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## Aspects of outpatient palliative care in Germany – a survey among office-based physicians

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## Abstract

**Background:** Currently, Palliative care is widely discussed. Aim of this study is to explore different aspects of the ambulatory treatment environment of palliative patients and its structure in Germany from the viewpoint of caring physicians.

**Methods:** A structured questionnaire was developed and sent to 1,003 office-based physicians in Germany. Topics were the delivery and effort of care, cooperation between health care providers, the perception of existing health care structures, the reimbursement system, as well as an assessment of future developments. Sub-groups analyses were conducted.

**Results:** 314 questionnaires were included in the statistical analyses. 50% estimate the additional time and effort for palliative patients compared to non-palliative patient to be 50% and more. The best cooperation is seen with caregivers; however, cooperation with psycho-social care should be improved. 50% state the outpatient health care situation as (very) insufficient, but improvements are expected in future. 90% assess German reimbursement structures as (very) insufficient.

**Conclusions:** This study gives an insight into the German outpatient health care setting for palliative patients. Palliative patients have a higher and more complex need with respect to health care than other patients. Further studies should focus on the collection of longitudinal patient data for a more comprehensive insight.

**Keywords:** Palliative care, Palliative medicine, constipation, Germany, reimbursement, SAPV

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## Background

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2 In Germany as well as in other European countries, the demographic structure is  
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4 characterized by an increasing number of elderly people. Today, about 20% of the  
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6 German population is over 65 years old and will increase up to 33% by 2050 (Federal  
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8 Institute for Population Research 2008). This change is accompanied by a rising  
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10 incidence of specific diseases which follow at least partly by an increase in age.  
11  
12 Especially the rising number of cancer patients results from this demographical shift  
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14 and reflects a major public health burden to society today and in the near future. For  
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16 instance, according to German data the incidence of cancer indications in Germany  
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18 is projected to increase from 461,000 in 2007 to 588,000 in the year 2050 (+27%) in  
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20 absolute figures (Beske et al. 2009).  
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29 With regard to health services which are to be provided for such life-threatening  
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31 diseases, the need for professional, extensive health care beyond acute phases of  
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33 disease as well as the development and more importantly implementation of specific  
34  
35 palliative structures became more and more apparent in the last years in Germany.  
36  
37 The World Health Organization defines palliative care as an “approach that improves  
38  
39 the quality of life of patients and their families facing the problem associated with life-  
40  
41 threatening illness...” (WHO 2002). Whereas palliative medicine focuses on medical  
42  
43 care for the patients, palliative care is understood as a more holistic, multi-discipline  
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45 approach, which involves for example caregivers, psychotherapists and spiritual  
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47 guidance in addition to care provided by general practitioners (GPs) and specialized  
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49 physicians (Pastrana et al. 2008).  
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1 According to the World Health Organization (WHO), the inpatient palliative sector is  
2 already well organized in Germany (Centeno et al. 2007). However, with respect to  
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4 the outpatient sector improvements are necessary (Radbruch et al. 2008).  
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9 In the German outpatient health care sector, there is a differentiation between  
10 general ambulatory palliative care and specialized ambulatory palliative care (SAPV).  
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12 The SAPV differs from the general palliative care mainly by higher qualification  
13 requirements (e.g. additional training in palliative medicine) and by a need for special  
14 palliative care teams due to higher intensity or complexity of disease events and  
15 symptoms a patient might be confronted with.  
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26 Over the last years, the palliative care sector gained a higher attention in Germany  
27 (Schneider et al. 2009). The German government and the Statutory Health Insurance  
28 (SHI) have tried to support the development of new palliative care structures e.g. via  
29 new regulations regarding SAPV. For instance, every person insured within the SHI  
30 who has a non-curable, progressive disease as well as limited life expectancy has  
31 the right to receive SAPV if needed. SAPV can then be prescribed by physicians with  
32 costs being covered by the SHI (Federal Joint Committee 2008).  
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46 However, even though efforts in this health care sector have been increased, there is  
47 a lack of scientific research in this field in Germany to date (Schneider et al. 2006).  
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49 Therefore, the aim of this study is to explore different aspects of the ambulatory  
50 treatment environment of palliative patients and its structure in Germany from the  
51 viewpoint of caring physicians.  
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## Methods

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2 A structured questionnaire was developed and sent to 1,003 office-based physicians  
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4 in Germany in January 2009 with a reminder sent in February. 50% of the contacted  
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6 doctors were members of the German Association for Palliative Medicine, the other  
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8 50% were office-based GPs taken from an IMS-database. Several issues were  
9  
10 addressed within the survey. Besides general information on the physicians'  
11  
12 specialization, information on the proportion of palliative patients as well as the  
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14 frequency and duration of visits either in the office or at home by palliative patients  
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16 were addressed.  
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24 Furthermore, since palliative care focuses on the improvement of quality of life, which  
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26 includes pain relief by opioids, an additional focus was laid on side-effects which in  
27  
28 turn are typically caused by opioids. Therefore, the physicians were asked to  
29  
30 estimate frequencies of various side-effects due to opioid medication in palliative  
31  
32 patients and to give information on the additional time needed for treatment of side-  
33  
34 effects, using the example of on opioid-induced constipation (OIC), which is known to  
35  
36 be the most frequent side effect (Clemens et al. 2008).  
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44 Additionally, the physicians were asked to classify and rate the ongoing cooperation  
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46 with other health care suppliers as well as the outpatient care situation for palliative  
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48 patients in general. Finally, their satisfaction with the current German reimbursement  
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50 system with regard to palliative care and their perceptions of future developments in  
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52 this health care sector was evaluated.  
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1 The data was analyzed with SPSS, version 16. As relative differences between the  
2 responses of GPs and specialists as well as physicians with and without a special  
3 training in palliative care were of special interest various subgroup analyses were  
4 conducted. Values from descriptive statistics are given as mean values in absolute  
5 terms or percentage. To explore possible statistical significances, the Mann-Whitney-  
6 U-test as well as the Wilcoxon-test was applied.  
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## 19 **Results**

20 Questionnaires from 314 physicians (70.3% male) were included in the statistical  
21 analyses (response rate: 31.3%). Mean and median age was 50 years. 64% were  
22 GPs, the others specialists (e.g. hematologist/oncologist (13.7%); anesthetist  
23 (11.5%)). On average, they already practiced in their office for 13 years, whereas  
24 GPs were significantly ( $p < 0.01$ ) longer office-based than specialists (15 vs. 10 years).  
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26 67% of the physicians had special formal palliative medicine (PM) training. 57% of  
27 those were GPs.  
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41 Physicians overall have 9.6% palliative patients on average. PM-trained physicians  
42 (13%) and other specialists (18.5%) treat more patients with a palliative status  
43 ( $p < 0.01$ ) than physicians without PM-training and GPs, respectively. According to the  
44 survey, 80% of the palliative patients suffer from cancer as primary condition  
45 (specialists: 90%; GPs: 75%).  
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56 A specific point of interest of this survey was the duration of the palliative phase (from  
57 first palliative health care need till death). According to our results, the palliative  
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period lasts for less than six months in 60% of all cases, with PM-trained physicians estimating this timeframe to be shorter than others (figure 1). No significant difference between GPs and specialists was identified.

*Insert figure 1 here*

Every second physician estimated the additional time and effort needed for a palliative patient compared to a non-palliative patient with at least 50%. For a more detailed view of the additional required time, participants were asked to approximate the number of home visits and office consultations as well as the timeframe needed per visit for palliative patients vs. non-palliative patients with chronic health problems. On average, GPs estimate to visit palliative patients 5.9 times per quarter at their home (non-palliative: 2.3;  $p < 0.01$ ). They also state to need more time per home visit (18 vs. 12 min;  $p < 0.01$ ). Palliative patients also have significantly ( $p < 0.01$ ) more office consultations per quarter in a specialist's practice (4.6 vs. 3.4) and need more time per visit (16 vs. 10 min).

As to the important treatment component, physicians were asked to estimate the frequency of various side effects due to opioid containing medications in palliative patients. The physicians should differentiate between patients who receive mild and strong opioids, respectively, whereas the WHO-pain ladder was used to distinguish between the opioid groups (WHO-2: mild opioids, i.e. codeine; WHO-3: strong opioids, i.e. morphine). According to the answers OIC is the most frequent side-effect, followed by nausea / vomiting, and fatigue. On average, physicians estimated the occurrence of OIC in 60 % of the palliative patients, who received a WHO-3-

1 opioid (figure 2). PM-trained physicians indicated significantly higher frequencies of  
2 OIC than physicians without this extra qualification (WHO-2 criteria: 32% vs. 26%;  
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4 WHO-3 criteria: 63% vs. 54%). Specialists noted nausea / vomiting, dizziness and  
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6 confusion as side-effects due to WHO-2-opioids significantly less often than GPs,  
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8 whereas specialists significantly more often observe fatigue as a result of more  
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10 potent formulations (WHO-3) ( $p < 0.05$ ). Since these side-effects might cause  
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12 additional time in patient care, physicians were asked to estimate this additional time  
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14 using the example of OIC. On average, physicians estimate the additional time to be  
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16 20%, whereas PM-trained physicians approximate slight less additional effort than  
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18 others (18% vs. 21%).  
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26 *Insert figure 2 here*  
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31 In the final part of the questionnaire, assessment of overall outpatient health care  
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33 structure for palliative patients, reimbursement system, and cooperation between  
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35 different groups of health care providers as well as perceptions on possible future  
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37 developments were outlined.  
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43 Every second physician considers the outpatient health care structure as to be (very)  
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45 insufficient. Furthermore, over 60% of the PM-trained doctors as well as specialists,  
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47 independent of their knowledge in palliative medicine, assess the situation as (very)  
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49 unsatisfactory (figure 3). A large discrepancy between statements of GPs could be  
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51 observed: 51% of the PM-trained GPs describe the situation as insufficient (13%:  
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53 very insufficient), whereas only 22% of the GPs without PM-training share this  
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55 opinion (3%: very insufficient).  
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2 With respect to the reimbursement system in the outpatient care sector, 95% of the  
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4 PM-trained physicians state that it is (very) insufficient (without PM-training: 87%).  
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6 However, 58% of the physicians who are informed about the current SAPV-  
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8 regulations believe that those will improve the health care structure in outpatient care  
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10 in Germany. Yet, only 31% expect improvements with respect to the reimbursement  
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12 situation. Specialists tend to be more optimistic than GPs in this question.  
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19 *Insert figure 3 here*  
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24 A main issue for an efficient provision of health care to palliative patients is the  
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26 cooperation between the different providers of health care. The results of this survey  
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28 show that physicians assess the existing cooperation structures as quite good, as  
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30 before, specialists being more optimistic than GPs in their assessment (figure 4).  
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36 The best cooperation is given with caregivers: Three in four participants describe this  
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38 form of cooperation as to be (very) good. In contrast, the assessment of the  
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40 cooperation with psychotherapists and parties providing spiritual guidance is  
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42 heterogeneous: 42% of the GPs give (very) good ratings, 30% are neutral and 28%  
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44 consider the situation as being (very) insufficient which is lower in values in  
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46 comparison to the answers given by specialists (60% - 22% - 18%). These results  
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48 are also reflected in the question in which field the cooperation should improve with  
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50 respect to extent and quality. As a result, especially psycho-social care and its  
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52 cooperation are seen as an area of future efforts.  
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*Insert figure 4 here*

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4 This German study sample was also asked if they would support changes in the  
5 treatment process with respect to the assignment of duties to other caregivers, as the  
6 spectrum of responsibilities of other groups is rather limited in comparison to other  
7 countries, e.g. the role of outpatient nurses in the UK (Taylor et al. 2009). 71% of  
8 specialists with PM-training (85% without) indicate that they would be willing to share  
9 or transfer duties to caregivers (only 66% of the GPs with PM-training (57% without)  
10 would support this).  
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24 Looking into the future, 60% of palliative care specialists believe that the quality of  
25 outpatient palliative health care will develop positively within the next five years. Only  
26 30% of the physicians without PM-training agree on this and 35% of this group even  
27 expects a deterioration of the quality of health care.  
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## 36 **Discussion**

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38 This study gives an overview of the perceptions of physicians working in palliative  
39 care in Germany about the outpatient health care structure of this very special area.  
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41 Following the findings palliative patients have a higher and more complex need with  
42 respect to health care than other patients which results in more time and effort the  
43 physicians have to spend on this special patient group.  
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53 According to the German Remuneration Scheme (EBM) physicians receive a lump-  
54 sum payment per quarter for office consultations, irrespective of the number or length  
55 of visits or the morbidity or palliative status of a patient (National Association of  
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1 Statutory Health Insurance Physicians 2010). GPs receive approximately EUR 35 per  
2 quarter and patient; specialists about EUR 31 (not including special procedures).  
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4 Furthermore, taking care of OIC, which was identified as the most common opioid-  
5 induced side-effect and very time-consuming, or any other complication, is also not  
6 reflected separately in the remuneration system. Regular home visits are reimbursed  
7 with approx. EUR 15. Hence, it is not surprising that 90% of the physicians consider  
8 the reimbursement regarding outpatient care of palliative patients as being  
9 insufficient. This inadequate compensation of the time-consuming services provided  
10 during palliative care was also recently explored via a series of expert interviews  
11 (Brueckner et al. 2009). Following new regulations regarding SAPV, special palliative  
12 care teams, which need to fulfill certain requirements (Federal Joint Committee  
13 2008), can make a special contract based on SAPV with individual sickness funds  
14 and receive additional remuneration. Started in April 2009, office-based physicians  
15 also might receive extra payments for prescribing SAPV which is connected with  
16 some bureaucratic effort (National Association of Statutory Health Insurance  
17 Physicians 2010). However, as the German health care system faces the challenge  
18 of an upcoming lack of practicing physicians (National Association of Statutory Health  
19 Insurance Physicians, German Medical Association 2007) – especially in rural areas  
20 – it still is highly indicated to further work on additional adjustments within the  
21 remuneration system. This might also improve the job satisfaction of German  
22 physicians which is – according to the results in the present study – quite poor. The  
23 responsibility of adjustment should not be born solely by the Health Ministry, but  
24 rather should be shared with health insurances and the different physician  
25 associations in this field.  
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Other studies have already issued the cooperation between health care providers (Schneider et al. 2007). The results of the study indicate that especially the cooperation between psychotherapists and other health care providers involved in palliative care is in need of improvement. This cooperation is essential for providing a more holistic health care approach which is indicated in palliative care (Borck 2006). With respect to the assignment of duties to caregivers, GPs seem to be more skeptical than specialists. An explanation for this finding might be that disproportionately more GPs have to give up tasks than specialists and hence receive less payment. Since 2009, qualified assistant personnel of physicians are allowed to undertake home visits on behalf of the GP which is reimbursed with normally EUR 17 including time and cost for the journey (National Association of Statutory Health Insurance Physicians 2010). However, this possibility of altering treatment paradigms is connected to some requirements. For instance, the respective regional area needs to be under-supplied and the assistant has to do undergo qualified training. As a result it is not expected that this change has the potential to serve as a significant support for physicians.

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The validity of findings from this survey might be limited due to different reasons. First of all, it cannot be ruled out that the cohort has a selection bias. However, as the study sample with over 300 physicians is rather big for this kind of health care services research the results might at least be considered as giving trend indications. If a selection bias was created by asking specialists with a background in palliative care in one subgroup of the study cohort, it is more likely that the results of the survey would be biased towards a more positive description of the average real world treatment environment.

1  
2 Another important aspect are different definitions of palliative status (Pastrana et al.  
3  
4 2008). Hence, this might explain why the figures concerning the relative importance  
5  
6 of palliative patient vs. patients in the outpatient setting in general are a bit higher  
7  
8 than in earlier works (Abholz 1998; Buser et al. 2004). Furthermore, it is important to  
9  
10 emphasize that the information in this study is not directly based on clinical data from  
11  
12 palliative patients files but rather on estimations from physicians who take part in the  
13  
14 treatment process. Therefore, the reliability and validity of the information (e.g. on the  
15  
16 proportion of side-effects as well as the length of a palliative period) might be limited.  
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18 An earlier study by Koch-Horn et al. (2002) analyzed in a prospective study setting,  
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20 that GPs on average need 15 minutes per patient including journey time which is less  
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22 than in the present study.  
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31 Summarizing, not only the results but also the limitations of the study call for a need  
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33 of further studies that should focus on the collection of longitudinal patient data to get  
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35 an even more comprehensive insight into the health care environment and the  
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37 specific needs of palliative patients.  
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### 43 **Conclusions**

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45 In comparison to non-palliative care there is a need for higher use of medical  
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47 resources among palliative patients – a need that currently might not be adequately  
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49 reflected in the remuneration system. Considering ongoing demographic  
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51 developments and the resulting importance of palliative care further research has to  
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53 identify room for improvement and corresponding strategies.  
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1  
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3

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Figure1

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**Figure 1: Duration of palliative phase**

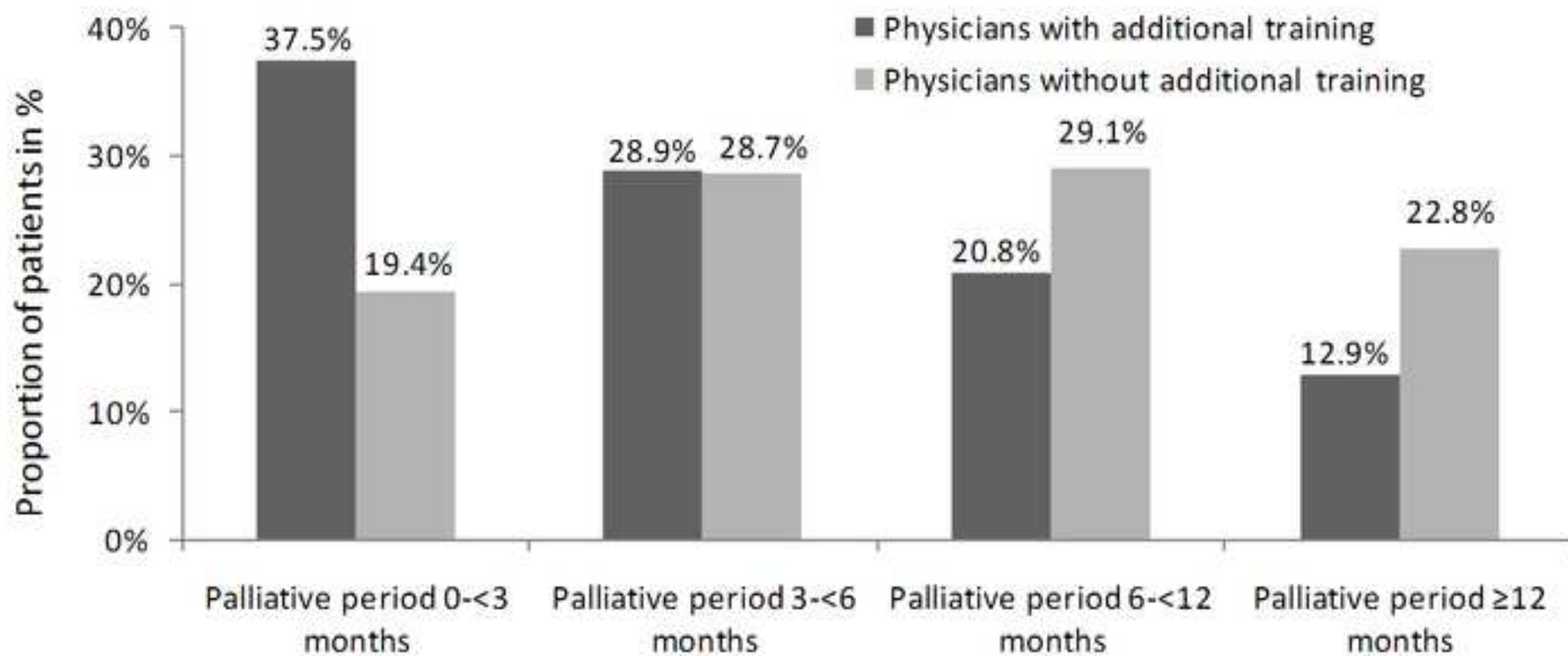


Figure 2: Side effects in palliative patients

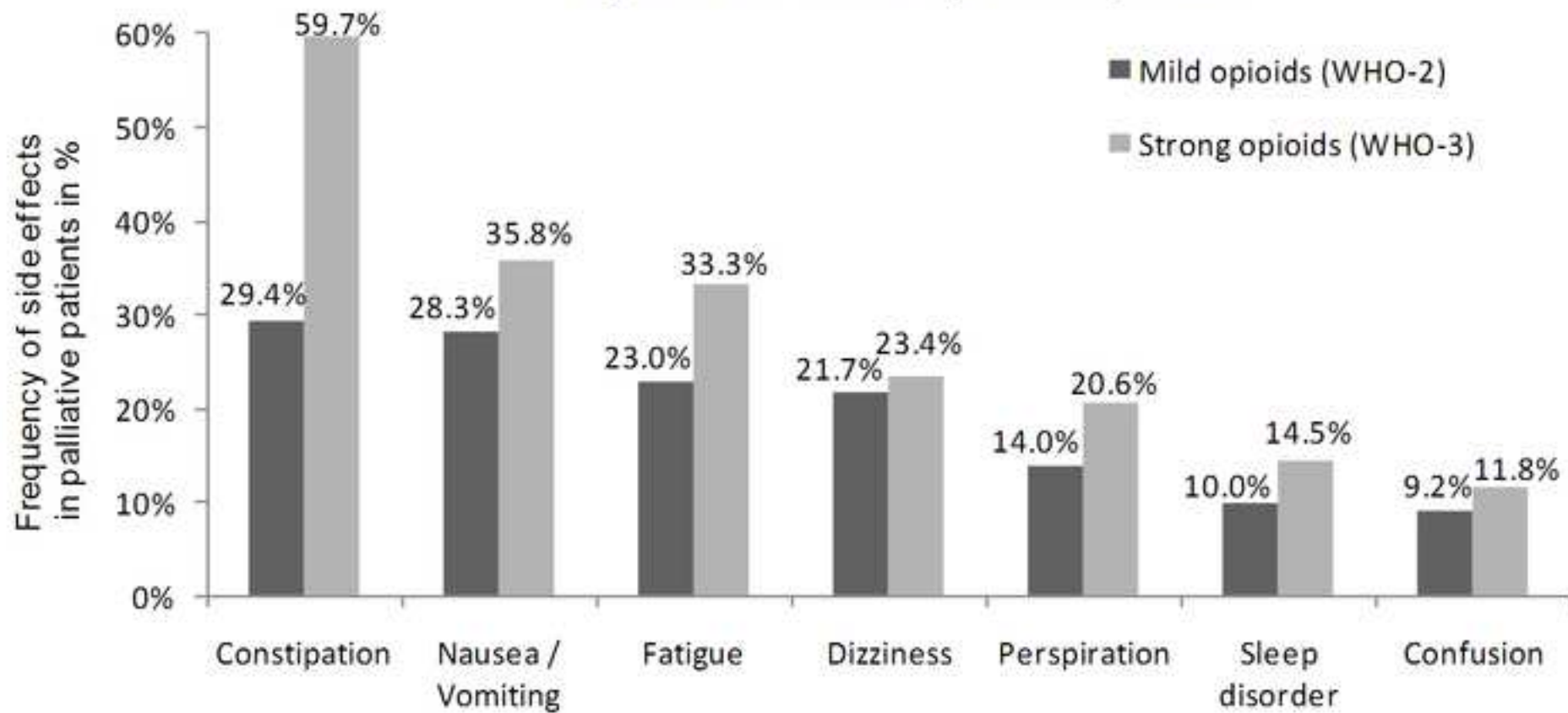


Figure3

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**Figure 3: Assessment of outpatient health care situation of palliative patients in Germany**

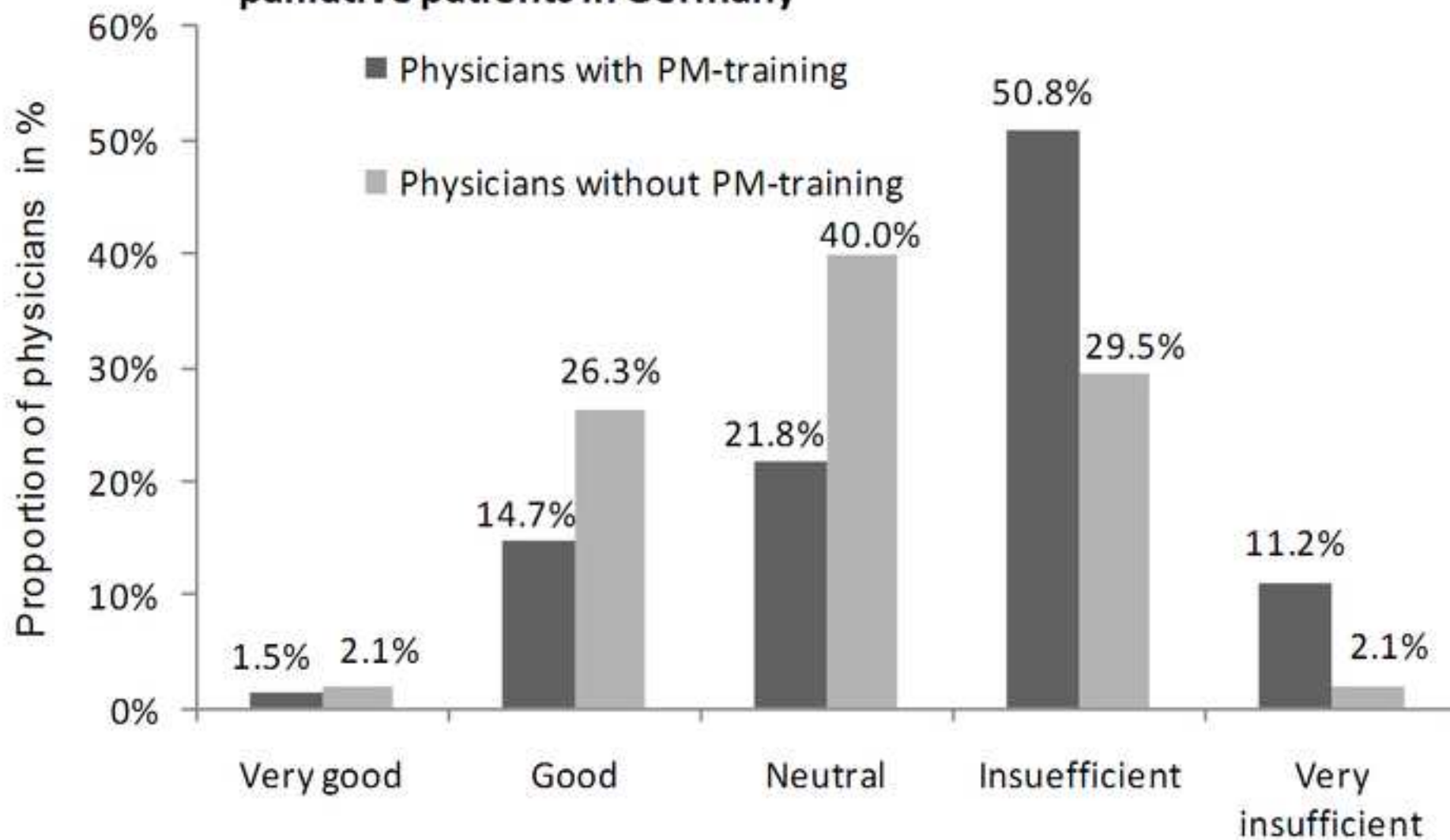


Figure4

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Figure 4: Assessment of cooperation structures with other health care providers

