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Patient demographics and centre description in European palliative care units

A cross sectional survey of the European Association for Palliative Care (EAPC) Research Network[1]

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Patients in palliative care are elderly, frail and in decline with multisystem disease. These and other factors make palliative care research particularly challenging, and has been one of several reasons why relatively little systematic research has been performed. The European Association for Palliative Care (EAPC) is seeking to emphasise the importance of research. The present project is the first empirical multicentre study organised by the EAPC Research Network, with the aim of identifying the patient population using specialised palliative care, and identifying a network of palliative care services across Europe, able to participate in a multicentre collaboration for research.

During a designated week in the autumn of 2000, data on patients were recorded from 143 centres. The survey was carried out by means of two questionnaires, one centre questionnaire and one patient questionnaire.

Data were submitted on 3013 patients from 22 different European countries. Almost all patients had cancer (94%), while some had neurological disease (3%). The majority (75%) had been referred to a palliative care service during the six to seven months before the survey was performed. Very few patients had less than one week of expected survival (6%), the majority were expected to live one to six months, while as many as 16% were expected to live more than one year. The majority of the patients (27%) were fully ambulatory – the ability to walk independently without any assistance. The majority of the patients (60%) received care as an outpatient, either at a traditional clinic in an outpatient cancer hospital (12%), in home-care programs from a specialised advisory service (24%), or external nursing care (24%).

The population of patients included in this survey was not a sample of dying patients. There were a substantial number of patients with an anticipated life expectancy of more than six months. The study demonstrated a considerable enthusiasm for research in the palliative care community across Europe. The heterogeneity of the sample is evident, and this will need careful consideration for future clinical trials. This calls for an international consensus on how to report on patient characteristics within palliative care research. This is necessary in order to be able to evaluate the representativity of the study population, as well as to compare data between studies. The range of services encountered in the survey highlights the need for the organisational and clinical standards for palliative care, which can be audited. *Palliative Medicine* 2007; **21:** 15–22

Key words: organisation; palliative care; research

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Introduction

Palliative care is a relatively young discipline, and epidemiological data are essential in order to provide a credible evidence-base for clinical practice.[1,2]

There are particular difficulties in conducting clinical research in a palliative care environment. Patients are elderly, frail and in decline with multisystem disease – patients are usually severely ill with a progressive condition and limited survival time; they may have many symptoms for which they will be receiving several drugs concurrently; and environmental and psychological factors have a variable, but potentially great effect on physical well being.[3–5]

All of these factors make palliative care research particularly challenging, and is one reason why relatively little systematic research had been carried out in this area. The European Association for Palliative Care (EAPC) has recognised these difficulties, but at the same time seeks to emphasise the importance of research.[6] The EAPC has set up a Research Network (RN), whose main objective is to encourage and facilitate research in palliative care.[7]

The present project is the first empirical multicentre study organised by the RN of the EAPC. A secondary objective of the investigation was to identify a collaborative group of palliative care services across Europe with the ability to provide epidemiological and clinical data for this and future studies.

The study was a cross-sectional survey, carried out in 2000, and encompassed 143 palliative care centres in 21 European countries. The project included all 15 member states (at the time of the research) of the European Union, as well as Norway, Switzerland, Iceland, Israel, Romania and Cyprus.

The aims of the study were:

1) To identify patient populations using specialist palliative care services in terms of demographic data, diagnostic groups, social circumstances and performance status in 21 different European countries.
2) To provide detailed information on the use of strong opioid analgesics and some other key drugs by specialist palliative care services.
3) To identify a network of palliative care services across Europe with the ability to participate in collaborative research.

In this paper, the demographics of the palliative care survey are presented together with basic patient characteristics.

Material and methods

Palliative care centres

One national co-ordinator in each country recruited a maximum of 10 eligible centres in that country. We did not attempt to collect a representative sample of patients and centres according to strict scientific principles. However, in the countries where the national co-ordinators identified more than 10 centres, he/she was asked to identify a representative selection based upon his/her own experience and knowledge of the centres and of the range and distribution of palliative care programmes in that country.

Study period

The study was performed during a designated week in Autumn 2000. All patients who were actively receiving care from the palliative care programme on one specific day in the designated week were to be included.

The questionnaires

The survey was carried out by means of two questionnaires. One ‘centre’ questionnaire to be completed for each centre/programme, and a patient questionnaire to be completed for every patient. The patient questionnaires were completed by the doctor, nurse or other health professionals who was the ‘primary carer’ or who knew the medical and social details of the patient.
The following information was collected.

Patient data

Anticipated life expectancy (on a categorical scale ranging from ‘ <24 hours’, one to six days’, ‘one week to one month’, ‘one to six months’, ‘six months to one year’ to ‘ >1 year’), mobility (ranging from ‘fully ambulatory’, ‘able to walk independently, but at an impaired level’, ‘needs assistance with walking’, ‘bed- or chair-bound, able to get to toilet’ to ‘bed- or chair-bound, unable to get to the toilet’).

Centre data

Type of service provided by the centre categorised as: ‘hospice (freestanding)’, ‘hospital palliative care ward (inpatient)’, ‘day hospital’, ‘ambulatory service (outpatient)’, ‘palliative care consultation service in a hospital’, ‘home care service’, ‘telephone consultation service (patient follow up)’, ‘telephone consultation service for community doctors and nurse’, and ‘other’. If more than one service was provided more than one box could be ticked off.

Place of palliative care service delivery

Place of palliative care delivery, categorised as: ‘cancer hospital’, ‘general hospital’, ‘hospice’, ‘ambulatory/outpatient-based service’, ‘day care’, ‘home care (specialist advisory service)', 'home care (extended nursing care, or 'hospice at home')' and other. More than one category could be ticked when care was delivered at several places simultaneously.

Ethics

Ethical approval was obtained at each centre according to national and/or regional recommendations.

Statistics

Descriptive statistics only are presented. Collection and organisation of the data was performed at the Unit for Applied Clinical Research, Norwegian University of Science and Technology. The statistical software SPSS for Windows v. 12 was used for all statistical analyses.

Results

Patients

Data were submitted on 3013 patients from 143 centres (Table 1). In most countries, with the exception of France, Ireland, Italy and Spain, the majority of the patients in this survey were female (56%), and the mean age for the total sample was 66 years (range 2–103 years) (Table 1). The majority of patients were married (54%), and the remaining were either widowed (25%), single (11%), divorced (7.5%), or living with a partner (3%).

Table 1 Patient characteristics

	No.	%
Age, years (mean; range)		
Male (66; 2–98)	1320	44
Female (66; 3–103)	1693	56
Marital status		
Single	316	10.5
Married	1625	54
Unmarried with partner	80	3
Widows	759	25
Divorced	227	7.5
Home circumstances		
Lives alone	851	28
Lives with spouse who is in good health	1320	44
Lives with spouse who is not in good health	317	10.5
Lives with other relative who is In good health	467	15.5
Missing home circumstances	58	2
Date of first referral to palliative care		
2000	2239	74
1999	472	16
1998	138	5
Diagnosis		
Cancer	2831	94
Neurological	90	3
Respiratory	16	0.5
Cardiac	15	0.5
AIDS	10	0.3
Other	43	1.5

Most patients were living with a spouse or other relative in good health (59%). Almost all the patients had cancer (94%), while some had a neurological diagnosis (3%), respiratory disease (0.5%), cardiac disease (0.5%), or AIDS (0.3%). The majority (75%) had been referred to the palliative care service during the six to seven months before the survey was performed; 16% had been referred during the year 1999, while 4% were referred before 1998.

Very few patients had less than one week of expected survival (6%), the majority were expected to live one to six months, while as many as 16% were expected to live more than one year (Figure 1).

The majority of the patients were fully ambulatory (27%) or able to walk independently (28%), while 21% were bed- or chair-bound unable to get to the toilet (Figure 2).

Service characteristics

The number of centres per country varied from one to 13, and the number of patients per country varied from five to 778 (Table 2). As shown in Table 2, the median number of patients per centre varied considerably from seven in Greece and the Netherlands, to 30 and 40 in Norway and the UK, respectively.

Looking at the range, a substantial number of centres (48/143) had <10 patients included in the study. The majority of the centres were either based upon a general hospital (33%), hospice (25%) or cancer hospital (8%), while a minority of the services were based upon home care (Table 3). Consequently as many as 2171 (74%) of the patients were recruited from inpatient-based services.

The type of service provided per centre is presented in Table 4. In the questionnaire, it was possible to check off more than one type of service per centre. In order to give a general overview, the raw scores are expressed in Table 4. In all countries, except Cyprus, all services provided at least day hospital care and/or ambulatory

Figure 1 Anticipated life expectancy estimated by the health care provider (physician)

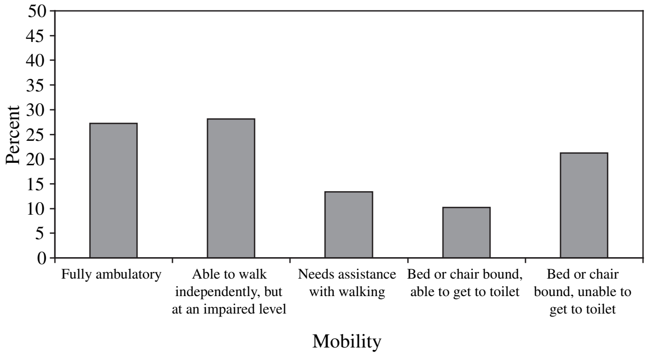

Figure 2 Mobility evaluated by the health care provider (physician)

services. Palliative care services within hospitals were established in most countries. It should be noted that the sample includes more hospital palliative care wards ($n = 49$) than free-standing hospices ($n = 35$).

Place of care delivery

Place of palliative care delivery was reported for each patient and included eight categories. More than one category could be ticked when care was delivered at several places simultaneously. The majority of the patients (60%) (Figure 3) received care as an 'outpatient', either at a traditional clinic in an outpatient cancer hospital (12%) or in home care programmes, and received care from a specialist advisory service (24%) or extended nursing care (24%). Less than one-quarter of the patients received care in a hospice.

Discussion

One of the objectives of this project was to identify a collaborative group of investigators in palliative care across Europe. The EAPC RN succeeded by recruiting 143 centres from 22 countries, and collected data on a total of 3013 patients. One reason for the successful outcome was the establishment of a data co-ordinating centre at the Palliative Medicine Unit in Trondheim, Norway. The need for such an organisation has long been recognised by other groups conducting clinical research in cancer patients, such as the EORTC, and by research funding bodies in many countries.

The data collection was successful in spite of severe constraints on the budget. The national co-ordinators organised the study in their countries without any financial reimbursement from the EAPC RN. Clearly, this reflects the considerable enthusiasm generated by the project and the keenness of the palliative care services in so many countries to be involved in research. This experience contradicts the scepticism, raised by many palliative care providers, about the willingness of palliative care centres to participate in research. Several countries in Europe have identified a need for research in palliative care. For example, a recent report from the National Cancer Research Institute in the UK points out that the organisation of research is fragmented, and that the challenge is to achieve genuine collaborative work.[8] In a Norwegian report, it is recommended that a Chair in Palliative Medicine should be established at all universities in the country in order to organise, regionally and

Table 2 Distribution of centres, patients, gender per country and patients per centres

Country	No. of centres	No. of patients	Gender per country		No. of patients per centres	
			Male (%)	Female (%)	Median	Range (min–max)
Austria	7	58	29	71	10	2–17
Belgium	10	109	49	51	9	1–27
Cyprus	5	132	36	64	21	15–56
Denmark	5	88	36	64	17	8–25
Finland	5	139	37	63	20	3–51
France	13	160	56	44	10	2–36
Germany	9	101	37	63	11	2–23
Greece	8	70	43	57	7	2–19
Iceland	7	72	39	61	8	1–33
Ireland	8	203	53	47	20	8–53
Israel	4	104	40	60	22	14–47
Italy	10	267	52	48	26	6–50
Luxembourg	1	5	20	80	–	–
Netherlands	6	42	31	69	7	4–10
Norway	4	121	39	61	30	20–40
Portugal	3	43	39	60.5	10	8–25
Romania	5	93	40	60	15	2–43
Spain	10	195	51	49	17	6–37
Sweden	7	168	42	58	16	5–48
Switzerland	6	65	43	57	11	6–20
UK	10	778	43	57	40	5–299
Total	143	301	44	56	13	1–299

Table 3 Centre identification 'What is your centre based upon?'

	No. of patients (%)	No. of centres (%)
Cancer hospital	227 (7.5)	12 (8)
General hospital	808 (27)	47 (33)
Hospice	1137 (38)	36 (25)
Ambulatory/outpatient hospital-based service	39 (1)	1 (0.7)
Day care	7 (0.2)	1 (0.7)
Home care (special advice service)	74 (2.5)	7 (5)
Home care – 'hospice at home'	380 (13)	17 (12)
Other	260 (9)	19 (13)
Missing centre identification	81 (3)	3 (2)

nationally, education and research within this field.[9] The poor evidence-base for much clinical practice in palliative care highlights the urgent need for well-conducted prospective studies, preferably randomised controlled trials.[10] There is no doubt that one common recommendation is the need for national and international collaboration in order to perform large enough studies with a representative sample of patients. Recent Cochrane reviews evaluating 'oral morphine for cancer pain',[11] and 'hydromorphone for acute and chronic pain,[12] conclude that too many small, non-conclusive, studies have been performed, the heterogeneity of the studies is enormous, and the possibility to perform meta-analysis is limited.

One interesting finding in this survey is the heterogeneity of the sample. However, it needs to be taken into consideration when the data are discussed that the sample is not representative of centres providing care at either a national or international level. The number of centres per country and number of patients per centre varied considerably. Furthermore, palliative care was delivered in cancer hospitals and general hospitals, as well as hospices. The type of services differed somewhat between countries, however, in most countries both inpatients, consultation services and home care services were provided. Such a heterogeneity of palliative care was also found in a recent report, which assessed the development of palliative care services.[13] Within the seven countries studied, UK, Sweden, Italy, Germany, Spain, Belgium and The Netherlands, the 'founding' initiative of palliative care took place over a period of 14 years, from 1967 to 1991. The 'founding' services varied from inpatient hospice and hospital inpatient units, to home care services and palliative care units within departments of medical oncology. In 1999, the number of inpatient hospice/palliative care units varied from 219 in the UK, to 18 in the Netherlands and three in Italy. A similar wide variation was found in the ratio of the inpatient hospice and palliative care beds to populations. In the UK, the number of beds per person was 1:17 866, in Spain 1:49 261 and in Italy 1:1 913 332. These numbers reflect, to some extent, the different periods of time during which palliative care has developed in different countries (with the UK being the longest, starting in 1967), but also differences in the way in which healthcare is organised and delivered in different countries. Another problem is related to differences between centres and/or

Table 4 Type of services provided per centre

Country	No. of centres	Hospice (free-standing)	Hospital palliative care ward (Inpatient)	Day hospital and/or ambulatory service (Outpatients)	PC consultation service in a hospital	Home care service	Telephone consultation service
Austria	7	2	4	1	1	1	5
Belgium	10	2	1	3	2	5	5
Cyprus	5	1				4	
Denmark	5	4	2	3	1	4	4
Finland	5	3	3	3	1	3	3
France	13		5	9	10		11
Germany	9		7	6	5	6	7
Greece	8		1	5	1	6	3
Iceland	7		3	3	2	5	2
Ireland	8	4		4	5	6	8
Israel	4	1	1	2	1	3	1
Italy	10	2	3	7	6	7	5
Luxembourg	1		1	1			
Netherlands	6	3	2	2			4
Norway	4		2	4	2	1	3
Portugal	3		2	1	1	2	2
Romania	5	2		1	2	3	2
Spain	10		5	6	5	5	8
Sweden	7	5	1	3		5	3
Switzerland	6	1	3	3	3		2
UK	10	5	3	8	6	3	5
Total	143	35	49	75	54	69	83

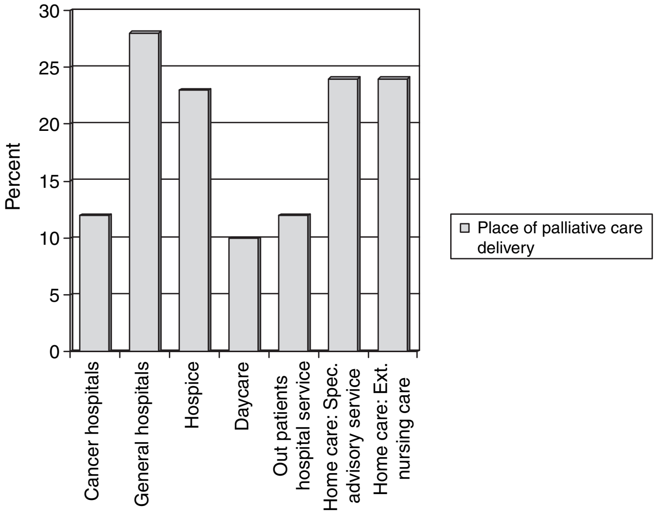

Figure 3 Place of palliative care delivery reported by each centre, more than one alternative could be ticked

countries on how the various types of facilities are defined according to the type of their actual care delivery. To our knowledge, there is no consensus internationally on this issue.

Most palliative care patients reported by the participating services were not imminently dying. One of the striking, and encouraging, findings of this survey was the number of patients with an anticipated life expectancy of more than six months. Indeed, the overwhelming majority of patients had been referred at least six months prior, and had an anticipated life expectancy of more than a month. These findings reflect referral and practice patterns that are in keeping with the WHO recommendations that palliative care be started relatively early in the trajectory of incurable illness.

The models of service delivery to palliative care varies considerably, with regard to the type of facility (inpatient units, hospice, day care, out patient clinics and home care services) and also the staffing. There are major national and international idiosyncrasies which have influenced the types of service which have been developed and the involvement and medical and nursing staff, social workers and rehabilitation staff. There are important differences even within individual countries in the availability of medical and paramedical staff to multidisciplinary palliative care teams. In a British survey performed in the Thames region, access to doctors was only provided in some centres, and some services describe themselves as more medically oriented, while other centres describe themselves as mostly socially oriented.[14] In Spain, there are no free standing hospices, and many home care teams consist of a core team of a physician and a nurse and, frequently, a psychologist.[15] During the last decade, palliative care has, in many countries, been incorporated into the public health care system with public funding.[16–18]

In this study, the majority of the centres were general or cancer hospitals; hospices were in a minority. This highlights the fact that, in many countries, ‘hospices’ do not exist, but palliative care is still widely provided within the secondary care sector. It is not necessary to have a hospice in order to provide high quality palliative care. An encouraging finding is that palliative care seems to be embedded in many countries into the mainstream of health care delivery. On the other hand, these data may reflect recruitment bias. We did not attempt to obtain a representative sample and it is not possible to draw firm conclusions about all of the issues raised. However, the data certainly present some interesting trends which need to be followed up.

Many centres reported on 10 patients. These centres are clearly very small services or presumably have very little infrastructure particularly to support research. The participation of such services in this study indicates a considerable enthusiasm to further research in palliative care. The small numbers again emphasise the need to be cautious in interpreting the data.

The national co-ordinators were asked to include all palliative care programmes in their country, up to a maximum of 10 centres. In five countries, the maximum of 10 centres was reached; Belgium, France, Italy, Spain and UK. In all other countries <10 centres were included, which may indicate either that very few palliative care programmes are developed in that country or that few are able to participate in such a study. Clearly, there remains an unmet need for specialist palliative care and the establishment of new palliative care centres in most European countries.

There are major differences between countries, even in Europe, in the way in which health care is organised and delivered, and for this reason alone it would be very difficult to produce guidelines on service delivery for specialist palliative care which would be widely applicable. A Task Force of the EAPC is now systematically collecting information on how palliative care is delivered in most European countries, and another group is working on Centres of Excellence in palliative care. The aim is to improve the understanding of how palliative care is and should be delivered, and ultimately, this should lead to international definitions and standards for palliative care.[7]

We believe that the data from the present survey together with the work performed by the EAPC groups and the political initiatives taken in many countries, will improve the quality of palliative care and identify palliative care as a speciality in other countries than the UK. With different types of palliative care services in hospitals, or dedicated beds and/or specialist units in nursing homes/hospices at the community level and home care programmes, a comprehensive national network of services will provide care for patients, wherever their preference is for this care.

Palliative care is assumed by many health care providers, politicians and the lay public to focus on terminal care, that is care of the dying patient. It is noteworthy that the population of patients included in this survey was not a sample of dying patients. There were a substantial number of patients with an anticipated life expectancy of more than six months, and only a minority was identified as dying patients. This emphasises that a palliative care approach may be applicable early in the disease trajectory, a concept incorporated in the EAPC definition of palliative care.[18]

Conclusions

This study has demonstrated a considerable enthusiasm for research in the palliative care community across Europe. However, it has also highlighted the fact that many palliative care services, whilst they may be interested in carrying out research, do not have the infrastructure to support it. It seems clear that, in terms of multicentre clinical trials, the EAPC has access to potentially very large numbers of healthcare workers who could participate in research and, thus, access to potentially large numbers of patients.

The heterogeneity of the sample is evident, and this would need careful considerations for future clinical trials. We have no doubt that prospective identification of suitable patients would be possible for a particular study.

The range of services encountered in the different countries highlights the need for organisational and clinical standards for palliative care which can be audited. These are already available in some countries, such as the UK, but need to be modified to make them applicable to other European countries. Finally, it is clear that palliative care services are serving a population of patients who may not necessarily be in the terminal phase of their illness. It is appropriate that the principles of palliative care be applied to the care of cancer patients, at whatever stage of their illness, when their needs demand it.

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