

# Assessment of Quality of Life among Pediatric Patients with Cancer in Khartoum Oncology Hospital: A Cross-Sectional Pilot Study

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## Abstract

**Background:** The quality of life (QoL) of pediatric oncology patients is multidimensional, including the social, physical, and emotional executive functions of the child and the family. The study aimed to assess QoL in pediatric patients with cancer on and off treatment and to determine the factors that affect the QoL. **Methodology:** This was a cross-sectional study that included 104 children aged between 7 and 17 years, who were recruited using a Non-probability convenient sampling method. The Pediatric Quality of Life Inventory (PedsQL™ 4.0) generic core scale and the PedsQL™ 3.0 cancer module were used as data collection tools. The data were coded, entered, and analyzed by using Statistical Package for Social Sciences. *T*-test and ANOVA tests were used for the data analysis. **Results:** Out of 104 patients, males were 70 (67.3%). The QoL score mean was (71.68 ± 11), with the highest score was found in subscale procedural anxiety (86.54 ± 23.09), and the lowest score was found in subscales general health (44.47 ± 30.76). The older children showed the lowest QoL score (mean 68.38 ± 8.22) comparing to with younger age (70.5 ± 13.15). There were no significant differences between overall QoL scores and gender, type of cancer, and treatment status. **Conclusion:** Children reported an acceptable overall QoL score mean. There was no significant difference in QoL between males and females, treatment status, type of cancer. The total score of the PedsQL™ 4.0 scale was significantly correlated with pain, nausea, worry, cognitive problem, perceived physical appearance, and satisfaction subscales.

**Keywords:** Health-related quality of life, Khartoum Oncology Hospital, pediatric cancer, quality of life

## INTRODUCTION

Cancer is a threatening health problem for both developed and developing countries, the number of annually diagnosed cases is on an increasing manner.<sup>[1]</sup> Pediatric cancers differ markedly from adult cancers in their nature, distribution and prognosis. Epidemiologically, the annual number of new cases of childhood cancer exceeds 200,000, and more than 80% of these are from the developing world.<sup>[2]</sup> In Africa, approximately 50000 new cases of childhood cancer are diagnosed every year.<sup>[3]</sup> Pediatric Cancer has its challenges, which may affect the child's health and growth, and this will affect their quality of life (QoL), which is an important factor in assessing the effect of disease on the patient health status.<sup>[4]</sup>

In Sudan, the cancer prevalence rate per year was 5000–7000 among adults and 300–400 among children.<sup>[5,6]</sup> Moreover, the

incidence of childhood cancers in Sudan is persistently rising.<sup>[7]</sup> The patterns of childhood cancers showed that Lymphoma was the most prevalent, followed by acute lymphoblastic leukemia and kidney tumors, with higher prevalence among boys than girls.<sup>[5,8]</sup> Furthermore, studied showed that the incidence of pediatric cancer is higher in children from rural areas than in urban areas.<sup>[8,9]</sup>

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QoL is a multi-dimensional concept consisting of the patient's perception about the impact of disease and its treatment on his/her functioning aspects of life, including the psychological, physical, and social aspects.<sup>[10,11]</sup> QoL of the children with cancer and their families is strongly affected, and their QoL quietly differs from those who are at the end of their therapy, or not receiving treatment.<sup>[12,13]</sup> Many studies showed that all aspects of QoL, regardless of age, gender, diagnosis as well as the kind of treatment, are affected immediately after diagnosis.<sup>[12-15]</sup> Health-related QoL is an important outcome which allows the patient to understand the impact of the disease and the treatment on different life aspect.<sup>[15]</sup> Several studies have a marked difference in health-related QoL between the parent and pediatric patients.<sup>[15-17]</sup> Moreover, supporting parents during the treatment of their children will improve their QoL,<sup>[13,18]</sup> while the parents who experience high levels of stress could making them less cohesive and more conflicted.<sup>[19]</sup>

Accurate health-related QoL could make an improvement in the QoL of children with cancer.<sup>[20]</sup> In Sudan, limited researches about QoL among pediatric patients with cancer were carried out, as comprehensive care in the form of support to the family and children is lacking in Sudan. Thus, we conducted this research to highlight and attract the attention of those interested in this important aspect of the impact of cancer by assessing the QoL among pediatric patients with cancer in Khartoum Oncology Hospital that may usefully serve the children who are suffering and their families in the future.

## METHODOLOGY

### Study setting

This study was a descriptive cross-sectional, hospital-based study. The study was conducted in the pediatric unit in Khartoum Oncology Hospital, Khartoum, Sudan. The data were collected in June 2018.

### Participants' selection

All patients were admitted to the pediatric unit in Khartoum Oncology Hospital, and those who came for follow up during the research period were selected (total coverage). The sample size in this study was 104 participants.

### Inclusion criteria

The study recruited all children diagnosed with cancer on treatment and off treatment, at the age between 7 and 17 years attended the hospital in June 2018.

### Data collection tool

In order to measure the health-related QoL in children with cancer, the data were collected by direct interviews of patients and co-patients (caregivers) by using a combined-structured questionnaire, included PedsQL™ 4.0 Generic Core Scale, and PedsQL™ 3.0 Cancer Module Scale.<sup>[21,22]</sup> The PedsQL™ 4.0 Generic Core Scale comprises 23 items in 4 domain-specific scales of functioning (physical, emotional, social, and school). In addition, it also generated a total scale score, a physical health summary score, and a psychosocial

health summary score.<sup>[21]</sup> The PedsQL™ 3.0 Cancer Module comprises 27 items on the following domain-specific scales (pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication).<sup>[22]</sup>

### Scoring the data

Similar five-point response scale is used for all items of the two scales. The items were then reverse-scored and linearly transformed as (0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0) and standardized to a scale range (0–100) so that higher scores represented a better QoL, while lower scores mean a poorer QoL, as described by Varni's method of scoring.<sup>[21,22]</sup> Regarding the scoring for PedsQL™ Generic Core Scale, we calculated the mean of the score. Psychosocial health summary score = sum of the items over the number of items answered in the emotional, social, and school functioning scales. While physical health summary score = physical functioning scale scores. Hence total score: The sum of all the items over the number of items answered on all the scales. For the PedsQL™ Cancer Module, we calculated the mean score, then the total score by the same method as mentioned earlier.

### Ethical consideration

Ethical approval was taken from the Faculty of Medicine, University of Bahri. Then further approved by Khartoum Discrete Ministry of Health, General Manager of Khartoum Oncology Hospital, and the head of the pediatric department in the hospital. Written informed consent was taken from the patients and their parents.

### Data analysis

The data were coded, entered, and analyzed using International Business Machines (IBM). Statistical Package for Social Sciences for Windows, Version 20.0 software (Armonk, NY, USA: IBM Corp). Descriptive statistics (Mean and standard deviation), as well as inferential statistics (*t*-test, ANOVA), were used for checking the significant differences between scores and variables.  $P < 0.05$  was considered significant.

## RESULTS

In this study, 104 pediatric patients were recruited. As shown in Table 1, 70 (67.3%) of them were males, and 34 (32.7%) were females with regard to age distribution, 53 (51%) of the participants aged 11–14 years. Clinically, 73% of the participants had the hematological type of cancer, and 79% of them were on cancer the treatment. 73% of them were newly diagnosed with cancer, and they were on cancer treatment. Moreover, 88.5% of the participants were treated with chemotherapy.

Regarding the QoL of the participants, the results indicated that children reported an acceptable overall health-related QoL score ( $71.68 \pm 11.01$ ) with the highest score was found in subscale procedural anxiety ( $86.54 \pm 23.09$ ), and the lowest score was found in subscale general health ( $44.47 \pm 30.76$ ) [Table 2]. Moreover, QoL values were

**Table 1: Sociodemographic and clinical characteristics of the studied participants (n=104)**

Variables	n (%)
Gender	
Male	70 (67.3)
Female	34 (32.7)
Age group	
7-10	41 (39.4)
11-14	53 (51.0)
14-17	10 (9.6)
Type of tumor	
Hematological	76 (73.1)
Solid	28 (26.9)
Treatment	
On	82 (78.8)
Off	22 (21.2)
State of disease treatment	
Newly diagnosed on treatment	76 (73.1)
Recurrent diagnosed on treatment	5 (4.8)
Termination of treatment in the past 12 months	13 (12.5)
Termination of treatment for longer than 12 months	10 (9.6)
Types of treatment	
Surgery	4 (3.8)
Chemotherapy	92 (88.5)
Others	8 (7.7)

**Table 2: Descriptive statistics for the total scores of Pediatric Quality of Life Inventory™ 4.0 and Pediatric Quality of Life Inventory™ 3.0 Cancer Module Scales among participants (n=104)**

Subscales	Mean ± SD
PHS	67.5±20.3
EM	80±18.8
SOC	82±17.7
SW	51.4±29.6
Psych	71.2±13.5
Pain and hurt	77.8±24.3
Nausea	73.2±22.2
PA	86.5±23.1
TA	76.8±32.9
Worry	81.7±20.9
CP	76.2±23.3
Perceived physical appearance	81.9±28.9
Communication	73.1±30.3
Satis	54.7±26.3
HealthG	44.5±30.8
Overall	71.7±11

SD: Standard deviation, PHS: Physical health, EM: Emotion, SOC: Social, SW: School working, Psych: Psychosocial, PA: Procedure anxiety, TA: Treatment anxiety, CP: Cognitive problem, Satis: Satisfaction, HealthG: General health

varied according to different scale domains. Hereby more evident in the social and emotional domains, where the mean of the scores were  $82 \pm 17.7$  and  $80 \pm 18.8$ , respectively. As compared to  $67.5 \pm 20.3$  for the physical domain, and the

most unsatisfactory QoL ( $51.4 \pm 29.6$ ) for the school working domain.

Independent sample *t*-test and one way ANOVA were performed to compare the means of overall scores of the scales with the socio-demographic and clinical characteristics of the participants, we found that there were no statistically significant differences between overall QoL scores and all of these characteristics [Table 3]. When Pearson correlation test was performed to determine the correlation between PedsQL™ 4.0 and PedsQL™ 3.0 subscales, we found that the total score of the PedsQL™ 4.0 scale was significantly correlated with subscale pain, nausea, worry, cognitive problem, perceived physical appearance, and satisfaction with  $P = 0.000, 0.000, 0.003, 0.007, 0.007$  and  $0.029$ , respectively. Moreover, pain and nausea had a significantly strong correlation with social and psychosocial scores ( $P < 0.001$ ).

## DISCUSSION

The health-related QoL of pediatric oncology patients is multidimensional, including the social, physical, and emotional executive functions of both the child and the family.<sup>[23]</sup> Therefore, the measurement of QoL should be performed from the perspective of the child and his/her family as well as be sensitive to developmental changes.<sup>[23]</sup> In the current study, 104 pediatric patients were recruited. 67.3% of them were males, which is in line with the other reports of higher tumor prevalence among boys.<sup>[8,9]</sup> On the other hand, 51% of the children in this study were aged 11–14 years. This finding is parallel with previous reports of a high percentage of cancer among this age group. Clinically, hematological types of the tumor were represented 73% of the studied patients, and this falls within Cancer Statistics 2018 (GLOBOCAN), which shows high incidences of these kinds of cancers in children.<sup>[6]</sup>

Regarding the QoL scores, the current study indicated that social and emotional parameters were better functionally controlled children with cancer. While the physical and school working domains were more related to poor QoL. These findings are in agreement with another study of among School Children with Cancer in Alexandria, reported a diminished QoL in the physical domains.<sup>[24]</sup> Furthermore, the total QoL score was found to be correlated with pain, nausea, worry, cognitive problem, perceived physical appearance, and satisfaction subscales. This is similar to a previous prospective, longitudinal study from the United States that showed that out of the 24 developed-symptoms, thirteen of them were independently associated with decreasing the overall health-related QoL score.<sup>[21]</sup>

Furthermore, the study showed that no significant difference was detected in the overall QoL between the two genders. In addition, older aged children (14–17) years have poorer overall QoL scores when compared with the younger age group (7–10). However, this difference in QoL was statistically insignificant. This finding is in contrast to previous researches, in which adolescents reported a significantly higher overall QoL

**Table 3: Comparison of the overall Pediatric Quality of Life Inventory™ 4.0 and Pediatric Quality of Life Inventory™ 3.0 Scale's scores with sociodemographic and clinical characteristics of the participants using an independent sample *t*-test and one-way ANOVA test (*n*=104)**

Variables	<i>n</i>	Mean±SD	<i>P</i>
Gender			
Male	70	72±11.3	0.71
Female	34	71.1±10.6	
Age group			
7-10	41	70.6±13.2	0.33
11-14	53	73.2±9.5	
14-17	10	68.4±8.2	
Type of cancer			
Hematological	76	71±11.6	0.32
Solid	28	73.5±9.3	
Treatment			
On	82	71.1±11.3	0.28
Off	22	73.9±9.7	
State of disease treatment			
Newly diagnosed on treatment	76	71.6±10.5	0.14
Recurrent diagnosed on treatment	5	63±21.5	
Termination of treatment in the past 12 months	13	71.4±11	
Termination of treatment for longer than 12 months	10	77±6.2	
Types of treatment			
Surgery	4	72.6±16.2	0.94
Chemotherapy	92	71.7±10.8	
Others	8	70.5±12.8	

SD: Standard deviation

compared with other children in all phases of the treatment.<sup>[13,24]</sup> Moreover, the type of treatment had a statistically insignificant difference with the overall score.

A similar overall score mean was observed in the children who were on treatment compared to those of off-treatment. This may be due to the effect of cancer itself on their psychological status regardless of being taking treatment or not, which this may affect directly on their QoL, this result is inconsistent with another study done in Malaysia in which the children with acute leukemia on maintenance chemotherapy had significantly poorer QoL than those off-treatment.<sup>[21]</sup> Additionally, those were statistically significant difference between overall score mean, and those who were diagnosed recurrently or were newly diagnosed, and they were on the treatment this result is in contrast to the findings reported in other studies.<sup>[21,25]</sup> In this study, pain and nausea had a significantly strong correlation with social and psychosocial scores, which suggested that the physically suffering children were feeling ill with disrupted social activity outcomes. These findings in agreement with the findings of the pediatric cancer scale study and attributed to be due to frequent hospital visits and medical procedures as the patient tolerate it with treating anxiety and worry.<sup>[26]</sup>

This study is not without limitations; the short time for conducting this research was at the top of our limitation. In addition, age was one of the factors that affect our study; some of those who were aged 7 years had difficulty communicating, understanding, and answering our questions. Moreover,

absence from school was another limitation those who never went to school before, failed to fulfill the question of subscale school working. Despite these limitations, our results are novel, as it is the first report to assess the QoL among Sudanese pediatric cancer patients. Thus, further multi-central studies with a larger population, and longer durations, are highly recommended.

## CONCLUSION

Our study concluded that children reported an acceptable overall health-related QoL score mean. There was no significant difference in the QoL between males and females, treatment status, type of cancer. The total score of the PedsQL™ 4.0 scale was significantly correlated with pain, nausea, worry, cognitive problem, perceived physical appearance, and satisfaction subscales.

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Nil.

## Conflicts of interest

There are no conflicts of interest.

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