

# CJON BOOK EXCERPT SERIES

# Survivorship

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This excerpt, chapter 10 from the book *Site-Specific Cancer Series: Head and Neck Cancer*, edited by Linda K. Clarke, MS, RN, CORLN, and Mary Jo Dropkin, PhD, RN, is part of a series of clinically relevant reprints that appear periodically in the *Clinical Journal of Oncology Nursing*.

*There is no profit in curing the body, if in the process we destroy the soul.*

Inscription on the Gate  
City of Hope National Medical Center  
Duarte, California

## Introduction

Cancer survivorship begins when the person receiving the diagnosis hears what was told and reaches out for information, a treatment plan, and hope. The National Coalition for Cancer Survivorship (2004) defines a cancer survivor as “any individual that has been diagnosed with cancer, from the time of discovery and for the balance of life.” An estimated 9.6 million survivors of cancer in the United States were alive in January 2000, and the overall five-year survival rate is 64% (American Cancer Society, 2005). This survival rate varies by the site, size, cell type, stage of cancer, and the time interval from detection to the start of treatment.

At the milestone of completing cancer treatment, the survivor once again faces untravelled ground and unknown expectations. The process and work of survivorship outcomes require expanded knowledge and roles for the oncology nurse and increased research to support intervention. Many survivors experience psychosociophysiology and financial challenges, treatment effects, and lengthy rehabilitation. The loss of speech and learning a new method of communicating can be costly as well as cause an alteration in lifestyle. Disfigurement related to anatomic changes after surgical procedures may lead to coping issues and result in avoidance of social activities. For others, efforts must focus on maintaining quality of life during palliative care.

Prior to the 1990s, little nursing literature used the term *survivorship* as it related to cancer care. That body of knowledge has significantly increased. The National Cancer Policy Board and Institute of Medicine commissioned Ferrell, Virani, Smith, and Juarez (2003) to examine the role of oncology nurses in caring for the cancer survivor. The outcome was a review of existing oncology nursing standards, textbooks, research-based articles, nursing education, certification, and professional organizations that addressed issues of the cancer survivor, the caregiver, and the nurse. The data gathered from this work set a framework for the future (see Figure 10-1).

To understand the evolution of the current state of care for the cancer survivor, a look at early survivorship concepts is helpful. Leigh (1992) related survivorship to a model of time intervals and

### Conclusions and Recommendations: Role of Oncology Nursing to Ensure Quality Care for Cancer Survivors

1. Increase the focus by the Oncology Nursing Society (ONS) and other professional nursing groups on survivors and survivor issues.
2. Increase support for oncology specialty education within graduate programs, including the full spectrum of the cancer experience.
3. Evaluate and support oncology content in curricula, with emphasis on survivorship, which has received minimal attention in general oncology graduate programs.
4. Promote certification in oncology nursing through the OCN® and AOCN® examination process.
5. Explore opportunities to integrate survivorship content in basic nursing education (baccalaureate and associate degree) programs.
6. Increase support for oncology nursing research in survivorship, including
  - Support for expanded pilot funding through the National Institute of Nursing Research, ONS, and the ONS Foundation
  - Targeted research for areas not addressed in current research.
7. Support extensive continuing education for clinical nurses regarding survivorship because of the limited exposure in this area of undergraduate education.
8. Explore opportunities for nursing research in cancer survivorship in conjunction with clinical trials and cooperative groups.

### Figure 10-1. Role of Oncology Nurses in Survivorship

*Note.* From “The Role of Oncology Nursing to Ensure Quality Care for Cancer Survivors: A Report Commissioned by the National Cancer Policy Board and Institute of Medicine,” by B.R. Ferrell, R. Virani, S. Smith, and G. Juarez, 2003, *Oncology Nursing Forum*, 30. Retrieved March 16, 2005, from <http://www.ons.org/publications/journals/ONF/Volume30/Issue1/300132.asp>. Copyright 2003 by the Oncology Nursing Society. Reprinted with permission.

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identified three stages: acute, extended, and permanent. During each stage, Leigh identified needs and applied the nursing process for care. Her work in 1998 further developed the model of time and increased the understanding of patients' psychosocial needs. In 2001, Leigh described the culture of cancer survivorship (see Table 10-1).

Previous chapters in this book describe the management of patient care during treatment of the primary head and neck cancer. During survivorship, this management continues; however, the foci may change. The survivor faces issues of determining the meaning of and obtaining and keeping quality of life. The survivor's perceptions of quality of life and the process to maintain it have been aided by family and friends, healthcare providers, and self-determination (Mellon, 2002). Oncology nurses have been paramount in identifying and defining the issues of cancer survivorship. Concerns include physiologic and psychosocial changes, late effects of treatment, short- and long-term complications, rehabilitation, fear of recurrence, economic burdens, spiritual effects, and palliative and end-of-life decisions (Dow, Ferrell, Haberman, & Eaton, 1999; Ganz, 2001; Leigh, 1992, 1998, 2001; O'Connor, Wicker, & Germino, 1990; Rowland, Aziz, Tesaro, & Fever, 2001; Zebrack, 2000, 2002).

Mellon (2002) explored the effects of cancer survivorship on family members. Finding positive meaning during survivorship helped to increase quality of life for survivors and families. Fear of recurrence became a chronic stressor but was lessened with genetic histories, early detection by monitoring exams, and expedient symptom management. Findings also suggested that existing strengths and styles of family communication could alter negative meaning and enhance quality of life. Nursing assessment in identification of these effects was critical to intervention for the process of survivorship.

Aziz and Rowland (2002) studied differences in cancer survivorship among ethnic minorities and the medically underserved. The American Cancer Society has reported survival rate statistics for minorities since 1974. Trends continue to define ethnic groups as having lower overall survival rates than Caucasian Americans. The authors noted that ethnic groups demonstrated issues related to past experiences, social mores, and cultural beliefs. These issues may affect coping, health behaviors, and use of resources differently than Caucasian American survivors. Education, access to care, and resources may be economically unavailable and/or the educational process nonexistent. Higher risks for second

cancers may result from poorer health or behaviors that increase risk for cancer.

Cancer recurrences and second primaries, unfortunately, are not uncommon. The survivor lives with this fear daily (Leigh, 1998). When conventional therapy has not controlled the cancer, end-of-life decisions must be considered. Different approaches for care, comfort, and understanding are necessary to provide supportive care. Supportive care encompasses many meanings. When applied to curative therapy, it may be interpreted as care to augment the existing prescribed therapy. When used in the domain of palliative care, it is described as care to promote comfort without prolonging or hastening death (Prochoda & Seligman, 1997).

## Survival Rates

Cancers of the head and neck remain as some of the most feared diseases. The cancer, treatment sequelae, and limitations of rehabilitation may significantly alter the survivor's lifestyle. Changes in body image, breathing, swallowing, and communicating may become disabilities. Rehabilitation and management of the changes may present many challenges to the survivor and the family. In addition to these obstacles, the patient faces survival statistics that can create continued fear of recurrence and death. Head and neck cancer survival rates are less than the overall average of 63% (see Table 10-2).

## Rehabilitation

In the textbook *Essentials of Head and Neck Oncology* (Close, Larson, & Shah, 1998), several chapters discuss the analysis of rehabilitation. Rehabilitation is categorized as functional, prosthetic, and psychosocial. Functional rehabilitation focuses on speech, swallowing, shoulder motion, and facial nerve activity. Prosthetic rehabilitation provides devices to assist with oral cavity defects (obturators) or cosmesis (nose, eye, and ear prostheses). Psychosocial rehabilitation deals with coping mechanisms to adjust to physical and functional changes that may alter the survivor's lifestyle. Each of these types of rehabilitation presents opportunities for oncology nurses and a multidisciplinary and highly specialized care team. Research studies continue to explore the impact of cancer treatment on the survivor in regard to depression, pain, difficulties with social functioning and role, swallowing, speech, dry mouth, body image, presence of indwelling body

**Table 10-1. The Culture of Cancer Survivorship**

STAGE	TIME FRAME	FACING/COPING	NEEDS	CULTURE
Acute	Diagnosis through care	Fear, losses Acute side effects of therapy	Acute care Management Education	Erroneous information, myths Language barriers
Extended	End of initial treatment	Adjusting to compromises	Rehabilitation Support	Lack of understanding
Permanent	Remission Potentially cured	Adaptation Long-term/late effects of therapy	Insurance/financial security; managing late effects of treatment	Conflicting attitudes, beliefs, values

*Note.* Based on information from Leigh, 2001.

**Table 10-2. Head and Neck Cancer Relative Five-Year Survival Rates**

SITE	ALL STAGES %	LOCAL %	REGIONAL %	DISTANT %
Hypopharynx	35–40	—	—	—
Larynx	64.7	82.6	47.9	20.0
Oral cavity	58.7	81.0	50.7	29.5
Thyroid	95.8	99.3	95.5	59.9

*Note.* Based on information from American Cancer Society, 2005; Gray & O'Malley, 2001.

tubes, shoulder function, substance abuse, and nutrition (Clarke, 1998; Dropkin, 1999; Fritz, 2001; Hanna et al., 2004; Pytynia et al., 2004; Taylor et al., 2004; Terrell et al., 2004).

Other characteristics of head and neck cancer survival have been studied. In the Terrell et al. (2004) study, survivors of head and neck cancer listed the presence of a feeding tube, medical comorbidities, the presence of a tracheostomy tube, chemotherapy, and neck dissections as predictors for quality of life. In this study, the two highest predictors were comorbidities and a feeding tube. Taylor et al. (2004) found that survivors who had undergone chemotherapy alone were 3.5 times more likely to have disabilities than those who did not receive chemotherapy. Those undergoing neck dissections had twice the chance of disability compared to survivors who did not have a neck dissection. Pain increased the odds of disability by 20%. Radiation therapy effects matched the disabilities of stage III or IV disease. However, disabilities decrease by 10% each decade of survival.

## Costs

The cost of quality cancer care also may require that the survivor reestablish economic stability and, therefore, undergo financial rehabilitation. Brown, Riley, Schussler, and Etzioni (2002) used SEER-Medicare data to estimate cancer costs. Using the value of a dollar in 1996, head and neck cancer cost \$1.6 billion. The cost included expenses for diagnostic testing, hospitalization for surgery and chemotherapy, and standard radiation treatment. This equated to 4% of all cancer costs. The average Medicare payment per individual with head and neck cancer was \$14,788. Head and neck cancer was listed as one of the 13 most common cancers, and 3.3% of all cancer costs were spent on patients with new head and neck cancers.

The cost of treatment correlates to the location, stage, and treatment modalities for the specific cancer. Cost of survivorship relates to the management of treatment side effects and rehabilitation of disabilities. This economic burden can be measured in direct and indirect costs (Terrell & Wilkins, 1998). Direct costs include monies needed for institutional and professional fees, medications, and durable medical equipment. Lang, Menzin, Earle, Jacobson, and Hsu (2004) used 1991–1993 SEER data to evaluate Medicare expenditures for older beneficiaries having newly diagnosed squamous cell cancer of the head and neck. A retrospective analysis of Medicare costs for initial treatments consisting of surgery and/or radiation and some chemotherapy was compared to a control group with no such diagnosis. The monies were converted to 1998 dollars, and the study found that Medicare payments would be three times higher than the control group payments. Statistics for advanced squamous cell

cancer demonstrated higher costs as well. This suggested that the financial burden for squamous cell cancer of the head and neck may be higher than for other tumors.

## Insurance

Health insurance is important to all cancer survivors. DeNavas-Walt, Proctor, and Mills (2004) reported that in 2003, an estimated 45 million people, or 15.6% of the population, did not have health insurance. Government-covered health insurance programs Medicaid and Medicare insured 35.6 million people (12.4%) and 39.5 million people (13.7%), respectively.

For the survivor of head and neck cancer engaged in functional, prosthetic, psychosocial, and economic rehabilitation, understanding and dealing with insurance policies, inquiries, and disclosures may become overwhelming. To offset company costs, insurance providers may discriminate against the survivors by raising premiums or may set time intervals before covering medical expenses. Insurance and care case managers, financial counselors, and advocacy groups may provide assistance (see Table 10-3).

**Table 10-3. Community Economic Rehabilitation Resources (Limited List)**

RESOURCE	CONTACT INFORMATION
<b>Financial</b>	
CancerCare, Inc.	www.cancer.org 800-813-4673
National Foundation for Credit Counseling	www.nfcc.org 800-388-2227
National Cancer Institute cancer information	www.cancer.gov 800-422-6237
OncoLink	www.oncolink.org
Pharmaceutical Research and Manufacturers of America—drug assistance	www.phrma.org 202-835-3400
<b>Insurance</b>	
American Cancer Society—insurance explanations	www.cancer.org 800-ACS-2345
America's Health Insurance Plans	www.ahip.org 202-778-3200
National Council on the Aging	www.ncoa.org 202-479-1200

Employment

Leigh and Thaler-DeMers (1997) found that 25% of cancer survivors experienced various types of employment discrimination. Methods of discrimination were identified as not being hired; being selected for a layoff; demotion; duty changes; failure to receive promotions or financial merit raises; and being perceived as unproductive workers. Taylor et al. (2004) found that 52% of the survivors of head and neck cancer studied were unable to return to work because of cancer treatment disabilities. Laws exist to prevent this type of discrimination, and advocacy groups continue to support this protection (see Table 10-4).

Support Groups

Support systems throughout the continuum of the head and neck cancer journey provide added opportunities for the survivor, family, and nursing staff. Building networks with others in the same situations creates new strengths for coping strategies and sets ideas about benchmarking for positive outcomes. Being able to talk to another about the similarities and differences of the individual's case helps to reinforce self-confidence and motivation.

Klemm and Hardie (2002) studied a common concern in survivorship—depression. They compared the traditional face-to-face support group method to the use of an Internet support group (contemporary). Previous literature supported the value and success of the face-to-face method, but little research existed regarding outcomes of Internet support groups. A reliable and validated depression scale was used. Although variables existed among the participants, such as demographics, treatment phase, and beliefs about terminal status, only the treatment phase was significant to the level of depression. The Internet group had significantly higher depression scores than

the face-to-face support group participants. The generation now surviving cancer is more Internet savvy and comfortable using the Internet as a resource.

This may require considerable rethinking for the oncology nurse in assessment and delivery of interventions for support. Nurses are instrumental in establishing support groups. The teaching and coordination skills of nurses promote partnering of survivors, other healthcare providers, social services, and community leaders to pool resources for support group development. Table 10-5 lists Internet and community resources for survivor support.

Palliative Care

Recurrence and/or second primaries are common in cancer of the head and neck. The recurrence rate is 25%–28%, and the risk of a second primary per year is 3%–7% (Stack & Weymuller, 1998). Additionally, some stage III and IV cancers are incurable at the time of presentation. For these patients, the best supportive care may be palliative symptom management and assistance with end-of-life decisions.

The survivor is once again thrown into decisional conflict while reclarifying values, seeking possible additional treatment options, or coping with unpleasant symptoms of disease progression. The fear of recurrence becomes a reality, and the survivor once again must find strength to withstand the reevaluation of the situation, a new plan, and an amended outcome. Most likely, the psychosocial and physiologic changes will require additional care strategies.

In the patient with head and neck cancer, symptoms that require treatment are anorexia, dysphagia, airway management, and pain (Stack & Weymuller, 1998). Comfort and safety measures often must be creative and intense. Invasive tumors may cause wounds that are challenging because of bleeding, odor, or infection. McMillan and Weitzner (2000) found that

Table 10-4. Community Legal Rights and Advocacy Groups (Limited List)

LAW	PURPOSE	DETAILS
Consolidated Omnibus Budget Reconciliation Act (COBRA), 1986	Continues insurance	Must request within 60 days of leaving workplace
Health Insurance Portability and Accountability Act (HIPAA), 1996	Ensures insurance portability and accountability	Protects from denial of insurance based on preexisting health problems and sets guidelines for waiting period of coverage when changing employer group insurance
Family and Medical Leave Act (FMLA), 1993	Allows family and medical leaves	Provides up to 12 weeks of job-protected leave
Americans With Disabilities Act (ADA), 1990	Protects Americans with disabilities	Helps to prevent discrimination for disabilities and provides accommodations
ADVOCACY RESOURCE		CONTACT INFORMATION
American Cancer Society		www.cancer.org 800-ACS-2345
National Coalition for Cancer Survivorship		www.canceradvocacy.org 877-622-7937
Patient Advocate Foundation		www.patientadvocate.org 800-532-5274



dyspnea and constipation were, in addition to pain, the most troubling symptoms in patients receiving hospice care. The combination of these symptoms may cause the acuity of care to become too burdensome for the family. Patients and families therefore may need assistance in the home to manage care. Home health agencies and hospices have become invaluable in supervising care, providing durable medical equipment, and coordinating the multidisciplinary team to meet the needs of the patient.

Additionally, support systems for family and patient, such as volunteer sitters, shopper services, housekeeping, transportation, and grief and bereavement counseling, are available through most hospice agencies. Some hospices have inpatient facilities that offer respite services.

Reb (2003) published a comprehensive policy analysis on palliative and end-of-life care. The study reviewed multiple care settings, legislative protection and activities, quality standards, costs, nursing roles, and education. The author concluded that integrating palliative care throughout the course of illness could provide improved symptom management, quality of life, and continuity of care along with referrals to hospices in a more timely manner. Resources for palliative care and end-of-life decisions are listed in Table 10-6.

**Table 10-5. Support Resources for Survivors of Head and Neck Cancer**

SUPPORT RESOURCE	CONTACT INFORMATION
American Cancer Society	www.cancer.org 800-ACS-2345
American Academy of Otolaryngology—Head and Neck Surgery	www.entnet.org 703-836-4444
Cancer Survivors Online	www.cancersurvivors.org
Coalition of National Cancer Cooperative Groups CancerQuilt	www.cancertrialshelp.org/cancerQuilt
International Association of Laryngectomees	www.larynxlink.com
Let's Face It—Resources for patients with facial differences	www.faceit.org 360-676-7325
Oncology Nursing Society	www.ons.org 866-257-4667
Oncology Nursing Society's resource on cancer symptoms	www.cancersymptoms.org
Society of Otorhinolaryngology and Head-Neck Nurses, Inc.	www.sohnurse.com 386-428-1695
Support for People with Oral and Head and Neck Cancer	www.spohnc.org 800-377-0928
Tobacco information and support links	www.tobacco.org
WebWhispers—Support for laryngectomees	www.webwhispers.org
Yul Brynner Head and Neck Cancer Foundation	www.headandneck.org 843-792-6624

**Table 10-6. Resources for Palliative Care and End-of-Life Decisions**

ORGANIZATION	WEB SITE
Center to Advance Palliative Care	www.capcmssm.org
International Association for Hospice and Palliative Care	www.hospicecare.com
National Hospice and Palliative Care Organization	www.nhpco.org

## Summary

Throughout this book, nursing care has been addressed. When relating it to a survivor of head and neck cancer, it seems appropriate to correlate nursing care with Leigh's (1992) model. The acute stage of survivorship is the assessment process. It is the proving ground for the novice of the disease to learn of his or her needs and abilities to understand what the challenge is. The nursing staff provides, directs, and demonstrates immediate care, which formulates the beginning of rehabilitation. The extended stage relates to the intermediate survivor who accepts the challenge to demand excellence in rehabilitation. The third stage, permanency, holds the expert strategist who has regained function and confidence and whose life is near normal. Maslow's concept of self-actualization (as cited in Volker, 1992) has returned. The survivor now can give back to others. Yet even with this gained self-confidence, the fear of cancer recurrence remains. To that end, the nurse remains the instiller of hope.

The nurse serves as the teacher, mentor, facilitator, validator, supporter, and evaluator and, with the rest of the team, coordinates the journey. Every tool and intervention known to nursing is used when and where required. At the completion of the task, whether it be a complete cure and recovery or the finality of death, the outcome is the same: one caring spirit who is there to help another to survive.

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