RESEARCH ARTICLE

Coping strategies in caregivers of patients with diabetes mellitus type-1

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Abstract

Objective: To determine coping strategies in caregivers of children with type-1 diabetes mellitus.

Method: This cross-sectional study was conducted at the Outpatient Department of Paediatric Endocrinology, National Institute of Child Health, Karachi, from September 2022 to October 2023, and comprised caregivers aged up to 60 years of children aged 1-14 years who were known cases of type 1 diabetes mellitus. Coping strategy scoring and interpretation was done using the shorter 28-item version of the Coping Orientation to Problems Experienced Inventory. Data was analysed using SPSS 26.

Results: Of the 227 caregivers with mean age 39.93±7.13 years, 106(46.7%) were mothers. Among the children with mean age 12.79±4.27 years, 127(55.9%) were girls. The mean duration of care was 5.71±4.05 years. Coping strategies were found present among 99(43.6%) caregivers. The age of the caregivers with coping strategies was significantly higher compared to those without coping strategies ($p<0.001$). Among the caregivers with coping strategies, there were significantly more Urdu-speaking individuals than of any other language ($p=0.025$). 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. The association between a child's education level and parental coping strategies highlights the importance of involving children in their care management.

Keywords: Brief-COPE, Caregivers, Parents, Type-1 diabetes mellitus, Urdu. (JPMA 76: 71; 2026)

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Introduction

Type 1 diabetes mellitus (T1DM) is an autoimmune disease characterised by total lack of insulin production, and it requires lifelong therapy with exogenous insulin for maintaining glycaemic levels.[1] The challenge to maintain euglycaemia poses an obvious burden for their caregivers since the effects of having a child with T1DM on parents are multifactorial.[2] According to the American Academy of Child and Adolescent Psychiatry, children who have major chronic medical disorders are at significantly higher risk of developing emotional issues, while intensive medical therapy, proper diet, regular health check-ups, proper nursing and dealing with bullying from peers are some of the most common related problems.[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, especially the caregivers, often experience stigma in all domains of life, including within healthcare settings. The stigma attached to diabetes has not been studied in low- and middle-income countries (LMICs) where clinical practices differ remarkably.[6] In developing countries, the awareness of diabetes is also low, and families face different kinds of challenges, like special diets, medications, schooling challenges, repeated hospitalisations and behavioural problems.[7] The parents who face increased social stigma have increased depressive symptoms, and cannot provide the best care for their child, which, in turn, leads to poor glycated haemoglobin (HbA1c) levels in children with T1DM.[8]

The current study was planned to determine coping strategies in caregivers of children with T1DM.

Subjects and Methods

The cross-sectional study was conducted at the Outpatient Department (OPD) of Paediatric Endocrinology, National Institute of Child Health (NICH), Karachi, from September 2022 to October 2023. After approval from the institutional ethics review board, the sample size was calculated using OpenEpi calculator (https://www.openepi.com/SampleSize/SSPropor.htm)[9] with 95% confidence level, 5% margin of error and 18% prevalence of stress among caregivers of

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children with T1DM.[10] The sample was raised using non-probability purposive sampling technique. Those included were parents or caregivers aged up to 60 years of T1DM children aged 1-14 years. Caregivers of children having othser concomitant chronic diseases were excluded, and so were caregivers with intellectual disability or those having diabetes mellitus, hypertension or any other psychiatric illnesses. A caregiver was defined as a close family member who was responsible for the day-to-day decision about the affected child's personal and disease-related matters.[11]

After taking written informed consent from all the caregivers, data was collected using a pre-designed self-structured proforma That included the shorter 28-item version of the Coping Orientation to Problems Experienced (Brief-COPE) inventory, which is a self-report questionnaire designed to measure effective and ineffective ways to cope with a stressful life event, and which has been validated for Pakistani population.[12] The items are categorised into 14 subscales: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame.[13] The respondents were asked to rate items on the basis of a 4-point Likert scale, ranging from 1=I have not been doing this at all to 4=I have been doing this a lot. Total score on each subscale ranged 2-8. All subscale scores were added to generate the total score, and any score above the mean total score indicate the presence of coping.[14]

Data was analysed using SPSS 26. Mean±standard deviation (SD) were computed for quantitative variables, whereas frequencies and percentages were calculated for qualitative variables. Correlation analysis was performed employing Pearson's correlation. Chi-square test and independent sample *t*-test were used to compare data elements. P<0.05 was considered significant.

Results

Of the 227 caregivers with mean age 39.93±7.13 years, 106(46.7%) were mothers. Among the children with mean age 12.79±4.27 years, 127(55.9%) were girls. The mean duration of care was 5.71±4.05 years. The most common spoken language was Urdu 87(38.3%). Cronbach's alpha value of Brief-COPE was adequate (0.67).

Coping strategies were found present among 99(43.6%) caregivers. The age of the caregivers with coping strategies was significantly higher compared to those without coping strategies (p<0.001). Among the caregivers with coping strategies, there were significantly more Urdu-speaking individuals than of any other language (p=0.025) (Table 1). Parents whose children were literate were more likely to have coping strategies (p=0.022) (Table 2).

Table-1: Comparison of caregiver characteristics with regards to coping strategies.

Characteristics	Coping [n (%)]		*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)	
Mean 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)	
Mean Duration of care (years)	5.67±3.76	5.74±4.27	0.892
Maternal Education			
Preliterate	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			
Preliterate	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
Caregiver's marital status			
Single	4 (4.0)	2 (1.6)	0.082
Married	91 (91.9)	126 (98.4)	
Divorced	2 (2.0)	-	
Others	2 (2.0)	-	

Strong positive correlations were observed between adaptive strategies, such as instrumental support and emotional support (r=0.627, p<0.01), active coping and planning (r=0.580, p<0.01), and positive reframing and planning (r=0.792, p<0.01). In contrast, denial was negatively correlated with planning (r=-0.368, p<0.01), while substance use was negatively correlated with positive reframing (r=-0.304, p<0.01). The strongest

Table-2: Comparison of child characteristics with regard to parent's coping strategies.

Characteristics	Coping [n (%)]		*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)	
Mean Age (years)	12.85±3.80	12.75±4.62	0.864
Mean 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)	
Mean **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)	

HbA1c: Glycated haemoglobin.

correlation of total score was observed for positive reframing (r=0.825, p<0.01). Conversely, substance use showed a negative correlation with overall coping (r=-0.213, p<0.01) (Table 3).

Discussion

The internal consistency of the 28-item Brief-COPE questionnaire in the current study was adequate, suggesting that the questionnaire effectively and reliably measured a range of coping strategies. 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 may be playing a significant role in how parents might be adapting to various challenges related to overall care of a T1DM child. It is also important to consider that that life experiences and maturity are typically expected with an increase in the age. Older caregivers may have developed more effective coping mechanisms over time, which enabled them to better manage the stress and emotional demands associated with caregiving. Also, 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.[15]

Some researchers have shown that no relationship exists among coping strategies used by parents/caregivers and the age or gender of the patients, or their educational status, family income, family type, or duration of illness.[16,17] The significant difference in coping strategies based on the

Table-3: Correlation matrix for the 14 subscales of the shorter 28-item Coping Orientation to Problems Experienced (Brief-COPE) inventory.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total
1	1	0.627**	0.395**	0.518**	0.287**	-0.257**	-0.414**	0.424**	0.240**	0.381**	0.036	0.580**	-0.373**	0.171*	0.554**
2	0.627**	1	0.315**	0.438**	0.186**	0.193**	0.018	0.317**	0.237**	0.095	-0.011	0.366**	-0.166*	-0.080	0.533**
3	0.395**	0.315**	1	0.580**	0.341**	-0.070	-0.292**	0.481**	0.435**	0.662**	0.182**	0.617**	-0.304**	0.372**	0.727**
4	0.518**	0.438**	0.580**	1	0.467**	-0.165*	-0.368**	0.359**	0.278**	0.484**	0.203**	0.792**	-0.521**	0.221**	0.693**
5	0.287**	0.186**	0.341**	0.467**	1	-0.271**	-0.017	0.414**	0.467**	0.119	0.807**	0.587**	-0.325**	0.099	0.676**
6	-0.257**	0.193**	-0.070	-0.165*	-0.271**	1	0.589**	-0.091	0.056	-0.356**	-0.314**	-0.337**	0.347**	-0.322**	-0.011
7	-0.414**	0.018	-0.292**	-0.368**	-0.017	.589**	1	-0.052	0.123	-0.665**	0.031	0.491**	0.556**	-0.496**	-0.041
8	0.424**	0.317**	0.481**	0.359**	0.414**	-0.091	-0.052	1	0.503**	0.279**	0.271**	0.607**	-0.101	0.152*	0.705**
9	0.240**	0.237**	0.435**	0.278**	0.467**	0.056	0.123	0.503**	1	.083	0.311**	0.503**	-0.144*	0.266**	0.687**
10	0.381**	0.095	0.662**	0.484**	0.119	-0.356**	-0.665**	0.279**	0.083	1	0.037	0.379**	-0.114	0.047	0.469**
11	0.036	-0.011	0.182**	0.203**	0.807**	-0.314**	0.031	0.271**	0.311**	0.037	1	1	-0.402**	0.292**	0.825**
12	0.580**	0.366**	0.617**	0.792**	0.587**	-0.337**	-0.325**	0.607**	0.503**	0.491**	0.379**	1	1	-0.396**	-0.213**
13	-0.373**	-0.166*	-0.304**	-0.521**	-0.325**	0.347**	0.556**	-0.101	-0.144*	-0.417**	-0.114	-0.402**	1	1	0.302**
14	0.171*	-0.080	0.372**	0.221**	0.099	-0.322**	-0.496**	0.152*	0.266**	0.540**	0.047	0.292**	-0.396**	1	1
Total	0.554**	0.533**	0.727**	0.693**	0.676**	-0.011	-0.041	0.705**	0.687**	0.421**	0.469**	0.825**	-0.213**	0.302**	

1: Instrumental support, 2: Emotional support, 3: Active coping, 4: Planning, 5: Acceptance, 6: Self-distraction, 7: Denial, 8: Humour, 9: Self-blaming, 10: Behavioural disengagement, 11: Venting, 12: Positive reframing, 13: Substance use, 14: Religion;
* Correlation was significant at 0.01 level (2-tailed), ** Correlation significant at 0.05 level (2-tailed).

language spoken by caregivers (p=0.025) indicates a potential cultural or linguistic influence on coping strategies. Urdu-speaking caregivers were more likely to have coping strategies. 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 in North Africa included caregivers of children diagnosed with T1DM, used the Brief-COPE scale to evaluate parents' coping strategies and the 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 coping strategies, such as distraction and avoidance from stressful social discussions/interactions about their child's illness.[18] 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=0.022). The 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 did not find any significant variations in terms of gender of the caregivers and coping strategies (p=0.597). Levels of stress among parents of young children having T1DM have been earlier compared, and variation in stress over time has been reported.[19]

The present study documented that literacy, language, age and experience play pivotal role in the coping strategies. Studies have demonstrated that caregiver literacy, language proficiency, and prior experience significantly influence the effectiveness of coping strategies and overall care outcomes.[20,21] Parental health literacy is anticipated to be associated with the ability to understand health information, communicate effectively with healthcare providers, and implement care plans, which, in turn, improves self-efficacy and coping skills. Language barriers often impede comprehension of medical instructions and support resources, but interventions that provide linguistically appropriate and culturally sensitive education can enhance engagement and coping efficacy among the caregivers. Higher age and caregiving experience have been linked with more adaptive coping and reduced caregiver stress, as experienced caregivers are better equipped to anticipate challenges and navigate health systems.[22,23]

In the present study, the non-significant difference in children's HbA1c levels in relation to parental coping strategies (p=0.109) suggested that parental coping strategies may not have a direct impact on children's glycaemic 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.[24]

While the present study successfully identified the factors influencing coping strategies among caregivers of children with T1DM, its broader significance lies in illuminating actionable targets for future intervention. There is value in considering how these factors can be addressed through targetted initiatives. Interventions such as developing age-appropriate and linguistically accessible educational materials, integrating multilingual support staff, and incorporating caregiver training sessions have demonstrated potential to enhance coping skills in various settings.[21-23] Involving children more actively in their disease management, especially when they are literate, may foster shared responsibility and mutual support. Despite initial evidence supporting these approaches, comprehensive, context-specific programmes remain scarce, particularly in low-resource settings. Future research should focus on designing and evaluating interventions that explicitly address caregiver literacy, language preference, and experiential factors, thereby strengthening family-centred care for children with T1DM. By doing so, healthcare systems can move beyond descriptive analyses towards the development of practical, equitable solutions that empower caregivers and improve both psychological and clinical outcomes.

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

Conclusion

Knowing that age of the caregivers and language may influence coping strategies, healthcare providers may 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, as this can indirectly influence the caregiver's ability to cope effectively. This suggests a need for educational programmes that not only target caregivers, but also involve children in understanding and managing their condition.

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Author Contribution:

NN, MNI, FSR, KR & UT: Concept, design, data acquisition, analysis, interpretation, drafting, revision, final approval and agreement to be accountable for all aspects of the work.