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Defining patients as palliative: Hospital doctors' versus general practitioners' perceptions[†]

M Farquhar, G Grande, C Todd and S Barclay Health Services Research Group, Department of Public Health and Primary Care, University of Cambridge, Cambridge

Abstract: There appears to be a lack of consensus on the classification of individual patients as 'for palliative care', although the extent of this is unknown. General practitioners (GPs) of 213 patients with a palliative diagnosis of lung or colo-rectal cancer were sent a one-page questionnaire to assess information sent by hospital doctors, and to establish the GPs' perception of patients' palliative status. A total of 185 questionnaires were returned (87% response rate). Of those GPs receiving information from the hospital, one in four rated the adequacy as less than positive; 26% reportedly received no information or received it 'too late'. In 20% of cases, GPs did not perceive patients as palliative, although hospital records suggested that they were, and death certificates received later potentially confirmed this. There was, however, no significant difference between GPs allocating a patient to palliative status or not, in terms of the promptness or adequacy of information received from the hospital, as rated by the GP. There was a significant difference in survival between patients whom GPs perceived as for palliative care and those they did not ('palliative' patients died, on average, 117 days earlier). Possible explanations of the differing perceptions of patient's palliative status are discussed. The findings have implications for patient care in the community, patients' informed choices, and palliative care research. *Palliative Medicine* 2002; **16**

Key words: communication; general practitioners; hospital doctors; palliative; patient status; primary-secondary interface

Resumé: Il existe un manque de consensus sur les catégories de patients qui relèvent des soins palliatifs, bien qu'on ne sache pas jusqu'à quel point. Les médecins généralistes (GPs) de 213 patients atteints de cancer pulmonaire ou colo-rectal en phase palliative, ont reçu un questionnaire d'une page permettant d'évaluer l'information envoyée par les médecins hospitaliers et de déterminer leur perception du «status palliatif» des patients. 185 questionnaires ont été remplis (taux de réponse de 87%). Parmi les GPs recevant une information de l'hôpital, 1 sur 4 la qualifiaient de moins que positive, 26% déclaraient n'avoir pas reçu d'information ou alors trop tard. Dans 20% des cas les GPs ne pensaient que leur patients étaient en phase palliative ce que l'hôpital leur indiquait pourtant et que venaient confirmer les certificats de décès ultérieurs. Cependant, d'après les GPs il n'y avait pas de différence significative dans l'appréciation du status palliatif des patients qu'ils aient rapidement et de façon adéquate reçu l'information de l'hôpital ou pas. Il existait une différence significative de la durée de survie selon que le patient était perçu par le GP en phase

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palliative ou pas (les «palliatifs» décédaient en moyenne 117 jours plus tôt). Nous discutons les causes à l'origine des différentes perceptions du status palliatif des patients. Les résultats ont des répercussions sur la prise en charge des patients par la collectivité, les choix éclairés des patients et la recherche en soins palliatifs. *Palliative Medicine* 2002; **16**

Mots-clés: palliatif; praticiens hospitaliers; médecins généralistes; interface primaire-secondaire; status du patient; communication

Introduction

General practitioners (GPs) have a pivotal role to play in the delivery of palliative care, as most patients with advanced disease are under their GPs' care during most of their illness.¹

There is a plethora of published definitions of palliative care and considerable debate on the interpretation of existing definitions. For cancer patients, palliative care has been defined as the 'active total care of patients whose disease is not responsive to curative treatment'.² More generically, palliative medicine has been defined as 'the appropriate medical care of patients with active and advanced disease for whom the prognosis is limited and the focus of care is the quality of life'.³ There is criticism of such segregation or temporal sequencing of curative followed by palliative care, with the proposition that palliation can be concurrent with curative interventions.^{4,5} Higginson describes how the concept of palliative care has broadened over time to include 'care of those who have a life-threatening disease but are not imminently dying, including people who have recently been diagnosed with advanced cancer and those who have other life-threatening diseases such as multiple sclerosis, motor neurone disease, AIDS, chronic circulatory, or respiratory diseases'.⁶

As the definition of palliative care is problematic at the abstract level, it is unsurprising that, anecdotally at least, there is lack of consensus between professionals on the classification of individual patients as 'for palliative care'. However, the extent of any lack of consensus is unclear. A series of studies has examined doctors' (poor) prognostic accuracy,⁷⁻¹³ but less is known of their recognition

and acknowledgement of patients' palliative status, which is a related, but separate, matter.

Methods

The recruitment process for a longitudinal study of patients with a palliative diagnosis of lung or colorectal cancer allowed for some exploration of the above issues. A total of 241 patients were identified as eligible for the study *via* copies of their outpatient consultation letter ($n=217$, 90%) or discharge summary ($n=24$, 10%). These were consecutive documents examined at one district general hospital. For the patient to be eligible, there had to be explicit reference to the need for palliation in the hospital notes (e.g., 'palliative right hemicolectomy' [ID No. 764] or 'palliative radiotherapy for incurable lung cancer' [ID No. 598]), or the disease staging of the patient had to be such that their palliative status was obvious to clinicians reading the notes (e.g., liver metastases with colorectal cancer). Thus, according to the information held by the hospital, these patients had incurable malignant disease and were, by any definition, for palliative care. The only other inclusion criterion was that due to the history and aims of the longitudinal study, patients had to be resident in the former Cambridge health district.

GPs of all 241 patients were sent a one page questionnaire appendix to: 1) assess the content and form of information from hospital (i.e., diagnosis, drugs, treatments, future management), and 2) to establish GPs' perceptions of patients' palliative status. Questionnaires were mailed approximately 1 week after the outpatient appointment or date of

discharge from hospital. The Office of National Statistics flagged the sample for deaths. Data were analysed using nonparametric statistical¹⁴ and regression techniques as appropriate, using SPSSpc.¹⁵

Results

Of the 241 patients, 28 were subsequently found to have died before the questionnaire was mailed to their GP, leaving a baseline sample of 213 patients for whom 185 questionnaires were returned (87% response rate). Of these 185, 117 patients (63%) died within 12 months, thus potentially confirming that they were for palliative care. With the exception of the Kaplan–Meier plot and Cox’s regression on survival, the analysis presented here is based on data from the 117 patients who were identified as palliative *via* hospital notes and for whom we received both a GP questionnaire and a death certificate confirming that death had occurred within 12 months.

GPs reported receiving a letter or discharge summary in 87% ($n=102$, 95% CI=79.7–92.6) of cases. In one case (1%), no letter or summary had been received at the time of questionnaire completion, but the GP reported having had a telephone call. In 14 cases (12%; 95% CI=6.7–19.3) GPs reported having received no information at the time of questionnaire completion. Of those who did receive information, 17 (17%; 95% CI=9.9–25.1) reportedly received it ‘too late’ (one did not answer the question). Overall, 26% of GPs ($n=31/117$, 95% CI=18.8–35.5) reportedly received no information or received it ‘too late’.

GPs were asked about the clarity of information received. Table 1 shows that in the majority of cases, communications did contain information regarding diagnosis, drugs/treatment, and future management (number of respondents ranged from 101 to 103 as two GPs did not answer all of the questions).

The GPs rated the adequacy of information received using a five-point scale (1 ‘totally inadequate’ to 5 ‘full and detailed’). Three quarters of GPs (75%, $n=77$, 95% CI=65.2–82.8) rated the information at 4 or 5, representing a positive rating of adequacy. However, this means that for one in four (25%, $n=26$, 95% CI=17.2–34.8), the rating was less positive.

Table 1 Information received by the GPs

Did the information you receive make the following clear	Percentage of cases of cases ($n=101-103$)	95% CI
<i>Diagnosis</i>		
Yes	97 (100)	91.7–99.4
No	3 (3)	
<i>Drugs/treatment</i>		
Yes	84 (85)	75.6–90.7
No	16 (16)	
<i>Future management</i>		
Yes	84 (85)	75.6–90.7
No	16 (16)	

Finally, GPs were asked whether they perceived the patient as ‘for palliative care’. We provided just two response categories – ‘yes’ and ‘no’. However, several GPs augmented these by writing on the questionnaire. In the majority of cases, GPs selected ‘yes’ (80%, $n=93$, 95% CI=82.9–95.2). However, a fifth chose other options: 8% ($n=9$) selected ‘no’, 7% ($n=8$) indicated that they were ‘uncertain’, and 5% ($n=6$) wrote ‘not yet’. Thus, in 20% of cases where hospital doctors had defined the patient as palliative and the patient subsequently died within 12 months, the patient’s palliative status was not recognised by their GP at the time of asking. Several of those who indicated that they were ‘uncertain’ wrote that this was because of a lack of information, e.g., ‘no idea – no info yet!’ (ID No. 688). However, there were no significant differences between GPs allocating a patient to palliative status or not, in terms of either the promptness or adequacy of information received ($P=0.897$ and 0.979 , respectively), as rated by the GPs. There were no significant differences in GPs allocating a patient to palliative status or not in terms of the patients’ diagnostic group ($P=0.154$).

The Kaplan–Meier plot of survival (Figure 1) for patients who died by a censor date of 7 July 2000 (i.e., not just those who had died within 1 year) and for whom we had received a GP questionnaire ($n=174$) reveals the significant difference in survival between patients that GPs perceived as for palliative care and those they did not (log rank test: 5.03, 1 *df*, $P=0.0249$). On average (median), patients perceived by GPs as for palliation died 117 days earlier than those they believed were not, or not yet, for palliation.

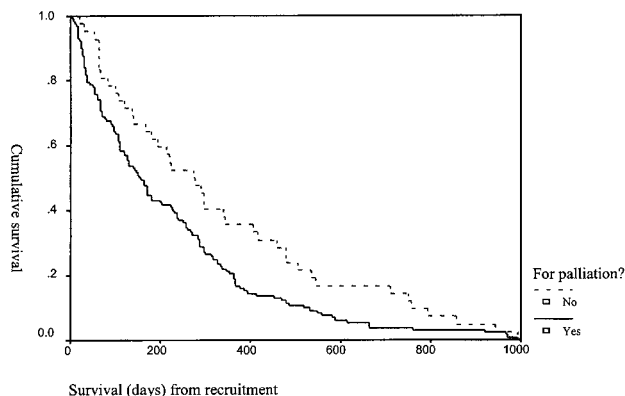


Figure 1 Survival function of GPs' classification of 'for palliation' for patients who had died by the time of analysis ($n=174$)

In a Cox's regression of the 174 patients entering age, sex, diagnosis, and 'for palliation' as independent variables and survival as dependent variable, the only significant predictor of survival was the GPs' perception of palliative status. Patients regarded as 'for palliative care' had a 1.55:1 hazard ratio of dying (95% CI: 1.07–2.25); age, sex, and diagnosis were not significant. Thus, whilst GPs may appear more reluctant than hospital doctors to define patients as palliative, when they do so, this definition is associated with patients with a poorer prognosis.

Discussion

Our response rate (87%) compares extremely favourably with response rates of published GP questionnaire studies (61%),¹⁶ suggesting that these data are reasonably robust.

Patients were identified as eligible for the study *via* data contained in outpatient consultation letters and discharge summaries whose limited nature may have introduced some bias towards the worst cases. If these are indeed the worst cases, then the findings reported here represent a conservative estimate of the level of discrepancy. A broader sample may have been achieved if consultants themselves were asked to identify patients who were 'for palliation', but this was felt to be impractical.

Whilst hospital and GP normally agree on the palliative status of a patient, in a notable proportion,

there may be a discrepancy between when a definition of palliative status is reached by the hospital and when it is reached by GPs, with GPs *appearing* to show a greater reluctance to define patients as palliative (although we do not know whether the opposite occurs, or whether this is true for patients with diagnoses other than lung or colorectal cancer). Agreement by GPs with the hospital doctors' view that the patient was for palliation was significantly associated with poorer survival among those patients who had died. On average, these patients died 117 days (4 months) earlier than patients whom GPs believed were not yet for palliation. Despite reported inadequacies with regard to communications from hospital doctors, the data presented here suggest that the lack of agreement is not related to the promptness or adequacy of information received, at least as rated by the GPs.

One explanation is that GPs and hospital doctors define 'palliative' differently. However, it may be that the GPs were not aware of all of the information available to the hospital doctors, and thus may not have realised that they had received inadequate information. This might then render their assessment of adequacy invalid. A different result might have emerged if the GPs were presented with the hospital notes of the patients and were then asked to judge their palliative status. In addition, GPs' knowledge and understanding of the aims of interventions for these patients (such as chemotherapy or radiotherapy) may be different from those of specialist hospital doctors, thus influencing their interpretation of infor-

mation they received on treatments prescribed to a given patient. It is also possible that patients' (lack of) understanding of the significance of their illness (see, e.g., The *et al.*¹⁷) may be conveyed to the family doctor and, particularly in the absence of other information, this may influence the GPs' classification of the patient. Thus, the GPs' apparent 'reluctance' to label a patient as palliative may not simply be a reflection of differing definitions of the term 'palliative' between specialists and generalists, but may be a function of their accessing differing datasets both in terms of individual patient information and their own knowledge base when coming to that decision. In addition, whether GPs and hospital doctors define 'palliative' differently may be less important than the differences that may exist between a definition of 'palliative' and 'palliative care'. For example, a medical oncologist giving 'palliative' chemotherapy may not regard this as 'palliative care' even though it is undoubtedly both 'palliative' and 'care'.

There are important implications for patient care in the community regarding the nonclassification of patients to palliative status by GPs. Symptom control decisions within primary care are likely to be informed by a palliative 'diagnosis' (e.g., there may be a reluctance to start morphine if palliative status is unclear), as may the appropriate and timely referral to specialist palliative care services (e.g., hospice or hospital at home services)¹⁸ and completion or noncompletion of the DS1500 form (i.e., fast tracking for financial allowances). In addition, whilst recognising that defining a patient as palliative is not the same as prognosticating, patients who so wish need the opportunity to be aware of their status in order to make informed choices about their care, put their affairs in order, or make appropriate end-of-life decisions. Finally, delays in identifying patients as palliative hampers palliative care research and its ability to inform future care developments.¹⁹

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was obtained from Cambridge Local Research Ethics Committee. There were no known conflicts of interest.

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Appendix

ASSESSMENT OF COMMUNICATIONS FROM HOSPITAL DOCTORS

ID No.: _____

Today's date: _____

1) Have you received information from the hospital summarising the outcome of this patient's attendance?

- ☐ yes, I have received a letter/summary (go to question 2)
- ☐ no, but I have received a telephone call (go to question 2)
- ☐ no, I have received no information at all (go to question 5)

2) Did the information you receive make the following clear:

a) diagnosis?

- ☐ yes
- ☐ no

b) drugs/treatments?

- ☐ yes
- ☐ no

c) future management?

- ☐ yes
- ☐ no

d) prognosis?

- ☐ yes
- ☐ no

3) Please rate the adequacy of the information you received using the scale from 1 to 5 where 1 is 'totally inadequate information' and 5 is 'full detailed information'. Please circle one number only.

Totally inadequate information	1	2	3	4	5	Full and detailed information
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☐ I received no information at all (go to question 5)

4) Did you receive the information promptly or was it too late for your needs?

- ☐ received promptly
- ☐ received too late
- ☐ I received no information at all (please answer question 5)

5) Do you perceive that this patient is for palliative care?

- ☐ yes
- ☐ no

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