Using Ethnography to Build Knowledge: Informal Caregivers Providing Care at the End of Life

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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.
Background

- Uncertainty is a condition of doubt (Penrod, 2007)
- Two perceptions undergird one’s sense of uncertainty:
  - Control
  - Confidence
- Uncertainty experienced by informal family caregivers
- Uncertainty marks *distressed caregiving* (Penrod, Hupcey, Baney, & Loeb, 2011)
Model of End-of-life Caregiving

- Sensing a Disruption
- Confirming Suspicions
- Challenging Normal
- Acknowledging the End of Life
- Building a New Normal
- Losing Normal
- Reinventing Normal
- Certainty of Death

(Penrod, Hupcey, Shipley, Loeb, & Baney, 2011)
Death Trajectories

• Specialty clinics serving patient systems in three distinct death trajectories
  • Expected Death Trajectory
  • Unexpected Death Trajectory
  • Mixed Death Trajectory
Death Trajectories

<table>
<thead>
<tr>
<th>Clinic 1</th>
<th>Clinic 2</th>
<th>Clinic 3</th>
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</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Graph" /></td>
<td><img src="image2.png" alt="Graph" /></td>
<td><img src="image3.png" alt="Graph" /></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

Care Delivery Model
Expected End-of-Life Caregiving Trajectory

- Confirming Suspicions
- Acknowledging the End of Life
- Certainty of Death
- Building a New Normal
- Losing Normal
- Reinventing Normal

(Penrod, Hupcey, Shipley, Loeb, & Baney, 2011)
Unexpected End-of-Life Caregiving Trajectory

Confirming Suspicions

Sensing a Disruption

Reiterative Cycles of Challenging Normal

Acknowledging the End of Life

Certainty of Death

Losing Normal

Building a New Normal

Reinventing Normal

(Penrod, Hupcey, Shipley, Loeb, & Baney, 2011)
Mixed End-of-Life Caregiving Trajectory

Sensing a Disruption

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(Penrod, Hupcey, Shipley, Loeb, & Baney, 2011)
Exploring the Formal/Informal Caregiver Interface Across Three Distinct Death Trajectories
Ethnographic Methods

• Context: Specialty clinics serving 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
Culture of Care

Context of Illness Experience

- Continuum of Care Across Trajectory
- Acknowledgement of the Certainty of Death
- Role/Interaction of Formal Caregivers
- Perception of Patient System
- Focus of Patient Visit Across the Trajectory
## Context of the Illness Experience

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<td>Initial efforts aim for cure; multiple treatment options are offered until exhausted; comfort care initiated (typically very late)</td>
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Acknowledgement of the Certainty of Death

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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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## Role/Interaction of Formal Caregivers

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<td>Multiple disciplinary perspectives integrated, including nursing, social work, clergy, nutrition, PT, OT, and counseling services</td>
<td>Medical specialist (MD) in a solo practice style; disciplinary team members support medical specialist’s needs</td>
<td>Medical focus; fragmented multidisciplinary support (primarily nursing)</td>
</tr>
<tr>
<td>Shared power and authority</td>
<td>Focused on lead provider</td>
<td>Hierarchical; supportive network with unequal power and authority</td>
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# Focus of the Patient Visit Across the Trajectory

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<td>Focus dynamically shifts to meet the holistic needs of the patient system</td>
<td>Sustained focus on medical stability with careful treatment based on pathology and symptoms</td>
<td>Focus on the response to treatment and control of side effects</td>
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Perception of Patient System

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<td>Informal caregivers consistently and purposefully integrated into the visit; anticipatory support offered</td>
<td>Narrowly focused on the medical status of the patient; in order to be recognized, informal caregivers must call awareness to a concern or need</td>
<td>Focused on disease status; patient system (including informal caregiver) addressed during de-briefing sessions</td>
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## Continuum of Care across Trajectory

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<td>Supportive network of care across trajectory and into bereavement</td>
<td>Clinic visits across illness trajectory; treatment options introduced progressively (‘always another option’)</td>
<td>Clinic visits during active treatment and stabilization; when treatment options exhausted, patient discharged to referring physician for coordination of end-of-life care</td>
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Death rarely anticipated; often occurs suddenly without supportive care.
Sensing a Disruption → Challenging Normal → Building a New Normal → Reinventing Normal

Confirming Suspicions → Acknowledging the End of Life → Losing Normal

Certainty of Death

Context of Illness Experience:
- Acknowledgment of Death
- Continuum of Care Across the Trajectory
- Focus of the Visit Across the Trajectory
- Perception of the Patient System
- Role Interaction of Formal Caregivers
Caregiving Trajectory Over Time

Everyday World of the Caregiver
Culture of Care

Context of Illness Experience

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

Healthcare Professionals

Family Caregivers

Theory-guided assessment and intervention protocol
References

