

Understanding Nurses' Experiences of Supporting Parents and Families to Care for Children who are Dying, in Qatar

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Overview

- Currently, there is no formal pediatric palliative care service in Qatar for pediatric patient and their family. Nurses have a variety of backgrounds and educational experiences. We wanted to learn more about how nurses could be prepared to care for dying children and their families.



Purpose:

- To gain a deeper understanding of the meaning of the lived experiences of nurses in Qatar who are supporting parents and families to care for children who are dying.
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Objectives:

- 1. To develop a description of a nurse's role in supporting parents and families to care for children who are dying.
- 2. To identify supports and resources that are used by nurses to support parents and families who are caring for a child who is dying.
- 3. To identify what education and resources nurses need to fulfill their role of caring for the parents and families of the dying child.



Question:

- We have one research question to guide our study:
- 1. What is the lived experience of registered nurses who support parents and families to care for a child who is dying?
- This question is addressed by two sub-questions:
- A. How do nurses describe their experiences of caring for a child who is dying?
- B. What resources and supports do nurses need in order to support parents and families who are caring for a child who is dying?



Description of Participants

- ▶ Female Pediatric nurses with experience in pediatric ICU and Hematology.
- ▶ Experience ranged from 1 to 25 years
- ▶ Nurses were from India, Philippines and Arabic speaking countries in the Middle East and Northern Africa (MENA)
- ▶ Frontline registered nurses working in HMC including educators and charge nurses
- ▶ Working in a multicultural and multilingual environment



Method – Interpretive Description:

- Interpretive Description draws on nursing's clinical practice background
- Can be used to address problems we face in clinical practice
- In this design the researcher identifies characteristics, structures, and patterns of a phenomenon, and then uses these elements to build knowledge about the study phenomenon for the study participants (Thorne, Kirkham, & MacDonald-Emes, 1997)



Data Collection/ Interviewing

- ▶ Learning about interviewing
 - ▶ Nursing students relied on their experiences interviewing patients and their knowledge from their research course in addition to some of the chapters in Sally Thorne's book on interpretive description
 - ▶ Students learned that interviewing would be done with open-ended questions, active listening, identifying themes, and inquiring more about the themes nurses brought up during the interview
 - ▶ Students used an interview guide to begin the interview with each participant – every participant was asked these questions.



Data Collection/ Interviewing Continued

- ▶ Students identified how the interview questions can answer the research question
 - ▶ Students then practiced interviewing research mentors several times and by themselves in their own time
 - ▶ Learning how to do reflective writing about the interview to use as field notes
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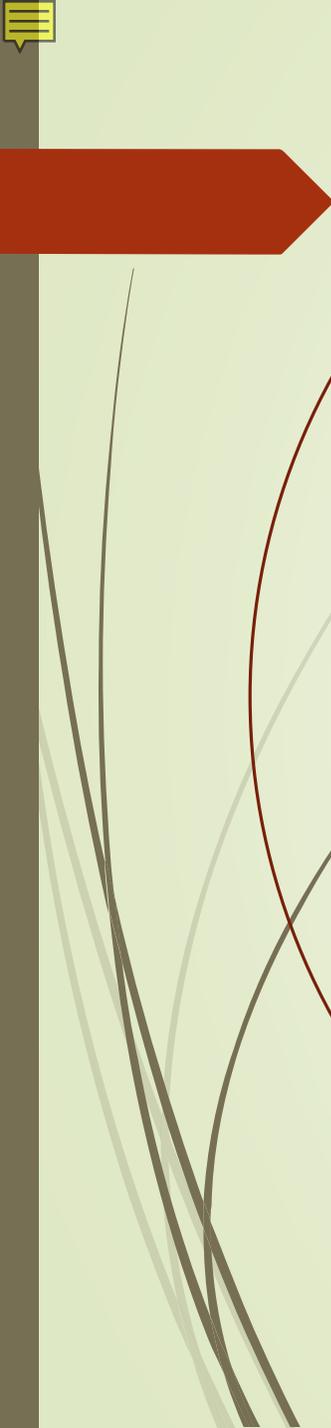
Data Analysis

- ▶ We reviewed the interview transcripts, while listening to the audio-recording of the interview
- ▶ We meet as a group to discuss how to do broad-based coding
- ▶ We worked in smaller groups to develop a collection of codes
- ▶ We came back together as a group to discuss how the codes and themes could create a pattern of the experience
- ▶ We developed a conceptual understanding of the experience



Findings

- Nurses' Role in supporting Parents & families
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Influenced by:

- Cultural and religious beliefs and customs
- Father/ Uncle (male) as decision-maker for family
- Physician communicates withdrawal of treatment and prognosis
- Nurses who are mothers are vulnerable when a child dies

Nurses focus:

- Child's care and comfort
- Support of mothers and other family members
- Offering help and hope in a difficult time
- Coordination of care
- Planning end of life care
- Communication

Supports:

- Other specialities, such as Anesthesia to assist with pain management
- Other nurses for support and education of nurses
- Access to networks and professional groups for courses and care pathways
- Preparation of the family for death of child

Implications for Practice

- Support the nurse educators to work with nurses and multidisciplinary team (MDT) to explore models of family-centered-care and pediatric palliative care
- Support nursing, medical and interdisciplinary staff to develop a two pronged process for debriefing after a death to what worked well and what needs to be improved
- Provide an opportunity for sharing of grief amongst team members so they may unburden and hence be better equipped to care for patients in the future



Implication for Education

- Having foundational knowledge built on palliative care principles, especially those that discuss caring from a family members point of view, encourages nursing students in the facilitation of family centered care.
- Grounding students in the very essence of what palliative care practice denotes facilitates upstream thinking as they prepare and encourage family participation in the care trajectory of persons with cancer.



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Questions???

Thank you