Pain in Long Term Survivors of Cancer:
Every Nurse’s Responsibility

2010

Carol P. Curtiss, MSN, RN-BC
Curtiss Consulting 73 James St. Greenfield, MA 01301
carol.curtiss@verizon.net 413-774-5238

Today’s Focus

1. Survivors of **ADULT** cancers
2. Common sequelae and pain syndromes associated with long term survival
3. Strategies to manage sequelae of cancer & cancer treatment
4. Resources for enhancing survivorship care

Defining a Cancer Survivor…?

- Individuals who are more than 5 years beyond diagnosis (Mullan)
- Anyone from diagnosis through the balance of life (NCCS)
- Including family and friends (NCI)
- Individuals who have completed treatment and are in remission ?????
- What about those surviving with active disease?
Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility
2010

The Good News...

- In the U.S., survivors of cancer are a growing minority population
  - 67% of adults diagnosed with cancer can expect to be alive in five years
  - 75% of pediatric cancer survivors will be alive after 10 years

Nearly 12 Million Survivors of Cancer in U.S.

- Nearly 12 million living who have had cancer diagnosis
- Widespread screening efforts have led to early diagnosis, better prognosis
- Advances in cancer treatment have improved survival
- Prolonged adjuvant therapies

Characteristics of the Current Survivors

Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

Today and the Future

- Cancer is a chronic disease for many
- Many live with disease for years, with or without treatment
- The needs of long term survivors of adult cancers are not clearly understood or met
- Few evidence based guidelines exist for health care of survivors of adult cancers

Survivor Issues & Unmet Needs

- Secondary health problems (53%)
  - 54% chronic pain
  - 33% infertility
- Non-medical support
  - 49% needs unmet
  - 53% practical & emotional consequences of cancer often harder than medical issues
- Emotional support
  - 70% deal with depression
  - 78% did not seek professional help

Survivor Issues & Unmet Needs (cont’d)

- Relationships
  - 58% dealt with loss of sexual desire &/or sexual function
- Financial problems
  - Decreased income (43%)
  - In debt from treatment (25%)
  - Turned down treatment option due to cost (12%)
- Job issues
  - Lack of advancement, demotion or job loss (32%)
  - Trapped in job to preserve health insurance (34%)
Looking forward...

- This population is growing in number
- Many long term consequences can be treated or managed, some can be prevented
- Majority of long term oncology care is from primary care providers in community settings

The Problems...

- We don’t really know much about what to do...
  - Incomplete or non-existent guidelines for long term survivors of most adult cancers
  - Lack of education for health care professionals
  - Lack of information about & for survivors of adult cancers
  - No national/international data base to follow long term survivors

Published Initiatives in the U.S.

- State of the Science Symposium on Nursing Approaches to Managing Late and Long Term Effects of Cancer and Cancer Treatment (The American Journal of Nursing, 2006)
- From Cancer Patient to Cancer Survivor: Lost in Transition (Institute of Medicine, 2006)
- Imperatives for quality cancer care: access, advocacy, action and accountability
  - National Coalition for Cancer Survivorship, 1996
- Living Beyond Cancer
  - Presidents Cancer Council, 2004
- National Cancer Institute Office of Cancer Survivorship
- American Cancer Society
- Oncology Nursing Society
- American Society of Clinical Oncology
Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

Selected Recommendations

• See cancer survivorship as a distinct phase of cancer trajectory & care
• Develop evidence-based clinical practice guidelines for long term follow-up care
• Create individual written summaries of care with a plan for follow-up and health promotion after completion of initial therapy (Survivor Care Plan)

The bottom line...

• Physiologic and psychosocial consequences of cancer and its treatment can be substantial and varied
  • Some experience few long term effects, others suffer permanent and disabling symptoms that impair normal function
• Once identified, sequelae can be prevented, treated or managed
• Survivor needs are often unmet
• Health care system does not address survivorship

Deb..
The real story

Carol P. Curtiss, MSN, RN-BC
©carol.curtiss@verizon.net
Examples: Long-term and Late Effects

Long-term Effects
- Prevalent early on but may resolve shortly thereafter
- Persist following acute care and become chronic problems

Late Effects
- Arise months, years after treatment

Examples
- Pain
- Treatment-related fatigue
- Cognitive impairment
- Skin sensitivity
- Congestive heart failure, neurological syndromes, secondary malignancies

Potential Physiologic Sequelae: Long Term Survivors of Adult Cancers
- Chronic pain/neuropathies
- Reproductive & hormonal changes
  - Osteoporosis
  - Menopause
  - Andropause
  - Thyroid changes
- Altered sexual function & infertility
- Impaired immune response
- 2nd malignancies

Potential Physiologic Sequelae (cont’d)
- Fatigue and sleep disturbances
- Hematologic changes
- Vital organ dysfunction
  - Cardiovascular
  - Pulmonary
  - Other organ & system dysfunction
- Oral mucosa changes
  - Decreased saliva
  - Dental caries

Pain in Long Term Survivors of Cancer: 
Every Nurse’s Responsibility 
2010

Potential Psychosocial Sequelae: 
Long Term Survivors of Adult Cancers

- Cognitive changes
- Family issues
- Psychological distress and coping
- Body image changes
- Depression
- Anxiety
- Changes in self-esteem
- Fear of recurrence

Potential Spiritual/Existential Sequelae: 
Long Term Survivors of Adult Cancers

- Renewed view of the meaning of life
- Changed view of self
- Changed view of place in the world/community/family
- Uncertainty
- Changes in religious values and beliefs
- Persistent suffering
- Dealing potentially life-threatening illness

It’s not over when treatment ends!

Carol P. Curtiss, MSN, RN-BC 
©carol.curtiss@verizon.net
Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

Note!

• Sequelae occur anytime from prediagnosis to many years after therapy
• Many either haven’t been told or did not remember being told
• Many did not make the connection between current health status and past cancer or cancer therapy


One Minute Screening

• “What was your treatment for cancer?”
• “Do you have or think you have any health problems related to your cancer or cancer treatment?”
• If “yes” or “I think so”, ask,
  • How are you managing the problem?
  • Would you like help dealing with it?

• Acknowledge person’s concerns
• Coordinate evaluation and management
• Refer if needed
• Identify local, written and electronic resources for long term survivors of cancer
Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

Carol P. Curtiss, MSN, RN-BC
carol.curtiss@verizon.net

Five Minute Screening

Instructions: First, circle the number 0 if no current pain or describe the pain as mild. Next, circle the number 1 if you have been experiencing pain for two or more years, or circle the number 2 if you have been experiencing pain for less than two years.

Quick Screening of Cancer Survivors for Pain

Have you had any pain or discomfort in the area where you had surgery or radiation therapy, or do you have pain or any unusual sensation from any other source, region, or place?

How much pain are you experiencing?

What does it feel like?

What makes it better or worse?

What measures do you take to alleviate pain?

Chronic Pain Syndromes

Post-Surgical Pain Syndromes

Post-mastectomy syndrome
Post-thoracotomy syndrome
Post-radical neck dissection pain
Post-amputation pain
Fistula formation
Lymphedema

Post-Radiation Pain Syndromes

Brachial or lumbosacral plexopathy
Myelopathy
Enteritis or proctitis
Lymphedema
Burning perineum syndrome
Osteoradionecrosis

Post-Chemo Pain Syndromes

Peripheral neuropathy with or without pain
Avascular necrosis of femoral or humeral head

Post mastectomy syndrome

- 20% women with mastectomy or lumpectomy
  - Burning, shooting, electric shock sensations in the skin around incision
  - More common among younger women & those who are overweight
- Treatment
  - Pharmacological, including adjuvants and topical capsaicin

Post thoracotomy syndrome

- 50-80% several months after thoracotomy
  - 30% may still have pain 4-5 years later
- Occurs along surgical scar, myofacial pain or frozen shoulder
- Prevention
  - Minimally invasive thoracotomy
  - Aggressive post-op pain management
  - Thoracic epidural analgesia with bupivacaine during surgery

Post-Amputation Pain

- Localized at site of amputation
- Referred ("phantom")
  - Neuropathic central pain
- 66% report phantom pain at 6 months
- Pharmacologic treatment
  - Antiepileptics, TCAs, NMDA receptor antagonists

Sources:
- Polomano & Farrar, AJN, 2006
Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

Pharmacologic Management of Neuropathic Pain

- Current practice: “trial and error”
- May only obtain a limited response:
  - 50% relief in about 50% of persons
- There may be advantages to combining two drugs

Evidence-based Recommendations for the Treatment of Neuropathic Pain

- First-line:
  - Tricyclic & SNRI antidepressants
  - Antiepileptics (calcium channel modulators),
  - Topical lidocaine
- Second-line:
  - Opioids and tramadol; these might be first-line in certain circumstances
- Third-line:
  - Mexiletine, NMDA-receptor antagonists, topical capsaicin

Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

The Evidence

- Hx and PE
- Psychosocial evaluation
- Appropriate diagnostics
- Individualized plan
- Multimodal interventions
  - Physical or restorative therapies
  - Cognitive behavioral therapies, biofeedback, relaxation training, group therapy and counseling
- Multi-modal interventions (cont’d)
  - Anticonvulsants, TCAs, SNRIs, opioids, NMDA receptor antagonists & topical agents as part of multimodal strategy for a variety of chronic pain conditions

EBP: Interventional therapies for neuropathic pain

- Cryoablation for selected patients
  - E.g.: peripheral nerve pain
  - Post-thoracotomy pain syndrome
- Subcutaneous peripheral nerve stimulation if no response to other therapy
- Conventional radiofrequency ablation for neck pain
- Celiac plexus blocks for chronic pancreatitis

Interventional (cont’d)

- TENS for neck and phantom limb pain
- Epidural steroid injections for radicular pain or radiculopathy
- Intrathecal preservative-free steroids for intractable post-herpetic neuralgia
- Peripheral somatic nerve blocks should not be used for long-term treatment of chronic pain
Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

Lymphedema

- Lifelong, chronic accumulation of lymph in interstitial space causing swelling
- Prevalence
  - 30% women with breast cancer; also with some prostate, ovarian, & abdominal cancer sites & elsewhere
- Issues
  - Pain, constant discomfort, body image issues, anxiety, depression, stigma, feeling handicapped
  - Time off from work (80% with lymphedema)
  - Affects employment status (9%)


Lymphedema Management (cont'd)

- Long term goals
  - Decrease swelling
  - Relieve symptom distress
  - Prevent acute exacerbations & infection
  - Provide psychosocial support

Lymphedema Management

- Early diagnosis is vital
- Risk reduction/management
  - Ideal body weight, healthy lifestyle
  - Normal exercise with gradual increase
  - Prevent infection
    - Maintain skin integrity
    - Avoid trauma/injury
  - Compression sleeve at first notice of swelling
  - Prophylactic anti-fungal powder & diabetic foot care for lower extremity lymphedema

National Lymphedema Network www.lymphnet.org
Managing Lymphedema (cont’d)

- Assess for signs of infection, degree of swelling, coping etc.
- Treatment options
  - Comprehensive decongestive physiotherapy
    - Manual drainage
    - Bandaging
    - + skin care/diet
    - Compression garments
    - Self-manual drainage
- Infection
  - Antibiotic therapy
  - Rest, elevation of affected limb, ↑ fluids
- Pain
  - Comprehensive assessment
  - Initiate plan appropriate to the type and intensity of pain

Lost in Transition:
Survivors of Adult Cancers

Essential Components of Survivorship Care

1) Prevention of recurrent and new cancers, and other late effects;
2) Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3) Intervention for consequences of cancer and its treatment;
4) Coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met.

From Cancer Patient to Cancer Survivor: Lost in Transition (IOM, 2006)
Pain in Long Term Survivors of Cancer:
Every Nurse’s Responsibility
2010

Why a Survivorship Care Plan?

1. Summarize & communicate what transpired during cancer treatment
2. Describe known & potential late effects with expected time course
3. Communicate to survivor and HCPs what has been done and what needs to be done
4. Promote a healthy lifestyle to reduce risk of recurrence & manage co-morbidities


“Prescription for Living”  AJN, April 2007

- Treatment summary
- Potential late and long term effects and what to do about them
- Screening and follow-up recommendations
- Prescription for wellness
  - Nutrition, optimum weight
  - Exercise
  - Health maintenance strategies
  - Smoking cessation
  - Other issues
Pain in Long Term Survivors of Cancer:
Every Nurse’s Responsibility
2010

Survivorship Care Plan Templates

- American Society of Clinical Oncology
  www.cancer.net/patient/Survivorship
- Lance Armstrong Foundation
  www.livestrong.org
- University of Pennsylvania
  www.oncolink.org/oncolife
- Other site-specific advocacy group web sites

YOU Can Help!

- See survivorship as a phase of cancer and cancer treatment
- Learn more about late effects and long term sequelae
  - Be on the lookout for them in your patients
- Ask for end of therapy treatment summaries and a written plan of care for follow-up
- Screen for late effects in anyone with a history of cancer to identify problems early
- Support wellness strategies
- Connect survivors with resources
- Establish systems to care for long term survivor needs
  - Education for HCPs
  - Survivor clinics


Cultural Differences

- Few studies have addressed the needs of survivors who are minorities or are medically underserved
- Adapt assessment to recognize and address the socioeconomic and cultural variables that affect adaptation to and survival from cancer among diverse groups

Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility 2010

Resources...

Nursing Approaches to Managing Late and Long Term Sequelae of Cancer & Cancer Therapy

American Journal of Nursing, National Coalition for Cancer Survivorship, American Cancer Society and others with a grant from AHRQ and other supporters

Cancer Survivors’ Tool Box

www.canceradvocacy.org

Health Insurance & Survivors

Carol P. Curtiss, MSN, RN-BC
carol.curtiss@verizon.net
Pain in Long Term Survivors of Cancer: Every Nurse’s Responsibility
2010

Employment Issues