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GPs' identification of the diagnosis and of imminent death in patients who died non-suddenly: a national survey

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ABSTRACT

Background
Nowadays, palliative care is considered as a care continuum that may start early in the course of the disease. In order to address the evolving needs of patients for palliative care in time, GPs should be aware in good time of the diagnosis and that death is imminent. The aim of the study was to gain insight into how long before a non-sudden death the diagnosis of the disease ultimately leading to death is made and on what kind of information the diagnosis is based. In addition, we aimed to explore when, and based on what kind of information, GPs identify imminent death.

Methods
A written questionnaire focusing on the GPs' experiences with their last patient who died non-suddenly was sent to a random representative sample of 850 GPs in the Netherlands.

Results
The data were analysed of the 297 GPs who responded. 76% of the reported cases were cancer patients and 24% were patients with another non-sudden cause of death. The diagnosis was made only in the last week of life for 15% of the non-cancer patients and 1% of the patients with cancer. GPs were most likely to have been informed of the diagnosis by the medical specialist, although particularly in the case of non-cancer patients GPs also relied on their own assessment of the diagnosis or on other information sources.

The GP remained unaware of the imminence of death until the last week before death in 26% of the non-cancer group, while this was the case for only 6% of the cancer patients. The recognition that death was imminent was most likely to be based on the GP's own observations of problems and/or symptoms.

Conclusions
The GP often only becomes aware of the diagnosis and imminent death at a late stage in the disease trajectory, particularly in the case of non-cancer patients. It can be assumed in cases where the diagnosis and imminent death are only recognised at a late stage that palliative care is either started at a very late stage or not at all.

BACKGROUND

Nowadays, care providers, policymakers and researchers are increasingly aware that palliative care is broader than terminal care. Figure 7.1 shows the 'model' of Lynn and Adamson (2003), displaying palliative care as part of a care continuum that starts early in the trajectory of a chronic illness and that ends with the death of the patient and aftercare for relatives.[1]

Figure 7.1. Palliative care as a care continuum (Lynn and Adamson 2003).
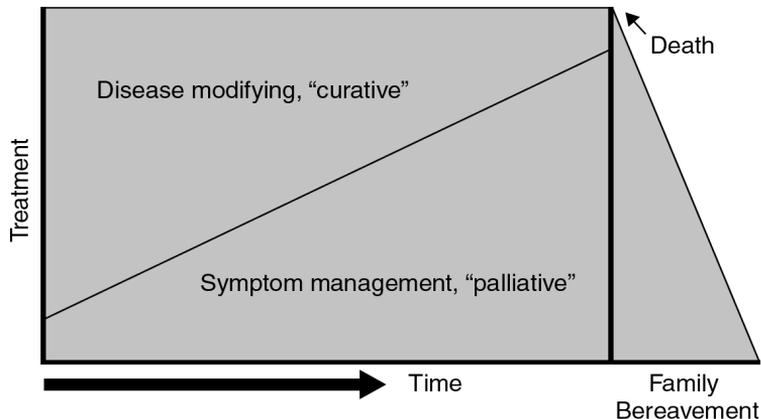
Timely diagnosis of a life-threatening disease as well as timely recognition of imminent death may be important in order to anticipate the frequent increase in symptoms and problems, to prevent crises, and to better meet patients' needs for palliative care. Because the GP is a key professional in palliative care[2,3], it is important that she/he is aware in good time of a diagnosis of a life-threatening condition and of imminent death.

To our knowledge, no previous studies have been conducted on what kind of information GPs use and in what phase of the illness trajectory GPs become aware of the diagnosis. Yet some studies have been conducted on identifying imminent death.[4,5] Sullivan et al. performed secondary analyses of interviews with hospital physicians.[5] They explored whether and when physicians reported that death was imminent. They found that 38% of physicians were uncertain when the patient was admitted whether the patient would die during this hospitalisation, but over the course of hospitalisation 86% reported that they knew that death was imminent. Eleven percent of physicians reported anticipating the patient would die weeks before the

death, 57.1% days before, and 18.3% hours before the death. Earlier recognition of imminent death was associated with greater reported overall satisfaction of the physicians with the end-of-life care provided to the patient. Furthermore, Abarshi et al. investigated how long before death GPs recognise that patients were likely to die in the near future.[4] They reported that GPs never recognised that death was imminent in about a third of their patients with a non-sudden death.[4] However, the study of Abarshi et al. did not explore which sources of information the GPs used to identify the imminence of death.

In addition, so far it has remained unclear whether there are differences between cancer patients and other patients with a non-sudden death cause regarding the 'when and how' of GPs' identification of the diagnosis and of impending death. However, common disease trajectories differ between patient groups[6-8], which may also have consequences for GPs' awareness of the diagnosis and the identification of impending death. Lynn and Adamson and also Murray distinguished three common disease trajectories leading to a non-sudden death.[1,9] First there is the common illness trajectory of patients with cancer, which is reasonably predictable and usually characterised by a clear terminal phase. In contrast, trajectories in patients with COPD or heart failure are often characterised by intermittent exacerbations and remissions and a relatively sudden death. In the frail elderly, such as people with dementia, there is often a prolonged gradual decline towards death.
Since disease trajectories vary, it can be expected that the timing of the recognition of the diagnosis and of the imminence of death are also different.

We conducted this study among a random sample of GPs in the Netherlands in order to gain more insight into the 'how and when' of GPs' identification of the diagnosis and of the recognition of imminent death. The following research questions are addressed:

1. How long before death is the diagnosis of a disease ultimately leading to death made in cancer patients and in patients with another non-sudden cause of death?
2. On the basis of what kind of information sources do GPs become aware of the diagnosis of the disease leading to death?

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3. How long before their patients die do GPs recognise that death is imminent in cancer patients and in patients with another non-sudden cause of death?
4. On the basis of what kind of information sources do GPs recognise that death is imminent?

METHODS

Design
A retrospective cross-sectional design was used based on survey data.

Study population and setting
A random sample of 850 Dutch GPs participated in this survey. The sample was drawn from a national registration base (NIVEL) with the addresses and background characteristics of all GPs working in the Netherlands.

Pilot and content of the questionnaire
The content of the questionnaire was largely based on existing questionnaires: in particular a questionnaire about end-of life care by GPs[10-12] and a registration form used by GPs participating in the Dutch Sentinel General Practice Network.[13] GPs were asked to base their answers on the case of their last patient with a non-sudden death. We explained in the questionnaire that this could be a patient who died of cancer, heart failure, COPD, stroke, dementia, other chronic diseases or "gradual decline because of frailty and old age''.

Face validity, content validity and comprehensibility of the draft questionnaire were assessed by the steering committee, which included three scientists in the field of end-of-life care and two GPs. The usability and comprehensibility were tested further among ten other GPs. This resulted in some minor revisions, e.g. regarding the time period to which questions relate. The final version of the questionnaire consisted of 44 semi-structured questions. The questions that are used for the analysis in this paper (translated from Dutch to English) are presented in Box 7.1.

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The random sample of 850 GPs received the final questionnaire, together with an explanatory letter and return envelope, in the summer of 2010. Reminders were sent after four weeks and seven weeks.

Box 7.1   Questions that are used for the analysis in this paper

1. What was the underlying disease leading to death? Only one answer possible.
   ❑ Cancer, namely ❑ lung ❑ bowel ❑ breast ❑ prostate❑ other,
      namely ....
   ❑ Heart failure
   ❑ Asthma/COPD
   ❑ Stroke
   ❑ Dementia
   ❑ Slow decline because of old age
   ❑ Other, namely ....
   ❑ Unknown

2. How long before death was the diagnosis made of the disease that ultimately led to the patient's death?
   ❑ ≤ 7 days before death
   ❑ 1–4 weeks before death
   ❑ 1–3 months before death
   ❑ 4–6 months before death
   ❑ 6–12 months before death
   ❑ 1–2 years before death
   ❑ More than 2 years before death
   ❑ I don't know
   ❑ Not applicable because ....

3. How did you become aware of the diagnosis? Multiple answers possible.
   ❑ Information from the medical specialist(s)
   ❑ Own diagnostics
   ❑ Patient him/herself
   ❑ Relative(s)
   ❑ Other, namely ....
   ❑ I don't know
   ❑ Not applicable because ....

4. How long before death did you know that death was imminent for this patient?
   ❑ ≤ 7 days before death
   ❑ 1–4 weeks before death
   ❑ 1–3 months before death
   ❑ 4–6 months before death
   ❑ 6–12 months before death
   ❑ 1–2 years before death
   ❑ More than 2 years before death
   ❑ I don't know

5. How did you know that death was imminent for this patient? Multiple answers possible
   ❑ Through problems and/or symptoms that the patient had and that I myself identified as the GP
   ❑ Through information from the medical specialist(s)
   ❑ Through information from home-care professionals
   ❑ Through information from the patient's relative(s)
   ❑ Other, namely ....
   ❑ Not applicable because ....

Statistical analysis

All questionnaires were scrutinised for errors and missing data, and the data were digitised by scanning. A random sample of 15 questionnaires was checked for errors arising during scanning. No errors were found.

Descriptive analyses and Chi-square analyses were used to answer the research questions addressed in this paper. A Fisher exact test was used instead of a Chi-square test if the expected value for one or more of the cells was less than five.

Ethics

GPs received information about the aim and content of the research in an explanatory letter, which was sent together with the questionnaire. The anonymity of the GPs and their patients was strictly preserved throughout the data entry and analysis process.

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According to Dutch law, no approval of a Medical Ethics Committee is needed for surveys among care professionals and for post-mortem anonymous patient data.

RESULTS

Response

Seventeen questionnaires were returned as 'undeliverable' (mainly because the address was unknown or incorrect), four other questionnaires were returned uncompleted because the GP was absent due to long-term illness or maternity leave and eleven were returned uncompleted because the GP had no experience with palliative care. Hence, 818 of the 850 GPs in the sample were considered eligible for this study. A total of 297 questionnaires were completed and returned (the net response rate was 36%, i.e. 297/818). About half of the respondents (47%) were aged between 40 and 54. The majority were male (57%) and 86% worked in a two-person or group practice (Table 7.1).

No differences between non-respondents and respondents were observed regarding gender, age, whether or not the GP had a solo practice, and degree of urbanisation (Table7.1).

Table 7.1   Characteristics of sample of GPs in percentages

	Sample		
	Non-respondents (n=521)	Respondents (n= 297)	P-value*
Gender Male Female	 58.5 41.5	 57.2 42.8	0.717
Age 25-39 40-54 ≥ 55	 25.0 46.8 28.2	 27.0 47.2 25.9	0.720
Solo practice Yes No	 17.9 82.1	 14.1 85.9	0.169
Degree of urbanisation Extremely urbanised / strongly urbanised Moderately urbanised Hardly urbanised / not urbanised	 47.2 18.8 34.0	 45.1 20.5 34.4	0.787

*Chi-square analysis

Characteristics of the deceased patients dealt with in the GPs' questionnaires

Of the 297 patients described by the GPs as being their last patient with a non-sudden death, 153 were female (52%). The median age at death was 72 (range: 39–103). The majority (76%) died from cancer, while 24% had another non-sudden cause of death such as heart failure (33%), general decline because of old age (27%), asthma/COPD (9%), dementia (6%), amyotrophic lateral sclerosis (4%), renal failure (4%), stroke (1%), other (11%), and an unknown non-cancer cause of death (6%). 70% of the patients died at home, 13% in a care home and 10% of the patients died in a hospital.

Time between the diagnosis of the disease ultimately leading to death and the death

Table 7.2   Timing of the diagnosis of the disease ultimately leading to death and sources of information

Timing of diagnosis of disease ultimately leading to death	Cancer n=220** %	Non-cancer n=65** %	P-value*
In last six months before death (also including last month and last week)	41	49	0.234
In last month before death (also including last week)	6	29	**<0.001**
In last week before death	1	15	**<0.001**
GPs' information about diagnosis was based on: (more than one answer possible)	Cancer n=226 %	Non-cancer n=71 %	
Information from the medical specialist	73	61	**0.046**
GPs' own diagnostics	35	49	**0.036**
Information from the patient	15	7	0.082
Information from relatives	3	13	**0.004**
Other	4	1	0.692
Doesn't know	0	0	–
Not applicable	0	3	0.143

*Chi-square analyses: significant differences between group with cancer and non-cancer group are in bold
**12 missing values, including 'don't know/not applicable' answers

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The diagnosis of the disease leading to the non-sudden death was made in the last six months of life (Table 7.2) in 41% of the group with cancer and 49% of the non-cancer group. The diagnosis was only made in the last month before death for 29% of the non-cancer patients versus 6% of the cancer patients (p<0.001). The diagnosis was only made in the last week before death for 15% of the non-cancer patients versus only 1% of the cancer patients (p<0.001).

In the case of 73% of the patients who died from cancer and 61% of the non-cancer patients (p<0.05) GPs learnt about the diagnosis through information from the medical specialist – whether or not combined with other sources of information (Table 7.2). Particularly in the case of non-cancer patients, GPs also relied on their own diagnostics for the diagnosis (49%, significant differences between cancer and non-cancer patients, p<0.05)) or information from relatives (13%, significant differences between cancer patients and non-cancer patients, p<0.01). In addition, GPs received information from the patients themselves about the diagnosis (Table 7.2).

Timing of GPs' recognition of imminent death and sources of information

In 86% of the group with cancer and 94% of the non-cancer group GPs' recognition of impending death was at some point in the last six months of life. GPs recognized that death was imminent in the last week before death in the case of 26% of the patients with a non-cancer death, versus 6% of cancer patients (Table 7.3, p<0.001). GPs realised during the last month that death was imminent for 30% of the cancer patients versus 60% of the non-cancer patients (P<0.001).

GPs' own observations of problems and/or symptoms was a source of information for the recognition of the imminent death of 78% of the patients who died of cancer versus 87% of the patients with another non-sudden cause of death. The medical specialist was a source of information for GPs' recognition of the imminent death of 53% of the cancer patients versus 28% of non-cancer patients (significant difference between cancer and non-cancer patients, p<0.001). Particularly in the non-cancer group, GPs also frequently used information from home-care professionals and information

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from relatives in the identification of imminent death (significant differences between cancer and non-cancer patients, see Table 7.3).

Table 7.3   Timing of GPs' recognition of imminent death and sources of information

Time between GPs recognition of imminent death and actual death	Cancer n=221** %	Non-cancer n=68** %	P-value*
In the last six months before death (including the last month and last week)	86	94	0.072
In the last month before death (including the last week)	30	60	**<0.001**
In the last week before death	6	26	**<0.001**
GPs' recognition of imminent death was based on: (more than one answer possible)	Cancer n= 225 %	Non-cancer n= 71 %	
GPs' observation of problems and/or symptoms	78	87	0.079
Information from medical specialist	53	28	**<0.001**
Information from home-care professionals	3	13	**0.002**
Information from relatives	15	27	**0.020**
Other	7	10	0.371
Not applicable	0	1	0.240

*Chi-squares analyses: statistically significant differences (P<0.05) between cancer and non-cancer group are in bold
**8 missing values, including 'don't know' answers

DISCUSSION

This study shows that the diagnosis was made for some patients only shortly before death. The diagnosis was not made until the last week of life in the case of 15% of the non-cancer group and 1% of the patients with cancer. Apparently, it is more difficult to make the diagnosis for patients with a non-cancer disease than for patients with cancer. The GPs' knowledge about the diagnosis was often based on multiple sources of information. For the majority of patients, GPs learnt about the diagnosis through information

from the medical specialist. GPs were more likely to rely also entirely or partly on their own diagnostics or information from relatives in the case of patients with diseases other than cancer.

In addition, our results show that GPs sometimes only became aware of the imminence of the non-sudden death late in the disease trajectory. The GP remained unaware that death was imminent until the last week before death in a quarter of the non-cancer group, while this was the case for only 6% of the cancer patients. This may be related to the fact that there is no clear diagnosis for some patients, such as the frail elderly with a general decline towards death. Another explanation may be that in the case of patients with COPD or chronic heart failure, for instance, the medical specialist has the main responsibility for the medical treatment of the patient until a late stage in the disease trajectory. If communication between the GP and medical specialists is poor, the patient's diagnosis may long be unknown to the GP, which hampers a timely start of palliative care provided by the GP.

The fact that GPs were asked to select their last patient with a non-sudden death may be related to the fact that GPs selected a relatively large number of cancer patients. Van der Velden reported in a death certificate study that about 77,000 people a year die from a chronic disease in the Netherlands. Just over half, 40,000 (52%), die from cancer.[14] In our study, 76% of the patients with a non-sudden death selected by GPs had cancer and 24% were non-cancer patients. Apparently, GPs associate a non-sudden death more with cancer than with a non-cancer disease. The relatively low proportion in our study of patients with stroke (1%) or dementia (6%) is particularly striking. One possible explanation for this under-representation might be that patients with stroke or dementia are more likely to die in nursing homes with their own nursing-home physician being responsible for medical care.

Recommendations for practice

The present study shows that particularly in the case of non-cancer patients, GPs sometimes remain unaware of a life-threatening disease and of imminent death until late in the disease trajectory. This may have consequences for advance care planning and timely anticipation of the evolving symptoms and care needs. In line with Fitzsimons et al.[15], we would like to point out the necessity of embracing the palliative care approach at an early stage of the disease in order to address the evolving needs of patients

with a life-threatening chronic illness in good time. Hence, a proactive attitude is required from GPs. From other recent research it is known that Dutch GPs in general have a reactive, rather than a proactive, attitude in the interactions with their patients.[16] GPs consider it important for a patient to indicate what support he or she needs and they do not want to patronise the patient or give care that is not needed. However, at the end of life a more proactive approach, e.g. involving initiatives by the GP for advance care planning, may result in better matching of patients' and family members' existing and evolving care needs.

Strengths and limitations

A strength of this study is that data are included about both cancer patients and patients with other chronic diseases and the frail elderly. Previous studies of palliative care have mainly focused on cancer patients.[17] However, the net response rate for the GP questionnaire was not high (36%), although comparable with other recent surveys among Dutch GPs.[18,19] It is known that Dutch GPs have a high workload[20], which may explain why the non-response in this group is often high. It could be that GPs with a specific interest in palliative care were more likely to respond, which may have led to overestimation of the GP's role in making the diagnosis and the identification of imminent death.

Another limitation of this survey is that it only involved GPs. It would also be interesting to explore the perspectives of medical specialists on making the diagnosis and on the communication about the diagnosis with the GP, patient and family. In addition, nurses or close relatives, for instance, may play an important role in the recognition of impending death, and are also an important information source for the GP. Future multi-perspective research on making the diagnosis of life-threatening diseases and on the identification of impending death is therefore recommended.

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