ORIGINAL RESEARCH

Patient, Caregiver, and Clinician Perspectives on Expectations for Home Healthcare after Discharge: A Qualitative Case Study

Christine D Jones, MD, MS[1]; Jacqueline Jones, PhD, RN, FAAN[2]; Kathryn H Bowles, PhD, RN, FAAN, FACMI[3,4]; Shara Schroeder, MA[5]; Frederick A Masoudi, MD, MSPH[6]; Eric A Coleman, MD, MPH[7]; Jason Falvey, PhD, PT[8,9,10]; Cari R Levy, MD, PhD[7,9]; Rebecca S Boxer, MD, MS[9,11]

[1]Division of Hospital Medicine, Department of Medicine, University of Colorado Anschutz Medical Campus, Aurora, Colorado; [2]College of Nursing, University of Colorado Anschutz Medical Campus, Aurora, Colorado; [3]School of Nursing, University of Pennsylvania, Philadelphia, Pennsylvania; [4]Center for Home Care Policy and Research, Visiting Nurse Service of New York, New York, New York; [5]College of Liberal Arts and Sciences, Department of Sociology, University of Colorado, Denver, Colorado; [6]Division of Cardiology, University of Colorado Anschutz Medical Campus, Aurora, Colorado; [7]Division of Health Care Policy and Research, University of Colorado Anschutz Medical Campus, Aurora, Colorado; [8]Physical Therapy Program, Department of Physical Medicine and Rehabilitation, University of Colorado Anschutz Medical Campus, Aurora, Colorado; [9]Veterans Affairs Medical Center, Denver, Colorado; [10]Yale School of Medicine, New Haven, Connecticut; [11]Division of Geriatric Medicine, University of Colorado Anschutz Medical Campus, Aurora, Colorado.

BACKGROUND: Patients discharged from the hospital with skilled home healthcare (HHC) services have multiple comorbidities, high readmission rates, and multiple care needs. In prior work, HHC nurses described that patients often express expectations for services beyond the scope of skilled HHC.

OBJECTIVE: The objective of this study is to evaluate and compare expectations for HHC from the patient, caregiver, and HHC perspectives after hospital discharge.

DESIGN/PARTICIPANTS: This was a descriptive qualitative case study including HHC patients, caregivers, and clinicians. Patients were discharged from an academic medical center between July 2017 and February 2018.

RESULTS: The sample (N = 27) included 11 HHC patients, eight caregivers, and eight HHC clinicians (five nurses and three physical therapists). Patient mean age was 66 years and the majority were female, white, and had Medicare. We observed main themes of clear and unclear expectations for HHC after discharge. Clear expectations occur when the patient and/or caregiver have expectations for HHC aligned with the services received. Unclear expectations occur when the patient and/or caregiver expectations are uncertain or misaligned with the services received. Patients and caregivers with clear expectations for HHC frequently described prior experiences with skilled HHC or work experience within the healthcare field. In most cases with unclear expectations, the patient and caregiver did not have prior experience with HHC.

CONCLUSIONS: To improve HHC transitions, we recommend actively engaging both patients and caregivers in the hospital and HHC settings to provide education about HHC services, and assess and address additional care needs. *Journal of Hospital Medicine* 2019;14:90-95. © 2019 Society of Hospital Medicine

Patients who are discharged from the hospital with home healthcare (HHC) are older, sicker, and more likely to be readmitted to the hospital than patients discharged home without HHC.[1-3] Communication between clinicians in different settings is a key factor in successful transitions. In prior work, we focused on communication between primary care providers, hospitalists, and HHC nurses to inform efforts to improve care transitions.[4,5] In one study, HHC nurses described that patients frequently have expectations beyond the scope of what skilled HHC provides,[5] which prompted us to also question experiences of patients and caregivers after discharge with skilled HHC (eg, nursing and physical therapy).

In a prior qualitative study by Foust and colleagues, HHC patients and caregivers described disparate experiences around preparation for hospital discharge—patients expressed knowing about the timing and plans for discharge, and the caregivers frequently felt left out of this discussion.[6] In other studies, caregivers of recently discharged patients have described feeling excluded from interactions with clinicians both before and after discharge.[7,8] In another recent qualitative study, caregivers described uncertainty about their role compared with the HHC role in caring for the patient.[9]

As of 2016, a majority of states had passed the Caregiver Advise, Record, and Enable (CARE) Act, which requires hospitals to (1) record a family caregiver in the medical record, (2) inform this caregiver about discharge, and (3) deliver instructions with education about medical tasks that they will need to complete after discharge.[10] In the context of the CARE Act, hospitals are encouraged to increase caregiver engagement to prepare for

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***Corresponding Author:** Christine D. Jones, MD, MS; E-mail: christine.jones@ucdenver.edu; Telephone: 720-848-4289; Twitter: @jones_delong

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TABLE 1. **Demographics for Patients, Caregivers, and Home Healthcare (HHC) Clinicians**

	Patient (n = 11)	Caregiver (n = 8)	HHC Clinician (n = 8)
Age, average (years)	66	61	40
Female	82%	100%	50%
Race/Ethnicity			
White	73%	—	—
Hispanic	18%	—	—
Asian	9%	—	—
Insurance			
Medicare	73%	—	—
Medicaid	9%	—	—
Private	9%	—	—
Other	9%	—	—

discharge, but it is unclear whether this engagement is occurring for patients in general and HHC patients in particular. Because more than 80% of HHC patients have a primary caregiver outside of HHC, caregiver engagement around the time of discharge could be a key factor in care transitions.[11]

The objective of this study is to evaluate and compare expectations for HHC from the patient, caregiver, and HHC perspectives after hospital discharge. By combining all three groups into a case study, we aim to build on our prior work with HHC nurses to explore how expectations for HHC compare within and across cases of patients, caregivers, and HHC clinicians.

METHODS

Study Design

In this qualitative descriptive case study, we interviewed HHC patients, an involved caregiver, and the HHC clinician completing the first HHC visit within 7-14 days following hospital discharge. We chose this timeframe to allow patients to receive one or more HHC visits following hospital discharge.

Population

A convenience sampling strategy was employed to recruit a sample that would reflect a national sample of Medicare HHC patients based on age, sex, race, and ethnicity. Because a majority of HHC users in the United States are Medicare beneficiaries $\geq$65 years old,[12] eligibility was initially limited to patients $\geq$65 years old. Due to recruitment challenges, the age range was broadened to $\geq$50 years old in October 2017. Because our goal was to better understand the experience of general medicine patients with multiple comorbidities, we recruited patients from one general medicine unit at an academic hospital in Colorado. Patients on this unit were screened for eligibility Monday-Friday (excluding weekends and holidays) based on research assistant availability.

Criteria included are as follows: HHC referral, three or more comorbidities, resides in the community prior to admission (ie, not in a facility), cognitively intact, English speaking, and able to identify a caregiver participating in their care. Eligible patients were approached for written consent prior to discharge to allow us to contact them 7-14 days after discharge for an interview by phone or in their home, per their preference. At the time of consent, patients provided contact information for their informal caregiver. Caregiver eligibility criteria included the following: age ≥18 years and provides caregiving at least one hour a week before hospital discharge. HHC clinicians approached for interviews had completed the first HHC visit for the patient following discharge. Both caregivers and HHC clinicians provided verbal consent for interviews. All participants received a $25 gift card for participation in the study.

Framework and Data Collection

Our interview guides were organized by the Agency for Healthcare Research and Quality Care Coordination Framework, an approach we have taken in prior work.[4,5,13] We added questions about patient preparation and self-management support to build on findings from a prior study with HHC nurses and on prior work by Coleman and colleagues.[5,14] Sample questions from the interview guides for patients, caregivers, and HHC clinicians within key analysis domains are included in Appendix 1. The patient and caregiver interviews were completed by an individual with prior experience in social work and healthcare (SS). The HHC clinician interviews were completed by either this individual (SS) or a physician-researcher with experience in qualitative methods (CJ). Patients and caregivers could choose to be interviewed individually or together. All interviews were digitally recorded and transcribed verbatim.

Analysis

This study aimed to evaluate the clarity of expectations related to HHC after discharge within and across cases. We primarily explored domains of patient preparation, assessing needs and goals, and creating a plan of care for skilled HHC from patient and caregiver perspectives. Because qualitative work had been completed previously with HHC clinicians, HHC perspectives were used primarily for triangulation of perspectives

TABLE 2. **Clear and Unclear Expectations within and across Cases: Quotes from Patients, Caregivers, and Home Healthcare Clinicians**

Case #	Patient	Caregiver	HHC Clinician
Clear Expectations across Cases			
1	Patient: In home care, you're in your own home… You're comfortable. They'll recommend how you should have your home so you don't feel afraid and I think that's important.	NA	HHC RN: Oh yes… she's very prepared for it (HHC). She has had a wound …for over ten years we've been trying to get healed... So she knows home healthcare well. She prefers home healthcare just because she's more comfortable in her own home.
2	Patient: I think it (the transition to HHC) was made fairly easy for me. Of course myself being in the health field, my daughter being in the health field …helps a lot too because, you know, we both know what to expect. We both, you know, know what we should be doing.	Caregiver: …yeah, my role is pretty well defined and as a family we've all got our roles pretty well defined as well so that helps… they do like physical therapy and those types of things and we take care of everything else so it's been a great relationship.	HHC PT: …I think (the patient is) very prepared of what's coming… she knows what's ahead of her.
3	Interviewer: …have you been surprised at all by what home health is able to help you with or not able to help you with? Patient: Not really. I'm so…it's cool. I like it.	Caregiver: I don't know…I can't look at his leg and say this is the appropriate color of red or it's not…or it's too swollen… Only a nurse can. So if I know (the HHC nurse) is coming to check on it, it does make me feel better knowing that I don't have to worry quite so much about it being, you know, beyond my control.	HHC RN: …I think he's adjusting well. He has the support of his (caregiver) for sure but, you know … she works a full time job so I think …his expectations are realistic.
Unclear Expectations across Cases			
4	Patient: Well, um…I don't know…I didn't expect it to happen but um… Interviewer: You didn't expect home health to happen? Patient: Yeah.	Caregiver: Well, one of the things that I was wondering about is that whether she would help her with her shower. …I think one of the things is that we don't know exactly what the home healthcare is supposed to do.	HHC RN: …I don't feel like (the patient) was totally clear on why we were there in the first place so… I don't think she really had any expectations.
5	Patient: And so they (the HHC agency) find out I'm in the hospital so as soon as I come home, I get all kind of telephone calls. They say …I'm physical therapist. I'm going to come and see you and I say, 'For what? We just talked to you at hospital' so I didn't know what to do.	NA	HHC PT: …you know, she kind of didn't seem like she knew like, you know, why I was there and this and … it took her a long time when I was in the house to just sit down and get started…
6	Patient: …I had never had home healthcare before. It was very reassuring. I was a little uncertain, like it was designed for someone in more of a chronic debilitated state than me but I think I just didn't know much about it, you know, so I thought wow, I don't need these people coming forever, but indeed they're not coming forever.	NA	HHC RN: You know, she didn't quite know what I was going to do. She knew I was coming. Actually she did… I take it back, she did kind of know that I was going to be there to show her what to do, how's that?

Abbreviations: HHC, home healthcare; RN, registered nurse; NA, not applicable; PT, physical therapist.

about expectations where possible. The analysis team was composed of the two interviewers (SS and CDJ) and a qualitative methods expert (JJ). We used our established team-based inductive approach to develop themes around patient expectations and preparation for HHC, with deductive connections to the framework as applicable.[15,16] Two team members completed the initial coding after every one to three interviews to ensure the themes were developing iteratively. Group discussions including the third team member were used to resolve discrepancies and to complete a team-based iterative analysis until informational saturation for expectations after discharge was reached from the patient and caregiver perspectives (ie, no new codes were identified).[17] Once the team reached informational saturation with codes, we recruited three additional patients to ensure no new codes were identified in key domains before concluding recruitment. ATLAS.ti version 7.5.17 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to facilitate coding and analysis. This study was approved by the Colorado Multiple Institutional Review Board (protocol 17-0553).

RESULTS

Between July 2017 and February 2018, patients were recruited for participation in this study. Because the discharge destination plans could change multiple times in a hospitalization, the eligibility of patients for the study could change throughout hospitalization. To give further context about patients on this unit during the study timeframe, we completed a retrospective review of the 1,024 patient discharges from the unit and found that 38 patients met the eligibility criteria. Overall, 15 patients provided written consent (11 women and four men), and 11 completed interviews. The remaining four were unable to complete interviews due to a change in postdischarge plans that no longer included HHC (two patients) and hospital readmissions prior to interviews (two patients). In total, interviews were completed with 27 individuals: 11 patients, eight caregivers, and eight HHC clinicians (five nurses and three physical therapists). For five of the interviews, the patient and the caregiver requested to be interviewed together. In four cases, interviews were missing from the caregiver (one case), the HHC clinician (one case), or both the caregiver and the HHC clinician (two cases). Overall, perspectives were available from the complete triad of patients, caregivers, and HHC clinicians in seven cases, and perspectives were available from the patient and at least one other individual (ie, caregiver or HHC clinician) in two additional cases.

Patient interviews lasted an average of 43 minutes, caregiver interviews an average of 41 minutes, and HHC clinician interviews an average of 25 minutes. Patients were on average 66 years old (range 52-85 years), and most were women and white. Six of the patients had prior experience with HHC services, and five were new HHC patients. Primary diagnoses for patients included the following: sepsis (three cases), urinary tract or kidney infections (two cases), bone/hardware infections (two cases), *Clostridium difficile* infection (one case), acute respiratory failure with hypoxia (one case), aortic stenosis (one case), and acute pancreatitis (one case). For caregivers, the average age was 61 years, all were women, and they had a spouse or other family member in six cases and a nonfamily caregiver in two cases. HHC clinicians were an average of 40 years old, half were women, and the average time providing HHC was 4.4 years (Table 1).

We observed the two main themes of clear and unclear expectations for HHC after discharge. Clear expectations occur when the patient and/or caregiver have expectations for HHC that align with the services they receive. Unclear expectations occur when the patient and/or caregiver expectations are either uncertain or misaligned with the services they receive. Although not all interviews yielded codes about clear or unclear expectations, patients described clear expectations in five cases and unclear expectations in another five cases.

In nine cases with more than one perspective available, expectations were compared within cases and found to be clear (three cases), unclear (three cases), or discordant (three cases) across perspectives. For the discordant cases, the description of clear and unclear expectations differed between patients and either their caregiver or their HHC clinician. Patients and caregivers with clear expectations for HHC frequently described prior experiences with skilled HHC or work experience within the healthcare field. In most cases with unclear expectations, the patient and caregiver did not have prior experience with HHC. In addition, the desire for assistance with personal care for patients such as showering and housekeeping was described by caregivers with unclear expectations. The results are organized into clear, unclear, and discordant expectations from the perspectives of patients, caregivers, and HHC clinicians within cases.

Clear Expectations within Cases

Clear expectations for HHC were identified across perspectives in three cases, with sample quotes provided in Table 2. In the case of patient 1, the patient and HHC nurse had known each other for over two years because the patient had a wound requiring long-term HHC services. A caregiver did not complete an interview in this case. With patient 2, the patient, caregiver, and HHC physical therapist (PT) all describe that the patient had clear expectations for HHC. In this case, the patient and caregiver describe feeling prepared because of previously receiving HHC, prior work experience in the healthcare field, and a caregiver with experience working in HHC. In the case of patient 3, the patient had previously received HHC from the same HHC nurse.

Unclear Expectations across Cases

For the three cases in which unclear expectations were described across perspectives, two of the patients described being new to HHC, with representative quotes in Table 2. Patient 4 and her caregiver are new to HHC and describe unclear expectations for both the HHC referral and the HHC role, which was also noted by the HHC clinician. Of note, the caregiver for patient 4 further described that she was unable to be present for the first HHC visit. In the case of patient 5, although the patient had previously received HHC, the patient describes not knowing why the HHC PT needs to see her after discharge, which is also noted by the HHC PT. Finally, both patient 6 and her HHC PT describe that the patient was not sure about their expectations for HHC and that HHC was a new experience for them.

Discordant Expectation Clarity across Cases

In three of the cases, the description of clear and unclear expectations was discrepant across roles. In case 7, the caregiver and patient are new to HHC and express different perspectives about expectations for HHC. The HHC clinician, in this case, did not complete an interview. The caregiver describes not being present for the first HHC visit and no awareness that the patient was being discharged with HHC:

> **Caregiver:** Well, we didn't even know she had home health until she got home.

The same caregiver also expresses unclear expectations for HHC:

> **Caregiver:** It's pretty cloudy. They (the HHC clinicians) don't help her with her laundry, they don't help with the housekeeping, they don't help… with her showers so somebody is there when she showers. They don't do anything. The only two things like I said is the…home healthcare comes in on Wednesdays to see what she needs and then the therapy comes in one day a week.

However, the patient expresses more clear expectations that are being met by HHC.

> **Patient:** They (HHC) have met my expectations. They come in twice a week. They do vitals, take vitals and discuss with me, you know, what my feelings are, how I'm doing and I know they have met my expectations.

In case 8, although the patient describes knowing about the HHC PT involvement in her care, she expresses some unclear expectations about an HHC nurse after discharge.

> **Patient:** As far as home health, I didn't have a real … plan there at the hospital… They knew about (the HHC PT) coming once a week but as far as, you know, a nurse coming by to check on me, no.

However, the HHC PT describes feeling that the patient had clear expectations for HHC after discharge:

> **Interviewer:** Can you reflect on whether she was prepared to receive home healthcare?
>
> **HHC PT:** Yeah, she was ready.
>
> **Interviewer:** …do you feel like she was prepared to know what to expect from you?
>
> **HHC PT:** Yeah, but I think that comes from being a previous patient also.

Finally, in case 9, the patient describes clear expectations for HHC even though they were new to HHC:

> **Patient:** …I knew what the PT was going to do and …I still need her because I've lost so much weight so she's been really good, instrumental, at giving me exercises… Occupational therapist…she's going to teach me how to shave, she's going to teach me how to get ready for the day.

The HHC PT describes that although the patient knew the PT role, they reflect that the patient may have been somewhat unclear about expectations for the first HHC visit:

> **HHC PT:** He knew all that it entailed with the exception of he didn't really know what the first day was going to be like and the first day I don't usually do treatment because it does take a long time to get all the paperwork signed, to do the evaluation and the fact that it takes two hours to do that note.

DISCUSSION

In this qualitative case study with HHC patients, caregivers, and clinicians, the participants described varying levels of expectation clarity for HHC after discharge. We triangulated across and within cases and found three cases with clear expectations and three cases with unclear expectations for HHC across perspectives. In three additional cases, we found discordant expectations across perspectives: patients and HHC clinician expectations differed in two of the cases and a patient and caregiver differed in one case. Of interest, in all three cases of clear expectations across perspectives, the patients and/or caregivers had prior HHC or healthcare work experience. In contrast, in the cases of two caregivers with unclear expectations, neither had prior HHC experience and both described expectations for assistance with personal care or housekeeping. Our findings suggest the need to improve caregiver engagement in HHC decision-making and care delivery, even in the time following the passage of the CARE Act. In addition, our findings suggest that patients and caregivers with unclear expectations for HHC may benefit from enhanced education about HHC services.

Prior studies in this area have included a qualitative study HHC patients, caregivers, and clinicians by Foust and colleagues in which multiple caregivers described finding out about the discharge from the patient or other caregivers, rather than being actively engaged by clinicians.[6] In another recent qualitative study by Arbaje and colleagues, a majority of caregivers described "mismatched expectations" about HHC services, in which caregivers were unclear about their role compared with the HHC role in caring for the patient.[9] Of interest, HHC clinicians in the Arbaje study described one of their key tasks to be "expectation management" for receipt of HHC services.[9] In our study, the caregivers who described unclear expectations were not able to be present for the first HHC visit, which may have been a missed opportunity for the HHC clinician to clarify and manage expectations. Overall, findings from each of these studies support that consistent engagement and education from the hospital and HHC clinicians are needed to prepare patients and caregivers to know what to expect from HHC.

When caregivers have unclear expectations for HHC, they could be expressing the need for more support after hospital discharge, which suggests an active role for hospital teams to assess and address additional support needs with the patients and caregivers. For example, if the patient or caregiver request additional personal care services, a home health aide could help to reduce caregiver burden and improve the support network for the patient. In a prior study in which patients were asked what would help them to make informed decisions about postacute care options, the patients described wanting to receive practical information that could describe how it would apply to their specific situation and perceived needs.[18] To provide this for patients and caregivers, it would follow that hospitals could provide information about skilled HHC nursing and therapies and information about services that could meet additional needs, such as home health aides.

In the context of the CARE Act, in which hospitals are encouraged to increase family caregiver engagement to prepare for discharge, findings from this and other studies suggest an opportunity to improve caregiver partnership in HHC transitions. As a result of this work, we recommend intentionally engaging and including caregivers in addition to patients in both the hospital and HHC settings to clarify expectations. Steps to clarify expectations with both patients and caregivers should include the following: (1) providing education and clear expectations for HHC through verbal interactions and written materials, and (2) assessing and addressing additional needs (eg, personal care) that patients and caregivers may have. To support these efforts, multidisciplinary teams could use previously studied interventions and tools for guidance as they engage caregivers throughout care transitions processes.[10,19]

Limitations of this study include that it was a small qualitative case study of patients, caregivers, and HHC clinicians from one medical unit at one academic medical center. Most patients in this study had Medicare insurance, were 65 years and older, white, and female. A recent analysis of Medicare HHC users found that 63% were female and 75% were white, which shows that females were overrepresented in our study.[1,2,11] The perspective of Black and non-English speaking patients are missing from our study. Finally, we only interviewed individuals in three roles of complex transitions to HHC, and there are likely many additional perspectives on each of these transitions, which could provide additional insights. Results are not generalizable or transferable beyond this context.

In conclusion, to improve care transitions for HHC patients and their caregivers, emphasizing engagement of caregivers is key to ensure that they are educated about HHC, provided with additional support as needed, and included in initial HHC visits once the patients are at home. Even though patients and caregivers with prior HHC experience often had clear expectations for HHC, a strategy to uniformly engage caregivers across a range of experience can ensure caregivers have all the information and support needed to optimize care transitions to HHC.

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