SPIRITUALITY OF ADOLESCENTS & YOUNG ADULTS IN TRANSPLANTATION

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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

THE FAULT IN OUR STARS
John Green

Chasing Life
Conor Ashlin
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.

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

Getting on the Same Page

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

AYA Basics

(Santacroce & Zebrack, 2010)
Spirituality & Health

- Unmet spiritual needs
  - Increase rates of depression (Pearce et al., 2012), (Evan & Zeltzer, 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), (Mann et al., 2015)
  - Growing evidence of positive health outcomes (Cotton, Grossoehme, & Tsvat, 2007), (Clark, Drain, & Malone, 2003)

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)

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
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)

Risks of Deferring Spiritual Care

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

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

(Balboni et al., 2013)
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)

Interventions for Care

A Chaplain’s Perspective

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
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

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

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
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

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.

References