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## Featured Article

# Patients' and caregivers' perspectives in determining discharge readiness from home health

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## ABSTRACT

There are no national, empirically derived clinical decision support tools to assist the interprofessional home health team in determining readiness for discharge from skilled home health. Eliciting patient and family caregiver perspectives around readiness for home health discharge is integral to developing tools that address their needs in this decision-making process. The purpose of this study was to describe the factors home health patients and their family caregivers perceive as critical when determining readiness for discharge from services. A qualitative descriptive study was conducted among skilled home health recipients and their family caregivers who were either recently discharged or recertified for additional care from two different Medicare-certified skilled home health agencies. Nine themes emerged: self-care ability, functional status, status of condition(s) and symptoms, presence of a caregiver, support for the caregiver, connection to community resources/support, safety needs of the home environment addressed, adherence to the prescribed regimen, and care coordination.

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## Introduction

In 2018, 3.4 million Medicare beneficiaries received approximately 6.3 million skilled home health episodes, costing Medicare 17.9 billion dollars from over 11,500 Medicare-certified skilled home health agencies.<sup>1</sup> Medicare relies upon home health clinicians to evaluate the needs of home health patients.<sup>1</sup> Based upon the needs identified, home health clinicians decide when to discharge from skilled home health or to recertify patients for additional care.<sup>1</sup> However, there are no national, empirically derived guidelines or clinical decision support tools to assist home health clinicians in making these common and important decisions. Currently, these understudied decisions rely upon individual clinicians' judgement to determine readiness for discharge from skilled home health services.

There is a lack of evidence-based practice recommendations for home health.<sup>2,3</sup> The Centers for Medicare and Medicaid (CMS)

Home Health Conditions of Participation specify that a home health recipient is to be discharged when needs are met, is no longer homebound or no longer requires skilled care.<sup>4</sup> Similarly, The Joint Commission—the certification and accreditation agency of health care quality in the United States—requires home health agencies to complete discharge planning and ensure that patient needs are met, but neither entity offers specific, evidence-based criteria to determine patient readiness for discharge. Prior research has noted inconsistent decision-making among home health clinicians.<sup>1,5</sup> Research has found the frequency, duration, and timing of home health to be entirely dependent on individual clinician judgement.<sup>5,6</sup> Individual nursing experience and agency protocols can further impact home health utilization.<sup>7</sup> A similar problem regarding readiness for hospital discharge exists in acute care. However, the use of a standardized, evidence-based screening tool to determine discharge readiness indicates that hospitalized patients flagged as ready for discharge are more appropriately discharged<sup>8,9</sup> and less likely to be readmitted to the hospital.<sup>10</sup> We aim to achieve these outcomes for home health patients.

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The ultimate purpose of this study and line of inquiry, is to develop a clinical discharge decision support tool that reflects all stakeholders (end-users and benefactors) in its development<sup>11</sup> including the voices of patients and their caregivers.<sup>12</sup> Therefore, the purpose of this qualitative descriptive study was to describe the factors skilled home health patients and their family caregivers perceive as critical when determining readiness for discharge. To our knowledge, this has not been previously studied.

#### *Growing population of chronically ill older adults*

Chronic illness is on the rise as 80% of older adults have at least one, and 77% have at least two.<sup>13</sup> Older adults suffer a disproportionately high rate of chronic illness; nearly 26% of all Medicare beneficiaries have five or more chronic conditions,<sup>14</sup> contributing to this population's higher rates of hospitalization and physician and emergency room visits. Older adults managing multiple comorbidities often experience transitions in care, which are often mismanaged,<sup>15</sup> making them vulnerable for poor outcomes.<sup>16</sup> Multiple studies reveal that many older adults discharged from hospitals are not ready for discharge due to a variety of reasons including a lack of required formal and informal support,<sup>17</sup> poor quality of discharge teaching,<sup>18–20</sup> medication discrepancies,<sup>19</sup> inadequate discharge instructions,<sup>21</sup> and living alone,<sup>20</sup> further increasing their vulnerability.

Compared to the general Medicare population, the 3.4 million older adults who receive skilled home health tend to be older, live alone, have two or more limitations with activities of daily living (ADLs), report fair or poor health, have an income under 100% of the Federal Poverty Level, and be more likely to suffer from multiple comorbid conditions. In fact, 51% of skilled home health recipients suffer from five or more chronic conditions compared to 25.9% of the general Medicare population.<sup>14</sup> Furthermore, early discharge from skilled home health among older adults is associated with an increased need for rehospitalization, a shorter time to hospitalization, and a shorter time to death.<sup>22</sup>

#### *Policy changes that challenge home health discharge decision making*

The Improving Medicare Post-Acute Care Transformation (IMPACT) Act of 2014 requires the submission of standardized patient assessment data across several post-acute providers including home health<sup>23</sup> to allow for comparisons across settings and to promote improvements in quality of care and patient outcomes.<sup>24</sup> The 'Discharge to Community' performance measure requires home health agencies to anticipate and plan to prevent death and unplanned hospital readmissions for 31 days following home health discharge. The Patient-Driven Groupings Model (PDGM) is a recent CMS policy change implemented on January 1, 2020 that shortened home health episodes from 60- to 30-days of care.<sup>25</sup> The PDGM was developed to improve payment accuracy and reduce payment incentives.<sup>26</sup> Both policies, providing care in 30-day episodes while remaining in good standing with the Discharge to the Community performance measure, pose challenges with determining discharge readiness from home health. Discharge from home health is a major care transition for older adults and their caregivers with serious implications for outcomes such as hospitalization and quality of life.<sup>15</sup>

Home health agencies, including those involved in this study, began to anticipate these changes to Federal home health policy as they were announced long before their effective dates resulting in reduced number of visits per patient and shorter episodes before the policy was instituted.<sup>1</sup> A clinical decision support tool could help to identify patients who, based on their characteristics as they near the end of a home health episode, need additional care. This evidence-based approach<sup>23</sup> to providing home health is especially timely given the current and expected increased population of older adults who

suffer from multiple chronic conditions<sup>13,14</sup> and recent policy changes aimed at reducing services.<sup>23–26</sup>

#### *Patient and family caregiver-centered research*

Patient-and family-centered outcomes are those considered meaningful to patients and their family caregivers<sup>27</sup> and are recommended by the Affordable Care Act of 2009.<sup>28</sup> A growing body of knowledge demonstrates that research aimed at supporting caregivers can significantly improve the quality of care delivered as well as improve the well-being and quality of life for both care recipients and their caregivers.<sup>29</sup> An important component of effective health innovation is to include all stakeholders in its development,<sup>11</sup> including the voices of patients and their caregivers.<sup>12</sup> However, prior research indicates family caregivers have a critical role to play but are often overlooked and have been described as invisible.<sup>21</sup>

At present, home health clinicians have no formal, evidence-based clinical criteria to assist them in determining an older adult's readiness for discharge. To begin to fill this gap in research and practice and to develop evidence-based criteria for home health discharge, we sought the opinions of skilled home health patients and their family caregivers. This qualitative descriptive study explored the factors skilled home health patients and their family caregivers perceive as critical when determining readiness for discharge. These data will inform the development of a clinical decision support tool that incorporates input from all stakeholders, including patients and their family caregivers.

## **Methods**

### *Design*

We used a qualitative descriptive design<sup>30</sup> and conducted separate interviews with patients and family caregivers. Individual interviews are commonly used in healthcare research as an effective way to elicit rich data around a participant's experience related to some phenomenon.<sup>31</sup> Individual interviews also provide an opportunity to obtain evidence that healthcare professionals can employ to develop improved healthcare practices.<sup>32</sup> As recipients of skilled home health, the opinions of patients and their family caregivers are critical in determining what is most meaningful and essential in assessing readiness for discharge.

### *Setting and participants*

The study was conducted in two large, Medicare-certified skilled home health agencies in two differing states in the Northeastern region of the United States. Eligibility criteria included skilled home health patients, 65 years of age or older, who were discharged or recertified for additional skilled home health (no more than two weeks prior) and their family caregivers. Patients and caregivers with moderate to severe cognitive impairment were excluded. A caregiver was not required for the eligible older adult to participate. Agency administrators at the two participating home health agencies scanned the agency's daily census looking for patients who were discharged or recertified for an additional 60-day episode of care within the prior two weeks. The administrator telephoned potentially eligible patients and/or their family caregivers to describe the study, elicit interest and obtain permission for the PI to contact them. If agreeable and after applying purposive sampling, the PI telephoned the potential research participant to prescreen for eligibility and to determine a time agreeable to the patient and/or caregiver if eligible. Participants were screened upon the interviewer's arrival of the participant's home. Patients and family caregivers with moderate to severe

cognitive impairment were excluded from participation (5 or more errors on the Short Portable Mental Status Questionnaire [SPMSQ]).<sup>33</sup>

Study participants were purposively sampled by the research team to achieve a sample diverse in age, race, primary diagnosis, and duration of home health length of stay among discharged and recertified patients and their family caregivers. Forty-two potential participants were called by agency staff and invited to participate. Thirty-nine home health patients agreed. However, one was deemed ineligible due to age, seven refused when called by the researcher and eight could not be reached within the specified time frame of two weeks from recertification or discharge from services. A final sample of eighteen home health patients and five family caregivers consented to participate. Individual interviews were conducted in 2016 in patient or family caregiver homes (based on participant preference), and one caregiver interview was conducted via telephone.

### Procedures

The Institutional Review Boards at Villanova University, Visiting Nurse Service of New York and Main Line Home Health and Hospice Home Health Agencies approved this study. Written informed consent was obtained from all participants prior to data collection in the home. Sociodemographic data including age, gender, and race were collected directly from the participants. Data on home health diagnoses and length of stay in home health were retrieved from the respective home health agencies' administrative records. Study participants were compensated with their choice of a \$25 gift card to Target, CVS, or Duane Reed.

The first author (MO) and a trained research assistant conducted the interviews. Effective individual interviews require careful consideration of the interview environment.<sup>34</sup> To encourage patients and caregivers to speak freely, patients and caregivers were interviewed separately. The interviewers created a nonthreatening atmosphere by emphasizing that all ideas were valued and respected<sup>35</sup> while maintaining privacy. They also stressed that there were no right or wrong answers to questions, and that we were interested in their experiences and opinions.

Interviews were conducted using a semi-structured interview guide with the following three questions: "What are the health and wellness-related factors you consider important when you think about your discharge or need of more care (recertification) from home health?" "What are the non-health and wellness factors you consider important when you think about your recent recertification/discharge from home health?" "Did you feel ready for discharge from home health?" In addition, prompts were used to encourage elaboration on factors that patients and caregivers identified and to elicit why they believed they were recertified for additional home health or why they did not feel ready for discharge.

The interviews took place between April and August of 2016. Mean interview time was 24 minutes. Interviews were digitally recorded and transcribed verbatim by a professional transcription service. Interviewers also took field notes during participant interviews to record nonverbal behaviors and home environment points of interest. All transcripts were compared to the audio files for accuracy prior to data analysis. Transcripts from individual interviews with patients and family caregivers were analyzed to provide a holistic perspective of discharge readiness.

### Data analysis

Using a naturalistic approach, qualitative content analysis<sup>30</sup> was first used for manifest coding of all data and second, for thematic analysis<sup>36</sup> to group fragments of coded data into themes for describing patient and caregiver responses. Significant statements and key phrases were assigned codes by three members of the research team

(MO, HM, AS). Disagreements were discussed among co-investigators until consensus was reached. Codes were then sorted and organized into themes. Refinements were made after discussion.<sup>36</sup> Atlas.ti version 7 was employed to store and facilitate data organization, coding, and retrieval.

### Trustworthiness/Rigor

Three approaches were employed to ensure trustworthiness of the data.<sup>37,38</sup> First, during the coding process, the investigators created an audit trail by recording initial codes, themes, and operational memos. Second, debriefings were held with research team members to assist with data analysis and the identification and consensus of themes. Finally, member checks supported credibility of the findings. The team reviewed findings with three patients and two caregivers, all of whom agreed that the findings captured the ideas they shared.

## Results

### Participant characteristics

Of the 23 study participants, 18 were home health patients, and 5 were caregivers (Table 1). Six interviews were among patients or caregivers who were recertified, and 17 interviews were among those discharged from home health services. Slightly more than half of home health patients were women (n=10), the majority White (n=13), and their mean age was 76 years (65-93 years). Similarly, the majority of caregivers were women (n=4) and White (n=3), and their mean age was 71 (64-78). Mean length of stay in home health was 51 days (10-129). Eleven interviews occurred with Main Line Home Care and Hospice Home Care Agency participants and the remaining 12 interviews with patients with the Visiting Nurse Service of New York Home Health Agency. Data saturation was achieved after 23 interviews were completed.

### Qualitative data

Seventy-five codes were first identified and then conceptually categorized into nine themes. The nine themes emerged when considering discharge from home health from the 23 home health recipient and family caregiver interviews: (1) self-care ability, (2) functional status, (3) status of condition(s) and symptoms, (4) presence of a caregiver, (5) support for the caregiver, (6) connection to community resources/support, (7) safety needs of the home environment addressed, (8) adherence to the prescribed regimen, and (9) care coordination. In presenting our results, we note when both patients and caregivers voiced similar perspectives and when one or the other (but not both) voiced other perspectives. Of interest, patients and caregivers reported similar perspectives in many themes.

**Table 1**  
Participant characteristics.

	N
Home health patients Mean age 76 (65-93)	18
Female	10
White	10
Black	4
Hispanic	1
Family caregivers Mean age 71 (64-78)	5
Female	4
White	3
Black	1
Hispanic	1

### Self-care ability

Patients and caregivers considered the ability to perform self-care a critical concern when preparing for discharge. Patients expressed the need to feel confident with respect to what to eat, how to exercise, and their perception that their home health clinician and caregiver felt they were ready for discharge. Common among patients and caregivers was knowing what to do if the patient should become unwell and that plans were in place for health care provider follow up after discharge. Patients acknowledged the logistics of equipment, the motivation for self-care, and the ability to take care of themselves or have their needs met were also noted as helpful in feeling prepared for discharge. Having received education from the interprofessional health care team on how to manage independently was also acknowledged.

“The purpose of the medications was emphasized very well. Um, which was my antihypertensive, which was my, I don’t know, antibiotic.”

Patients identified the need for emotional well-being prior to discharge by specifically describing depression and its impact on self-care ability.

“I think there are a lot of seniors who are depressed. . .it would impact whether or not they are going to take care of themselves.”

### Functional status

Patients and caregivers identified “getting around” as central to discharge readiness. The ability to complete activities of daily living (ADL) served as common examples.

“. . .you know could I control my hygiene; could I shower? Could I shave? Could I, you know, all those important things.”

Patients also reported that improved strength and endurance with decreased fatigue as well as safety related to mobility were essential prior to discharge from home health. Not having any falls and reaching their maximum potential or at least showing progress was of particular importance to both patients and caregivers.

“Now I was able to get in and outta the door. I was able to get in and outta the car. In and outta the bed. So, I was able to function. In and outta the tub. Very slowly, but I was able to do it.”

### Status of conditions and symptoms

Patients and caregivers were greatly concerned about their ability to manage and be knowledgeable of the condition(s) and symptoms that prompted home health, but they were equally concerned for their comorbidities. Many patients acknowledged that comorbid conditions could either worsen their current health problem or could become its own problem,

“. . .the sugar level started spinning out of control because, you know, the operation knocked off the, the whole regulating system in the body. But then, blood pressure became a key concern.”

Throughout the interviews, condition stability and severity of illness were identified as important to home health discharge by patients and caregivers specifically related to pain management, stable blood sugar and healed wounds.

“I was glad to see them when they came because they can give me some perspective on what I had to do.”

### Presence of a caregiver

Several patients and caregivers expressed caregiver support as critical to success following discharge from home health and a key to their ability to stay at home. While patients and caregivers identified the day-to-day caregiver tasks of meal preparation and bill paying as important, patients and caregivers recognized the overall capabilities of a caregiver as the necessary component to a successful transition from home health and in navigating the health care system. Patients also described caregivers as advocates and instrumental in providing information to health care providers.

“She still to this day, uh, doesn’t realize how fortunate she is to have all the assistance and all the help that she has. She still some ways, somehow believes that she could still live alone.”

### Support for the caregiver

Caregivers acknowledged that while they wanted to help, they also needed support, especially education regarding the patient’s care and condition(s). Caregivers were most concerned with meeting the needs of the patient and feeling prepared to do so prior to discharge. Caregivers noted that caregiving was physically and mentally challenging and that they also needed to make sure they also cared for themselves so they could continue in their role. One caregiver stated,

“I don’t know what someone does that really wouldn’t have a caregiver. . .”

Overall, identification of a backup caregiver, support of their role, and how to include respite for themselves were important to them for discharge readiness.

“There are stressors that we should really think about, to make sure that you have someone. You know, if you don’t have a caregiver, if something happens to your caregiver, you’re not doing your patient any good.”

Although patients and caregivers acknowledged the importance of the presence of a caregiver, only caregivers voiced the need for caregiver support.

### Connection to community resources and support

Patients expressed comfort in knowing to whom in the community they could reach out for help with various services prior to home health discharge. Mobilization of community resources such as Meals on Wheels, church groups, and other forms of socialization were considered necessary by patients and caregivers before feeling ready for discharge. Caregivers also identified transportation services and how to access additional outpatient services such as therapy, laboratory, shopping and food support as critical to feeling prepared for discharge.

“One of the things that I think that, in my experience anyway, as I was, was to uh, connect people with agencies that did some of this stuff, not that they have to do it themselves, but they should really be aware of what is available for that person.”

### Safety needs

Patients and caregivers expressed appreciation of home health's evaluation of home safety. Recommendations to remove clutter and other fall risks was noted to be very helpful for feeling safe and ready for discharge by both patients and caregivers.

"...they went through to the bathroom checking and seeing if it was convenient for me, you know, whether I could slip and hurt myself."

In addition, some caregivers identified home maintenance and upkeep as important to maintain a safe living space. Implementing the home modifications recommended was also identified as helpful for discharge readiness and feeling prepared to live without home health services.

"...she checked the bathroom. She went in the family room. She had him go up the – with the steps in the family room to the loft. She had him go up them to check on, you know, can he do that..."

### Adherence to the prescribed regimen

Both patients and caregivers voiced the importance of following the plan of care established with them by their health care provider, especially related to managing their medications. Understanding the purpose of medications, taking them as prescribed, and the ability to physically obtain the medications were all discussed. Patients also identified adhering to exercise regimens, immunization schedules, and follow-up with health care providers to be important to discharge readiness.

"I realize the importance of doing exactly – you know when you're dealing with neurological issues, you really have to listen carefully to the clinicians or you're not going to have a good outcome."

### Care coordination

Prior to discharge, patients and caregivers expressed the need for assurance that all members of the team be informed of the pending discharge from home health services. Some patients noted the importance of communication between disciplines stating,

"If I've got to see five different people, that's really uncomfortable. I don't want to have to tell you, you, and you...like, don't you all sit and talk to each other?"

However, other patients and caregivers noted home health providers reported visit findings to other providers including their doctor, stating this supported their readiness for discharge from services.

"She writes to him on the computer thing, whatever, email."

### Discussion

Through individual interviews, home health patients and their caregivers described the factors important to them when clinicians are determining discharge readiness from skilled home health including: (1) self-care ability, (2) functional status, (3) status of condition(s) and symptoms, (4) presence of a caregiver, (5) support for the caregiver, (6) connection to community resources/support, (7) safety needs of the home environment addressed, (8) adherence to the prescribed regimen, and (9) care coordination. These factors, if considered by the interprofessional home health team prior to discharge, could support more informed and accurate decision making

with the potential to reduce poor outcomes among skilled home health recipients following discharge from services. Our previous study identified the factors that the interprofessional team of home health clinicians perceived as important when considering an older adult for discharge from skilled home health.<sup>39</sup> Our present results extend this earlier research by uncovering the factors home health recipients and their family caregivers believe to be important when considering readiness for discharge from home health, and to our knowledge, is the first study to examine this topic.

Patients and caregivers were insightful in identifying a broad range of individual, family, and community factors important to consider prior to discharge from home health. Factors related to the patient's ability to care for themselves were of paramount importance to both patients and caregivers and repeatedly voiced. Knowing what to eat, how to exercise as well as plans for health care provider follow-up were frequently discussed. The importance of self-care on patient outcomes is well documented for its significant role in maintaining health and well-being<sup>40</sup> particularly among the chronically ill. Also, the importance of emotional well-being was noted as the presence of depression was identified as an impediment to a successful discharge from home health. Prior studies among older adults report that heart failure and diabetic patients with depression display reduced self-care behaviors, specifically decreased medication adherence, diabetes knowledge, and adherence to diet and physical activity recommendations.<sup>41–43</sup>

Related to self-care ability was concern for a patient's functional status. Functional status is the ability to perform activities essential to self-care and independent living such as walking, bathing, dressing, and toileting. Patients and caregivers identified important milestones prior to discharge such as having the patient's ADL needs met, decreased fatigue, and not having any falls. As older adults age, the inability to perform ADLs and instrumental ADLs (IADL) independently becomes more prevalent.<sup>44</sup> Moreover, reduced functional status often results from a hospital admission,<sup>45,46</sup> making home health recipients at risk for functional decline as one out of three Medicare-reimbursed home health episodes are preceded by a hospitalization.<sup>1</sup> Further, requiring assistance with ADLs and IADLs is associated with increased risk for hospitalization among older adults<sup>47</sup> reinforcing the importance of functional status as a factor to consider regarding a successful discharge from home health to self-care.

Both patients and caregivers identified the status of the home health recipient's health care conditions and symptoms as relevant to home health discharge, especially the patient and/or caregiver's knowledge of and ability to manage -multiple diagnoses and the severity of the illness(es). A recent report indicates that 60% of all Americans have at least one chronic condition and 42% have more than one. Moreover, a staggering 81% of adults 65 and older have multiple chronic conditions.<sup>48</sup> Patients with multiple chronic conditions have higher health care related costs<sup>49</sup> and experience higher hospital readmission rates,<sup>50</sup> making the status of a health recipients' conditions and symptoms critically important to both their success in self-care transitions and in reducing future health care utilization costs.

Many patients and caregivers described the presence of a family caregiver as essential to a successful discharge from home health. This highlights the central role of the caregiver, which often includes advocacy, navigating the health care system and communicating important information to providers. Interprofessional home health clinicians have also identified that having a willing and able caregiver able to assist older adults transitioning to self-care at home is critical to their success following home health discharge.<sup>39</sup> Older adults who live alone, or who have inadequate support from a caregiver have been shown to have an increased need for hospital readmission<sup>51</sup> and experience a higher frequency of falls,<sup>52</sup> social isolation,<sup>53</sup> poor nutrition,<sup>54</sup> frailty, or disease symptoms that may go unnoticed.<sup>55</sup> In



particular, social isolation or loneliness has been found to increase the risk for heart attacks, stroke, dementia, and death.<sup>56</sup> Over 42 million Americans age 45 or older report feeling lonely,<sup>57</sup> which often leads to increased health care utilization<sup>58</sup> costing Medicare an additional \$6.7 annually.<sup>59</sup> This will be of particular importance given the social isolation imposed by the COVID-19 pandemic.<sup>60</sup>

Caregivers are often family members, friends, and/or neighbors who are usually unpaid for their services<sup>29</sup> but who are critical to the successful management of chronically-ill older adults living in the community. The need to support caregivers is recognized as one of the largest but mostly overlooked challenges facing older adults<sup>61</sup> and was articulated by the caregivers interviewed in this study. Caregivers identified that receiving education about their loved one's care and condition(s) and identifying a back-up caregiver when needed were extremely important to them. In a recent Harvard Business School publication, a staggering 80% of caregivers who are employed reported that caregiving negatively affected their work productivity. Furthermore, employed caregivers expressed difficulty in balancing work, family and caregiving responsibilities often with limited financial and physical resources.<sup>58</sup> The support of family caregivers by both the health care system and employers will become even more requisite to managing older adults at home given the growing number of older adults, changing family structures, and the number of caregivers that are still employed.

According to AARP and the National Alliance for Caregiving (NAC),<sup>29</sup> adults taking on the role of caregiver has increased to 19.2% in 2020 from 16.2% in 2015, an increase of over 8 million caregivers. While more adults are taking on the role of caregiving, they are doing so for older adults who are medically more complex and who need increased support. Caregivers often report feeling physical, emotional, and financial stress.<sup>29</sup> One in four caregivers report having difficulty caring for their own health needs and report that caregiving has made their health worse.<sup>29</sup> Prior research confirms this, as caregivers of older adults have been found to be at greater risk compared to non-caregivers for depression, anxiety, stress, and emotional difficulties.<sup>61</sup>

In addition to the increased need to support caregivers, the demographics of caregivers are changing and will likely cause a shift in their needs. In the past, caregiving was considered mostly a role for women. However, Fernandez<sup>59</sup> reports 40% of caregivers are men and 25% are millennials – 73% of whom are still working.<sup>62</sup> One in 19 caregivers is enrolled in college classes, and 24% are caring for more than one individual.<sup>29</sup> Furthermore, single-parent, two working parents, and non-traditional family structures often have fewer resources to support their caregiving responsibilities.<sup>58</sup> Caregivers who reduce work hours or resign due to caregiving responsibilities suffer financial loss due to reductions in income, Social Security, and retirement benefits while simultaneously incurring out-of-pocket expenses to meet the older adult's care needs.<sup>61</sup> These factors highlight the need for the interprofessional skilled home health team to pay close and special attention to the needs of family caregivers as their role in supporting a home health recipient's transition from services to self-care is critical.

Patients and caregivers in this sample, initiated access to community-based resources, such as transportation services, Meals on Wheels, outpatient therapy, and outlets for socialization. These findings support prior research indicating that access to community services is important for chronically ill older adults living in the community,<sup>57</sup> particularly for those who live alone,<sup>39</sup> but it is also important for their caregivers.<sup>58</sup> Unfortunately, one in four caregivers report having difficulty finding affordable community support.<sup>29</sup> This could be even more challenging in the post COVID-19 environment especially among older adults who are socially disadvantaged.<sup>60</sup> When community-based services are out of reach for older adults, caregivers often bear that burden, compounding their stress as they juggle their own lives to fill the gaps.<sup>29</sup>

Like interprofessional home health clinicians,<sup>39</sup> patients and their caregivers agreed that home safety is important to establish prior to discharge. Patients and caregivers acknowledged the need for home maintenance and the removal of clutter and other fall risks for home health discharge to be successful. Often minor modifications of the home environment are necessary and successful in reducing functional disability and safety risks.<sup>63</sup> Some minor repairs include installation of bathroom grab bars, lowering kitchen shelves, and repairing unstable railings. These modifications have been found to allow older adults to navigate their own homes more easily and with increased safety.<sup>64</sup> However, interprofessional home health clinicians report that older adults who live alone often need increased time in home health or require additional referrals to community resources to safely discharge them from services despite home modifications.<sup>39</sup> While not the answer for all safety concerns in the home, many older adults report that having some home modifications helped them better care for themselves and increased their confidence in their self-care ability.<sup>65</sup>

Patients and caregivers recognized their role in a successful transition from home health to self-care by adhering to the regimen(s) recommended by their health care provider(s) and home health team. They voiced that medication management was of great importance and that exercising and follow up with their health care providers are also necessary. The concerns related to managing medications are supported by prior work that found medication errors among home health recipients experiencing a transition in care is common and can lead to poor outcomes.<sup>19,21</sup>

A documented 40% of patients do not adhere to treatment recommendations and could reach as high as 70% if recommendations are complex or require lifestyle changes.<sup>66,67</sup> Furthermore, non-adherence has been linked to increased vulnerability among older adults.<sup>68</sup> As previously noted, compared to the general Medicare population, older adults who receive home health are more likely to be older, live alone, require assistance with ADLs, and suffer from multiple comorbid conditions.<sup>14</sup> Therefore, it is crucial that the interprofessional home health team actively engage older adults and their family caregivers in applying individualized evidence-based teaching methods in order to successfully transition older adults to self-care,<sup>16</sup> specifically in relation to medication management.

The older adult's appreciation of the importance of care coordination and interprofessional communication between the home health care team and additional providers was striking. Home health recipients and caregivers typically have six to seven health care providers to coordinate,<sup>29</sup> often an overwhelming task as they navigate the health care system. The assurance that all members of the health care team are informed and in agreement with the patient's discharge from services gave great comfort to patients and caregivers. The impact of poor communication among health care providers on patient outcomes is well documented.<sup>69,70</sup> Care coordination is believed to improve the effectiveness, safety, and efficiency of health care<sup>71</sup> and involves activities such as communicating the care recipient's needs, goals, and status with the interprofessional members of the health care team, aligning resources with patient needs and connecting them with community resources.<sup>71</sup> Prior work also found that home health clinicians agree communication with other health care team members is central to an older adult's success in transitioning to independence,<sup>39</sup> especially during a care transition<sup>72</sup> such as home health services to self-care.

In summary, this study revealed nine overarching themes that reflect the factors older adults and their caregivers perceived as necessary to consider when evaluating discharge readiness from skilled home health. This work is among a growing body of evidence needed to develop an evidence-based home health discharge clinical decision support tool that provides a standardized approach in determining readiness for discharge from skilled home health services that can be

utilized by home health clinicians regardless of their discipline. Future research building on this study must include these factors in the development of the decision tool and require testing with a national sample to determine factors that are protective of and contribute to poor outcomes after home health services are discontinued. The results of this study provide a more comprehensive and patient- and family-centered understanding of the factors most important in determining readiness for discharge from skilled home health services. Including the factors older adult home health recipients and their caregivers believe are important to consider, along with those of the interprofessional home health team, will be integral to the development of such an urgently needed innovation. This study adds to the emerging understanding of readiness for discharge from skilled home health and clarifies the priorities of home health recipients and their caregivers when transitioning from home health to self-care.

### Limitations

The patients and caregivers in this study were a homogenous sample from two Medicare-certified skilled home health agencies in the Northeastern United States, limiting the transferability of the findings. Another limitation is that study data were collected in 2016. Patient and caregiver perspectives may have changed slightly given the passage of time and the COVID-19 pandemic. It is possible that older adult home health patients and their caregivers may welcome a reduced number of visits and a shortened length of stay to reduce exposure. It is also possible that given the isolation imposed by the stay-at-home orders, older adults and caregivers may welcome the access to health care and visitation, especially those patients who live alone. While it is difficult to surmise how the pandemic has altered the viewpoints of older adult home health patients and their caregivers, future research should include larger, national samples from varied regions with more male caregivers, racial diversity and an evaluation of how the pandemic may have changed perspectives related to discharge from home health.

### Conclusion

Overall, when considering discharge from home health to self or a caregiver's care, older adults and their caregivers were concerned with factors similar to those previously identified by interprofessional home health providers<sup>39</sup> – self-care, functional status, safety, stability of their conditions and symptoms, having and providing support to a caregiver, adherence to health care recommendations, connection to community resources, and coordination of care among all members of the health care team.

Identifying older adults who are not ready for discharge from skilled home health will provide the home health clinician with the knowledge and opportunity to provide additional care, assessment, and teaching to both the patient and family caregiver to potentially reduce adverse outcomes among this already vulnerable, chronically ill population. Decision support can assist health care providers to provide clinically appropriate care<sup>9,73,74</sup> and provide much needed direction in determining readiness for discharge from skilled home health. The input of patients and family caregivers in the development of such tools is critical to ensure patient- and family-centered home health care.

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