Working with families of children during and after Pediatric Intensive Care exposure (with and without Pediatric Delirium) to improve outcomes

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Objective
Engaging families to help mitigate the traumatic effects of critical care unit exposure

Hospitalized children and their families are exposed to extreme stress, familial and developmental disruptions. Pediatric Delirium complicates hospital experiences and outcomes through prolonged length of stay, increased time on ventilation, and through altered consciousness and cognition can alter the ability to process what is happening, at times causing delusional and false memories for the child, and confusing and frightening experiences for the family. New approaches that engage families separately or more comprehensively as part of ABCDEF Bundles may improve outcomes for children and their families. Deeper understanding of the hospital experience and memories retained may help outpatient providers.

Method
We piloted **a developmentally specific Toolkit** to help engage families and children in orienting, cognitively stimulating activities for the day, and sleep supportive measures for the night, as well as the introduction of a journal to help narrate, and process the experience in our Pediatric Intensive Care Unit (PICU). **We specifically targeted children at high risk for delirium (age <5 years, on invasive mechanical ventilation) and/or those children who were already delirious,** and obtained feedback from 15 families with whom we evaluated feasibility with leadership from Child Life.

Results
Of the 15 families, 3 did not use the kit at all. Of the 12 remaining families, nearly all used the headphones, DVD player, toys, and games. Most did not use the blank notebook for journaling. Importantly, many families (10/12) responded to the educational material by bringing in familiar items from home such as blankets and pictures, as suggested to help comfort and orient their child.
This pilot demonstrated good feasibility, and anecdotal satisfaction from patients and families. Future research is necessary to determine the effect of this toolkit on pediatric delirium rates.
In spite of the fact that there is a broad literature encouraging the use of journaling for various mental illnesses (eg. PTSD, depression, and anxiety), and it is one of the few psychological interventions described in the PICU literature (Jones et al., 2010), our blank journal was not used by most families in this pilot
To remedy this we developed a structured template for “My PICU Journal” (copyright in progress), a user-friendly kit with a pre-made pages that can be added or subtracted from the patient’s story to fit their own personal journey through the PICU.

Discussion
Using a developmentally appropriate toolkit to engage families in the hospital is one feasible approach to improving hospital experiences and moderating some of the effects of hospitalization.
Patients and families may take the experience of engagement to seek greater engagement on subsequent visits, and in helping themselves and their children to process the experiences after return home. One of our parents was inspired to create a PICU Journal for her son, and from that lead development of “My PICU Journal.”

Conclusion
Child and Adolescent Psychiatry can work collaboratively with families and with Child Life services to improve care in the PICU. These experiences can inform other work with children and their families who have had histories of critical care exposure. Engaging parents to support their children may help limit their trauma and therefore allow them to be better supports for their children.

Pediatric Delirium prevalence 20-65% in critically ill children
(Smith et al., 2015; Traube et al., 2014; Traube, Silver, Reeder, et al., 2017; Meyburg, et al. 2017)

Delirium Prevention Toolkit:
to involve family in improving orientation and cognitive engagement of children, and decrease need for sedation.

1. Educational Pamphlet
2. Age appropriate clock
3. Daily schedule
4. Developmentally appropriate toys, books, music
5. Headphones
6. DVD player
7. Eye Mask
8. Lotion
9. Blank Journal

Family Engagement:
Family-centered initiatives look to increase the parents’ involvement as members of the PICU team. One mother said, “I know how to parent him when he’s well, but am afraid to even touch him now that he’s so sick”.

Child Development:
Developmental considerations are of utmost importance in pediatrics (Silver, Kearney, Traube, & Hertzog, 2014), as our goal is to get a child onto a developmental track and optimize the developmental trajectory

Background Literature
Colville et al. (2009 ICCN)
Parents report of what most impacted them during child’s PICU stay:
1 vivid memories of admission
2 Distress re. **their ability to protect their child,**
3 Ongoing parental priorities.

Nelson and Gold, (2012)
Review of Lit re. PTSD post PICU:

children-5-28%
sxs 68%
parents-10-21%
sxs 84%

G Silver, C Traube, A Systematic Approach to Family Engagement:
Feasibility Pilot of a Pediatric Delirium Management and Prevention
Toolkit, Palliative and Supportive Care, 2019
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