



5<sup>th</sup> World Congress on

# Hospice and Palliative Care

July 18-19, 2018 Melbourne, Australia

## Scientific Tracks & Abstracts

Day 1

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# HOSPICE AND PALLIATIVE CARE

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## Quality advancement of children's and youth hospice work in Germany with QuinK

**Sven Jennessen**

Humboldt University Berlin, Germany

Germany, children's and youth hospice work is a very dynamic field which, during the last 25 years, has continued to establish, develop and professionalize itself in the German hospice and palliative movement. Since 2015, impulses for quality advancement are given by the "Qualitätsindex für Kinder-und Jugendhospizarbeit" (QuinK), a non-standardized questionnaire tool which was developed by a research team in cooperation with the Deutsche Hospiz- und PalliativVerband e. V. (DHPV). The process of growth and professionalization in children's and youth hospice work is illustrated by the growing number of inpatient children's and youth hospice establishments and home care services beginning to focus more on the needs of teenagers and young adults with life-shortening diseases. It networks closely with the equally fast-growing structures of pediatric palliative care and finds itself in the center of different interests and perspectives of health care, children's and youth aid, disabled people's aid and palliative care. Therefore, it is essential to focus on one's own objectives and tasks in establishing a closely-knit support network in order to guide children and youths with life-shortening diseases as well as their families. The preservation and continuous advancement of the quality of the work is a primary concern of children's and youth hospice work so that existing and future challenges can be met with confidence. As a non-standardized and yet very empirical instrument, QuinK can be understood as an opportunity for all contributors to critically reflect on their work from their own perspectives, and compare their work to the goals and principles of QuinK as well as initiate advancements within the individual establishments. It is conceivable and explicitly desired that QuinK be adapted beyond the German children's and youth hospice movement to the specific conditions and structures in other countries.

### Biography

Sven Jennessen has his expertise in children's and youth hospice work and in palliative care for people with disabilities. He has developed the instrument QuinK after years of experience in research, evaluation and teaching. He is a Professor for Pedagogy for people with physical disabilities and has another research focus on aspects of sexual self-determination of people with disabilities.

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## Palliative care in limited english speaking breast cancer patient with young children

**Min Min Win**

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**Introduction:** Patients with advanced cancer frequently develop devastating physical and psychosocial symptoms. In addition, their primary caregivers and other family members may also experience physical and emotional distress. Palliative care was developed to improve the quality of life of such patients facing life-limited illness, as well as their families. However, providing palliative care to patients with limited English proficiencies can be very challenging, especially if the issues underlying these challenges are not known. What can be done to improve the quality of palliative care provided to cancer patients who have limited English proficiencies, as well as young children?

**Research Objectives:** The aim of this case study was to identify the issues and challenges in providing palliative care to a patient who had advanced breast cancer, a Limited English Proficiency (LEP) and young children.

**Methods:** A case study approach was used in conducting this research. The study participant was a 37-year-old Cantonese-speaking mother of two was first diagnosed with triple negative breast cancer in 2012. The researcher first met the study participant during her first few months of Palliative Care Training. Till her death in 2016, the researcher gathered evidence-based data through observations and interviews with the patient and primary care givers, family members and medical team.

**Results & Discussion:** The issues and challenges identified in providing quality palliative care to the study participant were attributed to: (1) Managing delirium (she was not eligible to partake in a clinical trial to determine the efficacy of risperidone, haloperidol and placebo in relieving symptoms of delirium among patients receiving palliative care because of her LEP); (2) the lack of effective communication due to the presence of a language barrier; and (3) the absence of a support system for young children with parental illnesses. Additionally, it is crucial that clinicians have discussions with the family (and the patient, in lucid moments when they have the capacity), eliciting their concerns and wishes for the type of care that can best honour their desire to provide comfort and symptom control during the dying process.

**Conclusion:** This case study highlights the importance of integrating of palliative care in the trajectory of cancer to address symptom burden and psychosocial distress of patient and family. Early referral to palliative care can help to relieve symptom distress, as well as improve treatment outcomes, quality of life, minimize caregiver distress and decrease aggressive measures at the end of life. Relevant expertise, close collaboration, interdisciplinary teamwork and adequate resources are important requirements to comprehensively address acute issues, chronic issues, psychosocial issues, and existential and spiritual issues. To optimize patient outcomes, the oncology team, palliative care team, primary care team and other subspecialists need to collaborate closely and communicate often.

**Recommendations & Implications for Future Research:** Some lessons learnt from this case study included general principles and ethics of palliative care, complex symptom management, advance care planning, holistic approach to provide support to meet care needs and helping with decision-making to seek the patient's best interest of care. To achieve effective communication, it is recommended to use professional interpreters with LEP patients, as well as to train clinical staff in understanding the interpreter's role, and how to work confidently and effectively with professional interpreters. Thus, more clinically relevant studies are needed to identify communication barriers and the interventions that could be used to increase patients' satisfaction with palliative care and to improve the quality of care provided to LEP patients and families receiving palliative care services.

### Biography

Min Min Win is presently working as Palliative Medicine Advanced Trainee Registrar at the St Vincent's Private Hospital, Australia.

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## A multi-institutional, randomized, double-blinded, placebo-controlled trial of additive Duloxetine for cancer-related neuropathic pain refractory to opioids and gabapentinoids: JORTC PAL-08 (DIRECT study)

Hiromichi Matsuoka<sup>1,2</sup><sup>1</sup>University of Technology Sydney, Australia<sup>2</sup>Kindai University, Japan

**Introduction & Aim:** Management of cancer-related neuropathic pain refractory to opioids remains challenging. We have investigated the additional efficacy of duloxetine for cancer-related neuropathic pain refractory to opioids and gabapentinoids.

**Method:** A multicenter, randomized, double-blind, placebo-controlled trial. Patients with any cancer-related neuropathic pain, currently taking opioids, non-responsive or intolerant to gabapentinoids were eligible. Diagnosis of neuropathic pain was based on the International Association for the Study of Pain (IASP) algorithm. Patients with chemotherapy-induced peripheral neuropathies were excluded. Patients were administered 20 mg to 40 mg of duloxetine or placebo for 10 days. The primary endpoint was the average pain intensity (Brief Pain Inventory (BPI) item 5 at day 10 (BPI d10)).

**Result:** 70 patients were enrolled at 12 sites. BPI on day 0 (before treatment) were 5.6 in group D (duloxetine) and 5.7 in group P (placebo). BPI d 10 was: (1) Average of group D 4.03 [90% CI 3.33, 4.74], group P 4.88 [4.37, 5.38] (P=.053) (Complete Case: CC analysis) and (2) Group D 4.06 [3.37, 4.74], group P 4.91 [4.41, 5.41] (P=0.048) (Baseline Observation Carried Forward: BOCF analysis). Point estimate of the difference of average values between the two groups was -0.84 [-1.71, 0.02] (CC analysis) and -0.85 [-1.69, -0.01] (BOCF analysis). Compared to day 0, the improvement rate of 30% or more and 50% or more at day 10, were 44.1% in group D, 18.2% in group P (P=0.022) and 32.4% in group D, 3.0% in group P (P=0.002), respectively. Although there was one case of discontinuation of adverse events in Grade 3 (CTCAE version 4, JCOG), it was due to deterioration of the primary disease and there was no relation with protocol treatment.

**Conclusion:** Duloxetine is clinically effective for cancer-related neuropathic pain.

### Biography

Hiromichi Matsuoka has expertise in evaluation and passion in improving the health and well-being. He is currently working as a Visiting Professor in University of Technology Sydney and preceding his research in patients with cancer pain. He has built his backgrounds as an Anesthesiologist, Physician of Psychosomatic Medicine and Palliative Care Doctors after years of experience in research, evaluation and teaching both in hospitals and educational institutions.

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## When dreams come true!

**Michaela Bercovitch**  
Tel Aviv University, Israel

We are here not only to help you to die but to help you to live until you die” said Cecily Saunders when she began caring for the dying. Back then this seemed to be a metaphoric expression but today, after forty years, improving the quality of life of those with incurable disease is the basic and primary goal of palliative care. Calman has defined the process of end of life as a “gap at a particular time between the hopes and expectations of an individual and that individual’s present experiences”. The question is about what can we do when all the body functions are down, when the patient cannot eat, cannot move normally, cannot be an active part of his family anymore? What are we able to offer more than a regular nursing and medical treatment for symptoms control, in order to improve his/her quality of life? What really means quality of life for a terminally ill? We will try to answer these questions, while going through a real case presentation, by discussing the role of interdisciplinary team, and the importance of collaboration between medical professionals. We will present the creative efforts and contributions of each team member towards one goal; offer a touch of wellbeing to the terminally ill. We will discuss if quality of life, at the end of life, is a paradox, impossibility or reality, and what are the best ways to offer it to our patients and their families. Finally, we will present a short movie about a dream come true and the subsequent impact on the patient and his family.

## Biography

Michaela Bercovitch is the Director of the Oncological Hospice in Sheba Medical Center, Israel and a Lecturer at Tel Aviv University, Sackler School of Medicine. She was born in Romania, Bucharest, where she graduated from Medical School as MD in Pediatrics. In 1987 she emigrated to Israel and after two years training in Internal Medicine and Geriatrics she continued her medical practice in the Oncological Hospice. She is involved in the education of medical students, nurses and doctors across Israel.

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## Hydromorphone induced neurotoxicity in palliative care

**Olfat Zekry**

The University of Sydney, Australia

Opioids are commonly used for pain control in palliative care settings. Accumulation of active metabolites of opioids can cause a well-recognized toxidrome including sedation, hallucinations, myoclonus, seizures and cognitive dysfunction. Sedation, which is the most commonly seen symptom of toxicity, leads to delirium and obtundation. Opioid toxicity is often associated with the amount ingested and its speed of absorption in the body. This can have life-threatening effects on various body systems. Gaining expertise with the use of hydromorphone for chronic pain management should be the primary goal of those managing pain in the terminally ill patient. There is a wide choice of routes of administration and the adverse effects may be minimized by careful dose adjustment, particularly in patients with renal failure or in the elderly. When alternatives are indicated for more severe pain, methadone or fentanyl may be considered. When a patient is not responding to opioids, review the pain diagnosis with the causes of opioid-insensitive pain in mind, particularly bone and neuropathic pain. Rotation of the one opioid to another should be considered. Co-analgesics or one of the recently developed NMDA receptor antagonists may also be required. We will discuss a case study involving Anne-Marie, a 65 years old female with refractory myeloma, on a regular dialysis program and chronic back pain. She was due to commence radiotherapy to the femoral lesion and was admitted to RPA with escalating pain and severe drowsiness. She complained of pain everywhere, but it was worst in the left femoral and left L2/3 spinal regions with decreased mobility and sudden cramping. Her analgesic medication: Fentanyl patch 175 mcg/hr every 3 days, Fentanyl lozenges 200 mcg Q4h PRN if inadequate relief, Hydromorphone S/C 5 mg Q4h and PRN with rapid escalation by renal team and Gabapentin 200 mg pre-dialysis and 400 mg post-dialysis. Finally, a discussion about opioid induced neurotoxicity and management will be presented.

### Biography

Olfat Zekry has obtained her Bachelor of Pharmacy and Post Graduate Diploma in Hospital Pharmacy from the University of Tasmania. She has completed her Master of Science Medicine Pain Management from Sydney University. She is currently Unit Coordinator for the pharmacology components of the master's course with the Pain Management Research Centre in the Department of Medicine, Sydney Medical School at the Royal North Shore Hospital. She has had a strong interest in education and teaching for many years. She has had international publications including subanesthetic, subcutaneous ketamine infusion therapy in the treatment of chronic nonmalignant pain, and conversion of Gabapentin to Pregabalin. She also works as a Consultant Clinical Pharmacist in the Pharmacy Department at the Royal Prince Alfred Hospital at Camperdown, Sydney.

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## The relationship between dignity status and quality of life in Iranian terminally ill patients with cancer

Masoud Rezaei<sup>1</sup> and Mohammad Abbasi<sup>2</sup><sup>1</sup>Khatam Hospital, Iran<sup>2</sup>Qom University, Iran

Palliative care is an approach that has been used to care for terminally ill patients. The current study was performed to assess the association between the status of patient dignity and Quality of Life (QOL) in Iranian terminally ill patients with cancer. This descriptive correlational study was conducted on 210 end-stage cancer patients (102 men and 108 women) who were referred to Seyed Al-Shohada Hospital, Isfahan, Iran, in 2015. To assess dignity status, we used the Patient Dignity Inventory. The Persian version of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire was used for QOL assessment. There was a significant negative association between total dignity status and QOL scales. In addition, significant negative relationship was observed between dignity-related domains (loss of worth sense:  $r=-0.50$ ,  $P<0.001$ ; anxiety and uncertainty:  $r=-0.51$ ,  $P<0.001$ ; symptom distress:  $r=-0.62$ ,  $P<0.001$ ; and loss of autonomy:  $r=-0.61$ ,  $P<0.001$ ) and functional scale and some subscales of the QOL scale. In contrast, a significant positive relationship was found between dignity-related domains and total symptom scale and fatigue. No significant relationship was observed between different items of dignity and global health status/QOL scale. High dignity status in terminally ill patients was associated with higher QOL in terms of functional intactness and lower symptom distress. Further studies are necessary to shed light to our findings.

### Biography

Masoud Rezaei has completed his master's degree in Nursing Education from the University of Isfahan Medical Sciences. He has done his thesis on the care of the end of life in cancer patients. Currently he is a PhD student in Nursing Education at the Khatam Hospital's Neuroscience Research Center. His research interests focus on the care of cancer patients and palliative medicine.

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## The Perspective of Good Death among Advanced Cancer Patient under Indonesian Culture

**Wahyu Dewi S**

Wiyata Husada Nursing School, Indonesia

**Statement of the problem:** Good death has already been defined by previous studies. Most of them stated that good death definition included comfort which reflected as no suffering with physical and psychological comfort, support and connection to others and spiritual well-being. Some of them add several domains such as preparation of death, respected as individual and life completion. A good death may be influenced by personal values, social context, religions and cultural contexts, evidenced by different perspectives of some countries. Indonesia is a multicultural country and the most populous Muslim-majority country. Therefore, the purpose this study is to understand the components of good death among advanced cancer patients under Indonesian culture.

**Methods:** A cross-sectional survey was conducted with convenience sampling in Central Java, Indonesia. Exploratory Factor Analysis with principal axis factoring and promax rotation was used to identify the domains of good death. Descriptive statistic was applied to present each domain and determine the important component of good death.

**Result:** A total of 363 patients with advanced cancer were recruited. After factor analysis of the Components of Good Death questionnaire, 52 items were kept and covered by 5 domains. They were named as comfort, support & faith, dying with dignity, life completion and death awareness & death preparation and explained 51.87% total variance. The most important domain of good death is support & faith ( $M=6.28$ ), whereas death awareness and death preparation ( $M=4.42$ ) is the least important domain of good death.

**Conclusion:** The findings represent advanced cancer patients' perspectives regarding good death under Indonesian culture and beliefs. It can be used as a guidance to improve quality of care or end of life care for cancer patients, particularly in understanding what the patients desperately wants in the end of their life to achieve good death.

### Biography

Wahyu Dewi graduated from National Cheng Kung University, Taiwan with speciality in palliative care. She has conducted the first Indonesia study to develop of Component of Good Death Indonesian version that reflected advanced cancer patients' perspectives and beliefs in Muslim cultures. Before that, she also did several literature reviews regarding palliative care. The purpose of all her studies is to develop palliative care system in her country which is still at the stage of infancy.

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