Palliative Care;  
A Program of Research  

Huda Abu-Saad Huijer  RN, PhD, FEANS, FAAN  
Professor of Nursing Science  
Director Hariri School of Nursing  
American University of Beirut
Greetings from Lebanon
Greetings from Lebanon at Night
Greetings from American University of Beirut
Palliative Care
Program of Research in Lebanon
Affirms life
Promotes quality of life
Treats the person
Supports the family
Palliative Care; Program of Research in Lebanon

- Program of research is interdisciplinary.
- Faculty and students are involved.
- Faculty and students are co-authors on publications.
Palliative Care in Lebanon; knowledge, attitudes, and practices of physicians and nurses

Purpose of the Study

• To assess the knowledge, attitudes, and practices (KAP) of physicians and nurses towards palliative care in Lebanon.
• To assess the need for palliative care and the best model to provide the services.
Methods

- Data Collection: 15 hospitals geographically spread in Lebanon; 1873 nurses and 1884 physicians.
- IRB approval: AUB and all hospitals.
Results

- Majority of MDs & RNs believed terminally ill patients & families should be informed of diagnosis and prognosis.
- Only 19% percent of MDs routinely informed terminally ill patients about their diagnosis.
- The most frequently proposed model for delivering PC was ‘creating a specialized PC unit within the hospital including a palliative care team’, followed by hospice, and home care.
- Only 20.2% of nurses and 3.7% of physicians reported receiving continuing education in PC.
Conclusions

• Palliative care needs to be developed in Lebanon.
• There is a need for a variety of Palliative Care services.
• There is a need for Continuing Education in Palliative Care.
Quality of Palliative Care: Perspectives of Adults with Cancer
Purpose

The purpose of the study was to evaluate the quality of life, functional ability, symptom prevalence & management, and quality of care in adult Lebanese cancer patients.
Methods

- **Study design:**
  - Cross-sectional descriptive design.
- **Sample:**
  - 200 Lebanese oncology patients (age ≥ 18 years).
- **Exclusion criteria:**
  - Diagnosed less than one month, and
  - does not know his/her diagnosis.
Quality of Palliative Care Questionnaire-Adult” (QPCQ-A) is a combination of four instruments:

1. The European Organization for Research and treatment of Cancer-Quality of Life Questionnaire (EORTC-QLQ C-30)
2. The Memorial Symptoms Assessment Scale (MSAS)
3. Barthel Index for functional ability
4. Needs at the End of life Screening Tool (NEST)
5. Demographic and clinical characteristic
Symptoms & Distress

% of participants

- Lack of energy
- Feeling nervous
- Feeling sad
- Dry mouth
- Difficulty sleeping
- Pain
- Worrying
- Numbness & tingling
- Nausea
- I don't look like myself
- Lack of appetite
- Change in way food tastes
- Feeling bloated

Prevalence
Distress
Symptoms, treatment received, & effectiveness of treatment

- % of participants

- Lack of energy: Prevalence, Treatment received, Treatment successful
- Feeling nervous: Prevalence, Treatment received, Treatment successful
- Feeling sad: Prevalence, Treatment received, Treatment successful
- Dry mouth: Prevalence, Treatment received, Treatment successful
- Difficulty sleeping: Prevalence, Treatment received, Treatment successful
- Pain: Prevalence, Treatment received, Treatment successful
- Worrying: Prevalence, Treatment received, Treatment successful
- Numbness & tingling: Prevalence, Treatment received, Treatment successful
- I don't look like myself: Prevalence, Treatment received, Treatment successful
- Lack of appetite: Prevalence, Treatment received, Treatment successful
- Change in way food tastes: Prevalence, Treatment received, Treatment successful
- Feeling bloated: Prevalence, Treatment received, Treatment successful
Conclusion

- Lebanese adult cancer patients reported a fair QoL with high prevalence of physical and psychological symptoms.
- Inadequate symptom management was reported especially for the psychological symptoms.
- Nausea and pain were the symptoms mostly treated. The most prevalent symptoms were feeling nervous, feeling sad, lack of energy, and pain; symptom management was in general inadequate.
- Higher physical and psychological symptoms were correlated with lower health status, quality of life, and functioning.
- Participants reported a satisfactory level with the quality of care.
Publications

Qualitative Studies


Results

- Studies addressing the lived experience of patients in PC (Doumit, Abu-Saad Huijer et al. 2007) highlighted the distress of patients from being dependent; their dislike for being pitied; concerns related to their families; their dislike of hospital stays; their need to be productive; their fear of pain; and their need to communicate with others.
Bereaved Parents’ Evaluation of the Quality of a PC Program in Lebanon

Symptoms and their Burden

- Fatigue
- Anorexia
- Depression
- Pain
- Insomnia
- Dyspnea
- Nervousness
- Nausea/Vomiting
- Constipation
- Edema
- Diarrhea

Percentage of Children Suffering a lot or a great deal
Bereaved Parents’ Evaluation of the Quality of a Palliative Care Program in Lebanon

- Facilitators to PPC reported by participants:
  - Spiritual support; faith and prayer
  - Familial support; close family ties
  - Social support; friends and health care team
Bereaved Parents’ Evaluation of the Quality of a Palliative Care Program in Lebanon

- Recommendations on the care of children at end-of-life:
  - Improving organization of care provided: including psychological, social and spiritual support.
  - Managing care within the team to decrease waiting time for procedures.
  - Involving competent staff in the care process with structured educational programs.
  - Involvement of parents in the decision-making process.
  - Creating a specialized unit for Palliative Care
Lebanese Parents’ Experience with a Child with Cancer

Qualitative Study

“It is a continuous battle”.

- Living with the shock of the diagnosis;
- Change in the family quality of living conditions;
- Changes in the family life pattern with added responsibility;
- Changes in the family dynamics; sibling’s rivalry and couple’s relationship;
- Living with uncertainty.

Quality of Pediatric Palliative Care in Lebanon; The Perspectives of Children with Cancer
Study Purpose & Methods

**Purpose:** to evaluate the quality of life (QoL) and symptom management among pediatric cancer patients in Lebanon.

**Sample:** Convenience sample of 85 pediatric patients (7-18) with cancer; inpatients and outpatients.

**Data Collection:** Face to face interviews.
Questionnaire

Quality of Palliative Care Questionnaire-Pediatrics (QPCQ-P) (parent/child versions):

1. Pediatric Quality of Life Inventory (PedsQL): 2 child versions: 7-12 years and 13-18 years.

2. Memorial Symptom Assessment Scale (MSAS): Symptom prevalence, frequency, severity, and distress (2 versions: 7-12 years and 13-18 years).
Conclusions

- Children 7-12 had 1.71 symptoms; the most prevalent were **lack of appetite, pain and nausea**. Feeling tired, difficulty sleeping and feeling sad were the highest in terms of frequency, severity and distress.

- Adolescents 13-18 experienced 7.80 symptoms. Most common symptoms were lack of energy, pain, drowsiness, nausea, cough, and lack of appetite followed by psychological symptoms of sadness, nervousness, worrying and irritability; psychological symptoms had a prevalence of 44%.
Conclusion

- Children/adolescents reported good QoL & functional ability despite presence of physical & psychological symptoms.
- Symptom management & effectiveness of interventions were found to be inadequate.
- More attention to management of psychological symptoms.
Publications


Current Research

- PC in Older Adults
- Palliative Care in non-cancer patients e.g. Heart Failure
- End-of-Life Care
Barriers to Effective Palliative Care

- Perception of health professionals & parents that discontinuation of treatment reflects giving up & denotes failure!
- The ‘need to fight the good fight’ idealized, putting palliative care as second best!
- Inadequate training of professionals in management of pain and other symptoms.
- Poor & ineffective communication.
Impact on Policy Development
National Plan on Pain Relief and Palliative Care

- Education
- Practice
- Research
- Public Policy
UPDATE

- Launch of the National Committee; conference well attended with press coverage.
- Special Issue published by the Syndicate of Private Hospitals.
- Opioid recommendations were made and majority approved.
- Recognition of PC as a medical discipline approved.
- PC as a nursing specialty area with possible certification.
- Few PC services in hospitals and at home.
Thank You for Your Attention