Dementia Care in the Context of Primary Care Reform: An Integrative Review

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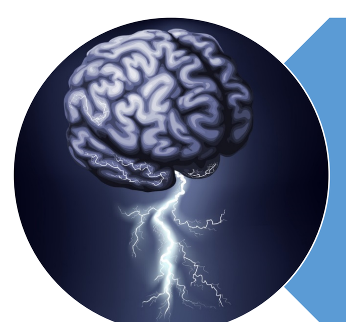
Introduction

The best chance of addressing the exploding health care demand driven by chronic disease is to get primary care (PC) right. So, primary care has been gearing up over the last decade to better manage chronic conditions.

Dementia is a chronic and progressive condition, and yet has not been discussed as a chronic condition in the same way as illnesses like diabetes or heart failure—yet statistics on dementia's prevalence tell us it is likely to be the chronic condition that tests primary care like no other.

Primary care physicians often lack knowledge about dementia, lack confidence in recognizing the symptoms, are unsure about how to conduct cognitive screening, are constrained in providing the time-intensive support needed, lack knowledge of how to manage symptoms, and often believe that little can be done in any case.



The complexity and increasing prevalence of dementia caused us to wonder about how the work on primary care reform was influencing the literature around primary care support for people living with dementia (PLWD) in the community.

Methods

An **integrative** review of the literature:

- includes a broad range of literature in the synthesis
- employs a wide sampling frame
- follows a systematic protocol established prior to approaching the literature

Questions Guiding the Review:

1. What does the evidence say about primary care team-based models of care that best support individuals and families living with dementia in the community?
2. What are the evident models of primary care for dementia, and what are the outcomes?
3. How do the models line up with the other attributes of high performing primary care (beyond team-based care)?

Inclusion: all published/grey literature 2000-2013 related to team-based primary care in the community AND diagnosed dementia; websites for dementia-related organizations.
Exclusions: editorials/commentaries; no discussion of outcomes.
Databases: Cumulative Index to Nursing and Allied Health Literature; Web of Science; Cochrane Collaborative Reviews; Medline; ProQuest Nursing & Allied Health Source; Google Scholar.

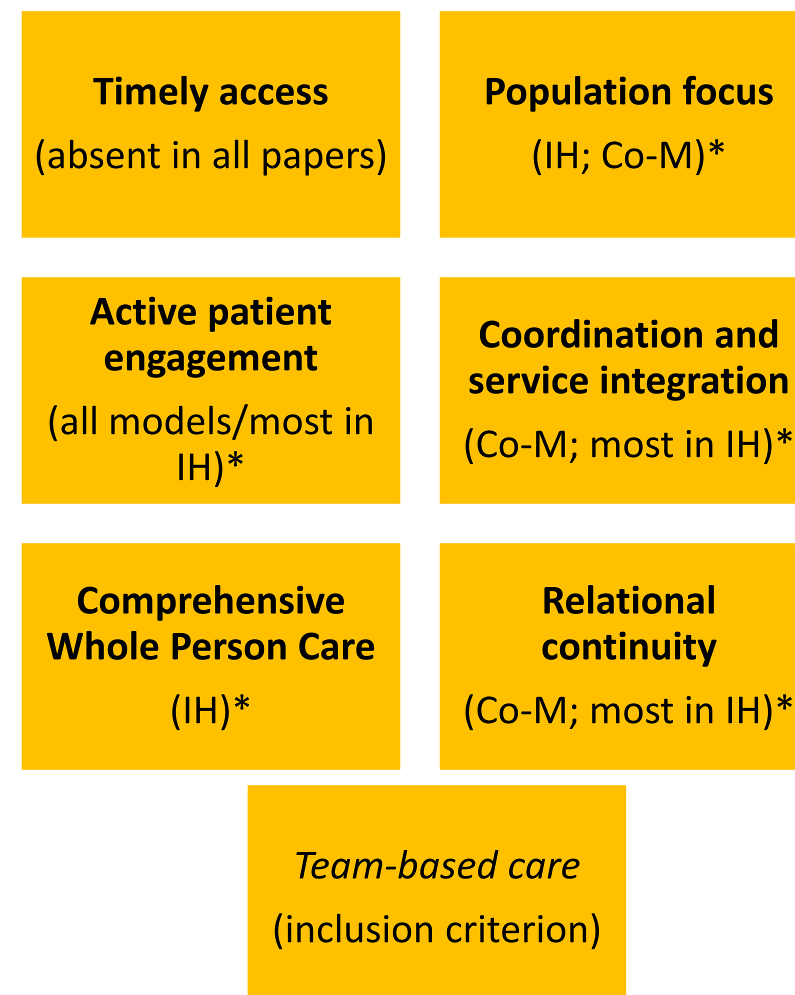
Results

- 2192 abstracts reviewed against criteria
- 67 articles selected for closer review

- Manual search of reference lists of all 67
- Recommendations of expert colleagues
- Websites searched and reviewed
- 14 additional articles/3 grey literature additions

- Total of 84 pieces of work for complete review
- 20 pieces of work for quality appraisal
- **15 final inclusions in the review**

Attributes of High Performing Primary Care



Conclusions

- ✓ There has been a slow penetration of the attributes of high performing primary care into the reviewed evidence related to primary care of dementia.
- ✓ "Integrative hub" models show the most progress related to exemplifying the attributes of high-performing primary care
- ✓ Overall, the disease-specific care plan and interventions still take the foreground, and the coordinating role of primary care is emphasized. To be consistent with more recent work in primary care reform, approaches to dementia care must place the person and the primary care relationship in the foreground, assume accountability for comprehensive, whole-person primary care, and resist siloed, carved-out approaches to care.

Findings

Model of Dementia Care	Definition	Assumptions of Model	Associated Outcomes	"Achilles Heel"	Included Studies**
Carved Out *[Not well aligned with the attributes of high performing systems of primary care]*	Responded by referring PLWD to organizational resources outside the practice or to another unit of a large health care organization; "carved" dementia care out of normal primary care.	-PC is not the place for dementia care as it lacks the resources to respond to dementia complexity. -Most appropriate care lies outside of the primary care relationship. -Any primary care intervention must be brief and simple to do because of time-compression in PC. **FOCUS:** early referral to outside resources for dementia-specific care.	**Measures included:** Cross-sectional or short term measures of patient/caregiver outcomes of (general well-being; caregiver strain; depression; satisfaction; patient behavior problems) and process of care indicators in dementia guidelines. Mixed outcomes.	Fragmentation of communication and of the dementia journey across the specialty-primary chasm.	➢ Barclay, Cherry & Mittman (2005) ➢ Bass, Clark, Looman, McCarthy & Eckert (2003) ➢ Burns, Nichols, Martindale-Adams, Graney & Lummus (2003) ➢ Cherry, Vickrey, Schwankovsky, Heck, Plauche & Yep (2004) ➢ Fortinsky, Kulldorff, Kleppinger & Kenyon-Pesce (2009) ➢ Fortinsky, Unson & Garcia (2002)
Co-Managed (Co-M)*	Clear that the appropriate anchor point or hub for dementia care and management was the PC relationship. Dementia was intensively and collaboratively co-managed between designated PC contacts and supplemental support services, engaged through referral mechanisms with specific providers.	-PLWD require more focused attention than is feasible within traditional PC, but acknowledge the centrality of the PC relationship **FOCUS:** robust communication between PC team member and co-manager(s) of a dementia-specific plan.	**Measures included:** Adherence to care guidelines across providers, follow through on referrals to resources and patterns of service utilization (all showed improvement). Health related quality of life, caregiver confidence—mixed outcomes.	Emphasizes coordination of services around the dementia (not aligned with whole-person, comprehensive care). Requires consistent, reliable mechanisms of electronic communication, and frequent communication between co-managers and with patients to avoid fragmentation.	➢ Boustani, Sachs, Alder, Munger, Schubert, Austrom, et al. (2011) ➢ Chodosh, Pearson, Connor, Vassar, Kaisey, Lee, & Vickrey (2012) ➢ Hogan, Bailey, Carswell, Clarke, Cohen, Forbes et al. (2007) ➢ Vickrey, Mittman, Connor, Pearson, Della Penna, Ganiats, et al. (2006)
Integrative Hub (IH)* *[Most consistent with attributes of high performing primary care]*	Capacity built and resources incorporated within the PC setting to better support patients and families from within the context of the primary care relationship. Resource deficits did not drive an approach that first looked outside the practice for higher levels of patient and family support.	-PC is the appropriate hub for comprehensive care that includes dementia care. -It's not only the intervention or even the plan of dementia care that matters to quality of care – but also the nature and continuity of the relationship with patients/families. -Referral to specialized resources needed for small number of very complex situations. **FOCUS:** comprehensive care, team learning and developing the practice to provide care as appropriate to population.	**Measures included:** Satisfaction of patient/caregivers; Physician satisfaction and confidence in care (significantly improved); quality of care as assessed by geriatricians; patient/caregiver experience; behavioral and psychological symptoms, caregiver depression/distress all improved over 18 months; referral to specialty (significantly reduced). Measurement of outcomes over the longer term and at different stages of the journey from patient/caregiver perspectives.	Requires commitment to substantially changing systems of care, and to intensive team development and ongoing learning.	➢ Callahan, Boustani, Unverzagt, Austrom, Damush, Perkins et al. (2006) ➢ Lee, Hillier, Stolee, Heckman, Gagnon, McAiney & Harvey (2010) ➢ Minghella (2012) ➢ Nichols, Martindale-Adams, Burns, Graney & Zuber (2011) ** One article did not fit well into any one model, a systematic review of case management interventions for PLWD. The authors reported a positive relationship between better care outcomes and more integration in clinical services and between health and social services (Somme, Trouve, Drame, Gagnon, Couturier & Saint Jean, 2012).

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