

Vol 46 (2) June , 2021

Print: ISSN 0304-4904
Online: ISSN 2305-820X



PAKISTAN PEDIATRIC JOURNAL



A JOURNAL OF PAKISTAN PEDIATRIC ASSOCIATION

Indexed in EMBASE/Excerpta Medica, Index Medicus WHO
IMEMR & Global Health/CAB Abstracts and UDL-EDGE Products and Services

www.pakpedsjournal.org.pk

<http://www.pakmedinet.com/PPJ>

ORIGINAL ARTICLE

Caregiver Burden, Psychological Distress and Hopelessness among Carers of Thalassemia Patients

IRAM BATOOL, IRAM MANZOOR, SADIA EMTEYAZ, Sana Fatima

Pak Pediatr J 2021; 45(2): 226-32

ABSTRACT

Objective: To assess the relationship between care giver burden, hopelessness and Psychological distress. To explore the impact of care giver burden on Psychological distress and mediating role of hopelessness among carers of Thalassemia patients.

Study Design: Descriptive cross-sectional study.

Place and Duration of Study: At the Thalassemia center of The Children's Hospital & the Institute of Child Health Multan, Pakistan, in seven month from 17th November 2018 to 26th March 2019.

Material and Methods: Two hundred and forty (240, 48.3% males and 51.6% female) carers of Thalassemia patients were assessed on Burden Scale for Family Caregivers (BSFC), Kessler Psychological Distress Scale (K10) and Beck Hopelessness Scale (BHS).

Results: Findings showed that caregiver burden was positively correlated with psychological distress ($p < 0.01$) and hopelessness ($p < 0.01$). Results also revealed that caregiver burden significantly positively predicted hopelessness ($p < 0.00$) and hopelessness mediated the relationship between care giver burden and psychological distress ($p < 0.00$). Outcomes also illustrated that there were differences on care giver burden ($p < 0.01$), Psychological distress ($p < 0.00$) and hopelessness ($p < 0.00$) among carers of patients with thalassemia disorders on the ground of carer's gender.

Conclusion: Care giver burden, Psychological distress and Hopelessness are interlinked phenomenon, while male have more hopelessness and female have more care giver burden and psychological distress.

Key Words: *Caregiver burden, Psychological Distress, Hopelessness, Carers, Thalassemia Patients.*

Correspondence to:

Iram Batool

Department of Applied
Psychology, Bahauddin Zakariya
University Multan, Pakistan

E-mail: i.batool@bzu.edu.pk

Received 17th December 2019;
Accepted for publication
9th April 2021

INTRODUCTION

Those who take care of patient and share emotional bonding with them are known as primary caregivers. Carers have an essential role in the life of physically and mentally disable family members. Mostly caregivers are family members or close relative like parents, spouse, children,

and siblings. They take care of patients and stay with them all the time. Their mental health directly effects the mental and physical health of patients besides of various treatments. Condition of patients repeatedly change and that effect the mental health of both patients and carers. The permanent and progressive worsening of

behavioural, cognition problems, personality issues and physical helplessness of the patients may have definite impact on caregivers. Caregiver burden was associated to stressors, helplessness, and the resources and funds of the carers, and the relations between these facets.¹

Caregivers face a lot of difficulties throughout the time span of illness of patients and the effect of that suffering is known as caregiver burden interpretations has been explored regarding caregiver burden but when the definition of burden comes it includes different phenomenon in it hence it's a multidimensional issue which includes financial problems, social issues, psychological problems, and some physical disturbances.² These problems become the core of all disturbances and ultimately leads towards anxiety, depression and other related issues.³

Psychological distress refers to a condition of emotional or psychological suffering which includes different symptoms of anxiety and depression like hopelessness, sadness, restlessness, loss of interest. Psychological health of carers are majorly affected by caregiving experiences. As carers are the essential parts of patients' life, caregiver anxiety and depression can convert their behavior into frustration and sometimes in abusive behavior towards patients. The Theory of Caregiver Burden was reviewed about because of the Roy Adaptation Model⁴ to use as dispatch in considerate the relationship among care givers and the strain confronted when thinking about a constantly sick relative.⁵

Hopelessness refers to no hope, destroyed feelings for hope and unsolved dilemma. It is a subjective emotional state which pessimistically see future. Common consequences are loss of control, confidence, courage, and the energy to achieve life targets. Hopelessness can not only affect physical and psychological well-being of patients but also threatened mental states of care givers.⁶ It is a very demanding and difficult task to take care of patients with permanent diseases which can lead caregivers towards depression, anxiety, and hopelessness. Hopelessness, depression, and anxiety all associated with suicidal thoughts and behaviour disturbances in people. According to hopelessness theory, negative circumstances and negative cognition develop hopelessness and this hopelessness is

enough to bring depression, anxiety and other behavioural problems.⁷ Experimental discoveries recommend that hopelessness is prominent future amongst the most continuous conditions portrayed in patients with mental and therapeutic sickness. Hopelessness is related with poor-related personal satisfaction, may speak to a pathway of trouble in medically sick populations and might be vital to understanding adjustments to stress.⁸ There is a cross-sectional research checking the relationship of caregiving burden, spirituality, and psychological well-being of parents of Pakistani thalassaemic patients. According to that study, caregiver burden directly influences psychological well-being of the parents of thalassemia patients and it effects psychological well-being through the spirituality.⁹ According to another research done in Hyderabad, the prolonged treatment of thalassemia, its expenses and awaiting health problems have diverse effects not only on the patients but on the caregivers as well who mostly spend their time with the patients and struggle and pray for their health but mostly care giver burden have been demonstrated specially with carers of patients with psychiatric problem. It has been investigated in many countries but in Pakistan, very few studies have been done in this regard. So, the purpose of the current study is to investigate the phenomenon of care giver burden with psychological distress and to explore the mediating role of hopelessness among carers of Thalassemia patients in Pakistani perspective.¹⁰

MATERIAL AND METHODS

Participants: This descriptive cross-sectional study was done at the thalassemia center of The Children's Hospital & the Institute of Child Health Multan. All participants were selected through purposive sampling technique and comprises carers of thalassemia patients. Both male and female carers participated in this research. Age range of patients was 10 to 16 years and caregivers were 26 to 50 years old.

Instruments

Burden Scale for Family Caregivers (BSFC): Burden Scale for Family Caregivers (BSFC) was used to measure care giver burden comprising of 28 statements for assessment of carers perceived subjective burden for looking after of persistently -

ill family member. Four response categories ranging from strongly agree = 0 to strongly disagree = 3 is used for each statement.¹³ BSFC has strong construct as items' exploratory factor analysis formed 1 factor with factor loadings > .45.¹¹

Kessler Psychological Distress Scale (K10): Kessler psychological distress scale was used to measure psychological distress. It is a five-point Likert scale ranging from 1 = none of the time through to 5 = all of the time.¹² Results from a study showed that Confirmatory Factor Analysis indicated a single-factor 10-item construct had an acceptable overall fit and has good validity.¹³

Beck Hopelessness Scale (BHS): Beck Hopelessness Scale (BHS) was used to analyze hopelessness. It assesses the answer through true and false for each statement. According to a

study, factor analysis showed that BHS has an acceptable overall fit and has good validity.¹⁴

Data Analysis: Differential statistical analyses were applied by SPSS to investigate the results which were Pearson correlation, linear regression, hierarchical regression analysis and independent sample t-test.

RESULTS

Statistical Analysis: Out of 240 carers 48.3% were male (n= 116,) and 51.6% were female (n=124). Most of the patients were illiterate. And they reported their monthly family income between five to ten thousand rupees and only 5.8% claimed that their monthly income is more than ten per month. Relationship between Caregiver burden, hopelessness and Psychological Distress were analyzed.

TABLE 1: Correlation between care giver burden, hopelessness and psychological distress (n=240)

Variables	Caregiver burden	Hopelessness	Psychological distress	p
Caregiver burden	-	.37**	.30**	0.01
Hopelessness	-	-	.35**	0.01
Psychological distress	-	-	-	0.01

*p<.05, **p<.01, ***p<.001

Table 1 shows the correlation between care giver burden, hopelessness and Psychological distress. Results indicated that care giver burden significantly positively correlated with hopelessness and psychological distress which showed that as care giver burden increases

hopelessness and psychological distress will also increases and hopelessness is significantly positively correlated with psychological distress which means that as hopelessness increases psychological distress will also increase.

TABLE 2: Regression analysis for care giver burden and hopelessness (n=240)

Hopelessness				
Variables	B	SE	B	p
Constant	26.05	1.90		
Care giver burden	.23	.03	.37***	0.000

R² = .37, ΔR² = .14***, F change = 39.97

Table 2 shows regression analysis for care giver burden and hopelessness. Results revealed that hopelessness showed 37 % variance for care giver

burden F (1,238) = 39.97, p < .000, and caregiver burden significantly positively predicted hopelessness.

TABLE 3: Hierarchical regression analysis for care giver burden, hopelessness and psychological distress (n=240)

Variables	Block 1				Block 2			
	B	SE	B	p	B	SE	B	p
Constant	17.44	2.44			26.75	2.50		
Caregiver burden	0.32	0.05	0.30***	0.000	0.21	0.06	0.20**	0.000
Hopelessness					0.46	0.11	0.27***	

R² = .30, ΔR² = .09***, F change = 26.02 for block 1 R² = .40, ΔR² = .06***, F change = 22.52 for block 2

Table 3 shows hierarchical regression analysis for care giver burden, hopelessness, and psychological distress to find out the mediating role of hopelessness. Psychological distress was regressed on care giver burden in the first block and hopelessness in second block. Results showed that hopelessness positively significantly predicted psychological distress and

hopelessness partially mediated the relationship between care giver burden and psychological distress. Overall model explained 40 % variance in the psychological distress, $F(1,238) = 22.52, p < .000$. The first model explained 30 % variance in the psychological distress $F(2,238) = 26.02, p < .000$ and care giver burden positively significantly predicts psychological distress.

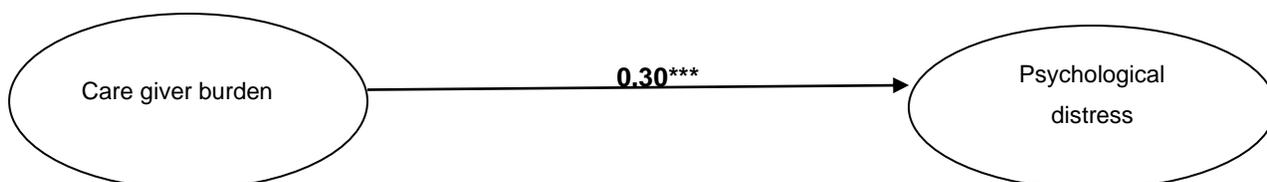


Fig 1: Direct Effect model

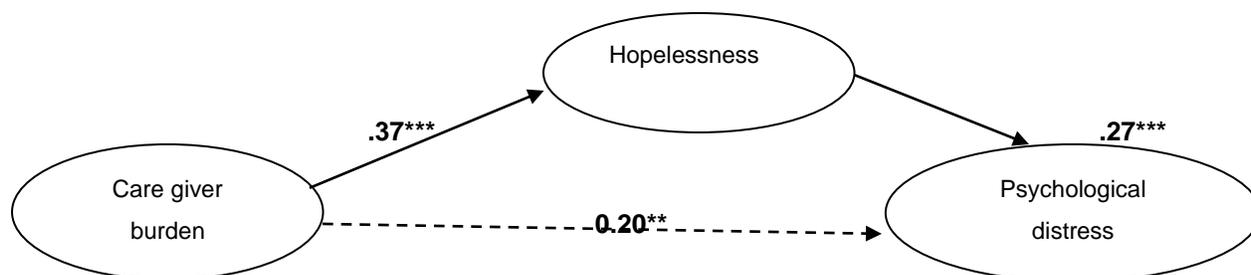


Fig 2: Emerged Model of Mediation

Note: Dotted line showed partial mediation between care giver burden and Psychological distress. B = standardized coefficient of model,

TABLE 4: Comparison of care giver burden, hopelessness and distress among males and females

Variables		N	M	SD	T	P	Lower	Upper
Caregiver burden	Female	124	38.50	9.63	9.63	.015	.6	5.71
	Male	116	35.34	10.40				
Hopelessness	Female	124	9.26	5.42	5.42	.000	4.74	1.70
	Male	116	12.49	6.45				
Psychological distress	Female	124	32.13	10.25	10.25	.000	2.67	7.84
	Male	116	26.87	10.07				

*p<.05, **p<.01, ***p<.001

Table 4 shows Comparison of care giver burden, hopelessness and distress among males and females. Results from independent Sample t-test

DISCUSSION

Present study explored the relationship between caregiver burden, psychological distress, and to explore the mediating effect of hopelessness among carers of thalassemia patients.

showed that male carers were more hopeless as compare to female carers and females had higher caregiver burden and psychological distress.

Psychosocial burden and problems faced by thalassemia major patients was explored but still a lot needs to be explored.¹⁵ According to previous researches, thalassemia not only has effects on patient life but also develop caregiver burden and psychological distress among patients' carers.^{11,12}

It was hypothesized that there will be positive association between caregiver burden, spirituality and psychological wellbeing among primary care givers of thalassemia patients. The outcomes from table 1 confirmed that the first hypothesis of this research was accepted. Many previous investigations were in the support of these findings. Thalassemia is one of those chronic illnesses that bring not only financial burden but also a lot of psychological burden. Hopelessness is common among carers of these patients.¹⁶ Association of psychological distress was investigated in an indigenous study and its relationship with quality of life and death anxiety among chronic patients was reported.¹⁷ Findings of current study will be a contribution in indigenous context.

It was assumed that care giver burden and hopelessness will be the predictors for psychological distress which was fully accepted. Outcomes revealed that the second hypothesis about care giver burden and hopelessness as predictors for psychological distress was successfully accepted. This result is in the line of with previous research done in Iran. According to that study, Thalassemia not only has effect on the life of patients, but also induce psychological, social, and economic burden on the parents, resulting in caregiver burden in parents.¹⁸ These findings are also steady with Western discoveries, it was found that carers burden of care was a powerful and clear indicator of psychological distress among the carers of chronically ill patients¹⁹. Similarly, results of another study showed that caregiver burden, anxiety and depression were positively correlated with different neuropsychiatric symptoms.²⁰

Another assumption of this investigation was that hopelessness will play mediating role for care giver burden and Psychological distress; this assumption was partially accepted. Results revealed that hopelessness partially mediated the relationship between care giver burden and psychological distress. The findings regarding mediating role of hopelessness were in harmony with other previous investigations. A longitudinal study noted the role of hopelessness as a mediator in the association between social aid and melancholy.²¹ Similar findings illustrated that hopelessness was a significant mediator between

the emotion of distress and acts related to killing oneself among males and females.²²

Hypothesis was that there will be differences between male and female carers on hopelessness and psychological distress. This hypothesis was also accepted and found that female carers had higher psychological distress with caregiver burden as compare to male carers and male carers were more hopeless than female carers. These results were also supported by a study, those levels of mental distress, unease and depression to be higher among female care providers when contrasted with male carers.²³ Furthermore results from the several different studies demonstrated that female carers had apprehension, distress and sadness to be elevated when compared with the male carers and female carers indicated more elevated amount of gloominess, nervousness, burden along with emotions of distress than male.²⁴⁻²⁵

CONCLUSION

Care giver burden, Psychological distress and Hopelessness are interlinked phenomenon, while male have more hopelessness and female have more care giver burden and psychological distress.

Limitations and suggestions

The study has been done with the sample of carers of patients suffering from Thalassemia, a further study should be conducted on family carers of other types of Thalassemia patients and carers of other chronic illnesses so that the findings can be more generalized. The sample for this study was selected only from government Institutes and carers from semi -government and private health institutions were overlooked. The results of the study were perhaps more related to Pakistani population and due to the culture related deviations there is limited scope for generalization the results in other countries.

Authors' affiliation

Iram Batool, Iram Manzoor, Sana Fatima
Department of Applied Psychology,
Bahauddin Zakariya University Multan, Pakistan

Sadia Emteyaz
Punjab University Lahore, Punjab Pakistan

REFERENCES

1. Bandeira DR, Pawlowski J, Gonçalves TR, Hilgert JB, Bozzetti MC, Hugo FN. Psychological distress in Brazilian caregivers of relatives with dementia. *Aging Ment Health*. 2007 Jan 1;11(1):14-9.
2. Girgis A, Lambert S, Johnson C, Waller A, Currow D. Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. *J Oncol Pract*. 2012; 9(4):197-202.
3. Belayachi J, Himmich S, Madani N, Abidi K, Dendane T, Zeggwagh AA, Abouqal R. Psychological burden in inpatient relatives: the forgotten side of medical management. *QJM: Int J Med Educ*. 2013; 107(2):115-22.
4. Stanley S, Balakrishnan S, Ilangovan S. Psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia. *J Ment Health*. 2017 Mar 4;26(2):134-41.
5. Hatami F, Hojjati H. Effect Of Roy's Adaptation Model On The Care Burden Of Mothers Of Children Under Chemotherapy (A Quasi-Experimental Study). *Medsurg Nurs* 2019 28;8(1) :e90489. doi: 10.5812/msnj.90489.
6. Liu RT, Kleiman EM, Nestor BA, Cheek SM. The hopelessness theory of depression: A quarter-century in review. *Clin Psychol (New York)* . 2015 Dec;22(4):345-65.
7. Holland JC, Andersen B, Breitbart WS, Buchmann LO, Compas B, Deshields TL, Dudley MM, Fleishman S, Fulcher CD, Greenberg DB, Greiner CB. Distress management. *J Natl Compr Canc Netw* 2013;11(2):190-09.
8. Anum J, Dasti R. Caregiver burden, spirituality, and psychological well-being of parents having children with thalassemia. *JORH*. 2016; 55(3):941-55.
9. Rajput Ah, Nadeem F, Kumar V. Depression, Anxiety and Stress Among Primary Caregivers of Thalassemia Patients in Hyderabad. *JPPS*. 2015; 12(4) 36-39.
10. Graessel E, Berth H, Lichte T, Grau H. Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC geriatrics*. 2014;14(1):23-32
11. Grasel E, Chiu T, Oliver R. Development and validation of the Burden Scale for Family Caregivers. Toronto: Comprehensive Rehabilitation and Mental Health Services. 2003
12. Kessler RC, Mroczek DK. Final versions of our non-specific psychological distress scale. University of Michigan. Ann Arbor: Survey Research Center of the Institute for Social Research. 1994.
13. Sampasa-Kanyinga H, Zamorski MA, Colman I. The psychometric properties of the 10-item Kessler Psychological Distress Scale (K10) in Canadian military personnel. *PLoS one*. 2018 Apr 26;13(4):e0196562.
14. Beck AT, Brown G, Berchick RJ, Stewart BL, Steer RA. Relationship between hopelessness and ultimate suicide: A replication with psychiatric outpatients. *Focus*. 1978; 147(2):190-296.
15. Batool. I, Ishfaq.K and Bajwa.R.S. Psychosocial Burden among Thalassemia Major Patients: An Exploratory Investigation of South Punjab, Pakistan. *Pak. Pediatr. J*.2017; 41(3): 158-62.
16. Anum J, Dasti R. Caregiver burden, spirituality, and psychological well-being of parents having children with thalassemia. *J Relig Health*. 2016; 55(3):941-55.
17. Perveen N, Batool I, Asghar M, Malik G. Quality of life, psychological stress and death anxiety among liver and renal transplant recipients. *Isra Med. J*. 2019;1(31):21.
18. Alizadeh M, Chehrzad MM, Mirzaee M, Leyli EK. Caregiver burden and related factors in parents of children with Thalassemia. *J. Adv. Pharm. Educ*. 2019; 9(S2) 35-39.
19. Pehlivan S, Ovayolu O, Ovayolu N, Sevinc A, Camci C. Relationship between hopelessness, loneliness, and perceived social support from family in Turkish patients with cancer. *Support Care Cancer*. 2012; 20(4):733-39.
20. Lou Q, Liu S, Huo YR, Liu M, Liu S, Ji Y. Comprehensive analysis of patient and caregiver predictors for caregiver burden, anxiety and depression in Alzheimer's disease. *J Clin Nurs*. 2015; 24(17-18):2668-78.
21. Thompson EA, Mazza JJ, Herting JR, Randell BP, Eggert LL. The mediating roles of anxiety depression, and hopelessness on adolescent suicidal behaviors. *Suicide Life Threat Behav*. 2005;35(1):14-34.
22. Dikeç G, Ergün G, Gumus F. Relation Among Anxiety and Family Burden in Primary First-Degree Caregivers of Outpatients with Mental Disorders in Turkey. *Issues Ment. Health Nurs*. 2018; 39(2):142-50.
23. Gratao AC, Vendruscolo TR, Talmelli LF, Figueiredo LC, Santos JL, Rodrigues RA.

- Burden and the emotional distress in caregivers of elderly individuals. *Texto & Contexto-Enfermagem*. 2012; 21(2):304-12.
24. Rhee YS, Yun YH, Park S, Shin DO, Lee KM, Yoo HJ, Kim JH, Kim SO, Lee R, Lee YO, Kim NS. Depression in family caregivers of cancer patients: the feeling of burden as a predictor of depression. *J Clin Oncol*. 2008; 26(36):5890-95.
25. Raj EA, Shiri S, Jangam KV. Subjective burden, psychological distress, and perceived social support among caregivers of persons with schizophrenia. *Indian J Soc Psychiatry*. 2016; 32(1):42-51.