Assessment of health- related Quality of Life of children and young adolescents with cancer in national cancer institute in Sohag Governorate, Upper Egypt

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Abstract: The study objectives are to measure the quality of life among children with cancer compared to healthy peers and to determine factors affecting the QoL among those children. Analytic cross-sectional study was conducted in Sohag National Cancer Institute in Sohag Governorate for children with cancer and a comparison group of healthy peers. There were 3 tools were used for this study: Demographic questionnaire, Socio-economic scale, and Peds QL4.0 Generic Core Scale had to measure HRQoL. All items of QoL: physical, emotional, social, school, psychological and total QL scores were lower among the cancer patients group than the control group with very high statistically significant difference. The mean total QoL score was 70.9 ± 13.3 among the cancer group versus 94.2 ± 2.4 for the healthy peers. Males represented 47.1% of the studied group versus 52.9% for females. Other QoL functions showed no statistical significance difference regarding disease duration. Conclusions: cancer is negatively affecting all the QoL functioning of the children. We recommend that Integrated programs between child's home, school and National Cancer Institute for educating and supporting children with cancer to improve their HRQoL.

Introduction

Health-related quality of life (QoL) is defined as a multidimensional assessment of physical, psychological, and social functioning. It's sensitive to developmental changes in children and adolescents, It's increasingly being used as an outcome metric in clinical trials and QoL research, as well as to monitor the occurrence of late effects in childhood cancer survivors. (Van Laar *et al.,* 2013).

Medically related fatigue and learning difficulties can influence patients' QoL.Pediatric patients with cancer often experience impaired physical performance, altered sleep patterns, and a reduced ability to talk or interact with others (Chirivella *et al.,* 2009). Several factors affect Qol of children with cancer including type of cancer particulary central nervous system cancers and leukemias, diagnosis of cancer before adolescence and female sex (Langeveld *et al.,* 2002). In children with cancer most of QoL research has focused on delayed effects of cancer. Yet, QoL studies in children had active treatment primarily was consisted of small studies that did not identify those at high risk of poor outcomes. (Mohamed *et al.,* 2013).

Our study was designed as a comparative study to determine the health-related quality of life in children with cancer on active treatment compared to healthy control and to detect the potential predictors of a total quality of life and its subscales.

Patient and Methods

Study design, setting and population

Analytic cross-sectional study. The study was done from September 2019 to August 2020 in Sohag National Cancer at Sohag city in upper Egypt. Sohag National Cancer is one of the largest cancer centers in upper Egypt receiving around 400 new childhood cancer cases/year. Children with cancer had active treatment were collected from those attending cancer clinics at Sohag National Cancer while their matched healthy peers were recruited from kindergarten and the schools within the same area and matched with children with cancer for age, gender and socio- economic level. Matched controls were apparently healthy and free from major illnesses, and they were asked about their HR-QoL apart from the current acute condition, so their answers were related to their healthy life time. . Four hundred and twenty-three children with cancer and

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another (423) healthy peers were recruited in the study. The study was conducted after approval by the institutional ethical committee (Institutional Review Board) and written informed consent from patients' guardians.

Eligibility criteria

Any child who received a history of any chronic non communicable diseases other than cancer were excluded from both study groups.

Data collection tools

Three tools were used for this study:

Tool I: Demographic questionnaire which included socio- demographic data: age, sex, birth order, disease duration and family history of cancer.

Tool II: Socio Economic Status Scale which consisted of 4 dimensions: Parent's level of education (8 items), Parent's occupation (2 items), total family monthly income (6 items), Lifestyle of the family (3 items). The item of income had been modified by the researchers according to the rate of inflation increase through comparing difference of the value of the golden pound in 2004 to that in 2015 and multiplying the rate of inflation to the income scale. The total score had classified into three classes as high from 85% 100%, moderate from 60% - 84%, low less than 60%. Validity of tool II were assessed by 5 experts in community and pediatric field and the content validity index was 0.88. Reliability of tool II was assessed using alpha–Cronbach test to test the internal consistency r =0.9.

Tool III: The Pediatric Quality of Life Inventory (Peds QL) 4.0 Generic Core Scales was done to measure HR-QoL. It is a 23-item, multidimensional quality-of-life instrument designed for use with children. Child self-report forms are available for age groups (5-7, 8-12, 13-18, and > 19 years). The two appropriate forms presented in the present study according to the child age (8-12 &13-18). The Peds QL Generic Core Scales consisted of 4 scales: Physical Functioning (8items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items) For ease of interpretability of Peds QOL Generic Core Scales, items are reversed scoring and application transformed to 0 -100 scale, so that higher scores indicate better HR-QoL. To reverse score, transform the 0-4 scale items to 0-100 as follows: $0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0$. To create Scale Scores, the mean is computed as the sum of the items over the number of items. To create the Psychosocial Health Summary Score, the mean is expressed as the sum of the items over the number of items in the Emotional, Social, and School Functioning Scales. To create the Total Scale Score, the mean is computed as the sum of all the items over the number of items on all the Scales. Acceptable levels of reliability and validity for the Peds QL have been reported in both healthy and children with cancer. Cronbach reliability for Peds QL 4.0 Generic Core Scale ($\alpha = 0.87$) is very satisfactory. the Cronbach is equally high for all age groups ($\alpha = 0.88$ for 8–12 yr. old; and $\alpha = 0.84$ for 13–18 yr old).

The Arabic version of the Peds QL General scale Score completed feasibility, reliability and validity that used for research purposes in public health sector for children 2-18 years old and their parents (Abdul-Ramous et al. 2012). The instrument took approximately 15 minutes to be completed. A pilot study was done on 10% of the sample. It was conducted to assess clarity of the questions, the need for any rewording and/or rephrasing and time needed to fulfill the questionnaire. As the result of the pilot study, it was no modifications in the questionnaire which needed a total of 20-25 minutes to be completed depending on the response of the shared individuals. Data of the pilot study were included in the study groups. Each child was interviewed individually during the waiting time.

Data management and statistical analysis

Data were entered, cleaned and recoded (if needed) using the Statistical Package for Social Science (SPSS Inc., Chicago, IL, USA) version 25. Data analysis was performed in the form of univariate analysis: descriptive statistics (frequency & percent) for quantitave data and chi-square for qualitative data.

Results

All items of QoL: physical, emotional, social, school, psychological and total QL scores were lower among the cancer patients group if comparison done to the control group with very high statistically significant difference. The mean total QoL score was 70.9 ± 13.3 among the cancer group versus 94.2 ± 2.4 for the healthy peers. Males represented 47.1% of the studied group versus 52.9% for females as shown in Table 1.

Physical and total QoL were significantly related to father age as shown in Table 2. Physical QoL was significantly related to father education level.

Social and psychological QoL were significantly related to mother education level (Table 3). Father and mother jobs were almost significant in all domains of QoL as shown in Table 4. The QoL was significantly related to residence and socioeconomic status but not significantly related to sex as shown in Table 5.

Distribution of cancer patients according to their socioeconomic status is shown in figure (1).

Table 1. Comparison between the cancer group and healthy group regarding socio-demographic characteristics and QOL items

Variables	Cancer group (No = 423)	Healthy group (No=423)	Statistical test	P
Gender				
Male	200 (47.1%)	200 (47.1%)	χ2 = 0	1.00
Females	223 (52.9%)	223 (52.9%)		
Quality of life items (Mean ± SD)				
Physical quality	70.2 ± 14.5	94.3 ± 5.1	19.4	< .0001
Emotional	66.7 ± 17.6	91.6 ± 7.5	14.5	< .0001
Social	78.3 ± 18.8	95.6 ± 5.1	12.6	< .0001
School	64.6 ± 18.8	90.8 ± 7.6	14.8	< .0001
Psychological	70.2 ± 14.5	92.7 ± 2.6	25.6	< .0001
Total QL	70.9 ± 13.3	94.2 ± 2.4	13.8	< .0001

Table 2. Quality of life items according to personal characteristics of children and parents with cancer

Variables	Items of Quality of life					
	Physical	Emotional	Social	School	Psychosocial	Total
Child age group						
1 < 6 years	56.6 ±2.3	64.1±1.9	68.8±26.2	62.±2.6	62.3±2.1	66.8 ±1.9
6 < 12 years	72.5±1.6	67±1.8	78±19.2	64.7±2	70.4±1.5	70.8±1.3
12 years& more	73.6±1.7	66.7±1.6	79.5±17.6	64.5±1.7	70.3±1.3	71.3±1.3
P	0.21	0.83	0.13	0.9	0.94	0.72
Father age group						
20 < 30 years	96.8 ± 8.3	78.3± 1.6	80±26.5	70±2.6	82.7±7.6	87.6±4.9
30 < 40 years	70.9 ± 1.6	36 ± 1.8	76.1±20.2	64.5±2.1	69.8±1.5	70±1.4
40 < 50 years	70.9 ± 1.6	65.7± 1.7	78.6±18.9	64.2±1.8	68.8±1.5	69.4±1.3
50 years &more	74.8 ± 1.8	67.1± 1.8	79.2±18.9	64.5±1.8	71.5±1.5	72.1±1.3
P	0.01	0.53	0.63	0.99	0.15	0.03
Mother age group						
20 < 30 years	71.6 ± 2	67.8± 2	77.8 ± 1.9	62.5±2.5	70±1.8	70.6 ± 1.7
30 < 40 years	70.9 ± 1.6	67.2± 1.7	77.6±19.7	64.7±1.8	70.3±1.5	69.9 ± 1.3
40 < 50 years	74.5 ± 1.8	65 ± 1.8	78.5±17.5	62.3±1.8	69.8±1.3	71.4 ± 1.
50 years &more	74.6 ± 1.7	66.2± 1.7	79.8±18.5	65.1±1.9	70.3±1.5	71.8 ± 1.3
P	0.24	0.90	0.94	0.80	0.97	0.63

Table 3. Quality of life items according to some family characteristics of children with cancer.

Variables	Items of Quality of life					
	Physical	Emotional	Social	School	Psychosocial	Total
Father education						
Illiterate/read & write	71.4 ± 1.7	67.6±1.7	78.1±19.7	61.4±1.8	69.1 ± 1.4	69.6±1.3
Primary/preparatory	67.5 ± 1.6	94.7 1.5	72.6±15.8	63.6±1.6	69.5 ± 1.5	67.8±1.2
Secondary education	69.3 ± 1.9	67.8± 1.6	78.2±17.3	61.9±1.8	70.5 ± 1.4	70 ± 1.4
University/higher	75.1 ± 1.7	69.3± 1.8	80. ± 20.7	69.1±1.9	72.9 ± 1.5	73.5±1.4
Higher degree	74.4 ± 1.7	63.9±1.8	79.1±17.8	64.5±2.1	69.1 ± 1.6	70.9±1.4
P	0.05	0.23	0.1	0.04	0.28	0.09
Mother education						
Illiterate/read & write	70.8 ±1.8	66.5±1.7	77.3 ±19.4	81.8±1.7	69.9±1.4	96.6±1.4
Primary/preparatory	71.9±1.6	65.4±1.9	74 ± 16.9	64.3±1.9	69.3±1.5	96.2±1.4
Secondary education	70.2±1.63	66.4±1.6	74.6±14.8	66.8±1.4	70.2±7.9	70.2±5.8
University/higher	75.5±1.7	68.3±1.6	67.8±19.8	64.8±2	70.7±1.4	72±1.3
Higher degree	74.4±1.8	65 ± 2	89.6±16.8	71 v 2.1	72.9±1.8	73.4±1.6
P	0.1	0.89	0.007	0.01	0.27	0.27

Table 4. Quality of life items according to some family characteristics of children with cancer.

Variables	Items of Quality of life					
	Physical	**Emotional**	**Social**	**School**	**Psychosocial**	**Total**
Father's Job						
Worker	81.7±1.8	68.2±1.8	93.6±12.8	55.3± 1.9	73.6± 1.1	76.4 ± 1.1
Clerk	75.3±1.6	66.8±1.6	80.4±18.6	69.3v 1.8	71 ± 1.2	72.6 ± 1.1
Free work	70.5±1.5	66.5±1.7	66.5 ± 1.8	75.8±18.1	66.9± 1.9	69.5 ± 1.5
Others	68.1±1.7	65.6±1.7	70.1±18.2	65.5± 1.9	67.7± 1.6	67.9 ± 1.4
P	0.000	0.77	0.000	0.001	0.89	0.000
Mother's Job						
Working	72.8±2.1	68.3±2.1	71.8 ± 24	57.6± 2.3	66.9± 1.9	69 ± 1.9
Housewife	72.6±1.7	66.5±1.7	78.8 ± 1.8	65 ± 1.9	70.5± 1.4	70.9 ± 1.3
P	0.01	0.66	0.008	0.003	0.03	0.006

Table 5. Quality of life items according to some family characteristics of children with cancer.

Variables	Items of Quality of life					
	Physical	**Emotional**	**Social**	**School**	**Psychosocial**	**Total**
Residence family						
Urban	79.2 ± 1.6	67.4 ± 1.7	87.4 ± 1.7	59.9 ± 1.9	72.5 ± 1.2	74.8±1.1
Rural	69.8 ± 1.7	66.4 ± 4.8	74.2 ± 18	66.4 ± 1.9	69.2 ±1.6	69.1±1.4
P	0.000	0.24	0.000	0.003	0.03	0.000
Sex of child						
Male	68.3 ± 1.8	65.7 ± 1.8	77.9 ± 18	62.2 ± 2	69.4 ± 1.5	70.3±1.9
Female	53.3 ± 1.8	67.5 ± 1.7	78.4 ± 19.5	66.5 ± 1.8	70.9 ±1.4	71.3±1.3
P	0.20	0.13	0.15	0.24	0.27	0.23
Social class						
Low	71.4 ± 1.7	66.2 ± 1.7	76.9 ± 19	62.9 ± 1.8	69.5 ± 1.4	69.8± 1.3
Moderate	76.3 ± 1.7	68 ± 1.9	82.4 ± 18	68.9 ±2	72.4± 1.6	76.8±1.5
High	66.9 ± 9	63 ± 7.5	67 ± 13.5	67 ± 1	65.6 ± 7	66.1±4.5
P	0.01	0.66	0.008	0.003	0.64	0.006

Discussion

Pediatric patients with cancer spend between 6 months and 3.5 years undergoing treatment, confronting their diseases while also dealing with developmental challenges (Macartney *et al*., 2014).

In cross-sectional study at Canada (2009) of multi-institutional showed children with cancer receiving some type of active treatment. The primary caregiver gave information on child (physical, emotional, cognitive and social QoL). Also reported children with acute lymphoblastic leukemia had better physical health while intensive chemotherapy treatment and these having a sibling with a chronic condition were associated with poor physical QoL. Good emotional health was associated with better prognosis, lower intensity chemotherapy treatment and greater household savings, instead female children and with a sibling with a chronic condition although had poor social QoL (Gibson *et al*., 2005; Lorenzi *et al*., 2011).

In this study, although the mean value of total heath related QoL was relatively good and similar to the score of some developed countries, however we observed low mean value in perceived physical appearance subscales. We find some statistically significant effect when the total QoL compared with the social and medical characteristic of study group similar to study was done in Brazil, maybe due to good sample size (Lins *et al*., 2016).

Findings were similar with others who have found that QoL scores are lower in children receiving treatment for cancer and lower compared to healthy children. These findings showed similarity with qualitative studies of children receiving treatment for cancer that have noted problems with fatigue, side effects of disease and treatment on physical activities as well as difficulties with social implications (Dickinson *et al*., 2002; Klassen *et al*., 2011).

The second objective was to evaluate predictors of poor QoL throughout treatment. Our results revealed that older children and girls had worse QoL and this was concordant with others (Kurt *et al*., 2012).

Domains of QoL. This study found that cognitive functioning worsened thorough because were not intuitive that children on maintenance therapy should be incorporated better into the school environment all time (Yaris et al., 2001).

Some research is warranted to determine whether this finding is doubled in other studies and if so, whether interventions targeted to improve cognitive functioning, physical appearance worsened all time. This finding might be due to side effect of therapy. However; further research is needed to know how to support patients to overcome this hindering concept from being active (Sung et al., 2009).

QoL in children and adolescents were affected with cancer duration and, after treatment, indicated that the lowest sub scores were on school functioning, this is consistent with previous studies, difficulty at school may be related to patients missing school during then after the completion of treatment, comeback to school and regular school attendance are obliged to promote growth and development, good school experience is thought to pave the way for successful integration into the adult workforce and the attendance of close inter-personal relationships (Chaudhry & Siddiqui 2012).

Successful school reentry barriers in pediatric patients with cancer are manifested and include anxiety about abnormalities due to visible treatment effects, ongoing school absences, separation from peers, teachers' over indulgence or unrealistic explanations regarding the abilities, illness-related disabilities (e.g., impairments of attention, memory, and executive skills; fatigue; pain), and lack of sufficient special needs support from teachers, peers, and families, as well as parents worries about their child becoming punishments or exposed to infections (Varni et al., 2003)

Attitudes healthcare professionals had provided of medical information to school personnel can ease school reentry, healthcare providers may assist the entrance by being aware of parents thoughts and patients' individual school concerns, promoting classroom and peer socialization during periods of extended absences and hospitalization. These results first revealed that 16- to 18-year-old adolescents mentioned poor school functioning and experienced more general fatigue and sleep/rest fatigue. The reason might be that they are transiting from adolescents into young adults, and this period is one of the most difficult with the consequence of cancer and treatment affecting their body image, relationships, role models, future perspectives, and identification from social development and peers (Bakker et al., 2007)

Fatigue could conflict many aspects of their life, such as impaired physical performance and reduced interaction with others, hence, there is a need for special care plan for this careful group of adolescents in adapting school life and fatigue in the best ways.

This study identified many factors that QoL in children and adolescents with cancer. Findings include less fatigue, greater time since diagnosis, and diagnosis at a younger age were associated with a better domain and a better QoL was concurrent with greater time since diagnosis of cancer, therefore this finding is similar to that of another study, which found that children who were older at the time of estimation had poorer domains (Huang et al., 2013)

Treatment status, and age at determination did not have a concurrence with domains in it, although female sex has been significantly associated with an impaired QoL. A study was done in Egypt 2013; they stated that the total QOL in children with cancer relatively low with mean value of 62.29 compared to the results of the Pakistani study which demonstrated a much lower total QOL score of 42.07. Moreover, they reported female sex and younger age, increased treatment intensity, long duration of hospital admission, and high frequency of hospital visits, were associated with a poorer total QOL (Chaudhry & Siddiqui 2012; Eman et al., 2016).

In study from Saudi Arabia reported that the score of total QOL in childhood cancer was 73.48 and seemed to be relatively good score for quality of life may be due to half of the study group had low intensity of therapy (represented the patients had surgery only and/or six months chemotherapy with a satisfactory prognosis), this means good prognosis and short period of chemotherapy. This result agrees with some studies done in different countries as United State (US), it was 73.6 (Bakker et al., 2007; Amal et al., 2019).

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