But, “She was comfortable . . .” – Hospice Referral When Something “Bad” Happens, Not As a Routine Referral*

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Background

- NHs increasingly the site of death
- Previous research: Hospice vs. nonhospice NH decedents had:
  - Fewer end-of-life hospitalizations,
  - Fewer invasive treatments, and
  - A greater likelihood of having pain assessment performed and pain treated.
- But, hospice underutilized both in terms of non-referral and very short lengths of stay
Project Aim

- Develop a more in depth understanding of the individual-level, organizational-level and policy related factors associated with hospice later referral and non-referral for nursing home-based older adults.

- and how the magnitude of hospice presence may be influenced by these factors.

The Individual Hospice Referral –
Nursing Home Residents

“The Referral”

Physician Input → Other Input → Recognition of Terminal Illness

- Coverage by Hospice of Current Care → Yes
- Knowledge of Criteria → Yes
- Fear of Oversight/Non-reimbursement → Yes
- Current Care vs. Alternative On Medicare SNF? → Yes
- Input from Patient/Family → Yes
- Input/Ref. Physician → Yes

→ Referral to Hospice → No (with 6 month prognosis)

→ No (focusing on NH staff)

→ Choose Hospice → No

→ Yes
Methodology — Sample

2 Hospices & 7 Nursing Homes

-- NHs had contracts with the hospices

Frequency of hospice referral determined

(based on referral history obtained from hospice)

<table>
<thead>
<tr>
<th>Less frequent</th>
<th>More frequent</th>
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<td>= 3</td>
<td>= 4</td>
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Methodology — Sample

• Selection of Decedents was Purposive

- Goal 2 nonhospice, 2 hospice with stay <= 7 days & 2 hospice stay > 7 days for each diagnosis group:
  • Cancer with Without Dementia / AD
  • Cancer with Dementia / AD
  • Dementia / AD without Cancer
  • Other diagnoses—No Cancer or Dementia /AD

- Goal at least 2 interviews at each NH
### Methodology — Sample and Staff Interviewed

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<th>CA/Dem</th>
<th>Dem</th>
<th>Other</th>
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<td>8</td>
<td>6</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>No Hospice</td>
<td>10</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>4</td>
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<tr>
<td>Hospice</td>
<td></td>
<td></td>
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<tr>
<td>&lt;= 7 days</td>
<td>9</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>3</td>
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<tr>
<td>&gt; 7 days</td>
<td>13</td>
<td>5</td>
<td>4</td>
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### Methodology — Staff Interviewed

- **Total Staff Interviewed**: 81
  - NH Nurses: 34
  - NH Certified Nurse Assistants: 30
  - Hospice Nurses: 17

**Additionally 7 Director’s of Nursing Interviewed**
- Structure in place to assess terminal status
- Degree DON promoted hospice care
Analyses

- Interviews were audio taped and transcribed verbatim.
- A multidisciplinary group of researchers / providers coded transcripts for themes relating to hospice referral and timing of referral.
- Additional themes relating to hospice benefits emerged.
- Coded gaps of >7 days between when NH staff stated recognized resident was within final weeks or months of life and when referred to hospice.

7 Director of Nursing Interviews

- Generally, no policies or procedures in place for assessing terminal status and/or hospice eligibility—1 NH appeared to have more structure in place.
- NH nurses and social workers initiate discussion of hospice.
- Two DON’s talked of frustration regarding unavailability of physicians & physician reluctance to discuss prognoses.
- In 3 of 4 higher-referring NHs DONs were considered to be hospice promoters / believers.
Belief that hospice is appropriate only when “something bad happens”

- NH nurses frequently use their assessments of the patient’s comfort and the family’s need for support as determining factor as to whether hospice care is needed.

I: “Do you feel that the hospice care could have benefited [resident] and her family. . .?”

R: “At that point, I don’t think so because she was comfortable. We’re usually [referring to hospice when] like, you know, the patient’s uncomfortable, we can’t well manage the pain or the family also [needs] support, hospice support, you know.”

--A NH nurse regarding an 85 year old resident with a diagnosis other than cancer or AD/dementia;
Impediments to Hospice Referral
Themes in Lower Referring NHs (N=3)

- Residents death was rapid and, therefore, a surprise.
- Belief among some NH staff that hospice does not add substantially to the end-of-life care of dying residents.
  - Although many respondents spoke of the benefits of hospice care for residents, their family members and NH staff, some did not see hospice services as adding substantially to the end-of-life care provided by NH staff.

Residents death was rapid and, therefore, a surprise—Example

- I: “And is there any particular reason why you did not expect her to die as quickly as she did?”

- R: “Well, she was calm. She was comfortable and she was very responsive and you know, maybe slightly more sleepy than the times... before but she was very responsive. She talked to us and answered to any questions.”

--a NH nurse regarding a 85 year old resident with a diagnosis other than cancer or AD/Dementia; no hospice services
Facilitators to Hospice Referral – NHs Who Referred More Frequently to Hospice (N=4)

- Resident had begun to decline and/or death was expected;
- Pain facilitated hospice referral; and
- NH staff played an important role in raising the hospice option.

Timeliness of Referral—Impediments to Earlier Hospice Referrals

- Family members who had difficulty accepting their loved one was dying.
  - Also, other family issues logistics of obtaining consent, other
Timeliness of Referral
Impediments to Earlier Hospice Referrals—When Gaps Present

- Hospice only appropriate for “very end.”
- Prognosis as an impediment

Hospice Appropriate Only for The “Very End” -- Example

I: “Can you discuss or tell me why she was referred so late?”

R: “Why? That’s a good question. I think maybe we feel we are a nursing facility and we can care for them well enough but we want to make sure we’re doing the right thing as far as making them comfortable towards the end, making sure they have the proper medication and so on and so forth.”

NH nurse on 89 year old resident with AD / dementia; hospice length of stay 1 day
Dominant Themes in the Nursing Home with a More Structured Assessment Process in Place

- NH staff played an important role in raising the hospice option.
- Good care results from the presence of both NH and hospice providers.

CNAs and Hospice

- CNAs were generally very position about hospice but some comments indicated underlying feelings of competition:
  - When asked if hospice care benefited resident, a CNA responded:
    “Well, as I said, nobody could do it like me (chuckles). No, that’s a joke, I shouldn’t. I’m sure they did cause they’re great. I think they’re great. I have high regard for them.”
Summary

• NH Staff (Nurses, aides)
  – Hospice only when something “bad” happens / for the “very end”
    • Not necessarily aware of full range of care provided.
  – No policies / procedures for assessing terminal status
    • Limited input from physicians
  – Belief among some NH staff that hospice does not add substantially to the end-of-life care of dying residents.
    • Mostly in lower referring NHs
    • May not understand the full range of hospice services
  – More NH staff involvement facilitates hospice referral
  – A structure assessment process facilitates hospice referral

Implications / Future Research

• Findings suggests DONs play a role in influencing whether residents are referred to hospice, as do assessment procedures.
  – Why are some DONs “true” believers? Are aspects of the collaboration responsible? How is the NHs culture / mission associated with the DONs feelings regarding hospice care?

• Necessity of 6-month prognosis is a barrier to hospice referral BUT the presence of GAPS and associated themes suggests this is not the whole picture.

• To what extent does a palliative care model of NH care influence the volume of hospice care and vice versa?