AYA HOPE: A Population-based Cohort Study of Adolescent and Young Adults with Cancer

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National Cancer Institute
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Study Objectives

• Feasibility study to obtain population-based data on:
  – Patient/guardian consent
  – Medical records (hospitals and physician offices)
  – Patient survey (paper or web-based)

• To address potential factors related to gaps in research, care, and outcomes for adolescent and young adult cancer patients

• Examines factors related to access to care, treatment and follow-up care, and the impact of cancer on physical and psychosocial functioning
Participants and Accrual

- 7 Surveillance Epidemiology and End Results (SEER) population-based cancer registries
- Eligible patients
  - Germ cell
  - ALL
  - HL
  - NHL
  - Sarcoma
- Diagnosed
  - Ages 15-39
  - Between July 1, 2007 - October 31, 2008
  - 6-14 months post-diagnosis
- Data collection August 2008 – October, 2009
- Follow-Up Survey 15-30 months post diagnosis
Recruitment

Potential Eligible, N=1405

Physician Refused, n=6
Ineligible, n=90

Mailed Survey & Phone F/U
N=1309

Ineligible
n=112
Deceased
n=16

Participant Refusal
n=447
Lost to Follow-up
n=209

Total Surveys Completed
n=525 (1=lost)

Medical Record Consents
Received
n=499

Medical Record Consent Refusals
n=26

Medical Records Obtained
n=490

Medical Records Not Found
n=9

Paper
n=397
Web
n=115
Phone
n=12

Harlan et al., 2011
Final sample

- 524 cancer patients, with:
  - Germ cell (ovarian, testicular): n=205
  - Hodgkin lymphoma, n=142
  - Non-Hodgkin lymphoma, n=131
  - Acute lymphoblastic leukemia, n=21
  - Sarcoma (Ewing, osteosarcoma or rhabdomyosarcoma), n=25
Response Rates at Recruitment Sites

Overall: 44%

Surveillance Epidemiology and End Results
providing information on cancer statistics to help reduce the burden of this disease on the U.S. population

Harlan et al., 2011
Results Overview

Survey Data:
Sample Characteristics
Insurance Status
Participation in Clinical Trials
Quality of Life
Impact of Cancer
Information, Service Needs
Open-Ended Responses

Medical Record Data:
Insurance Status
Participation in Trials
Treated under a Protocol
Specific therapy given
Comorbidities
Type of Healthcare Facilities
Physicians’ Subspecialties
Responders vs. Non-Responders

• Responders were more likely to be:
  – Non-Hispanic White
  – Female

• No differences by:
  – Age
  – Cancer site
  – Income
  – Education

Harlan et al., 2011
## Sample Characteristics

### Age, Gender, Race, n=524

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-19</td>
<td>13%</td>
</tr>
<tr>
<td>20-24</td>
<td>18%</td>
</tr>
<tr>
<td>25-29</td>
<td>25%</td>
</tr>
<tr>
<td>30-34</td>
<td>22%</td>
</tr>
<tr>
<td>35-39</td>
<td>22%</td>
</tr>
</tbody>
</table>

**Gender** (Female) 37%

**Race / Ethnicity**

<table>
<thead>
<tr>
<th>Race / Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>63%</td>
</tr>
<tr>
<td>African American</td>
<td>8%</td>
</tr>
<tr>
<td>Asian/PI/Al/AN</td>
<td>10%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>19%</td>
</tr>
</tbody>
</table>

### Family & Education, n=524

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>52%</td>
</tr>
<tr>
<td>Married/Partnered</td>
<td>42%</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>6%</td>
</tr>
</tbody>
</table>

**Live Alone** 9%

**Raising Children <18** 40%

**Education**

<table>
<thead>
<tr>
<th>Education</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HS or less</td>
<td>28%</td>
</tr>
<tr>
<td>Some College</td>
<td>36%</td>
</tr>
<tr>
<td>College Grad</td>
<td>25%</td>
</tr>
<tr>
<td>Graduate School</td>
<td>10%</td>
</tr>
</tbody>
</table>

**Comorbidity** 28%
## Quality of Life

### Short Form-12 Health Survey

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Overall Physical (PCS)</th>
<th>Overall Mental (MCS)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AYA HOPE</td>
<td>General US</td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>18-24</td>
<td>49.7*</td>
<td>(10.2)</td>
</tr>
<tr>
<td>25-34</td>
<td>49.7*</td>
<td>(10.9)</td>
</tr>
<tr>
<td>35-44</td>
<td>50.0</td>
<td>(9.2)</td>
</tr>
</tbody>
</table>

AYA HOPE = age 34-42

Smith et al., 2013
## Impact of Cancer On...

<table>
<thead>
<tr>
<th>Relationship with…</th>
<th>Negative</th>
<th>None</th>
<th>Positive</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>… Mother</td>
<td>9%</td>
<td>24%</td>
<td>62%</td>
<td>5%</td>
</tr>
<tr>
<td>… Father</td>
<td>6%</td>
<td>28%</td>
<td>52%</td>
<td>14%</td>
</tr>
<tr>
<td>… Brothers, Sisters</td>
<td>5%</td>
<td>27%</td>
<td>61%</td>
<td>7%</td>
</tr>
<tr>
<td>… Spouse/partner, Boy/girlfriend</td>
<td>16%</td>
<td>12%</td>
<td>49%</td>
<td>22%</td>
</tr>
<tr>
<td>… Child/children</td>
<td>5%</td>
<td>12%</td>
<td>24%</td>
<td>58%</td>
</tr>
<tr>
<td>… Friends</td>
<td>12%</td>
<td>27%</td>
<td>57%</td>
<td>2%</td>
</tr>
<tr>
<td>Spirituality and religious beliefs</td>
<td>5%</td>
<td>33%</td>
<td>52%</td>
<td>10%</td>
</tr>
<tr>
<td>Plans for the future / goal setting</td>
<td>31%</td>
<td>20%</td>
<td>46%</td>
<td>3%</td>
</tr>
</tbody>
</table>

N/A = individuals could indicate “Does not apply”

Bellizzi et al., 2012
<table>
<thead>
<tr>
<th>Area</th>
<th>Negative</th>
<th>None</th>
<th>Positive</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial situation</td>
<td>62%</td>
<td>26%</td>
<td>7%</td>
<td>4%</td>
</tr>
<tr>
<td>Body Image</td>
<td>59%</td>
<td>28%</td>
<td>10%</td>
<td>2%</td>
</tr>
<tr>
<td>Sexual function / intimate relations</td>
<td>48%</td>
<td>33%</td>
<td>4%</td>
<td>14%</td>
</tr>
<tr>
<td>Control over your life</td>
<td>47%</td>
<td>22%</td>
<td>29%</td>
<td>1%</td>
</tr>
<tr>
<td>Plans for having children</td>
<td>44%</td>
<td>24%</td>
<td>5%</td>
<td>26%</td>
</tr>
<tr>
<td>Plans for work</td>
<td>36%</td>
<td>33%</td>
<td>25%</td>
<td>5%</td>
</tr>
<tr>
<td>Confidence in your ability to take care of your health</td>
<td>34%</td>
<td>25%</td>
<td>40%</td>
<td>1%</td>
</tr>
<tr>
<td>Plans for education</td>
<td>18%</td>
<td>46%</td>
<td>18%</td>
<td>17%</td>
</tr>
<tr>
<td>Dating</td>
<td>18%</td>
<td>20%</td>
<td>4%</td>
<td>56%</td>
</tr>
<tr>
<td>Plans for getting married</td>
<td>11%</td>
<td>24%</td>
<td>8%</td>
<td>56%</td>
</tr>
</tbody>
</table>

N/A = individuals could indicate “Does not apply”  
Bellizzi et al., 2011
Unmet Information and Service Needs

- 35% reported a need for a service that was not met
  - financial advice related to healthcare
  - mental health counselor
  - support group
  - Having any unmet service need was associated with worse HRQOL on multiple domains
  - Needing mental health services had the strongest associations with worse HRQOL outcomes

- >50% reported a unmet need for more information
  - non-white participants were more likely to report unmet information needs

Keegan et al., 2012; Smith et al., 2013
Social Information Needs

• Talking about cancer
  – Hispanics
  – Quality of Care
  – Number of symptoms
  – Support services needed – not received

• Meeting peer survivors
  – Age 20-29
  – Number of symptoms
  – Support services needed – not received

Kent et al., 2013
Clinical Trial Participation

Overall 7% participated in a clinical trial

- Top Reason AYAs gave for not joining a trial: “Worried that you might get treatment that had not been sufficiently tested”
Hospital/Physician

- **Type of Healthcare facility***
  - Cancer Center: **45%**
  - Community hospital: **36%**
  - Academic Institution: **25%**
  - NCI cancer center: **18%**
  - Pediatric hospital: **2%**
  - Unknown: **1%**

- **Physician Sub-specialty***
  - Medical Hem/Onc: **76%**
  - Surgery, General: **47%**
  - Medical: **40%**
  - Radiation Oncology: **31%**
  - Peds Hem/Onc/Med: **5%**
  - Other/Unknown: **5%**
  - Surgery, Orthopedic: **4%**

*Categories are not mutually exclusive*
Planned Analyses

• Initial treatment
• Clinical trials involvement
• AYA comorbidity
• Follow-up survey
  – Medical Care in AYA cancer survivors
  – Fertility preservation
  – Insurance in AYAs – health and life
Future Directions

• Research is needed to explore possible delays in diagnosis

• Better understanding of this population in long-term survivorship is needed
  – Specific needs related to access to medical records
  – Continuing/Follow-Up Care
  – ACA, Insurance coverage and financial problems
Publications

• Smith AW, et al. Unmet support service needs and health-related quality of life among adolescent and young adults with cancer: the AYA HOPE Study. Frontiers in Pediatric Oncology, 2013, 3(75).
• Kent EE, et al. Talking about cancer and meeting peer survivors: social information needs in adolescents and young adults diagnosed with cancer. Journal of Adolescent and Young Adult Oncology 2013, 2(2):44-52.
AYA HOPE Study Group

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Consultants: Arnold Potosky, PhD.; Keith Bellizzi, Ph.D.; Karen Albritton, MD, Michael Link, MD; Debra Friedman, MD; Brad Zebrack, Ph.D.
For More Information

http://outcomes.cancer.gov/surveys/aya/

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