It is the role of the health care team, specifically the social worker, to ensure that communication is adopted to assist children and their families in understanding the disease process, treatment options, benefits, burdens, and consequences of treatments.

Hollye Harrington Jacobs
Pediatric Palliative Care Ethics and Decision Making, “Palliative Social Work”
How to Choose Compassion at All Crossroads

Understanding the suffering of parents when faced with the decisions at the end of life

Lori Seraphin, LCSW-C

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PICU and Medical Advances
How Communication Should Evolve in the PICU

- Directing
- Guiding
- Following
Compassion
Hope
Information
Burden of Choice
Case Study A

Not our job to fix the pain, but to walk along side of it

“The Wounded Healer” Henri Nowen
Physicians who find it difficult to give bad news may subject patients to harsh treatments beyond the point where treatment may be expected to be helpful.

- Creators of SPIKES
Case Study C

Don’t tell me that she will never heal, that there is no cure. You don’t know my GOD
Factors that Influenced Parents Decisions

- Spiritual: certainty of God’s will, testing parent’s faith, meaning making, reincarnation
- Emotional: definition of a good parent
- Cultural: education, receptivity to medical information, level of family and community involvement, shared decision making
End – of – Life Decisions

Recent California HealthCare Foundation survey in which “44% of adult African-Americans, 44% of Latinos, 28% of Asian-Americans, and 14% of non-Hispanic whites believed that “everything possible should be done in all circumstances to save a life.”

- Collins, A, McLachlan, S, Phillips, J
Paternalistic Decision Making Model

Shared Decision Making Model

Informed Choice Model
Is it All or Nothing?

Option A:
- What we say “chest compressions, epi, intubate…”
- What it means to them “We will do everything to save him.”

Option B:
- What we say “DNR, DNI…”
- What it means to them “We will do nothing”
Are We Helping or Harming?

- We tell half truths
- We provide options like “all or nothing”
- We make families wait for us, for results
- We monopolize the dialogue during family meeting
- We create false hope by using words that are positive
- We offer therapies or treatments that will not change outcomes
Are we losing our objective brains because we want to please?

Our emotions derail our decision making.
“If I can keep them happy, or at the very least, quiet, I’ll be good to go.”

Brené Brown, “Braving the Wilderness “
If we can’t handle these feelings, how can we expect the parents to?
Well, hello there, you look like a bad decision... come on over here!

I DON'T ALWAYS MAKE BAD DECISIONS

BUT WHEN I DO, I MAKE SURE TO REPEAT THEM OVER AND OVER AGAIN
REWRITE THE CONVERSATION
Suggested questions for Medical Team

- How can I be helpful?
- Is it ok if I ask a question?
- I would like to offer some suggestions, may I?
- I have some ideas, but I want to hear from you first?
- Knowing all this, what are you hoping for?
WHO SHOULD DECIDE?
Team Goal Versus Family Goal

- Make your treatment boundaries known.
- Give them a time frame for treatment.
- When can we revisit this?
- Who needs to be present when we revisit it?
Redefine the Question
It is not a decision to withdraw care. It is a decision on how they see their child growing up.
“This will not restore him to have a meaningful quality of life.”
After all is said, allow for silence

Did they not understand

OR

Are they processing...

- I wish it could be different
- I want a miracle too
- I can not make you happy right now, I can’t tell you that your child will be well again.
Use AND rather than BUT

**AND**

- builds, joins, connects words, phrases

**BUT**

- Stops the thought, the idea, the point you are trying to get across
- Using BUT makes their desire not valid

Terry Atilio
The Power of AND

We do not have any curative medicine that will restore your child’s health and wellbeing, AND

the medical team realizes this is not the goal you were hoping for AND

we will care for your child always AND

we will allow for a natural death.

We feel strongly that it is causing harm to your child’s body by delaying the dying process, AND

A curative path is no longer possible AND

We need to allow for a natural death.
As Social Workers, we can...

- Create a space for honest dialog between team members... encourage the huddle before the family meeting
- Ask the team to use consistent language that is in line with parents preferred context
- Provide timely family meetings or bedside chats with doctor, family, sw
- Create agreed upon goals for meetings, stick to planned agenda
- Provide research on parent satisfaction in meetings when they get to talk the majority of the meeting

Staying compassionate means not having all the answers
"Be yourself, everyone else is already taken."
- Oscar Wilde
Citation

◊ Atilio, Terry. Social Work Leadership conference, Baltimore, MD


