Cancer Survivorship: navigating the aftermath for patients

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Objectives

- Epidemiology of survivorship
- What is survivorship care?
- Chronic and late effects of cancer and treatments
- Treatment summaries and care plans
Cancer is a major public health problem
Majority of cancer diagnoses are in older adults

- Total people diagnosed with cancer: 1.6 million
- Cancer diagnoses ≥65 years old: 868,000
- 53% of cancer diagnoses were in individuals ≥65 years old in 2012
Majority of cancer **survivors** are older adults

- Total cancer survivors: 13.7 million
- Cancer survivors ≥65 years old: 8+ million
- 59% of cancer survivors were ≥65 years old in 2012
Distribution of stages

Howlader et al. National Cancer database

Breast (female)

Colon & rectum

Lung & bronchus

Prostate

Melanoma

Urinary bladder
Increasing Number of Cancer Survivors

US population: 300 million

2012: 14 million cancer survivors

2022: 18 million cancer survivors

de Moor et al. Cancer survivors in the United States, Cancer Epidemiology, Biomarkers, and Prevention, 2013
Objectives

- Epidemiology of survivorship
- **What is survivorship care?**
- Late effects of cancer and treatments
- Follow up after cancer treatment
- Treatment summaries and care plans
What is a cancer survivor?

A cancer survivor is any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life.

-IOM and NRC, 2005
What is survivorship care?
Cancer care continuum

**FIGURE 1-1** Domains of the cancer care continuum with examples of activities in each domain. The blue arrow identifies components of high-quality cancer care that should span the cancer care continuum from diagnosis through end-of-life care. The green arrow identifies three overlapping phases of cancer care, which are a way of conceptualizing the period of the cancer care continuum that is the focus of this report.

**SOURCE:** Adapted from National Cancer Institute figure on the “Cancer Control Continuum” (NCI, 2013b).
What is survivorship care?
Institute of Medicine (IOM)

- Prevention: of recurrent and new cancer and other late effects
- Surveillance: for cancer spread, recurrence, and second cancers
- Assessment: of medical and psychosocial late effects
- Intervention: for consequences of cancer and its treatment
- Evaluation: of concerns related to employment, insurance, and disability
- Coordination: between specialists and primary care physician

Screening Guidelines to Detect Recurrences

ASCo
National Comprehensive Cancer Network®
Ontario Cancer Care Ontario
Action Cancer Ontario

BCMA
BRITISH COLUMBIA MEDICAL ASSOCIATION

ESMO
European Society for Medical Oncology

Guidelines Group
Promoting Effective Health and Disability Services

Northwestern Medicine
National Comprehensive Cancer Network (NCCN)

Colon Cancer

<table>
<thead>
<tr>
<th>PATHOLOGIC STAGE(e)</th>
<th>ADJUVANT THERAPY(m,n)</th>
<th>SURVEILLANCE(t)</th>
</tr>
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<tbody>
<tr>
<td>Tis; T1, N0, M0</td>
<td>None</td>
<td>Colonoscopy at 1 y()</td>
</tr>
<tr>
<td>T2, N0, M0</td>
<td>None</td>
<td>▶ If advanced adenoma, repeat in 1 y</td>
</tr>
<tr>
<td>T3, N0, M0(k,l)</td>
<td>Clinical trial or</td>
<td>▶ If no advanced adenoma(v), repeat in 3 y, then every 5 y(v)</td>
</tr>
<tr>
<td></td>
<td>Observation or</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consider capcitabine(o)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>or 5-FU/leucovorin(o)</td>
<td></td>
</tr>
<tr>
<td>T3, N0, M0 at high risk for systemic recurrence(l,k) or T4, N0, M0</td>
<td>Capcitabine(o,p)</td>
<td>• History and physical every 3-6 mo for 2 y, then every 6 mo for a total of 5 y</td>
</tr>
<tr>
<td></td>
<td>or 5-FU/leucovorin(o,p)</td>
<td>• CEA(w) every 3-6 mo for 2 y, then every 6 mo for a total of 5 y</td>
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<td>or FOLFOX(o,p,q,r) or</td>
<td>• Chest/abdominal/pelvic CT(h) annually for up to 5 y for patients at high risk for recurrence(x)</td>
</tr>
<tr>
<td></td>
<td>CapeOx(o,p,q,r) or</td>
<td>• Colonoscopy(b) in 1 y except if no preoperative colonoscopy due to obstructing lesion, colonoscopy in 3-6 mo</td>
</tr>
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<td>FLOX(o,p,q,r,s) or</td>
<td>▶ If advanced adenoma, repeat in 1 y</td>
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<td>▶ If no advanced adenoma(u), repeat in 3 y, then every 5 y(v)</td>
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<td></td>
<td>Observation</td>
<td>• PET-CT scan is not routinely recommended</td>
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Node-positive disease, see COL-4

If Recurrence, See Workup (COL-9)
Screening Guidelines

History and Physical Exam
Every 3-6 months for 2 years
Then every 6 months for 3 years

CEA testing
Every 3-6 months for 2 years
Then every 6 months for 3 years

Computed Tomography (CT) Scan
Chest, abdomen, and pelvis scan annually for 5 years

Colonoscopy
Colon cancer - at one year, subsequent based on findings
Rectal - Proctoscopy every 6 months
Screening Guidelines

- **History and Physical Exam**
  - Every 3-6 months for 2 years
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How to monitor for late and chronic effects?

• There are NO standard, risk-stratified guidelines for late and chronic effects in adults

• There is no standard model to follow

CHECKLIST

- Annual H&P
- TSH if neck radiation
- CV- BP and lipids
- Echo?ECG?Troponin?
- Carotid US?
- Distress screening
Survivorship care is NOT part of current clinical practice or workflow.
Objectives

- Epidemiology of survivorship
- What is survivorship care?
- **Chronic and late effects of cancer and treatments**
- Treatment summaries and care plans
# Long-term and Late Effects of Cancer

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<th><strong>Late effects</strong></th>
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<td>❑ Medical problems that do not develop or become apparent <strong>until years after</strong> treatment ends.</td>
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<tr>
<td>❑ <strong>Persist for at least 5 years after</strong> completion of initial cancer treatment</td>
<td>❑ <strong>May develop as outgrowth of the effects of treatment on organ systems or the psychological process</strong></td>
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**Examples:**
- Neuropathies
- Pain
- Fatigue
- Sexual difficulties
- Anxiety and depression

**Examples:**
- Heart disease
- Diabetes
- Osteoporosis
Physical Effects

- Organ impairment: Sphincter control in pelvic surgery (colorectal, prostate, gyn malignancies)
- Secondary side effects: Lymphedema (breast cancer, non-Hodgkin’s lymphoma)
- Loss of function: removal of organ or limb
Long term effects - Lymphedema

- 10-50% of patients with full dissection affected. Less common with sentinel biopsy
- Symptoms: swelling, pain, difficult moving, burning, skin changes
- Treatment: Exercises, wrapping, compression, massage, pneumatic compression

Petrek JA et al. Cancer 2001
Peripheral neuropathy is a common dose limited toxicity for many chemotherapy agents.

Signs: Tingling (pins and needles), burning painful numbness in fingers and toes.

Chemotherapy drugs such as platinums, taxanes, bortezomib.

Can be reversible or irreversible.

Additional risk factors: Alcohol, Diabetes, previous chemotherapy, rapid weight loss.

Therapy: Antiseizure medications, Antidepressants, Opiods, Acupuncture, Vitamins B1, B6, B12, Physical Therapy.
Effects of cancer and treatments: Chemotherapy

- Bones
- Heart
- Lungs
- Fertility/sexual dysfunction
- Cognitive
- Pain
Effects: Bone density
Psychosocial effects
Psychosocial challenges

• Psychological- depression, anxiety, isolation, uncertainty, altered body image

• Social- changes in interpersonal relationships, jobs, school, financial burden

• Spiritual issues- sense of purpose or meaning, appreciation of life
Psychosocial challenges

• Anxiety and Depression
  – 29% of survivors
  – Suicide rate twice that of general population
    Management: Screen for anxiety and depression
    Treatment: exercise, medication treatment, cognitive behavioral therapy, and supportive psychotherapy

• Post traumatic stress disorder
  – Up to 19% of cancer survivors

Points of increased vulnerability to distress
Long term effects – Cognitive dysfunction “chemo brain”

• Common complaint among cancer survivors

• Especially common in survivors of Central Nervous Cancers or those with brain metastases

• Most commonly affected with chemotherapy, also related to radiation and endocrine therapy

• History of cancer associated with 40% increase of self-reported memory problems

• Screen for medications that can contribute to cognitive impairment

• Management: reminder notes, calendar, relaxation techniques, medications - methylphenidate or modafanil (medications should be last resort!)
Long term effects - Fatigue

• “a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to physical activity and interferes with usual functioning.”

• Treatment of contributing factors, physical activity, psychostimulants
Late effects - Colorectal

- Bowel dysfunction / stoma
- Peripheral neuropathy
- Risk of second primary

Petrek JA et al. Cancer 2001
Late effects- Prostate

- Incontinence
- Erectile dysfunction
- Bowel issues
- Hormonal therapy
- Osteoporosis
- Diabetes
- CV disease

**FIGURE 9. Prostate Cancer Primary Treatment Patterns by Age, 2008.**

* indicates the initial treatment received.
Data source: NCDB.
Late effects - Radiation

- Heart is susceptible to radiation damage
- Affects valves, myocardium, pericardium, arteries, and electrical conduction
- Synergy with cardiotoxic chemotherapy
- Latent period may be 10-20 years
- Incidence 10-30% by 5-10 years post tx
- In Hodgkin’s disease, CAD cause of ¼ of deaths

Vaughn DJ, JCO 2007
Objectives

• Epidemiology of survivorship
• What is survivorship care and the barriers?
• Chronic and late effects of cancer and treatments
• Treatment summaries and care plans
Commission on Cancer Standards include survivorship care by 2015

Cancer committee must:

• **Develop**

• **Implement** a process

• Comprehensive care summary and follow up plan to **ALL cancer patients finishing primary treatment**

• In the future, incorporate metrics

Provides care for approximately 70% of patients with newly diagnosed cancers
Functions of a Treatment Summary and Care Plan

- Summarize key aspects of care
- Make f/u care recommendations
- Promote knowledge, engagement, health behaviors & wellbeing
- Facilitate provider communication & coordinated services → improved continuity of care
Not many patients receive survivorship care plans
RCTs of SCP Interventions

- ↑ awareness of follow-up care  
  (Grunfeld et al., JCO, 2011)

- ↓ health worry  
  (Hershman et al., Breast Cancer Res Treat, 2013)

- ↑ satisfaction (info & care)  
  (van de Poll-Franse et al., ASCO, 2013)

- No significant group differences:  
  Cancer-related distress, depression, HRQL

- Ongoing trials
Existing Templates

American Society of Clinical Oncology
Making a world of difference in cancer care

Follow-up Care

Breast Cancer

After receiving treatment for breast cancer, it is important for survivors to adhere to their physician's plan for follow-up care. Guidelines developed by the National Comprehensive Cancer Network state that survivors who have had breast conserving therapy (lumpectomy) should have their first mammogram approximately 6 months after completing radiation therapy, then annually. Survivors who underwent single mastectomy should have a mammogram annually. In addition, breast MRI may be considered for survivors with the BRCA 1 or 2 genes. Those who have had double mastectomy do not need mammograms, but should examine the chest wall for swelling or a rash, and report any changes to their oncologist. However, some oncologists recommend that mammograms be performed of the reconstructed breast or breasts.

Survivors should be seen by their oncologist every 4 to 6 months for the first 5 years and then annually. Women who are taking tamoxifen and still have an intact uterus should be seen annually by a gynecologist and be sure to report any vaginal bleeding to their physician immediately. As this can be a sign of uterine cancer. Women taking aromatase inhibitors, which results in a decrease in estrogen levels and breast tissue, should have bone health evaluated by a DEXA scan at baseline and then periodically thereafter.

Routine CT scans or bone scans to look for evidence of cancer spread outside of the breast and regional lymph nodes (otherwise known as metastasis) are not recommended. This is because research has shown that if a woman develops metastatic disease, the subsequent type of treatment, response to treatment, and overall survival are equal, regardless of when the treatment is initiated. In other words, outcomes are similar for those who are treated for metastasis found on routine screening (with no symptoms present) and those who are not treated and whose metastatic cause symptoms. Therefore, no routine screening for patients at risk for metastatic disease needs to be developed for women.

Finally, research has demonstrated that leading an active lifestyle and maintaining a healthy weight, with a body mass index (BMI) of 20-25, may result in better breast cancer outcomes. Weight bearing exercise, such as walking, yoga and dancing, can also help maintain bone strength. Talk with your healthcare team about resources to help you get started (see page 4 and 5 for a healthy lifestyle).

The National Comprehensive Cancer Network produces Clinical Practice Guidelines that can be helpful in determining the general recommendations for follow up. The recommended follow-up care for patients with breast cancer includes:
All stakeholders benefit from coordinated survivorship care

**Patient**
- Patients seek understandability and knowing who is watching for recurrences and late/chronic effects

**Health care providers**
- What are the important patient outcomes or metrics?
- Need for improved survivorship follow-up guidelines
- Who/when/what?

**Health system**
- What is the most feasible and sustainable model?
- Reimbursement and cost-effectiveness issues
- Need for sufficient access to supportive resources
Take Home Points

• Talk to your doctor! Don’t be afraid to voice your concerns.


Thank you
Questions?