DEVELOPMENTAL AND PSYCHOLOGICAL STAGES AND DISRUPTIONS, ROLE OF THE FAMILY AND OWNERSHIP OF ONE’S HEALTH

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OBJECTIVES

• Life stage: Adolescence and young adulthood (AYA)

• Life disruptions in AYA with cancer

• Integration of a developmental understanding into AYA oncology care
Lisa’s Voice

“My friends from college and home and my family, this isn’t something they have experienced.

When you are a young adult, this is a turning point, when you are settling into a career, getting married, having a family. These are all issues that are normal and then you throw cancer into the mix, and you think what do I do now.

They are still getting on with their life. All my friends are buying cars, getting new jobs and buying houses and I am at home and my mom is making me toast. You start to feel a little helpless and other people don’t understand that.”
DEVELOPMENT MATTERS

Psychological Development

AYA

Family

Community

Impact of Cancer

Adapted from Carter and McGoldrick 2005
AYA DEVELOPMENT

- Impact of education, gender, trauma, race, ethnicity, sexual identity, temperament, family background, parenting style
  - Lack of studies on normative development for ethnically diverse populations
- Inconsistent across domains
- Mediated by emotional arousal

## Adolescent Development

<table>
<thead>
<tr>
<th>Cognitive</th>
<th>Emotional</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescence (15-18)</td>
<td>Abstract thinking, Reasoning ability, Moral reasoning (&quot;black or white&quot;)</td>
<td>Identity (sexual, ethnic, values, goals), Self-esteem, Emotion regulation, Sensation seeking, invincibility</td>
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# Early Young Adult Development

<table>
<thead>
<tr>
<th></th>
<th>Cognitive</th>
<th>Emotional</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early young adult (19-mid 20's)</td>
<td>Critical thinking Future consequences</td>
<td>Empathy Language for emotion</td>
<td>Mutual relationships Appreciate differences Modulation of risky behaviors Mentors sought Financial responsibility Spiritual questioning</td>
</tr>
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## Late Young Adult Development

<table>
<thead>
<tr>
<th></th>
<th>Cognitive</th>
<th>Emotional</th>
<th>Social</th>
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</thead>
<tbody>
<tr>
<td>Later young adult (mid 20 +)</td>
<td>Advanced complex thinking, decision making</td>
<td>Self evaluation Leadership capacity</td>
<td>Commitment to work, relationships, family</td>
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IT IS NORMAL....

- Be self-focused
- Disagree for the sake of disagreeing
- Jump to conclusions
- Find fault in the established position
- Take risks, challenge the rules and experiment
- Need control
- Seek peer role models
- Challenge professional boundaries
- Need identification of emotional responses
- Want to make a difference
- Be most concerned about their young children
- Feel responsible for work and family
OPPOSING DEMANDS

Demands of Illness
- Isolation
- Vulnerability
- Dependence
- Uncertainty
- Intimacy
- Invulnerability
- Independence
- Control

Demands of Life Cycle
# IMPACT OF CANCER FOR AYAS

<table>
<thead>
<tr>
<th>Negative impact</th>
<th>Positive impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Financial</td>
<td>• Relationships</td>
</tr>
<tr>
<td>• Body image</td>
<td>• Future goals/plans</td>
</tr>
<tr>
<td>• Control over life</td>
<td>• Health competence</td>
</tr>
<tr>
<td>• Work plans</td>
<td></td>
</tr>
<tr>
<td>• Relationship with partner</td>
<td></td>
</tr>
<tr>
<td>• Plans for having children</td>
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Bellizzi et al (2012) AYA HOPE study
### FAMILY CONTEXT

#### Development
- Tension between independence and dependence
- Oscillation: in and out of the family of origin
- Maturing relationships in family of origin
- Experimentation and definition of new chosen family

#### AYA Cancer
- Family members’ (role) perspectives contribute to distress
- Family support and cohesiveness important to adjustment
- Higher family functioning associated with less distress

“Don’t compare the beginning of your journey to the middle of someone else's and don’t feel like you are behind on anything or set back, because you haven’t taken a step back. You have moved onto a different path. Your life is different now.”
INTEGRATION OF DEVELOPMENTAL UNDERSTANDING INTO AYA ONCOLOGY CARE

- Pediatric v adult medical setting
- Illness phases
- Responsibility for health care
- Information needs
- Communication
AYA ONCOLOGY CARE

Pediatric

Adult

Hybrid

Ideal Treatment Setting
<table>
<thead>
<tr>
<th>DEVELOPMENTAL CONSIDERATIONS DURING THE ILLNESS CONTINUUM</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
</tr>
<tr>
<td>- Difficulty comprehending information and emotion</td>
</tr>
<tr>
<td>- Feeling impact on normality/anticipating disruptions</td>
</tr>
<tr>
<td>- Lacking skill to explain illness</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
</tr>
<tr>
<td>- Challenge to coping strategies</td>
</tr>
<tr>
<td>- Discomfort with dependence</td>
</tr>
<tr>
<td>- Challenge in balance of illness and life demands</td>
</tr>
<tr>
<td><strong>Post treatment</strong></td>
</tr>
<tr>
<td>- Less established life for reintegration</td>
</tr>
<tr>
<td>- Choices re-evaluated (peers, career, goals)</td>
</tr>
<tr>
<td>- Integration of uncertainty into future planning</td>
</tr>
<tr>
<td><strong>End of life</strong></td>
</tr>
<tr>
<td>- Identity formation in the face of death</td>
</tr>
<tr>
<td>- Meaning making with less skill/experience</td>
</tr>
<tr>
<td>- Unfulfilled legacy, overwhelming grief</td>
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DEVELOPMENTALLY INFORMED CARE: RESPONSIBILITY

**AYA**
- What kind of responsibility do I want?
- What responsibility do I give to others?
- What kind of privacy do I want?
- Who is in charge?

**Family**
- What is my responsibility?
- What support do they need to take responsibility?

**Provider**
- Assess and promote self efficacy
- Define who has responsibility for what
- Discuss responsibilities of defined family
- Define what is in the patient’s control
# Developmentally Informed Care: Information Needs

## AYA
- What do I need to know?
- How does it relate to me?
- How do I like to receive information?

## Family
- How is the information I need the same or different?

## Provider
- Understand cognitive style and capacity
- Present information in life context
- Provide places for reliable information
- Present information in useful format
- Offer information from peers
DEVELOPMENTALLY INFORMED CARE: COMMUNICATION

AYA
- How do I communicate what is most important to me?
- How do I want others to communicate with me?
- How can I advocate for myself?
- How do I communicate with others to help me make important decisions?

Family
- How do I communicate with the provider?
- Do I do this independent of the AYA?
- How do I communicate with my AYA?

Provider
- Discuss communication with parents/spouse
- Ask what is most important
- Ask about ways to communicate (provide examples)
- Propose shared decision making
- Balance support and with challenges
CONCLUSIONS

• Development and the experience of cancer are both stressors
• Development in ethnically diverse populations and implications for oncology care need further research
• Demands of illness and life cycle can be opposing
• Life disruptions can have both positive and negative impact
• Family cohesiveness can impact adjustment
• Challenges to providing appropriate treatment settings are ongoing
• Unique developmental needs during different illness phases
• Patient and family concerns often reflect developmental task and life stage
• Developmentally appropriate AYA oncology care matters
Franklin’s illness gave him the strength and courage he had not had before. He had to think out the fundamental's of living and learn the greatest of all lessons- infinite patience and never ending persistence.

Eleanor Roosevelt
FDR Memorial, Washington, DC
REFERENCES


• Arnett, J (2005) Emerging Adulthood: The Winding Road from Late Teens to Twenties, Oxford University Press.


• Zebrack, B (2011) Psychological, Social and Behavioral Issues for Young Adults with Cancer, Cancer, 5/15/2011, 2289-2294