EAPC Congress Highlights

26th May 2006

Venice 2006

EAPC

Welcome to the 4th EAPC Research Forum

Dr Franco de Conno, joint-Chair of the EAPC Executive Scientific Committee welcomed delegates to the 4th European Association of Palliative Care Research Forum on Thursday afternoon by introducing his fellow members of the Committee onto the stage wearing the decorative masks made famous by Venice; host city for this year's meeting.

Dr de Conno highlighted that, from a challenging beginning for the Research Forum, this year's meeting now boasts over 1000 delegates from all over the world – a marker of its incredible success and reflection of the hard work by all those involved in its organisation.

Dr Florian Strasser, another joint-Chair of the Committee then welcomed old friends and new to the Forum and highlighted this year's theme to 'Collaborate to Catalyse Research' in the area of palliative care. *"The research forum is driven by you"*, he reminded delegates. *"We are all here to inspire and learn from one another and I encourage you all to connect over the duration of the meeting"*. He then invited delegates to take a few seconds to get to know the person sat next to them.

Dr Strasser then introduced a short film based upon photographs provided by EAPC members from Zurich. The emotive film showed some of the individual faces of patients that benefit from palliative care services. *"These are the people that we are here to help and the reason we are all here today"*, he concluded.

A Quarter Century of Palliative Care Research

Speaking at Thursday's plenary session, Stein Kaasa of St Olav's Hospital Norway called for *'us all'* to continue to drive research into effective palliative care. Professor Kaasa provided a snapshot of the development of palliative care research since 1980 and the need for further funding and focused research in this area.

Professor Kaasa explained that for many years, it has been debated whether research into palliative care is appropriate. Some consider it to be unethical to perform research on patients that are very frail and weak. Others question the methodology and practicalities of achieving solid results. However, Professor Kaasa expressed that it may be unethical not to do such research. He explained that it is necessary to perform research in order to understand better and to gain evidence based knowledge on the subject and subsequently improve diagnosis, treatment and care.

Looking back over the 25 year period, Professor Kaasa and his colleagues Marianne Jensen Hjermstad and Jon Haavard Loge of Ulleval University (Oslo, Norway) conducted a review of research across 13 European countries. They found that the quantity of research has increased, and palliative care journals and textbooks in palliative care have been launched. This makes the research more visible and increases the potential for publication.

However, the quality, content and the clinical impact of this research is in question. For research to be strong, Professor Kaasa emphasised the importance of prospective studies and a closer link to the universities, which would help strengthen the case for funding.

Although an increase in randomised studies was seen across the medical journals, it was the UK that had the largest visible pool of research. However, many of the publications were dominated by small surveys and audits. Professor Kaasa suggested that had these funds been pooled, a larger body of work may have been conducted. Findings also showed that there were few full-time research chairs in palliative care and there were a few small research groups established.

Professor Kaasa closed by inviting all those attending the EAPC congress in Venice to collaborate to fulfil the objectives of the European Palliative Care Research Collaborative. The ultimate aim being to drive funding and ongoing investigations into palliative care research.

Budgeting for the Sisyphus Syndrome

Palliative Care services, and specifically health economists, are facing a challenging future according to Dr Konrad Fassbender, Edmonton, Canada. An ageing population of retired citizens who no longer contribute to the national revenue but who consume more health services than any other single section of society. The conundrum is known as the Sisyphus Syndrome in reference to the miscreant Greek sentenced by the Gods to ceaselessly rolling a boulder up an unending mountain, and the analogy was used to great affect in this plenary lecture on the patterns and predictors of health service consumption in palliative care.

The cost of health service provision is naturally a sizable concern for those responsible for budgeting health expenditure and it is not currently an equation that is balancing out. From his own research in Alberta, Canada, Fassbender reports that health funding has increased by 9.5% per annum while revenue growth over the same time period has only increased by 6.3%. To further compound the maths, policy makers traditionally combine all 'end-of-life' patients into one group and so individual high users, are lost. Consequently, Fassbender argues that if you breakdown the population into discreet categories, it is possible to identify those who will require the greatest service provision and at what time.

Consumption itself can be plotted along a trajectory that closely corresponds to functional decline – which is itself related to the type of illness each patient is suffering with. Of the 18,000 deaths per annum in Alberta it is possible to effectively divide them into 10% from sudden death and then equally between Fragility (Parkinson's, dementia); Organ Failure (CHF, COPD) and Terminal Illness (Cancer). Each of these groups shows a unique trajectory for their health consumption which could be used to inform and predict periods of increased expenditure. For example, patients with organ failure demonstrate a wave like consumption that reflects acute exacerbations of their chronic condition, whereas, patients with terminal illness show a gradual increase in consumption that spikes exponentially in the last few months of life.

Further sub-classification provides more specific information which may have some resonance with service delivery across society. The total cost of health services actually decreases with patient age and increasing mortality. Women tend to consume more health services than men, although that trend is reversed in the last few months of health. And low socioeconomic status does appear to confer a reduction in health service consumption.

Having outlined these crude trends in health trajectories Dr Fassbender stated his hope that this and similar data can help to address inequalities in the distribution of health services and contribute to the development of targeted strategies that will ease the economic burden. His concluding suggestion referred to the observation that hospital stay was the primary driver to cost in all patient groups, and is therefore an ideal target for cost saving initiatives. Any measure that can minimise hospital stay by a small amount will provide a large impact on the reduction in costs – and possibly help Sisyphus to finally overcome his mountain.

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Can the Institutionalisation of Cancer Pain Assessment as a 5th Vital Sign Improve Cancer Pain Control in the Acute Setting?

That was the question posed by Professor Marie Fallon, Director of Clinical Oncology at Western General Hospital, Edinburgh, UK, at the outset of her presentation.

A lack of a systematic approach to cancer pain assessment in the acute hospital setting is a challenging problem. The American Pain Society (APS) advocates that pain assessment should be integrated in the acute setting by adopting pain as the '5th Vital Sign'. However, this approach had never been evaluated.

Professor Fallon and a multidisciplinary team set out to develop a package designed to achieve institutionalisation of pain assessment, the Edinburgh Pain Assessment Tool (EPAT). Their aim was to assess if the introduction of EPAT in a Regional Cancer Centre might lead to improved cancer pain control. The team employed three assessment approaches: EPAT, the Brief Pain Inventory (BPI) and usual standard care (i.e. no bedside pain assessment).

Wards were randomised to 1 of the 3 assessments. Patients with a pain score of greater than or equal to 4/10 who were able to complete the pain questionnaires were recruited within 24 hours of admission and re-assessed on day four. The primary outcome measure was patient pain score reduced to less than or equal to 4/10 by day four.

Results of the pilot study involving 150 patients showed that the institutionalisation of cancer pain assessment as a 5th vital sign using EPAT gave better pain control than both the BPI and standard care. The advantage of EPAT was that it included guidance for the clinician on how to interpret and manage the patient's pain.

Following the pilot study, and with funding secured from Cancer Research UK, Professor Fallon said the next step would be to extend the use of the tool to a number of centres throughout the UK. *"We accept that it was possible that a high degree of bias would have been involved in the results from the pilot study. We are therefore extremely keen to see whether the tool might work on a larger scale and whether our encouraging initial results might remain robust in a wider setting".*

An 18-centre cluster randomised controlled trial is planned to begin in the late-summer and will involve centres from across the UK.

"We are hopeful that this will form the basis for further collaboration and research in the UK", she concluded.

Doctor's Perceptions of Palliative Care and Triggers and Barriers to Referral

Claire Johnson of The Cancer Council NSW and University of Wallsend, Australia, began her presentation on Thursday afternoon with the observation that palliative care is often perceived as care for those who are within a few months of death. This perception can lead to people with advanced cancer not having their needs adequately met when they are the very people that stand to benefit the most from early referral. Moreover, a great many do not access palliative care services at all.

Johnson, along with her fellow researchers from The Cancer Council, Alaf Gris, Chris Paul and David Currow, wanted to gain a better understanding of the doctor's perceptions of PC and what influences referral to such specialist services in Australia.

The authors undertook a series of telephone-based interviews with referrers to PC services and supplemented this research with a number of focus groups with providers of palliative care. Responses were sought from a mix of urban, regional and rural environments from across Australia.

Results from the study suggested that the majority of doctors associated palliative care with the physical management of the patient's illness and it was used most commonly when other treatment methods had been exhausted. Typically, physical symptom management served as the main trigger for referral to specialist services. *"There was limited knowledge around the holistic nature of palliative care"*, Johnson said.

In terms of reasons for non-referral, results highlighted lack of knowledge about PC, poor communication, a doctor's ability to manage symptoms, a rapid decline in the patient's symptoms. Service barriers were also a factor in terms of resource, location and access.

The study also highlighted that the psychological needs of the patients were often overlooked in favour of this physical need. Palliative care was perceived to provide comfort or symptom management for those nearing death. Johnson cited a comment from one respondent in the study suggesting that he would prefer the view of palliative care in minds of patients and healthcare professionals to away from 'end of life' to end of life issues.

Johnson concluded her presentation by highlighting the need for, *"education, education, education"*. This education should be focused around addressing the misconceptions around palliative care, communications training and better skills in the provision of end of life care. She also cited the need for promoting needs assessment across all domains of care with improved assessment tools and referral criteria.

Management of Breakthrough Pain

Breakthrough pain (BTP), as defined by the EAPC Research Network, is a 'transitory exacerbation of pain that occurs in addition to otherwise stable persistent pain' and this notoriously difficult-to-treat condition was the subject of discussion by Dr Philippe Poulain, Institute Gustave Roussy, France. One of the most perplexing problems with BTP is its variance between patients - two people with the same macroscopic condition are frequently observed to present with breakthrough pain of completely different intensity.

Poulain discussed the commonly accepted treatment protocol of morphine given at regular 4 hourly doses and then a second morphine dose provided on demand as and when BTP occurs. The two natural points of contention are defining an appropriate dose for the rescue analgesia and if pain remains uncontrolled, what are the alternatives to morphine?

In answer to the first question Poulain explained country specific and experimental variances in the level of rescue dosing that ranged from 30% - 100% of the normal 4 hourly morphine dose. In response to the second issue he conceded that morphine has significant limitations, specifically with regard to its varied response, bioavailability and side effect profile. However, there are now an increasing number of morphine formulations such as oromorph as well as a growing list of opiate alternatives like oxycodone and fentanyl, which are again available in a variety of formulations such as the fentanyl effervescent buccal treatment which is showing encouraging bioavailability much closer to IV fentanyl than the existing oral formulation.

In his conclusion, Poulain accepted that before we can ascertain a definitive treatment protocol for BTP, a great deal more research is required into its precise pathophysiology. In the mean time he re-affirmed his support for the current morphine based protocol with a rescue dose defined by careful titration.

Role of Titration for Rapid Onset of Pain Control

At the opening to the satellite workshop Professor Marie Fallon from St Columbia's Hospice at the University of Edinburgh discussed the numerous competing factors to consider in pain control and effective morphine titration.

Professor Fallon began by explaining the importance of considering not only previous pharmacological management, but also patient fears, assessment methods and adequate communication to all parties.

Assessment of the patient should include the cause of pain, pain severity, drug history and organ dysfunction. Communication to patients and carers should be clear, providing the aims and expectations of the opioid treatment. Fears should be dealt with on an individual basis, including concerns of addiction, tolerance and side effects.

In reality treating escalating pain can feel like 'chasing the pain' and in fact it is not being controlled effectively. At this point, background medication may become irrelevant.

Professor Fallon explained that the primary objective in treating patients with new onset pain is to manage the symptoms as quickly as possible using a rapid and effective titration protocol. For patients already on MR morphine it is possible to effectively increase that dose or leave it unchanged and add in a second, as required, dose for break through pain. Alternatively, MR morphine can be stopped and the patient titrated exclusively with NR morphine at 4 hourly doses.

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