Published in final edited form as:

J Aging Health. 2009 June ; 21(3): 528–542. doi:10.1177/0898264309332838.

Caregiving Tasks and Training Interest of Family Caregivers of Medically Ill Homebound Older Adults

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Abstract

Objectives—This study assessed the caregiving activities and training interests of family caregivers of medically ill older adults without dementia who receive home health care.

Methods—Participants were 101 family caregivers of patients from the Training in the Assessment of Depression (TRIAD) study. Caregivers were assessed using a sociodemographic questionnaire and measures of caregiver tasks and training interest.

Results—Family caregivers provided a variety of caregiving tasks and their interest in training was independent of current provision of tasks. Black caregivers expressed greater overall interest in receiving training than did White caregivers, as did younger caregivers compared to same-generation caregivers.

Discussion—Family caregivers in this study evidenced both a range of care provision and clear interest in improving caregiving skills through training. Research efforts should focus on meeting the specific training needs of family caregivers and determining the impact training can have on patient health outcomes.

Keywords

family; caregivers; home health care; training interest; assessment

The large majority of older adults will receive care from family members at some point, making family caregivers a significant component of the health care “workforce” (Schumacher, Beck, & Marren, 2006). In the United States, 21% of adults (44.4 million) provide care to another adult; 83% are family caregivers and 79% care for older adults (National Alliance for Caregiving/American Association of Retired Persons, 2004). This same study reported that family caregivers provide care to their mother (34%), grandmother (11%), and father (10%); 6% of care recipients over the age of 50 are cared for by their spouse. Family caregivers provide an array of services to their older adult family members, from providing transportation to assisting with basic needs (e.g., bathing, eating). Given the ubiquity of family caregivers who provide integral care to older adults, knowing whether and how we can enhance family caregivers’ skills and maximize their effectiveness has public health significance.

In addition to a substantial literature focused on family caregivers of dementia patients (Gallagher-Thompson & Coon, 2007; Sörensen, Pinquart, & Duberstein, 2002), other studies have looked at the kinds of caregiving behaviors and experiences of family members providing care to older adults with other medical problems, such as chronic heart failure (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006), stroke (Bakas, Austin, Jessup, Williams, & Oberst,

2004; Grant, Glandon, Elliott, Newman Giger, & Weaver, 2004; Hartke & King, 2002), Parkinson's disease (Carter et al., 1998), cancer (Bakas, Lewis, & Parsons, 2001), depression (McCusker, Latimer, Cole, Ciampi, & Sewitch, 2007), and nutritional needs (Silver, Wellman, Galindo-Ciocon, & Johnson, 2004). Family members' caregiving of older adult patients has been studied within hospice (Haley, LaMonde, Han, Burton, & Schonwetter, 2003) and hospital settings (Li, 2002; Messecar, Powers, & Nagel, 2008); however, less is known about family members involved in the care of medically ill older adults receiving home health care and the caregiving tasks involved in such care within this setting.

In keeping with a chronic disease management model within home health care (Aliotta et al., 2008; Suter et al., 2008), family members are considered powerful allies in home health care professionals' role in monitoring, treating, and managing chronic diseases and conditions (e.g., heart disease, stroke, and depression). For this reason, understanding family members' willingness to participate in such management and to learn more about specific caregiving skills is essential. In this study, we characterize the family caregivers of a sample of medically ill older adult home health care patients without dementia. We describe the range of current medical, physical, and emotional caregiving tasks reported by these family caregivers, the reasons that prevent and allow them to provide care, and also the extent to which these caregivers are interested in receiving training in caregiving tasks to enhance caregiving effectiveness. In doing so, we identify a group of family caregivers who could potentially benefit from focused caregiving training, which could strengthen chronic disease management within home health care.

Methods

Participants

The study sample comprised 101 adult family caregivers of patients newly enrolled in home health care services from agencies in Westchester County, New York. Family caregivers were recruited as part of the Training in the Assessment of Depression (TRIAD) study of geriatric patients who had recently started home health care (Bruce et al., 2007). Patients in TRIAD were 256 adults aged 65 years and older, English-speaking, and without dementia. Consistent with their need for home health services, these patients had considerable medical problems and disability, with most starting home health care following hospital discharge. Further information and details on the TRIAD study can be found elsewhere (cf. Bruce et al., 2007).

Of the 256 TRIAD patient participants, 158 gave permission for the researchers to contact a family member for interview and assessment. Ninety-eight patient participants either refused permission to contact a family member or were unable to provide a family member name. Of the 158 cases in which a family member name was provided, 101 family members (64%) provided informed consent and were assessed for the current study. Patient factors which differentiated those who provided names of family caregivers from those who did not were gender (71% of male patients provided a name versus 56% of female patients) and co-residency (74% of co-resident patients provided a name versus 40% of those who live alone). Gender and co-residency also differentiated participating family caregivers from the 57 nonparticipants: only 33% of female participants had a family member participate (versus 50% of men) and 16% of those living alone had a family member participates (versus 52% of those co-residing).

Of the 101 patients with family members who participated in the present study, 49 were men, 15 were Black or of unspecified ethnicity, and approximately two-thirds were married. The average patient age was 78 years, with a range of 65–96 years. Patient disability in activities of daily living averaged 1.97 (SD = 1.7; range = 0–6) while disability in instrumental activities of daily living averaged 4.10 (SD = 1.2; range = 0–6). Approximately half of the patients

provided information on their primary diagnosis for home health care, with cardiovascular problems being the most common (17), followed by recovery from surgery or medical procedure (14), fractures (6), and respiratory illness (6). The remainder had other medical problems, including infections, neurological problems, falls, renal failure, and cancer.

Measures

The majority of measures used in the family caregiver segment of the TRIAD study were developed specifically for the aims of this study. In addition to sociodemographic information, family members were asked about their provision of a range of caregiving tasks as well as their interest in skill training in particular caregiving tasks, using a response format of *yes*, *no*, *don't know*, or *refused*. Specifically, family members were asked if they provided the following caregiving tasks to the patient: speaking to the doctor about physical needs or about emotional needs; monitoring symptoms, medications and side-effects; assisting with arrangement of health-related services and medical insurance documentation; solving everyday problems; and providing emotional support and offering coping strategies. Other caregiving tasks covered assistance with personal care, household activities, transportation, and financial management. For purposes of analysis, a subset of caregiving tasks were summed to create a continuous variable, comprising a measurement of the number of caregiving tasks family members performed. Items that comprised this total caregiving tasks variable were selected because 1) they had a corresponding item on the training interest measure and 2) were not contingent response items (e.g., monitoring medication side-effects was asked only if the family member had responded affirmatively to the monitoring medications item). Thus, seven caregiving tasks, denoted in Table 2, were included to form the overall caregiving tasks score.

Family members were also asked whether they wished they could do more to help the patient (*yes*, *no*, *don't know*, or *refused* response format) and what prevents them from doing so (choice of time restraints, far distance, financial constraints, patient refusal of help, relationship strain, and communication problems). Another item asked if there were aspects of the family caregiver's life that make it easier to provide care (*yes*, *no*, *don't know*, or *refused* response format); if answered yes, family members could identify aspects by selecting from social support, emotional support, faith, availability of time, and financial resources.

A measure containing 10 items addressed family caregivers' interest in receiving training in a subset of the caregiving tasks included on the caregiving tasks measure. Using response options of *yes*, *no*, *don't know*, or *refused*, the measure assessed interest in training in speaking with the patient's doctor (both about physical and emotional needs), formally monitoring the patient's symptoms, monitoring the patient's medications, tracking medication side-effects, helping set up health-related services, helping to negotiate with insurance reimbursement, providing effective emotional support, and helping the patient cope better with emotional stress. In order to capture the total number of tasks in which a family member was interested in training, the sum of yes responses to seven training interest items was calculated. This overall training interest variable was comprised of training interest items that matched the seven caregiving tasks contained in the overall tasks variable.

Procedure

After receiving permission from the home health care patient, a research associate contacted that family member, explained the study protocol, and enrolled the family member into the present study if the individual provided informed consent. The research associate administered a battery of measures to the family member participant in person, when possible; otherwise, measures were administered by telephone.

Statistical Analyses

With the exception of age, years of education, length of residence with patient, overall caregiving tasks, and overall interest of receiving training, all data were categorical and thus were analyzed via frequencies and percentages. Continuous sociodemographic variables were analyzed descriptively (e.g., central tendency, standard deviation). Comparisons between caregiving tasks and training interest variables were completed using Chi-square analyses and Fisher's exact test (when cells numbers were less than five). Differences between sociodemographic groups on overall caregiving tasks and on overall interest of receiving training were analyzed using t-tests and ANOVAs; further analyses used correlation and regression to determine predictor variables for overall training interest. Given the large number of comparisons, we applied the Bonferroni correction to bivariate analyses, using the p-value of 0.001 to indicate statistical significance. Data were analyzed using SPSS software (version 14.0).

Results

Sociodemographics Characteristics of Caregivers

The majority of the 101 caregivers were U.S.-born non-Hispanic White women (Table 1). Slightly less than half (47%) of the sample were spouses of the home health care patient and 75% co-resided with the patient for whom they provided care. The average age of the family caregivers was 62.91 years (SD=13.62), most (64%) had at least some college education, and the majority had lived over 30 years with the patient.

Caregivers represented two distinct generational cohorts. Fifty-two caregivers were of the same generation as the home health care patient (i.e., spouse, significant other, sister, cousin, friend) while the others were one or two generations younger (i.e., adult child, niece, daughter-in-law, and granddaughter). Although both cohorts were similar in terms of gender, same-generation caregivers were significantly older (72.7 vs. 52.1 years) and more likely to live with the patient (96% vs. 55%). Although the majority of both generation caregivers were married, the proportion was higher among same-generation caregivers (88% vs. 51%). Similarly, 96% of same-generation caregivers lived in the same household as the patient compared with 55% of next-generation caregivers.

Family Caregiving Tasks

Table 2 lists the caregiving tasks in descending order from those most frequently provided. Most tasks were provided by a majority of family caregivers, with provision of emotional support the most common caregiving task (98%) and assistance with personal care the least common (34%). With the overall caregiving tasks continuous variable, on average family members provided 5.62 tasks (SD = 1.40; range = 2–7 tasks). There were no significant differences between generational cohorts on providing individual caregiving tasks or on the overall caregiving tasks variable ($t(99)=0.417$, $p=0.678$; same generation mean = 5.679; younger generation mean = 5.563).

When asked if there were additional things that they wished they could do with or for the patient, family caregivers responded with desire to: spend more time with the patient, help financially, encourage the patient in activity participation, and provide better living conditions, transportation, emotional support, assistance with daily needs, physical therapy, and household chores. Limited time and financial resources were common constraints on family caregivers providing additional care, while distance, patient refusal of help, relationship strain, and communication problems were also noted as barriers to caregiving. Family caregivers reported that availability of time was the most common factor that allowed them to provide care; also cited were social support, additional caregiver involvement, faith, emotional support, and

personal financial situation. A t-test on overall caregiving tasks between those who responded yes and no to wishing they could provide more care was not significant ($t(84)=-1.206$, $p=0.231$; 5.812 mean for yes, 5.460 mean for no). Another t-test on overall caregiving tasks between those who identified aspects that made it easier to provide care was also not significant ($t(94)=-0.735$, $p=0.464$; 5.647 mean for yes, 5.357 mean for no).

Family Caregiver Training Interest

The majority of family caregivers (78%) indicated interest in receiving training to improve their effectiveness in providing one or more caregiving tasks (Table 3). The level of interest was similar for those who already did or did not provide each of the tasks and there were no statistical differences between groups. The caregiving tasks with the most overall interest were coping strategies (61.3%), emotional support (53.5%), monitoring symptoms (48.5%), and medical insurance documentation (45.5%). On average, family caregivers were interested in training in 3.09 (SD = 2.45, range = 0–7) tasks. No significant difference in overall training interest existed dependent on family members' wish to provide more care ($t(85) = -0.733$, $p=0.466$; 3.270 mean for yes, 2.880 mean for no). There also was no significant difference in overall training interest based on identification of aspects that make caregiving easier for the family member ($t(94)=0.015$, $p=0.988$; 3.071 mean for yes, 3.061 mean for no).

Sociodemographic Differences in Caregiving Task Performance and Training Interest

The overall number of tasks provided by caregivers did not differ by sociodemographic characteristics of the caregivers, including gender, race, generational cohort, and whether or not the participant resided with the patient. In contrast, there was sociodemographic difference in the number of tasks in which caregivers were interested in receiving training. Black caregivers expressed greater overall interest than White caregivers in receiving training ($t(97) = -4.250$, $p<0.001$; 75.14 mean for Black, 43.95 mean for White). Caregivers who did not reside with the patient had greater interest than those who co-resided (4.191 vs. 2.812; $t(93) = 2.332$, $p = 0.022$), as did younger caregivers compared to same-generation caregivers (3.909 vs. 2.415; $t(93) = -3.014$, $p=0.003$). When these three sociodemographic characteristics were entered into a stepwise multivariate regression model to predict overall training interest, only race ($b=2.605$, $SE=0.640$, $p<0.001$) and generational cohort ($b=1.148$, $SE=0.460$, $p=0.015$) remained statistically significant predictors ($r=0.476$, $p<0.001$), explaining 22.7% of the variance.

Discussion

The major findings of this study are that family members of older medically ill home health care patients provide a large range of caregiving tasks and that many of these family members are interested in learning to provide more tasks and/or become more effective in providing caregiving tasks. Most of the family caregivers reported providing a majority of assessed caregiving tasks and provision of caregiving tasks was not significantly differentiated by any sociodemographic characteristic. Most caregivers also expressed interest in receiving further training in specific tasks; however, current provision of caregiving tasks was not directly correlated with training interest. While many caregivers who were already providing tasks expressed interest in training, there were other caregivers who were interested in training even though they were not currently assisting their family member through that particular task. Caregivers not only were eager to improve their effectiveness in caregiving, they also were eager to be trained beyond their current caregiving role. This may be for a number of reasons, for example, wanting to provide better care to their family member, wanting to feel more competent or confident in their assistance, or even preparing and anticipating caregiving needs that they would like to provide in the future. This is a heartening finding since perceived caregiving competence and tangible support from health care professionals have been

associated with optimum family caregiving, despite caregiving burden (Greenberger & Litwin, 2003).

Alongside an overall interest within the sample for caregiver training, race and generational cohort were significantly differential predictors of training interest. Increased training interest in Black caregivers is consistent with literature indicating that caregiving for elders is part of familial responsibility, a strong cultural value for Blacks (Dilworth-Anderson et al., 2005). Black caregivers are more likely to positively appraise caregiving for an older adult than are White caregivers (Lawton, Rajagopal, Brody, & Kleban, 1992). Many studies have shown that Black caregivers of older adult family members experience less stress and receive more reward from the caregiving role than their White counterparts (Chumbler, Grimm, Cody, & Beck, 2003; Roth, Ackerman, Okonkwo, & Burgio, 2008; White, Townsend, & Stephens, 2000). Strong social ties, use of multiple informal caregivers, and spirituality also have been proposed as sources of strength to Blacks in the role of caregiver (Dilworth-Anderson, Williams, & Gibson, 2002). While Black caregivers use formal caregiving services at a level similar to Whites (Pinquart & Sörensen, 2005), Black caregivers may be more dissatisfied with these services (Levkoff, Levy, & Weitzman, 1999). The value that Black family members place on providing care to older relatives may be behind the findings that Black family caregivers responded with greater overall interest in receiving training. Black caregivers may feel more personally responsible for the care of their older family member and may see training as a means to enhance commitment to this role. White family members in this sample may not have desired training to the same degree as Black family members because their older adult patients' caregiving needs were being met by home health care professionals. However, the lack of difference in overall caregiving tasks provided by Black and White family members does not support this explanation.

The greater overall interest in training among younger generation (i.e., primarily adult children) compared to same-generation (i.e., primarily spouses) caregivers is also consistent with some previous findings. Relational differences in caregiving have shown mixed results in terms of caregiver outcomes, such as caregiver burden, interest in various patient services, and physical and mental health (Barnes, Given, & Given, 1992; Chumbler et al., 2003; Cox & Albus, 2003). A meta-analysis of primarily dementia caregivers also concluded that adult children were more likely to benefit from caregiver interventions than were spousal caregivers (Sörensen et al., 2002).

This generational variation may reflect a number of differences between spousal caregivers and adult child caregivers. Adult children may have greater competing demands (e.g., employment outside the home, caring for their own children) that make acquisition of increased efficiency and competence in caregiving tasks more appealing. Potentially, adult children have had less time caregiving for their parent than a spouse has had caregiving for his or her partner (i.e., adult children may feel "thrown into" the caregiving role more so than a spouse). Co-residency, while a factor in other studies, was not a significant one in this study once analyzed alongside generational cohort. However, proximity to the patient and the duration of that proximity may leave adult children more or less prepared for caregiving.

At least 30% of home health care patients in the TRIAD study had family members who expressed interest in becoming more effective caregivers, indicating that pursuing development of relevant interventions for this group is worthwhile. Potentially this percentage could be increased by expanding the assessment of training interest to include other caregiving tasks and responsibilities. While the current sample was selected from only one region of the country, this limitation was attenuated by recruitment through three different home health care agencies. Constraints exist on the generalizability of the findings to other racial and ethnic groups beyond the Black and White dichotomy present in this sample. This study did not ask about caregiving

duration (i.e., how long the caregiver has provided care to the patient), which limits understanding of how this factor potentially influences the training interests of family caregivers.

The results present a picture of family caregivers of older adult medical patients that emphasizes the variety of caregiving tasks being performed in the presence of home health care services, as well as the high interest these caregivers have in learning more and becoming more effective in providing care. There is a clear message of the willingness of these caregivers to improve upon and enhance their caregiving skills, with a view to supporting family caregivers in chronic disease management models within home health care. This leads to the overarching question of what the health care system can do to capitalize on this interest and how to provide caregiver training. Type of training, training topics, format, and variations based on caregiver considerations (e.g., adult child vs. spousal caregivers) are just some of the aspects that require further thought and study. The need for continued research is highlighted by the discrepant findings of training and intervention studies for caregivers of older adults. For example, while there is some support for group formats (Burgio, Stevens, Guy, Roth, & Haley, 2003; Stoltz, Uden, & Willman, 2004), other analyses of the literature find group interventions to be less effective than those administered individually, at least for dementia caregivers (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007), although dementia caregivers overall do not benefit as much from interventions than do non-dementia caregivers (Sörensen et al., 2002). A recent review of psychological treatment for caregivers of older adult patients found that a number of approaches met criteria for evidence-based treatments, including certain forms of psychoeducation, cognitive-behavioral therapy, and interventions that combine theoretical approaches (Gallagher-Thompson & Coon, 2007). Although the studies mostly included dementia caregivers, the ones that included nondementia caregivers evidenced comparable results. Altogether, there is promise in further studying family caregivers of older adults without dementia as they appear to derive benefit from interventions, such as psychoeducation, that address caregiver effectiveness (Sörensen et al., 2002).

A final point in considering family caregiver training and interventions is that the population of caregivers of older adults without cognitive impairment is different from that of caregivers of older adults with dementia by virtue of the caregiving course. Many diseases and disabilities are chronic but manageable, can go into remission, or even resolve (e.g., cancer, depression). This is in contrast to the trajectory of dementia, and for this reason helping the caregivers of older adults receiving home health care not only can influence the well-being of the caregivers, but also potentially have effects on the well-being and health of the individuals for whom they care. Better understanding the needs and training interests of caregivers of homebound older adults without dementia and developing targeted and effective interventions for this particular caregiver group have the potential to affect multiple outcomes for both the caregiver and the caregiving recipient.

Acknowledgments

The TRIAD study was conducted as part of an Interventions and Practice Research Infrastructure grant funded by the National Institute of Mental Health (R24 MH64608, PI: Martha L. Bruce, PhD, MPH). This work was also supported by a National Research Service Award postdoctoral fellowship grant (T32 MH019132, PI: George S. Alexopoulos, MD).

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Table 1**Sociodemographic Characteristics by Generation**

Characteristic	Total (N=101)		Same generation (N=53)		Younger generation (N=48)		p
	N	%	N	%	N	%	
Gender							
Female	76	75	39	74	37	77	0.684
Male	25	25	14	26	11	23	
U.S. Born							
Yes	92	91	44	83	48	100	0.006
No	8	8	8	15	0	0	
Hispanic/Spanish							
Yes	4	4	2	4	2	4	1.000
No	95	94	50	94	45	96	
Race							
White	84	83	47	89	37	79	0.215
Black	13	13	4	8	9	19	
Other	2	2	1	2	1	2	
Marital Status							
Married	72	71	47	89	25	52	0.002
Widowed	4	4	1	2	3	6	
Separated	3	3	1	2	2	4	
Divorced	8	8	1	2	7	15	
Never married	14	14	3	6	11	23	
Live in same household							
Yes	76	75	49	92	27	56	<0.001
No	23	23	2	4	21	44	

	Total	Same generation	Younger generation	p
Age (years)				
Mean (SD); Range 34–88	62.91 (13.62)	72.98 (8.47)	52.00 (8.91)	<0.001
Education (years)				
Mean (SD); Range 6–22	14.38 (2.99)	13.75 (2.72)	15.06 (3.16)	0.028

	Total	Same generation	Younger generation	<i>p</i>
In same household (years)				
Mean (SD); Range 0–67	31.80 (22.99)	40.89 (19.00)	14.62 (20.08)	<0.001

Table 2

Family Caregiving Tasks Ranked by Frequency of Endorsement

Caregiving tasks	Yes response	
	N	%
Provide emotional support ^a	99	98
Monitor symptoms ^a	93	92
Speak to doctor ^a	91	90
Offer coping strategies ^a	90	89
Help solve everyday problems	88	87
Speak to doctor about physical needs	85	84
Help set up health-related services ^a	72	71
Monitor medications ^a	69	68
Monitor medication side-effects	56	55
Help with medical insurance documentation ^a	54	53
Help with transportation	50	50
Help with household activities	48	48
Speak to doctor about emotional needs	47	47
Help with financial management	36	36
Help with personal care	34	34

^a Items contributing to overall caregiving tasks continuous variable

Table 3

Family Caregiver Training Interest Based on Caregiving Tasks Response

Caregiving task	Currently perform task	Training interest		
		N	N	%
Provide emotional support	No	2	1	50.0
	Yes	97	53	54.6
Monitor symptoms	No	8	4	50.0
	Yes	93	45	48.4
Speak to doctor	No	10	4	40.0
	Yes	91	31	34.1
Offer coping strategies	No	11	7	63.6
	Yes	90	55	61.1
Speak to doctor about physical needs	No	3	2	66.7
	Yes	29	26	89.7
Help set up health-related services	No	29	12	41.4
	Yes	72	23	31.9
Monitor medications	No	32	12	37.5
	Yes	68	18	26.5
Monitor medication side-effects	No	11	5	45.5
	Yes	45	21	46.7
Help with medical insurance documents	No	46	16	34.8
	Yes	54	30	55.6
Speak to doctor about emotional needs	No	17	13	76.5
	Yes	13	12	92.3