Improving Care for Post-Treatment Cancer Survivors in the Primary Care Setting

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Disclosure

I have no disclosures
Acknowledgments for Survivorship Care Plan Survey

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Academy of Oncology Nurse & Patient Navigators
Commission on Cancer
Oncology Nursing Society
GATE Survivorship Special Interest Group
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LIVESTRONG
Advisory Board Members
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Learning Objectives

• Summarize the needs of post-treatment cancer survivors.
• Identify tools, guidelines and resources to guide post-treatment survivorship care.
What is Cancer Survivorship?
Who is a Cancer Survivor?
In the early 1950’s, Franny Rosenow, a breast cancer survivor and cancer advocate called the New York Times to post an advertisement for a support group for women with breast cancer. Rosenow was put through, puzzlingly, to the society editor of the newspaper.

When she asked about placing her announcement, a long pause followed. ‘I’m sorry, Ms. Rosenow, but the Times cannot publish the word breast or the word cancer in its pages. ‘Perhaps,’ the editor continued, ‘you could say there will be a meeting about diseases of the chest wall.’ Rosenow hung up, disgusted.

Mukherjee, 2010.
## National Academy of Medicine (Institute of Medicine) Recommendations *From Cancer Patient to Cancer Survivor: Lost in Transition*

<table>
<thead>
<tr>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish Cancer Survivorship as Distinct Phase of Care</td>
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<tr>
<td>Provide Survivorship Care Plan</td>
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<tr>
<td>Use Evidence-Based Clinical Guidelines</td>
</tr>
<tr>
<td>Develop Quality Survivorship Care Measures</td>
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<tr>
<td>Demonstrate and Test Survivorship Care Programs</td>
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<tr>
<td>Include Survivorship in Comprehensive Cancer Control Plans</td>
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<tr>
<td>Provide Educational Opportunities to Health Care Providers</td>
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<tr>
<td>Access to Affordable Health Insurance and Address Employment Issues</td>
</tr>
<tr>
<td>Expand Funding for Survivorship Research</td>
</tr>
</tbody>
</table>

*IOM, 2006.*
Focus on Survivorship

American Cancer Society, 2016.
Louisiana Average Annual Cancer Incidence Rates by Gender and Race, per 100,000 (2009-2013)

- **Lung**
  - White Men: 110.6
  - African American Men: 57.8
  - White Women: 86.8
  - African American Women: 50.8

- **Colorectum**
  - White Men: 69.9
  - African American Men: 38.6
  - White Women: 53.4
  - African American Women: 51.2

- **Prostate**
  - White Men: 213.1
  - African American Men: 136.1
  - White Women: 121.7
  - African American Women: 130.9

*Maniscalco et al. (Eds.), 2015.*
African American Cancer Disparities

• For majority of cancer types—greater mortality and shorter survival of any racial/ethnic group

• Instances of not receiving same cancer treatment care

• Barriers to care across continuum include lack of insurance, patient/provider communication, time off work, transportation

Hispanic/Latino Cancer Disparities

- Hispanic/Latina women have the highest incidence rate of cervical cancer compared to all other groups.
- Hispanics/Latinos also have higher rates of liver cancer, stomach and gallbladder cancer.
- Hispanics/Latinos are more likely to be diagnosed with later stage disease.
- Hispanics/Latinos are less likely to be insured compared to any other group.

National Cancer Institute, 2008; American Cancer Society, n.d.
Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) Cancer Disparities

- Higher rates of lung, breast, cervical, liver, anal cancer
- 14% of lesbians and 17.6% of bisexual women as compared to 11.9% heterosexual women report ever having had cancer
- Poorer mental health: depression, anxiety, suicidal ideation
- Avoidance of medical care
- Life-altering sequelae

Impacts of Cancer

Skolarus et al., 2014; El-Shami et al., 2015; Runowicz et al., 2015; Cohen et al., 2016.
Patient Perspectives: Impact of Cancer and Its Treatment

Kristin’s Experience: Long-term and Late Effects from Colorectal Cancer Treatment

Sam’s Experience: Long-term and Late Effects from Head and Neck Cancer Treatment

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WASHINGON, DC

GW Cancer Center
Cancer Survivor Needs

**Physical Well-Being**
- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain

**Psychological Well-Being**
- Control
- Anxiety
- Depression
- Fear of recurrence
- Cognition/attention

**Social Well-Being**
- Family distress
- Roles and relationships
- Affection/sexual function
- Appearance
- Isolation
- Finances/employment

**Spiritual Well-Being**
- Meaning of illness
- Religiosity
- Transcendence
- Hope
- Uncertainty
- Inner strength

Bird’s Eye View of Survivorship Care
• Role of Primary Care Providers in Survivorship Care

• Survivorship Care Plans

• Survivorship Care Guidelines

• Survivorship Care Models
Care Coordination
Primary Care Providers’ Role in Cancer Survivorship Care

• PCPs should play an active role in the care coordination of cancer survivors by:
  – Promoting healthy behaviors
  – Assisting in the surveillance for cancer recurrence and second primary cancers
  – Assessing and managing physical and psychosocial long-term and late effects
  – Clarifying care roles when needed with other members of the cancer treatment team
Survivorship Care Plans (SCP)

- Key survivorship component
- Road map for post-treatment care
- Tool for care coordination and communication

*Mayer et al., 2014.*
Review of ASCO Core Data Elements: Treatment Summary

- **Contacts**
  - Information of the treating institutions and providers

- **Surgery (y/n)**
  - If yes:
    - Surgical procedure with location on the body
    - Date of surgery (year required, month optional, day not required)

- **Chemo (y/n)**
  - If yes:
    - Names of systemic therapy agents administered (including individuals’ names rather than regimens)
    - End date of chemo treatment (year required, month optional, day not required)

Mayer et al., 2014.
Review of ASCO Core Data Elements: Treatment Summary (continued)

RT (y/n)
- If yes:
  - Anatomic area treated with radiation
  - End date of RT (year required, month optional, day not required)

Toxicity
- Ongoing toxicity or adverse effects of all treatments received
  - Including those resulting from surgery, systemic therapy, and/or radiotherapy at the completion of treatment
  - Any information concerning the likely course of recovery from these toxicities should also be covered

Genetic/Hereditary
- For selected cancers, genetic or hereditary risk factors or predisposing conditions and genetic testing results if performed

Mayer et al., 2014.
### Review of ASCO Core Data Elements: Follow-Up Care Plan

<table>
<thead>
<tr>
<th>Contacts</th>
<th>Oncology team member contacts with location of the treatment facility (repeat if separate document)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjuvant Therapy</td>
<td>Need for ongoing adjuvant therapy for cancer (include: Adjuvant therapy name, Planned duration, Expected adverse effects)</td>
</tr>
<tr>
<td>Follow-up</td>
<td>Schedule of follow-up–related clinical visits. To be presented in table format—to include: who will provide follow-up visits and how often and where these will take place</td>
</tr>
<tr>
<td>Surveillance</td>
<td>Tests for recurrence. To be presented in table format—to include: who is responsible for ordering or carrying out the tests, the frequency of testing, and where these will take place</td>
</tr>
<tr>
<td>Other periodic tests and exams</td>
<td>Rather than outlining specific testing, the group suggested an inclusion of a general statement to “continue all standard non–cancer-related health care with your primary care provider, with the following exceptions: [if there are any]”</td>
</tr>
</tbody>
</table>

*Mayer et al., 2014.*
Review of ASCO Core Data Elements: Follow-Up Care Plan (continued)

<table>
<thead>
<tr>
<th>Possible symptoms of recurrence</th>
<th>Rather than including a list of possible symptoms, the group suggested inclusion of a general statement: “Any new, unusual, and/or persistent symptoms should be brought to the attention of your provider.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Late and/or Long-term effects</td>
<td>A list of likely or rare but clinically significant late and/or long-term effects a survivor may experience based on individual diagnosis and treatment if known (including symptoms that may indicate the presence of such conditions)</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>A list of items (eg, emotional or mental health, parenting, work/employment, financial issues, and insurance) should be covered with standard language stating that survivors have experienced issues in these areas and that the patient should speak with oncologist and/or PCP if having related concerns; include a list of local and national resources to assist the patient in obtaining proper services</td>
</tr>
<tr>
<td>Healthy Behaviors</td>
<td>A general statement emphasizing the importance of healthy diet, exercise, smoking cessation, and alcohol use reduction may be included; statements may be tailored if particularly pertinent to the individual</td>
</tr>
</tbody>
</table>

*Mayer et al., 2014.*
Commission on Cancer

Standard 3.3: Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a treatment summary and follow-up plan to patients who have completed cancer treatment. The process is monitored and evaluated annually by the cancer committee.
Commission on Cancer Accredited Organizations in Louisiana
Requirement for CoC Accreditation

2015
Provide SCPs to ≥ 10% of eligible patients

2016
Provide SCPs to ≥ 25% of eligible patients

2017
Provide SCPs to ≥ 50% of eligible patients

2018
Provide SCPs to ≥ 75% of eligible patients

Commission on Cancer, 2016.
Survivorship Care Plan Survey: Methods

- Survey was conducted between November 14, 2016 and January 21, 2017 via REDCap
- Open to anyone who created, identified, referred, developed, saved or delivered SCPs to cancer survivors
- Sample: 395 individuals
- Number of states represented: 47 and DC
- Louisiana sample size: 10

Birken, Pratt-Chapman, Zhang, Raskin & Lane, 2017.
SCP Provider Survey Instrument

1. Create and/or revise SCP templates
2. Identify survivors who are eligible to receive SCPs
3. Refer survivors to receive SCPs
4. Develop SCPs
5. Save SCPs
6. Deliver to cancer survivors
7. Deliver to follow-up care providers
8. Update SCPs

Tumor Group Served (N=395)

Birken, Pratt-Chapman, Zhang, Raskin & Lane, 2017.
Components Typically Included in SCPs (N=221)

- Prevention/detection of new/recurrent cancers
- Monitoring/surveillance for recurrence/new primaries
- Late/long-term effects
- Care coordination with providers/specialists/PCPs
- Services provided for psychosocial and medical late effects
- Recommended screenings for other cancers
- Health ed. to survivors, including their dx, treatment exposures
- Referrals to other specialists/resources
- Genetic risk assessment
- Diet/exercise/health promotion
- Financial/insurance issues
- Survivor empowerment

Birken, Pratt-Chapman, Zhang, Raskin & Lane, 2017.
Influence of SCPs on Survivors’ Ability to Optimize Health & Care

When survivors see their completed SCP with the information on treatment summary, ongoing treatment, problems/concerns from treatment, all f/u recommendations, they are very appreciative for this document. They have a document they can refer to and share with their caregivers. They also know that their health care team is given this same document so all providers have the same information. Our area experienced severe flooding following a hurricane which caused unexpected relocation for some. All survivors in our area are now cognizant of this potential problem and are especially appreciative of the SCP document that they can take with them.

Birken, Pratt-Chapman, Zhang, Raskin & Lane, 2017.
Influence of SCPs on Survivor/Provider Communication

Helps them to have a treatment record to discuss with PCP…

Limited influence…

Birken, Pratt-Chapman, Zhang, Raskin & Lane, 2017.
Influence of SCPs on Ability to Share Care

...empowers PCPs...

...Our oncologists keep patients for long-term follow up...

Birken, Pratt-Chapman, Zhang, Raskin & Lane, 2017.
Influence of SCPs on Care Coordination

[N]egligible, most of our patients continue follow up with radiation and/or medical oncology...

...The SCPs outline both to survivors and PCPs when survivors should see PCP for f/u care.

Birken, Pratt-Chapman, Zhang, Raskin & Lane, 2017.
The Need for Survivorship Care Guidelines

- Rapidly growing population of survivors
- Survivors experience unmet physical, psychosocial, practical and unmet needs
- Inconsistent coordination of care and communication between primary care providers and oncologists
- Significant long-term and late effects
- Complexity of care, comorbid conditions

American Cancer Society, 2014; Institute of Medicine, 2006.
Cancer Survivorship Clinical Practice Guidelines

**By Topic:**
- Anthracycline-induced cardiac toxicity
- Anxiety and depression
- Cognitive function
- Exercise
- Fatigue
- Healthy lifestyles
- Immunizations and infections
- Menopause-related symptoms
- Pain
- Sexual function (female/male)
- Sleep disorders

**By Cancer Site:**
- Breast (ASCO/ACS)

**By Topic:**
- Anxiety and depression
- Cardiac dysfunction
- Chronic pain
- Fatigue
- Fertility preservation
- Neuropathy
- Palliative care

**By Cancer Site:**
- Breast (ASCO/ACS)

**By Topic:**
- Holistic:
  - Care coordination
  - Health promotion
  - Long-term and late effects
  - Nutrition and physical activity
  - Screening
  - Surveillance

**By Cancer Site:**
- Breast (ACS/ASCO)
- Colorectal
- Head and neck
- Prostate
Supporting Exercise Behavior Change

• Less than 10% of cancer survivors will be active during primary treatment

• Only 20-30% will be active after they recover from treatments

• Behavioral support is needed for the majority of cancer survivors to benefit fully from regular physical activity
  – Shown to improve quality of life among cancer survivors

*ACS Nutritional Physical Activity Guidelines, 2012; Irwin et al., 2017.*
Three Emerging Models of Survivorship Care

• Data source: Environmental scan with 232 CoC-accredited institutions

• Description of Models

  ➢ Specialized consultative model
    • Formal one-time visit in specialized setting, likely led by nurse practitioner

  ➢ Specialized longitudinal model
    • Visits (2+) at structured intervals in specialized setting, likely led by nurse practitioner

  ➢ Oncology-embedded model
    • Survivorship introduced prior to end of treatment and addressed as part of continual oncology follow-up, likely to be led by Onc MD

Mead et al., 2017.
Survivorship Care Quality Framework & Index

- Identified 9 prioritized components of survivorship from cancer survivor focus groups and survey
  1) Mental health & social support
  2) Information & resources on survivorship care
  3) Empowered & engaged patients
  4) Supportive & prepared clinicians
  5) Open patient-clinician communication
  6) Care coordination & transitions
  7) Access to full spectrum of care
  8) Practical life support
  9) Having a medical home

Mead et al., 2017.
Patient Reported Services from Survivorship Care Provider

- Referral for emotional concerns: 5.3%
- Referral to understand insurance coverage for drugs: 7.3%
- Instructions on how to move care to PCP: 8.6%
- Talk about getting support: 26.5%
- Set goals to improve overall health: 41.0%
- Talk about impact of Tx: 51.0%

Mead et al., 2017.
Takeaways

• Growing movement to improve post-treatment survivorship care
• Variation in implementation of survivorship care planning and survivorship models of care
• Further research needed to clarify how providers can meet the priorities of survivors
Cancer Survivorship E-Learning Series

bit.ly/PCPE-Learning
National Cancer Survivorship Resource Center Toolkit

Provider Checklist

Patient Visit Checklist

bit.ly/NCSRCToolkit
# National Cancer Survivorship Resource Center Toolkit

## Effects Summary

<table>
<thead>
<tr>
<th>Long-term Effects</th>
<th>Acute Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start during treatment and persist</td>
<td>Start after treatment ends</td>
</tr>
<tr>
<td><strong>Surgery Effects</strong></td>
<td><strong>Drug Effects</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Chemotherapy</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Radiation Therapy</strong></td>
</tr>
</tbody>
</table>

**Fatigue**
- Decreased energy level
- Fatigue
- Difficulty concentrating
- Feeling tired all day

**Memory**
- Difficulty concentrating
- Forgetting
- Difficulty with new information

**Sleep**
- Difficulty falling asleep
- Waking up frequently

**Sexual Function and Fertility**
- Decreased sexual desire
- Decreased ability to achieve and maintain an erection
- Decreased libido

**Bone Health**
- Osteoporosis
- Fractures

**Danish**
- Pain
- Fatigue

**Hormone Therapy Effects**
- Weight gain
- Hot flashes
- Night sweats
- Changes in sex drive

**Other**
- Frequent colds
- Sinus infections
- Yeast infections

**Signs of Mental Health Problems**
- Feelings of sadness
- Feelings of hopelessness
- Changes in appetite

**Other Symptoms**
- Night sweats
- Hot flashes
- Changes in sex drive

## Guideline Summary

- **AMERICAN CANCER SOCIETY COLORECTAL CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY**

- **Assessment and Management of Long-term and Late Effects**

- **Sexual Function and Fertility**
- Decreased sexual desire
- Decreased ability to achieve and maintain an erection
- Decreased libido

- **Bone Health**
- Osteoporosis
- Fractures

- **Other**
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**bit.ly/NCSRCToolkit**
GW Cancer Center
CANCER CONTROL TAP
Tap into resources to control cancer

cancercontroltaptap.org

• Online learning modules on:
  ➢ Patient navigation
  ➢ Cancer survivorship
  ➢ Communication and Media
• CCC toolkits and guides
• Webinars and Ask-the-Expert sessions
Supporting Cancer Survivors through Comprehensive Cancer Control Programs

Generation and Translation of Evidence (GATE) Website

cancerGATE.org

• Generation and Translation of Evidence (GATE) Cancer Community of Practice brings together practitioners, researchers and patients/caregivers to disseminate patient-centered outcomes research
• Read Practice-Based Insights on patient navigation & survivorship
• View archived webinars and Ask-the-Expert (AtE) sessions on patient navigation and survivorship topics
Stay Tuned!

Webinar: *Improving Care for Post-Treatment Cancer Survivors through Effective Communication and Community-Clinical Linkages*

September 21, 2017

6:00pm CT
Discussion & Questions
Thank you!

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Sign-up for the GW Cancer Center’s Patient Navigation and Survivorship E-Newsletter: bit.ly/PNSurvEnews

Sign-up for the GW Cancer Center’s Cancer Control Technical Assistance E-Newsletter: bit.ly/TAPenews
References


Lee, R. (2000). Health care problems of lesbian, gay, bisexual and transgender patients. Western Journal of Medicine, 172(6), 403-408.

References


References


