Palliative Care in Long-term Care: INNOVATIVE MODELS

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Care Settings for the Elderly

- Hospital
- Home
  - Private House
  - Assisted Living
  - Facilities
  - Residential Care
  - Communities
- Rehab Facilities
  - Acute Rehab
  - Sub-Acute Rehab
- Nursing Home

Diagram: Flowchart showing the connections between different care settings for the elderly, including hospital, home, and nursing home.
Penetration of Palliative Care Across Care Spectrum

53% of Hospitals with more than 50 beds have a palliative care program*
Penetration of Palliative Care Across Care Spectrum

- Hospital: 53% of Hospitals with more than 50 beds have a palliative care program*
- Home: Hospice services, Home Care Agencies, Special Programs
- Rehab Facilities: Symptom management
- Nursing Home: Hospice Services, Integrated Palliative Care Programs, Non-Hospice Palliative Care consultations

* caveat: palliative care program
The Facts: Part I

1.5 million people reside in nursing homes
  • 45% are 85 years or older
  • 51% are dependent in ALL 5 ADLs (bathing, feeding, dressing, toileting, transferring)
  • These residents are OLD and FRAIL!

Fried and Mor. Frailty and Hospitalization of Long-Term Stay Nursing Home Residents. JAGS 45:3. 1997.
Data from the 2004 National Nursing Home Survey
The Facts: Part II

By 2030, 40% of Americans who die will die in a nursing home (currently 23%)

2/3 of nursing home residents will die there

The Facts: Part III

Individuals with dementia make up the biggest group (48-66% prevalence)

Recently published data show that almost 55% of NH residents with advanced dementia die within an 18 month period.


Mitchell SL et al. The clinical course of advanced dementia. NEJM 2009.
And yet…

Estimated that 39% of NH residents are hospitalized in the last 30 days of life

Families of those who die in NH report overwhelmingly inadequate attention to pain, dyspnea, and emotional support

Only an average of 6% of residents who die in NH had Hospice services

“Good Geriatric Care IS Palliative Care”

Aggressive symptom management at ALL stages of life
  pain, shortness of breath, anxiety, depression

Establishing Advance Care planning and DOCUMENTING
  Communicating with families, medical staff, nursing staff
  Determining plan of care for transitions
  Preparing

Care and support at the end of life
  symptom management within capabilities of facility
Barriers to Palliative Care in NH

Regulatory

Financial

Staffing
Barriers to Palliative Care in NH

Regulatory

Intense regulation aimed at preventing abuse and neglect make it difficult to care for dying residents

- weight loss, psychotropic drugs

MDS/RAI
Barriers to Palliative Care in NH

Financial

Medicare reimbursements to NH focus on restoration and rehabilitation

Medicare does not pay for room/board, Medicaid does not pay for palliative care/hospice

Perverse incentive to hospitalize
Barriers to Palliative Care in NH

Staffing

- High turnovers
- Inadequate Palliative Care education
- Cultural Differences

Palliative Care expertise availability

End of Life care dependent on staffing availability and training
Models of Palliative Care Delivery in NH

Traditional Hospice

Non-Hospice Palliative Care Consultation Services

Integrated Palliative Care Programs developed by the NH “Home Grown”
Innovative Strategies

Bronx Jewish Home Project (nursing home based)

Manhattan Jewish Home Project (nursing home based)

Community Service Division Project (home care based)
PALLIATIVE CARE FOR END-STAGE DEMENTIA PATIENTS:
A PROACTIVE APPROACH
BACKGROUND

• Caring for persons with dementia (PWD) in nursing homes is particularly challenging as the disease progresses and treatment decisions must be made

• Palliative care may ease end-of-life transitions for dementia patients and their families

• Because there is no clear start of end-of-life decline, clinicians and families are unclear about when to re-consider goals of care
• Funding was sought to explore the effect of a palliative approach in nursing home residents with end-stage dementia (Joann Reinhardt, PhD, Principal Investigator)
“Enhancing Life Quality for Residents with End-Stage Dementia and their Families”

The Clinical Component

Supported by an Alzheimer’s Association grant
When in the course of dementia is the disease considered “advanced”?
Eligibility Criteria

Having a diagnosis of dementia in the chart
Having an MDS Cognitive Performance Score of 5 or 6
Having an MDS Cognitive Performance Score of 4 WITH ADLs=11-18
Being age 55 or older
Having a health care agent or designated representative available for participation
Not currently receiving either hospice or palliative care
Eligibility Criteria for Health Care Agents or Designated Representative

Having a relative who meets criteria described
Able to speak English or Spanish
Information Gathered for Research Purposes:

- Demographic information (age, sex, race, education)
- Functional status (using scores of functional disability from the MDS)
- Diagnoses of co-morbid conditions
- Sentinel events (i.e., hip fracture; pneumonia)
- Medical interventions used (ER visits, hospitalizations, venipunctures, urinary catheterizations, use of antibiotics, use of analgesics, intravenous hydration, feeding tube)
- Presence of any advance directive
Palliative Care Intervention

3 members of the palliative care team meet with family member for approximately one hour to:

- discuss resident’s condition
- determine goals of care
- put a plan into place to achieve those goals

Palliative care team members communicate outcome of meeting to primary care team members

Member of palliative care team visits patient every two weeks to ascertain comfort level and communicate with primary care team

Follow-up phone calls are made to family members every two months by PC team
Structure and Process of Family Meeting

Palliative care team meets with family
Quiet, private meeting area
Meeting lasts approximately one hour
Meeting content includes:
- family’s description of resident in the past, personal history, personality, likes/dislikes, etc.
- family’s perception of resident’s current condition
- PC physician’s assessment of resident’s condition
- family’s goals of care for the resident
- team members’ recommendations of how to achieve those goals
Families’ Comments about Residents’ Conditions

“I now have a one-sided relationship with my aunt. It’s the little connections that make it worthwhile. There are little windows where her old self shines through, and when she does, it fills my heart.”
Families’ Comments about Residents’ Conditions

“It’s so hard because I just really miss my mom, and she’s still here. I want to start grieving for her but she’s still with us. Sometimes she knows us, sometimes she doesn’t. I just really miss my mom…I just really miss her.”
Families’ Comments about Residents’ Conditions

“My mom was way ahead of her time. She took a class about dying and end of life in the ’70’s. She knew what she wanted and I just have to fight for it now. This would be her worst nightmare to have it go on for as long as it is right now.”
Families’ Comments about Residents’ Conditions

“I could see her lasting a while the way she is. She’s okay. It’s not much of a life, but it’s not a terrible life.’
Goals of Care as Articulated by Families

“Please just keep her comfortable”

“She’s going—don’t let her be uncomfortable”

“She has no quality of life—I just want her to be comfortable”
Decisions Typically Made to Ensure Comfort

Do not resuscitate (DNR)
Do not intubate (DNH)
Do not hospitalize (DNH)*
No I/Vs
No antibiotics*
No tube feeding
No diagnostic procedures
Use of analgesics and other methods to maximize comfort

* Unless this is the only way to provide comfort
Family responses to being in the project

“You made me aware that I am going to have to think ahead about caring for my parents (they are 72 and 74—currently caring for aunt). I am going to have to plan better; ask more questions; be more aggressive.”
Family responses to being in the project

“Before, I felt guilty that there was nothing I could do but put (my aunt) in a nursing home. I can’t do any more; I have a whole family to take care of, and I work. I do the best I can. But, I learned a lot of information by being in the study and my cousin learned even more. I learned more information about patient care.”
Family responses to being in the project

“...very good study. I enjoyed the conversations with the doctor. Very interesting. I pray that the researchers got all of the information they needed.
Family responses to being in the project

“I don’t get upset; I used to, but I don’t anymore”
Family responses to being in the project

“I don’t feel as isolated.”
Summary of our Experience to Date with 16 Families

• Several families did not clearly understand what was going on with their cognitively impaired relative prior to the meeting

• Describing dementia as a “disease of the brain” seemed to be helpful to families trying to understand what was going on

• Even in those residents whose dementia was very advanced, family member often mentioned an occasional “spark” of recognition
Summary of our Experience to Date with 16 Families

• In every case, after the family understood the seriousness of the resident's condition, the family’s stated goal of care for the resident was his or her comfort.

• In every case, at the conclusion of the initial family meeting, families expressed sincere appreciation for the opportunity to have discussed, in such detail, their relative, her condition, goals, and known or presumed treatment preferences.
Continuing and Next Steps (Clinical and Research)

The addition of 35 more resident/family dyads to the project

Ongoing physical (i.e., pain/symptom) assessments of resident subjects (every 2 weeks) by palliative care team

Calls to family members every two months by palliative care team

Pre-, post- and midway during the 6-month study period interviews of families by research team

Comparison of findings from these dyads with findings from a control group of resident/family dyads
The “Manhattan Project”

**Integrated Nursing Home Palliative Care**

Imbedding a palliative care physician into each of the NH communities for several months at a time to work closely with the primary care team.

- Role modeling of communication skills
- One-on-One teaching and demonstration to nursing staff and nursing aides of palliative care techniques in pain assessment and management, end-of-life care, communicating with grieving families
- Support to team to assist with completing advance care planning documentations (MOLST forms) Individuals with dementia make up the biggest group (48-66% prevalence)

*Supported by a Fan Fox and Leslie R. Samuels Foundation grant*
The “Manhattan Project”

Integrated Nursing Home Palliative Care

Role Modeling

Physician Behavior
- prescribing practices, pain management practices
- demonstrating new symptom management skills

Care team - social workers, nutritionists, therapists
- demonstrating effectiveness of certain phrases and communication techniques
- Addressing staff’s attitudes - attitude supersedes knowledge

De-emphasize “teaching” and instead DEMONSTRATE

Supported by a Fan Fox and Leslie R. Samuels Foundation grant
The “Manhattan Project”

*Integrated Nursing Home Palliative Care*

**Evaluation**

- Pre and Post tests/questionnaires for nursing staff
- Tracking of medication prescribing practices (standing pain orders vs. prns alone)
- MOLST completion rates
- Family Satisfaction surveys

*Supported by a Fan Fox and Leslie R. Samuels Foundation grant*
Enhancing Quality of Life for Community-Dwelling Frail Elders:

Palliative Care at Home
Background

On a daily basis, Jewish Home Lifecare’s home care program serves approximately 1,200 frail elders who suffer from chronic or life-limiting conditions.

The home care program had developed and implemented a useful model in 2005 to meet clients’ mental health needs.

In collaboration with Beth Israel’s Department of Pain Medicine and Palliative Care, and using the model developed for mental health, the home care program sought funding to develop a three-pronged home-based palliative care program.

Supported by a Fan Fox and Leslie R. Samuels Foundation grant.
Target Population

- All home health patients in Manhattan and the Bronx served by Jewish Home Lifecare’s Community Service Division
- Medicare and/or Medicaid insured
- Suffering from various chronic illnesses:
  - 35.7% CHF
  - 36.7% Cardiopulmonary disease
  - 18.5% Dementia
  - 17.8% CVA
The “prongs” of the palliative care program

• An educational training component for nurses, social workers, home health aides and escort-translators
• The use of telehealth to assist in case identification and monitoring
• Hiring a palliative care consultant to advise on care and visit clients on an as-needed basis
The Educational Component

Nurses and social workers participated in a 32-hour palliative care training covering:

- pain management
- psychological, emotional and spiritual issues
- social and cultural aspects
- preparing for a “good death”
- the future of palliative care in home care
The Educational Component

Escort translators and home health aides each participated in a 3-hour training session covering:

- pain and symptom management
- psychosocial and spiritual care
- cultural issues
- care of the imminently dying
- interdisciplinary teams
- the role of the escort translator and the role of the HHA in palliative care
The Teleheath Component

• The “Health Buddy” is a small, interactive unit placed in patients’ homes with a text based monitor that is used to collect information on a daily basis about patient symptoms, vital signs, and behavior by having the patient or caregiver respond to a series of simple questions that display on the monitor.
Example of Telehealth Unit

In the past week, have you taken all of your medicines as your doctor has ordered them?

1. Yes
2. No
3. I don't take any medicines
The Telehealth Component

• Prior to the implementation of the palliative care initiative, the home care program was using approximately 300 health buddies to monitor diabetes, congestive heart failure, and wellness

• With the start of the palliative care initiative, the existing telehealth units were modified to include palliative care items (in English or Spanish)
The Telehealth Component: Red Alert Items

• Do you have a poor appetite or loss of appetite? Have you lost 8 or more pounds in a month?
• On a scale of 0-5, please rate your pain. (3-5)
• Over the past month, have you been more tired than usual?
• Do you take more than 2 medications for pain?
The Teleheath Component: Red Alert Items

• Do you feel your pain is under good control? (No)
• Does your pain interfere with sleeping? (Yes)
• Does your pain interfere with doing activities and socializing? (Yes)
AMAC's iCare Desktop™
Web-based Care Management Tool

Population Summaries
Patient Notes
Care Providers

Patient Results
Daily Compliance
Patient Status

Patient Trend Plots
Monthly Compliance
Payor/Insurance Information
# Palliative Care Protocol

## PALLIATIVE CARE TELEHEALTH PROTOCOL

<table>
<thead>
<tr>
<th>RN Facilitator and DPSs responsibilities</th>
<th>Primary RN and RN Supervisors responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMAC Website, IMD Support Website and all current vendor Websites will be checked daily by each RN Facilitator. (Weekend checking of Website is done by designated staff)</td>
<td>Primary RN (RN Supervisor if Primary RN is absent) will contact patients, providing follow-up and documenting in Progresa.</td>
</tr>
<tr>
<td>If RN Facilitator is not available, the RN Supervisor will provide Telehealth coverage, If the RN Supervisor is not available, the DPS will provide Telehealth coverage.</td>
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</tbody>
</table>

### RED ALERTS

<table>
<thead>
<tr>
<th>Question</th>
<th>RN Facilitator and DPSs responsibilities</th>
<th>Primary RN and RN Supervisors responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a poor appetite or a loss of appetite? Yes I have lost 8 pounds or more</td>
<td>1. RN Facilitator will make the initial call to the patient to verify the red alert</td>
<td>Primary RN will:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. Receive communication from Palliative Care Consultant</td>
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<td></td>
<td></td>
<td>2. Collaborate with the interdisciplinary team to discuss a plan of action</td>
</tr>
<tr>
<td>On a scale of 0-5 (with 0=no pain to 5=worst pain), please rate your pain. 3-5</td>
<td>2. After speaking to the patient and providing the initial education in response to the red alert, the RN Facilitator will send a Palliative Care referral to Fernando Caday, Office Coordinator.</td>
<td>3. Follow up with the patient when the RN Facilitator is unable to reach patient by phone and document in Progresa</td>
</tr>
<tr>
<td>Over the past month, have you had more difficulty getting around your home? Yes</td>
<td>3. The RN Facilitator will then send an e-mail to the Primary RN, the RN Supervisor, Social Work Supervisor, DPS and PI Team informing them that a Palliative Care Referral was made. (DPS will schedule a Team Meeting including the Palliative Care Consultant)</td>
<td></td>
</tr>
<tr>
<td>Do you take any medication for pain? (Medications for pain include Opioids, Other Narcotics) Yes 2 or more</td>
<td>4. RN Facilitator will then document all findings in Progresa.</td>
<td></td>
</tr>
<tr>
<td>How often during the past 24 hours have you experienced pain? All of the time</td>
<td>5. If the patient does not answer the telephone, the RN Facilitator will document this in Progresa, and alert the Primary RN that they are unable to get in touch with the patient.</td>
<td></td>
</tr>
<tr>
<td>Do you feel that your pain is under good control? No</td>
<td></td>
<td></td>
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<tr>
<td>Does your pain interfere with your sleeping? Yes</td>
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<td>Does your pain interfere with doing activities and socializing? Yes</td>
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Palliative Care Consultant

A half-time palliative care consultant was added to the home care staff
Role of Palliative Care Consultant

• Case consultation

• Staff education through:
  • Role modeling
  • Periodic didactic sessions
  • Special projects, e.g.,
    • Compassion fatigue program for staff
    • Bereavement initiative
### Palliative Care Referrals
**1/1/08-6/30/09**

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
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<tbody>
<tr>
<td>No. of referrals</td>
<td>101 (82 patients)</td>
</tr>
<tr>
<td>Age range</td>
<td>43-100 (mean=77.04)</td>
</tr>
<tr>
<td>Gender</td>
<td>78 % Female</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>51.2% Latino</td>
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<tr>
<td></td>
<td>30.5% Black</td>
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<tr>
<td></td>
<td>18.3% White</td>
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<tr>
<td>Length of time in home care</td>
<td>1 day-16.18 years (median=3.31 years)</td>
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</table>
**Palliative Care Referral Source**  
(N=101)

<table>
<thead>
<tr>
<th>Referral Source</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Nurse</td>
<td>68.3%</td>
</tr>
<tr>
<td>Social worker</td>
<td>15.8%</td>
</tr>
<tr>
<td>Pre-existing health buddy</td>
<td>15.8%</td>
</tr>
</tbody>
</table>
Outcome of Referrals

Visit from palliative care consultant 70.3%
Patients followed by pain clinic 2.0%
Referred to other clinicians (e.g., psychiatry or social work) 2.0%
Determined not to be a palliative care issue 4.0%
Visit declined by patient 14.0%
Client died/discharged before visit 3.0%
Client could not be contacted 1.0%
Additional Outcome of Palliative Care Program

A total of 320 clients were assigned health buddies.
Next Steps

Project beginning in adult day centers, with
- educational sessions
- case consultation
- health buddy kiosks
Successful implementation of any palliative care initiative in long-term care setting will depend on:

Customizing program according to the characteristics of each NH or homecare program - one size does NOT fit all

Commitment from the leadership - administrative, medical, nursing, SW, unions

Relationship with palliative care expertise in the area (Hospice and non-Hospice)