Survivorship in Cancer Care: How to Deal with Long Term Toxicities and Quality of Life
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Survivorship in Cancer Care: How to Deal with Long Term Toxicities and Quality of Life

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15th Annual Miami Cancer Meeting
Learning Objectives

1. Identify the various types of survivorship models based on practice/ institution needs
2. Review common challenges and help identify patients' "new normal"
3. Review integration of guideline based survivorship care based on individual practices
4. Discuss examples of a survivorship program
Expanding Field of Survivorship

- New field of research and care
- Survivors face persistent, diverse challenges

Cardiac Health  |  Psycho-social Needs  |  Obesity  |  Sexual Health
Surveillance  |  Long-term Healthcare Costs  |  Disparities  |  Oncologist-PCP Coordination
Keep Focus on the Needs of the Patient

- Patient-reported outcomes
- Palliative care
- Survivorship
Estimated and Projected 1977-2022

2016: ACS/NCI – estimates > 15.5 million cancer survivors
Cancer Survivorship Statistics, 2016

As of January 1, 2016

**Male**
- Prostate: 3,306,760
- Colon & rectum: 724,690
- Melanoma: 614,460
- Urinary bladder: 574,250
- Non-Hodgkin lymphoma: 361,480
- Kidney & renal pelvis: 305,340
- Testis: 266,550
- Lung & bronchus: 238,300
- Leukemia: 230,920
- Oral cavity & pharynx: 229,880
- **Total survivors:** 7,377,100

**Female**
- Breast: 3,560,570
- Uterine corpus: 757,190
- Colon & rectum: 727,350
- Thyroid: 630,660
- Melanoma: 612,790
- Non-Hodgkin lymphoma: 324,890
- Lung & bronchus: 288,210
- Uterine cervix: 282,780
- Ovary: 235,200
- Kidney & renal pelvis: 204,040
- **Total survivors:** 8,156,120

As of January 1, 2026

**Male**
- Prostate: 4,521,910
- Colon & rectum: 910,190
- Melanoma: 848,020
- Urinary bladder: 754,280
- Non-Hodgkin lymphoma: 488,780
- Kidney: 429,010
- Testis: 335,790
- Lung & bronchus: 303,380
- Oral cavity & pharynx: 293,290
- **Total survivors:** 9,983,900

**Female**
- Breast: 4,571,210
- Uterine corpus: 942,670
- Colon & rectum: 885,940
- Thyroid: 885,590
- Melanoma: 811,490
- Non-Hodgkin lymphoma: 436,370
- Lung & bronchus: 369,990
- Uterine cervix: 286,300
- Kidney & renal pelvis: 284,380
- Ovary: 280,940
- **Total survivors:** 10,305,870

CA: A Cancer Journal for Clinicians
Volume 66, Issue 4, pages 271-289, 2 JUN 2016 DOI: 10.3322/caac.21349
Who is a “Survivor”?  

- A cancer survivor is anyone who has been diagnosed with cancer – from the time of diagnosis and for the balance of his or her life.

- An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.
  - Family members, friends, and caregivers are also impacted by the survivorship experience and are included in this definition.
Types of Survivorship Models
Multidisciplinary Cancer Survivorship Care

- Oncology
- Surgery
- Radiation Oncology
- Primary Care
- Specialists
- Support Services/Lifestyle
- Sexual Health/GYN/Urology/Fertility Preservation
- Cancer Rehab/OT/PT/Palliative Care
- Genetics
- Endocrine/Bone Health
- Cardiology
- Cancer Survivorship
Models of Survivorship Care

- Oncology Specialist Care
  - Follow-up care occurs with treating oncologist
  - Relationship with oncologist; high risk of recurrence
  - Focus remains on illness, not wellness
  - Primary care needs are unmet

- Multi-Disciplinary Survivorship Clinic
  - Extensive team and resources (pediatric, adolescent & young adult)

- Disease /Treatment Specific Survivor Clinic
  - Oncology setting
Models of Survivorship Care

- General Survivorship Clinic
  - Care for all, financially efficient
  - Limited expertise
- Consultative Survivorship Clinic
  - One time visit, no follow up required
- Integrated Survivorship Clinic
  - Part of survivorship team, communicate with all providers
Models of Survivorship Care

- Community Generalist Model
  - Care done by primary care provider
  - Focus on wellness
  - Limited provider knowledge

- Shared-Care of Survivor
  - Shared care between PCP and oncologist
  - With transition/Without transition
Question #1

Which of the following is an accurate description of a general survivorship clinic model?

A. One time visit (no follow up required)
B. Financially efficient
C. Extensive experience
D. Care provided by PCP
Common Challenges and Help Identify Patients' "New Normal"
“New Normal”

- The end of cancer treatment is often a time to rejoice. Most likely you're relieved to be finished with the demands of treatment. You may be ready to put the experience behind you and have life return to the way it used to be. Yet at the same time, you may feel sad and worried. It can take time to recover. And it's very common to be thinking about whether the cancer will come back and what happens now. Often this time is called adjusting to a "new normal." You will have many different feelings during this time.

Common Challenges

- “It is as if we had invented sophisticated techniques to save people from drowning, but once they had been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can.”
  - Dr. Fitzhugh Mullan
Case Study – Common Challenges

- 57 year old Hispanic female
- Married for 19 years
- 2 children (12 & 18 years old)
- Menopausal x 2 years
- Police officer
- No family history of cancer
May 2016:
Incidental finding in shower –
right breast palpated a “lump”

May 2016: saw PCP,
mammogram ordered
which showed a 2cm nodule

June 2016: ultrasound
guided biopsy
DX: invasive ductal
carcinoma of right breast
ER/PR + HER2 -

First contact with nurse
navigator who arranges
consults with surgical
oncology and medical
oncology at breast center

SLN biopsy
#1/3 LN positive
Genetic counseling:
negative for BRCA 1 & 2 mutations
Oncotype testing:
Result – 9

Complete work up
MRI & Labs

radiation oncology
Treated for 5 weeks
with IMRT to right breast
Case Study – Common Challenges

- Late August 2017: seen in f/u and RX anastrozole
- November 2017: seen in survivorship clinic
Physical Changes

- Fatigue
- Bone Loss
- Brain Changes
- Endocrine System Changes
- Hearing Loss
- Heart Problems
- Musculoskeletal Changes
- Lung Problems
- Sexual changes/decreased libido
- Lymphedema
- Mouth Changes
- Infertility
- Neurologic Changes
- Kidney & Liver Issues
- Scars
- Chronic Pain
- Second Primary Cancer
Psychosocial

- Depression
- Anxiety
- Fear of Recurrence
- Body Image disturbances
- Family Issues (changes in interpersonal relationships)
- Unrealistic expectations
- Finances (health or life insurance, job loss)

- New Normal (return to work/school)
- Depression, anxiety (fear of recurrence), uncertainty, isolation, altered body image
- Existential/spiritual issues
- Sense of purpose or meaning, appreciation of life
# Case Study – Common Challenges

**National Comprehensive Cancer Network distress thermometer**

<table>
<thead>
<tr>
<th>NCCN DISTRESS THERMOMETER</th>
<th>PROBLEM LIST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.</td>
<td></td>
</tr>
</tbody>
</table>

**Extreme distress**
- 10
- 9
- 8
- 7
- 6
- 5
- 4
- 3
- 2
- 1
- 0
**No distress**

**YES NO**

<table>
<thead>
<tr>
<th>Practical Problems</th>
<th>Physical Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child care</td>
<td>Appearance</td>
</tr>
<tr>
<td>Housing</td>
<td>Bathing/dressing</td>
</tr>
<tr>
<td>Insurance/Financial</td>
<td>Breathing</td>
</tr>
<tr>
<td>Transportation</td>
<td>Changes in urination</td>
</tr>
<tr>
<td>Work/school</td>
<td>Constipation</td>
</tr>
<tr>
<td>Treatment decisions</td>
<td>Diarrhea</td>
</tr>
</tbody>
</table>

**Family Problems**
- 1. Dealing with children
- 2. Dealing with partner
- 3. Ability to have children
- 4. Family health issues

**Emotional Problems**
- 1. Depression
- 2. Fears
- 3. Nervousness
- 4. Sadness
- 5. Worry
- 6. Loss of interest in usual activities

**Spiritual/Religious concerns**

**Other Problems:**

Be sure to check YES or NO for each.

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NCCN = National Comprehensive Cancer Network

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Sexual dysfunction

“I don’t know why, but I feel like a crazy person. I will be standing in front of a fan, in the middle of a restaurant, just to cool off. I have the same sensation at night sometimes too. I have gained weight and feel ugly. My husband thinks I’m “better” but I'm not. The LAST thing I feel like doing is being sexually intimate with him. I feel ugly and when we do have sex it’s painful! I really don’t want to and I just don’t have the desire.”
Sexual Dysfunction
J Clin Oncol 30, 2012 (suppl 27; abstr 67): perceived sexual dysfunction

- 30 question survey
  - 23% discussed the issue with a care provider while 60% desired a physician initiated conversation
    - fatigue, hot flashes, scars, dyspareunia, and breast

Conclusion
- Patients do not feel this issue is addressed during routine care.
- Majority of patients want this issue discussed with their physicians.
Sexual Dysfunction

**Concerns**
- Physiologic & emotional
- Fear of intimacy
- Decreased libido
- Vaginal dryness
- Vaginismus
- Reduced/shortened vaginal size
- Pain with intercourse
- Body self-image
- Interpersonal relationships

**Barriers**
- Providers don't address the issue(s)
- Providers don't have the training
- Embarrassment
- Time constraints
- Resources not identified
- Focus on other symptoms/issues
- Don't ask for help/burden provider
- Assume provider will address if important

Barsky, J 2017 Journal Cancer Survivorship
Sexual Dysfunction

**Disorders of desire**
- Psychoactive medications
- Antipsychotics
- Barbiturates
- Benzodiazepines
- Lithium
- SSRIs
- Tricyclic antidepressants
- Cardiovascular and antihypertensive medications
- Lipid-lowering medications
- Beta blockers
- Clonidine
- Digoxin
- Spironolactone
- Hormone preparations

**Orgasmic disorders**
- Amphetamines and related anorexic drugs
- Antipsychotics
- Antipsychotics
- Benzodiazepines
- Methyldopa

**Narcotics**
- SSRIs
- Trazodone
- Tricyclic antidepressants

**Disorders of arousal**
- Anticholinergic agents
- Antihistamines
- Antihypertensives
- Antipsychotics
- Benzodiazepines
- Methyldopa
- Narcotics
- SSRIs
- Trazodone
- Tricyclic antidepressants

SSRI = selective serotonin receptor inhibitor

Obstetrics and Gynecology Volume 11, Part 1
Case Study – Common Challenges

Sexual Changes/decreased libido

- Pharmacology
- Couples therapy, cognitive-behavioral therapy (psychologist, psychiatrist, sex therapist, urologist, gynecologist)
- Lifestyle modifications (light exercise, exercise physiologist)
- Guided imagery
- Dilators
- Water based lubricants
- Local estrogens

Dynamic Process

Physical/Medical

Psychosocial

Social/Well being

Psychosocial

Spiritual/Existential
Question #2

- For cancer patients, adjusting to a “new normal” often means dealing with:
  A. Feelings of distress, sadness, and worry
  B. Sexual dysfunction
  C. Spiritual changes
  D. A & C
  E. All of the above
Integration of Survivorship Care
Guidelines

- Commission on Cancer requirements
  - Cancer programs must develop and implement processes to monitor the formation and dissemination of a SCP for analytic cases with Stage I, II, or III cancers that are treated with curative intent for initial cancer occurrence and who have completed active therapy.
  - The survivorship care plan is given and discussed with the patient upon completion of active, curative treatment and recorded in the patient medical record. The timing of delivery of the SCP is within one year of the diagnosis of cancer and no later than six months after completion of adjuvant therapy (other than long-term hormonal therapy). The ‘one year from diagnosis’ requirement to have a SCP delivered is extended to 18-months for patients receiving long-term hormonal therapy. Providing the SCP by mail, electronically, or through a patient portal without discussion with the patient does not meet the standard.

SCP = survivorship care plan
https://www.facs.org/quality-programs/cancer/coc/standards
Guidelines

- Commission on Cancer requirements
  - Nationally Certified Breast Center
    - Include: DCIS

SCP = survivorship care plan
https://www.facs.org/quality-programs/cancer/coc/standards
Question #3

According to the Commission on Cancer, requirements of a survivorship care plan (SCP) must include:

A. An SCP is required for all patients with cancer regardless of whether they are receiving treatment for curative or palliative intent

B. Delivery of the SCP by mail, electronically, or through a patient portal is an acceptable alternative to an in-person discussion

C. Delivery of the SCP must be within 6 months of the diagnosis of cancer

D. The timeline for delivery of the SCP is lengthened for patients receiving long-term hormonal therapy
Examples of a Survivorship Program
One Example

- Sylvester Comprehensive Cancer Center
  - Oncology Specialist Care
  - Breast Clinics
  - Consultative Survivorship Clinic
  - All other specialties
Other Examples

- **Florida Cancer Specialists**
  - Consultative Survivorship Clinic
  - Integrated Care

- **University of Kansas Cancer Center**
  - Consultative Survivorship Clinic
  - Oncology Specialist Care
What’s Important?

- Who does what: understanding of roles and responsibilities of care
- Knowledge transfer
  - Treatment summary and care plan
    - Information on disease, late & long-term effects, follow up
  - Healthy living tips
  - Trusted resources
    - Local, community, national
What’s Relayed?

- **Survivorship Care Plan:**
  - Healthcare providers
  - Diagnosis and Stage
  - Treatment (surgery, chemotherapy, radiation)
  - Long term side effects
  - Information on recurrence or new primary DX
  - Follow up schedule

- **Resources & Healthy Living tips**
  - UM resources and contact information
  - South Florida and National resources
  - ACS and NCCN guidelines for Healthy Living
  - Additional: flyers or informational sheets
Eating smarter and being more active will help you feel better and reduce your cancer risk. These guidelines for nutrition and physical activity were developed by the American Cancer Society to help you reduce your risk of cancer.

**How Can I Use These Guidelines?**

You may already be following one or more of these guidelines. If you are not sure what to do, now is a great time to start.

**Get to and Stay at a Healthy Weight Throughout Your Life**

* Aim to be as lean as possible without being underweight.
* Try to eat less and be more active to reduce your risk of cancer.

**The Right Weight**

Knowing your body mass index (BMI) can tell you if your weight is right for your size and height. You can find your BMI using a simple chart such as the one online at: [http://www.cancer.org/living/healthyweight/healthyweight-bmi-calculator](http://www.cancer.org/living/healthyweight/healthyweight-bmi-calculator). This chart helps you to see where your weight falls, based on your height.

**Be Physically Active**

Physical activity can lower the risk of several types of cancer by helping you get in and stay at a healthy weight and by affecting the levels of some hormones that can increase cancer risk.

**How Much Activity Do You Need?**

- **Adults**: Get at least 150 minutes of moderate-intensity aerobic activity each week, in any combination of activities. 20 minutes of vigorous activity each week is even better.
- **Children and Teens**: Get at least 60 minutes of moderate to vigorous activity each day. A variety of physical activities are needed.

**Don’t Be a Couch Potato**

- Spend less time sitting and more time doing things that require standing or walking.

**It Adds Up**

Your body doesn’t need to be active all at once, but it’s more valuable if done at least 30 minutes of a time.

**Eat a Variety of Healthy Foods, With an Emphasis on Plant Sources**

Choose foods and beverages to improve your health and your quality of life.

**Eat These Food Labels**

- Read food labels to make sure you are getting the nutrients you need.

**Tips for Healthy Living**

- **ACS = American Cancer Society**
- **CDC 2009 reports only 14% of adults eat recommended servings/day**
- **Lester Intensive Cancer Center**
- **University of Miami Health System**
What’s Important?

- Communication channels
  - Contact information for providers and nurses

- Active patient involvement
  - Encouraged to contact providers with problems
  - Provide the information given to the primary care providers
Questions?
"It's exciting! Everyone on campus is talking about Survivorship."
- UM Sylvester ARNP

"This is exactly what I needed"
- Survivorship Clinic patient

"So other people feel the guilt that I do? That I survived and did well..."
- Survivorship Clinic patient