

Dementia Care at Home: the MIND at HOME project

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MEDICINE

Facing reality: balancing “cure” with “care”

- Rational treatment development ongoing: AD mostly
- Use of biomarkers is critical and evolving
- A long, hard slog: decades?
- ***Near and medium term outcome:*** extend the time course of MCI and dementia
- **We must take proper care of 100+ million patients & caregivers worldwide**

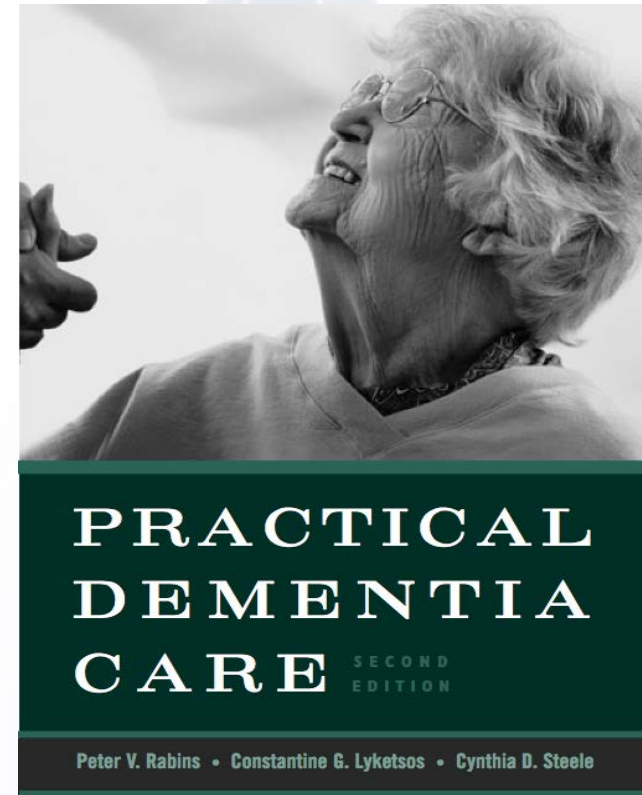
“There exists *currently* an effective, systematic care & treatment model for patients with dementia...” (2006)

POSITION STATEMENT

**Position Statement of the American
Association for Geriatric Psychiatry
Regarding Principles of Care
for Patients With Dementia
Resulting From Alzheimer Disease**

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Dementia Care is a PACKAGE



Dementia Care started in Memory Clinics

Johns Hopkins Memory and Alzheimer's Treatment Center



STATE OF THE ART “**DEMENTIA CARE**” DEVELOPED AT HOPKINS

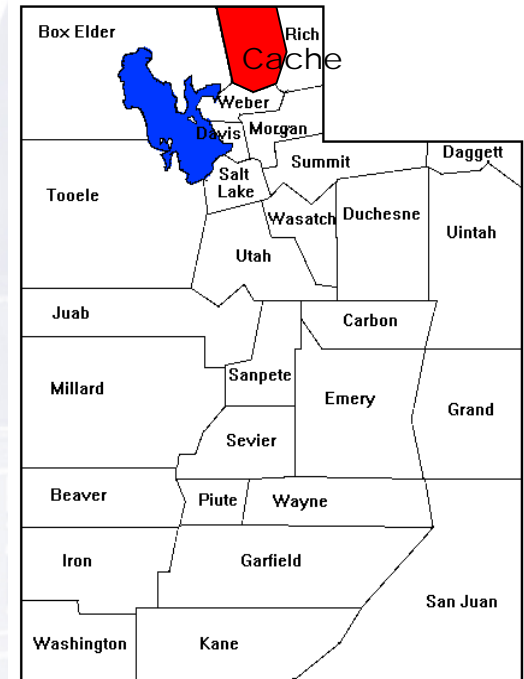
- Comprehensive, accurate diagnosis and medical management
- Comprehensive caregiver & family support & education guided by Johns Hopkins Dementia Care Needs Assessment
- Psychosocial interventions provided by dementia-care specialist psychologist, nurses, occupational therapists
- Access to clinical trials protocols for novel research therapies targeting Alzheimer's & related conditions



Epidemiology of dementia progression informs dementia care

Potentially modifiable:

- Medical co-morbidity
- FDA approved meds
- Early neuropsychiatric symptoms
- Use of psychotropic medications
- Early activities, especially mental
- Caregiver closeness, coping style



Cache County Dementia Progression Study
(MPIs: Tschanz and Lyketsos)

R01AG21136, R01AG11380, R01AG18712, R01HG02213

***Dementia Care* common activities**

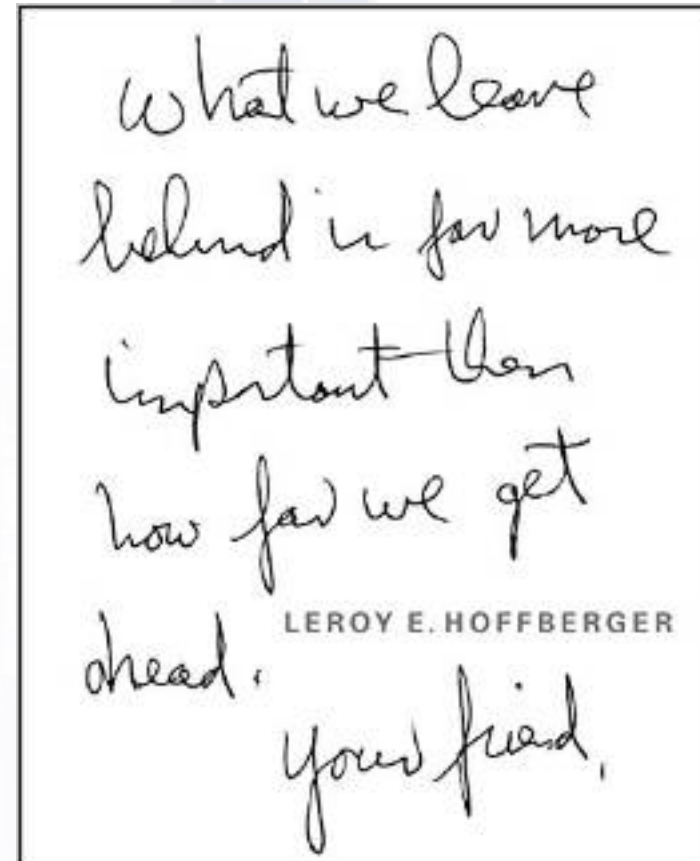
- Manage co-morbidities; prevent delirium
- Medication management and debridement
- Treat cognitive symptoms: FDA meds
- Treat neuropsychiatric symptoms (NPS)
 - Judicious use of psychotropics
- Support patients: activities, safety
- Caregivers: communication, skills, respite



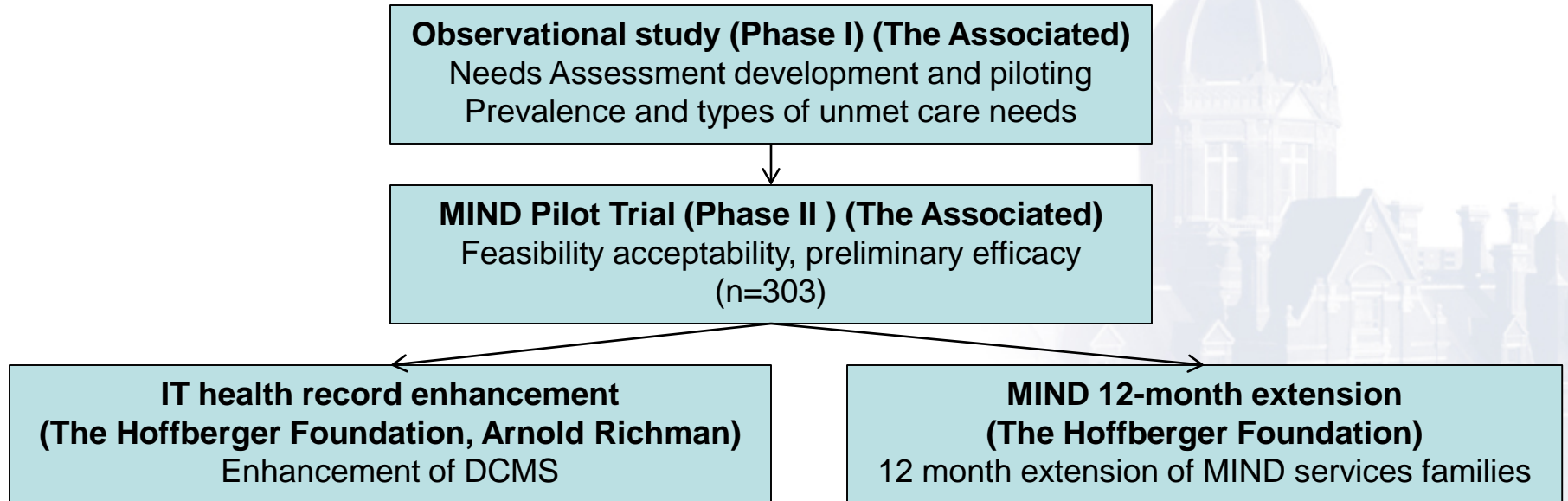
Maximizing Independence at Home

The MIND at HOME Project

- Conceived by Roy Hoffberger & Kostas Lyketsos
- Collaboration: Johns Hopkins with *The Associated*
- Raised \$2.5 million in support



MIND program development path: completed projects



Elements of MIND at HOME



Assessment and intervention protocol

- Developed from decades of clinical dementia care experience
- Epidemiology and behavioral intervention research
- Attention to all aspects of care (medical, social, supportive care)



Care coordination principles and family centric care

- Established process of individualized needs assessments, care planning, and monitoring for both patient and caregiver
- Attention to and empowerment of families by need assessments, education, skills training, and disease management support



Team composition and delivery model

- Links medical and community based care services
- Delivered by non-clinical staff supported by mental health practitioners
- Integrated Health IT- the Dementia Care Management System
- Affordable—estimated cost \$1000-2000 per patient/caregiver per year



Appropriate target population

- Focused on a broad group of persons at various stages of illness, from mildly impaired to severely impaired

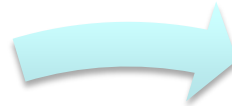
MIND at HOME process

over the course of dementia progression

Dementia patient living in community



Assess Needs



Prioritize Needs



Plan to Address Needs



Implement Plan



Evaluate Plan



Mild

Moderate

Severe

Terminal



Efficacy of MIND at HOME on QOL & clinical outcomes

- 18 month randomized trial
- 303 volunteers & 290 caregivers
 - At home northwest Baltimore (28 Zips)
- MIND at HOME: w/ patient & family to meet needs (n=110)
- Augmented usual care (N=193)
- Masked assessment
 - Q 4-5 months
 - 18 months on intervention
 - 26 months overall median

A Multidimensional Home-Based Care Coordination Intervention for Elders with Memory Disorders: The Maximizing Independence at Home (MIND) Pilot Randomized Trial

Quincy M. Samus, Ph.D., Deirdre Johnston, M.B., B.Ch., Betty S. Black, Ph.D., Edward Hess, M.S., Christopher Lyman, B.A., Amrita Vavilakolani, B.S., Jane Pollutra, R.N., Jeannie-Marie Leoutsakos, Ph.D., Laura N. Gillin, Ph.D., Peter V. Rabins, M.D., M.P.H., Constantine G. Lyketsos, M.D., M.H.S.

Objectives: To assess whether a dementia care coordination intervention delays time to transition from home and reduces unmet needs in elders with memory disorders. **Design:** 18-month randomized controlled trial of 303 community-living elders. **Setting:** 28 postal code areas of Baltimore, MD. **Participants:** Age 70+ years, with a cognitive disorder, community-living, English-speaking, and having a study partner available. **Intervention:** 18-month care coordination intervention to systematically identify and address dementia-related care needs through individualized care planning; referral and linkage to services; provision of dementia education and skill-building strategies; and care monitoring by an interdisciplinary team. **Measurements:** Primary outcomes were time to transfer from home and total percent of unmet care needs at 18 months. **Results:** Intervention participants had a significant delay in time to all-cause transition from home and the adjusted hazard of leaving the home was decreased by 37% (Hazard ratio: 0.63, 95% Confidence Interval: 0.42–0.94) compared with control participants. Although there was no significant group difference in reduction of total percent of unmet needs from baseline to 18 months, the intervention group had significant reductions in the proportion of unmet needs in safety and legal/advance care domains relative to controls. Intervention participants had a significant improvement in self-reported quality of life (QOL) relative to control participants. No group differences were found in proxy-rated QOL, neuropsychiatric symptoms, or depression. **Conclusions:** A home-based dementia care coordination intervention delivered by non-clinical community workers trained and overseen by geriatric

Received August 20, 2013; revised December 12, 2013; accepted December 31, 2013. From the Department of Psychiatry and Behavioral Sciences, Johns Hopkins Bayview School of Medicine, The Johns Hopkins University (QMS, EH, CL, JP, JML, LNC, CGL), Baltimore, MD; the Department of Psychiatry and Behavioral Sciences, School of Medicine, The Johns Hopkins University (DJ, BSB, PFR), Baltimore, MD; the Department of Epidemiology (AV), Columbia University, New York, NY; and the Department of Community Public Health Nursing, School of Nursing, The Johns Hopkins University (LNG), Baltimore, MD. A limited amount of data presented in this paper was presented at a poster presentation and press briefing at the Alzheimer's Association International Conference in Vancouver, British Columbia, July 14–19, 2012. Send correspondence and reprint requests to Quincy M. Samus, Ph.D., M.S., 5300 Alpha Commons Dr., 4th Floor, Baltimore, MD 21224. e-mail: qsamles@jhmi.edu

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TABLE 2. Baseline Characteristics of Participants with a Memory Disorder

Characteristic	Augmented Care Group (N = 193)	Intervention Group (N = 110)	Total	χ^2	t	p value
Primary Participant Characteristics						
Age, mean (SD), y	83.9 (5.9)	84.0 (5.8)	83.9 (5.9)		-0.202 ^c	0.840
Female, No. (%)	120 (62.2)	73 (66.4)	193 (63.7)	0.531 ^a		0.466
Black/African American or Other Race, No. (%)	55 (28.5)	32 (29.1%)	87 (28.7)	0.012 ^a		0.913
Education, mean (SD), y	13.2 (3.9)	13.0 (3.1)	13.2 (3.6)		0.430 ^c	0.668
Living with Caregiver, No. (%)	131 (67.9)	80 (72.7)	211 (69.6)	0.780 ^d		0.377
Time living at residence, means (SD), y	22.0 (18.3)	19.4 (18.2)	21.1 (18.3)		1.196 ^c	0.233
Dementia, No. (%)	166 (86.0)	99 (90)	265 (87.5)	1.017 ^a		0.313
Prescribed medication						
Cholinesterase inhibitors	91 (47.2)	45 (40.9)	136 (44.9)	1.103 ^a		0.294
Memantine	57 (29.5)	29 (26.4)	86 (28.4)	0.346 ^a		0.556
Antidepressants	59 (30.6)	38 (34.5)	97 (32.0)	0.509 ^d		0.476
Antipsychotics	15 (7.8)	7 (6.4)	22 (7.3)	0.206 ^a		0.650
No. routine medications taking, mean (SD)	6.1 (2.9)	6.9 (3.4)	6.4 (3.1)		-2.281 ^c	0.023
Cardiovascular disease, No. (%) [*]	154 (79.8)	96 (87.3)	250 (82.5)	2.716 ^a		0.099
Pulmonary disease, No. (%) [†]	12 (6.2)	7 (6.4)	19 (6.3)	0.003 ^a		0.960
Endocrine disease, No. (%) [‡]	104 (53.9)	66 (60.0)	170 (56.1)	1.064 ^a		0.302
≥1 hospitalization in past year, No. (%)	67 (34.7)	37 (33.6)	104 (34.3)	0.036 ^a		0.849
≥1 ED visit in past year, No. (%)	99 (51.6)	50 (45.5)	149 (49.3)	1.044 ^a		0.307
No. formal services/programs used, mean (SD)	3.2 (1.7)	3.2 (1.7)	3.2 (1.7)		-0.111 ^f	0.912
MMSE, mean (SD) [§]	19.2 (7.7)	19.0 (7.9)	19.1 (7.8)		0.234 ^c	0.815
NPI-Q, mean (SD) [¶]	7.1 (6.2)	7.2 (5.7)	7.2 (6.0)		-0.101 ^c	0.920
CSDD, mean (SD) [¶]	6.1 (4.6)	6.5 (4.8)	6.2 (4.7)		-0.570 ⁱ	0.569
PGDRS-B (mean, SD) [¶]	9.5 (8.0)	10.3 (7.8)	9.8 (7.9)		-0.833 ^d	0.406
Total % unmet JHDCNA needs, mean (SD)	10.2 (6.5)	9.8 (5.3)	10.1 (6.1)		0.553 ^c	0.580
Caregiver Characteristics						
Characteristic	Augmented Care Group (N = 183)	Intervention Group (N = 106)	Total	χ^2	t	p value
Age, mean (SD), y	67.3 (12.9)	65.7 (13.9)	66.7 (13.3)		0.972 ^h	0.332
Female, No. (%)	136 (74.3)	80 (75.5)	216 (74.7)	0.047 ^a		0.828
Relationship						
Spouse (%)	83 (45.4)	41 (38.7)	124 (42.9)	1.226 ^b		0.542
Child (%)	85 (46.4)	55 (51.9)	140 (48.4)			
Other person (%)	15 (8.2)	10 (9.4)	25 (8.7)			
Time as caregiver for participant, mean (SD), mths	38.4 (33.6)	37.1 (30.5)	37.9 (32.5)		0.339 ^g	0.735
Providing care to another, No. (%)	41 (22.5)	29 (27.9)	70 (24.5)	1.028 ^a		0.311
Employed, No. (%)	79 (43.4)	57 (54.3)	136 (47.4)	3.161 ^a		0.075

Johns Hopkins Dementia Care Needs Assessment JHDCNA

Unmet Needs of Community-Residing Persons with Dementia and Their Informal Caregivers: Findings from the Maximizing Independence at Home Study

Betty S. Black, PhD,* Deirdre Johnston, MB, BCh,* Peter V. Rabius, MD, MPH,* Ann Morrison, PhD, RN,[†] Constantine Lyketsos, MD, MHS,[‡] and Quincy M. Samus, PhD[‡]

OBJECTIVES: To determine the prevalence and correlates of unmet needs in a sample of community-residing persons with dementia (PWD) and their informal caregivers.
DESIGN: Analysis of cross-sectional, baseline participant characteristics before randomization in a care coordination intervention trial.
SETTING: Baltimore, Maryland.
PARTICIPANTS: Community-residing PWD (n = 254) and their informal caregivers (n = 246).

care, services, and support. Providers should be aware that unmet needs may be higher in minority and low-income community residents, caregivers with lower education, and individuals with early-stage dementia. Identifying and treating symptoms of depression in PWD and caregivers may enable them to address their other unmet needs. *J Am Geriatr Soc* 61:2087–2095, 2013.

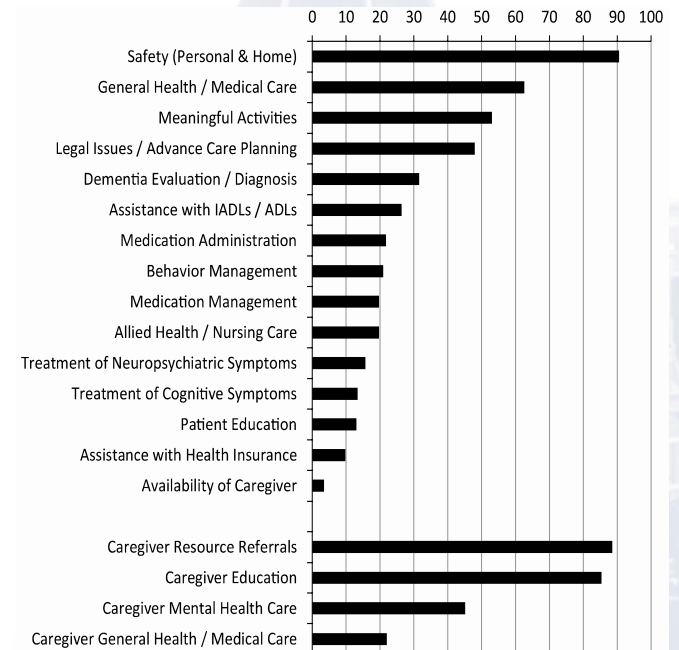
Key words: dementia; community-residing; informal caregivers; unmet needs

TABLE 1. JHDCNA Domains and Care Option/Strategy Examples

Memory Care Needs Domains of Participants	No. Items	Abbreviated Care Option/Strategy Examples*
A. Evaluation/diagnosis	5	In-depth review by DCC/DCS; Referral to PCP or specialist physician for dementia evaluation and workup; neurologic evaluation, substance abuse referral.
B. Treatment of cognitive symptoms	2	Evaluate whether a medication might be indicated and refer to PCP or Geriatrician or physician specializing in memory disorders for discussion/evaluation.
C. Treatment of neuropsychiatric symptoms	5	In-depth review and characterization of concerning symptoms by DCC. Assessment of potential causes (e.g. UTI, constipation, pain); Refer to PCP or Geriatrician or physician specializing in memory disorders for discussion/evaluation of possible medication indications.
D. Behavior management	3	In-depth review and characterization of concerning symptoms by DCC; provide instruction on specific behavior management/caregiver skills counseling; Assessment of potential causes (e.g. UTI, constipation, pain); Refer to Alzheimer's Association.
E. Medication management	4	Initial review of medications by DCS; Request PCP or prescribing physician to evaluate polypharmacy or regimen adjustment; Assist in coordination of multiple prescribing physicians/pharmacies.
F. Medication administration	3	Create medication administration routine that promotes compliance; Coordinate second party supervision or medication administration; Recommend specific devices or reminder tools.
G. General medical/health care	8	Referral to PCP, medical specialist or geriatric care manager; Recommend family and PCP consider hospice care.
H. Allied health specialist care	4	Referral to PCP. Recommend referral by PCP to PT, OT, SLP, home health care agency.
I. Safety	7	Identify possible environmental hazards (e.g. scatter rugs, out of date food, fall risks, fire risks, wander risks, guns/power tools) and make a plan to address each. Referral to driving evaluation program; home safety evaluation. Recommend asking PCP for PT, OT referral.
J. Assistance with daily activities	10	Arrange for informal or formal assistance for needed service. Provide caregiver skills counseling.
K. Meaningful activities	6	Evaluate and develop a list of activities that would match preferences, personality, and lifestyle and help caregiver implement. Provide caregiver skills counseling for help with creating a daily routine structure; Refer to friendly visitor programs, senior center, adult day, transportation service, etc.
L. Legal issues/advance care planning	5	Recommend patient and family engage in end-of-life care discussions with PCP and family members; Referral to eldercare attorney, or state attorney office about POA, will, advance directives.
M. Assistance with health insurance	5	Review current medical needs, medications and referral to SHIP (Senior Health Insurance Program), CMS, US Veterans Affairs, AARP, etc.
N. Patient education	1	Refer to PCP for discussion of illness. Refer to Alzheimer's Association support group.
O. Caregiver availability	3	Identify and arrange for someone to take responsibility for intermittent phone checks, in-person visits, supervision.
P. Other patient needs	—	Dependent on needs listed.
Memory Care Need Domains of Caregivers	No. Items	Abbreviated Care Option/Strategy Examples*
Q. Caregiver education	3	Educate CG about dementia course and impact; provide written learning material; inform of educational events or local resources (health fairs, clinicians, senior centers, day care/home care services, support groups); instruct and counsel CG on care management issues (behavioral issues, ADLs, communication, family conflicts, planning, safety).
R. Resource referrals	5	Refer to local or national chapter of Alzheimer's Association; eldercare attorney (e.g. estate planning, will, power of attorney, advanced directives); Maryland Dept. of Aging or local agency; private geriatric care management services; Adult protective services.
S. Caregiver mental health care	4	Proactively monitor CG stress levels; provide informal counseling, help with coping skills, and emotional support; Refer to licensed mental health professional; Arrange and plan regular respite care periods.
T. Caregiver general medical/health care	3	Referral to PCP, specialist physician; other health care professional (e.g., dentist, optometrist, PT).
U. Other caregiver needs	—	Dependent on needs listed.

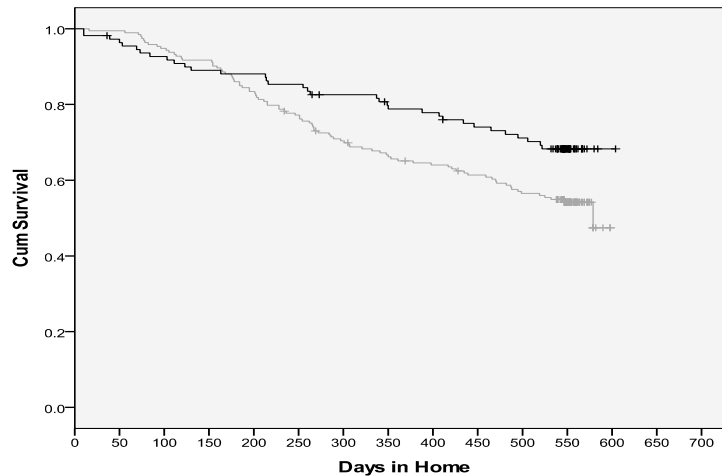
Notes: Each need item was assessed as being either "fully met" (i.e., need is being addressed and potential benefits of available interventions have been achieved to the extent possible for the individual) or "unmet" (i.e., [1] it has not been addressed and potentially beneficial interventions are available, or [2] it has been or is being addressed but potential benefits of available interventions have not yet been achieved).

*Listed recommended interventions are not exhaustive. Actual recommendations based on the individual's specific need within a category.



Risk of leaving current home

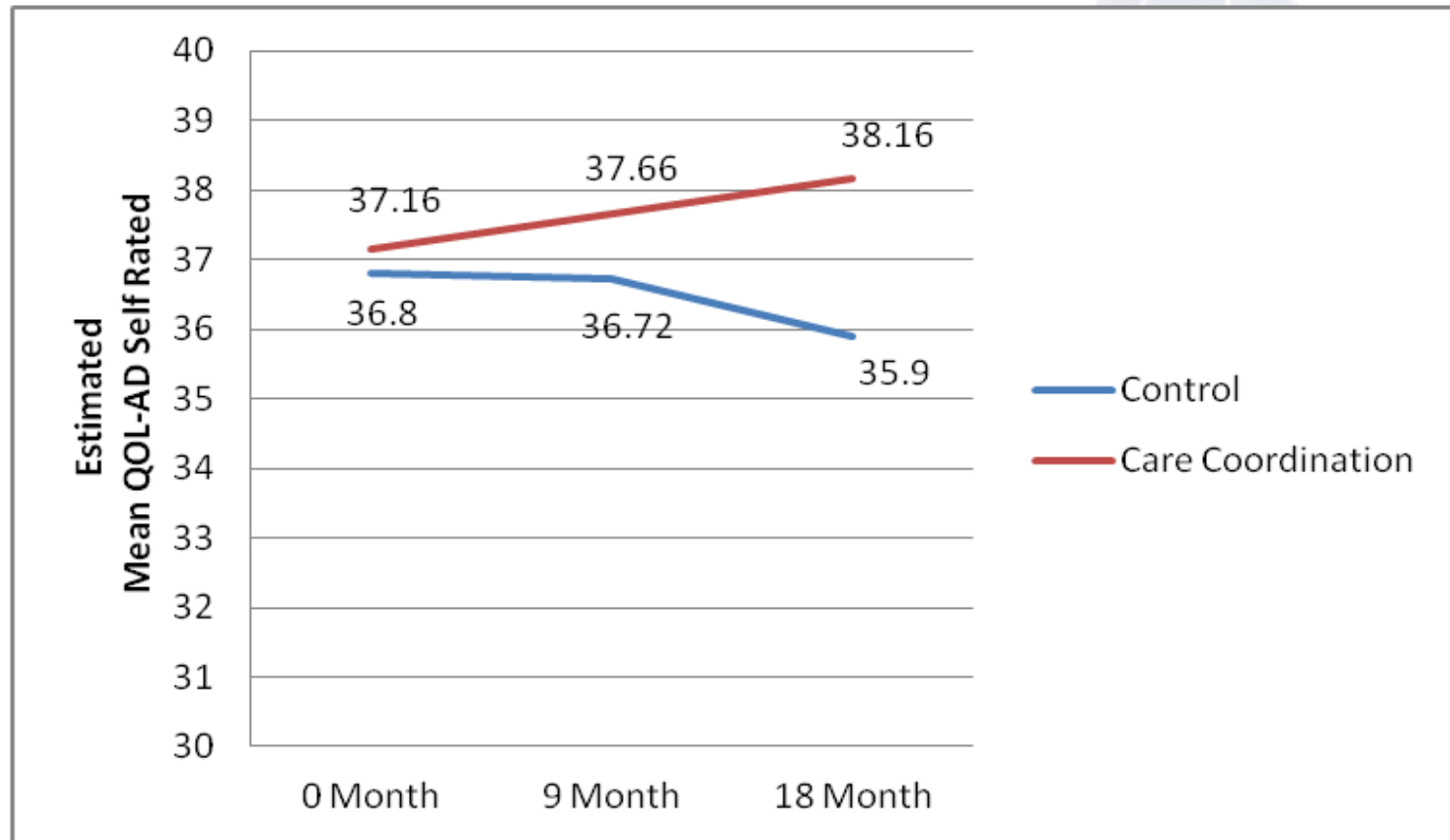
FIGURE 2. Kaplan-Meier survival graphs [A] at 18 months and [B] for extended follow-up after intervention cessation (median 26 months follow-up; range: 19–41 months).



MIND at HOME participants less likely to leave home or die v. control
31% vs. 46%

Usual care—median = 660 days
MIND—median = 948 days
Difference = 288 days

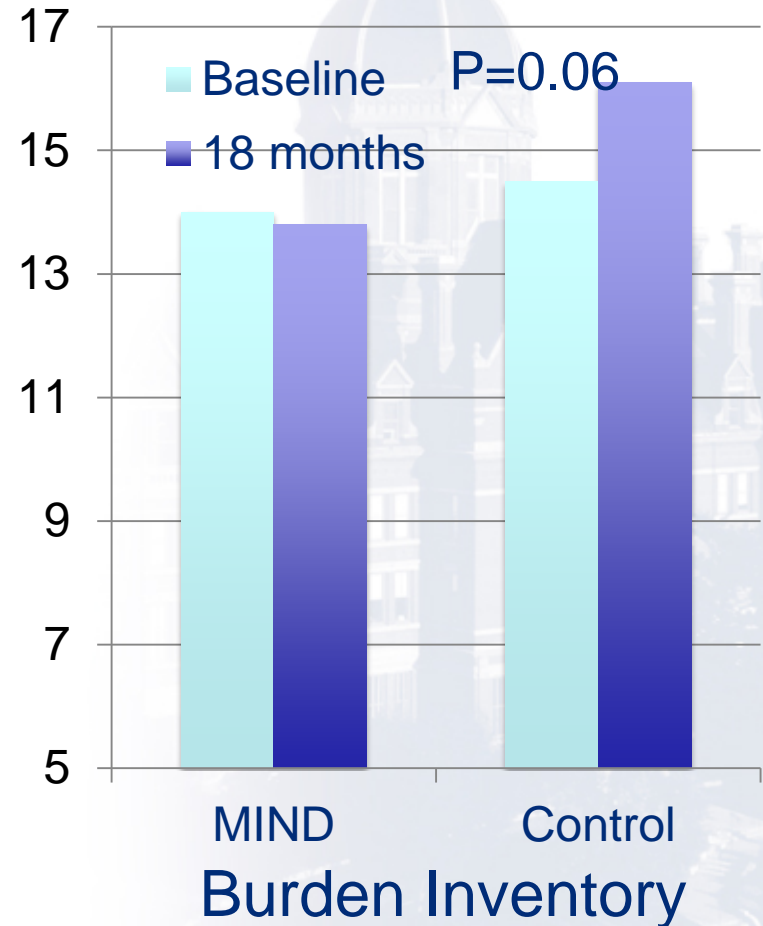
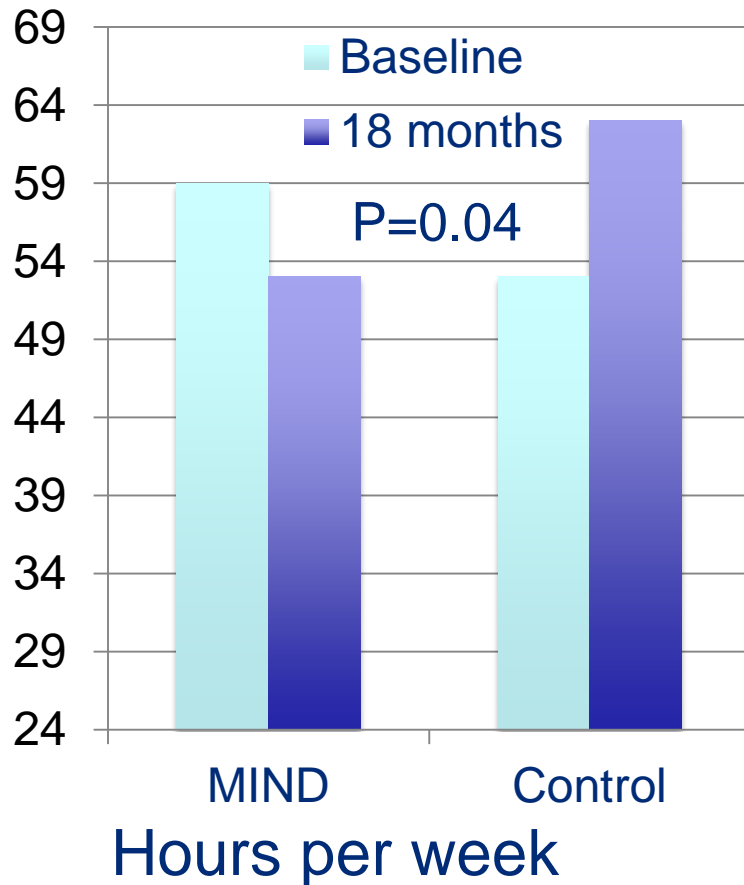
Improved self-rated quality of life



Caregiver benefits

A Randomized Controlled Trial of a Community-Based Dementia Care Coordination Intervention: Effects of MIND at Home on Caregiver Outcomes

Jeremy A. Tanner, B.A., Betty S. Black, Ph.D., Deirdre Johnston, M.B., B.Ch., Edward Hess, M.S., Jeannie-Marie Leoutsakos, Ph.D., Laura N. Gillin, Ph.D., Peter V. Rabins, M.D., M.P.H., Constantine G. Lyketsos, M.D., M.H.S., Quincy M. Samus, Ph.D., M.S.



Maximizing Independence at HOME

moving forward

Observational study (Phase I) (The Associated)
Needs Assessment development and piloting
Prevalence and types of unmet care needs

MIND Pilot Trial (Phase II) (The Associated)
Feasibility acceptability, preliminary efficacy
(n=303)

**IT health record enhancement
(The Hoffberger Foundation, Arnold Richman)**
Enhancement of DCMS

**MIND 12-month extension
(The Hoffberger Foundation)**
12 month extension of MIND services families

MIND-Plus Innovation Award (CMS HCIA)
Effect on Medicare and Medicaid costs, Develop
certification program, Develop payment model

MIND-Streamlined RCT (NIA R01AG046274)
Definitive efficacy on time to long term care (LTC),
cost savings, durability, moderators/mediators

Facing reality: balancing “cure” with “care”

We CAN take proper care of 100+ million patients & caregivers worldwide

Sincere thanks from the team
to MIND volunteers, and their loved ones
and to the donors and supporters.



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Thank you!
Ευχαριστω!



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