zeev Rosberger

APPENDIX B

THE USE OF TERMINOLOGY

Throughout the course of the CAPO Standards revisions work, the most significant challenge has been to reach consensus on the definition of key terms, particularly the term “psychosocial oncology”. In the 1999, CAPO Standards document this term was defined as follows:

Psychosocial Oncology is a professional sub-specialty in oncology. The domain of psychosocial oncology includes the formal study, understanding and treatment of the social, psychological, emotional, spiritual, quality of life and functional aspects of cancer as applied across the cancer trajectory from prevention through bereavement. It seeks to develop and integrate new knowledge and techniques of the psychosocial and biomedical sciences as it relates to cancer care (CAPO, 1999).

Since 1999 this definition has evolved and the current definition contained on the association website is:

Psychosocial oncology is 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.

This later definition seems to articulate a fuller breadth of psychosocial care that persons affected by cancer require and centres the focus of psychosocial oncology on the needs of patients and their family members rather than the roles of health professionals.

The committee struggled with the need to articulate the professional, specialist and non-professional or volunteer domains and contributions. Cancer care is complex, its effects are deep and long-lasting and the diagnosis, treatment and after effects have huge impact on the person’s coping, relationships, self-image, self-concept and functionality. These require assessment and interventions of the ‘whole person’ from all professionals who care for those affected by cancer.

Within Canada there has been tremendous variability regarding how the terminology of psychosocial oncology and supportive care is used and this is particularly noted in the naming of departments that provide such “whole person” care. For example, some current names of programs, departments, or portfolios in tertiary cancer centres across the country include “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” and “Integrated Psychosocial, Supportive and Palliative Care Program,” among others.

This variability is reflected also in recent documents published in Canada such as “A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient” (Howell et al., 2009), where some terminology is used interchangeably. For example, the term “psychosocial health care needs” are defined as including “physical, informational, emotional, psychological, social, spiritual, and practical domains that are common across cancer populations” (p. 4) and “relevant psychosocial and supportive care interventions and/or services” (p. 4) are identified as necessary to meet psychosocial health care needs. Throughout this document sometimes the term “psychosocial” is used alone and at other times it is used as “psychosocial and supportive care needs” (p. 6). There was no clear differentiation between the terms “psychosocial” and “supportive” in relation to needs, assessment or interventions.

The struggle around language is not unique to Canada and has been well articulated in the IOM report “Cancer care for the whole patient: Meeting psychosocial health needs” (Adler & Page, 2008). In the IOM

review of the literature in this area, the authors identified numerous terms such as “Psychosocial Support,” “Psychosocial Services,” “Psychosocial health services” and “Psychosocial oncology care”. The Australian document, “Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer,” define a psychosocial intervention as “treatment that is intended to address psychological, social, and some spiritual needs” (National Breast Cancer Centre and National Cancer Control Initiative, 2003, p. 212). In the review of this issue in the IOM report (Adler & Page 2008), the authors noted that there is a need for better definitional and conceptual clarity regarding “psychosocial services.” In their effort to contribute to resolving this issue in the United States, the IOM committee sought a conceptual and empirical base for its definition that would have face validity to cancer patients and oncology practitioners and arrived at the following definition:

Psychosocial health services are psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health. (p. 359-360)

The authors further noted that:

this definition uses the wording “psychosocial *health* services” to make clear that it refers to services that “enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological, social, and behavioral aspects of *illness*.” (p. 360)

In their discussion of the psychosocial needs and services to meet those needs, the IOM clearly considers psychosocial health needs and care to span the continuum from peer support through to the most specialized of services (see e.g. Adler & Page 2008, p. 364).

In our deliberation between 2007 and 2010 this issue has generated tremendous discussion and debate. The intent of the committee was to articulate psychosocial oncology as occurring on a continuum, acknowledging the contributions of peers and volunteers, the contributions of general health care professionals and oncology professionals through to the specialists in psychosocial oncology. Given the breadth of the psychosocial needs that are identified in the literature and the inclusion of “functional” aspects in our definition, we felt that “psychosocial health services” should be an umbrella term which would include those professionals that CAPO has previously defined as “supportive care,” such as rehabilitation specialists, dieticians and others. Two arguments supported this position: First, “psychosocial” aspects of cancer care are a focus and concern to many, if not all, health professionals and are not the unique domain of specialists in the field. Secondly, the original definition of psychosocial oncology would appear to include the full range of professionals who are committed to whole person care, care that goes beyond the necessary bio-medical interventions. This position would appear to have some support in the literature, including Howell et al (2009) and Adler & Page (2008) as two examples. Thus, the term psychosocial health services could be seen as an umbrella term within which specialists in psycho-social oncology provide one aspect of needed care, that which is specialized and required according to Fitch and colleagues (2008) by 15-50% of cancer patients. The other aspect of psychosocial health services would be supportive care and includes the care provided by nurses and physicians as part of whole person cancer care, as well as the work of other professionals such as rehabilitation specialists, physiotherapists, dieticians, speech language pathologists and others.

The second position that was considered was the idea that psychosocial oncology is the title that represents the work of specialists, those who provide counselling and mental health services as the primary focus of their work. This is the work of particular disciplines such as social workers, psychologists, spiritual care

professionals, psychiatrists and advanced practice nurses in psychiatry/mental health. From this point of view the umbrella term would be “supportive care” and those who were psychosocial oncology specialists would represent a specialist subset under the umbrella of supportive care.

The consensus position that the committee arrived at was to use the term psychosocial health services as the umbrella term and to consider that psychosocial oncology (specialist, mental health related practice) and supportive care (professionals such as rehabilitation specialists, dieticians as well as volunteers) were sub groups within this umbrella. The definitions that we arrived at are as follows:

Psychosocial Health Services address a range of psychosocial and supportive care needs of individuals and family members who are dealing with cancer. Psychosocial Health Services include the range of services that are provided by health professionals, including psychosocial oncology specialists, as well as non-professional peer support volunteers.

Psychosocial oncology is an interprofessional sub-specialty in oncology. The domain of psychosocial oncology includes the formal study, understanding and treatment of the social, practical, psychological, emotional, spiritual, quality of life and functional aspects of cancer as applied across the cancer trajectory from prevention through survivorship and bereavement. Professionals in this area seek to develop and integrate new knowledge and techniques of the psychosocial and biomedical sciences as they relate to cancer care. Psychosocial oncology specialists have education, clinical skills, and knowledge in psychotherapy and/or clinical counselling. Disciplines who commonly have this training include: social workers, psychologists, psychiatric/mental health APNs, psychiatrists, and spiritual care specialists.