

Research Article

Paid Caregiver Communication With Homebound Older Adults, Their Families, and the Health Care Team

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Received: January 25, 2019; Editorial Decision Date: April 16, 2019

Decision Editor: Barbara J. Bowers, PhD

Abstract

Background and Objectives: Although paid caregivers (e.g., home health aides and home care workers) provide essential care for homebound older adults with serious illness in their homes, little is known about how and to whom paid caregivers communicate about the health needs they encounter. This study explored how paid caregivers (i) communicate when older adults experience symptoms or clinical changes and (ii) interact with the health care team.

Research Design and Methods: We conducted separate one-on-one, semi-structured interviews ($n = 30$) lasting 40–60 min with homebound older adults (or their proxies if they had cognitive impairment) and their paid caregivers (provided they had worked with the older adult for ≥ 8 hr per week for ≥ 6 months). Interviews were audio-recorded, transcribed, and coded.

Results: Thematic analysis identified four themes: (i) older adults or their families were the gatekeepers to paid caregiver communication with the health care team; (ii) communication between older adults, their families, and paid caregivers was enhanced when close relationships were present; (iii) paid caregivers responded to health care team inquiries but rarely communicated proactively; and (4) most older adults, families, and paid caregivers were satisfied with existing paid caregiver communication with the health care team.

Discussion and Implications: Rather than discuss concerns with the health care team, paid caregivers communicated directly with older adults or their families about the health needs they encounter. Understanding how communication occurs in the home is the first step to maximizing the potentially positive impact of paid caregivers on the health of older adults living at home.

Keywords: Home care, Direct care worker, Caregiving, Qualitative research, Workforce

Family caregivers are the primary sources of support for functionally impaired older adults who wish to remain living at home (Kasper, Freedman, Spillman, & Wolff, 2015;

Wolff, Spillman, Freedman, & Kasper, 2016). As care needs grow, many family caregivers are unable to meet the extensive, hands-on care needs of their loved ones by themselves

and consequently turn to formal long-term care services including paid caregivers (also known as home health aides, home care workers, or personal care attendants) for support (Giovannetti et al., 2012; Kaye, Harrington, & LaPlante, 2010; Kemp, Ball, & Perkins, 2013). There are currently more than 2 million paid caregivers working in homes in the United States (“U.S. Home Care Workers”, n.d.). This number is expected to drastically increase in the coming decades not only because of changing national demographics favoring an older population but also because of a nationwide shift in long-term care service provision from institutions to the community (Eiken, Burwell, & Sredl, 2013; Kaye, 2014; Ng, Stone, & Harrington, 2015).

For many older adults, functional impairment goes hand in hand with complex serious illness (Kelley, 2014). As frontline workers, paid caregivers likely witness significant health needs such as new medical problems, exacerbation of chronic illness, and uncontrolled symptoms among the older adults for whom they provide care. This may be particularly true for homebound older adults, defined under Medicare as those who have trouble leaving home without help, have a normal inability to leave the home, and find leaving the home requires a considerable and taxing effort (“Home Health Services Coverage”, n.d.). Homebound older adults experience not only high levels of functional impairment but also significant symptom burden, frequent hospitalization, and increased mortality (Cohen-Mansfield, Shmotkin, & Hazan, 2010; Ornstein et al., 2015; Soones, Federman, Leff, Siu, & Ornstein, 2017; Wajnberg, Ornstein, Zhang, Smith, & Soriano, 2013).

Yet for homebound older adults and others with serious illness, little is known about how and to whom paid caregivers communicate about the health needs they encounter in the course of providing routine care. The limited literature that exists about paid caregivers has largely focused on workforce issues such as recruitment and retention, job satisfaction, and training (Brannon, Barry, Kemper, Schreiner, & Vasey, 2007; Butler, Brennan-Ing, Wardamasky, & Ashley, 2014; Ejaz, Noelker, Menne, & Bagaka's, 2008; Hewko et al., 2015; Menne, Ejaz, Noelker, & Jones, 2007; Stone et al., 2017). Evidence suggests that paid caregivers have low health literacy and minimal structured contact with other health providers (Lindquist, Jain, Tam, Martin, & Baker, 2011; Menne et al., 2007), which may hinder appropriate communication about health needs. A clear understanding about how paid caregivers communicate about health needs is therefore necessary to maximize the potentially positive impact of paid caregivers on the health of the older adults they care for.

To address this knowledge gap, we used semi-structured interviews with homebound older adults (or their proxies if they had cognitive impairment) as well as their paid caregivers to explore (i) how paid caregivers communicate when older adults experience symptoms or clinical changes and (ii) how paid caregivers interact with the health care team. For the purposes of this article,

we consider any licensed health care provider including but not limited to registered nurses, physicians, nurse practitioners, and physical or occupational therapists, as part of the health care team.

Methods

Participants

To obtain multiple perspectives on paid caregiver communication (Lincoln & Guba, 1985), we interviewed both older adults (or their proxies if they had cognitive impairment) and the paid caregivers who cared for them. Older adults were drawn from enrollees in a randomized controlled trial of home-based primary care (National Institute on Aging Study R01AG052557) described elsewhere in detail (Reckrey et al., 2018). This trial, currently underway at an urban academic medical center in New York, NY, recruited older adults aged at least 65 years with at least one hospitalizations in the last year and impairment in at least two activities of daily living who spoke either Spanish or English and who met the Medicare definition of a homebound person (“Home Health Services Coverage”, n.d.). Those who received at least 8 hr of nonfamily member paid caregiver support with a given paid caregiver for at least 6 months were approached consecutively following trial enrollment to participate in this qualitative study. Both older adults receiving home-based primary care and those receiving office-based primary care were included. If previous evaluation for the trial had indicated that an older adult did not have capacity to consent for a research study due to cognitive impairment, his or her proxy was approached. In addition, with permission from the older adult or their proxy, the older adult's paid caregiver was also approached. Written informed consent was obtained from all participants, who were provided a \$50 gift certificate as compensation for their time.

Design and Data Collection

The interdisciplinary research team had expertise in qualitative research methods, health services research, and clinical care (including geriatrics, primary care, home care medicine, and nursing), which contributed to rigorous study design and clinically relevant data interpretation. On the basis of a review of the literature and informed by direct clinical experiences, the team developed an interview guide that asked all participants (older adults or their proxies and paid caregivers) to describe recent instances when the older adults experienced symptoms (e.g., pain, leg swelling, and shortness of breath) or health changes (e.g., exacerbations of chronic illness and a new medical diagnosis). Participants were also asked to describe the circumstances surrounding any recent hospitalizations or emergency room visits. Participants were asked if and when paid caregivers communicated with other health care professionals (e.g.,

nurses, physicians, and therapists) who were involved in the older adult's care. They were then asked to describe about what that communication entailed. Interview guides for older adults, proxies, and paid caregivers shared the same structure and content with questions and prompts tailored to each group. The interview guide was piloted for clarity among clinicians experienced with care of homebound older adults and edited for both content and clarity following the first several participant interviews. Older adults, proxies, and paid caregivers were interviewed separately in a private location of their choosing and responses were not shared. English interviews were conducted by J. M. Reckrey and E. T. Geduldig and Spanish interviews were conducted by a trained, bilingual research assistant. Interviews lasted approximately 40–60 min and were audiotaped and professionally transcribed.

Analysis

Data were analyzed in an iterative process using thematic analysis (Guest, MacQueen, & Namey, 2012). Members of the research team (J. M. Reckrey, E. T. Geduldig, A. D. Federman, and A. A. Brody) independently reviewed several interview transcripts and met to discuss themes and revise the interview guide. The team created a preliminary coding scheme based on these themes, which was revised and expanded as codes were applied to further interviews. Two members of the research team (J. M. Reckrey and E. T. Geduldig) then independently applied the final coding structure to each of the interviews. Disagreements were rare and were resolved by consensus. Coded data were entered into NVivo qualitative data analysis software (QSR International, Melbourne, Australia). Interviews were continued until thematic saturation was achieved (Guest et al., 2012). The team then met to discuss the meaning of these themes and the relationships among them. This study was approved by the Mount Sinai Institutional Review Board.

Results

A total of 30 interviews were conducted among 15 dyads: 8 older adult-paid caregiver dyads (older adult cognitively intact) and 7 proxy-paid caregiver dyads (older adult cognitively impaired). Participants were only interviewed if both members of the dyad consented; in the course of recruitment, five older adults and one paid caregiver declined participation. Of 15 older adults, 12 were women, with a mean age of 83 years. They experienced significant functional impairment (average impairment in 3.2 activities of daily living and 5.3 instrumental activities of daily living) and high chronic disease burden (average 3.7 chronic conditions), including 7 of 15 with proxy respondents due to cognitive impairment.

Paid caregivers were overwhelmingly women (14 of 15) with a mean age of 44 years. Only 2 of 15 were born in the United States and English was a second language for

8 of 15. Several paid caregivers had training well beyond the 40-hr curriculum required for paid caregivers providing Medicaid-funded care in New York State ("Home Care Curriculum", n.d.), including one certified nursing assistant and one registered nurse. Of 15, 12 were employed through an agency and 11 had been a paid caregiver for more than 5 years (Table 1).

Thematic analysis identified four themes: (i) older adults or their families were the gatekeepers to paid caregiver communication with the health care team; (ii) communication between older adults, their families, and paid caregivers was enhanced when close relationships were present; (iii) paid caregivers responded to health care team inquiries but rarely communicated proactively; and (iv) most participants were satisfied with existing paid caregiver communication with the health care team.

Theme 1: Older Adults or Their Families Were the Gatekeepers to Paid Caregiver Communication With the Health Care Team

Older adults, their proxies, and paid caregivers described how older adults experienced acute health changes including vomiting, bleeding, and leg swelling. All three groups then explained how paid caregivers turned to the older adults themselves (if older adults were cognitively intact) or to families of the older adults (if older adults had cognitive impairment) to determine if and how paid caregivers would interact with the health care

Table 1. Older Adult and Paid Caregiver Characteristics

Older adults (<i>n</i> = 15)	
Age, mean	84
Female, %	80
White (non-Hispanic), %	47
≥ High school education, %	73
Has Medicaid, %	60
Lives alone, %	67
Number of chronic conditions, mean	3.7
Proxy respondent due to cognitive impairment, %	47
Number of activities of daily living impaired (mean, <i>SD</i>)	3.2 (2.2)
Number of instrumental activities of daily living impaired (mean, <i>SD</i>)	5.3 (1.7)
Paid caregivers (<i>n</i> = 15)	
Age, mean	44
Female, %	93
Born in the United States, %	13
≥ High school education, %	67
English as a second language, %	53
Works in paid caregiving ≥ 40 hr per week, %	60
Caring for current older adult ≥ 1 year, %	67
Worked as a paid caregiver for ≥ 5 years, %	73
Work for a licensed home care services agency, %	80

team about health needs. When paid caregivers and older adults disagreed about appropriate care, paid caregivers sometimes pushed older adults to agree to what they perceived as needed interventions. Yet, older adults and their families had the final say about how paid caregivers addressed acute health needs, and direct communication between the paid caregiver and the health care team was rare (Table 2). Furthermore, even among the large number of paid caregivers who worked for agencies, calling the agency was a means to report situations after the fact rather than to obtain guidance about how to address acute issues. As one paid caregiver stated: “I focused on her. I didn’t even call the agency until I was at home, after I practically left her stable at the hospital” (*Paid caregiver 12*).

Similar to when older adults experienced acute clinical changes, older adults or their families dictated the degree to which paid caregivers communicated with nurses, doctors, and other health care team members about the older adult’s chronic health needs. Older adults and their paid caregivers described that cognitively intact patients decided the extent to which paid caregivers would be

engaged during routine physician visits. Proxies and paid caregivers described that the families of those with cognitive impairment were the ones speaking to health care team members. One exception to this pattern was a paid caregiver who advocated for the older adult she cared for without his knowledge: “I have to insist on him getting things that I know that he needs. Like he didn’t want a wheelchair, he didn’t want a hospital bed, and I have to go behind his back and get with his providers and say listen we need this” (*Paid caregiver 11*).

Of note, paid caregivers communicated with families of cognitively impaired older adults in a variety of ways. Several dyads used daily communication through written logs, telephone calls, text messages, or daily visits to ensure ongoing communication about the older adult’s health needs. Others relied on paid caregivers to reach out by telephone or text with any needs or concerns. In addition, some paid caregivers communicated with family members about the details of the older adult’s day-to-day health (e.g., bowel movement frequency, amount consumed at meals) whereas others only communicated only when there were deviations from the normal routine.

Table 2. Older Adults or Their Families Were the Gatekeepers to Paid Caregiver Communication With the Health Care Team

Communication about acute health needs	
Cognitively intact older adults	
Older adult 2	“I was vomiting and I had been vomiting the day before when [my paid caregiver] left. And I wouldn’t go to the hospital. So she left and she went home because I’m grown. She can’t make me go.”
Paid caregiver 8	“The other [paid caregiver] called me around midnight because [the older adult’s nose] was still bleeding she couldn’t control it. And [the older adult] was not going to the hospital. I got on the phone with [the older adult] and screamed at her that she was going to the hospital or else she was going to bleed to death. That scared her, so she agreed to go to the hospital. So that is when [the other paid caregiver] called 911.”
Cognitively impaired older adults	
Paid caregiver 4	“I defer medical decisions to [the son.] Based on my observation I would call him if I think something is not right, and then he will have the final say. If it’s an emergency I know to call 911, but if it’s something I would call [the son] and then he would make the final call. Whatever he says goes.”
Proxy 10	“[The paid caregivers] will check her if her feet are swollen, so they are very aware of all these little signs and they will tell me.... And [the paid caregiver] knows her, I mean she takes care of her. She cleans her, so she notices. And she has been telling me, “At night she her feet are swollen” so I said, “Next week we are seeing the doctor.”
Communication about general health needs	
Cognitively intact older adults	
Paid caregiver 7	“Oh, I get involved a lot with my clients. If they accept. Because there are clients that don’t like someone to go in with them the doctor, but that they stay outside. There are people that don’t like anyone to come in. But I get very involved with her, because she has given me her confidence and permission for me to be there.”
Older adult 3	Interviewer: “Do [the paid caregivers] ever talk to the doctor?” Interviewee: “They stay in the waiting room. I’m capable of that. Believe me. All the people put me down because my speech is slurred but my brain matter is still working very, very well.”
Cognitively impaired older adults	
Paid Caregiver 4	“Usually I don’t contact her doctor directly. I always go through [the son]. I feel I stop there, that’s my boundary... I have spoken to [the doctor] directly along with [the son] before, but from the way [the son] said it wasn’t a written rule, but I sense that I have to tell [the son]. He never said it, but I remember in the beginning whenever we go to see [the doctor] he would go in with her. So I give them that space.”
Proxy 5	Interviewer: “Do they ever speak to doctors or nurses directly?” Interviewee: “No, I don’t usually let it go that far.”

Theme 2: Communication Between Older Adults, Their Families, and Paid Caregivers was Enhanced When Close Relationships Were Present

Older adults, proxies, and paid caregivers all described the importance of close relationships among older adults, their families, and paid caregivers. Older adults and proxies frequently described paid caregivers as “like family” and several paid caregivers described caring for older adults as if they were parents or grandparents. These close relationships, in turn, enhanced communication among older adults, families, and paid caregivers. In describing relationships, participants identified three distinct relationship attributes that were essential to good communication: adaptability of paid caregiver, a good personality fit, and trust between families and paid caregivers (Table 3). Perceptions of the amount of time needed to develop a close relationship varied from “the first day” to “a few years.”

In contrast, several older adults and proxies described how frequent changes among paid caregivers or paid caregivers who provided care for a single shift limited the ability to develop relationships. A proxy explained choosing the right paid caregiver for his mother: “[The first paid caregiver] cleaned very well ... she cooked for her and she did all those things, but then there was a lot of interchanging. She would bring her sister or cousin to stay later at night and it was just too many people. I said, ‘This is not going to work, I need someone who is going to be here 24 hours a day and that way [she and my mother] will develop a relationship’” (Proxy 4). An older adult described how these frequent paid caregiver changes affected how she communicated with the paid caregiver providing care: “That’s a nightmare because

if you have someone different every weekend, of course they don’t know you. They don’t know how you like to do things. [The agency] don’t tell them your health situation ... So for every weekend to have to say, ‘Oh, can you do this? Can you please do that?’ I made it through, but I’m grateful that I have someone steady” (Older adult 2).

Theme 3: Paid Caregivers Responded to Health Care Team Inquiries but Rarely Communicated Proactively

Older adults, proxies, and paid caregivers described another important corollary of close relationships: paid caregivers were in a unique position to report to the health care team about older adults’ day-to-day health. This was especially notable for older adults with dementia. One proxy described the role of the paid caregiver in her family member’s doctor visits: “I used to go in [alone], but then I realized they were asking me questions I didn’t know so I would call the aides in. So now I try to have them come in because they know her better than I do on a day-to-day basis” (Proxy 14). Similarly, a paid caregiver explained, “But you see the thing is they have to defer... to the home health aide because we are with them more, especially here where there’s no family member here” (Paid caregiver 4).

Yet, this role was most often passive, with paid caregivers responding to health care team members’ direct questions and confirming the older adults’ experience; paid caregivers rarely brought up concerns without being prompted by older adults, their families, or the health care team member. A paid caregiver highlighted this passive role in the following exchange: Interviewee: “When I go, I sit

Table 3. Relationship Attributes Essential to Good Communication Among Older Adults, Their Families, and Paid Caregivers

Adaptability of paid caregiver	
Proxy 13	“[The older adult] is stubborn, but once you get to know her then you can work around her... Instead of her adjusting to you, you adjust to her and that’s it.”
Older adult 1	“I don’t want someone that comes in here and says ‘Oh, you have to do this and you can’t do that.’ You can’t come in here and tell me what to do in my house... You’re working for me. Not, I’m not working for you, ya know? So that all goes with the job, ya know? That’s part of being a caregiver, ya know?”
A good personality fit	
Proxy 4	“Compatibility, I think. Someone who is going to be compatible to whoever the person is that they are going to be taking care of.”
Paid caregiver 7	“I like to treat the person well. I like that the person also treats me well too, that we mutually understand each other. So, I think that we hit it off from the first day that I came to this job, we have good chemistry.”
Trust between paid caregiver and proxy	
Paid caregiver 14	“And now three years in I can say it is more like a family because it’s about trusting someone. If you trust someone that means a lot.”
Proxy 14	“It would be good if everybody who has started to go through this got a booklet of some sort from someplace... talking very frankly about the aides and that you have to trust in them.”

in the visiting room and I listen to what the doctor says and the care and everything. I follow up, like if he says [the older adult] needs more moisturizing or... the toes are red you need to get another pair of shoes, and I call [the family]." Interviewer: "So it sounds like [you do] communicate directly with the doctors?" Interviewee: "No, the doctors just tell me what is happening" (Paid caregiver 9). Another paid caregiver described her relationship with the nurse from her agency: "When things happen [the nurse comes] and if nothing happens [the nurse] comes maybe every six months... when she asks me questions, I answer her. If she doesn't ask me, I don't answer" (Paid caregiver 14). Yet, another paid caregiver confirmed: "When [the nurses] come I say hello, how are you, and they take his pulse, check his heart and they ask about the sugar... That's it. I don't have any other conversation whatsoever" (Paid caregiver 15).

Theme 4: Most Participants Were Satisfied With Existing Paid Caregiver Communication With the Health Care Team

Though proactive communication was rare, few older adults, proxies, or paid caregivers desired more direct paid caregiver communication with the health care team or identified ways to improve paid caregiver communication with the health care team. Instead, all parties seemed satisfied that older adults and their families, rather than paid caregivers, served as gatekeepers to paid caregiver communication with the health care team. When asked if she would be willing to talk directly to the doctor when she had questions, one paid caregiver responded: "Well, I think I like it this way because I'm very lazy when it comes to emails and stuff [laughs.] So having [the proxy] do it is just amazing." (Paid caregiver 10).

Several paid caregivers identified barriers to communicating directly with the health care team that included concerns about either upsetting the older adult or overstepping boundaries with their family. For example, when the interviewer asked a paid caregiver if she thought it would be helpful for the doctors and nurses to know everything she knew about the older adult she cared for she replied: "No because... [the older adult] is gonna be mad at me. I don't want that. I don't want trouble" (Paid caregiver 2). When another paid caregiver was asked how she reacted to a situation in which the family did not want her to share information with the doctor, she responded: "You can't override their decision. It's not your place" (Paid caregiver 4).

Although direct communication between paid caregivers and the health care team was rare, two paid caregivers described how their relationships with health care team members actually facilitated such communication. One paid caregiver described how communication with the nurse who visited daily changed over time: "When I first started [we didn't talk] very often, but as of recently I have

her number in my phone. I have been talking to her more frequently" (Paid caregiver 3). A paid caregiver who was herself a registered nurse and communicated directly with her patient's doctor, who knew her well: "[The doctor] and her nurse practitioner obviously know I am a nurse and that I know what is going on here, so they trust me... so when I thought [the infection] was reaching her lungs they called in a prescription so she was started on antibiotics to prevent that from happening" (Paid caregiver 8).

Discussion and Implications

We found in this study that older adults or their families, rather than home care agencies or health care providers, dictated how paid caregivers communicated with the health care team when older adults experienced health needs. Close relationships enhanced communication among older adults, their families, and paid caregivers. However, proactive communication between paid caregivers and the health care team was rare. Despite these communication barriers, older adults, proxies, and paid caregivers were generally satisfied with how paid caregivers communicated with the health care team.

There are a growing number of interventions that seek to affect health outcomes for older adults through enhanced training and supervision of their paid caregivers. These interventions train paid caregivers to recognize clinical changes early (Dean et al., 2016), engage paid caregivers to help prevent falls (Shaw, Sidhu, Kearney, Keeber, & McKay, 2013), or improve physical activity (Muramatsu et al., 2017) at home, and train paid caregivers to help older adults manage chronic illness (Russell et al., 2017). Several of our key findings should inform such interventions.

First, the finding that patients and families are the gatekeepers to paid caregiver communication with the health care team suggests that paid caregivers may not feel comfortable participating in interventions without clear permission from the older adult they care for. To ensure that interventions are able to be broadly implemented, older adults, their families, paid caregivers, and health care providers should work together to develop interventions that acknowledge the central role that older adults or their families play in guiding paid caregiver interaction with the health care team. These efforts should be guided by a more person-centered conceptualization of the health care team that includes not only health care professionals but also older adults, families, and paid caregivers as part of the health care team (American Geriatrics Society Expert Panel on Person-Centered Care, 2016).

Second, the finding that paid caregivers rarely communicate proactively with the health care team may reflect not only deference to older adults and their families but also limited integration of paid caregivers in existing health care teams. An expansive vision of the multidisciplinary health care team values the unique contributions of all members. Yet in practice, those in the health care system

do not routinely acknowledge the ways paid caregivers may contribute to the health of the patients they care for or the ways the hierarchical nature of the health care system may limit those contributions (Osterman, 2017; Sterling et al., 2018). As a result, the interventions that are most successful in leveraging paid caregiving to improve patient health will likely pair direct paid caregiver training with broader health care team education and restructuring to ensure paid caregivers have adequate support and recognition within the health system.

In addition to their specific implications for interventions targeting older adults receiving paid caregiving, our findings underscore the importance of improving paid caregiver communication with older adults, families, and health care team in general. Training for paid caregivers varies significantly from state to state (Kelly, Morgan, & Jason, 2013). In addition, education tends to focus on meeting the personal care needs of functionally impaired older adults and may not emphasize the important ways that communication is a daily part of how paid caregivers address health needs (Kelly et al., 2013). A first step for improving communication could be encouraging explicit discussions among older adults, families, and paid caregivers to make sure all parties have shared expectations about how paid caregivers communicate about health concerns. Future work to build communication skills among paid caregivers is particularly important in care of older adults with cognitive impairment, where effective partnerships between family members and paid caregivers are an essential component of care (Kemp, Ball, Perkins, Hollingsworth, & Lepore, 2009; Sims-Gould & Martin-Matthews, 2010).

We found that this communication among older adults, families, and paid caregivers was enhanced by close relationships, which are known to be valued by both older adults and their paid caregivers (Franzosa, Tsui, & Baron, 2018b; Piercy, 2000). Previous work has considered the importance of improving retention among the paid caregiver workforce as a means to reduce costs and ensure an adequate supply of paid caregivers (Butler et al., 2014; Hewko et al., 2015; Mittal, Rosen, & Leana, 2009). Our findings suggest retention among paid caregivers may also contribute to longer relationships and therefore improved communication among older adults, families, and paid caregivers when older adults experience health needs. Future work should more directly explore ways that important workforce-related factors such as job satisfaction and low pay affect older adult–family–paid caregiver relationships and the older adult’s health. Such work could build on initiatives such as Better Jobs Better Care (Stone & Dawson, 2008) and help elucidate ways the paid caregiver workforce can directly affect the health and well-being of older adults with functional impairment and serious illness.

Finally, the finding that older adults, families, and paid caregivers were satisfied with existing patterns of paid caregiver communication prompts reflection on what the ideal role of paid caregivers should be. Are paid caregivers

responsible to members of the health care team for specific aspects of an older adult’s overall health? Or is serving as a gatekeeper between paid caregivers and the health care team an important way for older adults to maintain control of their health despite functional impairment? Should the paid caregiver role be fundamentally different in the care of those with cognitive impairment? Future work that examines these questions should explicitly explore the individual, family, and systemic factors that affect how the paid caregiver role is in the care of individuals with serious illness is perceived.

Of note, our finding of overall participant satisfaction with paid caregiver–health care team communication contrasts with other literature suggesting that paid caregivers would like further integration with the health care team (Franzosa et al., 2018b; Franzosa, Tsui, & Baron, 2018a; Sterling et al., 2018). This may be because our project assessed paid caregiver communication among older adults who received long-term care in the home from a particular paid caregiver for 6 months or more. In these longstanding relationships, older adults and families likely set communication parameters and the paid caregivers who remained working with a particular older adult accepted these parameters. Our finding of the importance of paid caregiver adaptability in the older adult–family–paid caregiver relationship supports this possible explanation.

As a result, our findings may not be generalizable to situations where older adult relationships to paid caregivers are not longstanding. Another important limitation of this project is that the perspectives of members of the health care team were not elicited. Older adults, proxies, and paid caregivers seemed satisfied with paid caregivers having limited communication with the health care team, but health professionals may expect or desire more communication.

This study incorporates the perspectives of older adults, proxies, and paid caregivers, providing an important examination of the ways that paid caregivers interact with the health care team and communicate about the health needs of the older adults they care for at home. Our results emphasize the importance of adopting a person-centered model of care that empowers older adults and their families to partner with their paid caregivers to advocate for health care that is aligned with their goals. Policies such as the CHRONIC Care Act acknowledge the broad range of older adults’ health-related needs and provide essential support for paid care in the home (Willink & DuGoff, 2018). A clear and shared understanding of how paid caregivers communicate with older adults, families, and health care professionals is essential to maximize the potentially positive impact of paid care on the health and well-being of older adults at home.

Funding

This work was supported by the New York State Department of Health Empire Clinical Research Investigator Program and

the National Institute on Aging [grant number P30AG028741, R01AG052557, R03AG060092]. Funders were not involved in study design, data collection, analysis and interpretation of data, and writing or submitting the manuscript.

Conflict of Interest

Authors have no potential conflicts of interest.

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