

“I Can Take Care of Myself!” Patients’ Refusals of Home Health Care Services

*A Report from a Roundtable Sponsored by United Hospital Fund
and the Alliance for Home Health Quality and Innovation*

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May 2017



Acknowledgments

United Hospital Fund acknowledges the support of the Alliance for Home Health Quality and Innovation as co-sponsor of this Roundtable. Jennifer Schiller, the Alliance's communications director, provided valuable assistance in organizing and implementing the Roundtable. Kristina Ramos-Callan, program manager of UHF's Families and Health Care Project, and Hillary Browne, administrative assistant, skillfully coordinated the event.

For more information on home care refusals, family caregiving, and the work of UHF's Families and Health Care Project, please contact Carol Levine at clevine@uhfnyc.org.

About United Hospital Fund

United Hospital Fund works to build a more effective health care system for every New Yorker. An independent, nonprofit organization, we analyze public policy to inform decision-makers, find common ground among diverse stakeholders, and develop and support innovative programs that improve the quality, accessibility, affordability, and experience of patient care. To learn more, visit www.uhfnyc.org or follow us on Twitter at @UnitedHospFund.

About Alliance for Home Health Quality and Innovation

The Alliance for Home Health Quality and Innovation (the Alliance) is a 501(c)3 research foundation comprised of leaders in the home health care community, with the mission of fostering research and education on the value of home health care to patients and the overall U.S. health care system. The Alliance is dedicated to improving the nation's health care system through development of high quality and innovative solutions aimed at achieving optimal clinical outcomes. To learn more, visit www.ahhqi.org or follow us on Twitter at @AHHQI.

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Foreword

With more than two decades of research, policy analysis, and forging of alliances, United Hospital Fund has had significant success in advancing an understanding of the role of family caregivers and the challenges facing them, both in the transition of patients from inpatient settings to home and in the often extended time following. One of the key issues that we have documented, in partnership with AARP Public Policy Institute and other colleagues, is the extent and complexity of caregiving for many elderly or chronically ill or disabled persons—with caregivers being pushed to carry out what are essentially nursing and medical tasks, often without adequate training and support.

It is paradoxical, then, that among patients eligible for home health care services post-discharge, a sizeable percentage decline to accept those services. That's a loss for both patients and caregivers, with studies documenting that patients receiving home health care are less likely to have unnecessary hospital readmissions, and more likely to have better quality of life.

In light of those findings, and with generous support from the Alliance for Home Health Quality and Innovation, UHF and the Alliance joined together to co-sponsor a roundtable, bringing together leaders from across the country, to further explore the issue of home care refusals and begin to craft policy and practical approaches to ensuring appropriate post-hospital care. This document presents the highlights of those day-long discussions and offers some initial pathways forward.

"I Can Take Care of Myself!" represents a continuation of UHF's commitment to empowering caregivers and to providing patients with optimal care and outcomes, as well as our longstanding tradition of partnering with other expert organizations to expand our knowledge and the impact of our work. We hope you find the report to be illuminating and useful, and welcome your comments on it and on our continuing efforts in this arena.

JAMES R. TALLON, JR.
President
United Hospital Fund

Highlights of the Report

- Medical care is moving from hospitals and other institutions into the community, which for most people means care at home, where they want to be. With shorter hospital stays and more complex post-discharge needs, the importance of home health care services, including skilled care and personal care, in discharge planning and transitional care is increasing.
- Some studies show that patients who receive home health care after hospital discharge are less likely to be readmitted. Other studies show that patients who receive home health care report better quality of life.
- Although data are limited, approximately 6-28 percent of patients eligible for home health care refuse these services, for a variety of reasons.
- Even less is known about the process by which hospital staff identify patients for referral to home health care, how they explain these services, and how well they address the full range of patients' and family caregivers' transitional care needs.
- Patients and their family caregivers have similar goals but may have different needs and attitudes about home health care.
- Policy and system barriers to accessing services include inflexible criteria for eligibility, inadequate payment for home health care agencies' services for patients with complex conditions, and shortages of trained workforce.
- Recommendations from Roundtable participants include interventions that improve communication about care challenges and home health care services, qualitative and quantitative research on all aspects of home health care refusals, policy changes to increase access and coordination, and continuity across providers and care settings.

Introduction: Untangling the Threads

Meet Mr. T, a hypothetical patient. He is 79 years old and frail. He was admitted to the hospital for treatment of his chronic obstructive pulmonary lung disease and wound care for a diabetes-related leg infection. Doctors in the hospital changed his medications, and a nutritionist recommended a special diet. Mr. T is a Medicare beneficiary. Because of his need for skilled nursing care (a nurse to check his medications, provide wound care, and monitor blood sugar and breathing) and because his functional limitations keep him homebound, he was eligible for Medicare home health care services. Yet when Mr. T went home, he did not receive these services. At home, he and his wife, who was not consulted on the discharge plan and who has health problems of her own, could not figure out which new medications were supposed to replace which old ones, and did not know how to treat the festering wound. Within 10 days, Mr. T was readmitted to the hospital, where he spent another difficult and costly week.

What happened? During his original hospital stay, a hospital discharge planner told Mr. T that he was eligible for home health care, but he immediately declined. “I can take care of myself,” he said, “and my wife can do whatever needs to be done. I don’t want any strangers in my house.” The discharge planner documented that home health care services had been offered and refused. End of story.

While this is a familiar scenario, it is not the only situation in which eligible patients* don’t get home health care services. Some patients may accept a referral for home health care in the hospital but refuse entry to the nurse when he or she arrives. Some patients may not be offered these services because, for example, they don’t fit the hospital’s criteria of “high risk for readmission.” Or the hospital may not have a clear understanding of Medicare guidance on whether the patient will meet the definition of “homebound.” Or there may not be enough time to organize the referral. Some insurance plans may have stringent requirements or high copayments for home health care services. And hospitals are not the only sites of potential referrals: skilled nursing facilities (SNFs), Emergency Departments (EDs), and community physicians can also refer patients who meet eligibility criteria for home health care. While Mr. T did not do well at home, some patients with similarly complex medical conditions manage quite well with only family care or previously established community services.

* “Patient” is used in this report to refer to hospitalized individuals, recognizing that “person” is the preferred term outside the hospital setting.

There is very limited information about how many people fall into each of these categories. So what is the problem? Patients can choose the services they want to receive, especially in their own home. Although family members are typically untrained, they can usually be counted on to provide post-discharge care that suffices to keep patients out of the hospital for 30 days or more. Navigators or other hospital staff can make follow-up phone calls. From a perspective solely focused on costs, some percentage of refusals is to be expected and not seen as problematic. Services that are refused do not add to costs.

From a broader perspective, however, the escalating trend toward providing care in the community depends on a smooth transition from hospital to home. Home health care can be an important part of a viable transition plan. Care at home is often complicated; nearly half of all family caregivers in a national survey reported that they performed complex medical/nursing tasks such as medication management, wound care, and operating machinery, and they did this mostly without training.¹ If the discharge plan falls apart and the patient has to be readmitted, or develops complications or adverse medication effects, there may be worse outcomes for the patient, financial penalties for the hospital, and additional costs to the payer.

The Purpose of the Roundtable

Recognizing the timeliness of the issue and the dearth of information about home health care refusals, in December 2016 United Hospital Fund's Families and Health Care Project (UHF), in partnership with the Alliance for Home Health Quality and Innovation, convened a one-day Roundtable to begin to unravel the interwoven threads of personal choice, quality care, and health system delivery and financing changes. The 27 participants included representatives of home health care agencies and consumer advocacy groups, clinicians, and policy experts.

The discussion focused on what is known about home health care refusals: the prevalence, who refuses, why patients refuse, and the implications for discharge planning practice and policy. Although the emphasis was on Medicare, which has a specific home health care benefit, other types of insurance were also discussed. The goal was not to increase caseloads for home health care agencies, but to ensure that patients and family caregivers have the information they need to make informed choices about the kinds of services and supports they need in post-acute care, and that the services offered are appropriate to their needs. Recognizing that the range of these services and supports includes many important non-medical needs, such as home-delivered meals, transportation, adult day care, and others, this Roundtable focused on Medicare home health care as an important part of a discharge plan. Recommendations for research, interventions, and policy analysis were also discussed.

Some initial questions that guided the discussion were:

- What is known about outcomes following refusal of home health care?
- What factors influence patients' choices about accepting home health care?
- What are patients told about their post-acute care needs at home?
- What do family caregivers understand in advance about their responsibilities, which may involve providing complex nursing care?
- What are systemic barriers in access and cost to home health care?
- What priorities should guide research?
- What practice changes can be instituted now?
- What policy changes would improve access and acceptance?

Over the course of the day, participants raised other questions and considerations. This report is a synthesis of the presentations and discussion, supplemented by additional research. It consists of seven sections:

- Regulatory framework and context
- Scope of the problem of home health care refusals
- Gaps in hospital discharge planning
- Differences in the views of patients and family caregivers
- Varying perceptions of the value of home health care
- Systemic barriers to access
- Recommendations

Regulatory Framework and Context

Home care is a complicated and often confusing sector of the health care system. Here are some basic definitions and distinctions that provide a context for the specific Roundtable discussions.

What Is “Home Care”? Definitions and Services

This report is about “home health care,” defined here as services provided under the Medicare home health benefit. Home health care is often confused with the more general term “home care” or the newer term “in-home care.” Under Medicare’s home health benefit, a beneficiary’s eligibility for home health care services is based on specific requirements. One such requirement is that a patient must need skilled care, and another is that care must be provided by a Medicare-certified home health agency (HHA).

Skilled care includes care related to a person’s medical condition, such as administration or management of medications, wound care, rehabilitation therapy, or other services. It is provided by a professional, such as a nurse, physical therapist, occupational therapist, speech therapist, respiratory therapist, wound care specialist, or social worker. Doctors must order skilled services and document that they are “medically necessary.” A patient who needs skilled care may also qualify for some personal care.

Personal care includes care to assist a person with bathing, dressing, mobility, toileting, and other Activities of Daily Living (ADLs). Depending on state regulations, it may also include offering (but not administering) medications and other health-related tasks, usually with nurse supervision. This level of care is provided by a home health aide, or by workers called home attendants, personal care attendants, or aides.

Companion and homemaker services, sometimes provided by workers called “in-home caregivers,” include meal preparation, laundry, and other nonmedical services.

Different Types of Agencies and Their Services

A **home health agency (HHA)** is licensed by the State and certified by Medicare and/or Medicaid to provide *skilled* care. These agencies may also provide personal care either by their own aides or by aides who work for the HHA’s subsidiary or for another agency with which they have a working arrangement.

A **home care agency** provides aides, personal care attendants, or homemakers who provide *personal care*, including assistance with activities of daily living,

transportation to appointments, and household tasks. Home care agencies may be contracted to provide personal care through Medicaid for someone who needs care at home for a long period of time. Some states require home care agencies to be licensed, regardless of whether they participate in Medicaid. Some states require that nurses supervise home care aides and do an initial visit.

A **non-medical or companion agency** is usually not licensed, regulated, or covered under insurance (some long-term care insurance plans may be an exception). The level of training varies. Some non-medical agencies are small, locally run businesses; some agencies are part of large organizations; still others are franchises of large companies. In general, patients or family caregivers pay privately for these services; some patients may, however, have long-term care insurance coverage.

Employment or registry agencies provide names of people available to provide home care. These can often be found through a state's department of health.

New CMS Regulations for Home Health Care Agencies

If all goes according to plan, on January 13, 2018, the first new [federal home health care Conditions of Participation](#) in almost 30 years will go into effect. The Centers for Medicare and Medicaid Services (CMS) rules strengthen patients' and caregivers' rights and increase their participation in care planning and delivery. While the rules don't address refusals of home health care services directly, the requirements may lead to more attention to patient goals and preferences and greater willingness to work with agencies to set up plans to meet these needs.

For the first time, home health care agencies will be required to assess family caregivers' "willingness and ability to provide care" as well as their "availability and schedules." Previous regulations required agencies to confer only with legal representatives such as guardians, not "personal representatives." A patient-selected representative is someone "who participates in making decisions related to the patient's care or well-being, including but not limited to, a family member or an advocate for the patient. The patient determines the role of the representative, to the extent possible."

Implementation of the regulations might be delayed to give agencies time to incorporate the new responsibilities into their practice, or they might be delayed indefinitely by the Trump Administration. In either event, the regulations still provide an outline for more patient and caregiver involvement and satisfaction.

Scope of the Problem of Home Health Care Refusals

How many patients refuse home health care services and why do they refuse? There is no simple answer to either of these basic questions. In her presentation at the Roundtable, Kathryn Bowles, the Van Ameringen Professor of Nursing Excellence at the University of Pennsylvania School of Nursing, and director of the Center for Home Care Policy and Research, Visiting Nurse Service of New York, reported on an international literature review and her own research in this area.

Several small studies found that between 6 and 28 percent of the participants offered home health care services refused them. The review covered articles from 1982 through 2016; of the 40 articles appropriate for full review, 22 were from the United States, with only a few each from seven other countries: Australia, England, Netherlands, Norway, Scotland, South Korea, and Sweden. The greatest number of articles published in a single time period (2011-2015) was 15, suggesting that the importance of the issue is becoming more visible, at least in the United States. Sixteen of the articles focused on the patient, 14 on the patient and caregiver, and 7 on the caregiver only. Lack of patient or caregiver engagement in decision making was the most common issue studied in these articles as a factor in home health care refusals (17 articles).

“From the literature review we learned that caregivers felt that decisions were made by providers without consulting them, decisions were not always reported to the patient and caregiver, and families wanted to be more involved. Some reports found that both patients and caregivers felt no one was in charge or accountable.”

—KATHRYN BOWLES, RN, PhD
University of Pennsylvania School
of Nursing and Visiting Nurse
Service of New York

Many studies counted refusals but did not ask for reasons. Where cited, the most common reasons were:

- Managing at the moment
- Invasion of privacy
- Care recipient does not want services
- Don't feel help is needed
- Services do not meet their needs
- Do not know about services
- Cost (co-pay in private insurance)
- Previous negative experience
- Fear of the unknown

This list does not include all the possible reasons. Some patients and families don't understand the difference between a nurse, an aide, or a coach or navigator, and what each can and cannot provide. Not all home health care services are of equally high quality, and prior unsatisfactory experiences or media stories about abuse or neglect may be a deterrent.

Home health care may be considered by some as an unwelcome reminder of illness, frailty, and loss of independence. Because of dementia or other cognitive impairments, some persons may not be able to understand their limitations and need for support at home. Because they are probably in the hospital for a fall, trauma, or chronic illness, their dementia may not be recognized or may be attributed to pain or delirium or other symptoms.

“You have to feel vulnerable in order to accept help, and most of us are very good at defending against being vulnerable because we don’t want to feel vulnerable.”

—RICHARD SIEGEL, LCSW
NYC Health + Hospitals/
Metropolitan Hospital

In their eagerness to get home, or as a result of faulty communication, some hospital patients have unrealistic expectations of how quickly they will recover and what their care at home will require. Some patients may want to hide hoarding behavior or illicit drug use by someone in the home. On the positive side, some patients, particularly those with longstanding chronic illnesses, already have systems in place to help them.

There may be tangible costs when patients refuse or are not offered home health care services. In her study of 30-day and 60-day readmissions among patients who were offered post-acute care services at two academic medical centers in New York City and Philadelphia, Dr. Bowles found that 28 percent of the 495 patients studied refused these services. These patients tended to be younger than those who accepted, better educated, and generally healthier. However, patients who refused services were twice as likely as the patients who accepted services to be readmitted to the hospital within 30 or 60 days.² The patients who accepted home health care generally reported better quality of life after discharge.

Gaps in Hospital Discharge Planning

While much of the Roundtable discussion focused on the lack of comprehensive information about patients' refusals of home health care, there is even less known about how home health care is offered as part of a discharge plan. Which patients are targeted? Who talks to them about a referral? What are the reasons given for a referral? How are the services described? Are family caregivers included in these conversations?

In her presentation, Suzanne Mitchell, MD, a family physician and one of the researchers of Project RED (Re-Engineered Discharge), developed at Boston Medical Center, described the experience of the project when it moved from a controlled study to implementation in a variety of hospitals. Project RED's checklist for hospital discharge is a list of 12 mutually reinforcing components, including medication reconciliation and follow-up appointments. Number five on the list is "post-discharge services," which includes home health care, called a "visiting nurse" in the RED toolkit.

"We see this over and over again. The person the patient trusts to give information in real time is the physician. But someone else may play that role. Increasingly, it's someone with the ability and title and the training to do it."

—JOE BAKER
President, Medicare Rights Center

Dr. Mitchell reported that hospitals implementing RED made a number of adaptations to the protocol, based on their self-assessments of practices and resource constraints. These adaptations lessened the efficacy of RED. Among other changes, hospitals might have paid more or less attention to "post-discharge services." Dr. Mitchell concluded that "despite streamlining the discharge process, care transition looks the same from the patient and caregiver perspective."

Carol Rodat, formerly senior program manager at the Center for Health Workforce Studies, State University of New York–Albany, also addressed this issue in her presentation. She stated that patients and caregivers want information on cost, how home health care relates to them, and opportunities to understand options and types of services. They want help in making decisions. The most effective interventions are tailored to risks, needs, and preferences. Continuity in providers and consistency of information are important in building trust and preventing readmissions.

Roundtable participants noted that the information patients receive about home health care may be incomplete, confusing, or treated as just another item on a checklist. They also felt that physicians should play a greater role in discharge planning and should be better informed about home health care so that they can talk about it knowledgeably with their patients. Patients in general look to physicians

for advice and confirmation of other practitioners' suggestions. Good clinical skills are important in discharge planning, as are communication skills and empathy. Home health care agencies should make better use of medical social workers; at present they are typically involved only in facilitating Medicaid applications or managing crises.

Many specific suggestions were made to improve practice, such as having photos of the home health nurse or aide to show to patients so they begin to feel comfortable about recognizing the person coming to the home. If feasible, the first visit can take place in the hospital.

Differences in the Views of Patients and Family Caregivers

What do family caregivers think about home health care? We know even less about their views than about patients' perceptions. There is some evidence, however, that patients and family caregivers may disagree about the need for home health care. As part of Project ACHIEVE, a PCORI (Patient-Centered Research Outcomes Institute)-funded, multiyear national study of patient and family caregiver

perspectives on transitional care, Dr. Mitchell and the Boston Medical Center team analyzed focus groups held across the country with different population subgroups.

"In Project ACHIEVE we learned that patients want to feel cared for and cared about. Caregivers want to feel prepared, confident, and capable. They want someone to anticipate their needs and communicate in ways that are purposeful, collaborative, and empathetic."

—SUZANNE MITCHELL, MD
Boston Medical Center

The focus groups revealed that patients and caregivers stated similar goals but have differing needs. Both want the best outcome for the patient, but caregivers feel responsible for ensuring the patient's adherence to the care plan and do not feel they have enough information and instruction. This is particularly true when the patient has dementia as well as the illness or accident that resulted in hospitalization. In these situations, the patient may not be able to adhere to the care instructions or may rely on the caregiver for assistance.

For both, role reversals can be challenging. Tasks such as keeping track of medications and appointments can be burdensome for caregivers with many other responsibilities. Conflict can arise due to lack of agreement on supportive care needs (including home health care services). In care transitions, the patient's role is often passive in the hospital due to illness,

but then can change to resistance to parts of the care plan, frequently related to medications. The caregiver is often put in the position of upholding the care plan despite the patient's preferences.

Here are a few quotes from the focus groups that illustrate this theme.

My mother doesn't want somebody to come in our house and help her. She wants to be able to do it herself, or I have to fight with her to let me do it... It's a day-to-day thing.

When they get at a certain age, like my dad and Nana... [with] home health care... they come in the house. I could see him tryin' to boss 'n rule... It wouldn't work for him... my grandmother wouldn't let them cook.

Notably, both of these caregivers see help at home as homemaking assistance, not skilled nursing care, the main eligibility criterion for home health care.

Varying Perceptions of the Value of Home Health Care

A basic assumption of the Roundtable organizers was that home health care services, appropriately targeted and competently delivered, are beneficial to

“We are grappling with enormous change in the health care system. We are trying to integrate families and patients with their own dynamics into a system that is fragmented. In this period of experimentation, we need patience, commitment, and community.”

—CAROL RODAT
Formerly with the Center
for Health Workforce Studies,
SUNY-Albany

patients and family caregivers and an important element in hospital discharge planning. This assumption is supported by a recent meta-review of 26 international randomized controlled trials, which concluded that “a home visit within three days of discharge by a nurse can address specific health care needs related to symptoms that patients experience. In addition, if the nurse performs a medication reconciliation, the number of adverse drug events can be reduced.”³ For patients at high risk of readmission, a visit within 24 hours is often recommended, as are timely follow-up physician office visits.⁴ In addition, nurses can train family caregivers to do complex procedures in their own or their family members’ homes, which are not equipped like hospitals.

Based on this study and other significant evidence, in November 2015 the Centers for Medicare and Medicaid Services (CMS) proposed regulations to the hospital Conditions of Participation that include home health care services as a key element in hospital discharge planning.⁵ As of May 2017, final regulations were not published, nor were the proposed regulations withdrawn. Their fate in the new Administration is unknown.

Nevertheless, in its 2016 guidance, *Hospital Guide to Reducing Medicaid Readmissions*, the Agency for Healthcare Research and Quality (AHRQ) noted that many hospitals had already begun to integrate the proposed regulations into their practice. AHRQ reminded providers to:⁶

- Arrange for (not just refer to) post-hospital services;
- Know the capabilities of post-acute and community-based providers, including Medicaid home- and community-based services;
- Provide patients data to help inform their choice of high-quality post-acute providers.

Despite the evidence, participants at the Roundtable reported, the value of home health care services is sometimes downplayed by health care providers, who might see these services as homemaking chores, not skilled nursing care. An unstated assumption in this view is that patients themselves—more likely family caregivers—can do the work of home health care nurses and aides, and at no cost to private or public payers.

To health care providers and payers such as Accountable Care Organizations (ACOs) looking to cut costs, home health care may be an easy place to start. For example, a recent *New England Journal of Medicine* “Perspective” by J. Michael McWilliams concluded that “much of the early savings in ACO programs has derived from reduced use of post-acute care in skilled nursing facilities (SNFs), home health care, and high priced hospital outpatient departments—all considered leading sources of wasteful spending” (emphasis added).⁷

Policymakers may see home health care as rife with fraud, and this perception has been exacerbated by some extreme examples of illegal practices.⁸ The U.S. Department of Health and Human Services Office of Inspector General’s nationwide analysis of home health care fraud cases found that they were concentrated in 12 states and had common characteristics, including a high percentage of episodes for which the beneficiary had no recent visits with the supervising physician. They were not cases in which the beneficiary was discharged from a hospital. The possibility of fraud is a continuing concern, but it should not overshadow the real benefits to patients and families of skilled care and monitoring.

Systemic Barriers to Access to Home Health Care

As the Center for Medicare Advocacy has noted, there are systemic barriers to accessing home health care, including inadequate reimbursement for home health care agencies that provide complex care and shortages of trained staff.⁹ These are particular problems in rural and other underserved areas. Many patients are not eligible because they do not meet Medicare’s stringent requirements: needing intermittent, short-term, episodic skilled care, and being homebound. Financial barriers are another problem: private insurance may have high copays or may not cover the required services. Health systems and health plans may recommend lower-cost “in-home care” (i.e., non-medical services), which may require the patient and family to pay out-of-pocket cost, instead of more expensive, nurse-led home health care, which would be covered by Medicare, Medicaid, or private payers.¹⁰

Underutilized Pathways

Early in the Roundtable discussions it became clear that the original focus on post-hospital access to home health care services was too narrow. Participants described other potential pathways: referrals from SNFs, EDs, and community physicians. Although there are some examples of cooperative agreements between EDs and home health care agencies, in general ED staff do not refer patients who are not admitted to the hospital but need ongoing care to a home health agency.¹¹ Some ED staff may believe that they are not allowed to make these referrals. Unlike referrals to SNFs, which require a minimum three-day hospital stay, referrals to home health care do not require a hospital stay of any length.

A recent study of Medicare beneficiaries found that every year over 10,000 people die soon after discharge from an ED even though they are relatively young and have no evidence of previous life-limiting illnesses. The authors identified a particular clinical “signature” of discharge diagnoses linked to shorter-term deaths, including altered mental state, shortness of breath, and fatigue. They suggest that “it is possible that additional testing or monitoring—whether via admission, monitoring at home, or expedited outpatient follow-up—could have benefitted at least some patients.” Referrals to home health care could partially fill this role.¹²

Referrals to home health from community physicians are also covered by Medicare, as long as the physician documents a face-to-face encounter with the patient or certifies that a non-physician practitioner, such as a nurse or physician assistant, conducted the interview. The certification must include a plan of care for each 60-day covered home health care episode.

Recommendations

Discharge Planning

Even with our current state of knowledge, interventions can be developed and tested that provide better information and options for patients and caregivers. Hospitals can take the lead in reviewing their current practices, but they should involve former patients and caregivers, HHAs, and other stakeholders. Among the possibilities:

- Improve discharge planning by providing complete and up-to-date information to post-discharge providers;
- Develop training sessions for physicians, nurses, and discharge planners to ensure that they understand home health care and why it may be appropriate for patients;
- Develop scripts for professionals to guide their discussions about home health care;
- Develop short videos for patients and caregivers about basics of home health care;
- Develop and test models for technology-based decision support for patients and caregivers;
- Develop collaborative relationships between EDs and HHAs so that appropriate patients can be referred to home health care even if they are not admitted to the hospital;
- Develop collaborative relationships between SNFs and HHAs so that discharge planning includes home health care referrals when appropriate;
- For HHAs, review how services are marketed so that patients and families have clear expectations.

Research

For the mid-term (the next few years), there are several areas in which more research is needed. Studies addressing these information gaps should include patients and family caregivers, as well as front-line hospital and HHA staff. Potential funders, including PCORI, the National Institute of Nursing Research, and private foundations with interest in aging, nursing, and/or family caregiving, might:

- Conduct qualitative and quantitative studies of patient refusals and caregiver participation in discussions of home health care, by geographic area, type of hospital, patient characteristics, health outcomes, cultural factors, and readmissions;
- Quantify and analyze offers of home health care for and refusals by SNF patients;

- Interview ED staff to learn about knowledge of and perceptions about referrals to home health care;
- Compare patient and family caregiver preferences and perceptions about home health care;
- Survey discharge planners, hospitalists, and social workers about their understanding and perceptions of the value of home health care services;
- Survey community providers about their understanding and perceptions of the value of home health care services;
- Develop better methods and tools to track refusals and outcomes;
- Explore new ways of using existing data sets, such as linking claims data to administrative data from home health care agencies, to provide greater insight on home health care acceptance or refusal and their relationship to hospital readmission;
- Integrate questions about home health care offers and refusals into existing surveys.

Policy

For the longer term, policy changes could make a difference in hospital discharge planning and appropriate use of home health care services. We recommend that policymakers:

- Initiate discussions with CMS about making Medicare eligibility requirements more flexible—in particular, to address limited waivers of the requirement of homebound status—and to make intake requirements more flexible so that services can begin more quickly;
- Monitor value-based payments and bundling to see if there are incentives for including home health care services;
- Develop financial or other incentives to make health care systems and hospitals more aware of the role of home health care in improving outcomes and reducing readmissions. Such incentives should encourage hospitals to initiate discharge planning before or immediately upon hospital admission, where possible, so that patients and caregivers anticipate what to expect upon their return home. Policymakers might also explore requiring hospitals to screen patients for potential home health care needs upon admission, during observation status, and in EDs;
- Explore how to provide incentives for primary care providers and other community-based providers to routinely evaluate their patients for home health care needs and provide patients with appropriate information and referrals.

Conclusion

The Roundtable was an initial step in exploring the range of issues related to patients' refusals of home health care. Participants agreed on the importance of understanding more fully why patients refuse, the gaps in communication that lead to refusals, and the outcomes for patients and costs. As the trend toward moving care from hospital to community escalates, it will become even more important to develop programs and practices, supported by policy and financial incentives, to give patients the best care possible in their own homes and to support the family caregivers who are essential partners in home health care.

Additional Resources

The Alliance for Home Health Care Quality and Innovation has information on [model transitions of care](#) as well as other resources.

United Hospital Fund's Next Step in Care family caregiver guides include a [hospital-to-home discharge guide](#), a [family caregiver's guide to home care](#), and a [guide to working with home health aides](#). All the guides are free and available in English, Spanish, Chinese, and Russian.

Also see information about home health care on the websites of the [Center for Medicare Advocacy](#) and the [Medicare Rights Center](#). For Medicare beneficiaries, see the [Medicare.gov](#) pages on [home health care](#). For Medicaid, see individual state offices; for private insurance, check with the health plan.

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December 7, 2016

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Endnotes

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