Issues in Cancer Survivorship

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What are we talking about & why?

• “Cancer Survivor” – definitions
• 12 million survivors in the U.S.
  ■ 5,168,889 men (2006)
  ■ 6,216,003 women (2006)
  ■ # will double by 2050 (Yabroff, Lawrence, et al, 2004)
• Lifetime: 1 in 3 males & 1 in 2 females
  ■ > 40% people born in 2008 (Travis & Yahalom, 2008)
• Adults w/ Cancer
• Children w/ Cancer (become adult survivors)
• Elderly

Estimated # of Living Persons
Ever Diagnosed w/ a Cancer, 1971 to 2001

~ 14% of survivors today were dx > 20 yrs ago...
  often w/ “harsh tx” →
  long term & late effects

* Estimated by scaling U.S. populations to SEER-9 and historical
  Cancer Incidence Registry data and adjusted to represent all cancer
  survivors. Survivor populations were based on average monthly
  survivor estimates through the U.S. Census Bureau.
Trends in Five-year Relative Survival Rate, U.S., 1975-2004

Cancer Death Rates* by Sex and Race, US, 1975-2005

Trends in Cancer Survival by Age Group, Children 0-14 Years, 1975-2004
Cancers by Age

Age = most important risk factor for cancer

- based on November 2008 SEER data

Even as the Survivor Population Increases...

The trend for the HCP Workforce is:
- Shortage of Oncology Specialists (physicians & nurses)
- Shortage of Primary Care Providers

Therefore...

We must learn what we need to know through research & translate this knowledge into clinical programs in order to care for cancer survivors
Oncologist Shortage
Ensuring Quality Cancer Care Through the Oncology Workforce,
http://www.nap.edu/catalogu/12613.html accessed April 11, 2010

Patient’s Voices
From Cancer Patient to Cancer Survivor:
Lost in Transition

4 Essential Components of Survivorship Care
1. Prevention - recurrent & new cancer, late effects
2. Surveillance - cancer spread, recurrence, 2nd cancers, assess medical & psychosocial late effects
3. Intervention – for sequelae of cancer and cancer tx
4. Coordination – b/ Specialists & PCPs to meet survivors’ health needs

Please show DVD
Something must be done – but what?

- NCI – Cooperative Groups (1955)
- NCCS (1986) – use term “survivorship”
- NCI Office of Cancer Survivorship (1996)
  - Distinct phase of care
  - Clinical, Research, Education, & Advocacy
  - 4 Essential Components of Survivorship Care
Evolving Standards – Survivorship Care Plan

- Treatment Summary
- Cancer Surveillance
- Long Term & Late Effects – 3P’s
  - (prevent, palliate, promote)
- Health Screening
- Health Promotion
- Biopsychosocial adjustment
- Genetic Counseling PRN
- ID health team roles & responsibilities
- Focus on “patient agency” – what is pt’s role?

Cancer Survivorship Today and Tomorrow
Patricia A. Ganz (Editor)
Springer, 2007

Care Plan Descriptions & Templates

- 2 IOM Reports - www.nap.edu
- ASCO Web Site – generic + 5 specific cancers
  www.asco.org/treatmentsummary
- Journey Forward - www.journeyforward.org
- Cancer Survivor’s Prescription for Living –
  http://tiny.cc/SFA83 (by RNs for RNs)
- LIVESTRONG Care Plan (powered by OncoLink)
  - www.livestrongcareplan.org (for patients)
For Patients and HCPs
• Survivorship Care Plan Builder
• Health History Builder
• Resources
www.journeyforward.org
UCLA Cancer Survivorship Center, NCCS, WellPoint & Genentech

Survivors of Childhood Cancers

• Children’s Oncology Group (COG)
  – Guidelines for follow-up based on treatment
  – www.survivorshipguidelines.org
• Lost to follow-up: < 30% of survivors 20 yrs from diagnosis return for follow-up care
• Inadequate care: Survivors who do return for care often do not receive proper surveillance

Models of Survivorship Care

• Shared Care Model
• Disease-Specific Clinics
• Comprehensive Survivorship Clinics
  – Consultative Model
  – Advanced Practitioner Clinician-led Clinic
  – Specialized Multidisciplinary Survivorship Clinic
• Blended Models
Evolving Standards – Quality of Life Screening

- HRQOL
- Symptom Prevalence and Intensity
- Patient-Reported Outcomes
- Mood (Distress, Anxiety, Depression)
  - Distress Thermometer, GAD-7, PHQ-9
- Cognitive Function
- ADL’s
  Prevalence, Treatment, Cost (time, resources, $)

Evolving Standards – Transitions in Care

- IOM Focus
- HFHS Primary Care (unpublished study, 2009)
  - 88% PCPs: Important to understand cancer patients’ follow-up plans
  - >50% PCPs: “Rely” on patients to inform them of their follow-up plan, yet...
  - >80% of providers believe their patients are confused about follow-up

Research Evidence to support adoption of Cancer Survivorship Care Plans is sparse. Many barriers to implementation remain. Should we continue to pursue?

With Education & a Treatment Algorithm, PCPs can deliver cancer surveillance care similar to oncologists for breast & colorectal cancer

Research Trends & Needs – Quantity AND QUALITY of Life

Is there a place for survivorship research in cancer clinical trials???

Office of Cancer Survivorship, NCI 1996

1. Understand, prevent & reduce adverse physical, psychosocial & economic sequelae of cancer & its treatment
2. Educate HCPs, Survivors & Family

Clinical Trials Cooperative Group Program

• Promote and support clinical trials (research studies) of new cancer treatments
• Explore methods of cancer prevention & early detection
• Study quality-of-life issues & rehabilitation during and after treatment


Cancer & Cancer Treatment: some possible Sequelae

• Second primary cancers (3rd or more)
• Cardiac disease
• Neurocognitive dysfunction
• Sexual Function / Infertility
• Osteoporosis
• Necrosis of
• Neuropathies
• Endocrine dysfunction
• Lymphedema
• Pulmonary disease
• Fatigue
• Prolonged emotional distress
• Benefit-finding & Resilience
OCS Call for Research – 2001
Six target areas

1. Descriptive epidemiologic data on outcomes
   > 1 yr s/p dx

2. Intervention Studies - develop & test strategies
   – Prevent or decrease adverse outcomes
   – Promote optimal health practices

3. Describe & develop patterns of care for post-tx
**OCS Call for Research – 2001**

**Six target areas**

4. Include under-represented: Elderly, low SES, ethnic / cultural minorities, live in remote areas, specific cancers (colorectal, lung, heme)

5. ID or develop instruments that accurately demonstrate outcomes for post-tx survivors

6. Describe impact on family

(Rowland, Aziz, Tesauro, Feuer, 2001)

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**OCS Research - “hot off the press”**

1. Aging
2. Biobehavioral Interface – persistent & late effects
3. Comparative Effectiveness
4. Adherence
5. Health Promotion & Health Behavior
6. Comorbidities – health care utilization & cost
7. QOPI Standards – Summary Care Plans
8. Caregivers

(Julia Rowland, PhD, Dir OCS, 2/20/2010, APOS Meet the Experts)

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**Translational Research**

- Data Challenges
  - Longitudinal & Prospective
  - Relevant Variables
  - Large Data Sets
  - Diverse populations
  - Use of surrogate biomarkers / genetic markers
  - Confounding Variables & Co-morbidities
  - Accurate measurement (vs. self report alone)
Translational Research

- Tension between
  - focus on “cure” and “quality of life”
  - Immediate and long term consequences
- Medical Record Documentation
- Programs that are practical to implement (Jacobsen)
- Funding

Survivorship Research informs treatment and follow-up care

ONS: Survivorship, Quality of Life & Rehabilitation SIG
http://survivorship.vc.ons.org

- Mission Statement: Promote excellence in nursing care of cancer survivors through education, communication and advocacy and enhance nursing knowledge of evidence based practices in caring for cancer survivors.
- Newsletters available by request
- Networking Meeting - 35th ONS Congress
  Saturday, May 15, 2010 / 4:15-5:45 PM Room 3
- SIG Poster Displays – ONS Congress Exhibit Hall

Henry Ford Health System --- Josephine Ford Cancer Center

- EMR & an integrated health care system
- Oncology Social Workers
- Support Groups – children & adults
- Yoga
- EXCITE! Program – exercise, diet, CAM
- CMS Project – screen & follow African Americans through a Medicare-funded program
Henry Ford Health System --- Josephine Ford Cancer Center

Psychooncology Services:
- Nurse Practitioner & Psychology Fellow
  - Distress Screening
  - Psychooncology Education for Therapists
  - Study of Primary Care Physicians
  - Survey of Patients and Significant Others attending a Cancer Survivors’ Program x 2 yrs
- GYN Advanced Nurse Practitioner Survivorship Pilot

SWOG Survivorship Studies

Active
- ↓ Ovarian failure s/p CTX early ER/PR (-) breast
- Antioxidant & CAM Use & Survival
- ONJ & Bone Mets – Starting Zoledronic Acid Tx
- Carnitine to Prevent Neuropathy from Taxanes

Closed
- > 70 yo & CTX x 3 trials (urothelial, breast, c/r)
- Older Age & barriers to clinical trials accrual

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Our Patients
What will you do next?