Cancer Survivorship in Primary Care

Tuesday Morning Conference
November 24, 2009
Objectives

- Define cancer survivorship
- Describe prevalence of cancer survivorship
- Outline domains of care for cancer survivors
- Understand the role of primary care in cancer survivorship
- Review clinical programs started at University of Colorado-Denver for survivors of adult and pediatric cancers
Who is a cancer survivor?

- “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 therefore included in this definition” (NCCS, NCI)

- “Period in which patients treated with curative intent have completed their initial therapy and require follow up care” (P. Ganz, 2006)

- “Period until recurrence, second cancer, or death and may include some ongoing treatment, such as hormonal therapy” (IOM, 2006)
There are almost 12 million survivors in the United States as of 2007

U.S. Cancer Survivors by Age

Estimated # alive with a diagnosis of cancer on January 1, 2006 by current age

Invasive/first primary cases only

N = 11.4 million

How did we get here?

- Improved treatment
- Earlier diagnosis/screening
- Aging population
Cancer survivors can become “lost” in follow up

IOM, 2006 “From Cancer Patient to Cancer Survivor: Lost in Transition”

Once patients complete treatment—even during their treatment—their care can become fragmented.
• Multimodal therapy
• Multiple providers
• What to do when active treatment stops? Who is responsible for following what?
Domains of care

- Physical
- Psychological
- Social
- Spiritual
- Informational
Domains of care

- Physical
- Psychological
- Social
- Spiritual
- Informational
Childhood Cancer Survivor Study

- Retrospective cohort study, diagnosis between 1970-1986
- Control group - siblings
- Outcomes: mortality, morbidity health status
  - Significant excess risk of death from secondary cancers, cardiac causes, pulmonary causes (n = 20,227) (Mertens et al, 2001)
  - Survivors 3.3 times more likely than siblings to have any chronic condition; 8.2 times more likely to have a severe condition (n = 10,397, includes only CNS tumors, NHL, Hodgkin’s, leukemia, Wilms tumor, soft tissue sarcoma or bone cancer) (Oeffinger et al, 2006)
Physical/Medical follow up of cancer survivors

- Late effects: conditions that were not present during or at the completion of treatment but manifest (sometimes years) later
  - i.e. basal cell skin cancer in radiation field, secondary cancers, cognitive deficits, infection following splenectomy, viral infections

- Long-term effects: conditions that were present during active treatment and persist
  - i.e. peripheral neuropathy, fatigue, lymphedema, cardiomyopathy
Physical/Medical follow up of cancer survivors

Activities involved in follow up:
1. Monitoring for recurrence
2. Management of late/long-term effects
3. Surveillance for secondary cancers
4. Addressing preventative care
5. Managing co-morbidities (esp. important for those diagnosed with cancer as adults)
Obtaining the medical history of a patient with a history of cancer is the first step in survivorship care

- Details of cancer and treatment (histology, stage, doses/exposures of tx, surgical procedures, complications)
- What surveillance?
- Current medications
- Family history
- ROS--perspective of previous dx/tx
“Cancer-focused” review of systems

- Constitutional (wt. Δ, fatigue)
- Skin (esp. w/ radiation history)
- ENT (dental, hearing, cataracts)
- Cardiac (CHF, CAD, vascular dz; anthracyclines, XRT)
- Pulmonary (bleomycin, XRT)
- Endocrine (thyroid, pituitary, growth, metabolic syndrome)
- Reproductive (infertility, menopause, sexual functioning)
- Renal (HTN)
- GI (cirrhosis, hepatitis, diarrhea, enteritis)
- Neurologic (neuropathy, cognition, pain)
- Musculoskeletal (arthralgias, scoliosis, osteoporosis)
- Psychosocial (depression, anxiety, cognitive)

(Ganz, P “Monitoring the physical health of cancer survivors: A Survivorship Focused Medical History”, Journal Clin Oncol 2006 24(32), 5105-5111)
Domains of care

- Physical
- Psychological
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Increasing psychological distress may impact interactions with health care system–

↓adherence to screening guidelines
↓interactions with providers
↓less satisfaction
↓as well as impacting QOL
Psychological care

(From Lance Armstrong Foundation LIVESTRONG Poll, n = 1020)

- 49% reported that non-medical cancer needs were unmet
- 53% reported practical/emotional consequences often harder to cope with than medical issues
- 70% dealing w/ depression
- 78% did not seek professional help
- 58% loss of sexual desire and/or function

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Male</th>
<th>Female</th>
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</thead>
<tbody>
<tr>
<td>Diagnosis made &gt; 2 years prior to survey</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Currently experiencing &quot;good health&quot;</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Optimistic that will die from something besides cancer</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Talk about cancer more than a few times/month</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Incurred financial debt due to cancer of &gt; $25,000</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Life still affected by cancer (&quot;more than a little&quot;)</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Dealing with cancer made life better</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Suffered depression due to cancer</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Had unmet non-medical cancer needs</td>
<td>50%</td>
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<td>50%</td>
<td>50%</td>
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<tr>
<td>Emotional needs harder than physical needs</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Would volunteer to assist in survivorship activities</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Would deal with chronic pain</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Would deal with non-medical issues</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Medically uninsured</td>
<td>50%</td>
<td>50%</td>
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<tr>
<td>Caucasian/African American/Hispanic distribution</td>
<td>50%</td>
<td>50%</td>
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<table>
<thead>
<tr>
<th>Age Group</th>
<th>Results</th>
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<tbody>
<tr>
<td>50-54 years</td>
<td>89% / 72% / 2%</td>
</tr>
<tr>
<td>55-64 years</td>
<td>73% / 52% / 8%</td>
</tr>
<tr>
<td>65+</td>
<td>59% / 47% / 6%</td>
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<tr>
<td>Survey Question</td>
<td>Results</td>
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<tr>
<td>-----------------------------------------------------</td>
<td>------------------------------</td>
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<tr>
<td>Male/female</td>
<td>50% / 50%</td>
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<tr>
<td>Median age</td>
<td>50-54 years</td>
</tr>
<tr>
<td>Without current health insurance</td>
<td>9%</td>
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<tr>
<td>Caucasian/African American/Hispanic distribution</td>
<td>89% / 2% / 2%</td>
</tr>
<tr>
<td>Diagnosis made &gt; 2 years prior to survey</td>
<td>73%</td>
</tr>
<tr>
<td>Currently experiencing “good health”</td>
<td>62%</td>
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<td>Optimistic that will die from something “besides cancer”</td>
<td>59%</td>
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<td>Incurred financial debt due to cancer of &gt; $25,000</td>
<td>9%</td>
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<tr>
<td>Talk about cancer more than a few times/month</td>
<td>46%</td>
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<tr>
<td>Life still affected by cancer (“more than a little”)</td>
<td>40%</td>
</tr>
<tr>
<td>Dealing with cancer made life better</td>
<td>47%</td>
</tr>
<tr>
<td>Emotional needs harder than physical needs</td>
<td>53%</td>
</tr>
<tr>
<td>Had unmet non-medical cancer needs</td>
<td>49%</td>
</tr>
<tr>
<td>Physician unable to assist with non-medical issues</td>
<td>70%</td>
</tr>
<tr>
<td>Suffered depression due to cancer</td>
<td>70%</td>
</tr>
<tr>
<td>Had to deal with chronic pain</td>
<td>54%</td>
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Increasing psychological distress may impact interactions with health care system--

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↓as well as impacting QOL
Assessment and referral are essential elements

- Subgroup of patients have significant symptoms of psychological distress, but underestimated by providers
- Approx. 20-40% report problems but less than 10% are referred for services
- ?Access
- Pilot work at MSKCC indicates that assessment done at survivorship follow up visits is feasible, acceptable to pts/providers
Assessment and referral are essential elements

- Both IOM and National Comprehensive Cancer Network (NCCN) have made recommendations or developed guidelines regarding identification of/ referral for psychosocial needs

- Little data exists on adherence
  - Institutional survey of 15 NCCN member institutions reported that about half (53%) routinely assessed patients; of those that screened 87.5% routinely referred to mental health professional (Jacobsen et al, 2007)
  - Medical record review of 388 CRC patients across 7 sites showed that
    - Current emotional well being assessed: 60%
    - If problem identified, action taken: 51% (range 0-100%)
    - Pain assessment done: 87% (p < .0001) (Jacobsen et al, October 2009)
Domains of Care

- Physical
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- Informational
Social considerations

- National Cancer Institute includes family members, friends in cancer survivor definition
- Isolation/stigma
- Economic
- (Return to) work issues
- Few studies done on impact of family members (for those with cancer as children)
- Different considerations for different age groups
• 25% had dating problems
• 43% dealt with decreased income
• 34% feel trapped in job d/t health insurance
• 81% did not make career change

(Wolff et al, 2005)
Economic issues

- Of patients with a history of cancer and had insurance
  - 23% insurance did not pay for something they thought was covered
  - 25% used up all or most of their savings
  - 11% couldn’t buy health insurance
  - 8% couldn’t buy life insurance

- Of those who were ever uninsured
  - 41% unable to pay for basic necessities
  - 6% declared bankruptcy

- Financial burden hit younger adults and those with incomes < $40K hardest

N = 930 adults age 18+
(USA Today/KFF/Harvard School of Public Health, National Survey of Households Affected by Cancer, 2006)
Work issues

- Most people employed at time of diagnosis, and supported well, but…
- 36% report unable to perform job as well as before
- 19% reported cancer dx caused other family member to lose/change jobs or work fewer hours

(USA Today/KFF/Harvard School of Public Health, National Survey of Households Affected by Cancer, 2006)
Psycho-social overlap

- Those in older age groups (65+) tend to report less of a “life-changing” impact.

- Level of physical/cognitive impairment may dictate psychological impact for patients and their family members. (KFF survey % reporting emotional/psych problems in family members 3x higher if activities limited at recovery)

- Growing recognition that adolescents/young adults have unique needs and issues (dating, body image, fertility, starting careers, establishing independence, lack of insurance).
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Spiritual Care

- Cancer diagnosis can lead to “existential suffering” *(Shirley Otis-Green, City of Hope)*
  - Meaning of life/purpose of life
  - Powerlessness/loss of control
  - Beliefs/worldview can be threatened
Spiritual Care

- Very few RCTs, mostly non-RCTs since 1960’s. Interventions (such as prayer or faith based psychotherapy) may help recovery from anxiety/depression, reduce blood pressure (Townsend et al, 2003)
- Much of work done in field of end-of-life and palliative care
- Some interventions are beginning to emerge (Dignity Therapy, Existential Meaning-Centered Psychotherapy Groups)
Spiritual Care--Challenges

- Spiritual care typically not reimbursed
- Lack of formal training
- In doing research to evaluate
  - The example of prayer:
    - How do you define/administer?
    - How do you “dose”?
    - How do you control for “confounding” (i.e. others praying?)
    - How do you standardize?
What we can do

- Ask questions (“How are you holding up?” “What sustains you?” “What has helped you provide hope/inspiration?”)
- Assess don’t assume
- Listen
- Facilitate benefit finding
- Referral
- Increase our own awareness of spirituality (i.e. www.meaninginmedicine.org)
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Information needs of patients--and providers

- Only about 35% of childhood cancer survivors understand that serious health problems could result from past treatment (JAMA, 2002)
- Patients can have difficulty remembering what tx received/when/complications
- Patients report receiving different pieces of information from multiple providers (USAToday/KFF/Harvard survey 2006)
- Models are being evaluated, but many unknowns exist in how to operationalize survivorship care
Barriers for PCPs

- Despite evidence showing patients receive better overall care when PCPs involved, PCPs need information as well.

- 2009 survey of GIM physicians: Of 227 Colorado internists surveyed:
  - 24% reported providing multidimensional care (lower if recent med school graduate)
  - 82% believed PCP follow up guidelines not clearly defined
  - 47% reported inadequate preparation and lack of formal training

The case for shared care

- **Earle et al, 2003**: Retrospective cohort of breast cancer survivors (n = 5965). Receipt of mammograms highest when followed by oncology; receipt of other preventive care (PAP, CRC screen) better when followed by PCP. Most comprehensive care when pts followed with both PCP and Oncologist

- **Grunfeld et al, 2006**: RCT of 968 breast cancer survivors. When PCPs provided w/ 1-page summary of frequency/content of exams, no difference in rates of recurrence, side effects, or quality of life

- **Snyder et al, 2008**: Retrospective cohort of 1st year CRC survivors (n = 20,068). Pts followed by both PCP and Oncologist most likely to receive preventive care (flu, lipid, mammogram, bone density), followed by PCP only, then Oncologist only
The Survivorship Care Plan

- May be the way to fill in informational gaps for patients and providers
- A document that reviews the diagnosis (including stage/grade/histology), treatments received, plan for surveillance, plan for assessing and monitoring late/long term effects
- A “teachable moment” for health promotion activities
- A key recommendation of the 2006 IOM Lost in Transition report
Survivorship Clinics at UCD

- Housed in Internal Medicine Department
- **THRIVE**: Breast Cancer, done w/ active tx, no PCP/concerns about resuming, medically “complex”
- **TACTIC** (Thriving After Cancer Treatment is Complete): age >21, >5 yr. from dx, >2 yr from tx
- Oncologist: Medical Record Review, Risk Assessment, Specialty Referrals
- Psychologist: Screening for Anxiety, Depression
- Internist: Routine Preventive Care, Late and Long-term Side Effects, Health Promotion, Coping, Fear of Recurrence
- Nurse Educator: Patient Education, Provider Communication, Survivorship Care Plan, Self-Care; Self-Efficacy, Cancer-Specific Information, Links to Support Services and Programming

Note: similar for adult cancer survivorship clinic except oncologist not present during clinic visit.
Lessons from UCD Clinics/Future Directions

- Resource intense
- Importance of psychosocial provider and nurse educator
- (TACTIC) Effect on family unit
- Care plan is a working document
- Evaluation to assess types of recommendations made/adherence to recommendations/pt. satisfaction
- Outreach to community outside of Denver