

THE EAPC RESEARCH NETWORK

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GENERAL

INTRODUCTION

For many years there has been a debate about the need for research in palliative care. Some clinicians have argued that research in seriously ill and dying patients is unethical. Others have argued that there is a great need of research in palliative care. The Board of Directors of the EAPC considers research is a key issue for the future of palliative care. Between 1992 and 1996 the EAPC organised three meetings of expert working groups. The results from two have been published as guidelines:

1. Hanks GW, De Conno F, Ripamonti C et al. Morphine in cancer pain: modes of administration. BMJ 1996; 312: 823–826. Elaborated by palliative care experts and pain specialists.
2. Bozzetti F, Amadori D, Bruera E et al. Guidelines on artificial nutrition versus hydration in terminal cancer patients. Nutrition 1996; 12: 163–167. Consensus among palliative care experts and cancer experts

Following the success and positive impact of these expert groups, organised in December 1995 the EAPC Board of Directors endorsed the proposal for a Research Network, appointing Franco De Conno, who had organised the three groups, chair of the Network.

STEERING COMMITTEE

The Network is established and managed by a Steering committee. Since 1996 the following experts, joined this committee. Its members are proposed by the collective members, the Board of Directors of the EAPC, and the members of committee themselves. The size is determined by necessities and financial resources available for its meetings.

Chair: Franco De Conno

Members:

Augusto Caraceni
Nathan Cherny
José António S. Ferraz Gonçalves
Carl Johan Fürst
Geoffrey Hanks
Stein Kaasa
Henry J. McQuay
Johan Menten
Sebastiano Mercadante
Juan Manuel Nuñez Olarte
David Oliviere
Philippe Poulain
Lukas Radbruch
Carla Ripamonti
Friedrich Stiefel
Mr. Peter Thomas

ORGANISATION

The co-ordinating secretariat of the research network is located at the Division of Rehabilitation, Pain Therapy and Palliative Care of the National Cancer Institute. The network must be self-financing. An annual meeting of the steering committee is guaranteed by an official link with SAMOT, and the Centre for Scientific Culture, Ettore Majorana. Most projects undertaken by the network should be self-funding.

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NETWORK MEMBERS

Palliative care units, teams, hospices or individuals can apply to join the Network. At the moment, it is difficult to produce criteria for the selection of centres. Individuals or centres joining the RN are classified into two groups: those with and those without research experience. Applicants must supply a list of their publications on peer review journals over the last two years. Minimum and maximum standards for the RN will be outlined in future, with the help of pilot projects. The steering group decided that once the Network will be well established its members had to be actively involved in the RN in order to retain membership and that the degree of member participation required would be outlined in these forthcoming standards.

OBJECTIVES

Reports on the situation of research in palliative care indicated that there are enormous differences between countries in Europe. These result in different needs

and expectations as far as a European research network is concerned. The committee decided that it would be premature to establish a network with the aim of multi-centre and multinational studies. Instead, it should make use of the considerable information and knowledge that exists among palliative care experts. The group will try to obtain the following objectives, depending on the resources available

1. Encourage the development of research respecting the ethical principles of Palliative Care
2. Encourage and address research in all fields: as well clinical, social, organisational, etc.
3. Offer teaching sessions with basic principles to all professionals
4. Discuss and assess where research is needed in Palliative Care
5. Discuss if, where and how such research is feasible in Palliative Care
6. Make the point of the current status
7. give the occasion to experts in research to meet
8. To organise expert working groups on a variety of research topics, to be reviewed regularly, especially where controversial issues are involved. These expert groups usually hold closed meetings but may start their work during international or national conferences. Expert group members may give presentations to an open audience. They then continue their work by corresponding with other members and the steering committee involved in the same project. The end result should be an official publication.

Authorship: For publications resulting from initiatives of the RSC or in collaboration with the RSC. The co-ordinator (or chairperson) is the first author followed by the names of those working in the expert group and the caption: "and the research steering committee of the EAPC. The names of the steering committee having participated in the work of this group shall be listed in a footnote.

ALL EXPERT GROUPS MUST GUARANTEE THAT RESULTS OF THEIR WORK AND PUBLICATIONS ARE ELABORATED INDEPENDENT FROM ANY INFLUENCE REPRESENTING COMMERCIAL INTEREST.

9. To draw up a European database, or encourage the establishment of national databases for:
 - Centres interested in joining the research network.
 - Experts in different fields of palliative care.
 - Centres needing help to initiate research.
 - Possible investigators.
 - Useful documents.
10. To provide expert panels.
11. To organise courses on:
 - Study design in palliative care.
 - New EC regulations for clinical trials.
 - The role of the investigator, sponsor, monitor and central co-ordinator in clinical trials.
12. To act as a co-ordinating /advisory body for sponsors and possible investigators.
13. To become itself, or establish, an advisory board for palliative care research for organisations in the EU.
14. To help countries where clinical trials and multi-centre studies have not yet been carried out or are difficult to organise.

ACTIVITIES (updated periodically) updated as to : August 1999

STEERING COMMITTEE MEETINGS

1. 8-9 February 97, Erice, Italy, Ettore Majorana Centre for Scientific Culture, hosts: Dr. F. De Conno, Dr. G. Trizzino, Prof. GP Velo
2. 28-29 February 98, Erice, Italy, Ettore Majorana Centre for Scientific Culture, hosts: Dr. F. De Conno, Dr. G. Trizzino, Prof. GP Velo
3. 16 October 1998, Oporto, Oporto, Portuguese Association of Palliative Care (Associação Nacional de Cuidados Paliativos), Institute of Oncology (Instituto Português de Oncologia) host: Dr. J. Ferraz Concalves
4. 4 March 1999, Athens, Greece, 2nd International and Hellenic Conference on Pain Relief Palliative Care, host: Dr. K. Mystakidou
5. 16-17 October 1999, Erice, Italy, Ettore Majorana Centre for Scientific Culture, hosts: Dr. F. De Conno, Dr. G. Trizzino

EVENTS

Workshop on the activities of the EAPC Research Network

(Geneva, Switzerland 6th congress of the EAPC, 23 September 1999)

Chair and introduction

Franco De Conno

PART 1: Individual lectures of the Chairpersons on the results of the current activities Participants: Augusto Caraceni, Geoffrey Hanks, Carla Ripamonti, Nathan Cherny, Lukas Radbruch & Sebastiano Mercadante

PART 2: Short introductions and roundtable discussion with the members of the Research steering committee on passed, ongoing and future activities.

Introduction to Research in Palliative Care - Seminar on Basic Research Knowledge (Geneva, Switzerland 6th congress of the EAPC, 24 September 1999)

Goal: To improve participants' basic skills in research methodology and thereby encouraging the number of projects undertaken in palliative care.

Target group: Nurses, doctors and other health carers who want to participate in a short introduction to research. It is no need for basic skills in neither statistics nor research methodology.

The chair Stein Kaasa will try to edit a booklet to be published as a stand alone publication from the EAPC Research Network of approximately 20 pages to be distributed to the Network members and the persons attending the Seminar.

Chair:

Stein Kaasa & Franco de Conno

Introduction - overview

Stein Kaasa

Ethical challenges Robert Dunlop

About the Research Network of the EAPC Onlus

Design of prospective clinical studies, general considerations
Measures of pain and other symptoms
How to conduct studies in symptom control
 A doctor's view -
 A research nurse's view -
Assessment of palliative care programs

Stein Kaasa
Augusto Caraceni
Geoffrey Hanks
Helen Morgan
Irene Higginson

Recommendations in Palliative Care, Florence, Italy, International Congress on Pharmacology and Therapy, July 2000

The director of the School which hosts the meetings in Erice, Giampaolo Velo has inserted a session on Palliative Care Research, in collaboration with the Research Network of the EAPC, in the scientific programme of the International Congress on Pharmacology and Therapy to be held in July 2000 in Italy. The session will be as follows:

Chair and introduction:	Franco De Conno
Methodology and ethics of research in Palliative Care	Stein Kaasa
Modes of Administration of third step Opioid Analgesics in Cancer Pain	Geoffrey Hanks
Difficult pain problems	Lukas Radbruch
Detection and Management of Depression in Palliative Care	Frédéric Stiefel
Corticosteroids in Palliative Care	Carl Johan Fürst

Conference on Research and Development in Palliative Care, Germany, Italy, First Congress of the Research Network, November 2000

After the first two years of its work the Steering Committee of the Research Network has decided that it was time to organise a conference dedicated only to Research in Palliative Care in the years intermediate to the Biennial European Congress of the EAPC.

The objectives of these conferences shall go hand in hand with the objectives of the Research Network. The Steering Committee wishes to give special attention to "ethical" considerations and Research and leave space for the controversial debate about ethics and research in PC. THE Congress will have the support and collaboration of the "Deutsche Gesellschaft für Palliative Medizin"

Chair, Scientific Committee: Dr. Lukas Radbruch

CURRENT EXPERT WORKING GROUPS

WHO guidelines on cancer pain management: Highlights Report on International Application and Current Appraisal, (collaboration with Excerpta Medica), London, 5th Congress of the EAPC, 13 September 1997.

The purpose of this working group was to review the current application of the WHO guidelines on cancer pain management in various countries around the world. In association with Excerpta Medica, a report of the meeting has been produced.

Chairs: Franco De Conno and Geoffrey Hanks.

About the Research Network of the EAPC Onlus

Experts: Robin Fainsinger, Carl Johan Fürst, Stein Kaasa, Sebastiano Mercadante, Wouter Zuurmond, Josep Porta, Lukas Radbruch, Nathan Cherny and Ben Zylicz. Additional commentators: Philippe Poulain and Jose Ferraz Goncalves.

This paper has been published by Excerpta Medica as a stand-alone publication. The EAPC will receive complimentary copies for RN members and the individual membership of the EAPC. The proposal of Janssen-Cilag to distribute further copies as a handout at the EAPC Congress was welcomed by the RSC.

Pain Measurement Tools and Methods in Clinical Research, Erice, Italy 27 February 1998.

Chair: Augusto Caraceni and Nathan Cherny. Experts: Robin Fainsinger, Stein Kaasa, Philippe Poulain and Lukas Radbruch.

The final version of the summary paper is under the last revision with the experts of the group and the RSC members. In the paper are included the translations of the Verbal Rating Scale of the SF36 as an Appendix. For Authorship will apply the internal rule of the RSC. The paper will be submitted to the JPSM. The editor of the Journal had expressed interest to publish the detailed review papers on the different subjects discussed together with the summary paper.

Guidelines on routes of administration for opioids, Rhodes, Greece, 19 the International Conference for Cancer Care 1 May

Chair: Geoffrey Hanks and Franco De Conno. Experts: Nathan Cherny, Magdi Hanna, Eija Kalso, Henry J McQuay, Sebastiano Mercadante, Jacques Meynadier, Philippe Poulain, Lukas Radbruch, Carla Ripamonti, Jordi Roca i Casas, Juliette Sawe, Robert Twycross, Vittorio Ventafridda.

This group met to discuss and update the following publication: Morphine in cancer pain: modes of administration. BMJ 1996; 312: 823–826. The new paper should be finalised by September 1999. The strength of the recommendations in this paper is

that it was produced without the support of the pharmaceutical industry, and is an independent consensus view.

What to do when oral morphine fails in treatment of cancer pain: Critical assessment of the strategies, Oporto, Portugal, Scientific Meeting of the Portuguese Association of Palliative Care, 17-18 October 1998:

Chair: Nathan Cherny and Carla Ripamonti, Experts: Carol L. Davis, Marie Fallon, Sebastiano Mercadante, Henry McQuay, Gavril Pasternak, José Pereira. RSC members participating: Augusto Caraceni, Franco De Conno, José Antonio Ferraz Goncalves, Stein Kaasa, Philippe Poulain

The Group decided not to use the term opioid rotation but opioid switching and agreed that the paper to be written by the group should have the following title: What to do when Oral morphine fails in treatment of cancer pain: Critical assessment of the strategies practised.

Breakthrough Pain - Episodic Pain, Athens, Greece, 2nd International and Hellenic Conference on Pain Relief Palliative Care, 5-7 March 1999

Chair: Sebastiano Mercadante and Lukas Radbruch, Experts: Augusto Caraceni, Nathan Cherny; Friedeman Nauck, Stein Kaasa, Carla Ripamonti. RSC members participating: Franco De Conno, José Antonio Ferraz Goncalves, Geoffrey Hanks, Philippe Poulain.

The first meeting of this group revealed big differences as to definition and approach within Europe and the USA, the group will try to produce a document analysing these differences.

FUTURE EXPERT WORKING GROUPS

Detection and Management of Depression in Palliative Care
(Geneva, Switzerland 6th congress of the EAPC, 24-25 September 1999)

Psychiatric disorders in patients with chronic and severe illnesses are prevalent and often remain undetected. The resulting undertreatment adds a considerable amount of suffering to the burden of having a disease. The research steering committee has therefore decided to organise an expert panel on the problem of depression in palliative care. The goal of this workshop is to discuss research strategies to improve the detection and treatment of one specific mental disorder frequently encountered in palliative care. The Experts will review and discuss the subject in a workshop and try reach consensus on in a subsequent closed session. The results of the workshop and closed session will be published in a leading palliative care journal.

Chair:	Frédéric Stiefel & Juan Manuel Nuñez Olarte
Detection and screening of depression	Darius Razavi
Education of physicians for increasing the recognition of depression	Peter Maguire
Psychotherapy of depression;	Maria Die Trill
Psychopharmacology of depression	Alexander Berney

The indications and use of steroids in Palliative Care Erice,
Erice, Italy, 15-16 October 1999

Corticosteroids are extensively used in palliative care. However, the indications for use and the use of different drugs and dosages are very much guided by clinical experience. The scientific evidence base is not comprehensive and the drugs do not seem to be economically interesting for the pharmaceutical companies selling them. The mechanisms behind the effects – and side effects – of corticosteroids are largely unknown. At the occasion of the next meeting of the RSC to be held at the Centre for scientific culture the RSC will organise the sixth expert working group.

This group will look into basic pharmacological principles of corticosteroids and investigate evidence and experience based knowledge related to the indications and use of corticosteroids in palliative care. Examples of areas that will be covered are pain, anorexia, cachexia, fatigue, neurological problems, nausea and somatic as well as psychiatric side effects.

Chair: Carl Johan Fürst and Stein Kaasa, Invited experts: Paul Andrews, John Ellershaw, Tali Siegal, Declan Walsh. RSC members: Franco De Conno, Augusto Caraceni, Jose Antonio Ferraz Goncalves, Geoffrey Hanks, Johan Menten, Sebastiano Mercadante, Juan M. Nuñez Olarte, David Oliviere, Philippe Poulain, Lukas Radbruch, Frédéric Stiefel, Peter Thomas

PROJECTS

Cross Sectional Survey

Nathan Cherny has drafted a form for a one day cross sectional survey to collect epidemiological data, for example - age, sex, pathology, diagnosis, pain yes no, assessment tool used, Actual Analgesics drug, dose, non drug therapy etc..... The members of the RSC have checked and completed the questionnaire considering legal aspects and feasibility in their country.

In 1998 Geoffrey Hanks had submitted on behalf of the Research Network of the EAPC an application to the European Union for funding to support the survey. In March 1999 he received a positive reply that EU funding would be partly granted if the group would collaborate with a centre who had submitted an application for another survey in Palliative Care. Geoffrey Hanks is in contact with this applicant to check for feasibility of such a collaboration.

The action plan once the feasibility of the collaboration will be confirmed, should be the following:

Study co-ordination: The steering group will appoint a study co-ordinator for each member states and each additional other country.

Translation: The study co-ordinator will be responsible for the translation of the questionnaire in his language, if English can not be used. The questionnaire being composed by simple words and not containing sentences or expressions that risk to be misunderstood, the group agreed that a translation - cross translation should be enough to guarantee the data collected for the different items in the different languages.

Centres: The study co-ordinator will select the Centres among the list of centres having adhered the Network and centres he may recruit with the help of the National Association.

Validation study of translations of the VRS of the SF 36

Stein Kaasa has obtained agreement to use the translations of the Verbal Rating Scale of the SF 36 validated for quality-of-life studies. The RSC plans to draft a

simple protocol to check and validate translations of the Verbal Rating Scale for the use in palliative care in the most common European languages and eventually compare it to VAS and NRS.

Survey on Opioid availability in Europe

Philippe Poulain is currently elaborating a project of a survey on Opioid availability in Europe.

Projects for Social Science Research in Palliative Care

David Oliviere is currently elaborating a list of possible projects **for Social Science Research in Palliative Care** to propose to the steering group.

The RSC wishes to express their thanks to the following institutions for their support to the Network and to the realisation of the projects:

- National Cancer Institute, Milan, Italy
- Portuguese Association of Palliative Care and the Portuguese League against Cancer Association for Pain Control
- Jenny Karezy Foundation and the Hellenic Association for Pain Control
- International School of Pharmacology at the Ettore Majorana Centre of Scientific Culture
- Regione Siciliana
- Assessorato alla Sanità della Sicilia
- SAMOT
- Angelini A.C.R.A.F. Spa
- ASTA Medica
- Janssen Cilag
- Zambon Italia

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