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## EAPC Abstracts

### EAPC President's Welcome

Dear Colleagues, Dear friends,

On behalf of the EAPC Board of Directors, and as President, I am delighted to welcome you to our 11th EAPC World Research Congress Online, the first ever palliative care virtual Congress. Although not exactly as we had originally planned, this congress has been a long time 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. Without your valuable contributions through the submission of regular and late breaking abstracts, this would not have been possible.

As you will all know the congress was originally planned to take place in Palermo in May 2020. This was a great choice of venue for our Research Congress for many reasons. Palermo hosted the 7th EAPC World Congress in 2001 at the same venue. Reflecting on the programme from 2001, the hot topics of the day included: Controversies in ethics, Prognostication at the end of life, Ethics within Latin Europe, Controversies in therapeutics, End-of-life care decision-making and End-of-life care in children. All giving the impression that many of the issues remain the same. Unfortunately, a global pandemic prevented the congress going ahead in person as planned. For us all, in particular for the Local Organisers led and inspired by the Local Chair Sebastiano Mercadante this was and remains a great disappointment. We would all have enjoyed the great weather, the wonderful city, the good food and the warm Sicilian hospitality! My special thanks go to Sebastiano and his team, their role in the conference organisation was enormous! Mille grazie per tutto President's quello che avete fatto. Speriamo nel futuro! We look forward to hearing Sebastiano's piano recital during the online opening ceremony.

There are many other people to thank for helping to bring this online event to fruition. Our Scientific Committee and the two chairs Marie Fallon and Lieve van den Block, our debt of thanks for their hard work over many long hours. We would also like to thank our Conference Partner, BIBA GROUP and Alessia Milella for supporting us through difficult times. Of course, my personal thanks to EAPC Head Office, Julie, Cathy, Avril and Claudia for the logistics, organisation and managing all the other EAPC demands at the same time as bringing a world research congress online together. I would also like to give sincere thanks to Augusto Caraceni and Alice Gallivanone, European Association for Palliative Care Research Network who have worked tirelessly to bring the programme together and ensure that the congress goes ahead despite the circumstances.

So, I wish us all a wonderful Congress Online, combined with the hope that we will soon meet again personally

Professor Christoph Ostgathe  
President, European Association for Palliative Care

**Methods:** A questionnaire was sent to the bereaved family members (primary caregivers) of 1023 cancer patients. We evaluated the specific contents of and satisfaction with sending "cards and letters". We also used the Brief Grief Questionnaire (BGQ) and Patient Health Questionnaire 9 (PHQ-9) to investigate the frequency of complicated grief (CG) and major depressive disorder (MDD) and measured the effects of care with the X<sup>2</sup> test. This study was conducted as a specific research of the J-HOPE4 study funded by the Japan Hospice Palliative Care Foundation.

**Results:** 563 (55.8%) family members responded of whom 319 (56.7%) had received a "card and letter". Preferred content included words concerning care during hospitalization (76.1%), caring for the family after discharge (73.1%), and understanding of the patient's personality (72.2%). The desired delivery times were 3-6 months (33.8%) and 1-3 months (31.2%). Regarding the need to send "cards and letters", 35.1% were positive and 12.0% were negative. The CG high-risk group (A:BGQ $\geq$ 8) was 16.3%, and the MDD high-risk group (B:PHQ-9 $\geq$ 10) was 24.0%, which was not significantly different from the incidence of bereaved family members (A:16.2%, B:22.7%). There was no significant difference in the relationship between the presence of care and BGQ and PHQ-9.

**Conclusions:** The contents of the "cards / letters" that are desirable for bereaved family care were related to knowing the personality of, and care for the patient and the bereaved family. Sending "cards and letters" had no major impact on CG or MDD. It is necessary to create a standard bereaved care program that includes other bereaved family member's care.

**Abstract number: P01-275**

**Abstract type: Poster**

**End-of-life patients' dignity: an exploration among the opinions of four different healthcare providers' categories**

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**Background/aims:** In palliative care clinical practice, the respect and the preservation of end-of-life patients' dignity, offering a dignified care, is one of the most important goals. In order to recognize the psychosocial and existential patient's needs, healthcare providers' (HCPs) perspectives on this theme are relevant and need to be explored. The aim of this study was to investigate four different HCPs' professional categories' points of view on end-of-life patients' dignity, collecting opinions about the meaning of dignity and the strategies that they daily use to maintain it.

**Methods:** To collect qualitative data, a sample of 104 HCPs (physicians, psychologists, nurses and nurse assistants) was interviewed, in a group situation, with two open questions. All the answers were audio recorded and then transcribed verbatim; content analysis was conducted to identify the emerged themes.

**Results:** Regarding the first question, thinking about what end-of-life patients' dignity means, nine themes emerged. Most of the sample agreed on respecting the patient as a person in his/her entirety as the key mean. In addition, other two themes appeared as the most cited: "Respect the patient's will/wishes/needs" and "Self-determination/Self-expression". About the second question, exploring the HCPs' strategies utilized to maintain dignity, a total of seven themes emerged. The "Caring Skills" theme (including acceptance, physical closeness, open dialogue, and respect for patient's timing, habits and personal characteristics) was the most frequent, followed by "Empathic Skills" and "Professional strategies".

**Conclusions:** This study allowed to enlarge the knowledge on HCPs' points of view on end-of-life patients' dignity. The results confirmed dignity as a multifaceted concept; maintaining it implies HCPs' attitudes, behavior and sensibilities. The group situation in which different opinions emerge, might help to enrich the HCPs' awareness on this core clinical topic.

**Abstract number: P01-277**

**Abstract type: Poster**

**Family members' perspective of care of the physical aspects, relationship with professionals and sharing with loved ones of residents of Spanish long-term-care centres**

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**Background/aims:** Little is known about how the process of dying is perceived in Spanish long-stay settings. The aim of this study is to know the perspective of family members on the quality of dying

**Methods:** Qualitative descriptive study. A thematic analysis was carried out from the cognitive interviews within the cultural adaptation process of the Quality of dying in Long-Term-Care (QOD-LTC). 11 caregivers of deceased patients attended at the Edades nursing home in Jaén, and in the San Rafael long-term-care hospital in Granada (Spain) were interviewed. All interviews were carried out three months after patients' death, were recorded and transcribed literally.

**Results:** Of which 7 were from nursing homes. 6 of the patients had no cognitive impairment. Three main categories aroused; Care of the physical aspects, Relationship with professionals, Sharing with loved ones, preparation to die, decision-making and decision-making. These abstract is focused in the first three ones.

- Care of the physical aspects: The absence of pain and suffering, and the good hygiene was high valued by caregivers, as well as the good treatment received on the behalf of the professionals.
- Relationship with professionals: Caregivers trusted professionals, although some of them believed that these centres were places where elderly are abandoned, before the patients lived there.
- Sharing with loved ones: Caregivers pointed out that they spend as much time as they wanted with the patients and they were able to express themselves freely. However, some family members preferred not to discuss certain topics such as death, to avoid residents suffering.

**Conclusions:** It is necessary to improve the perception that one has of these settings and to facilitate that all aspects related to death are spoken about.

**Abstract number: P01-279**

**Abstract type: Poster**

**Palliative care indicators in Quebec (part II): experts' interpretations and suggestions for the future**

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**Background/aims:** In the early 2000s, the Québec government (Canada) mandated the National Institute of Public Health to define indicators of palliative care development using large population databases. Using data from 1997 to 2001, ten indicators were developed. However, they have never been updated nor measured since that time. Our aim is to present the second part of a larger study that also included a quantitative research part to assess the evolution of eight of these indicators

from 2002 to 2016. This communication present the results of a qualitative research project carried out to complement the quantitative data gathering by interpreting the data and suggesting future orientations.

**Methods:** Using a qualitative study design, ten semi-directed interviews were conducted with experts in palliative and end-of-life care. These experts were Québec health care professionals from various disciplines as well as policy makers. Using a direct content analysis method, the interviews were systematically coded to give meaning to the quantitative data set and to identify potential research and professional practice implications.

**Results:** During the interviews, the experts reflected on how the quantitative data set mirror the difficulties reported in their clinical practice. Therefore giving meaning to the data set. The results also reveal gaps between the quantitative data set and the political decision making around palliative and end-of-life care in Québec. The results provide suggestions as to which additional indicators should be developed to better assess the access and quality of palliative and end-of-life care.

**Conclusions:** The results from this second part of the study on palliative care indicators will help contextualize the data from the first part, thereby supporting stakeholders from other jurisdictions who want to develop their indicators and/or compare their data to those from Québec.

**Abstract number: P01-281**

**Abstract type: Poster**

**Improvisational theater as a method to discuss experiences and needs for future care with patients with dementia and their family caregivers**

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**Background/aims:** In the Netherlands, people with dementia who are living in their own homes are supported to do so for as long as possible. The aim of this study was to gain insight in a. the needs and problems faced by patients with dementia who reside at home and their caregivers; b. the extent to which they want to discuss future care; and c. the use of improvisational theatre as a method to gain insight in problems of patients with dementia and their family caregivers.

**Methods:** Four improvisational theatre performances were organized for patients with dementia, family carers and professionals. Two experienced actors, accompanied by a pianist, played recognizable situations and songs. These were discussed with the participants.

**Results:** The performances were mainly attended by caregivers, but also people with dementia and professionals (mainly casemanagers) were present at each performance. The performances were evaluated positively. There was a great need for explanation of dementia related behaviour and ways how to deal with this. Recognition of the burden of taking care of a person with dementia and support from professionals was considered very important. The extent to which people wanted to think and talk about "the future" varied and was mainly restricted to the transition from home to the nursing home. Children of patients with dementia seemed to be more open to discuss future care than partners.

**Conclusions:** Interactive theatre performances can be a method to gain insight in the needs and problems of patients with dementia and their caregivers. Talking about the future can be challenging and has to be tailored to the individual needs of patient and carers.

**Funding:** ZonMw, the Netherlands Organization for Health Research and Development

**Abstract number: P01-282**

**Abstract type: Poster**

**Integrating palliative care in intensive care: results from a mixed-methods study with healthcare professionals**

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**Background/aims:** Integration of palliative care (PC) in intensive care (IC) has been studied in recent years. Despite the likely benefits of this integration for patients, families and ICU staff, it appears to be overlooked.

**Aims:** To study healthcare professionals' (HCP) perspectives on the integration of PC and IC, identifying knowledge about integration, organizational models, barriers and facilitators.

**Methods:** Mixed-methods study, including interviews and a questionnaire. A purposive and snowball sampling was done in Brazil for recruitment. Thematic content analysis and descriptive analysis were performed.

**Results:** 27 professionals (14 working in PC and 13 in IC) participated in the study from Feb-Oct 2019. The concept of integration seems fundamental among PC, while for IC HCP integration in ICU care is perceived as EOL and as a self-sufficiency of ICU multidisciplinary teams. An organizational model with integrated education is strongly recommended by PC HCP. Participants considered that there is PC expertise and integration in IC HCP practice - a consultation model is preferred rather than an education model, particularly in EOL situations or when forging life-support treatments. Behavior and lack of knowledge were barriers identified among IC, and the lack of institutional [meso] and public [macro] policy stood out among PC HCP. PC education was considered as the main facilitator for integration. Quantitative data showed agreement on dimensions of PC-IC integration, but not actually implemented in ICU practice: "patient-centered care", "participation in decision-making", "meeting persons' needs and values".

**Conclusions:** Evidence of integrating PC in IC is limited and heterogeneous, mainly among IC HCP. Integration is associated to EOL care, despite the recognition of its importance for patients/families. More research is needed on the integration of PC in IC to strengthen its cultural implementation.

**Funding:** Fundação Grünenthal. FCT Scientific Employment Stimulus.

**Abstract number: P01-283**

**Abstract type: Poster**

**Prevalence and predictors of symptoms of depression over time among older adults receiving palliative home care services**

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**Background/aims:** Depression among older adults is difficult to identify and is often under-diagnosed and undertreated.

**Aim:** To examine whether prevalence of depression symptoms improve or worsen over time, as well as the factors that may increase risk or protect against symptoms of depression over time among community dwelling persons receiving palliative care (PC) services.