Depression in palliative care patients in Australia: identification and assessment

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Summary

Depression is poorly recognised, under-assessed and under-treated in patients receiving palliative care for a life-limiting illness. There are barriers to assessment and diagnosis, and limited access to specialist clinicians who might assist in these complex assessments and who could provide options for treatment.

The three studies presented, using different research methodologies, and using both qualitative and quantitative analysis, seek to clarify these issues and to provide some solutions. A questionnaire was sent to all Palliative Care Services (PCS) in Australia. Questions included what part specialist psychological clinicians played in multi-disciplinary team meetings and in the treatment or coordination of patient care. Very few PCS used a valid screening instrument for psychological distress and very few had regular support from a psychiatrist or psychologist. Many did not have access to social work support.

There are two competing issues with regard to recognising and assessing depression in palliative populations. A rapid reliable screen that points to a likely problem would be useful, but also there is a need to understand something of the patient experience of depression.

In the second study, the one- and two-item screening instruments widely used in palliative care are examined and limitations that have been found in other settings are confirmed. A new novel screening tool is developed from this data and tested empirically. This algorithm is short, has good psychometric properties and is validated for an Australian palliative care population. Depending on the response pattern it is possible to identify that a particular patient has significant symptoms of depression by asking between one and four questions. Professional carer and patient acceptability of the questions is high.

The understanding of the experience and symptom profile of depression in

Australian palliative care patients is addressed in the third study. Patients and family carers were recruited prospectively from palliative care and oncology ambulatory clinics of two teaching hospitals in an Australian capital city. The Geriatric Depression Scale (GDS) was administered to the patient and the Collateral Source version of this instrument was asked of the carer. A subset of this sample completed the measures twice. The results using this 30-item scale were then compared with all the known previously published short versions of this scale. Two short forms met as many psychometric criteria as the longer forms. None of the versions of the GDS showed sufficiently high correlations between carer-completed and patient-completed forms. The frequency of symptoms was also assessed. Patients more frequently reported fatigue and anhedonia than depressed affect.

Despite many screening instruments being available for depression, their use is limited in Palliative Care Services. Although these studies have validated several options for Australian palliative care patients, the issues behind the low uptake rates for screening have not been resolved. The final chapter of this thesis constructs known and potential barriers into a logical structure and then offers some solutions to improve access to mental health professionals by considering service models and applying this theory to the problem of depression and its assessment in palliative care populations.

Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Acknowledgements

I wish to thank my wife, Christine Crawford for the time and effort and support she has given to me. This thesis would not have been completed without her constant encouragement, support and perseverance. She has provided stability, considered thought and sacrificed much of our time together for this to come to fruition. My daughter, Lucy Crawford merits particular thanks for her rapid reliable and friendly administrative support.

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I wish to thank Palliative Care Australia and their CEO in 2000, Ms Tonia Barnes for her assistance and willingness to assist me to locate all the known Palliative Care Services in Australia for Study1.

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Chapter 1

Thesis structure and contributions

The interface of two major issues, depression and palliative care, is considered in this thesis.

Developing interest

The first sparks of my interest in this particular area of palliative medicine arose in discussions with colleagues. Increasingly I had become aware of the burden of depression for both palliative care patients and their carers. The combination of terminal illness and depression seemed too much for any one person to bear; these patients made me feel inadequate and frustrated. Many of my acquaintances and colleagues seemed to expect that depression would naturally accompany a terminal condition, but not all of my patients were depressed.

Case study

To face either depression or the end of one’s life is not easy. Even when the diagnosis of depression was apparent, major difficulties of care were obvious to me. But depression may not always be obvious, and I was challenged to consider my skills of assessment, and to wonder how often I had not considered depression as an issue, or missed the diagnosis completely. The case study described in Chapter 2 was a particularly pertinent episode. It was a pivotal experience, one with the potential to change personal and professional values and interests.

Early influences

I had read some of the palliative care literature about depression and was able to visit Dr (now Prof) Mari Lloyd-Williams in 1999 when she was working in

Leicester, UK. I had worked in Leicester in my early post-graduate years and the coincidence of another Palliative Medicine colleague with a general practice background and an interest in depression was encouraging. Prof Lloyd-Williams generously spent an afternoon with me. Her knowledge and enthusiasm left me wanting to know more. I was stimulated to consider further the dilemma of depression in my clinical practice. Prof Lloyd-Williams kindly allowed me to adapt her questionnaire of psychosocial service provision in hospices in the United Kingdom for Study 1.

Availability of staff and the use of screening instruments

The first of the studies of this thesis was a postal survey of psychological and social service provision in all specialist Palliative Care Services in Australia. The survey assessed the availability of psychological and social service providers and the knowledge and use of screening instruments for psychological distress in Australian Palliative Care Services. The modification of the questionnaire, distribution, collation, data entry, statistical analysis and writing are all my work entirely.

Current brief screening instruments and developing a new one

I met Dr Julie Robinson, an academic psychologist with the School of Psychology at Flinders University, at about the same time. She had been studying cognitive failure in Daw House hospice patients. My growing interest in depression in this population led to a collaboration that resulted in Study 2. This study addressed the issue of screening within the palliative care population and assessed the psychometric properties of a one- and two-item screening instrument for depression in an Australian in-patient and community palliative care population. This study did not confirm previously published findings of a Canadian population using similar questions.[1] A novel brief screening tool with sound psychometric properties, not based on a scoring system, was derived empirically to offer a quick validated tool for use in Australian populations. The algorithm or “Short Screen for Depression Symptoms (SSDS)” has a series of conditional steps, which lead to a judgement, rather than being a scored screening instrument. This new instrument provides an alternative solution to the problem of recognition. A minimum of one and a maximum of four questions are asked, with less than 50% of participants being required to answer all questions. The psychometric properties of the SSDS were assessed using three different classification systems for depression; the Diagnostic and Statistical Manual of Mental Disorders (DSM), the International Classification of Disease (ICD) and the Psychogeriatric Assessment Scales-Depression (PAS-D). These assessments were independently confirmed by deriving consistent themes from an unstructured patient interview about emotions and feelings.

The research question about the utility of one- and two-item screening questions in Australian palliative care patients was mine. The design and organisational issues of the research became a joint effort. I was the lead clinician being responsible for discussions with and education of the clinical team who asked the initial screening questions of patients admitted to either the in-patient or community palliative care program. I provided clinical and emotional support to the research assistants who conducted the interviews of patients. The research assistants were honours students from the School of Psychology at Flinders University. They had interviewing skills but no experience of the confronting issues associated with terminally ill patients. Dr Robinson has played no part in recruitment or the writing of Chapter 5 of this thesis. However, part of the data on which Chapter 5 is based led to a co-authored publication, with her as the lead author (Appendix 5.1). [2] The concept of creating a stepped algorithm was hers. The development of this instrument, the writing of the *Palliative Medicine* article and data analysis for this article was conducted jointly. This publication was written to introduce a novel brief screening instrument to palliative clinicians. One of the honours students, Ms Grace Ellis was given permission to conduct a sub-study, in which part of the data on which Chapter 5 was based was supplemented with additional data collection. She was granted ethics approval for this work and it was presented as her Honours thesis. She was assisted by us to publish her study and this is cited in Chapter 3 in the literature review.[3] No part of that publication is in common with any chapter of this thesis.

Multi-item screening instruments tested in palliative care patients

The third study in this thesis also addressed the issue of assessing depression in palliative care patients. There are two complementary issues with regard to recognising and assessing depression in these populations. A rapid reliable screen that points to a likely problem, such as the one developed in Study 2, is useful, but there is also a need to understand something of the patient experience of depression. Palliative clinicians need to have both perspectives in mind and to have access to instruments that help examine both aspects of depression.

The Geriatric Depression Scale (GDS) is an instrument that is widely used in psychiatric practice and has many published short forms. This instrument allows clinicians to gain insight into the experience and symptom profile of depression. The utility of the GDS in Australian palliative care patients is the focus of the third and final study. Patients and family carers were recruited prospectively from attenders at palliative care and oncology ambulatory clinics of two teaching hospitals in an Australian capital city. Patients were assessed for cognitive capacity and a symptom assessment scale was administered which included a visual analogue scale for depression. The Geriatric Depression Scale (GDS) was administered to the patient and the Collateral Source version of this instrument was asked of the carer. Carers and family members are frequently asked to provide information about symptom issues of their family member, to act as proxies or to act as alternate or collateral sources of information. This is often done in clinical practice with little thought for the implications of such assessments. Many palliative care patients cannot complete standard assessments of psychological symptoms and illness because of illness-related fatigue, cognitive decline or cognitive failure. The value of proxy assessments in this population was measured. A subset of patients and carers completed the measures twice.

The third study also examined and compared the frequency with which patients showed a wide range of non-somatic symptoms of depression. Very few studies of depression that have used multi-item scales have reported the frequency of specific symptoms of depression. There is relatively little quantitative data about the way in which symptoms of depression are expressed in palliative populations. Neither has there been a focus on the types of symptoms of depression that collateral sources report being present in patients, although it is often clinical practice to ask a personal or professional carer to comment on a patient's condition or symptoms. Patients more frequently reported fatigue and anhedonia than depressed affect.

The data on which the third study was based formed a sub-study of a National Health and Medical Research Council (NH&MRC) funded project known as "The Objective Assessment of the Trajectory of the Course of Terminal Illness Study". I was one of the chief investigators and am indebted to my fellow chief investigators, Prof Neil Piller, Prof Adrian Esterman and Dr Roger Hunt, for allowing me to use this component of the research for this thesis. I provided the majority of the recruitment for the cancer arm of this multi-site, multi-disease study and the clinical support for the research assistant who was employed by this project to collect and enter data. The design of the psychological and cognitive components of this study was developed in consultation with Dr Robinson, although she is not a chief investigator of the project. Some of the analyses of this data were performed jointly and it is now impossible to separate individual contributions between myself and Dr Robinson. Material included in Chapter 6 has been submitted for publication to the journal *Palliative & Supportive Care* with me as the primary author.

Other barriers to the assessment and management of depression

Some of the patient, clinical and organisational barriers to the assessment of depression are then explored in Chapter 7, using a synthesis of the literature. Possible service delivery models are presented as a way of increasing access to psychological and mental health professionals. This provides clinicians and administrators of Palliative Care Services with some options to maximise existing resources, to improve linkages, relationships and access to mental health professionals. It is argued that there is a responsibility not only to detect depression but also to have adequate resources to manage the outcome of these assessments.

The synthesis of the literature and thoughts about real and perceived barriers to the assessment of depression in palliative care has come from conversations between me and Dr Robinson. I have presented the outline of the subject matter of Chapter 7 as an oral presentation at the 8th National Palliative Care Australia Conference in Sydney in 2005. The preparation of this talk and the writing of Chapter 7 are my own work entirely. Dr Robinson was cited as a co-author for this oral presentation because of her input into the reasoning behind this work.

Summary

Three separate studies, using different research methodologies, and using both qualitative and quantitative analysis, have demonstrated the paucity of mental health professionals in Australian Palliative Care Services and the limited use by palliative care clinicians of screening tools for psychological distress. The one- and two-item screening instruments widely used in Palliative Care Services are examined and limitations that have been found in other settings are confirmed in this Australian palliative care patient population. A new novel screening tool is developed from this data and tested empirically. Larger multi-item screening instruments are likely to provide understanding of the symptom burden in palliative care patients. A screening instrument that has been used extensively in psychiatric practice, the GDS and the many published short forms, are examined in another palliative population and the value of carer-reports assessed.

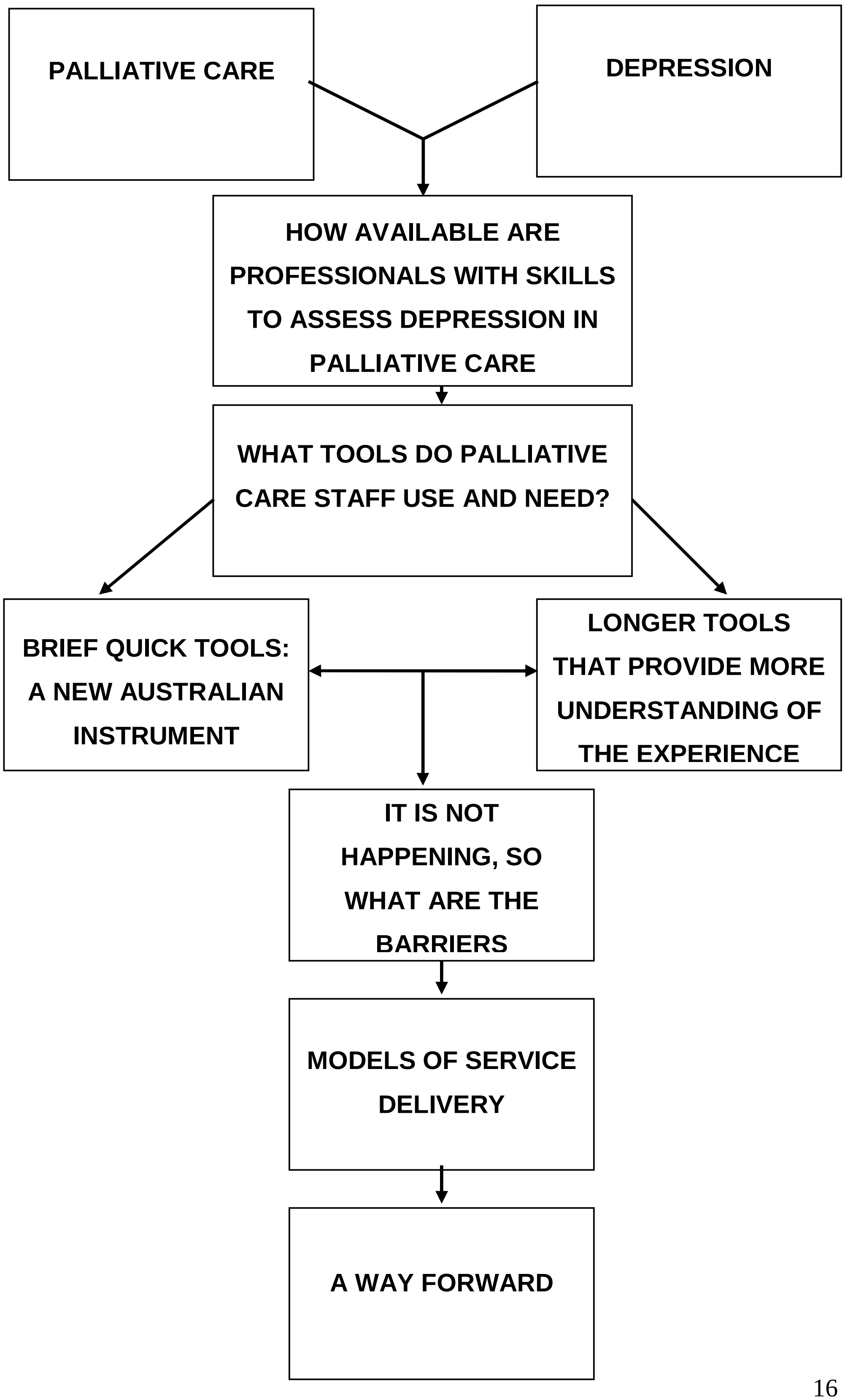
Despite many screening instruments for depression being available, their use is limited in Palliative Care Services. Although these studies have validated several options for Australian palliative care patients, the issues behind the low uptake rates for screening have not been resolved. Other barriers are likely to exist.

The final chapter of this thesis constructs known and potential barriers into a logical structure and then tries to offer some solutions to improve access to psychosocial professionals by considering service models and applying this theory to the problem of depression and its assessment in palliative care populations.

Diagram 1.1 is a pictorial representation of the structure of this thesis.

This thesis is limited to the identification and assessment of depression. It is acknowledged that the actual nosology of depression is open to diverse interpretations, but they are beyond the scope of this thesis. Furthermore, decisions about treatment options and the relative merits of different interventions and therapies for depression will not be considered.

Diagram 1.1 Pictorial representation of the thesis structure



Chapter 2

Introduction

I sat by the bedside of a 15-year-old girl. She had been diagnosed with a primary hepatocellular malignancy 18 months earlier. There had initially been great hope of cure and great expectations had been invested in surgery and chemotherapy to effect a cure.

Unfortunately the disease was now progressing. There was a large metastasis in her pelvis and this was now causing urinary difficulties and deep pelvic pain. She had exhausted simple analgesics and opioids had been introduced. Over the next weeks, bilateral leg oedema developed and her physical function was deteriorating. She had fallen several times. Diuretics had been introduced and a trial of steroids had been contemplated. All this came in the context of a young woman on the brink of adult life, living with her single mother and two younger sisters. There were many physical symptoms and no disease-modifying therapies available. The mother and the girl herself had declined to have palliative radiotherapy because of a previous bad experience.

Was she depressed? She was talking about death and the afterlife, and there were many stories about fairies. She was not eating very much and her sleep pattern was very disturbed. Was this normal teenage behaviour? At times she was tearful. Who would not cry at a time like this? At other times her mood appeared overly cheerful and forced. And then she was withdrawn, moody and less reactive. What is normal for a 15-year-old girl facing the end of her life?

And how did I feel about this? Was I being totally objective? I attempted to provide this girl and her family with supportive counselling. I sought assistance from the psychologist from the tertiary paediatric hospital where she had initially been treated. This girl was no longer able to travel easily. She and her mother asked me about a priest and I located a young woman priest who visited several times.

After several weeks I prescribed an antidepressant. There had been some disquiet from some members of the multi-disciplinary Palliative Care team with suggestions that perhaps I was trying to medicate a normal and expected reaction. The nausea became somewhat more of an issue, most probably caused by the antidepressant. And after two weeks there did not appear to be any benefits, although most of the other side effects were less intrusive. She continued taking the medication for another 10 days.

I sought advice from the adult liaison psychiatry service in the hospital in which I am based. I sought advice from the tertiary paediatric psychiatric service. I was getting conflicting recommendations. I changed antidepressants and with some trepidation visited 10 days later.

A smiling young woman, who was dressed, greeted me on the driveway. She almost ran to meet me. Her leg oedema was resolving. Her pain was diminishing and she had insisted that the urinary catheter be removed on the previous day and she was micturating normally. I had a sense of wonder and failure at the same time. What was happening? Why had I not started this medication earlier? Was it an effect of the medication at all? Was this response and its magnitude possible? It raised more questions than there were answers.

Was this depression? Could it have been diagnosed earlier? How can one recognise depression in the seriously ill and the dying? Are their symptoms different from the general population? What are the best interventions, and are responses to therapies different in this population? I had seen some barriers to diagnosing depression. It appeared that community psychiatric support was not always readily available. What other barriers and issues are there and what other resources might I have used? As a palliative medicine specialist I have some skills in assessing symptoms of depression and am able to coordinate supports and initiate treatments, but how might this be improved for others in my position or clinicians with less access to advice and support?

I had been accused of medicalising a normal process by some of the other team members. There had been large anxieties about medications and uncertainties about which to use. General Practitioners and Community Nurses are often the only palliative care health professionals for large parts of Australia. I am fortunate to work in a multi-disciplinary specialist Palliative Care team with access to many different professional services. What are the psychological supports available to Australians facing the end of their lives? Can psychological distress be recognised more readily and care be improved for this group of people? What are the barriers to recognising and managing this problem? These are some of the questions that have led me to this study.

Chapter 3

Literature review

Introduction

Palliative Care, the care of those anticipating the end of their lives, is a developing area of medical care. Depression is a significant issue for all Australians. There is a growing body of research about depression in palliative care populations and concern that it is a difficult and not particularly well-managed problem. This may relate to the inherent nature of depression, but is possibly compounded by the difficulties of assessment and management in palliative populations, a group of people with many physical symptoms and the added burden of the existential issues associated with anticipating the end of life. This review of the literature will consider depression, palliative care and how these two areas intersect.

Depression

Depression is a major health issue in Australia.[4] It has a significant and often unseen impact on the well-being and quality of life[5-8] of the people it affects and on those around them. However, the construct and definition of depression is difficult. It is poorly understood. The general public and even health professionals may have quite different and divergent concepts, understandings and beliefs about what depression is. The general public may consider crying, feeling sad, being melancholic or feeling “upset” or “down and blue” to be depression. Palliative care professionals are often untrained in psychological health assessment and management. They are likely to have varied and possibly inaccurate concepts about psychological illness. A mental health professional diagnosis of a major depressive illness requires a constellation of specific symptoms that may include feelings of sadness and feeling “down and blue” that are pervasive and persistent.[9,10] Symptoms are on a spectrum of severity and can extend to a psychotic illness with loss of contact with reality and with loss of hope for the present or the future. Even the diagnostic systems proposed by specialist psychological authorities vary in the symptom constructs that are described to make a diagnosis, and the instructions and advice offered may be difficult to interpret and implement.

Depression is a prevalent problem in our society.[11-15] Depression is poorly recognised and poorly treated[12,16-19] within palliative care patients,[a] causing increased suffering and hardship for these patients and their carers and families. Physical symptom control can be much more difficult to achieve in these patients.[20] Carers' ability to support their depressed family member or friend may be diminished, at a time when there may be very little pleasure remaining in their lives. Interaction with and assistance from health care providers can be impeded, resulting in poorer health outcomes.[21-25] Depressed patients are less likely to attend appointments.[22] They are likely to feel bad about themselves and to make people around them feel uncomfortable, further perpetuating their isolation. They are more likely to be seen as "bad" or "difficult" patients, further reinforcing these negative feelings.

Diagnosis of depression

There are accepted systems for classifying the symptoms and signs required to make a diagnosis of depression.[9,10] There is however no single universally agreed system to confirm such a diagnosis and no one objective measure. The "gold standard" for making a diagnosis remains a systematic, structured clinical interview followed by the judgement of a mental health professional. The two

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[a] In this thesis people living with a known life-limiting illness, those diagnosed with a terminal illness and those being cared for or supported by a Palliative Care Service, as well as those admitted to hospice or palliative care in-patient facilities, will all be referred to as "patients". This is not meant to be disrespectful or pejorative. For some disciplines "clients" may be the preferred term of reference. The terms used should not be a barrier to understanding.

widely accepted classifications of mental illnesses are the Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association[10] and the International Classification of Diseases (ICD) developed by the World Health Organisation.[9] Many of the symptoms that might be considered may be on the continuum from normal variation to a clinical disease or condition. There is also possible overlap of symptom criteria with other known physical and psychological diseases and conditions. The diagnostic process requires the patient to have the physical, mental and psychological capability to participate. There are clearly potential and real barriers to the assessment and diagnosis of depression, particularly in terminal illness.

Diagnostic and Statistical Manual of Mental Disorders, version IV (DSM-IV)

The DSM-IV is a widely accepted diagnostic system. It requires that symptoms have been present and persistent for two weeks. There must be depressed affect or anhedonia and at least four other symptoms, including guilt or worthlessness, thoughts of death or suicide, diminished concentration, disturbances in sleep, loss of appetite or weight, lack of energy or fatigue and psychomotor agitation or retardation. These symptoms can be divided into affective, i.e. related to mood, somatic, i.e. bodily symptoms, and cognitive, or symptoms of thinking.

The International Classification of Diseases, version 10 (ICD-10)

The International Classification of Diseases (ICD) has been developed by the World Health Organisation. For a severe depressive episode it states that the patient “suffers from lowering of mood, reduction of energy, and decrease in activity. Other symptoms may include reduced capacity for enjoyment, interest, concentration, and marked tiredness after even minimal effort. Sleep is usually disturbed and appetite diminished. Self-esteem and self-confidence are almost always reduced and, even in the mild form, some ideas of guilt or worthlessness are often present. The lowered mood varies little from day to day, is unresponsive to circumstances and may be accompanied by so-called “somatic” symptoms, such as marked psychomotor retardation, agitation, loss of appetite, weight loss and loss of libido. These symptoms are marked and distressing in a severe depression, typically with loss of self-esteem and ideas of worthlessness or guilt."[9] Suicidal thoughts and acts are common and a number of "somatic" symptoms are usually present.

These two reference standards have different decision rules and different classification systems. Patients meet DSM-IV symptom criteria if they report five or more of the listed symptoms, at least one of which must be anhedonia or depressed affect. Patients meet ICD-10 symptom criteria if they report two or more of the three "typical symptoms" (anhedonia, depressed affect and fatigue) and at least four of the "other symptoms" (Table 3.1).

Table 3 1 Comparison of symptoms assessed by DSM-IV and ICD-10

	DSM-IV	**ICD-10**	
Need ONE of these	**Depressed affect**	**Depressed affect**	**Need TWO of these**
	Anhedonia	**Anhedonia**	
Need FOUR of these symptoms	Fatigue	**Fatigue**	
	Weight loss or change in appetite	Change in appetite	**Need FOUR of these symptoms**
	Insomnia or hypersomnia	Sleep disturbance	
	Psychomotor agitation or retardation	Psychomotor agitation or retardation	
	Worthlessness or guilt	Guilt	
	Concentration problems or indecisiveness	Concentration or thinking problems	
	Recurrent thoughts of death or suicide ideation	Recurrent thoughts of death or suicide	

The similarities between the DSM-IV and ICD-10 classifications are striking and the differences relatively minor. These have been reviewed recently[26] and it has been suggested that the "small differences in definition [be] ironed out and a single set be used both clinically and for research."[26]

Barriers

Three types of barriers to effective management of depression in palliative care have been identified: recognition barriers, diagnostic barriers, and treatment barriers related to patients, clinicians and health care systems.[27]

Recognition and diagnostic barriers

Patient

Patients create an important barrier to the recognition of depression by their failure to disclose psychological distress.[28] Reasons may include a belief that talk about emotions is a waste of doctors' time,[29] that they are responsible for their own distress,[30] that depression is too common to be noteworthy,[31] and patient "stoicism".[31] Indeed, patients may actively deny their psychological distress in order to avoid the stigma associated with psychological disorders, because they believe depression is a sign of weakness, to avoid causing additional worry to their families, or because they fear being seen as ungrateful for the efforts of their family and clinicians.[31] Patient disclosure is also influenced by clinicians' conscious or unconscious use of tactics that limit the expression of emotional distress.[29]

Clinicians

Clinicians also directly contribute several barriers to the recognition and diagnosis of depression. Clinicians may have low motivation to identify patients with depression.[18] Depression can be difficult to detect accurately. It is a syndromal disorder: no biological markers can be used to identify it. Diagnosis relies on emotions, behaviours, and cognitions that overlap those reported by patients with other psychological disorders and patients with no psychological disorder. As a result, it is known that symptoms of depression may not be recognised accurately by day care staff,[32] nurses,[15,33-35] or doctors[12,34-36] who do not have specialist mental health training. Nurses recruited to palliative care services are rarely required to have mental health training and their continuing education generally fails to focus on these issues.[37]

Health care systems

Health care systems also provide barriers to a diagnosis of depression. Psychiatric illnesses detected prior to the patients' referral to a Palliative Care Service are often not mentioned in transfer letters[12] because such information is not explicitly asked for. The referral form designed for the transfer of information between specialist PCS in Adelaide, "Metropolitan Palliative Care Referral", is an example of such a gap in information provision. It has prompts for demographic information and physical diagnosis but no specific prompts for psychological information and very little space for free text (Appendix 3.1).

Treatment barriers

Patient

Patients can present barriers to the treatment of depression. They may be unable to participate in psychological "talking-therapies", because of a lack of psychological mindedness, cognitive deterioration or failure, or because of physical symptoms such as impaired speech and fatigue. The oral route for the administration of medication may be unreliable or not possible because of the patient's disease process or deteriorating physical function. Compliance may be erratic because of fears about medications and the stigma associated with taking anti-depressant medications. The concern about side-effects such as drowsiness may also limit willingness to take these preparations.

Clinician

Palliative care clinicians may create barriers to effective treatment. There may be a belief that patients cannot respond to anti-depressants at the end of their lives.[38,39] Gate-keeping behaviours may occur because of beliefs that these people have suffered too much already and that the administration of further medication or the provision of psychotherapy may cause an unnecessary and intrusive burden. The known delay in therapeutic benefit of anti-depressants may be a barrier to prescribing such medication.

Health care system

Health care systems can add to the difficulty of treating depression. There may be concerns that expending limited resources on the treatment of psychological illness may divert funds from other significant and perhaps more visible needs. Many palliative care services lack sufficient access to mental health specialists to allow timely and appropriate treatment of depression.[40,41]

There are only limited drugs for the pharmacological management of depression. They are all oral preparations. Palliative care patients frequently have difficulty with oral preparations as the end of their lives approaches. There is only one medication that is available as a liquid preparation in Australia, i.e. Fluoxetine, and this formulation has recently been removed from the Pharmaceutical Benefits Schedule (PBS), decreasing ease of access and increasing the cost to the patient. Fluoxetine is available as a dispersible tablet and Mirtazapine has an orally disintegrating preparation, both of which are available on the PBS. There are no parenteral anti-depressant drugs available in Australia. Some of the anti-depressants have Pharmaceutical Benefits Schedule restrictions limiting when they may be prescribed, e.g. in severe depression, for a major depressive disorder, for obsessive-compulsive disorder, for panic disorders. These restrictions may cause a delay in prescribing for a palliative care patient with a limited prognosis.

Prevalence of depression

In Australia, the current 1-month prevalence of major depression in the general population is 3 – 5%.[4] This is similar to the reported prevalence in the United States of America and the United Kingdom.[4] Depression is reported to be more common in the unemployed, smokers, and those having a medical condition,[42,43] as well as being in mid life,[44-46] those previously married and in females.[47,48] Depression is predicted to be one of the leading contributors to the burden of disease in the next two decades.[49]

In the medically unwell, the assessment of depression is more problematic and the prevalence is much more difficult to determine. In a systematic review of the prevalence of depression in patients with advanced disease, particularly advanced cancer and amongst mixed hospice populations, i.e. palliative care populations, Hotopf et al[13] found that depression was a common problem; however, the quality of research was poor. The prevalence of depression varied between 1% and 50%. This variation is likely to be because of small sample size, and large attrition and exclusion rates, due to deteriorating physical and mental function and death, and different definitions for making a diagnosis of depression. Many studies provided limited information about participants including demographic and clinical details, and failed to provide "any data on the extent or severity of the participants' disease and their survival." The generally agreed prevalence of depression in the medically unwell and in palliative care populations is 25%.[50] Depression in this population is greater in the young[44] and in some particular diseases (e.g. carcinoma of the pancreas).[51] There have been studies of the interaction between asthma and diabetes with depression, showing that with increased physical symptoms there is also an increase in depression.[52,53]

Diagnosing depression and somatic symptoms

A DSM-IV diagnosis of a major depressive episode requires that five symptoms, which may include both psychological and somatic symptoms, be present during the same period and that one of these is either depressed affect or anhedonia.[10] DSM-IV diagnostic criteria for a major depressive episode include somatic symptoms that are common amongst medically ill patients. These somatic symptoms of depression may overlap with the symptoms of many medical illnesses. DSM-IV instructs doctors to exclude potential somatic symptoms of depression "when they are clearly and fully accounted for by a general medical condition."[10] But this advice creates practical problems.[54] For a population with a large number of "somatic symptoms," this instruction is not as easily translated into practice as might be suggested. It is often impossible to determine the aetiology of symptoms. There is concern that including somatic symptoms of unknown aetiology may lead to over-diagnosing depression.[31,55-57] Alternatives to DSM-IV and ICD-10 classifications of depression have been proposed to differentiate depression from symptoms of a wide range of medical conditions, including cancer,[31] Parkinson's Disease,[58] dementia,[59] chronic pain[60] and generally for the elderly.[57,61] They include three approaches: "aetiological" (case-by-case or blanket exclusion from diagnostic criteria of symptoms judged likely to be due to medical illness or ageing); "inclusive" (inclusion of all symptoms regardless of aetiology); and "substitutive" (substitution of additional psychological symptoms for most or all somatic symptoms).[11,31,57,62,63]

Judging whether a symptom is "clearly and fully accounted for" by the patient's medical condition may be impractical. Ellis et al[3] compared the two extreme approaches that do not require this judgement:

a) inclusion of somatic symptoms regardless of aetiology (i.e. the DSM-IV guideline is ignored) and

b) exclusion of somatic symptoms which might be caused by the patient's medical condition or ageing.

Somatic symptoms regardless of their aetiology did not adversely affect the identification of patients who showed evidence of psychological distress warranting follow-up. In contrast, the exclusion of somatic symptoms potentially due to disease or ageing led to under-recognition of psychological distress.[3] Suggestions that somatic symptoms be excluded or substituted when assessing older and medically ill adults[57,64,65] were not supported. Whether somatic symptoms should be included, treated in a specific way or be excluded needs further clarification and investigation.

Screening instruments

One option to assist in the difficulty of making a diagnosis of depression is the use of screening instruments or tools. Screening is “the systematic application of a test or inquiry, to identify people at sufficient risk of a specific disorder to warrant further investigation or direct preventative action, amongst persons who have not sought medical attention on account of symptoms of that disorder.”[66] A wide range of screening tools for depression is available.[67-74]

However, concerns have been raised about the inability of many palliative patients to complete them,[75] the appropriateness of their content,[18,31] length,[76] and their psychometric properties when used in palliative contexts.[17,19,39,77]

Brief versus multi-item instruments

Assessment of depression in palliative care patients has taken two forms, which reflect two different aims. Brief screening instruments,[1,2] often consisting of only one or two items, have been developed within palliative care populations to identify patients who warrant further assessment or intervention. Longer multi-item instruments and interviews, originally developed for other populations, have been applied in[78-82] or adapted for[68,83] use in palliative care. Their aim is to provide insight into the patient’s experience and range of symptoms in addition to identifying patients who warrant further assessment or intervention. The multi-item tools currently in widest use have a number of disadvantages in palliative populations. Many include somatic symptoms of depression,[78,84,85] include more than 10 items[78,84] and use changing and complex response alternatives.[68,73]

A single question: Are you depressed?

A possible solution to the problem of screening for depression in palliative care patients was provided by a single question concerning depressed affect, drawn from the Schedule for Affective Disorders and Schizophrenia (SADS).[86] This question accurately identified depression in Canadian hospital in-patients receiving palliative care.[1] However, these results do not appear to generalise to other care settings or other cultural contexts. For example, the single question about depressed affect has poor sensitivity for identifying depression in British palliative patients receiving community care[87] or attending day care;[19] i.e. it fails to detect many patients who are depressed.

Two-question screening instruments

A similar screening tool consisting of two questions relating to depressed affect and anhedonia is drawn from the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD).[88] Patients warrant follow-up for depression if they answer “Yes” to either question. This tool identifies depressed medical patients in several populations[89,90] and is sensitive to the effects of anti-depressants in palliative patients.[91] However, its psychometric properties in palliative care populations are unknown and it has low specificity in other populations. That is, it yields positive judgements for many patients who do not have depression. Despite this, the tool has been publicised as the PRIME-MD two-question screen for depression;[92] and has been adopted for the screening of medical patients in draft guidelines for the National Health Service, UK.[66]

Priority

Until recently, the low priority palliative clinicians have given to screening for depression[37] has reflected its low priority for health care systems. However, this may now be changing. Screening for depression is now advocated for all medical patients, cancer patients and palliative care patients by the U.S. Preventive Services Task Force (USPSTF),[93] the National Institute of Health, USA,[66] and the European Association of Palliative Care,[41] respectively.

Clinical utility of a screening tool

The clinical utility of a screening tool can be assessed by using six measures that draw comparisons between the screening tool (e.g. one of the many screening tools available for depression[67-74]) and a reference standard (such as DSM-IV[10] or ICD-10.[9])

1. Total agreement: concordance between the screening tool and a reference standard, uncorrected for chance.

2. Cohen's Kappa statistic:[94] concordance between the screening tool and a reference standard, corrected for chance. Kappa values between .61 and .80 indicate "substantial" concordance, and those above .81 indicate "almost perfect" concordance.[95]

3. Sensitivity: Percentage of positive and negative cases identified by a reference standard that were also so identified by the screening tool.

4. Specificity: Percentage of positive and negative cases identified by the screening tool that were also so identified by a reference standard.

5. Positive predictive value: Percentage of positive cases identified by the screening tool that were also identified as positive cases by a reference standard.

6. Negative predictive value: Percentage of negative cases identified by the screening tool that were also identified as negative cases by a reference standard.

Ideally, the criteria for judging clinical utility using these psychometric properties would be informed by the relative cost of treating or failing to treat palliative care patients with symptoms of depression.

Instruments in use

Screening tools used in palliative populations include the Hospital Anxiety and Depression Scale (HADS),[81,96,97] the Edinburgh Postnatal Depression Scale,[83] the short form of the Beck Depression Inventory (BDI-13),[67] the Mood Evaluation Questionnaire,[87] the Brief Assessment Schedule Depression Cards (BASDEC),[98] the Rotterdam Symptom Checklist,[96] and a single item visual or verbal analogue scale.[1,87] When the reference standard was a psychiatric interview, all of these screening tools had sensitivity and/or specificity under 80% and a positive predictive value under 80% (under 60% for all but the GHQ). When Kappa was reported, it was under .61.[87] In other areas of medical care, the potential of missing or misclassifying more than 20% of cases would not be considered adequate.

Proxies and collateral sources

Because palliative patients are often able to make only limited contributions to the assessment of their psychological symptoms, it is also desirable for assessment tools to be psychometrically sound when they are completed by an informant, such as a nurse or family caregiver. Informants are likely to be relied upon during the assessment of depression when patients are not psychologically minded, or when they show cognitive impairment, are withdrawn, or have symptoms that interfere with communication.

Informants may be asked to respond on behalf of the patient (proxy or surrogate), for example, “Would your husband say he felt depressed?” or to provide their own subjective report about the patient (collateral source), for example, “Do you think your husband is depressed?” [99] Past research suggests that there is moderate to strong agreement between self-reports and reports by collateral sources concerning observable symptoms and lower agreement concerning the patient’s subjective experiences, such as depression.[100-103]

Palliative Care

Palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”[104] Patients’ mental health is therefore an integral dimension of palliative care.

History of Palliative Care

Care and hospitality to those in need, particularly those facing death has always been a part of caring communities. Religious orders, convents and monasteries were traditional refuges for the dying. The modern hospice or palliative care movement grew from unrest about the management of people with a life-limiting or terminal illness in the context of twentieth century health care.[105] Death had become a failure of the health system and of medical care and these people were seen as failures. The focus was returned not only to the physical issues and symptoms but also to the emotional, psychological/social and spiritual domains of the person’s life.[104]

In contrast to the United Kingdom where the hospice movement developed mainly in the charitable and religious sector outside of traditional health care, palliative care in Australia has been established within mainstream health funding.[106] Dedicated in-patient units, hospices or Palliative Care Units, were established in Australia particularly in the1980s. Community outreach programs to support primary health providers such as general medical practitioners and community nursing agencies were also established, usually within mainstream publicly-funded health care institutions. Many of the medical practitioners working in specialist Palliative Care Services and hospices in Australia, as in the United Kingdom, have come from a variety of medical disciplines and backgrounds, mostly without formal training in psychiatry or psychological medicine.[107,108] Even those that are currently receiving specialist training in palliative medicine do not have a formal requirement for some experience in psychiatric medicine.[109]

Symptoms and palliative care

Symptom control is a significant part of the healthcare interventions provided by a palliative care team. Physical symptoms are generally well recognised and have a considerable prevalence (e.g. lack of energy (73.4%), pain (63.1%), nausea (44.7%), lack of appetite (44.5%), constipation (33.6%), cough (29.4%) and shortness of breath (22.9%)).[110] Psychological symptoms are much more challenging to elicit and more controversy exists about what is normal and what might require intervention. Symptoms such as anxiety and depression may not be as easily acknowledged, diagnosed or treated by patients, carers or healthcare providers.[79,111-115]

What is normal – sadness and depression

The diagnosis of an incurable illness is associated with an expected emotional response to the loss of well-being and to a potentially limited and altered future. Sadness, tearfulness, altered sleep and change in appetite and eating habits are a normal response to receipt of this information and the impending loss it conveys. These symptoms constitute a grief reaction.[116-118] The symptoms of grief and sadness, as responses to such a situation, can be seen to be on a continuum with those of a major depressive illness. Depression is not necessarily the inevitable response to such a situation. This raises the dilemma of defining thresholds[2,11] at which a diagnosis is made and what might be considered to be the “normal” reaction to considering the possible end of one’s own life. Kübler-Ross introduced the concept of different types of depression – a reactive and a preparatory depression – the latter being seen as a normal part of the dying process and something that should not be interrupted.[119] She believed that “an understanding person will have no difficulty in eliciting the cause [of the depression]”. This is not as transparent as she has suggested but may help to explain why some palliative care clinicians feel inhibited or may fail to intervene in depression or even to assess systematically for psychological symptoms.

Who is referred to Palliative Care?

People referred to a specialist Palliative Care Service are facing a life-limiting illness. Previously, Palliative Care Services tended to accept only patients with a diagnosis of cancer. Now there is a greater readiness to accept referrals of people with a wider variety of diagnoses and needs. The percentage of patients referred to Australian Palliative Care Services with a non-malignant diagnosis is known to be increasing.[120] This population may have a greater incidence of psychological symptoms.[121] With this change in the referral pattern to Palliative Care Services, there is an increasing need to improve the assessment and management of psychological issues.

Specialist Palliative Care Services support primary health care providers. Their aim is to provide a comprehensive service with a multi-disciplinary team approach.[122] Specialist Palliative Care Services usually consist of specialist nursing and medical staff with varying access to allied health professionals, usually including social workers. Access to other allied health disciplines such as occupational therapy and physiotherapy, as well as chaplaincy, pastoral care and trained volunteer support is less uniform. Availability of mental health professionals in multi-disciplinary teams is even less consistent.[123]

Increasingly people being referred to specialist Palliative Care Services have complex needs that are not easily met by the primary providers. These referrals are increasingly for difficult patient symptoms – both physical and psychological, or for complex family issues. In Australia referral is generally not dependent on a specific diagnosis nor prognosis but on assessment of need.[104] Increasingly Palliative Care Services are supporting patients at differing times in the trajectory of their illness, not just in the terminal phase. The ability to assess quickly and reliably, and to have understanding about likely changes in psychological distress and in particular depression, is increasingly important.

People who are referred to a specialist Palliative Care Service are much more likely to have coordinated care. The use of home-based services is more likely to be appropriate and these people are more likely to die in their own homes.[124,125]

Depression and Palliative Care

Patients

Depression has pervasive effects on outcomes for palliative care patients. It affects their physical health,[126,127] reduces their quality of life and subjective wellbeing.[7,8,21,128] Depression, or patients' ability to cope with depression, also predicts mortality.[15,129-131] Patients' depression also adds to carer burden over and above illness severity and functional limitations.[132]

Clinicians

Depression affects clinicians' ability to manage patients' care. It adversely affects patient adherence to medication, compliance with advice from clinicians, and attendance at medical appointments.[21,22,133-135] It reduces the efficacy of conventional treatments for physical symptoms.[23,24] It is also associated with desire for death, requests for physician-assisted suicide or euthanasia, suicidal ideation and suicide.[25,136-140]

Health systems

Depression also affects outcomes for health services.[28,141] It precipitates admission to hospice and hospital and contributes to other treatment costs over and above the influence of illness severity alone.[142-144]

Despite the importance of depression, its recognition, assessment and treatment in palliative care may deviate from best practice in three ways:

1. patients with moderate or severe depression are often not identified or treated.[12,17,18,123,145]

2. palliative care patients who may not have depression are treated for depression.[39]

3. treatment for depression may be ineffective. Depression may not be of a severity likely to be responsive to antidepressants,[66,146] or there may be insufficient time prior to death for antidepressants to have a therapeutic effect.[39] Cognitive therapies may not be appropriate, possible or available.

Depression symptom profile in palliative care

There is little literature about the prevalence of specific symptoms of depression in palliative care patients suffering depression. There is discussion about depression having different symptom dominance, e.g. a predominantly depressive affect, anhedonic depression,[147,148] melancholia[149] and demoralisation.[150,151] There is increasing interest in more global concepts such as psychological distress,[152] including the development of instruments to measure distress.[153]

To treat or not to treat?

The information and understanding that comes with a diagnosis may be sufficient to provide better care for the patient and support for the carers, even if remaining life is short. Many clinicians are unclear about what action should follow the discovery that a patient meets DSM-IV or ICD-10 symptom criteria for depression.

Summary

Palliative is derived from the Latin word pallium, which means, “a cloak”.[154] The focus of care in palliative care is the relief of symptoms, that is the covering or cloaking of symptoms. Perhaps the cloaking of symptoms has not always been useful for every symptom and issue. Perhaps it is time to try to further lift the cloak, as it were, to see more clearly the problem of depression and to seek some understanding and some possible solutions to this significant, debilitating problem. Before an intervention can be considered there must be identification and assessment.

Chapter 4

Specialist psychological and social service provision in Australian Palliative Care Services (Study 1)

Introduction

Depression is common in people living with a life-limiting illness and is frequently unrecognised and untreated.[88,155] One possible reason may be that Palliative Care Services (PCS) have inadequate access to specialist psychological[b] and social service providers.

This study aimed to determine the current level of specialist psychological and social professional support available within Palliative Care Services in Australia during 1999, to determine the roles and expertise of professionals providing these services and their contribution to the multi-disciplinary team. This research is based on similar work by Lloyd-Williams in 1997, in which 160 questionnaires were sent to a representative sample of hospices in each region of the United Kingdom.[123]

Method

Questionnaires were mailed to all Palliative Care Services in Australia. Palliative Care Australia, the peak national body representing palliative care in Australia, provided mailing labels from national census data collected in 1999.[120] Responses

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[b] In this thesis the term "specialist psychological service providers or professionals" will be used to mean both psychiatrists and psychologists. "Specialist psychological and social service providers" will be used to mean psychiatrists, social workers, psychologists, chaplains, pastoral care workers and counsellors.

were not marked or tracked and were anonymous. A covering letter (Appendix 4.1) explaining the purpose of the study was included with a reply-paid envelope and the questionnaire (Appendix 4.2).

The questionnaire was similar to that used to study psychological and social service provision in hospices in the United Kingdom in 1997.[123] The original questionnaire was piloted and tested for face- and content-validity by professional groups and then distributed to a representative sample of 160 United Kingdom hospices. Modifications were made to account for variations in practice in Australia. Questions were also added to explore the range of other palliative services offered, the amount of Palliative Medicine Specialist input available and the age of the Service, in order to understand the size of the Service and the type of palliative care services they offered.

Enquiries were made about the level of access to specialist psychological and social professionals,[156] such as psychiatrists, social workers, psychologists, chaplains, pastoral care workers and counsellors. Services were asked whether these professionals were full-time or part-time or visited only if needed. Full- or part-time access implies a commitment by the Palliative Care Service to a salaried position, whereas “visiting” means a paid or unpaid sessional arrangement only. Information was sought about whether these professionals had special skills in palliative care and the approximate number of referrals of patients, relatives and staff made to them during 1999. Services were asked to define the roles of each professional group and the frequency with which they participated in multi-disciplinary meetings or ward rounds. Services were asked to indicate whether they used any formal screening instruments for psychological, social or spiritual distress and whether they had access to any other psychological or social services.

This study was approved by the Social and Behavioural Research Ethics Committee, Faculty of Social Sciences, Flinders University. Data were entered and analysed using the Statistical Package for Social Sciences 12.0.

Results

Two hundred and forty seven questionnaires were mailed using the labels provided by Palliative Care Australia. Eight questionnaires were returned because the addressee did not or no longer provided a clinical Palliative Care Service. There were 175 valid responses (73.2% response rate). Seventeen were clearly identified as generalist nursing services only and were excluded from analysis. Three respondents provided information for two different programs within their Services.

Information about the number of new patient referrals to Palliative Care Services was given for 97 Services (61%). The range was 6 – 3932 patients; mean 332, median 150. Eighty percent of Services had 500 or less new patient referrals per year. Only six per cent of Services received greater than 1000 new referrals per year. Seventy Palliative Care Services (45%) had access to dedicated in-patient beds (Range 1 – 52 beds). The mean number of beds was 10 and the median seven. The majority of Services provided a Community Outreach Program (78%). Fifty-two Palliative Care Services (33%) provided a Community Outreach Program only. Seventy-two percent had access to a Palliative Medicine Specialist. The majority of Palliative Care Services (70%) had commenced in the last 15 years (Table 4.1). These statistics give some understanding of the variety and breadth of Palliative Care Services in Australia.

The availability of different psychological and social professionals in Palliative Care Services in Australia is shown in Table 4.2. One hundred and fifty-seven Services responded to this question. All Services had access to at least one specialist professional; i.e. a psychiatrist, social worker, trained counsellor, psychologist, chaplain or spiritual adviser.[156]

Table 4.1 Range of different services offered by Palliative Care Services in Australia (n=158).

	Number (n)	%
In-patient beds	70	44.6
Community Outreach Program	123	78.3
Hospital Consultation Service	67	42.7
Outpatient Service	34	21.7
Day Program	17	10.8
Community Outreach only	52	32.9
Palliative Medicine Specialist available	113	72.4

Table 4.2 Availability of specialist psychological & social professionals in Palliative Care Services in Australia (n=157).

	Full-or Part-time		Visits		None available	
	n	%	n	%	n	%
Psychiatrist*	20	12.9	74	47.7	61	39.4
Psychologist	23	14.6	53	33.8	81	51.6
Social worker**	81	52.9	50	32.7	22	14.4
Chaplain	46	29.2	84	53.5	27	17.2
Pastoral care worker	43	27.4	33	21.0	81	51.6
Counsellor	47	29.9	51	32.5	59	37.6

Missing data * n = 155 ** n = 153

Social workers were the most widely available psychological or social professional group (86% of PCS), although they were only available on a full-time or part-time basis for 53% of Services. Comments from many Palliative Care Services suggest that social workers are generally held in very high regard. There was frustration about an inability to attract funding for a social work position, despite repeated applications, by several Palliative Care Services. Others only had access to social workers with shared responsibilities to many other community Health Service teams, or at regional hospitals, some with long waiting lists and often there was no option for home assessment. Accessibility to chaplains was at a similar rate (83%), however only 28% were available on a full-time or part-time basis; i.e. were employed rather than just visiting. Very few PCS (<15%) had regular support from a psychiatrist or psychologist, although 61% said that they had some access to a psychiatrist and 48% to a psychologist. Services with dedicated in-patient beds had better access to social work (96%) and chaplaincy professionals (96%) (Table 4.3).

Table 4.3 Availability of specialist psychological & social professionals in Palliative Care Services with in-patient beds in Australia (n=70).

	Full-or Part-time		**Visits**		**None available**	
	n	**%**	**n**	**%**	**n**	**%**
Psychiatrist*	13	18.3	43	60.6	15	21.1
Psychologist	9	12.9	24	34.3	37	52.9
Social worker	44	62.9	23	32.9	3	4.3
Chaplain*	31	40.3	43	55.8	3	3.9
Pastoral care worker*	26	36.1	19	26.4	27	37.5
Counsellor	18	26.1	24	34.8	27	39.1

* Some PCS have professionals in more than one category of employment

Most Services were able to provide data about new patient referrals to the PCS; however information about patient referrals to specialist psychological and social professionals was not as available. Information about referrals of relatives and staff to these professionals was even less available. Most information was provided about social work referrals, which was available for 80 (51%) Palliative Care Services. The range was 0 – 1400 patients referred to social work with a mean of 139 and median of 50 patients.

Fifty Services (32%) provided information about patient referrals to psychiatrists. The mean number of referrals was 17 patients, however the median was 5 patients, with a range of 0 – 250 patients. Seven Palliative Care Services referred more than 35 patients per year. These Services all either had more than 15 dedicated beds or had dedicated psychiatric sessions.

Patient referral data to chaplains was provided by 53 (34%) Services. The range was 0 – 576 patients with a mean of 92 and a median of 30 patients being referred. The ability of Services to provide data about referrals to psychologists, pastoral care workers and counsellors was much less (22%, 14% and 19% responses respectively). Even less information was known about referrals of relatives and staff to specialist psychological and social professionals.

Respondents were able to define the roles of social workers (84% response rate), chaplains (82%), psychiatrists (60%) and counsellors (61%) much more readily than the roles of psychologists (47%) and pastoral care workers (48%).

Social workers were identified as providing patient counselling in 53% of PCS and family support in 35%. Bereavement support was provided in 27% and staff support in nine per cent of PCS. Social workers were considered by 77% to have specialist skills in palliative care. One hundred and twenty-nine respondents (82%) defined the chaplain’s role. The dominant roles were of spiritual guidance, pastoral care, patient and family counselling. They were involved in bereavement services for 15 (10%) PCS and staff support for 13 (8%) Services. The conducting of Memorial Services was indicated as a role of chaplains by only four PCS. Counsellor roles were divided between patient counselling, family counselling and bereavement programs. The psychiatrist's roles were defined by 60% of respondents. Of those Services with access to psychiatrists, only fifty-one percent of these psychiatrists were considered to have special skills or interest in palliative care. The definitions of their roles were evenly divided between providing a consultation service to patients and advice to staff about mental health issues. Staff support was provided for ten (6%) Services.

Access to other psychological and social services were available to 67 (42%) PCS. The majority of Services cited private counselling practitioners, government mental health agencies, specific support groups and telephone help lines (e.g. Life Line). Only one Service described a Complementary Therapy Service, with 100 referrals per year, one Service had a music therapist and one a meditation class.

Attendance at multi-disciplinary meetings reflects the availability of the different specialist professionals (Table 4.4) and gives some indication of the ease of access to these disciplines. Social workers attended these meetings regularly in 50% of all PCS. All other groups attended rarely or were not available. Even in PCS with in-patient beds, attendance at multi-disciplinary meetings was not significantly better (Table 4.5).

Table 4.4 Attendance at multi-disciplinary meetings in Palliative Care Services in Australia (n=158)

	Regularly		Occasional		If requested		Never		Not available	
	n	%	n	%	n	%	n	%	n	%
Social worker	79	50.0	4	2.5	21	13.3	14	8.9	40	25.4
Pastoral care worker	42	26.6	5	3.2	15	9.5	17	10.8	79	50.0
Counsellor	31	19.6	2	1.3	21	13.3	27	17.1	77	48.7
Psychologist	18	11.4	5	3.2	13	8.2	27	17.1	95	60.2
Psychiatrist	8	5.1	6	3.8	22	13.9	45	28.5	77	48.7

Table 4.5 Attendance at multi-disciplinary meetings in Palliative Care Services with in-patient beds in Australia (n=70).

	Regularly		Occasional		If requested		Never		Not available	
	n	%	n	%	n	%	n	%	n	%
Social worker	42	60.0	1	1.4	12	17.1	7	10.0	8	11.4
Pastoral care worker	27	38.6	3	4.3	12	17.1	5	7.1	23	32.9
Counsellor	10	14.3	1	1.4	14	20.0	13	18.6	32	45.7
Psychologist	6	8.6	4	5.7	8	11.4	10	14.3	42	60.0
Psychiatrist	5	7.1	4	5.7	13	18.6	24	34.2	24	34.2

Smaller palliative care services without in-patient beds and less than 100 referrals per year were much less likely to have combinations of psychological and social professionals available. These were frequently small rural and semi-rural Services. They had better access to counsellors and pastoral care workers but much poorer access to psychiatrists, psychologists, social workers and chaplains than larger Palliative Care Services. Seventy-five per cent of small PCS did not employ any spiritual professionals at all.

Palliative Care Services do not appear to regularly use screening instruments to assess psychological, social or spiritual distress. Although 50 (32%) indicated use of a screening instrument, only 13 (8%) were able to nominate a valid instrument used in their current practice. Many considered clinical judgement and the use of admission documentation to be a valid screening instrument.

Discussion

Australians with mental health illness have difficulties gaining appropriate assessment.[157] People referred to specialist Palliative Care Services are likely to have at least comparable and possibly greater levels of mental illness. Australian and United Kingdom standards for the provision of specialist palliative care both require that access to specialist multi-disciplinary professionals is available for holistic assessment and care-planning.[122,156] There are recommended levels of staffing of psychiatrists and other psychological and social health professionals based on a population model for Australia.[158] Without the expertise of such professionals in psychological, social and spiritual care, the recognition, assessment and effective management of psychological distress and illness is likely to be compromised. Depression is the most prevalent of psychological disorders in palliative care populations,[11-13] and is known to affect quality of life[8,21] and mortality,[15,130] and adds to carer burden.[132] Depression precipitates inpatient admissions[28,141] and increases treatment costs.[144,159]

The levels of psychological services in hospices in the UK and Ireland have recently been described, confirming the earlier research of Lloyd-Williams.[123,160] Australian Palliative Care Services appear to have much less accessibility to psychological and social professionals than do hospices in the United Kingdom (Table 4.6). The analysis of Australian Palliative Care Services was further divided into those with access to in-patient beds. Palliative Care Services with in-patient beds are more likely to be larger and to have greater access to a wider range of services. The median number of beds in both UK studies[123,160] was 12, compared with a median of seven in Australia. The lack of access to psychosocial professionals has previously been identified as a problem for Australian cancer service provision.[161]

Table 4.6 Comparison of availability of specialist psychological & social professionals in Australia and United Kingdom[123] Palliative Care Services

	Available to PCS		**Available for multi-disciplinary meeting**	
	Australia	**United Kingdom**	**Australia**	**United Kingdom**
	%	**%**	**%**	**%**
Psychiatrist	60.6	85.7	51.3	79.4
Psychologist	48.1	61.9	39.8	61.9
Social worker	85.6	93.8	74.6	94.8
Chaplain	83.2	100	N/A	95.9
Pastoral care worker	48.4	N/A	50.0	N/A
Counsellor	62.4	74.2	51.3	74.2

Social workers

Medical and nursing staff in specialist Palliative Care Services may have skills in psychosocial care that varies from generic to advanced. Some social workers may only have time, energy or skills to deal with financial and practical accommodation issues rather than being able to be involved in family counselling and more advanced psychological support. The need for specific professionals with advanced psychosocial skills has been long recognised as an important need. Social workers are the most prevalent of these professionals. However, there is still relatively low access, even in the larger Palliative Care Services with in-patient beds. Staffing guidelines for Australian Palliative Care Services have been recommended by Palliative Care Australia.[122]

Chaplains and Pastoral care workers

Chaplaincy was available in almost all Palliative Care Service in the two studies[123,160] conducted in the United Kingdom (100% and 98 % respectively), but only 86% in Australia even if chaplaincy and pastoral care workers were considered together. The majority of Australian Services with access to chaplains were more likely to have a pastoral care worker as well in their team, rather than choosing between these spiritual advisers.

Psychiatrists and Psychologists

There are shortages of psychiatrists and psychologists in general health care.[162-164] It should not be surprising that there is limited access in palliative care populations. In the UK, National Institute for Clinical Excellence (NICE) guidelines[66] for professionals trained in psychological and psychiatric problems cannot be met because of “limited and inconsistent provision of specialist services.”[160]

Screening instruments

The inability to identify a valid screening instrument is of concern. Evidence-based practice[165] is not a new concept and not foreign to palliative care. Palliative care practitioners would not wish to subject their patients to interventions that are unlikely to provide a benefit. This should not be any different when considering psychological assessments and interventions. Transferring knowledge into practice is a continuing challenge for all health care practitioners.[166] However, there are a wide range of screening instruments for psychological distress, depression and anxiety that have been validated in palliative care populations and widely published in the palliative care literature.[1,2,64,68,81-83,85,90,93,96,97,153,167-176]

Summary

This study not only confirms the findings of others that there is limited access to specialist psychological care in specialist Palliative Care Services, but highlights the apparent greater paucity of access for Australian palliative care patients. Whether this lack translates into direct patient disadvantage is difficult to ascertain at an individual level. However, easy access to psychological and social professionals will only improve immediate service provision and also the awareness and skills of other clinicians working with these professionals. There are national guidelines[66,122,161,177] for clinical service availability. There is a general shortage at all levels of expertise of these professionals in Australia.[162,163] There is a need for continuing advocacy at Palliative Care Service delivery level, but also a need for increased funding by governments, to address the gap between national guidelines and current professional accessibility.

Chapter 5

Identifying palliative care patients with symptoms of depression: A novel short screening algorithm (Study 2)

Introduction

Palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[104] Consequently, caring for the mental health of patients is integral to the duty of care of palliative clinicians.

The assessment and treatment of depression in palliative care is a serious issue because it is both prevalent,[11-13,173] its consequences are pervasive, and long-lasting in this population.[14,15]

This study was divided into four parts.

1. to examine the clinical validity of the Whooley et al questions in Australian patients in two palliative care settings.[89] Clinical validity refers to a tool's ability to distinguish affected and unaffected populations.

2. to empirically derive an algorithm that showed better clinical validity than these questions. It was desirable for the algorithm to include conditional steps, since these minimise the number of questions asked of respondents.

3. to assess the construct validity of the algorithm by determining whether positive cases provided other evidence of depression.

4. to examine the patients' and nurses' perceptions of the acceptability of questions about depressed affect and anhedonia.

This study was approved by the Social and Behavioural Research Ethics Committee, Faculty of Social Sciences, Flinders University, Australia and the Research and Ethics Committee, Repatriation General Hospital, Daw Park, South Australia. Data were entered and analysed using the Statistical Package for Social Sciences 12.0.

Part 1

A possible solution to the problem of screening for depression in palliative care patients was provided by two questions concerning depressed affect and anhedonia, or a single question concerning depressed affect, specifically designed for use by palliative clinicians.[1] These questions accurately identified depression in Canadian hospital in-patients receiving palliative care. However, these results may not generalise to other care settings or to cultures with different patterns of disclosure. For example, the single question about depressed affect has poor sensitivity for identifying depression in British palliative patients receiving community care[87] or attending day care.[19] That is, it fails to detect many patients who are depressed.

A similar screening tool consisting of two questions drawn from the PRIME-MD,[88] “During the past month have you often been bothered by feeling down, depressed or hopeless?” and “During the past month have you often been bothered by a lack of interest or pleasure in doing things?”, has been proposed.[89] Patients warrant follow-up for depression if they answer “Yes” to either question. This tool identifies depressed patients in other medical populations in several cultures[89,90] and is sensitive to the effects of anti-depressants in palliative patients.[91] However, it has low specificity in these populations. That is, it yields positive judgements for many patients without depression. Despite this, the tool has been publicised as the PRIME-MD two-question screen for depression[88] and has been adopted in draft guidelines by the National Institute for Clinical Excellence of the National Health Service, UK.[66]

This part of the study examined the clinical utility of the questions proposed by Whooley et al[89] in community and hospice patients in Australia. Clinical utility refers to the effectiveness, clinical relevance and meaningfulness of the information an assessment provides. To overcome a criticism of previous studies,[174] one of the reference standards used to assess clinical utility was specifically designed for elderly Australians.[178]

Method

Participants

Participants were recruited from hospice (n=22) and community-dwelling (n=69) patients of a specialist Palliative Care Service with a catchment of 350,000 people in an Australian urban centre. Malignancy accounted for 86% of referrals to the Service. During the study, the average length of stay in the hospice was 9.5 days and the discharge rate was 50%. The average length of care for community patients was 126.2 days (Median = 50 days).

Only patients who were over 18 years of age, able to tolerate a 40 minute interview, willing to answer questions about emotions, able to provide informed consent, passed the Mini Mental State Exam[179,180] with a cut-point score of 24 and fluent in English were eligible. In addition, only those patients who clinicians judged to have a prognosis sufficient for the interview to be completed were invited to participate (hospice $\geq$ 3 days; community $\geq$ 2 weeks). Interviews were conducted at the hospice, in the patient’s home or in another place of the patient’s choice.

Data concerning recruitment were available for 355 referrals to the community service (Table 5.1). Of the 134 community patients who were eligible to participate, 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 in the study. Twenty-six agreed to participate and 22 provided useable data.

Table 5.1 Recruitment details for 355 referrals to community-based palliative care

Outcome	**n**	**%**
Not contacted		
Clinician did not ask permission for contact	38	10.7
Ineligible	133	37.5
Attempt to contact unsuccessful	9	2.5
Died	41	11.5
Declined	43	12.1
Recruited	89	25.6
Useable data obtained	69	19.4

Measures

Screening questions

The time frame of two questions used by Whooley et al[89] was changed to "the past two weeks" to match that for Diagnostic and Statistical Manual 4th ed. (DSM-IV),[10] ICD-10,[9] the Clinical Evaluation Guide for PRIME-MD[88] and the Psychogeriatric Assessment Scales-Depression (PAS-D).[181]

Also, the final word in the question about depressed affect was changed to "without hope" for ethical reasons, on the advice of specialist palliative nurses. The resulting two screening questions were:

- "During the past two weeks have you often been bothered by feeling down, depressed or without hope?" (depressed affect)

- “During the past two weeks have you often been bothered by a lack of interest or pleasure in doing things?” (anhedonia).

The clinical validity of a single question about depressed affect has sometimes equalled that for two-question screening tools.[1] Therefore, the clinical validity of using only the question about depressed affect was also explored.

Screening tools were compared to three reference standards:

1. Psychogeriatric Assessment Scales-Depression (PAS-D).[178] This 12-item screening questionnaire was specifically designed to assess clinical changes in depression among elderly Australians. Despite this, it has been widely used as a screening instrument. This is possible because it provides a cut-point that identifies 80% of cases of major depression as defined by DSM-IV in a number of different populations.[182] However, the scales were not designed to maximize sensitivity and specificity with any diagnostic criteria, and were not designed for use with medical patients. Response alternatives were “No’, “Depends on situation”, “Yes” and “Does not know”. It was delivered in an interview format. Two criteria for follow-up suggested in previous research were assessed: a total score above three[181,182] and a total score above four, which has been suggested for use with medically ill-patients.[183]

2. Symptom criteria for a major depressive episode in the Diagnostic and Statistical Manual of Mental Disorders (fourth edition) (DSM-IV).[10] This was assessed by using questions from the PAS-D and supplementing these with questions from the Canberra Interview for the Elderly (CIE).[184] The interview indicated whether or not the patient reported sufficient relevant symptoms to meet the DSM-IV diagnostic criteria for an episode of depression.

3. 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).[9] A similar process using questions from the PAS-D and supplementing these with questions from the CIE was again used.

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 generalisability is similar to those for biomedical screening tests (e.g. chest X-ray for tuberculosis). The four criteria were:

1. *Total agreement ≥80%.* That is, the screening tool and the reference standard lead to the same decision in at least 80% of cases.

2. *Cohen's Kappa statistic ≥.61.*[94] That is, concordance between the screening tool and the reference standard remains high after corrections for chance. Kappa values between .61 and .80 indicate "substantial" concordance, and those above .81 indicate "almost perfect" concordance.[95]

3. *Sensitivity≥80%.* That is, at least 80% of the positive and negative cases identified by the reference standard were detected by the screening tool.

4. *Specificity ≥80%.* That is, at least 80% of the positive and negative cases identified by the screening tool were detected by the reference standard.

Two additional "desirable" criteria were:

1. *Positive predictive value ≥80%.* That is, at least 80% of positive cases identified by the screening tool were also identified as positive cases by the reference standard.

2. *Negative predictive value≥80%.* That is, 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 assessments in a single session: the Mini Mental State Examination (MMSE),[179] 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 screening questions. All interviewers had completed an undergraduate degree with a major in psychology and had been provided with supervised training in the administration and scoring of the reference standards.

Results

Background

Recruitment of hospice and community patients took place between March 2001 and July 2002 and between January 2001 and March 2002, respectively. In the Palliative Care Service from which these patients were drawn, hospice patients generally have more difficult and complex symptoms and lower levels of social support than those living in the community. Community patients generally have social and other support that allows them to be cared for, and often to die, at home. Thus the profile of patients in the hospice and community samples differs (Table 5.2).

Table 5.2 Clinical and demographic details for participants

	Hospice (n=22)	Community (n=69)
Gender	**(%)**	
Males	45.5	56.5
Females	54.5	43.5
Age	**(years)**	
Mean	66.9	67.1
Range	43 – 88	36 – 85
Primary Diagnosis	**(%)**	
Malignancy		
Gastro-intestinal	9.1	20.3
Lung	13.6	17.4
Breast	13.6	14.5
Gynaecological	18.2	4.3
Urological	13.6	8.7
Haematological	9.1	7.2
Skin	4.5	4.3
Brain	4.5	1.4
Head and neck	–	1.4
Unknown primary	4.5	4.3
Non-malignancy	9.1	13.0
Missing data	–	2.9

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 5.3). 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.

Table 5.3 Percentage of community and hospice patients warranting follow-up for depression

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

[a] $\chi^2(1)=10.6$, $p<.01$ [b] $\chi^2(1)=5.1$, $p<.025$ [c] n= 20

Clinical validity of screening questions

In contrast to the findings of Chochinov et al,[1] the single question concerning depressed affect showed poor sensitivity and specificity for both reference standards. Poor sensitivity and specificity have also been reported in other research.[19,87]

Sensitivity and specificity for a single question about depressed affect has sometimes been greater than that for a two-question screening tool.[1] Neither screening tool showed clinical validity across settings of care (Table 5.4 and Table 5.5). The single question about depressed affect did not meet the essential criteria for clinical validity for any of the reference standards in either hospice or community settings. The two-question screening tool met the four essential and two desirable criteria for clinical validity for the ICD-10 reference standard, and came close to meeting these criteria for the DSM-IV reference standard, in the hospice setting. However, it did not meet the essential criteria for clinical validity for any of the reference standards in the community setting.

Both reference criteria identified a large percentage of patients in both samples warranting follow-up for depression. The results confirmed previous findings that many palliative care patients meet the symptom criteria for a diagnosis of depression.[11-13,185]

The two-item screening tool showed good clinical utility in identifying hospice patients who needed follow-up for depression. However, these results did not generalise to the community sample. In contrast to Chochinov et al's findings the two-item screening tool did not meet the criteria for clinical utility among palliative patients receiving care in the community. Despite this, the results for the community sample are similar to those reported in other research. When the reference standard was DSM-IV symptom criteria for depression, the specificity and sensitivity of the two-item screening tool were very similar to those reported by Arroll et al[90] and Whooley et al.[89]

The reasons for the greater similarity between the present findings and those reported by Whooley, than those reported by Chochinov is unclear. Differences in the wording of the questions, differences in the ways culture influenced patterns of response to the screening questions and differences in medical condition may all have contributed.

Table 5.4 Clinical validity of screening questions for patients in hospice settings (n=22).

Screen and reference standards	**Psychometric properties**					
	Essential				**Desirable**	
	Total agreement (%)	Cohen Kappa statistic	Sensitivity (%)	Specificity (%)	Positive predictive value (%)	Negative predictive value (%)
Depressed affect question 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

[a] n=20

Table 5.5 Clinical validity of screening questions for patients in community settings (n=69).

Screen and reference standards	**Psychometric properties**					
	Essential				**Desirable**	
	Total agreement (%)	Cohen Kappa statistic	Sensitivity (%)	Specificity (%)	Pos predictive value (%)	Negative predictive value (%)
Depressed affect question alone						
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[a]	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[a]	78	0.57	89	71	78	91

[a] n=20

Part 2

This part of the study aimed to derive the optimum clinical decision rules for identifying palliative patients with symptoms of depression. The aim was to identify a brief set of questions that was effective for both hospice and community patients.

Method

The community sample was randomly allocated to two subsamples. Subsample 1 (n=35) was used to derive an algorithm involving no more than 4 questions that maximised concordance with the DSM-IV reference standard. The psychometric properties of this algorithm were then assessed using community subsample 2 (n=34) and the hospice sample (n=20). Data for two questions required by the algorithm were missing from two hospice patients.

Clinical validity of the algorithm

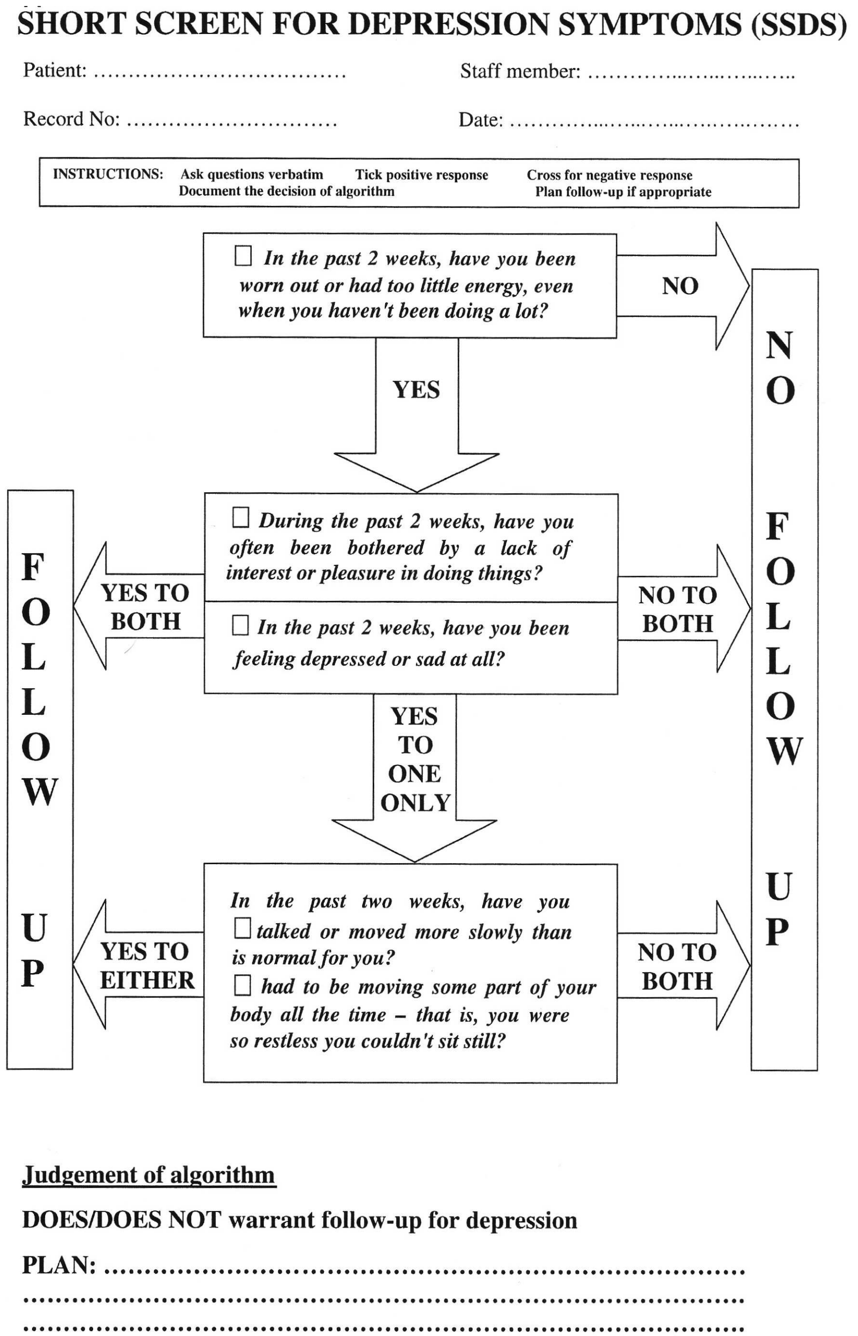
An algorithm is a "systematic procedure that produces – in a finite number of steps – the answer to a question or the solution of a problem".[186] Algorithms have been used in many areas of decision-making,[187,188] particularly in health care settings for diagnostic and treatment decisions,[189-194] including for depression[195,196] and other mental health issues.[197] The simplicity of an algorithm is that it does not rely on a scoring system, but rather a simple decision making process which comes to a decision. The decision-making process behind such an algorithm mirrors a "fast and frugal heuristic"[198-202] frequently used for rapid medical assessments.

The empirically-derived algorithm comprised four questions: items concerning fatigue, depressed affect and psychomotor agitation and retardation from the PAS-D, and the screening question about anhedonia (Diagram 5.1). The algorithm 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 5.6). However, for each of the PAS-D>3 and PAS-D>4 standards, the algorithm met the essential criteria for clinical validity for only one dataset.

Decisions informed by the algorithm met the criteria for clinical utility by showing high positive and negative predictive values, high Kappa statistics, and high levels of total agreement in all samples (Table 5.6). Thus, the algorithm simply, quickly, and accurately screens for palliative care patients who meet the DSM-IV symptom criteria for depression. One advantage of the algorithm format is that not all patients need to be asked all screening questions. In fact, fewer than 50% of patients in any of the datasets would have been asked all four questions (Table 5.7).

In addition, the clinical validity of the algorithm was generalisable within the limits in which it was tested (Table 5.8).

Diagram 5.1 The Short Screen for Depression Symptoms (SSDS)



SHORT SCREEN FOR DEPRESSION SYMPTOMS (SSDS)

Patient: ……………………………… Staff member: ……………………………

Record No: ………………………… Date: ……………………………………

INSTRUCTIONS: Ask questions verbatim   Tick positive response   Cross for negative response
Document the decision of algorithm   Plan follow-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?*

NO → **NO FOLLOW UP**

YES ↓

☐ *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 BOTH → **FOLLOW UP**

NO TO BOTH → **NO FOLLOW UP**

YES TO ONE ONLY ↓

In the past two weeks, have you
☐ *talked or moved more slowly than is normal for you?*
☐ *had to be moving some part of your body all the time – that is, you were so restless you couldn't sit still?*

YES TO EITHER → **FOLLOW UP**

NO TO BOTH → **NO FOLLOW UP**

Judgement of algorithm

DOES/DOES NOT warrant follow-up for depression

PLAN: ……………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………

Table 5.6 Clinical validity of an empirically derived algorithm for patients in hospice and community settings

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

[a] n=35 [b] n=34 [c] n=20

Table 5.7 Number of questions algorithm required for judgement about follow-up

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

Table 5.8 Diversity in three datasets in which the algorithm showed clinical validity

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

Part 3

It is unclear what clinical action should follow the discovery that a patient meets DSM-IV symptom criteria for depression. The overlap between symptoms of depression and those of approaching death has raised the possibility that both screening tools and DSM-IV falsely classify many palliative patients as being depressed.[18,31,65,203] The possibility of confusion between depression and grief has also been a concern.[118,204] This study examined the validity of judgements made using the algorithm by determining whether it selectively identified patients who showed other evidence of psychological distress associated with depression.

Method

Participants were the community patients. Patients were asked an open-ended question about their mood/feelings (e.g. “Can you tell me about the feelings you have had during the past few weeks?”). To avoid contamination, this question preceded all other measures except the Mini Mental State Exam. Responses were usually brief. The typical duration of interviews was 5 to10 minutes. All usable interviews were audio-taped, transcribed, and subjected to qualitative content analysis using standard inductive techniques (n = 58).[205] The themes were identified by use of particular words: “depressed”, “depression”, “dysphoria”, or “suicide”, or the expressions “very down in the dumps”, “very sad” or “mourning for yourself” or “grief”.

Patients were sorted into three groups:

1. those who were identified as warranting follow-up for depression by the algorithm and who fulfilled DSM-IV symptom criteria for depression.

2. those who were identified as not warranting follow-up for depression by the algorithm and who did not fulfil the DSM-IV symptom criteria.

3. those patients for whom the algorithm and DSM-IV and ICD-10 reference standards disagreed (n=4). In this subsample, ICD-10 and DSM-IV reference standards agreed in all cases.

All four transcripts in the last group were analysed. In addition, successive random samples of equal numbers of transcripts from the first two groups were analysed until theoretical saturation was reached. That is, sampling of transcripts continued until three consecutive transcripts yielded no novel themes. Theoretical saturation was reached after 28 transcripts (12 patients who warranted follow-up for depression, 12 patients who did not warrant follow-up for depression, and four patients for whom the two criteria made different judgements). After each sampling, transcripts were placed in random order for analysis.

Two assessors independently identified the themes in each transcript and the particular words and expressions related to these themes. They were blind to the identity of the patients and the group from which they were drawn. Cases in which the assessors disagreed about themes were discussed in depth until consensus was reached.

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 5.9). Fifteen (88%) of the 17 patient who referred to these themes were identified by the SDSS as warranting follow-up for depression. Another one 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 warranted follow-up for depression (33.3%) while others (66.7%) did not.

Table 5.9 Construct validity: Distinctive interview themes for patients identified by the algorithm as warranting follow-up for depression

Theme	Example
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"[a] "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" [a] "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 for 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]

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

This suggests that the algorithm is identifying patients with psychological distress rather than patients who predominantly show somatic symptoms of depression. The results are not consistent with an interpretation that either the algorithm or DSM-IV symptom criteria falsely identified patients with medical symptoms but without depression.

Discussion

All the reference standards used in this research indicated that a large percentage of patients in both settings warranted follow-up for depression. This is consistent with previous research.[11-13,83,185]

The psychometric properties of the screening questions proposed by Whooley et al[89] were often better than those reported for other tools.[1,87] However, by the stringent criteria used in this study, neither the one- nor the two-question screening tools showed clinical validity across care settings. Previous research has reported relatively poor sensitivity or specificity for similar screening tools.[19,87,89,90,171] The finding that the two-question tool showed better psychometric properties for hospice than for community patients is consistent with previous research on in-patients[1] and out-patients.[89,90] Overall, the findings suggest that the clinical validity of these screening tools has limited generalisability across care settings.

The psychometric properties of the empirically derived algorithm were superior to those for the screening questions proposed by Whooley et al[89] and for other screening tools in palliative populations: the Hospital Anxiety and Depression Scale (HADS),[81,96,97,206] the Edinburgh Postnatal Depression Scale,[83] the short form of the Beck Depression Inventory (BDI-13),[67] the Mood Evaluation Questionnaire,[87] the Brief Assessment Schedule Depression Cards (BASDEC),[98] the Rotterdam Symptom Checklist,[96,206] and a single item visual or verbal analogue scale.[1,77,87] When the reference standard was a psychiatric interview, all of these had sensitivity and/or specificity under 80% and a positive predictive value under 80%. When Kappa was reported, it was under .61.[87]

Use of the algorithm by clinicians is likely to change the patients who are identified as warranting follow-up for depression because the algorithm includes symptoms that palliative clinicians rarely include in the assessment of depression.[40]

Despite debate over the status of somatic symptoms in the diagnosis of depression among patients receiving palliative care,[18,31,203,207,208] two somatic symptoms (fatigue and psychomotor agitation or retardation) were included in the empirically-derived algorithm. Previous research supports the inclusion of somatic symptoms in the assessment of depression.[11] 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.[87,159,209-211]

The construct validity of the algorithm was supported by a content analysis of patients' interview responses. This demonstrates 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 clear differential diagnosis of depression are lengthy, and may not to be tolerated by many medical patients,[18] researchers may only ask questions about a subset of disorders[1,87,89,90] or include only the most robust patients.[83,97] The first strategy has no advantage over the reference standards used in this research, since it does not allow a differential diagnosis to be made. The second strategy limits the generalisability of results to clinical populations.

The validity of standard diagnostic interviews for palliative patients has been contested. It has been argued that over-diagnosis of depression may be frequently due to the overlap between symptoms of depression, symptoms of advanced disease, the side effects of palliative interventions,[11,18,31,40,43,65,203] and the characteristics of normal grief[43,118,204] and appropriate sadness.[212] This study overcame these disadvantages by locating independent evidence, from the patients' unstructured interviews about mood and emotions, that patients identified by the algorithm warranted follow-up for depression.

The algorithm was designed for maximum clinical utility. Data on clinical validity and construct validity show that the algorithm provides meaningful and relevant information. The algorithm shows generalisability across samples that differ in the prevalence of the symptoms it assesses and the percentage of patients that warrant follow-up for depression. By using conditional steps, the algorithm minimises the number of questions that need to be asked. The algorithm supplies the wording for the questions and states the decision, making it easy to use and eliminating the need for scoring and interpretation. Use of the algorithm requires no special training and the algorithm is widely available at low cost.

Part 4

Acceptability

Screening tools are unlikely to be used if they are perceived by patients or clinical staff to be inappropriate in their timing or content. Therefore, Part 4 of this study considered the social validity or acceptability of the algorithm. Social validity refers to consumers' subjective evaluations of the effectiveness and acceptability of a tool and the desirability of the outcomes resulting from the use of the tool.[213] Patients' and clinical staff members' perceptions of the acceptability and effectiveness of the two questions that were judged to be potentially confronting were assessed.

Some palliative care clinicians are reluctant to ask questions about depression.[76]

This may reflect personal discomfort or a fear that such questions will cause distress to patients.[29,214] Such fear is likely to influence the uptake of screening tools even though it is usually unfounded.[87,215]

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 psychological symptoms around the time of referral to a Palliative Care Service.

Method

There were two samples. The first sample compared matched data from patients and clinicians for 60 of the community patients who participated in the interviews. The second sample provided staff responses only, for 188 community patients who did not participate in the study, but who answered the two screening questions as part of their admission process. In both samples, the clinicians were palliative care clinicians (two doctors and eight nurses), who asked the screening questions concerning anhedonia and depressed affect during the patients' initial clinical assessment after referral to the Palliative Care Service.

Clinicians and patients were asked parallel questions 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?"). Participants were also asked to comment on each issue. Clinicians were asked to respond immediately after having asked the patient the questions. Patients made judgements retrospectively, as the last step in the research procedure.

Results

In the vast majority of cases, both patients and clinicians in both samples judged that the content and timing of the questions were acceptable (Table 5.10).

Table 5.10 Acceptability of the two screening questions for patients and clinicians in two samples

Respondent	% Content of both questions acceptable	 Ask in first visit acceptable
Patient did participate in Study 1 (n = 60)		
Patient	96.7	91.7
Clinician	93.3	88.3
Patient did not participate in Study 1 (n = 188)		
Clinician	96.8	91.8

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. Some of these clinicians had indicated though that the original timing was still acceptable.

Discussion

The question about anhedonia included in the algorithm and the question about depressed affect similar to the one in the algorithm were acceptable to almost all patients and clinicians. This is consistent with previous research.[87,215] Clinicians perceived that the questions were equally appropriate for patients who did and who did not subsequently agree to participate in a study that involved disclosure of emotions. Nevertheless, in some cases clinicians would prefer to defer such questions to their second visit to patients. Such a postponement remains consistent with recommendations to screen for depression as soon as possible after referral.[216]

General Discussion

Routine screening for depression among palliative care patients requires the availability of a simple, quick and psychometrically sound screening tool. The current findings and previous studies[17,19,87] suggest that the clinical validity of a single question about depressed affect or two questions about anhedonia and depressed affect is specific to particular cultural or care contexts. In this study, such questions did not meet the criteria for clinical validity for any of the reference standards across two care settings.

In contrast, a brief empirically-derived algorithm, the Short Depression Symptom Screen, met stringent criteria for clinical validity across care settings for two reference standards; DSM-IV symptom criteria for a major depressive episode and ICD-10 symptom criteria for a moderate or severe depressive episode without psychotic symptoms. It appears to be the first screening tool to do this. The construct validity of the algorithm was demonstrated by its ability to selectively identify patients whose unstructured interviews provided independent evidence that they warranted follow-up for depression. The algorithm includes questions about depressed affect and anhedonia, which may be perceived as sensitive or intrusive. However, the vast majority of patients and clinicians judged that the content of these questions was acceptable and that it was acceptable to ask them during the first or second contact between the patient and the Palliative Care Service.

The algorithm has two limitations. First, although its clinical validity generalised across datasets that differed in important variables, the algorithm is unlikely to be universally applicable. At present, the boundaries of the cultures, care settings and medical populations within which it is generalisable remain unknown. Second, like other screening instruments, the algorithm is designed to be used in contexts in which follow-up can be provided. It does not provide sufficient information to inform treatment because it does not allow a diagnosis that differentiates patients with depression from those with other disorders that have overlapping symptoms (e.g. dementia, schizophrenia) but that might benefit from different interventions. However, it is not realistic to expect that any brief tool would allow staff without specialist mental health training to make such a diagnosis.

Rather, the availability of psychometrically sound screening tools provides patients, family members and clinicians greater understanding of patient behaviour. This may yield clinical benefits whether or not interventions for depression are pursued.

In conclusion, widely publicised one- and two-question screening tools for depression have relatively poor clinical validity in some care settings. In contrast, a brief empirically-derived algorithm met stringent criteria for clinical validity across care settings, had construct validity, and was acceptable to patients and clinicians.

Chapter 6

The Geriatric Depression Scale in palliative care (Study 3)

Introduction

This research used the original form of the Geriatric Depression Scale (GDS-30)[64] for two distinct purposes; as the point of comparison in an examination of the psychometric properties of short forms of the GDS and as a means of determining the prevalence of a broad range of non-somatic symptoms of depression among patients receiving palliative care.

The Geriatric Depression Scale[64] is a multi-item scale that has many characteristics that are desirable in palliative care. It has excellent sensitivity and specificity in aged community[217,218] and primary-care samples,[219] was specifically designed for use with aged populations, uses simple and consistent response alternatives, focuses on non-somatic symptoms in order to minimise over-diagnosis in medically ill populations, is available in a wide range of Asian[220] and European languages,[221-223] identifies patients with suicidal ideation without direct questioning,[224] and uses both positively and negatively worded questions to avoid “yea-” or “nay-saying” and establishing expectations. Most other multi-item scales used in palliative care do not share these advantages.[1,31,37,77,97]

The GDS is also of interest because one of its forms has been recommended for routine use by the Royal College of Physicians and the British Geriatrics Society[225] and in many countries[226-228] it is the tool of choice for assessing depression during a Comprehensive Geriatric Assessment (CGA).[229] One form of the GDS is also a component in the Abbreviated Comprehensive Geriatric Assessment.[230,231] CGA has been advocated[232,233] and widely adopted in oncology and haematology.[234-236] Forms of the GDS are also widely used in cancer research.[237,238]

Because the length of the original form of the GDS (GDS-30)[64] precludes its use in many clinical settings, a variety of “short” forms of the scale have been developed. As a result, palliative clinicians interested in using the GDS are faced with a bewildering array of forms from which to choose. These include three different 4-item forms,[239-241] two different forms containing one,[239,240] and five items,[242,243] forms containing ten,[241] twelve[244] and fifteen items,[245] and an algorithm based on two of these short forms.[246] This study assists clinicians in making informed choices between these alternatives by comparing the psychometric properties of previously published short forms with those of the original GDS in patients receiving palliative care. There are few previous reports of short forms of the GDS being used in patients with advanced disease[247-249] and these reveal little about their psychometric properties.

One innovation in the present study is the examination of the psychometric properties of short forms at two points in the trajectory of illness. Patients receiving palliative care often show more marked changes in physical and cognitive function than other medical patients. Thus, the utility of particular symptoms (e.g. fatigue, changes in sleep) in the diagnosis of depression in palliative care patients may change over time. However, few studies have examined the properties of either single- or multi-item screening tools at more than one visit.

The original form of the GDS will also be used to examine the prevalence of non-somatic symptoms of depression among patients receiving palliative care.

Thus far, research on depression in palliative care has given greater attention to identifying effective screening tools[1,2,75,83,87] and determining the prevalence of depression[1,207,250] than to understanding how symptoms associated with depression are expressed in palliative populations. This shortcoming may have important implications for assessment. There is debate about the role that somatic symptoms of depression should play in the diagnosis of depression in palliative patients. Suggestions that diagnosis should focus on items concerning non-somatic symptoms [31,208] assume that these do not show elevated endorsement due to disease processes or treatment. Although little empirical evidence relevant to this assumption is available, it has been shown that some non-somatic items are endorsed by most patients receiving palliative care.[251] This is not surprising because it is well-documented that some non-somatic symptoms (e.g. impaired cognition) may result from disease processes or be side-effects of treatments commonly used in palliative care.[252,253] This research uses the broad coverage of non-somatic symptoms provided by the GDS-30 to provide descriptive data about the way in which these symptoms are expressed in an ambulatory palliative population. Although many previous studies have used multi-item scales with patients receiving palliative care, very few[251] have reported the frequency of specific symptoms of depression.

Because palliative patients are often able to make only limited contributions to the assessment of their psychological symptoms, it is also desirable for assessment tools to be psychometrically sound when they are completed by an informant, such as a nurse or family caregiver. Informants are likely to be relied upon during the assessment of depression when patients are not psychologically minded, or when they show cognitive impairment, are withdrawn, or have symptoms that interfere with communication. Informants may be asked to respond on behalf of the patient (proxy or surrogate); for example, “Would your husband say he felt depressed?” or to provide their own subjective report about the patient (collateral source), for example, “Do you think your husband is depressed?”[99] This study examines the agreement between patient and carer reports of the items of the GDS-30 when family caregivers serve as collateral sources.

The extent of agreement between patient-reports and proxy/surrogate reports reflect the informant’s knowledge of and ability to communicate the patient’s view. The patient’s report is the gold standard against which the accuracy of the proxy’s report can be judged. The extent of agreement between self-reports and reports by collateral sources reflects the overlap between the patient’s and the informant's views and their ability to communicate these views. Neither the patient's nor the informant's report is considered to be a gold standard and measures of agreement are not interpreted as measures of accuracy.[254,255]

This study also reports on patient- and carer-completed forms of the GDS at two time points.

In summary, this research had three aims

1. To compare, at two points in time, the psychometric properties of ten previously published multi-item short forms of the GDS[239-245] to those of the GDS-30[64] in ambulatory patients receiving palliative care.

2. To document the prevalence with which ambulatory patients receiving palliative care reported a range of non-somatic symptoms of depression at two points in time.

3. To compare, at two points of time, the agreement and relative frequency of symptom items between the patient-reported version of the GDS-30[64] and the collateral source version of the GDS-CS[254] when it was answered by family carers.

Method

Participants

One hundred and three patients attending outpatient palliative care and oncology clinics at two teaching hospitals in Adelaide were approached to participate. All patients were fluent in English, over 18 years of age, and judged by their primary medical specialist to be in the palliative phase of their illness, to be sufficiently robust to tolerate a 40-minute research interview, and to be free from severe cognitive impairments. Eighty-four patients were recruited (81.6%). Four patients declined to participate (3.9%), and 15 were unable to complete data collection due to physical decline (14.6%).

Sixty-six carers of these patients, who accompanied them to the clinic, were also recruited as collateral sources. Most carers were the patient's husband (21%), wife (52%) or daughter (19%) and were in daily contact with the patient (89%). All carers had lengthy relationships with the patient (Mean = 35 years, range 2-66 years).

Useable data were collected on a second clinic visit from 34 of these patients and 35 of the carers. The mean interval between the first and second data collection points was 35 days and was primarily determined by the patient's clinical needs. In every case, failure to complete the second data collection was due to physical decline or death.

Measures

Data were collected immediately after the patients' scheduled clinic visit by a research nurse who was not associated with the patients' care. Three measures were used:

1. *Geriatric Depression Scale* (GDS). The original 30-item form of the GDS[64] was administered. From this, the 1-,[239,256] 4-,[239-241] 5-,[242,243], 10-,[241] 12-[244] and 15-[245] item short form scores were calculated (Table 6.1).

2. The single-item relating to depression from the *Edmonton Symptom Assessment System* (ESAS).[76] This self-report item uses an 11-point numerical analogue format.

3. Custom-designed, single-items for self-reported rating of will-to-live and hope using an 11-point numerical analogue format.

4. *Geriatric Depression Scale Collateral Source* (GDS-CS). The 30-item version of the Geriatric Depression Scale adjusted for collateral source use was administered to carers away from the patient but at the same time.[254]

This study was approved by the Research Ethics Committee of Flinders Medical Centre, Adelaide, South Australia and the Research and Ethics Committee, North Western Adelaide Health Service, South Australia. Data were entered and analysed using the Statistical Package for Social Sciences 12.0.

Table 6.1 Items included in full and short forms of the Geriatric Depression Scale

	Item	**GDS-30**	**GDS-15**	**GDS-12R**	**GDS-10**	**GDS-5 (Hoyl)**	**GDS-5 (Molloy)**	**GDS-4 (Galaria)**	**GDS-4 (D’Ath)**	**GDS-4 (van Marwijk)**	**GDS-1 (D’Ath)**	**GDS-1 (Almeida)**
1	Basically satisfied with life? (No)	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
2	Dropped many activities and interests? (Yes)	✓	✓	✓	✓			✓		✓		
3	Feel that life is empty? (Yes)	✓	✓	✓	✓		✓		✓		✓	
4	Often get bored? (Yes)	✓	✓	✓		✓						
5	Hopeful about the future? (No)	✓										
6	Bothered by thoughts that can’t get out of head? (Yes)	✓										
7	In good spirits most of the time? (No)	✓	✓	✓								
8	Afraid that something bad is going to happen? (Yes)	✓	✓	✓	✓				✓			
9	Feel happy most of the time? (No)	✓	✓	✓	✓		✓		✓	✓		
10	Often feel helpless? (Yes)	✓	✓	✓	✓	✓	✓	✓				

	Item	GDS-30	GDS-15	GDS-12R	GDS-10	GDS-5 (Hoyl)	GDS-5 (Molloy)	GDS-4 (Galaria)	GDS-4 (D'Ath)	GDS-4 (van Marwijk)	GDS-1 (D'Ath)	GDS-1 (Almeida)
11	Often get restless and fidgety? (Yes)	✓										
12	Prefer to stay at home rather than going out and doing new things? (Yes)	✓	✓			✓				✓		
13	Frequently worry about the future? (Yes)	✓										
14	Feel that have more problems with memory than most? (Yes)	✓	✓		✓			✓				
15	Think it is wonderful to be alive now? (No)	✓	✓	✓								
16	Often feel downhearted and blue? (Yes)	✓					✓					
17	Feel pretty worthless the way you are now? (Yes)	✓	✓	✓		✓						
18	Worry a lot about the past? (Yes)	✓										
19	Find life very exciting? (No)	✓										
20	Hard to get started on new projects? (Yes)	✓										
21	Feel full of energy? (No)	✓	✓	✓	✓							
22	Feel that situation is hopeless? (Yes)	✓	✓	✓	✓							
23	Think that most people are better off? (Yes)	✓	✓		✓							

	Item	**GDS-30**	**GDS-15**	**GDS-12R**	**GDS-10**	**GDS-5 (Hoyl)**	**GDS-5 (Molloy)**	**GDS-4 (Galaria)**	**GDS-4 (D'Ath)**	**GDS-4 (van Marwijk)**	**GDS-1 (D'Ath)**	**GDS-1 (Almeida)**
24	Frequently get upset over little things? (Yes)	✓										
25	Frequently feel like crying? (Yes)	✓										
26	Have trouble concentrating? (Yes)	✓										
27	Enjoy getting up in the morning? (No)	✓										
28	Prefer to avoid social gatherings? (Yes)	✓										
29	Easy to make decisions? (No)	✓										
30	Mind as clear as it used to be? (No)	✓										

Results

Psychometric properties of short forms

Six conventional psychometric properties were assessed using the following criteria: a correlation above 0.75 with the GDS-30 (Table 6.2); internal consistency above 0.75 for scales with ten or more items, above 0.65 for scales with five items, and above .60 for scales with four items (Table 6.3); test-retest reliability similar to that for the GDS-30 (Table 6.4); convergent validity similar to that shown by the GDS-30 for two related but distinct constructs, will-to-live and hope (Table 6.5); and concurrent validity similar to that shown by the GDS-30 for patient ratings of depression on the ESAS (Table 6.5). Short forms of the GDS containing ten or more items showed good psychometric properties according to most criteria. In general, scales containing one, four and five items showed different patterns of results for different criteria. However, the 4-item scale by D’Ath et al[239] and the 5-item scale by Molloy et al[243] met as many criteria as the longer forms.

Table 6.2 Correlations between the full 30-item and short forms of the Geriatric Depression Scale at Visits 1 and 2

Short form	**Visit 1**	**Visit 2**
	r(62)	r(23)
GDS-1	.40	.44
Almeida (Qu1)		
D'Ath (Qu3)	.55	.55
GDS-4		
Galaria	.63	.77^
van Marwijk	.65	.74^
D'Ath	.77	.86^
GDS-5		
Hoyl	.81	.81^
Molloy	.78	.95^
GDS-10	.88	.94^
GDS-12R	.86	.93^
GDS-15	.94	92

^ r(22)

Table 6.3 Internal consistency (Cronbach α) for multi-item forms of the Geriatric Depression at Visits 1 and 2

GDS	**Visit 1**	**Visit 2**
GDS-4		
Galaria	0	.28
van Marwijk	.20	.39
D’Ath	.61	.68
GDS-5		
Hoyl	.41	.67
Molloy	.68	.79
GDS-10	.66	.79
GDS-12R	.76	.81
GDS-15	.75	.84
GDS-30	.87	.92

Table 6.4 Test-retest reliability of forms of the Geriatric Depression Scale

GDS	r(27)
GDS-1	
Almeida (Qu1)	.76
D’Ath (Qu3)	.31
GDS-4	
Galaria	.83^
van Marwijk	.89^
D’Ath	.65
GDS-5	
Hoyl	.60
Molloy	.70
GDS-10	.84^
GDS-12R	.73^
GDS-15	.82#
GDS-30	.85+

^ r(26) # r(24) + r(22)

Table 6.5 Correlation between forms of the Geriatric Depression Scale and ratings of will-to-live, hope and depression

	Will to live		**Hope**		**Depression**	
	Visit 1 (n=77)	Visit 2 (n=29)	Visit 1 (n=77)	Visit 2 (n=29)	Visit 1 (n=77)	Visit 2 (n=29)
GDS-1						
Almeida	r(75) = -.01	r(27) = -.38*	r(73) = -.03	r(27) = -.14	r(75) = .13	r(27) = .28
D'Ath	r(75) = -.39**	r(27) = -.47**	r(73) = -.17	r(27) = -.31	r(75) = .37**	r(27) = .48**
GDS-4						
Galaria	r(75) = -.14	r(26) = -.30	r(73) = -.01	r(26) = -.26	r(75) = .27*	r(26) = .25
van Marwijk	r(74) = -.23*	r(26) = -.35	r(72) = 0	r(26) = -.21	r(74) =.14	r(26) =.27
D'Ath	r(74) = -.19	r(27) = -.61	r(72) = -.21	r(29) = -.35	r(74) = .41	r(27) = .62
GDS-5						
Hoyl	r(74) = -.23	r(25) = -.40	r(72) = -.16	r(27) = -.28	r(74) = .30	r(25) = .28
Molloy	r(75) = -.29**	r(27) = -.63***	r(72) = -.18	r(27) = -.41*	r(75) = .33**	r(27) = .56**
GDS-10	r(70) = -.27	r(26) = -.52	r(68) = -.30	r(26) = -.42	r(70) = .42	r(26) = .48
GDS-12R	r(70) = -.28	r(26) = -.58.	r(68) = -.30	r(26) = -.37	r(70) = .45	r(26) = .50
GDS-15	r(70) = -.31	r(24) = -.57	r(68) = -.30	r(26) = -.44	r(70) = .40	r(24) = .52
GDS-30	r(61) = -.33	r(22) = -.62	r(59) = -.29	r(24) = -.46	r(61) = .33	r(22) = .55

* p.$\leq$ 0.5 ** p $\leq$ 0.01 *** p $\leq$ 0.001

Table 6.6 Distribution of scores on GDS short forms with fewer than ten items

	Patients receiving score(%)					
	0	**1**	**2**	**3**	**4**	**5**
GDS-1						
Almeida						
Visit 1	87.2	12.8				
Visit 2	82.8	17.2				
D'Ath						
Visit 1	85.9	14.1				
Visit 2	75.9	24.1				
GDS-4						
Galaria						
Visit 1	15.4	29.5	33.3	19.2	2.6	
Visit 2	21.4	17.9	32.1	21.4	7.1	
van Marwijk						
Visit 1	11.7	36.4	42.9	6.5	2.6	
Visit 2	10.7	32.1	39.3	14.3	3.6	
D'Ath						
Visit 1	58.4	23.4	11.7	3.9	2.6	
Visit 2	51.7	20.7	20.7	-	6.9	
GDS-5						
Hoyl						
Visit 1	13.0	36.4	23.4	15.6	9.1	2.6
Visit 2	22.2	18.5	18.6	18.5	18.5	3.7
Molloy						
Visit 1	47.4	21.8	14.1	11.5	2.6	2.6
Visit 2	41.4	31.0	6.9	13.8	–	6.9

The distribution was examined for the short forms with fewer than ten items since these necessarily yield a restricted range of scores. Ideally, the distribution of scores on brief screening instruments follow a reversed J-curve (i.e. bottom-heavy with a long positive tail) that allows a range of different cut scores to be used in different clinical contexts. Such distributions were produced by the GDS-4 by D'Ath et al[239] and the GDS-5 by Molloy et al[243] (Table 6.6).

Prevalence of non-somatic symptoms of depression

Patients did not equally endorse all symptoms of depression included in the GDS-30. The only somatic symptom included in the GDS-30, fatigue (not “full of energy”), was reported by more than half the patients at both visits. However, this was also true for non-somatic symptoms related to anhedonia (“Dropped many activities and interests”; “Hard to get started on new projects”, “Prefer to stay at home rather than going out and doing new things”) at both visits, and for psychomotor agitation (“Often get restless and fidgety”) at Visit 1. Patients also commonly reported helplessness, hopelessness, that their lives were not exciting and that their thinking was not clear. In contrast, none of the items relating to depressed affect (“Often feel downhearted and blue”; “Frequently get upset over little things”; “Frequently feel like crying”) were endorsed by more than one-third of patients at either visit. Indeed, at both visits more than 80% of patients endorsed items that reflected positive affect (“Basically satisfied with life”; “In good spirits most of the time”; “Feel happy most of the time”; “Think it is wonderful to be alive now”). Worrying about the past was also uncommon.

The results also show the importance of the wording of questions about non-somatic symptoms. Although the majority of patients endorsed anhedonia items relating to behaviours (e.g. Dropped many activities and interests), only a minority endorsed anhedonia items relating to perceptions. That is, only about one-third indicated that they were often bored and less than one-quarter felt that their lives were empty. Similarly, patients did not respond in the same way to the four items assessing impaired cognition. In particular, more patients rejected the idea that their mind was “as clear as it used to be” than the idea that it was “easy to make decisions”.

Despite the high frequency with which many items were endorsed, few individuals endorsed a large number of symptoms and therefore most patients did not meet the standard cut scores for the GDS-30.[64] At Visit 1, 42.3% and 5.1% of patients were identified as likely to be experiencing mild and severe depression, respectively. At Visit 2, 25.9% and 14.8% of patients were identified as likely to be experiencing mild and severe depression, respectively. That is, at Visits 1and 2, 47.4% and 40.7% of patients were identified as likely to be experiencing depression, respectively, although the severity appeared to worsen at Visit 2.

Most items on the GDS-30 were endorsed by at least one-third of patients at Visit1 and/or Visit 2. Despite this, 23 of the 30 items discriminated between patients identified as likely to have severe depression and other patients at Visit 1 and/or Visit 2. Ten of these items were the same at Visits 1 and 2 (Table 6.7). Included among these ten are the GDS-1 by D'Ath et al,[239] three items from the GDS-4 by D'Ath et al,[239] and four items from the GDS-5 by Molloy et al.[243] The larger number of items included in the GDS-10, GDS-12R and GDS-15 did not significantly improve their overlap with these ten items.

Table 6.7 Relative frequency of items from the Geriatric Depression Scale differentially endorsed by patients likely to have severe depression and other patients

		Patients (%)		**Differential endorsement ($\chi 2$)**	
	Item	Visit 1 n=84	Visit 2 n=34	Visit 1 n=84	Visit 2 n=34
1	Basically satisfied with life? (No)	13	17	0	3.1
2	Dropped many activities and interests? (Yes)	75	72	1.5	0
3	Feel that life is empty? (Yes)	14	24	12.9***	5.9*
4	Often get bored? (Yes)	36	36	7.5**	0.5
5	Hopeful about the future? (No)	28	21	1.0	7.6**
6	Bothered by thoughts that can't get out of head? (Yes)	34	24	8.3**	5.9*
7	In good spirits most of the time? (No)	6	14	33.1***	27.0***
8	Afraid that something bad is going to happen? (Yes)	31	38	9.3**	6.8**
9	Feel happy most of the time? (No)	12	10	16.6***	19.4***
10	Often feel helpless? (Yes)	42	45	5.7*	8.9**
11	Often get restless and fidgety? (Yes)	51	36	4.1*	5.9*
12	Prefer to stay at home rather than going out and doing new things? (Yes)	52	64	3.9*	3.0

		Patients (%)		**Differential endorsement ($\chi2$)**	
	Item	Visit 1 n=84	Visit 2 n=34	Visit 1 n=84	Visit 2 n=34
13	Frequently worry about the future? (Yes)	31	28	9.5**	11.2***
14	Feel that have more problems with memory than most? (Yes)	35	36	0	8.9**
15	Think it is wonderful to be alive now? (No)	5	7	17.5***	2.1
16	Often feel downhearted and blue? (Yes)	27	24	5.0*	13.4***
17	Feel pretty worthless the way you are now? (Yes)	35	31	3.0	9.4**
18	Worry a lot about the past? (Yes)	6	7	33.1***	2.1
19	Find life very exciting? (No)	45	75	1.5	1.4
20	Hard to get started on new projects? (Yes)	62	62	2.5	2.8
21	Feel full of energy? (No)	87	79	0.6	1.1
22	Feel that situation is hopeless? (Yes)	40	24	0.2	5.9*
23	Think that most people are better off? (Yes)	23	31	14.1***	3.7
24	Frequently get upset over little things? (Yes)	31	31	3.9*	0.6
25	Frequently feel like crying? (Yes)	32	17	9.1**	3.1
26	Have trouble concentrating? (Yes)	30	21	0.9	16.4***

		Patients (%)		**Differential endorsement ($\chi 2$)**	
	Item	Visit 1 n=84	Visit 2 n=34	Visit 1 n=84	Visit 2 n=34
27	Enjoy getting up in the morning? (No)	39	35	2.3	0.4
28	Prefer to avoid social gatherings? (Yes)	39	52	2.4	1.4
29	Easy to make decisions? (No)	21	28	7.5**	11.2***
30	Mind as clear as it used to be? (No)	39	48	2.4	5.9*

* $p. \leq 0.5$ ** $p \leq 0.01$ *** $p \leq 0.001$

Relationship between patient-completed and carer-completed measures

Scores

At Visit 1, none of the versions of the GDS showed sufficiently high correlations between carer-completed and patient-completed forms to allow substitution of carer reports for patient reports (Table 6.8). At Visit 2, insufficient matching data were available to allow analysis.

Presence of symptoms

There was generally low to moderate agreement between carers and patients concerning the presence or absence of particular symptoms (Table 6.8). Visual inspection shows that the frequency with which a symptom was reported was generally lower in patient-reports than in carer-reports about the patient, and that there was no consistent change in the level of agreement from Visit 1 to Visit 2 (Table 6.9).

Table 6.8 The agreement between patient and carer reports about patient symptoms

		Visit 1	Visit 2
	Item	Kappa	Kappa
1	Basically satisfied with life? (No)	.36***	.27
2	Dropped many activities and interests? (Yes)	.53***	.49*
3	Feel that life is empty? (Yes)	.38**	.52**
4	Often get bored? (Yes)	.28*	.47*
5	Hopeful about the future? (No)	.49***	.43*
6	Bothered by thoughts that can't get out of head? (Yes)	.13	.44*
7	In good spirits most of the time? (No)	.13	.42*
8	Afraid that something bad is going to happen? (Yes)	.43***	.58*
9	Feel happy most of the time? (No)	.14	.17
10	Often feel helpless? (Yes)	.49***	.49*
11	Often get restless and fidgety? (Yes)	.53***	.22
12	Prefer to stay at home rather than going out and doing new things? (Yes)	.30*	.12
13	Frequently worry about the future? (Yes)	.35***	.21
14	Feel that have more problems with memory than most? (Yes)	.31*	.82***
15	Think it is wonderful to be alive now? (No)	.22*	.13
16	Often feel downhearted and blue? (Yes)	.43***	.65***
17	Feel pretty worthless the way you are now? (Yes)	.44***	.49*
18	Worry a lot about the past? (Yes)	.29*	.18
19	Find life very exciting? (No)	.31**	.47*

		Visit 1	Visit 2
	Item	Kappa	Kappa
20	Hard to get started on new projects? (Yes)	.23	.02
21	Feel full of energy? (No)	.26*	-.08
22	Feel that situation is hopeless? (Yes)	.37**	.28
23	Think that most people are better off? (Yes)	.33*	.76***
24	Frequently get upset over little things? (Yes)	.41**	.47*
25	Frequently feel like crying? (Yes)	.33*	.14
26	Have trouble concentrating? (Yes)	.48***	.43*
27	Enjoy getting up in the morning? (No)	.42***	.14
28	Prefer to avoid social gatherings? (Yes)	.57***	.54*
29	Easy to make decisions? (No)	.33*	.68**
30	Mind as clear as it used to be? (No)	.49***	.65**

* $p \leq .05$ ** $p \leq .01$ *** $p \leq .001$

Table 6.9 Relative frequency of patient- and carer-reported patient symptoms

		% of informants			
		Visit 1		Visit 2	
	Item	Patient n=84	Carer n=66	Patient n=34	Carer n=35
1	Basically satisfied with life? (No)	13	37	17	35
2	Dropped many activities and interests? (Yes)	75	57	72	77
3	Feel that life is empty? (Yes)	14	23	24	33
4	Often get bored? (Yes)	36	44	36	57
5	Hopeful about the future? (No)	28	50	21	45
6	Bothered by thoughts that can’t get out of head? (Yes)	34	39	24	36
7	In good spirits most of the time? (No)	6	27	14	26
8	Afraid that something bad is going to happen? (Yes)	31	53	38	50
9	Feel happy most of the time? (No)	12	33	10	31
10	Often feel helpless? (Yes)	42	56	45	68
11	Often get restless and fidgety? (Yes)	51	50	36	50
12	Prefer to stay at home rather than going out and doing new things? (Yes)	52	63	64	68
13	Frequently worry about the future? (Yes)	31	59	28	49
14	Feel that have more problems with memory than most? (Yes)	35	28	36	40

		% of informants			
		Visit 1		**Visit 2**	
	Item	Patient n=84	Carer n=66	Patient n=34	Carer n=35
15	Think it is wonderful to be alive now? (No)	5	18	7	29
16	Often feel downhearted and blue? (Yes)	27	39	24	46
17	Feel pretty worthless the way you are now? (Yes)	35	33	31	51
18	Worry a lot about the past? (Yes)	6	18	7	15
19	Find life very exciting? (No)	45	70	75	78
20	Hard to get started on new projects? (Yes)	62	55	62	73
21	Feel full of energy? (No)	87	87	79	97
22	Feel that situation is hopeless? (Yes)	40	36	24	47
23	Think that most people are better off? (Yes)	23	28	31	34
24	Frequently get upset over little things? (Yes)	31	43	31	49
25	Frequently feel like crying? (Yes)	32	30	17	42
26	Have trouble concentrating? (Yes)	30	37	21	53
27	Enjoy getting up in the morning? (No)	39	25	35	29
28	Prefer to avoid social gatherings? (Yes)	39	53	52	44

		% of informants			
		Visit 1		**Visit 2**	
	Item	Patient n=84	Carer n=66	Patient n=34	Carer n=35
29	Easy to make decisions? (No)	21	31	28	29
30	Mind as clear as it used to be? (No)	39	48	48	51

Discussion

Patient-centred care requires that clinicians have insight into patients' experience of psychological distress. For this purpose, multi-item scales are superior to single-item and algorithm-based screening tools. A subset of five previously published short-forms of the GDS showed good psychometric properties in the current sample.[239,241,243-245] Overall these captured most of the information gained from asking patients the full 30 items, had good internal consistency and adequate test-retest reliability, showed concurrent and convergent validity similar to that of the full scale, and produced distributions of scores that may be of use in clinical contexts. In general, the psychometric properties of the 4-item short form by D'Ath et al[239] and the 5-item short-form by Molloy et al[243] were similar to those of the three short forms containing ten or more items.[241,244,245] The 5-item tool may be of particular interest in palliative contexts. In other settings it shows good psychometric properties in patients with cognitive impairment.[243]

In summary, five short forms of the GDS[239,241,243,244,257] hold promise as clinically useful tools in palliative care since they are psychometrically sound and use simpler and more consistent response alternatives than most other multi-item scales.[68,73] Preferences between these short forms will be influenced by the relative importance assigned to minimising burden versus understanding patients' experience, the relevance of their content to the clinical situation, and the results of subsequent investigations examining their validity against a gold standard.

This study also used the GDS-30 to gain insight into the ways in which non-somatic symptoms associated with depression are expressed in palliative populations. Some non-somatic symptoms of depression were endorsed by more than half the sample. These primarily related to behavioural indices of anhedonia that were also likely to be influenced by disease progression (e.g. “Dropped many activities and interests”). A similar pattern was reported by Sela,[251] who used a different screening instrument. The high frequency with which patients at both visits endorsed items relating to positive affect and satisfaction with life is noteworthy given these patients’ prognosis and their symptom burden, and helps to balance the high frequency with which these patients endorsed items relating to loss of activities and interests and lack of energy.

Despite the high level of endorsement of many non-somatic symptoms, there was little evidence that advanced illness and side effects of treatment led to an over-diagnosis of severe depression by the GDS-30. Moreover, most of the items on the GDS-30 helped to discriminate between patients likely to have severe depression and other patients at Visit 1 and/or Visit 2. Thus, those ambulatory palliative patients identified by the GDS-30 as likely to have severe depression report most of the non-somatic symptoms that are seen in the other geriatric populations on which the GDS was based.

The current research had several strengths, including assessment of the psychometric properties of the scales at more than one point during the trajectory of illness. However, the findings should be interpreted with caution since the sample size was limited, especially at Visit 2, and included only patients well enough to attend an ambulatory out-patient clinic. There was explicit comparison of these psychometric properties when these scales were answered by carers as well, although there was not sufficient correlation between carer-completed and patient-completed forms to allow substitution of carer reports for patient reports of the GDS.

For obvious practical reasons, scores for the nine short forms of the GDS were derived from the GDS-30 rather than from the independent administration of these scales. The psychometric properties reported here therefore need to be verified when the scales are administered independently. In addition, the effectiveness that the GDS-30[217,218] and these short forms[219,239,243,258,259] have shown in screening for depression in other populations needs to be confirmed in palliative contexts by validating them against a gold standard diagnostic test. It will also be important to verify that the high acceptability of these short forms in other populations is also observed among patients receiving palliative care.[239]

The current study yielded two outcomes. It identified the five existing short forms of the GDS[239,241,243-245] that hold the promise of providing insight into patients' experience of depression while limiting burden on patients and staff. Two of these are sufficiently brief to be included in routine screening (Diagram 6.1 and Diagram 6.2). It also showed that items concerning some non-somatic symptoms of depression are endorsed by many patients receiving palliative care. Despite this, most of the non-somatic symptoms assessed in this study were helpful in identifying patients with severe depression.

Diagram 6.1 The GDS-4 (D'Ath et al)[239]

	Item		
1	Basically satisfied with life?	Yes	**No**
3	Feel that life is empty?	**Yes**	No
8	Afraid that something bad is going to happen?	**Yes**	No
9	Feel happy most of the time?	Yes	**No**

Diagram 6.2 The GDS-5 (Molloy et al)[243]

	Item		
1	Basically satisfied with life?	Yes	**No**
3	Feel that life is empty?	**Yes**	No
9	Feel happy most of the time?	Yes	**No**
10	Often feel helpless?	**Yes**	No
16	Often feel downhearted and blue?	**Yes**	No

Chapter 7

Identifying the advantages and barriers to assessing depression in palliative care settings: A way forward

Introduction

Many caring and competent palliative clinicians do not routinely screen for depression,[40,123,160,260,261] despite understanding the burden of depression among their patients,[43,262] and the wide variety of screening tests that are available.[1,17] Arguments can be made both for and against routine screening for depression. To date, reviews of the effectiveness of such screening have focused almost exclusively on outcomes related to the treatment of depression.[66,114] However, screening and follow-up assessment for depression have costs and benefits regardless of whether depression is treated. The first issue for clinicians is whether to screen for depression, the second decision concerns which patients to screen. Both routine screening and screening only for patients "at risk" for depression have been recommended. Poorer information is available to inform the second of these choices because psychometric properties of screening tests are usually only known for routine screening. The third decision for clinicians who choose to screen patients for depression concerns how follow-up assessment will be provided.

There is a growing body of knowledge and work about service delivery models. A summary of service-delivery models and options is explored to offer palliative care administrators and clinicians insight and options to structure their Palliative Care Services and relationships with psychological service providers to better manage psychological symptoms.

Aims

The aims of this chapter are to understand why screening may not happen routinely and to find a possible way forward

To date, arguments for and against routine screening for depression in medically-ill populations have focused on whether screening increases the number of patients who are offered treatment for depression and/or whether this treatment is effective. This focus is overly narrow, ignoring many of the potential advantages of screening for depression and not addressing the barriers to screening that apply in clinical contexts. In particular, identification of depression can be useful even when its treatment is not appropriate or possible. Identification of depression can of itself, provide patients, family members and clinicians with greater understanding of difficult patient behaviours[263] and reduce patient anxiety.[66] It also allows improved case management.[264] The dual burden experienced by some carers can be recognised.[132] Clinicians can be alert to the increased likelihood of poor patient compliance[22,133,135] and the need for more effective symptom management strategies.[23,24,42] Palliative Care Services are more able to plan for the development of appropriate organisational and personal coping strategies for staff dealing with depressed clients.[265,266]

Given these possible benefits, Palliative Care Services and individual clinicians need to make four decisions:

1. whether or not to screen for depression
2. how to screen
3. what type of follow-up to provide
4. what model of service to use

1. whether or not to screen for depression

It appears that relatively few Palliative Care Services provide routine screening for depression among their patients.[40,123,160,260,261] There are many reasons why

Services and individual clinicians may choose not to screen for depression. Firstly, little is known about the emotional impact of such screening. Questions may focus patients' attention on negative aspects of their experience; there is a danger of unwelcome insight; and patients' self-concept or the attitude of others towards the patient may change in unhelpful ways (e.g. the nurse now sees the patient as someone with a mental health problem and so does the patient;[37] there may be a sense of being "labelled". However, the salience and emotional impact of screening questions can be minimised if they are presented as part of routine assessment. In addition, there is evidence that some screening instruments are well-received by patients.[2] In addition, alerting patients and staff to mental health issues is not necessarily a negative outcome. It is consistent with the "whole person" approach of the World Health Organisation definition of palliative care[104] and it increases the likelihood of patients with mental heath needs having those needs met. Unwelcome self-knowledge about depression can be avoided by using the same clinical strategies that are used to prevent or minimise unwelcome self-knowledge about other medical issues, e.g. disease progression. In both cases, clinicians should consider the level of information the patient has reported that they wish to know, consider the relevant patient values, and the benefit or distress the information may cause in the patient's current context.

Cases of depression will be missed without screening.[267] Despite this, palliative clinicians' approach to depression often deviates from best practice in two ways. On one hand, patients with moderate or severe depression are often not identified or treated.[12,17,18,39,145] On the other hand, patients are often treated for depression when it is unclear that this treatment is appropriate: palliative patients are prescribed antidepressants without a mental health specialist making a differential diagnosis[39] or determining that the depression is of a severity that is responsive to antidepressants,[268] and when there is insufficient time for antidepressants to have a therapeutic effect.[39]

Barriers to screening can be considered in the following categories:-

a) Distress

Probing into psychological experiences during screening and assessment may distress patients,[269] however other procedures in palliative care also carry a risk of causing distress to patients and their carers (e.g. lumbar puncture, giving diagnostic information, talking about death and dying) but this does not prevent them from being conducted if they are judged to provide a benefit. There are side effects associated with many palliative care interventions.

b) Stigma

Screening may place the patient at risk of stigma. Stigma is associated with the word “depression” in the minds of members of the community and palliative care clinicians.[37] Indeed, there is stigma associated even with a mental health assessment.[270] Stigma is associated with mental health problems in a wide range of cultural contexts. However, palliative care clinicians are highly skilled in dealing with patients with stigmatising conditions (e.g. cancer, AIDS) and the stigma of dying. Giving permission to speak about psychological experiences may act to reduce patients’ distress. It is not necessary to interpret mental health problems, such as depression, as a weakness in the individual, or as a failure in masculinity, or as malingering. Mental health problems are the outcome of a person-situation fit. However, there may be less stigma associated with depression in palliative care than in other contexts because depression may be judged to be “understandable” in the dying. Raising these issues may bring relief to patients – it may give them understanding about their own behaviour and help families and staff to see reasons behind unhelpful behaviours by the patient. The diagnosis of depression can provide understanding of “difficult” behaviours.[263]

c) Risk/Benefit ratio

The decision to screen is best considered as distinct from the decisions about whether to make a formal assessment and the decision about whether to intervene. Like other decision-making in palliative care, the issues revolve around the weighing of likely benefits against likely costs, with the patients' values informing assessment of costs and benefits. There is little empirical evidence about diagnosis and interventions for depression that is specific to depression in palliative care. Many medical interventions in wide use in palliative care have limited empirical evidence of effectiveness in this setting and much clinical practice in palliative care is based on evidence from other medical disciplines. Depression can be diagnosed and effectively managed in other medical populations and diagnostic criteria and methods of intervention used in other medical contexts are appropriate and effective with palliative care patients.

d) What is normal?

In the past, pain was judged to be part of the expected trajectory of many life-limiting illnesses. Now it is judged to be a "palliative care emergency" or at least not to be accepted passively as inevitable. Our duty of care to address the suffering of patients with pain was not diminished because pain was recognised to be present in a large number of patients. It is hard to sustain an argument that clinicians are absolved from a duty of care to reduce suffering due to depression because it is perceived that this is a common symptom. In addition, although Kübler-Ross argued that a stage of "preparatory depression" was part of the trajectory leading to "a good death", she also advocated for the aggressive treatment of "reactive depression" which would interfere with "a good death". Further exploration of the symptoms of depression experienced by patients is therefore warranted.

e) Spontaneous remission

There is a widespread belief that assessment and intervention for depression in palliative care populations are unnecessary because there are high rates of spontaneous remission.[271,272] It is believed by some palliative care practitioners that the number of symptoms and the severity of depression among palliative care patients are likely to decline as a result of the “normal” activities of a palliative care team, or by the standard measures provided when a patient is admitted to a hospice or Palliative Care Unit. That is, the number or severity of symptoms of depression may decline following interventions that target factors that contributed to the depression. For example, the severity of symptoms of depression may decline as a result of social work interventions aimed at reducing family conflict, medical interventions aimed at reducing physical symptoms or nursing interventions aimed at reducing the burden of care. Pain may also show spontaneous remission, but it is inconceivable that a competent palliative care practitioner would withhold treatment for pain assuming that remission might be the case.

f) Screening nihilism

Another potential barrier to proper assessment of depression can be categorised as “screening nihilism”. The argument is that there is no reason to screen for depression as the instruments available are all very poor at detecting depression. Most of the screening instruments available for use in palliative care populations have had low values of positive predictive value. However, brief screening instruments with high positive predictive values are now available.[2]

g) Therapeutic nihilism

“Why screen, as there is nothing that can be done to remedy the situation when depression is detected? All you are doing is adding to this patient’s misery.” This stance can be considered to be “therapeutic nihilism” – a belief that all interventions have either no benefit, that there is insufficient time for a therapeutic response or that they all have negative side-effects only. A general principle of good palliative care practice is that one should not assess or investigate an issue unless there is an intervention that is effective. It is well-known that therapeutic interventions for depression do not provide an immediate clinical benefit. Rather than this being an argument for inertia and lack of assessment, there is a need to recognise the condition earlier so that an informed decision can be made at a time when interventions are likely to be most effective. Many clinicians would appear not to realise that patients at the end of their lives can still respond to interventions and treatments for psychological disorders.[270] One should never assume that there is not enough time for an intervention to have an effect. The trajectory of the illness of a palliative care patient is always uncertain. Many interventions may still be possible, be desired by the patient and family, and be likely to provide some relief of distressing symptoms.

h) Limited resources

There may be concerns that the costs in the widest sense associated with introducing a screening program may lead to the diversion of limited time, energy and funds from other areas of need. If it is believed that screening for depression does not improve outcomes for patients, families, clinicians or health services, then there will be no imperative to investigate depression in an orderly and systematic manner. Expenditure of time and resources on screening for depression is likely to require the diversion of resources from other areas of need, which may be perceived to make a greater contribution to patient well-being. There is also a cost associated with not screening, assessing or treating depression for the individual, the informal carers and the health service. The patient is consigned to their continuing “misery of mood,”[273] the carers are left without clear explanation and understanding for the reasons for the difficult behaviours of their “bad patient,” and the functional status of the patient is likely to be under-assessed, increasing the possible loss of physical function and mental agility. There are simple validated screening instruments. There is demonstrated benefit not only to the patient but also to carers. This would seem to be an issue that is too important to neglect. Just because it seems too hard has not been an impediment for palliative care clinicians to advocate and care for their patients in other situations.

The US Preventive Services Task Force recommended screening for depression among medical patients only when there were adequate resources for accurate diagnosis, effective treatment and follow-up. The challenge for specialist Palliative Care Services is to assess the resources that are available to them, to use these in the most effective and efficient manner possible and to advocate for increased services if the current ones are inadequate for their patients' needs.

In summary, the decision whether to screen for depression or not depends on:-

a) What the human resource costs are, in terms of both clinical and administrative staff and the physical resource costs required, such as paper, and computer access.

b) What the patients', families' and clinicians' priorities are for care.

c) The level of stigma associated with mental health screening in the catchment population of the Palliative Care Service.

d) The culture of the Palliative Care Service:-

    i) Whether mental health concerns are part of the central philosophy of care

    ii) To what extent do individual clinicians and clinical teams have control over their own practice

e) The estimated prevalence of depression in the population seen by the Palliative Care Service. A plan to implement screening for depression is only likely to be successful if the clinicians involved perceive that depression may have a relatively high prevalence.

2. how to screen

Routine versus targeted screening

If they do decide to screen, clinicians also need to decide who to provide screening for (i.e. routine or targeted). Screening by its definition suggests that an entire population or group is at risk of having the condition it assesses. However, it is not uncommon to hear of clinicians screening patients whom they believe are at risk of suffering the condition (e.g. depression), i.e. targeted screening.

If true screening is desired then whole of population or cohort or group screening should occur. This has obvious resourcing issues but does ensure that a whole of population assessment of the burden of depression is assessed. By “gate-keeping” who will be screened, i.e. targeting screening, some individuals with depression are likely to be missed. The reasons for gate-keeping may be in good faith. Reasons have been explored in detail in the preceding paragraphs. There are examples of targeted screening in other areas of palliative care practice, e.g. risk assessment screening of bereaved clients.

Form of screening

Psychometric properties

To miss someone with depression or to label someone as having depression erroneously are both most undesirable. To date, many screening tests for depression in palliative populations have had variable psychometric properties, i.e. sensitivity, specificity, positive and negative predictive values. Often one parameter is compromised by an improvement in another. A desirable outcome is a test that produces a reliable and reproducible outcome psychometrically, is not confronting, is easily scored and interpreted.

Brief versus longer instruments

Most Australian Palliative Care Services that do provide screening do not use a validated instrument (Chapter 4). This certainly brings into question whether the screening is efficient or effective. Decisions about whether to use a single-item question,[1] or a longer and more detailed screening instrument need to be made. What instrument is used will depend on many factors, such as the cognitive state of the patient, the level of physical function and the need or desire for a more descriptive assessment of the symptoms of depression. Most screening instruments rely on a scoring system with agreed cut-off points to delineate a positive or negative result. Interpretation can be complex, answer sets may not be consistent and there may be dispute about valid cut-off points in different populations. The Short Screen for Depression Symptoms or algorithm developed in Chapter 5 uses a simple Yes/No option to a brief series of questions resulting in a Yes/No result and is one possible solution.[2] Palliative Care Services need to understand validated screening instruments and their proper use.

Patient versus proxy response

There are high levels of cognitive impairment and cognitive failure in palliative populations. Physical deterioration and extreme fatigue can also impact on a person's ability to participate in screening. It is not uncommon for proxies to be asked to make assessments for the patient – professional carers and family members and friends. Whether these screening tests have been validated in this population as a proxy measure is important. It is possible that assumptions are made without validating the modified instrument for the new respondent or proxy form. This issue has been investigated and discussed in Chapter 6.

3. what type of follow-up to provide

Palliative care best practice supports and encourages multi-disciplinary assessment for all patients. The input and relative importance of individual disciplines' expertise will depend to some degree on the needs of the particular patient, and unfortunately on the availability of disciplines. For someone with a possible mental health issue an adequate psychological assessment is needed. Whether this involves specialist clinicians or generalists is less clear and will depend on whether these clinicians are available and how they can be accessed for the particular patient. All medical practitioners, nurses and social workers should receive some knowledge of, and skills in, managing mental health issues and depression in their training. The diagnosis of mental disorders is covered in the training provided to general practitioners, oncologists and palliative care specialists.[274-276] Although they may wish to consult lecture notes or textbooks or to conduct a brief literature review to refresh their knowledge of this field, most are able to make a diagnosis of depression using DSM-IV or ICD-10 diagnostic criteria.[277]

If mental health professionals are not available and if the assessment for other conditions with overlapping systems is negative, it allows the clinician greater confidence that the patient has depression, even though depression is not a “diagnosis of exclusion”.

Medical assessment

Regardless of whether a mental health assessment is conducted, a comprehensive medical assessment is current best practice for people referred to a specialist Palliative Care Service. There is a need to conduct appropriate assessments to ensure that another condition with overlapping symptoms (e.g. renal failure, cerebral metastases, anaemia) are not being overlooked just because depression is suspected as a result of screening. A positive result does not rule out the possibility of co-morbid illness exacerbating or contributing to the depression.

Social assessment

It is important to investigate social stressors, social history, coping strategies and the meaning of events to the patient to determine if depression is a more or less likely explanation for the symptoms shown by the patient.

Nursing assessment

Nurses can use behavioural observations and information about care needs to determine if depression is a likely explanation for the symptoms shown by the patient. For example, if the patient requires frequent assistance with toileting and often complains of a dry mouth, diabetes might be explored as an alternative explanation for the patient’s fatigue, sleep disturbance and weight change.

Mental health assessment

What options there are for a mental health professional assessment and hence management of patients with depression will depend on availability of professionals such as psychiatrists, psychologists, social workers, counsellors and pastoral care workers. The expertise of these professionals in palliative populations and their availability in terms of physical presence and accessibility will dictate how these clinicians might be able to assist the specific patient. The following section is designed to offer Palliative Care Services some suggestions about how current and potential psychosocial professional resources may be harnessed for the best outcome for the patient with a mental health issue. There is clearly not one “correct solution,” and individual Palliative Care Services may come to quite different solutions for their own population, depending on the population demographics, the major issues for their population and the availability of psychosocial professionals.

4. what model of service to use

An important decision for clinicians who choose to screen for depression concerns models of care: who will provide follow-up assessment and/or decide on and implement interventions. This will be dependent on the access to mental health clinicians and how Services are structured. This decision may be affected by the size and composition of the population the Palliative Care Service supports and the availability of mental health specialists. Proximity, ease of access, cost in terms of time, travel and specific service provision fees will all influence the reality of access to mental health specialist support. A consideration of models provides an opportunity for clarity of options and a structure to argue and advocate for specific models.

A brief description of seven models of care is provided to help clinicians to clarify their options. Models are presented in order of increasing demand for specialists or specialised training and a stepped care approach is elucidated (Table 7.1).

Table 7.1 Models of psychological service delivery

Model	Description
1	Clinicians already have the skills to assess and manage depression
2	Clinicians are given guidelines for assessing and managing depression
3	Clinicians are all up-skilled in depression
4	One particular palliative care team member is given enhanced training in assessment and management of depression
5	Psychological assessment and management is outsourced
6	Liaison support comes to the team or patients, e.g. liaison psychiatry
7	A psychological professional is part of the clinical team

1. It can be argued that professional training already equips attending clinicians in a Palliative Care Service to diagnose and manage most episodes of depression in their patients without specialist support, i.e. they already have the necessary skills.[277]

2. A second model involves attending clinicians being aided by specific decision-rules to assist assessment, diagnosis and initial treatment but also rules about which patients to refer to a mental health specialist[43] if available.

3. The third model involves providing all palliative care clinicians with additional training in the diagnosis and management of depression.[23,34]

4. The fourth model involves focusing additional mental health training resources on one or two members of a palliative care team, who subsequently serve as the team's resource for mental health issues. This maintains a focus on mental health issues within the team.[265]

5. In a fifth model, patients judged to warrant follow-up for depression are referred to a specialist mental health unit, which may or may not have specific links to the treating palliative team, i.e. the assessment is "out-sourced."[278] One disadvantage is that if this unit does not have a staff member with expertise in both palliative care and mental health, there may be limited appreciation of special issues relevant to palliative patients. In addition, transporting the patient to a different site of care may present practical problems for bed-bound patients and may be burdensome for many palliative patients.

6. A sixth model involves palliative care teams being provided with access to a liaison mental health specialist. This can provide specialised support, but the understanding of specific palliative patient issues may not be appreciated by a generalist mental health specialist. Physical access and site of assessment may be problematic if the mental health specialist is not physically located at the same site as the Palliative Care Service or the patients.

7. A seventh model involves the palliative care team expanding to include a mental health specialist as a core member. The attachment of a mental health specialist to the team is a significant step. The basic initiative would be the provision of support to clinicians at a regular point such as clinical review or multi-disciplinary team meetings and as part of continuing professional development. The next step would be the addition of patient service delivery and feedback to the palliative care clinicians. This regular contact is likely to enhance the diagnosis and management of depression.[174,212]

Stepped care

In reality, Palliative Care Services will access mental health professionals in a manner that is appropriate to the situation. This is not unique to mental health issues. Examples may include whether a surgical problem for a patient requires immediate transfer to a surgeon for assessment and possible surgery, or that advice is required between treating practitioners, rather than needing a direct patient assessment. What the preceding discussion hopefully will clarify for Palliative Care Services is the assessment of what resources are available to them proximately and further afield and to make efforts to forge links with mental health professionals with some expertise in the needs of palliative populations. For some Palliative Care teams it may be appropriate to employ a psychiatrist or psychologist. For others it may be possible to improve the skills of all palliative clinicians to better recognise depression and for another team it may be more appropriate to seek special training for one member, so that they can be a local resource, providing information for other team members.[66]

The options that are available are resource-dependent and will relate to the priorities and other needs in the Palliative Care Service and the population in which they work. By considering possible service models, clinicians should be able to utilise a progressive approach to the assessment and management of patients that is location specific and appropriate. The important issue is to consider the local and distant psychological service providers and to cultivate relationships that will enhance patient assessment and care.

A stepped care approach implies that all options are available. This is clearly not the case. A pragmatic view needs to be taken and by considering possible service delivery models and linkages with existing psychological services, it places palliative clinicians and administrators in a better position to clearly identify gaps in service, to improve care by maximising the use of already available resources and to advocate for increased resources to meet a clearly articulated and well-assessed unmet need.

Chapter 8

Conclusion

Overview

This thesis grew from my desire to provide better care for patients with psychological symptoms, particular those with symptoms of depression. It came from an awareness of my own inadequacies in the face of patients with obvious symptoms of depression. This caused me to reflect on my own abilities to recognise this complex issue; one made more difficult by the potential for overlap between physical and psychological symptoms. I was aware of my limited skills and knowledge of depression. I was aware of the limited access to mental health professionals with special expertise and understanding of the particular issues of depression in palliative care. I wondered how my colleagues were managing these issues.

The first study asked all Palliative Care Services in Australia about their knowledge and use of screening instruments for psychological distress. Access to psychological and social service providers with special skills in palliative care was also explored. This study was conducted as a postal survey. It confirmed that there is very poor understanding of screening instruments by Palliative Care Services and that there are limited numbers of psychological and social professionals, such as psychiatrists, psychologists, social workers, counsellors, pastoral care workers and chaplains, available to assist these palliative clinicians. I was able to compare Australian service provision with the United Kingdom and demonstrated that Australian Palliative Care Services appear to have poorer access than those in the United Kingdom.[123]

These results motivated me to a review of all the screening instruments for depression that are currently available. There did not appear to be any that had been validated in Australian palliative care populations. There had been several studies in other populations that did not support[19] the excellent psychometric properties of one- and two-item screening instruments demonstrated by Chochinov et al.[1] These questions are attractive, particularly for palliative care patients. The questions are short and would appear to be well-suited for patients approaching the end of their lives, patients with limited time and energy. I was also interested in knowing something about how difficult it might be to introduce routine screening for depression into clinical practice. Study 1 had shown how infrequently screening was performed. What were the difficulties and reasons for this? These were the initial research questions that led to Study 2.

The second study examined the validity of one- and two-item screening questions for depression in palliative care patients. The psychometric properties of these screening instruments were measured in Australian in-patient and community palliative care populations. This study did not confirm previously published findings using similar questions. A novel brief screening tool with sound psychometric properties, not based on a scoring system, was derived empirically. This was to offer a quick validated tool for use in Australian populations, particularly community palliative care patients. These are the people with potentially longer prognoses and therefore possibly more time to gain benefit from interventions. The algorithm or “Short Screen for Depression Symptoms (SSDS)” has a series of conditional steps, which lead to a judgement. This new instrument provides an alternative solution to the problem of recognition. A minimum of one and a maximum of four questions are asked, with less than 50% of participants being required to answer all questions. This algorithm is brief. It is a novel instrument, not requiring a scoring system. Algorithms are something that are well-known in clinical medicine.[189-197] The psychometric properties are good, particularly in community palliative care patients – a group likely to benefit from interventions for depression.

The psychometric properties of the SSDS were assessed using three different classification systems for depression; the Diagnostic and Statistical Manual of

Mental Disorders (DSM),[10] the International Classification of Disease (ICD)[9] and the Psychogeriatric Assessment Scales-Depression (PAS-D).[181] These assessments were independently confirmed by deriving consistent themes from the unstructured patient interview about emotions and feelings. The final part of Study 2 assessed the acceptability of these questions for patients and clinicians. In the vast majority of cases, both patients and clinicians judged that the content and timing of the questions were acceptable. This is in contrast to the significant concerns when the introduction of this study was first discussed with the clinical team.

Brief screening instruments by their nature provide very little information about the symptoms that depressed patients may be experiencing. I wanted to understand more about the symptom issues for palliative care patients experiencing depression. The Geriatric Depression Scale (GDS)[64] is an instrument that is widely used in psychiatric practice. It was designed for use in elderly medically unwell patients. It has been recommended to be used as part of a Comprehensive Geriatric Assessment.[230,231] The GDS enquires about a range of symptoms of depression. It has a simple and consistent response set. This instrument allows clinicians to gain insight into the experience and symptom profile of depression. The collateral source version of the GDS was administered to carers, allowing comparison with the patients' responses.

The GDS has many published short forms. Palliative care patients are likely to find burdensome the answering of the 30-item full form of the GDS. The ten known short forms of the GDS were examined. Correlations between the full GDS-30 and the short forms were performed. Construct, convergent and concurrent validity were performed. Test-retest reliability and the spread of responses for each scale were assessed to determine whether particular short forms not only had psychometric validity but were likely to be useful in clinical practice. In general terms, the short forms consisting of 10, 12 and 15 items all showed good to excellent psychometric properties when compared with the full form. They all had a distribution of scores, making them likely to have clinical utility. However, in this population of palliative care patients, it is likely that these instruments may still be too burdensome, particularly if they are administered on repeat occasions. The more brief forms of the GDS were more variable in their psychometric properties. The 4-item form of the GDS by D'Ath et al[239] and the 5-item form by Molloy et al[243] are likely to have clinical utility for Australian palliative care patients. These two short forms have three items from the GDS in common – two relating to anhedonia and one asking about feelings that something bad is going to happen. The GDS-4 (D'Ath et al) also asks another question about depressed affect and the GDS-5 (Molloy et al) has a different question about depressed affect and one question that explored hopelessness. Preference between these short forms of the GDS should be governed by the balance between the burden of administration and the benefit of understanding of the patients' experience. Both these recommended short forms of the GDS have the same advantage as the longer forms by containing questions that require both positive and negative responses. This third study has assisted palliative care clinicians to know whether using one of the many short forms may continue to provide meaningful information. These are useful additions for Palliative Care Services and palliative clinicians when considering the use of more detailed screening instruments for depression.

The symptom profile of depression was also examined in the third study. Exploration of specific symptoms of depression suffered by patients is not common and this analysis provides an innovative and useful insight into patients' experience. Patients did not equally endorse all symptoms of depression included in the GDS-30. The only somatic symptom included in the GDS-30, fatigue (not "full of energy"), was reported by more than half the patients at both visits. The results also show the importance of the wording of questions about non-somatic symptoms. Although the majority of patients endorsed anhedonia items relating to behaviours (e.g. Dropped many activities and interests), only a minority endorsed anhedonia items relating to perceptions. Only about one-third indicated that they were often bored and less than one-quarter felt that their lives were empty. Patients did not respond in the same way to the four items assessing impaired cognition. More patients rejected the idea that their mind was “as clear as it used to be” than the idea that it was “easy to make decisions”. This is an important finding. The manner in which symptoms of depression are discussed with patients has implications for whether they may or may not be endorsed.

Patient responses were compared with the carers’ collateral reports, i.e. the carers’ assessment of how the patients would report each item.[254,255] There was generally low to moderate agreement between carers and patients concerning the presence or absence of particular symptoms. The frequency with which a symptom was reported was generally lower in patient-reports than in carer-reports about the patient. This is important for clinicians to understand when they may need to rely on collateral source information.

Depression in palliative care patients is not a new problem and there is already a significant body of evidence about assessment and management. Many caring and competent palliative clinicians still do not routinely screen for depression, despite understanding the burden of depression among their patients,[43,262] and knowing of the wide variety of screening tests that are available. Arguments can be made both for and against routine screening for depression. However, screening and follow-up assessment for depression have costs and benefits regardless of whether depression is treated. The final chapter of this thesis considered the likely barriers and difficulties associated with the screening and management of depression.

There is a growing body of knowledge and work about service delivery models. A summary of service delivery models and options explored in this chapter offers palliative care administrators and clinicians potentially new ways to structure their Palliative Care Services and their relationships with psychological service providers. This gives clear choices, allowing clinicians the opportunity to increase their skills, to improve linkages and access to psychological and social professional support.

Research methods

A wealth of data is available from these studies. Both quantitative and qualitative analyses have been performed. A postal survey was conducted of all Palliative Care Services in Australia, with an excellent response rate. There has been analysis of three different populations of palliative care patients; namely hospice in-patients, community-dwelling palliative care patients assessed in their homes and ambulant patients attending outpatient clinics. There has been access to patients from three different Palliative Care Services. Some patients provided information on more than one occasion. Parallel carer assessments have been conducted for some items.

Limitations

This thesis deals only with the early, initial issues of depression in palliative care patients, i.e. identification and recognition. All of the studies in this thesis have limitations. Postal surveys notoriously have poor response rates and respondents are likely to be those with a significant view, potentially biasing results. There is no ability to clarify responses or to ask further questions that might arise from the responses.

Both of the patient-based studies have relatively small sample sizes. The problems of recruitment and attrition are significant in palliative care populations. The algorithm was derived from the data of Study 1. It was tested on two other sub-sets of the data to confirm its psychometric properties. However, it was not administered as an independent instrument. Formal validation studies of the algorithm and assessment against a gold standard is still required.

The short forms of the GDS were constructed from administering the full 30-item form of the GDS and deriving the shortened forms. These short forms need to be administered independently to formally assess whether the findings of this study can be reproduced. It is pertinent to reiterate that the precise nosology of depression is open to interpretation, but this is beyond the scope of this thesis and neither this nor specific treatments have been pursued.

Summary

This work should encourage palliative care clinicians to increase their awareness and knowledge of the issues associated with depression and lead to a change in practice. With increased knowledge and skills in assessing psychological issues, there should come a greater acceptance and ease with management. And with increased knowledge, improved outcomes for patients and families will follow. The assessment of depression will become an accepted and routine part of palliative care clinical practice.

Palliative Care Services should be making an assessment of the knowledge currently within their teams, about whether more training is required and what is appropriate for them with regard to screening for depression. Services need to develop guidelines and document their best practice, to ensure consistency for all clinical encounters. They should consider referral options and models of service delivery. This work provides a framework to assist in advocating with fund holders and administrators for increased resources, to improve the care for these patients. Decision about whether to employ more palliative clinicians with advanced psychosocial knowledge and skills or the addition of a worker trained in a particular mental health discipline are for individual PCS to make, in the context of their own individual circumstances.

There are now instruments that have been validated for Australian palliative care patients that address the two complementary issues with regard to recognising and assessing depression. The SDSS or algorithm derived in Study 2 is novel, brief and easy to administer. It does not need scoring. This is an exciting and innovative new instrument. The short forms of the GDS have now been validated in an Australian palliative population. This will assist clinicians to understand something of the patient experience of depression. Palliative clinicians need to have access to instruments that can provide insight into both aspects of screening for depression – brief and more detailed instruments.

This work came from my own sense of bewilderment and inadequacy. I have shown that this lack of knowledge and access to mental health professionals is widespread. This thesis sets the scene for change. There is now a choice of instruments for Australian palliative care clinicians to use. What should Services be doing? They should be learning how to use the SDSS. Palliative care clinicians need to understand the prevalence of depression in their practice. With greater understanding of this problem, mental health professionals will need to be a greater part of the multi-disciplinary palliative care team. These clinicians will further highlight the issues of psychological distress and depression and assist in improving assessment and treatment for palliative care patients. There is much still to be done.

The first steps for clinicians and Palliative Care Services are to:

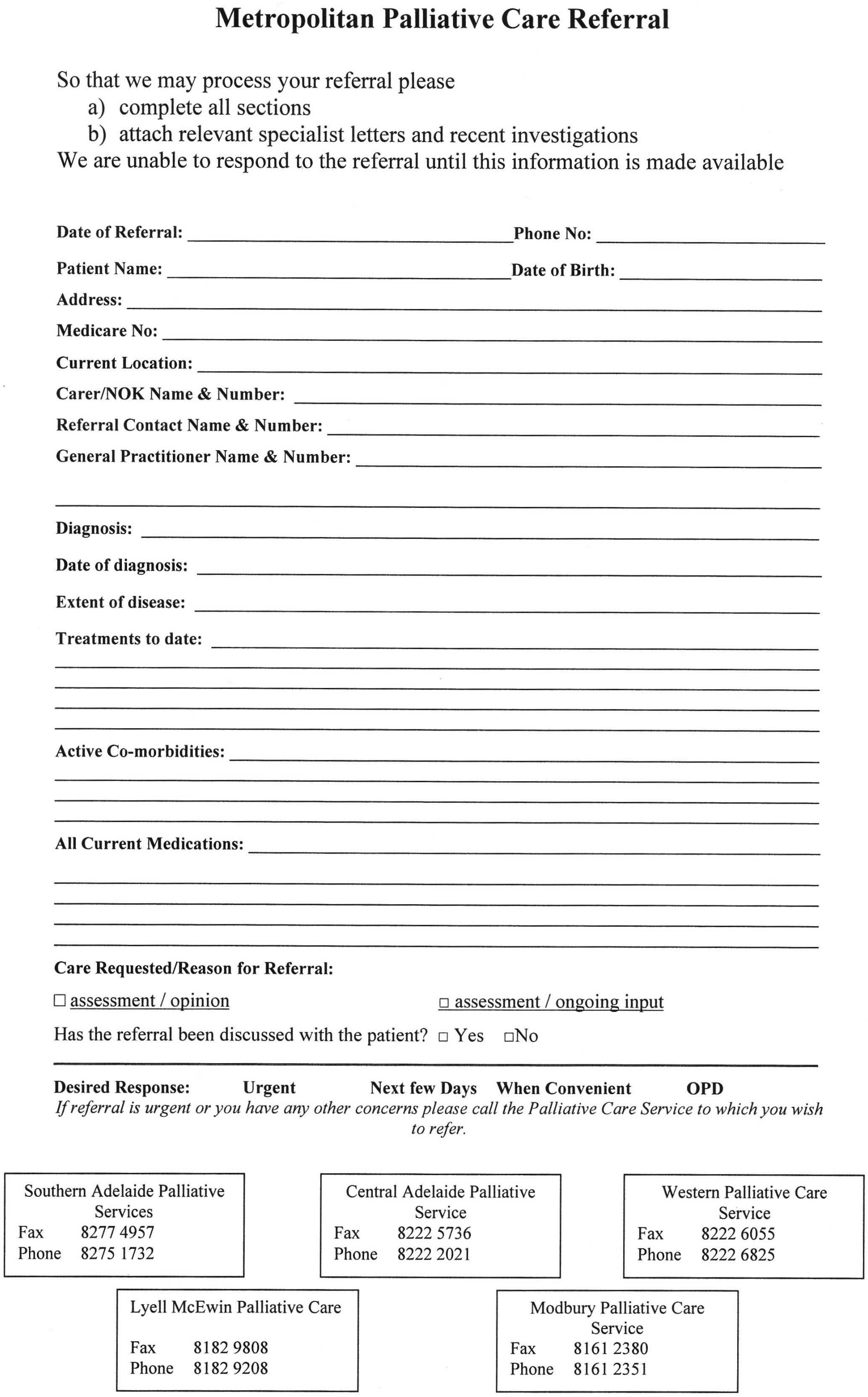
1. recognise the problem
2. decide how they will respond in their clinical situation
3. make and document policies
4. change practice.

In a medical emergency the priorities are the assessment of danger, airway, breathing and circulation.[279] In a mental health emergency the focus should be recognise, respond and restore function.[280] Depression in palliative care is not always easy to recognise. None-the-less this is an important added burden for arguably one of the most vulnerable groups of our society – the dying. The ability to identify, to recognise and to assess depression more fully in this population is a vital first step that must not be ignored.

Appendices

Appendix 3.1	Metropolitan Palliative Care Referral
Appendix 4.1	Letter of introduction
Appendix 4.2	Psychological and Social Service Provision in Palliative Care Questionnaire
Appendix 5.1	Robinson JA, Crawford GB. Identifying palliative care patients with symptoms of depression: An algorithm. Palliative Medicine 2005;19:278-287.

Appendix 3.1



Metropolitan Palliative Care Referral

So that we may process your referral please
a) complete all sections
b) attach relevant specialist letters and recent investigations
We are unable to respond to the referral until this information is made available

Date of Referral: ______________________ **Phone No:** ______________

Patient Name: ______________________ **Date of Birth:** ______________

Address: ______________________________________

Medicare No: ______________________________________

Current Location: ______________________________________

Carer/NOK Name & Number: ______________________________

Referral Contact Name & Number: ______________________________

General Practitioner Name & Number: ______________________________

____

Diagnosis: ______________________________________

Date of diagnosis: ______________________________________

Extent of disease: ______________________________________

Treatments to date: ______________________________________

Active Co-morbidities: ______________________________________

All Current Medications: ______________________________________

Care Requested/Reason for Referral:

☐ assessment / opinion ☐ assessment / ongoing input

Has the referral been discussed with the patient? ☐ Yes ☐No

Desired Response: **Urgent** **Next few Days** **When Convenient** **OPD**

If referral is urgent or you have any other concerns please call the Palliative Care Service to which you wish to refer.

Southern Adelaide Palliative Services
Fax 8277 4957
Phone 8275 1732

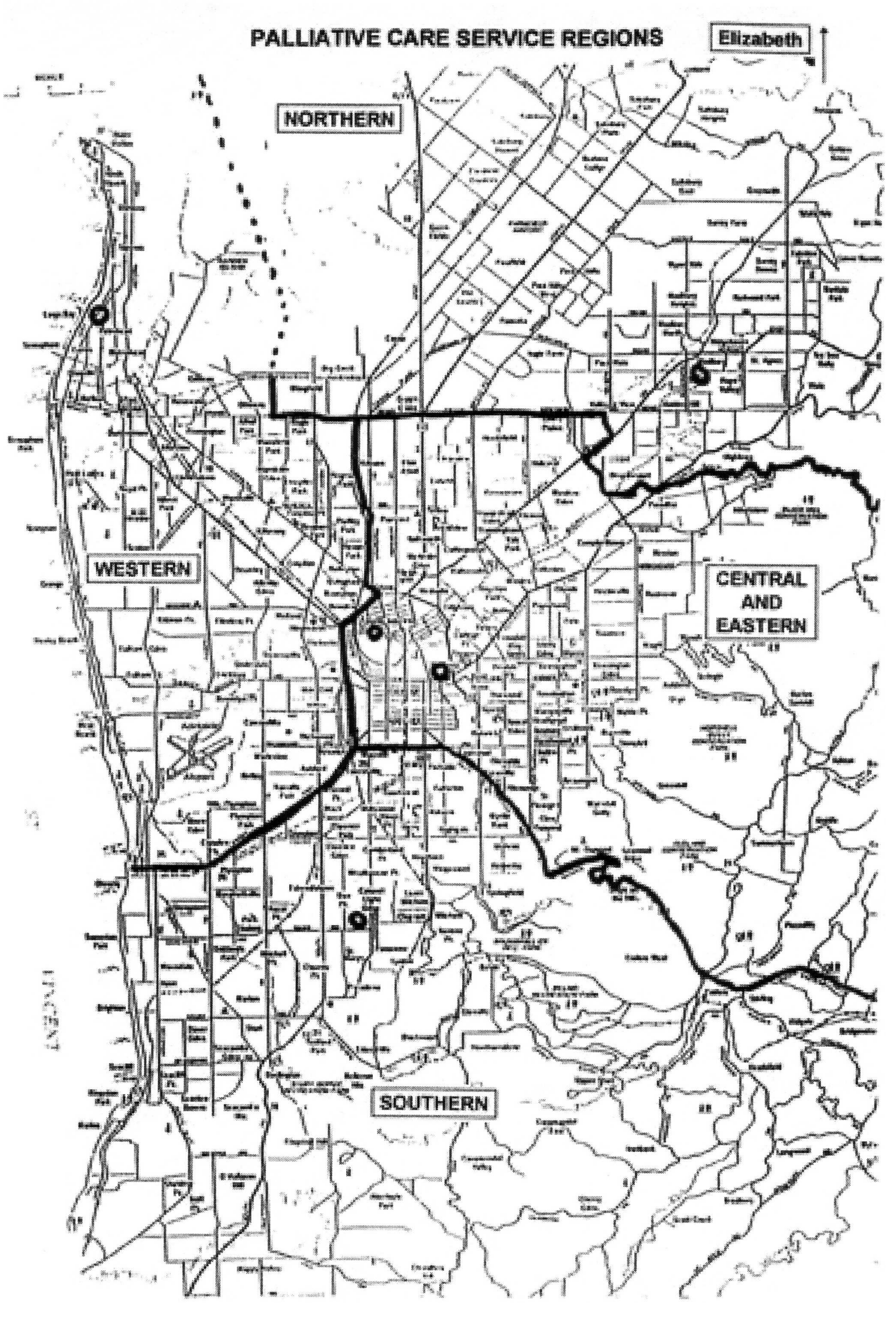
Central Adelaide Palliative Service
Fax 8222 5736
Phone 8222 2021

Western Palliative Care Service
Fax 8222 6055
Phone 8222 6825

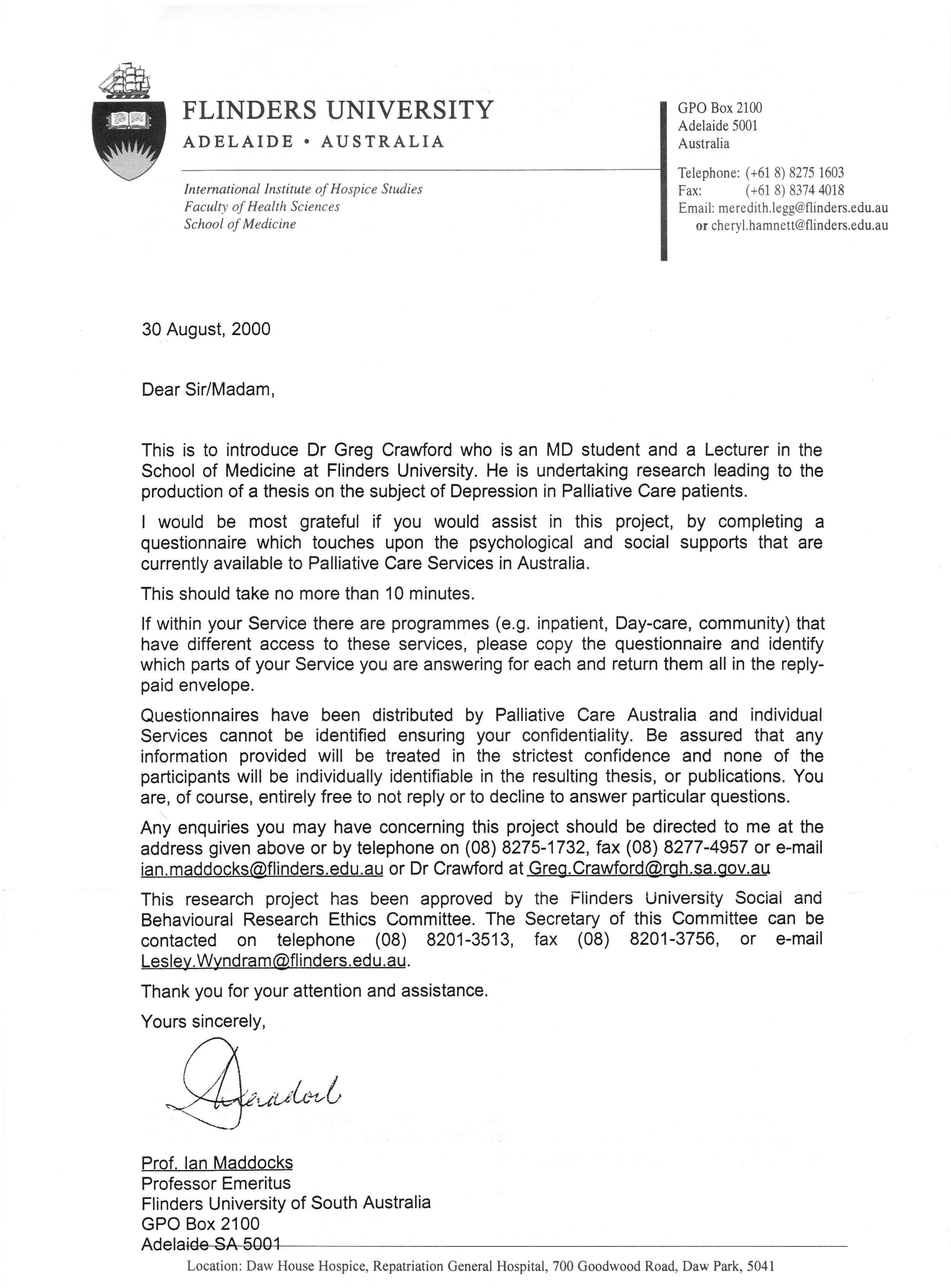
Lyell McEwin Palliative Care
Fax 8182 9808
Phone 8182 9208

Modbury Palliative Care Service
Fax 8161 2380
Phone 8161 2351

Map showing the areas serviced by each metropolitan Palliative Care Service



Appendix 4.1



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30 August, 2000

Dear Sir/Madam,

This is to introduce Dr Greg Crawford who is an MD student and a Lecturer in the School of Medicine at Flinders University. He is undertaking research leading to the production of a thesis on the subject of Depression in Palliative Care patients.

I would be most grateful if you would assist in this project, by completing a questionnaire which touches upon the psychological and social supports that are currently available to Palliative Care Services in Australia.

This should take no more than 10 minutes.

If within your Service there are programmes (e.g. inpatient, Day-care, community) that have different access to these services, please copy the questionnaire and identify which parts of your Service you are answering for each and return them all in the reply-paid envelope.

Questionnaires have been distributed by Palliative Care Australia and individual Services cannot be identified ensuring your confidentiality. Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, or publications. You are, of course, entirely free to not reply or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (08) 8275-1732, fax (08) 8277-4957 or e-mail ian.maddocks@flinders.edu.au or Dr Crawford at Greg.Crawford@rgh.sa.gov.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. The Secretary of this Committee can be contacted on telephone (08) 8201-3513, fax (08) 8201-3756, or e-mail Lesley.Wyndram@flinders.edu.au.

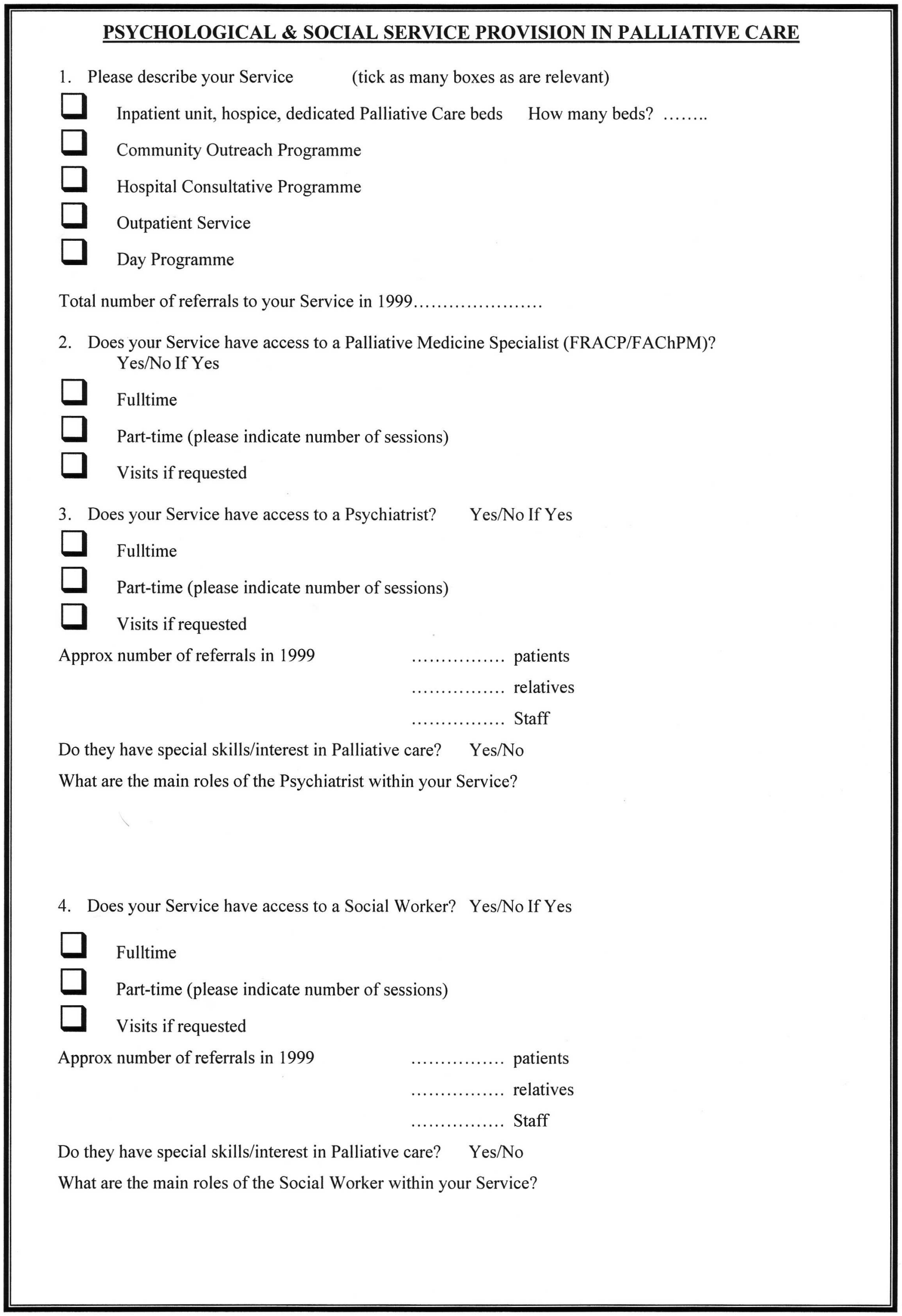
Thank you for your attention and assistance.

Yours sincerely,

Prof. Ian Maddocks
Professor Emeritus
Flinders University of South Australia
GPO Box 2100
Adelaide SA 5001

Location: Daw House Hospice, Repatriation General Hospital, 700 Goodwood Road, Daw Park, 5041

Appendix 4.2



PSYCHOLOGICAL & SOCIAL SERVICE PROVISION IN PALLIATIVE CARE

1. Please describe your Service (tick as many boxes as are relevant)

☐ Inpatient unit, hospice, dedicated Palliative Care beds How many beds? ……..
☐ Community Outreach Programme
☐ Hospital Consultative Programme
☐ Outpatient Service
☐ Day Programme

Total number of referrals to your Service in 1999…………………

2. Does your Service have access to a Palliative Medicine Specialist (FRACP/FAChPM)? Yes/No If Yes

☐ Fulltime
☐ Part-time (please indicate number of sessions)
☐ Visits if requested

3. Does your Service have access to a Psychiatrist? Yes/No If Yes

☐ Fulltime
☐ Part-time (please indicate number of sessions)
☐ Visits if requested

Approx number of referrals in 1999 ……………. patients
……………. relatives
……………. Staff

Do they have special skills/interest in Palliative care? Yes/No

What are the main roles of the Psychiatrist within your Service?

4. Does your Service have access to a Social Worker? Yes/No If Yes

☐ Fulltime
☐ Part-time (please indicate number of sessions)
☐ Visits if requested

Approx number of referrals in 1999 ……………. patients
……………. relatives
……………. Staff

Do they have special skills/interest in Palliative care? Yes/No

What are the main roles of the Social Worker within your Service?

5. Does your Service have access to a Psychologist? Yes/No If Yes

☐ Fulltime
☐ Part-time (please indicate number of sessions)
☐ Visits if requested

Approx number of referrals in 1999 .... patients
.... relatives
.... Staff

Do they have special skills/interest in Palliative care? Yes/No

What are the main roles of the Psychologist within your Service?

6. Does your Service have access to a Pastoral Care Worker(s)? Yes/No If Yes

☐ Fulltime
☐ Part-time (please indicate number of sessions)
☐ Visits if requested

Approx number of referrals in 1999 .... patients
.... relatives
.... staff

What are the main roles of the Pastoral Care Worker(s) within your Service?

7. Does your Service have access to a Chaplains? Yes/No If Yes

☐ Fulltime
☐ Part-time (please indicate number of sessions)
☐ Visits if requested

Approx number of referrals in 1999 .... patients
.... relatives
.... staff

What are the main roles of the Chaplain(s) within your Service?

8. Does your Service have access to other Counsellors? Yes/No If Yes

Are they Volunteer/Paid?

☐ Fulltime

☐ Part-time (please indicate number of sessions)

☐ Visits if requested

Approx number of referrals in 1999 .... patients

.... relatives

.... staff

What are the main roles of the Counsellors within your Service?

9. Do these professionals attend multi-disciplinary meetings/ward rounds? Please tick relevant boxes.

	Regularly	Occasionally	If requested	Never	Not available
Psychiatrist					
Social Worker					
Psychologist					
Pastoral Care Worker					
Counsellor					

10. Does your Service have access to other psychological and social services?

Yes/No If Yes please specify

11. Does your Service use any screening instruments to assess psychological, social and spiritual distress?

Yes/No If Yes please specify

12. In which year did you Service begin? ....

Please return this questionnaire in the reply-paid envelope to: -

Psychological & Social Service Provision
The International Institute of Hospice Studies
700 Goodwood Road
Daw Park SOUTH AUSTRALIA 5041

Thank you for taking the time to complete this questionnaire.

Appendix 5.1

Palliative Medicine 2005; **19:** 278–287

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 two-question 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.[1] 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.[7–9] Patient depression also adds to carer burden.[10] 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.[7,11–15] Depression also affects outcomes for health services by precipitating inpatient admissions and increasing treatment costs beyond those due to illness severity.[16–19]

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 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 one- and 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

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10.1191/0269216305pm1021oa

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:

1) 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.
2) To empirically derive an algorithm that showed better clinical validity than these questions.
3) 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 community-dwelling 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).

Table 1 Recruitment details for 355 referrals to community-based palliative care

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

Data concerning recruitment were available for 355 referrals to the community service (Table 1). Of the 134 community patients who were eligible to participate, 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 two-question screening tool was also explored.[31]

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

1) Psychogeriatric Assessment Scales-Depression (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]
3) 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 ≥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 ≥80%: at least 80% of the positive cases identified by the reference standard were detected by the screening tool.
4) 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:

1) 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.
2) 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)		
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	–	1.4
Unknown primary	4.5	4.3
Non-malignancy	9.1	13
Missing data	–	2.9

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

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

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

[a] $\chi^2_{(1)} = 10.6$, $P < 0.01$.
[b] $\chi^2_{(1)} = 5.1$, $P < 0.025$.
[c] $n = 20$.

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

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 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 alone						
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]	83	0.65	80	85	80	85
Community dataset 2[b]	85	0.70	76	100	100	72
Hospice dataset[c]	85	0.69	63	100	100	22
PAS-D >4						
Community dataset 1[a]	74	0.45	80	72	53	90
Community dataset 2[b]	79	0.58	80	79	75	83
Hospice dataset[c]	85	0.69	83	88	91	78
DSM-IV symptom criteria						
Community dataset 1[a]	94	0.88	100	91	87	100
Community dataset 2[b]	94	0.88	94	94	94	94
Hospice dataset[c]	85	0.69	83	88	91	78
ICD-10 symptom criteria						
Community dataset 1[a]	94	0.88	100	91	87	100
Community dataset 2[b]	91	0.82	93	90	88	94
Hospice dataset[c]	90	0.79	85	100	100	78

[a] $n=35$.
[b] $n=34$.
[c] $n=20$.

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

Number of questions	Patients (%)		
	Community dataset 1 (n =35)	Community dataset 2 (n =34)	Hospice (n =20)
1	29	18	5
3	46	41	60
4	26	41	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	59	37	47
ICD-10	65	37	44
Prevalence of symptoms assessed in algorithm			
Fatigue	96	71	82
Depressed affect	46	54	35
Anhedonia	55	31	44
Psychomotor retardation or agitation	91	74	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"[a] "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"[a] "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]

[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 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]

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	97	92
Clinician	93	88
Clinician only ($n = 188$)	97	92

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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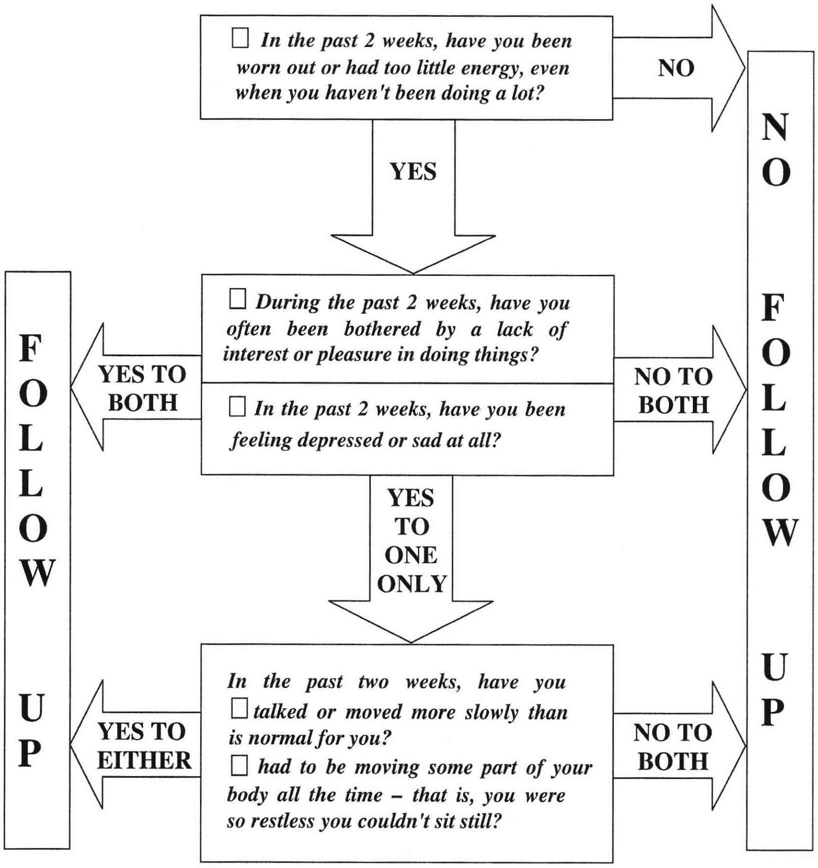
Appendix

SHORT SCREEN FOR DEPRESSION SYMPTOMS (SSDS)

Patient: ……………………………… Staff member: …………..…..…..…..

Record No: ……………………….. Date: …………..…..…..…..…..……

INSTRUCTIONS: Ask questions verbatim Tick positive response Cross for negative response
Document the decision of algorithm Plan follow-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?*

☐ *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?*

In the past two weeks, have you
☐ *talked or moved more slowly than is normal for you?*
☐ *had to be moving some part of your body all the time – that is, you were so restless you couldn't sit still?*

<u>Judgement of algorithm</u>

DOES/DOES NOT warrant follow-up for depression

PLAN: ……………………………………………………………………
…………………………………………………………………………….
…………………………………………………………………………….

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