Chapter 9

Educational Needs of General Practitioners in Palliative Care: Outcome of a Focus Group Study

W.J. Meijlera, FB. van Heestb, R. Otterc, D.Th. Sleijferd

a M.D., Ph.D, Integraal Kankercentrum Noord Oost, Groningen, the Netherlands
b GP, MSc Palliative Medicine, GP advisor in Palliative Medicine for Drenthe, Integraal Kankercentrum Noord Oost, Groningen, the Netherlands
c M.D., Ph.D, oncologist, University Medical Centre of Groningen, director of the Comprehensive Cancer Centre North-Netherlands (CCCN), Groningen, the Netherlands
d M.D., Ph.D., Professor of Oncology, University Medical Centre Groningen, the Netherlands


In the Netherlands, the general practitioner (GP) plays a central role in providing palliative care. Usually the GP supports not only the patient but the family of the patient as well. The patient's demands for palliative care at home are increasing due to shorter hospital stay, more treatment facilities in outpatient clinics, and the wish of the patient to spend more time at home. In the same time, much improvement in home care facilities and treatment opportunities was seen. This asks for more postgraduate education “to stay up-to-date.” (1)

In earlier studies, it has been concluded that postgraduate education in palliative care “increases the quality of this challenging part of the role of primary care physicians.” (2) Nevertheless, the need for education has hardly been studied. Although many courses in palliative care for GPs are organized, it remains unclear whether the content of these courses fulfils sufficiently the needs of GPs with respect to problems of palliative care in daily practice. It is clear that most organizations develop their classical-oriented educational courses with little or no input from the learners, and the attendance is low because GPs are overloaded with courses. There should be more interaction between the providers of education and the learners as to what and how the learners want and need. Generally, questionnaires and structured interviews are used for investigating the educational needs. (3) Health needs assessment using qualitative methods provides opportunities to develop a comprehensive understanding of this need in its local
context.(4) An open way to explore this need is by using focus-group formats.(5) We undertook an assessment concerning educational needs in palliative care of the GP with the focus group method.(6-8)

Methods

To assess the need of GPs in education in palliative care, 4 focus groups were composed. The focus group method is a group interview to collect qualitative data on "topics" by focusing on problem identification and needs.

Each group consisted of about 10 GPs who were considered to be representative. They originated from the 4 different provinces of the northern part of the Netherlands (4 provinces, 2.1 million inhabitants, 1000 GPs, 17 hospitals).

Although focus groups may vary in size, about 10 participants per group were invited to provide a reasonable crosssection of views. The sessions were conducted by a moderator who introduced the questions and ensured the necessary control that would ensure that the focus was maintained, whereas the regional GP advisor in palliative care as facilitator had a supportive role to keep the discussion on track.

The following standardized verbal introduction and set of questions were used to guide the group discussion: “You are regularly engaged with the patient's needs in palliative care that may include other chronic illness next to cancer. Some problems are undoubtedly easily to be solved, others are more complicated.

• Which problem can you remember that you were recently involved (physical, psychosocial, organizational, or ethical)?
• What knowledge or skills in palliative care would you need to solve this problem by yourself?
• How important are attitude and ethical issues in palliative care?
• Which educational needs in palliative care do you experience (for yourself and for other colleagues)?”

The purpose of the introductory question list was to permit the moderator to provide a focus as well as uniformity between the groups. Participants were asked to respond according to their own experiences, whereas the other participants were invited to comment on this.

The facilitator supported the moderator to achieve the goals of the group interview. The sessions were planned to last each for 1.5 to 2 hours. All sessions were recorded on tape for analysis. A written report of the sessions was produced by the moderator. Before further analysis, the report was presented to all participants for comment.
Results

The characteristics of the 4 regional focus groups are shown in Table 9.1. The number of years of experience as GP in the 4 focus groups was relatively high. It can be concluded that the focus groups represent much experience with the subject. The number of female GPs is disproportionately low compared with the average sex difference that is equal among GPs in the Netherlands.

In each group, the participating GPs counted palliative care as a valuable part of primary care. “The art of palliative care” was mentioned several times. “If you are skilled in palliative care, you are a good physician.”

Problems in palliative care are not restricted to cancer patients. End-stage heart failure and chronic obstructive lung disease were repeatedly mentioned as well as multiple sclerosis.

In Figures 9.1, 9.2, and 9.3, the subjects raised more than once are shown per focus group. Relevant remarks and quotes are described.

<table>
<thead>
<tr>
<th>Province</th>
<th>Groningen</th>
<th>Friesland</th>
<th>Drenthe</th>
<th>Overijssel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nr. participants</td>
<td>11</td>
<td>11</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Age mean (yr, mo)</td>
<td>48.8 ± 6.3</td>
<td>47.9 ± 5.0</td>
<td>46.1 ± 6.9</td>
<td>48.6 ±5.1</td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>10</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Experience as physician (yr, mo)</td>
<td>18.9 ± 7.6</td>
<td>16.8 ± 6.8</td>
<td>16.4 ± 8.5</td>
<td>17.0 ± 8.0</td>
</tr>
<tr>
<td>Single practice</td>
<td>4</td>
<td>8</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Group practice</td>
<td>5</td>
<td>3</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Health centre</td>
<td>2</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>City</td>
<td>5</td>
<td>6</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Countryside</td>
<td>6</td>
<td>5</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Full time</td>
<td>9</td>
<td>10</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Part time</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Attended courses in palliative care</td>
<td>1.0 ± 0.9</td>
<td>0.9 ± 0.7</td>
<td>1.4 ± 1.5</td>
<td>1.4 ± 1.4</td>
</tr>
</tbody>
</table>

Table 9.1 Characteristics of the focus groups
In each focus group, the problem with coordination of palliative care by the primary physician was mentioned repeatedly (Figure 9.1). Goals of care are often not made clear. It was stated that “(self confident) operating is much depending on the (basic) medical knowledge of the GP” and “this saves much energy.” As an example, the case was presented of advice asked by the patient concerning a (experimental) treatment option.

Palliative care and especially terminal care is primarily coordinated by the GP. Nevertheless, the GP considers this as a “course with increasing obstacles.” In addition, GPs feel themselves at times overwhelmed by (unexpected) new events. On the other hand, palliative care is judged as “a valuable part of the professional interest.” “It is primary care in all its aspects.” The problems in palliative care are mostly complex. On one side, there are many treatment options; on the other side, limitations are taken more into consideration than in patients with a normal life expectation. It was expressed that the GP often feels helpless and sometimes tends to compensate for that with paying more attention to the patient.

This may lead to much dependency of the patient to the doctor. Helplessness of the doctor also may lead to neglect of the patient or his/her problem.

The pros and cons of additional diagnostic procedures and the treatment options have to be taken into consideration. The subject of consultation in palliative care was raised 20 times in the 4 focus groups. Unfortunately, up until now, GPs may have experienced consulting a colleague as a failure of their skills. Consultation
is used more for review and support than related to a specific question. The medical specialist is especially consulted for specific questions. A multidisciplinary team with a (primary care) physician who specializes in palliative care has been proposed with an option for consultation at home, preferably as a 24-hour facility. It appeared that many GPs are not yet familiar with the new opportunities for consultation. A need is to learn to reduce complex problems to solvable questions. Problem solving is estimated to be both a skill and an art. A focused question increases the output of consultation. A second opinion may also support an anticipating and proactive attitude. Cooperation with other home care facilities was considered to be important. Generally, the available supply and support of (specialized) home care facilities in palliative care was highly appreciated.

The coordinating role of the GP can be improved by enhancing (basic) knowledge and opportunities of consultation. This role is a skill that can be learned. Postgraduate, problem-based education of regional primary and secondary care providers together was recommended to improve cooperation in palliative care.

**Figure 9.2** Symptoms in palliative care mentioned more than once in the four focus groups

**Physical Symptoms**

Physical symptoms mentioned more than once in the 4 focus groups are shown in Figure 9.2. The treatment of pain (most often raised subject) remains one of the most difficult problems. “When” and “how” to start opioids were frequently mentioned. A lack of knowledge was perceived with respect to the subcutaneous administration of opioids, especially when they have to be combined with other drugs.
Also, a lack of knowledge of the indications for and results of nerve blocks in case of pain was registered. The treatment of nausea was mentioned frequently together with diagnostic possibilities, parental nutrition, and PEG catheters. Treatment options remain frequently unused because of lack of knowledge of the cause of the nausea. Some participants mentioned that sometimes the treatment of nausea is more complicated than the treatment of pain.

Dysphagia and especially problems with the oral administration of medication was mentioned twice.

Delirium was also one of the most frequently raised problems in palliative care. Diagnosing delirium was perceived as difficult. The definition of delirium is complex; the diagnosis is often missed. An example of delirium caused by medication was mentioned. Consultation to support the diagnosis has been advocated. Special attention was drawn to subcutaneous administered midazolam as a treatment option.

Insomnia was discussed 4 times in 2 focus groups. Typical clinical cases have wakeful nights due to fear of dying but may also be due to drug interactions. Insomnia may be related to the beginning of delirium. Fear for the future was mentioned in all 4 focus groups as difficult to deal with. Open communication with the patient has an anxiety reducing effect and leads to a decreased use of drugs.

The diagnosis and treatment of depression was experienced as difficult and a subject for postgraduate education. It was a general opinion that the diagnosis was missed often. The distinction from appropriate sadness and adjustment disorder is not easy. One of the focus groups had the opinion that the prevalence of depression in palliative care was overestimated. Nevertheless, all focus groups advised to take depression (together with anxiety) as subject for postgraduate education for GPs.

**Psychosocial Subjects**

Psychosocial problems were mentioned 38 times in all 4 focus groups together (Figure 9.3). It was mentioned that generally psychosocial problems are not only related to the attitude and personality of the patient and his family but also to the attitude and personality of the physician.

The importance of communication was frequently mentioned in the 4 focus groups. It is considered to be complex because the GP has to deal with different relations, the patient, medical specialists, the family, and nurses who each may interpret the situation differently. Also, difficulties in communication with nonnatives and foreign speakers were mentioned.

The course of the disease may result in a crisis of confidence between the patient and the GP who was not involved during the curative treatment by the specialist. Communication during the transfer back from second to first line could be improved. GPs cited this problem as one of the reasons for a difficult start of palliative care.
Talking about death was considered to be a skill. Especially in the case of a dying child. Conflict management may be complicated, but there is the problem of "overdependency on the doctor" as well. Palliative care was felt to be a "ritual dance" with "several unspoken subjects." Expertise in communication is pivotal in preparing the patient (and his/her family) for the last phase of life. Related to this, "relabelling" the problem was mentioned.

Bereavement support has been recognized as a skill that can be practiced by means of typical clinical examples. Some primary care physicians choose time-related support in bereavement. They make an appointment in advance with relatives to visit them "on the third day, in the third week, and the third month afterwards."

Dealing with denial was mentioned 6 times in the focus groups and was agreed by the participants as a problem that can be difficult to deal with. Knowledge and skills in dealing with denial are important. Denial as a defense mechanism is sometimes more appropriate for the patient, and in this situation, it may be followed by severe problems in communication. Training in communication techniques was recommended by the participants of all 4 focus groups. "Which attitude should be chosen by the physician when psychosocial problems are denied?" However, it has been cited that denial of the disease and/or perspectives are no longer a taboo.

**Ethical Issues**

Ethical questions may be the most important subject in palliative care (Figure 9.3). It was brought up 10 times. GPs consider their own professional, personal experience and attitude to be involved. This also applies to the personal role.
and opinions about end of life, which may alter during time. “Fatalistic thinking care providers” tend to be less active. Too much attention and overdependency may take place due to uncertainty and powerlessness of the caregiver.

A postgraduate course in ethical issues is proposed including items on individual norms and values, not only “how to develop” but also “how to discuss” and share these subjects with other professionals. The participants felt much resistance to the statement that all problems with euthanasia can be solved with optimal palliative care. The role in and emotions around euthanasia of the primary care physician are readily shared with colleagues. The need of “debriefing” and “care for the carers” was mentioned but also an example in which a primary care physician shared his feelings in relation to voluntary life ending with a primary care physician colleague. The role of the (compulsory) second opinion in case of voluntary life ending was estimated as very valuable.

Postgraduate education concerning “when and how euthanasia is discussed with the patient” would preferably be organized together with specialist physicians with the advantage that discussing this object also elucidates the personal attitude of (professional) partners.

Discussion

During the sessions it was obvious that GPs are very dedicated to palliative care. Palliative care is a difficult but challenging part of their profession. Palliative care for the physician can be an emotional burden, especially when the patient's illness is protracted. The patient's demands increases, and the medical situation changes fast. The role of coordination is sometimes felt to be difficult.

The educational needs are difficult to determine since “you don't know, what you don't know.” However, it appeared that with the focus group method, a good overview could be made of the experienced educational needs of GPs on the basis of their daily problems in palliative care and their recommendations.

The subjects raised in the focus groups are quite similar to the GP educational preferences published by Shipman et al, such as treatment of pain, nausea and vomiting, the use of devices for parental drug administration, breaking bad news, bereavementcare, counseling skills, and communication skills.(9)

Recently, Epstein and Hundert defined and assessed professional competence.(10) They distinguished the use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice next to integration of knowledge and skills, context of care, management, teamwork, and patient-physician relationships.

The problems in palliative care encountered by the participating physicians in the focus groups can be divided alike.

Knowledge was insufficient concerning treatment of pain including treatment with opioids, of nausea and vomiting, dysphagia, and insomnia.
Pain is the most important subject, as also published by Haines and Thomas. Beside physical symptoms, a lack of knowledge regarding psychological and psychiatric symptoms was mentioned such as anxiety, restlessness, delirium, hallucinations, and depression. Also, psychosocial problems were mentioned.

A lack of technical skills was experienced in the subcutaneous administration of drugs, home care technologies such as oxygen supply and the use of gastric tubes, and in the treatment of pressure ulcers and wound dressing.

Communication skills were identified as being paramount. Communication between the primary care physician and other physicians, mostly medical specialists, can be complicated. This communication should include all aspects of the patient’s situation that might have an impact on the home care. Communication with the patient and the family, especially breaking bad news and discussion about diagnostic and therapeutic possibilities, is another problem area.

Fear of being blamed, especially when the course of the disease has resulted in a lack of confidence between doctor and patient, is reason for hampered communication as well. Talking about dying and death was recognized as an important issue. Blyth found that poor bereavement care was a major source of dissatisfaction by relatives, with many perceiving their GP to be uncaring and unhelpful.

A majority of GPs in the study of Lloyd-Williams and Lloyd-Williams found that learning in psychological and bereavement support was inadequate. Clinical reasoning skills are necessary to solve the patient’s problems. Although nowadays, clinical reasoning is a paramount content of a problem-based medical curriculum, most participants did not have formal training in clinical reasoning. A diagnostic or therapeutic dilemma during the assessment of a clinical problem was frequently mentioned. The pros and cons of procedures have to be taken into consideration.

What limitations does home care have and what are the expectations patients and family members? When the outcome of clinical reasoning is unsatisfactory, the question arises whether consultation is necessary. Unfortunately, primary care physicians may experience consulting a colleague as a failure of their skills. Although hospice services are available in the Netherlands, they are mainly organized as “low-care” facilities for patients who can not stay at home for primarily social reasons, with the own GP still as coordinator of care. Only a few hospices have a consulting function for palliative care.

Personal emotions of GPs are involved in palliative care, which makes it more complicated. Working alone can make it difficult to share problems with colleagues, although the need of sharing was clearly stated. Attention for this subject may stimulate the individual physician to find support from a reference group.

Ethical issues are important in palliative care. There is a direct relation between communication and ethics. Ensuring good communication among
the physician, health care professionals, patient, and family will facilitate care and avoid ethical problems. The number of times that the issue of euthanasia was raised in the focus groups shows that this subject is (like in other countries) a problem in palliative care in the Netherlands. Because of a liberal legislation of euthanasia, this subject is easily discussed. The issue about "good palliative care" and an euthanasia request was in the 4 focus groups not encouraged since this was not within the objective of this study.

GPs have difficulties in the timing of the discussion of "voluntary life ending" with the patient. To assess "unbearable suffering" is estimated as complicated. There is a need of reflection on the way of thinking, doing, and learning in palliative care focused on the patients, their families, and the care.

GPs appreciate palliative care as belonging to their profession. The management role is nevertheless complicated, reactive instead of proactive. The GP functioning in a solo practice may benefit most in consulting a fellow GP for both professional and emotional support.

Postgraduate education in basic knowledge, technical and communication skills, and ethical issues in palliative care for primary care physicians is needed. This is in accordance with Samaroo who also used the focus group method. He concluded that programs that focus on the dying process, pain, symptom control and comfort, and patient and family support meet the educational needs. The data of the 4 focus groups (Table 9.1) show that GPs occasionally attended courses on palliative care. Wakefield et al suggested that continuing education is required for GPs and that at the same time, palliative care should become an integral part of undergraduate education.

The practice of care should be taken into account when organizing a program on education. As a result from this study, the Comprehensive Cancer Center North-Netherlands has developed a multipurpose educational program in palliative care. Symptom control is supported by guidelines and regional interactive workshops. For the improvement of communication skills, an e-learning program is made as well as practicing courses. Ethical issues are discussed in special workshops. It is remarkable that the busy GP finds time to attend the courses, which supports the finding in this study that GPs are very dedicated to palliative care.

In summary, we conclude that the use of the focus group method is a useful means of identifying the educational needs of GPs in palliative care. This education should include basic knowledge, communication skills, and ethical issues in palliative care. It should be realized that teaching these different aspects asks for different teaching methods. Thematic lectures can convey teacher to learner information and can be used for groups of more than 50 learners. Practical sessions serve to allow learners to master technical or communication skills. In case of teaching communication skills, the group of attendees should be smaller. Finally, the discussion of ethical issues or the practice of reflection asks for groups less than 10. Reference groups with an expert in palliative care is also a good alternative. All these methods should be used to develop a successful educational program in palliative care for GPs.
References

5. Sherman CD, Davis DA. CME in oncology, from where we were to where we are going. J Cancer Educ. 1995;10:131-136.
Summary

Background
Many patients with cancer were found to have mental symptoms and syndromes such as anxiety and depression; these are often poorly recognised and therefore may be undertreated. However, the reported incidence and prevalence vary depending on the setting and the research method used. We were interested in data from primary care.

Methods
In a registration network of 17 GPs (30,000 patients) all cancer patients were identified by the International Classification for Primary Care (ICPC) codes. Registration for psychological complaints or psychiatric syndromes (P domain) in these patients was compared to matched control patients. Prescriptions issued to the patients were also compared.

Findings
Although GPs recorded more psychological complaints in relation to the stressful life event of the diagnosis, the incidence of P domain syndromes was not higher in patients with a cancer diagnosis. If the mortality due to the cancer was higher, there were more registrations in the P domain and more prescriptions. Prescriptions of anxiolytics, sedatives and antidepressants increased at time of diagnosis and remained at a higher level than pre-diagnosis. 117 of these patients (14%) discussed considering euthanasia but only 22 died of euthanasia.

Interpretation
GPs recorded symptoms in the P domain, especially sleep problems, in patients with a diagnosis of cancer. Symptomatic treatment with prescriptions by GPs was common (almost in 50% of the patients). It is unclear whether it is easier to discriminate (anticipatory) grief from depression in primary care or whether assessment in the home environment alters the outcome of a diagnostic interview with a patient. The interpretation of symptoms by GPs might also differ.

Keywords: primary care, diagnosis of cancer, anxiety, depression, ICPC coding