

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

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100%
kids.



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**



Photo credit Hania Thomas-Adams

(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)]

**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 (i carry it in
my heart)**



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- “[i carry your heart with me(i carry it in)]” Copyright 1952, © 1980, 1991 by the Trustees for the E. E. Cummings Trust, from *Complete Poems: 1904-1962* by E. E. Cummings, edited by George J. Firmage. Retrieved from <https://www.poetryfoundation.org/poetrymagazine/poems/49493/i-carry-your-heart-with-me-i-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

Retrieved from
https://www.goodreads.com/book/show/151809.The_Rose_That_Grew_from_Concrete

“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

-R



“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



-R



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.

R am I and I have a brain tumor.



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
R--- am I and I have a brain tumor



Doctor

"Doctor"

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

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.”



Challenges & Ethical Issues

- **Cultural**
- **Personal**
- **Practical**
- **Professional**

