“It’ll Take a Miracle!”

The role of the palliative care provider when engaging with a family’s hope for a miracle

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Disclosures

I have no relationships with any industry pertaining to this presentation.
"I think you should be more explicit here in step two."
Objectives

Identify perceived challenges to working with a patient or family who are hoping for a miracle at end of life.

Appreciate the role of ‘hoping for a miracle’ throughout the disease trajectory within familial and cultural systems.

Describe strategies for engaging with families hoping for a miracle, supporting medical decisions and optimal care while mitigating provider moral distress.
What is a miracle?
1: an extraordinary event manifesting divine intervention in human affairs

2: an extremely outstanding or unusual event, thing, or accomplishment

3: a divinely natural phenomenon experienced humanly as the fulfillment of spiritual law
An event which must be extremely unusual or historically unprecedented from the perspective of empirical scientific knowledge.

Must evoke widespread wonder

Must be something freely given by God and not conjured

So what gives us pause...

Do they “get it?”

We likely cannot provide what they are hoping for

Are we preparing them well enough?

Does hope for a miracle interfere with optimal care?
Why is this relevant for palliative care?

PC role is to understand the values and goals of the patient and family, and therefore help guide complex Medical Decision Making.

Aid in defusing conflict with staff and engage non-PC providers around such dialogue.

What makes kids different...

It can feel unnatural to consider a child at end-of-life

Patient vs. family centered care

Where does “best interests of the child” come into play and by whom?
The hope for a miracle when short term and long term prognosis is unclear
Meet babyboy “J”

Five-day-old baby boy prematurely born at 30 weeks complex internal anatomy

Event in OR s/p to complications of hydrocephalus, large hemorrhage,

PC consulted as no neurosurgical interventions were available.
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Family hoping for a miracle - Do they “get it”?

Do they understand what might come when J is extubated?
Conversation tool

Affirm
I hear your loving hopes for your child.

Meet
We are hoping with you.

Educate
And I also want to talk with you about some of our worries for your child

No matter what
Our team will walk this path with you.

Harbinger of Denial vs. Prognostic Awareness
Role of Spiritual Care

Chaplain colleagues are expert in honoring journeys of faith and unique spiritual needs.

Illuminate our own understanding of a case through their specialized perspective.

Support providers in aiming to be spiritual generalists.
The family had excellent prognostic awareness, sought guidance for possible funeral planning

Family was also hoping for a miracle - their child's life was in God's hands
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Family was also hoping for a miracle - their child’s life was in God’s hands.

J was extubated and able to breathe on his own.

PC continued as an extra layer of support for future decision making, as J has unknown neurologic impairment.
Hope for a miracle at End-of-Life
Meet Babygirl D

Two-month-old girl born at 26 weeks with chronic lung disease, renal failure, and severe brain abnormalities

Intubated since birth on high settings

Rapid clinical decompensation including hemorrhage, perforated bowel, gram negative bacteremia requiring pressor support
Meet Babygirl D

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PC consulted for goals of care and aid in decision making

“This is going on too long”
Parents wanted to continue all interventions including mechanical ventilation on the oscillator and pressor support.

Praying for a miracle after the loss of their first pregnancy at 16 weeks gestation - holding distrust in the medical system.

They would “take her in whatever state she was in” and shared “we will never unplug our child”
Staff moral distress

Time and high levels of medical support in situations that may seem therapeutically ineffective can cause moral distress

Does hoping for a miracle = suffering at end of life?

Does prolonged time in navigating medical decisions = staff distress?

Recognize the role of the consultant vs. bedside providers

How can we mitigate distress?

Aim to be transparent in communication, especially over time.

Remain in communication with nursing and floor staff.

Support staff in exploring their own stress and concerns.

Things to avoid
Potential pitfalls

Trying to change the family’s mind by presenting more medical facts about how sick the patient is

Reflecting that miracles are rare

Engaging in theological debate and leading prayer

Reframing the miracle in a way that ignores the original sentiment
Some language we can use

“What would a miracle look like to you and your family?”

“What I hear you saying is that you are worried for your child’s future while also wanting to be able to hold your hope for their survival.”

“Hope and worry can exist side by side.”

“What else do you hope for?”

“We hope too. And we are worried…”

What we did

Sat with the family, joined with them in their hope - reflected their hopes while expressing worry daily

Discussed the family’s fear that D was suffering

Supported the staff who experienced significant moral distress around performing chest compressions

Contacted local clergy for support along with Spiritual Care
What we did

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20 days later the parents endorsed limits to resuscitation including DNR. Pressors were discontinued and intubation maintained - D died in parents arms soon after
Final considerations
Hope for cure is not associated with long-term traumatic grief or depression.

Faith and hope can be useful in creating meaning, providing comfort, and aiding in decision making.

Giving accurate and honest information does not diminish hope.

Cultural iterations of this hope must be explored.

Bereavement

Engaging with a family’s hope for a miracle creates language for bereavement.

Hope for a miracle can affect members in bereaved family systems differently.

Early PC involvement can help create longitudinal support.
Hope for a miracle and prognostic awareness are not necessarily mutually exclusive.

Using empathic communication, patience, and assessing understanding can illuminate ways to support patients, families, and staff.

Familial and cultural hopes for a miracle vary as well as their role throughout the disease trajectory and into bereavement.
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References


Thoughts? Questions? Discussion?

Thank you!