CHAPTER 6

RETROSPECTIVE EVALUATION OF PALLIATIVE CARE IN ROMANIA: THE PERSPECTIVE OF INVOLVED PROFESSIONALS

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Abstract

Objective: Palliative care at home is a new service provision in Romania. This study evaluated retrospectively, after the patient’s death, the provision of care at home from the perspective of professionals directly involved in the care process. The evaluation included assessment of the role of the professional, the functioning of the team, communication with patients and family and overall judgment. This study is part of the development of palliative care at home by multidisciplinary teams in Romania.

Methods: Over a period of eighteen months, five teams with in total of 19 professionals, provided palliative care for 103 patients with cancer in its terminal stage. During this period 80 patients died. A questionnaire was send to the professional involved. All responded resulting in 181 evaluations. These evaluations are the base for analysis. The data was analyzed using a SPSS.

Results: Of the 181 cases evaluated, 63 indicated an emotional burden on the professionals. GPs and nurses reported such a burden more frequently. A lack of knowledge of how to treat a special case was reported 56 times. This was especially so when a case was judged as different from other cases, which often included (unexpected) complications. GP’s reported cases with complications more frequently than oncologists and nurses. The multidisciplinary teams functioned very satisfactorily in treating patients. Although communication with patient/family was generally judged positively, communication with patients was sometime viewed as problematic. The overall
verdict was that the care delivered to the 80 patients was positive. Most professionals reported that they would deal with the cases in the same way again.

**Conclusions:** The patients, who received palliative care and died, were treated well according to the professionals who evaluated the care process. Improvement of palliative care services at home may be achieved by provision of additional information on (acute) complications. Since palliative care at home is a new phenomenon in Romania, professionals working closely with the patient have to learn to cope with the emotional burden certain cases may include.

**Keywords:** palliative care, primary care, evaluation, palliative team, deceased patients
6.1 Introduction

The provision of palliative care can take place in a variety of settings, for example, in hospital, at a hospice, in a nursing home or at home. Palliative care, in all cases, includes the involvement of several disciplines such as nursing, oncology and in the case of home care, general practitioners. The number of patients dying at home or in institutions varies a lot between countries. According to figures presented by Doyle (1993), the percentage of patients dying at home in the USA ranges 13%, while in Denmark and UK the figure is 24% and in Poland 48%. In Romania this rises to more than 90%. These figures change over time. Recent data of WHO (2004) show that 22% of people die at home in the USA, 19% in England and Wales and 30% in Germany and the Netherlands. In Western Europe a growing number of people die in nursing homes or hospices. This is less the case in Central-Eastern European countries. In Romania nursing homes are largely absent and four hospice facilities exist. Palliative care at home is developing recently as an experiment in Romania.

Several studies have shown that most terminally ill patients would prefer to spend their final days at home and indeed, a great deal of care is provided at home by GPs and nurses during this period. The quality of this palliative care at home has, therefore become an important issue. Some studies have questioned the ability of GPs and district nurses to provide appropriate palliative home care, especially in view of possible complications which may be suffered by the patient. A Dutch study, however, shows that the opposite is true. Evaluation of palliative home care is important, but studies are rather scarce.

In Romania, palliative care at home is a relatively new phenomenon. For some years it was provided by teams from a hospice or a hospital in a few regions, but it never included multidisciplinary teams involving primary health care workers. This article presents an evaluation of such a new care provision.
Evaluation of palliative care can be done from various perspectives and in different settings. One important aspect is how the patient and his or her family view the quality of this care. Recent studies show that patients and families give their GPs high satisfaction ratings.\textsuperscript{8,9,10} However, an objective evaluation is not easy to achieve because it is bound up with the process of dying and grieving. Evaluation from each of the different perspectives is useful, because it may contribute to qualitative improvements in palliative care, that is, the outcome and/or process of palliative care.

When evaluating palliative care a choice has also to be made with respect to the moment and period of evaluation. This study evaluates the provision of palliative care at home following the death of the patient from the perspective of those professionals most directly involved in the care process.

The research questions in this study were:

1. How do the professionals evaluate their own role in the process of each specific case?
2. How well did the team function according to the team members involved in each specific case?
3. What was the involved professionals’ opinion on the communication with patient and the family in each specific case?
4. What is the overall opinion of the involved professionals on the care provision in each specific case?

Evaluation of professionals may be influenced by several factors. These may include previous experiences, special training and facilities available, as well as their own attitude.\textsuperscript{11,12} In this study we aimed to investigate whether the evaluation of the case of professionals was related to their discipline as well as to factors directly relating to the case, i.e. type of profession, the teams, complications during the care delivery process and duration of the palliative care process.
6.2 Methods

Five multidisciplinary teams were established to deliver palliative care at home in two urban (Bucharest and Olt) and two rural (Ilfov and Olt) areas in Romania. Each team had at least a GP, an oncologist (as consultant) and one nurse. The teams, consisting of 19 professionals in total, were trained to deliver palliative care at home in five sessions (total 15 days) (see www.pacaro.go.ro). The Olt urban team was the largest with two GP’s, one oncologist and three nurses. The smallest was the Bucharest team existing of one GP and one nurse with various oncologists as consultants. During 18 months between October 2002 and April 2004, the five teams, provided palliative care at home for 103 patients with cancer in its terminal stage. During the period of study, 80 patients died. The mortality rate varied between the five teams (see Table 1).

<table>
<thead>
<tr>
<th>TEAMS</th>
<th>Number of patients</th>
<th>Number of patients died</th>
<th>Answers by GPs</th>
<th>Answers by oncologists</th>
<th>Answers by nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bucharest urban 1</td>
<td>16</td>
<td>9</td>
<td>7</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Bucharest urban 2</td>
<td>18</td>
<td>12</td>
<td>12</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td>Ilfov</td>
<td>18</td>
<td>15</td>
<td>11</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Olt urban</td>
<td>32</td>
<td>30</td>
<td>22</td>
<td>0</td>
<td>40</td>
</tr>
<tr>
<td>Olt rural</td>
<td>19</td>
<td>14</td>
<td>9</td>
<td>9</td>
<td>26</td>
</tr>
<tr>
<td><strong>Total patients</strong></td>
<td><strong>61</strong></td>
<td></td>
<td><strong>24</strong></td>
<td><strong>96</strong></td>
<td></td>
</tr>
</tbody>
</table>

Between four to eight weeks after the death of a patient, the professionals involved were asked to fill in a questionnaire. The questionnaire consisted of 12 closed questions with four pre-coded answers. Space was also provided for additional comments. These additional comments are presented in the analysis where relevant. For quantitative analysis the answers were dichotomized. Not all team members answered the questionnaire: it was only filled in if the team member was actually involved in the care provision. In
summary, 5 GPs filled in 61 questionnaires, 4 oncologists filled in 24 questionnaires and 9 nurses filled in 96 questionnaires (see table 1), giving a total of 181 completed evaluations.

The following questions were asked with respect to the experience of the professional:

1. Opinion about the role: sense of comfort, emotional burden, perceived lack of knowledge.
2. Functioning of the team: cooperation on the case and communication within the team.
3. Communication with patient/family: communication with patient and family.
4. Overall judgment: overall judgment of care provision in this specific case was this case different from other cases and whether, retrospectively, they would have acted differently in the case.

Independent variables include: professional discipline; team; duration of care provided and complications. The average care period was ten weeks per patient: 5% of patients received this care for less than forty eight hours, 29% for between one and four weeks, 43% for between one and three months and 23% for over three months. Complications during the palliative care period were reported by GPs in 32 cases, and were more frequent in comparison to oncologists (9 times) and nurse (19 times). Responses relating to cases and from individual professionals were compared, since one professional may have filled in many questionnaires. The professionals did not report systematically complications on the same cases. Neither did they show a specific “biased” answer pattern.

The data was analyzed using SPSS. The analysis considered the description of frequencies. Only dependent variables which showed a clear differentiation in answering pattern (70: 30) would be analyzed further, by presenting associations with independent variables and other dependent
variables. For categorical variables, chi square testing for significance was used. For continuous variables Pearson correlations were calculated. Differences with background variables are presented immediately after the description of the frequencies. Significant differences (p < .05) are reported.

6.3 Results

Opinion of the professional on their role

Individual professionals were asked whether they felt comfortable with their role in the palliative care process. Of the 181 evaluations analyzed, 79% reported “yes, very much” and in 18% reported “yes”. Only 4 professionals did not feel comfortable with their role in specific cases. Responses to the open question “why did you not feel comfortable in this case?” reported rapid deterioration of a patient’s condition as a reason.

A clear emotional burden was reported by 12% of the individual professionals considering the specific cases, while 23% reported a burden, “but not too much”. The majority (65%) of the professionals did not feel the delivery of palliative care to these patients was a burden. A clear difference exists between disciplines: the oncologists report “no emotional burden” frequently, while over one-third of GP’s and nurses mention that the specific cases caused an emotional burden (Table 2). An open question on reason for emotional burden identified seeing the patient dying as the most common. GPs and nurses said that talking with colleagues in the team, and sometimes with family helped them to cope with this.

| Table 2: Profession and emotional burden / experienced lack of knowledge |
|--------------------------|-----------------------------|--------------------------|-----------------------------|
| PROFESSION | Emotional burden | Experienced lack of knowledge |
| | No | Yes | No | Yes |
| GP | 38 | 23 | 36 | 22 |
| Oncologist | 21 | 3 | 21 | 3 |
| Nurse | 59 | 37 | 68 | 26 |
| TOTAL | **118** | **63** | **125** | **56** |

Chi square - 6.079, P<.04
Chi square - 6.841, P<.04
Differences were also found between teams with respect to the emotional burden experienced (chi square 13,368, df 4, p < .01), with the teams in the Olt region reporting emotional burden more frequently than in the other regions. No significant differences were found with respect to duration of the disease process and complications during the palliative care process.

An important aspect in the role of the professional is their particular knowledge. Team members were asked if they perceived a lack of knowledge or expertise with respect of the specific case. Most professionals (69%) reported not having perceived a lack of knowledge or expertise. A few (5 professionals) recognized that their knowledge was clearly not sufficient to take care of the patient in this specific case and in 18% of the cases they felt it was lacking slightly. When asked for the reasons for “limitations” in knowledge, respondents mentioned control of complication (melena, dyspnoea, coma), lack of awareness of the disease’s rapid progression, technical skills (clisma) and a lack of communication. A significant difference was found between oncologists on the one hand, and nurses and GPs on the other with regard to lack of knowledge in specific cases (see table 2).

In the Ilfov team more than half of the evaluating professionals (55%) reported experiencing a lack of knowledge/expertise, while in the other teams it was a quarter. No significant correlations were found with respect to the duration of the care process. However, if complications in a case occurred during the palliative care process, professionals reported more frequently, a perceived lack of knowledge/expertise (r = .24) in that case. A significant correlation exists between a perceived lack of knowledge and emotional burden (r = .21), showing that if in a case lack of knowledge is perceived it goes with emotional burden in the same case. Analysis showed no specific cases where nurses, GPs and/or oncologists all reported a lack of comfort, emotional burden or lack of knowledge. This implies that each professional made their evaluation
Functioning of the team

When team members are asked how well the team worked together in this specific case, the majority (over 96%) reported “good” or ‘very good’; five professionals judged that the team work was ‘bad’ in some cases. Communication between members of the teams is considered to be (very) good by 98% of the professionals involved. The only pertinent other remark in this area was that the time was too short (since the patient died) to build up a properly functioning team.

Communication with patient/family

Communication with the patient was reported as positively by 76% of the evaluations, while communication with family was reported positively by 90%. In forty-four evaluations (18 professionals involved) communication with the patient respectively family was judged as bad or very bad. Negative communication was most frequently reported as negative by the Olt urban team. Negative communication with the patient (and family) is related with reporting negative communication in the team. The main reasons for bad communication were lack of awareness of the the disease on the part of the patient (upon request of the family) and the short time of care (progress of disease).
Overall judgment

Professionals were asked to give their overall judgment of the delivery of the palliative home care in the cases evaluated. The judgments were good in respect of 53% of cases and very good in respect of 39% of cases. Fourteen professionals involved made negative overall judgments. Reason for reporting negatively about a case included: patient who were unaware of the situation and/or bad communication with the patient; no possibility to visit the patient at home; distance and lack of time. However positive explanations are more frequently given. Good communication with patient and family was frequently mentioned.

Another question, also providing an overall evaluation, was whether the experience in this specific case was different from other cases. Over half (54%) of the professionals, who filled in the evaluation for a specific case, considered the case not to be different from any other. If a case qualified as different, reasons included the (unexpected) evolution of the disease, and the specific situation (coma, patient living alone). Significant differences were found between professionals (see Table 3). When compared to GPs and nurses, results show that for oncologists, cases were more or less “the same”.

A case qualified as different if medical or nursing complications occurred (r=.39). Also a significant relationship (r = .41) was show to exists between a case that was experienced as different from other cases, and a perceived lack of knowledge in that case. There was also a significant correlation between experiencing the case as different from other cases and feelings of discomfort (r = .26), and feeling of emotional burden (r = .29). If a case was seen as being different, it was usually accompanied by a feeling of discomfort and emotional burden. As mentioned before, agreement about which cases were different or not between the professionals was weak.
In assessing the overall judgment, team members were also asked if, retrospectively, they would have done things differently with regard to this specific case. Over two-thirds (68%) of the involved professionals answered this negatively. Those who answered affirmatively said that they would have communicated differently with the patient/family or offered a different treatment. GPs reported more frequently cases, which they would have treated differently looking back compared to nurses and oncologists (see Table 3). The oncologists rarely had any doubts in any case. The Ilfov and Olt urban teams reported more cases, which might have treated differently looking back, compared to the others (chi square 40.145 df 4  p < .000).

### Table 3: Profession and case different from other cases/acting differently afterwards

<table>
<thead>
<tr>
<th>PROFESION</th>
<th>Case was different from other cases</th>
<th>Retrospective view, acting differently in the cases</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>GP</td>
<td>27</td>
<td>34</td>
</tr>
<tr>
<td>Oncologist</td>
<td>18</td>
<td>6</td>
</tr>
<tr>
<td>Nurse</td>
<td>53</td>
<td>43</td>
</tr>
<tr>
<td>TOTAL</td>
<td>98</td>
<td>83</td>
</tr>
</tbody>
</table>

Chi square - 6.648  P<.04
Chi square - 14.813  P<.001

### 6.4 Discussion

Palliative care at home delivered by multidisciplinary teams, is a new approach in Romania. The five teams, which have started this new service in Romania, have had a unique experience. It is also the first time that a systematic evaluation has been undertaken among professionals involved, following the death of a patient in Romania. A review of the international literature reveals that this type of studies is scarce in palliative care. Further parts of this evaluation will include the families’ perspective and a case control study.
In these study professionals involved in delivering palliative care at home, were asked how they evaluated the care provision after the patient had died. In general, the professionals were quite positive about the care process. The teams and their 19 members are volunteers, i.e. they agreed to participate in the demonstration project on top of their normal jobs in health care. Each professional received special training in order to provide this new service. In general, they judged their knowledge and skills satisfactorily in the majority of the cases evaluated. Interestingly, they reported having experienced shortcomings in specific situations (unexpected complications, technical skills and communication). GPs and nurses were rather critical about their own competencies. It is recommended that additional expertise should be available on a consultative base for (sudden) complications. It is felt that the professional care delivered meets with West European standards. One problem which was not mentioned in the provision of an adequate level of care, but which is well known in the Romanian situation, is the prescription of morphine and acquisition of the necessary papers for this.\textsuperscript{10}

The way cases are treated by the teams and the professionals may differ because treatment is dependent on the specific local conditions, such as distance and rural infrastructure (with limited access). Such differences are found in this study, as are differences in knowledge and communication skills: Communication with patients is a special issue, since many patients are not informed about their diagnosis and prognosis and family members do not want these “facts” to be known to the patient. This places an additional element of stress on work being done by professionals in palliative care. This situation is particularly difficult for nurses to cope with. Indeed, it was found that when cases were evaluated less positively; lack of (time for) communication was mentioned regularly. In this context the reported communication problems and emotional burden in the Olt region could be explained. During meetings with
the teams, and as was subsequently found in the analysis, it was noted that communication was often more satisfactory with the family than with the patient. As mentioned, this is because patients are often not informed about their diagnosis and/or prognosis, making communication with the patient more complicated (e.g. “when will I get better?”). Communication problems with patients seem to also affect the communication in the multidisciplinary team.

Normally it would be expected that oncologists would be less impressed by the process of palliative care compared to other disciplines in the teams. Oncologists are more experienced at giving bad prognoses and operate at a greater distance in terminal cases. In cases where the patients were very young or suffering severely, or when (sudden) complications occurred, emotional burden was reported more frequently, but still different disciplines could have different evaluations on such a case. It was possible to alleviate the emotional burden by speaking with colleagues or with the family of the deceased patient.

In some cases team’s members expressed a need for more knowledge about the care of their patients. This involves some technical skills, but mainly treatment of complications and communication issues. Only GPs reported in what way they would act differently in the same case looking back. They reported that they might have tried another treatment or attempted a different method of communication with patients and their families. Some GPs seemed to feel uncomfortable when their patients die and were inclined to relate this feeling with their lack of skills and knowledge.\textsuperscript{13}
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