Huntsman-Intermountain Adolescent & Young Adult Cancer Care Program

R. Lor Randall, Carolyn Reynolds, & Sara Salmon
On Behalf of the HI-AYA Working Group

10th HICCP Annual Meeting

June 28, 2017
HI-AYA Working Group

- Julie Asch
- Anna Beck
- Brad Bott
- Brynn Fowler
- Cheryl Gerdy
- Daanish Hoda
- Anne Kirchhoff
- Tibor Kovacsovics
- Richard Lemons
- Mark Lewis
- Lauri Linder
- Craig Nichols
- Samantha Pannier
- Paige Patterson
- Elizabeth Raetz
- R. Lor Randall
- Carolyn Reynolds
- Sara Salmon
- Holly Spraker-Perlman
- John Sweetenham
- Yelena Wu
- Jeff Yancey
Agenda

• Review of the Facts, Population, & Need
• Overview of HI-AYA Vision & Mission
• Summary of 2015 HI-AYA Needs Assessment
• Discussion of Implementing HI-AYA Patient Navigation
• Preview of Next Steps
• Concluding Remarks
Review: The Facts

• >70,000 AYAs are diagnosed w/ cancer/year in US
  • Age: 15-39 years
  • Leukemia, CNS, melanoma, sarcoma, others

• Cancer is leading cause of AYA disease related death
  • Only accidents, suicide, homicide claim more lives

• AYAs are 6X more likely to be diagnosed w/cancer than children < 15 y.o.
  • Most programs focus on younger or older
Review: The Population

• Intermountain, HCI & the Community

• AYA
  • ~10,000 cancer diagnoses
  • AYA is ~5% of cancer
  • AYA in Utah: approx. 1,000 cancer cases

• AYA Survivorship
  • Cancer Survivors: 81,260
  • AYA survivors: 9%
  • AYA survivors in Utah: ~7,300 people
HI-AYA Vision

The vision of the HI-AYA program is to improve health outcomes for adolescents and young adults with cancer in the five-state Intermountain West (Utah, Idaho, Montana, Nevada, and Wyoming).
HI-AYA Mission

The mission of the HI-AYA (ages 15-39) program as approved by the HICCP Board of Trustee’s includes:

• Develop a collaborative AYA program for the Intermountain West to provide appropriate care & support for this underserved population.

• Establish a peer-reviewed funding base for original research in AYA populations.
Summary of 2015 HI-AYA Cancer Study

Aim: Conduct a needs assessment to inform the development of the HI-AYA cancer survivor navigation program.

A needs assessment in four parts:
1. AYA patient/survivor interviews
2. Provider survey
3. Supportive care interviews
4. Key informant interviews
Summary of 2015 HI-AYA Cancer Study

AYA Cancer Patient/Survivor Interviews (N=39)

- Patient navigators in Utah should provide targeted and accessible support for AYAs, with a focus on:
  - Social and emotional support
  - Access to fertility services
  - Connection to other AYA patients
- Most AYAs expressed a preference for phone or face to face communication
- AYAs expressed a desire to connect with the navigator at first diagnosis
Summary of 2015 HI-AYA Cancer Study

Statewide Oncology Provider Survey (N=106)
• 86.5% agreed that a navigator program would be very beneficial to their AYA cancer patients
• 85.7% cited that they would prefer to interact with the navigator via email.

Key Informant Interviews (N=11)
• All key informants support HI-AYA goals: AYA patients are needy of these services, and services are best disseminated through an informed centralized party
HI-AYA Patient Navigator: Timeline

September 19th
Patient Navigator began training

October 17th
Patient Navigator began pilot work with patients

May 1st
Public launch of HI-AYA Cancer Care program:
- Press release
- News coverage: KUTV, FOX 34 (Texas), FOX 13, Good4Utah, The Salt Lake Tribune, AACI announcement
- Social media engagement: Facebook Live event, Twitter chat, blog posts

June 7th
Patients to date: 66 patients
HI-AYA Patient Navigator: Patient Process

Process
1. Referral (self, care team, loved one)
2. Consultation and needs assessment
3. Provision of resources and information
4. Future check-ins
HI-AYA Patient Navigator: Current Status

• 66 patient cases
  • HCI – 28
  • Intermountain – 33
  • Community – 5

• Navigation status
  • Active – 54
  • Inactive – 12

• Needs include:
  • Fertility preservation
  • Employment discussions
  • Scholarships
  • Survivorship transitions
  • Social support
  • Insurance questions
# HI-AYA Research To Date

<table>
<thead>
<tr>
<th>Organization / Event</th>
<th>Type</th>
<th>Date</th>
<th>Title</th>
<th>Authors</th>
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</thead>
<tbody>
<tr>
<td>Utah Public Health Association</td>
<td>Poster</td>
<td>April 2016</td>
<td>Huntsman-Intermountain Adolescent and Young Adult Cancer Study: Developing an AYA Oncology Navigator Program</td>
<td>Pannier et al.</td>
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<tr>
<td>Utah Cancer Action Network</td>
<td>Breakout presentation</td>
<td>May 2016</td>
<td>Assessing Needs for Patient Navigation: The Huntsman-Intermountain Adolescent and Young Adult Cancer Study.</td>
<td>Pannier et al.</td>
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<tr>
<td>International Cancer Education Conference</td>
<td>Poster</td>
<td>September 2016</td>
<td>Identifying the Needs of Adolescents and Young Adults with Cancer in Utah: Huntsman-Intermountain Adolescent and Young Adult Cancer Study</td>
<td>Yancey et al.</td>
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<tr>
<td>Huntsman-Intermountain Adolescent and Young Adult Cancer Study</td>
<td>Poster AND Breakout presentation</td>
<td>October 2016</td>
<td>AYA Patient and Provider Perceptions of Fertility Preservation</td>
<td>Randall et al.</td>
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<td>Connective Tissue Oncology Society</td>
<td>Poster</td>
<td>November 2016</td>
<td>Supporting Adolescents and Young Adults (AYAs) with Cancer: Oncology Provider Perceptions of AYAs’ Unmet Needs</td>
<td>Spraker-Perlman et al.</td>
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<tr>
<td>NCCN: Improving the Quality, Effectiveness, and Efficiency of Cancer Care</td>
<td>Poster</td>
<td>Schedule conflict</td>
<td>A mixed-methods study of adolescent and young adult cancer patient's preferences for patient navigation services by distance from cancer treatment centers</td>
<td>Warner et al.</td>
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<tr>
<td>ASCO Quality Care Symposium</td>
<td>Poster</td>
<td>March 2017</td>
<td>Age-specific variations in patient navigation preferences among adolescent and young adult cancer patients and survivors</td>
<td>Warner et al.</td>
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<tr>
<td>ASPO 2017</td>
<td>Poster</td>
<td>March 2017</td>
<td>Supporting Adolescents and Young Adults (AYAs) with Cancer: Oncology Provider Perceptions of AYAs’ Unmet Needs</td>
<td>Pannier et al.</td>
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<tr>
<td>Utah Cancer Action Network</td>
<td>Breakout presentation</td>
<td>May 2017</td>
<td>Implementing a Patient Navigation Program for Adolescents &amp; Young Adults (AYAs) in Utah</td>
<td>Salmon et al.</td>
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<tr>
<td>Utah Cancer Patient, Survivor, &amp; Caregiver Conference</td>
<td>Breakout presentation</td>
<td>June 2017</td>
<td>Adolescents &amp; Young Adults (AYAs) with Cancer</td>
<td>Salmon et al.</td>
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<tr>
<td>Journal of Adolescent and Young Adult Oncology</td>
<td>Paper</td>
<td>Awaiting publication</td>
<td>Supporting Adolescents and Young Adults (AYAs) with Cancer: Oncology Provider Perceptions of AYAs’ Unmet Needs</td>
<td>Krichhoff et al.</td>
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<tr>
<td>Support Care Cancer</td>
<td>Paper</td>
<td>Submitted</td>
<td>A mixed-methods study of patient navigation preferences for adolescent and young adult cancer services by distance to treatment location</td>
<td>Warner et al.</td>
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<tr>
<td>Journal of Cancer Education</td>
<td>Paper</td>
<td>Pending Submission</td>
<td>Age-specific variations in patient navigation preferences among adolescent and young adult cancer patients and survivors</td>
<td>Pannier et al.</td>
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Next Steps: Working Groups

- Health Educator: Dx-Specific Working Groups
- Communications: Marketing & Digital Engagement
- Informatics: Tracking & Outcomes Database
- IRB: Biorepository, Clinical Trials, CCDR & Population Sciences
- Grants: Peer Reviewed Funding & Reporting
- Care Continuum: Care Pathways & Quality Measurement
Concluding Remarks

• GENUINELY collaborative with a team approach
• Underserved (“minority” oncology) population
• Initially a health education mission (v1.0)
• Ambitious clinical care & academic agenda (v2.0)
• On behalf of the working group and the AYAs, thanks to all those that are believing in us!
Contributions & Acknowledgments

• Sara Salmon MA and Carolyn Reynolds APRN contributed to this presentation

• Collaborators include:
  • Anne Kirchhoff PhD MPH, MPH Doug Fair MD, Holly Spraker-Perlman MD, Jeff Yancey, PhD CHES, Samantha Pannier HBA, Echo Warner MPH, Brynn Fowler MPH, Brad Bott, Mark A. Lewis MD, Craig R. Nichols MD

• We would also like to acknowledge the generous support of the Utah Department of Health and the Sarcoma Disease Oriented Team at Huntsman Cancer Institute
Thank you!

Dr. R. Lor Randall
• Lor.Randall@hci.utah.edu

Carolyn Reynolds, APRN
• Carolyn.Reynolds@imail.org

Sara Salmon, MA
• Sara.salmon@hci.Utah.edu
• Sara.salmon@imail2.org
Review: The Need

*The AYA Burning Platform: Medical “no man’s land”*

- Lack of survival progress in 30 years
- Biological differences
- Therapy tolerance, chemotherapy metabolism
- Treatment by physicians less familiar with the disease
- Delay in diagnosis
- Lack of new therapeutics
- Lack of availability and participation in clinical trials
- Lack of insurance/under-insured
- Poor adherence to therapy
- Lack of psychosocial and financial support
HI-AYA Patient Navigator: Role

• Advocate, liaison and informant to cancer patients (ages 15-39)/families for best practices
  • National Academy of Medicine’s AYA consensus statement
  • NCCN guidelines.
• Navigation for AYAs & caregivers at Huntsman Cancer Institute, Intermountain Healthcare, and Community Clinics in the state of Utah (and beyond)
Next Steps & Future Plans

• HI-AYA 1.0
  • Health Education & Patient Navigation

• HI-AYA 2.0 & Beyond
  • Comprehensive clinical/clinical research platform
  • Develop and apply for peer-reviewed and/or philanthropic funding
  • Move forward with working groups to push forward core programs
Next Steps from 2016

Strategy and Tactics

• Initially, utilize a non-disease-specific platform to develop the health educator/navigator position and subsequently catalyze the development of a comprehensive clinical/clinical research platform capable of developing and obtaining peer-reviewed funding and philanthropic support (1-3 years):
  • Develop a bold and balanced governance, business, and research plan to administer an AYA clinical/clinical research program to enable and inform navigation and best practices.
  • Define the responsibilities and obtain the authorities to build an appropriate and impactful platform.
  • Develop working groups to build the disease-specific and cross-cutting core programs for this platform. Cross-cutting programs include cancer care delivery research (CCDR), care pathways throughout the continuum of care (entry, treatment, survivorship, palliative care, end of life), cancer prevention and control (including psychosocial and behavioral research), cancer informatics, quality, biorepository, communications, and digital engagement.
  • Continue to develop and apply for peer-reviewed and/or philanthropic funding.