Building Bridges: Providing Optimal Pediatric Palliative Care Between Hospital and Home

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Disclosures

• The speakers of this workshop have no conflicts or disclosures.

The CASE

• *The case presented throughout this presentation is a compilation of years of experience and in no way represents a particular patient, family or care providers. Any such likeness is strictly coincidental.*
Who are we

- Tab Cooney, Pediatric Neuro-Oncologist
- Anita Sharma, Pediatric Nurse Practitioner & Neuro-Oncology Case Manager
- Hania Thomas-Adams, Child Life Specialist
- Christy Torkildson, PACT Team Coordinator, Pet Therapist

Members of the team not with us:

- Social Work
- Massage Therapist
- Music Therapist
Objectives

• Participants will be able to identify different interventions to foster emotional expression and legacy building within the setting of non-disclosure.

• Participants will be able to discuss challenges when caring for a complicated pediatric patient facing the end-of-life.

• Participants will be able to summarize strategies for integrating interagency and interdisciplinary perspectives to provide quality care.
Keep in Mind:

• Palliative care across the continuum
• What pops into your mind as we go through this case study?
• What are the challenges you have been faced with?
• Are there ethical challenges to be considered?
• Please do not hesitate to ask ?’s & join the discussion!
Meet Rain:

- Pain and symptom management
- Diagnoses & Prognostication
- Patient issues
- Ethical issues
Logistics/Practical Issues

• Biweekly visits with neuro-oncology team

• Cultural differences
Logistics/Practical Issues

• Low resources

• Multi-disciplinary services involved
Logistics/Practical Issues

• Prolonged suffering

• Dependence on mother
Logistics/Practical Issues

• Meeting outside of clinic visits

• Brainstorming to help Rain and her family out as much as possible
Awareness of Dying: Four distinct states

- Closed Awareness
- Suspicion Awareness
- Mutual Pretense
- Open Awareness

(Glaser and Straus, 1965)
Open Awareness

- Acknowledgement by everyone involved that the patient is dying
- Openness to discussing next steps, emotions, goals of care at EOL
- Stable state
- Allows for shared understanding, control, choices, and open discussions about care

Mutual Pretense

- Patient, family, and providers all know that the patient is dying but choose to pretend/act otherwise
- “The Ritual Drama” (Glaser and Straus)
- Fragile illusion-state that takes effort to maintain
- Allows for continued status quo and normalization of roles for as long as possible
- “I’d rather not talk about stuff with my mom.”
- “(little sister) asks what’s wrong with me but I just say I’m sick. I don’t want to upset her.”
- “We can’t tell her. If we tell her she will give up.”
- “When you (I) get better.......”
Protected Awareness

• “Protected awareness”: unspoken but voluntarily shared state of understanding between R and provider

• Highly protective and deliberate in nature

• Both parties knew and wanted to address R’s impending death, but did so in a coded, indirect and/or metaphorical manner

• Patient led

• “Address it without saying it”
How do we plan for something that we haven’t said is happening?

How do we talk about something without really acknowledging that it exists?
i carry your heart with me (i carry it in my heart) i am never without it (anywhere i go you go, my dear; and whatever is done by only me is your doing, my darling)

i fear no fate (for you are my fate, my sweet) i want no world (for beautiful you are my world, my true) and it’s you are whatever a moon has always meant and whatever a sun will always sing is you

here is the deepest secret nobody knows (here is the root of the root and the bud of the bud and the sky of the sky of a tree called life; which grows higher than soul can hope or mind can hide) and this is the wonder that's keeping the stars apart


/i-carry-your-heart-with-mei-carry-it-in
The Rose That Grew from Concrete

Did you hear about the rose that grew from a crack in the concrete?
Proving nature's law is wrong it learned to walk with out having feet.
Funny it seems, but by keeping it's dreams, it learned to breathe fresh air.

Long live the rose that grew from concrete when no one else ever cared.

-Tupac Shakur

“Ocean”

Out for a swim under the sea
Caked my skin with sun screen
Entering the blue sea
Achieving some fish to swim with me
Never have I thought I’d be in the blue sea

“Pineapple”

Past under the sun
In the neighborhood riding my bike
Next to me is my dog, Burrito
Eating a treat that I gave him
Across the street I see my friends
Playing outside the front yard
Pleasing to stop running around
Leaving back to my home
Entering my home, taking off my shoes to take a nap with Burrito
But you never know what it does
Resting to make it all feel better
Across from other kids playing
I wonder if I will ever be normal again
Never let anyone bring me down

Trying to fight for my life
Using all my strength
Many other people stop and stare
Only I know they don’t understand
--- am I and I have a brain tumor.
Dear doctor,

Only you know what’s going on

Choosing on a decision

Trying to understand

Ok I will just go home

Replaying the memories of what happened today
“The Rose that was Powerful”

A rose growing in concrete is strong and powerful. All the other roses laughed because they thought it couldn’t grow, but it still stretched and found a way out.

The rose was told it would get stepped on and die but the rose said no matter what happens I know I’ll still shine bright.

-R
Saying Goodbye without Saying Goodbye

“I love you. Even though we always fight I’m glad you’re my sister. You will always be with me.”

“You are the best mom in the whole world. I love you so much. I’m sorry for yelling at you.”

“Thank you for everything you do for me and for my mom. I love you.”

“Be brave and be kind.”

Photo credit: Hania Thomas-Adams
Challenges & Ethical Issues

• Cultural
• Personal
• Practical
• Professional