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Clinical priorities, barriers and solutions in end-of-life cancer care research across Europe. Report from a workshop

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ABSTRACT

Aim: The PRISMA project is aiming to co-ordinate research priorities, measurement and practice in end-of-life (EOL) care in Europe. As part of PRISMA we undertook a questionnaire survey and a subsequent workshop to (1) identify clinical priorities for EOL care research in Europe and propose a future research agenda and (2) identify barriers to EOL care research, and possibilities and solutions to improve the research.

Methods: Thirty participants selected among the principally medical survey responders from 25 European countries attended. Twenty-six answered a preparatory pre-workshop questionnaire based on the survey results. Group work was a main part of the workshop.

Results: Consensus was reached on the following priorities for EOL cancer care research in Europe: symptomatology, issues related to care of the dying, and policy and organisation of services. Methodology was regarded important in all areas, including assessment/measurement and classification. Symptom research should particularly emphasise pain, fatigue, cachexia, delirium and breathlessness. Research should move from descriptive to interventional studies. The lack of consensus on definitions and outcomes was identified as a substantial research barrier. Other barriers were related to capacity and funding, environment and culture and knowledge transfer and dissemination. These areas are interrelated and should not be addressed in isolation.

Conclusion: Consensus was obtained on priority areas and research nature for EOL care research in the next years, and a model for addressing barriers was developed.

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1. Introduction

Despite advances in cancer survival rates, end-of-life (EOL) care remains an essential aspect of cancer care. Likewise, research in EOL care should be an important part of cancer research in Europe. To date, however, there is a lack of high-quality research in EOL cancer care, and no co-ordinated plan for this type of research in Europe.[1] Several reasons for this have been identified: lack of agreement on what constitutes EOL care,[2] variations in assessment tools and outcomes, the heterogeneity of the palliative care population, limited number of original studies[3] and scarce information on public or clinical priorities for this research area.[2]

PRISMA is a coordinating action project in the European Commission's 7th Framework Programme.[4] This 3-year project of integrated work packages (WP) aims to support and drive forward EOL cancer care research across Europe. The work packages will undertake actions to identify cultural differences in EOL care, establish a collaborative research agenda informed by public and clinical priorities and draw together best practice and resources for quality assurance.

In spring 2009, a pan-European survey of EOL cancer care research in Europe was conducted as part of PRISMA Work Package 3.[5] The aim of the survey was to map research topics and activities, barriers and priorities. In September 2009, a European workshop was arranged to further explore the results and issues from the survey. This article is a report from the workshop, presenting and discussing its main conclusions.

The workshop had the following aims:

1. To identify clinical priorities for EOL cancer care research in Europe, and to propose a future research agenda.
2. To identify barriers to EOL care research, and possibilities and solutions to overcome the barriers and improve the research.

2. Materials and methods

2.1. *Workshop participants*

The workshop participants were selected from the group of responders to the survey (127 responders from 36 countries), based on the following criteria: representatives (one per country) should be actively engaged in EOL care or palliative care, and preferably also in research, they should be well informed about the situation for EOL care research in their respective countries and be involved in national bodies, and have sufficient command of spoken and written English to participate in a workshop conducted in English. The Open Society Institute was consulted regarding candidate participants from Eastern Europe and former Soviet Union member states. The organisers also consulted publication databases as well as local contacts in several countries.

A list of 31 representatives was identified. Ten invited participants were not able to attend due to other commitments; four of these invited persons were substituted by other representatives from their country. The final list included 30 participants from 25 European countries (see Appendix A). Three countries had more than one representative. A Ph.D. student from France working on a project on barriers to palliative care research was invited together with the country representative. The remaining four participants were PRISMA co-workers from Norway and United Kingdom.

The participants included 28 physicians, one statistician and one social scientist. Physicians were specifically targeted as 85% of the survey responders had this professional background. Males and females were present in equal numbers. Many of the participants in the group had 10–20 years experience in conducting and/or organising research.

2.2. *Preparatory work*

Before the workshop all participants were asked to respond by e-mail to a list of statements in a pre-workshop questionnaire. The statements were based upon the results from the survey,[5] and the participants were asked to rate their level of agreement for each statement using a 0–10 numerical rating scale (0, complete disagreement and 10, complete agreement). Furthermore, the pre-workshop survey was used to identify the most relevant research questions or subtopics within each of the highest ranked topics of the survey: pain, fatigue, cachexia, last days of life and quality of death, policy and organisation of services and assessment and measurement tools. The same was done for the two areas with the largest gap between perceived research needs and ongoing efforts: communication, cognitive symptoms and delirium. The lists of subtopics were based on the textbook Palliative medicine, especially chapter 34; Priorities for the future: the research agenda.[6] Similarly, participants were asked to rate the importance of several aspects related to the highest ranked research barriers from the survey; the respective subtopics were based on the EAPC Declaration of Venice.[7]

When analysing the results from the pre-workshop questionnaire survey, scores $\geqslant 7$ were defined as agreement, 4–6 as neutral and $\leqslant 3$ as disagreement.

2.3. *Workshop format*

The workshop took place in Trondheim, Norway, 14–16 September 2009. It was organised by members of PRISMA Work Package 3 at the Norwegian University of Science and Technology. The programme for the 3 d was a mixture of plenary sessions and group work. The workshop started with a plenary session giving the background and introduction to the work, followed by a presentation of the survey results[5] and two lectures on possibilities, needs and barriers to EOL care research in Europe – from a public health care as well as a clinical perspective. On day 2, country reports on barriers and potential solutions were presented from Bulgaria, Germany, the Netherlands and Spain, and examples of international collaboration from Croatia, Georgia, Sweden and Switzerland. Future collaboration was discussed in the contexts of the EAPC Research Network[8] and the newly established European Palliative Care Research Centre.[9]

The participants were divided into two workgroups based on their choice. Each group had a chair and co-chair and two rapporteurs. There were three group sessions: one on day 1 and two on day 2. All of day 3 was spent in plenum, discussing the conclusions from the workgroups.

2.4. *Group processes*

2.4.1. Group 1: Clinical priorities and future research agenda
The work started with an introduction by the chair about the aim to set up a prioritised research agenda on EOL cancer care. The results from the main survey and the pre-workshop survey served as background information material. The group had a common understanding of the task and agreed to the planned working process. The results from the pre-workshop survey were then used as a template for the discussions, starting with priorities, followed by thorough discussions of the five most highly ranked research topics and their respective subtopics. Within each topic area, the essence from the discussions was extracted and agreement within the group was sought. A consensus report was written by the rapporteurs and the report was presented and discussed in the plenary session on day 3.

2.4.2. Group 2: Barriers to end-of-life care research and potential solutions
In the first session, Group 2 started by brainstorming on any possible barriers to EOL care research. The identified barriers were then grouped into categories, and the group discussed possibilities to overcome the barriers in each category.

In the second session the participants were divided into four groups. Based on the results from the brainstorming, each group made a priority list of what they considered the four most important barriers and their respective solutions. From the resulting lists, the areas were grouped into domains and sub-domains. These domains were further explored in the third group session, which resulted in a graphical presentation of the final conclusions.

3. Results

3.1. *Pre-workshop survey*

Twenty-six out of 30 participants returned the pre-workshop survey questionnaire before the workshop. The answers confirmed the most highly rated research topics from the survey. The research topics as well as the subtopics obtaining the highest level of agreement in the pre-workshop survey are presented in Table 1.

The pre-workshop survey showed 76% agreement on the three main barriers identified in the survey: lack of funding, insufficient knowledge and expertise, and lack of time.[5]

3.2. *Group 1: Clinical priorities and future research agenda*

Results from the main survey and the pre-workshop survey were further explored in the group discussions. The following domains within the area of *symptomatology* emerged as high priority research areas: definition, assessment/measurement, classification (including pathophysiological mechanisms) and

Table 1 – Clinical research priorities: topics and subtopics from the pre-workshop survey, as scored by the participants before the workshop. Subtopics with the highest agreement (%) are presented for each research topic.

Topic	Subtopics
Pain	Consensus on assessment instruments to allow comparison and meta-analysis (92%) Opioids: evidence-based route of conversion and drug rotation potency (88%) Assessment, management and prevention of pain in patients with limited ability to communicate (88%) Universal classification to facilitate communication and devise treatment guidelines (77%) Comparative efficacy studies (77%)
Last days of life and quality of death	Standardisation of assessment tools at the end of life (88%) Setting quality standards in palliative care (88%) Establishing predictors of patients at high risk for suffering at the end of life (85%) Develop robust standards for care of the dying (84%) A greater understanding of the physiological basis for terminal symptoms (81%)
Cachexia	Therapeutics, pharmacological and non-pharmacological interventions (88%) Management; clinical guidelines (80%) Prevention; preventive measure in at risk population, nutritional counselling (80%) A standard definition of cancer cachexia (76%) Predictors, definition and clinical utility (76%)
Fatigue	Pharmacological interventions (84%) Non-pharmacological interventions (80%)
Policy and the organisation of services	Cost benefit analysis (100%) Outcome measurement (84%) Comparison of service delivery models (77%) Increased coordination of patient care and support among the multiple players to enhance delivery (76%) Predict future resource needs (76%)

Table 2 – Priority areas for end-of-life cancer care research in Europe. Conclusions from the workshop.

Area	Domains	Nature of research
• Pain Symptomatology • Cachexia • Fatigue • Cognitive symptoms and delirium • Breathlessness • Other symptoms	• Definition • Assessment/measurement • Classification • Treatment	• Clinical • Interventional • Sufficiently sampled • Interdisciplinary
Last days of life and quality of death	• Definition • Assessment/measurement • Treatment (developing guidelines and standards for care)	
Policy and organisation of services	• Cost effectiveness analysis • Outcome measurement	

treatment (Table 2). The group found it difficult to prioritise between symptoms, but finally agreed on a list of five symptoms on which research efforts should be focused in the upcoming years.

The domains of symptomatology were also regarded highly relevant for the second research priority, *last days of life and quality of death* (Table 2). The third agreed research priority was *policy and the organisation of services*. The group also emphasised the *nature and quality of the research* and the importance of moving from descriptive studies to interventional trials, as well as from cross-sectional to longitudinal study designs.

3.3. *Group 2: Barriers to EOL care research and potential solutions*

Group 2 started by brainstorming on the topic of barriers, identifying a list of potential barriers and grouping them into the following four categories: specific to the field (i.e. related to EOL care or palliative care), related to infrastructure, 'belonging in our hands' or other. The group 'belonging in our hands' comprised barriers that can be modified by professionals themselves such as structural and cultural challenges within the organisation, lack of mentors and giving low priority to research in clinical programmes. A list of corresponding solutions was then provided.

Prioritising between the barriers in the three main categories led to two new lists of barriers and potential solutions that finally were condensed and grouped into the following domains: *Funding and capacity, environment and culture, classification and better methods* and *knowledge support and transfer*. The domains and sub-domains are presented in Table 3. The conclusions from the group are presented graphically in Fig. 1.

4. Discussion

The main recommendations from this workshop on EOL cancer care research are summarised as follows:

1. Symptomatology should still have the main focus, including the development of guidelines. Basic research is necessary to increase the understanding of symptom pathophysiology.
2. Methodology is important in all areas, including assessment and classification. International consensus must be sought.
3. EOL care research should move from descriptive to interventional studies.
4. Health services research is needed to guide models of palliative care service delivery.
5. The lack of consensus regarding definitions and outcomes of several symptoms is perceived as one of the most important barriers to EOL research. Other barriers are related to capacity and funding, environment and culture and knowledge transfer and dissemination. These areas are interrelated and should not be addressed in isolation.

The participants from this workshop represented 25 countries from all parts of Europe (Appendix A), showing a great diversity in the development of palliative and EOL care. Some of the representatives were the only or among very few palliative care physicians in their respective countries, while others came from countries where palliative medicine has been a speciality for many years. Likewise, some regions have several academic chairs in palliative medicine, palliative care or EOL care, whereas others have no or very little research activity. This diversity automatically influenced the discussion on research needs and barriers, and will also influence how this report will be used. However, the survey as well as the workshop demonstrated the researchers' needs and wishes for research collaboration across Europe, and their willingness and ability to reach consensus on priorities.

Prioritisation has challenges. On the one hand research funders and policy makers encourage prioritisation because it may well help them to focus their objectives. For this reason prioritisation was included within the PRISMA WP3. Prioritisation also has the advantage of focusing efforts in a few areas, which may enable greater progress to be made. However, there are potential risks to prioritisation. Areas not included in this should not be assumed to be of low or no priority, merely because they are not in the list provided by this group of professionals (primarily physicians, leading palliative care in their countries). Other work packages within PRISMA are addressing the public priorities for EOL care, and it may be that the public view prioritises different aspects. Equally nurses, other clinicians, social scientists,

Table 3 – Barriers to end-of-life care research and solutions to overcome these barriers. PC = palliative care.

Domain	Sub-domain barriers	Sub-domain solutions
Funding and capacity	• Lack of funding to create capacity: numbers of people, skills/training/experience, funding streams with right breadth and depth of programmes, including funding to create better methods • Lack of training posts for seniors and juniors • Lack of allocated research time for busy clinicians • Lack of infrastructure and organisation • Lack of visible and accessible career paths that permit time/posts to conduct research, e.g. Ph.D.'s • Bureaucratic barriers (paper work needed to do research)	• Double benefit funding: funding for training and research and to develop better methods – invest in training coupled to commitment • Use of PC ambassadors to generate funding and put people with PC knowledge on funding bodies • Payment for clinical vacancies included in fund raising • Putting pressure on policy makers for funding • International 'pressure' on national funding bodies and national authorities • National and international co-operation in education and research • PC into national health care plans and programmes • Career pathways for doctors (clinical training) • Establish palliative medicine as a medical specialty • Combined positions, clinicians allocated time for research. More people involved in PC • Organising existing resources better, share infrastructure and personnel (statisticians etc) with other areas • Mentorship, encourage the one you mentor to become mentor to others
Environment and culture	• Lack of professional awareness and expertise • Lack of culture for research in PC services • Lack of clear career pathways • Lack of awareness of what research can do • Research included late in service development • Lack of mentors who do achieve clinicians conducting research • Lack of research networks • Disconnection in understanding between researchers and clinicians • Unwillingness to seek and collaborate with other areas and specialties	• Role models, mentors and ambassadors (pioneers), promote visions • Collaboration with other specialties – involve them from the start, invite other specialties in as collaborators for grant proposals • Empowering the public to increase their influence on policy makers and national bodies (be aware not to give them unrealistic expectations) • Combined positions • Research network and collaborations
Classification and better methods	• Frail patient population • Lack of innovative/complex research methodology • Challenge of defining and classifying populations, outcomes/assessments and measurements • Lack of access to robust methodological expertise	• Standardised outcomes and classification systems • Mapping key domains of PC practice • Developing specific and robust methodology and methods for best practice • Conducting a knowledge synthesis on what works in developing a PC research strategy • Learning from EU-funded projects
Knowledge support and transfer	• Insufficient knowledge and expertise • PC research not visible enough at conferences • Lack of high-quality publications • Too little user involvement	• Publications; publish and present outside PC • Conferences • Public relations and user involvement • Online courses for education • Research network and collaborations • Training in research methodology, centres (physical or virtual) to provide specific courses covering the breadth of PC

patients and service funders may prioritise different areas. Some individual countries have already conducted broader consultations on priorities.[2] However, this is the first time a European consensus has been attempted, and of particular value, we were able to include representatives from 25 countries.

Symptomatology was ranked as top priority area by this group for future research in EOL care, with pain as the first priority (Table 1). Pain is one of the most feared and serious symptoms in advanced cancer, with a prevalence of 40–90%, dependent on disease stages.[10–12] Even if pain control is regarded a key component of palliative care and pain is one of

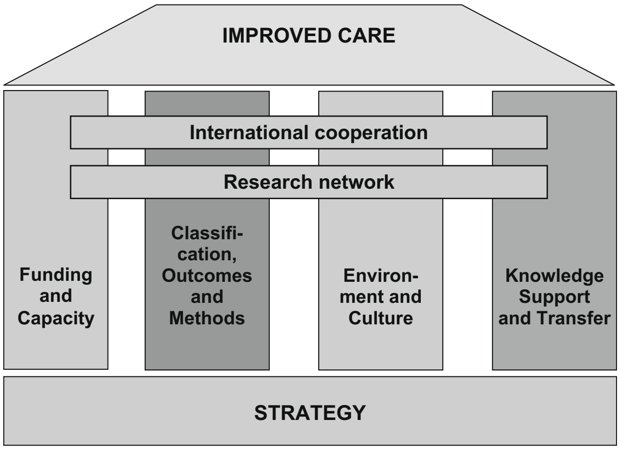

Fig. 1 – A framework for improving EOL cancer care research in Europe.

its most investigated areas, it is still underassessed and undertreated[13]. There is still no consensus regarding a classification system for cancer pain, neither a standardised way of measuring it.[14,15] The same applies to the other symptoms, probably to an even greater extent.[16–19] At the workshop, agreed and standardised definitions, assessment methods, classification systems and outcomes were identified as important goals for research in symptomatology. Likewise, standard descriptions of the study populations were regarded necessary to compare between studies and raise the external validity of the findings.[20] The lack of agreed definitions and outcomes was perceived as one of the important barriers to high-quality research in EOL care.

Several of the priority topics from the present workshop overlap with areas identified with urgent need for increased research efforts at the Birmingham International Workshop on Supportive, Palliative and End-of-life Care Research in 2005.[21] The Birmingham group also included symptomatology in their priority areas: measuring symptoms and symptoms clusters, study of the biological bases of complex symptom clusters and enhancing research in symptom interventions. The National UK consultation had a greater emphasis on health economic aspects and service delivery, but this was perhaps because of the greater involvement of service funders and providers in the consultation.[2] The current priorities are also in line with Kaasa and Radbruch,[22] who emphasised development/agreement about outcomes and patient cohort classification as important priorities for the years to come. This paper from 2008 also commented on how the research should be performed, much in line with the present recommendations (Table 2).

The workshop was limited by the range of professionals and countries present. Our survey sample included chairs and leaders of research groups in palliative care/medicine, and the majority of scientific team leaders proved to have medical background (85%). This was the reason for targeting this group at the workshop, which also allowed for greater similarities across countries. However, fronting medical priorities does not mean that other areas cannot be addressed, as all symptoms have physical, emotional, social and spiritual components.

The workshop was arranged to further explore and discuss the results from the pan-European survey on research in EOL care.[5] Consequently, methodological limitations of the survey will influence the workshop results.[5] This applies to the content and format of the questionnaire as well as the sample of responders. Results from the survey were further elaborated on in the pre-workshop survey. Although the pre-workshop survey questionnaire was based on the main survey conclusions, the selection of subtopics to some extent influenced the subsequent discussions.

The state of palliative care research is closely linked to the development of clinical palliative care services in a country or a region. There is a strong link between specialisation, training and research, and recruitment is a key issue. In most countries palliative medicine is not recognised as a medical specialty in its own right, and recruitment of doctors is difficult. Consequently, physicians will be absorbed by clinical duties. Establishing palliative medicine as a specialty is therefore essential for providing capacity both in clinical work and research. Furthermore, combined positions and allocated, protected time for research are important to attract and retain good co-workers. This applies not only to physicians but also to all other relevant professional staff.

The 2004 Report of the NCRI Strategic Planning Group on Supportive and Palliative Care Research in the United Kingdom pointed at the lack of capacity and coordination in these research fields, with lack of research posts and unsatisfactory infrastructure.[23] While EOL care research is still much less developed in many other parts of Europe, ear-marked funding to boost the efforts may be even more crucial in these countries. Sustainable posts funded by universities are seen as a major means in this respect. In addition, applying for funding has become an increasingly demanding exercise with assessment panels becoming more and more influential. This is especially challenging for palliative medicine, which is not recognised as a specific reference field with its own reference panel, and must compete in other fields. There is a clear need to have this changed, demanding ambassadors for EOL care research to influence the pathways, the calls and the funding bodies. The lack of recognition for palliative and EOL care also applies to publication and dissemination of research findings. To publish in high impact journals, palliative care must compete outside its own area or field.

The workshop participants agreed upon an integrated model of factors to promote and facilitate EOL care research (Table 3 and Fig. 1). All pillars of the 'temple' are necessary to attract and retain researchers and produce high-quality research. No barrier can be addressed in isolation; however, both short-term and long-term strategies are necessary, adapted to the actual situation and circumstances.

Many of the potential solutions were assessed by the group as 'belonging in our hands'. However, such an understanding may be too optimistic. A minimum of allocated time and other resources is a prerequisite for academic activity. Even so, the palliative care clinical and research communities must take the responsibility to foster mentors who can train new researchers, who in turn will mentor to others. Equally, advocates for palliative care must advocate not only for clinical palliative care services but also for research and academic resources and development. Also, we ourselves must change the mentality and culture in clinical units to integrate research as a natural part of their services.

The pillars of the 'temple' are strengthened and stabilised by connections across (Fig. 1). In the same way, international co-operation and networking are powerful means to promote EOL care research and engage new partners. The PRISMA project is evaluating possibilities to continue the collaboration after the 3-year project period. The EAPC Research Network[8], the European Palliative Care Research Centre[9] and Cicely Saunders International,[24] which is creating a purpose built Institute, all have important roles in facilitating future EOL care research and organising collaborative research efforts.

Conflict of interest statement

None declared.

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Appendix A. List of workshop participants

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