# Palliative care in primary care:

## a study to determine whether patients and professionals agree on symptoms

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## ABSTRACT

### Background
Difficulties in managing symptoms of palliative care patients at home have been identified, yet there has been no investigation of agreement on symptom assessment in primary care. Lack of agreement between patients' and primary care professionals' symptom assessments may be contributing to difficulties in symptom control.

### Aim
To investigate agreement on symptom assessments between patients at home and GPs and district nurses.

### Design of study
Prospective, self-completed, structured symptom assessments.

### Setting
Routine contacts with adult palliative care patients estimated to be in their last year of life.

### Method
Patient and professional symptom assessments were obtained using CAMPAS-R, a comprehensive and reliable measure validated for palliative care in the community. Prevalence of reported symptoms was calculated in patient–professional pairs. Intraclass correlation techniques (ICCs) and percentage agreement were used to determine how well symptom assessments of patients and professionals agreed.

### Results
Anxiety and depression were significantly more likely to be reported by professionals, and GPs over-identified nausea, vomiting and constipation. Professionals assessed emotional symptoms as more severe than patients. Agreement on scoring of physical symptoms was better, although this was at least partially due to agreement on absence of symptoms. Unlike previous reports, pain scores recorded by doctors in this study, were not significantly different from patients.

### Conclusion
This quick and easy to complete assessment tool, CAMPAS-R, has potential for monitoring quality of palliative care symptom control at home.

### Keywords
agreement; assessment; palliative care; primary health care; proxy; symptoms.

## INTRODUCTION

There is a renewed focus on palliative care at home with the UK Government's pledge to increase quality and choice over care at the end of life.[1] At present many patients are not able to exercise this choice. Only 20% of deaths from all causes and 24% of cancer deaths in England and Wales occur in people's homes.[2] This contrasts with an expressed preference to remain at home until death by half or more of terminally ill patients.[3,4] Many carers would also prefer to support the patient at home until death.[5,6] High-quality palliative care is required for patients to remain at home until death. GPs have a pivotal role to play in delivering palliative care, as most patients with advanced disease are under their GP's care during most of their illness,[7] while district nursing teams have a complementary role in promoting quality of life,[8] although they have been found to have more input in palliative care with cancer patients.[9]

Studies, however, have revealed problems with symptom management of palliative care patients in the community during the last year of life. Pain is reported as a very prevalent symptom,[10–12] rated as

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**Submitted:** 26 November 2004; **Editor's response:** 27 April 2005; **final acceptance:** 9 September 2005.

## *How this fits in*

There have been no studies reporting agreement on symptom assessment between palliative care patients at home and their primary healthcare professionals. This lack of knowledge may be contributing to reported difficulties in control of symptoms in community palliative care patients. Our study reports unique data on how well primary care professionals' and patients' self-assessments agree. Use of CAMPAS-R, a comprehensive and reliable symptom assessment tool, may improve the quality of symptom control among palliative care patients cared for in their own homes.

very distressing in 56–61% of patients.[9,10] Carers describe high levels of poorly controlled pain in general practice, in 33–48% of patients,[13,14] compared to GP reports of 16% of patients.[12] Other common symptoms are nausea and vomiting,[9–12] constipation,[9–12,15] dyspnoea,[9–12,15] and fatigue.[15] These symptoms are reportedly poorly controlled or untreated in 13–30% of patients, depending on whether lay carers[13,14] or health professionals[12] are rating symptom control. Difficulties in management are not confined to physical symptoms. In the last year of life, anxiety is also a common symptom, in 32–78% of palliative patients.[10–12] Reports of symptoms of depression or low mood range from 23% of patients when symptom rating is by GPs,[11] to 71% of patients when symptom reports are from the carer's perspective.[9] Poorly controlled symptoms of anxiety and depression are reported in 20–33% of patients.[12,14]

Patients are unlikely to achieve home care and death at home when symptoms remain uncontrolled. In a review of place of death and access to home care services, symptom control issues were found to be an important factor in inpatient admission.[16] Reasons for poor symptom control for palliative patients in primary care are not clear. In particular there has been limited investigation of symptom assessment, which underlies good symptom control. Studies comparing patients' and professionals' assessments of symptoms have been conducted in different settings: palliative care units,[17,18] cancer and oncology centres,[19–21] and at referral to specialist palliative care services,[22] but there is limited information from primary care.[23] Studies have found physicians tend to underestimate pain severity, which can lead to inadequate pain management.[18–21,23] In contrast, clinicians appear to overrate patients' levels of emotional distress.[17,24] These are important issues for palliative care research, which have not been evaluated in primary care. This paper investigates agreement on symptom assessments between patients at home and primary care professionals as part of a larger study examining provision of palliative care in primary care.[25]

### Box 1. Recruitment criteria.

Inclusion criteria

- Cancer diagnoses
- Other progressive illnesses (for example, respiratory, renal and cardiovascular)
- Under the care of the primary healthcare team

Exclusion criteria

- Estimated prognosis of less than two months
- Any major psychiatric disorder
- Unable to complete data collection forms without help

## METHOD

Patients recruited were adults, in the palliative phase of a progressive illness, estimated to be in their last year of life (Box 1). Health professionals in both primary care and secondary care assisted with identifying suitable patients for the study. In primary care GPs and district nursing teams were contacted approximately every 2–3 months. They were sent an information letter about the study, with an outline of recruitment criteria, and were free to discuss the study with prospective patients if they wished. Professionals were asked to provide contact details of patients who were suitable for the study. Following implementation of the revised Data Protection Act (1998) in March 2000, professionals passed on study information packs to suitable patients who replied directly to the research team if they were interested in taking part in the study. On receipt of contact details, the research team called patients to arrange a meeting to explain the study further and, if they decided to take part, to obtain their written consent.

To avoid bias from recruiting in primary care practices with a special interest in palliative care, we also recruited via secondary care clinics. Staff in oncology and palliative care and in non-oncology services, including cardiology, renal and chest medicine, assisted with recruitment using similar procedures as in primary care. In addition, two members of the research team helped identify clinic patients who met study eligibility criteria. Only nursing and medical staff known to patients approached them about possible participation and passed on information packs. On receipt of their contact details the same procedure for obtaining consent described above was followed. As recruitment focused on patients, their GPs and district nurses were approached to participate only once patients had agreed to take part. Full details of study recruitment procedures are given elsewhere.[26]

Patients and professionals used CAMPAS-R, a comprehensive measure validated for palliative care in

## COMMENTARY

An obvious method for examining the degree to which two methods (or, as in this case, scores on the same individual by different assessors) give the same answer would appear to be the correlation coefficient. However, this merely assesses the degree of linear association between the two and does not take into account any systematic bias between the measures (that is, one method that consistently under- or overestimates what is being measured compared to the other method could have perfect correlation). One way to deal with this is to calculate the intraclass correlation coefficient (ICC) which will equal 1 if and only if the two methods are exactly equal within each individual. Consistent bias with one of the measures will be reflected in a lower value of the ICC. The method is particularly useful when a characteristic that cannot be measured objectively is assessed by two or more raters and the level of agreement between the raters is critical to the way the data are used.[1]

The ICC has the same characteristics as the more usual standard (Pearson) correlation coefficient

- Its value is influenced by the selection of subjects over which it is defined. If the interval over which the observations are spread is increased, then the ICC will be higher.
- It combines information from the systematic difference between methods with the random measurement variation.

Thus, comparisons of intraclass correlations between studies are difficult to interpret, due to the differing amounts of measurement variation between studies.

In addition to the ICC, the data should be examined visually. A plot that has great value in this situation is the Bland-Altman plot,[2] where the individual differences between the two measures are plotted against their individual means. Such plots make it is easier to see whether there is any systematic difference between the methods or whether the degree of random variation changes with the mean value.

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### REFERENCES

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2. Bland JM, Altman DG. Statistical methods for assessing agreement between two methods of clinical measurement. *Lancet* 1986; **i:** 307–310.

the community,[27] to record their symptom assessments. CAMPAS-R includes eight of the most frequently reported symptoms (pain, nausea, vomiting, constipation, fatigue, breathlessness, patient anxiety and patient depression) experienced by palliative care patients.[28] Symptoms are scored using 100 mm visual analogue scales (VAS). To compare patient and professional ratings of symptoms, assessments were made over the previous 24-hour period. Scoring of symptoms also takes account of any medications or treatments in place. Paired data from patients and professionals came from routine contacts with patients at home. Patients completed a CAMPAS-R and GPs and district nurses were asked to complete a similar form, CAMPAS-P, when they had contact with the patient. The form completed by professionals is referred to as CAMPAS-P to distinguish it from the self-assessment CAMPAS-R form completed by patients. The symptom items and format of the two forms are the same.

Where possible, two sets of paired data were obtained; a patient–GP pair and/or a patient–district nurse pair. Duplicate patient–professional pairs and assessments completed more than 1 day apart were excluded from analysis. Visual analogue scales were measured to register a score out of 100 for each symptom. Higher symptom scores represent greater symptomatology. All data for statistical analysis were entered onto a SPSS for Windows database. The two sets of paired data were treated separately in each analysis. Missing data for any particular symptom from either a patient or professional were eliminated from analyses involving that symptom. All tests were two tailed.

Any score above zero was taken to indicate presence of a symptom. First, prevalence of symptoms from each perspective was calculated. The McNemar test was used to examine differences in proportions reporting individual symptoms. Then, within each paired data set, medians and 1st/3rd quartiles were computed to compare patient and professional ratings. Medians and 1st/3rd quartiles were computed for difference scores in each set of patient–professional pairs (difference score = professional score minus patient score). As scores were not normally distributed, the Wilcoxon matched pairs signed ranks test was used to test for differences in scores between raters.

Agreement on symptom scores between patients and professionals was measured using intraclass correlation techniques (ICCs) and percentage agreement. For ICCs, two raters were compared on each occasion, the patient and their GP/district nurse. A two-way mixed effect model was used, selecting the

**Table 1. Patient sample characteristics for data collected from patient-GP and patient-district nurse pairs.**

| | Patients paired with GPs (*n* = 74) | Patients paired with district nurses (*n* = 52) |
|---|---|---|
| Age in years | | |
| Range | 38–85 | 38–84 |
| Mean | 65.8 | 67.3[a] |
| Median | 68.0 | 69.5 |
| Sex (%) | | |
| Male | 46 (62) | 31 (60) |
| Female | 28 (38) | 21 (40) |
| Diagnosis (%) | | |
| Cancer | 58 (78) | 46 (88) |
| Non-cancer | 16 (22) | 6 (12) |
| Survival 60 days (%) | | |
| Yes | 67 (90) | 44 (85) |
| No | 7 (10) | 8 (15) |

*Significant difference between participants and non-participants in patient–district nurse pairs.* [a]*t = 2.07, degrees of freedom = 107,* P *= 0.04.*

absolute agreement definition. The single-measure ICC is reported. To assist interpretation, visual inspection of data was undertaken by plotting difference scores against means which permitted examination of patterns of discord[29,30] (see commentary). (The plots are presented as Supplementary Figures 1 and 2.) Difference scores were also used to examine percentage agreement between raters, accepting patient and professional scores within 10 mm of each other as the defined level of agreement. Overestimation and underestimation by professionals as compared to patient scores was also determined.

## RESULTS

Two subsamples, from a larger palliative care in primary care study sample,[25] provided data for patient–GP pairs and patient–district nurse pairs, described in Table 1. There were no differences between participants and non-participants in patient–GP paired analysis. In patient–district nurse pairs, participants were significantly older than those who did not contribute paired data. Full details of the main study sample are given elsewhere.[27] In brief, a total of 215 patients were approached to take part in the main study; 109 agreed (51%) and 106 (49%) declined. There were no significant differences between participants and non-participants in the main study sample with regard to sex or diagnosis, but non-participants were significantly older and more likely to have died within 2 months of referral to the study.

Paired data were not obtained from GPs or from district nurses for all patients who took part in the study. Twenty-five patients (23%) recorded no visit by or to their GP during the study. Some patients recorded that their GPs contacted them, though no CAMPAS-P was forwarded to the researchers. Altogether 74 patient–GP pairs were obtained. Forty-nine (45%) patients did not receive a visit from a district nurse during the study, though 60 patients reported a total of 191 district nurse visits. We received patient–district nurse pairs for 52 cases (eight GPs and six district nurses in the sample completed more than one CAMPAS-P, but for a different patient on each occasion, resulting in unique patient–GP and patient–district nurse pairings. Repeating the analysis

**Table 2. Prevalence of patient experienced symptoms over prior 24 hours as rated by patients themselves, GPs and district nurses.**

| | | % reporting symptom | | |
|---|---|---|---|---|
| | *n*[a] | Patients | Health professionals | *P*-value for difference[b] |
| Patient–GP | | | | |
| Pain | 68 | 76.5 | 85.3 | 0.15 |
| Nausea | 67 | 28.4 | 64.2 | <0.001 |
| Vomiting | 69 | 5.8 | 36.2 | <0.001 |
| Constipation | 62 | 27.4 | 53.2 | 0.002 |
| Fatigue | 68 | 86.8 | 94.1 | 0.13 |
| Breathlessness | 67 | 62.7 | 74.6 | 0.13 |
| Anxiety | 67 | 59.7 | 85.1 | 0.001 |
| Depression | 67 | 62.7 | 80.6 | 0.01 |
| Patient–district nurse | | | | |
| Pain | 52 | 73.1 | 82.7 | 0.13 |
| Nausea | 50 | 42.0 | 48.0 | 0.61 |
| Vomiting | 49 | 20.4 | 28.6 | 0.42 |
| Constipation | 50 | 26.0 | 46.0 | 0.03 |
| Fatigue | 51 | 92.2 | 96.1 | 0.69 |
| Breathlessness | 51 | 60.8 | 66.7 | 0.58 |
| Anxiety | 48 | 52.1 | 93.8 | <0.001 |
| Depression | 49 | 55.1 | 85.7 | <0.001 |

[a]*While there were 74 patient–GP pairs and 52 patient–district nurse pairs, not all symptom assessments were completed by both raters in each set of pairs which results in different numbers of pairs for individual symptoms.* [b]*McNemar test.*

## Table 3. Severity of symptoms over prior 24 hours as rated by patients, their GPs and district nurses.

| | | Median symptom score symptom score (IQR[b]) | | | | *P*-value for paired difference in symptom score[c] |
|---|---|---|---|---|---|---|
| | *n*[a] | Patient | | Health professional | | |
| Patient–GP | | | | | | |
| Pain | 68 | 21.5 | (1.8–55.8) | 18.0 | (4.3–39.8) | 0.17 |
| Nausea | 67 | 0.0 | (0.0–5.0) | 3.0 | (0.0–21.0) | 0.005 |
| Vomiting | 69 | 0.0 | (0.0–0.0) | 0.0 | (0.0–2.0) | <0.001 |
| Constipation | 62 | 0.0 | (0.0–5.3) | 1.5 | (0.0–15.0) | 0.52 |
| Fatigue | 68 | 39.0 | (11.0–60.8) | 49.5 | (26.5–69.0) | 0.007 |
| Breathlessness | 67 | 10.0 | (0.0–44.0) | 15.0 | (0.0–64.0) | 0.008 |
| Anxiety | 67 | 10.0 | (0.0–40.0) | 22.0 | (10.0–42.0) | 0.009 |
| Depression | 67 | 8.0 | (0.0–46.0) | 18.0 | (4.0–36.0) | 0.15 |
| Patient–district nurse | | | | | | |
| Pain | 52 | 18.0 | (0.0–38.3) | 18.0 | (5.0–46.0) | 0.94 |
| Nausea | 50 | 0.0 | (0.0–16.3) | 0.0 | (0.0–12.5) | 0.76 |
| Vomiting | 49 | 0.0 | (0.0–0.0) | 0.0 | (0.0–1.5) | 0.69 |
| Constipation | 50 | 0.0 | (0.0–4.0) | 0.0 | (0.0–10.5) | 0.08 |
| Fatigue | 51 | 35.0 | (16.0–72.0) | 47.0 | (24.0–83.0) | 0.006 |
| Breathlessness | 51 | 9.0 | (0.0–24.0) | 14.0 | (0.0–39.0) | 0.08 |
| Anxiety | 48 | 3.0 | (0.0–22.5) | 31.0 | (11.3–59.8) | <0.001 |
| Depression | 49 | 5.0 | (0.0–21.5) | 38.0 | (8.0–63.0) | <0.001 |

[a] *There are different numbers of pairs for individual symptoms because not all symptom assessments were completed by both raters in each set of pairs.* [b] *Interquartile range.* [c] *Wilcoxon signed rank test.*

without these duplicates resulted in broadly the same findings). Forty patients in the patient–district nurse pairs also contributed data as patient–GP pairs.

The prevalence of each symptom reported by patients and professionals is summarised in Table 2. Few patients paired with GPs reported vomiting. Prevalence of constipation reported by patients in both GP and district nurse pairs is low, but a substantial proportion of patients reported nausea in patient–district nurse pairs. The majority of patients scored the presence of all other symptoms. Anxiety and depression were significantly more likely to be reported by both GPs and district nurses than by patients. There were no significant differences between patients and district nurses with regard to prevalence of physical symptoms, except for constipation. There were significant differences between GPs and patients in reporting of nausea, vomiting and constipation.

Symptoms scores by professionals and patients are presented in Table 3. Overall, both GPs and district nurses assessed emotional symptoms as more severe than patients did. For physical symptoms, GPs assessed nausea, vomiting, fatigue and breathlessness as significantly more severe than patients did, whereas district nurses assessed only fatigue as significantly more severe.

Using ICCs (Table 4) patient–GP agreement appears higher on severity of physical symptoms than on emotional symptoms, with better agreement for pain, nausea, fatigue and breathlessness; however, 95% confidence intervals overlap, indicating this is not a significant difference. Similarly while agreement between patients and district nurses appears slightly better on most symptoms, ICCs did not differ significantly between GPs and district nurses on any of the symptoms.

## Table 4. Intraclass correlations for patient–professional pairs of symptom severity scores over prior 24 hours.

| | *n*[a] | ICC[b](95% CI) |
|---|---|---|
| Patient–GP | | |
| Pain | 68 | 0.58 (0.40 to 0.72) |
| Nausea | 67 | 0.67 (0.51 to 0.79) |
| Vomiting | 69 | 0.48 (0.27 to 0.64) |
| Constipation | 62 | 0.50 (0.29 to 0.67) |
| Fatigue | 68 | 0.55 (0.35 to 0.70) |
| Breathlessness | 67 | 0.70 (0.55 to 0.81) |
| Anxiety | 67 | 0.47 (0.25 to 0.64) |
| Depression | 67 | 0.50 (0.30 to 0.66) |
| Patient–district nurse | | |
| Pain | 52 | 0.59 (0.37 to 0.74) |
| Nausea | 50 | 0.53 (0.29 to 0.70) |
| Vomiting | 49 | 0.13 (-0.15 to 0.39) |
| Constipation | 50 | 0.55 (0.33 to 0.72) |
| Fatigue | 51 | 0.52 (0.28 to 0.70) |
| Breathlessness | 51 | 0.73 (0.57 to 0.84) |
| Anxiety | 48 | 0.49 (0.11 to 0.71) |
| Depression | 49 | 0.50 (0.13 to 0.72) |

[a] *Not all symptom assessments were completed by both raters in each set of pairs which results in different numbers of pairs for individual symptoms.* [b] *Two way mixed effect model; absolute agreement definition; single measure ICC. ICC = Intraclass correlation.*

**Table 5. Agreement, underestimation and overestimation of symptoms scored over prior 24 hours in patient–professional pairs.**

| | | Good agreement | | Uderestimation | | Overestimation | |
|---|---|---|---|---|---|---|---|
| | *n*[a] | % symptoms absent (0–0 scores) | % pairs[b] +/- 10[c] | 11–50[c] | >50[c] | 11–50[c] | >50[c] |
| Patient–GP | | | | | | | |
| Pain | 68 | 10 | 44 | 29 | 4 | 22 | 0 |
| Nausea | 67 | 33 | 70 | 8 | 2 | 18 | 3 |
| Vomiting | 69 | 61 | 90 | 1 | 0 | 9 | 0 |
| Constipation | 62 | 40 | 73 | 10 | 3 | 13 | 2 |
| Fatigue | 68 | 4 | 34 | 15 | 3 | 43 | 6 |
| Breathlessness | 67 | 15 | 49 | 10 | 2 | 36 | 3 |
| Anxiety | 67 | 10 | 43 | 18 | 0 | 33 | 6 |
| Depression | 67 | 13 | 42 | 13 | 6 | 36 | 3 |
| Patient–district nurse | | | | | | | |
| Pain | 52 | 15 | 52 | 21 | 4 | 19 | 4 |
| Nausea | 50 | 40 | 68 | 16 | 0 | 14 | 2 |
| Vomiting | 49 | 61 | 80 | 12 | 0 | 2 | 6 |
| Constipation | 50 | 46 | 78 | 2 | 4 | 14 | 2 |
| Fatigue | 51 | 0 | 37 | 10 | 6 | 35 | 12 |
| Breathlessness | 51 | 24 | 63 | 12 | 0 | 22 | 4 |
| Anxiety | 48 | 6 | 29 | 8 | 0 | 46 | 17 |
| Depression | 49 | 12 | 47 | 6 | 0 | 33 | 14 |

*[a]Not all assessments were completed by both raters resulting in different numbers of pairs for each symptom. [b]Pairs within +/-10 mm also contain pairs which are 0-0 scores. [c]Scores in mm.*

Percentage agreement between patients and professionals was also examined. Table 5 is based on difference scores, between patient and professional ratings for individual symptoms. As well as overall agreement on scoring of each symptom, the percentage of agreement that comes from 0–0 scores (agreement about absence of symptoms) is included. On the whole, the less prevalent the symptom, the higher the agreement between patient and professional. Hence, the highest levels of agreement were for vomiting, constipation and nausea in both datasets, where there was agreed absence of symptoms (many 0–0 scores). This contrasts with low agreement for fatigue which was the most prevalent symptom (fewest 0–0 scores).

The extent to which professionals over- or underestimated symptom severity was also examined. On the whole, overestimation of symptoms by professionals was more common than underestimation, particularly for fatigue, breathlessness and emotional symptoms. Among GPs, the exception was pain. We found that more GPs underestimated patient ratings of pain severity than overestimated it. District nurses more commonly overestimated symptom severity except for vomiting, although its prevalence was low. With pain and nausea, the same proportion of district nurses overestimated as underestimated patient ratings, the majority falling in the 11–50 mm range.

## DISCUSSION

### *Summary of main findings*

The main findings of this study are that anxiety and depression were significantly more likely to be reported by both GPs and district nurses than by patients, and GPs overidentified prevalence of nausea, vomiting and constipation compared to patients' scores (Table 2). Primary care professionals assessed emotional symptoms as more severe than patients did. Agreement on scoring of physical symptoms was good, although this was at least partially due to agreement on absence of symptoms (Table 5). Fatigue was a common symptom on which there was less agreement between GPs and nurses, and their patients. Unlike previous reports, pain scores recorded by doctors in this study were not significantly different from those reported by patients.

### *Strengths and limitations of the study*

A strength of the study is that it provides new data on symptoms experienced by patients in their last year of life, in combination with concurrent data from GPs and district nurses managing their care at home. The study also takes a prospective approach to data collection and therefore does not rely on retrospective accounts, the accuracy of which has been called into question.[31] Nevertheless, a prospective methodology can also have limitations in terms of the study sample obtained. The problem of obtaining representative samples in palliative care research is well known,[32] and for this study, the primary care setting introduced additional difficulties which have been discussed in full elsewhere.[26] Participation by younger patients with a longer period of survival after study entry compared with non-participants may be a potential source of bias to our sample, although patients close to death did take part. Our study sample was smaller than anticipated as we relied on clinical estimates of prognosis as part of the recruitment process which, in common with other studies, were over-optimistic.[33] We found in retrospect that often patients in the last few weeks of life had been contacted, and this clearly affected agreement to take part.

### *Comparison with existing literature and implications for clinical practice and future research*

The first requirement of good symptom management is good assessment of symptoms. Clearly, contact between patients and professionals needs to be made for this to occur yet only 84/109 study patients were visited by their GP and only 60/109 by their district nurse. It is worrying that so many patients, ostensibly in their last year of life, were apparently not contacted by primary care professionals for at least 4 months.

Furthermore, underpinning good palliative care is holistic assessment. In spite of this, we were unable to analyse the full complement of data for all symptoms. There were occasions where only 62/74 patient–GP and 48/52 patient–district nurse pairs were available for comparison, due to missing assessments for particular symptoms. Thus, holistic symptom management and quality of life for palliative patients is put at risk.

Where paired data analyses were possible, they showed that professionals over-identify a range of symptoms during routine contacts. GPs in particular, assessed patients as experiencing symptoms when patients did not record them as problematic. This could come about through selective reporting by patients of what they consider 'relevant' symptoms.[34] However, specific instructions were given to study patients about reporting all symptoms regardless of cause. Furthermore it is unlikely that this difference in reporting is due to non-disclosure by patients as district nurses' prevalence rates for physical symptoms were very similar to patients' (Table 2). It may be that GPs record the presence of symptoms because they have expectations based on previous experiences with palliative care patients rather than on individualised assessments.[17,35]

However, it is the prevalence and severity of emotional symptoms that both groups of professionals particularly overestimate. GPs and district nurses overestimated prevalence of both anxiety and depression and severity of anxiety, and district nurses also overestimated severity of depression. This finding concurs with other studies reporting anxiety[17,24] and depression[8,17] in cancer patients. Previous research has shown that professionals, even following training, have difficulty eliciting such symptoms and concerns.[36] Alternatively, these scores may reflect the discomfort of professionals themselves as they negotiate interactions at such difficult times. As one senior oncology clinician reported, he wasn't going to 'open up a can of worms when there isn't anything I can do'.[37] So they may simply be assuming that anxiety and depression must be problems for palliative patients. Needless to say, psychological wellbeing of patients is an integral component of palliative care, something that cannot be adequately addressed without accurate assessment.

Physical symptom agreement was very acceptable, measured both by ICCs and by percentage agreement: however, this was at least partially due to agreement that symptoms were absent. This is generally consistent with other studies of proxy agreement.[17,35] Assessment of more observable physical symptoms has been noted to be easier than assessment of psychological symptoms where lack of visible clues affects accuracy.[8,38] A novel finding compared to the rest of the literature relates to how proxy professionals underestimate the severity of pain.[18–21] More GPs underestimated the severity of patients' pain than overestimated it; as a group, GP pain scores were not significantly different from patients' scores. While it is encouraging that these professionals appear to be more accurate in pain assessment, there are many instances where patients indicated a problem where GPs and district nurses scored pain as less severe than the patients themselves did. Clearly this has important implications for pain control. Interventions may not be offered if practitioners do not believe a symptom is 'severe enough' or modifications to the treatment plan not made if they perceive the problem to have lessened. Further work on evaluation of interventions in place for symptom management is ongoing as part of a larger study of palliative care in primary care.[25]

In conclusion, this study adds a new dimension to the body of evidence about palliative care provision in primary care by combining patients' accounts of their symptoms with concurrent assessments by GPs and district nurses who have most contact in the last year of life. Overall it was found that district nurses were generally in better agreement with patients than GPs on physical symptoms; however these differences did not reach statistical significance. Both professional groups tended to over-identify emotional symptoms in patients. We believe our data provide a more reliable picture of palliative care within primary care as a result of the methodology used. Patients were queried directly and prospectively in their own homes rather than relying on the retrospective perceptions of bereaved proxies (that is, former carers) or taking a cross-sectional approach recruiting patients during acute care or hospice admission.

In any setting, not least primary care, lengthy and complex measures of quality of life for palliative patients are problematic. CAMPAS-R has proved to be a quick and easy to administer tool for use at home with palliative patients. Feedback from professionals in the study has also indicated that it provides a useful framework for assessment of symptoms other than those raised by the patient, serving as a mechanism for opening discussion of other symptoms. Importantly for primary care, we have found that its simple format, using a VAS to score a range of common symptoms, has yielded results not dissimilar from those of other studies of patient–proxy agreement in the literature which have used much more complex methodologies. As such CAMPAS-R is not only a reliable assessment tool but also because of its simplicity to complete, it offers the potential for monitoring quality of palliative care symptom control at home.

## Supplementary information

Additional information is available online at http://www.rcgp.org.uk/journal/supp/index.asp

## Funding body

This work was undertaken by Chris Todd who received funding from the Department of Health (198/1008)

## Ethics committee

The study was approved by Anglia and Oxford Multicentre Research Ethics Committee (MREC 00/5/34), Bedford North LREC (MREC/00/5/34), Northampton LREC (LREC 00/78), West Essex LREC (MREC 1336-08-00), North Hertfordshire LREC (LREC 54), South Lincolnshire LREC (MREC/00/5/34), King's Lynn LREC (LREC 34/00 MREC/00/5/34) West Suffolk LREC (MREC 00/5/34), West Hertfordshire LREC (MREC15/00), Bedford, South LREC (Aug00/4a), Kettering LREC (MREC 00/5/34), Cambridge LREC (LREC 00/282M), Huntingdon LREC (LREC 99/M/422), Peterborough & Fenland LREC (LREC P00/M/51)

## Competing interests

The authors have stated that there are none

## Acknowledgements

When this study was conducted Gail Ewing, Chris Todd, Margaret Rogers, Stephen Barclay and Anna Martin were members of the Health Services Research Group, Department of Public Health and Primary Care, Institute of Public Health, University of Cambridge, UK. The views expressed in the publication are those of the authors and not necessarily those of the Department of Health. We would like to thank all the patients, lay carers and health professionals who took part in the study. We are also grateful to members of staff at the Centre for Applied Medical Statistics, University of Cambridge for initial statistical advice.

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