 **JOHNS HOPKINS**
CHILDREN'S CENTER

When Cure is No Longer an Option

A Multidisciplinary Team Training Approach

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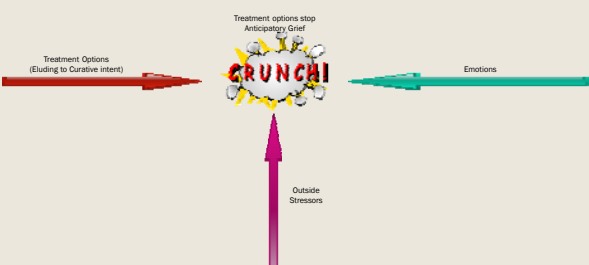
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Objectives

- Describe barriers for the transition of curative care to comfort care.
- Analyze the SPIKE model for sharing bad news and how the multidisciplinary team can partner with the family for the most effective advance care planning and end of life supports.
- Discuss methods for supporting the medical team in end of life discussions.
- Review initial assessment of pre training utilization and confidence of behaviors during difficult conversations.
- Discuss the steps for how to implement this multidisciplinary training model in various settings.

Collision



Treatment Options (Ebbing to Curative intent)

Treatment options stop
Anticipatory Grief

CRUNCH!

Emotions

Outside Stressors

High Stakes Communication Skills:

Why It Matters for the Family

- Reduces complicated grief^{1,2,3}
- Alliance between family & medical team^{4,5}
- Increases parent hope^{5,6,7}
- Reduces anxiety, depression, and PTSD^{8,9}

1. Jones et al. 2006; 2. Mensao et al. 2017; 3. Wolfe et al. 2008; 4. Studdert DM et al Pediatrics 2003; 5. Back Al; et al. JAMA 2005 ;-6. Meyer et al. 2006; 7. Boss et al. 2008; 8. Lauriette et al. 2007; Schwederman et al. 2003; 8.

High Stakes Communication Skills:

Why It Matters for the Institution

- ^{1/3} pediatric oncology deaths in the hospital¹
 - ^{1/2} PICU¹
- Reduced readmissions²
- Saves Money & Time³
 - Length of stay and \$ spent on each patient
 - Providing prognostic information alone did not produce any changes in LOS, costs, or team and family medical decisions
- Less litigation⁴
- Decrease in team conflict/burnout⁵

1. Kaye et al. 2019; 2. Auger et al., 2014; 3. Abrams et al., 2003; 4. 5. Embriaco et al. 2007

Communication Skills Training

- Oncology^{1,2}
- Palliative Care Training³
- Critical Care Communication Project⁴
- Program to Enhance Relational & Communication Skill (PERCS) ⁵
- Best model: lecture & hand's on experience⁶

1. Talsky et al. 2007; 2. De Vries et al. 2014; 3. Clayton et al. 2012; 4. Arnold et al 2015; 5. Meyer et al 2011; 6. Rosenbaum et al. 2004

Case Study A

- **Diagnosis:** Rhabdomyosarcoma (relapsed)
- **Additional Dynamics:** Transfer

Case Study B

- **Diagnosis:** T-Cell ALL
- **Additional Dynamics:** Low socioeconomic status. Chaotic household.

Multidisciplinary Team

"This training has opened my eyes to the different perspectives at the table and the mindset of different disciplines."

- Fellow
- Nurse
- Social Worker
- Child Life Specialist

Additional Team Members

- Attending
- Pharmacist
- Palliative Care Team
- Support Staff
- Chaplain
- Resident
- Nutrition
- Consult Services

Training Dynamics

- 11 PICU Nurses
- 5 Pediatric Social Workers (PICU, Cardiac, OB-GYN (2), Oncology)
- 4 PICU Fellows (3rd yr.)
- 1 PICU Child Life Specialist

Sessions

- 1st: Introductions (John Cagle PhD, MSW)
- 2nd: Tools & Practice (Dr. Renee Boss)
- 3rd: SIMs Practice
- 4th: Journaling & Review

Pre Training Surveys

**10 of 20 participants completed

- Demographics
 - Previous training
 - Experience with EOL
 - Ethnicity
- 2 Questionnaires
 - Utilization of SPIKES concepts
 - "Gives explanation in an organized manner using "bite-size" pieces."
 - "Allows family time to react (use of silence), allows for time to think."
 - Confidence in skills for difficult conversations
 - "Organize a strategy for disclosing information."
 - "Listen to families concerns."

Pre Training Surveys (cont.)

- Prior End of Life Experience
 - Job experience: 2 - 22 yrs.
- Prior Training
 - On the Job Training: 10
 - Continuing Education Sessions: 5
 - Formal Training: 4

Pre Training Surveys (cont.)

- Confidence in end of life discussion behaviors (M=5.94, SD=0.33) was significantly higher than utilization of SPIKES model specific behaviors (M=5.17, SD=0.58); $t(9)=-5.46, p<.001$.
- Why might this be?
 - Because I do this regularly, I must be good at it
- Is there a better way?

Goals for Training

- Evidence based targetable behaviors for end of life conversations
- Team perspectives/ team approach
- Increase confidence AND utilization of learned skills
- Develop use of common language during difficult conversations

Prognosis Conversation

Case Study A

- People present: Mother, Attending, Fellow
- Current prognosis (shared with family): Concerned but hopeful
- Family goals: Curative chemotherapy Team goals: Curative chemo/Amputation
- Reactions: Conflict, Chemotherapy

Case Study B

- People present: Parents, Attending, Fellow, Social Worker
- Current prognosis (shared with family): Positive
- Family goals: Curative chemotherapy Team goals: Curative chemotherapy
- Reactions: Therapeutic alliance

Case Study A: Rhabdomyosarcoma

Case Study B: T Cell ALL

SPIKES MODEL^{1, 2}

- Historically Oncological specific
- Base Model
 - Add on tools & skills
- SPIKES
 - (S)et up
 - (P)erception
 - (I)nvitation
 - (K)nowledge
 - (E)xpect Emotion
 - (S)ummary

1. Baile et al., 2000 2. Baile et al., 1999

HEADLINE:

- 1-2 sentences
- Keep it simple
- Focus on the patient & family

■ Pre-meeting huddle (w/o family present)

- Who has good relationships with the family
- Who is key to the discussion
- Who has key information
- HEADLINE
- How are we going to present this information
- SHARE responsibilities

"This training has built my confidence in asking higher stakes questions when I might have assumed that was the role of the fellow or attending. But I learned that is a lot of pressure for 2 people on an entire team."

PI – Family Perception

ASK-TELL-ASK

- Preunderstanding of patient & family
 - History
 - Expectations
 - Hopes/Concerns
- Is the family willing/ready for discussion
 - Listen to their answer

K – Knowledge

**HEADLINE
ASK-TELL-ASK**

- Headline
- Follow families example

EMPATHIC RESPONSES					
Meaning	Understanding	Respecting	Supporting	Exploring	"I Wish"
This result is: • Frustrating • Overwhelming • Scary • Difficult • Challenging • Hard	What you just said really helps me understand the situation better.	I really admire your: • Faith • Strength • Commitment to your family • Thoughtfulness • Love for your family	You will do our very best to make sure you have what you need.	Could you say more about what you mean when you say: • I don't want to give up • I am hoping for a miracle	I wish we had a treatment that would cure you (make your illness go away). (Remember we do have palliative treatments to offer the patient)
It's wonderful if you are feeling ... • Sad • Scared • Frustrated • Overwhelmed • Anxious • Nervous • Angry	This really helps me better understand what you are thinking.	Thank you for your dedication, skill, passion, and hard work. You are a strong person and handle stress through so much.	Our team is here to help you with this.	Help me understand more about ...	I wish I had better news.
It sounds like you may be feeling ...	I can see how feeling ... with this might be ... • hard on you • frustrating • challenging • scary	I can really see how (strong, dedicated, loving, caring, etc.) you are.	We will work hard to get you the support that you need.	Tell me more ...	I wish the situation were different.
In this situation, some people might feel ...	I can see how important this is to you.	You are such a (strong, caring, dedicated) person.	We are committed to help you in any way we can.	Tell me more about what (a miracle, fighting, not giving up, etc.) might look like for you?	I wish that for you has. (In response to what a patient or family member wishes, such as a miracle)
I can't even imagine how (SCARED, ANNOYED) this must be.	Dealing with this illness has been such a big part of your life and takes so much energy.	I'm really impressed by all that you've done to manage your illness (help your loved one deal with their illness).	We will go be here for you.	Can you say more about that?	I wish we weren't in this spot right now.

Goals of Core Conversations training materials were developed and made available for public use through U.S. Department of Veterans Affairs contracts with Westlab (DODMVA 1771-0-01-0002 and 1771-0-01-0003).

S – Summarize

- Check in on families retention
- Summarize
- What's next

ASK-TELL-ASK

Prognosis Conversation

What would your HEADLINE for Case Study A be?

- People present: Mother, Attending, Fellow
- Current prognosis (shared with family): Concerned but hopeful
- Family goals: Curative chemotherapy Team goals: Curative chemo/Amputation
- Reactions: Conflict, Chemotherapy

How would you Headline for Case Study B?

- People present: Parents, Attending, Fellow, Social Worker
- Current prognosis (shared with family): Positive
- Family goals: Curative chemotherapy Team goals: Curative chemotherapy
- Reactions: Therapeutic alliance

Case Study A: Rhabdomyosarcoma Case Study B: T-Cell ALL

Let's Talk Big Picture



- Percentages aren't personal
- Best Case – Worst Case
- Working together
- What could this look like next year

Comfort Care Conversation

(How would you Ask-Tell-Ask for Case Study A?)

- People present: Mother, Mother's boyfriend, Attending, Fellow, Social Worker
- Current prognosis (shared with family): Progression to lungs. No cure
- Family goals: Curative chemotherapy. Return to family for EOL Team goals: Palliative chemo/Amputation
- Reactions: Conflict. Continued Conversation. Family left US and experienced EOL with community.

What would your Ask-Tell-Ask for Case Study B be?

- People present: Parents, Attending, Fellow, Social Worker, Clinic Nurse, Child Life
- Current prognosis (shared with family): Progression on chemo.
- Family goals: Palliative care on the floor Team goals: Palliative care on the floor
- Reactions: Therapeutic alliance

Case Study A: Rhabdomyosarcoma

Case Study B: T Cell ALL

Practice Makes Perfect

- SIMS Lab
- SIMS Center
 - <https://www.ssih.org/Home/SIM-Center-Directory/Area/US>
- 2 case studies
 - Scenario #1: 8 month old.
 - Scenario #2: Pre BMT patient. International transfer- Military family.

Limitations & Learning

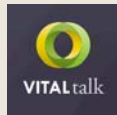
- Number of training participants
 - % of survey responses
- Time between training
- Buy In: Institution, Department, Discipline
- Voluntary/Mandatory
- Logistics
 - room availability and size of room
 - cost of sim center attendance
 - changing hospital schedules
- Focusing on the multiple teams
- Feelings, feelings, feelings

Next Steps

- PICU based training 2020
 - Leader from each discipline
- Expansion to other departments

Questions & Ideas

www.VitalTalk.org
www.ssih.org/Home/SIM-Center-Directory/Area/US



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