

Affective Response of Parents of Newly Diagnosed Type-1 Diabetes Patients: An Experience from a Developing Country

Aqeela Ayub, Gulbin Shahid, Rehmana Waris, Ayesha Abdul Razzaq, Syed Hashim Raza
Department of Paediatrics, Pakistan Institute of Medical Sciences, Islamabad

ABSTRACT

Objective: To analyze the affective response of parents of type 1 diabetes children in a developing country like Pakistan.

Methodology: One-year cross-sectional study, utilizing questionnaires, analyzed the economic and psychosocial aspects of newly diagnosed type 1 diabetes (T1D) parents, presenting in a tertiary care unit.

Results: Seventy-nine parents were part of the study. The monthly family income of 82% parents was less than 50,000/- rupees. 78% parents felt shocked and depressed, 14% experienced guilt and 8% were in denial after diagnosis. 93% did not accept injectable insulin as first line of treatment and wanted to try other treatments like homeopathic medicine because of financial constraints, pen prick fear for monitoring blood glucose and insulin injections for treatment. 83% parents concern was affordability of glucose strips and insulin pens and asked for complete financial support for management of their type 1 diabetes child.

Parents showed grave apprehensions about life expectancy and long-term medical complications. 81% were apprehensive about schooling, 8% about their marriage and 3% about future career and jobs. 69% parents asked about inheritance of the disease and chances in siblings.

Conclusion: Parents are prone to psychosocial affects with depression being the most prevalent followed by guilt and denial. The most stressing aspects were injections and regular monitoring pricks fear. Affordability of monitoring strips and insulin pens was also a stressor along with schooling and physical activities.

Key words: Affective response, Chronic illness, Insulin pens, Stress, T1D.

Authors' Contribution:

^{1,2}Conception; Literature research; manuscript design and drafting; ^{1,2}Critical analysis and manuscript review; ²Data analysis; Manuscript Editing.

Correspondence:

Aqeela Ayub
Email: aqeela.ayub1@gmail.com

Article info:

Received: November 07, 2024
Accepted: May 20, 2025

Cite this article. Ayub A, Shahid G, Waris R, Razzaq AA, Raza SH. Affective Response of Parents of Newly Diagnosed Type 1 Diabetes Patients. An Experience from a Developing Country. J Islamabad Med Dental Coll. 2025; 14(2): 183-190.

DOI: <https://doi.org/10.35787/jimdc.v14i2.1323>

Funding Source: Nil

Conflict of interest: Nil

Introduction

Type-1 diabetes is an autoimmune disease that results from the destruction of insulin producing beta cells of pancreas. It is a common chronic illness of childhood. Every year more than 15,000 children are diagnosed with T1DM. Global incidence of type 1 diabetes is increasing by 2- 3% every year especially in children younger than 15 years.¹ It is a

stressful situation for parents to raise a child with a chronic disease and life-threatening illness. Likewise, assigning the diagnosis of type-1 diabetes to a child not only has impact on child's life but the entire family, as management requires dietary restrictions, frequent blood glucose monitoring, regular injections of insulin and daily exercise routine. This daily self-management regime is crucial

to maintain optimal health to avoid acute complications of hyper and hypoglycemia and safeguard against grave chronic complications like retinopathy and nephropathy. Thus, entire family has a role in disease management.² Parents play crucial role in child's upbringing and health management as frequent blood glucose measurement is necessary for better metabolic control but associated with physical and emotional burnout, higher anxiety and stress in parents.³ T1D diagnosis, counseling, continuous monitoring and multiple daily insulin doses have strong effect on mental health of parents. According to family system theory, what happens to one member of a family its response affects the target family. Thus, type 1 diabetes can be defined as 'family disease.'⁴ Parents are the main source of emotional support for children with chronic illness but routine care and follow up vary in different countries. However, family factors in diabetes management in children have been emphasized in many studies including 2014 recommendations of International Society of Pediatric Endocrine and Diabetes (ISPAD).⁵ In most developing countries fathers are sole bread earners with additional financial burden of disease management. They are underrepresented in many studies as focus is on mothers only.⁶ Challenges of finance, worries of child's self-care neglect plus follow-up visits add up to stress of parents.⁷ Also in some hospitals, specialized care for follow up of type 1 diabetes patients is not available so, they have to travel long distances just for getting specialist follow up advice. Mothers have increased risk of depressive symptoms as studies observed mothers responded with shock, defensive retreat, weight loss and grief similar to bereavement.⁸ Early contact with behavioral team can normalize the emotional adjustment process as it provides opportunity for early identification and intervention for parents' mental health. Clinical interviews for emotions, apprehensions and mood at diagnosis are used for

identification of risk group.⁹ In most underdeveloped countries like Pakistan, absence of government support for provision of glucometers, glucose strips and insulin injections add to financial and emotional problems. People suffering with the burn out have hard time controlling their child's diabetes yet parents continue. People often think that taking care of themselves means not taking care of others which does not make much sense. However, it is true that if you don't care of yourself, you will have a difficult time taking care of others¹⁰ Thus, for Pakistan, managing such a chronic disease becomes a big challenge.

The purpose of this study is to estimate impact of diabetes diagnosis on family and social life of parents and highlight the challenges that family comes across after the diagnosis. This study will assess magnitude of problem and will call for early interventions including psychological counseling and financial support to the needy families.

Methodology

This cross-sectional study was conducted at the Pediatric Department, Children Hospital, Pakistan Institute of Medical Sciences, Islamabad from August 2019 till July 2020 using consecutive convenient sampling method.

Incidence of type 1 diabetes in Pakistan is around 1.02 per 100,000 population per year.¹ So, we decided to take all newly diagnosed patients who presented in children hospital, outpatient department during one year of study period as sampling frame.

All Parents of children with newly diagnosed type 1 diabetes and parents willing to share their feelings/concerns were included in the study. While, parents having other stresses like death of spouse, divorce, using antipsychotics were not included in the study. Parents with other chronic diseases were also not included in the study. Newly diagnosed were labeled as children in whom diagnosis of

diabetes was made about 1 month prior to inclusion in study.

Questionnaires were developed for study by taking help from previous studies and consultation with senior faculty members. Questionnaires were then checked for content validity by senior faculty. The questionnaire consisted of two sections with questions relating to personal specifications and income in one section and questions relating to different aspects of stress relating to their child's health in the other.

After informing parents regarding study, their consent was taken. Specific questions were asked relating to impact of diagnosis, parents' emotional response, mental state, concerns of child's wellbeing and financial worries. These were noted in proformas and quantified according to 5-point Likert scale. 1 point for strongly agree and 5 points for strongly disagree. Data was analyzed in SPSS version 21. Categorical variables like gender, age, educational, socioeconomic status and parental affects were measured as frequency and percentages. Permission from **institutional review board** of PIMS was taken having reference no. ECPIMS/22/09 dated 27-07-2021.

Results

A total of 79 participants were included in the study. The demographic characteristics are summarized in Table I. The age distribution showed that 25.3% of participants were aged up to 5 years, 39.2% were between 5 and 10 years, and 35.4% were 10 years or older. Female participants slightly outnumbered males (55.7% vs. 44.3%). A significant majority of families (82.2%) reported a monthly income of less than or equal to PKR 50,000. Only 5.0% earned more than PKR 100,000. Most participants (70.8%) reported having no prior knowledge of type 1 diabetes mellitus (T1DM), while 29.2% did. Regarding parental education, over half (54%) were either not educated or had only attended up to

primary class, whereas 30% had completed graduation and 16% had a bachelor's degree.

Almost half (50.6%) reported a family history of diabetes. A chi-square test showed no statistically significant association between family income and prior knowledge of T1DM ($\chi^2 = 2.83, p = 0.24$), or between education status and prior knowledge of T1DM ($\chi^2 = 4.91, p = 0.09$), suggesting that awareness levels were uniformly low across socioeconomic strata. Table II presents the responses to a series of questions assessing parental concerns and beliefs regarding the management and implications of their child's diabetes.

A significant proportion of parents expressed concern over insulin injections, with 89.8% agreeing or strongly agreeing with this sentiment. Additionally, 93.7% disagreed that insulin is the only form of therapy, suggesting widespread awareness or hope for alternative treatments. Notably, 81.1% of respondents had considered alternative therapies. Job-related stress was another major concern, with 81.0% of parents agreeing or strongly agreeing that managing their child's illness would impact their ability to work. Similarly, 83.4% expressed concern regarding the financial burden of the disease. School attendance was a notable issue, with 81.1% expressing worry about their child's ability to continue education.

More than half (60.9%) believed that their child might not be able to participate in physical activities like peers, and 69.7% were concerned about the health of other siblings. Dietary restrictions were a prominent worry, with 89.9% agreeing that the diabetic diet was perceived as highly restrictive, particularly regarding sweets and sugary foods.

Regarding long-term concerns:

- 81.0% were concerned about their child pursuing higher education.
- 64.6% were concerned about future marriage prospects, and 81.1% worried about employability.

Table I. Demographics of studied participants (n=79)		
Age (years)	Number	Percentage
Up to 5	20	25.3
5-10	31	39.2
More than 10	28	35.4
Sex		
Male	35	44.3
Female	44	55.7
Family income		
Less than Rs. 50000	65	82.2
Rs. 50000 to 100000	10	12.6
More than Rs. 100000	4	5.0
Prior knowledge of T1DM		
No	56	70.8
Yes	23	29.2
Educational status.		
Not educated/ till primary class	43	54
Graduation	23	30
Bachelor degree	13	16
Family history of diabetes		
Yes	40	50.6
No	39	49.4

When asked about potential diabetes-related complications:

- 100% were concerned about eye complications,
- 86.2% about foot problems, and 43% expressed concern over kidney issues.

Alarming, 89.4% of parents agreed or strongly agreed with the belief that their child might die early due to diabetes. Despite these concerns, 96.2% reported satisfaction with the counseling provided by healthcare professionals.

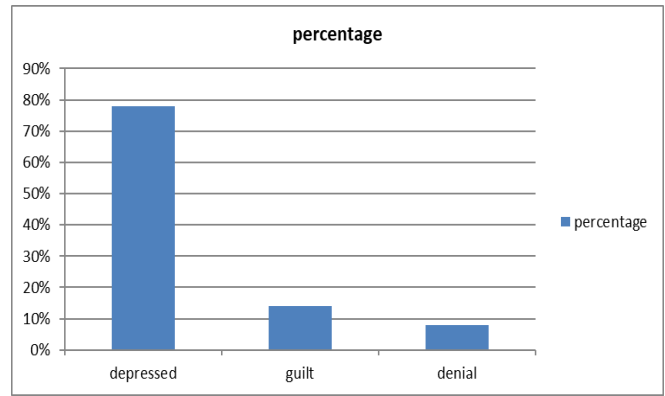


Figure 1. Percentage of affective response (n=79)

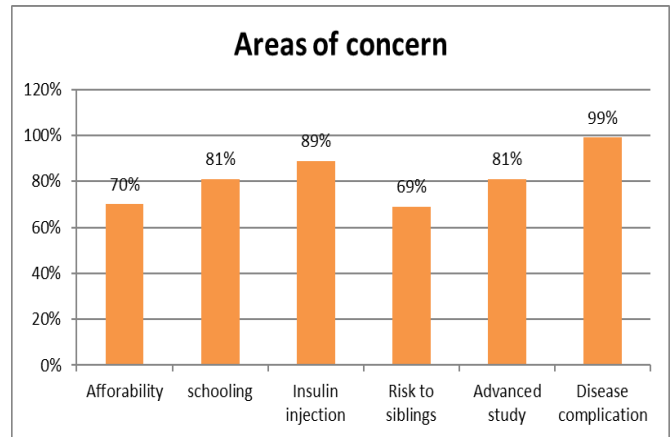


Figure 2. Parental areas of concern (n=79)

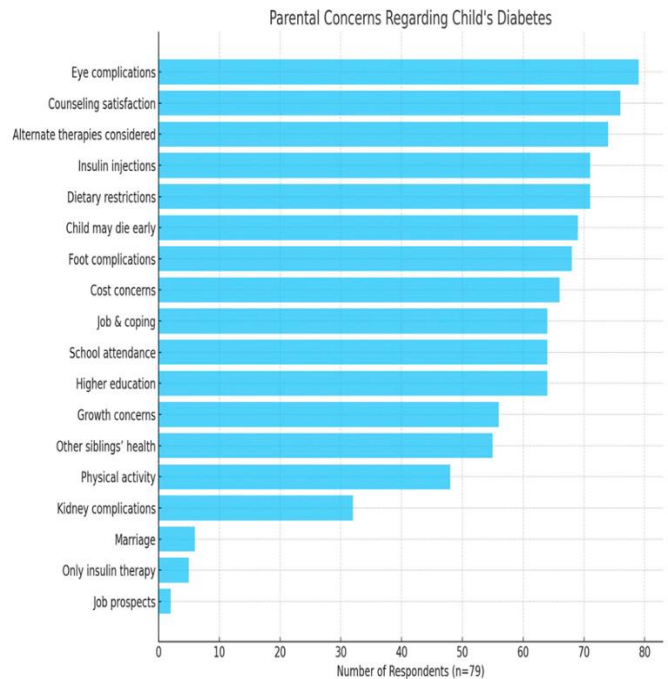


Figure 3. Parents concerns regarding child's Diabetes

Table II. Parental response to question relating to their child health (n=79)					
	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Are you concerned about the painful insulin injections	26 (32.9%)	45 (56.9%)	0 (0.0%)	8 (10.2%)	0 (0.0%)
Are you convinced that only therapy is by insulin injection and not oral medication	0 (0.0%)	5 (6.3%)	0 (0.0%)	64 (81.1%)	10 (12.6%)
Did alternate modes of therapy crossed your mind	64 (81.1%)	10 (12.6%)	0 (0.0%)	0 (0.0%)	5 (6.3%)
Do you have concerns about the ability to cope with illness along with your job	5 (6.3%)	59 (74.7%)	2 (2.5%)	13 (16.4%)	0 (0.0%)
Are you concerned about the cost that may be involved and how to cope with the expenses	10(12.6%)	56 (70.8%)	0 (0.0%)	2 (2.5%)	11 (14.0%)
Are you worried about sending your child to school and getting education	0 (0.0%)	64 (81.1%)	1 (1.3%)	14 (17.6%)	0 (0.0%)
Are you concerned that child will not be able to participate in physical activities like other children	2 (2.5%)	46 (58.4%)	4 (5.0%)	27 (34.1%)	0 (0.0%)
Are you worried about other sibs contracting some illness	0 (0.0%)	55 (69.7%)	19 (24.0%)	5 (6.3%)	0 (0.0%)
Did you think that diabetes diet is a special diet and your child will not be able to take sweat, sugary things	1 (1.3%)	70 (88.6%)	0 (0.0%)	8 (10.1%)	0 (0.0%)
Are you worried about his growth	18 (22.8%)	38 (48.1%)	1 (1.3%)	22 (27.8%)	0 (0.0%)
Which aspect of long-term are you concerned about most;					
• Getting advance studies	0 (0.0%)	64 (81.0%)	0 (0.0%)	15 (19.0%)	0 (0.0%)
• Getting married	0 (0.0%)	6 (7.6%)	0 (0.0%)	51 (64.6%)	22 (27.8%)
• Getting job	0 (0.0%)	2 (2.4%)	0 (0.0%)	64 (81.1%)	13 (16.4%)
What complications of diabetes are you worried about most;					
• Eyes	27 (34.0%)	52 (66.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
• Feet	36 (45.7%)	32 (40.5%)	0 (0.0%)	0 (0.0%)	11 (13.9%)
• Kidneys	0 (0.0%)	32 (40.5%)	0 (0.0%)	45 (56.9%)	2 (2.5%)
Did you think, your child is going to die early	32 (42.5%)	37 (46.9%)	10 (12.6%)	0 (0.0%)	0 (0.0%)
Are you satisfied by the counselling of doctor	12 (15.2%)	64 (81.0%)	0 (0.0%)	3 (3 %)	0 (0.0%)

A composite score was created from the 13 primary concern items (Cronbach's alpha = 0.82), indicating good internal consistency. Further analysis using Mann-Whitney U test showed significantly higher concern scores among families with no prior knowledge of T1DM compared to those with prior knowledge ($U = 407.0, p = 0.021$). Similarly, lower-income families had significantly higher concern levels than those earning above PKR 50,000 ($U = 421.5, p = 0.035$).

Discussion

It is believed that mental health of parents and children with chronic condition is linked with each other. In present study we have observed stress symptoms in parents of newly diagnosed type 1 diabetes children and social factors that influenced them.

There were three main trends in parental stress. On one hand stress was finance dependent while on the other hand concerns were related to life-long treatment with injections, life-expectancy and long-term complications of disease (Figure. 2). Another significant stress factor was the probability of genetic predisposition and occurrence in other siblings.

After diagnosis of T1D was made, 78% of parents were shocked, 14% were feeling guilt and 8% denial in our study. This parental shock was later converted to depression. Giulia and colleagues also narrated that parent felt depressed and less efficient for diabetic care of their child following diagnosis and this had an effect on child's metabolic control.¹² Depression was also reported by Noser et al which showed that 26% parents' depressive symptoms were type 1 diabetes specific.¹³

Dheyaa J and colleagues reported prevalence of mild and moderate depression 50% and 30% in diabetic children's mothers.¹⁴

Although denial was significantly less in our study yet guilt and blaming themselves for their child's

illness was also found in 4% and anger in 2% of parents. Similar feelings were reported by other studies for the illness of their child like anxiety (15.3%), lower satisfaction and self-confidence in caring for their child, difficulty in emotion regulation, all leading to depression and internalization.¹⁵

Similar findings of depression and grief are reported by other studies as it was concluded that more than 1 in 5 parents of children with type-1 diabetes suffer from depression and need screening plus interventions.¹⁶

83% parents in our study had low literacy, poor understanding of disease and its management. But data is collected from a government hospital where most of patients belong to low-income community and had low literacy level. 82% parents had income less than Rs.50,000/- and thus, were concerned about expenditures. Our results are supported by another study which showed maternal education is positively correlated with disease.¹⁷

81% parents were afraid of sending their child to school and main worry was hypoglycemia at school. Another study done in Turkey showed parents demanded greater knowledge of staff about diabetic care and were stressed to send their child to school for fear of hypoglycemia.¹⁸

93% parents wanted to explore other forms of treatment due to financial constraints, illiteracy and myths regarding insulin injections. Unlike developed countries, parents have to procure insulin and glucometer strips themselves. Therefore, parents often turn to traditional healers who prescribe traditional medicines which has no scientific backing.^{19,20}

Adhering to management with insulin was a big problem as 83% were unable to arrange insulin injections and glucose strips asking for full financial support. 16.4% asked for partial support arranging only glucose strips. This is supported by a national study which demonstrated that lower

socioeconomic status is associated with increased probability of diabetic ketoacidosis.²¹

Additional findings of more severe depressive symptoms associated with less age of child are also reported by one other study by Tully C et al²². Our study showed parents concern about marriage, education and job of child which are main issues in our society as 81% parents wanted their children to receive good education.²³

Our study thus concluded that a large number of parents of T1D children suffer from psychological symptoms that affect child's health and family functioning and therefore recommends parents screening at diagnosis.²⁴ Providers should also address parents' financial issues and suggest financial options which can considerably contribute to diabetes management of children and family functioning.

Limitations: This study lacks the follow up and regression of depressive symptoms as time passes. This study also lacks the affective responses of parents with good socio-economic status.

Conclusion

Parents of type-1 diabetes are susceptible to psychological affects with depression being the most prevalent. Stressing factor for parents were daily insulin injections, regular glucose monitoring with pen-pricks fear, affording of monitoring strips and insulin injections pens. All of these factors have their effect on a child's day to day life including: schooling, physical activities and psychological well-being. Therefore, screening of parents at diagnosis and addressing some management issues can help to defer future complications of T1D indirectly.

References

1. Preechasuk L, Tantasuwan S, Likitmaskul S, Santiprabhob J, Lertbannaphong O, Plengvidhya N, et al., Clinical characteristics, glycemic control, and

- microvascular complications compared between young-onset type 1 and type 2 diabetes patients at Siriraj Hospital—a tertiary referral center. *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy*. 2022 Jan 1:1375-87. <http://doi.org/10.2147/DMSO.S354787>
2. Bazus L, Perge K, Chatelain P, Nicolino M. Objective Burden and Emotional Distress of Parents of Children with Type 1 Diabetes. *Hormone Research in Paediatrics*. 2023 Jul 13;97(3):225-32. <http://doi.org/10.1159/000531885>
3. Cigdem Z, Guler S, Celik MY. Examining the caregiver burden of parents whose children have type 1 diabetes. *Journal of Public Health*. 2023 Sep;31(9):1523-31. <http://doi.org/10.1007/s10389-022-01698-z>
4. Fornasini S, Miele F, Piras EM. The consequences of type 1 diabetes onset on family life. An integrative review. *Journal of Child and Family Studies*. 2020 May;29:1467-83. <http://doi.org/10.1007/s10826-019-01544-z>
5. Tauber JL. Effects of adapted multi-dimensional family therapy on glycemic control, diabetes-related family conflict and distress in the families of adolescents with poorly controlled type 1 diabetes. 2019 Dec. <http://doi.org/2020-05-06T22:31:10Z>
6. Di Riso D, Bassi G, Mancinelli E, Zaffani S, Salcuni S, Maffei C. Mothers and fathers parenting stress and their perception of children's psychosocial functioning in paediatric diabetes: A pilot study. *International journal of environmental research and public health*. 2020 Jul;17(13):4734. <http://doi.org/10.3390/ijerph17134734>
7. Keklik D, Bayat M, Başdaş Ö. Care burden and quality of life in mothers of children with type 1 diabetes mellitus. *International Journal of Diabetes in Developing Countries*. 2020 Sep;40:431-5. <http://doi.org/10.1007/s13410-020-00799-3>
8. Theofilou P, Vlastos DD. The psychological burden of families with diabetic children: A literature review focusing on quality of life and stress. *Children*. 2023 May 26;10(6):937. <http://doi.org/10.3390/children10060937>
9. Burcham M. When your child is diagnosed with type 1 diabetes: Experiences of parents who also have the condition. *Journal of Diabetes Nursing*. 2023 May 1;27(3):1. <http://doi.org/27:JDN288>
10. Abdoli S, Vora A, Smither B, Roach AD, Vora AC. I don't have the choice to burnout; experiences of parents of children with type 1 diabetes. *Applied Nursing Research*. 2020 Aug 1; 54:151317. <http://doi.org/10.1016/j.apnr.2020.151317>

11. Shaikh W, Riaz M, Askari S, Basit A. Linear Growth and Final Height in People with Type 1 Diabetes: A Study from Karachi, Pakistan. *Cureus*. 2022 Feb;14(2). <http://doi.org/10.7759/cureus.22397>
12. Bassi G, Mancinelli E, Di Riso D, Salcuni S. Parental stress, anxiety and depression symptoms associated with self-efficacy in paediatric type 1 diabetes: a literature review. *International journal of environmental research and public health*. 2021 Jan;18(1):152. <http://doi.org/10.3390/ijerph18010152>
13. Noser AE, Dai H, Marker AM, Raymond JK, Majidi S, Clements MA, et al. Parental depression and diabetes-specific distress after the onset of type 1 diabetes in children. *Health Psychology*. 2019 Feb;38(2):103. <http://doi.org/10.1037/hea0000699>
14. Kadhim DJ, Kadhim SA, Ali FZ, Fawzi HA. Prevalence of Depression among Mothers of Children with Type 1 Diabetes Mellitus attending two Diabetes Centers. *Indian Journal Of Public Health*. 2019 Aug;10(8):44h <http://dx.doi.org/10.5958/0976-5506.2019.02011.4>
15. Öz BO, Miniksar DY, Kaban ŞÖ, Cangür Ş, Yavuzylmaz F. Comparison of mothers of adolescents diagnosed with type 1 diabetes mellitus and mothers of healthy adolescents in terms of difficulty in emotion regulation, depression and anxiety levels and clinical variables. *The Turkish Journal of Pediatrics*. 2023 Oct 25;65(5):789-800. <https://doi.org/10.24953/turkijped.2022.1019>
16. Chen Z, Wang J, Carru C, Coradduzza D, Li Z. The prevalence of depression among parents of children/adolescents with type 1 diabetes: A systematic review and meta-analysis. *Frontiers in endocrinology*. 2023 Mar 1;14:1095729. <http://doi.org/10.3389/fendo.2023.1095729>
17. Makara-Studzińska M, Somasundaram S, Ashraf GM, Gogacz M, Madej A, Izydorczyk B, et al. Assessment of psychosocial functioning of mothers of children with diabetes mellitus compared to mothers of healthy children. *BioMed Research International*. 2019;2019(1):6821575. <http://doi.org/10.1155/2019/6821575>
18. Hatun Ş, Mutlu GY, Gökçe T, Avcı Ö, Yardım N, Aycan Z, et al. Care and Support of Children with Type 1 Diabetes at School: the Turkish Experience. *Journal of Clinical Research in Pediatric Endocrinology*. 2021 Dec;13(4):370. <http://doi.org/10.4274/jcrpe.galenos.2021.2021.0060>
19. Usai R, Majoni S, Rwere F. Natural products for the treatment and management of diabetes mellitus in Zimbabwe-a review. *Frontiers in Pharmacology*. 2022 Aug 24; 13:980819. <http://doi.org/10.3389/fphar.2022.980819>
20. Ekpor E, Osei E, Akyirem S. Prevalence and predictors of traditional medicine use among persons with diabetes in Africa: a systematic review. *International Health*. 2024 May;16(3):252-60. <http://doi.org/10.1093/inthealth/ihad080>
21. Gesuita R, Maffei C, Bonfanti R, Cardella F, Citriniti F, D'Annunzio G, et al. Socioeconomic inequalities increase the probability of ketoacidosis at diagnosis of type 1 diabetes: a 2014–2016 nationwide study of 2,679 Italian children. *Frontiers in pediatrics*. 2020 Oct 22;8:575020. <http://doi.org/10.3389/fped.2020.575020>
22. Tully C, Wang CH, Sinisterra M, Clary L, Hilliard ME, Monaghan M, et al. Diabetes-specific functioning in parents of young children with recently diagnosed type 1 diabetes. *Health Psychology*. 2022 Jun;41(6):423. <http://doi.org/10.1037/hea0001164>
23. Iversen AS, Graue M, Haugstvedt A, Råheim M. Being mothers and fathers of a child with type 1 diabetes aged 1 to 7 years: a phenomenological study of parents' experiences. *International journal of qualitative studies on health and well-being*. 2018 Jan 1;13(1):1487758. <http://doi.org/10.1080/17482631.2018.1487758>
24. Zhao X, Ai Z, Chen Y, Wang J, Zou S, Zheng S. The effectiveness of parenting interventions on psychosocial adjustment in parents of children and adolescents with type 1 diabetes: a meta-analysis. *Worldviews on Evidence-Based Nursing*. 2019 Dec;16(6):462-9. <http://doi.org/10.1111/wvn.12399>