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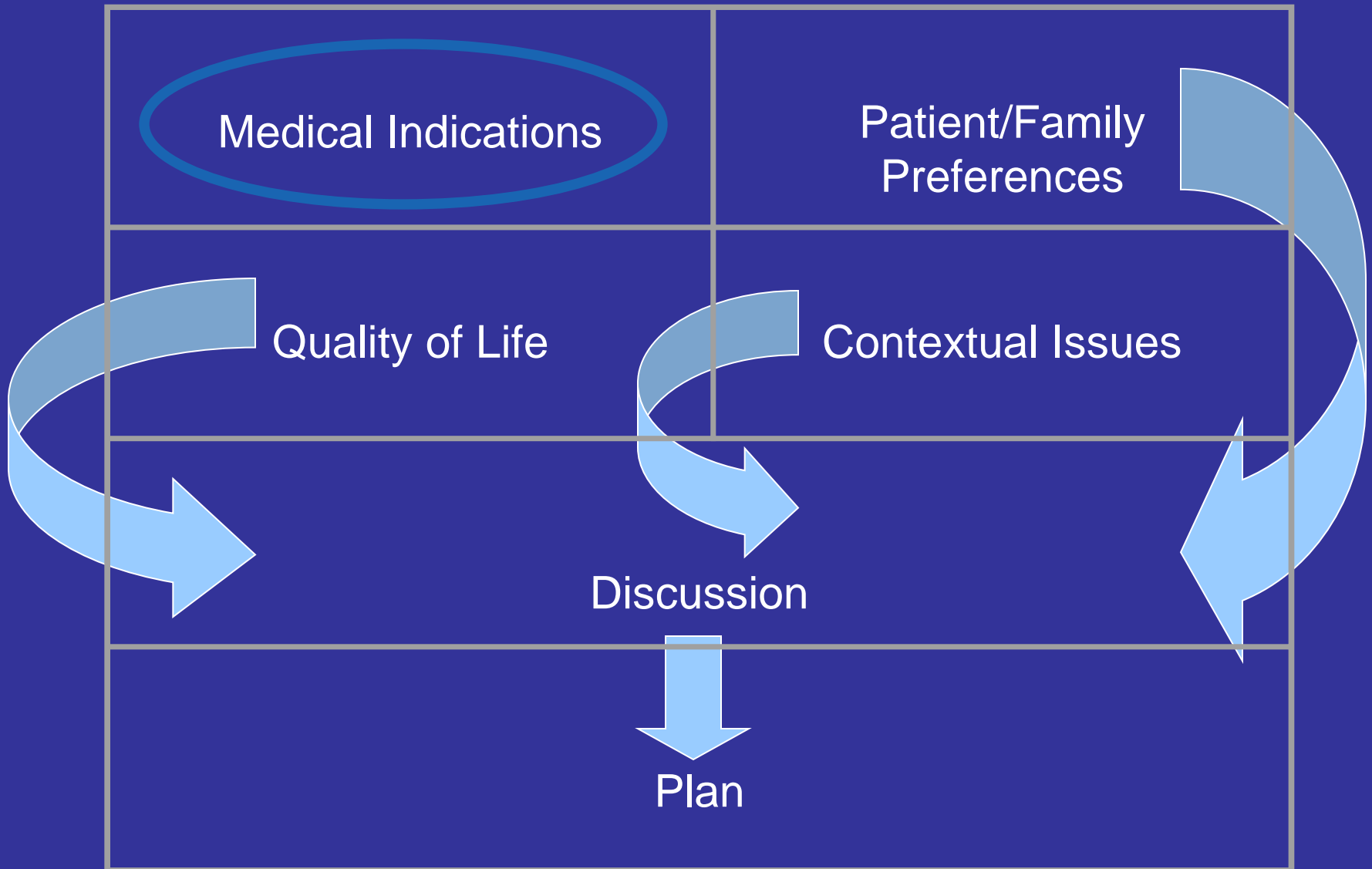
“An Introduction to Pediatric Palliative Care and the Decision Making Tool: An Ethical Framework”

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



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.

*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

Identify
Many
QOL
Issues

DMT

1



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

Medical Indications

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

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

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 time being with all his friends
His main connection to them is Facebook

Contextual

He lives in a community that does not have a home health care agency. He could not remain at home on assisted ventilation

They are building an addition onto the house so that Jack has his own room

Jack has made a very meaningful connection with his youth pastor; they talk about heaven a lot

Identify
Many
QOL
Issues

DMT

3

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

Patient Preferences

Jack decides to have surgery

Quality of Life

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

Contextual

Jack and his pastor have met with all his friends and family the know the risks and they are all supportive

Identify
Many
QOL
Issues

DMT

4



Medical Indications

Diagnosis: Duchenne Muscular Dystrophy s/p Spinal Instrumentation Surgery

Post-op pneumonia, ventilated for 4 weeks, hospitalized 17 weeks, lost 23 lbs. No tracheostomy,

Jack is now at home on BiPAP at night
Getting up in the wheelchair 8 hrs/day

Patient Preferences

Jack plans to complete high school with a combination of classroom and on-line classes

He wants to go to college

He thinks he might like to go to Seminary to become a minister

Quality of Life

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

Contextual

- 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

Identify
Many
QOL
Issues

DMT

5





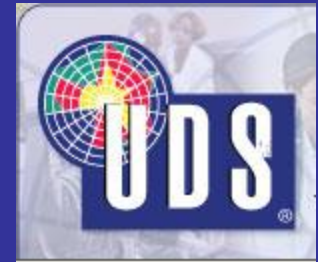
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Any Questions?

Group Discussion Questions

1. Could our clients benefit from palliative care offerings? What initial ground work 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?