EAPC news and views

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Recommendations for palliative care curricula

In November 2000, on the initiative of EAPC's education network, 30 experts from 12 countries, representing five disciplines, met in Lyon for two days. The aim of the work was to design recommendations for palliative care education for healthcare professionals in the fields of medicine, nursing, psychology, social work and pastoral work. Two postgraduate levels of education were developed; one for those healthcare professionals working part-time with palliative care patients, and one for care professionals working full-time in palliative care. The recommendations include core, multiprofessional, educational objectives, together with discrete, unidisciplinary, educational objectives. These have been finalised following the meeting and will be circulated to participants as well as other professionals in other countries to produce a definitive draft.

These recommendations will be presented at the forthcoming EAPC Congress, in Palermo (session 62).

It will be an excellent opportunity to meet those of you interested in palliative care education.

Bernadette Wouters, Belgium; John Ellershaw, UK, Co-Chairs of the EAPC Education Network

Progress in palliative care in Italy

The issue of palliative care has been given a huge boost over the last 12 months through the proposal of two important bills. The first provides financial support for all hospice structures throughout Italy and the second calls for a revision to the current law regulating the prescription and distribution of opioids.

In addition, an enquiry has been launched by the Floriani Foundation to discover how much the people of Italy know about palliative care. More than 1,000 people around the country, ranging from 15 to 70 years old, were asked. The results showed that 38% of the people surveyed had heard of palliative care but only 15% knew that this type of care dealt with the end of life.

Knowledge of palliative care is greater among those with high levels of education. The need for palliative care is recognised by 70% of the people. Fifty-four per cent thought that the GP was the right person to offer such care, while 29% thought that a hospital was the most appropriate place to provide palliative care.

Surprisingly, the results showed that the population in the north and north-east of the country were the best informed and that knowledge of this issue is greater in towns than in the villages.

Vittorio Ventafridda, Professor in Palliative Medicine, Honorary EAPC President, Scientific Director of the Floriani Foundation, Italy

Burnout prevention and capacity building

American healthcare organisations concerned with burnout prevention and capacity building turn to the Health Cares Exchange Initiative, Inc. (HCEI), a Boston-based educational public charity founded in 1992 by R Scott Boots.

Dealing with issues such as funding, client mortality, and even new drug treatments, carers are often at risk of compassion fatigue, creating huge gaps in expertise and compassion. However, it is possible to educate carers about how to identify and respond to stress.

HCEI works to create supportive networks for carers in various geographic areas and then focuses on burnout prevention, enhanced community-based care for their patients, and encourages collaborations. Carers also benefit from exchanging information with peers in supportive, non-conference settings.

Working out of his apartment with an annual budget of $500, Boots built networks of carers in six parts of the USA and held the first-ever focus groups for both paid and non-paid AIDS carers. As a result, HCEI developed a 'Beating Burnout' workshop, which has been presented to a wide variety of conferences and audiences, HIV-related and otherwise, and has also developed a capacity building workshop for rural and less-affected AIDS carers.

HCEI currently seeks seed grant funding or sponsorship opportunities, and is eager to network, collaborate, and subcontract. For further information, contact Scott Boots at HCEI, PO Box 131, Boston, MA, 02133, USA, or by email (rsbkc@yahoo.com).

R Scott Boots, Founder and Director of HCEI, Boston, USA

Gathering of social workers

31 March 2001, 16.00–18.00 Fiera, Palermo

This meeting is for social workers and others interested in developing social work within the field of palliative care.

The aim of the meeting is to foster a sense of colleagueship and commonality among social workers in Europe by looking at the similar problems, challenges and differences that range between the various contexts and approaches. It will also provide a good opportunity to learn from each other.

The previous meetings at other EAPC Congresses were informal but very supportive; people valued meeting across borders, and some good contacts have been established for ongoing work.

I do hope as many of you as possible will be able to come. Do let me know if you think you might be able to attend and I trust you will be able to say something about social work in palliative care in your part of the world.

The meeting will be conducted predominantly in English and French; however, other languages may be used, depending on the participants present.

David Oliviere, Macmillan Principal Lecturer, Middlesex University, London, UK

www.palliativedrugs.com

Produced by Dr Robert Twycross and Dr Andrew Wilcock, authors of the *Palliative Care Formulary*, the website, **www.palliativedrugs.com** offers essential, comprehensive and independent information about the use of drugs in palliative care for all healthcare professionals, particularly doctors, nurses and pharmacists involved in the care of patients with cancer.

The site was launched in November 2000. Currently, it has over 850 members and receives over 120 hits a day.

Unlicensed indications and unlicensed routes of administration are noted and there is a section on giving multiple drugs by continuous subcutaneous infusion.

Although some of the site content is specific to the UK, it contains information that will be useful to all practitioners. Other country-specific versions will soon be available, beginning with Australia, Canada, the Netherlands, New Zealand, Portugal and Sweden.

The site is free to browse and use but full access to all of its facilities requires registration. Registered users will have access to the contents and search facilities. In addition to providing drug information, it is hoped to develop a sense of community for users of the site through the bulletin board, which encourages advice, questions, sharing of experiences and feedback about the site. An email newsletter updated monthly containing the latest news about the use of drugs in palliative medicine is also offered.

Robert Twycross, Clinical Reader in Palliative Medicine, Oxford; Andrew Wilcock, Senior Lecturer in Palliative Medicine and Medical Oncology, Nottingham; Andrew Dickman, Specialist Pharmacist in Palliative Care, Whiston Hospital; Sarah Charlesworth, Palliative Care Information Pharmacist, Nottingham, UK

Palliative care at home: the views of terminally ill patients and their carers

This study explores the needs and experiences of terminally ill patients and their carers. It seeks to establish their views on the health problems or needs they have, and on the service provision and adequacy in addressing these problems or needs.

Semi-structured interviews have been held with patients in the last three months of their lives, their carers, providers (GPs and nurses); and with bereaved carers. The study is being conducted in Limburg, the Netherlands.

Interviews include questions regarding 1) the most salient health problems that patients and their carers encounter, 2) the needs of patients and their carers for home care, and 3) the extent that home health services meet these needs. Data are being analysed using the procedures and principles of grounded theory.

A total of 13 patients, 13 carers, 14 bereaved carers, and 13 providers have been interviewed. The results will focus on the needs of terminally ill patients and their family carers for palliative care at home. Based on these results, recommendations for good practice will be made to develop home care services for terminally ill patients and their carers.

For further information, please contact Ireen Proot, Institute for Bioethics, PO Box 616, 6200 MD, Maastricht or via email (i.proot@ige.unimaas.nl).

Ireen Proot, Centre for Nursing Research, Institute for Bioethics; Huda Huijer Abu-Saad, Centre for Nursing Research; Minke Goldsteen; Guy Widdershoven, Department of Health Ethics and Philosophy, Maastricht University, Maastricht, the Netherlands

If you have anything that you would like to contribute to EAPC news and views, please submit your contribution in French or English (200 words maximum) to bethan.france@hayward.co.uk in rich text format.

Resources

Never too young to know: death in children's lives

Phyllis Rolfe Silverman

New York: Oxford University Press, 2000
£19.95, 288 pages

This book skilfully integrates theory, research and narrative evidence to demonstrate how to support children through the painful experience of death, loss and grief.

The book starts with an exploration of how children make sense of death. It examines historical and theoretical perspectives, child development, the role of the family, and bereavement theories.

The second part 'stories people tell' validates the theories discussed in part one. It is aimed at the bereaved, to legitimise their experiences, and at healthcare professionals, to raise their awareness of complex and sensitive issues. Poignant stories demonstrate with clarity the effect of loss and grief on children. It comprehensively covers issues surrounding the death of a parent, the dying child, sibling death, suicide, anticipated death and the death of a friend.

The part 'Helping' discusses the practicalities of offering individual help, responsive to the needs of the bereaved, as time moves on and offers suggestions for sources for help. There is a critical review of US bereavement organisations, with advice as to the type of help that similar organisations may be able to offer.

'Teachable moments' draws the book to a close by reiterating the role and responsibilities of adults when talking to children about death and dying.

The book demonstrates with great sensitivity that children are never too young to know. Easy to read, it can be used as a resource to be consulted as required. The use of narratives clearly demonstrates the pitfalls of good intention and enhances the theoretical and research material. It will be valuable for healthcare professionals and teachers of children and nurses.

Beth Sepion, Paediatric Programme Leader, Centre for Cancer and Palliative Care Studies, London, UK