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Editorial

Collaborate to catalyse good and sustained research: reflections from Venice 2006

The (Venice) mask veils aspects of interlocutors face while emphasizing alert, inviting eyes

The Fourth EAPC Research Forum in Venice

Numerous opportunities to meet other people attracted to the same session, individually sought-out or coincidentally met at the convivial get-together on the terrace. A total of 1037 participants, from many disciplines (20% nurses, 70% physicians, 10% others), research settings and nationalities (79% from 19 west European countries, 6% from 10 east European countries, 8% from two north American countries, 1% from four south American countries, and 6% from 16 other countries (3% Australia)). The majority of participants were active researchers, involved as an invited speaker (58), presenter of an oral communication (115), poster (365), or as a co-author.

The Venice forum was encouraging

A (growing) research community could be felt radiating the indispensable sense of friendship essential to maintain the 'holy fire' to sustain research activities in palliative care. An interdisciplinary, constructive and critical (but respectful) discussion culture, seeking the best methodology and (collaborative) settings, was evident in the majority of sessions and encounters. It was apparent that what drives (most) relevant research questions on all aspects of multidimensional care is an underlying commitment to compassionate care for our patients and partners.

Research community

A research community in palliative care is about people, individuals who embark on the difficult but rewarding path to learn to perform, conduct and sustain research, while also engaged in developing and maintaining clinical services.

Sense of community

Wikipedia describes 'sense of community' as: 'With sustained connections and continued conversations, participants in communities develop emotional bonds, intellectual pathways, enhanced linguistic abilities, and even a higher capacity for critical thinking and problem-solving.'

Is it not this that we experienced in Venice? A sense of a palliative care research community of substantial potential, sharing the common sense of purpose, that research constitutes an essential part of palliative care, requiring special precautions to protect vulnerable patients who may be more willing to participate in research than one would expect of a 'usual' population of patients.

Responsible faculty

The palliative care research community, compared to other areas of healthcare, comprises a variety of disciplines and professions, and research and clinical settings. It bridges basic, biological, and behavioural research, clinical, psychosocial, and ethical research, to point out a few. A huge potential of individuals with various degrees of expertise in various aspects of research is available.

In Venice, there were numerous outstanding presentations by invited speakers and presenters of free communications, which invariably stimulated lively discussion. It was impressive that most participants – whether beginners or experienced mentors – aimed to share experiences, to embark on mutual learning, and to take responsibility to teach about their specific expertise. We were privileged to learn from a variety of disciplines about their specific areas of expertise.

Educational aspects served to share expertise to strengthen the research community, based on trust (ie, to admit mistakes and failures, to keep confidential information), honesty, and the preparedness to learn from each other. Pre-conference educational sessions dealt with the topics 'art of preparing grants', 'mixed methods approach', and 'symptom measurement', using small-group work. As a novelty, a special educational session focused on failed studies – senior faculty honestly narrated experiences and led a discussion on how to

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minimize the number of 'studies that never landed or never got off the ground'. This session was encouraging, helping to normalize experiences, benchmark one's own (failed) activities, and obtain clear hints on how to proceed. A highlight, in terms of faculty dedication, were the morning meet-the-expert sessions: 28 researchers offered 16 interactive sessions about research agendas (bereavement, depression, pain, service development, education), methodological issues (large trials, complex symptomatology, symptom assessment), shared care models (oncology and palliative care), and research development (resource-poor settings, institutional barriers, abstract writing, academic career). The fraction of participants snapping up this (too?) early opportunity seemed to have relished the encounters. Several people also dedicated time to lead poster-guided tours, an unforgettable experience for participants. A key feature was also the emphasis given to prepared discussion time in new research data sessions of oral presentations.

Community culture

Striving for a fair process of evaluation, in Venice all submitted abstracts were reviewed by three reviewers blinded to the institution and authors – at least one reviewer was from the same profession. A balanced scoring corrected for inter-individual variability of peer-reviewers. Approximately 8% of abstracts were rejected and the Scientific Committee offered editorial support and re-submission of incomplete abstracts.

In Venice, great emphasis was given to posters, an important platform to catalyse research. Dedicated poster viewing sessions in a spacious location were held at lunch, and poster awards distributed. In addition, poster discussion sessions focused on outstanding posters and summarized poster findings. An open and supportive atmosphere was evident to welcome the vast variety of people and professions, and to share sympathetic personal advice. We need friends to stay healthy and focused in daily 'battles'.

Personal development

What are the ingredients of a successful trajectory in palliative care research, from the first tentative steps to junior faculty and senior sustained research group activities?

Formal fellowship programmes with experienced mentors can build the palliative care workforce knowledgeable and virtuous in the handwork of research. Programmes are available in several, but limited, locations and few countries.[1] Fellowship grants and awards may further catalyse this development (provided financing can be attracted). However, criteria for grants and awards should not exclude applications from older investigators, since in palliative care, good clinical experience is essential for research, and many clinicians come relatively late to research in this area. In Venice, many variations of role models and trajectories of research careers could be encountered.

In several locations, research groups reach (beyond) a critical mass, integrate basic sciences, clinicians, and professionals from various backgrounds. Sustained research groups are based on basic – project independent – staff, a long-term strategy, and integration of students and post-doctorates.

Strive for best methodology

Good research is based on solid methodology and clearly defined outcome measures. Research should primarily be based on clear research questions or a hypothesis to be tested, then the best methodology should be sought, and as a final step, the necessary study population and required (collaborative) centres and individuals should be identified. We should offer our patients research projects of high quality – our community is obliged to 'set the bar'.

Opportunistic research projects

Frequently, the impression prevails that research projects are tailored to local resources and opportunities (*bridle the horse from the reverse*), rather than to the best methodology for the research question. This might be one reason for the predominance of reviews, surveys, and observational-retrospective-descriptive studies, and the paucity of randomized-controlled or well-powered observational (or prospective qualitative or mixed-methods studies).[2]

However, small and simple studies may be critical – but transient – elements of local, institutional research programme development.

Interdisciplinary potential

It is a privilege of palliative care to bring together researchers from various disciplines contributing specialized methodology and experience. Encouraging examples in Venice were the plenary lectures on two randomized, controlled trials on service development from Australia,[3] and the UK,[4] the incorporation of various disciplines in the European Palliative Care Research Collaborative (EPCRC), or phase I/II drug evaluation studies with translational elements in far advanced cancer patients.

Collaboration

A sentinel prerequisite to realize good and sustained research is the access to the necessary patient population. For many studies, local opportunities are sufficient, however, to explore many research questions, collaborators are vital. In other medical societies, collaborative groups conduct powerful studies, in palliative care, however, large prospective observational and randomized-controlled phase III studies are (still) rare.

In Venice, concrete collaboration was evident, the vibrating atmosphere at poster sessions was a (nice) symptom of the (rapidly) developing networks (UK pain study,[5] EPCRC, developing countries[6]).

Grants

Protected time and provision of key material are essential catalysts for research development, breaking through local barriers and lack of resources. In Venice, encouraging sessions and informal encounters emphasized this key issue.

Patient-driven research questions and hypothesis

Good research carries the potential to change (clinical) practice. A prerequisite to ask good and relevant research questions is a (local) state-of-the-art clinical and research culture. Only when the (unmet) patients' (and family) needs and lack of standards are perceived, a relevant research question can be asked.

In Venice, the invited sessions focused partly on the development of the research community, and partly on key (research) issues in palliative care.

An overview of participants' research topics clearly suggests most research questions were well embedded in clinical daily work.

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Share the enthusiasm to curiously ask (research) questions relevant for compassionate care, and discuss hypotheses applying the most suitable methodology, maybe making it mandatory to seek others to collaborate. Help to strengthen the workforce and research community. We look forward to meeting in Trondheim in 2008.[a]

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[a] The Fifth Research Forum of the EAPC Research Network.