

The Emotional Impact of Cancer on Adolescents and Young Adults:

Hidden in Plain Sight

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Learning Objectives

- Recognize the unique challenges and coping strategies for adolescent and AYA cancer patients
- Explore strategies to improve systemic provider communication with adolescents and AYAs to help them navigate the impact of their cancer diagnosis
- Identify resources that can be used with these patients

Young Adults are Diverse



**Not all
AYA's
are
created
equal**

$$15 \neq 15$$

$$25 \neq 25$$

$$35 \neq 35$$

$$15 \neq 35$$

$$25 \neq 30$$

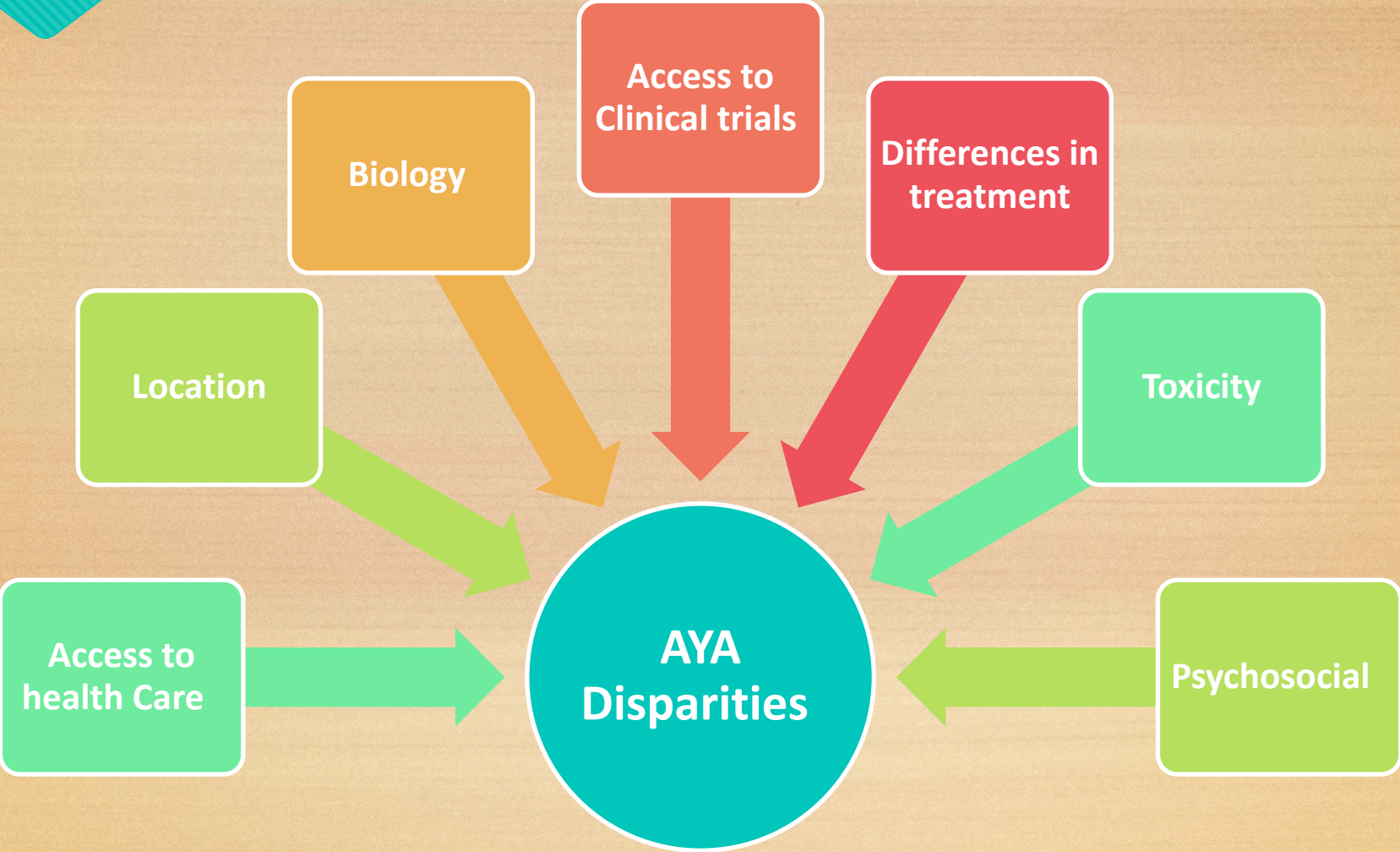
What we know

- About 5,000 – 6,000 adolescents aged 15 to 19 are diagnosed with cancer each year in the United States.
- The chance of getting cancer is about equal for teen boys and girls, but cancer survival rates are slightly higher in girls than in boys.
- Survival rates for cancer in young adults have not changed much in recent decades, unlike the improvements seen in many cancers in children and older adults. Survival rates can vary a great deal, based on the type of cancer and other factors.

Why is this important?

- Increased risk of depression related to disruptions in their developmental trajectory, greater physical symptom burden, and increased likelihood of developing aggressive disease.
- Adolescent and AYA cancer survivors face unique challenges, particularly social-psychological impacts in identity development, coping, distress and social relationship.
- Research suggests that AYA's are not getting their psychosocial care needs met to face these challenges

Etiology of the Disparity



The Challenges

Treatment Challenges

- They may also be more likely to present with advanced stage and aggressive disease, possibly due to inadequate insurance status, higher treatment burden, and limited treatment options
- Younger age is associated with greater cancer pain throughout all phases of cancer—active treatment, survivorship, and advanced or incurable disease
- More likely to have treatment compliance issues

Psychosocial & Financial Challenges

- Limited access to care
- Still be on parents' insurance or uninsured because they “are too young to need it”
- Treatment compliance issues
- May have lived independently and then had to move home
- Position in society is negatively impacted by reduced socioeconomic attainment, e.g. fewer survivors graduating college and gaining full-time employment
- Illness may interfere with working fulltime
- Decrease in long-term earning potential
- Newer to the workforce so limited financial resources and savings

Identity Challenges

- Loss of control and loss of identity
- Cancer forces adolescents to rely heavily on parents for financial and physical help
- Report greater concerns about body image, sexuality, fertility concerns, and cognitive issues
- Young adults who were living independently often have to move back home

Existential Challenges

- Burden of living with the threat of a potentially shortened life
- Fear of progression or recurrence

Relationship Challenges

- Peer relationships and social interactions are predominant activities in adolescence but friendships can be fractured by cancer as same-age peers rarely know how to meaningfully respond
- Significant friendships and romantic relationships are the defining features of young adulthood



Stable, mutually satisfying relationships



Isolated, lonely, and depressed

- Fatigue
- Lack of energy
- Sleep disruption
- Pain
- Weakness
- Appetite loss

<https://www.cancer.org/cancer/types/cancer-in-adolescents/key-statistics.html>

Symptoms of Major Depression

- Fatigue
- Lack of energy
- Sleep disruption
- Pain
- Weakness
- Appetite loss

Physical Symptoms of Advanced or Metastatic Cancer

- Fatigue
- Lack of energy
- Sleep disruption
- Pain
- Weakness
- Appetite loss

Risk of Suicide

- Some studies of US AYA patients found that a cancer diagnosis is associated with a 400% increase in likelihood of suicide attempts. This remained even after controlling for relevant variables such as alcohol use, depression, and demographic characteristics.
- In a small study of young adults with advanced cancer, more than 1 in 5 patients reported suicidal ideation. These results suggest that distress and suicide screening among the medically ill

Park & Rosenstein (2015) Depression in adolescents and young adults with cancer, Dialogues in Clinical Neuroscience

Screening and Treatment

- These results suggest that distress and suicide screening among adolescents and young adults with cancer are insufficient.
- Adolescents and AYA are more likely to report psychological challenges when screenings are built into the care system.

Coping Strategies

Five coping strategies which facilitated in living a normal life:

- (1) focusing on the “here and now,”
- (2) refraining from discussing the cancer experience,
- (3) recalling and preserving positive memories,
- (4) redefining the impact positively, and
- (5) consolidating and preserving a sense of togetherness.

Case Studies

Carlos

- Diagnosed at 12 with Acute Myeloid Leukemia
- Single Parent household because dad lives in Colombia
- Allogeneic Stem Cell Transplant
- Post- Treatment psychosocial issues – starting at 17 years
- Strained relationships with peers
- Poor follow-up in clinic due to turning 18 and losing Medicaid

Jennifer

- Patient is a 17 y/o female diagnosed with T-cell acute lymphoblastic leukemia
- She was diagnosed at a community hospital and was transferred to a large academic cancer center
- Complex relationship with her sister
 - Sister has made comments about the patient using the “c card”
- Parents are very involved in her life and care
- Difficulty communicating with her oncologist

Katie

- Patient is a 15 y/o female diagnosed with a **malignant peripheral nerve sheath tumor** with metastasis to the bones
- Patient has known pre-existing developmental delay
- Patient's parents divorced when she was young, and their relationship made an impact on patient care
- The patient's mother has a history of drug abuse (pain medications)
 - Patient found mother “passed out” regularly
- Social isolation:
 - The Patient does not have many friends or family members she can count on

Providing Support

- The Leukemia and Lymphoma Society's South Florida's YA Support Group began November 2008 with 5 members—today ~140 Facebook members with 15 to 20 participating in each group dinner
 - Peer managed support, networking group....professionally lead
 - Social Media: private Facebook page
- Expanded to Tampa Bay area working on expanding to Jacksonville and Orlando

Online Support

- CancerMatch is a networking and dating website for cancer survivors.
- Ulmanfoundation.org/patients
- StupidCancer.org
- Cancer & Careers
- Cancer Care
- Immerman's Angels
- Lacuna Loft

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Adolescents and Young Adults with Cancer

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Available online at NCCN.org/patients

Questions