The EAPC Task Force Development of Palliative Care in Europe

Carlos Centeno
Clínica Universitaria
Universidad de Navarra
Pamplona (SPAIN)



A Collaborative Effort







- David Clark, LIVERPOOL (UK)
- Luis Alberto Flores, VALLADOLID (SPAIN)
- Javier Rocafort, BADAJOZ (SPAIN)
- Anthony Greenwood, LIVERPOOL (UK)
- David Prail, LONDON, (UK)
- Liliana de Lima, HOUSTON (USA)
- Amelia Giordano, MILAN (ITALY)
- Silvia Paz (ALICANTE, SPAIN)
- Carlos Centeno (PAMPLONA, SPAIN)

IOEL

EAPC Member

EAPC Member

IOEL, Research Assistant

HELP THE HOSPICES

IAHPC

EAPC Head Office

Research Assistant

EAPC Board, Chair

52 *correspondent members*: one in each countrry

30 Boards of Nationals Association

With partial fianchcial support of...



Main Objective

 to assess the degree of development of palliative care in Europe



The World Health Organization (WHO) definition of the European region has

been considered to determine the 52 countries to be included in the study

Secondary Goals

- To facilitate and spread information about the situation of PC in each country
- To facilitate access and communication between relevant hospice and palliative care associations as well as societies that operate in Europe
- To identify key people who have studied the process of hospice and palliative care development in their own setting and who may provide country-specific data to assist our Task Force and policy makers, planners and professional associations, now and in the future.

A Combination of 4 Research Methods

- Literature review of any published work about the development of PC in each of the countries
- International survey to boards of the National Associations of Palliative Care:
 - A qualitative study addressing opinions, strong and softs points of palliative care, challenges, etc

- International survey to an expert within each country
 - A quantitative study addressing facts, numbers of teams or beds, etc.
- Research reviewing the national Directories of Services, whether published, printed or online.



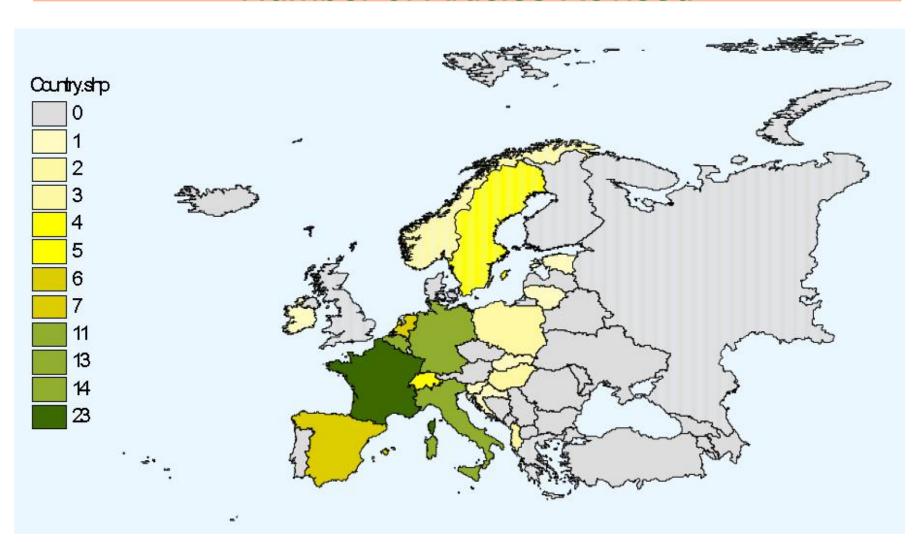
PRELIMINARY RESULTS: Current status of the literature revision

We have finished the work for:					
Country	N ^{er} of Articles	Enough information			
Albania	2	Yes			
Belgium	11	Yes			
Croatia	1				
Cyprus	3	Yes			
Eireland	1				
Estonia	1				
France	23	Yes			
Lithuania	1				
Malta	1				
Slovakia	1				
Slovenia	1	Yes			

Any articles found about other countries

Before finish the work, we have information for					
Country	N ^{er} of Articles	N ^{er} Revised	Enough information		
Finland	2	0			
Germany	14	13	Yes		
Greece	6	0			
Hungary	3	2	Yes		
Israel	6	5	Yes		
Italy	19	14	Yes		
Netherlands (the)	15	3	Yes		
Norway	6	3	Yes		
Poland	5	3	Yes		
Portugal	1	0			
Romania	3	0			
Russian Federation	1	0			
Spain	20	7	Yes		
Sweden	7	5	Yes		
Switzerland	6	4	Yes		

Number of Articles Revised



Germany: Criterion for literature choice

- Search strategy
 - "Palliative Care"[MeSH] or "Terminal Care"[MeSH] or "Hospices"[MeSH] or "Hospice Care"[MeSH]
 - 2. Germany
 - 3. #1 and #2
- Search limits
 - 1. Date: 1995 to 2004
 - 2. Languages: English, French or Spanish
- Choice after titles reading
- 2nd choice after abstracts reading





	Only	Only	Both	
	pubmed	cinahl	Pub+Cin	
Searched	24	8	8	
After titles reading	6	5	7	
After abstract reading	6	2	7	
DEFINITIVE CHOICE	15 + 2 referenced by K people			
Achieved (apr 2005)	13			
Revised (apr 2005)	12			

National Viewpoint

Palliative care in Germany -14 years on

A survey of palliative care services in Germany by Rainer Sabatowski, Lukas Radbruch, Georg Loick, Stephan Grond and Frank Petzke concludes that,

despite recent improvements, there are serious shortfalls in almost every area

directory of hospice and palliative care A services in Germany was published in 1993,1 following the example of the UK2 and Canada.3 Information was provided on 32 hospices and palliative care units, offering 302 beds for inpatient case.\ An update was published in 1997.

employ full-time doctors as well as nursing and have access to hospital facilities. M care at independent inpatient hospice i

usually provided on a part-time basis by G In both settings, additional profess personnel - for example, physiother social workers, the clergy and psycholog are also available, offering comprehe

Survey mess In the winter sent to all th

new palliati

services (clas

Pallitative c

Health Org

patient-pl

dition to

physician

Improving

Key points

· Germany's annual death nat

• It has been estimated that b

Although the 1997 survey li

and medical care.

palliative care wards

48 of these offer simultans

· Patients with AIDS are admi-

highlights its continuing she despite encouraging develop

care beds are needed in Gera

End-of-Life Decis Directives in Palli A Cross-Cultural and Health-Care

Raymond Volce MD Akira Ak PhD, and Hans-Martin Sees, Ph Department of Neurology (R.V.), Kita School of International Health (A.A. (C.R.) Ballac Tenn. USA: the first Westington, DC, USA

Vol. 16 No. J September 1998

Original Article

In order to explore punible different toward advance direction (AD) in in polluting one mulifulions and receivered important to Aution's a was a kigh providence of extrastithan 80% of the patients had neg States and Germany, in contrast I Japon, some patients had given a results serie used to derive a checkli-decision-making. This checklist maguide physicians, especially non-po-patients and their families in this 1998:16:153-162, © U.S. Grov

Introduction

Ourside specialized palliative care institutions, the care of dying patients still suffers ap-

Addissi reprint requests at Raymond Volta, MD, Department of Neurology, Box 52, Momortal Hospital, 1275 York Assume, New York, NY 10023 USA. Accepted for trubboution: December 24, 1997.

© U.S. Cancer Pain Rollel Committee, 1996 Published by Elevier, New York, New York

Informatio followed two years ago by an optional course for tution type; students and practitioners at the University of number of a Liège and later, in 1997, by a course at the Catholic University of Louvain. A course is also sition of sta additional se being set up within the Scientific General Medicine Society, aimed at creating networks of Using cri feeland,4 inst GPs in pulliative care. tive care we pices; hom

This year, all of these decisions, both good and bad, will be implemented and it is obvious that new problems will not take long to emerge from these poor standards

Bernadette Wouters, Member of the Belgian Society for Balliative Case. Vice-President of the East'

The German experience

Eberhard Klaschik and Friedemann

Nauck trace the German palliative care culture from its origins to the present day

Although the concept of hospice care first appeared in Germany in the late 1960s, it was not until the early 1980s that the first sallistive care unit (PCU) opened in Cologne. following this first initiative, the popularity of hospices did not increase significantly and in 1990, only three palliative care units and three hospices existed in the whole of Germany ever, since then, there has been a remarkable rise in the number of PCUs, hospices and home care services. In 1997, there were 34 PCUs,

40 hospices, two day-care of tres and more than 300 hos pice services, 48 of which

PCUs in Germany vary greatly in size, ranging between five and 25 beds. The hospices tend to have between four and 55 beds, with an average of about eight beds. The core team in a PCU consists of physicians and nurses, supported by clorgymen, psychologists, social workers, physiotherapists, occupational therapists and olunteers. The quality of care and psychosocial support s high in German hospices

but there is often inc and pain therapy. Home psychosocial support.

PCUs receive funding if the planning list. In 1997, the G passed a law that gives host of 350 deutschmarks per p legal obligation of health is tions only extends as far as th does not cover psychospetal to

The German Association Palliative Medicine

In 1994, the German Associat Medicine (DIGP) was founded. ship of the EAPC. The first nat-the DGP was held in 1996 and first German books on pallistis care were published.

Training in palliative care

For the past couple of years, ediing in the field of palltative care able in Bonri, Cologne, Limburg Medical students have received

The future of care in Gern

At the end of 1998, the centre for palliative med-The centre will include a PCU a day care centre a hospital support team, a home care service, a teaching institute for physicians, nurses

and medical students and an advisory board (welfare centre) for the state of North Rhine Westfalia.

Germany is still only a eveloping country in the field of palliative care and medicine but a growing number of physicians, murses, cler gymen, psychologists, physio-therapists, social workers and continuers are increasingly iterested and involved in putting the hospice concept

Eberhard Kluschik, Amaesthetist Areaesthetist, Intensive Care and Pain Therapy Unit, Malterer Hospital, Bane, Germany

DROPORN JOURNAL OF PALEATIVE CARE, 1999; SON

Support Case Cascat (1999) 7: 377-376 DOI 10.100790002(09000006

SUPPORTIVE CARE INTERNATIONAL

© Springer-Verlag yard

Thomas Binsack

Caring for terminally ill patients The Johannes Hospiz in Munich: a patiative care unit in southern Bayaria, Germany

Published seline: 9 September 1986

T. Dianach, M.D. Politoinetaine, Johanna Hospie am Kraskonikon dar Barrakerriara Bresier, Romanistano 15, D-20030 Munick, Comment | Outs 17972908

The hospice movement and the speciality of pullarity medicine have a rather short tradition in Germin While the desupment of the ideas behind then be the control of the state The hospice movement and the speciality of pulliative

by the religious order of the Buchers of St. John God, Early in the 1988, this traditional and inte God. Early in the 1900x, this traditional and inte-tional community one concerned with new challed in a changing world. What would have been the form of country, 50, foun of God, healthe walked it in the streets of a modern Griff. The inswer was world have or of in times people in our modern's ties, who have no loably and no place to go, term ill patients and the dydag, especially those AFSS.

ARCS."
After numerous discussions with government it was unions and beatth insurance companies it was do
to start a paliculate care unit at the Order's local to start a pulsative care unit at the Order's local in in Germany, a parliable care unit is define paralie for terminals if and dring patients we general template it is under the effection of a 1 sector and thoused by the public heavity assuma-ted. In contrast, a locytice is an institution of hoperants: a can, for expansies, be connected to a former. hospital: it can, for example, be connected to a

Support Care Cancer (2000) 8:80-83 DOI 10:1007/s005209900096

SUPPORTIVE CARE INTERNATIONAL

Wolfgang Schremi Jens-Peier Smub

Integrated palliative care within a general hospital

Published on

thiginal Article

Severe Undertreatment of Cancer Pain: A 3-Year Survey of the German Situation

Ma bard Zenz, Mill, Thorsten Zenz, Michael Topho, MD, and nativates accompa, MD Halvahores of Anathenings, Internet Care, and Pain Thomps, Beginnenshal University Calceller, Richan, Gernary

Introduction

W. Schrent, M.D. Kreiskrankenkens Innere Ableitung, Ludwig Heilmeyer D-89512 Gürzburg, Tel: +49-8221-9610 Fax: +49-8221-9610

In November 1985, in Günzburg starte necicine. Since one of internal medicine ant diseases. Consec help from our hospit disease, frequently up terminally ill posed a h burden on the medical they had too little time provide the care that w come these problems, th tive care" was developed tion for support to the

vided a grant for the yes

thereon of this survey uses to determine the presenting patterns of German physic The aim of this movey outs to determine the presenting patterns of German polynomes. Not recomment of concern point. The completioned pattern recentle of 3.50 persons, which records a total number of 1,104,415 polynolis sum a 3-years person, quere exclipate. "Showing received a dotal number of E, 1004, 475 perfected near a Syntr period, once exclipted, "Simong," operation, nation, compared to the neutrageneral of anotes concern pains, near personnel to journ \$202 of \$6.000 compared to \$7.000. Only \$9.000 period to construct some plants of the period personnel period to the period to \$7.000. Only \$9.000 period to the period control of the period period to the period to the period to the period of period period period to the period to the period period to the p

Opinitis, Germany, peopulities, prescription, conser pears, survey

Introduction

About 55%-60/5 of carrier patients viffer from pion desting the course of their disease. It from pion desting the course of their disease. It for many pion desting the course of their disease. The World Health Organization (WHO) has published the season of guident and their their disease of their protection of the protection of their protection of th

Address spirial reports to Michael Zerz, MB, Department of Amendmentaling. Internite Cart and Part Hospital Bergateerschell, Birkle-de-InCamp Plate 1, To 46201, Germany. tropped for publication: Separather 16, 1994.

© U.S. Garetz Pala Refer! Committee, 1995; Published by Election, New York, New York

conser pain could be created effectively by their printer physicians. Despite theme Each, under-terment of cancer pain remains a prominent global problems. Sociological designs of health-cation and problems, and patients, logist renti-tions are problems. The printer state of pain sentiment. To farther carrie-pain sentiment. To farther carrie-professional parties on the measurement of can-cer problems of printer physicians in the usual-ment of this condition over a lung period of one.

Materials and Methods

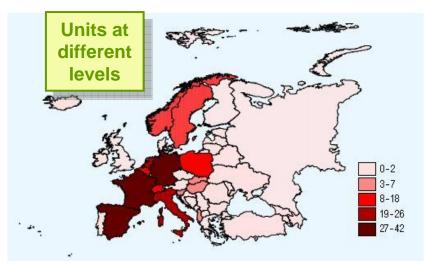
Journal of Pain and Sympton Management 187

The population investigated comprised the patients of 350 practices (general practitioners

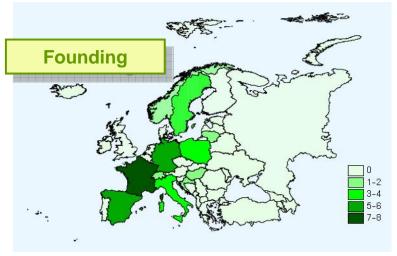
Articles selected for Germany

- 1. Strumpf M, Zenz M, Donner B. Germany: status of cancer pain and palliative care. J Pain Symptom Manage. 1996 Aug;12(2):109-11
- **Farnon C.** A personal exploration of the German hospice system. Am J Hosp Palliat Care. 1996 Jul-Aug;13(4):32-7. Erratum in: Am J Hosp Palliat Care 1996 Sep-Oct;13(5):5
- 3. Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM. Organization and patients' perception of palliative care: a crosscultural comparison. Palliat Med. 1997 Sep;11(5):351-7
- 4. Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM. End-of-life decisions and advance directives in palliative care: across-cultural survey of patients and health-care professionals. J Pain Symptom Manage. 1998 Sep;16(3):153-62
- 5. Radbruch L, Nauck F, Fuchs M, Neuwohner K, Schulenberg D, Lindena G. What is palliative care in Germany? Results from a representative survey. J Pain Symptom Manage. 2002 Jun;23(6):471-83
- 6. Ostgathe C, Nauck F, Klaschik E, Dickerson ED. German medical education in pain therapy and palliative medicine: a comparison of British, Canadian, and United States models. J Pain Symptom Manage. 2002 Jul;24(1):13-5
- 7. Radbruch L, Nauck F, Sabatowski R. Germany: Cancer pain and palliative care--current situation. J Pain Symptom Manage. 2002 Aug;24(2):183-7
- 8. Sabatowski R. Radbruch L. Loick G. Grond S. Petzke F. National viewpoint. Palliative care in Germany -- 14 years on. Eur J Palliat Care 1998 Mar-Apr; 5(2): 52-5 (18 ref)
- 9. Klaschik E. Nauck F. National viewpoints. The German experience. Eur J Palliat Care 1998 Nov-Dec; 5(6): 203
- 10. Tuffs A. Germany drafts guidelines for care of the dying. Lancet 1996 May 4; 347(9010): 1256
- 11. Kloke M, Scheidt H. Pain and symptom control for cancer patients at the University Hospital in Essen: integration of specialists' knowledge into routine work. Support Care Cancer. 1996 Nov;4(6):404-7
- **Binsack T.** Caring for terminally ill patients. The Johannes Hospiz in Munich: a palliative care unit in Southern Bavaria, Germany. Support Care Cancer. 1999 Nov;7(6):377-8
- 13. Schreml W, Staub JP. Integrated palliative care within a general hospital. Support Care Cancer. 2000 Mar;8(2):80-3
- 14. Sahm SW. Palliative care versus euthanasia. The German position: the German General Medical Council's principles for medical care of the terminally ill. J Med Philos. 2000 Apr;25(2):195-219
- 15. Principles of the German Medical Association concerning terminal medical care. J Med Philos 2000 Apr; 25(2): 254-8
- 16. Zenz M, Zenz Th, Tryba M, Strumpf M. Severe undertreatment of cancer pain: a 3-year survey of the German situation. J Pain Symptom Manage 1995;10:187-191.
- 17. Bausewein C, Hartenstein R. Oncology and Palliative Care. Onkologie. 2000 Dec;23(6):534-537

Quality of information gathered: number of sentences about each topic









Germany: Some results about Palliative Care funding

- 26 palliative care units exist in hospitals. Sixteen institutions are supported by grants from the Ministry of Health and three by grants of "Deutsche Krebshilfe" (Strumpf 1996)
- Whereas palliative care units are affiliated with a hospital, receiving full funding from the national health insurance system, reimbursement from the health insurance system is much less for hospice beds than for palliative care beds, and patients must pay part of the costs in many hospices. (Radbruch 2002)
- In hospices, reimbursement follows the lines for nursing homes, which means that part of the expenses are put forward to the patient and his family. (Radbruch 2002)
- Inpatient hospice units and palliative care wards received financial support from a variety of institutions, including state subsidies and funding by churches, charities and private groups. The German Cancer Foundation (Deutsche Krebshilfe eV) is a prominent supporter of palliative care services. (Sabatowski 1998)
- Palliative Care Units receive funding if they are on the hospital planning lists. In 1997, the Government passed a law that gives hospices partial funding of 350 deutschmarks per patient per day. (Klaschik 1998)

DIRECTORY OF GERMANY

 Hospiz- und Palliativführer 2003.
 Stationäre und ambulante Palliativ- und Hospizeirichtungen in Deutschland.

Sabatowski R, Müller M, Nauck F, Zernikow B. MediMedia

BAG Hospiz (Bundesarbitsgmeninschaft Hospiz e.V.)

DGP (Deutsche Gesellschaft für Palliativmedizin e.V.)

DGSS (Deutsche Gesellschaft zum Studium des Schmerzes e.V)

Eigenes Leben – Hilfen für Kinder mit Schmerzen oder lebensverkürzenden Erkrankungen e. V.)

GERMANY

PALLIATIVE CARE SERVICES IN GERMANY, YEAR 2003(*)

Total Services		947
Hospital Care		197
- PALLIATIVE CARE UNIT	84	
- HOSPICE	107	
- PEDIATRIC PC UNIT or HOSPICE	6	
Home Care		750
- HOME CARE TEAM	703	
- PEDIATRIC HOME CARE TEAM	47	

(*) Hospiz- und Palliativführer 2003. Stationäre und ambulante Palliativ- und Hospizeirichtungen in Deutschland.

2 International Surveys Preliminare Results

We identified key people in 47/52 countries

- We fail in Monaco, San Marino, Tajikistan, Turkmenistan, Uzbekistan,
- This network could become more important in others studies in the future

Preliminare Results

•Two questionnaires have been produced and sent on 01/March /05

- The 'Euro-barometer'
 questionnaire, to be
 answered by 'boards' of
 national associations or
 equivalent
- This questionnaire looks into general views and opinions on the development of palliative care in the country (qualitative data)

- The 'Facts' questionnaire, to be answered by 'key informants'
- It explores specific data relevant to the development of palliative care in each country (quantitative data)

Preliminare Results

The 'Eurobarometer' questionnaire

Completed questionnaires received:

16/42 (38%)

01 / April / 05

The 'Facts' questionnaire Completed questionnaires received:

13/42 (31%)

01 / April / 05

GERMANY

- Euro-barometer' questionnaire
 - DEUTSCHE GESEKKSCHAFT FÜR PALLIATIVMEDIZIN
 - Contact: Birgit Jaspers
 - Questionnaire sent on 14/FEB/05
- 'Facts' questionnaire
 - Key contact: Dr. Friedeman Nauck
 - Questionnaire sent on 14/FEB/05





