Caregivers' Perceptions of the Transition of a Family Member from Acute Care to Hospice Inpatient Care

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Background

- The number of persons using a hospice inpatient setting in the United States for part of their care increased from 17% in 2006 (NHPCO, 2007) to 31.8% in 2014 (NHPCO, 2015).
- Reasons for transition in hospice: Safety issues, uncontrolled symptoms, or imminent death (Evans et al., 2006).
- Admission to a hospice inpatient setting is chaotic and families experience feelings of vulnerability (Cronin, Arnstein & Flanagan, 2015).
- Challenges to family caregivers were feelings of loss of control, confusion, and anxiety (Broom, Good, Wooton, Yates, & Hardy, 2015; Meleis, 2010)

Conceptual Framework

- Theory of transitions (Meleis, 2010)

- Patient-and Family-Centered Care (Institute for Patient and Family Centered Care, n.d.; National Consensus Project, 2013)

Purpose

The purpose of this study was to explore the lived experiences of caregivers during the transition of a family member from acute care to a hospice inpatient care in a hospice facility.

Research Questions

Research Question 1:

What are the lived experiences of caregivers during the transition of their family member from an acute care to a hospice inpatient care?

Research Question 2:

What experiences mattered most to family caregivers during this transition?

Methodology

Descriptive phenomenology according to Giorgi was used in this study as one recalled the lived experiences. Transformation occurred as the participants brought to mind the objects of consciousness (Giorgi 1985).

Inclusion Criteria

- Self identifies as primary caregiver;
- Caregiver for a hospice patient who has spent one or more days in the hospital prior to admission to the hospice inpatient setting;
- Eighteen years of age or older;
- Able to read, speak, and understand English and;
- Hospice administrator approval for family caregiver to participate in an interview process.

Data Collection

- IRB approval was gained from Mercer University and one hospital system with approval from the hospice agencies through letters of support.

- Semi-structured interviews with an interview guide were used to collect data in two hospice inpatient units.

- Family members were recommended by a member of the hospice interdisciplinary team as a person or persons who were stable enough to discuss their current situation.

Select Interview Questions and Probes

- Share with me what it is like to have your family member transferred from the hospital to a hospice inpatient setting.
- What was it like to hear_____ was terminally-ill?
- How did you hear about your family members' condition? What was discussed?
  - Did you have questions and concerns? Were you able to discuss questions and concerns with members of the health team?
- What mattered the most?

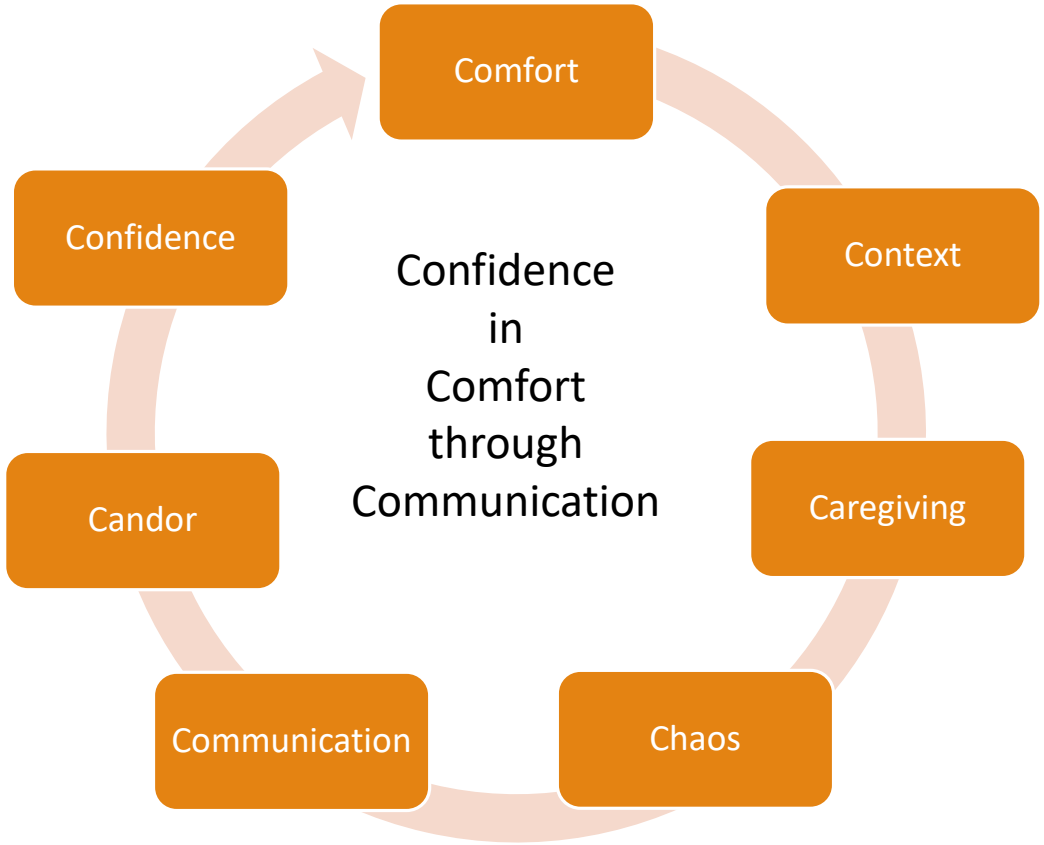
Demographics

- 77% if caregivers were female
- Nine caregivers (69%) were White
- Four caregivers (31%) were Black
- There were not any caregivers of Latino/Hispanic origin
- N=13 caregivers and N=12 hospice patients as two family members were interviewed for one patient.

Data Analysis

- Read the entire transcript for a sense of the whole.
- Re-read for meaning units.
- Transformation of meaning units into nurse-sensitive language.
- Writing the general structure of the experience through “free-imaginative variation” (Giorgi, 2009, p 132).
- Lincoln and Guba’s (1985) evaluative criteria for trustworthiness and rigor.

Presentation of Study Findings: 7 Constituting Parts



Constituent One: Context

- Context of family
- Unfolding story: Initiating events and turning points
- Justification for decisions

Constituent Two: Caregiving

- Positive and negative emotions
- Attending the patient: Presence and waiting

  Am I waiting for someone to come and tell me what's going to happen? You know, does the nurse do that or is there a social worker? I mean, who is that kind of person [who] helps with this transition?

- Giving up caregiving.

Constituent Three: Chaos

- Unanswered questions: “In a state of limbo”
- Second guessing
- “Chasing symptoms”
- “Surprised but not surprised”

Constituent Four: Communication

- Positive and negative communication
- Reaching consensus
- Advocate: *"Being the voice"* for the patient
- Caregivers may not know what questions to ask.

Constituent Five: Candor

- Honest communication: Eases guilt and anxiety
- Truth telling: Decreasing hope
- Protecting each other: Hiding the truth

Constituent Six: Comfort

- *"Doing the right thing"*
- Protect from suffering was what mattered the most
- Affirmation and support

Constituent Seven: Confidence

- Confidence in comfort

- *“Pulling it all together”*

Synthesis Statement

- Process in the context of family.
- Self-sacrifice and honoring patient wishes while hoping they are getting things right.
- Positive and negative emotions were influenced through the support received from other family members and healthcare workers.

Synthesis Statement

- Challenges of transition related the complex process of realizing an awareness of imminent death and a need for care outside of the hospital as death approached.
- A need for guidance in moving through the process was voiced.
- Thankful for honesty in communication and another caregiving option.
- Confidence erased uncertainties of transition when the presence of comfort surrounded the patient and family.

Significance of the Study

- Phenomenon of interest had not been studied while caregivers were actively providing care between acute care and hospice inpatient.
- Transition was in the context of family with reciprocal needs for the caregivers
- Informs nurses and other healthcare workers about caregiver needs during this specific transition between hospice settings with unique needs informed by caregiver experiences.
- Description of supportive nursing and healthcare worker interventions and unmet caregiver needs surrounding transition and patient- and family-centered care between acute care and hospice inpatient settings.

Questions

References

Broom, A., Good, E., Wooton, P., Yates, J., & Hardy, J. (2015). Negotiating futility managing emotions: Nursing the transition to palliative care. *Qualitative Health Research*, *25*, 299-309. http://dx.doi.org/10.1177/1049732314553123

Cronin, J., Arnstein, P., & Flanagan, J. (2015). Family members' perceptions of most helpful interventions during end-of-life care. *Journal of Hospice and Palliative Nursing*, *17*, 223-228. http://dx.doi.org/10.1097/NJH.0000000000000151

Evans, W. G., Cutson, T. M., Steinhauser, K. E., & Tulsky, J. A. (2006). Is there no place like home? Caregivers recall reasons for and the experience upon transfer from home hospice to inpatient facilities. *Journal of Palliative* Medicine, 9, 100-110. http://dx.doi.org/10.1089/jpm.2006.9.100

Giorgi, A. (1985). *Phenomenology and psychological* research. Pittsburgh, PA: Duquesne University Press.

Giorgi, A. (2009). *The descriptive phenomenological method of psychology: A modified Husserlian approach*. Pittsburgh, PA: Duquesne University Press.

References

Lincoln, Y. S., & Guba, E. G. (1985).*Naturalistic inquiry*. Beverly Hills, CA: Sage.

Meleis, A. F. (Ed.). (2010). *Transitions theory: Middle-range and situation-specific theories in nursing research and practice* New York, NY: Springer

National Consensus Project for Quality Palliative Care. (2013). Clinical practice guidelines for quality palliative care. Retrieved from http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

National Hospice and Palliative Care Organization. (2015). NPHCO's facts and figures: Hospice care in America. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf