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Older Persons, and Caregiver Burden and Satisfaction in Rural Family Context

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ABSTRACT

The present study is aimed at assessing the burden among the caregivers of the elderly in rural families and to standardize and compare Burden Assessment Scale (BAS) and Caregivers' Reaction Assessment scale (CRA) in Indian context. A Sample of 300 (176 women and 124 men) caregivers of the elderly was selected using a systematic sampling method from three village panchayats of a predominantly rural mandal (Padmanabham) of Visakhapatnam district, Andhra Pradesh. An interview schedule covering basic socio-demographic data and the two measures i.e. BAS and CRA was used to collect data from the caregivers. Findings reveal that burden and satisfaction of care giving is associated with sex and age of caregiver, and family income. A large percentage of caregivers expressed satisfaction about the care-giving role played by them. However, only a small percentage of women, as compared to men, expressed satisfaction about their care-giving role probably because the major burden of caring the elderly was actually shouldered by women rather than by men. Similarly, more women caregivers reported tiredness and worsening health due to stress arising out of their care giving roles. Lastly, evidence showed that higher age and lower income was found to bring down the caregiver satisfaction significantly.

Key words : Elder care, Caregiver burden, Caregiver satisfaction, Caregivers, Family relationships.

The growing number of aged population as a result of the increase in the life span of the individuals, and the continuing preference of older persons to stay with their young are some of the reasons which led to the emergence of caregiving as an important aspect of family life (Bali, 1999). In India, home based care with family members as primary caregivers still remains as the first and often the only option for a majority of the elderly (Puri, 2004). So, the most common type of living arrangement for the elderly in India is found to be living with married sons and their families (Prakash, 1999). According to 2001 Census, the aged (60+) in India constitute 7.4 percent of the total population whereas for A.P. it is 7.6 percent. There is an 11.8 percentage increase in the population of the older persons over the earlier decade, which was 6.54 percent. According to Census, 2001, nearly 75.0 percent of the elderly live in villages. The dependency ratio of the elderly is reported to be higher in the rural areas as compared to urban areas (NSSO 52nd round). Therefore, family care giving emerged as an important area of study.

One of the outcomes of caregiving is caregiver stress and burden. Several questions come to our mind when we think of caregiving and caregiver burden in family context. Who are the primary caregivers of the older persons in Indian family context? Which factors are associated with caregiver stress or lack of it? What measures are used to assess these variables and so on. Studies show that caregiver stress is reported to be associated with such variables as family income, age of caregiver, kinship relationship, caregiver's attitude and certain attributes of the care recipient i.e. the elderly (Jamuna, 1997). It is found that women are traditionally caregivers in Indian families (Prakash, 2001, 1999) especially in rural communities (Jamuna, 1997; Chakrabarthi, 1999; Sharma, 2003). Also women report greater levels of stress as they are often engaged in the care giving of two generations– rearing their own children and providing long term care to the elder relatives which results in great cost to their well-being both physical and psychological (Prakash, 1999; Hirst, 2005). Caregiver stress was reported to be high among daughters-in-law followed by spouse and daughter (Jamuna, 1997). Thus, there is a clear 'feminization of caring'. For men the most common caregiver was the wife followed by daughter-in-law and in the case of women, it was mostly the daughter-in-law followed by the daughter (Prakash, 1999; Sharma, 2003). The other stressors which affect the quality of

care giving were work demands, availability of social support, health status of the caregiver (Jamuna and Ramamurthi, 1999), and the changes and modifications which have been taking place in inter-personal relationships as a result of changes in external realities (Vijaykumar, 1999).

Another important aspect in studies on caregiving is caregiver satisfaction. Compared to the literature on the burden of caregiving, studies are sparse focusing on the rewards and gratifications of elder care (Decalmer and Glendenning, 1997). Davies (1980) observed that caregiver satisfaction is possible only when the recipient of care was seen as a valued person rather than as a problem. Similarly, Cartwright et al. (1994) observed that caregiver satisfaction is also dependent upon the meanings ascribed to care i.e. perceiving caregiving as a satisfying and pleasant relationship and of finding rewards in the several acts of care giving.

Caregiver burden is one of the most studied topics in gerontological literature. However, fewer studies are done on rewards and satisfaction of care giving than on caregiver stress. Therefore, it was thought that a study based on a large and a systematic sample of caregivers in a rural family context would yield meaningful comparison and conclusions on both caregiver burden and caregiver satisfaction. Moreover, the social and psychological stress experienced by family caregivers in the family context is an important area of study. Though several scales have been developed to measure caregiver burden and stress, not many scales are available to measure these aspects in Indian context. Hence, there is a need to identify and standardize independent measures of the caregiver burden and caregiver satisfaction on an Indian sample. Thus, the purpose of the present study is to examine the discriminating capabilities of two measures i.e. in measuring the caregiver burden and satisfaction and to explore how age, sex, income of the caregiver affect the different variables relating to care giving.

Objectives

1. To assess the burden and satisfaction experienced by the caregivers of the older persons in Indian rural family context.
2. To use and compare the two measures i.e. Burden Assessment Scale (BAS) and Caregivers Reaction Assessment (CRA) scale in

measuring the caregiver burden and caregiver satisfaction among the sample respondents.

3. To find out the association between the caregiver burden and caregiver satisfaction with relevant variables such as age, sex, income etc of the caregivers.

Method

Sample

Seven villages in three panchayats from a predominantly rural mandal (Padmanabham) of Visakhapatnam district, Andhra Pradesh formed the setting for study. A Census sample of these villages was taken and 822 elderly of both sexes were enumerated. From this sample, 300 caregivers who were having at least one older person (60+years) living with them under their care for a period of 6 months or more prior to the date of study were selected using a systematic sampling method. Thus, the median duration of stay of the older person with the caregiver came to be 31.5 years (range: 1year – 60 years). When there are more than two older persons in a family, one *referent* elderly was chosen by using a random procedure method. The caregiver responded to the interview keeping this referent elderly in mind.

Tools Used

An interview schedule was used which covered a) Socio demographic variables such as age, income, education, occupation and so on of the caregiver and the elderly, b) the Burden Assessment Scale (BAS) and c) the Caregiver Reaction Assessment (CRA) Scale. Both the measures were translated into Telugu. The reliability of the Telugu versions was determined by test-retest method by administering the test to 22 elder caregivers in an urban setting. The alpha coefficients for the pre and posttests came to be .81 and .87 for BAS and .52 and .72 for CRA respectively.

Explanation of the measures used

The Burden Assessment Scale (BAS)

The BAS developed by Reinhard and Horwitz (1995) is a 19-item questionnaire with response options on a 4-point Likert-type scale (from *not at all* to *a lot*). It is a unidimensional scale. Ten items

measure objective burdens (such as missed days at work), and nine assess subjective burdens (such as feelings of guilt). Objective burdens are those that alter an activity or resource, whereas subjective measures are measured by affect or perspective. Thus, missed days at work or school, reduced leisure time, and changes in personal plans are objective burdens, and feelings of shame, guilt, and worry are subjective burdens. The total burden score, which taps both objective and subjective dimensions, is calculated by summing response values for all items. Scores range from 19 to 76 with higher scores indicating greater levels of burden. In the present study the alpha coefficient for the Burden Assessment Scale (BAS) is 0.78

The Caregiver Reaction Assessment (CRA)

Given *et al.* (1992) developed this multi dimensional scale, which is a 24-item measure with response options on a 5-point Likert-type scale. The response options range from strongly agree to *strongly disagree*. Two questions from the original scale (22 and 23) were deleted as these questions were found to be repetitive and eliciting similar answers from the respondents caused confusion to the interviewer and the respondent. The measure assesses five dimensions of caregiver reactions. They are impact on schedule (5 items), caregiver's esteem/satisfaction (6 items), lack of family support (4 items), impact on health (4 items), and impact on finances (3 items). Five items (3,7,13,15, and 19) are reverse scored. Total scores range from 22 to 110 with higher scores indicating greater burden or stress. The alpha coefficient for the Caregiver Reaction Assessment (CRA) is 0.71.

Findings

Profile of the caregiver and the elderly

Table 1 gives the socio-demographic details of the sample caregivers. As can be seen, around 64 percent of the sample caregivers are women. The mean age of caregiver is 43 years (S.D=15.6). The age range is 16 – 75 years. Women caregivers are slightly younger (mean=42.9, S.D=14.84) than men (mean= 43.2, SD= 16.87). Majority of them belonged to backward castes (68.7 percent), followed by other castes (19.3 percent) and Scheduled castes (12.0 percent). More women are found to be illiterate as compared to men and nearly 86 percent of the caregivers are married. More than half (53.7 percent)

reported their family as extended type i.e. having two generations with unmarried extended relatives. The mean family income came to be Rs. 1730/- per month (S.D=278.8) with a range between Rs.100/ - Rs.3, 000/-. As regards the duration of stay of the elderly with the caregiver, around half of them reported the duration to be 16- 40 years. Of the older persons who were under the care of the sample caregivers, around 59 percent are women who are slightly younger (mean=67.0 S.D=6.44) to men (mean=67.5, S.D=6.77). In terms of marital status, around half of the elderly (51 percent) are married followed by widowed (48 percent).

Table 1 : Profile of the sample caregivers

Variable	**Men** (n=109)	**Women** (n=191)	**Total**
Sex	36.3	63.7	-
Age			
Below 30years	32.1	27.8	29.3
31 to 57 years	37.6	51.8	46.7
58 yrs and above	30.3	20.4	24.0
Marital status			
Married	86.2	86.4	86.3
Unmarried	9.2	3.1	5.3
Widowed	3.7	7.9	6.3
Divorced	0.9	0.5	0.7
Separated	-	2.1	1.3
Religion			
Hindu	97.2	100.0	99.0
Christian	2.8	-	1.0

Caste			
Backward Caste	71.6	67.0	68.7
Other Castes	17.4	20.4	19.3
Scheduled Caste	11.0	12.6	12.0
Educational level			
Illiterate	67.0	84.3	78.0
Primary	17.4	10.5	13.0
Secondary	13.8	5.2	8.3
Inter and above	.9	.3	0.3
Professional	.9	.3	0.3
Family type			
Nuclear	16.5	28.8	24.3
Joint	25.7	19.9	22.0
Extended	57.8	51.3	53.7
Duration of stay of the elderly			
Up to 15 years	14.7	31.4	25.3
16 – 40 years	58.7	46.6	51.0
41+ years	26.6	22.0	23.7
Income			
Belo Rs.1000/.	18.3	28.8	25.0
Rs.1001 to Rs.2000/.	57.8	48.2	51.7
Rs.2001 and above	23.9	23.0	23.3
N = 300	*100.0*	*100.0*	*100.0*

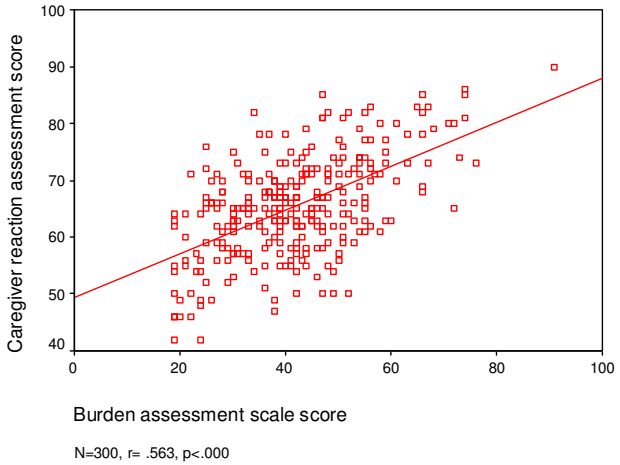
Relationship with the elderly

Coming to the relationship of the caregiver to the elderly, of the 300 sample caregivers, 25.7 percent are wives, 23.3 percent are sons followed by daughters-in-law (22 percent) and daughters (13 percent), and husbands (8.0 percent). The remaining eight percent (8.0) are other relatives. When enquired who takes care of the older person when she or he falls ill, the relationships figured were: wife, son, daughter, daughter-in-law and husband (in the case of women elderly), in that order.

Comparison of the BAS and CRA measures

To begin with, a strong positive relationship between burden assessment scale (BAS) and the caregiver reaction assessment score (CRA) can be seen by examining the scatter gram (Figure 1). There is a discernable pattern concentrating along the regression line which confirms the close association (r =. 563, p< .000) between the two scores.

Figure 1. Scatterplot of two measures -BAS and CRA



Next, Table 2 shows the means of BAS and CRA scores obtained on certain key variables such as age, sex, income, and type of family of the caregiver. As can be seen, both the measures showed a similar trend in reflecting the differences on all the variables. Thus, with the increasing age of the caregiver, the caregiver stress also increased.

Women caregivers reported higher levels of burden and stress (66.2 on CRA and 43.1 on BAS) as compared to male caregivers. Further, an inverse relationship is seen in the case of family income and the mean scores on these two measures i.e. the lower the income the higher the stress levels reported.

Table 2: Comparison of BAS and CRA scores of the caregivers

Caregiver Variable	BAS		CRA	
	Mean	SD	Mean	SD
Age				
Below 30 years	36.1	11.6	60.8	8.5
31 to 57 years	42.8	11.7	66.2	7.8
58 years	46.2	14.0	69.6	8.2
Sex				
Male	39.1	10.8	64.2	7.3
Female	43.1	13.6	66.2	9.4
Family income				
Up to Rs.1000	50.5	14.1	70.5	8.8
Rs.1001 to Rs.2000	38.5	10.4	63.7	7.7
Rs.2001 and above	38.9	12.1	63.8	8.8
Family type				
Nuclear	46.2	13.4	69.0	8.9
Joint	39.9	13.5	64.4	8.7
Extended	40.3	11.8	64.2	8.2

In terms of type of family, caregivers from nuclear family background reported higher levels of stress on both CRA and BAS.

As the caregiver reaction assessment scale is a multidimensional measure, an attempt is made in Table 3 to study the relationship between sex and the different dimensions of CRA measure. In this measure, of the four (4) subscales, caregiver esteem or satisfaction covers the rewards of care giving. The rest of the sub scales are: the

impact of caregiver's stress on the work schedule, family support, health and financial resources of the caregiver. The numbers of items in the original scale are given in the table. The responses to agree and strongly agree are combined and shown (Table 3)

Table 3 : Impact of care giving on caregivers esteem, on schedule, finances, health and family support

Item	Item No.	Agree / Strongly agree		
		Men (103)	Women (191)	Total (300)
Caregiver esteem				
Privileged to care for…	1	97.2	88.4	91.7
Resent having to take care of…	7	76.1	57.0	64.0
I really want to care for...	9	97.2	89.0	92.0
Not able to do enough for…	12	86.2	79.6	82.0
Caring makes me feel good…	17	87.2	78.5	81.6
Caring for …is important to me	20	94.5	89.5	91.3
Impact on Schedule				
My activities are centered around…	4	18.4	33.5	28.0
Have to stop work in the middle…	8	12.9	24.6	20.3
I visit family/friends less…	11	11.9	12.5	12.3
Have to eliminate things from schedule…	14	5.5	16.2	12.3
Difficult to find time for relaxation	18	5.5	16.7	12.7
Lack of family support				
Others have dumped caring for…	2	38.5	39.8	39.3
Very difficult to get help from family…	6	19.3	25.6	23.3

My family works together to care for…	13	11.0	22.0	18.0
Since caring for…my family abandoned	16	3.7	1.0	2.0
Impact on health				
Since caring tired all the time	5	12.9	27.2	22.0
My health gotten worse since caring for…	10	7.3	12.0	10.4
I have enough physical strength to care for…	15	7.3	16.7	13.3
I am healthy enough to care for…	19	15.6	18.8	17.7
Impact on finances				
My financial resources are adequate…	3	37.6	41.4	40.0
Caring put financial strain on family…	21	28.5	41.9	37.0
It is difficult to pay for the health needs of elderly…	24	34.0	46.6	42.0

As a whole, a large percentage of caregivers expressed satisfaction about the care-giving role played by them. More specifically, the trend shows that on caregiver esteem subscale a slightly less percentage of women, as compared to men expressed satisfaction about their care-giving role. At the same time, more men i.e. 76 per cent reported resentment for having to take care of the elder relative than women caregivers (57 percent). Similarly, with regard to impact on health, more women caregivers reported tiredness and worsening health because of stress arising out of their care giving roles. Moreover, on all other subscales, more women reported interruption of schedule, constraints on social interaction, less visiting of relatives, and strain on financial resources. On the whole, the reason for lower percentage of women expressing satisfaction over care giving and reporting of higher levels of burden on other scales could

be because the major burden of caring the elderly is actually shouldered by women rather than by men.

Relationship between caregiver stress and key variables

From the above discussion, it is found that caregiver stress is correlated with sex and age of the caregiver, and family income. To explore the relationships further, correlations between BAS and CRA scores, and the variables namely age of the caregiver, family income, including duration of stay of the older person with the caregiver – were explored. The values are shown in Table 4.

Table 4 : Inter correlations between BAS and CRA scores and the variables of the caregiver

	Family Income	**Duration of Stay**	**CRA**	**BAS**
Age of the Caregiver	–0.070	0.74**	0.44**	0.33**
Sig. (2-tailed)	0.224	0.000	0.000	0.000
Family income	–	–0.014	–0.18**	–0.19**
Sig. (2-tailed)		0.804	0.001	0.001
Duration of stay		–	0.39**	0.30**
Sig. (2-tailed)			0.000	0.000
CRA			–	0.56**
Sig. (2-tailed)				0.000

N= 300

** Correlation is significant at the 0.01 level (2-tailed).

As can be seen, there is a strong and statistically significant correlation between the age of the caregiver, the duration of stay, and the scores of the two measures, though there is no significant correlation with family income. While the age is positively correlated to both the scores (i.e. BAS and CRA), an inverse but weak relationship is seen between family income and the caregiver stress (r = -.19 for BAS and r = -.18 for CRA, both significant at p<. 001). Thus, this accounts for the stronger relationship between age of the caregiver and caregiver stress than with family income. It can also be seen that the duration of stay is strongly correlated with the scores of the two measures.

Now, the next step is to find out which of the three variables, that is, age of the caregiver, family income, and duration of stay of the elderly with the caregiver – are related to caregiver stress and which explains most of the variation in the caregiver stress?

As the duration of stay of the elderly is found to be positively correlated with age of caregiver (r =. 74, p< .000) and with the scores of the two measures, partial correlations were run controlling for the age of the caregiver. Then, the relationship between duration of stay with the BAS (r = .08, p<. 16) and CRA (r = .10, p<. 06) scores disappeared. However, the association between caregiver's age and BAS(r = .17, p<. 00) and CRA(r = .2, p<. 000) was still strong and was statistically significant even though duration of stay was controlled. That is, with the increasing age the caregiver is likely to face more caregiver stress, irrespective of family's economic background. And the caregiver burden is not related to the length of stay of the elderly with the caregiver.

Relationship between the sub scales of CRA and key variables

An attempt is made to analyze the relationship between the subscales of CRA and the key variables i.e. age of the caregiver, and family income.

Table 5 : Inter correlations between family income, age of caregiver by caregiver satisfaction and other subscales of CRA

Variable	Caregiver satisfaction	Impact on health	Impact on schedule	Lack of family support	Impact on finances
Age of the care giver	0.041	0.419**	0.280**	0.208**	0.241**
Sig. (2-tailed)	0.474	0.000	0.000	0.000	0.000
Family income	–0.016	–0.153**	–0.065	–0.125*	–0.174**
Sig. (2-tailed)	0.788	0.008	0.26	0.03	0.00
Caregiver satisfaction	–	–0.411**	–0.304**	–0.374**	–0.247**
Sig. (2-tailed)	–	0.000	.000	0.000	0.000

N=300

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

The data in Table 5 show the correlations between the five subscales of CRA and the two variables. It can be seen that the age of the caregiver shows strong and positive correlation with the four areas i.e. impact on health, schedule, lack of family support, and impact on finances. While the age has a strong association with the impact on health, there is a strong negative correlation between the caregiver satisfaction and impact on health. Similarly, family income is also inversely correlated with the impact on health. This indicates that, as the age of the caregiver is increasing the impact of stress relating to care giving on their health is increasing. With regard to family income, it was found that the lower the income, the greater the negative impact of care giving on health.

Impact on work schedule also shows positive correlation with caregiver's age and inverse relationship with caregiver satisfaction thus indicating that higher disruption of the daily routine results in lower care giving satisfaction and that the impact will increase with the age of the caregiver. In terms of lack of support, again with the increase in the age of caregiver, the chances of counting on family support to help to take care of the elderly seems to become less frequent. Similarly caregiver satisfaction appears to come down significantly with the financial constraints experienced because of care giving and this impact appears to scale up with the increase in the age of the caregiver. More importantly it was found that both the age of the caregiver and family income are weakly related to care giver satisfaction.

It may be recalled that the age of the caregiver and the family income were found to be strongly associated with the two measures of caregiver stress and burden. To explore the relationship further between, care giver's age and family income with the caregiver stress, stepwise regression analysis was done. It is observed that both the variables i.e. caregiver's age and family income put together explain 14 percent of the BAS score, where as caregiver age itself contributes up to 11 percent. In the case of CRA, both the variables were found to explain 22 percent of the variation, where as the age of the caregiver is found to contribute up to 19 percent variation of CRA scores. Both the relationships were significant for BAS and CRA at $F(2,297) = 24.97$, $p < .000$ and $F(2,297) = 41.41$, $p < .000$ respectively.

Conclusions

In the present study, the sample caregivers from rural family context are middle aged (mean age=43 years), predominantly illiterate, poor (mean income=Rs.1730 pm) and are mostly from extended households. Most of the caregivers of the elderly are wives followed by sons, daughters and daughters-in-law.

A significant finding is that the sex of the caregiver is one of the strong explanatory factors for caregiver stress and women reported higher levels of caregiver stress as compared to men. This may be probably because the major burden of caring the elderly is actually shouldered by the women who are the conventional caregivers in the family. Though a considerable number of caregivers expressed satisfaction over care giving role played by them, only a small percentage of women expressed their satisfaction about their care-giving role. The caregivers from nuclear households reported higher levels of burden as compared to joint or extended households.

Next, the caregiver burden was found to increase with the increase in the age of the caregiver. Similarly, caregivers from lower income households reported higher levels of burden and it decreased as the income level of the caregiver increased. Further analysis revealed that the age of the caregiver was an important contributing factor than the family income. That is, with the increasing age, the caregiver is likely to experience more stress irrespective of their income levels. Also, evidence shows that the lower the income of caregivers, the greater the impact of care giving burden on health of the caregiver. And that is found to bring down the caregiver satisfaction significantly.

Coming to the comparison of the two measures used in the study i.e. BAS and CRA, they reflected similar trend with reference to differences on sex, age, and income variables. Therefore, it can be concluded that these two measures are able to capture the caregiver stress and burden in a similar manner. Hence, either of the measures can be used effectively in studying the stress relating to elder care. Next, as compared to BAS, CRA being a multidimensional scale could bring out the impact of stress on such specific dimensions as health, family support and financial strain. Furthermore, except with the sex of the caregiver, the caregiver satisfaction did not emerge as a strong factor either with income or with the age of the caregiver.

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