Caring for Young Patients with VHL: Ensuring Needs and Demands are met

Damon Reed, MD

Cancer is More Common in 0-20 year olds than it is in 20-40 year olds

1. True
2. False

Why have an AYA Program?

» Young Adults with Cancer or Predisposed to Cancer are a special group

» Goal: to develop a comprehensive program to address the medical, psychosocial, reproductive, educational, survivorship, and research needs of this population
AYAs at Moffitt Cancer Center:

- 12% of all NP = 1,600 a year
- ~125 unique outpatient visits/day
- Occupy 10% of inpatient beds
- Within the last week every clinic has seen an AYA patient

12/15/15 Clinic AYA Patients

<table>
<thead>
<tr>
<th>Clinic</th>
<th>AYA Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMF</td>
<td>12</td>
</tr>
<tr>
<td>Cutaneous</td>
<td>3</td>
</tr>
<tr>
<td>H&amp;N/Endo</td>
<td>4</td>
</tr>
<tr>
<td>GI/GU</td>
<td>5</td>
</tr>
<tr>
<td>Hematology</td>
<td>9</td>
</tr>
<tr>
<td>Neurology</td>
<td>5</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>6</td>
</tr>
<tr>
<td>Thoracic</td>
<td>1</td>
</tr>
<tr>
<td>Women’s</td>
<td>9</td>
</tr>
<tr>
<td>Surgery</td>
<td>8</td>
</tr>
<tr>
<td>MIP</td>
<td>15</td>
</tr>
<tr>
<td>Radiation</td>
<td>8</td>
</tr>
<tr>
<td>Infusion</td>
<td>9</td>
</tr>
<tr>
<td>Other</td>
<td>30</td>
</tr>
<tr>
<td>Inpatient</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>133</strong></td>
</tr>
</tbody>
</table>


» Silos by Department
» Silos by Location
» Silos by Training

Staff and Resources
Organization needs to believe

- Know your environment
- Moffitt has: Staff, Leadership buy in, Physician Champion, some Resources

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VHL Alliance, 2017

Tampa, FL
Patient Navigation in the Adolescent and Young Adult (AYA) Cancer Population

Study Aims

• **Aim 1:** Adapt existing Moffitt Cancer Center patient navigator (PN) intervention strategies to AYA and develop an AYA PN intervention via formative research and key stakeholder involvement.

• **Aim 2:** Evaluate in a pilot randomized controlled trial (RCT; 50 cases and 50 controls) the feasibility and preliminary efficacy of an AYA PN intervention to reduce distress and enhance quality of life in newly diagnosed AYA patients by increasing access to, and utilization of, MCC resources by AYA patients and families.

• **Approach:** Pilot RCT participants will be identified in consultation with the patient’s primary oncologist and program social worker. Participants will be randomly assigned to the condition in equal numbers. AYA patient access to, and use of, MCC resources will be assessed via a brief survey of 15 services AYA have used and/or would like to use in the future.
Fertility and Reproduction in AYA Genetics: Improving Learning and Education (FRAGILE)

Susan Vadaparampil PhD, Gwendolyn Quinn PhD, & Tuya Pal MD

Study Aims

• **Aim 1:** Explore current experiences, practices, and future preferences for information to address fertility and reproductive needs health for high risk AYA.
  - **Approach:** Qualitative pilot study using individual interviews with genetics professionals, oncology professionals (n=10), and high risk AYA patients (n=10).
• **Aim 2:** Develop and evaluate the acceptability of a genetic education module focused on fertility and reproductive issues that meets the needs of high-risk AYA patients and providers.
  - **Approach:** Use information obtained in Phase 1 to inform the development of an educational intervention (likely a web based interactive learning tool) to help high risk AYA patients better understand fertility and reproductive implications based on genetic cancer risk. Qualitative interviews with genetics professionals, oncology professionals (n=12), and high risk AYA patients (n=24).

Research and Clinical Trials

- AYAs fare worse with an “old person” cancer
- AYAs fare worse with a “pediatric” cancer
- Limited research on etiology and biology of AYA cancer
- Under-represented in TCC
- Clinical Trial restrictions often exclude non-pediatric patients
Shared interest in AYA/peds from the beginning
- Started as pediatric patients and clinical care
  > Is biology different?
- Pathology complicated, Dr. Messina taking on that challenge
- Book chapters, editors
- Clinical research booming, SPORE, Center of Excellence

Atypical Spitz Tumors
A spectrum

Combination of morphologic, IHC, genetic, and chromosomal features can convey the best assessment of risk

Sreeraman Kumar et al. Clin Oncol AYA 2015;5:75-86

Treating melanoma in adolescents and young adults: challenges and solutions
Thus the solutions that we propose for AYA patients,
- Age to 12 for trials
- Age specific analysis of efficacy, PRO’s and toxicity (fertility)
- Look back on this dataset
- Increase AYA enrollment

“AYA’s don’t go on trials”
- During this time when it was a potentially life or death decision and when experimental arms were clearly of some benefit and with a department that bought into the AYA mission, what happened?
- Did the AYA program have anything to do with it?

<table>
<thead>
<tr>
<th>Group</th>
<th>Active trt. trial</th>
<th>Total patients</th>
<th>Mean age at diag.</th>
<th>Min age at diag.</th>
<th>Max age at diag.</th>
<th>Mean survival (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult</td>
<td>Not enrolled</td>
<td>10051</td>
<td>62.25</td>
<td>40</td>
<td>80</td>
<td>69.88</td>
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<tr>
<td>Adult</td>
<td>Enrolled</td>
<td>1497</td>
<td>58.81</td>
<td>40</td>
<td>80</td>
<td>65.41</td>
</tr>
<tr>
<td>AYA</td>
<td>Not enrolled</td>
<td>1803</td>
<td>31.63</td>
<td>2</td>
<td>78</td>
<td>99.14</td>
</tr>
<tr>
<td>AYA</td>
<td>Enrolled</td>
<td>311</td>
<td>31.85</td>
<td>11</td>
<td>72</td>
<td>85.65</td>
</tr>
</tbody>
</table>
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Young Adults with Colorectal Cancer

- MCC 15456: "Review of single institution experience in management of localized and metastatic colorectal cancers"
- A different look at an existing dataset
- TCC Patients <45 years old versus others
- Enriching AYA cohort with ~25 more samples

Figure 1: Patient Selection

- Initial Analysis
  - Assessed by eligibility (n=283)
  - Excluded (n=58): Known Genetic Syndrome, Lynch Syndrome associated with MSH6 mutation, MSI-H tumors without known familial syndrome
  - 225 patients included in initial analysis, using targeted exome panel

- Validation
  - Additional 21 patients younger than 45 at diagnosis identified for full exome sequencing

- 595 patients aged <65 at diagnosis

» 19 yo with CRC; 18 yo with NE tumor
» "I treat all my patients perfectly"
» “Don’t steal our patients” GIST rivalry
» 34 yo with stage IV CRC, no genetic cause (MSI)
  - $10,000 gift changed at last minute from GI to AYA after 2 tours
  - I walked up stairs to talk
Figure 2.

A. TCC expanded

B. TCGA

-$19,721.16
-Implication for targeted therapy and immunotherapy trials
-Implications for panel testing, basket trials

AYA Pathway Owners:
1. Navigation, optimal referrals and timing: Cathy
2. Psychosocial evaluation and components of assessment: Analise, Chris, Mary, Sean
3. Genetic predisposition or inherited concern: Kathleen and Xia
4. Fertility Preservation and Sexual health: Gwen
5. Survivorship: Drew
6. Palliative Care/ACP: Ritika and Marris
7. Nutritionist

Other themes:
AYA Tumor board
Caregiver
Research opportunities
Quality improvements
What to append through information and references?
AYA Care & Connections at Moffitt

Financial & Insurance Counseling
- Financial and health insurance struggles contributed to dissatisfaction with care
- AYA Survivors reported that a lack of health insurance was the biggest barrier to receiving medical care the first few years after diagnosis

Available Services:
- Moffitt’s Business Office
- Social Work
- Certified Application Counselors
- SAMFund, Ulman Fund, Patient Advocate Foundation

ALONE: AYA Connections at Moffitt

“Reach out to those patients while they are going through treatment - even if they don’t want to. I didn’t want to put myself out there while I was going through treatment, but now I wish I had.”

- Moffitt AYA Survivor

Available Services
- One-on-one with social workers
- Meet-Up!
- Connect-Up!
- Art-Up!
- Other Events

Lindsey Lucas, Peer Visitor, Patient and Family Advisory Program
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Support

• Gonzmart Family Foundation

• Chotiner Pediatric Research Award

• SAA

• Teen Cancer America

• Lewis Family Cancer Fund

• Ros Miller

• Cure on Wheels

How to Contact Us:

• Phone number: 813-745-4736

• Email: aya@moffitt.org

• Website: www.moffitt.org/aya

VHL Alliance, 2017