Archives of Advances
in Biosciences

Original Article:
Quality of Life for Parents of Children With Type 1 Diabetes

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Cite this article as: MirRashidi FS, Korkinejat F, Rezaie M, Gholami MH, Rezabeigi Davarani E, Daneshi S, et al. Quality of Life for Parents of Children With Type 1 Diabetes. Archives of Advances in Biosciences. 2021; 12(4):43-49. https://doi.org/10.22037/aab.v12i4.35477

https://doi.org/10.22037/aab.v12i4.35477

Article info:
Received: 13 Jul 2021
Accepted: 26 Aug 2021
Published: 17 Nov 2021

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Abstract

Introduction: Parents whose children suffer from diabetes face various issues and challenges, including reduced Quality of Life (QoL). On the other hand, they have an essential role in taking care of their diabetic children.

Materials and Methods: This descriptive correlational study was conducted in 2020 in Jiroft, Iran, to evaluate the QoL in 96 parents of children with type 1 diabetes. The sampling method in this study was census and the study population was parents with a child suffering from type 1 diabetes. Research tools included Demographic Information Checklist and Health-related QoL Questionnaire (SF36). SPSS software v. 19 was used for data analysis. Descriptive statistics was used as frequency tables, and indicators such as mean and standard deviation described the demographic characteristics and the QoL. Pearson correlation coefficient test was deployed to assess the QoL. Independent chi-square and t-test were used to relate this variable to demographic characteristics.

Results: There is a significant difference between life satisfaction, parental boredom, feeling of well-being, sufficient income, general health status, and being covered by supportive institutions of parents of type 1 diabetic children with the QoL ($P<0.05$).

Conclusion: By knowing this group of parents' living conditions and implementing programs to support these families, the QoL of parents with a diabetic child can be improved.

Keywords: Child, Parents, Quality of Life, Type 1 diabetes

Introduction

Diabetes is the most common metabolic disease and the fourth leading cause of death in Western societies [1]. Diabetes is referred to as a silent epidemic and is considered a public health problem worldwide due to its increasing prevalence and significantly reduced life expectancy [2].

This disease is caused by the body's inability to produce insulin and the imbalance between the need for insulin and its supply. The result is high blood sugar and impaired metabolism of fats, proteins, and carbohydrates [3]. The prevalence of this disease has increased globally, and it is predicted to increase from 4% in 1995 to 5.43% in 2025 [4]. Currently, the prevalence of type 1 diabetes in Iran is between 5 and 10%; besides, one in every 400 to 500 children has type 1 diabetes [5]. Type 1 diabetes becomes prevalent in childhood with age, which is 9.1 per 1000 children and adolescents, and increases with age [6].

It is a chronic disease that requires frequent daily insulin injections, accurate measurement of blood sugar, exercise and nutritional planning, and constant communication with health center staff to achieve disease control [7]. Therefore, the parents of these patients have almost all the responsibility for managing this disease. Managing diabetes is a full-time and uninterrupted duty that interferes with the family's daily life and negatively impacts it [8].

Caring for a child with special health conditions is complicated and stressful. Parents are always worried about shocking events related to the child and can hardly balance their daily activities such as work, social life, and other tasks [9]. These disorders also affect effective family communication, increase family conflicts, reduce adolescent psychological adjustment and Quality of Life (QoL), and reduce parental mental and physical health, and lower metabolic control in children [10].

Almost all studies in type 1 diabetes and the clinical guidelines of the American and Canadian Diabetes Association emphasize psychological interventions to improve the QoL of families with children with diabetes; this is meant to prevent mental disorders in parents and children with diabetes [11, 12].

Due to the increase in the number of type 1 diabetes in children and also the paucity of relevant studies, the researchers decided to evaluate the QoL in parents of children with type 1 diabetes. Therefore, this study aimed to evaluate the QoL in parents of children with type 1 diabetes.

Materials and Methods

This is a cross-sectional (descriptive-analytical) study conducted in 2020 in Jiroft, Iran, to evaluate children's QoL with type 1 diabetes. Due to the low incidence of type 1 diabetes, the sampling method in this study was census and all parents with diabetic children were included in the study. The sample size consisted of 96 parents. In this study, two questionnaires were used: parents' demographic information, which included: age, sex, marital status, education, occupation, income, government support, and patient relativity, and the other was the Iranian version of the Health-related quality of life Questionnaire (SF36). The SF-36 questionnaire consists of 36 items, which are used to calculate eight subscales: Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role Emotional (RE), and Mental Health (MH). The first four scores can be summed up to create the Physical Composite Score (PCS), while the last four can be tallied to create the Mental Composite Score (MCS). Scores for the SF-36 scales range between 0 and 100, with higher scores indicating a better Health-related Quality of Life (HRQoL) [13, 14]. The internal consistency of the Iranian version of the SF-36 questionnaire showed that all eight SF-36 scales met the minimum reliability standard; the Cronbach's alpha coefficients ranged from 0.77 to 0.90 except for the vitality scale (α=0.65) [15].

After preparing the questionnaires, we provided the study's target population with necessary explanations. This was accomplished through emphasis on the confidentiality of the information and the use of general results only in research and that no compulsion to participate in the research will be applied and the participation of individuals in the research is optional. When they were satisfied and prepared to participate in the study, they were invited to cooperate. After data collection, the analysis was performed with independent chi-square and t-tests using SPSS software, v. 19 at a significance level of 0.05.

This research is extracted from the doctoral dissertation which was approved by the Biomedical Research Ethics Committee at Jiroft University of Medical Sciences (ID: IR.JMU.REC.1399.037).

Results

In this study, 96 parents with children with type 1 diabetes were studied. Table 1 indicates the demographic information of the parents. The mean age of the onset of diabetes was 6.97±3.541 with a minimum age of 1 and a maximum age of 18 years, of which 43 were male and 53 were female.

Table 2 indicates the quality-of -ife scores of children with type 1 diabetes, which is the highest mean related to physical function (25.48) and the lowest mean related to vitality (11.71). The highest standard deviation is related to physical pain (53.78), and the lowest standard deviation is related to role limitation due to physical problems (4.94). In general, the quality-of-life score of children with type 1 diabetes is 30.76±9.27. There is a negative correlation between the child's age and the quality-of-life score of the parents (-0.09), but it is not statistically significant (P=0.44). There is a small correlation between the number of injections and the quality-of-life score (0.04). Statistically, it was not significant (P=0.7). Also, there was a slight correlation (-0.11) between the proximity of hospitalization time and quality-of-life score, and it was not statistically significant (P=0.41).

The results of Table 3 show the quality-of-life score of parents of children with type 1 diabetes. Based on the results of this study, which is shown in Table 3, it is found that feeling vivacity in parents of children with type 1 diabetes is severely impaired and has a significant impact on their quality of life. (P=0.009). However, having a child with type 1 diabetes has no significant effect on the quality of life of the parents in other dimensions.

The results of the independent t-test in Table 4 indicate that there is a significant difference between general health status and sufficient income (P=0.007), also between public health status and being covered by supportive institutions (P=0.004). There was a significant difference between the mean feeling of vitality during the last four weeks and the job (P=0.003). This difference between unemployed and employed women (P=0.003) and businessmen and employees (P=0.011) reached sta-

Table 1. Demographic information of parents of children with type 1 diabetes

Variables		No.(%)
Gender	Male	18(18.8)
	Female	78(81.2)
Level of education	Academic	39(40.6)
	Diploma	36(37.5)
	Under diploma	18(18.8)
	Illiterate	3(3.1)
Occupation	Retired	2(2.1)
	Businessman	23(24.0)
	Employee	18(18.8)
	Unemployed	53(55.2)

Table 2. QoL score of children with type 1 diabetes

QoL Dimensions Index	Mean±SD
General health	15.65±39.16
Physical function	25.48±26.72
Physical pain	24.72±53.68
Role limitation due to physical problems	14.78±4.94
Social Performance	22.28±50.49
Feeling vivacity	11.71±39.16
Mental health	24.06±34.10
Role limitation due to mental problems	18.72±5.90
Total	9.27±30.76

Table 3. QoL score in parents of children with type 1 diabetes

QoL Score	P-Value	QoL Score	P-Value
General health	0.692	Social performance	0.826
Physical function	0.186	Feeling vivacity	0.009
Physical pain	0.379	Mental health	0.085
Role limitation due to physical problems	0.283	Role limitation due to mental problems	0.805

Table 4. Relationship between demographic characteristics and QoL in mothers of children with type 1 diabetes

Demographic Characteristics	General Health	Physical Function	Physical Pain	Role Limitation Due to Physical Problems	Social Performance	Feeling Vivacity	Mental Health	Role Limitation Due to Mental Problems
Level of Education	0.083	0.768	0.051	0.800	0.756	0.699	0.141	0.116
Occupation	0.217	0.895	0.147	0.112	0.266	0.003	0.195	0.119
Marital status	0.134	0.860	0.904	0.918	0.888	0.077	0.097	0.908
Adequate income	0.007	0.649	0.070	0.220	0.297	0.254	0.276	0.009
Being covered by support institutions	0.004	0.176	0.162	0.872	0.662	0.392	0.725	0.305

tistical significance. There was a significant difference between the average difficulty in doing work or daily activities due to mental problems and insufficient income (P=0.009).

The results of the independent t-test in Table 5 indicate the relationship between demographic characteristics and the quality of life in fathers of children with type 1 diabetes that there is a significant difference between general health status and adequate income (P=0.003). There was a significant difference between physical performance and sufficient income (P=0.019). There was a significant difference between the severity of physical pain during the last four weeks and education level (P=0.031). There was a significant difference between impaired social activities due to health status or emotional and occupational problems (P=0.023). There was a significant difference between the mean assessment of mental health status and occupation (P=0.029). This difference was significant between the retired and the unemployed (P=0.021).

Discussion

Assessing the non-physical effects of diabetes on children and their families is a topic that is less addressed in the country. In this study, therefore, we decided to investigate this case. Constant conflict with a sick child and the limitations that the treatment of a child with diabetes imposes on parents can lead to negative emotions, dissatisfaction with life, and thus a reduced quality of life.

Findings of this study showed that there is a significant difference between the general health status of parents,

Table 5. Relationship between demographic characteristics and QoL in fathers of children with type 1 diabetes

Demographic Characteristics	General Health	Physical Function	Physical Pain	Role Limitation Due to Physical Problems	Social Performance	Feeling Vivacity	Mental Health	Role Limitation Due to Mental Problems
Level of education	0.850	0.433	0.031	0.201	0.417	0.794	0.251	0.369
Occupation	0.564	0.144	0.833	0.683	0.023	0.770	0.029	0.372
Marital status	0.486	0.423	0.140	0.761	0.405	0.436	0.182	0.520
Adequate income	0.003	0.019	0.553	0.366	0.128	0.553	0.251	0.084

sufficient income, being covered by health insurance institutions, and quality of life. There was also a significant difference between the average feeling of the vitality of mothers during the last four weeks, job and average difficulty in doing work.

There was a significant difference between daily activities due to psychological problems and insufficient income. Also, there was a significant difference between impairment in social activities due to health status or mental health problems and the average assessment of mental health status and occupation.

The findings of Table 3 showed that there was a significant difference between the quality-of-life score in parents of children with type 1 diabetes and the score of vitality (emotional dimension).

These findings are consistent with the results of the study by Sullivan et al., who reported in a qualitative study that parenting a child with type 1 diabetes can be very stressful. Parents described the need for constant vigilance, a sense of constant responsibility to maintain metabolic control and prevent hypoglycemia. These issues can lead to a decline in the quality of life of parents [16].

Standards of medical care in diabetes also identify mothers of young diabetic children at risk of "experiencing high levels of anxiety" because their children do not have the cognitive ability to diagnose and respond to symptoms of hypoglycemia. It can lead to psychological problems in mothers [17].

Cameron et al. reported that parents of children with type 1 diabetes were more likely to be depressed. Therefore, attention to "parental psychological pathology and family conflicts" using standard therapeutic approaches is a topic that has been suggested as a complement to routine interventions in diabetic children [18].

Similarly, the findings of Herbert et al.'s study showed that reduced quality of life in parents of diabetic children is a major issue that is associated with the frequency of hypoglycemia in sick children and the intensity of care required by the sick child [19].

Inverso et al. found that suffering of parents due to their children's diabetes (Diabetes Distress) is directly related to increased family conflicts and glycosylated hemoglobin levels; on the other hand, increased family conflicts were associated with decreased quality of life and higher levels of glycosylated hemoglobin [20].

The results of a study by Herbert et al also showed that parents of children with diabetes do not have adequate sleep quality due to concerns about their children's hypoglycemia, which can lead to a decline in their quality of life [21].

In a study of "Depression in Diabetes", Goldney et al. concluded that the prevalence of depression in the population of diabetic patients is higher than the general population; this in turn has a major impact on reducing the quality of life of patients [22].

The results of the present study also show that parents of diabetic children had lower quality of life and feeling of vitality, which may be related to the symptoms of depression.

These results are consistent with the results of a study by Moreira et al. Their research showed that children's diabetes changes the quality-of-life score in the physical and emotional dimensions of parents of diabetic patients [23].

In the present study, Table 4 shows the relationship between demographic variables and mothers' quality of life. They had a direct relationship. This finding is in some ways similar to the Streisand' study.

A study by Streisand et al. examined the relationship between parental coping, well-being, and stress in mothers with diabetic children. The results showed that stress in mothers of diabetic children was higher in those with lower mental health. Mothers with weaker maternal coping were those with poorer physical and mental health [24].

In a study conducted by Rumburg et al. on mothers with diabetic children, it was found that suffering from pediatric diabetes in mothers (Diabetes Distress) was significantly associated with depressive symptoms and glycosylated hemoglobin levels in affected children [25].

In the present study, Table 5 shows the relationship between demographic variables and fathers' quality of life. The variables of general health and physical function were directly related to adequate income, the severity of physical pain with a lower level of education, and employment with mental health. This finding is in some ways similar to the Cunningham's study.

The results of a study by Cunningham et al. on parents of children with diabetes demonstrated that 33% of parents had depressive symptoms. Severe depression was directly related to lower education, family stress, older child age, and poorer glycemic control [26].

The findings of this study indicate the need to pay attention to the psychological and emotional dimension of families with diabetic children, although factors such as general health, adequate income, and health insurance coverage can affect the emotional dimension. As a result, it either strengthens or weakens the involvement of parents and patients in the management of diabetes treatment.

The findings of a study by Eckshtain et al. also showed that parental depression in children with diabetes is an issue that can lead to reduced parental involvement in the management of the child's treatment, depression in children with diabetes, and ultimately poor metabolic control of diabetes [27].

Similarly, the results of the Whitmore's study showed that most families with diabetic children can meet the complex treatment needs of a sick child, although this event may require extensive psychological support because treatment management of the chronic and complex disease is stressful and can be difficult [28].

A study by Lewin et al. also showed that family support for managing diabetes treatment through adherence to treatment has led to better metabolic control in affected children [29].

Conclusion

A lack of family-based research and interventions in families with diabetic children is observed in Iran; thus, an educational and supporting package can be designed to improve the quality of life in these families by taking into account the specific needs and challenges in these families. This program was organized and supported by the Deputy Minister of Non-communicable Diseases of the Ministry of Health and finally; the target clients and families should be provided through health centers across the country.

In this support program, in addition to strategies to improve metabolic control, psychological-emotional dimensions should also be addressed to improve the quality of life of clients and their parents. Improving the condition of the psychological or physical dimensions can promote it.

Ethical Considerations

Compliance with ethical guidelines

This research was approved by the Jiroft University of Medical Sciences (Biomedical Research Ethics Committee) (Approval ID: IR.JMU.REC.1399.037).

Funding

This research did not receive any grant from funding agencies in the public, commercial, or non-profit sectors.

Author's contributions

All authors equally contributed to preparing this article.

Conflict of interest

The authors declared no conflict of interests.

Acknowledgments

We would like to express our appreciation to all participants, staff, and managers who made this study possible.

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