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Effect of Caregiver Family Status on Care Recipient Symptom Severity and Caregiver Stress at Nursing Home Intake

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Abstract

The present research investigates differences between primary informal caregivers who were in the care recipient's immediate family (adult children or spouses) versus those primary caregivers who were outside the immediate family. Measurement occurred at the time of admission of the care recipient to an urban nursing home. We hypothesized that immediate family caregivers would report greater behavioral disturbance among care recipients and increased caregiver depression and stress. Data were collected from 115 consecutive caregiver-elder dyads at nursing home intake. Non-immediate family caregivers comprised 43% of the sample. Consistent with our hypotheses, immediate family caregivers reported significantly greater caregiver depression and caregiver stress. Immediate family care recipients demonstrated greater behavioral disturbance. Implications for policy and caregiver interventions are discussed.

Keywords

caregiver; family status; nursing home; obligation

As the prevalence of the older adult population booms in the United States, the individual's or family's decision to seek institutional care for an elder is quickly becoming a matter of social concern. Even with decreased rates of nursing home admissions, the sheer volume of older adults threatens our long-term care (LTC) system. The economic value of informal caregiving, the primary alternative, was estimated by Houser and Gibson (2008) at \$375 billion in 2007, exceeding total Medicaid spending that year (Burwell, Sredl, & Eiken, 2008). The present study investigates how the caregiver's relationship to the patient (immediate family versus non-immediate family) influences the decision to seek long term care.

Perceived obligation to provide care has been identified as central to descriptions of filial (Rossi & Rossi, 1990) and spousal caregiving (Mayer, 2001). Among individuals who lack immediate family, or whose immediate family members are unavailable or unwilling to provide care, alternative arrangements for informal caregiving must be devised. Spouses and adult children may be, by comparison to informal care providers from outside the immediate

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family, subject to greater perceived obligation to an ailing elder. Consequently, immediate family caregivers may tolerate greater care-recipient disability, behavioral symptoms and caregiver stress and depression than might non-immediate family caregivers. Nursing home intake represents a point at which caregivers have decided that they can no longer provide support that meets care recipient's needs. To evaluate this hypothesis, the present study compared immediate-family caregiving dyads to dyads comprised of non-immediate family members at nursing home intake.

FAMILIAL OBLIGATION

Rossi and Rossi (1990) articulate a model of caregiving obligation wherein those with the closest kinship to an elder (i.e., adult children) perceive the greatest degree of responsibility for his or her wellbeing; an effect termed kinship obligation. Rossi and Rossi further argue that social definitions of family relationships, and the obligations suggested by those relationships, are more consistent for closer kin such as children, than for more distant kin such as cousins or step-children for whom the typical degree of responsibility is less consistent between families. Consistent with Rossi and Rossi's (1990) thesis, Ganong and Coleman (2006) reported that a sample of American adults reported greater perception of caregiver obligation toward their own parents than toward step-parents. Furthermore, among adult children, perceived filial obligation directly influences the extent of caregiving involvement (Campbell & Martin-Matthews, 2008).

Similarly, many spousal caregivers report that taking care of their significant others is a deeply meaningful personal experience (Farran, Miller, & Kaufman, 1999). Within couples, style and quality of marital attachment predict willingness to provide care (Feeney & Hohaus, 2001), and elders with an emotionally close marriage are more likely to identify a spouse as their primary caregiver (Allen, Goldscheider, & Ciambrone, 1999). Mayer (2001) reported that spousal caregivers experience a compelling sense of duty despite sadness that comes from loss of the relationship with their partner.

Caregiving is typically conceptualized as a function of the care recipient's immediate family; however, there are important reasons to explore alternative sources of informal care, especially in an urban environment. America has an aging population and decreasing birthrate, creating a scarcity of immediate-family caregivers. Urban adults ages 55 to 64 years, a common demographic for caregivers, die at over 100% the rate of non-urban adults of the same age (Detroit Area Agency on Aging, 2002). Furthermore, research suggests that adult children comprise roughly 75% of caregivers in minority families, compared to 40% to 60% in non-Hispanic White families (P. Montgomery, 1996). Such underutilization of formal LTC by African American families (Dilworth-Anderson, Williams, & Gibson, 2002) may reflect socioeconomic (Dolgoft, Feldstein, & Skolnik, 1993) and cultural factors (Dilworth-Anderson, Goodwin, & Williams, 2004).

TIME TO INSTITUTIONALIZATION

A number of factors predict the time until institutionalization. For instance, In a sample of almost exclusively immediate-family caregivers, long term care placement was best predicted by caregiver depression, elder's neuropsychiatric change, caregiver employment status, and even mild ADL deficits at the time of diagnosis (Coehlo, Hooker, & Bowman, 2007). Cohen-Mansfield and Wirtz (2007) found that older care recipients who have low frequency of socializing, and meet criteria for a psychiatric diagnosis such as depression, sought LTC sooner than did their peers.

CAREGIVER FACTORS

Common caregiver factors include caregiver stress, caregiver reward and depression. Caregiver stress is described as “the extent to which the caregiver role is judged to infringe upon an individual’s life space and be oppressive” (Montgomery, 1989). By contrast, the concept of caregiver reward (Thibaut & Kelley, 1959) reflects positive aspects of caregiving such as the joy of having helped another person (Kramer, 1997). Stephens, Franks, and Townsend (1994) reported that in women’s mixed roles as caregivers, mothers and employees, caregiver rewards better accounted for well-being across multiple spheres than did caregiver stress. Caregiver depression, common among caregivers of individuals with dementia (Schulz, O’Brien, Bookwala, & Fleissner, 1995), is associated with an array of negative outcomes, including anger, which suggests the risk for harmful behavior toward the care recipient (Macneil et al., 2010).

RESEARCH QUESTIONS

The primary objectives of the present study were to determine, among incoming residents at an urban nursing home, (1) how the base rates of immediate versus extended family or non family caregiving compare; and (2) how caregiver and care recipient characteristics may differ for immediate family versus extended family or non-family caregivers with respect to caregiver demographics, caregiver stress, depression and care recipient factors such as cognitive functioning, and behavior disturbance.

Immediate family caregivers are subject to feelings of obligation to provide care. As a result, they may delay institutionalization because they are more willing to tolerate greater stress, depression and greater care recipient mood, cognitive and behavioral symptoms. Non-immediate family caregivers may seek LTC services earlier in the course of dementia or other illness. For this reason, we hypothesized that by comparison to non-immediate family caregivers, immediate family caregivers would experience more depression and strain at the time of nursing home placement. It was further hypothesized that elders entering institutional care, who have recently been in the care of an immediate family member, would have greater problems in behavioral functioning, and exhibit more dementia symptoms, particularly severe symptoms.

METHODS

Sample Description

The study investigated new nursing home residents who had an affective or cognitive impairment. The nursing home was a 250-bed facility with 98% of its long-term beds occupied by Medicaid residents. The home also had a 25-bed rehabilitation unit. Consecutive admissions were from either the rehabilitation or LTC unit. At the time of the study the nursing home, affiliated with a major urban medical center, was located 10 miles from the downtown hospitals in a large, midwestern city. Of 199 consecutively admitted long-term care residents, 169 were found to have depressive and/or cognitive impairment and because this caregiving study was nested in an integrated mental health care study only those with the above noted disorders were included. Within this group, 115 caregivers (66.9%) responded to requests to participate in the study protocol and received caregiver education if they so chose. Immediate family caregivers were identified as those who were spouses or adult children of the resident. Non-immediate family caregivers were those other than spouses or adult children of the resident. Of the 50 non-immediate family caregivers, 17 had no family relationship with the resident.

Measures

Behavior Pathology in Alzheimer's Disease Rating Scale—Measures used included the Behavior Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD; Riesberg, Bornstein, Salob, Ferris, Franssen, and Gerogotas, 1987), a 25-item assessment tool, in which the caregiver rated the presence of specific behaviors of the resident on a 4-point scale (0=not present, 3=most severe). This scale is divided into 7 pathologies: Paranoid and delusional ideation, Hallucination, Activity disturbances, Aggressiveness, Diurnal rhythm disturbances, Affective disturbance, and Anxieties and phobias. As part of the Behave-AD, caregivers were also asked to globally rate the symptoms by how troubling they were for the caregiver or how dangerous they perceived them to be for the resident (0=not at all, 1=mildly troubling, 2=moderately troubling, 3=severely troubling) and to state the most problematic specific behavior. The total score reflects the summed value of item responses. Scan and colleagues (1996) determined inter-rater reliability of the scale transculturally to be excellent, with agreement coefficients ranging from .65 to .91. Chronbach's alpha for the BEHAVE-AD scale was .756 in the present sample.

Dementia Rating Scale—The Dementia Rating Scale-2 (DRS-2; Jurica, Leitten, & Mattis, 2001) provides a general measure of cognitive ability among older adults. The DRS-2 does not produce floor effects characteristic of many instruments, and is particularly useful in assessment of low cognitive functioning (Jurica et al., 2001). The DRS-2 involved no revisions to the 36 tasks, 32 stimulus cards, five subscales or administration of the DRS, but only minor revisions to scoring guidelines. The DRS has a one-week test retest reliability of .97 and split half reliability of .90. The DRS has been found to be robust to differences in race and gender (Marcopulos, McLain, & Guiliano, 1997). Chronbach's alpha for the DRS-2 was .817 in the present sample. The DRS-2 was administered by trained research assistants supervised by a geriatric neuropsychologist.

Caregiver Stress and Rewards Scale—The Caregiver Stress and Rewards Scale assesses the stresses and rewards related to being a caregiver. This adapted scale is based on both the Kinney & Stephens (1989) Caregiving Hassles Scale and Stephens and Townsend (1997) Caregivers Stress and Rewards Scale. Caregivers rated how stressful it had been during the last two months to complete specific tasks. Each item was rated on a 5-point scale (1=not at all, 2=just a little, 3=somewhat, 4=very much, 9=inapplicable). Fourteen tasks were rated including: personal care such as grooming and dressing, bathing, feeding, toileting or problems with incontinence, and mobility. Using the same scales, caregivers were then asked to rate how rewarding their caregiving role had been in the last 2 months on six different dimensions including, "doing things to help your (parent)," "feeling needed by your (parent)," "seeing your (parent) do things for (himself/herself)," "doing things with your (parent)," "seeing your relationship with your (parent) mature and grow," "fulfilling family obligations or expectations." We used the total scores for the items in these scales as our caregiver stress and reward measures. Internal consistency was robust for both the Stress and Rewards scales, with Cronbach's alpha values of .908 and .856, respectively.

Beck Depression Inventory-II—The last assessment tool used was the Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996). Caregivers were asked to complete this 21-item questionnaire, in terms of their own depression level. They were asked to rate the presence of depressive symptoms on a 4-point Likert-type scale (0=no significant presence or change to 3=extreme presence of symptom). Items rated include sadness, pessimism, loss of pleasure, suicidal thoughts or wishes, etc. Test/retest reliability is very strong for BDI-II with a coefficient alpha of .92 (Beck et al., 1996). Factorial validity has been established by the inter-correlations of the 21 items (Beck et al., 1996). In the present sample, Cronbach's alpha for the BDI-II was .88.

Statistical Procedure

Independent samples *t*-tests were used to explore differences between the immediate family and non-immediate family caregiving dyads. Additional independent samples *t*-tests were completed for each item for measures with significant between-group differences. For between-group comparisons with unequal variances, adjusted *t*-values were interpreted (Runyon, Coleman, & Pittenger, 2000).

RESULTS

Caregiver ages in the sample ranged from 30 to 93 with a mean age of 57.13 (*SD*=13.28). The average caregiver had 13.2 (*SD*=2.3) years of education. The sample included 90 female caregivers (78.3%), 67 African American and 48 White caregivers. In this sample, 43% of the primary caregivers were not immediate family members. Family members other than spouse or child comprised 28.3% of caregivers, and 15% of caregivers were not related to the resident. The average care recipient age was 77.70 years of age (*SD*=8.62) and had 10.32 years of education (*SD*=3.16). Care recipients were predominantly female (55.3%) and African American (53.5%).

Shown in Table 1, results of the chi-square analysis indicate that the gender distribution differences by group show a trend toward significance ($\chi^2(1)=3.114$; $p=.078$), where 72% of the immediate-family and 86% of the non-immediate family caregivers are female. African Americans comprised roughly 58% of both groups ($\chi^2(1)=.002$; $p=.960$). Women continue to be the predominant caregivers for urban elders; non-immediate family caregivers almost exclusively being women. These trends are consistent with the findings of most caregiver research (Dilworth-Anderson et al., 2002).

Independent-samples *t*-tests were used to evaluate group differences. Across the *t*-tests there were significant differences between the immediate and non-immediate family group on three variables: behavioral disturbance in care recipients, caregiver stress and caregiver depression (see Table 1). To better understand these differences, we compared responses to scale items between the two groups. Risk of familywise type-1 error was controlled by applying a Bonferroni correction for the 7 comparisons of Behavioral AD items, 14 comparisons of caregiver stress items, and 19 comparisons of caregiver depression. The effective alphas were .0071, .0037, and .0027, respectively.

Specifically, immediate family caregivers reported greater care recipient behavioral disturbance than did non-family caregivers ($t(113)=2.184$; $p=.031$). Inspection of the Behavioral AD measure suggested elders in the care of immediate family members displayed greater affective disturbance ($t(113)=3.230$; $p=.002$), and anxieties and phobias ($t(113)=2.734$; $p=.007$) than did elders in the care of non-immediate family caregivers. There was a strong trend suggesting greater aggressiveness ($t(113)=2.371$; $p=.020$) among care recipients of immediate family members, but no other subscale items differed between groups.

Immediate family caregivers also reported a greater degree of caregiver stress than did caregivers from outside the immediate family ($t(101)=2.209$; $p=.029$). Although immediate family caregivers reported greater stress overall, individual caregiver stress items did not differ between groups. The greater depression reported by immediate family relative to non-immediate family caregivers was marginally significant ($t(97)=2.014$; $p=.047$). On caregiver depression items, there was a trend for immediate family caregivers to report greater sadness ($t(97)=2.113$; $p=.037$), but no other differences existed between groups. Cognitive performance of care recipients using the DRS-2 ($t(105)=-.415$; $p=.679$) did not differ

significantly between groups. Perceived caregiver reward did not differ significantly ($t(101)=-.787$; $p=.433$) between groups.

A post-hoc analysis of ethnic differences within caregiving groups was completed. By comparison with Black care recipients, White care recipients' DRS-2 scores were 16.01 points higher ($t(60)=-2.561$; $p=.013$) in the immediate family group and 16.29 points higher in the non-immediate family group ($t(43)=-2.631$; $p=.012$). Because DRS-2 scores are independent of race and gender (Marcopulos et al., 1997), these differences suggest that Black elders in this sample experienced significantly greater impairment than White care recipients. No other racial differences were found.

DISCUSSION

In the present sample, non-immediate family caregiving dyads constituted roughly 43% of the sample. The frequency of non-immediate family caregiving in the present sample was startling and indicates the importance of non-family caregivers in an urban community. Because the cases were based on consecutive admissions, the data do represent current base rates for this urban nursing home. Typically, caregiving research on elders focuses almost exclusively on immediate family, but the current data indicate that non-immediate family caregiving is a frequent occurrence in urban populations. There are likely several reasons for this high base rate of non-immediate family caregivers, including higher rates of childlessness and earlier mortality of spouses and adult children in urban populations (Lichtenberg, 1998).

The relatively high base rate of non-immediate family caregivers has significant implications for both our understanding of informal caregiving and the development of caregiver interventions. In fact, 92% of caregivers in the large (1,222 caregiving dyads), multi-site REACH research program were either spouses or children, with only 8% comprised of siblings, grandchildren, nieces and nephews; non-immediate family caregivers were excluded from this sample (Wisniewski et al., 2003). The present findings call into question the transportability of such interventions to non-family caregiving dyads. Our results suggest that interventions may be adapted for non-immediate family caregivers by emphasizing methods of coping with care recipient mood and anxiety symptoms and aggression.

Immediate family caregivers reported increased caregiver stress, depression, and sadness compared to non-immediate family caregivers. Reasons for this difference might include family members feeling greater guilt over the decision to seek LTC, grief related to loss of the loved ones' ability for self-care or loss of their own caregiving role. Family status of caregivers was not associated with elder cognitive functioning. However, elders cared for by immediate family members were found to have more severe caregiver-rated behavior disturbance than were those whose caregivers were from outside the immediate family. Specifically, caregivers of immediate family members were more likely to report care recipient aggressiveness, affective disturbance, and anxiety and phobia symptoms. There were no significant differences between groups on demographic characteristics.

Taken together, these results convey useful differences between immediate and non-immediate family caregiving for this urban population. Immediate family caregivers appeared more disposed than non-immediate family caregivers to provide care at home in the face of more problematic care recipient behaviors, often coping with aggressive behavior, care recipient sadness and anxiety. In addition, immediate family caregivers were more likely than non-immediate family caregivers to experience increased stress and depression, and particularly an acute sense of sadness. Overall, these results are consistent

with the hypothesis that perceived family obligation and attachment facilitate greater tolerance of caregiving-related burden and disordered care recipient behavior. Furthermore, this suggests that immediate family caregivers postponed use of LTC until later in the disease process. Overall, these findings fit well with Rossi and Rossi's (1990) proposal that more proximal familial relationships imply greater caregiver responsibility.

No significant differences were observed on measures of care recipient cognitive functioning. While this finding may not influence the relationship between family status and the decision to seek formal caregiving services, the absence of a significant between-group difference is consistent with past research that indicates level of cognitive functioning impacts caregivers less than does behavioral disturbance (Li, 2005).

Limitations and Future Research

One primary limitation of the present findings is that they are based on a small sample size of those patients and caregivers who were willing to participate. Nonetheless, the present data is the only dataset to our knowledge that suggests such high frequency of non-immediate family caregiving. Another limitation of the present research is that it utilizes a cross sectional design at time of admission, precluding conclusions directly addressing duration of the informal caregiving relationship. Furthermore, the present data do not permit the examination of caregiving dyads in which the decision to institutionalize is not made, and therefore is not representative of the broader aging population. The available data also does not include a measure of filial obligation, precluding an analysis of perceived obligation within the immediate and non-immediate family caregiver groups. The use of a caregiver-reported measure of behavioral disturbance provides different information than would have the report of an external rater or an objective rating scale. Although a shortcoming, the BEHAVE-AD scale is well validated (Sclan et al., 1996) and scores were based on interviews by trained research assistants. Finally, the use of a single nursing home is considered a clear limitation. However, by focusing on one site we were able to collect in-depth information on both caregivers and care recipients. Future research should utilize a multi-site design revealing how cost and quality of care factors associated with a single long-term care facility might impact the decision to institutionalize with respect to caregiving dyad family status. There is likely an interaction between characteristics of the family and the residence that drive the decision to seek institutional care.

More research is needed to better understand the impact of family relationships on the timing of the decision to seek institutional care. Of particular interest may be the contrast of rural, suburban and urban samples after controlling for SES. Improved understanding of these dynamics may eventually contribute to beneficial and more well informed decision making in domestic healthcare policy. Specifically, such findings may guide the development of future caregiver intervention programs, thereby promoting more effective utilization of long-term care resources.

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TABLE 1
Means and Standard Deviations (*SD*) of Dependent Variables and Demographic Information

Item	$n_{IF}/n_{NIF}/df^*$	Immediate family (<i>SD</i>)	Non-immediate family (<i>SD</i>)	t or (χ^2)	p -Value
Caregiver Age	63/50/111	55.71 (13.18)	58.92 (13.32)	-1.278	.204
Caregiver Gender (% Female)	65/50/1	72.3%	86.0%	(3.11)	.078
Caregiver Education	63/50/111	13.03 (2.21)	13.34 (2.40)	-.709	.480
Ethnicity (% African American)	65/50/1	58.5%	58.0%	(0.002)	.960
Dementia Rating Scale	62/45/105	95.43 (25.38)	97.38 (21.37)	-.415	.679
Behavior AD Total Severity**	65/50/113	7.46 (6.37)	4.86 (6.28)	2.184	.031
Caregiver Stress	59/44/101	19.37 (8.58)	15.27 (10.23)	2.209	.029
Caregiver Rewards	59/44/101	16.88 (5.59)	17.73 (5.312)	-.787	.433
Beck Depression-12	58/41/97	6.38 (3.76)	5.04 (3.86)	2.014	.047
Total					

Notes:

* Numbers reflect number of participants in the immediate family (*nIF*) and non-immediate family (*nNIF*) groups, respectively. Numbers in the *df* position reflect the degrees of freedom for the group comparison

** Behavior AD is a caregiver report of care recipient behavioral disturbance.