None of this is “normal”: Psychological and behavioral challenges faced by adolescents/young adults in palliative care

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September 16, 2016
Disclosures

• I have no financial relationships to disclose
Overview

• Demographics of AYAs in US
• Life threatening illness and death in AYAs
• Developmental goals of AYAs
• Case examples and tips for providers
• Discussion
Defining adolescents/young adults (AYAs)

• What defines an AYA?
  – No clear consensus

• For the purposes of this talk, we will be focusing on patients ranging in age from about 12-29

• Discussing in the context of US culture

<table>
<thead>
<tr>
<th>Term</th>
<th>Age range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescence- WHO, 2016</td>
<td>12-20 years old</td>
</tr>
<tr>
<td>Emerging adulthood- Arnett, 2000</td>
<td>18-25 years old</td>
</tr>
<tr>
<td>Young adult- Adolescent and Young Adult Oncology Progress Review Group, 2008</td>
<td>15-39 years old</td>
</tr>
</tbody>
</table>
AYAs in the US

• According to the 2012 US census, there were:
  – 41,844,000 youth between the ages of 10 and 19
  – 42,771,000 youth between the ages of 20 and 29
  – Nearly 85 million AYAs in the US

• In total, AYAs comprise almost **30%** of the US population
Life threatening illness and death in AYAs

• Approximately 500,000 children and adolescents in the US are living with a life-threatening condition

• Common life-threatening conditions seen in AYAs in palliative care/hospice
  – Malignancies
  – Neuromuscular disorders (DMD, SMA, etc.)
  – Cystic fibrosis
  – Renal failure
  – Other neurological conditions (e.g. severe CP)

Himelstein, et al., 2004
Life threatening illness and death in AYAs

- In 2013, 52,455 children, adolescents, and young adults between the ages of 10 and 29 died of any cause
- Death during AYA is relatively rare in our society

<table>
<thead>
<tr>
<th>Age range</th>
<th>Top 3 causes of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-14 years of age (both sexes, all races)</td>
<td>1. Accident</td>
</tr>
<tr>
<td></td>
<td>2. Cancer</td>
</tr>
<tr>
<td></td>
<td>3. Suicide</td>
</tr>
<tr>
<td>15-34 years of age (both sexes, all races)</td>
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<tr>
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<td>2. Suicide</td>
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<td></td>
<td>3. Homicide</td>
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Life threatening illness and death in AYAs

• In percentages, that means…
  – 0.6% of AYAs in the US are living with a life-threatening illness
  – 0.06% of AYAs in the US die of any cause annually

• Although chronic illness is relatively common, life threatening illness and death is rare

• Typically the healthiest time of life
Adolescence

• From Latin adolescere- “to grow up”
• The transitional developmental period marked by the onset of puberty and ending with the “achievement” of adulthood
• Cognitively similar to adults, but emotionally and socially distinct
  – Problems with judgement
Young Adulthood

• Typically starts at the end of adolescence and can range anywhere from the ages of 18 to 40

• Usually characterized by achievements of various developmental milestones
  – Marriage/partnering
  – Career establishment
  – Having children
Developmental goals of AYAs

• Erik Erikson
  – Identity vs. Role confusion (adolescence)
    • Fidelity
    • Separation from family
  – Intimacy vs. Isolation (young adulthood)
    • Love
    • Exploration of relationships and sexuality

Erikson, 1967
# Realities for AYAs with life-threatening conditions

<table>
<thead>
<tr>
<th>Developmental Goal</th>
<th>Interruption by life-threatening illness</th>
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<tbody>
<tr>
<td>Creating unique identity</td>
<td>• Interruption of “normal” daily functioning and activities</td>
</tr>
<tr>
<td></td>
<td>• Inability to engage in activities associated with self-concept and identity (e.g. sports, hobbies)</td>
</tr>
<tr>
<td></td>
<td>• Changes in appearance, resulting in lower-self esteem</td>
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# Realities for AYAs with life-threatening conditions

<table>
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<tr>
<th>Developmental Goal</th>
<th>Interruption by life-threatening illness</th>
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</table>
| Increasing autonomy | • Increased, rather than decreased reliance on parents/family for practical and emotional support  
• Inability to move out, become independent |
## Realities for AYAs with life-threatening conditions

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<tr>
<th>Developmental Goal</th>
<th>Interruption by life-threatening illness</th>
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<tbody>
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<td>Establishing intimate relationships</td>
<td>• Unable to keep up with “typical” social activities</td>
</tr>
<tr>
<td></td>
<td>• Difficult to relate to peers who are “starting” their lives while yours is potentially ending</td>
</tr>
<tr>
<td></td>
<td>• Strain on existing romantic relationships, hard to establish new ones</td>
</tr>
</tbody>
</table>
Cultural implications

- What are the representations of palliation/death for AYAs in our culture?
Psychological/Behavioral challenges faced by AYAs with life-threatening illness

- Three case examples highlighting common psychological/behavioral challenges
- Tips for how to address AYAs in these situations
- Tips for when to refer to a mental health professional
- Note: names and some details have been changed to protect privacy
Case example 1: Non-adherence

- Scott, 23-year-old male with end-stage CF
  - Multiple pulmonary and endocrine complications
  - Conflicted relationship with family and CF team
  - Over the course of several years, refusing to engage in treatments or meaningful conversation with CF team
  - Psychology consulted while Scott was inpatient to assess possible causes for his non-adherence
Case example 1: Non-adherence

- Scott was demonstrating symptoms of severe depression
  - Withdrawal
  - Excessive sleeping (in excess of what would be medically expected)
  - Not eating (in excess of what would be medically expected)
  - Not engaging in basic self-care activities
Case example 1: Non-adherence

- Scott was helped to identify his values, including spending more time with his sister and friends.
- Eventually this provider was able to challenge Scott’s behavior in the context of his values.
- Scott’s adherence improved, and he received a lung transplant.
- However, his current adherence is unclear.
Non-adherence

- Extremely common in AYAs with chronic illness
- Can be particularly confusing for palliative care providers when non-adherent to treatments that alleviate symptoms (e.g. pain medication)

Rapoff, 2010
Non-adherence

• Multifactorial in nature
  – Cognitive factors
    • Understanding of disease/treatment, ability to adhere
  – Developmental factors
    • Harder time imagining future implications for their decisions
  – Psychological factors
    • Mental health, motivation
  – Treatment factors
    • Side effects
  – Family/Environment factors
    • Access to care, support network

Rapoff, 2010; Graves et al., 2010
Non-adherence: Provider tips

• Be as non-judgmental as possible
• Try to take the patient’s perspective
• Express your concern in an open, honest way
• Helpful questions to understand the patient’s perspective:
  • What is most important to you in your life right now?
  • How do your treatments fit into your day?
  • What parts of treatment are helpful? What aspects are less helpful?
  • What would you change about your treatment regimen?
  • What is the easiest treatment to get done? What is the hardest?
  • How can we help you get the most out of your treatments?
Non-adherence: When to refer

• If you suspect the non-adherence is related to a mental health problem, including depression or anxiety
• If you suspect the non-adherence may be related to a desire to hasten death
• If the non-adherence is becoming a source of distress for the patient or their family
• If the non-adherence is having a significant impact on the patient’s health and functioning
Case example 2: Social withdrawal

- Matt, 18-year-old male with metastatic osteosarcoma
  - Advanced disease in his lungs
  - Still undergoing intensive treatment in an attempt to slow disease progression
  - Difficult family situation
Case example 2: Social withdrawal

- Matt became more withdrawn from friends as his disease progressed
- Eventually told one best friend that his treatments weren’t working
- His team became very concerned about Matt’s disengagement from “typical” activities
- At the time of his death, his friends were reportedly very surprised and had not realized the severity of his illness
Social withdrawal

• Some level of social withdrawal is common and expected in AYAs in palliative care, especially in AYAs approaching death
  – Difficulty relating to peers
  – Desire to protect peers
  – Dissolution of relationships in advance of death

• Life-threatening illness is in direct contrast to the more typical adolescent reality of preparing for adult life (e.g. the “beginning” of “real life”)
Social withdrawal: Tips for providers

• Get to know the patient as an individual
• Talk to the patient about their support network
• Normalize social challenges for the patient
• Helpful questions for talking to patients about social withdrawal:
  – Tell me about your friends. Do you have a best friend?
  – Who is in your support network?
  – Do you feel comfortable talking about your condition with any friends?
  – Tell me about what you would like to do with your friends, if you were feeling up to it. Is there a way that we can help you do these things?
Social withdrawal: When to refer

• If you suspect social withdrawal is a symptom of more significant depression
• If the patient lacks other sources of support (e.g. lack of family support)
• If the patient or family seems distressed by the social withdrawal
Case example 3: Risk-taking behavior

• Cathy, 19-year-old female with metastatic osteosarcoma
  – Long, complex psychological/psychiatric history
  – Completed initial treatment for osteosarcoma in June 2015
  – Had a relapse to her lung in April 2016
  – Elected to not receive additional chemotherapy
Case example 3: Risk-taking behavior

• Leading up to her relapse, Cathy was engaging in a number of risk-taking behaviors, including multi-substance use and unsafe sexual encounters.

• This provider followed Cathy through her initial treatment course and reconnected with her following her first lung surgery.
Case example 3: Risk-taking behavior

- Cathy required intensive therapy (at least weekly) and medication management to help her improve her behavior.
- A partial hospitalization program was recommended.
- Cathy remains in intensive psychological treatment.
Risk-taking behavior

• Could include:
  – Unsafe sexual encounters
  – Drug use (including inappropriate use of prescribed drugs)
  – High-risk novel situations

• Limited research exists on risk-taking behavior in this population

• Risk-taking behavior is somewhat more common in AYAs with chronic illness

Valencia & Cromer, 2000
Suris et al. 2008
Risk-taking behavior

• Developmentally, AYAs may not be able to process the possible negative outcomes of their behavior
  – “Adolescent egocentrism”
  – Boundary testing and risk-taking part of adolescent development

• The addition of a life-threatening illness may heighten this sense of invulnerability, or a “whatever” attitude about risky behaviors

• Highly correlated with depression

Bender, 2006
Risk-taking behavior: Tips for providers

- Having a well-established relationship with the patient is extremely helpful
- Be as non-judgmental as possible
- Express your concern in an authentic way
- Helpful questions:
  - Are you using drugs or alcohol right now? How about in the past? What types?
  - When are you likely to use drugs or alcohol?
  - Are you having any sexual relationships right now (hooking up/talking to people)?
  - Would you feel comfortable talking about [alternatives to drug use, drug treatment, safe sex practices] with me? If not, is there someone else on our team who you would feel comfortable talking to?
Risk-taking behavior: When to refer

• In general, err on the side of referring out
• Consider referrals to the appropriate mental health specialist
  – Substance abuse expert
  – Therapist with adolescent experience
  – Therapist with experience in chronic illness/palliative care
Take home points

• Life threatening illness/death is not “normal” for AYAs in the US
• All aspects of typical AYA development are interrupted by a life-threatening illness
Take home points

• Having an open, authentic, and non-judgmental relationship with the AYA patient is crucial in trying to manage psychological challenges

• Common psychological and behavioral problems can include non-adherence, social withdrawal, and risk-taking behaviors

• Mental healthcare providers are excellent resources to help manage these issues
Resources

• Reflection for providers
• To find mental health providers:
  – [www.psychologytoday.com](http://www.psychologytoday.com) – Use the “Find a Therapist” tool
  – Contact the patient’s insurance provider
  – Discuss resources available through the patient’s treating hospital/palliative care program
Questions and Discussion

- My contact information:
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  - Phone: 312-942-8597

THANK YOU
References


