

The Experiences and Challenges of Caregivers of Frail or Chronically Ill Elderly: An Integrative Review

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Introduction

The world's population has continued on its rapid transition path from a state of high birth and death rates to one characterized by low birth and death rates (United Nations [U.N.] Department of Economic and Social Affairs, 2003). At the heart of that transition has been the growth in the number and proportion of older persons as a result of various factors including improvements in technology, medical care, and nutrition, as well as increases in wealth and education and the shift to a postindustrial society (Olshansky, Carnes, & Cassel, 1993). From 2000 to 2050, projections indicate that one out of five will be 60 years or older; and by 2150, one out of three persons will be 60 years or older, as compared to one out of every ten persons now (U.N. Department of Economic and Social Affairs, 2003).

The impact of population ageing is increasingly evident in the old-age dependency ratio, the number of working age persons (age 15-64 years) per older person (65 years or older) that is used as

an indicator of the 'dependency burden' on potential workers. Between 2000 and 2050, U.N. estimates that the old-age dependency ratio will double in more developed regions and triple in less developed regions (U.N. Department of Economic and Social Affairs, 2003). As our society is getting older and limitations on activities among older populations inevitably increase, the number of informal or family caregivers and the care that the informal caregivers provide are also increasing. The potential short- and long-term impact of this 'silver tsunami' on caregivers and society is an area of growing research.

The goals of this review are to synthesize what is known about caregiving among diverse groups in the United States (U.S.) and to identify gaps in knowledge to guide future research on caregiving. Even though the focus of this review is on studies conducted and published in the U.S., it is believed that the key findings of this review can provide meaningful insights to other researchers who are seeking to design a study to meet the needs of caregivers in similar contexts throughout the world.

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Increasing Needs for Informal Caregiving and Health Spending

With an aging population, the need for informal caregiving is likely to increase. For example, almost 75% of the elderly (age 65 and over) have at least one chronic illness (Calkins et al., 1999). Many chronic diseases are debilitating and can lead to severe disabilities, such as hip fractures and stroke, as well as progressive disability that slowly reduce the ability of elders to care for themselves (Fried & Guralnik, 1997). The moderate to severe forms of stroke, for example, often require sudden intense and frequent caregiving interventions, with caregiving needs changing over time. According to 1996 U.S. Medical Expenditure Panel Survey, about 14.3 percent of people age 65 and over--4.5 million elderly Americans--needed assistance with bathing, dressing, preparing meals, or shopping (Banthin & Cohen, 1999). Similarly, in 1997, more than half (54.5%) of the older U.S. population (≥ 65 years) reported having at least one disability of some type, many of whom requiring personal assistance (McNeil, 2001). The number of Americans who will suffer functional disability due to a variety of chronic conditions such as arthritis, stroke, diabetes, coronary artery disease, cancer, or cognitive impairment is expected to increase at least 300% by 2049 (Boult et al., 1996).

The definition of informal caregivers (Biegel, Sales, & Schulz, 1991) includes those individuals who provide extraordinary, uncompensated care, predominantly in the home setting, involving significant amounts of time and energy for months or years. Families have traditionally cared for their frail older members without compensation or assistance throughout much of our history. Informal

or unpaid care of the elderly is estimated to account for 95% of all care given to older adults (U.S. Administration on Aging, 2003). The number of informal caregivers in the U.S. doubled from 1996 to 2003, according to a National Alliance for Caregiving/American Association of Retired Persons (NAC/AARP) study (2004). Using a national sample of 1,247 caregivers randomly selected in the U.S., the NAC/AARP study (2004) estimated that there were 44.4 million caregivers age 18 and older in the U.S. who provided informal or unpaid care, representing 21% of total U.S. households.

Although one profile does not fit all caregivers, a typical caregiver in the U.S. in 2003 was a 46-year old female, who had some college education, works, and spent more than 20 hours a week providing care to her mother (NAC/AARP, 2004). Specifically, the NAC/AARP national survey (2004) indicated that more caregivers were women (61%) than men (39%) between the ages of 18-49 years (58%) than were 50 years of age or older (42%). Many worked either full or part-time while providing care (59%). In addition to the stresses of juggling multiple roles, 62% of these employed caregivers reported that their caregiving responsibilities had affected their work. They had passed up promotions, lost job benefits, been forced to take a leave of absence, scaled back from full time to part time, or had to leave their jobs altogether (NAC/AARP, 2004). Nearly half (48%) of all caregivers provided 8 hours or less of care per week and about one in five (17%) reported providing more than 40 hours of care per week.

Caregiving responsibilities appear to fall heaviest on ethnic minorities. According to the NAC/AARP survey (2004), only 11% of African American caregivers reported using a paid care

and 14% and 13% of Hispanic and Asian American caregivers, respectively, as compared with 22% of White caregivers. This may reflect cultural differences in caregiving structure salient to each ethnic group. For example, a recent analysis of data obtained from a random sample of Korean American elderly (≥ 60 years) in a major metropolitan city on the East coast ($N = 205$) found that adult children were the main source of support utilized by elders, even when the elder had a living spouse (Han et al., 2006). Korean elderly persons often live with their children and heavily rely on them for a variety of needs. Studies have reported that ethnic minorities have stronger kinship ties (Green, 1999; Gustavson & Lee, 2004), whereas white older adults often prefer to live alone and to be independent (Johnson & Barer, 1997; Silverstein & Litwak, 1993). This unique caregiving structure may reflect the fact that adult children of certain ethnic groups (e.g., subgroups of Asian Americans with a large proportion of immigrants such as Chinese and Korean) often act as brokers between a confined ethnic community and the wider mainstream society for their old parents.

Informal caregivers are the backbone of the health care system. While this care is not paid, the economic value of informal care is substantial in chronic medical conditions such as dementia (Langa et al., 2001; Ernst & Hay, 1997; Zhu et al., 2006), cancer (Hayman et al., 2001), stroke (Hickenbottom et al., 2002), or depression (Langa et al., 2004). The total economic value of informal caregiving in the U.S. has been estimated to be \$257 billion annually, or more than twice the amount paid for home care and nursing home care combined, and comparable to 20% of all health care spending (Arno, 2002). Certain chronic

conditions appear to be associated with higher informal caregiving cost. For example, a recent analysis of a nationally representative survey of people age 70 years or older ($N = 6,649$) revealed that caregiving associated with depressive symptoms in elderly Americans represents a yearly cost of about \$9 billion (Langa et al., 2004), as compared to \$18 billion for dementia-related informal caregiving (Langa et al., 2001). Using a different, but nationally representative sample of older adults age 70 years or older ($N = 7,443$), Hickenbottom et al. (2002) estimated an annual cost of up to \$6.1 billion for stroke-related caregiving. These population-based analyses of informal care demonstrate the significant burden that these chronic conditions place both on families and on society.

Stress and Strain of Caregiving

Often, tasks performed by caregivers are physically, emotionally, socially, or financially demanding. For example, caregivers of patients with Alzheimer's disease are twice as likely to be providing constant care and 38% have been providing care for more than five years (Alzheimer's Association & National Alliance for Caregiving, 1999). The caregiving required is intense and includes assistance with activities of daily living, incontinence, feeding, and transfer or use of a wheelchair or walker. As a result, they are more likely to face family conflict, to spend less time with other family members, and to give up vacations, hobbies, and other personal activities. The NAC/AARP study (2004) reported more than one third of caregivers (37%) having no one else to provide unpaid help to the person they had cared

for during the past year, while spending 21 hours per week on average. Many had unmet needs such as finding time for themselves (35%), managing emotional and physical stress (29%), or balancing work and family responsibilities (29%).

Carrying the load of informal care can take a personal toll, placing the caregiver at heightened risk of illness and chronic disease onset. To illustrate, a review of 20 published research articles on caregiving for stroke patients (Han & Haley, 1999) found several caregiver well-being issues including depression, concern for future care, and caregiver burden. Burden was related to level of patient disability and psychological distress. Caregiver depression was related to more concern for future care, fewer social contacts, more physical symptoms in the caregiver, and stroke patient symptoms. Teel and Press (1999) reported that caregiver fatigue and sleep difficulties were significantly greater for spousal caregivers of patients with Alzheimer's disease, Parkinson's disease, or cancer when compared with a control group of little or no caregiving requirements (Teel & Press, 1999). Likewise, caregivers of patients with Alzheimer's disease were twice as likely to report emotional and physical strain as a direct result of caregiving responsibilities (Alzheimer's Association & National Alliance for Caregiving, 1999). A recent meta-analysis of 84 studies (Pinquart & Sörenson, 2003) revealed that family caregivers are under more stress, exhibit a disproportionate incidence of mental health problems such as depression, and they rate low in subjective well being, physical health, and self-efficacy (confidence) regarding caregiving-related tasks than their non-caregiving counterparts. In the NAC/AARP study (2004), 15% of caregivers

admitted to having emotional health problems directly related to caregiving. In the study (NAC/AARP, 2004), the two greatest predictors of emotional stress were the caregivers' level of burden and whether or not they felt they had had a choice in assuming the role of caregiver. Other factors associated with caregivers' emotional stress were caregivers' reported health, living in the same household with the care recipient, and being female.

Although an abundance of research has focused on the adverse psychosocial effects of caregiving, there have been a relatively fewer studies of the physical effect of caregiving. Nonetheless, researchers have suggested that the combination of loss, prolonged distress, and physical demands of caregiving may compromise caregivers' risk for physical health problems, even death (Vitaliano, 1997; Vitaliano et al., 2002). For example, in a population-based cohort study (Schulz & Beach, 1999) of 392 caregivers and 427 non-caregivers aged 66 to 96 years who were living with their spouses, caregivers who experienced mental or emotional strain related to caregiving had mortality risks 63% higher than non-caregiving controls, after controlling for sociodemographic factors and morbidity. The finding suggests that having caregiver strain is an independent risk factor for mortality among older spousal caregivers. Some of this increased mortality might relate to the high cardiovascular risk profile in caregivers such as hypertension (Shaw et al., 1999), hyperlipidemia (Vitaliano, Russo, & Niaura, 1995) or reduced physical activity (Schulz et al., 1997). Recent studies have reported potential physiologic mechanisms to understand increased morbidity and premature death in caregivers. Specifically, higher levels of

proinflammatory cytokine interleukin (IL-6) and the procoagulant molecule D-dimer have been observed in Alzheimer caregivers (Lutgendorf et al., 1999; Kiecolt-Glaser et al., 2003; Von Känel et al., 2005; 2006). Elevated plasma levels of IL-6 and D-dimer have been identified as biological accompaniments of frailty (Walston et al., 2002; Cohen, Harris, & Pieper, 2003). These physiologic alterations in response to caregiving strain provide one biological pathway through which caregivers might age more rapidly and as a consequence manifest increased morbidity (e.g., coronary artery disease) at a younger age than their non-caregiving counterparts might.

Coping with Stress

Previous studies have reported various coping mechanisms used by caregivers to deal with the demands of caregiving. The most common are praying and seeking guidance and support from friends or relatives. For example, nearly three quarter (73%) of the national sample of caregivers in the NAC/AARP study (2004) reported praying as a way to cope with difficulties of caregiving. Differences were found among ethnic groups in using this method; African American (84%) and Hispanic (79%) caregivers used prayer significantly more than white (71%) or Asian American (50%) caregivers. The result is partly consistent with other studies in which African American caregivers were found to use prayer and faith in God more often than White caregivers (Picot, 1995; Wykle & Segall, 1991; Haley et al., 2004). This strong cultural practice of religiosity may be based on African American caregivers' belief that God is a part of their informal support to

the same extent as family, friends, and neighbors (Wood & Parham, 1990).

While three in five caregivers (61%) in the NAC/AARP study (2004) were found to use behavioral coping strategies such as seeking guidance and support from friends or relatives, women tended to adopt this method (67%) more than men (51%). Seeking information and help through the Internet is another increasingly popular form of behavioral coping. In the NAC/AARP study (2004), the Internet ranked number one as the place family caregivers turned to for information about caregiving (29%). Those more likely to use the Internet as a tool for dealing with caregiving demands included: Asian Americans (43%), college educated (41%), upper income (44% of those making \$100,000) caregivers as well as those caring patients with Alzheimer's disease (42%).

Higher levels of emotion-focused coping (i.e., avoidance, escape) are associated with greater negative effects of caregiving such as depression (Haley et al., 1996; McCausland & Pakenham, 2003). Studies have demonstrated that certain groups of caregivers (e.g., African American) tend to use more emotion-focused coping (e.g., escape, avoidance, worrying). For example, Knight and colleagues (2000) studied a sample of 41 African American and 128 non-African American caregivers of dementia patients and found that African American caregivers had lower levels of burden but equal levels of depression and anxiety than White caregivers. Using structural equation modeling, Knight et al. confirmed a tendency of African American caregivers to use emotion-focused coping and, therefore, increase emotional distress, despite their lower appraisal of caregiving as burdensome. In their study of 123 White

and 74 Black family caregivers of patients with Alzheimer's disease and other progressive dementias, Haley et al. (1996) also found that African American caregivers reported higher levels of avoidance coping and lower levels of behavior-focused coping than White caregivers. These results indicate that caregiving does not affect well-being through direct paths, but they are mediated by coping strategies.

Formal Support Services in the Community

Long-term care represents a variety of services provided over an extended period of time to people who need help to perform because of cognitive impairment or loss of muscular strength or control. Care may include rehabilitative therapies, skilled nursing, and palliative care, as well as a wide range of supportive personal care and social services (e.g., nursing home care, personal care attendants, home health care, adult day care, or assisted-living facilities). These services have been critical to sustaining family stability, avoiding out-of-home placements, and reducing health risks as a result of stress associated with continuous caregiving (Abelson, 1999; Zarit et al., 1998; Wade et al., 2003).

While 70% to 80% of U.S. national long-term care funds for older people are still spent on institutionalized care (e.g., nursing homes), home and community-based services (HCBS) have grown in importance to the long-term care system over the past decade, and are increasingly used by older adults (AARP, 2003; Polivka & Zayac, 2006). The goal of HCBS is to help people with disabilities live in the community for as long as

possible and function as independently as possible (Stone, 2000). On-going shifts from institutionalized care to HCBS are due, in part, to the Olmstead decision, a 1999 U.S. Supreme Court ruling, giving citizens with disabilities--including frail elders--the right to care in their own homes and communities when appropriate. HCBS are also responsive to the preferences of frail elders. For example, according to a national sample study (AARP, 2003) of people with disabilities age 50 or older, 87% favored receiving assistance with everyday activities in their own home, and only 6% wanted to have nursing home care for 24-hour needs.

The NAC/AARP study (2004) reported that approximately half of all caregivers (48%) used HCBS such as respite services, adult day services, home-delivered meals, or transportation services. Studies have found, however, considerable variation across groups in the use of HCBS. Cultural and demographic factors (e.g., age, gender, race/ethnicity) may affect use of these formal support services. For example, a recent analysis of the 1998 Medical Expenditure Panel Survey found that use of HCBS increased sharply with age (AARP, 2003). In the analysis (AARP, 2003), women age 50 and older were more likely than men to use HCBS. Race and ethnicity also influence formal service utilization. Researchers have illustrated that African American and Hispanic caregivers tend to use more informal as opposed to formal support services in the community than White caregivers (Cox & Monk, 1990; Miller & Guo, 2000). Language barriers, dissatisfaction with the services or cultural misunderstandings (Levkoff, Levy, & Weitzman, 1999; Delgado & Tennstedt, 1997) have been suggested as reasons for the underutilization of

formal services by these ethnic groups. The studies point to the need to develop more culturally relevant support services for use by caregivers of different ethnic groups.

Caregiver Support Interventions

Caregivers provide the bulk of long-term care in the community (Spillman & Pezzin, 2000), which is often a complex responsibility, involving emotional support, household management, medical care, decision-making, and dealing with a variety of agencies (e.g., insurance company). One national survey (N = 1,002) found that 43% of caregivers performed at least one medical task, defined as bandaging and wound care, operating medical equipment, or managing a medication regimen (Donelan et al., 2002). Yet, formal instruction is sporadic and inadequate and caregivers have reported strong needs for information and training. For example, in the NAC/AARP study (2004), 73% of caregivers reported needing more information on a variety of caregiving issues such as medication, managing challenging behaviors (e.g., wandering) or incontinence or toileting problems. Minority caregivers (Hispanic 80%, African American 75% and Asian American 73%) were much more likely to say they needed more help with information than white caregivers (64%).

While a number of supports through public and private programs (e.g., adult day care services, respite services, increased social support) have been identified as helpful interventions (Chappell & Reid, 2002; Zarit et al., 1998), the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program is one of the most ambitious

interventions designed to date in order to address the causes of stress among caregivers. The multi-site trial of multiple interventions began in 1995 and is targeting caregivers of dementia patients, who operate under some of the most difficult caregiving situations (Schultz, 2000). Among the interventions in the REACH program have been behavioral skills and management training, a telephone-based intervention of automated monitoring and personal support services, family therapy, mood management classes, and environmental skill-building support (Schultz et al., 2003). Study findings have included significant reduction in caregiver burden and depression (Gitlin et al., 2003). The study also demonstrated that involving patients and families through interventions tailored to the caregivers' needs is an important element in producing positive results in research on caregivers of people with dementia (Brodsky et al., 2003).

Recommendations

Caregiving research has come a long way over the last two decades. While there are numerous potential areas for research, this review presents several research agenda that build upon accumulated knowledge and experience through previous caregiving research. The following research agenda are diverse but not mutually exclusive, and are provided as examples that would extend current research.

1. Caregiver physical health

The physical health of caregivers is as important as their mental health. While caregiving stress in Alzheimer's disease has been shown to affect

caregiver physical health (Schultz et al., 1997; Schultz & Beach, 1999), current literature is limited as to whether caregiving for other chronic conditions affects caregivers' physical health. Previous studies have often used caregivers' self-rated health as their main physical health indicator (NAC/AARP, 2004; Han & Haley, 1999). Without comparison to a non-caregiver group, however, it would be hard to tease out to what extent caregiver physical health is affected by caregiving for chronic conditions (e.g., stroke). In designing studies, it would be important to investigate both caregiver and care recipient of continuing involvement of an informal family caregiver across and within different genders, ages, geographic regions, racial/ethnic groups, and by recipient health conditions. In particular, understanding the physical health effects of caregiving is of major concern for ethnic minority caregivers because of their high prevalence of informal caregiving, underutilization of formal support services, and potentially high likelihood of long-term health risks associated with caregiving without adequate outside support.

2. Positive outcomes of caregiving

Previous studies have been focused on the negative impacts of caregiving. Even though caregivers are often challenged by the huge amount of physical, emotional, and financial burden, a number of researchers have reported positive feeling about caregiver roles. For example, about 17% of caregivers of dementia and stroke patients in one study found that caregiving improved their relationship with care recipients (Draper et al., 1992). Farran et al. (1997) reported that caregivers who assigned positive meanings to their roles fared better in terms of depression and role strain. Such

positive experiences and effects of caregiving can provide a new theoretical frame to view caregiving beyond burdensome experience as highlighted in most previous research.

3. Quality of care and the outcomes of HCBS

Much of the policy preference for HCBS, together with increasing demands for HCBS, is based on the assumption that the quality of care, satisfaction with care, well-being and quality of life for people receiving these services are better than for people in institutions. There is, however, little evidence on the quality of care and the effectiveness of HCBS on caregivers' satisfaction and well-being. A primary reason may be that caregivers frequently do not feel comfortable leaving their loved one in the care of strangers (Harding & Higginson, 2001). This is particularly true for those whose cultural tradition is based on strong familism and filial piety such as Korean immigrants (Han et al., 2006). Strategies such as using faith communities to provide respite volunteers have been suggested to make HCBS more palatable to these caregivers (Hebert, Koenig, Arnold, & Schulz, 2006).

4. Technology and caregiving

Technological caregiving in the home is becoming more prevalent. Examples of technology use in the home include kidney dialysis, intravenous lines, electronic monitoring, nutritional tube feedings, or ventilators. Care recipients who are technology dependent often require constant vigilance and monitoring. The need for long-term technology re-education, support, and caregiving guidance was well demonstrated in the NAC/AARP survey (2004) and yet, has not been adequately addressed.

Informal technology caregiving success is related to caregiver and care recipient abilities to share responsibilities, to understand tasks, and to coordinate efforts with multiple health professionals (Smith, 1996). The use of technology in informal caregiving will remain a major problem for caregivers and care recipients as advances in medical technology become more common and further sophisticated. Developing appropriate lay training programs, which can help caregivers in caring for the care recipient at various stages, is critical. In the same line, it is also important to investigate the role of telehealth or technology in improving informal caregiving and strategies that enable effective caregiving with new or advanced technologies.

Conclusions

Social changes in family size, in numbers of women in the workforce, and in the increased longevity of older adults have been affecting the ability of natural caregivers to meet the needs of family members (U.S. Administration on Aging, 2003). During the next decade informal caregiving will continue to increase, there will be more employed caregivers with an increase in workplace issues, an increase in male caregivers, and an increase in long-distance caregiving (NAC/AARP, 2004). In response to the increased current and future need for informal caregiving, more research is warranted to explore the general pattern of informal caregiving and to test interventions to enhance the quality of caregiving while reducing caregiver burden across a range of caregiving populations. When the functional decline of the elderly is gradual, family members

might initially provide the care themselves. As the burden of care becomes physically or emotionally demanding or too technically complex, this informal network may start mobilizing the formal long-term care system such as HCBS (Gustavson & Lee 2004). Future studies should investigate the actual needs to be met by formal support services. As James (2005) stated, a key challenge for the 21st century will be to ensure that the dramatically added years in life expectancy in the 20th century are quality years. Caregiving research may help us to find the most effective interventions to improve the quality of life of caregivers and care recipients, reduce the burden of caregivers, and decrease the need for long-term institutionalization.

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Abstract

**The Experiences and Challenges of Caregivers
of Frail or Chronically Ill Elderly:
An Integrative Review**

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BACKGROUND: Social, legal, and economic factors have changed the delivery of care to elderly who are frail and/or chronically ill. Increasing number of the elderly are now treated in the community, while living with or in close proximity to their family. It is evident that families play a major role of support for elderly persons in our society. This paper provides a review and analysis of studies that have investigated informal caregiving issues encompassing physical, psychological, emotional, and social domains.

RESULTS OF THE REVIEW: Family caregiving often interfered with workplace and other responsibilities, creating physical, emotional, and financial stress for caregivers. Relatively high volumes of research addressed caregiving issues in the families of Alzheimer patients and in the areas of emotional and psychological impact of caregiving. Few studies explicitly investigated the role of informal caregivers in the management of other chronic conditions such as stroke or depression or physical consequences of long-term caregiving. While most studies were focused on negative aspects of caregiving, a few studies found it rewarding. Often the burden, stress, and socio-economic effects on the family caregiving for an elderly person were not sufficiently appreciated.

CONCLUSIONS: Positive outcomes for both the caregiver and the care recipient are more likely to occur when effective levels of collaboration exist between health professionals and caregivers. As a first step, a better understanding of the caregiving experience such as caregiver characteristics, care recipient characteristics, and social stigma is important for nurses to minimize the burden of care so that appropriate interventions can be developed. In addition, further studies are needed to examine the role and needs of informal caregivers in the care of increasing number of frail and/or chronic ill elderly treated in the community.

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