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

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RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports
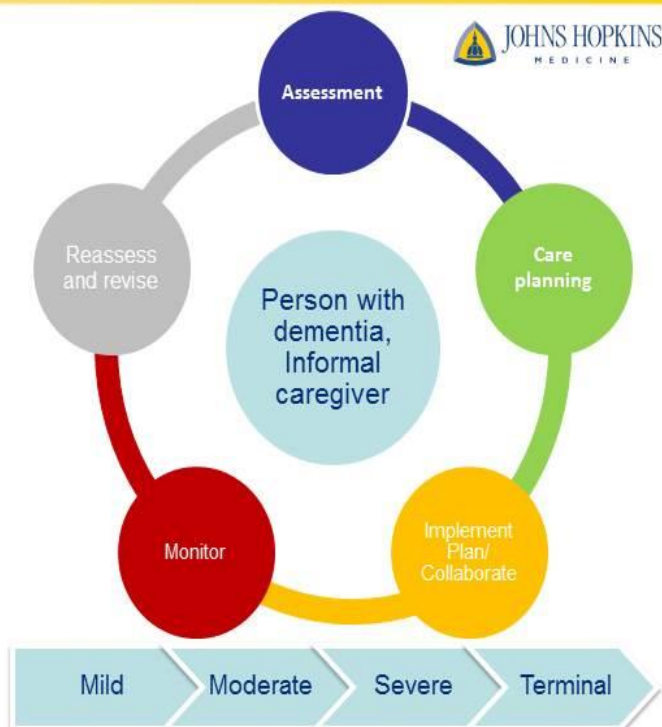
#DementiaCareSummit

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National Research Summit on Care, Services, and Supports
for Persons with Dementia and Their Caregivers
October 17, 2017

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

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Assessment → Care planning → Implement Plan/Collaborate → Monitor → Reassess and revise

Person with dementia, Informal caregiver

Mild → Moderate → Severe → Terminal

Community-Based Dementia Models as potent tool to "connect the dots"

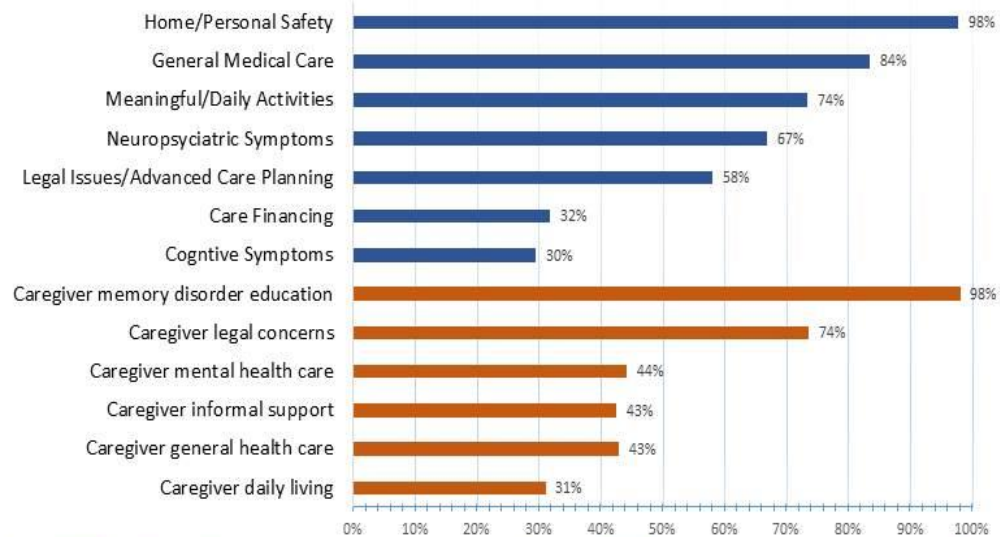JOHNS HOPKINS MEDICINE

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

Alzheimer's Association. 2017 Alzheimer's Disease Facts and Figures.

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Common needs of persons with dementia

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

- Home/Personal Safety — 98%
- General Medical Care — 84%
- Meaningful/Daily Activities — 74%
- Neuropsyciatric Symptoms — 67%
- Legal Issues/Advanced Care Planning — 58%
- Care Financing — 32%
- Cogntive Symptoms — 30%
- Caregiver memory disorder education — 98%
- Caregiver legal concerns — 74%
- Caregiver mental health care — 44%
- Caregiver informal support — 43%
- Caregiver general health care — 43%
- Caregiver daily living — 31%

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

Brodaty H, Green A, Koschera A. 2003; Pimouguet 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 Pschogeriatrics; Reilly et al., 2015, Cochrane Database Stystematic review

	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

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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

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Goal	Recommendation
Accelerate adoption of successful interventions	• 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 value to adopters, effectiveness, and to refine for scalability.
Strengthen trial methods to support rigor and practicality	• 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). • Use pragmatic trial and rapid-cycle quality improvement methods combined with standardized process measurement to balance internal and external validity and accelerate adoption.
Increase CBO capability, capacity, workforce, role in value-driven care	• Use health care technology to develop dementia-competent service capacity in CBOs and to support collaborative partnerships with health systems and health plans. • Develop practice standards, defined roles, value proposition, and certifications for dementia-competent nonclinical workers (e.g. community health workers).
Create the business case and value proposition	• Require development of value propositions (e.g. patients, families, sponsors, payers, potential adopter, advocates) in Stage II –Stage IV intervention studies