Coordinating Cancer Care and Survivorship with the Primary Care Physician and the Patient-Centered Medical Home

2014 Nevada Cancer Control Summit
University of Las Vegas School of Medicine
April 25, 2014

Amy E. Shaw, MD
Primary Care Oncology
Cancer Survivorship Program
Cancer Risk Reduction Program

St. Joseph Health
Annadel Medical Group
From surviving cancer to “cancer survivorship”

“More often than not, those who receive a diagnosis of cancer now no longer ask themselves how long they have to live, but rather how well they can expect to live from that moment onward.”

Challenges

- Growing number of cancer survivors
- Aging population with multiple comorbidities
- Declining supply of Oncology specialists and Primary care providers
- Managing long-term effects of cancer therapies
- Culture of cancer care in America
- Educating primary healthcare providers
Strengths

- Midlevel practitioners
- Patient advocacy
- Clinical guidelines
- Research
- Philanthropy
- Educational programs like this one

What is taking us so long?

- Not a new problem
  - IOM report “Lost in Transition” 2006
- Most cancer treated in community setting
  - Most “Survivorship Programs” in academic cancer centers
- “Buy in” from Oncologists and PCP

* Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. 2006
  Rowland JH et al. J Clin Oncol. 2006;24:5101-5104. 2. Clark EJ. You have the right to be hopeful.
“Cancer Survivor” and “Cancer Survivorship”

The Definition of a **Cancer Survivor**
(National Coalition for Cancer Survivorship)

“Anyone with a history of cancer, from the time of diagnosis and for the remainder of life, whether that is days or decades.”

THE ALL ENCOMPASSING DEFINITION

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A paradigm shift or confusion?

- “Survivorship” is a distinct phase of the cancer care trajectory that begins with diagnosis, extends beyond active cancer treatment, and continues through follow-up care and long-term survival.

- “Oncologists should consider Survivorship when treating cancer.”

Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. 2006

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**Functional Definition of a Cancer Survivor**  
(American Society of Clinical Oncology)

“Individuals who have successfully completed curative treatment or those who have transitioned to maintenance or prophylactic therapy.”

THE PRACTICAL DEFINITION

Cancer Survivorship Care

Survivorship Care is not Cancer Treatment

- Does not include:
  - Patients undergoing treatment with surgery, chemotherapy, radiation, end-of-life care
  - Patients with active disease

- May include:
  - adjuvant endocrine therapy

- What medical problems are encountered in these patients?
- Who is best trained to address these problems?
Survivorship Care is not Cancer Treatment

Should Oncology Specialists be the primary medical specialists in care of these patients?

HR-QOL in Cancer Survivors

- 1 in 4 report poor physical health
- 163 women with breast cancer
  - 92% had one or more physical impairments
  - fewer than 30% received treatment
- 63% of survivors of the 10 most common cancers reported the need for at least one rehabilitation service

Late-Onset or Long-Term Side Effects of Cancer Treatments (incomplete list)

- Cardiac issues
- Osteoporosis and fractures
- Myelosupression
- Peripheral neuropathy
- Eyes (vision, cataracts, inc. lacrimation)
- Thyroid dysfunction
- Dental and gum disease
- Secondary Malignancies
- Chronic gastritis
- Lymphedema
- Fatigue
- Cognition changes
- Insomnia
- Sexuality & Body Image
- Weight gain
- Menopausal symptoms
- Pain
- Incontinence
- Infertility


Competing Risks: Cancer survivors die from other diseases

Breast Cancer Survivors

- Death CVD > death from breast cancer:
  - Stage I -- by 2 years after surgery
  - Stage II -- by 5 years after surgery
  - Stage III -- by 10 years after surgery
- CV risk higher than age-matched controls at all stages

Yancik, JAMA 2001; Keyserlingk, ASCO Breast Cancer Symposium, San Francisco 2013
Comorbidities and Chronic Illness

- The more comorbidities, the higher risk of dying of cancer – at all stages
- Worse cancer outcomes with poorly managed co-morbidities


Insulin Resistance & Breast Cancer Prognosis

Cancer Survivorship in America: Triumph of cancer detection and treatment

Cancer Death Rates Among Women

Cancer Death Rates Among Men


Improved 5-Year Survival

Source: The State of Cancer Care in America: 2014; ASCO
Growing Number of Cancer Survivors

Estimated 18 million by 2020

Age-specific cancer incidence rates

Data from the National Cancer Institute on estimated number of cancer survivors and age-adjusted cancer deaths per 100,000 people

Erikson C et al. JOP 2007;3:79-86
Projected # of cancer cases for 2000–2050 by age


US Cancer Prevalence

Approximately one-fourth are breast cancer survivors

Caring for Cancer Survivors: Supply and Demand
Insufficient number of Oncologists

Between 2001 and 2007:
- Total number of oncologists increased by 6%
- New cancer patient volume increased by 23%
- “Survivor” patient volume increased by 93%
  - breast cancer patients increased by 126%

Competing needs:
- Patients undergoing active treatment
- Essentially “well” cancer survivors
Projected supply of and demand for Oncologist visits, 2005 to 2020.

Erikson C et al. JOP 2007;3:79-86

Projected Supply of Primary Care Providers

http://www.ruralmedicaleducation.org/new_US_workforce_design.htm
The Components of Survivorship Care

IOM: Goals of “Survivorship Care”

- To Improve:
  - Quality of life
  - Survival
  - The cancer “experience”
  - Coordination of care
    - Continuity of care between specialists and primary care physicians

IOM: Domains of Survivorship Care

- **Palliation**
  - Of ongoing or late-onset symptoms of cancer or cancer therapies
  - Physical and psychological complaints

- **Health Promotion**
  - Maximize future wellness.

- **Prevention**
  - Of late effects of cancer treatment or second cancers
    - Screening
    - Risk reduction
    - Surveillance

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Routine Surveillance for asymptomatic BrCa and CRC: **Is it necessary?**

- Routine follow-up does **not:**
  - Provide survival benefit
  - Lead to earlier diagnosis of distant recurrences

- Both PCP and Oncologists often depart from guideline recommendations
  - i.e., CA15-3 in asymptomatic breast cancer survivors

- Patients value the psychological and social support that cancer follow-up provides
  - So do Doctors

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Lewis, RA. *Br J Gen Pract* 2009; e234, Potosky AL. *JGIM* 2011:1403
“A Treatment Summary and Survivorship Care Plan” (TSSP)

“A roadmap for long-term care”
Moving from short-term cancer treatment to longer-term health maintenance.

Institute of Medicine, 2006

- “Patients completing primary cancer treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.”

Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. 2006
TSSP Essentials

- Summary of Cancer pathology and treatment
  - Type of CA, stage, treatment
- Names and phone #s of oncology specialists
  - Surgeon, Med Onc, Rad Onc
- Patient’s residual risk for recurrence
  - Give #: “5% recurrence risk over 10 years”
- Potential long-term risks of cancer treatments
  - Be specific and report likelihood of risk
- Schedule of f/u visits and surveillance studies
  - Specify who will do what and when
- Possible symptoms of recurrence
  - What to watch out for.

JNCCN May 2013: New NCCN Guidelines for Survivorship Care. 11(5.5)

Current State of Cancer Survivorship
Institute of Medicine, 2006

“Comprehensive, coordinated long-term care of cancer survivors in the United States is the exception rather than the norm.”

…It is still the exception in 2014

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Oncologists and Survivorship Care

- ASCO Cancer Survivorship Committee, 2011

1. Assist ASCO members in the delivery of quality survivorship care
2. Clinical management guidelines for oncologists
3. **Increasing collaboration with PCPs**

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Ganz PA, et al. JCO 2006 24: 2948-2957
Can PCPs provide high quality care for cancer survivors?
PCPs are already involved

- Most patients diagnosed with cancer today will not die from their cancer
- Patients have multiple comorbidities that PCPs should be managing
  - impact cancer treatment
  - impact cancer survival
  - impact quality of life
- Patients want their PCP to remain involved
- PCPs are experts in Preventive Health


PCPs are already involved

- New symptom of cancer recurrence most often evaluated first by PCP, not by oncologist

Even in patients followed routinely by oncologists

Caring for Survivors: 
PCP and Oncologist confidence in PCP?

<table>
<thead>
<tr>
<th>HIGH CONFIDENCE IN:</th>
<th>ONCOLOGIST Answering</th>
<th>PCP Answering</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCP able to screen/detect BrCa or CRC recurrence*</td>
<td>38%</td>
<td>75%</td>
</tr>
<tr>
<td>PCP able to provide Psychological support to cancer survivors</td>
<td>8%</td>
<td>51%</td>
</tr>
<tr>
<td>PCP to conduct appropriate testing in BrCa and CRC survivors*</td>
<td>23%*</td>
<td>59%*</td>
</tr>
</tbody>
</table>

* Both groups departed from guidelines

JGIM Dec 2011, 26(12):1403-1420

Caring for Survivors: 
MD Confidence in their own ability?

<table>
<thead>
<tr>
<th>HIGH CONFIDENCE IN:</th>
<th>ONCOLOGIST Answering</th>
<th>PCP Answering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being primary provider of cancer survivors?</td>
<td>75% &quot;me&quot;</td>
<td>74% &quot;me&quot;</td>
</tr>
<tr>
<td>Having skills to be primary provider of cancer survivors?</td>
<td>60%</td>
<td>51%</td>
</tr>
<tr>
<td>Ordering appropriate surveillance tests for breast and colorectal cancer survivors</td>
<td>85%</td>
<td>40%</td>
</tr>
<tr>
<td>Able to detect cancer recurrence in breast and colorectal cancer survivors?</td>
<td>75%</td>
<td>74%</td>
</tr>
<tr>
<td>Knowledge about long-term and late adverse effects of cancer and cancer tx?</td>
<td>77%</td>
<td>23%</td>
</tr>
<tr>
<td>Knowledge of psychological outcomes of cancer and its tx</td>
<td>50%</td>
<td>41%</td>
</tr>
</tbody>
</table>

Care outcomes: PCP vs Oncologists

- As of 2013 - NO study has demonstrated any harmful effects of PCP-led cancer follow-up
- No difference in patient survival or quality of life

Doesn't mean care was optimal at both venues, only that care was the same.

Lewis, RA. Br J Gen Pract 2009; e234

Care of Low Risk Cancer Survivors: Oncologists vs. PCPs

<table>
<thead>
<tr>
<th>Oncologists</th>
<th>Primary Care Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overuse of surveillance testing for CRC, BrC, Prostate CA</td>
<td>Overuse of surveillance testing for CRC, BrC, Prostate CA</td>
</tr>
<tr>
<td>Less non-cancer-related preventive care</td>
<td>More non-CA-related preventive care</td>
</tr>
<tr>
<td>More cancer screening</td>
<td>Less cancer screening</td>
</tr>
<tr>
<td>Less CVD risk surveillance</td>
<td>More CVD risk surveillance</td>
</tr>
<tr>
<td>Less tx of comorbidities</td>
<td>Improved tx of comorbidities</td>
</tr>
<tr>
<td>Understand CA Tx comps</td>
<td>Incomplete knowledge of CA Tx comps</td>
</tr>
<tr>
<td>More expensive</td>
<td>Less expensive</td>
</tr>
<tr>
<td></td>
<td>Better care for underserved</td>
</tr>
</tbody>
</table>

Preventive health care for Survivors depends on who follows them

1\textsuperscript{st} Best: Combination PCP + Oncology
2\textsuperscript{nd} Best: PCP only
3\textsuperscript{rd} Best: Oncology only

Snyder, J Genl Med 23(3), 2008; Grunfeld, JNCI 40, 2010

Why are Oncologists reluctant to transfer low risk patients to the PCP?

- Strong emotional bond with patient
  - Especially if the patient is doing really well
- Enjoy variety of care during the day
  - Sick and healthy
- Need to see the healthy long-term “successes” to balance the “failures” (patients who aren’t doing well)
  - Avoid burn-out
- Lack of Confidence in skills of PCP
  - “I had a patient once who…."

Source: Dr. Shaw’s personal observations based on 20+ years of clinical experience.
What are PCPs saying about Oncologists?

- “Patients are never sent back to me”.
- “Over-treat cancer and under-treat everything else”
- “Don't communicate with me”
  - “How am I supposed to learn what to do for the patient if the Oncologist never tells me?”
- Asked to help only when patient is:
  - “Difficult”
  - Depressed
  - Dying

Source: Dr. Shaw’s personal observations based on 20+ years of clinical experience.

What do PCPs know about Oncology?

- Survey of Physician attitudes regarding the care of cancer survivors, 2012
- 1072 PCPs and 1130 Oncologists completed survey
- TEST:
  - Given list of 4 widely used chemo agents then asked to identify the most common late effect caused by each agent.

JCO 30, 2012 (suppl; abstr 6008)
What do PCPs know about Oncology?

<table>
<thead>
<tr>
<th>CHEMO + SIDE EFFECT</th>
<th>Oncologists</th>
<th>PCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doxorubicin + Cardiac Dysfunction</td>
<td>95%</td>
<td>55%</td>
</tr>
<tr>
<td>Paclitaxel + Peripheral Neuropathy</td>
<td>97%</td>
<td>26%</td>
</tr>
<tr>
<td>Oxaliplatin + Peripheral Neuropathy</td>
<td>96%</td>
<td>22%</td>
</tr>
<tr>
<td>Cyclophosphamide + Premature Menopause</td>
<td>71%</td>
<td>15%</td>
</tr>
<tr>
<td>Secondary Malignancies?</td>
<td>62%</td>
<td>17%</td>
</tr>
<tr>
<td><strong>All Correct</strong></td>
<td>65%</td>
<td>6%</td>
</tr>
</tbody>
</table>

JCO 30, 2012 (suppl; abstr 6008)

PCPs vs Oncologists in Canada

- 968 early-stage BrCa and CRC patients who had completed adjuvant treatment were randomized to follow up in a Cancer Center or with own PCP
  - All PCPs received TSSPs from the patient’s oncologist
- **Results:**
  - Same # cancer recurrences
  - Same # cancer-related deaths
  - Same # recurrence-related serious clinical events
    - i.e., spinal cord compression from missed spinal metastasis
  - Same # patient reported QOL

Challenges for PCPs

- **Education/training:**
  - Unfamiliar with consequences of cancer and cancer treatment

- **Communication:**
  - Unclear role & recommendations from Oncologists
  - Treatment Summaries and Care Plans?

- **Infrastructure:**
  - Additional screening and monitoring, surveillance

- **Space/Time/Personnel/Finances:**
  - Overburdened already with other chronic diseases
  - Competing demands of time

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Successful models of care for cancer survivors
Keys to successful models for survivorship care

- Patients and healthcare providers must feel and see that the model provides high quality care.
- Multidisciplinary
  - PCP and Oncology specialists
- Communication, communication, communication

Survivor Subgroups – No single model fits all patient types

- Risk stratified approach:
  - Recurrence: high, low, changes over time
    - 20% of patients monitored in oncology practice have a “low risk” for recurrence
  - Lingering side effects from treatment?
    - Need treatment or not?
  - Risk for late-onset cancer treatment effects?
    - What to watch for and how to watch for it?
  - Comorbidities?
    - Serious, multiple, higher mortality risk than cancer?

Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. 2006
McCabe MS, et al. JCO 2013;31(6)
### United Kingdom National Cancer Survivorship Initiative

- Integrates a risk-stratified approach to survivorship care
- PCP refers to Cancer Specialist
- **Cancer Specialist:**
  - At beginning of tx: Provides PCP with a written cancer treatment plan
  - At end of tx: Provides PCP and patient with written cancer tx summary and survivorship plan
  - Cancer care provider during tx and post-tx when recurrence risk highest
- **PCP continues to deliver non-cancer-related care**
  - Takes over cancer surveillance once pt transferred back

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Institute of Medicine. From Cancer Patient to Cancer Survivor: Lost in Transition. 2006
McCabe MS, et al. JCO 2013;31(5)

### Models of Delivering Survivorship Care

**Oncologist only**
- Ongoing care from Oncologist +/- Nurse Practitioner

**Multidisciplinary within Oncology**
- Physician (PCP/Med Onc), NP/PA, Psychologist, MSW

**Consultative service**
- One-time comprehensive visit (PCP or Onc) then transfer to PCP, Survivorship Care Plan

**Community-Based Shared Care Model**
- Collaboration between Oncologist and patient’s own Primary Care Physician
Community Based Shared-Care Model

- UK Model
- Already standard for managing chronic disease
  - Diabetes, heart disease, arthritis, etc.
  - Demonstrated value in improving patient outcomes
- Multidisciplinary: PCP + Oncologist specialist
  - Care is coordinated
  - Leadership of team may change over time
- Cornerstone:
  - Personal two-way communication
  - Periodic transfer of knowledge between specialist and PCP

Oncologist only care of Cancer Survivors

Solid Line: primary responsibility  
Dotted Line: unclear responsibility and frequent discontinuation of care

Shared Care of Cancer Survivors

Solid Line: primary responsibility  
Dashed Line: secondary responsibility
Shared Care Model

**Oncologists - Roles and Responsibilities**
- Cancer therapy
- Keep PCP informed during and after treatment
- Guidance in long-term survivorship care
- Transition patient to PCP at appropriate time
- Availability for questions, consults, referrals
- Provide PCP with summary of cancer stage, treatment, potential long-term risks of treatment ("Survivorship Care Plan")

Oeffinger K C, and McCabe M S JCO 2006;24:5117-5124

Shared Care Model

**PCP - Roles and Responsibilities**
- Ensure physical and emotional health needs of the survivors are addressed
- Assume responsibility for care or chronic disease that is feasible in the PC setting
- Refer for problems and/or periodic assessments
- Consult in areas of uncertainty

Oeffinger K C, and McCabe M S JCO 2006;24:5117-5124
Shared Care Model

Communication Points for Oncologists

- Planned treatment and rationale for it, brief overview of chemotherapy and/or surgery
- Treatment summary at end of acute treatment
- Survivorship Care Plan – even if oncologist will perform all functions
- Continued update with changes in surveillance recommendations and potential late effects

Oeffinger K C , and McCabe M S JCO 2006;24:5117-5124

Shared Care Model

Communication Points for PCPs

- Keep Oncologists “in the loop”:
  - Office notes
  - Lab tests
  - X-ray tests
  - Major health events

Oeffinger K C , and McCabe M S JCO 2006;24:5117-5124
Caring for Survivors: PCP vs Onc Preferred model of care?

<table>
<thead>
<tr>
<th>PREFERRED MODEL TYPE</th>
<th>ONCOLOGIST Answering</th>
<th>PCP Answering</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2009</td>
<td>2013</td>
</tr>
<tr>
<td>Oncology-led Survivorship Care</td>
<td>57%</td>
<td>59%</td>
</tr>
<tr>
<td>PCP-led Survivorship Care</td>
<td>2%</td>
<td>Not asked</td>
</tr>
<tr>
<td>NP/PA-led Survivorship Care</td>
<td>10%</td>
<td>21%</td>
</tr>
<tr>
<td>Specialized “Survivorship Program”?</td>
<td>22%</td>
<td>Not asked</td>
</tr>
<tr>
<td>Shared-Care Model (PCP + Onc)</td>
<td>16%</td>
<td>18%</td>
</tr>
</tbody>
</table>

JGIM Dec 2011;26(12):1403-1420; Cheung, J Cancer Surviv 2013 Sep;7(3):342-54

Unmet Needs of Cancer Survivors

- Psychosocial concerns
- Sexuality issues
  - 90% prostate cancer patients
  - 75% rectal cancer patients
  - 50% breast and gynecologic cancer patients
- Menopausal symptoms in breast cancer patients
  - Estrogen alternatives
- Management of cancer-treatment effects
  - Radiation fibrosis
  - cancer-related fatigue
  - cognitive impairment
  - bowel or bladder dysfunction
  - Sleep dysfunction
  - others.

Symptom Management?

- Not addressed in Care Models
- Consider Consultative Service
  - For both low risk and high risk patients
  - Treatment of adverse effects of cancer therapies
    - Menopausal symptoms, AI-induced arthralgias, bone health, fatigue, PTSD, neuropathy, radiation fibrosis, etc.
  - Can work within existing practices in a community
  - Oncologist or PCP or NP/PA
    - “Primary Care Oncology”

Who is primarily responsible for the cancer survivor?

- Where do the responsibilities of the oncologists end and the responsibilities of the PCP begin?
- Who is best qualified to address the complex medical and psychosocial issues that arise during and after cancer treatment?
  - Knowledge and Expertise?
  - Experience?
  - Time?
  - Staff and institutional resources?
1. Take aways

1) Survivorship is a distinct phase of cancer care
   - Patients and medical team need to know when it starts and who is in charge

2) Primary Care Providers are integral to every phase of cancer care

3) PCPs must learn more about cancer treatments
   - Oncologists can help by providing Treatment Summaries and Survivorship Care Plans

4) Oncologists must become better communicators
   - So should PCPs

2. Take aways

5) Patients have lingering effects from cancer Tx
   - NOT adequately addressed by Onc or PCP

6) Not all cancer survivors are the same
   - Risk of recurrence & comorbidities

7) In the community setting, Shared Care Model may be the best model for providing highest quality care for cancer survivors