

## Introduction

The death of a child is a devastating experience. While there have been significant advances in medicine, there are still children who will experience life-threatening illnesses in which some will die.

Children facing life-threatening illnesses & their families should have access to competent, compassionate, & developmentally appropriate palliative care offered at time of diagnosis (American Academy of Pediatrics [AAP], 2000).

Palliative care should begin at the time of diagnosis & continue concurrently with curative efforts regardless of outcome in all pediatric settings. Pediatric nurses typically spend significant amounts of time with these children & their families attempting to identify, advocate for, and manage the palliative care needs of these children & their families.

Formal education for pediatric ICU nurses is sorely lacking. Few systems, are in place to assist the pediatric ICU nurse with feelings associated with caring for a dying children

Pediatric ICU nurses may be confronted with numerous physical, psychological, ethical, social, and spiritual dilemmas which may create a personal challenge while handling the various situations which may arise during this difficult time for the child and family (Malloy, Ferrell, & Virani, 2006).



## Aim

To explore the meaning of Pediatric ICU nurses experience regarding delivery of palliative care to children with life-threatening and their families.

## Sample and Methods

Semi-structured interviews conducted with 12 pediatric ICU nurses in a rural tertiary level, non- freestanding hospital in the northeastern United States

Hermeneutic Phenomenological Analysis as delineated by Cohen et al. (2000) to uncover the essence and examine the meaning within the contextual experience.

## Background

- 500,000 children coping with life-threatening illness (Knapp et al.,2011)
- 53,000 deaths annually (Levetown, Hellsten & Jones, 2010)
- 200 children/100,000 admissions require PICU (Shudy et al., 2006)
- Nationally 80% of children who die in the hospital die in the PICU (Levetown, Hellsten, & Jones, 2010)
- Reality - Parents & healthcare providers often choose & continue aggressive treatment to very end of child's life (Sumner, 2010)
- Pediatric ICU nurses may be challenged by numerous quandaries of their own
- Pediatric nurses may not feel adequately prepared to address & meet needs of the child & family
- Nurses are working in a complex environment with rapid change, limited resources & sicker patients (Foglia et al., 2010).
- Caring for a dying child is personally & professionally multifaceted for pediatric ICU nurses.

## Results

Five major themes and respective sub-themes were identified from the data.

### Table 1. Major Themes & Sub-themes

#### Journey to Death

- **The Emotional Impact of the Dying Child** - Children dying part of their job: each situation unique & remarkably demanding
- **The Emotional Impact of the Child's Death** – Very trying to watch families experience such sadness
- **Concurrent Grieving** - Making sense of a senseless situation; grieve with families
- **Peaceful Ending** – Make a “positive” for the family

#### Lifelong Burden

- **Parental Burden of Care** - Parents not able to reach acceptance and reality of child's condition

#### Challenges Delivering Care

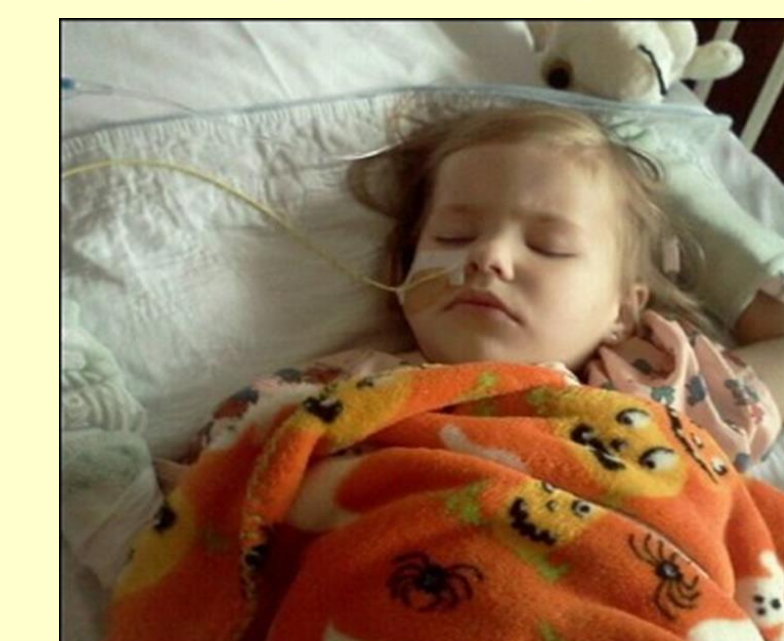
- **Maintaining Hope** for Families – Try to instill a sense of hope despite disease progress
- **Unclear Communication** – Family misunderstandings due to “sugar coating” of medical situation
- **Need to Hear the Child's Voice** – Children should have a “say” in their medical care
- **Remaining Respectful of Parental Wishes** Trying to be mindful when not in agreement with parental wishes

#### Maintaining Self

- **Colleague camaraderie & support** – Important to share feelings with someone having similar experience
- **Personal support** - Rely on family to get through difficult situations

#### Crossing Boundaries

- **Relationships** – Develop relationships with children and families



## Conclusion

The death of a child is devastating. Providing pediatric palliative care can be demanding as well as rewarding. These themes offer insight into the complexity of caring for these children and their families. The experiences depicted and shared by the participants provided an understanding of their journeys in delivering palliative care for children with life-threatening and life-limiting illnesses and families through this difficult period.

### Pediatric Palliative Care – What It Should Be

- Recognize and respond to palliative care needs
- Encompass child, family, and extended community
- Support the rights of children living with life-threatening illnesses
- Provision of well-coordinated, compassionate integrative care
- Assist with decision making re: life-sustaining interventions
- Communication and the Art of Listening
- Maintaining hope, continuity of care
- Bereavement follow-up
- Support for caregivers and nursing staff (O'Shea & Kanarek, 2013)

## Future Directions

Future research is suggested to explore spirituality and nurses' experiences of caring for children with life-threatening and life-limiting illnesses and their families as this was not evident in the study's findings. Additional research to discover pediatric ICU nurses experiences in urban settings with a more diverse sample of participants, with and without a pediatric advanced care team (PACT) could further expand this study's findings.