

Oncology Nursing in Cancer Survivorship Care

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Puget Sound Oncology Nursing Society:
Fundamentals of Oncology Nursing
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Objectives

- Describe cancer survivorship definitions and prevalence.
- Discuss the unique health risks and needs of cancer survivors.
- Discuss Survivorship Clinics/Programs and Survivorship Care Plans and Treatment Summaries
- Awareness of possible issues addressed at a Survivorship visit
- Describe the role of oncology nurses in survivorship care.

Who is a Cancer Survivor?

From the National Coalition of Cancer Survivors (NCCS):

Anyone who has been diagnosed with cancer *from the time of cancer diagnosis*, through the balance of his or her life. Includes those dying from untreatable cancer.

Family members, friends, and caregivers are also impacted by the survivorship experience.

Cancer Survivorship



After a cancer diagnosis . . .

“Cancer may (or may not) leave your body, but it never leaves your life. It impacts mind, body and spirit. It is a family disease, even when familial genetics do not play a role; once you are diagnosed, it impacts all.”

-Therese Billings, breast cancer survivor

You may be “cancer-free” but not free of cancer!

Cancer Survivorship: Changing Times

- Cancer has become a curable disease for some and a chronic illness for others.
- Patients with terminal disease are also “survivors.”
- Patient needs go beyond surgery, chemo, radiation.
- Increasing survival poses *opportunities* for patients, family members, and the health care team.
- Changing medical economics: cost of medical care rising exponentially (not sustainable), development of Accountable Care organizations & Medical Home models.
- Emerging role for health professionals (e.g., **oncology nurses**, primary care, psychosocial support, Survivorship clinics/programs, etc.)

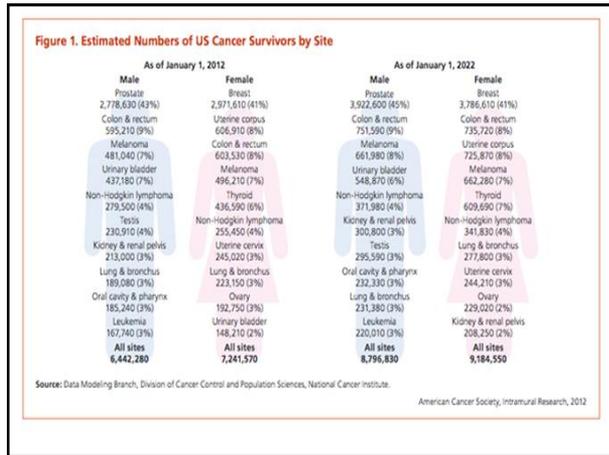
History of Survivorship Activities: Private & Government Sponsored

- 1986 - National Coalition for Cancer Survivorship
- 1988 – ACS: 1st Survivor’s Bill of Rights
- 1990 – National Breast Cancer Coalition
- 1997 – Office of Cancer Survivorship at NCI
- 1997 – Lance Armstrong Foundation
- 2004 – ASCO Survivorship Task Force
- **2006 – IOM Report on survivorship *From Cancer Patient to Cancer Survivor: Lost in Transition***
- 2007 – IOM Report on care for *whole patient*
- **2015 – COC: Survivorship component required. Also other accrediting groups (e.g., NAPBC, ASCO/QOPI)**

How many survivors are there?

- ◆ **15.5 million** cancer survivors in the United States in 2016
 - ◆ Does not include *in situ* of any site except the urinary bladder, and does not include basal cell and squamous cell skin cancers.
- ◆ By January 1, 2026, it is estimated that the population of cancer survivors will increase to 20.3 million: almost 10 million males and 10.3 million females

American Cancer Society (2016)



- ## Currently...
- 67% were diagnosed 5 or more years ago
 - 17% were diagnosed 20 or more years ago
 - 1 in 2 men and 1 in 3 women will be diagnosed with cancer in their lifetime
 - 47% of survivors are 70 or older
 - 11% under age 50
- American Cancer Society (2016)

Trends in Five-year Relative Survival Rates (%), 1975 - 2012

Site	1975-1977	1987-1989	2006-2012
All sites	49	55	69
Breast (female)	75	84	91
Colorectum	50	60	66
Leukemia	34	43	63
Lung & bronchus	12	13	19
Melanoma of the skin	82	88	93
Non-Hodgkin lymphoma	47	51	73
Ovary	36	38	46
Pancreas	3	4	9
Prostate	68	83	99
Urinary bladder	72	79	79

5-year relative survival rates based on patients diagnosed in the 9 oldest SEER registries from 1975-1977, 1987-1989, and 2006-2012, all followed through 2013.
Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2016

- ### Why is the number of people alive after diagnosis increasing?
- Earlier diagnosis through screening
 - More effective treatment
 - Aging population
 - Prevention of secondary disease and disease recurrence
 - Decreases in mortality from other causes

Problems with Five-year Survival Rates

- A valid measure in a randomized trial of cancer therapy, yet can be misused.
- Cancer testing has a powerful effect on 5-year survival rates.
- Every year we find cancer earlier, so expect that the 5-year rates will increase over time.
- Also, surviving for 5 years – even with metastatic disease - DOES NOT mean you are “cured” (e.g., breast cancer).
- Be cautious in interpreting!

Survivorship Services: Is There a Need?

Livestrong Study (2004): 50% of cancer survivors felt their secondary needs were unmet. (n = 1024)

- ◆ Chronic pain
- ◆ Depression/Anxiety
- ◆ Fear of Recurrence
- ◆ Long-term physical and psychological effects of cancer and treatment
- ◆ Infertility
- ◆ Sexual Dysfunction
- ◆ Relationship Difficulties
- ◆ Financial Problems/Job Insecurity

Survivorship Services: Is There a Need?

Livestrong Study Conclusions (2006)

- ◆ Cancer survivors' post-treatment concerns should be addressed and understood more fully.
- ◆ Health care providers should engage with their patients to understand the multifaceted nature of survivorship.
- ◆ More research to understand the survivorship experience.

How Cancer has Affected Post-Treatment Survivors: A Livestrong Project. June 2010

From Cancer Patient to Cancer Survivor: Lost in Transition (2006 IOM Report)

Barriers facing patients & providers

- Fragmented, poorly coordinated cancer care system
- Absence of a locus of responsibility for follow-up care
- Poor mechanisms for communication
- Lack of guidance on what constitutes quality survivorship care

Transition Points Distress

“The highest level of distress occurs at transition points in treatment: at the time of diagnosis, awaiting treatment, during and on completion of treatment.”

Institute of Medicine.
From *Cancer Patient to Cancer Survivor: Lost in Transition*. 2006

End of Active Treatment: Unexpected Stress

- ◆ Feeling of abandonment.
- ◆ Continued symptoms (e.g., pain, fatigue, anxiety).
- ◆ *Active* treatment over → fear of cancer resurgence.
- ◆ Reluctance to transition back to a primary care provider.
- ◆ Many providers are unaware of long-term physical and psychological issues associated with cancer and its treatment.

Quality of Life Issues

Medical Problems:

- ✓ Cardiovascular disease and cardiac failure
- ✓ Fatigue
- ✓ Osteoporosis / osteopenia
- ✓ Hypothyroidism
- ✓ Premature menopause
- ✓ Pulmonary function
- ✓ Lymphedema
- ✓ Urinary incontinence
- ✓ Infertility
- ✓ Neurologic problems (balance, neuropathy, memory)
- ✓ GI (bowels, bloating, acid reflux)
- ✓ Dental impairments
- ✓ Increased risk of 2nd cancers

Symptoms and Functions:

- ✓ Restricted social and physical activities
- ✓ Memory loss (“chemo brain”)
- ✓ Muscle and joint stiffness, weakness, cramps or pain
- ✓ Sexual dysfunction
- ✓ Fatigue / lack of stamina
- ✓ Distress and worry

and more...

Late Effects vs Long Term Effects

- **Late Effects** are toxicities of treatment that are absent or subclinical at the end of therapy but manifest months or years later.
 - Injury to organs or failure to compensate (e.g., pulmonary fibrosis)
 - Non-medical (e.g., employment discrimination).
 - Quality of Life Issues (e.g., sexual dysfunction)

Late Effects vs Long Term Effects

- **Long Term Effects** are chronic or persistent effects that appear during treatment and continue beyond the end of treatment.
 - Cancer related fatigue
 - Peripheral neuropathy
 - Sexual Dysfunction



Let's talk about sex...

- Just being asked about sex can be a huge relief
- Importance of Intimacy
 - Sex and Intimacy don't always go together
- Pelvic Floor Rehab ("Pelvic PT") for men and women
- Talk therapy, individually or as a couple
- Have resources to offer your patients!

Psychosocial Distress Risk Factors

- History of mental health issues
- High number of stressful life events
- Substance Abuse
- Strained or very limited social support
- Younger age
- Decreased physical and/or cognitive functioning as a result of treatment

Psychosocial Effects: Distress

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- “Distress” is less stigmatizing term
- Assessing distress: Use evidence-based instruments:
 - NCCN Distress Thermometer
 - NCCN Survivorship Assessment
 - At minimum, can just ask 1-2 questions (PHQ 1 or 2)
- Pharmacologic support (aka Meds). “This is the rainy day!”
- Psychosocial Care increases emotional well being AND can decrease disease symptoms & treatment-related adverse effects (e.g., fatigue, pain).

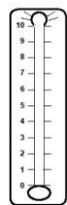


NCCN
National
Comprehensive
Cancer
Network

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today:



PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	<input type="checkbox"/>	Family Problems	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Festering sores/ulcers
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Fever
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Emotional Problems	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Noise dry/croaked
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Spiritual/religious concerns	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Other Problems:	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Substance abuse
<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

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SURVIVORSHIP ASSESSMENT (Patient version)

Please answer the following questions regarding possible symptoms that you may have experienced:

Symptoms/Concerns	Survivorship Care Issues
Cardiac Toxicity	1. Did you receive antihypertensive therapy (eg, diuretics, epinephrin, dexamethasone, AC [acetaminophen + cyclophosphamide])? Yes/No 2. Do you have shortness of breath or chest pain after daily activities (eg, walking up stairs) or exercise? Yes/No 3. Do you have shortness of breath when lying flat, wakes up at night coughing or get up, or have persistent leg swelling? Yes/No
Anxiety, Depression, and Distress	4. Have you been bothered more than half the days by little interest or pleasure in doing things? Yes/No 5. Have you been bothered more than half the days by feeling down, depressed, or hopeless? Yes/No 6. Have you been bothered more than half the days by not being able to stop or control worrying, or have you felt nervous or on edge? Yes/No
Cognitive Function	7. Do you have difficulties with multitasking or paying attention? Yes/No 8. Do you have difficulties with remembering things? Yes/No 9. Does your thinking seem slow? Yes/No
Fatigue	10. Do you feel persistent fatigue despite a good night's sleep? Yes/No 11. Does fatigue interfere with your usual activities? Yes/No 12. How would you rate your fatigue on a scale of 0 (none) to 10 (worst) over the past month? 0-10
Pain	13. Are you having any pain? Yes/No 14. How would you rate your pain on a scale of 0 (none) to 10 (worst) over the past month? 0-10
Sexual Function	15. Do you have any concerns regarding your sexual function, sexual activity, sexual relationship, or sex life? Yes/No 16. Are these concerns causing you distress? Yes/No
Sleep/Insider	17. Are you having problems falling asleep or staying asleep? Yes/No 18. Are you experiencing excessive sleepiness (ie, sleepiness or falling asleep in inappropriate situations or sleeping more during a day than you would like to do)? Yes/No
Health/Lifestyle	19. Have you been told that you smoke frequently or that you stop breathing during sleep? Yes/No 20. Do you engage in regular physical activity or exercise, such as brisk walking, jogging, bicycling, swimming, etc.? Yes/No • SA: If you answered “yes,” how often? 21. Eating a diet that includes at least 2½ cups of fruits and/or vegetables each day? Yes/No 22. Do you have concerns about your weight? Yes/No 23. Do you take vitamins or supplements? Yes/No
Immunizations and Infections	24. Have you received your flu vaccine this season? Yes/No 25. Are you up to date on your vaccines? Yes/No/Don't know

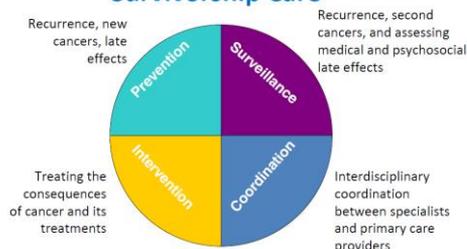
Note: All recommendations are category 1B unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of your cancer will be to participate in a clinical trial. Participation in clinical trials is especially encouraged.
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Barriers to Distress Assessment

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- For Provider**
- “Uncomfortable” conversation
 - Daunting
 - Lack of time
 - Lack of confidence
 - No resources
 - Reluctance to stigmatize patients
- For Patient**
- Just need to “bite the bullet”
 - Embarrassed
 - Lack of trust in clinician

Essential Components of Quality Survivorship Care



Health 11, et al. 4th. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington DC: The National Academies Press; 2009

Survivorship Care Plan and Treatment Summary

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- Gaps in communication between health-care providers are a major impediment to necessary coordination of care after treatment.
- IOM recommends 2 reports after treatment:
 - A treatment summary
 - A survivorship care plan
- Upon completion of Active Treatment (surgery, chemotherapy, radiation therapy). Ongoing endocrine therapy okay.

What does a Care Plan and Treatment Summary include?

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- Diagnosis: Cancer type, stage, histology, date and age at diagnosis
- Treatment facility and oncology health care providers and PCP with contact information
- Treatment details: Chemotherapy, with selected cumulative doses, radiotherapy fields, surgical procedures, blood product exposures
- Complications on/off treatment with long-term implications
- Associated potential risks of treatment including second malignancy or specific organ toxicity with screening and follow-up recommendations send to survivor and healthcare providers

Case Study

- 50yo female recently dx Invasive Ductal Carcinoma of left breast (Stage 2: pT2 pN0 cM0), ER+, PR+, H2N-.
- Lumpectomy, chemotherapy with dose dense AC and weekly Taxol, radiation therapy all complete. Started anastrozole (AI), plans 5 years of endocrine therapy.

Case Study (continued)

- Distress screening: feelings of worry about recurrence, difficulty with partner, hot flashes, vaginal dryness, decreased libido, peripheral neuropathy.
- Discuss long term/late effects: common, uncommon, rare (including secondary cancers). DEXA screening for bone density, Vitamin D discussion. Consider lipid screening and counseling prn.

Case Study (continued)

- Referrals to Onc Rehab (pelvic floor PT, OT for peripheral neuropathy); acupuncture for hot flashes, neuropathy; Discuss lubricants, vaginal hormonal creams (try to avoid in breast cancer pts); Genetic counseling depending on family history.

Survivorship Clinics

- Patients meet with member of treatment team and review Care Plan and Treatment Summary, then have copies for future reference and to share with providers.
- Discuss treatment received, current condition, and what to expect and watch for in the future.
- Bridge back to PCP care.
- Refer for specialty follow up (e.g., PT/OT, Genetic counseling, mental health/support...)

Survivorship Clinics

- Often ARNP-led
- May be stand alone visit (60-90 minutes). May have shorter follow up visits. May have annual follow up or follow up as needed.
- Covered by insurance as MedOnc visit (including Medicare/Medicaid)

Challenges to Survivorship Clinics

- Reimbursement versus Time: creating Care Plans is very time consuming.
- Referrals: a challenge for most Survivorship programs, at least initially

Patient and Physician Expectations for Survivorship Care

- ◆ PCP only care: Fewer screening tests for cancer
- ◆ Oncologist only care: Suboptimal noncancer-related care
- ◆ Confusion between oncologists and PCPs about who is responsible for what: Both felt they should be responsible for primary cancer follow-up
- ◆ Combining strengths of cancer specialty and primary care is the best option

Cheung et al. (2009)



Primary Care vs Oncology Follow Up

Canadian multicenter study found no differences in recurrent disease, deaths, serious clinical events or health-related QOL for breast cancer survivors whether receiving care from oncology specialists or primary care physicians.

So... either PCP or Oncology can provide good (or lacking) follow up.

Grunfeld et al. (2006)

Primary Care as Primary Follow Up

- ◆ Most PCPs indicate interest in caring for survivors, yet felt transfer of care from oncologist was poor; felt inadequately informed about the treatment course and appropriate surveillance guidelines.
- ◆ **PCPs need more specific guidance regarding surveillance for cancer recurrence.**

Nissen et al. (2007)

Resources for Primary Care

- George Washington University Cancer Survivorship E-Learning Series for Primary Care Providers
 - Free online modules for physicians, nurse practitioners, physician assistants, nurses.
 - CE eligible.
 - Good resources – kept updated

<http://gwcehp.learnercommunity.com/elearning-series>

Childhood Cancer Survivors

- 5-year childhood cancer survival rates combined increased from 58.1 percent in 1975–77 to 82.5 percent in 2001–2007.
- Due to significant advances in treatment, resulting in cure or long-term remission for many.
- As many as two-thirds of childhood survivors may develop a late effect.
- By age 40, the risk for breast cancer is 35% for women who are survivors of childhood Hodgkin's disease who were treated with mantle or chest radiation.

Oeffinger (2000)

Role of oncology nurses in survivorship

- Nurse-led model of cancer follow-up promising
- Nurses central to any interdisciplinary effort
- In some instances, nurses may be best providers
- Barriers to adopting nurse-led models
 - Shortage of trained oncology nurses, especially in outpatient settings
 - Potential preference of some patients to see physician

Institute of Medicine (2006)

In Summary . . .

- Number of cancer survivors is growing
- Survivor definition is broad
- Survivor needs can be significant
- Oncology nurses play a critical role
- Survivor Care Plans needed

100% of patients need symptom management.

Only some need chemo.

*Life isn't about waiting for the storm to pass . . .
It's about learning to dance in the rain.*



Harmony Hill Retreat Center

- Located in Union, WA on the Hood Canal
- Free three-day retreats for anyone ever diagnosed with cancer & a companion. Also family retreats and grief/loss retreats.
- Beautiful, informative, supportive, restorative & delicious!
- www.harmonyhill.org
- 360-898-2363



Questions?

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