

Introduction

Each day, more than 4 million family members care for disabled elderly people at home (Stone and Kemper, 1989). They help them in and out of bed, administer their medications, cook their meals, drive them to doctors, manage their finances, mow their lawns, and replace their broken windows. Although these "informal caregivers" typically are absent from analyses of long-term care, they render the great bulk of services the elderly receive.

Most people 65 and over can care for themselves and their households without assistance, but approximately one-quarter require at least occasional help (Liu, Manton, and Liu, 1985). Moreover, the prevalence of disability rises steeply with age. Sixteen percent of people 65 to 74 living in the community need some type of practical assistance, compared to 47 percent of those 85 and over (Special Committee on Aging, 1989:236). Despite the widespread belief that Americans rely extensively on nursing homes, just 1.4 million disabled people 65 and over reside in such facilities (Liu, Manton, and Liu, 1985). Almost four times as many live at home (Macken, 1986).

Researchers have exploded the myth that families abandon their elderly relatives. From her classic study conducted in 1975, Ethel Shanas concluded that elderly people do remain in close contact with surviving kin. Over half of the older persons in her survey who had living children had seen at least one child either the day of the interview or the day before; 75 percent had seen a child within the previous week. Approximately 40 percent of those who had not seen a child during the preceding week had seen another relative. Elderly persons without children tended to interact more closely with siblings and other relatives (Shanas, 1979a).

Frequency of contact translates into assistance during times of crisis. Researchers consistently find that families deliver 70 to 80

percent of long-term care (Community Council of Greater New York, 1978; Comptroller General of the United States, 1977; Stone, Cafferata, and Sangl, 1987). Three quarters of unpaid caregivers to the noninstitutionalized disabled elderly live with the care recipient, and the majority render care every day of the week, devoting an average of four hours a day to caregiving activities (Stone, Cafferata, and Sangl, 1987). Although the frequency and level of care vary dramatically, a study conducted in 1976 found that two-fifths of the people who care for elderly parents in their own homes perform the equivalent of full-time jobs (Newman, 1976). Caregiving can last a long time. Approximately 44 percent of caregivers have been furnishing assistance for one to five years, a fifth for five years or more (Stone, Cafferata and Sangl, 1987).

The burdens of care typically fall disproportionately on a single individual. Although friends and neighbors constitute an essential source of support, family members deliver most care. Because married elderly people turn first to their spouses in times of need, husbands and wives are the most common caregivers. They are more likely than other caregivers to live with the person they tend and to take responsibility for such intimate aspects of caregiving as bathing, dressing, and feeding (Stone, Cafferata, and Sangl, 1987). Although they frequently care for very impaired people, they receive little assistance from either paid providers or other family members. Because many spouses are disabled themselves, caregiving often imposes extreme burdens (Hess and Soldo, 1985, Horowitz, 1985a; Johnson, 1983).

Adult children constitute 37 percent of all caregivers. Although they provide a smaller proportion of the total care and receive more help than spouses, they are more likely to hold paid employment and face competing demands from other family members (Stone, Cafferata, and Sangl, 1987). Caregiving also appears to be especially difficult for them emotionally (Johnson and Catalano, 1983; Unger-son, 1987).

Like other forms of domestic labor, care for the elderly continues to be allocated on the basis of gender. Women represent 72 percent of all caregivers and 77 percent of the children providing care. Almost one-third (29 percent) of all caregivers to frail elderly persons are adult daughters (Stone, Cafferata, and Sangl, 1987).

Daughters are more likely than sons to live with dependent parents (Wolf and Soldo, 1986) and to serve as the primary caregivers (Stone, Cafferata, and Sangl, 1987). Sons and daughters also assume responsibility for very different chores. Sarah Fenstermaker Berk (1988:295)

writes, "Husbands are more likely to undertake those household tasks that have clear and identifiable boundaries (such as mowing the lawn) [and] tasks that have greater discretion in both how and when to complete them (such as minor household repairs)." Sons and daughters divide caregiving responsibilities along similar lines. Sons are more likely to assist parents with routine household maintenance and repairs, while daughters are far more likely to help with indoor household chores and personal health care (Coward and Rathbone-McCuan, 1985; Stephens and Christianson, 1986; see Stoller, 1990). This gender division of labor may help to explain why caregiving has different consequences for sons and daughters. Sons take responsibility for tasks they can perform whenever they choose. Daughters, however, often assume responsibilities that keep them on call twenty-four hours a day.

Nevertheless, daughters who provide care are less likely than sons to receive assistance (Stone, Cafferata, and Sangl, 1987). Sons caring for elderly parents obtain more help from their wives than daughters can expect from their husbands (Horowitz, 1985b.) Some evidence suggests that formal services also are distributed inequitably. Men caring for elderly spouses or parents seem to obtain more in-home services than their female counterparts (Evandrou et al., 1986; Hooyman and Ryan, 1985; Wright, 1983).

Daughters and sons choose different solutions to the conflict between waged work and informal caregiving. Daughters are more likely than sons to curtail labor force participation, while sons are more likely than daughters to reduce caregiving responsibilities. According to data from a 1982 government survey, the proportion of caregiving daughters who relinquished paid employment was more than twice that of sons (11.6 and 5.0 percent). Of those who worked at some point during the caregiving experience, higher proportions of daughters than sons reduced their working hours as a result of caregiving obligations (22.8 versus 15 percent), rearranged their schedules (34.9 versus 27.7 percent), and took time off without pay (24.8 versus 14.1 percent) (Stone, Cafferata, and Sangl, 1987). Conversely, a 1983 study found that sons who held paid employment reduced the number of hours they helped their parents but that labor force participation had no significant impact on care by daughters (Stoller, 1983).

Not surprisingly, daughters are more likely than sons to perceive caregiving as stressful. The proportion of sons who reported in a recent study that caregiving presented "no problems" was more than three times that of daughters (34 versus 11 percent); the proportion of

daughters who believed that caregiving had negatively affected their health was nearly twice that of sons (59 versus 31 percent) (Horowitz, 1985b).

Although caregiving is predominantly women's work, care for the elderly is largely absent from the feminist agenda in the United States. Feminist scholars lavish attention on motherhood, but they continue to slight other forms of caregiving. Numerous observers note, however, that child rearing occupies a much smaller place in women's lives today than in the past. Colonial women devoted most of their adult years to bearing and raising children. But today the typical mother has preschool children for slightly longer than a decade and can expect to live well into her seventies (Gerson, Alpert, and Richardson, 1984). Rather than reducing the period of caregiving, however, the demographic revolution may have shifted it to other parts of the life course. Some women devote more years to caring for aging parents than to raising children (Subcommittee on Human Services, 1987).

The shape of women's caregiving responsibilities may change even more dramatically in the future. The elderly were just 4 percent of the population in 1900 (Feldblum, 1985), but they increased to 8 percent in 1950 and 12 percent in 1984. It is projected that those 65 and over will constitute approximately 17 percent of the population by 2020 (Siegel and Taeuber, 1986). The rate of increase of the very old, who are most at risk of illness and disability, is even greater (Manton and Soldo, 1985). The number of those 85 and over rose 165 percent between 1960 and 1980 and is expected to increase a startling 500 percent by 2050 (Day, 1985). The "old old" constitute the fastest growing segment of the population (Siegel and Taeuber, 1986). Analysts project that the number of elderly people who require help at home with some of their daily activities will increase from 2.5 million in 1984 to 6.5 million in 2025 (Kovar, Hendershot, and Mathis, 1989:779).

The analytic framework that feminists have developed to understand mothering also can illuminate informal care for the elderly. Gerontologists frequently remind us that care of elderly persons differs in fundamental ways from care of small children. Nevertheless, feminist scholarship on motherhood can help guide the study of family care for aged people.

For example, the concept of choice is an important focus of feminist writing. Because child-care services and paid maternity leaves frequently are unavailable, many women have little choice about the amount and type of care they render. Inadequate access to family

planning and abortion services even deprives some women of the ability to decide whether to become mothers. There also are more subtle pressures on women to bear and rear children. When women are denied opportunities for achievement in the public arena, they tend to look to mothering as the sole source of pride and self esteem (Gerson, 1985; Glenn, 1986; Johnson, 1988).

In addition, feminists have called attention to the ways in which external conditions shape the experiences of mothers. Ever since productive activity left the home in the nineteenth century, most women have tended children in isolated settings; as a result, they receive little support from other adults.* Some critics charge that isolation encourages women to become too involved with their children and thus distorts the mother-child relationship (Arcana, 1979; Chodorow, 1978; Chodorow and Contratto, 1982; Dinnerstein, 1976; Flax, 1978; Glenn, 1986; Jaggar, 1983; Johnson, 1988; Rich, 1976; Trebilcot, 1983). If feminists focus on the context of mothering, however, they also emphasize the need to illuminate women's lived experience as mothers. Feminist scholars have examined the powerful, if ambivalent, feelings evoked by mothering, noting the ways this activity can gratify as well as frustrate and burden (Boulton, 1983; Rich, 1976).

Feminists also have highlighted the connection between women's responsibilities for children and their disadvantaged position in the labor market. Although the majority of women now work for pay during their child-rearing years, some mothers still delay entry into the labor force, accept only part-time positions, or quit their jobs. The belief that all women are intermittent workers serves as a rationalization for relegating them to jobs with depressed wages, limited fringe benefits, few routes for advancement, and high turnover rates (see England and McCreary, 1987; see Sokoloff, 1981).

Finally, feminists have criticized the social devaluation of mothers. Although mothers are widely romanticized in our society, their growing impoverishment, the absence of adequate day care, and the failure of many men to share their responsibilities both create and reveal the low status accorded to care of young children (Glenn, 1987).

Each of these themes is relevant to family care of the frail elderly. The paucity of long-term care services, like the dearth of publicly funded day care, narrows women's freedom of choice. Obligations for elder care can have the same impact on labor force participation as

*Some observers argue that in many African-American communities, mothering is not such an isolating experience (see Stack, 1974).

responsibilities for child rearing. Just as mothering often imposes isolation, so care for disabled elderly family members confines many women to the home. Informal care for aged people, like child rearing, frequently provokes a range of intense but contradictory emotions. And cultural attitudes toward family members caring for elderly people resemble those toward mothers. Caregivers, like mothers, are simultaneously sentimentalized and devalued.

These themes inform this book, which explores family care for disabled elderly people in several ways. Chapter 2 examines how public policies affect the nature of caregiving at home. It argues that the amount of care women deliver to elderly relatives is determined not only by inexorable demographic trends but also by the inadequacies of the long-term care system in the United States. These deficiencies have the greatest impact on low-income people and members of racial and ethnic minority groups.

Chapter 3 traces the history of family caregiving in the United States since 1800. It challenges the persistent belief that the nineteenth century offers a superior model of care for sick and disabled persons. It also demonstrates that many features of caregiving we accept as immutable actually are conditioned by specific social and historical forces. Although caregivers deal with biological universals—pain, illness, and death—the content and meaning of their work has changed dramatically over time.

Chapter 4 criticizes the current research agenda on caregiving, which has focused almost exclusively on the issue of stress. In part, this emphasis represents a response to recent governmental policies seeking to shift responsibility for care from the state to the family. By demonstrating that caregiving poses severe strains, researchers have been able to argue that families cannot absorb additional obligations and that the government must devote adequate resources to support them. But this preoccupation with stress has denied us a full understanding of the experience of caregivers. Furthermore, studies that view caregivers as objects without consciousness foster policies that treat caregivers in an instrumental manner. This chapter argues that we need to understand women's actual experience rather than manipulate their actions to suit government demands for efficiency and cost containment.

Chapters 5 through 9 present my study of women caring for disabled elderly parents. Although their experiences do not provide simple answers to the problems policymakers encounter, an understanding of women's perspectives can help broaden the policy debate.

The concluding chapter (Chapter 10) returns to the policy issues with which I began. It asks how the accounts of the women I interviewed can guide policy analysis and how we can frame an agenda for change that responds to their needs.

The study on which this book is based involved in-depth, open-ended interviews with fifty-one women. Thirty-seven (73 percent) were caring exclusively for mothers, seven (14 percent) for fathers, and seven (14 percent) for both. Thirty-eight (75 percent) stated that at least one parent suffered from Alzheimer's disease or a related dementia. Some researchers report substantial differences between the experience of caring for elderly persons with dementia and those without cognitive impairments (Silliman and Sternberg, 1988), but other researchers find similarities between these two types of experiences (Liptzin, Grob, and Eisen, 1988; Montgomery, Kosloski, and Borgatta, 1988–89). I identify the distinctive aspects of caring for parents with dementia whenever appropriate.

Additional demographic information may help to introduce the women in this study. Approximately two-thirds were married, and over three-fourths were between the ages of 45 and 64. The great majority were white (two were African-American, and one was Asian-American). Just two had children under the age of 18 at home. Three-fourths lived apart from their parents. Over half were working for pay.

Caregiving was not a short-term event for these women. At the time of the interviews, three (6 percent) had rendered care for less than one year, twenty-five (49 percent) for one to four years, and twenty (39 percent) for longer. (The father of one woman had died one month prior to the interview; two women had placed their mothers in nursing homes during the year preceding the interviews.)

The women I interviewed and the parents they cared for were disproportionately middle class. Many had adequate resources to live apart and to purchase some formal services. Most of the daughters who worked full time held middle-class positions: seven were professionals, five were managers, and nine held administrative support positions. The caregivers also were relatively well educated. Just five had no schooling beyond high school, fifteen had one to three years of college, thirteen had graduated from college, and eighteen had some form of advanced education.

Although most of these women enjoyed considerable advantages, five delivered care under very difficult conditions. The latter all were unmarried and lived alone with severely impaired parents. None was working for pay; four had left the work force, largely in order to care

for their parents (the fifth had quit her job several years earlier when her husband was dying). These women also experienced more economic insecurity than most of the women I interviewed; as a result, none was able to purchase services privately. Comparisons between the members of this group and the other caregivers in the study reveal some of the ways in which financial resources affect the experience of delivering care.

(Further information about the sample and the research methods is included in the Appendix.)