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Lebanese parents' experiences with a child with cancer

May Naifeh Khoury^a, Huda Abu-Saad Huijer^a, Myrna Abi Abdallah Doumit^{b,*}^aAmerican University of Beirut, School of Nursing, Lebanon^bLebanese American University, Faculty of Nursing, Byblos, Lebanon

A B S T R A C T

Keywords:

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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.

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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.

* Corresponding author. Tel.: +961 9 546262; fax: 961 1 744476.
E-mail address: myrna.doumit@lau.edu.lb (M.A.A. Doumit).

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 Diekemann 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. (Lincoln 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 (Lincoln 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

cancer”; “tell more about it”, “give me more examples”, “can you explain more about this idea”.

Data analysis

Interviews were analyzed following a 7 stage hermeneutical process as described by Diekmann and Ironside (1998). The research team conducted the analysis. Each original text was studied as a whole to gain a general understanding of the story and the background in which the interview text was obtained. Each researcher identified common ideas from the text with exemplar quotations to support interpretation of meaning. The researchers compared their similarities and differences at biweekly meetings, reaching further clarification and agreement by returning to the original text. All texts were re-read to find categories that linked them. Identified categories were further analyzed to reach common themes. Researchers depicted a constitutive pattern (overarching linking) that illustrated the relationship across themes among all texts. According to Diekmann and Ironside the discovery of a constitutive pattern represents the highest level of hermeneutical analysis; it is constitutive in that it expresses the relationship between the themes, and it is present in all interview text. At the end researchers produced the final summary, including verbatim quotes that allow for validation by the reader. This multistage process allowed elucidation and validation, which assisted in reducing unverified meanings, and continuous reference to the text ensured that interpretations were grounded and focused.

Trustworthiness of the study

In keeping with the phenomenological approach, to confirm credibility, member checking and peer debriefing were done. Lincoln and Guba (1985) believe that a study meets the criterion of transferability when findings can be applied in diverse settings and the data base that makes transferability judgment possible on the part of potential appliers is provided. In this case the data base is provided through the translated excerpts from the participants' interviews. Dependability is met through within-method triangulation (observation field notes and recorded interviews) and confirmability was assured by having an audit trail which recorded all activities done in order to illustrate as clearly as possible the evidence and thought processes that led to the conclusions (Lincoln and Guba, 1985).

Sample description

Parents

The sample consisted of 12 participants, 10 mothers and 2 fathers; 11 were married, one divorced. Number of children in the family ranged from 1 to 7 including the diagnosed child. Five parents received intermediate education (between 8 and 10 years of schooling); three parents received secondary education (up to 13 years of schooling) and four parents reached the university level. The age range of the interviewed parents was 24 years–48 years with a mean age of 36 years. At the time of the interview the total time spent by parents with their child since cancer diagnosis ranged from 3 months to 6 years.

Children

The children were 6 boys and 6 girls. Their ages ranged from one year to 14.5 years. The dominant diagnosis was mostly Acute Lymphoblastic Leukemia (ALL) with one case of Neurofibroma, and another case of Hodgkin Lymphoma and one case of Rhabdomyosarcoma. As noted above, these children had been diagnosed with cancer from 3 months to 6 years before their parents were interviewed.

Findings

This first study of the experiences of Lebanese parents of children with cancer yielded a constitutive pattern: “It is a continuous battle”. This overarching linking pattern permeated all participants' experiences with their children's cancer. All interviewed parents described their journey with their children's cancer as a continuous battle that they have to engage in to help their children fight against cancer. The participants talked about this battle in a positive way since it is something coming from a merciful GOD. They all dealt with the situation with acceptance but not with agreement. Parents accepted the situation as it is something coming from the merciful GOD but did not consent to it. A previous study by Doumit et al. (2008) conducted with caregivers of adult Lebanese cancer patients highlighted the reliance on God as it is practiced within the Lebanese culture. The Lebanese people are adherents of several major religions and variations with each. The role of God is paramount in all cultural expressions of each religious belief system. Most Lebanese have a fatalistic approach to God that He is in control. Some see God as a benevolent Supreme Being working for the good of the individual; others see God as in control but not approachable and accept circumstances with resignation.

Five themes emerged from the data analysis as well: Living with the shock of diagnosis, alterations in the quality of the family's life, living with added burdens, disease impact on the family and sibling dynamics and living with uncertainty. In the following analysis, participants' pseudonyms are used.

Five main themes

Living with the shock of the diagnosis

The shock of diagnosis affects not only the ill child but the whole family circle, especially the mother and father. Doha, a 48 year mother of a 12 year old child who has been diagnosed with rhabdomyosarcoma 9 months ago expressed feelings of guilt because she was unable to do anything to protect her child and feelings of shock. She said:

“when I knew, I was like in a shock, it was too blunt, - You are not prepared”; “The worst thing in this disease is that mothers cannot do anything.” The whole family is in shock. My parents collapsed, the whole family collapsed”.

Nawal a 34 year old mother of an 8 year old boy diagnosed with ALL 6 years before the interview emphasized: *“It was the shock of my life”; “It is the worst thing that can happen to me the sickness of my son”; “I cannot do anything about it, and this is what bothers me”; “my husband also, for sure, he was shocked like me and even more, you know men are unable to bare this shock, it is big for us”; “My Mom and father, my husbands' family, my brothers and his brothers found it a very big issue, and got affected by the situation.”*

Participants emphasized the impact of the shock of being told that their children have cancer. They also highlighted the effect on the whole family which really delineates the close relationships that exist among Lebanese family members. Also participants had some feelings of guilt which are worth investigating in future studies. This feeling of guilt could be related to the fact that they are not able to do anything to prevent their children from getting cancer or to save their children's life or to help them combat the disease.

Alterations in the quality of the family's life

All interviewed parents talked about the deterioration of the quality of their living conditions. Fadia, a 24 year old mother for a 6 year old girl diagnosed with ALL 7 months before the interview said:

“There is a change in our family life, we used to live a nice life, outings, happiness, now we do not go out as a family anymore; I stayed a long period very tired at home, we were crying all the time, we felt frustrated, all my life changed; the waiting time in the hospital is very disturbing and the trip is very difficult on her.”

Abeer, a 32 year old mother of an 11 month old girl diagnosed with ALL five months before the interview said:

“Our life changed a lot”; my husband and myself are depressed, we cannot talk with anyone. All our life is upside down now. We are no more going out at all”; our contacts with people decreased especially when my daughter had low immunity; “I feel disturbed when I go to the Mall, to buy stuff for her because I see children with their parents, playing around and I cannot bring my daughter. This disturbs me a lot”.

This theme reflects the changes that Lebanese are passing through when a child is diagnosed with cancer. Parents talked about the impact of the diagnoses on the parents and the repercussion on the family system. It is worth noting that Lebanese are very well known for their love for social interaction and frequent visits to restaurants and friends. So a sick child with cancer is disrupting to this family social interaction with others.

Living with added burdens

All participants alluded to the added burdens that emanated from the disease. Burdens were described as financial burden, added responsibilities, and changes in the family patterns. Parents presented those loads as very disturbing to the family patterns.

Ahmad, a 41 year old father of a 6 year old boy diagnosed with ALL 3 years before the interview said:

“Our life changed at home by 180°, it is not like before any more, my son 20 years old left the university because we are financially unable to cope; I have moved my daughter to a public school; my salary is not enough anymore”.

Rami, a 42 year old father for a 5 year old girl diagnosed with ALL 2 years before the interview talked about the added responsibility and the changes in family pattern. He said:

“I put someone else in my shop to replace me, it isn't easy but I had to do it in order to be next to my daughter. Her mother is working double because she is making special food for her. Of course we will never feel ok, it is very difficult”.

Nawal described the changes in the life pattern and the added responsibility she said:

“my son cut his school twice because of his brother's sickness. My husband lives in a country and we live in another country. We had to do like this because of my son's sickness; my son's sickness dispersed the family and now I feel I have more responsibilities on my shoulders”. Nawal's descriptions illustrate the difficult situation that she is passing through with her family and the added responsibilities on her as a mother.

Disease impact on the family and sibling dynamics

Cancer can impose considerable demands on parents and cause stress that dramatically can affect the family dynamic. The sibling rivalry was clearly expressed by parents. Mariam, a 34 year old mother of a 14.5 year old girl diagnosed with neurofibromatosis 1 year before the interview said:

“my other children are staying most of the time alone at home. They are feeling jealous from their sick sister. They feel disturbed maybe because we are not going out anymore because of our sick child”.

Claudia, a 45 year old mother of a 7 year old boy diagnosed with ALL 3 months prior to the interview reported the following:

“When we go back home, without feeling it you discriminate, and you do not mean it. My daughter deteriorated at school. She feels jealous from her brother. She likes him and she misses him too but she feels jealous at the same time”.

Hind, a 29 year old mother of a 4 year old boy diagnosed with ALL 2 years and 4 months before doing the interview said in this regard:

“my daughter told me why do you stay with my brother and you do not stay with me? Let daddy stay with him and you sleep with me”.

Siblings rivalry is very clear in this study and it is obvious that sibling's attentional needs are not met, leaving them vulnerable to emotional isolation and difficulty. This situation might create an additional problem for the parents.

On the other hand regarding the couple's relationship different experiences were reported.

Hind said:

“my son's sickness affected my relationship with my husband. We both became very nervous and we shout at each other. Our relationship deteriorated”.

On the other hand, Jana a 29 year old mother of a 6 year old girl diagnosed with ALL 3 years prior to the interview said:

“my daughters' sickness made the relation more intimate in the family. I feel more close to my husband. We are closer to each other now”.

Living with uncertainty

All participants shared their fear of the unknown. They all talked about the fear of the future and the uncertainty that made them feel anxious all the time.

Zoha a 30 year old mother of an 8 year old boy diagnosed with ALL 7 months before the interview said:

“I am scared, scared of tomorrow. It is a big exam from GOD. Hopefully things would be ok but I am fearful from the future”.

It is not unusual of Lebanese people to look at cancer as an exam from God to their faith and religiosity. The term GOD is frequently used in the Lebanese language. Most Lebanese, regardless of religion, consider God as powerful, capable and the source of miracles.

Katia a 40 year old mother of a 12 year old girl diagnosed with Hodgkin lymphoma 3 months prior to the interview talked about her fears and said:

“I hope this situation will never come back but it might and this is what frightens me, I am living with this idea.” Katia added: “what might happen after 3 years?” “This disease, we cannot finish from it, we need to adapt, but at any moment it might surprise us and come back again”.

This theme needs further studying in view of the great impact that parental stress and fears may have on the family relationship at all levels. More caregivers studies are needed in order to clarify different parental fears and uncertainty.

Discussion

Regardless of improvements in medical treatment and constantly increasing survival rates, childhood cancer is still a distressing life experiences for parents (Neil and Clarke, 2010). Participants of this study viewed their experiences as a “continuous battle”. This explained it as a battle against cancer as a disease and also against life

changes that resulted from that disease. All interviewed parents viewed their journey as a continuous battle against cancer and also against the repercussions of cancer on their family life.

A cancer diagnosis defies the conviction that our lives will be long and joyful. The family system is confronted with new exigencies, and the whole family is challenged when a child is diagnosed with cancer (Abu Saad Huijjer, 2008; Da Silva et al., 2010; Doumit et al., 2008). The results of this study of Lebanese parents of children with cancer revealed a complete change in the family quality of living, which compares well with the international literature (Kars et al., 2008; Ow, 2003; Van Dongen-Melman et al., 1998).

The shock of having a child diagnosed with cancer appeared in almost all studies related to parents' experiences with a child with cancer (Bjöek et al., 2009; Neil and Clarke, 2010; Yeh, 2003). As a consequence of this existential shock, parents were faced with the loss of their way of life. Those results are consistent with the findings of Bjöek, et al. (2009) and those of a study by Kars et al. (2008) which reported damaged family and marital relationship.

Added burden and responsibilities was a major theme revealed by the participants. Interviewed parents talked about added responsibility and its consequences on the family. Interviewed fathers talked mainly about the financial added responsibility, whereas mothers talked about being tired, feeling guilty for leaving other children at home. The theme of living with added responsibility is very well explained by the Lebanese family system where the father is usually responsible for the financial aspect of the family and the mother takes care of the household and children. These results are consistent with the findings of Murphy et al. (2008), who reported increased work outside the home for the fathers and adjustment for mothers.

Sibling rivalry and positive and negative changes in the couples' relations also appeared as a theme in the Lebanese parents' experiences while living with a child with cancer. Parents justified this rivalry by the extra time, concern, and care they were giving to the sick child which was taken away from the siblings. Similar results were reported by Yeh (2003) and Bjöek et al. (2009).

Regarding parental relationship, the description was not consistent among all parents. Most of them said that the child's sickness made them feel closer to each other, while one mother spoke about a detachment in the relationship with her husband. The positive and negative relationships were influenced by the couple's ability to manage their child's sickness. It is evident that the couple felt closer when they successfully managed to overcome the stresses of their child's condition. Lebanese families are very well known for their strong family bonds, especially in threatening situations, when family members want to be with one another to protect each other and feel safe. Similar results about the multiple sources of stress and uncertainty associated with a child's cancer that affected parents' relationship and difficulties in communication were also reported in the literature. Studies reported distress and marital dissatisfaction in addition to communication and marital dyads conflicts (Brody and Simmons, 2007; Da Silva et al., 2010; Yeh, 2003).

Uncertainty emerged as a major theme in all interviews. This feeling was related to the fear of recurrence of the disease, as mentioned by all participants. Uncertainty created feelings of anxiety and fear with regards to the future in terms of disease reoccurrence, loss of the loved child, and additional complications. Uncertainty has more and more been recognized as an important construct in the clinical and empirical literature on families' responses to serious childhood illnesses (Norberg, 2010; Stewart and Mishel, 2000; Van Dongen-Melman et al., 1998). More studies regarding this concept are suggested within Lebanese families having a child with cancer.

The results of this study support the findings of a previous study conducted by Doumit et al. (2008), with Lebanese caregivers of adult cancer patients except for two themes which are siblings rivalry and impact of cancer on parental relationship. Also, the experience of Lebanese parents' closely parallels the experiences lived by other parents in different countries and culture. However, the constitutive pattern "it is a continuous battle" which did not appear in any of the reviewed literature on parents experiences with a child with cancer. This pattern is worth further investigation within the Lebanese culture.

Conclusion and clinical implication

Regardless of the substantial progress in the treatment of cancer, childhood cancer is still emotionally distressing for parents. This qualitative study provided a culturally sensitive perspective of parental responses embedded in the Lebanese culture.

Findings suggest that nurses should be alert for parents' reactions or possible reactions to their child's illness and treatment, and consider the various dimensions of life that may be affected for these parents. The need for this understanding is important not only during the child's hospitalization, but also during the whole journey of the disease. Consequently, findings also emphasize the importance of exploring with the parents their subjective perceptions of the situation. In fact, this awareness would help health care professionals in general and nurses in particular understanding parents' experiences as a basis for offering support, initiating communication of feelings and examining possibilities for forming a partnership during the challenging course of the child's illness.

Because this research is the first phenomenological study of Lebanese parents with a child with cancer, its findings have a distinctive implication for the research endeavor in the area of cancer and its impact on the family. It is important to stress that one single study, regardless of its qualitative or quantitative design, cannot examine any phenomenon to its full extent. The theme highlighted in this study offer opportunities for additional qualitative and quantitative research in the field of oncology and its impact on Lebanese parents and the Lebanese family system.

Study limitations

As with all qualitative studies, the sample cannot be considered representative of all Lebanese parents with a child with cancer. Certainly, parents who were not involved in the study might have different needs or concerns. However, purposeful sampling of participants is a typical qualitative method and is successful when greater depth of information is needed. Accordingly, the intentional selection of participants for this study is accepted.

The extent to which results of this study can be empirically generalized to Lebanese parents of a child with cancer is unknown; however, generalizability is not a goal of phenomenology (Guba and Lincoln, 1981). Further studies are needed to investigate and validate findings of the lived experience of Lebanese parents of children diagnoses with cancer. Once several similar studies have been completed, and studies limiting the participants to groups with similar time since diagnosis, prognosis, or parental age groups, a baseline of themes may be created to be used for developing clinical guidelines for health professionals caring for such Lebanese parents and children.

Conflict of interest statement

The authors report that they do not have any conflict of interest.

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