Objectives

- Describe cancer survivorship definitions and prevalence.
- Discuss the unique health risks and needs of cancer survivors.
- Highlight physiologic, psychosocial & social aspects of survivorship.
- Explain the need for Survivor Care Plans.
- Describe the role of oncology nurses in survivorship care.

Cancer Survivorship: Changing Times

- Cancer has now become a curable disease for some and a chronic illness for others.
- Patients with terminal disease are also “survivors.”
- Patient needs beyond surgery, chemo, radiation.
- Increasing survival poses opportunities for patients, family members, clinicians, researchers and administrators.
- Emerging role for health professionals (e.g., oncology nurses, primary care, psychosocial support, etc.)
Cancer Survivorship

But first . . .

Review of terms, definitions & data

Incidence & Mortality

- **Incidence**: The number of newly diagnosed cases of a disease. The cancer incidence rate is the number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population at risk.
- **Mortality** (death): The mortality rate is the number of deaths due to a disease divided by the total population.

Prevalence & Morbidity

- **Prevalence**: Cancer prevalence is the number of people alive today who have been diagnosed with cancer. This includes individuals who are newly diagnosed, in active treatment, have completed active treatment, and those living with progressive symptoms of their disease.
- **Morbidity** (illness): Morbidities are NOT deaths. A person can have several co-morbidities simultaneously.
Who is a Cancer Survivor?

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.

How many survivors are there?

≈ 13.7 M cancer survivors in the United States
- Does not include in situ of any site except the urinary bladder, and does not include basal cell and squamous cell skin cancers.
- 18 million by 2022
- 64% were diagnosed 5 or more years ago
- 15% were diagnosed 20 or more years ago
- 1 in 2 men and 1 in 3 women will be diagnosed with cancer in their lifetime
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

Washington State: 2008 – 2010 Annual Average # of Cases

- All Cancer Sites Combined
  - Incidence: 36,938
  - Mortality: 11,778
- Breast
  - Incidence: 6,358
  - Mortality: 797

WA Prevalence & Morbidity

Breast Cancer Stage at Diagnosis & Survival

<table>
<thead>
<tr>
<th>Stage at Diagnosis</th>
<th>WA 2010: % of Cases (n=6,250)</th>
<th>Relative Survival Rates: 2009 National 5-year Rates</th>
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<tbody>
<tr>
<td>In situ</td>
<td>22%</td>
<td>100%</td>
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<tr>
<td>Local</td>
<td>49%</td>
<td>98%</td>
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<tr>
<td>Regional</td>
<td>23%</td>
<td>84%</td>
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<tr>
<td>Distant</td>
<td>4%</td>
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<tr>
<td>Unstaged</td>
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<tr>
<td>Overall</td>
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<td>92%</td>
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</table>
WA Cases & National Five-year Survival Rates

- WA (2010): 37,222 new cases (incidence)
- National 5 year survival rates (2009): 68%
  - Based on cancers diagnosed between 2004 – 2008 with follow-up through 2009
- WA (2012) Prevalence ≈ 250,000

Problems with Five-year Survival Rates

- A valid measure in a randomized trial of cancer therapy, yet often 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 DOES not mean you are cured (e.g., breast cancer).
- Be cautious in interpreting!

History of Cancer Survivorship Activities

- 1986 - National Coalition for Cancer Survivorship (NCCS)
- 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 care
- 2007 – IOM Report on care for whole patient
- 2015 – COC: Survivorship component required

Survivorship Activities: Private & Government Sponsored
**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

**Livestrong Study (2006):** 99% reported at least one concern after treatment ended (n = 2307)
- Physical, emotional, & practical concerns
- Half of those reporting emotional or practical concerns did not receive help.
  - Learned to live with the concern
  - Addressed the issue on their own
  - Was told issue would go away with time

**Survivorship Services: Is There a Need?**

**Livestrong Study (2006)**
- Percentage of post-treatment cancer survivors who received help for physical concerns from medical providers:
  - 60% from a Medical Specialist (e.g., fertility specialist)
  - 58% Oncologist
  - 55% Primary Care Physician
  - 22% Psychologist
  - 20% Other Medical Staff
- Medical professionals were not often selected for emotional and practical concerns.

**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.
Pennsylvania DOH Study (2007): Focus on Unmet Psychosocial Needs of Cancer Patients and Their Families (n = 614)

- Almost 2/3 reported unmet psychosocial needs—particularly emotional, physical, and treatment-related needs.
- High need due to mismatch between needs and services.
  - Lack of access issues
  - Lack of awareness of resources
  - New needs that have arisen in a changing healthcare climate

Survivorship Services: Is There a Need?

Survivorship: Evolving Knowledge

- Screening and treatment needs
- Changes in toxicity profiles
- Quality of life issues
- Long term effects
- Late medical and physiologic consequences of cancer and its treatment

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.
  - Non-medical (e.g., employment discrimination).
- **Long Term Effects** are chronic or persistent effects that appear during treatment and continue beyond treatments end.

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.”

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

Dimensions of Quality of Life

**Physical:**
- Functional Ability
- Strength/Fatigue
- Sleep & Rest
- Nausea
- Appetite
- Constipation

**Psychological:**
- Control
- Anxiety
- Depression
- Enjoyment/Luxure
- Fear of Recurrence
- Cognition/Attention
- Distress of D & A

**Social:**
- Family Distress
- Roles & Relationships
- Affection/Social Function
- Appearance
- Employment
- Isolation
- Finances
- Work

**Spiritual:**
- Meaning of Illness
- Religion
- Transcendence
- Hope
- Uncertainty

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, "Seven Time Cancer Survivor"

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

- Cancer patients vs. others with serious illness
  - Triple the risk of depression within 2 years of diagnosis
- Significant minority of cancer survivors will meet criteria for a mental disorder
  - BUT majority will experience psychosocial distress at a significant level
- Who can best identify and assess psychosocial distress?
  - History and comfort level
  - Timing – Distress may not manifest until AFTER treatment ends
  - Manager of other services and resources

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

- "Distress" is less stigmatizing term
- Distress is the 6th vital sign
- Assessing distress: Use evidence-based instruments:
    - At minimum, can just ask 1-2 questions (PHQ 1 or 2)
- Please do not just prescribe meds
- Psychosocial Care increases emotional well being AND can decrease disease symptoms & treatment-related adverse effects (e.g., fatigue, pain).

Barriers to Distress Assessment

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
**IOM 2005:**

*From Cancer Patient to Cancer Survivor: Lost in Transition*

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**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

**Survivorship Needs**
- Prevention, surveillance and detection of new and recurrent cancers.
- Prevention, surveillance and detection for consequences of cancer and its treatment.
- Coordination between specialists and primary care providers to ensure that survivor health needs are met.
- Every survivor should receive a **treatment summary** and **care plan** at the end of treatment.
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

Survivor Care Plan: When?
- Upon completion of the active intensive phase of cancer treatment.
- When the patient is resuming regular PCP follow-up, is in remission, and either off of all oral daily or intermittent hormonal therapy with the expectation of infrequent visits to the oncology clinic.

Treatment Summaries and Survivorship Care Plans

- 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 doses and 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

Templates: Survivorship CPs
www.journeyforward.org
### Background Information

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<thead>
<tr>
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<th>Value</th>
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<td>Multiple relatives</td>
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<td>Recent health</td>
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<td>Prior diagnosis or testing</td>
<td>Nil or 4%</td>
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<tr>
<td>Medication history</td>
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### Left Breast

<table>
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<th>Parameter</th>
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<td>HER2 status</td>
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### Right Breast

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<tr>
<td>HER2 status</td>
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### Follow-up Care

#### Medical history and physical (MPH) examination
- First year: every 3 months, for the first two years after the first 10-year period, then every 6 months; years 11, 12, and 13.
- Second year: every 6 months; years 14, 15, and 16.
- Third year: every 6 months; years 17, 18, and 19.
- Fourth year: every 6 months; years 20, 21, and 22.
- Fifth year: every 6 months; years 23, 24, and 25.

#### ASCO Surveillance Guidelines

1. **Medical history and physical (MPH) examination**
   - First year: every 3 months, for the first two years after the first 10-year period, then every 6 months; years 11, 12, and 13.
   - Second year: every 6 months; years 14, 15, and 16.
   - Third year: every 6 months; years 17, 18, and 19.
   - Fourth year: every 6 months; years 20, 21, and 22.
   - Fifth year: every 6 months; years 23, 24, and 25.

2. **Follow-up surveillance**
   - First year: every 3 months, for the first two years after the first 10-year period, then every 6 months; years 11, 12, and 13.
   - Second year: every 6 months; years 14, 15, and 16.
   - Third year: every 6 months; years 17, 18, and 19.
   - Fourth year: every 6 months; years 20, 21, and 22.
   - Fifth year: every 6 months; years 23, 24, and 25.

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### Consent to Withdraw

- Patients should report any symptoms or concerns:
  - Breast lump or discharge
  - Nipple retraction
  - Skin changes
  - Changes in the appearance of the breast or nipple
  - New or changing symptoms
  - Any new or changing symptoms should be reported to their doctor immediately.

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### Patient Education

- It is important to continue with regular mammograms and physical exams after the first 10 years.
- Patients should consult with their healthcare provider to determine the appropriate follow-up schedule for their specific situation.
Survivor Care Plans Online

- http://www.survivorshipguidelines.org
- http://www.oncolink.org/
- http://www.cancer.net/patient/survivorship/ASCO+cancer+treatment+summaries
- http://www.livestrongcareplan.org

Risk of Comorbid Conditions

- The major threat to life for many cancer survivors.
- Survivorship associated with increased likelihood of not receiving recommended care across a broad range of chronic medical conditions.
- Having both primary care physicians and oncologists involved in follow-up appeared to ameliorate this effect significantly.

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 Efficacy: Cancer Survivors

- 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.
- 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.

Primary Care/Oncology Coordination of Care

...transfer of care to a PCP... should be formalized and include follow-up recommendations and defined physician responsibilities. Providers and patients should be educated regarding surveillance care and current guidelines incorporated into standard clinical practice.

Hollowell et al. (2010)

Childhood Cancer Survivors

Mary Johnson, a 28-year-old patient whom you have followed-up for several years, comes to your office because she feels a lump in her breast. From her previous history you know that she had Hodgkin’s disease when she was 12 years old and was treated with chest radiation. She was “cured” and has not seen anyone from the pediatric cancer center in more than 10 years.

Oeffinger (2000)

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 cumulative actuarial risk for breast cancer is 35% for women who are survivors of childhood Hodgkin’s disease who were treated with mantle or chest radiation.
From Cancer Patient to Cancer Survivor: Lost in Transition (2006 IOM Report)

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

The Role of Nurses

Nurses make significant contributions to improving survivorship care, not only through direct patient care, but also through ongoing professional development and certification, programs, publications, and research. Meeting the needs of the growing survivor population will likely require more nurses with advanced training in oncology.

Prevention

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<th>PCP</th>
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Detection

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Management of Side Effects/Late Effects

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Care Models

- Multiple models proposed dependent on multiple factors
- Models include
  - Academic/Oncology Based Care
  - Disease-based, treatment-based or comprehensive community-based care
  - Family practice/Internal medicine-based
  - Shared Care between oncology and primary care
  - With or without transition

Who will meet these needs?

- 48% increase in demand for oncologists by 2020
- Shortfall of 40,000 Primary Care Providers over the next decade
  - Inadequate prep to address complex needs in cancer patients
- Nursing shortage continues to worsen
  - Nurses can play critical role in long term follow-up

What specialty is best suited for:

- Quality of life discussions
- Routine monitoring
- Routine screening
- Being there for the patient – present for ongoing life, normal aging, and the threat of recurrence
### Survivor Feedback
**Olympia Pilot Study (n = 80)**
- Want providers to communicate with each other (and pt)
- Want providers to be prepared for appointments
- Would like more support group options
- Would like resources for disease sites other than breast
- Anger regarding missed diagnoses and length of time to diagnosis
- Want easier process to switch doctors within practice
- Want compassionate, confident yet humble providers
- Want providers to be honest about prognosis

### Survivor Feedback
**Olympia Pilot Study (n = 80)**
- 24 yr female
- 64 yr male
- 60 yr male and 11 yr son

### The Business Case: Value Proposition for Survivorship Services
- **Clinical Necessity**
  - Completing cycle of care
  - Improving outcome & long-term health
  - Enhancing clinical operational efficiency
- **Mission relevance**
  - Providing integrated care
  - Enhancing excellence, value & efficiency of care
  - Providing education for patients & providers

### Survivorship Services: The Risks of Non-Action
- Loss of competitive advantage and leadership
- Suboptimal patient care
- Unmet Mission goals
- Lost opportunities for new knowledge
- Loss of patient revenue
  - New patients
  - Secondary malignancies
  - Incremental billable services for survivors
Survivorship Services: Is There a Need?

Survivorship Services are a “No Brainer” *

- Low to moderate resource investment
- Moderate to high patient preference


Survivorship, Palliative Care and Hospice in One Room?

Survivorship, Palliative Care & End of Life Issues Taskforce

WA CARES About Cancer: Survivorship Taskforce

- Campaign to educate WA residents about Treatment Summaries, Survivor Care Plans & Palliative/Supportive Care
- Currently disseminating Survivor Care Plan fact sheets for patients and providers
- Currently disseminating Palliative Care fact sheets for patients and providers
- Join us!

Care plan

- Treatment summary
- Ongoing care information
- Personalized set of recommendations
- Information regarding late and long term side effects of cancer treatments
- Full contact info of all your health team
Goal: Build consensus on what any effective survivorship program must provide.

- Three tiers of elements
  - Tier 1: Must Have
  - Tier 2: High-Need
  - Tier 3: Strive

- Tier 1
  - Care plan and treatment summary
  - Screening for new cancers & surveillance recurrence
  - Care coordination
  - Health promotion education
  - SYMPTOM MANAGEMENT & PALLIATIVE CARE!

In Summary . . .

- Number of cancer survivors is growing
- Survivor definition is broad
- Survivor needs can be significant
- Prevention, Detection & Symptom Management
- Cancer Survivorship is an embryonic field
- Oncology nurses play a critical role
- Survivor Care Plans needed

100% of patients need symptom management.

Life isn’t about waiting for the storm to pass . . .
It’s about learning to dance in the rain.
Questions?

cobwhitten@yahoo.com