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# Assessment of quality of life of children and adolescents with cancer during their treatment

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## Abstract

**Objective:** The purpose of this study was to evaluate the quality of life of children and adolescents with any type of cancer in all phases of their treatment.

**Methods:** Fifty-six newly diagnosed patients diagnosed with malignancy and hospitalized in a Pediatric Hematology-Oncology Unit in Athens were included in the study. Minneapolis-Manchester Quality of Life Instrument was used for data collection from July 2010 to December 2012. The assessment of children and adolescents' quality of life who were under treatment was performed in three different stages of treatment.

**Results:** The results of the study showed that the quality of life of children and adolescents with cancer did not change notably during their treatment ($F = 0.16$, $P = 0.86$ and $F = 0.03$, $P = 0.97$). For the first measurement, at the beginning of the therapy, the score on the scale for quality of life for children and adolescents was 3.44 and 3.88, respectively, in the middle of the treatment 3.36 and 3.89, respectively, and 3.43 and 3.89, respectively, when therapy was completed. Children and adolescents diagnosed with hematologic cancer stated higher quality of life scores ($z = -1.61$, $P = 0.05$ and $t = 2.64$, $P = 0.007$). Moreover, teenage patients ($F = 13.22$, $P = 0.001$) and male patients ($t = 2.31$, $P = 0.02$ and $t = 2.27$, $P = 0.02$) expressed better quality-of-life scores.

**Conclusion:** According to the results, children and adolescents with any kind of cancer have better quality-of-life scores at the end of their treatment, and when they are supported by their family.

**Key words:** quality of life, children, adolescent, treatment, cancer, gender, age

## Introduction

According to the international literature, pediatric cancer patients in the acute phase of the disease show reduced quality of life (QoL) (1–6). Nowadays, the measurement of QoL in pediatric patients with cancer is perceived that provides an important assessment of the welfare of children and families. Especially, by evaluating different QoL dimensions and in different treatment stages is supported that will assist in detecting children and families with an expected poorer QoL and guide health professionals with targeted interventions to improve it (7–9).

Many studies show that all aspects of quality of life, regardless of age, gender, diagnosis as well as the kind of treatment, are affected immediately after diagnosis. Children and adolescents express reduced organ function and autonomy, poor psychological status with reduced

self-esteem and depression, especially during the first 3 to 6 months after cancer diagnosis (1,2,7). According to previous studies, key determinants of QoL deterioration in pediatric cancer patients seem to be painful clinical interventions, surgery, intensive chemotherapy and hospitalization. However, clinical data support that QoL seems to improve about 6 months after diagnosis and much more after completion of the first year of treatment (1–8).

According to parental reports from earlier studies, the physical, emotional and social dimensions of the QoL of children with cancer is differentiated according to children's age, gender, diagnosis and the type of treatment. Moreover, in a number of studies, children compared with adolescents expressed a lower level of QoL for the immediate period after diagnosis. In addition, even though female children express greater autonomy than males, results from several studies have shown that they have a lower level of QoL than boys, especially in cognitive and emotional dimensions (2–4,7,9).

For example, children with leukemia, especially during the immediate period after diagnosis and the first months of treatment, state a major effect on their QoL with limited autonomy. This is partly attributed to the highly aggressive chemotherapy protocols applied during the therapeutic treatment as well as its complications. Interestingly, there is a noticeable improvement in their QoL, observed during the first year after diagnosis of leukemia (2–4,10,11). In contrast, in cases such as children suffering from brain tumors, since chemotherapy is not much aggressive, their QoL is not significantly affected during the first period after diagnosis and the first year of treatment. However, they express lower QoL after the first year of therapy due to the reduced physical, cognitive, emotional and social function (2,3,7,12,13).

Parental support immediately after diagnosis and during treatment has been associated with good QoL for children and adolescents, particularly for the subscale measuring emotional functions and less for the subscales measuring cognitive and social functions of children and adolescents (2,3,10,11,14–18).

## Aim

The main aim of this study was to evaluate the QoL of children and adolescents suffering from any form of cancer, in all phases of their treatment. Moreover, the effect of many possible determinants, such as gender, type of cancer, age and other demographic characteristics, on the QoL was assessed.

## Patients and methods

The sample of the study was all the children and adolescents 8–20 years of age diagnosed with any type of malignancy during the study period. Data were collected from July 2010 to December 2012 in a Pediatric Hematology-Oncology Unit in Athens. Thirty-four children aged 8–12 years old were diagnosed with cancer during the study period. In total, 30 children joined the study, since two mothers denied to sign the informed consent, one patient passed away due to treatment complication before the first measurement, and one child was transferred to another hospital just after the diagnosis. Concerning adolescents, 28 adolescents were diagnosed for cancer during the study period and 26 were included. In one case, mother did not sign the informed consent and one adolescent was excluded from the study due to mental disorder. Research was approved by the Scientific Council of the hospital (reference number: 7853/04-04-08).

Inclusion criteria were:

(i) Appropriate age: children 8–12 years and adolescents 13–20 years old
(ii) Diagnosis of any form of malignancy
(iii) Signed informed consent from both children and their parents
(iv) Sufficient knowledge and understanding of Greek language

Exclusion criteria were:

(i) Diagnosis of any mental disorder or illness
(ii) Patients and parents who cannot speak and write in Greek

### Tools for data collection

The questionnaire of Minneapolis-Manchester Quality of Life Instrument (MMOL—version for children and adolescents patients) was used for the collection of data. MMOL evaluates the QoL of children and adolescents who are under treatment. The children's version includes 32 items whereas the teenagers' version includes 41 items. It consists of seven subscales related to the body image, the cognitive functioning, family relationships, prospects for life, physical functioning and symptoms, psychological functioning and social functioning. The rating for each question ranges from 1 to 5. Level 5 refers to the highest level of QoL and to the minimal negative effect of cancer and its treatment in the QoL.

Many studies have checked validity and reliability of the Minneapolis-Manchester QoL questionnaire (19–21). According to the study of Klassen et al. carried out on 162 children and 268 adolescents with cancer, internal consistency reliability Cronbach's $\alpha$ was found to be 0.72 in the children's version (c8–12 years old) in all subscales, and 0.78 in the adolescents version (aged 13–20 years), in six of the seven subscales (22).

Prior to the translation, we obtained permission to use directly from Smita Bhatia by email. The translation of instruments was performed in three stages. First, the researcher and two independent translators translated the versions of the tool. At the second stage, the Greek translation for each version was given to two independent translators for reverse translation. At the third stage, the reverse translation for each version of the tools and their original English versions were distributed to a group of experts (two Professors from the University of Athens, two Pediatric Oncologists and two oncology nurses). In this stage, small changes took place according to experts' notices and applied to Greek translation of each version. Then the scale was assessed in a pilot sample of children and adolescents. The results showed that the scales of children were reliable and showed a high correlation between the first measurement (test) and the measurement after 4 weeks (retest).

According to the therapeutic protocols used during the study period the duration of treatment varied from 6 months to 2 years. More specifically, children and adolescents were under treatment for ~2 years for leukemia, 1 year for solid tumors, 1 year for lymphomas and 6 months for non-Hodgkin's lymphoma and B-cell lymphoma Burkitt's. The assessment of the QoL of children and adolescents who were undergoing treatment was accomplished in three (3) different stages of their treatment. The measurements of the QoL in the different phases of treatment at each type of cancer are presented in Table 1. The first measurement was performed at the beginning of the treatment, the second one in its middle and the third one upon completion of the treatment.

The period of time at the middle of the treatment, depending on the protocol for each type of cancer, was assigned as the 'middle' of the whole therapy for the second measurement of the QoL. Consequently, the second measurement of the QoL of children and adolescents with any type of leukemia was accomplished 1 year after the first measurement, with any type of solid tumor or lymphoma was performed

**Table 1.** The measurements of the quality of life (QoL) in the different phases of treatment at each type of cancer

| Type of cancer | First measurement | Second measurement | Third measurement |
|---|---|---|---|
| Leukemias | At the beginning of the treatment | One year after the first measurement | Two years after the first measurement |
| Tumors | At the beginning of the treatment | Six months after the first measurement | One year after the first measurement |
| Lymphomas | At the beginning of the treatment | Six months after the first measurement | One year after the first measurement |
| Non-Hodgkin's lymphoma and B-cell lymphoma Burkitt's | At the beginning of the treatment | Three months after the first measurement. | Six months after the first measurement |

6 months after the first measurement and for those treated for non-Hodgkin's lymphoma or B-cell Burkitt's was measured 3 months after the first measurement. In case that children and adolescents were not hospitalized by the time that their QoL should be measured, the researcher would arrange an appointment in order to collect data.

Treatment was considered as 'completed' when the last medication of the last circle of therapy was administered, either in the hospital or in an outpatient clinic, and before the patient entered in the 'maintenance phase', and he/she did not receive any chemotherapeutic agent or even if during this phase he/she was receiving any chemotherapy in small doses in a regular basis.

### Statistical analysis

The Statistical Package for Social Sciences (SPSS) program, version 21.0 (SPSS Inc., Chicago, IL, USA) was used for statistical analysis. Continuous data were expressed as means (±standard deviation), while categorical and dichotomous variables were expressed as percentages of the groups. Descriptive statistical techniques were used to estimate means and frequencies. Kolmogorov–Smirnov and Shapiro–Wilk statistical tests were used to test the normal distribution of the quantitative variables. The comparisons of the variables followed a normal distribution were performed by using parametric tests (*t*-test, analysis of variance, ANOVA), while non-parametric methods (Mann–Whitney test) were used for variables that violated normality. Moreover, the analysis of data was performed by using the General Linear Model for repeated measures. The reliability of the instrument, as well as its subscales was tested by using the internal consistency coefficient Cronbach's $\alpha$. A $P$ value of <0.05 was considered statistically significant.

### Pilot study

The pilot study took place from July 2010 to January 2011 on a sample of 23 adolescent patients and 40 survivors of childhood cancer. After the pilot study and recognizing the methodological difficulties encountered mainly due to the small sample, it was decided to merge the leukemia's and lymphomas into one category (type hematologic cancer) and the integration of the two cases mastocytosis (a case in a child and adolescent) in hematologic cancer type too. Finally, the variable 'marital status' was divided into two categories: 'married parents' and 'divorced, separated or single-parent family'.

## Results

### Demographic data

A total number of 56 children diagnosed with cancer were included in the study. Thirty of them were at school age whereas 26 were adolescents. The mean age of children was 10.93 ± 1.28 years, while the mean age of adolescent patients was 15.31 ± 1.72 years. The demographic characteristics of children and adolescent patients are presented in Table 2.

### Children

The reliability of the tool concerning the scale and the subscales for the QoL in children with cancer ranged from 0.56 to 0.99. The reliability of the subscales about 'physical functioning' and 'somatic symptoms' was low and presented a great level of heterogeneity. In contrast, the higher values of reliability were observed in both at the subscale of 'mental functioning' and the total. The sphericity assumption for the variable of the 'QoL' is not violated (Mauchly's $W = 0.96$, $x^2 = 0.88$, df = 2, $P = 0.64$). The application of the linear-model analysis of variance for repeated measures (GLM-repeated measures) did not prove any statistically significant difference for any variation for the QoL of children during treatment ($F_{(2,44)} = 0.16$, $P = 0.86$).

The results of the linear-model analysis for the variance of repeated measures did not show any statistically significant interaction between the variation for the QoL during the treatment therapy of children and the gender, the type of cancer, the age group (children aged 8–10 years and children in pre-teens 11–12 years). Furthermore, none of the examined demographic factors were found to affect statistically significantly the change of the QoL of children during the treatment therapy. The *t*-test analysis showed the existence of statistically significant differences in relation to gender in the first measurement (at the start of the treatment) and the second measurement (at the middle of the treatment). More specifically, at the beginning and at the middle of the treatment, boys reported better QoL than girls ($t_{(28)} = 2.31$, $P = 0.02$) and ($t_{(24)} = 2.12$, $P = 0.02$), respectively. The results on the differences in ratings for the QoL between boys and girls in all three phases of treatment therapy are presented in Table 3. *T*-test analysis demonstrated the existence of statistically significant differences regarding the marital status of children's parents and thus the influence of parental support in the second and third measurement. Specifically, children who were living with both parents reported better QoL at the middle and at the end of the treatment compared with those whose parents were divorced or separated ($t_{(24)} = 2.08$, $P = 0.02$ and $t_{(21)} = 2.70$, $P = 0.007$, respectively). The above study results are presented in Table 3.

Mann–Whitney *U*-test analysis test demonstrated statistically significant differences at the second and third measurement between gender and the subscale 'physical functioning'. For the second measurement, it was found that boys reported better QoL than girls ($z = -2.85$, $P = 0.002$). Similar results were observed at the end of the treatment ($z = -1.95$, $P = 0.02$). Statistically significant difference with respect to gender was found in the third measurement for the subscale for 'mental functioning'. Boys recorded the highest score for QoL

**Table 2.** Demographic characteristics of the sample (children and adolescents)

| Variables | Total, *N* % | | Children, 7–12, *N* % | | Adolescent, 13–20, *N* % | | Leukemia/ lymphoma, *N* % | | Solid tumor, *N* % | |
|---|---|---|---|---|---|---|---|---|---|---|
| Gender | | | | | | | | | | |
| Male | 32 | 57.1 | 19 | 63.3 | 13 | 50.0 | 18 | 60.0 | 14 | 53.8 |
| Female | 24 | 42.9 | 11 | 36.7 | 13 | 50.0 | 12 | 40.0 | 12 | 46.2 |
| Diagnosis | | | | | | | | | | |
| Leukemia/lymphoma | 30 | 53.6 | 14 | 46.7 | 16 | 61.5 | – | – | – | – |
| Solid tumor | 26 | 46.4 | 16 | 53.3 | 10 | 38.5 | | | | |
| Nationality | | | | | | | | | | |
| Greek | 51 | 91.1 | 27 | 90.0 | 24 | 92.3 | 29 | 96.7 | 22 | 86.4 |
| Other | 5 | 8.9 | 3 | 10.0 | 2 | 7.7 | 1 | 3.3 | 4 | 15.4 |
| Brother or sister | | | | | | | | | | |
| Yes | 51 | 94.4 | 27 | 93.1 | 24 | 96.0 | 27 | 3.6 | 24 | 92.3 |
| No | 3 | 5.6 | 2 | 6.9 | 1 | 4.0 | 1 | 96.4 | 2 | 7.7 |
| Educational level of the mother | | | | | | | | | | |
| Primary education | 14 | 25.9 | 10 | 34.5 | 4 | 16.0 | 5 | 17.9 | 9 | 34.6 |
| Secondary education | 22 | 40.7 | 10 | 34.5 | 12 | 48.0 | 14 | 50.0 | 8 | 30.8 |
| Higher education | 18 | 33.3 | 9 | 31.0 | 9 | 36.0 | 9 | 32.1 | 9 | 34.6 |
| Educational level of the father | | | | | | | | | | |
| Primary education | 17 | 31.5 | 8 | 27.6 | 9 | 36.0 | 8 | 28.6 | 9 | 34.6 |
| Secondary education | 23 | 42.6 | 13 | 44.8 | 10 | 40.0 | 13 | 46.4 | 10 | 38.5 |
| Higher Education | 14 | 25.9 | 8 | 27.6 | 6 | 24.0 | 7 | 25.0 | 7 | 26.9 |
| Marital status of parents | | | | | | | | | | |
| Married | 51 | 91.1 | 27 | 90.0 | 24 | 92.3 | 29 | 96.7 | 22 | 84.6 |
| Separated | 5 | 8.9 | 3 | 10.0 | 2 | 7.7 | 1 | 3.3 | 4 | 15.4 |
| Total | 56 | 100 | 30 | 53.6 | 26 | 46.4 | 30 | 53.6 | 26 | 46.4 |

**Table 3.** Rating for the QoL of children by gender and their parents' marital status during their treatment

| Gender | Boys, M (SD)[a] | Girls, M (SD) | t | P | Mean difference | 95% Confidence interval of the difference |
|---|---|---|---|---|---|---|
| First measurement | 3.54 (0.32) | 3.26 (0.33) | 2.31 | 0.015 | 0.28 | 0.03–0.54 |
| Second measurement | 3.47 (0.35) | 3.16 (0.35) | 2.12 | 0.023 | 0.31 | 0.008–0.60 |
| Third measurement | 3.52 (0.38) | 3.25 (0.37) | 1.61 | 0.061 | 0.27 | −0.08–0.61 |
| Marital status | Married | Separated | | | | |
| First measurement | 3.47 (0.33) | 3.19 (0.46) | 1.31 | 0.10 | 0.27 | −0.15–0.70 |
| Second measurement | 3.41 (0.36) | 2.96 (0.20) | 2.08 | 0.024 | 0.45 | 0.003–0.89 |
| Third measurement | 3.50 (0.34) | 2.92 (0.36) | 2.70 | 0.006 | 0.58 | 0.13–1.02 |

[a]Mean (standard deviation).

compared with girls ($z = -1.83$, $P = 0.034$). Moreover, gender was found to be a statistically significant factor for the subscale 'somatic symptoms' for the measurement concerning the middle of the treatment, where boys outweighed girls ($z = -1.83$, $P = 0.03$). In addition to this, statistically significant difference was found in the same subscale for the second and the third measurement, while testing the type of malignancy, where children with hematological malignancy reported a higher level of QoL compared with those suffering from solid tumors ($z = -1.61$, $P = 0{,}05$ and $z = -2.62$, $P = 0.003$, respectively). Finally in the subscale for 'perspective for life' statistically significant difference was found only for the second measurement, where children aged 8–10 years reported better QoL and consequently optimistic about their future when compared with older children ($z = -1.77$, $P = 0.04$). The results are shown in Table 4.

## Adolescents

The reliability of the tool for the QoL in adolescent patients with cancer ranged from 0.84 to 0.94. Similarly to children, the sphericity assumption for the variable of 'QoL' is not violated (Mauchly's $W = 0.83$, $x^2 = 3.80$, df = 2, $P = 0.15$) in adolescents. The application of the linear-model analysis of variance for repeated measures (GLM-repeated measures) did not found any statistically significant difference for the variation in the QoL for children during treatment ($F_{(2,42)} = 0.03$, $P = 0.97$). The analysis of the observed means demonstrated a statistically significant difference only for the first measurement, where adolescents suffering from solid tumors had lower scores for the QoL compared with their peers with hematologic malignancy ($t_{(23)} = 2.17$, $P = 0.02$).

Statistical analysis for the subscale 'physical functioning' for adolescents with malignancy demonstrated for the first measurement only, a statistically significant difference with respect to the diagnosis since, at the beginning of the treatment, adolescents with hematological malignancy indicated a higher level of QoL compared with those diagnosed with some form of solid tumor ($t_{(23)} = 2.5$, $P = 0.02$). In addition to this, for the subscale for 'mental functioning' there was statistically significant difference regarding gender for the second measurement only, where boys scored higher ratings than girls

**Table 4.** Statistically significant differences of QoL according the subscales of the tool

| | Measurements | | |
|---|---|---|---|
| | First | Second | Third |
| Children | | | |
| Gender | Total ($t_{(28)} = 2.31$, $P = 0.02$) | Physical functioning ($z = -2.85$, $P = 0.002$)<br>Somatic symptoms ($z = -1.83$, $P = 0.03$)<br>Total ($t_{(24)} = 2.12$, $P = 0.02$) | Physical functioning ($z = -1.95$, $P = 0.02$)<br>Psychological functioning ($z = -1.83$, $P = 0.034$) |
| Diagnosis | NS[a] | Somatic symptoms ($z = -1.61$, $P = 0,05$) | Somatic symptoms ($z = -2.62$, $P = 0.003$) |
| Marital status | NS | Total ($t_{(24)} = 2.08$, $P = 0.02$) | Total ($t_{(21)} = 2.70$, $P = 0.007$) |
| Age group | NS | Outlook on life ($z = -1.77$, $P = 0.04$) | NS |
| Adolescents | | | |
| Gender | Body image ($t_{(22)} = 2.27$, $P = 0.03$)<br>Social functioning ($z = -2.79$, $P = 0.002$) | Psychological functioning ($z = -1.78$, $P = 0.04$)<br>Social functioning ($z = -2.31$, $P = 0.01$) | NS |
| Diagnosis | Physical functioning ($t_{(23)} = 2.5$, $P = 0.02$)<br>Intimate relations ($z = -1.91$, $P = 0.03$)<br>Total ($t_{(23)} = 2.17$, $P = 0.02$) | Social functioning ($z = -1.79$, $P = 0.04$) | Social functioning ($z = -1.74$, $P = 0.04$)<br>Intimate relations ($z = -2.46$, $P = 0.006$) |

[a]Not statistically significant.

**Table 5.** Comparison of QoL scores for children and adolescents during treatment

| | *M* (SE)[a] | *t* | *P* | Mean difference | 95% Difference confidence of the interval |
|---|---|---|---|---|---|
| First measurement | | | | | |
| Children | 3.44 (0.06) | −4.25 | 0.000 | −0.44 | −0.65 to −0.23 |
| Adolescents | 3.88 (0.08) | | | | |
| Second measurement | | | | | |
| Children | 3.36 (0.07) | −4.39 | 0.000 | −0.53 | −0.77 to −0.29 |
| Adolescents | 3.89 (0.10) | | | | |
| Third measurement | | | | | |
| Children | 3.43 (0.08) | −3.51 | 0.001 | −0.46 | −0.73 to −0.20 |
| Adolescents | 3.89 (0.1) | | | | |
| Total | | | | | |
| Children | 3.28 (0.10) | 13.22[b] | 0.001 | −0.73 | −1.05 to 0.41 |
| Adolescents | 4.01 (0.12) | | | | |

[a]Mean (standard error).
[b]Test *F*.

($z = -1.78$, $P = 0.04$). The subscale for the 'body image' demonstrated statistically significant difference regarding gender only at the beginning of the therapeutic treatment where boys scored a higher level of QoL when compared with girls ($t_{(22)} = 2.27$, $P = 0.03$).

Statistically significant differences were found in the subscale for 'social functioning' in the first and the second measurement with reference to gender where teenage girls reported better QoL in social relationships than boys ($z = -2.79$, $P = 0.002$ and $z = -2.31$, $P = 0.01$, respectively). There was also statistically significant difference in the same subscale for the second and the third measurement in relation to the diagnosis, where adolescents with hematologic malignancy reported better social relationships compared with those with a solid tumor ($z = -1.79$, $P = 0.04$ and $z = -1.74$, $P = 0.04$, respectively). Moreover, a statistically significant relationship was found in the second measurement, for the same subscale, between QoL and the father's educational level ($\chi^2 = 7.13$, df = 2, $P = 0.03$). Regarding the diagnosis, there was statistically significant difference in the subscale for the 'relations with others' in the first and the third measurement, where adolescents suffering from hematologic malignancy scored higher ($z = -1.91$, $P = 0.03$ and $z = -2.46$, $P = 0.006$, respectively). These results are presented in Table 4. No other demographic data were found to be statistically significant.

## Children vs. adolescents

Statistical analysis of the data using the linear-model analysis for repeated measurements demonstrated statistically significant difference for the scores of QoL between children and adolescents for each of the three different measurements and for the total measurement as well. More specifically, adolescents reported better overall QoL compared with children ($F_{(1,43)} = 13.22$, $P = 0.001$) in all phases of the treatment when QoL was assessed between the two age groups (Table 5). No other demographic factor was found to be statistically significantly interacted in the variation of the QoL during treatment of children and adolescents with any type of malignancy. Table 6 summarized the change in the QoL mean scores for children and adolescents during the treatment course.

Statistical analysis of data concerning the subscales of the tool demonstrated statistically significant difference in the first and the second measurement and marginal statistically significant difference in the

**Table 6.** The change of the QOL in children and adolescents with cancer during the treatment course

| | *Beginning* (first measurement) | *Middle* (second measurement) | *End* (third measurement) |
|---|---|---|---|
| Children | 3.44 (0.35)[a] | 3.36 (0.37) | 3.43 (0.39) |
| | 3.31–3.57[b] | 3.21–3.51 | 3.26–3.60 |
| Adolescents | 3.88 (0.43) | 3.89 (0.47) | 3.89 (0.49) |
| | 3.71–4.06 | 3.69–4.09 | 3.67–4.10 |

[a]Mean (SD)
[b]95% Confidence intervals.

third one. Adolescents recorded higher score in physical functioning than children (first measurement: $z = -1.79$, $P = 0.04$ and second measurement: $t_{(49)} = -3.17$, $P = 0.003$). For the third measurement, the difference was marginal toward the adolescents ($t_{(44)} = -1.90$, $P = 0.07$). In contrast, the results in the subscale for 'somatic symptoms' have demonstrated statistically significant difference toward children in all the three measurements (first measurement: $z = -5.39$, $P = 0.000$, second measurement: $z = -4.12$, $P = 000$, third measurement: $z = -4.33$, $P = 0.000$). It seems that children are less affected by the symptoms of the disease, the treatment therapy and especially the pain and adolescents indicate better psychological functionality compared with children in the second and the third measurement while the difference is marginal for the first measurement (first measurement: $z = -1.70$, $P = 0.05$, second measurement: $z = -2.73$, $P = 0.003$, third measurement: $z = -2.16$, $P = 0.02$). As far as the rating for the subscale for 'perspective for life', adolescents were more positive than children in all the three measurements but statistically significant difference was found only in the first and the third measurement ($z = -2.68$, $P = 0.003$ $z = -1.93$, $P = 0.024$, respectively).

## Discussion

Our results are in accordance with results from previous studies that suggest the types of malignancies, the chemotherapeutic treatment with strong cytotoxic drugs (along with the number of therapy cycles) and various demographic factors are correlated, positively or negatively, to the QoL of children and adolescents with cancer during the whole treatment (23–27). Moreover, the present study corroborates previous findings on the long-term effects of surviving cancer, suggesting that QoL is stabilized at a level comparable with that found among healthy children in the community. More specifically, our results revealed that the QoL of children and adolescents did not significantly change during the treatment. In addition, research findings suggest that childhood cancer survivors do not experience impaired QoL or behavioral maladjustment compared with population norms or matched controls (23–27).

In contrast, some other studies concluded that pediatric patients with any kind of cancer, during the acute phase of the disease and when subjected to particular therapeutic protocols, state impaired QoL regarding the physical and emotional functioning, but these impairments disappeared at subsequent assessments and QoL is improved after the successful completion of treatment (1–7). Besides the initial shock, cancer diagnosis in a child or in an adolescent is usually accompanied by the development of a protective background by the family in Greek culture (3). Within this background of 'overprotection', the parents offer affection and love in an attempt to escape from the threat of cancer. At the same time, the children develop their own defenses, thus the impact of the disease upon their QoL may be limited (3).These results suggest in a level that negative life events, such as life-threatening diseases, do not necessarily lead to long-term impairment of well-being but can also generate positive effects.

According to Landolt et al., Meeske et al., Shankar et al., Eiser et al., diagnosis with cancer is a very stressful situation for children and adolescents. During the first 3–5 months after diagnosis, they have reduced organ function and autonomy, poor psychological status with reduced self-esteem and depression. These disorders are mainly due to the aggressive outset of treatment, the pain arising from multiple interventions and to the limitations imposed by the disease and due to the prolonged hospitalization, the lack of activities and the fear for the future. Furthermore, complications related to diagnosis and the type of malignancy (such as endocrinological, neurological, etc) have been related to an impairment to patients' and their family's level of QoL. Nowadays, a number of treatment improvements such as the use of central venous catheters for chemotherapy and prolonged therapy, the satisfactory management of pain with adequate analgesics, the use of antiemetics and the early management of treatment complications seem to have a positive effect on QoL, especially after the first stages of disease. However, cancer treatment remains a 'heavy load' for both children and parents. Our findings support these evidence since QoL was improved during the first 3–6 months after diagnosis and even more after the completion of the first year of the treatment (1,2,4,5,28).

Many studies refer to the need for specific interventions in order to improve QoL in children with malignancies. More specifically, Garland et al., Lane, Madden et al., Martel et al. and Post-White et al., suggest that the use of alternative therapies (creative arts therapy, such as dance, music, poetry, drama, etc) may contribute positively to the improvement of the QoL of children and adolescents with cancer during treatment. These are successfully applied in children and adolescents during their treatment in many oncology centers and they have been linked with increased ability to cope with hospitalization and significantly reduce the negative symptoms, improving in this way their QoL (28–32). Moreover, the program for chemotherapy at home (Lane, 2006), which is applied during the last decade in many pediatric oncology centers, gives the opportunity to children and adolescents with cancer to spend more time at home and have less disruption to family schedule, having as a result in the improvement of their QoL (29).

According to previous studies, parents believe that physical, emotional and social status of their children is depended mainly on the type of malignancy, child's age and gender. This evidence is justified by the parents' tendency to project their HRQoL onto their children. This aspect should receive special attention from those who care for these children and families, since parents may have a direct and indirect effect on their child's QoL in many ways (2,4,7,9,33). Our results revealed that children and adolescents diagnosed with solid tumors stated lower QoL scores in comparison with their peers who had hematologic cancer. Moreover, these findings are similar to the results of other studies reporting that children and adolescents with hematologic cancer and particularly leukemia, show initially a reduced level QoL, which is improved as the treatment progress, especially after the first year of their diagnosis (1,2,4,11). Reduction of the administered toxic chemotherapy, supportive treatment and appropriate treatment of the disease's and the chemotherapy's complications such as the treatment of the anemia and the reduction of the transfusions, supports the increase in the level of QoL. However, according to the National Cancer Institute, during the final stage of the disease and 6 months before the end of their life, children and adolescents diagnosed with hematologic malignancy report again a very low level of their QoL (34). In contrast, for children and adolescents diagnosed with

solid tumors, especially brain tumors, QoL is not influenced significantly during the first year of treatment, since the very first chemotherapeutic treatment is not much aggressive (2,4,7,12,13). In conclusion, the experience of the different stages along the course of the disease allows for a progressive adaptation of the child and parents to the situation and, consequently, an improvement of HRQoL.

Children and adolescents diagnosed with brain tumor who were treated with radiotherapy, comparing to those treated with other kind of therapies, present a significantly lower level of QoL, having any alterations in their physical, emotional and social function. Children receiving radiation therapy express variability in their QoL with increased morbidity and deteriorated physical and psycho-emotional status. Their school performance is reduced and they need special services for their education. On the other hand, children receiving radiotherapy in combination with chemotherapy have a better QoL. Moreover, children and adolescents receiving radiation combined with chemotherapy, with or without surgery, have reduced physical functions compared with those undergoing only surgery (4,12,19,30).

Overall, boys of the studied population reported better QoL, mainly in the subscales of physical and mental functions, compared with girls who reported better QoL in social functions. These results are in accordance to similar studies reporting that, although girls have greater autonomy, they have lower QoL than boys especially with regard to the cognitive and emotional functioning (2,4,7,9). In the study of Huda Abu-Saad et al. (42), girls with cancer aged 7–18 years compared with boys, had a lower average scale score in their QoL, due to pain, somatic symptoms and their poor body image. Perdikaris et al. (2009) (35) found that the girls with cancer reported statistically significant higher fatigue scores (overall fatigue) than the boys. In our study, changes in the body image primarily influenced girls. Girls usually pay more attention to their physical appearance than boys (36,37). On the other hand, in the study of Matziou et al., girls with cancer did not have significantly higher depression score than the boys did, although changes in body image influence mostly girls (33,36,37). Depression has obviously a negative impact on young patients' QoL (33).

According to our finding, the adolescents reported better QoL compared with children, especially in the subscales of physical, psychological and perspectives for life. Children reported better QoL only in the subscale about physical symptoms, since they appeared to be less affected by the symptoms of the disease and its treatment, especially concerning pain. In addition, in a number of studies, youngest children reported lower QoL compared with older children, especially at the first stage after diagnosis of the malignancy (2,4,7,9). In contrast, Tomlinson et al. (38) found that older children, who have been diagnosed with cancer a long time ago (cancer survivors), compared with younger children who have recently been diagnosed with cancer, may have lower QoL because they are too concerned for the future. Huda Abu-Saad et al. (42) came to a similar conclusion, demonstrating that adolescents with cancer (13–18 years old) report lower QoL than younger children (7–12 years) attributed to anxiety, fatigue and nausea.

Children and adolescents living with both of their parents reported better QoL than those whose parents were divorced or separated. Many other studies support also that parental support at the time of the diagnosis of the cancer and during treatment has been linked to a satisfactory QoL of children and adolescents, mainly for the subscale measuring emotional functions and less for the subscales for cognitive and social functions (1,3,11,15–18). Moreover, some other studies have shown that QoL of children diagnosed with cancer is affected negatively when there are health problems, physical or psychosocial, for any other members of their family (23–27). In particular, it has been found that there is a positive correlation between maternal depression and other chronic health problems in parents or siblings where children and adolescents with cancer express reduced QoL (23,25,26).

Sung et al (9) report that the measurement of QoL in cancer pediatric patients becomes increasingly necessary as it provides a meaningful assessment of their prosperity. The concept of the QoL supports the identification of children and adolescents expected to express poor QoL and helps health professionals to provide timely interventions. More specifically, pediatric oncology nurses should provide personalized care not only for the implementation of strict treatment protocols but for the continuous assessment of the physical, mental and emotional health status of children and adolescents with cancer as well, focusing to reduce pain, fatigue, sleep disorders, stress, anxiety and fear and increasing hope and positive emotions in order to prevent permanent psycho-emotional disorders, improving in this way their QoL (39–41).

## Conclusion

According to the results of the study, QoL of children and adolescents with cancer does not change significantly during treatment therapy. In accordance to other authors we conclude that pediatric cancer patients experience positive QoL outcomes, despite physical and psychosocial impairments due to this life-threatening event. Children and adolescents diagnosed with hematologic cancer, adolescents and boys and patients living with both of their parents, expressed higher scores for their QoL. In conclusion, illness interpretation and attitude against cancer and its treatment is crucial for their self-reported stress, strain, and well-being levels. QoL measures can be used as an early indicator of disease progression and an endpoint for treatment comparisons in many cancer types, particularly in advanced stages.

## Limitations of the study

The study presents limitations related mainly to the small sample size that does not allow generalization of the results. The sample was based on a single blood unit pediatric oncology hospital and this can lead to an error selection (selection bias), for possible systematic differences (e.g. sex, socio-economic status) within the population and study addressed the final population represents sample. However, collecting a sufficient sample of patients from a public hospital oncology unit, a reference center for childhood malignancies effort was made to reduce the selection bias.

Another limitation was the heterogeneous composition of the sample in terms of medical diagnoses, symptom severity and diverse treatments. Furthermore, during the conduct of this study, the material was classified according to the type of cancer and thus showed the class of tumors of the hematopoietic system and the category of solid tumors. So as each type requires its own treatment protocol. Therefore, it is understood that the two categories of cancer followed different study protocols with different chemotherapeutic drugs. Conclusively, we cannot exclude that more fine-grained comparisons between diagnostic categories may demonstrate differences.

The studies involving pediatric patients with the same tumor type will help to better assess the QoL during treatment. Such analyses, however, will require more subjects for each diagnostic category than were available for the present analyses and they are practically unavailable in Greece. Moreover, young patients with brain tumors are usually excluded from such studies, because they face special problems. This study included patients with brain tumors due to the small number of

cases in the solid tumors category. Teenagers of the study who were receiving treatment had an average age of 15 three years and those who had completed 17.5 years. Among the middle (14–17 years) and distal adolescence (18–20 years) there may be differences in the QoL. The impact on QoL of children and adolescents diagnosed with cancer is best understood by comparing the QoL of healthy peers. The studies involving healthy peers will help to better assess the QoL of children and adolescents during treatment and after its completion.

In conclusion, the absence of long-term consequences after the end of treatment does not imply that QoL is not affected for a short time interval during treatment, in relation to complications or adaptation to the disease. Especially concerning the level of disease adaptation, we recommend to conduct longitudinal research, involving different observers (child, peers, parents, healthcare professionals).

## Nursing implications

To date, most research studies on the QoL of children, adolescents and cancer survivors were directed toward the development of reliable and valid measurement tools and description. The application in clinical practice and the Greek data is necessary as it helps to provide individualized nursing care to children and adolescents who have been diagnosed with cancer. It is of great importance the Greek version of Minneapolis-Manchester Quality of Life Instrument to be extended to other centers and be tested in a future larger cohort associated with an intervention toward pediatric cancer after the stratification of the patient group.

In our study, there was no statistically significant difference in QoL scores of the young patients with cancer. According to the findings of the survey, nurses should accept QoL as an important and concrete issue of the treatment for childhood cancer and be aware of its achievement. An important step would be the incorporation of QoL into the routine nursing assessments of young patients who suffer from cancer. The acute recognition and identification of indicators and factors that negatively affect QoL will be of critical importance for the early diagnosis and the proper treatment as well. By including education of patients, parents and healthcare professionals in order to recognize signs and symptoms that may negatively affect the treatment, the goal of providing a better QoL in children and adolescents with cancer will be succeeded. To create a change in practice and challenge assumptions, education will be fundamental and this must be underpinned by evidence from research and clinical practice.

In an era in which the participation of children and adolescents with cancer and family in decision-making and planning of care continues to grow, the assessment of QoL seems to be extremely important. Their views about their needs (physical, psycho-emotional and social) may be useful for hospital data to improve the care provided, which opens new horizons for future research studies.

## Conflict of interest statement

None declared.

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