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“A Home-Based Care Research Agenda by and for Homebound Older Adults and Caregivers”

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Abstract

BACKGROUND / OBJECTIVES: Homebound older adults have not had voice in establishing a research agenda relevant to their needs and perspectives. We aimed to engage them and develop a patient and caregiver-centered research agenda for home-based care.

DESIGN: Homebound older adults receiving home-based primary care and caregivers were engaged to serve as Stakeholder Advisors to develop a patient and caregiver-centered research agenda for home-based care. Over 9 months, we facilitated 8 tablet-enabled videoconference meetings with Advisors. We oriented Advisors to the nature of scientific research and research question development. Advisors then developed and prioritized a list of research domains and questions for home-based care

SETTING: Home-based primary care

PARTICIPANTS: 4 homebound older adults receiving home-based primary care and 4 caregivers from Baltimore, MD and San Francisco, CA

INTERVENTION: Recruitment, engagement, and training of Stakeholder Advisors in patient-centered outcomes research

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Portions of this work were presented at the American Geriatrics Society 2019 meeting and the American Academy of Home Care Medicine meetings in 2018, 2019, and 2020.

MEASUREMENTS: Development of research domains and questions for a patient and caregiver-centered research agenda

RESULTS: Advisors (50% black, 88% female) understood and participated in the requested tasks. Advisors developed a list of 14 research domains and 127 associated research questions. The research domains (number of associated research questions), were: access to home-based care and related policy issues(19), relationship with doctors(15), quality of nursing homes(14), understanding patient and caregiver needs and well-being(13), out of pocket costs of caregiving(10), issues regarding paid caregivers(9), specialist care in the home(8), getting to know patients and caregivers as individuals(7), dementia(7), challenges of receiving care outside the home(6), technology in the home(6), communication(5), home as a therapeutic place(4), delivery services(4).

CONCLUSION: Using videoconferencing technology, homebound older adults and their caregivers can be engaged as Advisors to inform a patient and caregiver-centered research agenda for home-based care that spanned multiple domains.

Keywords

home-based primary care; home-based care; patient-centered outcomes research; research agenda; caregivers

Introduction

Two million older adults in the U.S. are completely or mostly homebound. Another 5.3 million have difficulty or need assistance to get out of their homes (Ornstein et al., 2015). The homebound live with multiple chronic conditions and functional impairment, and have difficulty accessing traditional office-based care. Despite being a high-need, high-cost population, they are often invisible (Ritchie et al., 2018) to health systems because they are difficult to identify.

The care of homebound older adults and the delivery of home-based care (Harris-Kojetin et al., 2014) are attracting the interest and attention of the research community in the wake of studies demonstrating the benefits of home- and community-focused delivery models (LaFave et al., 2020). Such models include home-based primary care (HBPC; Stall et al., 2014; Totten et al., 2016), home-based palliative care (Cassel et al., 2016), Community Aging in Place Advancing Better Life for Elders (CAPABLE; Szanton et al., 2019), home-delivered meals (Morris et al., 2019), home- and community- based services (Valluru et al., 2019), and others. This emerging research finds that such models can improve outcomes and lower health care costs for this population with preventable health care costs (Figueroa et al., 2017).

In recent years, patients and other key healthcare stakeholders have become increasingly engaged in the planning and conduct of research. The Patient-Centered Outcomes Research Institute (PCORI, 2020) has helped to accelerate such stakeholder engagement in research. Because the homebound are generally older, frail, and isolated, they have not been engaged in, nor have they had a voice in, patient-centered outcomes research (PCOR) or in establishing research priorities relevant to their needs and perspectives. Our aim was to

engage homebound older adults and their caregivers to develop a patient- and caregiver-centered research agenda relevant to their needs and perspectives.

Methods

Development of Strategies to Engage Future Stakeholder Advisors

We conducted preparatory qualitative research to investigate (a) the experience of being homebound or providing care to a homebound individual (Eaton England et al., 2020), (b) the experience of receiving HBPC (Shafir et al., 2016), and (c) patient and caregiver preferences on engagement approaches as potential stakeholder advisors to researchers in the field of home-based care (Mickler et al., 2019).

Recruitment of Stakeholder Advisors

We recruited eight Stakeholder Advisory Board (SAB) members, four from each of the HBPC practices of the two participating institutions; four of these eight SAB members (two from each participating institution) also participated in the preliminary qualitative work. The SAB comprised four patients and four caregivers, and insofar as was possible with a small group, attempts were made to recruit individuals with different sociodemographic characteristics.

Engagement Strategy

Preparatory qualitative work suggested that phone was the preferred method of communication for homebound older adults, but also revealed a willingness to try videoconferencing using tablet devices. After reviewing multiple tablet computer options in terms of cost, data plans, ease of use for older adults with limited previous exposure to technology, data security, and ability to host a videoconference, we elected to use GrandPad® (2020) tablet devices. GrandPads are android-based tablets specifically designed for older adults who otherwise may have difficulty with traditional technology built for younger adults.

Engagement, Training, and Work of Stakeholder Advisors

We conducted eight, approximately monthly, 1-hr SAB meetings via GrandPad tablets (Perissinotto et al., 2019) with Zoom videoconferencing capability at each study site. SAB members received 1-hr in-person training on the operation of the GrandPad prior to the first meeting. Parallel SAB meetings were held at each site using the same presentations to guide discussions. Parallel meetings were conducted to ensure that meetings were a suitable size to be certain that all SAB members could engage in discussion and to accommodate time differences between study sites. Each meeting was attended by up to four SAB members and two to three members of the research team from each site.

A lead facilitator participated in all of the meetings across both sites. Each SAB meeting started with an “ice-breaker” question to ease the group into discussion. The facilitator was experienced in focus group methodology and made efforts to elicit feedback and perspectives of all SAB participants. The goals of each meeting were articulated at the outset of each meeting. The facilitator fostered discussions that sought to understand differences

and similarities across participants' experience and perspectives. Research team members took notes during and after the SAB meetings to refine the approach and content of subsequent meetings.

Figure 1 depicts the PCOR-focused curriculum and tasks covered in each of the SAB meetings. In brief, in the early meetings, SAB members were asked to consider issues that they felt were not well understood about their own or their loved one's needs, which led to discussions of research domains and the development of research questions. SAB members prioritized domain importance for researchers to study. We mailed SAB members the list of research domains they developed with written instructions to rank the domains in order from the most to the least important for researchers to address. The mailing was followed up by a telephone call from a research assistant to ensure that SAB members understood and could complete the prioritization process. At a final meeting, the SAB members from both sites were convened in a single meeting for joint open discussion and to reflect on their experience of being an SAB member and their involvement in this project.

Assessment of SAB Member Satisfaction with Video Teleconferencing Technology

In a telephone interview 1 month after all SAB meetings were completed, SAB members were surveyed and asked to rate their satisfaction with and ease of using the Grandpad® device and associated videoconferencing technology on a 1–5 Likert scale (*strongly disagree, disagree, neutral, agree, strongly agree*).

Results

SAB Member Characteristics

The eight SAB members consisted of 4 homebound older adult patients who received HBPC and four caregivers of homebound older adults who received HBPC. About 88% of the SAB members were female, 50% were Black/African American, and ages ranged from 66 to 87 years for the patients and 58 to 74 years for the caregivers. All patients were insured by Medicare, and two were eligible for Medicare and Medicaid insurance programs (dual-eligible); caregivers were all Medicare beneficiaries with private secondary payers. All SAB members had high school education or greater, and seven of eight SAB members reported mid- or high-socioeconomic status. In terms of difficulty with daily tasks, all patients reported some or much difficulty with eating, dressing, bathing, walking indoors and transfers (including two SAB members who were bedbound), and three of four reported used a walking aid. All caregivers were fully functional except for one who had some difficulty walking indoors. All of the homebound patients described their general health as either fair or good. Of the four caregivers, one reported excellent, two reported good, and one described being in fair health. All the patients had been homebound for at least 3 years. In terms of life space in the last 3 days, all patient advisors reported moving beyond the room in which they sleep but none had gone outside their home. All caregivers had left the home and traveled to places outside their immediate neighborhood.

SAB Meetings

SAB members developed ground rules to guide the conduct of their meetings. Ice-breaker questions facilitated the sharing of personal stories. Examples of ice-breaker questions include “Tell us something about your name” and “Tell us about yourself and some of the important people in your life.” Discussions often led SAB members to reflect on what was challenging about their own experiences. They frequently provided encouragement and support to one another.

List of Research Domains and Research Questions

The SAB members developed a patient- and caregiver-centered research agenda consisting of 14 research domains and 127 associated research questions. Table 1 lists in descending order of importance as ranked by the SAB members: (a) the research domains; (b) the total number of associated research questions generated by SAB members for each domain; and (c) two sample research questions related to that domain. Research questions developed by the SAB members were minimally edited by the research team for clarity and then approved by the SAB members. The full list of research questions is available in Online Appendix 1.

The 14 research domains fall into several key general categories. Access to services to facilitate and maximize care and quality of care received at home and their associated costs spanned several specific research domains, including out-of-pocket costs for caregivers and associated resources, access to long-term social supports, specialist care in the home, paid caregivers, and other services. Other domains focus on issues related to interpersonal relationships and communication between patients, caregivers, and care providers of various types. Dementia emerged as the only specific chronic illness that SAB members addressed.

Prioritization of Research Domains by SAB Members

In discussions regarding the prioritization of the research domains, SAB members expressed their view that all the domains were important and that research in all 14 areas was needed. In formal rankings of the 14 research domains, the following were ranked among the top 3 most important domains by all the SAB members and never appeared among the least important 3 domains in the rankings of any of the SAB members: out-of-pocket costs of caregiving, access to home-based care and related policy issues, and relationships with doctors.

Videoconferencing Technology

It took approximately 10–12 minutes and some ongoing coaching at the start of each SAB meeting to get the televideoconferencing fully functional for all SAB members. The swiping function on the Grandpad was sometimes challenging to use. In formal ratings of the videoconferencing technology, seven of eight SAB members completed the telephone survey. Five of six SAB members strongly agreed or agreed and one disagreed that the Grandpad and videoconferencing technology was easy to use. Six SAB members strongly agreed or agreed and one was neutral that they were satisfied with the videoconference meetings using the Grandpad.

Discussion

Research focused on homebound older adults and their caregivers has been researcher-driven, rather than patient- and caregiver-driven. Prior work suggests that patient perspectives are valuable in driving research towards areas that are more meaningful to patients than those conceived by researchers alone (Vaida, 2016). Engaging a socially isolated and functionally-limited population such as the homebound poses additional challenges to developing patient-driven research. In prior work, frail older adults who attended a senior daycare center were engaged as advisors to researchers (Eisenstein & Berman, 2018). However, to our knowledge, ours is the first work to partner with homebound individuals as Stakeholder Advisors using videoconferencing technology. Our SAB members could be trained to understand PCOR constructs and were able to generate and prioritize a robust set of domains and research questions to advance research relevant to them and the field of home-based care.

SAB members generated 14 distinct research domains they thought worthy of investigation by researchers. The research domains emanated from their own life experiences and shared stories. They focused on areas related to care of various types: primary and specialty care, formal caregivers, care services delivered to the home, issues related to communication and being understood by providers and the health care system, and the home as a setting for the delivery of care.

Several research domains identified by SAB members focus on access to services to facilitate and maximize care and quality of care received at home and their associated costs. These services span from long-term social support services to medical care. This likely reflects gaps in care experienced in a delivery system in which social supports and medical care remain fragmented in terms of how they are (or are not) provided and how they are (or are not) covered by health insurance. In addition, several research domains and associated questions focused on communication issues and the generative desire of SAB members to develop methods to educate health care providers in those areas.

None of the SAB members had a diagnosis of dementia. However, dementia was the only specific medical condition identified by the SAB members. This may relate to the high prevalence of this condition among homebound older adults, in general, and the impact it has on caregivers. All advisors expressed fear about their vulnerability during transitions of care, such as hospitalizations or short stays in skilled nursing facility.

SAB members prioritized the importance of the research domains they identified. During the prioritization exercises, SAB members expressed their view that all the domains were important and that research in all 14 areas was needed. In the formal ranking exercise, there was general agreement that the important domains for research were the out-of-pocket costs of caregiving, access to HBPC and related policy issues, and the relationship between patients/caregivers and providers. These areas are compatible with prior research on high-quality home-based medical care (Ritchie et al., 2018; Shafir et al., 2016).

A number of questions developed by the SAB members relate to the understanding of best practices in areas such as resources for caregivers, caregiver well-being, the training

and education of physicians in skills such as communication and the care of people living with dementia. Clearly, some of these areas have been addressed in prior research. It is not surprising that such information was not known to our SAB members. This knowledge gap does highlight the need to develop approaches to disseminate more widely useful and important information that is already available to appropriate audiences, especially lay audiences.

In the preparatory work for the SAB, most did not express high levels of enthusiasm to the use of tablet-based video teleconferencing approaches, but voiced preference for the telephone. Given the logistic challenges of bringing functionally impaired SAB members to a single physical location for meetings, and our desire to maximize engagement and interaction with and between them, we used the videoconferencing approach. This proved feasible and maximized recruitment, sampling, and inclusion opportunities. The research team was able to help SAB members use and enjoy using such technology (Harrison et al., 2021). Although our sample was limited and may not be generalizable, this should provide assurance to a range of stakeholders in health care regarding the use of technology by frail older adults.

An unexpected, but welcomed, outcome of the SAB meetings was the self-reported “therapeutic” benefit of participation experienced by the SAB members. The SAB members assigned high value to having the opportunity to describe their experiences with others who shared similar lived experiences and in being able to contribute to work that could advance research in a field that is relevant to them (Sheehan et al., 2020).

Conclusion and Implications

We engaged a group of homebound older adults receiving HBPC and caregivers using videoconferencing technology, trained them in issues related to PCOR, and facilitated the development of a patient- and caregiver-centered research agenda for the field of home-based care. Domains related to access, cost, and aspects of communication were highly prioritized. We are working to translate this research agenda into practice through various mechanisms. This research can help guide the private- and public-sector, payors and health systems to ensure that the priorities of this population are incorporated into research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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The sponsor had no role in the design, methods, subject recruitment, data collection, analysis or preparation of paper.

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Impact Statement:

We certify that this work is novel. No study to date has specifically characterized the perspectives of homebound persons and their caregivers regarding priorities for future research related to homebound populations.

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SAB Meeting Content and Tasks	SAB Meeting Number							
	1	2	3	4	5	6	7	8
Welcome and introductions / Ice-breaker question / review purpose and goals of project								
SAB administration – review of meeting ground rules, development of group charter, group naming								
Training of SAB members								
Generate list of research domains								
Generate research questions								
Prioritization of research domains								
Open discussion of all SAB members from Baltimore and San Francisco								

Figure 1 –.
SAB Meeting Content and Tasks

Table 1:

Prioritized list of research domains and sample research questions generated by SAB members

Domain (Number of Research Questions Generated)	Sample questions
Out-of-pocket costs of caregiving (10)	What are the effects on caregivers who are burdened by out-of-pocket costs? What are the best processes/practices for caregivers to learn about resources that are available to assist with out-of-pocket costs of caregiving?
Access to home-based care and related policy issues (19)	What are the changes needed in the system to get more social services/assistance covered under medical / health insurance? What are the policies that make life most difficult for homebound people and their families?
Relationship with doctors (15)	How can a patient get the provider they want as they transition to home-based care? What makes for a good relationship between a homebound patient and the doctor?
Getting to know patients and caregivers as individuals (7)	What is the process to make sure providers know what medications the patient is taking? What activities/ programs improve quality of life for patients (e.g. reading to patients, canine therapy)?
Understanding patient and caregiver needs and well-being (13)	What gets in the way of caregivers reaching out for help? What happens to caregivers when they can't get the help they need? What are the best resources for caregivers to learn about trustworthy volunteer organizations or programs that provide respite care?
Specialist care in the home (8)	What are the best processes to access specialist care at home? What are the best ways to create a master booklet with lists of services and contact information for these services at home?
Challenges of receiving care outside the home (6)	How do out-of-home appointments affect home-bound patients and caregivers physically? What are the best ways to minimize the number of out-of-home appointments?
Communication (5)	How to improve communication between patients, caregivers and the home-based care team and others involved in the care of the patient – nurses, aides, providers etc.? What are the best ways to teach providers to communicate information clearly to patients and caregivers without using medical jargon?
Issues regarding paid caregivers (9)	What is the best process for vetting paid caregivers (i.e., background and employment check) and how much should caregivers be paid? What are the ways to improve relationships between family caregivers and paid caregivers?
Home as a therapeutic place (4)	Does living at home help a patient to be healthier? What are the benefits of living at home for a home-bound patient?
Quality of nursing homes (14)	What is the impact of having family advocates when a patient is in a nursing home? How can people be less vulnerable to poor care in nursing homes?
Technology in the home (6)	What is the cost for new technologies available to homebound patients and who would pay for it? How can the health system ensure that homebound patients receiving care at home have access to the appropriate technology?
Dementia (7)	What are the best ways to approach patients with neurological disorders (including dementia) receiving home-based care? What are the best ways to educate providers and caregivers on the various stages and risks associated with dementia?
Delivery services (4)	How can homebound patients learn about supportive services like delivery? What kind of delivery services are covered under different insurance plans?