Integrating Agendas: A “Team Sports” Approach to Translating Evidence to Care for Cancer Survivors

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SBM Master Lecture
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In the fall of 1991, the Andrea Gail left Gloucester, Mass, and headed for the fishing grounds of the North Atlantic.

Two weeks later, an event took place that had never occurred in recorded history.

THE PERFECT STORM
Estimated and projected number of cancer survivors in the United States from 1977-2022 by years since diagnosis

de Moor et al, *CEBP*, 2013;22(4):561-70
Cancer Survivors are at risk:
Chronic & Late Effects of Cancer

- Recurrence/new cancers
- CVD
- Endocrine dysregulation
- Diabetes
- Osteoporosis
- Disability
- Neuropathy
- Pain
- Sexual Impairment
- Lymphedema
- Incontinence
- Poor Quality of Life
- Financial burden
- Obesity
- Depression, Anxiety
- Uncertainty
- Relationship changes
- Job & Insurance problems
- Poor body image
- Fatigue
- Functional limitations
- + Changes: purpose, priorities
Incidence of Chronic Health Conditions in 10,397 Adult Survivors of Childhood Cancer

Mean age of 26.6 years (18-48 years)

By 30 years post cancer:

- 73% survivors with at least one chronic health condition
- 42% with a Grade 3-5 (severe, life-threatening, death)
- 39% had ≥2 chronic health conditions

Survivors – 8.2 times more likely to have a severe or life-threatening condition compared to siblings

Childhood Cancer Survivor Study
% with Limitations: Survivors vs. General Population

Group Statistics Mask Individual Differences

Vs...
Projected Increase in US Cancer Survivors by 2020

Parry et al, CEBP; 20(10) October 2011

Number of cases

Year


0 2,000,000 4,000,000 6,000,000 8,000,000 10,000,000 12,000,000 14,000,000 16,000,000 18,000,000 20,000,000

65+ 42% ↑ 65+ 65+ 65+ 65+ 65+ 65+ 65+ 65+ 65+ 65+

<65 <65 <65 <65 <65 <65 <65 <65 <65 <65 <65

Parry et al, CEBP; 20(10) October 2011
Baby Boomers & Expectations:
What a Difference a Generation Makes

THEN

Old vs. New 
Definitions of 
Quality of Life

COMING SOON...
Delivering Survivorship Care

- Who should be responsible for survivorship care?

Oeffinger & McCabe, *JCO* 2006
Delivering Survivorship Care – Patient Preferences

Adult Cancer Survivors Discuss Follow-up in Primary Care: ‘Not What I Want, But Maybe What I Need’

Shawna V. Hudson, PhD,1,3 Suzanne M. Miller, PhD,1 Jennifer Hemler, MA1 Jeanne M. Ferrante, MD1,3 Jennifer Lyle, MA1 Kevin C. Oeffinger, MD1 Robert S. DiPaola, MD1

The Cancer Institute of New Jersey, UMDNJ-Robert Wood Johnson Medical

ABSTRACT

BACKGROUND Nearly one-third of office visits for cancer are handled by primary care physicians. Yet, few studies examine patient perspectives on these physicians’ roles in their cancer follow-up care or their care preferences.

METHODS We explored survivor preferences through qualitative, semistructured, in-depth interviews drawing on patients recruited from 2 National Cancer Institute-designated comprehensive cancer centers and 6 community hospitals. We recruited a purposive sample of early-stage breast and prostate cancer survivors aged 47 to 80 years, stratified by age, race, and length of time from and location of cancer treatment. Survivors were at least 2 years beyond completion of their active cancer treatment.

52% survivors want follow-up care from cancer specialist

Survivor concerns about PCPs:
• Lack of cancer expertise
• Lack of involvement with original cancer care
• Lack of care continuity

Hudson et al, Ann Fam Med 2012
Delivering Survivorship Care

- Who should be responsible for survivorship care?
  
  *Erikson et al., 2007, JOP*

- Divergent perceptions about who should provide care for survivors

  *Potosky et al, JGIM 2011*
Delivering Survivorship Care

- Knowledge gaps among PCPs (& oncologists)

![Bar chart showing knowledge levels for testing for recurrence, physical effects, and psychosocial effects between primary care physicians and oncologists.]

*Potosky et al, JGIM 2011*
Costs of Cancer Care (US)

- $157.77 billion by 2020
- Survivorship excess medical costs: $25-48 billion
- Lost productivity among survivors: $8-16 billion
Survivors 2.65 X more likely to file bankruptcy
Ramsey, Medical Affairs, 2013

Bankruptcy among survivors: 1.79 X higher risk of mortality
Ramsey, JCO, 2016

Yabroff, JCO, 2016
Effective, Efficient Care

Efficiency: Doing things right
Effectiveness: Doing the right things

- Doing things right
- Doing the right things right
- Doing things
- Doing things right
What Does “Doing the Right Things Right” Look Like for Survivors?

- “Whole person” survivorship care focused on creating healthy survivors
- Goal: Develop efficient pathways of care
  - Keep people OUT of the healthcare system as much as possible
  - Intensity of care varies with need
  - Prevent long-term problems to lighten load in primary care
  - Engage patients; Leverage technology
- Coordinate care
- Increase the VALUE of care (outcomes vs. cost)
IOM 4 Pillars of Survivorship Care

- **Surveillance**
  - Recurrence, 2\textsuperscript{nd} cancers, late effects

- **Intervention** for treatment consequences
  - Medical/psychosocial/economic

- **Prevention** of recurrence/new CAs, late effects, new comorbidities, disability

- **Coordination** between PCP, ONC, and specialists to ensure all needs are met
For comprehensive, patient-centered care

- Screening, surveillance for new/recurrent cancers
- Management of late/long-term effects
- Psychosocial, Rehabilitation, & Palliative Care
- Specialist care (Cardiac, Endo, Ortho)
- Prevention, lifestyle recommendations
- Coordination of care
Clinical Care Follow-up Guidelines

- **Prostate Cancer** – Published online in *CA Cancer J Clin* on June 10, 2014. (www.bit.ly/ACSPrCa)

- **Colorectal Cancer** – Published online in *CA Cancer J Clin* on September 8, 2015. (bit.ly/acscolorc)

- **Breast Cancer** – Collaboratively developed and released with ASCO. Published online in *CA Cancer J Clin* and *JCO* on December 7, 2015. (bit.ly/BrCaCare)

- **Head and Neck Cancer** – Published online in *CA Cancer J Clin* March 22, 2016. (bit.ly/acsheadneck)

- Insufficient data to develop guidelines for other cancer sites at this time
Guidelines are Useless if We Cannot Deliver Guideline-Consistent Care

Next Step:
How Do We DELIVER High-Quality Survivorship Care?
How Do We Get to the Future?
Need Multi-modal, “Team Sport” Partnership Approach

- Researchers
- Health IT, EHR vendors
- Industry
- Healthcare Administrators
- Clinicians
- Advocacy
- Public Health, Community partners
- Healthcare Payers
- Policy Makers
- Clinical Educators
- Employers
- Survivors & Families
- Advocacy
- Public Health, Community partners
- Healthcare Payers
- Policy Makers
- Clinical Educators
- Employers
- Survivors & Families
“Team Sport” Strategies to Improve Survivorship Care

- Individualized Care Pathways
- Assessment, triage, & surveillance
- Patient activation/empowerment
- Healthcare Delivery Innovation
- Provider Training
- Legislative/Regulatory/Policy
- Technology, Digital health, EHR innovation
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Image: Female basketball players on a court.
1. Assessment, triage, and surveillance

- “Precision medicine” Comprehensive Assessment of Needs & Resources: Integrate molecular, genomic, cellular, physiological, clinical (w PROs), behavioral, and environmental data
- Risk-stratify into care pathways
  - Modeling: supercomputer, systems science
- Repeat Assessments: Ongoing surveillance for survivors’ needs
2. Create individualized care pathways:

- **Targeted:** Identify what works for whom? Type & Dose? Especially older adults
- **Feasible** interventions (survivors & system)
- **Assess outcomes:** morbidity, referrals, costs, mortality; outcomes that matter to survivors
- **Change the process** of conducting research—improving communication, collaboration, evaluation, and feedback through partnerships with ALL stakeholders

**WHO?:** All
Creating Better Research through Partnerships

An Action Plan for Translating Cancer Survivorship Research Into Care

Catherine M. Alfano, Tenbroeck Smith, Janet S. de Moor, Russell E. Glasgow, Muin J. Khoury, Nikki A. Hawkins, Kevin D. Stein, Ruth Rechis, Carla Parry, Corinne R. Leach, Lynne Padgett, Julia H. Rowland

The Translational Science Process for Survivorship

Mechanisms; Preclinical Studies; Phase I & II trials

Scientific Discovery

T1

Promising Applications & Interventions

T2

Collaboration (Researchers, Survivors, Clinicians, Stakeholders)

Knowledge Integration

Multi-level Analysis

Survivor Population Health & Disease Burden

T0

Programs in Practice, Organization, & Community Settings

T3

Evaluation of Interventions (Phase III Trials)

T4

Evidence Based Recommendations, Guidelines or Policies

Successful implementation & dissemination in real-world settings

Describe health outcomes & determinants

Evaluating outcomes in real-world settings

Change our Thinking about “Outcomes” to Translate Science into Care

- Differ with intended audience
- Providers: morbidity, mortality, referrals, clinic flow
- Survivors: morbidity, mortality, feasibility, out of pocket costs
- Payers: outcomes, costs, ROI
- Legislators & Regulators: new care model value & off-sets
Collect Data to inform USPSTF*:

- Intervention effects by symptoms, comorbidities
- Feasibility of referral from primary care
- Dose response for different outcomes
- Independent contribution of intervention components
- Adverse events/potential harms
- Use standardized measures to facilitate pooling
- Intervention effects on health outcomes, prognosis, intermediate markers

*Murray DM, Kaplan RM, Ngo-Metzger Q, et al. Enhancing Coordination Among the USPSTF, the AHRQ, and the NIH. *American Journal of Preventive Medicine*, 2015, Sept; 49 (3 Suppl 2), S166-73

*These same data will help make the case to other funders as well*
3. Patient Activation & Empowerment

• Help survivors self-manage health, become active participants in care = ↑ care efficiency, ↑ adherence, better outcomes
• mHEALTH tools, education, communication & decision making aids
• Workplace solutions
4. Provider Training

• Medical school education in survivorship (oncology, primary care, nursing, pharmacy)

• Hybrid practitioners (cardioncology, cancer rehabilitation, palliative care)

• Continuing education for existing workforce
E-Learning Series for Primary Care Providers

Cancer Survivorship E-Learning Series for Primary Care Providers

A program of the National Cancer Survivorship Resource Center

There are more than 13.7 million cancer survivors in the U.S., many of whom face physical, psychological, practical, informational, and spiritual challenges after the completion of cancer treatment. Primary care providers play a critical role in providing much-needed follow-up care for cancer survivors.

The Cancer Survivorship E-Learning Series is a free continuing education program that provides a forum to educate primary care providers (PCPs) (e.g., general medicine physicians, generalists, gynecologists, physician assistants, nurse practitioners, nurses) who may have patients who are cancer survivors about how to better understand and care for survivors in the primary care setting. Continuing education credits (CEs) are available at no-cost to participants for each 1-hour module.

The audience will learn about caring for survivors of adult-onset cancers, including:

- Module 1: The Current State of Survivorship Care and the Role of Primary Care Providers
- Module 2: Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers
- Module 3: Late Effects of Cancer and its Treatment: Meeting the Psychosocial Health Care Needs of Survivors

The series consists of three (3) initial enduring online educational modules with new modules added throughout the year. Self-paced modules can be completed in any order and include:

- One or more on-demand webinar presentations by clinicians and experts;
- Interviews with cancer survivors;
- Interactive features such as quizzes and patient/survivor case studies; and
- Access to tools and resources to improve providers' knowledge and competencies related to post-treatment care of cancer survivors.

To begin, first review the important information in the overview section. Then access each module through the links on the side of the page.

www.cancersurvivorshipcentereducation.org
ASCO/Primary Care Training

Cancer Survivorship Symposium: Advancing Care and Research
A Primary Care and Oncology Collaboration

Save the Date:
Join Us January 27-28, 2017, in San Diego, CA

Browse Abstracts

View Virtual Meeting

Learn About Cosponsors
5. Healthcare Delivery Innovation

• Interventions: meet the IHI triple aim
• Improve referral, care coordination, & communication
• Develop tech, mHEALTH, EHR tools to facilitate guideline-consistent care delivery
6. Legislative, Regulatory, Policy Reform

- Legislative: Reform insurance coverage:
  - Care coordination
  - Care planning
  - Survivorship care interventions

- Regulatory: Reform carrots & sticks
  - CoC, ASCO QOPI
  - Revise CMS Oncology Care Model (bundle) to optimize survivorship
6. Legislative, Regulatory, Policy Reform

WHO?

Policy
Need Multi-modal, “Team Sport” Partnership Approach

How do we get everyone together?

- Researchers
- Advocacy
- Health IT, EHR vendors
- Public Health, Community partners
- Healthcare Payers
- Policy Makers
- Employers
- Industry
- Clinicians
- Healthcare Administrators
- Clinical Educators
- Survivors & Families
ACS & ASCO are founding:

**The Survivorship Care Roundtable:**

- Bring together organizations with a stake in the care of cancer survivors
  - Clinical groups, advocacy, industry, lifestyle change, payers, regulators, policy makers
- Overarching goal: *enhancing delivery of survivorship care* to meet survivors’ needs and keep them active and functional
- Tackle agendas that no one organization can do alone
The Survivorship Care Roundtable:
Subgroups will tackle each of these collaborative agendas:
• Assessment, triage, & surveillance
• Individualized Care Pathways
• Patient activation and empowerment
• Provider training
• Healthcare delivery innovation
• Legislative, regulatory, policy reform

*All leveraging changing technology
Engaging Stakeholders

Understand Their Specific Motivators, Realities of their Business Model

• What will they get out of participation?
• ROI?
• Value added?
• Drivers are Different...
Match the Motivators

Stakeholder

...is motivated by:

• Manuscripts, Grant funding Tenure & Promotion

• Healing as many patients as possible; Easy clinic flow

• Meeting customer needs to drive market share & revenue

• Making voices count, driving patient-centered care

• Pleasing constituents, getting re-elected
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A Challenge Lies Before Us…
It's how we rise to a challenge that defines us.
- Unknown
TOGETHER
WE CAN DO THIS!
THANK YOU, DEB BOWEN

2016 SBM Distinguished Research Mentor Awardee
THANK YOU!

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