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QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES IN COMPARISON TO THEIR PRIMARY CAREGIVERS

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Abstract: The purpose of this study was to evaluate and compare the quality of life of children and adolescents with type 1 diabetes mellitus (T1DM) and their primary caregivers.

Methods: A cross-sectional descriptive-analytical study was carried out with a total of 100 participants, including 50 children and adolescents with T1DM and their 50 primary caregivers. To assess the quality of life of children, the Pediatric Quality of Life Inventory™ (PedsQL 4.0™) and the PedsQL 3.0™ Diabetes Module were employed. The impact of the disease on parents and family dynamics was evaluated using the PedsQL™ Family Impact Module.

Results: The analysis indicated that primary caregivers reported a significantly lower quality of life across all evaluated domains compared to children and adolescents. They experienced greater stress, heightened concerns, and reduced emotional and social functioning in comparison to their children.

Conclusion: The presence of T1DM in a child significantly affects parental quality of life. Providing adequate support to families is essential for improving treatment outcomes and overall family well-being.

Keywords: quality of life, type 1 diabetes, children and adolescents, primary caregivers

1. INTRODUCTION

The quality of life related to diabetes varies among children and adolescents and is influenced by various factors, including challenges in disease management, family conflicts and relationship dynamics, emotional burden due to the chronic nature of the disease, and the perceived lack of progress in treatment (Saoji N. et al., 2018). Type 1 diabetes mellitus (T1DM) affects almost all aspects of a child's daily life, including play, meals, sleep, family relationships, peer interactions, and adaptation to school and preschool environments (Mackey ER et al., 2016). Individual characteristics of the child, such as temperament, attention, impulsivity, overall functioning, behavior, dietary preferences, acceptance of new foods, appetite, and physical activity, can significantly influence disease management and adherence to therapeutic guidelines (Pierce JS et al., 2017). Beyond its direct effects on the child, T1DM can substantially diminish the health-related quality of life of both affected children and adolescents, as well as their families (Saoji N. et al., 2018). Chronic illnesses in children represent a significant source of stress for parents, with mothers, who are most often the primary caregivers, experiencing the greatest emotional burden. The intensive care and communication required with the child further increase stress, which can negatively affect their health and the overall functioning of the family. Parental stress, especially among mothers, is associated with various factors, including daily disease management, financial challenges, fluctuations in blood glucose levels, as well as feelings of guilt and fear of future complications (Asadi Shavaki M et al.). Studies show that mothers of children with diabetes experience higher stress levels than their children, and elevated maternal stress is linked to poorer metabolic control in the child. (Lohiya et al., 2021). Parental emotional well-being plays a vital role in the child's physical and psychosocial health, while effective coping with emotional challenges supports a healthier lifestyle for both the child and the entire family (Žilinskienė J et al., 2021).

2. OBJECTIVE

To compare the quality of life of children and adolescents with type 1 diabetes and the quality of life of their primary caregivers.

3. METHODS

Process and Participants

This cross-sectional study was conducted using a descriptive-analytical approach, involving a total of 100 participants—50 children and adolescents with type 1 diabetes mellitus (T1DM) and their 50 primary caregivers. The participants are members of the Association of Diabetic Children and Youth of the Canton of Sarajevo. After obtaining written consent from the parents, the participants were surveyed. Inclusion criteria for the study were: a diagnosis of T1DM for more than six months, the child/adolescent being between two and eighteen years old, membership in the Association of Diabetic Children and Youth of the Canton of Sarajevo, and voluntary written consent from the parents for themselves and their child to participate. Exclusion criteria were: illness duration of less than six months, age under two or over eighteen years, children and adolescents with developmental difficulties who are unable to respond to questionnaires, and refusal of voluntary participation by the parent or child.

1. INSTRUMENTS

Pediatric Quality of Life Inventory with Diabetes Module

The Pediatric Quality of Life Inventory™ (PedsQL 4.0™) along with the PedsQL 3.0™ Diabetes Module was used to evaluate the quality of life in children and adolescents. PedsQL 4.0™ is a general tool designed to assess health-related quality of life (HRQoL) in children and adolescents aged 2 to 18 years. It includes 23 questions across four subscales: physical functioning (8 questions), emotional functioning (5 questions), social functioning (5 questions), and school/daycare functioning (5 questions). The questionnaire enables self-reporting from children aged 5–18 years and parent-reporting for children aged 2–18 years. Responses are rated on a Likert scale (0 = never, 1 = almost never, 2 = sometimes, 3 = often, 4 = almost always), and the results are converted into a scale ranging from 0 to 100, with higher scores reflecting better quality of life (Varni et al., 2003).

The PedsQL 3.0™ Diabetes Module includes 28 questions across five subscales: diabetes symptoms (11 questions), treatment barriers (4 questions), treatment adherence (7 questions), worry (3 questions), and communication (3 questions). The response scale and scoring method are the same as those used in PedsQL 4.0™, with higher scores indicating fewer diabetes-related symptoms or issues. These two questionnaires combined provide a comprehensive assessment of quality of life in children with diabetes (Varni JW et al., 2001; Nansel TR et al., 2008).

Family Impact Module to Assess the Impact of Chronic Pediatric Health Conditions

The PedsQL™ Family Impact Module was used to evaluate the effect of children's chronic illnesses on parents' quality of life and family dynamics. The questionnaire comprises 36 questions across eight subscales. Six of these subscales assess parents' quality of life: physical functioning (6 questions), emotional functioning (5 questions), social functioning (4 questions), cognitive functioning (5 questions), communication (3 questions), and worry (5 questions). The other two subscales evaluate family functioning: daily activities (3 questions) and family relationships (5 questions). A five-point Likert scale is used for responses (0 = never, 1 = sometimes, 2 = often, 3 = almost always, 4 = always). Items are reverse scored and linearly converted into a range from 0 to 100, with higher scores reflecting better family functioning and a lesser negative impact of the illness on the family (Varni et al., 2004).

The questionnaires were used in Bosnian and Croatian versions, with prior written consent and a license obtained from the MAPI Research Trust.

Comparative Analysis

The study analyzed and compared the quality of life dimensions of children/adolescents and their primary caregivers, using data from the PedsQL™ 4.0, PedsQL™ 3.0, and PedsQL™ Family Impact Module. In addition to the overall quality of life evaluation, specific subscales for worry and communication, which were the same in both questionnaires, were examined. The goal was to identify differences in the perception of quality of life between children/adolescents and their parents and to assess the impact of the child's chronic health condition on caregivers and family dynamics

Statistical Data Analysis

After the research was conducted, the collected data were entered into an electronic database created using Microsoft Office Excel 365. Categorical variables were presented as frequencies, expressed as absolute numbers and relative percentages within the examined groups. Descriptive statistical analysis results were presented using mean values (Mean) and standard deviations (SD) for various aspects of quality of life. To test the differences in the total scores between children/adolescents and their primary caregivers, an independent samples t-test was used. IBM SPSS Statistics version 26.0 (IBM Corporation, Armonk, New York, USA) was used for the statistical data analysis. The statistical significance threshold was set at $p < 0.05$. The research results were presented in text, table, and graphical formats.

Ethical Aspects

The study was carried out in accordance with the Ethical Code of Research with Children and About Children in Bosnia and Herzegovina, which was approved by the Decision of the Council of Ministers of BiH at its 51st session on May 28, 2013. This Code aligns with the United Nations Convention on the Rights of the Child and aims to protect children from any form of harm. It governs the status of children and their families as participants in various types of research—humanitarian, social, educational, and medical—that could potentially impact their personal integrity, either directly or indirectly (Muratbegović & Janjetović, 2013).

The study was approved at the 10th session of the Ethics Committee of the Faculty of Health Studies, held on February 12, 2021. Consent was obtained from the Association of Diabetic Children and Youth of the Canton of Sarajevo, as well as written voluntary consent from parents for their and their children's participation in the study.

The questionnaires were anonymous, and the collected data were used solely for research purposes, with strict adherence to confidentiality and privacy protection principles for the participants.

2. RESULTS

The study included 50 children aged 5-18 years. The average age of the participants in the children and adolescent group was 12.92±2.842 years, with 48% male and 52% female. Of the total 50 primary caregivers, 98% were the child's mothers, with an average age of 41.28±5.64 years.

Table 1. Comparative analysis of Quality of life of children and adolescents based on self-report and Quality of life of primary caregivers

QUALITY OF LIFE	Children and adolescents		Primary caregivers		t	p
	Mean	SD	Mean	SD		
Generic Quality of life score of child/family	82,77	9,16	59.15	19.58	7,97	<0,001*
Physical Functioning	84,84	11,89	57.58	21.37	9,027	<0,001*
Emotional Functioning	72,87	16,57	49.50	21,03	5,911	<0,001*
Social Functioning	95,21	8,14	63.88	27.61	7,862	<0,001*
School/Cognitive Functioning	76,92	14,70	66.90	23,1	3,203	0,002*
Worry	73,94	19,71	60.50	26.18	5,325	<0,001*
Communication	81,74	22,43	51.10	24.63	5,168	<0,001*

*p <0,05

Source: author's research

The analysis of the quality of life of children and adolescents and the quality of life of the primary caregiver revealed that, in all aspects, the quality of life of the primary caregiver was assessed significantly worse compared to the quality of life of the children and adolescents.

Table 2. Comparative analysis of Quality of life of children and adolescents according to primary caregiver's report for the child/adolescent and Quality of Life of the primary caregiver

QUALITY OF LIFE	Children and adolescents		Primary caregivers		t	p
	Mean	SD	Mean	SD		
Generic Quality of life score of child/family	78,83	15,23	59.15	19.58	8,639	<0,001*
Physical Functioning	83,06	18,34	57.58	21.37	8,774	<0,001*
Emotional Functioning	67,2	19,51	49.50	21,03	5,678	<0,001*
Social Functioning	87,8	16,76	63.88	27.61	7,045	<0,001*
School/Cognitive Functioning	74,7	19,23	66.90	23,1	2,565	0,013*
Worry	70,33	23,88	60.50	26.18	5,537	<0,001*
Communication	72,17	26,55	51.10	24.63	2,315	0,025*

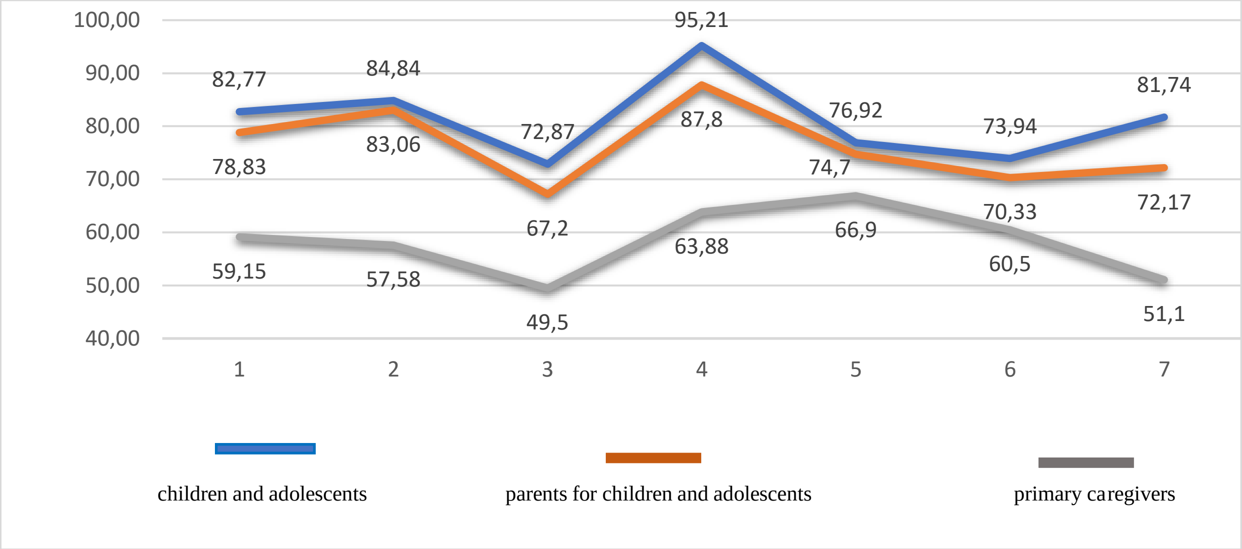
*p <0,05

Source: author's research

The analysis of the quality of life of children and adolescents, as reported by primary caregivers, and the quality of life of the primary caregivers themselves, revealed that in all aspects, the quality of life of the primary caregiver was assessed significantly worse compared to the quality of life of the children and adolescents, as reported by the parents for the children and adolescents.

The results obtained from the quality of life assessments, both as reported by the children and adolescents and by the parents for the children and adolescents, in comparison with the quality of life of the primary caregivers, are presented both in tabular and graphical form.

Chart 1. Quality of life of children and adolescents according to the report of children/adolescents and the report of the primary caregiver for children/adolescents in relation to the quality of life of the primary caregiver



Source: author's research

3. DISCUSSION

The diagnosis of type 1 diabetes mellitus (T1DM) represents an extremely stressful and challenging life event for both the child and their family. The experience of coping with this chronic illness is often described as traumatic, with parents experiencing intense emotional stress (Zysberg L et al., 2015). Although it is primarily expected that the illness affects the sick child or adolescent the most, research findings, including this one, confirm that a child's chronic illness has a significant impact on the quality of life of the entire family. Furthermore, it has been shown that family members may experience higher stress and a decrease in quality of life compared to the child with diabetes (Shah R et al., 2021). This study analyzed the difference in quality of life between children and adolescents with T1DM and the quality of life of their primary caregivers, using subscales to assess physical, emotional, social, and cognitive functioning, as well as levels of concern and communication within the family. The results indicate a significantly poorer quality of life for parents compared to their children in all aspects – physical functioning, psychosocial health, emotional stability, social interactions, and communication. In addition, parents reported a higher level of concern compared to the children and adolescents, supporting the thesis that a child's chronic illness can represent an additional emotional and psychological burden for the family. Particularly concerning are the findings indicating significantly poorer cognitive functioning in parents compared to the school functioning of children and adolescents, which may be related to the continuous stress and exhaustion of primary caregivers. This data underscores the importance of providing adequate psychological support to parents, as their emotional state and ability to cope with stress can directly affect the success of managing the illness in the child.

To improve T1DM management, healthcare professionals play a key role in assessing and overcoming barriers that may hinder the implementation of the treatment plan. This includes not only medical aspects but also psychosocial factors, behaviors, and emotional challenges the family faces (Naranjo D et al., 2014). Continuous education and an individualized approach, which includes working with the family, can ease adaptation to the illness and reduce stress levels in parents. In addition to education about the medical aspects of diabetes, parents need support in managing the emotional challenges that the illness brings. Educational programs aimed at reducing parental stress have proven to be useful tools in improving parents' mental health (Aldubayee M et al., 2020). Family educational programs that promote teamwork between parents and children improve family communication and help address problems related to the illness, which can result in better glycemic control in children (Whittemore R et al., 2019). A holistic approach, which includes medical education, emotional support, and practical guidance for disease management, can significantly contribute to improving the quality of life for children with T1DM and their families.

4. CONCLUSION

To enhance the quality of life for families of children with T1DM, it is crucial to adopt a multidisciplinary approach that incorporates not just medical treatment, but also psychological and educational support for parents. Ongoing education, counseling, and family-focused educational programs can help alleviate parental stress and improve the overall functioning of the family.

Healthcare professionals play a key role in recognizing and addressing barriers that may complicate disease management, with particular attention given to supporting parents in terms of emotional and psychosocial adjustment. A holistic approach, which includes diabetes education, improving communication within the family, and promoting healthy lifestyle habits, can significantly improve treatment outcomes and contribute to a better quality of life for children and their families.

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