Overview of Cancer Survivorship in AYAs

Michael Feuerstein, PhD, MPH
June 23, 2019
jcancersurvivorship@gmail.com
Overview

• Patient and researcher perspective
• Cancer Survivor: Case definitions
• AYA Cancer Survivor: Case definition
• “Global” burden of AYA Cancer Survivors
• Concerns of AYA Cancer Survivors “in their own words”
Personal and Research Perspectives
Anaplastic Astrocytoma: Grade III

At Diagnosis- 6/03

At year 15- 4/18
Who is an “adult” cancer survivor?

• **Classic/Traditional**
  - Period after diagnosis and during primary treatments
  - Patients focused on dealing with the physical and psychological consequences after completion of treatment
  - Period when patients are living with cancer as a chronic disease or when individuals are in remission
    - Mullan, NEJM, 1985

• **NCI-General**
  - One who remains alive and continues to function during and after overcoming cancer
    - From the time of diagnosis to the end of life.

• **NCI- Office of Cancer Survivorship**
  - Survivorship
    - Health and life of a person with cancer post treatment until the end of life.

• **WHO**
  - Survivorship care-*after active* treatment for cancer
    - Surveillance plan- monitor cancer recurrence or spread
    - Follow up and management-health problems related to cancer diagnosis and treatment
    - Evaluate development of new cancers
    - [https://www.who.int/cancer/treatment/en/](https://www.who.int/cancer/treatment/en/) 2019
Cancer Survivorship

Feuerstein, 2004
Who is an “AYA” Cancer Survivor?

AYA - adolescent and young adult cancer care or research focused on those diagnosed with cancer between the ages of 15 to 39 years old

US National Cancer Institute, 2019
Two common views on AYA Cancer Survivors

• **Developmental**  Aubin 2011
  – Early young adulthood 15-18
    • individuation
  – Young adulthood 19-24
    • flux social/sexual experimentation, dating, academic goals
    • Full maturation frontal lobes (early-mid 20s)
  – Late young adulthood 25-39
    • Settling down, consolidation of existential goals, starting a family, caring for young children, maintaining couple relationship, further career to achieve financial autonomy

• **Bio-psychosocial/ Contextual**  Barr 2011
  – Age range, 15-39 NIH and SEER
  – Important to consider context (variability)
    • developmental age, psychosocial circumstances but also **underlying biology of the malignant disease being treated**
Cancer Incidence: Country (20-39 yo)

[Map showing the incidence of cancer by country and age group (20-39 years old), with the most common cancer types indicated by color and number.]

Fidler et al 2017
Survival rates of Common Cancers in AYA in US
Bleyer, 2011

Cumulative Incidence of Second Cancers in the Childhood Cancer Survivor Study
Friedman et al 2017

SN=subsequent neoplasm, NMBC=non-melanoma skin cancer, SMN=subsequent malignant neoplasm
Neurocognitive outcomes in long-term (29 yrs post diag) survivors of Wilms tumor

Table 4. Cognitive outcome associated to HRQOL and social attainment

Separate models for each cognitive variable and each outcome variable. Generalized linear models for HRQOL outcomes, logistic regression models for social attainment; reference category least favorable outcome (<college graduate, household income <$40000/year). **Bold type** indicates p<0.05

<table>
<thead>
<tr>
<th></th>
<th>Education College graduate or higher</th>
<th>Household income</th>
<th>SF-36 Social functioning</th>
<th>SF-36 Mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>P-val</td>
<td>OR</td>
<td>P-val</td>
</tr>
<tr>
<td>Verbal reasoning</td>
<td>2.23</td>
<td>&lt;0.001</td>
<td>1.59</td>
<td>0.029</td>
</tr>
<tr>
<td>Word reading</td>
<td>3.47</td>
<td>0.0025</td>
<td>2.82</td>
<td>0.024</td>
</tr>
<tr>
<td>Mathematics</td>
<td>2.55</td>
<td>&lt;0.001</td>
<td>1.74</td>
<td>0.050</td>
</tr>
<tr>
<td>Sustained attention, CPT variability</td>
<td>1.59</td>
<td>0.0067</td>
<td>1.12</td>
<td>0.51</td>
</tr>
<tr>
<td>Long-term verbal memory CVLT LD</td>
<td>1.35</td>
<td>0.045</td>
<td>1.24</td>
<td>0.23</td>
</tr>
<tr>
<td>Initiation: verbal fluency FAS</td>
<td>1.289</td>
<td>0.14</td>
<td>1.04</td>
<td>0.86</td>
</tr>
</tbody>
</table>

Time since diagnosis=29 yrs, SD=9.1 vs. Community controls

Olson et al, JCSU, in press (St Jude Lifetime Cohort)
Health Outcomes in Asian Survivors of Childhood Cancer
Poon et al J Cancer Surv, in press

**Methods**
- 213 abstracts reviewed
- 81 full text reviewed
- 59 quality studies, $k=0.82$
  - n=13,442 survivors
- Japan, South Korea, Hong Kong, Taiwan, Singapore, Thailand, Malaysia, mainland China (7 studies, 12%)

**Outcomes**
- Neurologic, neurocognitive 20%
- Endocrine, metabolic, growth, fertility 19%
- Cardiac 15%
- Secondary malignancy 12%
- Other-dental, hepatic, renal, immunological, multiple organ systems
Psychosocial Concerns of AYAs  
Team=pediatric oncologist, library scientist, OT, psychologist, AYA communication specialist  
Wong et al. 2017

**Methods**

Extracted papers in peer reviewed GLOBAL literature (n=1324 AYAs )

Entered text verbatim into nVivo Software

Conducted line by line text coding (nVivo)

Identified “descriptive themes” n=3
“subthemes” n=13 with consensus

Computed prevalence of themes/subthemes

Generated an AYA -survivor specific reported measure- concerns in AYAs based on their own words

**Outcomes**

**Themes (n=3)**

Health and health care
Communication and relationships
Life role

**Subthemes (n=13)**

Emotional well being
Health care system
Health management
Reproductive health
Symptoms
Function
Social interactions
Cancer disclosure
Romantic relationships
Normalcy
Career development and employment
School
Fiscal concerns