Cancer Survivorship:
Perspective of a Physician Survivor

2018 NC Cancer Survivorship Summit
1. My Journey

2. Status of Cancer Survivorship

3. Cancer Survivorship Medical Clinic at Levine Cancer Institute
Internal Medicine Nerd

Left Lower Quadrant pain

“The doctor who treats himself has a fool for both a doctor and a patient.”
November 4, 2011

• Denial: The doctor must be wrong.
• Guilt: I’m a doctor. Why didn’t I know?
• Anger: How dare my body do this?
• Grief: Oh no! Sarah’s 11, Josh is 9
• Action: Let’s assemble the team.
What’s that in my liver?

- Metastatic Disease
  - Breast
  - GI tract
  - Kidney
  - Lung
  - Skin
  - Pancreas

- Biopsy and labs
What’s that in my liver?

• **Biopsy – Carcinoid**
  - Neuroendocrine tumor
  - Cells from the lining of the GI tract that make hormones
  - Less than 1% of GI tumors (3 in Charlotte a year)
  - Slow growing – good, but “Superdoc” had missed this for years
  - Well-differentiated
    - A Fozzie instead of an Animal
  - Making hormones
    - Super Prozac Serotonin levels

• Octreotide receptors on the surface
  - Octreotide scans
  - Octreotide treatment
Surgery

• Primary carcinoids need to come out

• Right side of colon and some small bowel removed

• 13 regional lymph nodes, 7 filled with carcinoid

• PCA
Where else is it hiding?

• Octreotide receptors
• Octreotide scans

• Liver
Liver Anatomy and Star Wars

• Liver chock full of carcinoid nodules
  • Big and Little

• Liver has two blood supplies
  • Portal vein from the GI tract (food rich)
  • Hepatic artery from the Aorta (oxygen rich)

• Cancers in the liver want oxygen rich blood

• Deliver therapy through the Hepatic artery
SIR-Spheres
8 months later

- Recovery from Surgery
- Radiation Therapy
- Monthly injections (Harpoons)

- Scans and labs
  - 8-10 carcinoid nodules left in the liver
  - Signs of growth

- Next step? The brain.
Brain Health
Back to the Battle

“Battle???”

• Laparoscopic Radiofrequency ablation
14 months out. Now What?

- A single one-inch lesion left side of the liver
- A cluster of lesions right side of the liver
  - Too close to major blood vessels for a laparoscopic approach
- Going for a “cure”
  - NED
- Plan:
  - Remove the right lobe of the liver
  - Zap the left-sided lesion on the way out
- Simple, right? What could possibly go wrong?
Uh Oh

• First 5 minutes in the OR
• Mobilizing the right lobe of my liver, the vena cava tore
• Clamping the vena cava, my diaphragm tore and my left lung collapsed

• In the hospital a month
• 3 trips to the ICU
• 2nd major surgery with 3 Attending Surgeons
2013 Hospital Memories

• Hiccoughs
• Strawberry flavored smoothies
• Profound sleep deprivation
• Loss of sense of time
• Vivid dreams

• The nurse who saved my life by wrapping everything that couldn’t get wet in plastic and plopping me in a seat in the shower
• The doctors who just sat with me and filtered all my nonsense.
• Monthly harpoons from my oncology nurse continued

• Scans and labs stable
  • 1 inch ball of carcinoid on the left side of my liver

• July 2016
  • Signs of tumor growth
  • Finally got up enough courage to return to the OR
  • One more ablation
  • Home in 5 days
Present Day

• 6 years, 5 months and counting

• No Evidence Of Disease
  • Labs
  • Scans

• Staying on the monthly harpoons
  • Almost certainly have microscopic deposits of carcinoid
  • Therapy seems to be working
Living Life with just a little bit of Cancer

- Monthly trip to oncologist’s office grounds me

- Sharp stick in the behind once a month
  - Life is precious
  - Time is short
  - Priorities change
The Gifts of the Experience

- Empathy and understanding of the patient perspective
- Tolerance of little things
- Tolerance of people needing time
- Knowledge of the need to understand someone’s perspective, not just argue them into mine
- Realization that time is finite
- Focus on where I should be spending my time
The Gifts of the Experience

- Understanding of the cancer community
- Cliff-like loss of support
Sole Survivor

- 2000 Book and Movie by Dean Koontz
- March 2018 Marvel’s Jessica Jones Season 2, episode 3
Sole Survivor

• What is feels like to finish active cancer therapy
  • Exit Community of Care
  • Exit strict schedule
  • Exit certainty about uncertain things

• Side effects of treatment
• Waiting for the other shoe to drop
• New outlook on goals, health, relationships
Professional Changes

• 29 years of practice Internal Medicine
• Seeing up to 32 patients a day
• Hospital rounds, On Call nights and weekends

• Adopted at Levine Cancer Institute as their token Internist

• Program Development
  • Cancer Genetics
  • Cancer Survivorship
Cancer Survivorship

- Definition of Survivorship: An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life.

- Operational Definition
  - A cancer patient who has received treatment with the intent to cure their cancer
  - Currently has no evidence of cancer
  - Usually 3 years out from the end of cancer therapy
Cancer Survivorship – Why Now?

• Epidemiology of Cancer has changed

• Most adults diagnosed with one of the major cancers will be a long-term survivor

• That’s 18 million people by 2022

• 1 out of every 5 persons over age 65
Cancer Survivorship – Why Now?

• Lots’ more cancer survivors

• Understanding their increased health risks
  • Cancer
  • Cancer Treatment
  • Medical Conditions
  • Genetic Risks
  • Lifestyles and Behaviors
Cancer Survivorship – Why Now?

• A severe shortage of Oncology trained physicians is forecast

• Medicare claim data: after 3 years, only 1/3 of long-term cancer survivors continue to see specialists related to their original cancer
Cancer Survivorship – Why Now?

• Primary Care resources stressed

• Time pressure in the office

• Lack of training in the specific healthcare needs of cancer survivors
Cancer Survivorship – How are we doing?

• A survey reported in the Journal of Clinical Oncology in 2013 documented that > 70% of survivors had unmet medical needs...
  • Completion of recommended tests and procedures
  • Addressing residual side effects and symptoms related to cancer and cancer therapy
  • Recommended cancer screenings
  • Recommended vaccinations
  • Unhealthy Lifestyles
Survivorship Care Plans

- Survivorship Transition Visit
- Written Treatment Summary
  - Names and contact info for cancer team
  - Details of your cancer diagnosis
  - Record of treatment received
Survivorship Care Plans

- Written Survivorship Care Plan
- Recovery
- Lingering side-effects
- Late-onset side-effects of treatment
- Signs and symptoms of recurrence
- Ways we will monitor you
- Taking charge of your health

1702 times in 2017
Cancer Survivorship at LCI

- Cancer Survival
- General Longevity
- Baby Boomer Tsunami
- Limited pipeline for Oncologists
- Limited time/training for Primary Care
At the Cancer Survivorship Medical Clinic, our goal is to help people who have had cancer stay healthy.

We make sure that you are getting the care you need.

We fill any gaps between your cancer treatment team and your primary care doctor.
Cancer Survivorship Clinic

- Who will benefit from these clinics?

- The Survivorship Medical Clinic is for adults who:
  - Were found to have cancer
  - Have finished treatment
  - No longer have any signs of cancer
Cancer Survivorship Clinic

Based on your cancer history and your health, we:

• Order any tests needed to be sure your cancer has not returned
• Check for any other cancers you might have
• Check to see if you need genetic testing
• Look for and get you help for health problems that can be worsened by your cancer or cancer treatment
• Help you follow a healthy lifestyle
• Help your primary care provider and cancer team work together
Cancer Survivorship at LCI

Supportive Oncology

Survivorship Medical Clinic

- Survivorship Medical Clinic - Disease Site Overview
- Survivorship - Breast Cancer
- Survivorship - Cervical Cancer
- Survivorship - Colorectal Cancer
# Cancer Survivorship at LCI

## Survivorship Medical Clinic - Disease Site Overview

<table>
<thead>
<tr>
<th>Disease</th>
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<tbody>
<tr>
<td>Breast Cancer</td>
<td>Endometrial Cancer</td>
<td>Epithelial Ovarian</td>
<td>Kidney Cancer</td>
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<td>Fallopian Tube</td>
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<td>Primary Peritoneal Cancer</td>
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<td>Bladder Cancer</td>
<td>Thyroid Cancer</td>
<td>Non-Epithelial Ovarian</td>
<td>Lung Cancer</td>
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<td>Cervical Cancer</td>
<td>Non-Hodgkin Lymphoma</td>
<td>Testicular Cancer</td>
<td>Small Cell Lung Cancer</td>
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<td>Colorectal Cancer</td>
<td>Head and Neck Cancer</td>
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<tr>
<td>Prostate Cancer</td>
<td>Gastric Cancer</td>
<td>Hodgkin Lymphoma</td>
<td>Pancreatic Cancer</td>
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## Referral

- Survivorship Medical Clinic - Provider Information
- Survivorship Medical Clinic - Patient Information

For referrals to the LCI Survivorship Medical Clinic, follow these steps in Encompass:
- Visit LCI Survivorship Medical Clinic

## Screening, Vaccination, Health Promotion

- Vaccination Recommendations
- Health Promotion
Cancer Survivorship at LCI

**Survivorship - Breast Cancer**

- Surveillance
  - H&P Recommendations
  - Laboratory Recommendations
  - Imaging
  - Patient Education

- Long-Term and Late Effects of Breast Cancer and Treatment

- Indications for Genetic Counseling

- Screening Protocols for Second Cancer Primaries
• 67-year-old female, referred to SMC by her PCP who had also just heard a presentation about our clinic
• At age 40, felt a lump in her left breast
• Left breast cancer with 1 positive lymph node
• Treated with chemotherapy, surgery, radiation therapy, and 5 years of Tamoxifen.
• Mild lymphedema
- Past Medical History
  - Heart disease with myocardial infarction in 1997
  - Hypertension – treated
  - Hyperlipidemia - Treated
  - Osteopenia

- Family History – heart disease, leukemia

- Social History – 2 children and multiple grandchildren
MR, Breast Cancer 27 years ago

**Surveillance for Breast Cancer Recurrence**

**H&P**
- Every 3-6 months x 1 year including clinical breast exam (CBE)
- 6-12 months next 4 years including CBE
- Annually thereafter including CBE

**Laboratory:** no routine testing

**Imaging**
- Annual mammogram
  - Should begin 6 months after radiation therapy in those receiving radiation therapy
  - Any imaging of the reconstructed breast is not indicated
- MRI only if meets high-risk criteria
  - BRCA mutation – start at 25
  - 1st degree relative of BRCA mutation but untested – start at 25
  - Lifetime risk of 20% or greater by predictive model
  - Radiation to chest wall between ages 10-30
  - Other inherited syndromes (Li-Fraumeni, Cowden)
MR, Breast Cancer 27 years ago

- Screening for second cancer primary
  - Breast - Mammograms
  - Cervical – Done (over 65, 2 previous normal HPV and Cytology)
  - Colorectal – due 2018
  - Endometrial - Education
  - Lung Cancer - Nonsmoker
MR, Breast Cancer 27 years ago

• Assess need for cancer genetics consultation
  (NCCN Guidelines Version 2.2016)
  • Women with age < 50 y at diagnosis
  • Women with > 1 primary breast cancer (in same breast or both breasts, simultaneously or at different times)
  • Women with age ≤ 60 y at diagnosis with “triple negative” breast cancer
  • Women with
    ≥ 1 close blood relative* with breast cancer diagnosed ≤ 50 y
    ≥ 1 close blood relative* with ovarian cancer, or
    ≥ 2 close blood relatives* with breast cancer and/or pancreas cancer
  ≥ 1 male close relative with breast cancer
MR, Breast Cancer 27 years ago

- Is genetic counseling for inheritable cancer risk genes indicated?
- Has genetic testing previously been done?
- When was it done?
- Are there new tests to consider?
MR, Breast Cancer 27 years ago

• Assess need for cancer genetics consultation
  Breast Cancer (NCCN Guidelines Version 2.2016)

• DW was 40 at time of original diagnosis therefore met criteria for genetics consultation
  • Breast cancer screening techniques
  • Risk for Ovarian Cancer
  • Risk for children and grandchildren
MR, Breast Cancer 27 years ago

Assess/Manage cancer-related health problems:

- Lymphedema left arm
- ASCVD
- Radiation risk for skin and soft-tissue cancer
- Bone health
MR, Breast Cancer 27 years ago

Health Promotion

• Vaccination Needs
• Healthy Weight
• Physical Exercise
• Dietary Pattern
• Tobacco
• Alcohol
MR, Breast Cancer 27 years ago

- 4/13/2017 Survivorship visit
- 4/24/2017 Genetic Counseling visit

Pathogenic mutation in BRCA2 gene found
Pathogenic Mutation in BRCA2 Gene

- Breast Cancer Screening
  - 84% lifetime risk
  - 12% risk second primary within 5 years
- Ovarian Cancer Risk-Reduction Surgery
  - 27% lifetime risk
- Melanoma Risk Awareness
- Pancreatic Cancer Risk Awareness
Pathogenic Mutation in BRCA2 Gene

• Family
  • Brother
  • Son
  • 2 Daughters
  • Grandchildren
Assessment and Management of Long-Term and Late Effects

- Surgery Effects
- Radiation Therapy Effects
- Hormonal Therapy Effects
- Chemotherapy Effects
- Immunotherapy Effects
Benefits of Radiation Therapy

• Significant improvements in disease free survival
• Often with less morbidity and mortality of alternative treatment
• Better and better at limiting side effects
• A personal Thank You
Assessment and Management of Long-Term and Late Effects
Long-Term and Late Effects: XRT

• Body Image Concerns
  • What concerns YOU?
  • Referrals for
    • Cosmetic changes
    • Adaptive devices
    • Psychosocial care

• Radiation Fibrosis
  • Physical changes in soft tissue
    • Are changes consistent with expected treatment response?
Long-Term and Late Effects: XRT

• Lymphedema
  • Meticulous skin and nail care to prevent infection
  • Weight Loss Counseling
  • PT or OT for progressive resistance training
  • Lymphedema Clinic
    ▪ Therapeutic exercise
    ▪ Manual lymphatic drainage
    ▪ Limb compression
Long-Term and Late Effects: XRT

• Cardiovascular Disease

• In early stage breast cancer treated with radiation therapy, heart disease is now the most common cause of death.

• Usually appears 2-3 decades after therapy

• Cardiovascular Disease

Adjuvant radiation decreased annual mortality rate from breast cancer
Adjuvant radiation increased the annual mortality rate from other causes
Death rate from CVD 1.27 (p = 0.0001)

Increased cardiovascular disease in breast cancer patients treated with XRT
with a particularly strong association in smokers
   Dutch Late Effects Cancer Cohort (J National Cancer Institute) 2007

Left vs Right breast risks. Chart survey of 961 breast cancer patients. 78 had nuclear medicine stress tests within 12 years of treatment. Positive studies in 59% who had left breast treatment vs 8% of those with right breast treatment
   Correa et al (J Clin Oncol 2007)
Long-Term and Late Effects: XRT

• Cardiovascular Disease

• Pathophysiology and Histopathology of the damage

Direct damage to blood vessel wall
Disruption of DNA
Generation of oxygen free-radicals launches inflammatory cascade
Basement membrane thickens, collagen deposition and fibrosis
Damages the tiny blood channels that feed bigger blood vessels
Plaque forms inside the blood vessel
Blockages in important spots - left main disease
Atherosclerosis

- Risks:
  - Radiation therapy before 2012
  - Radiation therapy to the anterior or left chest wall
  - Amount of Radiation Therapy (> 30 Gy)
  - Chemotherapy (anthracyclines or traztuzumab)
  - Other cardiovascular risk factors

- Monitoring – evaluate symptoms; routine screening/testing
- Manage blood pressure, cholesterol and blood sugar
- Lifestyle – smoking cessation, diet, exercise
Long-Term and Late Effects: XRT

• Cardiovascular Disease

All heart components get zapped – effects show up decades later

Pericardium (the sac around the heart):
  Incidence has dropped from 20% to 2.5% with better techniques
  10-20% of those get chronic pericarditis 5-10 years later

The heart muscle:
  Can get scarring and fibrosis throughout the muscle
  Heart muscle doesn’t relax well in between beats

Heart valves

Conducting system
Long-Term and Late Effects: XRT

- Risk of Skin Cancer including Melanoma
  Alert to risk and monitor for signs

- Musculoskeletal Health

  Joint pain and mobility – Where any major joints in the radiation field?
  Exercise Therapy - 20% reduction in pain with vigorous exercise
  Acupuncture
  Physical Therapy
  Rehab
Long-Term and Late Effects: XRT

• Pelvic Radiation Therapy Effects
  Bladder, Cervical, Colorectal, Testicular Cancers

• Secondary cancer risks
  • Skin cancers including melanoma
  • Soft tissue cancers
  • Bladder cancer

• Musculoskeletal Health

• Lymphedema
Long-Term and Late Effects: XRT

- Pelvic Radiation Therapy Effects

- Bladder dysfunction is a common long-term concern for those receiving pelvic radiation

- 20-50% of patients may have treatment-induced bladder symptoms

- Mechanism
  - Fibrosis of bladder wall
  - Weakening of pelvic floor muscles
  - Thinning of bladder lining
  - Urethral stricture formation
Long-Term and Late Effects: XRT

• Pelvic Radiation Therapy Effects
  • Treatment of Incontinence/Bladder irritability
    • Timed voiding
    • Pads and protective garments
    • Weight loss
    • Avoid bladder irritants: caffeine, citrus, tomatoes, diet sodas
  • Treatment/avoidance of constipation
  • Pelvic floor rehabilitation
Long-Term and Late Effects: XRT

• Pelvic Radiation Therapy Effects

• Treatment of Incontinence/Bladder irritability
  • Drugs
  • Botox
  • Tibial nerve stimulation
  • Surgical options
Long-Term and Late Effects: XRT

• Pelvic Radiation Therapy Effects
  • Vaginal Dryness and Pain
  • Prostate
  • Erectile Dysfunction
  • Bowel – acute and chronic
    • Bleeding, Fistula tracts, Blockage, Diarrhea, Incontinence
Long-Term and Late Effects: XRT

• Pelvic Radiation Therapy Effects

• Bone fractures in the pelvis
  • Bone density testing
  • Exercise
  • Don’t smoke
  • Vitamin D

• Aorta
Long-Term and Late Effects: XRT

- Pelvic Radiation Therapy Effects
  - Bone Marrow
    - Risk for leukemia
    - Higher radiation dose
    - Use of Cisplatin
Long-Term and Late Effects: XRT

• Head and Neck

• Dry Mouth
  • Moist soft foods, room humidifier
  • Artificial saliva
  • Mouth and dental care
  • Medications of limited use
Long-Term and Late Effects: XRT

• Head and Neck

• Bone damage 5-7%
  • Osteoradionecrosis (blood vessel effect)
    • Pain
    • Bad breath
    • Infections
    • Difficult chewing and swallowing
    • Bone fracture
Long-Term and Late Effects: XRT

- Head and Neck
  - Difficulty swallowing
  - Difficulty with speech
  - Dental Decay
  - Mouth Infections
  - Changes in taste
Dental Decay: disruption of salivary flow and composition as well as direct damage to dental structures from treatment.

- Regular dental care to prevent caries and gingival disease
- Avoid tobacco, alcohol (including mouthwash), spicy or abrasive foods, extreme temperature liquids, sugar-containing gums and soft drinks, acidic or citric liquids
- Daily care with soft toothbrush and floss
- Prescription 1.1% sodium fluoride toothpaste
- Drink fluorinated tap water, not bottled water
Long-Term and Late Effects: XRT

• Head and Neck
  • Affect muscles and nerves
    • Jaw Motion
    • Neck Motion

• Blood vessels
  • Carotid Artery
  • Baroreceptors

• Thyroid Gland
Long-Term and Late Effects: XRT

• Head and Neck

• Vision
  • Early cataracts
  • Retinal and Optic Nerve damage

• Hearing
Long-Term and Late Effects: XRT

• Lungs

• Skin sensation
Cancer Survivorship

• It’s complicated
• Need a programmatic approach which EAPathways facilitates
• There are a paucity of guidelines
• LCI volume creates an opportunity to set the standard for screening protocols
Center for Supportive Care and Survivorship
Center for Supportive Care and Survivorship

- Expert clinical care for cancer survivors:
  - Survivorship Medical Clinic
  - Gyn Survivorship Medical Clinic
  - Survivorship Cardio-Oncology Clinic
  - Integrative Oncology Clinic
  - Psychiatry Clinic
  - Palliative Medicine Clinic
  - Cancer Rehab Clinic
  - Senior Oncology Clinic
  - Neuropsychiatry

Support Oncology Services
- Healing Touch
- Oncology Massage
- Shared Medical Acupuncture
- Group Tai Chi
- Integrative Pharmacy Consult
- Sleep 101 Workshop
- Psychotherapy

Supportive Oncology Services offered at other locations:
- Cancer Rehabilitation
- Oncology Nutrition
- Patient & Family Cancer Resource Center
- Patient Navigation
- Quit Smart
- Senior Oncology
- Social Work & Counseling
- Spiritual Care
- Survivorship Care Planning
Cancer Survivorship

Questions Welcome

Answers Invited