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**Family Caregiving: Contemporary Trends and Issues**

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## **Family Caregiving: Contemporary Trends and Issues**

### **Introduction**

Family caregiving in adulthood, which until recently was relatively “invisible” family work (Daniels, 1987), is now a fast-growing public as well as private issue. It seems paradoxical that the years characterized by family developmentalists as “postparental” and “empty nest” may be the ones when caregiving for dependents becomes of such intense concern. Families have always been the primary source of emotional, financial, and instrumental support for human beings during our inevitable times of dependency--e.g., during the physical and social immaturity of infancy, childhood, and adolescence; and during the acute illnesses, health crises, rehabilitation following accidents, and extended periods of disability that can follow the onset of a chronic mental or physical illness or condition at any age. What has radically changed during the last century is that the global load of family dependency has begun to shift from meeting the needs of young dependents to addressing the growing needs of older dependents. Persons born during the last few decades can expect to live more years with a parent over the age of 65 (and at an increased risk of dependency) than with a child under the age of 18 (Watkins, Menken, & Bongaarts, 1987). Thus, caregiving provided to family members during later life can often exceed caregiving provided to younger family members in both intensity and duration.

The focus of this chapter is to provide an overview of current theoretical and empirical understanding of family caregiving in later life families. We begin with a brief description of the demographic and public policy trends that lead us to expect a continuing increase in informal caregiving. As part of this description, we provide new information from a U.S. national survey of adults regarding the incidence and transitions into and out of various types of family caregiving across a five-year period. We then describe some contemporary theoretical perspectives that

inform research on family caregiving, and briefly summarize what we now know about the determinants and consequences of providing care. Finally, we discuss directions for future family caregiving research.

### **The Growth of Family Caregiving: Demographic and Public Policy Trends**

Several social demographic trends are converging to increase the likelihood that midlife and older adults will become family caregivers (and family care recipients):

Human life expectancy is increasing and the U.S. and world population is aging. There has been a dramatic increase in life expectancy for men and women of all race/ethnic groups during the twentieth century. In 1900, years of life expectancy at birth for white males and females in the U.S. were 46.6 years and 48.7 years, respectively. The comparable (and notably lower) rates for males and females of all other races were 32.5 years and 33.5 years, respectively (U.S. Bureau of the Census, 1975: Series B 107-115). By 1994, a white male child at birth could expect to live, on average, 73.2 years; a white female child, 79.6 years. A nonwhite male born in 1994 might expect a life of 67.5 years, while a nonwhite female child born in 1994 had a life expectancy of 75.8 years (U.S. Bureau of the Census, 1996: No. 118). This represents an increase in life expectancy of more than 50% for whites and more than 100% for nonwhites in less than one century. At all ages, mortality rates overall have been declining. Fewer deaths occur during infancy, childhood, and young adulthood now than ever before. More of the population are surviving to become elders. The fastest growing age subpopulation in the U.S. now is the group aged 85 and older (the “oldest-old”) (U.S. Bureau of the Census, 1996: No. 14).

Additionally, the elderly constitute a growing proportion of the population in the U.S. and worldwide. While in 1900 only about 4% of the U.S. population was aged 65 and older (U.S.

Bureau of the Census, 1975: Series A 119-134), by 1995, 12.8% of the population were elders (U.S. Bureau of the Census, 1996: No. 14), and projections suggest that by 2050 about one in five persons will be age 65 and older (U.S. Bureau of the Census, 1996: No.17).

Chronic illnesses and health conditions that can result in long-term disability and need for care have replaced infectious diseases as the major public health concern. A major transformation in public health has occurred during the twentieth century. While in 1900 the majority of deaths were caused by infectious diseases and other acute conditions (e.g., typhoid, diphtheria, pneumonia, whooping cough, tuberculosis), as we approach the end of the twentieth century improvements in sanitation, water quality, inoculations, antibiotics, and acute care have dramatically curtailed the number of deaths due to acute conditions at all ages. As noted above, this has helped drive life expectancy up (Pol & Thomas, 1992).

Concomitant with increased life expectancy has come the greater likelihood that persons will live to ages where more long-term chronic illnesses and health conditions occur--e.g., diabetes, arthritis, musculoskeletal disorders, hearing impairment, vision impairment, heart disease, kidney disease. The major causes of death are now heart disease, cerebrovascular disease, and cancer--diseases which often include an extended period of disability and need for caregiving before death (Verbrugge, 1989; Biegel, Sales, & Schulz, 1991).

Socioeconomic inequalities in health in the U.S. are growing. One of the most consistent predictors of health is socioeconomic status (SES) (Adler, Boyce, Chesney, Folkman, & Syme, 1993; Feinstein, 1993). Lower SES persons tend to have more physical and mental illnesses and die at younger ages than higher SES persons. The reasons for these differences are not totally understood. Research to date suggests that disparities in life stress, social support, perceived

control, work environments, neighborhood environments, and health habits that favor the advantaged over the disadvantaged help to account for these inequalities (Adler et al., 1993; Feinstein, 1993; House, et al., 1994; Marmot et al., 1991; Marmot, Ryff, Bumpass, Shipley, & Marks, 1997).

In spite of an overall decline in death rates, socioeconomic differences in mortality rates have actually increased in recent decades in the U.S. (Pappas, Queen, Hadden, & Fisher, 1993), reflecting a widening gap between the richest and the poorest (Danziger & Weinberg, 1994). The size of disparities in health by SES are largest in the middle adulthood years, but continue to be significant well into older age (House et al., 1990, 1994; Longino, Warheit, & Green, 1989). A disproportionate number of the socioeconomically disadvantaged are women and minorities (Longino et al., 1989). As a larger proportion of the population experiences relative socioeconomic disadvantage and its accompanying health disadvantage, often accumulating since childhood, we might expect rates of morbidity at young, middle, and older adult ages to increase in the future. This trend would lead us to project an increased need for earlier and more intense family care.

Divorce rates have increased, rates of nonmarrying have increased, and remarriage rates have decreased, resulting in more adults reaching middle adulthood and older adulthood without a spouse to help with potential care needs. Even though life expectancy has increased for both men and women such that widowhood for intact couples comes at older ages, a growing proportion of the population is expected to spend middle adulthood and older age unmarried. Uhlenberg and his colleagues (Uhlenberg, Cooney, & Boyd, 1990) estimated that among women born in the 1950s, approximately one in three will be unmarried at age 50 and about one in two

will be unmarried at age 65. Since a spouse is usually the first person called upon to provide caregiving support (Cantor, 1979), if a spouse is not available more elders will turn to adult children, other relatives, and nonkin when they have caregiving needs.

Fertility rates have declined resulting in fewer potential adult child caregivers for aging parents. Contemporary women of childbearing age, on average, are having fewer children than older cohorts of women did, and a growing proportion of them are bearing only one child or remaining childfree (May, 1995; Sweet & Bumpass, 1987). This demographic trend in a few decades will result in fewer children for the aged to rely upon for help with care (Himes, 1992). More only children will shoulder care alone. Smaller sibships will result in more all-male (or only male) sibships, which may necessitate that more men become caregivers for parents. Siblings, nieces, and nephews of elders may also be called upon to take a more integral part in caregiving for elders.

A larger proportion of women are employed at all ages. Women have been the traditional labor pool of caregivers. Now that more women are working longer hours and more continuously throughout the adult life course (Bianchi & Spain, 1986), fewer full-time homemakers are available to assume full-time caregiving responsibility for impaired elders. A large proportion of contemporary caregivers do combine caregiving with employment (Marks, 1996; Stone, Cafferata, & Sangl, 1987), yet this often leads to role conflict and stress (Brody, 1981; Stone et al., 1987; Seccombe, 1992; Scharlach & Boyd, 1989). Additional family members, male as well as female, are likely to be increasingly called upon to share the caregiving load of employed caregivers.

Health care policy (both private and public) increasingly favors home care vs. institutional

care, intensifying the need for family caregiving. Americans have always been loathe to institutionalize their elders. During the last several decades only about 5% of Americans over 65 have been found to be residing in an institution at any given time (Sweet & Bumpass, 1987; Soldo & Freedman, 1994), and it has been estimated that approximately 80% of the care needs of disabled elders are provided for by family members (Soldo & Freedman, 1994). Private health care policies provide strong incentives and pressures to maintain home care as long as possible, even in the face of major disablement. Health care policies, both private and public (e.g., Medicare), have put regulations in place that limit hospital stays and send people home sooner and sicker from hospital episodes (Biegel, Sales, & Schulz, 1991). Mental health care in the U.S. also encourages community-based care rather than institutional care. This care also falls squarely on the shoulders of family members.

### **Toward a Definition of Family Caregiving**

There is no single agreed-upon definition of family caregiving (Stone, 1991). It has been difficult to draw a definitive line between the routine activities of social support family members regularly engage in and those extraordinary activities that constitute something different and therefore fall into another related, yet distinguishable category that might be labeled “caregiving.” Undoubtedly, any determination regarding where the line between routine and extraordinary care exists is an arbitrary one.

It is useful to keep in mind that the range of care and support provided between family members (and friends) is a wide-ranging continuum. At one end there is the routine exchange of emotional support, advice, and information. Family members often also voluntarily provide each other with financial support--often in the form of gifts and loans, but additionally in the form of

helping with payment for particular needs, such as education, child care, health insurance, vacations, a down payment on a home, etc. An additional category of social support family members provide to each other is instrumental support. Instrumental support is generally defined to include help with such activities as transportation, shopping, home maintenance, housework, and personal care. Instrumental support can often be voluntarily provided to a family member who could well do these tasks for him or herself, and in these cases it is usually considered under the rubric of “social support” by current family studies research.

By contrast, there are times when a family member becomes functionally disabled by a mental or physical health condition. Functional health status is one of several dimensions of health status that can be measured (Patrick & Erikson, 1993). Functional health status refers to the amount of difficulty a person has doing their routine activities of daily living. For purposes of measuring functional health status, gerontological researchers developed measures that assess whether adults can carry out two levels of normal adult activities (Jette, 1996; Weiner, Hanley, Clark, & Van Nostrand, 1990). The most basic activities of daily living (BADLs or ADLs) are bathing, eating, dressing, walking, getting in and out of bed, and getting around inside the house. Persons who have difficulty doing these things are considered to have a major functional disability. At the next level of difficulty are instrumental activities of daily living (IADLs), which include preparing meals, light housework, using the telephone, taking medications, managing finances, shopping, and getting around outside the home. Persons who indicate having some level of difficulty with these activities are considered to have a more moderate level of disability.

Functional disability due to chronic mental and physical conditions is currently tracked by public health researchers using assessments of ADL and IADL limitations. Beginning at middle

age, rates of chronic mental and physical conditions become substantial and continue to increase; concurrently, at each older age, rates of ADL and IADL limitation also increase (Verbrugge, 1989; Jette, 1996).

There are significant gender and SES differences in rates of chronic health conditions and rates of functional disability (Verbrugge, 1989; Longino et al., 1989). Women report more chronic conditions (morbidity) overall than men. However, the types of conditions reported by men and women vary. Men tend to report more life-threatening conditions (e.g., heart disease, cerebrovascular disease, atherosclerosis, liver disease, and lung disease) and women tend to report more nonfatal but long-disabling conditions (e.g., arthritis, orthopedic impairment, cataracts, gastrointestinal conditions) (Verbrugge, 1989; Jette, 1996). Thus, while women live longer than men, they live more disabled years than men, and they live a larger proportion of their lives disabled (and needing caregiving) than men (Verbrugge, 1989). Additionally, persons of lower SES, which include an overrepresentation of ethnic minority group members, report higher rates of functional disability at midlife and older ages (Longino et al., 1989; Markides & Black, 1996).

Since the need for care often derives from disablement, one current approach to measuring caregiving is based on the need for help due to functional disability. In this view, caregiving is *extraordinary help with routine activities of daily living which is provided to a family member or friend due to a long-term mental or physical condition, illness, or disability that makes it difficult or impossible for them to take total care of themselves.*

It is obvious that this definition omits caregiving in the form of emotional support and financial support. These kinds of support are often provided in abundance along with the hands-

on instrumental help included in the above definition. Additionally, caregiving may be provided indirectly--i.e., by hiring others to provide care. The management role in caregiving is also important to consider (Soldo & Freedman, 1994). Employment of formal service providers, when utilized, is often done in conjunction with informal hands-on help.

### **The Prevalence of Family Caregiving in the U.S.**

With all its limitations, the above definition of caregiving has given researchers a start for estimating the national prevalence of family caregiving. Stone and her colleagues (1987) used data from the 1982-83 Informal Caregivers Study (ICS) to provide the first major profile of caregiving for the frail elderly in the U.S. The ICS included a sample of 1,924 caregivers representing 2.2 million persons caring for 1.6 million disabled elders. Caregivers who participated in this study were nominated by a national sample of elders aged 65 and older who reported difficulty with at least one ADL when they responded to the 1982 National Long-Term Care Survey of Medicare participants age 65 and older. Stone et al.'s (1987) analysis of ICS data revealed that those giving care for an elder with a major disability were predominantly women (72%). Three-quarters of the caregivers in the ICS shared a residence with the care recipient. Adult daughters made up 29% of the caregiving population, wives made up another 23%, husbands 13%. Approximately one-fifth of caregivers (one quarter of adult child caregivers) reported children under age 18 in the household. Nearly one in three caregivers overall were employed; about one in two adult child caregivers were employed. Almost one in ten caregivers reported they had left the labor force to provide caregiving help to a frail elder (Stone et al., 1987).

While Stone et al.'s (1987) analysis provided a solid and important national benchmark, it

had certain limitations in estimating the prevalence of informal caregiving. For example, it only examined caregiving for persons over age 65 and for those persons who had a severe functional impairment (requiring help with one or more basic activities of daily living). Additionally, caregiver participants in the ICS were nominated by care recipients; this may have biased the sample toward an overrepresentation of women to some extent, since there is evidence that care recipients are less likely to nominate an adult son for participation in a study. Respondents are more likely to view their sons and not their daughters as “too busy” to be imposed upon to participate in a survey (Horowitz, 1992).

An additional national prevalence study of caregiving was undertaken by Marks (1996) using data from the 1987-88 National Survey of Families and Households (NSFH). The NSFH conducted personal interviews with 13,008 persons who constituted a representative sample of noninstitutionalized adults age 19 and older in the U.S. (response rate was about 74%; see Sweet, Bumpass, & Call, 1988, for more design details). In Marks' (1996) analysis of the NSFH 1987-88 data, caregiving was inferred from affirmative responses to two questions. Respondents were asked about in-household caregiving first: “Does anyone living here require care or assistance because of a disability or chronic illness?” Additionally, respondents were queried: “Sometimes people help take care of relatives who are seriously ill or disabled, and who do not live with them. Have you provided such care at any time during the last 12 months?” Respondents who answered “yes” to either or both of these questions reported also the age and relationship to them of all the persons to whom they gave care. Five care recipient categories were created based on these responses: child (biological, adopted, step, or foster); spouse (current married or cohabiting partner); parent (biological, adopted, step, in-law), other kin (e.g., grandparent, sibling, aunt,

uncle, grandchild); and nonkin (friend, neighbor, ex-spouse).

Marks' (1996) analysis indicated that overall, about one in seven (15.9%) of the U.S. adult population aged 19 and older reported caregiving for someone as defined above. The results of this study also suggested that if the age of care recipients is not limited to the elderly and the definition of disability and caregiving activities is made less restrictive, a much larger proportion of men report being a caregiver (primary or secondary). The ratio of women to men in the Marks (1996) prevalence study was about 4:3--much less extreme than Stone et al.'s (1987) finding of 3:1.

Caregiving was found to peak in the midlife years. Across ages 35-64 about one in five women reported giving care. Men's caregiving rates also approached one in five during ages 50-64. At young-old ages (age 65-75) caregiving continued at significant rates for both men and women. Even among those 75 and older, about one in ten persons continued to report providing care.

About one-third of caregivers reported giving care for a nonelderly person (less than 65 years old). Caregiving for parents and spouses was significant, but additionally a considerable proportion of persons reported giving care for other relatives and a disabled child (Marks, 1996).

### **Family Caregiving Incidence and Transitions in the U.S. during a Five-Year Period**

About 82% of surviving respondents to the 1987-88 NSFH (Time 1; N=13,008) were also reinterviewed about 5 years later in 1992-93 (Time 2; N=10,008). During the reinterview respondents were asked even more directly than at Time 1 about in-household caregiving: "During the last 12 months have you, yourself, given anyone who was living with you at the time any help with personal care because of their long-term physical or mental condition, illness, or

disability?” Additionally, they were asked about out-of-household caregiving: “Sometimes because of a physical or mental condition, illness, or disability, people require the assistance of friends or relatives. During the last 12 months have you, yourself, given anyone not living with you at the time any help or assistance because of their health problem or disability?” For each of these questions, if an answer of “yes” was given, respondents were furthered queried, “What was the relationship to you of the person to whom you gave the most care?” On the basis of these answers, five care recipient categories were again created, and respondents were coded as appropriate for their in-household and/or out-of-household caregiving.

We know that the caregiving role is likely to change over time as persons cared for either get better, transfer to the care of another informal caregiver, transfer into institutional care, or die. To further our understanding of national patterns and prevalence of family caregiving, we used the NSFH data to examine additionally the transitions into and out of family caregiving over approximately five years. We differentiated caregivers who reported caregiving at the first interview into two groups: those who either *ended caregiving* (i.e., caregiver at Time 1, but not at Time 2), and those who *continued caregiving* (i.e., caregiver at Time 1 and also caregiver at Time 2). Additionally, we created a category for *new caregivers* (i.e., noncaregiver at Time 1, but caregiver at Time 2). We report a total *family caregiver* rate, which includes the proportion who reported any type of kin caregiving at Time 1 and/or Time 2, and also a *total caregiver* rate, which includes the proportion of adults who reported kin and/or nonkin caregiving at Time 1 and/or Time 2.

We do not claim that these estimates of caregiving incidence are precise for a number of reasons. First, sample attrition between waves resulted in a response rate of approximately 61%

of the original surviving sample population by Time 2 (74% X 82%). It is possible that respondents who were reinterviewed are a somewhat more select group in terms of stability and social responsibility conducive to caregiving than nonrespondents--therefore upwardly biasing our estimates of caregiving in the population. These data also do not allow us to construct an complete event history of caregiving transitions during this period. What is available is 1) a description of in-household caregiving at the time of interview in 1987-88 and caregiving out of the household during the last 12 months prior to 1987-88, and 2) information about caregiving in-household during the last 12 months prior to the 1992-93 interview and caregiving out-of-household during the last 12 months prior to the 1992-93 interview. It is very possible that some respondents also had a caregiving "spell" that both began and ended between the periods covered by the questions asked in the two interviews. Respondents having such a spell of caregiving would not be included in the incidence rates provided here. We also know that nonkin out-of-household caregiving was underreported in 1987-88, since the question only asked about caregiving to a family member (respondents volunteered reports of nonkin caregiving anyway!). In 1992-93, the question about out-of-household caregiving was not restricted to kin and, as a result, a much higher proportion of the population reported this type of caregiving. We have chosen to report nonkin caregiving here for two reasons. In many cases nonkin are "fictive kin" or as significant and close to respondents as blood kin, and therefore this type of caregiving should not be ignored. Additionally, as the burden of family caregiving enlarges, it is likely that multiple persons will more often become involved in caregiving for any one particular person. Tracking rates of nonkin caregiving in conjunction with rates of kin caregiving may begin to help us evaluate how nonkin are also helping to "fill in" to meet the needs for informal care (Cantor,

1979; Penrod, Kane, Kane, & Finch, 1995).

There was one more difference in the questioning between the two interviews of the NSFH; at the first interview respondents provided information about all persons (four was the maximum) for whom they provided care. About 2.6% of the population in 1987-88 reported that they were caregiving for more than one person in and/or out-of-household; those multiple reports are included in the statistics provided in Table 1 (e.g., someone might be providing care to both a parent and a spouse and would be included in the count for both relationship types). During the 1992-93 interview, respondents were only asked about the relationship to them of the person for whom they were providing the *most* care. Yet even during the reinterview, a nontrivial proportion (8.9%) of respondents reported giving care to both someone in the household and someone out-of-the household. In all but a few of these cases, care was provided to persons of different relationships (e.g., spouse in-household and parent out-of-household). These cases of dual care are also included in the rates provided in Table 1. With all of these caveats, these data provide the best estimates we have to date of U.S. national incidence and transitions in caregiving status over a period of approximately five years.

The results of our analysis provided in Table 1 indicate that the incidence of family caregiving over a five-year period among adult Americans is quite sizeable. Overall, almost two in five adults reported caregiving of some type (38.4%); about one in three men (33.4%) and over two in five women (43%). If we eliminate the people only reporting caregiving to nonkin and examine family caregiving alone, we find that about one in three U.S. adults reported a family caregiver role over a five-year period; 36.2% of women and 28.4% of men.

Even at young adult ages (19-34 in 1987-88, 24-39 in 1992-93), almost one in three

persons (31.8%) reported providing care at one or both times of measurement. At Time 2, we found that parent care was becoming more prevalent--12.1% of women and 7.8% of men reported parent care as they began to move closer to middle age. About one in eight persons (12.6%) reported transitioning into new care for other kin or non-kin at the reinterview.

Across the midlife years we find substantial caregiving rates. For the young midlife age group 35-49 in 1987-88, across the two time periods, we find that about one in two women (48.1%) and about one in three men (37.7%) reported some type of caregiving. Caregiving during these years of adulthood was predominantly for parents, with care for nonkin and other kin coming next in prevalence. A small minority provided care to a spouse or disabled child.

For the older midlife group aged 50-64 in 1987-88, similar overall rates are in evidence, with men's rates edging up slightly during these ages. Caregiving rates for parents begin to dip during the older midlife years, while caregiving rates for a spouse begin to increase. For those who were young-old adults (aged 65-74) in 1987-88, nearly two in five women (39.1%), and over one in three men (35.8%) played a caregiving role sometime during this five-year period for a disabled family member or friend. For the oldest age group studied here (75 and older) rates of caregiving were still significant; about one in four for both men (27.5%) and women (26.3%).

## **Theoretical Perspectives on Family Caregiving**

### *A Social Ecological Perspective on Caregiving*

The majority of research on family caregiving has focused exclusively on the caregiver-care recipient dyad. Yet family caregiving occurs amidst a complex social ecology. Recently, Kahana, Kahana, Johnson, Hammond, and Kercher (1994) have mapped out the components of this multifaceted ecology by elaborating a comprehensive family caregiving paradigm (see Figure

1). They propose that a more complete framework for considering family caregiving must include attention to both the personal caregiving context and the social caregiving context (see also Cantor, 1991).

The personal caregiving context Kahana et al. (1994) delineate includes both informal and formal dimensions. The informal dimension is comprised of family caregivers themselves (both major/primary and secondary), nonfamily caregivers, the care receiver, and the caregiver-care receiver dyad. Most research attention thus far has focused only on the primary caregiver, but increasing attention is being paid to the fact that other family members besides the primary caregiver often also get involved in care (Penrod et al., 1995; Stone et al., 1987). While women are most often the primary caregiver, men are more likely to be secondary caregivers (Stone et al., 1987). Although most research has focused on only family members providing care, our research results noted above suggest that nonfamily members need to be considered more consistently in telling the story of informal/family caregiving. In cases when relatives live at some distance, friends and neighbors may be important sources of help. In the social ecology paradigm, formal caregivers who provide care (often in conjunction with family caregivers) include paraprofessionals (paid helpers and agency workers) and professional caregivers (physicians, nurses, and social workers).

The social caregiving context also includes both informal and formal sectors. The informal sector includes the primary group of the nuclear family and extended family of the caregiver and care recipient. The implications for the entire family system when caregiving is taking place for one member of that system are just beginning to be considered (Beach, 1997; Cantor, 1992). Parent care provided by an adult daughter, for example, may well spill over into

relationships with husband, children, and siblings. Neighbor networks and friend networks also can provide social support, which has been found to moderate the burden of caregiving. At the formal sector level, service organizations (both medical and social) influence the course and consequences of family caregiving, as do societal institutions (including local, state, and national governments) and their policies and service provision (Kane & Penrod, 1995).

While it is important to take this larger perspective on family caregiving, the majority of caregiving research has thus far focused on the predictors of giving care and the consequences of caregiving. We examine theories related to these issues next.

#### *Theoretical Approaches to Understanding Why and Who Gives Family Care*

Biegel, Sales, and Schulz (1991) have recently suggested that theoretical approaches to understanding the motivation for caregiving fall into two major categories. Egoistic or self-serving motives are emphasized by the first group of explanatory schemes. For example, individuals may provide care to reap rewards such as payment (e.g., future inheritance), social approval, fulfilling social norms and role expectations, perpetuating one's genes (a sociobiological account), an internal sense of "mattering" (Pearlin, Aneshensel, Mullan, & Whitlatch, 1996), and/or to avoid punishments such as social censure, personal guilt, and experiencing uncomfortable indebtedness to another that is not repaid.

A second group of explanations focuses on altruism and empathy as motivators. These perspectives emphasize how humans are motivated to help others because of our capacity to take the perspective of the other. Taking the other's perspective, we experience the feelings of the other, which leads us to desire to respond in ways that will provide for the other's needs (Batson, 1991).

Additionally, Cicirelli (1983a, 1991, 1993) has suggested attachment as a motivator for caregiving, particularly caregiving to an aging parent. Using the attachment framework, he has posited that just as a young child is motivated to engage in “protective behavior” to preserve or restore the existence of the attachment figure (usually the parent), so might an adult child be motivated to protect and do what is possible to extend the life of a parent who is disabled and needs care. Secondary attachments across the life course to a spouse, other kin, and even other nonkin might also provoke similar protective behavior in the form of caregiving.

Studies of the social demographic predictors of giving care have yielded a theory of the “hierarchical substitution principle” (Cantor, 1979) for the choice of primary caregiver. A spouse is the first to be enlisted in family caregiving if available. Next in line is an adult daughter, followed by an adult son (Coward, Horne, & Dwyer, 1992). Proximity understandably plays a role in who becomes a caregiver; adult children living closer to a parent are more likely to become caregivers. Evidence for birth order effects, however, has not been found (Horowitz, 1985). Historically, unmarried children (especially daughters) were more likely to be enlisted than married children (Ikels, 1983). However, there is now some evidence that formerly married children (in contrast to never married children) may be somewhat less likely to become caregivers than married children, perhaps due to additional responsibilities they may carry alone for rearing children and self-support (Cicirelli, 1983b; Marks, 1996). When children are not available, siblings and other relatives (e.g., nieces, nephews, cousins), close friends, and neighbors may be enlisted. Formal services are turned to usually only as a last resort (Horowitz, 1985).

#### *Adaptation Models for the Consequences of Caregiving*

The majority of caregiving research has been devoted to describing the outcomes (mostly

negative) of caregiving on family caregivers. This research began with a somewhat atheoretical approach that focused on the measurement of *burden* experienced by family caregivers (Montgomery, 1989). Numerous studies in this tradition documented the considerable burden expressed by caregivers, particularly women caregivers (Miller & Cafasso, 1992), as measured by indicators of frustration, guilt, resentment, fatigue, and time strains.

Over time, more research considered caregiving from a family systems perspective. Caregiving has often been viewed as one instance of family stress and coping, and models such as the ABCX family crisis model (Hill, 1949), the double ABCX model of family adaptation (McCubbin & Patterson, 1983), and the family systems resilience, adjustment and adaptation model (McCubbin & McCubbin, 1993) have been used in this research. Additionally, Pearlin, Mullan, Semple, and Skaff (1990) suggested a related model of the stress process that has been applied to caregiving. In all of these theoretical frameworks, caregiving is considered a stressor that is expected to have implications (usually negative) for the caregiver's well-being. Moderators of the consequences of this stress include caregiving demand characteristics, caregiver financial and psychological resources, caregiver social support, and caregiver appraisal of the situation. Research in this tradition has slowly evolved from emphasis on the more caregiver role-specific outcome of burden to more general well-being considerations, including positive psychological well-being (e.g., life satisfaction), negative psychological well-being (e.g., depression, anxiety), and physical health (George & Gwyther, 1986; Biegel, Sales, & Schulz, 1991).

More recently, there has been an increased interest in better mapping the potential gains as well as strains of family caregiving (Kramer, 1997). A two-factor adaptational model of the

caregiving process has now been suggested (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Kramer, 1997), which takes both positive and negative well-being outcomes into account.

Kramer's (1997) version of a two-factor model (Figure 2) blends elements of the stress and coping model with elements of social exchange theory, role theory, and existentialism. This model accommodates the inclusion of a number of factors that a considerable body of research now suggests are important in helping determine the adaptation and well-being effects of caregiving for the caregiver. Background and context factors that may influence outcomes include care receiver characteristics (e.g., illness severity, type of illness, cognitive status, functional status, and problematic behavior) and caregiver characteristics (e.g., age, gender, relationship type, socioeconomic status, employment status, parental status, other role responsibilities), and attitudinal and effort variables (e.g., motives, values, goals). Intervening process factors include internal resources (e.g., coping styles, personal control, self-efficacy, health knowledge, hardiness) and external resources (e.g., social support, formal support), appraisal of role gain and strain (in the caregiver role, but also across the multiple roles the caregiver occupies). All of these factors are then linked to well-being outcomes, both positive and negative.

A voluminous multidisciplinary literature has accrued studying family caregiving and its consequences for caregivers during the last few decades. We can only provide a briefest of summaries here (see Horowitz, 1985; Given & Given, 1991; Chappell, 1990; Biegel, Sales, & Schulz, 1991, for useful reviews). Overall, a sizeable body of research now suggests that caregiving is associated with higher levels of depression and poor health (Schulz, Visintainer, & Williamson, 1990). Moderators of this relationship include care recipient's degree of impairment

(more impairment leads to more negative effects), care recipient's prognosis (poor prognosis is worse), onset of care recipient's illness (sudden is worse), caregiver's gender (evidence is inconclusive but, in general, it appears that women may be more distressed by caregiving), prior relationship with the care recipient (better prior relationship leads to less distress), caregiver's satisfaction with social support (more satisfaction helps reduce distress), caregiver's psychological resources (e.g., more sense of control and better coping strategies lead to less distress).

*A Life Course Approach to Caregiving: The Caregiving Career*

Another recent theoretical advance in caregiving research has been to incorporate a life course perspective on caregiving. This theoretical orientation suggests that caregiving be viewed as a life course role that one is likely to enter and exit one or more times during adulthood (Moen, Robison, & Fields, 1994; Suiitor & Pillemer; 1990). Following life course perspective principles (Elder, 1992), it becomes useful to consider the developmental timing of transitions into and out of the caregiver role, the intersection of other roles in relation to the caregiving role, the changing historical context for enactment of the caregiving role, and the cumulative patterns of caregiving across the life courses of varying birth cohorts (Moen, Robison, & Fields, 1994).

Not all caregiving follows the same "career" sequence. Some caregiving is relatively short term and the care recipient improves and returns to near-normal if not totally normal functioning (e.g., sometimes after major surgery or a nonfatal heart attack). However, in care for some conditions like Alzheimer's disease, AIDS, and terminal cancer, a certain sequence may occur. Pearlin and his colleagues (Pearlin, 1992; Pearlin & Aneshensel, 1994; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995) have outlined one prototypical "career of caregiving" (see Figure 3). The major stages within this typology include role acquisition (the transition into the

role of caregiving), role enactment (both in-home and possibly the transition to institutional care), and role disengagement (the cessation of caregiving, bereavement, and social readjustment following the death of the care recipient). By adding a more explicit temporal dimension, the caregiving career perspective allows researchers and practitioners to better differentiate needs and outcomes among caregivers that may be operative during different phases of caregiving.

### **Directions for Future Research**

Considerable progress has been made to bring the family caregiving role out of invisibility and into private and public awareness. Several social demographic trends that are leading to an increased need for family caregivers have aided this process and promise to continue to keep family caregiving at the forefront as a major social issue as far into the future as we can project.

We are now beginning to understand the considerable national prevalence and incidence of family caregiving, but many issues await continued development of caregiving theory and research. To better monitor the prevalence of caregiving and the need for care, it would be useful if additional theoretical attention was directed toward improved measurement of caregiving in large as well as small-study research. Currently, the definition adopted in this chapter, and in much national sample research, emphasizes instrumental help provided due to the functional disability of care recipients. The choice of this definition obviously underestimates family caregiving in the population, since it excludes consideration of such additional factors as financial support, emotional support, employment foregone to provide caregiving, and the arrangement and payment for formal caregiving services (Horowitz, 1985; Soldo & Freedman, 1994). Our knowledge of the full range of activities that constitute what caregivers provide for care recipients is truly quite sparse. Time diary research studies of caregivers--men and women--might be one

step in the direction of helping us to develop a more adequate understanding and definition of caregiving.

It is becoming increasingly likely that more than one person will share the load of informal caregiving for each disabled person. Very little work has been done to map the social networks of care recipients and how they converge to provide needed care (Penrod et al., 1995; Wolf, Soldo, & Freedman, 1996). Also, very few studies thus far have mapped the way formal caregiving services coincide and complement (or complicate) informal caregiving (Soldo & Freedman, 1994; Litwak, 1985; Cantor, 1991). The effects of different types of caregiving on care recipients has yet to be adequately explored. More dimensions of the social ecology of the caregiving system--formal and informal--need to be included in the caregiving research designs of the future (Kahana et al., 1994).

It is not easy to design research that can adequately assess the impact of various changes in social policies and laws on the experience of individuals, but it is essential that better evaluation studies of programs and policies that are designed to provide complementary support to caregivers be undertaken (Kane & Penrod, 1995). One of the biggest challenges of the twenty-first century will be to develop social policies that facilitate an optimal integration of public and private resources for families to draw upon in carrying out their caregiving commitments to a growing number of dependent family members. Information and understanding derived from family caregiving research is critical for forging the decisions that will shape these policies.

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Table 1  
 Weighted Percentage of U. S. Adults Who Reported Giving Continuous Care, Transitioning Out of Caregiver Status,  
 or Transitioning into Caregiver Status From 1987-88 to 1992-93 By Relationship Type of Care Recipient

Respondent Age 1987-88	Total Unweighted N	Caregiver to Child			Caregiver to Spouse			Caregiver to Parent			Caregiver to Other Kin			Caregiver to Nonkin			Caregiver to Kin or Nonkin %	Caregiver to Kin Only %
		% End	% Continue	% New	% End	% Continue	% New	% End	% Continue	% New	% End	% Continue	% New	% End	% Continue	% New		
19-34 years																		
Women	2503	1.2	.4	2.6	1.2	.0	1.5	4.4	1.6	12.1	5.8	1.2	7.4	.6	.1	6.8	40.9	35.6
Men	1717	1.1	.0	.8	.7	.1	2.5	2.6	.9	7.8	4.9	.9	6.2	.3	.1	4.8	29.3	26.1
Total	4220	1.1	.2	1.7	.9	.0	2.0	3.5	1.2	10.0	5.3	1.1	6.8	.4	.1	5.8	35.1	31.8
35-49 years																		
Women	1733	2.3	.9	3.5	3.2	.6	2.9	7.2	4.7	15.2	3.2	.8	5.5	.5	.1	7.9	48.1	40.6
Men	1153	1.8	.3	2.2	1.1	.3	3.9	5.1	1.8	13.8	2.5	.9	3.6	.2	.1	6.4	37.7	31.6
Total	2886	2.1	.6	2.8	2.1	.5	3.4	6.2	3.2	14.4	2.8	.9	4.5	.3	.1	7.2	43.0	37.0
50-64 years																		
Women	1005	2.3	1.3	3.5	2.8	.9	4.3	7.4	3.4	7.8	2.9	1.0	4.4	.8	.2	11.0	45.4	37.7
Men	592	1.9	.2	.7	3.3	.3	2.5	7.1	4.3	9.3	2.4	.7	2.7	.4	.0	5.2	35.6	29.1
Total	1597	2.1	.8	2.3	3.0	.6	3.5	7.3	3.8	8.5	2.7	.9	3.6	.6	.1	8.4	41.1	34.5
65-74 years																		
Women	526	1.4	.6	1.5	6.1	1.5	6.1	4.9	.8	.9	3.8	2.4	4.2	.4	.8	11.7	39.1	28.5
Men	283	3.8	.0	1.3	4.5	2.0	10.0	5.9	1.4	.8	1.6	.0	5.0	.4	.2	5.6	35.8	30.4
Total	809	2.5	.3	1.4	5.3	1.7	7.9	5.4	1.1	.8	2.8	1.3	4.6	.4	.5	8.9	37.6	29.2
75+ years																		
Women	253	1.4	.0	.9	4.4	2.2	2.8	.0	.0	.0	4.0	.5	5.5	1.3	.0	4.7	26.3	20.6
Men	95	2.9	.0	.0	9.4	1.1	3.5	1.6	1.2	.9	1.4	.0	1.3	.0	.0	4.9	27.5	22.1
Total	348	1.9	.0	.6	6.1	1.8	3.1	.6	.4	.3	3.1	.3	4.0	.8	.0	4.8	26.8	21.0
Total																		
Women	6020	1.7	.7	2.9	2.6	.6	2.9	5.7	2.6	10.5	4.2	1.2	5.9	.6	.2	8.3	43.0	36.2
Men	3840	1.7	.1	1.2	1.8	.4	3.6	4.4	1.8	9.0	3.4	.8	4.6	.3	.1	5.4	33.4	28.4
Total	9860 <sup>a</sup>	1.7	.4	2.1	2.2	.5	3.2	5.1	2.2	9.8	3.8	1.0	5.3	.5	.1	6.9	38.4	33.1

Source: National Survey of Families and Households, primary respondents, 1987-88 and 1992-1993 (N=9,860).

Note: Percentages across care recipient types can total more than subcomponents because 2.6% of respondents at Time 1 and 8.9% of respondents at Time 2 reported providing care to more than one person in and/or out of their household, and also because of rounding error.

<sup>a</sup> Respondents missing data on age or caregiving were excluded.

	SPATIAL AXIS: WHO? (key individuals and groups relevant to caregiving)	TEMPORAL AXIS: WHEN? (time frames relevant to caregiving)	TRANSACTIONAL ANALYSIS: WHAT? (processes involved in caregiving)
PERSONAL CAREGIVING CONTEXT (individual level)	Informal Family caregivers Major family caregiver (c.g., spouse or adult children) Secondary family caregiver (c.g., other family) Nonfamily caregivers Friends, neighbors as caregivers  Care receiver  Caregiver-care receiver dyad	Length/stage of illness  Age/life stage  Length of caregiving  Cohort/historical influences	Social Support Perceived/received Given/withheld Negative social interactions
	Formal Paraprofessional caregivers Paid helper (supervised by care receiver or family) Agency worker (supervised by formal organization)  Professional caregivers Physician Nurse Social worker	Length of employment  Length of service  Cohort/historical influences	Compliance  Work of caregiving  Exchange
SOCIAL CAREGIVING CONTEXT (system or group level)	Informal Primary group Nuclear family Extended family  Informal group Neighbor network Friend network	Life stage  Cohort/historical influences	Cohesion/conflict  Social integration
	Formal Formal group/service delivery system Service organization--medical Service organization--social  Societal institutions Local government State government National government	Length of service  Cohort/historical influences	Financing/access provision  Control  Legislation  Enforcement

Figure x.1. Spatial, Temporal, and Transactional Dimensions of the Caregiving Paradigm

From "Developmental challenges and family caregiving," by E. Kahana, B. Kahana, J. R. Johnson, R. J. Hammond, and K. Kercher, 1994, in E. Kahana, D. E. Beigel, and M. L. Wykle (Eds.), *Family caregiving across the lifespan*, p. 3-41. Copyright 1994 by Sage Publications. Reprinted with permission.

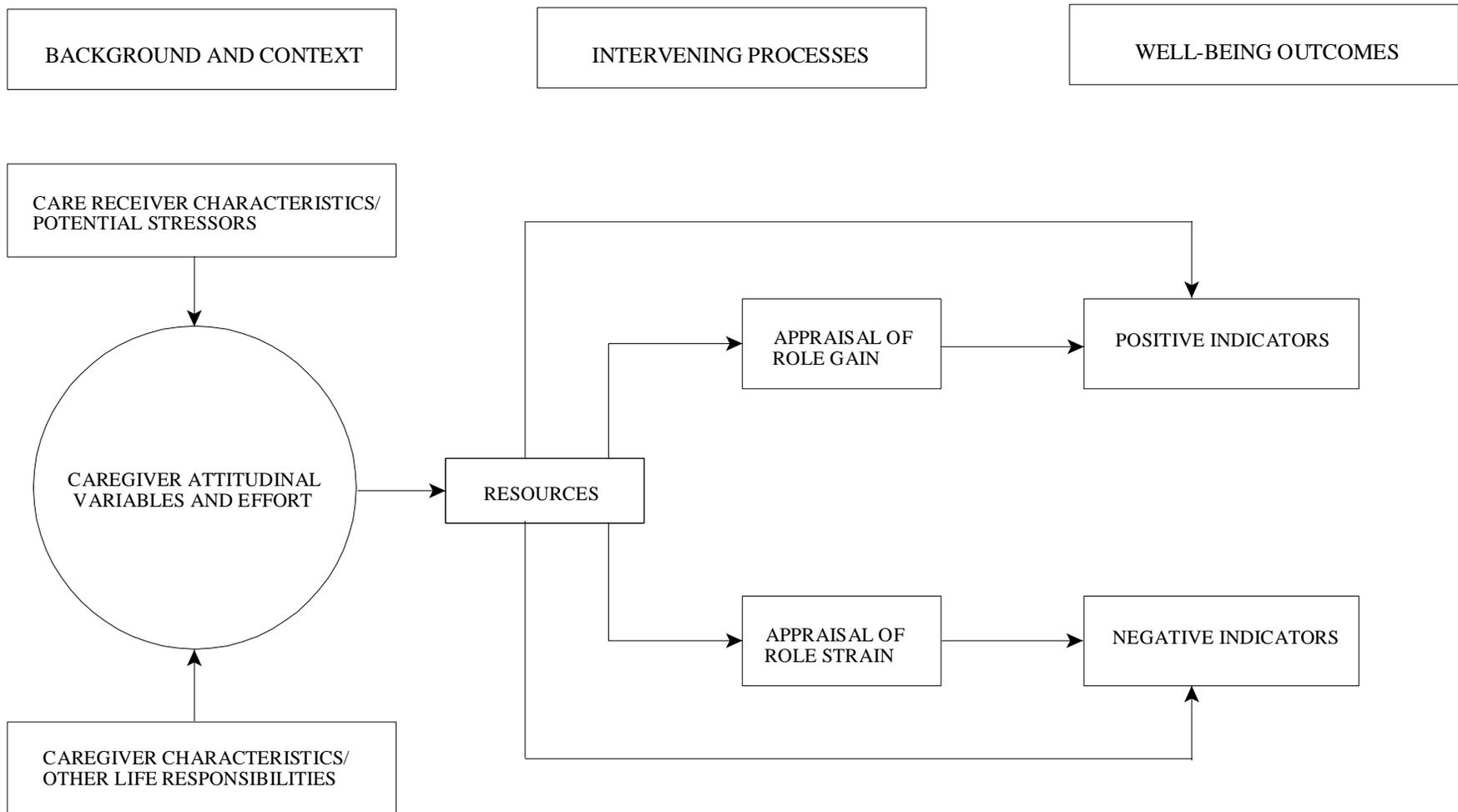


Figure x.2. A conceptual model of caregiver adaptation.

From "Gain in the caregiving experience: Where are we? What next?," by B. Kramer, 1997, *The Gerontologist*, 37, p. 218. Copyright 1997 by the Gerontological Society of America. Reprinted with permission.

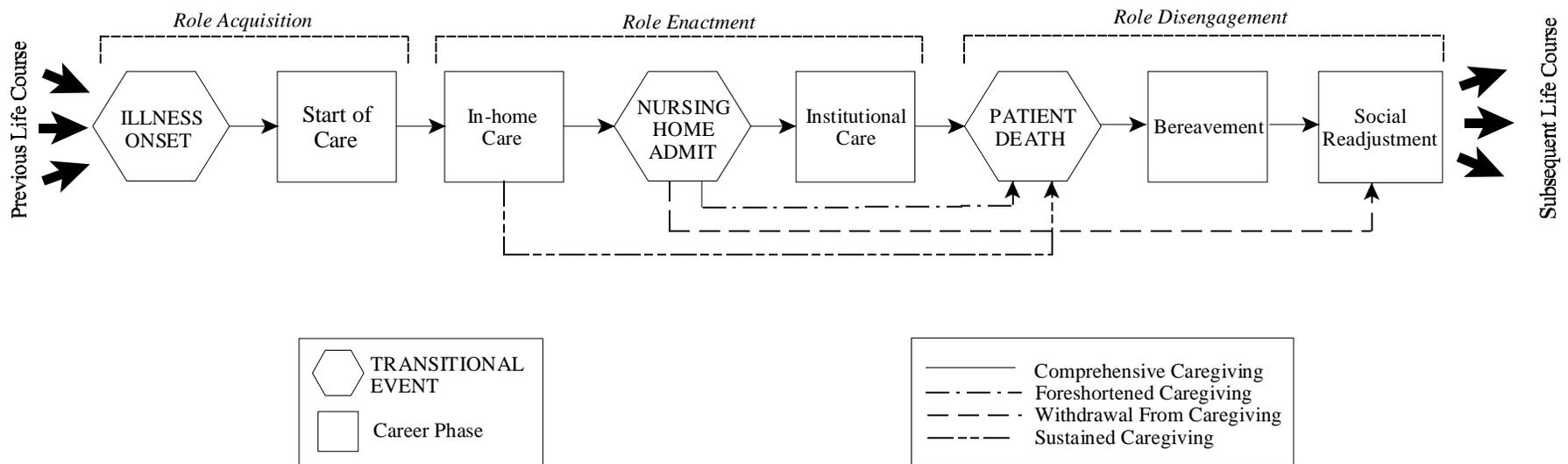


Figure x.3. Progression of caregiving careers

From "Profiles in Caregiving: The Unexpected Career," by C. S. Aneshensel, L. I. Pearlin, J. T. Mullan, S. H. Zarit and C. J. Whitlatch, 1995, p.24. Copyright 1995 by Academic Press. Reprinted with permission.

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