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Overcoming Reluctance to Accept Home-Based Support from an Older Adult Perspective

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OBJECTIVES: To understand older adult perceptions about accepting help at home, in particular fears related to potential loss of independence.

DESIGN: Qualitative focus groups.

SETTING: Rural, suburban, and urban areas of Fort Wayne, Indiana, and Chicago, Illinois.

PARTICIPANTS: Community-dwelling adults aged 65 and older (N=68).

MEASUREMENTS: Participants discussed decision-making, reluctance to accept home-based care, barriers, and resources that might affect remaining in the home. Three independent coders used constant comparative analysis to interpret results.

RESULTS: Analysis revealed that reluctance to accept home-based support was associated with concerns over inability to complete tasks, perceptions of being burdensome to others, lack of trust in others, and lack of control. To overcome these concerns, some participants reframed the concept of independence to be "interdependence," with people continually depending on each other throughout their lives. Subjects noted that, even if one becomes more limited over time, the recognition that one is still contributing something meaningful to society is important to overcoming refusal of home assistance. Another strategy presented to overcome negative perceptions of accepting assistance in the home was the recognition that helping someone who is in need may engender positive emotions in those providing the help.

CONCLUSION: Older adults perceived multiple reasons for refusing home-based assistance and offered potential strategies to overcome this reluctance. Addressing the reasons and promoting strategies to accept home-based support may lead older adults to have fewer unmet home-based needs, enabling them to remain safely in their homes. **J Am Geriatr Soc 66:1796–1799, 2018.**

Key words: aging in place; home-based services; older adults

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As their physical, functional, cognitive, and social needs increase, older adults may require more care in their home, which some may illogically refuse.[1–3] Healthcare providers, social workers, case managers, and family caregivers experience this refusal first hand when they see older adults struggling in their activities of daily living but repeatedly decline assistance or services, jeopardizing their safety and causing ongoing frustration. Nearly 11 million community-dwelling people in the United States needed long-term services and support to help address limitations in activities.[4–7] Prior studies, including our research, have shown that older adults underestimate the likelihood that they will need assistance in the future.[8–10] The 2012 National Health Interview survey results showed that 60% of older adults believed that they were unlikely to need long-term services and supports in the future, whereas the evidence suggests that nearly 70% of older adults will need them at some point.[11] In addition, many older adults worry about being removed from their homes and placed in nursing homes.[12–15]

We sought to understand older adults' fears related to potential loss of independence and reluctance to accept support in the home and to examine possible strategies of overcoming refusal to accept home-based support.

METHODS

Participants and Setting

Focus groups were conducted in Chicago, Illinois, and Fort Wayne, Indiana. Academic and community partners

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recruited participants using flyers, e-mail, newsletter announcements, and word of mouth. Organizations assisting in recruitment efforts included Aging & In-Home Services of Northeast Indiana; Lincoln Park Village and Skyline Village Chicago, 2 older adult community groups in Chicago, Illinois; Northwestern Medicine Geriatrics Outpatient Offices; and the University of Chicago Geriatrics Clinics. Recruitment through this range of sites allowed for participants with a wide range of socioeconomic status from rural and urban communities. Participants were English-speaking adults aged 65 and older and had adequate cognitive abilities (blind-Montreal Cognitive Assessment (MOCA)>18).[16] Recruitment continued until saturation occurred, constituting consensus of the research team that no new information was emerging in additional focus groups.[17,18]

Data Collection

Because this project was a subproject of a larger study (Advanced Planning for Home Services/ PlanYourLifespan.org), a semistructured focus group protocol was designed to elicit participants' views and experiences of their future health care options, including discussion of potential reluctance to accept help in the home.[19] The protocol also called for asking participants about concerns regarding remaining in their own homes as they aged and prompting discussion of any planned changes in their current living situation.[9] Focus group sessions began with introductions and written informed consent, which included consent for digital recording of the group. At the conclusion of the focus group, participants completed a brief sociodemographic survey and received a $50 gift card as compensation. The Northwestern University institutional review board approved the study.

Data Analysis

Digital recordings of the focus groups were transcribed verbatim, personal identifiers were removed, and transcripts were uploaded into NVivo version10 (QSR International, Doncaster, Victoria, Australia) for analysis. Three authors (KAC, LAL, VRZ) analyzed transcripts using constant comparative techniques,[17,20] independently assessing participant responses for focal themes and then convening to compare and compile findings and create a preliminary list of categories and major themes. Identified themes were discussed and refined through a series of coder meetings, during which coders triangulated their perspectives and resolved any identified discrepancies through discussion. In no cases were the coders unable to reach consensus. The coders organized the content into themes relevant to participants' discussions of reluctance in accepting home-based care. Descriptive statistics were used to analyze participant surveys.

RESULTS

Sixty-eight adults (mean age 73.8 ± 6.5) participated in 1 of 8 focus groups; focus groups ranged from 4 to 12 participants. Most (72.1%) participants were female, 30.9% were married, and 44.1% reported completing college or postgraduate education. Most focus group participants reported living in an urban setting (70.6%) in a home or apartment in the community (70.6%) (Table 1).

Table 1. Participant Characteristics (N=68)

Characteristic	Value
Age, mean±standard deviation	73.8 (6.5)
Female, %	72.1
Marital status, %	
Married	30.9
Never married	11.8
Widowed	23.5
Divorced, separated	29.4
Did not respond	4.4
Education, %	
Some high school, did not graduate	8.8
High school or GED	14.7
Some college (1–3 years)	26.5
College graduate (4 years)	19.1
Higher degree (≥5 years)	25.0
Did not respond	5.9
Employment status, %	
Retired	83.8
Working	4.4
Unemployed, looking for work	2.9
Other	4.4
Did not respond	4.4
Current residence, %	
Home in community (apartment, house, condo)	70.6
Retirement community (independent living)	8.8
Other	16.2
Did not respond	4.4
Area of residence, %	
Urban	70.6
Suburban	17.6
Rural	5.9
Did not respond	5.9

Reluctance to Accept Home-Based Support

In response to open-ended questions about losing independence, with follow-up probes including a brief story of an older adult who needed but resisted accepting home-based support, many older adults stated that they had personal experiences with or had acquaintances or family who had had home-based care. Four overarching themes emerged describing reluctance to accept help.

Inability to Do Tasks

Participants reported feeling fearful when asking for help because they perceived it meant that they were no longer able to do a task—tasks that many felt were basic (e.g., driving a car) and should be part of their adult skill set.

> *"I think one of the difficulties is when you're asking for help, you're kind of looking in the mirror and saying, 'I can't do this anymore,' and I think that's a hard thing to get over."*

Burden on Others

Participants also discussed their feelings that asking for or receiving help from others connoted that they would be a burden on loved ones.

> *"I don't want to be a hinder. I don't want to stop their living. Because I have enjoyed my life, and I want them to enjoy their life."*
>
> *"I think that's the part that bothers me the most, that I cannot be that independent, that I may have to call my daughter to do this while I don't want her to take her time when she needs free time also, and I can't call my son because he may be working, and that annoys me. Not that they wouldn't want to do it, but that I have to degrade myself to ask, so I have to learn to accept that."*

Lack of Trust

Consideration of home-based care led to concern of some participants, who voiced worries that they could be taken advantage of as an older adult.

> *"At times, it seems like trying to get across a mine field avoiding exploitation from caregivers, from relatives and it is very disconcerting. Who can you trust?"*

Loss of Control

Participants also voiced apprehension relevant to losing control, noting that, when asking others to assist or complete a task one has formerly done independently, one must accept that others now control the situation.

> *"I had to depend on friends and neighbors to fix food or shop or do anything, and I thought, I don't want to be in that position."*
>
> *"You want to have power over yourself. Not someone else have power."*

Overcoming Refusal to Accept Home-Based Help

After identifying these reasons for being reluctant to accept home-based help, participants discussed ways of overcoming such reluctance. Such strategies included reframing independence, contributing to others, and overcoming the initial ask.

Strategy #1: Reframing Independence

Participants often expressed how "being independent" connoted the essence of being an adult and was seen as part of their identity. Discussion led to the suggestion that older adults consider reframing the idea of "independence" because most humans are interdependent, from birth to death.

> *"I have a problem with the word independence… we're always dependent in certain ways. As we move through this growing old…get it to a point where we understand dependent is a fine thing."*
>
> *"I prefer interdependence because I think, from the time we're born until the time we die, everybody gives something even if they're in…a state where they can't do as much."*

Strategy #2: Contributing to Others

Participants stated that, by accepting help, they were in turn helping the person providing the help. Thus, accepting help was actually contributing to others and provided the opportunity for positive effects on the care receiver and caregiver. Because many of the older adult participants had helped others in their lifetimes and had experienced joy and satisfaction in helping, they noted the dual aspect of contributing to others. Caregivers and those who help might receive joy and satisfaction in the act of giving help. Therefore, they should accept help to contribute to the well-being of the helper.

> *"When I'm on the receiving end, I've got to remember that that's giving somebody else some joy."*
>
> *"I think we forget what the other person is contributing… the person who is able to see his grandchildren to smile at them; I mean he's giving them something as well."*

Strategy #3: Overcoming the Initial Ask

A common theme among the participants was conquering the "first time I asked for help" concept. Much like the first time participating in any activity (e.g., riding a bicycle, asking for a dance), there is a degree of trepidation as to what will happen. There are also stated concerns about rejection or what the other will think of the requestor. After older adults initially asked for help, they reported finding it easier to ask again.

> *"Many of us grew up, you had no idea how hard it was to get anybody to ask for anything. It was really tough. Now that's changing, and I think the more we get used to and comfortable asking for help and understanding that help is a two-way street. It really, really is."*

DISCUSSION

Most geriatricians, healthcare providers, social workers, and nurses have had experience with an older adult refusing home-based assistance. For many older adults who have increasing and unmet home-based needs, reluctance to accept help may lead to an unsafe living situation. To our knowledge, our study is the first to explore older adults' refusal to accept home-based help and their own strategies to overcome such fears in relation to home-based needs. This person-centeredness provides a unique perspective on such strategies.

In our sample, older adults discussed multiple reasons for their reluctance to accept home-based help, including fear of asking for help, guilt of being a burden on others (particularly one's offspring), lack of trust, and feelings of loss of control. Several participants discussed strategies that they felt could be used to overcome such reluctance, including reframing the concept of independence as interdependence, focusing on their own contributions to others, and sharing their experiences in asking for help to make the initial ask. These results could affect clinical practice, because they provide healthcare providers with a way to overcome this resistance. Clinicians can focus on the contributions of helping one another or how people of all ages depend on one another. These strategies are fairly easy to attempt, have the potential to be effective, and

could be generalized in multiple healthcare settings, including home visits.

Next steps of this research include leveraging these strategies to develop further negotiating and conflict resolution education for healthcare providers and loved ones to reduce the unmet home-based needs of older adults. In response to the focus groups, we created an online tool, PlanYourLifespan.org, to support older adults and caregivers in communicating and planning for their home-based health needs in the event of a health crisis.[21] PlanYourLifespan.org also informs older adults about resources available locally and nationally that can assist when a health crisis occurs. Tools such as this may help older adults overcome reluctance to accept help as they become more informed about resources and assistance available to them, potentially allowing them to maintain independence in their own home for longer.

A strength of this research was the person-centeredness and engagement. Community-based stakeholder partners recruited participants, which meant that our sample was representative of people in the community and included many who had never previously participated in research. Older adults spoke out about their reluctance to accept help at home and provided strategies to overcome such reluctance. The large number of women who participated in the focus groups limited the generalizability of this study, and although participants were diverse in terms of urban and rural locations, all of the sites were in the Midwest.

In conclusion, this is the first study to identify reasons for refusal to ask for home-based care and offer potential strategies to overcome such reluctance. Ultimately, our goal is for older adults to remain in their own homes as long as safely possible and feel comfortable asking for and accepting needed assistance to allow them to age in place successfully.

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