Quality of life and symptom prevalence as reported by children with cancer in Lebanon

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ABSTRACT

Keywords:
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Purpose: To date, there are no studies on quality of life (QoL) and symptom prevalence reported by pediatric oncology patients in Lebanon. The purpose of this study was to evaluate the QoL, symptom prevalence and symptom management among a sample of pediatric oncology patients.
Methods: The study design was cross-sectional. The Pediatric Quality of Life Inventory (PedsQL) cancer module and the Memorial Symptom Assessment Scale were administered in Arabic using face-to-face interviews to a convenience sample of 85 pediatric cancer patients (7–18 years) at a tertiary hospital in Lebanon.
Results: The mean age of the study group was 12.5 years with leukemia being the most common cancer (43.5%). The lowest scores on the PedsQL subscales were in nausea (score = 64.82; SD = 25.76) and worry (score = 68.14; SD = 30.07), thus indicating more problems in these areas. A comparison based on age showed significant differences in pain and hurt, nausea, and worry. In children (7–12 years), lack of appetite, pain, and nausea were mostly prevalent whereas adolescents (13–18 years) experienced lack of energy, irritability, and pain. In both age groups, pain and nausea were the most frequently treated symptoms.
Conclusion: Overall, the participants had good health-related QoL as indicated by most of the PedsQL subscales. Symptom management was found to be inadequate and in some cases ineffective. More attention should be given to the management of symptoms in general using pharmacological and non-pharmacological techniques. Of particular importance is the importance of providing psychological support to alleviate symptom burden and improve QoL.

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Introduction

Cancer affects the quality of life (QoL) of children and touches the different spheres of life. These changes are related to daily physical activities, maintaining relationships with family and friends, emotional well-being, and difficulties in coping with the symptoms experienced during their illness (Erickson et al., 2011; Hinds et al., 2004). Throughout this period, pediatric patients suffer from multiple physical and psychological symptoms like pain, fatigue, nausea, to feelings of sadness, worrying and irritability (Collin et al., 2000, 2002; Drake et al., 2003; Goldman et al., 2006). These distressing symptoms are either directly related to the cancer or are the side-effects of treatments that are aimed at achieving cure in this vulnerable population (Eiser et al., 2005; Hockenberry and Hooke, 2007; Yeh et al., 2009). Hence, the presence of these symptoms, regardless of their etiology jeopardizes and decreases the quality of children's lives (Woodgate and Degner, 2003), and necessitates the implementation of pediatric palliative care services.

The World Health Organization defines Pediatric Palliative Care (PPC) as "the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective PC requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centers and even in children's homes" (World Health Organization, 1998).

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In Lebanon, Pediatric Palliative Care (PPC) is still in its infancy; efforts are underway however to train physicians and nurses in this field and to develop palliative care teams at a number of teaching hospitals in the country. The study of PPC has focused on parental perceptions regarding the symptoms experienced by their children, and the importance of early integration of PC. A study by Saad et al. (2011) focusing on the perspective of bereaved parents showed that children suffered a great deal from fatigue, anorexia, depression, and pain during the last months of their lives. The most treated symptoms with the highest success rates were pain and dyspnea. A recent study by Abu-Saad et al. (2013) on the QoL and symptom prevalence of children with cancer from the perspective of parents reported the most encountered health-related QoL problems were in nausea, worry and treatment anxiety. During the course of the treatment, Lebanese children mostly experienced symptoms like feeling irritable and nervous, lack of energy, lack of appetite, pain and feeling sad. In symptom management with success rates ranging between 56.3% and 73.7%, the most treated symptoms were nausea, vomiting cough, and pain. A phenomenological study by Khoury et al. (2013) explored the lived parental experiences of cancer children and found that families experienced decreased QoL due to the burden and uncertainty of their child's disease. Two case reports on PPC from the Children's Cancer Center of Lebanon (CCCL) showed that early integration of PC at home and in the hospital can improve children's QoL (Abboud et al., 2007).

However in order to ensure effective PC outcomes, adequate knowledge of symptomatology and proper management is needed. A study by Abu-Saad Huijer et al. (2008) regarding PPC practices found that only 20.2% of nurses and 3.7% of physicians received continuing education in PC. However nurses were more likely to include the family in the treatment choice. The study recommended further training of pediatric health care professionals in symptom management in pediatric palliative care.

Although these studies provide valuable insight into the field of PPC, it is important to assess its outcomes such as QoL and symptom prevalence and management from the perspective of children, which is currently lacking in Lebanon. Thus, the purpose of this study was to evaluate the QoL, symptom prevalence and symptom management in Lebanese children with cancer.

Methods

Study design

This was a cross-sectional descriptive survey of pediatric cancer patients presenting to the CCCL at the American University of Beirut Medical Center (AUBMC); inpatient and outpatient units for oncologic treatments. Affiliated with St. Jude's Children's Research Hospital in Memphis, Tennessee; this regional referral center located in the heart of Beirut provides care to Lebanese and non-Lebanese children with cancer from different socioeconomic backgrounds.

The study was approved by the American University of Beirut-Institutional Review Board and the medical directors of AUBMC and CCCL.

Sample

Between 2010 and 2011, a convenience sample of pediatric patients aged 7–18 years was enrolled in the study. On daily basis, the research assistant (RA) visited the inpatient and outpatient units and identified potential participants with the help of the unit nurse managers. The identification process relied on the appointment and admission lists of scheduled patients for treatment. The eligibility criteria included participants between 7 and 18 years of age,

diagnosed with cancer for more than one month, aware of their diagnoses, currently receiving cancer treatments (like chemotherapy or radiation), had assented or consented to participate, and had a parent or significant other consenting their participation.

Data collection procedure

Data collection started with the RA securing both the informed consent of parents and the assent/consent of children (7–12 years) and adolescents (13–18 years) prior to their participation in the study. Face-to-face interviews were conducted by the RA either in the conference room of the outpatient unit or in the patient's hospital room where any possible disruption was limited. Parents were not present during the interviews in order to avoid influencing their children's responses. The RA read the questionnaire for both age groups, re-read if needed, explained the rating scales, and documented their feedback immediately. Each patient interview lasted around 20–25 min.

Questionnaire

The "Quality of Palliative Care Questionnaire-Pediatrics" was a combination of the Pediatric Quality of Life Inventory (PedsQL) cancer module and the Memorial Symptom Assessment Scale (MSAS). The PedsQL 3.0 cancer module evaluates 8 dimensions of health-related QoL among pediatric cancer patients and exists in two versions: 7–12 years and 13–18 years. Both versions are identical except in the administered language that is age-specific. The subscales measure pain and hurt (2-items), nausea (5-items), procedural anxiety (3-items), treatment anxiety (3-items), worry (3-items), cognitive performance (5-items), perceived physical performance (3-items), and communication (3-items). The instrument was found to be reliable and valid in the pediatric cancer population (Varni et al., 2002).

The authors added two items from the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) that represent the Global Health Status (GHS)/QoL subscale. It measures the overall global health and the QoL as perceived by the participants in the previous month. The Lebanese Arabic EORTC QLQ-C30 had good results of reliability and validity among a sample of Lebanese adult cancer patients. The GHS/QoL subscale had an internal consistency of $\alpha = 0.89$ (Huijer et al., 2012).

The MSAS measures symptom prevalence, frequency, severity, and distress (two versions: 7–12 years and 13–18 years) rated by the patients. In children, the MSAS 7–12 was used to measure eight symptoms only (feeling tired, feeling sad, worrying, difficulty sleeping, pain, itching, nausea and lack of appetite). In adolescents, the MSAS 13–18 measures a broad range of 30 symptoms. In both age groups, the MSAS had good results of reliability and validity reported in the literature (Collins et al., 2000, 2002). On the MSAS, an additional section was added by the authors that asks the interviewee if he/she received any treatment when experiencing a symptom, and how successful the treatment was in controlling the symptom (1 = successful, 2 = somewhat successful, and 3 = not successful).

A demographic section was added that encompassed questions related to age, gender, child's status at school, cancer type, time since diagnosis, treatment location, cancer treatments received, and the presence of other medical problems.

Translation and pilot study

The translation of the questionnaire to the Lebanese Arabic language followed forward and backward translation procedures. This process known as the back-translation method preserves the

meaning of each item in the targeted culture hence ensuring a semantically equivalent instrument (Varricchio, 2004). Initially, the researchers translated the questionnaire from English to Arabic and sent the translated version to two experts in the Arabic language for evaluation. During the evaluation, only grammatical changes were required. The backward translation was carried out by an independent translator with no prior knowledge of the original English instrument. The translated version was compared to the original English version for accuracy in order to avoid any inconsistencies. A team of four experts; two in PC, and two in research design and instrument development rated the Arabic version of the instrument for cultural appropriateness. The experts suggested removing the third item (get scared about having needle sticks; i.e. injections, blood tests) from the procedural anxiety subscale because it was similar in the Arabic translation to the two items measuring the same subscale. No further changes were recommended and the final PedsQL 3.0 cancer module contained 26 items.

The Arabic questionnaire was pilot tested on four oncology patients from both ages for clarity, length, comprehension, and presence of any difficult or bothersome items. The participants did not report any problems and no further changes were made.

Statistical analysis

In analyzing demographic and clinical characteristics, frequencies (N) and percentages, as well as means and Standard Deviations (SD) were used to describe the categorical and continuous variables. For the PedsQL, all the items ranged from 0 (never a problem) to 4 (almost always a problem) were reverse scored and linearly transformed to scores from 0 to 100, where higher scores represent better health-related QoL in the past month. The subscale scores were computed by summing the scores of the items in each subscale divided by the number of the items representing the subscale (Varni et al., 2002). As for the two items in the GHS/QoL subscale, patient responses ranged from 1 (very poor) to 7 (excellent), and the scale score was linearly transformed from 0 to 100 according to the scoring manual (Fayers et al., 2001). For the MSAS (7–12 and 13–18), individual symptom scores represented the mean scores on the frequency, severity and distress scales, where higher symptom scores indicate higher frequency, greater severity and more distress (Portenoy et al., 1994).

Independent sample t-tests were used to evaluate the differences in the mean scores of the PedsQL subscales and demographic/clinical characteristics. Cut-off points for the variables; days skipping school and time since diagnosis were based on median of the sample in order to generate equal subgroups for comparison purposes. In addition, Chi square was used to test the differences between demographic and clinical characteristics with respect to age too. A P value of <0.05 was considered statistically significant.

Data management and analyses were done using SPSS software version 20.

Results

Sample characteristics

Over a period of one year, 99 eligible pediatric patients were identified and invited to partake in the study. Fourteen patients refused enrollment because they preferred to play, watch television, or felt tired. The sample size was 85 with an 85.9% response rate. The participants had a mean age of 12.54 years (SD = 3.49) with both females and males equally represented; the majority came from the outpatient clinic (82.4%) and had a mean time of 18.78 months (SD = 21.76) since diagnosis. Around 44% of the

participants had leukemia and 64.7% were receiving chemotherapy. There were no significant differences between children and adolescents with respect to the demographic and clinical variables. Table 1 summarizes the demographic and clinical characteristics of the participants.

PedsQL subscales

Five of the eight scales had scores greater than 80 with the exceptions in pain and hurt (score = 75.15; SD = 28.18), nausea (score = 64.82; SD = 25.76) and worry (score = 68.14; SD = 30.07), thus depicting problems in these areas. A comparison based on age showed that the 7–12 subgroup had six of the eight subscales scores greater than 80 with procedural anxiety, treatment anxiety, and perceived physical appearance being the highest. The lowest scores were found in nausea (score = 76.15; SD = 20.82) and worry (score = 79.05; SD = 22.85). In the 13–18 subgroup, adolescents scored higher in the same subscales, whereas the lowest scores were in nausea (score = 55.22; SD = 25.82), worry (score = 58.88; SD = 32.50) and pain and hurt (score = 66.58; SD = 31.40). There were significant differences between children and adolescents in pain and hurt ($P = 0.001$), nausea ($P = 0.000$) and worry ($P = 0.001$) subscales. It is noteworthy that adolescents scored lower on all the subscales when compared to children (Table 2).

In the GHS/QoL subscale, there were significant differences between the two age groups with children reporting better overall health and QoL (Table 2).

MSAS 7–12 and 13–18

Table 3 is a summary of symptom prevalence, mean scores and symptom management in children. The 7–12 age group experienced on average 1.71 symptoms (SD = 1.29; Range = 0–5), with the most prevalent being lack of energy ($n = 19$; 48.7%), pain and nausea ($n = 11$; 28.2%), while the least prevalent were worrying and difficulty sleeping ($n = 4$; 10.3%). Higher mean scores were found in less common symptoms like feeling tired and difficulty sleeping. Children were mostly treated for pain (90.9%) and nausea (81.8%), and the treatment of these symptoms from the perspective of children was mostly successful.

Table 4 presents symptom prevalence of >20% in adolescents, their mean scores and symptom management. On average, 13–18 age group experienced 7.80 symptoms (SD = 4.97; Range = 0–24). The most common symptoms (>50%) were lack of energy ($n = 29$; 63.0%), feeling irritable ($n = 26$; 56.5%), pain, worrying, and lack of appetite ($n = 25$; 54.3%), while the least were itching ($n = 2$; 4.3%) and problems with urination ($n = 1$; 2.2%). In view of symptom prevalence and administration of treatments, vomiting (81.8%), cough (70.0%), pain (68.0%), and nausea (66.7%) were most frequently treated with higher success rates as reported by the adolescents.

Relationship between participants' characteristics and PedsQL subscales

Males reported significantly higher scores on procedural anxiety than females (96.80, SD = 8.22 vs. 85.71, SD = 21.66; $P = 0.003$); no other gender differences were found. There were no differences between participants with blood cancer and solid tumors. When the study group was compared based on the child's status at school (full time vs. part time), those attending school regularly reported better scores on pain and hurt, procedural anxiety and better global health/QoL than part-time students (83.88, SD = 20.40 vs. 66.36, SD = 21.33; $P = 0.000$). On the other hand, there were no significant differences between the participants on the number of days lost

Table 1
Demographic and clinical characteristics of the participants (N = 85).

Characteristic	Total N (%)	7—12 yrs. n = 39	13—18 yrs. n = 46
Age			
Mean (SD)	12.54 (3.49)	9.20 (1.66)	15.36 (1.61)
Gender			
Male	43 (50.6%)	21 (53.8%)	22 (47.8%)
Female	42 (49.4%)	18 (46.2%)	24 (52.2%)
Nationality			
Lebanese	77 (90.6%)	36 (92.3%)	41 (89.1%)
Non-Lebanese[a]	8 (9.4%)	3 (7.7%)	5 (10.9%)
Days lost from school in the past 6 months			
Mean (SD)	71.50 (61.90)	71.31 (60.32)	71.65 (63.95)
Child Status at school			
Full-time Student	30 (35.3%)	14 (35.9%)	16 (34.8%)
Part-time Student	55 (64.7%)	25 (64.1%)	30 (65.2%)
Siblings			
Mean (SD)	2.84 (1.80)	2.62 (2.00)	3.02 (1.59)
Treatment location			
Outpatient unit	70 (82.4%)	29 (74.4%)	41 (89.1%)
Inpatient unit	15 (17.6%)	10 (25.6%)	5 (10.9%)
Time since diagnosis (months)			
Mean (SD)	18.78 (21.76)	19.31 (20.81)	18.37 (22.67)
Primary cancer type			
Lymphoma	17 (20.0%)	1 (2.6%)	16 (34.8%)
Head and Neck	12 (14.1%)	9 (23.1%)	3 (6.5%)
Leukemia	37 (43.5%)	22 (56.4%)	15 (32.6%)
Bones	11 (12.9%)	4 (10.3%)	7 (15.2%)
Others	8 (9.4%)	3 (7.7%)	5 (10.9%)
Treatment received			
Chemotherapy	55 (64.7%)	26 (66.7%)	29 (63%)
Chemotherapy + (Radiation or Surgery)	29 (34.1%)	12 (30.8%)	17 (37%)
Don't know	1 (1.2%)	1 (2.6%)	—
Presence of other medical problems	6 (7.1%)	2 (5.2%)	4 (8.7%)

[a] Non-Lebanese are children born and living currently in Lebanon though they hold Syrian and Palestinian nationalities.

from school, despite the fact that those who have skipped school for more than 45 days were performing poorer on all the subscales. Regarding time elapsed since diagnosis, participants who were diagnosed with cancer for more than 9 months had less procedural anxiety than those diagnosed within the last 9 months (96.56, SD = 8.00 vs. 86.58, SD = 21.35; P = 0.007) (Table 5).

Discussion

The findings of this study provided valuable information on the QoL and the symptom experience of children and adolescents with cancer in Lebanon. Overall, the participants reported mean scores of greater than 80 in most of the PedsQL subscales thus indicating good QoL. When compared to the child-self report findings in the original study by Varni et al. (2002), most of our findings with exceptions in pain and hurt, nausea, and worry had higher mean scores. The procedural anxiety had the highest score of 91.32 whereas in Varni et al. (2002) had the lowest score of 68.26. Fewer problems with procedural anxiety or even treatment anxiety among our pediatric patients may be related to the sample's mean time since diagnosis. The participants, who were diagnosed with cancer and were on chemotherapeutic regimens for more than 18 months had time to adapt to the disease changes. A study by Landolt et al. (2006) in children diagnosed with blood cancer reported improvements in health-related QoL after one year of oncologic treatment when compared to the first 6 weeks of their diagnoses.

In our sample, one of the suboptimal scores was found in the worry subscale that indicates children worrying about the

Table 2
PedsQL 3.0 subscales (children and adolescents).

	No. of items	Score mean (SD)		
		Total	7—12 yrs.	13—18 yrs.
Subscales				
Pain and hurt[a]	2	75.14 (28.18)	85.26 (19.84)	66.58 (31.40)
Nausea[a]	5	64.82 (25.76)	76.15 (20.82)	55.22 (25.82)
Procedural anxiety	2	91.32 (17.15)	92.30 (17.35)	90.49 (17.12)
Treatment anxiety	3	88.62 (14.93)	90.17 (14.79)	87.32 (15.08)
Worry[a]	3	68.13 (30.08)	79.05 (22.85)	58.88 (32.50)
Cognitive problems	5	85.35 (15.96)	88.72 (12.12)	82.50 (18.25)
Perceived physical appearance	3	89.41 (15.18)	92.09 (10.97)	87.14 (17.80)
Communication	3	85.29 (20.32)	86.97 (19.09)	83.88 (21.40)
Added				
GHS/QoL[a]	2	72.54 (22.52)	77.78 (18.07)	68.11 (25.04)

SD = Standard Deviation; GHS = Global Health Status; QoL = Quality of Life.
PedsQL = Pediatric Quality of Life Cancer Module; the scores range from 0 to 100 where higher scores indicate better performance.
[a] P-value <0.05 for differences between 7—12 years and 13—18 years.

Table 3
MSAS symptom prevalence and symptom management in children with cancer aged 7—12.

During the past week	Prevalence N (%)	Score mean (SD)	Treatment received N (%)	Success of treatment N (%)
1. Lack of appetite	19 (48.7%)	1.61 (0.73)	4 (21.1%)	2 (50.0%)
2. Pain	11 (28.2%)	1.51 (0.52)	10 (90.9%)	8 (80.0%)
3. Nausea	11 (28.2%)	1.60 (0.61)	9 (81.8%)	7 (77.8%)
4. Feeling tired	6 (15.4%)	2.05 (0.95)	3 (50.0%)	2 (66.7%)
5. Feeling sad	6 (15.4%)	1.72 (0.71)	0 (0.0%)	
6. Itching	6 (15.4%)	1.50 (0.72)	3 (50.0%)	2 (66.7%)
7. Worrying	4 (10.3%)	1.25 (0.56)	0 (0.0%)	
8. Difficulty sleeping	4 (10.3%)	2.08 (0.56)	1 (25.0%)	1 (100%)

MSAS = Memorial Symptom Assessment Scale; A mean score represents higher frequency, more severity, and greater distress of a symptom.

reoccurrence of cancer, and the side effects or effectiveness of medical treatments. This finding is a common concern among pediatric oncology patients from different parts of the globe; Australia, Brazil, China, Germany, Indonesia and the United States (Ewing et al., 2009; Felder-Puig et al., 2004; Ji et al., 2011; Scarpelli et al., 2008; Sitaresmi et al., 2008; Varni et al., 2002) where patients face life-threatening diseases. These results indicate the importance of providing a thorough education about treatments and their expected outcomes, in addition to providing psychological support during the course of the disease.

When the PedsQL subscales were compared by age groups (7—12 and 13—18), significant differences were found in pain and hurt, nausea, and worry; adolescents had lower mean scores compared to younger children. A Turkish study by Tanir and Kuguoglu (2011) in cancer children aged 8—12 years reported significant age differences in procedural anxiety and worry. As the participants became older, they reported less anxiety during procedures and being more worried. Moreover, the study highlighted the impact of age on QoL; children as they grew older scored lower in most of the subscales except for procedural anxiety, communication, and nausea. In our study and despite the lack of statistical significance, the findings showed that Lebanese adolescents had lower mean scores in all the subscales when compared to younger children. We can presume that as children with cancer experience a rapid psychological and biological growth (Bleyer et al., 2008), they experience fluctuations in health-related QoL that necessitate the close monitoring and early intervention of health care professionals in addressing them.

As for the MSAS, Lebanese children on average had 1.71 symptoms; the most prevalent were lack of appetite, pain and nausea. The results of the symptom scores showed that feeling tired, difficulty sleeping and feeling sad were the highest in terms of frequency, severity and distress. Likewise, Collins et al. (2002) found that children with cancer aged 7—12 years experienced 1.9 symptoms, and the second most common symptom was pain. Moreover the study showed that sadness despite being less prevalent was highly frequent and distressing. Another study by Collins et al. (2000) reported that children aged 10—18 years of age experienced lack of energy, pain, drowsiness, nausea, cough, and lack of appetite followed by psychological symptoms of sadness, nervousness, worrying and irritability. The occurrence of these symptoms was similar among the older age group in our study; however the psychological symptoms experienced by Lebanese adolescents were higher (around 44% prevalence). Landolt et al. (2006) reported that adolescents receiving oncologic treatments in addition to their physical complaints faced problems in emotional functioning and mood.

Evidently, the participants in our study experienced highly prevalent symptoms of pain, nausea, lack of appetite, and lack of energy. Likewise, studies from Taiwan (Yeh et al., 2009) and the United States (Miller et al., 2011) have identified this group of symptoms in the same population. Walker et al. (2010) reported fatigue, nausea, appetite changes and pain being most frequent, intense and distressing among pediatric oncology patients receiving chemotherapy. Moreover, the study did not find significant differences in symptom occurrence before and after

Table 4
MSAS symptom prevalence (>20%) and symptom management in adolescents with cancer aged 13—18.

During the past week	Prevalence N (%)	Score mean (SD)	Treatment received N (%)	Success of treatment N (%)
1. Lack of energy	29 (63.0%)	2.27 (0.98)	3 (10.3%)	1 (33.3%)
2. Feeling Irritable	26 (56.5%)	2.16 (0.77)	1 (3.8%)	0
3. Pain	25 (54.3%)	2.54 (1.05)	17 (68.0%)	10 (58.8%)
4. Worrying	25 (54.3%)	2.00 (0.61)	3 (12.0%)	1 (33.3%)
5. Lack of appetite	25 (54.3%)	2.04 (0.84)	1 (4.0%)	1 (100%)
6. Feeling nervous	21 (45.7%)	1.93 (0.81)	1 (4.8%)	1 (100%)
7. Feeling sad	20 (43.5%)	2.33 (0.99)	3 (15.0%)	2 (66.7%)
8. Nausea	18 (39.1%)	1.92 (0.89)	12 (66.7%)	6 (50%)
9. Difficulty sleeping	14 (30.4%)	2.64 (0.91)	3 (21.4%)	3 (100%)
10. Weight loss	14 (30.4%)	1.45 (0.95)	1 (7.1%)	0
11. "I don't look like myself"	13 (28.3%)	2.30 (0.76)	0 (0.0%)	
12. Dry mouth	12 (26.1%)	1.50 (0.98)	4 (33.3%)	3 (75%)
13. Vomiting	11 (23.9%)	1.90 (0.77)	9 (81.8%)	6 (66.7%)
14. Change in the way food tastes	11 (23.9%)	2.30 (0.73)	0 (0.0%)	
15. Difficulty concentrating	11 (23.9%)	2.00 (0.68)	0 (0.0%)	
16. Cough	10 (21.7%)	2.36 (0.92)	7 (70.0%)	4 (57.1%)
17. Dizziness	10 (21.7%)	1.70 (0.89)	0 (0.0%)	
18. Sweats	10 (21.7%)	2.03 (0.88)	0 (0.0%)	

MSAS = Memorial Symptom Assessment Scale; A mean score represents higher frequency, more severity, and greater distress of a symptom.

Table 5
Relationship between demographic and clinical characteristics of Adolescents and Children and PedsQL Subscales ($N = 85$).

Characteristics	N	Pain/Hurt	Nausea	Procedural anxiety	Treatment anxiety	Worry	Cognitive problems	Perceived physical appearance	Communication	GHS/QoL
Gender										
Male	43	74.71 (29.69)	67.79 (23.73)	96.80 (8.22)	90.89 (12.03)	69.37 (28.09)	86.39 (15.13)	89.92 (14.15)	88.95 (16.33)	69.76 (24.46)
Female	42	75.59 (26.90)	61.78 (27.62)	85.71 (21.66)	86.30 (17.24)	66.86 (32.27)	84.28 (16.87)	88.88 (16.32)	81.54 (23.31)	75.39 (20.24)
P-value		0.886	0.285	**0.003**	0.161	0.702	0.545	0.756	0.095	0.252
Primary cancer site										
Solid	30	77.50 (32.56)	58.33 (28.38)	89.58 (19.44)	88.05 (15.73)	68.88 (31.02)	82.00 (18.82)	87.22 (16.48)	83.05 (20.35)	67.49 (25.27)
Blood	54	73.84 (25.95)	67.77 (23.54)	92.12 (15.97)	88.73 (14.67)	67.28 (29.93)	86.94 (14.02)	90.43 (14.51)	86.26 (20.48)	75.30 (20.79)
P-value		0.574	0.106	0.519	0.843	0.817	0.215	0.358	0.492	0.131
Child status at school										
Full-time	30	82.91 (23.78)	66.83 (23.46)	95.83 (7.58)	90.27 (12.96)	70.27 (29.08)	86.50 (17.77)	92.50 (12.82)	87.77 (16.77)	83.88 (20.40)
Part-time	55	70.90 (29.66)	63.72 (27.06)	88.86 (20.22)	87.72 (15.94)	66.96 (30.80)	84.72 (15.01)	87.72 (16.18)	83.93 (22.03)	66.36 (21.33)
P-value		0.060	0.598	**0.025**	0.455	0.631	0.627	0.167	0.408	**0.000**
Days skipping school										
≤45 days	39	77.56 (27.53)	70.64 (19.67)	95.19 (8.89)	90.17 (12.51)	70.29 (28.01)	87.56 (16.61)	92.52 (11.43)	89.10 (16.68)	78.20 (22.01)
>45 days	37	71.28 (28.08)	63.37 (27.63)	89.18 (19.13)	87.61 (16.96)	67.11 (31.30)	83.37 (15.45)	87.83 (16.02)	82.43 (23.38)	68.01 (23.77)
P-value		0.328	0.194	0.088	0.455	0.642	0.260	0.149	0.159	0.056
Time since diagnosis										
≤9 months	41	74.08 (25.67)	62.43 (27.32)	86.58 (21.35)	87.39 (16.46)	66.86 (29.60)	88.04 (13.17)	89.63 (15.78)	87.80 (19.46)	68.89 (16.66)
>9 months	40	73.75 (31.11)	66.12 (23.73)	96.56 (8.00)	89.58 (13.31)	67.29 (31.31)	83.25 (18.10)	89.37 (15.21)	83.95 (19.82)	75.62 (27.37)
P-value		0.958	0.519	**0.007**	0.514	0.950	0.176	0.940	0.381	0.188

PedsQL = Pediatric Quality of Life Cancer Module; GHS/QoL = Global Health Status/Quality of Life.
The bolded numbers represent significance at 0.05 level.

chemotherapy administration; indicating the persistence of these symptoms in varying distress levels throughout the treatment process that may last up to three years.

As for symptom management, children were mostly treated for pain and nausea while the most distressing symptoms like feeling tired or difficulty sleeping were less frequently addressed. Similarly adolescents were treated for nausea, vomiting, pain, cough and constipation whereas distressing symptoms like "I don't look like myself" and feeling sad were not treated. Despite the use of advanced pharmacological and recent adjunct therapies in symptom management (Rheingans, 2007), children with cancer continue to suffer throughout their illness. A study by Heath et al. (2010) among dying children with cancer found ineffective symptom management in pain, fatigue and poor appetite. Another study by Saad et al. (2011) found that pain and dyspnea were mostly treated among children with cancer during their last months of life; success rates however remained at 42.1% and 55.5% respectively. A similar trend of inadequate symptom management was reported by Abu-Saad Huijer et al. (2012) among Lebanese adult cancer patients, where more emphasis was given to treat the physical symptoms. This lack of proper symptom management as reported by patients may be related to communication problems among the health care team, patients and their families (Abu-Saad Huijer et al., 2008), to the Lebanese medical practices in treating mostly the physical symptoms, and to the inadequate number of specialized PPC teams in Lebanon. Research has emphasized the early integration of PC in alleviating symptom burden that will lead to improved QoL of children with cancer and their families (Mack and Wolfe, 2006; Temel et al., 2010).

As a final note, our participants reported having good QoL while experiencing inadequate symptom management and relief, which should be mutually exclusive. Contrary to the literature where symptom experience impacts quality of life, our findings may be explained by the fact that 82.4% of the participants were from the outpatient clinic, and who were participating in activities of daily living like playing, studying or watching television. In addition, these patients in the center would receive their scheduled cancer treatments, blood transfusions, medications, do follow up blood tests and undergo certain procedures and disease evaluations.

In addition, good QoL despite significant symptom prevalence might, be in part due to the quality of the services offered, ease of accessibility, and close monitoring. It could be also related to low expectations with children and parents accepting significant symptom burden simply because they do not think they should expect anything better.

Limitations

A number of limitations are addressed in this study; one is related to selection bias where most of the participants were from the outpatient clinic, thus limiting generalizability of our findings to the hospitalized pediatric cancer population. Another is related to the cross-sectional design that limits the understanding of symptom distress throughout the illness. Finally, the small sample size does not allow comparative subgroup analyses, considering the different types of cancer and treatments represented in this sample.

Conclusion

In general, the participants had good performance on most of the PedsQL subscales, while the MSAS findings indicated insufficient symptom management. This highlights the importance of early integration of PPC services at the time of diagnosis that will facilitate early detection and management of these symptoms. Moreover, the management of pain should be a priority that needs to be addressed rigorously in order to enhance the daily performance and well-being of children with cancer. Another important finding was the effect of age on QoL that necessitates the presence of a strong supportive system throughout the progress of the disease.

Although we are cautions in generalizing our findings to current PPC practices in Lebanon, however the current study recommends providing pharmacological interventions coupled with tailored psychological support, and assessing treatment success from the patient's own perspective; all geared to alleviate symptom burden and improve the QoL of children and adolescents with cancer.

Conflict of interest statement

No conflicts of interest exist.

Acknowledgments

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