CAREGIVERS’ CHARACTERISTICS AND NEEDS

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INTRODUCTION

This section provides a comprehensive review of current knowledge regarding the characteristics, needs, and vulnerabilities of family caregivers. While existing data primarily are national in scope, they provide a general framework for developing effective caregiver support programs to meet the particular needs of family caregivers in California. This review is by no means exhaustive, but rather is intended to address several general areas of family caregiving research, including: the prevalence of caregiving, characteristics of caregivers, care responsibilities, the impact of caregiving, caregiver needs, and trends in family caregiving that have been identified over time.

Defining “Caregiver”

The term “caregiver” encompasses a wide range of experiences and situations. Caregiving may include caring for a loved one in the caregiver’s home, the care recipient’s home or in an institutional setting. It may include attending to an individual’s emotional well-being and/or physical health. It may involve long-term caregiving for an individual with a chronic illness or physical disability, or may be intermittent and sporadic as in the case of caring for someone with an acute illness or an acute episode of a chronic illness.

While experts from varied fields agree that family care responsibilities encompass a variety of situations and experiences, it is often necessary to delineate the concept of “caregiver” when conducting research, making policy, or delivering services. The 1982 National Long Term Care Survey (Stone, Cafferata, & Sangl, 1987), for example, classifies caregivers into one of three categories: 1) primary caregivers who have complete responsibility for the care recipient, 2) primary caregivers whose efforts
are supplemented by either informal or formal assistance, and 3) secondary caregivers who do not have primary responsibility for the care recipient. Caregiving scenarios also may be differentiated in terms of the age of the care recipient, the level of the care recipient’s impairment, the intensity of caregiving duties, and the duration of the caregiving relationship. Some nationwide surveys on caregiving, for example, have focused on individuals who provide unpaid care for a relative or friend who is over the age of 50 (NAC/AARP, 1997). Narrower definitions also have been used, describing a caregiver as an adult who provides assistance with at least two instrumental activities of daily living (IADL) or at least one activity of daily living (ADL) to an individual who is at least 50 years of age (AARP/Travelers, 1987). Essential to understanding the body of literature on family caregiving is that different definitions of the term caregiver can significantly impact research findings. For example, variations in estimates of the number family caregivers in the U.S. are due in large part to different methods of operationalizing the concept of “caregiver.”

Title III-E of the Older Americans Act Amendments of 2000, the National Family Caregiver Support Program, defines caregiver as “an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual” (Public Law 106-501, 2000). This “older individual” is identified in the Older Americans Act as a person over the age of 60, the age group to whom most Older Americans Act programs are directed. This definition of “caregiver” provides descriptive boundaries as to who is eligible to receive services under the National Family Caregiver
Support Program. Moreover, it guides the assessment of caregiver needs, program planning and program implementation.\(^1\)

**BACKGROUND**

**Need for Care**

Estimates suggest that more than 1.5 million adults in California have physical or mental disabilities necessitating ongoing assistance with day-to-day activities (GAO, 1995). Nationally, approximately 6.4% of community-dwelling elderly Americans (ages 70 or older) are functionally disabled, requiring assistance with one or more activities of daily living (ADLs), such as bathing, eating, walking, or dressing (Crimmins, Saito, & Reynold, 1997; Katz, Ford, Moskowitz, Jackson, & Jafee, 1963). Another 13.8% need assistance with instrumental activities of daily living (IADLs), such as using the telephone, shopping, cooking, laundry, driving, taking medications, or budgeting (Doty, 1986; Lawton & Brody, 1969). Approximately 75% of these frail or disabled elderly adults are cared for at home or in the community by family members or other informal care providers (Bengtson, Rosenthal & Blum, 1996; Liu & Manton, 1994). Indeed, the availability of family members to provide care has been found to be a major factor predicting whether or not a disabled elderly person can remain at home rather than being institutionalized.

It is estimated that the number of persons requiring long-term care nationwide may nearly double in the next 25 years, as the baby boom generation grows older (GAO, 1995).

\(^1\) Title III-E also permits up to 10% of all state funds to be used to assist grandparents or older individuals who are relative caregivers. These individuals are defined as “a grandparent or stepgrandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older” and who “lives with the child, is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally” (Public Law 106-501, 2000).
By 2040, California will experience a 200% increase in the number of persons 85 years and older, more than 50% of whom can be expected to require care (Lee & Villa, 2001; Scharlach, Torres-Gil, & Kaskie, 2001). Despite this, the availability of family members or friends to offer that assistance is expected to decrease. The ratio of working age adults to older adults is anticipated to decline, leaving fewer family members to assist in the care of a growing number of older individuals. Additionally, kinship forecasts show that by 2030 there will be a sizeable portion of the older adult population with no biological or step-children (Wachter, 1998). Smaller family size, greater geographic dispersion of family members, increasing numbers of women in the workforce, and the prevalence of divorce and remarriage all contribute to an expected decline in availability of family caregivers (Ory, 2000).

Prevalence of Caregiving

A 1996 telephone survey of 1,509 randomly selected English-speaking individuals conducted for the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) reported that 16.8 million households, slightly more than 17% of all U.S. households, contained at least one person who was providing unpaid care for a relative or friend over the age of 50 (NAC/AARP, 1997). A 1996 survey by the National Council on Aging found that 25 million Americans had provided or managed care for an individual aged 55 or older within the past year (NCOA, 1997). This is the equivalent of an estimated 2.9 million Californians (Scharlach, 2001).

CHARACTERISTICS OF CAREGIVERS

While the characteristics of caregivers vary tremendously, survey research findings have been used to create a profile of the “typical” American caregiver. This caregiver has been described as a married Caucasian woman, age 46, working full-time
while caring for her 77 year old mother, mother-in-law or grandmother. She is a high school graduate and has an average household income of $35,000 per year. This caregiver provides care for an average of 18 hours per week for approximately 4.5 years (NAC/AARP, 1997). While this profile describes a likely caregiving scenario, it does not illuminate other important insights about the caregiving population. Indeed, the prevalence of family caregiving in minority communities is higher than among the non-Hispanic Caucasian population (NAC/AARP, 1997). In addition, men increasingly fill caregiving roles, and family caregivers can be found across the spectrum of household incomes. Therefore, such an illustration of the “average” caregiver should not be the driving force behind program development. Rather, more nuanced assessments of the caregiving population should be taken into account.

There appears to be a predictable order in the selection of a primary caregiver for frail elders (Doty, Jackson & Crown., 1998; Seltzer & Li, 2000; Tennstedt, 1999). If married, the care recipient is likely to be cared for primarily by his or her spouse. If the spouse is unable to fulfill that role, children most frequently become caregivers. Among children, daughters and daughters-in-law tend to serve as the primary caregivers (Montgomery & Kosloski, 1999). Spouses, therefore, serve as the first line of defense.

**Gender**

Three key findings have materialized from the body of literature that explores issues of gender. First, most caregivers are female. Second, there are differences in the way that men and women fill caregiving roles. Third, female caregivers tend to report greater levels of stress or strain than do males (Neal, Ingersoll-Dayton, & Starrels, 1997).

Most reports indicate that women make up about three quarters of all primary caregivers (Montgomery & Kosloski, 1999; Wagner, 1997; NAC/AARP, 1997; Stone et
al., 1987). However, the number of male caregivers appears to be rising, and a survey conducted by the National Family Caregiver Association (NFCA) in 2000 found that 44% of the caregivers interviewed were male (NFCA, 2000). Moreover, among spousal caregivers, men are as likely to be the primary caregiver as are women (Tennstedt, 1999).

Less conclusive are findings on caregiver gender differences in the amount and type of care given. Studies have found that women provide more intensive care than do men (NAC/AARP, 1997); male spousal caregivers are more likely than female spousal caregivers to obtain in-home services to aid in their responsibilities (Tennstedt, 1999; Abel, 1991); and sons and daughters tend to choose different solutions when caregiving situations arise (Abel, 1991). For example, women are more likely to perform tasks such as cooking and cleaning, which often require more time or more frequent contact than do the tasks that males are more apt to perform, such as financial management and home repairs (Tennstedt, 1999). However, a meta-analysis of gender differences in caregiving suggests that differences in caregiver involvement, while statistically significant, are small and communicate little substantive difference between how men and women give care (Miller & Cafasso, 1992).

Distinct from gender differences in the delivery of care, are gender differences regarding the impact of family caregiving. Studies show that women experience greater caregiver strain than do men, regardless of the level of disability of the care recipient (Neal et al., 1997; Young & Kahana, 1989). Daughters and wives in particular experience greater strain than do other relative caregivers (Young & Kahana, 1989; Neal et al, 1997).
Race/Ethnicity

Although the evidence is somewhat equivocal, there seems to be a slightly higher prevalence of caregiving among Asian Americans (31.7%), African Americans (29.4%) and Latinos (26.8%) than among non-Hispanic Caucasians (24%) (NAC/AARP, 1997). Moreover, when controlling for the level of disability, minority caregivers tend to provide more care than do Caucasian caregivers (Tennstedt & Chang, 1998). Latino elderly are more likely than their non-Latino Caucasian counterparts to live in multigenerational households, and have multiple family members involved in providing care (Feinberg, Pilisuk & Kelly, 1999). Of the three racial/ethnic groups, Caucasian caregivers are the most likely to provide care for a spouse; Latinos are the most likely to provide care for a parent; and African Americans are the most likely to be caring for other family members or unrelated individuals (NAAS, 2000; Burton et al., 1995).

A higher proportion of African American and Caucasian caregivers care for dementia victims than do Asian American or Latino caregivers. Indeed, African-American caregivers are one-and-a-half times as likely to care for someone who is demented rather than cognitively intact, whereas Asian American caregivers are nearly twice as likely to care for someone who is not demented (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Among caregivers for persons with dementia, non-Caucasian caregivers are more likely than Caucasian caregivers to be younger and employed. Thus, the design of support services and programs should consider those factors, particularly in communities with large minority populations (Janevic & Connell, 2001).

Differing levels of stress, psychosocial outcomes and levels of service utilization among caregivers of different racial, ethnic, and national origins have also been observed. For example, multiple studies have found that African American caregivers report lower
levels of caregiving-related stress than do Caucasian caregivers (Connell & Gibson, 1997; Hinrichsen & Ramirez, 1992; Lawton, Rajagopal, Brody, & Kleban, 1992; Macera et al., 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Mui, 1992; White, Townsend, & Stephens, 2000). However, it is unclear whether these differences are due to levels of religiosity, values or beliefs about aging, role expectations, social support or other factors (White, Townsend & Stephens, 2000). Moreover, socio-economic status, cultural differences and within-group variability may confound research findings, making it more difficult to determine if and how ethnicity differentially impacts the caregiving experience. Indeed, some scholars have suggested that race may function as a proxy variable for other important factors that are more likely to impact caregiving experiences, such as income, health, and family structure (Young & Kahana, 1995).

**Employment**

It is estimated that 11.7 million full-time and 2.7 million part-time U.S. employees balance their work obligations with caregiving duties (NAC/AARP, 1997); this equates to approximately 1.5 million full-time and 300,000 part-time California workers. The relationship between employment and caregiving is difficult to clearly discern; however, employment does appear to impact individuals giving care. Research reveals that frequently working heaps additional demands onto already burdened caregivers. Despite this, working outside of the home may also serve as a social outlet, a source of self-confidence for individual caregivers, or a “break” from caregiving tasks.

The profile of working caregivers is slightly different than that of caregivers who are not employed outside of the home. According to a 1988 survey by the AARP and The Travelers Foundation, caregivers who were employed full-time were on average younger than non-working caregivers; they also were more likely to be college educated,
have higher incomes, be male, and care for a family member who was less disabled (AARP & Travelers, 1988). Employed caregivers are especially likely to experience additional strain when a job is very demanding and there is little flexibility or support (Scharlach, Sobel, & Roberts, 1991). However, employed caregivers may be able to take steps to ease stress that non-employed caregivers cannot afford to take. For example, employed female caregivers, when compared to non-employed female caregivers, tend to use more hours of paid and unpaid assistance to help manage work-related time constraints (Doty et al., 1998).

At the aggregate level, it is unclear how employment impacts caregiving trends, particularly those involving gender-related patterns in caregiving. Concern exists that increased female participation in the labor force will preclude women from filling caregiving roles, and there is evidence that women are more apt to relinquish family care roles than employment (Moen, Robinson, & Dempster-McClain, 1995). However, employment does not necessarily prevent women from functioning as caregivers. An analysis of female primary caregivers revealed that employed caregivers often make use of informal support networks (including friends, spouses and other relatives) to assist in the provision of care (Velkoff & Lawson, 1998; Doty et al., 1998). Furthermore, many caregivers do not face major eldercare-employment conflicts, and a large number of primary caregivers take on their care duties after having left the workforce (Doty et al., 1998).

**CARE RESPONSIBILITIES**

**Care Recipient Characteristics**

The 1997 NAC/AARP survey reports that the typical care receiver is someone over the age of 80; indeed, almost two-thirds of care recipients are over age 75.
Approximately 40% of caregivers provide assistance to a parent, and 5% care for a spouse. The remaining 55% of caregivers care for grandparents, parents-in-law, other relatives, or neighbors or friends (NAC/AARP, 1997).

One-fifth of caregivers (21%) provide assistance to someone who lives with them; by comparison, 37% of caregivers lived with their care recipient ten years ago. One quarter (24%) of caregivers live more than 20 minutes away from the person for whom they provide care, up from 16% ten years ago. Approximately one-half (55%) of caregivers live within 20 minutes of their loved one, but not together (NAC/AARP, 1997).

The level of informal care that an older adult receives is directly related to the level of his or her disability (Branch and Jette, 1983; Horowitz and Dobrof, 1982; Sherwood, Morris, & Gutkin, 1981; Tennstedt, 1999). As the level of disability increases, so does the amount of unpaid care that families provide. This holds true even when the care recipient uses formal care. A 1999 report notes that this reflects the importance of informal family care, as families contribute a great deal of care despite the fact that highly disabled care recipients may utilize formal services (Tennstedt, 1999).

Types and Amounts of Assistance Provided

Ninety eight percent of caregivers assist their care recipients with at least one IADL and 81% assist with three or more IADLs, including transportation (79%), household chores (74%), and grocery shopping (77%) (NAC/AARP, 1997). More than one-third of employed caregivers assist with home maintenance activities and repairs, and more than one-fourth do housecleaning, make phone calls for care recipients and/or manage the care recipient's finances (Wagner, 1997). About 15% of caregivers provide
direct hands-on care with intensive personal needs such as bathing, toileting, and dressing.

There appear to be slight gender differences in the type of care that care recipients receive. While women are more likely than men to receive assistance from families, men receive higher levels of care (Tennstedt, 1999). Regardless of functional status, men tend to receive help with more time consuming activities such as personal care, meal preparation and housekeeping chores. Women, on the other hand, frequently receive assistance with activities that require less time, such as transportation, home repairs and shopping. Differences in the type and amount of care received by men and women may, in part, be due to the perception of gender roles and the likelihood that older adults will continue to perform those daily tasks with which they are familiar (Tennstedt, 1999). As a result, men and women may be more likely to receive help with those daily activities that are less familiar to them.

National data indicate that the average caregiver in the U.S. provides care for 18 hours per week. Close to one in five provides either “constant care” or at least 40 hours of care per week, with the caregivers of highly disabled individuals providing an average of 56.5 hours (NAC/AARP, 1997). Smaller studies have found that frequently even more care is provided when the caregiver and care recipient share a residence. Care recipients living with caregiver spouses receive an average of 78 hours per week of informal care, and elders who live with a non-spousal caregiver receive an average of 66 hours/week of care (Tennstedt, 1999; Tennstedt, McKinlay & Sullivan, 1989). Additionally, caregivers who care for elderly individuals with dementia spend, on average, a greater number of hours giving care than do caregivers caring for elderly with normal cognitive status (Langa, et al., 2001).
Based on these national estimates of the number of hours that families and other informal care providers spend giving care, the economic value of caregiving has been estimated at $196 billion annually (Arno, Levine, & Memmott, 1999). The economic value of care in California alone is more than $20 billion.

**Direct vs. Indirect Services**

Caregiver utilization of formal care services, such as home health care, housework and adult day care, has increased dramatically in the past decade, from 22% in 1987 to 38% in 1996 (Wagner, 1997). Indeed, analyses of National Long Term Care Survey data show that, whereas family members and other informal care providers were the sole source of assistance to 67% of community-dwelling disabled elderly in 1982, by 1994 this percentage had dropped to 58% (Lui, Manton & Aragon, 2000). At the same time, the percentage of disabled elderly receiving assistance from both formal (paid) and informal (unpaid) sources climbed from 19% in 1982 to 25% in 1994.

As indicated earlier, within the provision of informal care, women are more likely than men to provide direct care, including laundry, shopping, cooking, feeding, dressing, and bathing, whereas men are more likely to manage care, including arranging services. In addition, male caregivers receive more help from their wives than female caregivers receive from their husbands. Not only do women have more caregiving responsibilities and less help from their spouses, but they also have more trouble than men affording or finding outside resources to help alleviate role strain (Scharlach, 2001). Older adults who are unmarried and live alone in public housing are less likely to receive care from informal caregivers and more likely to utilize services (Tennstedt, 1999). Indeed researchers have found that living alone means that an older adult is twice as likely to use formal, paid services (Tennstedt, Crawford, & McKinlay, 1993). Additionally, African
Americans, Latinos and Asian Americans are more likely to provide direct care than Caucasians, resulting in part from cultural values about family care as well as the lack of affordability of support services (Scharlach, 2001).

**Direct and Imputed Economic Support**

Almost 40% of long-term care costs are paid directly by individuals and their families (U.S. General Accounting Office, 1995). Families with a care recipient have an average of about $171 a month in extra expenses, contributing to a total of $1.5 billion per month spent by caregivers nationwide (NAC/AARP, 1997). California caregivers alone pay an estimated $203 million per month. Out-of-pocket expenses for caregiving are greatest for those who care for the most disabled care recipients. For example, caregivers for persons who need assistance with at least two ADLs spend an average of $357 per month (27% of their monthly income) on caregiving-related expenses, whereas those who care for persons who require minimal help spend an average of only $95 per month (NAC/AARP, 1997).

When examining formal and informal care costs only for people with Alzheimer’s disease in California, the 1990 total direct and imputed costs of caring for a person with the disease were $47,083 per year for patients in the community and $47,591 per year for institutionalized patients. However, the distribution of costs for formal and informal care for the two groups is quite different. For institutionalized patients, informal care services comprise 12% of the total costs of care while 88% is attributable to formal services. Conversely, for patients residing in the community 73% of the total cost of care is for assistance provided informally while 2% is for formal services (Rice et al., 1993). Combining these estimates with Alzheimer’s disease prevalence and population projections, costs for California’s community-resident dementia patients are expected to
increase 83% in the period 2000 ($23.4 billion) to 2020 ($42.8 billion), and an additional 59% from 2020 to 2040 ($68.1 billion). Costs for California’s institutionalized Alzheimer’s disease patients are expected to increase 84% from 2000 ($2.5 billion) to 2020 ($4.6 billion), and 61% from 2020 to 2040 ($7.4 billion), assuming the supply of nursing home beds meets projected demand. Total costs of caring for Alzheimer’s disease patients in California will nearly triple between 2000 and 2040 (Fox et al., 2001).

IMPACT ON THE CAREGIVER

Caregiving Stress

The contributions of family caregivers are not made without taking a toll on the mental and physical health of the individuals who provide care. Caring for disabled elderly relatives can negatively impact both physical and emotional well-being (Schulz & Beach, 1999; Schulz, O’Brien, Bookwala, & Fleissner, 1995). However, caregiving may also have beneficial elements for the caregiver. Indeed, research on caregiver stress has resulted in two broad conclusions about the mental health of caregivers. First, caregivers can experience high levels of stress and overload, contributing to symptoms of depression and burnout (Moen et al., 1995). Second, caregivers frequently report that their caregiving role is a positive one, contributing to a sense of personal and familial well-being (Moen et al., 1995; Noonan & Tennstedt, 1997).

While all caregivers may experience some deleterious impacts associated with caregiving, some groups of caregivers are particularly at risk for negative outcomes. For example, primary caregivers of Alzheimer’s disease sufferers commonly experience higher levels of depression, anxiety and greater utilization of psychotropic drugs than the general population (Ory et al., 1999; Pruchno & Postashnik, 1989; Fox et al., 2001; Bourgeois & Schulz, 1996; Schulz et al., 1995). Factors associated with high levels of
caregiver stress include the health status of the care recipient and advancement of the debilitating illness; the existence of any problematic behavior from the care recipient; the level of daily dependency of the care recipient; sharing a home with the care recipient; conflictual familial relations; occupational conflicts or strains; financial hardships; and the constriction of social and recreational roles in the caregiver’s life (Pearlin et al., 1990; Mittelman et al., 1995; Mittelman et al., 1996). Fluctuating levels of stress experienced by caregivers can result from changes in any of these variables (Pearlin et al., 1990). Broadly speaking, the risk for caregiver depression rises as the length of the caregiving relationship increases, the health status of the care recipient declines, and the emotional well being of the care recipient declines (Schulz et al, 1995).

Many caregivers also experience threats to personal identity and a loss of social roles when they take on caregiving responsibilities (Skaff & Pearlin, 1992). Female caregivers, younger caregivers and caregivers who do not have a spouse tend to have a greater sense of self-loss. Similarly, individuals who care for someone who is despondent or has behavior problems may also experience greater self-loss.

Caregivers also frequently report that their caregiving experience has positive aspects (Moen et al., 1995; Scharlach, 1994). These include feelings of satisfaction in helping a loved one, repaying the care recipient for past activities, spending time together with the care recipient, feeling closer to the care recipient, and the satisfaction of knowing that their loved one is receiving good care. Caregivers also often appreciate the opportunity to express feelings of empathy and love to the care recipient. They may experience greater self-respect and altruistic feelings, knowing that they play an important role in the life of their loved one (Toseland, 2001). Additional benefits include
assistance the care recipient may provide with childcare, household work or finances (Scharlach, 1994).

It appears that positive beliefs about caregiving can have an important impact on the mental health of caregivers. Regardless of the level of demand placed on caregivers, individuals who find meaning in their role and those who are searching for meaning express fewer depressive symptoms and greater self esteem than caregivers who do not find meaning in their caregiving role (Noonan & Tennstedt, 1997). Among female caregivers, individuals with higher levels of education and greater emotional health experience less stress and are more likely to report that they have benefited from their caregiving role (Moen et al., 1995).

Other factors associated with positive caregiving experiences include a caregiver’s access to effective coping strategies and coping resources (Nolan, Gordon, & Keady, 1996). Coping refers to the efforts made by an individual to overcome demands or challenges that are perceived as taxing or stressful (Folkman & Monat, 1991). A coping style refers to the general approach an individual takes to stressful situations and is generally seen to fall into one of two broad categories: problem-focused coping and emotion-focused coping. Problem-focused coping refers to an individual’s efforts to improve a stressful situation through action. Examples of this include seeking information when confronted with a new situation or resisting an impulsive action in favor of more thoughtful action. Emotion-focused coping refers to thoughts or actions taken in an effort to reduce the impact of a stressful situation. Examples of this are crying, detaching oneself from the situation, or finding ways to relax (Folkman & Monat, 1991). For each style of coping, many different coping strategies may emerge; some of these may have positive outcomes for the individual (meditating, learning more about an
illness), and others may have negative side effects (drug or alcohol use, problem
avoidance). Certain situations are more amenable to one style of coping over another.
For example, when a situation calls for direct and immediate action, emotion-focused
coping may be detrimental. However, in other situations when it enables a person to
maintain a sense of well-being, emotion can be useful and healthy (Folkman & Monat,
1991). Finally, it should be noted that individuals do not employ one style or another
exclusively, but usually combine complex combinations of both in different situations
(Folkman & Monat, 1991).

Researchers have found that an individual caregiver’s coping style may be
mitigated or influenced by ethnic or cultural background (Aranda & Knight, 1997; ;
Knight, Silverstein, McCallum, & Fox, 2001; Young & Kahana, 1995). Caucasian
caregivers typically employ problem-solving and avoidance strategies more frequently
than do African American caregivers, perhaps because Caucasians perceive caregiving
situations as a greater threat or stressor than do African Americans. Moreover, African
American caregivers are more likely to view their situation in more positive terms, and
draw upon religious faith and social networks to mitigate caregiving stress. Latino
caregivers also are more likely to pray or draw upon their own religiosity when faced
with caregiving stress. They are less likely, however, to express their feelings or obtain
professional help than are Caucasians or African Americans. As a result, Latino
caregivers may be at higher risk of depressive outcomes than caregivers of other cultural
backgrounds (Adams et al., 2001; Aranda & Knight, 1997; Knight et al., 2000; Young &
Kahana, 1995).
Impact on Caregiver Health

Caring for a disabled family member or friend also can affect caregivers’ health and physical well-being. Caregivers tend to report more physical ailments than do non-caregivers, including arthritis, back trouble, hearing problems, insomnia, rectal problems and diabetes (Pruchno & Postashnik, 1989; Scharlach, Runkle, Midanik, & Soghikian, 1994; Schulz et al., 1995). Some groups of caregivers have been found to exhibit poorer immune function, more respiratory tract infections, lower antibody and virus-specific T-cell responses to influenza, and slower rates of wound healing than do non-caregivers (Vitaliano, Schulz, R., Kiecolt-Glaser, J., & Grant, 1997). Spousal caregivers for Alzheimer’s disease victims report higher rates of diabetes, arthritis, ulcers and anemia than the general population (Pruchno & Postashnik, 1989). Women caregivers tend to experience more health problems than do their male counterparts (NAC/AARP, 1997). Male caregivers experience higher lipoprotein cholesterol levels, greater triglycerides, and more problems with obesity than do non-caregiving males, whereas women caregivers have more problems with weight gain and obesity than do non-caregiving women (Vitaliano et al., 1997).

Spouses, more broadly, tend to mirror one another in terms of their reported physical health status (Satariano, Minkler, & Langhauser, 1984). Individuals who report that their spouse has been ill within the previous six months are more likely to report that they themselves are in poor physical health. Among the possible reasons cited for this covariance is the deleterious impact of spousal caregiving (Satariano et al., 1984).

Among elderly persons caring for a disabled spouse, those who experienced strain as a result of their caregiving role were 63% more likely to die within four years than non-caregiving individuals in one study (Schulz & Beach, 1999). Caregivers who were
not experiencing strain had mortality rates at the same level as non-caregivers. Caregivers who were at the greatest risk for negative health outcomes included individuals with very demanding caregiving responsibilities, chronic stress as a result of their caregiving role, and negative psychological outcomes such as depression (Schulz & Beach, 1999). A Kaiser Health Plan study found that poor health practices were more common among caregivers who were non-Caucasian, employed part time, low income or in poor health. The researchers concluded that caregivers, if given access to preventative health care services, may not suffer negative health effects due to their caregiving role (Scharlach, Midanik, Runkle, & Soghikian, 1997).

Despite increased health risks, caregivers do not seek medical services for themselves at higher rates than non-caregivers. Caregiving members of the Kaiser Foundation Health Plan in Northern California, for example, were more likely than noncaregivers to report stress-related health problems, when controlling for age, gender, and race; however, they were not more likely to seek health services (Scharlach et al, 1994). One interpretation of these results has been that caregivers often to not find time to address their own health care needs (Pruchno & Postashnik, 1989). For example, even though female caregivers are more likely than other women to report that they suffer from hypertension or heart problems, they use medical services at similar or lower rates. The National Center for Health Statistics found that caregivers reported spending less sick time in bed than the general population. Moreover, caregivers reported fewer visits to a physician than did the general population (National Center for Health Statistics, 1986).

Findings such as these have led researchers to recommend that practitioners treating both the caregiver and care recipient consider the health status of both
individuals when discussing the caregiving situation and future caregiving options (Pruchno & Postashnik, 1989; Schulz & Beach, 1999). Specifically, recommendations include the examination of elderly couples by physicians as a unit, in order to assess if the caregiving spouse is at risk (Schulz & Beach, 1999). Interventions that decrease the level of stress caregivers experience may also improve their physical well-being.

**IMPACT ON WORK**

As a result of their caregiving responsibilities, employed caregivers frequently are forced to make substantial accommodations in their work activities, so as to balance most effectively the potentially competing demands of work and family roles. Juggling caregiving duties and employment can lead to a decrease in productivity. Moreover, some caregivers may find it necessary to leave the workforce altogether in order to care for a loved one.

**Effects on Productivity**

More than half of respondents to a 1996 national survey of family caregivers reported losing time from work as a result of their caregiving duties, up from only about one-third in 1987 (NAC/AARP, 1997; AARP, 1988). In the 1996 study, 49% of caregivers reported that they went to work late, left early or took time off during the day to meet caregiving obligations (NAC/AARP, 1997). In a 1997 study of only employed caregivers, 84% reported that caregiving duties caused them to make personal phone calls during the workday; 69% arrived late or left work early; and 67% took time off during the workday to attend to caregiving duties (Metropolitan Life Insurance Company, 1997). Research on Australian caregivers found similar patterns of disruption in the workplace, with 20% reporting that they had to decrease the numbers of hours that they worked (Schofield & Herrman, 1993). While there are diffuse reasons for missed time at work,
generally speaking a caregiver’s employment is more likely to be disrupted when the care recipient is more disabled and when the caregiver feels that he or she has a lack of support in providing care (Scharlach, Sobel, & Roberts, 1991).

These disruptions are believed to contribute to significant losses in productivity. A 1997 study estimated that U.S. employers lost between $11.4 (full time) and $29 billion dollars (full time and part time) each year in productivity because of work disruptions experienced by employees with caregiving. This suggests an estimate of $1.7 billion lost in California due to productivity losses for full time employees. Caregiving crises and employee turnover also contribute to a decrease in productivity (Metropolitan Life Insurance Company, 1997).

Impact on Working Caregivers.

Juggling work and family care responsibilities also can impact caregivers’ careers. Some employees are forced to take a temporary leave of absence or quit work altogether to accommodate their caregiving responsibilities. A national survey of family caregiving found that 20% of all caregivers left their jobs either temporarily or permanently because of care responsibilities: 11% took a leave of absence, 4% took early retirement, and 6% gave up work entirely (NAC/AARP, 1997). An Australian study found that 28% of the caregivers surveyed responded that they took leaves of absence in order to tend to caregiving duties (Schofield & Herrman, 1993). The intensity of caregiving duties may also play a role in defining a caregiver’s professional path. For example, caregivers of dementia patients report more frequently than non-dementia caregivers having to take less demanding jobs, turn down promotions, retire early, or leave the workforce altogether (Ory et al., 1999).
Disruptions in workforce participation may also impact a caregiver’s economic circumstances. Women who leave employment for a caregiving role make $3,965 less per year than those who retire for other reasons. Lost wages and lost opportunities for promotion detrimentally affect women caregivers’ financial situation as they themselves grow older, resulting in reduced Social Security benefits (Kingson & O’Grady-LeShane, 1993). An analysis of data from the National Longitudinal Caregiver Study, a survey of spousal caregivers for elderly male U.S. military veterans diagnosed with dementia, found that caregivers lost an average of $10,709 in earnings annually due to a reduction in hours of work or early retirement necessitated by caregiving responsibilities (Moore, Zhu, & Clipp, 2001).

For those caregivers who remain in the workforce, employment can have a positive impact, providing them with financial, social and psychological resources (Fredriksen-Goldsen & Scharlach, 2001). Paid employment can offer caregivers a much-needed break from their care duties, access to social support through co-worker relationships, and improved relations with the person for whom they provide care (Fredriksen-Goldsen & Scharlach, 2001; Schofield & Herrman, 1993). Employed caregivers are less likely to be depressed than nonworking caregivers, and they express higher levels of life satisfaction and self-esteem (Tennstedt, Cafferata & Sullivan 1992; Moen et al., 1995). Moreover, caregiving can have positive impacts on work performance. Employed caregivers may be more effective and compassionate during customer interactions, may demonstrate greater self-confidence, and may have enhanced feelings of job competence as a result of their caregiving experiences (Scharlach, 1994).
CAREGIVING CONTEXT

Caregivers’ experiences providing care and their resulting need for assistance are affected by the context within which caregiving occurs. While each caregiving situation is unique, a number of broad patterns of caregiver needs have been identified. These shared characteristics contribute to a better understanding of how programmatic efforts to assist caregivers might be structured. Of particular interest are the developmental phase of the caregiving process, the caregiver-care recipient relationship, the cultural context, and family relationships.

Researchers have found that caregiving activities change over time in a relatively predictable developmental progression, in accordance with the care recipient’s increasing need for care and caregiver role expectations. Montgomery and Kosloski outline this trajectory of caregiving with seven benchmarks: 1) performing caregiving tasks, 2) defining self as a caregiver, 3) providing personal care, 4) seeking out or using assistive services, 5) considering institutionalization, 6) placing the care recipient in a nursing home, and 7) the termination of the caregiving role (Montgomery & Kosloski, 1999). Not all caregivers will move sequentially through all of the markers, and in fact, the order of the markers may vary for different types of caregivers. Nonetheless, each point signifies the further development of the caregiving process and the subsequent changes in caregiver needs that accompany such development.

In order to best meet caregiver needs, services need to be matched with caregivers’ position in their developmental trajectory. For example, typically in the early stages of their caregiving experience individuals are more likely to seek information than services, while those individuals who are long-term caregivers may be more inclined to seek respite care (Montgomery & Kosloski, 1999). Caregivers will not use services that
they perceive as inappropriate for their circumstances; thus, the proper targeting and marketing of services to caregivers should contribute significantly to their success in assisting caregivers.

One benchmark not included in the Montgomery-Kosloski model is a phase that precedes all of the others, a phase that is defined by the disabled individuals’ ability to maintain their own care with little or no assistance from would-be caregivers. This phase can be described from the potential caregivers’ perspective as “watchful waiting.” It encompasses the period of self-care wherein disabled older adults are able to coordinate and manage their care and largely meet their own needs with minimal reliance on informal supports. Recognizing this phase in the caregiving trajectory is crucial because with appropriate interventions and formal supports that facilitate self-care for disabled adults, the period of “watchful waiting” may be lengthened and the period of active caregiving shortened. Bolstering the ability of individuals to manage their own needs can thereby delay or decrease the care obligations that family caregivers face.

The relationship between the caregiver and the care recipient also can impact a caregiver’s needs and decision to seek services (Montgomery & Kosloski, 1999). For example, differing caregiving trajectories have been identified among spousal caregivers and children. Spousal caregivers tend not to identify themselves as caregivers until they have begun to provide hands-on assistance, making it unlikely they will seek assistance during the first stages of their caregiving experience. Conversely, adult children are more apt to identify themselves as caregivers when the care recipient first becomes disabled, so they are more likely to seek information and outside assistance early on (Montgomery & Kosloski, 1999).
Cultural norms also may play a role in caregiver needs and service utilization. For example, among racial and ethnic minority groups, nearly 75% of caregivers are children—notably higher than the 40% to 60% estimations that have been found among Caucasian populations (Montgomery & Kosloski, 1999). Non-white and Hispanic daughters also tend to provide more personal and household care than do Caucasian daughters (Montgomery & Kosloski, 1999). Moreover, though kin and non-kin social networks are generally larger for Latina and African-American caregivers, the benefits of social support are often accompanied by additional stressors and/or conflicts with familial obligations (Aranda & Knight, 1997; Connell & Gibson, 1997). Thus, programs that are constructed to primarily serve minority caregivers should take into account the high prevalence of daughters as caregivers, who though often surrounded by sources of informal support, may still desire access to formal services as a means of minimizing familial conflict. For example, while African-American caregivers report that they receive more informal assistance from family and friends than do Caucasian caregivers, they also express a greater need for services. When factors such as these are taken into account, effective interventions can be tailored to cultural norms among minority caregivers.

Fourth, while caregiving may impact families in important ways, family dynamics, in turn, may impact the caregiving experience. Families particularly at risk for negative impacts are those that have poor communication, greater demands on limited resources and time, familial conflict, poor parent-child relationships, and greater resistance to change (Toseland, 2000). Open communication can prevent or minimize familial conflict, and thereby reduce some of the psychological stress that caregivers may
experience, while also facilitating the sharing and coordination of caregiving responsibilities among family members (Toseland, 2000).

**SUMMARY**

Essential to ascertaining what needs caregivers have is understanding who gives care, what kinds of care they give, and to whom it is given. The research findings highlighted in this paper can, in part, aid in answering those questions. First, survey research has offered evidence that caregiving is widespread. By some estimates, nearly one out of every six households gives care nationwide, equating to 2.9 million households in California alone (NAC/AARP, 1997; Scharlach, 2001). Most caregivers are female (Montgomery & Kosloski, 1999; NAC/AARP, 1997; Stone et al., 1987; Wagner, 1997); and, there are slightly higher frequencies of caregiving among minority ethnic groups than among Caucasians (NAC/AARP, 1997). Almost half of all caregivers nationwide are employed (NAC/AARP, 1997), suggesting that approximately 1.8 million caregivers in California balance care duties with work. The care given ranges significantly, based upon the needs of the care recipient; however, 98% of caregivers assist with at least one IADL, and 81% assist with three or more (NAC/AARP, 1997). Individuals who care for someone with a dementia-related illness provide more care, measured by both the number of hours of care given and the number of IADLs or ADLs with which the care recipient needs assistance (Ory et al., 1999).

Second, while caregiving can prove to be a positive experience for some individuals, it frequently has negative impacts on the health and well-being of the caregiver. Caregivers can experience high levels of stress that lead to burnout or depression (Moen et al., 1995). They may also experience a loss of social roles (Skaff & Pearlin, 1992). Physically, caregiving can take a toll on individuals; female caregivers
particularly tend to report more physical ailments than do non-caregiving females (Pruchno & Postashnik, 1989; Scharlach et al., 1997; Schulz et al., 1995). Indeed, there is some evidence that mortality rates may be higher for caregivers than non-caregivers (Schulz & Beach, 1999). Yet despite these increased emotional and physical health risks, family caregivers do not tend to seek out health services at higher rates than do non-caregivers (Pruchno & Postashnik, 1989; Scharlach et al., 1994).

Third, certain individuals are more vulnerable to the deleterious effects of caregiving. Those who care for someone with problematic behaviors, dementia, or a high level of daily dependency are at greater risk for negative outcomes (Bourgeois & Schulz, 1996; Fox et al., 2001; Mittelman et al., 1995; Ory et al, 1999; Pruchno & Potashnik, 1989; Schulz et al., 1995). Caregivers who experience family conflict, financial hardships, or loss of social roles are also at particular risk (Mittelman et al., 1995; Skaff & Pearlin, 1992). Other vulnerable caregivers include those who care for persons with Alzheimer’s Disease, have health problems of their own, share a home with the care recipient, have conflictual familial relations, experience occupational conflicts or strains, or are socially isolated (Bourgeois & Schulz, 1996; Fox, Kohatsu, Max, & Arnsberger, 2001; Mittelman et al., 1995; Ory et al, 1999; Pearl, Mullan, Semple, & Skaff, 1990; Pruchno & Postashnik, 1989; Schulz et al., 1995; Skaff & Pearlin, 1992). These characteristics help to identify those caregivers who are at greatest risk for deleterious impacts of family caregiving, for whom formal supports may be particularly beneficial.

Finally, the current state of knowledge of family caregiving has implications for program development as well as research. Caregiver needs may be mediated through a complex network of characteristics, including gender, ethnicity, the caregiver-care recipient relationship, and employment status. Understanding how those characteristics
interact is essential for identifying how best to meet caregivers’ unique needs. Moreover, caregiver needs transform over time, as a caregiver moves through the care trajectory (Montgomery & Kosloski, 1999). Focusing on the intersection of individual characteristics and environmental or time-dependent circumstances may produce important insight into how caregivers might best be served during each phase of their caregiving experience.

The emerging complexities and characteristics of the changing nature of family life are particularly relevant to the development of caregiver support programs in California. Demographic shifts make it apparent that family caregivers are a growing segment of the population; moreover, caregiving contexts are likely to grow more diverse as well. As single parent households, blended families, grandparents raising grandchildren, gay and lesbian homes, and other nontraditional family structures become more common, new complexities within family caregiving arise. Researchers and service providers face the challenge of expanding their conceptual models of caregiving to encompass these changes in California’s families and their caregiving needs (Fredriksen-Goldsen & Scharlach, 2001).

Understanding the characteristics of caregivers, the care responsibilities that they take on, and the impact that those duties have on their well-being all contribute to a clearer picture of caregiver needs. Research to date has captured the broad landscape of family caregiving nationally. Further data collection on the nuances of caregiving in California’s racially and ethnically diverse context will serve to clarify and enrich that picture. As research proceeds at both a national and state level, the complexities of family care can be unraveled, and programs to support family caregivers can be based on stronger empirical and theoretical foundations.
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