

DIFFICULT DECISIONS

The Illusion of Choice: Why Decisions About Post-Acute Care Are Difficult for Patients and Family Caregivers

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Introduction

For most health care decisions, the traditional advice is: talk to your doctor or health care provider. Ideally, the result is shared decision-making, with the ultimate choice up to the patient. Patient choice and shared decision-making are not incompatible. They are both intended to respect and honor individual preferences and needs in the context of full disclosure of risks and benefits.

But it often does not work out this way. As the introduction to this series of reports reveals, nearly 300,000 New Yorkers face a serious health care decision each year, and—in the name of patient choice—shared decision-making is largely absent and even avoided. These are patients, often older adults, who have been hospitalized for an acute illness, accident, or medical procedure. At some point in the typically short hospital stay, discharge planners begin asking patients and their families to choose a post-acute care (PAC) provider to continue treatment or monitor the progress begun in acute care.

The advice about talking to your doctor or health care provider has limited value in this situation because health care professionals themselves have limited evidence with which to help individual patients and families choose the most appropriate PAC setting and provider. Hospital staff have even less understanding of individual patient and family situations and constraints.ⁱ The Medicare Payment Advisory Commission noted that, when it comes to Medicare spending on post-acute care, “Decisions about where to place patients often reflect several factors—the availability within a given market, the proximity to a beneficiary’s home, patient and family preferences, and financial relationships between the referring hospital and the PAC provider—but not necessarily where the patient would receive the best care at the most reasonable cost to the program.”¹ As a result, patients and families are left to make important decisions on their own.

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The **Difficult Decisions** series examines the challenges faced by patients who need post-acute care after hospital stays for major surgery or serious illness. Prepared by United Hospital Fund and supported by the New York State Health Foundation, the reports in this series cover the many factors that go into hospital discharge planning, with context for patients and their families, for hospital teams, and for policymakers.

This report, the second in the series, focuses on the experiences of patients and caregivers and the often-overwhelming burdens they face in making decisions about post-acute care. Other reports in this series examine [the perspectives of health care providers](#), [what makes informed decision-making in this area so challenging](#), and the best practices, innovations, and policy levers that could help support New Yorkers who need to make decisions about post-acute care.

ⁱ The [third report](#) in the UHF *Difficult Decisions* series, released jointly with this report, notes that hospital staff may take into account a “wide range of factors” when weighing an appropriate PAC setting for patients. These factors may include the patient’s characteristics, preferences, functional status, medical history, caregiver support, recovery trajectory, and insurance coverage.

To better understand the challenges facing patients and caregivers confronted with PAC decisions, United Hospital Fund collected the accounts of 17 individuals—four patients and 13 family caregivers—through a series of discussion groups and individual interviews, in person or by phone. Fifteen of the participants were women, and two were men. To take part in the project, interview subjects and discussion group participants had to be a patient or family caregiver who had experienced discharge from a hospital to a nursing home for short-term rehabilitation or skilled nursing care within a six- to nine-month window from the time of the interview. Participants were recruited from a variety of patient and caregiver support programs in various New York City social service agencies, hospitals, and disease-specific support organizations. In the vignettes that follow, all names have been changed. For further details on methodology, see the Appendix.

The Context for Patient and Caregiver Decision-Making

PAC has been vividly described as “an archipelago of small islands, with no bridges, poor transportation, and limited communication options to the rest of the health care system.”² If health care professionals and policymakers have trouble navigating this complex geography, patients and family caregivers are even more at sea—with no maps, no GPS system, and no one at the helm of the ship guiding them to a safe port: the best quality, most appropriate PAC setting. What can result is a communication vacuum—patients don’t know how the system works, and the system doesn’t know what’s going on in their lives. Compounding this can be a flurry of other factors: unintended consequences of regulation, language barriers, lack of clarity on how medical complications will be addressed, insurance requirements, and tight time constraints—just to name a few.

In this context, it is not surprising that patients and family caregivers are confused and that the result is the “patient choice paradox.”³ Fuller and Naylor explain the paradox: “If patients are expected to choose which type of post-acute facility will best fit their needs, they need quality data. But in most cases, the data either are not available or not credible. And even when the data are available and understandable, research indicates that many patients prefer that clinicians make post-acute care decisions on their behalf. Despite all these realities, patient choice requirements ironically still result in decisions that may be less optimal and force patients into a post-acute care gamble.”

The Knowledge Gap About Post-Acute Care

Most people understand what happens in hospitals, doctors' offices, and emergency departments. As patients, family members, or friends, they have been in some or all of these places. They also know something about nursing homes (where people go to live when they need help taking care of themselves) and home health care (visits by nurses and aides). They may have heard about in-patient rehabilitation facilities (IRFs), places that treat people who have suffered severe trauma, such as a spinal cord or traumatic brain injury. But what about long-term acute care hospitals (known as LTACHs to health policy experts)? Most people would probably say: "Never heard of them." Yet all these different settings come under the heading of post-acute care (PAC), places that provide medical care after a hospital discharge.

One of the most frequently used PAC settings is a skilled nursing facility (SNF)—a nursing home-for a short-term rehab program or continued nursing care. Unless a person has experienced a recent stay in a SNF, this health care setting is poorly understood and often confused with nursing home placement or an IRF. A SNF is an interim stop on a longer journey of which the final destination may be uncertain. There may be repeated cycles of hospital and SNF stays with intermediate stays at home. Or the person may be unable to return home and be transferred to a long-stay unit in the same or another nursing home. And, to complicate matters, the health care system and the role of PAC is constantly evolving. Because of changes in clinical care and the pressures of cost containment, what someone experienced in a SNF 10 years ago may not be relevant today.

Over the past 20 years, largely because of financing opportunities related to shortened hospital stays and penalties for preventable readmissions, many nursing homes that were formerly long-stay residences expanded their short-term units for hospital patients who were not well enough to go home but not sick enough to require hospital care.⁴ The co-location of short-term and long-term units in a "nursing home" is a source of ongoing confusion.

Hospital patients and their families faced with choosing where to go after discharge are typically unprepared. Often, there is little time to research or consult others. Yet the choice can make a significant difference in the person's recovery from an illness or trauma. Making the most informed choice about a transition to a SNF is a "difficult decision" because a lot depends on the available information (which has gaps) and the guidance provided by hospital staff (which is scant). As Robert Kane, a noted geriatrician, explained, "Each decision to move an older person along the long-term care continuum can affect the rest of that person's life."⁵

To understand this challenge from the perspectives of patients and family caregivers, we asked several people who recently experienced post-acute care in a SNF what and how they were told about the services they or their family member would need after discharge, and what mattered most in deciding which PAC facility to go to. This report presents a sampling of their stories and comments and places their experiences in the

context of findings in the PAC literature. What emerges is a picture of inconsistency, gaps in knowledge, and a compelling need for change. An accompanying report in this series describes the perspectives of hospital staff charged with both facilitating speedy discharges and reducing readmissions. We wanted to learn what happened or did not happen during discharge planning, how patients and caregivers arrived at their decisions, what they considered the most important factors in their choice, and what information would have been helpful but was not provided.

What the Literature Reveals

In searching the literature, we focused on the specific aspect of patient and family perspectives and found, as Gadbois, Tyler, and Mor point out, “there is a dearth of literature focusing on PAC SNF selection, although somewhat more focuses on LTC [long-term care] selection.”⁶ Some studies use the term “nursing home” to include both short- and long-term stays without noting which one (or both) they are reporting on.

Research on the experience of PAC has revealed that patient and caregiver preferences are often based on location and suggests that location is the dominant force in decision-making due to lack of guidance from hospital staff during the planning process.

While discharge planners may seem like an obvious resource for information on PAC options, Medicare rules—informally known as “anti-steering regulations”—prohibit them from making specific recommendations.⁷ In addition, many discharge planners may not know enough about the quality of individual PAC facilities to be helpful to patients and families. Furthermore, such planning often occurs when people are most vulnerable, and the planning itself is stressful.

In a national study conducted by Robert Burke and colleagues, patients commonly expressed resignation and a perceived lack of choice or autonomy, leading to dissatisfaction with the outcome.⁸ Lauren Penny’s capsule commentary on Burke’s article emphasizes that “providing patients with information is insufficient. Frequently, we think we empower patients by giving them information and ‘choice’ (e.g., Medicare’s Nursing Home Compare); however, this neglects how patients and families are often circumscribed in their ability to make sense of and meaningfully act on information provided, particularly in uncertain and changing circumstances, and limited resources.”⁹ The limitations of websites comparing quality are described in detail in the introduction to this series.

These studies and the others we found were conducted in a variety of regions. Our interviews confirmed that New Yorkers trying to make an informed choice face similar challenges. Nevertheless, we found some variations on the theme that may help provide a more nuanced view. We learned that they had the illusion of choice but not the reality.

How Were PAC Choices Presented?

Some participants were either unaware that they had a choice in PAC settings or were not actively engaged in decision-making. There was no standard way hospital staff presented the options for post-acute care. Alternative PAC settings such as home-health care or outpatient rehabilitation were described by only one of the interview participants.

Mike, caregiver for his partner Zach who had been hospitalized for major surgery, said that the discharge instruction was 10 pages long and included 17 medications. Mike thought he could handle it. He found the reality was much harder than he realized.

When I think about it now, this was a really complex coordination of care and services. Meanwhile, I was working full-time in a very demanding and high-pressure job as well. The home care team was superb, but it was just too complex for us to manage. When Zach fell in the bathroom trying to get to the door to let in the home care attendant, he had to be rehospitalized. From there he was admitted to a nearby SNF, where he spent several weeks. Someone, maybe a nurse practitioner, should have told me how complicated this was going to be.”

In all the other cases reported by our participants, a nurse or social worker informed the patient and family that discharge was imminent (one to three days) and told them that they should select a PAC facility (sometimes phrased as “a nursing home”) for follow-up care. This timing is consistent with literature on overall hospital discharge practices—in one study, 30 percent of patients reported less than one day’s notice of hospital discharge.¹⁰

Some participants did not distinguish between the message and the messenger. One caregiver felt that “social workers run the hospital” because a social worker was the person who told her that her mother had to be discharged the next day. While the message was delivered only by the social worker, the decision was discussed by the health care team and influenced by what patients and caregivers perceived as “hospital policy” to discharge patients as soon as possible.

Even though hospital staff stressed patient choice, patients and families felt that they had little choice. Several participants noted that their “choice” was limited by the availability of a bed. As one caregiver said, “Wherever they had a room, the first one is where you went.” Other participants just said that “the hospital sent my [family member] to a nursing home.” This repeated statement suggests that family members were, or felt, excluded from the decision-making process and did not have a way to question the hospital’s decision.

The most common information provided was a list of facilities, as required by regulations. While all those who commented on getting a list felt it was inadequate, there were more serious shortcomings in some cases. The following example illustrates

how a list of facilities is inadequate when the primary caregiver is dealing not only with the medical situation but also other stressful family responsibilities.

Donna, a long-distance caregiver, helps her mother take care of Paula, Donna's sister and an ALS (amyotrophic lateral sclerosis) patient. The mother also takes care of Paula's 10-year-old daughter. When Paula was hospitalized with severe pneumonia related to her ALS, hospital staff asked her mother to decide where Paula would go for post-hospital care. Donna reported, "My mother is 82 years old. She's dealing with my sister and my 10-year-old niece. This is a situation that's very, very difficult. So, a social worker just gives my mother a list of 12 facilities and says, 'Pick one.' How is that OK?"

Staff sometimes encouraged family members to visit a few facilities before deciding, but most were reluctant to give any advice or recommendations. Even when the patient and family had indicated a first choice, if a bed was not immediately available at that SNF, the patient was sent to the first available facility.

Some participants reported their experiences in a hospital with a transitional care unit (TCU), located in the hospital but not run by the hospital.ⁱⁱ Stephanie, a caregiver for her 90-year-old mother, reported being confused when her mother was transferred to this unit, which is certified as a SNF but looks like just another hospital floor. She was not consulted on the transfer, nor was she told that the process involved being discharged from the hospital and admitted to the TCU.

Stephanie said, "I was told, 'You're going to [floor and room number].' So they send a woman with the wheelchair. I've got all the bags; I'm down there, with a plant in one hand and, we get there, and... this woman comes rushing at me, yelling, 'There's no bed for her, what's going on here?' When I explained that I was told that my mother has a bed here, the woman said, 'No! She doesn't. I haven't gotten paperwork, nothing happens here until I have paperwork.'"

A different problem was reported by a patient who was transferred to a TCU two days after she had surgery. Because she had not been in the hospital for the three days required by Medicare for SNF reimbursement, she faced a large bill for the rehab services. This kind of error may be less likely to occur when the patient is physically moving to a different facility for SNF services.

ii Ten hospitals in New York State (seven of them in the New York City metropolitan area) have created transitional care units (TCUs), which have been certified by the New York State Department of Health as Skilled Nursing Facilities. These units are located in the hospital but have separate admission, discharge, and payment policies.

How Did Family Members Research Options?

Although the number of participants in our interviews was limited, the family caregivers reflected a wide range of responses to the task of researching SNFs. Some did little or no investigation; they seemed bewildered by the responsibility and awaited guidance that did not come. At the other extreme, some family members embarked on a full-scale project of visiting facilities, combing websites, and consulting friends who were health care workers or had been through the experience.

Several caregivers described relying on friends or family members who had experience with the PAC setting, either through being current or former employees, or having been a patient or caregiver to a patient at a facility. These caregivers described how friends and family with prior experience helped them investigate options, go on site visits, and make choices.

Betty, who had recently been a caregiver to several family members, said, “My cousin did the best thing—she brought one of the ladies that used to work at the rehab! What she [the former employee] said was, ‘They [the rehab staff] used to care for half of the number of patients, and all-of-a-sudden, because of funding, instead of caring for four patients, they had to care for 12.’ And she said, ‘Regardless how much you would like to help people, and they need your help, you don’t have, physically, the time.’”

At the same time, patients and caregivers occasionally described the downside of relying on word-of-mouth recommendations from family and friends. Their experience may reflect outdated expectations of care, such as the length of stay in the hospital and the post-acute setting or whether that setting was in their health plan’s managed care network.

The caregivers who were comfortable with computers searched for information about facilities on the list. They used Google or other search engines and found the facility websites, which were largely promotional and lacked specific information about what services are offered and what activities are available.

Jim and Abby, caregivers to Jim’s parents, noted that being told to use the Internet to research facilities was not a good option, when what they really wanted was specific advice from professionals about what setting would be best for their family member. Jim said: “It’s not like we look for this information every day. Hopefully only once, twice in your life you need to do that, and you really don’t know. And for somebody to say, “Do research on the internet” didn’t feel sufficient.”

Patients and caregivers interviewed often said consumer sites like Yelp, where they could read about other people's experiences, were more helpful. These sites had comments about the helpfulness and responsiveness of staff, meals, ease of reaching staff by phone, and other characteristics they valued. Importantly, sites like Yelp provide reviews of facilities in, or close to, real time, providing an important window into recent patient experiences.¹¹

Emily, who is caregiver to her sister who suffers from end-stage COPD (chronic obstructive pulmonary disease), said, "I just went on the internet, and I just put in the name of the facility, and it came up with its overall rating, and then it had different parts of the rating, for food, for customer service... I will always look at the reviews. It's better to hear from a person who has experience with it than from any other person because they can speak on anything, but an experienced person is better. So, I will always go for the reviews and see what people are saying about the place."

Echoing findings in other studies, very few of the participants we interviewed knew about the CMS website Nursing Home Compare or the New York State Department of Health's Nursing Home Profiles. A few said that a nurse had suggested they look at the sites, but the patients and caregivers reported that they didn't find them helpful or relevant to short-term stays. That experience is consistent with a recent critique of Nursing Home Compare that appeared in *Health Affairs*, which found that less than half of the quality measures on the Nursing Home Compare site are relevant to short-term stays and that the facility quality profiles do not indicate what proportion of patients are there for short or long stays (which are very different patient experiences).¹² Some caregivers and patients reported real difficulty with accessing the websites of post-acute care facilities via the internet:

Therese, an older adult who is caregiver to her husband Phil, and who also recently had a post-acute care stay, noted "Our generation is not that comfortable or savvy with computers. You can ask at the hospital if you find a pleasant social worker, but it's not that easy for someone to do on your own."

Therese's peers in the discussion group agreed. Patti, a caregiver who also happens to work with older adults for her job, noted that many of her clients will call her on the phone to ask for help researching facilities. Patti would look up places on her computer and, over the phone, describe the images from the website or internet search results and read the reviews. But she also always advised people that it would be better to see facilities in person.

Patients and caregivers also noted that language was another barrier for accessing information about PAC settings. The participants in one discussion group, most of

whom spoke Spanish, said that consumer reviews were frequently only in English. Many facilities have automated phone systems that default to English, making accessing information about the SNF much more difficult for speakers of languages other than English. Another aspect of cultural diversity that was mentioned a few times was whether the facility attracted people from a particular culture or religion and had staff that could relate to their specific concerns.

Overall, the participants painted a picture of inconsistent and impersonal presentation of information. Decisions were not based on patient needs or preferences, but on efficiency and rapid transitions. Some of these transitions turned out reasonably well, but it was usually because an individual either at the hospital or a friend or family member took a special interest in making it work.

What Were the Most Important Elements in the Decision?

The most commonly reported elements in the decision process were location, availability of special medical services, and whether the facility was in the person's health plan network.

As expected, and consistent with other reports, location was a major factor. Patients and family members wanted to be in a place that was easy to get to and in a familiar area.

Mary, who cares for her 94-year-old partner Tom, had visited several facilities. She said, "It [the choice] was based on the quality of the PT, that it was close to home, and that the rooms were nice. Being able to get there and back easily was important. That was because even those four subway stops, after a while... become very long."

However, several participants reported that they were willing to choose a more distant but higher-quality facility, especially if it had specific services that the patient needed. The most vigorous advocates insisted on finding a facility that could provide these services, which could include on-site dialysis or long-term ventilator support. Since they found that hospital staff were not very well informed about which facilities offered the special services the patient needed, they had to investigate this aspect of care on their own.

Emily reported, "I was checking them out, but I remember what the social worker told me—whatever place I choose, I had to make sure they had the services that she needs. A couple of places on the list didn't have the services, so I automatically eliminated them."

Finances played a major role, and whether a facility was in an insurer's network was a critical factor in the choice of PAC setting. Sometimes there was a delay in getting authorization to arrange the transfer, either because the hospital staff failed to submit the request quickly or because there was a delay on the payer's side. If that happened, the patient was forced to accept the first available bed in the network. State regulations require that hospitals provide lists of PAC facilities that are in the person's managed care network (e.g., Medicare Advantage or Medicaid Managed Long-Term Care), but these lists are not always up to date, and the facilities recommended by friends and others may not be in the network.

Olivia, an older adult who lives alone, had an elective hip replacement. Concerned about her ability to recover at home and fearing falling while on her own, she sought an assurance to go to a PAC setting after surgery to recover for a few days. She regrets her decision to go to rehab because of what she described as "the hospital policy" not to provide PT if a transfer to rehab is in process. Olivia noted how nurses and therapists all said, "that's the policy" when she asked about receiving physical therapy in the hospital. Meanwhile her surgeon complained that she wasn't doing enough therapy [to recover], because he was under the impression Olivia was receiving it throughout the hospital stay.

Olivia later described being asked by PAC admissions staff if she was "in a bundle,"ⁱⁱⁱ because once she arrived at the SNF, she learned she would only have a very limited number of days to stay in rehab because she had been delayed leaving the hospital.

Although the people we interviewed had no financial barriers to SNF admission, others have reported that SNFs were unwilling to accept the relative who required expensive medications such as chemotherapy. The importance of staying in the network was noted by Emily, who said:

"My sister has Long-Term Managed Care [insurance], so some of the nursing homes are affiliated with it, in their network, so I wanted to keep it like that, too, because I found out if you go in the network, you keep everything covered. And I don't want to go into a place where it goes into out-of-pocket money because my sister doesn't have money like that."

On the other hand, one potential participant we talked to was ineligible for the interview process because her mother, who had severe health problems and had been

ⁱⁱⁱ According to Healthcare.gov, bundled payment is "a payment structure in which different health care providers who are treating you for the same or related conditions are paid an overall sum for taking care of your condition rather than being paid for each individual treatment, test, or procedure. In doing so, providers are rewarded for coordinating care, preventing complications and errors, and reducing unnecessary or duplicative tests and treatments." Extra services outside the bundle, such as extended stays, are discouraged.

hospitalized many times, refused to go to a SNF. In this instance, the patient and caregiver feared that the patient would be transferred to a long-stay unit and that discharge to home might be complicated by what they perceived as the nursing home's financial interest in keeping her as a long-stay Medicaid patient.

Other concerns that influenced decision-making were the PAC facility's ability to address other health conditions. Several caregivers described wanting to know that a short-term rehabilitation arrangement in a SNF would be able to either help them preview what the care would be like in the long-term or how other health conditions, beyond the acute event that caused the hospitalization, would be addressed. Mary, the caregiver caring for her 94-year-old partner, worried that his early-stage dementia might interfere with physical therapy—but no one had considered this in the care plan. Many caregivers voiced frustration about the lack of attention paid to the patient's overall health when considering placement, especially when a patient had a serious condition that would likely require long-term, skilled nursing care. As Donna, the caregiver to a sister with ALS, noted:

"I asked. 'Has a neurologist come to see my sister?' And [the doctor] said, 'No,' and his reason was, 'She came in with an upper respiratory problem.' So, if I came into the hospital with pneumonia, and you treated my pneumonia, but if I had a broken leg, you wouldn't do anything for the broken leg? The broken leg is OK, you wouldn't even deal with that? That's essentially what you're saying to me."

What Patients and Caregivers Would Have Wanted to Know But Weren't Told

Participants wanted to know what to expect in a rehab setting; what kinds of therapy would be provided and how often; what a typical day would be like, what to bring and what not to bring; what clothes the person would need; and what other activities would be available. Although they did not say this explicitly, they were unprepared for the different culture of rehab, where the emphasis was on the patient's willingness to work hard during therapy sessions with less reliance on hands-on nursing care. One seemingly unimportant difference suggests the difference in cultures: In hospitals, patients wear standard-issue gowns; in rehab, they wear their own sneakers and sweat pants. A hospital has a clearly medicalized atmosphere; a SNF is more like a fitness center with hospital beds.

Patients and caregivers wanted to know what to expect from the stay: Was this a prelude to going home or, as some believed, a stop on the way to a long-stay unit? They wanted to be involved in the care plan and be trained to take over at home if that was the destination. Sometimes, even with the most intensive investigation and multiple visits, the reality of the facility and staff did not measure up to their expectations. Jim and Abby, who were taking care of Jim's father, expected that the care plan was to work toward ambulation without assistance. However, as Jim and Abby reported:

“Somewhere in the middle, that changed, and they said, ‘He is going to need a walker.’ And I know I became frustrated. ‘Why did you relax the goal—in order for him to leave?’ I said, ‘Is this money-related, Medicare-related?’ And they said, ‘Yes! ‘Yes, it is.’ And I kept saying, ‘Then why did you set the expectation of what he would achieve in this month, and then change it?’ They never really answered that question, and for about a week it was very frustrating to me, and we tried to get them to extend, we kind of fought it a bit, and it was three days. And they said, ‘You can probably get another two [days], but you’re gonna have to...’ There was a process you go through, and I was debating it, but for two days it seemed ridiculous. So, he did leave there still needing a walker, which was not the original expectation.”

Summary

For many patients, PAC is an essential part of a coordinated plan for continued treatment and improved quality of life following a hospitalization. Most programs that coordinate hospital discharges to PAC focus on the transition from hospital to home. Transitions to SNFs have not received the same level of analysis, program development and investment, and staff training. Yet this transition is just as significant to patients and family caregivers and even more confusing because it involves a new setting, new staff, and unfamiliar care routines and daily activities. When patient and family needs are considered in the discharge plan and the SNF has the staff and capacity to meet them, the transition to PAC is likely to be a successful match.

Unfortunately, as our interviews and discussion groups revealed, this outcome is often elusive. While the literature on transitions to SNFs is still sparse, the key points raised by research studies were echoed in vivid stories told by our participants. While patients were told that they could choose where to go, in fact the choice was limited and sometimes seen more as a burden than a benefit. Being given just a list of facilities felt dismissive—not much more important than choosing from a lunch menu.

Even if government websites were recommended, patients and families found them hard to navigate and lacking in information about services that were important to them. Hospital staff did not have (or did not share) information about the quality of care at different sites or the relevance to specific patient conditions. In the end, location and access to transportation were often the pivotal factors in a patient’s choice—the only ones that were easy to identify. But even when a patient made a choice, the deciding factor in the discharge was the site where the first bed became available.

Beyond these barriers, some participants felt that only the immediate need for treatment—not their other chronic conditions and the emotional impact of the whole experience on them and their families—was important to hospital staff. Finances were an important factor as well, and many participants spoke about “being in the network” as essential for insurance coverage.

A final report in this series will include recommendations for short- and long-term change. The findings of this report suggest that change is necessary at all levels—from the regulatory framework to individual staff interactions with patients and family caregivers to the information and guidance needed to help support more informed decisions when there is so much at stake. Involving patients and family caregivers in making appropriate PAC choices is a moral imperative that demonstrates transparency and respect for individual differences. Professional responsibility requires creating the framework in which patient autonomy can flourish.

Appendix A: Methods

Interviews and discussion groups were moderated by members of UHF's Quality Institute or Families and Health Care Project staff, using a moderator's guide developed for this project (see Appendix B).

Participant Demographics and Eligibility

Seventeen individuals—four patients and thirteen family caregivers—participated in a series of discussion groups and individual interviews, in person or by phone. Fifteen of the participants were women, two were men. To participate in the project, interview subjects and discussion group participants had to be a patient or family caregiver who had experienced discharge from a hospital to a nursing home for short-term rehabilitation or skilled nursing care within a six- to nine- month window from the time of the interview.

This requirement may have contributed to the challenge of recruitment. Several potential participants who expressed interest were either outside the eligibility time-range or had difficulty finding time to participate in discussion groups or interviews in person because of their caregiving commitments or ongoing rehabilitation and health care schedules.

Recruitment and the Interview Process

Participants were recruited via convenience sampling from a variety of patient and caregiver support programs in various New York City social service agencies, hospitals, and disease-specific support organizations. Each organization received a tailored recruitment flyer with details of the project.

The moderator introduced the project, obtained verbal consent for discussion group participation and audio-recording, and facilitated the conversation. Patients and caregivers were informed that the discussion was confidential and that, in a report about the project, their names would be changed to protect their privacy. Discussion groups generally ran 75-90 minutes, and individual interviews ran 45-60 minutes. Refreshments were offered to participants of discussion groups and in-person interviews, and each participant was offered a \$40 stipend.

Each interview or discussion group probed five major themes: how choices were presented; the process of choosing a PAC setting; how patients and family members made their decisions; what were the most important elements in decision-making; and what information would have made this process easier.

Appendix B: Moderator’s Guide for Discussion Groups for Difficult Decisions on Post-Acute Care

Note: This guide assumes that all participants will have had recent (within 6-9 months) experience in making a post-acute care decision.

Welcome

Thank you for coming. My name is [MODERATOR TO FILL IN], and I will be your moderator today. All of us involved in this project at United Hospital Fund appreciate your willingness to share your experiences and ideas. I look forward to talking with you.

Describe the project very briefly.

This discussion group has been organized by United Hospital Fund, an independent nonprofit organization working to improve our health care system. UHF is not affiliated with any hospital, or health care provider, or drug company. The project is funded by the New York State Health Foundation, a private foundation.

The goal of this project [INSERT FORMAL NAME] is to learn what matters most to patients and family caregivers when they are making a decision about where to go after a hospital stay. A hospital stay is called acute care; post-acute care is what happens after you leave the hospital. You might go home, with or without home health care services. If you do not go directly home, you might go to a nursing home for short-term rehabilitation services. This setting is the primary focus of our discussion.

This group is one of several we will be convening across the city. We want to hear from you what you were told about discharge options, when this conversation happened, what influenced your decision, and how what you were told matched up to reality once you had made the transition. Other groups will be made up of hospital staff so that we can learn what they understand about patient and caregiver needs for information.

Ultimately, there will be recommendations about how to best communicate the many aspects of this often-complicated decision.

Some Housekeeping Information

- Location of bathroom
- Refreshments—help yourself at any time.

Ground Rules for Our Discussion

- We have some ground rules for the group today:
- We'd like you to write your first name—or any name you choose—on a name tag. Your name tag makes it easier for other people to refer to your comments when they want to add to what you have said.
- There are no right or wrong answers.
- We have several topics to cover, so we will not be able to talk about every aspect of your experience.
- We want to give everyone an opportunity to talk about each topic, so try to be brief.
- I may sometimes need to stop you, so we can get back on target and get through all of our topics.
- This discussion is being audiotaped to make it easier for us to listen and not take too many notes. We are conducting several discussion groups and will use the recordings to summarize patients' and caregivers' perspectives on this topic. We will not disclose your identity to anyone or attribute the recorded comments to you.
- Since we are taping, we all need to speak up, one person at a time.
- The discussion in this group is confidential. Please do not share what you hear in this conversation with others.
- Any questions?

Most people enjoy these groups as an opportunity to talk with others about experiences they have shared. Please relax and be as open as possible. Write down a few ideas as we move long if it helps.

Let's Get Started

Introductions: First, I'd like to go around the room and ask each of you to give the name you have chosen and a little about yourself.

Probe for:

- Relationship to patient (for caregiver)?
- How recently was the hospital stay and how long was it?
- What was the reason for the hospital admission?
- Anything else you want to be sure we know?

Elapsed time: 20 minutes

Now let's focus on your experiences during the hospital discharge process. In other words, tell us how and when you received information about the need for post-acute care. What choices were you given about where to receive that care? Was home care an option? Why or why not? How well did the information about rehab in a nursing home (Skilled Nursing Facility) answer your questions? Did it match the reality of your experiences after the transition? That's a lot to cover but try to focus on what kinds of information were most important to you during this time, and how well or poorly this information was conveyed.

Note: The probes in the following sections are suggestions and may be modified.

- Did you understand why post-acute care was recommended by the hospital doctor or nurse?
- At what point in the hospital stay did you learn about the recommendation?
- Who presented this information to you?
- Were you expecting this recommendation?
- Was the hospital staff helpful as you tried to make the best choice?
- Did you feel that the decision was rushed?
- Were any particular facilities singled out as better quality or more appropriate for your condition?
- If you were the patient, was your family caregiver present during this conversation?
- What were you told about the financial aspects of the choices?
- Did anyone in your family have time to visit any facilities?
- What was missing? Is there anything that you wish you had known that you were not told?
- What was the most significant influence in your final choice?
- Now that you've had some time since the hospital stay, what do you think are the most important points hospital staff should tell patients and caregivers about post-acute care?

Elapsed time: 30 minutes

Some Final Questions

We have focused on the post-acute care choices you may have encountered after a hospitalization. I want to close our discussion by asking you what other kinds of information you would like to recommend a patient and caregiver receive as part of the post-acute care selection process.

- Where would you go to find information on post-acute care choices? An organization website? YouTube? Somewhere else?
- Google?
- Nursing Home Compare or NYS Department of Health nursing home profiles?
- Written information in brochures or flyers?
- Videos?
- Family members or friends?
- More specific guidance from a health care provider such as your primary care doctor?
- Anything else?

Elapsed time: 20 minutes

Thank you for coming. You have been a great group, and your comments will be very helpful as the project moves forward. I hope everything goes well for you and your family in the future. If there's anything else you'd like to tell us, please send Kristina Ramos-Callan a follow-up e-mail or phone call. Her e-mail is kcallan@uhfnyc.org and her phone is 212-494-0791.

Endnotes

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