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Caregivers' Perceptions Managing Functional Needs among Older Adults Receiving Post-Acute Home Health Care

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Abstract

Caregivers play important roles in managing the physical functioning (PF) needs of older adults transitioning home after a hospitalization. Training and support of caregivers in the post-acute home health care (HHC) setting should incorporate caregivers' perspectives. To explore caregivers' experiences managing PF needs in the post-acute HHC setting, we conducted semi-structured, telephone interviews of 20 caregivers. Conventional content analysis revealed patient-, caregiving-task, caregiver, and home environment-related themes consistent with the Theory of Dependent Care. Caregivers highlighted the dynamics and contributors of PF needs for older patients in the post-acute HHC setting; and depicted the enormity of caregiving tasks needed to manage older patients' PF needs. Caregivers also described their perceived roles and challenges in managing PF deficits, including a sense of isolation when they were the sole caregiver. Findings from this research can guide nursing efforts to target caregiver training and support during this critical care transition.

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Introduction

Deficits in activities of daily living (ADL) and instrumental activities of daily living (IADL) become increasingly common as older adults age, which often necessitates help from informal caregivers (Reinhard, Levine, & Samis, 2012). Moreover, hospitalizations of older adults frequently lead to declines in physical functioning (PF) (Chase, Lozano, Hanlon, & Bowles, 2016; Gill, Allore, Holford, & Guo, 2004), creating new challenges for caregivers in the post-acute setting (Archbold, Stewart, Greenlick, & Harvath, 1990; Gibson, Kelly, & Kaplan, 2012). Nevertheless, caregivers can play an active role in recovery of patients transitioning from hospital to home, which may contribute to improvements in functional status (Cho, Kim, & Lee, 2013; Hahn-Goldberg, Jeffs, Troup, Kubba, & Okrainec, 2018).

Many older adults transitioning from hospital to home will receive skilled home health care (HHC) services (Alliance for Home Health & Quality and Innovation, 2017). Older HHC patients are clinically complex, with multiple chronic conditions and functional impairments (Murtaugh et al., 2009). Consequently, the demands on their caregivers are likely to be high. Nonetheless, post-acute HHC services provide opportunities for patients, caregivers, and clinicians to work collaboratively to optimize older adults' functional status. With services potentially including skilled nursing visits, as well as rehabilitative therapy (e.g., physical and/or occupational therapy) and home health aides, multiple occasions may exist for information exchange among healthcare providers and caregivers. Almost two-thirds of older HHC recipients have an informal caregiver present at the start of HHC (Peng, Navaie-Waliser, & Feldman, 2003); thus, HHC nurses have the unique potential to positively impact outcomes for a large population of caregivers and older patients.

Theoretical Framework: The Theory of Dependent Care

To effectively tailor future interventions aimed at helping nurses train and support caregivers, we must first understand caregivers' perspectives and experiences managing PF needs of older adults in the post-acute HHC setting. The Theory of Dependent Care (Taylor, Renpenning, Geden, Neuman, & Hart, 2001) is a middle-range nursing theory related to Orem's Theory of Self-Care (Orem, 1985), and describes the complex interactions among individuals who have self-care dependencies, caregivers who address these dependencies, and health systems. An important theme within the Theory of Dependent Care is the incorporation of caregivers' perspectives in the development of interventions to manage dependent individuals' self-care needs (Taylor et al., 2001). Taylor and colleagues (2001) describe four areas of focus – the dependent individual (e.g., older patient), complexity of caregiver tasks, the caregiver, and home environment (e.g., other sources of assistance, such as HHC and home and community based services [HCBS]) – that should be evaluated within health systems. Specifically, eliciting caregivers' experiences, perceived role in managing care, and the extent to which they are able to manage caregiving tasks in the context of a patient's PF needs and the home environment can uncover knowledge and skills deficits to target strategies for training and support. Thus, this theory is highly relevant to the post-acute HHC setting given the unique, ongoing opportunities for HHC nurses to engage with caregivers during a critical transition in care for clinically complex older adults.

Literature Review

There is a dearth of qualitative research exploring the experiences and perspectives of caregivers of older adults who specifically transition from hospital to home with HHC. Existing qualitative work has captured caregivers' challenges during other types of care transitions. For example, Dossa and colleagues (2012) conducted a longitudinal, qualitative study of older men with mobility impairments returning home after hospitalization. Patients and caregivers in this study described provider-related communication challenges, including who to contact after discharge, provider response time, and provider-provider communication (Dossa, Bokhour, & Hoenig, 2012). Other qualitative literature on care transitions among older adults and their caregivers has illustrated caregivers' lack of preparedness and poor discharge planning, as well as caregiver burden (Coleman & Roman, 2015; Foust, Vuckovic, & Henriquez, 2012; Giosa, Stolee, Dupuis, Mock, & Santi, 2014; Solan et al., 2015). Despite this body of work, there has been little research exploring caregivers' perspectives specific to managing the PF needs of older patients in the post-acute HHC setting. Only one of the studies listed above involved caregivers of patients who transitioned from hospital to home with HHC; however, this study focused on discharge planning and discharge instructions (Foust et al., 2012). Provider participants in that study identified poor preparation among caregivers during this care transition; furthermore, patients and caregivers both reported additional training and support needs after returning home, especially regarding information from discharge instructions (Foust et al., 2012).

The existing body of literature on care transitions highlights poor preparedness among caregivers of older adults and the need for enhanced communication. However, there is scant literature to explain caregivers' perspectives that can be used to tailor future training and support efforts particular to the post-acute HHC setting. Therefore, the purpose of this qualitative, descriptive study was to explore caregivers' experiences managing the PF needs of an older adult who transitioned from hospital to home with post-acute HHC. Our primary research question was "How do caregivers describe managing the PF needs for an older adult who received HHC after hospitalization?"

Design and Methods

Design

We conducted a qualitative descriptive study (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2009) to explore caregivers experiences managing PF needs of older adults who transitioned from hospital to home with HHC. In qualitative descriptive studies, the researcher stays close to the actual data collected, with minimal transformation of the data (Sandelowski, 2009). Thus, caregivers' voices, rather than the voice of the researcher, come through (Neergaard et al., 2009). Remaining close to the caregivers' descriptions of their experiences uncovers their perceptions of training gaps that will be useful for HHC providers working with older adults and their caregivers during care transitions.

Setting and Participants

We used maximum variation sampling (Polit & Beck, 2014) to obtain a racially/ethnically diverse sample of 20 caregivers of older adults who received HHC services following hospitalization. This sampling strategy facilitates identification of central themes relevant to our study purpose using a small, varied sample (Polit & Beck, 2014). Approximately 60% of caregivers are from racial/ethnic minority groups (AARP Public Policy Institute & National Alliance for Caregiving, 2015). Thus, we selected race/ethnicity as a particular sample characteristic for which we planned to obtain substantial variation. Specifically, we purposefully recruited equal numbers of non-Hispanic White caregivers as caregivers from racial/ethnic minority groups to explore consistent themes across participants with diverse racial/ethnic backgrounds. Caregivers were recruited from a large not-for-profit HHC agency in the northeast region of the US. First HHC patients were identified who: 1) received HHC after hospitalization; 2) were age 65 years or older at the start of HHC; and 3) reported having a caregiver to assist with ADL and/or IADL. Patients who also received HCBS (e.g., long-term home-based care) were eligible, as long as they also received skilled HHC after a hospitalization. The Theory of Dependent Care incorporates HCBS as part of the home-environment construct which can impact caregivers' experiences managing PF needs. Next, caregivers of eligible patients were contacted, screened, and consented. Eligible caregivers had to speak English and score a 3 or greater on the Callahan Six-Item Screener for Cognitive Impairment (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). Institutional review boards of X and X approved the project.

Data Collection

Individual, semi-structured telephone interviews were conducted with eligible caregivers. Interview questions (Table 1) were modeled after the theoretical foci (e.g., patient-, caregiving tasks-, caregiver, home environment-related) within the Theory of Dependent Care (Taylor et al., 2001). The theory was used as a guide to ensure relevant questions and variables were explored. Interviews were digitally recorded and transcribed verbatim. To ensure trustworthiness, we employed multiple strategies suggested by Lincoln and Guba (1985). Strategies to maintain credibility and authenticity of data collection included recording and meticulous review of interviews. Transcriptions were compared line by line with the audio files for accuracy. Caregiver demographic data, such as age, gender, race/ethnicity, and education, were collected. Additionally, we collected data on self-reported health, caregivers' relationship to the older adult, years of experience being a caregiver, and living arrangement (e.g., lives with older adult, yes/no).

Coding and Data Analysis

We used descriptive statistics to summarize caregiver characteristics. Dedoose software (https://app.dedoose.com/App/?Version=8.0.35) was used to analyze the qualitative data. We analyzed the qualitative data using conventional content analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Conventional content analysis is a systematic method of coding text and identifying patterns in qualitative data (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Two research team members independently read through each full interview, then re-read them line-by-line to develop in vivo codes. Similar codes were then grouped into categories of themes (Hsieh & Shannon, 2005). Data were minimally transformed from the original text and direct text from the interviews were used to create final themes and descriptors, and organized by theoretical foci of the Theory of Dependent Care (Table 1) (Taylor et al., 2001).

The team maintained an audit trail of coding decisions and analysis. Two researchers independently coded each interview and reviewed coding results (investigator triangulation). Interrater reliability was assessed for several frequently applied codes. These tests yielded kappa scores between 0.82 and 0.84, suggesting excellent agreement among coders. Finally, our findings were discussed with a Patient Advisory Board consisting of community stakeholders, including patients and caregivers, as an additional form of member checking.

Results

Sample Characteristics

Table 2 depicts caregiver and caregiving characteristics for the 20 caregiver participants. A majority of caregivers (85%) were caring for a family member, with 13 of the 20 caregivers (65%) providing care for a parent. Half of the caregivers lived with the older adult. Caregivers had been caring for the older individual for a range of three to 36 years (mean=14, standard deviation [SD]=13). Mean age of the caregivers was 58 years (SD=13, range 29 – 84), and most participants were female (70%). Overall, participants were racially/ ethnically diverse with 35% of the sample being white, 40% black, and 25% Latino-Hispanic ethnicity. Participants were well-educated with 70% of caregivers having some college education. Half of the sample was still working, and 40% were retired. Regarding self-rated health, 45% of caregivers reported their health as excellent-very good, 55% reported their health as good-fair, and no caregivers reported their health as poor. Of note, all care recipients had received HCBS in the form of long-term home-based care (e.g., home health aides) either before or during the study time period.

Patient-Related Themes

Always been like that—Overall, the PF needs of the older adult transitioning from hospital-to-home were described as “not new” by caregivers since the hospitalization. One caregiver reported: “It’s always been like that, for the last, I want to say about six years now.” However, some caregivers described the evolution and worsening of these PF issues after hospitalization, with one caregiver stating: “This is not new. It’s been going on. It’s getting, it’s getting worse now.”

Caregivers described physiological symptoms and conditions that contributed to the worsening PF difficulties of the older adult transitioning from hospital-to-home, including poor balance (e.g., “she has no balance”), limited strength (e.g., “She just needed help… opening things that her strength did not open anymore”), pain (e.g., “She all in pain”), and individual preferences (e.g. “…she never liked the idea of people having to help her. She always liked being independent…she didn’t want it, want to not be independent like she was. That disturbed her emotionally”). Prior hospitalizations and medical procedures also contributed to progressive PF difficulty (e.g., “she done had like God knows, six or seven operations”).

Caregiving Task-Related Themes

Everything—Caregivers managed an assortment of basic and instrumental activities of daily living for older care recipients in the post-acute HHC setting. Older adults needed assistance with mobility, personal care (e.g., bathing), and had issues with incontinence. One caregiver summarized: “I basically gotta do everything that I would do for myself if I gotta go to the doctor, wash up, take a bath and get dressed and stuff, I gotta do her first, then I gotta do me.” Caregivers also reported fully assisting older adults with household management (e.g. food preparation, grocery shopping, financial management).

Fighters, Watchdogs, and Chasers—In the post-acute HHC setting, caregivers’ “involved” themselves with doctors and other providers, giving providers feedback (e.g. “tell them when something’s not right”), “writing notes,” “chasing down” healthcare providers and hospital staff to secure needed services and equipment (e.g. “I had to chase them down”; “get to the bottom of”), staying abreast of what different healthcare providers are doing, and coordinating issues between providers. Caregivers sometimes described themselves as “watchdogs” who were “very involved” in caring for their loved ones. They kept a watchful eye and were ready to step-in when necessary (e.g. “so, you know, the home health aide knows that I’m on top of her, too, there’s somebody watching”).

In addition to “watchdogs,” caregivers also used the analogy of a “fight” to describe their care management efforts. One caregiver explained:

> “I can’t share anything positive because everything positive that I have I have to fight for it, and if I have to fight for something good, I mean, the good things should come, not me fighting for it, especially with a patient like her.”

Caregiver-Related Themes

I study her to see how I can better help her—To manage the complexity and variety of PF needs, caregivers used a variety of strategies. Almost all caregivers talked about the assistance that they received from home health aides after the hospitalization (“the aide does everything”). However, despite home health aides providing assistance with a majority of personal care needs during the post-acute period, caregivers were very involved in managing older adults’ PF needs. For example, several caregivers described accommodations, such as canes, walkers, wheelchairs, lifts, commodes and disposable toilets, which they used to help older adults adapt to their home environments and cope with PF difficulties. One caregiver explained:

> “I keep to try to be informed of what’s happening with her, you know, I look at her disabilities and I study her to see how I can better help her. She now needs to use the walker at home more than ever because she was using a cane before and the cane is not really helping her so the benefit of the walker at home is, it’s such an excellent tool for them to use at home. So clearing the way and getting rid of certain things that are in the way, you know, chairs and stuff like that, makes it easier for her to be able to move around with the walker.”

Confidence comes from experience—Despite the challenges experienced by caregivers, overall, they felt well-prepared to care for the older adults’ PF needs. This sense of confidence and preparedness largely came from their experiences caring for the older individual over time (e.g., “I’ve known that she’s been to the hospital before and I knew that when she came home, I knew like automatically what to do."), or from "years and years" of experiences caring for other family members or friends.

Natural instinct—Additionally, caregivers also discussed how a "natural instinct" helped prepare them to care for the older adult. Many stated that they "know what [they] needed to do to take care" of the older care recipient. Several caregivers described their love for the older adult as a central theme in overcoming the challenges of being the primary caregiver. One caregiver stated: "L-O-V-E. You love, if you love, when you love somebody, you will make a way." When another caregiver was asked about training to manage the complex PF needs of the older adult, the caregiver replied: "I love her so I know her needs. I haven't received no training, and I know exactly the way she likes things to be done." Several caregivers talked about how they know their family members' preferences and subsequently trained home health aides in these preferences (e.g., "I taught them how to prepare her meals in the way that my mother likes"). Some caregivers also described caring for their older parent in particular as an obligation, or reciprocating the care the parent once provided them. One caregiver explained:

> "I know my mom. She take care of me when I was little, so I gotta take care of her because they become like, you know, it's my turn now. You know, when you're little, they take care of you, so now they become children. So I gotta take care of her. She's my baby. That's how I call her, my baby."

Another caregiver summarized the importance and degree of family caregivers' involvement in managing older adults' care needs:

> "I think taking care of my wife down through the years, I think the best caregivers is family and your loved ones. I think that's the best medicine, I think that's the best healing, and because we have had home attendants here but she's still calling me… So that's the confidence that sick people have when they get in that situation. They really want their loved ones to do the private stuff. They feel more comfortable."

Home Environment-Related Themes

The only one—Caregivers reported receiving little assistance from other family members or friends, which left them feeling like the only person able to manage the constant PF needs of the older adult. One caregiver described her experience as "difficult because I can't go to work when she's in the hospital and she's come back from the hospital. I have to miss work because I'm the one, I'm the only one, and I don't have anybody else helping me." Being "the only one," seemed to give caregivers a sense of loneliness, "[wanting] to do more," and the feeling of being pulled in different directions by their responsibilities caring for the older adult, for themselves and their work, and for their homes. One caregiver explained:

> "It was just too much because I have my husband here, and I'm not a young person either, and it was just you know, and she wants me to be there more than I can afford to be, you know…it's just my husband is pulling me on one side, she's pulling me on the other so, I'm in the middle and my brain is coming out through my head!"

…a big relief—Caregivers viewed the additional assistance they received from HHC in the post-acute setting as generally helpful to managing the complex PF needs of the older adult. Furthermore, existing HCBS that were in place prior to the hospitalization, and reinstated once the older adult returned home, were also perceived as being supportive. Home health aides and physical therapists were specifically identified as indispensable. In addition to attending to the older adults' personal care needs, home health aides helped ensure older adults' safety and provided them "company." However, caregivers frequently cited the need for more training for home health aides, particularly regarding how to work with older adult patients who have chronic health conditions that affect PF. One caregiver stated:

> "You know, she's hunched over because, of course, she's old and she has like arthritic, you know, osteoporosis also. So she's bent forward, her back. So, I think they should, you know, prepare these people a little better to be more professional with these people that have these problems and physical disabilities, you know."

Multiple caregivers described how home health aides from HCBS provided opportunities for respite, so they could "go to the store, go shopping, or whatever I do." One caregiver said: "Well, if I'm being perfectly honest, the home health aide is really a blessing because if she wasn't here, I wouldn't be able to work and that would have been a big problem." Another caregiver explained:

> "…they aide assisted me [by] actually being there and helping my mother, taking care of her. That was a big relief. If I didn't have that, I would have gone nuts because I have to work myself to support myself and help my mother. You know, it's very costly to maintain two households, so having the home attendants for me has been a big, big plus."

Many caregivers also had positive comments on the teaching and assistance they received from physical therapy. Caregivers described how physical therapists exercised older adults and taught them how to "continue doing what they [physical therapists] were doing" after the patient was discharged from physical therapy. Caregivers were grateful for the different strategies physical therapists taught them and the older adult for how to accommodate and manage PF issues. One caregiver listed various ways physical therapy helped: "[the older adult] had to learn how to get in and out of the bathtub, how to get, walk properly with it, how to do, how to, the side of her walker had to be adjusted cause there was a whole bunch of things the therapist helped with." Another caregiver explained:

> "Well, I mean, like I said, my mom is bedridden. Her physical therapist, he showed her other ways how she can get up out of the bed and sit up out of the bed without causing herself too much pain because she suffers from back pain so it's very difficult for her to sit up. But, like I said, he showed her ways and how to do it, and she's sitting up now by herself, so….. Yeah, she can get up and sit up on the side of the bed by herself, so I owe that to him. And I'm very grateful for that because, like I said, he worked with her."

Although HHC services were generally perceived as helpful in managing PF needs in the post-acute setting, many caregivers had concerns regarding the amount of services received. The frequency and length of time that caregivers received HHC services varied across interviewees, among whom some reported daily support while others perceived themselves to be on their own. HHC services were perceived as short-lived (e.g., “No, they weren’t there that long.”) and several caregivers reported needing “more help.” Some caregivers described taking whatever assistance they could secure, often settling for less than they actually needed. One caregiver explained: “So you take a half a loaf, half bread, piece of bread than if you don’t have the whole one you just take the half.”

Discussion

We uncovered rich descriptions of caregivers’ experiences managing a range of PF needs in the post-acute HHC setting. While there have been similar explorations of caregivers’ experiences in specific clinical conditions (Ang, Lang, Ang, & Lopez, 2016; Jack, Mitchell, Cope, & O’Brien, 2016), and in other settings (Dossa et al., 2012; Lutz et al., 2017), the post-acute HHC setting is notable due to the nature and frequency of contact between HHC providers, caregivers, and patients to promote stabilization and recovery. The post-acute HHC setting also presents opportunities for nurses to prepare caregivers for the transition to discharge from post-acute care. The Theory of Dependent Care emphasizes the assessment and engagement of both patients and caregivers to successfully manage care needs. By employing this framework, and interweaving caregiver-related themes across patient-, caregiving task-, and home environment-related themes, our study facilitates identification of areas in which nurses and other HHC providers can target caregiving training and support strategies during a common care transition for older adults.

In the patient-related theme, caregivers highlighted both the static and dynamic nature of PF needs for older patients in the post-acute HHC setting. Although most caregivers felt that the PF needs were ongoing and chronic, there were instances where older patients’ functional status had worsened after hospitalization. Importantly, caregivers expressed interest in learning the safest and most efficient ways to manage these new and ongoing care needs, and some may need additional training in the post-acute setting (Shyu, 2000). While many caregivers actively seek information on their own, receiving information and training from HHC staff on managing care in the post-acute period is associated with reduced caregiver burden (Weaver, Perloff, & Waters, 1999). Thus, HHC nurses need to be alert to changes in older adult’s PF, especially after care transitions such as a recent hospitalization, and adapt training and support to assess and address caregivers’ new and ongoing needs.

Within the caregiving tasks-related themes, caregivers described the enormity of their caregiving tasks in the post-acute HHC. All caregivers in our sample received both HCBS and HHC, including longer-term home health aide assistance. Nevertheless, caregivers in our study were highly engaged in managing care needs in the post-acute HHC setting, which is consistent with past research examining caregivers’ perspectives during other care transitions (Hahn-Goldberg et al., 2018). In addition to providing direct physical care, caregivers were overseeing home health aides’ activities, and educating them in the patient’s preferences. Nurses can leverage caregivers’ existing knowledge regarding the older adults’ health history and preferences to anticipate care needs and to provide practical, tailored information to manage them (Mitchell et al., 2018). Caregivers also coordinated appointments, obtained equipment, and communicated with providers. However, many caregivers described coordinating care as a struggle or a fight. Dossa et al. (2012) identified communication issues – among providers, patients, and caregivers – as primary contributors to the challenges both patients and caregivers experience during care transitions. To reduce caregivers' stress of managing complex care needs in the post-acute setting, nurses should ensure caregivers are well-integrated and well-informed of the older patient's plan of care (Foust et al., 2012). Nurses can also facilitate obtaining the supports and equipment needed for PF needs, which can positively impact caregiver preparedness and reduce caregiver strain (Toye et al., 2016).

Caregivers in our study received little assistance from other family or friends. Encapsulated by the words "the only one," many caregivers in our study perceived their intense caregiving role as a solitary endeavor. As such, caregivers described the challenges of balancing the care for the older adult with their own health needs, and family and work responsibilities. Past experiences and a sense of love and obligation for care recipients helped prepare caregivers in our sample to manage the complex PF needs in the post-acute HHC setting. Prior research also suggests that caregivers are able to reconcile the management of diverse care needs by drawing on the confidence of their experiences (Byrne, Orange, & Ward-Griffin, 2011). Nevertheless, caregivers' well-being is associated with patient outcomes, such as symptom expression and quality of life (Bidwell, Lyons, & Lee, 2017). Caregivers of older adults transitioning from hospital-to-home are especially vulnerable to the physical and emotional effects of stress associated with balancing life responsibilities with evolving caregiving activities (Hajek & König, 2016). Thus, when evaluating patients, HHC nurses should also incorporate an assessment of caregivers' psychosocial and physical health status to identify those who may need additional supports and services, referral to healthcare providers for their own health issues, or even to discontinue their caregiving role.

Most caregivers perceived post-acute HHC services as highly beneficial in helping with the reported challenges managing the PF needs of older adults. Caregivers were generally receptive and appreciative of the training received from HHC providers. Nevertheless, caregivers provided some insight into possible areas for improvements in HHC services. One recurring issue mentioned among caregivers was that they felt that HHC services were too short, leaving them in a position where they scrambled to fill gaps in care, often providing needed care themselves. Decision-support tools could enhance determinations of when to discharge patients from HHC services (O'Connor, Moriarty, Madden-Baer, & Bowles, 2016), and to identify patients who may need longer term services and supports. Additionally, diverse interventions to enhance support and training could be employed to better prepare caregivers for the completion of post-acute HHC services. Such interventions may include caregiver workshops to enhance training and preparedness (Leutz et al., 2002), connecting caregivers with internet resources (Stone, 2014), telephone follow-up by nursing staff after discontinuation of HHC services (Feld, Madden-Baer, & McCorkle, 2016), and the use of telemedicine for ongoing evaluation of the older adults' health (Lindauer et al., 2017).

Limitations

Our study had some important limitations. We recruited caregivers from a single HHC agency in the northeast, which may limit transferability of study findings to other groups across the nation. Our study sample was small; however, we did achieve data saturation. Although we were able to recruit a racially/ethnically diverse sample, most of our caregiver participants were female. A majority of caregivers are female (AARP Public Policy Institute & National Alliance for Caregiving, 2015), which may account for the difficulty in recruiting more males for our study. Nevertheless, research regarding the experiences of male caregivers of older adults is growing, and future qualitative work should incorporate the voices of this underrepresented group of caregivers. All caregiver participants in our study were experienced, having cared for the older adult for several years. This characteristic was expected due to recruitment of caregivers of HHC patients who were older and likely had multiple chronic conditions. Thus, findings from this study may differ for newer or less experienced caregivers. Purposive sampling methods designed to select less experienced caregivers may be needed to increase representation of this population and give voice to their unique training and support needs during the post-acute period. Additionally, examining different stressors by work status could provide greater insight into unique issues faced by working and non-working caregivers. Our study specifically focused on PF needs. Caregivers in our study also reported difficulties managing additional caregiving activities, especially medical-nursing tasks. Future research should address the perceptions of caregivers in performing these tasks and in the receipt of training and support for these tasks in the HHC setting. This added information would be useful for identifying important training gaps for caregivers managing complex care needs of older adults in the post-acute setting.

Conclusion

Caregivers play an active and critical role in managing the PF needs of older adults who return home after hospitalization. Nurses delivering care in the post-acute setting are uniquely poised to train, and support caregivers. Understanding caregivers' perceptions of their activities and role in managing PF needs for older adults across care transitions can inform future research and practice in the post-acute HHC setting.

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Table 1.

Sample Caregiver Questions Modeled after Theory of Dependent Care

Theoretical Focus	Question
Patient	Could you tell me about X's recent hospital stay?
Caregiving Tasks	After X came home from the hospital, what activities did X needed help with?
Caregiver	I would like you to think about the time after the home care provider left. What were your reactions after the home care provider left? – Probe: Were you confident about caring for X? – Probe: Did you have some remaining questions or concerns? If so, what were they? – Probe: Did you understand the plan for X's care? What were any barriers to being prepared to care for/help X? What were the things that helped you be prepared to care for X?
Home Environment	How involved were other family members and/or friends during this time?

Table 2.

Caregiver Characteristics (N=20)

Variable	n (%) unless otherwise noted
Caregiver Characteristics	
Age (mean, SD)	58 (13)
Gender	
Male	6 (30)
Female	14 (70)
Married	7 (35)
Race/Ethnicity	
White	7 (35)
Black	8 (40)
Hispanic/Latino Ethnicity	5 (25)
Education	
Some high school, did not graduate	1 (5)
High school or GED	5 (25)
Some college or 2-year degree	7 (35)
College graduate	3 (15)
Post-graduate	4 (20)
Employment status	
Retired	8 (40)
Working part-time	1 (5)
Working full-time	9 (45)
Unemployed	2 (10)
Self-reported health	
Excellent – Very Good	9 (45)
Good-Fair	11 (55)
Caregiving Characteristics	
Care recipient	
Parent	13 (65)
Spouse	1 (5)
Sibling	3 (15)
Other	3 (15)
Lives with care recipient	10 (50)
Years providing care (mean, SD)	14 (13)

Note. SD=standard deviation, GED=general education