Original Article

HEALTH SCIENCES
MEDICINE

DOI: 10.32322/jhsm.1344400
J Health Sci Med. 2023;6(6):1285-1292

The psychosocial status of siblings and mothers of children with cancer from the perspective of mothers

Evin İlter Bahadur[1], Feryal Karahan[2], Asena Ayça Özdemir[3]

[1]Department of Developmental Pediatrics, Mersin City Training and Research Hospital, Mersin, Turkey
Division of Pediatric Hematology, Department of Pediatrics, Faculty of Medicine, Mersin University, Mersin, Turkey
[3]Department of Medical Education, Faculty of Medicine, Mersin University, Mersin, Turkey

Cite this article as: İlter Bahadur E, Karahan F, Özdemir AA. The psychosocial status of siblings and mothers of children with cancer from the perspective of mothers. *J Health Sci Med.* 2023;6(6):1285-1292.

Received: 16.08.2023 ◆ **Accepted**: 09.10.2023 ◆ **Published**: 29.10.2023

ABSTRACT

Aims: In the low/middle income countries (LMIC), a few of health centers provide psychological support to siblings and mothers of children with cancer. The aim of study was to draw attention to psychosocial status of siblings and mothers of children with cancer in a LMIC.

Methods: The study was a case-control study which was conducted at a tertiary center in Mersin, Turkey. The sample consisted of two groups as follows; siblings of children with cancer (n=39) were included as study group and children without cancer diagnosis in family (n=49) were included as control group. Behavioral problems of the children were evaluated with the Child Behavior Checklist 4-18. Beck Depression Inventory (BDI) and Multidimensional Perceived Social Support Scale (MSPSS) were used for maternal depressive symptoms and maternal perceived social support.

Results: In contrast to what was expected, there was no statistical difference in behavioral problems among two groups. Maternal BDI was higher and MSPSS was lower in the study group compared to the control group. Study group had more school difficulties such as absenteeism ($p<0.001$) and poor school performance ($p=0.011$). Grandmother caregiving, less maternal social support from her spouse, poor school performance, less knowledge about the cancer diagnosis, mother's depressive symptoms, longer hospital stay for cancer treatment, being female and being older were found to be risk factors for behavioral problems of study group.

Conclusion: Mothers of children with cancer had more depressive symptoms and lower social support. Behavioral problems of siblings of children with cancer may be related to school adaptation, maternal mental health, maternal social support, and socio-demographic characteristics. The intervention of maternal mental health should provide to optimize well -being of mother and siblings. School absenteeism and poor school performance should be investigated for intervention programs for behavior problems of siblings of children with cancer.

Keywords: Behavioral problems, mothers of children with cancer, siblings of children with cancer, low/middle income countries

INTRODUCTION

The diagnosis of childhood cancer and experiences during cancer treatment is an important psychosocial stress factor for the whole family. The diagnosis and treatment of process may lead to change family dynamics, affect parental relationships, and cause reorganization of roles and responsibilities within the family.[1] Siblings witness the suffering of their siblings with cancer, are worried about losing a sibling and stay away from their parents and siblings due to prolonged hospitalization. During this period, they may face many problems such as experiencing family, school, and social problems.[2,3] Adaptation of parents and siblings to such events may range from resilience to clinically significant psychopathology.[4]

Psychosocial care standards have been developed through multidisciplinary studies to evaluate and meet the psychosocial needs of children with cancer and their families.[5] According to psychosocial care standards, it is recommended that siblings ("SCC") and parents of children with cancer be considered a psychosocially high-risk group and included in support programs.[5]

In our country, this issue is not given enough attention, and only a few health centers have a family-centered approach that provides psychosocial support to children diagnosed with cancer and their families6. Although studies in this area are mostly from high-income western countries, there are limited studies in the literature investigating the behavioral problems and

Corresponding Author: Evin İlter Bahadur, evinbahadur@gmail.com

experiences of SCCs in low/middle income countries (LMIC).[1,7] The period of adaptation to cancers differs between culture.[8] So, in this study, we aimed to assess the behavioral needs of a sample of school-aged SCC compared to a control group without a family history of cancer in a LMIC. And to identify risk factors (maternal mental health, maternal social support, parental relationship, difficulties in their lives such as having to move, school difficulties and caregivers) for behavioral problems of school-aged SCC.

METHODS

The study was a case-control study conducted at Mersin City and Training and Research Hospital, a tertiary care hospital, between August and December 2022. The study was carried out with the permission of Toros University Clinical Researches Ethics Committee (Date: 27.05.2022, Decision No: 109).

Participants

Mothers who had a child diagnosed with childhood cancer for at least one year in the Pediatric Hematology and Oncology Service of Mersin City and Training and Research Hospital and also had a healthy child aged between 4-18 years without chronic diseases were included in the study. A total of 41 mothers were interviewed to participate in the study. Two mothers could not participate in the study due to language problems.

The control group consisted of mothers who applied to pediatric outpatient clinics, did not have a family history of cancer, had healthy children between the ages of 4 to 18, and were willing to participate in the study. In the control group, 54 mothers were interviewed and the aim of the study was explained. Since five mothers did not want to participate due to lack of time, a total of 49 mothers were included in the control group.

67 SCCs were included in the study. Having more than one sibling in a family may lead to biased findings. Therefore, only one healthy sibling was included in the study. Siblings were randomly selected. As a result, 39 children were included in the study group and 49 children were included in the control group.

The cancer diagnoses included hematologic malignancies (50%); solid tumors (25%); brain tumors (15%); and other (10%).

Procedure

The data form filled out by the mothers included sociodemographic data, the caregiver of the healthy child, the healthy child's school life (school achievement, absenteeism, the effect of cancer diagnosis on school achievement), and changes in the child's life after the diagnosis. Sociodemographic data included maternal and paternal education levels (less than or more than nine years of education), monthly income (below minimum wage, minimum wage and above minimum wage), children's school achievement (grouped as good, fair and poor). Recurrence, remission status and duration of hospitalization during cancer treatment were obtained from hospital medical records. Duration of hospitalization was categorized as less than 1 year, one to two years, more than two years. Duration of cancer diagnosis was categorized as 1-2 years, 2.1-4 years, >4 years.

The mothers in the study group were asked open-ended questions about important changes [about their address, job, marriage) that they experienced during the treatment of their children with cancer. Examples of open-ended questions are "How did your marriage change after your child was diagnosed with cancer?", "How did your professional life change after your child was diagnosed with cancer? "How did your healthy children learn about their siblings' cancer diagnosis?" "Did you change your address for cancer treatment?".

In addition, all participants were asked to complete three validated tools: Beck Depression Inventory (BDI) for mother's depressive symptoms, the Multidimensional Scale of Perceived Social Support (MSPSS) for maternal social support, and the Child Behavior Checklist/4-18 (CBCL/4-18) for children behavior assessment.

Assessment Tools

Beck depression inventory: It is a 21-item self-assessment scale developed by Beck et al and used to evaluate depressive symptoms.[9] Each item is scored between 0-3. Higher scores indicate more depressive symptoms. Turkish validity and reliability study was performed by Hisli et al.[10]

Multidimensional scale of perceived social support (MSPSS): It is a widely used social support scale that developed by Zimet et al.[11] In Turkey, adaptation, validity and reliability studies were conducted by Eker and Akar.[12] It includes social support perceived from family, friends and a special person (spouse, fiancé, etc.). Total score obtained from the 12-item scale, where each item is graded between 0-7 points. High score indicates a high level of support.

Child behavior checklist/4-18 (CBCL/4-18): It was used in the study to evaluate the behavioral problems of children. CBCL was developed by Achenbach[13] and the validity and reliability study was performed by Erol et al.[14] The questions are three Likert-type questions answered by parents. "Not true"; 0, "sometimes or

somewhat true"; 1 and "very or often true"; 2. It consists of eight subgroups: withdrawn, somatic complaints, anxiety/depression, social problems, thought problems, attention/hyperactivity problems, delinquent behaviors, aggressive behaviors and other problems. The sum of the scores of withdrawn, somatic complaints, and anxiety subgroups includes internalizing behavior problems; the sum of the scores of the aggression and delinquent subgroups constitute externalizing behavior problems, and the sum of the scores of all subgroups constitutes the total problems. Higher scores indicate more behavioral problems.

Statistical Analysis

Normality control of continuous variables was evaluated with the Shapiro Wilk test. Since the variables did not fit the normal distribution, nonparametric methods were used in the comparisons. The Mann Whitney U test was used to compare two independent groups and Kruskal Wallis test was used to compare more than two groups. Spearman Rho correlation coefficients were used to examine the linear relationship between continuous variables. Chi-Square and Fisher Exact tests were used to analyze categorical data. Multiple Linear Regression models were created with the variables that could affect the problem scores in the study group. Data analysis was performed in IBM SPSS 21 package program.

RESULTS

The mean age of the study group was 10.03±3.98 years, 43.5% (n=17) were female and the mean age of the control group was 10.59±3.95 years, 39% (n=19) were female. There was no statistically significant difference between the two groups in terms of age and gender (p=0.507, p=0.648, respectively). The median duration of cancer diagnosis (IQR) was 3 years (2.5-5 years). Sociodemographic and disease-specific data are summarized in Table 1. In addition, changes in family life during cancer diagnosis and treatment are shown in Table 1.

The maternal BDI score was statistically higher (p=0.005) and the MSPSS score was lower (p<0.001) in the study group compared to the control group. Maternal BDI was found to be positively associated with internalizing and total problems in the study group (r=35.3, p=0.027; r=32.3 p=0.045). However, the study showed that there was no relationship between the social support perceived by the mothers and the behavioral problems of the sibling in the study group.

There was no statistically significant difference between the two groups in terms of behavioral problems (Table 2).

Table 1 Descriptive sociodemographic and cancer-related parameters

	Case group (n=39)	Control group (n=49)	p value
Age*	10.03±3.98	10.59±3.95	0.507
Maternal age*	37.46±7.55	38.61±7.70	0.484
Paternal age*	43.03±9.40	42.47±7.33	0.756
Age of children with cancer*	9.98±4.56		
Maternal educational level <9years n(%)	33 (84.6)	28 (57.1)	0.006
Paternal educational level <9years n (%)	30 (76.9)	26 (53.1)	0.021
Non-employee mother n (%)	35 (89.7)	32 (65.3)	0.008
Monthly family income n (%)			
Above than minimum wage	8 (20.5)	11 (22.4)	<0.001
Minimum wage	14 (35.9)	34 (69.4)*	
Below than minimum wage	17 (43.6)*	4 (8.2)	
School absenteeism n (%)	11 (35.5)	1 (2.3)	<0.001
School achievement n (%)			
Good	16 (51.6)	28 (65.1)	0.011
Fair	9 (29)	15 (34.9)	
Poor	6 (19.4)*	0	
During cancer treatment negatively impact of school achievement n (%)	13 (41.9)	NA	
Birth of order n (%)			
Older than children with cancer	19 (48.7)		
Younger than children with cancer	20 (51.2)		
Drop out of school n (%)	5 (16.1)		
Duration of diagnosis, year, median (IQR)	3 (2.5-5)		
Duration of diagnosis, year, n (%)			
1-2 years	13 (33.3)		
2.1-4 years	14 (35.9) 12 (30.8)		
>4.1 years			
Recurrence n (%)	8 (20.5)		
Remission n (%)	27 (66.7)		
Duration of stay at hospital n (%)			
<1year	22 [56.4)		
1-2 years	11 [28.29)		
>2.1 years	6 [15.4)		
Talking about cancer diagnosis n (%)			
Hidden	18 (50)		
Face to face talking	18 (50) 18(46.2)		
Negatively impact of partner relationship n (%)			
Changing in address n (%)			
Had to move another city	9 (23.1)		
Going another city for cancer treatment	5 (12.8))		
None changed	25 (64.1)		
Negatively impact in job n (%)	8 (20.5)		
Caregiver of healthy children during cancer treatment, n (%)		NA	
Mother	7 (17.9)		
Father	9 (23.1)		
Older sister	9 (23.1)		
Grandmother	14 (35.9)		

*: mean±SD

p valueComparison of sociodemographic data, cancer treatment parameters and behavioral problems of the study group are summarized in Table 3.

In the study group, the externalizing problems of children with good school achievement were found to be lower (p=0.036). According to the statements of the mothers, the externalizing and total problem scores of children whose school achievement was negatively affected during the cancer period were found to be higher than those whose school achievement was not affected (p=0.028 and p=0.01, respectively). No significant relationship was found between change of address and marriage and behavioral problems. When the caregivers of healthy children were examined, the internalizing and total problem scores of children who were cared for by their grandmothers were higher than those of children who were cared for by their mothers, fathers and older sisters (Table 4).

In multiple linear regression analysis, caregiver, change of address, mother's perceived social support, school achievement, the way of learning the diagnosis, mother's BDI score, duration of hospitalization for cancer treatment, being a girl, being older than children with cancer, and children's age were found to be risk factors for behavioral problems in siblings of children with cancer (see Table 5).

DISCUSSION

The study examined the behavioral problems of school-age SCC to comprehensively compare with the control group. We examined multifactorial independent variables potentially associated with behavioral problems, such as social, school and family functioning. The study found several important implications for developing cost-effective and feasible intervention programs.

In the study, it was found that the lives of the majority

Table 3. Descriptive the Relationship Between Sociodemographic Parameters and Behavioral Problems of Siblings of Children with Cancer

	Internalizing Problems	Externalizing Problems	Total Problems
Sex*			
Female (n=17)	9 (1.5-18.5)	5(2-11)	25 (13-41.5)
Male (n=22)	8 (2-12.5)	7.5 (2.75-12.25)	26 (13.25-46.75)
p value	0.798	0.609	0.989
Birth of Order*			
Older Than Children with Cancer (n=20)	6.5 (1-12)	5.5(2.25-10.5)	23 (11-41.5)
Younger Than Children with Cancer (n=19)	8 (2-24)	7 (2-28)	26 (15-101)
p value	0.242	0.317	0.439
Maternal Educational Level*			
<9 Years (n=33)	8 (2-12.5)	6 (2.5-12)	26 (14.5-44.5)
≥9 Years (n=6)	7 (2-23)	4.5 (0-20.75)	24.5 (3.75-72.5)
p value	0.740	0.640	0.830
Paternal Educational Level*			
<9 Years (n=30)	8 (2-12)	5.5 (2-11.25)	24.5 (14.75-43.75)
≥9 Years (n=9)	10 (1.5-18)	8 (1.5-14.5)	33 (7.5-54)
p value	0.867	0.828	0.790
Family monthly income*			
Above than minimum wage (n=8)	5 (1.25-12.5)	8 (0.75-12.75)	25 (5.75-41.5)
Minimum wage (n=14)	9 (1.75-12.25)	5.5 (2-10.5)	27.5 (14-38.5)
Below than minimum wage (n=17)	9 (2.5-20)	5 (2.5-9.5)	25 (14.5-50)
p value	0.612	0.944	0.826
Duration of Cancer Diagnosis*			
1-2 Years (n=13)	9 (2.5-19.5)	8 (4-23.5)	26 (19-72)
2.1-4 Years (n=14)	9 (1.75-12.5)	5.5 (1.75-11.25)	30.5 (10.75-46)
>4.1 Years (n=12)	5.5 (1.25-9.75)	4 (2-13.5)	17.5 (12-43.25)
p value	0.458	0.425	0.698
Remission*			
Yes (n=27)	8 (2-13)	7(2-12)	26 (15-43)
No (n=12)	6 (2-19.5)	4.5(2.25-13.5)	18.5 (11-48.25)
p value	0.855	0.594	0.749
Recurrence*			
Yes (n=8)	8 (2-14)	6 (3-10)	26 (15-39)
No (n=31)	7 (1-12)	4 (2-12)	18 (9-34)
P-value	0.232	0.589	0.376
Duration of Hospitalization *			
<1 Year (n=22)	9 (1.75-22.5)	6.5 (1.75-13.75)	26 (9.25-50)
1-2 Years (n=11)	8 (2-10)	6 (3-13)	20 (16-34)
>2.1 Years (n=6)	5(1.75-10.5)	4 (1.75-65)	20 (9-39.25)
p value	0.698	0.413	0.822

*: median (IQR)

of families were negatively affected after the diagnosis of cancer. Approximately half of the mothers stated that their marriages were negatively affected,[15] 23.1% stated that they had to move to another city due to cancer treatment and 20% stated that their jobs were negatively affected.[16] Most of the mothers accompanied the sick child during hospitalization. Only 17.9% (n=7) of the mothers were able to take care of their healthy children during treatment. This finding is similar to the literature.[17] The results of previous studies on family adaptation and experience are similar to the present findings.[15,16]

Certainly, the diagnosis of cancer in their child is one of the worst experiences for parents. Maternal depressive symptoms are still higher and maternal perceived social support is lower than the control group. Consistent with our study, a previous study by Howard showed that maternal depressive symptoms may persist for 5 years after diagnosis.[18] In the literature, previous studies have shown that maternal perceived social support was lower, consistent with this study.[19,20]

SCC can lead to severe acute and long-term difficulties. The results of various studies on sibling behavior in the literature are inconsistent.[6,7,21] Contrary to our expectation, this study showed that there was no significant difference between the siblings of the children and the control group in terms of behavioral problems. In our study, the duration of diagnosis was approximately 3 years, at least one year. In parallel with the studies by Houtzager and Alderfer, we thought that the psychosocial adjustment of the sibling improved over time.[2,22,23] However, school problems may become apparent approximately 2 years after the diagnosis.[2,7] In this study, in line with the literature, siblings of children with cancer experienced more school-related difficulties than the control group according to maternal reports (16.1% siblings dropped out of school, could not attend preschool education, were absent from school and had poor school achievement).[7,17] Siblings may experience academic problems and school absenteeism due to lack

Table 4. To demonstrate the relationship between changes in family life and behavioral problems

	Internalizing problems	Externalizing problems	Total problems
School absenteeism*			
Yes (n=11)	10 (3-14)	8 (2-13)	29 (17-52)
No (n=20)	2 (1-9)	4 (2-9.75)	15.5 (7.25-27.5)
P-value	0.023	0.279	0.079
School achievement*			
Good (n=16)	3 (2-8.75)	2.5 (0.25-7.75)a	15.5 (4-27.5)
Fair (n=9)	9(1.5-18)	8 (3-14.5)b	33 (12-54)
Poor (n=6)	6 (0.75-13.75)	8.5 (4.75-20.75)ab	23 (16.75-65.75)
P-value	0.621	0.036	0.095
The impact of school achievement*			
None change	2.5 (2-9)	3 (0.73-7.5)	15 (5.5-26.5)
Negatively impact	10 (2-23.5)	8 (3.5-14.5)	33 (16.5-57)
p-value	0.068	0.028	0.010
Talking about cancer diagnosis*			
Hidden (n=18)	8 (2-16.75)	6 (2.75-12.25)	26 (16.5-43.75)
Face to face talking (n=18)	6.5 (1.75-12)	5 (2-10.25)	18 (10.75-37.75)
p-value	0.389	0.563	0.323
The impact of marriage relationship*			
None (n=21)	8 (2-14)	6 (2.5-12.5)	25 (12.5-44.5)
Negatively affect (n=18)	8.5 (2.5-12.5)	5.5 (2-11.5)	27.5 (14-47.5)
p-value	1.000	0.910	0.683
Changing in address*			
Changing city (n=9)	8 (2.5-18.5)	6 (2.5-31)	26 (13.5-78)
Going another city only during treatment (n=5)	2 (0.5-20.05)	12(1-20.5)	26 (7.5-66.5)
None (n=25)	9 (2-13.5)	5(2-10.5)	25 (12.5-44.5)
p-value	0.528	0.706	0.848
Caregiver of healthy children during cancer treatment*			
Mother (n=7)	4 (1-8)[d]	3(0-12)	17 (4-28)[g]
Father (n=9)	7(0.5-9.5)[c]	6 (3-9.5)	24 (13-34.5)[f]
Sister (n=9)	3 (2-12)	4(1-7)	16 (7-31)[e]
Grandmother (n=14)	13 (8-25.25)[cd]	13 (4.5-34.25)	40.5 (28.25-104.25)[efg]
p-value	0.017	0.055	0.016

*: median (IQR)

Table 5. To demonstrate the risk factors of behavioral problems for sibling of children with cancer

Model	Standardized Coefficients	Sig.	95.0% Confidence Interval for B	
	Beta		Lower Bound	Upper Bound
Internalizing problems R2:0,879 F:11,238 p<0,001				
(Constant)		0.007	-17.460	-3.221
Age of children with cancer	0.914	0.000	0.842	1.616
Changing city	-0.546	0.002	-13.224	-3.729
Going another city only for treatment	-0.865	0.000	-23.588	-12.146
Grandma caregiving	0.613	0.000	4.644	12.041
Sister caregiving	-0.304	0.009	-7.683	-1.257
Being female	0.287	0.035	0.276	6.940
Talking about diagnosis	-0.544	0.000	-9.803	-3.885
Poor school achievement	0.308	0.008	1.409	8.163
School absenteeism	0.273	0.095	-0.685	7.775
Social support from family	0.619	0.000	0.288	0.746
Social support from spouse	-0.425	0.003	-0.475	-0.115
Externalizing problems R2:0,884 F:7,657 p<0,001				
(Constant)		0.025	-26.137	-2.036
Being older than children with cancer	2.636	0.000	-20.070	-8.764
Duration of stay at hospital	0.335	0.047	0.005	0.730
Remission	0.609	0.003	4.393	16.778
Changing city	0.475	0.043	0.362	18.987
Going another city only for treatment	-1.039	0.000	-39.366	-16.974
Mother caregiving	0.605	0.001	6.452	20.020
Grandma caregiving	0.822	0.000	8.028	21.313
Talking about diagnosis	-0.714	0.000	-16.551	-7.055
Poor school achievement	1.134	0.000	16.882	29.356
Fair school achievement	0.627	0.001	5.814	17.349
School absenteeism	-0.890	0.003	-24.283	-5.992
Maternal Beck Depression inventory	0.593	0.001	0.239	0.684
Social support from family	0.769	0.000	0.490	1.197
Social support from spouse	-0.522	0.004	-0.775	-0.176
Total problems R2:0,801 F:8,488 p<0,001				
(Constant)		0.349	-17.578	47.343
Maternal age	-0.372	0.015	-1.773	-0.214
Age of children with cancer	0.854	0.000	2.472	5.366
Changing city	-0.362	0.014	-34.043	-4.331
Going another city only for treatment	-0.682	0.000	-69.611	-26.470
Grandma caregiving	0.636	0.000	15.641	43.338
talking about diagnosis	-0.532	0.000	-33.855	-11.811
Poor school achievement	0.537	0.000	15.000	41.934
Social support from family	0.405	0.010	0.312	1.995
Social support from spouse	-0.260	0.067	-1.279	0.048

of concentration and lack of parental attention and supervision.

Studies have indicated that being older and female may be risks factor for behavioral problems.[21] This may be related to taking more responsibility in the family.[2] In the study, depressive symptoms of the mother, less social support from the spouse, caregiving by the grandmother, longer duration of hospitalization and talking about the cancer diagnosis were found to be associated with the sibling's behavior. According to a review by Long, family functioning plays an important role for psychosocial adjustment of school-age SCC.[7] Family is a very important social support system for children.[24] Better family functioning supports better sibling adjustment.[25] Consistent with our study, low level of knowledge about the diagnosis of cancer has been shown to be a risk factor for sibling adjustment in a previous study.[26]

School is another important social support system for children. Many studies in the literature have shown that school adjustment plays an important role for the psychosocial status of the sibling.[7,27] According to the findings of the present study, poor school performance may be a risk factor for behavioral problems.

The study has some limitations. The study is a cross-sectional study. The psychosocial status of siblings and

mothers were examined once. We do not have any information about the first time of diagnosis. The study was conducted in a single center and only one sibling from a family participated in the study to avoid bias. Therefore, the sample size is small. Therefore, the results should be interpreted with caution. The questions were answered only by mothers, so the psychosocial situation was analyzed from the mother's perspective.

Despite these limitations, the study also has strengths. As mentioned above, the first step for intervention programs for high-risk groups is to identify risk factors. In Turkey, this issue has been less studied and the awareness on the subject is low compared to high-income countries.

CONCLUSIONS

The study found several important implications for developing cost-effective and feasible intervention programs. The results showed that mothers of children with cancer had more depressive symptoms and had lower social support. Mothers should have speedy and permanent assessment for depressive symptoms and social support.

School-aged SCC did not exist more behavior problems compared to control groups. However, parents of SCC reported poor school achievement and higher school absenteeism than the control group. Poor school achievement, family functioning (caregiver, mother's mental health, change of address, style of learning the cancer diagnosis), mother's perceived social support from her partner, and sociodemographic parameters (being female and being older than children with cancer) were associated with the behavior of siblings with cancer.

Maternal mental health and lower maternal social support from her partner may impact sibling's adjustment. To arrive intervention for parent mental health should be provided for optimize parent and sibling's well-being.

In additional school adjustment can play important role in sibling's behavioral adaptation. Attention should be paid to school absenteeism and school success. School and family-based intervention may be effective for behavioral problems of siblings. School social services and school guidance and psychological counseling units should be included in intervention programs.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Toros University Clinical Researches Ethics Committee (Date: 27.05.2022, Decision No: 109).

Informed Consent: Written informed consent forms were obtained from the parents of all patients.

Referee Evaluation Process: Externally peer reviewed.

Conflict of Interest Statement: The authors have no conflicts of interest to declare.

Financial Disclosure: The authors declared that this study has received no financial support.

Author Contributions: All the authors declare that they have all participated in the design, execution, and analysis of the paper, and that they have approved the final version.

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