“An Introduction to Pediatric Palliative Care and the Decision Making Tool: An Ethical Framework”

Dr. Ross Hays
June 2nd, 2016
Webinar Objectives

• Understand the differences between palliative and hospice care
• Appreciate the differences between adult and pediatric palliative care
• Obtain strategies to approach end-of-life decision making
• Identify the timeline for onset of grief and bereavement
• Articulate the five domains of pediatric palliative care
Decision-Making Communication Tool

- Medical Indications
- Quality of Life
- Contextual Issues
- Discussion
- Plan
- Patient/Family Preferences
The DMT

The **Decision-Making Communication Tool (DMT)*** is an excellent format to follow in planning health care for any child.

**DMT Care Planning**
- Is ethics based
- Integrates the problem list with other important decision-making elements of a family’s life
- Establishes a balanced partnership in decision making between the family and the health care team
- Is updated at regular intervals as well as in response to a new problem.
- Creates a comprehensive action plan, signed by the physician.

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*Developed by the Pediatric Palliative Care Consulting Service at Children’s Hospital and Regional Medical Center, Seattle, and adapted from an ethical decision-making model developed by Albert Jonsen, Mark Siegler and William Winslade, in their book CLINICAL ETHICS (McGraw-Hill, 2002, fifth edition).*
Research Supports the Model

- Improvements in Quality of Life (PedsQL4.0)
- Statistically significant improvements in the emotional well-being measure
Medical Indications

Diagnosis: Duchenne Muscular Dystrophy
Treatment Option: Spinal Instrumentation Surgery
Benefit: Reduce the progression of scoliosis, reduction of future discomfort, respiratory complications
Risk: perioperative pain, loss of flexibility, inpatient care, related mortality risk, need for assisted ventilation

Patient Preferences

Both Jack and his parents are ambivalent about the surgery

Jack doesn't want surgery, but he doesn't want to be uncomfortable in the future

Jack doesn't want to live on a ventilator

Quality of Life

Being at school
Being with his dad
Katie Perry
God
Zelda – his dog
his mom
Jonathan - his brother who died
His picture of Katie Parry
WWF
Being with all his friends at school
Facebook
All his video games

Contextual

• Jack is 3rd of 5 children
• He lives in Wenatchee
• His mom is a former ICU nurse
• Jack is active in his church
• Excellent community support
• Enjoy good family support
• Jack’s brother died during spinal instrumentation surgery 3 years ago
Quality of Life
### Medical Indications

**Diagnosis:** Duchenne Muscular Dystrophy one year later  
**Treatment Option:** Spinal Instrumentation Surgery  
**Benefit:** Reduce the progression of scoliosis, reduction of future discomfort, respiratory complications  
**Risk:** perioperative pain, loss of flexibility, inpatient care, related mortality risk, need for assisted ventilation

### Patient Preferences

Both Jack and his parents are ambivalent about the Surgery  
Jack doesn’t want surgery, but he is clearly more uncomfortable  
Jack doesn’t want to live on a Ventilator  
Jack would prefer to not make this Decision  
His parents don’t want to make this Decision either

### Quality of Life

*Being at Home*  
He can no longer attend school for a full day  
He has more pain but doesn’t talk about it  
He dreams about Jonathan - his brother who died  
He spends more time in bed and less being with all his friends  
His main connection to them is Facebook

### Contextual

Jack is 3rd of 5 children  
He lives in Wenatchee  
His mom is a former ICU nurse  
Jack is active in his church  
Excellent community support  
Enjoys good family support  
Jack’s brother died during spinal instrumentation surgery 3 years ago

### Identify Many QOL Issues

DMT # 2
<table>
<thead>
<tr>
<th>Medical Indications</th>
<th>Patient Preferences</th>
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</thead>
<tbody>
<tr>
<td><strong>Diagnosis:</strong> Duchenne Muscular Dystrophy six months later&lt;br&gt;<strong>Treatment Option:</strong> Spinal Instrumentation Surgery&lt;br&gt;<strong>Benefit:</strong> and <strong>Risk:</strong>&lt;br&gt;Jack’s forced vital capacity is less than 28%. If he waits much longer he May not be a candidate for surgery. Regardless the post-op risk of remaining on the ventilator is greater</td>
<td>Both Jack and his parents are ambivalent about the surgery&lt;br&gt;Jack doesn’t want surgery, but he is clearly more uncomfortable&lt;br&gt;Jack doesn’t want to live on a ventilator&lt;br&gt;Jack would prefer to not make this decision&lt;br&gt;His parents don’t want to make this decision either</td>
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<th>Quality of Life</th>
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<td>He can no longer attend school for a full day&lt;br&gt;He has more pain but doesn’t talk about it&lt;br&gt;He dreams about Jonathan - his brother who died&lt;br&gt;He spends more time in bed and less time being with all his friends&lt;br&gt;His main connection to them is Facebook</td>
<td>He lives in a community that does not have a home health care agency. He could not remain at home on assisted ventilation&lt;br&gt;They are building an addition onto the house so that Jack has his own room&lt;br&gt;Jack has made a very meaningful connection with his youth pastor; they talk about heaven a lot</td>
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</table>
**Medical Indications**

*Diagnosis:* Duchenne Muscular Dystrophy two months later  
*Treatment Option:* Spinal Instrumentation Surgery  
*Benefit* and *Risk:*

Jack’s forced vital capacity is less than 25%. If he waits much longer he may not be a candidate for surgery. Regardless the post-op risk of remaining on the ventilator is greater.

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**Patient Preferences**

Jack decides to have surgery

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**Quality of Life**

Jack just wants to be with his family and friends either here or in heaven

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**Contextual**

Jack and his pastor have met with all his friends and family the know the risks and they are all supportive.
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<tr>
<td><strong>Diagnosis:</strong> Duchenne Muscular Dystrophy s/p Spinal Instrumentation Surgery</td>
<td>Jack plans to complete high school with a combination of classroom and on-line classes</td>
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<tr>
<td>Post-op pneumonia, ventilated for 4 weeks, hospitalized 17 weeks, lost 23 lbs. No tracheostomy,</td>
<td>He wants to go to college</td>
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<tr>
<td>Jack is now at home on BiPAP at night Getting up in the wheelchair 8 hrs/day</td>
<td>He thinks he might like to go to Seminary to become a minister</td>
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<td>He attends school for a half day He enjoys entertaining friends in his new “man cave” As his pain has decreased his appetite for Philly Cheese Steaks has increased He spends less time in bed and more time being with all his friends Katie Perry called him when he was in the hospital He has 600 friends on Facebook</td>
<td>• His family was able to negotiate a plan for BiPAP with a local home-health agency, but there is still no in-home nursing available • Jack’s parents needed a second mortgage on their house to pay their out-of-pocket medical expenses His sister has delayed college and is working for a year to earn college money Jack’s mother is his full-time caregiver Jack’s father is investigating taking a job in and moving the family to Seattle</td>
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Group Discussion Questions

1. Could our clients benefit from palliative care offerings? What initial groundwork would we need to have in place in order to start a palliative care program?
   - staff training
   - policy/procedures
   - environmental set up
   - resource obtainment

2. How can we maximize the effectiveness and quality of communication between all members of the palliative care team?
   - best practices
   - setting reasonable goals and expectations
   - marking progress / charting change / outcomes

3. Who can refer to the palliative care team? What patient criteria would trigger a referral?

4. How can we weave the rehabilitation and palliative goals together to maximize patient benefit and quality of life? Are rehab services underutilized in this population?

5. Is there additional education that should be provided to our staff to fully integrate care?

6. How do we prepare staff before a palliative care admission? How do we support those who may be in conflict with a family’s choice of care?