OMG RUS (Oh my God, are you serious?): Talking to Teens About Dying
Jennifer S. Linebarger, MD, MPH, FAAP
Linda White, RN, MSN

Objectives:
1.) Translate developmental tasks of autonomy, identity, cognition, and spirituality into a thoughtful approach toward adolescents who are living with a terminal illness.
2.) Learn strategies to help an adolescent feel comfortable opening up about their thoughts on death and dying.
3.) Become familiar with the current tools available for exploring an adolescent’s wishes at the end-of-life.

### Developmental Tasks of Adolescence

<table>
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<tr>
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<th>Physical (Tanner)</th>
<th>Autonomy (Gilligan)</th>
<th>Identity (Erikson)</th>
<th>Cognition (Piaget)</th>
<th>Spirituality (Fowler; Puchalski)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early (10-14 years)</td>
<td>Onset and tempo vary</td>
<td>Ambivalence “Dependence”</td>
<td>Am I normal?</td>
<td>Concrete operational</td>
<td>Mythical/Literal; “Extrinsic religiosity”</td>
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<tr>
<td>Middle (15-16 years)</td>
<td>Females before males</td>
<td>Limit-testing and risk-taking “Independence”</td>
<td>Who am I?</td>
<td>Transitional • Personal fable • Imaginary audience</td>
<td>Synthetic /Conventional; Transitional</td>
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<tr>
<td>Late (17-21 years)</td>
<td>Adult appearance</td>
<td>Ambivalence “Interdependence”</td>
<td>Who am I in relation to others?</td>
<td>Formal operational (75%)</td>
<td>“Intrinsic religiosity”</td>
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</tbody>
</table>

* Ages based on classifications from the World Health Organization

### Translation of the Developmental Tasks of Adolescence

**Physical development**
- Body alterations and body image
- Sexual health and function
- Brain development (pruning and increased efficiency of gray matter)

Adolescents with chronic illness may experience delays in physical and sexual development. There may also be changes in body shape and function because of the illness or treatments for the illness (hair loss, increased acne, obesity or weight loss, muscle weakness, disability/deformations, fatigue).
**Autonomy**
- Legal rights of minors and ethical responsibilities of health care providers
- Confidentiality
- Limit-testing and treatment non-adherence

Often, adolescents with a life-threatening illness have increased dependence on their family when compared to their peers. Some will exert themselves to regain a sense control (often through treatment non-adherence), while others with long-standing illness may have a degree of “learned passivity.”

In addition, health care providers can be authoritarian. Some providers find it best to take a more authoritative approach, determining what is essential for health and cannot be compromised and allow negotiation for things that are not essential.

**Identity**
- Deeper understanding of self
- Experimentation / Trials (substances, eating habits, sexuality)

Adolescents with life-threatening illness may not have access to the same peer groups and activities as they might otherwise (especially if they are frequently in the hospital or home-bound). The social isolation and greater dependence on others makes it difficult for such adolescents to establish functional roles in life. In addition, there are some adolescents who become defined by their illness, and their identity shifts to that of a “patient” rather than of a “teen who has an illness/condition.”

**Cognition**
- Focus on the “now”
- Provide information of personal relevance
- Reassure about normalcy

Even amongst healthy adolescents and adults, the capability for abstract thinking is strongly impacted by health status. And for the most-ill of the adolescents, their future is determined by limitations rather than possibilities. By about the age of 9 to 10 years, an “adult” understanding of death is achieved. Death is defined by irreversibility, nonfunctionality, universality, and causality. With the development of abstract thinking, adolescents question the existential implications of death. Teens may attempt to confront or defy death as if it were an adversary.

**Spirituality**
- Establishing “personal faith” (conventional ways of finding meaning with a lot of questioning of parents and teachers)
- “Foxhole faith” suggests reverting back to conventional beliefs in a time of crisis
Finding out what an adolescent has learned about faith and what beliefs they are developing can help identify possible conflicts and spiritual distress.

**Strategies for Engagement**
- Start with a conversation; listen
  - Attitude of respect, candor, and collaboration
  - Have them tell you about their “usual” day (and be interested)
  - Find what makes them ‘light up’
    - What is one thing you wish you could be doing right now?
    - What is the first thing you will do when you get home?
    - What have you accomplished in your life?
  - Find out what is worrying them
    - Is there anything that is worrying you or making you feel afraid?
    - Is there anything about how you’re feeling that is making you feel worried or afraid?

- Build trust: be upfront about confidentiality as well as the importance of the health care team sharing information with each other
- Empower all members of the team (including ancillary staff)
- Play, create, explore --- oftentimes conversation comes out through activities

Adolescents often continue to speak and plan as if there is no understanding of the reality of prognosis ("denial" of impending death), and having survival goals is common – wish trips, graduation, school dances, or other social functions. Providers should be aware, and understanding, of this psychological dynamic.

**Decision-Making**
Decision-making at the end of life can be more complicated for adolescents than for adults because of issues with competency and capacity.

Competency is the ability to choose for oneself. The concept is based on the ethical value of autonomy, and is a legal term. In the U.S., competency begins at the age of majority (18 years), and implies the ability to consent (to make independent personal, medical, and financial decisions).

Capacity is sometime referred to as “functional competency.” A person with capacity has the skills to make an informed decision. As such, it is not necessarily related to age, and can be impacted by developmental stage, and conditioning and experience.

Capacity is considered to be “task related.” When there is a greater risk, a greater assessment of capacity is needed. Capacity is impacted by disease-state (it can be partially or temporarily impaired – by pain, medications, neurologic injury, or psychiatric illness) and cultural influences.

The elements required for capacity include:
- Patient has adequate awareness (understanding and appreciation) of disease and treatment options
- Patient uses reasoning to make a choice
- Patient makes a choice and communicates wishes
- Choice is consistent with patient’s goals and values

Capacity does not mean agreeing with the medical team.

The adolescent cannot participate in health care decisions if they are not told of their disease state and prognosis.

**Communication Tools**
- Adolescents prefer “straight talk” about diagnosis, treatment, and prognosis.
- They generally seek autonomy *without* the exclusion of parents. Many parents prefer to talk with the provider first.
- Hold discussions during a stable period.
  - Anticipate need for decisions and include them in advance care plan
- My Wishes®; Five Wishes®; Voicing my Choices®
- Adapted versions of the Seattle Decision-Making Tool

Further reading:
Freyer DR. Care of the dying adolescent: Special considerations. *Pediatrics* 2004; 113:381-388
Children’s Project on Palliative/Hospice Services (ChiPPS) Pediatric Palliative Care Newsletter — Issue #5; September 2006 – “Teens who are coping with a life-threatening illness”

And, when it’s the death of an adolescent’s parent:
Christ GH, Siegel K, Christ AE. Adolescent grief: ‘It never really hit me... until it actually happened’. *JAMA* 2002; 288:1269-1278