
Secondary dementia caregiving and its consequences

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Abstract

The purpose of this study was to ascertain variations between primary and “secondary” caregivers (those who play a more supplemental role in the care of a relative). Survey data were collected from a sample of dementia caregivers recruited from the University of Kentucky Alzheimer’s Disease Research Center (N = 1,016). Bivariate analyses found that primary and secondary caregivers varied on a number of background characteristics, and regression models indicated that primary caregivers provided a wider range of assistance with instrumental activities of daily living (IADLs), but not help with activities of daily living (ADLs). Primary and secondary caregivers did not differ significantly in reports of subjective health. The findings suggest that future research and interventions should be inclusive of primary and secondary caregivers.

Key words: primary caregiver, secondary caregiver, caregiver health and well-being, ADL/IADL assistance, dementia, Alzheimer’s

Introduction

A major focus of gerontological research is family care

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for disabled older adults, particularly those suffering from dementia.^{1,2} Much of this work focuses on caregivers who assume major care responsibilities, or the “primary caregivers.”³ Since one person often provides the bulk of informal assistance, such conceptual and empirical approaches are justified.⁴ However, other family members and friends (i.e., “secondary caregivers”) often provide supplemental assistance.⁵⁻⁷ The purpose of this study was to examine how primary and secondary caregivers differ on important background characteristics and the range of care provided. Moreover, this study ascertains whether primary and secondary caregivers vary in reports of subjective health. We expected the findings would expand current knowledge about the role of secondary caregivers in the informal long-term care system and may also help guide the development of interventions designed to provide relief to overburdened families.

Secondary support in family caregiving

Family members, particularly adult children, are recognized as major sources of secondary support to primary caregivers.⁸ The help provided by secondary caregivers ranges from intensive personal care (e.g., activities of daily living [ADLs] such as eating, dressing, and toileting) to instrumental tasks (e.g., instrumental activities of daily living [IADLs] such as shopping and running errands) to emotional support.^{9,10} Several studies have examined the potentially positive aspects of secondary assistance; primary caregivers with a supportive network of family and friends may have fewer care demands, experience less burden and psychological distress, and be able to delay care recipient institutionalization when compared to those without such support.¹⁰⁻¹²

Fewer studies consider the experiences of secondary caregivers. Early work using data from the National Long-Term Care Survey and the National Channeling Demonstration reported that the majority of older adults received informal care from two or more individuals.^{5,6} Follow-up studies of primary and secondary caregivers of disabled older adults reported that secondary caregivers provide supplemental (rather than complementary) help to frail older adults and offer much less assistance than primary caregivers.^{7,13} Secondary care provision also appeared closely linked to whether the secondary caregiver lived with the older adult, as opposed to level of frailty and other characteristics of the care recipient. A study of caregivers of elderly African-Americans found that informal help exchanged within families involved various types of caregiving structures (i.e., different combinations of primary, secondary, and tertiary caregivers providing assistance).¹⁴ The findings appear to support the cultural tradition of extended caregiving in African-American families. Additional work has examined agreement between primary and secondary caregiver reports on dimensions such as primary caregiver stress and health.¹⁵

Several studies have also explored whether different types of caregivers experience similar levels of distress. Kleban and colleagues reported that even though sons-in-law offered little help, many still experienced strain because of the assistance they did provide.¹⁶ Similarly, severity of cognitive impairment among people with Alzheimer's was associated with the health and well-being of spouses, adult children, and spouses of adult children.¹⁷ Empirical models of stress and depression operated in a similar fashion for primary caregivers of older adults, their husbands, and coresident children.¹⁸ While these efforts examine the influence of caregiving on multiple family members, few analyses explicitly compare primary and secondary caregiver outcomes. In a recent study of 63 pairs of primary and secondary caregivers of Alzheimer's patients, Bedard and associates found that primary caregivers reported significantly greater burden than secondary caregivers.¹⁹

Research focus

While an increasing number of research studies explore the role and importance of secondary caregivers, there are several gaps in the literature. Many of the samples included in the aforementioned studies are small (especially those focusing on dementia caregivers), making generalizations or conclusions about particular empirical findings difficult. In addition, the majority of research efforts in this area focus solely on describing

who secondary caregivers are and what they do; very few studies examine the consequences of secondary caregiving. The present study attempted to address these concerns by using information collected from a large, clinic-based sample of dementia caregivers (N = 1,016). The data available in this study allowed for the testing of three research questions/hypotheses:

1. What are the distinguishing background characteristics of primary and secondary caregivers and their loved ones? While some research has focused on differences among primary and secondary caregivers,⁷ the findings here provide additional insight into variations between the two groups.
2. Based on the findings of past research,^{7,13} we hypothesized that secondary caregivers would offer less ADL and IADL assistance to their loved ones suffering from dementia. These analyses provide support to the postulation that older adults with dementia often receive the bulk of their assistance from one family member.
3. Due to diminished care demands, we anticipated that secondary caregivers would report higher levels of subjective health than primary caregivers. Prior research suggested that secondary dementia caregivers are likely to report less burden.¹⁹ We expected similar patterns when examining more global indices of well-being.

Methods

Data

We included in this study the listed contacts of patients who visited the University of Kentucky Alzheimer's Disease Research Center (UK-ADRC) since 1989. Prior to a diagnostic assessment, the UK-ADRC identified the names and contact information of caregivers (family members, friends, or other individuals) for each patient. As of April 2001, the UK-ADRC maintained a database of 2,743 contacts.

A brief Community Care Survey (CCS) was mailed to patient contacts in May 2001. The CCS collected data on background characteristics of the caregiver, primary caregiver identification, range of care provided, caregiver subjective health, and duration of care. It was limited to one two-sided page, and follow-up queries were mailed in June 2001 to ensure a good response rate. Clinical information on care recipient background characteristics

(i.e., date of diagnosis, age, gender, education) and care recipient functional status during the most recent visit (i.e., type of diagnosis, Mini-Mental State Examination [MMSE] score, Global Deterioration Scale [GDS] score, ADL and IADL dependencies) was available from the UK-ADRC.

Sample

Of the 2,743 surveys mailed, 1,059 were returned completed. Of the 1,059 respondents, 59 were individuals who were not listed on the original UK-ADRC contact list (i.e., often additional family members assumed responsibility for the patient). There were several reasons surveys were not returned: the contact information maintained by the UK-ADRC was out of date and a correct mailing address could not be located ($n = 603$), the contact or patient was deceased ($n = 54$), or the survey was sent to an address but not returned ($n = 1,086$). Chi-square analyses found that contacts who did not return a survey were more likely to be men than women (40.6 percent vs. 31.5 percent, respectively; $p < .05$) and less likely to be a spouse of the patient (30.4 percent vs. 35.1 percent, respectively; $p < .05$) when compared to those who completed the survey. ANOVAs, however, found no differences between functional/cognitive status indicators (e.g., MMSE, GDS, ADL, and IADL dependencies) for care recipients of individuals who refused to fill out the survey and those who completed the CCS.

Exclusion criteria were applied to identify primary and secondary caregivers. Respondents who replied “no” when asked if they considered themselves the “one person who provides the most care to your loved one” (i.e., primary caregiver status) and who did not provide any assistance with ADLs or IADLs were excluded from the study, since these individuals likely had no care responsibilities ($n = 43$). Following the exclusion of these respondents, the final sample included 1,016 caregivers.

Table 1 presents background and descriptive information for the sample. As indicated, almost 89.8 percent of respondents cared for a loved one suffering from a diagnosed form of dementia ($n = 912$). Almost all of the patients not receiving a formal diagnosis of dementia were classified by UK-ADRC clinicians in consensus conferences as having “mild cognitive impairment.”²⁰ For comparison purposes, individuals who cared for nondiagnosed loved ones were included. A covariate representing formal diagnosis of dementia was incorporated in subsequent analyses.

Measures

In addition to sociodemographic characteristics, the

CCS collected various data on other aspects of the caregiving situation. Table 1 presents descriptive information on these variables.

Caregiver subjective rating of health. One item measured the overall well-being of caregivers. Caregivers were asked: “In general, would you describe your physical health as?” with the following response categories: (4) excellent, (3) good, (2) fair, and (1) poor. The one-item subjective rating of health has shown considerable use in the literature and is a potent predictor of important health outcomes in older populations.²¹

Care provision. Six yes/no items determined whether the caregiver provided ADL assistance to a loved one (help with eating/drinking, dressing/undressing, bathing/showering, using the toilet/changing diapers or pads, getting in and out of bed, getting around the house). In addition, six yes/no items measured whether caregivers ever assisted with IADLs (taking medications, cooking/preparing food, housekeeping/cleaning, doing laundry, providing transportation, managing finances). ADL and IADL tasks were summed, separately, to represent the range of assistance provided to loved ones.

Care recipient cognitive/functional status. In addition to diagnosis, the UK-ADRC provided several clinical indices of care recipient cognitive and functional status assessed during care recipients’ most recent visit. These measures including summed scores of the MMSE²² and the GDS.²³ In addition, average scores of ADL dependencies (e.g., toileting, dressing, physical ambulation, eating, grooming, bathing) and IADL dependencies (food preparation, ability to use telephone, laundry, ability to handle finances, shopping, housekeeping, medication, transportation) were included, with responses ranging from 1 = independent to 5 = totally dependent.

Caregiving onset. Three indicators measured caregiving onset in the CCS. *Symptom recognition* was determined by asking caregivers, “How long ago did you realize something was wrong with your loved one?” The second indicator, *duration of care*, was measured by asking respondents, “How long ago did you first have to start helping (her/him) do things that (she/he) was no longer able to do?” *Time since diagnosis* was collected from UK-ADRC records.

Care recipient living status. A dummy variable was created to capture care recipients’ living status (i.e., whether the relative remained in the community, was placed in a nursing home, or died) at the time of the CCS survey.

Analyses

Analysis 1: Background characteristics of primary and secondary caregivers. A series of chi-squares and ANOVAs explored significant statistical differences between primary and secondary caregivers.

Table 1. Background and descriptive data for the sample (N = 1016)

Variable	Number (n) or Mean (M)	Percent (%) or standard deviation (SD)
Primary caregiver identification (primary)*	n = 640	63.0%
Caregiver background characteristics		
Gender (female)	n = 690	67.9%
Race (Caucasian)	n = 973	95.8%
Marital status (married/living with partner)	n = 759	74.7%
Work status (working at full-/part-time job)	n = 450	44.2%
Relationship to care recipient (spouse or partner)	n = 373	36.7%
Age	M = 60.05	SD = 13.26
Education (1 = did not complete junior high; 8 = graduate degree)	M = 5.27	SD = 2.09
Annual income (1 = less than \$5,000; 10 = \$80,000 or over)	M = 7.58	SD = 2.15
Care recipient background characteristics		
Gender (female)	n = 667	65.6%
Age	M = 77.83	SD = 8.91
Education (measured in years)	M = 12.43	SD = 3.55
Caregiver subjective health (1 = poor; 4 = excellent)	M = 2.97	SD = 0.75
Care provision**		
ADL assistance (range 1 – 6)	M = 2.11	SD = 2.32
IADL assistance (range 1 – 6)	M = 4.47	SD = 2.00
Care recipient cognitive/functional status		
Care recipient was diagnosed with dementia	n = 912	89.8%
Mini-Mental State Examination (range 0 – 30)	M = 16.11	SD = 7.37
Global Deterioration Scale (range 1 – 7)	M = 4.66	SD = 1.07
ADL dependencies (range 1 – 5)	M = 1.93	SD = 0.84
IADL dependencies (range 1 – 5)	M = 2.79	SD = 0.94
Caregiving onset (measured in months)		
Time since diagnosis	M = 43.86	SD = 30.47
Duration of care	M = 50.15	SD = 31.09
Time since symptom recognition	M = 64.59	SD = 38.17
Care recipient living status (in the community)	n = 582	57.3%

*Denoted by asking, “Are you the one person who provides the most care to your loved one?” (yes/no).
**ADL = Activity of daily living; IADL = Instrumental activity of daily living.

Table 2. Analysis 2: Primary caregiving and ADL/IADL assistance (standardized regression coefficients shown)		
Variable	ADL assistance R² = .34	IADL assistance R² = .25
	β	β
Primary caregiver identification (primary)	.05	.21***
Caregiver background characteristics		
Gender (female)	.07*	.06
Race (Caucasian)	.07**	.01
Marital status (married/living with partner)	-.06	-.04
Work status (working at full-/part-time job)	-.03	-.07*
Relationship to care recipient (spouse or partner)	.09	.08
Age	-.06	-.05
Education	.01	-.01
Annual income	.03	.07
Care recipient background characteristics		
Gender (female)	.09**	.05
Age	-.05	.03
Education	-.09**	-.06
Care recipient cognitive/functional status		
Care recipient was diagnosed with dementia	.01	.08**
Mini-Mental State Examination	-.07	-.01
Global Deterioration Scale	.09*	.14***
ADL dependencies	.16***	.00
IADL dependencies	.15**	.20***
Caregiving onset		
Time since diagnosis	.13***	.08*
Duration of care	-.01	-.10*
Time since symptom recognition	.06	.14**
Care recipient living status (in the community)	-.16***	.01

* p < .05; ** p < .01; *** p < .001.

Analysis 2: Differences in care provision. The second analysis examined whether primary and secondary caregivers provided varying ranges of ADL and IADL assistance to care recipients. Two multiple regression models were conducted to determine reported differences in care provision, with ADL and IADL assistance the dependent variables and primary caregiver status as the independent variable. Covariates included caregiver and care

recipient background characteristics, care recipient functional/cognitive status, caregiving onset, and care recipient status. These covariates were selected because they may influence range of care provided above and beyond primary caregiver identification.⁷

Analysis 3: Differences in subjective health. A multiple regression was used to determine whether primary and secondary caregivers varied in reports of subjective

Table 3. Analysis 3: Primary caregiving and subjective well-being (standardized regression coefficients shown)

Variable	Subjective health $R^2 = .27$
	β
Primary caregiver identification (primary)	-.01
Caregiver background characteristics	
Gender (female)	.00
Race (Caucasian)	.05
Marital status (married/living with partner)	-.07*
Work status (working at full-/part-time job)	.09**
Relationship to care recipient (spouse or partner)	-.06
Age	-.15**
Education	.05
Annual income	.28***
Care recipient background characteristics	
Gender (female)	.08*
Age	.04
Education	.12***
Care provision	
ADL assistance	.03
IADL assistance	-.03
Care recipient cognitive/functional status	
Care recipient was diagnosed with dementia	-.03
Mini-Mental State Examination	.05
Global Deterioration Scale	-.03
ADL dependencies	-.10*
IADL dependencies	.10
Caregiving onset	
Time since diagnosis	-.02
Duration of care	-.06
Time since symptom recognition	.03
Care recipient living status (in the community)	-.07*
* $p < .05$; ** $p < .01$; *** $p < .001$.	

health in the CCS. The one-item subjective health rating was the dependent variable, while primary caregiver status was the independent variable of interest. Covariates to control for other potential influences on caregiver subjective health included background characteristics of caregivers and care recipients, care recipient cognitive/functional status, ADL and IADL care provision, caregiving onset, and care recipient status.

Results

Analysis 1: Background characteristics and caregiver identification. A series of chi-square statistics and one-way ANOVAs found several significant differences between primary and secondary caregivers. A greater proportion of secondary caregivers were working at either a full-time or part-time job (56.4 percent vs. 37.2 percent, respectively; $p < .001$). More primary caregivers were spouses of care recipients (45.9 percent vs. 21.0 percent, respectively; $p < .001$). Primary caregivers were also, on average, approximately five years older than secondary caregivers ($M = 61.99$ vs. $M = 56.74$, respectively; $p < .001$). Secondary caregivers reported more formal education than primary caregivers ($M = 5.61$ vs. $M = 5.08$; $p < .001$) and slightly higher annual incomes ($M = 8.18$ vs. $M = 7.23$; $p < .001$). More primary caregivers assisted a loved one with a diagnosis of dementia (92.0 percent vs. 85.9 percent; $p < .01$). Secondary caregivers provided help to slightly older care recipients than primary caregivers ($M = 78.69$ vs. $M = 77.33$; $p < .05$).

Analysis 2: ADL/IADL care provision and caregiving identification. Two multiple regression analyses were conducted to determine the role of primary caregiver identification in predicting range of ADL and IADL dependencies. As presented in Table 2, the regression models accounted for moderate amounts of variance in ADL provision ($R^2 = .34$) and IADL provision ($R^2 = .25$). A number of covariates were significantly associated with ADL and IADL care. However, contrary to expectation, primary caregiver identification was not significantly predictive of ADL care provision. Primary caregiving identification was significantly associated with IADL assistance; primary caregivers were more likely to report a wider range of IADL assistance than secondary caregivers ($\beta = .21$; $p < .001$).

Analysis 3: Caregiving identification and subjective health. As Table 3 shows, the regression model accounted for a moderate amount of variance in subjective health ($R^2 = .27$). As expected, a number of covariates accounted for caregiver subjective health. However, subjective ratings of health did not significantly differ between primary and secondary caregivers.

Discussion

The purpose of this study was to examine variations in the caregiving experience among primary and secondary caregivers of dementia patients. Specifically, differences in caregiving characteristics, range of care provided, and subjective health between primary and secondary caregivers were identified. Particular strengths of this analysis include the large clinic sample available to address research objectives of interest. Moreover, analyses of differences in subjective health between primary and secondary caregiving offer an important contribution to the literature by determining the ramifications of family care for individuals across contexts.

Bivariate analyses suggested several important variations in background characteristics. Primary caregivers were older, less educated, and spouses of dementia patients. As prior research suggests,²⁴ spouses are the family members most likely to assume primary care responsibilities, with adult children often in supportive roles. The findings here lend support to the “hierarchical compensatory” model of informal care; spouses are often the first line of informal caregivers to help disabled older adults, followed by adult children, siblings, or other family members. Conversely, secondary caregivers were more likely to work and to assist dementia patients who were older. The findings here, as well as in other research, suggest that inflexibility of work schedules may interfere with caregivers’ ability to restructure time accordingly.²⁵ Such work responsibilities may not allow secondary caregivers to assume more “primary” roles when providing assistance to a loved one suffering from dementia.

The comparative analysis of ADL and IADL care resulted in findings somewhat similar to past studies; primary caregivers consistently provide more types of IADL assistance than secondary caregivers.¹³ Interestingly, and contrary to our hypothesis, it appeared as though secondary caregivers were likely to provide a similar range of ADL assistance when compared to primary caregivers. It may be that many secondary caregivers are responding to the areas of greatest need for both the elderly relative and the primary caregiver; primary caregivers may require immediate help from other family members or friends with basic daily tasks such as dressing or eating with the goal of keeping a loved one at home.¹² Because of extensive ADL needs and time restrictions due to work, secondary caregivers may have been unable to assist with more instrumental tasks to help relieve the primary caregiver of additional time-intensive care demands (e.g., running errands, taking care recipient to appointments, doing housework, preparing meals, etc.).

The most striking finding—again one that was contrary to our initial hypothesis—was the lack of significant differences in subjective health between primary and secondary caregivers. As prior research on smaller samples has indicated, primary caregivers are more likely to report feelings of burden.¹⁹ However, the findings here suggest that after controlling for differences in background characteristics, care provision, caregiving onset, and care recipient cognitive/functional status, whether one is a primary or secondary caregiver does not guarantee variations in subjective health or global well-being. It appears that, regardless of caregiving role, some of the consequences related to providing assistance to a loved one suffering from dementia may be similar throughout the informal long-term care network, even when there is a primary caregiver who provides the bulk of assistance.¹⁶⁻¹⁸ The loss of intimacy or emotional exchange experienced by multiple family members within the caregiving network may operate in a similar fashion, leading to the wide-ranging effects of Alzheimer's disease or related disorders on those who provide care. Unfortunately, data were not available to explore whether emotional strain variably influenced subjective health or global well-being among primary and secondary caregivers.

In addition to a lack of emotional distress measures, there are several other limitations of this study that must be noted. While the sample was large for an analysis of Alzheimer's caregiving, it was predominately Caucasian and well-educated. More diversity is needed in analyses of caregiving to generalize results to the empirical population. Similarly, caregivers responding to the CCS were recruited from the UK-ADRC. Self-selection bias may have occurred in the sample, since individuals and their family members visiting the UK-ADRC may not be representative of dementia caregivers in the community. The present study enjoyed a good response rate, but there were a considerable number of nonresponses. A prospective longitudinal analysis that allowed for more direct study of the causal influence of primary caregiver identification on outcomes would have added to the empirical findings.

The results have important implications, particularly in the conceptualization of dementia caregiving and the development of interventions that provide support to family caregivers of Alzheimer's patients. As dementia caregiving research progressed in the past 15 years, complex stress process models were developed to describe how caregiving becomes problematic over time.¹ While grounding caregiving research in the stress process approach has greatly enhanced our knowledge of how emotional distress and negative outcomes change throughout the caregiving career, almost all of this work

has focused on primary caregivers. Some attempts have been made to determine if empirical models of stress and well-being apply across various family members,¹⁸ but more work is needed on the dynamics of dementia caregiving for secondary providers. Little is known about how the stress process operates for secondary caregivers and whether stress in secondary caregivers influences negative outcomes among secondary caregivers, primary caregivers, care recipients, or all three. Broadening the conceptual scope of dementia caregiving will provide a greater understanding of how the informal care network operates throughout the progression of chronic illness.

Similarly, the large majority of interventions, ranging from psychoeducational programs to support groups to adult day services, are targeted at primary caregivers. While primary caregivers often do provide the majority of hands-on care and are in need of relief, caregiving can occur among multiple family members and friends. Designing comprehensive, community-based psychoeducational interventions that include multiple family members may be most effective in providing emotional and psychological relief to all caregivers and, perhaps as important, offer the opportunity for cognitively impaired older adults to remain at home for as long as possible.

Acknowledgment

These analyses were supported by a grant from the National Institute on Aging (#AG05144, Alzheimer's Disease Research Center). The authors would like to thank Dr. William Markesbery and Dr. Wes Ashford for their diagnostic expertise. In addition, the authors would like to thank Amanda Rush, Niki London, Tiffany Magness, and Stephanie Mullins for their assistance with data collection and management of this study.

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