ORIGINAL ARTICLE

Reliability and Validity of the COPE Index among Caregivers of Hemodialysis Patients in Pakistan

Sumaira Nasim[1*], Nicola M. Lowe[2], Victoria Hall Moran[2], Stephanie Dillon[2], Sidra Zaheer[1], Ian Philp[3]

ABSTRACT

Objective: To assess the reliability and validity of the COPE (Carers of Older People in Europe) index tool among the caregivers of dialysis-dependent patients in Pakistan.

Study Design: Cross-sectional study.

Place and Duration of Study: The study was conducted at the Dialysis Unit of Pakistan Kidney Patients Association Rawalpindi, Bahria International Hospital Rawalpindi and Fauji Foundation Hospital Rawalpindi, Pakistan, from December 2018 to January 2019.

Methods: A 15-item COPE index questionnaire was administered, and data were collected from 124 caregivers of patients undergoing regular hemodialysis. A Principal Component Analysis (PCA) was performed on all items of the COPE index to retain the underlying components. Further, Cronbach's alpha was used to assess the internal consistency of the retained component structure and loadings obtained from the PCA and the entire instrument separately.

Results: The PCA analysis revealed that, with the context of this study, the COPE index had good internal consistency for the negative aspects of caregiving and social support (Cronbach's alpha scores were 0.864 and 0.781, respectively). For the positive impact items, a Cronbach's alpha score of 0.655 indicated modest internal consistency. Cronbach's alpha of 0.714 for the entire 15 items indicated that the COPE index had good overall internal consistency in our study population.

Conclusion: The COPE index was found to be a valid tool for use in Pakistan to assess the caregiver experience, including both positive and negative aspects of caregiving.

Keywords: *Caregivers, COPE-index, Validation, Pakistan.*

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Introduction

Due to the rise in chronic diseases, there has been a shift from institutional care to informal care within the home.[1] A person living with one or more chronic diseases may require a modified diet, have altered sleep patterns, impaired physical activity, and limited socialization, all of which can lead to functional limitations and disabilities and increased dependency on family members.[1,2] Such caregivers often provide physical, mental, and/or social support to dependent family members.

Their religion or culture can influence the caregiving role, the relationship to the care recipient, the caregiver's health, and the healthcare system of a society.[2-4] Often in High-Income Countries (HIC), support is available to caregivers, such as a stipend, respite, and information given about self-care. However, in Low and low-middle-income countries (LMIC), there is often little support for caregivers due to the high burden of chronic diseases together with

[1]*School of Public Health, Dow University of Health Sciences Karachi, Pakistan*
[2]*UCLan Research Centre for Global Development University of Central Lancashire, Preston, PR1 2HE UK*
[3]*Honorary Professor, Centre for Health Services Studies (CHSS) University of Kent, Canterbury, UK*

Correspondence:
Dr. Sumaira Nasim
Assistant Professor, Public Health
School of Public Health, Dow University of Health Sciences Karachi, Pakistan
E-mail: sumaira.nasim@duhs.edu.pk

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a fragile healthcare system. This lack of support can negatively hurt the caregivers, who may feel overburdened due to time and financial constraints imposed by the requirement to provide care. Population-based studies have reported that the caregiving process is associated with depression, anxiety, and increased risk of disease in the caregiver.[5]

It has also been recognized that the caregiving role can also be a positive experience as caregivers may consider their role to be a meaningful experience in their lives.[3,6,7] Evaluation of the impact of the caregiving role has mainly focused on capturing the negative aspects of caregiving, referred to as the caregiver burden.[7] Several caregiver assessment tools have been developed, validated, and translated in different languages to assess the caregiver burden and negative aspects of caregiving.[1] A leading example is the Zarit Burden Scale, comprised of 22 questions validated in different cultures and for caregivers looking after patients with varied diseases and conditions. However, the tool is limited in its lack of assessment of the positive aspects of caregiving.

Understanding both the negative and positive aspects of caregiving can improve the health of care recipients and caregivers.[3,7] For example, an observational study assessing the subjective and objective burden and the positive dimension among 118 caregivers of people living with severe disability due to spinal cord injury found that those who perceived positive aspects of caregiving reported better mental health, as compared to those who reported a high subjective burden.[8] Similarly, in Asian caregivers who value “filial piety,” healthcare and social service providers reported positive aspects of caregiving.[4]

To capture both negative and positive aspects of caregiving, the COPE (Carers of Older People in Europe) index was initially developed for caregivers looking after older relatives and spouses in European countries.[9] This tool has also been validated for caregivers looking after people living with different disabilities or disease.[6,9-11] The literature indicates that compared to other diseases, hemodialysis-dependent patients' need more intense support from caregivers as hemodialysis is usually performed at a hospital or a dialysis center, repeated two to three times a week and takes a minimum four hours.[3] Hemodialysis also requires modified dietary intake, fluid restriction, and regular monitoring of vital signs such as blood pressure and body temperature.[2,3] This modified lifestyle is usually assisted by caregivers.

Pakistan is in the North-Western region of South Asia. It is the fifth most densely populated country in the world and has an average annual population growth rate of 2.4%. There is a severe shortage of qualified healthcare professionals and resource-constrained healthcare services in most public sectors. Moreover, there are specific gender roles and usually females are caregivers of family members living with a chronic disease. Thus, our study aims to assess the reliability and validity of COPE index among caregivers caring for hemodialysis patients in Pakistan. An enhanced understanding of the caregivers' experience will facilitate the development of health promotion interventions by public health professionals for the informal, unpaid caregivers in Pakistan.

Methods

Participants and Recruitment

The cross-sectional study was conducted in Rawalpindi Pakistan. Rawalpindi is the capital city of Punjab province in Pakistan. With an estimated population of 110 million (2017 census), it is the fourth most populated city in Pakistan and neighboring city of Islamabad, the capital of Pakistan. Due to the increase in job opportunities and comparatively low cost of living (as compared to Islamabad), an expansion in the population of the city has been observed in recent years.

For data collection, several dialysis units were contacted, three of which granted permission to recruit study participants. This includes Dialysis Unit of Pakistan Kidney Patients Association Bahria International Hospital and Fauji Foundation Hospital Pakistan. All dialysis units offered services in three shifts, from trained staff, offering dialysis on payment and free-of-cost depending on the affordability to patients and their caregivers. The data was collected from December 2018 to January 2019.

The socio-demographic characteristics such as age (years), gender of care recipients (male or female),

education (years), income (Pakistani rupees), and family structure (nuclear/joint) of the patients and the caregivers were gathered using an interview administered questionnaire. The inclusion criteria were: female adult caregivers in an unpaid capacity (for at least last six months) of an adult family member admitted for dialysis in a hospital and needing assistance in daily living (ADL), such as personal hygiene (bathing, grooming and oral care), dressing (including making clothing decisions), eating (preparing food and feeding), continence maintenance (toileting), and, transferring from seated to standing and getting in and out of bed.

The sample size of this study was calculated by using PASS Software to test for correlation. The correlation between COPE index and the General Health Questionnaire for negative impact was taken as 0.51. For the positive impact, it was -0.35[6], with an 80% power and 95% confidence interval (CI); the total sample size came out to be 99 caregivers (for negative impact) and 112 caregivers (for positive impact). The final analysis included 124 caregivers. In assistance with the hospital staff, the first author invited all caregivers accompanying the patients to participate. If they did not meet inclusion criteria or refused to participate, the next caregiver was contacted.

Data Collection

Data were collected from the caregivers who gave consent and met the inclusion criteria. The data was collected using interviewer-administered questionnaires in a separate room (to ensure privacy and confidentiality) adjacent to the waiting area for the caregivers. All interviews were conducted in Urdu.

The COPE index is a 15-item questionnaire comprised of both negative and positive aspects of caregiving, together with a measure of perceived quality of support. Six questions explore negative aspects of caregiving, for example, “Do you feel trapped in your role as a caregiver?” Five questions focus on the positive aspect: “Do you feel you cope well as a caregiver?” The remaining four questions probe information about the perceived quality of social support given to the caregivers. Response options are Never=1, Sometimes=2, Often=3 and Always=4. For scoring positive and negative aspects and quality of support, a high score indicates a high level of perceived positive and negative experience and support quality, respectively. This tool has been translated into several languages and validated in different cultural contexts of caregivers looking after patients with varied diseases or conditions.

Ethical Considerations

Ethics approval was obtained from the University of Central Lancashire (UCLan) ethics committee (STEMH 693), Preston, UK held on August 23, 2017. The consent form, participant information sheets, and questionnaire were translated into Urdu by the first author. Interviews were undertaken in Urdu, and any queries raised by participants were clarified to ensure appropriate understanding.

Data Analysis

The data were analyzed using STATA version 16.0.1 (Stata Corp., College Station, TX, USA). The demographic characteristics of the study participants and their care recipients were analyzed descriptively. A Principal Component Analysis (PCA) was performed on all items of the COPE index to retain the underlying components. PCA was performed with orthogonal rotation (varimax) with Kaiser normalization employed following extraction. A part was retained if its eigenvalue was more significant than one, and items were extracted if their loading was 0.40. Further, Cronbach's alpha was used to assess the internal consistency of the retained component structure and loadings obtained from the PCA and the entire instrument separately. For examination of extracted components for reliability, Cronbach's alpha reliability score ≥0.70 was considered as good reliability.

Results

Descriptive Characteristics of Participants

The socio-demographic characteristics of the caregivers are presented in Table 1. A total of 124 female caregivers completed the COPE index, and there was no dropout. The average age was 40.18 years (± SD 12.26), 69.1% were married, 81.5% (n=101) were not in formal paid employment, and 26.6% (n=34) had at least 12 years of education. Most of the participants were the spouses (44.64%), parents (23.38%), or in-laws (18.54%) of the care recipients. The remaining caregivers were close

relatives (nieces), siblings, and grandparents. Half of them had a monthly family income of less than PKR 50,000 (USD 175), and 61.0% lived within the extended family (joined). The average length of time

Table 1: Characteristics of caregivers (n=124)

	Total
Characteristics	**Mean ± SD**
Age (years)	40.18 ± 12.26
Duration of CG role (years)	3.65 ± 3.97
Marital status	**n (%)**
Single	28 (22.6)
Married	85 (68.5)
Widow/divorced	11 (8.9)
Occupation status	
Full time	13 (10.5)
Part-time	10 (8.1)
Not working	101 (81.5)
Education status	
No education	20 (16.1)
5 years	9 (7.3)
10 years	29 (23.4)
12 years	34 (27.4)
14 years	21 (16.9)
16 years	11 (8.9)
Relatively to CR	
Husband	36 (29.0)
Parents	29 (23.4)
Siblings	16 (12.9)
Children	14 (11.3)
In-laws	23 (18.5)
Cousin	2 (1.6)
Niece/Nephew	1 (0.8)
Grandparents	3 (2.4)
Family income	
up to 10000	5 (4.0)
10001-30000	33 (26.6)
30001-50000	24 (19.4)
50001-70000	10 (8.1)
>70000	14 (11.3)
Refused	32 (25.8)
Not known	6 (4.8)
Living arrangement	
Nuclear	48 (38.7)
Joined	76 (61.3)

SD: standard deviation; CG: caregiver, CR: care recipient

Table 2: Responses of caregivers to COPE index (n=124)

Items	Responses			
	Never=1 n (%)	Sometimes=2 n (%)	Often=3 n (%)	Always=4 n (%)
Negative				
Do you find caregiving too demanding?	77 (62.1)	26 (21.0)	14 (11.3)	7 (5.6)
Does caregiving cause difficulties in your relationships with friends?	69 (55.6)	31 (25.0)	17 (13.7)	7 (5.6)
Does caregiving have a negative effect on your physical health?	62 (50.0)	37 (29.8)	18 (14.5)	7 (5.6)
Does caregiving cause difficulties in your relationship with your family?	66 (53.2)	33 (26.6)	19 (15.3)	6 (4.8)
Do you feel trapped in your role as a caregiver?	90 (72.6)	23 (18.5)	4 (3.2)	7 (5.6)
Does caregiving have a negative effect on your emotional wellbeing?	63 (50.8)	37 (29.8)	14 (11.3)	10 (8.1)
Positive				
Do you feel that anyone appreciates you as a caregiver?	2 (1.6)	8 (6.5)	19 (15.3)	95 (76.6)
Do you feel you cope well as a caregiver?	2 (1.6)	6 (4.8)	22 (17.7)	94 (75.8)
Do you find caregiving worthwhile?	-	1 (0.8)	10 (8.1)	113 (91.1)
Do you feel well supported by your family?	8 (6.5)	14 (11.3)	20 (16.1)	82 (66.1)
Do you have a good relationship with the person you care for?	9 (7.3)	12 (9.7)	18 (14.5)	85 (68.5)
Other				
Does caregiving cause you financial difficulties?	40 (32.3)	31 (25.0)	23 (18.5)	30 (24.2)
Do you feel well supported by your friends and/or neighbors?	39 (31.5)	38 (30.6)	32 (25.8)	15 (12.1)
Overall, do you feel well supported in your role of caregiver?	11 (8.9)	46 (37.1)	42 (33.9)	25 (20.2)
Do you feel well supported by health and social services?	27 (21.8)	48 (38.7)	31 (25.0)	18 (14.5)

that the participants had been involved in caregiving was 3.65 ± 3.97 years, ranging from 0.5 to 20 years.

Responses of the COPE index

Participants' responses to the 15-item COPE index are presented in Table 2. Most caregivers (72.6%) reported that they never felt trapped as a caregiver and never found caregiving too demanding (62.1%). Most of the caregivers (91.1%) reported that caregiving was always worthwhile, and 76.6% always felt appreciated as caregivers. Regarding other social support, a third of caregivers (32.3%) reported that caregiving never caused financial difficulties, and nearly a third felt well supported in their role by friends and neighbours (31.5%). Most caregivers felt that they coped well in their role as caregivers (75.8%), while 14.7% felt that they were always well supported by health and social care services.

Principal component analysis (PCA) of the COPE index

PCA identified the three components with an eigenvalue > 1 explaining a total variance of 59.3% (Figure 1 and Table 3). The first component explained 27.2% of the total variance containing the following items: “Do you find caregiving too demanding?”, “Does caregiving cause difficulties in your relationships with friends?” “Does caregiving have a negative effect on your physical health?”, “Does caregiving cause difficulties in your relationship with your family?” “Do you feel trapped in your role as a caregiver?” “Does caregiving have a negative effect on your emotional wellbeing?”. The first component in our study included an additional seventh item: “Does caregiving cause you financial difficulties?”. This component was labeled as a “Negative Impact.” The second component explained 17.4% of the total variance and contained the following four items with the highest loadings: “Do you feel that anyone appreciates you as a caregiver?”, “Do you feel you cope well as a caregiver?”, “Do you find caregiving worthwhile?” and “Do you have a good relationship with the person you care for?”. This component was labeled as “Positive Impact.” The third component

explained 14.7% of the total variance and contained the following items: “Do you feel well supported by your friends and neighbours?”, “Overall, do you feel well supported in your role of caregiver?” and “Do you feel well supported by health and social services?”. The third component in our study included an additional fourth item: “Do you feel well supported by your family? Therefore, this component was labelled as “Social Support”.

Reliability and Internal Consistency of the COPE Index

We used the component structure and loadings obtained from the PCA to establish internal consistency by calculating the Cronbach's alpha coefficient for the complete COPE Index and for all three subscales separately (Table 3). We found a coefficient of 0.714 for the entire 15 items, indicating that the COPE Index had good overall internal consistency in our study population. The alpha value (α = 0.864) for the negative impact increased after adding the new item. For the positive impact items, a coefficient of 0.655 indicated modest internal consistency, and a coefficient of 0.781 indicated a good internal consistency for the social support construction.

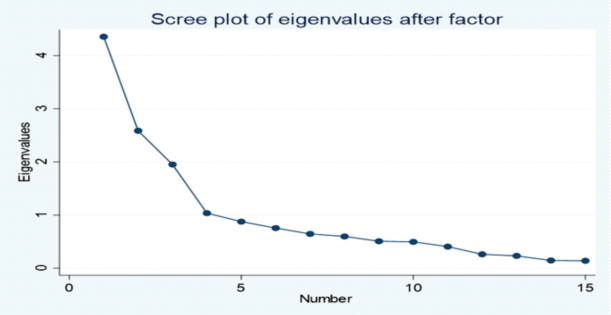

Fig 1: Scree plot of eigenvalues after factor analysis

Discussion

The aim of this study was to assess the validity and reliability of COPE index among female caregivers of hemodialysis patients. In our population, the COPE index was found to be a valid and reliable tool for assessment of caregiving experience and quality of support. Three components emerged, which identified as the negative impact of caregiving, the positive value of caregiving, and the social support

Table 3: Principal component analysis and internal consistency of the COPE index

Items	Mean (SD)	Components			α
		1	2	3	0.714
Negative					
Do you find caregiving too demanding?	1.60 (0.90)	0.662			0.864
Does caregiving cause difficulties in your relationships with friends?	1.69 (0.91)	0.799			
Does caregiving have a negative effect on your physical health?	1.76 (0.90)	0.801			
Does caregiving cause difficulties in your relationship with your family?	1.72 (0.89)	0.790			
Do you feel trapped in your role as a caregiver?	1.42 (0.81)	0.758			
Does caregiving have a negative effect on your emotional wellbeing?	1.77 (0.94)	0.839			
Does caregiving cause you financial difficulties?	2.35 (1.16)	0.478			
Positive					
Do you feel that anyone appreciates you as a caregiver?	3.67 (0.67)		0.670		0.655
Do you feel you cope well as a caregiver?	3.68 (0.64)		0.762		
Do you find caregiving worthwhile?	3.90 (0.32)		0.777		
Do you have a good relationship with the person you care for?	3.44 (0.94)		0.518		
Social Support					
Do you feel well supported by your friends and/or neighbours?	2.19 (1.01)			0.849	0.781
Overall, do you feel well supported in your role of caregiver?	2.65 (0.90)			0.827	
Do you feel well supported by health and social services?	2.32 (0.97)			0.880	
Do you feel well supported by your family?	3.42 (0.92)			0.478	
Total Variance		27.2	17.4	14.7	59.3

1=Negative impact; 2=Positive impact; 3=Social support; α=Cronbach alpha Rotated loadings< 0.4; Rotation Method: Varimax with Kaiser Normalization

for caregiving. Our study indicated a good internal consistency for negative impact and social support, with modest consistency for positive impact.

The results of our study are in contrast with studies conducted in HICs, where there were lower reported levels of positive value and higher reported levels of negative impact using the COPE Index. This is consistent with the view of caregiving as a social norm in many Asian countries including Pakistan.[4] However, the recipients of caregiving were very different in our study compared with other published studies of use of the COPE Index conducted in HICs with better health care facilities and social support , which could explain differences in patterns of experience of caregiving. Comparative studies of caregiving to people with similar needs would need to be undertaken to draw firm conclusions about the cultural and situational factors affecting caregiver experience.

The composition of the component item across other studies was identical, except for a single item "Does caregiving cause you financial difficulties?" that loaded on the negative component while previously being loaded in quality of support items/other items. A similar loading pattern was found in a study conducted in a large sample of caregivers drawn from six European countries.[9] This might be due to lack of financial support, such stipends or compensation, available to the caregivers in Pakistan. Similarly, four items loaded on the third component "social support" included an additional item "Do you feel well supported by your family?" This finding is in line with previously published literature endorsing family relations and the joint family system as providing support for caregivers.[3]

The COPE index was originally developed and validated for different vulnerable groups living in European countries. To best of our knowledge, this is the first study to validate this tool in Pakistan, where the burden of disease is high and there is a shortage of a qualified health workforce. Thus, family members are the main caregivers. The literature provides evidence that caregivers from South Asia report positive aspects of caregiving. Studies conducted in Pakistan to assess the caregiver burden also suggested exploring the positive aspect of caregiving.

Several tools are available to assess the caregiver burden. However, most tools focus on only one aspect, either the negative or the positive, but not both. This is not sufficient to assess the diverse experiences of caregivers. COPE index is found as a validated tool considering the cultural value of Pakistan towards caregiving role.

Strengths

To best of our knowledge, this is the first study conducted in Pakistan to validate a tool to assess the caregiver experience tool which describes both positive and negative aspects of caregiving. The data was collected in three healthcare settings, where dialysis services are offered either free of cost or in a charged capacity amongst those who can afford to pay. Caregivers from different socio-economic status participated in the study. Moreover, females were from both urban and rural areas, increasing generalizability.

Limitations of the Study

In Pakistani culture, usually all family members are involved in the caregiving role. Thus, further validation of such a tool should include at least two to three family members of a family.

Conclusion

Societal differences exist in terms of the caregiving role. Most tools to assess caregiver experience have been developed in high-income countries. Our study helps to validate the use of the COPE index in Pakistan as a tool with strong psychometric properties and factor structure, which measures positive as well as negative experiences of caregiving in caregivers for dialysis patients. The positive experience outweighed the negative, despite there being little additional support available to caregivers. This finding is consistent with the value attached to caregiving in Pakistan culture. Further studies with the COPE index should be undertaken in Pakistan with caregivers for other groups, such as older people or caregivers of children with special needs, which could be compared with studies with the COPE index in HICs to see if these differences in patterns of experience remain.

Authors Contribution

SN: Idea conception, study designing, data collection, data analysis, results or interpretation

manuscript writing or proof reading
NML: Study designing, data analysis, results or interpretation, manuscript writing or proof reading
VHM: Study designing, data analysis, results or interpretation, manuscript writing or proof reading
SD: Study designing, data analysis, results or interpretation, manuscript writing or proof reading
SZ: Study designing, data analysis, results or interpretation, manuscript writing or proof reading
IP: Study designing, data analysis, results or interpretation, manuscript writing or proof reading

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