Dear CRC Directors and Staff:

This Information Letter is to inform you of recently published research regarding caregiving for patients who have had a stroke. Stroke is the leading cause of disability in the United States. Thirty-one percent of stroke survivors require help in taking care of themselves following the incident, while 16 percent require placement in an institution (http://www.emedicine.com/neuro/topic9.htm).

According to a new study by the United Hospital Fund and the University of Pittsburgh, family caregivers are burdened with three-quarters of care responsibilities even when being assisted by home care agencies, and this assistance typically only lasts for a few weeks following the stroke patient’s discharge from the hospital. Ninety-nine New York City family caregivers were studied, and one-third to one-half reported being insufficiently prepared for home care assistance to end.

The study makes several policy and practice recommendations, highlighting the need for greater involvement of social workers, education of family caregivers with respect to their rights to appeal the reduction of Medicare assistance, and training of home care workers in communicating more effectively with family caregivers, including teaching methods of home care and being available to offer necessary information. The study was published in the Milbank Quarterly and is available for download at: http://www.uhfnc.org/usr_doc/Milbank.pdf.
The United Health Fund’s press release, which summarizes the report, is provided below:

NEW YORK, NEW YORK, June 19, 2006—In the first-ever study following family caregivers of stroke and brain injury patients through their initial experiences with formal home care services, the termination of services, and for an average of nine months thereafter, researchers at the United Hospital Fund have determined that unpaid family caregivers provide substantial amounts of care but receive inadequate support from health care providers.

Stroke patients discharged from hospitals, typically a week after the incident, require an enormous amount of care at home. While most are eligible for some services from home care agencies, family caregivers shoulder three-quarters of the care responsibilities even when agency services are being delivered. And when these services end, typically after six or seven weeks, it is family members who, ready or not, must take over or seek other sources of assistance. Between one-third and one-half of family caregivers reported being inadequately prepared for agency home care services to end. And, at all stages, family caregivers experienced significant isolation, anxiety, and depression.

“This study demonstrates the gap between the needs of caregivers of patients with chronic conditions and the services that are provided under a system based on short-term, acute care rehabilitation,” says Carol Levine, lead researcher of the study and director of the Fund’s Families and Health Care Project. “The home care agencies are doing their job; they are providing the services policymakers have decided to pay for. But, as we move toward even shorter lengths of hospital stay and toward home- and-community-based services, policymakers and practitioners should view our findings with concern. Without adequate support for family caregivers, no system of chronic care in the community can function.”

Published in June in The Milbank Quarterly, the study, titled “‘This Case Is Closed’: Family Caregivers and the Termination of Home Health Care Services for Stroke Patients,” enrolled and periodically interviewed a sample of 99 New York City family caregivers taking care of stroke or brain injury patients following their discharge from a hospital or short-term nursing home stay. Caregivers were recruited through three collaborating Certified Home Health Agencies and represented a geographically and ethnically diverse sample.

Interviews were conducted at three points in time: as soon as possible after formal home care services began, as soon as possible after the case was closed, and approximately nine months later. Some caregivers participated in a fourth, in-depth interview. In other arms of the study, Fund researchers conducted focus groups with home care clinicians, such as nurses and physical therapists, and with home care aides to gain their perspectives on case closings. Many of the clinicians and aides also expressed frustration with the system. While all of the clinicians pointed out that they told the families that services would be short-term, they also acknowledged that this message was often lost on caregivers who were dealing with major life changes.

The study demonstrates that current home care policies are falling dramatically short of family needs. Most insurance (Medicare, Medicaid, private insurance) covers the delivery...
of skilled nursing and therapy services after an episode such as a stroke for a limited duration of approximately six weeks. In this study, the median duration of home health care services was 40 days, and the mean was 54.2 days, even though stroke patients often require many more months of rehabilitative care before they recover the full level of possible functioning.

Medicare and commercial insurers do not cover chronic, long-term care services at home—services that assist patients and their caregivers with such tasks as bathing, toileting, and meal preparation. Only the Medicaid program offers some assistance with these types of tasks. Though some families opt to pay out-of-pocket costs for such services, others cannot afford to do so.

“This study gives us insights into the experiences of family caregivers from their perspective,” says Jim Tallon, president of the United Hospital Fund. “And what the study tells us is that caregivers are willing to take on care responsibilities, but they desperately need more assistance in order to provide care to very impaired patients while keeping themselves healthy and strong.”

“Regardless of their insurance status, family caregivers generally increased their hours of care when the agency case was closed,” said Steven M. Albert, Ph.D., a gerontological researcher at the University of Pittsburgh and a co-author of the study. “At nine months they were providing nearly the same amount of care needed when the case was opened. 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.”

Other highlights of the study include:

• Almost three-quarters of the family caregivers were women; about half were spouses; their mean age was 57.
• Forty-one percent of the caregivers were working full- or part-time, and 19 percent had stopped working because of their caregiving responsibilities.
• Family caregivers provided, on average, 32 hours of care a week while they were receiving formal home health care services, which provided, on average, 11 hours a week of support.
• Social workers, who may have been able to provide assistance to families, were used infrequently and were mainly brought in when there was a problem closing the case.
• Speech therapy was seldom provided, even though stroke patients often have difficulty recovering language skills.
• The patient's type of insurance coverage did influence care and case closings. While their cases were open, Medicaid patients were less likely to receive occupational therapy services. Patients with Medicaid, who were older and more likely to be from a minority group, had longer lengths of service than did those with Medicare or private insurance.
• Nearly 40 percent of family caregivers reported that they learned about the case closing (i.e., termination of formal home care services) only when a therapist, nurse, or home care aide informed them. “The physical therapist gave notice on Thursday that Friday was going to be the last visit,” was a frequent comment.
• 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. None of the caregivers reported a discharge process that addressed their ongoing needs for further training and provided referrals to other supportive services.

- Regardless of whether any additional professional care services were secured after formal home care services ended, the time burden on family caregivers increased, on average, between 10 and 20 hours per week.
- Not surprisingly, the total amount of formal home care and family care was higher for patients with mobility impairments. The family time commitment for patients with impairments was striking, however. Family care rose from 39 hours a week during formal home care, to 66 hours after the case was closed, to 53 hours at 10 months after formal services ended.
- While 68 percent of family caregivers said they felt “psychologically ready” for the end of home care services, the burden levels reported by caregivers went up during this transition—with the greatest increases reported by those providing care for more disabled recipients.

Based on the study, the researchers offer both policy and practice recommendations.

**Policy recommendations:**

1. Social workers, already part of the home care team, should 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 are now no financial incentives to do so, and disincentives not to provide social work services persist.
2. 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.
3. Programs that count on families should include support for family caregivers, such as information, training, respite, and financial assistance, where necessary.

**Practice recommendations:**

1. Certified home health agencies should spend more time educating family caregivers so that they will better understand and more easily navigate the home care system.
2. Family caregivers' needs, as well as those of the patient, should be considered in the home care plan and discharge plan.
3. Home care workers should receive additional training in communicating more effectively with family caregivers, teaching family caregivers methods of care, when needed, and offering necessary information.

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CRC staff are encouraged to share the information provided in this Information Letter with colleagues and clients as appropriate. For other questions, please feel free to contact Jennifer Kaufer at jkaufer@caregiver.org, or Ethan Moore at emoore@caregiver.org.