Original Article

Validation of a Symptom Measure Suitable for Use Among Palliative Care Patients in the Community: CAMPAS-R

Gail Ewing, BSc, PhD, RGN, Chris Todd, BA, MA, PhD, AFBPsychSoc C Psychol, Margaret Rogers, BSN, RN, MPH, RGN, PhD, Stephen Barclay, MA, MSc, FRCGP, Janet McCabe, MB BS, and Anna Martin, RGN

Center for Family Research (G.E.), University of Cambridge, Cambridge; School of Nursing, Midwifery & Health Visiting (C.T.), University of Manchester, Manchester; East Anglia's Children's Hospices (M.R.), Cambridge; Dept of Public Health and Primary Care (S.B.), Institute of Public Health, Cambridge; Arthur Rank House (J.M.), Brookfields Hospital, Cambridge; and General Practice and Primary Care Research Unit (A.M.), Institute of Public Health, Cambridge, United Kingdom

Abstract

The purpose of the study was to investigate psychometric properties of CAMPAS-R, an instrument for prospectively monitoring patients' symptoms and needs during palliative care at home. CAMPAS-R was piloted for face and content validity and then administered alongside criterion measures to a home care sample. Cronbach's alpha was used to test internal consistency and criterion-related validity was tested by non-parametric correlation with Brief Pain Inventory (BPI), Hospital Anxiety and Depression Scale (HADS) and EORTC QLQ-C30. Predictive validity was assessed by relating CAMPAS-R scores to survival. One hundred and nine patients were recruited to the study. Good reliability and high correlations between CAMPAS-R and criterion measures were found. Predictive validity was demonstrated by significant differences in symptom scores between groups differing in length of survival. CAMPAS-R is acceptable to patients, families and primary care professionals and is a valid, reliable instrument, which has the benefit of being easy to score. J Pain Symptom Manage 2004;27:287–299.

Key Words

Palliative care, symptom measurement, reliability, validity, home care, quality of life

Introduction

In an English population of one million, there are some 11,000 deaths/year, 2,800 resulting from cancers. Palliative care is appropriate for most if not all of these patients. In addition, some 6,900 die from nonmalignant disease and many of these patients would also benefit from palliative care.[1] In 1998, 20% of deaths from all causes and 24% of cancer deaths in England and Wales occurred in people's own homes.[2] However, half or more of terminally ill patients express a preference to remain at home until death.[3–5] Death at home is also preferred

Address reprint requests to: Gail Ewing, BSc, PhD, RGN, Center for Family Research, University of Cambridge, Free School Lane, Cambridge CB2 3RF, United Kingdom.

Accepted for publication: August 2, 2003.

0885-3924/04/$–see front matter
doi:10.1016/j.jpainsymman.2003.12.012

by a majority of the general public[6] and primary care professionals.[7] Furthermore, informal carers are more likely to state that the place of death was right if the patient died at home rather than in hospital.[8]

Although most of the last year of life is spent at home,[9] studies have revealed that many patients do not receive optimal pain control.[10,11–13] There are some suggestions that pain control in the community may be improving[14] but this is not a consistent finding.[10] Vomiting, nausea and constipation remain sources of high levels of distress to patients with advanced cancer and are symptoms in which treatment needs are not fully met.[8,10] This is also the case with dyspnea, which is frequently reported to be inadequately controlled.[8,10,15] In addition, there are reports of unmet emotional needs of dying patients. In the last year of life, anxiety was reported in 32% of dying patients.[10] Similarly, levels of depression ranged from 36%[9] to as much as 69%[10] when the term 'feeling low or miserable' was substituted for 'depression.'

Informative though these studies are in terms of revealing that there are problems with symptom management in the community, the reasons why these problems occur have not been explored. It is not clear whether health professionals identify problems, but are unable to control them or whether they fail to identify symptoms in the first place, and, therefore, symptoms remain untreated. Furthermore, if it is a matter of inadequate identification of symptoms, is this due to communication difficulties with patients and carers or deficiencies in palliative care education? Additionally, methods used in these studies require scrutiny. Many have interviewed the carers of dying patients anywhere between 6 weeks and 15 months post-bereavement.[8–14] The reliability of such retrospective accounts has been called into question in the assessment of pain, symptoms, anxiety and depression.[16,17] Proxy reporting of symptoms has also been found to be unreliable in prospective studies, with agreement poorest for subjective aspects of the patient's experience such as pain, anxiety and depression.[18]

Important questions remain to be investigated about symptom assessment for palliative care patients in the community and about proxy accounts from carers and from health professionals. However, any such investigation is hampered by the paucity of validated measures for symptom assessment in the primary care setting. The Support Team Assessment Schedule[19] (STAS), is used by specialist palliative support teams but is not suitable for use, unmodified, with non-specialist primary care professionals.[20] The Edmonton Symptom Assessment System[21] (ESAS) is sufficiently brief and simple to use on a daily basis with home based palliative patients, but does not address the broad range of symptoms found in the primary care setting.[20,22,23] Furthermore, the ESAS is limited in terms of symptom dimensions, since only severity and not impact of symptoms is assessed. In the home palliative care setting, the administration of lengthy instruments is inappropriate.[24] Thus more comprehensive scales such as the Memorial Symptom Assessment Scale (MSAS)[25] are too long for patients to complete on a repeated basis or for primary care professionals to complete at a brief face-to-face contact.

Therefore, to be able to examine concurrent perspectives of symptoms from palliative care patients, their lay carers and primary care professionals in patients' homes,[26] we needed to develop a new tool for symptom assessment specific to primary care. The purpose of this paper is to describe the development of the Cambridge Palliative Assessment Schedule (CAMPAS-R) and to report testing of its reliability and validity.

Methods

Development of CAMPAS-R

A core list of symptoms was derived from the CAMPAS audit tool[20] to reflect the holistic nature of palliative care. This comprised six commonly experienced symptoms (pain, nausea/vomiting, constipation, diarrhea, breathlessness and patient anxiety). An item on carer anxiety, rated by the patient, was also included, as palliative care addresses family needs as well. On the basis of feedback from the audit,[22,23] we also extended emotional symptoms to include patient depression/feeling low and carer depression/feeling low (also rated by the patient). Symptoms were scored, using 100mm visual analogue scales (VAS), on two dimensions. First, severity of symptoms experienced by patients was rated (Fig. 1). Then the same set of symptoms was scored a second time, in terms of how 'troublesome' they had been (Fig. 2). Anchor

PRESENCE OF SYMPTOMS IN THE LAST WEEK

In this section we would like to know which symptoms have been present in the last week. For any symptom not present, please circle 'None'.

If a symptom has been present, please score **how bad it has been** (even with treatment or other help in place) by marking along the line as shown.

For example: If there was a little soreness of the mouth, even with treatment, you would mark the line as shown.

Sore mouth None ——|—— Very severe

If details about a symptom are not known, please tick 'Not known'.

		Not known	Office use only
Pain	None —— Very severe	☐	☐
Nausea	None —— Very severe	☐	☐
Vomiting	None —— Very severe	☐	☐
Constipation	None —— Very severe	☐	☐
Fatigue/tiredness	None —— Very severe	☐	☐
Breathlessness	None —— Very severe	☐	☐
Patient anxiety/ feeling tense	None —— Very severe	☐	☐
Patient depression/ feeling low	None —— Very severe	☐	☐
Carer anxiety/ feeling tense	None —— Very severe	☐	☐
Carer depression/ feeling low	None —— Very severe	☐	☐
Others, specify	None —— Very severe	☐	☐
.....	None —— Very severe	☐	☐

Fig. 1. Severity of Symptoms scoring sheet.

INTERFERENCE IN THE LAST WEEK

If a symptom has not interfered with normal activities, please circle 'Does not interfere'.

If a symptom has interfered, please score how much it has got in the way of normal activities (even with treatment or other help in place) by marking along the line as shown.

For example: If a sore mouth interferes greatly with eating, even with treatment, mark the line as shown.

Sore mouth — Does not interfere ——|—— Completely interferes

If details about interference in the last week are not known, please tick 'Not known'.

			Not known	Office use only
Pain	Does not interfere	Completely interferes	☐	☐
Nausea	Does not interfere	Completely interferes	☐	☐
Vomiting	Does not interfere	Completely interferes	☐	☐
Constipation	Does not interfere	Completely interferes	☐	☐
Fatigue/tiredness	Does not interfere	Completely interferes	☐	☐
Breathlessness	Does not interfere	Completely interferes	☐	☐
Patient anxiety/ feeling tense	Does not interfere	Completely interferes	☐	☐
Patient depression/ feeling low	Does not interfere	Completely interferes	☐	☐
Carer anxiety/ feeling tense	Does not interfere	Completely interferes	☐	☐
Carer depression/ feeling low	Does not interfere	Completely interferes	☐	☐
Others, specify	Does not interfere	Completely interferes	☐	☐
.....	Does not interfere	Completely interferes	☐	☐

Fig. 2. Interference of Symptoms scoring sheet.

points of 'None' represented a score of 0 and 'Very Severe/Very Troublesome' a score of 100. An explanation and illustration of scoring the VAS was included on both sections of the assessment tool.

Patient Recruitment

Patients recruited to the study were adults who were in the palliative phase of a progressive illness, being cared for at home and estimated to be in their last year of life. (It is important to note that recruitment procedures were based on estimates of prognosis by health professionals. Actual survival times, which are reported in the Results, were often different.) Palliative care is most commonly associated with cancer, but, in line with contemporary paradigms, we included patients in the palliative phase of other illnesses, such as end-stage respiratory, renal and cardiovascular diseases.[27] Exclusion criteria included any major psychiatric disorder and patients who were unable to complete data collection forms without help. When health professionals referred a patient to the study, if they estimated their prognosis to be less than two months, we excluded those patients on the basis that they were likely to be too ill to take part in a period of data collection lasting four weeks. The study was approved by the Multi-Center Research Ethics Committee and by the relevant local research ethics committees.

Patients were recruited with the assistance of professionals in both primary care and secondary care sectors. In primary care, we approached GPs and District Nursing (DN) teams approximately every 2 to 3 months. In each approach, individual GPs and DN teams were sent an information letter about the study, with an outline of recruitment criteria. Professionals were asked to provide contact details of patients who were suitable for the study. With implementation of the revised Data Protection Act (1998) in March 2000, they also had to provide written consent from patients agreeing for their details to be passed on to the research team. Patients were contacted by telephone to arrange a meeting, to explain the study further and, if they decided to take part, to obtain their written consent.

In secondary care, we had assistance from oncology services and palliative care teams, both hospital and community-based. Non-oncology services also agreed to help with recruitment, including renal and chest medicine, cardiology and medicine for the elderly. We provided professionals with information about the study and recruitment criteria. Additionally, two of the research team assisted staff in identifying patients who met the eligibility criteria. Nursing and medical staff known to patients approached them about possible participation and gave them an information letter about the study. If they wished to have further information, they signed and returned a form giving their agreement for contact by the research team. Thereafter, the same procedure of contact, described above, was followed.

Data Collection

Home visits for data collection were carried out by four members of the research team: two research associates (GE and MR), one GP/Research Training Fellow (SB) and one research nurse (AM). The initial visit was arranged to seek consent of the patient (and lay carer if present); collect background information and details of any symptoms or support needs at that time; and provide a 'practice' opportunity in the use of CAMPAS-R. At this point, the patient (and lay carer) were entered into a four-week study period. Each week they were visited at home and asked to complete a CAMPAS-R form on symptoms and needs, as recalled over the previous week. The weekly contacts also were used to administer the additional criterion validation measures: the Brief Pain Inventory (BPI) (used with the permission of Charles S Cleeland, Professor of Medicine and Director, Pain Research Group, MD Anderson Cancer Center),[28] the Hospital Anxiety and Depression (HADS) Scale[29] and the EORTC QLQ-C30 (EORTC) (The EORTC QLQ-C30 (Version 2) was used with permission of the EORTC Quality of Life Group).[30]

Data Analysis

Visual analogue scales on CAMPAS-R were measured with a ruler template that was used to calculate a score out of 100 for each symptom. A higher score represents greater symptomatology. All data for statistical analysis were entered on to SPSS for Windows Version 9.0.1. We obtained frequency distributions for individual symptoms, for both severity and interference measures. Mean severity and mean interference scores for all symptoms were also computed. Means were calculated on the basis of

symptoms experienced, with symptoms rated at zero excluded from the analysis. For individual symptoms, correlations between severity and interference scores were investigated using Spearman's rank correlation coefficient.

We investigated internal consistency, i.e., whether different items making up sub-scales on CAMPAS-R were measuring the same underlying construct, using Cronbach's Alpha.[31] Test-retest reliability in palliative care research is, however, more problematic, especially given the relationship between test-retest reliability, sensitivity to change and validity of an instrument.[32] Thus, as CAMPAS-R is designed to pick up changes in symptoms on a week-by-week basis, test-retest reliability, which is normally done over 2 to 4 week periods, is not appropriate.

We addressed issues of face and content validity of CAMPAS-R during pilot work. Our criterion validation strategies included concurrent validation, predictive validation and criterion groups validation.[32] In selecting 'gold standard' measures for the purpose of criterion validation (BPI, HADS and EORTC), as well as taking account of the measurement properties of the instruments, consideration was also given to the time taken for completion of the measure as patients and carers were completing them concurrently with CAMPAS-R. Criterion measures chosen all appeared to be of acceptable reliability and validity given these practical constraints.

Raw scores from criterion measures were transformed in the standard way, as described in manuals (Scoring Procedures for the EORTC QLQ-C30; Version 2) and/or journals (BPI[28] and HADS[29]), to calculate symptom scales for pain, other physical symptoms, patient anxiety and patient depression. Spearman's rank correlation coefficient was used to investigate criterion validity.

We hypothesized that there would be a difference in symptom scores in participants who were nearer to death and chose an arbitrary but clinically realistic cut off of 60 days post-completion of the first CAMPAS-R to group patients into 'survivors' and 'non-survivors.' These groupings were thus used to investigate predictive validity. We report the z approximation for the Mann-Whitney Test to detect differences in symptom scores between groups. We also hypothesized that different patient groups would have different profiles of scores; cancer patients would differ from non-cancer patients, lung cancer patients would differ from colorectal cancer patients, etc. (criterion groups validity). Due to poorer than anticipated recruitment,[26] we did not have sufficient numbers of patients in diagnostic subgroups to permit meaningful criterion groups validation analysis.

Results

Face and Content Validity (Pilot Study)

The initial tool was tested in a pilot study in which CAMPAS-R data were collected over a four-week period from 20 patients and their lay carers. Those primary care professionals who had contact with the patient during the period of the pilot study were asked to participate. We obtained 10 assessments of symptoms from GPs, 10 from DNs and two from Community Macmillan Nurses (Macmillan Nurses are specialist nurses in palliative and terminal care for cancer patients, who provide advice, support and care for patients and their families). We also sought feedback from participants on face and content validity of the CAMPAS-R tool. This included interviews with 10 patients, eight carers, six GPs, six DNs and one Community Macmillan Nurse. We also arranged a discussion session about the pilot study with feedback on CAMPAS-R from one of the local Community Macmillan teams.

The comprehensiveness of content of CAMPAS-R was assessed by patients, lay carers and professionals. On the basis of feedback, we added a 'don't know' column to both symptom pages. We substituted the term 'interference' for 'troublesome,' to bring it into line with the term used on criterion measures and in response to informants' comments. The item fatigue/tiredness was added to the list of physical symptoms. Any other symptoms patients had beyond the core list could be added in the 'other' section on each of the symptom scoring pages.

Sample Characteristics (Main Study)

There were 317 patients identified by colleagues for the study. Fifty-six of these patients (18%) did not meet eligibility criteria. In a further 46 cases (15%), we did not have permission

from GPs for patients to take part in the study. Of the 215 patients who were approached to participate, 109 agreed (51%) and 106 (49%) declined. There were no significant differences between participants and nonparticipants with regard to gender or diagnosis (Table 1), but the groups differed significantly in terms of age at referral to the study and period of survival. Nonparticipants were significantly older and more had died within two months of referral to the study.

Criterion Measure Subsamples. Patients were entered into the study on the basis of an estimated prognosis of more than 2 months. For some, actual survival time was less and they were not able to complete the study before becoming too ill or dying, resulting in datasets without all criterion measures completed. To check whether our sample was biased, we tested the representativeness of our surviving subsamples. There were no differences between those who did and those who did not complete the EORTC (completed $n = 90$; not completed $n = 19$) with regard to age ($t = 0.64$, $df = 107$, $P = 0.53$), gender ($\chi^2 = 0.50$, $df = 1$, $P = 0.48$) or diagnosis ($\chi^2 = 1.45$, $df = 1$, $P = 0.23$). The groups did differ significantly in terms of survival for 60 days after study entry ($\chi^2 = 41.14$, $df = 1$, $P < 0.001$). The pattern for HADS completion (completed, $n = 94$; not completed, $n = 15$) was similar to that of EORTC with no differences between groups with regard to age, gender or diagnosis. The only difference between completion groups was in relation to survival for 60 days after study entry ($\chi^2 = 24.0$, $df = 1$, $P < 0.001$). There were no differences at all between groups who completed or failed to complete the BPI (completed, $n = 101$; not completed, $n = 8$).

Symptom Scoring

Prevalence of symptom severity (i.e., any score indicating the patient had the symptom) ranged from 92.2% for fatigue to 15.2% for vomiting, and symptom interference from 89.2% for fatigue to 14.3% for vomiting (Table 2).

For all patients, the mean severity score for all symptoms was correlated with the mean interference score ($r = 0.89$). For individual physical symptoms, correlations between symptom severity and symptom interference were high and ranged from $r = 0.83$ for constipation to $r = 0.91$ for the correlation between severity and interference of breathlessness. The exception was vomiting severity and vomiting interference, which had a lower correlation ($r = 0.57$), but the symptom was present in few patients (Table 2). For emotional symptoms, correlations between severity and interference dimensions were similarly high, ranging from $r = 0.86$ for patient depression to $r = 0.93$ for patient rating of carer depression.

Internal Consistency

Two scales were investigated: severity and interference of pain, nausea, vomiting, constipation, fatigue, breathlessness, patient anxiety and patient depression. Cronbach's alpha for severity was $\alpha = 0.77$ ($n = 96$) and for interference $\alpha = 0.80$ ($n = 94$). Alpha scores with items removed ranged from 0.69 to 0.79 (severity scale) and from 0.73 to 0.81 (interference scale).

Table 1
Sample Characteristics

		Participants $n = 109$	Non-participants $n = 106$	Statistical Significance
Age	Range	38–85 years	48–99 years	
	Mean	64.9	70.3	$t = 3.80$, $df = 213$ $P < 0.001$
	Median	66.0	71.0	
Gender	Male	68 (62%)	62 (59%)	$\chi^2 = 0.20$, $df = 1$ $P = 0.66$
	Female	41 (38%)	44 (41%)	
Diagnosis	Cancer	90 (83%)	92 (87%)	$\chi^2 = 0.45$, $df = 1$ $P = 0.50$
	Non-cancer	19 (17%)	14 (13%)	
Survival	Dead 60 days after referral	6 (6%)	26 (25%)	$\chi^2 = 13.89$, $df = 1$ $P < 0.001$
	Alive 60 days after referral	103 (94%)	80 (75%)	

Table 2
Symptom Prevalence

Symptom	Percentage Scoring Severity of Symptom	Percentage Scoring Interference of Symptom
Pain	77.2	60.0
Nausea	39.2	27.3
Vomiting	15.2	14.3
Constipation	37.0	25.5
Fatigue	92.2	89.2
Breathlessness	64.0	61.9
Patient anxiety	66.3	57.0
Patient depression	55.4	52.5
Carer anxiety[a]	68.4	57.5
Carer depression[a]	58.4	53.2

[a]Scored by patient.

Criterion Validity

Pain. Pain severity and pain interference scores on CAMPAS-R were correlated with corresponding severity and interference scores on BPI and EORTC (Table 3). Correlations between different dimensions on criterion measures and CAMPAS-R varied: EORTC pain severity and pain interference on CAMPAS-R ($r = 0.79$), EORTC pain interference and pain severity on CAMPAS-R ($r = 0.77$). In addition, the EORTC pain scale (PA) is a composite of both severity and interference items. When a similar composite score was computed for the mean of pain severity and pain interference items on CAMPAS-R, it correlated highly with the PA scale ($r = 0.91$).

Table 3
Validation of Pain on CAMPAS-R Against Criterion Measures

Criterion Measure	CAMPAS-R Measure	*n*	Correlation[a]
BPI Severity score	Severity of pain	99	0.87
BPI Interference score	Interference of pain	98	0.82
EORTC Pain severity	Severity of pain	88	0.87
EORTC Pain interference	Interference of pain	88	0.86
EORTC PA scale	Severity of pain	88	0.87
	Interference of pain	88	0.88

[a]All correlations significant at the 0.01 level.

Other Physical Symptoms. For validation of other physical symptoms we used the relevant symptom scales and items on the EORTC (Table 4). Very strong correlations were found between breathlessness items on EORTC and CAMPAS-R and between constipation items on the two measures. The fatigue items on CAMPAS-R produced moderately good correlations with the EORTC Fatigue scale. The separate items for nausea and vomiting correlated less well with the EORTC Nausea and Vomiting (NV) scale. When CAMPAS-R items on severity of nausea and of vomiting were combined as a composite score there was a very strong correlation with the NV scale ($r = 0.87$).

Patient Anxiety and Depression. CAMPAS-R scores for patient anxiety and patient depression were tested with the anxiety and depression subscales on the HADS and with the EORTC Emotional Functioning (EF) scale (Table 5). There were stronger correlations between patient anxiety scores on CAMPAS-R and the HADS anxiety subscale than between the measures for depression. The EF scale is a functional measure for which higher scores represent a higher level of functioning. This is the reverse of the scoring system on CAMPAS-R, resulting in negative correlations. The EF scale also combines items on severity of anxiety and depression. As with physical symptoms, a composite score for severity of anxiety and depression on

Table 4
Validation of Other CAMPAS-R Physical Symptoms Against Criterion Measures

Criterion Measure	CAMPAS-R Measure	*n*	Correlation[a]
EORTC DY item	Severity of breathlessness	89	0.91
	Interference of breathlessness	88	0.89
EORTC CO item	Severity of constipation	89	0.87
	Interference of constipation	89	0.74
EORTC FA scale	Severity of fatigue	89	0.64
	Interference of fatigue	90	0.65
EORTC NV scale	Severity of nausea	88	0.83
	Interference of nausea	89	0.65
	Severity of vomiting	87	0.48
	Interference of vomiting	88	0.31

[a]All correlation significant at the 0.01 level.

Table 5
Validation of CAMPAS-R Patient Anxiety and Depression Against Criterion Measures

Criterion Measure	CAMPAS-R Measure	*n*	Correlation[a]
HADS anxiety subscale	Severity of anxiety	90	0.63
	Interference of anxiety	89	0.66
HADS depression subscale	Severity of depression	90	0.56
	Interference of depression	88	0.55
EORTC EF scale	Severity of anxiety	89	−0.77
	Interference of anxiety	90	−0.73
	Severity of depression	88	−0.72
	Interference of depression	88	−0.67

[a]All correlations significant at the 0.01 level.

CAMPAS-R correlated well with the EF scale ($r = -0.77$).

Predictive Validity

There were significant differences between 'survivor' and 'non-survivor' groups for severity of pain, fatigue, patient scores of carer anxiety and patient scores of carer depression (Table 6). The groups also differed significantly for interference ratings of pain, nausea, vomiting, constipation, patient scores of carer anxiety and patient scores of patient depression (Table 7).

Discussion

Few assessment tools for palliative care have been validated in the primary care setting in the UK. An exception is the STAS,[19] but it is intended for use by specialist palliative care teams rather than generalist primary care professionals. We conducted a psychometric analysis of CAMPAS-R, a symptom assessment tool to be used by palliative care patients, lay carers and primary care professionals.

As it is intended for use in primary care, CAMPAS-R needs to reflect the reality of community-based palliative care in the UK, in terms of core symptoms and methods of scoring, as well as to demonstrate good reliability and validity. Items on CAMPAS-R were derived from the literature on palliative care and from input from primary care professionals.[20] Included are both physical and emotional symptoms experienced by the patient and also the patient's perspective on the carer's situation. In the home setting, not only is the carer likely to be seen by health professionals, but with palliative care there is recognition of carer needs as well as those of the patient.[33] Face and content validity of CAMPAS-R is demonstrated by high symptom prevalence for the majority of the core symptoms. Patients, their families and professionals all reported that we had included essential symptoms for community-based palliative care on the tool.

Symptoms are scored on two different dimensions, severity and interference, which were highly correlated. The MSAS, which investigates three dimensions, (severity, frequency and distress), has been reported to have highly inter-correlated scales.[25] Frequency and distress assessment is reported as augmenting information about impact of symptoms.[25] From a clinical perspective, there might well be an expectation that the dimensions we investigated would have some degree of inter-relationship. For example, with breathlessness, it is intuitively plausible that the greater the severity of breathlessness, the greater the interference (impact) on everyday life. What is interesting to note is that correlations, while high, are not perfect, and in fact the levels of Cronbach's alpha calculated for our scales reveal that additional information is forthcoming by using two dimensions for each symptom.

Visual analogue scales are widely used for symptom assessment in palliative care and in other patient populations and have been found to be valid measures, easily understood and used by most patients.[34–38] This is consistent with our finding that most participants found the VAS for scoring symptoms easy to use, with its completion easily incorporated into the patient's daily routine. The VAS has other advantages. Being a continuous scale, it permits parametric statistical analysis. Previous scores are also less likely to be recalled than when a categorical scoring method is used (e.g., none, mild, moderate and severe) and comparison of scores by patients and other raters is less likely.

Reliability testing of CAMPAS-R has focused on internal consistency, combining VAS items as a severity scale and as an interference scale.

Table 6
Predictive Validation for Severity of Symptoms

	Survival 60+ days			Survival <60 days			
Symptom Severity	*n*	Mean	SD	*n*	Mean	SD	Statistical Significance
Pain	89	23.3	24.4	12	42.8	30.5	Z = 2.20 *P* = 0.03
Nausea	90	9.2	19.3	12	21.6	29.8	Z = 1.71 *P* = 0.09
Vomiting	87	2.1	7.6	12	6.1	13.5	Z = 1.10 *P* = 0.27
Constipation	88	8.1	17.6	12	15.0	24.2	Z = 1.18 *P* = 0.24
Breathlessness	89	21.9	27.0	11	24.7	27.8	Z = 0.31 *P* = 0.76
Fatigue	90	35.1	26.3	12	51.3	27.3	Z = 2.01 *P* = 0.04
Patient anxiety	89	18.8	24.7	12	27.3	28.1	Z = 0.99 *P* = 0.33
Patient depression	89	16.4	24.9	12	26.6	28.9	Z = 1.28 *P* = 0.20
Carer anxiety[a]	68	17.4	22.8	11	37.6	31.8	Z = 2.53 *P* = 0.01
Carer depression[a]	67	15.0	21.4	10	36.4	34.5	Z = 2.12 *P* = 0.03

[a]Scored by patient.

The results indicate good internal consistency for both scales on CAMPAS-R. With alpha coefficients of 0.77 (severity scale) and 0.80 (interference scale), none of the items appear redundant.[32] All items appear to relate to the same underlying construct and add information in terms of either severity or interference.

Results for criterion validation are also good. CAMPAS-R pain scores and pain scales on the BPI and EORTC were very highly correlated. Strong correlations were also achieved for other symptoms where the same dimensions were used in the analysis, i.e., severity items on CAMPAS-R were correlated with severity items on criterion measures (or when interference items on CAMPAS-R were correlated with interference items on criterion measures). Criterion validation *across* severity and interference dimensions resulted in weaker correlations. For example, the EORTC constipation score (CO)

Table 7
Predictive Validation for Interference of Symptoms

	Survival 60+ days			Survival <60 days			
Symptom Interference	*n*	Mean	SD	*n*	Mean	SD	Statistical Significance
Pain	88	20.8	26.5	12	45.4	32.9	Z = 2.59 *P* = 0.01
Nausea	87	6.8	18.3	12	13.6	16.8	Z = 2.51 *P* = 0.01
Vomiting	86	1.3	4.9	12	9.6	14.8	Z = 2.30 *P* = 0.02
Constipation	86	5.7	15.4	12	16.0	22.1	Z = 2.24 *P* = 0.03
Breathlessness	85	21.6	28.1	12	20.5	21.2	Z = 0.27 *P* = 0.79
Fatigue	90	33.3	26.6	12	46.4	30.5	Z = 1.44 *P* = 0.15
Patient anxiety	89	15.8	24.6	11	24.3	25.0	Z = 1.31 *P* = 0.19
Patient depression	89	14.9	24.0	10	22.9	25.2	Z = 1.37 *P* = 0.17
Carer anxiety[a]	69	16.3	23.7	11	31.3	29.8	Z = 1.97 *P* = 0.05
Carer depression[a]	66	14.5	22.6	11	28.6	31.3	Z = 2.06 *P* = 0.04

[a]Scored by patient.

is derived from a single question that refers to symptom severity, not interference. Correlations with the CO item are stronger for the CAMPAS-R score for severity of constipation than for the interference score. The same holds true for validation *across* severity and interference dimensions for other symptoms. These findings suggest that severity and interference on CAMPAS-R are different measurement components. However, further work is needed on these different dimensions to clarify their relationship in scoring individual symptoms.

Predictive validation of CAMPAS-R, whereby we compared two groups with different periods of survival after the study period, is also reassuring, however more limited. We would have expected those who died very quickly, within two months of study entry, to have different symptom scores to those who survived longer. This was demonstrated by statistically significant differences in the majority of symptom interference scores between the two groups. With symptom severity scores, just less than half of the items were significantly different between groups. As Kline[39] has pointed out, establishing predictive validity is not as simple as it appears. During the terminal period, it would be expected that interventions are put in place for symptoms experienced. What is not clear is the effect of such interventions on differences in symptom scores. This is clearly indicated for future validation studies, as is investigation of criterion groups with different disease groups, which we were unable to examine in this study because of the small size of our subgroups.

While we have demonstrated that the CAMPAS-R has good reliability and validity, it has to be acknowledged that the tool was tested on a limited, non-random sample. We experienced problems with patient recruitment and attrition, which have been recognized as difficulties in palliative care research.[24,40–42] Our level of refusal is not unusual in this research context. In another recently reported study, also of cancer and non-cancer patients near the end of life, 41% of hospitalized patients did not participate.[43] Our criterion subsamples also had slightly reduced numbers due to withdrawal from the study as patients became too ill to continue. It was, therefore, important that we were able to collect data to test for differences between participants and non-participants to consider the extent to which our findings are generalizable.

In prospective studies of palliative care, participation by more able patients is an important source of sample bias.[18] In this study sample, participants did survive longer than non-participants and those who withdrew from the study. This can be explained, to some extent, by our reliance on clinical estimates of prognosis that have been shown to be usually over-optimistic.[44–46] On reviewing actual survival times, we found that patients very close to death had been approached to take part, and this clearly affected both refusal rate and attrition from the study. But overestimation of prognosis also extended to participants and as a result CAMPAS-R was tested on patients very close to death as well. Nevertheless, it would be useful to undertake further validation of CAMPAS-R on a larger sample. However, the imprecise nature of clinical estimation of survival will remain a problem for any palliative care research that is dependent on the use of clinical prognosis for identification of possible study participants.

Conclusion

In this paper, we have demonstrated that CAMPAS-R is a reliable and valid tool for the measurement of symptoms in patients with advanced, progressive disease. A great strength of CAMPAS-R is its potential use as a patient held record for palliative care in the community. The simple visual analogue scale format, listing common symptoms that are often part of the lives of patients during palliative care, is intuitively attractive to patients. The tool is easy to use and can be completed in a short time, approximately 5 minutes. Furthermore, if patients are unable to complete CAMPAS-R unaided, it can be filled in by a lay carer recording the assessment made by the patients themselves. However, in this case it is important to know that it has been done by proxy assistance. In the context of the clear commitment in the NHS Cancer Plan[47] to improving the experience of care for cancer patients, such a straightforward reporting mechanism could have great benefits in palliative care practice in the UK.

Palliative care patients and their carers are often faced by problems of communication about symptoms and needs. Patients and carers

find it difficult to report to their doctors or nurses how they are feeling especially if changes in symptoms are relatively subtle over time. CAMPAS-R provides a different mechanism for communication of symptom states between patients, carers and health care professionals. GPs and district nurses could use the tool as part of their everyday clinical practice to monitor patients' self-reported health and symptoms. Future research will have to investigate whether CAMPAS-R does prove to be a useful patient held record for communication and for clinical practice.

CAMPAS-R also has potential for use in both educational and research settings. With the Cancer Plan's focus on principles and practice of palliative care for district nurses, CAMPAS-R, which was developed in the community setting, has direct relevance to their education and support in the key area of management of symptoms. Evaluation of the provision of care and services for palliative patients also needs reliable data collection methods. The CAMPAS-R tool is capable of recording changes in symptom scores and could be used by health professionals to evaluate interventions they have put in place. Randomized controlled trials also need methods of obtaining the patient's perspective on treatment regimens. This technique provides one way in which prospective data on symptoms could be collected.

CAMPAS-R, in overview, provides a simple, acceptable and psychometrically sound instrument for the monitoring of symptoms of palliative care patients in primary care.

Acknowledgments

When this study was conducted, Gail Ewing, Chris Todd, Margaret Rogers, Stephen Barclay and Anna Martin were members of the General Practice and Primary Care Research Unit, Dept. of Public Health and Primary Care, Institute of Public Health, University of Cambridge, United Kingdom. This work was undertaken by Chris Todd who received funding from the Department of Health. The views expressed in the publication of this article are those of the author's and not necessarily those of the Department of Health.

The authors would like to thank all the patients, lay carers and health professionals who took part in the study. They are also grateful to Barbara Arch and Toby Prevost, Center for Applied Medical Statistics, Department of Public Health and Primary Care, University of Cambridge for their advice and support.

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