Gaps in the Evidence Base and Research Priorities for AYA Oncology Care

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Disparity in survival progress

Veal et al. JCO 2010
AYA: A unique population

- Psychosocial and medical needs associated with cancer diagnosis that are challenging to developmental phase:
  - Loss of independence
  - Isolation from peers
  - Concerns for future fertility
  - Impact on academic/vocational goals
  - Threat to future health care and insurance access
AYA: A unique population

Delivery of medical care must:

- Respect communication preferences
  - Information sharing with caregivers
  - Involvement by caregivers in decision-making
  - Evolving modalities of communication
- Acknowledge need for independence and autonomy
- Address age-appropriate experimentation with health risking behaviors
- Recognize impact on body image, sexuality and intimacy
Cancer histology prevalence by age

- Distinctive distribution of cancer histological subtypes
- Variable source of care

Figure 15.4: The Interface Between Pediatric and Adult Oncology

http://seer.cancer.gov/publications/aya/
AYA delays in diagnosis

- Diagnosis lagtime: interval between onset of symptoms/signs and date of pathology confirmation of cancer
- Study cohort: 270 cancer patients (15–29 years) evaluated between June 2001 and June 2003
- Lagtimes evaluated in 235 (88%) and associated with type of cancer and health insurance status
  - NHL, Hodgkin lymphoma, leukemia predictive of shorter lagtimes
  - Mean lagtime by insurance status: Public (124 d) v Private (76 d) v Self-pay (32 d)
- In cancers evaluable for stage at diagnosis, advanced stage associated with longer lagtimes

Martin et al. The Oncologist 2007
AYA participation in clinical trials

- Study population: 1,358 AYA patients with cancer (age 15 to 39 years) from SEER
- 14% enrolled on clinical trial
- Enrollment on trial varied by diagnosis:
  - Diagnosis: ALL (37%), sarcoma (32%) v GCT (<1%)
  - Age: 15–19 (34%) v 35–39 (3%)
  - Race/ethnicity: white (9%) v black (11%) non-Hisp
  - Provider: ped onc (70%) v heme onc (11%)
  - Insurance: Public (14%) and Private (14%) v HMO (7%) and None (3%)

Parsons et al. JCO 2011
AYA time to initiation of treatment

- Median time to treatment: 3 days
- Time to treatment varied by:
  - Diagnosis: HL (21d), NHL (19d) v ALL (1d), GCT (0 d)
  - AJCC stage: stage III v I (4-fold excess risk of longer time to Rx)
  - Facility: outpatient v. inpatient (3-fold excess risk of longer time to Rx)

Parsons et al. JCO 2011
## Disparities in AYA outcomes

<table>
<thead>
<tr>
<th>Trial</th>
<th>Pediatric</th>
<th>Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>FRALLE-93/LALA-94(^{28})</td>
<td>5-y EFS: 67%</td>
<td>5-y EFS: 41%</td>
</tr>
<tr>
<td>CALGB/CCG(^{34})</td>
<td>7-y EFS: 63%</td>
<td>7-y EFS: 34%</td>
</tr>
<tr>
<td>MRC ALL 97-99/UKALLXII-E2993(^{29})</td>
<td>5-y EFS: 65%</td>
<td>5-y EFS: 49%</td>
</tr>
<tr>
<td>GIMEMA/AIEOP(^{30})</td>
<td>2-y OS: 80%</td>
<td>2-y OS: 71%</td>
</tr>
<tr>
<td>HOVON/DCOG(^{31})</td>
<td>5-y EFS: 71%</td>
<td>5-y EFS: 38%</td>
</tr>
<tr>
<td>Adult ALL Grp/NOPHO-92(^{32})</td>
<td>5-y OS: 74%</td>
<td>5-y OS: 39%</td>
</tr>
<tr>
<td>Finnish Leukemia/NOPHO(^{33})</td>
<td>5-y OS: 67%</td>
<td>5-y OS: 60%</td>
</tr>
</tbody>
</table>

Are disparities due to differences in cancer biology, treatment approach or environment of care?

Wood & Lee, Blood, 2011
AYA: Unique biologic differences

Drug disposition in the adolescent

- Increase in height and weight
- Tobacco, alcohol, drug use
- Oral contraceptives
- Compliance with treatment plan
- High/low BMI
- Organogenesis
- Hormonal environment
- Change in body composition
Non-adherence and risk of relapse

- N=327 ALL patients
  - 169 Hispanic
  - 158 non-Hispanic
- Factors associated with risk of non-adherence
  - Longer time on Rx
  - Older age (> 12y)
  - Household (single mother)
  - Ethnicity (Hispanic)
- Progressive increase in risk of relapse associated with decreasing levels of adherence

Bhatia et al. JCO 2012
## Health status of AYA survivors

<table>
<thead>
<tr>
<th>Outcome</th>
<th>AYA</th>
<th>Non-AYA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current smoking</td>
<td>26%</td>
<td>18%</td>
</tr>
<tr>
<td>No leisure time physical activity</td>
<td>31%</td>
<td>24%</td>
</tr>
<tr>
<td>Obesity</td>
<td>31%</td>
<td>27%</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>14%</td>
<td>7%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>35%</td>
<td>29%</td>
</tr>
<tr>
<td>Asthma</td>
<td>15%</td>
<td>8%</td>
</tr>
<tr>
<td>Disability</td>
<td>36%</td>
<td>18%</td>
</tr>
<tr>
<td>Poor mental health</td>
<td>20%</td>
<td>10%</td>
</tr>
<tr>
<td>Physical health</td>
<td>24%</td>
<td>10%</td>
</tr>
<tr>
<td>Not receiving medical care due to cost</td>
<td>24%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Based on 2009 BRFSS data from AYA survivors (15–29 years) compared with non–cancer AYA. Tai et al. Cancer 2012
AYA survivor health care access

Based on 2009 BRFSS data from AYA survivors (20–39 years) who self-reported cancer at age 15–34 compared with non-cancer AYA. Kirchhoff et al. Cancer 2012
Based on 2009 BRFSS data from AYA survivors (20–39 years) who self-reported cancer at age 15–34 compared with non-cancer AYA. Kirchhoff et al. Cancer 2012
AYA health care utilization

- Higher prevalence of chronic health conditions
- Unable to get/delayed necessary medical care
- Have higher medical expenditures
- Experience greater physical limitations
  - Health related unemployment
  - Limited ability to work
  - Lost household productivity
- Disparities in access to care for publicly insured and uninsured

Yabroff et al, MEPs: Experience with Cancer Survivorship
Factors contributing to disparities

- Delays in diagnosis of primary cancer
- Inadequate access to and low participation on clinical trials
- Differences in tumor biology
- Differences in body composition, hormonal status and maturity of organs
- Non-adherence to treatments
- Suboptimal access to medical and psychosocial services
- Lack of awareness of cancer treatment-related health risks
Cancer is leading disease–related cause of death AYA in United States and affects eight times as many individuals between the ages of 15 and 40 as those younger than 15 years of age.

Substantial prevalence of cancer and treatment–related morbidity among AYA cancer survivors

Substantial prevalence of unmet needs among AYA cancer survivors
Metrics for quality AYA care

- Assistance with managing disease and treatment effects
- Cognizance among providers of the unique psychosocial context for AYA growth and development
- Assessment of and attention to cognitive, psychiatric, and psychosocial needs of AYA
- Referral to available age-appropriate resources during treatment
- Facilitation of transition to survivorship
Models of AYA oncology care

- Expertise in AYA oncology
- Expertise in AYA developmental issues
- Cancer center based
- Community based
- Hybrid

“A young person’s development is not postponed in the event of a cancer diagnosis, so it is also important to ensure that these aspects are revisited during the treatment journey.”
Morgan et al. JCO 2010

“...it is not only the fabric of an environment that matters, it is the ethos of care that does.”
Morgan et al, JCO 2010
AYA transition issues

- Growth and development
- Promotion of healthy lifestyle
- Symptom management
- Cancer–related chronic health problems
- Fertility preservation
- Sexuality
- Contraception
- Sexually transmitted infections
- Impact of cancer on fertility
- Impact of cancer on reproductive outcomes
- Sexual dysfunction

Physical health

Sexual–reproductive health
AYA transition issues

- Psychological adjustment to cancer survivorship
- Cognitive functioning
- Psychopathology
- Emotional well-being
- Goal attainment
- Health-related hindrance
- Partnerships/marriage
- Interpersonal relations
- Reintegration into social systems
- Educational progress/resources
- Vocational planning
- Employment

Mental health

Social competence
AYA transition issues

- Alcohol consumption
- Tobacco use
- Illicit drug use
- Physical activity
- Dietary habits
- Sun protection
- Risky sexual behavior
- Adherence to treatment
- Adherence to health screening/surveillance
- Diagnostic/treatment history
- Cancer-related health risks
- Self-management of medical issues
- Impact of health behaviors on cancer-related risks
- Health screening/surveillance recommendations
- Navigation of the adult health care environment
- Insurance and health care access

Health behaviors

Health education
Strategies to improve survival

- Education to enhance awareness, early detection and diagnosis of AYA cancers and cancer treatment–related health risks
- Establishment of care models to promote timely referral, initiation of treatment, attention to adherence, and transition of care
- Awareness by providers of biomedical and psychosocial issues specific to AYAs
- Development of AYA oncology research investigations
<table>
<thead>
<tr>
<th>Survival outcomes</th>
<th>Health outcomes</th>
<th>Health promotion</th>
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<tbody>
<tr>
<td>Biologic variations</td>
<td>Biomedical</td>
<td>Adherence</td>
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<tr>
<td>Therapeutic approach</td>
<td>Psychosocial</td>
<td>Self–management</td>
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<tr>
<td>Location of care</td>
<td>Patient reported</td>
<td>Health behaviors</td>
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<tr>
<td><strong>Models of AYA Care</strong></td>
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<td>Health screening/surveillance</td>
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<tr>
<td>Metrics of quality care</td>
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<td>Care coordination</td>
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<td>Care transition</td>
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<td>Utilization and access</td>
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<tr>
<td>Cost–benefit analyses</td>
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