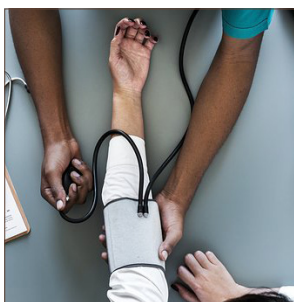

Scientific Tracks & Sessions

September 23, 2019

Palliative Care 2019

Clinical Trials 2019



Joint Event on
2nd International Conference on
Palliative Care
&

Clinical Trials and Pharmacovigilance
September 23-24, 2019 | Prague, Czech Republic

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Changing the face of death and dying in our community

Christiane Zeithammel
Death Doula Ottawa, Canada

Disease to death is often shrouded in fear. Fear of death is like a plague that devours the life force and steals living from lives. Death anxiety exists in various degrees and cultivates suffering in our culture. Some people are afraid of all things associated with death. Others may fear their own mortality, and some may be afraid of it all. We have become a death fearing society that spends vital energy seeking out ways to stay young to avoid death. As we know death is a part of life. As a death doula I am part of a death positive movement. A movement that is required to change the culture of fear and silence around death. Death needs to stand amongst us; visible and heard amongst the living. Death is happening in every moment; death is as natural as our next exhale.

Open and honest advocacy around death can make a difference. A difference that is essential. It was made aware to me in my young years working as a nurse. People were not dying the way that I knew they should be. They were abandoned, left dying alone, in institutions, lying in cold bathroom, the doors closed on death so no one would bear witness to it. I knew this is NOT the way this should be! I was made so clearly aware that changes were essential. Changes such as bringing death to the living, in this death positive approach we can provide a different death experience. One that can be supported in the comfort of people's place of

celebration, love and life, at home, with families and loved ones nearby. An experience that is lived all the way to and through death and beyond is supported by a death doula who encourages the dying person and their loved ones to come face to face with death, to move beyond the death denial and to engage in an open and authentic exploration of dying.

In the experiences as a death doula in a death positive movement it is found that death can be all that it is part of life with all of its curiosity, emotionality and fears alive and safely supported in a matter of fact way. A death positive movement and the role of a death doula is a panacea for death phobia and a potent catalyst of change to bring death back to the living in a holistic and fully honoring way.

Speaker Biography

Christiane Zeithammel worked as a nurse in Germany for many years. After marriage she moved to Canada where she dedicated her energy and nurturing nature to raising a family of four boys. As her children have now reached adulthood, it has made for a long-anticipated return to her work. A work that focuses on caring for the dying and supporting their families. With her skills as a nurse, a mother, a certified yoga teacher and a graduate of the Contemplative End of Life Care Program at the Institute for Traditional Medicine in Toronto she passionately supports those in her community as a death doula.

e: deathdoulaottawa@gmail.com

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Walking the walk of palliative care

Pastor Bruce Hanson

Society of Critical Care Medicine, Iowa

Within the confines of Academia and Research the Human side of Palliative Care sometimes gets lost. On a personal basis and as a Pastor, Care Giver and a Patient Advocate I have gained an understanding of the dynamics and humanity of Palliative Care. This personal involvement has been greatly influenced by multiple life experiences. As a young man in my early teens the daily vigil with my dying grandmother introduced me to a, up to then, life experience that many young people don't experience. Of course, this experience was at a time when "Palliative Care" was neither noted as such, nor fully understood as a needful concept.

As a young Adult, this self-development was more formally influenced through classes in College and Seminary. This was further influenced by multiple job experiences particularly as a hospital orderly in the Emergency Room where multiple facets of medical care came together and had to be coordinated. This formal education time was further influenced over the next thirty-eight-year span of time with my involvement in caring for the families and individuals in various churches. This involved dealing with the complexities of long-term health and multiple medical issues for people and families who were dealing with everything conceivable health wise as well as life ending journeys, be it sudden or over a long period of time

As a Parent and a Husband my personal walk was most significantly influenced partly through my daughters' premature birth, lifelong heart condition and multiple code

situations where life defining decisions that were called for. This was further influenced via my wife (our whole adult married life), her multiple medical issues and multiple "pull the plug" events. At times, the coordination of up to twelve doctors and numerous medical departments and multiple medical facilities in many ways tested the limits of the definition of Palliative Care.

As Palliative Care Professionals and Researchers, study, classes, and roll playing can prepare one to be a care person who addresses many situations much as a doctor or surgeon can likewise learn. But the life experiences can never be taught. They have to be walked. And the personal, human side of this care must always be paramount, and it is to this point that all Palliative Care Professionals must keep themselves focused on. And it is to this point that I have become passionate at keeping professionals focused on.

Speaker Biography

Pastor Bruce Hanson continues with his Patient Advocacy work as an Ambassador for PCORI, a Technical Expert for several Medicare Study groups through the Health Services Advisory Group (HSAG), a couple of patient care study's through Society for Critical Care and through Northwestern University of Chicago. Additionally he serves on several National Organizations as a Patient Advocate Advisor/Consultant (Pharmacy Quality Alliance (PQA), Patient Family Advisor Network PFA network, Institute for Patient and Family Centered Care (IPFCC), University of Iowa City Hospital ICTS advisory board, and the HIT-PFCA that is working on the development of Open Notes and the Patient Portal.

e: prhanson1@mediacombb.net

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Effect of erythropoiesis-stimulating agent therapy in patients receiving palliative care of chronic kidney disease

Ka Wai Alice Mok¹, Kai Ming Chow², Cheuk Chun Szeto², Agnes Shin Man Choy², Jack Kit Chung Ng², Jack Kit Chung Ng², Chi Bon Leung² and Philip Kam Tao Li²

¹Shatin Hospital, Hong Kong

²The Chinese University of Hong Kong, Hong Kong

Palliative care program for patients with chronic kidney disease was started a decade ago in Hong Kong, aiming to provide a cross-specialty multidisciplinary palliative care for those who choose not to proceed with dialysis. Anemia is a common complication seen in patients with chronic kidney disease, leading to significant morbidity and mortality, contributing to the top symptom of fatigue among this group of patients. While the benefits of erythropoiesis-stimulating agent (ESA) have been well established for patients with chronic kidney disease receiving dialysis, the effect of this treatment for those who decide for non-dialysis palliative care is less well studied.

Objective: Our center conducted a retrospective observational study to evaluate the effect of ESA in treating anemia of chronic kidney disease among adult patients receiving palliative care who decided not for dialysis in terms of the transfusion burden and hospitalization need. Thirty-nine patients receiving ESA were matched with a control group of 39 patients without ESA.

Results: Over a 1-year observation period, both the transfusion rate and admission rate were found to be significantly lower in the in the ESA group after adjustment for comorbidities. The mean hemoglobin concentration


at the end of study period was significantly higher in the ESA group than the control group. No patients in the ESA group had to terminate the drug treatment due to adverse effects.

Conclusion: ESA could lessen the burden of palliative care for patients with chronic kidney disease by reducing transfusion requirement and hospitalization. The option of ESA should be considered in the care plan for patients with chronic kidney disease opted for non-dialysis palliative care.

Speaker Biography

Ka Wai Alice MOK attained her degree in medicine from the Chinese University of Hong Kong. She completed her specialist training in Palliative Medicine and is the fellow of the Hong Kong College of Physician. She is currently the Associate Consultant of the Palliative Care Unit of Shatin Hospital in Hong Kong and has actively participated in the development of palliative care service for patients with end-stage renal failure. She is a regular invited speaker to talk on the different topics in palliative care by many healthcare societies. She is also the clinical tutor for undergraduate medical students and the lecturer for post-graduate degrees in End-of-Life Care Program of the Chinese University of Hong Kong.

e: mkw474@gmail.com

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Could mobile team improve palliative care in nursing homes?

Cernesì Simone

Ausl Modena, Italy

Background: According to Bone research deaths occurring in care homes in the UK could more than double in the next 25 years if trends continue. Our Mobile team tries to struggle with this challenge. The team consists of a General Practitioner PC expert, Nurse PC expert, and Psychologist. We established a mobile team that visits all the public nursing home (NH) regularly.

Objectives: Find target patients. Involvement of the multi-professional team help to define Advanced Care Plan or Anticipate Care Plan. Symptoms control and Therapy modulation. Audit in difficult cases. Different kind of intervention (phone calls, NH visits, writing reports).

Method: Peer education. Other aims are data collection and promote reflective learning.


Results: From May 2018 to September 2018 we have helped to find 56 cases (10 are in charge, 46 dies). We performed 20 on site consultations. We performed PC consultations in 8 Nursing homes. We performed 3 audits for difficult cases. In 3 cases we facilitated the PC specialist, in 3 cases we suggested psychologist. More than 95% died in NH with symptom control. We help to define Advanced Care Plan for every patient.

Conclusion: We have to consider NH as Large diffuse Hospice. Our team seems to be efficient to help to find the case and we have positive feedback from the staff. We have avoided hospitalization in >90% of the cases we have been in contact. Most of the difficulties (>60%) concerned the relationships with the caregiver. Still difficult to estimate prognosis but most of the target patient died in 5 months. We use Focus group to maintenance this project.

Speaker Biography

Cernesì Simone is from Modena, Italy. He graduated in Medicine (the University of Modena and Reggio Emilia) in 2008 he is a General Practitioner in Modena. He works in a nursing home and he is palliative care consultant, tutor of Family Medicine. He led Movimento Giotto palliative care and Intermediate care interest group. He has MSc degree in Palliative Care (ASMEPA-University of Bologna) MSc in Geriatric Medicine (University of Pavia) attended the European Palliative Care Academy leadership course (EUPCA) in 2015-2017, he participated in different International Palliative Care trainings (Houston, Oxford, Pamplona, Amsterdam, Rotterdam).

e: dott.cernesì@gmail.com

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Psychological counseling curriculum in palliative care

Caruntu Adriana

Archdiocese of Bucharest-Center for Palliative Care St. Nectarios, Romania

In Romania, the first psychological counseling curriculum in palliative care was developed on the basis of an innovative project developed internationally within the European Palliative Care Academy (E.U.P.C.A.). The medical knowledge of the staff can be significantly improved with psychological skills working with patients receiving palliative care.

Objective: Obtain a psychological counseling curriculum in palliative care adapted to the needs of Romanian specialists between 2015 and 2017, based on the EUPCA studies in Germany. Great Britain. Poland. Switzerland and Romania.

This project was developed in collaboration with psychologists from the Institute for Trauma Study and Treatment (I.S.T.T.) in Bucharest. Romania.

Methods: Quantitative and qualitative methodological research was used to draw up a psychological counseling curriculum in palliative care.

In the first stage, a study was carried out with the support of the Palliative Care Associations of 7 countries on the existence of a psychological counseling curriculum in palliative care.

The members of the EUPCA leadership, but also the teachers, provided me relevant materials for this project, checked every stage of the curriculum, offered counseling, supervision and specialized guidance.

in the second stage the materials received were analyzed by 7 members of the project team and data were selected for writing the curriculum.

I have organized focus group meetings with palliative care specialists from the center: Doctors, nurses, social worker, priest and psychologist who identify the needs of palliative care staff.

Result: In 2017, the first psychological counseling curriculum for palliative care in Romania was published. The curriculum was developed with the expertise of EUPCA and in collaboration with ISTT specialists in Romania and is an innovative project for psychologists in palliative care.

Speaker Biography

Caruntu Adriana started to work as a Manager in the first centre for palliative care from Bucharest. She worked as deputy manager at Healthcare House within Pasarea Monastery – Arhiepiscopia Bucureștilor in 2002 – 2006. After 5 years, she obtained funding from Embassy of Switzerland for construction of the new centre in District 2, Bucharest with 28 beds and modern medical equipment. She is also a member of the European Association for Palliative Care (EAPC), Belgium, International Association for Hospice & Palliative Care (IAHPC), USA, Palliative Care Research Society, United Kingdom and Association of Palliative Care Social Workers (APCSW), United Kingdom.

e: ingrijiripaliative@yahoo.com

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Associations between home death and the use and type of care at home

Rebecca McEwen¹, Yukiko Asada², Frederick Burge² and Beverley Lawson²

¹County of Frontenac, Canada


²Dalhousie University, Canada

Despite wishes for and benefits of home deaths, a discrepancy between preferred and actual location of death persists. Provision of home care may be an effective policy response to support home deaths. Using the population-based mortality follow-back study conducted in Nova Scotia, we investigated the associations between home death and formal care at home and between home death and the type of formal care at home. We found (1) the use of formal care at home at the end of life was associated with home death and (2) the use of formal home support services at home was associated with home death among those whose symptoms were well managed.

Speaker Biography

Rebecca McEwen completed her MSc in community health & epidemiology from Dalhousie University, Canada. She recently completed her post-graduate primary health care nurse practitioner diploma from Queen's University, Canada. She has been the clinical co-lead for the Northwest Local Health Integration Network's Regional Palliative Care Program and is currently a facilitator for the learning essential approaches to palliative care program. She is collaborating with Trent University to develop a graduate diploma in dementia studies. She will be the nurse practitioner for the County of Frontenac- Fairmount Home

e: rebeccaamcewen1@gmail.com

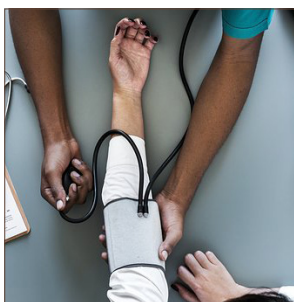
 Notes:

Scientific Tracks & Sessions

September 24, 2019

Palliative Care 2019

Clinical Trials 2019



Joint Event on
2nd International Conference on
Palliative Care
&

Clinical Trials and Pharmacovigilance
September 23-24, 2019 | Prague, Czech Republic

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Advance care planning evaluation: A 3-fold plan for the future

Ros Johnstone

Betsi Cadwaladr University Health Board, UK

Advance care planning (ACP) is a patient driven discussion about wishes and preferences for future care. Discussions are documented in a patient held ACP document. An ACP is of particular relevance if disease progression impacts on capacity or capability of the patient to speak for their self. Evaluating ACP as a complex intervention requires a mixed method, multi-study approach assessing impact on patients, those important to them, healthcare professionals, service development and delivery. A three-part evaluation was developed with two parallel

Aims: i) To evaluate the impact of ACP education on practice and to inform the continued provision of ACP training. ii) To understand the unanswered questions relating to ACP and the research challenges these raise. Awareness of ACP amongst the general public and healthcare professionals is varied, to support the introduction of ACP discussion opportunities a series of 24 half day ACP workshops were provided, training 363 healthcare professionals from a variety of clinical backgrounds and settings.

Results: Immediate feedback indicated understanding (98%) skills (89%) and confidence (86%) were increased. Six months later we evaluated the transfer of knowledge from the classroom to the clinical setting. Utilizing ACP workshop registers a 14 item electronic survey was distributed to all workshop attendees. The response rate was 19% and indicated that ACP understanding, skills and confidence were increased. Transfer of ACP knowledge into practice was positively indicated by 68% of respondents with barriers


identified as: “staff shortages,” “not enough time,” “not my role to do this”. Exploration of the survey outcomes was done by inviting survey respondents to participate in a focus group session concerned with ACP. Twenty-two participants were identified with 19 agreeing to attend a focus group.

Conclusion: Combined outcomes will support training provision and inform development of future ACP evaluation and research.

Speaker Biography

Ros Johnstone has managed a range of palliative care projects over the past twenty years With a background in psychology and health psychology and considerable post- graduate experience in health services research. As project manager for the palliative care department (West) of BCUHB. She managed the all-Wales project concerned with the care decisions for the last days of life formerly Integrated Care Priorities (ICP) for the last days of life and local North Wales projects. She has published widely and regularly in peer reviewed journals on various aspects of the care decisions work and advance care planning as well as giving personal and poster presentations at national and international conferences. Local work has involved assessing the outcomes of complementary therapy in palliative day care and improving palliative care education in North Wales nursing homes through the introduction of care decisions for the last days of life. Recently, she was appointed as Macmillan BCUHB ACP Lead, an initiative promoting advance care planning discussion opportunities for people across North Wales. She holds an honorary lectureship at Bangor University and regularly gives lectures on advance care planning to undergraduate nursing students. Wider interests include developing research studies identifying the most appropriate methodology for use in clinical trials involving dying patients.

e: Rosalynde.Johnstone@wales.nhs.uk

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Palliative nursing – caring for people at the end of life

Nadine Lexa

DBfk nordost ev, Germany

The need for care of palliative patients is constantly increasing. The care and support of terminally ill people are extremely complex and challenging. Thus, symptoms such as shortness of breath, restlessness and pain can occur individually, but also simultaneously. As a companion to the practice, the book provides nurses with suggestions and safety in dealing with palliative care patients and provides nursing practical knowledge for the care of people at the end of life by for example represents suitable aids and introduces their handling. In this way, professional palliative care workers, nursing staff, outpatient care, acute

care hospitals, and their relatives can provide professional palliative care.

Speaker Biography

Nadine Lexa is a Nurse at MAS Palliative Care and she is also a procedural care lecturer, author & journalist in the field of Palliative Care, Nursing & Ethics and she also serve as a auditor for palliative care units, publisher of a palliative care book series "Palliative Care for beginneres" (Hospizverlag) and councilwoman.

e: nadinelexa@gmail.com

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

A 10-year retrospective analysis of hospital admissions of cancer patients in Brazil (2008-2017)

Cledy Eliana dos Santos¹, Barros N¹, Klug D¹, Cruz RP¹, Serafim, J A² and Caldas J M P³

¹Grupo Hospitalar Conceição, Brazil

²University Foundation of Cardiology, Brazil

³University of Porto, Portugal

Cancer figures among the leading causes of morbidity and mortality in Brazil. Overall, 600,000 new cancer cases and 200,000 deaths are estimated to occur annually in Brazil.

Yearly around 1.2 million deaths were reported to the Brazilian Mortality Information System, being 16.2% of these related to people living with cancer.

The hospital admission procedure for “Treatment of Clinical Intercurrences of Oncological Patients” is related to a complication of the disease or its treatment, predictable or not, which requires hospitalization in specialized, general or day hospitals, for control of the complication.

Between 2008 and 2017, there were more than 6.7 million hospitalizations (6,746,226) related to cancer in Brazil. Of all the hospital admissions of cancer patients, 1,895,735 (28%) were related to clinic intercurrents of the disease.

According to the retrospective analysis of hospital admissions of cancer patients, data recorded in the Hospital Information System of SUS, approximately 90% of the hospital admissions made in the procedure “Treatment of Clinics Intercurrences of Cancer Patient” were related to palliative care for terminally ill patients.

Through the hospital admissions of cancer patients in the procedure “Treatment of Clinical Intercurrences of Oncological

Patients”, we can estimate patients with indication of palliative care at the end of life, as well as identify parameters for the estimated need for cancer palliative care hospital beds. In this regard, we propose studies to size the target population, the demand and supply of health services, the level of attention required by selecting, to that, certain items likely to comparability between national and international data parameters, such as utilization of palliative care services, the prevalence of pain and other symptoms. Also, further study of hospital procedure “Treatment of Clinical Intercurrences of Oncological Patients” should be considered as a parameter for scaling of palliative care services in Brazil.

Speaker Biography

Cledy Eliana dos Santos has a bachelor's degree in Engineering of Production at the Pontifícia Universidade Católica do Rio Grande do Sul (1977). Graduation in medicine at the College of Medical Sciences of Porto Alegre (1980), MSc in community health in Developing Countries-University of London (1991), MSc in AIDS from the University of Barcelona (2001); PhD in Medicine – University of Porto/Portugal (2018). She is a Medical Doctor at Hospital Nossa Senhora da Conceição/ GHC, specialist in Family and Community Medicine and Palliative Medicine. Since 2009 she has been working on Service of Pain and Palliative Care of Hospital Nossa Senhora da Conceição/ GHC. Member of the Palliative Care Technical Chamber of the Regional Medical Council of Rio Grande do Sul State (from July 2011 to January 2019).

e: cledy.eliana@gmail.com

 Notes:

Palliative Care & Clinical Trials and Pharmacovigilance

September 23-24, 2019 | Prague, Czech Republic

Results of the application of an antiretroviral protocol to pregnant women with human immunodeficiency virus in a service of North Eastern Brazil: A step towards improving in palliative care

Otávio Soares de Pinho Neto

USP University Hospital, Brazil

Background: This study sought to analyze ART protocols used in a cohort of HIV-positive pregnant women and exposed newborns followed at a university hospital in Northeast Brazil.

Methods: Retrospective cohort study of 153 pregnancies.

Descriptive statistics were used to characterize the sociodemographic profile of mother- child pairs, prenatal care, use of ART, and delivery, and an analysis of antiretrovirals used and associated maternal and neonatal outcomes was conducted. The t-test was used to evaluate potential associations between categorical variables.

Results: The overall mother-to-child transmission rate was 3.9%. More than 50% had been diagnosed before pregnancy, 41% were on ART, and 70% had an undetectable viral load at 34 weeks pregnancy. The mean CD4 count was 440 cells/mL at baseline and 516 cells/mL after ART. Overall, 92% of women were on ART with protease inhibitors and 98% received intrapartum intravenous AZT. Prematurity, presence of neonatal morbidity, and failure to administer intrapartum AZT were associated with 84 increased risk of vertical transmission. There was a


low incidence of side effects associated with ART during pregnancy; the most common was anemia, both maternal (58.4 %) and neonatal (21.6%).

Conclusion: In this sample, mother-to-child transmission was mainly associated with prematurity, neonatal morbidity, and failure to administer intrapartum intravenous AZT. These results may support interventions toward improving health quality in palliative care methodologies.

Speaker Biography

Otávio Soares de Pinho Neto has Graduated in Medicine from the Federal University of Paraíba (1985), Specialization in STD by the Brazilian Society of STD (2000), Master in Human Development from the Federal University of Paraíba (2006) and Doctorate in Tocogynecology from the State University of Campinas (UNICAMP-2014). He is a member of Iberoamerican Observatory of Health and Citizenship and member of the Editorial Committee of the Iberoamerican Journal of Health and Citizenship since 2013. He was an Invited Professor at Rey Juan Carlos University - Madrid and University of Porto - Portugal (2015). Medical Director Assistance at the Lauro Wanderley University Hospital / UFPB and eventual replacement of the Superintendent Director (2010-2013), Bayeux Municipality Doctor 1998-1999, Lucena Municipality Doctor 2008-2014, Santa Maria Maternity Doctor 1997-2013.

e: drotavio.pinho@gmail.com

 Notes: