Cancer Survivorship and Care Planning

Objectives

• Define cancer survivorship.
• Discuss key components of cancer survivorship care plans.
• Identify barriers to effective cancer survivorship care planning.
• Discuss methods to help remove cancer survivorship care planning barriers.

Cancer Survivorship Definitions

<table>
<thead>
<tr>
<th>Source</th>
<th>Definition</th>
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<tbody>
<tr>
<td>From Cancer Patient to Cancer Survivor: Lost in Transition (IOM &amp; NRC, 2006)</td>
<td>Following diagnosis and treatment and prior to the development of a recurrence of cancer or death.</td>
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<td>National Coalition for Cancer Survivorship (NCCS, 2007)</td>
<td>From the time of diagnosis and for the balance of life.</td>
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<td>Lance Armstrong Foundation (LAF, 2007)</td>
<td>From the time you find out you have cancer, through your treatment, and for the rest of your life.</td>
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<tr>
<td>National Cancer Institute (NCI, 2008)</td>
<td>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, therefore, included in this definition.</td>
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<td>People Living with Cancer (2007)</td>
<td>The process of living with, through, and beyond cancer. By this definition, cancer survivorship begins at diagnosis.</td>
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The Numbers of Cancer Survivors are Increasing!

- Nearly 13.7 million cancer survivors alive in the United States today.
- About two-thirds of people with cancer are expected to live at least five years after diagnosis.

IOM Report

*From Cancer Patient to Cancer Survivor: Lost in Transition*  
(November 2005)

“The transition from active treatment to post-treatment care is critical to long-term health.”

“If care is not planned and coordinated, cancer survivors are left without knowledge of their heightened risks and a follow-up plan of action.”

(Hewitt, Greenfield, & Stovall, 2005)

IOM Report

*From Cancer Patient to Cancer Survivor: Lost in Transition*  
(November 2005)

Key Recommendations That Oncology Nurses Can Implement:
1. ALL cancer stakeholders should work to raise awareness of cancer survivorship and to establish this as a distinct phase of cancer care.
2. Each patient should be given a survivorship care plan.
3. Plan components should be developed and refined using evidence-based clinical practice guidelines and assessment tools.

(Hewitt, Greenfield, & Stovall, 2005)
Survivors Feel They Need More

- Feel abandoned
- Have distinct needs
- Are living longer and are more numerous
- Have more health issues
- Need more documentation of their treatment
- Want their primary care physicians to be informed

(Institute of Medicine, 2005)

Survivorship Wisdom

- Pediatric oncology – where most of our knowledge in survivorship has evolved.
- Most survivors are tired emotionally and physically after treatment.
- May have found how resilient they can be to stress and illness.
- Survivors need support, guidance, and hope that they can resume life and the “new normal.”
- A personalized action plan confronts fears and frustrations and empowers them to move forward.

When Should Survivors Receive a Survivorship Care Plan (SCP)?

The best time to provide the SCP is at completion of treatment (exceptions: on hormonal therapy, on Herceptin therapy).
Models of Survivorship Care

- SCP is given as part of ongoing care by a survivorship expert
- Consultative: separate visit with a separate team performing a survivorship visit in a clinic
  - One time visit or multiple visits
- Transition of patient to a multidisciplinary survivorship clinic after completion of treatment
  - Multidisciplinary, usually disease specific
- Transition to primary care after completion of treatment or at 3-5 years

A Survivorship Visit

- Survivorship visit at some point after acute treatment is complete (3-6 months for most)

Referral

- Intake form sent to patient to complete

Preparation

- Survivorship nurse navigator
- Survivorship MD/NP Clinic Visit

- Patient – paper & electronic
- PCP

Survivorship Visit Components

- Identifying a teachable moment
- Counsel about diet, exercise, and smoking cessation
- Assessment of physical, social, psychosocial, and spiritual needs
- Provide treatment summary & survivorship plan
- Surveillance schedule for recurrence, if any
- Secondary malignancy screening
- Long-term toxicities from treatment
- Roadmap of physician follow-up care
- Interdisciplinary coordination between PCPs, specialists, and support services (i.e., Art therapy, rehab, etc.)

Outcome: Individualized survivorship care plan that is provided to patient and PCP
National Standards For SCPs

QOPI – Initiatives Survivorship Quality Indicators in audit regarding survivorship

- Chemotherapy treatment summary provided to patient within 3 months of chemotherapy end
- Chemotherapy treatment summary provided or communicated to practitioner(s) within 3 months of chemotherapy end
- Chemotherapy treatment summary process completed within 3 months of chemotherapy end

National Standards For SCPs

- SCP is given to each patient with cancer upon completion of treatment.
- SCP contains a record of care received, important disease characteristics, and a written follow-up care plan incorporating available and recognized evidence-based standards.

American College of Surgeons
Commission on Cancer (CoC)

Updated Guidelines on SCPs (Phase-In 2015)

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 committee and documented in minutes.
**Standard Implementation (2012)**

All CoC-accredited programs and those programs seeking accreditation began implementation of new standards January 1, 2012

**Process requirements:**

a) A survivorship care plan is prepared by the principal provider(s) who coordinated the patient’s oncology treatment.

b) The survivorship care plan is given to the patient with cancer upon completion of treatment.

c) The survivorship care plan contains a record of care received, important disease characteristics, and a written follow-up care plan incorporating available and recognized evidence-based standards of care, when available. The Institute of Medicine’s Cancer Survivorship Care Planning Fact Sheet includes minimum plan standards.

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**Treatment Plan vs. SCP**

**Treatment Plan**

- Recommended prior to starting a treatment
- Written document outlining treatment plan, side effects, and length of treatment

**Survivorship Care Plan**

- Treatment summary & care plan
- Cancer type & stage
- Treatment details & complications
- Education on long-term effects
- Screening and follow-up recommendations

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**Examples of SCPs**

5. Other: Institution created
Sample Care Plans

Background Information
Treatment Plan

- BSA and BMI are calculated automatically.
- The lymphoma regimen selection list includes:
  - CEPP
  - RCHOP
  - RCHOP14
  - RDHAP
  - REPOCH
  - RESHAP
  - RICE

Users can add additional regimens to the lymphoma regimen library at their discretion.

Treatment Summary

- The table of chemotherapy agents is displayed based on the regimen selected. Can add information such as dose reductions.

Follow-Up Care

- The Coordinating Provider selection list is based on the Care Team contact list entered on the General Information page.
Patient Treatment Summary

Automatically created and updated from OIS/EMR interfaces.
Able to add supplemental detail as appropriate.

Surveillance and Follow-Up Plan

Template derived follow-up plans. Individualized to patients' diagnosis/history.
Institution-specific follow-up templates or guidelines based (NCCN, ASCO, etc.)
Identifies overdue, completed.

Individualized Educational Materials

Clinicians select appropriate educational materials for patient based on patient diagnosis and treatment history.
Education includes:
• Side effects
• Potential late effects
• Surveillance
• Support services
• General healthy living
Charting & Recording Assessments

Structured formats for capture of assessments and chart notes within Equicare.
Flags indicate follow-up required; graph indicates history recorded.
Enables monitoring and population-based outcomes reporting.

Equicare CS: Follow-Up Plan

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Comparisons
Review of SCPs in Research and Practice

- Salz et al (2012) examined studies regarding SCP use among NCI designated cancer centers
- Studies looked at multiple stakeholders (survivors, PCPs, and oncology providers):
  - Looked specifically at use in breast and colorectal patients
  - Concordance with 2005 IOM Report’s recommendations
  - Details about SCP delivery

Individual Practice / Centers

- Developing own SCPs from ASCO Word template (need additional information)
- Developing own document and scanning into EHR
- Pathology reports – ? accompany SCP
- PDF file in addition to paper copy

***Make sure they meet standards / guidelines***

National Comprehensive Cancer Network (NCCN)

- Alliance of now 25 leading cancer centers
- Guidelines determined by results of panel member review of best evidence available at time they are derived
- Categories of evidence and consensus
- Continuously updated to revise new data
**The Future**

For meaningful use, participants will have requirements at each phase that will help:
- Patient portals
- Clinical summaries for each visit
- Sharing of information between providers of care
- Summary of care for each transition of care

*more info: [www.cms.gov](http://www.cms.gov)*

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**How Can EHRs Facilitate Cancer Treatment Planning?**

What electronic tools can assist the formation and discussion of a cancer treatment plan with a patient?

- Need to have menu of options to personalize it
  - Amount of understandable information
  - Local resources
- Need to populate template if within EHR
- Need interfaces with other systems for flow of patient data, tests, etc.

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**Automatic Entry from EHR Examples**

- Diagnosis and disease stage
- Treatment summary
- Follow-up appointment schedule
- Follow-up tests & who will order
- Healthcare team names & contacts
- Specific resources in community
- Referrals or list of possible referrals for Integrative medicine (massage, acupuncture)
What Do We Need Now?

- Reimbursement for survivorship care
- Automatic entry of data already in EHRs
- Best practices
- Tracking system
- Evidence-based research
- Education

Lessons Learned

What are some of the lessons from different models of treatment planning that could improve implementation and quality of cancer treatment plans?

- Get buy in from providers.
- Automate prompts in EHR for survivorship visits.
- Automatically create SCP for review within EHR.
- Ability to modify templates for practice, population, and local resources.

Patient Barriers

- Reluctancy
- Life gets in the way
  "I don’t have time for this yoga stuff."
  "I just want this over with so I can get on with my life."
- Feel overwhelmed
  Not objective
  Not thinking rationally
- Feel uncomfortable with empowerment
  "Whatever you say, doc."
  "I don’t know I need this."

SURVIVORS DON’T KNOW THEY NEED THIS
Empower Patients to Use SCPs

- Use it in discussions with their healthcare providers.
- Reminders of follow-up appointments and symptoms to call and report.
- Use it in discussions with family and friends.
- Use it to change lifestyle and health habits.

Professional Barriers

Physician Buy In to Concept of Survivorship

- Practice patterns:
  - “I cover all that during my clinic visits.”
  - “They don’t need another (appointment to remember, meeting to go to, notebook to keep track of).”
- Have you asked whether the patient wants this or do you assume based on your years of experience it won’t make a difference?
  - “I have 25 years of experience treating cancer patients. I haven’t needed it before, why do I need to do it now?”
- Committed leadership
- Not a money maker

Developmental Pearls

- Clinical experience is invaluable.
- Knowledge of system/community is vital.
- More important than new program experience.
Survey of Physician Attitudes Regarding the Care of Cancer Survivors (SPARCCS)

SPARCCS Web site: http://healthservices.cancer.gov/surveys/sparccs

First publications from that data:
Differences between primary care physicians’ and oncologists’ knowledge, attitudes and practices regarding the care of cancer survivors.
Potosky et al. (2011). J Gen Internal Med. Dec;26(12):1403-10

- Provision of treatment summaries/SCPs to patients is relatively low.
- Provision to PCPs is higher, but still quite low.
- PCPs’ skills in caring for cancer survivors is rated low by oncologists and ambivalent by PCPs.

Bottom Line: We have a big job ahead of us and need physician buy in

Right Referrals for the Right Patient

- A survivorship assessment, which can be done in various locations and using different models, is critical for accurate and thorough screening and assessment.

- Post-treatment timing is also vital — a post-treatment assessment is very different than pretreatment assessments of the same patient.

Right Referrals for the Right Patient

- Objectivity can also be helpful — a different provider allows additional eyes and possibly different conversations or framing of questions with the same patient.

- Finally, all of these components optimize survivors’ ability to evaluate their own lifestyles (a better “teachable moment”) and to embrace change behavior.
Encompass All Facility and Community Resources

- Develop collaborations with other departments / programs / organizations for chronic diseases
- Nutritional counseling
- Rehabilitation programs
- Home health and congestive heart clinics for chronic disease management programs
- Community council on aging for their programs
- Local advocacy organizations
- Hospital volunteers
- Etc.

Case Study: J.B.

- Diagnosed with stage I breast cancer at 30 years old, single, no children, white, cosmetologist.
- Genetic testing: *BRCA2* positive.
- Bilateral mastectomies + six months chemotherapy followed by reconstruction.
- Out of work during chemo and surgeries - parents paid for health insurance during that time.
- She has now returned to work, plans to schedule oophorectomy later, and wants to go back to school.
- No regular PCP.

Snapshot View of J.B.’s Status

- Back to work but still *fatigued*
- 40 pounds overweight (was 25 pounds at diagnosis)
- Working full time but otherwise sedentary – *not exercising*
- *Isolated* – “I really feel different now compared to most of them who are busy raising families, husbands, and normal looking bodies!”
- Has not scheduled appointment with gynecologist for oophorectomy (since she is *BRCA2* positive)
Difference Survivorship Clinic
   Made for J.B.
   • Discussed fears–oophorectomy
   • Established risk reduction goals:
     o Weight loss
     o Exercise – pedometer class
   • Referral to new primary care physician
   • Arranged GYN appointment
   • Connected to survivorship group

Conclusion
   • Many survivors do not receive SCPs.
   • Barriers to providing SCPs (resources, time, commitment of the organization).
   • Education about the need and utilization of SCPs is important.
   • As oncology nurses, we have great opportunity to advocate for patients and enhance quality of care through effective survivorship care planning.

References
   • Full list of references included with your handouts
Special Thanks: Authors

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