

## Chapter 8

### Telephone consultation in palliative care for cancer patients: 5 years of experience in the Netherlands

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*In palliative cancer care symptoms mean everything*

## **Abstract**

### **Purpose**

To analyze cancer patient-related consultations of a Telephone Helpdesk (TH) for palliative care, over a period of 5 years in the region of Utrecht, the Netherlands.

### **Patients and methods**

A descriptive analysis was performed of consultations over a period of 5 years (2001-2006). Discipline and location of requesting professionals, patient characteristics, reasons for calling, symptoms, palliative care problems and needs for support were registered.

### **Results**

1794 consultations were analyzed. There were an increasing number of consultations during the study period. Fifty-one percent of the patients were male and their median age was 65 (range 0-104). Eighty-four percent were treated at home by their general practitioner. Two thirds of the patients had a life expectancy <4 weeks. Most questions referred to pain (49%), delirium (20%), nausea & vomiting (16%) and dyspnea (12%). The median number of symptoms was 1 (0-6). Fifty-four percent of the questions were related to pharmacological problems, 19% to psychological problems and 21% to the organization of care. Seventeen percent of the requesting professionals asked for support for themselves. Fourteen percent of the consultations were related to end-of-life issues: palliative sedation (11%) and euthanasia (3%).

### **Conclusion**

After more than five years the 24-hour telephone consultation service fulfils a need for general practitioners dealing with daily dilemmas in palliative care treatment for cancer patients at home during the last period of their life.

## **Introduction**

Since 1998 (the start of a National Program for the Development of Palliative Care funded by the Dutch government) consultation in palliative care has developed increasingly in The Netherlands. In the region of Utrecht, a central region covering more than 1.6 million inhabitants, health care is provided by 750 general practitioners, 1 university hospital, 8 general hospitals and 4 home care organizations. To optimize palliative care, two types of consultation service were developed under the flag of the Center for Development of Palliative Care Utrecht. The goal was to create an integrated regional system of palliative care based on previously existing but independently operating general practice, home care, specialist care, nursing home and hospice services<sup>12</sup>. In order to provide the possibility of consultation for palliative care patients, the University Medical Center Utrecht developed a hospital based palliative care team in 1998 and in collaboration with the Comprehensive Cancer Center Middle Netherlands (CCCMN) a regional telephone consulting service was conceived in 1999.

In this paper we focus on the telephone consultation service, 'the telephone helpdesk' (TH), of the CCCMN. The consulting team of the TH is accessible for all professionals involved in palliative care in the region of the CCCMN on a 24-hour basis, seven days a week. The purpose of this service is to provide specialized palliative care expertise for the benefit of all professionals in the region.

During the first two years of the TH (May 1999- April 2001) there was a growing number of consultations (192 consultations in the first year and 287 in the second year), mainly from general practitioners (72%) and mainly about physical symptoms (75%)<sup>13</sup>. Almost 25% of the consultations took place outside office hours. Consultations required a mean of 85 minutes (range 20 minutes- 6.5 hours) including time spent on the telephone with the caller, consultation with others, writing notes, looking up references, writing advice and sending reports. In 40% of the cases consultation of other team members or professional experts outside the TH took place. The nurse consultant conferred often with his or her medical colleagues, as specified by standard procedure. Based on these results the service was developed further: enlargement of the team, more specification of the working methods, development of written guidelines on symptom management<sup>5</sup> and improvement of the registration procedure.

A national database for registration of all consultations of the participating services in the Dutch National Program was started in 2001. Kuin et al. analyzed the data of the first year (March 2001- March 2002) of 19 Dutch palliative care consultation teams (including ours) offering a variety of services (e.g. telephone, bedside, mono- and multidisciplinary)<sup>12</sup>. The majority of the 2,040 consultations were

requested by doctors (66%) and nurses (22%), most of them working in primary care (61%); 60% of the consultations were by telephone. The mean age of the patients, who were the subject of the consultation, was 64; 50% were male; 90% had cancer and most were treated at home (77%) Their functional status was low to very low (87% ECOG performance status<sup>3-4</sup>) and life expectancy as estimated by the requesting professional was maximally one week for 35% of patients, one week tot one month for 32% and more than one month for 33%. The consultations referred to physical, pharmacological, psychological and organizational problems in 77%, 34%, 33%, and 36% of the cases, respectively. General palliative care questions (unrelated to a specific patient) were registered in 8% of the consultations. In two other Dutch studies, results of a 2-year registration were analyzed<sup>6,18</sup>. Similar outcomes in terms of patient and professional characteristics were found.

These three studies were heterogeneous with regard to the type of consultation and covered only the first 1-2 years of the services. Studies of palliative care services from other countries also often covered the first year(s) after the set up of a service, and are seldom restricted to a telephone service for professionals<sup>7,9,11</sup>. Results of an analysis of one type of consultation over a longer period after the first 1-2 years have not been published. Therefore, we aimed to provide a descriptive analysis of the patient-related consultations of our TH over a period of five years (January 2001 to January 2006) following the first 2 years. As the great majority of the consultations referred to cancer patients and their symptoms and problems are likely to be different from those of patients with non-malignant disease, we restricted our analysis to cancer patients. We will address the following questions:

1) which professionals consult the TC?; 2) what kind of patients are the subject of the consultation?; and 3) which symptoms and palliative care problems are discussed during consultation?

## **Patients and methods**

### ***Working methods of the telephone helpdesk***

During the study period the TH team increased in size. In 2001 the team consisted of 1 general practitioner, 1 nursing home physician, 2 medical specialists (a medical oncologist and an anaesthesiologist/pain specialist) and 3 clinical nurse specialists in palliative care. During the years more general practitioners and nurse specialists were added to the team; in 2005 the team consisted of 3 general practitioners, 1 nursing home physician, 1 hospice physician, a medical oncologist, an anaesthesiologist/ pain specialist and 5 clinical nurse specialists. Each con-

sultant has at least several years experience in palliative care. All team members are practicing and continue their primary activities in addition to their work for the TH. The team members rotate in daily shifts. The consultant on call is available 24 hours a day through a central telephone number.

All professionals in the region can contact the TH on a 24-hour basis, seven days a week, with questions concerning palliative care. Questions can be patient-based, pertaining to a specific individual case, or general questions, concerning palliative care treatment and palliative care services.

The consultant interviews the requesting professional to clarify the problem. If possible, the consultant gives his advice immediately. Alternatively, if consultation of other team members, other professionals or literature is necessary, the consultant proposes a follow-up contact within a few hours. All consultants are considered to be able to give advice independently, regardless of their discipline. For nurse-consultants there is the possibility of conferring with a medical team member.

All advice given is based on the Palliative Care Guidelines of the CCCM5 and on a systematic and multidimensional way of problem analysis. Eighteen guidelines for symptom control (anorexia/weight loss, ascites, constipation, dehydration, delirium, depression, diarrhea, dyspnea, genito-urinary symptoms, hiccups, hypercalcaemia, intestinal obstruction, lymph edema, mouth symptoms, nausea/vomiting, pain, pruritis and oncological ulcers) and three guidelines for other issues in symptom management (complementary medicine, palliative sedation and euthanasia) had been developed by team members and other palliative care experts in the region between 1992 and 2001 and were issued as a book in January 2002.

After the telephone contact the requesting professional receives a written summary (in standardized format) of the consultation by fax or e-mail. For each consultation, the consultant completes a standardized registration form. Registration forms and procedures changed three times due to the collaboration in the National Program.

Professionals are invited to call again for any remaining or newly arising problems. Each case is reported and discussed in a bi-weekly team meeting.

## **Analysis**

A descriptive analysis was performed of the following issues as registered in the registration form:

- discipline and location of the requesting professional
- patient characteristics (gender, age, place of care, diagnosis, comorbidity and life expectancy)

- the primary reason for calling
- symptoms, palliative care problems and needs for support (absent or present) using a checklist derived from a nationally developed symptom registration instrument by the Dutch Centers for Development of Palliative Care<sup>12</sup>. The nine most frequently occurring symptoms are registered routinely: pain, nausea & vomiting, constipation, delirium, dyspnea, mouth symptoms, skin symptoms, fatigue and appetite loss. There is a possibility of adding volunteered symptoms.

Data were entered into 4 different databases. Files could not be clustered because during the years of development of the service a) different aspects of registration were required and b) different institutes were responsible for the registration and used different databases. Therefore only frequencies were computed with the statistical software package SPSS (version 14.0).

## Results

Between January 1<sup>st</sup> 2001 and January 1<sup>st</sup> 2006 2089 consultations were registered by the TH team; 1997 were patient-related questions and 1794 (90%) concerned cancer patients. These consultations are the subject of the present analysis. During the study period, there was an increase in the number of patient-related consultations from 319 in 2001 to 452 in 2005. About 25% of the consultations took place during out-of-office-hours.

### Consulting professionals (Table 1)

The TH was mainly consulted by medical doctors (94%) of whom 86% were general practitioners (GP's). There was an average of 3 consultations per GP per year. Only 5% of the requesting professionals were nurses.

**Table 1. Consulting professionals (n=1794)**

Medical doctors*	1665 (93%)
GP	1548 (86%)
MO	39 ( 2%)
NH	-
Other	-
Unknown	78 ( 5%)
Pharmacologists	10 (<1%)
Nurses	93 ( 5%)
Other	11 (<1%)
Unknown	15 (<1%)

\* GP=general practitioner; MO=medical oncologist; NH=nursing home doctor

**Patient characteristics (Table 2)**

Fifty-one percent of the patients were male and the median age was 65 (range 0-104). The majority (84%) of these patients was at home at the time of consultation. Two thirds of the patients had a life expectancy (as estimated by the requesting professional) of less than 4 weeks. Over the period of 5 years there was no trend toward changes in patient characteristics (data not shown).

**Table 2. Patient characteristics (n = 1794)**

Gender		
	Male	917 (51%)
Age (years)		
	Median (range)	64 (0-104)
Physician estimated life expectancy*		
	< 1 week	606 (34%)
	1-4 weeks	567 (32%)
	1-6 months	281 (16%)
	> 6 months	14 (<1%)
	unknown	326 (18%)
Place of care		
	Home	1502 (84%)
	Hospital	106 ( 6%)
	Nursing or elderly home	69 ( 4%)
	Hospice	88 ( 5%)
	Unknown	29 ( 2%)

\* by the requesting professional

**Content of the consultations**

*Physical symptoms (Table 3)*

Most questions with regard to physical symptoms referred to pain (49%), delirium (20%), nausea & vomiting (16%) and dyspnea (12%). Only 2% concerned fatigue and appetite loss. The median number of symptoms per consultation was 1 (0-6).

**Table 3. Symptoms referred to during consultations (n=1794)**

Pain	877 (49%)
Delirium	354 (20%)
Nausea & vomiting	288 (16%)
Dyspnea	213 (12%)
Constipation	164 ( 9%)
Mouth symptoms	69 ( 4%)
Skin symptoms	33 ( 2%)
Fatigue	31 ( 2%)
Appetite loss	36 ( 2%)
Other symptoms	233 (13%)
Median number of symptoms (range) per consult	1 (0-6)

\* More symptoms per patient possible in 1 consultation



### Other palliative care problems (Tables 4 and 5)

Fifty-four percent of the questions were related to pharmacological problems and 19% to psychological problems. Spiritual problems were not registered during this study. In 21% of the consultations advice was requested for the organization of care and 17% of the requesting professionals asked for support for themselves. Fourteen percent of the consultations were related to issues concerning end-of-life decision making: palliative sedation (11%) and euthanasia (3%).

**Table 4. Palliative care problems referred to during the consultation process (physical symptoms excluded) in 1794 consultations**

Pharmacological problems	969 (54%)
Organization of care	381 (21%)
Psychological problems	333 (19%)
Support professional caregivers	308 (17%)
Social problems	117 ( 7%)
Support informal caregivers	155 ( 9 %)
Problems in daily functioning	112 ( 6%)
Other	141 ( 8%)
Median number of problems (range) per consultation	1 (0-5)

\* More problems per patient possible in 1 consultation

**Table 5. Questions for support in end-of-life decision making**

End-of-life decision making	2003	2004	2005	Total
Palliative sedation	25 ( 8%)	76 (20%)	100 (22%)	201 (11%)
Euthanasia	4 ( 1%)	20 ( 5%)	35 ( 8%)	59 ( 3%)
<b>Total</b>	<b>29 ( 8%)</b>	<b>96 (23%)</b>	<b>135 (27%)</b>	<b>260 (14%)</b>

No systematic registration in 2001-2002

## Discussion

Five years of experience of the Telephone Helpdesk (TH) shows an obvious need for support of general practitioners in the management of physical symptoms, pharmacological issues and end-of-life decision-making of patients with advanced and terminal cancer treated at home. In line with previous studies in the Netherlands<sup>6,12,18</sup> and other European countries<sup>1,4,8</sup>, we found that most questions related to patients treated at home with a (very) short life expectancy. After a period of more than 5 years the TH receives a still increasing number of questions; this 5 year 'survival' of a consultation service is seen as crucial for success<sup>3</sup>.

Few other doctors than GP's and few community nurses consulted the TH. The lack

of requests for consultation from doctors from nursing homes and hospitals may be explained by the availability of institution based protocols, internal possibilities for consultation and ongoing collaboration between medical and other disciplines. Nurses working in community care should encounter serious problems in palliative care. The lack of consultations on their part may be explained by the availability of a network of advanced nurse practitioners and clinical nurse specialists and/or reluctance in seeking advice without involvement of the GP.

In the Netherlands the general practitioner is considered to be the coordinator of palliative care for cancer patients<sup>19</sup>. It has been argued that cancer patients may suffer unnecessarily due to insufficient knowledge of doctors caused by lack of training during the medical study and lack of experience in daily practice<sup>2,19</sup>. Schuit and colleagues studied the efficacy of an educational intervention on symptom control for GPs<sup>19,20</sup>. The effects were significant, but small.

Considering the low number of psychosocial issues discussed during the consultations and the absence of questions about spiritual issues, it seems that requesting GPs focus on symptom control and the organization of care. This could reflect the long relationship GPs have with their patients, support not being necessary because of the familiarity with the patients' coping mechanisms and their social network. In addition, GPs could assume that the consultants of the TH have more expertise on physical than on psychological, social and spiritual issues. It may also be assumed that consultation by telephone is not suitable to address psychosocial and spiritual issues and that bedside consultation is necessary for a more comprehensive approach.

The possibility of a bedside consultation is available for the majority of other palliative care services. Before the start of the TH in 1999 the needs for consultation of professionals in the region were explored by a questionnaire and interviews. The outcome clearly showed that there was no need for bedside consultation. During the following years, after completion of each consultation, an evaluation questionnaire was sent to the requesting professional. One of the questions referred to the possibility for bedside consultation; only a minority of the respondents would appreciate a bedside visit by the TH consultant. However, analysis of the differences between telephone and bedside consultation by Schrijnemaekers and colleagues showed that most 'telephone patients' were at home (most questions came from GPs), and most 'bedside patients' were treated in hospital (most questions came from nurses and medical specialists)<sup>ref</sup>. Several hospitals in de the region of the CCCMN have the disposal of a palliative care team for bedside consultation within the hospital. Until now, the TH remains reluctant to extend their service, but does not preclude the possibility for bedside consultation in the future.

Palliative sedation is used frequently in the Netherlands<sup>15</sup>. Approximately 48% of all

GP's in the Netherlands has used palliative sedation at least once. In the guidelines used by the TH5 this topic is also addressed. During the study period a national guideline was developed<sup>17</sup>. During the first two years of our study questions concerning this topic were not registered separately, but included in the category 'other questions'. Over the last three years of the TC registered an increasing number of consultations about palliative sedation. With regard to euthanasia, the TH has never given advice. For this purpose, the (compulsory) consultation may be provided by a nationwide project 'Support and consultation on euthanasia in the Netherlands (SCEN)'<sup>10</sup>. The consultation of the TH regarding euthanasia dealt usually with the question whether patients requesting euthanasia had received optimal palliative care.

As there is no standardized follow-up contact with requesting professionals or patients, the effectiveness of the consultations on a patient level could not be assessed. Therefore, the question of the impact of the consultations on patient well-being remains to be addressed. Proving the efficacy of palliative care has been recognized as an ethically and methodologically trying theme world-wide<sup>1,14,16</sup>. How to include some indicators of success based on patient parameters has been under debate for several years<sup>19,20</sup>. Due to the working method of the consultation service, advices are given to the requesting professional without becoming a secondary attendant and without a request for report about the effect of the consultation. Thus, in this model, measuring patient outcomes would interfere with the working principles. For the future, we believe that assessment of the effectiveness of consultation, based on patient outcomes such as symptom intensity and quality of life, are still needed in evaluation studies of consultation services. Alternatively, competencies of professionals could be measured<sup>20</sup>.

After more than five years our TH has not been able to reach all the professionals involved in palliative care for cancer patients in our region. Thus, the primary goal to realize an integrated system of palliative care has not been achieved. Despite this, the findings of this study clearly show that a 24-hour telephone consultation service fulfills a need for GP's for help with the daily dilemmas of palliative care treatment at home. In addition, members of the TH provide continuing education concerning symptom management to the regional palliative care networks, which have been established over the past years. It is our belief that both consultation and education will result in improvement of care for dying patients at home in our region.

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