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Development and Validation of Psychosocial Stressors and Coping Strategies Scale for Alzheimer's Caregivers

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Abstract

Caregiving of terminal illnesses is far hectic job which can negatively affect the caregivers' physical, psychological, social and financial life. To measure the extent of these harmful effects a culturally appropriate measure of Stressors of Alzheimer's caregivers and Coping Mechanism Scale (SACCMS) was developed in current study. An Item pool was collected through open-ended interviews using a case study approach was done in first study of this PhD dissertation and this item pool was used to generate items in first phase of this study and these items were validated by 05 subject matter experts. Content validity index 5-point Likert Stressors of SACCMS having 56 items was generated for the development of psychometric properties. For standardization of SACCMS, 168 caregivers (Men=43, Women= 125) with age range from 25 to 56+ years were recruited through purposive sampling from different areas of Punjab. Through Exploratory Factor Analysis (EFA) five factors were generated namely psychological strain, Physical strain, Social strain, Religious coping and Positive reframing. SACCMS found to have remarkable internal consistency (α = .94). Caregiver Burden Scale by Zarit et al. (1980)) was chosen for convergent validity and The Subjective Happiness Scale (Lyubomirsky & Lepper, 1999) was used for discriminant validity. These results suggested that SACCMS would be a promising indigenous measure of caregiver's stressors. Results were discussed further in the context of cultural implications.

Keywords: *Alzheimer, Caregivers, Exploratory factor analysis, Reliability, Scale development, Validity*

Alzheimer (AD) is characterized by gradual decline in the patient's cognitive, behavioral, and functional capacities. In the West, dementia prevalence ranges from 1% in those 60 to 64 years old to 24 to 33% in people 85 years and older, whereas 60% of the world's population with dementia lives in developing nations (Sansoni et al., 2007). Dementia significantly increases the disease's burden on both patients and their carers. The majority of caregivers (a person who gives assistance to a disabled or incapable person (Irfan et al., 2017) experience caregiver distress along with psychological, physical, social, emotional, or financial issues(Kim et al., 2012).

Giving care to someone who is ill, disabled, or requires assistance with daily activities is known as caregiving. It includes providing for the well-being of both the caregiver and the person receiving care in terms of their bodily, emotional, social, spiritual, and psychological needs. As a developing nation with a high illness load and scarce resources in Pakistan (Qidwai, 2015) where government spends very little money on health, and the private sector is poorly organised and subject to political interference (Qidwai, 2016) caregiving is even burdensome. Families are finding it extremely difficult to care for their family members who require long-term care due to the joint family system's rapid disintegration (Itrat et al., 2007)

Due to the high demand for caregiving and scarce resources, a recently released study from Pakistan involving 400 caregivers shows the harmful effects of caregiving on caregivers. 64 percent of the participants were found to be caretakers, and 48 percent of them said that caring for others was generally negatively affecting their physical, psychological, and professional life. The study found that in order to help caregivers mitigate the negative effects of caregiving on their health, healthcare providers should investigate, identify, and support them (Irfan et al., 2017). According to a substantial body of research, the ongoing stress that comes with caring for a loved one who has AD can negatively affect both physical and mental health. Indeed, providing care has been linked to a higher chance of developing ailments and diseases (Schulz et al., 1990), like coronary heart disease (Vitaliano et al., 2002; Von Känel et al., 2010). There have been several recognized risk factors for caregivers developing psychological distress and morbidity ((Oyebode, 2003).

As earlier research suggested that caregivers of Alzheimer's Disease experience burden so to measure that burden or stress different tools have been developed at different times and by different authors such as Caregivers' Stress Scales (Pearlin et al., 1990), Care-giving Burden Scale (Gerritsen & Van der Ende, 1994), Caregiving Hassles Scale (Kinney & Stephens, 1989), Memory and Behaviour Problems Checklist, MBPC (Zarit et al., 1985), Screen for Caregiver Burden, SCB (Vitaliano et al., 1991) etc.

Present study also aimed to develop an indigenous tool to measure stress experienced by caregivers of AD patients in Pakistan as well as to assess coping strategies opt by caregivers of patients with AD. It was also aimed to establish psychometric properties of the scale.

Method

Phase I: Item Generation

In study 1 of this dissertation a series of case studies was conducted with primary caregivers of Alzheimer (Talib et al., 2021). The verbatim from the case studies were transcribed after reaching the saturation point, and themes were extracted and later those themes were used to create a list of items. 69 statements were initially obtained after this exercise. Correction of errors and identification of repetitive and double-barreled items was done where necessary following the supervisor's and co-supervisor's evaluations. After eliminating the redundant phrases, well-formed statements were constructed. A list of 59 items was penned down for empirical validation after a comprehensive review.

Phase II: Empirical Validation

In this phase, items generated in the first phase were tested for content validity.

Sample and Procedure. To collect endorsements for the Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS), a purposive sample of three clinical psychologists, one counsellor, and one psychology professor with more than five years of professional experience was chosen. On a three-point response scale, they were asked to score each item's relevance to the construct and clarity as 0 (No), 1 (To some extent), and 2 (Yes). Percentages were determined to find items that the experts chose as consistent with the construct and relevant to clarity. In order to demonstrate content validity for the psychological construct, this data was loaded into SPSS (Version 25) and used to analyze the frequency and percentages for each item on a three-point scale. Based on the ratings of all experts, a league table was constructed, and only those items with consensus (at least 80%) among experts were retained.

Results. The SACCMS content validity was confirmed. Items 19, 35, and 53 were removed since they had a "NO" score of more than 20% regarding the construct's applicability. Items that bear more than 20% of "NO" in terms of clarity were extensively rephrased to improve clarity, such as the item مجھے اکثر اپنے فیصلوں پر پچھتانا پڑا was modified to " میں اکثر فیصلہ کرنے میں دقّت محسوس کرتا/کرتی ہوں۔ " A clear transcript of 56 items was produced by carefully rephrasing and revising the draft of the remaining items after a thorough evaluation by the supervisor and co-supervisor to minimize ambiguity and grammatical errors. A draft of 56 items with the primary identifier SACCMS was created, and each item had a 5-point Likert scale rating from 1 (Strongly Disagree) to 5 (Strongly Agree).

Phase III: Establishing the Psychometric properties

The final phase of the research was to establish the construct validity through internal consistency, exploratory factor analysis, and convergent and divergent validity of the Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS).

Sample

Using a snowball sampling strategy, 168 individuals (43 men and 125 women) with a minimum age of 25 were selected from Government and Private Hospitals in Faisalabad. Two general guidelines were employed to calculate the sample size for factor analysis. First, Cattell (1978) suggested using three participants per question, and second, Comrey and Lee (1992) suggested using the following general scale to determine an appropriate sample size: "100=poor, 200=fair, 300=good, 500=very good, and 1000 or more=excellent.". Thus, for factor analysis of current indigenous scale, the sample size was handled as per the subjects' variable ratio. The ratio of 3 respondents to 1 variable/item was employed to do factor analysis. The existing scale had 56 questions, so it required 168; as a result, a sample of 168 people was fair and pertinent. The 168 participants in the current research sample fairly met the conditions mentioned earlier. Recruiting enough individuals to complete the questionnaire was challenging, therefore, snowball sampling was chosen. In a snowball sampling procedure, chosen individuals were invited to name additional participants who shared the same demographic traits as the nominated participants and were then asked to complete the survey. The same procedure was repeated until the required sample size was reached (Johnson et al., 2017).

Instrument

A five-point Likert scale was assigned for 56-item Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) where 1 reflected strongly disagree and 5 represented strongly agree. A cumulative score of 280 represents extremely high levels of burden and stress on caregivers) and a minimum score "1" represents no psychosocial pressures on AD caregivers. whereas high score for particular coping strategy, suggested that person more often use that coping mechanism.

Procedure

Following a proper debriefing of the questionnaire, all participants gave their informed consent before being given the Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) form and were instructed to complete it properly and thoughtfully, answering all questions following their approaches, perceptions, and feelings about their position as caregivers. Participants were assured that their Personal and demographic data and answers would be kept private and would be used only for research purposes, with no other parties receiving access to their answers. After data was gathered, it was entered into SPSS to establish the scale's factorial validity and psychometric qualities.

Results

Table 2 showed lots of diversity in age ranges and a non-equal distribution of men and women. The illiterate groups, primary and middle level, were few, while respondents in the intermediate category and those with higher education were predominant.

Table 2 *Demographic characteristics of the sample (N=168)*

Baseline Characteristics	*F*	%
Gender		
Men	43	25.6
Women	125	74.4
Education		
Illiterate	3	1.8
Primary	3	1.8
Middle	9	5.4
Matric	9	5.4
Intermediate	42	25.0
Graduation	48	28.6
Post-Graduation	54	32.1
Age		
25-35	74	44.0
36-45	49	29.2
46-55	27	16.1
56 and above	18	10.7

Exploratory Factor Analysis

In order to identify the SACCM primary dimensions or components, exploratory factor analysis (EFA) was used. The sampling adequacy score calculated by Kaiser-Meyer-Olkin is .85 (shown in table 3). Given the KMO measure's high value, it is likely that principal component factor analysis will be beneficial for these variables. To examine the scale's potential structure, Bartlett's sphericity test revealed significant (*p* =.000) results as well (Bartlett, 1954).

Table 3 *Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity*

Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS)			
KMO	**Bartlett's Test**		
.854	***Chi-square***	***Df***	***Sig.***
	6370.954	1176	.000

Scree plot graphically determine the number of factors in a scale. In the current study eleven factors were revealed on the plot where Eigen values of 1 or more were used to determine factors. Series of factor analysis i.e. two, three, four to eleven factor solutions were carried out to get a clear picture. Finally, five factors solution was retained because it gave a clearer picture with fewest number of cross loadings.

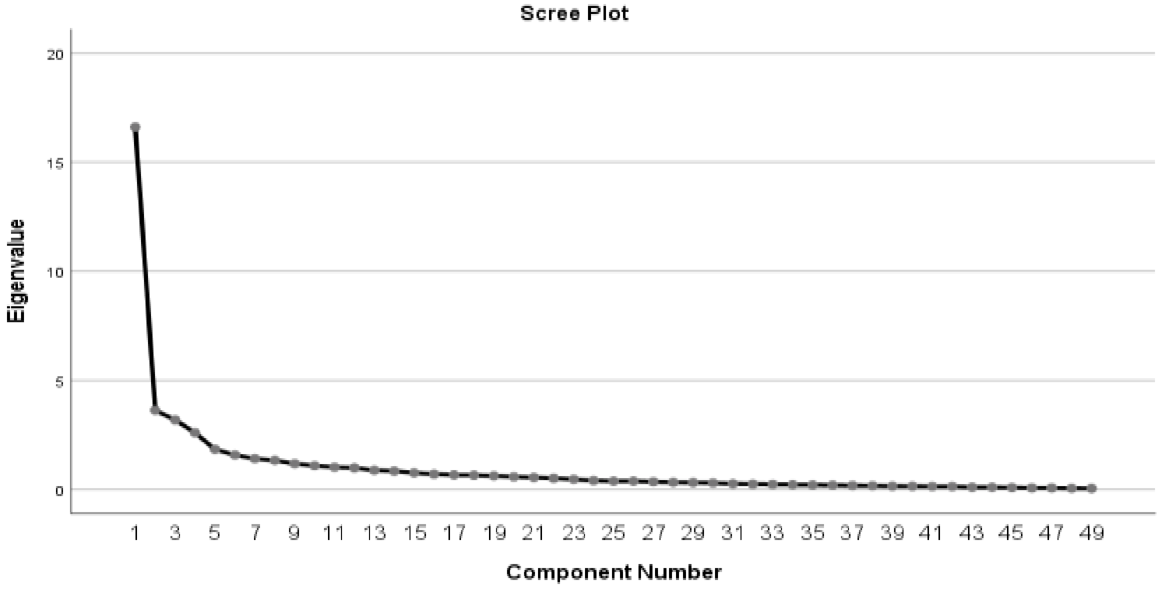

Figure 1. *Scree Plot*

Five factors solution was finer, covering the whole items. Thus, those items bearing 0.4 and above on factor loading were retained, while those items were excluded having a value below 0.4. Item no. 16, 17, 19, 28, 34, 46, and 53 were excluded as the loading was below .4, thus leaving 49 items for further analysis. Items having cross existence between five factors were recorded where those items bear the highest loading. However, an exception was made regarding item 31, "Mujhe lagta hai k log meri izzat nahi kartay," (people do not give me respect) and item 38, "meri izzat e nafs kam ho Gayi hai." (My self-esteem has decreased) These items bear high loading in factor 3, labeled as a physical strain, but conceptually these items best fit factor 2, labelled as social strain. Therefore, above mentioned two items were placed into factor 2.

The factor loadings of 49 items over five variables are displayed in Table 4. The factor analysis identified five factors: Psychological strain, Social strain, Physical strain, Religious coping, and Positive reframing.

Table 4 *Factor loading of 49 items on five factors through varimax rotation*

Item#	Items	Factor 1	Factor2	Factor3	Factor4	Factor5
1	I often feel anxiety.	**.763**	.107	.067	.101	-.064
2	I generally feel mentally stressed.	**.836**	.101	.125	.047	-.016
3	I lose my temper a lot.	**.702**	.137	.108	-.196	.085
4	I generally feel a sense of deprivation.	**.575**	.168	.249	.211	-.138
5	I feel sad.	**.815**	.181	.136	.051	-.101
6	I feel more irritable now.	**.779**	.169	.182	.059	-.081
7	I keep feeling a sense of hopelessness.	**.448**	.361	.289	.293	-.188
8	I feel like I am constantly struggling.	.326	**.611**	.212	-.175	.174
9	I cannot sleep soundly.	**.482**	.325	.386	-.158	.056
10	I often feel fatigued.	**.580**	.381	.054	-.260	.209
11	My life has become disturbed.	**.578**	.255	.236	-.057	.107
12	I often feel discouraged.	**.538**	-.014	.466	.044	.110
13	I feel like my mental capabilities have lessened.	**.608**	.293	.233	-.116	.152
14	I often feel dizzy.	.205	.195	**.664**	-.235	-.054
15	I often get headaches.	**.585**	.135	.175	-.215	.116
16	I often do not eat a balanced meal	**.476**	-.076	.195	-.429	.176
17	My blood pressure is normal.	-.322	.056	**-.427**	.356	-.270
18	I generally suffer from joint pain.	.185	.202	**.618**	-.317	.001
19	My responsibilities have increased a lot.	.100	**.758**	.013	-.057	.173
20	I have too much pressure from work.	.186	**.710**	-.080	.133	.078
21	Sometimes I feel like a patient myself.	**.539**	.537	.148	-.101	.128
22	I am unable to concentrate on one task for a long period of time.	**.559**	.341	.131	-.121	-.016
23	I feel my life to be meaningless.	**.379**	.347	.344	.182	-.136
24	I feel myself to be emotionally apathetic at times.	.440	**.465**	.299	-.022	.049
25	I often feel myself to be like a machine.	.238	**.693**	.201	.134	.006
26	I often have difficulty making decisions.	**.684**	.188	.001	-.106	-.023
27	I feel that people do not respect me.	.133	.284	**.682**	.046	-.101
28	I often feel myself to be helpless.	**.703**	.351	.246	-.001	-.132
29	I often feel discouraged in regards to my circumstances.	.458	**.497**	.337	.038	.087
30	There is a negative effect on my personal (married) life.	**.498**	.377	.163	-.372	.111
31	My family supports me.	-.282	-.268	-.001	**.571**	.145
32	My self-confidence has lessened.	**.499**	.260	.376	.018	-.233
33	My self-respect has lessened.	.341	.107	**.582**	-.022	-.264
34	I tend to feel empty inside.	.412	**.493**	.288	.296	-.284
35	I do not ever feel happy.	.263	**.490**	.294	.162	-.375
36	I feel hopeless about my future.	.273	**.598**	.371	-.094	-.115
37	I feel socially isolated.	.434	**.586**	.159	-.196	-.110
38	Usually people do not exhibit sympathetic behaviour.	.296	**.417**	.125	-.359	-.273
39	I have good relations with my neighbours.	-.344	-.231	.305	.227	**.432**
40	My identity has diminished.	.158	**.583**	.425	.134	-.265
41	I often pray to Allah to grant me courage.	.346	.041	-.098	**.536**	.140
42	I have full faith in Allah.	-.131	.197	.027	**.852**	-.011
43	My hardships have made me stronger.	-.071	.100	-.157	.270	**.560**
44	My religious faith has gotten stronger.	.033	.053	.009	.007	**.824**
45	I take care of the sick for the sake of heavenly reward.	.171	.086	-.084	.013	**.769**
46	I often engage in prayer to relieve my doubts.	.175	.030	-.193	**.595**	.392
47	I feel a lot of mental stress.	**.610**	.392	.161	-.115	-.131
48	I often feel frustrated.	.459	**.546**	.239	-.270	-.162
49	I am fulfilling my responsibilities efficiently.	-.427	**.580**	-.002	.250	.223

Note. Items having factor loadings of .40 & above are given in bold.

The first factor contained 22 items; the second factor contained 16 items. The third factor contained three items, the fourth factor included four items, and the last factor consisted of 4 items. Table 5 indicates that the first factor had an Eigen value of

16.60, the second factor had an Eigen value of 3.63, and the third factor had an Eigen value of 3.19. The fourth factor indicated 2.60, and the fifth factor represented 1.84 Eigenvalues, respectively. Brief detail about factors is given below:

Factor 1: Psychological strain. This factor concerns the person's perceived psychological stress and burden, which can lead to mental health problems. Item 1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 15, 16, 21, 22, 23, 26, 28, 30, 32, and 47 are included in this factor, such as (" میں اکثر بیچینی کا شکار ہو جاتا /جاتی ہوں۔ I often become restless)," "میں عموما "ذہنی دباؤ محسوس کرتا /کرتی ہوں۔" I usually feel mental stress)," and other items related to psychological symptoms. (

Factor 2: Social strain. Item 8, 19, 20, 24, 25, 27, 29, 33, 34, 35, 36, 37, 38, 40, 48, and 49 are included in this factor related to stress and burden influenced by societal relationships and pressures thus identifying social stress and burden in caregivers. Items like " میں مسلسل آزمائش سے گزر رہا/رہی ہوں۔ Main (I am going through trial consistently)" and "meri zimadarian bohat barh gayi hain (my responsibilities have been much increased)."

Factor 3: Physical strain. This includes items 14, 17, and 18 related to the physical burden one faces, like " مجھے اکثر چکر آتے ہیں۔ (" I often feel dizziness)."

Factor 4: Religious coping. 31, 41, 42, and 46 items reflect coping strategies related to one's faith and trust in Allah. Items are like "(مجھے ﷲ پر مکمل توکل ہے۔ I firmly believe in ALLAH)."

Factor 5: Positive reframing. Items 39, 43, 44, and 45 related to caregivers' positive approach towards their responsibilities include " (مجھے میرے حالات نے مضبوط بنا دیا ہے۔ My circumstances made be strong)" and similar items.

The first three factors are related to the perception of stress and the caregivers' burden on their responsibility to take care of Alzheimer's patients. In contrast, factors four and five relate to their efforts to cope positively, face their circumstances, and feel stress-free. Therefore, conceptually, three factors: psychological, social, and physical strain, are opposite and negatively related to religious coping and positive reframing factors.

Scoring of the SACCMS

Scoring of SACCMS was carried out by adding up score of related items of each subscale separately. High score would depict high level of stress regarding particular domain and more frequently used to specific coping mechanism.

Table 5 *Eigenvalue, Percentage of Variance, and Cumulative Percentages of 49 items of SACCMS with five factors solution through factor Analysis*

Factors	Eigenvalue	Percentage of Variance	Cumulative Percentages
1	16.60	33.89	33.89
2	3.63	7.42	41.31
3	3.19	6.51	47.83
4	2.60	5.30	53.14
5	1.84	3.75	56.90

The Correlation between the total scores for the Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) and the selected 49 items revealed that each item significantly impacted the scale's overall score. Item retention requires that the item-total Correlation be ≥.30 (Tabachnick & Fidell, 2007). According to Cristobal et al. (2007), the subscales with corrected item-total correlation lower than 0.30 are not acceptable. However, for exploratory study 0.20 is an acceptable value for inter-item and item-the-total correlation. Furthermore, acceptable corrected item-total correlations for a multidimensional questionnaire/scale are 0.2 to 0.4 (Hobart, 2009).

An exception to this rule is that certain items (17, 42, 43, 44, 45, 46 and 49) on this scale have negative correlations while others have correlations that are less than 0.2 but theoretically related to the construct. This is because those items are related to a person's coping mechanisms and negatively connected to how they perceive load and stress. The item-total correlation table demonstrates the strong link between remaining items and the outcome. It demonstrates that choosing these components was a sound technological decision.

Table 6 *Correlation of 49 Items of SACCMS with Total Score of SACCMS*

Sr. No	Item No	Correlation with Total Score	Sr. No	Item No	Correlation with Total Score
1	1	.630**	26	26	.597**
2	2	.708**	27	27	.519**
3	3	.619**	28	28	.793**
4	4	.603**	29	29	.733**
5	5	.742**	30	30	.622**
6	6	.728**	31	31	-.320**
7	7	.632**	32	32	.656**
8	8	.658**	33	33	.530**
9	9	.679**	34	34	.693**
10	10	.666**	35	35	.574**
11	11	.648**	36	36	.666**
12	12	.551**	37	37	.704**
13	13	.696**	38	38	.498**
14	14	.605**	39	39	-.226**

15	15	.576**	40	40	.607**

16	16	.394**	41	41	.251**
17	17	-.04	42	42	.042
18	18	.536**	43	43	-.020
19	19	.516**	44	44	.082
20	20	.518**	45	45	.165*
21	21	.746**	46	46	.095
22	22	.650**	47	47	.723**
23	23	.614**	48	48	.730**
24	24	.697**	49	49	.040
25	25	.636**			

*** Shows Correlation is significant at 0.01 levels*

The Correlation of factors/subscales items with their total score on subscales was also calculated. The findings reveal that all items with their respective factor are significantly correlated, indicating diversity for each subscale. Results are shown in Table 7.

Table 7 *The table shows the Correlation of items with Subscales of Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) (N=168)*

Sr.#	Item no.	Psychological strain	Social strain	Physical strain	Religious coping	Positive reframing
1	1	.676**				
2	2	.792**				
3	3	.666**				
4	4	.605**				
5	5	.78**				
6	6	.769**				
7	7	.547**				
8	9	.622**				
9	10	.661**				
10	11	.632**				
11	12	.567**				
12	13	.671**				
13	15	.60**				
14	16	.451**				
15	21	.71**				
16	22	.657**				
17	23	.52**				
18	26	.64**				
19	28	.791**				
20	30	.605**				
21	32	.609**				
22	47	.715**				
23	8		.638**			
24	19		.544**			
25	20		.534**			
26	24		.649**			
27	25		.703**			
28	27		.512**			
29	29		.663**			
30	33		.448**			
31	34		.655**			
32	35		.612**			
33	36		.741**			
34	37		.697**			
35	38		.512**			
36	40		.677**			
37	48		.704**			
38	49		.19**			
39	14			.555**		
40	17			.141**		
41	18			.567**		
42	31				.346**	
43	41				.424**	
44	42				.608**	
45	46				.52**	
46	39					.282**
47	43					.443**
48	44					.62**
49	45					.484**

*** Shows Correlation is significant at 0.01 levels*

Internal Consistency

Chronbach's alpha was calculated to determine the degree of agreement between the scale's items on SACCMS. All entries were checked in the "item if deleted" column to see if any went over Chronbach's Alpha range, and none were discovered.

Table 8 *Cronbach's Alpha (α) reliability of the scale and five factors (n=168)*

Factor	No of Items	Alpha Reliability
Total SACCMS	49	.94
F1-Psychological strain	22	.94
F2-Social strain	16	.91
F3-Physical strain	3	.59
F4-Religious coping	4	.71
F5-Positive reframing	4	.70

SACCMS: Stressors of Alzheimer's Caregivers and Coping Mechanism Scale

As indicated in Table 7, the inter-item reliability of the SACCMS with 49 items was .94, deemed appropriate for exploratory measures (Nunnally, 1978). It indicated that the items assessed were of the same construct and were very homogenous. Additionally, the alpha reliability of the SACCMS five factors was determined.

Inter correlation among five factors and full SACCMS was also calculated, as shown in Table 9.

Table 9 *Mean, Standard Deviation, and inter-correlation among five factors and* SACCMS

Measure	I	II	III	IV	V	Total SACCMS
Psychological strain		.751**	.428**	-.110	-.100	.946**
Social strain	-	-	.449**	-.071	-.143	.902**
Physical strain	-	-	-	-.210**	-.158*	.509**
Religious coping	-	-	-	-	.297**	-.002
Positive reframing	-	-	-	-	-	-.029
Total SACCMS	-	-	-	-	-	-
Mean	73.06	48.30	8.81	16.20	16.54	162.92
Standard Deviation	22.36	15.58	3.32	3.34	2.92	36.82

***Correlation is significant at p<0.01; *correlation is significant at p<0.05,* SACCMS*: Stressors of Alzheimer Caregivers and Coping Mechanism Scale*

A significant positive correlation was found between psychological strain and social strain (r=.75, p<0.01), with physical strain (r=.42, p<0.01) and Total SACCMS (r=.94, p<0.01). At the same time, a negative correlation occurred between psychological strain and religious coping (r=-.11) and with positive reframing (r=-.10) at p>0.05. Similarly, the social strain also showed a negative Correlation with religious coping (r=-.07, p>0.05) and with positive reframing (r=-.14, p>0.05) meanwhile having a positive correlation with physical strain (r=.44, p<0.01) and Total SACCMS (r=.90, p<0.01). The physical strain was also negatively associated with religious coping and reframing, while a significant positive relationship with Total PSSC was observed. Religious coping positively correlated with positive reframing, and these factors showed a negative relationship with total SACCMS. The negative Correlation is justified because the factors measuring stress and burden are negatively associated with the factors that measure one's efforts to cope with the stress.

Convergent Validity

The Caregiver Burden Scale by Zarit et al. (1980) is chosen for exploring convergent validity of SACCMS. Therefore, in this study, it was hypothesized that the currently developed scale named Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) would have a significant positive Correlation with the caregiver burden scale.

Sample.

A total of 30 participants (8 males, 22 females) were selected from different hospitals and clinics in Faisalabad. All the participants were above 25 years of age. Male subjects were less than females because females provide mostly the primary care to AD patients in the role of wife, sister, or daughter. Males are supposed to provide secondary care to patients, as is common in our society.

Instruments

Stressors of Alzheimer Caregivers and Coping Mechanism Scale. In the first phase of the study, SACCMS was developed having 49 items under five factors or subscales, namely psychological strain indication one's psychological and mental stress, social strain referring to one's perceived societal pressure, physical strain depicting one's physical symptoms resulting from overburden, religious coping indicating the use of one's faith and trust in Allah to face the situation, and positive reframing indicating the use of positive behavior modification. The reliability of the full scale was noted to be high (α = .94).

Caregiver Burden Scale. The Caregiver Burden Scale, widely recognized as the Zarit Burden Interview, is a brief instrument that consists of 22 questions for assessing the caregiver's perception of the burden of providing family care and has cross cultural use. (Tang et al., 2017). These questions cover important topics for caregivers such as health, mental wellbeing, interpersonal relationships, physical exhaustion, social support, financial affairs, and the home's physical environment. An interviewer or the interviewee may fill out the 10-minute questionnaire. This caregiver burden scale was developed to quantify the stress level that family caregivers of dementia patients believe they are under. There is a 5-point rating system, with 0 (never) through 4. (nearly always). A total score is calculated from the item scores and ranges from 0 to 88, with higher scores signifying more burden. If the score is between 0 and 20, there is either no burden or very little stress.

Procedure. Participants were selected through purposive sampling. The caregiver burden scale and SACCMS were administered to the participants simultaneously after taking informed consent. Participants were properly informed about the scales and asked to complete the questionnaires without skipping any item; for further analysis, data was entered in the SPSS version 25.

Results.

To find the Correlation between the scales of the same construct, i.e., the Caregiver burden scale and SACCMS, bivariate Correlation was calculated. Results showed low to moderate positive correlation between the Caregiver burden scale and SACCMS and its sub scales i,e. Psychological Strain, Social Strain and Physical Strain whereas negative correlation between CBC and Religious coping and Positive Reframing (See Table 10 below).

Table 10 *Item consistency between SACCMS and CBC (N=30)*

Scale	K	α
SACCMS	49	.94
CBC	22	.93

Mean, standard deviation, and correlation statistic is given in table 10 below.

Table 11 *Intercorelations between CBS and SACCMS and its subscales.*

	Measure	I	II	III	IV	V	VI	VII
1	CBS	-	.72**	.82**	.47**	.48**	-.39*	-.40*
2	SACCMS	-	-	.64**	.46**	.39*	-.38*	-.37*
3	Psychological strain	-	-	-	.62**	.51**	-.37*	-.41*
4	Social strain	-	-	-	-	.65**	-.38	-.52
5	Physical strain	-	-	-	-.	-	-.51**	-.63**
6	Religious coping	-	-	-	-	-	-	.94**
7	Positive reframing	-	-	-	-	-	-	-
	Mean	40.96	160.1	80.23	58.03	9.26	12.96	13.26
	Standard Deviation	16.57	33.11	24.16	17.83	3.22	4.58	4.51

**Correlation is significant at p<0.01

*Correlation is significant at *$p<0.05$*

Discriminant Validity

According to Boateng et al. (2018), discriminant validity is defined by possibly low correlational scores between the chosen instrument and other instruments/scales that are not meant to evaluate the same construct, variable, or concept. The Subjective Happiness Scale (Lyubomirsky & Lepper, 1999) was used to test discriminant validity. It was hypothesized that SACCMS would negatively correlate with the subjective happiness scale.

Sample.

A purposive sample of 30 respondents, of which 8 were males and 22 were females over 25 years, was recruited from clinics and hospitals in Faisalabad. Most respondents were females since, in our society, basic and primary care is supposed to be provided by women.

Instruments

Stressors of Alzheimer Caregivers and Coping Mechanism Scale. In the first phase of the study, SACCMS was developed having 49 items under five factors or subscales, namely psychological strain indication one's psychological and mental stress, social strain referring to one's perceived societal pressure, physical strain depicting one's physical symptoms resulting from overburden, religious coping indicating the use of one's faith and trust in Allah to face the situation, and positive reframing indicating the use of positive behavior modification. The reliability of the full scale was noted to be high (α = .95).

4-item Subjective Happiness Scale. The original 13-item scale, a valid and reliable instrument across various cultures, age groups, and languages, served as the basis for the subjective happiness scale, which now contains four components. Furthermore,4-item Subjective Happiness Scale has been recommended as a valid and reliable measure for the measurement of general happiness on Pakistani population (Mubassar, et al., 2024). The scale gauges overall subjective happiness by asking participants to rank or compare themselves to others in a series. of statements. A 7-point Likert scale with a range of not a very happy individual (1) to a very happy person (7) is used for the response format. Internal consistency of this scale ranged from 0.79 to 0.94 (*M*=0.8), indicating highly acceptable ranges in different samples (Lyubomirsky & Lepper, 1999). Participants are asked to define themselves in two items using an absolute rating of their happiness (item 1; from 1 = not at all happy to 7 = extremely happy) and an evaluation of their interpersonal relationships (item 2; from 1 = less happy to 7 = happier). The participants in the next two items (items 3 and 4; from 1 = not at all to 7 = a great lot) indicate how much these assertions about happy and unhappy people apply to them.

Procedure. Participants were selected through purposive sampling. Subjective happiness scale and psychosocial stressors and SACCMS were administered simultaneously to the participants following their readiness to participate in the study. They were well informed about the scales, guided the procedure, and assured them of confidentiality and anonymity in the case of sharing the information retrieved from their data for research purposes only. Further analysis was done after data entry in the SPSS version 25.

Results.

Bivariate correlation was calculated to find the Correlation between the scales of different constructs. Results disclosed a positive negative correlation (*r*=-71**) at 0.01 level between the Subjective happiness scale and SACCMS, which showed SACCMS had strong discriminant validity.

Table 12 *Item consistency between SACCMS and SHS (N=30)*

Scale	K	A
SACCMS	49	.94
SHS	4	.75

Note: SHS=Subjective happiness scale

Table 13 Intercorrelation between SHS and SACCMS and its subscales

	Measure	I	II	III	IV	V	VI	VII
1	SHS	-	-.57**	-.60**	-.83**	-70**	.55**	.65**
2	SACCMS	-	-	.64**	.46**	.39*	-.39*	-.38*
3	Psychological strain	-	-	-	.66**	.54**	-.38*	-.46**
4	Social strain	-	-	-	-	.65**	-.39*	-.51**
5	Physical strain	-	-	-	-.	-	-.51**	-.63**
6	Religious coping	-	-	-	-	-	-	.91**
7	Positive reframing	-	-	-	-	-	-	-
	Mean	18.66	154.1	79.23	55.03	8.26	11.96	13.26
	Standard Deviation	4.22	33.11	24.16	17.83	3.22	4.44	4.51

**Correlation is significant at p<0.01, SHS=Subjective happiness scale
*Correlation is significant at p<0.05

This way, it is concluded based on results revealed by factor analysis, internal consistency, convergent and discriminant validity that the newly developed tool to measure psychosocial stressors and coping strategies of caregivers of Alzheimer's patients is valid and reliable.

Discussion

Present study aimed at development and validation of Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) compatible to Pakistani culture. Development of SACCMS was gone through three main phases. Phase I includes the identification of domain and generation of item's pool; phase 2 contains the empirical validation of scale whereas phase 3 consist to maintain psychometric properties of SACCM. Factor analysis resulted into five subscales i.e. Psychological Strain (PsyS), Social Strain (SS), Physical Strain (PS), Religious Coping (RC) and Positive Reframing (PR).

First factor that emerged was PsyS, which contained items related to feeling of restlessness, anger bursts, irritability, dis tress, worthlessness, insomnia etc. Previous literature also identified that depression (Dawood, 2016; Kamkhagi et al., 2015; Zawadzki et al., 2011) anxiety and distress (Dauphinot et al., 2015; Dawood, 2016; Gallagher et al., 2011), apathy, helplessness (Hosseini et al., 2016) sleeplessness (Dauphinot et al., 2015; Hashimoto et al., 2017), despair, and a sense of loneliness arise among caregivers of Alzheimer's patients as caregiver burden grows, and they typically use sedative medicines (Gallagher et al., 2011; Lou et al., 2015). Additionally, over time, this workload strain results in an increase in aggressive behaviours (Park et al., 2015).

Second factor that explored by EFA was Social Strain (SS) which carried out the items related to increased responsibilities, excessive workload, social inhibition etc. The majority of caregivers for Alzheimer's patients have reported having more duties in their daily lives. Due to their increased job and duties, they have noticed that they don't get enough restful sleep. As a result of their increasing responsibilities, they no longer have the time to complete their daily tasks and poorly manage their social life. Occasionally, this increased duty also results in changes in their personal lives. The long-term care concerns and issues that caregivers encounter lead to chronic care stress. Alzheimer's patients' caregivers lament the decline in their social skills as it shows up as a breakdown of the patient's previous relationships with friends and relatives, loneliness, high levels of responsibility, difficulties managing family responsibilities, increasing workload and preoccupations, quitting a job, losing opportunities, losing friends, and long-term disturbances in everyday activities(Bailes et al., 2016; Dawood, 2016; Kamkhagi et al., 2015; Kang et al., 2014; Koca et al., 2017; Zucchella et al., 2012).

Third factor was Physical Strain (PS) which encompassed the items related to physical symptoms such as abnormal Blood Pressure level, dizziness and body aches. Being an Alzheimer's caregiver is thought to be a physically unhealthy, persistently stressful task (Mannion, 2008). Physical exertion that exacerbates previously identified chronic diseases, detrimental dietary and exercise modifications, and the physiological impacts of carers' psychological distress can all contribute to their poor health (Pinquart & Sörensen, 2003). For instance, Keicolt-Glaser et al. (1996) discovered that Alzheimer's carers' immune systems differed significantly from those of their colleagues who were not caring for the diseased patient. Many carers report having little time to engage in healthy preventative behaviours like going to the doctor, eating a balanced diet, or exercising. This is due to the time required to provide care. In fact, caring husbands had higher blood pressure labs than their non-caregiving friends when they were clinically tested (Moritz et al., 1992). Additionally, it is suggested that informal dementia carers a re more likely to die as a result of bad habits and the stress of providing care (Schulz & Beach, 1999). The National Alliance of Caregivers (2004) published a report on the deteriorating physical health of caregivers for Alzheimer's disease. Alzheimer's caregivers (N=1247), in particular, felt that their health was poorer than that of non-caregivers (NAC & AARP, 2004).

Fourth and fifth factors that emerged were related to coping such as Religious Coping (RC) and its items were related to trust in God, courage and pray from God, feelings of contentment after praying etc., Positive Reframing and its items were related to expected reward, feeling more strengthen and brave. Previous literature also supported that caregivers of Alzheimer's patient used emotion-focused coping mechanisms included: acceptance (accepting the reality of what happened and learning to live with it); emotional support (seeking comfort and understanding from others); humour (joking about it or making fun of the situation); positive reframing (trying to see it in a different light, make it seem more positive/look for something good in it); and religion (trying to find solace in my religious or spiritual beliefs) (Cooper et al., 2006, 2008).

Furthermore, SACCMS was validated by finding out convergent and divergent validity. Convergent validity of SACCMS was evaluated by finding out the association with the score of similar construct scale which was Caregiver Burden Scale. Results indicated significant positive correlation between CBS and psychological, social and physical strain whereas negative correlation between CBS and religious coping and positive reframing. Divergent validity of SACCMS was evaluated by associating the score of SACCMS with opposite construct's tool which was Subjective Happiness Scale. Negative correlation indicated that care giver burden reduced the caregiver perception of happiness whereas religious coping and positive reframing positively associated with perception of happiness. Finally, a valid and reliable indigenous tool was developed to measure stress and assess coping methods adopted by Alzheimer's caregivers.

Limitations

The main limitation of the study was sample size. The sample size of the current research was not very large. In Pakistan mostly Alzheimer cases are reported when it reaches at chronic level and moreover caregiving of ageing considered responsibility. So sample was difficult to approach. Sample was drawn only from Lahore and Faisalabad. Thus, findings cannot be generalized to whole population. Studies shows that fastest growth in the elderly population is taking place in China, Pakistan, and their south Asian and western Pacific neighbors. The scale requires future validation against larger population.

Implication

There was no indigenous tool available for the evaluation of caregiver's stressors and coping strategies. This is the first kind of work with reference to measure the caregiver's stressors and coping strategies within a Pakistani context. An indigenous developed scale will represent the cultural dimensions related to caregiving services in more appropriate way. The scale will enable the researcher to identify the positive and burnout feelings and attitudes of caregivers towards their services. The scale will provide a valuable insight to the health practitioners about caregivers physical and mental health which is highly neglected phenomenon in our society. Using this scale health practitioner can help caregivers to cope with their stressors associated with caregiving services and to develop positive coping strategies by adopting healthy lifestyles.

Suggestions

Public awareness campaigns should be started, and Alzheimer Dementia teaching programs and workshops should be arranged for neurologists, psychiatrists, psychologists, general physicians and public specially who are caring their loved one's fighting with Alzheimer. It would also beneficial for cognitive neurology and neuropsychiatry to be introduced as a separate entity in departments. Exchange scholar/research programs and scholarships should be promoted by medical institutions and universities in the field of neuroscience and neurogenetics. Collaborations should be developed to share data and technology with other centers within the country as well as with neighboring countries of Asia like India, China. These countries are more advanced but face similar cultural, economic and management problems regarding caregiving services.

Studies to translate and validate psychological instruments for Alzheimer are vital and it is inconceivable that if cognitive psychology were introduced to graduate and post graduate students. They could work to translate, develop and validate instruments for care providers.

Pakistani physicians should be open to learning new information, skills and technology with regard to behavioral and cognitive neurology. Working together physicians, policy makers, psychologists and neighboring countries can help Pakistan to achieve the goal of providing patients with Alzheimer and their caregivers the assistance that is urgently needed.

More important Alzheimer daycare centers should be established in all big cities of Pakistan where skills and capabilities can exchange and caregivers can train well to utilize their maximum energies and how they can overcome their psychological, social and other problems. Furthermore, this may help to understand the nature and manifestation of behaviors and thinking patterns related to caregiving services specifically elderly population and also in future, this standardized tool will be helpful and useful for further researchers.

Conclusion

The reason for constructing a scale for Alzheimer's caregivers was the need of appropriately assess the caregiver's stressors and coping strategies concerns and to define how individuals perceives or thinks about their journey of caregiving. Previous studies indicated many scales that assess the caregiver's stressors, some caregiver's coping strategies whereas every scale has their own validity, reliability, and cultural norms. However, caregiving discussed in our culture as responsibility and never understood the stressors of caregivers and there was no indigenous tool available for its evaluation. It is a first scale to measure the types of stressors and coping behaviors in Pakistani context. Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) is considered to deal with the limits present in previous scales of caregiver's stressors and coping strategie s. The conceptual foundations for the items used in the scale were generated empirically and also supported by detailed review of literature. 49-items Stressors of Alzheimer Caregivers and Coping Mechanism Scale (SACCMS) highlighted the five factors: namely psychological strain, Social strain, Physical strain, for stressors and Religious coping, and Positive reframing for strategies to coping one's stressors which had not been discussed in previous scales.

As the psychometric strength of the scale is well established, it can be used with future researches for health psychologists, policy makers and Dementia care centers. This scale is considerable in understanding the stressors and feelings of caregivers (positive and negative) and attitude of common people towards caregivers of Alzheimer. The data related to present research is lacking in Pakistani context, it is hoped that the current study will open the new horizons for upcoming researchers.

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