

PARTICIPANT HANDOUT

LEARNING OBJECTIVES

Participants will be able to:

- Recognize the importance of empowering children and parents to make choices regarding day-to-day as well as long-term concerns regarding the child's treatment.
- Identify the types of choices and range of options that are available or could be implemented in your hospital to increase the voice of children and families in the organization and implementation of family-centered pediatric palliative care.
- Identify existing institutional constraints to the implementation of family-centered programs and policies, and discuss strategies for addressing these constraints.
- Explore the extent to which the child's experience of life-threatening illness and of the hospital culture is recognized and validated on a clinical and organizational level.

DISCUSSION QUESTIONS

Question 1:

Mattie and Jeni each give examples of big choices and little choices that children and parents need to have control over while in the hospital and throughout the course of illness. Imagine for a moment that you are a preadolescent child hospitalized with a life-threatening illness. What are the choices, large or small, that you might want to have control of or input into?

Now imagine that you are the parent of this same gravely ill child in the hospital. What choices, large or small, would *you* want to be able to make?

Question 2:

- (a) Jeni asserts that parents should have the option to be included in any and every conversation that has to do with their child. List all the "family-centered" programs, policies, and procedures you can think of that are currently in place in your hospital.
- (b) Should there be limits to parental involvement? Should parents serve on family advisory councils? Should they be involved in daily rounds? Treatment planning meetings? Discharge planning meetings? How should children and adolescents be involved? How does family participation relate to the idea of a "working partnership" between practitioners and children/families?

Question 3:

Mattie describes his experience while a patient in the intensive care unit. How well do *we* attend to the interior thoughts and feelings of children who are hospitalized? When are thoughts and feelings unseen or neglected? Whose role or responsibility is it to understand a child's personal thoughts and emotions? Are there any policies or procedures in place that inhibit or prevent us from being as responsive as we might be to a child's experience?



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Intensive Sense

In the PICU. . .
I see bright lights,
But there is no sun,
And almost a loss of time.
I hear machines alarming,
But though they ring warnings,
Lives are not always saved.
I feel pain, intense at moments.
But I also feel the hurt of anxiety,
And neither anguish is good for the spirit.
Someday, I will leave the PICU, again.
I will see the sun,
Rising into new days,
but I will know it must set, too soon.
I will hear music sounding,
Ringing from so many instruments,
But most of it will be memories of my Heartsongs.
I will feel my spirit rejuvenated,
And I will be filled with hope again.
But, I will feel a sad sense of loss
For the children
Who will be Still
With the anguished sounding loss of time. . .
In the PICU.

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