

Quality of Life in Parents of Turkish and Syrian Pediatric Bone Marrow Transplant and Oncology Patients

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ABSTRACT

Background: The success of the treatment depends on the well-being of the parents in pediatric cancer patients. In addition, migrants need to deal with the consequences of war. **Aim:** Our purpose was to compare the HRQoL of parents of Syrian and Turkish children followed in our bone marrow transplant and oncology units. **Materials and Methods:** One hundred SF 36 questionnaires, fifty from each group were collected between October 2019 and March 2020 in this cross-sectional study. Demographic characteristics of the patients (sex, age, cancer type, presence of relapse, duration of follow-up) and education level of parents were recorded. Analyses were performed using IBM SPSS Statistics version 20.0. **Results:** Turkish parents reported better results in physical functioning, emotional well-being, physical pain, general health, and physical health composite score ($P < 0.05$). There were more fathers in the Syrian group and education status was significant between the two groups ($P = 0.01$, $P = 0.001$, respectively). There was no correlation between QoL and education levels in the Turkish group. In Syrian parents, pain score was high in middle school graduates ($P = 0.043$). In the presence of relapse, although the physical function score decreased, the physical role function score increased in Turkish parents ($P = 0.0035$, $P = 0.005$, respectively). Syrian parents' emotional role function and energy/fatigue score were both increased when children had relapses ($P = 0.027$ for both). **Conclusion:** Migration is a complex issue. Turkish parents were better in physical functioning, emotional well-being, physical pain, general health, and physical health composite score. Screening for parental burden, assisting them to find appropriate support services is essential in improving the health and QoL of both our patients and their parents.

KEYWORDS: Childhood cancer, health-related quality of life, migration, parents

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INTRODUCTION

A migrant is any person who is moving or has moved across an international border or within a state away from his/her habitual place of residence. The conflict in Syria resulted in the displacement of nearly 5.0 million people. Currently, Turkey hosts over 3.6 million registered Syrians.^[1]

Worldwide, approximately 273,000 children and adolescents younger than 20 years of age are diagnosed with cancer per year.^[2] The diagnosis of cancer in children imposes high levels of pressure on the family, especially the parents.^[3] In addition, migrant pediatric

cancer patients and their families face stress due to displacement and financial needs.^[4]

Parent well-being is central to the quality of life and adaptation of children with cancer to treatment. Psychological distress of the parents is associated with poorer outcomes in pediatric cancer patients. The psychosocial support of pediatric cancer patients and their families is as important as their treatments.^[5,6]


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Health-related quality of life (HRQoL) is defined as the perceived health status and daily living with any changes in physical and mental health, and social functioning. Short Form-36 Health Survey (SF-36) questionnaire is one of the most widely used questionnaires in health studies for assessing the health status of adults aged 18 and older. The SF-36 questionnaire is a psychometrically reliable, reasonably brief, and simple instrument that is available in many languages.^[7]

Interest in measuring the health-related quality of life of the immigrants increased in recent years.^[8,9] Our purpose was to compare the HRQoL of parents of Syrian children welcomed in Turkey to parents of Turkish children getting treatment in our pediatric bone marrow transplant and oncology units by using the validated Short Form (SF36) questionnaires in Arabic and Turkish.^[10-13]

MATERIALS AND METHODS

This is a cross-sectional study using SF 36 questionnaire both in Arabic and Turkish. Parents from the outpatient clinics of pediatric oncology and bone marrow transplant units were approached for participation. Inclusion criteria were; the child aged 18 years or younger; the child was in active treatment; the child was at least 2 months post-diagnosis, the parent/sibling was not diagnosed with any physical/psychological illness and the parent/sibling was the primary caregiver of the child. The data were collected between October 2019 and March 2020.

The study was conducted according to the principles of the Helsinki Declaration. The study was approved by the Institutional Review Board. A pediatric oncology nurse approached eligible participants to invite them for their participation. After explaining the goals of the study, the questionnaires were given to one parent. Demographic characteristics of the patients (sex, age, cancer type, presence of relapse, duration of follow-up) and the education level of parents were recorded.

The Short-Form 36 is a generic questionnaire that measures the quality of life in adults that is composed of 36 items and eight scales, *i.e.*, physical function, role physical function, bodily pain, general health perception, mental health, role emotional function, energy, and social function. Scores for each domain range from 0 to 100, and lower scores indicate poorer QoL.

The SF-36 also can be scored in terms of a physical (PCS) and a mental (MCS) health composite score. The composite scores have a mean of 50 and a standard deviation of 10 and represent the mean and standard deviation of the country's population. Unfortunately, we did not have these data for Syria and

Turkey so we calculated the PCS and the MCS using the mean and standard deviation of the US general population as a reference.

Statistical analysis

Variables were summarized as mean and standard deviation. The normality of distribution for continuous variables was confirmed with the Shapiro–Wilk test. The relationship between sociodemographic variables (nationality, education, age) and having relapse with outcomes (eight domains) was evaluated using the Student's *t* test (nationality and having relapse), one-way ANOVA (parent's education level), and Pearson correlation coefficient (age). For *post hoc* multiple comparisons (for education levels), regarding the homogeneity of variances, Tukey, and Games–Howell tests were used. All analyses were performed using IBM SPSS Statistics version 20.0 statistical software package (IBM Corp. Released 2011, IBM SPSS Statistics for Windows, version 20.0. Armonk, NY: IBM Corp.). The statistical level of significance for all tests was considered to be 0.05.

RESULTS

One hundred questionnaires, fifty from each group were collected. In total, there were 68 oncology and 32 bone marrow transplant patients [Table 1]. More than half the children were males (69%). In the Turkish group, there were 13 transplants and 37 oncology patients. The median age of the patients was 105 months (range 3–219 months) and there were 18 girls and 32 boys. An equal number of hematologic malignancies ($n = 21$) and solid tumors ($n = 21$) were present and 8 patients had a non-hematologic condition. Sixteen patients had a relapse and the median follow-up time was 130 months (range

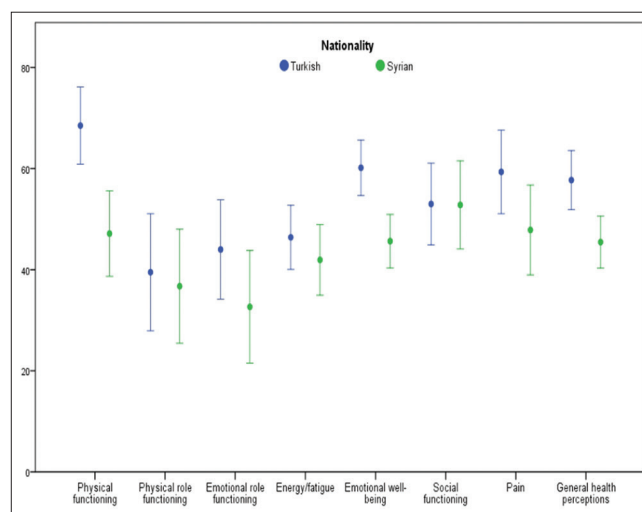


Figure 1: Turkish parents reported better results in physical functioning, emotional well-being, physical pain and general health, $p < 0.05$. The other parameters did not show any significant differences

Table 1: Demographic findings of the parents and the children

Children	Syrian	Turkish	P
Age (months) (Median, Min–Max)	84 (6–216)	105 (3–219)	0.2
Gender			
Female	17	18	
Male	33	32	
Diagnosis			0.14
Solid tumors	23	21	
Hematologic malignancies	18	21	
Non-hematologic conditions	8	8	
Relapse	10	16	0.17
Follow-up (months) (Median, Min–Max)	20.5 (8–118)	34 (11–136)	
Clinic			
SCT	19	13	
Oncology	31	37	
Parents			
Mother/father/sibling	15/33/2	28/22/0	0.01
Age (years) (Mean±SD)	35.6±8.6	38.6±7.5	0.63
Education			0.001
Elementary	31	13	
Middle	8	9	
High school	7	23	
University	4	4	
None	–	1	

Table 2: SF 36 domain scores of Turkish and Syrian parents

SF domain	Syrian (Mean±SD)	Turkish (Mean±SD)	P
Physical functioning	47.4±29.2	68.5±26.8	<0.001
Role limitations due to physical functioning	36.0±39.1	39.5±40.7	0.662
Role limitations due to emotional functioning	32.0±38.6	43.9±34.6	0.106
Energy/fatigue	41.8±24.0	46.4±22.3	0.324
Emotional well-being	44.8±19.1	60.1±19.3	<0.001
Social functioning	52.2±30.2	53.0±28.4	0.899
Pain	47.3±30.8	59.3±29.0	0.047
General health perception	45.5±17.7	57.7±20.5	0.002
Health change	56.0±32.1	54.0±26.1	0.746
Physical health composite	37.7±8.5	42.6±8.7	0.006
Mental health composite	36.2±10.8	39.6±9.5	0.09

11–136 months). There were 28 mothers and 22 fathers; the mean of age was 38.6 ± 7.53 years. Most of the parents were high school graduates (46%), 26% finished elementary school, 18% had graduated from middle school, 8% had university degree, and 1 (2%) parent never went to school but was literate in the Turkish group.

There were 15 mothers, 33 fathers, and 2 siblings in the Syrian group. The siblings were the main caregivers so

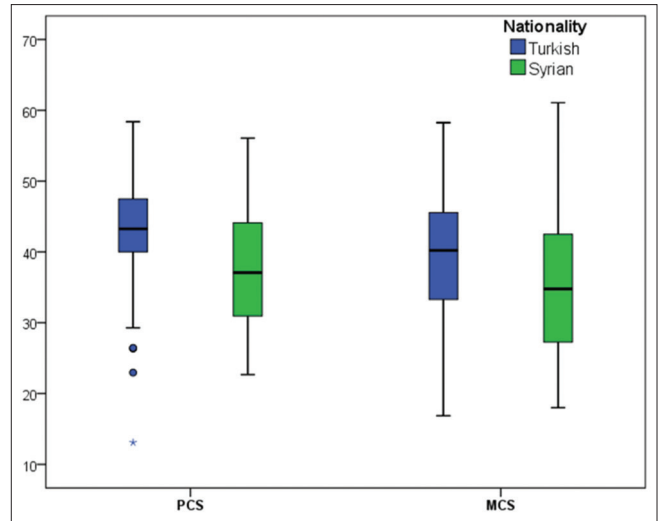


Figure 2: Physical and mental health composite scores of Syrian and Turkish parents, **p* < 0.05, PCS; Physical Health Composite Score, MCS; Mental Health Composite Score

they were included in the study. The mean of the age was 35.6 ± 8.6. Most Syrian parents were elementary school graduates (62%), 16% graduated from middle school, 14% were high school graduates, and 8% had university degrees. Thirty-one patients were followed at the oncology, whereas 19 patients were followed at the transplant clinic. The median age of the patients was 84 months (range 6–216 months); there were 13 girls and 37 boys. Twenty-three patients had solid tumors, 19 had hematologic malignancies, and eight had non-hematologic conditions. Ten patients had a relapse, median follow-up time was 20.5 months (range 8–118 months).

There was no statistical difference in parents' age (*P* = 0.63), patients' age (*P* = 0.2), and the diagnoses of the patients (*P* = 0.14) and relapse (*P* = 0.17) between the two groups. Most of the Syrian parents were elementary school graduates (*n* = 31), whereas most of the Turkish parents finished high school (*n* = 23) (*P* = 0.001). There were more fathers in the Syrian group compared to the Turkish parents (*P* = 0.01).

Turkish parents reported better results in physical functioning, emotional well-being, physical pain, and general health. The other parameters did not show significant differences [Table 2, Figure 1]. The duration of time after diagnosis did not correlate with QoL scores of both groups of parents except in the Turkish group; physical role function (*r* = 0.36 *P* = 0.01) and emotional role function (*r* = 0.28 *P* = 0.044) were weakly positive correlated; i.e., as the duration increased the scores increased. No correlation was found between the education levels and QoL scores in Turkish

parents. In Syrian parents, only the pain score was higher in middle school graduates than in elementary and high school graduates ($P = 0.043$). As the score increased, less pain is felt. Relapse gave different results in both of the groups. Turkish parents' physical function and physical role function were affected by relapse ($P = 0.0035$, $P = 0.005$, respectively). In the presence of relapse, although the physical function score decreased, the physical role function score increased. Syrian parents' emotional role function and energy/fatigue score were affected by the relapse of the disease; i.e., both scores were increased ($P = 0.027$ both). Physical health composite score was found to be statistically significant between Syrian and Turkish parents ($P = 0.006$), whereas mental health composite score was not ($P = 0.09$) [Figure 2].

DISCUSSION

Short Form 36 health survey has been used widely to assess the health-related quality of life. Sabbah *et al.*^[10] evaluated QoL in rural and urban areas in Lebanon using the short form SF-36 adapted into Arabic. Guermazi *et al.*^[11] translated SF 36 scale into Arabic language and adapted it for use in the Tunisian population. Both found that the Arabic version is reliable and valid.^[10,11] Kaya *et al.*^[12] investigated the reliability and validity of the Turkish version of SF-36 in patients with rheumatoid arthritis. Pinar assessed the reliability and construct validity of the SF-36, Turkish version on 419 cancer patients. They both concluded that the Turkish version of the SF-36 is a suitable instrument that could be employed in research in Turkey.^[12,13]

Results of the present study showed that Turkish parents were better in physical functioning, emotional well-being, physical pain, and general health as compared to Syrian parents. There is a statistically significant gender difference between the two groups ($P = 0.01$). In general, men score better in all SF36 domains compared to women in the population.^[14] In a study done in Iran using the GHQ-28 scale (GHQ-General Health Questionnaire), the mental health status of the mothers who have children with cancer, the physical symptoms, anxiety, and depression subscales were significantly worse than that of the fathers ($P < 0.05$).^[5] Although there were more fathers in the Syrian group than in the Turkish group, the scores in the aforementioned domains were lower in the Syrian group. On the other hand, Reinfjell *et al.*, on parents of 40 children with cancer in remission, the mental health status of the fathers in anxiety and depression subscales was found to be worse than that of the mothers and they also used GHQ to collect data in their study.^[15]

The education status was also statistically significant between the Syrian and Turkish parents ($P = 0.001$). There was no correlation between QoL and education levels in the Turkish group. However, in Syrian parents pain score was found high in middle school graduates as compared to elementary school and high school graduates. Being unaware or being too much aware of the situation (being an elementary or high school graduate) can lead to a decrease in the pain score, i.e., increase in the pain felt. Litzelman *et al.* showed that higher parental education is associated with worse QoL in their article investigating the quality of life among parents of children with cancer or brain tumors.^[16] Highly educated parents prefer to be actively involved in the medical decision-making process, and this may increase their stress and negatively impact their QoL.^[3,17]

Turkish and Syrian parents gave different responses in the presence of relapse. This can be due to sociocultural differences and factors affecting an individual's quality of life. In previous studies, fear of relapse has been shown to be prominent in many parents. When the actual relapse occurs, parents try to adapt psychologically to the reality of relapse.^[18]

De Graves *et al.* found that parents expressed a desire to maintain normalcy and avoid letting cancer dominate their lives after relapse, which is distinct from the new diagnosis period when the families' lives were centered around the child's treatment, hospital, and caring for the child.^[19]

Physical health score but not the mental health score was found to be statistically significant between Turkish and Syrian parents. The parents of children with cancer already have extensive psychological stress. Some of the stressors are an adaptation to an unpredictable treatment outcome, painful procedures and side effects of treatments, uncertainty about the possible late effects, and financial difficulties.^[6,20,21] In addition, Syrian parents face the psychosocial impact of war on them. While we were working on this project, the World witnessed another major forced migration crisis due to the Russian-Ukrainian conflict. Ukrainian parents who have children diagnosed with cancer reported their concerns about the emotional stress related to the dangers of war and uncertainty regarding their future.^[4]

This study has several limitations. The first one is the significant gender difference between the groups. There were more fathers in the Syrian group which may be due to sociocultural differences and residing in another country. This may be overcome by increasing the sample size in future studies. The second limitation is that we did not have the mean and standard deviation

of the Syrian and Turkish population to calculate the MCS and PCS and we used the US population values as a reference. Further population studies are needed to determine these values. Migration management itself is a complex issue. The most significant contribution of our study is that it is the first study that deals with the quality of life in caregivers of migrant pediatric oncology patients. At the time this paper was written, there was no solution to the war and it will take considerable time to establish the healthcare systems in the countries affected by war. Chronic life-threatening diseases like cancer have a high priority due to the need for high-cost and complex tertiary care. Psychosocial care of the family is as important as the child's medical and surgical treatment and a pediatric oncology patient's treatment success depends on parental well-being. Thus, screening for parental burden, role functioning, and stress and assisting them to find appropriate support services or treatment is essential in improving the health and QoL of both our pediatric oncology patients and their parents, regardless of their migration status.

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Conflicts of interest

There are no conflicts of interest.

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