

Coping Strategies in Caregivers of Patients with Diabetes Mellitus Type -1

¹Dr Muhammad Hassan Siddiqui, ²Muhammad Adnan Sarwar, ³Farhan Khan, ⁴Dr Taimoor, ⁵Dr. Shaiq Ur Rehman, ⁶Dr Muhammad Mashkoor Aslam

¹Resident Paediatric Medicine, National Institute of Child Health, Khi,

²Professor Paediatric Medicine, National Institute of Child Health, Khi,

³Senior Instructor, Deptt of Psychiatry, The Agha Khan University Khi.,

⁴Fellow Child and Adolescent Psychiatry, The Agha Khan University, Khi,

⁵Resident Paediatric Medicine, National Institute of Child Health, Khi,

⁶Assistant Professor Oncology department, National Institute of Child Health, Khi,

Keywords: Brief-COPE, caregivers, parents, type-1 diabetes mellitus, Urdu. Injuries, Renal Trauma, Bladder Trauma, and Urethral Trauma.

Abstract

Objective: To determine coping strategies in caregivers of children with type-1 diabetes mellitus (T1DM) using 28 Item BRIEF-COPE scale.

Study design: A cross-sectional study.

Place and duration: Outpatient department of Paediatric endocrinology, National Institute of Child Health (NICH), Karachi, Pakistan from January 2021 to July 2023.

Methodology: A total of 227 caregivers (both genders) aged up to 60 years of children (both genders) aged between 1-14 years and known (already diagnosed) cases of T1DM (as per medical record) were analysed. All study data were collected on a pre-designed self-structured proforma and coping strategy scoring and

interpretation using Brief-COPE 28 item self-report English Urdu questionnaire.

Results: In a total of 227 caregivers, the mean age of the caregivers and children studied were 39.93 ± 7.13 years and 12.79 ± 4.27 years. The most common relation of the caregivers was mothers, noted in 106 (46.7%). The mean duration of care was 5.71 ± 4.05 years. Cronbach's Alpha of the total 28-items Brief-COPE questionnaire was adequate showing a score of 0.67. Coping strategies were present among 99 (43.6%) caregivers. The age of the caregivers with coping strategies was significantly higher compared to those without coping strategies (43.05 ± 6.12 vs. 37.51 ± 6.93 , $p < 0.001$). There were differences in the speaking language of caregivers with coping strategies, with Urdu being the most common language (40.4% vs. 36.7%, $p = 0.025$). Parents

whose children were literate were more likely to have coping strategies ($p=0.022$).

Conclusion: Recognizing that age of the caregivers and language may influence coping strategies, healthcare providers should consider tailoring support and interventions to the specific needs of caregivers in different age groups and linguistic communities. Moreover, the association between a child's education level and parental coping strategies highlights the importance of involving children in their care management.

Introduction

Type 1 diabetes mellitus (T1DM) is an autoimmune disease characterized by total lack of insulin production and therefore requires lifelong therapy with exogenous insulin for maintaining glycemic levels.¹ The challenge to maintain euglycemia poses an obvious burden for their caregivers since the effects of having a child with T1DM on parents are multifactorial.² According to American Academy of Child & Adolescent Psychiatry, children who are diagnosed with a serious and chronic medical illness are at greater risk for developing emotional problems, while intensive medical therapy, proper diet, regular health checkups, proper nursing and dealing with bullying from peers are some of the most reasons.^{3,4}

Recent data among children with epileptic disorders showed that physical and social challenges created by these kind of illness increases parents' psychological and physiological reactions in the form of severe stress, anger, guilt, fear, anxiety, depression, shame, self-blame, and sense of rejection which points out the psychosocial difficulties faced by these parents.⁵ Patients with chronic illnesses and their families specially the caregivers often experience stigma in all domains of life and specially within healthcare settings. Although,

the stigma attached to diabetes has not been studied in lower to middle-income countries where clinical practices differ remarkably.⁶ In developing countries, the awareness of diabetes is also low, and families face different kind of challenges considering the special diets, medications, schooling challenges, repeated hospitalizations, behavioral problems for supporting these children.⁷ The parents who face increased social stigma have increased depressive symptoms and cannot provide the best care for their child which in turn lead to poor HbA1C levels in the children with T1DM.⁸ Since very few researches have been done in Asia keeping in consideration the knowledge gaps and unresolved questions coping strategies in caregivers of patients with T1DM that is why this study was planned. The Brief-COPE is an abbreviated version of the COPE (Coping Orientation to Problems Experienced) Inventory, a self-reported questionnaire developed to assess a broad range of coping responses. The objective of this study was to determine coping strategies in caregivers of children with T1DM using 28 ITEM BRIEF-COPE scale. The findings of this study may help in improving the understanding of parent's coping resources and strategies to ultimately help both mental health specialists and paediatricians to develop potent and practical approaches for reducing emotional burden of caregivers' dealing with children suffering from T1DM.

Methodology

This cross-sectional was conducted at the outpatient department of Paediatric endocrinology, National Institute of Child Health (NICH), Karachi, Pakistan from January 2021 to July 2023. Approval from Institutional Ethical Review Board was obtained. Sample size of 227 cases was calculated considering 18% prevalence of stress amongst caregivers of

children with T1DM⁹, keeping confidence level of 95% and margin of error as 5%. Non probability purposive sampling technique was adopted. Inclusion criteria were parents of caregivers (both genders) aged up to 60 years of children (both genders) aged between 1-14 years and known (already diagnosed) cases of T1DM (as per medical record). Parents/caregivers unwilling or withdrawing consent for their inclusion in this research were excluded. Caregivers of children having other concomitant chronic diseases like congenital adrenal hyperplasia, tuberculosis, thyroid disorders, or celiac disease were also not included. Caregivers with intellectual disability or those having diabetes mellitus, hypertension or any other psychiatric illnesses were also excluded. Caregiver was labelled as a close family member who was responsible for the day-to-day decision about the affected child's personal and disease related matters.¹⁰

Informed consent of the available parent/guardian and patients were taken. Participants were allowed to withdraw themselves at any point during the study. All study data were collected on a pre-designed self-structured proforma and coping strategy scoring and interpretation using Brief-COPE 28 item self-report English Urdu questionnaire. The Brief-COPE is a 28 item self-report questionnaire designed to measure effective and ineffective ways to cope with a stressful life event, validated for Pakistani population.¹¹ In addition, the following 14 subscales are reported: Self-distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, & Self-blame. Respondents were asked to rate items on the basis of a four point Likert scale ranging from "1, I haven't been doing this at all" to "4 I've been doing this a lot

" Total score on each scale ranges from minimum 2 to maximum 8. Total score on each sub-scale was calculated by summing the total score. Deviation of score from mean score of each sub-scale was used to interpret the results. Higher score on any subscale from the mean score was taken as use of that specific coping strategy.¹²

Data analysis was done using IBM-SPSS Statistics, version 26.0. Mean and standard deviation (SD) were computed for quantitative variables whereas frequency and percentages were calculated for qualitative variables. Chi-square test and independent sample t-test were used to compare data taking $p < 0.05$ as significant.

Results

In a total of 227 caregivers, the mean age of the caregivers and children studied were 39.93 ± 7.13 years (ranging between 11-57 years), and 12.79 ± 4.27 years (ranging between 3-18 years). The most common relation of the caregivers was mothers, noted in 106 (46.7%). Among children, 127 (55.9%) were female. Speaking language of 87 (38.3%) caregivers was Urdu. The mean duration of care was 5.71 ± 4.05 years. Cronbach's Alpha of the total 28-items Brief-COPE questionnaire was adequate showing a score of 0.67.

Coping strategies were present among 99 (43.6%) caregivers. The gender distribution of caregivers with respect to coping strategies was not significantly different (p -value = 0.597). The relationship of the caregiver to the patient suggests that this difference was not statistically significant ($p=0.099$). The age of the caregivers with coping strategies was significantly higher compared to those without coping strategies (43.05 ± 6.12 vs. 37.51 ± 6.93 , $p < 0.001$). There were differences in the speaking language of caregivers with coping strategies, with Urdu

being the most common language (40.4% vs. 36.7%), and there was a significant difference (p-value = 0.025) in the language spoken between caregivers with these adjustment strategies and those without. The duration of

care for patients did not significantly differ between caregivers with coping strategies and those without (p-value = 0.892). Table-1 is showing comparison of characteristics of caregivers with respect to coping strategies.

Table-1: Comparison of Characteristics of Caregivers with Regards to Coping Strategies (n=227)

Characteristics		Coping		P-value
		Yes (n=99)	No (n=128)	
Gender	Male	53 (53.5%)	64 (50.0%)	0.597
	Female	46 (46.5%)	64 (50.0%)	
Relation	Mother	44 (44.4%)	62 (48.4%)	0.099
	Father	41 (41.4%)	39 (30.5%)	
	Maternal relative	8 (8.1%)	8 (6.3%)	
	Paternal relative	6 (6.1%)	19 (14.8%)	
Age (years)		43.05±6.12	37.51±6.93	<0.001
Speaking language	Urdu	40 (40.4%)	47 (36.7%)	0.025
	Sindhi	31 (31.3%)	28 (21.9%)	
	Punjabi	16 (16.2%)	13 (10.2%)	
	Baluchi	16 (16.2%)	13 (10.2%)	
	Pushto	5 (5.1%)	18 (14.1%)	
	Others	6 (6.1%)	17 (13.3%)	
Duration of care (years)		5.67±3.76	5.74±4.27	0.892
Maternal Education	Pre-literate	53 (54.6%)	59 (46.5%)	0.245
	Primary	16 (16.5%)	21 (16.5%)	
	Secondary	2 (2.1%)	9 (7.1%)	
	Matriculation	16 (16.5%)	21 (6.5%)	
	Intermediate	8 (8.2%)	8 (6.3%)	
	Graduation or above	2 (2.1%)	9 (7.1%)	
Father's Education	Pre-literate	33 (35.5%)	45 (36.0%)	0.440
	Primary	15 (16.1%)	21 (16.8%)	
	Secondary	3 (3.2%)	9 (7.2%)	
	Matriculation	18 (19.4%)	27 (21.6%)	
	Intermediate	14 (15.1%)	9 (7.2%)	
	Graduation or above	10 (10.8%)	14 (11.2%)	
Maternal occupation	House wife	90 (90.9%)	119 (93.0%)	0.569
	Working	9 (9.1%)	9 (7.0%)	
Family type	Nuclear	61 (61.6%)	91 (71.1%)	0.132
	Joint	38 (38.4%)	37 (28.9%)	
Consanguineous marriage		51 (51.5%)	78 (60.9%)	0.155
Single		4 (4.0%)	2 (1.6%)	0.082

Caregiver's marital status	Married	91 (91.9%)	126 (98.4%)
	Divorced	2 (2.0%)	-
	Others	2 (2.0%)	-

Table-2 is showing details about the comparison of characteristics of children with regards to parent's coping strategies. The gender distribution of children did not significantly differ between coping strategies of the caregivers (p-value = 0.917). The age of children was relatively similar with no significant differences (p-value = 0.864). The age at which the children were diagnosed with diabetes also did not significantly differ (p-value = 0.402). The HbA1c levels of children did not show a significant difference between parents with coping strategies and those without (p-value = 0.109). The educational status of the children did have significant association with coping strategies. Parents whose children were literate were more likely to have coping strategies, while those who were preliterate or illiterate were less likely to have coping strategies (p-value = 0.022). Table-3 is showing correlation matrix for the 14-coping dimensions model studied in the present research. The correlation matrix provides valuable insights into how different coping strategies were related to each other and to the overall coping effectiveness of caregivers.

Table-2: Comparison of Characteristics of Children with Regards to Parent's Coping Strategies (n=227)

Characteristics		Coping		P-value
		Yes (n=99)	No (n=128)	
Gender	Male	44 (44.4%)	56 (43.8%)	0.917
	Female	55 (55.6%)	72 (56.3%)	
Age (years)		12.85±3.80	12.75±4.62	0.864
Age at the time of diagnosis (years)		7.48±4.01	7.05±3.73	0.402
Sibling affected		10 (10.1%)	8 (6.3%)	0.287
Other diseases	None	92 (92.9%)	109 (85.2%)	0.199
	Bardet–Biedl syndrome	1 (1.0%)	-	
	Celiac disease	4 (4.0%)	15 (11.7%)	
	Epilepsy	1 (1.0%)	-	
	Tuberculosis	-	1 (0.8%)	
	Thyroid disorders	1 (1.0%)	2 (1.6%)	
Others		-	1 (0.8%)	
HbA1c (%)		11.33±3.56	10.64±2.82	0.109
Educational status	Preliterate	20 (20.2%)	10 (7.8%)	0.022
	Illiterate	10 (10.1%)	17 (13.3%)	
	Literate	69 (69.7%)	101 (78.9%)	

Table-3: Correlation matrix for the 14 coping dimensions model (n=227)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total
1	1	.627**	.395**	.518**	.287**	-.257**	-.414**	.424**	.240**	.381**	.036	.580**	-.373**	.171*	.554**
2	.627**	1	.315**	.438**	.186**	.193**	.018	.317**	.237**	.095	-.011	.366**	-.166*	-.080	.533**
3	.395**	.315**	1	.580**	.341**	-.070	-.292**	.481**	.435**	.662**	.182**	.617**	-.304**	.372**	.727**
4	.518**	.438**	.580**	1	.467**	-.165*	-.368**	.359**	.278**	.484**	.203**	.792**	-.521**	.221**	.693**
5	.287**	.186**	.341**	.467**	1	-.271**	-.017	.414**	.467**	.119	.807**	.587**	-.325**	.099	.676**
6	-.257**	.193**	-.070	-.165*	-.271**	1	.589**	-.091	.056	-.356**	-.314**	-.337**	.347**	-.322**	-.011
7	-.414**	.018	-.292**	-.368**	-.017	.589**	1	-.052	.123	-.665**	.031	-.325**	.556**	-.496**	-.041
8	.424**	.317**	.481**	.359**	.414**	-.091	-.052	1	.503**	.279**	.271**	.607**	-.101	.152*	.705**
9	.240**	.237**	.435**	.278**	.467**	.056	.123	.503**	1	.083	.311**	.503**	-.144*	.266**	.687**
10	.381**	.095	.662**	.484**	.119	-.356**	-.665**	.279**	.083	1	.037	.491**	-.417**	.540**	.421**
11	.036	-.011	.182**	.203**	.807**	-.314**	.031	.271**	.311**	.037	1	.379**	-.114	.047	.469**
12	.580**	.366**	.617**	.792**	.587**	-.337**	-.325**	.607**	.503**	.491**	.379**	1	-.402**	.292**	.825**
13	-.373**	-.166*	-.304**	-.521**	-.325**	.347**	.556**	-.101	-.144*	-.417**	-.114	-.402**	1	-.396**	-.213**
14	.171*	-.080	.372**	.221**	.099	-.322**	-.496**	.152*	.266**	.540**	.047	.292**	-.396**	1	.302**
Total	.554**	.533**	.727**	.693**	.676**	-.011	-.041	.705**	.687**	.421**	.469**	.825**	-.213**	.302**	1

1-Instrumental support; 2-Emotional support; 3-Active coping; 4-Planning; 5-Acceptance; 6-Self-distraction; 7-Denial; 8-Humor; 9-Self-blaming; 10-behavioral disengagement; 11-Venting; 12-Positive reframing; 13-Substance use; 14-Religion

Correlation is significant at 0.01 level (2-tailed); Correlation is significant at 0.05 level (2-tailed)

Discussion

For this research, the internal consistency of the 28-item Brief-COPE questionnaire was adequate (Cronbach's Alpha = 0.67), suggesting that the questionnaire effectively measures a range of coping strategies. This indicates that the tool is a reliable instrument for assessing coping strategies in caregivers of children with T1DM. This study shed light on the complex relationship between caregiver and child characteristics and adaptation methods in the context of T1DM caregiving. Understanding these factors can help healthcare providers and policymakers design more targeted and effective interventions to support caregivers and improve the overall well-being of children with T1DM. The finding that caregivers with coping strategies were significantly older than those without coping strategies (43.05 years vs. 37.51 years, $p < 0.001$) suggests that age plays a

significant role in how caregivers adapt to the challenges of caring for a child with T1DM. This could be attributed to the life experience and maturity that typically comes with age. Older caregivers may have developed more effective coping mechanisms over time, which enable them to better manage the stress and emotional demands associated with caregiving. Additionally, older caregivers may have access to a larger social support network, which could influence their coping strategies positively. Findings of a study from Malaysia reported similar observations where the caregivers' age was significantly correlated with the coping mechanisms.¹³

Some researchers have shown that no relationship was found between adjustment strategies used by parents and the age of patients, gender of patients, age of caregivers, education level of caregivers, family income,

family type, duration of illness and age of onset, urban or rural background.^{14,15} The significant difference in coping strategies based on the language spoken by caregivers (p-value = 0.025) indicates a potential cultural or linguistic influence on coping strategies. Urdu-speaking caregivers were more likely to have problem-solving approaches. This finding may reflect cultural differences in the perception of health, social support, and the way caregivers seek help. Urdu-speaking caregivers might have a more open and supportive environment that encourages coping strategies. Future research could delve deeper into the cultural factors that contribute to these differences. A study conducted in North Africa, included caregivers of children diagnosed with type 1 diabetes mellitus, used the Brief COPE scale to evaluate parents' coping strategies and Hospital Anxiety and Depression Scale (HADS) to assess their depressive and anxiety symptoms. Results showed that the more parents were depressed or anxious, the more they used maladaptive response tactics such as distraction and avoidance from stressful social discussions/interactions about their child's illness.¹⁶ The significant association between the educational status of caregivers' children and the presence of coping strategies is noteworthy. Caregivers whose children were literate were more likely to have coping strategies (p-value = 0.022). These finding suggests that the education level of the child may indirectly impact the caregiver's coping strategies. Literate children may better communicate their needs and cooperate in their own care, reducing the caregiver's stress and thereby influencing their coping strategies positively. The present study

Conclusion

The findings of this study have important implications for healthcare professionals and policymakers. Recognizing that age of the

did not find any statistically significant differences in terms of gender of the caregivers and coping strategies (p=0.597). Levels of paediatric parenting stress in fathers and mothers of young children with T1DM have been compared and variation in stress over time has been studied. Results showed that within families with a young child with T1DM, the burden of care increases in fathers and decreases in mothers, suggesting fathers assume more responsibility for care of their child with T1DM as the child grows older.¹⁷

In this study, the non-significant difference in children's HbA1c levels in relation to parental coping strategies (p-value = 0.109) suggested that parental coping skills may not have a direct impact on children's glycemic control. It is crucial to acknowledge that other factors, such as medical treatment adherence, healthcare access, and the child's own self-management, may also be influential in determining HbA1c levels. Some researchers have shown that higher caregiver stress was associated with lower HbA1c levels.¹⁸

Future research should explore the cultural, social, and psychological factors that underlie the language-based differences in coping mechanisms among caregivers. Additionally, a longitudinal study could examine the evolution of adjustment strategies over time and their impact on the well-being of both caregivers and children with T1DM. Being a single center study and a relatively modest sample size were some of the limitations of this study. As information was recorded during interviews from the caregivers based upon recall, there could be a bias in the recorded information.

caregivers and language may influence coping strategies, healthcare providers should consider tailoring support and interventions to the specific needs of caregivers in different age groups and linguistic communities. Moreover,

the association between a child's education level and parental coping mechanisms highlights the importance of involving children in their care management, as this can indirectly influence the caregiver's ability to cope effectively. This suggests a need for educational programs that not only target caregivers but also involve children in understanding and managing their condition.

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