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Palliative care in Bulgarian general practice

Abstract

Background. GPs in Bulgaria provide basic care to people with advanced disease; there is no legislative framework for palliative care. The aim of the study was to investigate the activities of the GPs involving patients who need palliative care.

Material and methods. The 42 GPs followed up a total of 211 patients, meeting the diagnostic criteria for inclusion. A form was developed for the purposes of the study, reflecting the activities during the 625 consultation. The subjective opinion of the patient was also registered. The statistical processing of data was made by a SPSS 17.


Results. The patients above 60 years of age predominated. The ratio by gender was balanced. The distribution by diagnostic criteria was: oncological disease (87/41.28 ± 3.38%); chronic heart failure (CHF) (65/30.80 ± 3.17%); chronic obstructive pulmonary disease (COPD) (20/9.47 ± 2.01%) and combinations (39/18.48 ± 2.67%). No significance was found between the referrals and the social and diagnostic characteristics. Weak correlations were found between the lower level of education, the lower social status, COPD patients and the greater frequency of home visits. Principal symptoms in our study were pain and fatigue. Discrepancy between the evaluations of patients and GPs was found regarding the ones that are subjective. In cases of oncological diseases the diagnosis and prognosis, were discussed more frequently with the relatives.

Conclusion. Within the framework of their general obligations, GPs perform activities characteristic of palliative care. The investigation of these activities and the analysis of the results can serve as a first step in the formation of structured palliative care in our country.

Key words: palliative care; general practitioner; consultation

Adv. Pall. Med. 2011; 10, 1: 17–22

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 Advances in Palliative Medicine 2011, 10, 17–22
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Introduction

Bulgarian citizens have health insurance that gives them the right to obtain services from general practitioners (GPs), out-patient specialists and hospitals, as well as a pre-determined number of medications. Access to primary health care is available if a patient has registered with a GP. GPs provide the usual, mainly basic care to people with advanced progressive disease and their families as part of the routine practice; at the moment there is no legislative framework for palliative care. The aim of the study was to investigate the activities of the GPs involving patients who need palliative care.

Material and methods

Sixty GPs, chosen at random, were informed about the aim of the study, which already had the approval of the Ethics Committee of the Medical University — Plovdiv. Forty-nine consented to cooperate and were trained to conduct the study. Seven GPs dropped off — three because of change of work place, two owing to health condition and two because of other subjective reasons.

The 42 GPs involved in the study followed up a total of 211 patients (an average of 5.02 patients), meeting the following criteria for inclusion in the study — age above 18; diagnosis according to the International Classification of Diseases (ICD), 10th Revision, at a given stage:

- chronic heart failure (CHF) (I50), New York Heart Association (NYHA) functional class III and IV, with persistent symptoms on the background of an optimal treatment and frequent hospitalizations;
- chronic obstructive pulmonary disease (COPD) (J44), more than three annual hospitalizations because of exacerbations; shortness of breath after walking 100 metres;
- oncological disease with metastasis.

One of the requirements of the study was a minimum of three outpatient examinations of the patients included, and for the period January 2009 — April 2010 the GPs registered 625 outpatient consultations, an average of 2.29 per patient. $25.11 \pm 2.98\%$ of the patients died during the course of the investigation.

A form was developed for the purposes of the study, reflecting the functional status of the patient and his/her presenting symptoms on examination at the outpatient clinic, the groups of the medications used and referrals to other specialists and/or institutions. The subjective opinion of the patient

concerning his/her symptoms and their degree of manifestation was registered after a guided conversation.

The statistical processing of data was made by a SPSS 17.

Results

As expected, the patients above 60 years of age predominated, only three patients (1.43%) being between 18 and 40; the distribution by age is shown on Figure 1. The ratio by gender was balanced — 103 ($48.81 \pm 3.44\%$) men and 108 ($51.18 \pm 3.44\%$) women. The greater part of the patients had high school education (11th/12th grade) — $109/51.56 \pm 3.44\%$, $63/29.85 \pm 3.15\%$ had secondary education (8th grade), and $39/18.48 \pm 2.67\%$ had higher education. Twenty-three ($10.90 \pm 2.14\%$) determined themselves as socially weak, only $7/3.31 \pm 1.23\%$ considered their social status as excellent, whereas the main part of the patients found their social status as satisfactory ($98/46.44 \pm 3.43\%$) or good ($83/39.33 \pm 3.36\%$). As far as social support was concerned, the latter was supplied mainly by the family ($190/90.04 \pm 2.06\%$) and friends ($70/33.17 \pm 3.24\%$). Thirty patients ($14.21 \pm 2.98\%$) obtained support from the social services and only $6/2.84 \pm 1.14\%$ from non-governmental organizations; $30/14.21 \pm 2.98\%$ of the patients lived alone. The distribution of the investigated patients by diagnostic criteria is presented in Table 1.

One hundred and twenty ($56.87 \pm 3.40\%$) of the patients were diagnosed with a disease more than one year ago.

The number of consultations that resulted in referrals was as follows:

- referral to a narrow specialist — $404/64.64 \pm 1.91\%$;
- referral to a hospital for admission to the respective department (depending on the disease profile) — $271/43.36 \pm 1.98\%$;
- referral to a specialized department for palliative care — $91/14.56 \pm 1.41\%$;
- referral to a hospice — $55/8.80 \pm 1.13\%$.

No significance was found between the referrals and the social and diagnostic characteristics of the group of patients studied; the correlation concerning the increase in the number of hospitalizations of the elderly was very weak — $P < 0.01$ ($\chi^2 = 11.19$).

Home visits were made in $171/81.04 \pm 2.69\%$ of the patients; the average number of home visits was 4.90 for the period studied. The activities of the GP in home setting were varied — clinical ex-

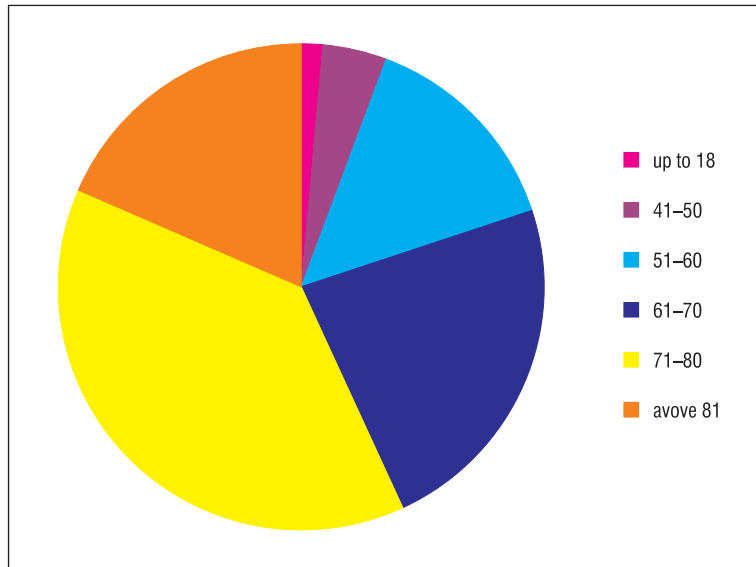


Figure 1. The distribution by age of the group of patients studied

Table 1. The distribution by diagnostic criteria

Diagnosis	N	p ± Sp%
Oncological disease	87	41.28 ± 3.38
CHF	65	30.80 ± 3.17
COPD	20	9.47 ± 2.01
Oncological disease and CHF	21	9.95 ± 2.06
COPD and CHF	14	6.63 ± 1.71
Oncological disease and COPD	2	0.94 ± -
Oncological disease, CHF and COPD	2	0.94 ± -
Total	211	100.00

Table 2. The range of symptoms

Symptom	N	%	Sp%
Pain	141	96.69	1.23
Fatigue	189	89.57	2.10
Sleep disturbance	171	81.04	2.69
Loss of appetite	162	76.77	2.90
Shortness of breath	133	63.03	3.32
Depression	127	60.18	3.37
Dizziness	118	55.92	3.41
Nausea	88	41.71	3.39
Vomiting	64	30.33	3.16

amination, manipulations — injections, infusions, placement/taking off of a urinary catheter, treatment of decubital wounds, as well as offering psychological support to the patient and his relatives. Weak correlations were found between the lower level of education [P < 0.05 ($\chi^2 = 6.15$)], the lower social status [P < 0.05 ($\chi^2 = 7.17$)], COPD patients [P < 0.01 ($\chi^2 = 10.84$)], and the greater frequency of home visits.

In almost half of the outpatient examinations registered (279/44.64 ± 1.98%) the Karnofsky performance status of the patients was 50 and below that value (an average of 55.92), which shows their need of constant aid and frequent medical care.

The range of symptoms, which were manifested in all patients irrespective of their underlying disease, is given according to their frequency in Table 2.

The follow-up based on the forms, in which the outpatient examinations were registered, showed that the GPs reported pain as the presenting symptom at 401/64.16 ± 1.98% of the consultations, whereas the patients reported a different figure — 438/70.08 ± 1.81%, P < 0.05 (u = 2.21); difference was also found in the GPs' evaluation of the symptoms vomiting P < 0.05 (u = 2.99), depression P < 0.01 (u = 3.92), appetite P < 0.001 (u = 14.74) and sleep disturbance P < 0.001 (u = 12.83), as compared to the sub-

jective evaluation of the patient. Apart from the above-mentioned symptoms, the GPs found that the patients manifested anxiety in $47.04 \pm 1.99\%$ of the consultations.

The diagnosis was reported to $173/81.99 \pm 2.64\%$ of the patients, and the prognosis was discussed with $126/59.71 \pm 3.40\%$ of them. More frequently the patients with CHF and COPD were told their diagnosis (95%), whereas in patients with an oncological disease and more than one disease the percentage was lower (71%), $P < 0.001$ ($\chi^2 = 17.12$). In cases when the patient's prognosis was discussed with him/her, no difference was found associated with the type of diagnosis, $P > 0.05$ ($\chi^2 = 0.88$). In cases of oncological diseases the diagnosis, as well as the prognosis, were discussed more frequently with the relatives, rather than the patient himself/herself, $P < 0.001$ ($\chi^2 = 5.35$). In more than two-thirds of the consultations ($484/77.44 \pm 1.67\%$) the patients looked actively for additional information concerning their condition.

Discussion

According to normative documents, "palliative care is rendered by the general practitioner (GP), health institutions for non-hospital and hospital care, dispensaries and hospices" [1]. Their functions and interrelations are not formally defined, there are no health policy decisions concerning palliative care (PC).

Organizing PC with the participation of the GP is accepted as an appropriate model, meeting the patients' expectations. The involvement of GPs in this activity is based on the fact that the physician is familiar with the case history and already has professional interrelations with the patient and his family. The GP is expected to be the informer and PC co-ordinator [2–8].

In the group of patients studied by their GPs, the distribution by age and incidence, localization of the oncological process included, was consistent with the statistical data on a national scale [9].

Because of the lack of generally accepted recommendations concerning palliative care, the criteria for inclusion in the study were based on those discussed in the literature. The so-called "golden standard" is used in the UK, which includes objective criteria — association between disease entities, performance status and clinical laboratory indices, as well as the subjective opinion of the GP who knows the patient not only from point of view of his disease state, but also from point of

view of his mental state and social medium [10]. In the USA, the temporal prognostic criterion of expected life duration of up to 6 months is mandatory before a patient is referred to a hospice for PC [8]. This temporal criterion is also used in our country for hospital admission based on clinical path No. 297 for PC in conformity with the 2010 National Frame Contract [11]. In our study, $91/14.56 \pm 1.41\%$ of the total number, or $88.34 \pm 3.16\%$ of the patients with carcinoma were referred to the hospital department for PC. According to the present regulations, this single opportunity for PC financed by the public health insurance is at the disposal of terminally ill oncological patients. Only $55/8.80 \pm 1.13\%$ patients were referred to a hospice, because patients have to pay themselves for care in these health institutions. Whenever hospitalization was required, the greater part of the patients ($271/43.36 \pm 1.98\%$) was referred to general departments of the respective disease profile, because palliative care is not provided for CHF and COPD patients at an advanced stage. The late stages of COPD are evaluated as requiring PC by specialized professional societies, such as the American Thoracic Society, the European Respiratory Society and the Canadian Thoracic Society, and if the PC approach is not applied in such cases, the patients are considered to have obtained inappropriate health care [12, 13]. The main obstacle in providing PC to patients with CHF is the difficulty in making a prognosis of the disease progression in NYHA stage III and IV [14]. The Handbook of Prevention, Diagnosis and Treatment of CHF Patients, published in Australia in 2006, has preserved a place for PC. Clearly defined are the criteria that will help the GP to make a decision concerning a patient's referral for PC [15]. The considerable number of consultations with non-hospital narrow specialists — $404/64.64 \pm 1.91\%$ — is a peculiarity of the health care system and the requirements of the National Frame Contract for mandatory consultations in cases of certain health problems. Home visitation — rendering actual palliative care in home setting — carried out by the GP himself/herself, are considerable in frequency ($171/81.04 \pm 2.69\%$) as well as amount of activities performed.

The patients' performance status, the manifestation and control of symptoms, irrespective of the underlying diagnosis, were the main criteria for rendering PC, as well as for its quality. The average value of 55.92 of the Karnofsky performance status in the patients studied, which was registered

on examination, clearly showed the need of palliative care.

Principal symptoms in our study were pain and fatigue, which have been found in a number of studies [12, 16, 17]. Pain is a frequent and indicative symptom, but it is often also not managed to a sufficient degree, in spite of the opportunities of modern medicine [18]. When administering medications, the likelihood of a possible dependence on narcotic analgesics is overestimated. The latter remain, as if preserved, only for patients with oncological diseases. Modern drugs can provide effective analgesia in 95% of the patients [19]. Discrepancy between the evaluations of patients and GPs was found mainly regarding the ones that are subjective to a considerable degree, such as pain, appetite, sleep. Their subjective character accounts for the discrepancy in the evaluation, especially of pain [20].

The results obtained confirm the tendency in our country [21] for physicians and GPs in particular, to be more willing to discuss the diagnosis and prognosis with the patient's family, not the patient himself. This is in spite of the fact that in two-thirds ($484/77.44 \pm 1.67\%$) of the consultations studied the patients actively looked for information about their condition. The problems arising in reporting bad news influence not only the psychological aspect of care, but they also lead to delay in the patients' referral for palliative care [22]. GPs find it difficult to initiate and maintain communication regarding death in their daily practice. They have to face the questions about what the patients and their families expect to understand and comment [23–27].

Conclusion

Bulgaria has no national guidelines, recommendations, standards or policy concerning palliative care.

On the background of the demographic situation — increase in the relative portion of elderly people — as well as the raised incidence level of severe chronic diseases, there is an urgent need of palliative care services.

Within the framework of their general obligations towards the patients that have chosen them, GPs perform activities characteristic of palliative care — identification, co-ordination, control of symptoms and home care. The investigation of these activities and the analysis of the results can serve as a first step in the formation of structured palliative care in our country.

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