

Caregiver burden from caring for impaired elderly: a cross-sectional study in rural Lower Egypt

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ABSTRACT

BACKGROUND: increased life expectancy and an aging population have made home care for the elderly a major responsibility for families. Caring for a chronically ill or physically disabled person has been referred to as physically or emotionally stressful, placing the caregiver at a heightened risk of burden. This study aimed to identify factors related to caregiving burden among caregivers who care for their disabled older family members.

METHODS: a cross sectional descriptive study was conducted from October 2008 to January 2009 in two randomly selected villages of Shebin El-Kom Menoufiya, Egypt. In an interview setting, questionnaires were used to collect the required data from 288 primary caregivers. Independent variables included the demographic characteristics of caregivers and care recipients, the severity of care recipients' functional abilities, financial adequacy and caregivers' degree of social support. Hierarchical regression was used to predict the levels of caregiver burden. The objective of the study was adequately explained to participants and their consent was obtained with assured confidentiality.

RESULTS: caregivers who had little informal social support, inadequate financial resources and more caregiving hours were more likely to experience intense caregiving burden. Burden was also positively associated to the functional disabilities of care recipients and the degree of caregiver burnout. The results of this study indicated that the female spouse was the most common caregiver within the sample, which indicates that cultural norms in Egypt still affect caregiving burden.

CONCLUSIONS: identifying predictors of caregiver burden promotes a more comprehensive understanding of burden experiences when caring for older adults, and this may help prevent their deterioration to burn out syndrome

Key words: Home Care; Elderly; Caregiver burden; Burnout

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INTRODUCTION

In almost every country, the proportion of people aged over 60 years is growing faster than any other age group, as a result of both longer life expectancy and declining fertility rates (1).

The world's elderly population is expected to be 2 billion in the year 2020, most of which will be living in developing countries that can least afford the health care burden encountered by this population group (2). In Egypt, The Central Agency of Public Mobilization and Statistics

(CAPMUS) has reported that persons age 65 and older comprised 3.5% of the general population in 2000, a percentage that is estimated to increase to 10% by 2020 (3). This population trend can be seen as a success story for public health policies and for socioeconomic development, but it also challenges society to adapt, in order to maximize the functional capacity of older people that require ongoing care services to support and maintain an optimal quality of life (1, 4).

Recent research has revealed that eighty percent of the non institutionalized elderly have one or more chronic health problems or disabilities. The shift in the provision of health care services from institutional to community-based settings is translating into an increased requirement for individuals to care for family members in the home (5). Despite the rapidly growing demands for home services, short term respite programs are extremely limited in rural Egypt. Family members, therefore, take upon themselves the considerable responsibilities and stress associated with providing adequate care and supervision for their older relatives (6, 7).

Caregiver burden is identified as a state resulting from providing the necessary care to an impaired older adult but that threatens either the physical or psychological well-being of the caregiver (8, 9). Nevertheless, the difficulties experienced by caregivers are often considered only after the signs of burnout are apparent. These signs indicate the progression of caregiver burden to the point where the experience is no longer a viable or healthy option for either the caregiver or the person receiving care (8). Informal care for the disabled elderly has proved to be a heavy burden for family caregivers in many countries, and burden has been shown to be related to the socio-demographic characteristics of both the caregiver and the recipient of care (10-12). Factors such as activities of daily living (ADL) of the impaired elderly also influence perceived burden (13, 14). However, mitigating factors may buffer the impact of burden such as resources and social support (15, 16).

This study sheds further light on the relationship between these variables within a sample of rural caregivers from lower Egypt, with the aim of identifying the factors that best explain the level of caregiver burden and to assess the degree of burnout among those caregivers. Findings from the current study provide a basis for

a richer understanding of care provision in Egypt and help identify factors that combine to make the issue of care giving a burden, a phenomenon that demands societal attention.

METHODS

Design and Setting

A cross sectional descriptive study was conducted between October 2008 and January 2009 in two randomly selected villages of Shebin El-Kom Menoufiya, Egypt, namely, Shobra Bus and Betabs.

Participants

Caregivers providing home care to family members with chronic illness or functional disabilities. The primary health care center (PHC) outreach service workers (Ra'aidat Rifiat) of these two villages helped with the purposive selection of caregivers, thus fulfilling the required inclusion criteria. A sample of 288 caregivers was recruited for this study on the basis of the following four criteria: 1) primary caregivers are defined as persons who are responsible for the day-to-day decisions and providing care, 2) providing care for someone chronically ill or disabled, 3) care recipient being 60 years of age or older, 4) informal caregiver referred to family members who provide care to an impaired older adult in the community.

Ethical consideration

The required administrative regulations were fulfilled. The district health authorities approved the content of the study before it was conducted. The objective of the study was adequately explained to participants and their consent was obtained with assured confidentiality.

Data collection

Data collection tools included the following:

1. *A structured interview questionnaire*; a 10-question tool that took about 25 minutes to be administered to the caregiver. Interviews took place in the caregiver's home. The questionnaire covered socio-demographic characteristics of both the caregiver and care

recipient, the nature of the relationship with care-recipients, duration of care giving/year, daily hours spent on care giving, information on patients' illness-related characteristics, and availability of formal or informal social support. Formal social services, including paid-home care service, or respite care, that might provide care to the disabled older adults during the daytime instead of family caregivers. Informal social services, defined as secondary caregivers, if the primary caregiver were absent or unavailable.

2. *Zarit Burden Interview (ZBI)* is a 22-item instrument for measuring the caregiver's perceived burden from providing family care. The 22 items are assessed on a 5-point Likert scale, ranging from 0="never" to 4="nearly always". Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater perceived burden. The questions focus on major areas such as caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the patient (9).
3. *Maslach Burnout Inventory (MBI)* is a 22-item survey designed to assess and measure three scales of the burnout syndrome which include: Emotional exhaustion (EE), which measures feeling of being emotionally overextended and exhausted by one's care giving; Depersonalization (DP), which measures the unfeeling and impersonal response towards recipients of the caregivers' services, care treatment, or instruction; and Personal accomplishment (PA), which measures feelings of competence and successful achievement experienced by caregivers from their work with care recipients. The 22 items are assessed on a 7-point Likert scale, ranging from 0="never" to 6="everyday". Burnout was conceptualized as a continuous variable, ranging from a low to high degree of the experienced feeling. A high degree of burnout was reflected in high scores in the EE (≥ 27) and Depersonalization (≥ 13) scales, and in low scores of PA scale (≤ 31). An average degree of burnout was reflected by the average scores on the three scales (EE 17-26, DP 7-12, PA 38-32). A low degree of burnout was reflected in low scores of Emotional exhaustion (≤ 16) and Depersonalization (< 6) and high scores of Personal accomplishment scale (≥ 39) (17).
4. *The Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) instruments* were used to assess the

care recipients' functional status. The assessment included 14 items that inquired about the extent to which the care recipient can perform basic ADLs such as eating, bathing, dressing, toileting, mobility and continence, and the IADLs that inquired about more complicated tasks which have an impact on linking social competency with independent living, such as using the telephone, shopping, travelling or using transportation, taking medications, handling personal finances, preparing meals, doing housework, and washing clothes. For each of the items, respondents were asked to report on the ability of care recipients to perform the task without help, rated as follows: 0=independent, 1=with some help, and 2=totally dependent. The total scores ranged from 0 to 28, with higher scores indicating the recipients' need for more assistance to carry out ADLs (18).

The questionnaire was translated into Arabic and the required corrections and modifications were carried out accordingly. A group of experts had tested the content validity.

Pilot study

A pilot study was undertaken to test the validity and reliability of the data collection tools and to identify possible field problems. Necessary modifications were made accordingly.

Data analysis

The data were entered in an IBM compatible computer, using the Statistical Package for Social Science (SPSS), version 18. A descriptive analysis using means with standard deviation, frequency counts and percentages was carried out. Pearson correlation coefficients (r) were employed to address the relationship between caregiver burden and study variables. A hierarchical multiple regression was used to identify the significant factors that affect the level of caregivers' burden. The level of statistical significance was set at $P < 0.05$.

RESULTS

The study included 288 caregivers aged 20 or older who were the primary caregivers for disabled older family members. Most of them (86.8%) were

women and 13.2% were men. The female primary caregivers were, in the majority of cases, spouses 58.3% and daughters 28.5%. The caregivers' mean age was 41.35 ± 8.44 years. More than half of them, 55.2%, had completed secondary school, 18.8% were illiterate or just read and write, and only 7.9% had received a university education. The monthly family income was 461.5 ± 116.8 Egyptian pounds. Ninety percent of respondents reported financial inadequacy (Table 1). None of them used paid home care or respite care, and only 24.7% of the respondents used informal social services. Overall, the sample spent 7.29 ± 2.02 hours a day in care provision, and the mean duration of caregiving was 5.84 ± 2.34 years (Table 2).

The mean age of care recipients was 70.7 ± 6.23 , and 67.7% were male (Table 1). The mean score for ADLs/IADLs scale was 27.9 ± 5.6 . Over

90 percent of caregivers in this study reported a medium to high range of functional disabilities on the ADLs scale. The mean duration of the chronic illness was 4.66 ± 1.72 years (Table 2).

Descriptive and bivariate analyses were performed to determine the degree of caregiver burden. It was observed that respondents reported a varied degree of burden with a mean score of 35 ± 14.1 . The majority of them (63.9%) experienced severe burden. Consequently, 43.1% of the caregivers studied had experienced feelings of burnout. Out of these women who had experienced burnout, 19.4% had a high degree of burnout syndrome and this was reflected in high scores in the EE, and DP scale and low scores in the PA scale. 46.8% of them experienced a low degree of burnout as reflected in low scores in the EE and DP scales, and high scores in the PA scale (Table 2). A significant positive

TABLE 1

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS AND CARE RECIPIENTS

	CAREGIVERS (N=288)		CARE RECIPIENTS(N=288)	
	N	%	N	%
Age (years)	41.35 ± 8.44		70.70 ± 6.23	
Gender				
Female	250	86.8	93	32.3
Male	38	13.2	195	67.7
Education (Years)				
Illiterate	16	5.6		
Read & write	38	13.2		
Primary school	52	18.1	-	-
Secondary school	159	55.2		
University or higher	23	7.9		
Monthly Family income (L.E.)^a				
< 400	114	40.0		
400-600	154	53.3		
> 600	20	6.7	-	-
Mean \pm SD	461.5 ± 116.8			
Family financial adequacy				
Not adequate	260	90.3		
Adequate	28	9.7		
Relation to care recipient				
Wife	168	58.3		
Husband	23	8.0	-	-
Daughter	82	28.5		
Son	15	5.2		

^a L.E. = Egyptian Pound

correlation was found between degree of caregiver burden and range of experienced burnout ($r=0.762$, $p\leq 0.05$). Severe burden was associated with feeling a high level of burnout (Figure 1).

In analyzing burden within the sample, however, some differences emerged regarding the experience of caregiving. Table 3 showed the relationship between the degree of caregiver burden and the variables studied. The caregivers age (elderly), gender (females), level of education (secondary school), relationship to care recipient (wives), years of chronic illness (more), care giving hours/day (more), ADLs (more severe, dependant), financial adequacy

(lower) and use of secondary caregiver during daytime (less) were all significantly related with feelings of higher caregiving burden in the study group. No correlation was found between caregiver burden and family income.

Table 4 shows the results of hierarchical regression analyses that identified the significant predictors of caregiving burden based on all variables included in the study.

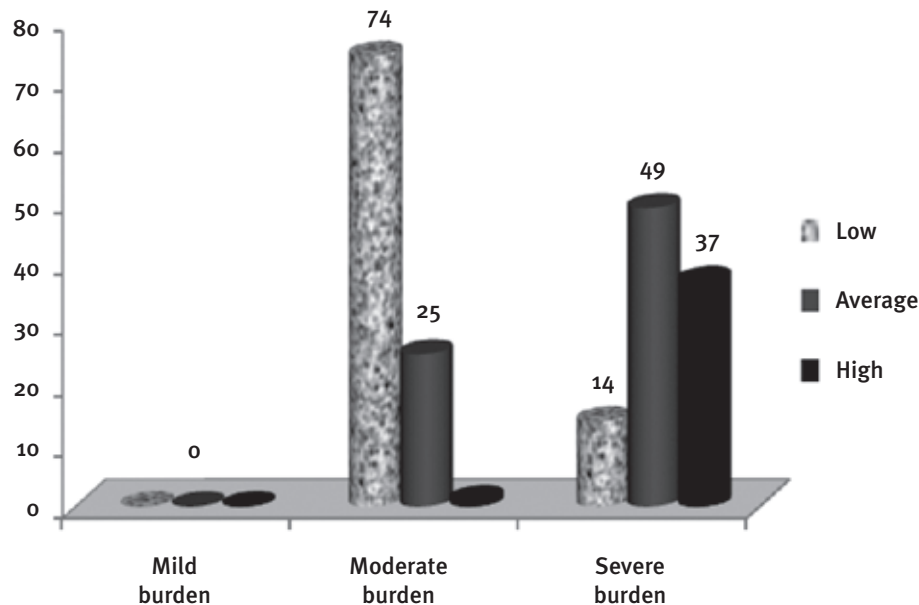
Step1 analyzed the relationship between the caregiver's characteristics and the degree of caregiver burden ($F=11.221$, $p<0.001$). These characteristics explained 5.8% of the dependent variable. When the care provider was the care recipient's wife ($\beta=-0.081$, $p<0.05$) and

TABLE 2

FREQUENCY DISTRIBUTION OF THE CAREGIVING EXPERIENCE AND PATIENTS' ILLNESS RELATED CHARACTERISTICS				
	CAREGIVERS (N=288)		CARE RECIPIENTS (N=288)	
	N	%	N	%
Availability of secondary caregiver				
Yes	71	24.7	-	-
No	217	75.3		
Duration of caregiving /year				
Min-Max	1-15		-	-
M \pm SD	5.84 \pm 2.34			
Daily hours spent on caregiving				
Min- Max	6-10		-	-
M \pm SD	7.29 \pm 2.02			
Functional status				
Dependent			142	49.3
Partial dependent			121	42.0
Independent	-	-	25	8.7
Mean \pm SD			27.9 \pm 5.6	
Duration of chronic illness/years				
Min- Max	-	-	3-11	
Mean \pm SD			4.66 \pm 1.72	
Burden Levels				
No burden	0	0		
Mild	29	10.1		
Moderate	75	26.0		
Severe	184	63.9		
Mean \pm SD	35 \pm 14.1			
Range of experienced burnout				
No experience	164	56.9		
Low burnout	58	20.2		
Average burnout	42	14.6		
High burnout	24	8.3		

FIG. 1

CORRELATION BETWEEN LEVELS OF CAREGIVER BURDEN AND DEGREE OF BURNOUT



Degree of burnout: Low, Average and High

was female ($\beta=0.077$, $p<0.05$), the level of caregiver burden increased. Caregiver age and monthly household income were not significant predictors in this study.

Step 2 tested the actual level of caregiving involvement, such as hours per day devoted to caregiving, and the overall duration of caregiving ($F=15.81$, $p<0.001$). This step explained approximately 10.6% of the variance, and the R square value also significantly increased ($p<0.001$). Caregiver gender ($\beta=0.083$, $p<0.05$), and the relationship with care recipient ($\beta=-0.078$, $p<0.05$), remained within the model as significant predictors of caregiver burden. A greater number of hours spent caregiving per day ($\beta=0.241$, $p<0.001$) was an additional predictor of higher caregiver burden.

Step 3 added descriptive data about the care recipient ($F=19.64$, $p<0.001$). The adjusted R square (0.183) significantly increased ($p<0.001$). The findings showed that caregiver gender ($\beta=0.099$, $p<0.01$), caregiving hours ($\beta=0.182$, $p<0.001$), care recipient's age ($\beta=-0.104$, $p<0.01$), care recipient's gender ($\beta=0.062$, $p<0.05$), and ADLs ($\beta=0.075$, $p<0.05$) were all significantly associated with caregiver burden. There was a positive correlation between functional impairment and burden. As the level of the recipient's physical disabilities

increased, the greater the caregiver's reported burden. Interestingly, the age of the care recipient was negatively correlated with the level of burden.

In the next analyses (Step 4 and 5), two mediating variables were added to the model. Step 4 included the caregiver's financial capacity to provide adequate care ($F=18.87$, $p<0.001$). The results showed an increase in the adjusted R square (0.189) which was statistically significant ($p<0.01$). Less burden was reported by caregivers who had adequate financial resources ($\beta=-0.101$, $p<0.01$). Step 5 utilized all predictors for caregiver burden, adding informal social support ($F=17.17$, $p<0.001$). The adjusted R square (0.195) increased and this change was statistically significant ($p<0.01$). Caregiver gender ($\beta=0.096$, $p<0.01$), their relationship with care recipient ($\beta=-0.071$, $p<0.05$), hours of care devoted to caregiving ($\beta=0.165$, $p<0.001$), the care recipient's age ($\beta=-0.092$, $p<0.01$), gender ($\beta=0.063$, $p<0.05$), ADLs ($\beta=0.077$, $p<0.05$), the caregiver's financial status ($\beta=-0.094$, $p<0.01$), and informal social support ($\beta=-0.083$, $p<0.01$) were all significantly associated with the degree of caregiver burden experienced. In particular, as the number of persons who provided aid to the caregivers increased, their degree of burden decreased.

TABLE 3

RELATIONSHIP BETWEEN PARTICIPANTS' CHARACTERISTICS, ACTUAL LEVEL OF CAREGIVING, MEDIATING VARIABLES AND DEGREE OF CAREGIVER BURDEN				
	CAREGIVER BURDEN			SIG.TEST ^{aw}
	MILD (N=29)	MODERATE (N=75)	SEVERE (N=184)	
Age (years) Mean \pm SD	39.75 \pm 7.94	43.37 \pm 9.07	46.37 \pm 6.93	r=0.267 P=0.000
Gender Male Female	4 (13.8%) 25 (86.2%)	29 (39.7%) 46 (61.3%)	5 (2.7%) 179 (97.3%)	r=0.298 P=0.000
Education Illiterate Read & write Primary school Secondary school University or higher	2 (6.9%) 0 (0.00%) 0 (0.00%) 21 (72.4%) 6 (20.7%)	9 (12.0%) 0 (0.00%) 10 (13.2%) 38 (50.3%) 18 (24.0%)	12 (6.5%) 16 (8.6%) 28 (15.1%) 100 (54.1%) 28 (15.1%)	r=0.034 P=0.011
Monthly family income (L.E.)**	681.4 \pm 148.1	666.08 \pm 143.0	579.65 \pm 115.6	r=0.187 P=0.110
Financial adequacy Not adequate Adequate	6 (20.7) 23 (79.3)	73 (97.3%) 2 (2.7%)	181 (98.4%) 3 (1.6%)	r=-0.101 P=0.01
Relation to care recipient Wife Husband Daughter Son	19 (65.5%) 4 (13.8%) 6 (20.7%) 0 (0.0%)	28 (37.8%) 17 (23.0%) 17 (23.0%) 12 (16.2%)	121 (65.4%) 2 (1.0%) 59 (31.9%) 23 (1.6%)	r=0.118 P=0.000
Duration of chronic illness/ years Mean \pm SD	4.23 \pm 1.04	4.39 \pm 1.35	6.62 \pm 2.67	r=0.403 P=0.000
Functional status Dependent Partial dependency Independent	8 (27.6%) 11 (37.9%) 10 (34.5%)	24 (32.0%) 46 (61.3%) 5 (6.7%)	110 (59.8%) 64 (34.8%) 10 (5.4%)	r=0.314 P=0.000
Caregiving duration (year)	6.06 \pm 2.37	6.25 \pm 2.20	6.72 \pm 2.68	r=0.870 P=0.000
Caregiving hrs/day	8.08 \pm 1.08	8.35 \pm 1.05	9.48 \pm 0.99	r=0.168 P=0.051
Availability of secondary caregiver No Yes	2 (6.9%) 27 (93.1%)	41 (54.7%) 34 (45.3%)	174 (94.6%) 10 (5.4%)	r=0.255 P=0.000

^a Statistical significant at p<0.05 - **L.E. means Egyptian Pound & One dollar= 5.9 Egyptian

TABLE 4

ESTIMATES USING HIERARCHICAL REGRESSION (N=288)					
	STEP 1 β	STEP 2 β	STEP 3 β	STEP 4 β	STEP 5 β
Caregiver age			0.040	0.040	0.022
Caregiver gender			0.099 ^b	0.095 ^b	0.096 ^b
Relationship with care recipient		-0.004	-0.057	-0.068	-0.071 ^a
Income \$	0.058	0.083 ^a			0.063
Caregiving hours	0.077 ^a	-0.078 ^a	0.011	0.055	0.165 ^c
Duration of caregiving	-0.081 ^b		0.182 ^c	0.170 ^c	0.035
Care recipient age		0.024	0.046	0.040	-0.092 ^b
Care recipient gender	0.006	0.241 ^c	-0.104 ^b	-0.097 ^b	0.063 ^a
ADLs		0.037	0.062 ^a	0.060	0.077 ^a
Financial adequacy			0.075 ^a	0.070 ^a	-0.094 ^b
Informal social support				-0.101 ^b	-0.083 ^b
F	11.2 ^c	15.81 ^c	19.64 ^c	18.87 ^c	17.17 ^c
R square	0.063	0.113	0.193	0.198	0.207
Adjusted R square	0.058	0.106	0.183	0.189	0.195
R square change	0.063 ^c	0.050 ^c	0.080 ^c	0.005 ^b	0.006 ^b

^a p<0.05^b p<0.01^c p<0.001

DISCUSSION

With the increase in health care expenses, particularly those associated with inpatient care, and given rising societal ethos emphasizing that care for aging individuals is best offered in the community, family members are increasingly finding themselves in the role of supporting and caring for their elderly or disabled relatives at home. The documented stressors to family members are vast and include depression, anxiety, grief, and overload (19). One of the populations most vulnerable to the burden caused by providing long-term care are spouses, who often view caring as an extension of their marital commitment, and who are more likely to continue caring despite the limited support services available to them, or the emotional suffering they experience (20). The current findings indicated that 66.3% of the primary caregivers are spouses, which adds to the sense of burden experienced by caregivers within this cultural context. Females comprised 86% of caregivers, with the spouse representing the highest proportion (58.3%) of women. This gender distribution represents a similar gender

ratio seen in Western families where 75%-80% of care provision is assumed by women (21-24).

The mean burden score for this sample was 35 ± 14 . A meta-analysis (25), which included 58 studies that used the Zarit Burden Interview, reported a mean burden level of 29.9 ± 9.3 , suggesting that the caregivers in this study were more burdened than those in a variety of other caregiving studies. Consistent with previous research, this study also identified several significant predictors of higher burden experienced by caregivers. Higher levels of caregiver burden are associated with being a female spouse who receives little informal support and assumes greater amounts of daily caregiving hours. The present study also confirmed that caregiver burden is affected by the degree of the care recipient's dependency for carrying out tasks of daily life (17, 26, 27). The participants in this study reported a medium to high range of ADL challenges posed by the people for whom they were caring. These challenges remained significantly associated with caregiver burden when examined alongside other variables. Other findings from the current study demonstrated that the caregiver's

level of education and informal social support were significantly associated to the intensity of caregiver burden experienced (28). There was an inverse correlation between caregiver's educational level and perceived burden, with those having lower levels of education being able to derive more self-esteem from caregiving, and this may have had an impact on their perception of burden (29, 30). Additionally, the data showed that family income did not buffer the level of caregiving burden experienced.

Considering the principal significant associations found between the degree of caregivers' burden and other variables examined alongside, a syndrome of emotional exhaustion, depersonalization, and low personal accomplishment emerged among more than one third of the studied primary caregivers. This indicated that increased degree of burden was reflected in an increased feeling of burnout.

Our findings should be viewed in the context of some limitations. First, the external validity of the study may be affected by the purposive sampling of the participants in the randomly selected villages where outreach services are more readily available, as compared to other urban areas. In addition, 75% of the sample were older adults who did not previously use, or were currently using, social and/or medical services due to their impairments. As a result,

the findings might have some limitation for their generalization to the disabled older adult population, who use any formal services or who live in more rural or urban areas of the country. Given the non-probable nature of the sample, the use of statistical significance tests in this manuscript is for illustrative purposes only. Future research, employing a nationally representative sample, would allow a better generalization of the results of this study. Secondly, a cross-sectional design was employed, and the data, therefore, did not provide an opportunity to determine changes in burden over time. A longitudinal design could test the determinants of caregiving burden according to changing conditions in the demographic characteristics of both caregivers and care recipients.

The study concluded that, providing care for a chronically ill and/or disabled family member is stressful. Several factors have been identified that could promote a more comprehensive understanding of the cultural experiences inherent to caring for older adults.

Taken as a whole, these findings provide support for emphasizing early community interventions through redesigning in-home services that better meet the social needs of disabled elderly and provide more efficacious respite to caregivers, specifically in rural communities'.

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