The Role of Pediatric Palliative Care in the Cardiac Population

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I have no financial interests or relationships to disclose

There is no money in palliative care...
Objectives

Describe pediatric palliative care

Debunk some of the myths surrounding palliative care

Discuss palliative care in cardiac specific populations
Building a Palliative Team
A Truth and a Story

Some day, we will all die, Snoopy!

True, but on all the other days, we will not.
The Nature of Suffering and the Goals of Medicine

- “The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick.”
- “Failure to understand the nature of suffering can result in medical intervention that, though technically adequate, not only fails to relieve suffering but becomes a source of suffering itself.”

Eric Cassell, NEJM. 1982;306:639-45
A typical day on the Palliative Care Team, unplugging everything that can be unplugged.
1. "They're just a team you can vent to; it doesn't mean your child is dying."

2. "Palliative care has a bad rap, but they're not bad."

3. "I didn't manage why I should be removed."

4. "That was the reason in the open word, because a family had not been informed by the palliative care team."

5. "They said, you're the team we can talk about."

6. "Does this mean we're signed up for palliative care?"

7. "Her palate has been ok."

8. "You haven't really done any palliative care yet, right?"

9. "I haven't really done any palliative care yet, right?"
Palliative care should begin at the time of a potentially life-limiting diagnosis and continue throughout the disease trajectory, regardless of the expected outcome.

It’s about understanding the patient’s and family's goals, hopes and values in order to best support them with appropriate disease-directed treatments.

“Goals before holes”

Dan Mahoney, MD
Why is Palliative Care Important?
It is Important for Patients Because:

~50,000 children die each year, many in the ICU

~750,000 Living with a complex chronic condition

↓Mortality, ↑ Morbidity

#1 cause of death in infancy is a cardiac diagnosis and #3 overall of children 1-19 years

Discharging children to home with increasing technology

It is Important for Providers Because:

Palliative Care adds an extra layer of support for staff by:

- Helping to facilitate family conferences
- Helping staff to debrief after a death
- Educating on how to improve communication skills
- Assisting with goals of care and advanced care planning for shared patients.
• What was once a rare occurrence has become more standard

• Families are challenged with difficult decisions everyday such as:
  - Transplantation
  - VAD
    • Bridge
    • Destination therapy
Palliative Care – Not Just End of Life Care

It is just one piece of what we do.

Every encounter cannot be about end of life, and it isn’t.
Out with the Old

1. Incompatible Domains of Curative Versus Palliative Care:
   - Curative Care
   - Palliative Care

2. Competing Domains of Curative Versus Palliative Care:
   - Curative Care
   - Palliative Care
In with the New Better

- Cure-Seeking Care
- Life-Extending Care
- Quality-of-Life and Comfort Maximizing Care
- Family Supportive and “Grief and Other Emotions” Care
- Health Care Staff Supportive and “Grief and Other Emotions” Care

TIME

Diagnosis to Death
How Can We be Helpful to Our Cardiac Patients?

Offering an interdisciplinary approach that addresses the whole patient

Providing support for family AND caregivers

Providing care that is available wherever the child is located

Assisting with goals of care discussions, advance care planning and family meetings

Providing bereavement follow-up
“Actually, all of our physical, social, psychological, and spiritual needs are met right now, thank you.”
- Said by no one, ever.
The Path forward

- Looking at patient as a whole
- Getting perspectives from all team members
- Eliciting expectations from teams and patient/family
- Providing clear options
- Using Time limited trials
- Acknowledging emotions/fears
- Listening to patient’s and family’s goals/hopes
How we can help

• Clarifying goals that align with patient & family values

• Help with “regoaling”

• Address suffering

• Advance Care Planning/Legacy building

• Support and debriefing for medical teams
Are the Goals of Care in Alignment?

**Patient/Family Stuff**
- Survive at all cost
- Know they have done everything
- Maximize quality
- Be home
- Meeting life milestones
- Not suffer
- Not prolong dying
- Leave a legacy

**Medical Team Stuff**
- VAD
- Mechanical Ventilation
- Chest Compressions
- Transplant or Re Transplant
- Defibrillation
- ECMO
- Artificial Nutrition
- Tracheostomy
- More Surgery
Perceived Barriers

• Family wants us to do everything.
  We probably are doing everything.

• We don’t want to take away hope.
  You won’t and you may learn what else they are hoping for.

  “Use Hope as a verb, not as a noun” - Dan Mahoney, MD

• They’re not ready yet.
  They probably are and have unmet needs.

• We’re not there yet.
  If our goal is to integrate palliative care from time of diagnosis, we are there
Survey of pediatric cardiologists and cardiac surgeons from 19 pediatric medical centers n=155

- 60% felt that palliative care consultations occur “too late”
- 85% agreed that palliative care consultations are helpful

Pediatric Cardiology Provider Attitudes About Palliative Care: A Multicenter Survey Study

Emily Morell Balkin¹ · James N. Kirkpatrick² · Beth Kaufman³ · Keith M. Swetz⁴ · Lynn A. Sleeper⁵ · Joanne Wolfe⁶ · Elizabeth D. Blume⁵
When Should Palliative Care Be Consulted for Cardiac Patients?

• If you have periods of stability interrupted by acute decompensations

• Unexpected life threatening events or your patient has suffered a major neurologic event

• If there is uncertainty whether adding more technology may improve quantity or quality of life

• Prolonged or frequent hospitalizations

• Their serious illness make them vulnerable to life limiting complications
The Darkening Veil of “Do Everything”

We can’t do everything

There are trade-offs

Chris Feudtner & Wynne Morrison
Tell me more about your child?

What do you know about your child’s illness?

Where does your family find support and strength?

Do you have any spiritual or religious beliefs? Does it help you when making decisions?

Does your family make decisions privately or with others?

What are you worrying about and what are you hoping for?
“MOST PEOPLE DO NOT LISTEN WITH THE INTENT TO UNDERSTAND; THEY LISTEN WITH THE INTENT TO REPLY.”

STEPHEN COVEY
### Communication Tools

#### Ask – Tell – Ask
**Tool for eliciting Knowledge**
Ask: “What do you think about...?”
Tell: “Here’s what the tests show...”
Ask: “Can you share with me what you understand about...?”

#### Tell Me More
**Tool for understanding patient’s stance**
“Tell me more about...” When you are not sure what someone is talking about (Rather than jumping to conclusion)

#### I Wish...
**Tool for aligning with patients**
“I wish I could say that chemotherapy always works...”
(Enables you to align with the patient while acknowledging the reality of the situation)

#### I Worry...
**Tool for Firing a Warning Shot**
“I worry that Johnny’s lungs are not responding to the therapy...” (Enables the patient to hear the seriousness of the situation)

### SPIKEs Protocol for Breaking Bad News

| S – Setting | Find a quiet location, private. Decide who needs to attend. Have tissues, chairs and turn pages off. |
| P – Perception | **Tells you what the patient already knows** “Tell me what you understand about Johnny’s illness” or “What have the other doctors told you about Johnny’s illness?”
|   | **Look for knowledge and emotional information as they respond**
|   | **ASK-TELL-ASK** |
| I – Invitation for Information | **Ask permission to share difficult news** “Would it be okay for me to discuss the results of the tests/scans?” |
| K – Knowledge | **Give the information** Fire a warning shot...”I have something serious we need to discuss” or “I wish I had better news for you” or “I am very worried that...” Avoid medical jargon. Say it simply and the STOP talking. |
| E – Empathy | **Respond to emotion** Wait for the patient in silence. Touch if appropriate. Then, “I know this is not what you expected to hear today”. NURSE model |
| S – Summarize/Strategize | **Next steps** “We have talked about a lot of things today and sometimes I know I don’t make myself clear, can you please tell me what you understand about Johnny’s illness?” |

### NURSE Tool for Responding to Emotion

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<thead>
<tr>
<th>NURSE</th>
<th>Example</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Naming</td>
<td>“It sounds like you are frustrated.”</td>
<td>Turn down the intensity a notch when you name the emotion</td>
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<tr>
<td>Understanding</td>
<td>“This helps me understand what you are thinking and feeling.”</td>
<td>Kind of acknowledgement but stops short of suggesting you understand everything (you don’t).</td>
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<td>Respecting</td>
<td>“I can see you have really been trying to follow our instructions.”</td>
<td>Praise fits here</td>
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<tr>
<td>Supporting</td>
<td>“I will do my best to make sure you have what you need.”</td>
<td>Commitment to patient is powerful statement</td>
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<tr>
<td>Exploring</td>
<td>“Could you say more about what you mean when you say that...” or “Help me understand what you mean by...?”</td>
<td>Asking a focused question prevents this from seeming too obvious</td>
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**Baylor College of Medicine**

**Texas Children’s Hospital**
Resources

The Center to Advance Palliative Care (CAPC)
Resource for palliative care knowledge and skills, focused training opportunities

American Academy of Hospice and Palliative Medicine Hospice and Palliative Nursing Association
Organization providing education, resources, and training opportunities

AAP section on Hospice and Palliative Medicine
Pediatric-specific information and resources

End of life Nursing Education Consortium (ELNEC)
Adult and pediatric education, training and resources for nurses

My Wishes and Voicing My Choices
https://agingwithdignity.org/
One Last Myth…
It takes a village  PACT @ TCH