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Lebanese parents' experiences with a child with cancer

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ABSTRACT

Background: The impact of childhood cancer on the family has been studied in different cultures and continues to be an object of study and concern, In Lebanon, a country of 4 million people 282 new pediatric cases of cancer age <20 years diagnosed in 2004 were reported in 2008.

Objectives: The purpose of this study was to explore the experiences of Lebanese families living with a child with cancer.

Method: The study followed purposeful sampling in which 12 parents (mother or father) of a child with cancer were interviewed. Data were analyzed following the hermeneutical process as described by Diekelmann and Ironsides (1998).

Results: A constitutive pattern "It is a continuous battle" and five themes emerged from the data analysis. Living with the shock of the diagnosis; Alterations in the quality of the family's life; Living with added burdens; Disease impact on the family and sibling dynamics; Living with uncertainty represent the major themes that emerged from the participants' experiences while living with a child with cancer.

Conclusion: The study contributes to the knowledge that would help health care professionals understand the experiences and challenges that are faced by Lebanese families living with a child with cancer. This awareness would serve as a basis for health care professionals in general and nurses in particular to understand parents' experiences, and offer support, elicit communication of feelings, and examine possibilities for forming a partnership during the challenging course of the child's illness. Supported parents are more likely to provide more effective care to their child with cancer.

Introduction

The impact of childhood cancer on the family has been examined in different cultures and continues to be an area of study and concern (Neil and Clarke, 2010; Norberg, 2010; Syse et al., 2011). One of the most distressing life experiences for families is having a family member diagnosed with cancer (Doumit et al., 2008; Svavarsdottir, 2005). In Lebanon, cancer itself is still a taboo topic and is not openly discussed. This lack of openness has led parents to ignore their own needs to tell of their experience, and to a lack understanding on the part of those in health care in Lebanon. Lebanon is a country of 4 million people. The latest national cancer statistics (for the year 2004) reported 282 new cancer cases in children less than 20 years of age (Ministry of Health, World Health Organization, and National Non- Communicable Diseases Programme, 2008). This number constitutes around 5% of the new cancer cases diagnosed in Lebanon. In Lebanon, when a family member is sick the whole family becomes involved and worried due to the close family ties in the Lebanese culture (Doumit et al., 2008). This is consistent with the family systems theory, alterations in one family member influences all family members (Wright and Leahey, 2000). Because cancer still carries a strongly negative connotation in Lebanon, little is known about how Lebanese parents react or live the experience of having a child with cancer. Consequently, the aim of this study is to understand the Lebanese parents' experiences with a child with cancer.

Background

Despite improvement in medical treatment and increasing survival rate, childhood cancer is still considered as an emotional and existential challenge. Parents having a child diagnosed with cancer live a very distressing experience (Bjöek et al., 2009; Da Silva et al., 2010; Woodgate and Yanofsky, 2010). Dixon-Woods et al. (2001), in a study looking into the parents' accounts of obtaining a diagnosis of childhood cancer, noted that interviewed families experienced disputes with doctors, delays in diagnosis, and felt that doctors ignored their specific knowledge of their child.

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James and Johnson (1997) identified three needs of parents of pediatric oncology patients during the palliative care phase. Those needs were highlighted as follows: The need to have the child recognized as special while retaining as much normality within the child's and family's lives as possible; the need for caring and connectedness with health care professionals; and the need to retain responsibility of parenting their dying child. Furthermore, Mack and Wolfe (2006) studied the situation of families who have the opportunity to prepare for the end-of-life period, including learning what to expect. Their study concluded that early integration of palliative care allows for improved symptom management, parental adjustment and preparation for the end-of-life care period. Those families were more likely to believe that their care has been of high quality. In addition to information about what to expect, parents valued sensitive and caring communication from the physician and health professionals.

Moreover, Kuan (2000) reported in a study of Chinese family caregivers of children with cancer in Hong Kong, that the perceived needs of families in descending order of importance were: obtaining information; accompanying the sick child, negotiating with health care professionals; facilitating the continuous growth and development of the sick child; maintaining the caregiver's own strength, confronting family issues; and lastly mobilizing community resources.

Woodgate and Yanofsky (2010) in a study with Canadian parents of children with cancer highlighted the families' stressors including decision making that parents have to do in their child's treatment. Parental support throughout the whole process of the disease was a major recommendation of the study.

Pacing the discussion according to the family state of preparation was also noted to be an important attribute in cancer care (Contro et al., 2002; Semple and DPhil, 2010). Parents also valued direct communication between the child and the physician during the end-of-life period, as long as the parents considered the child old enough for such communication (Mack and Wolfe, 2006). Svavarsdottir (2005) reported that most time-consuming and difficult care giving activities for both mothers and fathers were giving emotional support to the child with cancer, and to other children in the family. Mothers also found it difficult and time consuming to manage behavioral problems and to structure and plan family activities. On the other hand, Murphy et al. (2008) reported that fathers of children with cancer spent more hours at work. Coping was manifested by work outside the home for fathers and adjustment for mothers.

In conclusion, multiple studies conducted in different cultures reported multitude of stressors and needs that characterize the parental situation in childhood cancer. Nevertheless, to date, no studies have explored the experience of Lebanese parents with a child with cancer. The aim of this manuscript was to highlight the results of the first study conducted with Lebanese parents with a child with cancer.

Methods

Design

This qualitative study followed the Heideggerian interpretive phenomenological approach as described by Diekelmann and Ironside (1998). A phenomenological-Heideggerian approach is basically a philosophy of the nature of comprehending a particular phenomenon and the scientific explanation of phenomena appearing in text or written word. This approach was used because it fits well with the specific character of the problem under investigation: the intricacy of the human experience. This methodology allows for increasingly sensitive understanding of humans and their ways of being-in-the-world. (Lincolin and Guba, 1985; Streubert and Carpenter, 2011).

Participants

Twelve participants were chosen based on purposive sampling. The number of participants was determined by reaching a point of data saturation whereby no new ideas were being offered in the newly discovered information and confirmation of previously collected data (Morse, 1994). Participant's inclusion criteria were as follows: 1) Lebanese speaking Arabic; 2) living in Lebanon; 3) parent of a child currently living with cancer; 4) agreement to be interviewed.

It is worth noting that the most useful sampling for the naturalistic approach is maximum variation sampling which was followed in this study (Lincolin and Guba, 1985).

Ethical issues

Approvals for studying human participants were obtained before the study from the Institutional Review Board (IRB) of the American University of Beirut, the American University of Beirut—Medical Center director and the director of St Jude Children's Cancer Center at the American University of Beirut-Medical Center. Established procedures for protecting confidentiality were strictly followed. All participants read and signed a consent form and received a pseudonym to maintain anonymity. At the first meeting and at all subsequent interactions, the participant was reminded that his/her participation was voluntary and that at any time he/she could decline or withdraw from the study without any obligation. None of the participants opted to withdraw from the study. Each interview was coded so that only the researcher and the co-researchers had the knowledge of the persons who participated. The code list and the original tapes are being kept in a locked file cabinet in the PI's office for a period of three years.

Because the interviews were conducted in Arabic, translated and typed, the transcriptionist signed a confidentiality agreement as well.

Process of recruitment

Parents of children with cancer receiving care at the Cancer Center at the American University of Beirut were contacted by the unit secretary about their willingness to participate in the study. After they had consented to participate, the researcher contacted the parents to confirm consent to participate in the study and an appointment was made at a convenient time and place for the parent. This approach fits well the tenets of sample selection for a qualitative study (Cohen et al., 2000; Patton, 1990). All face- to-face interviews took place at the Medical-Center in a quiet environment as per the participants' request.

Data collection

Data were collected in Arabic between May 1, 2009 and August 30, 2009, using semi structured in-depth interviews by the primary investigator (PI). The interviews, which lasted between 50 and 55 min each, were tape recorded in Arabic and later excerpts translated to English. The PI also recorded observation field notes. In each interview the PI prompted the participant to share his/her perspectives on his/her experience without leading the interview.

The interview questions focused on the experiences of parents' feelings, responses to, and dealing with their child's cancer diagnosis, treatment and progress through the illness such as " tell me about your experience since your child was diagnosed with