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

Karen Kooyman Gauthier, RN; BSN
Mihirani Chandraratne; Alka Cherian; Nicole D’Souza; Maria Elpuz; Suzette Isaac; Inca Kriel;
Arlene Masaba, MSN, BSN, RN;
Jessie Johnson, RN, PhD; Kathryn Banks, PhD, MSN, RN
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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.
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, & Mac Donald-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
Data Analysis

- We reviewed the interview transcripts, while listening to the audio-recording of the interview.
- We met 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
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.
Questions???

Thank you