Making the Transition to Hospice: Exploring Hospice Professionals’ Perspectives

Deborah Waldrop, LMSW, PhD
University at Buffalo School of Social Work

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Introduction

The Medicare Hospice Benefit makes care available for a minimum of 6 months before death.

The median length of stay in 2009 was 21.1 days.

34.4% died within 7 days of admission in 2009.

National Hospice & Palliative Care Organization, 2010
Background

Hospice utilization varies widely; short enrollments are most common (NHPCO, 2010)

Short utilization: “Hyper-acute death care” (Christakis, 1994); End-stage crisis (Andershed, 2006)

Late admissions: influence life closure, comfort with dying, effective grieving (Miller et al, 2003a,b; Teno, et al., 2007)
Comprehension of Terminality

Differential perspectives on the understanding of a terminal prognosis:

Physicians’ abilities for prognosication/communication & attitudes (Christakis, 2000; Lamont, 2005)

Families’ awareness contexts: closed, suspected, mutual pretense or open (Glaser & Strauss, 1965) + assimilation of information (McGrath, 2004), observation & experience of changes (Waldrop, et al., 2005)
The Purpose of the Study

To explore and describe hospice professionals’ views on the appropriate timing for & communication about hospice with patients & their families.
Research Questions

1. How do hospice professionals define a “timely” admission?
2. What factors influence the timing of hospice admission?
3. How do hospice professionals view their communication with patients, families & physicians about the transition to end-of-life care?
Theoretical Framework

Symbolic Interaction

Human beings act toward events and interactions on the basis of the meanings they attribute to them.

Meaning arises from social interaction.

The meaning of events, actions, & interactions is modified through interpretation.
Methods

Overall Design: 2 phases (developmental)

I. Ethnography

Systematic observations of hospice professionals during Interdisciplinary Team (IDT) meetings
Develop specific questions to guide discussions with hospice professionals’ about the transition to hospice

II. Focus groups-Individual Interviews

To develop understanding of individual hospice professionals’ perspectives on the nature & timing of the transition to hospice care.
Procedures

• Invitation letters were sent to all involved staff at the participating hospice, including a mailed response form
• Focus groups &/or interviews were scheduled before/after work (7-8am or 4-5pm on site)
• Individual interviews- at their convenience
• Written survey questions asked of all participants.
Analysis

Phase I: Ethnography
- Field notes: Completion & memos
- Content analysis for the discovery of emergent themes

Phase II: Focus Groups/Interviews
- All groups & interviews were audiotaped, transcribed & entered into Atlas ti
- Written interview questions were typed as Word documents for entry into Atlas ti
Coding

• Three data sets were examined independently: Focus group, Individual interview & written questionnaire data

• Iterative process- movement from inductive to deductive
  – Open coding; “Free” codes
  – Constant comparative analysis

• Analytic rigor: triangulation, prolonged exposure, co-coding & audit trail
Results: Phase I

**Brief Reports** - short, uncomplicated descriptions

- Mutual understanding of hospice, team roles & shared care

**Complex reports** - lengthier discussions

- Problem solving & intervention plan
- Uncontrolled symptoms, patient-family communication; timeliness of hospice admission
Results: Phase II

Sample
- 106 recruitment letters
- 53 participants (50% participation rate)
- Nurses: N=32
- Social Workers: N=9
- Chaplains: N=7
- Physicians: N=1
- Clinical Secretaries: N=4

Professional experience: 3-38 years; (M=16.6)
Hospice experience: 3 months-25 years; (M=6.25)
Timely Hospice Admissions

Terminal Prognosis: given & understood

- Specific Terminal Characteristics: nausea, fatigue, shortness of breath; need for symptom management
  - Timely = before (N=16) & after (N=17)
  - Actual time (N=16): 1-12 months before death
Communication about the Transition to Hospice

- **Patient-Family Communication** - mutual understanding about terminality
- **Family-Physician communication** - clear, understandable information about prognosis
- **Family-Hospice Communication** - openness to building a relationship
- **Hospice-Physician Communication** - PMD is supportive of hospice admission (or not)
## Communication about the Transition to Hospice

<table>
<thead>
<tr>
<th>Dynamics</th>
<th>Factors that contribute</th>
<th>Potential Dynamics</th>
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<tr>
<td>Family Communication</td>
<td>Family members, including the person who is dying, have different levels of awareness about the terminal prognosis</td>
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<td></td>
<td></td>
<td>• Mutual understanding that death is approaching</td>
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<td>• Family members have uneven comprehension of the terminal prognosis and each thinks that the other is unaware</td>
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<td>▪ Family grasps the approaching death but patient does not</td>
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<td></td>
<td></td>
<td>▪ Patient grasps the approaching death but family does not</td>
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<tr>
<th>Family-Physician Communication</th>
<th>Families and physicians have different knowledge of the diagnosis, prognosis and available options</th>
<th>Families have:</th>
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<td>• individual perceptions of the illness</td>
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<td>• variable levels of information/knowledge about the diagnosis</td>
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<td>DMs have:</td>
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<td>• different levels of comfort discussing a terminal prognosis</td>
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<td>• professional opinions about dis/continuing treatment</td>
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<td>• potentially numerous other MDs including specialists</td>
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<td>• Mutual understanding: open communication</td>
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<td>• Both MD and family know but avoid discussing the approaching death</td>
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<td>• Either the family or the doctor avoid discussing the approaching death</td>
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<td>• Medical abandonment; patient-family need but do not get assistance</td>
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# Communication

| Family-Hospice Communication | Patient meets hospice admission criteria but the decision for transfer must be made | Families bring:  
- Personal, emotional, philosophical, religious perspectives about continued treatment vs. death, end-of-life and a palliative approach  
- Hospice professionals bring:  
  - Professional knowledge and expertise in palliation  
  - Experience/expertise managing symptoms at life’s end |  
- Family requests transition to hospice  
- Family finds relief with hospice care  
- Family wants to continue pushing food/fluids  
- Family seeks cure  
- Family is uncomfortable preparing for death |

| Hospice-Physician Communication | Family wants hospice physician’s orders are required |  
- MD misunderstanding of hospice care or guidelines  
- MD resists discussion of prognosis with the family |  
- Physician agrees and refers  
- Physicians do not think the person is ready for hospice. |
Discussion

• There isn’t one “right” time for hospice admission

• Timeliness is situation-specific
  – Characteristics of the illness trajectory
  – Nature of family-physician communication

• Introduction of hospice care earlier on the illness trajectory

• Reframe palliative care as continuous vs. supplemental
Living Proof.

WE MAKE A DIFFERENCE IN PEOPLE'S LIVES.