



Honoring a family's goals about a meaningful life and death.

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Palliative Care Program

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Introduction/Aim

- To explore how a family's own micro culture impacts views on quality of life and their child's death.
- To identify how a family's understanding of their child's illness can evolve and change over time and how that impacts their choices.
- To talk about and understand some of our own internal biases, why they are normal, and how we can incorporate awareness into our practice so that it does not impact patient care.

Bias Self-Assessment

- Ground Rules:
 - Be honest and open
 - What is shared in this room stays in this room
 - Try not to make assumptions of others reactions and what people are able to share
 - Remember that we all hold biases

Thought/Reactions

Were you surprised or uncomfortable by any of your answers?

Are you willing to share more with the group?

How might others at your organization answer some of these questions?

Definitions

Bias is the cognitive tendency among humans to make systematic decisions in certain circumstances based on cognitive factors rather than evidence. Bias becomes a concern when it interferes with how we make fair decisions.

-**Conscious Bias**-the person is very clear about his or her feelings and attitudes, and related behaviors are conducted with intent.

-**Implicit/Unconscious Bias**-operates outside of the person's awareness and can be in direct contradiction to a person's beliefs and values.

Implicit Bias in Healthcare

Negative Implicit Bias of providers:

- Health outcomes
- Family centered communication
- Patient/Family Satisfaction
- Trust
- Providers access to contextual information
- Impacts clinical decision making**
- Who do we want to live?**

Case Narrative

Crystal:

- Infant with progressive neurodegenerative disorder caused by a gene defect
- Chronic respiratory failure
- Hypotonia, developmental delay, microcephaly
- Parents declined tracheotomy

Parents:

- White married couple
- Highly educated
- Jobs/Employment as great part of identity
- Adventurers

Family as Micro Culture

- Preferences for Care
- Communication Patterns
- Meanings of Suffering
- Decision Making Process

Themes

Shifting goals

- Families are continually assessing their child
- How can we support you and your child today?

Perceptions of Suffering/Quality of Life

- Who defines suffering? Quality of Life?

Communication

- Amongst primary medical, hospice, home care
- Between parents and with medical team

Bias in this Case

- My own
- Others

Questions/Strategies

- How can we best support your family in the hospital/going home/planning for the future?
- What is important for us to know about your faith or spiritual needs?
- How are decisions made in your family? (Is there a head of the household? Does family adhere to more traditional/cultural roles within their family?)
- Where do you find your strength to make sense of this experience?
- How has your family's life changed?
- What were other important times in your life and how might these experiences help us understand your situation?
- How can you partner with spiritual care and other support services to best support this family? What relationships do you or your organization have with supports outside of the hospital/organization?

Small group discussion

- Review your case study
- Have you made any assumptions about race/class/identities of patient and/or family?
- What are your initial thoughts about this families choice?
- How might that impact your ability to support this family?
- How might you navigate your bias in order to support this family?

Large Group

- Share thoughts/answers from small group discussion
- Any other thoughts or your own experience/examples
- Cases from your organization you would like to share?

Crystal's death

A “good death”

- Died at home in her parents' arms
- Hospice/home care supports in place
- Continued support by SCH Palliative Care
- Continued support and relationships with their care teams

Questions/Comments



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