

# Current Situation of Outpatient Palliative Care in Germany

Jens Papke<sup>1\*</sup> and Ute Rosenbaum<sup>2</sup>

<sup>1</sup>Praxis and Day Clinic for Oncology, Rosa-Luxemburg-Strasse 6, 01844 Neustadt, Germany

<sup>2</sup>Westsächsische Hochschule Zwickau, University of Applied Sciences, Faculty of Health and Nursing Sciences, PF 201037, 08012 Zwickau, Germany

## Abstract

In 2007, over a period of 2 months, 26 outpatient nursing services were surveyed for posts, services offered and experiences in palliative care. Interviews were carried out following a self-developed questionnaire and free conversation.

65% of the services reported insufficient funding of outpatient palliative care. Despite this, 42% were still able to offer specific services in palliative care; 88% offered support around the clock and 54% gave continuous care in the final phase. The fact that 61% of carers realized the need for palliative care was the main reason for these figures.

Services networking with clinics, hospice groups and specialised physicians seemed to have a higher success rate in care. All service providers appeared highly motivated and had appropriate qualifications. The main problems appeared to be the poor co-operation between services, inadequate funding, and lack of information in general about palliative care and the lack of structured guidelines for palliative care in the health care system. This could be solved with a prompt introduction of legal guidelines.

**Keywords:** Home care; Palliative care; Nursing; Germany

## Introduction

Germany has a relatively short history of Palliative Care (PC) [1]. Initial steps were taken in the 1980's, consisting mostly of individually organized and heterogeneous regional projects [2]. This has evolved over the last 20 years with a growing number of PC units in hospitals, outpatient PC services and hospices [3,4]. Postgraduate education for physicians in PC has been available since 2004, but currently not all medical universities are able to offer lectures in palliative medicine.

At the present moment, appropriate financing of outpatient PC and its implementation are the greatest challenges. A law was passed in 2007 laying down legal conditions, and since then the government has made funds available. Unfortunately, due to the lack of structure for PC within Germany, funding could not yet begin everywhere. Now, outpatient PC in Germany is provided by qualified carers, based on regional contracts with health insurances. More than half of the area is actually provided.

The aim of our study was to explore the situation of outpatient community-based PC in the federal state of Saxony, situated in the South-East of the Federal Republic of Germany, home of 4.3 million inhabitants prior to the structural changes.

## Methods

Part of the curriculum for students of the Faculty of Health and Nursing Sciences of the Westsächsische Hochschule Zwickau (University of applied sciences) is to take part in project seminars. 10 students volunteered for our group and were delegated the task of exploring outpatient nursing services in the individual home regions. This was based on a questionnaire followed up with interviews. Students were requested to develop a structured interview guideline for interviewing heads of various nursing services. The survey was done between May and June in 2007. Services were selected from the students. Every student was asked to explore three services in his home area. Interviews were recorded on audio tape and documented in written form and narrative. Results were analysed with SPSS software.

An overview of the questionnaire and most important results of the interviews are given in Tables 1 and 2.

## Results

In the following we would like to describe only the most important results of the interviews.

### Needs in outpatient PC

26 outpatient nursing services in Saxony were approached. 16 services (61%) reported a need for specialised PC; 11 services (42%) offered specialised PC.

The main reasons given for this were a requirement from 35% of General Practitioners (GPs), 12% as a result of everyday practice, 8% individual experiences. Only 4% of services (one service) reported the wish of patients to die at home as a reason for providing specialised care.

1. How high is the death rate of your patients at home and in hospital?
2. How many patients do you have in your care? How many of these are palliative patients?
3. Who is the head of finance for your service (private/communal)?
4. Do you offer education in palliative care?
5. Are there private rooms for talks with employees, supervision and talks to relatives of patients?
6. Is the organisational head only responsible for administration or does he/she also work in nursing?
7. Is there a concept for palliative care?
8. Do you have a guideline for caring?
9. Do you care for patients following a special caring model?
10. Does the service undertake quality management?

**Table 1:** Questionnaire.

**\*Corresponding author:** Jens Papke, Praxis and Day Clinic for Oncology, Rosa-Luxemburg-Strasse 6, 01844 Neustadt/Sachsen, Germany, Tel: 0049-3596-58530; Fax: 0049-3596-585349; E-mail: [mail@drpapke.de](mailto:mail@drpapke.de)

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## Differences between specialised PC and common care

Results are shown in table 3; the perceived differences between palliative and curative intended care were given as; in 8 cases (31%) a higher intensity of caring; 6 cases (23%) an increase in the time required for PC and the more important role of maintaining quality of life; 3 cases (11%) an increase in qualificational requirements.

16 services (61%) had qualified nurses specializing in PC; 10 services (39%) had no qualified personnel. 21 services (81%) gave advice for personal carers. 23 (88%) of services offered 24-hour-support. 14 services (54%) offered care around the clock for patients in their final phase. 6 services (23%) offered supervision only Table 3.

## Networks

4 services (15%) reported permanent cooperation with: hospice services (23%), social workers (31%) specialised physicians (35%) and psychologists (27%). These services reported a greater ability to provide PC than services working independently. For example, nurses from these services reported a higher average qualification, an increase in qualified services in caring and an increase in service offers for personal carers.

## Problem areas

17 nursing services (65%) indicated the main problem as insufficient funding of PC from public health insurance companies (Table 4); despite this, 11 services (42%) still offered specialised PC. Common outpatient care provided by the majority of carers was financed by the German public health insurances. 9 services (35%) additionally offered self-paid services. 19% of services criticised the lack of, or poor information regarding special PC available for doctors, personal care providers and patients.

The final question was the number of requests received for PC: 6 services (23%) received requests from GPs; in contrast, one service reported a GP informing them that they would rather send patients to a hospital than send them to an outpatient service. 2 services reported continuing care for a patient up to the final phase stemming from the development of a trustful relationship between patient and carers. In the majority of cases, both patients and carers appeared to be poorly informed about PC provision, resulting in a minimal number of

Realization for the need for PC	16	61%
PC offered	11	42%
Reason	Requirements	9 35%
	Everyday practice	3 12%
	Own experience	2 8%

Table 2: Needs in PC (n = 26 services).

Higher intensity of care	8	31%
Increased time requirement	6	23%
Maintaining quality of life	6	23%
Qualification of nurses	16	61%
24-hour-service	23	88%
Supervision	6	23%

Table 3: Specialised PC and common care (n = 26).

Funding of specialized PC	17	65%
Poor information regarding PC	5	19%
Lack of cooperation with other services	6	23%
No request for PC	6	23%

Table 4: Difficulties (n = 26).

requests for it. Hospitals frequently referred their patients to a local hospice service. PC services tended to receive patients in the later stages when caring and control of symptoms were much more complicated. 6 of the 26 services (23%) received no requests for PC Table 4.

## Discussion

This report, derived from a survey, describes the situation in Germany before the establishment of national community-based specialised PC. The number of investigated services is certainly rare; but the results are representative for the situation in Saxony and Germany in 2007. For the majority of services, outpatient palliative nursing is undertaken by professional carers. The national provision of outpatient PC is still in its infancy due to the current unavailability of funds and structures in providing care.

Despite this, from our survey, professional carers still appear to be highly motivated and willing to gain specialist qualifications.

When a PC team joins the carers in the outpatient setting, the rate of home deaths e.g. from cancer can increase. This is a surrogate marker for quality of PC administered in the final phase [5]. Evidence suggests that a side effect of this may be a reduction of costs for the health insurance companies compared to caring for the patients' final phase in hospital [6].

With the passing of specialised outpatient palliative caring law (§ 37b of German Social Law Book V) in 2007, a major improvement in the quality of care in outpatient nursing should be achievable.

A large number of the explored services (16 out of 26) have nurses with qualifications in PC. Services with the most palliative patients, highest qualified personnel and most experience cooperate with private oncologists, internists and GP's in the region and other specialists (gynecologists, urologists, psychologists, hospitals and hospice services).

The main hurdle is sufficient funding of specialised palliative care. Health insurance companies did not cover specialized care for a long time. A number of services cover the cost by offering private-paid care. Education in PC and simplifications of financial and legal conditions for outpatient palliative nursing are challenging. It is interesting despite the problems in financing, motivation of the nurses and qualification seem to be high. This can be seen within around-the-clock services, education in PC, consultation for family carers and patients and intensive caring in the final phase.

5 services reported a problem in the education and information for family carers and patients. They recognised that the problems of palliative situations in life are not highlighted enough within society in general. There is a requirement for increased availability of information for doctors, nurses, patients and family carers. Many German GP's experience of dealing with palliative patients is gained through "learning by mistake" due to the lack subject study available during the gaining of their qualification and the resulting errors when working as practising doctors [7].

In summary, for Germany three important things are needed:

1. A stable and adequate financing of PC,
2. A national information campaign consisting of lectures for medical students and in nursing schools, establishing academic education for nurses and information for people in the communities
3. Nation-wide unified structure of caring.

## Conclusions

From our survey and interviews with the 26 community-based nursing services, we found that the majority were able to maintain a high level of motivation and involvement in dealing with PC. The main difficulties are insufficient funding of specialised PC, poor availability of information for the public, GP's and nurses and lack of a unified structure in caring. A financial improvement is extremely likely due to the clarification in 2007; solving of the other problems will take a little longer. Unfortunately the nationally unified structure continues to develop at an extremely slow pace.

It is planned to undertake a second survey within the next years, when sustainable structures for caring are developed.

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