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Experiences, Knowledge, and Opinions on Palliative Care among Romanian General Practitioners

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Aim To assess experience, knowledge, and opinions of Romanian general practitioners (GPs) on palliative health care in Romania.

Methods A questionnaire survey was performed among 1283 GPs in five districts of Romania in 2004. The data were collected on the GPs' self-assessed experience in, knowledge of, and opinion on palliative care, entered into a database, and analyzed. The GPs were also asked to indicate if they needed to improve their knowledge about palliative care.

Results The response rate was 71%. GPs mostly reported having limited experience in providing palliative care, with 24% reporting to have provided palliative care frequently, and 55% reporting to have it provided sometimes. Significant correlations were found between the GPs' experience in palliative care provision and their age, sex, and place of work. The majority of Romanian GPs reported that their medical knowledge was inadequate for the provision of care to terminal patients at home. Over 80% of GPs agreed to develop palliative care services and to participate in a training program.

Conclusion GPs in Romania reported to recognize the need for improvement of palliative care delivery in their country. They expressed a need for better knowledge of palliative care and agreed that multidisciplinary teams to provide palliative care at home would be the best form of delivering this type of health care.

Unlike in Western Europe, where palliative care has been an established health care specialty for decades, in Central-Eastern European (CEE) countries it is a relatively new form of health care provision (1,2). The most widely used model of palliative care provision in CEE countries is the hospice model. However, the number and availability of hospices and financial means allocated to these institutions have been insufficient. and the population in need of palliative care has been increasing. Palliative care professionals are less focused on the needs of patients and possible development of a new model for palliative care provision than they are on the "vested interests" of the model, ie, preventing the hospices in which they work from being closed down.

With aging of the population, morbidity profile in CEE countries has changed and so have the health care needs. The need for nursing and care, including palliative care, is increasing and largely uneven distribution of medical care facilities between urban and rural areas only aggravates the problem. All these factors bring the palliative care issues to focus (3).

Until recently, palliative care in Romania and many CEE countries was primarily associated with terminal care of patients with cancer and the hospice movement (4,5). In the last few years, however, the hospice model as a preferred model of palliative care has been reevaluated and questioned by many (3). Because of the over-institutionalization of health care and the decrease in the number of hospital beds, health care policymakers are increasingly thinking about promoting palliative care at home, which would be supported by a palliative care team (1). Furthermore, people in most CEE countries prefer to die at home, as there is still a strong tradition of family care (6).

The expectation of the Romanian primary health care system, which includes general practitioners (GPs) and nurses, to play an important role in palliative care at home is relatively far from realization. Not only that this aspect of health care provision is new and partly unknown to great majority of GPs, but the complementary services and expertise in home care and pain management are not well developed either. This problem is also present in Croatia, Hungary, and Slovakia (1), where various initiatives are being taken to develop palliative care as the need for it increases. As Doyle et al (7) have stated, palliative care at home is dependent on the attitudes and perceptions of family physicians and wider socio-cultural attitudes. Also, the lack of information on the latest techniques and developments in palliative care may prohibit the development of that health care area (8).

The first hospices in Romania were established in Oradea and Brasov (9); by 2004, five hospices had been opened. Although a government policy from 1998 tried to strengthen the role of the GP in the health care delivery system (10), no systematic attention had been given to palliative care in general practice or hospitals until 2002 (4). Thereafter, family physicians have increasingly started to provide palliative care, but they have not been reimbursed for the service. Thus, it may be said that the efforts to develop a system of palliative care provision in Romania are still not organized.

We asked GPs in five districts in Romania to self-assess their experience in palliative care provision, their knowledge and need for better education in palliative care, and their opinion on the best way to deliver this type of care.

Methods

A questionnaire survey was conducted among GPs in five out of a total of 42 districts in Romania between July 2002 and February 2003. The five districts – Alba, Arges, Dimbovita, Ilfov, and Olt – varied in socioeconomic aspects and infrastructure, but had a well organized register of GPs, which allowed us to deliver a multichoice questionnaire by mail to each registered GP. The districts were representative of the whole country with respect to male/female ratio (49% men vs 51% women) and death rate (12.8/1000 population in the five districts vs 12.4/1000 population in Romania) (11), but not with respect to urban vs rural areas (57% rural in the districts vs 47% in Romania). There were differences in rural/urban distribution and the availability of health care services among the districts.

Respondents

The survey included a total of 1283 GPs practicing in the five districts. The number of patients on a GP's list ranged between 1200 and 2200. In rural areas, a GP usually covered the whole area or village. In the urban areas, since there are many more GPs, patients could choose their GP irrespective of the place of residence.

Questionnaire

The multichoice questionnaire collected data on GPs' sociodemographic characteristics (sex, age, place of work) and asked them to self-asses their experience in palliative care delivery (eg, if and how often they had delivered care to terminally ill patients), knowledge (eg, how well they had been informed about treatment methods for patients with cancer), and opinions on the (future) development of palliative care (eg, their opinion on the opportunities to deliver palliative care in Romania and their need for better training in palliative care). When applicable, more answers could be chosen. The questionnaires were sent only once, without a second reminder. The objective of the study was explained in a cover letter and a return envelope was enclosed. All returned questionnaires were included in the analysis, although some were not fully completed.

Statistical analysis

The answers were entered into a database and analyzed with SPSS version 11.0 for Windows (SPSS Inc, Chicago, IL, USA). The answer frequencies and associations between sociodemographic variables and self-assessed experience, knowledge, and opinions were analyzed. Pearson correlations were used for continuous variables, and χ^2 test for categorical variables. The level of statistical significance was set at *P*<0.05.

Results

The response rate was 71% (914 out of 1283 GPs). Age and sex of surveyed GPs were not associated with response rate (Table 1). The place of work was described as urban (city), urban/rural (small town), or rural (village). A low response rate of 43% was obtained from GPs practicing in small towns, and the highest response of 84% was obtained from GPs working in rural areas.

Table 1. Demographic data and the response rate of general practitioners (GP) in Romania						
Characteristics	No. of GPs	No. (%) of respondents				
Sex:						
men	282	194 (69.0)				
women	1001	709 (71.0)				
Age (y):						
<35	167	118 (71.0)				
35-50	872	619 (71.0)				
>50	244	175 (72.0)				
Place of work:						
urban	449	318 (73.0)				
urban/rural	254	108 (43.0)				
rural	580	485 (84.0)				
Total	1283	914 (71.0)				

Most respondents (68%) were aged between 35 and 50 years; almost one in five was older than 50. Over two-thirds (78%) of respondents were women, which is in line with the proportion of women in the whole population of GPs in Romania. A little more than half (53%) of GPs worked in rural areas, which indicated the overrepresentation of the rural areas, whereas about one-third (35%) worked in an urban setting.

Experience

Most GPs reported being "sometimes" asked to provide care to patients with incurable diseases; whereas only 2% reported never to have received such a request (Table 2). A positive association was found between age and experience of GPs and the frequency of providing palliative care (r = 0.35). Older GPs, ie, those with lon-

	Total %	No. of general practitioners					
			age group (y)		place of work		
Question		<35	35-50	>50	urban	urban/rural	rural
Experiences to provide palliative care for terminal patients:							
frequently	23.0	22	140	52	61	24	130
sometimes	55.0	57	354	89	166	61	271
infrequently	19.0	35	111	27	74	21	78
never	2.0	3	10	7	15	2	3
missing data		7			8		
Have medical knowledge about terminal patients at home:							
yes	40.0	31	245	89	129	41	195
no	60.0	85	363	81	182	62	285
missing data		20			20		
Informed about treatment methods in oncology:							
yes	6.0	9	34	10	20	6	26
moderately	62.0	57	396	110	199	72	293
no	32.0	52	186	53	97	29	164
missing data		7			8		
Possibilities for delivering palliative care in Romania:							
very good	1.0	0	4	1	2	0	3
good	12.0	27	131	47	75	19	109
bad	52.0	53	332	81	179	54	235
very bad	25.0	37	146	42	59	34	131
missing data		13			14		
Need for palliative care service in your region:							
yes	82.0	76	414	122	216	68	326
no	42.0	42	205	53	102	40	159
missing data		2			3		
Need for training in palliative care for terminally ill patients:							
yes	95.0	110	587	163	300	102	458
no	5.0	6	28	45	15	6	24
missing data		9			9		
Directly interested in participation in such a course:							
yes	92.0	107	573	148	284	95	450
no	8.0	10	43	26	30	13	35
missing data		7			7		

Table 2. The association of age and place of work with experience, knowledge, and opinion of Romanian general practitioners on palliati-
ve care in Romania

ger working practice and greater experience, reported providing palliative care more frequently than younger GPs. Interestingly, there were GPs who had never had such an experience and these were mainly older GPs. Women GPs reported to have had fewer patients to provide palliative care for than their male colleagues ($\chi^2_2 = 6.599$, P = 0.037). GPs working in the rural areas reported to have had provided palliative care for patients with incurable diseases more often than their urban colleagues ($\chi^2_4 = 25.389$, P < 0.001).

Knowledge

To the question whether their medical knowledge was sufficient to provide care for terminal patients at home, 40% of GP who answered this questions gave a positive answer, whereas majority of 60% reported having insufficient knowledge (Table 2). The association between age and medical knowledge showed that younger GPs had less medical knowledge about the care for terminally ill patients, whereas GPs older than 35 reported having more knowledge ($\chi^2_2 = 18.969$, P < 0.001). Also, women GPs reported having less knowledge about care for terminally ill patients at home than their male counterparts ($\chi^2_1 = 8.271$, P = 0.004).

GPs were asked to assess how well informed they were about methods of treatment of patients with cancer. The majority (62%) could not assess whether they were well informed or not, 32% considered themselves not to be well informed, and only 6% believed they were well informed.

A significant association was found between self-assessed knowledge of care for terminally ill patients and self-assessed knowledge of treatment methods for patients with cancer (r = 0.41). GPs who believed their knowledge of treatment of patients with cancer was insufficient also stated that their knowledge was inadequate to provide care to terminally ill patients at home. When asked to indicate the aspect of palliative care they needed more knowledge and information about, GPs provided the following answers: treatment of pain (68%), communication with other specialists (49%), communication with patients (42%), treatment of depression/anxiety (42%), and technical skills (25%).

GPs clustered into two groups according to their self-assessed need for better knowledge about palliative care. One group of GPs had a preference for improving technical skills and showed less interest in obtaining more training in communication with patients (r = -0.21). Another group of GPs, especially the younger ones, said they would prefer to improve their knowledge of treatment of pain, depression, anxiety, and digestive problems, but were less interested in improving communication with other medical specialists.

Opinions

The opinion of GPs on the opportunities for provision of palliative care in Romania was rather negative. Over one half (52%) of GPs assessed the opportunities as poor, whereas a quarter (25%) thought they were very poor (Table 2). Only 5 GPs saw the opportunities as being very good. The vast majority of GPs (82%) felt there was a need for palliative care services in their region. More female than male GPs thought that there was a need to develop services for palliative care in their area ($\chi^2_1 = 5.722$, P = 0.017).

The need for training in palliative care was overwhelmingly recognized as 95% of GPs reported it as useful. Almost the same percentage of GPs explicitly stated they were interested in training programs for palliative care.

An open-ended question was asked about the composition of a palliative home care team. There was a clear agreement among respondents that a GP (524 answers) and a nurse (558 answers) should be members of the team. GPs also reported that a palliative care team should include social medical workers (223 answers), nursing assistants (118 answers), clinical specialists, including oncologists (108 answers), and psychologists (80 answers). Clearly, palliative care was considered to be delivered by a multidisciplinary team.

GPs thought that the coordination of palliative care at home should be in the hands of GPs (66%), followed by a medical specialist (31%) and a nurse (18%). One group of respondents indicated a preference for the GP as a coordinator of the team rather than another medical specialist, whereas another group of GPs preferred a nurse together with family.

Discussion

This study showed that the experience of Romanian GPs in palliative care was limited and that, in their opinion, care for terminal patients should be provided at home. GPs perceived a need to acquire more knowledge related to the special medical, social, and psychological needs of terminally ill patients and their families. For this reason, they were willing to participate in training programs.

In many countries, patients prefer to die at home (6). A study in Scotland showed that 93% of the GPs preferred patients to die at home (12). Our results showed that GPs in Romania also preferred to take care for the terminally ill patients at home. In Romania, care for these patients is usually provided by the family, but to treat pain and complications and to comfort the patients, special – palliative – care is needed. GPs included in our study were aware of their need to acquire this specialized knowledge.

However, we found that 60% of GPs were not satisfied with their knowledge of methods of providing care to terminally ill patients. The same was found in other, more developed, countries (8). Romanian GPs' knowledge was associated with their age and sex. They were also aware of their need for more knowledge about treatment of patients with cancer. This may come as no surprise, since the guidelines for family physicians contain no information on the treatment of terminally ill patients, and no medical literature had been available in the Romanian language on this subject until a handbook on palliative care was published in Romanian language in 2004 (13).

The relationship between age and experience of GPs in providing care to terminally ill patients was not surprising. GPs who practiced for longer time had more opportunities to improve their skills and knowledge. Young physicians had not yet had the same chance to establish regular contacts with terminally ill patients, not only because they had less experience, but also because such patients may be referred to older and more experienced colleagues.

In the rural areas, GPs had more experience with providing care to terminally ill patients than their urban colleagues. This is probably because in rural areas, a GP office is the only medical facility available. A rural community is smaller and more isolated (lack of transport and communication infrastructure), and the GP is more familiar with a patient and patient's family, medical history, and social and spiritual needs.

The response rate to this questionnaire was relatively high, which in itself indicates the importance of this issue to GPs. In Romania, responding to a questionnaire for research purposes is not part of everyday practice, and citizens are still reserved when it comes to expressing one's own thoughts (14).

The low response rate from GPs in small towns is difficult to explain. Maybe it was related to the organization of the GP association in these places. The high response rate from GPs in rural areas may be caused by the felt need for palliative care in these areas. Generally, the results might be seen as representative for GPs in Romania.

Most GPs thought that there was a strong need for palliative care provision in Romania.

Quite recently, the Ministry of Health of Romania decided to restructure the medical system and expand facilities for palliative care. By establishing qualified multidisciplinary teams for palliative care, the need for palliative care may be in higher degree and more efficiently. It would be necessary to form a team consisting of physicians, nurses, and volunteers in each district to take care of terminal patients at home. GPs included in our survey showed a desire to improve their level of cooperation with other specialists through effective communication, and to provide the needs requested by patients at home.

References

- van den Heuvel WJ, Olaroiu M. Palliative care: an European dimension [in Romanian]. Revista Medical Romana. 1999; 46:35-8.
- 2 Baumgarten J. Making palliative care a priority topic of the European Health Agenda, Eurage, Graz, Eurage 2004.
- 3 Davies E, Higginson IJ, editors. The solid facts. Palliative care. Copenhagen: World Health Organization; 2004.
- 4 Dumitrescu L, Olaroiu M, Bogdan C. History of the development in palliative care [in Romanian]. Revista Medicala Romana. 2003;50:156-9.
- 5 Mosoiu D. Romania 2002: cancer pain and palliative care. J Pain Symptom Manage. 2002;24:225-7. <u>Medline:12231151</u>
- 6 Tiernan E, O'Connor M, O'Siorain L, Kearney M. A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. Ir Med J. 2002;95:232-5. <u>Medline:12405498</u>
- 7 Doyle D, Hanks GW, Cherny N, Calman K, editors. Oxford textbook of palliative medicine. 3rd ed. Oxford: Oxford University Press; 2004.
- 8 Yuen KJ, Behrndt MM, Jacklyn C, Mitchell GK. Palliative care at home: general practitioners working with palliative care teams. Med J Aust. 2003;179(6 Suppl):S38-40. <u>Medline:12964936</u>
- 9 Cowling K, Fowler-Kerry S. Developing a paediatric hospice programme in Romania. European Journal of Palliative Care. 2004;11:73-4.
- 10 Bara AC, van den Heuvel WJ, Maarse JA. Reforms of health care system in Romania. Croat Med J. 2002;43:446-52. <u>Medline:12187523</u>
- 11 Bucur A, Dragomir L, Calomfirescu C, Beloiu D. Annual health statistics [in Romanian]. Bucharest: Ministerul Sanatatii; 2002.
- 12 Vellupilai T, Welsh J, Ewen J. The perceptions of general practitioners and district nursing of the patients' preferred place of death and obstacles preventing this happening. Palliat Med. 2000;14:347-8.
- 13 Olaroiu M, editor. Compendium of palliative care at home [in Romanian]. Bucharest: Editura Viata Medicala Romaneasca; 2004.
- 14 Bara C. The Romanian health care system in transition from the users' perspective [dissertation]. Groningen: University of Groningen; 2003.