

# Case Study: Hospice of the Valley's Palliative Care for Dementia Program

A Cost-Effective Model for Home-based Case Management and Caregiver Support

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“Over the years, we have seen thousands of requests for hospice services for patients living with dementia who did not yet meet the criteria, but whose caregivers desperately needed education and support. We created the PCD program to fill this gap.”

*Maribeth Gallagher, DNP, Director of Dementia Program, Hospice of the Valley*

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## BACKGROUND

Hospice of the Valley, Phoenix's largest hospice provider, has developed a home-based case management and psychosocial support program for people living with dementia and their caregivers. The Palliative Care for Dementia (PCD) program accepts patients at any stage of dementia and in any setting of care (most live in their own homes), regardless of ability to pay. Modeled after the organization's long-standing dementia education and support services for hospice patients, the PCD program intervenes earlier in the course of the disease with evidence-based care that can improve health outcomes and quality of life for people living with dementia and their caregivers.

Launched in 2013 as a two-year grant-funded pilot, the PCD program successfully demonstrated improvements in quality and cost-effectiveness in a study published in 2017.<sup>1</sup> The ongoing program receives funding from a mixture of grants, private pay, contracted services with a Medicaid managed care plan, and support from Hospice of the Valley.

## IN BRIEF: DEMENTIA CARE AT HOSPICE OF THE VALLEY

**Program Name:** Palliative Care for Dementia

**Institutional Home:** Hospice of the Valley is one of America's oldest and largest not-for-profit hospices, serving approximately 2,000 patients per day. The organization provides hospice, palliative care, dementia care, family caregiver support, and pediatric services.

**Location:** Phoenix metro area, AZ

**Patient Population:** Patients at any stage of dementia and in any site of care (most patients are seen in private homes, group homes, and assisted living facilities)

**Caregiver Support:** Social workers provide dementia care education, support goals-of-care conversations and advance directives, and teach coping strategies. Volunteers provide weekly respite care. Staff connect families with legal, financial, in-home help, and other community resources.

**Staffing Model:** Social workers make all home visits; physician/geriatrician, psychiatric nurse practitioner, and clinical pharmacologist are available for phone support; triage nurses provide 24/7 phone support; volunteers provide weekly respite care. A team leader provides full-time oversight of the program while working on additional projects.

**Funding Model:** Grants, private pay, contracted services with a Medicaid managed care plan (Mercy Care), and support from Hospice of the Valley

## APPROACH

The central component of the PCD program consists of home visits from a Dementia Educator (DE)—a social worker with expertise in dementia care. Dementia Educators make 2 visits in the first month with new patients, followed by monthly visits and ongoing phone support as needed. DEs can call on a physician (geriatrician), psychiatric nurse practitioner, or clinical pharmacologist for limited medical oversight as needed, and people served by the program have access to a 24/7 phone line staffed by triage nurses. Volunteers are typically available to provide caregivers with up to 4 hours of respite care per week, with some seasonal variability.

During a DE's first 2 visits, which can be between 90-120 minutes long, he or she establishes a relationship with the person living with dementia and their caregiver to learn about and try to address their most immediate needs. The DE conducts standardized cognitive and functional assessments for the person with dementia,<sup>2</sup> reviews their other medical conditions, and evaluates the safety of the home environment. Caregivers complete a questionnaire about their own interests, what brings them peace and enjoyment, and their loved one's life and interests. DEs also discuss goals of care and advance care planning in these introductory visits. This includes providing caregivers with education on disease progression and realistic outcomes associated with CPR, hospitalizations, antibiotics, feeding tubes, and fractures. To ensure that the patient's treatments align with their goals, DEs will connect with the program's geriatrician or nurse practitioner by phone for input about medications and maximizing comfort. The PCD program's medical professionals do not prescribe medications for patients, but make recommendations to the patient's primary physician.

Caregiver support is an important part of the DE's role. DEs evaluate caregiver well-being using the Zarit Burden Interview.<sup>3</sup> Once they identify a caregiver's needs, they have a substantial toolkit for supporting them, including connection with volunteer-provided respite care, in-home help, legal and financial services, or other community

resources. DEs help caregivers support their loved one by providing education on disease progression and common complications, such as how to recognize and respond to symptoms (e.g., delirium, swallowing problems, pain) and how to prevent or respond to distressing behavior or sleep issues. DEs also offer guidance in how caregivers can take care of themselves, with mindfulness-based stress reduction classes and information about coping with ambiguous loss—the feeling of grieving someone who is still alive.<sup>4</sup> Hospice of the Valley also leads support groups for caregivers of people living with dementia, and collaborates in educational and social events for caregivers hosted by the Dementia Friendly Tempe project, part of Dementia Friendly America, in Tempe, AZ.

The PCD program accepts people living with any stage of dementia. About half of the program's patients are identified during an evaluation for hospice services for which they did not yet qualify. The remainder are referred to the PCD program by their Medicaid case managers, primary care physicians, neurologists, hospitals and nursing facilities, or community partners who provide senior care and home-based services.

In addition to a formal contract with Mercy Care, a Medicaid managed care plan, Hospice of the Valley has established informal partnerships across the continuum of care to support providers caring for patients and families in need of dementia education and services. These partnerships were in part a natural evolution of the organization's decades of service for hospice patients, but they were also the result of concerted outreach efforts. In local hospitals, for example, Hospice of the Valley has hospice admission coordinators who inform hospital staff about the PCD program as a consideration for discharge planning. In the community, PCD program staff conduct lunch and learn sessions with providers and facilities on best practices in palliative dementia care, in which they explain the program and give common examples of how it could benefit their clients.

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**“Emergency Department staff really appreciate PCD’s potential for bridging the gap for those who have run out of aggressive treatment options but still frequent the ED.”**

*Dr. Gallagher*

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The PCD program serves around 150 patients at any one time, with a staff of 4 dementia educators, 3 of whom work part time. DEs do not require any formal certifications in dementia care, and are selected based on their experience, personality traits, and perspectives on dementia. New DEs receive on-the-job training shadowing others. In addition to visits with patients, DEs participate in weekly care conferences led by PCD's director, Dr. Gallagher, who is also the program's psychiatric DNP. Conferences provide an opportunity to discuss cases and hear updates on dementia care research, providing a practical forum for ongoing training based on current cases. The program director, geriatrician, and clinical pharmacologist each provide around 3 hours a week to the PCD program. A team leader oversees the program by supervising

social workers and administrative team members, developing and tracking metrics as well as handling any customer service issues that may arise. The program taps into the hospice's established 24/7 triage phone service to provide patients and caregivers with around-the-clock support.

## RESULTS TO DATE

The PCD program has demonstrated improvements in care quality and cost-effectiveness. In its initial pilot, 91% of caregivers reported feeling either "highly satisfied" or "satisfied" with the program's support, and experiencing a significant reduction in stress. Cost savings were significant: program participants spent \$304 less per member per month (PMPM) on their health care than a comparison group, not including the cost of the PCD program. At the time of the pilot, the PCD program was priced at \$275 PMPM, demonstrating cost effectiveness with an overall savings of \$29 PMPM. The most significant savings were due to reductions in nursing home placements, hospitalizations, and transportation. Savings were also attributed to the completion of advance directives and reductions in polypharmacy.

The success of the pilot, which cared for patients referred by an Arizona Medicaid managed care program, resulted in a contract with Medicaid for ongoing services. The contract covers the in-person PCD program for 3 months, and members are then covered for phone support for an additional 9 months. The PCD program has also cared for self-pay patients since its inception. Hospice of the Valley has reduced the price of the service to \$150 PMPM to make the program more affordable for families, and is experimenting with offering the first month free of charge. The PCD program also serves as a referral stream for the organization's hospice service. The program has served more than 1,300 patients to date, with 27% of patients later enrolling in hospice.

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## TOOLS

- The PCD program uses standard geriatric assessment tools to evaluate patients' cognition and function.<sup>2</sup>
- The program collects a medication list and medical records from the patient's primary care provider and/or neurologist.
- Caregivers are assessed using the Zarit Burden Interview. DEs collect a baseline at the first visit and then repeat the interview 3 months into the program.
- DEs learn about their patients' lives and interests using an "About Me" form that is completed by patients and caregivers.

→ The PCD program tracks patient and caregiver information using cloud-based electronic health software for home health agencies called Homecare Homebase. The software allows staff to access a patient's medical record and care notes from the office or the field. Every contact with the patient and caregiver, including after-hours support, is noted.

## LESSONS LEARNED

- **Provide 24/7 phone support:** One-third of PCD-enrolled families make use of the phone service. According to the program director, this is one of the most important elements of the program, allaying anxiety for overburdened caregivers and regularly preventing unnecessary trips to the emergency room and hospitalizations. Programs that lack the infrastructure for 24/7 phone support may be able to provide it by contracting with local hospices.
- **Visit patients at home:** The home environment provides a rich context for how best to support a patient and their caregiver. DEs can assess the safety of the home, see what may aggravate behaviors or provide comfort, and help conduct a full medication reconciliation.
- **Wait for results:** The PCD program pilot demonstrated that it takes about 3 months to cultivate positive outcomes with patients and caregivers. Families spend an average of 75 days on the service.

- 1 Hamilton, G., Gallagher, M., Pierson, K., Lowes, S., Lin, P., Ortega, R. "Palliative Care for Dementia: A Randomized Controlled Study of a Replicable and Financially Viable Model for Organizations Providing Caregiver Support (SA518A)," *J Pain Symptom Manage*, 2017; 53(2): 401. Web access: <http://doi.org/10.1016/j.jpainsymman.2016.12.196>.
- 2 A list of standardized cognitive and functional assessments is available in the CAPC toolkit.
- 3 Information on the development and validation of the Zarit Burden Interview, together with instructions on how to access and use the assessment tool, is available at <http://mapi-trust.org/questionnaires/zbi>.
- 4 The term "ambiguous loss" was coined in the 1970s by Pauline Boss, PhD, a researcher who studied families of soldiers who went missing in action. Dr. Boss's later work examined unresolved grief caused by a variety of circumstances, including when a person is still physically there, but psychologically absent, as in cases of dementia. Information on ambiguous loss and family coping strategies can be found at Dr. Boss's website: [www.ambiguousloss.com](http://www.ambiguousloss.com).

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