Formal services utilization by family caregivers of persons with dementia living in rural southeastern USA

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ABSTRACT. This paper examined the service utilization by family caregivers of dementia relatives in rural Alabama, a southeastern state in the U.S. Data were collected from a probability sample of 141 caregivers living in 45 rural counties of the state. The average number of formal services used was low. The most frequently used services were visiting nurses (38.3%), home health aids (32.6%), and homemakers (24.8%). A modified stress coping model was used to predict the six most frequently used services and the overall number of services used. The dementia severity of care recipients was related to the use of home health aids, visiting nurses, case management, and home delivered meals. Caregiver physical and emotional health predicted the use of psychological/counseling services. Caregiver employment status, age, and education level were related to the use of homemakers and use of delivered meals. Practice implications for rural social workers are discussed.

Background

It has been well documented in the caregiving literature that providing care to a person with dementia can be demanding and stressful for family caregivers (Donaldson & Burns, 1999). Compared to non-dementia caregivers, dementia caregivers report greater levels of physical strain, emotional distress, hardship (Ory, Hoffman, financial Tennstedt, & Schulz, 1999). Empirical studies have suggested that use of formal services can offset the negative effects of care recipients' impairment on the psychosocial well-being of caregivers (Bass, Noelker, & Rechlin, 1996) and delay the need for institutional care of older persons with dementia (Shapiro & Taylor, 2002; Gaugler, Kane, Kane, & Newcomer, 2005). Formal community-based services provide families with the types of care that are hard to obtain from informal networks. Even though a large number of older people mainly rely on family members for assistance with their daily living, many simultaneously receive formal assistance (Houde, 1998). In addition, the relatively low cost of community services, compared to high costs of institutional care, has caught the attention of policymakers and

program administrators concerned about the mounting costs of health care. It is the purpose of this paper to examine the utilization of formal services by dementia caregivers living in a rural southeastern area of the U.S.

The past two decades have witnessed growing evidence that providing care for a demented family member can be stressful and costly, and may negatively affect caregivers' physical, emotional and psychosocial health (Donaldson & Burns, 1999). Even when services are available and affordable, research findings consistently indicate low rates of formal service use among community dwelling older people and their familial caregivers (Bookwala, et al., 2004; Pedlar & Biegel, 1999). In rural areas, the under-use of community services by older persons and their caregivers is more pervasive (Li & Blaser, 2005). Kenny and Dubay (1992) found that Medicare (a U.S. health insurance program for people aged 65 or older) patients in rural areas were 17% less likely than those in urban areas to use home health services. Kosloski et al. (2002) found that rural caregivers used respite services less than their urban counterparts. Krout and Bull (2006) pointed out that such factors as lack of public transportation, limited

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Several conceptual models have been proposed to elucidate factors that may influence service use by older adults and their family caregivers. Many studies have adopted or modified the Andersen (1995) behavior model as a theoretical framework (Borrayo, Salmon, Polivka, & Dunlop, 2002; Mitchell & Krout, 1998). The Anderson model includes three categories of predictor variables for formal service use: Predisposing, enabling, and need. Differing from the behavior model that focuses on the characteristics of service users; a second model, called a "practiceoriented model," focuses on individual and structural barriers to service use by older adults, such as their knowledge about services and service accessibility (Yeatts, Crow, & Folts, 1992). Limited studies have used a third model, a stress coping model (Lazarus & Folkman, 1984), to explore service use among family caregivers. This model suggests that seeking formal services is a way to deal with caregiving stress, and that use of formal services may mediate the relation between caregiving stressors and caregiving outcomes (Ho, Weitzman, Cui, & Levkoff, 2000).

Our study adopted the stress coping model as a framework to help identify factors that may influence formal service use. Dementia caregivers face stress from their caregiving tasks that can impact their daily lives. Particular stressors may result in differential service use by caregivers. The application of the stress coping model may lead to a better understanding of the relation between specific stressors and particular types of service use. Such knowledge may be useful for rural program planning and service delivery.

Guided by the stress coping framework, two primary categories of stressor variables were identified: caregiving-related stressors and non-caregiving related stressors. Types of caregiving-related stress (closely tied to the care recipients' characteristics) include care recipients' recent hospitalization, limitations in performing daily living activities, and dementia level (Leon et al., 2000). Other caregiving-related stress types result from caregivers' perceptions of caregiving burden and their health status (Bookwala, et al., 2004). Levels of caregiving burden have been found to be directly related to the likelihood of seeking

symptoms and their perceptions of activity restrictions have also been found to predict service use (Bookwala, et al., 2004). Non-caregiving stressors (e.g., low socioeconomic status) are imbedded in caregivers' daily lives which, combined with caregiving stress, may cause extra hardship for caregivers.

The effect of low income on service use depends on the amount of discretion t clients have in using services. Kadushin (2004) posits that when disability is low and income is high, older people can do without services or can exercise discretion to purchase services to make life easier. Caregivers who are employed while taking care of loved ones often find themselves with dual pressure resulting from work- and caregiving-related responsibilities. Though the relation between employment and service use is not consistent, it is believed that full-time while also responsibility for the care of a relative can be very stressful (Mawby, Clark, & Kalucy, 1996).

In addition to stressors, formal service use may be related to caregiver demographic characteristics, such as age, race and education. Old age predicts more service use, as age is related to declining health status and reduced functional ability (Mawby, Michael, & Kalucy, 1996). Findings with regard to the relations between race, ethnicity, and formal service use are not consistent (Bookwala, et al., 2004). Although it is generally believed that caregivers from minority backgrounds tend to rely more on support from their extended families than non-minority caregivers and, thus, are less likely to use formal services, some studies have found that ethnicity and race do not predict service use. For example, based upon a systematic analysis of conclusions from 64 studies published between 1985 and 2000, Kadushin (2004) concludes that race does not significantly influence use of formal services.

Purpose

The term "formal services" includes many possible programs and services. This study focused solely on formal community-based social and health services seeking to meet the needs of dementia patients and their family caregivers. A review of studies on the use of formal services by dementia caregivers suggests that categorization of formal services has generally been based upon the location of services. These studies have categorized community services as either provided in

Hinrichsen, & DiGiuseppe, 1998). The dichotomy of location-based categorization has several potential problems. For example, some physical services (such therapy, as occupational therapy, and respite care) can be delivered both in the home and outside the home. Bass, Looman, and Ehrlich (1992) indicated that aggregating different communitybased services together with the assumption that they have the same predictive factors is questionable. Thus, our study chose to analyze services on an individual basis.

We also found that a preponderance of previous studies used non-probability samples, and did not adequately explore factors that predicted patterns of service utilization. Using a probability sample, this study sought to identify factors that affect the use of community-based health and social services by persons with dementia and their family caregivers living in Alabama, a largely rural southeastern state in the U.S. The purpose of this study was threefold: to explore the extent of formal service utilization among rural families caring for persons with a dementia; to use a modified stress coping model to identify variables that may influence formal service use; and to identify factors that may influence the use of different service types.

Methods

This paper is based upon data from the Rural Dementia Caregiving Study, a project funded by the U.S. Agency for Health Care Research and Quality. Data were collected in Alabama, a state with a significant rural population. There were approximately 84,000 Alabamians with dementia in 2000; 70% of them lived at home and, on average, dementia family caregivers provided 35 hours of care per month (Alabama Department of Senior Services, 2005). This project used a cross-sectional design to explore service use by the study population.

Measures

DEPENDENT VARIABLE: FORMAL SERVICE UTILIZATION Formal service utilization was measured by 14 items that asked respondents whether or not they used any of 14 types of services over the past month. Total scores for formal service utilization had a possible range from 0 to 14. After examining the frequency of the 14 services, we identified the six most frequently used services (each of them used by 20% or more of the caregivers): homemaker, home health aid, home delivered cooked meals, visiting nurse, case management, and

counseling. Each of these six services was treated as outcome variables.

INDEPENDENT VARIABLES

Data on caregiver demographics included age, education and race. Care recipient-related stressors were measured in two ways. First, the functional ability of care recipients was measured by the Activity of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) scales developed by Lawton and Brody (1969). The combined ADL/IADL scale has a range from 0 to 14, with high scores indicating more difficulty performing these activities. The Cronbach's a for these combined scales was .80. Second, care recipients' cognitive ability was measured by the Dementia Severity Rating Scale (DSRS) (Clark & Ewbank, 1996). This scale contained 12 items that asked caregivers to rate the care recipient's cognitive functioning on a six-point Likert scale. Scores ranged from 0 to 60, with higher scores indicating greater cognitive dysfunction. The Cronbach's α for this scale was .90.

Three caregiver-related stressors were measured: caregiver bother due to care recipient behavioral problems; caregiver physical and emotional health status; and provision of care to a second recipient. To measure behavioral problems of dementia care recipients, we used the Revised Memory and Behavior Problem Checklist (RMBPC) from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) Project (Roth, et 2003). This 24-item instrument, administered to the caregiver, provides ratings of the occurrence of care recipient problem behaviors during the past week. For each problem behavior noted, caregivers were asked to rate how bothered they felt by that particular behavior using a Likert scale ranging from "not at all" to "very much." We divided the total bother score by the number of behavior problems reported, to obtain a mean score for this stressor.

To measure caregivers' perceived health status, we used the physical and emotional health subscale of the Consequences of Care Index (CCI) (Kosberg & Cairl, 1986). This 4-item subscale asked caregivers to respond to statements such as "I feel that caring for the care recipient has negatively affected my physical health or that of my family." The four response categories ranged from "Strongly Disagree to "Strongly Agree." Scores had a possible range from 4 to 16, with higher scores

indicating greater burden. This scale had a Cronbach's q of .74.

We created a dichotomous variable indicating whether the caregiver reported providing care to a second person. Although infrequently noted in other caregiving studies, we found that that 31 (about 22%) of the caregivers in our study provided care to a second care recipient. We assumed that such caregiving activities may cause caregivers more stress and could possibly lead to greater use of formal services.

Non-caregiving demographically-related stressors examined included a measure of subjective income adequacy and a measure of Subjective employment status. adequacy was measured by asking respondents to rate how much economic difficulty they had in meeting their basic needs. Responses were measured on a Likert scale ranging from "Not difficult at all" to "Very difficult." To measure employment status, caregivers were asked to indicate whether they were currently "Employed" or "Unemployed."

Data collection

Potential participants were initially contacted using a modified computer-assisted random digit dialing process that sampled phone numbers in non-Metropolitan Statistical Areas of Alabama (Kosberg et al., 2007). This sampling procedure allowed for the inclusion of unlisted telephone numbers. In this way, we were able to obtain a probability sample of dementia caregivers in rural areas of Alabama. Thus, we were able to reach and query a relatively invisible group of rural caregivers composed of both service users and nonservice users. Once respondents were found to meet the inclusion criteria, and indicate a willingness to participate in the study, telephone interviews were scheduled and conducted by specially trained staff from the Capstone Poll of The University of Alabama's Institute for Social Science Research.

Participants

A total of 141 research participants were recruited for this study: 67 were African Americans and 74 were non-Hispanic Whites. caregivers and dementia care Family recipients in the study either lived together in a community-based, non-institutional rural setting or lived within commuting distance (60 miles or one hour) of each other in such settings. Care recipients were 60 years old or over, and had at least moderate dementia, as

measured by a score of 8 or above on the DSRS. All respondents were self-described primary family caregivers who provided at least 10 hours a week of face-to-face assistance to meet the physical or emotional care needs of their care recipients.

As shown in Table 1, below, caregivers were mainly females, married, and Protestant. They averaged 52 years of age, and they were almost evenly divided between those who had at least a high school education and those who had attended college. Over 40% of the caregivers had yearly incomes at or below \$20,000 USD and about half believed that paying for daily living basics was somewhat or very difficult. The mean age of care recipients was 79.5 years. Over one-fifth of the caregivers reported providing care to a second recipient. These caregivers reported providing 50 hours a week to the first care recipient and 30 hours a week to the second care recipient. Also, 39% of the caregivers were employed and worked an average of 34 hours a week.

Table 1. Demographic Characteristics of Caregivers

Demographic Characteristics	N (n=141)			
Gender % female	85.1%			
Mean age	52.0			
Mean age of first care recipients	79.5			
Martial status				
% married	60.3%			
% widowed/divorced/separated	22.7%			
% never married	17%			
Education				
% less than high school	18.4%			
% high school/GED	36.9%			
% some college	29.1%			
% college graduate	15.6%			
Income				
% <\$20,000 USD	41.5%			
% \$20,000-\$40,000 USD	31.1%			
% >\$40,000 USD	27.4%			
Paying bills				
% not very difficult	48.9%			
% somewhat difficult	30.5%			
% very difficult	19.9%			
Employment status % employed	39%			
Work hours / week	34.2			
Religion % Protestant	93.6%			
Mean hours of care to 1st person	49.9			
Care to 2nd person	22%			
Mean hours of care to 2nd person	30.9			

Results

Community service utilization

The overall utilization rate of 14 community services by our sample of 141 rural dementia caregivers was low. The mean number of formal services utilized by caregivers was 2. The highest reported number of services used was 7. Over one-quarter (28%) of the caregivers reported not using any type of service. Table 2, below, shows the most frequently used services, in descending order, were visiting nurses (38%), home health aids home-makers (25%). management (21%), home delivered meals (21%), and psychological /counseling (18%). Minimally used services included senior day care (7%), respite care (6%), support groups telephone assurance transportation (6%), house repairs (4%), and recreation service (3%).

Table 2. Use of Community Services by Breaking Down Categories

	Percentage of frequency (n=141)
Visiting nurse	38.3%
Home health aids	32.6%
Homemaker	24.8%
Case management	20.7%
Cooked-meals	20.6%
Counselor/Psychologists	18.4%
Senior day care	7.1%
Physical therapist	7.1%
Respite care	6.4%
Support groups	5.0%
Telephone assurance	5.0%
Transportation	5.7%
House repairs	3.5%
Recreation	2.8%

Predicting most frequently used formal services

Focusing upon the six most frequently used formal services, Table 3, overleaf, shows logistic regression results with the individual six services as dependent variables. The use of visiting nurse services was related to severity of care recipients' dementia level (OR=1.04) and more ADL/IADL problems (OR=1.22). Home health aid use, similar to use of visiting nurses, was significantly related to more limitations of care recipients' cognitive status (OR= 1.05) and functional ability (OR=1.31). Homemaker service use was

related to caring for a second care recipient (OR=3.38) and the educational level of the caregiver (OR=1.50). Caregivers who looked after a second care recipient were three times more likely to use homemaker services than those who took care of one person. Homemaker services were also more likely to be used by persons with higher levels of education. Case management service use was related to care recipients' dementia severity (OR=1.01). Neither caregiver characteristics nor non-caregiving stressors showed a relation to the use of case management services. Home delivered meal service was used by those caring for persons who were more severely demented (OR=1.05), those who were not working (OR= .17), younger caregivers (OR=.95), and those with greater educational attainment (OR=1.50). Counseling or psychological services were significantly correlated with caregiver self-perceived physical and emotional health strain (OR=1.40). Higher scores on physical and emotional health stress were predictive of greater use of this service.

Discussion

This paper examines the utilization of different forms of community-based formal services by a probability sample of family caregivers of persons with dementia living in rural Alabama. We found the overall use of such resources by this rural population to be quite low. The mean number of services used by the caregivers in our study was 2, which is similar to the finding reported in the Bookwala et al. study (2004) mentioned earlier. Even visiting nurse services, the most frequently used service, were utilized by only 38% of the caregivers in our sample. This finding is similar to those of Gill, Hinrichsen, & DiGiuseppe (1998).

Among the six formal services used by a substantial number of families in our study, two services are related to care recipient-related stressors: visiting nurses and home health aids. Compared to these two services, other types of caregiver relief services (such as senior day care, respite care, and support groups) have been less used. We suspect that the low use of these services may be attributed to the limited availability of these services in rural settings, the lack of caregiver awareness of these service programs, and/or difficulty in service access. Exploration of the reasons for lower service utilization of caregiver relief services is needed to improve the utilization of these services by rural dementia caregivers.

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Table 3. Logistic Regression of Six Most Frequently Used Formal Services

		Visiting Nurse		Home Health Aids		Home maker		Case Management		Delivered Meals		Counselor/ Psychologist	
		В	Exp (B)	В	Exp (B)	В	Exp (B)	В	Exp (B)	В	Exp (B)	В	Exp (B)
Constant		1.72		-4.10		-8.48		-1.55		-1.93		-3.94	
Caregiving-related Stressors													
Care recipient- related stress	ADL & IADL	.20*	1.22	.27**	1.31	.13	1.14	07	.94	09	.92	05	.95
	DRS	.04*	1.04	.04*	1.05	01	1.0	.07*	1.01	.05*	1.05	.03	1.03
Caregiver- related stress	Physical/ emotional health	.01	1.0	01	1.0	.20	1.22	20	.82	12	.89	.33**	1.40
	Bother Score	02	.98	06	.94	.19	1.21	21	.81	.24	1.27	27	.77
	Caring second person ^b	.27	1.31	.14	1.15	1.21*	3.38	.033	.97	.05	1.05	.91	.40
Non-caregiving-related Stressors													
Income Ade	equacy	10	.91	.09	1.10	.31	1.36	.01	1.01	.25	1.28	.16	1.18
Employmer	nt ^a	47	.63	81	.45	43	.65	.09	1.10	-1.76**	.17	03	.97
Demographics													
Age		02	.98	02	1.0	.04	1.04	.04	1.04	06*	.95	03	.97
Education		13	.88.	.02	1.0	.34*	1.50	26	.77	.40*	1.50	.20	1.22

Note

Surprising was the low utilization of transportation services (6%), considered the "glue" of service utilization. Yet, this figure is similar to the findings of Netzer and colleagues (1997) who, in their study of 596 caregivers in four rural counties in north Florida, reported that 7% of older people used transportation services. The finding of the low use of transportation services underscores the need for further study of whether such low service use is tied to the unavailability of public transportation. unreliable infrequent or schedules, the existence of relatives or friends having cars, or due to a lack of desire to utilize public transportation. Inasmuch transportation brings together those with problems with the resources they need (especially important for those living in rural areas), our findings beg further research.

In addition to transportation services, case management services have been often discussed as playing an important role in linking families to multiple services (URV-Wong & McDowell, 1994). People who have complex physical, psychological, and social problems can greatly benefit from the use of case management. Case managers can coordinate and facilitate the use of existing resources by rural families. We found case management service users had a higher proportion of utilizing other types of services. Thus, we suspect that care recipients' dementia problems led to an involvement of case managers, who -- in turn - were instrumental in the use of other formal services.

This study identified significant correlates of the six most frequently used services for rural dementia caregivers. The level of functional ability and the dementia severity of the dementia patients largely predict the use of home health aid and visiting nurse service, findings consistent with those of Leon et al. (2000) and Li, Edwards and Morrow-Howell

^{*} p < .05., ** p <.01.

Reference group is those who do not provide care to a second person.

^b Reference group is the unemployed

(2004). We found that the caregiver burden score was not tied to service use, which was consistent with the findings of Gill, Hinrichsen, and Digiuseppe (1998). We found an inverse relation between the employment status of caregivers and their use of delivered meals, which differs from the findings of other studies. Yet, in a study focusing on dementia caregivers, Hawranik (1998) found no significant relation between dementia caregiver employment status and use of delivered meals. When we compared the unemployed caregivers in our study with those who were employed, we found that the former group spent more time providing care, had poorer health, and had lower household incomes than those who were employed. We suspect that poorer health and limited income might increase the likelihood that these unemployed caregivers were enrolled in government delivered meal programs and, as a result of that, a higher proportion of them actually used delivered meal.

Care recipient stressors were predictive of four individual types of services: home health aid, visiting nurse, delivered meals, and case management. These findings suggest that the type and extent of services used by rural dementia families are largely dependent on the need of the person with dementia. It is suspected that rural families utilize formal services as a result of outreach efforts by professionals rather than by the efforts of the caregivers, themselves, to seek services. Service use often occurs after the person with dementia, or their caregiver, is found to be eligible for a service under various social or health policies and programs.

There are several limitations in our study that need to be mentioned. This crosssectional study does not allow us to test causal relations and, thus, we are only able to speculate possible reasons for formal service use or non-use. Inasmuch as our study was state-wide, it is not possible to explore the existence of local community resources and their proximity to specific rural participants in our study. In addition, the sample size of our study limits the number of variables we were able to include in our regression model. Therefore, variables that may mediate stressors and formal service use (e.g., informal support and coping strategies) were not included in the analyses. Insurance coverage (i.e., Medicaid, a means-test health insurance program for poor older adults) may have been an important factor affecting service use, but,

unfortunately, we did not obtain data to allow us to examine this question. In addition, data that would have allowed us to examine structural and cultural variables were not obtained. Thus, though we suspect that a rural culture (resulting in distrust of public services) may have influenced some people from using formal services, we were not able to examine this question. Finally, due to the small number of identified service users, we only were able to run regression analyses on the six relatively well-used services. The small sample size of our study might have repressed the emergence of statistical significance for some of the relations between study variables.

Implications for rural gerontological social workers

Our sample of rural dementia caregivers utilized only a modest number of community resources. Services related to care recipient health needs were used more than other types of formal services, leaving us to question whether other types of caregiving supportive services are accessible to this population. We found that caregiver-related stressors (e.g., their physical and emotional health status and caring for a second person), noncaregiving-related stressors (e.g., employment status), and caregiver demographics (e.g., education level and age) were found related to separate individual types of service use.

Further research is needed to examine whether structural and cultural factors (e.g., characteristics of service agencies and rural caregivers' attitudes toward formal services) may influence the use of formal services. In addition, research efforts should conceptualize and categorize formal services in a more reasonable way. We suspect that services that mainly target caregivers and those targeting mainly care recipients may be influenced by different factors. Research is needed on larger probability samples of rural dementia caregivers, so that more sophisticated analysis methods can be employed to examine service

We think our study has practice implications for gerontological social workers. The U.S. National Family Caregiving Support Program, a nationwide recognition of the importance of family caregiving, was passed by the U.S. Congress in 2000 and, as a consequence, diverse programs have been established across the country. In Alabama, this initiative is known as the Alabama Cares Program and

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has been launched to help family caregivers with a dependent relative by providing them with a \$1000 USD voucher per year for home care. This program has shown its effectiveness in assisting family caregivers (Feinberg, Newman, & Steenberg, 2002). However, due to restrictions of personnel and financial resources, the program grows slowly and does not seem to give priority to dementia caregivers. In 2005, Alabama legislators proposed a bill that would provide an income tax credit to caregivers for home health care, personal care services or the purchase of health care equipment and supplies for elderly family members. It was not passed. On the whole, family caregiving has not received sufficient attention from the legislators.

Under such circumstances, gerontological social workers need to continue efforts to advocate for innovative programs that will assist family caregiver by either providing direct cash support to them or by allowing caregivers to have more discretion in their selection of services. Secondly, it is essential for rural gerontological social workers to recognize the urban/rural differences in the caregiving experience. Given the fact that most existing rural programs turn out to be scaled down urban programs, rural social workers need to outreach and deliver services in a way that is tailored to the needs of rural family caregivers. In addition, more professionals, such as social workers, case managers or other health service providers, should be available in rural settings to help clients reach and use services that better meet their needs. When developing and implementing new health and social service programs. administrators and planners need to make accessible more supportive services for caregivers and care recipients who live in rural settings.

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