



## Developing Primary-care-based Palliative Medicine in Germany

# The PAMINO PROJEKT

### Background

Modern medicine can extend lifetime even in case of life-threatening diseases. Many patients suffer from pain and other symptoms from respiratory, gastrointestinal or cerebral dysfunction based on a chronic malignant or non-malignant disease. Therefore the concept of palliative medicine was developed in the past 50 years. In Germany the hospice and palliative care movement started in the seventies of the past century, but until now palliative medicine is underdeveloped structurally and not well established in community-based primary care. For the health care system palliative care is a challenge both in quantity and in quality. Inpatient and outpatient care need to be improved. In Germany die about 800.000 people per year, more than 250.000 people of the aftermath of malignant tumours, of which many suffer from unbearable symptoms. Regarding to a study of the German Hospice Foundation, in 2002 only 1.8% of dying people received structured palliative care and 4.3% were cared for in hospices or specialized palliative care units. To secure the highest possible quality in health care and to improve quality of life of dying patients, palliative care needs to be further established in the German health care system. As in other European countries most patients (87 to 90%) wish to die at home, a mismatch to reality where the hospital is the most common site of death. Many patients express fears of social isolation, loss of independence and self-reliance, and pain at the end of life. As a primary goal, outpatient care for the incurable should be managed at their home, which is often hampered by deficits in communication between patients and medical care givers. Patients prefer to die in the home setting they are used to, if they have positive experiences of specialist community-based palliative care services and primary care service. Competent and supportive communication between patients and general practitioners, based on a trustful relationship, helps both patients and physicians to discuss treatment strategies and end-of-life care and reach mutual agreements. Half of the patients with malignant tumours would like to participate in their care on the foundation of such shared decision making. With general practitioners, who are long-time confidants of the patients in their role as family physicians, patients speak confidently about their wishes regarding end-of-life care.

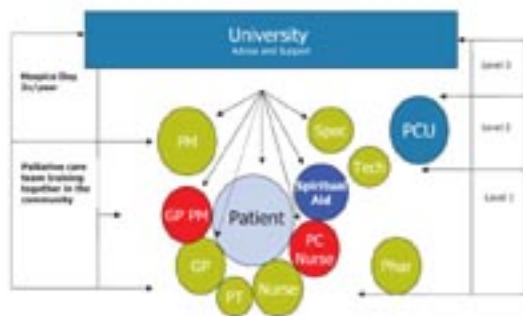


Fig. 1: Concept for community-based palliative medicine

PCU: Palliative care unit  
 Spec: other specialists  
 PE: Psychotherapy  
 Pharm: Pharmacy  
 PH: Specialist in Palliative Medicine  
 Tech: Technical Support  
 PC Nurse: Nurse specialized in Palliative Care  
 GP/PH: General Practitioners with education in palliative medicine

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Ferdinand Hodler: The dying woman Good-Dame, 1915

### Results

In the area around Heidelberg, District North-Baden, there are about 1100 General Practitioners in a distance up to 150 km settled. From December 2003 until May 2007 127 colleagues from 69 cities and villages (Map 1 & 2) followed the vocational training and improved in palliative medicine. A network for care, education and research in palliative medicine was founded. The Department offers four weekend meetings every year for discussing problems in palliative medicine. These meetings are well accepted by the General Practitioners. Until now five regional networks for community-based palliative care were founded. The vocational training was very well accepted by 96% of the participants.

The effects of the training on patients remain unclear until now. Therefore the PAMINO-Projekt will be followed by a two-armed controlled, non-randomized evaluation study, which starts in September 2007. Because of the very interesting and important care issue this study will be financed by the German Ministry for Education and Research. From the community-based care system we can develop palliative care in any area in cooperation with the local and regional palliative care units and the universities in these districts (figure 1). Important for best palliative care are several meetings per year to maintain a network on different levels to provide end-of-life care with motivated members of multidisciplinary teams with best knowledge, skills and attitudes in palliative medicine.

### Methods

The Department of General Practice and Health Services Research of the University Clinics Heidelberg started in cooperation with the Center for Pain and Palliative Medicine Heidelberg in December 2003 a structured vocational training for General Practitioners. From particular interest was the development of palliative medicine for people and their families at home and care for the dying in this setting. Another aim was the development of community-based palliative care teams. PAMINO contains a curriculum consisting of a 40 hours training course, which is based on the training course of the German Medical Association. Important issues as psychology, diagnostic and therapy of pain or other distressing symptoms, several units with respect to communication with dying people and their relatives and some intensive training units, which can help to deal with all the difficult legal aspects at the end of life, especially problems like nutrition and hydration, palliative sedation, assisted suicide or mercy killing, ethics and attitude are covered. The training takes place either at the University of Heidelberg or in other cities and rural areas around Heidelberg to give general practitioners the possibility to follow the training beside the work in the practice without other barriers. The training courses were held on three consecutive weekends (Friday afternoon and Saturday). Until now we have realized ten courses.



Department of General Practice and Health Services Research

Map 1: Germany

Map 2: District North-Baden, Distribution of General practitioners with experience in palliative care.

„Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through prevention and relief from suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.“  
 WHO 2002



### Conclusion:

General practitioners have the potential to provide palliative medicine in the community and they are able to help patients at the end of life at home. Primary care

teams may know patients over a long time. To help all suffering patients at the end-of-life stage the development of palliative medicine in the community based on General practitioners and specialist palliative care teams is very important for

patients and their relatives. University based vocational training can help to improve the structure for palliative care very effective in cities and in rural areas. A multiprofessional network is helpful for all participants. For all dying patients it is

necessary to extend the palliative medicine concept to non-malignant diseases, because than these patients can get an appropriate care too.