Lebanese parents’ experiences with a child with cancer

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My Lebanon and AUB

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Lebanon from the skies

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CEDARS OF LEBANON
BEIRUT THE CAPITAL OF LEBANON
RAOUCHEH
Bay of Jounieh
Baalbek

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THE MOUNTAINS OF LEBANON
938 A.D. - 1268 A.D.
Photos from Lebanon
AUB the place to be…

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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. (Syse et al., 2010; Lindahl Norberg, 2010; Neil & Clarke, 2010).

- Lebanon, a country of 4 million people, reported 282 new pediatric cases age < 20 years in 2008 according to the latest national cancer statistics which constitute around 5% of the new diagnosed cases.

- One of the most distressing life experiences for families is having a family member diagnosed with cancer (Svavarsdottir, 2005; Doumit et al, 2008).

- In Lebanon the family ties are very close which means that when a family member is sick the whole family becomes involved and worried (Doumit, Huijer & Kelley 2008).

- According to family system theory, alterations in one family member influence all family members (Wright & Leahey, 2000).
SIGNIFICANCE TO NURSING IN LEBANON

• Very little is known about the experiences, concerns and attitudes of parents of children receiving cancer care services in a renowned university hospital in Lebanon.

• Difficulty to generalize from international studies.

• Better understanding of Lebanese families’ experiences with children with cancer will lead to a comprehensive and holistic care.

• Sets a basis for further research
**AIMS**

- To explore the experiences of parents of children with cancer receiving cancer care in Lebanon, specifically at Children Cancer Center in Lebanon (CCCL)
METHOD

Study Design

This qualitative study followed Heideggerian interpretive phenomenological approach as described by Diekelmann and Ironside (1998).
Sample

Twelve participants were chosen based on purposive sampling and saturation principles

- **Selection Based on:**
  - Particular knowledge of the phenomena
  - Willingness to share that knowledge

- **Inclusion Criteria:**
  1. Lebanese Arabic speaking;
  2. living in Lebanon;
  3. parent of a living cancer patient (age <18) receiving currently cancer care;
  4. agreement to be interviewed.

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Recruitment Strategies and Techniques:

- Discussions with nurses and doctors at St Jude Cancer Care Center
- Identification of potential participants
- Extension of invitation to participate in the study
- Time and date of the interview based on the participants' discretion
- All participants read and signed a consent form
Description of the Sample:

- 10 mothers & 2 fathers
- All are married except one is divorced
- Family size range: 3 and 9 members
- The participants’ educational background varied between intermediate (5), secondary (3) and university (4).
- Age range: 24 and 48 years. Mean age 36 years.
- Children's age range: 1 year 8 months and 14.5 years
- Total time spent with the patients since diagnosis range between: 3 months and 6 years
METHOD (CONT’D)

- Demographic data
- Semi structured in-depth interview were tape-recorded along with observation field notes
- Probing techniques were used
- All interviews were conducted in Arabic
- Each participant was interviewed twice in order to validate the results of the analysis obtained from the initial interview
- Interviews were transcribed verbatim
- Excerpts from interviews were translated
- Interview guide revolved around the experiences of parents with their child’s sickness
The interview guide contained questions in the following areas:

1. Level of child’s ability to carry on activities of daily living.
2. Type of health problems currently encountered by child such as pain, mobility, stress, depression, diet etc...
3. Effectiveness of management of health problems.
5. Home/health care services currently received and types of health care professionals involved.
6. Adequacy of services in meeting needs: positive and negative aspects of services
7. Ideal type of health services to meet their needs.
8. Expectations regarding health care services.
9. Satisfaction with services provided.
METHOD (CONT’D)
PROTECTION OF HUMAN SUBJECTS

- Each interview was **coded** so that only the researcher will have knowledge of the individuals who participated.

- Participants were assured of **confidentiality** and **pseudonyms** were used.

- The code list and the original tapes are kept in a locked file cabinet in the researcher’s office for a period of three years.
METHOD (CONT’D)
PROTECTION OF HUMAN SUBJECTS

The research was approved by the:

- Institutional Review Board (IRB) at the American University of Beirut;
- American University Beirut Medical Centre hospital director;
- American University Beirut Medical Centre director of St. Jude CCCL.
Trustworthiness of the Study

- **Within-method triangulation** for data collection and peer debriefing were done.

- **Dependability and conformability** were assured by doing **inter coder reliability** (Polit & Beck, 2004) & (Marques & McCall, 2005).

- **Selecting and integrating participants’ quotes** to describe the results which contributed to the neutrality of the research findings.

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Data Analysis

Data were analyzed following a 7 stage hermeneutical process as described by Diekelmann and Ironside (1998).
RESULTS

- Five main themes and a constitutive pattern of “It is a continuous battle”
  1. Living with the shock of the diagnosis
  2. Changes in family life pattern - Family quality of living conditions & added responsibility
  3. Employment and financial burdens
  4. Impact on family - sibling dynamics & couples relationship
  5. Living with uncertainty

- This is the first study that addresses this topic in Lebanon.
1. Living with the shock of the diagnosis

“when I knew It was like 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”

(Doha a 48 year mother of a 12 year old child who has been diagnosed since 9 months)
RESULTS (CONT’D)

2. Changes in family life pattern with a change in the family quality of living conditions

• “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 has 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.”

(Abeer a 32 year old mother for an 11 month girl diagnosed since 6 months)
2. Changes in the family life pattern with added responsibility

- “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 O.K., it is very difficult”.

(Rami a 42 year old father for a 5 year old girl)
3. Employment and financial burdens

“*Our life changed at home by 180 degree, 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*”

(*Ahmad* a 41 year old father for a 6 year old boy diagnosed since 3 years)
4. Impact on the family and siblings’ rivalry

• “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”
  (Claudia a 45 year mother for a 7 year old boy)

• “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 any more because of our sick child.”
  (Mariam a 34 year old mother for a 14.5 year girl)
RESULTS (CONT’D)

4. Impact on the family with couples’ relationship changes

• “my son’s sickness affected my relationship with my husband. We both became very nervous and shout at each other. Our relationship deteriorated”.
  
  (Hind a 29 year old mother for a 4 year old boy )

On the other hand,

• “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.”
  
  (Jana a 29 year old mother of a 6 year old girl )
5. Living with uncertainty

• “I am scared, scared of tomorrow. It a big exam from GOD. Hopefully things would be O.k. but I am fearful from the future”
  (Zoha a 30 year old mother of an 8 year old boy)

• “I hope this situation will never come back but it might and this is what frightens me, I am living with this idea”
  (Katia a 40 year old mother of a 12 year old girl talked about her fears)

• “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”
  (Jana a 29 year old mother of a 6 year old girl added)
RESULTS (CONT’D)

“*It is a continuous battle*”

- This common idea represents the constitutive pattern that permeates all participants’ experience 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 in order to help their children fight against cancer.

- The participants talked about this battle in a positive way since it is something coming from the merciful GOD. They all dealt with the situation with acceptance but not with agreement.
**RELEVANCE**

- **Education Level:** Educators need to be aware and understand the challenges, problems and needs faced by family members and **teach students to explore their patients’ needs.**

- **Practice Level:** Nurses have the privilege of accompanying families through their ups and downs of this journey; therefore should make every effort to assist them to explore ways to meet these needs.
RELEVANCE

Research Level: This study contributes to previous research by providing the experiences and challenges experienced by Lebanese families with children receiving cancer care.

Policy Level: Results of this study highlight the importance of initiating national strategies for pediatric cancer care that meet the needs of Lebanese pediatric cancer patients.

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LIMITATIONS OF THE STUDY

- Only families willing to discuss their experiences were asked to participate in the study
- Limited generalizations can be made from this study
- Missing of some nuance meanings due to translation
RECOMMENDATIONS

- Cross cultural study comparing Lebanese families’ experiences with families of other Middle Eastern cultures.
- Include in Nursing and Medical curricula the importance to address the needs of families of patients living with cancer.
- A study investigating children's experiences and perceptions while living with cancer.
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