

# VIGILANT AT THE END OF LIFE: FAMILY ADVOCACY IN THE NURSING HOME

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# AIMS OF TODAY'S TALK

- ◉ My background and work
- ◉ Mixed methods research at Brown
  - Collaboration with Drs. Joan Teno, Terrie Wetle, Susan C. Miller, Vincent Mor
- [www.chcr.brown.edu/pcoc/toolkit.htm](http://www.chcr.brown.edu/pcoc/toolkit.htm)
- [www.chcr.brown.edu/dying/factsondying.htm](http://www.chcr.brown.edu/dying/factsondying.htm)
- ◉ The family perspective in the NH
- ◉ Advocacy efforts at the end of life
- ◉ Recent work
- ◉ Implications



# BACKGROUND



# ETHNOGRAPHY OF NH IN '80S

- ◉ In addition to resident and staff perspectives, I noticed residents *with and without family*

“Residents with local family... are privileged...[They] can ... protect the resident... intercede...talk to the social worker... appeal to the administration... ask the nurses...Coming from the resident, these requests carry little weight... [Because of families] the institutional existence can be softened...”

Shield, *Uneasy Endings: Daily Life in An American Nursing Home*  
(Cornell U Press, 1988)



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# OTHER NH WORK

- ◉ Relationships between CNAs, NH residents, families
- ◉ Culture change practices in NHs
- ◉ Communication among physicians, nursing staff, residents and family
- ◉ End-of-life care
  - Physicians' views of end-of-life care, hospice
  - Family perspectives on end of life in NHs



# AS A VISITING DAUGHTER

“[I said] my mother... preferred a normal tone of voice... later, a nurse ... appreciated that I had ‘backed off’... That put me in my place. It was one of the ways I realized... [I was] perceived as intrusive.”

Shield, Wary partners: Dynamics of interactions between nursing assistants and family members in nursing homes. In Stafford P (Ed.) *Gray Areas: Ethnographic Encounters with Nursing Home Culture*. Santa Fe (NM): SAR Press, 2003.



# CNAS I INTERVIEWED TOLD ME

- ◉ Family members often
  - Take time to develop trust
  - Are in the way
  - Don't see there are other residents to care for
  - Should be there more often
- ◉ When residents are dying, family members
  - Can't understand what is happening
  - Become angry at staff
  - Expect miracles



# FAMILIES TOLD ME

- ◉ Trust has to be based on experience
- ◉ They felt powerless
- ◉ They were confused by who is who
- ◉ They can see work burden for staff
- ◉ What is their role supposed to be?
- ◉ How much they appreciated support of staff
  - CNAs
  - Housekeepers
  - Anyone





# MOST OF US HERE ARE...

- ◉ Care providers and/or researchers, educators
- ◉ Past, current and/or future family members of NH residents, and...
- ◉ We are aging

We should all keep in mind that we all have a stake in enhanced understanding



# FOCUS ON FAMILY PERSPECTIVES

What is the quality of end-of-life care  
of dying NH residents?

What can families of dying NH  
residents tell us about these  
experiences?

Quantitative-qualitative approach...



# THE STUDIES



# QUANTITATIVE & QUALITATIVE

## ◉ National mortality follow-back survey

- ◉ Teno, Clarridge, Casey, et al., JAMA, 2004

Supported by Robert Wood Johnson Foundation

## ◉ Qualitative follow-up study

- ◉ Wetle, Teno, Shield, et al., 2005, AARP Public Policy Institute
- ◉ Wetle, Shield, Teno, et al., 2005, The Gerontologist
- ◉ Shield, Wetle, Teno, et al., 2005, JAGS
- ◉ Shield, Wetle, Teno, et al., 2010, J of Palliative Care

Supported by AARP



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# QUANTITATIVE SURVEY (N=1578)

- Mortality follow-back survey
- Two stage probability sample
- Total accounted for 70% of deaths in 2000
- Was patient in pain? Was there emotional support?
- Was patient treated with dignity and respect?
- Did physician communicate about treatment and prognosis?
- Was family informed about what to expect?
- Did family receive emotional support?



# RESPONDENTS' PERSPECTIVES

- Almost 70% of sample died in hospital or NH
  - About half in each kind of facility
- 24%: not enough pain medication
- 50%: not enough emotional support
- 24%: concerns about physician communication and treatment
- 20%: dying person not always treated respectfully
- 35%: insufficient support for families
- >70%: hospice care perceived as excellent



# QUALITATIVE FOCUS ON NHS

- ◉ Little known about end-of-life experiences in NH though more and more die there
- ◉ We describe NH end-of-life care from perspectives of families and others close to decedents
- ◉ Follow-up interviews with 54 who had already participated in quantitative survey

Wetle T, Shield R, Teno J, Miller SC, Welch L. 2005. Family perspectives on end-of-life care experiences in nursing homes. *The Gerontologist* 45 (5): 642-650.



# QUESTIONS & ANALYSIS

- Focused on last year and last week of life
  - Symptoms and treatments
  - Treatment decisions
  - Communications
  - Was hospice offered and/or used?
  - Was there support for family?
  - How was the NH care?
- Qualitative analysis of transcripts





# THEMES



# DYING TRAJECTORY OFTEN UNRECOGNIZED

- Symptoms, needs, and illness trajectories are insufficiently recognized, resulting in:
  - Missed opportunities for palliative intervention
  - Missed or late hospice referrals
  - Less advance care planning

*"We were trying to decide whether we would introduce tube feeding, and we had decided that we would not... and then, she suddenly came into a period of consciousness that made us rethink the game plan and then we did decide to do the tube placement. [But] by the time we got the tube placement in, she had lapsed into unconsciousness again."*

Daughter of 76-year-old woman with dementia



# INADEQUATE PHYSICIAN CONTACT

- ◉ In addition to a need for more, better-trained staff, physicians are viewed as “missing in action”

*“I never saw the doctor. I don’t even know his name!”*

-97-year-old husband

Shield RR, Wetle T, Teno J, Miller SC, Welch L. 2005.  
Physicians “missing in action”: Family perspectives on physician and staffing problems in end-of-life care in the nursing home. *Journal of the American Geriatrics Society* 53 (10): 1651-1657.



# HOSPICE OFTEN HELPS

- Hospice services often enhance the care of dying persons in NHs

*"They had counselors in talking with her every day. Her doctor was there a lot! I mean, he was right there. Hospice was there. The social worker was there. The counselors were there. There was a tremendous amount of support available for both her and I."*

Niece of an 86-year-old woman with pancreatic cancer

- But—frequently late or no referral
- Some conflicts between hospice and NH staff
- Some unrealistically high expectations



# NEED FOR ADVOCACY

- ◉ Whether coming with low or neutral expectations about the nursing home...
- ◉ Family members are often turned into vigilant “advocates” for their dying loved ones.

Shield RR, Wetle T, Teno J, Miller SC, Welch LC. 2010.  
Vigilant at the end of life: Family advocacy in the nursing home, *Journal of Palliative Medicine* 13(5):573-9.



# ADVOCACY



# ADVOCACY OVERVIEW

- ◉ Becoming an advocate
- ◉ Caregiving concerns
- ◉ The strategy of overall vigilance
- ◉ Burdens of advocacy
- ◉ Gratifications of advocacy
- ◉ Hospice as advocate



# BECOMING AN ADVOCATE

- ◉ Many respondents have initially low expectations of NHs
- ◉ Others become advocates after experiences with poor quality of care in the NH

*"His bed was not clean...They didn't help him bathe...And they wouldn't answer when you called..."*





*"I didn't set out to make waves, but I think I've lived long enough that I have the right to speak up, especially with my mother. I didn't go looking for a fight, but I sure was there enough to keep an eye on things. And I'd advise anybody that has a family member or whatever in a nursing home, that's what you have to do."*

-Daughter of an 89-year-old woman with dementia



# CAREGIVING ISSUES



# PERCEPTIONS OF GOOD CARE

- ◉ Hominess of nursing facility
- ◉ Some residents were well “known.”
- ◉ Doctors and staff members provided compassionate and individualized care.
- ◉ Full information about what to expect was conveyed.

*“In the nursing home, they treated him like he was as normal as you and I...like he was a person, a human, and they showed love and affection for him.”*

-Daughter of an 81-year-old man with dementia



# CAREGIVING CONCERNS

## ◉ Nutrition

*"A lot of times... we came ourselves and made sure that we would be there during mealtime. We'd sort of cut his food or try to feed him."*

-Daughter of a 77-year-old man with dementia

## ◉ Personal care

*"... keeping her clean... she just wasn't taken care of the way I think that she should have been taken care of."*

-Son of an 88-year-old woman with Alzheimer's disease

## ◉ Changing medical conditions

*"I can remember having to speak with the staff about his [cough]... I was right on them when I was there."*

-Niece of 99-year-old man with pneumonia



# NEED FOR INFORMATION

- ◉ Getting basic information

[Staff members] *"...never said anything about his condition... I was the one who always went up to the doctor and said, 'What's going on?'"*

- ◉ What to expect in dying course

*"I did not know what to expect... But I didn't get anything direct from the nursing home that said, 'Now, your mother is slipping away. This is how long we think she might last.'"*



# THE STRATEGY OF OVERALL VIGILANCE

- ◉ *“They did pay more attention to her because we were there.”*
- ◉ *“...the more that a family goes to a nursing home... they're not going to be neglected...”*
- ◉ *“... if you didn't stay on them, they wouldn't do nothing...”*



*"I was very satisfied with all of the care that she got... but it required my constant attention, and you know, constantly being there..."*



# FREQUENT, UNSCHEDULED VISITING

*"...[We] never made it a point to make it a special time... so they... wouldn't have had any inkling to do anything to her."*

Younger brother of an 82-year-old woman

*"... I could go by as I went to the grocery store and... just pop in and out..."*

Son of a 94-year-old woman





# DEALING WITH PHYSICIANS

*"A lot of times the doctors would come in early, and I didn't want to miss them if they came."*

-Wife of a 76-year-old man with cancer

The wife of a resident said that she had to *"chase [the physician] down"* to obtain basic information from him.



# BURDENS OF ADVOCACY

- ◉ Friction with staff
- ◉ Time and effort
- ◉ Tasks
- ◉ Sacrifice

*"I mean, I practically spent the last few weeks entirely dedicated to her care. I'm self-employed so I abandoned my job and pretty much my family and everything although other family members rallied around to help."*

Niece of an 86-year-old woman with cancer



# GRATIFICATIONS OF ADVOCACY

- ◉ A sense of having done the right thing
- ◉ Positive collaboration with staff

*"They met periodically and discussed all of the situations about him, not just medical but social, you know... like to improve his condition, whether it was getting him out or getting him to swallow better or whatever... They discussed his problems and how better to improve them. And I was really impressed with that, and I liked that. I liked that a lot."*

-Niece of 95-year-old man with colon cancer



# HOSPICE AS ADVOCATE

- ◉ Hospice added surveillance
- ◉ *"... [Hospice] was kind of a watchdog over my mother and someone I could talk to... what they provided was just a couple more pair of eyes watching over her."*
- ◉ Hospice seemed to relieve some of their need to advocate; they perceived their work to be shared.



# RECENT WORK ON HOSPICE

- ◉ Focus groups with family members about quality of hospice at end of life
- ◉ Is confirming concerns in earlier research and literature about NH care at end of life, e.g.,
  - Inadequate control of symptoms
  - Insufficient communication, information
  - Lack of responsiveness, timeliness
  - Sometimes problematic NH-hospice interaction
- ◉ Hospice often acts as an advocate



# A FAMILY MEMBER RECALLED

"... when I called to check on [my mother] in the morning, she was again experiencing pain, frightened, alone... [no one was with her]... And I immediately called hospice 'cause I was really annoyed about this. I was beyond annoyed. And I'm only about 15 minutes away... Hospice beat me there... I hear the [hospice] nurse saying [to the NH DON], 'What is it you don't understand about hospice?' And she's got my mother's records. The chaplain was already in with my mother. The social worker arrived along with me... I don't even know how they got there that fast. But they were wonderful."



# KNOWLEDGE OF HOSPICE AND PALLIATIVE CARE IN LONG TERM CARE SETTINGS

- ◉ We explored barriers to palliative care provision in long term care settings

Miller SC, Shield R. 2007. Palliative care/hospice for persons with terminal and/or chronic progress illness: The role of state and federal policies in shaping access and quality for persons receiving long-term care. Available online at:

[http://www.chcr.brown.edu/PDFS/JEHT\\_4\\_FINALREPORT07.PDF](http://www.chcr.brown.edu/PDFS/JEHT_4_FINALREPORT07.PDF)



# OUR APPROACH

- ◉ We interviewed 44 policymakers & experts on palliative care and hospice
- ◉ 16 interviews were with providers, researchers payor/regulator, caregiver, industry or advocacy groups
- ◉ 9 interviews with persons involved in changing or introducing new policy (including some at the Centers for Medicare and Medicaid Services [CMS])





# MAIN FINDINGS

- “Palliative care” held little meaning for those not directly involved in care provision or research, including

- Policy makers
- Providers
- Consumers

*“...does the average American know what [palliative care] means?... I think people, at least, heard of hospice... But I have never heard anyone in the community saying... my mom’s on palliative care...”*



# CONCLUSIONS & IMPLICATIONS

- ◉ Watchful assertiveness is often needed
- ◉ Families need ongoing information
- ◉ Reassurance of compassionate and competent care
- ◉ Often burdensome, yet often gratifying, role



# WHAT CAN BE DONE?

- Enhance family-staff communication early
  - Ease transition to NH and foster communication
  - To understand care practices and routines
  - Clarify roles and encourage collaboration
  - Encourage participation in care planning
  - Educate family about hospice benefit



# STAFF TRAINING IS NEEDED TO

- ◉ Recognize terminal decline
- ◉ Collaborate about the goals of care
- ◉ Attend to family concerns
- ◉ Understand needs of dying NH residents
- ◉ Understand and offer palliative care
- ◉ Provide appropriate hospice referral
- ◉ Improve collaboration with hospice



# THE FUTURE

- ◉ Demographics of rapidly aging US
- ◉ More and more people die in NHs
- ◉ Needs must be met with skilled, compassionate care
- ◉ Families are potentially great resources
- ◉ Partnership between family and staff should be strengthened to benefit resident



THIS IS ABOUT ALL OF US



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# THANK YOU

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