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RESEARCH ARTICLE

QUALITY OF LIFE IN CHILDREN TREATED FOR NEUROBLASTOMA: A MULTICENTER STUDY.

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Abstract

Objective: To determine the quality of life (QOL) of neuroblastoma patients in KSA using the WQOLQ, and to compare the QOL of patients with that of a comparison group and with respect to different variables.

Methods: On 2015 a cross section study conducted by reviewing neuroblastoma data of three referral oncology centers in Riyadh, KSA. From 01 January 2006 to 31 December 2013, 46 neuroblastoma patients were recruited. Patients' parents were interviewed and answered questions according to the WQOLQ (total score range –3 to 3). The same questionnaire was completed by interviewed the parents of 40 healthy children, and the findings from neuroblastoma patients and healthy comparisongroup were compared.

Results: The mean QOL score was 1.68 ±0.57 for neuroblastoma and 1.89 ±0.49 for **comparison** group, with no significant difference between the two groups (p=0.863). Patients who received a combination of chemotherapy, radiotherapy, and surgical intervention had no significant difference QOL score in comparison to those who received less (p=0.226). Patients who attended school had higher QOL scores than lower-educated patients (p<0.001).

Conclusion: This study revealed no difference in QOL scores between children with neuroblastoma and healthy children (p=0.863).

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Introduction:-

Neuroblastoma is a tumor that arises from the nervous system, with most tumors originating in the adrenal glands. This tumor can arise from any neural tissue in the head, neck, chest, abdomen, or pelvis. Neuroblastoma is the most common solid tumor in children and infants, representing 8–10% of all childhood tumors worldwide [1][2]. Since the discovery of neuroblastoma in 1864 by Rudolf Virchow, research has been conducted in order to elicit more information about its nature and treatment [2]. Many studies have been conducted with the aim of improving patients' outcomes and ameliorating suffering. However, little attention has been paid to the long- and short-term quality of life (QOL) of these patients and their families. QOL is fast becoming a standard measure of management outcomes, and good QOL is considered a target for clinicians across all medical fields. Although management guidelines unify clinical practice, QOL varies among patients. Different aspects unique to each patient can affect the individual's QOL.

Wengenroth et al. (2015) studied the QOL of survivors of childhood cancer. They looked at five QOL dimensions: physical well-being, psychological well-being, autonomy, peers, and the school environment. They found although self-reported physical well-being was similar among survivors and norms, parent-reported physical well-being was lower for survivors. Survivors were also comparable with norms in terms of the school environment [3]. Mort et al. (2011) reported on a health-related QOL survey among survivors of childhood cancer. They found that neuroblastoma survivors had low health-related QOL compared with children who had survived other cancers.[4] Gurney et al. (2007) reported problems with school performance and psychological well-being in children with neuroblastoma. They studied children with neuroblastoma suffering from hearing loss and found significantly decreased QOL in this group.[5] Nathan et al. (2007) measured the QOL of adult survivors of neuroblastoma. Although they reported no difference between those who had survived neuroblastoma and population norms overall, they did find compromised emotional well-being in neuroblastoma survivors.[6]

In Saudi Arabia, neuroblastoma is the third most common cancer among children. Eleven new cases were reported in 2012 [7]. However, no previous studies have looked at QOL outcomes among neuroblastoma patients in Saudi Arabia. Therefore, the aim of this study was to measure the QOL of neuroblastoma patients in order to help improve patients' lives.

Methods:-

In this cross-sectional study, 2015, we identified four referral oncology centers in Riyadh, Kingdom of Saudi Arabia. Three centers agreed to participate in this study: King Fahad Medical City (KFMC), King Khalid Medical City (KKMC), and King Abdulaziz Medical City (KAMC). An institutional review board approved this study.

P7atients diagnosed with neuroblastoma from 01 January 2006 to 31 December 2013 at the three centers were enrolled in this study. No specific inclusion or exclusion criteria were set. Our aim was to include all patients with neuroblastoma. A total of 71 patients were identified. We failed to retrieve 25 patients contact details and they were excluded from the study. Only 46 patients were being able to contact them through the three centers (30 patients from KFMC, four patients from KKMC, and 12 patients from KAMC). The sociodemographic and clinical data of the patients were collected from hospital records (medical charts) and used as variables for comparisons of QOL scores. Sociodemographic data included patient age, age at diagnosis, and education level. Detailed clinical data included: the origin of the tumor (primary place); tumor stages; metastasis; type of treatment; cognitive status; and management approach.

We used the Wisconsin Quality of Life Client Questionnaire (WQOLQ) to measure the QOL of our sample due to the validity and free access to this tool. The WQOLQ measures QOL based on seven fields: (1) general life satisfaction, (2) activities and occupations, (3) psychological well-being, (4) physical health, (5) social relations/support, (6) family economics, and (7) goal attainment. [8] Patients' parents were telephoned for an interview and the WQOLQ was completed. All of the parents (46 parents) who were asked to join this study agreed to participate. The WQOLQ scores QOL from –3.0 to 3.0, with –3.0 considered the worst QOL and 3.0 considered the best.

Our comparison group was taken from participants in a children's social activity held on behalf of the Saudi Ministry of Health. We randomly interviewed parents of children who were not known to have any medical illnesses, and the WQOLQ questionnaire was completed. The objectives of this study were thoroughly explained to the parents (disease and comparison groups), and their participation was recorded after the consent form was taken. SPSS version 22 Mac was used to analyze the data.

Results:-

Of the 46 neuroblastoma patients included in the study, 22 males and 24 females with an age range of 2.0–132.0 months (mean 62.4 months) (Table I). The mean ±standard deviation (SD) QOL score of the patient group was 1.68 ±0.57 (range –0.27 to 3.0). We compared these findings with those from a healthy comparison group containing 23 males and 17 females, with an age range of 6.0–132.0 months (mean 79.8 months). The mean ±SD QOL score of the healthy comparison group was 1.89 ±0.49 (range –0.24 to 2.73). There was no significant difference in the QOL of the neuroblastoma patients and healthy comparison group (p=0.863; Table II). We then studied the QOL scores of neuroblastoma patients with respect to different variables. There were no significant differences in mean ±SD QOL between males and females (1.71±0.51 vs. 1.65 ±0.63, respectively, p=0.741; Table III). There was also no significant difference in QOL between patients with a high vs. low family monthly income (p=0.577), with incomes ranging from US$133 to 6,931 (mean ±SD US$2, 159 ±1,533). Furthermore, there were no significant differences with respect to patients' age or age at diagnosis and QOL (p=0.714 and p=0.891, respectively). The mean ±SD age at diagnosis was 24.3 ±25.5 months. There were also no significant differences in patients' QOL among the tumor stages or the tumor origin (p=0.90 and p=0.466, respectively). The three centers included in this study tended to manage neuroblastoma patients using almost the same combination regimens. There was no significant difference between patients who received a combination of chemotherapy, radiotherapy, and surgical intervention or those who received less (p=0.226). Eight patients (17.4%) had an underlying cognitive illness, and these patients had a mean QOL score of 0.498; however, there was no significant difference in QOL in comparison with other patients (p=0.323). In terms of education, 12 patients (26.1%) were enrolled in a school, whereas 27 patients (58.7%) did not; the educational status of seven patients (15.2%) was unknown. A total of 17 patients (36.96%) in our study were of school age (i.e. ≥7 years), whereas 29 patients (63.04%) were not. Of those 17 school-age patients, only 12 patients (70.59%) (mean QOL score 0.677) attended school, while five patients (29.41%) (mean QOL score 0.333) did not. There was a significant difference in QOL between those patients who attended school and those who did not (p<0.003; Table III).

Table I:- Clinical and sociodemographic data from patients with neuroblastoma (*n* = 46)

Characteristic	***n***	**%**
Sex		
Male	22	47.8
Female	24	52.2
Mean (range) age, months	62.4 (2.0–132.0)	
Mean age at diagnosis, months	24.31	
Educational level		
None	27	58.7
Elementary school	12	26.1
Unknown	7	15.2
Mean (range) family monthly income, US$	2,159$ (133–6,931)	
Underlying cognitive illness		
Yes	8	17.4
No	37	80.4
Unknown	1	2.2
Tumor origin		
Head	1	2.2
Chest	6	13.0
Abdomen	39	84.8
Metastasis		
Yes	30	65.2
No	16	34.8
Tumor stage		
Stage 1	5	10.9
Stage 2	2	4.3
Stage 3	4	8.7
Stage 4	25	54.3
Unknown	10	21.7
Management approach		
Chemotherapy	38	82.6
Radiation	17	37.0
Surgical	40	87.0
Data are *n* and %, unless otherwise indicated.		

Table II:- Descriptive comparison between neuroblastoma patients and **comparison** group

Variable	**Neuroblastoma patients (*n* = 46)**	**Comparison group (*n* = 40)**	***p* value**
Sex, *n* (%)			
Male	22 (47.8)	23 (57.5)	0.554
Female	24 (52.2)	17 (42.5)	
Mean (range) age, months	62.4 (2.0–132.0)	79.8 (6.0–132.0)	0.661
Mean±SD (range) QOL score	1.68±0.57 (–0.27 to 3.0)	1.83±0.49 (–0.24 to 2.73)	0.863
QOL, quality of life; SD, standard deviation			

Table III:- Quality of life scores by different variables

Variable	**Mean**	**SD**	***p* value**
Sex			
Male	1.71	0.51	0.741
Female	1.65	0.63	
Age, months	62.4	34.5	0.714

Age at diagnosis, months	24.3	25.5	0.891
Education level			
None	1.45	0.54	0.002
Elementary school	2.03	0.33	
Family income			
Above average	1.69	0.62	0.577
Below average	1.52	0.57	
Underlying cognitive illness			
Yes	1.49	0.50	0.323
No	1.72	0.59	
Tumor origin			
Head	1.41		
Chest	1.84	0.50	0.466
Abdomen	1.66	0.58	
Metastasis			
Yes	1.59	0.59	0.157
No	1.84	0.49	
Tumor stage			
Stage 1	1.54	1.01	
Stage 2	1.43	0.09	0.907
Stage 3	1.73	0.477	
Stage 4	1.68	0.54	
Management approach			
Chemotherapy			
Yes	1.69	0.51	0.668
No	1.60	0.81	
Radiation			
Yes	1.59	0.45	0.417
No	1.73	0.63	
Surgery			
Yes	1.62	0.57	0.088
No	2.05	0.441	
Combination			
Yes	1.53	0.63	0.226
No	1.75	0.42	
SD, standard deviation.			

Conclusion:-

This study revealed no difference in QOL scores between children with neuroblastoma and healthy children (p=0.863). Treat neuroblastoma children by chemotherapy, radiation, and surgical intervention will not improve the QOL. Enhance their education can help to improve their QOL and the disease prognosis.

Discussion:-

There are no long-term data on patients with neuroblastoma in Saudi Arabia, which makes it difficult to study the impact of this tumor on children. In 2012, the Saudi Arabian Tumor Registry showed that neuroblastoma was the third most common childhood cancer after acute lymphoblastic leukemia and retinoblastoma in females, and the seventh most common childhood cancer in males (King Faisal Specialist Hospital and Research Centre, 2012).

In the current study, we interviewed parents about the QOL of their children. All of the parents who were asked to join this study agreed to participate. A recent study by Kamihara et al. (2015) reported that the parents of children with advanced cancer often maintain hope of a cure and better QOL, even if they do not believe that a cure is possible.[9] Link and Fortier (2015) reported that parents' anxiety can have a significant impact on their perception of their child's cancer.[10] We were worried about parents' anxiety and how that would reflect on their answers, but fortunately, we did not notice any influence; however, we did not measure anxiety as a variable or record its effect. In a long-term study conducted from 1979 to 1999 by Hayward et al. (2001) on the neurobehavioral outcomes of

neuroblastoma patients, they reported that some children with neuroblastoma were able to enroll in school without additional help, whereas others needed special education. They also assessed the cognitive effects of neuroblastoma and found no significant changes. Adaptive behavioral skills, daily living skills, social skills, academic performance, and QOL were all evaluated; with the results show variability among patients.[11] This study reported some very important results, but with new surgical techniques and fast improvements in all fields of medical and behavioral science, the improved ability of patients with neuroblastoma to attend school should be noted, and our study showed significantly better QOL for patients who attended school.

Margelisch et al. (2015) reported significant cognitive dysfunctions in children with brain tumors and recommended early intervention to improve cognition.[12] Neuroblastoma is a highly metastasizing tumor, and the brain is one of the most vulnerable organs for metastasis. In our study, 65.2% of patients had metastasis to different organs, with 8.7% experiencing metastasis to the brain. We found high QOL in educated patients; therefore, providing early interventions for patients with brain metastasis might improve their QOL by enhancing their cognitive abilities. In a study by Gains et al. (2012), the authors recommended multimodal therapy with chemotherapy, radiotherapy, immunotherapy, and surgical intervention to optimize the outcomes of neuroblastoma patients.[13] The QOL scores in patients receiving multi-management approaches in our study failed to show any difference.

Limitation:-

Unfortunately, our study has several limitations. First, Due to the lack of appropriate QOL measurement instrument, we used Wisconsin Quality of Life Client Questionnaire but it does not consider as an optimal instrument to measure QOL of childhood cancer. Second, we were able to recruit only a small sample size. Because there is no pediatric cancer registry in Saudi Arabia, and pediatric cancer, in general, is rare, we could not include more than 46 patients. Third, QOL is dynamic measurement tool. Changes in QOL with time and disease complications are highly possible. Therefore, a well-structured prospective study should be performed to follow-up patients with neuroblastoma. Finally, the recurrence rate of this cancer after the completion of therapy was not measured. This is considered to be one of the most important variables affecting patients' final QOL score.

Disclosures:-

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