

Older Persons' Preferences for Site of Treatment in Acute Illness

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OBJECTIVE: To explore how older persons form preferences for site of medical care by examining their perceptions of home care and hospital care.

DESIGN: Qualitative analysis of in-depth interviews using the constant comparative method.

SETTING: Respondents' homes.

PARTICIPANTS: Twenty-nine persons age 65 to 89 years who had been hospitalized with congestive heart failure, chronic obstructive pulmonary disease, or pneumonia and were receiving home care services.

MAIN RESULTS: Respondents, who thought of home care only as a means to provide low-intensity and low-frequency services, were initially skeptical about expanded home care services to treat acute illness. Regardless of their opinions about home and hospital, all respondents preferred the site associated with the greatest chance of survival. If the sites offered equal survival, 52% of the respondents preferred treatment at home because of freedom from the constraints of the hospital and the comfort of familiar surroundings. For respondents who preferred the hospital, the home represented a frightening and lonely place to be sick. Respondents' views of the home and hospital were shaped by their social supports, self-reliance, religious beliefs, and past illness experiences.

CONCLUSIONS: Because survival appears to be the most important determinant of preference, home treatment of acute illness is a viable alternative only if it provides outcomes equivalent to those of hospitalization. Strongly held perceptions that home care can only be a low-intensity service may limit preferences for home treatment. When expected outcomes at the two sites are similar, the challenge to the health care system will be incorporating patient preference about the process of care into decisions about the appropriate site of care.

KEY WORDS: patient preference; home care; qualitative research.

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The acute care of older persons is moving out of the hospital and into the home. This movement is in part a response to concerns about the iatrogenic complications associated with hospitalization of frail older persons and the hypothesis that home care may avoid these complications.^{1,2} An even more powerful incentive for shifting acute care into the home is economic. Medicare's prospective payment system gave an initial boost to the provision of "high-tech" care outside the hospital,³ and managed care continues to see reductions in hospital utilization and associated costs.

Advocates of expanded home care programs maintain that patients find such programs desirable because of their inherent dislike of hospitals as foreign and inhospitable environments.⁴ Conversely, others are concerned about the burdens that home care places on patients and their families, contending that patients do not want to have their homes converted into hospitals.^{5,6} In the midst of this debate, however, only one study has directly asked patients about their preference for home care versus hospital care. This study of young patients (average age of 44 years) with pneumonia revealed that almost three fourths of those surveyed preferred home to hospital treatment but did not determine the reasons underlying the preference.⁷

To assess whether the shifts in health care delivery will meet the needs and expectations of older persons, it is important to know not only their preferences for site of care but also the aspects of care and the perceptions of home and hospital underlying these preferences. Because so little is known about how patients form their preference for site of care, we undertook a qualitative study using open-ended interviews to examine this question.⁸ The purpose of the study was to explore how older persons form preferences for site of care and specifically to determine the aspects of care delivered in the home and hospital that influence preference.

METHODS

Participants

The 45 potential participants were persons aged 65 years and older who met the following criteria: had had an episode of congestive heart failure, chronic obstructive pulmonary disease, or pneumonia serious enough potentially to require hospital care 1 to 6 months earlier; were receiving home care services through a single home care agency; were English-speaking; and were cognitively intact. The three diseases were chosen because of their prevalence among older persons and the potential for treating these diseases in the home. The selection of per-

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sons receiving home care services resulted in participants who were able to reflect on both their experience with treatment for an acute illness and their experience with receiving care in the home.

The sample size was determined according to the concept of theoretical saturation.⁹ Interviews continued until the investigators believed that more participants were unlikely to introduce new concepts. In order to include the 29 participants necessary to reach saturation, the nurse asked 34 clients for permission to bring the principal investigator to their home to explain the study, and 30 (88%) agreed. Of these 30, 29 (97%) subsequently provided informed consent to be interviewed. This protocol was approved by the Human Investigations Committee of the Yale University School of Medicine.

Data Collection

An open-ended interview instrument was developed to ask participants about their experience with home and hospital care, their preferences for site of care, and the reasons underlying their preferences. In addition, specific probes were included to ask about aspects of care identified in the literature as potentially important to patients, including the outcome of care, the importance of a nursing presence 24 hours per day, and the importance of physician opinion. All interviews were conducted in the participants' homes by a single investigator (TRF). Interviews lasted between 30 and 60 minutes. The interviews were audiotaped and transcribed.

Data Analysis

The transcripts were analyzed by means of multiple close readings by two of the investigators (TRF and CVD). Segments of the transcripts were initially coded into discrete themes by each of the investigators independently. This use of the software program HyperRESEARCH (Researchware, Randolph, Mass., 1991 to 1993) facilitated the assignment of codes to text. The investigators then met to review the themes in each interview. If there was disagreement about the presence of a theme, consensus was reached through discussion. From these themes arose more theoretical concepts according to the constant comparative method of qualitative analysis of Glaser and Strauss.⁹ This method, designed to generate grounded theory, calls for the comparison of individual incidents, or themes, among respondents. The constant comparison of themes across respondents results in the generation of more abstract concepts. As these concepts are compared across respondents, their theoretical properties, such as their dimensions, their relation to one another, and their consequences, emerge.

By this method, we began with the themes of perceptions of care delivered in the home and in the hospital. From these themes, we developed concepts of how older persons formulate their preference for site of care. Analy-

sis occurred concurrently with data collection in order both to inform the sample size and to allow for any questions or points of particular interest to be explored in subsequent interviews. For example, analysis of the first several interviews revealed that none of the respondents mentioned their physician when asked about the services they would like to receive at home. This prompted us to ask the next respondents specifically why they did not talk about their physician.

RESULTS

A total of 29 interviews were conducted with persons ranging in age from 65 to 89 years (mean \pm SD, 77 \pm 7 years), of whom 21 (72%) were female, 18 (62%) were white, and 11 (38%) were African American. The majority of the respondents, 17 (59%) lived alone; 6 (20%) lived with children; 4 (14%) lived with a spouse; and 2 (7%) lived with other relatives. All respondents had been hospitalized with their illness episode, and none reported having been given a choice about treatment site.

Perceptions of Services Available in the Home

Because we wanted participants to tell us their needs for home care as a treatment site for acute illness, we did not initially define the services they might receive. Participants' initial perceptions were that services provided in the home would be limited in both frequency and intensity. They believed that the services would be similar in frequency to those they were currently receiving as part of their post hospitalization care, such as a nursing visit several times per week and a home health aide visit for several hours each day. In addition, they were concerned that they could not receive the same therapies at home as in the hospital, such as intravenous medications or oxygen therapy. Only one respondent was aware that she could potentially receive intravenous antibiotics for her frequent pulmonary infections at home.

Beliefs about what medical care was possible at home shaped preferences so fundamentally that a number of respondents could not form a preference distinct from these beliefs. Although we encouraged respondents to consider the possibility of a wide variety of home care services, many simply could not imagine receiving the services necessary to meet their needs. For example, respondents concerned about being alone at night could not conceive of having a home health aide at night. Another respondent, who wanted to be in the hospital because that was where her doctor was, refused even to consider the possibility of physician house calls, stating:

I don't think that will ever happen, because who is gonna pay for it? Ha, like it is now, [Medicare] don't even want to pay for what they are doing. So how would they pay for that extra?

Of the 10 respondents who were specifically asked about the role of the physician in home care, all shared

this skepticism about the possibility of physician house calls.

The perception that home care could provide only limited services arose from respondents' experience of home care as a supportive service rather than as an integral part of their medical treatment. When asked about home care, 21 (72%) of the 29 respondents talked about their homemaker and home health aide. They talked about their nurse only when specifically asked and did not feel that nursing care was important to their treatment. Of the eight respondents who spoke about their nurse, only one felt that nursing care was important in keeping her well and at home. Although these respondents spoke about having their nurses monitor their symptoms, their experience was that in the event of a change or a problem, the nurse's role was to report this to the physician but not to participate in changes in therapy.

One respondent said about the nurses who came to see her:

The only thing they can do is test my blood [pressure] and see if it is high or low If it's out of hand, they will call my doctor, and my doctor will tell them what to do—take me to the hospital.

Only one respondent felt that her nurse's monitoring had averted more serious problems, referring to home care as a "preventative service."

Importance of Outcome Over Process of Care

Preferences for site of care depended on the anticipated outcome of the illness episode. The likelihood of surviving the illness was the most important determinant of preference for home or hospital. All respondents preferred the hospital if it would provide a greater chance of surviving the illness. Even respondents who expressed a strong dislike of the hospital did not hesitate in saying that they would go to the hospital if the hospital offered a survival advantage. The perception of home care as a low-intensity service was strong enough in 6 (21%) of the 29 respondents that they appeared to believe home care could never provide survival outcomes equivalent to those that hospitalization provided. When asked what they would do if their physicians told them that home care would provide them with outcomes equal to or better than hospitalization, these respondents replied with statements such as, "I wouldn't believe him" and "I think he would be kidding me."

It also became apparent that some respondents initially preferred home care because they simply could not believe they would be as sick if they were at home rather than in the hospital. One respondent recognized that she could be thinking this way:

I think when you're in the hospital, you always feel as though you're not coming home Some people, well older people, even older than me, feel that once they're in the hospital they're going to die, but home, no matter how sick they are, they are better because they're home.

Although they were unable to articulate this sentiment as clearly, two other respondents appeared to use similar reasoning in forming their preference.

Preference also depended on whether the illness was terminal. In the case of a terminal illness, 6 (21%) of the 29 respondents who generally preferred one site changed their preference to the other site. Equal numbers, three respondents each, changed their preference from hospital to home and from home to hospital. One woman who felt strongly that she belonged in the hospital with her congestive heart failure stated:

If I were to know in advance that there was no hope for me, I prefer dying at home. I would at least have my children around, my relatives, you know.

Conversely, a woman with chronic obstructive pulmonary disease who generally preferred treatment at home wanted to be in the hospital if she were dying because of her belief that people who were that sick needed people around who would not panic:

When you're that bad, go [to the hospital]. This way you're right there. If you need them [the nurses], they're there. That's why they're supposed to be called the angels of mercy.

Preferences for Care at Home and in the Hospital

If home care and hospital care were associated with an equal chance of survival, there were clear differences in preference for the two sites. Preferences were based on differences in perceptions of the process of care at home and in the hospital. Slightly over one half of the sample, 15 (52%) of the 29, preferred home care, both because of positive aspects of home and negative aspects of the hospital. The comfort of home was a frequently recurring theme, cited by 8 of the 15 who preferred home care. The hospital was felt to be constraining and restraining by four who preferred home.

Three respondents preferring care at home stated:

You are always more comfortable and sleep better in your bed, and all that.

You know what I mean. I can't really describe it or how to tell you, but you know the old figure, "there's no place like home."

I got this deep ingrained dislike for hospitals, being confined in the hospital. I'd rather be home. . . . There's nobody telling me you can't do this, you can't do that.

Two other advantages of care at home were not being surrounded by other sick people, cited by 4 of the 15 who preferred home, and receiving the undivided attention of the nurse during a home visit, cited by 2 of the 15. For example, two respondents stated:

If you could stay home . . . I think that's the best place for you. You get along better. You don't see sick people next to you all the time. It gives you a better chance to fight . . .

When you're in a hospital with all those poor sick people, you don't feel bright. You feel sorry, and it's making it worse for yourself.

The sense of safety and closer monitoring was cited by 10 of the 14 respondents who preferred the hospital. For example, one said:

I would want somebody who had nurse's training, and this is 24 hours. I would feel safer. You want to be right where people get to you quick. There are times when in case you needed a nurse, you got to ring the bell; she'll come right away.

Another respondent summed it up this way: "When you belong in a hospital, you belong in a hospital."

Another aspect of care very important to 2 of the 14 respondents preferring the hospital was the availability of help at night. Nighttime help was important both from a practical viewpoint, for providing assistance with such tasks as getting to the bathroom, and a more emotional viewpoint, for providing reassurance at times of greatest fear. Another two respondents worried about burdening their families with their illness. In direct contrast to the views of those preferring home care, the presence of other patients was also explicitly cited as an advantage of hospitalization by one of the respondents.

Factors Influencing Perceptions

Because perceptions of home and hospital differed so dramatically between respondents preferring home care and those preferring hospital care, and because these perceptions determined preference, we sought to understand the factors influencing respondents' perceptions. Four factors appeared to be closely associated with preference: social support, religiousness, self-reliance, and past experience with illness. Whereas the availability of family members for assistance was mentioned by 8 of the 15 respondents who preferred home care, the absence of family was cited for 4 of the 14 respondents who preferred hospital treatment. Three respondents, each of whom lives alone, expressed their concerns this way:

In the daytime, I am doing fairly well. At night is when I suffer. Who gonna be there if I can't answer my phone? If I need to go to the bathroom and can't get to the bathroom, who gonna be there to help me?

I have no one to stay with me. And it's terrible even at nighttime, like 12 o'clock at night, you have diarrhea, and you're all alone, and you're so weak. It's an awful, awful feeling, terrible.

Living by yourself is no fun, especially if you are sick. No fun.

Three respondents who preferred home care despite the absence of strong social support did so with a sense of self-reliance, leading to the conclusion that it was easier to cope with symptoms at home than in the hospital. In contrast to the respondents above, another respondent who had experienced diarrhea and who lived alone felt this way:

I had a lot of diarrhea, and I wouldn't make it from the bed to the bathroom If that ever happened again

where that became a problem, I would get a commode. I would be less likely to make a mess with a commode at home, than to have to get up out of a high hospital bed and all that and walk the cold floor to the bathroom.

One respondent who preferred home care held the spiritual belief that the outcome of illness was under divine control. The only respondent who did not believe that the outcome of care was linked to the site of care and did not see the need for the advanced technology or closer monitoring available in the hospital stated:

When the good Lord in heaven decides that it's time to go, you're going to go. Don't make no difference where you are, who you're with, or what you're doing.

Previous experiences with illness and its symptoms influenced preference for site of care. The two respondents who described the experience of an acute onset of shortness of breath preferred hospital care. One woman whose children in general provided her with a lot of support worried that they would not know how to help her if she became symptomatic:

I don't think my kids would know what to do. I might make them nervous. . . . I couldn't catch my breath, you know, and then you don't want them to leave. You're afraid.

DISCUSSION

The qualitative findings of this study suggest that preference for site of care in acute illness among older persons is determined first by beliefs about the availability of services in the home and hospital and a consideration of the outcome of care in terms of survival. Secondly, it is shaped by perceptions about the process of care. Perceptions about process of care are, in turn, shaped by several factors, including the availability of social support, religious beliefs, self-reliance, and past illness episodes. The importance of outcome is seen in the desire for the site of care that provides the greatest chance of survival, even if that site would not be preferable under other circumstances. This is consistent with recent findings from the SUPPORT study, which demonstrated a preference among severely ill and dying patients for aggressive treatment.¹⁰ It is also consistent with earlier work demonstrating the preference among recipients of intensive care for repeated episodes of such care,¹¹ and it runs counter to the notion that for some older persons, "comfort" is more important than "cure."⁶ These findings are also consistent with a study of younger pneumonia patients who preferred home treatment only if it was, on average, associated with no more than a 1% increased risk of death compared with hospital treatment.⁷

Our study suggests that if hospital and home treatment are associated with similar outcomes, the process of care determines the preference for site of care. Although the importance of incorporating patients' preferences into medical decision making has long been widely accepted, the focus has been on eliciting preferences regarding the

outcomes, rather than the process, of care.¹² For example, whether surgery is the appropriate therapy for benign prostatic hypertrophy depends heavily on how the patient views operative risk versus relief of symptoms.¹³

Consideration of preferences for different processes of care resulting in similar outcomes has received much less attention, most likely because of the frequent assumption that there are unique pathways of care providing a given outcome. However, that assumption is rapidly changing, especially regarding the necessity of hospitalization. Against the backdrop of dramatically shortened lengths of stay in hospitals, recent research has shown the efficacy of forgoing hospitalization altogether in the treatment of certain conditions. Home treatment has been shown to be as effective as hospital treatment of deep venous thrombosis¹⁴ and to decrease the need for hospitalization relative to that of historical controls.¹⁵ In addition, the development of definitions of low-risk acute conditions implies that these illnesses can be treated outside the hospital.^{16,17}

Moving from the conclusion that certain illnesses can be treated outside the hospital to the conclusion that these illnesses should be treated outside the hospital depends on the weight to be placed on patients' preferences for the process of care. Incentives can work against preferences for both home and hospital. On the one hand, the greater convenience of hospital versus home care for physicians treating an acutely ill patient may prevent patients who would prefer this treatment option from receiving it. This notion is supported by the findings that among low-risk pneumonia patients, 69% felt their physicians alone made the decision about treatment site,⁷ and among our respondents, none reported having been given a choice about site of care.

On the other hand, a major goal underlying the determination of low-risk conditions and the development of outpatient treatment regimens is to control costs. The effort to contain costs may prevent hospital treatment for patients who prefer the hospital as their site of care. Decisions to provide care in the home will be difficult for those older persons to whom home represents a lonely and frightening place to be sick. One major challenge will be to reconcile the preferences of individual patients with the global need to reduce health care costs. A second challenge will be to identify and meet the needs of informal caregivers. Several respondents explicitly worried about the burden that home treatment would place on their caregivers, and it appeared that the ability of home care to meet the preferences of other patients is contingent upon the support provided by their family members. It will therefore be important to determine the impact of home care and hospital care on these family members as well as the patients. The identification of particular areas of concern, such as the need for help at night, suggests that provision of a few key services may greatly ease the burden that expanded treatment at home can place on some patients. It also suggests the potential advantages of alternative sites of care, such as subacute facilities, to

accomplish both the goals of meeting preference and lowering costs.

Our results demonstrate several difficulties in eliciting preferences for the process of medical care. First, the reasoning employed by some respondents, that home care would be preferable because they would necessarily not be so sick if they were treated at home as they would be if treated in the hospital, is an example of patients' propensity to use optimistic methods when thinking about risk.¹⁸ This finding gives support to the warnings about the limitations of closed-ended instruments to elicit preferences and the contention that preferences can only be understood in the give-and-take of semistructured or open interviews, during which clinicians can confirm what patients are actually thinking.¹⁹

Second, it was difficult for some of the respondents to think abstractly about components of care. Respondents' answers were intricately tied to the kind of care they believed to be possible. It was so difficult for some respondents to imagine physicians in their home or assistance available at night that they could not perceive home care to be an option if these aspects of care were important to them. Although we chose to interview persons who were receiving home care services in order for home care not to be a purely hypothetical treatment option, it is possible that the respondents' actual experiences with home care made it difficult for them to move beyond their fixed conceptions regarding the capabilities of this care. It was also difficult for some respondents to believe that home care could provide outcomes equal to hospitalization.

As long as home care means, in the minds of older people, home health aides and homemakers rather than physician house calls and the provision of acute therapies, it will not be considered a viable alternative to hospitalization. The recent documentation of the decline of the physician house call suggests that our respondents' perceptions reflect the prevailing current practice.²⁰ This finding has profound implications for eliciting and acting on patient preferences. It is possible that we cannot know the true preference for a system of care until that system is in place and is recognized by patients and their families as a feasible alternative.

As a qualitative examination of the preferences of older persons for treatment site, the findings of this study reflect the range of perceptions about home care and hospital care and the complexities of eliciting and understanding preferences. They do not, however, provide data on the frequency of preferences for home care or hospital care among older persons, nor do they provide more than hypotheses regarding the association between certain characteristics, such as social support and preferences. The estimation of preference frequencies and the establishment of statistical associations will require quantitative analysis among a larger sample. The findings of this study also suggest further directions for future quantitative research. Given the importance of preconceived notions about home care and hospital care on preference, it

will be important to determine whether education about and actual experience with these sites influence preference. In addition, it may be possible to isolate the specific components of care most prized by patients independent of site, so that new systems of care can honor preference while containing costs. Only if preferences are explicitly assessed can we determine if the changing health care environment can accommodate both of these goals. Fundamental to this accommodation will be both the recognition of preference and the flexibility to provide different pathways of care according to preference.

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