Sunday 6 June 2004

EAPC Research Forum Highlights

3rd Forum of Research Network of the European Association for Palliative Care (Onlus)

Measurement Tools in Palliative Care – towards a new common standard

Marianne Hjermstad of the University of Oslo and Norwegian Cancer Society, Norway, looked at the assessment of cognitive failure and delirium in palliative care. Cognitive failure is under diagnosed and often goes unrecognised in 28-67% of cases. Hjermstad's research found that there are few studies that specifically assess cognitive failure or delirium in palliative patients, and she advised that the interchangeable use of cognitive failure as a diagnostic term should be avoided, as it yields prevalence rates that are not representative. There is a need for precise definitions of cognitive failure, dementia and delirium, she noted, to improve reporting and diagnosis.

Gerd Inger Ringdal, of NTNU, Norway, looked at the role of the FAMCARE Scale for measuring satisfaction with palliative care services amongst family members. She warned that caution is necessary in interpreting results from family satisfaction evaluations, due to methodological problems. It was suggested that practitioners could ask family members in advance what their expectations of palliative care will be, and then measure success in achieving those expectations.

Jacob Chr Holden, also of NTNU, Norway, described the development of a hand-held computerised palliative-assessment tool currently in production at his institution. The PAT-C will utilise computer adaptive testing and item response theory to measure pain, according to a set of determinants agreed following a rigorous review of current assessment tools and expert panel advice.

Clinical Trial Research in Palliative Care

This lively session on the challenges associated with conducting clinical trials in palliative care was co-chaired by Carla Ripamonti of the National Cancer Institute, Italy and Eduardo Bruera of the Department of Palliative Care and Rehabilitation Medicine, USA.

Carla Ripamonti provided an overview of the clinical trial experience from the patient point of view. She noted that there are conflicting priorities in participant selection: on one hand, it is desirable to ensure homogeneous patient group enrolment to reduce statistical "noise", but conversely, enrolling heterogeneous groups will enable the demonstration of efficacy across varying patient populations. Ripamonti suggested that there are a number of issues that must be considered when determining the patient population for a trial, including cognitive status, care setting, stage of disease and type of cancer. Patients must also be free to leave the trial at any time, which can lead to a significant attrition rate.

Eduardo Bruera discussed the limitations of randomised, controlled trials in palliative care from the researcher's perspective. He noted that all research is useful, whether trials are uncontrolled or observational. He cautioned delegates to "beware the cult of evidenced-based medicine" and to instead engage in the "global collective process" of research, which contributes to overall learning. Bruera provided an overview of the different types of trials and their usefulness in assessing various aspects of palliative care, and advised delegates that outcomes should be specific "but not too specific". This will allow for research that adds value, rather than frustrating the researcher by not providing answers large enough to meet the question. For example, Bruera suggested that trials for anti-emetic agents should focus simply on reducing emesis, without attempting to link back to overall patient quality of life.

The discussion session that followed provided delegates with an opportunity to ask the chairs about such diverse issues as maintaining motivation amongst a research team and tips for getting research published.

EAPC 3rd Research Forum Closes with Announcement of Poster Winners

The EAPC 3rd Research Forum included 715 participants, including a growing number of nurses and delegates from professions allied to medicine. There were representatives from all over the world in attendance, and the forum attracted a record 308 abstracts and 211 posters. Franco de Conno thanked the Scientific Committee and the Research Team for their work in organising the programme. He also thanked all of the sponsors and delegates for their participation.

Friedermann Nauck announced the winners of the poster awards, which were decided on the basis of originality, scientific methodology and presentation. The winners were:

- **Peter Hudson – Austria**
  Positive consequences of supporting a dying relative: findings from a randomised, controlled trial.
  Poster 86
- **Carol Thomas – UK**
  Place of death: preferences among cancer patients and their carers.
  Poster 101
- **Ulrika Kreicburgs – Sweden**
  Ethics and statistics: a population-based nationwide study on parents' perception of a questionnaire on their child's death from cancer.
  Poster 207

Each of the winners received a free registration to the next research forum.

Nauck also announced that the 9th Congress of the EAPC would be held on April 6-10, 2005 in Aachen, Germany.

Stein Kaasa concluded the session with his summation that this had been "the best research forum I've been at in palliative care, due to all the work done by the delegates, in terms of the work done, the excellent presentations and the lively discussions." He added that he hoped that the delegates would continue with their research in palliative care, and that they had been able to generate new ideas, new friends and new research collaborators during the forum. He thanked Franco de Conno and Heidi Blumhuber for their work over the past year to organise the congress. Kaasa also announced that the 4th Research Forum would take place in Venice in May 2006.

Franco de Conno at the Closing Session of the EAPC Research Forum

Copies of each day's EAPC Reseach Form highlights are available online at: **www.eapcnet.org/research2004/forum/default.asp**

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Researchers on Spiritual Care Should Declare Their Bias

Authors who research aspects of spiritual care should declare their premises and bias, according to Vicky Robinson, St Christopher's Hospice, London, UK.

Robinson, who presented a study that examined the spiritual care given at the end of life, scored papers on the subject using criteria from the BSA Medical Sociology Group. Her research selected 17 UK studies from the period 1990-2002, and scored them on the extent to which they met criteria such as the clarity about their position in relation to the subject matter and the relationship of researchers to the subject matter. A maximum of score of 18 was possible depending on whether the criteria were fully met.

Analysis of results showed that while spirituality and belief could be evaluated, all but two of the authors failed to indicate their own beliefs and analytic bias. "The paper that scored the lowest was actually one of the most cited papers. We recommend that all research on spiritual issues should be objective in matters of belief."

GPs Cannot Cope with Spiritual Needs of Dying Patients

GPs recognise that dying patients have spiritual needs but few believe that they have the time or knowledge to give it, according to a study presented by Elizabeth Grant, University of Edinburgh, Scotland.

Grant outlined details of a study which tape recorded 66 interviews with 20 dying patients who described their spiritual needs and interviewed GPs one week after the patient interviews.

While few patients used the term 'spiritual' many described significant existential needs such as 'Why me?' or 'What have I done to deserve this?' At diagnosis many patients felt a deep sense of loss and a great fear of the unknown. Those who had established religious beliefs seemed better able to cope than those whose beliefs were wholly secular.

The study also showed that GPs, because they had experience of dying, were looked to in order to provide advice and spiritual support. But while GPs recognised their patients spiritual needs, and also recognised that patients with unmet spiritual needs were more anxious than other patients, they felt that they had neither the time nor knowledge to deal with the problem.

Assessment of depression and anxiety in Palliative Care

Mari Lloyd Williams, University of Liverpool, UK and Friedrich Stiefel, University Hospital, Lausanne, Switzerland, chaired Sunday's final New Research Data Session, focusing on the assessment of depression and anxiety in Palliative Care.

Unnur Valdimarsdottir, Karolinska Institute, Sweden, explained that evidence based palliative care is dependent on the valid measurement of anxiety and depression, and as such a simple valid visual-digital scale could be useful for this purpose.

Results of a study of 3057 individuals, including cancer patients, bereaved relatives and a control population, were presented, showing that simple and short visual-digital scales may be a valuable measure of depression in a palliative care, owing to lower attrition and high agreement with lengthier psychometric scales such as the Centre for Epidemiological Depression Scale (CES-D). More research is needed to establish if visual-digital scales for anxiety can be used to replaced other psychometric state measures of anxiety such as the Strait-Trait Anxiety Inventory (STAI-T).

Results from the EURELD Study Presented

Sunday Morning's EAPC workshop session focused on presenting and discussing the results of the "Palliative care and end of life decisions in six European countries (EURELD) study, chaired by Luc Deliens, EMGO Institute, Netherlands and Agnes van der Heide, Erasmus MC, Netherlands.

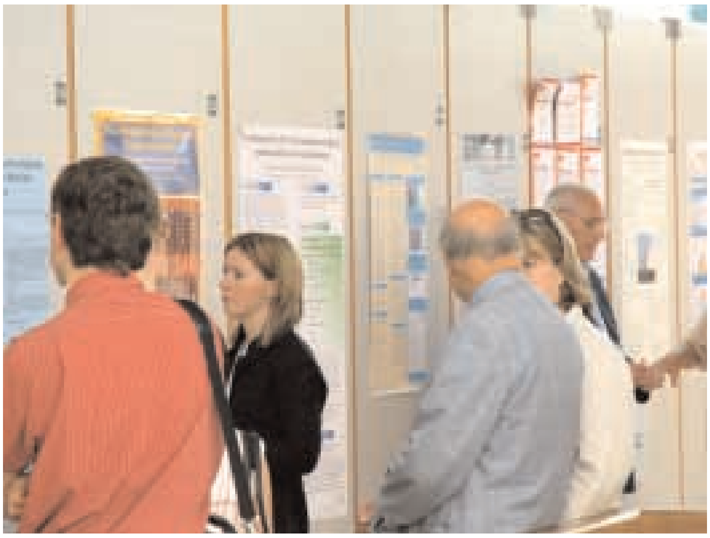
EURELD, an empirical study of end of life (EOL) decision making, was conducted in 6 European countries – Belgium, Denmark, Italy, The Netherlands, Sweden and Switzerland, and involved the study of 20,480 deaths.

Within EURELD, EOL decisions were understood to include decisions about whether or not to withhold or withdraw potentially life-prolonging treatment (e.g. mechanical ventilation, tube-feeding, dialysis), decisions about the alleviation of pain or other symptoms (for example with opioids, benzodiazepines or barbiturates in doses large enough to hasten death as a possible or certain side effect), and decisions about euthanasia or physician assisted suicide, defined within the study as the administration, prescription or supply of drugs to end life at the patient's explicit instructions.

A vast array of the study's results were presented, over the course of the session, including:

- On average, palliative care professionals involved in EURELD had received 3-6 days specific palliative care training, however almost all of the physicians questioned would like more training
- Opioids are commonly used in EOL practices in all study countries, however their route of administration varies considerably.
- Strong' opioids are used in all countries, however the type of opioid varies considerably – raising questions about appropriate use of guidelines
- Deep sedation until death (DSUD) is a frequently applied practice in all the countries involved in the study, although rates differ considerably

Referees Lars Johan Matersvedt, Norwegian University of Science and Technology, Norway and Andrew Davies, University of Bristol, Southampton, underlined the importance and relevance of the study, and discussed a number of points they felt needed to be elaborated. Matersvedt explained he felt a need for precise definitions and rationales for the terms used within the study and for detailed information regarding which drugs were used by physicians, and in which instance. Davies also explained that the study prompted a number of interesting questions and worries for palliative care professionals, such as the difference between DSUD and physician assisted suicide, and the ethical role of physicians in providing pain relief for a patients who have not requested pain relief.



EAPC Delegates Discussing Poster Presentations

The EAPC daily congress highlights report service is supported by an educational grant from the Purdue Mundipharma Napp associated independent companies