Identifying palliative care patients with symptoms of depression: an algorithm

Julie A Robinson Senior Lecturer, School of Psychology, Flinders University and **Gregory B Crawford** Senior Consultant in Palliative Medicine, Repatriation General Hospital, Daw Park, Australia

Introduction: Even though depression has serious and wide-ranging effects on outcomes in palliative care, errors in the identification of depressed patients are common. **Objectives**: To examine the clinical validity of widely publicised one- and two-question screening tools for depression in two palliative care settings. Also, to examine the construct validity and acceptability of a new empirically derived algorithm. Method: Participants were Australian palliative care patients in an inpatient hospice (n=22) or the community (n=69). Patients completed an unstructured interview about their feelings, questions relevant to three reference standards, two screening questions for depression and questions about the acceptability of the screening questions. Results: The clinical validity of the one- and twoquestion screening tools did not generalise across the two care settings. In contrast, the algorithm met stringent criteria for clinical validity for two reference standards in both settings. The algorithm also selectively identified patients whose unstructured interviews referred to themes consistent with depression. The algorithm includes potentially sensitive questions about anhedonia and depressed affect. However, almost all patients and staff reported that asking such questions soon after referral was acceptable. **Conclusions**: A four-question algorithm designed to identify patients who warrant follow-up for depression showed clinical validity, generalizability and construct validity, and the content was acceptable to patients and clinicians. Palliative Medicine 2005; 19: 278–287

Key words: depression; palliative care; assessment; psychometrics; patients' acceptance of health care

Introduction

Patients' mental health is an integral dimension of palliative care, as defined by the World Health Organization. Depression is a serious mental health problem in palliative care. It is both prevalent and long lasting in this population. ²⁻⁶

Moreover, it has pervasive effects on outcomes. Depression affects patients' quality of life and mortality. Patient depression also adds to carer burden. Depression restricts clinicians' ability to manage patients' care by its effect on patient compliance, the efficacy of treatments for symptoms and patients' desire for death. Depression also affects outcomes for health services by precipitating inpatient admissions and increasing treatment costs beyond those due to illness severity. Moreover, and the proposed services by precipitating inpatient admissions and increasing treatment costs beyond those due to illness severity.

Despite its importance, the recognition, assessment and treatment of depression in palliative care are often less than ideal. Patients with depression are often not identified or treated.^{3,20-22} Those patients who receive

Address for correspondence: Dr Julie Robinson, School of Psychology, Flinders University, GPO Box 2100, Adelaide SA 5001, Australia.

E-mail: julie.robinson@flinders.edu.au

treatment may not have depression or may be given ineffective treatment.²⁰

This paper focuses on one method of overcoming barriers to the recognition of depression – the use of screening tools by attending clinicians to identify patients who warrant follow-up for depression. Until recently, the low priority that palliative clinicians have given to screening for depression has reflected its low priority for health care systems.²³ However, screening for depression is now advocated for all medical, cancer and palliative care patients by the US Preventive Services Task Force (USPSTF), the National Institute of Health, USA and the European Association of Palliative Care, respectively.^{24–26}

A wide range of screening tools for depression is available. However, many palliative patients cannot complete them.²⁷ Concerns have also been raised about the appropriateness of their content and length, and their psychometric properties when used in palliative populations.^{21,22,28–30}

This research examined whether widely publicised oneand two-question screening tools for depression have clinical validity in two palliative care settings. Because the properties of these tools proved to be setting-specific, a new algorithm for identifying patients who warrant

follow-up for depression was empirically derived and its clinical validity, construct validity and acceptability were assessed.

Study 1

Two brief screening tools for identifying medical patients who warrant follow-up for depression have been widely publicised. One accurately identifies depression in Canadian hospital inpatients receiving palliative care,³¹ but fails to detect many depressed patients in other palliative care settings.^{32–34} The other screening tool has unknown psychometric properties in palliative populations.³⁵ However, in other medical populations it yields false positive judgements for many patients who do not have depression. 35,36 This study focuses on the questions proposed by Whooley et al., as they have been publicised as the PRIME-MD screen for depression and adopted in draft guidelines for the National Health Service, UK. 35,37,38

Study 1 had three aims:

- To examine the clinical validity of the Whooley et al. questions in Australian patients in two palliative care settings.³⁵ Clinical validity refers to a tool's ability to distinguish affected and unaffected populations.
- To empirically derive an algorithm that showed 2) better clinical validity than these questions.
- To assess the construct validity of the algorithm by determining whether positive cases provided other evidence consistent with depression.

Method

Participants

Participants were Australian hospice- and communitydwelling patients served by a specialist palliative care service with a catchment of 350 000 people. During the study, malignancy accounted for 86% of referrals to the service, the average length of stay in the hospice was 9.5 days, discharge rate from the hospice was 50% and the average length of care for community patients was 126.2 days (median was 50.0 days).

Patients were eligible to participate if they were over 18 years of age, fluent in English, able to pass the Mini Mental State Examination (MMSE),³⁹ and if clinicians judged that they could tolerate a 40 minute interview and had a survival time sufficient to allow data collection (hospice ≥ 3 days; community ≥ 2 weeks).

Data concerning recruitment were available for 355 referrals to the community service (Table 1). Of the 134 community patients who were eligible to participate,

Table 1 Recruitment details for 355 referrals to communitybased palliative care

Outcome	n (%)
Not contacted Clinician did not ask permission for contact Ineligible Attempt to contact unsuccessful Died Declined	38 (11) 133 (37) 9 (2.5) 41 (12) 43 (12)
Recruited Deteriorated, failed MMSE or withdrew Usable data obtained	20 (5.6) 69 (19)

contactable and alive at the time when they would have been interviewed, 68% were recruited and 52% completed the interview. Data for two patients were withdrawn.

Data were available for 34 hospice patients who were invited to participate. Twenty-six agreed to participate and 22 provided usable data.

Measures

Screening questions. Adaptations of the questions proposed by Whooley et al. were used: 'During the past two weeks have you often been bothered by feeling down, depressed or without hope?' (depressed affect) and 'During the past two weeks have you often been bothered by a lack of interest or pleasure in doing things?" (anhedonia).³⁵ This wording matched the timeframe usually used in identifying depression and addressed palliative nurses' ethical concerns about the word 'hopeless'. 40-43

The possibility that a single question about depressed affect had clinical validity equal to that for the twoquestion screening tool was also explored.³¹

Clinical validity. Screening tools were compared to three reference standards:

- Psychogeriatric Assessment Scales-Depression 1) (PAS-D): a brief standardized interview designed to identify depressed elderly Australians. 41 Two criteria for follow-up suggested in previous research were assessed: a total score above three and a total score above four. 44-46
- 2) Symptom criteria for a major depressive episode in the Diagnostic and Statistical Manual of Mental Disorders (fourth edition) (DSM-IV).⁴⁰
- Symptom criteria for F32.1 Moderate depressive episode or F32.2 Severe depressive episode without psychotic symptoms in the International Statistical Classification of Diseases and Related Health Problems (tenth revision) (ICD-10).⁴³

The symptoms assessed by the three reference standards only partially overlap and they use different decision rules to identify cases.

Stringent criteria for clinical validity were applied because screening tools for depression are unlikely to be adopted unless their clinical validity and generalizability approaches those for biomedical screening tests (e.g., chest X-ray for tuberculosis). The four criteria were:

- 1) Total agreement $\geq 80\%$: the screening tool and the reference standard lead to the same decision in at least 80% of cases.
- 2) Cohen's Kappa statistic ≥0.61.⁴⁷ That is, concordance between the screening tool and the reference standard remains high after corrections for chance. Kappa values between 0.61 and 0.80 indicate 'substantial' concordance and those above 0.81 indicate 'almost perfect' concordance.⁴⁸
- 3) Sensitivity $\geq 80\%$: at least 80% of the positive cases identified by the reference standard were detected by the screening tool.
- Specificity ≥80%: at least 80% of the negative cases identified by the reference standard were detected by the screening tool.

Two additional 'desirable' criteria were:

- Positive predictive value ≥80%: at least 80% of positive cases identified by the screening tool were also identified as positive cases by the reference standard.
- Negative predictive value ≥80%: at least 80% of negative cases identified by the screening tool were also identified as negative cases by the reference standard.

Procedure

Clinical validity of screening questions. Patients completed an ordered sequence of assessment in a single session: the MMSE, an unstructured interview about moods and emotions, questions relating to the three reference standards, the two screening questions and questions about the acceptability of the timing and content of the screening questions. All interviewers had completed an undergraduate major in psychology and supervised training in the procedure.

Clinical validity of the algorithm. Data from the community sample were randomly divided into two sets. Dataset 1 (n = 35) was used to derive an algorithm that maximized concordance with the DSM-IV reference standard. The psychometric properties of this algorithm were then assessed using community Dataset 2 (n = 34) and the hospice dataset (n = 20).

Construct validity of the algorithm. De-identified transcriptions of community patients' unstructured interviews (n=58) were sorted into three groups: those for patients identified as warranting follow-up for depression by the algorithm and DSM-IV and ICD-10 reference standards (n=21), those for patients that neither the algorithm nor these two reference standards identified as warranting follow-up for depression (n=33) and those for patients for whom the algorithm and the two reference standards disagreed (n=4). In this subsample, ICD-10 and DSM-IV reference standards agreed in all cases.

A qualitative content analysis using standard inductive techniques was conducted. ⁴⁹ Successive random samples of transcripts were drawn from each group and presented in a random order for independent coding by the two authors. Cases of disagreement were discussed until consensus was achieved. Theoretical saturation was reached after 28 transcripts (i.e., three consecutive transcripts yielded no novel themes). Transcripts were then unblinded and themes that discriminated between patients who were and who were not judged by the algorithm to warrant follow-up for depression were identified. The remaining 30 transcripts were then blind-coded for these themes.

Results

Background

Recruitment of hospice and community patients took place between March 2001 and July 2002 and between January 2001 and March 2002, respectively. The profile of patients in the hospice and community samples differed (Table 2).

Symptoms of depression were prevalent in both the hospice and community samples, even though participants were among the most robust members of their populations (Table 3). Note that the PAS-D > 3 reference standard is not useful in the hospice dataset since it identifies near ceiling levels of patients as requiring follow-up for depression.

Clinical validity of screening questions

Neither screening tool met the essential criteria for clinical validity across settings of care (Table 4).

Clinical validity of the algorithm

The empirically derived algorithm comprised four questions (Appendix). It met all essential criteria and at least one of the desirable criteria for clinical validity for the DSM-IV and ICD-10 reference standards in all three datasets (Table 5). However, for each of the PAS > 3 and PAS > 4 standards, the algorithm met the essential criteria for clinical validity in only one dataset. Therefore,

Table 2 Clinical and demographic details for participants

	Hospice $(n=22)$	Community (n=69)
Gender (%)		
Males	46	57
Female	55	44
Age (years)		07.4
Mean	66.9	67.1
Range	43-88	36–85
Primary diagnosis (%) Malignancy		
Gastro-intestinal	9.1	20
Lung	14	17
Breast	14	15
Gynaecological	18	4.3
Urological	14	8.7
Haematological	9.1	7.2
Skin	4.5	4.3
Brain	4.5	1.4
Head and neck	- 4.5	1.4 4.3
Unknown primary Non-malignancy	4.5 9.1	4.3 13
Missing data	J. I —	2.9
TVIISSITIG GGEG		2.0

the algorithm cannot be recommended in settings in which PAS-D is the most relevant standard.

Because the algorithm contains conditional steps, fewer than 50% of patients in any of the datasets would have been asked all four questions (Table 6).

In addition, the clinical validity of the algorithm was generalizable within the limits in which it was tested (Table 7). Kappa values remained high across datasets that differed in the prevalence of cases and all measures of clinical validity remained high across datasets that differed in the frequency of the symptoms assessed by the algorithm.

Construct validity of the algorithm

The algorithm selectively identified patients whose interview responses referred to three themes: depression, suicide and grief over loss of self (Table 8). Fifteen (88%) of the 17 patients who referred to these themes were identified by the algorithm as warranting follow-up for depression. Another patient of the 17 (5.9%) indicated that he was receiving effective antidepressant therapy. An additional six patients actively denied being depressed. The algorithm judged that some of these

Table 3 Percentage of community and hospice patients warranting follow-up for depression

Reference standard	Hospice (n=22)	Community (n=69)
PAS-D > 3 PAS-D > 4	91 64	52 ^a 36 ^b
DSM-IV symptom criteria	59	42
ICD-10 symptom criteria ^c	65	41

 $[\]chi_{(1)}^2 = 10.6$, P < 0.01.

warranted follow-up for depression (33%), while others (67%) did not.

Discussion

All reference standards indicated that a large percentage of patients in both settings warranted follow-up for depression. This is consistent with previous research. 2-4,32,50,51

The clinical validity of the one- and two-question screening tools had limited generalizability across care settings in this study. This confirms earlier reports of relatively poor sensitivity or specificity for such tools in some settings. 33-36

The psychometric properties of the empirically derived algorithm were superior to those for the screening questions proposed by Whooley et al. and those previously reported for other screening tools in palliative populations:35 the Hospital Anxiety and Depression Scale, ^{30,52} the Edinburgh Postnatal Depression Scale, ^{32,51} the short form of the Beck Depression Inventory,³¹ the Mood Evaluation Questionnaire, 34 the Brief Assessment Schedule Depression Cards,⁵³ the Rotterdam Symptom Checklist,⁵² and a single item visual or verbal analogue scale. 31,32,34

Because the algorithm includes symptoms that palliative clinicians rarely include in the assessment of depression, its use is likely to change the patients who are identified as warranting follow-up. 54

Despite debate over the status of somatic symptoms in the diagnosis of depression among patients receiving palliative care, two somatic symptoms (fatigue and psychomotor agitation or retardation) were included in the empirically derived algorithm. 22,28,55 Previous research supports the inclusion of somatic symptoms in assessment of major depressive episodes.² In particular, fatigue has been identified as a marker of depression in previous research and is accorded the same status as anhedonia and depressed affect in ICD-10 diagnoses of depression.⁵⁶

The construct validity of the algorithm was supported by a content analysis of patients' interview responses. This demonstrated that the algorithm and the DSM-IV and ICD-10 reference standards selectively identified patients who showed other evidence of psychological distress consistent with the construct of depression. This strategy for assessing construct validity overcame limitations associated with using a diagnostic interview as a 'gold standard'. Because interviews that allow a differential diagnosis are lengthy, researchers either assess a subset of disorders or include only the most robust patients. 31,34-36 The first strategy has no advantage over the reference standards used in this research, while the second limits the generalizability of results to clinical

 $[\]chi_{(1)}^2 = 5.1$, P < 0.025.

Table 4 Clinical validity of screening questions for patients in hospice and community settings

Screen and reference standard	Psychometric properties						
		Essential				Desirable	
	Total agreement (%)	Cohen Kappa statistic	Sensitivity (%)	Specificity (%)	Positive predictive value (%)	Negative predictive value (%)	
Hospice patients (n = 22) Depressed affect question	n alone						
PAS-D >3	41	-0.03	40	50	89	7.7	
PAS-D >4	59	0.22	50	75	78	46	
DSM-IV symptoms	73	0.47	62	89	89	62	
ICD-10 symptoms ^a	80	0.61	69	100	100	64	
Both screening questions							
PAS-D >3	68	0.09	70	50	93	86	
PAS-D >4	73	0.41	79	63	79	63	
DSM-IV symptoms	91	0.81	100	78	87	100	
ICD-10 symptoms ^a	100	1.00	100	100	100	100	
Community patients (n = 69) Depressed affect question							
PAS-D >3	75	0.51	69	82	81	71	
PAS-D >4	77	0.52	80	75	65	87	
DSM-IV symptoms	74	0.55	72	75	68	79	
ICD-10 symptoms	78	0.47	75	81	72	83	
Both screening questions							
PAS-D >3	73	0.45	78	67	72	73	
PAS-D >4	69	0.38	84	59	54	87	
DSM-IV symptoms	74	0.49	86	65	64	84	
ICD-10 symptoms	78	0.57	89	71	78	91	

a n = 20.

populations. Moreover, the validity of standard diagnostic interviews for palliative patients has been contested. 2,22,28,54,55,57

In conclusion, the algorithm provides meaningful and relevant information in samples that differ in the prevalence of the symptoms it assesses and the percen-

Table 5 Clinical validity of an empirically derived algorithm for patients in hospice and community settings

Screen and reference standard	Psychometric properties					
	Essential				Desirable	
	Total agreement (%)	Cohen Kappa statistic	Sensitivity (%)	Specificity (%)	Positive predictive value (%)	Negative predictive value (%)
PAS-D >3 Community dataset 1 ^a Community dataset 2 ^b Hospice dataset ^c	83 85 85	0.65 0.70 0.69	80 76 63	85 100 100	80 100 100	85 72 22
PAS-D >4 Community dataset 1 ^a Community dataset 2 ^b Hospice dataset ^c	74 79 85	0.45 0.58 0.69	80 80 83	72 79 88	53 75 91	90 83 78
DSM-IV symptom criteria Community dataset 1 ^a Community dataset 2 ^b Hospice dataset ^c	94 94 85	0.88 0.88 0.69	100 94 83	91 94 88	87 94 91	100 94 78
ICD-10 symptom criteria Community dataset 1 ^a Community dataset 2 ^b Hospice dataset ^c	94 91 90	0.88 0.82 0.79	100 93 85	91 90 100	87 88 100	100 94 78

a n = 35. b n = 34.

 $^{^{\}circ}$ n = 20.

Table 6 Number of questions algorithm required to make a judgement about follow-up

Number of guestions	Patients (%)			
questions	Community dataset 1 (n=35)	Community dataset 2 (n=34)	Hospice $(n=20)$	
1 3 4	29 46 26	18 41 41	5 60 35	

tage of patients that warrant follow-up for depression. By using conditional steps, it minimises the number of questions that need to be asked. The algorithm supplies the wording for the questions and states the decision rule, making it easy to use and eliminating the need for scoring and interpretation or any special training.

Study 2

Some palliative clinicians are reluctant to ask questions about depression.²⁹ Questions regarding anhedonia and depressed affect are included in the algorithm. This study assessed whether it was acceptable to patients and clinicians to ask about these two potentially sensitive symptoms around the time of referral to a palliative care service.

Method

Clinicians (two doctors and eight nurses) asked the screening questions about anhedonia and depressed affect during the patient's initial clinical assessment. Clinicians and patients were asked about the acceptability of the content ("Would you rather not have asked this patient one or both of the questions about mood?") and

timing of the screening questions ("Was the timing of questions about mood appropriate for this patient?") and to make comments. Clinicians responded after the assessment. Patients made judgements retrospectively, in the final step of the research procedure in Study 1. Matched data for clinicians and 60 community patients and clinician-only data for an additional 188 community patients were available.

Results and discussion

In both samples, the vast majority of patients and clinicians judged that the content and timing of the questions was acceptable (Table 9). This is consistent with previous research.^{34,58} Clinicians perceived that the questions were equally appropriate for patients who did and who did not agree to participate in a study that involved disclosure of emotions.

Relatively few patients or clinicians accepted the invitation to make additional comments. However, in five instances, clinicians would have preferred to ask the questions on the second visit to the patient. Such a postponement remains consistent with recommendations to screen for depression as soon as possible after referral.5

General discussion

Routine screening for depression among palliative care patients requires a simple, quick and psychometrically sound screening tool. The current findings and previous studies indicate that the clinical validity of a single question about depressed affect or two questions about anhedonia and depressed affect is context specific. 33,34

In contrast, a brief empirically derived algorithm met stringent criteria for clinical validity across care settings for two reference standards. It is the first screening tool

Table 7 Diversity in three datasets in which the algorithm showed clinical validity

	Patients (%)			
	Hospice (n=35)	Community dataset 1 (n=34)	Community dataset 2 (n=20)	
Demographic characteristics Male	46	54	59	
Patients warranting follow-up DSM-IV ICD-10	59 65	37 37	47 44	
Prevalence of symptoms assessed in algorithm Fatigue Depressed affect Anhedonia Psychomotor retardation or agitation	96 46 55 91	71 54 31 74	82 35 44 65	

Table 8 Construct validity: distinctive interview themes for patients identified by the algorithm as warranting follow-up for depression

Theme	Examples
Depression	"I've had feelings of deep depression and probably a little bit of guilt I've never felt so low in all my life I was in that awful down depressed situation and I just didn't want to talk to anybody. I just wanted to lie in bed and die". "Three weeks ago I was a basket-case virtually I was overcome by moods I spoke to Dr X about depression. Ah, it's hard to describe depression 'cos I dunno if I've ever had it before. But I was definitely down the chute" "Depression really has just really hit I think that (is) probably a little bit of a concern. I don't like feeling like that. I don't like that feeling at all I'm not coping as well when I'm depressed" "I did feel a bit depressed". "I have been feeling a bit down, well, very down in the dumps" "A new word that I've discovered, dysphoria, which is the opposite of euphoria, brought home to me by Dr X. So that's what I was experiencing. But I was experiencing very bad feeling"
Suicide	"The options are from suicide to to anything possible really. That depends on my mental state probably. You see how disappointed I feel" "(I'm not) doing anything about it myself. I haven't got the guts to do – but I'm very much for euthanasia I can remember saying, ' Get hold of Philip Nitschke (Australian advocate for physician-assisted suicide and euthanasia)"
Mourning loss of self	"Very sad You smile and act happy and get on with it and inside you don't. Inside you you're mourning for yourself, what it used to be." "I feel self-pity I feel sad, grief. I already grieve the losses I've had There's just one more loss. And obviously I grieve over those losses. I guess losses of all sorts of things I grieve over, and I think that's the hardest part to accept — whatever accept means — those losses."

^a Patients judged to warrant follow-up by the algorithm but not by DSM-IV or ICD-10 reference standards.

to do so. The algorithm also shows good construct validity by selectively identifying patients who provide other evidence that they warranted follow-up for depression. In addition, the vast majority of patients and clinicians judged that it was acceptable to ask questions about the sensitive topics in the algorithm soon after referral to the palliative care service.

The choice of an algorithm rather than a scale format avoids giving a score for symptoms that are not relevant to decisions about follow-up. Fatigue was included because its absence was the best single identifier of patients who did not warrant follow-up. Similarly, because the algorithm is an ordered sequence of questions, psychomotor retardation and agitation are assessed only for patients with fatigue and either depressed affect or anhedonia. The psychometric properties of the algorithm were achieved without reference to the cause (e.g., disease, treatment) of the symptoms.

The algorithm is an effective screening tool for symptoms of depression. However, it does not provide

Table 9 Acceptability of the two screening questions for patients and clinicians in two samples

Respondent	Content of both questions acceptable (%)	Ask in first visit acceptable (%)
Matched data (n=60) Patient Clinician	97 93	92 88
Clinician only (n=188)	97	92

sufficient information to inform treatment because it does not differentiate patients with depression from those with other disorders that have overlapping symptoms (e.g., dementia, schizophrenia) but benefit from different interventions. Rather, it allows clinicians to make three choices that will influence outcomes for patients, carers, themselves and their health service: whether or not to screen patients for depression, which patients to screen and who will provide follow-up assessment.

Assessment of depression provides patients, family members and clinicians with greater understanding of patient behaviour. This may yield clinical benefits whether or not interventions for depression are pursued. However, many clinicians who choose to screen for depression do so with the intention to treat. There are insufficient high quality evaluations of interventions for depression in palliative care settings to inform treatment decisions. Clinicians should therefore be guided by the wider research literature on the treatment of depression in medically-ill populations. ^{59,60}

Ethics

This study was approved by the Social and Behavioural Research Ethics Committee of Flinders University, Adelaide, Australia and the Research and Ethics Committee, Repatriation General Hospital, Daw Park, South Australia.

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Appendix SHORT SCREEN FOR DEPRESSION SYMPTOMS (SSDS)

Patient:		
	csk questions verbatim Tick positive response Cross for nega ocument the decision of algorithm Plan follow-t	tive response up if appropriate
	☐ In the past 2 weeks, have you been worn out or had too little energy, even when you haven't been doing a lot? YES	NO NO O
F O BOTH L L O W	During the past 2 weeks, have you often been bothered by a lack of interest or pleasure in doing things? In the past 2 weeks, have you been feeling depressed or sad at all? YES TO ONE ONL	F O L L O W
U YES TO EITHER	In the past two weeks, have you talked or moved more slowly than is normal for you?	NO TO BOTH
Judgement of a	<u>gorithm</u>	

DOES/DOES NOT warrant follow-up for depression	
PLAN:	• • •
•••••••••••••••••••••••••••••••••••••••	•••