Pediatric Palliative Care: Treating the Whole Infant, Child, or Teen Case Based Practice

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Objectives:

• Use cases to more deeply investigate the unique challenges faced in pediatric palliative care (medically, ethically, legally and socially)

• Outline as a group an approach to managing some of these challenges

• Describe the ways interdisciplinary team members are critical to overcoming some of these challenges

• Discuss systems-issues that can be barriers to success
Objectives:

- Talk through a Pediatric PC case
- Discuss special challenges in Pediatric PC
- Discuss ways to overcome these
- Discuss systems-issues and other barriers
How Does this Work?

• You will hear details of a case
• At each decision point, vote with your feet
• Move to the area with the letter you choose
• We will have a short discussion at each point
A Decision is Made

A: I agree with this family’s choice and will support them

B: I disagree with this family’s choice but will support them

C: I disagree with the family’s choice and will tell my team how I feel

D: I disagree with the family’s choice and will tell the family how I feel
Disclaimer

- This case is fictional
- I am not an Oncologist!
- All of the photos are taken from the internet
Sofia

- Sofia is a 6 year old girl
- Her parents are Anita and Ivan
- Sofia loves Princesses—especially Disney’s Rapunzel
- She started Kindergarten this year and loves school
- She has no siblings but loves spending time with her cousins
- She has a dog named Sock
Sofia

- For the past two months, Sophia has been having headaches
- Sometimes ibuprofen helps but sometimes it does not
- Her parents took her to the PCP who felt it was allergies
- Sofia was started on Claritin
Sofia

• The Claritin didn’t help much
• On Tuesday, Sofia’s head hurt so much that she did not want to play with her cousins
• Her parents also noticed that she’s been clumsier than usual
• Today, Sofia started vomiting
• Her parents brought her to the MB ED for evaluation
Sofia
Medulloblastoma

- Most common malignant brain tumor in children
- 80-90% of those without disseminated disease can be cured
- Treatment often results in long-term neurological sequelae

https://reference.medscape.com/article/987886-overview#a1
Sofia

• Sofia undergoes neurosurgery
• The tumor cannot be completely resected due to its location
• She is brought to the PICU on a ventilator to recover
Sofia
Sofia

- Sofia has evidence of CSF metastasis
- The Oncologists determine that Sofia’s tumor is high-risk
- The 5-year survival rate is estimated to be 30-60%
- The Oncologists recommend chemotherapy and radiation

https://reference.medscape.com/article/987886-overview#a1
Sofia’s parents decide to go forward with chemo and radiation

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Sofia

- Sofia fails several attempts to be extubated
- An evaluation reveals vocal chord paralysis
- This is likely a complication of the neurosurgery
- It is not clear whether it will improve in the future
- The ENT consultant has recommended a tracheostomy
The ENT consultant describes the risks of tracheostomy
She describes the care that will be required in the home
Her likelihood of survival is still 30-60% with chemo and rads
Sofia’s parents decide to go forward with tracheostomy

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Sofia

- Sofia undergoes tracheostomy surgery
- She has a reaction to anesthesia and arrests in the OR
- She is resuscitated and receives 22 minutes of CPR
- She is returned to the PICU and is stabilized
MRI

https://emedicine.medscape.com/article/341293-overview#a3
Sofia

- Sofia’s MRI reveals diffuse hypoxic ischemic encephalopathy
- She remains intubated in the PICU
- She begins having seizures
Sofia

- Neurology is consulted and assists with seizure control
- They explain that her neurologic prognosis is unclear
- She is very likely to have some lasting deficits
- Could range from learning disability and difficulty with coordination to non-verbal spastic quadriplegia
- The impact of chemo on her neurologic recovery is unknown
Sofia
Sofia

- After two weeks, Sofia has stabilized enough to discuss the plan going forward
Sofia

- One option would be to continue with the planned tracheostomy and chemotherapy
- Her likelihood of survival is still around 30-60%
- Her risk of neurodisability is high; the severity is unknown
- The other option is to withdraw life support
Sofia

- Middle-ground options were also considered
- Waiting to allow time for neurologic recovery
- Tracheostomy without chemo
- Chemotherapy without tracheostomy was not recommended
Sofia’s parents decide to go forward with trach, chemo, and radiation

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Sofia

- Sofia receives a tracheostomy and recovers uneventfully.
- Chemotherapy is started.
- Her neurologic status remains very limited, although she has started opening her eyes at times and appears to respond to her parents’ voices and touch.
Sofia
Sofia

- Sophia becomes neutropenic from chemo
- She develops a fever and is started on antimicrobials
- She develops worsening respiratory distress
- Blood cultures are positive for candida albicans
Sofia

- Sofia develops multi-system organ failure
- She is believed to have fungal sepsis and meningitis
- She requires vasoactive infusions
- She begins having bleeding from her tracheostomy site
The PICU and Onc teams meet with Sofia’s family. They compassionately explain that her outlook is grave. She is unlikely to survive this infection, and if she does, she will likely have additional neurologic deficits. In addition, her neurologic recovery had been very minimal.
Sofia

- The team suggests to the family that they withdraw life support and allow Sofia to experience a natural death
Sofia

- Sofia’s parents do not wish to withdraw life-support
- They understand that the “odds are against her” but explain “we can’t give up on our little girl!”
- They explain that family and friends across the country are praying for Sofia and hoping for a miracle
- They show the team photos of Sofia from before her illness
Sofia
Sofia’s parents do not agree to withdraw life support

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Sofia

- Sofia continues to worsen
- The ICU team lets Sofia’s family know that they do not have any other therapies to offer that they believe will help
- They will not be able to escalate therapy
- They will not provide CPR as it will not be effective
- They will focus on keeping Sofia as comfortable as possible
Sofia

- Sofia’s family is very sad to hear this but they express understanding and are amenable to this plan
- They have her cousins visiting at the bedside daily
- They sneak in her dog “Sock” to provide her comfort
- They play Disney’s Rapunzel continuously in the room
Sofia

- They cry and look exhausted
- They speak to Sofia and tell her how much she is loved
Sofia’s parents do not want to withdraw life support but have agreed not to escalate care

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Sofia

- One night in the ICU, Sophia’s heart rate begins to fall
- Her parents are present at the bedside
- They ask if they can hold her without “all of the machines”
- With the physician’s approval, her RN and RT remove Sofia from the ventilator and places her in her parents’ arms
- They provide her with morphine and versed for comfort
- Sofia passes away peacefully
- Her parents thank the team for their kindness and care