



Palliative Care; A Program of Research

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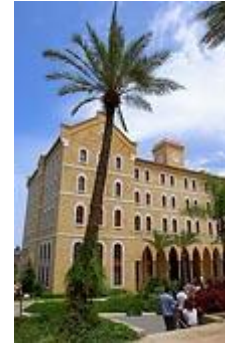
Greetings from Lebanon

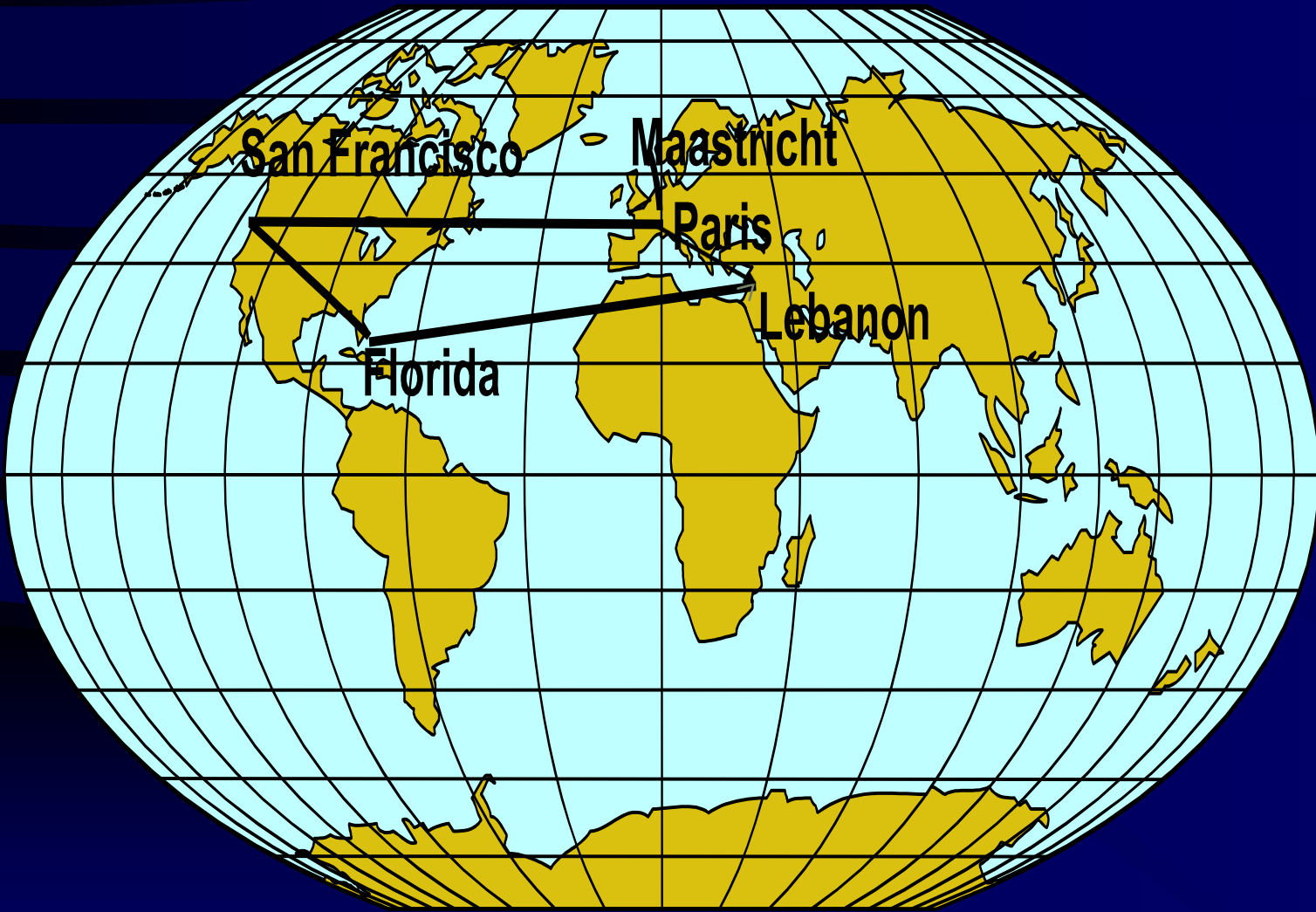


Greetings from Lebanon at Night



Greetings from American University of Beirut





San Francisco

Maastricht

Paris

Lebanon

Florida



Hariri School of Nursing



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.
- MSN thesis/projects & PhD dissertation.
- Faculty and students are co-authors on publications.

Palliative Care in Lebanon; knowledge, attitudes, and practices of physicians and nurses

- Abu-Saad Huijer, H. & Dimassi, H. (2007). Palliative Care in Lebanon; knowledge, attitudes, and practices of physicians and nurses. *Lebanese Medical Journal*, 55(3):121-128.
- Abu-Saad Huijer, H. Abboud, S., and Dimassi, H. (2008). Practices in pediatric palliative care in Lebanon. *European Journal of Palliative Care*, 15 (4): 190-192.

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.

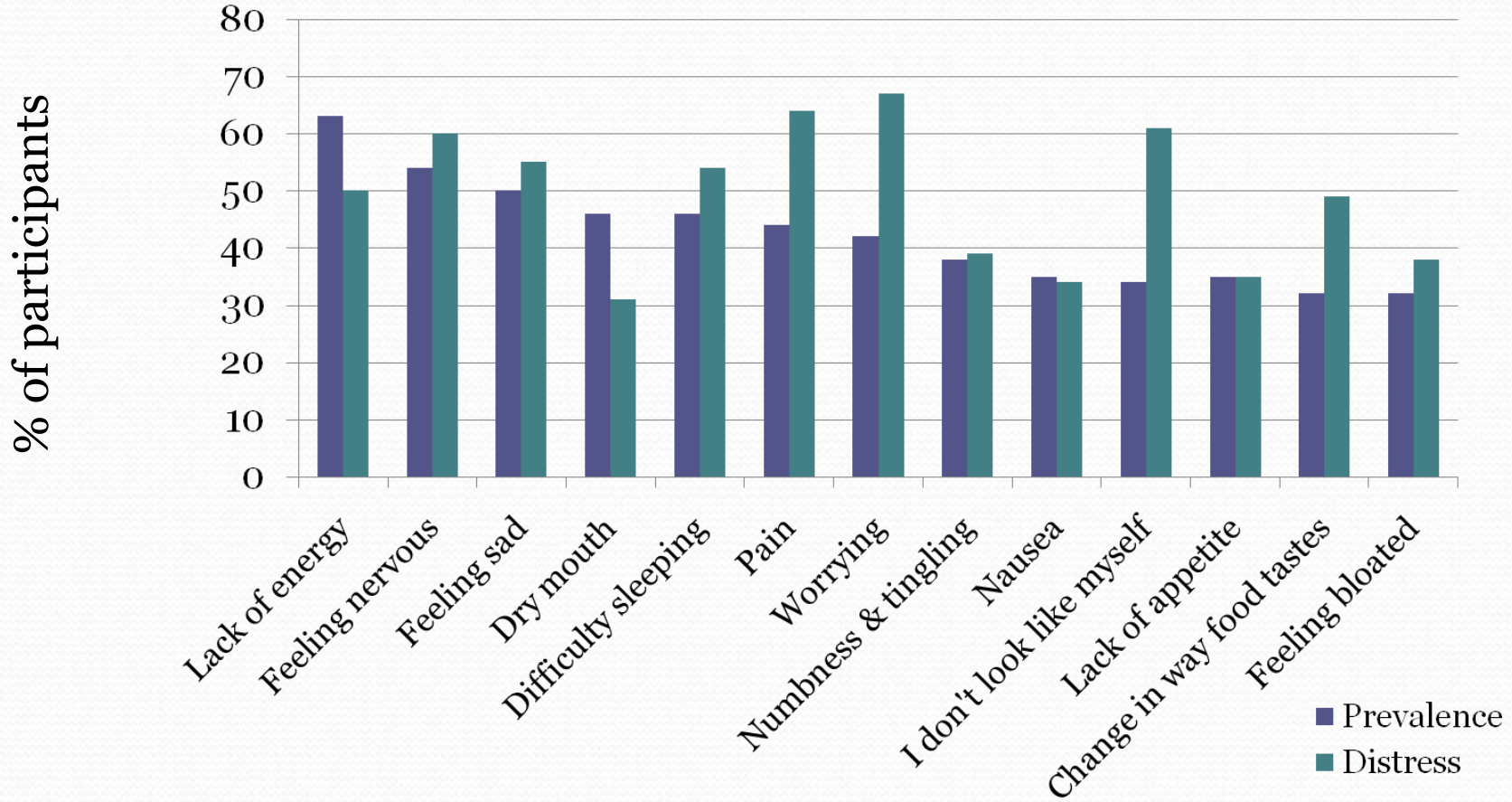
Methods

- Study design:
 - Cross-sectional descriptive design.
- Sample:
 - 200 Lebanese oncology patients (age \geq 18 years).
- Exclusion criteria:
 - Diagnosed less than one month, and
 - does not know his/her diagnosis

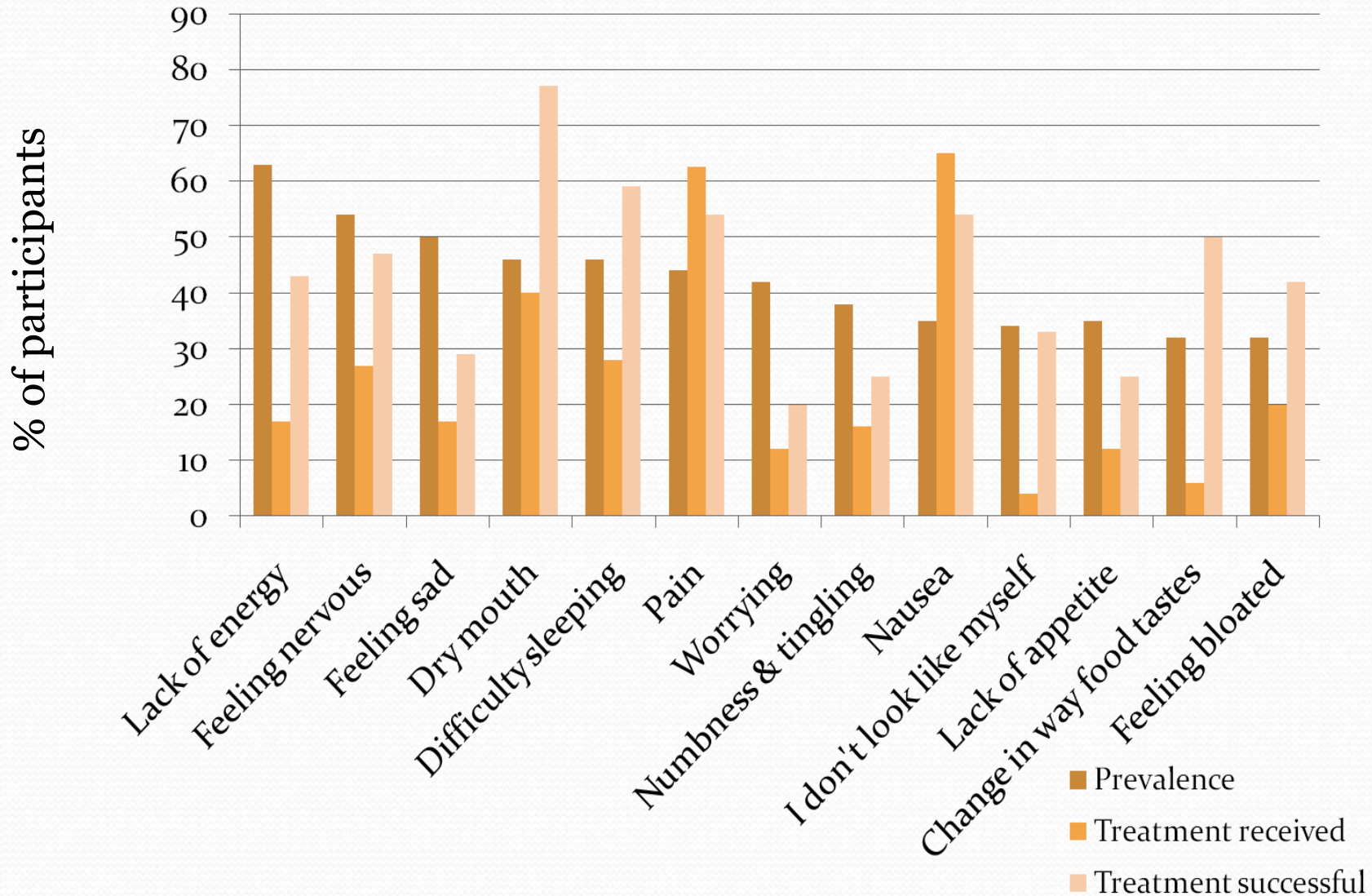
Questionnaire

- 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



Symptoms, treatment received, & effectiveness of treatment



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

- Abu-Saad Huijer, H., Sagherian, K., Tamim, H. (2012). Validation of the Arabic Version of the EORTC QLQ Quality of Life Questionnaire among Cancer Patients in Lebanon. *Quality of Life Research*. (DOI) 10.1007/s11136-012-0261-0
- Abu-Saad Huijer, H., Abboud, S. (2012). Predictors of Quality of Life in a Sample of Lebanese Patients with Cancer, *Europe's Journal of Psychology*. (Accepted)
- Abu-Saad Huijer, H. Doumit, M., Abboud, S. Dimassi, H. Quality of Palliative Care; Perspectives of Lebanese Patients with cancer, *Lebanese Medical Journal*, 60 (2) : 2012.
- Abu-Saad Huijer, H., Abboud, S. Doumit, M. (2012). Symptom Prevalence and Management of Cancer Patients in Lebanon *Journal of Pain and Symptom Management*, (In Press). doi: 10.1016/j.jpainsymman.2011.10.019
- Abu-Saad Huijer, H., Abboud, S. Health-Related Quality of Life among Breast Cancer Patients in Lebanon. *European Journal of Oncology Nursing*, (1-7). (In Press). doi:10.1016/j.ejon.2011.11.003.

Qualitative Studies

- Doumit, MA, Abu-Saad Huijjer, H, Kelley, JH. (2007). The lived experience of Lebanese oncology patients receiving palliative care. *European, Journal of Oncology Nursing*, 11: 309–319.
- Doumit, M, Abu-Saad Huijjer, H, & Kelley, J, Nassar, N. (2008). The lived experience of Lebanese family caregivers of cancer patients. *Cancer Nursing*, 31(4): 36-42.
- Bejjani-Gebara, J, Tahshjian, H, Abu-Saad Huijjer, H. (2008). End-of-Life care for Muslims and Christians in Lebanon. *European Journal of Palliative Care*, 15(1); 38-43.

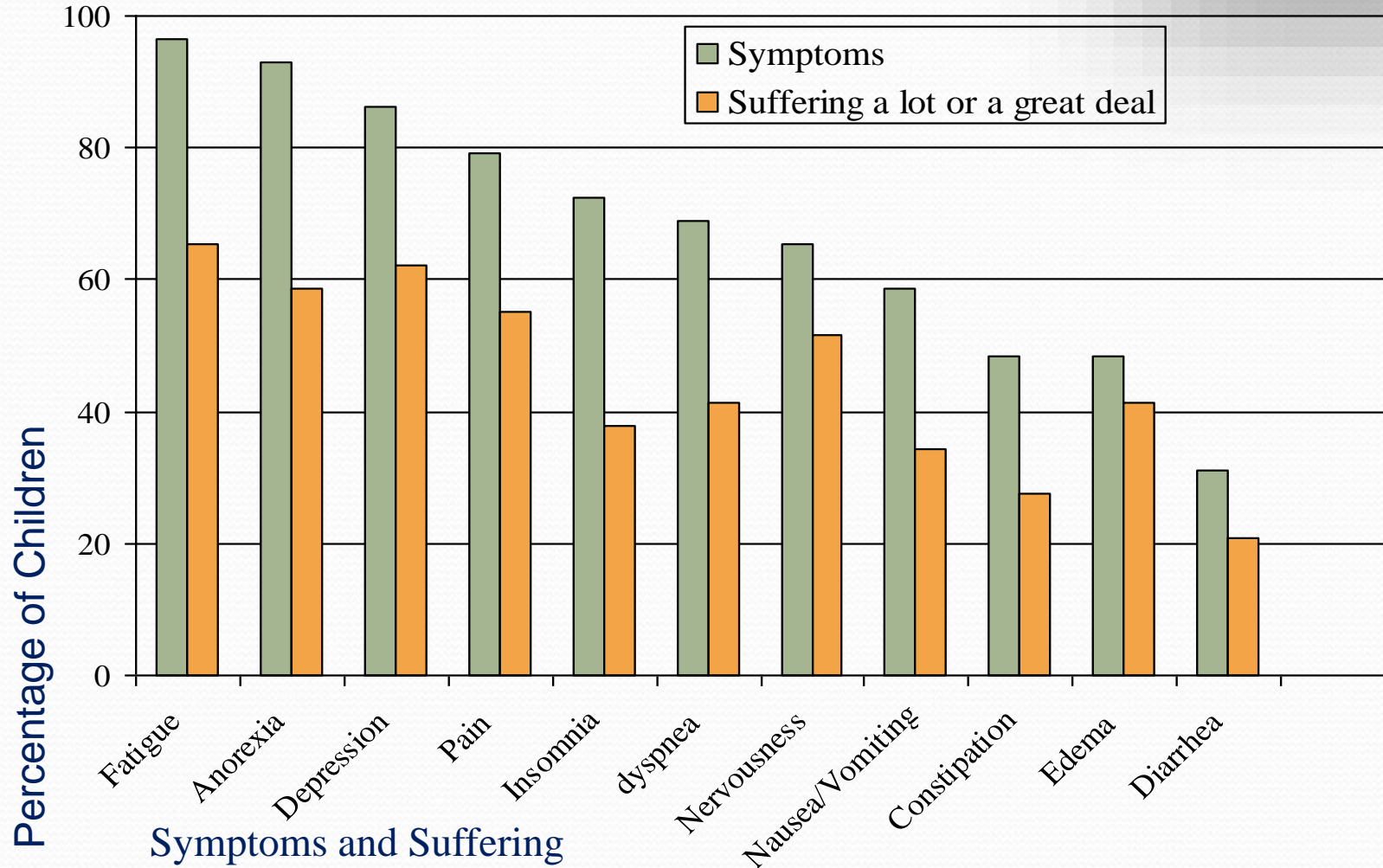
Results

- 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

Saad, R. Abu-Saad Huijer, H. Nouredine, S. Muwakkit, S. Saab, R. Abboud, MR. (2011). Bereaved Parents' Evaluation of the Quality of a Palliative Care Program in Lebanon. Pediatric Blood & Cancer, 57, 310-316.

Symptoms and their Burden



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.

Naifeh Khoury, M. Abu-Saad Huijer, H. Doumit, M., Lebanese parents' experience with a child with cancer. European Journal of Oncology Nursing, 17 (1): 16-21.



**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.

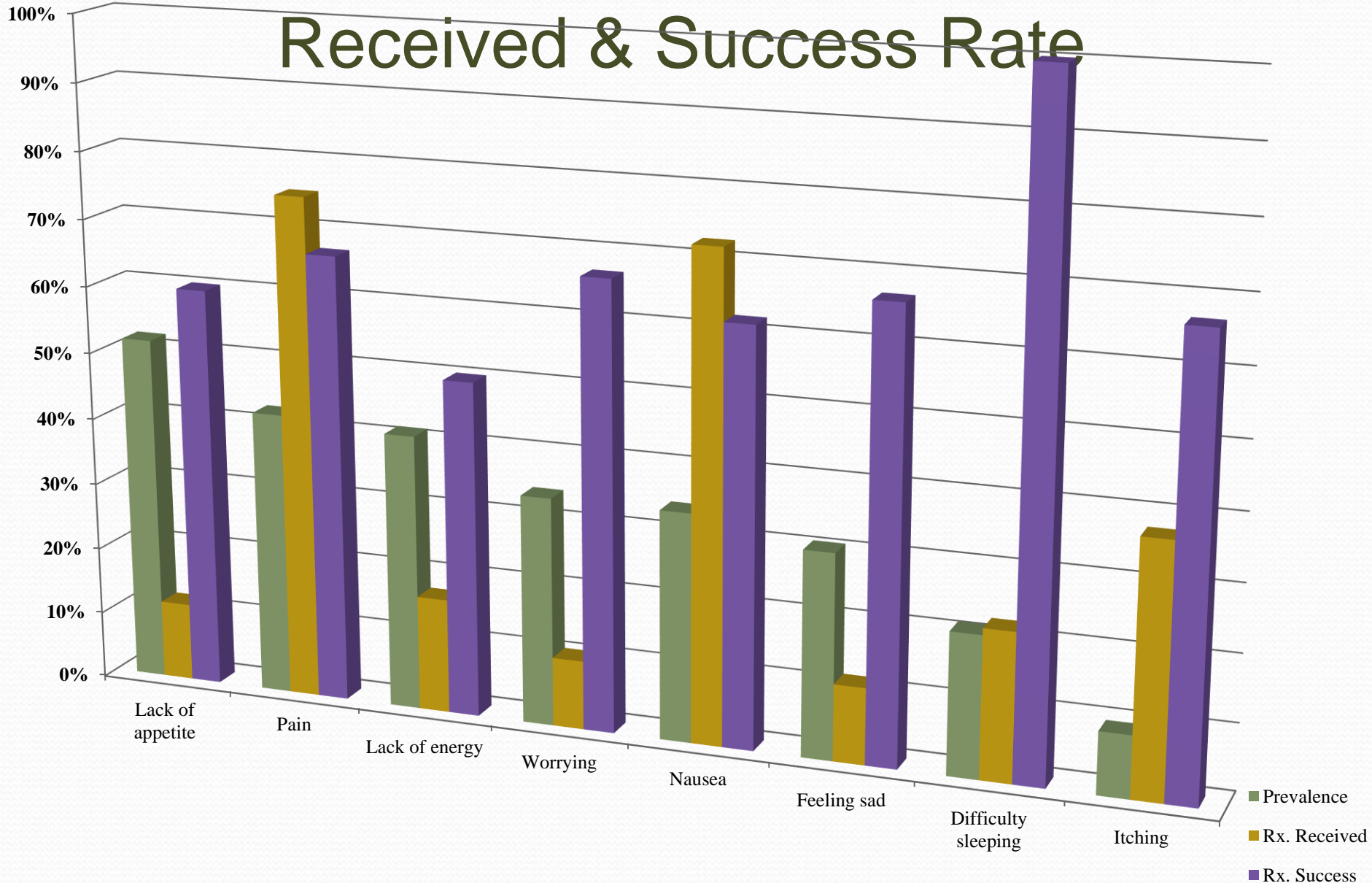
Data Collection: Face to face interviews.

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).

Symptom Prevalence, Treatment Received & Success Rate



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

- Abu-Saad Huijer, H., Sagherian, K., Tamim, H. Khoury, M.N., Abboud, A.R. (2013). Quality of palliative care in cancer children at a major hospital in Lebanon. *Lebanese Medical Journal*. (In Press).
- Abu-Saad Huijer, H., Sagherian, K., Tamim, H. (2013). Quality of life and symptom prevalence among pediatric cancer patients in Lebanon. *European Journal of Oncology Nursing* (In Press).
- Abu-Saad Huijer, H., Sagherian, K., Tamim, H. (2013). Quality of life and symptom prevalence in children with cancer in Lebanon: the perspective of parents. *Annals of Palliative Medicine*, 2(2): 59-70.

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.
- Special issue published. **LMJ Volume 61 (4), 2013.**
- 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