Comparison of Stress Experienced by Family Members of Patients Treated in Hospital at Home with That of Those Receiving Traditional Acute Hospital Care

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OBJECTIVES: To compare differences in the stress experienced by family members of patients cared for in a physician-led substitutive Hospital at Home (HaH) and those receiving traditional acute hospital care.

DESIGN: Survey questionnaire completed as a component of a prospective, nonrandomized clinical trial of a substitutive HaH care model.

SETTING: Three Medicare managed care health systems and a Veterans Affairs Medical Center.

PARTICIPANTS: Two hundred fourteen community-dwelling elderly patients who required acute hospital admission for community-acquired pneumonia, exacerbation of chronic heart failure, exacerbation of chronic obstructive pulmonary disease, or cellulitis.

INTERVENTION: Treatment in a substitutive HaH model.

MEASUREMENTS: Fifteen-question survey questionnaire asking family members whether they experienced a potentially stressful situation and, if so, whether stress was associated with the situation while the patient received care.

RESULTS: The mean and median number of experiences, of a possible 15, that caused stress for family members of HaH patients was significantly lower than for family members of acute care hospital patients (mean ± standard deviation 1.7 ± 1.8 vs 4.3 ± 3.1, $P<.001$; median 1 vs 4, $P<.001$). HaH care was associated with lower odds of developing mean levels of family member stress (adjusted odds ratio = 0.12, 95% confidence interval = 0.05–0.30).

CONCLUSION: HaH is associated with lower levels of family member stress than traditional acute hospital care and does not appear to shift the burden of care from hospital staff to family members. **J Am Geriatr Soc 56:117–123, 2008.**

Key words: "Hospital at Home"; caregiver; stress; aged; hospital care; acute care for the elderly

Providing acute hospital-level care at home, in a Hospital at Home (HaH), as a substitute for traditional acute hospital admission,[1] has been demonstrated in a U.S. model to be feasible, efficacious,[2] and associated with greater patient and family member satisfaction with care.[3]

Although some believe that patients "mend better at home,"[4] others, including ethicists, policymakers, and other potential stakeholders in dissemination of HaH into widespread practice, may be concerned that providing acute hospital-level care in the home will shift the burden of care provision from hospital staff to family members and cause them significant stress or burden.[5]

Although examined in the context of providing care to chronically ill frail elderly people in a number of care settings,[5–15] there are few published data on stress experienced by family members of patients during an episode of acute hospitalization. The burden imposed by HaH on caregivers has been examined, although these studies chiefly examined early-discharge models of HaH outside the United States[16–18] and used a measure[19] focused on stress experienced by caregivers after discharge from acute care rather than stress associated with an episode of acute illness.

The aim of this study was to describe and compare self-reported stress experienced by family members of acutely ill older patients cared for in a substitutive HaH with that experienced in the traditional acute hospital. It was

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hypothesized that family members of HaH patients would experience fewer potentially stressful situations and report less stress when they did occur.

METHODS

Study Design

The HaH National Demonstration and Evaluation Study

The HaH National Demonstration and Evaluation Study has been described previously.[2] The study was a prospective, nonrandomized clinical trial conducted in two consecutive 11-month phases in three Medicare managed care plans and a Veterans Affairs Medical Center. The study population consisted of community-dwelling patients aged 65 and older who required acute hospital admission for one of four target conditions: exacerbation of chronic heart failure, exacerbation of chronic obstructive pulmonary disease, community-acquired pneumonia, or cellulitis.

The HaH Model of Care

A patient requiring acute hospital admission for one of the target conditions and who met previously validated HaH eligibility criteria were identified, consent was obtained, and they were transported home.[20,21] The HaH nurse met the ambulance at home and provided initial direct one-on-one care for a mean of 16.9 hours. After direct nursing supervision, the patient had intermittent nursing visits at least daily. The HaH physician made at least daily home visits and was available at all times for urgent visits. A partner Medicare-certified home health agency provided nursing and other care components such as durable medical equipment, oxygen therapy, skilled therapies, and pharmacy support, and independent contractors provided some services (e.g., home radiology). Diagnostic studies such as electrocardiograms, radiographs, intravenous fluids, intravenous antimicrobials and other medicines, and oxygen and other respiratory therapies were provided at home.

Development of a Stress Measure

No published survey tool suitable to the study's needs could be found. The Carer Strain Index, a questionnaire, has been used in previous HaH studies,[19] but it focuses on difficulty and strain experienced by caregivers after hospital discharge rather than on the burden or stress associated with being a family member or caregiver of a patient during an episode of illness requiring hospital-level care. Therefore, a pilot study was conducted to develop an instrument to define stressful situations experienced by family members of elderly patients hospitalized with acute medical illness. Interviews were conducted with family members of 25 elderly patients hospitalized to document family members' concerns related to stressful experiences associated with having a family member cared for in the acute care hospital. In addition, it was possible to document concerns related to stressful experiences associated with having a family member cared for in HaH from family members of patients involved in earlier HaH pilot studies.[21–23] From these sources, structured questions were developed and tested in telephone interviews with a family member 2 weeks after a patient was discharged from an acute care hospital. From this, questions were finalized for 15 events that could potentially cause stress. For each question, the family member was asked whether he or she experienced the potentially stressful situation and, if so, whether the experience caused them stress. Reliability of the scale was assessed using the Cronbach alpha statistic, showing an acceptable level of reliability of 0.76.

Although never identified by family members in either care venue as potentially stressful, stress associated with provision of assistance to the patient with activities of daily living (ADLs),[24] instrumental activities of daily living (IADLs),[25] changes in their health-related behaviors during the acute episode, and whether providing care affected their ability to work outside the home were also asked about.

Identification of Family Members

At the time of HaH or acute hospital admission, patients were asked to identify a single "family member, friend, or caregiver who could tell us about the patient before his or her hospitalization." These persons are collectively referred to as "family members."

Outcome Variables

The primary outcome variables of the study were the proportion of family members who experienced each of the 15 potentially stressful situations and the proportion who reported that the situation caused them stress. Research staff not privy to study hypotheses obtained this information in a telephone interview 2 weeks postacute hospital or HaH admission.

Independent Variables

Characteristics of family members obtained were age (dichotomized at 75), sex, self-reported health (categorized as excellent, very good, or good vs fair or poor), respondents' ability to perform ADLs or IADLs, whether the family member lived with the patient, and whether the family member gave ADL or IADL help to the patient in the month before the index acute hospital or HaH admission.

Characteristics of patients obtained in the interview during the acute care hospital or HaH admission were age (dichotomized at 75), sex, whether the patient lived alone, and whether reported family income was below the poverty level according to 1996 Social Security tables. Indicators of health status were primary admission diagnosis, illness severity at time of admission as measured using the Acute Physiology and Chronic Health Evaluation II[26] (dichotomized at 16), comorbid conditions abstracted from the medical record (dichotomized at 6), impairment in functional status as assessed according to ADLs and IADLs (dichotomized as dependent in >2 ADLs or IADLs), symptoms of depression as measured using the 15-item Geriatric Depression Scale[27] (dichotomized as no symptoms of depression present (score 0–5) vs moderate to severe symptoms of depression present (score >6)), and cognitive function as measured using the Mini-Mental State Examination (dichotomized as no cognitive impairment (score >24) vs cognitive impairment (score <24)).

Approval

The study received institutional review board approval from each study site, the coordinating center, and officials at

the Center for Medicare and Medicaid Services. Informed written consent for participation was obtained from all participants.

Analysis

The HaH National Demonstration and Evaluation Study was powered on the outcome of costs of care and employed an intention-to-treat analysis that compared all observation-phase subjects who were treated in the acute hospital from November 1, 2000, through September 30, 2001, with intervention-phase subjects, whether treated in HaH or the acute care hospital from November 1, 2001, through September 30, 2002.[2] In this current study, no data from the observation phase were used, the analysis was restricted to the intervention phase only, and an "as treated" approach was employed. This "as treated" analytical approach is appropriate in this circumstance, because it reduces potential temporal effects and examines potential differences in family member stress experienced by patients. To be included in the analysis, complete data had to be available for each member of a family member–patient dyad.

The proportion of family members experiencing a potentially stressful situation and the proportion of family members who reported stress related to those situations in HaH and the acute hospital were compared using the chi-square or Fisher exact test, as appropriate for each of the 15 items on the stress scale and for the questions related to family member stress associated with provision of ADL or IADL assistance and family member health behaviors. Mean and median numbers of stressful situations experienced by family members according to site of care were compared with *t*-tests and Wilcoxon rank sum tests, respectively.

Factors associated with family member stress with acute care were explored using the mean number of stressful situations experienced by the entire study population and dichotomized at that level (≥ 3 vs < 3). Logistic regression was used to determine whether there was an independent relationship between site of treatment and family member stress. Other independent variables associated with greater levels of experiencing mean number of stressful situations in bivariate analyses that reached statistical significance level of $P < .05$ were included as covariates in regressions. Odds ratios and 95% confidence intervals are reported.

RESULTS

Figure 1 describes patient flow and data availability according to study group. Two hundred fourteen patients were eligible for HaH care during the intervention phase of the study. Eighty-four patients were treated in HaH. All 84 of those patients consented to data collection and completed a baseline patient interview, and 64 family members completed family member stress interviews at 2 weeks, resulting in 64 patient–family member dyads for analysis. Of the 130 acute hospital patients, 57 (44%) consented to data collection and completed a baseline patient interview. In the hospital-treated group, 40 family members completed interviews at 2 weeks, resulting in 40 patient–family member dyads for analysis.

Characteristics of the study population are described in Table 1. Patients treated in HaH and in the acute care hospital were similar in sociodemographic and most health status characteristics except that HaH patients were more likely to be impaired in at least two IADLs. There were no statistically significant differences in the measured sociodemographic and health status characteristics of family members of patients treated in HaH and the acute care hospital.

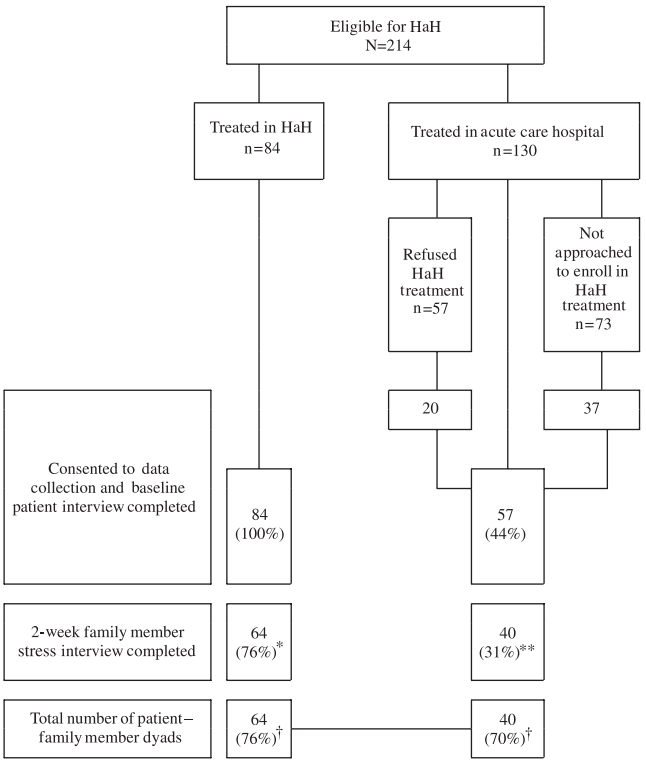

Figure 1. Patient flow and data availability according to study group. *Percentage of all patients treated in Hospital at Home (HaH). **Percentage of all patients treated in the acute care hospital. †Percentage of patients who consented to data collection.

The mean and median number of experiences that caused stress for family members of HaH patients was significantly lower than for family members of acute care hospital patients (mean $\pm$ standard deviation 1.7 ± 1.8 vs 4.3 ± 3.1, $P < .001$; median 1 vs 4, $P < .001$). Possible range was 0 to 15. Table 2 describes the potentially stressful situations for family members, the proportions of family members who experienced them, and the proportion who reported that an experience caused them stress, according to study group. The most commonly experienced potentially stressful situation in both groups related to difficulty monitoring the patient for new symptoms or taking on new responsibilities and difficulty watching the patient lose the ability to take care of himself or herself. Family members of HaH patients were less likely to report stress for 13 of the 15 situations, and this difference was statistically significant for nine of the situations. The situation most commonly associated with stress for family members in both treatment venues related to difficulty watching the patient lose the ability to take care of himself or herself.

In addition to the 15-item stress measure, effort and emotional strain associated with providing the patient help in ADLs and IADLs were evaluated. The only significant

Table 1. Characteristics of the Study Population

Characteristic	Hospital at Home (n = 64)	Acute Care Hospital (n = 40)	*P*-Value
Patient			
Age, mean ± SD	77.1 ± 6.5	76.7 ± 7.2	.78
Aged ≥75, n (%)	40 (63)	25 (63)	>1.00
Male, n (%)	45 (70)	28 (70)	.97
Living alone, n (%)	19 (30)	12 (30)	.97
Income below poverty level, n (%)	16 (26)	6 (16)	.22
Primary diagnosis, n (%)			
Pneumonia	18 (28)	18 (45)	.27
Chronic heart failure	16 (25)	9 (23)	
Chronic obstructive pulmonary disease	18 (28)	6 (15)	
Cellulitis	12 (19)	7 (18)	
Acute Physiology and Chronic Health Evaluation II score ≥16, n (%)	9 (14)	5 (13)	.82
≥6 comorbid conditions, n (%)	41 (64)	20 (50)	.16
Impairment in >2 ADLs, n (%)*	34 (53)	14 (35)	.07
Impairment in >2 IADLs, n (%)†	48 (76)	21 (53)	.01
Geriatric Depression Scale score >6, n (%)	22 (36)	13 (33)	.76
Mini-Mental State Examination score <24 n (%)	19 (30)	6 (15)	.09
Family respondent			
Age, mean ± SD	59.3 ± 17.0	62.5 ± 13.0	.32
Aged ≥75, n (%)	16 (25)	9 (24)	.85
Male, n (%)	13 (20)	7 (18)	.72
Relationship to patient, n (%)			
Spouse	22 (35)	19 (48)	.70
Child	16 (25)	11 (28)	
Other family	9 (14)	4 (10)	
Nonfamily	10 (16)	5 (13)	
Unknown	7 (11)	1 (3)	
Living with patient, n (%)	43 (67)	25 (63)	.63
Health status, n (%)			
Excellent, very good, or good	48 (75)	30 (75)	>1.00
Fair or poor	16 (25)	10 (25)	>1.00
Family member has ADL or IADL impairment, n (%)	8 (13)	5 (13)	>1.00
Family member gives ADL or IADL care to patient, n (%)	38 (59)	18 (45)	.15

* Activities of daily living (ADLs): bathing, dressing, eating, toileting, transferring, walking.
† Instrumental activities of daily living (IADLs): telephone use, managing money, medication use, light housework, heavy housework, meal preparation, shopping.
SD = standard deviation.

difference here was an increase in the proportion of family members providing help in preparation of meals during the acute episode (17% of HaH vs 3% of hospital family members, $P = .02$), although nearly 95% of respondents from both groups reported no additional emotional strain associated with this activity. Ninety-five percent of family members of HaH patients and 82% of hospital patients reported having less time for meals ($P = .03$). There were no differences between groups for time to sleep, taking care of home responsibilities, and performance of usual activities. For "other" responsibilities, a greater percentage of family members of patients in HaH reported taking on a new responsibility (32.0% vs 6.1%, $P = .005$), although there were no differences according to group in declaring stress associated with this responsibility. Twenty-six percent of respondents in both groups were employed in a paying job outside the home; there were no differences according to group in the proportion who reported change in their work schedule or who lost compensation.

HaH care was associated with lower odds of experiencing mean levels of family member stress (odds ratio (OR) = 0.12, 95% confidence interval (CI) = 0.05–0.30), in a logistic regression model that also controlled for better family member health (OR = 0.26, 95% CI = 0.09–0.75), and higher levels of patient comorbid illness (OR = 0.60, 95% CI = 0.24–1.51).

DISCUSSION

Although family member and caregiver stress has been described in the contexts of a number of patient populations and care settings,[6,7,9–15] to the authors' knowledge, this is

Table 2. Proportion of Family Members Who Experienced a Potentially Stressful Situation and Proportion Reporting Stress Related to the Situation

	Experienced a Potentially Stressful Situation			Experienced Stress Associated with Situation		
Question	Hospital at Home n = 64	Acute Care Hospital n = 40	*P*-Value	Hospital at Home n = 64	Acute Care Hospital n = 40	*P*-Value
	n (%)					
Found it difficult to monitor patient for new symptoms or take on new responsibilities	49 (89)	37 (97)	.14	5 (9)	7 (18)	.16
Watching (patient) lose the ability to take care of himself or herself was difficult	28 (46)	20 (61)	.17	28 (46)	20 (61)	.17
During (hospital or home) stay, could not use time in the best way	10 (16)	15 (39)	.01	8 (13)	12 (31)	.03
During (hospital or home) stay could not relax	10 (16)	6 (17)	.87	9 (14)	4 (11)	.69
Having (patient) in (hospital or home) raised fears that he or she might die	8 (13)	16 (41)	<.001	8 (13)	16 (41)	<.001
During (hospital or home) stay, family routine was disrupted	7 (12)	19 (50)	<.001	6 (10)	14 (38)	<.001
Troubling that other family members were not helping out as much as thought they could	4 (7)	6 (16)	.17	4 (7)	6 (16)	.17
Anxious that (hospital or home) was not safe enough medically	4 (7)	4 (10)	.52	3 (5)	4 (10)	.31
Too much noise in (hospital or home)	3 (5)	2 (5)	.90	2 (3)	1 (3)	.88
Overall, having (patient) in (hospital or home) made role as a caregiver more difficult	3 (5)	8 (20)	.01	3 (5)	8 (20)	.01
(Patient) was not comfortable with unfamiliar people and equipment	3 (5)	8 (21)	.01	1 (2)	7 (18)	.002
Patient did not want to be treated at (hospital or home)	1 (2)	17 (44)	<.001	0	12 (31)	<.001
Routines caring for (patient) were disrupted in (hospital or home) and caregiver felt patient was disturbed by this change	1 (2)	8 (22)	<.001	1 (2)	6 (16)	.005
Felt a loss of companionship	0	22 (55)	<.001	0	21 (53)	<.001
Getting to visit with patient during (hospital or home) stay was a hassle	0	9 (24)	<.001	0	8 (21)	<.001

the first study to describe the stress experienced by family members during an episode of acute illness requiring hospital-level care. The stress experienced by family members of patients treated in a substitutive model of HaH was compared to the stress experienced by family members of patients treated in the acute hospital, and it was found that family members of HaH patients experienced potentially stressful situations at lower rates, and that when such situations occurred, they were less often associated with self-reported stress. The specific nature of these data may allay the concerns of those who fear that HaH care may impose excess burden on family members.

Based on experience treating patients in both care venues, it was hypothesized that HaH care would be associated with less stress overall, although it was surprising that certain items on the 15-item measure were favorable to HaH care. For instance, acute care hospital patients are commonly perceived to be "under observation," as opposed to HaH patients who may not always have healthcare providers present in the home. Thus, it was interesting to note that most family members in both HaH and the acute hospital groups experienced difficulties in monitoring the patient for new symptoms or taking on new responsibilities, and that family members of acute hospital patients were more likely to experience stress with this. Similarly, although there is a concern that HaH family members may have to take on more duties with regard to dealing with medical equipment and that the delivery of new equipment into the home could be disruptive, this was more stressful for acute hospital family members.

Participant characteristics were examined in a post hoc manner to explore the association between such characteristics and the odds of experiencing various threshold numbers of stressful situations. HaH care was associated with lower odds of family members experiencing stress and remained significant when controlled for covariates. Family member health was associated with lower odds of stress. The lower rates and odds of family member stress may have been due to several factors, including the higher family member satisfaction with HaH care as earlier described,[3] the sense of control, comfort and convenience of receiving care in HaH, or the specific features of the HaH model studied, such as initial continuous nursing care and daily physician visits.

Previous studies of caregiver burden associated with HaH care from the United Kingdom and New Zealand were chiefly early-discharge models for patients, many of whom had surgical conditions.[16–18] These studies examined caregiver strain using the Caregiver Strain Index,[19] an instrument that was developed to assess strain experienced by caregivers in the postdischarge period, rather than on stress associated with the acute hospitalization itself, and results were mixed.

The strengths of the current study include its focus on the stress experienced by family members during the hospitalization phase of acute illness, its focus on a substitutive

model of HaH care, and its policy relevance. This study provides a measure of stress based on items reported by family members of elderly patients requiring hospital-level care for common acute medical illnesses. Furthermore, it explores covariates of family stress associated with acute hospitalization of older patients. It may also be the first study to provide information on stress experienced by family members of patients treated in a traditional acute hospital.

The results should be viewed with caution. Patients were not randomly assigned to treatment, and differences between study groups may have been due to selection bias. The stress measure instrument has not been fully evaluated in development and validation sets or tested rigorously for construct validity. The study sample was small, and the number of variables in the analysis was large, thus increasing the risk of randomly occurring significant differences for each item. In addition, despite similarities in baseline characteristics, the overrepresentation of HaH patients relative to acute hospital patients may have biased the overall results. A significant proportion of patients in the acute care hospital group did not consent to data collection, although rates of data collection were similar to those in previous studies.[16,18] This study was limited to patients with four acute illnesses and was performed at a Veterans Affairs Medical Center and several Medicare managed care sites; therefore, the results may not be generalizable to other patient populations. Self-report of stress, which is difficult to validate, were relied on. Finally, the overall HaH study from which these data were derived was not powered on the outcome of family member stress.

This study provides empirical data to suggest that HaH care is not inherently more stressful for family members than care provided in the acute hospital and that HaH care does not appear to shift the burden of care from hospital staff to family members. These data may be especially important given recent research that described increased death rates in spouses of hospitalized elderly patients.[28] To the extent that HaH can deliver acute hospital-level care and less family member stress, it may mitigate such adverse outcomes for family members. Finally, the data may be useful to policymakers interested in promoting dissemination and adoption of HaH.

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