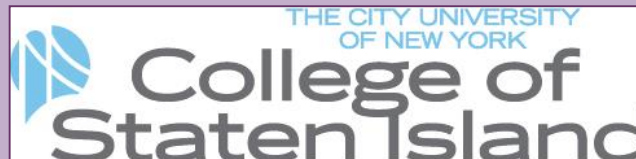


The Lived Experiences of Nurses Caring for Dying Children: Preparing Students and Nurses for Practice



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Faculty Disclosure

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The goal of this presentation is to provide insight and knowledge for students and nurses about the experiences of pediatric nurses while their patients are in the process of dying.

Objectives will allow for:

- Identification of how nurses use adaptation to care for dying children, and the importance of the need to adapt using the knowledge, skills, attitudes, and actions of nurses involved in caring for dying children.
- Utilization of nurses' experiences, attitudes, and actions in caring for the dying child to educate others on how to enhance adaptation, provide reasoning, and substantiate nursing practice.

Why is this information important?

- Many research sources provide information to help the patient and family during the dying process.
- However, there is a paucity of research that provides information for nursing students and bedside nurses to help **themselves** during the dying process of their patients.
- Learning about the insights of nurses helps to supply knowledge, skills, and attitudes as well as validate personal experiences.
- These insights can be learned, translated, and transferred into nursing curriculum.

Dissertation Research

The Lived Experiences of Nurses Caring for Dying Pediatric Patients:

1. Qualitative study
2. Roy Adaptation Model
3. Documented nurses knowledge and experiences
4. Supported this knowledge with evidence based literature

Qualitative Research

- Max van Manen, a phenomenologist, explained that individuals have unique perceptions of their own experiences.
- Through interviews with individuals interpretations of their communication can lead to meaning, description, and interpretation of specific phenomena, known as the “lived experience”.
- Methodology of van Manen
 - Identify a phenomenon that interests us
 - Conduct an investigation of the phenomenon as the lived experience, not as it is conceptualized
 - Reflect on illuminated essential themes that characterize the phenomenon
 - Write and rewrite in order to describe the phenomenon
 - Maintaining a strong relation to the phenomenon in terms of pedagogy
 - Balance the context by considering the parts as well as the whole

(van Manen, 1990)

Research and Participants

- Face to face interviews 35 – 45 minutes in length
- Study sample consisted of 9 female Registered Nurse participants
- All 9 were employed at large metropolitan hospitals and had between 1 and 4 years experience in pediatrics
- Ages ranged from 24 to 37 years of age
- 3 were married, 6 were single, 4 were mothers

Seven Themes

- Empathy
- Feelings of Ambivalence
- Inevitability
- Inspiration
- Relationship
- Self-Preservation
- Sorrow



The nurses described the context of their experiences in relation to:

1. the dying pediatric patient
2. the families
3. nursing

Empathy

- You are working with parents almost more than you are working with children
- Nursing is more rewarding and there is more pride in helping a patient die peacefully
- It's just too hard to wrap your head around a child dying... it's not the natural order of things



Feelings of Ambivalence

- You're not making life better for the child, you are making life better for you
- It's hard to feel good about what you are doing
- Sometimes you should let them go and not do all these extra heroic things

Inevitability

- You just can't prepare yourself for it, it's just something that happens (death)
- You try to do the best because it doesn't matter if you do or not, it's still going to happen (death)
- Because I've seen this so much (death), I can predict how this is going to go

Inspiration

- Even if I just came here to be that moment, in that moment for that person, then everything else is worth it
- Every day I will have a smile on my face for her, because I know she would



Relationship



- You fall in love with them
 - You become very attached to these kids
 - There is always somebody who picks that kid to love, and becomes attached to that child
- Remember the name and
child I've seen
die
- I'll never forget him

Self-Preservation

- It's almost easy to compartmentalize and forget
- Trying to manage, today I'm just managing today, I'm just taking care of today
- ...distance yourself from them (dying children) because otherwise you couldn't go back the next day
- They just don't understand how close we all have to become (the staff) in order to be as professional as we are

Sorrow

- You have to get in your car some days and cry the whole way home
- It moves you....you have to pull for these kids; you pull for their families
- If you weren't crying, I would be very concerned about you right now, you really would be in the wrong spot (nursing)
- You cry later when you get home....I got out of the building and I sat in my car and I cried
- I'm no good to them (children and families) if I am crying

Interpretive Statement

- Censoring, as an adaptive process by the pediatric nurse, is a result of confrontation by the stimuli of the dying child, creating behaviors of empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow.
- Censoring is a combination of these themes as they relate to the dying pediatric patient, the families, and nursing.
- An interpretive statement was formulated from the 7 themes and an overall descriptive meaning of adaptation became apparent when understanding how the stimuli affected the nurses' behavior

The Roy Adaptation Model (RAM)

Stimuli (the dying child)

Adaptation Process (Censoring)

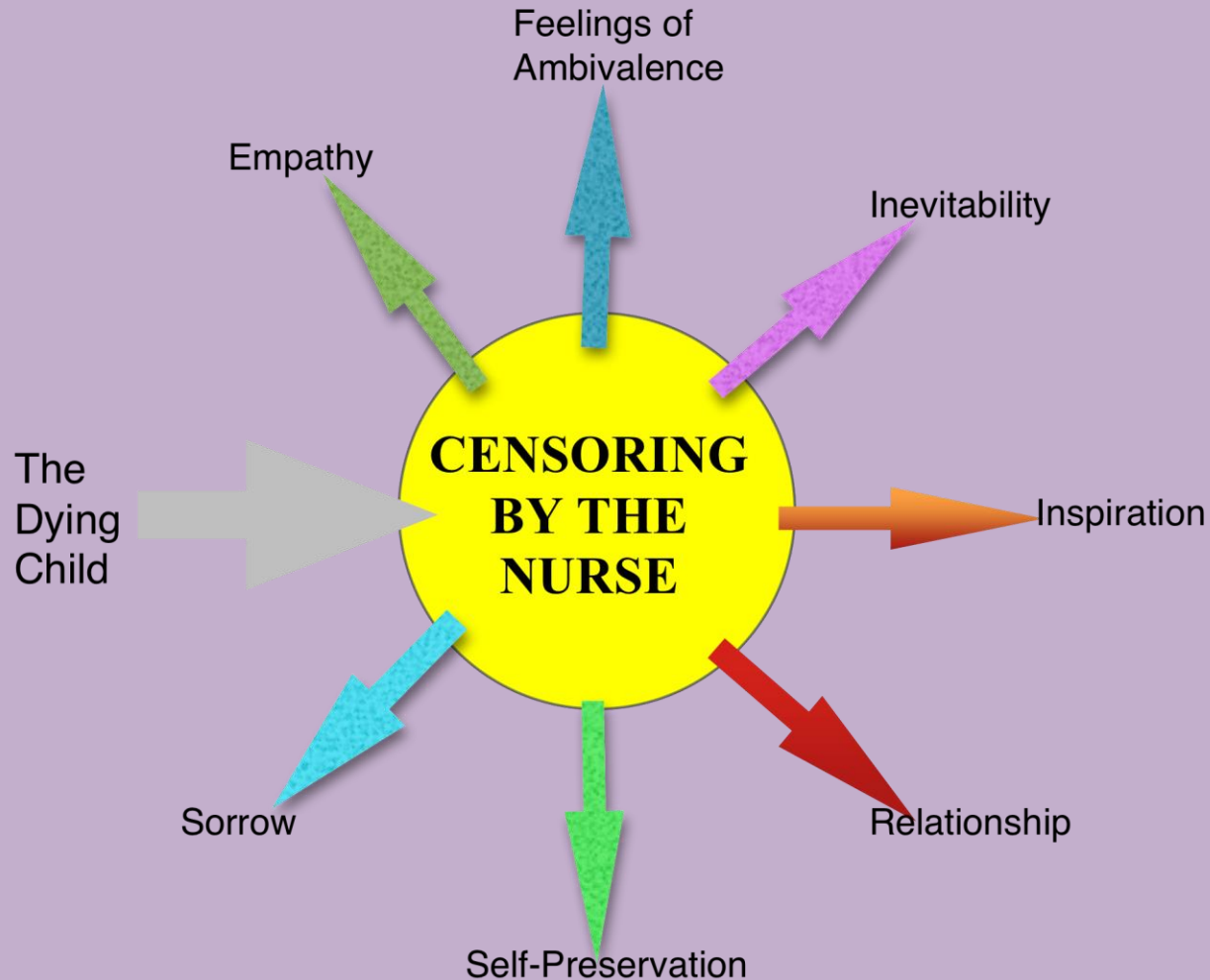
Behaviors (empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, sorrow)



- The nurse creates conscious choices that influence his or her personal level of adaptation
- This study concluded that it is censoring of stimuli that create the adaptive process
- Censoring then becomes a compensatory adaptation process in pediatric nurses

(Roy & Andrews, 1991; Roy, 2009)

Thematic Model of Censoring



Implications for Nursing Education and Practice

1. This research provides a better understanding of what it is like to be a pediatric nurse caring for dying children
 - Experiences of other nurses need to be understood in order to provide the best, effective care to dying children (Adesina, DeBellis & Zannettino, 2014).
 - When nurses care for the dying, without any understanding or education on the subject, they tend to suffer from anxiety, limit their involvement with the dying patient and family, and are likely to withdraw from patient care (Mutto, Errazquin, Rabhansl & Villar, 2010).
 - Education about this subject can help nursing students and bedside nurses apply their knowledge on the concepts of censoring to aid in the adaptation process for themselves and provide better care for dying children (Adesina, DeBellis & Zannettino, 2014).

Implications for Nursing Education and Practice

2. This research illuminated the behavior, self-discipline, and knowledge of nurses for future use in nursing education and practice
 - Nursing students and novice nurses may face ethical dilemmas and lack of knowledge in this area due to inadequate preparation and exposure to dying patients (Adesina, DeBellis & Zannettino, 2014).
 - Nurses are at the bedside preparing patients for death, however they themselves are not prepared about the experience they will face in dealing with this issue (Mutto, Errazquin, Rabhansl & Villar, 2010).
 - The emotional stress and feelings of being overwhelmed can potentially cause nurses to think they are the only ones who feel that way, mainly because of lack of knowledge and lack of understanding that this is a natural process within themselves (Morgan, 2009).
 - Experienced nurses have learned to “let go” and leave emotional burdens at work (Zander, Hutton & King, 2009).

Implications for Nursing Education and Practice

3. This research allowed for identification of authentic patterns of behaviors, feelings, and actions that nurses use in the last moments of a child's life
 - Nurses have the most contact with patients and families and therefore need knowledge and practical expertise for care of the dying patient and their family (Adesina, DeBellis & Zannettino, 2014).
 - Nurses have expressed being emotionally unprepared to cope with patient deaths and the need for formal education preparation in this area of nursing (Forster & Hafiz, 2015).
 - Lack of identification of these issues is even more evident due to the difficulty in comprehending the death of a child, in which children are the future and are not supposed to die (Mutto, Errazquin, Rabhansl & Villar, 2010, Morgan, 2009).

Implications for Nursing Education and Practice

4. This research revealed preservation of the nurses' mental well being which lead to the conclusion that they use censoring to carry on
 - Physical, emotional, and moral distress are key issues for nurses and this adds to the heavy burden placed on nurses in effectively caring for dying children (Forster & Hafiz, 2015).
 - Caring for dying children lends to difficulty in controlling feelings and emotions due to the amount of grief and loss in this nursing care setting (Zander & Hutton, 2009).
 - There are many programs that address the nurse's role in supporting dying children and their families, however nurses admit to feeling uncertainty, pain, helplessness, anger, sadness, anxiety, and suffering themselves (Forster & Hafiz, 2015, Morgan, 2009).

Implications for Nursing Education and Practice

End of Life (EOL) education includes:

- Definitions
- Pain management
- Symptom management
- Ethical/legal issues
- Cultural/spiritual considerations
- Communication with patients and families
- Grief/loss/bereavement for patients and families
- Quality care
- Care at the time of death (Crozier & Hancock, 2012)

However:

- EOL education does not include the nursing factor in which nurses need to understand how other nurses before them experienced child death and “censored” their experiences to be able to adapt.
- These nurses’ experiences will help to develop educational programs that teach effective coping strategies for nursing students and nurses (Dunn, Otten & Stephens, 2005).

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