

QUALITY OF LIFE AMONG PARENTS OF CHILDREN WITH TYPE 1 DIABETES MELLITUS

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ABSTRACT

Background: The quality of life is considered exceptionally imperative for the family of children with unremitting infection. Parents have a critical part in choosing the quality of life among families of children with chronic illnesses. **Aim:** The study aims to assess the level of quality of life and to measure the socio-demographic profile among parents of children with type 1 diabetes mellitus. **Methods and Materials:** The study used an Explanatory research design, and quantitative data collection was employed in this study. **Results:** The results of the current study showed that parents of children with type 1 diabetes mellitus reported higher levels of quality of life in the physical, social, and environmental domains. When compared to other quality of life domains, the psychological quality of life domain has demonstrated a lower quality of life. **Conclusion:** The findings of this study will assist various stakeholders, including policymakers, medical professionals, medical social workers, mental health specialists, and researchers, in comprehending the challenges faced by parents and caregivers.

Keywords: Quality of Life, Chronic illness, Diabetes Mellitus, Parents, Children.

INTRODUCTION

A person's or a community's overall state of well-being is regarded as their quality of life, and health-related studies typically assess life quality (Sathyananda & Manjunath, 2017). According to the World Health Organization, quality of life means "Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (The WHOQOL Group, 1995, p.1403). The World Health Organization

has defined four domains of measuring quality of life, which are physical, psychological, social relationships, and environmental factors. Physical health refers to human functions such as daily life, sleep, work capacity, rest, energy, discomfort, weakness, and medication. Psychological health includes an individual's thinking, feelings, appearance, mental background, focus, and self-confidence. Social relationship creates individual support systems, sexual needs, and relationships with others. Environmental factors include an individual's ability to appreciate freedom, the economy, transportation, home and other environments, leisure activities, health services, skill

development, and climate change (World Health Organization, 1996). Quality of life evaluates "an individual's sense of wellbeing and the degree to which he or she can participate in the human experience" (Zhan, 1992, p. 779).

The quality of life is considered exceptionally imperative for the family of children with unremitting infection (Toledano-Toledano et al., 2020; Feeley et al., 2014). Parents have a critical part in choosing the quality of life among families of children with chronic illnesses (Janse et al., 2005). Appraisal of quality of life among parents of children with chronic illnesses is considered vital, as the appraisal is based on the parental quality of life, such as social, psychological, and well-being (Abreu Paiva et al., 2019). The severity of chronic illness and the family's financial status are fundamental components of parental quality of life (Siboni et al., 2019). Children with persistent ailments directly influence family and parental quality of life. The parental quality of life depends on the seriousness of the child's illness and how much time is spent caring for the affected children. The parents of children with chronic illness and their quality of life influence the family's social, psychological, and medical support (Spore, 2012). Chronic diseases are recognized to affect family circumstances significantly and create unpleasant circumstances. Parents' stress may lead to confusion, anger, time constraints, isolation, and bitterness (Cherry, 1989). When the child features a persistent ailment, diverse variables such as social, mental, physical, and monetary stability influence the parent's quality of life (Zhang, Wei, Shenand, and Zhang, 2015). Chronic illness is considered a challenging circumstance for families; the child's sickness impacts everyday activities. Great quality of life is fundamental for these families (Amirian et al., 2017). Children with long-term persistent conditions have

adversely influenced their parents quality of life (Witt et al., 2010). Type 1 diabetes mellitus is considered a disease and needs lifelong medical treatment (Vehik et al., 2007).

Type 1 diabetes mellitus is considered childhood diabetes, but it can occur in people of any age. Currently, there is no vaccine to prevent this disease. A person with type 1 diabetes can live a healthy life, but they need diabetes test equipment, continuous insulin hormone, diabetes education, and social support. Type 1 diabetes is caused by an autoimmune problem and affects the immune system of the beta cells of the pancreas, which produce the insulin hormone in the human body. In this case, the pancreas does not produce enough or less insulin in the human body. The acute cause of type 1 diabetes is unknown. Type 1 diabetes is considered a chronic disease in childhood (Kahanovitz, Slussand, and Russell, 2017). Parents play a vital role in the administration of type 1 diabetes mellitus, and the parents have to give quality well-being care to their children with type 1 diabetes mellitus (Uhm & Kim, 2020). Poor communication, increased family conflict, decreased adaptation, and poor support lead to serious issues among parents of children with type 1 diabetes mellitus (Almeida, 1995). The adapting techniques of parents of children with type 1 diabetes mellitus have affected the parental quality of life (Pierce, Kozikowski, Lee, and Wysocki, 2017). Parents of children with type 1 diabetes mellitus were faced with diverse psychosocial and physical issues related to caring for children with type 1 diabetes. Numerous responsibilities must be fulfilled in caring for their child with type 1 diabetes (Spezia, Faulkner, & Clark, 1998). The well-being status of children with Type 1 diabetes has impacted their parents' quality of life (Herbert et al., 2014). In this context, the study aims to assess the level of quality of life and to measure the socio-demographic profile among parents of children with type 1

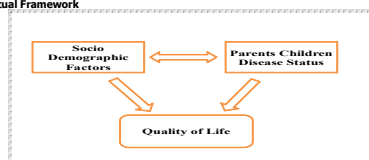
diabetes mellitus.

METHODS & MATERIALS

Explanatory research design and quantitative data collection were employed in this study. The convenience sampling technique was employed to get information from respondents. The study's participants are parents of children with diabetes mellitus who are registered with Kerala's Mittayi Project. The Kerala state government oversees the Mittayi Project, which aims to support children with type 1 diabetes and their families (Mittayi, 2017). Parents of children with type 1 diabetes mellitus are the study's participants, and organised interview schedules were used to gather data from the respondents. 338 samples in all were taken from the Mittayi project area. The Mittayi Project granted permission to carry out the study. The Central University of Kerala's institutional human ethics committee accepted the research.

The respondents' socio-demographic profile included details about the age, gender, marital status, type of family, parents' education, parents' job, and gender of the child with type 1 diabetes. The parents of children with type 1 diabetes mellitus were asked to rate their quality of life using the World Health Organization Quality of Life BREF (WHOQOL BREF, 1996). The 26 statements that make up the scale's subdomains include environment, social relationships, psychology, and physical health. Based on the raw score, the WHO quality of life BREF score was computed and then transformed to a range of zero to one hundred. A higher score denoted a greater standard of living, whereas a lower score showed a poorer standard of living (World Health Organization, 1996).

Conceptual Framework



RESULTS

Table-1: Socio-Demographic profile of parents of children with type 1 diabetes mellitus.

Variable	Item	Percentage (%)
Parent Gender	Father	35%
	Mother	65%
Total	N	338
Age	25-34	23.1%
	35-44	53.0%
	45-54	23.1%
	55-64	0.9%
Total (N)	338	100%
Marital Status	Married	96.20%
	Divorced/Separated	1.80%
	Widowed	2.10%
Total (N)	338	100%
Type of Family	Joint Family	96.70%
	Nuclear Family	3.30%
Total	N	338
Education of the Family Head	Graduation	18%
	Intermediate or Diploma	26%
	High school certificate	48.2%
	Middle school certificate	5.6%
	Primary school certificate	1.2%
	Illiterate	0.9%
Total (N)	338	100%
Occupation of the Family Head	Professionals	0.9%
	Technicians and Associate Professionals	2.1%
	Clerks	4.7%
	Skilled Workers and Shop & Market Sales Workers	26.9%
	Skilled Agricultural & Fishery Workers	11.2%
	Craft & Related Trade Workers	1.2%
	Plant & Machine Operators and Assemblers	6.8%
	Elementary Occupation	42.2%
	Unemployed	4.1%
	Total (N)	338
Gender of Type 1 Diabetes Children	Male	53.80%
	Female	46.20%
Total (N)	338	100%

Table-1 above shows that 65 percent of parents are female and 35 percent of parents are male. 53 Percentage of the parents of children with type 1 diabetes mellitus were in the age group of 35 to 44. 23.1 percent of parents of type 1 diabetes children belong to the age group of 25 to 34 years. Another 23.1 percent of parents of children with type 1 diabetes mellitus were in the age group of 45 to 54. A small proportion (0.9 percent) belongs to the 55 to 64-year age group. The marital status: 96.20 percent of parents of children with diabetes mellitus were married and living with their spouse, followed by 2.10 percent of parents who reported their marital status as widowed, and 1.80 percent of parents of children with diabetes mellitus included in the study were divorced or separated. Type of family: 96.70 percent of parents of children with type 1 diabetes

mellitus belong to the nuclear family system. The remaining 3.30 percent of parents of type 1 diabetes children are living in the joint family system. Parents' Education: 48.2 percent of parents of children with type 1 diabetes mellitus have a high school education, and only 0.9 percent of the parents were illiterate. Parents Job: 42 percentage had an elementary occupation, which was followed by Skilled Workers and Shop & Market Sales Workers who formed 26.9 percentage of the total respondents, Skilled Agricultural & Fishery Workers are 11.2% percentage, Plant & Machine Operators and Assemblers form 6.8% percentage of total respondents, Clerks made 4.7 percentage of the total respondents' pool. 4.1 percent of respondents were unemployed, Technicians and Associate Professionals form 2.1 percent of the total respondents, Craft & Related Trade Workers are 1.2 percent, and professionals are 0.9 percent of the total percentage. Diabetes Child Gender: 53.80 percent of children are boys, and 46.20 percent of children are girls.

Figure-1: Level of Quality of Life among the Parents of Children with Type 1 Diabetes Mellitus.



Table 2: Level of Quality of Life among the Parents of Children with Type 1 Diabetes Mellitus.

	QOL Level	Frequency	Percentage
Total Quality of Life	Low	97	28.7%
	Average	160	47.3%
	High	81	24.0%
	Total	338	100%

The result showed the quality of life among parents of children with type 1 diabetes mellitus. 47.3 percent of parents of children with type 1 diabetes mellitus reported an average level of quality of life. 28.7 percent of parents of children with type 1 diabetes mellitus showed a low level of quality of life. 24 percent of parents of children with type 1 diabetes mellitus reported a high level of quality of life.

Table 3: Descriptive statistics of quality of life among the Parents of Children with Type 1 Diabetes Mellitus

Variables	N	Minimum	Maximum	Mean	Std. Devi
Quality of life	338	40.00	99.00	75.5444	9.2831
Physical	338	5.00	22.00	16.2811	2.7841
Psychological Health	338	5.00	22.00	13.9793	2.7461
Social relationship	338	5.00	15.00	10.4763	1.6981
Environment	338	13.00	37.00	27.4379	4.1281

The study showed that the minimum and maximum points of the total quality of life were 40 and 99. The mean score of parents of children with type 1 diabetes was 75.54, and the standard deviation was 9.28. The physical quality of life score showed a minimum and maximum quality of life composite score of 5 and 22. The mean score of parents of children with type 1 diabetes was 16.28, and the standard deviation was 2.78. The minimum score in the field of psychological quality of life was 5, and the maximum score was 22 for parents. The mean score was 13.97, and the Std Deviation score was 2.74. Parents of children with type 1 diabetes reported a minimum social quality of life score of 5 and a maximum score of 15. The mean score was 10.47, and the parental standard deviation was 1.69. The minimum environmental quality score of parents of children with type 1 diabetes was 13, and the

maximum score was 37. The mean score of 27.43 and standard deviation score of 4.12 showed the quality of life of the parents in the environment.

The results of the current study showed that parents of children with type 1 diabetes mellitus reported higher levels of quality of life in the physical, social, and environmental domains. When compared to other quality of life domains, the psychological quality of life domain has demonstrated a lower quality of life.

Table 4: t-test for Quality of Life among the Parents of Children with Type 1 Diabetes Mellitus based on Parents' Gender.

	Sex	N	Mean	Std. Deviation	t	P value
Quality of Life	Female	219	90.0639	8.65260	1.78	.085
	Male	119	91.7479	8.37796		

The Quality of Life among Parents of Children with Type 1 Diabetes Mellitus: The t value achieved is 1.78 ($p > 0.05$), as the above table demonstrates. At the 0.05 level of significance, the t values are greater than the table value of 1.96. This indicates that there is no significant difference between the parents of children with type 1 diabetes mellitus who are male or female. Therefore, it may be said that the quality of life experienced by male and female parents is equal.

Table 5: ANOVA test for Quality of Life among the Parents of Children with Type 1 Diabetes Mellitus based on Marital Status

Quality of Life	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	923.103	2	461.551	6.470	.002
Within Groups	23899.087	335	71.341		
Total	24822.189	337			

The above table describes the F value obtained for quality of life among parents of children with type 1 diabetes mellitus as 6.47 ($p < 0.05$), and these F values are greater than the table value 4.60 at the 0.05 level of significance. That means there is a significant difference in the Quality of Life among parents of children with type 1 diabetes mellitus based on the marital status of the parents. To find out the difference among the marital statuses, Scheffer's post hoc test was applied for analysis.

Table 5.1: Scheffe post hoc test Quality of Life among the Parents of Children with Type 1 Diabetes Mellitus based on Marital Status

Marital Status	N	Subset for alpha = 0.05	
		1	2
Widowed	7	79.4286	
Divorced/separated	6		89.0000
Married and stays with the spouse	325		90.9292

Table 7.1 indicates the Scheffe post hoc test of quality of life based on the marital status among parents of children with type 1 diabetes mellitus. The parents who are married and stay with their spouse category have reported a high mean score (57.60) compared to other marital categories. So, it can be concluded that there is an increased level of Quality of Life among the parents who live together.

DISCUSSION

The current study set out to evaluate the quality of life for parents whose children had been diagnosed with type 1 diabetes. type 1 diabetes mellitus is a chronic, lifelong illness. The family is the one who has to take care of their sick child the most. According to the current study, parents of children with type 1 diabetes mellitus showed a marked decline in their quality of life. According to Witt et al.

(2010), parents of children with chronic illnesses reported worsening mental health problems and a lower quality of life for their children. Diabetes mellitus type 1 is regarded as a chronic condition that has an adverse impact on the administration of health care (Ozyazıcıoğlu, Avdal and Sağlam, 2017). The primary determinants of the diabetes-related quality of life for parents of children with type 1 diabetes mellitus have been found to be family support and glucose management (Hirose, Beverly and Weinger, 2012). Concerns regarding their children's diabetes problems are a persistent concern for parents of children diagnosed with type 1 diabetes mellitus (Hilliard, Herzer, Dolan and Hood, 2011). A similar result was found in a study by Toledano-Toledano et al., (2020) based on the WHO Quality of Life BREF tool, which found that 59.1 percent reported average or average overall quality of life. and then 33.2 percent reported high overall quality of life and 6.7 percent reported low quality of life among parents of children with chronic conditions. Wiedebusch, Pollmann, Siegmund, and Muthny (2008) found moderate parental quality of life for parents of children with hemophilia. Spezia Faulkner and Clark reached a similar conclusion (1998); Keklik, Bayat and Bağdaş (2020), where the author observes at the average quality of life of parents of children with type 1 diabetes. Hilliard, Herzer, Dolan, and Hood, (2011) documented that parental care for children with diabetes complications affected the quality of life of parents of children with type 1 diabetes.

The results of the current study showed that parents of children with type 1 diabetes mellitus reported higher levels of quality of life in the physical, social, and environmental domains. When compared to other quality of life domains, the psychological quality of life domain has demonstrated a lower quality of life. Keklik, Bayat, and Bağdaş (2020) reached

a similar conclusion about the average psychological quality of life of parents of children with type 1 diabetes. Mahani, Rostami, and Nejad (2013) note that the psychological domain of parents' quality of life was related to their children's illnesses. Delamater et al. (2001) documented that psychosocial factors play an important role in the management of diabetes and in determining the quality of life of parents. Thorsteinsson, Loi, and Rayner (2017) described that increasing the psychological quality of life of parents of children with type 1 diabetes requires adequate parental social support. The same conclusion was reached by Yamada et al., (2012), where the author observes that the deterioration of the quality of life of parents related to mental health occurred in parents of children with developmental disorders. Koc, Bek, Vurucu, Gokcil and Odabasi (2019) found that the psychological health of parents of children with epilepsy impaired quality of life and was associated with a decrease in parental emotional well-being. The present study's parents who are married and stay with their spouse category have reported a high mean score (57.60) compared to other marital categories. So, it can be concluded that there is an increased level of Quality of Life among the parents who live together. The results of the study conducted by Toledano-Toledano et al. (2020) show that there is a significant difference in the marital status and quality of life of parents of children with chronic diseases. The results of the study by Uhm and Kim (2020) suggest a similar result, where the authors found a significant difference in the marital status and quality of life of parents of children with type 1 diabetes. The same conclusion was reached by Faulkner and Clark (1998), who found that parents of children living together reported a better quality of life compared to widowed, separated, and divorced parents.

A growing body of evidence suggests that caring for these children puts a strain on parents. Coping with the negative consequences of care delivery, developing and implementing realistic and appropriate response strategies is a major challenge. The stakeholders of chronic illness should also focus on the mental health of parents of children with type 1 diabetes mellitus. According to the aforementioned study results, parents frequently perceive that managing their child's type 1 diabetes mellitus has an adverse effect on their lives. The parents are unquestionably the centre of the family; they must not only manage the medical concerns of their ill child but also keep the house in order. Hence, it is the duty of mental health specialists to take on this task and offer care to this group that is both in need and vulnerable. In order to give parents of children with type 1 diabetes mellitus greater and more targeted support and interventions, policymakers must take these findings into consideration.

CONCLUSION

The study found that quality of life domains such as physical, social relationships and environment reported improvements in quality of life for parents of children with type 1 diabetes. The psychological domain of quality of life showed a decrease in quality of life compared to other domains of quality of life. To summarize, the findings of this study will assist various stakeholders, including policymakers, medical professionals, medical social workers, mental health specialists, and researchers, in comprehending the challenges faced by parents and caregivers. This will facilitate the development of programmes and initiatives aimed at promoting the psychosocial well-being of parents of children with chronic illnesses.

LIMITATIONS AND FUTURE SCOPE

This study has potential limitations. A limitation was the use of a cross-sectional design. The study did not take into account the history/profile of children with type 1 diabetes, which would have helped to compare the mental state of the parents and the health status of the child with type 1 diabetes. In the future, a study of parents of children with type 1 diabetes mellitus should be conducted on the condition of the children with a longitudinal study design, because type 1 diabetes mellitus is identified as a lifelong chronic illness and needs to be assessed through the psychosocial variables from time to time.

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