NIA IMPACT COLLABORATORY
TRANSFORMING DEMENTIA CARE

IMPACT Demonstration Project | Improving How PLWD are Selected for Care Coordination: ePCT in an Accountable Care Organization

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Housekeeping

- All participants will be muted
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
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Learning Objectives

Upon completion of this presentation, you should be able to:

1. Understand the concept of healthcare fragmentation in general
2. Understand the relevance of healthcare fragmentation specifically for people living with dementia
3. Reflect on the results of a pragmatic clinical trial that included people living with dementia who had highly fragmented care

Disclosures

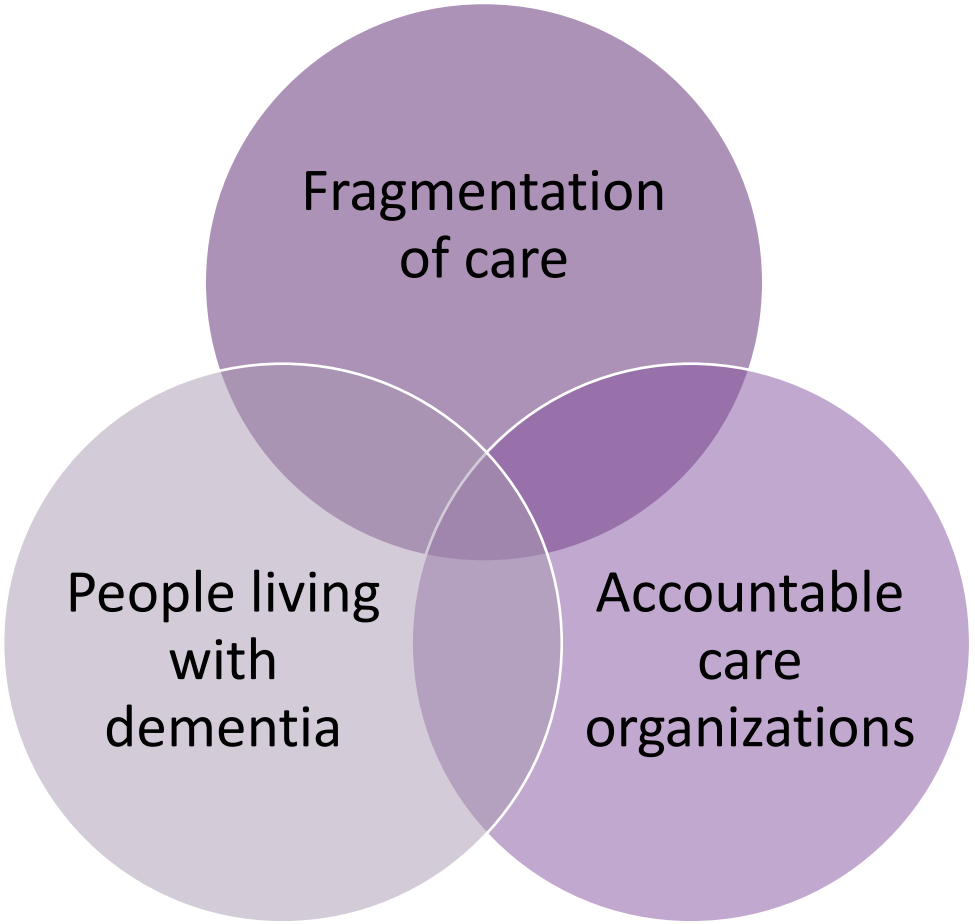
- Funding for my work comes from the NIA IMPACT Collaboratory; the National Institute on Aging; the National Heart, Lung, and Blood Institute; and the Agency for Healthcare Research and Quality.
- I have no financial conflicts of interest.
- This talk represents my own views and not the views of my institution or my funders.

Case (hypothetical but typical)

- 75-year-old women with mild dementia, diabetes, and coronary artery disease comes to establish care with me, as her primary care physician.
- She says she is switching primary care physicians because she recently moved to be closer to her daughter.
- Her cardiologist, who is in a different health system with a different electronic health record, recently started new medication, drew blood, and did an echo, but the patient does not have the details.
- The patient also has an endocrinologist and ophthalmologist, who are in separate outside practices.
- And the patient went to urgent care last night for foot pain.

Outline

1. Discuss fragmentation in general, distinguishing it from care continuity and care coordination
2. Discuss the relevance of fragmentation for people living with dementia (PLWD)
3. Present a pragmatic clinical trial designed to address fragmented care for PLWD in the context of an accountable care organization (manuscript under review)



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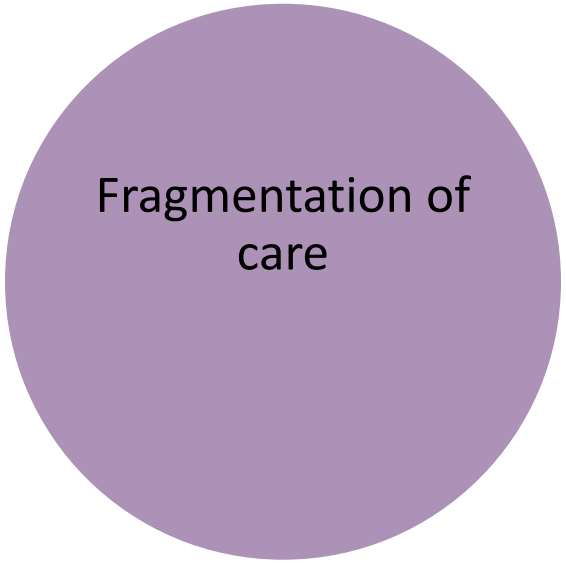


Continuity

- Care continuity = the use of the same ambulatory physician repeatedly over time, such that the usual physician (who can be a primary care or specialist physician) accounts for a substantial proportion of visits

Kern et al. JAMA Intern Med 2024.

Coordination

- Care coordination = the extent to which physicians are collectively operating in a team-like manner to develop and implement an overall care plan to meet the patient's goals

Kern et al. JAMA Intern Med 2024.

Two Problems

Continuity and coordination have been topics of discussion for decades, but:

- Evaluations of previous care coordination interventions have shown that many of them have not been effective.
- This may be because efforts to promote continuity and coordination have typically focused on a small number of providers, potentially omitting many others who may be involved.

Kern et al. JAMA Intern Med 2024.

Ambulatory Utilization in the U.S.

- In 2000-2002, the median Medicare beneficiary saw 7 ambulatory physicians each year (interquartile range [IQR] 4, 11).

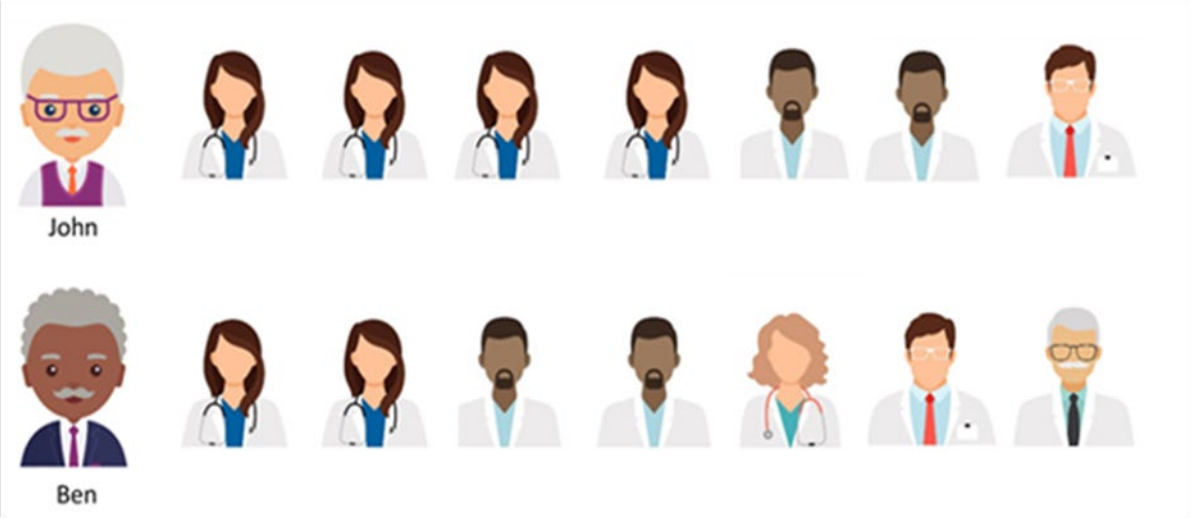
  Because different beneficiaries see different specialists (i.e., Mr. Jones and Mr. Brown may see different cardiologists), the typical primary care physician has 229 (IQR 125, 340) other physicians with whom care must be coordinated, equivalent to an additional 99 physicians for every 100 Medicare beneficiaries managed by the primary care physician.

- From 2000-2019, the proportion of Medicare beneficiaries seeing 5 or more physicians annually increased from 19.1% in 2000 to 35.1% in 2019.

Pham et al. NEJM 2007. Pham et al. Ann Intern Med 2009.
Barnett et al. Ann Intern Med 2021.

Fragmentation

- Care fragmentation = ambulatory care that is diffusely spread across many providers such that no single provider accounts for a substantial proportion of visits



Patient	Number of visits	Number of providers	Proportion of visits with the most frequently seen provider
John	7	3	4/7 = 0.57
Ben	7	5	2/7 = 0.29

Who has more fragmented care?

Kern et al. JAMA Intern Med 2024.

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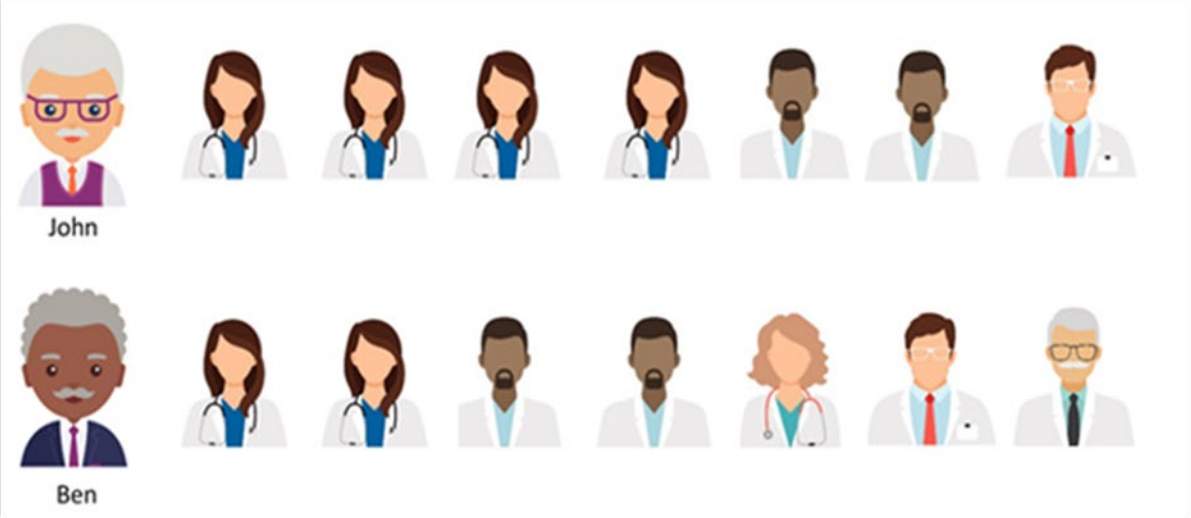

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Who has more fragmented care?

Ben – and there are millions of Medicare beneficiaries like him (likely ~25% of beneficiaries)!

Kern et al. JAMA Intern Med 2024.

Concepts

- Continuity and fragmentation are measures of utilization.
- Coordination is a measure of communication.
- Fragmentation may be clinically appropriate, but it creates challenges for physicians and can cause harm without communication.
- Even in the era of electronic health records, gaps in communication persist (Timmins, Kern, et al. Ann Fam Med 2022).
  - Data from a 2019 survey found that approximately one-third of primary care physicians nationally do not always or most of the time receive information back from a specialist after a consultation.

Previous Work

- I have now published >30 articles on fragmentation of care.
- Some key findings from this work include:
  - There are more than 40 (!) causes of fragmentation, according to patients and primary care physicians.
  - There are also at least 24 consequences of fragmentation, with 3 consequences desirable and 21 undesirable, including provider burnout.
  - Quantitative studies have found that more fragmentation is independently associated with more radiology tests, more emergency department visits, more hospitalizations, higher costs, and for some subsets of the population more incident heart attacks and strokes.

Need for Novel Interventions

- Despite how common it is for patients to see multiple physicians, there have been relatively few studies of fragmentation and few interventions explicitly designed to address it.
- Because fragmentation is caused by many factors, no single intervention will fix the problem.
- However, a new framework published in JAMA Internal Medicine may guide the development of novel interventions (Kern, Bynum, Pincus. JAMA Intern Med 2024;184(3):236-237).

6P Framework*

Level of action (6P)	Contribution to fragmentation	Potential intervention
Patients (and caregivers)	Assumption that providers are communicating with each other	Patient-facing educational intervention about fragmentation
Providers (physicians and others)	Lack of communication with each other	With financial incentives from payers, improve communication across all providers
Practice settings	Lack of notification when a provider sees a patient with highly fragmented care	Plans can identify patients with highly fragmented care in real time and work with patients and physicians to address it
Plans (public and private payers)	Undervalue cognitive work of communication among providers	Increase compensation for cognitive work of coordinating care across all providers
Purchasers (employers)	Lack of identification of fragmentation as an opportunity for improvement	Put pressure on public and private payers to hold them accountable for addressing fragmentation
Populations (communities)	Lack of consistent communication between primary care and urgent care	Improve communication between primary care and urgent care centers

*This table, adapted from our JAMA IM 2024 paper, is not comprehensive; it is illustrative. Also, a cause at one level of action could lead to an intervention at another level.

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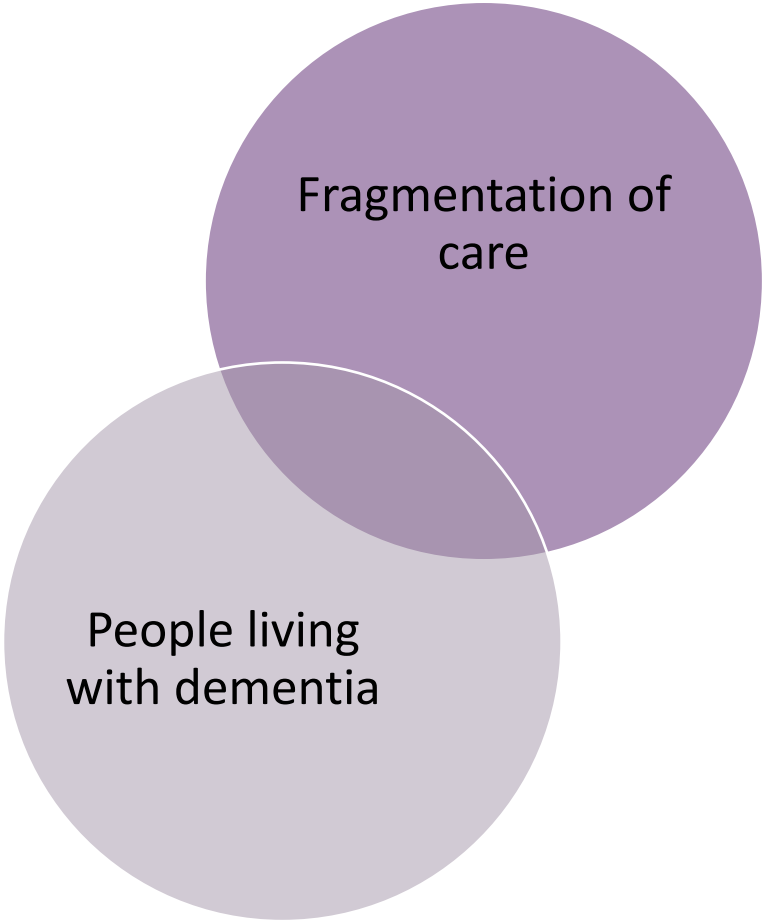
*The trial I will present is one version of the second row.

Outline

2. Discuss the relevance of fragmentation for people living with dementia (PLWD)



Fragmentation of care is highly relevant to PLWD

Although PLWD are not the only ones who have highly fragmented care, it is particularly relevant to them for at least 5 reasons:

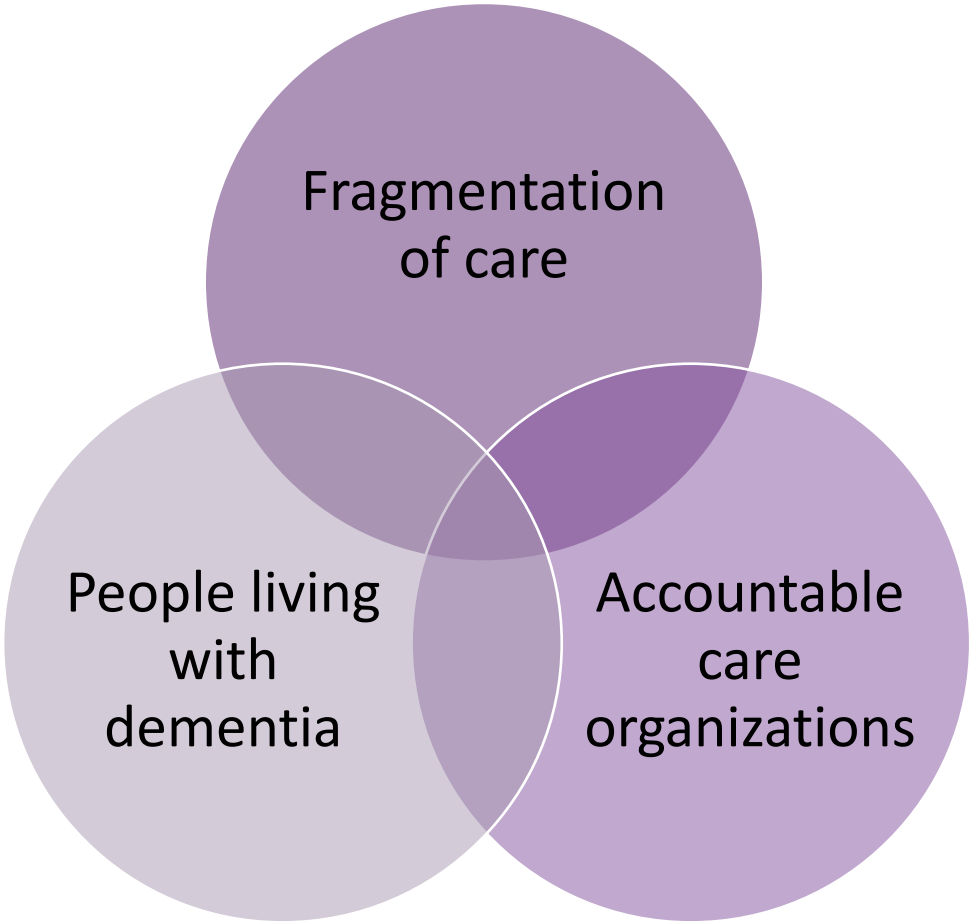
1. Highly fragmented care among PLWD is common.
    - A national study found that one-third of community-dwelling PLWD had care so fragmented that their ambulatory care pattern was an independent risk factor for emergency department visits and hospitalizations.
    - Those with highly fragmented care had an average of 16 visits to 7 different providers in a year, compared to 11 visits to 3 providers for those with the least fragmented care.
2. PLWD may be particularly vulnerable to the adverse effects of fragmented care.
    - Memory loss → difficulty reporting symptoms and medical history
    - Caregivers may not consistently be available to attend visits.

Fragmentation of care is highly relevant to PLWD (cont.)

3. The number of PLWD is increasing, and health systems are not prepared.
    - In 2023, an estimated 6.7 million Americans were PLWD. This number is expected to reach 12.7 million by 2050.
    - Fragmentation of care is the #1 barrier to improving dementia care, according to the 2021 NEJM Catalyst Insights Council (>500 healthcare leaders).
4. Care of PLWD almost always involves stakeholders other than physicians.
    - A survey by AARP in 2020 found that 31% of family caregivers reported difficulty coordinating care among their care recipient's providers, up from 25% in 2015.
5. New drugs to treat early-stage dementia may unintentionally worsen fragmentation.
    - New medications are IV infusions that may become the domain of neurologists.

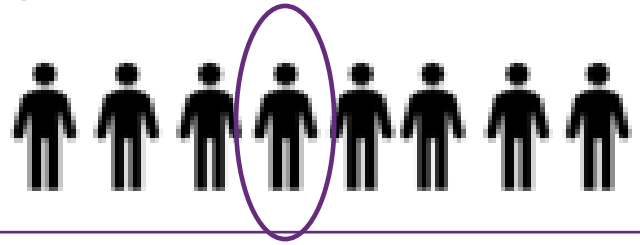
Outline

3. Present a pragmatic clinical trial designed to address fragmented care for PLWD in the context of an accountable care organization



Background

- Accountable care organizations (ACOs) are alliances of providers, hospitals, and others that contract with Medicare for value-based payment.
- They are incentivized to improve care coordination.
- Care coordination has been shown to be beneficial among PLWD.
- Yet, there are two few care coordinators (typically nurses or social workers) to help all who might benefit.
- For example, an ACO may have 9,000 attributed patients, but only have 3 care coordinators, who can care for approximately 350 patients each, or 1,050 patients total (12%, or ~1 in 8).
- There are no data to guide which patients should be selected.



Background (2)

- Previous work has shown that:
  - Highly fragmented ambulatory care (i.e., care spread across many providers without a dominant provider) is common among PLWD.
  - Highly fragmented care increases the likelihood of gaps in communication among providers, which can lead to preventable emergency department visits and hospitalizations among PLWD.
  - Care partners of PLWD perceive gaps in communication among providers.
- Current approaches for assigning care coordinators to PLWD do not take into account fragmented ambulatory care or care partners' observations.

Objective

To determine the comparative effectiveness of two different approaches for selecting PLWD for care coordination services:

1) Usual care, which assigns care coordinators to PLWD after hospital discharge or direct physician referral, vs.

2) Usual care + proactive outreach, a novel approach that assigns care coordinators to PLWD based on their care partners' self-reported difficulty with care coordination

Aims

- Aim 1: To determine the comparative effectiveness of the two different approaches for allocating care coordinators to PLWD on the combined outcome of emergency department visit or hospitalization over 12 months of follow-up, as measured in claims
- Aim 2: To measure implementation outcomes for the trial conducted in Aim 1 (acceptability, appropriateness, fidelity, and efficiency), as measured with data from the electronic health record, to inform future dissemination

Methods (1)

- Design: Embedded, pragmatic clinical trial, using randomization stratified by care management team
- Setting: NewYork Quality Care (NYQC), the accountable care organization (ACO) that brings together NewYork-Presbyterian Hospital, ColumbiaDoctors, and the Weill Cornell Physician Organization
- Inclusion criteria: Medicare beneficiaries 65 years and older, who have been attributed to NYQC, have dementia, reside in the community, had fragmented ambulatory care in the previous 12 months (reversed Bice-Boxerman Index ≥50th %ile), in the catchment area of the 3 main care management teams
- Exclusion criteria: Enrolled in home hospice

Methods (2)

- Usual care group: Care coordinators are assigned to patients who are discharged from the hospital or directly referred by physicians
- Intervention group: Usual care plus care coordinators administer a previously validated 7-minute telephone survey to care partners about their perceptions of care coordination and then, if a problem with care coordination is reported, the care coordinator is “assigned” to that patient to follow-up and address the problem
- Timeline: Staggered entry starting December 5, 2022, with qualifying events over 3 months, 1 month for care management, and follow-up for 12 months or until April 30, 2024 (whichever came first)
- Human subjects: Received a waiver of informed consent and waiver of HIPAA authorization

Methods (3)

- Analytic plan:
  - Compared characteristics of usual care and intervention groups using standardized mean differences for continuous variables and Mahalanobis distances between group-specific proportion vectors, where values >0.30 suggest imbalance
  - Compared median follow-up times across groups using Kruskal-Wallis test
  - Compared frequencies of events requiring censoring (deaths or losses to follow-up using Pearson chi-squared or Fisher's exact test)
  - Compared rates of events using Poisson regression models

Derivation of the trial population

People ≥65 years old who were attributed by Medicare to the New York Quality Care accountable care organization (ACO) in the 12 months ending June 30, 2022 (N = 34,003)

↓

People meeting the Bynum Standard 1-year definition for dementia (N = 1,373; 4.0%)

↓

People who are community-dwelling and not in hospice (N = 1,285; 93.6%)

↓

People who had 4 or more ambulatory visits in the past 12 months (N = 1,070; 83.3%)

↓

People whose ambulatory care patterns had fragmentation scores equal to or above the median score (N = 538; 50.3%)

↓

People in the catchment area of the 3 main care management teams (N = 385; 71.6%)

Characteristics of the study population (N = 385)

	Control group	Intervention group	Standard mean difference (SMD)*
N	192	193	
Age, mean (SD)	82.3 (7.0)	82.8 (6.9)	-0.07
Sex, female, N (%)	108 (56.3)	109 (56.5)	<0.01
Race, white, N (%)	153 (79.7)	154 (79.8)	<0.01
Dual eligibles, N (%)	33 (17.2)	48 (24.9)	0.24

*SMD > 0.30 would suggest imbalance.

Ambulatory care patterns of the study population (N = 385)*

	Control group	Intervention group
N	192	193
Ambulatory visits, mean (SD)	14.6 (9.7)	15.2 (8.3)
Ambulatory providers, mean (SD)	8.6 (4.0)	9.1 (3.9)
Proportion of visits with the most frequently seen provider, mean (SD)	0.25 (0.06)	0.24 (0.07)
Fragmentation score (reversed Bice-Boxerman Index), mean (SD)	0.92 (0.03)	0.93 (0.03)

*By contrast, those excluded due to low fragmentation had an average of 11.0 visits to 4.6 providers, with the most frequently seen provider accounting for 50% of visits and an average fragmentation score of 0.72.

Which PLWD received care management in usual care group

PLWD who were randomized to the control group (N = 192)

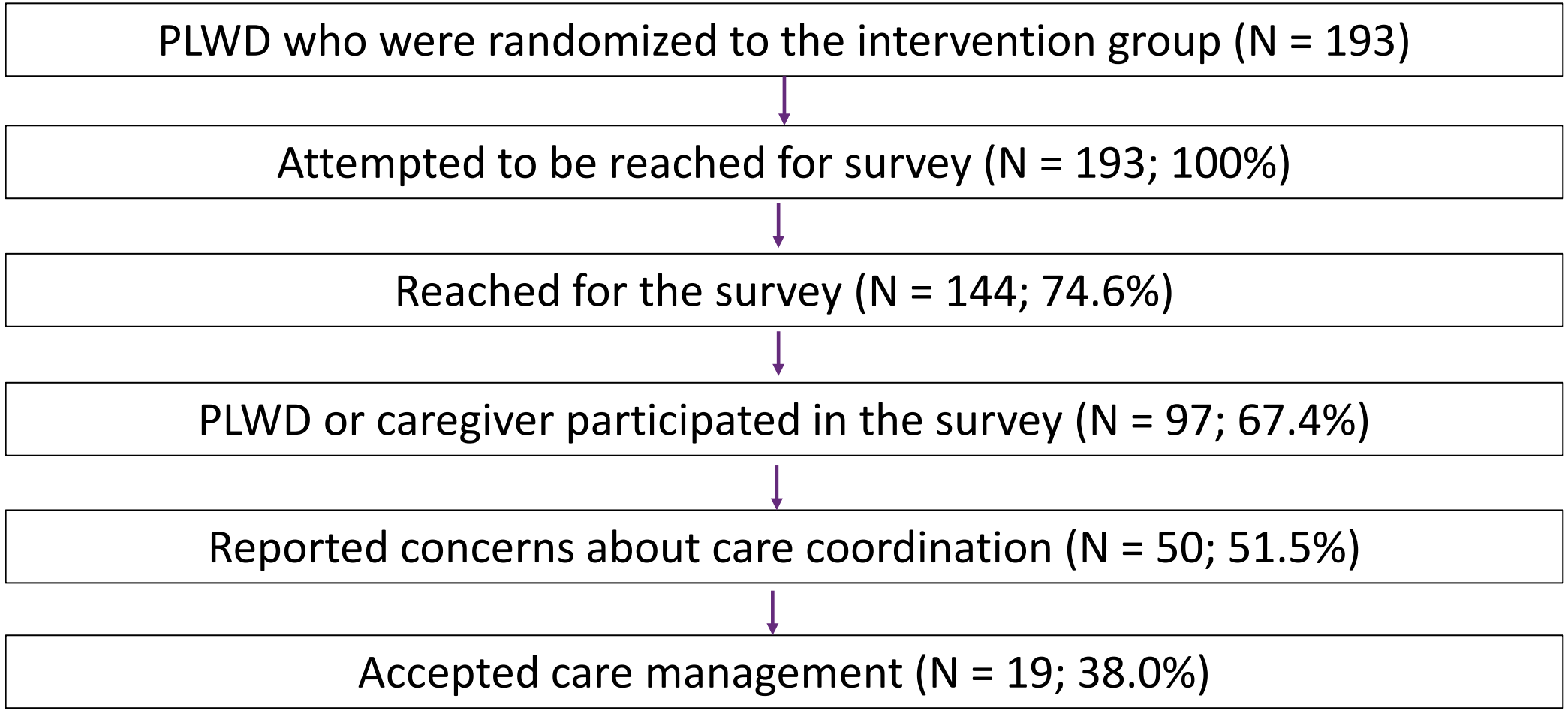
↓

Referred for care management services based on hospitalization or physician referral (N = 19; 9.9%)

↓

Accepted care management (N = 14; 73.7%)

Which PLWD received care management in intervention group



Follow-up time and frequency of events requiring censoring

	Total	Control	Intervention	P-value
N	385	192	193	
Median observation time, days (IQR)	284 (179, 365)	237 (179, 365)	303 (167, 353)	0.50
Lost to follow-up, N (%)	48 (12.5)	23 (12.0)	25 (13.0)	0.77
Deaths, N (%)	69 (17.9)	37 (19.3)	32 (16.6)	0.49

Outcomes (intention-to-treat [ITT] analysis)

	Total	Control	Intervention	P-value
N	385	192	193	--
Number of ED visits	149	84	65	--
Rate of ED visits per 100 person-days alive (95% CI)	0.16 (0.14, 0.19)	0.18 (0.15, 0.23)	0.14 (0.11, 0.17)	0.07
Number of hospitalizations	167	74	93	--
Rate of hospitalizations per 100 person-days alive (95% CI)	0.18 (0.15, 0.21)	0.16 (0.13, 0.20)	0.20 (0.16, 0.24)	0.23
Number of ED visits or hospitalizations	316	158	158	--
Rate of ED visits or hospitalizations per 100 person-days alive (95% CI)	0.34 (0.30, 0.38)	0.35 (0.30, 0.41)	0.33 (0.28, 0.39)	0.71

Outcomes (among those who received care management)

	Total	Control	Intervention	P-value
N	33	14	19	--
Number of ED visits	20	11	9	--
Rate of ED visits per 100 person-days alive (95% CI)	0.20 (0.13, 0.31)	0.29 (0.16, 0.52)	0.15 (0.08, 0.28)	0.12
Number of hospitalizations	26	15	11	--
Rate of hospitalizations per 100 person-days alive (95% CI)	0.26 (0.18, 0.38)	0.40 (0.24, 0.66)	0.18 (0.10, 0.32)	0.04
Number of ED visits or hospitalizations	46	26	20	--
Rate of ED visits or hospitalizations per 100 person-days alive (95% CI)	0.46 (0.35, 0.62)	0.69 (0.47, 1.01)	0.32 (0.21, 0.50)	0.01

Aim 2 outcomes

- Acceptability: 38% (of those offered care management in the intervention group accepted it)
- Appropriateness: 100% (all issues raised to care managers were within their scope of practice)
- Fidelity: 100% (all eligible individuals who wanted care coordination received it, and all who received it had completed the survey)
- Efficiency: 77 care management encounters for the 193 PLWD in the intervention group and 54 care management encounters for the 192 PLWD in the control group; the number of minutes per encounter was not well documented by the care managers.

Discussion (1)

- In this pragmatic clinical trial of 385 PLWD with highly fragmented care and their caregivers, half (51.5%) of those surveyed reported concerns about the coordination of their ambulatory care.
- Of those expressing concerns, only one-third (38%) accepted the immediate help of skilled care managers.
- Approximately 7-10% of people in each arm of the trial received care management.
- The ITT analysis found a trend toward fewer ED visits in the intervention group ($p = 0.07$), but the primary outcome of ED visit or hospitalization was not significant.
- A subgroup analysis including only those who received care management found that the intervention group had a lower rate of ED visit or hospitalization ($p = 0.01$), but this should be interpreted with caution.

Discussion (2)

- This is the first trial (for any disease) to use highly fragmented care as an inclusion criterion.
    - The frequency of concerns about care coordination was indeed higher (51%) than for PLWD irrespective of ambulatory care patterns (31%), confirming that those with highly fragmented care are at high risk of self-reported gaps in communication and thus an appropriate target for intervention.

Discussion (3)

- The acceptance rate of care management was higher in the control group (73.7%) than the intervention group (38.0%).
    - Possibly due to perceived urgency post-hospitalization
    - Those who declined care management in the intervention group frequently reported that they knew providers were not communicating with each other but that they were actively compensating for that.
        - ➢ *"Patient's wife is a strong advocate and refused care management."*
    - Those who did accept seemed to accept for the intended reasons
        - ➢ *"Patient forgets everything from visit. Daughter asks for provider to reach out to her, but they don't…"*

Discussion (4)

- Limitations:
  - The study took place in one accountable care organization in NY, which may limit generalizability.
  - The patient population was nearly 80% White; additional research is needed in more diverse populations.
  - We cannot tease apart the potential impact of proactive care management from the potential impact of the survey.
  - We cannot be certain which component of care management may have made a difference; care managers focused on communication in the intervention group but could do other tasks as well.

Discussion (5)

- The ITT did not show a benefit, possibly because the numbers of people who accepted care management were small.
- The subgroup analysis did show a benefit, but the balance achieved by randomization may not persist in this subgroup analysis.
- Taken together, the next steps for future research seem to be:
    - Determine how to increase acceptability, and/or
    - Find those who would accept care management more efficiently

Discussion (6)

- In conclusion, a small but important subset of PLWD with highly fragmented care and their caregivers were concerned about gaps in communication among providers and were willing to accept care management.
- This subset would not have been fully identified through usual care.
- This trial provides preliminary evidence of partial effectiveness of proactive outreach.
- That is, among PLWD with highly fragmented care and their caregivers, care management may reduce ED visits and hospitalizations more for the subset who experience problems with care coordination and engage with care managers proactively than for the subset who is post-discharge.

Next steps

- New R01 from NIA on “Understanding Ambulatory Care Utilization in Alzheimer’s Disease and Related Dementias (ACUA) (R01AG087243)”
  - Understand whether fragmentation of care affects time-to-diagnosis of dementia (Aim 1) and whether it affects medication management (Aim 2)
  - Qualitative interviews of stakeholders in dementia care to develop new interventions (Aim 3)

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Questions?

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