Working With Young Adult Patients in Hospice

Acknowledgements

Objectives

- Recognize the differing needs and concerns of patients who are 15-40 compared to older adults
- Discuss and illustrate communication techniques that will elicit those needs and concerns
- Discuss flexibility required and approaches to meeting their needs

Special thanks to Drs. Donna Zhukovsky and Carla Cheatham for generously sharing their knowledge and resources for the preparation of this talk.

Marcia Levetown, MD FAAHPM
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Just Imagine Being 15

- What were your interests and concerns?
- Aspirations?
- Hopes?
- Fears?
- How did you feel about your parents, other adults?

What Was Happening When You Were 20?

25-30?
Paul Kalanithi, MD
36 yo NS Chief Resident, Stanford
Dx: Metastatic NSCLC, EGFR+
Lung CA during final yr of training
No life insurance
First child born after prolonged hospzn for relapse

Verb conjugation became muddled. Which was correct? “I am a neurosurgeon,” “I was a neurosurgeon,” “I had been a neurosurgeon before and will be again”? What tense was I living in? Had I proceeded beyond the present tense and into the past perfect? The future tense seemed vacant and, on others’ lips, jarring. I recently celebrated my 15th college reunion; it seemed rude to respond to parting promises from old friends, “We’ll see you at the 25th!” with “Probably not!”

Clearly We Are Not in Kansas Anymore!
Adolescents and Young Adults– their needs are different
What Are Your Experiences Working with AYA Patients?

What went well?
What went badly?


A roadmap to psychosocial and behavioral assessment

- Individual characteristics
- Individual behaviors
- Individual existential/spiritual issues
- Relationships
- Socioeconomic issues

Psychosocial Interventions and Support: Peer Support

- Build interpersonal and problem-solving skills, sharing of information
- Create sense of community
- Address areas of concern:
  - uncertainty about the future
  - establishing autonomy while dealing with forced dependence
  - social exclusion, body image, sex and sexuality, infertility

Zebrack B and Isaacson S. J Clin Oncol 2012; 30:1221-1226
Psychosocial Interventions and Support: Technology-based Interventions

- Majority of AYA express need/desire for more age-appropriate information
- Use of electronic technology associated with ↑ self-efficacy, knowledge and treatment adherence
- AYA need help evaluating vast amount of information available online

Zebrack B and Isaacson S. J Clin Oncol 2012; 30:1221-1226

Psychosocial Interventions and Support: Skill-based Interventions

- Problem-solving and cognitive-behavioral therapies (CBT) are evidence-based
- Teach new skills or new ways of thinking → new ways of acting
- Evidence suggests that AYA perceptions of how illness has affected their lives are associated with distress and QOL outcomes

Zebrack B and Isaacson S. J Clin Oncol 2012; 30:1221-1226

Spiritual Tasks of AYAs

(Lerner, 2002; Erikson & Erikson 1997; Fowler & Dell, 2006)

Adolescence: Identity
- Concrete to analytical
- Identity achievement, search for other ideologies
- Centration, imaginary audience, personal fable
  - focus of attention, misunderstood, isolated

Emerging Adulthood: Intimacy
- Reevaluation of ideas/values to form life-long intimacy commitments to self, others, and groups
**Spiritual Task of “Emerging Adults” (17-30)**

- Reconstructing reality and Capacity for “other”
- Faith matures in response to doubt
- Belief—away from dogma to “what one holds dear”
- Becoming self—journey (to autonomy) and to new capacity for connection (inter-dependence)

  Daloz Parks, 2000

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**Unique Needs — Spiritual**

- Illness may challenge future, identity, & beliefs
- May or may not accept family faith/beliefs
- Tension b/t support need & honest doubts
- Spiritual questions often aren’t verbalized
  - Need to make meaning, leave a mark, continuity
- Reinforce sense of worth and meaning

  (Thornes, 2001)

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**Unique Needs — Sexual**

- Less access to normal AYA discussions
- Less privacy for exploration
- Redefine a “new normal” for sexual identity and behavior
- When to disclose to: peers, new acquaintances, employers, dating partners
  (Zebrack, 2011)
- Space to connect with healthy peers and other AYA patients and survivors
  (Zebrack, et. Al, 2006)
- Need for safe space to discuss “taboo” topics
It is “absolutely fair game” to ask young adults about lifestyle issues. “The key is to be open and create an atmosphere that encourages young people to talk about topics such as sex, drugs, and alcohol use, how cancer and its treatment are affecting them medically and psychologically, or whatever is potentially a barrier to them getting the best cancer treatment they need.”

(Dr. Hayes-Lattin, dx’d w/ testicular cancer during residency, at 28. He later completed an oncology-hematology fellowship) (Bath, 2012)

Advance Care Planning with AYA Patients: Voicing My Choices
Weiner and Lyons

- www.agingwithdignity.org/forms/voicingmychoices.pdf
- How I wish to be comforted
- How I wish to be supported
- Who should make decisions if I cannot
- Treatments I do/do not accept
- What I want family/friends to know about me
- My spiritual thoughts, wishes
- How I wish to be remembered
- How I want to share my belongings
- A letter

References

- Zebrack B, Isaacson S. Psychosocial Care of Adolescent and Young Adult Patients with Cancer and Survivors. J Clin Oncol, 30(11):1221-1226.
References


References, con’t

Butow, P., Palmer, S., Pai, A., Goodenough, B., Luckett, T., & King, M. Review of Adherence-Related Issues in Adolescents and Young Adults With Cancer JCO November 10, 2010 vol. 28 no. 32 4800-4809

Cooke, L., Chung, C., & Grant, M., Psychosocial Care for Adolescent and Young Adult Hematopoietic Cell Transplant Patients J Psychosoc Oncol. 2011; 29(4): 394-414.


References, con’t


References, con’t


Advance Care Planning Refs


Zadeh S, Pao M, Wiener L. Opening end-of-life discussion: How to introduce Voicing My Choices™, an advance care planning guide for adolescents and young adults. Palliative and Supportive Care. 2014 DOI: 10.101
### AYA CA Specific Info, Support

Zebrack B and Isaacson S. J Clin Oncol 2012; 30:1221-1226

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<thead>
<tr>
<th>Category</th>
<th>Resource</th>
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<td>American Society of Clinical Oncology: <a href="http://www.cancer.net/patient/Coping/Agesspecificinformation/CancerinYoungAdults">http://www.cancer.net/patient/Coping/Agesspecificinformation/CancerinYoungAdults</a></td>
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<td>Ullman Cancer Fund for Young Adults: [<a href="http://www.cancer.org/about">http://www.cancer.org/about</a> cancer/who suffer from cancer/donate to cancer fight/ullman cancer fund/ullman cancer fund medical research](<a href="http://www.cancer.org/about">http://www.cancer.org/about</a> cancer/who suffer from cancer/donate to cancer fight/ullman cancer fund/ullman cancer fund medical research)</td>
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<td>Livestrong: <a href="http://www.livestrong.org">http://www.livestrong.org</a></td>
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<td>Physical Support and key to day-to-day living</td>
<td>MyEatingRite/Cancer Foundation: <a href="http://myeatin.org">http://myeatin.org</a></td>
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<td>with cancer</td>
<td>Disability Consultant at Northeastern University: <a href="http://www.disability.org">http://www.disability.org</a></td>
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<td>Work, employment, and legal support</td>
<td>CancerCare.net: <a href="http://www.cancerandcareers.org/en">http://www.cancerandcareers.org/en</a></td>
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<td>Cancer Legal Resource: <a href="http://www.disabilityrighslegalcenter.org/about/cancerlegalresource.cfm">http://www.disabilityrighslegalcenter.org/about/cancerlegalresource.cfm</a></td>
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<td>Financial support services</td>
<td>Contact your state’s vocational rehabilitation office</td>
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<tr>
<td>Social networking and peer support</td>
<td>I’m Too Young for this Cancer Foundation: <a href="http://stupidcancer.com">http://stupidcancer.com</a></td>
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<td>Imerman’s Angels (one-to-one cancer support connecting patients, survivors, and caregivers): <a href="http://www.imermanangels.org">http://www.imermanangels.org</a></td>
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<td>mA$$kickers: <a href="http://masskickers.org">http://masskickers.org</a></td>
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<td>Planet Cancer: <a href="http://www.planetcancer.org">http://www.planetcancer.org</a></td>
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<td>Camps, retreats, and adventure programs</td>
<td>CaringBridge: <a href="http://caringbridge.org/profile/mycaringbridge">http://caringbridge.org/profile/mycaringbridge</a></td>
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### Resources for AYA


- **Resources for Clinicians**
  - ACT Care Pathway Series: The Transition Care Pathway. [www.act.org.uk/carepathways](http://www.act.org.uk/carepathways)
  - ACT Care Pathway Series: Let’s talk about sex: let’s talk about you and me. [www.act.org.uk/carepathways](http://www.act.org.uk/carepathways)

- **Resources for AYA**
    - iwannaknow.org, scarleteen.com, teenwire.com, among others, are intended to provide information about a range of contraceptive and other sexual health issues, and many also allow adolescents to (anonymously) submit questions and participate in discussions.
    - Excellent review of next steps in the AYA field: Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer. Adolescent and Young Adult Oncology Progress Review Group. National Cancer Institute, LIVESTRONG Young Adult Alliance, 2006. Available at [http://planning.cancer.gov](http://planning.cancer.gov).
Suggested Movies

- The Fault in Our Stars
- Rory O'Shea was Here