A Good Ending – Good for All
Bergen – Norway  6-7 November 2019

Final conference of the ERANet-LAC CODE project and 6th Annual Research Conference of the International Collaborative for Best Care for the Dying Person, 6-7 November 2019, Radisson Blu Royal Hotel, Bergen, Norway.

SCIENTIFIC PROGRAM (may be subject to changes)

Wednesday 6 November

09:00  Registration

Chairpersons 10:00-12:10: John Ellershaw and Dagny Faksvåg Haugen

10:00 Opening

Professor Per Bakke, Dean, Faculty of Medicine, University of Bergen, Norway
Professor John Ellershaw, Chair of the International Collaborative, University of Liverpool, UK

10:30 Death and dying in the 21st century – what are the challenges?

Kjell Erik Strømskag, anesthesiologist experienced in disaster medicine and palliative care, researcher and author

11:00 The ERANet-LAC CODE Project: Care of dying cancer patients as perceived by bereaved relatives

- The CODE questionnaire – a global tool to assess care of the dying?
  Dr. Catriona Mayland, University of Sheffield, UK
- CODE International Survey: A picture of current care for the dying in four European and three South American countries. What did we learn?
  Professor Dagny Faksvåg Haugen, University of Bergen, Norway
- CODE free text comments: What do bereaved relatives want to tell us?
  Dr. Christina Gerlach, University Medical Center of the Johannes Gutenberg University, Mainz, Germany
- Proof of Concept: Experiences in quality improvement based on CODE results
  Dr. Vilma Adriana Tripodoro, Institute Alfredo Lanari, University of Buenos Aires, and Pallium Institute Latin América, Buenos Aires, Argentina

12:10 Break and poster viewing

Presentations based on selected abstracts

Chairpersons 12:30-15:30: Carl Johan Fürst and Katrin Sigurdardottir

12:30 Dare to Care: patients with advanced cancer and their informal caregivers want personal well-organized care.

Natasja Raijmakers, PhD, The Netherlands Comprehensive Cancer Organization, Utrecht, the Netherlands

12:45 Comparison of the quality of care of the dying in acute, intensive and palliative care: Next-of-kin perspectives using the CODE-GER. Johannes Radon, Medical Student, Johannes Gutenberg University, Mainz, Germany

13:00 Lunch

13:50 Does advance care planning improve quality of life and symptoms in patients with advanced cancer? Results from the EU-funded ACTION project in six European countries

Assistant Professor Ida Korfage, Erasmus University Medical Center, Rotterdam, the Netherlands

14:35 How to respond to patients’ wishes for a hastened death. Results from the DeDiPOM project in Germany (Desire to Die In Palliative care Optimizing Management)

Professor Raymond Voltz, University of Cologne, Germany

15:15 Coffee and poster viewing
15:30 Parallel sessions and workshops:

1. How can we improve care in the last days of the patient’s life – for patient, relatives and staff?
Learning from the CODE project and conference participants’ experiences

Chairpersons: Vilma Tripodoro and Christina Gerlach

15:30-15:45 Strategies for unfolding the concepts of palliative care in a public hospital.
**Juliana Nalin de Souza Passarini**, Physiotherapist MSc, State University of Campinas and Sumaré State Hospital, São Paulo, Brazil

15:45-16:00 Do relatives of dying patients need emotional support and information about symptoms of incoming death?
**Katarzyna Wolszczak**, Psychologist, Coordinator, Sue Ryder House, Bydgoszcz, Poland

16:00-16:15 Participatory Action Research on Quality improvement based on results of the international survey ‘Care the Dying Evaluation’ (i-CODE) in Córdoba, Argentina.
**Dr. Gabriel Goldraij**, Hospital Privado Universitario de Córdoba, Argentina

16:15-16:30 Digital educational kit in palliative and end of life care.
**Grethe Skorpen Iversen**, RN, Network Coordinator, Haukeland University Hospital, Bergen, Norway

2. Advance care planning (workshop, from 15:30 to 16:30, max 50 participants)
Facilitators: Ida Korfage and Sanne Wouters

3. How to respond to patients’ wishes for a hastened death (workshop, from 15:30 to 16:30, max 50)
Facilitators: Raymond Voltz and Kathleen Boström

4. Research on care in the last days of life:

Chairpersons: Mark Boughey and Carl Johan Fürst

15:30-15:45 Improving the provision of information about hydration in the last days of life: a local initiative in a large UK teaching hospital.
**Dr. Catriona Mayland**, Royal Liverpool and Broadgreen University Hospitals, University of Liverpool, and University of Sheffield, UK

15:45-16:00 Discontinuation of anti-cancer drug therapy near end of life (EOL) in patients with advanced disease – a retrospective cohort study at a single institution in Norway.
**Dr. Anne Nadine Lorentzen**, Haukeland University Hospital, Bergen, Norway

16:00-16:15 Scopolaminebutyl to prevent death rattle: a first impression of the SILENCE study.
**Dr. Harriette (Jet) Johanna van Esch**, Hospice Laurens Cadenza and Erasmus University Medical Center, Rotterdam, the Netherlands

16:15-16:30 Effectiveness of three oral moisturizers in palliative care patients.
**Siri Flagestad Kvalheim**, Specialist Dentist, University of Bergen, Bergen, Norway

16:30 End of scientific sessions

17:30 Informal gathering for summary and networking, with light supper

Thursday 7 November

Chairpersons 08:30-11:30: Susie Wilkinson and Grethe Skorpen Iversen

08:30 Welcome and introduction

08:40 Hydration in the dying patient: Can we measure it? Should we give it?
**Dr. Ami Nwosu**, University of Liverpool, UK

09:10 Societal engagement in death and dying
- **Dying matters!**
  **Claire Henry** MBE, Independent consultant in end of life care and Quality Improvement
- **Death Education – experiences and tips from Sweden**
  **MSc Jamie Woodworth**, Lund University, Sweden
10:00  Break and poster viewing

10:20  A Good Ending – Good for All? Care for the dying in India
      **Professor Naveen Salins**, Manipal Comprehensive Cancer Care Centre, Kasturba Medical College, Karnataka, India

10:50  The i-LIVE project. Live well, die well. A Horizon 2020 project to support living until the end.
      **Professor Agnes van der Heide**, Erasmus University Medical Center, Rotterdam, the Netherlands

11:30  **Parallel sessions:**

1. **Use of volunteers in the last days of life**
   Chairpersons: Marisa Martín Roselló and John Ellershaw
   - 11:30-11:55  Training Volunteers to Support Dying Patients, and their Families, in the Hospital Setting – iLIVE study.
     **Professor Anne Goossensen**, University of Humanistic Studies, Utrecht, the Netherlands
   - 11:55-12:20  iLIVE Project: Seeking international consensus on the content of a hospital volunteer training programme to support patients at the end of life, and their families. A Delphi study.
     **Tamsin McGlinchey**, Research Assistant, University of Liverpool, UK
   - 12:20-12:40  Social importance of volunteering in palliative care in the Netherlands.
     **Fleur Imming**, Director of VPTZ Nederland, Amersfoort, the Netherlands

2. **How can we engage society in care at the end of life?**
   Chairpersons: Claire Henry and Jamie Woodworth
   - 11:30-11:50  Collaboration and coordination are important when engaging society in care at the end of life.
     **Susanne Lier Fagerbakke**, MPA, Advisor, The Dignity Centre – Care for the Old, Bergen, Norway
     **Dr. Christel Wihlborg** and **MSc Jamie Woodworth**, Lund University, Sweden
   - 12:20-12:40  Discussion

**Sessions in Norwegian:**

3. **Advance Care Planning (Forhåndssamtaler)**
   Chairpersons: Marc Ahmed and Ørnulf Paulsen
   - 11:30-11:45  Advance Care Planning with patients having advanced pulmonary disease – A qualitative study in a hospital setting in Western Norway.
     **Dr. Nina Elisabeth Hjorth**, Haukeland University Hospital and University of Bergen, Bergen, Norway
   - 11:45-12:00  Clarifying conversations in palliative care – nurses’ experiences.
     **Sølvi A. Eide Lunde**, RN, Assistant Professor, Western Norway University of Applied Sciences, Haugesund, Norway, and **Kristin Bie**, Consultant, Development Center for Nursing homes and Homecare, Helse Fonna, Norway
   - 12:00-12:15  Make the best of whatever time remains; advance care discussions and a structured Palliative plan in primary healthcare.
     **Dr. Bardo Driller**, Department of Oncology, Møre and Romsdal Hospital Trust, Ålesund, Norway
   - 12:15-12:40  Panel discussion including the above speakers in this session (session 3)

4. **Practical improvement projects – what do I take home from the conference?**
   (Praktisk kvalitetsforbedring – hva tar jeg med hjem fra konferansen?)  Workshop 11:30-12:40
   Facilitators: Lars Helge Myrset, Janet Bakken and Dagny Faksvåg Haugen


13:00  Lunch

---

*Thank you for attending the final conference of the ERANet-LAC CODE project and 6th Annual Research Conference of the International Collaborative for Best Care for the Dying Person - “A Good Ending – Good for All”!*
The conference has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) for 7 European CME credits (ECMEC®s):

“The A Good Ending - Good for All. 6th Annual Research Conference of the International Collaborative for Best Care for the Dying Person, Bergen, Norway, 06/11/2019-07/11/2019 has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME®) with 7 European CME credits (ECMEC®s). Each medical specialist should claim only those hours of credit that he/she actually spent in the educational activity.”

“Through an agreement between the Union Européenne des Médecins Spécialistes and the American Medical Association, physicians may convert EACCME® credits to an equivalent number of AMA PRA Category 1 CreditsTM. Information on the process to convert EACCME® credit to AMA credit can be found at www.ama-assn.org/education/earn-credit-participation-international-activ...”

“Live educational activities, occurring outside of Canada, recognised by the UEMS-EACCME® for ECMEC®s are deemed to be Accredited Group Learning Activities (Section 1) as defined by the Maintenance of Certification Program of the Royal College of Physicians and Surgeons of Canada.”