Supportive Care for Dementia & GUIDE: Guiding an Improved Dementia Experience

Dementia Care and Education Campus, an innovation of Hospice of the Valley, Phoenix AZ

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1

Supportive Care for Dementia(SCD)

A no-fee program, census 750, to support people living with MCI or any level of dementia living alone or with family/caregivers:

- **Monthly visits for 5 visits from "Dementia Educator": social worker or similar, caseload 55: first visit virtual or home, second at home, last 3 virtual. All at home if live alone.**
- **First visit Neuropsychiatric Inventory (NPI) of behaviors, Zarit Burden Inventory (ZBI) of caregiver stress; MMS and/or MOCA; other assessments, develop care plan**
- **Second visit complete advance directives, including Medical Power of Attorney and preferences re: CPR and hospitalizations (including if hip fracture)**
- **All visits provide local resources, education on approach, support for caregivers**

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Supportive Care for Dementia

- Administrative team answers phones weekdays; hospice nurse triage team answers phones nights/weekends to advise and defuse crises
- Medical Director and Nurse Practitioner review medications and make suggestions to family and/or PCP
- For those who live alone RN/NP can visit for medication organization
- Occupational therapist available for phone or in-person consultations
- 5th visit repeat NPI and ZBI. If living alone or unstable, may continue on program past 6 months.

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Results

- Cared for over 4000 patients in past 3 years: 3800 with caregivers, 480 living alone, 50 with IDD/Alzheimer's
- 22% discharged to hospice (despite average only moderate dementia)
- Highly statistically significant ($p<.001$) reduction in aggression, agitation, calling out, wandering, insomnia (NPI)
- Highly statistically significant ($p<.001$) reduction in stress to caregiver (ZBI)
- 48% reduction in hospitalizations during the 6-month program, 28% reduction in hospitalizations in the 6 months after the program

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Michael and Janet

- 70yo male living with wife of 49 years, one disabled daughter died age 8, no other family in touch
- Independent in ADLs, continent, MMS 8/30
- Hospital because hallucinating, brandishing gun
- Wife received much education on approach; care-giver provided through ADPI grant 4 hrs/week to reduce stress, wife incredibly appreciative of all
- Then wife called triage when he took car keys, advised on approach, helped with placement options
- Then found roaming in underwear – hospitalized
- In hospital diagnosed with pneumonia/sepsis, declined, died
- Wife called to thank team, very grateful

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5

JOURNAL OF PALLIATIVE MEDICINE
Volume XX, Number XX, 2023

DOI: 10.1089/jpm.2022.0534

Brief Report

Open camera or QR reader and scan code to access this article and other resources online.

Supportive Care for Dementia: A Replicable Model to Reduce Neurobehavioral Symptoms, Caregiver Stress, and Hospitalizations, and Increase Hospice Referrals

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Abstract

Objective: This report describes a hospice-supported no-fee program to support patients living with all levels of dementia and their caregivers.
Background: Our medical system struggles to serve the rapidly increasing numbers of patients with dementia. Hospice of the Valley developed a low-cost six-month program to reduce caregiver stress and reduce neurobehavioral disturbances of patients living with dementia, reduce costs for insurers, and increase hospice referrals.
Methods: Data were analyzed from 532 patients living with caregivers admitted over 22 months. Caregiver burden, behaviors, hospitalization, and hospice admissions were tracked.
Results: Severity of neurobehavioral disturbances and burden to caregivers decreased significantly. Hospitalizations decreased during and after the program, resulting in cost savings for insurance programs. Twenty-five percent of participants were admitted to hospice.
Discussion: The Supportive Care for Dementia program was welcomed by community physicians, leading to improved supportive care and increased hospice referrals. The program is replicable and has been adopted by one health plan and is being evaluated by others.

https://www.liebertpub.com/doi/10.1089/jpm.2022.0534

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Diversity – African Americans

Did we enroll a representative population of Blacks/AAs?

- **Blacks/AAs are 5.2% of Maricopa Co population, but only 3.2% of adults over 60.**
- **Program enrolled 4% blacks/AAs.**
- **Began program with statistically significantly more severe symptoms and greater caregiver stress than whites.**
- **Showed higher reduction in symptoms than whites during the program, and caregivers completed the program with significantly lower stress than whites.**

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Race Analysis: NPI (Behaviors) and ZBI (Caregiver Stress)

Patient Race	NPI Severity Pre-test	NPI Distress Pre-test	ZBI Pre-test	NPI Severity Post-test	NPI Distress Post-test	ZBI Post-test
Black/ African American	13.15 (6.6)*	18.62 (11.4)*	19.04 (12.2)	9.08 (5.5)	11.42 (9.4)	11.37 (7.7)*
White	10.12 (6.0)	12.55 (8.9)	19.87 (9.0)	7.55 (5.3)	8.93 (7.6)	16.11 (8.9)

Patient Race	NPI Severity Pre-to-Post Improvement	NPI Distress Pre-to-Post Improvement	ZBI Pre-to-Post Improvement
Black/ African American	4.07 (6.8) N=26	7.19 (9.5)* N=26	7.67 (6.7)* N=24
White	2.56 (5.2) N=595	3.62 (7.7) N=594	3.76 (8.1) N=568

*significant group difference at p<.05

NPI: Neuropsychiatric Inventory, ZBI: Zarit Burden Inventory

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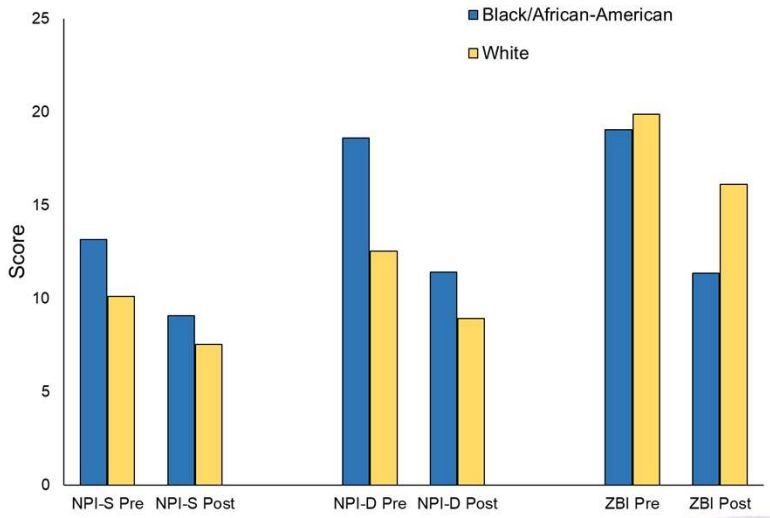
Race Analysis: NPI (Behaviors) and ZBI (Caregiver Stress)



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Diversity – Hispanics

Did we enroll a representative population of Hispanics?

- **Hispanics are 30% of Maricopa County population, but only 11% of adults over 60.**
- **Program enrolled 13% Hispanics.**
- **Compared with non-Hispanic patients, Hispanics showed significantly greater improvement in challenging behaviors ($p<.01$) and marginally greater reduction in caregiver stress ($p=.052$) as a result of the program.**

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Ethnicity Analysis: NPI (Behaviors) and ZBI (Caregiver Stress)

Patient Ethnicity	NPI Severity Pre-test	NPI Distress Pre-test	ZBI Pre-test	NPI Severity Post-test	NPI Distress Post-test	ZBI Post-test
Hispanic	11.88 (6.7)	14.87 (10.7)	20.60 (10.6)	8.14 (5.8)	8.77 (7.9)	15.00 (8.8)
Not Hispanic	10.09 (5.9)	12.66 (88.8)	19.77 (8.9)	7.56 (5.3)	9.14 (7.7)	16.07 (8.9)

Patient Ethnicity	NPI Severity Pre-to-Post Improvement	NPI Distress Pre-to-Post Improvement	ZBI Pre-to-Post Improvement
Hispanic	3.74 (5.6)* N=74	6.09 (8.8)* N=75	5.60 (8.9) N=65
Not Hispanic	2.52 (5.2) N=558	3.52 (7.7) N=556	3.70 (8.0) N=536

*significant group difference at p<.05

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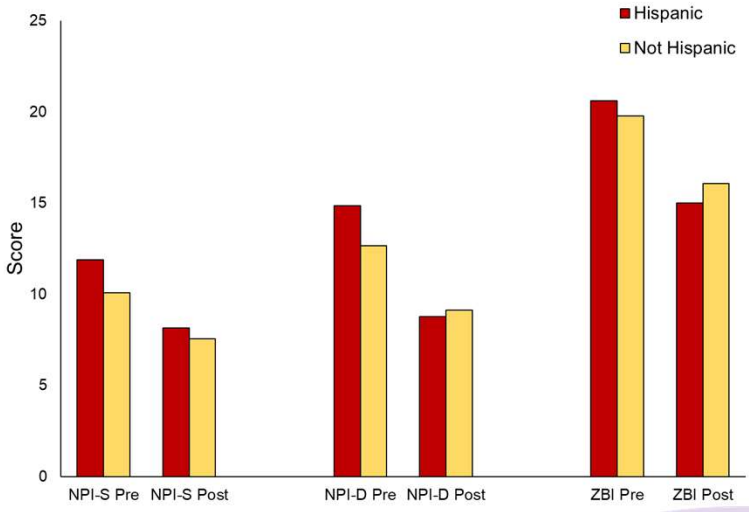
11

Ethnicity Analysis: NPI (Behaviors) and ZBI (Caregiver Stress)



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Living Alone with Dementia

- Research: 65% in community; 26% of those live alone
- 73% female, 27% male (compared with those with caregivers: 56% F, 44% M)
- Mean MMS 21/30 (range 8-26); MOCA 17 (8-26)
- Same ethnic distribution as those living with caregivers for whites and AAs; for Hispanics 13% Hispanics lived with caregivers vs. 6% lived alone
- Same results as those with caregivers: less neurobehavioral disturbances and hospitalizations, increased supportive services and family engagement
- **Stress of distant caregivers was as great as stress of live-in caregivers, and reduced equally with program**

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Wang

- 87yo Asian M living alone own home, referred by Sr Ctr
- First seen 8/23: Indep ADLs, continent, MMS 16/30, rotten food, pills from 1984, no hot water, thermostat off
- Seen monthly; by 7/24 MD visit: he said he had always been alone, brother confirmed he would rather die than move into AL; refused AC despite $99,000 bank account
- Hospitalized with hematuria 8/24: delirium, restraints. Home with home care, brother signed AD for no hospital even if hip fracture
- Hospitalized 8 days later with dehydration; went to hospice, died one week later. Brother supported comfort.

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Return On Investment for a Hospice

An incredible service to the community

- **Physicians LOVE the program, provided 50% of over 4000 referrals**
- **Although we accept referrals living with any level of dementia (or no diagnosis), the average level is moderate (MMS 16/30)**
- **22% of SCD patients were discharged to hospice, usually after 2-3 months on the program**
  - ➢ **Why? Discussions with families about goals of care (easier with dementia)**

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GUIDE Model (federally reimbursed): Guiding an Improved Dementia Experience

- **Beginning 2024, Medicare (CMS) reimburses an average of $275/month first 6 months, then $150/month for SCD-model care until memory care or hospice**
- **Components: Navigator, Clinician/Medication review, 24/7 Helpline**
- **Provides $2500/yr. per patient for respite care**
- **30% of SCD patients qualify (those who have Medicare fee-for-service, not managed care/advantage plans)**
- **Program will continue 8 years**
- **Data will track program payments, and costs of all medical services, to compute costs/savings; also track caregiver stress**

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16


Questions?
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17


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(602) 636-6363
Thank you for listening!
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18