Choosing Best Venues for Research Dissemination: A Case Study

Self-Described Nursing Roles Experienced During Care of Dying Patients & Their Families

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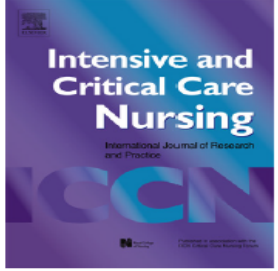

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Self-described nursing roles experienced during care of dying patients and their families: A phenomenological study

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Problem: New nurses unprepared for roles encountered at end-of-life care.

Important because: Affects patient/family experience, RN on deeply personal level, long term implications. My early clinical experiences.

Research question: What roles are experienced by bedside clinicians as they care for dying patients and their families?"

Study methods: Descriptive phenomenological study/purposive sampling strategy.

- 19 critical care nurses with experience caring for dying patients and their families.
- Individual interviews were conducted, recorded and transcribed verbatim.
- Open-ended questioning about experiences and roles encountered caring for dying patients/their families.
- Coliazzis method: Inductively determine themes, clusters and categories.

Themes Identified

- **Patient Advocacy/Managing Symptoms**
- **Protecting families/Mentoring**
- **Conclusions**
  - Nurses may be unprepared for roles/feelings encountered during end-of-life care
  - Teaching these roles in nursing education/orientation is essential
  - Mentoring/role-modeling: Teach/prepare nurses for optimal end-of-life care

Key Considerations!!

- **Is your research finding ready for dissemination?**
  - How strong/generalizable is your evidence?
  - Will this research make a difference?
  - What are the implications?

- **Internal dissemination**
  - Celebrate team, how does this inform practice, thank mentor(s)
  - Relationship to mission of organization!
  - Lunch & learns, “Research Days”
  - How will this inform MY practice

Dissemination

- **Start: Focus-critical care (CC) team members, end-of-life (EOL) issues**
  - Intended audiences: CC colleagues
  - Ask question-If this a concern here (my center), others have similar concern(s)
- **Seek out audiences: CC journals**
  - First journal query: AACN publication
  - Read journal, review editorial style, author guidelines
- **A "match" then send query letter: email to journal editor: Name/contact on masthead**

Dissemination

- **DETAILED query letter:** Topical outline, neat, spell-checked: More information in query, more detailed/helpful response
- **This study- word count issue:** Cutting too much content-limits effectiveness/scope of article
- **Is this a setback???**
  - No, look in a new direction
- **Multiple critical care publications**
- **Want wide audience, other options**

Dissemination

- **Second outreach:** International audience-ICCN/Elsevier-Read journal: Writing/editorial style
- **Query letter**
  - Detailed content outline and research abstract
  - Identify Editor-in-Chief; Journal masthead
  - Say “thank you” for opportunity and any consideration
- **Affirmative response: “Yes, we are interested…”**
  - Allow for excitement/nervousness.
  - Develop timeline
  - Time zero: establish readiness for dissemination
  - Set goals: 1 week, 1 month
  - Schedule writing time
  - Even 30 min/day or 1-page/day (incremental steps) will get your manuscript done

Dissemination

- Goal-directed writing: Contribute to overall nursing body of knowledge
- Manuscript draft done!!!
- Take well-earned break!
- Have paper reviewed by trusted colleague/mentor
- Consider revision
- When comfortable >>> ready for submission
- Allow uninterrupted time
- Separate figures, tables, etc…all uploaded as separate files

Dissemination

- Curriculum dissemination: Schools of nursing
- Informal professional networks
- Professional conferences
- Abstract submission: Consider grant support (AACN funded) >>> AACN conference abstract
- International nursing conferences

Dissemination

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Intensive and Critical Care Nursing

ORIGINAL ARTICLE

Self-described nursing roles experienced during care of dying patients and their families: A phenomenological study

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KEYWORDS
Palliative care;
End-of-life;
Nursing roles;
Family presence;
Patient/family advocacy

Summary
Background: Critical care nurses frequently care for dying patients and their families. Little is known about the roles experienced and perceived by bedside nurses as they care for dying patients and their families.
Objectives: The purpose of this study was to understand the experiences of critical care nurses and to understand their perceptions of activities and roles that they performed while caring for patients and families during the transition from aggressive life-saving care to palliative and end-of-life care.
Methods: A descriptive, phenomenological study was conducted and a purposive sampling strategy was used to recruit 19 critical care nurses with experience caring for dying patients and their families. Individual interviews were conducted and audio-recorded. Coliazzi's method of data analysis was utilised to inductively determine themes, clusters and categories. Data saturation was achieved and methodological rigour was established.
Results: Categories that evolved from the data included educating the family, advocating for the patient, encouraging and supporting family presence, managing symptoms, protecting families and creating positive memories and family support. Participants also identified the importance of teaching and mentoring novice clinicians.
Conclusions: The results of this study have important implications for clinical practice, education and research for optimal preparation in providing end-of-life care.

Self-Described Nursing Roles Experienced During Care of Dying Patients and Their Families: A Phenomenological Study.

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STUDY PURPOSE
Study purpose was to understand the experiences and roles of critical care nurses encountered while caring for dying patients and their families. This fills gaps in research about the lived experience and roles of bedside caregivers during end-of-life care.

BACKGROUND/SIGNIFICANCE
Critical care nurses frequently care for dying patients and their families. Clinicians caring for patients and their families have multiple roles during end-of-life care. Role confusion, stress and personal context of perceiving death may add to job dissatisfaction and risk of burnout. Little is known about the roles experienced and perceived by bedside nurses as well as how these roles affect them as they care for dying patients and their families.

METHOD
A descriptive phenomenological study was conducted and a purposive sampling strategy was used to recruit 19 critical care nurses with experience caring for dying patients and their families. Individual interviews were conducted, audio-recorded and transcribed verbatim. Each nurse was asked open-ended questions about their experience and roles when caring for dying patients and their families. Coliazzi's method of data analysis was utilized to inductively determine themes, clusters and categories. Data saturation was achieved and methodological rigor was established.

RESULTS
Critical care nurses described their main roles as patient advocacy, educating and supporting the patient and family, as well as optimal symptom management while helping to promote a comfortable, dignified death. Roles evolving from the data also included encouraging family presence during the dying process, protecting families and creating positive memories for the family. Role-modeling coping and self-care skills while mentoring and teaching novice clinicians was important.

EDUCATING THE FAMILY
•Most effective when perceived by family members as sensitive, respectful, patient-specific and empathetic.
➢A nurse discussed morphine administration with a patient's family: "they were very worried that the morphine would kill him and so they like got nervous when you went in to give him morphine." The nurse understood that the family "wanted him to be comfortable but didn't want like a Kevorkian style."
➢The nurse responded by explaining about misconceptions regarding analgesia, that "The medicine may decrease respiration…..and lower the blood pressure a little bit but wasn't what was killing him….. wasn't a direct cause of the death." The nurse stated …."They already knew he was going to go, they just didn't know what time it would be." Family education took the form of explaining the dying process "like comfort issues….medications" and what to expect .

ENCOURAGE/SUPPORT FAMILY PRESENCE
➢One nurse described: "It was like a Lifetime movie..all in there..actually caring for the patient, you could almost see them embracing her and the process of death. They knew at that point she's going to die and she's accepted it."
➢One nurse stated, "I felt good that they were going to be OK, you know and I know her husband would be OK because he felt better that she had that lucid period. That she was able to say that she loved him and that made him feel really good……So I felt good that they (both) would be OK."
➢One critical care nurse described, "Every family member just went around and wanted to say something…to tell a story…..I think that actually helped a lot with the family. That was a happy moment that was a happy death and dying."
➢Another nurse mentioned, "….having family presence at end-of-life was an opportunity to help family understand what was happening." "

ADVOCATING FOR THE PATIENT
➢Another nurse described a patient who "really needed the power of attorney and an advanced directive before she got worse….so we got the case manager, social worker and her (the patient's) person of choice in the room, sat down and talked with her. We got all the paperwork that needed to be done and it went smooth. I felt good about the referral and being able to follow through." Part of the nursing role is advocating for patient wishes to be honored.
➢In a third instance, the nurse felt for the mother and father with her (the patient) having "her whole life ahead of her." When the parents came in, the patient had already "coded" six times. The father said "….please don't let her die and there was nothing I could do and I knew. I put my arms around the mother and she said what can I do? I said….you've got to leave her go and they did." Patient advocacy meant helping the family to let go.
➢One nurse described, "The patient said: "'please, no more!'" Once the family understood what that (please no more) meant, there was a peace in the room. The whole atmosphere changed from being very tense to actual peace, the patient was put on hospice, he got the pain medication and we did no more. We could see calm in the room, it was amazing." This helped the patient and family dynamic come to terms with death.

MANAGING SYMPTOMS
Effectiveness of symptom management was tied to self-appraisal of individual performance.
➢ As described by one participant, "Once the patient's decision was made….the ventilator was discontinued and the morphine drip was started, he was finally able to get what he and his family wished. In the end, I was happy to be able to see that."
➢ Some participants felt that providing and facilitating good symptom management or a good death had a bearing on how they felt after a particular working shift. In other words, making sure that everyone involved concentrated on doing "the right thing."
➢ In one instance, … "When we see the patient die comfortably, on their own terms, it's a more pleasant experience for everybody, for people to watch. That is (good symptom management/comfortable death) what you would want for anyone as a human being."

STUDY DEMOGRAPHICS

•Participants (n)	19
•Age (years)	35 (mean)
	21-52 range
Gender: Female/Male	17 (89.4 %)/2 (10.6 %)
Racial/ethnic background:	
•Asian or Pacific Islander:	1 (5.3 %)
•Black, not of Hispanic origin:	4 (21 %)
•White, not of Hispanic origin:	14 (73.7 %)
Marital status.	
•Single/never married:	7 (36.8 %)
•Married/living with partner:	9 (47.4 %)
•Separated/divorced:	3 (15.8 %)
Level attained in nursing education:	
•Associate's degree:	2 (10.5 %)
•Diploma program:	9 (47.4 %)
•Bachelor of Science in Nursing:	7 (36.8 %)
•Master's Degree	1 (5.3 %)
Religious Affiliation:	
•Protestant:	2 (10.5 %)
•Catholic	12 (63.1 %)
•Hindu/Jain:	1 (5.3 %)
•None:	1 (5.3 %)
•Other (Christian):	3 (15.8 %)
Number of years in clinical practice:	
•0-1:	2 (10.5 %)
•2-4:	3 (15.8 %)
•5-10:	7 (36.8 %)
•11-15:	3 (15.8 %)
•16-20:	1 (5.3 %)
•21-25:	3 (15.8 %)
Number of years in critical care practice:	
•0-1:	2 (10.5 %)
•2-4:	5 (26.3 %)
•5-10:	7 (36.8 %)
•11-15:	4 (21 %)
•16-20:	0
•21-25:	1 (5.3 %)

PROTECTING FAMILIES & CREATING POSITIVE MEMORIES
➢One participant shared frustration when faced with transferring a dying patient to a general medical floor bed stating: "…I feel that's very rude to the family…it's rude to the patient and it's a disservice to the patient…..and personally stressful getting rid of that patient to get another crashing patient.".
➢Having to transfer a dying patient out quickly "is… one of the crappiest things you can have a family watch, yes, I am passionate about this."
➢As stated by one participant, …"If the family wants to see, let them come in…if the family wants to hold their hand, let them hold their hand." This gave the family the experience of being these as much as possible, seeing a comfortable and dignified death and being able to say their final good-byes.

FAMILY SUPPORT
➢A participant described …"Family members aren't sure about continuing certain things….they need to be helped to understand…and the best thing you can do is make them comfortable." "Making them comfortable is nursing's role as they move toward acceptance and making informed end-of-life decisions.
➢Another participant had a "feeling" that death was imminent and supported the family by continuing caring and a non-judgmental attitude as …"they rescinded the DNR, I put myself in their position….what would I do at a time like this if a dying family member rallied and became lucid. It was important to support the family.….I didn't have to agree because it was ultimately their decision." Support kept a caring relationship rather then put up barriers.
➢Family support and advocacy took the form of seeing that family wishes were honored by supporting the patient and timing of extubation and withdrawal of vasopressors. As shared by one clinician, "……it felt actually good when her (the patient's) daughter made it there….and she died, with her daughter. It gave the daughter peace of mind and allowed her to say good-bye.

MENTORING & TEACHING
➢One participant; "I would like them to keep in mind anything that they do for this patient that this is someone's husband, wife, grandmother, grandfather….."
➢A second participant described, "When precepting I think it's important that they have those experiences so that they can hear dialogue, so they can see what goes on, the chain of events, the course of action. I love it when orientees ask a lot of questions…. "what if' type of questions. It needs to be a part of orientation.
➢A third shared her experience. "I was fortunate to have her with me as a mentor. I had my first patient here who died and she was explaining a lot of that stuff to me, the gurgling, the fluids, like what it all meant. I think (as a part of orientation) it would be a good idea to sit with them (the novice) and talk about death and whether they had experienced death before with family members."
➢A fourth stated; "It's important to work with people through the process, make sure they don't feel abandoned. Even guidance on things like creature comforts…enough chairs, tissues, water in the room…knowing that is very helpful for a new nurse to start with in helping the family."

CONCLUSIONS
The results of this study have important implications for clinical practice, education and research. Critical care nurses may be unprepared for roles encountered when caring for dying patients and their families. Teaching these important roles in nursing education and critical care orientation classes is essential. Future research should be directed at studying the best ways to mentor, teach and prepare nurses to provide optimal end-of-life care.

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World Federation of Critical Care Nurses (WFCCN): Podium presentation.

Query Letter Language

- **Good Afternoon Dr. Dawson,**

Hope this message finds you well. Am reaching out to you to initiate an author query regarding a possible submission to Intensive and Critical Care Nursing. In my facility, we recently completed a qualitative study exploring roles and responses experienced by bedside nurses caring for dying patients and their families. We also had opportunity to explore qualitative data including staff behavior based on previous experience and age. I feel this would be a good fit with your journal as this has implications for nursing growth and development, mentoring, patient/family experience, retention and relational aspects of clinician, patient and family care.

Please feel free to contact me at any time with questions or if there is anything additional I can do for you. Look forward to our ongoing collaboration.

Writing Process Flow

- **Research completion and data analysis**
- **Review journal/conference possibilities**
  - Theme (s)/types in journal versus conference agenda
- **Select journal for query**
  - Review (again) author guidelines
  - Write query letter and include detailed outline
  - Await response
  - May have additional questions….
- **Start writing!**


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