SIOP PODC Supportive Care Education

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COMMUNICATION ISSUES IN PEDIATRIC ONCOLOGY

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INTRODUCTION

- Breaking bad news is one of a physician's most difficult duties
- Medical education typically offers little formal preparation for this daunting task
- Without proper training, physicians experience uncertainty and discomfort when breaking bad news
- This can lead physicians to emotionally disengage from patients

WHAT IS BAD NEWS?

- 'Any news that drastically and negatively alters the patient's view of his or her future'
- Lance Armstrong's recollection of being diagnosed with metastatic testicular cancer:
  - ' I left my house on October 2, 1996, as one person and came home another'

COMMUNICATING BAD NEWS IN PEDIATRIC ONCOLOGY

- For the family of a child with cancer, the time of diagnosis is a time of emotional anguish
- The formal discussion on diagnosis comes after a period of uncertainty
- The child has to go through many unpleasant procedures to get to the diagnosis
- When the pediatric oncologist finally discusses the diagnosis, the fear of the news to come combined with uncertainty, creates an anxiety that is difficult for the family to endure

The Day One Talk

- The discussion that occurs between the pediatric oncologist and family when they first hear about the child's new diagnosis of cancer
- In a 2012 survey of 62 parents:
  - 97% parents felt the 'Day One Talk' was extremely important
  - 99% parents believed the word 'cancer' should be used in this first conversation
  - 77% parents wanted numbers regarding cure rates
  - 84% parents felt that children under 14 years of age should not be present at this meeting

Kessel et al

The Day One Talk

What is needed most at this time?

A highly reputed oncologist known for his/her medical expertise

or

An oncologist who is compassionate and has the communication skills and ability to establish rapport with the patient and family

BOTH QUALITIES ARE EQUALLY IMPORTANT!

THE PROBLEM

- Medical skills are taught all through medical school while communication skills are not!
- Hence, a brilliant physician can be a very poor communicator!

BACKGROUND

- Communication between physicians and patients is a fundamental aspect of cancer care
- Most physicians have had very little training in communication
- Poor communication skills can 'make or break' your relationship with the patient and family
- Communication skills are important for all caregivers of an oncology team

THE ONCOLOGY TEAM

- Pediatric oncologist or pediatrician
- Oncology NP or nurse
- Social worker
- Child life or Art therapist
- Chaplain
- Parents

WHY ARE THESE SKILLS SO IMPORTANT TODAY?

- In the last 20 years, there have been rapid advances in the treatment of cancer
- Much easier to offer hope to the patient
- Created more situations where increased clinician skill is required for communication with patients and families
  - disease recurrence
  - failure of treatment to halt progression
  - irreversible side effects
  - raising the issues of DNR status and hospice care

WHY ARE THESE SKILLS IMPORTANT?

When an illness is serious or a child dies, parents deserve to be told in a way that helps them cope with their grief

- The news will result in a critical change in the future of the child and family
- The way bad news is presented to a family may influence the parent's ability to hear the news and cope with the situation
- Parents vividly remember the manner in which the diagnosis of their child's illness was communicated to them for years after the event
- The experience tests the strength of the doctor - patient relationship

ADVANTAGES OF GOOD COMMUNICATION SKILLS

- Good communication skills
  - Allow for development of rapport between caregivers and families
  - Good rapport leads to trust
  - Trusting relationships lead to compliance in treatment
  - Help with difficult decision making

BARRIERS TO DEVELOPING GOOD COMMUNICATION SKILLS

- A good physician can be a bad communicator because of the strong emotions he/she experiences while delivering bad news:
  - anxiety
  - burden of responsibility for the news
  - fear of negative evaluation
  - News is too close to home

- This stress creates a reluctance to deliver the news "MUM" effect

- An ASCO survey of 500 physicians revealed additional stressors:
  - how to be honest with the patient without destroying hope - 55%
  - dealing with the patients emotions - 25%
  - not having had any formal training in breaking bad news - 90%
  - opportunity during training to observe bad news being delivered -34%

SCENARIO NO I

- BL is a 12 year old athletic AA male with a new diagnosis of metastatic osteosarcoma of left leg
- Treatment recommended by Orthopedic oncologist included chemotherapy and limb-sparing surgery
- Parents went for second opinion to renowned orthopedic oncologist
- He told parents outright they were wasting their time
  - The child was going to die anyway
  - Just do an amputation
  - Spent 10 minutes maximum with family
- Parents devastated by interaction with doctor, left very angry

REASONING BEHIND DOCTOR'S BEHAVIOR

- Very busy practice – little time to spend with patients
- Felt uncomfortable discussing the eventual outcome of this disease with family
- Had a son the same age as the patient-also an athlete
- Took refuge in his medical training which had taught him to suppress his own thoughts and emotions
- Came across as uncaring and emotionally detached

SCENARIO NO 2

- JD was a 7 yr old WF with a diagnosis of refractory AML.
- From the day of initial diagnosis, she and her parents had established a strong bond of trust and partnership with her oncologist
- She had undergone 2 BMT's and the leukemia was back
- She was now hospitalized for progressive pneumonia, bacteremia and severe abdominal and bone pain
- Treatment included blood products, antibiotics, fluids, anti-fungals and morphine
- Patient was drawing pictures of herself as an angel in heaven and handing them to her oncologist
- **Mother still wanted to pursue curative therapy**

A GOOD DEATH - AND HOW IT EVOLVED

- It took the bond of trust previously established over the years and communication skills of the entire oncology/palliative care team to help the parents accept JD's imminent death
- The oncologist, social worker and chaplain spent time daily with the family discussing alternative options
- Mother finally started asking 'what will her death be like?'
- Dialogue was established between the mother and daughter
- All treatment except morphine and platelets was discontinued
- JD died peacefully surrounded by her parents and medical caregivers
- Mother still keeps in touch with medical team

HOW CAN A STRATEGY FOR IMPROVING COMMUNICATION SKILLS HELP THE CLINICIAN AND THE PATIENT?

- Physicians who are uncomfortable giving bad news tend to
  - Come across as detached and uncaring
  - avoid discussing distressing information such as poor prognosis
  - convey unwarranted optimism to the patient or parents

- A plan for determining patient values and a strategy for addressing their distress when the news is given
  - can significantly increase the physician's confidence
  - may encourage parents to participate in difficult treatment decisions
  - can significantly reduce stress and burn-out in the physician

ABCDE

- A - Advance Preparation
- B – Build a Therapeutic Environment
- C – Communicate Well
- D – Deal with Patient and Family Reactions
- E – Encourage and Validate Emotions

Rabow and McPhee

STRATEGY FOR BETTER COMMUNICATION WITH PATIENTS

- Set up an interview
- Determine who will participate
- Prepare to communicate the news
- Use specific techniques for sharing the news
- Anticipate parental reactions
- Negotiate future plans
- Arrange follow-up meetings
- Health care team “debriefing”

COMMUNICATING WITH CHILDREN

- Children are often told little about their illness
  - to protect them from fear and feeling of being overwhelmed
  - cultural issues, family hierarchy, relationships among family members influence decisions on how much to tell
  - younger children have limitations in reasoning
- Most children know when something serious is going on
  - over time experience similar distress as older more informed children
  - figure it out themselves
  - non disclosure tends to make them feel isolated

TALKING TO CHILDREN WHO ARE DYING

- One of the most daunting aspects of palliative care is talking to a terminally ill child
  - Should the child be told?
  - If so, by whom and how much?
- Challenges:
  - Children's concept of death changes over time
  - Highly variable from child to child
  - This information should be used to adjust our approach to the child and guide the family

OVERVIEW OF CHILDREN'S CONCEPT OF DEATH

Age Range	Perception of Death
• 0 - 2 yrs	• Separation or abandonment • Protest and despair from disruption in caretaking • no cognitive understanding of death
• 2 – 6 yrs	• Reversible or temporary • Often seen as punishment • Magical thinking – wishes can come true
• 6 – 11 yrs	• Gradual awareness of irreversibility and finality • Specific death of self or loved one difficult to understand • Concrete reasoning with ability to see 'cause and effect' relationships
• Older than 11 yrs	• Death is irreversible, universal and inevitable • All people and self must die, although latter is far off • Abstract and philosophical reasoning

AAP, 2000

TALKING TO CHILDREN WHO ARE DYING

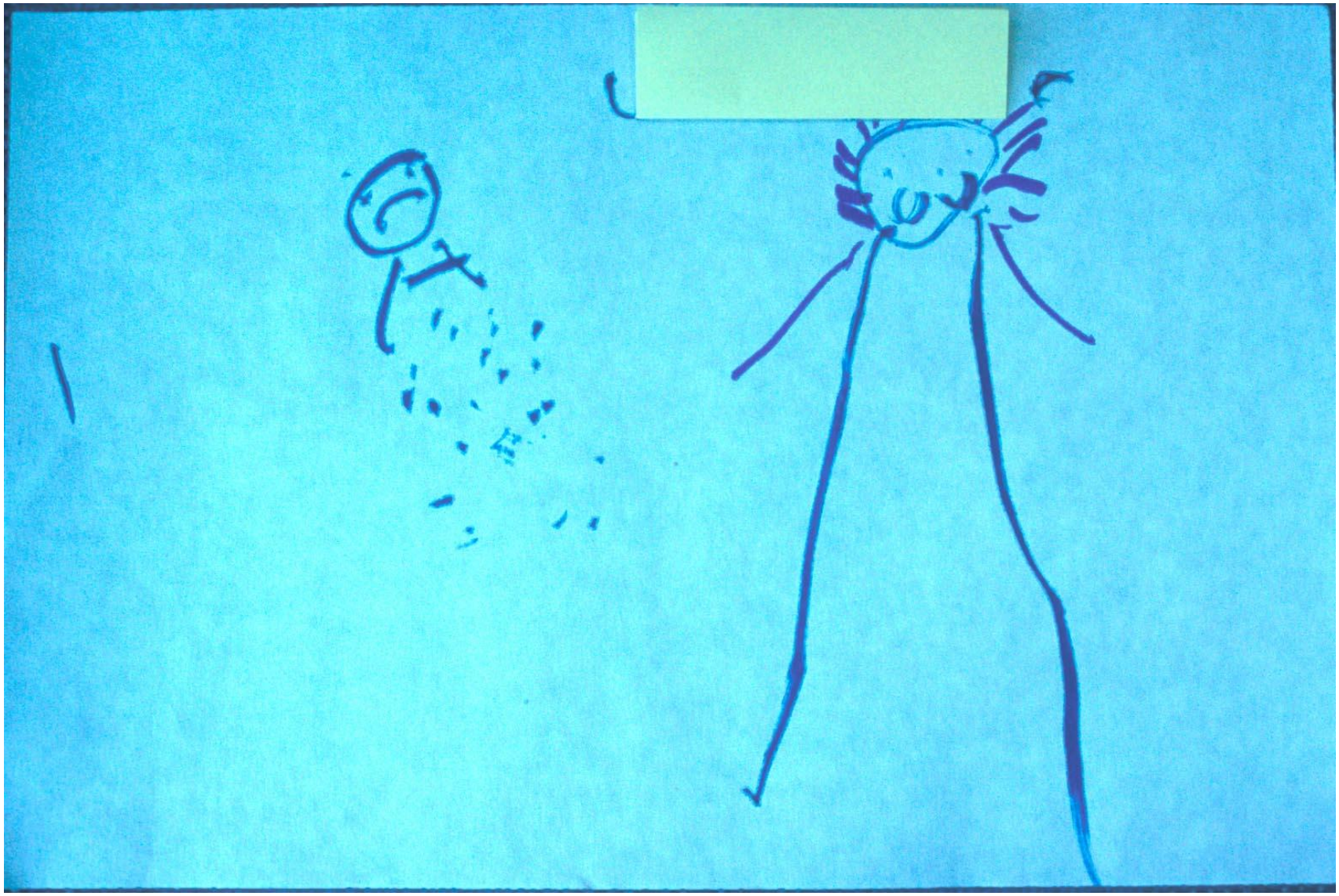
- Studies have shown:
  - Dying children fare better when they know what is happening to them
  - Dying children often know that they are dying, whether or not they have been told
  - Children not informed of the gravity of their illness, feel isolated and alone
  - Physician may not necessarily be the best person to talk to the child about death
  - Children may benefit from concrete information about the actual and physical process of dying
  - Some children may not want to talk about dying
  - Children give clues through play, drawings, dreams and reference to family members and friends who have died

Big tumor in the arm

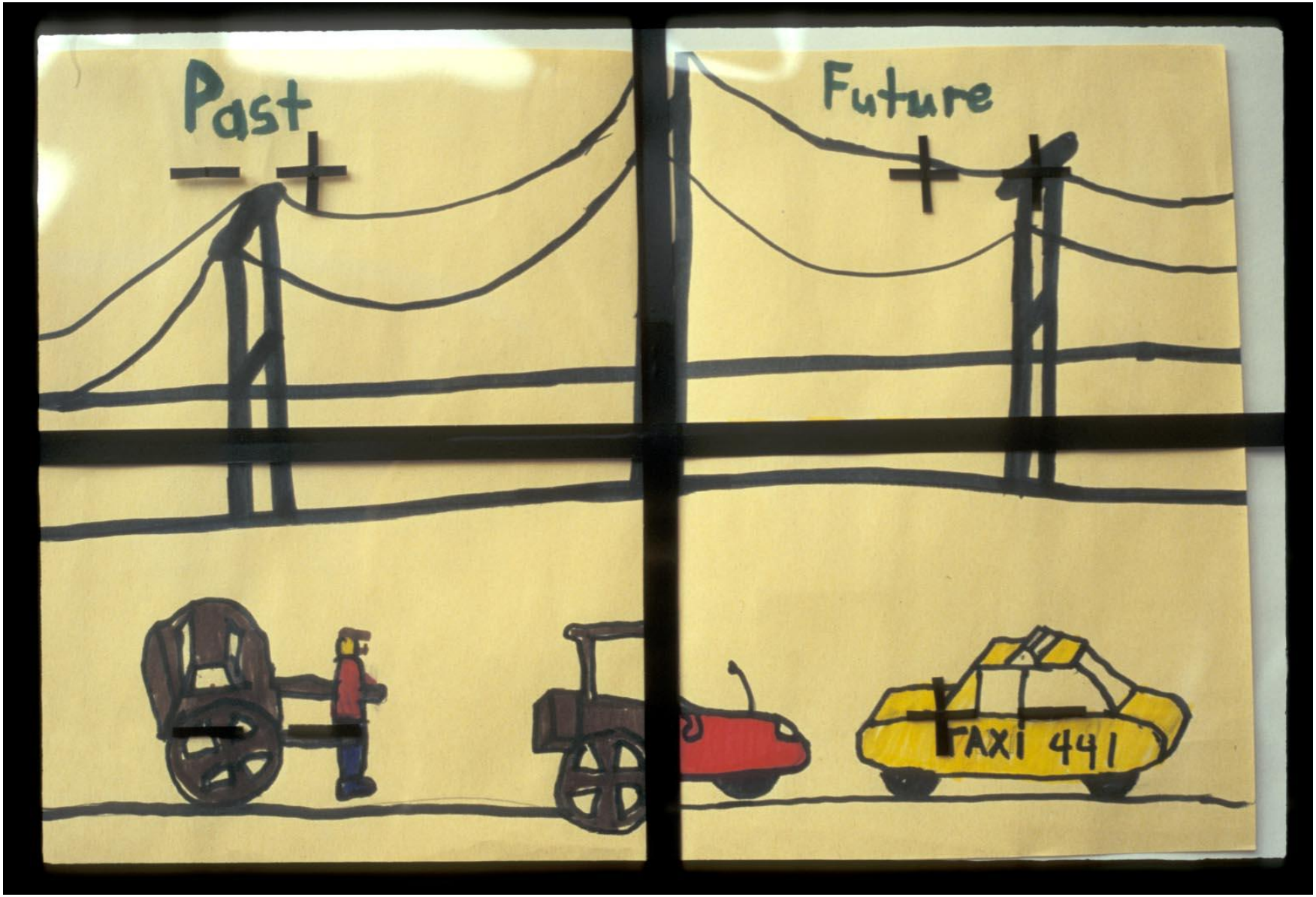

dunk
it!

Angel


Kelley



Moving van



Past, Present and Future

SIBLINGS
'THE FORGOTTEN FAMILY MEMBERS'

- Siblings of chronically ill, dying children are at risk of becoming forgotten
- Siblings feel isolated
  - Parents frequently are absent
  - Feel their own needs are no longer a priority
- Siblings are at high risk
  - Subsequent school problems
  - Problems with parent-child relationships
  - Psychological and social problems following their sibling's death

GUIDELINES FOR ASSISTANCE TO SIBLINGS OF CHILDREN WHO HAVE CANCER

- Include sibs in discussions of care from time of diagnosis through death of child, and beyond
- 'Protecting' sibs by excluding them may cause long term harm
- Sibs should be included in discussions of end-of-life care
- Sibs should be included in funeral planning
- Resources should be made available to support sibs through their grief and bereavement

COMMUNICATION SKILLS TRAINING IN ONCOLOGY

- Undergraduate courses in medical school and residency programs
- Observing more experienced colleagues in clinical situations
- Videotaping actual encounters and evaluating them later
- Role playing
- Interactive workshops

‘Stop! Don’t run away. I am scared. Talk to me.
I don’t know what its like. You see – I’ve never died before!’

Translated from Arabic- courtesy Dr Brown