



The Gift of Sophie:
How UNC is Transforming Care for AYA Patients and Survivors &
How YOU CAN TOO

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What you don't have to be...

1. Cool
2. Up to date on recent slang terms
3. A snap chat user
4. Young
5. Cool

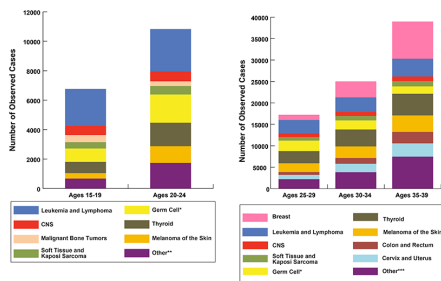
What you do have to be...

1. Authentic
2. Flexible
3. Compassionate
4. Honest
5. Willing to get to know the PERSON not just the PATIENT

What's this AYA business all about?

- NCI refers to AYAs as 15-39
- 70,000 new AYA patients diagnosed each year in US
- Clinical trial enrollment is miniscule
- Less likely to access adult oncology support services
- Financial toxicity
- **BOTTOM LINE:** AYAs have **UNIQUE** and **UNMET** medical and psychosocial needs

Common Types of Cancer Affecting AYAs

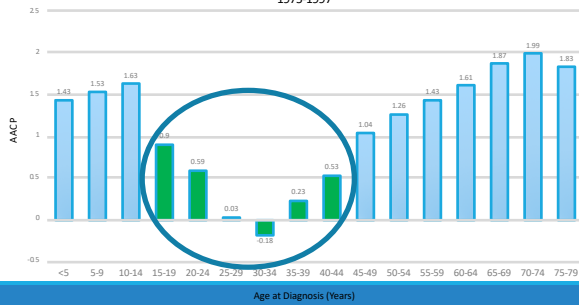


Acute Lymphoblastic Leukemia Outcomes

Age (years)	5 year EFS	10 year EFS
0-14	87.5%	83.8%
15-21	61.4%	60.4%
20-30	44.8%	30.8%

Shafer E and Hunger S. Pulte, D., Gondos, A. & Brenner, H. 2011

Average Annual % Change (AAPC) in 5-Year Relative Survival for All Invasive Cancer, SEER 1975-1997



Age at Diagnosis (Years)

Why poor outcomes?

- Tumor biology
- Delay in diagnosis
- Adherence to therapy
- Underinsured/not insured
- Psychosocial issues
- Financial issues
- Low clinical trial enrollment rate(1-2% vs. 60-70% in peds)
- Treatment protocols used vary

Barr, D. et al, 2016

AYA developmental tasks

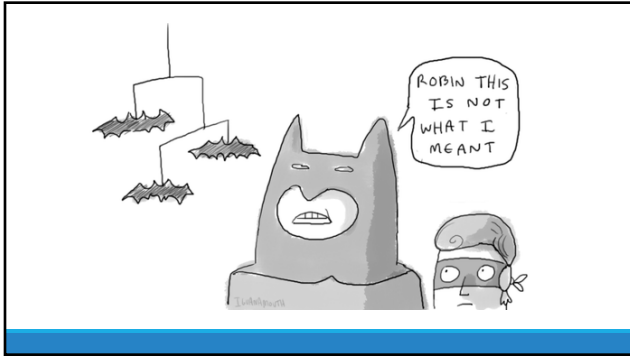
- Establishing autonomy from parents
- A personal set of values and identity
- Strong peer relationships, including intimate and sexual relationships
- Obtaining adequate preparation to join the workforce
- Financial independence

**A note about frontal lobes

POLL

Select some of the unique needs of AYA cancer patients

“The simplest advice I can give to facilitate conversations with adolescents and young adults is this: be respectful, and genuine. We are forced to confront our mortality at a time in our lives when society tells us we are invincible, fearless, limitless. When this construct crashes down around us and shatters, we can feel vulnerable...”



Communication

- Honesty is key
- Legal piece- who can you talk to?
- See patients alone
- Non-judgmental
- Avoid controlling/punitive language
- Help AYA understand how they best receive information
- Repeat, repeat, repeat
- Text vs. Phone vs. Email
- **Discuss things other than cancer**

Caregivers, Partners & Confidentiality

- Consent, confidentiality, and decision making capacity
- Legal obligations
- Ethical considerations
- Establish expectations from the beginning
- How do we support caregivers?

Bottom Line

- AYAs require a different style and type of communication from providers
- Must be more flexible and engaged
- Think about methods of communication (social media, text, etc)
- Remember that this is a time for autonomy grabs– give control where you can

“Can you come talk to me bout that sperm thing?”

Oncofertility Facts

- As AYA cancer survival rates are improving, the need to address fertility preservation is even more imperative
- In most circumstances it's not the cancer that is the cause of infertility or subfertility (difficulty getting pregnant), but treatment itself
- There is a real possibility that many of these long term survivors may experience fertility issues based on the effects of treatment and lack of preservation prior to treatment, which can lead to the phenomenon of reproductive regret

Meistrich (2009)

Risks of Infertility

Chemotherapy

- Type
- Duration
- Dose

Surgery

- Location
- Scope of Surgery

Radiation

- Location
- Dose

Other

- Age
- Pre-treatment fertility status
- Cancer type

Fertility Preservation Options

Men

- Sperm Banking
- Testicular Sperm Extraction (TESE)
- Radiation Shielding
- Testicular Tissue Freezing*

Female

- Embryo freezing
- Egg (oocyte) freezing
- Ovarian shielding
- Ovarian transposition
- Fertility-sparing surgery
- Ovarian tissue freezing*
- Ovarian suppression*

Possible Fertility Outcomes

- Normal Fertility
- Fertility followed by early menopause
- Compromised fertility
- Immediate menopause (female)
- Permanent sterility (male)

“What’s the deal with having sex IN the hospital?”

Sex is Part of the Human Experience

- Sexuality is an integral part of normal life for most individuals and is an important aspect of **quality of life**
- Health care providers must be prepared to assess problems in this area and to provide anticipatory guidance related to treatment and the resumption of sexual activity
- **It is our obligation to initiate this discussion**

Sexual Side Effects

- Fatigue
- Pain
- Restriction of movement
- Body image changes and disfigurement
- Change in physical appearance
- Weight loss
- Weight gain
- Functional issues, especially if sex organs have been directly effected, which may affect blood flow and sensation
- Psychological issues: depression, anxiety, adjustment, trauma, and substance use

How Do We Talk About This

- Include partners
- BETTER Model:
 - Bring up the topic
 - Explain that sex is an important part of life
 - Tell patients that resources will be found to address their concerns
 - Timing of intervention
 - Education re: sexual side effects of tx
 - Record

Murphy, Klosky, Termuhlen, Sawczyn, Quinn. 2013, Katz, A. 2005

“What if I just eat the pot instead of smoke it?”

Drug and Alcohol Use

- Very little data about substance use and AYA
- Some indication that substances are used to cope with stressors
- Open, honest conversations
- Inform of risks
- Provide better options
- Sticky situations– Providers lack of consensus
- Adherence
- Developmentally normal behavior within the context of cancer

Daniel, C. et al. 2015

Exercise, Nutrition, & Lifestyle Choices

- Fatigue literature – importance of getting people to move
- Telling people what they can do instead of just what they can't
- Survivorship outcomes
- Reminder that meals are a shared and social experience– AYAs with cancer may not experience food in the same way as their peers
- Integration of alternative therapies – open communication with medical team about these choices – we must ask about this
- Patients that want to continue to work or go to school

Bottom Line

- When to intervene and when to normalize age appropriate behavior
- Remember what is happening in peer relationships
- Ideal vs. Reality
- Med adherence – understand AYA's priorities
- Understand and interpret how cancer is going to impact AYA development and how AYA development is going to impact treatment
- Provide psychoeducation to patients, caregivers, and providers – we are the mediators between these groups

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At your institution, which of the following are barriers to providing AYA appropriate medical and psychosocial needs?

“I don’t think I can do this anymore.”

-30 year old rhabdomyosarcoma patient and
lover of good food

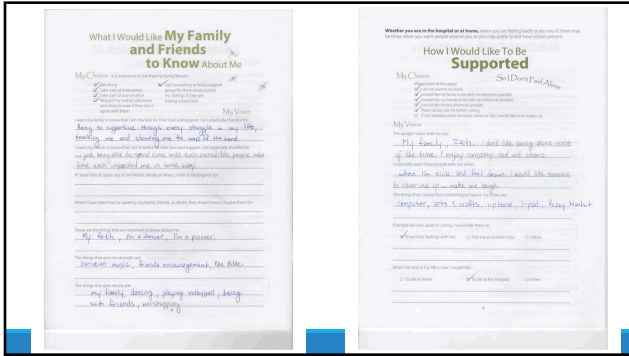
Decision making & end of life care

- 2015 study looking at high intensity end of life care among AYA's in NY state Medicaid program
 - 75% of patients used at least 1 aspect of intensive EOL care (chemo, ICU, ED, hospitalizations)
 - 38% received chemo in last 2 weeks of life
 - 65% died in acute care setting (inpatient hospital or ED)
- Many AYA patients enter last month of life wishing for life-prolonging care
- Most ultimately wish for comfort, but intensive care is prevalent even among such patients

Mack, Chen, Boscoe, Gesten, Roohan, Schymura, Schrag. December 2015

Legacy building & support

- How do we help patients tell their stories?
 - For themselves and for their families
- Understand the tension between hope and realism
- Use “Voicing My Choices”
- Do not forget spirituality



"I thought when I'd finished treatment—when they looked at my tests and they said it looked good—I thought, OK, I'm done. But now I'm starting to realize that it's not over"

Survivorship Stats

- 388,501 childhood and adolescent cancer survivors in US
- Mortality rates declined more than 50% between 1975-2006
- 70% of these survivors are 20 years and older

Howlader et al, 2016, Smith, et al, 2010, Ward et al, 2014

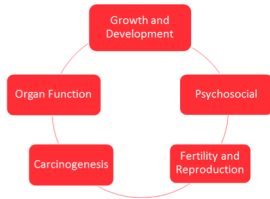
Morbidity, Mortality and QOL

Childhood Cancer Survivor Study (CCSS)

- 73.4% chronic health condition-30 years post diagnosis
- 42.4% severe, life-threatening, disabling condition or death
- 44% reported at least 1 adversely affected health domain

Deffinger et al, 2006, Hudson et al, 2003

Late Effects



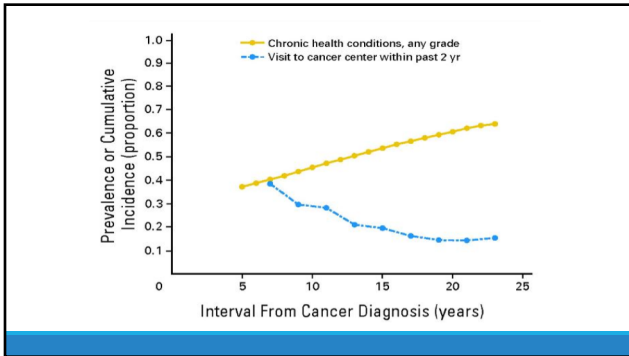
Robinson & Hudson, 2014

Issues for AYA survivors

Lost to Care

- Less than 1/3 reported ANY cancer-related follow up in 2 years
- 31.5% adult survivors received survivor focused care
- 17.8% = past 2 years received risk reduction teaching or underwent screening tests

Nathan et al, 2009



Issues for AYA survivors

- Unhealthy Behaviors (*smoking, exercise, alcohol etc*)
- Patient issues (*educational preference & preparation, parental role, knowledge deficit*)
- Provider Issues (*knowing risks, strong bond with patient/family, insurance, who can take care of them*)
- Lack of AYA focused models of care

Model Type	Features	Advantages	Disadvantages
Cancer Center Care	Oncology team or specialized clinic within an oncology setting leads care	Multi disciplinary specialist can meet needs of high-risk AYA survivors	May discourage AYA survivor from developing a relationship with PCP
Primary Care Provider	General and cancer survivor care provided by internist, family practice or nurse practitioner	Convenience for AYA survivor, most appropriate for patients at low risk for late effects from therapy	PCP's lack knowledge and expertise of cancer treatment effects and risk of late effects from therapy
Shared Care	Care led by a team of providers including PCP, oncologist, and oncology nurse practitioner	Access to general medical care and cancer survivor-focused risk based follow up care: potential for communication between providers	Potential Cost and extensive resources

Programming

- AYA clinic days
- AYA advisory council
- Social media
- Local and national AYA organizations
- Stupid cancer meet ups
- Blog
- PEERS

POLL

Name one practical change you can make in your work to better care for AYA's with cancer

Resources

- | | | |
|---|---|---|
| <p>General</p> <ul style="list-style-type: none"> • Stupid Cancer • Critical Mass • NCCN Guidelines "Caring for Adolescent and Young Adult Patients" • Teen Cancer America <p>Fertility Preservation</p> <ul style="list-style-type: none"> • Livestrong • Save My Fertility (also and App) • Fertile Action • MyOncofertility.org • NCI | <p>Financial</p> <ul style="list-style-type: none"> • SamFund • Hope for Young Adults with Cancer • The Ulman Cancer Fund for Young Adults • Patient Advocate Foundation • Cancer Care <p>Parenting with Cancer</p> <ul style="list-style-type: none"> • Single Father's Due to Cancer • NCI • Cancer.gov • Cancer.org • Mghpact.org (Parenting at a challenging time) • American Cancer Society | <p>Cancer Peer Connections</p> <ul style="list-style-type: none"> • Instapeer • Stupid Cancer Meet Ups • Inermian Angels • Young Survival Coalition • Cancer Support Community <p>Career & Legal</p> <ul style="list-style-type: none"> • Cancer and Careers • National Cancer Legal Services Network <p>Adventure Programs</p> <ul style="list-style-type: none"> • First Dissents • Epic Experience • True North Treks |
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