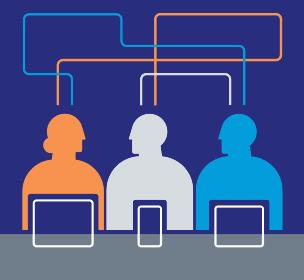


# Palliative Care for Dementia

**Maribeth Gallagher, DNP,  
PMHNP-BC, FAAN  
Gillian Hamilton, MD, PhD  
Hospice of the Valley**

October 3, 2017





# CAPC National Seminar and Boot Camp 2017

## Practical Tools for Making Change

November 9-11, 2017

Sheraton Grand Phoenix | Phoenix, Arizona

## Pre-Seminar Boot Camp: Developing Palliative Care in Community Settings

November 8, 2017

### 2017 SEMINAR THEMES

- Program design for all care settings
- High-functioning teams
- Health equity in palliative care
- Quality measurement

### HIGHLIGHTS

- Interactive sessions on cutting edge topics
- Networking events to connect and share ideas
- Office Hours with Seminar faculty for deep dive Q&A
- Poster session and reception

## KEYNOTE LINEUP



**Diane E. Meier, MD, FACP**  
Director, Center  
to Advance  
Palliative Care



**Eric Widera, MD**  
Co-founder,  
Geri-Pal



**Kimberly  
Sherell  
Johnson, MD**  
National Health  
Disparities  
Expert



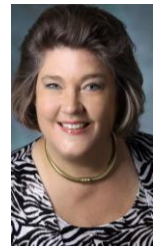
**Ira Byock, MD**  
Co-founder,  
Providence  
Institute for  
Human Caring



**Lauren Taylor,  
MDiv, PhD(c)**  
Co-author, *The  
American Health  
Care Paradox*

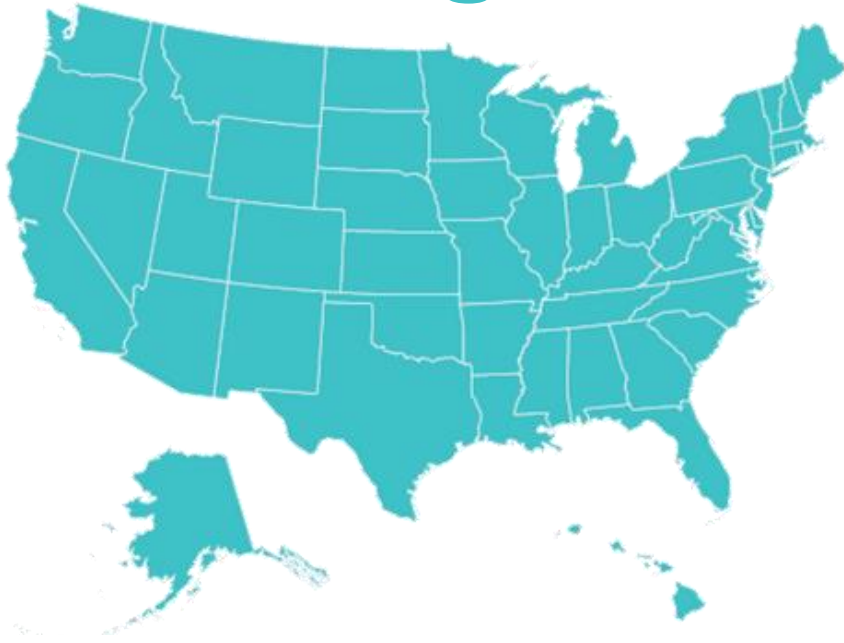


**Matthew  
Gonzalez, MD**  
Associate  
Medical Director,  
Providence  
Institute for  
Human Caring



**Lynn Hill  
Spragens,  
MBA**  
Leading National  
Palliative Care  
Consultant

# Introducing...



Are you a community-based palliative care program? Put yourself on the map!

A new CAPC initiative to map all palliative care programs providing care in the community across the U.S.

<https://mapping.capc.org/>

Participating programs will have the option to be included in GetPalliativeCare.org's Provider Directory

**Put your program "on the map" today!**

# Palliative Care for Dementia

**Maribeth Gallagher, DNP,  
PMHNP-BC, FAAN  
Gillian Hamilton, MD, PhD  
Hospice of the Valley**

October 3, 2017



# Objectives

- Identify the basic components of the Palliative Care for Dementia (PCD) program model.
- Discuss the outcomes in the two-year study for those who participated in the PCD program compared to a group who received usual care

# Background:

## Hospice of the Valley (HOV) Est. 1977

- One of the largest non-profit hospices in U.S.
- Serves Phoenix (1.6M) and Maricopa County (4.5M)
  - Retirement destination for U.S. & Canada
- HOV daily census
- 10 In-Patient Care Units (PCU)
- Dementia Program (est. 2003)
- Partnered with Beatitudes Campus for best practices in dementia care project (2005) evolved into Comfort Matters
- Dementia-specific PCU (est. 2013)
- Palliative Care for Dementia Program (est. 2013)

# Barriers to Effective Dementia Care

- Providers have minimal training in dementia
- Fragmentation of care services
- Families are unprepared and experience high burden
- Resources to help people stay in their homes are scarce
- High rate of unnecessary ED and hospital visits that result in poor outcomes

# Background

- Most adults report they would not want aggressive medical interventions if they had advanced dementia.
- Most proxy decision-makers report that comfort is the primary goal of care for their person with advanced dementia.

**And yet...**



# Background

## People with end-stage dementia have:

- Fewer completed advanced directives
- More distressing symptoms amenable to treatment (pain, neuropsychiatric symptoms)
- More costly & burdensome interventions with little to no clinical benefit (antibiotics, IVs, feeding tubes, restraints, labs)
- More transitions of care that can be avoided
  - Almost 3X ER visits & hospitalizations
  - 4X hospital days
- Less use of hospice services

# The Critical Question...

- How do we bridge the gap between the care people say they want and the care they actually receive?



# Palliative Dementia Care

- Hospice dementia services benefit patients and families
  - Improved symptom management, quality of life, and dying experience
- But hospice requires prognosis of 6 months or less

## ***Why wait until the last 6 months of life for this type of care?***

- What if we offered palliative care for people at any stage of dementia if it aligns with their goals and treatment preferences?
- What elements would comprise such a service?

# Evidence-Based Palliative Dementia Care

Specialized team to help with relief from symptoms, improve quality of life, and connect with resources.

- Decision-making support
  - Identify MPOA/MHOA
  - Complete advance directives
  - Align all treatments with goals of care in context of dementia
- Simplify meds
- Provide options to avoid unnecessary hospitalizations / ED visits
- Maximize comfort with effective symptom management
- Educate & support caregivers
- Liberalize diets - hand feed v. feeding tubes
- Include hospice referral as a treatment option

# Evidence-Based Dementia Caregiver Support

- Informational Support (Dementia education)
- Emotional Support
- Instrumental Support
  - Legal & financial assistance
  - In-home help
  - Respite opportunities (e.g., day centers)
  - Identify key support persons

# Hospice of the Valley's Palliative Care for Dementia Program (PCD)

- Started October 2013
- Goal: To provide evidence-based care to improve health outcomes and quality of life for both persons with dementia and their caregivers
- Emphasis is education/psychosocial support with medical oversight/input by those with dementia expertise
- Focus: WHOLE PERSON COMFORT CARE

# PCD Program Core Components

- **Home Visits** by a Dementia Educator (SW)
  - 2 visits/1<sup>st</sup> month, then 1 visit/month
  - Ongoing phone support as needed
- **Phone Support** – Physician (Geriatrician), Psychiatric Nurse Practitioner, and Clinical Pharmacologist
- **24/7 phone support** – experienced triage nurses
- **Weekly respite** by experienced volunteers
- **Cost/month**

# Dementia Educator (DE Roles)

- Identify MPOA/MHPOA
- Discuss goals of care/complete advance directives
  - What would (s)he want?  
Educate re: realistic outcomes associated w/ CPR, hospitalizations, feeding tubes, antimicrobial use, fractures
- Assess cognitive/functional levels
- Assess safety & general living situation
- Provide alternative options to prevent unnecessary hospitalizations & ED visits
- Connect families w/ resources (legal, financial, community, respite, in-home help)
- Connect MPOA w/ MD or NP for input regarding reducing polypharmacy & maximize comfort



# DE Roles (cont'd)

## → Educate caregivers:

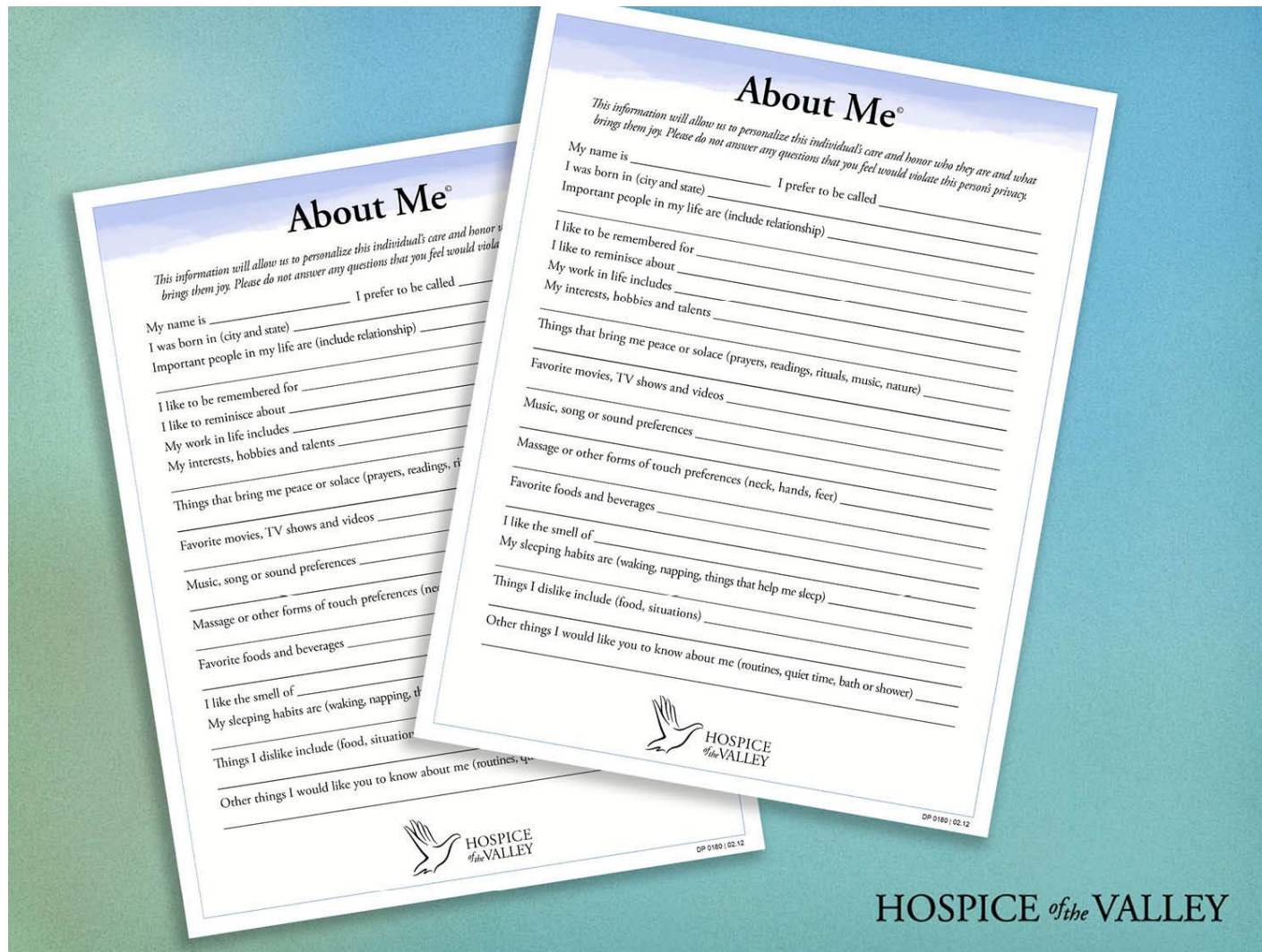
- Disease progression & common complications
- Behaviors and sleep issues
- Recognizing delirium, dysphagia, & pain
- Methods to connect beyond words (sensory)
- Preparing for further decline

## → Facilitate caregivers' self-care:

- Volunteers provide respite hours
- Mindfulness for Dementia Caregivers
- Education about Ambiguous Loss

## → Avoid/delay SNF placement

# There's a story behind every person....



HOSPICE of the VALLEY

# PCD Program Pilot Study: Objectives

1. Develop a cost-effective model to improve care and quality of life for persons with dementia and their caregivers.
2. Avoid unnecessary hospitalizations and institutional placement.
3. Demonstrate that the model saves health care costs.

# PCD Program Pilot Study: Methods

ALTCS health plan (managed care Medicaid program of 'dual eligible' clients in AZ) contracted for the pilot study, and provided referrals and cost data.

- Participants were considered to be at SNF level of care but resided in homes
- Each pair of referrals randomized - 95 Intervention / 95 Usual Care
- Health care costs - tracked for one year & analyzed independently
- Comparisons - total health care costs, hospitalizations, nursing home placements, home care aides, pharmacy, and other costs
- Both groups completed satisfaction surveys
- PCD participants completed Zarit Burden Interview (ZBI) at admission and after 3 months of services

# PCD Program Pilot Study: Outcomes

- Cost savings in intervention group = \$304/month/member (PCD program costs \$275, therefore it was cost effective, saving plan members \$29/member/month)
  - Other costs reduced (e.g., chemotherapy, dialysis, surgery, physician visits and other outpatient services)
- Savings for PCD group were most significant due to reduced:
  - Nursing home placements
  - Hospitalizations
  - Transportation (ambulances, taxis)

# Outcomes (cont'd)

Savings also related to educating and discussing the importance of:

- Completing advance directives
- Reducing polypharmacy
- 24/7 triage line & urgent care *instead of* ED/hospital
- Educating and understanding how to prevent, minimize and effectively respond to dementia-related behaviors
- Encouraging care for the caregiver (respite/mindfulness)
- Avoiding SNF placement with in-home help or Group Home

- The AZ Medicaid managed care plan valued the PCD program's services and contracted to pay for PCD services
- The Private sector expressed interest for PCD program and a willingness to pay (\$275/month)
  - Average length of stay on the program – 75 days
- To date, 909 patients served
- 27% of patients later enrolled in hospice

# Experiences of PCD Caregivers

- ALTCS Caregivers – 91% reported feeling either “Highly Satisfied” or “Satisfied” with PCD’s support for caregivers after 3 months on the program.
- Private sector:
  - 86% report being “highly satisfied”
  - 89% would “definitely recommend”
- ZBI showed significant reduction in stress ( $p < .01$ ) particularly in the domains related to:
  - Social and family life
  - Role strain



# PCD Respite

To date...

- Over 1500+ volunteers received specialized dementia training for visits
- Provided over 8000 hours of respite for PCD caregivers
- Some serve as 'buddies' so person with dementia can 'work' at a White Dove store

# PCD Feedback

- *“We couldn’t have done it” without the Palliative Care for Dementia Program. “Their support made all the difference. We loved hearing ‘you’re doing it right’; suggestions of how to do it better were so welcome and reassuring.”*
- *“Everyone who is caring for someone with dementia should have this service.”*
- *“I feel like I have learned so much from our Dementia Educator and feel comforted knowing that my mother’s behaviors are part of the disease progression and I should not take them personally.”*

# Case Study

→ Richard and Barbara

→ Referring provider: Dr. Jay

→ Dementia Educator: Amy



# Lessons Learned

- Length of service: 3-months on average provides families with the effective support needed at any given time
- Cost: \$150 / month appears to be an acceptable price point by families
  - Grant and agency support will always be needed to provide necessary services for those unable to pay
- 24/7 phone support is more important to private/underserved families
  - Usage is around 33% for this group

# Lessons Learned (cont'd)

- NP / Physician Roles: Support is vital but each average 2-3 hours a week for PCD, so they are cost-effective
  - This component was used significantly more by families (49%) who do not receive some sort of case management support
- PCD team – Experienced ‘Dementia-capable’ staff are essential for navigating the broad array of challenges
- Respite – both by volunteers for a few hours & for days by facilities are essential component
  - Particularly for private payers and the underserved
  - Not as important to those on an ALTCS because they receive this benefit from the plan

# Future Directions

- Increase contracts with health care organizations
- Find additional sources of funding to supplement the underserved
- Recruit additional student volunteers for respite from ASU Dementia Course
- Build new dementia campus
  - Education for professional and lay caregivers
  - Adult day services
  - One bed in AL dedicated to PCD overnight respite (current dementia PCU not a good fit for those in earlier stages)

# Voices of People Living with Dementia: Ideal Care

- Keep me comfortable
  - Recognize, evaluate, and treat pain and other physical symptoms
- Uphold my dignity
- Facilitate self-determination & informed decision-making
  - Be frank re: realistic outcomes from chronic illnesses & acute events.
  - It is important my family is present to advocate for my wishes.
- Provide staff skilled in palliative dementia care
- 100% of participants did not wish for resuscitation or ‘heroics’



# In Conclusion

- HOV's PCD program is a valuable, cost-effective, and replicable model that improves comfort and QoL for persons with dementia and their caregivers.
- We invite others to replicate this program and offer to share our materials and support.

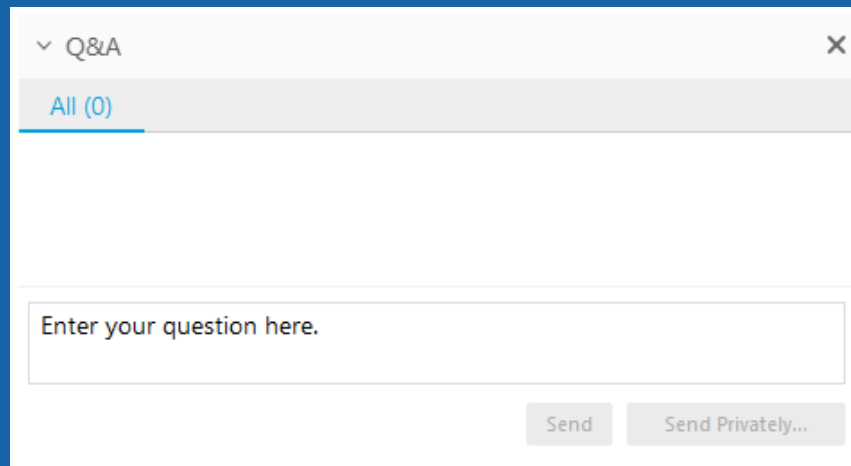
Special thanks to supporters of the pilot project: Virginia G. Piper Charitable Trust, BHHS Legacy Foundation, St. Luke's Health Initiatives

Thank you.



# Questions?

Please type your question into the questions pane on your WebEx control panel.



The image shows a screenshot of the WebEx Q&A interface. At the top, there is a header with a dropdown arrow and the text "Q&A" and a close button "X". Below the header is a tab labeled "All (0)". The main area is a large empty space. At the bottom, there is a text input field with the placeholder text "Enter your question here." and two buttons: "Send" and "Send Privately...".

# References

- Givens, J., Jones, R., Shaffer, M., Kiely, D., & Mitchell, S. (2010). Survival and comfort after treatment of pneumonia in advanced dementia, *Archives of Internal Medicine*, 170(13), 1102-1107.
- Mitchell, S. (2017). Palliative care of patients with advanced dementia. Up-to-date. Retrieved from <https://www.uptodate.com/contents/palliative-care-of-patients-with-advanced-dementia>
- Mitchell, S., Black, B., Ersek, M., Hanson, L., Miller, S., Sachs, G.,...Morrison, S. (2012). Advanced dementia: State of the art and priorities for the next decade. *Annals of Internal Medicine*, 156(1Pt1), 45-51.
- Mitchell S., Kiely D.K, Hamel, M.B., Park, P.S., Morrison, J.N., & Fries, B.E. (2004). Estimating prognosis for nursing home residents with advanced dementia. *Journal of American Medical Association*, 291(22), 2734–2740.
- Mitchell, S. Kiely, D., Miller, S., Connor, S., Spence, C., & Teno, J. (2007). Hospice care for patients with dementia. *Journal of Pain and Symptom Management*; 34(1), 7-16.
- Mitchell, S., Miller, S., Teno, J., Davis, R., & Shaffer, M. L. (2010). The advanced dementia prognostic tool: A risk score to estimate survival in nursing home residents with advanced dementia. *Journal of Pain and Symptom Management*, 40(5), 639-651.
- Mitchell, S., Teno, J., Kiely, D., Shaffer, M., Jones, R., Prigerson, H.,.....Hamel, M. B. (2009). The clinical course of advanced dementia. *New England Journal of Medicine*, 361(16), 1529-38.
- Shega, J., Hougham, G., Stocking, C., Cox-Hayley, D., & Sachs, G. (2008). Patients dying with dementia: Experience at the end of life and impact on hospice care. *Journal of Pain and Symptom Management*, 35(5), 499-507
- Stewart-Archer LA, Afrooz A, Toyce CM, Gomez FA.(2014). Dialogue on ideal end-of-life care for those with dementia. *Am J Hosp Palliat Med*. Apr 29 doi: 10.1177/1049909114532342
- Teno, J. M., Gozalo, P. L., Lee, I. C., Kuo, S., Spence, C., Connor, S. R., & Casarett, D. J. (2011). Does hospice improve quality of care for persons dying from dementia?. *Journal of the American Geriatrics Society*, 59(8), 1531-1536. AGS. doi: 10.1111/j.1532-5415.2011.03505.x
- Volandes AF, Paasche-Orlow MK, Barry MJ, et al. (2009). Video decision support tool for advanced care planning in dementia: Randomized controlled trial. *BMJ*, 338;b2159