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*How do GPs identify a need for palliative care in their patients?  
An interview study*

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Susanne J.J. Claessen, Anneke L. Francke, Yvonne Engels, Luc Deliens

Submitted

## **ABSTRACT**

### **Background**

Little is known about how GPs determine whether and when patients need palliative care. Little research has been done regarding the assumption underpinning Lynn and Adamson's model that palliative care may start early in the course of the disease. This study was conducted to explore how GPs identify a need for palliative care in patients with cancer or other chronic diseases and in frail elderly.

### **Methods**

A qualitative interview study was performed among 20 GPs in the Netherlands.

### **Results**

GPs reported that a combination of several signals, often subtle, made them identify a need for palliative care: signals from patients (increasing care dependency and not recuperating after intercurrent diseases) and signals from relatives or reports from medical specialists. GPs reported differences in how they identified a need for palliative care in cancer patients versus those with other diseases. In cancer patients, the need for palliative care was often relatively clear because of a relatively strict demarcation between the curative and palliative phase. However, in patients with e.g. COPD or in frail elderly, GPs' awareness of palliative care needs often arises gradually, relatively late in the disease trajectory. GPs consider the diagnosis of a life-threatening illness as a key point in the disease trajectory. However, this does not automatically mean that a patient needs palliative care at that point.

### **Conclusions**

GPs recognize a need for palliative care on the basis of various signals. They do not support the idea underlying Lynn and Adamson's model that palliative care always starts early in the course of the disease.

## BACKGROUND

Today, relevant policy makers and other experts are increasingly aware that palliative care is a broader concept than terminal care. In 2003, a 'model' of palliative care was introduced by Lynn and Adamson<sup>1</sup> that underlined the necessity of an early start of palliative care. Initially, curative, disease-modifying and life-prolonging treatments may be given alongside palliative treatments, with a gradual shift to an emphasis on palliation. However, previous studies in Belgium and the Netherlands indicated that in practice the shift from curative and life-prolonging treatments towards palliation often occurs at a late stage in the disease trajectory<sup>2,3</sup>, suggesting that sometimes GPs or other relevant professionals only recognize patients' need for palliative care late in the disease trajectory.

Nowadays there is also an increasing awareness that palliative care is not only for patients with incurable cancer but also for patients with COPD, heart failure or dementia, for instance. GPs' recognition of a need for palliative care may be different for cancer patients than for patients with other diseases since disease trajectories vary.<sup>4,5</sup> Lynn and Adamson have described three common disease trajectories.<sup>1</sup> First, there is a trajectory often seen in cancer patients, characterized by a relatively short period of evident decline, a rather clear demarcation between the curative and palliative stages and a foreseen death. In contrast, the disease trajectory of patients with heart failure or COPD is often characterized by long-term limitations, intermittent exacerbations and remissions, resulting in a relatively sudden death. In frail elderly there is often a prolonged gradual deterioration towards death. Various disease trajectories can therefore be distinguished that may be related to variations in the timing and nature of the recognition of a patient's need for palliative care. However, few studies have been conducted to date on GPs' recognition of their patients' need for palliative care.<sup>6</sup>

The scarcity of research literature on GPs' recognition of a need for palliative care is remarkable, since GPs often have a long 'history' with the patient and family and also play a pivotal role in palliative care. In the Netherlands, for example, palliative care is mainly provided by 'general' health care professionals, like the GP and home care professionals, to guarantee that this care is accessible for everyone who is in need of it. Hence, palliative care is integrated into the regular healthcare system, in which GPs function as

gatekeepers for specialized care services and as family doctors. Considering GPs' pivotal role in palliative care this qualitative study was conducted to explore how GPs recognize a need for palliative care in various patient groups.

The specific research questions addressed in this paper are:

1. How do GPs recognize a need for palliative care?
2. Does this recognition generally arise in the diagnosis stage or in later stages of the disease trajectory?
3. Are there any differences in the timing and nature of GPs' recognition of the need for palliative care between:
  - a. cancer patients;
  - b. patients with other chronic diseases, for example heart failure or COPD;
  - c. frail elderly?

## **METHODS**

### **Sample and recruitment**

GPs were recruited in several ways. First, GPs who had participated in a previous survey about palliative care in general practice had been asked whether they were also willing to be interviewed. Secondly, GPs were recruited by 'snowball sampling' and via the researchers' personal networks. Purposive sampling was conducted to guarantee variation in background characteristics such as age, gender, experiences with palliative care, degree of urbanization and kind of practice.

Recruitment of GPs stopped after data saturation was reached (i.e. no additional themes relevant for answering the research questions emerged during additional interviews and subsequent data analysis).

### **Ethical procedures**

According to Dutch law, approval by a medical ethics committee is not needed for non-experimental interview data involving competent adults. The anonymity of the GPs was strictly preserved throughout the data entry and analysis process. All GPs were given verbal and written information about the aim and scope of the interviews and all GPs gave written informed consent.

## Interviews

The interviews were semi-structured with a topic list. The topics included the GP's own definition of palliative care, and their recognition of the need for palliative care in cancer and other patients. The main interview questions related to these topics were: "Can you describe your patients who currently receive palliative care and the care you give them", and "How did you recognize that these patients had a need for palliative care?"

The interviews were audio taped, transcribed verbatim and rendered anonymous.

## Analysis

As usual in qualitative research, data analysis started after the initial interviews were conducted as part of a cyclical process of data collection - data analysis - new data collection, et cetera.

The first author (SC) analyzed all the interview transcriptions, while the second author (ALF) analyzed half of the interviews. Both authors independently summarized their individual analyses in 'memos' describing important findings from each interview. These memos were compared, and any apparent disparities were discussed until agreement was reached.

In addition, the interview transcripts were systematically coded by the first author, initially by 'open coding' of text fragments. Open coding is the stage in the analysis concerned with identifying, naming and categorizing phenomena found in the text. Subsequently, 'axial coding' was done. Axial coding involves looking for connections between categories of codes. Ultimately, 'selective coding' took place: one core concept (viz. subtle signals from patients) was determined and related to other categories. The coding process was supported by the Atlas.ti program.<sup>7</sup> This software program sorts relevant fragments and links these to other fragments with the same codes within a single interview and in other interviews. Results of the interim and final analyses were reported and discussed during meetings with the other co-authors.

## RESULTS

### Participating GPs

We conducted qualitative interviews with ten male and ten female GPs between spring 2011 and spring 2012. Mean interview duration was about 50 minutes. Mean age of the GPs was 48 years (range of 30 – 62). GPs on average worked 38 hours a week (range 20 – 60). There was a mix of GPs working in group practices (n= 17) and in one-person practices (n= 3). The practice location areas ranged from highly urbanized regions (n= 11), slightly urbanized (n= 5) and less urban/rural regions (n= 4).

### INTERVIEW RESULTS

#### GPs' views on the start of palliative care

GPs mainly associate palliative care with a relatively circumscribed period of a few weeks or months in which incurably ill people need a great deal of physical, psychosocial and spiritual care. Some GPs add that they realize palliative care may start years before death in the case of certain chronic diseases such as COPD or heart failure. However, the immediate association is still with a limited period at the end of life in which the patient (and often their close relatives) make increasing demands on the GP, care needs become more intensive, and contacts become more frequent.

*(GP 10, male): Well, I think my feeling is that the palliative phase starts when the care needs start to get more intensive. So when you notice that contact isn't just once every three months... just asking hey, how's it going, if that shifts to more intensive care, where your help is demanded on a more regular basis or where you feel perhaps I should pop in more often to keep an eye on things, to my mind that is a kind of start to the palliative phase.*

While GPs do see palliative care as more than just terminal care, and some are clearly familiar with Lynn and Adamson's model (see introduction), that is not sufficient reason for them to start using the term palliative care right from the moment of diagnosis. Nevertheless, GPs do see the diagnosis phase as an important phase, and they offer support to the patient and relatives to cope with the diagnosis. However, GPs feel there is little to be gained from seeing this as the start of palliative care, especially as many people with cancer, for example, will eventually recover. Patients are often not yet dependent on healthcare in the early stage of a life-threatening disease, and

in such situations GPs feel it does not make sense to talk of 'palliative care'.

*(GP 19, female) Well yes... if it really is about people with COPD or people with heart failure and so on – and I think these are mainly the people we are talking about, or people with muscular conditions – even though you know someone is eventually going to die from this there is a long period before dying, you can say it's really a chronic disease. You know they will eventually die from it. I find it difficult to say whether you should call that entire period palliative care. Well... as I said, well we discussed it earlier when I said that I'm not thinking about that, I don't start offering different care because it's suddenly called palliative care or chronic care. Because you always try just to make things as comfortable as possible for the patient. So perhaps the label applied to it is just not so important. That's my feeling... why should you call it that?*

It is often not the diagnosis but a combination of generally subtle signals that prompts GPs to consider palliative care needs. These signs come initially from the patient, frequently in combination with reports by other care professionals and close relatives. We explain the different signs below.

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## Subtle signals given by patient

### ***Changes in self-care abilities and care dependency***

The recognition of a need for palliative care is often a gradual process steered by a combination of signals. One key signal is a reduction in a patient's self-care ability, in the sense that it costs a patient an increasing amount of effort to look after himself. Often, a patient also becomes increasingly bedridden and dependent on care by relatives and professionals. The care needs addressed to the GP also become more frequent and more intense. A patient who always used to come to the GP practice may suddenly request a home visit. Two GPs describe increasing healthcare demands in the interview excerpts below.

*(GP 3, male): 'It starts when the care need increases.*

*Interviewer: Could you explain that?*

*Well, as a patient you obviously try to keep to your old lifestyle as much as possible. And if you have to give that up and ask for help because you can no longer manage to eat or sleep or because of the pain, that is the point when*

*you can give a patient support.'*

*(GP 1, female): 'Yes, there are different kinds of palliative care. And the real palliative care is the final stage as it were, because then more care is needed from the people around them or from outside. And if someone becomes progressively dependent on others. I think that this... is so for various activities of daily living, that they can no longer do themselves.'*

### ***Not recuperating***

Not recuperating fully after an additional condition, such as bladder infection, is also a signal for GPs that they need to monitor this patient particularly closely. Normally people should be back to normal, but the anticipated recovery never happens or is only partial, and this is a signal for GPs that their patients are 'sliding' into the palliative phase.

*(GP 4, female): 'These are people who sometimes don't recuperate after a particular condition as you expect – hey, I treated that bladder inflammation and... so it is partly a case of expectations and knowing that if I treat that condition they should recuperate after a certain period. Then someone should be back to normal, but look, they're not. And that's often the start.'*

### ***Social changes***

Social changes are also a signal for GPs that there is a need for palliative care, for example if people become withdrawn, less focused on contacts beyond their close relatives and no longer get pleasure from hobbies or going out. Life becomes more 'existential' in the sense that they concentrate on the people and things that are most important to them, and focus on closure and taking leave of life.

## **Signals from close relatives**

GPs also often get signals from close relatives. A partner or other close family member will often report deterioration in the patient's situation or say that the burden of care is becoming very heavy and that they need to discuss matters.

*(GP 9, male): 'Yes, or the family carers for example. They may well be the biggest source. You see the family carer, who often ends up dealing with*

*most of the demands for help and care, and they say, well, I'm finding it a bit too much, I'm finding the going too tough, I need someone I can discuss things with now and then. And you see the family carers are often just as pleased with a GP who visits regularly as the patients themselves are. So they also play an important part.'*

## **Reports by other professionals**

Another signal for GPs that a patient may require palliative care is a message from the medical specialist that cure is not, or no longer, a possibility. This is also the point at which the medical specialist refers the patient back to their GP, who once again becomes the primary treating physician.

*Interviewer: 'If you now think more generally about patients who require palliative care, how do you recognize their need for that care?*

*(GP 3, male): The need that arises or comes automatically if people are discharged from hospital or if they say there is nothing more we can do for you. That's really when it begins...'*

The home care organization may also sound the alarm. For instance, the district nurse may phone the GP to say there are problems with the patient, the family is overburdened and something needs to be done. A signal like that in combination with other signals alerts a GP and makes them feel there is a need for palliative care.

### ***Differences in recognition of palliative needs for different conditions***

GPs mention differences in the recognition of a need for palliative care depending on the conditions people are suffering from. There is often a relatively clear demarcation between the curative and palliative phases for cancer patients, as a medical specialist will say curative treatment is no longer possible. An additional factor is that the diagnosis of cancer is often experienced as a 'bombshell' by the patient, their close relatives and sometimes even the GP. Even if GPs feel that palliative care does not automatically start with the diagnosis, in the case of cancer everyone is aware of the real chance that the patient will die. As a result, the option of palliative care is on top of mind at an earlier stage than is the case for many chronic diseases.

*(GP 10, male): 'Usually it's the case that as soon as they have had the diagnosis, people start to think this could well mean I die and I am still so young. Or fine, I've had a good life, I have to die of something... but at any rate they'll be aware they might die when they get the diagnosis. So that's a totally different process. So I feel these people often... of course they sometimes also get the shock of seeming to have completely recovered and then they collapse again. But of course often people... the attempts at a cure don't work out and they gradually get reconciled to the idea. And then it's a very clear process, then they are thinking about it. And for you as a doctor... these are very intensive things... but I do think there is a certain clarity.'*

GPs explain that it is often more difficult to predict how other chronic, ultimately terminal conditions will progress compared with cancer. People with COPD, heart failure or Parkinsonism are often still being treated by a medical specialist in the final stages. They do not have a clear point where the medical specialist says there are no more treatment options. In the excerpt below, a GP explains how he often gradually becomes aware of a need for palliative care.

*(GP 9, male): 'Well, as I said, it is relatively somewhat easier with cancer patients because then you often get a message from the hospital that the curative treatment has failed, so then you know that from that moment on these people are officially palliative. Although certainly at first we often don't get that involved. And in the case of COPD or heart failure and so on it's more of a question of noticing at a particular point, well, we seem to be doing palliative things, without it being an explicit decision, but more that you... yes, there comes a point where the policy gradually changes... and there comes a point when you realize, yes, we really are giving palliative care.'*

GP also often have the feeling with frail elderly patients who eventually die following a general physical and cognitive decline that patients slowly, gradually veer off into 'a palliative process'. They describe this as a natural development, the 'circle of life'. A GP explains:

*(GP 8, male): But after they get to 85 or so, lots of people are finished with life, or no longer see it as a real... yes, as a diversion that they are going to die or that it is coming to an end. They're finished with life, so dying is a very*

*natural thing. And then you don't have so much of an explicit feeling of now we are going to opt for palliative care.'*

## DISCUSSION

### Summary of main findings

GPs recognize a need for palliative care on the basis of various, often subtle signals. An important signal is a rise in a patient's care dependency, in the sense of an increasing need for help in daily functioning and a growing reliance on family members and professionals. In addition, not recovering after intercurrent diseases may be a signal that there is a need for palliative care. These signals are often accompanied by reports by family members, home care professionals and medical specialists. Thus, GPs take into account the patients' context and environment when recognizing palliative care needs.

We found differences between recognizing palliative care needs among patients with cancer, patients with other chronic diseases and the frail elderly. In cancer patients, the demarcation between the curative and palliative phases is often relatively clear for GPs. In the case of these patients, the medical specialist informs the GP when curative treatments are not an option or have been stopped. Then the patient is referred from the medical specialist to the GP and a palliative care policy is started. This makes it relatively easy for GPs to demarcate the need for palliative care. However, in patients with chronic diseases such as COPD and heart failure, the course of the disease is often less predictable and patients continue to be treated both by a medical specialist in the hospital and their GP. Consequently, recognition of the need for palliative care often arises gradually. Furthermore, in the case of frail elderly where physical and cognitive functions deteriorate steadily, GPs experience the gradual decline as the normal course of life. Therefore, recognition of the need for palliative care also arises gradually.

Currently, experts like Lynn and Adamson consider the palliative phase as a care continuum which starts early in the course of a life-threatening illness.<sup>1,8</sup> Dutch GPs also consider the diagnosis stage as an important stage in the patient's disease trajectory. However, they do not necessarily see the

diagnosis as the starting point for palliative care. Although GPs may give support at the time of the diagnosis, they do not call it palliative care as long as cure is still a possibility or as long as patients are not care-dependent. They see no added value in talking about 'palliative care' when cure is still an option or when the patient does not need much care.

In line with Lynn and Adamson<sup>1</sup>, Fitzsimons et al. pointed to the necessity of embracing the palliative care approach at an early stage in order to address the needs of patients with life-threatening chronic illnesses.<sup>9</sup> Our findings indicate that Dutch GPs have a somewhat different view and that they do not think that palliative care always starts early in the disease trajectory. They identify the need for palliative care on the basis of a variety of often subtle signals from the patient, combined with signals from relatives and other professionals. GPs do give support around the diagnosis, but they do not want to designate this as palliative care. Some of them also indicated that the word 'palliative' in communication with a patient who is still living life to the full, is also not a very useful term.

### **Strengths and limitations**

So far, little empirical research had been conducted regarding the assumption that palliative care should start early in the course of the disease. Our research seeks to close this gap. Most previous palliative care research has focused exclusively on patients with cancer.<sup>10-12</sup> A strength of this study is that it also focuses on GPs' experiences with other (growing) patient groups, such as the frail elderly and people with chronic non-cancerous diseases. This study was based on qualitative interviews. Qualitative interviews provide 'rich' detailed data on subjective experiences and views. Qualitative methods are recommended when research topics are relatively unexplored and no structured measurement instruments are available, as was the case in our study. However, qualitative designs have limitations regarding generalizability and the external validity of the findings.

### **Implications for research and practice**

Future quantitative research is recommended in which the hypotheses derived from this qualitative study are tested with a larger group of GPs. This would provide a more complete and generalizable picture of the recognition by GPs of the need for palliative care. In addition, it would be interesting to combine and compare multiple perspectives in a future study: those of the

patients, the family members, the GPs and of other professional caregivers.

The interview study indicated that GPs prefer to avoid the term 'palliative' as long as they have not received signals from the patient that he/she is in need of palliative care or if curative treatments are still possible. Nevertheless, GPs often give support even in the early stage of the disease trajectory, when the patient has just heard the life-threatening diagnosis. It is recommended that discussions should be initiated on the use of the term 'palliative' or options for alternative terms, for instance in the training and education of healthcare professionals. The education and training of GPs could also include further discussion of what attitude GPs should take in palliative care. It is known from other recent research that Dutch GPs in general have a reactive rather than a proactive attitude in the interaction with their patients<sup>13</sup>, since GPs assume that the patient should say what kind of support they want from the GP and what kind of problems they have. GPs do not want to patronise their patients or give care that is not needed. However, a more proactive approach, e.g. with the GP taking initiatives for advance care planning, may result in a better match with patients' and family members' existing and evolving care needs.

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