

SPIRITUALITY OF  
ADOLESCENTS & YOUNG  
ADULTS IN  
TRANSPLANTATION

February 14, 2015 Rev. Geila Rajae, MDiv, BCC

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What's a Chaplain: About the Role

- Existential, religious and spiritual
- Spiritual assessment
  - ▣ Including resource assessment
- Exploration of religious/spiritual/existential distress
- Board-Certified, professional

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The image shows two promotional materials. On the left is the cover of the book 'The Fault in Our Stars' by John Green, featuring a blue background with a black cloud containing the title and a white cloud containing the author's name. On the right is a promotional image for the TV show 'Chasing Life' on ABC Family, showing a car on a road with the text 'Chasing Life' and 'Cancer sucks.' and the ABC Family logo.

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## Session Goals

- Recognize the importance of acknowledging and supporting the spirituality of adolescents and young adults (AYA) while undergoing stem-cell/bone marrow transplant.
- Learn direct and indirect spiritual care interventions for the AYA population.

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## Knowledge Gaps

- AYA oncology research is *limited*
  - ▣ Even more limited in regards to spirituality
- Available research comes from the context of a single Midwestern pediatric hospital

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## Getting on the Same Page

- Religious/Religiosity
- Spiritual/Spirituality
- Adolescent & young adults

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### What is considered the “single greatest psychological stressor” for AYA’s?

1. Misdiagnosis and/or delayed diagnosis
2. Financial issues
3. Interpersonal relationships
4. Existential concerns
5. Being dependent versus independent

Results

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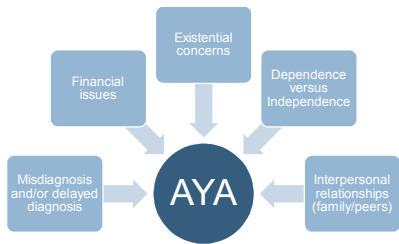
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### AYA Basics



(Santacroce & Zebrack, 2010)

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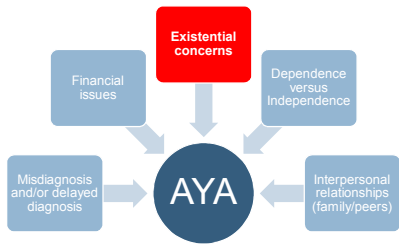
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### AYA Basics



(Santacroce & Zebrack, 2010)

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## Spirituality & Health

- Unmet spiritual needs
  - ▣ Increase rates of depression (Pearce et al., 2012), (Evan & Zeitler, 2006)
- Spiritual distress in older adults
  - ▣ Poor health related outcomes (Pargament, Koenig, Tarakeshwar, & Hahn, 2001)
- When spiritual needs are met
  - ▣ Higher rates of patient satisfaction with medical care (Pearce et al., 2012), (Marin et al., 2015)
  - ▣ Growing evidence of positive health outcomes (Cotton, Grosseohme, & Tsvat, 2007), (Clark, Drain, & Malone, 2003)

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## What does spiritual distress look like?

- Grief/Grieving
- Concerns about death and afterlife
- Conflicted/Challenged belief system
- Loss of faith
- Concerns with meaning/purpose of life
- Concerns about relationship with deity/divine
- Isolation from religious community
- Guilt
- Hopelessness
- Conflict between religious beliefs and recommended treatment
- Ritual needs (sacramental, etc.) (NCCN, 2014)

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## Which of the following would be considered a barrier for receiving spiritual support?

1. Embarrassment/Stigma from needing support
2. Staff uncertainty about spiritual care issues
3. The spirituality of AYA's
4. Lack of awareness of spiritual care needs
5. All of the above

Results

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### Barriers for Receiving Spiritual Support

- Changing Dynamics of Spirituality in AYA populations
- Feelings of Stigma/Embarrassment (Gardner et al., 2014)
- Uncertainty of Medical Staff (Balboni et al., 2012), (Clark, Drain, & Malone, 2003)
  - ▣ Spiritual Care/Chaplaincy services
  - ▣ Use of self
  - ▣ Discomfort with spirituality/religion
- Minimization/Lack of Awareness of Spiritual Care Needs (NCCN, 2015)

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### Risks of Deferring Spiritual Care

Spiritual Support from Religious Community

- More aggressive end-of-life care
- More likely to die in the ICU
- Less likely to be referred to Hospice

(Balboni et al., 2013)

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### Risks of Deferring Spiritual Care

Spiritual Support from Medical Team

- Higher rates of hospice use
- Fewer aggressive interventions
- Fewer ICU deaths

(Balboni et al., 2013)

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### AYA Use of Spirituality/Religion

- Small sample size (n=12)
- Spirituality/Religion **is a supportive resource**
  - ▣ Under recognized by medical staff?
- Using R/S to interpret and understand diagnosis and treatment
- Spiritual distress indicators
  - ▣ Fear of hell, pain and death
- Positive religious coping
- AYA's open to discussing spirituality/religion

(Ragsdale, Hegner, Mueller, & Davies, 2014)

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### Interventions for Care

A Chaplain's Perspective

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### Case Study 1

- 24yo F, ALL, HSCT Unrelated Donor, no S/R tradition
- Relapsed 4-5 months s/p HSCT
- Palliative Consult
  - ▣ Code status & awareness of diagnosis and disease process
- Chaplain Intervention
  - ▣ Rapport
  - ▣ Use of metaphors
  - ▣ Re-framing of hopes, values and goals
- Outcome
  - ▣ Lived desired hope
  - ▣ Enrolled in hospice within two weeks of death without re-hospitalization

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## Case Study 2

- 32yo M, relapsed AML, Cord HSCT, Christian (Evangelical), Latino
- Chemotherapy regimen difficult after diagnosis
  - ▣ Spiritual distress, psychosocial and family concerns
- Chaplain Intervention
  - ▣ Clarified hopes, values & goals
  - ▣ Provided religious resources (prayer, local connections)
- Outcome
  - ▣ Lived into values (quality of life)
  - ▣ Improved communication with family, team
  - ▣ Sense of support

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## Case Study 3

- 22yo F, AML, Cord HSCT, Chinese Immigrant, no social support, no S/R tradition
  - ▣ Expressed spiritual distress (anger and punishment)
- Chaplain Intervention
  - ▣ Explored feelings of distress
  - ▣ Affirmed resources for coping
- Outcome
  - ▣ Spiritual distress mitigated
  - ▣ Sense of connection and support

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## Case Study 4\*

- 24yo M, glioblastoma, suicidal ideation, Christian, Mainline Protestant
  - ▣ Expressed spiritual distress (abandonment and anger at God)
- Chaplain Intervention
  - ▣ Provided outlet to express spiritual distress
- Outcome
  - ▣ Following intervention, no spiritual distress

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## Things to Remember

- Relationships Matter
- Provide opportunities for autonomy
- Re-Frame actions in context of individuals values/goals
- Religious/Spiritual requests
  - ▣ Wonderment & curiosity
  - ▣ Prayer, reading a sacred text, or participating in rituals
- Utilize professional chaplains for existential, spiritual and religious concerns
  - ▣ Spiritual distress

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## Final Thought

The knowledge gaps between spirituality and AYA's receiving oncology care is great and we need more investigation to determine best practices for support and intervention.

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