Overview of Cancer Survivorship

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Director, UCLA-LIVESTRONG Survivorship Center of Excellence
Jonsson Comprehensive Cancer Center
Who are the Cancer Survivors?

• More than 1 in 3 Americans will be diagnosed with cancer in their lifetime
• 11.1 million Americans have a personal history of cancer
• The number of cancer survivors will increase sharply during the next 25 yrs

❖ IOM report focuses on the post-treatment/ence/end-of-life phase of...
American Cancer Society

Public Service Advertisement ca. 1988

More people have survived cancer than now live in the City of Los Angeles.
Cancer Survivor Facts

✓ 60% of survivors are currently over the age 65 years.

✓ Breast, Prostate, and Colorectal, are the 3 most prevalent cancer sites.

✓ Approximately 14% of the 11.1 million estimated cancer survivors were diagnosed over 20 years ago.

✓ The current average age of male and female cancer survivors is 69 and 64 respectively.

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<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>All sites</td>
<td>50</td>
<td>54</td>
<td>66</td>
</tr>
<tr>
<td>Breast (female)</td>
<td>75</td>
<td>79</td>
<td>89</td>
</tr>
<tr>
<td>Colon</td>
<td>51</td>
<td>59</td>
<td>65</td>
</tr>
<tr>
<td>Leukemia</td>
<td>35</td>
<td>42</td>
<td>50</td>
</tr>
<tr>
<td>Lung and bronchus</td>
<td>13</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>Melanoma</td>
<td>82</td>
<td>87</td>
<td>92</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>48</td>
<td>53</td>
<td>64</td>
</tr>
<tr>
<td>Ovary</td>
<td>37</td>
<td>40</td>
<td>45</td>
</tr>
<tr>
<td>Pancreas</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Prostate</td>
<td>69</td>
<td>76</td>
<td>99</td>
</tr>
<tr>
<td>Rectum</td>
<td>49</td>
<td>57</td>
<td>66</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>74</td>
<td>78</td>
<td>81</td>
</tr>
</tbody>
</table>

*5-year relative survival rates based on follow up of patients through 2004.
Survivors by Cancer
Invasive /1st Primary Cases Only
(N = 11.1 million)
How did we make such incredible strides?

- Earlier detection
- New drugs and other treatments
- Combined modality therapy
- Prolonged adjuvant and/or maintenance therapies
- High dose chemotherapy with HCT
- Prevention of second malignancies
But there is a cost...

- Time
- Money
- Human
- Interpersonal
- Existential
For many individuals, cancer is now a chronic disease.....
Burden of Illness in Cancer Survivors: Findings From a Population-Based National Sample

K. Robin Yabroff, William F. Lawrence, Steven Clauser, William W. Davis, Martin L. Brown

• Comparison of cancer survivors and age-matched individuals from the National Health Interview Survey (NHIS) in 2000

• Multiple measures of burden embedded within the survey

JNCI 96:1322, 2004
Health Status is Significantly Poorer in Cancer Survivors

Cancer Survivors (N=1817) vs Noncancer Controls (N=5465)

- **Cancer Survivors**: 31% Fair & Poor
- **Noncancer Controls**: 18% Fair & Poor

Yabroff, JNCI 2004

P < .001
Number of Comorbid Conditions

Burden of Illness is Greater

Yabroff et al. JNCI 2004

P < .001
Cancer Survivors Need More Help with Activities of Daily Living (ADLs)

<table>
<thead>
<tr>
<th></th>
<th>Cancer survivors N=1817</th>
<th>Noncancer controls N=5465</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs help with</td>
<td>11.4%</td>
<td>6.5%</td>
</tr>
<tr>
<td>instrumental ADLs</td>
<td></td>
<td>P &lt; .001</td>
</tr>
<tr>
<td>Any limitation in any way</td>
<td>36.2%</td>
<td>23.8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P &lt; .001</td>
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<tr>
<td>Needs help with ADLs</td>
<td>4.9%</td>
<td>3.0%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P = .003</td>
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Yabroff et al. JNCI 2004
IOM Findings: Survivorship Care

- Survivorship care is a neglected phase of the cancer care trajectory
- Cancer recurrence, second cancers, and treatment late effects concern survivors
- Few guidelines on follow-up care
- Providers lack education and training
IOM Findings: Survivorship Care

- Survivors may:
  - be unaware of risk
  - have no plan for follow-up
- Opportunities to intervene may be missed
- Cancer care is often not coordinated
- Models of survivorship care
IOM Findings: Quality Survivorship Care

- Chronic care model applies
- Essential care components
  - Prevention
  - Surveillance
  - Intervention
  - Coordination
Why is cancer different from other chronic diseases?

• Cancer treatment is….
  – Complex
  – Multi-modal
  – Multi-disciplinary
  – Toxic
  – Expensive
  – And often poorly coordinated

• Cancer treatment usually occurs in isolation from primary health care delivery
Other Challenges

• Limited systematic study of the late effects of cancer therapy
• Follow-up care plans have been *ad hoc*, with focus on surveillance for recurrence
• When should health promotion and chronic disease prevention become the focus?
• Infertility? “Dear, you should just be happy to be alive.”
Why does cancer care present such a challenge?

• An average of 3 specialists/patient, with treatments across time and space…outpatient, inpatient, specialized treatment facilities…. limited communication among treating physicians, multiple medical records

• *In addition*, aging of the population AND work force shortage
Proposed Strategies to Address these Challenges

• Integrated, electronic medical records
• Patient navigators
• Consultation planning

None of these strategies are widely available for patients receiving active treatment!

What happens when treatment ends?
Why do we need a survivorship care plan?

• To summarize and communicate what transpired during cancer treatment
• To describe known and potential late effects of cancer treatments, with expected time course
• To communicate to the survivor and other health care providers what has been done and what needs to be done in the future
• To promote a healthy lifestyle to prevent recurrence and reduce the risk of other comorbid conditions
Survivorship Care Plan flows from other IOM Recommendations

- Continuous healing relationships
- Customization based on needs and values
- Patient as the source of control
- Shared knowledge and free flow of information
- Evidence-based decision making
- Safety as a system property
- Need for transparency
- Anticipation of needs
- Decrease in waste
- Cooperation among physicians
Key Elements Included in Survivorship Care Plan

- Specific tissue diagnosis and stage
- Initial treatment plan and dates of treatment
- Toxicities during treatment
- Expected short- and long-term effects of RX
- Late toxicity monitoring needed
- Surveillance for recurrence or second cancer
- Who will take responsibility for survivorship care
- Psychosocial and vocational needs
- Recommended preventive behaviors/interventions
Where does the Survivorship Care Plan fit in the Chronic Care Model?

Survivorship Care Plan

Functional and clinical outcomes

What are the barriers to routine generation of a treatment summary and survivorship care plan?

• An expectation in some specialties and not others (e.g. radiation therapy vs. medical oncology)
• Lack of appreciation of the need and value added
• Lack of time/reimbursement
• Lack of awareness that survivors and primary care physicians need improved communication
Oncology Community’s Response to the IOM Report

- American Society of Clinical Oncology (ASCO) has developed templates for patients finishing adjuvant therapy for breast and colon cancer
- Generic template and lung cancer templates also available
- ASCO has worked with electronic health record vendors to extract treatment plan and treatment summary directly from the electronic record
- See www.asco.org/treatmentsummary
**Colon Cancer Adjuvant Therapy Treatment Plan & Summary**

The Treatment Plan and Summary provide a brief record of major aspects of colon cancer adjuvant chemotherapy. This is not a complete patient history or comprehensive record of intended therapies.

<table>
<thead>
<tr>
<th>Provider name:</th>
<th>Patient name:</th>
<th>Patient ID:</th>
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<table>
<thead>
<tr>
<th>Patient DOB:</th>
<th>Age at diagnosis:</th>
<th>Patient phone:</th>
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<td><em><strong>/</strong></em>/___</td>
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<table>
<thead>
<tr>
<th>Support contact name:</th>
<th>Support contact relationship:</th>
<th>Support contact phone:</th>
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<tr>
<th>Cancer detection:</th>
<th>Screening</th>
<th>Symptoms</th>
<th>Incidental</th>
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<td></td>
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<table>
<thead>
<tr>
<th>Site in colon:</th>
<th>Right</th>
<th>Transverse</th>
<th>Left</th>
<th>Sigmoid</th>
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<tr>
<th>Predisposing conditions:</th>
<th>None</th>
<th>Inflammatory bowel disease</th>
<th>FAP</th>
<th>HNPCC</th>
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<tr>
<th>Family history:</th>
<th>None</th>
<th>2nd degree relative</th>
<th>1st degree relative</th>
<th>Multiple relatives</th>
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<tr>
<th>Pre-op colonoscopy to cecum:</th>
<th>Yes</th>
<th>No</th>
<th>Other lesions:</th>
<th>None</th>
<th>Low risk polyps</th>
<th>High risk polyps</th>
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<table>
<thead>
<tr>
<th>Primary colon operation:</th>
<th>Date of surgery:</th>
<th>CEA pre-op:</th>
<th>CEA post-op:</th>
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<tr>
<th>Surgery type:</th>
<th>Elective</th>
<th>Emergent</th>
<th>T stage:</th>
<th>N stage:</th>
<th>Number of lymph nodes removed:</th>
<th>Number of lymph nodes positive:</th>
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<tr>
<td></td>
<td></td>
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<td>T1</td>
<td>T2</td>
<td>T3</td>
<td>T4</td>
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<table>
<thead>
<tr>
<th>Number of lymph nodes removed:</th>
<th>Number of lymph nodes positive:</th>
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Notable pathology findings:
### White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy

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<thead>
<tr>
<th>Height: in/cm</th>
<th>Pre-treatment weight: lb/kg</th>
<th>Post-treatment weight: lb/kg</th>
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**Pre-treatment BSA:**

**Name of regimen:**

**Treatment on clinical trial:** □ Yes □ No

**Start Date:** (____/____/____) **End Date:** (____/____/____)

<table>
<thead>
<tr>
<th>Bio/Chemotherapy Drug Name</th>
<th>Route</th>
<th>Dose</th>
<th>Schedule</th>
<th>Dose reduction needed</th>
<th>Number of cycles administered</th>
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<tr>
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<td></td>
<td></td>
<td>□ Yes_____% □ No</td>
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<td>□ Yes_____% □ No</td>
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<td></td>
<td>□ Yes_____% □ No</td>
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</table>

**Possible side effects of this regimen:**
- □ Hair loss
- □ Neuropathy
- □ Low blood count
- □ Fatigue
- □ Diarrhea
- □ Dehydration
- □ Nausea/Vomiting
- □ Other:

**Number of cycles containing oxaliplatin:**

**Serious toxicities during treatment (list all):**

**Hospitalization for toxicity during treatment:** □ Yes □ No

**Reason for stopping adjuvant treatment:**

**Disease status at end of treatment:** □ No evidence of disease □ Possible recurrence □ Recurrence
Current status:
Implementation and Evaluation

• In 2008, ASCO introduced treatment summary & care plan as a quality improvement measure
• Increasing visibility of cancer survivorship and survivorship programs using some form of treatment summary
• LIVESTRONG Survivorship Centers of Excellence
• Other efforts – www.journeyforward.org
When does long-term survivorship begin?

- Definitional problems...should it begin at the moment of diagnosis when treatment decisions are being made?
- The eye is in the beholder...for some patients and providers, it is only many years later, or after some of the late effects are apparent
- Problem of labeling
Survivorship Health Care Delivery

- Ganz’s Three P’s of Survivor Care
  - Palliation
  - Prevention
  - Health Promotion
Symptom Management/Palliative Care: An Integral Part of Survivorship Care

• **Definition of Palliative Care:**
  – Medical care or treatment that concentrates on reducing the severity of disease symptoms (particularly if there is not a curative medical treatment)
  – Goal is to prevent and relieve suffering and to improve QOL for people facing complex illness

• Focus on the most severe and prolonged symptoms
Common Palliative Care Concerns

- Pain
- Fatigue
- Depression
- Physical limitations
- Cognitive changes
- Lymphedema
- Sexual dysfunction
- Menopause related symptoms
- Body Image
Consultant Specialists Required

- Mental health
- Pain management
- Physical medicine/vocational rehab
- Endocrinology
- Cardiology
- Gynecology/fertility
- Pulmonary
- Neurology/neuropsychology
Prevention

• Systematic ongoing follow-up required for screening
  – Goal: early detection and early intervention for potentially serious late-onset complications e.g., cataracts, osteoporosis, cardiac disease
  – Chemoprevention when available
  – Life style modification to prevent second cancers
Health Promotion

• Health promotion counseling
  – **Goal**: promote risk reduction for health problems that commonly present during adulthood (esp. for childhood cancer survivors)
  – Avoid weight gain
  – Increase physical activity
  – Avoidance of exposures that are harmful
  – Decrease risk of other chronic diseases, e.g. diabetes, heart disease
Cancer Care Trajectory

Start Here

- Diagnosis and Staging
- Treatment With Intent to Cure
- Safer therapies
- Risk assessment and intervention at diagnosis

Medical Outcomes and Quality of Life

Cancer-Free Survival

Recurrence/Second Cancer

Survivor health care delivery: Palliation, Prevention and Health Promotion
Opportunities

• At the minimum, we must prepare a treatment summary on every patient completing curative-intent therapy…

• Focus on primary, secondary and tertiary prevention of long-term and late effects

• Use treatment summary & care plan to facilitate sharing and coordination of care
Outcomes & Metrics

- Adherence to cancer surveillance
- Adherence to cancer therapies (e.g. adjuvant endocrine therapy)
- Other health maintenance and promotion, e.g. smoking cessation, weight control, physical activity, immunizations
- Management of psychosocial distress, depression
- Prevention of second cancers
Resources

- IOM: Lost in Transition report from 2005
- IOM: Implementing the Survivorship Care Planning, Workshop Report, 2006
- JCO Special Review Issue: Cancer Survivorship, November 10, 2006
VITA stands for....
“Vital Information and Tailored Assessment”

The VITA Program is the clinical arm of UCLA-LIVESTRONG Survivorship COE

http://vita.mednet.ucla.edu/
What is needed to implement the survivorship care plan?

- Acceptance of *cancer as a chronic disease*—following an initial period of extraordinarily complex therapy!
- Reimbursement for evaluation and management time required to prepare and communicate the plan
- Expand the evidence-base of knowledge re: late effects, follow-up needs and survivorship care
- Train all health professionals in the needs of the growing number of cancer survivors—how to act on the care plan recommendations

*UCLA Jonsson Cancer Center*
Cancer Survivorship Care Plans: A model for integration of QOL & QOC