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Analyzing data from more than 1,500 family caregivers from the 1996 National Caregiver Survey, this study documents the ways in which dementia care is different from other types of family caregiving. Not only do dementia caregivers spend significantly more hours per week providing care than nondementia caregivers, they also report greater impacts in terms of employment complications, caregiver strain, mental and physical health problems, time for leisure and other family members, and family conflict. Differential impacts remain even after controlling for intensity of caregiving involvement and sociodemographic factors. Study findings suggest the need to tailor programs and services to the unique challenges faced by dementia caregivers.
Key Words: National survey, Stressors, Families, Services

Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers

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Numerous studies carried out over the past decade have addressed the nature and extent of caregiving as well as its impacts on the health and well-being of the caregiver (e.g., Bookwala, Yee, & Schulz, 1998; Schulz & Quittner, 1998). The personal, social, and health impacts of dementia caregiving have been well documented (Schulz, O'Brien, Bookwala, & Fleissner, 1995). The direct costs of dementia care are also staggering, with recent estimates exceeding $50 billion per year (Leon, Cheung, & Neumann, 1998). With the aging of the population, the number of people in the United States aged 65 and older with Alzheimer's disease and related disorders is expected to increase from nearly two million in 1995 to nearly three million by the year 2015 (U.S. General Accounting Office, 1998).

Given the characteristic cognitive, behavioral, and affective losses associated with the progression of the disease, caring for relatives with dementia is assumed to be more difficult and burdensome than caring for loved ones with other chronic conditions and disabilities (Light, Niederehe, & Lebowitz, 1994). However, this assertion has never been adequately examined in a large, representative population that includes both dementia and nondementia caregivers.

To date, few studies have been conducted that examined differences between dementia and nondementia caregivers. The results of these prior studies have been inconsistent with respect to the impact of caregiving on dementia versus nondementia caregivers. Some studies have reported few differences between dementia and nondementia caregivers in terms of burden or depression (Cattanach & Tebes, 1991; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992). In contrast, some investigators have noted that dementia caregivers suffer more negative effects, such as increased depression and anxiety levels, than do nondementia caregivers (Hooker, Monahan, Frazier, & Shifren, 1998; Moritz, Kasl, & Berkman, 1989). However, most of these studies relied on relatively small convenience samples that were not nationally representative. In addition, these studies primarily investigated differences in caregivers' mental health and did not include detailed descriptions concerning characteristics of dementia and nondementia caregivers. Furthermore, in examining differences in mental health outcomes between dementia and nondementia caregivers, these studies did not control for other factors known to influence mental health outcomes, such as level of caregiving involvement and sociodemographics (e.g., gender, income). Thus, it remains to be seen whether differences in mental health outcomes between dementia and nondementia caregivers are due to the dementia status of care recipients or other uncontrolled factors.

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Recent innovations—such as the development of new cognitive enhancing drugs and the emergence of new residential care facilities—are likely to affect the course and care of people with dementia. Similarly, with a rapidly expanding population of older adults, smaller family sizes, and more women in the paid labor force, there are concerns regarding the availability and willingness of future generations of family caregivers (Hooyman & Gonyea, 1995; Marks, 1996; Wolf, 1994). However, functional deficits are still likely to occur, particularly at the later stages of the disease, and there is no reason to believe that, for the foreseeable future, family members will not remain primary caregivers throughout most of the course of illness. As a result, research on caregiving remains a priority because of the need to strengthen family members' abilities to provide needed care without jeopardizing caregivers' own health or well-being or relinquishing their caregiver responsibilities prematurely (Schulz & Quittner, 1998). In order to establish the different needs that dementia and nondementia caregivers may have for services, it is important to develop a detailed characterization of the differences between these two types of caregivers.

Thus, the primary purpose of this study is to provide a detailed description of the differences between dementia and nondementia caregivers with regard to several areas that are germane to caregivers' well-being. Differences between dementia and nondementia caregivers are examined in terms of who is providing care, impacts of caregiving on the caregiver (caregiver strain, role strain, family conflict), involvement in caregiving (hours spent caregiving, tasks performed), effects of caregiving on employment, and service utilization. In addition to developing a detailed description of dementia and nondementia caregivers, multivariate analyses are performed that control for factors known to influence caregivers' mental health, (e.g., gender, income and level of caregiving involvement) in order to determine whether there are differences in caregiver strain by dementia status over and above those due to other factors. Unlike prior research, differences between dementia and nondementia caregivers are investigated using nationally representative data from the 1996 National Caregiver Survey (National Alliance for Caregiving and American Association for Retired Persons [NAC/AARP], 1997). The guiding question throughout this article is how caring for someone with dementia or related problems affects the caregiving experience. In addition, implications for policy and practice will be noted.

Method

Sample

In 1996, the National Alliance for Caregiving and the American Association of Retired Persons conducted a survey to identify and profile the impacts of caregiving. Two samples were employed in this survey. One sample was a fully replicated, stratified, single-stage random-digit-dialing (RDD) sample of U.S. households with telephones generated in-house by the ICR Survey Research Group, Inc., of Media, Pennsylvania. In addition to this sample, a supplemental sample was generated from ICR's EXCEL Omnibus Service. This sample included respondents who previously had identified themselves as Black, Hispanic, or "other race" and was used to oversample by race for Black, Hispanic, and Asian caregivers. Because funds were not available to conduct interviews with non–English-speaking participants, the telephone survey was administered only to individuals previously identified by ICR as English-speaking.

In the overall sample, there was a total of 1,509 participants (623 Whites, 306 Blacks, 307 Hispanics, 264 Asians, and 9 "other") who were at least 18 years of age; the mean age of all caregivers was 46. The actual number of participants used in our analyses was somewhat smaller due to missing data on items of interest. In order to be considered a caregiver for the present study, potential respondents either currently had to be providing unpaid care or had provided unpaid care within the last 12 months to a relative or friend who was at least 50 years of age. Caregiving could include helping with personal needs, household chores, financial matters, outside service arrangement, or regular visitation. It was not necessary for the caregiver to live with the care recipient to be included in this study.

The caregivers were asked about the health status of the care recipients. Those who said they provided care to someone with Alzheimer's disease, confusion, dementia, or forgetfulness were classified as "dementia" caregivers.

Survey Format and Measures

The survey consisted of 44 questions about topics such as amount and type of care, caregiving impacts, and service utilization. This survey could be completed in about 20 minutes. Participants were assured anonymity and when contacted were told that the data would be beneficial to government and private agencies who are interested in assisting caregivers.

Amount and Type of Care

In addition to standard demographic measures, there were items concerning amount and type of care provided.

Activities of Daily Living (ADLs).—Respondents answered yes/no questions as to whether they assisted the care recipient with getting out of bed or a chair, getting dressed, getting to and from the toilet, and bathing or showering. They also were asked if they helped feed the care recipient and if they changed diapers.

Instrumental Activities of Daily Living (IADLs).—Respondents also answered yes/no questions concerning whether they managed the care recipient's finances, shopped for groceries, did the housework, prepared meals, and administered pills, medications, or injections. In addition, the caregivers reported whether they were responsible for transportation as well as arranging or supervising outside services.

Caregiving Impacts

Employment-Related Issues.—The following seven yes/no questions were used to measure the effects of caregiving on respondents who had been employed or who were currently employed while they were providing care: (1) Did you ever have to go to work late, leave work early, or take time off? (2) Did you ever have to take a leave of absence? (3) Did you ever have to go from working full-time to part-time or take a less demanding job? (4) Did you ever have to turn down a promotion? (5) Did you lose any of your job benefits? (6) Did you have to give up working entirely? (7) Did you have to choose early retirement?

Physical, Emotional, Financial, and Role Stress.—Several items assessed the various types of stress that caregivers might experience. Participants were asked about the following yes/no items: if they spent less time with other family members as a result of caregiving; if they gave up vacations, hobbies, or other activities due to caregiving; and if they suffered mental or physical problems as a result of caregiving. They also were asked to estimate the amount of money they spent in a month to fulfill caregiving duties. To measure various aspects of caregiver strain, using a scale ranging from 1 to 5, participants rated the degree of physical strain, emotional strain, and financial hardship that resulted from caregiving. In addition, caregivers were asked two questions concerning family conflict over caregiving. Caregivers were asked a yes/no question about whether other family members were doing their fair share to help with caregiving, and then they were asked to rate the degree of family conflict they experienced as a result of caregiving on a scale of 1 to 3.

Service Utilization

Caregivers were asked whether they utilized any of the following services: financial information service, support group, temporary care service, adult day care/senior center, personal or nursing care services, housework, mail service, transportation service, home modification, and assistive devices.

Caregiving Involvement Level Index

Five questions asked participants to assess different aspects of their involvement of care, such as amount of care, intensity of care, or degree of difficulty involved in informal caregiving, based on caregivers' reported experiences. As reported in *Family Caregiving in the U.S.* (NAC/AARP, 1997), a factor analysis conducted on these five questions revealed one factor that represented intensity of care. The number of hours of care provided per week and the type of care provided loaded on this construct. Based on the results of this factor analysis, a Caregiving Involvement Level index was created that combined the number of hours of care and ADL/IADL difficulties that caregivers reported (see NAC/AARP, 1997, for further details on the creation of the Caregiving Involvement Index). This intensity of care index consisted of five caregiving levels that ranged from Level 1 (20 hours or less per week and assistance with IADLs) to Level 5 (41 hours or more of care/constant care and assistance with 2 or more ADLs).

Data Analysis

To test for significant differences between dementia caregivers and nondementia caregivers, chi-square tests of independence were conducted on the yes/no survey items, and *t* tests were employed on the Likert scale items. In addition, multivariate regression analyses were performed on the caregiving strain items in order to investigate whether differences between dementia and nondementia caregivers are due to differences in the experiences of these two groups of caregivers after controlling for other factors known to influence caregiver strain.

Results

Demographic Characteristics

A summary of the demographic statistics are presented in Table 1. Women constitute the majority of caregivers whether providing care for someone with dementia (72.5%) or someone with another condition (68.1%). Both dementia and nondementia caregivers were similar in terms of socioeconomic status with comparable education and income levels. Although no differences between dementia and nondementia caregivers were found with regard to gender, marital status, income, education, and the presence of children in the household, several notable differences were observed. Dementia caregivers were more likely than nondementia caregivers to be spouses versus adult children (7.2% vs 3.1% spouses; 48.9% vs 52.8% adult children). Also, compared with nondementia caregivers, dementia caregivers were less likely to report being employed full- or part-time and were more likely to be retired (61.6% vs 68.3% employed; 16.6% vs 10.8% retired). In addition, differences were observed between dementia caregivers and nondementia caregivers with regard to the age of the caregiver and care recipient. Dementia caregivers were significantly older than nondementia caregivers ($M = 46.26$ vs $M = 42.99$) and dementia caregivers were caring for recipients who were significantly older than the recipients of nondementia caregivers ($M = 78.39$ vs $M = 75.65$). In terms of race, Black caregivers were more likely (26.9% vs 18.4%) and Asian caregivers (10.3% vs 19.4%) were less likely than their White counterparts to be caring for elders with dementia.

Number of Caregivers

The first issue of concern is documenting the number of people providing care. However, one must keep in mind that estimates of the magnitude and nature of family caregiving will be influenced by the definition of caregiving utilized (Ory, Yee, Schulz, & Tennstedt, in press). The National Alliance for Caregiving (NAC/AARP, 1997), estimated that nearly one

Table 1. Demographic Characteristics of Dementia and Nondementia Caregivers

Demographic Variable	Dementia Status		Statistic
	Dementia	Nondementia	
Mean Age	46.26 (14.85)	42.99 (14.05)	$t(1496) = 3.65$***
Mean Age of Care Recipient	78.39 (10.10)	75.65 (10.67)	$t(1496) = 4.11$***
% Female	72.5	68.1	$\chi^2(1, N = 1498) = 2.30$
Race %			$\chi^2(3, N = 1498) = 21.25$***
White	42.8	41.0	
Black	26.9	18.4	
Asian	10.3	19.4	
Hispanic	19.4	20.5	
Relationship to Recipient (%)			
Spouse/partner	7.2	3.1	Test of dementia vs nondementia for
Parent/parent-in law	48.9	52.8	spouse, parent, or other relationship:
Other family member or friend	43.9	44.1	$\chi^2(2, N = 1494) = 11.65$**
Median Income Category	$30,000–$39,999	$30,000–$39,999	
Median Highest Education Level	Some college	Some college	
Marital Status (%)			
Married/living with partner	62.3	63.8	$\chi^2(3, N = 1488) = 4.73$
Single, never married	14.2	17.4	
Divorced/separated	16.5	12.5	
Widowed	7.0	6.3	
Children Present (%)	43.5	49.0	$\chi^2(1, N = 1488) = 5.21$
Employment Status (%)			
Full- or part-time	61.6	68.3	$\chi^2(2, N = 1495) = 8.77$*
Retired	16.6	10.8	
Not employed	20.9	21.9	

Note: Values in parentheses are standard deviations.
*$p < .05$; **$p < .01$; ***$p < .01$.

in four U.S. households with a telephone contains at least one caregiver. This translates into over 22 million caregiving households nationwide that met these criteria in the past 12 months. The majority of caregiving households (approximately 18 million) are White, non-Hispanic. A dementia-related condition was reported in more than 20% of the households surveyed. Nationwide, this translates into more than five million households providing care for someone with dementia or related symptoms.

Caregiving Involvement Characteristics

In terms of time spent on caregiving, overall, dementia caregivers spent significantly more hours per week providing care than did nondementia caregivers, $t(1243) = 4.61$, $p < .001$ (see Table 2a). In order to determine whether there were significant differences between dementia and nondementia caregivers with regard to specific categories of time spent on caregiving, individuals were placed into one of five hours-of-care categories. A chi-square test performed on these data revealed additional differences between dementia and nondementia caregivers in terms of time spent caregiving per week, $\chi^2(4, N = 1414) = 28.80$, $p < .001$. As seen in Table 2b, a higher percentage of dementia caregivers provided 40 or more hours of care and constant care than did nondementia caregivers. In addition, a lower percentage of dementia caregivers than nondementia caregivers spent 8 hours or less per week

Table 2a. Means of Caregiving Involvement Characteristics for Dementia and Nondementia Caregivers

Caregiver Involvement Characteristic	Dementia	Nondementia	*t* test
Duration of Care (years)	5.10 (1.28) (n = 309)	5.07 (1.28) (n = 1,122)	$t(1429) = .056$, n.s.
Hours of Care	17.06 (17.37) (n = 251)	12.45 (14.54) (n = 994)	$t(1243) = 4.61$***

Note: Values in parentheses are standard deviations. n.s., not significant.
***$p < .001$.

Table 2b. Caregiving Hours Performed by Dementia Status (Percentages)

Caregiving Hours Performed (Average Week)	Dementia Status	
	Dementia (n = 299)	Nondementia* (n = 1,115)
≤8 hours of care	36.8	51.8
9–24 hours of care	27.1	24.4
25–39 hours of care	8.0	6.8
40+ hours of care	12.0	6.1
Constant care	16.1	10.9

*$\chi^2(4, N = 1,414) = 28.80$, $p < .001$.

Table 3. Dementia and Nondementia Caregivers Who Report Helping With ADLs/IADLs

Activity Helped With	Dementia Status (%)	
	Dementia (n = 320)	Nondementia (n = 1,178)
ADLs		
Getting out of a bed or chair	45.9 (147)	34.5*** (406)
Getting dressed	46.6 (149)	27.9*** (329)
Getting to and from the toilet	38.1 (122)	23.2*** (273)
Bathing or showering	39.4 (126)	23.0*** (271)
Continence or dealing	25.9 (83)	10.8*** (127)
Feeding him or her	33.1 (106)	16.2*** (191)
Giving pills, medications, or injections	55.0 (176)	37.1*** (437)
IADLs		
Managing finances	61.9 (198)	54.5* (642)
Grocery shopping	74.4 (238)	79.5* (937)
Housework	76.3 (244)	73.9 (871)
Preparing meals	68.4 (219)	59.8** (704)
Transportation	78.4 (251)	79.6 (938)
Arranging/supervising outside services	63.8 (204)	52.9*** (623)

Note: Values in parentheses represent the number of dementia or nondementia caregivers who responded yes to each item. *$p < .05$; **$p < .01$; ***$p < .001$ using chi-square tests of independence.

on caregiving. There was no difference between dementia and nondementia caregivers with regard to how long care had been providing to the recipient (duration of care provided; see Table 2a).

Assistance in ADLs and IADLs

There was a significant difference in the total number of activities for which the caregivers provided assistance, $t(1490) = 7.04$, $p < .001$, with dementia caregivers ($M = 7.07$) assisting with more activities than did nondementia caregivers ($M = 5.73$). When analyzing ADLs and IADLs separately, a similar pattern of results emerged. Dementia caregivers ($M = 2.29$) provided more aid with a higher total of ADLs than did nondementia caregivers ($M = 1.36$), $t(1496) = 7.86$, $p < .001$. Furthermore, as seen in Table 3, a significantly higher percentage of dementia caregivers provided assistance for each type of ADL. In addition, dementia caregivers ($M = 4.78$) also provided help for more IADLs than did nondementia caregivers ($M = 4.37$), $t(1496) = 3.47$, $p < .001$. With the exception of housework and transportation, a significantly higher percentage of dementia caregivers provided assistance for each IADL (Table 3).

Impacts of Caregiving

Effects of Caregiving on Employment.—One important area in life that caregiving can affect is employment. Table 4 shows the percentages of caregivers who experienced employment complications due to caregiving. For most employment-related items, a significantly higher percentage of dementia caregivers reported problems than did nondementia caregivers. Specifically, more dementia than nondementia caregivers reported having to take less demanding jobs, having to take early retirement, turning down a promotion, losing job benefits, and having to give up work entirely.

Physical, Emotional, Financial, and Role Stress.—The duration, amount, and intensity of caregiving tasks have been related to reported stresses and burdens, although studies repeatedly show variability based on the caregiver role and other factors. Table 5 summarizes data on reported physical, emotional, and financial strain as well as interference with other activities.

We see that, in general, many caregivers report some type of negative effect; however, those individuals caring for people with dementia are more likely to report negative effects. The impact on social and personal time is especially notable, with a greater proportion of dementia caregivers reporting having to give up pleasurable personal activities (55% vs 40.9%) or having less time for other family members (52% vs 38.1%). In addition to having less time for other relatives, dementia caregivers were more inclined than nondementia

Table 4. The Effects of Caregiving on Dementia and Nondementia Caregivers Who Have Been or Currently Are Employed

Item	Dementia Status (%)		
	Dementia (n = 239)	Nondementia (n = 944)	Chi-square Test
Did you ever have to go to work late, leave work early, or take time off?	56.9 (136)	48.6$^+$ (459)	$\chi^2(1, N = 1183) = 5.42^+$
Did you ever have to take a leave of absence?	12.1 (29)	15.3 (144)	$\chi^2(1, N = 1183) = 1.76$
Did you ever have to go from working full-time to part-time, or take a less demanding job?	13.4 (32)	6.6*** (62)	$\chi^2(1, N = 1182) = 13.29^{***}$
Did you ever have to turn down a promotion?	6.7 (16)	3.1** (29)	$\chi^2(1, N = 1182) = 6.82^{**}$
Did you lose any of your job benefits?	7.5 (18)	3.7* (35)	$\chi^2(1, N = 1182) = 6.50^*$
Did you have to give up working entirely?	9.2 (22)	5.6* (53)	$\chi^2(1, N = 1181) = 4.20^*$
Did you have to choose early retirement?	5.9 (14)	2.8* (26)	$\chi^2(1, N = 1181) = 5.61^*$

Note: Values in parentheses represent the number of dementia or nondementia caregivers who responded yes to each item. *$p < .05$; **$p < .01$; ***$p < .001$; $^+p < .10$ using chi-square tests of independence.

Table 5. The Effects of Physical, Emotional, Financial and Role Stress on Dementia and Nondementia

Item	Dementia Status (%)		Statistic
	Dementia (n = 320)	Nondementia (n = 1176)	
Give up vacations, hobbies, or your own activities (%)	55.0	40.9	$\chi^2(1, N = 1496) = 20.30$***
Less time for other family members (%)	52.0	38.1	$\chi^2(1, N = 1494) = 20.05$***
Other relatives doing their fair share of caregiving (%)	59.4	74.1	$\chi^2(1, N = 1072) = 19.03$***
Extent of family conflict over caregiving (mean of 1–3 range)	1.55 (0.96)	1.34 (0.76)	$t(1134) = 3.67$***
Emotional strain of caregiving (mean of 1–5 range)	2.99 (1.48)	2.22 (1.36)	$t(1490) = 8.74$***
Physical strain of caregiving (mean of 1–5 range)	2.40 (1.42)	1.80 (1.16)	$t(1490) = 7.72$***
Did you suffer mental or physical problems as a result of caregiving (%)	22.3	12.6	$\chi^2(1, N = 1494) = 18.66$***
Financial hardship of caregiving (mean of 1–5 range)	1.87 (1.34)	1.50 (0.99)	$t(1488) = 5.48$***
Own money spent per month (mean)	$104.00	$106.22	$t(1283) = 0.12$

Note: Values in parentheses are standard deviations.
***$p < .001$.

caregivers to perceive that other family members were not doing their fair share (74.1% vs 59.4%) of caregiving and to report a greater degree of family conflict (M = 1.55 vs M = 1.34).

In terms of emotional and physical strain, overall, caregivers reported a moderate degree of strain (means are approximately 2 to 3 on a 5-point scale). However, dementia caregivers reported a higher level of emotional (M = 2.99 vs M = 2.22) and physical strain (M = 2.40 vs M = 1.80) than nondementia caregivers. Furthermore, dementia caregivers were more likely than nondementia caregivers to mention that they had suffered mental or physical problems as a result of caregiving (22.3% vs 12.6%), although such caregivers were in the minority.

Overall, caregivers reported a low degree of financial hardship (means were between 1 and 2 on a 5-point scale), although dementia caregivers reported higher levels of financial hardship (M = 1.87 vs M = 1.50) than nondementia caregivers. However, dementia caregivers and nondementia caregivers reported spending about the same amount of money per month on caregiving (approximately $105 per month).

Impact of Caregiving on Caregiver Strain Controlling for Sociodemographics and Level of Caregiving Involvement.—Multivariate regression analyses were performed in order to determine whether there were differences among dementia and nondementia caregivers with respect to caregiving strain after controlling for sociodemographics and level of caregiving involvement. Sociodemographics, such as gender, race, education and income, have been shown in prior research to influence caregivers' well-being. For example, research has revealed that Whites, women, and those with lower incomes are at higher risk for experiencing caregiver strain or psychiatric morbidity (e.g., Draper, Poulos, Poulos, & Ehrlich, 1995; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Haley et al., 1995; Rose-Rego, Strauss, & Smyth, 1998). In addition, some research has established that level of involvement in caregiving can affect caregiver's well-being (Baumgarten et al., 1992).

Three separate multivariate regression analyses were performed using the three measures of caregiving strain (physical strain, emotional strain, and financial hardship) as dependent variables. The results of these analyses are displayed in Table 6. On Step 1, for all three regression models, we entered the control variables, which included sociodemographics (gender, age, income, education, race), and the level of caregiving involvement index variable described earlier. In order to compare racial groups with respect to caregiving strain, effect coding was performed on the race variable using White as the referent group. Effect codes were assigned that contrasted Whites with each other ethnic group (Asian, Black, Hispanic). Nine participants who described their ethnic background as other or Native American were excluded from the analyses. On Step 2 of these analyses, we entered the dementia status variable.

As a set, the control variables explained 19% of the variance in physical strain, 17% of the variance in emotional strain, and 14% of the variance in financial hardship. With regard to the sociodemographics, caregiver gender was a significant predictor of physical and emotional strain (Table 6). Similar to other research on gender and caregiving, women reported more physical and emotional strain than did men. Consistent with previous caregiving research, income was a significant predictor of physical strain and financial hardship such that those with lower incomes experienced increased financial hardship and physical strain. However, those reporting higher levels of education reported greater emotional strain. As one would expect, caregiver age significantly predicted physical strain. None of the race comparison variables were significant predictors in any of these regression analyses. In terms of caregiving involvement, caregivers with a higher level of caregiver involvement (e.g., those spending more hours on caregiving each week and those caring for recipients with more ADL difficulties) reported high levels of emotional strain, physical strain, and financial hardship.

With regard to dementia status, even after controlling for sociodemographics and caregiving involvement level, dementia status continued to be a significant predictor in all three regression equations and added modest increases in variance explained. Dementia caregivers

Table 6. Multivariate Regression Analyses of Caregiver Strain Measures Regressed on Sociodemographics, Level of Caregiver Involvement, and Dementia

Variable	Physical Strain	Emotional Strain	Financial Hardship
Step 1	$F(8,1282) = 36.85^{***}$ $R^2 = .19$	$F(8,1280) = 32.20^{***}$ $R^2 = .17$	$F(1,1282) = 25.75^{***}$ $R^2 = .14$
Race (White as referent group)			
X1 White = −1/Black = 1	.02	−.04	.02
X2 White = −1/Asian = 1	.06	−.02	.06
X3 White = −1/Hispanic = 1	−.02	−.05	−.02
Age	.05*	.04	−.04
Gender (1 = female/2 = male)	.08**	.13***	−.01
Income	−.09**	.01	−.15***
Education	.01	.06*	.03
Level of caregiving involvement	.36***	.34***	.30***
Step 2	$F(1,1281) = 13.46^{***}$ $R^2 = .01$	$F(1, 1279) = 22.18^{***}$ $R^2 = .01$	$F(1,1281) = 7.56^{**}$ $R^2 = .01$
Dementia status (1 = dementia/ 0 = nondementia)	.09***	.12***	.07**
Overall F	$F(9,1281) = 34.57^{***}$	$F(9,1279) = 31.56^{***}$	$F(9,1281) = 23.85^{***}$
Intercept (unstandardized beta)	.649***	.258	1.34***

Note: Unless otherwise noted, values displayed are standardized regression coefficients for the last step in each regression model. $^{*}p < .05$; $^{**}p < .01$; $^{***}p \leq .001$.

reported greater levels of all three types of caregiving strain (physical strain, emotional strain, and financial hardship) than nondementia caregivers.

Service Utilization

Because numerous findings in the present study show that dementia caregiving can be more burdensome than nondementia caregiving, one might expect dementia caregivers to have reported utilizing more services than did nondementia caregivers. Indeed, for most types of services, this was the case. As shown in Table 7, compared with nondementia caregivers, a significantly higher percentage of dementia caregivers reported using temporary care service, adult day care/ senior centers, personal or nursing care services, meal services, and assistive devices. In addition, a higher percentage of dementia caregivers reported making some form of home modification to provide better care. Finally, dementia caregivers were also more likely to participate in support groups.

Discussion

To summarize, analyses from a nationally representative caregiver survey (NAC/AARP, 1997) demonstrated that caregiving has greater effects on dementia caregivers than nondementia caregivers in a variety of important domains. Specifically, results from these analyses demonstrated that dementia caregivers are more involved in caregiving in terms of the hours per week that they spend on caregiving tasks as well as the number of ADL and IADL tasks with which they assist. Further, results from this study showed that dementia caregivers

Table 7. Service Utilization by Dementia and Nondementia Caregivers

Item	Dementia Status (%)		Chi-Square Tests
	Dementia (n = 310)	Nondementia (n = 1117)	
Financial Information Service	19.1 (59)	16.2 (181)	$\chi^2(1, N = 1424) = 1.41$
Support Group	9.7 (30)	5.6 (62)	$\chi^2(1, N = 1426) = 6.83^{**}$
Temporary Care Service	20.3 (63)	10.9 (122)	$\chi^2(1, N = 1426) = 18.95^{***}$
Adult Day Care/Senior Care	19.4 (60)	8.6 (96)	$\chi^2(1, N = 1426) = 29.10^{***}$
Personal or Nursing Care	47.7 (148)	32.6 (361)	$\chi^2(1, N = 1419) = 24.30^{***}$
Housework	14.9 (46)	15.7 (175)	$\chi^2(1, N = 1432) = 0.13$
Meal Service	20.4 (63)	13.0 (145)	$\chi^2(1, N = 1424) = 10.58^{***}$
Transportation Service	20.0 (62)	17.2 (191)	$\chi^2(1, N = 1423) = 1.34$
Home Modification	38.1 (90)	30.6 (290)	$\chi^2(1, N = 1184) = 4.94^{*}$
Assistive Devices	53.6 (165)	45.0 (502)	$\chi^2(1, N = 1424) = 7.15^{**}$

Note: Values in parentheses are the number of dementia or nondementia caregivers responding yes to each item. $^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$.

are affected more negatively by their caregiving responsibilities in terms of employment complications, caregiver strain, mental and physical health problems, time for leisure and other family members, and family conflict. In addition, as one would expect based on the greater burden of caregiving on dementia caregivers, those caring for someone with a dementia-related disorder were more inclined to utilize formal services than those caring for someone without a dementia-related condition. Also, multivariate analyses that controlled for sociodemographics and level of caregiving involvement demonstrated that dementia caregivers' greater strain levels appear to be due to the different experiences that dementia and nondementia caregivers have with caregiving. Thus, it appears that there is something unique about caring for a demented older adult, apart from caregiver characteristics and level of caregiving involvement, which leads dementia caregivers to experience greater strain. Perhaps, dementia caregivers experience higher levels of strain than nondementia caregivers because they more often have to contend with behavioral problems in the care recipient, such as wandering, screaming, or destroying property. As Schulz and colleagues (1995) noted in their review of the dementia caregiving literature, recipient behavior problems overwhelmingly predicted caregiver depression. Another contributing factor to the greater impact of dementia caregiving may be the caregiver's anticipation that things will only get worse and that this will happen in an unpredictable and uncontrollable manner.

Limitations

Although the present study provided a detailed characterization of the differences between dementia and nondementia caregivers, there are some acknowledged limitations that must be considered when interpreting the results from this study. First, the classification of dementia and nondementia caregivers is based on caregivers' reports of patient symptoms. In the National Caregiver Survey, caregivers were simply asked by phone whether the care recipient suffered from Alzheimer's disease, memory problems, or other mental confusion. Thus, there was no independent verification of patient status. It is possible that at least some of these caregivers were providing care to a family member suffering from other conditions, such as delirium associated with an acute illness episode. Even so, the inclusive definition of dementia used in this study is likely to dilute rather than exaggerate differences between dementia and nondementia caregivers. We suspect that a sample restricted to confirmed Alzheimer's disease caregivers would demonstrate even greater negative impact than our group of mixed dementia caregivers. A second limitation is that the results reported here are cross-sectional, and thus, implied causal inferences need to be interpreted with caution. Results from longitudinal data would allow us to establish more clearly the stability of the impact of caregiving on dementia and nondementia caregivers and enable us to better understand the nuances of different caregiving experiences.

Despite these limitations, the present study has some notable strengths. This study is the first to investigate the differences between dementia and nondementia caregivers using a fairly large, nationally representative sample. Most previous research in this area relied on small convenience samples that were drawn primarily from caregiver support groups, Alzheimer's associations, or hospitals. In addition, this study investigated differences between dementia caregivers and nondementia caregivers with regard to outcomes important to caregivers' lives besides caregivers' mental health. Furthermore, this study is the first to establish that dementia caregivers' higher burden levels are due to differences in the experiences of these two types of caregivers rather than to sociodemographic factors or caregiver involvement.

Implications for Policy and Practice

An important implication of these data is that it is not appropriate to generalize the findings from studies of dementia caregivers to nondementia caregivers and vice versa. Doing so would likely result in over- or underestimates, respectively, of the need for support and services. The strains and needs of both groups of caregivers should be acknowledged yet clearly distinguished for at least two reasons: (a) to identify accurately how best to assist caregivers in each group because their stressors, perceived stress, and resulting needs may differ; and (b) to estimate more accurately the demand for long-term care and caregiver support services (both types and amount).

Contrary to the continued concerns of public policy makers, families do not relinquish their caregiving role unnecessarily. Yet this interface between the informal and formal sources of care has been of public policy interest in response to the concern that changing social trends—smaller family size, increased geographic mobility, greater participation of women in the work force, and rising rates of marital disruption—will decrease the availability or willingness of family members to provide care to a disabled elder. Data from a longitudinal study of nondementia care by Tennstedt, Crawford, and McKinlay (1993a) support the conclusion that services are used as intended—to support and sustain the informal caregiving arrangement or to fill gaps in needed care. Although home and community-based services are used by many, informal care typically predominates in these mixed care arrangements (Tennstedt, Crawford, & McKinlay, 1993a, 1993b; Tennstedt, Harrow, & Crawford, 1996; Tennstedt, Sullivan, McKinlay, & D'Agostino, 1990). Data from this study indicate greater informal care involvement for elders with dementia than for those without dementia. In addition, results from this study suggest that dementia caregivers have a greater need for and are more likely to utilize formal services. However, longitudinal data regarding dementia care are needed before conclusions similar to those of Tennstedt and colleagues (1993a) can be drawn regarding the stability and durability of informal care for demented elders.

The findings from the National for Caregiver Survey support the notion of applying a cognitive weighting factor to the degree of ADL/IADL impairment in

establishing eligibility for services. This is consistent with the cost analyses performed by Paveza, Mensah, Cohen, Williams, & Jankowski (1998) who "suggest that changes in cognitive impairment are independent factors affecting cost regardless of the magnitude of ADL/IADL impairment" (p.79). Similar findings from the National Long-Term Care Channeling Demonstration Project were reported by Liu, McBride, and Coughlin (1990).

In sum, this study, employing national data from a survey by the National Alliance for Caregiving and the American Association for Retired Persons, has provided an important comparative snapshot of caregivers for elders with and without dementia. Specifically, results of this study showed that dementia caregivers are more affected by caregiving and utilize more formal services. However, future research conducted on longitudinal data of a comparable nature would be invaluable in helping us further understand the nuances and differences of caregiving for these distinct populations of care recipients.

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