

*Research Article***Assessment of Quality of Life in Pediatric Cancer Patients and their Parents.****Ali R. Abd-El-Aal, Emad N. Ebeid, Gehan L. Abdel Hakeem, and Rehab M. Ahmed**

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**Abstract**

**Introduction:** Childhood cancer patients are now long term survivors with current survival rates approaching 90%. Contemporary therapies for pediatric malignancies represent the main contributor for such advancement.<sup>(2)</sup> However, same treatments leading to increased survival rates are reported to participate in the creation of debilitating physical and psychosocial deficits for cancer survivors. **Aim of the work:** The present study was designed to identify the HRQOL profile in Egyptian pediatric cancer patients and their parents while employing Pediatric Quality of Life Inventory version 4.0 Generic core scales (PedsQL 4.0) and Pediatric Quality of Life Inventory version 3.0 Cancer Module (PedsQL 3.0) and comparing them with healthy children group. It is hypothesized that the HRQOL of pediatric cancer patients is lower than the healthy children. It is also assumed that HRQOL of pediatric cancer patients and their parents' perception is affected due to illness, its treatment and its impact. In this study also, the impact of childhood cancer on the HRQOL of families assessed by using the PedsQL Family Impact Module, which is a multidimensional instrument developed to assess the impact of chronic medical conditions on the HRQOL of parents and family functioning. **Patients and Methods:** This study was carried out at El-Minya Oncology Center and Egyptian National Cancer Institute (NCI) in the period from January 2014 to January 2016. Two hundreds and fifty five (255) children and their parents were enrolled in this study, 155 cancer patients (group I) and 100 control (group II). Patients involved were 90 males (58.1%) and 65 females (41.9%), and the control group comprised 55 males (55%) and 45 females (45%). All enrolled children were between 2 - 18 years old, and according to PedsQL questionnaire they were divided into 4 age groups : A (2-4 years), B (5-7 years), C (8-12 years) and D (13-18 years). **Results:** The patients age were ranged from 2 to 18 years with a mean age (9.4). while the age of control group ranged from 2 to 18 with a mean of (8.8) the sample divided in to 4 age groups: from 2 to 4 years (group A) , from 5 to 7 years (group B), from 8 to 12 years (group C) and from 13 to 18 years (group D). **Discussion:** The purpose of the present study was to assess the HRQOL of paediatric cancer patients and the perception of their parents about the HRQOL of their children as it is compromised by the illness and its treatment and impact of disease of child on parents QOL. **Recommendations:** 1) HRQOL measurement should be done as a routine for all children with cancer. 2) Further studies of larger scale of patients with different types of cancer are individually necessary for accurate judging of QOL status.

**Key Words:** EBV: Epstein-Barr virus, ES: Ewing Sarcoma, FIM: Family impact module**Introduction**

Childhood cancer patients are now long term survivors with current survival rates approaching 90%.<sup>(1)</sup> Contemporary therapies for pediatric malignancies represent the main contributor for such advancement.<sup>(2)</sup> However, same treatments leading to increased survival rates are reported to participate in the creation of debilitating physical and psychosocial deficits for cancer survivors.<sup>(3)</sup> Health-related morbidity among childhood cancer survivors is

mainly attributed to late effects including chronic health conditions and life-threatening complications during adulthood.<sup>(4,5)</sup> Measures of health-related quality of life (HRQOL) are designed to tap such consequences of cancer treatment together with the impact of the disease itself.<sup>(3)</sup> HRQOL targets a variety of dimensions including physical, mental and social domains.<sup>(6)</sup> For childhood cancer patients, assessment of HRQOL at relevant points throughout the treatment process can help in the

identification of acute dysfunction associated with both illness and treatment, as well as figuring out expected residual dysfunction in long-term survivors.<sup>(7,8)</sup>

The impact of disease and treatment on family functioning plays an important role in a child's adaptation to chronic disease. The family's capacity to cope with the multiple sources of stress and uncertainty associated with their child's diagnosis and treatment is likely to affect the child's quality of life. The functioning and well-being of parents/guardians depend on the child's situation as well. Information on the quality of life of pediatric cancer patients and their families allows the identification of families with special needs for support or psychological intervention.<sup>(9,10)</sup> There is a vast range of coping strategies displayed by families in relation to both practical and emotional difficulties.<sup>(11)</sup>

### **Aim of the work**

The present study was designed to identify the HRQOL profile in Egyptian pediatric cancer patients and their parents while employing Pediatric Quality of Life Inventory version 4.0 Generic core scales (PedsQL 4.0) and Pediatric Quality of Life Inventory version 3.0 Cancer Module (PedsQL 3.0) and comparing them with healthy children group. It is hypothesized that the HRQOL of pediatric cancer patients is lower than the healthy children. It is also assumed that HRQOL of pediatric cancer patients and their parents' perception is affected due to illness, its treatment and its impact. In this study also, the impact of childhood cancer on the HRQOL of families assessed by using the PedsQL Family Impact Module, which is a multidimensional instrument developed to assess the impact of chronic medical conditions on the HRQOL of parents and family functioning.

### **Patients and Methods**

This study was carried out at El-Minya Oncology Center and Egyptian National Cancer Institute (NCI) in the period from January 2014 to January 2016. Two hundreds and fifty five

(255) children and their parents were enrolled in this study, 155 cancer patients (group I) and 100 control (group II). Patients involved were 90 males (58.1%) and 65 females (41.9%), and the control group comprised 55 males (55%) and 45 females (45%). All enrolled children were between 2 - 18 years old, and according to PedsQL questionnaire they were divided into 4 age groups: A (2-4 years), B (5-7 years), C (8-12 years) and D (13-18 years).

The studied patients included different diagnosis of hematological malignancies as leukemia and lymphoma and solid tumours as (wilms tumor, brain tumors, neuroblastoma, germ cell tumors, bone tumors, soft tissue sarcomas and others). Full history taking from patient stressed on onset of disease, starting of therapy, hospital staying and for any complication either from disease or chemotherapy. According to the treatment status the patients were divided into two groups 'In-treatment' status which is defined as individuals who were receiving chemotherapy to induce remission (n =119, 76.7%). And 'Off-treatment' status which is defined as individuals for whom all therapy was completed for a period of at least one month (n =36, 23.2%). Children were excluded from this study if they had comorbid disease, unstable health condition or major developmental disorders or refused to share. Parents were interviewed first, and were asked for consent of sharing by their children and themselves. They were asked to complete the PedsQL 4.0 Generic Core Scales and the PedsQL 3.0 Cancer Module. Parents of cancer children were asked to complete the PedsQL Family Impact Module.

In the control group (group II), children and their parents were asked to complete the PedsQL 4.0 Generic Core Scales. The criteria of being healthy was not having any serious physical illness or medical condition for the past six months. The questionnaires interviews were conducted during the school day. Written information was sent to parents who completed questionnaires at home, returning them to school by a specified date.

## Results

Table (1) Demographic data for involved children.

		Cases		Controls	
		Number	%	Number	%
Age(yrs.)	Mean± SD	9.4±5.0		8.8±4.8	
	Range	2-18		2-18	
Age groups(yrs.)	2-4	33	21.2%	24	24 %
	5-7	38	24.5%	28	28 %
	8-12	33	21.2%	36	36 %
	13-18	51	32.9%	12	12 %
Sex	Male	90	58.1%	55	55 %
	Female	65	41.9%	45	45 %
Residence	Rural	67	43.2%	36	36 %
	Urban	88	56.7%	64	64 %
Type of Cancer	<b>Hematological</b>	<b>101</b>	<b>65.2%</b>	-	-
	HL	10	9.9%	-	-
	Others	5	4.9%	-	-
	<b>Solid</b>	<b>54</b>	<b>34.8%</b>	-	-
	Wilm's tumour	17	31.4%	-	-
	Brain tumours	8	14.8%	-	-
	GCT	6	11.1%	-	-
	NB	6	11.1%	-	-
	OS	4	7.4%	-	-
	ES	3	5.5%	-	-
	Others	10	18.5%	-	-
Status of Ttt	In treatment	119	76.7%	-	-
	Off treatment	36	23.2%	-	-

ALL = acute lymphoblastic leukemia. NHL = Non-Hodgkin Lymphoma . HL=Hodgkin Lymphoma. GCT = Germ Cell Tumour, NB = Neuroblastoma, OS = Osteosarcoma, ES = Ewing sarcoma

## Discussion

The patients age were ranged from 2 to 18 years with a mean age (9.4). while the age of control group ranged from 2 to 18 with a mean of (8.8) the sample divided in to 4 age groups: from 2 to 4 years (group A) , from 5 to 7 years (group B), from 8 to 12 years (group C) and from 13 to 18 years (group D).

Involved patients include 90 males (58.1%) and 65 females (41.9%). While control group include 55 males (55 %) and 45 females (45%).

According to residence the diseased group divided to 67 (43.2%) live in rural and 88 (56.7%) live in urban. While the controls

divided to 36 (36 %) live in rural and 64 (64 %) live in urban.

Involved patients include 101 Hematological malignancies (65.2%) [ALL (56.4%), NHL (28.7%), HL(9.9%) and others (4.9%)] and 54 solid malignancies (34.8%) [Wilms tumour (31.4%), brain tumours (14.8%), GCT (11.1%) NB (11.1%), OS (7.4%) , ES (5.5%) and others (18.5%)].

According to treatment status 119 patients were in treatment (76.7%) and 36 off treatment (23.2%).

The purpose of the present study was to assess the HRQOL of paediatric cancer patients and

the perception of their parents about the HRQOL of their children as it is compromised by the illness and its treatment and impact of disease of child on parents QOL. The questionnaires used in this study were PedsQL Generic Core scales, PedsQL Cancer module and PedsQL Family Impact Module. The study in itself has an exploratory aspect. There are a comparatively small number of studies done in Egypt on the chronically ill patients after the diagnosis of their disease and the effect of their treatment. The researchers are more focused upon the adult assessment of the HRQOL.

The study comparing between the cancer patients and healthy children regarding PedsQL generic core scales (child self report and parent proxy report), significant difference is suggested between the two groups. The difference is evident on the physical, emotional, school achievement and social functioning domains as well as total score. Our results agreeing many different studies as Zainab & Salma, 2012, Varni, et al., 2001 and Diana & Mohammed, 2013.

Low physical activity (PA) of cancer patients could be multifactorial. It may be due to anemia which is induced by the disease itself, chemotherapy and radiotherapy. Anemia result in fatigue, effort intolerance and decrease oxygen delivery muscle leading to decrease muscle strength and subsequently decrease physical performance. Cancer is hypercatabolic condition result in decrease muscular fat, muscle wasting and weight loss (cachexia) all of which leading to decrease physical performance.

### Conclusions

From this study, it is wise to conclude that the HRQOL of children with cancer in Egypt is not promising. The cancer is a major event that severely affect life of diseased child as well as surrounding family members. Cancer patients regardless type of cancer have poor QOL for them and their parents. This bad QOL is more obvious in emotional functioning and school performance domains of generic module, while in cancer module bad QOL is more in nausea, worry and physical appearance. In family impact module parents have more poor QOL in

emotional functioning and worry. poor QOL more in males and young age.

### Recommendations

- 1) HRQOL measurement should be done as a routine for all children with cancer.
- 2) Further studies of larger scale of patients with different types of cancer are individually necessary for accurate judging of QOL status.
- 3) Improvement of the services provided to children with cancer through the Student's Hospital whether diagnostic or therapeutic are recommended.
- 4) There is still much need to be done to improve the QOL of children with cancer.
- 5) Much collaboration between social health services and educational organization for more improvement for the services provided to cancer patients.

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