



Medical and Supportive Care Considerations for Adolescents and Young Adults (AYAs) with Cancer

Bhavana Bhatnagar, DO
Associate Professor of Medicine
Director of Hematology and Medical Oncology
West Virginia Cancer Institute
Wheeling Hospital




Disclosures

- Funding, Teen Cancer America



Overview

- Definition of the AYA population
- Unique needs of AYA cancer patients
- WVU CI AYA Program Development






Background

- AYAs (aged 15-39 years) with cancer represent a growing patient demographic with ~ 89,500 new diagnoses in 2020¹.
- Survival outcomes have not improved for this age group compared to pediatric and adult oncology patients → "AYA Gap"²⁻⁴
 - Cancer-related death is #1 cause of non-accidental deaths
- Reasons for AYA Gap²⁻⁴
 - Delays in diagnosis and treatment
 - Lack of access to novel therapies on clinical trials
 - Geographic barriers
 - Limited understanding of the role of tumor and germline genetics

¹ American Cancer Society. Cancer Facts & Figures 2020.
² Smith EC, Zogas A, Anton-Culver H. Delay in surgical treatment and survival after breast cancer diagnosis.
³ Blair RD, Ferris A, Rice L, Whelan J, Steyer WA. Cancer in Adolescents and Young Adults: A Narrative Review of the Current Status and a View of the Future. JAMA. 2018; 319: 486-501.
⁴ Tricoli JV, Blair SD, Anders CK, et al. Biologic and clinical characteristics of adolescent and young adult cancers: Acute lymphoblastic leukemia, colorectal cancer.




Leading Cancer Sites for AYAs

Figure 52. Leading Sites of New Cancer Cases in AYAs, Both Sexes Combined - 2020 Estimates


Estimated New Cases	Ages 15-19	Ages 20-29	Ages 30-39
Thyroid	800	4,600	11,100
Hodgkin lymphoma	800	3,000	9,000
Brain & ONS	500	2,200	5,500
Non-Hodgkin lymphoma	500	2,000	4,200
Testicular germ cell tumors	400	1,500	3,300
Acute lymphoid leukemia	400	1,400	3,000
Bone tumors	400	1,300	2,700
Soft tissue sarcomas	400	1,200	2,400
Melanoma of the skin	200	1,000	2,000
Acute myeloid leukemia	200	800	1,800
		Testicular germ cell tumors	3,000
		Melanoma of the skin	2,200
		Hodgkin lymphoma	2,000
		Breast (female)	1,500
		Non-Hodgkin lymphoma	1,400
		Colon & rectum	1,300
		Soft tissue sarcomas	1,200
		Uterine cervix	800
		Breast (female)	11,100
		Thyroid	9,000
		Melanoma of the skin	5,500
		Colon & rectum	4,200
		Testicular germ cell tumors	3,300
		Uterine cervix	3,000
		Non-Hodgkin lymphoma	2,700
		Kidney	2,400
		Uterine corpus	2,000
		Brain & ONS	1,800

ONS = other nervous system. Estimates are rounded to the nearest 100 and exclude basal cell and squamous cell skin cancers, benign and borderline brain, and in situ carcinomas of any kind. Ranking is based on included progress and may differ from the most recent observed data.
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AYA cancer patients are unique

- "Too old to be pediatric and too young to be geriatric."
- Cancer disrupts a fundamental stage of growth, development and life milestones (college, career productivity, family planning, etc.)
- Underlying biology of AYA cancers is different compared to other age groups.
- Long term effects and late toxicities may permanently affect the remainder of their lives.



In their own words...



Suleika Jaouad, diagnosed with AML at age 22

"When you survive something that was thought to be unsurvivable, the obvious is gained. You have your life – you have time. But it's only when you get there that you realize your survival has come at a cost."




Paul Kalanithi, diagnosed with metastatic lung cancer at age 36

"The tricky part of illness is that, as you go through it, your values are constantly changing. You try to figure out what matters to you, and then you keep figuring it out."

— When Breath Becomes Air



Care Considerations for AYA Patients



SIDE EFFECTS




AYA Care Consideration #1: Fertility Preservation


- Gonadotoxicity, infertility and radiation injury to reproductive organs affects 12% of childhood and 62% of AYA cancer survivors.^{1,2}
- Reproductive late effects include gonadal failure, infertility, genital graft-versus-host disease, and vaginal stenosis.³
- Standardized assessment for reproductive late effects improves outcomes.⁴

1. Hudson MM, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. JAMA. 2013; 309(22): p. 2371-2381

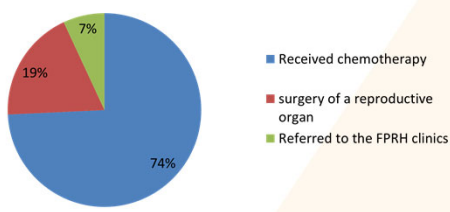
2. Anderson RA, Brewster DH, Wood R, et al. The impact of cancer on subsequent chance of pregnancy: a population-based analysis. Hum Reprod. 2018;33(7):1281-1290. doi:10.1093/humrep/dpy216

3. Newman D, et al. Cancer survivors and infertility: a review of a new problem and novel answers. J Support Oncol. 2006; Apr;4(4):171-8


4. Kerney LB, Cohen LE, Sirothaveeratan M, et al. Male reproductive health after childhood, adolescent, and young adult cancers: a report from the Children's Oncology Group. J Clin Oncol. 2013;31(7):949-949. doi:10.1200/JCO.2011.38.6508



AYA Care Consideration #1: Fertility Preservation



Category	Percentage
Received chemotherapy	74%
surgery of a reproductive organ	19%
Referred to the FPRH clinics	7%



AYA Care Consideration #2: Genetics counseling

- ~ **10-20%** of AYAs have an inherited germline mutation in a cancer-causing gene¹
- The tumor tissue from AYA cancer patients is genetically distinct compared to pediatric and adult patients.^{2,3}
 - Discovery of specific mutations can help with treatment selection
- Only a small percentage of AYAs are referred to genetic counseling even though this is recommended in the NCCN guidelines and covered by insurance (including Medicaid)

1. Stadler ZK et al. Germline mutation prevalence in young adults with cancer. In: Proceedings of the 11th Annual Meeting of the American Association for Cancer Research; 2020 June 22-24. Philadelphia (PA): AACR; 2020. Abstract 1122.
2. Troost JV, Boardman LA, Ptasnik R, et al. A mutational comparison of adult and adolescent and young adult (AYA) colon cancer. Cancer. 2018; 124: 1070-1082.
3. Troost JV, Blair DG, Anders CK, et al. Biologic and clinical characteristics of adolescent and young adult cancers: Acute lymphoblastic leukemia, colorectal cancer, breast cancer, melanoma, and sarcoma. Cancer. 2016; 122: 1011-1028.

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AYA Care Consideration #3: Financial toxicity

- AYAs are disproportionately affected by financial toxicity and are more likely to be uninsured compared to older adults (15% vs 10%)¹
 - Leads to delays in diagnosis → poorer outcomes
- AYAs have more out-of-pocket costs compared to general population leading to **higher rates of bankruptcy**^{2,3}
- Expenses related to education (student loans) and childcare further compound this toxicity⁴

1. US Census Bureau. Current Population Survey, Annual Social and Economic Supplement, 2018.
2. Kagan TM, Stevens RM, Chen Y, et al. Impact of health insurance on stage at cancer diagnosis among adolescent and young adults. J Natl Cancer Inst. 2018.
3. Day SP, Yabuchi YH, Ekwonwu SO, et al. Understanding the health and economic burden of cancer among those diagnosed as adolescents and young adults. Health Aff (Millwood). 2014;33: 1024-1031.
4. Cheng J, Jemal A, Han X, et al. Medical financial hardship among cancer survivors in the United States. Cancer. 2018;125: 1737-1747.

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AYA Care Consideration #4: Survivorship

- Post-treatment psychosocial, physical and financial impact of cancer diagnosis
- Over **half** of AYA cancer survivors report unmet needs following completion of treatment, especially within the first year¹
 - Counseling/mental health services (56%)
 - Cancer rehabilitation/physical therapy (58%)
 - Pain management (63%)
- AYA HOPE** study → showed that AYA survivors report worse psychosocial and cognitive functioning
- Monitoring for late chemo effects (e.g cardiotoxicity following anthracycline use, fertility, endocrine issues) as well as screening for second cancers.

1. Kagan TM, Lichtenstam DY, Katz L, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. J Cancer Surviv. 2012;3: 202-209.
2. Smith AV, Kwan J, Hamilton A, et al. Understanding care and outcomes in adolescents and young adult with Cancer: A review of the AYA HOPE study. Front Oncol. 2019;9: 407466.

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AYA-HOPE

Adolescent and Young Adult Health Outcomes and Patient Experience Study (AYA-HOPE)

Adolescent & Young Adult Health Outcomes & Patient Experience Study

- 530 AYA
- Ages 15-39
- Study patients were diagnosed between July 1, 2007 and October 31, 2008
- Germ cell, Hodgkin lymphoma, non-Hodgkin lymphoma, acute lymphoblastic leukemia, or sarcoma

Primarily designed to understand how to obtain consent, records, and survey newly diagnosed AYA in community settings

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AYA-HOPE

Work or School Status Before Diagnosis

Work/School Status	Patients (%)
Full-Time Work/School (n = 388)	~65%
Part-Time Work/School (n = 41)	~15%
Homemaker (n = 14)	~10%
Unemployed/Disabled (n = 20)	~10%

Work/School Status at Follow Up (15-30 months after diagnosis)

Work/School Status	Patients (%)
Full-Time Work/School	~35%
Part-Time Work/School	~15%
Unemployed/Disabled	~30%
Homemaker	~15%

Issues Reported

Issue	Initial Survey (0-14 months after diagnosis)	Follow-Up Survey (15-30 months after diagnosis)
I miss work or school to go to the doctor or hospital	~35%	~45%
I miss work or school because of not feeling well	~15%	~25%
I have trouble keeping up with my work or studies	~25%	~35%
I forget things	~45%	~55%
It is hard to pay attention at work or school	~25%	~35%

Parsons et al. J Clin Oncol. 2012

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Supportive Care Needs of AYA Cancer Survivors: Results


- A retrospective chart review was performed on AYA cancer survivors (ages 18 to 39) at OSU who completed active treatment between January 2016 and April 2019.
- 236 AYA cancer survivors were provided a TS/SCP.
 - AYA survivors averaged 0.8 referrals to clinical support, which increased to 3.8 referrals if linked with the Survivorship clinic (51%).
- Predominant co-morbidities included depression (20.4%), obesity (18.7%) and anxiety (16.5%)
- Highly utilized clinical services included **physical therapy** (35%), **psychosocial oncology** (25%), **cancer genetics** (24%), and **gynecology/fertility** (21%).

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AYA Care Consideration #5: Psychosocial support

- Psychosocial stressors¹
 - Information issues → how to effectively communicate with this age group?
 - Practical issues → navigating the health system, interactions with numerous providers
 - Emotional issues → psychologic distress regarding treatment and mortality, changes in physical appearance, sexuality
 - Interpersonal issues → reliance on parents and other caregivers, changes in peer interactions
 - Spiritual issues → “why did this happen to me?”


1. Zabrack B, Isaacson B. Psychosocial care of adolescent and young adult patients with cancer and survivors. J Clin Oncol. 2012;30: 1221-1228.



Psychosocial interventions

- Referrals to peer support programs
 - 50% of AYA cancer patient express a desire to connect with other AYA cancer patients
- Technology based interventions
- Skill based interventions
 - Cognitive behavioral therapy to help with coping

1. Zabrack B, Isaacson B. Psychosocial care of adolescent and young adult patients with cancer and survivors. J Clin Oncol. 2012;30: 1221-1228.
2. BJ Zabrack. Information and service needs for young adult cancer patients Support Care Cancer 16: 1253-1262 2008 Crossref. Medline. Google Scholar
3. B Zabrack. Information and service needs for young adult cancer survivors Support Care Cancer 17: 340-347 2009




AYA Programs are Growing Nationally and Internationally: To name a few....





AYA Programs: One size does not fit all

- Acknowledge different population needs
- Health care system needs
- Careful evaluation of local resources and demands
- Evaluate sustainability




AYA Program Development

- **Consider:**
 - Early access to services including psychosocial
 - Refer to age-appropriate specialists
 - Access to optimal care including clinical trials
 - Evaluate challenges in communication and adherence throughout program development and appraisal
 - Resources for fertility preservation
 - Resources for body image and sexuality
 - Financial and return to work/school considerations
 - A space of their own



FACES (S)


- F: Fertility preservation
- AC: Access to clinical trials
- E: Expertise in AYA cancers
- S: Support services
- (S): Clinical space for AYA





Ferrari, Barr, Pediatric Blood Cancer 2017

Summary: NIH Progress Review Group Recommendations

- ✓ Identify characteristics of unique cancer burden in AYA oncology
- ✓ Improve awareness, prevention, access, and quality care
- ✓ Create tools to study AYA cancer
- ✓ Ensure excellence in service delivery across cancer control continuum
- ✓ Strengthen and promote and support of AYA cancer patient





The Future of AYA Care at WVU-CI




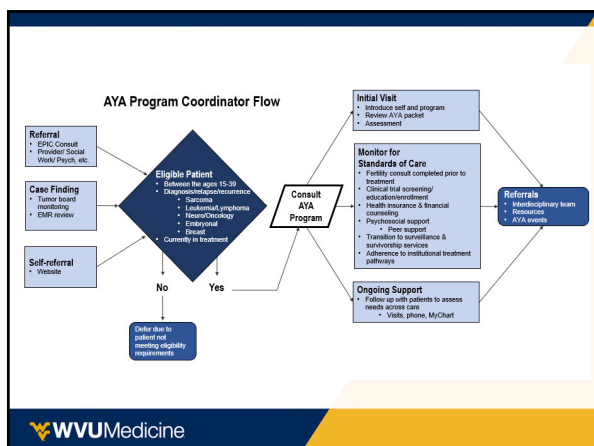
AYA Steering Committee

- Chair: Laurie Lyckholm, MD
- Members:
 - Nicole Stout, DPT, CLT-LANA, FAPTA
 - Patrick Tomboc, MD
 - Ashley Meyer, MD
 - Patricia Policicchio, MSW, OSW-C
 - Rob Riley
 - Bhavana Bhatnagar, DO

AYA Program Planning

- Joint adult and pediatric program with plans to contain all regional sites
- Study protocol for AYA needs assessment and focus groups for WV patients (IRB approved)
- In discussions with Teen Cancer America for pilot funding (accepted as mentees!)
- CDC minigrants awarded (Drs. Lyckholm, Stout and Bhatnagar) for AYA survivorship programs.
- Working out space considerations

Conclusions

- Adolescent and young adult cancer patients/survivors are a growing demographic whose survival outcomes have not improved as well compared to pediatric and adult cancer patient populations.
- AYAs have a unique set of disease-related, physical, psychosocial and practical needs which must be assessed and addressed at all stages of their cancer care.
- AYA programs are growing nationally (including ours) in order to properly tailor care of these patients.

