

4th International Conference on
Palliative Care, Medicine
and Hospice Nursing
August 27-28, 2018 | Boston, USA

Workshop DAY 1



Palliative Care 2018

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Sebastian Sepulveda

At Death's Door, USA

The PCP role in end of life care

Biography

Sebastian Sepulveda M.D. is a private practice physician in Massachusetts. He is the author of "At death's door", the book, which was chosen as one of the best books of the year by Foreword Review Magazine for the year 2017. He is also the creator and producer of "End-of-life", the documentary, which can be seen at the conference in our booth. And, finally, he is also the creator and executive producer of "Death Door", the TV series pilot, presently seeking national distribution. Dr. Sebastian Sepulveda has been a doctor for almost 30 years. After med school at the University of Chile, he worked in emergency medicine for a couple of years, and a few years later, he was a professor of medicine for three years in Georgia. Since 2005, he has been in private practice, and now specializes in hospital medicine, kidney diseases, and caring for the terminally ill. The reference for this lectures "The role and Decision making of the PCP on end-of-life" is published stories and data is on his book "At death Door", which can be found especially through Amazon. All of this based on real life stories. Trailers to Sebastian's two productions can be seen at his website

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Yvonne Heath

Love your Life to Death, Canada

Love your life to death: Exploring the 7 take aways so you can live well, grieve well, die well and teach others to do the same

As a follow-up discussion to Yvonne's plenary I Just Showed Up, we explore the 7 Take Aways further and discuss in the detail the things we can do as medical professionals both personally and professionally. How do we grieve? What is self-care? Why have we become scared of Death? What is your legacy as a Do you avoid those hard conversations or situations? Why should we change? Why do we need to do better? Why? Because Grief shows no mercy. It arrives unannounced and uninvited. It does not care what else you are going through and it does not care if you've had enough. Everyone grieves—regardless of age, race, culture, gender, sexual orientation or economic situation; Divorce, diagnosis, mental health issues, financial stress and yes, facing an end of life. The 7 Take Aways are the culmination of my learning in 30 years of nursing and in interviewing hundreds of people. Living by these principles, you will learn to live well, grieve well and die well—and teach others to do the same.

The 7 Take-Aways

- The best time to talk about, plan and prepare for grief is when we are young and healthy. The Next Best Time is Now!
- It Takes a Village to support: the ill, the caregiver, the dying, the bereaved and each other.
- When someone is grieving,
- Just Show Up! To be empowered, resilient and compassionate,
- Show Up For Yourself First! Structure Your Life in such a way that you are self-reliant. (and so are the people surrounding you.
- Find your Post, and hold onto it.
- What will Your Legacy be?

Biography

As a Registered Nurse for 30 years, working in the United States and Canada, Yvonne has witnessed our society's death phobia and our reluctance to talk about, plan to prepare for grief, causing excessive suffering. Her new purpose? To empower compassionate communities and professionals to live life to the fullest, learn to grieve and support others and have "The Talk" about the end of life... long before it arrives and diffuse the fear. Yvonne shares her message—with heart and humor— using intelligence, empathy and genuine uplifting spirit, to combine a powerful mix of personal insights and lessons. Yvonne demonstrates how we can live well, die well, and transform our world into a happier place. She is the Founder of the I Just Showed Up movement (Teaching people of all ages to show up for themselves and others, so they are empowered and resilient when grief arrives) and Love Your Life to Death.

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Scientific Tracks
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Development and initial cross-cultural validation of the Confucian Orientation Beliefs scale (COB)

Yvonne Hsiung and In-Fun Li
Mackay Medical College, Taiwan

A series of cross-cultural studies were conducted to develop and validate a cultural measure, Confucian Orientation Beliefs (COB) Scale. The original 66-item acculturation scale was constructed among Chinese-American immigrants residing in greater Chicago area (n=211) with specific aims to assess a broad range of traditional Chinese beliefs. Through examinations of content validity, internal consistency ($\alpha = .86$), and an inter-item correlation of .27 ($p < .001$), the initial exploratory factor analysis (EFA) suggested 3 principal components: familialism ($\alpha = .84$), male and physician paternalism ($\alpha = .82$), and death taboos ($\alpha = .89$). CO among overseas Chinese was found highly positively correlated with American acculturation, attitudes toward life-sustaining treatment, and palliative care usage. A following confirmatory factor analysis (CFA) was supported with a goodness of fit of 0.95 in a relatively smaller Taiwan suburban sample (n = 122). Further EFA and CFA among hospitalized patients from various Taiwan areas (n = 508) yielded a slightly different structure: male paternalism, filial piety, and death taboo jointly captured a salient cultural factor ($\alpha = .83$); a single dimension was revealed as an individual's propensity to conform to Confucian traditions, and this orientation is specifically related to life-sustaining treatment attitudes (AVE= 55.39, AGFI= .966, $p = .009$). A data-driven and efficient tool, the 6-item COB scale (short form), was created with strong psychometric properties. While CO remains prominent in modern Chinese-ethnic societies to affect family caregivers' life-sustaining treatment decision-making, future research is necessary to replicate studies for temporal stability across heterogeneous Chinese-speaking and Confucianism-oriented samples.

Biography

Yvonne Hsiung received her Ph.D. in Palliative Care Nursing in 2011. Being an ethical consultant for terminal patients and family surrogates, her previous research, teaching, and clinical experiences mostly focused on the health promotion, community education, and cultural advance care planning among minority groups in the Greater Chicago Area. She returned to Taiwan in 2012 because her father required cancer care. Now she is at Mackay Medical College teaching courses about Oncology Nursing, Palliative Care, Medical Ethics, Spiritual Nursing Care, and Life and Death Education.

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Enhancing end of life discussions: A guide to practical tips when using translated materials

Ingrid See and Sarah Lau
Vancouver Coastal Health, Canada

Sensitive topics in palliative care, such as goals of care and advance care planning conversations, can be challenging for healthcare professionals (HCP) to discuss when patients and families speak another language. HCP often resort to using translated materials to assist in these discussions. Ariadne Labs in Boston has developed the Serious Illness Conversation Guide (SICG) which guides HCP in having early conversations so that patient's wishes, values, and beliefs are known earlier to the healthcare team. In Vancouver Coastal Health, the guide has been translated into 4 main languages: Chinese, Punjabi, Farsi, and Arabic. With direct translation into English, it has been noted that several of the questions had lost its original meaning and intent as some words cannot be translated directly into a language, therefore, the translators chose a word that may or may not reflect the original meaning and intention. Translation is not a one-step process; it involves translating the materials into a different language, back-translating to see if the meaning is maintained, reviewing by interpreters/people who speak the language, and then tested by clinicians. Given the sensitivity of topics discussed in the SICG, it is important that this is done correctly. The goal of this presentation is to share with HCP the challenges of translating patient materials directly into second languages. Using the Serious Illness Conversation Guide as an example, the barriers to translation will be identified along with learning helpful processes which will assist HCP to create more culturally appropriate materials.

Biography

Ingrid See is a Clinical Nurse Specialist with the Vancouver Home Hospice Palliative Care Service in BC, Canada. She started her home care nursing career in Massachusetts before returning home to Vancouver to specialize in palliative care. She completed her Masters in Education in 2001 with a focus on teaching health care professionals in providing culturally competent care. She is currently the Vancouver lead in implementing the Serious Illness Conversation Guide project across home health.

Sarah Lau is a home care nurse who is currently working as an educator for the Serious Illness Conversation Guide implementation in Vancouver home health. She has worked as a home care nurse for several years and has a specialty in palliative care.

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Aberant behaviors towards Opioids

Sorin Buga

City of Hope, USA

Aberrant behaviors towards opioids Pain, whether related or not to a cancer diagnosis, can be addressed by multiple medications where the opioids are considered to represent the gold standard approach in the management of cancer and cancer treatment-associated pain. But the same opioids could cause euphoria by stimulating the brain reward system, particularly the mesolimbic dopaminergic circuits, that could lead to various aberrant behaviors towards the opioids. The aberrant behaviors should be of significant concern to prescribing physicians especially in the context of the opioid crisis that we are currently experiencing in the United States. Therefore, it is imperative for clinicians to detect and monitor these behaviors while striving to alleviate the suffering of their patients in pain. Concurrently, there is increased need to educate the opioid prescribers to understand certain aberrant behaviors to avoid mislabeling of those patients as drug addicts when in reality they are not and also to avoid increasing their already heightened psychosocial distress. This presentation will review the definitions for various substance use disorders with a particular emphasis on the addiction, pseudoaddiction, and chemical coping, behaviors that are intertwined yet differs based on the patient's ultimate goal that is euphoria for addiction, relieving non-pain symptoms for chemical coping and nothing else but pain relief for pseudoaddiction.

Biography

Sorin Buga MD is an Associate Clinical Professor in the Department of Supportive Care Medicine at City of Hope, Duarte, California. He is board certified in internal medicine and hospice and palliative medicine and a fellow of the American College of Physicians and of the American Academy of Hospice and Palliative Medicine. He completed his fellowship in palliative medicine at H. Lee Moffitt Cancer Center in Tampa, Florida. He is the City of Hope's representative on the NCCN Adult Cancer Pain Panel and an active member of the American Academy of Integrative Pain Management, the American Academy of Hospice and Palliative Medicine, the International Association for Hospice and Palliative Care and International Association for the Study of Pain. He has published in the peer review literature and is often invited to speak at scientific meetings.

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Time Is Precious (TIP): Person centred end of life care in the emergency department

Daniela Vasquez

South Western Sydney Local Health District, Australia

A primary focus of the Emergency Department (ED) is to provide urgent medical treatment in the hope of minimizing suffering and preventing treatment delays for patients whose death is imminent or inevitable. The focus of palliative care is on quality of life through symptom management, utilizing a multi-disciplinary approach, whilst providing support to the carer and family. Though not oppositional to the ED process, there are gaps in the approaches to achieving patients' goals of care. Additionally, palliative care patients are often forgotten or seen as a low priority, and as a result, they are having delayed medical review, commencement of inapplicable investigations and inappropriate management. Further, they are not receiving appropriate nursing care and unnecessary stress is put on the patient and families by exposing them to an undesirable busy environment with little privacy and compassion. There is an expected 21% increase in patients with palliative care needs using EDs by 2021 in the South Western Sydney Local Health District. This will translate into longer wait times unless a system to cater for this patient cohort is in place. In response to this need, we have designed a detailed model of service named Time is Precious (TIP). The aim of the TIP Project is to improve the care of patients who present to the ED in their last week's/ days of life. TIP involves early identification, escalation particularly for acutely distressed patients or families, fast-tracked medical review to improve disposition planning, and discussion on goals of care (GOC) which empowers the patient and the family to make a decision where to die at home or the hospital. We have developed the concept of a ED Specific End of Life Care Project in the ED for patients with palliative care needs, consisting of a guide to assist with care and disposition planning, checklists, education, a resource folder and a collaborative approach to care planning, incorporating the multidisciplinary team in the ED and extending to inpatient medical and nursing teams.

Biography

Daniela's nursing began in 2007 as an Enrolled Nurse, she worked in geriatrics, psycho geriatrics, surgical & cardiology. She successfully completed her graduation program at Liverpool hospital, her 1st rotation in Emergency then, 2nd rotation in Haemodialysis. She returned to ED and stayed there for 5 years. Recently she have started working as a clinical Nurse Specialist in Palliative care.

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Does the number of co-morbidities influence the length of terminal stay in the palliative care unit?

Johan Menten, Coppens G, Lembrechts M, Brackenier C, Vandyck Hendrik, Haemels Veerle, Peeters Elise and Bollen Heleen
Catholic University Leuven, Belgium

Introduction: Many terminal patients in a palliative care unit have different co-morbidities along the main diagnosis. It is generally assumed that patients with more co-morbidities are frailer and will die sooner compared to patients that have none or one co-morbidity. We didn't find any support in the scientific literature to support this assumption.

Material and Methods: In a database of 3010 patients that passed away in the palliative care unit of the University Hospital of Leuven (1999-2016) we searched for the effect of the number of co-morbidities on the length of stay of these patients until the date of dying

Results: Patients with 0-2 co-morbidities were a median time of 9 days until death in the palliative care unit while patients with 3 or 4 co-morbidities died after 7 days. After statistical ANOVA analysis it is shown that the number of co-morbidities does not influence the length of stay of terminal patients in the palliative care unit ($p = 0.6381$). The curves of survival probability of patients with 1 to 4 co-morbidities superimpose on each other.

Conclusion: There is no correlation between the number of co-morbidities and the length of stay until death in the palliative care unit for terminal patients. Patients with 1 to 4 co-morbidities die after equally lengths of stay.

Biography

Johan Menten completed his Graduation in Medicine from Limburgs University Center and Catholic University Leuven. He is also a Member of the board of Belgian society of palliative Care till 2000. Now, he is President of the research task group in the Flemish Federation of Palliative Care.

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Last word: Important information about human rights at the end of life

Tercia Soares Sharpe
End of Life Consultant, USA

Statement of the Problem: People in general are surprised as to what happens in a hospital setting and are overwhelmed when trying to understand and make decisions in regards to all that is offered by the physicians that are taking care of them or their loved ones, especially when living naturally is no longer an option. End-of-Life care decision making requires knowledge, not only on what medical sciences can offer, but also on hospital culture, the paradox of resuscitation and prolonging life artificially. The purpose of this study is to discuss the importance of allowing the population to learn ahead of time about what happens in a critical care setting through other people's experience.

Methodology & Theoretical Orientation: An interdisciplinary ethnographic study using explanatory dialogue was utilized during participant observation, through group discussions (family meetings) and individual interviews. A social ecological framework was utilized to focus on the interaction between physicians, participants and the staff to understand the context and timing of when information was received.

Findings: It is difficult for the general population who seek medical care to understand the concept of limited treatment. Healthcare providers and physicians are working towards this challenging task of making patients understand the need to refuse treatment as it may not benefit them, and in some cases, may cause harm.

Conclusion & Significance: Decisions about the end of life are more effective when based in knowledge and discussed ahead of time, without the possibility of imminent loss. Last Word is a book that gives the public the opportunity to know and understand life's cycle before making decisions. It also gives healthcare professionals the chance to reconnect to their human side, and let it flourish above science, skills and technology.

Biography

With over 40 years of experience, as well as working as bedside nurse in critical care, she has also acted in the administrative and educational fields of nursing in Brazil and in the United States. A specialist in palliative care, she founded and headed the End of Life program at INOVA Loudoun Hospital, VA, for nine years. She is an Author, speaker and consultant on topics regarding the end of life. ELNEC (End-of-Life Nursing Education Consortium) trainer and recipient of the ELNEC Excellence Award in 2012 for her commitment to deliver excellent palliative care to critical patients. Recipient of the INOVA Loudoun Hospital Innovation Nurse Award in 2013 for initiating that institution's end-of-life program

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Lessons learned from a feasibility prospective study of palliative care eligible patients with chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD)

Naouma Siouta, Heylen A, Aertgeerts B, Clement P, Vermandere M, Janssens W, Van Cleemput J and Menten J
KU Leuven University, Belgium

Background: Initiation of PC practices in cardiology and pulmonology wards for patients with Chronic Heart Failure (CHF) and Chronic Obstructive Pulmonary Disease (COPD) remains a challenging topic.

Objective: A feasibility prospective study was designed and implemented in the cardiology and pulmonology wards of the University Hospital of Leuven (Belgium) to measure the quality of life (QoL) and the quality of care in both chronic CHF and COPD patients and their informal caregiver.

Methods: Eligible patients and their informal caregivers were asked to complete the Palliative Care Outcome Scale (POS), the Can Help Lite questionnaire and a self-developed ad-hoc questionnaire. These questionnaires were completed at inclusion and after a three-months follow-up. Informed consent was required.

Results: The feasibility assessment has overall been positive. The sample size (23 CHF and 25 COPD patients) was collected but older patients were underrepresented. The majority of the participants were younger and with milder symptomatology. Despite the well-designed eligibility criteria, it became necessary to read just the recruitment process and directly involve the main researcher in the identification of eligible patients.

Conclusion: The positive feasibility assessment and the lessons learned from this study can assist similar future efforts in this area. However, the implementation of integrated PC interventions is expected to raise further challenges that will need to be investigated in separate studies.

Biography

Naouma Siouta is a doctoral candidate from KU Leuven (Belgium), Department of Experimental Radiotherapy. The aim of her Ph.D. is the investigation of the early integrated palliative care in chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD). She obtained a bachelor degree in psychology from the Aristotle University in Thessaloniki (Greece) and a Master of Public Health degree from KU Leuven (Belgium).

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Through the introduction of palliative care, quality of life has improved and the course of illness has been positively influenced thus leading to an increase in referrals

Julia Ambler

Umduduzi – Hospice Care for Children, South Africa

Palliative care should be provided from the point of diagnosis and beyond death. However, within the South African context, palliative care is poorly understood. Many practitioners believe it to be synonymous with the end of life care or ‘giving up’ and are thus reluctant to refer early to the team. Through our work, we have come to realize that this misunderstanding is common and is not specific to any discipline. In addition to this, palliative care is not a recognized specialty in South Africa hence there are limited numbers of health professionals trained in palliative care. As they cannot specialize in the field, there are no government posts. Currently, almost all palliative care services are offered by the not-for-profit / non-governmental sectors (NPO/NGO). The authors have compiled a retrospective case study analysis of their patient base. They have explored how presenting palliative care cases to health care professionals at academic meetings has led to increased referrals. Referrals are also being made earlier in the course of illness. Healthcare professionals, when they have seen the benefits of palliative care, are more inclined to recognize the need for a palliative care approach and refer earlier. Through their interactions with the palliative care team, health care professionals have been empowered and are more willing to provide palliative care themselves, accessing the team for telephonic support. Discussing and presenting such case studies with and to health care professionals improves referrals and thus improves access to palliative care.

Biography

Julia graduated from University of Cape Town with her MBChB in 1998. She trained and worked as a general practitioner and a children’s hospice doctor at Helen and Douglas Houses in Oxford, the UK for 6 years. On returning to Durban, she continued her passion for pediatric palliative care and is Deputy Director of Umduduzi – Hospice Care for Children. Through this NPO she consults in children’s palliative care and trains health professionals and medical students in the Department of Paediatrics, UKZN.

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