



Evaluation of Family Life Quality of Parents with Intellectual Disability Children

Çiğdem Müge Haylı^{1*} Dilek Demir Kösem,¹ Nazlı Melis Misyağcı²

¹Hakkari University, Faculty of Health Sciences, Department of Nursing, Hakkari, Turkey

²Bahçeşehir University, Faculty of Health Sciences, Department of Nursing, İstanbul, Turkey

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ABSTRACT

This study was conducted to evaluate the quality of family life of parents with intellectually disabled children and to emphasize its importance. It is a descriptive study. The study group of the research consisted of parents with intellectual disabilities children. The data required for the research are; It was collected by online survey (Google form) method from 300 parents who participated voluntarily and selected by simple sampling with written consent. The socio-demographic data collection form for parents and the Beach Center Family Quality of Life Scale (BCFQLS) were used to collect data, and t-tests and regression analysis were used in data analysis. It was concluded that the family quality of life perceptions of the parents participating in the study was moderate. However, it was determined that the quality of family life related to family interaction, parenting, emotional competence, physical/material/financial competence, and support for inadequacy was low. In the study, it was found that the variables of the number of children of the participating parents and the disability level of the disabled child had a significant effect on family interaction, parenting, emotional competence, financial/physical/material competence, and support for disability ($p < 0.05$). It has been concluded that the quality of family life of the parents is affected by many variables such as the disabled status of their children. Conducting research that will increase the family life quality of parents in the field will be guiding.

Keywords: Intellectual disability, family quality of life

INTRODUCTION

Having a disabled child negatively affects the lives, feelings, thoughts, and behaviors of family members. It requires the reorganization of the duties and activities of the parents, financial resources, and all their behaviors to cope with the needs of this new individual (Akandere, Acar, & Baştuğ, 2009; Soresi et al., 2007). Especially in families with intellectual disabilities children, health problems such as anxiety, depression, emotional distress, low self-esteem, and stress are more advanced than in families with normal children (Hastings & Brown, 2002). Changing mood with anxiety, depression and stress reduces the individual's life satisfaction and affects the quality of life (Aysan & Özben, 2007). While the concept of quality of life is defined as the whole of subjective perception, emotion, and cognition processes based on the individual's self-evaluation, it is an expression of individual well-being and includes subjective satisfaction statements regarding various aspects of life. The quality of life scale provides information on

psychological health, general health, satisfaction with life, general health, quality of life, physical health, and social and environmental areas (Çivi, Kutlu, & Çelik, 2011).

Despite the long history of studies on quality of life, the majority of studies focused on measuring the individual quality of life and the concept of family quality of life has recently attracted attention (Aydiner-Boylu, 2007). The family life quality of individuals with disabilities is developing as an important area of research (Bertelli, Bianco, Rossi, Scuticchi, & Brown, 2011). Researchers suggest that parents of intellectually disabled children are more vulnerable to physical and mental problems and have a lower quality of life (Şipos, Predescu, Mureşan, & İftene, 2012). An undeniable goal of services for individuals affected by disabilities and their families is to improve their quality of life by increasing their life satisfaction. The main goals of educators and researchers are to help parents get more satisfaction from their personal lives and to help their children get more satisfaction from their own lives so that they can better help their intellectually disability children (Milgram & Atzil, 1988).

The physical, mental and social changes caused by the mental child and his family have led to the discussion of the quality of life of these people. It has been found that there are a limited number of studies examining and evaluating the quality of life of families with intellectual disabilities children (Erdoğanoglu & Kerem-Günel, 2007). For these reasons, it is thought that

*Corresponding Author's Email: mugehayli@hakkari.edu.tr

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effective solutions can be produced for the psychological and social problems experienced by families with disabled children by determining how and in which areas the quality of life of families with disabled children are affected, with the study planned to cover all disability groups. In addition, legal regulations, social services, education services, etc. are to be provided for intellectually disabled children and their families. He is also expected to guide in planning and program development studies in his fields. In addition, increasing the quality of life of intellectually disabled children and their families may enable families who play a very important role in the rehabilitation of disabled children to deal with their children more effectively, and may contribute positively to their adaptation to society and their future lives.

This study aims to evaluate the quality of family life of parents with intellectually disabled children and to emphasize its importance.

METHOD

Design: It was a descriptive study to evaluate the quality of family life of parents of a children with intellectual disabilities and to emphasize their importance.

Participants: The research population consisted of parents with intellectual disabilities children. The sample is in the provinces of Istanbul and Hakkari with an intellectual disability child; It was collected online (Google Form) between 09 August 2022 and 31 November 2022 from 300 parents who participated voluntarily and were selected by simple sampling method with written consent. Parents were reached through social media and Whatsapp groups, and a link to the data collection tools regarding their participation in the research and their completion was shared.

Research Questions: Is there a relationship between sociodemographic characteristics (mother/father, age, marital status, educational status, employment status, number of children, disability level of the child with mental retardation, and educational status of the intellectually disability children) and family quality of life of parents with intellectual disability children?

Research inclusion criteria:

- Parents with mentally disabled children
- Parents who are willing and willing to work
- Parents filling out the informed consent form

Study exclusion criteria

- Parents who do not have mentally disabled children
- Parents who do not accept to participate in the study voluntarily and willingly
- Parents who did not complete the informed consent form

Tools Used for Data Collection

- Socio-demographic Data Collection Form for Parents
- Beach Center Family Quality of Life Scale (BCFQLS)

Socio-Demographic Data Collection Form for Parents: This form; consists of 8 questions about age, marital status, educational status, employment status, number of children, disability level of the child with mental retardation, and

educational status of the intellectually disabled children, who filled out the data collection form (Mother/Father).

Beach Center Family Quality of Life Scale (BCFQLS): BCFQLS was developed by the University of Kansas Beach Disability Center (Beach Center on Disability, 2006). The Turkish adaptation, validity, and reliability studies of the scale were carried out by Meral & Cavkaytar (2013). BCFQLS is a data collection tool consisting of 25 questions, 5 sub-domains, and five-rating type answers to determine the quality of life of families with children with developmental disabilities. BCAYKQ assesses the family quality of life as a whole (25 questions, Cronbach's alpha = .94) and "Family Interaction (6 questions, Cronbach's alpha = .92)", "Parenting (6 questions, Cronbach's alpha = .88)", "Emotional Competence (4 questions, Cronbach's alpha = .80)", "Financial/Physical/Material Competence (5 questions, Cronbach's alpha = .88)" and "Support for Disability (4 questions, Cronbach's alpha = .92)" sub-domains of "satisfaction" and provides information based on the perception of 'importance'. While 'satisfaction' and 'importance' perceptions related to the quality of life variables of families with children with special needs can be measured together, only 'satisfaction' perception can be measured based on the initial development of the scale. The highest score that can be obtained for the whole of the BCFQLS is 125 (25x5) points, and the lowest score is 25 (25x1) points. High scores obtained from the scale without negative items indicate a high level of family quality of life perception, and low scores indicate a low level of perception. The perception of family life quality can be calculated according to the total scores obtained from the scale, or it can also be calculated by dividing the total score obtained by the number of items (Akın, Abacı, & Çetin, 2007). Accordingly, for a 5-point Likert-type scale; 1 is the lowest, 2 is low, 3 is medium, 4 is high, 5 is the highest, and those with a score below 3 can have low family life quality perceptions, and those with a higher score can be evaluated as high. For example, it can be said that the person's perception of family quality of life is high because the 4 points obtained by dividing the 100 points obtained from the whole scale by the number of items 25 (100/25=4) are above 3 points.

Independent Variable: Mother/Father, age, marital status, educational status, profession, family structure, number of children, gender of the mentally disabled child, age, educational status, diagnosis of the child, disability status.

Dependent variable: Family interaction, parenting, emotional competence, financial/physical/material ability, disability support

Statistical Analysis: SPSS (Statistical Package for Social Sciences) 26.0 package program was used in the analysis of the data. T-tests and regression analysis were used to evaluate the family quality of life of parents with intellectual disabilities children.

RESULTS AND DISCUSSION

Eighty percent of the parents participating in the study are mothers and 20% are fathers. When analyzed according to age

groups, 58.7% of them are 30-34 years old and 17.3% of them are 35 years old and over. 92% of them are married and 8% are single-parent families. 10.7% of the participants graduated from primary school and 43.7% from secondary school. 80.3% of them are working and 19.7% are non-working (housewives, unemployed, etc.). It was stated that 3% had only one child, and 55% had 2 children. 65.7% of parents' children have "moderate" disabilities and 10.7% of them are "high/severe" disabled. 10.7% of children with disabilities continue their education and 36% attend a guidance and research center (Table 1).

It was determined that the total score of the parents' family quality of life was 65.72. This result shows that the perception of family quality of life is moderate. The sub-dimensions of the family quality of life scale of parents with intellectually disabled children are related to the "medium level", "parenting, emotional competence, physical/material/financial competence" and "support for disability" dimensions of the quality of life-related to "family interaction". low level" (Table 2). The sub-dimensions of the family quality of life scale of parents with intellectually disabled children are related to the "medium level", "parenting, emotional competence, physical/material/financial competence" and "support for disability" dimensions of the quality of life-related to "family interaction". low level" (Table 2). This finding is in line with the studies conducted by Jin-Ding et al., (2009), in which they examined the quality of life and the factors affecting the quality of life of the caregivers of intellectually disabled children and adolescents in Taiwan, and Tunç (2011)'s the study of families with intellectual disability children. It is similar to the research that examined the factors affecting the quality of life. Similarly, in the study conducted by (Shu & Lung, 2005), it was determined that immigrant Chinese families living in the United States who have children with mental/developmental disabilities and autistic disorders have low perceptions of family quality of life.

As a result of the research, it was revealed that there was no difference between the means of the Family Quality of Life Scale sub-dimensions according to the participating parents ($p>0.05$) (Table 3). (Yıldırım and Conk, 2005)'s research (mothers 80.0%; fathers 20.0%); (Çam & Özkan, 2009)'s research (mothers 87.8%; fathers 12.2%); The study (Zincir et al., 2010) conducted together (mothers 87.8%; fathers 12.2%) and (Hidroğlu et al., 2013) conducted together (mothers 85.7%; fathers) 14.3% shows parallelism with the results that there is no difference between the averages of the sub-dimensions of the family quality of life scale. Fathers and mothers differ in their perception of health and care services. The father is less involved in the treatment of the child than the mother (Özşenol et al., 2003). This situation can be explained by the fact that the father, who has to provide for the family, works and is in business life, and the mother plays a greater role in the care and education of the child compared to the father.

In the study, it was found that the difference between the averages of "emotional competence" and "support for inadequacy" of those who were single parents and those who were single parents and those who continued their marriage was

Table 1. Socio-Demographic Characteristics of Parents

Variables	Variable category	f	%
Parents	Mother	240	80,0
	Father	60	20,0
Age group	25-29 age	72	24,0
	30-34 age	176	58,7
	35 age and over	52	17,3
Marial status	Single parent	24	8,0
	Married	276	92,0
Education level	Primary education	32	10,7
	Middle School	131	43,7
	High school	87	29,0
	High education	50	16,7
Working status	Not work	241	80,3
	Worker	59	19,7
Number of child	1 child	9	3,0
	2 chilf	165	55,0
	3 child	78	26,0
	4 and over child	48	16,0
Child's disability level	So light	71	23,7
	Light	197	65,7
	Heavy	32	10,7
Education level of the disabled child	Discontinued	32	10,7
	Special education school	93	31,0
	Private rehabilitation center	65	21,7
	RAM (Guidance and research center)	110	36,7

Table 2. Family Quality of Life

Domains	Total point	Std. Defl. ^a	\bar{X}	SD	Result
Family interaction	18,13	0,32	3,02	0,05	Intermediate
Parenthood	14,64	0,34	2,44	0,06	Low level
Emotional competence	10,16	0,22	2,54	0,06	Low level
Physical/material/financial Competence	12,72	0,31	2,54	0,06	Low level
Support for Disability	10,06	0,26	2,52	0,06	Low level
Grand Total	65,72	0,87	2,63	0,03	Intermediate

Table 3. Sub-Dimensions of Family Quality of Life of Parent

	Parents	\bar{X}	Std. Deflection	t	p
Family interaction	Mother	18,11	5,60	-0,129	0,897
	Father	18,22	5,51		
Parenthood	Mother	14,97	5,91	1,953	0,052
	Father	13,30	6,00		
Emotional competence	Mother	10,19	3,74	0,254	0,800
	Father	10,05	4,32		
Physical/material/financial/Competence	Mother	12,61	5,18	-0,730	0,466
	Father	13,18	6,46		
Support for Disability	Mother	10,02	4,49	-0,335	0,738
	Father	10,23	4,40		

significant ($t=3.487$; $p<0.05$: $t=-3.413$; $p<0.05$). This finding shows that the family life quality of single parents related to emotional competence is higher and the average differs from the married ones. On the other hand, it was found that the quality of family life of single-parent families related to support for disability was lower than those of married ones and their averages differed, and there was no difference between the averages of family interaction, parenting and physical competence dimensions ($p>0.05$) (Table 4). The results of these findings are compatible with the results of a study conducted by Karadağ (2009) to determine the difficulties experienced by mothers with a disabled child, perceived social support from the family, and their hopelessness, and our findings that the quality of life of single parents is low. In the study conducted by Tunç (2011) in which he examined the factors affecting the quality of life of mothers with intellectually disabled children, when multiple comparisons were examined according to marital status, according to Whoqol-Bref 0-20, there was a statistically significant difference between married mothers and widowed mothers in social area quality of life. a significant difference was found. However, in the social area of quality of life, it was determined that the quality of life of married mothers was significantly lower than the quality of life of mothers whose spouses had died. These results are not similar to our research findings.

Table 4. Marital Status and Family Quality of Life

	Marital Status	\bar{X}	Std. Deflection	t	p
Family interaction	Single	16,83	5,77	-1,193	0,234
	Married	18,25	5,55		
Parenthood	Single	13,42	5,90	-1,046	0,296
	Married	14,74	5,96		
Emotional competence	Single	12,75	3,89	3,487	0,001
	Married	9,94	3,78		
Physical/material/financial Competence	Single	14,54	7,24	1,708	0,089
	Married	12,57	5,26		
Support for Disability	Single	7,13	3,29	-3,413	0,001
	Married	10,32	4,47		

Table 5. Family Quality of Life & Working Or Not Statous

	Work Status	\bar{X}	Std. Deflection	t	p
Family interaction	Not work	17,64	5,44	-3,153	0,002
	Worked	20,15	5,68		
Parenthood	Not work	14,59	5,95	-0,303	0,762
	Worked	14,85	6,04		
Emotional competence	Not work	9,81	3,72	-3,225	0,001
	Worked	11,59	4,13		
Physical/material/financial Competence	Not work	12,31	5,00	-2,672	0,008
	Worked	14,91	6,82		
Support for Disability	Not work	9,32	3,72	-6,184	0,000
	Worked	13,10	5,84		

It was found that the difference between the averages of family interaction, emotional competence, physical/material/financial competence, and support for the inadequacy of working and non-working parents was significant ($p<0.05$). The result was in favor of the parents. However, it was found that there was no difference between the mean family life quality of parenting according to employment status ($p>0.05$) (Table 5). As a result of his study (Meral, 2011), it was found that there is a difference between the income level, the mother's working status, and the place of residence variables in predicting the family's perception of family quality of life. This finding is in parallel with our findings. In the study conducted by (Altun, 2010), the difference between the physical, mental, and social quality of life scores of the occupational groups of the mothers with intellectually disabled children was not significant. The difference between working and non-working mothers in the private sector was found significant. In the study, it was observed that there was a significant decrease in the mean quality of life score from mothers who were civil servants to mothers who were housewives. These results are not similar to our research findings.

Table 6. Socio-demography and Child's Disability Level and Family Quality of Life

	B	Std. Deflection	Beta	r	t	Sig.
Constant	17,48	2,294			7,592	0,000
Level of age	0,423	0,475	0,050	0,083	0,890	0,374
Education level (Parents)	0,555	0,337	0,091	0,084	1,647	0,101
Number of child	-,892	0,379	-0,130	-0,115*	-2,351	0,019
Education level	0,148	0,478	0,017	-0,036	0,309	0,758
Disability level	-,903	0,538	-0,305	-0,295*	-5,40	0,000
	F =7,718; $p<0,05$		R ² =0,116; $p<0,05$			

As a result of the analysis, it was found to be significant ($F=7.718$; $p<0.05$). In the study, it was found that the variables of the number of children of the participating parents and the disability level of the disabled child had a significant effect on family interaction, parenting, emotional competence, financial/physical/material competence, and support for disability ($p<0.05$). The effects of age, education level, and educational status of the disabled child on family quality were found to be insignificant ($p>0.05$). As the number of children of the parents participating in the research and the disability level of the disabled child increase, the quality of family life related to family interaction, parenting, emotional competence, financial/physical/material competence, support for disability decreases, and the effect of the parent's education level on the quality of family life is 11.6%.

It was determined that the education level of the parents had an effect ($R^2=0.116$; $p<0.05$) (Table 6). This finding was determined in the study (Hu et al., 2012) which aimed to determine the perception of family quality of life of Chinese families with children with intellectual disabilities, and it was determined that family household income was an important predictor of family quality of life. (Deveci Şirin, 2014) in his

study examining the perceived family quality of life of families with children, found that the higher the income level of the families, the higher the family members' perception of their quality of life in the areas of family interaction, emotional competence, and financial well-being. (Özyurt, 2011) found in the study conducted by mothers with mildly intellectual disability children that the "Family Interaction", "Parenting" and "Physical-material well-being" Family Quality of Life subscale scores differed significantly in terms of family income, which is consistent with our results

CONCLUSION

It has been concluded that the quality of family life of the parents is affected by many variables such as the disabled status of their children. According to the provisions of the relevant laws and regulations, which are thought to have positive reflections on the improvement of the quality of life of the families of disabled children, the number of care fees and pensions paid to families in cash due to their children should be higher, they should be adapted to the conditions of the day and increased regularly. From the moment the child is diagnosed and the family starts special education centers and institutions, a team of experts from different disciplines working in the field should evaluate and monitor the physical, social, mental, and environmental health conditions of the families of children with disabilities, appropriate intervention methods should be developed in the face of the detected problems, necessary persons and It should be tried to find solutions to their problems by getting the support of institutions, psycho-social support should be provided to the family, they should be guided and necessary studies should be carried out to increase their quality of life.

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REFERENCE

- Akandere, M., Acar, M., & Baştuğ, G. (2009). Examination of Life Satisfaction and Hopelessness Levels of Parents with Mentally and Physically Handicapped Children. *Selcuk University Journal of Social Sciences Institute*, 22:23-32.
- Aydiner-Boylu, A. (2007). Examination of Some Objective and Subjective Indicators Affecting Families' Quality of Life, (*Unpublished doctoral dissertation*), Hacettepe University/Social Sciences Institute, Ankara.
- Aysan, F., & Ozben, S. (2007). Examination of Variables Related to Quality of Life of Parents with Disabled Children. *Dokuz Eylül University Buca Education Faculty Journal*, 22:1-6.
- Beach Centre on Disability at the University of Kansas (2006). In partnership with families, service providers, and researchers. *Family Quality of Life Survey*. Beach Center: University of Kansas.
- Bertelli, M., Bianco, A., Rossi, M., Scuticchio, D., & Brown, I. (2011). Relationship between individual quality of life and family quality of life for people with intellectual disability living in Italy. *Journal of Intellectual Disability Research*, 55(12):1136-1150.
- Erdoğanoglu, Y., & Kerem-Günel, M. (2007). Investigation of Health-Related Quality of Life of Families of Children with Cerebral Paralysis. *Bulletin of Community Medicine*, 26(2):35-39.
- Hastings, R. P., & Brown, T. (2002). Behavior Problems of Children with Autism, Parental Self-Efficacy, and Mental Health. *American Journal on Mental Retardation*, 3(107):222-232.
- Meral, B. F. (2011). Investigation of Family Quality of Life Perceptions of Mothers of Children with Developmental Disabilities, (*Unpublished doctoral dissertation*), Anadolu University/Institute of Educational Sciences, Eskişehir.
- Meral, B. F., & Cavkaytar, A. (2013). Turkish Adaptation, Validity and Reliability Study of the Beach Centre Family Quality of Life Scale. *Education and Science*, 38(170):48-60.
- Milgram, N. A., & Atzil, M. (1988). Parenting Stress in Raising Autistic Children. *Journal of Autism and Developmental Disorders*, 3(18):415-424.
- Nail, S., Kutlu, R., & Celik, H. H. (2011). Depression and factors affecting quality of life in relatives of cancer patients. *Gülhane Medical Journal*, 4(53):248-253.
- Şipoş, R., Predescu, E., Mureşan, G., & Iftene, F. (2012). The Evaluation of Family Quality of Life of Children with Autism Spectrum Disorder and Attention Deficit Hyperactive Disorder. *Applied Medical Informatics*, 30(1):1-18.
- Soresi, S., Nota, L., & Ferrari, L. (2007). Considerations on Supports That Can Increase the Quality of Life of Parents of Children with Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4(4):248-251.