

“This Case Is Closed”: Family Caregivers and the Termination of Home Health Care Services for Stroke Patients

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Policies promoting home- and community-based services and disease management models implicitly rely on family care, still the bedrock of long-term and chronic care in the United States. The United Hospital Fund studied family caregivers of stroke and brain injury patients when home care cases were opened and closed and found that even with short-term formal services, family caregivers provided three-quarters of the care. Patients' mobility impairments and Medicaid eligibility were the main factors in determining the amount and duration of formal services. Between one-third and one-half of family caregivers reported being inadequately prepared for the case closing. At all stages, family caregivers expressed significant isolation, anxiety, and depression. Therefore, home care agency practice and public policies should provide better education, support, and services for family caregivers.

Keywords: Family caregivers, home health care, transitions, Medicare, Medicaid, stroke.

THE UNITED STATES LACKS A COMPREHENSIVE, coherent long-term care public policy for people who are chronically ill, frail, or disabled. Even so, the federal government and the states are moving to restructure services away from institutional settings toward home- and community-based care. This trend is driven by economics and consumer preferences, as well as the U.S. Supreme Court's

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1999 decision in *Olmstead v. L.C.*, which requires the states to provide community services for people with disabilities.

In addition, health care providers' concerns about patients' safety and quality of care, as well as cost, are leading to the development of models of disease management for chronic illnesses and transition management when patients are transferred to a different setting. These policy and practice trends implicitly assume that individuals in these fragile conditions will be able to manage on their own with some undefined but probably modest formal support. In reality, the bedrock of home- and community-based services is family care.

"Informal" caregivers—informal because they are unpaid—are mostly invisible to policymakers and practitioners; if mentioned at all, they are add-ons in the phrase "patient and family." Studies of family caregivers' actual work—how it relates to "formal" or paid care and the impact of these tasks on the caregivers' own lives—can help policymakers make more realistic assessments of the kinds of services that will be needed to keep patients with extensive needs in their homes and the additional services that will be required to support their family caregivers.

This article presents one such study: an analysis by the United Hospital Fund of the experience of family caregivers of patients with stroke and brain injury from the time the patients were discharged from a hospital or nursing home and accepted by a certified home health agency (CHHA), through the transition when the CHHA closed the case, and for an average of nine months thereafter. The study focused on the experience of family caregivers, not the patients, and not on the agency's reimbursement or overall cost. Inevitably, of course, the CHHA services affected the family members' roles while the case was open, and so the relationship between family care and formal care became a central issue for analysis. Although the patient's insurance coverage was not an initial focus, it too emerged as an essential determinant of service availability in the long term and therefore of the family caregivers' experience.

This article discusses three issues that emerged from the data: the division of labor between the services provided by CHHAs and those by the family caregivers as cases were opened, closed, and thereafter; the impact of the patients' mobility impairment and Medicaid eligibility on service provision; and the timing and impact of closing the case as perceived by the family caregivers. Finally, these discussions informed our practice and policy recommendations.

Strokes and Family Caregiving

Each year, about 500,000 to 600,000 people in the United States suffer a stroke, and another 347,000 people suffer a brain injury severe enough for hospitalization. Although the onset is acute and dramatic, the recovery is slow and may last for months and even years (Elliott and Shewchuk 1998; Grant 1996). Stroke and brain injuries affect cognition, speech, mobility, and relationships with others, creating particular difficulties for family caregivers, who themselves are at risk for negative health outcomes such as depression, isolation, and deterioration of chronic health conditions (Bakas et al. 2002; Bakas et al. 2004; Brazil et al. 2000; Han and Haley 1999; Low, Payne, and Roderick 1999).

Family caregivers help achieve better outcomes for stroke patients in such key areas as rehabilitation, mental health, and overall quality of life (Han and Haley 1999; Kalra et al. 2004; Low, Payne, and Roderick 1999). Family caregivers' unpaid labor also is an economic contribution to the health care system. Without family caregivers, many chronically ill patients would probably not be able to survive at home and would end up in more expensive settings, such as nursing homes, typically at public expense through Medicaid. A national study of informal caregiving for the elderly with stroke estimated its annual economic value to be \$6.1 billion (Hickenbottom et al. 2002).¹

When family caregivers embark on the long and arduous journey of caring for a relative who has suffered a stroke or brain injury, they have no map, no compass, and frequently no knowledgeable guides. As Brashler explained, "What starts as a medical emergency evolves into a long-term, complex, bio-psycho-social emergency" (Brashler 2004, 317). Although each journey is different, family caregivers encounter similar critical milestones—especially those transitions that mark major changes in the setting of and responsibility for care. These transitions may involve moving the care recipient from one setting to another, such as hospital to home (Coleman and Berenson 2004; Levine 1998), rehabilitation facility to home (Brashler 2004; Martone 2004), or nursing home to home (Graham, Anderson, and Newcomer 2005). These transitions occur against the backdrop of disease progression, rehabilitation improvements or plateaus, and the assumption of new roles and relationships within the family and community.

The transition from formal home care services to family-directed care is largely hidden because most research on home care has been conducted

while formal services are in place, and most research on family caregiving, other than population-based telephone surveys, has been conducted on the minority of family caregivers connected to formal services such as Alzheimer's disease or cancer support programs. Although transitions in chronic care are now receiving more attention (Coleman et al. 2004; Naylor et al. 2004), the main focus remains on those points at which agencies and professionals are still in charge.

An extensive literature search found no studies that followed caregivers through the process of beginning and ending formal home care and management after the case was closed. Given the increasingly prevalent combination of family and formal care in home care, it is surprising how little is known about the division of labor between family caregivers and formal providers and how family caregivers prepare for the end of formal home health care (Liu, Manton, and Aragon 2000). Accordingly, the United Hospital Fund's "Closing the Case" study was designed to begin to fill that gap.

The Complexities of the Home Care "System"

"Home care" is not a single, clear-cut benefit but a complex, quasi system encompassing different types of providers, payers, and regulators, each with their own rules, policies, and practices. Different payers may be involved in the same case at the same time or at different times. In this study patients received services paid for by Medicare, Medicaid, and employer-sponsored insurance; some patients and family caregivers also paid for services out of pocket.

To be reimbursed by private or public third-party payers, skilled services such as nursing and physical therapy generally must be provided through a CHHA; home health aide services may be provided directly by a CHHA or subcontracted to a licensed home health agency. Individuals who purchase services on their own may use a certified or licensed agency or a registry (an employment agency) or may hire workers independently. Medicare, Medicaid, and private insurance generally provide similar home care services (skilled nursing, physical therapy, home health aide services) following an acute episode such as a stroke, although the amount and duration of specific services may vary. But when the patient needs chronic or long-term care, significant differences emerge.

Typically a stroke patient is discharged from a hospital or short-term rehabilitation setting with a doctor's order for follow-up home care services. Although patients may select any CHHA that will accept them, they usually follow one of the hospital or nursing home discharge planner's referrals, often because they (or their caregivers) have little time after being informed of their discharge to investigate other options. Once the patients are at home, the CHHA must send a nurse or therapist within twenty-four hours to evaluate them. The agency then determines whether it can safely and adequately provide the services in the home. If so, it develops a plan of care and "opens the case."

Almost all payers basically follow Medicare's eligibility rules under which home health benefits are available if all the following conditions have been met: a doctor has certified that a patient needs medical care at home and has approved a plan of care; the patient needs part-time or intermittent skilled nursing care, physical therapy, or speech therapy; he or she is "homebound," that is, normally unable to leave the home unassisted; and care is provided through a CHHA.

Medicare and commercial insurers do not cover long-term "custodial care," that is, care that does not require the delivery of skilled nursing or therapy services. The dominant payers for custodial care are individuals and families and Medicaid; long-term care insurance currently has a very small role. Medicaid services are heavily oriented toward nursing home care, but half the states have opted to provide a personal care benefit. Most states also have obtained waivers that allow flexibility in using federal funds to provide home- and community-based services to individuals who are eligible for nursing home care. New York State provides personal care services through several programs. The New York City Medicaid Home Care Services Program, for example, serves approximately 52,500 frail elderly and disabled recipients at an approximate annual cost of \$2 billion (NYC Department of Social Services 2005). Nearly all suffer from one or more chronic conditions, and a quarter are eighty-five or older (Hokenstad 2002).

How the Study Was Conducted

The "Case Is Closed" study enrolled and periodically interviewed a sample of ninety-nine New York City family caregivers taking care of stroke and brain injury patients. The patients had been discharged after a

hospital or short-term nursing home stay to one of three CHHAs.² The study collected data on the type, frequency, and duration of CHHA services and also on the care the family caregivers provided while the case was open and after it was closed. Another important goal was to explore how home care providers informed family caregivers when the case would be closed and what community resources might be available to them. Finally, the study asked family caregivers about their burdens at different time points. We also conducted focus groups of clinical home care staff (Hokenstad et al. 2005) and home care aides (Hokenstad et al. 2006), and a series of in-depth interviews with a subsample of the family caregivers in the study to learn more details than disclosed in the survey questionnaire. Some of the information from the focus groups, case studies, and interviews is discussed here.

Recruitment and Retention

Between January 2003 and July 2004, ninety-nine family caregivers were enrolled in the study. Nearly all ($n = 95$) were caring for stroke patients; the remaining four were caring for a patient with a traumatic brain injury. Not surprisingly, their recruitment was challenging. After lengthy negotiations, the Institutional Review Boards (IRBs) of each of the three CHHAs required the home care client's authorization before the family caregiver could be invited to join the study (Albert and Levine 2005). Each of the care recipients (or health care proxy, if the care recipient was unable to respond) and family caregivers in the study provided his or her informed consent. For every family caregiver eventually enrolled, the CHHAs had to supply as many as four potentially eligible patients, since after the initial screening many did not meet the inclusion/exclusion criteria. Once the CHHAs obtained authorization from both the patient and family caregiver to be contacted, participation rates ranged from 78 to 82 percent across the three agencies.

This multistage and labor-intensive recruitment process yielded a diverse sample on those indicators critical to the study. African American and Hispanic family caregivers ranged from 55 to 81 percent of the sample across the three agencies, and Medicaid enrollment similarly ranged from 10 to 47 percent. Family caregivers were recruited from all five New York City boroughs as well as from surrounding suburbs. The multistage

recruitment process took thirty or more days for each participant, and two-thirds of the sample were first interviewed during the home care service period.

Retaining the family caregivers was difficult. Eighty-one family caregivers (82 percent) were interviewed a second time at about three months; seventy family caregivers (71 percent) were interviewed a third time at about six months; and fifty-six family caregivers (57 percent) were interviewed a fourth time at ten months, for a total of 306 interviews.

The timing of the interviews varied. Of the ninety-nine family caregivers enrolled, seventy-two were interviewed while the patients' cases were open, and seventy-nine completed an interview shortly after these cases were closed. Of the ninety-nine family caregivers, fifty-two were interviewed at both time points. However, since their responses were very similar to those of the full sample of seventy-two and seventy-nine at the two time points, the results reported are for the larger number of respondents. Seventy family caregivers completed the third or fourth interview an average of nine months after the case closing. These assessments offer a glimpse into the family caregivers' adjustment nearly a year after the cases were closed.

Research Interview

The core of the thirty-minute family caregiver phone interview was a series of questions about the tasks and hours of caregiving support from all sources. The domains were selected on the basis of pilot research (Albert et al. 2002). The family caregivers were first asked to report on whether they provided any help in eleven different categories: nursing care, personal assistance, household maintenance, arrangement of services, physical or occupational therapy, administration of medications, speech therapy, cognitive rehabilitation support, counseling or psychological support, use of medical equipment (including injection medications), and other help. They then were asked to estimate how many hours of care they had provided on a typical day in the prior two weeks, and about three-quarters were able to do so. The family caregivers provided similar information for the formal providers. They also were asked about the number of hours of care per week provided by volunteer caregivers, such as friends and other family members, which was so small in the sample (less than 1 hour/week on average) that we excluded this category

from our analyses. Other than CHHA services, these family caregivers were essentially on their own.

Other parts of the interview asked questions about the family caregivers' readiness for the case closing ("Were you given a date for the closing of the case?" "Did you have time to prepare?"). Also recorded were the family caregivers' and care recipients' socioeconomic features, including insurance coverage, and indicators of the care recipients' disability. These indicators were activities of daily living (ADL) and cognitive status indicators drawn from the Outcome and Assessment Information Set (OASIS), a standard tool for assessing patient services and outcomes in home health care.

A series of questions elicited the perceived burden of caregiving. The thirteen items were drawn from a representative sample of caregiving appraisal measures (Lawton et al. 1989) and covered loss of privacy, uncertainty in caregiving challenges, isolation, fatigue, anxiety, sleep deprivation, depression, inability to leave the home, use of drugs or alcohol, and related effects of caregiving. Items were scored 0 ("never a problem for me") to 3 ("a problem for me nearly all the time"). We constructed an unweighted sum, with scores ranging from 0 to 39, and also examined individual items. The coefficient alpha in our sample for this scale was 0.87, suggesting adequate reliability.

The semistructured questions were intended to capture the experience of receiving formal care, preparing for the end of home care, and planning and putting the services in place.

Analyses

Given the strong association between caregiving hours and patient disability, we stratified the analyses according to disability, dividing the sample into care recipients without mobility impairment ("no help needed"; 44 percent of the sample) and care recipients with mobility impairment ("some" or "a lot of help" needed in transferring or movement). For categorical measures, we used the χ^2 test, and for other continuous measures, we used t-tests or an analysis of variance.

Limitations

The findings from this research should generally be interpreted in light of the small study sample. Also, results may not be generalizable to other areas of the country, since Medicaid beneficiaries in New York

City may have access to personal care services not available in other localities.

The Patients and Their Family Caregivers

Almost three-quarters of the family caregivers were women; about half were spouses; and nearly two-thirds lived with the care recipients. The family caregivers' mean age was fifty-seven. Forty-one percent were working full or part time, and 19 percent had stopped working because of their caregiving responsibilities. Notably, a quarter of these family caregivers reported other caregiving responsibilities (besides child care), such as care for another elderly or disabled relative.

The care recipients were older (mean age 73) and not as well educated as their caregivers. Slightly more than half (56 percent) were female. Nearly three-quarters (73 percent) had no regular caregiving help before their stroke or brain injury, but 13 percent already had help with personal care. Two-thirds of the care recipients were discharged directly from hospital to home. The average length of hospital stay for a stroke patient in New York City is seven days (United Hospital Fund analysis of 1997–2002 SPARCS data). The remainder had an intervening short-term stay in a rehabilitation facility or the rehabilitation unit of a nursing home.

At the time the home care case was opened, nearly all the care recipients required support in IADLs (instrumental activities of daily living, such as preparing meals and using transportation), and about two-thirds needed assistance with five to eight ADLs (activities of daily living, such as moving from bed or chair, using the toilet, dressing, and walking indoors).

Fifty-seven percent of the care recipients had Medicare as their only insurance; 18 percent were eligible for both Medicare and Medicaid; 12 percent were covered by Medicaid alone; and 12 percent had private insurance. Patients receiving services through Medicare and their family caregivers only were older (patients, 78; family caregivers, 63) compared with people covered through Medicaid (patients, 70; family caregivers, 51) or private insurance (patients, 52; family caregivers, 46), $p < .001$. Minorities were overrepresented among Medicaid beneficiaries. The proportion of white family caregivers was 20 percent in the Medicaid group, 64 percent in the Medicare group, and 42 percent in the private insurance group ($p < .01$).³

These statistics tell only part of the story, however. The following two excerpts from the in-depth interviews reveal a glimpse of the human side of family caregiving. (Names and identifying information have been changed to protect privacy.)

Mr. Johnson

Donald Johnson Jr., forty-six years old, is the primary caregiver for his ninety-year-old father, who suffered his latest stroke shortly after the study began and also has signs of dementia. Donald Johnson Jr. is estranged from his siblings, who do not help with their father's care. He is married and has a son in high school; a younger son recently died from an asthma attack. His father lives with the family.

Mr. Johnson Jr. is disabled himself, having suffered a series of chronic illnesses, including asthma, diabetes, hypertension, and a bad back. He recently had two heart attacks, which he attributes to the stress of his son's death. His wife works full time outside the home.

Mr. Johnson Sr. first became ill in 1999 and has had several strokes in the last few years. After his most recent stroke, his son observed, "I got approximately eight hours of home care a week; Medicare would only permit two hours a day. The home care aide would give him a bath, feed him, and give him his medications." A physical therapist came twice a week for five weeks, Mr. Johnson noted, and "the physical therapy did help him get up and down the stairs." A nurse came in for two weeks "but she didn't stay long."

Since Mr. Johnson Sr. had a pension that made him ineligible for Medicaid, his son tried to get Medicare's home care extended. "I talked to the lady at the agency. I tried to keep the home care aide. The more I called the more they seemed like they weren't taking the time to return my calls. I just started making other plans."

Without a home care aide, Mr. Johnson said, "I was on lockdown, like being in jail in your own home. You can't go too far with my father because he slows you down. If I'm going to the store and running errands, trying to take care of my own health, I have to take him with me." Eventually he hired an aide to help him. She currently comes three days a week, but Mr. Johnson, a deacon in his church, is planning to increase her hours to include Sundays.

Mrs. Valentine

Adelina Valentine, a woman in her fifties, is an experienced caregiver, for when she was a nurse's aide in a hospital, she worked with all kinds of patients. Mrs. Valentine has four adult children, and she stopped working to care for a daughter in her twenties who later died. Then Mrs. Valentine became her husband's caregiver when he had a massive stroke at the age of fifty-six. He has private, employer-based insurance.

When Mr. Valentine got home from the hospital, the only word he could say was "lovely." "He never got speech therapy at home," Mrs. Valentine said, which was "a big problem because he wasn't talking. I kept asking, but they said they were short of speech therapists." Her husband finally got outpatient speech therapy almost a year after the stroke.

Mr. Valentine also could not walk when he got home from the hospital. The physical therapist "came for only two weeks," and Mrs. Valentine felt that this was inadequate. She said she needed to learn "how to get him to stand and sit. He didn't start taking steps until he was home with me."

The "aide got him up, got him his breakfast, got him dressed, and that's about it." The nurse just "checked his vital signs." The home health aide came for five days, and the physical therapist came three times a week, "but my husband got out of hospital on October 15, and they were all gone by Halloween."

After the agency-provided home care ended, Mrs. Valentine admitted, "It was hard. Very hard. He couldn't get himself up, he couldn't get into the chair, stand alone. I already knew how to do these things, but they should have given him a little more time, help me to take care of him a little better." She thought home care would continue until "at least he could get around a little bit, or at least until he started speech therapy or physical therapy where I didn't have to do everything."

The Division of Labor between Formal and Family Care in Open and Closed Cases

As these case studies suggest and as our analyses confirmed, even while the case was open, families provided most of the care. Because most stroke and brain injury patients need so much assistance and monitoring

when they are sent home, the CHHAs cannot safely provide their limited services unless a family member or other paid help is available. Therefore, the availability of family care is a major factor in the CHHAs' decision to open a case.

CHHA Services

According to agency administrative data for the time the case was open, skilled nursing care (99 percent) and physical therapy (91.1 percent) were the most common elements of the care plans, followed by home health aide assistance (50 percent) with personal care (i.e., support in bathing, dressing, grooming, using the toilet), occupational therapy (46.3 percent), and social work (32.2 percent). Although only half the patients received home health aide assistance, the majority of those received more than one visit a week. The reverse was true of social work: of the third who received a social work visit, most received only one visit. Surprisingly, given the diagnosis of stroke, less than a fifth (17.4 percent) received any speech therapy at all.

With one exception, the formal services provided while the case was open did not differ significantly between Medicaid and non-Medicaid recipients. Medicaid patients were less likely to receive occupational therapy one or more times per week, and 40.9 percent of the non-Medicaid sample received this service, compared with only 6.9 percent of the Medicaid sample ($p < .001$).

Family Caregiver Services over Time

At each interview, the family caregivers were asked how many hours of help they provided and how much paid care the patient had received on a typical day in the prior two-week period. In interpreting answers to these questions, we assumed that for those patients without Medicaid coverage, most of the "paid care" was provided by the CHHA while the case was open and was purchased privately after the case was closed, as many respondents reported. We also assumed that CHHAs provided most of the "paid care" for patients with Medicaid while the case was open and that New York City's Medicaid personal care program provided care after the case was closed.

Regardless of the insurance coverage, while the cases were open, family caregivers provided about three quarters (74.4 percent) of the care (32 of

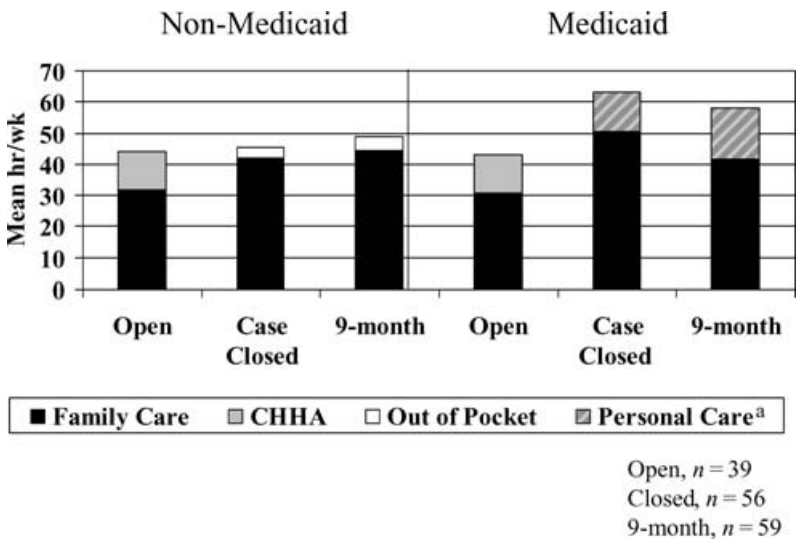
43 total hours). Nearly all (91 percent) were managing household affairs; 80 percent were arranging services; and about three-quarters (73 percent) were providing personal care. Sixty-five percent were dispensing medications, and nearly half (48 percent) were providing skilled nursing care such as monitoring symptoms, checking blood pressure, and other tasks performed by nurses on their visits. More than half (58 percent) were providing counseling. Other tasks were offering physical/occupational therapy (39 percent), speech therapy (14 percent) and cognitive support (14 percent) and managing equipment (16 percent).

While the case was open, as shown in figure 1, there was no difference between non-Medicaid and Medicaid patients. After the case was closed, the total number of caregiving hours remained the same for non-Medicaid patients, but the number of paid weekly hours dropped from twelve to three. About 41 percent of the non-Medicaid patients had this minimal level of paid care. The total number of caregiving hours increased for the Medicaid patients, but the total of formal hours of care (12) remained the same. About 85 percent of Medicaid patients received formal care after the CHHA case was closed, but the amount dropped to 74 percent at nine months. At nine months the Medicaid beneficiaries received four times the amount of paid care received by non-Medicaid beneficiaries: sixteen hours a week compared with four. Even so, the family caregivers of Medicaid patients continued to provide substantial levels of care, an average of forty-two hours per week.

The Impact of Mobility Impairment and Medicaid Eligibility on Services

Duration of Home Care Services

For the entire group, the median duration of home care services was forty days, and the mean was 54.2 days. Care recipients with severe mobility limitations had a longer median duration of services (59 days) than did those who needed only “some” (39 days) or “no” (28 days) help with indoor mobility ($p < .001$ by the Kruskal-Wallis test). Cognitive deficits also affected service plans, although to a lesser degree. Those care recipients who were rated as “dependent on help for cognitively demanding tasks” received a median of forty-three days of service, compared with thirty-eight days for those who were rated as alert and oriented ($p = \text{N.S.}$).



Notes: There are more data on closed cases than on open cases because the lag time in enrolling participants, particularly through one CHHA, meant that the first interview took place just after the case was closed.

^aPersonal care includes assisting with ADLs such as bathing, toileting, and grooming and IADLs such as meal preparation and household chores.

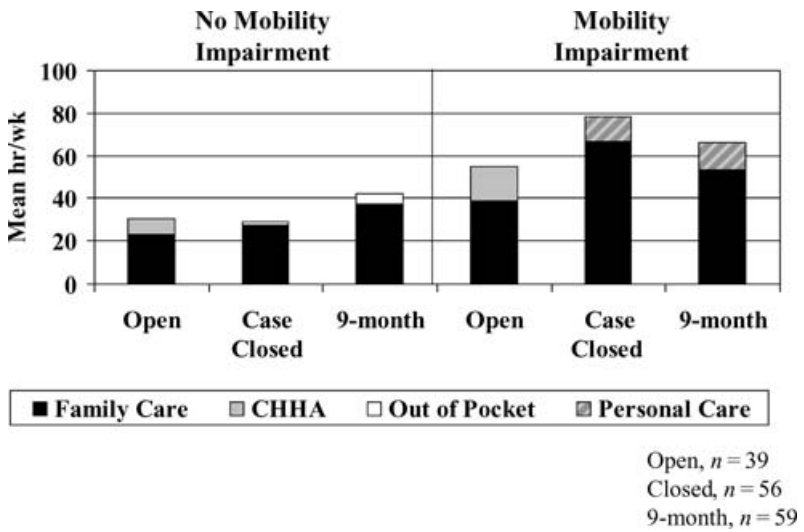
Source: Family caregiver interviews.

FIGURE 1. Paid and Family Care by Insurance Status

The duration of services also differed by insurance coverage, with the Medicare-only and private insurance patients receiving a median of thirty-six days of service, and those with Medicaid receiving fifty-nine days ($p < .01$). Post-hoc pairwise tests suggest that the Medicaid group differed significantly from both the other insurance groups. The significant difference in duration of service by insurance status persisted in the analysis of variance models that adjusted for patients' mobility impairments.

Total Amount of Care

Across the time points, mobility impairment was the most significant factor in determining the amount of total care—family and formal home care—the patients received. Figure 2 shows that while the cases were open, patients with mobility impairments (56 percent of all cases)



Source: Family caregiver interviews.

FIGURE 2. Paid and Family Care by Patient Mobility Status

received twice as much CHHA-provided care (16 hours per week) as did those without mobility impairments (8 hours). Family care was also greater for mobility-impaired individuals (39 hours a week) compared with non-mobility-impaired individuals (23 hours). The total amount of care went up over time, suggesting that these patients had long-term chronic care needs. The total for mobility-impaired individuals climbed to seventy-eight hours a week soon after the case closed and fell to sixty-six hours a week at nine months. Of this total, family care rose from thirty-nine hours a week to sixty-six hours after the case was closed and dropped to fifty-three hours at nine months. From case open to case closed, families increased their caregiving, in effect more than substituting for the loss of formal care.

In contrast, for those care recipients with no mobility impairment, the mean number of total hours of weekly caregiving increased 30 percent, from twenty-three to forty-two hours at nine months, with family care accounting for 88 percent of the total. Paid care decreased to 1.5 hours per week after the case was closed and then climbed to five hours. The family's contribution rose from twenty-three hours while the case was open to thirty-seven hours per week nine months later.

Medicaid coverage raised the level of services for patients with mobility impairments. The total number of hours of care for non-Medicaid patients remained stable over the three time points, at a mean of more than sixty hours per week. For the Medicaid group, help increased from a total of forty-six hours a week while the case was open to 103 hours when the case was closed and then declined to seventy-five hours nine months later.

Regardless of their insurance status, family caregivers generally increased their hours of care when the CHHA case was closed and then decreased them at nine months to nearly match the total amount of care (paid plus family) initially provided. This suggests both a period of instability at the time of the case closing and an ongoing need for assistance for a very impaired population whose needs do not decline significantly over time. This observation is consistent with the views expressed in focus groups and in-depth interviews.

The Process and Aftermath of Closing the Case

Cases are “closed” for many reasons, most commonly because the CHHA determines that the patient no longer meets the skilled care requirement, having successfully completed the treatment plan or no longer having rehabilitation potential. Service providers may tell patients and family caregivers, for example, that “Medicare will not pay.” Even though this shorthand explanation is technically correct, family caregivers may not understand that the CHHA decides to close the case and, in so doing, is guided by Medicare regulations and the oversight of the regional fiscal intermediary that reviews cases for appropriateness of care. The reimbursement rules usually favor short-term cases in which recovery is relatively rapid and predictable, which is not, however, the case for stroke and brain injury.

Although most of the patients served by the CHHAs had substantial ongoing needs for care, many family caregivers felt that they were not adequately prepared for the case closing. Even though the majority said that they were told in advance, in some cases this meant weeks but in others, just a day or two. Nearly 40 percent reported that they learned about the case closing only when a therapist or home care aide informed them. A typical comment was, “The physical therapist gave notice on Thursday that Friday was going to be the last visit.”

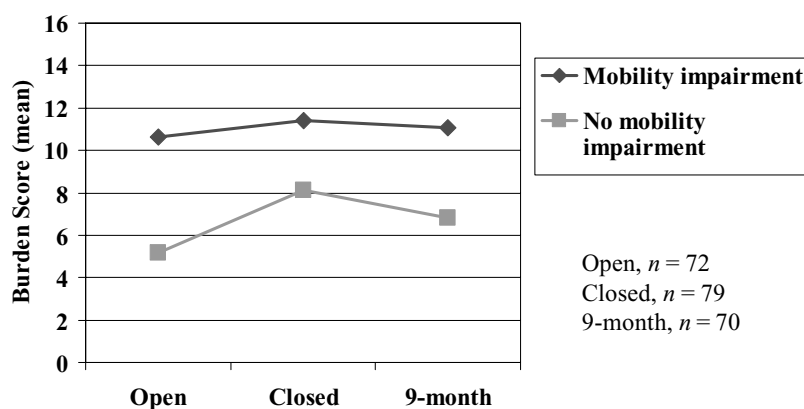
In the focus groups, all the clinicians pointed out that they told the families and patients when the case was opened that the service would last only a short time. They acknowledged, however, that this message was often lost on family caregivers who were dealing with major life changes. One nurse in a focus group explained, "You are supposed to be the patient's advocate, and here we are on the first day [emphasizing] that Medicare is short term." And a social worker in a focus group observed, "It's very hard to explain to somebody whose mother is sick and really does need help that this isn't the kind of help we offer, that this is a skilled service and what she needs is custodial care" (Hokenstad et al. 2005, 392).

Slightly more than half the family caregivers reported that they had made some preparations for the end of the services, and 68 percent felt psychologically ready for the transition.

Being "ready," however, did not mean being without burden. Although less than 5 percent said that they constantly (every day) felt overwhelmed, one in five (22 percent) reported continuing problems, such as not having enough time for themselves, when the case was open, which rose to a third (32 percent) after the case was closed. A fifth (20 percent) reported that they had no privacy after the case was closed, and 12 percent reported this as a never-ending problem. Although substance abuse among caregivers was almost never reported while the case was open, 4 percent reported it as a persistent problem when the case was closed. Overall, a majority reported at least some weekly challenge in each measure of caregiver burden. These proportions are comparable to those originally reported in Lawton and colleagues' (1989) validation sample, from which the items were originally drawn, and also to national surveys of caregivers.

Figure 3 shows the burden levels reported by family caregivers. The reported burden at all three points was higher among family members providing care to more disabled care recipients ($p < .001$). The burden grew heavier in both groups across case closings, although this difference did not achieve statistical significance. Our analysis of individual burden items did not suggest clear patterns for particular items or groups of items. By nine months, the burdens had lightened, suggesting the family caregivers' adaptation, insensitivity of the questions, or social desirability bias.

The relationship between paid home care and family caregivers' stress and burden is not clear-cut. Caregivers are not always less stressed when home care starts or more stressed when it ends. A recent study of family



Note: The burden scale (Lawton et al. 1989) includes 13 items scored from 0 to 3, with an unweighted sum of 0 to 39.

FIGURE 3. Caregiver Burden by Patient Mobility Status

caregivers of people with dementia found that when family caregivers began to receive paid help, their level of worry rose and that when the paid care ended, they became less depressed. The sustained use of paid care, however, did reduce the overload (Pot et al. 2005). This finding indicates that family caregivers find the transition to paid care to be stressful in itself and that they need time to adjust to accepting and managing outside help. When they do make this adjustment, their overall burdens are decreased. Several participants in the in-depth interviews said that they had accepted the patient's wishes to forgo home health aide services because they felt guilty having someone else providing personal care but that it was a decision that they now regretted. Their advice to other family caregivers was "take as much help as you can get."

Policy from the Family Caregiver Perspective

From the perspective of current policy, the CHHAs in this study did what they were designed and paid to do; they provided short-term, limited service. They opened cases for those patients they could serve, and they closed cases in accordance with regulations and fiscal oversight. The types of services that most of the recipients received seem appropriate

to stroke and brain injury; family caregivers did not report any abuse or neglect of care recipients by home care providers; and the patients with the most disability received the most services.

From the family caregivers' perspective, however, this study demonstrated the mismatch between their needs and expectations and the regulatory and payment system under which the services are determined and provided. Although it is not made explicit to family caregivers and care recipients, CHHAs base their services partly on their assessment of the availability of family care. In contrast, families expect the care provided to be based on the patient's need; in their view, it is obvious that a person who has been disabled by a stroke needs continued assistance. The infrequent use of speech therapists for patients with stroke is particularly troubling, given that one of its common consequences is difficulty communicating. Social workers, who might have provided assistance to families, were used infrequently and, according to the clinicians in the study's focus groups, mainly when there was a problem in closing the case. While acknowledging the essential contributions of family caregivers as "resources," agencies operate within a system that does not provide incentives or rewards for supporting family caregivers. Instead, agencies must manage cases within workforce and financial constraints. In this study, insurance coverage, as reported by family caregivers, did influence case closings. Those patients with Medicaid (including those dually eligible for Medicare and Medicaid) had longer lengths of service than did those with Medicare or private insurance alone. Medicaid beneficiaries may be entitled to ongoing personal care services paid for and arranged by the Medicaid program, and service providers sometimes accepted Medicaid applications for eligible but not enrolled patients. Even though Han and colleagues (2004) did not find differences in the length of home health care according to insurance status, the situation in New York may be different because of the availability of Medicaid's personal care services. Those patients with only Medicare or private insurance, however, had to pay out of pocket for any services beyond the case closing.

Family caregivers encounter the home care system at a time of great stress and need. They understand little about the system when the case is opened and not much more when it ends six to seven weeks later. As Chiplin (2005, 3) pointed out,

Medicare beneficiaries are left on their own to sort out and apply the bits and pieces of Medicare law, regulation, and policy relevant

to discharge planning and transitions. In many instances, the need to assert these rights arises when Medicare beneficiaries and their advocates are confronted with a discharge or reduction in services in hospital, skilled nursing, and home health care settings.

For example, patients and family caregivers often do not understand the difference between an “episode of care,” which Medicare defines as sixty days for financial purposes but for patient care purposes as “the period of time when a patient is under the direct care of a home health agency.” The typical term of care for a stroke patient in this study was forty days (beginning with the start of care and ending when the patient was discharged from the CHHA or transferred to a hospital or other facility), but the CHHA receives payment based on each sixty-day financial term of care. Using the same definition for two different time periods is confusing to patients and family caregivers, who may understandably believe that they are entitled to sixty days of home care, which is not the case.

In our interviews, many family caregivers reported that they did not understand how the level of home care services was determined, who was paying for what, which agencies supplied the different kinds of workers, and what they should expect from each. In particular, they did not understand or appreciate the nurse’s role in coordinating and managing the case beyond the brief clinical visits. None of the family caregivers reported a discharge process that addressed their ongoing needs for respite, referrals, or further training.

Between one-third and one-half of the families said that they were not adequately prepared for the case closing. The CHHAs in this study did not have a systematic or consistent way of preparing family caregivers for case closing or referrals to community resources. Whether the closing was handled well or poorly from the family caregivers’ perspective appeared to depend on the skills of the individual clinician. Whereas many family caregivers reported being psychologically ready for the transition, some of them also reported that they had been uneasy and ambivalent about the presence of “strangers” in their homes. They may have seen the case closing initially as a relief in not having to deal with workers’ changing schedules and unfamiliar habits. And they may have thought that they could manage on their own but sooner or later realized that they needed help.

Clearly, Medicare and private insurance do not deal adequately with conditions with long-term consequences, like stroke, yet these are the

only mechanisms available to most individuals and families. Some Medicaid recipients may be eligible for nonskilled personal care services after their CHHA case has closed. In contrast, for reasons that should be explored, Medicaid recipients were less likely to receive occupational therapy services while their cases were open.

Practice and Policy Recommendations

Practice Recommendations

Based on the results of this study, we offer three practice recommendations: *First, CHHAs should spend more time educating family caregivers so that they will better understand and more easily navigate the home care system.* Family caregivers frequently have unrealistic expectations about the level and duration of service that will be available, which is understandable, since insurance booklets, including Medicare's, are vague and even misleading. "Medicare and Home Health Care," described as the "official government booklet," claims that "Medicare covers your home health services for as long as you are eligible and your doctor says you need these services" (Centers for Medicare and Medicaid Services, n.d., p. 11). "Eligible" in this sentence can mean either "eligible for Medicare" or "eligible for home health care." Although a doctor must approve a plan of care and authorize renewals, in practice it is the CHHA that determines whether the patient meets the skilled care requirement. Physicians usually are not closely involved in home care planning.

Another source of misinformation may be the hospital staff, who may reassure family caregivers that the patient will get whatever home care is needed. Furthermore, family caregivers may believe that the hospital, "Medicare," or "the doctor" is responsible for sending the nurse or therapist, without realizing that it is the CHHA and its subcontractors that supply home care aides, therapists, or other workers. This education should begin in the hospital or rehabilitation facility, but the ultimate responsibility lies with the CHHA.

Second, CHHAs should consider the family caregivers' needs, as well as those of the patient, in the home care plan and discharge plan. Information about the timing, rationale, and plans for outpatient care when the case is closed should be specifically directed to the family caregivers. This information should include a list of resources in the community specifically for the

family caregiver, such as support groups, resource centers, legal and financial advisers, and the Internet.

Third, CHHAs should train home care workers to communicate more effectively with family caregivers, to teach the family caregivers methods of care when needed, and to offer information when needed. Home care aides particularly need this training, as they spend the most time with patients and family caregivers but are not well informed by the CHHA about patient and caregiver circumstances or trained to help with case-closing procedures (Hokenstad et al. 2005).

Policy Recommendations

These practice recommendations have policy corollaries. To be able to implement them, CHHAs need financial support and incentives. *As a first step, we recommend that social workers, already part of the home care team, be used more extensively and frequently, particularly when it is clear that family caregivers will be responsible for the patient's long-term care needs.* There is no financial incentive to bring social workers into the case more closely, and there are financial disincentives under the Medicare Prospective Payment System (PPS), introduced in 2000, that limit their involvement. Social work is not a “qualifying” service under Medicare equal to nursing or physical therapy, and the social work reimbursement rate, included in the calculation of the overall agency rate, is low (Malinowski 2002). Kadushin and Egan (2003) found that 63 percent of the social workers they surveyed reported a decrease in home care visits after the introduction of Medicare PPS.

Adding a Medicare-funded case manager to the team would be of only limited assistance to family caregivers unless that manager coordinated services for the family caregiver. Nurses now are supposed to coordinate care, but their activities are limited mainly to the patient's clinical care. Without clear responsibility and accountability for supporting family caregivers, case managers will stick to the areas they know best: patient services.

Second, notices of recipients' rights to appeal the denial or reduction of home care services under Medicare should include help in the transition from formal services to family care. The right to appeal a home care case closure or reduction in services is less well known and established than the right to appeal a hospital discharge. A recent requirement expanded the CHHAs'

obligation to provide notice. The U.S. Court of Appeals for the Second Circuit held in the case of *Lutwin v. Thompson* (61 F.3d 146, 156 [2nd cir. 2004]) that CHHAs must provide written notice before reducing or terminating services, regardless of the reasons for the action (Kapp 2004). The “Home Health Advance Beneficiary Notice” approved in January 2006 lists the services or items and the reason for terminating or reducing them and gives the beneficiary three options: (1) I don’t want the services or items and have no appeal rights since I will not receive them; (2) I want the services or items and agree to pay for them myself since I don’t want a claim submitted to Medicare or any other insurance, also with no appeal rights; or (3) I want the services or items and agree to pay myself if Medicare or my other insurance doesn’t pay (Centers for Medicare and Medicaid Services 2006). This formality will be helpful to family caregivers and care recipients only if the notice is accompanied by assistance in planning for future needs.

Our third recommendation is that programs that count on families should include support for those family caregivers, such as information, training, respite, and financial assistance where necessary. The most important policy question concerns the inadequacy of considering only the beneficiary in determining the provision of services. The official view of the family is as an expected or potential resource with responsibilities but no rights. Our study should serve as a warning to those states and localities moving toward the goal of home- and community-based care. For persons with extensive needs, the home care services provided in our study would be grossly inadequate unless their families were able and willing to provide most of the care. If hospice—which is a Medicare-funded service—can establish the family as the unit of care and build consultations and family training into payment schedules for as long as six months, why can’t home care do the same when the average duration of services is only six weeks?

Medicare has taken one small step in this direction: as of October 24, 2005, Medicare allows a specific category of skilled nursing care, called “teaching and training activities,” for family and other caregivers of Medicare beneficiaries with behavioral symptoms of Alzheimer’s disease. But this policy is applicable in only sixteen southern and midwestern states covered by Palmetto GBA, a Medicare Regional Home Health and Hospice Intermediary (Alzheimer’s Association 2005).

Family caregivers play a critical role while CHHA cases are open and subsequently replace lost formal hours after the cases are closed. The policy fiction that the only actors with speaking roles in this ongoing

drama are the patients and the formal providers must be unmasked. Family caregivers are not only the leading players but often the directors, stage managers, and financial backers as well.

Endnotes

1. An estimate of the annual overall economic value of informal caregiving in the United States in 1997 was \$196 billion, updated to \$306 billion in 2004 (Arno 2006; Arno, Levine, and Memmott 1999). This figure, not counted in the nation's \$1.9 trillion health enterprise, is more than the combined cost of public spending for formal home care (\$43.2 billion in 2004) and nursing home care (\$115.2 billion in 2004).
2. The CHHAs' initial responsibility was to identify and contact patients with involved family caregivers who fit the study's inclusion and exclusion criteria: discharged home with stroke or traumatic brain injury as the primary ICD9 diagnosis; both patient and caregiver older than eighteen living in the metropolitan New York City area; nonhospice care; family caregiver able to speak English; and availability in the electronic record of the family caregiver's name. Because this was a study of family caregiving, patients without family caregivers were excluded. The CHHAs also agreed to recruit clinical staff and home care aides for the focus groups and to supply administrative data on the types and duration of services provided. The family caregivers and focus-group participants were paid a modest honorarium.
3. Family caregivers with a relative receiving services through private insurance were more likely to have a postsecondary school education, although the differences were not significant. Seventy percent of care recipients covered under Medicaid had mobility impairments, compared with 48 percent of the Medicare-only group and 50 percent of the private insurance group, but this difference was not significant by χ^2 .

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