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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.

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

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