

Seventh Annual Research Conference

Global Research and Future Innovations in Best Care for the Dying Person



Liverpool, UK – 13th October 2022

CONFERENCE GUIDE

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WELCOME TO LIVERPOOL

13th October 2022

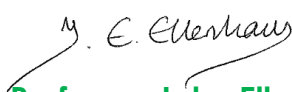
Dear Colleague,

On behalf of the University of Liverpool and the International Collaborative for Best Care for the Dying Person, it gives me great pleasure to welcome you to Liverpool for this one-day conference on Global Research & Future Innovations in Best Care for the Dying Person.

The programme for the event aims to provide an overview of innovative developments relating to end of life care, and offers an opportunity to share research, education ideas and best practice at both national and international levels.

I very much hope that you enjoy the conference and that you find it beneficial in your current and future practice. If you require any assistance during the day, please don't hesitate to approach a member of the team.

Kind regards,



Professor John Ellershaw MA FRCP

Professor of Palliative Medicine

Head of the Palliative Care Unit, University of Liverpool

Chair of the International Collaborative for Best Care for the Dying Person

PROGRAMME

SESSION 1 – Chaired by Professor Carl Johan Furst	
08:45	Registration, coffee, and poster viewing
09:40	Welcome and introduction to the International Collaborative for Best Care for the Dying Person <i>Professor John Ellershaw, Chair of the International Collaborative</i> <i>Professor Terry Jones, Liverpool University Hospitals NHS Trust/University of Liverpool</i>
09:55	Experiences of end of life care: An international study across 13 countries <i>Professor Agnes Van Der Heide, Erasmus University Medical Centre, Netherlands</i>
10:15	The National Audit of Care at the End of Life (NACEL): Learning from the last five years <i>Dr Suzanne Kite, Leeds Teaching Hospitals NHS Trust & NACEL Clinical Lead</i>
10:35	Parliamentary and public engagement in end of life care <i>Professor Ilora Baroness Finlay of Llandaff</i>
10:55	Coffee and poster viewing
SESSION 2 – Chaired by Professor Catherine Walshe	
11:20	Innovations in drug delivery at the end of life <i>Dr Andrew Dickman, University of Liverpool, UK</i>
11:40	Diagnosing Dying – myth or reality? <i>Dr Seamus Coyle, University of Liverpool, UK</i>
12:00	Impact of Restrictive Measures for Dying Patients on Healthcare Providers During the COVID-19 Pandemic: The International CO-LIVE study <i>Associate Professor Ida Korfage, Erasmus University Medical Centre, Netherlands</i>
12:20	Panel Discussion
12:30	Lunch and poster viewing
SESSION 3 – PARALLEL SESSIONS	
13:30 – 14:20	In-person delegates may choose any two of the following 50-minute sessions: <ol style="list-style-type: none"> 1. Oral presentations from submitted abstracts (Open to all attendees) <i>Dr Vilma Tripodoro and Dr Susie Wilkinson</i> 2. Quality Improvement in Care for the Dying – international comparisons † <i>Dr Suzanne Kite and Assoc Professor Mark Boughey</i> 3. Writing for publication † <i>Professor Catherine Walshe</i> 4. Technology in palliative and end of life care † <i>Professor Mark Taubert and Dr Amara Nwosu</i> <p style="text-align: right;">† Open to in-person attendees only</p>
14:25 – 15:15	
15:15	
15:15	
15:15	Tea and poster viewing
SESSION 4 – Led by Roger Phillips	
15:35	Doctors: What do they know? People: What do they think? <i>Roger Phillips, BBC Broadcaster, in conversation with:</i> <ul style="list-style-type: none"> • <i>Professor Mark Taubert, Cardiff University (Digital Legacy)</i> • <i>Alison Germain-Martin, Liverpool University Hospitals NHS Foundation Trust (Patient Experience)</i>
16:15	Reflections on the day, including prizes for oral and poster presentations <i>Professor John Ellershaw</i>
16:30	Close

PLENARY PRESENTATIONS

Welcome and Introduction to the International Collaborative for Best Care for the Dying Person



Professor John Ellershaw & Professor Terry Jones

University of Liverpool / Liverpool University Hospitals NHS Foundation Trust, UK

The International Collaborative for Best Care for the Dying Person was formed in 2014 by a group of leading thinkers, practitioners and researchers from 12 countries who had previously worked together on an EU FP7 Co-ordination and Support Action Grant to optimise research for the care of cancer patients in the last days of life, known as OPCARE9. The vision of the Collaborative is “A world where all people experience a good death as an integral part of their individual life, supported by the very best personalised care”.

John Ellershaw is Professor of Palliative Medicine at the University of Liverpool, where he leads the development of palliative care research and education. He is the founding Chair of the International Collaborative for Best Care for the Dying Person.

Terry Jones is Professor of Head and Neck Surgery at the University of Liverpool, Director of the Liverpool Head and Neck Centre, Director of Research and Innovation at Liverpool University Hospital NHS Foundation Trust, and the Lead for Genomics England H&N GeCIP.

Experiences of End of Life Care: An international study across 13 countries



Professor Agnes van der Heide

Erasmus University Medical Centre, Rotterdam, NL

In the 21st century, most people die as a result of chronic disease and illness. Dying from chronic illness typically involves a period of declining health, deteriorating functioning and increasing symptom load. The imminence of death is often not recognized or acknowledged in patients with an advancing chronic illness, due to an omnipresent focus on diagnosis, therapy and cure. Individually and as a society, we are afraid to face our mortality, resulting in a ‘conspiracy of silence’ around death and dying. The iLIVE project is an EU funded study where researchers from 13 countries collaborate to better understand the experience of dying and end-of-life care, as well as the added value of optimal medication management and volunteer support. In the study, patients with a limited life expectancy and their family are asked to share their concerns, preferences and care needs. The presentation will provide some preliminary insights from this ongoing study.

Professor Agnes van der Heide, MD, PhD, is a researcher working at the department of Public Health at Erasmus MC, University Medical Center Rotterdam, in the Netherlands. Her research focuses on clinical, epidemiological and ethical aspects of palliative and end-of-life care. She has a special interest in end-of-life decision making.

The National Audit of Care at the End of Life (NACEL): Learning from the last five years



Dr Suzanne Kite

Leeds Teaching Hospitals NHS Trust & NACEL Clinical Lead, UK

The NHS Benchmarking National Audit of Care at the End of Life (NACEL) has been running since 2017. NACEL is commissioned by the Healthcare Quality Improvement Programme Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme. HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices and aims to promote quality improvement in patient outcomes, in particular to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. This talk outlines key findings, challenges and learning from the first 3 rounds of NACEL, and the future direction of the audit.

Dr Suzanne Kite has been a Consultant in Palliative Medicine at Leeds Teaching Hospitals NHS Trust since 2000. As Clinical Lead for Palliative and End of Life Care from 2007 she has embedded a culture and governance framework for best possible care of the dying across one of the largest acute hospital trusts in Europe. She has been joint Clinical Lead for the National Audit of Care at the End of Life since 2017.

Parliamentary and Public Engagement in End of Life Care



Professor Ilora Baroness Finlay of Llandaff

House of Lords, London, UK

In Wales in 2008 the principle was established of fair access to palliative care, with 24/7 advice to all healthcare professionals and 7-day services. However, in England service provision remained variably funded resulting in patchy provision. In 2022 government agreed to amend the Health and Care Act to require commissioners to provide palliative care including specialist palliative care to meet the needs of the population served. This is in marked contrast to palliative care provision in other parts of the world.

Baroness Ilora Finlay is an independent Crossbench Peer in the House of Lords, where she is also a Deputy Speaker and Deputy Chairman of Committees. She is an elected member of the BMA ethics committee, an Honorary Professor of Palliative Medicine at Cardiff University, and a past-President of the Royal Society of Medicine, British Medical Association, Medical Women's Federation and the Association for Palliative Medicine. She is currently a Vice-President of Hospice UK, Marie Curie Care, Chartered Institute of Environmental Health, and an International Scientific Panel member for the Cicely Saunders Foundation.

Innovations in Drug Delivery at the End of Life: Continuous subcutaneous infusions – practice update



Dr Andrew Dickman

University of Liverpool, UK

The challenge of providing adequate end-of life care in the presence of unfilled medical and nursing posts, coupled with the falling number of qualified district nurses, is daunting. As a result, new ways of providing and structuring services are required to optimise care for patients and make the best use of available resources. Changes will be required to ensure treatment continues to be provided to the best standard possible. Continuous subcutaneous infusions (CSCIs) represent an effective method of multiple drug administration in end-of-life care when the oral route is compromised. Avoidance of incompatibilities and instabilities of drug combinations represents prevention of medication error. The best confirmation of stability and compatibility will always be the performance of an appropriate laboratory analysis to examine the range of concentrations commonly used, prepared in the preferred diluent(s) and stored over a range of temperatures and light exposure, reflecting use in the clinical situation. Available chemical and microbiological stability data limit the infusion time of a CSCI to a maximum of 24 h. The possibility of increasing the duration of CSCI to 48h or more is one potential method of improving health service resource utilisation.

Dr Andrew Dickman is the Consultant Pharmacist for Palliative Care at the Academic Palliative and End of Life Care Centre, Royal Liverpool University Hospital. He is an honorary Fellow at the University of Liverpool and Honorary Lecturer at the School of Pharmacy and Biomolecular Sciences, Liverpool John Moores University. He has been recently designated as a Fellow of the Royal Pharmaceutical Society for his distinction in the Profession of Pharmacy. Dr Dickman has authored two essential textbooks, both being highly commended by the BMA, and is also a founding member of the Association of Supportive and Palliative Care Pharmacy.

Diagnosing Dying – myth or reality?



Dr Seamus Coyle

University of Liverpool, UK

Nobody knows how we die from cancer. Post-mortem studies show that people die from an infection or from a pulmonary embolus; however, this is not true. This talk will describe recent research at Liverpool looking at changes in urinary metabolites during the last weeks of life and describe biochemical pathways that change as death approaches.

Dr Seamus Coyle is a Consultant in Palliative Medicine at The Clatterbridge Cancer Centre and an Honorary Senior Clinical Lecturer at the Liverpool Head and Neck Centre at the University of Liverpool. His main research area is the Biology of dying and the development of a urine test to predict dying (recently patented).

Impact of Restrictive Measures for Dying Patients on Healthcare Providers During the COVID-19 Pandemic: The International CO-LIVE study



Associate Professor Ida Korfage

Erasmus University Medical Centre, Rotterdam, NL

How did restrictive measures for dying patients impact healthcare providers during the COVID-19 pandemic? In an online survey among 2925 healthcare providers from 14 countries during the COVID-19 pandemic, we found that visiting restrictions for dying patients and evaluating the medical and nursing care as provided as insufficient were in general associated with a worse quality of life of healthcare providers (OR 0.63, $p < 0.001$; OR 0.77, $p = 0.01$; OR 0.64, $P = 0.01$, respectively). We also found some heterogeneity between countries. We conclude that restrictive measures in the care of dying patients during the COVID-19 pandemic had a significant but varying impact on healthcare providers.

Ida J. Korfage is Associate Professor of decision making (including advance care planning) and quality of life, and has expertise considering patient and public involvement in research. She is an economist and epidemiologist by training. She co-chaired the EAPC Task Force on advance care planning and co-chairs the current one on advance care planning and dementia. From 2016-19 she was elected member of the Board of Directors of the International Society of Quality of Life Research (ISOQOL).

Doctors: What do they know? People: What do they think?

A conversation between Roger Phillips, Professor Mark Taubert and Alison Germain-Martin.



Roger Phillips

BBC Broadcaster, UK

Roger Phillips is a renowned broadcaster who presented a daily phone-in programme on BBC Radio Merseyside until his retirement in 2021. His abilities have been recognized on many occasions as the winner of countless awards, including "Sony Speech and Talk Broadcaster of the Year". He has been honoured by the University of Liverpool with an honorary Doctorate of Laws, and Liverpool John Moores University with an honorary Fellowship. He is Visiting Professor in Broadcast Journalism at Liverpool Hope University.



Professor Mark Taubert

Cardiff University, UK

Professor Mark Taubert is a palliative medicine hospital consultant and clinical director at Velindre University NHS Trust. His teaching and research activities at Cardiff University include advance care planning, acute palliative care, technology & new media and DNACPR decision making. He is the founder of TalkCPR.com and has a national lead role to improve public understanding on topics relevant to care in the last years of life and at the extreme ends of medicine. He has delivered a Ted Talk on subtleties in language that are relevant to modern healthcare delivery, and writes for international news outlets like the Washington Post.



Alison Germain-Martin

Liverpool University Hospitals NHS Foundation Trust

Alison Germain-Martin currently works as a Patient Experience & Engagement Manager at Liverpool University Hospitals Foundation Trust. She previously managed the Volunteer Service at the Trust and coordinated the Care for the Dying Volunteer service. Alison worked for over twenty years in Palliative and End of Life Care as a family support lead, providing psychological and emotional support to families and facilitating a bereavement counselling service. She worked with children and families, coproducing a suite of resources to explain the dying phase to children of different developmental ages and opening the first "Garden of Hope" for bereaved children in Liverpool in 2007.

ORAL PRESENTATIONS FROM SUBMITTED ABSTRACTS

Programme

SESSION 1	
13:30	Validation of 'Care Of the Dying Evaluation' (CODE™), a post-bereavement tool, within an international context <i>Dr Catriona Mayland, Sheffield University, UK</i>
13:40	Challenges in providing end of life care: Experiences from health care professionals from ten countries - iLIVE project <i>Hana Kodba Ceh, Klinika Golnik, Slovenia</i>
13:50	The impact of fear of failure on confidence and comfortableness in delivering end-of-life care <i>Johnny Latham, University of Liverpool, UK</i>
14:00	"Sometimes it's sort of left to us": Critical care nurses preparing for withdrawal of life-sustaining treatment <i>Emily Johnson, Liverpool University Hospitals NHS Foundation Trust, UK</i>
14:10	Trends in Essential Medicines Consumption Influencing Massive Global Disparities in Palliative & End-of-Life Care <i>Barbara Hastie, Indiana University, US</i>
14:20	Break
SESSION 2	
14:25	Non-invasive technology to assess hydration status and symptoms in dying people with advanced cancer <i>Dr Amara Nwosu, Lancaster University, UK</i>
14:35	Development of a Virtual End of Life Ward in an acute hospital <i>Trudy Nurse and Paul Fernandez, Bradford Teaching Hospitals NHS Foundation Trust, UK</i>
14:45	iLIVE Cohort Study: Insight and experience of engaging patients at end of life in research <i>Beth Morris, University of Liverpool, UK</i>
14:55	Translation, cultural adaptation and content validation of the Serious Illness Care guide for use in Swedish health care settings <i>Sofia Andersson, Linnaeus University, Sweden</i>
15:05	Virtual palliative and end of life care education - sustainable learning from the pandemic <i>Professor Fiona Rawlinson, Cardiff University, UK</i>
15:15	Tea

Validation of 'Care Of the Dying Evaluation' (CODE™), a post-bereavement tool, within an international context

Author(s): Catriona R Mayland,^{1,2} Anju D Keetharuth,¹ Clara Mukuria,¹ Dagny Faksvåg Haugen³
¹ University of Sheffield, UK; ² University of Liverpool, UK; ³Haukeland University Hospital and University of Bergen, Norway

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Background: Measuring care provided during the dying phase with validated instruments helps provide quality assurance and recognises areas of unmet need.

Aim(s): To assess construct validity and internal consistency of 'Care Of the Dying Evaluation' (CODE™), a post-bereavement tool assessing quality of care in the last days within an international context.

Methods: Post-bereavement survey (August 2017-September 2018) using CODE™; respondents' next-of-kin to adult cancer patients (≥ 18 years old) who had an 'expected' death within study sites (n=22 hospitals) in 7 countries: Argentina, Brazil, Germany, Norway, Poland, UK and Uruguay. Exploratory Factor Analysis (EFA), Confirmatory Factor Analysis (CFA) and internal reliability conducted (Cronbach alpha (α)). Known group validity assessed by ability to discriminate different perceptions in quality of care expected a priori. Hypotheses: perceptions higher in Palliative Care Units (PCUs) and in Poland (most deaths occurred in PCUs within Polish hospitals). Differences were quantified using standardised effect sizes (SES).

Results: 914 CODE™ questionnaires completed (54% response rate). EFA identified 4 factors: 'Overall care', 'Communication and support', 'Trust, respect and dignity', and 'Symptom management' with good reliability scores (α = 0.628 – 0.862). CFA confirmed the 4-factor model; these were highly correlated and a bifactor model showed acceptable fit. The SES for quality of care in PCU's was 0.727; SES for

Poland was 0.657 in keeping with a priori hypotheses of higher quality of care. These findings support the sensitivity of CODETM to detect differences.

Conclusions: Within an international context, CODE™ was a valid, reliable tool for assessing the quality of care provided in the last days of life.

Challenges in providing end-of-life care: Experiences from health care professionals from ten countries - iLIVE project

Author(s): Hana Kodba Čeh¹, Urška Lunder¹, Miša Bakan¹, Elisabeth Romarheim², Vilma A. Tripodoro^{3,4}, Verónica Veloso⁴, Belén Carballo⁴, Silvina Montilla⁴, Sandra Castro⁵, Gabriel Goldraj⁵, Gabriela Florit⁵, Guðlaug Helga Ásgeirsdóttir⁶, Sofia C. Zambrano⁷, Melanie Joshi⁸, Beth Morris⁹, Qiaoling Marilyn Ho⁹, Berivan Yildiz¹⁰, Eva Víbora-Martín¹¹, Birgit H. Rasmussen^{12,13}, & on behalf of the iLIVE consortium

¹University Clinic of Pulmonary and Allergic Diseases Golnik, Slovenia; ²Regional Centre of Excellence for Palliative Care, Western Norway, Haukeland University Hospital, Bergen, Norway; ³Instituto Pallium Latinoamérica, Buenos Aires, Argentina; ⁴Institute of Medical Research A. Lanari, University of Buenos Aires, Argentina; ⁵Private Univesritary Hospital from Córdoba, Argentina; ⁶Landspítali – The National University Hospital of Iceland, Iceland; ⁷University Center for Palliative Care, Department of Oncology, Inselspital, Bern University Hospital, Bern, Switzerland; ⁸University of Cologne, Faculty of Medicine and University Hospital, Department of Palliative Medicine, Germany; ⁹Palliative Care Unit, University of Liverpool, Liverpool, the United Kingdom; ¹⁰Erasmus MC, University Medical Center Rotterdam, The Netherlands; ¹¹CUDECA Institute for Training and Research in Palliative Care, CUDECA Hospice Foundation, Málaga, Spain; ¹²Institute for Palliative Care, Region Skane and Lund University, Sweden; ¹³Department of Health Sciences, Lund University, Sweden.

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Background: In recent decades, increasing attention has been given to the development of end-of-life care around the world. Exploring challenges in providing end-of-life care across countries can help identify priorities for improving care.

Aim(s): To explore health care professionals' experiences of challenges in providing end-of-life care in ten countries.

Methods: Cross-cultural study applying a collaborative thematic analysis of data from semi-structured interviews with 53 health care professionals from Argentina, Germany, Iceland, Netherlands, Norway, Slovenia, Spain, Sweden, Switzerland and United Kingdom.

Results: Challenges in providing high-quality end-of-life care exist even in countries that are considered advanced in end-of-life care provision. Cross-cultural challenges fell broadly into three levels:

System level: coordination challenges across institutions/services due to fragmentation of health care systems, insufficient resources, ineffective handover of patient care, insufficient national strategies or poor implementation.

Health care professional team level: teamwork translates differently in different contexts, i.e. variable extent of communicating and adhering to care plans, hierarchies in clinical practice, inter-professional tensions.

Patient/family/health care professional individual level: i.e. unrealistic patient/family expectations, anxiety or low understanding of their health situation, health care professional's fear of difficult cases (i.e. young patients with children, non-functional families). Challenges on this level are not emphasized in data from all countries.

Conclusions: Challenges fell into three levels: individual-, team- and system-level. Individual level challenges showed the greatest difference in emphasis across countries.

Funded by the EU Horizon 2020 program under grant agreement ID: 825731

The impact of fear of failure on confidence and comfortableness in delivering end of life care

Author(s): John S Latham¹, Stephen Mason², Sarah Butchard¹
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Contact: John.latham@liverpool.ac.uk / john.latham@nhs.net

Background: Only one systematic review has examined the emotions and psychological processes that clinicians experience when providing end-of-life (EOL) care. That review highlighted how emotions of fear, and a sense of personal and professional failure may influence interactions between clinicians and patients.

Few empirical studies have measured the impact of psychological processes on the delivery of EOL care.

- Aim(s):** To investigate whether fear of failure (FOF) influences clinicians' (physicians & nurses) perception of their confidence and comfortableness in delivering EOL care.
- Methods:** We completed a cross-sectional questionnaire study across two large NHS hospital trusts in the UK, and invited participation from national UK professional networks. Participants completed three questionnaires: the Performance Failure Appraisal Inventory, the Self-Efficacy in Palliative Care scale and the Thanatophobia Scale. We used two-step multiple regression for analysis of this data.
- Results:** We recruited 206 clinicians (105 doctors/101 specialist nurses) from 20 hospital specialities. The study validated the use of the PFAI (FOF) measure and its subscales within a novel population (medical professionals). The more EOL conversations a clinician had positively impacted comfortableness and confidence with EOL care. 'Discomfort with death' was significantly associated with male gender and doctors. The FOF subscale 'Fearing loss of interest from important others' was shown to negatively impact a clinician's confidence in communicating. The FOF subscale 'Fear of devaluing one's self-estimate' was shown to negatively impact confidence in decision making, working with others, and a clinician's total self-efficacy.
- Conclusions:** Our study suggests that psychological processes may influence the approach to end-of-life care, which highlights the need for clinicians to be aware of factors which may affect their performance. Further exploration of how psychological strategies to reduce a FOF may positively help clinicians to deliver end of life care more effectively. We make some suggestions of what these strategies could be, drawing from broader FOF literature.

"Sometimes it's sort of left to us": Critical care nurses preparing for withdrawal of life-sustaining treatment

- Author(s):** Emily Johnson & Prof. Barbara Jack
- Contact:** Emilyjanejohnson84@gmail.com
- Background:** Critical-care nurses are regularly required to facilitate the withdrawal of life-sustaining treatments and provide end-of-life care, which in turn can cause moral distress and burn-out. Despite a wealth of research specifically investigating intensive-care unit nurses' experiences of end-of-life care, there remains limited data on high-dependency unit nurses' experiences in managing withdrawal of life-sustaining treatments.
- Aim(s):** Identify the experiences and needs of high-dependency unit nurses when caring for patients approaching withdrawal of life-sustaining treatment.
- Methods:** Digitally recorded individual semi-structured interviews were conducted with 15 qualified nurses within one high dependency unit in Northern England. Qualitative thematic analysis was used. NHS and University Ethical approval were obtained.
- Results:** Participants reported difficulties caused by a conflict in decision making, which they perceived to prolong treatment and suffering for patients who were not expected to survive. Such conflict resulted in moral distress, especially in situations where nurses voiced their concern that the patient was dying, but the decision was made to continue life-saving treatments. Participants identified a need for better education and training regarding how to wean and withdraw life-sustaining treatment, and provide good end-of-life care in this setting.
- Conclusions:** Evidence presented here suggests that HDU nurses need better education in weaning and withdrawal of life-sustaining treatment, and end-of-life care in a critical-care setting. Such may provide improved support and lead to better provide good care. To date, this study has resulted in several local changes to this end, including debriefing sessions for HDU nurses. There is a need for the development of a bespoke education programme.

Trends in essential medicines consumption influencing massive global disparities in palliative and end of life care

- Author(s):** Barbara A. Hastie, Ph.D. and James F. Cleary, MD
- Contact:** bhastie@iu.edu
- Background:** The global pandemic exacerbated the need for Palliative Care (PC) and End-of-Life (EOL) services. Low

and middle-income countries (LMICs) have been at greatest risk with little to no access to essential controlled medicines as integral interventions. UN, WHO and INCB's Joint-Call-to-Action asserted the importance of considering morphine-equivalence (ME) consumption trends as significant indicators for identifying and addressing global inequities in access, availability and PC/EOL care.

- Aim(s):** This study evaluated opioid consumption trends with special examination of the impact on reporting and consumption of essential controlled medicines and PC in pre-, peri- and into post-pandemic years.
- Methods:** Utilizing INCB data, reported annually by every country, ME metrics were calculated and trends analyzed globally and for WHO regions of WHO List of Essential Controlled Medicines for PC (morphine, hydromorphone, fentanyl, oxycodone, pethidine, codeine, excluding methadone). Secondary analyses examined COVID-19's impact on consumption and PC globally and regionally.
- Results:** A consistent rise in global opioid consumption was shown in 1998-2012. For Morphine in 1989-2014, there were slow, steady increases globally and regionally. Since 2014-15, overall levels decreased with further reduction during COVID (2018-20). Globally in 2019-20, morphine increased (despite decreases in EMRO, EURO, SEARO). Current global morphine consumption has returned to 2006 levels. These vagaries reflect INCB-reported challenges with tracking and/or supply chains secondary to COVID-19, non-report ranging 0.5% (morphine) to 58.5% (hydromorphone) and significantly more countries reporting "0" than previous years.
- Conclusions:** COVID-19 worsened global disparities by profoundly disrupting supply chains and governments' ability to report and obtain appropriate quantity of opioids and cancer medications to thwart disease and mitigate suffering. Some LMICs and many high-income countries with robust systems, PC services and cancer plans fared slightly better but COVID's lasting consequences continue. These findings bolster the urgency of the UN-WHO-INCB-Joint-Call-to-Action to address gaping global inequities in PC/EOL care.

Non-invasive technology to assess hydration status and symptoms in dying people with advanced cancer

- Author(s):** Amara Callistus Nwosu ^{1,2,3}, Sarah Stanley ³, Alexandra McDougall ⁴, Catriona R Mayland ^{5,6,7}, Stephen Mason ⁶, Professor John E Ellershaw ^{2,6}
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- Background:** The role of hydration in causing or alleviating suffering in advanced cancer is poorly understood. Bioelectrical impedance analysis (BIA) is an accurate validated method of assessing hydration status. Previous BIA research demonstrates significant relationships with hydration status, symptoms, and survival in advanced cancer. Further work is needed to study these associations in the dying.
- Aim(s):** To evaluate hydration and its relationship with clinical symptoms in dying cancer patients.
- Methods:** We conducted an observational study of patients with advanced cancer in 3 centres (two hospices and a hospital-based specialist palliative care inpatient unit). We used an advance consent methodology to conduct hydration assessments of participants as they entered in the dying phase. We recorded hydration status (via BIA Impedance index: Height – H²/Resistance - R), symptoms, physical signs, and quality-of-life assessments.
- Results:** One hundred and twenty-five people were recruited (males n=74 (59.2%), females, n=51 (40.8%). We repeated assessments in 18 (14.4%) participants when they were dying. Hydration status (H²/R) of the dying patients (n= 18, M= 49.55, SD= 16.00) was not significantly different compared to their baseline hydration assessment (M= 50.96, SD= 12.13; t(17)= 0.636, p = 0.53). Increasing hydration level (increased H²/R) was significantly associated with oedema (r= 0.509, p<0.001). Lower hydration level (reduced H²/R) was associated with patient concern of poorer health (r=-0.19, p=0.034), improved sleep (r=-0.235, p=0.009), poorer appetite (r= -0.273, p=0.002), increased anxiety (r= -0.192, p=0.032), worsening dry mouth (r= -0.242, p=0.007) and sunken eyes (r= -0.333, p<0.001).
- Conclusions:** Hydration status was significantly associated with physical signs and symptoms in advanced disease. No significant difference in hydration status were observable in dying patients compared to baseline.

Bioimpedance analysis was well tolerated and has potential use as a non-invasive tool to evaluate hydration status in the dying.

Development of a Virtual End of Life Ward in an acute hospital

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- Background:** In response to the challenges of caring for patients in their last days of life during the Covid pandemic the Bradford Hospital Palliative Care Team (HPCT) established a Virtual End of Life Ward. The Virtual Ward cares for patients regardless of diagnosis and supports ward staff to care for patients and their families in their last days of life.
- Aim(s):** Increase the number of dying patients who have a face to face assessment undertaken by the HPCT; Improve end of life care including communication with families and symptom management; Support ward staff when providing end of life care including providing a sitting service for patients who are alone.
- Methods:** All patients identified as dying are 'flagged' on the Electronic Patient Record (EPR) and proactively seen by the HPCT. Additional staff including Health Care Assistants were seconded to the Team to support this model.
- Results:** 54% of all patient deaths are seen by the HPCT in comparison to 25% pre Virtual End of Life Ward. Excellent evaluation from patients, family and staff.
- Conclusions:** This more consistent approach to delivering end of life care has improved care for the patient and their family. This has improved results for the National Audit for the Care at End of Life. There has been an increase in referrals to the HPCT which has demonstrated the additional support ward teams are currently requiring. Additional staff allowed the HPCT to focus on patients with complex symptom management needs and supporting clinicians to make difficult end of life decisions.

iLIVE Cohort Study: Insight and experience of engaging patients at end of life in research

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- Background:** The iLIVE study is an innovative observational cohort study being conducted in the palliative care setting to better understand patient and significant others' experiences of death and dying. Reflection on the experiences of researchers working on this novel project highlight key learnings across ethical and practical domains. Adaptations to researcher activity made in line with these learnings facilitated recruitment.
- Aim(s):** Through monthly operational meetings, researchers discussed their experiences to reflect, debrief, and optimise recruitment. Discussions were documented, producing a catalogue of learnings to draw on.
- Methods:** Through monthly operational meetings, researchers discussed their experiences to reflect and debrief, and optimise recruitment. Discussions were documented, producing a catalogue of learnings to draw on.
- Results:** Key learnings included:
- Patient:
The questionnaire was too burdensome for some patients to complete without the help of another person
Completion rate of questionnaires was higher when facilitated by a researcher in person or over the phone, compared to when patients had a preference to complete the questionnaire privately
- Perceptions of research:
Patients valued the opportunity to participate in research, even when in poor health
The perceived importance of research varied amongst health care professionals
Positive and negative gatekeeping by medical professionals and significant others of the patient occurred. At times, negative gatekeeping could be overcome through education around research and the aims of the iLIVE cohort study
- General:
Challenges developing and implementing a work flow at different recruitment sites

Conclusions: The ambitions of the iLIVE project compounded some of the inherent challenges of recruiting patients from a palliative care setting to a research study, but ad hoc adaptations made by researchers resulted in improved recruitment outcomes. Successes within the project reinforce how research in the palliative care settings is feasible, important and acceptable to the target population.

Translation, cultural adaptation and content validation of the Serious Illness Care guide for use in Swedish healthcare settings

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Background: Background: Initiating conversations early with patients and families concerning prognosis, diagnosis, goals and preferences increases participation, reduces anxiety and improves the quality of life. The Serious Illness Care Program was developed at Adriane Labs in Boston and includes a Serious illness care guide.

Aim(s): To translate, culturally adapt and validate the Serious Illness Care Guide for use in the Swedish healthcare settings.

Methods: The English Serious Illness Care Guide (version 4.0) was translated into Swedish, including both forward and backward translation. Then cognitive interviews were conducted at three different times (T1-3); with patients (T1 n=11; T2 n=9; T3 n=7), family members (T1 n=5; T2 n=2; T3 n=3), as well as healthcare professionals (T1 n=4; T2 n=3; T3 n=5). After every step, the research group and facilitators worked together with the SICG until a consensus was reached. The Serious illness Care Guide was then tested at a training day with physicians and nurses which led to some minor adjustments.

Results: The questions in the guide were considered challenging, however the guide was considered to be a good support for physicians and nurses. The explicit questions about prognosis were excluded from the Swedish Serious Illness Care Guide. Instead, questions about 'hope for the best and preparing for the worst' were included to explore patient's thoughts about the future.

Conclusions: The Serious Illness Care Guide needed to be culturally adapted to be used in the Swedish healthcare settings. The participants assessed the translated conversation guide to be useful in Swedish healthcare context.

Virtual palliative and end of life care education – sustainable learning from the pandemic

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Background: The urgent need for palliative care education was highlighted by COVID-19. Face to face teaching moved online during the pandemic. Recognising widening opportunities for future education, we explored the impact of using technology on learning experience of participants of a previously face to face Masters course over 2 years.

Aim(s): To evaluate the impact of technology on learning and comfort with the virtual environment

Methods: Prospective evaluation using a 5-point Likert scale in 2020 and 2021

Results: 13 sessions forming a 3-day programme were evaluated in 2020. 252 responses were received (45% response rate). 223/252 (89%) reported no negative impact on learning due to technology, 18/252 (7%) mentioned technical difficulties but no negative impact, 8 mentioned technical issues with impact on learning, 2 mentioned being uncomfortable with the virtual environment but no impact on learning, 1 person described being uncomfortable with negative impact.

In 2021, 87% had no technology issues. Of the remaining 13%, none were uncomfortable, 9% had no impact on learning, 4% an impact on learning. The issues with technology related to the platform used and video playback during communication skills sessions.

Conclusions: With attention to teaching techniques (delivery style, focused content and use of interaction), neither the technology or virtual learning environment negatively impacted learning for the majority of students. This finding adds support to the continued use of virtual platforms for aspects of palliative care education. This will enable collaboration and widening reach and participation with greater impact on patient care.

POSTER PRESENTATIONS

Palliative Care Emergency Department (ED) In-reach Project

- Author(s):** Emma Dawson, Dr Harriet Preston, and Sarah Roberts
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- Background:** Emergency admissions to hospital increase in the last year of life and can be avoidable. In 2016 there were over 1.6 million such admissions in the UK, at a cost of £2.5 billion. Early palliative care involvement can reduce length of stay.
- Aim(s):** Provide daily in-reach into ED at the local teaching hospital to reduce unnecessary admissions, provide responsive and timely palliative care support, and increase the number of patients achieving their preferred place.
- Methods:** Introduction of a dedicated bleep as main point of contact for ED for support during normal working hours & days a week. Daily visits and liaison with nurse in charge to identify suitable patient and promote service. Data collected including evidence of any advance care planning prior to admission.
- Results:** 1st Feb 2021 – 31st Jan 2022. 69 patients were supported. 19 (28%) were discharged back to their place of residence or the local hospice, avoiding admission and reducing length of stay by on average a day, saving 78 bed days. 38 (55%) did not have a completed EPaCCS in place prior to admission. 10 (14.5%) died the same day.
- Conclusions:** A larger number of patients have been seen than anticipated, reflecting current pressures on local health care systems.
A significant proportion of patients attending without a DNACPR or EPaCCS highlights the need for further work to promote anticipatory advance care planning.
Early palliative care in-reach into ED can prevent unnecessary admissions for patients in their last year of life as well as providing support and education to staff.

Dying in times of COVID-19: Experiences in different care settings – An online questionnaire study among bereaved relatives (the CO-LIVE study)

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- Background:** The COVID-19 pandemic and restricting measures have affected end-of-life care across different settings.
- Aim(s):** To compare experiences of bereaved relatives with end-of-life care for a family member or friend who died at home, in a hospital, nursing home or hospice during the pandemic.
- Methods:** An open observational online survey was developed and disseminated via social media and public fora (March–July 2020).
Data were analyzed using descriptive statistics and logistic regression analyses. Individuals who lost a family member or friend in the Netherlands during the COVID-19 pandemic.
- Results:** The questionnaire was filled out by 393 bereaved relatives who lost a family member or friend at home ($n = 68$), in a hospital ($n = 114$), nursing home ($n = 176$) or hospice ($n = 35$). Bereaved relatives of patients who died in a hospital most often evaluated medical care (79%) as sufficient, whereas medical care (55%) was least often evaluated as sufficient in nursing homes. Emotional support for relatives was most often evaluated as sufficient at home (68%) and least often in nursing homes (40%). Sufficient emotional support for relatives was associated with a higher likelihood to rate the place of death as appropriate. Bereaved relatives of patients who died at a place other than home and whose care was restricted due to COVID-19 were less likely to evaluate the place of death as appropriate.
- Conclusions:** End-of-life care during the COVID-19 pandemic was evaluated least favourably in nursing homes. The

quality of emotional support for relatives and whether care was restricted or not were important for assessing the place of death as appropriate.

Volunteer companionship: developing theory on what works, for whom, in what circumstances and why?

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- Background:** Volunteers are a popular provision in palliative care. The role is diverse and despite widespread recognition the literature has not been able to thoroughly explain how volunteers impact beneficiaries. Innovative methods to understand what works, for whom, in what circumstances and why are needed.
- Aim(s):** The aim of the research was to undertake the first phase of a realist evaluation to develop explanatory, and context specific, ideas about how volunteer support impacts beneficiaries.
- Methods:** The first phase of the realist evaluation included participant observation, interviews, and document analysis.
- Results:** Four distinct programme theory areas are proposed. The areas include being there, being the middleman, being a loving friend, and offering support for the journey. Volunteering is envisaged to influence a range of outcomes through the mechanisms of identity, social connection, beliefs, capabilities, and hope.
- Conclusions:** The findings are the first to articulate the necessary elements, and benefits realisation of, volunteering in palliative care. These results outline emerging theories about the conditions, resources, and explanations of the impact companionship can have. These results provide weight and direction for future work in this area.

Caregiver views about artificial hydration use in dying people with advanced cancer: a questionnaire study

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- Background:** Evidence for the use of artificial hydration (AH) in people dying with cancer is inconclusive, which creates challenges for healthcare professionals. These situations can be distressing for family caregivers, who may have unmet information needs. Better understanding of caregiver perspectives about AH in the dying, can potentially help healthcare professionals to identify information needs to improve support for caregivers.
- Aim(s):** To examine caregivers' beliefs, experiences and information needs about AH use in people dying with advanced cancer.
- Methods:** Questionnaire study of caregivers for people with advanced cancer, who were participants in a research study which was evaluating hydration status, and its association with symptoms, in advanced cancer. Caregivers were recruited from three UK study sites, consisting of two hospices and one hospital palliative care inpatient unit.
- Results:** Fifty-two caregivers participated. Most participants were female (N=38, 73.1%) and aged between 50-59 (N=12, 23.1%) and 60-69 (N=13, 25%). Most participants (N=33, 63.5%) said they were not aware of the term 'artificial hydration'. Most (N=35, 67.3%) believed that AH represented good care for the patient, with the majority stating that AH improved thirst (N=33, 63.5%) and dry mouth (N=30, 57.7%). Most participants did not believe AH affected prognosis, with 11 (21.2%) stating that AH prolonged life and 8 (15.4%) indicated that prognosis would be shorter without AH. Most expected AH to be available for patients in hospitals (N=42, 80.8%), hospice (N=43, 82.7%), nursing home (N=37, 71.2%) and home (N=31, 59.6%) settings. Most participants believed patients had the right to demand (N=39, 75%) or refuse (N=48, 92.3%) AH in the dying phase.
- Conclusions:** Our study provides information about caregivers' views and expectations of the use of AH in dying cancer patients. Further work should explore how healthcare professionals can better identify and address unmet information needs of caregivers, concerning the use of AH in the dying.

Developing a process to support the wellbeing of children facing the death of a parent.

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Background:	<p>It is estimated that 1/29 children in the UK will experience parental death. Without support, there are profound long-term implications for the child's wellbeing.</p> <p>Our experience as a Hospital Specialist Palliative Care Team (in an acute adult hospital in the Northwest of England) was that children of parents with life-limiting illness were commonly not involved in important conversations about the healthcare needs of their parents, including the dying phase.</p> <p>Improving systems to proactively support bereaved children can improve their long-term wellbeing.</p>
Aim(s):	To develop process with the Paediatric Liaison Service (PLS) to improve support for children with ill parents.
Methods:	<p>We conducted a literature review and several meetings with senior nurses and the safeguarding team to agree the role of PLS, identify referral criteria and clarify legal frameworks.</p> <p>We met with managers of a local charity focussing on the needs of young carers.</p> <p>We developed and implemented of a hospital-wide digital referral form, to enable staff to refer children and families to the PLS.</p> <p>We developed on the process for PLS to notify school nurses of pupils who required support.</p> <p>We conducted staff education sessions to promote the service and gather feedback.</p>
Results:	<p>Our digital referral form is now operational, and we are improving this continually based on feedback.</p> <p>We received 8 referrals to PLS in the first 3 months of launching the service. We have received positive feedback from school nurses who are grateful to be informed about pupils who are bereaved, as this helps them to provide support.</p>
Conclusions:	Our new PLS has streamlined the referral process, which has improved collaborative support we can provide to bereaved children. We plan further evaluation to explore how we can better integrate with other voluntary and community settings (e.g., hospice, charities, school health professionals).

Advancing Palliative Care Education in Eastern Europe and Central Asia: Regional consultation

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Background:	The Foundation for Palliative Care Education (PACED) works in Eastern Europe and Central Asia (EECA) to support the development of palliative care through a focus on professional education. COVID-19 has widened technology opportunities for facilitating/supporting education for practitioners delivering palliative care and those teaching these skills.
Aim(s):	A consultation aimed to identify priorities for palliative care education in the region.
Methods:	<p>Two 35-minute discussions were held using Zoom™ in English and simultaneous Russian translation. They focused on: 1) support for palliative care practitioners 2) support for palliative care educators. 2 facilitators supported each session – one from within EECA, one from the West. Participants responded to 3 questions in each session and contributed by adding written information using 'chat' and speaking. All contributions were recorded and data analysed by 2 people for themes.</p>
Results:	<p>54 people attended from 14 countries, (practitioners, educators, NGOs and government representatives). 3 main themes emerged from both workshops:</p> <ul style="list-style-type: none">• The education and training needs of different groups of practitioners• Challenges in providing palliative care education and training in the context of diverse resource availability• Different methods of providing education and training <p>The meeting identified priorities for action and demonstrated participants' interest in strengthening collaboration between countries in the region to advance palliative care education.</p>
Conclusions:	Using a virtual platform enabled participation and presented PACED with priorities for future work. The collaborative nature of facilitating education was highlighted and plans for provision of face-to-face sessions, online learning and on line resources are underway to continue to support palliative care delivery in EECA.

A retrospective review of palliative sedation in advanced cancer patients in a palliative care unit

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- Background:** Palliative sedation is a treatment for refractory symptoms in imminently dying patients by lowering their consciousness. There are limited studies regarding the local practice.
- Aim(s):** The objectives are 1. to describe the administration of palliative sedation in patients admitted to a local palliative care unit (PCU); 2. to investigate factors associated with higher dose of midazolam (midazolam maximum daily infusion and as needed doses higher than 15mg given intravenously or subcutaneously) used for sedation.
- Methods:** This was a retrospective descriptive study including patients with advanced malignancy receiving palliative sedation in PCU of Caritas Medical Centre over 5 years. Midazolam used merely for seizure control or unintended for reduction in consciousness were excluded. Demographic data, clinical characteristics and details of palliative sedation were retrieved. Factors associated with the dose range of midazolam were studied.
- Results:** 81 patients received palliative sedation during study period, with prevalence of 4.1%. The most common refractory symptom for palliative sedation was dyspnoea, followed by delirium and pain. Nearly two-thirds of patients had more than one refractory symptoms warranted palliative sedation. The median duration of palliative sedation was 45.6 hours. Longer time from discussion to start of sedation, patients' involvement of discussion, longer duration of palliative sedation, higher dose of strong opioids used were factors significantly associated with use of higher dose midazolam.
- Conclusions:** Two-thirds of patients had multiple symptoms warranted palliative sedation, while dyspnoea was the most common symptom. The dose of maximum daily midazolam was associated with multiple factors such as the dose of concomitant opioids, duration of sedation.

EXPERIMENTAL CASE Implementation of a volunteer program through new technologies to palliative patient: Pilot study.

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- Background:** Essential volunteers accompanying palliative patients and their family. New technologies (NTs) have become an important tool for social support during the pandemic.
- Aim(s):** Detect needs and positive aspects of a volunteer's accompaniment to a palliative patient through NTs
- Methods:** Volunteer with 7 years of experience in a Hospitalization Unit in palliative care to palliative patient 75 years old. Criteria of loneliness, poor social network, communicative and prolonged prognosis. Both agreed two weekly telephone contacts from the volunteer to the patient. After each, the volunteer would record: date and duration of the call, topics addressed and needs detected in the patient. Social worker (SC) and medical team evaluated patient's satisfaction with the volunteer in their contacts. Weekly telephone contacts established with the volunteer to track her performance and monthly virtual organizational meetings to make an assessment. Accompaniment from December 2020 to February 2021.
- Results:** 34 scheduled contacts made from the volunteer to the patient. Average duration 45 minutes. Main topics addressed: general as politics, religion, current news and life story. 13 unscheduled contacts also established from the patient to the volunteer; In these cases, topics addressed were health. The social worker and the medical team have twice contacted the volunteer about patient's health. Volunteer Department maintained 18 follow-up contacts with her and 9 follow-up meetings with the social worker.
- Conclusions:** Observed service useful and need to design protocols adjusted to the situation of voluntary digital accompaniment. NTs favor creation of affective links and mutual assistance by overcoming mobility constraints and social distancing motivated by pandemic.

Bright and dark sides of providing end-of-life care: Health care professionals' experiences in iLIVE project

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Background: Health care professionals (HCPs) providing end-of-life care (EoLC) deal with a variety of emotions at their work. Previous research on psychological impact has tended to focus at either personal growth or compassion fatigue, and to a lesser extent on the experience as a whole.

Aim(s): To explore the psychological impact of delivering EoLC on the personal and professional lives.

Methods: We thematically analysed data from interviews with 53 HCPs from Argentina, Germany, Iceland, Netherlands, Norway, Slovenia, Spain, Sweden, Switzerland and United Kingdom. Following analyses per country, we identified cross-cultural themes.

Results: Identified themes:

- Enhancing existential thinking and developing a new perspective on oneself and others;
- Struggling with difficult existential emotions;
- Transferring prosocial behaviours;
- Feeling satisfaction over doing something meaningful;
- Being humble in front of a difficult reality.

EoLC provision leads HCPs to enhanced sense of mortality, which helps them be “fully immersed in the present” and to “strive for a meaningful life”. Simultaneously, providing EoLC can lead to emotional exhaustion and a sense of alienation in relation to everyday issues, making them “trivial”. Furthermore, some HCPs experienced a “dark inner world”, sadness and temper issues as a consequence of their work. On the other side, prosocial behaviors gained through EoLC practice, such as improved communication, are often transferred to other interpersonal situations. Participants felt satisfaction and humbleness from performing meaningful yet uncertain and difficult tasks.

Conclusions: The bright and dark sides of EoLC provision refer to simultaneously rewarding and challenging aspects of everyday confrontation with death, which clearly manifest in HCPs' everyday lives.

A two-week student-selected component in palliative medicine for undergraduate medical students: design and outcomes

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Background: Medical School at the University of Bergen includes student-selected components (SSC) in clinical subjects.

Aim(s): We wanted to offer a SSC in palliative medicine and systematically assess the learning outcomes.

Methods: Systematic literature review in PubMed of courses/rotations in palliative medicine. Design of a course program using Blended Learning. Assessment of learning outcomes by multiple-choice questionnaire (MCQ), Thanatophobia Scale (TS) and Self-efficacy in Palliative Care (SEPC) Scale.

Results: Based on review findings we developed a two-week interactive SSC with the following topics: Principles of palliative medicine, pain and symptom management, psychosocial and spiritual/existential challenges, ethics, communication, and care of the dying. Four days are clinical placements, on hospital wards or with specialist palliative care services. Students present a patient case to the group and hand in two written assignments and a reflection paper.

Since 2018, we have run the SSC four times for altogether 48 students from study year 5 or 6 (from 2021 only year 6). The students' course evaluations have been very good. Test results have improved from pre-course to post-course assessments for all groups: Mean change for MCQ score 22% (range 13-33); TS score 28% (24-32); and SEPC score 50% (42-64), implying increased confidence in caring for seriously ill and dying patients and their close ones. The reflection papers show that clinical placements and communication sessions with role-plays are central to achieving the learning outcomes.

Conclusions: A two-week SSC in palliative medicine improves knowledge and skills and increases the confidence in providing palliative care.

The Impact of COVID-19 Pandemic delivering End-of-Life Communications from Clinicians Perspectives: Thematic Analysis

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Background: In early 2020, a national lockdown was implemented to prevent the spread of the COVID-19 virus. The pandemic brought emotional and physical challenges to doctors and nurses who continued to discuss end of life prognosis. As part of a wider study exploring fear of failure in delivering end of life care, we report on clinicians' experiences of end of life communication during the COVID-19 pandemic.

Aim(s): To explore the challenges of end-of-life communications during the COVID-19 pandemic, and examine its impact on doctors and nurses in hospital trusts in the North West and North East of England.

Methods: Participants were invited to respond to an online anonymous survey with a 'free-text response' asking about their experiences of communicating end-of-life prognosis during the COVID-19 pandemic. Participants were invited from NHS Trusts in the North West and North East England and the national network. 104 doctors and 101 specialist nurses responded to the questionnaire. Free-text response data was examined using Thematic Analysis.

Results: Six broad themes were generated describing the notable challenges clinicians encountered during the COVID-19 pandemic. Themes reflected the uncertainties of COVID-19, unfamiliar roles and responsibilities, barriers to in-hospital regulations, the difficulty of remote end-of-life conversations, increased exposure to death and the emotional impact the pandemic on frontline staff.

Conclusions: The themes reflect clinicians struggling to cope with the negative emotional impact and the barriers to end-of-life communication. Gaining insight into healthcare workers' experiences may lead to improvements in access to support for clinical practice and enable trust policy development for current and future pandemics.

How can technology be used to support communication in palliative care beyond the COVID-19 pandemic?

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Background: Developments in digital health have the potential to transform the delivery of health and social care by creating new opportunities for healthcare professionals to deliver care. During the COVID19 pandemic, palliative care services have used technology to support communication with staff, patients and caregivers. There is limited data on staff perspectives of using digital health for communication during the pandemic, limiting our ability to learn technology can be used to support palliative care communication beyond the pandemic.

Aim(s): To describe how UK based palliative care professionals used technology to support communication during the COVID-19 pandemic.

Methods: We developed an electronic questionnaire for UK based palliative care healthcare professionals, to identify how they have used digital health to support communication during the COVID19 pandemic. We circulated the questionnaire through professional networks and through social media. The questions

involved: (1) communication within the multidisciplinary team (MDT), (2) education and (3) to support communication with patients and carers. We used thematic analysis to analyse free text responses and identify themes.

Results: Two hundred and thirty-four palliative care professionals participated. Most (n= 227, 97%) had increased their use of technology, to support communication, since the pandemic started. We describe benefits and challenges for digital health communication and have identified factors which can support meaningful adoption of technology in palliative care practice.

Conclusions: We have identified facilitators and barriers for future practice. We believe that should work should identify support to enable organisations to implement the models of care needed to improve access and quality of palliative care services.

Change of urinary extracellular vesicles proteins in the days before dying

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Background: Currently, there is uncertainty in consistently and accurately identifying the dying phase. Therefore, biomarkers are needed that can provide insight in the physiology of dying and assist clinicians in recognising imminent death. Urine raised great interest in this aspect, since it can be collected non-invasively. Within urine, extracellular vesicles (EVs) are present that contain a diversity of molecules, including proteins. The content of (urinary)-EVs has already demonstrated significant biomarker value for different diseases.

Aim(s): To perform a pilot study to identify changes in proteins within urinary EVs to potentially mark the dying phase.

Methods: Urine was collected daily from patients admitted in a hospice, after signed informed consent. Urine samples 11-0 days before dying were selected and EVs isolated using the ME-kit. Protein profiles were measured (n=8 patients, total n=35 samples), using LC-MS/MS-based proteomics. Statistical analyses were performed using Limma, Rho-correlation, and differential proteins were annotated for biological processes using Gene Ontology and String-network. Approval was obtained from the ethical committee.

Results: We identified >2000 proteins within urinary EVs, which was heterogenous amongst different patients. In total, 118 proteins were increased up to 4 days before dying. It seems that the highest protein-changes occur 1 day before dying. Most of these 118 proteins were highly connected and involved in water homeostasis or (stress)-hormonal signalling.

Conclusions: These results suggest that the urinary EV protein spectrum changes shortly before dying. Whether these changes are related to the dying phase needs further exploration in a larger patient cohort.

Palliative Virtual Ward (PVW)

Author(s): Dr Esraa Sulaivany, Mrs Sara-Marie Black and Mrs Tracy Griffin

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Background: The Warrington Integrated Palliative Care Hub (WIPCH) launched in March 2020 and became an integral part of service delivery. Service review indicated the next phase would be to develop Palliative Virtual Ward (PVW) offering additional support to palliative patients and preventing hospital admission. NHSE/I bid was submitted to develop a 10 bedded PVW offering support through a 14-day plan of care.

Aim(s): To be able to provide hospice level care for palliative patient in their home
This proposal achieves against NHSE/I service priorities and is consistent with the national @home model at level 4 and Cheshire & Merseyside's strategic intent.

- Methods:** Multiple levels of monitoring are deployed dependent on patient need, with a variety of access points and escalation managed via a single digital platform. Evaluation will combine quantitative and qualitative data aligned to the Better Care impacts to improve experience, resource utilisation and outcomes. The data will include patient experience, demographics, and processes.
- Results:** PVW was launched on 25th April 2022. The pilot operating model clearly defines criteria for admission, discharge and plans of care to support patient flow. The development of the PVW will provide opportunity to deliver on 5 of the 6 Ambitions of PEOLC 2021-2026 and will be integral part of the strategy for Warrington 2022-2026.
- Conclusions:** The 12-month pilot will provide the blueprint for development of a standardised operating model for further virtual wards across Warrington. This prototype model will inform the development of virtual wards in line with the national ambition for Integrated Care Systems to work towards the comprehensive development of 40 to 50 virtual ward 'beds' per 100,000 population by year end 2023.

Communication at the end-of-life and bereavement settings: a review of interpreting services in Spain

- Author(s):** Elena Pérez Estevan
- Contact:** elena.perezestevan@ua.es
- Background:** Language barriers have a direct impact on communicating with limited Spanish proficiency (LSP) patients and their families in end-of-life situations and with LSP mourners in Spain including access to psychotherapy services and quality care of palliative services offered.
- Aim(s):** To describe the situation of professional interpreting services and to determine their possible improvements on the delivery of palliative care services and bereavement support to LSP patients, families and mourners.
- Methods:** We conducted 71 interviews with healthcare professionals working in palliative and bereavement settings and 35 interviews with LSP patients. Surveys to healthcare professionals, students, patients were also distributed to analyse their perspectives on interpreting services. A comparative study among using professional interpreters and the absence of them was performed.
- Results:** The studies found that the use of professional interpreters can increase the quality of care provided to LSP patients, families and mourners. When interpreters were not used, LSP patients, families and mourners had an inadequate understanding of the palliative care visits and, in some cases, it enabled mourners to access to bereavement support sessions.
- Conclusions:** Professional interpreters can influence the quality of end-of-life care and bereavement support goals but specialized training should be required and support from healthcare institutions is needed to professionalise interpreting services in these settings.

Treating Hyperkalaemia: A pragmatic approach for hospice patients using novel potassium binders

- Author(s):** Dr Kate Campbell (Specialty Doctor, Palliative Medicine) & Dr Saeed Rahman (Consultant Renal Physician)
- Contact:** katec@willowbrookhospice.org.uk
- Background:** Hyperkalaemia is a potentially life-threatening emergency which can be corrected with treatment. Many hospices still treat hyperkalaemia in their patients with salbutamol nebulisers, intravenous (IV) calcium gluconate and calcium resonium. Recent 2020 guidance from the Renal Association shows that IV calcium gluconate and salbutamol nebulisers are only recommended in a monitored hospital environment, leaving only calcium resonium as a potential hospice treatment. For some patients in a hospice, transfer out to a hospital is not appropriate or desirable. For those patients in whom transfer to hospital is not appropriate, and yet would benefit from treatment of their hyperkalaemia, consideration should be given to using newer potassium binders, rather than using calcium resonium.
- Aim(s):** To ensure current hospice guidelines for the treatment of hyperkalaemia are up to date.
- Methods:** Literature Search and discussions with local hospices
- Results:** Newer potassium binders such as Patiromer and Sodium Zirconium Cyclosilicate (SZC) have been approved by NICE, and cheaper than calcium resonium for the emergency treatment of hyperkalaemia. They are highly effective at lowering potassium. They also have a less burdensome dosing regimen than calcium resonium. The Renal Association guidance does recommend use of the newer potassium

binders for the outpatient/community setting for certain patients.

Conclusions: Our updated hospice guidance leans heavily on the Renal Association guidance. For the small cohort of patients, in whom transfer out of the hospice would not be appropriate, yet who would benefit from treatment, we will consider using these novel potassium binders in preference to calcium resonium to improve their quality of life.

Japanese Version of the 'Care Of the Dying Evaluation' for Bereaved Families: Cognitive Interview

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Background: There has been a remarkable increase in the mortality rate in Japan due to the aging members of the society. Thus, maintaining the quality of care for patients nearing the end of life is a major concern. Evaluation using an appropriate scale to measure the quality of patients at the end of life is important to ensure the care received by patients and their families. The 'Care Of the Dying Evaluation' (CODE™) has been translated into five languages and standardized across seven countries. However, the Japanese version of CODE™ has not yet been validated.

Aim(s): The study aimed to conduct a pilot study for the validation of the Japanese version of CODE™.

Methods: The translation process was followed as per the European Organization for Research and Treatment of Cancer guidelines. Cognitive interviews will be conducted using the face-to-face "think-aloud" method with Japanese bereaved families.

Results: After the completion of the cognitive interviews of at least 15 bereaved families, the data will be analyzed and presented at the conference.

Conclusions: The Japanese version of CODE™ will be a useful tool to evaluate the quality of care for Japanese patients at the end of their lives. After the cognitive interviews, a subsequent validation study will be conducted. Further research is needed to compare the Japanese CODE™ data with the CODE™ used in other countries to determine its strengths and identify improvements needed in the care for Japanese patients.

From OPCARE9 to the iLIVE Volunteer Study: A story of International Collaboration and Research.

Author(s): Tamsin McGlinchey, Stephen Mason, Ruthmarijke Smeding, John Ellershaw, on behalf of the iLIVE Consortium

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Background: Across Europe hospital palliative and end-of-life-care volunteer services (EOLC-VS) are relatively uncommon, particularly for patients in the last weeks of life. The iLIVE Volunteer Study will evaluate the use of hospital EOLC-VS's across 5 countries.

Aim(s): Describe the development of the iLIVE Volunteer Study, through a rigorous process of international collaboration and research generated from two innovative projects.

Methods:

- 2008 – 2011: OPCARE9 Work Package 5: Voluntary Service
Funded by the EU FP7 Coordination & Support Action grant, OPCARE9 systematically investigated current practice and evaluated the evidence base for Volunteering in EOLC across different healthcare environments and diverse cultures. Two specific methods were used:
 - Systematic Review of the literature
 - Delphi study on the role of volunteers
- 2012 – 2014: Development of a hospital EOLC-VS in one UK hospital
Funded by the Dimpleby Marie Curie Research Fund, a hospital EOLC-VS was developed and implemented. A qualitative interview study explored perceptions of the service with:
 - Relatives/friends
 - Healthcare professionals
 - volunteers

Results: Findings and recommendations from OPCARE9 supported the development and implementation of a UK hospital EOLC-VS. The subsequent qualitative evaluation led to further improvements to the UK

service, and a recommendation to explore the transferability of hospital EOLC-VS's across other cultures and contexts. The international Collaborative for Best Care for the Dying Person, formed following OPCARE9, developed the research protocol for the iLIVE Volunteer Study.

Conclusions: Knowledge and understanding from OPCARE9 and the UK EOLC-VS paved the way for the development of the iLIVE Volunteer Study, facilitating the development of hospital EOLC-VC's across 5 countries

Weighted blankets in palliative care

Author(s): Ida Malmström, physiotherapist; Sarah Jönsson, occupational therapist

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Background: Today, sleeping difficulties are common and one third of the Swedish population regularly experience sleeping difficulties. Persons with palliative care needs have reported an even higher degree of insomnia. Weighted blankets can give the feeling of safety, relaxation and comfort and have so far not shown any side effects. However, their use in palliative care has not been investigated.

Aim(s): To investigate if weighted blankets is an effective method for treating insomnia in persons in palliative care.

Methods: The study was conducted during ten weeks at a palliative care unit in Sweden, where patients after informed consent, were given the opportunity to try a weighted blanket (chain type, 4 or 6 kg). Data was collected with a survey of sleep habits and patients' experiences of the weighted blankets.

Results: Eleven patients participated in the study (F 10/ M 1, age 55-90). Four of the patients were very satisfied with the blanket and used it from the beginning of the study until they died (18-45 days). Four patients did not appreciate the weighted blanket felt this immediately and stopped using it. The night staff expressed that the weighted blankets were heavy and unwieldy but beneficial for the participants.

Conclusions: If the weighted blanket was appreciated by the patient, it was used for a long time. If the weighted blanket was not appreciated by the patient, this was immediately apparent. The study aroused interest and awareness among the staff. The positive result in this study needs to be confirmed in larger studies.

Visiting restrictions during the COVID-19 pandemic and bereaved relatives' quality of life

Author(s): Madison Gulbin, Ida J. Korfage, Mirte van der Ham, Dagny Faksvåg Hauge, Katrin Sigurdardottir, Catriona R Mayland, Stephen R Mason, Vilma Adriana Tripodoro, Verónica Veloso, Marta Ximena León, Angela Acero, Pedro Pérez-Cruz, Sebastián Soto, Esther Angélica Luiz Ferreira, Estela Corrazo, José Mario López Saca, Marco Rodríguez, Agnes van der Heide

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Background: In 2020 SARS-COV-2 presented a challenge for healthcare systems. Visiting for family members was restricted to reduce viral transmission. This may have presented additional challenges for relatives.

Aim(s): To better understand the associations between visiting restrictions and relatives' quality of life.

Methods: An online survey for bereaved relatives was created and distributed in 10 countries in April 2020: the Netherlands, the UK, Norway, Sweden, and Czech Republic, Brazil, Argentina, Colombia, El Salvador, and Chile. Questions measured respondents' quality of life on a scale from 1-7 (EORTC QLQ-C30 item) and visiting restrictions. Analyses were conducted using descriptive statistics and regression analysis. The results were then pooled in a multilevel analysis in Cochrane Review Manager.

Results: From the 2,359 participants, 75.9% were female (mean age 54), and over half reported on the death of their parent (57.5%). The average quality of life rating was above 4 in every country. Overall, the multilevel analysis showed no association between quality of life and visiting restrictions (OR 1.02 95% CI 0.82-1.27, p=0.86; I²= 32%).

Conclusions: There was an overall absence of effect. This could be because different countries responded differently to the pandemic which had some positive and negative effects leading to a neutral association with quality of life. Relatives may have felt the restrictions were protective even though not being able to see their beloved ones was difficult, they were able to see it was for the benefit of all.

Familialism in palliative care. A view from healthcare providers in Spain and Argentina.

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Contact: In Spain and Argentina, the family is an essential support for patients facing end of life, participating in communication, decision-making, managing health resources and providing emotional support. However, family care is unpaid, unequally distributed, overburdened and has different actors responsible for its provision. Healthcare providers generally support family care strategies by reinforcing cultural mandates.

Background: In Spain and Argentina, the family is an essential support for patients facing end of life, participating in communication, decision-making, managing health resources and providing emotional support. However, family care is unpaid, unequally distributed, overburdened and has different actors responsible for its provision. Healthcare providers generally support family care strategies by reinforcing cultural mandates.

Aim(s): We explored socio-cultural aspects of family involvement in caring for people with palliative needs through the experiences of professionals who assist them.

Methods: This qualitative and collaborative study is part of the iLIVE project. For this presentation, we worked with Spain and Argentina as countries with Latin cultural similarities. In addition, a thematic analysis of semi-structured interviews with healthcare professionals who assist patients with palliative needs was carried out. The focus was on category of Familism, understood as solid identification with family, with close-knit family relationships characterized by obligation, emotional support and consideration in making important decisions.

Results: Eleven interviews were conducted with professionals, six doctors, four nurses and one social worker who works in hospice, hospitals and home-based care. The most relevant themes concerning the category of Familism were:

Family as a primary care resource; Support in decision making/Communication; Caregiver overload; Cultural mandate care/protection-denial/hiding.

Conclusions: The experiences from Spain and Argentina showed similarities in cultural context and families' involvement as main caregivers of people with palliative needs. However, the cultural diversity of the communities participating in the iLIVE project could be made more visible by investigating the narratives of patients, families and professionals.

Timely palliative care interface for terminally ill patients in intensive care units and availing concession.

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Background: The Indian Association of Palliative Care became a member of the international collaborative for best care for the dying person and 'Project India' was initiated in 2016. The integrated guidance and care plan for the dying (GCP-D) document of project India was then continued in Baptist Hospital. A 6-month experience of this palliative care interface through the Integrated Care Plan in the Intensive Care Units at three different periods is presented.

Aim(s): To improve end-of-life care for terminally ill patients admitted to ICU by applying the Integrated 'Guidance and Care Plan for the Dying Person'.

Methods: Terminally, ill patients admitted to ICU with an acute crisis and not improving by one week are referred

for Palliative care and the integrated care plan is begun. Joint patient reviews and counselling with the family were done. Patients were then transferred to the ward or discharged home as appropriate. Data of dying patients who availed concession, were collated, and analysed over 6 months periods, pre, immediately post, and one year, after start of integrated care plan.

Results: The average length of stay was significantly reduced, also resulting in reduced bill amount for the patient, better turnover of patients and appropriate utilisation of ICU beds. The revenue for hospital also increased significantly.

Conclusions: The average length of stay was significantly reduced, also resulting in reduced bill amount for the patient, better turnover of patients and appropriate utilisation of ICU beds. The revenue for hospital also increased significantly.

Palliative Care in Mexico: Review and Needs Assessment

Author(s): Carlos Valencia Ortiz, Stephen Mason

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Background: Mexico is one of the largest countries in the world and home to a rapidly aging population. Healthcare policy is changing, but delivery of palliative care services is still falling short to provide people with adequate care.

Aim(s): *A Scoping Review to identify and understand:* the current state of Palliative Care services in Mexico; the limitations and obstacles the healthcare system faces in providing people with better access to palliative care services.

Methods: Through a comprehensive search of databases (PUBMED, MEDLINE, COCHRANE) the scoping review will be conducted using the principles outlined by Arksey and O'Malley and the Joanna Briggs Institute (JBI) methodological guidance, and reported using PRISMA-ScR conventions. Both English and Spanish literature will be included.

Results: The results will be presented through an analysis that will include healthcare policy, recent reforms, Palliative Care services delivery, needs, and medical education. The EAPC Health indicators for Monitoring Palliative Care development will be used as reference.

Conclusions: The ever-growing need for palliative care has become more evident. Despite reforms seeking to facilitate access to palliative care services, countries with underdeveloped palliative care services are struggling to provide adequate care. A structured review may signpost areas for future development in an attempt to improve services and provide better care for the people of Mexico.

Complexity, not multimorbidity or prognosis, is key in allocating care to a specialized response team.

Author(s): Carneiro, Rui; Simões, Catarina; Carneiro, António

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Background: Complexity is the by-product of a pluripathological situation with the psycho-social vulnerability and health resource utilization pattern. Multimorbidity means the presence of two or more diseases. These terms are often (and wrongly) used interchangeably.

Aim(s): We seek to evaluate the presence of multimorbidity and the presence of high complex palliative care needs in Internal Medicine Department (IMD, ward and ICU). We also seek to calculate the penetration rate of PCT among complex and/ or poor prognosis patients admitted to IMD.

Methods: Our 100-bed hospital has a Palliative Care Team (PCT) embedded in the Internal Medicine Department (IMD – covering emergency, ICU and ward). An IMD doctor with PC competence works alongside with a specialized nurse, with the support from a psychologist and nutrition professional, seeing primarily patients from the IMD but also consults other specialities and have an outpatient clinic. Analytical cross sectional study conducted in the IMD of a private Portuguese hospital. Sample: 400 patients; average age 76 (35-101). A data collection tool was used: Charlson Comorbidity Index (CCI), Goldstandards Framework (GSF), Prognostic Indicator Guidance (2nd edition) and Diagnostic Instrument of Complexity in Palliative Care (ICD-Pal).

Results: Almost half the patients admitted had CCI above 4 (meaning high comorbidity and a 21% 10-year chance of survival) and nearly 40% had complex/high complex palliative care needs, according to IDC-Pal. The numbers were seen both in the ICU as in the ward. 20% of patients with low CCI were, in fact,

complex/highly complex, whereas three quarters of people with high CCI were non-complex situations. About 15% of all IMD patients were comanaged with PCT. Nearly one third of limited prognosis patients and two thirds of complex/ highly complex patients were followed by the PCT. All patients receiving input from the PCT were in end-of-life scenario and almost 90% had complex/ high complex palliative needs.

Conclusions: (1) When selecting patients to specialized intervention, multimorbidity should not be a sole trigger. Multimorbidity and complexity are two distinct clinical entities. The penetration rate of the PCT was 71% for complex or high complex patients.(2) Amongst the end of life patients, the PCT penetration rate was of 35%. These numbers are higher than those seen in literature, demonstrating the good level of integration of a PCT in the IMD.

Difficulties and Opportunities in Providing Care to Patients in the Last Hours or Days of Life: Focus Group

Author(s): Carneiro, Rui; Simões, Catarina; Capelas, Manuel; Carneiro, António

Contact: ruicarneiro77@gmail.com

Background: In Portugal, two thirds of deaths occur in the hospital and it is estimated that these numbers will increase considerably in the coming decades.

The proper organization of care at this stage promotes peaceful deaths and catalyzes healthy bereavements. The Project MiMI (Morte Iminente em Medicina Interna; Imminent Death in Internal Medicine) is a collaboration between the Portuguese Society of Internal Medicine, the International Collaborative for the Best Care for the Dying Person and the Institute of Health Sciences of the Portuguese Catholic University, whose ultimate goal is to create a training model adjusted to the needs identified by the health professionals involved in the care of these patients and their families

Aim(s): (1) Identification of the main difficulties and opportunities for improving the quality of care for patients with imminent death and their families hospitalized for Internal Medicine care, from the perspective of the professional care provider (doctors and nurses working in the Internal Medicine environment); (2) Identification of training needs in the various moments of monitoring patients in a situation of imminent death (diagnosis; adjustment of individual and integrated care plan; death and post-mortem care).

Methods: Qualitative methodology of response to a semi-structured script, by a group of professionals considered relevant in the contributions they can provide to the construction of a training curriculum in the area in question. Thus, a convergent discussion will be promoted with a convenience panel consisting of: two doctors with the Specialty of Internal Medicine and with responsibility for the service management, two doctors of the Specialty of Internal Medicine with at least 5 (five) years of experience and who has taken on the role of training supervisor, two Internal Medicine residents, two nurses working in the Internal Medicine environment and two members of the behavioral sciences area (Psychiatrist and/or Psychologist) with experience in supporting to Internal Medicine war.

Results: The meeting is scheduled to early September and results will be available in October

Conclusions: In the construction of the curriculum, it is essential to incorporate the elements that respond to the main difficulties regarding the diagnosis, elaboration of the care plan, communicational management and care after death.

Validation of an assessment and monitoring instrument for the care of patients in imminent death situation admitted in internal medicine wards

Author(s): Carneiro, Rui; Simões, Catarina; Freire Elga; Capelas, Manuel; Carneiro, António

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Background: In Portugal, two thirds of deaths occur in the hospital and it is estimated that these numbers will increase considerably in the coming decades. The proper organization of care at this stage promotes peaceful deaths and catalyzes healthy bereavements. There is no validated instrument that supports health teams in the organization of care in the situation of imminent death syndrome.

Aim(s): We propose the validation of an instrument for organizing care for patients in the last hours or days of life in Internal Medicine wards.

Methods: We recruited an incidental sample of Internal Medicine doctors with Competence in Palliative Medicine. We will evaluate the response to a semi-structured questionnaire of the Delphi rounds type, evaluating the degree of agreement with the principles proposed by the instrument, which was already validated in

accordance with the best international practices and derived from the best scientific evidence by the International Collaborative for the Best for the Dying Person

- Results:** The Delphi rounds are underway
- Conclusions:** The validation of this instrument will be the basis for the subsequent development of a national audit on the subject and the mainstay for the construction of a training model for national Internal Medicine based on the proposed principles of action, that constitutes the main goals of the MiMI Project (Morte iminente em Medicina Interna) of the Portuguese Society of Internal Medicine.

“You died on me”: Internist narratives about the caring patients in the final hours or days of life

- Author(s):** Carneiro, Rui; Simões, Catarina; Magalhães Susana; Capelas, Manuel; Carneiro, António
- Contact:** ruicarneiro77@gmail.com
- Background:** In Portugal, two thirds of deaths occur in the hospital and it is estimated that these numbers will increase considerably in the coming decades.
The Internist is, therefore, called upon to take care of patients for whom cure is not expected and whose confrontation with the limits of existence is palpable. This is a great opportunity to assume the Suffering of the Other as a therapeutic target, but also to invite reflection on the limits of science, opening space for the relationship. Narrative medicine aims not only to validate the patient's experience, but also to stimulate the physician's creativity and self-reflection and to reinforce the clinical bond.
- Aim(s):** The goal of this project is to characterize the experience of Portuguese internists in the follow-up of their patient(s) in the final phase of their life(s).
- Methods:** A semi-structured questionnaire will be used using a narrative medicine work methodology - parallel chart, focusing on a convenience panel of doctors with the specialty of Internal Medicine. The data will be analyzed in four cycles:
In the first cycle, the NVivo software will be used, which allows the analytical process of the data, not replacing the researcher's responsibility in the interpretation of the results.
In the second cycle, the analysis of parallel clinical records will be guided by the following narrative categories (and the questions that emerge from them): Voice, Characters, Time, Space and Plot.
A third cycle of analysis will follow, in which the autobiographical/personal elements will be identified in the texts; dialogic/interpersonal; socio-cultural and institutional.
The fourth and final cycle of analysis will allow the evaluation of previous cycles and the identification of contents that stand out for their novelty and/or relevance.
- Results:** The collection of records is underway.
- Conclusions:** The appreciation of the results of the reflection will lead to relevant contributions for the construction of a training model for the integral care of patients in the last hours or days of life by the national Internal Medicine, the main purpose of the MiMI Project (Morte Iminente em Medicina Interna) of the Portuguese Society of Internal Medicine.

Can we set standards for the ongoing assessment of patients using national audits of palliative care?

- Author(s):** Yasmin Rees Khan, Tamsin McGlinchey, Stephen Mason, John Ellershaw
- Contact:** y.rees-khan@student.liverpool.ac.uk
- Background:** Clinical audits identify whether healthcare is being provided in line with identified standards, to assess what is being done well, and where improvements could be made. In 2007, the first national care of the dying audit was conducted in England, with subsequent audits repeated at least every two years. However, no agreed 'standards' exist for end of life care to audit care against.
This project was undertaken to review the last 5 rounds of national audits of care of the dying (2011 – 2020), to determine the potential to set 'standards' of care.
- Aim(s):** Review the content of 5 rounds of national audits of care of the dying, to assess the consistency of questions related to the ongoing assessment of the patient and family in the last days/hours of life.
- Objectives:
- Map questions across 5 rounds to assess question consistency
 - Compare consistent data over time
 - Assess potential for 'standard' setting from data collected

- Methods:** Create a question matrix, listing all questions related to ongoing care across 5 rounds, to document:
- Question wording
 - Response options
 - Question consistency
- Results:** 50 questions regarding the ongoing assessment of the patient were asked across 5 rounds. Of those, 21 were consistent across the two most recent rounds; documentation of ongoing review of signs and symptoms at the end of life.
- Conclusions:** Lack of consistent audit questions prohibit comparisons over time. No 'standards' were able to be set from data available. Consistency in data collection and reporting is essential for 'standards' of care to be established. These insights may be of interest for ongoing work in national audits of care of the dying.

Does hospice care affect informal carers of people with COPD? A scoping and systematic review

- Author(s):** Mrs Lonan Challis, Mrs Anne Mills, Prof Dyfrig Hughes, Prof John Ellershaw, Dr Stephen Mason
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- Background:** Informal carers provide a significant proportion of the care for people with life-limiting illnesses, such as chronic obstructive pulmonary disease (COPD). However, informal carers often experience burden, financial strain and poorer quality of life (QoL). Moreover, their contributions are often overlooked in economic evaluations due to methodological challenges.
- Hospice care may improve the QoL of informal carers, as studies have shown a reduced risk of major depressive disorders and complicated grief. Nevertheless, the evidence is unclear and the economic effects of hospice care on informal carers are seldom considered.
- Aim(s):** To identify and explore the impact(s) of hospice care on informal carers of people with end-stage COPD using review methodology.
- Methods:** A scoping literature review will be conducted in accordance with the 2020 Joanna Briggs Institute (JBI) methodological guidance (version 6.3) and will explore and define key concepts and evidence gaps. A systematic literature review, using the Cochrane Handbook for Systematic Reviews of Interventions, will address a focussed research question developed from the findings of the scoping review. Protocols for both reviews will be registered on the PROSPERO database.
- Results:** The literature reviews will synthesise evidence on if and how hospice services are able to support informal carers' QoL and reduce economic burden (due October 2022). Further understanding of the methodological approaches to measure and value informal care time will inform future research.
- Conclusions:** Informal carers are increasingly being relied upon to provide care. Hospice involvement may aid informal carers and the literature reviews will synthesise the evidence needed to underpin such support.

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North West Cancer Research (NWCR) are an independent charity dedicated to putting our region's cancer needs first. Since 1948, NWCR have been funding pioneering research to tackle the cause, improve the care and find the cure for cancer. Residents in the North West of England and North Wales remain significantly more likely to be diagnosed with cancer than the rest of the UK.

NWCR's focus is on improving cancer outcomes for people in the North West and creating a cancer-free future. Through research, awareness and health promotion work, NWCR wants to reduce the incidence of cancer, understand what causes the raised levels of cancer incidence and through research, work to improve the diagnosis of this condition. It will work towards improving the treatments of and the care for people with cancer. The goal is that through NWCR's work, deaths through cancer are reduced in our region.