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

Quincy Samus, PhD
Johns Hopkins School of Medicine

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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

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**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)

- Home/Personal Safety: 98%
- General Medical Care: 84%
- Meaningful/Daily Activities: 74%
- Neuropsychiatric Symptoms: 67%
- Legal Issues/Advanced Care Planning: 58%
- Care Financing: 32%
- Cognitive Symptoms: 30%
- 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Unpublished data from MIND at Home Studies baseline assessment data, Samus, 2017

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

Turner 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

<table>
<thead>
<tr>
<th>Language(s)</th>
<th>ACCESS (Vickroy et al. 2008; Duru et al., 2009; Chodosh et al., 2015)</th>
<th>BRI (Bass et al., 2003; Clark et al., 2004)</th>
<th>Dementia Care EcoSystem (Possin et al., 2017)</th>
<th>MIND at Home (Samus et al., 2014; Tannen et al., 2014)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of intervention</td>
<td>12 months +</td>
<td>12 months</td>
<td>12 months, 5 years</td>
<td>18 months</td>
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<tr>
<td>Staff type</td>
<td>Social workers (predominantly), or nurse</td>
<td>Social worker or non-clinical staff (Care Consultant)</td>
<td>Non-clinical staff (Care Team Navigator), nurse, social worker, pharmacist</td>
<td>Non-clinical staff (Memory Care Coordinator), nurse, psychiatrist</td>
</tr>
<tr>
<td>Standardized staff training</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>PWD/CG dyad per coordinator-case manager</td>
<td>50</td>
<td>60-80</td>
<td>45-50</td>
<td></td>
</tr>
<tr>
<td>Interdisciplinary case conferencing</td>
<td>✓ (care manager and physician champion)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Contact frequency</td>
<td>Monthly, average</td>
<td>Monthly, average</td>
<td>At least monthly</td>
<td>Twice-a-month, average</td>
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<tr>
<td>Home visits</td>
<td>✓</td>
<td>No</td>
<td>No</td>
<td>✓</td>
</tr>
<tr>
<td>Mode of contact</td>
<td>In-person, Phone</td>
<td>Phone</td>
<td>Phone, mail, web</td>
<td>In-person, Phone</td>
</tr>
<tr>
<td>Communication with physicians</td>
<td>Mail, fax, in-service trainings</td>
<td></td>
<td>Phone, email, fax</td>
<td>Phone, mail, fax</td>
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<thead>
<tr>
<th>Direct provision of medical care/orders writing</th>
<th>ACCESS</th>
<th>BRI</th>
<th>Dementia Care EcoSystem</th>
<th>MIND at Home</th>
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</thead>
<tbody>
<tr>
<td>Medication review/reconciliation</td>
<td>✓</td>
<td>No</td>
<td>No</td>
<td>✓</td>
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<tr>
<td>Resource referrals</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Active facilitation to link to services</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Legal/Financial/Advance care planning</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>CG problem solving/emotional support</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>CG disorder education</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>CG skills training (e.g. Behavior management, Communication, PT Advocacy)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Home safety assessment</td>
<td>✓</td>
<td></td>
<td>Via Phone screen only</td>
<td>✓</td>
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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

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<tr>
<th>Goal</th>
<th>Recommendation</th>
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<tr>
<td>Accelerate adoption of successful interventions</td>
<td>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.</td>
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<tr>
<td>Strengthen trial methods to support rigor and practicality</td>
<td>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.</td>
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<td>Increase CBO capability, capacity, workforce, role in value-driven care</td>
<td>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).</td>
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<td>Create the business case and value proposition</td>
<td>Require development of value propositions (e.g., patients, families, sponsors, payers, potential adopter, advocates) in Stage II–Stage IV intervention studies</td>
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