HISTORICAL OVERVIEW

Andrew Scharlach
University of California at Berkeley

FOUR DECADES OF SCHOLARSHIP and changing public policy on family and informal caregiving for older adults have brought us far, but we have far yet to go. Many issues and concerns raised long ago (Abel, 1986; Brody, 1985; Kane & Penrod, 1995; Troll, 1982) continue to confront us today as a result of their complexity and the limitations of scholarship and public policy on this important issue.

Modern scholarly interest in family caregiving dates to the 1960s, when Shanas and Streib's (1965) groundbreaking examination of the "myth of the abandoned elderly" showed that earlier predictions about the "demise of the extended family" (Parsons & Bales, 1955) were greatly exaggerated. Families were not abandoning their older members, but many were experiencing substantial challenges in providing care. Changes in family composition, community support networks, and labor force participation all reduced the capacity of families and other informal support systems to provide the assistance disabled older adults needed. Scholars and clinicians began to believe that older adult care constituted a crisis for families (Brody, 1966) that led to "caregiver burden," a construct that has framed much of the caregiving research over the past 40 years.

Interest in family caregiving expanded in the 1970s with studies such as Troll's examinations of intergenerational family relationships (Troll, 1971), Cantor's (1991) hierarchical model of family care, Archbold's (1983) investigations of parent care, and the development of caregiver-burden measurement tools such as the widely used Zarit Burden Interview. This period was also notable for the publication of self-help books for family caregivers, including *You and Your Aging Parent* (Silverstone & Hyman, 1976) and *The 36-Hour Day* (Mace & Rabins, 1981), and for the founding of caregiver support organizations such as the Alzheimer's Disease and Related Disorders Association (renamed the Alzheimer's Association) and the Family Survival Project (now called the Family Caregiver Alliance).

The 1980s saw the conducting of the first national surveys of informal caregivers for

Reprinted with permission from the *American Journal of Nursing 108*(9), 16–22 (2008).

disabled older adults—the U.S. Department of Health and Human Services' National Long Term Care Surveys (Stone et al., 1987) and the AARP/Travelers Foundation (1988) National Survey of Caregivers. The effect of caregiving on employment (Scharlach et al., 1991; Subcommittee on Human Services, 1988) received increased attention, but not as much as the even greater effect employment has on families providing direct care for older adults (Scharlach et al., in press). In 1983, hospice care became reimbursable under Medicare, enabling terminally ill individuals and their families to receive in-home nursing care along with psychosocial support services. In 1989, Connecticut became the first state to pass legislation that explicitly granted workers the right to unpaid leave with job protection so they could care for a seriously ill parent, spouse, or child.

The 1993 federal Family and Medical Leave Act made the United States one of the few countries to grant workers the right to unpaid leave in order to care for a parent, spouse, or child with a serious health condition. At about the same time, the United Kingdom passed the Carers (Recognition and Services) Act, which established the right of family members to have their own needs assessed when a disabled relative entered the community care system. The National Alliance for Caregiving was founded in the United States in 1996; in conjunction with AARP, it conducted the Family Caregiving in the U.S. national survey in 1997. Several other studies of caregiving prevalence and needs also took place in the 1990s, as did a number of intensive, rigorously designed evaluations of interventions intended to alleviate caregiver distress (Brodaty et al., 1994; Mittelman et al., 1995) and more conceptually sophisticated explorations of the caregiving stress process (Pearlin et al., 1990). The physiologic and psychological toll of the chronic stress experienced by caregivers was recognized (Kiecolt-Glaser et al., 1991).

The past decade has brought increasing attention to aging baby boomers with regard to both their current caregiving responsibilities and their own future care needs. The 2000 reauthorization of the Older Americans Act created the National Family Caregiver Support Program (NFCSP), allocating resources to providing support services to family caregivers. Administered by state and local agencies on aging, the NFCSP has been shown in preliminary evidence to reduce caregiver knowledge gaps and unmet needs (Dal Santo et al., n.d.). In 2006, Congress passed, but hasn't yet funded, the Lifespan Respite Care Act to promote development by the states of "a coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs" (Lifespan Respite Care Act of 2006). In 2003, California enacted the country's first paid family leave policy, which grants workers who take leave to care for ill or disabled relatives the right to receive payments through employee contributions to state disability insurance funds.

Support systems for family caregivers have been affected by changes that have made social work and nursing more managerial than clinical. Funding and regulatory constraints and an increased emphasis on individual accountability have shifted their emphasis to providing information and referrals rather than discharge planning and care management. In general, families are on their own to a greater degree than they have been in decades.

Caregiving research has also evolved, using increasingly sophisticated analytic tools to address complex conceptual models. For example, the Resources for Enhancing Alzheimer's Caregiver Health project evaluated interventions designed to reduce caregiver distress, whereas Medicaid's ongoing Cash and Counseling program examines the effect of long-term care policies and programs on family caregivers. The advances gained in understanding have led to family caregiving now being viewed as a complex process that affects and is affected by gender, culture, socioeconomic status, and lifespan developmental processes.

Changing Characteristics of Family Caregivers

Family caregivers have changed during the past two decades, reflecting national trends as well as greater options for care. The four most recent National Long Term Care surveys (Spillman & Black, 2005; Wolff & Kasper, 2006) and three national household caregiver surveys conducted in collaboration with AARP (AARP & The Travelers Foundation, 1988; National Alliance for Caregiving & AARP, 1997, 2004), revealed some relatively consistent trends in family life over the past 20 years:

- Men have taken on more caregiving responsibilities, although women still make up more than 60% of caregivers.
- Like the general population, caregiving families have become more diverse racially and ethnically.
- Fewer caregivers are married than those 20 years ago, and fewer are caring for a spouse.
- Fewer caregivers live with their care recipient, and more live at least 20 minutes away.
- Caregiving is more likely to be done by one person, and caregivers generally have less time for family or friends.

The types of care provided are changing as well. Today's primary caregivers frequently care for persons with high levels of disability, rather than shopping, transporting, and doing household chores for more able older adults. Approximately 30% of all disabled older adults receive no human assistance of any kind, making use instead of assistive devices such as microwave ovens and walkers (Spillman & Black, 2005).

Who Is a Caregiver?

The 1982 National Long Term Care Survey estimated that 2.2 million American households were providing assistance to disabled elderly relatives (Stone et al., 1987), and the prevalence now is substantially higher. The 2003 Caregiving in the U.S. survey put the number caring for someone age 65 or older at 9.5 million households—more than 18 million adults—and another 4.9 million households—9.5 million more adults—had done so within the previous year.

Estimates of the total number of caregivers vary from 3 million (Mack et al., 2005) to 52 million (U.S. Department of Health and Human Services, 1998), with discrepancies likely arising from differences in the populations studied and the way caregiving was defined. Studies also vary in their selection criteria, such as the age of the care recipient, the level and type of impairment, and the type and amount of assistance provided. These differences reflect scholars' and the public's ambiguity over who is a caregiver. Indeed, the 2001 AARP Caregiver Identification Study found that 44% of respondents who were providing informal care did not identify themselves as "caregivers" (Kutner, 2001). Cultural differences among ethnic groups have also been found to affect people's self-identification as caregivers as opposed to being family members simply fulfilling familial roles (Scharlach et al., 2006a).

Matching Interventions to Caregiver Needs

To determine what interventions will best assist a particular caregiver, it is useful to separate caregivers' functions into general types: hands-on care and close supervision, household care, and care coordination. In addition, caregivers both give and need social support. More than one type of care and one kind of intervention may be needed within the same care situation.

Hands-on care and close supervision involves physically demanding care responsibilities, and family caregivers have been found to benefit from various types of respite care (Dal Santo et al., 2007) and from customized training and assistance (Mittelman et al., 1995). *Household care,* including housework, meal preparation, shopping, transportation, and other basic tasks, may be eased by technologic developments such as microwave ovens, assistive devices, and programs such as grocery and meal delivery and paratransit services. *Care coordination* involves obtaining information about resources; arranging for, monitoring, and paying for care; and responding to unmet needs—all responsibilities that might be made less burdensome with assistance from the NFCSP (Scharlach et al., in press). *Social and emotional support* is provided to some extent by all caregivers. In addition, caregivers themselves may experience emotional distress as a result of, for example, conflict with other family members, compassion fatigue, or changes in the care recipient's ability to function. Caregivers experiencing emotional effects are especially likely to utilize some form of counseling (Dal Santo et al., 2207). Cognitive behavioral psychoeducational support groups, for example, have been shown to be very effective in reducing anger and depression in family caregivers who are caring for older adults with dementia (Gallagher-Thompson et al., 2003).

The Family Context

The caregiving literature generally has considered family caregivers to be independent actors who provide unilateral assistance to objectified, dependent care recipients. But the care recipient's ability to perform "self-care" and give other tangible and intangible contributions to caregivers and other family members belies the ageist view of disabled older adults as objects requiring care. Actually, the care process is embedded within complex relationships and historic patterns of behavior and involves the entire social support network. Nearly half of disabled older adults have multiple family helpers (Wolff & Kasper, 2006), especially among nonwhites and Hispanics (Pinquart & Sorenson, 2005). Moreover, there is ample evidence that older adult impairment reverberates throughout the family system and that families can be a source of support as well as a source of additional stress for both caregivers and care recipients (Scharlach et al., 2006b; Semple, 1992).

The costs and benefits of caregiving are determined not only by the care recipient's needs, but also by family relationships and norms (Archbold et al., 1990). These result from lifelong structural factors, including hierarchies of privilege associated with gender, social class, sexual orientation, race, and ethnicity. Moreover, in contrast to the familiar emphasis on caregiver burden, caregivers frequently say that the rewards exceed the costs involved (Kane & Penrod, 1993; Scharlach, 1994), contending that caring for a loved one affirms personal and family values, strengthens family bonds, teaches life lessons, and creates stories and myths that contribute to personal resilience and development. For some families, maximizing benefits such as these may be more important than minimizing caregiver distress.

Care recipients also experience costs as well as benefits. Although caregiving scholarship seems to be more concerned about the effect of care on the caregiver, caregiver characteristics clearly influence the care recipient's well-being. For example, while caregiver employment has primarily been considered to be a problem for the caregivers, their care recipients are more likely to experience difficulties such as service problems and unmet care needs (Scharlach et al., in press).

Integrating Caregiver and Long-Term Care Policies

Caregiving and long-term care policies currently are separate, with caregiving public policy measures set out in Title III-E of the Older Americans Act, the Family and Medical Leave Act, and state caregiver programs, and long-term care policy primarily controlled by Medicaid, Medicare, and state and local community-based long-term care programs. In practice, however, policy and programs are inseparable. Indeed, the explicit rationale behind Title III-E and other caregiver support policies and programs is to enable families to provide care for people with disabilities, thereby reducing the likelihood of their needing more intensive residential care, which has associated public expenditures (Administration on Aging, 2004). The Centers for Medicare and Medicaid Services (CMS) established a Caregiver Workgroup that meets quarterly and includes representatives of caregiver, aging, and disease-specific organizations; federal agencies; employers; and others. However, fragmented service delivery systems, conflicting financing models, and inadequate continuity of care hamper policy integration.

Long-term care policies, such as Medicaid policies on home care, inevitably affect caregivers. Some community-based long-term care programs, such as adult day care, have been found to have a greater effect on caregivers than on older adult participants. Moreover, current federal and state efforts to "rebalance" the long-term care system by reducing access to nursing home care, prompted by cost-saving efforts and the Supreme

Court's 1999 Olmstead decision (*Olmstead v. L.C.*) requiring states to place qualified people with mental disabilities in communities rather than institutions, likely will increase demands on families and other informal supports. Rebalancing plans envision providing increased support to community-based long-term care services, but cost-saving expectations and prior experience in deinstitutionalizing people with chronic mental illness suggest that these measures may not be able to offset the added stress on families and communities.

The distinction between family caregiving and formal care is even becoming ambiguous with the advent of Cash and Counseling and other Medicaid waiver programs that allow disabled adults to use Medicaid funds to pay family members for providing care that otherwise might be provided by paraprofessionals. Policymakers will have to determine whether informal caregivers who provide skilled or semiskilled care are entitled to basic worker protections, including time off, disability insurance, and adequate compensation, and whether they will be expected to meet basic standards in the amount and quality of care they provide.

Although the goal of integrating caregiver and long-term care policy seems rather straightforward—providing for adequate older adult care and well-being without undue hardship for family members—it includes challenging policy dilemmas that involve societal norms about family members' roles when an older adult relative is ill. A number of recent efforts (Eckenwiler, 2007; Levine, 2006; World Health Organization, 2002) have documented unresolved issues such as:

- Whether adequate long-term care is a right, and, if so, of whom—all older adults or only those who meet certain criteria?
- How much care families should be expected to provide. As of 2005, 30 states had filial responsibility laws requiring adult children to provide care to impoverished parents. Section 4400 of the California Family Code, for example, allows elderly parents to sue their adult children for financial support (Wise, 2002).
- How much caregiver distress is too much? Is relief from distress a right of all caregivers, or only of those who suffer tangible or intangible costs that reach some vaguely defined sociocultural level? Should caregivers who experience "undue hardship" be entitled to some form of residual compensation?
- Whose needs predominate when care recipient well-being conflicts with caregiver well-being? Recent public policies, such as the CMS's New Freedom Initiative, the Health Insurance Portability and Accountability Act, and the Cash and Counseling program, are increasingly recognizing the rights of persons, including those with disabilities, to make decisions, control resources, and protect the privacy of their health information, but they pay little or no attention to their potential effect on families.

Promising Private-Sector Developments

A central emphasis in caregiving and long-term care policy for the past 25 years has been on convincing Americans that they will need long-term care but cannot expect the government or their families to provide it. Nevertheless, private-sector responses to the needs of caregivers and disabled older adults have received relatively little scholarly attention. Family caregivers are directly affected by private-sector initiatives such as efforts to organize and regulate the home care workforce, the development of private long-term care insurance products, employer sponsorship of elder care programs and benefits, and the dramatic growth in assisted living facilities.

Technologic innovations may ease caregiving by making information more accessible and reducing the need for hands-on care. New Web sites offering information and social networking for family caregivers include www.caregiving.com, www.caring.com, www.care.com, and www.strengthforcaring.com; some evidence suggests that online caregiver support can reduce caregiver strain and depression (Beauchamp et al., 2005). Videophones and other devices that enhance communication between caregivers and care recipients and among multiple caregivers (Parker Oliver et al., 2005) are promising advances, as are technologic instruments and devices that can be used at home (Smith, 1996). "Smart homes" reduce the need for hands-on care with supportive features such as stoves that shut themselves off, toilets customized to individual hygienic needs, mobility supports such as handrails that adjust automatically to the correct height, and home monitoring systems. (See "Technology and Web-Based Support" on p. 75.)

Looking Ahead

Families are changing at a dizzying pace. Changes in family composition, cultural diversity, geographic mobility, and societal norms, coupled with increasing numbers of older adults living with high levels of disability, are changing how caregiving for older adults is balanced among families, informal networks, and formal supports. Social policy, practice models, and empirical research have not kept pace with these changes. This country has yet to develop a comprehensive, integrated, long-term care system that views informal caregivers both as care partners and as service recipients in their own right. Moreover, recent policy changes designed to reduce government expenditures put families at risk for having to take on even greater care responsibilities.

For better and for worse, communication and technologic interventions are gradually replacing some forms of direct human contact. It is still unclear whether older adults and their caregivers will become more isolated or whether new social contracts within families and between families and society will arise, rooted in the belief that even disabled older adults have a contribution to make, that they deserve to have their basic needs met, and that families should not be solely responsible for meeting those needs.

We have come a long way in the past 40 years. We still have a long way to go.

References

AARP & The Travelers Foundation. (1988). *A national survey of caregivers: Final report*. Washington, DC: Author.

Abel, E. K. (1986). Adult daughters and care for the elderly. *Feminist Studies*, *12*(3), 479–497.

Administration on Aging, U.S. Department of Health and Human Services. (2004). *The Older Americans Act. National Family Caregiver Support Program (Title III-E and Title VI-C). Compassion in action*. Washington, DC. Retrieved from http://www.aoa.gov/prof/aoaprog/caregiver/careprof/progguidance/resources/FINAL%20NFCSP%20Report%20July22,%202004.pdf14

Archbold, P. G. (1983). Impact of parent-caring on women. *Family Relations*, *32*(1), 39–45.

Archbold, P. G., et al. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health*, *13*(6), 375–384.

Beauchamp, N., et al. (2005). Worksite-based Internet multimedia program for family caregivers of persons with dementia. *Gerontologist*, *45*(6), 793–801.

Brodaty, H., et al. (1994). Quasi-experimental evaluation of an educational model for dementia caregivers. *International Journal of Geriatric Psychiatry*, *9*(3), 195–204.

Brody, E. M. (1966). The aging family. *Gerontologist*, *6*(4), 201–206.

Brody, E. M. (1985). The Donald P. Kent Memorial Lecture. Parent care as a normative family stress. *Gerontologist*, *25*(1), 19–29.

Cantor, M. H. (1991). Family and community: Changing roles in an aging society. *Gerontologist*, *31*(3), 337–346.

Dal Santo, T. S., et al. (n.d.). Caregiver service use and the National Family Caregiver Support program. Unpublished manuscript.

Dal Santo, T. S., et al. (2007). A stress process model of family caregiver service utilization: Factors associated with respite and counseling service use. *Journal of Gerontological Social Work*, *49*(4), 29–49.

Eckenwiler, L. (2007). *Caring about long-term care: An ethical framework for caregiving*. Washington, DC: Center for American Progress. Retrieved from http://www.americanprogress.org/issues/2007/07/pdf/caregiving_report.pdf

Gallagher-Thompson, D., et al. (2003). Tailoring psychological interventions for ethnically diverse dementia caregivers. *Clinical Psychology: Science and Practice*, *10*(4), 423–438.

Kane, R. A. , & Penrod, J. D. (1993). Family caregiving policies: Insights from a longitudinal study. In S. H. Zarit et al. (Eds.), *Caregiving systems: Informal and formal helpers* (pp. 273–292). Hillsdale, NJ.

Kane, R. A., & Penrod, J. D. (1995). Toward a caregiving policy for the aging family. In R. A. Kane & J. D. Penrod (Eds.), *Family caregiving in an aging society: Policy perspectives* (pp. 144–170). Thousand Oaks, CA: Sage.

Kiecolt-Glaser, J. K., et al. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic Medicine*, *53*(4), 345–362.

Kutner, G. (2001). *AARP caregiver identification study*. Washington, DC: AARP. Retrieved from http://assets.aarp.org/rgcenter/post-import/caregiver.pdf

Levine, C. (2006). *An ethical framework for New York State policy concerning family caregivers*. New York: United Hospital Fund. Retrieved from http://www.uhfnyc.org/usr_doc/Ethical_Framework_final.pdf

Lifespan Respite Care Act of 2006, Pub. L. No. 109-442, 120 Stat. 3291 (2006).

Mace, N. L., & Rabins, P. V. (Eds.) (1981). *The 36-hour day: A family guide to caring for persons with Alzheimer's disease, related dementing illnesses, and memory loss in later life* (1st ed.). Baltimore, MD: Johns Hopkins University Press.

Mack, K., et al. (2005). *A decade of informal caregiving*. Washington, DC: Center on an Aging Society, Georgetown University.

Mittelman, M. S., et al. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. *Gerontologist*, *35*(6), 792–802.

National Alliance for Caregiving & AARP. (1997). *Family caregiving in the U.S. Findings from a national survey: Final report*. Retrieved from http://www.caregiving. org /data/Family%20Caregiving%20in%20the%20US.pdf

National Alliance for Caregiving & AARP. (2004). *Caregiving in the U.S.* Retrieved from http://www.caregiving.org/data/04finalreport.pdf

Olmstead v. L. C. (98-536) 527 U.S. 581 (1999).

Parker Oliver, D. R., et al. (2005). The usability of videophones for seniors and hospice providers: A brief report of two studies. *Computers in Biology and Medicine*, *35*(9), 782–790.

Parsons, T., & Bales, R. F. (Eds.). *Family, socialization and interaction process*. Glencoe, IL: The Free Press.

Pearlin, L. I., et al. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, *30*(5), 583–594.

Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *Gerontologist*, *45*(1), 90– 106.

Scharlach, A. E. (1994). Caregiving and employment: Competing or complementary roles? *Gerontologist*, *34*(3), 378–385.

Scharlach, A. E., et al. (1991). *Elder care and the work force: Blueprint for action*. Lexington, MA: Lexington Books.

Scharlach, A. E., et al. (2006a). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work*, *47*(1–2), 133–156.

Scharlach, A. E., et al. (2006b). Family conflict as a mediator of caregiver strain. *Family Relations*, *55*(5), 625–635.

Scharlach, A. E., et al. (in press). Assistance received by employed caregivers and their care recipients: Who helps care recipients when caregivers work full-time? *Gerontologist*.

Semple, S. J. (1992). Conflict in Alzheimer's caregiving families: Its dimensions and consequences. *Gerontologist*, *32*(5), 648–655.

Shanas, E., & Streib, G. F. (Eds.). (1965). *Social structure and the family: Generational relations*. Englewood Cliffs, NJ: Prentice-Hall.

Silverstone, B., & Hyman, H. K. (1976). *You and your aging parent: The modern family's guide to emotional, physical, and financial problems* (1st ed.). New York: Pantheon Books.

Smith, C. E. (1996). Quality of life and caregiving in technological home care. *Annual Review of Nursing Research*, *14*, 95–118.

Spillman, B. C., & Black, K. J. (2005). *Staying the course: Trends in family caregiving* (Pub. No. 2005-17). Washington, DC: AARP Public Policy Institute. Retrieved from http://assets.aarp.org/rgcenter/il/2005_17_caregiving.pdf

Stone, R., et al. (1987). Caregivers of the frail elderly: A national profile. *Gerontologist, 27*(5), 616–626.

Subcommittee on Human Services. House Select Committee on Aging. (1988). *Exploding the myths: Caregiving in America. A study by the Subcommittee on Human Services of the Select Committee on Aging. House of Representatives, Second Session* (House-Comm-Pub-100-665). Washington, DC: U.S. House of Representatives. Retrieved from http://eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/1e/07/04.pdf

Troll, L. E. (1971). The family of later life: A decade review. *Journal of Marriage and the Family, 33*(2), 263–290.

Troll, L. E. (1982). Myths and themes about elders and their families. *Generations, 7*(5), 42.

U.S. Department of Health and Human Services. (1998). *Informal caregiving: Compassion in action*. Retrieved from http://aspe.hhs.gov/daltcp/Reports/carebro2.pdf

Wise, K. (2002). Caring for our parents in an aging world: Sharing public and private responsibility for the elderly. *New York University Journal of Legislation and Public Policy, 5*(2), 563–598.

Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *Gerontologist, 46*(3), 344–356.

World Health Organization. (2002). *Ethical choices in long-term care: What does justice require?* Retrieved from http://www.who.int/mediacentre/news/notes/ethical_choices.pdf

Andrew Scharlach is Kleiner Professor of Aging and director of the Center for the Advanced Study of Aging Services at the School of Social Welfare, University of California at Berkeley.

Reprinted with permission from the *American Journal of Nursing*. This article was first published as a supplement to the September 2008 issue of the *American Journal of Nursing*. Continuing education contact hours are available to nurses at www.NursingCenter.com/ajnfamilycaregivers.

Address correspondence to author at scharlach@berkeley.edu.