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Why Older Adults May Decline Offers of Post-Acute Care Services: A Qualitative Descriptive Study

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Abstract

The most common post-acute care (PAC) services available to patients after hospital discharge include home care, skilled nursing facilities, nursing homes, inpatient rehabilitation, and hospice. Patients who need PAC and receive services have better outcomes, however almost one-third of those offered services decline. Little research exists on PAC decision-making and why patients

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may decline services. This qualitative descriptive study explored the responses of thirty older adults to the question: “Can you, from the patient point of view, tell me why someone would not want post hospital care?” Three themes emerged. Participants may decline due to 1) previous negative experiences with PAC, or 2) a preference to be home. Some participants stated, “I'd be there” and would not decline services. Participants also discussed 3) why other patients might decline PAC which included patients’ past experiences, fear of the unknown, and preferences. Clinical implications include assessing patients’ knowledge and experience before providing recommendations.

Introduction

Post-acute care (PAC) encompasses a diverse offering of services patients may receive directly following a hospital discharge. In general, these services occur in varied environments, including community-based (e.g., home health care, hospice in the home setting) and institution-based (e.g., inpatient rehabilitation, skilled nursing facility, nursing home (NH), inpatient hospice) settings. For older adult patients, receipt of PAC can promote functional recovery (1), improve quality of life (2), and reduce hospital readmissions (3, 4). Despite the documented improvements in patient-centered outcomes among patients who receive PAC, almost one-third of older patients who are eligible for such services decline them (4). These patients are at risk for negative consequences, such as higher likelihood of 30- and 60-day hospital readmissions compared to patients who accept PAC (4). Given the known benefits of PAC and the potential health risks of declining services, a greater understanding of why older patients might decline PAC is needed to better support informed decision-making among patients and their caregivers.

There is a dearth of research that explores patient decision-making regarding PAC services and factors related to their refusal. Topaz et al. (4) found that being married, shorter index hospital length of stay, non-Medicare/Medicaid medical insurance coverage, and lower patient acuity were factors significantly associated with patient refusal of PAC services. Harrison et al. (5) conducted a qualitative study (n=6) to understand how patients with a diagnosis of chronic obstructive pulmonary disease who refused post-acute rehabilitation services understood their own illness and the implications of care refusal. Findings highlight that patients who refused PAC felt shame and stigmatization related to their diagnosis, which the authors posited may be reflected in their feelings of self-worth. The authors hypothesized that a lack of self-worth may reduce help-seeking behavior and thus contribute to refusal of PAC. Other studies have highlighted the relationship between race and underutilization of healthcare resources. For example, an analysis by Katz (6) discussed the impact of inequities and disparities in healthcare policies on patient preference and suggested that “misinformation, bias, and resignation to the status quo” may underlie many preferences and decisions about care.

In a recent qualitative study, Sefcik and colleagues (7) found that patients preferred practical information about how PAC services relate to their individual needs to make informed decisions regarding these services. Additionally, patients reported that they needed opportunities to understand the diverse PAC options available. Although limited, the

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literature shows that decisions about PAC are likely complex and that patients themselves may be influenced by how their PAC options are presented, their current biomedical status, personal supportive network, and previous experiences when contemplating healthcare decisions.

The purpose of our study is to understand the reasons why older adult patients might decline PAC in order to inform clinicians and researchers of possible intervention targets to support patient decision-making.

Methods

Design

This study was part of a larger qualitative descriptive study aimed at gaining an understanding from hospitalized patients about their knowledge of PAC services and discharge decision making. Thirty participants were enrolled in the larger study and all transcripts were used for this qualitative descriptive study. The findings presented in this article are specific to the qualitative analysis of participants' responses to the question, "Can you, from the patient point of view, tell me why someone would not want post hospital care?" This question was part of the structured interview guide.

A qualitative descriptive design for the larger study was chosen for its ability to explore the topic of why older adults may decline offers of PAC services and to present the findings by staying close to the participants' words (8). Individual interviews for the study were selected for data collection because they could be completed in the participants' hospital room when they were available and feeling well enough to talk with a research assistant (RA). This study was approved by the University of Pennsylvania's Institutional Review Board. Other findings from the larger study are published elsewhere (7).

Setting and Participants

Study participants were recruited from seven medical–surgical units of an urban, academic medical center providing highly specialized tertiary and quaternary levels of care located in the Northeast region of the US. The electronic health record was used by hospital staff to prescreen participants to establish eligibility. Eligibility inclusion criteria were study participants must have been (1) age 55 or older and (2) determined to have been in need of PAC as indicated by the Discharge Decision Support System (D2S2), an evidenced-based screening tool used by the hospital that identifies patients upon hospital admission who are likely to need PAC services (8, 9). Study participant exclusion criteria were: cognitive impairment, inability to respond to interview questions, inability to speak English, and those documented as do-not-resuscitate (DNR) comfort care. Cognitive impairment was established by documentation in the medical record, corroborated by the nurse, or through administration of the Animal Fluency Test which is a short screening test where patients were asked to recall as many names of animals as they can in 60 seconds. Patients who recalled less than 15 animals were deemed not appropriate for this study. The animal fluency test has a sensitivity of 88% and specificity of 96% in detecting cognitive impairment (10).

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Sampling for variation in gender, age, race, and the admitting hospital unit (i.e., cardiac, medicine, and surgery) was conducted.

Daily reports of patients who met the eligibility criteria were sent to study RAs. These reports, were reviewed by the RAs and with each potential participant's primary care nurse to determine cognitive ability to consent. Consent to participate was obtained for thirty participants in the larger study who were interviewed between July and October 2014.

Coding and Data Analysis

Conventional content analysis (11) was the analytical technique for this study. The technique involved being immersed in the data and deriving in vivo codes from the transcripts when reviewing them word-by-word. The codes were then sorted and based on their relationship, organized into categories, and then further organized into themes (11-13).

The lead author (JS) led the analysis process with three other authors (EF, RN, & JC) assisting with coding of the transcripts in Atlas.ti version 7, a software used to store and manage the data. These authors together created and refined the project codebook with the identified categories and definitions. The full team discussed the codebook, made further refinements and came to agreement of the findings.

Trustworthiness

The trustworthiness of this study was guided by Lincoln and Guba (14). An audit trail was kept with the team's detailed account of codes, categories, and decisions made during the ongoing data analysis. Investigator triangulation involved multiple coders and full team discussions to reduce coding bias and to come to a consensus on the findings. Peer debriefing involved the lead author engaging in discussions of the project and findings with an Advanced Qualitative Collective, a group of pre- and post-doctoral students with a qualitative focus, but not involved with the project.

Findings

Two hundred thirty-six patients were screened to participate in the larger study; 164 were ineligible due to cognitive impairment (80%); non-English speaking (11%); unable to answer interview questions (4%) or DNR (5%). Seventy-two participants were deemed eligible, 32 were not interested in participating, and 10 were recently changed to DNR or were transferred to a non-study unit. The average age of those who declined to participate was 70 and 50% were male.

The 30 consented participants were evenly split; 50% males and 50% females. The mean age was 70 years old (range = 55 to 91 years), with most (73.3%) having Medicare coverage and almost 17% had Medicaid coverage. The majority were White, non-Hispanic (N=20,66%) with almost one-third Black or African American, non-Hispanic (N=9, 33%) and one individual (1%) who identified as Black or African American, Hispanic. Almost 87% (86.7%) of participants completed high school or had additional education beyond a high school diploma. In response to the question on self-rated health, 76.6% rated their health as *fair* or *poor*, with participants experiencing 7.6 comorbid conditions on average

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(range = 3 to 23, *SD* = 4.4). There was a distribution of primary diagnoses with 36.7% classified as cardiovascular, 20% having a respiratory primary diagnosis, 6.7% had a primary diagnosis of sepsis and the remaining 36.6% had various other diagnoses.

Through the course of the interviews we learned that 24 of the 30 participants previously were enrolled in at least one PAC service (home care, inpatient rehabilitation, skilled nursing facility care, nursing home care, and/or hospice care) and five had also worked for a PAC service in the past (i.e. Licensed Practical Nurse in a NH). Of the 30 participants, 15 mentioned that they had known at least one person (relative or a friend) who had received a PAC service. Of the other 6 participants who had not received a PAC service previously, one had worked for an insurance company that covered PAC services and the rest mentioned that they knew someone who had received at least one PAC service.

Data analysis revealed three themes (see Table 1). For the first theme we found that some participants may decline offers of PAC services because of **previous negative experiences with PAC services**. The second theme, **a preference to be home,** was identified as the basis for declining facility-based PAC services (i.e. inpatient rehabilitation, skilled nursing facility care, nursing home care, and/or non-home based hospice care); however many of these participants were open to potentially accepting home care services. Five participants however told us they would not decline any PAC services offered and this additional finding is discussed further as “I'd be there”.

The third theme is a focus on participants’ ideas of **why other people might decline PAC.** This includes their ideas on declining services overall (cost, lack of understanding and preconceived ideas, more comfortable at home, personal traits and personality of the individual, previous negative experience, and wanting family members as caregivers). It also includes ideas commented on why others might decline home care services specifically. Reasons given include that patients may be embarrassed about home conditions, concerned about invasion of privacy, and worried about personal safety.

Previous Negative Experiences with PAC Services

Some of the participants relayed negative experiences with PAC services from their perspectives in the role of patient, visitor, or previous employee. These negative experiences included both in their home (home care services) and in facility-based settings (inpatient rehabilitation, skilled nursing facility care, NH care, and inpatient hospice) and were described by participants as negatively influencing future decisions of accepting PAC services.

Specific to home care services, a subset of all participants who had previously received the service spoke about their expectations not being met in regards to quality of services and care. One participant explained “...they start out gung ho the first day, and then after that it goes downhill. They used to come right on time...”. Another participant felt the information she was provided about the service was misleading which resulted in her daughters taking on the unexpected bulk of the caregiver responsibilities. Inconveniences of receiving home care were also shared. One participant explained that she had home care services in the past, but had not agreed to home care services the last time it was offered because “I hate the

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intrusion of having to make an appointment and someone coming to your house, and you have to get up, or you have to make time." She however did say "I would go along with any [PAC service], if I had no one else". She also noted that her husband is currently able to provide all the care she needs at home including checking blood pressures and managing oxygen.

Some participants talked about being dissatisfied with one PAC service because of a previous negative experience but shared positive experiences with other PAC services they received. For example, in a case where the participant expressed overall satisfaction with home care services, the participant also reflected on a recent negative experience in a skilled nursing facility. She told us that her admission followed heart surgery and during her stay she developed pneumonia. When reflecting on her experience she said "I almost died" and now is "a little leery" of any PAC services not in her own home.

Some of the participants formed a negative opinion after visiting a relative or friend who was in an inpatient PAC setting. One participant shared her past experience of visiting her sister-in-law at an inpatient hospice and hearing patients "suffering and screaming in pain". Based on this experience she would not accept offers of hospice services. "Somebody told me I had to go to a hospice, guess what? This old girl would run and live in a box under a bridge first". Another participant talked about wanting to stay in her own home and not wanting to enter an inpatient PAC service. Part of this decision was based on experiences with visiting a friend in a "very nice nursing home" but was bothered with observing the older adults spending time only watching television and eating meals, and these activities being the only points of conversation.

By chance, five of our participants had previously worked for a PAC service and they expressed opinions formed from those experiences. Three participants said they were against going to a NH based on their previous employment experience. For example, one participant had worked short term in a NH as a Certified Nursing Assistant and subsequently resigned from her position after witnessing poor quality care delivered to the residents including extended wait time for basic needs. She said "Sometimes you're left to lie in your feces, in your urine.... you've got to wait your turn." Another participant said that she used to "tour nursing homes" for her job (did not specify job title). She said she was not satisfied with the limited amount of attention that the residents received and expressed that she witnessed poor quality of care with negative outcomes suffered by the residents as a result. For other PAC services, this participant said it would depend on her condition as to whether she would decide to accept offers of services in the future; at the time of the interview she had family to help her.

Preference to be Home

One subset of participants talked about their preference to be home following hospitalization which would affect their decisions to accept inpatient PAC services. Some of these participants would potentially be open to accepting home care services. This preference to be home was heard to be related to having and wanting family members to assist with care and participants' ideas of comfort. As one participant told us, "My wife would take care of

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me. I have two children at home that would take care of me. That is why; it would have to be some major problem for me to go to a place like that." Another participant explained,

> I think that if I had to choose between hospice and nursing home...I would prefer hospice because I would like to be at home. I would like to go home as opposed to going to a facility where I do not know people. If it is possible, I would prefer to be home. Or my daughter's home.

Another participant preferred the comfort and control of being within his own home as opposed to going to a NH. For him that meant knowing where everything is, getting up and walking whenever and wherever (i.e. outside) he wanted, and not having to ask for things such as snacks and food. Another participant explained her preference to be home by saying, "We want to grow old in our house and around our things". An additional participant who was already receiving home care services prior to the hospitalization said "I want to be at home. I want to be in my own bed, have my own bathroom, have my own everything".

"I'd be there"

Five of the participants were surprised to hear that some patients refuse PAC services when they are offered. Three of these participants had previously received home care services, one had previously received home care services and nursing home care, and one participant had a family member who received hospice care. One participant responded to the interview question by saying "Well, I guess I'd be there". Examples of other comments we heard were "Why wouldn't anybody want it? If they had it available to them, they should take it." and "I think any of it would be helpful". Another participant responded in terms of home care services that she thought everybody would be glad to have a nurse or nursing assistant to come to their home to assist them.

Ideas of Why Others Would Decline Offers of Services

Participants also shared their ideas of why they thought other people would decline services. This included thoughts on PAC services overall (the cost, lack of understanding and preconceived ideas, more comfortable at home, personal traits and personality of the individual, previous negative experience, and wanting family members as caregivers) and specific to home care services (embarrassed about home conditions, invasion of privacy, and personal safety).

Cost—One participant said, "A lot of them can't afford it. They don't have insurance, and they can't afford to pay for that". In addition to the inability to pay for services or insurance not covering cost, frustration from dealing with insurance companies and the "red tape" involved with getting services covered were also mentioned as reasons people may decline services.

Lack of understanding and preconceived ideas—Participants who had previous experiences with PAC services had thoughts that others may decline offers of services because of a lack of understanding of enrollment requirements, what the services could do for a patient, and inaccurate preconceived ideas. One participant's response was,

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> Basically not understanding or believing what the person they are dealing with is telling them. They have preconceived ideas. They may have talked it over with other friends or relatives, neighbors, whatever. I think it deals with that. Everybody has preconceived ideas as to...when you say nursing home, it is like a red flag pops up and says, "Wait a minute, find out more about it before you commit to it".

Another participant thought services need to be explained more clearly and added:

> I didn't understand what it was that they were offering me. Was it a scam? Was it a come on? What is this? I raised my hands and said...I'll just accept it and see how it goes and it went well so I was happy.

We also heard a story from a participant about receiving home care for the first time and she had the misunderstanding that she wasn't to leave her house at all. She left her house to get a haircut and said "I felt like I had my hand in the cookie jar and somebody was going to smack it at any moment" until her nurse explained to her that it was fine for her to go out of her home on rare occasions for essential activities. This participant thought a similar lack of understanding about services could negatively influence patients' decisions to accept services. Another participant spoke about not having a clear understanding of services prior to enrolling but after receiving home care services and inpatient rehabilitation services now thinks "It is really crazy to not embrace these things". Additionally, two participants thought that others may decline services because of a "fear of the unknown".

More Comfortable at Home—In terms of inpatient PAC services, participants expressed that people may refuse these services because of their desire to stay home. Participants explained that people are more comfortable in their home, in their familiar environment, surrounded by their belongings, and with their family present.

Personal traits and personality of the individual—Some participants thought that individuals' personal traits and personalities may be the reasons that they may decline PAC services. "Stubborn" and "hard headed" were words used to describe people who did not think they needed help from others, did not want someone waiting on them, and believed that they can do everything for themselves. "Stubborn" was also used to describe someone who is resistant to enrolling into inpatient PAC services like hospice and NHs because "they have heard horrible stories about them". Someone's "pride" might also contribute to declining services because they may feel that accepting services is "beneath them". Additional reasons people may decline PAC services from the perspectives of our participants were situations where someone is "depressed", "do not want to live no more", "are tired and they do not want to be bothered" or "they just don't want it".

Previous negative experience—Another idea participants shared about others declining offers of services was that they may have had a negative experience in the past with PAC services. One participant offered that others may have had a previous situation where "they weren't treated right" and "were forgotten about". Another participant felt that providers may have been "meddling" in their business in the past thus making people not wanting to participate again.

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Wanting family members as caregivers—Having or feeling that family support is available, wanting “their family to take care of them instead” of being admitted into a facility post-hospitalization, or “figuring their family's going to do the same thing that the home care would” are other perceived reasons why patients would decline PAC services. One participant shared that he had family members to take care of him, and thought this could be the case for others. Another participant thought the opposite and said people may not want services post-hospitalization because “you do not have nobody to help you. Some care maybe needs to be, someone has to drive you, and you have no means to get there”.

Thoughts on Others Declining Services Specific to Home Care

Embarrassed about home conditions—Participants offered their thoughts on the condition of the peoples’ homes as a reason that they may decline offers of home care. As one participant put it, “Maybe they are ashamed of where they live, of their surroundings”. Another participant said:

> They don't want nobody in the house. Some people don't want anybody in the house. And some people have the house so cluttered full of stuff that should be thrown away, they don't want them coming in because they think they're going to tell them where to put all that trash......so they don't like people to come to their house because, you know, to see the conditions. But they need help.”

Invasion of privacy—It was also thought that people may feel that it's an invasion of privacy to have providers entering homes and a nuisance to have someone “meddling in their business”. A participant said:

> I think some people might think it was an invasion of privacy or the nuisance factor of having somebody come into your home and the sense that if you let them in it's kind of like Big Brother is now watching me.

Personal safety—Participants expressed that other people may decline home care services because of concerns about personal safety with letting “strangers” into their homes. Worries about being in physical danger or people stealing their belongings was mentioned. One person told us “Well, it is a trust issue with most seniors. They don't trust people nowadays. Most seniors, they don't trust people coming in and out of their house.”

Discussion

This study explored why older adults may decline PAC services. Our study suggests that individualized perceptions and preferences play a key role in decisions to decline PAC services. We found that some of the participants may decline offers for PAC services because of previous negative experiences from a time when enrolled in a PAC service, visiting family or friends in an inpatient facility, or during past employment with a service. Some participants expressed having a desire to stay in their own home following hospitalization, thus affecting their decision to enroll in an inpatient PAC service. Some participants with previous experiences with PAC services were surprised to hear that patients would decline or refuse services offered and told us that they themselves would not decline

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services. Participants also expressed ideas regarding why “other patients” might decline PAC services, both in terms of services overall and specific to home care services.

Past personal experiences and those of acquaintances, the type of service offered, and familiarity with services offered may influence patient decision making. Our study suggests that these underlying beliefs could impact decisions to decline PAC services, potentially incongruent with patient care needs. Patient preferences are a salient factor in decision making, particularly following an acute illness. A study evaluating post stroke patients’ preferences about rehabilitation after hospitalization found nearly 85% preferred rehabilitation in their homes versus inpatient rehabilitation or skilled nursing facility even though more aggressive inpatient rehabilitation may result in improved functional outcomes (15). Shared decision making among discharge planners, healthcare providers, patients, and families is essential to promote the most appropriate plan for each individual balancing personal preferences with available resources and care needs. Based on our study findings, we recommend that any healthcare providers assisting with hospital discharge planning assess the patients’ knowledge and experience with PAC prior to offering any pertinent services. PAC planning should start early in the hospital stay allowing time for individualized discussion about services, setting expectations, and addressing patient concerns.

Concerns expressed by the participants regarding costs incurred due to co-payments for post-acute care services were also expressed by participants in a large study conducted in Korea (16). Willingness to use home care services varied according to whether a co-payment was required. One half of the participants said they would not use home care services, 43% said they would use them if there was no co-payment, and only 5% were willing to use them if there was a co-payment. Findings such as these may indicate that participants do not value the benefits of home care services. Similar to our findings, patients who had experienced homecare in the past were much more willing (five times more likely) to accept the service in the future (16). These findings suggest the need to educate the public about the benefits of the services for them.

For many, the realities of care needs after a hospital stay may present taxing burden on patients and family caregivers (17). When faced with decisions regarding PAC, many patients turn to their healthcare providers to make recommendations, although, provider referral patterns for PAC are also subject to personal preferences (18) and varied levels of risk tolerance and expertise (19). Presenting explanations of the professional services PAC encompasses such as medication reconciliation, continued monitoring of symptoms, teaching, care coordination, pain management, and wound care could improve acceptance of these valuable services. Informing patients and families about the specifics of potential services they might receive and how a particular service matches their needs, may provide important opportunities for making more informed decisions (7). Educational campaigns aimed at providers and patients and their family caregivers may benefit the PAC industry by highlighting positive aspects, dispelling negative stereotypes, and managing expectations as in reality family caregivers may not be able to meet PAC needs as is often the hope.

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Additional factors influencing PAC options include payment models favoring a specific destination and the provider making the recommendation (20). New reimbursement models such as bundled payments aim to distribute risk and profits across multiple sites of patient care, including PAC destinations. Our findings are important to understand patient decision making because patients who decline PAC services in such models may present financial risks should they decline options meant to optimize health in more cost efficient environments (21). Healthcare providers involved in discharge planning who are equipped with the skills to navigate patient preferences and the evolving intricacies of the healthcare system, including payment and practice models, are essential to optimal PAC coordination.

This study reinforces probes for future research investigating the decision making and outcomes of individuals who have declined PAC services. Previous research by Katz (6) summarized three explanations for variable acceptance of rehabilitation services among patients. These themes included a lack of financial or functional eligibility, a failure to recognize the need for services during a hospital stay, and the patients' preference to return home. Further inquiry in a broader population is needed to discern patient misperceptions about PAC and interventions that can promote shared decision-making between health professionals, patients and families to promote overall wellbeing and optimal function following hospitalization. Factors of importance when choosing a PAC destination may include how medical facts are weighted in decision making, what objective data is available regarding the value of PAC services, how the commodity of time plays into decisions, and the capacity of individuals to make educated decisions within the acute care setting. Interventions targeted at closing gaps between patient perceptions and provider recommendations regarding PAC needs may help individuals see additional value in services offered.

Limitations

Although this was a rigorous qualitative study, some limitations need to be acknowledged. Results are limited to participants' responses from one focused question on why a person may not want PAC services. Due to the question being open-ended, many of the participants responded by both discussing their own experience and what they thought others might have experienced. Additionally, the four different RAs who completed the interviews may have varied their approach and probes to the question when eliciting further details. All the participants in this study were hospitalized and identified as likely needing PAC services. They were all in one Northeastern US academic medical center and are of a convenience sample.

Conclusion

The results of this study begin to fill the gap in knowledge related to why older adults who are identified as in need of PAC services decline these services. The thirty adult participants interviewed for this study had significant past exposures to PAC; 24 participants had previously been enrolled in a least one PAC service, and participants were also familiar with PAC through working at one of the services or having a friend or family member receive care from one of the PAC options. These past experiences with PAC were found to influence

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patients' discharge decisions related to PAC, with negative past experiences involving specific PAC services leading patients to decline those services. In addition, patients described a desire to be at home as a reason for declining PAC services that are outside of ones' home, such as inpatient rehabilitation, skilled nursing facility, nursing home, or inpatient hospice. Past experiences and preferences are both vital when patients are making decisions about post-acute care. These study findings have implications for healthcare providers involved with discharge planning when approaching patients about PAC options and have the potential to lead to increased shared decision making among providers, family members, and patients. It is important for anyone involved in discharge planning to continue to assess patients' knowledge and past experiences with PAC in order to provide relevant and desired education about the options and to determine patient preferences. From this knowledge, those involved in discharge planning can try to recommend services that align with the expectations and priorities of patients.

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Table 1

Themes of Reasons for Declining PAC Services

Context	Theme	
Why the participant would decline PAC services	1	Previous negative experiences
Why the participant would decline inpatient PAC services	2	Preference to be home
Why other people might decline PAC services overall	3	Fear of the unknown/preconceived ideas
		Personal traits and personality
		Wanting family members as caregivers
		Cost
		Previous negative experience
		More comfortable at home
Why other people might decline home care services	3	Invasion of privacy
		Embarrassed about home condition
		Personal safety