PALLIATIVE MEDICINE

EAPC Abstracts

EAPC President's Welcome

Dear Colleagues, Dear Friends,

On behalf of the Board of EAPC, and as President, I am delighted to welcome you to our 16th World Congress in Palliative Care. As ever, this Congress is two years in the planning and it has been my honour to work with a dedicated group of colleagues, who have worked tirelessly to bring this programme to fruition.

Berlin is an amazing choice of venue for our Congress for many reasons. Everyone can find something to capture the imagination in this beautiful city. It resonates with history, diversity and vibrancy but most of all, with life. And that, of course, is a key message for palliative care. We who work in this field are as much about life as death, supporting patients and families to live and live well until the end. So, as the people of Berlin, we should embrace life and savour every moment that this Congress and this city will offer us over the next few days.

The 16th World Congress focus on global health is a strong message that EAPC is a world player in the development and practice of palliative care. We have a voice which echoes the interface between clinical, research and policy engagement. We represent a critical perspective in national and international understanding of palliative care and showcase our work through this Congress and that of the EAPC Research Network (don't forget Palermo 2020!). Please take time to sit and listen, debate and reflect on the important issues to be discussed here at Congress. Your views are important and help us to shape our EAPC thinking on the way forward. I am also delighted that for the first time, we will have a parallel day on children's palliative care, ably organised by our CEO, Dr. Julie Ling. We expect over 700 delegates will attend this event, a remarkable achievement and one which heralds a new strand in our Congress material which I hope will continue in future years.

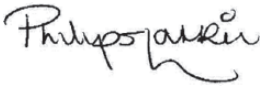
There are many people to thank for this event. Our Co-Chairs, Dr. Sébastien Moine and Dr. Anne Letsch, who was also leading the local organising committee, our debt of thanks for the hard work and long hours. Thanks also to the members of the Scientific Committee and Local Organising Committee who have provided the ideas and proposals which shape the 2019 Congress. Your support is, as always, much appreciated. We cannot forget our Conference Partner, Interplan and Elke Jaskiola in particular for organising us and keeping us to task. Of course, my personal thanks to EAPC Head Office, Julie, Eleanor, Cathy and Avril for the logistics, organization and managing all the other EAPC demands at the same time as bringing a world congress together. I would also like to give sincerely thanks to our colleague Claudia Sütfeld our congress administrator who has worked tirelessly to ensure that everything runs smoothly.

Finally, I wish to thank our German friends and colleagues for welcoming us to Berlin and for agreeing to host this Congress.

Liebe Freunde,

die Wahl des Landes und des Tagungsorts für einen EAPC-Kongress ist immer eine Herausforderung. Diesmal allerdings fiel es uns wirklich leicht, denn Sie haben uns überaus herzlich willkommen geheißen. Im Namen des EAPC-Vorstands danken wir der Deutschen Gesellschaft für Palliativmedizin für alles, was sie in den letzten zwei Jahren geleistet hat.

So, I wish you a wonderful Congress, time to meet old friends and make new ones and opportunities for creativity and relaxation when you can. Welcome to Berlin 2019.



Professor Philip J Larkin
President, European Association for Palliative Care

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Results: There were 60 papers that met the inclusion criteria. Meta-analysis was neither possible nor appropriate and therefore a systematic mapping approach to the literature was adopted. Using a thematic analysis to categorise findings, papers fell into three broad groups

i) pain and symptom management,
ii) homeless and marginalised groups, and
iii) alcohol-related papers.

Conclusion: There was only a small and diverse literature that lacked depth and quality. There are clear challenges for health and social care professionals in meeting the end-of-life needs of this heterogeneous population since people with substance problems often present with multiple co-morbidities and complex health needs. Addressing issues like safe prescribing for pain management becomes more challenging in the presence of alcohol and illicit drug use and requires flexible service provision from both drug and alcohol services and end of life care providers. More research is needed, particularly to identify models of good practice in working with co-existing substance use and end of life conditions as well as prevalence studies to provide a wider context for policy and practice development.

FC21 Vulnerable Populations and Marginalised Groups
The Application of SDM Regarding People with Intellectual Disabilities in the Palliative Phase: A Scoping Review
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Background: Shared decision making (SDM) is the process in which the professional caregiver and patient (or the representative) jointly discuss and decide which treatment policy will be followed. The importance of shared decision making is increasingly being endorsed, also in palliative care. Little is known about SDM in people with intellectual disabilities (ID).
Aims: To provide an overview of the application of SDM in people with ID in the palliative care phase.
Methods: In this scoping review, we systematically searched in the Embase, Medline and PsychINFO databases for studies that evaluated the SDM process in people with ID in the palliative phase.
Results: Of 402 titles and abstracts 21 full studies were included. Some papers fall under multiple categories. Twelve were empirical studies, 11 were opinion papers and 7 were legal reports. Ten papers focused on medical decisions in general, 10 papers specifically on medical end-of-life decisions (e.g. foregoing life-sustaining treatment) and 9 papers emphasized end-of-life decisions without a specific medical context. Even though many authors stressed the importance of involving patients in the decision-making process, none of the papers described SDM in the palliative care phase, and no best practices, guidelines or definitions were shown for SDM in the palliative care phase. Papers show an increasing focus on the involvement of people with ID themselves, or at least their loved ones, in making difficult medical decisions around the end of their lives.
Conclusion: This study shows that there is no univocal meaning about what SDM regarding people with an ID should look like. General recommendations indicate that we should involve people with an ID more in the decision-making process by providing them an appropriate environment full of support. More knowledge about the preferences and values, quality of life and life history of people with ID could improve the decision-making process.

FC21 Vulnerable Populations and Marginalised Groups
'We Are Who We Are, Not What We've Done': End of Life Care for People with Alcohol/Other Drug Problems
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Aims: As part of an interdisciplinary, multi-method scoping study, this qualitative research aimed to explore:

1. How substance use and hospice services support people with alcohol/drug problems who are approaching the end of their life.
2. The good practice and challenges that people with alcohol/drug problems face in accessing support and their suggestions about how care may be improved.

Design: Accessed through hospices, substance use services and peer communities, eleven people with life-shortening conditions (who had used substances problematically) participated in semi-structured interviews.
Analysis: Interview transcripts were subject to inductive thematic analysis and detailed case studies were developed to contrast between interviewees accessing hospice care and those not.
Results: Interviewees described experiencing multiple complex health problems, including mental health and social care support needs. Yet many were minimising contact with services or trying to manage how healthcare professionals perceived them in order to avoid stigmatising attitudes and discrimination. Fragmented healthcare delivery and poor communication about their approaching end of life left them little scope to come to terms with dying. The often unpredictable and rapidly deteriorating nature of their health conditions, combined with poor mobility and memory problems, made it extremely challenging for many to access the support they desperately needed - although good care from hospices was commonly described.
Conclusion: Palliative care has much to teach substance use services about explicitly addressing life-shortening conditions with service users. Moreover, cross-fertilization of palliative and substance use approaches, would allow behavioural cues (eg: substance use relapse, self-isolation and deteriorating mental health) to receive greater attention and tailor palliative care better to individual needs.
Funding: Big Lottery Fund (UK)

FC21 Vulnerable Populations and Marginalised Groups
Do Adult Persons with Chronic Psychiatric Conditions Receive Fair Access to Specialist Palliative Care? Results from a Systematic Review
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Background: The linkages between palliative care (PC) and psychiatry are widely described in the literature. Little is known on whether persons with chronic psychiatric conditions have access to specialist PC.
Aims: To review the existing evidence about PC for persons with chronic psychiatric conditions with respect to the access to specialist PC and its specificities.
Methods: Systematic review, following PRISMA 2009. Data sources: PubMed, Web of Science, PsycINFO, EBSCOhost, CINAHL, MEDLINE, Nursing & Allied Health Collection: Comprehensive, Database of Abstracts of Reviews of Effects, Cochrane Central Register of Controlled Trials,

Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Library, Information Science & Technology Abstracts, MedicLatina, Health Technology Assessments, NHS Economic Evaluation Database, PsycARTICLES, Psychology and Behavioral Sciences Collection. Search terms: 'palliative care' OR 'end of life care' AND 'psychiatry' OR 'mental illness' OR 'mental health' OR 'mental disorder' OR 'chronically mentally ill' OR 'serious mental illness' OR 'psychiatric disorders' OR 'severe mental Illness'. Inclusion criteria: studies focusing on PC provision for adults with chronic psychiatric conditions, in English, German, Spanish and Portuguese. Articles independently reviewed by two researchers. Quality appraisal was performed.
Results: 293 articles retrieved, 4 met inclusion criteria. Three articles focused on professionals' perspectives about palliative and end of life care provision, suggesting the need for further education and collaboration between psychiatry and PC. The other article revealed that patients with psychiatric conditions were less likely to receive specialist PC when compared to other patient groups.
Conclusions: This study shows the lack of research on the access and provision of PC for persons with chronic psychiatric conditions. It emphasizes the ethical issue of justice in the access to PC at the end of life.

FC22 Audit and Quality Improvement
Half a Million Patient Registrations Later - Where Do We Stand and What Are We Aiming for?
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Background: The Swedish Register of Palliative Care (SRPC) is a national quality register which through a web-based end-of-life questionnaire (ELQ) gathers data on quality of care for dying patients, regardless of care setting, age or diagnosis. The ELQ, with 30 questions, is based on the principles of a good death proposed by the British Geriatrics Society and is completed by healthcare staff after the death of a patient. The SRPC started in 2005 and today collects data from approximately two thirds of all deaths in Sweden; 90 % of all cancer deaths are reported.
Aims: To give an update on the current status of the register, achievements so far and plans for the future.
Methods: Data collected in the ELQ is matched with the central population register for validation purposes. Validity is also examined via visits to a selection of units. Add-on questions to the ELQ on specific research questions are now in use through separate modules. Aggregated results are accessible online at the register's website.
Results: Data from over 530 000 patients has been registered since 2005 and over 4000 units are reporting data each year. Quality indicators with corresponding goals defined by the Swedish National Board of Health and Welfare shows continuous national improvement. Systematic improvement is now being organized by the government with support from the SRPC. Since 2011, 24 scientific papers based on register data have been published. The focus has mainly been on comparing quality of care between different diagnoses and care settings.
Discussion: The SRPC forms the basis for measurement of quality of end-of-life care in Sweden and the working method has proven to be both feasible and valid. Management of more than 4000 reporting units and decreasing financial support to national quality registers from the government are challenges met. Data collection from electronic medical records, bypassing the ELQ, and further use of add-on modules are opportunities in the near future.

FC22 Audit and Quality Improvement
"Did a Member of the Healthcare Team Talk to You about what to Expect when Your Relative was Dying?" - "No." Quality of Care for Cancer Patients Dying in Hospitals: First Results from the International CODE (Care of the Dying Evaluation) Survey
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Background: Quality of care for dying cancer patients has global relevance. Although many cancer patients wish to die at home, a substantial group will need hospital care in their final days. The aims of the ERANet-LAC CODE project (2017-2020) were to conduct an international post-bereavement survey of hospital cancer deaths and subsequently use the results for direct quality improvement work.
Aims: To assess quality of care, as perceived by bereaved relatives, for adult cancer patients dying an 'expected' death in hospitals across seven countries.
Methods: Post-bereavement survey (August 2017-September 2018) by post (Germany, Norway, UK) or interview (Poland, Argentina, Brazil, Uruguay) using the international version of the CODE questionnaire (i-CODE). Analysis of responses according to the i-CODE user guide. Results from near complete dataset.
Results: 1485 eligible deaths identified; 866 relatives responded, minimum 100 per country. Response rates 33-95%, depending on recruitment strategy. 57% of the deceased were male; 67% of the respondents female. 49% died on a medical or surgical ward, 25% on a palliative care unit. Respondent cases did not differ from non-respondents with respect to patients' gender, age, type of cancer, and type of ward. Overall score for the primary outcome respectful and dignified care of the dying was 3.7 (SD $\pm$ 0.8, 95% CI 3.6-3.8, 0="never", 4="always"), and adequate support for the family 89% (95% CI 87-91%; variation between countries 82-97%). 87% (variation 79-96%) were informed about impending death, but 36% (variation 11-52%) lacked information about the dying process. Several other areas for improvement were identified in individual countries.
Conclusion / Discussion: The overall quality of care and support was rated well by most participants. The perceived poor communication about what to expect in the dying phase is a complex discovery and will be further explored. Areas needing improvement will be targeted in the last project year.

FC22 Audit and Quality Improvement
Healthcare Professionals' Views on Implementation of Advance Care Planning for Patients with Advanced Pulmonary Disease - A Pilot Study
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