Influencing the Culture of Care: The Nursing Role

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Funding

The project described was supported by 1 R01NR010127; Penrod, J (PI), Exploring the Formal/Informal Caregiver Interface across 3 Death Trajectories (2009-2012) from National Institutes of Health/National Institute of Nursing Research. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of NIH/NINR.

Acknowledgments

The authors wish to thank their collaborating clinical and research partners and the family caregivers who graciously gave their precious time to share their experiences and insights.
National Consensus Project for Quality Palliative Care (NCP)

- Treatment of a life-threatening illness includes care for the patient and family
- Treatment begins at diagnosis
NCP Model of Care Delivery

(NCP 2009)
Culture of Care

• Values and beliefs in a closed, coherent system
• Shapes experiences and expectations
Purpose

To illustrate the role of the nurse in shaping the culture of care to embrace supportive care across the trajectory of life limiting illnesses
Ethnographic Methods

• Context: Specialty clinics serving patients and families traversing three distinct death trajectories (Exemplars: ALS, heart failure, lung cancer)

• Data sources:
  • Observations of patient visits (n=350)
  • Brief interviews with key informants
  • Observations of general clinic milieu
  • Sustained immersion (12 months)
Ethnographic Methods

Analytic Approach:

• Team approach: Senior researchers and all field assistants
• Cyclical, iterative process of analysis
• Progressed from item-level analysis to pattern analysis
Findings: Key Characteristics of the Culture of Care

- Continuum of Care Across Trajectory
- Acknowledgment of the Certainty of Death
- Role/Interaction of Formal Caregivers
- Perception of Patient System
- Focus of Patient Visit Across the Trajectory
Death Trajectories

<table>
<thead>
<tr>
<th>Clinic 1</th>
<th>Clinic 2</th>
<th>Clinic 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Graph 1]</td>
<td>![Graph 2]</td>
<td>![Graph 3]</td>
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<td>Upon diagnosis, Illness explicitly described as terminal with anticipated progressive incapacity</td>
<td>Disease is approached as chronic and serious, but manageable; aim for medical stability, not cure</td>
<td>Initial efforts aim for cure; multiple treatment options are offered until exhausted; comfort care initiated</td>
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Shapes Expectations

Values and Beliefs are Communicated through the Care Delivery Model
Context of the Illness

• Extends beyond functional status of the patient
• Extends beyond the physical setting of the clinic
## Acknowledgement of the Certainty of Death

### Continuum of Care Across the Trajectory

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<td>Emphasis on quality of life through death and into bereavement</td>
<td>Emphasis on medical stability, typically until death; end-of-life issues not anticipated</td>
<td>Emphasis on successful treatment; discharged to specialty service for supportive end-of-life care</td>
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<td>Infusion of palliative/comfort care begins following diagnosis</td>
<td>Death rarely anticipated; often occurs suddenly without supportive care</td>
<td>Abrupt shift toward comfort care</td>
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Clinic 1

Expected Death Trajectory

Diagnosis

Certainty of Death

Time

Health Status
Clinic 2

Unexpected Death Trajectory

Health Status

Diagnosis

Crisis

Certainty of Death

Time
Clinic 3
Mixed Death Trajectory

Certainty of Death

Health Status

Diagnosis

Courses of Treatment

Time
# Death Trajectories

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**Shapes Expectations**

Values and Beliefs are Communicated through the Care Delivery Model
Role of HCPs
Interdisciplinary team with shared power

Patient System
Caregivers are co-providers and co-recipients of care

Acknowledgment
At or soon after diagnosis

Continuum of Care
Diagnosis through bereavement

Focus
Shifts to meet the holistic needs of patient system

Interdisciplinary Model
Context of Illness Experience
Role of HCPs
Solo practice style; team support lead provider

Acknowledgment
Late; often days or hours prior to death

Continuum of Care
Always another option

Patient System
Caregivers must call awareness to concern or need

Focus of Visit
Medical stability
Role of HCPs
Fragmented multidisciplinary support (primarily nursing)

Patient System
Addressed by nursing during de-briefing sessions

Acknowledgment
Options exhausted; Abrupt shift to comfort care

Continuum Of Care
Visits during active treatment

Focus of visit
Response to treatment and control of side effects

Network Cooperative Model
Context of Illness Experience
Culture of Care

Context of Illness Experience

- Role/Interaction of Formal Caregivers
- Acknowledgement of the Certainty of Death
- Continuum of Care Across Trajectory
- Perception of Patient System
- Focus of Patient Visit Across the Trajectory
Shifting Culture through the Nursing Role

Nurses interpreted messages delivered by other disciplines in an effort to allay anxiety or to clarify meaning.

*Your disease has progressed....you need more treatment.*

*The physician is such a pleasant man, but it’s the nurses around here that make the difference.*
Shifting Culture through the Nursing Role

Nurses take time with troubled families to allow them time to process bad news or complicated procedures.

*It is time to consider getting hospice involved...*
Nurses moved into distressed situations, providing support, information and referral services.

I thought that hospice was for when you were closer to dying?

The patient said, I don’t need hospice. I am not dying.
Nurses at all levels must recognize their power in shaping a culture of care (Newman, 2011)

- Re-focus organizational policy to reflect shared values of nested cultures
- Recognize the value of decision-making arising from within the nested culture
- Staff driven decision-making leads to excellent patient care  
  
Porter-O’Grady & Finnigan, 1984
Through sustained and consistent efforts, nurses can influence spheres of culture, shifting the culture of care and infusing supportive strategies into outpatient settings serving patients and families at the end of life.