Communication in Pediatric Palliative Care

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Caring for a dying child is one of the most difficult responsibilities a healthcare professional will ever encounter because of its intensive management of the physical, psychosocial, and spiritual issues facing both the child & the family.
To lose a parent is to lose a part of your past
To lose a child is to lose your hopes and dream for the future
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

WHO 1990
The Cure - Care Model: The Old System

Life Prolonging Care

Disease Progression

Palliative/Hospice Care

DEATH
Disease discovery
Curative

Palliative Care

Death

Life closure - preparedness

Final hours of life care

Bereavement care

From Frank D. Ferris MD, San Diego; EPEC Course
Why is Pediatric Palliative Care a Challenge?

- Death in childhood rare/untimely
- Unusual diseases: 20-40% cancer,
  Congenital anomalies
  Metabolic conditions
  Neuromuscular degenerative diseases
- Illness trajectory long/unpredictable
- Symptom assessment – difficult
- Neonates & adolescents-special challenges
Why is Pediatric Palliative Care a Challenge?

Ethical questions

- At what age is the child competent to make decisions?
- Who decides what is the best interest of the child?
- Whose wishes should be followed?
- What should the child be told?
- How to communicate with the child?
Differences Between Palliative Care for Children and Adults

- Patient issue
- Family issue
- Care provider issue
- Societal issue
- Medical management
Most adult program admit patients close to the time of death

Children programs admit children close to the time of diagnosis
Length of stay may be longer than adults
The Patient

• Legal competence:
  Patient vs. parent

• Decision-making capacity
  Development vs. cognitive clarity

• Information sharing (how much, how little)
  – Diagnosis, prognosis, treatment
  – Hope
  – Treatment plan development
The Patient

• Concept of Life and Death
  – Developmental stage (not age)
  – Cultural
  – Duration/complexity of Illness

• Quality of Life
  – Need to be a child
    Play, School, Peer interaction
The Family

Cycle of Life
- Parents should not bury their children
- Children don’t die

Grief/Losses
- Expectation of having a “normal” baby/child
- Loss of child’s future
Family

• More inclusive: parents, grandparents, siblings, friends

• Bereavement needs: families suffer the death of a child more severe than the death of an adults

Bereavement care must be a major program component
The Family

• Sibling Struggles
  – How much do we tell them?
  – Isolation
  – Guilt/Anger
The Health Care Providers

- Lack of experience with dying children
- Lack of knowledge regarding developmental stages
- Fear of using opioids in children
Society

• Lack of organized care for dying children
  – Hospice, respite, home health nursing
  – Cost of care

• Lack of facilities providing in-patient hospice care

• Limited reimbursement

• Lack of research
Spirituality

- Children should not die/suffer
- Finding meaning in child’s life/death
- Preserving memories
What do Patients Want?

• Pain and symptom control
• Achieve a sense of control
• Consistent communication
• Relieve burdens on family
• Avoid inappropriate prolongation of the dying process

Recognition of prognosis by both physicians and parents is associated with a stronger emphasis on treatment directed at lessening suffering and greater integration of palliative care.

What Are the Needs?

1. Pain/Symptom Relief
   Symptoms at the end of life in children
   - Fatigue
   - Pain
   - Dyspnea
   - Swelling of extremities
   - Mouth sores, dysphagia
   - Nausea/Vomiting
   - Diarrhea, constipation, urinary
What Are the Needs?

2. Family Support
   Parents
       Increased divorce rates
       Financial devastation
       Prolonged or dysfunctional grieving
   Siblings
       School failure, delinquency
       Depression
       Loss of self esteem, Isolation
       Anger, aggression
What are the solutions?

• **Effective communication**
  Early, open, complete
  Prognosis, options, uncertainty
  Recommendations
  Probing questions

• **Establish consistent relationships**
  Primary physician
  Social services, nursing, child life
Supporting the Parents

• Reassure that we are doing all we can and will do all we can

• Help parents to maintain a realistic focus on what the child can still do

• Do not destroy parent’s hope
What to do to Help Siblings?

- Reassure them that they are not responsible for the illness
- Encourage their participation in care
- Don’t send the sibling away – allow them to be in the circle of sadness
- Giving them special attention
- Be patient and loving
What Are the Needs?

3. Education

Communication skills
Cultural sensitivity
Pain and symptom control

Meier, Morrison & Cassel.
80% of residencies in U.S. offer no training in end of life care

35% of medical students never discussed care of a dying patient with attending

Majority of Pediatric residents feel unprepared for dealing with dying children

Billings & Block JAMA 1997;278:733.
Why?
Teaching - Palliative Care

Palliative care - good model for teaching:
• Medical professionalism and ethics
• Holistic care
• Advanced communication
• Work as a team
• Concept of health promotion in the ill
Communication

Who Is Involved?

Parents, close family, and friends

Extended family and community

Clinicians

Ill child
Communication is fundamental to the physician-patient relationship.

Poor communication is a significant problem affecting the medical profession.

Professional communication is a skill and like any skill can and must be learned.

Communication with terminally ill children and their parents are the most challenges.
When a person is diagnosed with a serious or life-threatening illness and is nearing the end of life:

**Good communication**

Convey:
- Seriousness
- Expected course
- Treatment alternatives
- Palliative care
Effective Communication

Communication is needed to establish a therapeutic relationship. Without trust, good quality of care cannot be provided.

Decision-making may fail to take into consideration the dying person’s goal, beliefs and values. Patients may not receive treatment they want, or may undergo unwanted interventions.
Goals of Communication at the End of Life

• Convey respect and understanding for the patients as a person first, patient second
• Convey information about illness, likely course and treatment options
• Communicate empathy and support
• Convey appropriate hope
• Develop a treatment plan in context of patient’s goal, values and notions of quality of life
• Arrange follow up meetings and reassure about ongoing care and support
Barriers to Effective Communication

Barriers due to patients and families

• Misunderstanding of illness, treatment options and pronosis
• Biases over the role of palliative care
• Lack of support, coping mechanisms
• Physical and emotional depletion
• Strong emotions
• Differences in values, beliefs or culture
Barriers to Effective Communication

Barrier due to health care providers

- Depth of the physician-patient relationship
- Personal experiences of illness and death
- Lack of training and poor role models
- Fear of emotional outbursts
- Personal beliefs and values regarding treatment, death, and palliative
- Fear of being messenger
- Guilt and self-blame due to iatrogenic complications
Health professionals Should be Aware that

• They have their own beliefs, fear, practices, & expectations
• Their values may differ from the patient, family &/or their colleagues
• Their culture shapes how information is shared, how children & families are involved in decisionmaking
Approaches to Discussing Cultural Issues

• When meeting with new family, try & find out as much as possible about how they make decisions

• Find out if there is anyone that they may want to talk with about the decisions to be made

• Understand that different people have different beliefs about medical treatment
Traditionally, children were not involved in difficult discussion.

Children figured out that they are seriously ill and possibly dying even when their families and healthcare providers have attempted to protect them from this information.

Every child should be given the opportunity to discuss his/her situation and to receive further information at his level, and emotional support.
What to tell a child about his or her illness, and whether and when to say death is near?

It is valuable to know that evidence suggest that those families who can express themselves openly benefit both during the child’s illness and after the death.

Spinetta et al. 1981
Laying the ground work: Assessing Family and Patient Communication

- How does the family communicate currently?
- How much and in what format the family/patient prefer to receive information?
- What information is shared between family members and with whom?
- What and how is information shared with the patient? siblings? larger family?
- How does the patient communicate with his/her family?
- How are emotions and needs communicated?
Culture and Pediatric Palliative Care
Decision-making

• The child’s role in decision making
• Who the key decision-maker is
• The degree of authority granted to the clinician
• The involvement of extended family
• Quality of life concerns V.S. extension of life
• Acceptability of options and interventions
• Desire to have the child cared for in hospital or at home during the last period of life
Way of Communicating

- Play
- Art
- Talking
BEGINNINGS AND ENDINGS WITH
LIFETIMES
IN BETWEEN
A BEAUTIFUL WAY TO EXPLAIN
LIFE AND DEATH TO CHILDREN

Bryan Mellonie and Robert Ingpen
Objectives of Workshop

• Recognize the components of effective communication in dealing with serious ill pediatric patients and their families
• Be able to breaking bad news
• Be able to communicate and discuss end-of-life decision-making in a way that is sensitive to culture and religion
• Be able to support the patient and the families from beginning until after the death of the child
"We don't have to wait until we are very sick and know this might be 'it.' We can get support from the day we learn something could happen."

– Mattie Stepanek, February 2000