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Parents' Quality of Life Caring for Child with Type 1 Diabetes Mellitus: A Cross-Sectional Study from Eastern Pakistan

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ABSTRACT

Background and Objective: Diabetes Mellitus (DM) is a chronic metabolic disorder characterized by high blood sugar levels due to a fault in insulin production or function. Families function as interconnected systems, where the challenges faced by one member can impact the well-being of others. This research focused on evaluating the Quality of Life (QoL) of parents who are caring for children diagnosed with Type 1 Diabetes Mellitus (T1DM) and examining the relationship between sociodemographic factors and QoL of parents. **Materials and Methods:** This analytical cross-sectional study was conducted at the Tehsil Headquarters Hospital, Sadiq Abad, Pakistan. Data were collected from 164 participants using a validated diabetes-specific QoL within the PedsQL™ Family Impact Module Version 2.0. Frequencies, percentages, and means were used for descriptive analysis, while for inferential statistics, the Mann-Whitney U test and the Kruskal-Wallis test were used. **Results:** The overall mean quality of life across all domains was 53.71±22.00. Among the domains assessed, physical health scored the lowest (45.88±8.46), while family relationships demonstrated the highest (66.89±17.88). Of the 164 participating parents, 36.58% were male and 63.42% were female, with 68.91% of parents reporting unemployment. In sociodemographic factors, gender and employment status were found statistically significant ($p<0.001$). Mothers, in particular, experienced a marked decline in the physical health domain of QoL. **Conclusion:** The study concluded that parental QoL, particularly of mothers, and unemployment influenced QoL outcomes. These results highlight the need for targeted interventions addressing gender and employment-related disparities.

KEYWORDS

Type 1 diabetes mellitus, Pakistan, metabolic disorder, sociodemographic factors, quality of life

INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is an autoimmune disease in which the body's immune system targets the pancreas, where it damages beta cells that produce insulin, resulting in insulin deficiency. The T1DM is more common in younger individuals and differs from type 2 diabetes, which primarily affects older populations. The T1DM requires lifelong insulin therapy, as without it, patients may experience severe hyperglycemia and life-threatening diabetic ketoacidosis. The disease has heterogeneous metabolic and

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immunogenetic characteristics that influence its onset[1]. Almost 652,000 children are suffering from type 1 diabetes globally[2] and annually, 6500 children under the age of 15 years can develop T1DM with Diabetic Ketoacidosis (DKA)[3].

In Pakistan, T1DM is a growing concern, with approximately 22,000 individuals currently living with the condition. The disease is increasing at a rate of 6.7% annually, which is higher than the 4.8% annual increase observed for type 2 diabetes in the country[4]. Also, managing a child with T1DM is an important critical issue that requires the continuous involvement of parents in numerous daily activities[5]. The PedsQL™ Family Impact Module Version 2.0 can be used to evaluate the consequences of this long-lasting disease on parents' QoL and the well-being of the family. This module works across different domains, including physical, emotional, social, and mental well-being, along with family communication, fear, everyday activities, and relationships of parents. The 36-item tool uses a Likert scale with 5 values (scaled: 0 to 4) and results are converted into 0 to 100 values, with higher values demonstrating good QoL. Widely used in research and clinical practice, it helps identify caregiver burdens, monitor changes over time, and guide family-centered care[6,7].

The components of QoL include psychomotor behavior, neuromuscular function, cognitive abilities, social interactions, and physical activities, all of which can be impacted by illness. The QoL is the apparent difference between one's hopes and one's actual physical, emotional, and social functioning. It includes domains of life that depend on the availability of treatment. The illness and its consequences have an impact on the quality of life for parents and other guardians of children with type 1 diabetes. A considerably reduced QoL often results in decreased self-care, leading to the development of further complications[8]. Additionally, parents must tackle the psychological strain brought on by their worry of long-term issues and continued attentiveness. The development and general well-being of children with type 1 diabetes mellitus are thought to be greatly aided by the psychological well-being of their parents[5].

The primary barriers to the effective management of T1DM present in developing countries like Pakistan could be limited resources, a poor health care system, a lack of healthcare options, shortages of medical services in schools, inadequate healthcare infrastructure, and widespread poverty[9,10]. Additionally, the quality of life could be adversely affected by poor literacy rates and social stigma associated with being diagnosed with type 1 diabetes[11].

The daily treatment and exercise routines that children and adolescents with type 1 diabetes must follow are complicated, multidimensional, and difficult, requiring enthusiasm and work from parents and caregivers. Maintaining an optimal blood glucose level is the aim of T1DM in order to avoid immediate and long-term consequences. Managing good glucose regulation in T1DM young people can severely impact the QoL of their parents. This stress may sometimes lead to inadequate child care and failure of glucose management. Consequently, parents' QoL can be significantly impaired due to the need of intensive treatment regimens as well as the psychosocial consequences such as depression, anxiety, and social challenges[9].

There are limited studies in Pakistan assessing the quality of life for parents and children with type 1 diabetes mellitus, making this field especially understudied. Thus, the purpose of this study is to assess the parents' QoL whose children are diagnosed with type 1 diabetes and investigate the association between sociodemographic characteristics and parents' QoL.

MATERIALS AND METHODS

Study area and duration: This analytical cross-sectional study was conducted in participants from Tehsil Headquarters Hospital, Sadiq Abad, from July to August, 2024. This is a 120-bed healthcare facility operating under the domain of the district hospital in Rahim Yar Khan. The diabetic clinic within the

hospital provides free-of-cost treatment to underprivileged patients, including government-funded insulin for children diagnosed with Type 1 Diabetes Mellitus (T1DM). A non-probability convenience sampling technique was used to select 164 parents for an interview.

Ethical statement: The study was approved by the Research Ethical Committee (REC) of The University of Lahore (REC No. 207/24), dated 22 May, 2024. Ethical approval was granted following committee review and amendments. Prior to the interview, all participants gave their informed consent, and the participants' information confidentiality was maintained.

Inclusion and exclusion criteria: This research included parents of children and adolescents with type 1 diabetes mellitus who were between the ages of 2 and 18 years, provided that they had no prior history of mental disorders that could negatively influence their Quality of Life (QoL). Parents were excluded if they had experienced a major traumatic event, such as separation or the death of a close family member, within six months before data collection.

Sample size: About 164 parents of children and adolescents between the ages of 2 and 18 were chosen for research using a non-probability convenience sampling technique.

Data collection: Data were collected using the licensed PedsQL™ version 2.0 Family Impact Module scale from Mapi Research Trust. The authors obtained official permission to use the Urdu-translated version of the tool, ensuring cultural relevance, comprehension, and accuracy. Data was entered and stored securely using Microsoft Excel for management and preliminary organization. Data for sociodemographic variables were also collected.

Study variables: The primary outcome measured was parents' Quality of Life (QoL), determined using the PedsQL™ Family Impact Module scale. Age, education level, gender, socioeconomic status, and medical history are the independent variables that were recorded.

Data analysis: The Data was analyzed using R software. Numerical data were presented as Mean±Standard Deviation (SD), and categorical variables were summarized and presented as frequencies and percentages using descriptive statistics. Items are reverse-scored and linearly transformed as follows in the PedsQL TM Version 2.0 Family Impact Module: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. By summing and dividing the total number by the number of items that were answered, we calculated transformed values. Quality of Life (QoL) is good if values are high. A non-parametric test was used to evaluate sociodemographic determinants of parents' QoL, as the data are not normally distributed. To compare means of two groups, the Mann-Whitney U test was used, while to compare means of more than two groups, the Kruskal-Wallis test was employed.

RESULTS

The study population comprised children aged 2-18 years, with the majority being aged 9-12 (38.42%) and 13-18 (34.15%). The parents' gender distribution was uneven, with females making up 63.42% of the population and males 36.58%. Most households had an income of 0-20,000 PKR, 73.78%, and parental ages were almost evenly split between 25-40 years, 52.44% and 41-55 years, 47.56%. Regarding education, 46.34% of parents had a high school education, 14.02% had a bachelor's degree, 1.83% had a master's degree, and 37.81% were illiterate. The urban residence was slightly more common, 55.48% than rural, 44.52%, and the majority owned their homes, 68.91%. Unemployment was high among parents, 68.91%. Most children had been diagnosed with diabetes for more than a year 75%, and the vast majority had HbA1c levels below 6.4% (98.78%) (Table 1).

Table 1: Demographic characteristics of the study population (n = 164)

Variable	Category	Frequency (n)	Percentage (%)	p-value
Child age (years)	2-5	27	16.46	0.82
	6-8	18	10.97	
	9-12	63	38.42	
	13-18	56	34.15	
Child gender	Male	60	36.58	0.12
	Female	104	63.42	
Income (PKR)	0-20000	121	73.78	0.15
	21000-40000	38	23.17	
	41000-60000	5	3.05	
Parents' age (years)	25-40	86	52.44	0.12
	41-55	78	47.56	
Parents gender	Male	60	36.58	<0.001*
	Female	104	63.42	
Parent education	High school	76	46.34	0.19
	Bachelor's degree	23	14.02	
	Master's degree	3	1.83	
	Illiterate	62	37.81	
Residence	Urban	91	55.48	0.55
	Rural	73	44.52	
Residence ownership	Own house	113	68.91	0.99
	No own house	51	31.09	
Working status	Unemployed	113	68.91	<0.001*
	Employed	51	31.09	
Time since diabetes was diagnosed	6 months	21	12.81	0.25
	1 Year	20	12.19	
	More than a year	123	75	
HbA1c level	>5.7%	0	0	0.43
	5.7-6.4%	2	1.22	
	<6.4%	162	98.78	

*Significant at p<0.05

Table 2: Mean scores of quality-of-life domains (n = 164)

Scale	Mean	SD
Physical domain	45.88	28.46
Emotional domain	56.89	22.59
Social domain	48.82	28.99
Cognitive domain	52.38	26.50
Communication	58.56	26.01
Worry	53.32	18.41
Daily activity	47.15	30.00
Family relationship	66.89	17.88
Summary of all domains	53.71	22.00

The study's quality-of-life assessment for 164 participants revealed a minimum value of 23.85, while the first quartile (25th percentile) was 36.76. The median, or the 50th percentile, was 44.95, and the mean was slightly higher at 53.71, suggesting potential skewness in the data Fig. 1. The third quartile (75th percentile) was 72.07, and the maximum value observed was 72.07. The Family Relationship domain scored the highest with a mean of 66.89±17.88, indicating relatively strong family ties (Table 2). The Communication domain followed closely with a mean of 58.56±26.01, suggesting effective communication among participants. Emotional Domain scored a mean of 56.89±22.59, while the Worry domain had a mean score of 53.32±18.41. The Cognitive Domain mean was 52.38±26.50, and the Social Domain mean was 48.82±28.99. Daily Activity and Physical Domain had lower mean scores of 47.15±30.00 and 45.88±28.46, respectively. The overall summary of all domains yielded a mean score of 53.71±22.00, reflecting a moderate quality of life across the assessed areas. Of the participating parents, 36.58% were male and 63.42% were female. Unemployment was prevalent, with 68.91% of parents reporting being unemployed. In sociodemographic factors, gender (Fig. 2) and employment status were found statistically significant (p<0.001).

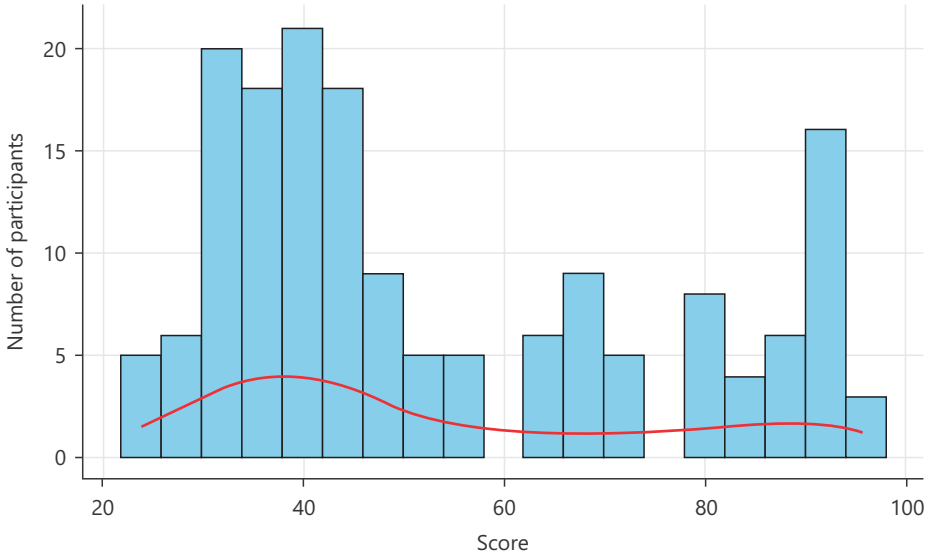

Fig. 1: Distribution of pediatric quality of life scores (family impact module 2.0) among study participants
Scores were derived using the PedsQL™ version 2.0 family impact module, with higher values indicating better quality of life and the majority of participants scored in the mid-range, with peaks around specific score intervals

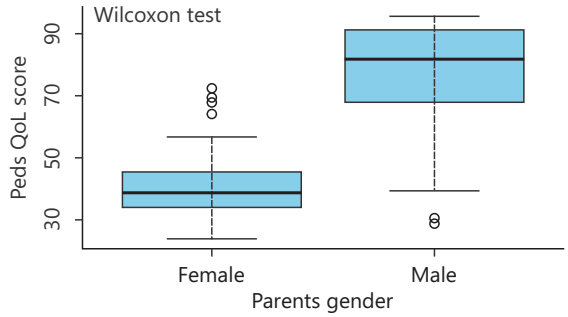

Fig. 2: Comparison of pediatric quality of life scores by parents' gender
Median PedsQL™ scores were significantly higher among male parents compared to female parents ($p<0.001$), indicating gender-based differences in perceived family quality of life

DISCUSSION

The current study revealed that parents are more likely to experience higher levels of psychosocial burden about their child's diabetes. We identified that the overall QoL score of parents was 53.71±22, which is lower than one study conducted in Karachi, Pakistan, where the overall mean was 56.3±0.98 (Table 2)[9]. The differing mean score is attributed mainly to the difference in regions and variations in cultures and behaviors. Karachi is a well-developed urban region compared to the current study setting. The health care facilities in urban regions are way better than those in small cities/rural settings in Pakistan.

The majority of the participants (63.42%) in our study were mothers. Statistical analysis revealed a significant difference ($p<0.001$) between mothers' and fathers' QoL, indicating that gender is a significant factor influencing parental wellbeing. In Fig. 2, mothers demonstrated poorer QoL scores as compared to fathers. A study reported that mothers of children with diabetes had higher depression symptoms and weaker tolerance than mothers of peers in good health[12]. A possible explanation is the pressure placed on women because of societal norms and expectations to conform to certain roles and behaviors. In our society, fathers are usually not involved in the direct care of their diabetic child throughout the day and tend not to hold responsibility for medication and insulin administration due to cultural differences, so their QoL is not as impacted as that of mothers. Similarly, a cross-sectional study conducted among

guardians of teenagers with T1DM emphasized that fathers showed less stress as compared to mothers in the General Strain Subscale. The study also revealed a correlation between higher caregiving burdens and increased feelings of loneliness[13].

A study conducted on parents of children aged eight or younger suffering from type 1 diabetes identified that they often experience heightened levels of worry and anxiety as compared to those with older children. This increased concern is mainly attributed to the constant management demands and the perceived vulnerability of younger children to diabetes-related complications[14].

Current findings showed that employment status significantly impacts parental quality of life. In our study, 113 (68.91%) parents were unemployed, while 51 (31.09%) were employed, with a statistically significant difference ($p<0.001$) (Table 1). This result is consistent with findings from a study conducted in Turkey, where 69.5% of mothers were unemployed, suggesting a consistent pattern across different cultural contexts[8]. Care burden among mothers was moderate (34.95±12.48) and found a statistically significant difference ($p<0.05$) between care burden and income status[15]. Unemployment may increase the emotional and psychological strain of caregiving, as parents become more sensitive to their child's illness and its complications. In addition, diabetes remains stigmatized in many societies, contributing to parental anxiety and reduced QoL. Parents often worry about disease-related complications, uncertain career paths, educational and employment prospects for their child, and broader social concerns such as marriage, mortality, and the hereditary nature of diabetes.

Numerous studies involving children and adolescents with type 1 diabetes have been carried out in the US[16], Europe[17-19], and the Middle East[20,21] using Peds QL Diabetes Module. Many parents of children with type 1 diabetes experience physical and mental stress, as the condition demands lifelong treatment and care. They also need emotional support and are heavily burdened financially[22]. The measures used in this study have also explored the impact on the physical, psychological, and social aspects of QoL of the parents.

The current study found the mean score for the physical domain to be 45.88±28.46, while a similar study conducted in China reported a mean score of 47.75±7.37[23]. The findings from both studies are comparable.

Mean score of emotional domains is 56.89±22.59, and this value is lower than the value of a study conducted in Saudi Arabia in which AlBuharian measured the impact of child TIDM on family and their QoL. In this study, the mean was 59.89±1.58[13].

Speaking in the context of the social domain, the mean score in our study was determined to be 48.82±28.99, which is less than the results of a study that evaluated the QoL of parents whose child had been diagnosed with type 1 DM in Baghdad. Mean score for the social domain was 51.1±16 in this study[24]. The rationale behind this difference is that with limited and inadequate social services, healthcare education, and social welfare programs are usually unavailable.

The mean score of cognitive domains in study is 52.38±26.50, and this finding is higher than a study conducted in Turkey, in which the mean value of the cognitive domain was reported to be 43.36±23.8. Moving towards the communication domain, the mean score was 58.56±26.01, and this value is higher than a study conducted in Turkey in which the mean value was reported as 50.97±19.1[25].

Moreover, the present study revealed the mean score of the worry domain to be 53.32±18.41, and this score is lower than a study conducted in Indonesia, in which the mean score was found to be 60.8[4].

The present study demonstrates a mean score of 66.89±17.88 for family relationships. This result differs from a study conducted in Saudi Arabia, where the mean family relationship score was 80.9±1.29[7]. One possible reason for this variance could be the varying levels of socialization outside the family. In Saudi Arabia, there tends to be a more traditional approach to social interactions outside the family, which may lead to stronger familial bonds. In contrast, socialization outside the family is more prevalent in Pakistan, which could contribute to a more diverse set of influences on family relationships.

The current study examined the multiple variables related to quality of life that provide a comprehensive foundation for subsequent studies in the field. However, several limitations should be acknowledged. First, it was a single-center, hospital-based study, which may limit the generalization of its findings to global community settings. Second, use a non-probability convenience sampling technique due to the unavailability of a sample frame. Third, there was an unequal gender distribution, with mothers representing 63.42% of participants. Finally, the cross-sectional study design is prone to bias and temporality issues; therefore, we recommend longitudinal approaches to track future changes over time. Comprehensive counseling, along with psychological and economic support, is crucial to mitigate the burden of caregiving. Furthermore, fostering self-control and promoting self-care practices play a pivotal role in effective disease management and improving overall well-being.

CONCLUSION

This study highlights how parenting a child with type 1 diabetes can affect the quality of life for parents. The overall mean quality of life across all domains remained moderate (53.71±22). However, physical health emerged as a particularly affected area, with comparatively lower scores than other domains. The Socio-demographic factors such as gender and employment status influence parental well-being. Female caregivers were more likely to experience a decline in quality of life, and unemployment was prevalent among parents in this study. These findings highlight the multifaceted nature of the difficulties faced by parents of children with diabetes and emphasize the need for targeted support and interventions.

SIGNIFICANCE STATEMENT

Caring for a child with type 1 diabetes mellitus deeply affects parents' quality of life as they have to constantly monitor blood glucose levels, look for insulin administration and dietary management while coping with emotional stress, sleep disturbances, and financial burden. This study shows that parents, particularly mothers, experience a diminished quality of life when caring for a child suffering from type 1 diabetes mellitus. Gender and employment are influential factors that highlight the need for targeted intervention to support affected families.

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