

A pan-European survey of research in end-of-life cancer care

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Abstract

Background To date, there is no coordinated strategy for end-of-life (EOL) cancer care research in Europe. The PRISMA (Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-life Care) project is aiming to develop a programme integrating research and measurement in EOL care. This survey aimed to map and describe present EOL cancer care research in Europe and to identify priorities and barriers.

Material and methods A questionnaire of 62 questions was developed and 201 researchers in 41 European countries were invited to complete it online in May 2009. An open invitation to participate was posted on the internet.

Results Invited contacts in 36 countries sent 127 replies; eight additional responses came through websites. A total of 127 responses were eligible for analysis. Respondents were 69 male and 58 female, mean age 49 (28–74) years; 85% of the scientific team leaders were physicians. Seventy-one of 127 research groups were located in a

teaching hospital or cancer centre. Forty-five percent of the groups had only one to five members and 28% six to ten members. Sixty-three of 92 groups reported specific funding for EOL care research. Seventy-five percent of the groups had published papers in journals with impact factor ≤ 5 in the last 3 years; 8% had published in journals with impact factor > 10 . Forty-four out of 90 groups reported at least one completed Ph.D. in the last 3 years. The most frequently reported active research areas were pain, assessment and measurement tools, and last days of life and quality of death. Very similar areas—last days of life and quality of death, pain, fatigue and cachexia, and assessment and measurement tools—were ranked as the most important research priorities. The most important research barriers were lack of funding, lack of time, and insufficient knowledge/expertise.

Conclusions Most research groups in EOL care are small. The few large groups (14%) had almost half of the reported publications, and more than half of the current Ph.D.

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students. There is a lack of a common strategy and coordination in EOL cancer care research and a great need for international collaboration.

Keywords Neoplasms · Palliative care · Terminal care · Research · Europe · Survey

Introduction

More than 1.7 million people die from cancer in Europe each year, and the WHO predicts that the number will increase to over 2.1 million by 2020 (a 24% increase) [1]. Estimates show that each year, 1.6 million cancer patients in Europe experience pain related to their disease, and one third of them will require complex treatment [2]. The number experiencing other distressing symptoms is also high [2]. Therefore palliative and end-of-life (EOL) care must be an essential component of cancer care and equally scientifically and evidence based. However, research in palliative care/EOL care constitutes a very minor part of European cancer research. In the UK, less than 0.2% of research spending in cancer addresses palliative and EOL care [2]. Similar figures are not known for most other European countries, but are likely to be even lower for many of them.

Research in EOL care did not appear systematically on the agenda in Europe until the 1990 s with the establishment of the European Association for Palliative Care (EAPC) and its Research Network (EAPC-RN) in 1996 [3]. However, there is still little coordination of research in EOL cancer care in Europe today [4]. This may be due to lack of agreement on what constitutes EOL care, scarce information on public or clinical priorities, few appropriate measures of quality, and a lack of established best practice [5]. Methodological, organisational, attitudinal, and societal challenges have been identified, as well as a lack of research knowledge/skills in the area of EOL care research [6–9]. For the purposes of PRISMA, EOL care is defined as care in the last year of life.

In recent years, some well-funded palliative care research initiatives have emerged in Europe, Canada, the USA and Australia [10–13]. PRISMA is a project within the European Commission's Seventh Framework Programme with the overall purpose to deliver an integrated programme to co-ordinate research priorities, public priorities, and practice in EOL cancer care in Europe, with a focus on measurement [14]. In order to develop a future research agenda and strategic plan for EOL care in Europe, an overview of current research resources, activities, and challenges must be established. To our knowledge, no such overview currently exists. The National Cancer Research Institute's Strategic Planning Group on Supportive and Palliative Care report (SuPaC) [15] examined the past and

present state of UK research in the field of supportive and palliative care for cancer, identified needs and opportunities for the future, clarified specific issues and barriers, and developed proposals for national strategic actions. An analysis of research workforce capacity and stakeholder views was in the form of a questionnaire survey. In addition to this survey from the UK, EOL care research has been surveyed in Latin America [16] and Australia [17]. The survey from Latin America (17 countries) aimed to determine the current status of palliative care research in Latin America. In order to develop a palliative research network in Queensland, Australia, a survey was conducted to map the current research activity, create a database and identify problems that had been encountered in undertaking research [17].

The aim of the present study was to conduct a questionnaire survey to map EOL cancer care research across Europe and to identify priorities, needs and barriers in this research area.

Material and methods

Questionnaire

A cross-sectional online self-completed survey comprising 62 items was developed in English ([Electronic Supplementary Material](#)). The survey focused on clinical research in adults with cancer in their last year of life. Clinical research was defined as research directly involving patients or family members/care givers. The questions addressed research conducted in the previous 3 years, current ongoing research, and future plans. In addition to demographic characteristics, questions were related to research topics, methodology and trial design, staffing, organisation and funding, quality indicators (completed doctoral degrees in the last 3 years, number of publications in peer-reviewed journals last 3 years, number of conference abstracts last 3 years), and priorities in, and barriers to, research.

An outline of the contents of the questionnaire was developed at the first meeting of PRISMA work package 3 (WP3). Based on this draft and consulting identified related surveys [15–17], two WP3 members selected and designed questions. The draft was circulated to all WP3 members and PRISMA work package leads for comments. Some of the items were adapted from the SuPaC survey [15]. The list of EOL care research topics was based on the abstract categories used for the EAPC conferences and the list of research topics used in the SuPaC survey [3, 15].

A web-based solution was developed using SelectSurveyASP Advanced 8.1.10 software [18]. It was pilot tested by nine experts in EOL care. Respondent access level was single response. Respondents returning a completed survey could edit their original responses. The survey was

designed with a combination of mandatory and optional responses. Skip logic was used.

Sample

We wanted to include all chairs in palliative medicine, palliative care or EOL care in Europe. In countries without such chairs, palliative care researchers or other identified contact persons were approached. Through the EAPC, Open Society Institute, UK Hospice Information Service, leaders of national associations for palliative care and/or palliative medicine in European countries, literature searches, and a number of international contacts, a list of 233 contacts in a total of 41 European countries was identified. At the country level, e-mails were sent with information about the survey and lists of proposed respondents in each country, asking about chairs in palliative medicine and also if important researchers were missing from our list. Contacts in 28 countries responded to our inquiries. By January 2009, a list of 201 chairs, researchers or other contact persons in 41 European countries had been compiled. All of these received a personal invitation to participate by e-mail with a link to the survey. In addition, an open invitation to participate was posted on the websites of the EAPC [3] and the European Palliative Care Research Collaborative [11].

The data collection started on the 30th of April 2009 and closed after 1 month. Reminders were sent to non-responders after 2 and 3 weeks.

Analyses

The data was cleaned and checked to identify and correct potential divergence/errors and ensure missing data was coded uniformly. The responses were entered into an SPSS database version 15.0. Data was analyzed using descriptive statistics.

We hypothesised that the state of EOL care research in a country would be linked to the development of palliative care in that country. Due to the limited number of responses from many countries it would be difficult to compare countries or even regions within Europe. We decided to divide the countries into two groups based on their level of palliative care development, as described by the International Observatory on End-of-Life Care in 2008 [19]. The following categorisation was developed through a multi-method approach combining published and grey literature, information from websites, directories, and databases, expert opinion, and the work of a task force of the European Association for Palliative Care [19]:

1. Countries with developed palliative care (i.e. countries where palliative care activities are approaching integra-

tion with mainstream service providers): Austria, Belgium, Denmark, Finland, France, Germany, Hungary, Iceland, Ireland, Italy, Netherlands, Norway, Poland, Romania, Slovenia, Spain, Sweden, Switzerland, and UK.

2. Countries with underdeveloped palliative care (i.e., countries with localised palliative care provision only): Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Estonia, Georgia, Greece, Latvia, Lithuania, Luxembourg, Moldova, Montenegro (no known activity), Portugal, Russia, Serbia, and Ukraine.

Ethics

We contacted the Regional Committee for Medical Research Ethics in Central Norway. Due to the nature of the study no application was required.

Results

Responses

We received 127 responses from the 201 invited contacts. The responses came from 36 European countries (Table 1). A further eight replies were submitted in response to the open invitation on the websites. Eight responses were excluded, three duplicates and five non-serious responses submitted through the websites.

Altogether, 127 responses were eligible for analysis: 104 complete (all mandatory questions answered) and 23 incomplete responses. Respondents were 69 (54.3%) male and 58 (45.7%) female, mean age of 49.4 (range, 28–74) years.

Location of research groups

Seventy-one of the 127 groups were located in either a teaching hospital (44) or a cancer centre (27), with a further 18 being on a university campus but not attached to a hospital. Ten groups were based in hospices and eight in district general hospitals.

Work force

The survey showed that 85% of the scientific team leaders were physicians (104/123), most commonly with a palliative medicine background, followed by oncology.

The survey identified a total of 965 research staff in 88 groups. The mean number of members in a research group was 11 (1–58); 460 (48%) had part-time and 505 (52%) full-time positions. Eighty-three groups reported a total of

Table 1 Number of responses per country

Country	Responses
Austria	7
Belarus	1
Belgium	4
Bosnia and Herz	2
Bulgaria	2
Croatia	1
Czech Republic	1
Denmark	5
Estonia	1
Finland	1
France	3
Georgia	3
Germany	6
Greece	4
Hungary	3
Iceland	1
Ireland	5
Italy	7
Latvia	2
Lithuania	1
Luxembourg	1
Moldova	1
Montenegro	1
Netherlands	7
Norway	6
Poland	7
Portugal	6
Romania	1
Russia	2
Serbia	1
Slovenia	2
Spain	8
Sweden	8
Switzerland	3
Ukraine	1
UK	12

371 research staff having combined positions with clinical work.

Ninety-two groups reported on their research staff. Seventy-three (79%) of these groups had scientific team leaders who were professors or held another academic position (95 team leaders in all), 67 groups had a total of 128 experienced/senior researchers, and 52 groups reported having a total of 119 early researchers or post-docs. There were 172 Ph.D. students in 54 groups, and 32 groups had a total of 111 Master degree students. More than half of the current Ph.D. students are in the few large groups. Thirty groups reported having managers/administrators, and 33 groups reported a total head count of 59 technical staff.

Most of the groups were small: 45% of the groups had one to five members, and 28% six to ten members. Thirteen groups (14%) were defined as large groups, having more than 15 members.

Thirty-nine of the groups were multidisciplinary, defined as having four or more different disciplines represented among the research staff. A wide range of professions contribute to the research workforce, including physicians (35%), nurses (29%), psychologists (8%) and sociologists (4%) (Fig. 1).

Research network, collaboration and strategy

National collaboration with other palliative care research groups was reported by 77/92 groups (84%); 60/92 (65%) reported international research collaboration.

Four out of 33 countries (12%) reported to have a formalised palliative care research network (Estonia, France, Switzerland and Ukraine; Estonia and Ukraine had only one respondent each). Twelve countries answered this question with both “yes” and “no”. Twenty-four of 33 countries (73%) reported no national strategy for EOL care research; from eight countries (24%) there were both “yes” and “no” answers to this question. One country reported having a national strategy for EOL care research; however, this country had only one respondent.

Funding

Seventy-four of the 92 groups (80%) answered the question concerning funding sources; 63 (85%) of these had specific funding for research on EOL care. Out of this number, 60 were groups in countries with developed palliative care services. The funding sources were governmental (76%), institutional (45%), pharmaceutical (45%), charity (42%), international (33%), scientific awards (30%), and private (16%).

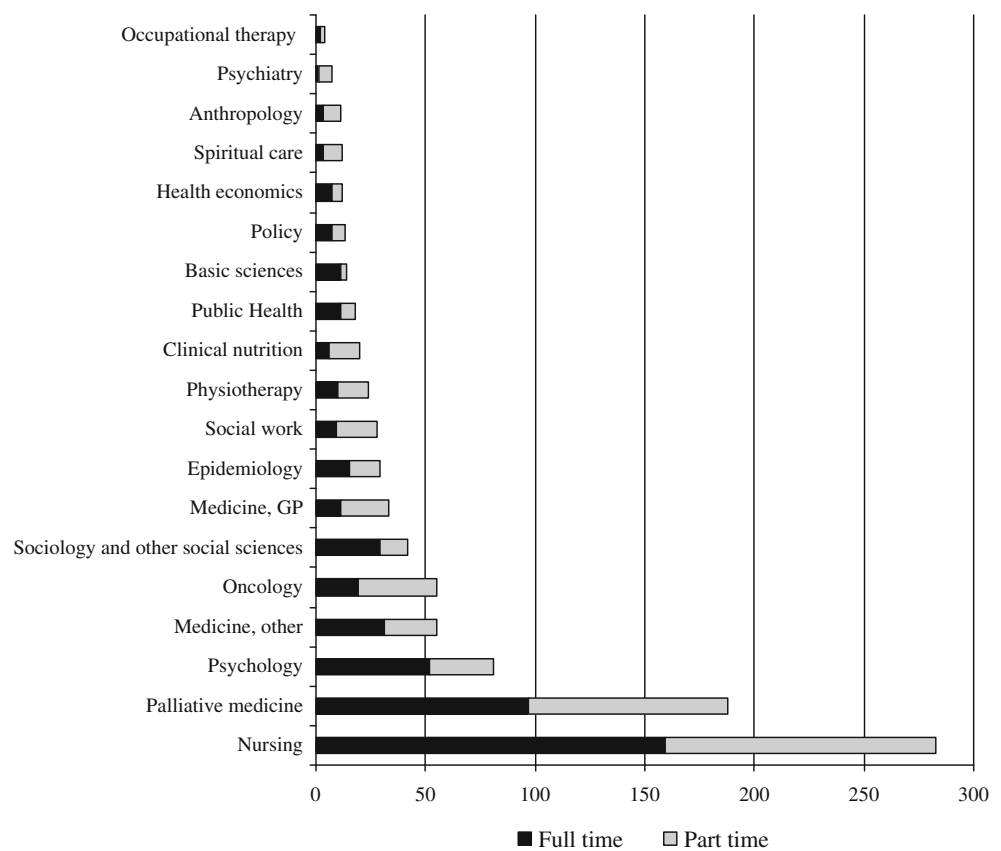
Research completed in the last 3 years

One hundred and four (86%) out of 121 research groups reported completed research on EOL care in the previous 3 years. Ninety-six groups (92%) reported on their specific areas of research and the most frequently reported areas were pain (82%), assessment and measurement tools (69%), last days of life and quality of death (56%), other symptoms (55%), and policy and the organisation of services (53%).

A total of 1,714 (median, 11; range, 0–149) conference abstracts were published from 89 research groups in the last 3 years.

The total number of publications in peer-reviewed journals in the last 3 years was 1,329 (median, 7; range 0–154) from the 89 groups. Nine groups had no publications. Five percent of the publications were from countries with underdeveloped

Fig. 1 Discipline of the research staff in 88 groups. Numbers working full time and part time. Note that physicians are spread over several categories



palliative care services. Most of the groups (75%) had published papers in journals with an impact factor ≤ 5 . Only 8% of the groups had published papers in journals with impact factor >10 [20]. Journal of Pain and Symptom Management, Palliative Medicine, and Supportive Care in Cancer were the three most common publication journals. The majority of publications were in palliative care journals, followed by general oncology journals to a lesser extent.

The large research groups had 48% of the reported publications in peer-reviewed journals, and 34% of the reported conference abstracts the previous 3 years. The average number of publications per person was two for the large groups and 1.6 for the small groups. The two largest groups had an average of 3.9 publications per person.

The total number of reported Ph.D. degrees or equivalent obtained during the previous 3 years was 119 (mean, 1.3; range, 0–8). Twelve (10%) of the 119 degrees were obtained in countries with underdeveloped palliative care services. Forty-one Ph.D. degrees (34%) were completed in the large groups. Forty-four (49%) out of 90 research groups answering this question reported one or more completed Ph.D. degrees in this time period.

Ongoing research

Ninety-five research groups were carrying out EOL care research at the time of the survey. Eighty-four percent of

the research was conducted in countries with developed palliative care services (16 countries). In 90/95 groups (95%) the research was directly involving patients, and in 54/95 (57%) directly involving family members.

Figure 2 reports the research topics, reported by 94 groups. The most frequently reported areas of research were pain (70%), assessment and measurement tools (63%), other symptoms (52%), last days of life and quality of death (44%), and family and caregivers (40%).

The research methodologies reported by the groups ($n=89$) were clinical trials (74%), audit and quality control (51%), health service research (38%), production of guidelines (34%), systematic reviews and meta-analysis (31%), epidemiology (30%), basic research (15%) and translational research (12%).

The study designs of the clinical trials ($n=66$) were randomised controlled trials (65%), observational studies (61%), prospective nonrandomized trials (58%), qualitative studies (47%), retrospective studies (35%), and cross-sectional studies (32%).

Barriers to EOL care research

Figure 3 presents barriers in general ($n=104$). More than half of the groups considered the following barriers of importance: lack of funding (85%), lack of time (64%), insufficient knowledge and expertise (62%), lack of personnel (54%), and lack of infrastructure and support (52%). Groups in

Fig. 2 Ongoing research. Research topics. Number of groups

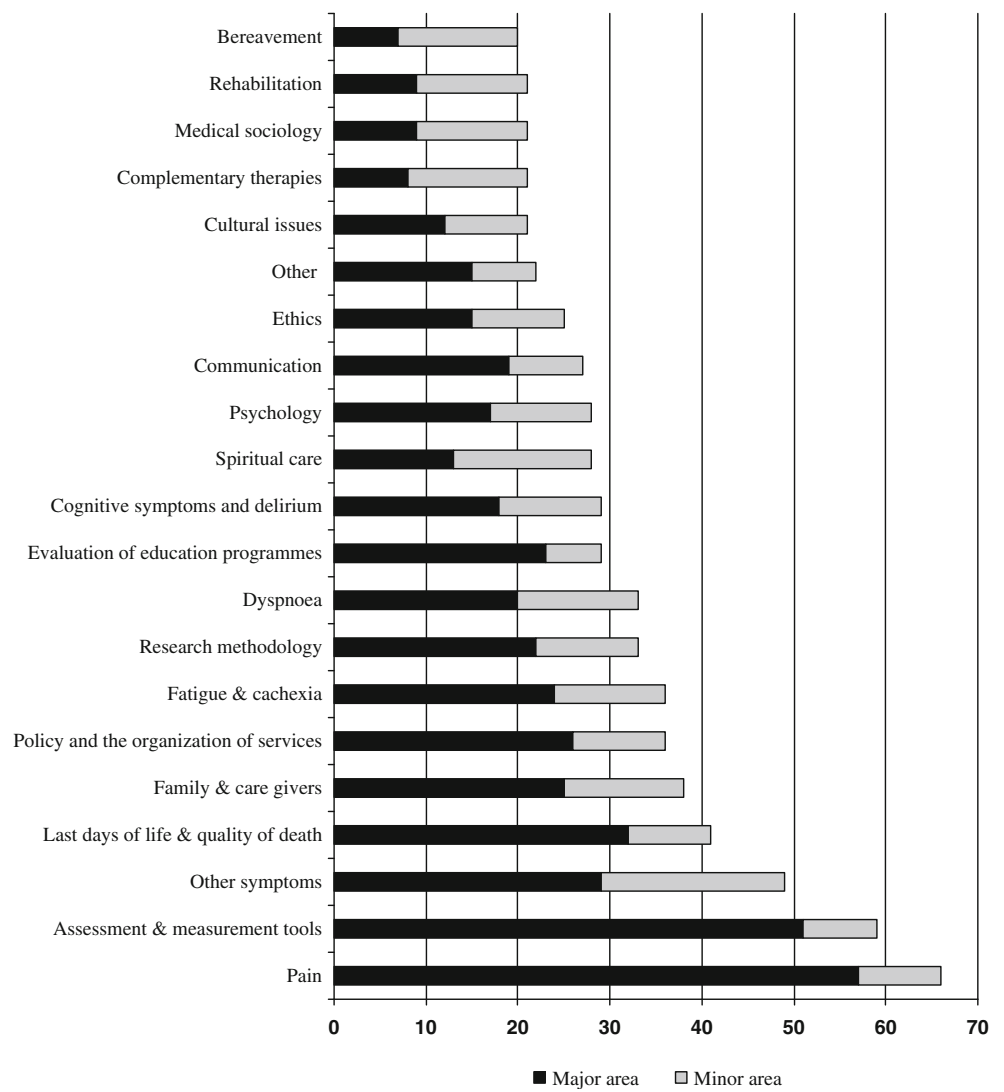
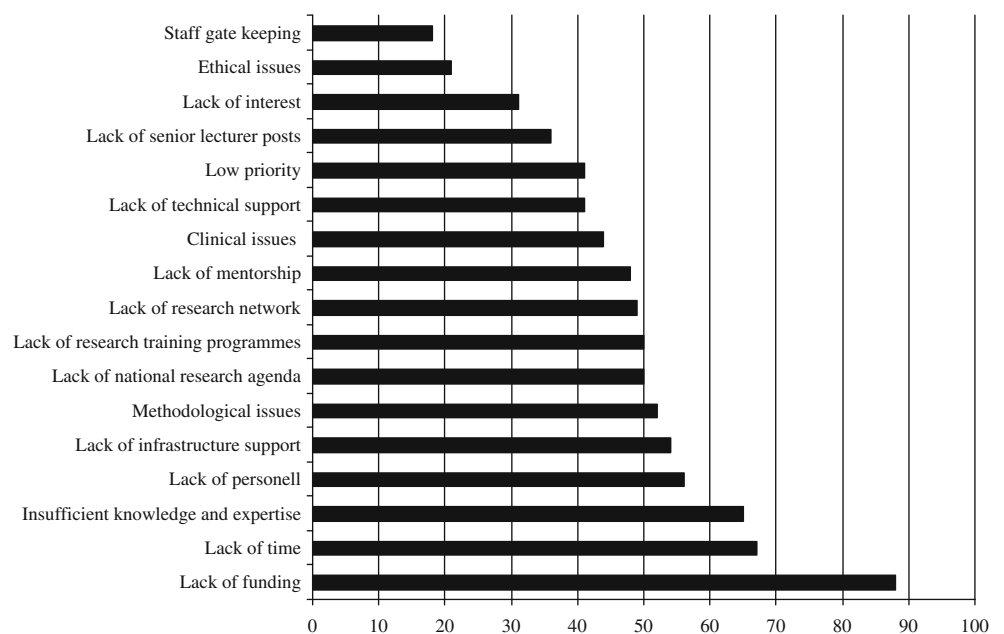


Fig. 3 Barriers in general. Number of groups



countries with underdeveloped palliative care services reported more lack of technical support (52% vs 35%), lack of research training programmes (67% vs 42%), and lack of a national research agenda (63% vs 43%). On the other hand, countries with developed palliative care services reported more often clinical issues (51% vs 18%), lack of time (69% vs 52%), and staff gate keeping (21% vs 7%) as barriers.

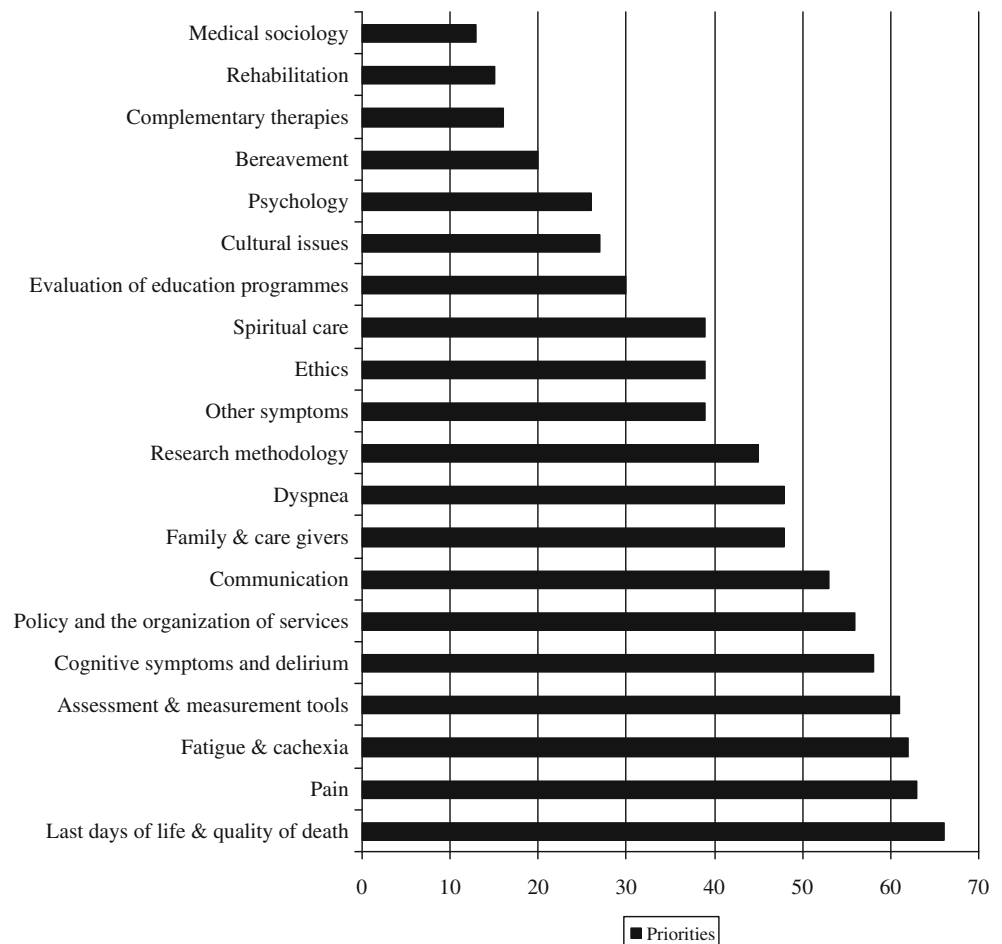
Priorities for the field

Figure 4 presents the future research priorities for the field ($n=104$). More than half of the groups reported that research on last days of life and quality of death (63%), pain (61%), fatigue and cachexia (60%), assessment and measurement tools (59%), cognitive symptoms and delirium (56%), policy and the organisation of services (54%), and communication (51%) should be prioritised.

Discussion

To our knowledge, this is the first study reporting on the current state of EOL cancer care research across Europe.

Fig. 4 Priorities for the field concerning future research on adults with cancer in their last year of life. Number of groups



The most frequently reported current research areas were pain, assessment and measurement tools, other symptoms, and last days of life and quality of death. The results show that although some large groups were identified, most of the research groups were small. Almost 50% of all positions were part time. Very few European countries reported to have a formalised palliative care research network. Lack of funding was the most commonly reported barrier.

Workforce

A previous, limited survey of palliative care research in 13 European countries suggested that there were very few groups reaching a critical size [21]. This impression is confirmed by the present study. Even though a few large groups exist, the picture is dominated by small and scattered groups and initiatives, without national or international coordination. The few large groups reported almost half of the publications, and more than half of the current Ph.D. students are in these groups. These findings are also well in line with the SuPaC report [15], which also found that the palliative care research workforce was fragmented

across multiple sites; there were inadequate numbers of postdoctoral and senior lecturers, and scarce infrastructure, with poor access to expertise in research methodology.

Our findings show a great need for structured collaboration both nationally and internationally to promote EOL cancer care research in Europe. Larger groups should try to include smaller groups in their work. Studies have shown that research groups are complex interacting systems with a strong size dependency, and that is it important to achieve critical mass [22].

Research topics and methodology

The most frequently reported areas of completed research were pain, assessment and measurement tools, last days of life and quality of death, other symptoms, and policy and the organisation of services. Ongoing research showed the same areas, but less research on policy and organisation, and more on family and caregivers. All these areas were included in the list of the most common research topics in the SuPaC report of 2004 [15]; however, the most commonly reported area of research in the SuPaC survey was psychological research, followed by information/communication. While the SuPaC report was restricted to the UK, the present survey had respondents from 36 European countries.

The strong focus on symptomatology may reflect the predominantly medical sample in our survey. However, symptom relief is at the core of palliative care, and a review of palliative care research publications by Kaasa and co-workers in 2006 found that symptom control/management was one of the two most frequent topic areas, service development (policy and organisation) being the other [21]. The literature review [21] indicated that the majority of research publications in palliative care were surveys and descriptive/observational studies, and that rather few randomised, controlled trials were published. These findings were confirmed in 2008 in a paper on research methodologies in palliative care [23]. In the present survey, 66 out of 89 groups reported conducting clinical trials, and the most common study design for the clinical trials was the randomised controlled trial (65% of the groups), followed by observational studies (61%) and prospective non-randomized trials (58%). Randomised, controlled trials remain the gold standard for evidence, and a development with more groups doing this type of studies would be very welcome. However, it remains to be seen whether this finding will be reflected in publications over the next years.

Barriers

More than half of the groups reported lack of funding, lack of time, insufficient knowledge and expertise, lack of

personnel and lack of infrastructure support as barriers to EOL care research. Similar barriers have been identified by others [15–17, 24]. Almost one third of the responders in the present study had no specific funding for EOL care research. Sixty-three groups had specific funding for research on EOL care and 60 of these were groups in countries with developed palliative care services. Thus the state of palliative care research is closely linked to the development of clinical palliative care services in a country. Research collaboration between countries with developed palliative care services and countries with less developed palliative care could also enhance the development of clinical palliative care services in the latter. Ear-marked funding to boost the efforts can be crucial in these countries.

Our data shows that almost half of the research staff (48%) had combined clinical and research posts. People in combined positions often face serious difficulties in relation to pressure from clinical commitments, and this might result in lack of time being ranked as the second most important barrier. This point is important to address when planning combined clinical and academic careers.

Priorities

A number of research topics were identified as priority areas for the future (Fig. 4). The future priority areas identified by the respondents were very similar to the areas in which the respondents were currently working (Fig. 2), except that research into the last days of life and quality of death emerged as a stronger priority. It is possible that the respondents often prioritised areas of research with which they were already familiar. However, several of the priority topics from the present survey overlap with the ten 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 [25]. 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 priority areas identified in the present survey have later been further developed in an international workshop with 30 participants from 25 European countries selected from the survey responders [26]. These priorities, as defined by clinicians and researchers, will later be integrated with public priorities and preferences in the context of PRISMA and give guidance to coordinating bodies aiming to promote pan-European research [14].

Study limitations

The present study is the first broad survey of EOL care research in Europe. The invitation to participate in the survey was sent to all chairs (professors) in EOL care,

palliative care, and palliative medicine in Europe, and to other leaders of research groups in these areas that we were able to identify. Despite our broad approach to identify professionals involved in relevant research, we might have missed groups, especially research groups dealing with EOL care issues in areas defined outside EOL care or palliative care.

Although the survey had a high response rate (67%), there might be a selection bias among the respondents. The majority of responders belonged to countries with developed palliative care (76%). However, this is where most EOL care research groups are located. The majority of the scientific team leaders in the responding groups were physicians. This predominance has probably led to more biomedically oriented answers than if researchers from other professions had been asked about their priorities.

The language, format and contents of the survey questionnaire, especially the proffered lists of response options, represent additional limitations. One example is the list of EOL care research topics, which also was used for defining future needs and priorities.

Conclusions

The results of this pan-European survey demonstrate that EOL cancer care research is in its infancy. Small and scattered groups and initiatives without national or international coordination dominate the picture. However, a few large groups exist. These large groups reported almost half of the publications, and more than half of today's Ph.D. students are in these groups.

We conclude that there is a great need for structured collaboration both nationally and internationally to promote palliative and EOL cancer care research in Europe. The EAPC-RN, the European Palliative Care Research Centre [27] and Cicely Saunders Institute [28] all have important roles in facilitating future EOL care research and organising collaborative research efforts. Hopefully this will facilitate high-quality research within Europe and enhance the development of clinical palliative care.

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where end-of-life care is delivered. Principal Investigator: Richard Harding. Scientific Director: Irene J Higginson. Work Package 3 Lead: Stein Kaasa. PRISMA members: Gwenda Albers, Barbara Antunes, Ana Barros Pinto, Claudia Bausewein, Dorothee Bechinger-English, Hamid Benalia, Lucy Bradley, Lucas Ceulemans, Barbara A Daveson, Luc Deliens, Noël Derycke, Martine de Vlieger, Let Dillen, Julia Downing, Michael Echteld, Natalie Evans, Dagny Faksvåg Haugen, Lindsay Flood, Nancy Gikaara, Barbara Gomes, Marjolein Gysels, Sue Hall, Richard Harding, Irene J Higginson, Stein Kaasa, Jonathan Koffman, Pedro Lopes Ferreira, Johan Menten, Natalia Monteiro Calanzani, Fliiss Murtagh, Bregje Onwuteaka-Philipsen, Roeline Pasman, Francesca Pettenati, Robert Pool, Tony Powell, Miel Ribbe, Katrin Sigurdardottir, Steffen Simon, Franco Toscani, Bart van den Eynden, Jenny van der Steen, Paul Vanden Berghe, Trudie van Iersel.

Conflicts of interest statement None declared.

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