Cancer Survivorship & Cancer Rehabilitation: Building a New Integrated Model of Survivorship Care in the United States

European Cancer Rehabilitation & Survivorship Symposium
September 17, 2012
Copenhagen, Denmark

Catherine M. Alfano, Ph.D.
Deputy Director
Office of Cancer Survivorship, DCCPS
National Cancer Institute
Definitional Issue: Who is a Cancer Survivor? (NCCS, 1986)

• Philosophically, anyone who has been diagnosed with cancer is a survivor—from the time of diagnosis and for the balance of life

• Differentiate types of survivors:
  • Active treatment
  • Disease-free long-term survivors (≥5 yrs post-dx);
  • Those living with CA as a chronic disease
Changing Demography of Cancer Survivorship in the US

• 65% of adults Dx’d today will be alive 5+ years; Children: 10 year relative survival rate > 75%

• Cancer for many has become a chronic illness
  – Implications for care; economic impact ($125 billion in 2010) (Yabroff et al, 2011; CEBP 20: 2006-2014)

• Cancer is for most, a family illness
  – Effects extend to workplace, society

• ↑# survivors = ↑ attention to chronic, late effects of cancer/treatment
  – Physical, psychological, social, economic, existential
“[Survivors] have special psychological, physical, and health care counseling needs that we are only beginning to understand... the [OCS] will support the much needed research that will help cancer survivors deal with the problems they face even after their cancer is cured.”

President Clinton, October 27, 1996, at the Rose Garden ceremony to formally announce the launch of the OCS.
OCS Goals

• The ultimate goal of the OCS is to enhance the length and quality of survival of all cancer survivors.

• To provide a focus for the support of research that will lead to a clearer understanding of, and the ultimate prevention of, or reduction in, adverse physical, psychosocial, and economic outcomes associated with cancer and its treatment.

• To educate professionals who deal with cancer survivors about issues and practices critical to the optimal well-being of their patients. This educational commitment extends to cancer survivors and their families.
Estimated Number of Cancer Survivors in the United States From 1971 to 2008

Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2008 by Site (N = 11.9 M)

Female Breast 22%
Prostate 20%
Colorectal 9%
Gynecologic 8%
Hematologic (HD,NHL,Leukemia, ALL, Myeloma) 8%
Urinary Tract (Bladder, Kidney, Renal Pelvis) 7%
Melanoma 7%
Lung 3%
Thyroid 4%
Other 12%

Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2008 by Time From Diagnosis and Gender (Invasive/1st Primary Cases Only, N = 11.9 M survivors)

Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2008 by Current Age
(Invasive/1st Primary Cases Only, N = 11.9 M survivors)

Projected Increase in US Cancer Survivors by 2020

Parry et al, CEBP; 20(10) October 2011
Chronic Effects of Cancer Treatment

Physical, Psychosocial, & Economic:

- Fatigue
- Pain, neuropathy
- Cognition problems
- Lymphedema
- Sexual impairment
- Incontinence
- Depression & anxiety
- Uncertainty
- Altered body image
- Relationship changes
- Health/life insurance problems
- Concerns re: Job lock/loss, financial burden

...And some positive changes: sense of purpose or meaning, appreciation of life
Cancer Survivors at Increased Risk for Late Effects

- Disease recurrence/ new cancers (>756K multiple CA; 16% of new diagnoses)*
- Cardiovascular disease
- Endocrine dysregulation
- Obesity
- Diabetes
- Osteoporosis
- Upper/lower quadrant mobility & functional limitations
- Functional decline $\rightarrow$ disability

* Mariotto et al., CEBP 2007
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
Percent with Limitations:
Survivors vs. General Population

Many survivors will die of competing causes, NOT cancer...

- Older breast cancer survivors: more likely to die of CVD than breast cancer (Patnaik, *Breast Cancer Research* 2011, 13(3):R64)

- 15-year prostate cancer-specific mortality: 5.3% vs. 30.6% non CaP-mortality (Shikanov, *Prostate Cancer Prostatic Dis.* 2012 Mar;15(1):106-10)

- Testicular CA survivors treated w/ XRT under age 35: 1.7 x more likely to die of circulatory Dz than general population (Fossa, *JNCI* 2007 April 4; 99(7), 533-44)
Current Thinking in the US about a “New” Model of Care is PCP v ONC

Oeffinger & McCabe, JCO 24(22), 2006
2011 US Meeting on Survivorship Care Planning; Risk-Stratification

Risk of recurrence

Low/low

Oncology

High/high

Primary Care

Well-being

Outside resources

Late Effects (severity)

Patient-reported outcomes—physical, psychological, functional, social work (must be determined using screening/assessment tool)
Projected supply of and demand for oncology providers

Erikson et al. (2007), Journal of Oncology Practice
Moving forward to a new model of post-treatment survivorship care
IOM components of survivorship care

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

- **Intervention** for treatment consequences
  - Medical/psychosocial/economic chronic & late effects

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

- **Coordination** between PCP and specialists to ensure all needs are met
Recommendations from the President’s Cancer Panel & IOM Reports

• **When treatment ends**, all survivors should receive
  • a summary record that includes info re: *disease, treatments & complications*.
  • a follow-up care plan incorporating available evidence-based standards of care describing *who to see for what & when*.

• ACS CoC accreditation mandate for 2015
But equally importantly…

HOW DO WE TREAT ALL OF OUR SURVIVORS & MEET ALL OF THEIR NEEDS?
Time for a new model of survivorship care

- Dramatic ↑ in # survivors
  - Especially in older adults
- Multiple comorbidities
  - Many will die of comorbid conditions
- Chronic effects of tx; At risk for late effects
  - Physical & emotional issues not being met
- Need to prevent spiral into disability
- Need to promote healthy behaviors
- Shortage of providers
Finding a new model

Cancer Survivorship and Cancer Rehabilitation: Revitalizing the Link

Catherine M. Alfano, Office of Cancer Survivorship, National Cancer Institute/National Institutes of Health/Department of Health and Human Services, Bethesda, MD
Patricia A. Ganz, School of Medicine, School of Public Health, and Jonsson Comprehensive Cancer Center, University of California, Los Angeles, Los Angeles, CA
Julia H. Rowland, Office of Cancer Survivorship, National Cancer Institute/National Institutes of Health/Department of Health and Human Services, Bethesda, MD
Erin E. Hahn, School of Public Health and Jonsson Comprehensive Cancer Center, University of California, Los Angeles, Los Angeles, CA
Why a comprehensive rehab model?

- Joint focus on optimizing functional status & QOL
- **Intervention:**
  - Address pre-existing or tx-related comorbidities
  - Treat chronic effects of tx
- **Prevention:** Promotion of self-management and healthy behaviors prevents further problems;
  - ↓risk of recurrence & ↓death due to comorbidities
  - ↓risk for late effects
- **Coordination:** Evaluates sum total problems/needs & coordinates care
- Prevents spiral into disability; preserve work, roles
- Add in **surveillance** to embody 4 pillars of IOM defined SC
Comprehensive Cancer Rehabilitation

• Need to change “traditional” beliefs:
  – Rehabilitation only for survivors needing “complex care”
  – Rehabilitation is PT only or exercise only
  – Rehabilitation is a consult service

• Turn on its head: Lens not a Service

• Unification: Survivorship care = Rehabilitation care
Pressing Questions

• How do we build an evidence base for the best model of post-tx survivorship care?
  • Need international collaboration to build/evaluate models that might serve as “best practices”
  • Show improvements in patient, health care system, and cost outcomes?
• Risk stratification into care? Referral back to primary care?
  • Types of care? How to deliver care?
• How to keep up with changing needs as tx changes?
• How can we train enough providers?
• Who will pay for this?
• UK risk-stratification into 3 pathways of care:
  (2 million survivors)

Barriers to a new model in the US

- Divergent perceptions about who should provide care for survivors
  
Potosky et al, JGIM 2011

- Need training for knowledge gaps; build trust & communication; international outcome data; bring rehab into dialogue
Barriers to a new model in the US

• Oncologists have to give up their long-term survivors
• Survivors have to give up their oncologists
• Need risk-stratification algorithm; outcome data
• We have to start talking about supported self-management (not just return to PCP)
  – How to give survivors what they need re: what to look for, when to contact healthcare team, rebuild their confidence to do this – make it patient-centered?
  – How to utilize technology to facilitate this?
  – How to overcome ‘fee for intervention’ model?
Supporting Self-Management

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- Lack of coordination across providers
Care Coordination: A Case Study

Just Before Cancer Dx

PATIENT

PCP

Slides courtesy of Neeraj Arora, PhD
Care Coordination: A Case Study

Post-Treatment Care 6-10 years

ONCOLOGIST

NEUROLOGIST

GI SPECIALIST

PCP

CARDIOLOGIST
Importance of Care Coordination

Post-Treatment Care For the Elderly Survivor

1 in 4 survivors 65 – 74 years old have 5+ comorbidities and are likely to see up to 12 physicians per year
A Time of Great Opportunity…

• Growing attention to survivors’ long-term well-being and preventive health (US)
• International focus on designing better, more integrated healthcare for survivors that meets all of survivors’ needs
• More sophisticated technology is invented daily that can help us meet survivors’ needs with better reach & efficiency
• Growing numbers/disciplines of researchers and clinicians entering survivorship science and practice
• Articulate and effective advocacy community: The power of survivors’ voices!