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Understanding the Daily Experiences and Perceptions of Homebound Older Adults and Their Caregivers: A Qualitative Study

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Abstract

More than 7.3 million older adults in the United States have difficulty leaving their homes or are completely homebound, yet little data exist on the experiences of homebound older adults and their caregivers. We conducted 30 semi-structured qualitative interviews with homebound older adults and caregivers recruited through home-based medical care practices in Baltimore and San Francisco. Thematic template analyses revealed that homebound older adults experience varying degrees of independence in activities of daily living, although their degree of dependence increases over time. Caregivers have a multifaceted, round-the-clock role. Both patients and caregivers experience burdens including social isolation and guilt. Navigating medical care and caregiving was further complicated by the complexity of the U.S. health care system; however, home-based medical care was viewed as a high-quality alternative to hospitals or nursing homes. Our findings suggest that providers and health care systems should expand the availability and accessibility of home-based care and improve caregiver support opportunities.

Keywords

caregiving; qualitative research; homebound; home-based primary care

Introduction

More than 2 million older adults in the United States are unable to leave their homes and another 5.3 million have difficulty or need assistance (Ornstein et al., 2015). These numbers are expected to grow substantially over the next 10 years (Qiu et al., 2010). Homebound older adults experience a combination of multiple chronic conditions, frailty, functional

impairment, and limited social capital (Fulmer, 2017; Qiu et al., 2010). Many of these individuals have limited or no access to adequate office-based primary care due to their inability to leave the home. Consequently, homebound older adults often receive inadequate or disjointed care, including a high utilization of emergency departments and hospitals (Fulmer, 2017; Ritchie & Leff, 2016). Home-based medical care (HBMC), where medical providers attend to patients at their place of residence, can partially alleviate this fragmented care by providing comprehensive longitudinal primary and palliative care services at home (Decherrie et al., 2012; Norman et al., 2018). However, only 11.9% of homebound older adults in the United States have access to HBMC (Ornstein et al., 2015).

Most older adults wish to “age in place” and stay in their homes, which often requires the support of family members or other unpaid caregivers (AARP, 2018). In the United States, approximately one quarter of adults provide unpaid care to another adult family member, of whom the majority (79%) care specifically for older adults (Wilkins et al., 2009). Caregivers provide essential health care management and daily social and emotional support to homebound individuals (Wilkins et al., 2009). When compared with caregivers who do not provide any health care support, caregivers providing substantial help with health care are significantly more likely to experience emotional, physical, and financial difficulties (Wolff et al., 2016). These may include restricted participation in their own valued daily activities and decreased work productivity (Wilkins et al., 2009; Wolff et al., 2016).

HBMC provides the opportunity for clinicians to evaluate a patient’s individual home and social environment, including the availability and capacity of caregivers (Norman et al., 2018; Ritchie & Leff, 2016). However, homebound older adults and their caregivers remain a largely overlooked population in medical research, having limited opportunity to provide input on research priorities relevant to their unique clinical care and daily needs (Crawford Shearer et al., 2010). Research engagement strategies, such as those supported by the Patient-Centered Outcomes Research Institute (PCORI), leverage the daily experiences and expertise of patients and other caregiver stakeholders to ensure that health care research is patient-centered, relevant, and pertinent (Fleurence et al., 2013; PCORI, 2018). As the proportion of aging adults rises, so will the demand for HBMC, particularly among Medicare beneficiaries (Yao et al., 2018; Schuchman et al., 2018). Therefore, it is critical that research efforts align with the needs and priorities of both clinician-researchers and patient and caregiver stakeholders.

Prior research on HBMC has highlighted the challenges faced by caregivers of patients with dementia and emphasized the importance of developing relevant frameworks, quality indicators, and outcome measures to promote the further development of patient-centered research agendas (Van Kempen et al., 2012). Whereas patient or caregiver input has been sought regarding perceptions of HBMC quality (Cheng et al., 2020; Shafir et al., 2016; Van Kempen et al., 2012), no studies, to our knowledge, have investigated both caregiver and patient perspectives on how being homebound, caregiving, and receiving HBMC interplay into the day-to-day lives of American HBMC beneficiaries. To inform future research and policies needed to support improvements in HBMC delivery, it is necessary to gain a more

in-depth understanding of the daily life and perspectives of homebound older adults and their caregivers.

Given that little research has focused on the daily experiences of this population, the aim of this study was to explore the nuances of the daily experiences and perceptions of homebound older adults and caregivers. This study represents the first step of a larger PCORI project, which culminated in the development of a research agenda by and for homebound older adults and their caregivers (Eaton England et al., 2020; Sheehan et al., 2020).

Methods

Participant Selection and Setting

We recruited homebound older adults and caregivers from two HBMC practices in Baltimore, Maryland and San Francisco, California. Homebound older adults were eligible to participate if they were (a) 65 years or older, (b) never or rarely leave their homes (Ornstein et al., 2015), and (c) receive care from an HBMC practice. Caregivers were eligible to participate if they were (a) at least 18 years old, and (b) responsible for routinely providing unpaid care to an older adult or family member who received HBMC from either practice. Additional criteria for both homebound older adults and caregivers included (a) residing within 1-hr drive time, (b) English-speaking, and (c) cognitively able to consent for themselves and fully participate in the interview.

Clinical staff from both HBMC practices identified eligible homebound patients and caregivers. All eligible individuals were called or mailed a letter introducing the study. Potential participants who did not opt out of contact were screened over the phone to confirm interest and eligibility prior to enrollment. To represent the perspectives of a diverse group of caregivers and homebound older adults, we aimed to recruit sample reflecting the following targets: Medicaid recipients, as a proxy measure of being less well-resourced (50%), non- White people of color (20%), caregivers of patients with dementia or severe cognitive impairment (30%), and home- bound older adults who live alone (30%). These targets reflect established U.S. demographic characteristics of older adults and their caregivers, as well as the clinical experience of the research team (Ornstein et al., 2017; Smith et al., 2006; Wolff et al., 2018). Recruitment continued until we reached these targets and observed thematic saturation across interview domains. All participants signed an informed consent form prior to participation. This study was approved by Johns Hopkins University (JHU; IRB No.: 00162052) and University of California San Francisco (UCSF; IRB No.: 18-24302).

Data Collection

We conducted semi-structured qualitative interviews to better understand the daily activities, needs, and perceptions of homebound older adults receiving HBMC and the caregivers of homebound individuals. All interviews were conducted between April and October 2018 at participant's homes, over the phone, or, for some caregivers, at the research facilities in Baltimore and San Francisco.

The interview questions relevant to this article focused on the individual's experiences and perceptions of being homebound or providing care to a homebound individual. The questions prompted interviewees to describe a typical day and how they spend their time. All participants were asked about their own health conditions, personal needs, challenges they face related to the nature of homebound care, and where and how they could access additional support if needed. Homebound older adults were asked to describe health factors affecting their homebound state, activities they do independently versus those that required assistance, and how they accessed additional care or assistance when needed. Caregivers were asked about their relationship with the homebound patient, daily activities they

All interviews were audio-recorded and transcribed verbatim. Identifying information was redacted and each transcript was reviewed for accuracy and completeness by authors A.K.M. and A.E.E. Where necessary, A.K.M. and A.E.E. listened to the audio recording alongside the transcribed interview to review and correct any inaccuracies. After conducting each interview, both authors wrote analytic memos summarizing their general reflections, verbal and nonverbal data (such as key ideas and interactions), and observations on the context of the interview, including the physical environment. These memos also aided in the data analysis by promoting reflexivity throughout data collection (Scott, 1997).

Data Analysis

We utilized a thematic template analysis approach to develop both inductive and deductive codes concurrently with data collection (Brooks et al., 2015; Fereday & Muir-Cochrane, 2006; Hashimov, 2015). Authors A.K.M. and A.E.E. began with an open coding structure, whereby each author independently reviewed analytic memos alongside the first five transcripts. For example, we used deductive codes such as "Patient Daily Activities" to identify broad a priori concepts of interest and developed inductive codes such as "Physical Facilitators" and "Independent Activities" to further identify themes and subthemes emerging from the data through comparisons within and across transcripts (Brooks et al., 2015; Fereday & Muir-Cochrane, 2006). This hybrid analytic approach, which combines content analysis and grounded theory, was appropriate given that although similar qualitative work has explored patient's perceptions of HBMC specifically, limited information exists on the broader day-to-day experiences and perceptions of HBMC among both home-bound older adults and their caregivers (Cheng et al., 2020; King, 1998; Shafir et al., 2016; Wool et al., 2019). Furthermore, this approach allows researchers to observe themes emerging from the data (i.e., inductive reasoning) while also approaching the data with preformed hypotheses (i.e., deductive reasoning; Kavalieratos et al., 2017; King, 1998).

To establish inter-coder agreement, A.K.M. and A.E.E. double-coded the first five interviews and met regularly to review each transcript code by code, noting discrepancies and coming to consensus on either how to apply the code or modify the code definition. Drawing upon the constant comparative technique and to enable confirmability and reflexivity, both coders maintained a logbook of discussions and decisions about coding applications, including refining code definitions and revising the organization of themes and subthemes as new themes emerged throughout subsequent interviews (Hashimov, 2015). Prior to finalizing the codebook, the entire authorship team reviewed the codebook and provided feedback

on all code definitions. Four of the coauthors (O.C.S., K.L.H., B.L., and C.S.R.) also independently tested the codebook on a transcript.

Authors A.K.M. and A.E.E. applied the finalized codes across all interviews, with each author coding an equal number of transcripts from each study site. In total, one third of the transcripts were double-coded and cross-examined in-depth, using the constant comparative technique to ensure inter-coder agreement (Hashimov, 2015; Kavalieratos et al., 2017). In cases where there were any inconsistencies or different interpretations of coding applications utilizing the finalized codebook, authors O.C.S. and K.L.H. were available for input and to review and confirm the appropriate code application. The qualitative data analysis software, ATLAS.ti version 7 (Muhr, 2016), was used to apply codes and organize all transcripts and memos.

Results

Participant Characteristics

Thirty participants (13 homebound older adults and 17 caregivers) were interviewed: 16 were from Baltimore and 14 were from San Francisco, 73% of all interviewees were female, 57% were non-White, and 38% were Medicaid beneficiaries. In some cases, homebound older adults and caregivers from the same household participated. For these eight individuals, interviews were conducted separately and all data were analyzed independently. Additional descriptive characteristics of the study sample are presented in Table 1.

Among the 13 homebound older adults interviewed, 92% were female, 84% lived in a private residence, 8% lived in an assisted living or continuing care retirement community, and 8% lived in subsidized housing arrangement. Less than half (46%) of all homebound older adults lived alone. When asked about their current health conditions, homebound older adults self-reported an average of four chronic conditions, with hypertension (92%) and arthritis (62%) as the most common. More than half (61%) of homebound older adults rated their overall health as either “fair” or “poor.”

Among the 17 caregivers, 59% were female, 59% cared for someone with dementia, and 70% provided full-time care. Less than half (47%) of caregivers were the adult children of homebound patients and 35% were the homebound patient’s spouse. When asked about their own health conditions, caregivers reported experiencing an average of three chronic conditions; the most commonly reported conditions were arthritis (41%) and anxiety (35%).

Three major themes emerged as both homebound patients and their caregivers described their daily experiences and perceptions of their role as either an HBMC recipient or caregiver: (a) assistance and functional impairment, (b) experiences with receiving or providing care, and (c) interactions with the health care system. Within each theme, multiple subthemes emerged and are expanded upon in the narrative. Illustrative quotes for each theme and subtheme are outlined in Table 2.

Theme 1: Assistance and Functional Impairment

Functional Independence and Dependence: Despite some limitations, many homebound individuals described independently feeding themselves, taking medications, and reading or listening to the news. The majority of homebound participants managed their own finances, enjoyed reading or completing crossword puzzles, and engaged in other relatively stationary? activities like watching television, writing cards, or calling friends and loved ones. In some cases, homebound older adults were able to take care of their basic hygiene needs, but needed additional assistance with bathing, toileting, or changing clothes.

Conversely, almost all participants explained that any activities requiring them to walk or transfer positions necessitated additional assistance from their caregivers. For most participants, their degree of dependence for these tasks has increased over time. Homebound older adults described using assistive devices such as walkers and canes, as well as physical modifications or installations in their home to help them complete their daily tasks.

Homebound older adults also described relying on caregivers and other services for assistance with picking up medications, managing medical appointments and transportation, and shopping for groceries. Participants described how household delivery services often provide significant support in their ability to function day-to-day. However, these services impart additional costs and the burden of having to pick up packages with limited-to-no mobility.

Assistance Provided by Caregivers: Caregivers detailed a multi-faceted role that often entailed round-the-clock duties. Most caregivers described assisting with meal preparation, bathing, toileting, managing medication and other health care related tasks, and facilitating transfers. In between these caretaking activities, caregivers navigate managing household duties like grocery shopping, cleaning, and caring for additional dependent family members.

Caregivers also described providing basic clinical care such as managing wounds, bedsores, and oral hygiene, facilitating physical therapy exercises, and monitoring health conditions including basic suctioning, breathing treatments, and checking blood sugar levels. Many caregivers also rely on other family members or friends as sources of caregiving support. These family and friends comprise a complex and dynamic network of caretakers, often managing household cleaning, transportation, and providing respite care for the primary caregivers.

While the majority of caregivers tended to rely on these familial networks, caregivers of patients with more severe physical limitations hired additional paid assistance for help with bathing and changing services, particularly when the primary caregiver was a family member of a different sex or older age.

Theme 2: Experiences with Receiving and Providing Care

Burdens of Caregiving: Both homebound patients and caregivers expressed a high degree of concern about the burden of receiving and providing full-time care, respectively. Patients frequently felt guilty about the demands of full-time care on their loved ones, who are often providing care to other dependents.

Caregivers commonly mentioned their own health conditions as major challenges to providing care for their loved ones. In some cases, caregivers sacrificed their own health and self-care in order to provide for their loved ones, typically due to situations with significant financial or logistical barriers. In addition, many caregivers expressed concern about their own old age as a significant drawback in their ability to provide full-time care.

Coping with change: Navigating the challenges associated with changes in roles, routines, and hobbies was frequently a source of anguish for both patients and caregivers. Some participants described developing coping mechanisms, while others explained that they have to actively work on changing their outlook on their situation.

Social Effects of Receiving and Providing Care: Both homebound older adults and caregivers often became emotional when describing feelings of isolation, loneliness, and occasionally, depression. These feelings tended to stem from sadness about their previous abilities and current health conditions, as well as the solitude imparted by their homebound state or after the death of a loved one.

All caregivers reflected on how the obligation of full-time caregiving requires them to make many sacrifices, including their personal time, hobbies, routines, and self-care. Many caregivers stressed the need for time away from their caretaking responsibilities for their own mental and physical health, though most caregivers stated that this need often goes unfulfilled. In some cases, going to another workplace or fulfilling other personal obligations was viewed as a source of freedom from caregiving responsibilities.

Theme 3: Interactions with the Healthcare System

Costs and Qualifying for Assistance: A prevalent theme among homebound individuals and caregivers was the challenge of navigating health care costs, including barriers to purchasing necessary medical supplies and equipment. Many participants have paid large out-of-pocket costs or dealt with long wait times for in-home installations of lifts or wheelchair-accessible ramps. A few patients and caregivers felt that their income was always either too high or too low in order to qualify for certain health care benefits, while others expressed the need for greater awareness about available grants and support services based on their loved one's conditions.

Hiring additional help: For patients receiving care from both family members and hired assistance, navigating constant turnover in hired caretakers was also a significant challenge. Whereas some patients expressed empathy towards caretakers due to the nature of the work, many believed the care they received was inadequate or, in some cases, disrespectful.

Value of HBMC: Despite the challenges of being homebound or providing care to a homebound individual, participants consistently expressed gratitude for the availability of HBMC across both study sites. Caregivers described HBMC as alleviating some of their burden as caregivers, as well as allowing them to keep their loved ones in a safe, trusted place, rather than institutions like nursing homes.

Some participants also described dissatisfaction with care received in the hospital and perceived the general health care system as divisive between patients and physicians. However, HBMC providers were perceived as more relatable, more likely to listen, and more accessible.

Discussion

Our findings highlight key issues impacting the lives of homebound older adults and caregivers, with a particular emphasis on their daily activities, perceived burdens and challenges, and experiences with the health care system as recipients of HBMC. Importantly, these results reflect the perceptions of older adults, who are often excluded from research due to their medical conditions and home boundedness, alongside a unique population of primary caregivers for homebound older adults. Our findings emphasize the importance of preserving activities of daily life for homebound older adults, recognizing and addressing feelings of guilt and isolation among both caregivers and homebound older adults alike, expanding broader access to training and respite care for caregivers, and the need to scale-up HBMC services amid a growing population of older adults.

Despite the multitude of comorbidities generally experienced by homebound older adults, our participants clearly wished to focus on preserving function, rather than mitigating individual disease processes (Cheng et al., 2020; Fulmer, 2017; Qiu et al., 2010). Participants highlighted a variety of abilities they perform independently and others for which they required assistance. These findings are significant in that they emphasize the need for HBMC medical practitioners to identify and prioritize functionally oriented interventions, such as the Community Aging in Place–Advancing Better Care for Elders (CAPABLE) program, for this unique population. Programs like CAPABLE address both function and cost by developing a team of nurses, occupational therapists, and handy workers to address both the health and home environment of older adults. The goal of this approach is to build upon the strength of older adults and address their bio-psycho-functional capacities to function and thrive at home (Szanton et al., 2014). Similarly, a recent qualitative study among homebound older adults who do not receive HBMC found that pain and physical disability were the largest burden on homebound adults' overall functionality, yet patients felt that their pain was not treated or understood adequately in office-based primary care (Cheng et al., 2020). Furthermore, these mobility restrictions limited patients' access to such facility-based primary care and physical therapy, particularly among rural-dwelling patients, thereby further exacerbating health inequities (Cheng et al., 2020). Relatedly, our findings among homebound adults receiving HBMC specifically underscore the importance of HBMC as a health service delivery model as it minimizes transportation and access barriers among a population with high-need and high-health care utilization.

While homebound patients described a range of independent and dependent activities, caregivers outlined a multifaceted role that often included assisting with physical movement, facilitating daily household activities, and providing basic medical care. Despite undertaking a complex role, many caregivers expressed feelings of duty and gratitude to be able to provide care to their loved ones and described caregiving as a community-based effort with

many rewards. These findings contribute new knowledge on the perspectives of caregivers of homebound patients, while also underscoring similar research findings among non-spousal medical visit companions who, despite describing many frustrations and challenges, viewed their experience of providing assistance to a loved one or friend in a positive light (Sheehan et al., 2019).

Many caregivers felt that caregiving resources—including training and financial support—were either inadequate or completely unavailable. Similar to past research findings involving caregivers of frail elders and medically ill older adults, caregivers in our study expressed interest in attending caregiver classes or training to improve their own basic competencies and ultimately improve the quality of care they can provide to homebound older adults (Wilkins et al., 2009; Wolff et al., 2018). The impact of caregiving on the physical, psychological, social, and financial health of caregivers, as described by the caregivers in our study, underscores the importance of considering how HBMC services can link caregivers to resources and interventions that may help minimize or mitigate caregiver burden (Frederick, 2018; Van Kempen et al., 2012). Furthermore, our findings emphasize the need to consider additional support structures for aging caregivers who often expressed concern about their ability to care for their loved one, given their own impending or current physical limitations.

Homebound older adults in our study also highlighted how receiving care or assistance can lead to feelings of guilt, echoing similar qualitative findings from caregivers for patients with dementia (Boots et al., 2015). Patients frequently perceived their homebound status as burdensome to their caregivers and loved ones, which parallels other research suggesting that older adults fear dependence and being perceived as “old”; however, these feelings can lead to social exclusion, further highlighting the need to address social isolation in this vulnerable population (Bell & Menec, 2015; Warner et al., 2019).

Both homebound patients and their caregivers experienced challenges in receiving and providing care, including physical and social burdens and difficulties in adjusting to changes in functional ability. Whereas some resources like home delivery of medications, groceries, or other services may facilitate staying at home, our participants also highlighted the additional barriers these resources may impart, such as increased costs. This finding underscores the need to thoroughly assess and evaluate such solutions to ease the burden on both homebound older adults and their caregivers. Furthermore, despite their experiences navigating increasing health care costs and complexities in qualifying for additional assistance within the medical system at large, homebound patients and caregivers expressed a high degree of satisfaction with HBMC—particularly when comparing the quality of care with that of a hospital or skilled nursing home facility. Notably, participants highlighted stronger patient–provider interactions, enhanced person-centered care, and the advantages of receiving care at home and not having to navigate transportation and mobility barriers. These advantages were also raised among a sample of homebound older adults who do not currently receive HBMC, but were asked to reflect on this care model, which further emphasizes the importance of scaling-up HBMC to reach a high-need population (Cheng et al., 2020; Schuchman et al., 2018).

As the U.S. demographic shifts with a larger proportion of adults living to older ages, our society needs to prepare to accommodate the demands of an aging population (Robinson & Reinhard, 2009). The perspectives of caregivers and patients indicate the timely need for the health system to address both the medical and social determinants of health for homebound older adults and their caregivers. Their views are consistent with recent updates to Medicare Advantage Supplemental benefits, which aim to provide patients with the health care services they need, as well as provide access to necessary social supports to address the social determinants of health (“[Medicare.gov](https://www.medicare.gov),” 2020). Our findings align with these national updates, which prioritize improving HBMC technology, increasingly emphasize community-based services, and support the implementation of higher fee-for-service payments. These factors, coupled with health care reform that acknowledges quality and value over volume and the demonstrated beneficiary interest among our sample, support the importance of scaling-up HBMC care models (Schuchman et al., 2018).

Limitations

The homebound population are often not included in research studies as they are viewed as particularly vulnerable and hard-to-reach. Despite our success in recruiting from this population, we acknowledge some limitations. Our study sample of homebound older adults reflects a relatively longlived group, given that the annual mortality rate in HBMC practices is approximately 20%. Thus, our participants may have been in HBMC longer than average, which may have impacted their perceptions of care (Schuchman et al., 2018; Soones et al., 2017). Our study participants were recruited from two HBMC practices at JHU and UCSF, thereby limiting the generalizability of these findings to homebound older adults and caregivers in other areas of the United States, including more rural settings. In addition, the prevalence of dementia is high in the homebound population, yet we limited our sample to those without cognitive impairment as we were unable to consent patients with dementia. However, we were able to gain perspectives relevant to dementia by including caregivers of people with dementia or cognitive impairment in the sample. Furthermore, although the research staff were not clinicians from the HBMC practices and clearly defined their role to all interviewees, it is possible that participants may have expressed more positive views of HBMC as a recipient of care from the HBMC practice related to the overarching study team.

Conclusion

The day-to-day experience of homebound older adults and their caregivers is a dynamic, challenging, and generally underrepresented perspective in the healthcare system. Both patients and caregivers navigate complex burdens, substantial limitations, and personal sacrifices in either receiving or providing home-based care. In comparison with hospital or facility-based care, participants described a high degree of satisfaction with HBMC, which has demonstrated impact on the quality of life of both homebound older adults and their caregivers, while also reducing health care costs (Schuchman et al., 2018). As the U.S. demographic continues to shift toward more adults living into older age, health care systems must provide this vulnerable population with the appropriate care and resources, as well as improve support for the caregivers of homebound older adults.

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Table 1:

Participant Demographics

	Homebound Patients (n=13)	Caregivers (n=17)
	n (%)	n (%)
<i>Location of Interview</i>		
In-Person	12 (92)	16 (94)
<i>Gender</i>		
Female	12 (92)	10 (59)
<i>Race</i>		
Black or African American	7 (54)	4 (24)
White	4 (31)	9 (53)
Latinx/Native American/Asian/Other	2 (15)	4 (24)
<i>Education Level</i>		
Some college and above	7 (54)	8 (47)
<i>Type of Health Insurance *</i>		
Medicare	11 (85)	9 (53)
Medicaid/MediCal	6 (45)	5 (29)
Private/Other	7 (54)	10 (59)
<i>Self-Reported Socioeconomic Status **</i>		
High	6 (46)	9 (53)
Mid	5 (38)	6 (35)
Low	2 (15)	2 (12)
<i>Relationship Status</i>		
Married	2 (15)	8 (47)
Widowed	4 (31)	0 (0)
Other	7 (54)	9 (53)
<i>Self-Reported Chronic Health Conditions</i>		
Hypertension	12 (92)	5 (29)
Arthritis	8 (62)	7 (41)
Osteoporosis	2 (15)	5 (29)
Diabetes	6 (46)	2 (12)
Heart Disease	5 (38)	3 (18)
Chronic lung disease	5 (38)	5 (29)
Anxiety	5 (38)	6 (35)
Depression	4 (31)	5 (29)

* Multiple participants reported a combination of insurance types

** High/Mid/Low correspond to the following answers on the SES question in the interview guide: High = After paying the bills, you still have enough money for special things that you want; Mid = You have enough money to pay the bills, but little spare money to buy extra or special things; Low = You have money to pay the bills, but only because you have cut back on things or you are having difficulty paying the bills, no matter what you do.

Table 2:

Illustrative Quotes

Theme	Subtheme	Quote
1. Assistance and Functional Dependence	Functional Independence and Dependence	<i>"I do my prayers. You have to keep going. That's the thing, keep going, and with my little buddy here (referring to the participant's walker) I'm all over the house, and I had a ramp put from the kitchen to the utility room so I can go do my laundry, take care of the cat, put the trash out, and then in the bathroom I had the tub cut out so I can get in and take my shower." – Patient, Baltimore</i>
		<i>"Little by little, most of the transfer tasks have gone over to [my husband], so he's doing most of that." – Patient, San Francisco</i>
		<i>"I don't go out unless it's necessary. And sometimes I have to go to do the shopping but I rely on [Amazon] more and more so I don't have to go out because it's difficult. I have to carry the cane. Besides, I can only walk with the walker."- Patient, San Francisco</i>
	Assistance Provided by Caregivers	<i>"Well, like the mail, that disturbs me, because I know it's out there, but I can't get to it. If I'm here the mailman will bring it in to me, which he did today. The thing that upsets me I guess is the young lady that gets my groceries. I know that's a drain on her. She has a family, but she's willing to do it, and I appreciate that, and I have a lot of angels." – Patient, Baltimore</i>
		<i>"Well, we get up in the morning, first thing I do is change my wife's diaper. Then we bring her into the chair. And then I start to feed her breakfast. And about 9:30 or so, I'm finished with that. And then I do the dishes or whatever has to be done. And look for anything has to be done in the house...some days I have to get clothes together and wash them and dry them. I spend a lot of time sitting with my wife if she's awake...If she's sleeping, that gives me opportunity to get things done - run out and drive to the store I stay busy. Very busy."- Caregiver, Baltimore</i>
		<i>"One [family member] takes care of financials and one takes care of her with me when they can get here, because, see, they work during the daytime, and they can't get off from work in time, so I do most of the care in the day."- Caregiver, Baltimore</i>
2. Experiences with Receiving and Providing Care	Burdens of Caregiving	<i>"[My daughter] doesn't have a lot of spare time but she devotes some of what she has to me and she is willing to devote even more if I just asked for it. I don't want to put any more pressure on her...I know there's so much pressure on women these days, or on people in general."- Patient, San Francisco</i>
		<i>"I have knee problems, back problems...I'm in a lot of pain a lot of times, and I can't move her the way she needs to be moved. – Caregiver, Baltimore</i>
		<i>"I truly feel sorry for the people that are the same age as the people that they have to provide care for or older, because I know how physical it is. It's very hard for the person as a caregiver to be not physically shaped to provide care for them, so I'm very blessed." – Caregiver, Baltimore</i>
	Coping with Change	<i>"Well, for years I did all the gardening out in patio and I had flowers ringing the whole patio. If you look out there now it's just a barren wasteland. That was my pleasure. And now I don't-- I don't feel like I have a lot of pleasure. Being with my daughter is a certain kind of pleasure. And so my pleasure is I like magazines now."- Patient, San Francisco</i>
	Social Effects of Receiving and Providing Care	<i>"Now, I've never been depressed, but to me I've been lonely...It's very lonely to cook something for yourself, sit down at the table and have nobody to talk to or look at or whatever."- Patient, Baltimore</i>
<i>"Well, when you are providing...you become selfless. I used to take long walks and you know, I have no weekends anymore. I used to go to concerts and go out with my wife. So, [caregiving] took away kind of my freedom for me. But I brought a treadmill in the apartment, so I try squeeze in as much as I can, you know, to stay healthy otherwise it's not going to work out."- Caregiver, San Francisco</i>		
3. Interactions with the Healthcare System	Costs and Qualifying for Assistance	<i>"Every time I ask for assistance or I go ask questions and stuff, the first thing (they) want to know is what's your income level? And then I'm turned down a lot because of income level. And I don't think that's fair. I think they need to look at that and readjust or however they look at it because he's a veteran and we've been denied veteran benefits because of our income level."- Caregiver, Baltimore</i>
	Hiring Additional Help	<i>"This woman, she kind of snapped 'I don't need to be taught how to do the dishes.' Some of them were just wonderful, kind women, who wanted to help, but one, in particular, that I remember, she was there the first day. The second day that she was supposed to come, she didn't show up. She didn't call. So then the third day, she called, and she had an excuse By the fifth day, I told her, "This is not working"... A lot of people don't feel appreciated, and so they don't want to do a good job. They just want to put in the hours...there's a big turnover. – Patient, San Francisco</i>

Theme	Subtheme	Quote
	Value of HBMC	<p data-bbox="597 262 1372 352"><i>“I love, absolutely love the home care program for the elderly. I think that that is one of the best things that they could’ve ever done because it’s very hard - it was so hard for me to get her in a cab to go the doctors and bring her home. And now, you know, the doctors come in and they see her and they’re very good.”- Caregiver, Baltimore</i></p> <p data-bbox="597 365 1372 455"><i>“You really lose your identity, and I don’t think doctors realize that. They don’t care who you are. They just care about your condition, and it’s a bad thing. I think it’s always been the case, and it hasn’t really changed for many doctors. I think it’s a little bit different with the gerontologists. I don’t feel it as much with them.” – Patient, San Francisco</i></p>

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