

Attitudes of Homebound Older Adults and their Caregivers around Engaging in Research

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Background

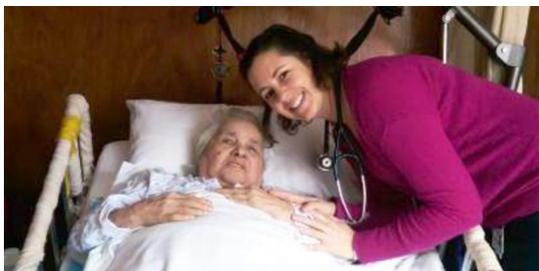
A patient and caregiver-centered research agenda for the field of home-based medical care requires incorporating the voices of homebound older adults and their caregivers. An initial step in incorporating the views of this population is to better understand their attitudes toward research.

Aim

To understand the attitudes of homebound older adults and their caregivers toward research

Methods

- We completed qualitative semi-structured interviews with homebound older adults and their caregivers recruited from home-based medical care practices at UCSF and JHU.
- Interview questions addressed opinions on research and engaging as advisors to researchers in home-based medical care.
- We identified themes using descriptive thematic analysis of transcripts.



Results

Themes

Attitudes

Most participants viewed research as:

- Important
- An opportunity to learn and share knowledge

Relevance

When asked about the impact of research:

- Many felt that research could impact people like them
- If not, most still felt research is good if it could help someone else

Roles

When given examples of ways to contribute to research as advisors:

- Most reported interest
- Some expressed fears over having the ability to contribute

“Research is very important in all areas of life“

“It would be very educational and helpful to the new caregivers coming in“

“I think it could help me better myself“

“Yes, of course“

“It sounds interesting“

“If I could be of any help, I don't mind“

“Me teaching someone else or helping them learn ways to do better at caregiving would make me feel so good“

“We need these opportunities...you know, to learn from and to teach others“

“They might not could fix me, but they can fix someone else...I would love to hear that someone else got healed“

“I'm no expert“

“I'm not a candidate for most things ...I'm not a clean slate“

“If I could get out“

“I wish I could, but I don't have the time to do it“

Participant Characteristics

N = 30

- 13 Homebound Older Adults
- 17 Caregivers
- 38% Medicaid beneficiaries
- 73% Female
- 57% Non-White



Conclusions

- A diverse group of caregivers and homebound older adults reported generally positive attitudes towards research and an openness to engaging in the development of a research agenda for home-based medical care.
- Incorporating the voice of this usually invisible population will help ensure that patient and caregiver-centered research is promoted and conducted.
- Interview results were used to inform the development of a patient and caregiver stakeholder advisory group. This group will convene for 6 meetings to develop a research agenda in the field of home-based medical care.

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