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Family caregiver perspectives on benefits and challenges of caring for older adults with paid caregivers

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Abstract

Background—Many older adults receive help from both family caregivers and home care workers. We aimed to understand family caregivers' perspectives on home care workers.

Methods—This qualitative study took place at an academic medical center in New York, N.Y. We interviewed family caregivers of community-dwelling older adults about their experiences with home care workers. We analyzed transcripts thematically.

Results—We interviewed 17 family caregivers and identified four major themes: 1) home care workers provide functional and emotional support; 2) home care is logistically challenging; 3) finding the right fit between home care workers, older adults, and families is essential; 4) home care workers and family caregivers coordinate care well beyond the initiation of home care.

Conclusion—Despite its logistical challenges, home care benefits patients and family caregivers. Given the growing prevalence of caregiving, clinicians and family caregivers might benefit from training and support about working with home care workers.

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Supplemental Material
Supplemental Text S1. Interview guide
Supplemental Table S1. Codes

INTRODUCTION

Millions of older adults receive help with personal and health-related care, and the proportion of older adults receiving help rises with age (Freedman & Spillman, 2014). Older adults most commonly receive this help from family members or friends. Family caregivers help older adults in many ways, including assisting with basic and instrumental activities of daily living (ADLs and lADLs), performing medical tasks, and providing emotional support (National Alliance for Caregiving & AARP Public Policy Institute, 2015).

In addition to family caregivers, home care workers assist community-dwelling older adults in various ADLs and health-related tasks. In the United States, almost 2.3 million people work as home care workers (PHI, 2019). This diverse group—encompassing aides with a variety of job titles—provides both post-acute care and long-term assistance (Sterling & Shaw, 2019). In 2015, almost 4.5 million people 65 years and older in the United States received care from a home care agency (Harris-Kojetin et al., 2019).

Although they have different roles, training, and payment, home care workers and family caregivers often share patients—more than a third of unpaid caregivers of community-dwelling adults age 50 or older report that the patient to whom they provide care also received paid home assistance in the past year (National Alliance for Caregiving & AARP Public Policy Institute, 2015). Although conceptual frameworks suggest that people receive care through dynamic networks of caregivers (Kemp, Ball, & Perkins, 2013; Sims-Gould & Martin-Matthews, 2010), few studies have empirically examined the relationship between family caregivers and home care workers. That is, literature is sparse from the family caregiver perspective in the community setting, rather than in long-term care facilities, in the United States. To address this gap, we sought to elicit the perspectives of family caregivers of community-dwelling older adults on their experiences providing care alongside home care workers. A better understanding of the shared caregiving experience could provide important insight into effective strategies for improving home health care delivery for an aging population with increasing personal, functional, and emotional needs (AARP Public Policy Institute, 2017) and cognitive impairment (Alzheimer’s Association, 2019).

METHODS

Setting and participants

This qualitative study took place between July 2018 and October 2019 in New York, N.Y., and involved three sites affiliated with NewYork-Presbyterian Hospital/Weill Cornell Medicine: an outpatient geriatric medicine practice, an outpatient internal medicine practice, and a hospital-affiliated free program that provides education and links to community resources for older adults (NewYork-Presbyterian Hospital, n.d.). We included family caregivers of community-dwelling older adults who reported that their family member had received services from a home care worker within the past year. We used convenience sampling to recruit participants; caregivers were approached in the geriatrics practice waiting room, were referred by physicians, or responded to fliers and signup sheets at the community resource program. Participants were recruited by two study authors (A.L.S., C.A.R.) and a research assistant. Participants did not receive financial incentives to participate. All participants provided written informed consent. This study was approved by the NewYork-Presbyterian Hospital/Weill Cornell Medicine Institutional Review Board (protocol number 1704018177). Methods and results are presented according to the consolidated criteria for reporting qualitative research (Tong, Sainsbury, & Craig, 2007).

Data collection

One author (A.L.S.), trained in qualitative research methods, conducted semi-structured one-on-one interviews using a topic guide (Supplemental Text S1). She is a geriatrician and is not part of the care team for any participant or care recipient. Interview questions were informed by caregiving literature and clinical experience and addressed the general experience of having a home care worker; the roles and duties of home care workers; the involvement of home care workers in medical visits; care recipients' relationships with home care workers; and participants' relationships and communication with home care workers (National Alliance for Caregiving & AARP Public Policy Institute, 2015; Sterling et al., 2018). We piloted and refined the interview guide with six family caregivers who were not included in the final study. For participant convenience, we conducted most interviews by telephone. Interviews were audio-recorded and professionally transcribed. The interviewer also took notes in real time during interviews. Interviews lasted approximately 25 minutes. Participants also completed a brief demographic survey.

Data analysis

Our analyses were informed by an integrative framework developed by Sims-Gould and Martin-Matthews (2007, 2010). In this framework, not only do family and other caregivers directly care for care recipients, but these multiple caregivers also assist each other in providing care. Guided by this framework, we used a flexible, deductive approach to coding whereby we started with a list of pre-existing codes but added codes when new concepts arose from the transcripts; this approach is frequently used in health services research (Fereday & Muir-Cochrane, 2006). Three authors (A.L.S., A.S., H.K.) independently coded transcripts, comparing codes every three transcripts. Another author (M.R.S.) reviewed the independent lists of codes and reconciled differences. We developed a preliminary codebook based on the consolidated code list and applied it to the initial transcripts. We used the constant comparative approach to expand and edit the codes as further transcripts were read, then applied a final codebook comprised of 68 codes to all transcripts (Supplemental Table S1) (Merriam & Tisdell, 2016). We collapsed these codes into 11 categories based on similar properties and dimensions, then collapsed the categories into broader themes. We discussed themes until reaching consensus. We organized data with QSR International's NVivo 12 qualitative data analysis software. We achieved thematic saturation, or the point at which no new themes emerged, after 14 interviews.

RESULTS

Participant characteristics

We interviewed 17 family caregivers, whose characteristics are shown in Table 1. Of these, eight (47%) reported caring for a parent, seven (41%) for a spouse or partner, and two (12%) for another relative; none acted as a caregiver for a friend. Their ages ranged from 36 years to 86 years (mean 65.5 years, median 64 years). Thirteen (76%) family caregivers lived with their care recipient. Characteristics of their care recipients are shown in Table 2; their ages ranged from 72 years to 98 years (mean 87.8 years, median 90 years), and 59% had dementia. Seven (41%) received care paid for by Medicaid, two (12%) by other insurance, and 10 (59%) directly by the patient or family (including one person with both Medicaid and private payment and one person with both other insurance and private payment). Most participants reported having more than one home care worker. Seven (41%) used care only from a certified home care agency, seven (41%) used only non-agency caregivers, and three (18%) used both.

Major themes

We identified four major themes representing the perspectives of family caregivers about home care workers of older adults (Figure 1). Quotations are included to illustrate these themes; additional quotations are found in Table 3.

Theme 1. Home care workers provide both functional and emotional support to patients and family caregivers

All family caregivers reported that home care workers provided functional or instrumental support to patients. This support included tasks that family caregivers were physically unable to do (e.g., lifting patients), felt unprepared to do, or felt uncomfortable doing for their loved ones (e.g., bathing). Notably, the majority of participants remarked that home care workers' assistance benefited them in addition to the care recipient.

> "I wouldn't even say they [home care workers] are my right-hand men because they replace me. They do whatever I could do and more."

> "I'm a little afraid … to take her outside alone—what if she falls, you know?"

Some family caregivers also reported that home care workers provided emotional support such as companionship or even friendship to patients and family caregivers, although not all participants perceived this closeness:

> "It doesn't seem to mean that much to her [patient] if it's not the face of someone [she's] really close to."

Although not all family caregivers felt an emotional connection to home care workers, many remarked that home care relieved caregiver stress or allowed them to maintain their usual activities.

> "It's a huge lifesaver because you don't feel anxious every time you leave that she's [patient] going to fall or not eat or not go out."

Finally, participants reported that home care enabled patients to avoid moving to a nursing home, which was an outcome they valued.

Theme 2. Home care is logistically challenging to initiate and maintain

Participants described home health care as complex, often involving multiple people and entities, including patients, family caregivers, home care workers, home care agencies, and insurance companies. For example, many participants noted that increasing the hours of home care required making a request to the home care agency or privately paying for more hours, which was expensive and cumbersome to coordinate. Compounding this, most participants reported having more than one home care worker for one patient at a time and found that turnover of home care workers disrupted patient care.

> “Overall, it’s really difficult to find people…Yeah, for about 2, 2 1/2 years I’ve gone through like 13 or 14 people. I mean they last anywhere from a day to, you know, a couple of months, and then either they quit or they just don’t work out.”

Some participants provided care alongside agency-employed home care workers, some directly hired non-agency-employed home care workers, and some worked with both, using non-agency care to supplement the hours of agency care. Navigating these options and then finding, hiring, and training home care workers presented family caregivers with logistic obstacles.

> “I hired [a home care worker] through word of mouth … but that’s a lot more headache … constantly changing, availability, this and that.”

Although agency and non-agency home care workers presented unique challenges for family caregivers, frustration related to turnover and training or orientation was common to families regardless of agency status.

Theme 3. Finding the right fit between home care workers, patients, and families is essential

Although hiring and orienting home care workers presented logistical challenges that could be stressful, participants reported that their ultimate goal was to find a home care worker who fit into the patient and family’s needs. These needs included cultural congruence, disease-specific knowledge (especially for dementia), and technical skills (for medical tasks).

> “We became, over time, like a family … I take care of them. They take care of us… They are getting paid for it and I’m getting a fantastic relationship for him.”

Participants varied in their expectations of home care workers, however, and this often was driven by participants’ perception of their family members’ functional and medical needs, as well as their own ability and availability to provide care. Although some participants primarily needed someone for companionship and supervision, others needed specific expertise.

> “We had the most disastrous weekend trying to figure out how to work this catheter. No one knew how. I had a home aide come, but she had never done a catheter. … I had someone coming weekends to look after the Foley catheter when it was unexpectedly changed to an intermittent catheter. We had a truly disastrous week.”

For many families, congruence in language and culture were crucial. Despite variation in caregivers’ specific expectations, common concepts arose around characteristics and habits that family caregivers perceived as desirable in home care workers:

> “They’re [home care workers] caring and they’re gentle with her [patient] … They are very diligent… They’re just good people. They’re reliable.”

Dementia presented additional challenges for caregivers. Participants wanted home care workers to have the knowledge and patience to care for people with dementia, especially when patients were agitated, resistant to care, or difficult to reason with.

> "I don't think they [home care workers] understand dementia. They say they do every time. Some of them argue with my mom, back and forth, not understanding that that's her illness, it's not personal."

Theme 4. Home care workers and family caregivers coordinate care well beyond the initiation of home care

The majority of participants described the importance of understanding who was doing what for the patient in the home. When a home care agency was involved, a formalized care plan often guided personal and health-related care tasks in the home. When families hired non-agency-employed home care workers, they reported having fewer guidelines about how care should be delivered and often had to direct and negotiate with home care workers.

> "We sort of said, like, 'We would like you [home care worker] to do the meal preparation and the bathing and bathroom,' because my mother doesn't want us doing that. I think that is more humiliating for her."

Notably, home care workers' involvement in medical encounters varied—they could accompany family caregivers to important appointments; take patients on their own to appointments when the family caregiver could not attend or perceived the appointment as less important; or remain in the waiting room when patients and family caregivers saw clinicians. In general, family caregivers in this study appreciated the input of home care workers in medical visits.

> "They [home care workers] are the ones that know what was going on because they were the ones to tell me. … I like for them to participate [in medical visits], to feel that they are doing more than just being there like a robot, you know?"

To improve issues of care coordination between themselves and home care workers, participants reported that ongoing communication was necessary. Frequent caregiving tasks in which coordination was necessary included food preparation, medication management, symptom monitoring, and interaction with medical providers.

> "When she [patient] needs a refill, they [home care workers] know what they are, so they keep an eye [out.]. … They call us. For example, 'In 2 days she needs the medication, please make sure that the doctor sends the prescription.'"

Participants explained that good communication and delineation of tasks provided a roadmap for caring for their loved one in the home and reduced their stress.

DISCUSSION

In this qualitative study of family caregivers of community-dwelling older adults, we found that complex interactions exist between home care workers, family caregivers, and patients. Overall, we found that (1) home care workers provided both functional and emotional support to patients and family caregivers; (2) home care was logistically challenging to set up and maintain; (3) finding the right fit between patient, home care worker, and family caregiver was critical; and (4) family caregivers and home care workers coordinated care not only at the beginning of home care but throughout the period in which caregiving existed.

Our findings add to a growing body of literature on the "shared care experience," that is, when patients receive care from both family caregivers and home care workers (Sims-Gould & Martin-Matthews, 2010; Sterling & Shaw, 2019). The concept of "assistive care" has been described by Sims-Gould and Martin-Matthews (2007, 2010) to highlight the ways in which family caregivers and home care workers collaborate and extend one another's contributions, ultimately leading to enhanced patient care. In our study, we saw instances of this with tasks such as medication management, food preparation, symptom monitoring, and interaction with medical providers. For instance, family caregivers and home care workers worked together to ensure that medications were refilled, organized, and taken correctly. Some family caregivers noted that care from home care workers helped to preserve intra-family relationships; this concept of home care services' increasing patient autonomy and decreasing the feeling of burdening family has been described previously (Lee, Barken, & Gonzales, 2020). We also found that home care workers often performed health-related tasks, which was recently described in studies by Reckrey, Tsui, et al. (2019) and Sterling et al. (2018). However, in contrast to another recent study on paid caregiver communication (Reckrey, Geduldig, et al., 2019), we found that many home care workers took a proactive role in interactions with clinicians, which family caregivers appreciated. In fact, often, participants explained that these proactive approaches led to benefits for both the patient (e.g., self-care, ability to remain in the community) and the family caregivers themselves (e.g., reduced stress, more free time).

Another unique finding of our study was the diversity of home care workers involved—that is, participants used home care workers hired through certified and licensed home care agencies but also used home care workers hired independently (out of pocket or through Medicaid's Consumer-Directed Personal Assistance Program (New York State Department of Health, 2015). This trend is likely to continue, particularly as the population ages and the demand for home care workers rises (PHI, 2019). Different sources of paid home care workers have important implications for the shared care experience. For example, studies involving agency-employed home care workers note the importance of the care plan, despite its shortcomings, in delineating the tasks of home care workers (Sims-Gould, Byrne, Tong, & Martin-Matthews, 2015; Sterling et al., 2018). The family caregivers in this study who used agency-employed home care workers mentioned the important role of the care plan and agency supervisors in defining tasks. On the other hand, family caregivers independently hiring home care workers bore the full responsibility of recruiting, hiring, training, and supervising them—tasks that they often felt unprepared to do. Although several family caregivers in this study appreciated the difficulty of home care workers' jobs and tried to respect the limits of their roles, independent home care workers are potentially at risk for exploitation, and so the education of home care workers has important policy implications.

Findings from this study suggest the need for dyadic interventions—targeting both the family caregiver and the home care worker—that provide training in collaborative techniques for optimizing patient care. Following the "assistive care" paradigm, such interventions may incorporate strategies for helping family caregiver–home care worker dyads to set ground rules for cooperation and establish the tasks to be provided by each caregiver. Health interviewing by home care workers has been shown to be an effective strategy for identifying patients' care preferences (Danilovich, Diaz, Boyken, Eisenstein, & Johnson, 2020). Leveraging this technique to ascertain the preferences and capabilities of family caregivers, home care workers, and patients has the potential to enhance patient care by delegating care activities according to individuals' preferences and abilities. Health interviewing may also facilitate the identification of individuals' specific training needs, which is critical given low rates of training among family caregivers (Burgdorf, Roth, Riffin, & Wolff, 2019) and task-specific challenges described by health care workers (King, Holliday, & Andrews, 2018). Intervention to address these training needs could, in turn, alleviate caregivers' sense of discomfort or lack of preparation with certain tasks (for example, as reported by our study participants, physical tasks such as assisting with bathing). Clinicians and clinicians-in-training may also benefit from education regarding the challenges that family and paid home care workers face since many medical professionals are unaware of the intricacies of caregiving and its effect on patient care (Sterling et al., 2020).

Strengths and limitations

Strengths of this study include the different types of family caregivers interviewed, the breadth of experiences with home care that family caregivers spoke about (agency and non-agency aides), and the use of an established framework to inform data analysis. Additionally, the patients for whom they cared had a variety of caregiving needs, medical conditions, and primary languages, which contributes to insight into the care landscape in [city]. Limitations to generalizability exist, however, and include the use of convenience sampling for study recruitment, interviews in English only, and single-center design located in a major city. In order to expand generalizability, future studies could recruit participants from multiple medical practices as well as home care agencies and community-based organizations. Additionally, survey-based research is needed to quantify the prevalence of themes found in this study. Although participants were candid in their interviews, it is also possible that social desirability bias could have influenced their responses.

Conclusion

Despite logistical and interpersonal challenges, family caregivers of older adults worked closely with home care workers and reported that these workers provided both functional and emotional support. Our findings have important implications for clinical care and healthcare delivery, given the rapid pace at which the population is aging, the escalating demand for home care workers, and the projected shortfall in family caregivers. Increased awareness of who is caring for patients in the home, the dynamics that may exist, and the care activities that are negotiated is critical for medical providers. Additionally, our findings suggest that family caregivers may require additional training as to the types of resources available to them and how to navigate the process of initiating and maintaining home care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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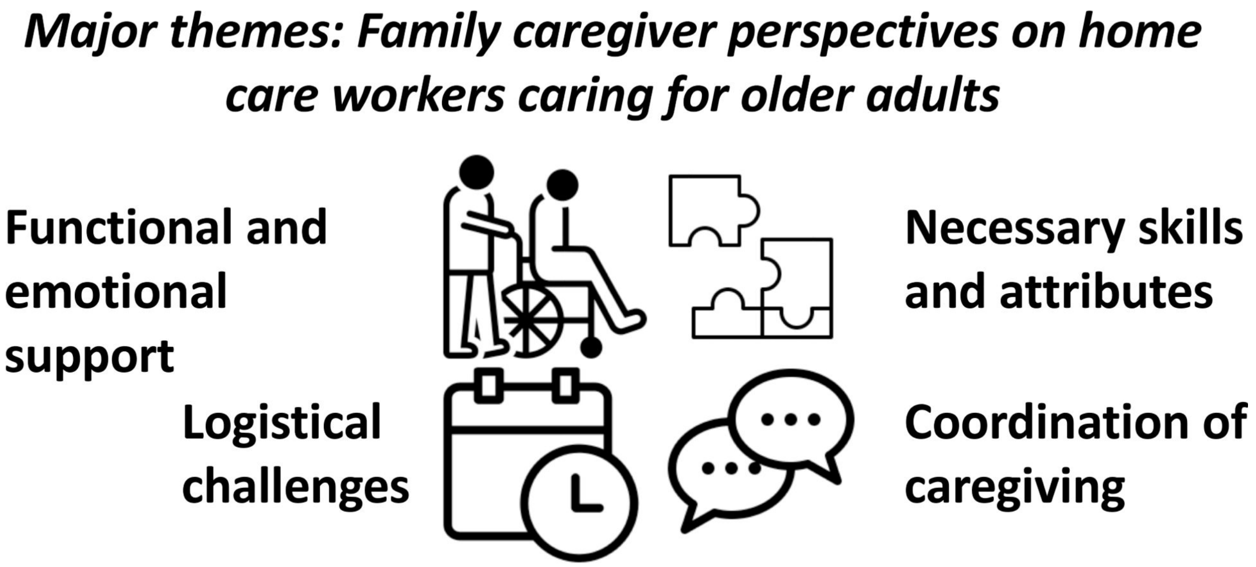

Figure 1.

Major themes: Family caregiver perspectives on home care workers caring for older adults

Table 1.

Characteristics of family caregivers of older adults

Characteristic	**N = 17**
Age, mean, years	65.5
Female gender, N (%)	13 (76%)
Living with care recipient, N (%)	13 (76%)
Duration of care, years, mean (range) *	6.2 (1–25)
Relationship to care recipient, N (%)	
Child	8 (47%)
Spouse/partner	7 (41%)
Other relative	2 (12%)
Race, N (%) *	
White	12 (71%)
Asian	2 (12%)
Black/African-American	1 (6%)
Other (South Asian)	1 (6%)
Ethnicity, N (%) *	
Not Hispanic or Latino	13 (76%)
Hispanic or Latino	1 (6%)

**Note.* Variables with missing data include duration of caregiving (n = 6), race (n = 1), and ethnicity (n = 3). Percentages do not add up to 100 because of missing data.

Table 2.

Characteristics of older adult patients as reported by family caregivers

Characteristic	**N = 17**
Age, mean, years	87.8
Female gender, N (%)	11 (65%)
Dementia, N (%)	10 (59%)
Race, N (%) [*]	
White	12 (71%)
Asian	2 (12%)
Black/African-American	1 (6%)
Other (South Asian)	1 (6%)
Ethnicity, N (%) [*]	
Not Hispanic or Latino	12 (71%)
Hispanic or Latino	2 (12%)
Unknown	1 (6%)
Overall health, N (%) [*]	
Excellent	2 (12%)
Good	4 (24%)
Fair	5 (29%)
Poor	2 (12%)

[*] Missing data: race, n = 1; ethnicity, n = 2; overall health, n = 4

Table 3.

Summary of major themes and illustrative quotations

Theme 1. Home care workers provide both functional and emotional support to patients and family caregivers.
"She [HCW] takes full charge of getting my husband to bed, out of bed, washed, cleaned, looking after his bathroom needs, which are enormous."
"They [HCW and patient] can just chat, which is part of the idea of … having a companion."
"The best thing about having these caregivers is you can sort of have a relationship with your mother again."
"Before, I didn't have the chance to sleep at night … I took care of him [patient] at nighttime. That was very hard."
Theme 2. Home care is logistically challenging to initiate and maintain.
"That was a maze of finding the right person and figuring out the right amount of money to pay them, quite frankly, and trusting them."
"I get nervous about my schedule working well enough with her [HCW] schedule. … It's really important for me to keep continuity with an aide that we like."
"There's Medicaid, there's the managed long-term care provider, and then … a network of other providers who deal directly with the home attendants."
"The problem with the agency is that they don't return your calls. They change the aides without notice. … They don't communicate with the aide about what type of client they're going to be meeting and their needs."
Theme 3. Finding the right fit between home care workers, patients, and families is essential.
"When I get her [patient] cookies, they [HCWs] say, 'Oh, she doesn't like that.' … They know her, her habits, and … they are very observant."
"The minute she [patient] got aggressive, that's it, it's not what they [HCWs] wanted to do and didn't expect … even though they had Alzheimer's experience."
"My mom, you know, she's Mexican, and she wanted the people [HCWs] cooking like us."
"They're [HCWs] both very decent people, and I treat them both with respect, and then we kind of all like each other, too, which I think sort of helps."
Theme 4. Home care workers and family caregivers coordinate care well beyond the initiation of home care.
"The natural tendency is to be more passive, so there needs to be some degree of encouragement and monitoring."
"When she [HCW] looks at my mom and she's not feeling well, she calls me … I've got to run over there after my job."
"They [HCWs] do everything, except I do everything, too."

HCW = home care worker