THE LIVED EXPERIENCE OF CAREGIVERS PROVIDING HOME CARE FOR TERMINAL CANCER PATIENTS: A PHENOMENOLOGICAL STUDY

A Dissertation Submitted in Part Fulfilment of the Degree of Master in Science in Nursing
RCGI-BAHRAIN

Researcher: Fatima Saleh Mohamed, MSN, RN
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The author certify that she has NO affiliations with or involvement in any organization or entity with any financial, or non-financial interest in the subject matter or materials discussed in this manuscript.

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WHY THIS TOPIC?

* From January (1998) to December (2007) there were 4,212 Bahraini diagnosed as cancer patients 1

* Females: (51.8%) Males: (48.2%)

* Breast cancer was the most common cancer in females and lung cancer was common in males (Al-Madouj, A., et al, 2011).

* Cancer is the fourth cause of death among the top ten causes of death in Bahrain (Health statistics, 2013).

To explore the lived experience of caregivers providing home care for terminal cancer patients.
Research Question

What is the caregiver experience of giving care to terminally ill cancer patient at home and what are the needs required in providing home care?
Methodology

Qualitative

Phenomenology

Heideggerian hermeneutic phenomenology
Family Caregivers

Purposive Sample

Semi-structured Interviews

8 Family Caregivers
Sample Characteristics

- (8) Family Caregivers: Age: 28 – 62 years
- Females: 5
- Males: 3
- CA Diagnosis: Breast, Ovarian, Brain, Lung, Bladder, Thyroid with metastasis.
Method of Data Analysis

Interpretative Phenomenological Analysis (IPA)

Literature Review \[\leftrightarrow\] More number of studies utilized (IPA)
Findings: Three Themes

- The Burdens of Care
- Comforts
- Coping
1- The Burdens of Care

- Physical Burden
- Emotional Burden
- Financial Burden
- Lack of Professional Support

2- Comforts

- Changing Home Arrangement
- Arranging Resources
- Spiritual Care

3- Coping

- Faith
- Personal Strategies
- Distributing the Care Responsibilities
Participant 1: “I felt very tired, my health, my stomach, I got irritable colon, and now cancer returned back to me for the third time”.

Participant 2: “It was difficult for me, he had difficulty walking; I had to hold him always from the left side, all the weight is on the left side so I must hold him if I need him to walk to take him to the bathroom. Our flat is on the third floor, it is difficult to walk on the stair to go up or come down. I wait for him walking step by step. I call him until he concentrate with me, he shouts ‘wait’. I was alone carrying him in the morning to change his cloth, bath him, clean him after voiding, he used to void all over the flat”
Participant 6: “After her sickness, she could not go upstairs, and if she could it would make her tired, so we built for her in the home garden, a room in the ground, its door is to the hall, bathroom, everything is dawn, no need for her to go upstairs”
Participant 4: “I tolerated and maintained my patience. Why a one cannot have hope?”
Implications for Nursing Practice

Regular needs assessment on admission (Policy)*

* Hudson and Payne (2011) systematic review documented that unless need assessment is conducted, health professionals will continue to provide deficient support without baseline data that demonstrate the status of patients and families needs.
Implications for Nursing Education

Only 23% of oncology nurses hold a certificate in oncology (unpublished Bahraini study)

Train Nurses in oncology & palliative care

Advance Practice Nursing in Palliative Care
Implications for Nursing Management

Palliative care clinic services to be re-activated

Home nursing care and hospice services.

Provide good quality resources in affordable prices

Ferrell and Coyle (2010) documented that the best way to monitor patients’ needs and management of care is through home nursing care.
First Bahraini study
- Findings identical to reviewed literature.
- Changing Home Arrangement.

Findings could not be generalized.
- Limited time.
References

Patients presented with advanced cancers

- Distant Metastasis: Males: 13%
  Females: 12%.
- Regional Metastasis: Males: 6% of males
  Females: 11%
- Unknown Extent: 73% of cancer patients:
  - Males: 77%