Establishing a Survivorship Program Within a Large Academic Medical Center

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Disclosures

• I have no disclosures.
Program Goals

• Discuss the role of survivorship care in current cancer treatment
• Discuss requirements of accredited cancer programs
• Discuss best practices for creating a survivorship program
• Questions
What is Survivorship?

- Is it some new fad?
- Is it “just checking off another box?”
Survivorship in Cancer Care

• The concept of survivorship is not new, initially proposed in 2005 IOM report “From Cancer Patient to Cancer Survivor”
• ASCO released the first three survivorship care guidelines in April 2014
• Survivorship starts at the time of diagnosis.
• More than monitoring for recurrence.
• Late/After effects
• Standard of care surveillance based on disease, stage and treatment received
  – NCCN released survivorship care guidelines beginning in March 2013
Who is a survivor?

• The National Coalition for Cancer Survivorship (NCCS) pioneered the definition of a survivor as an individual from the time of diagnosis and for the balance of life. NCCS later expanded that definition of survivor even further to include family, friends and voluntary caregivers who are affected by the diagnosis in any way.
Standards of Survivorship Care

• Early detection of recurrent or new cancers and other late effects
• Surveillance of cancer spread, recurrence or secondary cancers
• Assessment of late psychosocial and medical effects
• Intervention for consequences of cancer and treatment
• Coordination of care between PCP and specialist to ensure that all survivor’s health needs are met
ASCO

• Evidence based guidelines on prevention and management of neuropathy, fatigue, depression and anxiety in cancer survivors
• Stressed screening and early intervention
• Encouraged use of supportive care resources within the institution treating, but also community resources
After effects and Late effects

• After effects are long term, or late side effects of cancer treatment. These can range in severity from mild to serious and vary from survivor to survivor

• After effects can often be delayed and can even manifest months to years after treatment has ended. The earlier these effects are identified, the easier they are to treat.

• Long term effects may develop during treatment and are chronic. They persist after treatment has concluded. Many of these effects will improve or even resolve over time, but some may be permanent.
- Physical after effects may include menopause, infertility, chronic pain, chronic infections, loss of a limb, loss of limb function, lymphedema, impotence, GI disturbance, peripheral neuropathies, and even heart disease.
- Psychological after effects may include body image change, sexuality changes, insomnia, depression, chronic fatigue, anger, anxiety and fear.
- Practical after effects can include difficulty working due to physical/emotional after effects, changes in relationships with family and loved ones, difficulty with obtaining or retaining health/life insurance, challenges communicating with healthcare providers, financial stressors, and even employment discrimination.
• After effects and late effects (both physical and psychological) can occur as late as 20 years after treatment.
• Intervening in after effects and late effects can limit their severity if done early!
• Currently, this is a very hot area of research in cancer care.
After effects
Survivorship Care

National Comprehensive Cancer Network®

Invasive Breast Cancer

SURVEILLANCE/FOLLOW-UP

- History and physical exam 1–4 times per year as clinically appropriate for 5 y, then annually
- Periodic screening for changes in family history and referral to genetic counseling as indicated
- Educate, monitor, and refer for lymphedema management
- Mammography every 12 mo
- Routine imaging of reconstructed breast is not indicated
- In the absence of clinical signs and symptoms suggestive of recurrent disease, there is no indication for laboratory or imaging studies for metastases screening
- Women on tamoxifen: annual gynecologic assessment every 12 mo if uterus present
- Women on an aromatase inhibitor or who experience ovarian failure secondary to treatment should have monitoring of bone health with a bone mineral density determination at baseline and periodically thereafter
- Assess and encourage adherence to adjuvant endocrine therapy
- Evidence suggests that active lifestyle, healthy diet, limited alcohol intake, and achieving and maintaining an ideal body weight (20–25 BMI) may lead to optimal breast cancer outcomes
- See NCCN Guidelines for Survivorship

See Recurrent Disease (BINV-17)
Survivorship Care

Ductal Carcinoma in Situ (DCIS)

DCIS POSTSURGICAL TREATMENT

Risk reduction therapy for ipsilateral breast following breast-conserving surgery:
• Consider endocrine therapy for 5 years for:
  † Patients treated with breast-conserving therapy
  (lumpectomy) and radiation therapy (category 1), especially for those with ER-positive DCIS.
  † The benefit of endocrine therapy for ER-negative DCIS is uncertain
  † Patients treated with excision alone
• Endocrine therapy:
  † Tamoxifen® for premenopausal patients
  † Tamoxifen® or aromatase inhibitor for postmenopausal patients with some advantage for aromatase inhibitor therapy in patients <60 years old or with concerns for thromboembolism

Risk reduction therapy for contralateral breast:
• Counseling regarding risk reduction

See NCCN Guidelines for Breast Cancer Risk Reduction

SURVEILLANCE/FOLLOW-UP

• Interval history and physical exam every 6–12 mo for 5 y, then annually
  † Mammogram every 12 mo (and 6–12 mo postradiation therapy if breast conserved [category 2B])
  † If treated with endocrine therapy, monitor per NCCN Guidelines for Breast Cancer Risk Reduction
Cancer Survivorship = Chronic disease?

- A complex chronic disease is one that affects multiple organ systems, involves multiple morbidities, requires the attention of multiple health care providers and presents patients with unique needs, disabilities or limitations.
- Nervous system: difficulty with concentration and memory problems, peripheral neuropathy, pain
- Cardiovascular: cardiomyopathies (anthracyclines, antiangiogenic tx, XRT), ASCVD, HTN, valvular disease
- Respiratory: changes in lung function, scarring, inflammation (surgery, bleomycin, methotrexate, long term corticosteroids, XRT)
- Hematopoietic: anemia, increased risk for blood clots (or treatment of blood clots)
Cancer Survivorship = Chronic disease?

• Reproductive: Early onset menopause (surgery, meds)
• Endocrine: Thyroid, diabetes (surgery, steroids, XRT)
• Psychiatric: depression, anxiety
• Immunity: depressed immune system (surgery, chemo)
• Insomnia & Chronic fatigue: multi-factorial
## Screening

- **Screening for cancer recurrence (standard risk*)**

<table>
<thead>
<tr>
<th>Site</th>
<th>Test for cancer recurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>Mammogram yearly</td>
</tr>
<tr>
<td>Prostate</td>
<td>PSA, digital rectal exam</td>
</tr>
<tr>
<td>Lung</td>
<td>Chest CT</td>
</tr>
<tr>
<td>Colorectal</td>
<td>C/A/P CT annually x 305 yrs, CEA q 3-6 months for up to 5 years, C-scope 1 5 yrs/rectosigmoidoscopy q 6-12 months x 3-5 yrs</td>
</tr>
<tr>
<td>Bladder</td>
<td>C/A/P CT, urine cytology, LFTs, Cr up to 2 years</td>
</tr>
<tr>
<td>Thyroid</td>
<td>Biomarkers, US</td>
</tr>
<tr>
<td>Melanoma</td>
<td>CXR/CT, brain MRI +/- PET x3 yrs (IIb-IV)</td>
</tr>
</tbody>
</table>
Increased risk for secondary malignancies

<table>
<thead>
<tr>
<th>Primary</th>
<th>Second cancer site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hodgkin’s lymphoma</td>
<td>Multiple</td>
</tr>
<tr>
<td>Transplant patients</td>
<td>Multiple</td>
</tr>
<tr>
<td>Testicular</td>
<td>Multiple</td>
</tr>
<tr>
<td>Lung</td>
<td>Lip, bladder, lung</td>
</tr>
<tr>
<td>Prostate</td>
<td>Bladder, colorectal (if radiation)</td>
</tr>
<tr>
<td>Breast</td>
<td>Endometrial (tamoxifen), sarcoma (if radiation)</td>
</tr>
<tr>
<td>Colon</td>
<td>none</td>
</tr>
</tbody>
</table>
## General population screening

<table>
<thead>
<tr>
<th>Site</th>
<th>Tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breasts</td>
<td>Mammogram (Clinical breast exam)</td>
</tr>
<tr>
<td>Cervix</td>
<td>PAP test, HPV</td>
</tr>
<tr>
<td>Colorectal</td>
<td>Fecal occult blood, endoscopy, barium enema or CT colongraphy</td>
</tr>
<tr>
<td>Lung</td>
<td>Low dose helical CT for smokers</td>
</tr>
</tbody>
</table>
How do we bring ALL of this together?
Survivorship Care Plan (SCP)

- A Survivorship Care Plan (SCP) is a comprehensive document provided to patients at the conclusion of active cancer treatment that outlines the following: disease, date of diagnosis, staging and all pathology information pertaining to the disease, genetics relevant to the diagnosis, all treatment information (surgical, radiation or medical) including a list of agents used for treatment, dates of treatment, response to treatment, any alterations to treatment or deviation from treatment plan and reasoning for this, follow-up recommendations, screening recommendations for secondary malignancies.
IOM: Cancer Survivorship Care Planning

- Diagnostic tests and results
- Site, Stage and grade, hormonal status, marker information of tumor
- Dates of treatment initiation and completion
- Surgery, Chemotherapy, Radiotherapy, transplant, hormonal therapy, gene, or other therapies provided including treatment regimen, total dose, clinical trials, indicators of treatment response, and toxicities experienced during treatment.
- Psychosocial, nutritional, and other supportive services provided
- Full contact information on treating institutions and key providers
- Identification of a key point of contact and coordinator of continuing care
Survivorship Care Plan (SCP)

• What is your impression of what a SCP is based upon the two prior slides?
• What are you doing at your facility?
• The SCP is just the beginning, the minimum.
  – Survivorship care includes: support groups, nutrition counseling, rehabilitation, education on long term and after effects, surveillance and symptom management.
Requirements of Accredited Cancer Programs

- Commission on Cancer (Standard 3.3)
  - The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer care committee and documented in minutes.
  - Purpose: Summarize and communicate what occurred during cancer treatment, recommended follow-up care including surveillance intervals, exam intervals, referrals to additional support services as needed and any other information relevant to the immediate and long term care required after completion of cancer treatment.
Requirements of Accredited Cancer Programs

• Commission on Cancer
  – SCP Process Requirements:
    1. A SCP is prepared by the principal provider(s) who coordinated the oncology treatment for the patient with input from the patient’s other care providers.
    2. The SCP is given to the patient on completion of treatment.
    3. The written or electronic SCP contains a record of care received, important disease characteristics, and a follow-up plan incorporating available and recognized evidence-based standards of care.
    4. The **minimum** SCP standards are outlined in the IOM Fact Sheet: Cancer Survivorship Care Planning.
Requirements of Accredited Cancer Programs

• Commission on Cancer
  – All Stage I – III cancer patients treated with curative intent who have completed all active cancer treatment (the exception is long term anti-hormonal treatment)
  – Stage 0 and IV patients are NOT required to receive a SCP, but this can be provided at the discretion of the treating provider
  – Required to be provided 6 months after completion of active treatment
## Requirements of Accredited Cancer Programs

- **Commission on Cancer**

<table>
<thead>
<tr>
<th>End of Year</th>
<th>Requirement</th>
</tr>
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<tbody>
<tr>
<td>End of 2015</td>
<td>Implement process to provide SCP to $\geq 10%$ of eligible patients who have completed treatment</td>
</tr>
<tr>
<td>End of 2016</td>
<td>Provide SCP to $\geq 25%$ of eligible patients</td>
</tr>
<tr>
<td>End of 2017</td>
<td>Provide SCP to $\geq 50%$ of eligible patients</td>
</tr>
<tr>
<td>End of 2018 and on</td>
<td>Provide SCP to $\geq 75%$ of eligible patients</td>
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Requirements of Accredited Cancer Programs

- NAPBC (National Accreditation Program for Breast Programs)
  - Standard 2.20
    - “A comprehensive breast cancer survivorship care process, including a survivorship care plan with accompanying treatment summary, is in place within six-months of completing active treatment and no longer than one-year from date of diagnosis. The survivorship care process is evaluated annually by the Breast Program Leader (BPL)”
    - Effective January 1, 2016. The expectation of the Standard 2.20 is that 100% of eligible survivors receive a Survivorship Care Plan (SCP).
    - All patients treated (surgery, chemotherapy, radiation or any combination thereof) with Stage 0 – III disease are eligible for a SCP
Requirements of Accredited Cancer Programs

• NAPBC
  – Patients treated with long term hormonal therapy, e.g., Herceptin, should receive a SCP within 18 months of diagnosis (up to 6 months after completing Herceptin treatment)
  – Patients receiving anti-hormonal therapy, e.g., tamoxifen, anastrozole..., should receive a SCP at the beginning of this treatment if all other active treatment (surgery, chemotherapy and/or radiation therapy) is complete (not at the conclusion of 5 years of anti-hormonal therapy)
  – If two different facilities are providing treatment, both facilities should work together to collaborate in providing a completed SCP.
  – The facility providing follow-up and monitoring of the patient (medical oncology) should provide the SCP.
Best Practices for Creating a Survivorship Program

• There is no “one size fits all,” but is this bad?
• Examine your current program and determine the following:
  – Who will provide SCPs?
  – Do you have program support?
  – What is your target population?
  – How can you best utilize current resources to provide SCPs?
Models for Survivorship Programs

- Nurse-led program
- NP-led Survivorship Clinic
- Multidisciplinary Survivorship Clinic
- PCP-led Survivorship Clinic

- Context*
Survivorship Care Plan formats

• ASCO template: free, manual data entry, multiple formats, available through ASCOs website
• LiveStrong: free, manual data entry, can be completed by patients, available in Spanish, available through LiveStrong website
• Journey Forward: free, manual data entry, downloadable, capable of automation with CNext registry interface
• Homegrown
• Paid third-party software developers to interface with existing E.H.R.
Survivorship Program: an example (UTMCK-CI)

- University of Tennessee Medical Center, Cancer Institute
  - >2900 cancer cases annually
  - CoC and NAPBC Accredited
  - Multi-disciplinary team treating a wide variety of cancer diagnoses spread out over six locations (including satellite offices for medical oncology between two medical oncology practices)
  - >20 individual providers
  - All practices have paper based charts, no common charting system, no out-patient EMR
UTMCK-CI

• Identified point person to develop program in coordination with administration
  – Ensure program meets minimum requirements for accreditation
  – Improves likelihood of success
• Pilot project on small scale for 2015 year
• Utilize current resources
  – Start from a paper based SCP, transitioned into a hybrid using the hospital EHR and voice recognition software to streamline process for completing SCPs
UTMCK-CI

• Results
  – Exceeded requirement for CoC of 10% SCPs provided
  – Provided SCPs to patients representing 15 different disease types in first year alone (for patients just treated by Surgical Oncology)
  – Identified keys to success
    • Pilot
    • Buy-in
    • Looking inside for answers, rather than to external sources
UTMCK-CI

- Standardized template for SCP made available system wide
- Working towards CoC and NAPBC goals for 2016
- Survivorship Steering Committee
- Partnering with specialty groups to offer survivorship services to patients not seen within the Cancer Institute
Survivorship - Future

• Role for Survivorship care and services will only increase in the future
• Will require a multi-disciplinary approach
  – Partner with cancer registry to:
    • Identify survivors
    • Harvest registry data
    • Export registry data

• Huge research potential, data rich field
  – Show quality improvements
  – Reduce resource utilization over time through auto-screening, standard of care f/u and engaging patients in follow-up
  – Best practices
Conclusions

• Survivorship needs will only grow in the future
• Required to address for accreditation
• CoC
• NAPBC
• Requires a multidisciplinary approach
• Requires support from administration, providers and patients to ensure success
• Benefits everyone involved!
Questions?