Health Care Transition and Gaps in AYA Survivorship Care

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Institute of Medicine-National Cancer Policy Forum
July 16, 2013
Disclosures

• No financial conflicts of interest
• No off-label medications discussed
Acknowledgements

• **Children’s Hospital Los Angeles and the USC Norris Comprehensive Cancer Center**
  – Alan Wayne, MD and members of Children’s Center for Cancer and Blood Diseases
  – Stuart E. Siegel, MD, Debu Tripathy, MD, Laurel Barosh, MPH of AYA@USC Program

• **Children’s Oncology Group**
  – COG AYA Oncology Discipline Committee members, past and present
  – Archie Bleyer, MD (Founding Chair, COG AYA Committee)
  – Peter Adamson, MD (Group Chair)

• **Southwest Oncology Group**
  – Charles Blanke, MD (Group Chair)
  – Brandon Hayes-Lattin, MD (Chair, SWOG AYA Committee)

• **National Cancer Institute/CTEP and DCP**
  – Nita Seibel, MD
  – Ashley Wilder Smith, PhD
  – Anne O’Mara, PhD, RN

• **Advocacy Organizations**
  – LiveSTRONG
  – Critical Mass Young Adult Cancer Alliance

• **Funding**
  – NIH/NCI CA98543 - Unihealth Foundation
  – Aflac Foundation
  – Sigma Tau Pharmaceuticals (unrestricted to COG AYA Committee)
  – CureSearch

…and many other investigators, collaborators and colleagues too numerous to list separately.
Outline

1. AYA Survivors—Who Are They?
2. Needs of AYA Survivors
3. The Central Challenge in AYA Survivorship
4. Health Care Transition in Survivorship
5. Barriers to Survivorship Transition
6. Addressing the Barriers
AYA Survivors—Who Are They?

• Age
  – NCI definition for AYA Oncology = 15-39 years
  – Applies to survivorship because age continues to drive many survivorship issues
    • Developmental biology-physiology of host
      – Characteristic types of late effects (e.g., AVN)
      – Some late effects emerge only or principally during this age interval (e.g., infertility, SMNs)
    • Psychosocial challenges
      – Backdrop of normal maturation into young adulthood
      – Access to care
      – Adherence to medical recommendations
AYA Survivors—Who Are They?

- AYA Survivors vs. Survivors of AYA Cancer
- Population
  - Survivors of *childhood cancer* (treated < 15 years old)
  - Survivors of *adolescent cancer* (treated 15-19 years old)
  - Survivors of *young adult cancer* (treated 20-39 years old)
- Potential implications for service models
Key Issues for Young Adult Survivors

- Detection and management of late effects
  - Continued management if present
  - Continued risk-based surveillance and preventive practices

- Psychosocial functioning
  - Interpersonal relationships (including sexuality)
  - Chronic anxiety, depression

- Health-related education
  - Previous diagnosis and cancer therapy
  - Current state of health and health risks
  - Disease prevention and wellness practices

- Financial challenges
  - Health insurance—obtaining and maintaining
  - Employment—relative to disabilities

Freyer DR. *J Clin Oncol* 2010; 28:4810-18
Friedman D, Freyer DR, Levitt G. *Pediatr Blood Cancer* 2006; 159-68
Suboptimal Longitudinal Follow-up

• Endpoints
  – Clinical assessments with providers
  – Risk-based monitoring for late effects

• Implications
  – Late diagnosis of late effects
  – Missed opportunities for risk modification and secondary prevention
  – Incomplete anticipatory guidance
  – Inability to conduct longitudinal research
Suboptimal Medical Follow-up for Young Adult Survivors

Fewer Medical Assessments with Age

Low Proportion of Medical Assessments

<table>
<thead>
<tr>
<th>Type</th>
<th>%</th>
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<tbody>
<tr>
<td>None</td>
<td>11.2</td>
</tr>
<tr>
<td>General</td>
<td>57.3</td>
</tr>
<tr>
<td>General survivorship</td>
<td>13.7</td>
</tr>
<tr>
<td>Risk-based</td>
<td>17.8</td>
</tr>
</tbody>
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Low Proportion of Screening Tests

<table>
<thead>
<tr>
<th>Test</th>
<th>Received (at risk)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Echocardiogram</td>
<td>511 (1810)</td>
<td>28.2</td>
</tr>
<tr>
<td>Mammogram</td>
<td>169 (414)</td>
<td>40.4</td>
</tr>
</tbody>
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Oeffinger et al. Ann Fam Med 2:61-70;2004


www.survivorshipguidelines.org
**Health Care Transition for AYA Survivors**

- **What**— *The planned movement of older adolescents and young adults from a child-centered to an adult-focused health care provider and environment*

- **Why**— *To continue age-appropriate risk-adapted monitoring, psychosocial support, and health-related education relevant to cancer survivorship*

- **Potential Impact**
  - Earlier diagnosis, reduction or prevention of late effects
  - Improved health-related quality of life
  - Enhanced self-efficacy and general quality of life

*Adapted from Blum et al. *J Adolesc Health* 1993; 14:570-6
Health Care Transition in Pediatric Oncology

• Several published reviews
  – Case statement and conceptual framework
  – General models of care

• Some data
  – Prevalence and types of adult-focused services
  – Current transitional care practices
  – Patient-level barriers and perceptions
  – Provider-level perceptions

• Little or no empiric data (yet)
  – Outcomes with specific care models
  – Determinants of transition-readiness or interventions
  – Predictors of successful transition or interventions
# Potential Barriers to Transition for Young Adults

<table>
<thead>
<tr>
<th>Level</th>
<th>Selected Barriers</th>
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| **Patient**          | • Complex medical history, multiple risks  
                        • Low personal priority for young adult (awareness)  
                        • No prior relationship with new provider |
| **Family**           | • Over-protectiveness, loss of control  
                        • Emotional dependency on survivor  
                        • No prior relationship with new provider |
| **Provider**         | • Lack of relevant knowledge, experience and comfort  
                        • Burden of care for medically complex patient  
                        • No prior relationship with new patient |
| **Health Care System** | • Loss of health insurance coverage  
                            • Lack of seamless referral networks linking providers  
                            • Lack of inclusion of survivorship in medical training |
Schwartz LA, Tuchman LK et al. Child Care Hlth Develop 2011; 37:883-895
Addressing the Barriers

Patient and Family Levels

“Window of Modifiability”

- Treatment for health condition in paediatric medical setting
- Periodic assessment of transition readiness
- Transition planning intervention
- Transition readiness increases
- Application of Targeted Interventions

- Transfer of care
- Engagement in adult medical care

Schwartz LA, Tuchman LK et al. Child Care Hlth Develop 2011; 37:883-895
Addressing the Barriers

Provider Level

• Medical Training
  – Undergraduate (concept)
  – Graduate (practice)
    • Pediatric and Medical Oncology Fellowship
    • Primary Care Residencies (FM, IM, MP, Ped)

• Continuing Education
  – Journals
  – Continuing medical education conferences

• Support Systems for Clinical Guidance
  – Web-based
    • Family Physicians
    • Passport for Care

CHLA-USC
• Required rotation in 2nd-3rd yrs pediatric hem-onc fellowship
• Elective available to pediatric residents
• Next: primary care residencies at USC

J Cancer Surviv 2012:163-71
www.passportforcare.org
Models of Transitional Care

- Three basic models recognized
  1. Continued care within cancer treatment center
  2. Transfer of care to community-based provider (primary care)
  3. Hybrid: transfer of care with continued support from center

- Needed
  - Innovation with specific models
  - Comparison of resource intensity and outcomes

- Success influenced by attitudes and preferences
  - Patient—levels of awareness and activation
  - Providers—trust and acceptance of responsibility

1 Hudson SV et al. Transl Behav Med 2012; 2:322-31
2 Cheung WY et al. J Cancer Surviv 2013 Mar 24, epub
• Tiered Transitional Care
  – Concept
    • Survivors can be differentiated according to long-term risk
    • Type and intensity of required follow-up differs by group
    • Implicit in risk-adapted monitoring guidelines (e.g., COG)
  – United Kingdom
    • Three risk levels based on treatment exposures\(^1\)
    • Followed by specialized center, PCP or by mail
  – CHLA (LIFE Clinic for Adult Survivors)
    • Transition at 21 years of age
    • Two risk levels based on treatment exposures

\(^1\)Eiser C et al. Eur J Cancer 2006; 42:3186-90
**LIFE Cancer Survivorship & Transition Program**

**CLINICAL PATHWAY**

**Group 1 (Lower Risk):** To PCP for annual surveillance with virtual follow-up by LIFE Program

- No RT
- Low alkylators and anthracyclines

**Group 2 (Higher Risk):** Annual follow-up in LIFE Clinic for Adult Survivors

- Any RT
- High alkylators or anthracyclines
- BMT

- 21 years old and “Transition-ready”

**Within 2 yrs off treatment**

- Return to LIFE Clinic (Annual Evaluation with LIFE Support)

- LIFE Transitional Care Visit

- LIFE High-Complexity Clinic (Annual Evaluation)

- New to LIFE Clinic (Initial Evaluation)

- Primary Oncologist or Other Referral

**High Complexity**

-Key Grade 3 and all Grade 4 late effects

**Standard Complexity**
Unified Adult Cancer Survivorship Program

Three Streams of Survivors

- CHLA
- AYA@USC
- USC Norris CCC

One Adult Survivorship Program

- “Adult Survivors of Childhood Cancer”
- “Adult Survivors of AYA Cancer”
- “Adult Survivors of Adult Cancer”

- Common population: adult survivors
- More alike by current age than different by age at treatment
- Opportunities for clinical efficiency, resource sharing, and research
- Modeled on successful CHLA-PSJMC pilot experience
Health Care System Level-3

• Opportunities afforded by health care reform
  – Problems
    • ~ 30% of Americans 18-24 yrs old uninsured
    • AYA survivorship care currently fragmented
  – How the PPACA may help AYA survivors
    • National high-risk pool created for adults with pre-existing conditions
    • Dependents covered by parent policies until 26 yrs old
    • No lifetime limits on coverage
    • No exclusions for children with pre-existing conditions
    • Coming 2014
      – No exclusions for adults with pre-existing conditions
      – Premiums not driven primarily by health status
      – Expanded patient-centered care coordination (e.g., ACOs)

Summary Observations and Recommendations

**Successful Transition of Survivorship Care**

**Patient-level**
1. More funded research in defining and supporting transition readiness and competency

**Provider-level**
2. Introduction of survivorship in professional training, especially primary care fields
3. Increased development of clinical support tools for PCPs

**Family-level**

**Health System-level**
4. More funded research for innovation and comparison of care models
5. Seamless survivorship care networks
6. Continuous insurance

**Follow-Up Gap**
- Increased utilization of PCPs for care delivery
- Effective methods to “push” key health education to survivors