
PALLIATIVE CARE NEEDS OF CANCER SURVIVORS

DENICE ECONOMOU

OBJECTIVES: *To describe the importance of early integration of palliative care into cancer survivor care. To discuss common symptoms experienced by cancer survivors and how integration of palliative care can improve management.*

DATA SOURCES: *Peer-reviewed literature, Clinical Practice Guidelines for Quality Palliative Care, Institute of Medicine report: From Cancer Patient to Cancer Survivor-Lost in Transition.*

CONCLUSION: *Primary symptoms may vary depending on disease, age, treatment, and other comorbidities. A multidisciplinary palliative care team can help manage the primary late effects for cancer survivors including fatigue, depressive symptoms, anxiety and distress, pain, and sleep disturbance.*

IMPLICATIONS FOR NURSING PRACTICE: *The long-term and late effects of cancer survivors will best be provided for by knowledgeable nurses who can anticipate and integrate palliative care into survivorship care early in their treatment plan.*

KEY WORDS: *Cancer survivor, palliative care, late effects, long-term effects, multidisciplinary care*

AS the numbers of cancer survivors continue to increase in the United States, providing optimal care will be challenging. Currently there are 14 million cancer survivors. Recognizing the long-term and late effects of cancer and its treatment, as well as the multiple comorbidities associated with aging, will require knowledgeable nurses and multidisciplinary care to anticipate and meet the needs of this population. This article will describe

ways to integrate survivorship care with palliative care.

Survivors are defined as any patient who has been diagnosed with cancer and continues throughout their lifespan. Survivorship care was first recognized as an essential need for cancer survivors in 1986 with the establishment of the National Coalition of Cancer Survivors (NCCS).¹ The Office of Cancer Survivorship (OCS) was established by the National Cancer Institute (NCI)

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in 1996.² One of the most important reports to establish the components of survivorship care and to define the essential care needs for survivors was the Institute of Medicine (IOM) report “From Cancer Patient to Cancer Survivor: Lost in Transition.” (Fig. 1).³⁻⁵ The recommended components of survivorship care in the IOM report include communication and coordination of care, prevention and detection of recurrence or new cancers, surveillance for cancer recurrence, and assessment and management of long-term and late effects of cancer.

Deficits in survivorship care include anticipating potential effects and management of late and long-term side effects associated with cancer and/or its treatment. Communication of survivors’ needs between oncologists, primary care physicians, nurses, patients, and caregivers is essential to the quality of care provided to survivors.⁶ Anticipation of potential effects as well as managing long-term effects involves multidisciplinary care. This type of multidisciplinary management of symptoms is a key aspect in palliative care as well as survivorship care, especially during the post treatment phase of care.⁷ There is an intersection of domains and components of palliative and survivorship care where resources can be shared (Table 1).

Palliative care has become a standard for the provision of quality cancer care in the US.⁸ Palliative care as defined by the National Quality Forum includes the focus of optimizing quality of life by anticipating, preventing, and treating suffering. Recent research has shown the significant differ-

ence that palliative care management makes for patients with advanced disease and those at the end of life.⁹ Additionally, palliative care interventions can improve quality of life across the cancer trajectory including cancer survivors at any age or stage of disease.¹⁰

Cancer survivors face many potential negative effects related to their disease or treatment.^{11,12} Many survivors do not receive the baseline care necessary for general surveillance, such as cholesterol monitoring or preventative care.¹³ Major side effects related to tumor site or type of cancer treatments can be anticipated and managed when knowledgeable providers are delivering oversight and care to cancer survivors. Primary long-term side effects identified in the literature include physical symptoms such as pain, neuropathy, lymphedema, urinary tract symptoms, colorectal symptoms, sexual dysfunction, infertility, and chronic fatigue. Psychosocial symptoms, such as anxiety and depression, distress, cognitive changes, fear of recurrence, and effects on family and work function, are experienced by survivors.^{11,14-16} Working together, multidisciplinary management of survivor’s symptoms can be efficiently and effectively improved.

PALLIATIVE SYMPTOM MANAGEMENT

The challenge to providing essential survivorship care is the integration between survivorship and palliative care. Griffith et al⁷ described a framework for the integration of palliative and

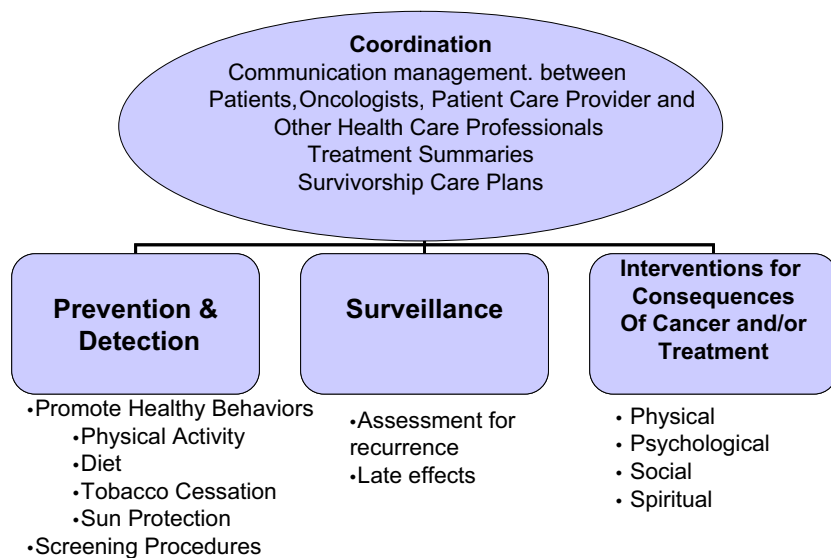


FIGURE 1. Essential elements of survivorship care. (Reprinted with permission. © 2010 by Oncology Nursing Society.⁵)

TABLE 1.
Overlap of Survivorship Care and the Domains of Palliative Care

Domains of Palliative Care	Components of Survivorship Care			
	Prevention/Detection	Surveillance	Interventions	Communication
Structure and process of care				X
Physical aspects of care			X	X
Psychosocial and spiritual			X	X
Cultural aspects of care				X
Imminently dying patient				X
Ethical and legal aspects			X	

survivorship care. Although the multitude of symptoms that can be experienced by survivors post treatment may vary depending on the specific disease and treatment, the symptoms that affect most survivors long-term regardless of their disease type are fatigue, depressive symptoms, anxiety, pain, and insomnia.^{11,17} These five symptoms experienced by the majority of cancer survivors are discussed in relation to how palliative care and survivorship care can be integrated to manage these effects.

Fatigue

Chronic fatigue is a recognized side effect associated with certain tumor sites like breast, lung, prostate, gastrointestinal (GI), and hematologic cancers.¹⁶ Multiple factors in cancer survivors

contribute to the experience of fatigue. Hormonal changes, sleep disturbance, decreased blood counts, pro-inflammatory cytokines, and normal aging all contribute to the experience of chronic fatigue.^{16,18} The cumulative effect of multiple factors, such as disease-related and psychosocial factors like anxiety, depression, pain, anemia, and sleep deprivation, can result in the experience of fatigue in the cancer survivor.^{16,19} Recent research has evaluated a syndrome called *Sickness Syndrome* that includes both depression and fatigue. Activation of pro-inflammatory cytokines by distress related to cancer and treatment has been implicated as leading to this syndrome.^{18,20} Multiple mechanisms may be contributing to the end product of depression and fatigue but new research is exploring the impact of

TABLE 2.
Resources for Major Five Symptoms of Cancer Survivors

Symptoms	Resources
Fatigue	http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf http://www.nccn.org/professionals/physician_gls/pdf/fatigue.pdf http://www.asco.org/screening-assessment-and-management-fatigue-adult-survivors-cancer-american-society-clinical
Depression/anxiety	http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf http://www.asco.org/screening-assessment-and-care-anxiety-and-depressive-symptoms-adults-cancer-american-society
Distress	http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf
Pain	http://www.nccn.org/professionals/physician_gls/pdf/pain.pdf http://www.asco.org/prevention-and-management-chemotherapy-induced-peripheral-neuropathy-survivors-adult-cancers
Sleep dysfunction	http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf
General	http://www.nationalconsensusproject.org/guideline.pdf www.acor.org www.cancer.org www.cancercontrolplanet.cancer.gov http://cancercontrol.cancer.gov/ocs/

reducing these pro-inflammatory cytokines, thereby reducing these distressing symptoms in the cancer survivor.²⁰ Fatigue management, as in pain management, requires multidisciplinary and multimodal interventions. The National Comprehensive Cancer Network (NCCN) survivorship guidelines, which were recently incorporated into the American Society of Clinical Oncology (ASCO) guidelines, recommend including pharmacologic and non-pharmacologic strategies and describe how healthcare providers can help cancer survivors conserve energy and improve quality of life.^{21,22} Chronic fatigue management lies strongly in the domains of palliative care and includes physical, psychological, social and spiritual aspects.

The Clinical Practice Guidelines for Quality Palliative Care, the NCCN Survivorship Guidelines, and recently the ASCO Fatigue Guidelines describe the need for screening, assessment, and management of fatigue in the adult cancer survivor. Palliative care includes a coordination of pharmacologic and non-pharmacologic interventions necessary to help manage fatigue and improve quality of life.^{8,23}

More research is needed in methods to manage chronic fatigue where psychological interventions and activity-based interventions are measured in a comparative manner.^{24,25}

Depressive Symptoms, Anxiety, and Distress

Psychological distress includes symptoms such as depression and anxiety. In cancer survivors, psychological distress may range in prevalence from 0% to 44%.^{11,15,26} The long-term experience of these symptoms has significant implications for the necessity of assessment and regular follow-up with cancer survivors. The variability of these symptoms can be related to age, socioeconomic status, disease stage, and multiple other symptoms occurring simultaneously.^{15,27,28} Jarrett et al,¹⁵ in a review of psychological and social problems experienced by cancer survivors, found moderate evidence that younger patients, patients with multiple physical symptoms, and those with advanced disease were more likely to experience depression than the general public. Awareness of these symptoms is the first step toward making a difference in the survivors' long-term symptom experience. Palliative care interventions include assessment with quantitative analysis tools, evaluation of additional comorbidities that contribute

to fatigue (such as cardiac, pulmonary, and renal disease), unrelieved pain, sleep disturbance, and nutritional issues or deconditioning.^{17,18}

Psychological and social symptoms related to cancer survivors benefit from the palliative care model. The IOM report from 2008¹⁰ and NCCN Survivorship guidelines²¹ recommend the identification of psychosocial needs followed by developing and implementing an interdisciplinary plan for referral of survivors to appropriate support, follow-up, and re-evaluation. As described in the palliative care domains of psychological and social, the inclusion of screening, assessment (including comorbidities, pharmacologic and non-pharmacologic interventions for anxiety and depression) display the integration of care defined as *palliative care* based on the best available evidence to maximize patient and family coping and quality of life.^{10,21}

Pain

Pain has been recognized in 14% to 100% of cancer survivors, depending on the point of their treatment and disease type.²⁹ Long-term effects of peripheral neuropathy post-neurotoxic chemotherapy affects 20% to 40% of cancer survivors.³⁰ Chronic pain syndromes related to other treatments such as surgery, radiation, or stem cell transplant can include chest pain or tightness, cystitis, dry burning eyes, oral pain and xerostomia, arthralgia's and myalgia's, chronic graft versus host disease (GVHD), bone pain, and dyspareunia.³¹ In a secondary analysis conducted by Mao et al,¹¹ symptom burden was examined between survivors and the general public without cancer. Through interviews performed in 2002 by the National Health Interview Survey (NHIS), statistics were evaluated on 1,904 cancer survivors and 29,092 controls. Recurrent symptoms were significantly higher than the controls for pain (34%), psychological distress (26%), and insomnia (30%).^{11,32} Managing pain appropriately requires the use of pharmacologic and non-pharmacologic medications and following evidenced-based guidelines. An example of appropriate care for the treatment of chemotherapy-induced peripheral neuropathy (CIPN) is based on the pathophysiologic mechanism behind CIPN and using serotonin and norepinephrine reuptake inhibitors.^{30,33} The NCCN Cancer Pain guidelines, the NCCN Survivorship guidelines, and recently the ASCO guidelines for management of CIPN describe the evidence associated with managing CIPN.^{21,34,35} Although the

standard management strategies used at this time to manage CIPN are not strongly associated with CIPN, and are related largely to neuropathy research from other sources (such as diabetic neuropathy), they remain the standard of care.³³⁻³⁵ New research in the area of chronic neuropathic pain management has shown that the use of duloxetine after 5 weeks for the treatment of CIPN decreased pain greater than placebo.^{30,33} Difficulty in managing pain is a key example of the importance of integrating the multimodal/multidisciplinary aspects of a palliative care team. Managing different sources of pain continues to be a challenge for cancer survivors because pain often becomes chronic and early recognition and management is essential to prevent greater severity and reduction in quality of life.

Sleep Disturbance/Insomnia

Insomnia in cancer survivors occurs in 30% to 59% of patients at different times over the course of their disease.^{14,36,37} In breast cancer survivors 2 and 5 years post diagnosis, 14% reported sleep disturbance.¹⁷ For prostate cancer patients, insomnia affected up to 40% as late as 2 years post treatment.¹⁷ Managing sleep disturbances starts with assessing patients for symptoms that may be interfering with their ability to rest or sleep. Helping patients with good sleep hygiene interventions is important. Managing pain and depressive symptoms such as sadness and anxiety can be initial steps toward improving sleep. The NCCN Survivorship Guidelines include specific guidelines for sleep disorders. In addition to standard recommendations for promoting good sleep hygiene, the guidelines also include cognitive behavioral treatments such as cognitive therapy, relaxation training, and stimulus control, in addition to pharmacologic recommendations.³⁶

As the survivorship population increases, the need for follow-up of additional diagnoses will grow as well. Management of late and long-term effects will benefit from the expertise of the palliative care team. Integration of palliative care and survivorship

care continues to be a challenge, but clearly the shared focus of multidisciplinary teams providing the most efficient care to this complex population of patients of a variety of cancer diagnosis and the addition of multiple comorbidities requires the advanced skills of a coordinated palliative/survivorship focused model of care. Resources for symptom management found in [Table 2](#).

RESEARCH IMPLICATIONS

These major symptoms experienced by a majority of cancer survivors, regardless of their diagnosis, can occur singly or as a cluster where they may relate to one another and significantly impact the quality of life cancer survivors experience long after their treatments are completed. But depending on the specific disease, treatments, age, and comorbidities, these patients may be experiencing many more cumulative symptoms. Clinical practice guidelines were developed to help provide consistent standards of care and support continuity and coordination of palliative and survivorship care. Integration of palliative care with survivorship care can provide robust assessment and management of symptoms, provide access to resources, and make referrals to other specialists as needed. Coordination of this care and communication among oncologists, palliative care professionals, and primary care practitioners is needed. Continuing work to provide coordinated care and communication through treatment summaries and survivorship care plans that integrate palliative care with the follow-up care post treatment is needed.²⁴ Continued research focused on symptom management in long-term cancer survivors is needed and will continue to provide evidence of late and long-term effects of cancer and cancer treatment that fit well with integration of palliative care with survivorship care.^{11,14,17}

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