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A Preliminary Evaluation of a Family-Centered Educational Program on Treatment Adherence in Children with Type I Diabetes in Pakistan

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ABSTRACT:

Introduction: Type 1 diabetes in children requires strict lifelong management; however, treatment adherence is often poor, particularly in Pakistan. Family-centered care may improve adherence by actively involving families in the child's treatment and providing them with the knowledge and support needed to manage the condition.

Objective: This study aimed to preliminarily evaluate the effectiveness of a family-centered educational program in improving treatment adherence among children with Type 1 diabetes in Pakistan.

Methods: This was a one-group pretest-posttest study was carried out in 2026 in Pakistan and included 45 children diagnosed with type 1 diabetes. Participants were selected through convenience sampling and were provided with family-centered empowerment training. Treatment adherence was measured using Modanloo Treatment Adherence Questionnaire for chronic diseases before the intervention and again three months afterward. The collected data were analyzed using SPSS version 26, applying descriptive statistics and paired t-tests.

Results: The mean age and standard deviation of the children were 10.43 ± 2.21 years, and for the parents were 41.92 ± 6.74 years. The mean $\pm$ SD adherence score increased significantly from 108.11 ± 22.45 before the intervention to 168.44 ± 5.51 after the intervention ($P < 0.001$). The family-centered care program led to a statistically significant improvement in treatment adherence.

Conclusion: Family-centered education was effective in improving treatment adherence among children with type 1 diabetes. The improvement in adherence observed in children suggests that involving parents in diabetes education can positively influence children's treatment behaviors.

INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is a chronic autoimmune disease characterized by destruction of pancreatic β -cells, leading to absolute insulin deficiency and lifelong dependence on insulin therapy (1). It is one of the most common endocrine and metabolic disorders in childhood and adolescence, and its incidence has been increasing globally over recent decades (2). According to the International Diabetes Federation, more than 1.5 million children and adolescents worldwide are living with type 1 diabetes, with approximately 108,000 new cases diagnosed annually. The incidence continues to increase by about 3–4%

per year in many countries (3). According to international estimates, the rising burden of T1DM poses significant challenges for healthcare systems, particularly in low- and middle-income countries where access to structured diabetes care is limited (4).

Effective management of T1DM requires complex self-care behaviors, including regular insulin administration, frequent blood glucose monitoring, carbohydrate counting, dietary regulation, and physical activity (5). However, maintaining long-term treatment adherence remains a major challenge in pediatric populations. Poor adherence has been strongly associated with suboptimal glycemic control, increased risk of diabetic ketoacidosis, hospital admissions, and long-term microvascular complications (6). Children and adolescents are particularly vulnerable to adherence difficulties because diabetes management is shared between the child and caregivers. Family involvement plays a critical role in ensuring daily adherence to treatment regimens. Parents are responsible for supervising insulin injections, monitoring glucose levels, managing diet, and providing emotional and behavioral support (7). Evidence shows that higher levels of parental engagement are associated with better glycemic outcomes and improved self-management behaviors in children with T1DM (8). Several strategies have been proposed to improve treatment adherence in children with T1DM, including structured diabetes education, behavioral and psychological interventions, digital health technologies, peer-support programs, motivational interviewing, and multidisciplinary diabetes care. Although these approaches have shown beneficial effects, many require substantial healthcare resources or primarily target the individual patient. Consequently, increasing attention has been directed toward family-centered interventions, which recognize parents and caregivers as essential partners in pediatric diabetes management (9). Family-centered care (FCC) has been recognized as an effective approach in pediatric chronic disease management. FCC emphasizes collaboration between healthcare providers, patients, and families, and promotes shared decision-making, communication, education, and active family participation in care planning (10). In pediatric diabetes care, family-centered interventions have been increasingly used to improve both clinical and behavioral outcomes (11). A randomized clinical trial by Mansour et al. demonstrated that family-centered education significantly improved treatment adherence and reduced HbA1c levels in patients with T1DM (12). Similarly, Katz et al. showed that family-based psychoeducation interventions significantly improved glycemic control in youth with diabetes (13). Evidence also suggests that structured family interventions can improve metabolic outcomes and reduce caregiver burden (14). In addition to clinical benefits, psychological and social factors strongly influence adherence in children with T1DM. Diabetes-related distress, fear of hypoglycemia, emotional burden, and family conflict may negatively impact adherence behaviors (15). Supportive family environments, on the other hand, enhance self-efficacy, coping skills, and long-term disease management (16). In Pakistan, the burden of childhood type 1 diabetes continues to increase, while access to structured diabetes education programs, multidisciplinary pediatric diabetes services, and family support interventions remains limited in many regions (17). In low- and middle-income countries, the economic burden of childhood type 1 diabetes extends beyond direct medical costs to include transportation expenses, loss of parental working hours, and out-of-pocket payments for insulin, glucose monitoring supplies, and diabetes education. These financial challenges may reduce treatment adherence and limit access to comprehensive diabetes care. Recent evidence suggests that strengthening family-centered educational models may provide a practical and cost-conscious strategy to improve diabetes management in resource-limited settings (18,19).

The present study aimed to preliminarily evaluate the effectiveness of a family-centered educational program in treatment adherence among children with Type 1 diabetes in Pakistan.

METHODS

This study was a one-group pretest-posttest conducted in 2026 on 45 children with type 1 diabetes who were referred to the endocrinology clinics and educational–therapeutic centers in Lahore, Pakistan. The sampling method was convenience sampling from the target population. The inclusion criteria were: a confirmed diagnosis of type 1 diabetes by a physician with documented evidence, at least one year since diagnosis, regular use of prescribed diabetes medications during the previous year, and school-aged children between 7 and 14 years. The exclusion criteria included parents' unwillingness to continue participation before the intervention, severe psychological or cognitive disorders, and the presence of other chronic or underlying diseases. Participants who missed more than two sessions of the family-centered education program were considered lost to follow-up (attrition) and were excluded from the final analysis. The research tools included a demographic information questionnaire and the Modanloo Treatment Adherence Questionnaire for chronic diseases (20). This questionnaire consists of 40 items across six domains: treatment commitment, willingness to participate in treatment, ability to adapt treatment to daily life, integration of treatment with lifestyle, insistence on treatment adherence, and treatment implementation strategies. Each item is scored on a five-point Likert scale ranging from 1 to 5. The total score is calculated by summing the scores of all items, yielding a possible

range of 40 to 200, with higher scores indicating greater treatment adherence. The Commitment to Treatment and Doubt in Treatment Implementation subscales are reverse-scored. Therefore, lower scores on these subscales indicate better treatment adherence, whereas higher scores on the remaining subscales and the total questionnaire indicate greater adherence. The original developers reported acceptable psychometric properties, and the questionnaire has subsequently demonstrated good validity and reliability in several studies. Nevertheless, face and content validity and internal consistency were reassessed in the present study because the instrument was applied to a different study population. Content validity and face validity were assessed by a panel of 12 experts in pediatric nursing, endocrinology, and pediatric medicine. Necessary revisions were made based on their feedback. The reliability of the questionnaire was confirmed using Cronbach's alpha coefficient, which was obtained as 0.90 in a pilot study on 20 patients. The validity and reliability of this instrument have also been confirmed in previous studies.

After obtaining approval from the ethics committee and permission from the research deputy, the purpose of the study, importance of the research, and confidentiality of information were explained to parents. The family-centered educational program was developed and implemented exclusively for the purposes of this research and was not part of the routine diabetes care provided at the participating healthcare centers. All participants continued to receive the standard medical care routinely available at the centers throughout the study, while the educational intervention was delivered in addition to usual care by the research team. Written informed consent was obtained from all participants. Initially, the Treatment Adherence Questionnaire was completed by parents or first-degree family members. Educational content was developed based on library resources and scientific literature from reliable databases. The content was reviewed by nursing and endocrinology experts to ensure validity, and necessary corrections were applied.

The educational program included training sessions on dietary management, physical activity, daily living activities (such as dressing, bathing, and hygiene), self-monitoring of blood glucose, medication adherence, side effects of medications, and the rationale for prescribed treatments (21). Questions and answers were also addressed during sessions. Family members were selected in coordination with the researcher, prioritizing first-degree relatives such as parents, siblings, or caregivers who had the most contact with the child. At the end of the intervention, an educational package including a CD and pamphlet was provided to families. After completing the intervention, the Treatment Adherence Questionnaire was completed again. Follow-up was conducted through telephone contact to provide additional support and feedback. The main caregiver was selected from among family members with the highest level of interaction with the child. Education was delivered both individually and in groups using lectures, question-answer sessions, and face-to-face training. Sessions were held weekly over a period of two months. Six structured group sessions, each lasting 60 minutes, were conducted with 5–8 participants per group in hospital classrooms.

Following the intervention, families were given three months to apply the acquired knowledge and caregiving skills in managing the child's condition. During the follow-up period, the primary caregiver of each child was contacted by telephone every two weeks (six scheduled follow-up calls in total) to reinforce the educational content, answer questions, encourage treatment adherence, and remind families about the post-intervention assessment. Additional telephone consultations were provided whenever needed, and follow-up assessments were scheduled flexibly to accommodate family availability. Regular telephone follow-up, flexible scheduling of follow-up assessments, and ongoing communication with caregivers were used as retention strategies to maintain participant engagement throughout the study. At the end of the three-month follow-up period, the Treatment Adherence Questionnaire was administered again. All 45 participants completed both the intervention and the follow-up assessment.

Written informed consent was obtained from all parents or legal guardians before participation. In addition, age-appropriate written assent was obtained from all participating children. The study protocol, including the consent and assent procedures, was reviewed and approved by the Institutional Ethics Committee (Approval No. UOL/IREB/26/22/04/0012).

Data were analyzed using SPSS version 26. Descriptive statistics (mean and standard deviation) and inferential tests such as paired t-test and Shapiro-Wilk test for normality were used. A significance level of 0.05 was considered in all analyses.

RESULTS

The mean age and standard deviation of the children were 10.43 ± 2.21 years, and for the parents were 41.92 ± 6.74 years. On the other hand, the mean duration of diabetes was reported as 5.7 ± 1.88 years. Other demographic characteristics are presented in Table 1.

Table 1. Demographic characteristics of the participants

Variable	Category	Frequency	Percentage
Child's gender	Boy	25	55.6
	Girl	20	44.4
Parental occupation	Self-employed	15	33.3
	Employee	14	31.1
	Unemployed/Retired	16	35.6
Parental education	Illiterate	3	6.7
	Middle school	3	6.7
	Diploma	14	31.1
	University	25	55.6
Family history of diabetes	No	38	84.4
	Yes	7	15.6
Presence of underlying disease	No	42	93.3
	Yes	3	6.7

Based on the normal distribution of the variables and their subscales, statistical analysis was performed using a paired t-test. According to the obtained results, the mean score of treatment adherence after the intervention was significantly higher than the mean score before the intervention (mean difference $\pm$ SD = 60.33 $\pm$ 23.45, effect size = 2.57, $P \leq 0.001$) (Table 2). Effect size was calculated using Cohen's d_z for paired-sample comparisons by dividing the mean of the paired differences by the standard deviation of the paired differences.

Following the intervention, significant improvements were observed in the total treatment adherence score and all subscales ($P < 0.001$). The mean scores of the Commitment to Treatment and Doubt in Treatment Implementation subscales decreased significantly after the intervention. Since these subscales are reverse-scored in the Treatment Adherence Questionnaire, lower scores indicate better treatment adherence; therefore, these decreases reflect improvement rather than deterioration.

Table 2: Comparison of treatment adherence and its subscales before and after the intervention

Variable	Mean (Pre-intervention)	SD	Mean (Post-intervention)	SD	Mean Difference	SD of Difference	Effect Size	P
Adherence to treatment	20.53	7.17	42.53	2.37	22.00	7.46	2.94	0.001
Willingness to participate in treatment	16.17	5.14	31.48	2.35	15.31	5.90	2.59	0.001
Adaptation ability	16.26	5.50	31.35	2.23	15.08	5.86	2.57	0.001

Variable	Mean (Pre-intervention)	SD	Mean (Post-intervention)	SD	Mean Difference	SD of Difference	Effect Size	P
Integration of treatment into life	12.02	3.81	23.40	1.87	11.37	4.37	2.60	0.001
Treatment adherence (stickiness)	9.71	1.98	19.73	1.30	10.02	2.41	4.15	0.001
Commitment to treatment	19.08	1.67	13.42	1.77	-6.37	2.67	-2.38	0.001
Doubt in treatment implementation	13.06	1.23	6.51	1.40	-7.08	1.97	3.59	0.001
Total score	108.11	22.45	168.44	5.51	60.33	23.45	2.57	0.001

DISCUSSION

The findings of the present study demonstrated that following the implementation of the family-centered care program, the mean treatment adherence scores significantly increased compared to the pre-intervention period.

Through active involvement of parents in diabetes education, the family-centered intervention may have improved caregivers' understanding of treatment requirements, strengthened their confidence in managing the child's diabetes, and reduced uncertainty regarding treatment implementation. Consequently, caregivers may have developed a more accurate and confident perception of treatment commitment, leading to lower scores on these reverse-worded subscales while simultaneously demonstrating better overall adherence. Furthermore, improved knowledge and practical caregiving skills may have reduced anxiety related to diabetes management, thereby facilitating more confident and consistent treatment behaviors (22-24).

These results are consistent with previous studies indicating that family-centered interventions are effective strategies for promoting positive health behaviors among families of children with diabetes (11-13). Furthermore, a study investigating the effect of family-centered care on treatment adherence among patients with type 2 diabetes reported that adherence scores significantly improved in the intervention group compared with the control group following the implementation of the program. In addition, the mean levels of fasting blood glucose, random blood glucose, and glycated hemoglobin (HbA1c) showed significant improvements in the intervention group, further supporting the effectiveness of family-centered care in enhancing diabetes management (12,25).

The findings of another study examining the effects of family-centered care on quality of life and glycated hemoglobin levels among patients with type 1 diabetes revealed that the mean HbA1c level was significantly lower after the intervention compared to before the intervention. Furthermore, the quality of life of diabetic patients improved following family-centered education (11). Similarly, another study reported that the Family-Centered Empowerment Model had a positive effect on glycemic control and medication adherence among patients with diabetes, highlighting the important role of family involvement in improving disease management outcomes (26).

These findings are consistent with the results of the present study. The improvement in treatment adherence observed following the family-centered care intervention may be attributed to enhanced communication and interaction between patients and their families. Family-centered care can increase patients' knowledge, self-efficacy, confidence, and motivation to manage their disease more effectively (27).

Recent systematic reviews have also emphasized that accurate assessment of treatment adherence in children with chronic diseases remains challenging because self-report questionnaires may overestimate adherence. Combining validated

questionnaires with objective indicators, such as electronic monitoring, pharmacy refill records, or glycemic outcomes, is recommended to improve the validity of adherence assessment in future intervention studies (28).

The present study has several limitations. First, it employed a one-group pretest–posttest design without a control group. Therefore, the observed improvements in treatment adherence may have been influenced by factors such as the passage of time, participant maturation, concurrent events, or regression to the mean. Accordingly, the findings should be interpreted with caution. Second, treatment adherence was assessed using a self-report questionnaire, which is subject to response bias, including social desirability bias. Participants may have tended to report more favorable adherence behaviors after completing the educational intervention. Because no formal measure of social desirability was included, the potential influence of this bias cannot be completely excluded. Third, the study evaluated only treatment adherence and did not include objective clinical outcomes, such as HbA1c or blood glucose levels, to determine whether the behavioral improvements translated into better glycemic control. Owing to resource and time constraints, as well as limited access to participants' laboratory data, these clinical indicators could not be assessed. Fourth, the relatively small sample size and recruitment from a single center may limit the generalizability of the findings. Finally, maintaining participants' engagement throughout the educational program and occasional environmental distractions during the training sessions posed practical challenges, although efforts were made to minimize their impact by scheduling sessions appropriately and providing a quiet learning environment. Future randomized controlled trials with larger, multicenter samples, longer follow-up periods, objective measures of treatment adherence and glycemic control, and validated measures of social desirability are recommended to confirm and extend these findings.

CONCLUSION

The findings of this one-group pretest–posttest study suggest that a family-centered education program may improve treatment adherence among children with type 1 diabetes. The active involvement of family members in the educational process may enhance support for diabetes self-management and promote adherence to prescribed treatment. However, given the absence of a control group, these findings should be interpreted with caution. Further randomized controlled studies with longer follow-up periods and clinical outcomes, such as HbA1c and glycemic control, are needed to establish the effectiveness of family-centered education and its impact on long-term diabetes management.

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