NIA IMPACT COLLABORATORY
TRANSFORMING DEMENTIA CARE

Grand Rounds

D-CARE: Results of a Pragmatic Intervention Trial and Implications for the GUIDE model

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Housekeeping

- All participants will be muted upon entry
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
- Visit impactcollaboratory.org
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The Dementia Care Study
D-CARE
Supporting Individuals and Caregivers

D-CARE: Results of a Pragmatic Intervention Trial and Implications for the GUIDE model

IMPACT GRAND ROUNDS, April 16, 2026

pcori PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

NIH National Institute on Aging

PCORI: PCS-2017C1-6534 Comparative Effectiveness of Health System-based versus Community-based Dementia Care

NIA: 1 R01 AG061078-01 A Pragmatic Trial of the Effectiveness and Cost-effectiveness of Dementia Care

Comprehensive Dementia Care

- Focuses on patient and caregiver and includes:
    - Continuous monitoring and assessment
    - Ongoing care plans
    - Psychosocial interventions
        - Aimed at persons living with dementia
        - Aimed at caregivers
  - Self-management
  - Medication management
  - Treatment of related conditions
  - Coordination of care

Boustani M, et al. An Alternative Payment Model To Support Widespread Use Of Collaborative Dementia Care Models. Health Aff (Millwood). 2019 Jan;38(1):54-59. PMID: 30615525.

New Models of Comprehensive Care for Dementia

- **BRI Care Consultation**: by phone at CBOs by SWs, RNs, MFTs
- **MIND at Home**: in person at home by staff, RNs, geri psychiatrists
- **The Care Ecosystem**: by phone by unlicensed staff, APN, SW, Pharmacist
- **Indiana University Healthy Aging Brain Center**: in-person visits in community by staff, RN, SW, Psychologist, MD
- **The UCLA Alzheimer's and Dementia Care Program**: in-person NP or PA co-management with PCP
- **Integrated Memory Care**: in-person primary care of PLWD by NPs
- **Dementia care management integrating palliative care**: calls from a RN or SW, evidence-based protocols for behavioral and palliative care issues

Lees Haggerty K, et al. Recommendations to Improve Payment Policies for Comprehensive Dementia Care. J Am Geriatr Soc. 2020 Nov;68(11):2478-2485. PMID: 32975812.

The D-CARE Study

Goal of D-CARE Study

To compare the effectiveness and cost-effectiveness of community-based (CBDC) versus health system-based dementia care (HSDC) and to compare both interventions to Usual Care (UC) in:

- Pragmatic randomized clinical trial
- 4 clinical trial sites
  - Wake Forest Baptist Health/Atrium
  - Geisinger Health;
  - Baylor Scott & White Health
  - University of Texas Medical Branch

The D-CARE Study

Study Design and Sample

- Pragmatic 18-month randomized (patient/caregiver dyad) 3-arm superiority trial
- **Sample size**: 2150 dyads, 1000 in each intervention arm and 150 in the Usual Care group
- **Inclusion criteria:**
  - ✓ community-living (not nursing home or hospice)
  - ✓ diagnosis of dementia
  - ✓ have family or friend caregiver(s) who spoke English or Spanish and had a phone
  - ✓ have a partnering physician
- **Randomization:** 7:7:1 ratio
- **Intervention and follow-up:** 18 months

Interventions:

Health-Systems Based Dementia Care

(Based on the UCLA ADC)

- Dementia care delivered by a nurse practitioner or physician's assistant Dementia Care Specialist based within health system
- Writes orders and accessible 24/7, 365 days/year
- Telemedicine or face-to-face visits

Community-Based Dementia Care

(Based on BRI Care Consultation)

- Dementia care delivered by a social worker or nurse Care Consultant based at a community-based organization
- Provides coaching on doctors' visits & educational resources
- Telephone visits

Usual Care

Provides standardized educational materials and as-needed referral to the Alzheimer's Association Helpline

Outcomes: Interviews at 3, 6, 12, 18 months & CMS data

Primary	NPI-Q Severity Scale (person living with dementia)		
	Modified Caregiver Strain Index (caregiver)		
Secondary	NPI-Q Distress (caregiver)		
	Caregiver depression (PHQ-8)		
	Caregiver self-efficacy		
Tertiary	Cognition (MOCA)	Inpatient hospital use	Dementia Burden Scale-Caregiver
	Functional status (FAQ)	Inpatient rehabilitation use	Clinical Benefit
	Quality of Life in Alzheimer's Disease	Post-acute SNF use	Caregiver Rating of Dementia Care Quality
	Goal attainment scaling	Hospice use	Positive Aspects of Caregiving
	Mortality	Long-term nursing home use	Caregiver satisfaction with dementia care
	Days spent at home	Cost-effectiveness analysis	

Other measures

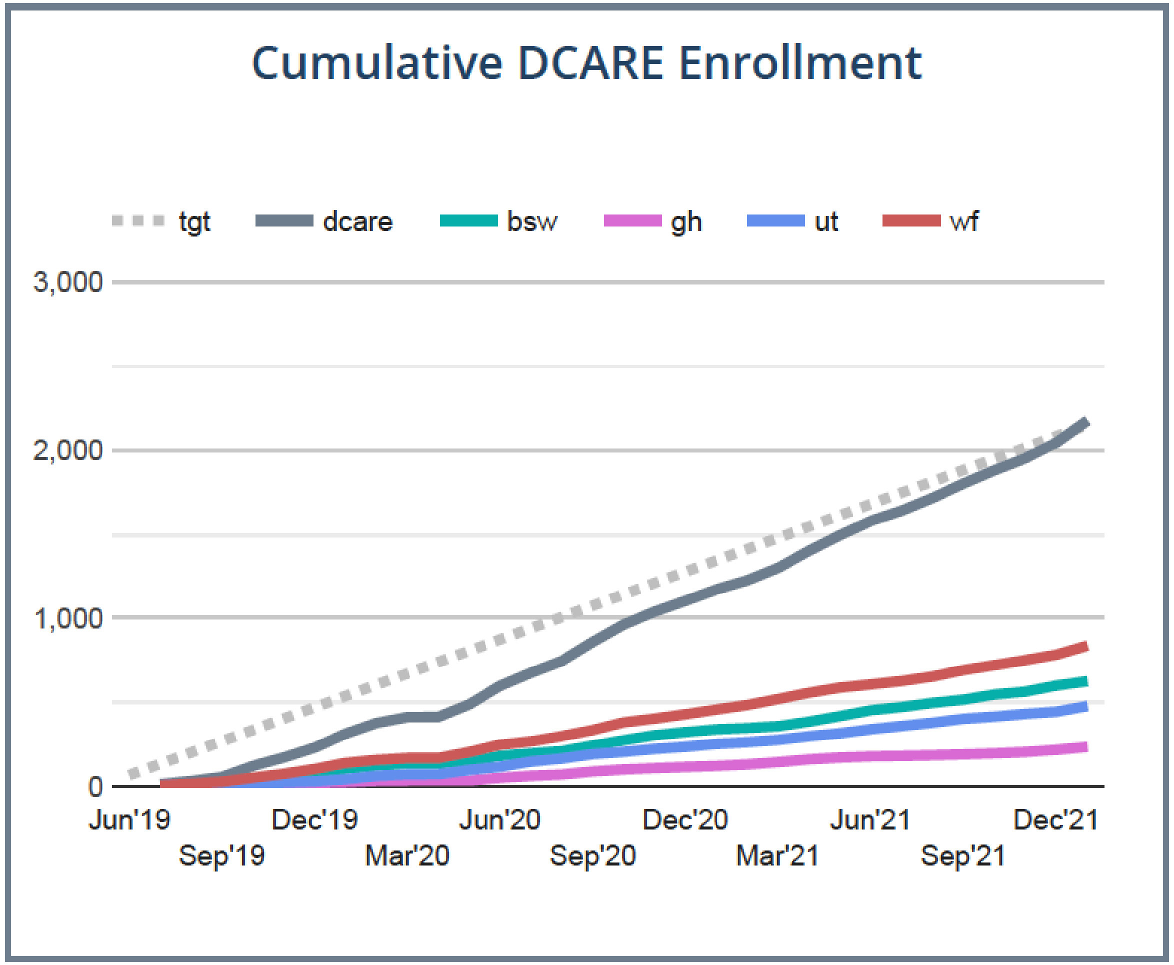
Physician Feedback Questionnaire	Physician satisfaction with dementia care (5 items)-18 months
Fidelity and quality measures	Health Systems Dementia Care (HSDC) Community Based Dementia Care (CBDC)
COVID-19 impact questionnaire	▪ A 10-item questionnaire assessing the impact on PLWD and caregivers was implemented on January 10, 2021. ▪ An 11th question on COVID vaccine status was implemented on May 7, 2021.
Dementia Quality Indicators	• 15 Dementia Quality of Care indicators • EHR Abstraction (HSDC, UC) • CCIS (CBDC)

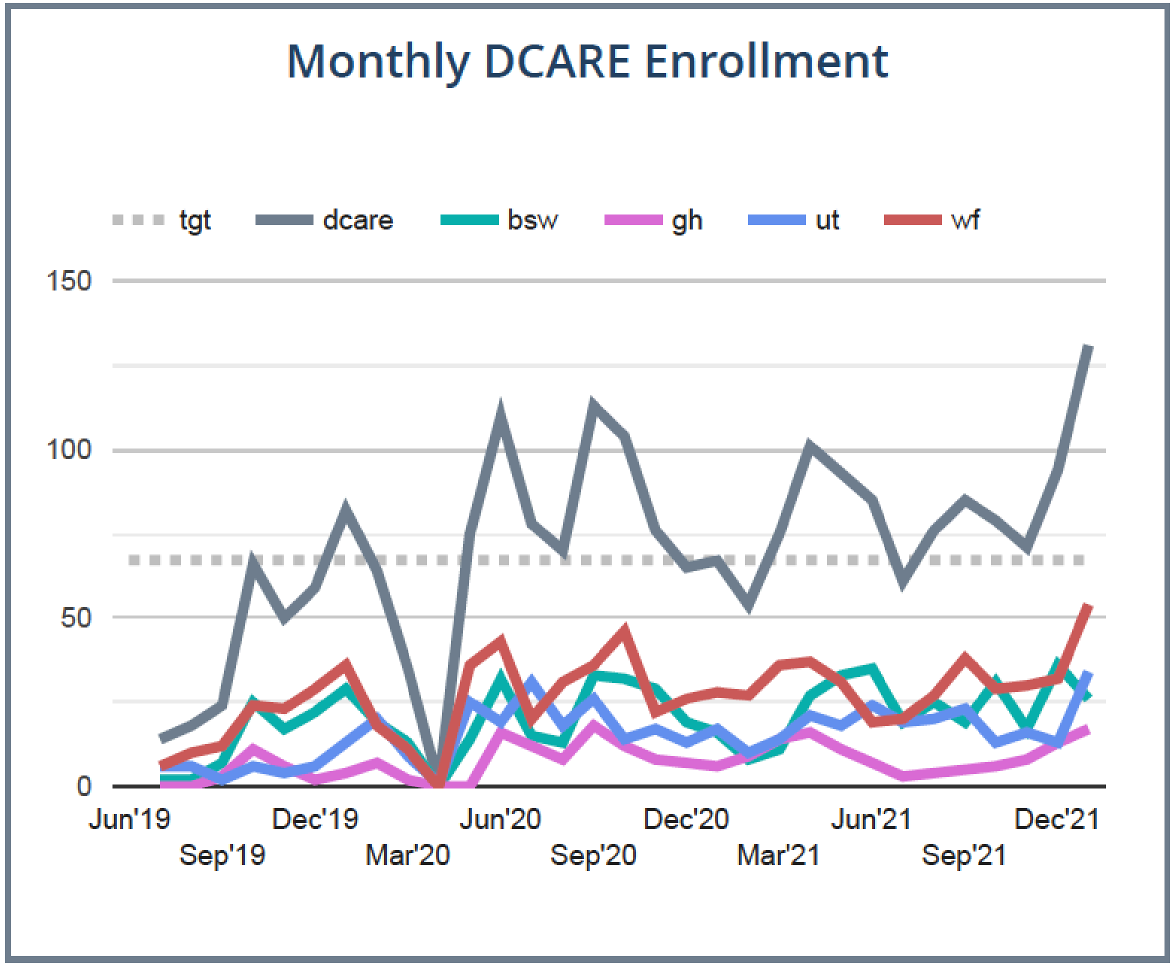
Analysis

Heterogeneity of Treatment Effects (HTE) across sites and in 6 subgroups:

1. high vs. low patient function by FAQ
2. high vs. low patient function by ADL
3. high vs. low NPI-Q Severity
4. high vs. low MCSI at baseline
5. spouse caregiver vs. other caregiver
6. white non-Latino vs. nonwhite or Latino

D-CARE Recruitment: June 2019 – January 2022 (30 mo)





The Dementia Care Study
DCARE
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Death and Withdrawal Rates per 100 Person Years of Follow-up (PYF)

(Data as of 10/17/23)

Site	Enrolled	Observed PYF	Died	Death rate per 100 PYF	Withdrew	Withdrawal rate per 100 PYF
BSWH	626	752	141	18.7	79	10.5
GMC	235	301	43	14.3	14	4.6
UTMB	478	585	128	21.9	49	8.4
WFU	837	1046	202	19.3	49	4.7
Total	**2176**	**2684**	**514**	**19.1**	**191**	**7.1**

Completeness of Follow-Up Interviews

(Follow-Up data as of 10/17/23)

Follow-Up Timepoint	Expected*	Died	Withdrawn**	% Died and Withdrawn	Alive and on study	Completed interview	% completed interview of resolved
3-month	2155	62	57	5.5%	2036	1824	**89.6%**
6-month	2030	84	34	5.8%	1912	1737	**90.8%**
12-month	1906	177	50	11.9%	1679	1528	**91.0%**
18-month	1676	191	14	12.2%	1471	1343	**91.3%**

* Expected: alive and on study and reached follow-up interview window

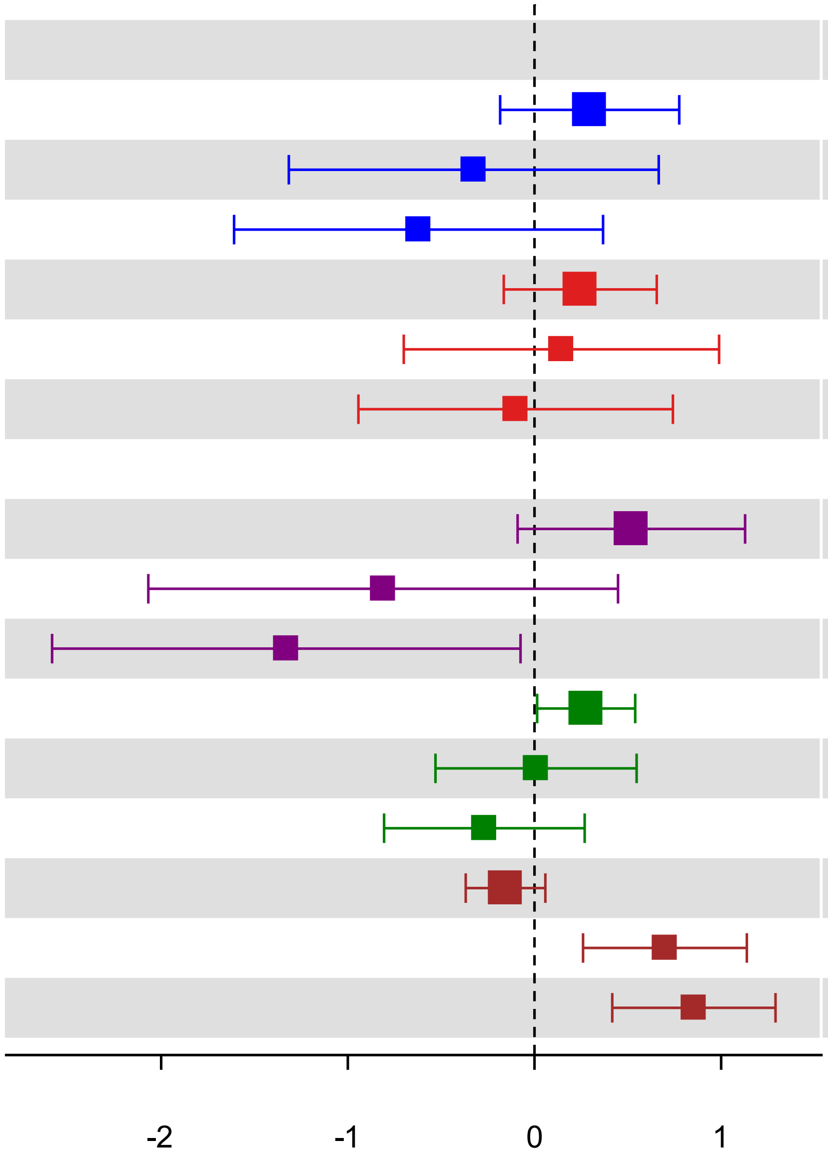
** Died or withdrawn: number of deaths and withdrawals (full study withdrawal and passive participation) within the follow-up window

- Full study withdrawal: withdrawal from study interventions and unwilling to provide study outcomes by questionnaire/interview or allow analysis of medical records and CMS claims data
- Passive participation: withdrawal from study interventions and unwilling to provide study outcomes by questionnaire/interview but willing to allow analysis of medical records and CMS claims data

Results: Baseline Characteristics

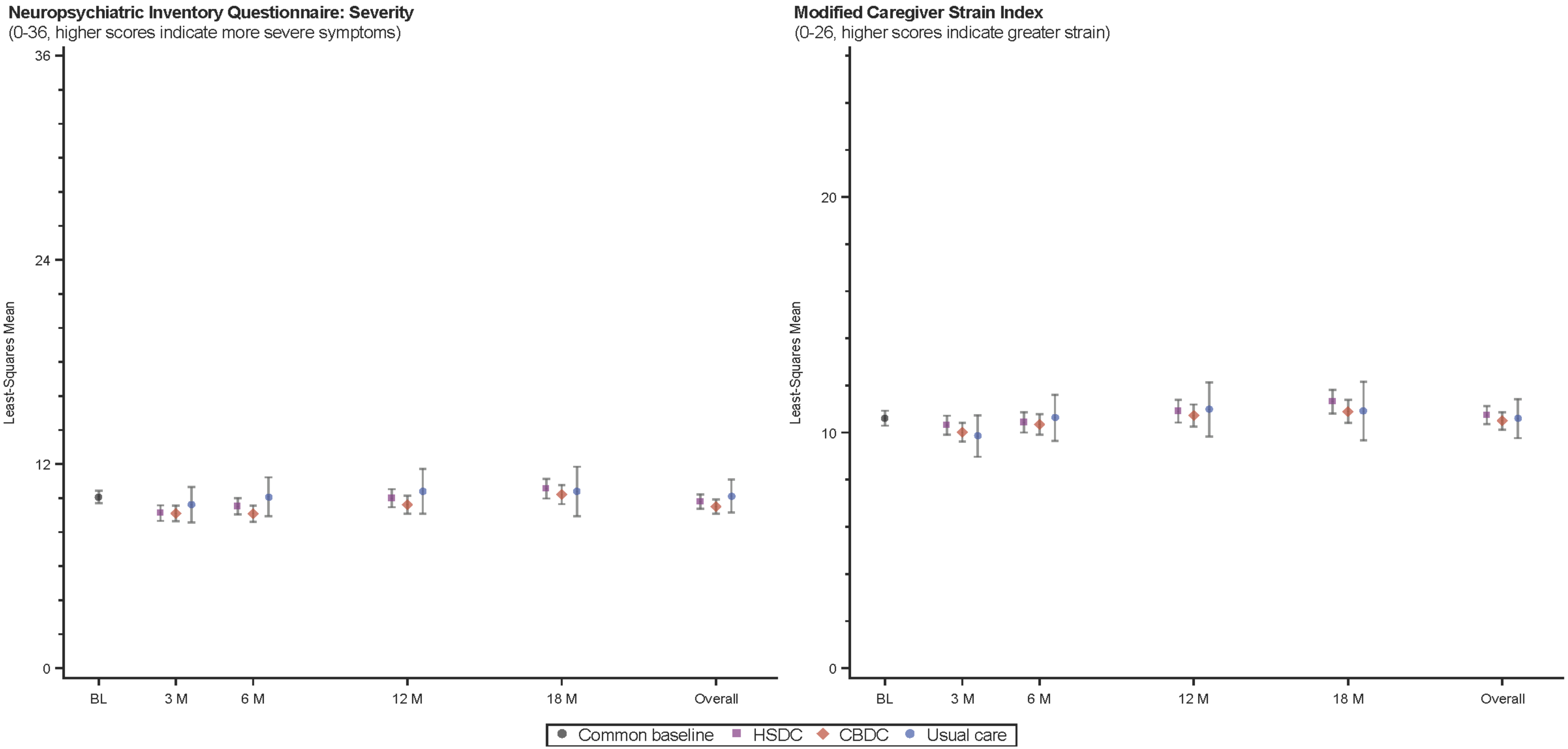
Characteristic	Health System Dementia Care	Community-Based Dementia Care	Usual Care
	(N=1016)	(N=1016)	(N=144)
Age, mean (SD), y	80.6 (8.3)	80.6 (8.7)	81.0 (8.4)
Female	611 (60.1)	583 (57.4)	77 (53.5)
Black and/or Hispanic, No. (%)	213 (21.0)	201 (19.8)	34 (23.6)
Lives at home with caregiver	723 (71.2)	753 (74.1)	105 (72.9)
Lives at Assisted living facility	57 (5.6)	50 (4.9)	9 (6.2)
3-item MoCA, median (q1, q3) (0-12)	3.0 (2.0, 6.0)	3.0 (2.0, 6.0)	4.0 (2.0, 6.0)
Functional Assessment Questionnaire, median (q1, q3) (0-30, worse)	24.0 (17.0, 28.0)	23.0 (17.0, 27.0)	23.0 (15.0, 28.0)
Katz Index , median (q1, q3) (0-6)	5.0 (3.0, 6.0)	5.0 (3.0, 6.0)	5.0 (4.0, 6.0)
NPI-Q Severity, median (0-36, worse)	9.0 (5.0, 15.0)	9.0 (5.0, 14.0) [990]	9.0 (5.0, 14.5)
CG Relationship to person with dementia, No. (%)			
Son, daughter, or son-/daughter-in-law	513 (50.5)	487 (47.9)	65 (45.1)
Spouse/Partner	443 (43.6)	470 (46.3)	70 (48.6)
Modified Caregiver Strain Index, median (q1, q3)	11.0 (6.0, 15.0)	10.0 (6.0, 15.0)	11.0 (6.0, 16.0)
NPI-Q Distress, median (q1, q3)	11.0 (4.0, 19.0)	11.0 (5.0, 19.0)	12.0 (5.0, 18.0)
PHQ-8, median (q1, q3)	3.0 (1.0, 7.0)	4.0 (1.0, 7.0)	4.0 (1.0, 8.0)
Caregiver Self-efficacy, median (q1, q3)	13.0 (11.0, 16.0)	13.0 (11.0, 16.0)	13.0 (11.0 – 16.0)

Results: Primary and Secondary Outcomes Over All Timepoints



Outcome	Treatment Comparison	Difference of Overall Least-Square Means	Hochberg P value
PRIMARY		(97.5% CI)	
NPI-Q Severity	HSDC vs CBDC	0.30 (-0.18 – 0.78)	0.33
	HSDC vs UC	-0.33 (-1.32 – 0.67)	0.46
	CBDC vs UC	-0.62 (-1.61 – 0.37)	0.33
MCSI	HSDC vs CBDC	0.25 (-0.16 – 0.66)	0.54
	HSDC vs UC	0.14 (-0.70 – 0.99)	0.79
	CBDC vs UC	-0.10 (-0.94 – 0.74)	0.79
SECONDARY		(95% CI)	
NPI-Q Distress	HSDC vs CBDC	0.52 (-0.09 – 1.13)	0.48
	HSDC vs UC	-0.81 (-2.07 – 0.45)	0.62
	CBDC vs UC	-1.33 (-2.58 – -0.07)	0.23
PHQ-8	HSDC vs CBDC	0.28 (0.01 – 0.54)	0.23
	HSDC vs UC	0.01 (-0.53 – 0.55)	0.98
	CBDC vs UC	-0.27 (-0.81 – 0.27)	0.65
CGE	HSDC vs CBDC	-0.16 (-0.37 – 0.06)	0.62
	HSDC vs UC	0.70 (0.26 – 1.14)	0.01
	CBDC vs UC	0.85 (0.42 – 1.29)	0.001

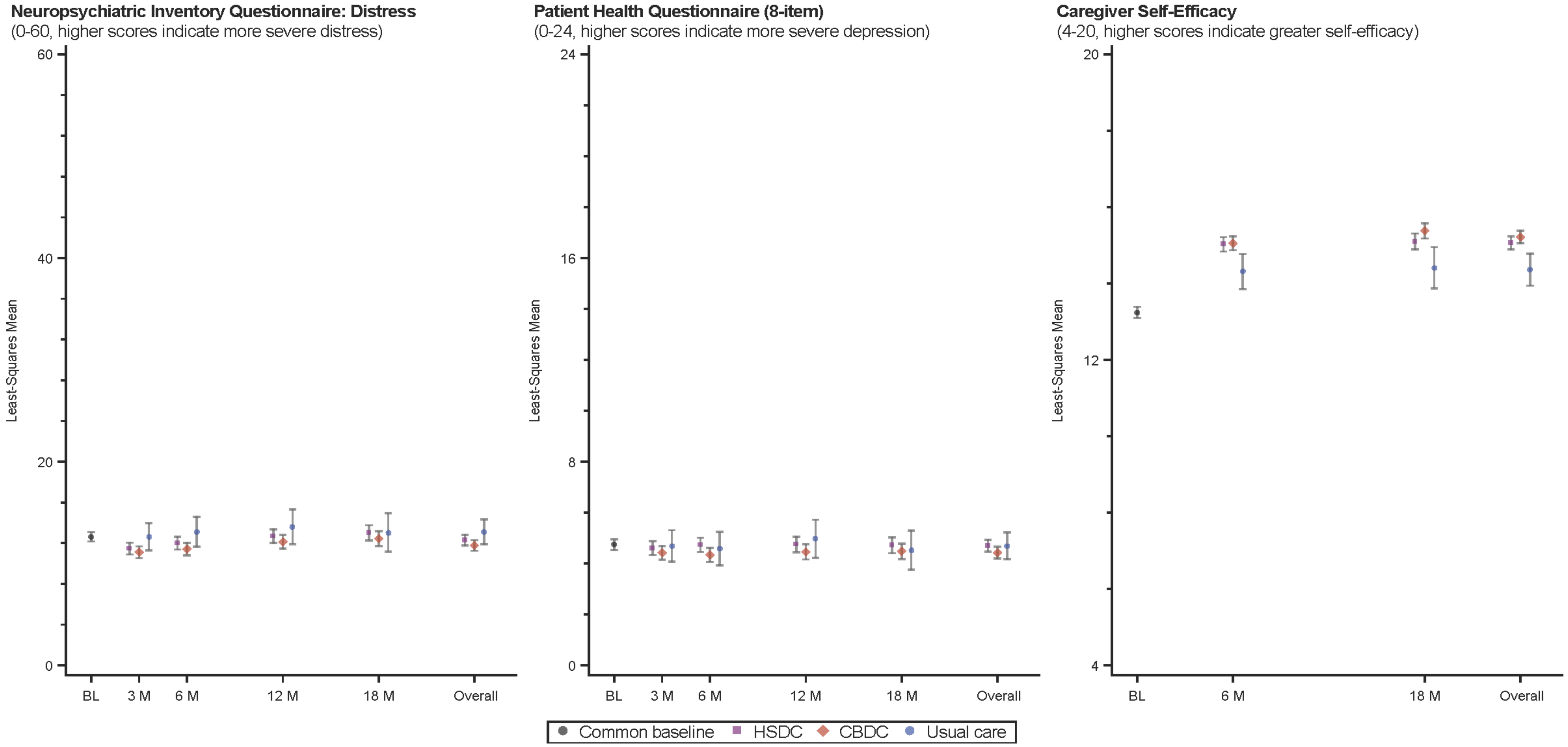
Results: Primary Outcomes Over Time (97.5% CIs)



Neuropsychiatric Inventory Questionnaire: Severity
(0-36, higher scores indicate more severe symptoms)

Modified Caregiver Strain Index
(0-26, higher scores indicate greater strain)

Results: Secondary Outcomes Over Time (95% CIs)



Significant vs. Non-significant Outcomes Scorecard

Primary	NPI-Q Severity Scale (person living with dementia)		
	Modified Caregiver Strain Index (caregiver)		
Secondary	NPI-Q Distress (caregiver)		
	Caregiver depression (PHQ-8)		
	Caregiver self-efficacy		
Tertiary	Cognition (MOCA)	Inpatient hospital use	Dementia Burden Scale-Caregiver
	Functional status (FAQ)	Inpatient rehabilitation use	Clinical Benefit
	Quality of Life in Alzheimer's Disease	Post-acute SNF use	**Caregiver Rating of Dementia Care Quality** (CBDC only)
	Goal attainment scaling	Hospice use	Positive Aspects of Caregiving
	Mortality	Long-term nursing home use	**Caregiver satisfaction with dementia care**
	Days spent at home	Cost-effectiveness analysis	

The Dementia Care Study
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Interpreting D-CARE's Findings

At odds with some observational studies and clinical trials of similar interventions. Potential reasons:

- Highly pragmatic trial using clinical and community staff in real-world settings to deliver the treatments. Did this affect intervention fidelity?
- Usual Care may have provided access to more resources than in other trials
- CTS may have implemented other quality efforts that led to better care among those in Usual Care
- Choice of primary outcomes may not have captured benefit
- The vast majority of the study was conducted during the COVID pandemic, which may have exerted independent effects and impeded the ability to fully deliver HSDC and CBDC as designed

D-CARE Next Steps: Current Grant

- Goal Attainment Scaling (in process)
- Medical record abstraction for fidelity of HSDC intervention, dementia-related quality-of-care, and elder mistreatment (completed, analysis in process)
- Utilization through 18 months (delayed pending release of CMS Part C data)
- Net costs (intervention costs minus any the cost offsets from reduced medical care and caregiving)
  - Primary perspective of Medicare, both FFS and MA
  - Secondary societal perspective including costs to Medicaid and consumers in addition to Medicare

D-CARE: Future Steps

- End-of-life care (1RF1AG089510-01, PI Jennings)
- Caregiver utilization (submitted R01 grant)
- Differences in quality of care across treatment groups and the relationship of quality of care to clinical and utilization outcomes (submitted R01 renewal)
- Effect of COVID-19 on intervention delivery and outcomes (R01 renewal)
- Role of caregiver self-efficacy as a predictor of outcomes (R01 renewal)
- Comparison of use of potentially harmful and appropriate medications across treatment groups (submitted R03)

D-CARE Conclusions

- D-CARE found no significant differences across groups on persons living with dementia and caregiver clinical outcomes, except for caregiver self-efficacy, satisfaction, and ratings of quality which were significantly higher in both HSDC and CBDC compared to Usual Care.
- Effects on personal goal attainment, quality of dementia care, health care utilization, and net costs remain to be determined
- Many unanswered questions about why the main findings were null
- Future proposed research will build upon the rich data set created by D-CARE
- Set the stage for GUIDE

Guiding an Improved Dementia Experience (GUIDE) Model

On July 31, 2023, the Centers for Medicare & Medicaid Services (CMS) announced a new voluntary nationwide 8-year model – the Guiding an Improved Dementia Experience (GUIDE) Model that aims to:

- improve the quality of life for people living with dementia,
- reduce the burden and strain on unpaid caregivers of people living with dementia, and
- prevent or delay long-term nursing home care

GUIDE Model: Design

- **Defining a standardized approach to dementia care delivery**
- **Providing an alternative payment methodology** – CMS will provide a monthly per-beneficiary payment to support a team-based collaborative care approach
- **Addressing unpaid caregiver needs** –by caregiver training and support services, including 24/7 access to a support line, as well as connections to community-based providers.
- **Respite services** – Payment for respite services, which are temporary services provided to a beneficiary in their home, at an adult day center, or at a facility that can provide 24-hour care
- **Screening for Health-Related Social Needs** – and help navigate them to CBOs to address

GUIDE Model: Beneficiary Eligibility

- Diagnosis of dementia
- Medicare is their primary payer
- Enrolled in Medicare Part A and B (not in MA, SNPs or PACE)
- Not enrolled in hospice
- Not residing in long-term nursing home

GUIDE Model: Payment

- Per-beneficiary-per-month payment
- Amount per beneficiary by tier (5 categories) based on:
  - Whether beneficiaries have a caregiver
  - Severity of dementia (mild, moderate, or severe)
- Payment adjustments based on geography, health equity, and performance
- Respite care payment for moderate or severe patients up to an annual cap of $2500, adjusted for geographic area and updated yearly

GUIDE: Where We Are on April 7, 2026

7.2 million Americans with Alzheimer's disease

390 GUIDE sites anticipated to care for 200,000 patients (~40,000 now)

- 96 Established-track (began providing care July 2024)
- 294 New-tract (began providing care July 2025)
- 69 dropouts (as of March 2026)

Questions?

The Dementia Care Study
D-CARE
Supporting Individuals and Caregivers

Questions?

Email us @
IMPACTCollaboratory@hsl.Harvard.edu

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D-CARE: Publications

- “D-CARE: The Dementia Care Study: **Design** of a Pragmatic Trial of the Effectiveness and Cost Effectiveness of Health System-Based Versus Community-Based Dementia Care Versus Usual Dementia Care.” J Am Geriatr Soc. 2020 Nov;68(11):2492-2499. doi: 10.1111/jgs.16862. Epub 2020 Oct 6. Erratum in: J Am Geriatr Soc. 2022 Jun;70(6):E19. doi: 10.1111/jgs.17200. PMID: 32949145; PMCID: PMC8086629.

- “The dementia care study (D-CARE): **Recruitmen**t strategies and demographic characteristics of participants in a pragmatic randomized trial of dementia care.” Alzheimers Dement. 2024 Apr;20(4):2575-2588. doi: 10.1002/alz.13698. Epub 2024 Feb 15. PMID: 38358084; PMCID: PMC11032530.

- “Utility of a short, telephone-administered version of the Montreal Cognitive Assessment.” J Am Geriatr Soc. 2021 Oct;69(10):2741-2744. doi: 10.1111/jgs.17318. Epub 2021 Jun 17. PMID: 34106473; PMCID: PMC8516406.

- “Considerations when designing and implementing pragmatic clinical trials that include older Hispanics.” Ethn Dis. 2024 Apr 10;33(2-3):76-83. doi: 10.18865/ed.33.2-3.076. PMID: 38845738; PMCID: PMC11145730.

D-CARE: Publications

- Dissemination of a successful dementia care program: Lessons from early adopters” J Am Geriatr Soc. 2022 Sep;70(9):2677-2685. doi: 10.1111/jgs.17887. Epub 2022 May 25. PMID: 35553424; PMCID: PMC9489618. 6

- “**Health System, Community-Based, or Usual Dementia Care for Persons With Dementia and Caregivers**” JAMA. 2025 Mar 18;333(11):950-961. doi: 10.1001/jama.2024.25056. Erratum in: JAMA. 2025 May 6;333(17):1549. doi: 10.1001/jama.2025.4753. PMID: 39878968; PMCID: PMC11780506.

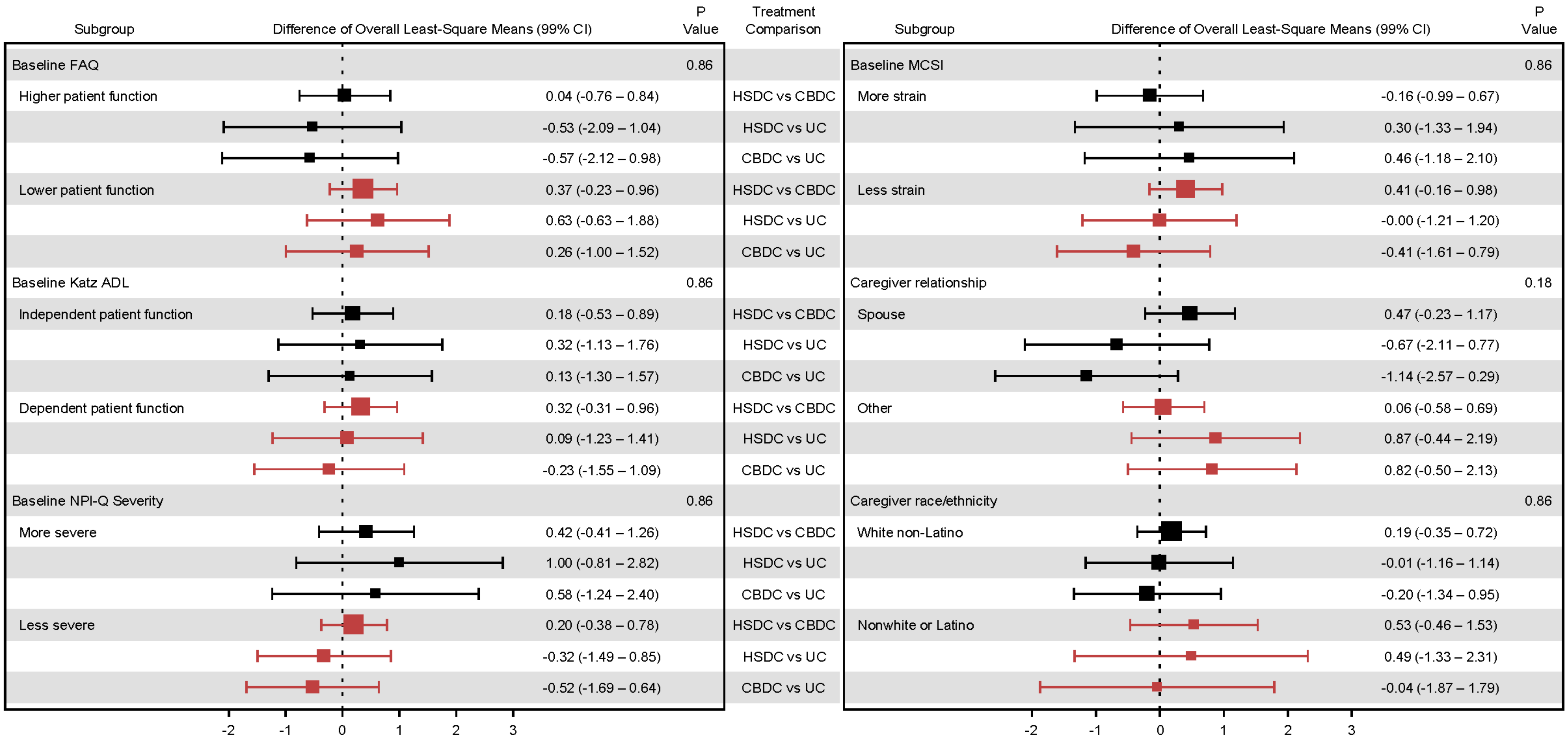
- **“Patient and Caregiver Outcomes of Health System, Community-Based, and Usual Dementia Care** “JAMA Intern Med. 2025 Oct 1;185(10):1227-1236. doi: 10.1001/jamainternmed.2025.4247. PMID: 40892399; PMCID: PMC12406143.

- Self-Efficacy Change Among Diverse Family Caregivers in Dementia Care *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 2026 Jan 12;81(2):gbaf233. doi: 10.1093/geronb/gbaf233. PMID: 41243731.

D-CARE: Publications in the Pipeline

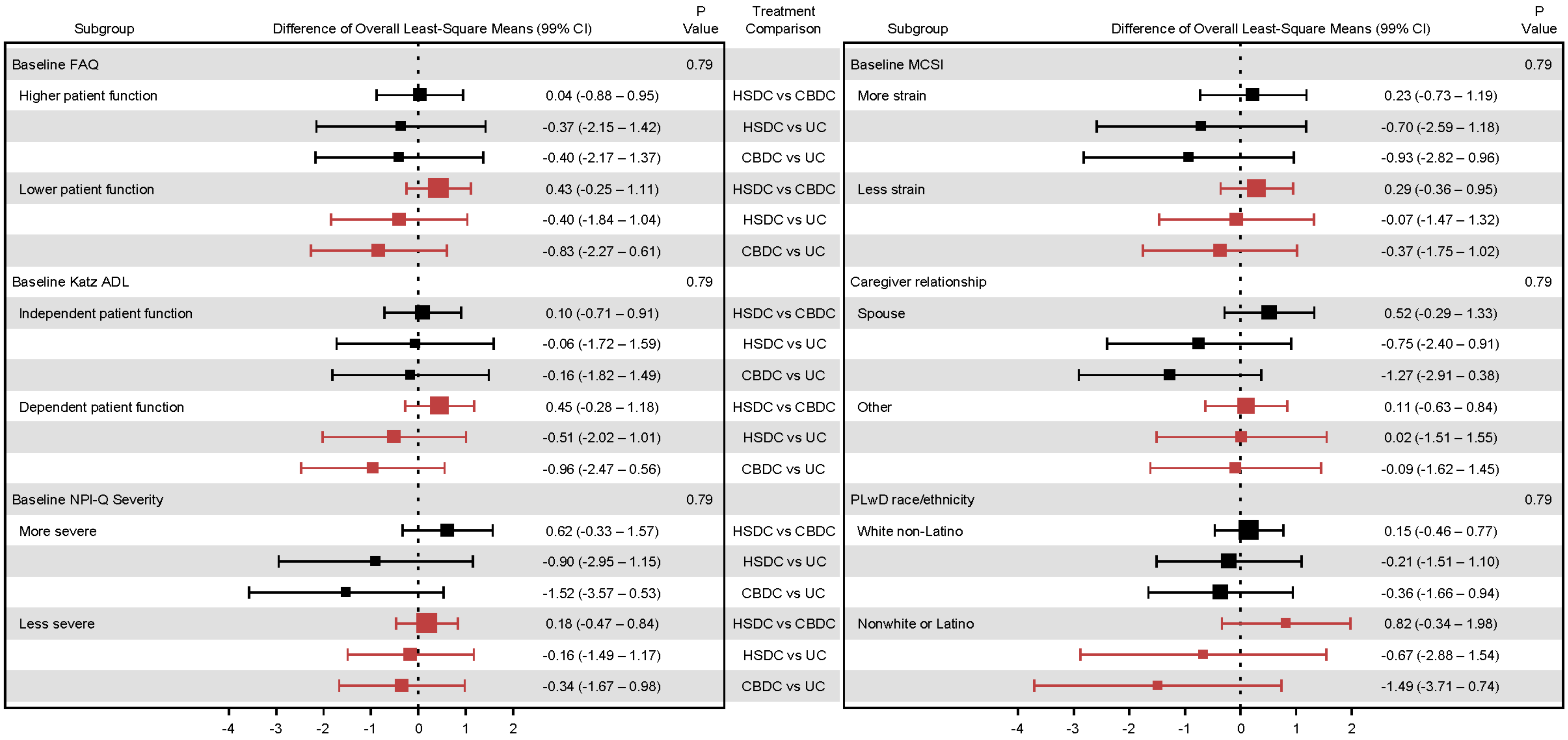
- The Effects of Caregiver Strain on the Impact of COVID19 among Caregivers (In process)
- Associations of baseline stress with dyad type and race/ethnicity in caregivers of (In process)
- Impact of PLWD living arrangement on caregiver psychosocial characteristics (Submitted)
- Shared Stories: The D-CARE Experience (In process)
- Factors affecting Caregiver Self-efficacy (Submitted)
- Many more in earlier stages

Results: Subgroup Analyses for MCSI



Subgroup	Difference of Overall Least-Square Means (99% CI)	P Value	Treatment Comparison	Subgroup	Difference of Overall Least-Square Means (99% CI)	P Value
Baseline FAQ		0.86		Baseline MCSI		0.86
Higher patient function	0.04 (-0.76 – 0.84)		HSDC vs CBDC	More strain	-0.16 (-0.99 – 0.67)	
	-0.53 (-2.09 – 1.04)		HSDC vs UC		0.30 (-1.33 – 1.94)	
	-0.57 (-2.12 – 0.98)		CBDC vs UC		0.46 (-1.18 – 2.10)	
Lower patient function	0.37 (-0.23 – 0.96)		HSDC vs CBDC	Less strain	0.41 (-0.16 – 0.98)	
	0.63 (-0.63 – 1.88)		HSDC vs UC		-0.00 (-1.21 – 1.20)	
	0.26 (-1.00 – 1.52)		CBDC vs UC		-0.41 (-1.61 – 0.79)	
Baseline Katz ADL		0.86		Caregiver relationship		0.18
Independent patient function	0.18 (-0.53 – 0.89)		HSDC vs CBDC	Spouse	0.47 (-0.23 – 1.17)	
	0.32 (-1.13 – 1.76)		HSDC vs UC		-0.67 (-2.11 – 0.77)	
	0.13 (-1.30 – 1.57)		CBDC vs UC		-1.14 (-2.57 – 0.29)	
Dependent patient function	0.32 (-0.31 – 0.96)		HSDC vs CBDC	Other	0.06 (-0.58 – 0.69)	
	0.09 (-1.23 – 1.41)		HSDC vs UC		0.87 (-0.44 – 2.19)	
	-0.23 (-1.55 – 1.09)		CBDC vs UC		0.82 (-0.50 – 2.13)	
Baseline NPI-Q Severity		0.86		Caregiver race/ethnicity		0.86
More severe	0.42 (-0.41 – 1.26)		HSDC vs CBDC	White non-Latino	0.19 (-0.35 – 0.72)	
	1.00 (-0.81 – 2.82)		HSDC vs UC		-0.01 (-1.16 – 1.14)	
	0.58 (-1.24 – 2.40)		CBDC vs UC		-0.20 (-1.34 – 0.95)	
Less severe	0.20 (-0.38 – 0.78)		HSDC vs CBDC	Nonwhite or Latino	0.53 (-0.46 – 1.53)	
	-0.32 (-1.49 – 0.85)		HSDC vs UC		0.49 (-1.33 – 2.31)	
	-0.52 (-1.69 – 0.64)		CBDC vs UC		-0.04 (-1.87 – 1.79)	

Results: Subgroup Analyses for NPI-Q Severity



Subgroup	Difference of Overall Least-Square Means (99% CI)	P Value	Treatment Comparison	Subgroup	Difference of Overall Least-Square Means (99% CI)	P Value
Baseline FAQ		0.79		Baseline MCSI		0.79
Higher patient function	0.04 (-0.88 – 0.95)		HSDC vs CBDC	More strain	0.23 (-0.73 – 1.19)	
	-0.37 (-2.15 – 1.42)		HSDC vs UC		-0.70 (-2.59 – 1.18)	
	-0.40 (-2.17 – 1.37)		CBDC vs UC		-0.93 (-2.82 – 0.96)	
Lower patient function	0.43 (-0.25 – 1.11)		HSDC vs CBDC	Less strain	0.29 (-0.36 – 0.95)	
	-0.40 (-1.84 – 1.04)		HSDC vs UC		-0.07 (-1.47 – 1.32)	
	-0.83 (-2.27 – 0.61)		CBDC vs UC		-0.37 (-1.75 – 1.02)	
Baseline Katz ADL		0.79		Caregiver relationship		0.79
Independent patient function	0.10 (-0.71 – 0.91)		HSDC vs CBDC	Spouse	0.52 (-0.29 – 1.33)	
	-0.06 (-1.72 – 1.59)		HSDC vs UC		-0.75 (-2.40 – 0.91)	
	-0.16 (-1.82 – 1.49)		CBDC vs UC		-1.27 (-2.91 – 0.38)	
Dependent patient function	0.45 (-0.28 – 1.18)		HSDC vs CBDC	Other	0.11 (-0.63 – 0.84)	
	-0.51 (-2.02 – 1.01)		HSDC vs UC		0.02 (-1.51 – 1.55)	
	-0.96 (-2.47 – 0.56)		CBDC vs UC		-0.09 (-1.62 – 1.45)	
Baseline NPI-Q Severity		0.79		PLwD race/ethnicity		0.79
More severe	0.62 (-0.33 – 1.57)		HSDC vs CBDC	White non-Latino	0.15 (-0.46 – 0.77)	
	-0.90 (-2.95 – 1.15)		HSDC vs UC		-0.21 (-1.51 – 1.10)	
	-1.52 (-3.57 – 0.53)		CBDC vs UC		-0.36 (-1.66 – 0.94)	
Less severe	0.18 (-0.47 – 0.84)		HSDC vs CBDC	Nonwhite or Latino	0.82 (-0.34 – 1.98)	
	-0.16 (-1.49 – 1.17)		HSDC vs UC		-0.67 (-2.88 – 1.54)	
	-0.34 (-1.67 – 0.98)		CBDC vs UC		-1.49 (-3.71 – 0.74)	

Results: Primary and Secondary Outcomes Over Time