

Tuesday, 10:00 – 11:30, A1

Finding Hope in Palliative Care

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Objectives:

1. Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities
2. Identify advances in clinical assessment and management of selected healthcare issues related to persons with developmental disabilities
3. Discuss the ethical issues related to persons with developmental disabilities
4. Identify and emphasize attitudes that enhance the opportunities for persons with DD to achieve their optimal potential
5. Develop strategies to promote community inclusion in meeting the needs of persons with developmental disabilities.

Notes:

Finding Hope in Palliative Care

Denise Egeland, MSN, NP-C
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Jodi Winsett Nohel, Child Life Specialist

Objectives

- Define palliative care vs. hospice
- Describe barriers to effective palliative care
- Determine appropriate palliative care interventions
- Review communication strategies

Definitions

"Palliative care focuses on quality of life, control of pain and symptoms, and attention to the psychosocial and spiritual experiences of adapting to advanced illness."

"Hospice care is a specialized and intensive form of palliative care for patients with advanced, life threatening illnesses and for their families, emphasizing quality of life, life-closure issues, and the relief of suffering."

From the Center to Advance Palliative Care in Hospitals and Health Systems report: *Hospital-Hospice Partnerships in Palliative Care: Creating a Continuum of Service.*

☛ NOT all Palliative Care is Hospice Care

☛ All Hospice Care is Palliative Care

What Do You Think...

☛ 19 year-old with RLE DVT and right saddle PE

- 9/10 pain in right chest despite multiple opioids
- ++ anxiety

What Do You Think...

☛ 55 year-old woman with cerebral palsy admitted with MS changes, UTI and dysphagia

- Father is guardian
- Does not want his daughter to have feeding tube
- Caregivers disagree with father's decision

What Do You Think...

- ☞ 85 year-old admitted to hospital for 3rd time in 3 months with HF exacerbation
 - ++ dyspnea
 - Deconditioned and unable to participate in physical therapy
 - States "I can't do this anymore!"

What Do You Think...

- ☞ 3 year-old recently diagnosed with acute lymphoblastic leukemia with 90% prognosis
 - Facing 2 ½ years of treatment
 - Parents anxious
 - Symptoms include leg pain, constipation, nausea/vomiting, heartburn, & hypertension from chemotherapy

Which of These Patients Need Palliative Care?

- ☞ 19 year-old?
- ☞ 55 year-old?
- ☞ 85 year-old?
- ☞ 3 year-old?

And The Answer IS...

- ✔ ALL of them!!!

And The Answer IS...

- ✔ ALL of them!!!
- ✔ Pain and symptom management

And The Answer IS...

- ✔ ALL of them!!!
- ✔ Pain and symptom management
- ✔ Comfort care and quality-of-life focus

And The Answer IS...

- ✓ ALL of them!!!
- ✓ Pain and symptom management
- ✓ Comfort care and quality-of-life focus
- ✓ End-of-life and hospice care

And The Answer IS...

- ✓ ALL of them!!!
- ✓ Pain and symptom management
- ✓ Comfort care and quality-of-life focus
- ✓ End-of-life and hospice care
- ✓ Patient and family supportive care throughout the disease trajectory

Medical Care Continuum

Curative

Palliative

H
O
S
P
I
C
E

Grieving

death

Palliative care

- ✔ Treats the patient and family as one unit of care
- ✔ Pays attention to physical, psychological, social and spiritual needs
- ✔ Uses interdisciplinary team approach

Palliative care is...

- ✔ Back rubs & hand massages
- ✔ Morphine for pain
- ✔ Rocking a sick, fussy child
- ✔ Surgical procedures to lyse adhesions or debulk tumors

It is the cool washcloth on a hot face, and prayers, and delivering bad news compassionately

Types of Palliative Care

- ✔ Primary
- ✔ Secondary
- ✔ Tertiary

Palliative Care Approaches

- ☛ Daily at the bedside/in the clinic
- ☛ Consultation model
- ☛ Integrated Palliative Care model

Barriers

- ☛ Adult
- ☛ Pediatric
- ☛ Disabilities



How do I provide palliative care?

- ☞ Educate yourself in palliative care
 - ELNEC
 - CAPC
 - CHIPPS-pediatrics
 - NHPCO

Finding Hope

- ☞ There is always hope...
 - For a cure
 - For control
 - For symptom management
 - For closure
 - For a good death

How do I provide palliative care?

- ☞ Be present with the patient/family
 - Listen, listen, listen
 - OK for silence
 - Don't have to have all the answers
- ☞ Do advance planning
- ☞ Use resources
 - Interdisciplinary team
 - National resources

Finding the Words

- ✓ Help identify what their worries are
- ✓ Help identify what they are hoping for
- ✓ Ask what brings them joy
- ✓ Identify other support systems
 - Friends
 - Clergy

What if cure is not an option?

- ✓ "Death is not a failure of medical science but the last act of life." - Patch Adams



Creating Memories

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Death leaves a heartache no one can heal, love leaves a memory no one can steal. ~From a headstone in Ireland



Ideas for Creating Memories: Scrap Booking

Our Last Vacation Together: 4th of July weekend 2011



Having Fun with "Sissy"
Lake Michigan



"Wild Man" Hair
After a Day at the Beach



Fun with Cousins after a
Rain Storm at the
Campground



Ideas for Creating Memories: "A Penny for Your Thoughts"

A jar can be provided for the family to decorate and/or fill. Every time a penny is found, it can represent a thought or memory.



**Ideas for Creating Memories:
Bracelets**

- A long strand of 3 is braided together and placed on the wrist of the loved one and then the same strand is placed on the wrists of immediate family members



**Ideas for Creating Memories:
Hand Print / Memory Boxes**



**Ideas for Creating Memories:
Stuffed Animal**



<http://www.intimeofsorrow.com/childrens-loss-of-grandparent-gift-basket.html>

Ideas for Creating Memories





My Sister


She knows
about 1 name of
Governments
where you live.

She accepts
me as I am -
And is
my helpful friend.

She is always
there for me
throughout
my life and more.

And every time
I'm with her
I'm home again.

More Ideas for Creating Memories



- Build - a - Bear: place something special inside
- Write a book together / Have a "quote book" of funny, cute or memorable things that are said and record who said them
- Create t-shirts or something that can be left in the home like a welcome mat, picture or frame or journal.
- Make special gifts for each other. Such as bracelets, throw pillow, or picture.
- Create a Video
- Photography
- Continue traditions: video tape it or photograph it (i.e. game night or movie night)
- Tape record messages
- Create a time-capsule or frame & put special things inside that represent the family, individuals and memories: include any special notes or drawings
- Pre-written letters or cards from the loved one to family members (Special Occasions or Holidays)
