National Coalition for Cancer Survivorship

Strategies for Designing a System for Survivorship Care

Wednesday, June 3, 2015
3:00pm-4:30pm EDT
NCCS Mission

Advocate for quality cancer care for all people touched by cancer
NCCS Public Policy Priorities

...ensure that every cancer patient has access to cancer care planning and coordination services
Cancer Policy Advocate Training

• Late and long-term effects – recent research findings
• Survivorship care plans
• Cancer care workforce challenges
• New value-based cancer care payment systems – do they foster better survivorship care
• Disparities in survivorship care

knepote@canceradvocacy.org

June 25-26, 2015
Washington, DC
Join the conversation on Twitter

#CPAT15
@canceradvocacy
Dr. Smita Bhatia
Q&A

• Type your question in the chat box area located on the lower left corner of your screen

• If you are dialed in, select *1 on your telephone keypad
Strategies for designing a System for Survivorship Care

Smita Bhatia, MD, MPH
Why Cancer Survivorship?

A generation ago...

- Less than half of those diagnosed with cancer survived more than 5 years
- Treatment was less precise and more disabling
- Cancer was a topic shrouded in social silence
Estimated number of Cancer Survivors in the US 1971 to 2008

Cancer Survivors (in millions)

- 1971: 14,000,000 (1.5%)
- 2010: 16,000,000 (4.0%)

Cancer Epidemiol Biomarkers and Prev, 2011
Cancer Survivors: Time from Diagnosis by Gender

>65% = 5+ year survivors

Cancer Epidemiol Biomarkers and Prev, 2011
Cancer Survivors by Diagnosis

- Breast: 23%
- Prostate: 19%
- CRC: 10%
- Gyn: 9%
- GU: 6%
- Heme: 7%
- Other: 26%

Cancer Survivors by current age

- <20 years: 1%
- 20-39 years: 4%
- 40-64 years: 35%
- 65-69 years: 13%
- 70-79 years: 25%
- 80+ years: 22%

J Natl Cancer Inst 2006
Estimated number of persons with a history of cancer (1971 to 2008)
“Being cancer-free is not the same as being free of cancer”

- Julia Rowland PhD
  Director, NCI Office of Cancer Survivorship
What is Cancer Survivorship?

Defined in a variety of ways:

- **Person affected**
  - Patient
  - Family members, friends
  - Caregivers

- **Time frame**
  - The day of diagnosis
  - The end of treatment
  - Five years from diagnosis
## The Cancer Continuum

### Survivorship: A Distinct Phase of Cancer Care

- Psychosocial coping
- Surveillance
- Long-term follow-up
- Management of late effects
- Health promotion

Institute of Medicine, 2006
Cancer Survivorship: Addressing the Challenges

- Transition from active treatment to post-treatment care is critical to long-term health
- Lasting effects of cancer experience require long-term follow-up
- Survivorship care requires planning and coordination
- Health promotion important component of long-term care

Hewitt, Greenfield & Stovall, 2006
Cancer Survivorship: Addressing the Challenges

- Need for provision of appropriate psychosocial health services to address:
  - Information needs
  - Coping
  - Health-related behaviors
  - Identification of resources
  - Disruption in work, school and family life
  - Financial issues

Adler & Page, 2008
Late Effects: A Short History

• Prior to the 1970s, the diagnosis of cancer and the concept of long-term survival were almost mutually exclusive

• As progress was made in cancer treatment, a cohort of pediatric cancer survivors began to emerge
  • unfortunately, late effects of cancer treatment were evident in many of them

• The emerging reality: “Cure comes at a cost”
Childhood Cancer Survivors

80% of all children diagnosed with cancer are cured.

By 2020, there will be over 500,000 childhood cancer survivors.
Long-term Sequelae in Cancer Survivors

<table>
<thead>
<tr>
<th>Health-related</th>
<th>Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fertility and Reproduction</td>
<td>Health status</td>
</tr>
<tr>
<td>Fertility</td>
<td>Healthcare Utilization</td>
</tr>
<tr>
<td>Health of Offspring</td>
<td>Premature Mortality</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vital Organ Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac</td>
</tr>
<tr>
<td>Pulmonary</td>
</tr>
<tr>
<td>Renal</td>
</tr>
<tr>
<td>Endocrine</td>
</tr>
<tr>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>Vision/Hearing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Second Neoplasms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign</td>
</tr>
<tr>
<td>Malignant</td>
</tr>
</tbody>
</table>
Cognitive Dysfunction

1 to 2 years following radiation
  • progressive

Academic difficulties
  • reading, language, mathematics
  • significant drops in IQ scores

Risk Factors
  • Leukemia, brain tumors
  • Radiation to the brain
  • Intrathecal chemotherapy
  • Young age - less than 5 years
  • Female gender

Special Education Services

<table>
<thead>
<tr>
<th></th>
<th>Survivors</th>
<th>Siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>23%</td>
<td>8%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>36%</td>
<td>30%</td>
</tr>
<tr>
<td>CNS</td>
<td>70%</td>
<td>20%</td>
</tr>
</tbody>
</table>
Cardiac Complications

Can occur years after completion of treatment
Spontaneous or coincide with exertion or pregnancy

- Chemotherapy (anthracyclines)
- Chest radiation
- Females
- Younger age
Lung Complications

**Causes**
- Radiation
- Chemotherapy

**Symptoms**
- Chronic cough
- Shortness of breath

**Prevention**
- Caution about smoking
- Frequent checks
Second Primary Cancers

1. Radiation
2. Chemotherapy
3. Smoking
4. Diet
5. Exercise
6. Genetic susceptibility
Breast Cancer after Hodgkin lymphoma in girls receiving radiation

20 to 55-fold increased risk as compared to the general population
Premature Death
Late Mortality experience in Childhood Cancer Survivors

**Cause of death**
- Recurrence
- Subsequent malignancies
- Cardiopulmonary compromise

Burden of Morbidity in Survivors of Childhood Cancer?
Growth Impairment After Radiation
Second Cancers

Radiation
Chemotherapy
Cardiac Complications
Anthracyclines
Chest Radiation

Pulmonary dysfunction
Chest Radiation
Chemotherapy
Chronic Diseases in Childhood Cancer Survivors

Cumulative Incidence

Grade 1-5

Grade 3-5

The implications of cure are not trivial...

...Burden of morbidity in survivors of childhood cancer is substantial
Burden of Morbidity in Survivors - Implications

Need for continuing follow-up of childhood cancer survivors into adult life

Survivors and healthcare providers need to be aware of “at risk” populations

Only 35% of survivors understand that serious health problems could result from past treatment

Impairs survivors' ability to seek and receive appropriate long-term follow-up care
Primary care providers are unfamiliar with the problems faced by childhood cancer survivors.
Survivorship Issues

- Extended and standardized follow-up of survivors

- Who provides the follow-up?
  - Primary oncologist
  - Primary health care provider
  - Both

- Issues related to transitioning of care
  - From pediatrics to adult-centered care
  - From oncology to primary care

- Issues related to lack of insurance

- Issues related to lack of awareness regarding potential late effects
  - Survivors
  - Health care providers
Long-term survival is an expected outcome for most children with cancer.

Infrastructure for long-term specialized care for survivors
Childhood Cancer Survivorship Program

- Diagnosis of cancer at age 21 or younger
- In remission and off-therapy for at least 2 years
- Consent to participate in IRB-approved protocol
- No upper age limit
<table>
<thead>
<tr>
<th>Protocol</th>
<th>Title/Description</th>
<th>Initiated</th>
<th>Completed</th>
<th>On-Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCG 1882, Regimen B</td>
<td>Poor Prognosis Acute Lymphoblastic Leukemia</td>
<td>2-3-97</td>
<td>5-8-00</td>
<td>No</td>
</tr>
</tbody>
</table>

### Chemotherapy

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Route</th>
<th>Cumulative Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vincristine</td>
<td>IV</td>
<td>48 mg/m²</td>
</tr>
<tr>
<td>Prednisone</td>
<td>PO</td>
<td>1905 mg/m²</td>
</tr>
<tr>
<td>Dexamethasone</td>
<td>PO</td>
<td>985 mg/m²</td>
</tr>
<tr>
<td>L-Asparaginase</td>
<td>IM</td>
<td>90,000 units/m²</td>
</tr>
<tr>
<td>Daunorubicin</td>
<td>IV</td>
<td>100 mg/m²</td>
</tr>
<tr>
<td>Doxorubicin</td>
<td>IV</td>
<td>75 mg/m²</td>
</tr>
</tbody>
</table>

**Total anthracycline chemotherapy**  
= 175 mg/m²  
First dose at age 4 years

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Route</th>
<th>Cumulative Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclophosphamide</td>
<td>IV</td>
<td>3000 mg/m²</td>
</tr>
<tr>
<td>6-Thioguanine</td>
<td>PO</td>
<td>840 mg/m²</td>
</tr>
<tr>
<td>6-Mercaptopurine</td>
<td>PO</td>
<td>titrated to WBC</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>PO</td>
<td>titrated to WBC</td>
</tr>
<tr>
<td>Cytarabine (max single dose = 75 mg/m²)</td>
<td>IV</td>
<td>1800 mg/m²</td>
</tr>
<tr>
<td>Cytarabine</td>
<td>IT</td>
<td>70 mg (1 dose)</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>IT</td>
<td>288 mg (24 doses)</td>
</tr>
</tbody>
</table>

Total #LPs during therapy = 25

### Radiation

None
Recommendations for Follow-Up

Children’s Oncology Group

Long-Term Follow-Up Guidelines
for Survivors of Childhood, Adolescent, and Young Adult Cancer

Version 4.0 – October 2013

www.survivorshipguidelines.org

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The world's childhood cancer experts
Keeping Your Heart Healthy after Treatment for Childhood Cancer

Most childhood cancer survivors do not develop heart problems; however, certain types of cancer treatment given during childhood can sometimes result in problems with the heart. Since heart problems may occur many years after cancer treatment, it is important for childhood cancer survivors to be aware of any treatments they may have received that can affect the heart. That way, they can take steps to keep their heart healthy, including regular medical check-ups and tests to monitor heart function. And if a problem develops, it can be detected and treated early.

How does the heart work?

The heart is a muscular organ that is at the center of the body’s circulatory system. The heart is responsible for pumping blood with oxygen and nutrients to body tissues. There are four chambers (two atria and two ventricles) within the heart that work together to pump blood. Valves direct the flow of blood through the heart chambers and into the blood vessels. The rhythm of heart contraction and rate of the heartbeat are coordinated by nerves...
<table>
<thead>
<tr>
<th>BODY SYSTEM</th>
<th>RECOMMENDATIONS FOR HEALTHY LIVING</th>
<th>WHY IMPORTANT?</th>
<th>HEALTH LINK</th>
</tr>
</thead>
</table>
| Heart       | • Do not smoke or use other tobacco products  
                  • Maintain healthy weight  
                  • Eat low fat diet  
                  • Exercise regularly  
                  • Do aerobic exercises (running, biking, swimming, etc)  
                  • Avoid activities that cause sudden strain on the heart (such as heavy weight lifting/body building)  
                  • Check with healthcare provider before beginning new strenuous exercise program or sports (such as wrestling, football, varsity level sports)  
                  • If you have had a limb salvage procedure, have a VP shunt, or have problems with heart valves: take antibiotics before having dental work or other invasive procedures (such as a colonoscopy, or intestinal surgery)  
                  • If you are pregnant or planning a pregnancy: arrange a consultation with a cardiologist  
                  • See an obstetrician who specializes in caring for women with high-risk pregnancies | Cancer treatment may cause heart problems | Heart Health |
| Lungs       | • Tell all your health care providers that you had Bleomycin  
                  • Avoid high levels of oxygen  
                  • Get the pneumococcal vaccine (pneumonia shot)  
                  • Get the Influenza vaccine “flu shot” every fall  
                  • Do not smoke or use other tobacco products  
                  • Do not SCUBA dive | Cancer treatment may cause lung problems. | Pulmonary Health Bleomycin Alert |
Follow-Up – Patient Report

Survivorship Clinic Visit Report

Patient: John Doe

Clinic date: Wednesday, August 22, 2007

<table>
<thead>
<tr>
<th>Test</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Echocardiogram (heart function) | Borderline | • This test indicates that your heart function has declined somewhat compared to your previous tests.  
• We will continue to monitor your heart at regular intervals to make sure that this does not become a problem. |
| Echocardiogram (heart valves) | Normal | • Normal test result. |
| Kidney function tests         | Normal  | • This is a variation of normal and of no significance to your health. No further testing or treatment is required. |
| Blood count                   | Normal  | • Normal test result. |
| Blood salts and minerals      | Normal  | • Normal test result. |
| EKG                           | Normal  | • Normal test result. |
August 6, 2007

John Smith, MD
123 Main St.
Anytown, USA

RE: Jane Doe
DOB: 1/2/1993

Dear Dr. Smith,

We recently evaluated your patient, Jane Doe, in our Survivorship Clinic for long-term survivors of childhood cancer. As you know, Jane was diagnosed with ALL on 3/21/1999 at age 6, and completed therapy on 6/3/2001. She currently remains in complete remission.

Below we have summarized the therapeutic plan regarding the visit's assessment, please review the enclosed clinic note dictation and reports of diagnostic findings:

PLAN FOR ANNUAL SURVIVORSHIP CLINIC
It was a pleasure to see Jane in the Survivorship Clinic. Our plan is as follows:
1. History/Physical
2. Yearly urinalysis
3. Yearly CBC through 2011
Comprehensive Follow-up of Cancer Survivors

- Summarization of therapy exposures
- Long-term Follow-up Guidelines

End of therapy
Planning Actively for Cancer Treatment Act (PACT Act)
What is Care Coordination?

Care coordination involves deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient's care...

...the patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and...used to provide safe, appropriate, and effective care to the patient.

-AHRQ (Agency for Healthcare Research and Quality)
Why is Cancer Care Planning and Coordination Important?
What will the PACT Act Do?

- Guarantee Medicare beneficiaries a new service that encourages:
  - doctors to create a written care plan
  - discussions to ensure a shared-decision making process
  - alternations of the plan with the patient’s active involvement
  - doctors to create a written summary of care a patient received and information about monitoring and follow-up post treatment
What Can the PACT Act Achieve?
Why is now the time to consider a new Medicare cancer care planning service?

• The PACT Act is consistent with ongoing efforts to improve the quality of care provided to individuals with cancer

• The Center for Medicare and Medicaid Innovation (CMMI) is implementing a new model of payment for cancer care, the Oncology Care Model, which will encourage transformation of cancer care delivery

• There are other initiatives underway to reform the fee-for-service system
Take Action!
Thank You

While we hope for the cure, we must focus on the care.