

Quality of Life in Egyptian Children with Cancer

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ABSTRACT

Background and Objectives: Cancer treatments leading to increased survival rates are reported to participate in the creation of debilitating physical and psychosocial deficits for cancer survivors. 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.

Methods: Parents of 67 included patients aged 8 - 12 years, were asked to complete the parent proxy report of PedsQL™ 3.0 Cancer Module (Arabic version), as well as a separate sheet for socio-demographic data. **Results:** The ratio of Males to females was 1.8:1 among study patients with a median age of 8 years at diagnosis. Hematological malignancies represented 70.1% of the sample, with the highest proportion for ALL (52.2%). Total QOL showed to be relatively low with mean value of 62.29 for the whole group. Subscales with least scores were for; worry (44.11), perceived physical appearance (50.6), and procedural anxiety (55.34). On the other hand, the best score was 75.98 for communication, followed by 72.63 for cognitive problems. The impacts of some medical and socio-demographic variables on QOL and its subscales were elicited in our results. **Conclusion:** Increased treatment intensity, long duration of hospital admission, higher frequency of hospital visits, female sex, younger age at diagnosis, and large family size were all associated with a poorer total QOL and/or its subscales among Egyptian pediatric cancer patients.

Keywords: Quality of Life; Children Cancer Patients; PedsQL™ 3.0 Cancer Module

1. Introduction

Childhood cancer patients are now long term survivors with current survival rates approaching 90% [1]. Contemporary therapies for pediatric malignancies represent the main contributor for such advancement [2]. However, same treatments leading to increased survival rates are reported to participate in the creation of debilitating physical and psychosocial deficits for cancer survivors [3]. Health-related morbidity among childhood cancer survivors is mainly attributed to late effects including chronic health conditions and life-threatening complications during adulthood [4-6]. 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 [3]. HRQOL targets a variety of dimensions including physical, mental and social domains [7]. 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 [8-11].

The present study was designed to identify the HR-QOL profile in Egyptian pediatric cancer patients. The impact of underlying disease, treatment and sociodemographic variables on the total QOL and its domains was also evaluated.

2. Patients and Methods

Patients: a convenient sample of 67 pediatric cancer patients aged from 8 to 12 years with established diagnosis at the pediatric inpatient as well as outpatient clinic of the National Cancer Institute of Egypt were included onto study. Parents of every included patient were asked to complete the PedsQL™ 3.0 Cancer Module [3] (Arabic version), as well as a separate sheet for sociodemographic data.

Instrument: the PedsQL™ 3.0 Cancer Module—designed to measure HRQOL dimensions specifically tailored for pediatric cancer—was the instrument in use. It

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investigated 8 domains with the total of 27 items for the whole module; 2 items for pain and hurt, 3 for each of procedural anxiety, treatment anxiety, worry, perceived physical appearance, and communication, whereas 5 items for each of nausea and cognitive problems.

Linguistic translation: the parent proxy-report for children aged 8 - 12 years of the "PedsQL™ 3.0 Cancer Module" was translated into Arabic (native language of the study sample) using the PedsQL™ Measurement Model Translation Methodology. Linguistic validation process included forward translation from the source language (English) to the target language (Arabic), backward translation to the source language, and finally cognitive debriefing step according to PedsQL™ Cognitive Interviewing MethodologySM [12,13]. Detailed reports for every step throughout the whole process were sent to Mapi research Institute in Lyon, France, on behalf of Dr. James W. Varni, the copyright owner of the PedsQL™ for approval. A 5 point likert scale ranging from 0 for "never a problem" till 4 for "almost always a problem" was used for each item. The scale is converted to a corresponding score from 0 to 100, where 0 represented the worst quality of life and 100 represented the best one. The total QOL is the average of the scores for all domains, while QOL for each domain is the average of scores of its items.

Treatment related measures: a) *intensity of cancer therapy*: scored from 1 to 3: low intensity such that surgery only and/or six months chemotherapy with a favorable prognosis had a score 1, medium intensity took the score of 2 for cases with chemotherapy longer than 6 months according to the treatment protocol in addition to an intermediate prognosis, 3 was the score for high intensity of therapy that represented treatment according to high risk protocols, bone marrow transplantation, and/or diseases with less favorable prognosis [14,15]. b) *Phase of treatment*: the on-treatment group was defined as any patient actively receiving anticancer therapy at any phase of the treatment protocol, whereas the follow-up group indicated patients ended their treatment and scheduled for timed interval follow up. c) *Frequency of hospital visits*: classified into either ≤ 3 or >3 visits per month. d) *Length of hospital admission*: had 3 levels: low for admission periods within one third of the total duration of therapy, medium if admission period was about 1 - 2 thirds the total duration, and high if it exceeded 2 thirds the total treatment duration. e) *Therapy duration*: ≤ 6 month was considered to be low, between 6 month and 1 year was medium, and ≥ 1 year represented high duration of therapy. Indirect method for measuring treatment compliance (compliant or non-compliant) [16] was used through a single screening question "Is your child used to strictly follow instructions and take medications as the doctor prescribed?" with a parent report of "yes" or "no".

Other sociodemographic data included; residence (urban or rural), family size, and gender.

Statistical analysis: scores for total QOL and the 8 subscales for each participant were calculated after the guidelines of the PedsQL™ 3.0 Cancer Module developer. Descriptive statistics were expressed as mean and standard deviation. Data analysis was performed using the student t-test with SPSS version 18. p value < 0.05 was considered to be significant.

3. Results

Descriptive demographic and medical data for the study sample are shown in **Table 1**. Study patients were 43 males and 24 females (1.8:1) with a median age of 8 years at diagnosis and 5.25 as mean value for family size. Patients with hematological malignancies represented 70.1% versus 29.9% with solid tumors, with the highest proportion for ALL (52.2%). The on-treatment and follow-up cancer groups had very close percentages of 53.7% and 46.3% respectively, together with 50.7% had treatment duration of 1 year or above at time of evaluation. The urban and rural distribution for residence was also 50.7% and 49.3%, respectively. Medium and high intensity of therapy (59.7% & 31.3% respectively) were much more represented than low intensity (9.0%). While hospital visits for 70.1% of the sample exceeded 3 times/month, 43.3% had hospital admissions for more than two thirds of their treatment duration with a compliance rate of 89.6% of the whole sample.

Total QOL showed to be relatively low with mean value of 62.29. Subscales with least scores were for; worry (44.11), perceived physical appearance (50.6), and procedural anxiety (55.34). On the other hand, the best score was 75.98 for communication, followed by 72.63 for cognitive problems, (**Table 2**).

Table 3 shows the impact of different variables on QOL and its subscales. High and medium treatment intensities as well as long duration of hospital admission were associated with a poorer total QOL ($p < 0.05$). Perceived physical appearance was also affected by treatment intensity ($p < 0.01$) with more negative impact on female patients who also suffered more than males from treatment anxiety and worry ($p < 0.05$). Pain & hurt was increased among patients with; lower age (≤ 5 years) at time of diagnosis ($p < 0.05$), longer hospital admission ($p < 0.01$), and non-compliance to treatment ($p < 0.01$). The latter also affected the procedural anxiety domain significantly ($p < 0.05$), while long periods of hospital admission deteriorated treatment anxiety subscale ($p < 0.05$).

Larger family size (>5 members) was associated with a negative effect on communication subscale ($p < 0.01$).

None of diagnosis subtypes (hematological/solid malignancies), phase of treatment (on-treatment/follow-up),

Table 1. Descriptive demographic and medical characteristics.

Variable	n (%)
Gender	
Female	24 (35.8%)
Male	43 (64.2%)
Type of malignancy	
Hematological:	47 (70.1%)
ALL	35 (52.2%)
NHL	5 (7.5%)
AML	1 (1.5%)
HD	4 (6.0%)
LCH	2 (3.0%)
Solid:	20 (29.9%)
Brain	8 (12.0%)
ES	5 (7.5%)
STS	1 (1.5%)
RMS	1 (1.5%)
OS	2 (3.0%)
Ca Colon	1 (1.5%)
NB	2 (6.0%)
Phase of treatment	
On treatment	36 (53.7%)
Follow up	31 (46.3%)
Intensity of therapy	
Low	6 (9.0%)
Medium	40 (59.7%)
High	21 (31.3%)
Therapy duration	
≤ 6 month	12 (17.9%)
> 6 month	21 (31.3%)
≥ 1 year	34 (50.7%)
Hospital admission	
Low	18 (26.9%)
Medium	20 (29.9%)
High	29 (43.3%)
Hospital visits	
≤3/month	47 (70.1%)
>3/month	20 (29.9%)
Compliance	
Compliant	60 (89.6%)
Non-compliant	7 (10.5%)
Residence	
Rural	33 (49.3%)
Urban	34 (50.7%)

ALL = Acute Lymphoblastic Leukemia; NHL = Non Hodgkin Lymphoma; AML = Acute Myeloid Leukemia; HD = Hodgkin Lymphoma; LCH = Langerhan's Cell Histiocytosis; ES = Ewing's sarcoma; STS = Soft-Tissue Sarcoma; RMS = Rhabdomyosarcoma; OS = Osteosarcoma; Ca Colon = Cancer Colon; NB = Neuroblastoma.

or residence (urban/rural) appeared to have a statistically significant effect on either total QOL or its subscales in our study.

4. Discussion

The parent-proxy report for pediatric cancer patient showed a total QOL of 73.6 for the US, 72.2 for the Indonesian and 71.02 for the Chinese mandarin child-

Table 2. Scores of total QOL and its subscales among study group.

Scale/Subscale	Mean	Median	Std. D	Min.	Max.
Total QOL	62.29	66.50	18.85	19.4	92.5
Pain & Hurt	66.98	75.00	33.89	0.0	100.0
Nausea	68.32	80.00	29.39	0.0	100.0
Procedural anxiety	55.34	75.00	36.17	0.0	100.0
Treatment anxiety	63.64	75.00	32.24	0.0	100.0
Worry	44.11	50.00	30.70	0.0	100.0
Cognitive problems	72.63	80.00	26.99	5.0	100.0
Perceived physical appearance	50.60	58.30	28.09	0.0	100.0
Communication	75.98	91.70	31.80	0.0	100.0

hood cancer patients [3,17,18]. Although the total QOL for Egyptian pediatric cancer patients showed to be relatively poorer than aforementioned studies with a score of 62.3, yet it showed to be better than results of the Pakistani data which showed much lower total QOL score of 42.07 [10]. Relatively poor QOL was attributed according to our results to intensity of therapy which was reported to represent an independent predictor of poor QOL [9]. As shown by the illustrated data, high and medium intensities of treatment showed significant lower total QOL ($p < 0.05$) compared to low intensity therapy, with mean values of 60.4, 60.4 and 81.0 respectively. Adverse effect of therapy intensity on QOL could be explained in terms of more intensive chemotherapy and poor disease prognosis [9,19]. The participation of intensive chemotherapy on the deteriorated QOL could be emphasized again by the highly significant decrease in perceived physical appearance subscale among medium and high intensity of treatment in comparison to low therapy intensity patients ($p < 0.01$). Hair loss and other distressing adverse effects on physical appearance as a result of using anti-neoplastic agents in childhood cancer protocols could perfectly explain the low QOL for this domain [20,21]. In the same context, high frequency of hospital visits was significantly correlated to reduced QOL score in nausea subscale (60.0) compared to higher value in case of less frequent visits (80.0) ($p < 0.05$). Such findings indicated more that frequent exposure to hospital atmosphere and consequently more therapy administration could be a leading factor.

Hospitalization, was another therapy related factor which showed significant impact on the total QOL ($p < 0.05$). Patients with hospital admissions exceeding two thirds of their treatment duration showed a more deteriorated QOL (55.6) compared to others with lower duration in consistence to others' data [22]. Similarly, a significant decrease in QOL was also shown in the pain and hurt ($p < 0.01$) and treatment anxiety ($p < 0.05$) domains in relation to duration of hospital admission resulting in

Table 3. Total QOL and its 8 subscales in relation to study variables.

Variable	Total QOL	Pain & Hurt	Nausea	Procedural anxiety	Treatment anxiety	Worry	Cognitive problems	Perceived physical appearance	Communication
Age at diagnosis									
<5 yrs	59.2 (19.0)	51.0 (41.0)	65.0 (31.0)	58.3 (37.2)	59.6 (38.1)	45.0 (23.0)	69.0 (24.0)	53.0 (26.0)	2.1 (34.4)
≥5 yrs	63.4 (18.9)	73.0 (30.0)	69.0 (29.0)	54.3 (36.2)	65.0 (30.3)	44.0 (33.0)	74.0 (28.0)	50.0 (29.0)	77.3 (31.1)
p value	*	0.02	*	*	*	*	*	*	*
Gender									
Female	57.9 (20.3)	64.0 (35.0)	65.0 (28.0)	48.3 (38.5)	52.0 (30.4)	34.0 (30.0)	79.0 (26.0)	41.0 (28.0)	71.9 (36.3)
Male	64.7 (17.8)	69.0 (34.0)	70.0 (30.0)	59.3 (34.4)	70.1 (31.7)	50.0 (30.0)	69.0 (27.0)	56.0 (27.0)	78.3 (29.2)
p value	*	*	*	*	0.02	0.04	*	0.03	*
Intensity of treatment									
Low	81.7 (5.3)	90.0 (9.0)	79.0 (15.0)	73.6 (26.0)	81.9 (8.2)	62.0 (10.0)	92.0 (14.0)	79.0 (18.0)	95.8 (10.2)
Medium	60.4 (19.8)	61.0 (36.0)	71.0 (29.0)	52.3 (38.0)	63.1 (32.8)	45.0 (33.0)	70.0 (26.0)	45.0 (28.0)	73.9 (32.6)
High	60.4 (16.7)	72.0 (32.0)	60.0 (32.0)	56.0 (34.9)	59.5 (34.6)	36.0 (28.0)	71.0 (30.0)	53.0 (26.0)	74.2 (33.2)
p value	0.02	*	*	*	*	*	*	0.01	*
Family size									
≤5	61.8 (18.9)	64.0 (35.0)	69.0 (30.0)	47.1 (36.1)	61.0 (32.9)	42.0 (32.0)	76.0 (26.0)	52.0 (28.0)	83.3 (26.6)
>5	63.1 (19.2)	72.0 (32.0)	68.0 (29.0)	70.1 (31.9)	68.4 (31.2)	48.0 (28.0)	67.0 (29.0)	49.0 (29.0)	62.8 (36.4)
p value	*	*	*	*	*	*	*	*	0.01
Hospital admission									
Low	65.9 (20.0)	69.0 (37.0)	68.0 (25.0)	51.8 (40.6)	69.8 (28.3)	55.0 (30.0)	71.0 (26.0)	58.0 (27.0)	81.9 (27.8)
Medium	68.8 (11.3)	83.0 (26.0)	74.0 (28.0)	63.4 (27.9)	74.1 (24.0)	47.0 (33.0)	79.0 (19.0)	51.0 (25.0)	77.5 (33.6)
High	55.6 (20.5)	54.0 (32.0)	65.0 (33.0)	52.0 (38.6)	52.6 (36.7)	35.0 (28.0)	69.0 (32.0)	45.0 (31.0)	71.2 (33.2)
p value	0.03	0.01	*	*	0.04	*	*	*	*
Hospital visits									
≤3/month	67.4 (16.0)	78.0 (24.0)	80.0 (19.0)	60.8 (39.7)	56.1 (32.1)	49.0 (26.0)	75.0 (25.0)	58.0 (25.0)	82.1 (32.8)
>3/month	60.1 (19.7)	62.0 (37.0)	63.0 (32.0)	53.0 (34.7)	66.9 (32.1)	42.0 (33.0)	72.0 (28.0)	47.0 (29.0)	73.4 (31.4)
p value	*	*	0.02	*	*	*	*	*	*
Compliance									
Compliant	63.5 (18.9)	72.0 (29.0)	69.0 (30.0)	58.7 (35.6)	63.8 (32.8)	46.0 (30.0)	73.0 (28.0)	51.0 (29.0)	75.4 (33.4)
Non-compl.	52.1 (16.7)	25.0 (43.0)	66.0 (28.0)	26.2 (29.0)	61.9 (29.6)	29.0 (31.0)	72.0 (20.0)	49.0 (17.0)	80.9 (12.5)
p value	*	0.00	*	0.02	*	*	*	*	*
Therapy duration									
≤6 month	64.9 (21.6)	72.0 (37.0)	63.0 (39.0)	54.2 (41.7)	74.3 (24.7)	47.0 (42.0)	77.0 (28.0)	54.0 (25.0)	80.6 (29.8)
>6 month	65.2 (21.6)	74.0 (33.0)	70.0 (24.0)	43.6 (35.5)	64.7 (33.2)	43.0 (31.0)	83.0 (19.0)	57.0 (33.0)	78.2 (31.9)
≥1 year	59.6 (18.0)	61.0 (33.0)	65.0 (25.0)	63.0 (33.5)	59.2 (33.8)	44.0 (27.0)	65.0 (29.0)	46.0 (26.0)	73.0 (33.0)
p value	*	*	*	*	*	*	0.04	*	*

*no significant difference.

increased physical and psychological distress [23,24].

Moreover, pain and hurt and procedural anxiety domains; regarded as treatment related variables were shown to be correlated to patients' compliance to treatment protocols in agreement to related studies [23,25]. Decreased compliance; in form of missing appointments and schedule non adherence showed to be associated with deteriorated scores for both subscales at p values <0.01 and <0.05 respectively.

While an association between phase of treatment and QOL was reported by some investigators [15,26], our

results did not show any significant difference between patients under current therapy and those at follow-up. Similarly, Speechley and colleagues [27], found that type of cancer can affect QOL which was on the contrary to our data.

Some socio-demographic factors such as family size and gender also showed a crucial role in determining QOL [28]. Risk factors for poor QOL included family size [29]. According to our results, patients related to small families with 5 or less members had a significantly better scores in the communication subscale with a mean

value of 83.3 compared to 68.2 in larger sized families ($p < 0.05$). This could be explained by difficult interpersonal relationships and less parental care offered to their children with the increased number. The poorer QOL among female versus male patients ($p < 0.05$) in more than one domain was also matched with similar studies [30,31]. Such domains included treatment anxiety, worry and perceived physical appearance. For residence, on the other hand, on showing no significant differences in QOL and its subscales between the urban and rural residences, our results agreed with literature reporting the weak influence of such a parameter on QOL [32].

In summary: increased treatment intensity, long duration of hospital admission, high frequency of hospital visits, female sex and younger age were all associated with a poorer total QOL and/or its subscales among Egyptian pediatric cancer patients.

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