The Lived Experience of Family Caregivers of Cancer Patients

*Myrna A. A. Doumit, PhD, RN
Huda Abu Saad Huijer, RN ,PhD, FEANS
Jane H. Kelley, PhD, RN
Nada Nassar, RN, MSN
Background

- Paternalistic culture
  - Close family ties
  - Traditions
- Cancer as a taboo
Many studies were conducted in different countries and cultures.

Canada: study by Grunfeld et al (2004) reported that caregivers were more anxious, depressed and had higher levels of perceived burden than did the patients.

Sweden: Winterling et al (2004) reported that more patients than spouses seemed to accept their situation.
Background (cont’d)

• Japan : Fukui (2004) reported that family caregivers wanted disease related information, patient and family care-related information such as Patient’s physical and psychological care, and family care.

• Netherland : Proot et al(2003) reported fatigue, vulnerability and burnout
Purpose of the study

The purpose of this study is:

- To explore the lived experience of Lebanese family caregivers of cancer patients.
Study Design

- Dutch hermeneutic phenomenological approach based on the Utrecht School.
Sample

- Purposive sampling guided by saturation.

Selection based on:

- Particular knowledge of the phenomena
- Willingness to share that knowledge
Inclusion criteria

1. Lebanese speaking Arabic
2. Living in Lebanon
3. Age 18 and above
4. Currently a non-paid primary caregivers for at least one year of a living cancer patient
5. Agreement to be interviewed without the presence of a third person
Recruitment Strategies and Techniques

- Discussion with community intermediaries
- Identification of potential participants
- Extension of invitation to participate in the study
- Time and place of interview based on participants’ discretion
Description of the Sample

- Nine participants; Seven women and two men
- Age range: 41 and 70 years. Mean age of 51.33 years
- Two mothers, two daughters, two sisters, one brother, one husband and one wife.
- Lived experience with the role of caregiver for a cancer patients ranged between one and eight years
- Educational background. Illiterate (n=1); Primary (n=1); intermediate (n=1); secondary (n= 1); university (n=5)
- Area of living: Urban (n =5); Rural (n=4)
Data Collection

- Demographic data
- In depth semi-structured interviews along with field notes
- Interview guide
- Probing techniques
- All interviews were conducted in Arabic
- Each participant was interviewed twice.
Interview Techniques

- Grand tour question
  Can you tell me how you are living this experience of caregiver?

- Probing technique
  Please tell me more about it; what does it mean to you?; is it possible to give an example?

- Interview guide
  Where should I begin? Pick a typical day and talk about it. Pick an unusual day and talk about it.
Data Analysis

- Data were analyzed based on the Utrecht School of Phenomenology as described by Barritt, Beekman, Bleeker, and Mulderij (1984).
- Analyses of the data began following the first interview (concurrent with data collection).
- Each tape recorded interview was transcribed verbatim.
- Transcribed interviews were translated to English then back translated to Arabic.
- Each interview was read at least twice (immersion).
Data Analysis (cont’d)

- Data were examined line by line, excerpts were extracted, and categories were formed.
- Themes were created (thematic analysis).
- Themes were compared between different interviews.
- A list of common themes was created.
Data Analysis (cont’d)

- Data were managed using the electronic software NVivo (QSR International, 2002).
Protection of Human Subjects

- American University of Beirut IRB approval
- Written explanation of the study and consent form read and given to all participants to sign in
- Data kept in the researcher’s office in a locked cabinet
- Clerk typist and back translator signed a consent of confidentiality
- Pseudonyms were used
Trustworthiness of the Data

- Credibility → member check
  peer debriefing
  Within method triangulation for data collection

- Confirmability → Intercoder reliability

- Dependability

- Transferability → Thick description.
Trustworthiness of the Data

- Audio-taping
- One researcher for data collection
Living With Fears and Uncertainty

There is no one on earth like a mother. I am afraid of the separation from my mom. I am afraid that something might happen while I am alone with her.

(Badia, a 52 year, daughter)

I mean I have the fear that this disease might also hit me.
Living With Fears and Uncertainty (Con’d)

- I feel like I am waiting for something bad to happen at any time, I am living with this feeling. I feel over anxious. (Lama, a 41 year old, sister).
Loss of Happiness

My life shadows my sister’s life. You know when we first knew, it was a drama and when she started the treatment it was a second drama. We used to be a happy family, we love to be happy, but after my sister’s sickness we forgot happiness…

(Rasha, a 40 year old, sister)
Feeling of Added Responsibility

Even if we have to sell our clothes we will treat him. They requested $1500 for the x-ray but the money was not available. Every time you have to go to the doctor you need to have lots of money in your pockets.

(Faten, a 70 year old wife).

I have to look after her family, I have to cook, clean and iron. I say to myself if something happens to my daughter, the responsibility of her family will become mine. I am her mother, I am obliged, and I am responsible for her children. The responsibility of her children makes me feel I am going to be a mom again for them. I have to take care of them and my age does not permit anymore.

(Joumana a 60 year old mother).
Living in a State of Emergency

I feel myself constrained. Constrained, because at any time I have to be available. I have to be on standby, ready on the spot. I cannot even go on a date because I have to be ready all the time.... It is affecting me because I do not feel that I am free. I do not think of getting married for example and leave them because who is going to take care of them? I have to take her to the doctor and if she is admitted to the hospital I have to take my vacation on the spot and stay with her. I am not complaining but the feeling of being always on the alert makes me feel uneasy... I am always on the alert at home...

(Bana a 42 year old daughter)
Sharing the Pain

When she is ok, I feel ok. But when she deteriorates or has the pain I feel suffocated. The worst thing is to see her in pain. Dying is within God’s hands, but suffering is what hurts. Pain and sufferings that result from this disease are the main things that bother me, and make me feel frustrated and hopeless

(Lama 41 years old, sister).
Living the Dilemma of Truth Telling

To tell you the truth I do not know what we are supposed to do. I do not have the courage to tell my brother you have cancer. I keep on wondering if I am the one to tell him or not? Or, should we tell him or not? Is what we are doing right? Is it better for him to hear from an outsider that he has cancer? My sisters and I, we keep on discussing the issue of telling him or not. I met a patient who knows about his diagnosis but who told him? I do not know (Zuheir, 50 years old, brother)
Disturbed by Being Pitied

I do not like it at all when people come for visiting and they start pitying you. As if they are putting you down. I hate this attitude. It makes me feel frustrated. Why pitying me?

(Fares, 64 years old husband)
Reliance on God

I mean at the beginning I had difficulty in accepting it. Then I started praying and praying. I said our God will help us accept and I think this is what God sent us, so what can we do? We have to deal with it.

( Rasha, 40 years old, sister)
Discussion of Findings

Results of this study are comparable with other international studies except for:

- Loss of happiness
Limitations

- Purposeful sampling not reflective of a larger population
Implications for practice

Nurses and Physicians: forefront of health care system
Nursing and Medical schools: family caregivers care and communication
Acknowledgment

- Mr Saleh Boundak
- Community intermediaries
- Ms Samar Nassif, GA
- Participants