



Palliative Care Research Society

Newsletter

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PCRS AGM

The PCRS held its Annual General Meeting as part of the one day meeting, reported later, in September. The minutes of the meeting are now available on the PCRS website at www.pcrs.org.

Forthcoming conferences and study days

7th Palliative Care Congress

A reminder that abstracts for this conference, jointly organized by the PCRS, need to be submitted by 5pm, Friday 12th October. Abstracts are welcomed in three categories: Research; Clinical innovation and Art. Abstracts submitted under the 'Clinical Innovation' and 'Art' categories will be reviewed by a panel with an interest and/or working within this field. Research abstracts will be reviewed by the Scientific Committee. Please see the website <http://www.pccongress.org.uk> for up to date information

EAPC Research Forum

The 5th Research Forum of the EAPC is in Trondheim, Norway from the 29th to 31st of May 2008. Abstract submission closes soon, on 15th October 2007. Abstracts can be submitted on line at <http://forskningweb.org/eapc2008/abstract-submission/>.

The 7th Palliative Care Congress

The Glasgow Royal Concert Hall
Glasgow, Scotland

Tues 29th April - Thurs 1st May 2008



KEYNOTE

- An international perspective on palliative care research - Sanchia Aranda

SESSIONS WILL INCLUDE:

- symptom management from lab to bedside
- psychological distress
- palliative care for children and young people
- debate - 'choice is a myth that we collude in'
- palliative care for non cancer patients
- research abstracts

CALL FOR PAPERS

Call: Friday 25th May 2007

Close: Friday 12th October 2007

Registration will be available from August.

For further information visit our website:
www.pccongress.org.uk



The Palliative Care Congress
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Hampshire, SO17 1DL
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Charles Rennie Macintosh 'Harvest Moon' supplied courtesy of The Glasgow School of Art



NCRl Supportive & Palliative
Care (SuPaC) Research
Cancer experiences: supportive and
palliative care needs, problems and
solutions



Master Class: Ethical Issues in Supportive and Palliative Care Research

Chancellors Hotel and Conference Centre, Manchester
4th December 2007

- **Ethical Issues of Intervention in Research:**
Martin Johnson (University of Salford)
- **Palliative Care Research: An Ethicist's Perspective:**
Eve Garrard (University of Keele)
- **Ethical Issues within Supportive and Palliative Care Research:**
Gunn Grande (University of Manchester)
- **Insights into the Ethics Committee:**
Gary Young (Chair of Wigan Ethics Committee)
- **Navigating Ethics Committees:**
The Conflict between Ethics and Research & Development
Eleanor Thomas (Wythenshawe Hospital)
- **Mini-Master-class: The new National Research Ethics Service (NRES) Application form (formerly COREC)**

For queries regarding registration details and payment, please email: susan.tizini@manchester.ac.uk

For further information about the event or travel to the venue: www.ceco.org.uk or
www.conference.manchester.ac.uk

Chancellors Hotel and Conference Centre, Chancellors Way, Moseley Rd, Manchester, M14 6NN.

The Ethical Issues in Supportive and Palliative Care research master-class is aimed at researchers, clinicians and service users who have an interest in research ethics in palliative and supportive care.

APM study days

In October 2007, two study days are planned:

"Appraising Literature in Palliative Care" on Thursday 18th October 2007 and **"Getting Started in Palliative Care Research"** on Friday 19th October 2007. These are designed as a high quality introduction to research for specialist registrars, but will also be very suitable for other palliative care professionals. All are welcome to attend, and there will be a combination of presentations and workshops to get you thinking about the practicalities and realities of research. The days will be held in Newport, Wales, and can be attended either singly or together - further details and booking contacts will be available shortly on the Association for Palliative Medicine website at <http://www.palliative-medicine.org/> and also on the PCRS website.



Social and Psychological Aspects of Dying in Old Age ESRC Seminar Series

The aim of the series is to develop new thinking about the processes of dying in old age drawing on a range of social science disciplines including geography, psychology, sociology and gerontology and older people themselves. Two seminars remain:

| Seminar Programme | Location | Date |
|---|-------------|-----------------|
| Seminar 3 <i>Priorities for Older People Facing Death in Old Age</i> | Southampton | 1 November 2007 |
| Seminar 4 <i>Planning for Death in Old Age</i> | Edinburgh | May 2008 |

For further information about the seminars or to book a place, please contact Katherine Froggatt on k.froggatt@lancaster.ac.uk or telephone 01524 593309.

Research in Primary Palliative Care Masterclass

March 6th 2008, Edinburgh

Organised by NCRI Primary Palliative Care group, NCRI SuPaC collaboratives and PCRS, this is a 1 day event covering methodological aspects of this important new field and examples of studies from leading researchers. Further information will be available from www.pcrs.org, but put the date in your diaries now.

Research funding

Dimbleby Cancer Care Research Fund

The closing date for initial bids to the Dimbleby Cancer Care Research Fund is the 22nd November 2007. The aim of the fund is to enable a better understanding of the needs of patients – from diagnosis, through treatment, to recovery or end of life – and to discover how those needs can best be met, to offer improved psychosocial care to patients, their families and carers, to facilitate better communication and continuity of care throughout a patient's cancer journey, and to test the efficacy of, and improve, existing support strategies. Full details are available at www.dimblebycancer.org

PCRS Annual Scientific Meeting

At the recent PCRS One Day Scientific Meeting, held in Oxford on the 13th September, a broad range of topics were covered, incorporating a variety of research methodologies: preferred place of death, cachexia, cardiopulmonary resuscitation at the end of life, research methodology in clinical trials, the validation of screening and measurement tools, depression and demoralisation, primary palliative care, and end-of-life stroke care.

Place of care: Opening the day, Deirdra Sives (Strathcarron Hospice) examined challenges in exploring the wishes of patients and carers with regard to preferred place of death. A retrospective case notes review revealed that a preferred place of care was recorded for only 33% of patients, suggesting the need for a more structured and consistent approach to raising

what can seem to be a sensitive topic for patients. Dr Sives was this year's recipient of the Frances Sheldon Novice Researcher Award for students studying for a higher degree.

Cachexia: Various aspects of cachexia were considered in three different papers. Joanne Reid (Belfast City Hospitals Trust and Queens University, Belfast) presented the findings of her interpretative phenomenological study of patients' and their carers' experiences of living with cachexia, showing the ways in which families focussed on food as an indicator of well being, while patients developed strategies to avoid conflict related to eating. The response of health care professionals was perceived by patients and their carers to be inadequate. Simon Coulter (Northern Ireland Hospice Care, Belfast) challenged the palliative care professionals' notion that weight assessment causes distress to patients. The vast majority of patients in his sample (91%) wanted to know about weight changes, emphasising the need not to assume that patients would prefer to avoid information on their weight loss, and highlighting the importance of asking patients what support would be preferred. Jane Hopkinson (University of Southampton) presented a model of patients' self-management of changed eating habits, and considered the impact of carers on patients' self-management behaviour. She described the ways in which some carers' behaviours enhanced patients' self-management, while others were obstructive, and argued that self-management might best be facilitated using a family-centred approach.

Self care: Picking up on the theme of self-management, Bridget Johnston (University of Stirling) described a systematic review of self care in end-of-life care, demonstrating some of the difficulties encountered in reviewing literature incorporating a wide range of research designs, and concluding that self care in chronic illness, and self care at the end of life, should not be taken to mean the same thing.

CPR: In the final paper of the morning session, Steve Brummell (University of Nottingham) gave a fascinating insight into the strategies used by staff in Accident and Emergency departments to deal with the emotional labour of unsuccessful cardiopulmonary resuscitation attempts. Using an ethnographic approach incorporating non-participant observation and semi-structured interviews, the data revealed three strategies used by staff, corresponding to different phases of the resuscitation process: an emotional dissociation during active resuscitation, followed by the re-humanising of the patient upon cessation of resuscitation, and concluding with the concealment of personhood as the body is prepared for removal.

Keynote: In an excellent and highly thought-provoking key-note address, Professor Irene Higginson (King's College London) considered the implications of our aging society (and corresponding increase in numbers of deaths) for palliative care research, asking what the future priorities for palliative care research should be. She began by querying the usefulness of the term 'end of life care': is it a definition that can only be applied in retrospect, with a meaning so diverse and context-dependent as to be useless? She then went on to report on the recommendations for future palliative care research which have emerged from a recent appraisal carried out for the NHS Service Delivery and Organisation Research and Development Programme. Noting that the majority of research in palliative care is descriptive, she posed the question: 'should we prioritise programmatic research and intervention studies?', and encouraged the audience to engage in a debate on the way forward for palliative care research.

Trials: After lunch, Sir Andrew Fowell (North West Wales NHS Trust) described the development and design of switchback cluster randomisation as a novel approach to trials in palliative care, proposing that this methodology has the potential to overcome issues surrounding consent, gate-keeping and attrition, and enables research to be undertaken as part of routine care.

Prognostication: Paddy Stone (St George's Medical School, University of London) reported on the development and validation of a prognostic scale, assessing its value in predicting 14 day survival. Four factors were found to be independently predictive of survival: a raised CRP, poor performance status (ECOG 4), primary lung cancer, and secondary liver cancer. While a high score on the prognostic index was associated with poorer survival, the clinical utility of the scale was limited by the relatively low predictive power of the score.

Distress: Chitra Venkateswaran (St Gemma's Hospice Leeds) presented the findings of a study seeking to validate screening tools for detecting distress in palliative care patients. Three measures were used: Brief Symptom Inventory-18, General Health Questionnaire-12 and the Distress Thermometer. Results indicated a predominance of adjustment disorder (22%) with major depression accounting for only 7.3% of diagnosable psychiatric illness. Taking further the discussion of psychological morbidity, Suzanne Edwards (University of Liverpool) outlined the methodology to be used in a study to determine the prevalence, aetiology and natural history of depression and demoralisation in patients with advanced cancer.

Primary Care: Stephen Barclay and colleagues (University of Cambridge) presented two papers looking at topical issues in primary palliative care. In the first, four out-of-hours service providers were surveyed with regard to the needs of patients requesting assistance in the palliative or terminal phase of their illness. The majority of calls were for management of distressing physical symptoms, highlighting the need for an educational agenda for GPs working out-of-hours. In the second paper, the views of a large sample of GPs and community nurses were sought on their role in providing specialist palliative care, team-working across primary care and specialist services, and current and future palliative care provision. Both GPs and community nurses viewed the provision palliative care as central to their role, valuing the support of specialist care when appropriate. Bringing the day to a close, Amanda Young (University of Southampton) reported on a VOICES survey of the satisfaction with care in the last three days of life of stroke patients.

Feedback from the meeting was extremely positive – 'interesting range of methodologies and content', 'stimulating discussions', 'very enjoyable' – although there were a number of requests for 'more quantitative presentations' and 'more science content'. A preliminary date for the next One-Day Scientific Meeting has been set for around March 2009.

Many thanks to all who participated, for a most interesting and stimulating day.

Gail Eva

Frances Sheldon Novice Researcher Award

Congratulations to Deirdra Sives, the recipient of this years Frances Sheldon Novice Researcher Award. Deirdra was appointed to the post of Medical Research Fellow at Strathcarron Hospice Denny, Stirlingshire in March 2007, from Third Year Specialist Registrar Training on the West Of Scotland Palliative Medicine rotation. During this two year post Deirdra hopes to complete her MD at Edinburgh University before returning to complete Specialist Registrar training in March 2009 obtaining her CCST in October 2009.

Her areas of research interest include non-malignant disease, particularly COPD and Renal disease, and preferred place of care at the end of life. She hopes to develop this area of preferred place of care and advance care planning further through her proposed MD study.

Membership fees

Can we please remind you that the membership fee for the PCRS has gone up from £20 to £30? This still represents excellent value for money, particularly as you can re-coup some or all of this fee in reduced admission rates to PCRS or EAPC conferences. Standing orders to

the society can be easily amended on-line or by telephone with your bank or building society. Unfortunately we are not allowed to do this for you. Alternatively, you can send the monies to our treasurer, Dr Gunn Grande, The School of Nursing, Midwifery and Social Work, The University of Manchester, Coupland 3, Oxford Road, Manchester, M13 9PL or contact her at gunn.grande@manchester.ac.uk

PCRS website

Have you checked out the PCRS website recently? This is where you'll find information about the PCRS such as our constitution and strategy, executive committee, details of abstract submission, archived newsletters and useful links. Make sure you've bookmarked it at www.pcrs.org.uk!

PCRS Committee

The role of secretary to the society has been handed over at the AGM from Jane Seymour to Marilyn Kendall. Many thanks to Jane for her work for the PCRS, and to Marilyn for taking on this role. Full details of the committee can be found on the website.

Joining the PCRS

The society is easy to join, with full details and an on-line form on the website at www.pcrs.org.uk. Membership costs just £30 per year and benefits include:

- Reduced registration fees for some of the conferences organised, or jointly organised by the PCRS (note: individuals who are considering attending at least one such conference during the year will often find it economically advantageous to join the PCRS simply in order to benefit from the reduced conference fee). Note: this does not apply to every conference.
- Access to a list of members' contact details and research interests to facilitate multi-professional and multi-centre research initiatives.
- PCRS newsletters.
- Reduced subscription fees to the journal 'Mortality'.

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