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**Original Article**

# The relation between sleep habits, fatigue, impact on family and quality of life in children with first-time cancer and recurrent cancer

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**Abstract**
**Aim:** This study was planned to determine the conditions related to sleep, fatigue, and impact on family in children with Acute lymphoblastic leukemia (ALL) and acute myeloid leukemia (AML) who had cancer for the first time and children who had recurrent cancer.
**Material and Methods:** The study included 74 children (41 girls, 33 boys) with a mean age of 8.11 ± 3.77 years. Children evaluated with child and parent report of Pediatric Quality of Life "and PedsQL Healthcare Satisfaction Generic Module" should be aded. Inventory (PedsQL) Cancer Module, Children's Sleep Habits Questionnaire (CSHQ), Borg Scale and Impact on Family Scale (IPFAM).
**Results:** There was a statistically significant difference, in terms of PedsQL parent report total score (p=0.003), between the children who had cancer for the first time and children who had recurrence cancer, and the values of latter were higher. A positive correlation was found between the PedsQL child and parent report scores for all children with cancer (p= 0.000).
**Conclusion:** According to the results of our study, it was seen that children who have recurrent cancer had reported a better quality of life and that children and parents have similar perceptions in terms of quality of life.

**Keywords:** Child; Cancer; Recurrence; Quality of Life.

## INTRODUCTION

Cancer is less common in children than in adults and 0.5% of all cancers are seen in children less than 15 years of age. According to the Centers for Disease Control and Prevention (CDC) (2007) data, the most common childhood cancer is acute lymphoblastic leukemia (ALL) with a 27.5% rate (1). ALL is an aggressive type of leukemia characterized by the presence of too many lymphoblast or lymphocytes in the bone marrow and peripheral blood. ALL is the most common childhood cancer and 78% of leukemia are reported to be ALL (2,3). Acute myeloid leukemia (AML) is another type of cancer that is common in children, with bone marrow forming a large number of abnormal blood cells (4).

Children diagnosed with cancer often stay in hospitals for a long time during treatment. In many studies, it has been reported that children and adolescents with cancer often experience symptoms of pain, nausea, vomiting, insomnia, fatigue, anxiety, and emotional and physical stress (5-7). These conditions may affect the quality of life of children negatively. Recurrence of cancer has been investigated as one of the determinants of quality of life in children in various studies and it has been stated as a factor that negatively affects the quality of life (8).

There are negative effects of childhood cancers and chemotherapy agents used in treatment on sleep and fatigue (9). Children with cancer are reported to be extremely sleepy during daytime most (10). Considering the great effects sleep has on cognitive status, psychological health, cognitive skills, and quality of life, it is seen how important it is to evaluate and improve sleep quality. Similar to sleep disorders, fatigue may also

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affect children with cancer (11,12). Since fatigue related to cancer emerges simultaneously with disturbances in sleep patterns, it is assumed that there is a strong relationship between these two conditions (13).

Musculoskeletal system problems due to cancer and cancer treatment, which is a long-lasting, painful process, affect not only children with cancer but also their families, and they are also exposed to major difficulties in this process (14). In this respect, it is important to evaluate the impact on the family in children with cancer.

The studies on quality of life have been increasing in childhood cancer patients by prolonging treatment processes and increasing rate of survival. However, these studies generally evaluate the quality of life of the child based on the parent reports. Despite it is known that the child's own report is more reliable for assessing quality of life, family report is required when the child is too young, cognitively affected, cannot provide valid information when they are sick and tired, since these types of cancer are most frequently seen between 2-6 years of age (15). In this respect, it is important to evaluate the quality of life with the family report (16,17). However, in order to fully understand the quality of life, both the family's and the child's answers are very important. Therefore, both family and child reports were used to evaluate the quality of life in our study. The aim of this study is to determine the effects of sleep, fatigue, and family impact in children with ALL and AML, and to determine the effects of these conditions on the quality of life of children who had cancer for the first time or who had recurrent cancer.

## MATERIAL and METHODS

### Participants

The families accepted to participate in the study of the children aged between 2 and 18 who were being treated with cancer at the Pediatric Oncology Service of Gaziantep University Oncology Hospital were included in this study. In addition to the diagnosis of cancer, children with different diagnosis of neurological or metabolic disease were not included in the study. In order to carry out the study, ethics committee approval was obtained from Hasan Kalyoncu University, Faculty of Health Sciences, Non-interventional Clinical Researches Ethics Board (Dec. 12, 2017, numbered 2017-13). Parents of the children included in the study were informed about the study and written informed consent was obtained.

The evaluation of children included in the study was conducted between January 1, 2018 and August 1, 2018. The design of the study was determined as a prospective, descriptive study.

The study was registered to the clinicaltrias.gov website with the name of Quality of Life in Children and Cancer and number of NCT03190499.

(Can be reached at https://clinicaltrials.gov/ct2/show/NCT03190499?term=numano%C4%9Flu&rank=1.)

For all children; information about age (years), height (cm), body mass (kg), gender, exercise history, whether the cancer is a recurrent one or not were recorded.

Health-related quality of life of children is evaluated with the Turkish language version of child and parent report of Pediatric Quality of Life Inventory (PedsQL) Cancer Module (18,19). This survey consists of eight domains as Pain and Hurt, Nausea, Procedural Anxiety, Treatment Anxiety, Worry, Cognitive Problems, Perceived Physical Appearance, and Communication. The scores range from 0 to 100 and high scores indicate better quality of life. In our study, all domain scores and the total score of the scale were calculated. The Turkish version of the Pediatric Quality of Life Inventory "Healthcare Satisfaction Generic Module" was used to evaluate families' views on health services (20).

Children's sleep habits were evaluated with the Turkish translation of the Children's Sleep Habits Questionnaire (CSHQ) (21,22). This scale consists of 33 items and is filled in by parents. The scale total score above 41 represents clinical sleep disorder. Total scores were calculated for CSHQ.

The family impact was evaluated with the Turkish translation of the Impact on Family Scale (IPFAM), which was developed specifically for families with chronic health problems in their children (23,24). IPFAM scores ranged from 24 to 96 and high scores indicate high impact.

The fatigue of the cases was evaluated with Borg Scale between 0-10. According to the Borg scale, high scores indicate more fatigue.

All evaluations were performed by one of the authors of this study who is a physical therapist, at Pediatric Oncology Service of Gaziantep University Hospital.

### Statistical Analysis

Statistical analysis was performed using Statistical Package for Social Sciences (SPSS Version 22, Armonk, NY: IBM Corp.). The level of statistical significance was set at $p < 0.05$. The data were analyzed by Kolmogorov Smirnov test to see whether they show normal distribution or not. As the data did not show normal distribution Man Whitney U Test was used for group comparisons and Spearman Correlation Analysis for correlation analysis.

## RESULTS

Of the 100 families who were sent surveys for this study, 81 agreed to participate and fill in the questionnaires. Among them, 7 cases were not included in the analysis since there were missing values in the questionnaire forms. The remaining 74 cases with a mean age of 8.11 ± 3.77 years were included in the study. The quality of life of 15 patients under 5 years of age was evaluated with PedsQL parent report and the quality of life of all other cases was evaluated with PedsQL child and parent reports. Among them, 41 cases were girls and 33 were boys. Demographic data of the cases are shown in Table 1.

**Table 1. Demographic Characteristics of Participants**

| Demographic Characteristics | | (n=74) | |
|---|---|---|---|
| | | Frequency | Percent (%) |
| Diagnosis | ALL | 53 | 71.6 |
| | AML | 21 | 28.4 |
| Gender | Girl | 41 | 55.4 |
| | Boy | 33 | 44.6 |
| Recurrent condition | First-time | 62 | 83.8 |
| | Recurrent | 12 | 16.2 |
| Exercise History | No | 71 | 95.9 |
| | Yes | 3 | 4.1 |
| | Minimum | Maximum | Mean± Std. Deviation |
| Age (year) | 2 | 17 | 8.11 ± 3.77 |
| Height (cm) | 71 | 173 | 124.34 ± 20.76 |
| Weight (kg) | 10.0 | 68.0 | 26.8 ± 12.18 |

ALL: Acute Lymphoblastic Lymphoma, AML: Acute Myeloid Lymphoma

When the results were examined according to the CSHQ, it was seen that the minimum scores of the children who had cancer for the first time and those who had cancer recurrence were above the score of 41, which is the cut-off point of the questionnaire.

It was determined that there were significant statistical difference between the children who had cancer for the first time and who had recurrent cancer in terms of the Technical Skills domain score of PedsQL health service satisfaction questionnaire (p= 0.047), PedsQL parent report total score (p= 0.003), Pain and Hurt domain score (p= 0.006), Nausea s domain score (p= 0.009), Procedural Anxiety domain score (p= 0.008), and the values of recurrent cancer children were higher. Table 2 shows the fatigue, sleep habits, family impact and daily life activities, satisfaction with health services, and quality of life of the first-time and recurrent cancer patients, as well as the differences between these two groups.

**Table 2. Differences in terms of fatigues, sleep habits, family impairment, healthcare satisfaction and quality of life among first-time cancer patients and patients with recurrent cancer**

| Evaluations | | First-time cancer (n=62) | | | Recurrent (n=12) | | | Mann Whitney U |
|---|---|---|---|---|---|---|---|---|
| | | Minimum | Maximum | Mean ± Std. Deviation | Minimum | Maximum | Mean ± Std. Deviation | p |
| Borg Scale | | 1.00 | 8.00 | 4.12±1.59 | 1.00 | 5.00 | 3.83±1.11 | 0.674 |
| CSHQ | | 46.00 | 72.00 | 57.53±5.44 | 47.00 | 69.00 | 57.08±6.27 | 0.977 |
| IPFAM | | 42.00 | 87.00 | 62.53±9.15 | 49.00 | 74.00 | 61.91±8.31 | 0.930 |
| PedsQL Healthcare Satisfaction Generic Module | Information | 15.00 | 100.00 | 76.69±20.42 | 60.00 | 100.00 | 79.58±13.39 | 0.971 |
| | Inclusion of Family | 0.00 | 100.00 | 70.46±21.83 | 50.00 | 87.50 | 65.62±12.91 | 0.179 |
| | Communication | 0.00 | 100.00 | 58.46±18.47 | 40.00 | 90.00 | 63.33±16.96 | 0.534 |
| | Technical Skills | 0.00 | 133.33 | 73.38±20.73 | 58.33 | 125.00 | 86.80±20.24 | **0.047** |
| | Emotional Needs | 0.00 | 100.00 | 66.33±25.00 | 43.75 | 87.50 | 64.06±13.62 | 0.586 |
| | Overall Satisfaction | 25.00 | 100.00 | 75.00±18.16 | 16.67 | 91.67 | 67.36±29.40 | 0.795 |
| | Total | 5.21 | 87.50 | 60.13±14.34 | 50.00 | 72.92 | 62.23±6.22 | 0.523 |
| PedsQL Child Form | Pain and Hurt | 0.00 | 100.00 | 39.71±29.11 | 0.00 | 100.00 | 53.12±31.13 | 0.086 |
| | Nausea | 0.00 | 70.00 | 39.19±25.01 | 0.00 | 75.00 | 52.08±26.41 | **0.039** |
| | Procedural Anxiety | 0.00 | 91.67 | 31.85±26.50 | 0.00 | 66.67 | 40.97±26.22 | 0.177 |
| | Treatment Anxiety | 0.00 | 100.00 | 40.99±29.38 | 0.00 | 83.33 | 42.36±25.73 | 0.917 |
| | Worry | 0.00 | 100.00 | 39.38±26.95 | 0.00 | 66.67 | 40.97±21.45 | 0.846 |
| | Cognitive Problems | 0.00 | 100.00 | 38.99±28.95 | 0.00 | 80.00 | 45.41±27.00 | 0.450 |
| | Perceived Physical Appearance | 0.00 | 100.00 | 38.44±27.59 | 0.00 | 58.33 | 40.97±20.85 | 0.917 |
| | Communication | 0.00 | 91.67 | 44.35±28.77 | 0.00 | 100.00 | 55.55±29.80 | 0.213 |
| | Total | 0.00 | 69.44 | 38.81±22.20 | 0.00 | 64.81 | 46.52±22.34 | 0.086 |
| PedsQL Parent Form | Pain and Hurt | 0.00 | 100.00 | 48.58±17.103 | 37.50 | 100.00 | 61.45±17.23 | **0.006** |
| | Nausea | 0.00 | 80.00 | 48.14±17.97 | 30.00 | 90.00 | 62.91±16.30 | **0.009** |
| | Procedural Anxiety | 0.00 | 91.67 | 33.33±23.76 | 0.00 | 83.33 | 52.08±24.65 | **0.008** |
| | Treatment Anxiety | 0.00 | 100.00 | 40.18±22.10 | 8.33 | 66.67 | 43.05±18.40 | 0.650 |
| | Worry | 0.00 | 83.33 | 44.82±20.81 | 25.00 | 100.00 | 53.47±20.85 | 0.447 |
| | Cognitive Problems | 0.00 | 100.00 | 54.24±21.91 | 0.00 | 81.25 | 49.47±22.26 | 0.552 |
| | Perceived Physical Appearance | 0.00 | 83.33 | 46.90±21.02 | 33.33 | 83.33 | 50.00±12.81 | 0.856 |
| | Communication | 0.00 | 100.00 | 52.68±21.75 | 0.00 | 100.00 | 59.02±25.98 | 0.388 |
| | Total | 11.46 | 72.92 | 50.73±12.27 | 46.88 | 79.17 | 62.23±9.17 | **0.003** |

CSHQ; Children's Sleep Habits Questionnaire. IPFAM: Impact on Family Scale, PedsQL: Pediatric Quality of Life Inventory

Correlation analyzes were performed separately for the data of all children and for the data of ALL and AML children who had cancer for the first time and who had recurrent cancer. A correlation was found between the PedsQL child and parent report scores (r= 0.804) in the analysis of all children. For children with cancer for the first time, a correlation was found between the PedsQL child and parent report scores (r= 0.792). Moreover, for children with recurrent cancer, correlations between age and PedsQL children report score (r= 0.648), between PedsQL children report score and CSHQ (r= -0.640), between PedsQL children report score and PedsQL Health Care Satisfaction (r= 0.815), between PedsQL child and parent report scores (r= 0.817), as well as between PedsQL child and parent report scores of children with ALL and AML (r= 0.763, r= 0.895) were found. No relation was found between the other scores (p> 0.05). Correlations presented in Table 3.

**Table 3. Relation between fatigues, sleep habits, family impairment and healthcare satisfaction with quality of life of patients**

| Evaluations | All Cases (n=74) | | First-time cancer (n=62) | | Recurrent (n=12) | | ALL (n=53) | | AML (n=21) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | r | p | r | p | r | p | r | p | r | p |
| PEDSQL Child Form-Age | 0.255 | 0.051 | 0.161 | 0.270 | 0.648* | 0.043 | 0.312* | 0.044 | 0.131 | 0.617 |
| PEDSQL Child Form-BMI | 0.101 | 0.444 | 0.080 | 0.584 | -0.107 | 0.769 | 0.103 | 0.516 | 0.079 | 0.763 |
| PEDSQL Child Form - Borg Scale | -0.192 | 0.146 | -0.243 | 0.093 | 0.342 | 0.333 | -0.159 | 0.315 | -0.317 | 0.214 |
| PEDSQL Child Form - IPFAM | 0.003 | 0.981 | -0.053 | 0.720 | 0.097 | 0.789 | 0.111 | 0.486 | -0.333 | 0.191 |
| PEDSQL Child Form -CSHQ | -0.095 | 0.427 | -0.024 | 0.871 | -0.640* | 0.046 | 0.020 | 0.899 | -0.415 | 0.097 |
| PEDSQL Child Form -PEDSQL health care satisfaction scale | -0.070 | 0.600 | -0.233* | 0.107 | 0.815** | 0.004 | -0.076 | 0.630 | -0.147 | 0.574 |
| PEDSQL Child Form -PEDSQL Parent Form | 0.804** | 0.000 | 0.792** | 0.000 | 0.817** | 0.004 | 0.763** | 0.000 | 0.895** | 0.000 |
| PEDSQL Parent Form- Age | 0.212 | 0.069 | 0.165 | 0.201 | 0.142 | 0.660 | 0.152 | 0.276 | 0.352 | 0.118 |
| PEDSQL Parent Form -BMI | -0.025 | 0.834 | -0.127 | 0.326 | 0.154 | 0.633 | -0.076 | 0.588 | 0.103 | 0.657 |
| PEDSQL Parent Form -Borg Scale | -0.176 | 0.133 | -0.194 | 0.130 | 0.125 | 0.700 | -0.083 | 0.557 | -0.408 | 0.067 |
| PEDSQL Parent Form- IPFAM | -0.105 | 0.372 | -0.194 | 0.131 | 0.284 | 0.372 | -0.131 | 0.352 | -0.057 | 0.805 |
| PEDSQL Parent Form -CSHQ | 0.014 | 0.909 | 0.045 | 0.730 | -0.329 | 0.297 | 0.054 | 0.702 | -0.241 | 0.292 |
| PEDSQL Parent Form -PEDSQL health care satisfaction scale | -0.020 | 0.866 | -0.085 | 0.511 | 0.495 | 0.102 | 0.071 | 0.613 | -0.334 | 0.139 |

**CSHQ; Children's Sleep Habits Questionnaire. IPFAM: Impact on Family Scale, PedsQL: Pediatric Quality of Life Inventory**

## DISCUSSION

In this study, the quality of life of the child in terms of the sleep, fatigue, and impact on the family was analyzed from the perspective of child and family according to the acute cancer types of children and the recurrence situation of cancer.

Sleep disorder was detected in all patients included in the study and the sleep quality was associated with decreased quality of life in the group with recurrent cancer. Zupanec et al. concluded that sleep disorders during childhood ALL is very common (87%) and this increases fatigue (25). Van Litsenburg has shown that sleep disorders during treatment are a contributing factor to the low quality of life (26). In our study, it was concluded that fatigue levels were similar at a moderate level in patients with first-time and recurrent cancer, and, contrary to the literature, did not affect the quality of life of children. Gordjin and colleagues reported that although children with ALL reported less sleep and fatigue problems than the normal population, and the sleep disorder and fatigue reported by the family were negatively correlated with quality of life (27).

In the present study, the level of family impact was similar in the first-time and recurrence groups and no correlation were found with the quality of life of the child. When the literature is examined, it is reported that parent's coping skills are one of the important determinants of quality of life in children with cancer however, no such relationship was found in our study (8,28,29).

When the satisfaction of health services evaluated, the Technical Skills domain score was higher in children with recurrent cancer. This may be due to the fact that parents are prepared for the practices in the hospital from their previous experience.

In our study, in the total score of quality of life and scores of Pain and Hurt, Nausea, and Procedural Anxiety domain assessed by parental reports were found to have statistically significant differences between first-time and recurrent cancer groups, and the recurrent group had higher scores. When the literature is reviewed, there are studies reporting that recurrence of cancer is associated with poorer quality of life, as well as studies reporting that children with first-time and recurrent cancer (ALL) had a similar health-related quality of life outcomes (except for general health) (8). In the studies that the recurrent patients with ALL report their overall health lower than the patient with no cancer recurrence, the late effects of the cancer was shown as responsible for this situation, and the difference was found to be an insignificant difference when late effects were shown to be an important underlying factor for quality of life in recurrent individuals (30). In our study, it was found that children in the recurrence group rated their quality of life as lower than their families, but it was concluded that the quality of life of the children in the group without recurrence was similar. In the study of Zebrack and Chesler, it was observed that recurrence did not contribute to health-related quality of life even when adapted to late effects (31).

In the literature, it is reported that the ability of the family to solve different stress sources related to the child may affect the quality of life of the child (32). The reason for the higher quality of life is reported by parents of children who have recurrent cancer, can be considered as parents have improved their coping and adaptation skills due to their previous experiences, and reduced their expectances form the life, and accepted their child's current physical or psychosocial symptoms (27). In the literature on the quality of life of childhood cancers, the tendency to deny the difficulties and to report high quality of life even under difficult living conditions, i.e. the "satisfaction paradox", was discussed (33). In our study, families may have experienced the desire to be normal, rather than children, so families may have higher scores on pain, hurt, nausea, and procedural anxiety in the quality of life of their children. It can be thought that the families rated symptoms such as pain, hurt, and nausea in quality of life in better levels by underestimating physical symptoms and think they are less important compared to the life-threatening disease they face.

In our study, a positive correlation was found between the child and the parent reports in terms of quality of life when considering the situation of recurrence and cancer types in all cases. According to a study conducted by Ness et al., a difference between the quality of life of children scores of child and parent reports in newly diagnosed ALL patients was determined. According to this, physical function, emotional and behavioral role, pain, mental and general health, family activities sub-parameters were found to be lower than expected apart from the behavioral sub-parameter (34). In previous studies, it has been concluded that for child's quality of life, scores of the family is always worse than the scores of the child (35, 36). In a longitudinal study of newly diagnosed cancer patients, children reported a higher quality of life than their families. The biggest difference occurred in emotional functions with a score of 9.1 points, while the smallest difference occurred in physical functions with 2.8. These differences were observed to increase in terms of emotional, social, and school functions as children's ages increased (36). Parents often report that their children's quality of life is worse than that of their children because of their worries about their children. Nevertheless, Yeh et al. also found that the parents reported higher quality of life for their children during or after treatment (37). The variety of the results can be explained by the differences in communication gaps between children and parents or differences in family styles. In this study, this situation is faced only in the parents of children who have recurrent cancer.

The results showed a similar quality of life and many parameters for ALL and AML groups in our study, which ALL cases had the majority. According to a study conducted in Canada, it was found that the treated leukemia patients showed better physical, emotional, and social function scores than other types of cancer according to PedsQL (38). There are no known studies investigating AML and ALL types in terms of quality of life.

In our study, it was concluded that the quality of life of children who have recurrent cancer increases with age. Similar to our study, it was found in leukemia patients that the scores of procedural anxiety, treatment anxiety, and communication steps were lower in young children (39). Nonetheless, there are studies in the literature reporting that quality of life decreases with age as well (8).

### Limitations

In our study, children were divided into groups as who were diagnosed with cancer for the first time and who had the cancer recurrence, as well as ALL and AML-diagnosed. However, for the cancer types, an equal number of patients were not found due to the high incidence of ALL. Besides, the lack of detailed information about the type and treatment phases of medical treatment applied to children and the lack of a healthy control group can be counted as the limitations of this study.

## CONCLUSION

There may be an inconsistency between child and parent reports on the health-related quality of life in children with chronic illness. These differences, in fact, provide important opportunities for clinicians and researchers to demonstrate the potential causes of these differences, which may have an impact on treatment plans and clinical decision-making processes. Therefore, quality of life scores from both perspectives gained importance. In this study, many sub-parameters of health-related quality of life affected in children with ALL were examined and relations of them with various factors that could affect the quality of life were revealed. Overall, a higher quality of life was reported for children with recurrent cancer. It is hoped that the findings obtained from this study will guide the health care personnel to the specific areas to be improved in order to raise the quality of life of these children.

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