WHAT’S SO DIFFERENT?
Working with cancer survivors between 15-39 years.
WHO ARE YOUNG ADULTS?

- Cancer survivors between 15-39 years
- Age limit primarily defined based on research indicating a gap in survivorship rates
- Developmental “fuzzy area” on each side of age limit
- About 78% of all cancers are diagnosed in persons 55 years and older. (ACS, 2010)
- Compared to most oncology patients, <40 years is “young”
- 70,000 AYAs diagnosed each year
  - 8 times greater incidence than children < 15 yrs
  - 6% of all cancer diagnosis
- #1 cause of disease related death in AYAs
MOST COMMON AYA DIAGNOSIS

86% of cancers in AYA:
- Breast
- Lymphoma
- Germ Cell Tumors (including Testicular)
- Thyroid carcinoma
- Sarcoma (bone and soft tissue)
- Cervical carcinoma
- Leukemia
- Colorectal carcinoma
- CNS Tumors

15-19 years old
- Lymphoma
- Leukemia
- Germ Cell Tumors (Testicular)

20-39 years old
- Decline of lymphoma, leukemia and GCT
- Increase in Carcinomas (especially breast)
Figure 2. Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975-1997

SEER Monograph 2006
FACTORS LIMITING PROGRESS

- Delayed Diagnosis
- Barriers to Access to Care
- Knowledge Gap in AYA Biology
- Emotional Needs
- Practical Needs
# Delayed Diagnosis

- **Symptoms dismissed**
  - Medical Team
  - Young Adults
  - Family

- **Symptoms attributed to other things**
  - Sports injury
  - Work related stress
  - Stigma
Delayed Diagnosis: What Can We Do About It?

- Recognize and validate anger, frustration and difficulty trusting the medical team
- Allow for sadness, guilt and regret for “lost time”
- Reframe focus on present oriented tasks around self care
- Become a strong advocate for our clients acknowledging ongoing needs may continue to be misunderstood
- Support skill building around clear, straightforward communication with medical team
- Empower clients to assume personal responsibility for their health and wellness
ACCESS TO CARE

- The AYA population is the most uninsured and/or underinsured group in the US (recent changes related to healthcare reform)
- AYAs are at the crossroads of pediatric and adult care, which creates medical management challenges
- Less familiar with the healthcare system
- Often lacking built in advocacy of resident family support
- Less prepared for how treatment will impact work, family and self care
Lack of Insurance

Figure 15.2: Percent without Health Insurance, Under 65 Years of Age, U.S., 2003
The increased coverage among young adults occurred specifically among those who benefit from the new law: individuals between the ages of 19 and 25. For comparison, insurance coverage among adults 26 to 35 was not significantly affected (from 72.3% in Q3 2010 to 71.8% by the end of 2011).

Gains particularly large for young men (from 57.9% to 72.0%). Young men ages 19 to 25 had the highest rates of being without insurance of any particular gender-age group combination. Coverage among young women also increased from 71.2% to 77.5%.
ACCESS TO CARE

- Single parents
- Financial instability
- Lack of knowledge regarding supportive resources
- Unique needs compared to older patients (e.g. fertility preservation) that can be less attended to by medical teams and unknown to the patient
**Access to Care: What Can We Do About It?**

- Provide guidance in assisting AYAs to understand the members of their medical team
- Become familiar with AYA specific resources to enable appropriate referrals
- Advocate alongside AYAs for treatment schedules that may work more easily with other life demands
- Help AYAs broaden their coping strategies for managing side effects (including stress and anxiety)
- Repeatedly initiate conversations about work, family, physical and/or practical issues that are having a negative impact on quality of life
KNOWLEDGE GAP

- Cancer is biologically different in the AYA population as compared to pediatric and older adult populations
- Sparse basic research
- Low enrollment in clinical trials
- Lack of specialized training in AYA care
- Fewer clinical trails specific to the AYA population are available to help determine age related treatment protocols
In the AYA population, the older the age the less likely to be treated at a cancer center or enrolled on a clinical trial

- < 15 year olds – 90% treated at cancer centers
  - Two thirds are enrolled on protocols
- 15-19 year olds – 20-35% treated at cancer centers
  - 10% enrolled on protocols
- 20-39 year olds – mainly treated at community hospitals
  - 1-2% on clinical trial protocols
- Overall: 10% of all AYA survivors aware of clinical trials
NATIONAL TREATMENT TRIAL ACCRUALS, 1990-1998

NATIONAL CANCER MORTALITY REDUCTION, 1990-1998

Clinical Trial Data courtesy of Montello M, Budd T, CTEP, NCI
**Knowledge Gap**

- The distinct needs and the need for distinct care structure for AYAs have been historically overlooked in healthcare policy and delivery
  - Childhood Cancer Success = Advances in Treatment
  - Adult Cancer Success = Screening and Early Detection

- Inconsistency in treatment
- Poor follow-up for long term effects
- Minimal emphasis on prevention and early detection for AYAs
  - Including those at high risk:
    - Childhood cancer survivors
    - AYAs with strong family history of cancers

- Lack of psychosocial interventions
**Knowledge Gap:** What Can We Do About It?

- Help dispel myths while addressing questions and concerns about clinical trial involvement
- Network with other professionals working closely with young adults
- Familiarize yourself with the small but growing body of literature on the experiences of young adult cancer survivors
- Advocate for AYA specific support within your organizations
- Empower AYA survivors to become advocates for their population in meaningful ways
WHO ARE YOUNG ADULT REALLY...?
DEVELOPMENTAL THEORY: CLASSIC STAGES

**Erikson**
- Identity v. role confusion
- Intimacy v. isolation

**Valliant**
- Conflict management
- Intimacy
- Work

**Levinson**
- Form a dream
- Cultivate mentor relationships
- Love relationship
- Occupation
DEVELOPMENTAL THEORY: CONTEMPORARY

Arnett: Emerging Adulthood

• Age of Identity Exploration
• Age of Instability
• The Self Focused Age
• The Age of Feeling In-Between
• The Age of Possibilities
AYA DEVELOPMENT CONTINUUM

Adolescent  Emerging adult  Young adult  “Young” adult
COGNITIVE DEVELOPMENT

- Expanding concept of greater world
- Developing cognitive capacities
  - Formal operations
  - Complex thinking
  - Examining own thinking
- Questioning beliefs of authorities
- Seeing uniqueness and invulnerable
- Regressing under stress
Developmental Tasks of AYAs

- Establishing independence from parents
  - Financially, housing, decision-making
- Developing long term relationships
- Setting professional goals & aspirations
- Defining identity, body image, values, priorities
- Acknowledging needs & impulses
- Maximizing strengths and negotiating weaknesses
COMMON AYA MENTAL HEALTH ISSUES

- Adjustment disorders
- Eating disorders
- Drug abuse
- Suicide
- Self injurious behaviors
- Anxiety
- Depression
EMOTIONAL NEEDS OF AYA SURVIVORS

- Loss of control
- Loss of independence
- Loss of normalcy
- Loss of feeling of invincibility
- Negative impact on career
- Stress of family planning decisions and/or losses
- Strain on relationships
- Isolation/loneliness is a major issue for most AYAs due to timing of diagnosis and cancer’s impact on relationships with peers, co-workers, spouses and other family members
Psychological Issues for AYAs Diagnosed with Cancer:

Demands of illness
- Isolation
- Vulnerability
- Dependence
- Uncertainty

Demands of life cycle
- Intimacy
- Invulnerability
- Independence
- Control
EMOTIONAL NEEDS
WHAT CAN WE DO ABOUT IT?

- Cognitive reframing
- Values clarification
- Enhancing emotional coping skills
- Emotional tolerance
- Identification of needs
- Mindfulness
- Anticipatory grieving
- Navigating interpersonal interactions (communication, assertiveness, advocacy)
- Existential exploration
EMOTIONAL NEEDS DIAGNOSIS:

Difficultly Comprehending Information

- Assist AYAs in formulating questions for their medical team
- Focus AYAs on building knowledge about the individuality of their diagnosis
- Regulate and provide support around the pace of the AYAs information processing

Life Stage Appropriate Information

- Discussing diagnosis with children
- Single life and cancer
- Negotiating work environment
- Body image and sexuality
“When I was 16 I was diagnosed with cancer. My parents and I didn’t think to ask about options for fertility preservation. We were so overwhelmed by the diagnosis; I wasn’t even sick... I just had muscle pain. Later, I met a girl who had the same tumor as me and her doctor suggested that she have her eggs harvested prior to starting treatment. So I asked my oncologist why fertility preservation options were not discussed with me.

The answer: “I personally don’t like to delay starting chemotherapy for the time it takes to harvest eggs”

My reply: “What gives you the right to make that decision for me?”
EMOTIONAL NEEDS TREATMENT:

Reduced Coping Strategies
- Identify healthy coping and craft ways continued use of these tools
- Challenge AYA to embrace new ways of caring for self. Remain interested in the process.

Immature Sense of Self – Self Blame
- Help AYAs learn to minimize negative self talk
- Thoughtfully support AYAs development of sincere self affirmations

Need for Control
- Provide practical information on “day to day” expectations from treatment
- Compartmentalize issues and periods of time that seem more manageable
EMOTIONAL NEEDS
MANIFESTATIONS OF DISTRESS

Behavioral
- Validate the feelings behind the behavior
- Recognize when referrals need to be made to other supports
- Broaden coping tools to manage extreme levels of distress

Relationship Strain
- Help AYAs categorize relationships and manage expectations of others
- Prepare “scripts” with AYAs in advance of challenging situations

Withdrawal
- Validate the feeling behind the behavior
- Name and allow for grief reactions to diagnosis
EMOTIONAL NEEDS
POST-TREATMENT & RECOVERY

**Difficulty Reconnecting with Peers**
- Honor how shifts in relationships provide information on value shifts within self
- Allow for feelings of loss
- Regulate pacing and provide insight on positive interactions

**Sense of Abandonment**
- Normalize and encourage peer to peer support
- Provide guidance on using thought challenging techniques

**Existential Meaning**
- Challenge AYAs to consider ways in which they recognize changes in self
- Encourage AYAs to find personal value in perspective, value and relationship changes
“I was actually worried about getting my life back to normal after treatment. I had such a set schedule while going through treatments... I was actually worried about the stress of day to day activities, of going back to work, of all the things I didn’t have to worry about when I was sick. I was happy that I was in remission but also sad in a way that my responsibilities would be back.”
“Cancer wasn’t all bad, but I’m one of the lucky ones who besides being cured found direction in my life. I was in college majoring in political science to please my parents. After my BMT, when I was told I could go back to school, I had the courage to pursue my dream of being a chef, instead of being a lawyer like my parents wanted. They were so happy I was doing well, that they supported me; something they would not have done before. Cancer helped our whole family grow and realize what was important.”
EMOTIONAL NEEDS
ONGOING SURVIVORSHIP

Impact on Identity
- Encourage gradual build up of participation in social activities, work or school
- Facilitate integration of cancer experience
- Connect pre-cancer life to post-cancer life

Impact on Developmental Trajectory
- Assist AYAs in creating short and long term personal goals
- Recognize feelings of lost time, experiences and limitations

Management of Long-term and Late Effects
- Empower AYAs to assume personal accountability for health
- Normalize and prepare AYAs for emotional responses related to post-treatment medical issues
I had the perfect life and was always upbeat. When I was diagnosed with cancer at 17, I took it in stride. I learned all the medical terminology and followed all the instructions to a “T”. I was the poster child of “having a positive attitude”. So many things happened! I took my family to Hawaii on a MAW, got a cancer survivors scholarship and met the man of my dreams at an oncology camp. Without cancer that wouldn’t have happened. Life was great – cancer was no big deal.

When I was 30 and trying to get pregnant I missed 2 periods, we were so excited. That’s when the reality of cancer hit; I wasn’t pregnant I had Premature Ovarian Failure. That’s when I started to grieve and realize that cancer may not have taken my life, but it still took a life from me.”
EMOTIONAL NEEDS
END OF LIFE

Protective Denial
- Gently challenge distorted thought processes
- Allow for the discussion of fears

Shifting Concept of Hope
- Redirect focus to present-oriented, realistic and tangible goals
- Emphasize the value of everyday interactions

Co-existence of Dependence and Independence
- Mediate impact on dependent self by reaffirming aspects of independent self
- Prioritize the manageable tasks that are most valuable

Expressing End of Life Wishes
- Help clients understand grieving does not mean they are giving up
- Help define the significance of their personal legacy
THE VALUE OF SUPPORT GROUPS “YA STYLE”!

Goals:

- Connection to other young adult survivors
- Understanding of the spectrum of supportive others
- Defining a “safe space” within the cancer experience
- Understanding their unique identity within the larger cancer community
“I heard there were “others” out there but I had never met anyone else my age with cancer. The group helped me not feel so alone.”
THE VALUE OF SUPPORT GROUPS RECRUITMENT

- **ACTIVE**
- Proactive vs. Reactive
- Very descriptive in early interactions:
  - Type – Open vs. Closed group
  - Facilitator’s role
  - How members typically interact
  - Topics covered during sessions
  - Common uncertainties expressed by others

- **Begin building group cohesion even before the first session!**
  - Encouraging (“try it out”)
  - Follow up in/out of group
THE VALUE OF SUPPORT GROUPS
LESSONS FROM THE FIELD

- Facilitator unique balance between being “relatable” but separate.
  - Verbalize (or infer) to group
- Email reminders (encourages group dialogue)
- Promote and encourage development of unique group identity (names, rituals, etc.)
- Early modeling of group communication. Taking a back seat later in the group.
- Try out innovative and creative platforms for group support...
“The experience of cancer is easier than you think...

...and harder than you could ever imagine.”