

Resource Use and Decision Making in Caregiving of Frail Elders: Is Research Informing Public Policy?

Quality research seems essential to inform long term care policy and program development. The purpose of this workshop was to critique the current status of research regarding the use of informal and formal resources and decision making in caring for frail elders. Implications for informing key public policy issues were discussed.

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Caring for Frail Elders: Public Policy Dilemmas

Caring for an increasing proportion and number of heterogeneous elderly as abilities to remain independent change has emerged as a major economic, political and social issue. Long term care policy reform is being driven by increasing demands, quality concerns, need for cost controls, and overall dissatisfaction with the current fragmented approach to delivering and financing. The number one theme identified as essential to address at the 1995 White House Conference on Aging was assuring comprehensive health care including long term care. Specific public policy dilemmas regarding caring for elders revolve around: a) what family, marketplace and/or government resources should be used to protect against the risk of long term care; 2) what long term care benefits or services should everyone have access to; 3) whether eligibility for benefits should be based on impoverishment, age, role of family as caregivers, or other criteria; and 4) how to provide quality care while controlling costs.

As long term care policy develops it seems essential that quality research help inform the discussion. This workshop focused on understanding the current strengths and weaknesses of existing research regarding: a) human capital or social support as a resource (Hong), b) the role of ethnicity and caregiving (White-Means), and c) the impact of the current financing system on families (Stum). Brief overviews of each research area follows. Workshop participants engaged in dialogue about the implications of the current knowledge base for informing local, state and federal public policy dilemmas.

Who Are the Caregivers?

Factors Affecting Who Provides Care

Gender. The provision of informal care to the elderly is predominantly a female role. In a national study of caregivers, Stone, Cafferata, & Sangl (1987) reported that about 70% of caregivers were women, with 29% of adult daughters and 23% of wives constituting this population. The 1988 survey conducted by the American Association of Retired Persons (AARP) found that three-fourths of caregivers were women and about 40% were involved in parental responsibilities.

Age. The mean ages of caregivers vary depending on the data used. The average age of caregivers was 57 years in the study by Stone et al. (1987); 25% of them were between 65 to 74 years old and 10% were 75 years or older. The study indicated that the young-old help the old-old. The AARP (1992), however, reported 46 years as the average age of caregivers. Among children, the oldest children tend to provide more assistance than other children (Horowitz, 1985).

Marital Status. About 70% of all caregivers are married. Among the nonspousal caregivers, about 50% are married. Female caregivers tend to be widowed and male caregivers are likely to be never married. Caregivers age 45 to 54 years old are less likely to be married than their age peers in the general population. In contrast, older caregivers, age 65 and older, tend to be married than their age peers in the general population because they are caring for their spouses (Select Committee on Aging, 1987).

Family Income. Approximately 57% of caregivers reported their family incomes in the low to middle range. One in three had incomes falling within the poor or near poor category, and most of them were women (Select Committee on Aging, 1987). The average caregiver spent \$117 per month on care-related expenses (AARP, 1992). The lost earnings due to caregiving responsibility were \$20,400 per year on average (Enright & Friss, 1987, cited in Neal et al.). The financial status of the caregiver also determines the type of care provided to the elder. Low income households tend to live with the elder and provide direct assistance whereas high income households are likely to provide financial assistance to the elder and purchase the services (Horowitz, 1985).

Employment Status. The 1988 AARP survey indicated that over half of all caregivers are employed outside the home and approximately 12% of all female caregivers leave employment because of caregiving demands. Stone et al. (1987) reported that 31% of all caregivers are employed. Both husband and wife had an equal probability of quitting work, and more daughters (12%) left their jobs to become caregivers as compared to sons (5%). Stone and Short (1990) reported 29% of caregivers quit jobs, accommodate their work schedule, or assume care responsibilities.

Occupation. The occupation of caregivers influences the way they adjust their work and demand for care. More clerical and sales workers either reduced their work hours or rearranged work schedules than those who were professionals and managers (Stone et al., 1987). More operators, laborers, clerical and sales workers took time off without pay than those in other types of occupation (Select Committee on Aging, 1987).

Living Arrangement. About three-quarters of the caregivers shared households with the care recipients (Stone et al., 1987). Stephens and Christianson (1986) reported that about 57% of the caregivers participating in the National Long-Term Care Channeling Demonstration shared their households. Sharing a household is likely to be determined by the functional ability of parents, socio-economic status, and the gender of the parent and the child. The amount of caregiving is influenced by living arrangement. Care recipients receive more extensive care if they share a household (Horowitz, 1985).

Health Status. One-third of all caregivers perceive their health status as fair or poor. Among spousal caregivers, about 44% of wives and about 50% of husbands reported that their health status as fair or

poor. Overall, caregivers perceive themselves in poorer health. This indicates that stress experienced by caregivers might contribute to the deterioration of their health (Select Committee on Aging, 1987).

Informal Caregiving: Current and Future Perspectives

Demographic, family, and social changes have brought about the increasing concerns regarding the supply and demand of family caregiving. First, the American population is aging. According to the US Department of Health and Human Services (1990, p. 23), people over 65 will constitute 13% of the total population by the year 2000. The most rapid population increase over the next decade will be among those over 85 years of age. This group will constitute a substantial share of people who are not independent in physical functioning which in turn requires assistance with their activities of daily living.

Second, the number of adults with disabilities has increased because of advanced medical technology. Lives from fatal injuries and accidents are saved but many survivors have functional limitations that require informal care at home or institution. Third, escalating health care costs for the elderly population brought the emphasis on non-institutional care (i.e., home health care, homemaker services, adult day care). Families provide long-term care services for their frail elderly parents and relatives. Families are also responsible for those who are discharged earlier from hospitals (Neal et al., 1993). Fourth, the increasing number of divorced and remarried older persons suggests that there will be more parents of which to take care. At the same time, the number of divorced adult children has increased, leaving more children without a spouse's assistance (Select Committee on Aging, 1987).

The number of adults who are able to provide informal care has been shrinking, while the demand for informal care has been increasing. The declining fertility rate indicates that there will be fewer children to care for the elderly. The female labor force participation rate for women aged 20-54 in 1993 was 73%. The number of employed women with children under age 18 increased from 39% to 62% (Bureau of Labor Statistics, 1993). Moreover, the number of women in the labor force is expected to increase since two pay checks are needed to achieve a middle-class life style (Akabas, 1990). These statistics indicate a decreasing pool of caregivers in the future and time available for the services traditionally provided by wives, mothers, and daughters. On the other hand, these trends might encourage adult sons to take the responsibility for frail elderly parents.

Ethnicity and Caregiving

Ethnic identification is the way one perceives he/she is a part of a group that race, religion, or national origin defines. Ethnicity influences interactions within families and between families and their environment, life course experiences, and the aging process (Jackson, 1989).

American elderly are ethnically diverse. Based on the 1990 census, the most frequently reported ethnic elderly groups (in order of percent of the population) are German-, English-, Irish-, American, and Afro-Americans. Ethnic minority populations are projected to compose a higher and growing percentage of the elderly. With Hispanic elderly projected to represent 15 percent of the elderly by the year 2050. Non-Hispanic blacks, American Indians, and Asians will represent 20 percent (Bureau of Census, 1993). This changing trend in the ethnic composition of the elderly suggests that public policy strategies for addressing the needs of the elderly should correspondingly change.

What Do We Know About Ethnic Caregivers?

Caregivers are an essential resource for disabled ethnic older persons. The primary emphasis of research on caregivers is describing the size of caregiving support networks and the types of persons who provide care.

Two primary national probability data sources have assisted in the development of this literature. They each have large samples of caregivers for older disabled blacks. The data sources are the National Long Term Care Channeling 1982-84 (Channeling) and the 1982 and 1989 waves of the National Long Term Care Survey (NLTCs). The 1982 NLTCs is unique because white caregivers provide information about their ethnic identification.

Data from the Channeling survey indicate that disabled black older persons have caregiving networks that are larger than those of frail white older persons. The networks are also more likely to include nonkin. Blacks are more likely to have distant relatives and friends who provide live-in care. About 52% of other relatives and 22% of nonrelatives share housing with frail black older persons, compared with 31% and 11% of other relatives and nonrelatives, respectively, of frail white older persons (White-Means, 1993).

Data from the NLTCs (1982) indicate that when African-Americans are compared to German-, Irish-, and English-Americans, African-Americans have much larger caregiving networks and are more diverse in composition (Thornton & White-Means, 1993). Caregiving networks for older African-Americans are more likely (17% vs. 9%, 8%, and 9%, respectively) to include five or more

caregivers. Compared to the three other ethnic groups, African Americans are least likely to have networks with immediate family members only (42% vs. 54%, 63%, and 57%, respectively).

The NLTCs also provides data on the amount of caregiving effort provided by informal caregivers. We know that African-American caregivers provide considerable informal support hours to older persons (White-Means & Thornton, 1990). When compared to German-, Irish-, and English-American caregivers, African-American caregivers provide more total hours of assistance, even after controlling for differences in the functional levels of impairment (which is much higher among African-American older persons).

Other research on ethnic caregivers is based on small non-population based samples who experience particular medical ailments. For example, Cox and Monk (1993) present data on 86 Hispanic caregivers of Alzheimer's patients in New York City. The data suggest that primary caregivers for Hispanic older persons work in small networks, with about 60 percent of caregivers indicating that no substitute caregiver was available to assist the older person if the primary caregiver was unavailable.

Ethnic Caregiving and Use of Formal Care

While the limited use of institutionalized nursing home services among racial minority populations is well documented (National Caucus and Center on Black Aged, 1987), a paucity of research examines the relationship between informal and formal care utilization among ethnic groups.

A recent paper by Mui and Burnette (1994) asks the question of whether ethnicity is a factor in long-term care and contrasts patterns of service use for African-Americans, whites and Hispanics. African-Americans rely more heavily on informal helpers and support from churches than the other race/ethnic groups. Whites use nursing home and meals on wheels more frequently. Hispanics are more likely than either African-Americans or whites to obtain counseling services. Logistic regression analysis indicates that, compared with whites, African-Americans are 18% less likely to use in-home services and Hispanics are 91% more likely to use community-based services. African-Americans and Hispanics are 82% and 58% less likely than whites to use nursing home services. The rationales for these patterns are left unexplained in most analyses.

Ethnic Caregiver's Employment, Stress and Health

The literature addressing this question is also limited. With these extensive informal care time commitments, many black caregivers quit their jobs in the

labor market to engage in care of older persons. The National Channeling data indicate that spouses (36%), daughters (26%), sons (17%), siblings (20%), and other relatives (18%) quit their jobs due to caregiving responsibilities (White-Means, 1993). However, African-American caregivers are no more likely than white ethnic caregivers to quit their jobs (White-Means & Thornton, 1990). Extensive hours of informal caregiving also limit the family, free and sleep time of black caregivers. Emotional and physical strains of caregiving are problems not only for immediate family members, but also for distant relatives and nonrelatives who provide informal care.

Does Research Inform Public Policy?

Ethnic variations in family caregiving result due to a multiplicity of factors, some seldom isolated in current research (Gibson, 1989). The distinction between the roles of family norms/culture, minority status and racial experience are seldom examined in research on ethnic caregivers. Although important in expanding the understanding of the family caregiving process, these distinctions are difficult to isolate because of limited data that ascertain both race and ethnic background of caregivers. Additionally, data seldom include variable measures that are relevant to the experiences of ethnic and/or racial populations. Data are needed on attitudes regarding family perspectives on caregiving responsibilities.

Multifarious definitions of family impact on family preferences for the use of informal and formal care. Much more information is needed regarding these types of family strategies.

Socioeconomic status may influence the role and activities of the family caregiver, as well as use of formal care services. Family networks may also develop as adaptations to being discriminated against and excluded from mainstream institutions. The structure of race relations in the United States leads to unresponsiveness to cultural differences, including language barriers and lack of respect. There is some evidence that racist experiences in the past cause a reluctance among black aged to go to white doctors or to use formal in-home services for long-term care needs (National Caucus and Center on Black Aged, 1987). Public policy must not only emphasize changing the structure of the financing of care, but also it must consider structural barriers resulting from racial discrimination.

Analysis that clarifies the relative importance of family norms, socioeconomic status, and racial experience will inform public policy. If socioeconomic status is of import then public policy emphasis may be more effective when directed toward changing the

financing of formal and informal care for older persons. Public policy that does not acknowledge variations in family norms of responsibility will not have the same impact on each ethnic population, some groups benefiting more than others.

The greatest impairment to our understanding of the experiences of older ethnic populations is inadequate national, population-based longitudinal data on caregivers. There are ethnic minority populations about which we know very little, i.e., Native-, Asian-, and Hispanic-Americans. Additionally, the database for understanding white ethnic caregivers was constructed in 1982.

Impact of Financing Long Term Care on Families

The current fragmented delivery and financing of long term care in the United States has proven costly to the chronically ill elderly and their families as demands have outpaced available resources. Evidence suggests that worry and fear about impoverishment and lack of financial security due to long term care expenses is very real and also very justified given the lack of planning and lack of long term care risk protection options.

Existing research has primarily focused on understanding two key areas: a) the financial capacity of elders and their family members to afford the financial risks of long term care; and b) the realities of private and public expenditures for various long term care service use. Very little research has examined decision making processes and outcomes at the family system level as resources are allocated to protect against and/or pay for long term care.

Financial Capacity

Are the financial resources of elders adequate to meet long term care costs? Studies examining whether elders can afford long term care have measured resources and long term care costs in different ways but with similar conclusions—that many elderly are at risk of financial impoverishment (EBRI, 1990). Moon and Smeeding (1989) suggest that it is the variation in wealth among the elderly which is the major determinant of ability to afford long term care. While overall wealth of the elderly population has increased over the last decade, subgroups of the heterogeneous elderly population remain at risk (EBRI, 1990).

The vast majority of research has investigated the affordability of institutionalized care as opposed to the broader continuum of long term care services and settings preferred by elders. Studies have typically measured some combination of available income, liquid assets, and

home equity of elderly against the cost of the median length of stay in a nursing home. Conflicting messages of capacity to afford emerge depending upon assumptions regarding financial resources, probability of risk, and cost of risks. Holden and Smeeding (1990) raise the dilemmas of how to conceptually define and operationalize costs and resources for couples and family systems versus individual elders as well as adjust for the impact of gender on use and therefore potential costs. National datasets typically do not have sufficient measures for both economic and health status to examine interrelationships of variables over long term care transitions.

A closely related body of research focuses on examining the risk and rate of spend down to become eligible for Medicaid. Issues of how many elderly are affected by catastrophic nursing home expenses is a major part of the policy debate regarding Medicaid reform. National data suggest the magnitude is small, while state-specific data indicate it is greater and reflect circumstances particular to each state. Estimates of spend down range from 14–44.9% of nursing home residents reflecting varying measures and sampling techniques (Adams, Meiners & Burwell, 1993). Adams, Meiners & Burwell (1993) provide an overview of research methods used to examine spend down issues. Additional studies suggest that spend down issues may be a more common problem for home and community-based care than in nursing homes.

The role of voluntary poverty or divestment in the impoverishment process is also of great interest to policy makers; however no comprehensive studies have been conducted to determine the scope and prevalence of divestment. Understanding divestment requires longitudinal data which can capture the numerous transitions in types of service use overtime; changes in the mixture of sources of payment, income and asset status changes within and between generations and intentions behind the transfers. What is known is that elders are using a number of legal strategies to transfer assets and effectively transform themselves from affluence to voluntary poverty and eligibility for Medicaid (Burwell, 1991). Two recent studies have begun to examine decision making and transfer of assets with an emphasis on family caregiver perceptions (Frazer & Stum, 1994; Walker et al., 1994). The qualitative approaches in these studies are designed to capture the dynamics involved in resource allocation decisions.

Various studies continue to examine the capacity of elders to insure against the risks of long term care through long term care insurance products. Research focuses on long term care insurance affordability, potential market size, purchase behavior, and marketing

practices. Cude (1994) suggests that although the quality of long term care insurance has increased, consumer issues of affordability and true availability remain.

Who Currently Pays for Long Term Care?

A majority of long term care costs are currently borne by the income, assets, and human capital of individuals and family members (EBRI, 1990; Rowland & Lyons, 1991). In addition, research suggests that 40 percent of the elderly with some activity of daily living dependency have unmet needs, primarily due to the lack of ability to obtain or pay for long term care (GAO, 1988). When private resources are defined broadly to include informal care as well as private expenditures, 73 percent of the elderly rely entirely on private resources for the care (Spillman & Kemper, 1992).

The vast majority of what is known about the use and costs of long term care has focused on institutional care provided in nursing home settings. Various studies have examined the likelihood of nursing home use, lengths of stay, and differences in use and costs given various sociodemographic variables. Studies have only begun to examine use patterns related to community and home care. Liu, Manton and Liu (1985) suggest that out-of-pocket costs for intensive home care or adult day care can be as high as those for nursing home care. Liu, Perozek and Manton (1993) added an examination of a broader continuum of selected acute and long term care costs. Findings consistently reinforce the importance of understanding need or health status as a key eligibility criteria with implications for measuring physical and or cognitive abilities.

Existing Challenges

Existing research offers some insight into the financial capacity of elders to afford long term care risks as well as current use and expenditures. To adequately inform public policy, future research should: a) examine the impact of delivery and financing systems on families as well as government; b) improve our understanding of decision making processes in families; c) understand long term care as a dynamic process vs. discrete events; d) assist in understanding the intergenerational exchange of resources; e) examine actual behaviors versus intentions; and f) recognize the impact of varying states' infrastructures.

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