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Pain and its Impact on the Functional Ability in Children Treated at the Children's Cancer Center of Lebanon

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ABSTRACT

Purpose: The purpose of this study was to describe the characteristics of pain in children under treatment at the Children Cancer Centre of Lebanon at the American University of Beirut Medical Centre.

Design and Methods

A cross-sectional correlational survey was used. The Adolescent Pediatric Pain Tool and the Functional Disability Inventory were used to examine the characteristics of pain experienced in a consecutive sample of children treated at the CCCL and its impact on their functional abilities.

Results: The mean age of the 62 participants was 12.3 (SD 2.9). The overall mean pain intensity rating for the sample was 5.06 (SD 1.87) on a 10 cm Word Graphic Rating Scale. More than one-half of the children in the sample (57.4%) reported having pain "sometimes" with a median duration of two hours per pain episode. The most frequently reported locations of pain were the forehead, the abdomen, and the lower back. For the most part, the children used sensory words to describe their pain experience. The children reported moderate levels of functional disability (mean FDI score 25.04, SD 13.81). Multivariable linear regression analysis identified frequency, duration, location, use of affective descriptors, and treatments as statistically significant predictors of pain intensity.

Conclusion: Regrettably, the findings reported attest once again to unrelieved pain in a pediatric oncology population.

Practice Implications: Policy makers can contribute to pain control by introducing legislation and national policies to ensure adequate pain management for children with cancer in Lebanon.

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Introduction

Cancer in children is a significant and worldwide health problem and major cause of death, ranking second in child mortality after accidents (National Cancer Institute 2014). In 2017, an estimated 10,270 new cases of cancer were diagnosed in U.S. children aged 0 to 14 years and 1,190 children were expected to die from cancer (American Cancer Society 2017). In Lebanon, the National Cancer Registry (NCR) reported 281 new cases of cancer in children and adolescence aged 0 to 19 in 2010 (National Cancer Registry 2010). This number constitutes around 5% of the newly diagnosed cancer cases in Lebanon. More recent data have not been published by NCR due to political instability in the country. The Children Cancer Center of Lebanon (CCCL) at the American University of Beirut Medical Center (AUBMC) registry reported 125 new pediatric cases in 2016. The lack of recent data for Lebanon limits international comparisons. Similarly, there is a lack of data on cancer pain and its management in Lebanon.

Although the incidence rates of cancer in U.S. children have increased in recent decades, the mortality rate has declined by 50% since 1975. This significant improvement in the survival rates, approximately 83%, is thought to be related to advances in cancer treatment (American Cancer Society. Cancer facts and figures 2012). Comparable survival rates, 80%, were stated in the CCCL registry. The CCCL is an affiliate of St. Jude Children's Research Hospital in Memphis, Tennessee and uses the same treatment modalities and protocols as those used at leading treatment centers in the U.S. The majority of oncologists treating patients at CCCL are board certified in the U.S, which might explain the comparable survival rates achieved in Lebanon. Although international studies show that children with cancer are living longer, the majority are experiencing unnecessary pain. Almost 87% of children with cancer report moderate to severe pain (Jacob, Hesselgrave, Sambuco, & Hockenberry 2007; Jacob, McCarthy, Sambuco, & Hockenberry 2008; Ljungman, Gordh, Berg, Sorensen, & Kreuger 1999; Mathews 2011), are undertreated and suffer unrelieved pain (Daher et al. 2002; Jacob et al. 2007; Mathews 2011).

Pain is the most common and fearful symptom reported by children with cancer (Beretta et al. 2009; Forgeron, Finley, & Arnaout 2005;

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International Association for the Study of Pain 2009; Jacob et al. 2007, Jacob et al. 2008; Miller, Jacob, & Hockenberry 2011; Uman et al. 2013; Van Van Cleve, Muñoz, Riggs, Bava, & Savedra 2012). Unrelieved cancer pain in children has negative physiological and psychological effects that have been linked to changes in functional ability (International Association for the Study of Pain 2009; Ruccione, Lu, & Meeske 2013). Pain severity delays treatment effectiveness and recovery and has a negative impact on quality of life (Huijer, Sagherian, & Tamim 2013; Miller et al. 2011). Thus, a comprehensive approach to pain assessment (sources, location, quality, intensity, frequency, duration) is essential for timely intervention.

Studies of the characteristics of pediatric cancer pain are scarce and have mostly been conducted in the West (Forgeron et al. 2005; Jacob et al. 2008; Mathews 2011; Twycross, Parker, Williams, & Gibson 2015; Van Cleve et al. 2004; Windich-Biermeier, Sjoberg, Dale, Eshelman, & Guzzetta 2007; Zernikow et al. 2005). With this study we fill a gap in the literature by identifying the characteristics of pain in children and adolescents with cancer in Lebanon and its impact on functional ability.

Background

Culture and Pain

Early in childhood, children learn how to react to pain (Abu-Saad 1984). However investigations of the relationship between culture and pain are scarce, especially in the Eastern Mediterranean Region. Generalizations based on cultural stereotypes can be made, but caution is needed before attributing the characteristics of pain to cultural factors. Although there are people in Lebanon and in the Arab world more generally who believe that illness and, therefore, pain is a punishment from God, or the result of 'evil forces', it is wrong to overstate the extent of such beliefs. As more Lebanese have had access to higher education and Western education, there has likely been a decline in superstition and theocratic-centered explanations for cancer. No doubt there are sections of the population who use rituals such as praying, herbs and fumigations to repel the 'evil eye', but there are others who value Western medicine, and yet others who combine traditional practices with Western medical interventions. Reliance on ritual acts, 'Ra'weh' (Zahr & Hattar-Pollara 1998) alone is as likely to be the result of inability to afford treatment as it is to be out of fear of God and belief in holy retribution.

Children in the Arab world are treated with affection, love and indulgence. They are habitually hugged, kissed and cuddled. When a child is sick, parents and the extended family provide care, comfort and emotional support (Lipson, Reizan, & Meleis 1987; Meleis 1981; Zahr & Hattar-Pollara 1998). Mothers, in particular, are constant companions (Lipson et al. 1987) and ever present to console and comfort their sick children (Abu-Saad 1984). This is a responsibility that mothers in Middle Eastern countries do willingly without prompting (Meleis 1981).

The caring role of the mother in the Arab family as the primary source of comfort for children cannot be overstated (Zahr & Hattar-Pollara 1998). Sex role differentiation comes into play when a Lebanese or other Arab child is sick. Boys are expected to be brave and to endure pain without complaint, while girls are expected to express their pain and emotional distress (Abu-Saad 1984; Kurdahi Badr (Zahr), Puzantian, Abboud, Abdallah, & Shahine 2006; Zahr & Hattar-Pollara 1998).

Pain Characteristics in Children With Cancer

Few studies have investigated the characteristics of pain in children with cancer. Those that have been conducted have focused mostly on pain intensity (Cunha Batalha, Fernandes, de Campos, & Costa 2015). The common finding is that cancer pain in children occurs throughout the course of the disease (Forgeron et al. 2005; Jacob et al. 2008; Van Cleve et al. 2004; Zernikow et al. 2005). The legs, abdomen, head, neck, and back are the most commonly reported locations of pain (Van Cleve et al. 2004). The abdomen, followed by the chest and lower back have been reported as other sites of cancer pain in children (Jacob et al. 2007; Jacob et al. 2008). Pain duration and frequency are the least reported characteristics of cancer pain in children. Zernikow et al. 2005) found that 49% of children with cancer report at least one episode of pain, 24% report continuous pain, and 26% report repeated and irregular pain. The median duration of cancer pain reported by children experiencing pain in the past 24 h was 2 h (Zernikow et al. 2005).

Sources of Cancer Pain in Children

Cancer pain in children is related to the disease process, treatment modalities, and diagnostic procedures (Lebel 2005; McClain, & Suresh, S. (Eds.). 2011). Cancer-related pain, resulting from tumor invasion of tissues or organs, is usual at the time of diagnosis (Ljungman et al. 1996; Ljungman et al. 1999; McGrath 1990; Miser, Dothage, Wesley, & Miser 1987; Miser, McCalla, Dothage, Wesly, & Miser 1987; Zernikow et al. 2005). Cancer-related pain generally subsides when treatment begins (McGrath 1990; World Health Organization 1998; Zernikow et al. 2005). Children with cancer consistently report pain from treatments and procedures rather than from the cancer itself (Blount, Piira, Cohen, & Cheng 2006; World Health Organization 1998). The primary cause of treatment-related pain in children is chemotherapy (Bossert, Van Cleve, & Savedra 1996; Elliott et al. 1991; McGrath 1990; Zernikow et al. 2006. Most chemotherapy-related pain is due to mucositis, mucosal damage, infection, peripheral neuropathy, gastritis and other adverse effects (Ljungman et al. 1999; Van Cleve et al. 2004; Zernikow et al. 2005). Children are traumatized and distressed by pain caused by lumber puncture (LP), and bone marrow aspiration (BMA) (Blount et al. 2006; Kazak & Kunin-Batson 2001; Liossi 1999; Ljungman et al. 1999; Twycross et al. 2015; Walco, Conte, Labay, Engel, & Zeltzer 2005; Windich-Biermeier et al. 2007; World Health Organization 1998; Yeh 2001; Zernikow et al. 2005). Needle sticks are another common source of pain in children with cancer (Cummings, Reid, Finley, McGrath, & Ritchie 1996; Dufresne et al. 2010; Gupta et al. 2014; Kurdahi Badr (Zahr) et al. 2006; Ljungman et al. 1999; Taddio et al. 2012; Zernikow et al. 2005).

Impact of Cancer Pain on Daily Functioning of Children

Functional impairment is generally defined as "specific deficits in multiple domains of functioning developing subsequent to a disorder" (Winters, Collett, & Myers 2005, p. 309). It is a devastating consequence of unrelieved cancer pain (Gauntlett-Gilbert & Eccleston 2007; International Association for the Study of Pain 2009; Logan & Scharff 2005; Peterson & Palermo 2004). Functional ability is commonly assessed in adult cancer patients, but little research has been directed to the measurement of functional limitations in children with chronic or recurrent pain (Palermo 2000). Cicogna, Nascimento, and Lima (2010) reported that children receiving chemotherapy perceived the experience as restrictive due to intense pain.

Cultural Specificity

The most common words children with cancer select from the Adolescent Pediatric Pain Tool (APPT) (Van Cleve et al. 2004) to describe pain are: annoying, uncomfortable, comes and goes, sore, aching, and hurting. Zernikow et al. (2005) reported that German children more commonly use words meaning: sharp, dull, burning, throbbing, cramping and colicky. This difference in use of pain descriptors highlights the importance of cultural specificity in descriptions of pain in children. Since culturally appropriate assessment of pain is a prerequisite for effective pain management, the aim of this study was to

establish a comprehensive baseline for assessing pediatric cancer pain at the Children's Cancer Centre of Lebanon (CCCL).

In the absence of descriptive data on pain and functionality of children treated at the CCCL, the specific objectives of the study were to:

1. Describe the characteristics of pain in Lebanese children with cancer.
2. Identify the major sources of pain among children treated at the CCCL.
3. Examine the impact of pain on the functional ability of children treated at the CCCL.
4. Determine the factors associated with pain intensity and FDI in CCCL patients.

Method

Design

A cross-sectional correlational survey was designed to meet the study objectives.

Setting

The study was conducted at the American University of Beirut (AUBMC) affiliated

CCCL. Lebanon is a small middle-income country in Western Asia on the Eastern coast of the Mediterranean Sea with a surface area of 10, 452 km^2, and an estimated population of four million (Daher et al. 2002). AUBMC, a 420 bed academic medical center is Joint Commission International accredited and Magnet designated. The CCCL was established in 2002. The CCCL is a regional center for the comprehensive treatment of pediatric cancer and provides services to the children of Lebanon and the Middle East region.

Participants

Children were eligible for the study if they were aged 8–17 years, had been diagnosed with cancer of any type for at least a month, and were receiving treatment. Children were excluded from the study if they had a pre-existing mental disorder, intellectual disability, a hearing or speech problem, or were critically or terminally ill.

Sample

Fig. 1 shows how 62 children were recruited to the study from the 635 listed in the CCCL Central Database.

Sample Size

Assuming a mean overall pain intensity score of 5.7 and adjusting for a SD of (2.7)

(Jacob et al. 2008), the sample size of 62 was sufficient to estimate a 95% confidence interval (CI) for APPT score with a margin of error (half-width) of ± 0.780 (0.25 SD). When estimating within subgroups, a sample size of 35 was sufficient to estimate a 95% CI for the mean APPT score with a margin of error of ± 1.040 (0.333 SD).

Ethical Considerations

The study was approved by the American University of Beirut Institutional Review Board, the Director of AUBMC, and the Director of CCCL. Parents gave written informed consent. Children gave oral assent after the first author answered their questions and checked that they really did want to take part in the study.

Procedures

The children were recruited in collaboration with CCCL nurse managers and staff. The first author received daily lists of children admitted to the inpatient and outpatient departments. The children were interviewed in a quiet hospital location using a structured questionnaire. The first author conducted the interviews to standardize data collection. The children answered questions about pain characteristics (location, intensity, quality, frequency, and duration), sources of pain, and functional ability. Only one interview was needed for each child and most interviews took <25 min.

The Interview Questionnaire

The interview questionnaire consisted of a demographic and health-related section, additional questions background questions devised by the first author, the APPT (Savedra, Tesler, Holzemer, Wilkie, & Ward 1989), and the Functional Disability Inventory (FDI) (Walker & Greene 1991). The APPT and FDI were translated into Arabic before they were included in the interview questionnaire. The WHO process for translation and adaptation of instruments was adopted (World Health Organization 2010). This process consists of the following steps: forward translation, back-translation, expert panel review, and pretesting. The translation process will be reported in a separate article.

The APPT is a multidimensional self-report pain measure for children and adolescents aged 8–17 years. It has a body diagram to record pain location, a 10-cm Word-Graphic Rating Scale (WGRS) to rate pain intensity, and a word descriptor list to describe sensory, affective, and evaluative qualities of pain (Savedra, Tesler, Holzemer, & Ward 1989). The age-appropriate body diagram consists of two line drawings representing the front and back of the body. The right and left sides of the body outlines are labeled. The WGRS is a 10-cm horizontal line with word anchors ranging from 'no', through 'little', 'medium', and 'large' to 'worst' possible pain. There are 67 word descriptors; 37 sensory dimension descriptors, 11 affective dimension descriptors, 8 evaluative dimension descriptors, and 11 pain dimension descriptors. The three APPT scales have acceptable to good reliability (Cronbach's α 0.55-0.91) and validity (convergent validity 0.68–0.97) for hospitalized multi-ethnic children and adolescents between the ages of 8 and 17 years (Savedra et al., 1989a; Savedra, Tesler, Holzemer, Wilkie, & Ward 1990; Savedra, Holzemer, Tesler, & Wilkie 1993; Tesler et al. 1991; Wilkie et al. 1990). APPT has undergone extensive psychometric testing with multi-ethnic hospitalized children and adolescents experiencing various pain related conditions including pediatric cancer (Van Cleve et al. 2004).

The FDI (Walker & Greene 1991) is the most commonly used tool to assess the impact of pain in children (Eccleston, Jordan, & Crombez 2006; Hermann, Hohmeister, Zohsel, Tuttas, & Flor 2008). It is a validated instrument for assessment of pain-related disability in children between 8 and 17 years of age (Eccleston, Crombez, Scotford, Clinch, & Connell 2004; Eccleston, Malleson, Clinch, Connell, & Sourbut 2003; Kashikar-Zuck, Vaught, Goldschneider, Graham, & Miller 2002; Lynch-Jordan et al. 2010; Reid, McGrath, & Langa 2005). It consists of 15 items that measure limitations in daily living activities during the past two weeks. The 15 daily activities are grouped in the domains of school, home, recreation, and social interaction. Examples of activities include "walking to the bathroom", "being at school all day", and "doing homework". The child rates his/her functional ability for each activity on a five category rating scale (0, 'no trouble' to 4, 'impossible'). Total FDI scores are computed by summing the ratings for each item.

The FDI was chosen for its sensitivity to change, its well-established reliability and validity across a broad range of painful pediatric conditions and its ease of administration, scoring, and interpretation. The efficiency of the FDI has been demonstrated in pediatric pain research (Eccleston et al. 2006; Palermo et al. 2008) and in cancer pain research (Ameringer 2010). The psychometric properties of the FDI have been well-established in different populations (Claar & Walker 2006;

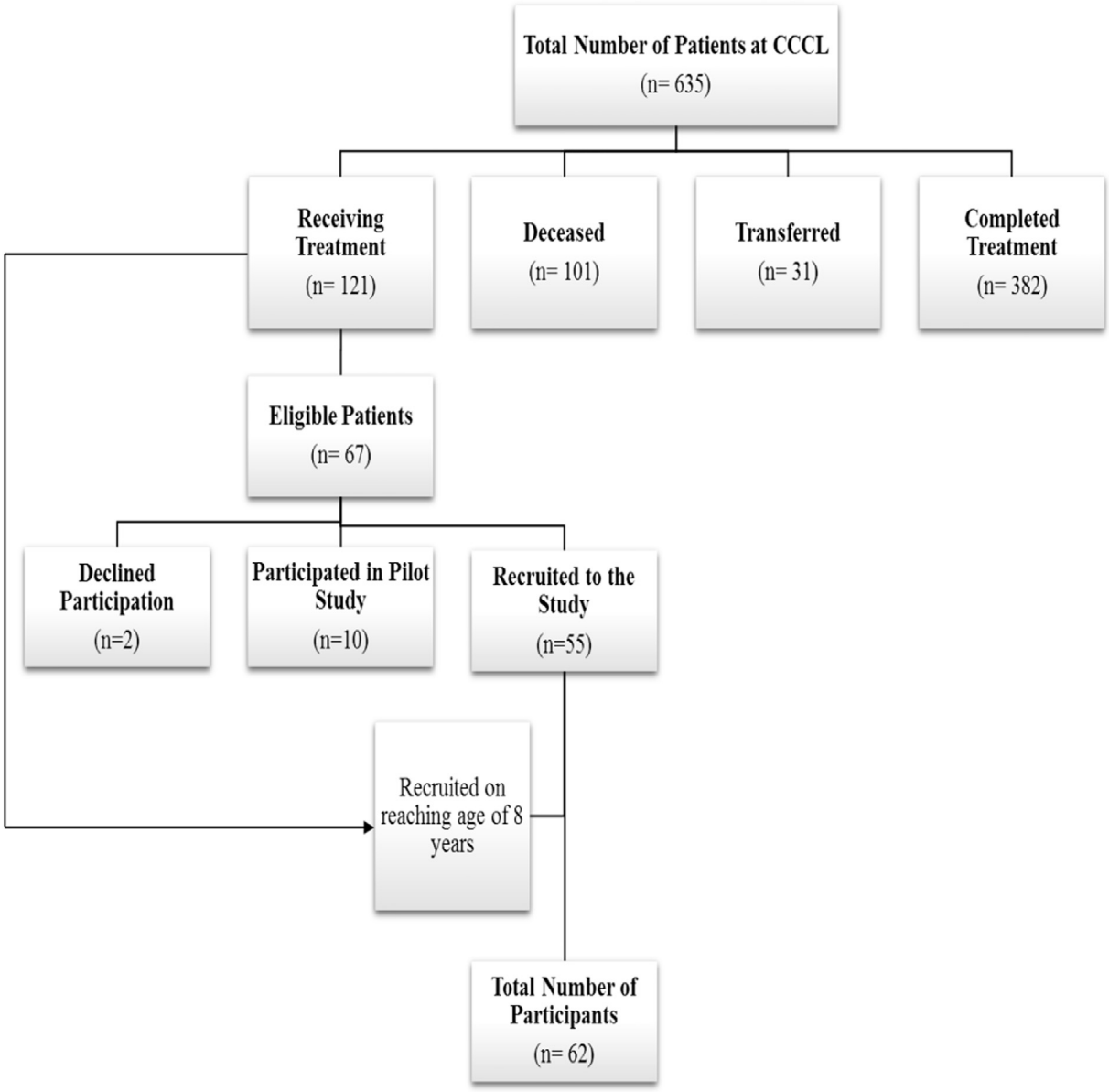

Fig. 1. The CCCL central database and recruitment summary.

Lynch-Jordan et al. 2010; Palermo et al. 2008; Reid, Lang, & McGrath 1997; Vervoort, Goubert, Eccleston, Bijttebier, & Crombez 2006). The PedIMMPACT international consensus process recommended the FDI for use in clinical trials that involve measuring the impact of pain on functional ability in children and adolescents (McGrath et al. 2008).

Two questions were included in the interview questionnaire to assess the frequency and duration of pain. A list of sources of pain identified from the literature were included in the questionnaire to measure sources of pain using a four category rating scale (0 to 4), with additional categories for 'Do not know', and 'Not Applicable'.

Medical records were reviewed to collect information on age; gender; primary caregiver; school grade; reason for admission; place of residence; admission; cancer diagnosis; date of diagnosis; metastasis; metastatic sites; current cancer treatment; previous cancer treatment and health insurance coverage.

Statistical Analysis

SPSS for Windows version 16 (SPSS Inc., Chicago, IL) was used for all data analysis.

Categorical demographic and clinical data were summarized using frequencies and percentages. Means and standard deviations were computed for normally distributed numerical variables. Medians and the interquartile range (IQR) were used to describe numerical data deviating from normality. Average pain intensity scores were calculated by source and compared using Friedman's test. FDI item scores were summed and compared across pain characteristics using one-way analysis of variance (ANOVA), and the Kruskal-Wallis test. Pearson's r and Kendall's Tau were used to estimate linear and ordinal relationships between variables. Linear regression was used to evaluate predictors of pain intensity and FDI. All predictors with a p-value of $p < 0.1$ at the univariate level were entered into a backward stepwise multivariable regression model. All tests were two-tailed; a p-value <0.05 was considered significant.

The child was asked about the source and related intensity of pain and provided with a list of possibilities that included intravenous therapy and BMA. The scores for responses related to tumors, treatment and procedures were averaged separately to calculate scores for cancer-related sources, treatment-related sources, and procedure-related sources. Mean scores across the three dimensions were explored with repeated measures ANOVA and Friedman's test.

Results

Demographic Characteristics

Sixty-two children participated in the study. Forty-seven children (75.8%) were recruited from outpatient departments and 15 children (24.2%) from the inpatient department. The mean age of the children was 12.3 ± 2.9 years. The children were evenly distributed between those of school age and adolescents, with 34 (54.8%) living in urban areas and 28 (45.2%) living in rural areas. The majority of the children had leukemia and was primarily admitted for chemotherapy (n = 30, 48.4%). Almost all of the children were receiving chemotherapy at the time of the study (n = 58; 93.5%) (Table 1).

We compared inpatients and outpatients to identify differences in gender, age, reason for admission, diagnosis, time since diagnoses and treatment. The only statistically significant difference was for the proportion of children with a diagnosis of leukemia or lymphoma (inpatients 40.0%, outpatients 53.2%, $p < 0.006$). All further analyses were conducted for the sample as a whole.

Characteristics of Pain

Pain intensity: The distribution of pain intensity scores for children in the sample was normal (Kolmogorov-Smirnov test statistic, $p = 0.362$). The overall mean pain intensity was 5.06 ± 1.87, with a median of 4.58 (3.95–6.66) and a range of 2.33 to 9.83. Intensity of pain reported by the participants was categorized as mild <3 cm, moderate 4–7 cm, and severe >7 cm (Paul, Zelman, Smith, & Miaskowski 2005). Ten children (16.1%) reported mild pain, mean 2.57 ± 0.19; 44 (71%) had moderate pain with, mean 5.01 ± 1.10; and 8 (12.9%) had severe pain, mean 8.47 ± 1.0. Mean pain intensity ratings did not vary with age, gender or cancer diagnosis (Table 2).

Table 1
Demographic & clinical characteristics of study participants (n = 62).

Characteristic	Frequency	Percentage
Age (years)		
Mean (SD)	12.3 (2.9)	
8–12	34	54.8
13–17	28	45.2
Gender		
Male	33	53.2
Female	29	46.8
Area of admission		
Outpatient	47	75.8
Inpatient	15	24.2
Reason for admission		
Chemotherapy	30	48.4
Routine monitoring	28	45.2
Procedures	13	21.0
Fever	6	9.7
Cancer diagnosis		
Leukemia & lymphoma	31	50.0
CNS tumour	16	25.9
Bone tumour	5	8.0
Other	10	16.1
Time from diagnosis (months)		
Mean (SD)	26.58 (23)	
Median (range)	18 (1–84)	
Current treatment[a]		
Chemotherapy	58	93.5
Cortisone	13	21.0
Radiotherapy	6	9.7
Antibiotics	2	3.2

[a] Some children were receiving more than one treatment simultaneously.

Table 2
The mean intensity ratings by gender, age and cancer diagnosis.

Characteristics	Frequency	Pain intensity mean (SD)	T/F[a]	df	p-Value
Gender					
Male	33	5.14 (2.06)	0.359	60	0.721
Female	29	4.97 (1.66)			
Age (years)					
8–12	34	4.77 (1.97)	−1.345	60	0.184
13–17	28	5.41 (1.71)			
Cancer diagnosis			0.63	(3.58)	0.601
Leukemia & lymphoma	31	4.92 (1.87)			
CNS tumor	16	5.19 (2.07)			
Bone tumor	5	6.06 (1.24)			
Other	10	4.78 (1.86)			

[a] T/F: t test and F for the one way ANOVA.

Frequency and duration: Most of the children reported having pain *sometimes* (n = 35; 57.4%). The median duration of pain was two hours per pain episode.

Quality of pain: Table 3 shows that the children used a median of 3.40 sensory words to describe the pain experience. The most frequently used sensory word was "*aching*" (67.7%). The least frequently used sensory word was "*cramping* (33.9%)". Temporal words were next in frequency of use.

Pain location: Fig. 2 shows percentage frequencies for the locations of pain reported by the children. The forehead (38.7%) was the most frequently reported pain site, followed by the abdomen (right = 24.2%, left = 22.6 %) and the lower back (right = 24.2% and left = 22.6%).

Major Sources of Pain

Table 4 shows that tumors and metastasis were the sources of the most intense pain (mean intensity = 3.60 ± 0.55 SD). Pain of the lowest intensity was reported for injections of steroids (mean intensity = 0.94 ± 1.24 SD) and needle insertions into polysites (mean intensity = 1.00 ± 1.11 SD). When mean pain intensity scores related to cancer, treatment, and procedures were compared, there were no statistically significant differences. The highest mean score was for cancer-related pain (1.89 + 1.72, median 2). Treatment-related pain had the next highest mean score (1.65 + 1.34, median 1.50). The lowest mean score was for procedure-related pain (1.56 + 0.8, median 1.40).

Table 3
Most frequently words selected to describe the quality of pain by category.

Words	Frequency	Percentage
WORDS Mean (SD); Median		
Number of sensory words (out of 15)	3.40 (2.06); 3.50	
Number of temporal words (out of 5)		
	2.43 (0.86); 3.0	
Number of affective words (out of 6)	1.09 (1.05); 1.0	
Number of evaluative words (out of 4)	0.95 (0.93); 1.0	
Total number of words (out of 30)	7.88 (3.39); 8.0	
Temporal		
Comes and goes	53	85.5
Comes on all of the sudden	40	64.5
Sometimes	30	48.4
Once in a while	24	38.7
Sensory		
Aching	42	67.7
Hitting	23	37.1
Numb	22	35.5
Cramping	21	33.9
Affective		
Crying	31	50.0
Evaluative		
Annoying	28	45.2
Uncomfortable	23	37.1

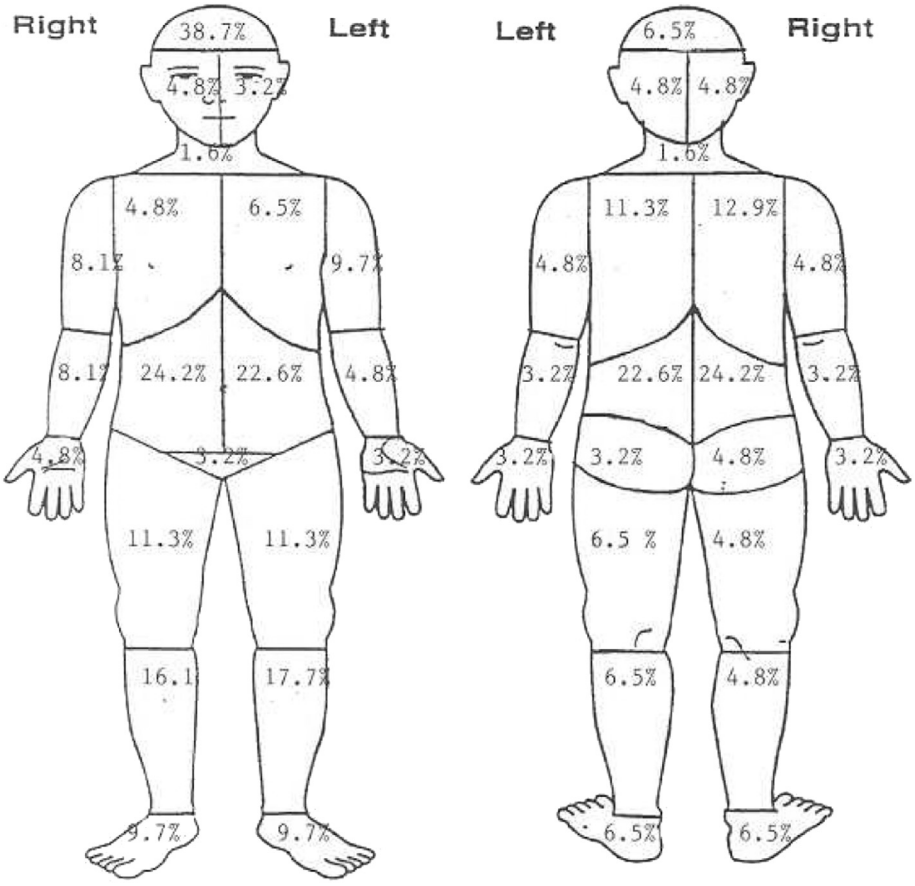

Fig. 2. Frequency of marking body areas by children as painful.

Impact of Pain on Daily Living

The mean total FDI score was 1.67 (SD 0.91). The greatest physical limitations reported by the children were running the length of a football field (mean = 2.85), doing activities in gym class (mean = 2.40), and walking the length of a football field (mean = 2.07). The lowest limitation scores were for watching television (mean = 0.45) and basic activities of daily living, such as going to the bathroom (mean = 1.08). Table 5 shows that there were no statistically significant differences in the mean pain intensity scores of children with mild, moderate and severe pain.

Table 4
The mean intensity ratings per source of pain.

Characteristic	Mean (SD); median
Pain intensity by cause[a]	
Cancer	1.89 (1.72); 2.00
Tumors	1.90 (1.74); 2.00
Tumors in other sites	3.60 (0.55); 4.00
Treatment	1.65 (1.34); 1.50
Surgeries	2.04 (1.43); 2.00
Chemotherapy	2.02 (1.58); 2.00
Radiotherapy	1.04 (1.42); 0.00
Steroids	0.94 (1.24); 0.00
Procedures	1.56 (0.80); 1.40
Bone Marrow Aspirate (BMA)	2.02 (1.51); 2.00
Needle pricks	1.64 (1.20); 1.00
Insertion of IV line	1.37 (1.13); 1.00
Lumbar Puncture (LP)	1.24 (1.34); 1.00
Inserting needle in polysite	1.00 (1.11); 1.00

[a] Means reported on a scale from 0 to 4; where 0 indicates 'no pain' and 4 indicates 'Worst pain'.

Table 6 shows that FDI scores (Cronbach α 0.93) were significantly correlated with pain duration ($p = 0.02$). FDI scores correlated more highly with cancer-related pain ($p = 0.01$) and procedure-related pain ($p = 0.001$). A significant moderate correlation was found between FDI scores and the number of sensory words used by the children ($p = 0.01$). The correlation between FDI scores and proportion of the body surface area affected by pain was small to moderate ($p = 0.057$).

When entered into the multivariable regression model only procedure-related pain remained significantly associated with FDI ($B = 0.41$; $SE = 0.15$; $t = 2.74$; $p = 0.009$; Adjusted $R^2 = 0.26$).

Factors Associated With Pain Intensity

Multiple regression analysis was used to identify the predictors of pain intensity. The variables significant at the univariate level in a regression analysis were: gender, age, area of admission, reason for admission, cancer diagnosis, metastasis, frequency, sources, body surface area, word descriptors, previous and current treatment, as well as specific areas of pain. The variables that remained significant after backward stepwise regression are shown in Table 7. Time since diagnosis, treatment-related pain, previous surgical treatment, radiotherapy,

Table 5
Mean functional disability inventory scores by pain severity.

Characteristic	N	Mean (SD)	p-Value[a]
FDI	62	1.67 (0.91)	
FDI per intensity			0.557
Mild	10	1.69 (0.82)	
Moderate	44	1.61 (0.92)	
Severe	8	2.07 (0.95)	

[a] p-Value from Kruskal-Wallis Test.

Table 6
Correlation of FDI score with pain intensity, sources of pain, word descriptors, body surface area affected by pain, duration, and frequency of pain.

Variables	Correlation	p-Value
Pain intensity	0.15	0.236
Duration	0.30	**0.020**
Frequency	0.09	0.497
Word descriptors		
Temporal words	0.12	0.359
Sensory words	0.33	**0.009**
Affective words	0.22	0.083
Evaluative words	0.05	0.712
Total words	0.31	**0.013**
Sources of pain		
Pain related to cancer	0.34	**0.013**
Pain related to procedure	0.45	<**0.001**
Pain related to treatment	0.001	0.996
Body surface area affected by pain	0.24	0.057

Bold values indicate significance at $p < 0.05$.

pain duration and frequency of pain remained explained one third of the variance in the pain intensity scores (adjusted $R^2 = 0.36$).

Discussion

The findings of this study depart in important respects from those reported by other investigators.

Pain Intensity

The proportion of children who reported moderate to severe pain in this study 83.9% (n = 52) was higher than that reported in overseas studies (Caran, Dias, Seber, & Petrilli 2005; Jacob et al. 2008; Miser et al. 1987; Miser et al. 1987;Van Cleve et al. 2004). The most likely reason is sample bias in favor of children with intense pain. An important alternative explanation is that Lebanese children may have become less accepting of cultural stereotypes that require stoicism. Stereotypically, boys in Arab countries are expected to endure pain stoically because it comes from God (Kortesluoma, Nikkonen, & Serlo 2008; Li et al. 2010; Zahr & Hattar-Pollara 1998). However, such cultural stereotypes are put in doubt by our finding that the children's ratings of pain intensity did not differ by age and gender, contrary to the results reported for similar studies (Bossert et al. 1996; Helenius et al. 2005; Keogh & Eccleston 2006; Myers et al. 2006; Sundblad, Saartok, & Engstrom 2007). A plausible explanation is that Lebanese children are more 'Westernized' than their counterparts in more conservative Arabic speaking countries (Kurdahi Badr (Zahr) et al. 2006).

Frequency and Duration of Pain

The finding that the children reported frequency of pain as *rarely* or *sometimes*, with few reports of *all the time*, may be due to the high proportion of outpatients in the sample (75%) who likely have more opportunities for distraction. However, 50% of the children reported pain duration of two hours or longer, and five reported experiencing pain *all of the time*, which suggests that CCCL pain management protocols need to be reviewed. The reported duration of pain in this study cannot be compared to the findings of international studies because few studies have investigated pain duration and almost none have investigated pain frequency.

Table 7
Multivariate regression analysis with overall pain intensity as the dependent variable.

Independent variables	B (SE)	T	p-Value	Adjusted R^2
Time since diagnosis	0.022 (.010)	2.271	**0.027**	
Treatment-related pain	0.350 (.153)	2.296	**0.026**	
Surgery as previous treatment	1.608 (.688)	2.338	**0.023**	
Radiotherapy current treatment	1.792 (.690)	2.597	**0.012**	
Pain duration in hours	0.017 (.008)	2.196	**0.032**	
Frequency of pain	0.928 (.368)	2.525	**0.015**	
				0.362

Bold values indicate significance at $p < 0.05$.

Pain Location

All 62 participants were able to use the body diagram to report the location of pain. The most frequently reported sites were the forehead, the abdomen (right & left), and lower back (right & left), which is consistent with the findings of other studies (Bossert et al. 1996; Jacob et al. 2007; Jacob et al. 2008; Ljungman & McGrath 2003; Van Cleve et al. 2004).

Chemotherapeutic agents (Van Cleve et al. 2004) and LP (Miser et al. 1987) are the most commonly reported sources of headache in pediatric cancer patients. The abdominal pain reported by the children was secondary to the use of chemotherapeutic agents, especially

Vincristine (which was specifically mentioned by the children). Other chemotherapeutic agents known to cause abdominal pain are Asparginase and Dexamethazone (Van Cleve et al. 2004). Abdominal pain can also occur due to repeated vomiting caused by these and other chemotherapeutic agents (Miser et al. 1987; Van Cleve et al. 2004), including those taken orally (Jacob et al. 2008). The back pain reported by children was most probably related to the use of LP and BMA procedures (Jacob et al. 2007).

Pain Descriptors

The pain descriptors used by the children were similar to those reported for Western countries (Jacob et al. 2007; Jacob et al. 2008; Van Cleve et al. 2004). The highest frequency sensory word used by children was '*aching*'. This finding is consistent with that of Van Cleve et al. (2004), but different from those of Jacob et al. (2007) who reported '*hurting*' as the most frequently used sensory word. Investigators have noted that '*ache*' and '*hurt*' are used interchangeably by children and adolescents (LaFleur & Raway 1999), including those with post-operative pain (Savedra et al. 1993). In English, the words '*ache*' and '*hurt*' both connote '*throb*'. The Arabic words for '*ache*' (وجع) and '*hurt*' (الأذى) do not share the same meaning. Consistent with the findings reported by Van Cleve et al. (2004) and Jacob et al. (2007) the idiom '*comes and goes*' was the most commonly used temporal descriptor among children in the sample. Crying and the use of evaluative words (*annoying, uncomfortable*) were other findings that confirmed the results of other studies (Jacob et al. 2007; Jacob et al. 2008; Savedra et al. 1993; Van Cleve et al. 2004).

Sources of Pain

In children with cancer, treatment-related pain is the major source of pain (Bossert et al. 1996; Elliott et al. 1991; Zernikow et al. 2006), followed by procedure-related pain (Elliott et al. 1991; Ljungman et al. 1999; Miser et al. 1987; Zernikow et al. 2005), and disease-related pain (Ljungman, Gordth, Sorenson, & Kreuger 2000). In this study, the highest pain intensity was cancer-related, specifically, due to tumors and metastasis.

Children at CCCL identified surgeries and chemotherapy as major sources of pain with approximately equally frequency. Similar results have been reported for chemotherapy in previous studies (Bossert et al. 1996; Elliott et al. 1991; Zernikow et al. 2006). However, the findings reported for surgery-reported pain are inconsistent (Bossert et al. 1996; Elliott et al. 1991; Ljungman et al. 1999; Ljungman et al. 2000; Miser et al. 1987; Zernikow et al. 2005; Zernikow et al. 2006). The reason surgery-related pain was reported a major source of pain in this study might be due to how the data were collected. The children were given a list of sources of pain, including surgery and asked to rate the

amount of pain caused by each source. This departs from the usual practice in which children are asked to report sources of pain without a list of possible sources. The inclusion of 'surgeries' in the list of sources may prime children to recall the intensity of post-operative pain, rather than report accurately on surgery as a continuing major source of pain.

Congruent with the findings reported by Zernikow et al. (2005), children reported BMA as the most intense source of procedure-related pain. Consistent with the findings by Ljungman et al. (1999), needle pricks were another important source of pain. These results imply that the CCCL policy on topical anesthesia may not be followed.

Activities of Daily Living

Studies of functional disability in children with cancer have reported diverse findings due to the use of different measures and research designs. Therefore, it is not possible to compare the findings of the CCCL study with those of previous studies. However, the CCCL data confirm the moderate functional disability reported in children with chronic conditions other than cancer (Gauntlett-Gilbert & Eccleston 2007; Guite, Logan, Sherry, & Rose 2007; Kashikar-Zuck et al. 2005; Kashikar-Zuck et al. 2011; Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey 2001; Logan, Guite, Sherry, & Rose 2006; Walker & Greene 1991; Wicksell, Melin, Lekander, & Olsson 2009). The greatest limitation reported by children at the CCCL was restricted participation in sports. Similar findings have been reported from studies of children with abdominal pain (Claar & Walker 2006), children with other chronic pain conditions (Walters & Williamson 1999) and children with cancer in one qualitative study McCaffery (2006). The limitation in sports activities is consistent with the finding that the highest pain intensity reported by the children was in the upper back, lower back, and thigh areas. Since these areas are involved in motion and weight bearing activities, the children may have limited their sports activities to avoid pain (Cucchiaro 2009). Watching television was the least restricted activity reported by the children. This finding confirms those of studies that have identified watching television as a distractive method of pain control commonly used by children (Board 2005; Bossert et al. 1996; Bossert, Van Cleve, Adlard, & Savedra 2002; Boyd & Hunsburger 1998; Landolt, Vollrath, & Ribi 2002; McCaffery 2006; Sharrer & Ryan-Wenger 1991; Van Cleve et al. 2012). The participants reported few limitations on activities of daily living. Children hospitalized for cancer report limitations in activities more frequently (Jacob et al. 2007). Since our sample was recruited mainly from outpatients, we may have missed considerable limitations on activities of daily living among inpatients.

Factors Associated with Overall Pain Intensity

FDI scores correlated significantly with procedure-related pain, cancer-related pain, and pain duration. Similar findings have been reported in previous studies (Claar & Walker 2006; Eccleston et al. 2004; Gauntlett-Gilbert & Eccleston 2007). Greater pain intensity is related to poor functioning (Claar & Walker 2006; Gauntlett-Gilbert & Eccleston 2007; Logan & Scharff 2005). A moderate significant correlation was found between FDI and duration of pain children at the CCCL; the longer the duration of participants' pain, the higher the level of functional disability.

Predictors of the Pain Intensity

This study has filled a gap in the knowledge of pain and its impact on the functional ability on Lebanese children with cancer. The pain experience in the Lebanese pediatric oncology population was not different from that in other pediatric oncology populations, which strongly suggests that cancer pain is a universal experience. We shed light on the functional ability of children with cancer, a variable barely searched in other studies. Also, the findings reported add to the potential for pain prevention by confirming the importance of significant predictors, not reported previously, of the pain experience. Regrettably, the results provide further support to the unrelieved pain in the pediatric oncology population. Further research is demanded to know more about the functional ability of children with cancer and, to confirm the reported predictors of pain or to further identify new predictors.

Practice Implications

Body diagrams should be used routinely to assist children to describe the location and intensity of their pain. Nurses can include word descriptors as reported in this study to assist children with cancer to verbalize their pain experience. Coordination among the multidisciplinary team needs to be strengthened to control treatment-related pain. Functional disability in children with cancer should be monitored using the FDI or other standardized assessment scales with acceptable reliability and validity. Functional assessment should be included in the nursing assessment of children receiving inpatient treatment and repeated when children attend outpatient appointments. Pain management should include control of treatment- related pain, especially that related to current treatment with radiotherapy and previous surgeries. Care needs to be taken to ensure policies on anesthesia and topical anesthesia are followed. Policy makers can contribute to pain control by introducing legislation and national policies to ensure adequate pain management for children with cancer.

Limitations of the Study

The relatively small sample size of 62 children limited the power of the study and may have concealed differences in the pain experience of girls and boys and children in different age groups. None of the children in the study were aged <8 years so we have no information to report on younger children with cancer. There was likely interaction between data collection methods and children's reports of the sources of pain. The study needs to be repeated with a larger and more diverse sample of children with cancer in Lebanon. A longitudinal study is required to investigate pain control during and after inpatient treatment. More work needs to be done to identify whether changes in pain intensity are best monitored using English or Arabic words when treating Lebanese children with cancer. There were only six children with metastasis in the sample of which four reported moderate pain, and two reported severe pain. This finding requires confirmation in future studies because the relative frequency of moderate pain and severe pain in children with metastases is unreliable in small samples.

Conclusion

This study has filled a gap in the knowledge of pain and its impact on the functional ability on Lebanese children with cancer. The pain experience in the Lebanese pediatric oncology population was not different from that in other pediatric oncology populations, which strongly suggests that cancer pain is a universal experience. We compare the findings of the study with those of international studies and shed light on the functional ability of children with cancer, a variable barely searched in other studies. Also, the findings reported add to the potential for pain prevention by confirming the importance of significant predictors, not reported previously, of the pain experience. Regrettably, the results provide further support to the unrelieved pain in the pediatric oncology population. Further research is demanded to know more about the functional ability of children with cancer and, to confirm the reported predictors of pain or to further identify new predictors.

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