

# Community Based Models of Dementia Care: characteristics, challenges, and opportunities

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#DementiaCareSummit



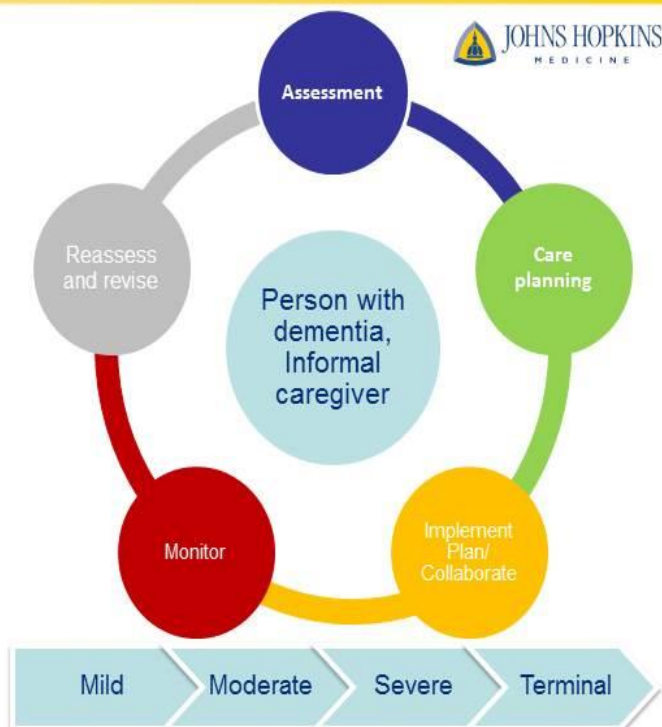
National Research Summit on Care, Services, and Supports  
for Persons with Dementia and Their Caregivers

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## Broad definition

### Community-based dementia care coordination models

- primarily (but not exclusively) implemented through community based organizations (CBO), **and**
- involve at a minimum:
  - systematic assessment;
  - care planning; and
  - delivery of or referral or linkage to care, services and supports for persons with dementia and their families over time



## Community-Based Dementia Models as potent tool to “connect the dots”



### Rationale

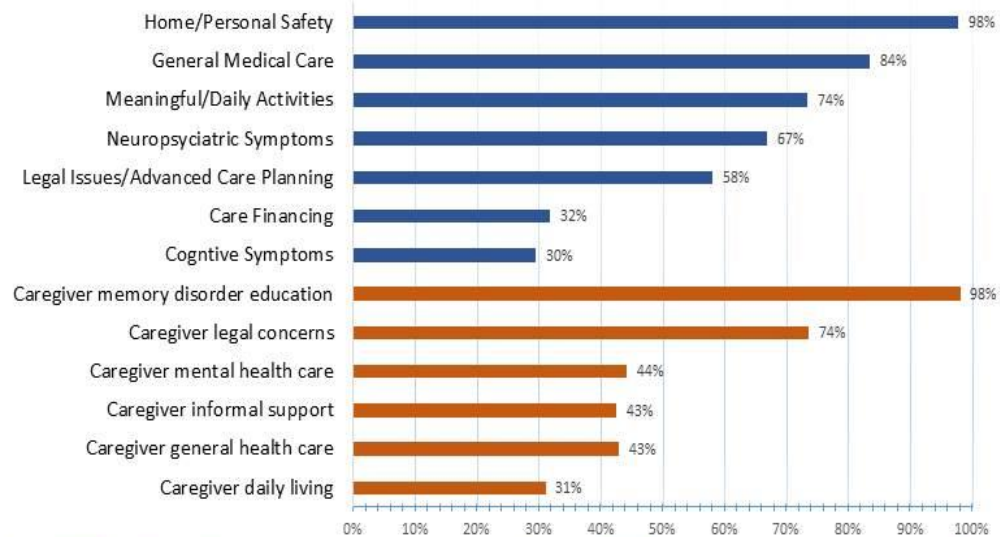
- High prevalence of dementia (1 in 10 Older Americans)
- High direct and indirect costs attributable to dementia
- Prolonged duration, change over time, and high prevalence of clinical AND non-clinical unmet needs
- Impact on self-management abilities, judgement, behavior
- Impact on > 15 million family members

### Opportunity

- Bridging medical, social, supportive formal and informal services and resources
- Encourage value-based care

# Common needs of persons with dementia

## One or More Unmet Care Need by Domain (n=647)



Unpublished data from MIND at Home Studies baseline assessment data, Samus, 2017

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## Brief review of evidence

### Studies of Community-Based Dementia Care Coordination models

- 4 completed RCTs
- 2 ongoing RCTs
- 1 ongoing quasi-experimental
- Pooled n > 2200 person with dementia-caregiver dyads

### Variability in trials

- Intervention content, scope, and area of focus
- Duration (most 12-18 months, some longer)
- Partnerships and integration with health system(s)
- Front-line staff type (e.g. social workers, non-licensed staff)
- Caseload
- Team composition (though most interdisciplinary)
- Primary format (home visits, telephone)
- Intensity of contact
- Targeted primary and secondary outcomes



Vickrey et al. 2006; Duru et al., 2009; Chodosh et al., 2015; Bass et al., 2003; Clark et al., 2004; Possin et al., 2017; Samus et al., 2014  
Tanner et al., 2014

# Brief review of evidence



## Finding summary

- Reductions in caregiver burden/strain, depression (moderate effect size)
- Guideline adherence, QOL, behavior (low to moderate)
- No effect or inconsistent effects on health care use, some evidence to suggest increase social care services (low to moderate)
- Short to medium term reduction in risk of NH placement, some evidence of delay in time to leaving home (low to moderate)
- No effect or inconsistent effects total healthcare costs (low)

**Difficult to draw precise conclusions BUT culmination of evidence suggests can be beneficial for both PT and CG outcomes**

Brodsky H, Green A, Koschera A. 2003; Pimouget et al 2010; Somme et al 2012; Knapp et al. 2012; Hickam 2013; Spijker et al. 2008; Tam-Tham et al., 2012; Low, Fletcher 2015 Int Psychogeriatrics; Reilly et al., 2015, Cochrane Database Systematic review

**HEALTH ACTION**  
Development of an adaptive, personalized, and scalable dementia care program: Early findings from the Care Ecosystem

**Authors:** Kathleen L. Brackbill<sup>1,2,3,4</sup>, Jennifer Brackbill<sup>5</sup>, Rachel S. Cooper<sup>6</sup>, Sarah DeMaio<sup>7</sup>, Steven Chong<sup>8</sup>, Kerry Lee<sup>9</sup>, Lewis Wilson<sup>10</sup>, Sarah M. Cooper<sup>11</sup>, Sarah DeMaio<sup>12</sup>, Terence Wang<sup>13</sup>, David Lachy<sup>14</sup>, Julie E. Foye<sup>15</sup>, Amy B. Clark<sup>16</sup>, Michael W. Scahill<sup>17</sup>, A. Kevin Granger<sup>18</sup>, Julia Isaacs<sup>19</sup>, Patricia Ong<sup>20</sup>, John W. Scahill<sup>21</sup>, Josephine Lee<sup>22</sup>, Anna Chaturvedi<sup>23</sup>, Giovanni Leone<sup>24</sup>, B. Brent Han<sup>25</sup>, David Cohen<sup>26</sup>, Christine Minkus<sup>27</sup>, Bruce L. Wilson<sup>28</sup>

**Summary points:**

- Our objective was to develop and test a viable model of comprehensive primary care with additional caregiver consultation and support to planning the best care for cognitively impaired elders. Care is delivered via a team of geriatric care coordinators (GCCs), who are trained and supported to deliver care in the home.
- The "Care Ecosystem" is being tested via a program that provides an adaptive, personalized, and scalable dementia care program. The program is being tested in a program that provides an adaptive, personalized, and scalable dementia care program.
- The trial will evaluate the impact of the program on caregiver burden, depression, and quality of life.
- The trial will also evaluate the impact of the program on patient outcomes, including cognitive function, functional status, and quality of life.

**Annals of Internal Medicine** | ARTICLE

### The Effect of a Disease Management Intervention on Quality and Outcomes of Dementia Care

A Randomized, Controlled Trial

Barbara G. Vickrey, MD, MPH, Brian S. Mittman, PhD, Karen I. Connor, RN, MBA, Marjorie L. Pearson, F. Theodore G. Canalis, MD, Robert W. Dunlop, Jr., MD, Joshua Chodosh, MD, MSW, Xinying Cai, PhD, Melissa Dun, PhD, and Martin Lee, PhD

**Background:** Adherence to dementia guidelines is poor despite evidence that some guideline recommendations can improve symptoms and quality of life in dementia patients. We evaluated the effect of a disease management intervention on dementia patients and their caregivers.

**Design:** 28-month randomized controlled trial of 303 community-dwelling adults with cognitive impairment, community-dwelling, English-speaking, and having a study partner.

**Intervention:** 18-month care coordination intervention to systematically identify and address dementia-related care needs through individualized care planning, caregiver and family support, and caregiver training.

**Measurements and Main Results:** At 18 months, the intervention group had significantly higher adherence to dementia guidelines (42% vs 30%, P < .001), higher caregiver burden (P < .001), and higher caregiver depression (P < .001). The intervention group also had significantly higher patient quality of life (P < .001), higher patient functional status (P < .001), and higher patient cognitive function (P < .001). The intervention group also had significantly higher patient adherence to dementia guidelines (42% vs 30%, P < .001).

**Conclusion:** A home-based dementia care coordination intervention improved adherence to dementia guidelines, caregiver burden, caregiver depression, patient quality of life, patient functional status, and patient cognitive function.

**Annals of Internal Medicine**

### The Cleveland Alzheimer's Managed Care Demonstration: Outcomes After 12 Months of Implementation

David M. Bass, PhD,<sup>1</sup> Patricia A. Clark, MA,<sup>1</sup> Wendy J. Looman,<sup>1</sup> Catherine A. McCarthy,<sup>1</sup> and Shura Eckert, MS<sup>2</sup>

**Purpose:** This demonstration evaluates the effects of integrating Alzheimer's Association care consultation services with health care services offered by a large managed care system. The primary hypothesis is that Alzheimer's Association care consultation will decrease service utilization, increase satisfaction with managed care, and decrease caregiver depression and unmet needs. Secondary hypothesis hypotheses posit that the effects of the intervention will be identified when patients have not received a first dementia diagnosis, patients have more severe memory problems, caregivers use other Association services, and when patients are older, have more comorbidities, and live in urban areas. **Design and Methods:** The demonstration is a randomized trial that examines outcomes after a 12-month study period. Intervention data from 157 primary family caregivers are combined with data obtained from medical follow-up visits, caregiver surveys, and caregiver telephone interviews. **Results:** Support for the primary hypothesis is found for satisfaction with managed care, caregiver depression, and caregiver depression. Support for secondary hypothesis hypotheses is found for satisfaction outcomes and caregiver depression outcomes. **Implications:** Care consultation delivered within a partnership between a managed care health system and an Alzheimer's Association is a promising strategy for improving selected outcomes for patients with dementia and their caregivers.

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

Quincy M. Somes, PhD,<sup>1</sup> Deirdre Johnston, M.R., B.Ch., Betty S. Black, Ph.D., Edward Hess, M.S., Christopher Lyman, R.N., Amrita Vardhola, R.S., Jane Pollara, R.N., Jeanette-Morie Leontsakos, Ph.D., Laura N. Gillis, Ph.D., Peter Y. Kabius, 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-dwelling adults with cognitive impairment, community-dwelling, English-speaking, and having a study partner.

**Intervention:** 18-month care coordination intervention to systematically identify and address dementia-related care needs through individualized care planning, caregiver and family support, and caregiver training.

**Measurements and Main Results:** At 18 months, the intervention group had significantly higher adherence to dementia guidelines (42% vs 30%, P < .001), higher caregiver burden (P < .001), and higher caregiver depression (P < .001). The intervention group also had significantly higher patient quality of life (P < .001), higher patient functional status (P < .001), and higher patient cognitive function (P < .001). The intervention group also had significantly higher patient adherence to dementia guidelines (42% vs 30%, P < .001).

**Conclusion:** A home-based dementia care coordination intervention improved adherence to dementia guidelines, caregiver burden, caregiver depression, patient quality of life, patient functional status, and patient cognitive function.

	ACCESS (Vickrey et al. 2006; Duru et al., 2009; Chodosh et al., 2015)	BRI (Bass et al., 2003; Clark et al., 2004)	Dementia Care EcoSystem (Possin et al., 2017)	MIND at Home (Samus et al., 2014 Tanner et al., 2014)
Language(s)	English, Spanish		English, Spanish, Cantonese	English
Duration of intervention	12 months +	12 months	12 months, 5 years	18 months
Staff type	Social workers (predominantly), or nurse	Social worker or non-clinical staff (Care Consultant)	Non-clinical staff (Care Team Navigator), nurse, social worker, pharmacist	Non-clinical staff (Memory Care Coordinator), nurse, psychiatrist
Standardized staff training	✓		✓	✓
PWD/CG dyad per coordinator-case manager	50		60-80	45-50
Interdisciplinary case conferencing	✓ (care manager and physician champion)		✓	✓
Contact frequency	Monthly, average	Monthly, average	At least monthly	Twice-a-month, average
Home visits	✓	No	No	✓
Mode of contact	In-person, Phone	Phone	Phone, mail, web	In-person, Phone
Communication with physicians	Mail, fax, in-service trainings		Phone, email, fax	Phone, mail, fax

	ACCESS	BRI	Dementia Care EcoSystem	MIND at Home
Direct provision of medical care/ order writing	No	No	No	No
Medication review/reconciliation	✓	No	No	✓
Resource referrals	✓	✓	✓	✓
Active facilitation to link to services	✓	✓	✓	✓
Legal/Financial/ Advance care planning	✓		✓	✓
CG problem solving/ emotional support	✓	✓	✓	✓
CG disorder education	✓	✓	✓	✓
CG skills training (e.g. Behavior management, Communication, PT Advocacy)	✓	✓	✓	✓
Home safety assessment	✓		Via Phone screen only	✓

# Opportunities and Challenges



## Opportunity

- “De-medicalize” dementia care
- Family centered (vs. patient)
- Perception of “complementary” vs “competing” support
- Expansion of novel dementia competent workforce
- Cost efficiency, and value based care
- Offer a different understanding and connection to local groups

## Challenges

- Contracting with health system
- Financing fragmentation
- Differences in CBO mission/goals
- Balance between fidelity to core components and adaptation
- Communication between and among agencies and PHI

# Research recommendations



Goal	Recommendation
Accelerate adoption of successful interventions	<ul style="list-style-type: none"> <li>• <b>Encourage pilot research on community-based care coordination models that focus on deployment linked to alternative and value-based payment approaches (ACOs, managed care, value-based) to demonstrate <u>value</u> to adopters, effectiveness, and to refine for scalability.</b></li> </ul>
Strengthen trial methods to support rigor and practicality	<ul style="list-style-type: none"> <li>• <b>Use standardized reporting methods (e.g. modified CONSORT) and standardized outcome measures to support meta-analysis, replication, and generalization to practice settings (e.g. sample characterization, fidelity, adverse event, delivery costs, cost-effectiveness, cost-benefit, risk adjustment, moderators and mediators).</b></li> <li>• <b>Use pragmatic trial and rapid-cycle quality improvement methods combined with standardized process measurement to balance internal and external validity and accelerate adoption.</b></li> </ul>
Increase CBO capability, capacity, workforce, role in value-driven care	<ul style="list-style-type: none"> <li>• <b>Use health care technology to develop dementia-competent service capacity in CBOs and to support collaborative partnerships with health systems and health plans.</b></li> <li>• <b>Develop practice standards, defined roles, value proposition, and certifications for dementia-competent nonclinical workers (e.g. community health workers).</b></li> </ul>
Create the business case and value proposition	<ul style="list-style-type: none"> <li>• <b>Require development of value propositions (e.g. patients, families, sponsors, payers, potential adopter, advocates) in Stage II –Stage IV intervention studies</b></li> </ul>