

## "Family Caregivers Thrust into Nursing Responsibilities"

Phyllis, in her early 60s, is a devoted wife and mother. When her husband, disabled by strokes and diabetes, came home from the hospital with a feeding tube, Phyllis was terrified. "My generation doesn't know from computers," she said. "I cursed that machine so much that it's broken twice. But now I've got experience. I could pass for a nurse." Phyllis was one of nearly 60 family caregivers who participated in six focus groups organized by the United Hospital Fund's Families and Health Care Project. The theme of the focus groups was transitions in care setting, especially going home from the hospital. These transitions are particularly traumatic to family caregivers, but they are also opportunities for professionals to provide education, support, and referrals for further assistance. The focus groups, as well as applications from 16 hospitals for the Fund's Family Caregiving Grant Initiative, were the major sources for the Special Report, "Rough Crossings: Family Caregivers' Odysseys through the Health Care System." (See the Fund's website, <http://www.uhfny.org> for further information.) Both sources provided compelling evidence that cost containment and earlier discharge policies put many family caregivers in the uncomfortable role of "passing as a nurse," while limiting the time and resources professional nurses have to train and support families. Even when home care nursing is available, it is usually limited to a few, brief visits. Many hospital nurses become frustrated when family members have difficulty absorbing new information. Focus group participants emphasized that they were expected to learn an unfamiliar and often unpleasant task with a loved one as their first subject (Levine, 1998). This issue of Nursing Counts explores caregiving from several perspectives, including the economic contribution made by caregivers to the health care system and the methodological problems inherent in research on caregiving. As guest editor of this special edition of Nursing Counts, I draw on my own personal experience of caregiving as well as on data from a variety of sources that shed new light on the experience of informal caregivers (Levine, 1999). Training and supporting family caregivers while their relative is hospitalized and following up at home should be routine. A health care system that fails to do this shortchanges patients, nurses, and family caregivers.

Levine, C. (1999). The loneliness of the long-term caregiver. *New England Journal of Medicine*, 340(2), 1587-1590.

Levine, C. (1998). *Rough Crossings: Family caregivers' odysseys through the health care system*. New York, NY: United Hospital Fund.

*Carol Levine, Guest Editor*

*Director, Families and Health Care Project*

United Hospital Fund

### FAST FACTS

#### Informal Caregivers

- ▶ Currently an estimated 12.8 million adults need assistance from others to carry out activities of daily living, e.g., bathing, feeding, toileting (Robert Wood Johnson Foundation, 1996).
- ▶ By 2020, 134 million adults will have chronic health conditions, and of this population, 29% (38.8 million) will have a chronic condition that limits their ability to live independently (GAO, 1994).
- ▶ One in 10 persons over 65, and close to half of those 85 and older have Alzheimer's Disease (Alzheimer's Association, 1998).
- ▶ Over 70% of persons with Alzheimer's Disease live at home, and of this population, 75% receive care from family and friends (Alzheimer's Association, 1998).
- ▶ By 2020, as many as 14 million elderly people will need long-term care---double the number who need

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### Forthcoming...

**Fall 1999:  
To Be  
Announced**

<ul style="list-style-type: none"> <li>▶ One in four adults currently provide some kind of care for an adult who has a chronic health condition (National Alliance for Caregiving and the American Association of Retired Persons, 1997).</li> <li>▶ Over 83% of all caregiving is given to persons 65 and older; 66% of all caregiving is given to people 75 and older (Family Caregiving Alliance, 1997).</li> </ul>	<p>it today (GAO, 1994).</p>
<p><b>Sources:</b> The complete list of citations can be obtained from Tammy Fisher at <a href="mailto:tjf207@nyu.edu">tjf207@nyu.edu</a></p>	

## Bringing The Hospital Home

Recent changes in health care are placing unparalleled demands on families to care for their sick and elderly relatives. Throughout history, families have typically provided the bulk of care to the sick: rendering personal care, comforting and assisting in childbirth. In the 20<sup>th</sup> century, many families learned basic home nursing and care of newborns from public health nurses who visited patients' homes.

But never before have families faced the current demands to provide care at home. Many people with dementia, stroke, and cancer, who might have died or been institutionalized in the early part of the century, now live, but require sustained and skilled care over a long period of time. Patients at home often need assistance with very personal needs: eating, toileting and bathing. They take medications with complex dosing schedules. They receive treatments such as injections, wound care, oxygen, intravenous medications, parenteral nutrition, chemotherapy, and respirators. Many patients at home require emotional care and, in the case of the very old with cognitive impairments, psychiatric treatment.

Society has come to expect that family members can and should coordinate and deliver care to these patients at home, sometimes with the help of professional and non-professional paid assistance, all too often with little or no help. What society has failed to consider is the burden that such caregiving places on the caregiver, most of whom are women, many of whom are themselves elderly and in poor health, and many of whom hold jobs outside the home. Arras (1995) describes this caregiving in his aptly titled book, Bringing the Hospital Home.

When we describe the nurse workforce, we rarely count the family members who provide that care at home. Nor do we count family care when we estimate the cost of health care in this country. Such care saves money for Medicare and Medicaid, but at enormous physical, emotional, and financial costs to families. Families now lose more time from work for parent care than they do for childcare. Nurses need to partner with families to assure families that they are not alone, and that nurses are there to help them acquire the knowledge and skills necessary for providing optimal care to their loved ones.

Arras, J. (1995). Bringing the hospital home: Ethical and social implications of high-tech home care. Baltimore, MD: The Johns Hopkins University Press.

*Mathy Mezey, EdD, RN, FAAN*

### R E S E A R C H   B R I E F S

#### ***CAREGIVERS UNDERGO MANY BURDENS***

Altman, Cooper, and Cunningham (1999) suggest that caregivers undergo extreme emotional, financial, and physical burdens. Although primary caregivers

#### ***COMPREHENSIVE DISCHARGE PLANNING REDUCES READMISSIONS***

In an effort to reduce costs, comprehensive patient discharge planning has reduced short-term hospital readmissions. Until recently, intervention

are often the focus of such studies, serious burdens are also placed on other family members living with a disabled person. They used the National Medical Expenditure Survey to analyze health care utilization of all family members living with a disabled person. Depending on the definition of disability, the researchers found that 7% to 48% of all multi-person families have one or more members with a disability. Overall, results showed that being in a family with a disabled member contributes to increased utilization of health care resources. Moreover, stress-related health care needs and resource limitations may be factors in health care utilization and expenditures. Altman et al. further suggest that results show future policy changes should not treat disability as an isolated case, but rather within a family context.

Altman, B.M., Cooper, P.F., and P.J. Cunningham. (1999). The case of disability in the family: Impact on health care utilization and expenditures for nondisabled members. The Milbank Quarterly 77 (1), 39-75.

programs for discharged patients who were at high risk for readmission had not been thoroughly explored. However, a randomized clinical trial at two Philadelphia hospitals investigated the outcome of a program using advanced practice nurses (APNs) to do extensive discharge planning, as well as an intensive home intervention for elders at high risk for readmission. APNs targeted both the patient and the family caregiver's ability to manage health problems by focusing on key factors that include: sleep, diet, and emotional status. Naylor et al. (1999) found that the APN discharge planning and home intervention significantly reduced readmissions and lengthened the time between discharge and readmission. At 24 weeks after discharge, total Medicare expenditures were 50% lower in the intervention group than in the control group.

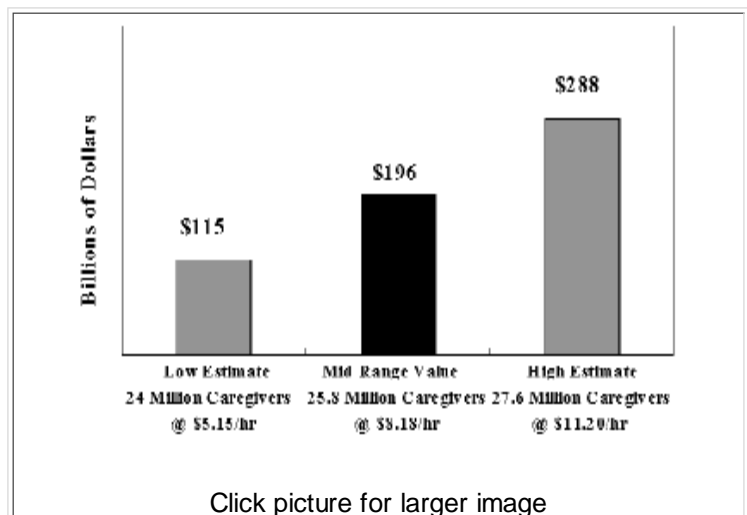
Naylor, M.D., Brooten, D, Campbell, R., Jacobsen, B.S., Mezey, M.D., Pauly, M.V., and J.S. Schwartz. (1999). Comprehensive discharge planning and home follow-up of hospitalized elders. JAMA, 281(7), 613-620.

Alexis Kuerbis

## Counting Family Caregivers

On this we all agree: most of the care required by chronically ill adults, persons 65 and older, and persons 65 and older with cognitive impairments is provided by "informal caregivers"---unpaid family members, friends, or neighbors. But documenting informal care, i.e., how many caregivers exist, what counts as caregiving, and how much time caregivers spend with their care recipients leads to methodological inconsistencies.

One problem is that data sources count different populations at different times and with different purposes. Some surveys query care recipients as to who provides care; others ask caregivers about their caregiving activities. Surveys use somewhat different definitions of the care recipient of caregiving. Most use some form of Activities of Daily Living and Instrumental Activities of Daily Living in their definition. Although both are useful, neither reflect the degree of difficulty inherent in caring for people with various conditions, or recent additions of high-tech medical procedures and monitoring to home



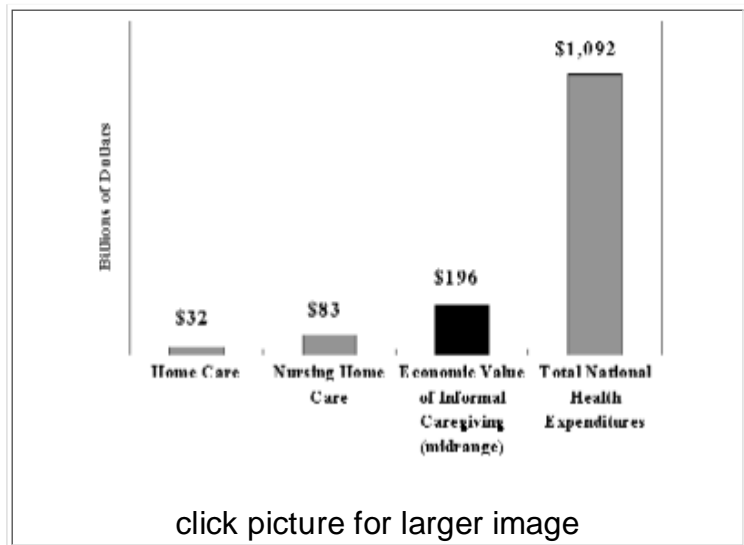
Arno, P.S., Levine C., and Memmott, M.M. (1999). The economic value of informal caregiving. Health Affairs, 18(2), 182-188.

care.

In an attempt to quantify aspects of caregiving, researchers have conducted a number of studies that employ various methods and techniques. For example, Arno, Levine, and Memmott (1999) used the methodology below to determine the mid-range value of informal caregiving per year. They applied the average weekly figure of 18 hours of informal caregiving per week (National Alliance for Caregiving & American Association of Retired Persons, 1997) to the number of estimated caregivers (25.8 million) who care for persons 15 and older. This yielded a midrange estimate 24 billion hours/year. Then, 24 billion hours was applied to a midrange wage rate of \$8.18/hour; the wage rate estimate was derived from averaging the current minimum wage (\$5.15/hour) and the national rate for home health aides (\$11.20/hour). Thus, the midrange value of informal caregiving totaled \$196 billion (Exhibit 1), illustrating that the value of informal caregiving is 6 times greater than national health expenditures for home care and 2.4 times greater than expenditures for nursing home care (Exhibit 2).

Another study, conducted by the Alzheimer's Association (1999), provides some insight into the number of informal caregiving hours among recipients who have Alzheimer's Disease. As demonstrated in Exhibit 3, Alzheimer's caregivers report spending an average of 17.6 hours per week giving care. However, results from a study directed by Ernst and Hay (1994) yielded an average of 52.5 hours per week, thereby illustrating the inconsistencies found when using different methodologies.

To gain a richer understanding of patterns and problems associated with caregiving, the United Hospital Fund (UHF) and the Visiting Nurse Service of New York, collaborated with the Harvard University School of Public Health to conduct a national survey of family caregivers. The survey results, which will be available from the UHF later this year, will document the particular roles and needs of elderly caregivers and their care recipients. For example, respondents were asked the sources (if any) of training to perform complex medical tasks, as well as assist with ADL's. Caregivers were also asked about their interactions with the formal health care system, including home care nurses and home health aides. By identifying the needs of vulnerable groups of elderly caregivers and care recipients, the study will help policy makers to develop appropriate public policies and health care providers to promote more responsive administrative practices.




Arno, P.S., Levine C., and Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs*, 18(2), 182-188.

We expect that this survey, and work conducted by other researchers, will define more accurately the spectrum of informal caregiving and develop more nuanced ways to report the caregiving experience as it is lived, not just as it is counted.

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*Senior Vice President for Program*

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