Too Old for Dora, Too Young for Dentures: Adolescents and Young Adults with Cancer
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Disclosure
Grimes, Allison MD and Langevin, Anne-Marie, MD have no relationships with commercial companies to disclose.

Learning Objectives
- At the end of this presentation the participant will be able to:
  - Define AYA Oncology in terms of age and recognize the “AYA Gap” in care access, trials, and survival
  - Appreciate the unique challenges AYA’s experience and list the current guidelines for AYA Cancer Care
  - Understand AYA Cancer Care requires significant cross-disciplinary collaboration

AYA and Cancer: Model of Care and Research

Improving Outcomes for AYAs with Cancer

Measures & Activities Leading to Improved Outcomes and Enhanced Knowledge

Collaboration between Medical and Pediatric Oncologists:

① Participation in joined tumor board or case conference.
① Joining additional cooperative group (adult cooperative group for pediatric and COG for medical oncologist).
① Joined training program and other education activities.
④ Creation of Physical Or Virtual Treatment Units giving access to appropriate Treatment Expertise and Social Services.

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Ramphal et al. Cancer 2011
Improving Outcomes for AYAs with Cancer

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Ramphal et al. Cancer 2011

CASE: 21 yo with B-ALL

- 21yo M with newly diagnosed B-ALL seen at the request of medical oncology in 9/2014 for enrollment and treatment on clinical trial
- CT Enrollment: AALL08B1 (biology) and AALL1131 VHR Arm (treatment)
- Leukemia Characteristics:
  - VHR – Age >13
  - High Risk Cytogenetics
  - MRD positive at Day 8, 29 and until treated with targeted monoclonal antibody in 10/2015

Q #1: WHERE SHOULD TREATMENT BE DELIVERED?

Q #2: WHO DO YOU CALL?

Q #3: WHERE DO YOU TRANSFER?

Q #4: WHO DO YOU CONSULT?

- Septic Shock with E. coli requiring pressors
- Bacillus bacteremia followed by Meningitis & Altered Mental Status

Q #5: WHO INFORMS THE PATIENT ABOUT CHOICES?

Q #6: WHO HANDLES THE DENIALS AND APPEALS?

AYA Oncology: Background

- PROBLEM: 70,000 young people (ages 15-39) are diagnosed with cancer each year in the United States
- ~6x the number of cancers diagnosed in children ages 0-14
- Unlike younger children and older adults, AYA Cancer survival rates have NOT IMPROVED in 40 years
- This age gap in survival trends has been termed the AYA Gap

AYA Cancer Types

Incidence and Epidemiology

- AYA Cancer incidence increased steadily during the past 25 years.
- Males have a higher risk of developing cancer, directly proportional to age, and have a worse prognosis.
- Majority of cancers are spontaneous and unrelated to either carcinogens in the environment or family cancer syndromes.
- Some cancers in adolescents and young adults may have genetic and biological features unique to this age group.

Incidence

Figure 1.1: Incidence of All Invasive Cancer, SEER 1975-2000

Survival

Figure 1.5: Incidence of All Invasive Cancer by Race/Ethnicity, SEER 1990-1999
NCI: Declares AYA cancer a health disparity and issues call for action.

NCI and Lance Armstrong Foundation form AYA Progress Review Group. Identify key factors in poor AYA outcomes.

NCI defines AYA population ages 15-39.

Recent Updates in AYA Cancer:
- NCI and Lance Armstrong Foundation form AYA Progress Review Group
  - Identify key factors in poor AYA outcomes
- Children’s Oncology Group establishes AYA Committee

KEY FACTORS IN POOR AYA OUTCOMES:
- Restricted or delayed access to care
- Delays in diagnosis
- Inconsistency in cancer treatment and follow-up
- Low participation & scant clinical trial availability
- Data lacking on unique psychosocial challenges: education, employment, social/family issues, fertility
Recent Updates in AYA Cancer

NCI: Defines AY population ages 15-39

SEER AYA Monograph = 1st publication on cancer incidence & outcomes in AYA’s

HHS and LIVESTRONG Young Adult Alliance publish recommendations for improving AYA cancer care

Doubled survival for AYA patients with ALL treated with pediatric regimen

NCCN Clinical Practice Guidelines for AYA Cancer Care

IOM + LIVESTRONG: “AYA Gap” Workshop in Washington, DC
- Identify research gaps
- Improve care & outcomes

NCCN AYA Oncology Clinical Practice Guidelines

- Comprehensive assessment should include:
  - Age-appropriate information related to cancer
  - Discussion of fertility risks and options for fertility preservation prior to starting cancer therapy
  - Psychosocial assessment including socioeconomic issues
  - Genetic and familial risk assessment within 2 months of Tx start
  - Age-appropriate Palliative and End-of-Life Care
NCI AYA HOPE Study

- Population-based Cohort Study of Adolescents and Young Adults with Cancer
- Data compiled from 7 SEER cancer registries across the U.S.
- 524 patients Ages 15-39 diagnosed Between July 1, 2007 - October 31, 2008 with:
  - Germ cell
  - ALL
  - HL
  - NHL
  - Sarcoma
- Initial survey=6-14 months post-diagnosis
- Follow-Up Survey 15-30 months post diagnosis

NCI AYA HOPE Study

- Major AYA Challenges:
  - Financial and health insurance struggles contribute to dissatisfaction with care
  - Lack of health insurance and financial concerns = biggest barriers to receiving medical care
  - Likelihood of having health insurance decreased with increasing time since diagnosis
  - Older AYAs with lower levels of education were most likely to lack insurance.

AYA HOPE and Clinical Trials

- Overall, 7% participated in a clinical trial

Where are AYA’s Treated?

<table>
<thead>
<tr>
<th>Location</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown</td>
<td>1.00%</td>
</tr>
<tr>
<td>Pediatric Hospital</td>
<td>2.00%</td>
</tr>
<tr>
<td>NCI Cancer Center</td>
<td>18.00%</td>
</tr>
<tr>
<td>Academic Institution</td>
<td>25.00%</td>
</tr>
<tr>
<td>Community Hospital</td>
<td>36.00%</td>
</tr>
<tr>
<td>Cancer Center</td>
<td>45.00%</td>
</tr>
</tbody>
</table>

For NCCN: AYA care should be provided at centers with broad access to clinical trials

Low trial participation = one main reason for poor improvement in AYA outcomes
Where are AYA’s Treated?

Unknown 1.00%
Pediatic Hospital 2.00%
NCI Cancer Center 18.00%
Academic Institution 25.00%
Community Hospital 36.00%
Cancer Center 45.00%

AYA’s treated at pediatric centers have higher clinical trial enrollment (26% vs 4%)

Where are AYA’s Treated?

Unknown 1.00%
Pediatic Hospital 2.00%
NCI Cancer Center 18.00%
Academic Institution 25.00%
Community Hospital 36.00%
Cancer Center 45.00%

AYA’s with pediatric-type cancers have better outcomes on pediatric protocols (ALL, Rhabdo, Ewing)

Where are AYA’s Treated?

Unknown 1.00%
Pediatic Hospital 2.00%
NCI Cancer Center 18.00%
Academic Institution 25.00%
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Many pediatric protocols are open to patients age ≤30

Who Treats AYA’s?

Medical Oncologist 76%
General Surgeon 47%
Medicine 40%
Radiation Oncology 31%
Peds Heme/Onc 5%
Orthopedic Surgeon 4%

These patients are HERE NOW: AYA Cancer in South Texas

Texas Health Service Region

<table>
<thead>
<tr>
<th>Childhood (Ages 0-14 Years)</th>
<th>N</th>
<th>% of Total</th>
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</thead>
<tbody>
<tr>
<td>All Cancers Combined</td>
<td>587</td>
<td>100.0%</td>
</tr>
<tr>
<td>Embryonal Rhabdomyosarcoma</td>
<td>60</td>
<td>10.1%</td>
</tr>
<tr>
<td>Brain/Central Nerves System</td>
<td>235</td>
<td>39.8%</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>115</td>
<td>19.9%</td>
</tr>
<tr>
<td>All Other Groups</td>
<td>115</td>
<td>19.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adolescent (Ages 15-19 Years)</th>
<th>N</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Cancers Combined</td>
<td>463</td>
<td>100.0%</td>
</tr>
<tr>
<td>Ewings</td>
<td>92</td>
<td>17.4%</td>
</tr>
<tr>
<td>Acute Lymphocytic Leukemia</td>
<td>39</td>
<td>13.8%</td>
</tr>
<tr>
<td>All Other Groups</td>
<td>220</td>
<td>47.3%</td>
</tr>
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The Texas Health Service Region is a network of hospitals and healthcare providers that serve patients in South Texas. It includes the University Health System, which is a major provider of cancer care in the region.
Texas Cancer Registry: Child & Adolescent Cancers in Texas

Trends in Child & Adolescent Cancer Incidence

Final Thoughts...

- DOES OUR CURRENT CARE OF AYA’s meet NCCN GUIDELINES?
- HOW CAN WE WORK TOGETHER to achieve BEST OUTCOMES FOR AYA CANCER PATIENTS IN SOUTH TEXAS?
- HOW CAN WE PROVIDE AN AGE-APPROPRIATE SETTING that addresses AGE-SPECIFIC NEEDS?