

# Research Priorities and Inclusion Preferences of Homebound Older Adults Receiving Home-Based Medical Care and Their Caregivers

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## Background

- Homebound older adults and their caregivers are a largely invisible population who haven't had a voice in establishing patient-centered research agendas
- Research priorities developed without stakeholder input may overlook significant questions of importance to this population
- Opportunities to engage caregivers and patients in patient-centered outcomes research provides a unique opportunity to advance geriatric care

## Aim

- To understand research priorities of homebound older adults and their caregivers to inform future research engagement strategies and the development of a stakeholder-centered research agenda

## Methods

- Qualitative semi-structured interviews explored:
  - the experience of being homebound
  - prior research experiences, topics of interest
  - strategies to engage stakeholders as research advisors
- Participants were recruited from home-based medical practices at JHU and UCSF from April to October 2018
- Themes identified using descriptive thematic analysis of transcripts

## Results

### Participant-Identified Research Priorities

#### Condition-Specific Questions

Research is needed in certain things...like research on dementia and Alzheimer's. We need the opportunities to learn from...without research, without studies, how can we learn?"



#### Caregiver Training and Respite Care

"...there should be somebody to come in to show you how to handle them properly. Just starting out, I was just winging it."

"Respite care for caregivers, that's a topic I'd like discussed. We need to get away sometimes. And help financing that."

#### Healthcare Delivery and Financing

"I know a lot of seniors that can't afford their medicine. The medication is ridiculously high, and because of that they won't go to a doctor."

"U.S. medical care is fabulous but it's very, very inconvenient and very restrictive"

#### Home Environment Adaptations

"Researchers should look at how the home should be set up for someone like him."

"A lot of people have rugs with walker, and the next thing you know, they're.. back into hospital because nobody told them [its unsafe]."



### Research Engagement Strategies

- Participants had positive perceptions of research and were energized by future collaboration with researchers
- Participants preferred connecting in person or via phone initially, but were amenable to videoconferencing
- Sharing their own lived experience as a way to help other people motivated participants
- Barriers to future research engagement included mobility, transportation access, and time away from loved ones

## Participant Characteristics

N = 30

- 13 Homebound Older Adults, 17 caregivers
- 73% Female,
- 57% non-white
- 38% Medicaid beneficiaries

## Conclusions

- This work highlights research questions of interest to homebound older adults and their caregivers
- Homebound adults and caregivers are interested in engaging as research advisors through multiple platforms
- Opportunity exists to engage stakeholders as advisors to establish future research priorities
- Interview results were used to inform the development of a patient and caregiver stakeholder advisory group. This group will convene for six bicoastal meetings to develop a research agenda in the field of home-based medical care

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