



P-ISSN: 2664-3685

E-ISSN: 2664-3693

[www.paediatricjournal.com](http://www.paediatricjournal.com)

IJPG 2024; 7(1): 94-99

Received: 05-02-2024

Accepted: 11-03-2024

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## Quality of life in children and adolescents surviving cancer in Basra

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DOI: <https://doi.org/10.33545/26643685.2024.v7.i1b.232>

### Abstract

**Background:** Cancer in patients below 19 years of age is relatively uncommon, but its impact on affected children and their families is significant. Understanding the quality of life (QoL) in childhood cancer survivors is essential for comprehending the long-term effects of the disease and its treatment. This study aims to assess the QoL of children and adolescents who have survived cancer for more than three years, treated at Basra Maternity and Children Hospital and Basra Specialty Hospital for Children. Additionally, it seeks to understand parental assessments of their children's QoL and evaluate the degree of agreement between survivors and their parents.

**Methods:** This case-control study was conducted between October 2011 and November 2012. Participants included 31 childhood cancer survivors (24 males, 7 females) aged 8-18 years, who had completed cancer treatment and survived at least three years' post-diagnosis. The control group consisted of 32 healthy children (25 males, 7 females) matched by age and sex. Data were collected using the Arabic version of the KINDL questionnaire, answered by both children and one of their parents.

**Results:** The study found no significant differences ( $p$ -value  $> 0.05$ ) in most QoL subscales between survivors and their controls based on self-assessment reports. Similarly, parental reports showed no significant differences ( $p$ -value  $> 0.05$ ) in most QoL subscales between the two groups. However, children scored lower than their parents in the Physical Well-being subscale ( $p$ -value = 0.002). Adolescents showed no significant differences from their parents' reports. Overall, survivors reported no significant differences ( $p$ -value  $> 0.05$ ) in all QoL subscales except for self-esteem, where survivors had poorer scores than their parents ( $p$ -value = 0.036).

**Conclusion:** The study concludes that the QoL of children and adolescents surviving cancer is similar to that of their peers. Parents generally report a good QoL for their children surviving cancer, comparable to parents of healthy children. There is a high degree of agreement between survivors and their parents in perceiving QoL.

**Keywords:** Childhood cancer, quality of life, cancer survivors, KINDL questionnaire, parental assessment, case-control study, Basra, pediatric oncology

### Introduction

Cancer in patients below 19 years of age is relatively uncommon, with an age-adjusted annual incidence rate of 16.6 per 100,000<sup>[1]</sup>. Despite its rarity, childhood cancer remains a significant public health concern due to its profound impact on the affected children and their families. Hematopoietic tumors, such as leukemia and lymphoma, are the most common types of childhood cancers, followed by brain and central nervous system (CNS) tumors and sarcomas of soft tissue and bone<sup>[2]</sup>. The clinical presentation of childhood cancer varies depending on the type of cancer, and treatment protocols are typically standardized internationally to optimize outcomes<sup>[2]</sup>. The management of childhood cancer often involves a multidisciplinary approach. Acute lymphoblastic leukemia (ALL), the most common childhood leukemia, is usually treated with chemotherapy alone. In contrast, solid tumors often require a combination of surgery, chemotherapy, and sometimes radiotherapy<sup>[3]</sup>. The treatment of childhood cancer, however, is not without its challenges. Adverse treatment effects can be categorized as either acute or late. Acute adverse effects include metabolic disorders such as hyperuricemia, hyperkalemia, hyperphosphatemia, hyponatremia, and hypercalcemia, as well as hematologic disorders like anemia, thrombocytopenia, disseminated intravascular coagulation, neutropenia, hyperleukocytosis, and graft-versus-host disease<sup>[3]</sup>.

Late adverse effects, which may manifest months to years after the completion of treatment, can significantly impact survivors' long-term health and quality of life [4]. Late effects of childhood cancer treatment are defined as any physical, psychological, or social consequences that appear months or years following treatment [5]. Approximately two-thirds of childhood cancer survivors experience some form of physical or psychosocial late effects [4, 5]. Common somatic late effects include endocrine dysfunction, impaired gonadal function, cardiomyopathy, obesity, osteopenia, kidney dysfunction, dental problems, and secondary malignancies [5, 6]. Psychosocial late effects are also prevalent, with survivors at increased risk for issues such as poor self-esteem, anxiety, depression, social skill deficits, and learning difficulties [7]. The survival of childhood cancer patients has improved significantly over the past decades, with a five-year survival period often considered a criterion for long-term survival [4, 8]. Survival rates, however, vary widely depending on the type of cancer and the country in which treatment is received. While some cancers, such as late-stage neuroblastoma, remain challenging to cure, others, like ALL, have survival rates exceeding 80% [1]. Assessing the quality of life (QoL) in childhood cancer survivors is crucial for understanding the long-term impact of the disease and its treatment. QoL is a multidimensional construct that includes both objective and subjective aspects of social, physical, and emotional functioning [9]. According to the World Health Organization, QoL is defined as "the individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" [10]. There are three basic aspects of QoL: objective preconditions (Such as somatic or mental disease, psychosocial factors, and medical treatment), the ability to act and function (Objective QoL, best evaluated externally), and well-being and satisfaction (Subjective QoL, best evaluated by self-report) [5]. While some studies report poor QoL outcomes for childhood cancer survivors [11, 12], others suggest that survivors' QoL may not substantially differ from that of the general population [4, 5, 13]. Some research even indicates increased resilience and adaptation among survivors [6, 14, 15]. QoL assessment in childhood cancer survivors involves the use of both generic and disease-specific instruments. Generic measures are useful for comparing survivors with the general population, while disease-specific measures are more appropriate for examining the specific impacts of cancer and its treatment on the patient's life [8, 16]. Reliability and validity are critical properties of these instruments, ensuring consistent and accurate representation of the study population [4, 8]. This study aims to assess the QoL of children and adolescents who have survived cancer for more than three years, treated at Basra Specialty Hospital for Children. It also seeks to understand parental assessments of their children's QoL and to evaluate the degree of agreement between survivors and their parents.

## Methods

This case-control study, conducted between October 2011 and November 2012, includes children and adolescents aged

8 to 18 years. Data were collected using the Arabic version of the KINDLR questionnaire, answered by children and one of their parents. Children Surviving Cancer: Eligible survivors were born between 1994 and 2004, diagnosed with cancer between 2000 and 2009, survived at least three years from diagnosis, free of cancer at the time of the study, and alive at the end of 2012. Data were collected through direct interviews at Basra Specialty Hospital for Children and visits to three schools in Basra city, with consent from head teachers. Of 43 eligible children, 31 (72%) participated, including 24 males and 7 females, with a median age of 12.9 years. The group included children with leukemia (n=25), lymphoma (n=8), Wilms tumor (n=2), and germ cell tumor (n=1). Control Group: The control group was matched by sex and age ( $\pm 1$  year) to the study group, with no history of cancer and free of any chronic condition. Data were collected from three schools in Basra city. Of 41 eligible families, 32 (78%) consented to participate, including 25 males and 7 females, with a median age of 12.75 years. Study Variables: The KINDLR questionnaire assessed QoL in children surviving cancer, as reported by the child and their parent. It evaluated physical and mental health, self-esteem, and various life domains such as school, family, and friends, along with a global QoL evaluation. The KINDLR Questionnaire: Developed by Ravens-Sieberer and Bullinger (2000), the KINDLR questionnaire is designed for epidemiological use in healthy and clinical groups of children and adolescents aged 4-16 years. It demonstrates high reliability (Cronbach's alpha 0.70 for most sub-scales) and validity [17, 18]. Versions of the KINDLR Questionnaire: The questionnaire includes three self-report versions for age groups 4-7, 8-12, and 13-16, and two proxy versions for parents of children aged 4-7 and 8-16 [17]. Structure of Scales and Sub-scales: The KINDLR consists of 24 items across six subscales: physical well-being, emotional well-being, self-esteem, family, friends, and school. These can be combined for a total score [17]. Calculation of Sub-Scale Scores: Sub-scale scores are calculated by summing the item scores, then dividing by the number of items in the subscale. Total scores are the sum of all items divided by 24. Sub-scales can be transformed to a 0-100 range using the formula:  $(\text{Sub-scale score} - \text{lowest possible score}) / (\text{Possible range of raw score} \times 100)$  (Sub scale score - lowest possible score) / Possible range of raw score  $\times 100$ . Statistical Analysis: Data analysis was performed using SPSS for Windows version 17.0. QoL scores are presented as mean values and standard deviations. Group differences in proportions were analyzed using Chi-square statistics, and one-way ANOVA was used to compare scores between cases and controls. A p-value  $< 0.05$  was considered statistically significant.

## Results

Sixty-three children and adolescents and one of their parents included in study: (31) were survivors and (32) were control. Table (1) shows that there is no statistically significant difference (p-value  $> 0.05$ ) between survivors and control group concerning children age. Sex and the parents' educational level.

**Table 1:** Selected socio-demographic data of children included in the study

Data	Survivors N (%)	Survivors Values	Controls N (%)	Controls Values	p-value
Sex	Male	24 (77.4)	Male	25 (78)	1
	Female	7 (22.6)	Female	7 (22)	
Age	(8-12)	16 (50)	(8-12)	16 (50)	0.99
	(13-18)	15 (48.4)	(13-18)	16 (51.6)	
Education of father	Illiterate	5	Illiterate	3	0.98
	Primary school	7	Primary school	6	
	Secondary school	10	Secondary school	10	
	High school	9	High school	13	
Education of mother	Illiterate	7	Illiterate	5	0.98
	Primary school	7	Primary school	5	
	Secondary school	8	Secondary school	10	
	High school	9	High school	12	

Self-report assessment of QoL by children (8-12 years) surviving cancer shows no significant differences (p-value >0.05) as compared to their controls in terms of total QoL, physical well-being, self-esteem, emotional well-being,

friends as well as the school subscales. Children surviving cancer reported higher mean scores on family subscales (p-value=0.02) as compared to their control. as in table 2.

**Table 2:** QoL of children surviving cancer and control group.

Subscale	Survivors N=16 Mean±(SD)	Controls N=16 Mean±(SD)	p-value
Physical well-being	79.4±3.03	80.65±2.90	0.81
Emotional well-being	84.4±2.28	75.65±3.34	0.09
Self-esteem	76.9±3.05	84.7±2.57	0.13
Family	82.5±3.10	70.65±2.28	0.02
Friends	80.65±0.96	85.3±2.84	0.22
School	79.35±4.0	74.05±3.31	0.43
Total quality of life	80.53±9.52	78.5±9.30	0.7

Self-report assessment of QoL by adolescents (13-18years) surviving cancer shows no significant differences (p-value >0.05) as compared to their control in terms of total QoL, emotional well-being, self-esteem, family friends as well as

the school subscales. Adolescents surviving cancer reported higher mean scores (p-value=0.042) on physical well-being subscale as compared to their control. As in table 3.

**Table 3:** QoL of adolescents surviving cancer and control group

Subscale	Survivors N=15 Mean±(SD)	Controls N=16 Mean±(SD)	p-value
Physical well-being	82±2.64	70.95±3+10	0.042
Emotional well-being	75±2.39	76.9±3.34	0.72
Self-esteem	78.35±2.99	72.8±2.68	0.29
Family	74.65±3.63	73.75±3.61	0.89
Friends	81.65±1.99	74.7±2.69	0.11
School	60±3.23	53.45±3.05	0.62
Total quality of life	75.27±5.01	70.43±8.81	0.13

Parents of children (8-12 years) surviving cancer did not report significant differences (p-value >0.05) in assessment of QoL of their children as compared to the parents of healthy children in terms of total QoL, emotional, self-

esteem, family, friends, as well as the school subscales. Parents of children surviving cancer reported higher mean (p-value =0.002) scores for their children on the Physical well-being subscales. As in table 4.

**Table 4:** Parental assessment of QoL of children surviving cancer control group

Subscale	Survivors N=16 Mean±(SD)	Controls N=16 Mean±(SD)	p-value
Physical well-being	93.15±1.09	73.75±4.39	0.002
Emotional well-being	91.25±1.69	80.95±3.82	0.06
Self-esteem	86.9±2.50	81.9±3.07	0.32
Family	77.5±2.37	74.05±1.52	0.34
Friends	85.65±2.16	79.7±2.41	0.15
School	70±4.71	72.8±3.33	0.70
Total quality of life	84±8.61	77.2±10.16	0.08

Parents of adolescents (13-18years) surviving cancer did not report significant differences (p-value >0.05) in all

subscales of QoL as well as total QoL of their children as compared to parents of healthy adolescents. As in table 5.

**Table 5:** Parental assessment of QoL of adolescents surviving cancer and control group

Subscale	Survivors N=15 Mean±(SD)	Controls N=16 Mean±(SD)	p-value
Physical well-being	72.65±4.55	70±3.10	0.70
Emotional well-being	80±3.61	76.25±2.82	0.52
Self-esteem	82.65±2.10	75±3.35	0.14
Family	80.35±2.15	74.05±3.56	0.25
Friends	79.35±0.92	75.3±3.26	0.36
School	59.65±3.27	65±2.56	0.32
Total quality of life	75.77±10.14	72.60±10.95	0.49

This table shows no significant differences (p-value >0.05) between self-report and parental report of QoL of survivors

(13-18 years) in all subscales as well as total QoL. As in table 6.

**Table 6:** QoL as assessed by parents and their surviving adolescents

Subscale	Survivors N=15 Mean±(SD)	Controls N=15 Mean±(SD)	p-value
Physical well-being	72.65±4.55	82±2.64	0.18
Emotional well-being	80±3.61	75±2.39	0.38
Self-esteem	82.65±2.10	78.35±2.99	0.37
Family	80.35±2.15	74.65±3.63	0.31
Friends	79.35±0.92	81.65±1.99	0.42
School	59.65±3.27	60±3.23	0.95
Total quality of life	75.77±10.14	75.27±5.01	0.84

This table shows no significant differences (p-value) between survivors (8-18 years) and their parents in terms of total QoL, physical well-being, emotional well-being, family, friends as well as the school subscales. Children surviving

cancer reported lower mean scores on the self-esteem subscales (p-value=0.036) as compared to their parents. As in table 7.

**Table 7:** QoL as assessed by parents and their children and adolescents surviving cancer

Subscale	Survivors N=31 Mean±(SD)	Controls N=31 Mean±(SD)	p-value
Physical well-being	83.25±3.82	80.65±2.81	0.55
Emotional well-being	85.8±2.97	79.85±2.48	0.09
Self-esteem	84.85±2.32	77.6±2.98	0.036
Family	78.85±2.25	78.7±3.41	0.97
Friends	82.6±1.77	81.15±1.52	0.49
School	65±4.14	70±4.12	0.36
Total quality of life	80±9.66	77.99±7.98	0.35

## Discussion

The treatment of childhood cancer, the centralization of care, and clinical trials have significantly improved survival rates for these patients. However, surviving cancer in childhood does not mark the end of its impact; the experience continues to affect survivors and their families physically, psychologically, and socially throughout their lives [4]. This study aims to assess the quality of life (QoL) of children and adolescents who have survived cancer, with a focus on self-reports from survivors and proxy reports from their parents. According to the results of this study, most childhood cancer survivors from Basra evaluated their QoL as good or better compared to their controls. However, significant differences were only found in the family subscale for children aged 8-12 years and the physical well-being subscale for adolescents aged 13-18 years, where survivors reported higher scores than their controls (Tables 3-2 and 3-3). These findings align with previous studies conducted in various countries, including Norway, Finland, the USA, Belgium, the Netherlands, and Germany, where survivors reported similar or better QoL compared to their healthy peers [5, 6, 13, 14, 15]. Conversely, studies from Canada reported lower QoL scores among survivors [12, 19]. Several factors might explain the good QoL reported by survivors in this study. First, the theory of response shift suggests that survivors' internal standards, values, or conceptualizations

of QoL may change as a result of their cancer experience, leading to a better appreciation of life and minimizing the impact of possible impairments [8, 15, 16, 20]. Second, survivors might compare their current status with their condition during illness, perceiving their QoL as similar or superior to that of healthy controls [6]. Third, increased parental attention and psychological adjustment improvements may positively impact the child's perceived QoL, as observed in some sibling studies [6, 15, 21]. Fourth, younger children, with their limited cognitive capacity and focus on the present, might not experience the negative psychosocial impacts of cancer and its treatment as acutely as older individuals [5]. Lastly, a repressive-adaptive style may contribute to resilience in children surviving cancer, enhancing their psychosocial health and QoL [4, 22]. Parental reports of their children's QoL also indicated good outcomes, generally aligning with the children's self-reports. Parents of children aged 8-12 years reported significantly higher scores for their children's physical well-being compared to parents of healthy children (Table 3-5). Similar trends were observed in Finland, Belgium, and the Netherlands, where parents reported equal or higher QoL for their children compared to controls [4, 14, 23]. However, some studies from Canada and Norway reported lower QoL scores from parents of survivors [5, 24]. The observed excellent QoL in parental reports might result from an adjustment in attitude and



overall view of life following a life-threatening situation, leading parents to appreciate their children's current health status more [6]. Parents may also compare their child's current health with their condition during illness, perceiving it as better or similar to that of healthy controls. Comparing self-reports from survivors and proxy reports from parents revealed a strong correlation, with no significant differences except in the physical well-being subscale for children aged 8-12 years and the self-esteem subscale for those aged 8-18 years, where parents reported higher scores (Table 6 and Table 7). These findings suggest that parents and children share similar perspectives on QoL after experiencing cancer [5]. However, assuming parents can objectively evaluate their child's feelings may overlook potential emotional adjustments or cognitive processing by the child [25]. Some studies from Norway and Finland found discrepancies between survivors' self-reports and parental reports, highlighting the importance of obtaining information from both perspectives for a comprehensive understanding of QoL in childhood cancer survivors [4, 5]. Overall, this study demonstrates that children and adolescents surviving cancer generally perceive their QoL as similar to that of their peers, and parents' reports corroborate these findings. The high degree of agreement between survivors and their parents underscores the importance of considering both self-reports and proxy reports in assessing QoL in this population.

### Conclusion

Children and adolescents who have survived cancer as a group rate their quality of life as comparable to that of their peers, according to this study. This study additionally demonstrates that parents of children who have survived cancer generally express a positive perception of the quality of life for their children, which is not statistically significant when compared to parents of children who are healthy. In addition, this study demonstrates that parents and children and adolescents who have survived cancer express a high level of concurrence regarding their perceptions of the quality of life following complete recovery.

### Conflict of Interest

Not available.

### Financial Support

Not available.

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**How to Cite This Article**

Hashim BI, Hasan JGH, Khudair AM. Quality of Life in children and adolescents surviving cancer in Basra. *International Journal of Paediatrics and Geriatrics*. 2024;7(1):94-99.

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