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Original Article

Development and Validation of Caregiver Social Isolation Scale

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ABSTRACT

Objective: To develop an indigenous Caregiver Social Isolation Scale (CSIS) in Urdu for caregivers of mental and physical disorders in Pakistan.

Study Design: Mixed method study.

Place and Duration of Study: Department of Psychology, University of Gujrat, Pakistan, from Jan to Jun 2021.

Methodology: An item pool of 48 was generated based on a thematic analysis of structured interviews with six experts and nine caregivers. The content validity was evaluated by three PhDs in Psychology and two Physicians. The reliability calculated on thirty participants for a tryout was 0.95. Item total correlation of item tool was in the acceptable range. A pilot study was done on three hundred individuals. The value of the KMO was 0.952, which showed the adequacy of the data, with the value of Bartlett's test significant. No item was deducted. The reliability of 48 items on 300 individuals was 0.976, with two factors. First, for the validity of CSIS, data was collected from 120 individuals with standardized Ryff's psychological well-being scale, Scale of Social Support and Delong Loneliness Scale. Second, confirmatory factor analysis was conducted on 200 caregivers of children with cleft lip and palate.

Results: Exploratory factor analysis yielded two factors, mental agony and lack of social cohesion, with 48 items. Model fit indices of CFA on caregivers of children with cleft lip and cleft palate were in an acceptable range.

Conclusion: CSIS is a reliable and valid scale for assessing the social isolation experiences of caregivers of either mental or physical diseases in Urdu.

Keywords: Cleft lip, Cleft palate, Caregiver social isolation scale, Exploratory factor analysis.

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INTRODUCTION

Social isolation is a multi-faceted construct defined as the insufficient quantity and/or quality of interactions with other persons, including those interactions at the individual, group, and/or community level.[1,2] The common speculation about children with cleft lip and palate (CLP) and caregivers is that they might experience some psychosocial distress due to the child's condition, which leads to social isolation.[3] Several literature reviews explain the mental status of individuals with CLP (i.e., increased levels of depression and anxiety among children with facial disfigurement and their parents.[4]

More scales have yet to be developed to measure social isolation in Western countries.[5] The Subjective Isolation Scale and The Objective Isolation Scale are developed to measure social isolation in hearing-impaired elderly.[6,7] The friendship scale measured social isolation in older people residing in Australia.[8] The Social Disconnected Scale and The Perceived Isolation Scale were developed by Cornwell and Waite in 2009 for The National Social Life, Health, and Aging project among older adults in New York.[9] The Impact of a Child with Congenital Anomalies on Parents (ICCAP) questionnaire was developed in the Netherlands to measure the psychophysical problems of parents caring for children with congenital anomalies.[9] In Pakistan, Social Isolation Scale was developed,[10] but no scale was available to measure the social isolation experiences of caregivers of children with congenital anomalies. Therefore, the present study has developed Caregiver Social Isolation Scale in Pakistan to assess caring attitudes to family members' diseases. Further, ostracism of caregivers of children with cleft lip and cleft palate is measured.

METHODOLOGY

The mixed method study was conducted at the Department of Psychology, University of Gujrat, Pakistan, from January to June 2021 after Institutional Ethical Review Board (ERC/IERB) Permission.

Inclusion Criteria: Caregivers (children, parents, and grandparents) involved in caring for their physically and/or mentally sick family members were included in the study.

Exclusion Criteria: None

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The sample of one hundred and twenty individuals (18 males and 102 females) was taken. The purposive sampling technique was used for data collection from the general population. For the pilot study, the data was collected from 30 participants, aged eighteen to thirty-two years. Informed consent was taken from the participants.

In Phase-I, the scale development process of the Caregiver Social Isolation Scale followed the steps described by Trochim in 2006.[11] Primarily, the construct of social isolation was defined, and to generate the item pool for the Caregiver Social Isolation Scale (CSIS), structured face-to-face interviews were taken from one neurologist from Mid-City Hospital Sahiwal, three psychologists, each one from Mohsin Complex Kamalia, Faisalabad, from Yousaf Shaheen Medical Complex Jhang, and University College of Montgomery Sahiwal. A Plastic Surgeon from Cleft Hospital Gujrat, a Medical Officer from Cleft Hospital Gujrat, and nine caregivers of children with cleft lips and palate. Three fathers, five mothers, and one grandmother were included as caregivers. The interviews of the caregivers of children with cleft lip and cleft palate were taken from Cleft Hospital Gujrat, Pakistan. All the interviews were recorded and transcribed in the Urdu Language.

The thematic analysis aims to identify patterns of experiences that are important for understanding the phenomenon,[12] particularly social isolation in caregivers of children with cleft lip and cleft palate. After transcribing and coding the interviews, the results were divided into codes, sub-themes and a main theme. The codes were classified into different categories, each category was designed under a sub-theme, and a final main theme was formulated from these sub-themes. To assess the content validity of the items for CSIS, five professionals evaluated 48 items on four points Likert scale type ranging from 0 to 3 (0= Never, 1=to some extent, 2=to more extent, 3=completely). The content validity index and content validity ratio values are one or near 1 of all 48 items.[13]

The Cronbach's Alpha of CSIS was 0.95, and the items had cultural content equivalency. The language that was used in the scale was easy and understandable manner. All the participants understood the scale language in a good manner.

In Phase II, Forty-eight items of CSIS were administered to three hundred participants for data collection.

A sample of two hundred individuals (aged: 20 to 75 years old) was taken from the caregivers of children with cleft lip and palate from the cleft hospital in Gujrat, Pakistan. Inclusion criteria include caregivers (father, mother, grandmother, grandfather, uncle, aunt, etc.) of children with cleft lip and palate before or after surgery. At the same time, exclusion criteria include the caregivers of children with other facial deformities or physical disabilities.

Four scales were used, namely, CSIS, 48 items with two factors, lack of social cohesion and mental agony; the Urdu version of Ryff's Psychological Well-being Scale, 18 items 14; the Urdu version15 of loneliness scale developed by De Jong Gierveld and Tilberg, 2010. The scale of Social Support in Urdu contained 16 items.[16] Informed consent was presented to the participants before participating in the research process. The clients were assured in verbal and written form that all the information they provided would be kept confidential, and they had the right to leave their participation at any stage. The information related to the purpose of the research was also provided to them. After data collection from the participants, the data was entered in SPSS, and the following analyses were run.

CSIS has 48 items and two factors - lack of social cohesion and mental agony. All the items were in the Urdu Language. Informed consent was taken before the administration of scales. The data of 300 participants were entered in SPSS. Item analysis was done by applying inter-item total correlation. In addition, exploratory factor analysis was run. Factor loading was also analyzed and Confirmatory factor analysis (CFA) in the AMOS-21 version was carried out.

RESULTS

The item analysis of forty-eight items on three hundred participants was performed. Interitem Correlation Matrices (n=300) is shown in Table-I. Table-II depicts KMO and Bartlett's test Sphericity. The value of the result is 0.952, which further shows the data's adequacy. The value of Bartlett's test is significant at $p<0.001$. Table-III indicates that factor one, lack of social cohesion, shows a 27.68 variance with a percentage of 27.68, while factor 2, Mental Agony, shows a 25.97 variance with a percentage of 53.66 in the CSIS. The Table shows exploratory factor analysis (EFA) two factors rotation of factor structure. Cronbach's Alpha was found through SPSS which measures reliability or internal consistency with 0.976. Table-IV indicates the correlation between social isolation, psychological

well-being, social support and loneliness among caregivers of children with cleft lip and palate. Bivariate correlation analysis was run. Results revealed that there is a significant negative relationship between social isolation and psychological well-being (r=-0.36, p<0.01). Social isolation also shows a significant negative correlation with social support (r=-0.53, p<0.01). Social isolation is also showing a significant positive relationship with loneliness (r=0.39, p<0.01). CFA for Validity of CSIS in Caregivers of Children with Cleft Lip and Cleft Palate is shown in Table-V.

Table-I: Interitem Correlation Matrices (n=300)

Items	r	Items	R	Items	r
1	0.56**	17	0.47**	33	0.75**
2	0.58**	18	0.78**	34	0.62**
3	0.65**	19	0.71**	35	0.59**
4	0.67**	20	0.64**	36	0.67**
5	0.66**	21	0.72**	37	0.56**
6	0.64**	22	0.74**	38	0.53**
7	0.66**	23	0.63**	39	0.73**
8	0.65**	24	0.69**	40	0.73**
9	0.73**	25	0.79**	41	0.71**
10	0.72**	26	0.67**	42	0.73**
11	0.71**	27	0.69**	43	0.73**
12	0.75**	28	0.82**	44	0.77**
13	0.72**	29	0.72**	45	0.73**
14	0.79**	30	0.69**	46	0.69**
15	0.72**	31	0.67**	47	0.74**
16	0.72**	32	0.68**	48	.75**

p<0.001

Table-II: EFA of Caregiver Social Isolation Scale (n=300)

KMO		Bartlett's Test of Sphericity		
		Chi-Square	Df	p-value
SIS	0.952	12412.706	1128	<0.001

DISCUSSION

The study aimed to develop and assess the psychometric properties of the Caregiver Social Isolation Scale (CSIS). 48 items were administered to 30 and later on 300 caregivers. The inter-item total correlation was calculated. Item analysis was used to assess the objective evaluation of examinations. KMO and Bartlett's test Sphericity was run to test the adequacy of the sample and the determination of this thing that either the data is best for further analysis. For this, the value of KMO should be greater than 0.8019. A value greater than 0.9 showed excellent of the data, and the value of the result was 0.952, which showed the adequacy of the data. Further, the value of Bartlett's test is significant at the rate of p<0.001. That was acceptable for the sample size. The reliability was also very good, showing Cronbach Alpha 0.976. EFA two factors were fixed with 0.4 absolute value of suppression. The factor loading range was 0.413 to 0.8120. There were 24 items in factor one, named lack of social coherence, and there were 24 items in factor two, named mental agony.

Table-III: Factor Loading of 48 items of CSIS (n=300)

Items	Factor 1	Items	Factor 2
41	0.813	03	0.767
46	0.807	26	0.761
43	0.777	4	0.743
39	0.718	5	0.718
13	0.716	30	0.702
47	0.704	23	0.699
40	0.699	29	0.672
44	0.683	31	0.660
48	0.675	27	0.648
15	0.651	22	0.646
42	0.643	32	0.639
14	0.634	20	0.637
18	0.637	12	0.607
35	0.634	02	0.601
36	0.622	25	0.598
34	0.619	10	0.587
8	0.614	28	0.584
16	0.589	09	0.581
17	0.556	07	0.571
45	0.549	33	0.562
6	0.545	11	0.548
24	0.526	19	0.542
37	0.467	21	0.523
01	0.413	38	0.448
Total Variance	13.29		12.46
% of Variance	27.68		25.97
Cumulative %	27.68		53.66

Table-IV: Correlation between Variables (n=120)

	2	3	4	Mean ±S.D
1. CSIS	-0.36**	-0.53**	0.39**	30.73±22.47
2. Psychological well being	-	0.30**	-0.36**	86.46±9.72
3. Social support		-	-0.33**	46.75±9.81
4. Loneliness			-	3.32±1.81

Table-V: CFA for Validity of CSIS in Caregivers of Children with Cleft Lip and Cleft Palate

$\chi 2$	p	CFI	NFI	RFI	IFI	TLI	RMR
151.447	<0.001	0.946	0.926	0.905	0.946	0.930	0.02

The convergent validity of the social isolation scale with loneliness was significant and positive. A significant relationship exists between two variables, social isolation and loneliness.[12,15] A significant associa-

tion exists between social isolation and loneliness.[11,16] Thus convergent validity of the social isolation scale with loneliness has been confirmed. The discriminant validity of social isolation with social support and well-being was significant and positive. Families who fall prey to social isolation also experience a lack or decline in social support.[17] The people who are disabled experience high levels of social isolation, loneliness and low levels of perceived social support compared to those who are not disabled.[18] Thus the Discriminant validity of the social isolation scale with social support and well-being has been confirmed.

The social isolation yielded two factors, namely lack of social cohesion and mental agony, that can have strong implications regarding Pakistan.[16,18] Since Pakistan is considered a collectivistic society, any kind of ostracism of individuals due to any reason (particularly having children with cleft lip and cleft palate) make it difficult for caregivers to live their life with support from others. Similarly, they experienced mental agony that might hamper their interaction and caregiving tasks for looking after their children with cleft lip and palate. Therefore, psychologists and Clinical Psychologists can play their role to counsel caregivers to cope effectively with their mental agony and simultaneously reduce social interaction with others. In addition, they can organize workshops and seminars on a community level to raise awareness in others for being kind and soft-hearted towards the people sufferings due to deformities in children.

CONCLUSION

The results show that CSIS is a reliable and valid tool with 48 items in Urdu to assess ostracism in caregivers of various psychological and physical disorders in Pakistan.

Conflict of Interest: None.

Author's Contribution

Following authors have made substantial contributions to the manuscript as under:

SS: Conception, interpretation of data, drafting the manuscript, approval of the final version to be published.

MAM: Study design, data analysis, drafting the manuscript,

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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