





Determination of the Quality of Life of Parents with Children Treated in the Pediatric Oncology Clinic during the COVID-19 Pandemic and **Affecting Factors**

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Abstract

Introduction Even in the absence of a pandemic, pediatric oncology patients have decreased immunological levels. This condition requires families to monitor their children's risk of infection on a frequent basis. The possibility of being exposed to coronavirus disease 2019 (COVID-19) in a hospital or community environment has created significant concern among cancer families.

Objectives This study sought to ascertain the quality of life of parents who sought treatment for their children at a pediatric oncology clinic during the COVID-19 epidemic, as well as the factors that influenced it.

Materials and Methods This cross-sectional study included 62 parents with children ages 0 to 19 who receive treatment for their children at the pediatric oncology clinic of an application and research center in Turkey's Western Black Sea area. "The Participant Information Form" and "The Scale of Quality of Life-Family Version (QOL-FV)" were used to collect data. The researchers used the face-to-face interview approach to obtain data. To investigate the differences in scale levels based on the descriptive characteristics of the parents, one-way analysis of variance, t-test, and post hoc (Tukey, least significant difference) analyses were used.

Results The total mean score of the parents' QOL-FV was found to be 148.097 ± 25.843 (87–258). In the study, it was determined that financial difficulties, difficulties in accessing the hospital during the treatment process, and changes in daily activity/behavior had negative effects on parents' quality of life.

Conclusion Most of the parents who participated in our study stated that their quality of life got worse with the pandemic. It was determined that the COVID-19 pandemic had effects on the quality of life of parents of pediatric oncology patients in various ways.

Keywords

- ► COVID-19
- ► quality of life
- ► child
- cancer

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Introduction

The public health measures necessary to reduce viral spread, pose a major threat to children with medical complexity, especially to pediatric oncology patients. ^{1,2} Childhood cancers are curable when correct diagnosis and appropriate treatment are provided on time. ³ Children with cancer often require long-term intensive chemotherapy. ⁴ They are at risk for reduced response rates, worsening disease prognosis, and disease relapse due to delays, interruptions, or significant changes in their treatment. ³ Although the real impact of coronavirus disease 2019 (COVID-19) on children undergoing treatment for cancer is still unknown, it is advised that standards of diagnosis, treatment, and supportive care remain unchanged during the pandemic. ⁴⁻⁷

Pediatric oncology patients have suppressed immune levels even without a pandemic. This condition forces families to regularly manage their children's risk of infection.⁸ It is assumed that children with cancer are more susceptible to COVID-19.9 Virus infections are also linked to higher mortality and morbidity in immunocompromised children. 10 As a result, the potential of COVID-19 exposure in hospital or community settings has created substantial concern among cancer families.4 It has been determined that parents of pediatric oncology patients face a high psychological risk as a result of COVID-19-induced posttraumatic symptoms, high stress, and anxiety levels. 11 Lack of information about COVID-19, increased precautions due to fear of infection, concerns about the change of treatment and going to hospital, future uncertainty of COVID-19, and its psychosocial and economic impacts negatively influence the quality of life (QOL) of parents. 12,13

Pediatric oncology nurses are of great importance in coordinating the child's care and identifying their needs.² However, the health of the child is closely related to the health of the caregivers as a result of the family-centered approach, which is the most important component of pediatric care.¹⁴ Nurses should consider not only the child's but also the emotional and social needs of the family.¹⁵ Therefore, this study was carried out to examine the QOL of parents whose children were treated in a pediatric oncology clinic during the COVID-19 process and to determine the affecting factors.

Materials and Methods

Design, Population, and Sample

The research is a descriptive study to determine the QOL of parents who applied to the pediatric oncology clinic for the treatment of their children during the COVID-19 pandemic and to determine the affecting factors. The study's population included 62 parents with children aged 0 to 19, were literate and applied to the pediatric oncology clinic of an application and research center in the Western Black Sea region of Turkey between June 1, 2021 and January 1, 2022 for the treatment of their children. Sample selection was not made. Only the universe was studied. Inclusion criteria for family caregivers in the study were as, having a child aged 0

to 19 and receiving cancer treatment, being able to read and write, and having no psychiatric diagnosis. The exclusion criteria were to refuse to participate in the study.

Data Collection Tools

To collect data, the "Participant Information Form" and "The Scale of Quality of Life Family Version (QOL-FV)" were utilized. The researchers collected data using the face-to-face interview approach in the pediatric oncology service of the application and research hospital during working hours between the study periods.

Participant Information Form

Based on the literature, the researchers developed this form, which comprised 45 questions regarding the sociodemographic features of parents and their children, their present disease, and treatment-related status. 12,16

The Scale of Quality of Life Family Version

The scale developed by Ferrell and Grant was adapted into Turkish by Okçin and Karadakovan. 17,18 Physical health, psychological health, social issues, and spiritual well-being are the four subdimensions of the 37-item measure. The study's test–retest reliability was $r\!=\!0.86$, and the internal consistency Cronbach's alpha value was $r\!=\!0.90$. The scale's scoring ranges from 0 to 10. The total score and subdimension scores are used to interpret the scale, and a high score indicates a high QOL. 18 The Cronbach's alpha value of the scale was found to be 0.817 in our study.

Data Analysis

The research data were analyzed in a computer environment using the SPSS 24.0 statistical program. ¹⁹ The frequency and percentage analyses were used to identify the descriptive features of the parents, and the scale was examined using mean and standard deviation statistics. The normal distribution of the research variables was discovered. Parametric approaches were used to examine the data. The links between the dimensions that affect the scale levels of the parents were investigated using correlation and regression analysis. To evaluate variations in scale levels depending on the descriptive features of the parents, t-tests, one-way analysis of variance, and post hoc (Tukey and least significant difference) analyses were utilized. The findings were evaluated within a 95% confidence range, with p < 0.05 considered significant.

Ethical Considerations

The Human Research Ethics Committee of Zonguldak Bülent Ecevit University granted permission to perform the research (Decision No: 30.04.2021/43431, Protocol no: 191). The institution where the research was conducted provided the necessary institutional permission. Prior to the study, participants were asked to sign informed consent forms. All methods in studies involving human subjects were carried out in line with the institutional and/or national research committee's ethical standards, as well as the 1964 Helsinki Declaration and its subsequent revisions or similar ethical standards.

Results

When the sociodemographic characteristics of the parents constituting the sample of the study were examined, it was determined that 32.3% of the mothers were 35 years old and younger, 32.3% were between 36 and 40 years old, and 35.5% were 40 years old and older. The mothers' educational level was 45.2% high school graduates and 30.6% associate degree graduates. It was determined that 32.3% of the mothers were employed, 67.7% were housewives/retired, and 90.3% did not have a chronic disease. It was found that 17.7% of the fathers of the children were 35 years old and younger, 30.6% were between 36 and 40 years old, and 51.6% were 40 years old and older, 38.7% were university graduates, 98.4% were employed, and 96.8% did not have a chronic disease. It was found that 66.1% of the parents had another child/children at home, 48.4% had a lower income than their expenses, 51.6% had an income equal to their expenses, and 53.2% resided in a district/town, and 12.9% had another patient/elderly dependent at home.

When the sociodemographic characteristics of the children participating in the study were examined, 58.1% were boys, 22.6% were between the ages of 1 and 3, 30.6% were between the ages of 4 and 6, 27.4% were between the ages of 7 and 12, and 19.4% were between the ages of 13 and 18. It was determined that 56.5% of those who cared for a sick child at home were mothers, while 43.5% were parents together. Note that 41.9% of the families did not reside in the same city as the hospital where they were treated, and 67.7% provided transportation by their own vehicle and 12.9% by taxi. Also, 43.5% of the children were under treatment for the diagnosis of acute lymphoblastic leukemia and 59.7% were inpatients.

The distribution of parents according to the COVID-19 pandemic and related problems is given in **►Table 1**. The QOL-FV mean scores of the parents were found to be 148.097 ± 25.843 (87–258). When the subdimensions of the scale were examined, mean score of "physical health" was determined to be 26.919 ± 7.521 (13–42), "psychological health" 59.871 ± 12.775 (32–107), "social concerns" 61.307 ± 13.388 (39–122), and "spiritual well-being" $6.177 \pm 2.207 (2-10) (
ightharpoonup Table 2).$

When the difference between the scores of the QOL-FV according to the sociodemographic characteristics of the parents was examined, the total QOL scores of those who did not have other children (x = 138.571) were found to be lower than those who had, and a significant difference was found between them (p = 0.037 < 0.05). The social concerns scores of those who did not have other children were found to be lower than those who had (p = 0.05). The social concerns (p = 0.027 < 0.05) and spiritual well-being (p = 0.018 < 0.05)scores of the parents who did not have dependent patients were lower than those of the parents who did. The total QOL-FV (x = 139.694) (p = 0.004 < 0.05), psychological health (p = 0.004 < 0.05) = 0.007 < 0.05), and social concerns (p = 0.014 < 0.05) scores of those who did not reside in the same city with the hospital where the treatment took place were higher than those who resided in the same city (>Table 3).

Table 1 Distribution of parents by COVID 19 and related problems

Variables	n	%					
Diagnosis of COVID-19 in child's family							
No	43	69.4					
Yes	19	30.6					
Experiencing financial difficulty due to COVID-19							
No	14	22.6					
Yes	48	77.4					
Having challenges in the treatment of tl COVID-19	ne child du	ie to					
No	18	29.0					
Yes	44	71.0					
Delay/cancellation of the child's checkup to COVID-19	appointm	ents due					
No	46	74.2					
Yes	16	25.8					
Change/Cancellation in child's treatment due to COVID-19							
No	52	83.9					
Yes	10	16.1					
Transportation difficulties due to COVID	-19						
No	29	46.8					
Yes	33	53.2					
Inability to access medicine due to COV	ID-19						
No	61	98.4					
Yes	1	1.6					
Behavior changes in parents due to COV	′ID-19						
No	34	54.8					
Yes	28	45.2					
Daily activity changes in parents due to COVID-19							
No	34	54.8					
Yes	28	45.2					
Thinking that the pandemic process affected quality of life							
My quality of life did not change.	23	37.1					
My quality of life got worse with the pandemic.	39	62.9					
Total	62	100.0					

Abbreviation: COVID-19, coronavirus disease 2019.

In the study, when the scores of the QOL-FV were examined according to the descriptive characteristics of the child and treatment methods, the physical health score of girls were lower than that of boys (p = 0.005 < 0.05). The physical health scores of the outpatients were higher than those of the inpatients (p = 0.003 < 0.05) ($rac{\text{Table 4}}$).

QOL-FV of children with COVID-19 in the family was found to be lower than that of children without a COVID-19 diagnosis at home (p = 0.028 < 0.05). The social concerns ratings of individuals without a COVID-19

	n	Mean	SD	Minimum	Maximum		
Scale total score mean	62	148.097	25.843	87	258		
Subdimensions							
Physical health	62	26.919	7.521	13	42		
Psychological health	62	59.871	12.775	32	107		
Social concerns	62	61.307	13.388	39	122		
Spiritual well-being	62	6.177	2.207	2	10		

Table 3 Variation of the Quality of Life Family Version (QOL-FV) scores of parents by sociodemographic characteristics

Variables	n	Quality of life total mean \pm SD	Physical health mean \pm SD	Psychological health mean \pm SD	Social concerns mean ± SD	Spiritual well-being mean ± SD		
Presence of other	Presence of other children at home							
No	21	138.571 ± 22.342	24.810 ± 6.824	57.095 ± 12.930	56.667 ± 10.047	5.667 ± 2.153		
Yes	41	152.976 ± 26.398	28.000 ± 7.710	61.293 ± 12.616	63.683 ± 14.345	6.439 ± 2.214		
t		-2.137	-1.601	-1.230	-2.000	-1.312		
р		0.037	0.115	0.224	0.050	0.195		
Family income	Family income							
Income is less than expenses	30	142.900 ± 16.612	25.767 ± 7.408	58.400 ± 10.371	58.733 ± 7.710	6.433 ± 1.832		
Income is equal to expenses	32	152.969 ± 31.708	28.000 ± 7.582	61.250 ± 14.712	63.719 ± 16.872	5.938 ± 2.514		
t		-1.551	-1.172	-0.876	-1.480	0.883		
р		0.121	0.246	0.384	0.144	0.376		
Presence of other	patien	ts/elderly dependent						
No	54	146.241 ± 23.081	27.241 ± 7.658	59.130 ± 11.845	59.870 ± 11.380	5.926 ± 2.171		
Yes	8	160.625 ± 39.756	24.750 ± 6.541	64.875 ± 18.083	71.000 ± 21.401	7.875 ± 1.727		
t		-1.484	0.872	-1.191	-2.268	-2.423		
р		0.143	0.386	0.238	0.027	0.018		
Residing in the same city as the hospital where the treatment took place								
No	26	159.731 ± 29.749	28.654 ± 7.761	64.923 ± 14.910	66.154 ± 15.470	6.615 ± 2.246		
Yes	36	139.694 ± 18.939	25.667 ± 7.191	56.222 ± 9.643	57.806 ± 10.553	5.861 ± 2.153		
t		3.238	1.561	2.790	2.528	1.337		
р		0.004	0.124	0.007	0.014	0.186		

Abbreviation: SD, standard deviation. (p<0.05)

diagnosis at home were found to be lower than those with a COVID-19 diagnosis at home ($p\!=\!0.034\!<\!0.05$). When the score of experiencing financial difficulties due to COVID-19 were compared with the scale scores, the total QOL-FV scores ($p\!=\!0.008\!<\!0.05$), psychological health scores ($p\!=\!0.014\!<\!0.05$), and social concerns scores ($p\!=\!0.029\!<\!0.05$) of families who did not experience financial difficulties due to COVID-19 were found to be higher than those who did. Social anxiety scores of parents who thought that their QOL did not change were found to be higher than those who did not ($p\!=\!0.02\!<\!0.05$) ($\sim\!$ **Table 5**).

Discussion

Cancer is a complicated and sometimes fatal disease that affects many parts of life and exposes patients and their families to a wide range of psychological and health-related issues.²⁰ The COVID-19 pandemic has a wide variety of consequences for parents who care for children with cancer.^{11,21,22} Compared to the studies in the prepandemic period, it was observed that the QOL-FV total scores of the parents who constituted the sample of our study were higher.^{23,24} However, the total QOL-FV scores of the parents in our study were found to be below the

Table 4 Variation of the Quality of Life Family Version (QOL-FV) scores according to children's descriptive characteristics and treatment types

Variables	n	Quality of life total mean $\pm\text{SD}$	Physical health mean ± SD	Psychological health mean \pm SD	Social concerns mean ± SD	Spiritual well-being mean \pm SD
Age						
1–3 y	14	143.214 ± 22.461	23.214±9.545	59.643 ± 12.616	60.357 ± 7.841	5.500 ± 2.175
4–6 y	19	141.632 ± 23.966	26.895 ± 5.980	56.421 ± 12.764	58.316 ± 13.246	5.947 ± 2.272
7–12 y	17	153.882 ± 22.613	29.294±7.856	62.471 ± 10.736	62.118 ± 12.108	6.765 ± 1.678
13-18 y	12	155.833 ± 34.701	27.917 ± 5.518	61.917 ± 15.716	66.000 ± 19.475	6.500 ± 2.747
t		1.218	1.841	0.792	0.845	0.995
р		0.311	0.150	0.503	0.475	0.402
Gender						
Girl	26	145.039 ± 31.041	23.615 ± 8.280	59.115 ± 15.050	62.308 ± 15.041	6.346 ± 2.244
Boy	36	150.306 ± 21.535	29.306 ± 5.971	60.417 ± 11.041	60.583 ± 12.227	6.056 ± 2.203
t		-0.789	-3.147	-0.393	0.497	0.509
р		0.433	0.005	0.696	0.621	0.613
Treatment type						
Outpatient	25	150.200 ± 18.385	30.240 ± 6.064	60.840 ± 11.564	59.120 ± 7.775	6.680 ± 1.994
Inpatient	37	146.676 ± 30.019	24.676 ± 7.649	59.216 ± 13.649	62.784 ± 16.057	5.838 ± 2.304
t		0.524	3.045	0.488	-1.058	1.489
р		0.602	0.003	0.627	0.294	0.142
Number of course treatment						
4 times and less	34	144.941 ± 26.122	26.088 ± 6.690	59.059 ± 12.964	59.794 ± 13.984	5.794 ± 2.422
5 times and more	28	151.929 ± 25.438	27.929 ± 8.437	60.857 ± 12.707	63.143 ± 12.631	6.643 ± 1.850
t		-1.061	-0.958	-0.548	-0.980	-1.523
р		0.293	0.342	0.585	0.331	0.133
Presence of another chronic disease						
No	59	148.441 ± 25.933	27.034 ± 7.536	59.780 ± 12.457	61.627 ± 13.604	6.203 ± 2.211
Yes	3	141.333 ± 28.184	24.667 ± 8.387	61.667 ± 21.733	55.000 ± 6.083	5.667 ± 2.517
t		0.462	0.529	-0.248	0.834	0.408
р		0.646	0.599	0.805	0.407	0.685

Abbreviation: SD, standard deviation.

(p < 0.05)

average. Approximately two-thirds of the parents participating in our study stated that their QOL got worse with the pandemic, and our results indicated that various factors during the COVID-19 pandemic period had effects on the QOL of families who had a child with cancer.

In the study, it was found that the QOL-FV score of parents with a family history of COVID-19 was surprisingly high compared to those without a family diagnosis of COVID-19. It is thought that this result may be coincidental or may be due to the difference in the methods of families coping with the disease.

In studies conducted before the pandemic and during the pandemic, it was revealed that parents with a child with cancer experienced financial difficulties.^{8,25-29} None of the parents in our study stated that their income was more than their expenses, and it was observed that the QOL of families

whose income was less than their expenses was already lower. In a study conducted with mothers of children with leukemia, it was found that mothers quitted their jobs in order not to transmit infection to their children, which led to economic difficulties, and therefore they had difficulty in taking their children to the hospital (finding a vehicle, etc.).²⁵ In the study conducted by Wimberly et al, 9% of caregivers of children receiving pediatric oncology treatment reported that they had transportation difficulties in order to arrive at their appointments on time. 12 In our study, it was observed that more than half of the parents (53.2%) had difficulties with transportation. Therefore, it is possible to say that the problem of transportation to the treatment center, which is closely related to financial difficulties, negatively affects the QOL of parents who have children receiving pediatric oncology treatment during the COVID-19

Table 5 Variation of the Quality of Life Family Version (QOL-FV) scores according to the problems families experienced due to COVID-19

Variables	n	Quality of life total mean \pm SD	Physical health mean ± SD	Psychological health mean \pm SD	Social concerns mean \pm SD	Spiritual well-being mean \pm SD		
Diagnosis of COVID-19 in the child's family								
No	43	143.349 ± 21.372	25.698 ± 7.186	58.721 ± 11.348	58.930 ± 10.003	5.977 ± 2.241		
Yes	19	158.842 ± 31.966	29.684 ± 7.718	62.474 ± 15.565	66.684 ± 18.163	6.632 ± 2.114		
t		-2.247	-1.969	-1.068	-2.165	-1.079		
р		0.028	0.054	0.290	0.034	0.285		
Experiencing financ	Experiencing financial difficulty due to COVID-19							
No	14	164.000 ± 34.331	25.286 ± 6.888	67.143 ± 14.507	71.571 ± 19.848	6.571 ± 1.910		
Yes	48	143.458 ± 21.059	27.396 ± 7.698	57.750 ± 11.544	58.313 ± 9.117	6.063 ± 2.292		
t		2.755	-0.923	2.525	3.559	0.757		
р		0.008	0.360	0.014	0.029	0.452		
Having difficulty in	the tr	eatment of the child	due to COVID-19					
No	18	152.333 ± 22.562	26.500 ± 8.515	61.778 ± 10.514	64.056 ± 13.050	5.833 ± 1.978		
Yes	44	146.364 ± 27.122	27.091 ± 7.175	59.091 ± 13.626	60.182 ± 13.508	6.318 ± 2.300		
t		0.823	-0.279	0.749	1.035	-0.783		
р		0.414	0.781	0.457	0.305	0.437		
Behavioral changes	in pai	rents due to COVID-1	9					
No	34	147.853 ± 21.545	26.059 ± 8.431	60.294 ± 10.182	61.500 ± 11.657	6.177 ± 1.914		
Yes	28	148.393 ± 30.682	27.964 ± 6.233	59.357 ± 15.540	61.071 ± 15.451	6.179 ± 2.554		
t		-0.081	-0.993	0.285	0.124	-0.004		
р		0.936	0.311	0.776	0.901	0.997		
Daily activity chang	es in	parents due to COVID)-19					
No	34	151.677 ± 28.355	26.765 ± 7.636	61.853 ± 12.943	63.059 ± 15.807	6.206 ± 2.115		
Yes	28	143.750 ± 22.147	27.107 ± 7.515	57.464 ± 12.369	59.179 ± 9.538	6.143 ± 2.353		
t		1.206	-0.177	1.355	1.138	0.111		
р		0.232	0.860	0.180	0.259	0.912		
Thinking that the pandemic process affected quality of life								
My quality of life did not change	23	153.739 ± 19.610	24.783 ± 8.107	62.565 ± 9.024	66.391 ± 11.011	6.304 ± 2.032		
My quality of life got worse with the pandemic	39	144.769 ± 28.615	28.180 ± 6.954	58.282 ± 14.417	58.308 ± 13.879	6.103 ± 2.326		
t		1.328	-1.747	1.282	2.383	0.345		
р		0.189	0.086	0.205	0.020	0.731		

Abbreviations: COVID-19, coronavirus disease 2019; SD, standard deviation. (p<0.05)

period. However, in our study, it is surprising that the total QOL of parents who did not reside in the same city with the hospital where the child was treated was higher than those who did.

As COVID-19 cases increased and governments implemented stay-at-home measures, applications to the hospital for treatment decreased significantly, and children were undoubtedly the population most affected by this situation caused by COVID-19.³⁰ In a study conducted in the United States, 26% of caregivers reported delay/cancellation in their pediatric oncology appointments during the pandemic.¹² In

our study, although the rate of delay/cancellation of control appointments (25.8%) was quite consistent with the study of Wimberly et al, the QOL of parents who had difficulties in the treatment process due to COVID-19 was found to be lower.¹²

Even if there is no pandemic, parents of cancer children must constantly monitor their child's infection risk. ⁸ Patients are at risk of getting several infectious infections due to the immunosuppressive effect of cancer and accompanying therapies. ³¹ Prior to the commencement of the pandemic, parents who participated in the Steinberg et al study said that their daily lives were packed with routines, and once

COVID-19 cases arose, they felt obliged to make modifications in their children's daily routines to safeguard them due to their medical issues.³² Additional variables, including as social distance and new daily behaviors adopted by parents of pediatric cancer patients as a result of COVID-19, were found to have a significant influence on parents' OOL in other research. 11,33 In line with the literature, our findings suggested that daily activity and behavioral changes caused by COVID-19 had a detrimental impact on parents' QOL.

Limitations

This research has some methodological limitations. Since all the data were collected during the pandemic period, a comparison with the same participants before the pandemic could not be made. We compared our study with other studies conducted before the pandemic. In addition, the results are limited to the sample group, clinic, and date in which the research was conducted.

Conclusion

The main findings of this study show that the COVID-19 epidemic has negative consequences on the QOL of parents of pediatric cancer patients. An examination of these issues offers a fresh perspective on how to improve parents' QOL during challenging times. The COVID-19 pandemic has had a substantial effect on pediatric cancer care, presenting an unprecedented global threat to the safe and effective care of children with cancer. More studies are required to quantify these challenges and to develop solutions that relieve the stress and suffering of those children and their families. With the outbreak of the COVID-19 epidemic, nurses have taken on increased obligations to ensure that parents spend this time with little physical and psychological harm.

Ethical Considerations

The Human Research Ethics Committee of Zonguldak Bülent Ecevit University granted permission to perform the research (Decision No: 30.04.2021/43431, Protocol no: 191). The institution where the research was conducted provided the necessary institutional permission. Prior to the study, participants were asked to sign informed consent forms. All methods in studies involving human subjects were carried out in line with the institutional and/or national research committee's ethical standards, as well as the 1964 Helsinki Declaration and its subsequent revisions or similar ethical standards.

Authors' Contributions

Concept: A.T., Z.A., Ö.Ö.Ş.; Design: A.T., Ö.Ö.Ş.; Literature search: A.T., Z.A.; Data acquisition: D.B., T.K.A.; Statistical analysis: A.T., Z.A., T.K.A.; Manuscript preparation: A.T., Z.A.; Manuscript editing: A.T., Z.A., Ö.Ö.Ş.; Manuscript review: Ö.Ö.Ş., T.K.A.

Data Availability Statement Data available on request from the authors.

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Conflict of Interest

None declared.

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