Caregiver Burden Inventory

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Abstract

The present study was carried out to develop an indigenous scale on caregiver burden for the assessment of caregivers who care for patients with chronic illness. The non-probability purposive sampling strategy was used in the study. To generate the items, 8 caregivers of dementia patients were interviewed at the outdoor patient ward of Department of Neurology, General Hospital, Lahore. Later on, for the validation of the study, sample of (N=150) caregivers were taken and the initial item pool was administered on them at the outdoor patient ward of Neurology at General Hospital and Services Hospital. Component factor analysis revealed 4 factors which were labeled as financial and physical burden, emotional caregiver burden and patient's dependency, psychological burden and social burden. Item analysis revealed moderate to high levels of inter-item correlations. Total 24 items were retained. Each item of the scales described a situation which carried potential caregiver burden. Reliability analysis revealed that subscales had alpha values.92, .74, .75 and .81 respectively, much greater than the required value.

Keywords: Caregiver burden, Caregivers of patients with chronic illness, caregiver burden inventory

INTRODUCTION

The present study was carried out to develop an indigenous scale on caregiver burden. This indigenous scale was developed for the assessment of caregivers who care for patients with chronic illness.

Caregiver Burden

Caregiver burden has been defined as the stress or load borne by a person who cares for a chronically ill, disabled, or elderly family member. Hoenig and Hamilton (1996) first suggested the theory of burden and suggested that burden could be separated into subjective and objective burden. Subjective burden mainly comprises of the personal emotional state of carers produced while performing the caring role, while objective burden is defined as occasions or deeds connected to undesirable caring experiences. Collins et al. (1999) suggested that caregiver burden refers to psychological discomfort, physical health issues, economic and social stresses, compromised family relations, a sense of hopelessness and other adverse consequences of care responsibilities.

Caregiver burden is a multidimensional concept that comprises both optimistic and pessimistic features of providing care (Nijboer et al., 1994). The three main features of caregiver burden identified from the literature are self-perception, many-sided strain, and over time Bhattacharjee et al., (2012).

Self-perception is about the caregiver reflecting on his/her own experience for the duration of the caregiving process. According to Bhattacharjee et al., (2012), caregiver burden refers to "the positive or negative emotional state

and opinions of the caregiver linked to providing caregiving tasks. A mixed method study on caregiver burden conducted by De Korte-Verhoef et al. (2014) reported that more than half of family carers experienced a high level of burden; however, only a quarter of the caregivers stated that their burden damagingly affected their daily life.

The fact that caregiver burden is multidimensional has been expansively demonstrated in the literature. Due to the long-term care, the caregivers of patients pay restricted care to their own state of wellbeing and often suffer from health complications, such as weight loss, exhaustion and sleep turbulences (Arian, Younesi & Khanjani, 2017). Moreover, providing long-term care can upset the caregiver's timetable and lifestyle, thereby restrictive social activities and, causing the feeling of being socially lonely. Unpredictable degrees of financial difficulties confronted by caregivers have also been regularly reported (Park et al. 2012)

Caregiver burden, in essence, is not always stagnant. The longevity of caregiving, social/family support, and the course of disease are all dynamics that significantly affect the level of burden on caregivers (Lee et al. 2018)

Prior research has used role strain theory to provide a context for how caregivers deal with the many hassles they are presented with (Gaugler, Zarit & Pearlin, 2003; Goode, 1960; Skaff & Pearlin 1996). Although, there are many roles that individuals must accomplish, role stress sets in when individuals have a hard time fulfilling all roles. In other words, there are many demands placed on caregivers and they cannot meet all of their responsibilities (Goode, 1960). This theory may clarify why caregivers have feelings of burden and strain, as they often have many roles to sustain.

In Pakistan, cultural and moral values regarding elderly are different. Also, there are not many oldage homes and caring facilities available by the state as in western countries which make caregivers face tougher circumstances. all previously developed scales could not fulfill this cultural gap. So, it was essential to develop an indigenous scale to assess caregiver burden keeping in view Pakistani culture.

METHOD

Sample

To generate the items, 8 caregivers of dementia patients were interviewed at the General Hospital, Lahore. Later on, for the validation of the study, sample of (N=150) caregivers was taken and the initial item pool was administered on them. The caregivers were approached in the outdoor patient ward of Neurology at General Hospital and Services Hospital. They were referred by the on duty Neurologist in the outdoor patient ward. After being referred, the initial questioning was done from the caregivers to make sure that they meet the inclusion criteria of the research. Primary caregivers of dementia who spend at least 10 hours in a day with the patient were included in the research. Caregivers who have some kind of physical or psychological disease were excluded

Sampling strategy

The non-probability purposive sampling strategy was used in the study.

Ethical considerations

Prior permission was taken from the Director of Institute of Applied Psychology and supervisor of the research. Further permission was taken from head of Neurology Department, General Hospital before conducting interviews. Prospective participants were briefed about the nature of the interview. . The informed consent was taken from the research participants. The participants were instructed on the method of the interview and

their anonymity and confidentiality of information generated was insured. All endeavors were made to report information in accordance with American Psychological Association ethical guidelines.

Interviews

The interviews were conducted as part of process to develop questionnaire exploring perception of caregiving burden. Interviews were semi structured. Interview consisted of 6 open ended questions which were extracted keeping in view the previous literature. Interviews were conducted on 8 caregivers of dementia patients.

Procedure

With permission from the supervisor, departmental permission was taken from the Institute of Applied Psychology and further permission was taken from head of Neurology department, General Hospital before conducting interviews. They were referred by the on duty neurologist in the outdoor patient ward. After being referred, the initial questioning was done from the caregivers to make sure that they meet the inclusion criteria of the research. 8 caregivers of dementia patients were interviewed. The aim of interviews was explained to the participants. The researcher posed 6 open ended questions and noted the responses. Each interview lasted for around 30 minutes. After taking interviews, themes were generated from the responses of the participants. Then, self-reporting statements were made from the themes.

Item Generation

With the themes being generated from the responses of the participants, item were made. Initially 36 items were made which were then piloted on a sample size of n=15. The feedback was taken from the participants and the statements which were difficult to understand for them. So, the diction was significantly made easy. A Likert type 5-point forced option scale was used to allow participants to record their responses for each item (1=never, 2= rarely, 3=sometimes, 4=often, 5= almost always).

After generating the item pool, try out was conducted on the sample (N=150). The sample comprised of 150 caregivers of dementia patients who spend more than 10 hours with the patients in a day and do not have any chronic illness. The caregivers were approached in the outdoor patient ward of neurology at General Hospital and Services Hospital. They were referred by the on duty neurologist in the outdoor patient ward. After being referred, the initial questioning was done from the caregivers to make sure that they meet the inclusion criteria of the research.

RESULTS

Statistical Package for Social Sciences was used for data analysis. Data for 150 participants was coded into the SPSS. KMO measure was 0.79. Bartlett's test of sphericity was observed highly significant, at p= 000.

Table 1.1 Showing values of KMO and Bartlett's test

Kaiser-Myer-Olkin Test for Sampling Adequacy	.719
Bartlett's test of sphericity, Approx. Chi- Square	2766.276

P<.000

Factor Analysis was run to explore the factor loadings. An initial analysis was run to obtain eigen values for each component in data. Ten components had eigen values over Kaiser's criteria of 1 and in combination explained 62% of the variance. The factor loadings are reported in table 2.

Table 1.2 Showing extraction of the items of caregiver burden scale

Item	Extraction
My responsibilities at job……	.403
I feel really annoyed when I am with him….	.756
I feel embarrassed over his….	.845
I feel, he deliberately……..	.384
I feel embarrassed in presence……..	.692
A lot of money spent……	.632
I feel annoyed over his…….	.559
Our financial condition is poor because……	.787
A lot of money is wasted on him…	.808
Our financial needs don't…..	.656
He is an extra burden……..	.571
I am facing sleep issues because……	.364
My health is suffering…….	.685
Caregiving has physically…..	.773
I am always physically………-	.758
I feel deprive of happiness…	.543
Things in my life should have been…	.626
I want to escape this……	.591
I have to help him in so many……	.648
I am always mentally worried….	.778
I feel really sad ……	.679
My family has never appreciated….	.483
He cannot do anything without…..	.431
Caregiving for him constantly……..	.433

Scree plot

Factors were selected by consulting screen plot. Screen plot showed that 4 factors were adequate. So factors were fixed at 4.

Scree Plot
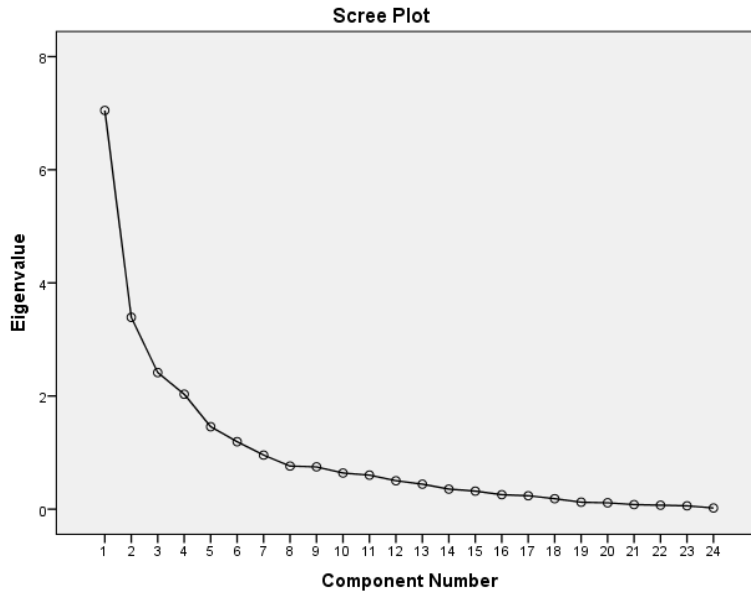
After fixing the factors, pattern matrix and structure matrix were consulted. These matrices confirmed that which of the items should be placed in which particular factor which is shown in the table below.

Table 1.3 Factor Loadings of the Items for caregiver burden scale

	Item	1	2	3	4
1	Expenses on medicine	.892			
2	Reason for poor financial condition	.878			
3	He is reason for my poor physical health	.797			
4	A lot of money spent on him	.780			
5	My health is suffering beacause of him	.777			
6	Aour financial need don't fulfill because of him	.776			
7	I stay physically tired	.773			
8	He is an extra burden	.742			
9	I feel annoyed over his conversation	.690			
10	I am facing sleep problems ……	.539			
11	I am always mentally worried ……		.850		
12	I feel really sad because…….		.798		
13	I have to help him……		.672		
14	My responsibilities at job…….		.543		
15	He can't do anything without my…..		.539		
16	No one in my family appreciated		.465		
17	Things in my life should……			.765	
18	I want to escape….			.746	
19	I feel deprived of happiness….			.714	
20	Giving him constant caregiving exhausts me mentally.			.649	

21	I feel embarrassed over….						.866
22	When I am with him/her, I feel……..						.834
23	In presence of my friends, I feel…..						.791
24	I feel, he/she deliberately……						.597
	Eigenvalues		7.0	3.3		2.4	2.0
	% of variance		29.37	14.12		10.06	8.46

The analysis revealed the presence of 4 factors. Total 24 items were retained. Initial Eigenvalues indicated that the four factors explained 29.37%, 14.12%, 10.06% and 8.46 % of the variance respectively. The rotated solution revealed the presence of a simple structure with 4 components showing several strong loadings and all variables loading substantially on all four factors.

Reliability

Reliability analysis was done on the factors of the scale.

Table 1.4 Reliability Analysis of Caregiver burden Scale (N=150)

Variables	k	M	SD	α
Factor 1	10	31.82	5.86	.92
Factor 2	6	20.82	5.04.77	.74
Factor 3	4	14.01	1.56	.75
Factor 4	4	11.03	2.27	.81

*p < .05. **p < .0001

All the factors had alpha value much greater than required value which shows that subscales have good internal consistency.

Table 1.5 Chronbach alpha values if item deleted

Item no.	r	α if item deleted
1	.397	.885
2	.372	.886
3	.369	.886
4	.136	.891
5	.459	.884
6	.163	.891
7	.538	.881
8	.453	.884
9	.709	.876

10	.724	.875
11	.690	.876
12	.604	.879
13	.493	.883
14	.687	.877
15	.752	.875
16	.714	.876
17	.307	.887
18	.338	.886
19	.223	.888
20	.432	.884
21	.327	.886
22	.471	.883
23	457	.884

Table 1.6 Inter item correlations among the items of caregiver burden scale

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Expenses on medicine	1																							
Reason for poor financial condition	.197	1																						
He is reason for my poor physical health	.319	.83	1																					
A lot of money spent on him	.068	.41	.460*	1																				
My health is suffering beacause of him	.061	.50	.551*	.343*	1																			
Aour financial need don't fulfill …	.032	)	-.121	.013	6	1																		
I stay physically tired	.004	.11	.026	.108	.211	.517*	1																	
He is an extra burden	.244	.07	.077	.063	.119	.672*	.65	1																
I feel annoyed over his conversation	.298	.10	.097	.013	.067	.681*	.60	.896	1															

I am facing sleep problems ……	.438	.17	.165*	.051	.081	.585*	.42	.754	.780	1										
I am always mentally worried ……	.192	.16	.124	.061	.067	.555*	.42	.614	.661	.706	1									
I feel really sad because…….	.281	.11	.176*	.107	-3	.243*	.26	.406	.424	.339	.28	1								
I have to help him……	.161	.13	.117	.133*	-0	.526*	.41	.581	.587	.454	.45	.53	1							
My responsibilities at job…….	.259	.13	.150*	.054	-7	.492*	.41	.591	.603	.524	.51	.61	.9	1						
He cant do anything...	.256	.13	.129	.041	-7	.504*	.36	.539	.595	.525	.54	.54	.8	.9	1					
No one in my family appreciated	-4	.38	.229	.158*	.032	.074	.065	-	.046	.038	.09	.20	.1	.2	.2	1				
Things in my life should……	.044	.23	.192*	.139*	.077	.229*	-)	.110	.093	.178	.21	.19	.2	.2	.2	.	1			
I want to escape….	.193	.11	.217*	.082	.152	.050	-2	.158	.176	.126	.16	.12	.0	.1	.1	.	.5	1		
I feel deprived of happiness….	.239	.08	.113	.101	-)*	.037	-)	.059	.018	.083	-l	.06	.1	.3	.3	.	.3	.	1	
Giving him constant	.333	.20	.266*		-1	.074	-*	.206	.195	.220	.09	.22	.2	.2	.3	.	.2	.	.	1

caregiving exhausts..				.197*																				
I feel embarrassed over….	.242	.26	.280*	.137*	- 0	.039	.08	.212	.229	.158	.11	.29	.3	.3	.3	.	.1	.	.	.	1			
When I am with him/her, I feel……..	- **	.12	.102	.060	.319	.173*	.18	.181	.175	.004	.13	.19	.2	.2	.2	.	.1	.	-	-	- 2	1		
In presence of my friends, I feel…..	.353	.21	.352*	.162*	.149	.224*	.11	.333	.292	.297	.20	.23	.2	.2	.3	.	.2	.	.	.	.34	- *	1	
I feel, he/she deliberately ……	.124	.07	.185*	.128	.081	-.109	- **	- 1	.030	.017	.03	.10	-	.0	.0	.	.2	.	.	.	- 3	.1	.0	1

Item analysis revealed moderate to high levels of inter-item correlations for the items of the inventory and this is the reason to retain the items in the scale.

DISCUSSION

The research was conducted to develop an indigenous scale on caregiver burden. The scale was developed for the assessment of burden which is caused by caregiving for people living with chronic disease in Pakistani culture. Caregiver burden scale is a 24 item Likert type scale with 5 point scoring categorized as (1=never, 2= rarely, 3=sometimes, 4=often, 5= almost always). The scale comprises of 24 items referring to the situations and factors that may cause burden while caregiving for the patients. There is empirical evidence support the findings.

Exploratory factor Analysis was run to check the factor structure of the scale. The principal component analysis with varimax rotation clustered twenty four items into four factors with a different number of items in each factor. The items selection criterion to retain items in a factor was value >.35 and items with high loadings were retained in a particular factor.

Factor 1 comprised of ten items merging all items related to financial burden and physical burden. Six items were related to financial burden and four items were explaining physical burden. Therefore, the factor was labeled as "financial and physical burden". The pattern shows that caregivers experience the financial and physical burden. Caregiving affect their financial and physical health. Etters et al. (2008) reported that dementia caregiving has been linked to negative effects on caregiver's health and many aspects influence the impact of the caregiving experience such as gender, culture, and individual characteristics. "financial and physical burden", as "emotional caregiver burden and patient's dependency"

Hooker et al., (2002) also reported that problematic behaviors among persons living with dementia patients, along with residence status, were significant predictors of caregivers' mental health and also their physical health.

Second factor consisted of six items related to both emotional burden and showing different aspects of patient's dependency on caregiver and eventually affecting caregiver's roles in daily life. So, the factor was labeled as "emotional caregiver burden and patient's dependency". Nijboer et al. (1994) argued that caregiver burden was a multidimensional concept that included both optimistic and pessimistic aspects of providing care. In the dictionary, burden is defined as "a duty, possibility, etc., that causes worry, difficulty or hard work". To date, literature supports the notion that caregiver burden is a complicated concept due to its multidimensional construction (Costa-Requena G., Espinosa Val M., Cristofol R, 2000).

Previous research has used role strain theory to provide a context for how caregivers deal with the many demands they are presented with (Gaugler, Zarit & Pearlin, 2003; Goode, 1960; Pearlin & McKean Skaff 1996)

Pearlin, McKean, and Skaff (1996) also revealed that dementia caregivers may feel burden in trying to fulfill the demands of caregiving, other duties, and the feeling of loss. Caring for the patient, such as with activities of daily living, as well as dealing with behavioral problems, can also cause higher levels of role burden (Robertson, Zarit, Duncan, Rovine, & Femia, 2007).

Third factor consisted of six items related to psychological tiredness. So, the factor was labeled as "psychological burden". Findings are supported by previous literature. Longitudinal analysis linking change in behavior to caregiver outcomes revealed that increases in problem behaviors among persons living with dementia were significant predictors of caregivers' psychological health (Hooker et al., 2002). Fauth and Gibbons (2014) also found disruptive behaviors to be most disturbing to caregivers and causing psychological distress.

Fourth factor consisted of four items related to social relationships and embarrassment caused due to the illness. This factor was labeled as "social burden". The findings are supported by previous literature.

Rodriguez (2009) reported Social embarrassment adds a unique component of distress to caregivers, controlling for other factors known to cause depression; second, the negativity of the embarrassment. The isolation associated with caring may contribute to caregiver strain in developing social connections (White & Hastings, 2004).Meaningful relationships, such as support from friends and family, have been associated with lower reported caregiver stress (Yatchmenoff et al., 1998).

Song and Singer (2006) found, satisfaction with social support was shown to have buffering effects on stress and depressive symptoms in caregivers of patients with psychiatric disorders. In a study of the effects of social support on psychological outcomes and self-esteem, findings indicate that social support may act as a mediator on indicators of well. Others (Quittner, Glueckauf, & Jackson ,1990) have found that social support mediated the relationship between social support and symptoms of outcomes of anxiety and depression. Caregivers who are motivated by a sense of duty, guilt, or social and cultural norms are more likely to resent their role and suffer greater psychological distress than caregivers with more positive motivations (Cohen CA., Colantonio A., Vernich L., 2002).

Limitations and suggestions

The clinical sample was small in number, however, this was due to limited availability of the sample and restricted time limit but future researchers should recruit larger samples from other provinces as well.

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