Instrumental help and caregivers′ distress: Effects of change in informal and formal help

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Abstract

Family caregivers of persons with dementia rely on a range of resources to provide care and cope with caregiving stressors. Informal (unpaid) and formal (paid) instrumental support contribute to diverse caregiver outcomes. Previous research of caregiver support has focused on subjective measures of help or has compared caregivers receiving formal services to those who do not. We focused instead on the effects of change in the amount of formal and informal instrumental assistance on caregivers' distress. We expected that greater gains in assistance would be associated with greater reduction of caregivers' distress. Increases in formal but not informal levels of assistance were associated with improvement in each measure of distress. Additional measures may be needed to fully understand the effects of informal and formal assistance.

Key words: dementia, caregiving, informal help, formal help, caregiver distress

Introduction

Caring for an elderly relative with dementia has been related to proliferation of stress for the caregiver.[1-5] Levels of burden, depression, and family conflict tend to increase, whereas physical health and well-being decline. Despite this overall pattern, great diversity in outcomes exists, with caregivers in seemingly similar situations experiencing varying degrees of stress. Caregiver and care recipient characteristics and the amount of support received are factors that may explain differential caregiver outcomes.[6-9] The present study considered the relationship between change in the hours of instrumental support caregivers received from informal (unpaid help from family and friends) and formal (paid help from nonfamily members) sources and their experience of distress.

Help received from formal and informal sources affects caregiver stress. Informal help includes emotional and instrumental assistance, which have been identified as important psychosocial resources.[1,10-13] Cross-sectional studies have identified benefits of informal support on depression, role conflict, life satisfaction, and physical health.[10-12,14] In contrast, other researchers have found no effect or negative effects of informal support on caregiver distress or perceived quality of care.[1,9,15]

The reported effects of formal instrumental assistance on caregiver distress are also equivocal. Although some researchers have identified an association between formal service use and lower levels of caregiver strain,[8,9] other researchers have reported mixed or null effects.[6,16] Finding that formal service use results in little or no benefit may be partially explained by low utilization rates.[16-18]

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Consequently, it cannot be determined if limited caregiver benefits owe to the fact that formal services are ineffective in relieving caregiver distress, or if the caregivers studied received inadequate amounts of help to make a difference.

Ensel and Lin proposed an independent stress deterrent model, in which stressors and resources impact individual distress independently with no relationship between the stressors and the resources.[19] Aneshensel and colleagues' work[1] supports the independent stress deterrent model, which added to our hypothesis that care-related strain [i.e., memory and behavior problems and dependencies in activities of daily living (ADLs)] and resources (e.g., instrumental assistance) would have independent effects on caregiver distress.

The current study provides an analysis of the relationship between change in the number of hours of informal and formal instrumental help received and change in caregiver distress over time. Data were from a larger study comparing family caregivers who used adult day services (ADS) to a control group of caregivers who did not have access to such services.[5] Whereas the larger study compared caregivers who used ADS regularly to those who did not, the present study examines change in the total amount of formal and informal assistance caregivers received, regardless of their treatment status. Change in levels of help reflects the dynamic nature of caregivers' lives (e.g., taking a vacation or having a family member visit and help with caregiving) that affects increases and decreases in the amount of assistance received. The present analysis, then, clarifies how people respond to changing levels of informal and formal help, and considers formal help from a variety of sources. We expected that a greater increase in assistance from either type—formal or informal—would be associated with greater reduction of caregiver distress.

Methods

Procedures

The present study stems from a larger quasiexperimental study comparing two groups of family caregivers recruited from two sites.[5] The treatment group included caregivers enrolling a care-recipient relative in one of 45 ADS programs in New Jersey, whereas the control group was composed of caregivers from Ohio not using ADS and where such services are not widely available. For the present analyses, these groups have been combined into a single group.

Caregivers in the larger study met the following inclusion criteria: 1) they had primary responsibility for the care recipient; 2) the care recipient had a diagnosis of dementia; 3) the caregiver received little or no formal help (i.e., no more than eight hours per week) in the month before the baseline interview; 4) the caregiver was not currently using ADS; and 5) the care recipient was mobile (a prerequisite for enrollment in most ADS programs). There were no limits on the amount of informal assistance caregivers could be receiving when they enrolled in the study.

Participants were interviewed three times during one year. The first interview was a baseline interview. For members in the treatment group, the baseline interview occurred immediately before their relative began ADS. The second interview (T2) was conducted three months later, and the third interview (T3) was conducted 12 months after the baseline interview.

In the present analyses only baseline and three-month (T2) interviews were used, for two reasons. First, considerable attrition between the second and third interviews would limit generalizability of findings.[8] Second, the initial eligibility requirements for the study limited prior use of formal help to a relatively small amount. One consequence was that formal help increased a lot during this three-month period. This change was found for the treatment group members who were using ADS and also for some members of the control group who spontaneously used a variety of community-based formal services. Change in formal help between the three-month and 12-month interviews was not as great.

Sample

Baseline and three-month interviews were completed by 432 caregivers, 405 of whom are included in the present analysis. Twenty-seven caregivers were deleted from the analyses because they were not the primary caregiver at Time 2, the care recipient was in a hospital or nursing home at Time 2, or the interview was conducted more than six weeks late. The majority of the caregivers were women (81 percent), with daughters (39 percent) and wives (30.3 percent) being the most common caregivers. Most caregivers were white (90 percent), married (80 percent), not employed (68 percent), and had at least a high school education (90 percent). The median income category was $25,000 to $29,999, and the large majority (86 percent) lived with the care recipient (Table 1).

The majority of care recipients were women (60 percent). Most were widowed (81 percent) and had been receiving care for their memory problems from their current caregiver for three years (SD, 31.28 months; range, 2 to 204 months). Alzheimer's disease was the most common diagnosis, reported for 58.7 percent of the care recipients. Impairment among care recipients was quite

Table 1. Caregiver and care recipient characteristics (N = 403)

Characteristic			Value
Caregivers	Relation (percent)	Wife	30.3
		Husband	13.6
		Daughter	39.2
		Son	4.0
		Daughter-in-law	6.0
		Son-in-law	0.5
		Other	6.5
	Race (percent)	White	89.6
		Black	9.4
		Asian	0.2
		Hispanic	0.7
	Marital status (percent)	Married	80.1
		Widowed	4.0
		Divorced	7.7
		Separated	1.2
		Never married	6.9
	Mean age (SD) (years)		60.0 (13.8)
	Range		23 – 85
Care recipients	Mean age (SD)		77.69 (8.2)
	Lives with caregivers (percent)		85.6
	Mean number of ADLs (max = 5) (SD)		2.5 (1.7)
	Mean number of IADLs (max = 5) (SD)		4.7 (0.8)
	Mean number of memory problems (max = 6) (SD)		5.3 (1.0)
	Mean number of behavior problems (max = 13) (SD)		6.6 (2.8)

high. At the baseline interview, care recipients required assistance with most of the named ADLs, independent ADLs (IADLs), and memory and behavior problems. Table 1 presents descriptive information on care recipients.

Measures

Measures for the current study included variables associated with caregiving that represent Ensel and Lin's Life Stress Process Model: stressors, caregiver distress, and resources, including measures of informal and formal support.

Stressors. Three measures of care-related stressors were used that assessed severity of the care recipient's impairment. Shortened versions of the ADL (T1a, 0.77; T2a, 0.87) and IADL[20] scales (T1a, 0.67; T2a, 0.80) were used to determine the care recipient's degree of impairment in independent and self-care tasks. Most care recipients were impaired on all IADLs; consequently, this indicator was excluded from analysis owing to lack of variability.

Two important caregiver stressors are the care recipient's behavior and memory problems. These problems were assessed separately with items from a revised, short version of the Memory and Behavior Problem Checklist (RMBPC).[21] Six dementia-related memory problems were assessed, including trouble remembering recent events and concentration difficulties (T1a, 0.39; T2a, 0.34). Fourteen behavior problems were assessed, including wandering, yelling, and incontinence (T1a, 0.68, T2a, 0.74). Caregivers were asked if the care recipient had exhibited any of these problems in the past month. Scores for memory and behavior problems were significantly correlated in the current study ($r = 0.38$, $p < 0.01$) and were summed to create a single indicator of memory and behavior problems.

Caregiver distress. Four measures were used to assess caregiver distress; two general measures (depression and anger), and two specific to the caregiving context (overload and worry/strain).

- Depression. The 20-item Center for Epidemiologic Studies Depression Scale (CES-D)[22] was used to assess depressive symptomatology (e.g., emotional distress) and how often caregivers experienced each symptom in the past week. Individual item scores were summed. Sum scores could range from 0 to 60, with a higher score associated with greater depressive symptomatology (T1a, 0.91; T2a, 0.91).

- Anger. Feelings of anger and irritation were assessed in a scale consisting of four items from the Hopkins Symptom Checklist.[23] Subjects indicated how often each statement was true for them during the past week using a 4-point Likert scale ranging from "not at all" to "very much," with higher scores indicating more anger (T1a, 0.78; T2a, 0.79).

- Overload. The 7-item measure of caregiver overload assessed the degree to which caregiving demands exhausted the individual's time and energy.[8,13] Caregivers were read statements regarding their energy level and time spent giving care. They were then asked how often each statement was true for them in the past month. Higher scores indicated greater overload (T1a, 0.73; T2a, 0.72).

- Worry/strain. The degree to which caregiving is a physical and psychological strain was assessed with eight items developed for this study.[8] Caregivers were asked how often each statement was true for them in the past month, with higher scores indicating greater levels of worry/strain (T1a, 0.79; T2a, 0.78).

Resources

Interviewers assessed the amount of instrumental assistance received from formal and informal sources in the month before the interview. Caregivers were asked if they had received help from various sources with IADLs, ADLs, sitting with the care recipient, or taking the care recipient out of the house. They were then asked how many hours of help they had received in the past month from each source of assistance. Informal help could be provided by spouses of married adult child caregivers, other family members, friends, or neighbors. Formal assistance included any aid for which caregivers paid, and that was not provided by another family member. Separate sum scores were created for informal and formal help by adding hours of help from the different sources of support.

Data analysis

Data analysis was conducted in four steps. Measures of caregiver distress were examined first to determine how change would be analyzed. Because there was no evidence of floor or ceiling effects and sufficient change from the baseline to three-month interviews was present, difference scores were used to test the relationship between change in help received and change in the dependent variables. Difference scores have been criticized for unreliability owing to measurement errors at each time of assessment that are compounded when difference scores are calculated.[24] These criticisms have been determined to be largely unfounded.[25] When there are individual differences in change, difference scores are the most direct way to evaluate change, and the reliability of the difference score in these instances can be acceptable.[25,26] An alternative to the difference score is the residual-change score, but the problem with this approach is that it assesses change in rank order among subjects on the dependent variable, and not actual change in levels.[27] An optimal approach would have been to measure three or more points in time, but that was not possible in the present study owing to the amount of attrition before the third interview.

Second, correlations were used to assess the relation of demographic variables and baseline indicators of the dependent variables. Those demographic variables significantly correlated with the dependent variables at Time 1 were retained for inclusion in the regression analyses.

Finally, a series of hierarchical linear regressions was conducted to determine the association between independent stressor variables (i.e., ADLs and memory and behavior problems), change in the amount of help received, and change in the dependent variables (i.e., anger, depression, overload, and worry/strain). Demographic variables significantly correlated with initial levels of the dependent variables were entered as the first block. Independent stressor variables were entered in the second block, including 1) change in

Table 2. Mean levels of instrumental support and caregiver distress

Variable	Baseline interview	Three-month interview
Informal help in hours (SD)	47.6 (85.0)	51.3 (89.0)
Range	0 – 744	0 – 672
Formal help in hours (SD)	3.1 (6.8)	35.4 (51.5)
Range	0 – 32	0 – 564
Anger (max = 16) (SD)	7.52 (2.85)	7.61 (2.94)
Range	4 – 16	4 – 16
Depression (max = 60) (SD)	16.03 (11.36)	15.43 (11.2)
Range	0 – 59	0 – 53
Worry (max = 32) (SD)	18.89 (4.5)	18.19 (4.5)
Range	9 – 31	9 – 32
Overload (max = 28) (SD)	21.27 (3.45)	20.73 (3.32)
Range	10 – 28	10 – 28

ADLs, 2) change in memory and behavior problems, 3) baseline levels of ADLs if they had a significant main effect in the baseline model, and 4) baseline levels of memory and behavior problems if they had a significant main effect in the baseline model. The help variables formed the third and final block with change in levels of informal assistance and change in levels of formal assistance.

Difference scores for informal and formal help received were highly positively skewed and kurtotic, and log transformations were taken to normalize distributions. Regression analyses were repeated with the untransformed and transformed values of informal and formal help. Because there were no differences in which predictors were significantly associated with the dependent variables using transformed or untransformed values, results are presented for analyses using the original untransformed values of informal and formal help.

Results

Caregiver support and distress

Levels of distress experienced by caregivers in the present study varied considerably. Similarly, caregivers reported receiving wide-ranging levels of assistance with the care recipient's care. Mean levels of caregiver outcomes as well as levels of informal and formal assistance received at baseline and three-month interviews are presented in Table 2.

Regression results

Baseline indicators of caregiver distress were regressed onto demographic characteristics, baseline levels of the care-related stressors, and baseline levels of informal and formal support. Baseline levels of the care recipient's memory and behavior problems were associated with each of the dependent variables ($p < 0.01$), with greater impairment associated with higher levels of caregiver anger, depression, worry/strain, and overload. Greater ADL impairment was associated with higher levels of caregiver overload only at the Time 1 interview ($p < 0.05$). Neither baseline levels of informal nor formal help were associated with caregiver distress at Time 1 ($p > 0.1$). Table 3 presents the results for the baseline regression analyses.

The association between change in help received and

Table 3. Baseline regression analyses				
Dependent variable		B	SE B	β
Caregiver anger	Caregiver gender	0.74	0.37	0.10*
	Caregiver age	-0.04	0.02	-0.23*
	Spousal relationship	0.41	0.41	0.07
	Baseline memory/behavior problems	0.12	0.04	0.13*
	Baseline PADL problems	0.11	0.09	0.07
	Baseline levels of informal help	-0.00	0.01	-0.02
	Baseline levels of formal help	-0.01	0.02	-0.03
	$R^2 = 0.9$; Adjusted $R^2 = 0.07$			
Caregiver depression	Caregiver gender	2.36	1.70	0.08
	Care recipient gender	-2.13	1.53	-0.09
	Spousal relationship	1.21	1.61	0.05
	Months caring for relative	0.03	0.02	0.09
	Caregiver income	-0.20	0.25	-0.04
	Caregiver education	-0.60	0.27	-0.12*
	Baseline memory/behavior problems	0.02	0.17	0.27*
	Baseline PADL problems	0.28	0.34	0.04
	Baseline levels of informal help	-0.00	0.01	-0.02
	Baseline levels of formal help	-0.00	0.08	-0.03
	$R^2 = 0.15$; Adjusted $R^2 = 0.12$			
Caregiver overload	Caregiver age	-0.04	0.01	-0.17*
	Caregiver gender	0.66	0.47	0.08
	Relative gender	-1.10	0.37	-0.16*
	Months caring for relative	0.01	0.01	0.08
	Baseline memory/behavior problems	0.22	0.05	0.21*
	Baseline PADL problems	0.25	0.10	0.13*
	Baseline levels of informal help	-0.00	0.00	-0.01
	Baseline levels of formal help	0.03	0.03	0.05
	R2 = 0.15; Adjusted R2 = 0.14			
Caregiver worry/strain	Caregiver income	-0.21	0.09	-0.11*
	Baseline memory/behavior problems	0.52	0.07	0.40*
	Baseline PADL problems	0.01	0.13	0.00
	Baseline levels of informal help	0.00	0.00	0.02
	Baseline levels of formal help	-0.03	0.03	-0.04
	$R^2 = 0.17$; Adjusted $R^2 = 0.16$			
* $p < 0.05$.				

change in caregivers' experiences of distress over three months was tested with the expectation that greater increases in help received would be associated with greater decreases (i.e., improvement) in the dependent variables.

Change in the amount of informal help caregivers received over the three-month period was not significantly associated with change in any of the dependent variables analyzed. Change in formal help was significantly negatively associated with each of the indicators of caregiver distress. That is, greater increases in levels of formal help were associated with greater decreases in anger, depression, overload, and worry/strain. The regression results are presented in Table 4.

Anger. Baseline levels of memory and behavior problems and change in memory and behavior problems were associated with change in caregiver anger over the three-month period. Caregivers whose relative had more memory and behavior problems at the baseline interview or who experienced an increase in these problems experienced an increase in anger. Greater increases in levels of formal help were associated with greater decline in anger.

Depression. None of the demographic variables or indicators of impairment were significantly associated with change in depression. Increases in formal help predicted greater decline in depressive symptomatology.

Overload. Change in levels of formal help was the only variable significantly associated with change in overload. Caregivers experiencing greater increases in formal help experienced greater declines in overload.

Worry/strain. Change in memory and behavior problems was positively associated with change in caregiver worry. Caregivers of relatives who experienced an increase in these problems were more likely to experience an increase in worry between the baseline and three-month interviews. In this model also, change in levels of formal help was negatively associated with change in worry. Caregivers with greater increases in formal help at the three-month interview experienced greater declines in worry.

Discussion

Family members who become caregivers often experience considerable physical and mental strain inherent to the caregiving role. Available resources may ease some strain associated with caregiving. Instrumental support from informal or formal helpers has been demonstrated as one way of lessening the impact of care-related stress on family caregivers' lives.[8,9,28-32]

Different studies of formal help have identified benefits of service use for family caregivers of relatives with dementia.[8,9,28] Research on in-home help and overnight respite and ADS programs reveals benefits for the caregiver that include improved mood, decreased time in caregiving activities, decreased costs to reduce burden, and lower levels of depression and anger.[28-32]

Current results demonstrate that greater increases in levels of formal help are associated with greater decline in caregiver overload, worry/strain, anger, and depression. To the degree that increases in formal assistance relieve some of the supervisory and physical care responsibilities of caregivers, they also serve to ease caregivers' overload and worry/strain. These results are consistent with other reports on the relation of the amount of formal help to caregivers' distress.[6,33] Yates, Tennstedt, and Chang reported that hours of formal help received were not associated with caregiver overload or depression.[34] This study measured hours of formal help at only one point in time, however, rather than change in formal assistance. By including data from two points of measurement, it was possible to consider the magnitude of change in the dependent variables as a result of changing levels of assistance, something that has not been done previously.

The findings of the present study suggest that neither the baseline level nor changes in informal assistance affect caregiver distress. This finding contradicts some research of informal help. Studies that found informal support affected caregiver distress have often used subjective measures,[14,29,35] such as perceived support or centrality of the helper. One study that did focus on the amount of instrumental help caregivers received reported findings similar to those of the current study, that the amount of informal support was not associated with measures of caregiver depressive symptomatology.[10]

More needs to be known about the informal help caregivers receive. The quality and utility of assistance, along with conflict between the helper and caregiver may influence the effect of informal assistance on caregivers.[29,36] It is possible that informal help does not benefit caregivers as is commonly assumed. Help from family and friends may be intertwined with feelings of guilt as well as anger and resentment. The feeling of being supported, which has been captured in previous research by subjective measures, may be more important than the amount of instrumental support received. Although the amount of change in informal help was smaller than for formal help, there was considerable intraindividual variability, with some caregivers experiencing great additions or losses of help from family and friends between the two interviews.

One limit of the current study involves reliability of estimates of help received. Interviewers worked with caregivers to help calculate help received in the prior month from each source (spouse, family, friends and

Table 4. Regression analyses for variables associated with change of levels of care-related stressors and caregiver distress

Dependent variable		B	SE B	β
Change in caregiver anger	Caregiver gender	-0.12	0.34	-0.02
	Caregiver age	-0.01	0.01	-0.06
	Spousal relationship	0.81	0.38	0.15*
	Baseline memory/behavior problems	0.09	0.04	0.11*
	Change in memory/behavior problems	0.11	0.06	0.10*
	Change in PADL problems	-0.02	0.11	-0.01
	Change in informal help	-0.00	0.01	-0.01
	Change in formal help	-0.01	0.01	-0.14*
	$R^2 = 0.05$; Adjusted $R^2 = 0.03$			
Caregiver depression	Caregiver gender	-1.33	1.41	-0.06
	Care recipient gender	-2.68	1.27	-0.15*
	Spousal relationship	-0.67	1.30	-0.04
	Months caring for relative	0.01	0.02	0.04
	Caregiver income	-0.38	0.22	-0.10
	Caregiver education	-0.05	0.23	0.01
	Baseline memory/behavior problems	-0.06	0.14	-0.02
	Change in memory/behavior problems	0.10	0.19	0.02
	Change in PADL problems	0.11	0.39	0.01
	Change in informal help	0.00	0.01	0.01
	Change in formal help	-0.02	0.01	-0.12*
	$R^2 = 0.05$; Adjusted $R^2 = 0.02$			
Caregiver overload	Caregiver age	0.01	0.01	0.06
	Caregiver gender	0.01	0.04	0.00
	Relative gender	0.05	0.30	0.01
	Months caring for relative	-0.00	0.00	-0.03
	Baseline memory/behavior problems	0.06	0.04	0.08
	Baseline PADL problems	-0.13	0.09	-0.08
	Change in memory/behavior problems	0.10	0.06	0.09
	Change in PADL problems	0.01	0.12	0.01
	Change in informal help	0.00	0.01	0.05
	Change in formal help	-0.01	0.01	-0.27*
	$R^2 = 0.10$; Adjusted $R^2 = 0.07$			
Caregiver worry/strain	Caregiver income	0.07	0.08	0.05
	Baseline memory/behavior problems	0.04	0.05	0.04
	Change in memory/behavior problems	0.06	0.15	0.02
	Change in PADL problems	0.40	0.07	0.28*
	Change in informal help	0.00	0.01	0.06
	Change in formal help	-0.01	0.01	-0.20*
	$R^2 = 0.12$; Adjusted $R^2 = 0.11$			

* $p < 0.05$.

neighbors, paid help, and other). Caregivers were prompted to think of areas in which they may have received help (e.g., IADLs or sitting with the relative) rather than simply asking how much help they had received in the last month. It is possible that formal help estimates are more reliable than estimates of informal assistance because caregivers pay for the help, or they qualify for a certain number of hours of help. Informal assistance may be regular and frequent or inconsistent and rare. Additionally, estimates of informal help may be influenced by caregivers' subjective evaluation of the usefulness of the help or the person providing it. Another limitation to interpretation of our findings is that the magnitude of the effect of formal help on the dependent variables is small. The models onto which anger, depression, overload, and worry/strain were regressed are significant but account for a small percentage of the sample's variance.

Although formal help was significantly associated with the dependent variables, the magnitude of the effect (Adjusted R^2) was small. The models onto which anger, depression, overload, and worry/strain were regressed accounted for a relatively small percentage of the sample's variance for each variable. Including additional indicators of the type of help provided during formal and informal assistance and the caregiver's evaluation, or an objective assessment of the quality and usefulness of the help would be useful in strengthening the model predicting the dependent variables.

Results of the current study indicate that greater increases in levels of formal help are more beneficial to caregivers than increases in informal assistance. As such, formal services should be made more widely available and more affordable to family caregivers of frail elderly. Although policy makers are concerned that provision of formal services will result in the withdrawal of family support, our research illustrates that formal services are essential to caregiver well-being because the amount of informal instrumental help received does not have an impact on distress.

By considering the amount, the providers, and the nature of formal and informal help, the relationship between support and caregiver outcome can be better understood. Untangling the permutations of formal and informal help can assist policy makers in determining what formal services should be provided to whom, at what level, and how informal help can be promoted to best support caregivers. The goal of providing support to family caregivers is to help meet the care recipients' needs and ease the strain caregivers experience in this difficult role. The ideal balance of informal and formal help needed cannot be ascertained without considering the multiple interacting factors that determine their effect.

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