DEPRESSION IN THE TERMINALLY ILL -
CURRENT TREATMENT AND ASSESSMENT

THESIS SUBMITTED FOR THE DEGREE OF
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BY

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My family and friends for understanding why I needed to hide away to complete this thesis.
So I now have a diagnosis. Hodgkin's disease. Let's call it cancer. I've heard of that. I know what it is - Fiona, a woman I live with is having chemotherapy for breast cancer. This is different, I'm told. They don't tell you that an 80% chance of cure means a 20% chance of death. You're left to work that one out for yourself. Death. Life is bad enough, that's what I thought. But who do I tell? Mum, I want to die. Hey, lover of mine, I think forever might be closer than I thought. Hi good friend, want to talk about euthanasia and writing a will?

"We're all in pain, why can't we share our pain?"

Death and illness are almost taboo subjects even though we will all die eventually. Who isn't frightened and doesn't find it difficult to talk to someone they know might be dying? I wasn't prepared, neither were my family and friends. Who's going to help me, listen to me, understand me, be there for me - just for me. Not be frightened by my thoughts and feelings of having my life threatened, changed, and maybe dying at the end of it all anyway.
1.1 INTRODUCTION

"It's not only the pain in my leg, it's the pain in my heart and the pain in my mind"

David who said the above to me whilst I was working in a Hospice, was twenty one years old and dying of osteosarcoma. He was withdrawn, had an air of hopelessness and despair that did not resolve and he died three weeks after we had the above conversation. During my palliative care training, I have become aware that several patients who were terminally ill appeared distressed and depressed, whilst others who were equally ill, appeared sad but relatively content as they approached the end of their life.

This thesis is written by a non psychiatrist and originated from the above observations and the subsequent conversations and discussion with many medical and nursing staff who shared my desire to learn more about psychiatric morbidity in the terminal phase of cancer and how to distinguish between what may be called "appropriate" sadness at the end of life and a treatable depressive illness. The question of whether a screening instrument may be helpful in this situation was also debated and discussed.

A literature review yielded many papers on depression in patients undergoing treatment for cancer, but comparatively little literature on psychiatric morbidity during the last months and weeks of life of a patient with cancer. A further literature search revealed no information on the nature of psychosocial
service provision available to Hospices nor on the pharmacological treatment of depression in the terminally ill within the United Kingdom.

The introduction establishes certain definitions and explores in detail the relevant literature for the three studies in the thesis. The normal process of adjusting to a diagnosis of a terminal disease will be discussed as will definitions of psychiatric disorders including adjustment disorder, depression, psychotic disorders and suicide in terminally ill patients. The range of therapies and treatment available for psychiatric morbidity, psychosocial service provision and the use of rating scales to assess for psychiatric morbidity will also be discussed.

1.1.2 What is Cancer?

Cancer is defined as the uncontrolled proliferation of a cell group resulting in disturbance of function at the primary site and having the ability to spread either directly or via the lymphatic or haemapoetic systems to other organs in the body. Cancer can present either due to its local effect e.g. lung cancer presenting as haemoptysis due to direct invasion into a blood vessel or as a secondary manifestation e.g. jaundice due to liver involvement from a cancer of the colon. It is frequently this secondary spread of the tumour affecting vital organs e.g. liver, lungs that causes serious morbidity and death. Cancers are not rare. One third of the population in the U.K. will develop cancer during their lifetime and one quarter will die from the disease. The incidence has increased over the last thirty years and is still increasing due to two major factors: tobacco smoking and an ageing population. There were
300,000 recorded cases of cancer in the U.K. in 1988 and of these 44,000 were cases of lung cancer. The majority of cancers occur in the elderly which is thought to be due to increased mutation of genetic material with increasing age, but certain cancers e.g. testicular cancer and some leukaemia's are almost exclusive to young adults and children. Most cancers have no attributable cause with a few notable exceptions. Lung cancer, has a causative association with cigarette smoking. There are also notable socio-economic differences in cancers e.g. mortality from lung cancer has increased in social classes four and five and decreased in social classes one and two. The probable explanation for this is that men and women in social class five are nearly four times more likely to be smokers than those in social class one.

It is also known that mesothelioma (a tumour of the pleura of the lung) has a causative association with asbestos exposure. Malignant melanoma, a tumour of the melanocytes is known to be linked with excess sunlight exposure and is increasing in incidence due to increasing overseas travel and excessive sunlight exposure.
1.1.3 Prevention of Cancer

Certain life style factors e.g. not smoking, limiting the intake of alcohol, eating a high fibre / low fat diet, and avoiding excess sunlight can help prevent cancers occurring. There is considerable interest in screening for cancer, but for a screening programme to be initiated certain criteria must be present. These include the disease having a recognisable early stage, an acceptable screening test and an adequate treatment (Wilson and Junger 1968). For breast and cervical cancers, screening programmes where diagnosis can be made at an earlier and more treatable stage are available. Although screening has many recognisable benefits, the disadvantages of screening include the possibility of longer morbidity for those cases whose prognosis is unaltered by early detection and also the not inconsiderable psychological and psychiatric morbidity for those patients with false positive results.

In the U.K., the possibility of screening programmes for prostate and colon cancers are currently being evaluated (Austoker 1995).
1.1.4 Cure Rates

In certain cancers e.g. early stage Hodgkin’s Disease and testicular cancer the cure rate exceeds 90%. All cancers have a more favourable prognosis if diagnosed and treated at an early stage before metastatic spread has occurred e.g. the five year survival for patients diagnosed with stage I cancer of the breast is over 80% compared to 18% for those diagnosed with stage IV (advanced) disease. Some cancers have a poorer prognosis - due to the type of cancer and its late presentation, e.g. lung and pancreatic cancers are often only diagnosed after metastatic spread has occurred to other organs. The five year survival for cancer of the lung is 7%.
1.1.5 Palliative Care

The word palliative is derived from the Latin "pallium" meaning "to cloak or to hide". Palliative care is the active total care of patients and their families by a multi professional team when a disease is no longer responsive to curative treatment. Palliative care also responds to the psychological, social and spiritual needs of patients and to the needs of the relatives during bereavement.

Palliative care:

1) Affirms life and regards dying as a normal process

2) Neither hastens or postpones death

3) Provides relief from pain and other distressing symptoms

4) Integrates the psychological, social and spiritual aspects of care so that patients may come to terms with death as fully and constructively as possible and offers a support system to help patients live as actively as possible until death.

Palliative medicine as a speciality has been recognised in the U.K. for 10 years. The founder of the modern hospice movement, the impetus for palliative care is Dame Cicely Saunders. She found, while working in London Hospitals during the 1950's, that patients were dying in physical and emotional distress in the side rooms of busy wards. St. Christopher's Hospice was established in London in 1967 and today there are over 3,200 hospice beds in the U.K. (Directory of Hospices and Specialist Palliative Care 1997) (Table 1.1).
It is now recognised that palliative care does not belong exclusively in a hospice and palliative care support teams have been established in hospitals and in the community - their remit is not only to provide palliative care for patients but also to educate and share expertise with other professionals. The principles of palliative care are still focused on patients with cancer, Motor Neuron Disease and HIV / AIDS, but increasingly the principles are being applied to other patients with end stage diseases.

The modern palliative care team comprises a number of professionals - medical and nursing staff, physiotherapists, occupational therapists, art therapist, complementary therapist, social worker, chaplain, dieticians and counsellors etc. Volunteers are also important members of this team. It is by working as a multi disciplinary team that patients and their families can be offered true individual holistic care. Palliative care can offer much in the way of symptom control at diagnosis and whilst patients are receiving active treatment such as psychological support, the control of pain or the prescribing of appropriate emetics during radiotherapy or chemotherapy. The majority of patients, however are referred during the last weeks or days of life.
TABLE 1.1 PALLIATIVE CARE SERVICES IN THE UNITED KINGDOM

<table>
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<tr>
<td>Marie Curie Centres</td>
<td>11</td>
<td>289</td>
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<tr>
<td>Sue Ryder Units</td>
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<td>151</td>
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<tr>
<td>NHS Units</td>
<td>56</td>
<td>595</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>223</strong></td>
<td><strong>3253</strong></td>
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1.1.6 The prevalence of symptoms at the end of life

Some of the earliest work looking at the physical and mental distress of dying patients was by Hinton (1963). He studied 102 patients who were dying and hospital inpatients who were not terminally ill as controls, by conducting thirty minute informal, focused interviews. He found that terminally ill patients had higher levels of both physical and emotional distress, 45% had depression and 37% were suffering from anxiety. He concluded that both depression and anxiety had significant associations with the degree and duration of the terminal illness with patients under fifty years of age having greater physical and mental distress. Addington Hall and McCarthy (1995) looked at the care giver's perception of symptoms in the last year and week of life and found that 88% of care givers believed their relatives had experienced pain at some time during the last year of life and 66% during the last week of life. Other major physical symptoms perceived were, loss of appetite (78%), dry mouth and thirst (60%) and sleeplessness (60%). Perceptions of feeling low and miserable were reported by 69% during the last year and 52% during the last week of life. It must be stressed that these are care giver's perceptions which other research has shown tends to reflect the respondent rather than the patient's level of distress. Fulton (1997) found that 50% of patients with breast cancer had symptoms of depression in the last few weeks of life. Coyle et al (1990) studied the symptoms volunteered by patients during the last four weeks of life. They found that 54% of patients included in their survey had some degree of pain during the last four weeks of life, anxiety was spontaneously mentioned by 21% four weeks before death and 18% in the
last week before death. Depression was only spontaneously mentioned by 8% during the last four weeks - a much lower percentage than has been reported elsewhere. It is interesting to note that 20% of patients had spontaneously spoken of suicide and two patients were reported to have committed suicide, but further information regarding these patients is not included. The methodology of this study and criteria used however is unclear - for example the paper states that four patients with a clear suicidal plan were clinically depressed, but does not state how this diagnosis was made.

1.1.7 Reaction to a Diagnosis of Terminal Cancer

When a patient is told that their cancer is incurable they tend to show a characteristic emotional response. There is period of shock and disbelief followed by a period of turmoil with anxiety, irritability and disturbance in appetite and sleep pattern. Concentration on daily tasks is impaired and thoughts regarding the diagnosis and fears for the future may intrude. There is also the grief that life will be shortened and at the loss of future hopes. These symptoms usually resolve within seven to ten days with support from family and friends (Massie et al 1994). Medical and nursing staff can help by providing information and more importantly reassuring the patient that they will not be abandoned or die in pain or distress. It is thought that patients with little social support are more likely to go on to develop psychiatric morbidity (Goldberg and Cullen 1985) at this time than those who have supportive family and friends.
1.2 CAUSES OF PSYCHOLOGICAL DISTRESS

1.2.1 Social Correlates and Physical Factors

The exact aetiology of depression in cancer and terminal illness is unknown, but theories have been put forward. Greer and Silberfarb (1982) suggested that the emotional impact of a cancer diagnosis; side effects of treatment; progression of cancer with associated disability and symptoms; and cerebral dysfunction associated with carcinomatosis were all important factors. Goldberg and Cullen (1986) believed that the five psychosocial factors leading to significant depressive symptoms were disruption of key relationships; dependence; disability; disfigurement and approaching death.

Patients referred to palliative care will normally have undergone a considerable part of their "cancer journey" and already have experienced a range of emotions. The shock and disbelief of diagnosis, the acceptance of treatment and the fact that something can be done, is followed by the uncertainty of radiotherapy and chemotherapy. The detection of metastases, further hope and further treatment and final referral to a palliative care team is the "emotional cancer journey" for the majority of patients who are referred for palliative care. The so called "crisis points" of a cancer illness i.e. initial diagnosis, failure of treatment and relapse, trigger further psychological distress and are peak times when psychiatric morbidity may occur. In newly diagnosed patients, the concerns tend to be more immediate e.g. the effects of treatment on ability to perform tasks (Harrison et al 1994). In population studies, the lack of a close confiding relationship was found to be a
vulnerability factor, increasing the risk of a psychiatric disorder when faced with a major life event (Campbell et al 1983). The ability to confide in friends or family is known to be an important factor in helping to prevent psychological morbidity. Gender differences have been found between males and females in terms of confiding - females using a larger number of confidantes to males (Harrison et al 1995), but both males and females confided their main concerns to others.

Much of the research work on the adjustment to a cancer diagnosis has been with patients with breast cancer. It was found that patients followed up for a year after mastectomy, 25% of patients had required treatment for anxiety and/or depression (Maguire et al 1978). Factors influencing the adjustment to a cancer diagnosis include adequate information giving and social support (Morris et al 1977) (Goldberg and Cullen 1985). Physical factors and physical performance also influence the development of psychiatric morbidity - the emotional states of patients may be a consequence of uncontrolled pain, but also contributes to their experience of uncontrolled pain. Kaasa et al (1993) explored the nature and extent of cognitive behavioural response in patients with advanced cancer in a study of 247 patients and found that 70% reported a high level of psychological distress using the Impact Event Scale, General Health Questionnaire and two pain scales. Those patients with worst performance status and pain were the most distressed.
The influence of pain on the incidence and presentation of psychiatric disorders was examined by Massie and Holland (1992). They reported that of patients receiving a psychiatric diagnosis, 39% experienced pain greater than 50mm on a 100mm visual analogue scale, but only 19% of patients who did not have a psychiatric diagnosis experienced significant pain. Although these diagnoses were predominantly mixed affective disorders or adjustment disorders, 15% of patients with significant pain had symptoms of a major depression. Pinder et al (1993) studied one hundred and thirty nine women with advanced breast cancer using the Hospital Anxiety and Depression Scale, a physical performance scale, socio demographic information and past psychiatric history. They found that probable clinical depression (using a cut off threshold of 11 on the HAD scale) was significantly more prevalent in patients in lower socio-economic classes and in those patients with poor performance status suggesting that both these indices may be useful indicators for patients at risk of depression. Glover et al (1995) studied patients in the Oncology out patients setting using the Profile of Mood Status, Karnofsky Performance Scale and descriptive numeric rating scales for pain intensity and duration. They concluded that depression, anger, fatigue and confusion was moderately correlated with increases in pain intensity and that they were also correlated with increasing duration of pain.

Age also appears to be an important factor in adjustment to cancer - younger patients reacting more acutely and dramatically than older patients, but having a greater capacity to adapt and develop new interests than older patients.
(Novotony et al. 1984). Age is also thought to be an important factor in the development of psychiatric morbidity. Harrison and Magurie (1995) found in their study that cases of anxiety and depression were found in a significantly younger population.

Lampic et al. (1994) studied 197 consecutive cancer patients attending outpatient clinics. Those with anxious preoccupation and hopelessness/helplessness had low levels of psychological well-being and more cancer-related worry. Not surprisingly, patients with a "dismal" prognosis had higher levels of hopelessness/helplessness and they concluded that those patients should be targeted for psychological support.

Cancer of the pancreas has a very poor prognosis with little progress in the development of effective treatment for this disease. Patients with cancer of the pancreas can also develop severe pain due to infiltration of the coeliac plexus. Depression and anxiety occur more frequently in pancreatic cancer than in other cancers and may predate the diagnosis, possibly due to the disruption in the release of neurotransmitters. Passik and Breitbart (1996) in a review article concluded that Oncologists need to be aware of the frequency of psychiatric morbidity in this group of patients.

A study to determine if psychosocial factors influenced survival was carried out by Cassileth et al. (1985) - a prospective study of a homogeneous group of 154 patients with metastatic disease at diagnosis, using a specifically constructed Likert response scale. Their findings were that psychosocial
variables including hopefulness, social ties, use of psychotropic drugs, job satisfaction, perception of adult health and amount of adjustment required did not influence survival or the disease process in patients with metastatic disease.

Furthermore, work on the mental adjustment to cancer (Greer and Watson 1987) found no difference in variables including helplessness, avoidance and fatalistic approach between patients with early disease and those with advanced disease, apart from anxious preoccupation which was significantly more prevalent in patients with advanced metastatic disease.

A maladaptive cycle of coping has also been suggested as a contributory factor to the later development of an affective disorder (Parle et al 1996).

A feeling of hope is vital to all patients and even in the terminal stages of illness, hope can still be fostered ensuring that patients feel supported and cared for. Hope also has a positive effect on quality of life - Ringdal (1995) found that cancer patients generally experienced low levels of hopelessness, but that advanced physical disability had a negative effect on feelings of hope.

All these studies supporting the integration of psychosocial and physical assessment, serve as a reminder that both are closely linked and support the need for psychosocial interventions to be an integral part of every cancer patient's management plan (Fallowfield 1995).
1.2.1 Communication of Information

Over the past 10 - 15 years, there has been an increased awareness of the impact of a cancer diagnosis on the patients and their families and the need for sensitive, yet accurate information. It is known that poor communication can cause increased levels of stress and anxiety (Steptoe et al 1991) and it is thought that the mode in which patients are communicated bad news may have an impact on their psychological adjustment. Fallowfield et al in 1995 and (Fallowfield 1997) found many patients to be dissatisfied with the amount of information given to them by clinicians with patients wanting more information on specific issues e.g. mode of death. There are also difficult ethical issues when family members may express a wish that patients must not be told the truth regarding their illness (Fitch 1994). This issue can only be resolved if the medical and nursing staff caring for the patient have effective and sensitive communication skills.

Many doctors are criticised for imparting a diagnosis in an insensitive manner or for withholding information and indeed many acknowledge their lack of skills in this area (Doyle 1997).

Most medical schools now include training in communication skills and breaking bad news in the undergraduate curriculum and several courses have been established to improve the communication skills of Doctors and Nurses caring for cancer patients (Heaven and Maguire 1996). Patients want, need and expect truthful answers to their queries regarding diagnosis and prognosis and furthermore truthful answers may well dispel many hidden fears (Buckman 1996) (Doyle and O’Connell 1996). A study in West Scotland
found that patients wanted to know full information regarding prognosis, treatment options and side effects (Meredith et al 1996). Maguire (1995) has suggested that the initial consultation when bad news is broken can influence the development of affective disorders at a later stage and stresses the importance of acknowledging the patients distress and then exploring their resultant concerns and feelings before the patient is given advice and reassurance.

The support received by patients with terminal cancer has been greatly enhanced by the provision of Macmillan clinical nurse specialists who work in hospitals and the community. They have a remit to provide support and information to the patient and in many cancer centres patients are seen at diagnosis and followed into the community. The Macmillan Nurse acts as a link person during treatment and disease progression for the patient and other health professionals. Although patients report that this support is helpful, when evaluated by Maguire (1995), regular follow up was found to foster patients dependence, however a greater number of patients were appropriately referred for psychological and psychiatric support. It has been suggested that rather than intensive "blanket support", support should be targeted for those at greatest risk of psychological and psychiatric morbidity (Watson 1983). It is important to acknowledge that the primary health care team, especially the General Practitioner have a role in providing information, but many patients report that General Practitioners have not discussed psychological issues with
them (Gilhooly et al 1988). The onus for ensuring patients have access to adequate information and support appears to be with hospital staff.

1.2.2 Spiritual Distress

At the time of referral and transition to the palliative / terminal phase of an illness, many patients have an increased spiritual awareness. A large number of hospices were founded as religious orders or have religious affiliations, however the needs for spiritual care is not governed by a religious belief and although patients may have no religious affiliations, they may still request to see a hospice chaplain. The concerns of these patients are often based on the existential questions: Who am I, What am I, Will I be remembered, How will I be remembered etc. (Grey 1994). For some, predominantly the elderly, dying is viewed as a natural part of life and a reward for a life well lived (McCue 1995). Patients experiencing emotional suffering often have what Michael Kearney (1996) describes as "Soul pain", but this may go unrecognised. The integration of spiritual care into the palliative care team is therefore vital to ensure patients have the opportunity to disclose and discuss these concerns which can cause great emotional distress.

However the spiritual needs are often not included in the assessment of quality of life of terminally ill patients (Ellison 1982) and may not be identified by health professionals (Doyle 1992).

The assessment of spiritual distress is not included in this thesis, but it's importance is recognised and acknowledged.
1.2.3 Social Factors

The social effects of a terminal illness in terms of fiscal issues and care of dependants are enormous and can have a profound effect on a patient's emotional well being. Schulz et al (1995) studying 268 patients with recurrent cancer found that many were unaware of the community support available and also not surprisingly that patients with financial concerns had greater emotional distress. The role of the patient within the family and their relationships with partners may also be a contributory factor for psychological morbidity. Silberfarb et al (1980) found that difficulties in personal and sexual relationships were a major contribution to the development of psychological morbidity at three stages of breast cancer including the palliative stage. These studies highlight the importance of social workers being included as part of the multidisciplinary team caring for terminally ill patients.
1.2.4 The Influence of Chemotherapy on Psychiatric Disturbance

Many chemotherapeutic drugs administered to patients with terminal cancer may be associated with the development of depression. Vinca alkaloids, Vinblastine, L-asparaginase and Dacarbazine have all been implicated in causing psychiatric morbidity (Silberfarb et al 1980).

A study of fifty-three women with advanced breast cancer by Payne (1992) found that anxiety and depression predominantly accounted for poor quality of life. Thirteen women died during the study and the author comments that the chemotherapy appeared to contribute to their psychological distress. It is important to consider quality of life and psychological sequelae of treatment during all stages of cancer and especially during the last few months and weeks of life. Other medications e.g. steroids can cause depression as can metabolic imbalances e.g. hypercalcaemia.

There have been a number of studies on the influence of chemotherapy on psychiatric disturbance. These papers have not been included in this review as they refer almost exclusively to patients receiving chemotherapy for early or metastatic treatable disease - as with all work in terminally ill patients - there is a very little literature on the psychiatric sequalea of chemotherapy in this patient group.
Psycho-oncology has developed over the past fifteen years and includes the research remit to study the psychological and social consequence of cancer and cancer treatment and also to develop and evaluate psychological therapies to reduce cancer related morbidity. Greer (1994), looks at the way forward for psycho-oncology, but no mention is made of the needs of terminally ill patients and indeed much quoted research on evaluating psycho-oncology services has focused on those patients either with newly diagnosed malignant disease or receiving active treatment. However the needs of terminally ill patients and their families for such support is just as essential.

The nature and provision of support and what is appropriate for patients is subject to debate. McQuellon et al (1996) described a two phase approach in an Oncology unit of patient support groups, volunteer be-frienders and formal support from psychologists and psychiatrists and suggested this as a framework for psychosocial service provision. He emphasised that an integrated approach with multi disciplinary discussion of cases allows appropriate referrals to be made. The problem identified by McQuellon and others is which patients should be referred to which service.

Others have aimed to evaluate whether psychosocial support needs can be measured. Zabora et al (1990) devised an 18 item structured interview focusing on patients past life experiences and level of support and found in a sample of 30 patients they could predict those requiring further psychosocial
support in 84% of cases. Further work to identify the needs of patients for psychosocial support was carried out by Barg and colleagues (1994) who looked at the development of a 47 item self-administered psychosocial cancer screening tool using information on, disease status, psychological status, social situation, information needs and concerns. The patients' scores in each sub-section were calculated and patients were referred for the most appropriate support for their needs. The effectiveness of such a method is however not proven.

Palliative care defines total care as responding to total pain. Total care includes physical care and psychosocial care, but how is psychosocial care defined?

The National Council for Hospice and Specialist Palliative Care (1997) in a report on psychosocial care defines psychosocial care as: “including psychological approaches concerned with enabling the patient and those close to them to express thoughts, feelings and concerns relating to the illness. It includes assessing each patient's individual needs and ensuring that psychological and emotional support is available. A range of informal and planned interventions may be used to relieve different forms of psychological distress e.g. anger, anxiety, low mood and intrusive thoughts. For some patients this will also include the recognition and treatment of specific psychiatric disorders such as depressive illness.”
The boundaries of psychosocial care are unclear and interwoven. Although the report acknowledges that many professionals working in palliative care e.g. medical and nursing staff have well developed psychosocial skills, it emphasises that in order to meet each patients needs access to other professionals may be necessary. The report lists psychologists, psychiatrists, social workers, counsellors, chaplains and complementary therapists. It is also important that when assessing patients needs, other factors such as concurrent life stresses and absence of social support are elicited as it is known that these factors may increase the risk of psychological and psychiatric morbidity (Breitbart 1995) (McMahon 1987).

In order to provide patients with services that meet their needs, it should be possible for patients to have access to all psychosocial service providers when they are receiving palliative care. Regular multidisciplinary team meetings in hospices allow patients to be discussed holistically, their needs identified and the most appropriate referral for specialist input to be made. Little is known however, of the availability of psychosocial care within palliative care and the first study in this thesis will look at the current provision of psychosocial care within palliative care and the contribution of these professionals to the multidisciplinary team.
1.4 PSYCHIATRIC DISORDERS

1.4.1 Prevalence

The presence of psychiatric morbidity in physically ill patients and the fact that it is often not diagnosed is well recognised (Rodin and Voshart 1986) (Harper et al 1990) (Kathol et al 1990). It is also recognised that psychiatric disorders occur more frequently in cancer patients than in the general population. It is estimated that 50% of patients will have no significant psychiatric symptoms, 30% will have what is defined as an adjustment reaction and 20% will have a formal psychiatric diagnosis, the most common being depression. It is estimated that for a quarter of all patients admitted to a palliative care unit, depression will be a significant symptom. (Barraclough 1994). Bergevin and Bergevin (1995) in a review paper highlight the fact that as the prevalence of depression in the general population is 6 - 10%, a number of patients with advanced cancer may have a pre-existing psychiatric disorder and the advancing cancer will place these patients at greater risk of developing further episodes.

Both nursing and medical staff have a role in identifying patients who may have psychiatric symptoms (Valentine and Saunders 1989) (McVey 1998). Nurses spend more time in direct patient contact enabling them to observe behaviour more closely and the nature of intimate nursing tasks may give an opportunity for patients to express any psychological distress. In a study of 100 oncology nurses caring for 475 patients on one particular day, Pasacreta and Massie (1990) used a questionnaire developed to help nurses identify
patients with psychiatric symptoms. These nurses perceived that 55% of patients had symptoms requiring further psychiatric evaluation - a higher figure than would be expected - which included 13% already under psychiatric care. They concluded that although nurses may not be able to identify specific psychiatric disorders, they are skilful in recognising significant psychological distress. Fincannon (1995) however, found that Oncology nurses were skilful at recognising psychological distress in their patients.

The rates of depression differ widely as shown in the following studies. Grassi et al (1989) studied patients with a recent diagnosis of cancer and a good performance status using the Hamilton Depression Rating Scale and the Illness Behaviour Questionnaire and found that one third of patients had symptoms of moderate depression and a quarter more severe depression. In a more recent paper Grassi et al (1996) studying eighty six terminally ill patients being cared for at home and using the HAD scale and quality of life tool EORTC -QLQ-C30, they found that 45% of patients were depressed and reported correlations between quality of life and depression. The importance of psychosocial care provision was also stressed in this study. Levine, Silberfarb and Lipowski (1978) studied 100 consecutive referrals of patients with cancer to a psychiatrist - 56% of patients were diagnosed as being depressed and 40% had an organic brain disease. Buckberg et al (1984) interviewed 62 oncology patients according to DSM-111 criteria and found that 42% met the criteria for major nonbipolar depression and 14% had symptoms of depression that did not meet the criteria for major depression.
In Hughes' prospective study (1985) of 50 patients with advanced inoperable lung cancer, 16% had a major depressive illness. Hughes and Lee (1988) found that 26% of patients admitted to a hospice had what they described as severe depression. Ramsay (1992) looked at all referrals to a liaison psychiatry service during one year - 26 patients were referred - 10% of the total number of patients admitted to the unit during the year. Of these 26 patients, 50% had a diagnosis of depression. Galuszko (1996) studied 410 patients admitted to a hospice and found that 37% had evidence of a psychiatric disorder in which she included adjustment disorder - patients were all given a clinical interview according to DSM III R criteria, but the methodology of this study is unclear.

In Hinton's work (1972) looking at fifty referrals of patients with a terminal illness, he found that twenty one of the fifty were depressed, seven were diagnosed with an anxiety state and two were diagnosed with paranoia. Hinton also found that the mean time between referral and death was 24 weeks with a third being referred during the last month of life.

Rathbone et al (1994) looked at developing a quality of life instrument for use in palliative care. Forty four patients were suitable for inclusion and 58% of patients identified problems not recognised by medical or nursing staff. Of these, 52% were psychosocial related problems, but their exact aetiology is not stated.

Up to 80% of the psychological and psychiatric morbidity which develops in cancer patients goes unrecognised and untreated (Maguire 1985 a).
A reason for this low rate of detection is thought to be due to nondisclosure by patients who may either feel they are wasting the Doctors time or that they are in some way to blame for their distress and therefore choose to hide it (Maguire and Howell 1995).

To leave major depression undiagnosed and untreated in patients with terminal cancer is unconscionable (Greenberg 1992).

In a review of depression in terminal illness, Brugha (1993) highlights the mistaken belief that terminal illness invariably causes depression and suggests that doctors working with terminally ill patients may not be confident in eliciting psychological and psychiatric morbidity.

All the above studies suggest that we do not know the exact prevalence of psychiatric disorders in the terminally ill and that recognition and diagnosis of depression is random.
1.5 **CLASSIFICATION OF PSYCHIATRIC DISORDERS**

Psychiatric disorders are classified on the basis of symptom patterns. Classification is necessary in order that the natural history of an illness can be examined and evaluated and so that there is some meaningful way of communicating about a patient's illness.

The International Classification of Diseases has been devised by the World Health Organisation as a means of classifying physical and psychiatric illness. It classifies patients on a single psychiatric axis and is the most commonly used classification in the United Kingdom. The latest edition (ICD10) contains a glossary to assist the correct classification of an illness and each illness is allocated a specific code.

1.5.1 **Psychopathology and Phenomenology**

When studying psychiatric illness, it is important to discuss why diagnosis in psychiatry is different to that in any other medical speciality. The study of abnormal states of mind is known as psychopathology.

Phenomenology is the objective description of abnormal states of mind which avoids preconceived ideas or theories. It examines the conscious experiences and observable behaviour of patients and aims to understand what the patient is experiencing (Gelder, Garth, Mayou - Oxford textbook of Psychiatry 1989). In psychiatry, a diagnosis cannot and is not made on the presence of a single symptom (Williams et al 1980). The whole of the psychiatric history and the intensity and persistence of each symptom is taken into account when making
a diagnosis. The grouping of symptoms into a syndrome or diagnosis is also important in making a diagnosis. Thus a psychiatrist will take a thorough history of the patient looking at present events and past experiences which may explain the behaviour occurring at present. The childhood history, developmental milestones, academic and personal development and premorbid personality are included in the history. The second part of the interview comprises the mental state examination when the patients observable behaviour and symptoms e.g. auditory hallucinations are documented. Patients are asked about their thoughts regarding the future, the presence of tearfulness, guilt regarding past events and to rate their own mood. They are also asked if they have any suicidal ideation. At the end of the history a formulation—-a summing up of the findings of both the history and mental state examination which includes the possible aetiology of the diagnosis, predisposing, precipitating and maintaining factors. A plan is then made to include both psychological and social measures to aid the patients recovery and also medication is prescribed when appropriate.
1.6 PSYCHIATRIC DISORDERS

1.6.1 Adjustment Disorders

Adjustment disorders are a maladaptive reaction to an identifiable psycho-social stressor which occur within three months of the onset of the stressor and which do not persist for longer than six months (Cody 1990). This is classified in both the Diagnostic and Statistical Manual - fourth edition (DSM IV) and in the International Classification of Diseases (ICD 10). The symptoms are not specified but the commonest presenting symptoms are depression and anxiety.

These conditions do not respond to antidepressants and generally improve as new levels of adaptation are reached. Certain interventions such as problem oriented psychotherapy may be helpful (Casey 1994). The symptoms may fluctuate in severity on a daily basis and patients can often be distracted from their distress. Clinical presentations can include anger, bitterness and blaming others. Cavanaugh (1984) makes the distinction that the patient with adjustment disorder feels bad about the situation whereas patients with a depressive disorder feel bad about themselves.
1.6.2 Anxiety

Anxiety is a normal emotion experienced by everybody at some time in their lives. Cancer patients will almost universally experience some degree of anxiety especially at the time of diagnosis, and at times when their disease status changes for example when metastases are diagnosed or when they are informed that no further active treatment is possible. This "normal" anxiety often dispels when patients adjust to their new situation, but in a proportion of patients anxiety can become severe and disabling. Patients with severe anxiety complain of both physical and psychological symptoms. The physical symptoms can be explained by increased autonomic activity and include palpitations, sweating, headaches, breathlessness, gastrointestinal symptoms and feelings of inability to swallow "lump in the throat".

Anxiety can be present most of the time - the so called free floating anxiety or in certain situations for example in relation to chemotherapy injections causing a phobic anxiety. A generalised anxiety disorder can be defined as an unrealistic or exaggerated anxiety in regard to life events and has a duration of more than six months (Steifel and Razavi 1994).

Although it is easier for palliative care staff to recognise the anxious patient, it is important that patients asked about his / her anxiety as it may be possible for fears to be allayed. Cassileth et al (1986) studied 378 patients receiving palliative care and found high levels of anxiety using the Spielberg State and
Trait Anxiety Inventory scores and suggested that anxiety may not be adequately addressed in terminally ill patients.

Anxiety and depression are often present in the same patient and it is suggested that there is a high concordance of both symptoms in patients with cancer (Cassileth et al 1985).

The HAD scale has been found to be a useful indicator of anxiety when used in research with cancer patients Walker (1990).
1.6.3 Depression

There are no universally accepted criteria for diagnosing depression in the medically ill. In the physically healthy population, depression is diagnosed if patients have a persisted low mood and at least four of the following symptoms which are present most of the day for the preceding two weeks:

1) Diminished interest or pleasure in all or almost all activities
2) Psychomotor retardation or agitation
3) Feelings of worthlessness or excessive and inappropriate guilt
4) Diminished ability to concentrate and think
5) Recurrent thoughts of death and suicide
6) Fatigue and loss of energy
7) Significant weight loss or gain
8) Insomnia or hypersomnia

In patients with advanced cancer, symptoms 6 - 8 are almost universal and there had been considerable controversy as to whether physical symptoms should be included and their importance in diagnosing depression in the terminally ill. Buckberg, et al (1984) believed that anorexia, weight loss and low energy were such common symptoms in the medically ill and proposed eliminating these somatic symptoms as a criteria for diagnosis of depression. They also found that the point prevalence of major depression dropped from 42% to 24% when all somatic symptoms were eliminated as criteria.
1.6.4 Psychosis and Organic Brain Syndromes

Cerebral metastases, metabolic disturbance and iatrogenic drug interactions are all common causes of organic brain syndromes in terminally ill patients, with many patients suffering from episodes of confusion during the terminal phase. Stedeford and Bloch (1979) found that 21 of the 49 patients (43%) referred to a psychiatrist from a hospice, were diagnosed as being in a psychotic state, 6 of which were organic brain syndromes, 3 were paranoid reactions and 2 hypomania. They also found that 13 of the 49 patients had been assessed by a psychiatrist in the past. Patients may also present with an acute psychotic reaction to their diagnosis of a terminal disease. It must also be remembered that patients with long standing psychiatric disorders e.g. Schizophrenia may also develop malignancies and that they may require psychiatric intervention both during active treatment and palliative care.
1.6.5 Suicidal Ideation

Although suicidal ideation can not and is not classed as a psychiatric disorder it is important that it is discussed in the context of psychiatric morbidity in the terminally ill. The incidence of suicide is anecdotally thought to be rare in the terminally ill patient. However a recent paper by Grzybowska and Finlay (1997) reported a total of 21 suicides and 37 attempted suicides in a five year period in 24 Hospices within the U.K. As depression is increased in patients with terminal cancer and the incidence of suicide is increased in depressed patients, these figures should not be surprising.

Cancer patients have twice the risk of committing suicide as the general population (Louhivuori and Hakama 1979). Whitlock (1978) found that of patients who had committed suicide, there was a far higher than expected number with malignant disease. Factors such as depression, advancing disease and hopelessness increase the risk of suicide. Other risk factors include, actual suicidal thoughts, uncontrolled pain, exhaustion and fatigue, past suicidal attempts, substance abuse, recent bereavement, poor social support and family history of suicide. It is also thought that certain sites of cancer i.e. oropharyngeal, lung, gastrointestinal, urogenital and breast may increase the risk of suicide.

In a study of 100 patients (Owen et al 1994) found that a desire for suicide was positively related to a younger age and past psychiatric history. Cancer patients tend to commit suicide by overdose of analgesia or sedative drugs.
Many Doctors believe that by enquiring about suicidal intent they may precipitate a suicide. Contrary to this belief, talking and sharing their thoughts of self harm, permits the patient to describe their feelings and also gives them a sense of control - thought to be an important issue for patients expressing a wish to die (Massie et al. 1994). In a review of three cases, Dubovsky (1978) also indicates this need for control or what he calls "mastery" in some patients who express a desire to kill themselves - this was also postulated by Danto (1972). It has been assumed that those who commit suicide do not readily disclose this information, but the three cases reported by Dubovsky all indicated to somebody their desire to take their own life.

Suicidal ideation must not however be confused with patients who request death to be hastened - these patients may also be depressed, but may have other underlying fears e.g. of a painful or undignified death. Patients referred to a palliative care service rarely request that their death is hastened (Block and Billings 1994) (Block and Billings 1995). Others have different beliefs - Siegel and Tuckel (1984) in a review paper discussed that the terminally ill patient who wishes to bring their life to an end should have the right to do so. The patients who request for assistance with dying should receive assessment from a psychiatrist as many of these patients may have undiagnosed psychiatric morbidity (Baile et al. 1993). Physical frailty does not preclude patients from committing suicide if they wish and in Farebarrow's study of suicide in patients with cancer (1971), 16 patients who were terminally ill and severely incapacitated committed suicide.
Farebarrow concluded that intention rather than physical strength is the important variable. Advanced physical disability was also present in more than two thirds of the eighty eight cancer suicides studied by Bolund (1985a and 1985b). Thirty five of the eighty eight suicide patients had developed a mental illness after the cancer was diagnosed, the most frequent conditions being depression and what Bolund terms a "reaction to illness" presumably an adjustment reaction. Bolund also highlighted the difficulty in obtaining information on the mental status of cancer patients as this is not documented in medical case notes. It would be anticipated that patients found to be suicidal within a palliative care setting, would receive a psychiatric assessment.

The initial assessment and evaluation of a patient with suicidal ideation should include the following: (Roth and Breitbart 1996)

1) Establish rapport and empathic approach

2) Assess patients understanding of illness and symptoms

3) Assess mental status

4) Assess other factors e.g. poor pain control

5) Assess external support system

6) Establish prior psychiatric history

7) Obtain family history

8) Record past suicide attempts or threats

9) Assess suicide thinking and plans

10) Formulate treatment plan
Patients may require initial close supervision on a one to one basis. Careful attention should be paid to pain relief and relief of other distressing symptoms. It may be necessary to commence neuroleptic medication initially in addition to antidepressant medication.

Another of the aims of this thesis will be to validate a question on suicidal thoughts as part of a screening instrument.
1.7. THERAPEUTIC OPTIONS FOR PSYCHIATRIC MORBIDITY

1.7.1 Non pharmacological therapies

When a patient is found to have symptoms of psychological distress or psychiatric morbidity, it is important that they are given optimum treatment. Although patients who are suffering from depression may require psychotropic medication, psychological support can enhance well-being and promote recovery.

Many patients with terminal cancer feel isolated by their illness and derive benefit from meeting other patients in a similar situation. Many Hospices have attached day centres to give patients the opportunity to meet others in a social environment. The value of such informal patient group support has been reported (Vachon and Lyall 1976).

Over the past 10 years, there has been an enormous increase in the availability and uptake of counselling. Counselling is defined by the British Association for Counselling as giving the client as opportunity to explore, discover and clarify ways of living more resourcefully and towards greater well-being. Many patients find the opportunity to talk about their concerns and fears to be helpful and may find this opportunity from their clinical nurse specialist and other nurses, doctors, paramedical staff and clergy. Some units have designated counsellors who fulfil this role, but there is little evidence to suggest that designated counsellors are more effective role than other staff caring for the patient who are able to build a caring relationship and to listen effectively. A study by Linn et al (1982) studied the effects of counselling on
one hundred and twenty two men with late stage cancer of which sixty two of
the men were seen regularly by a counsellor. It was found that the group
receiving counselling had a significant improvement in quality of life within
three months of counselling. However, the counsellors in this study had a very
high degree of involvement with the patient. They saw the patient several
times a week, were often with the patient at the time of death and were
frequently the first person to be called if the patient died at home.

Psychotherapy is designed to achieve lasting change and is often used in the
psychiatric settings for patients with deep seated psychopathology. Spiegel
(1996) identified four basic components of Psychotherapy when used in
patients with cancer i.e. social support especially when group psychotherapy is
used, emotional expression, cognitive restructuring and coping skills training.
There have been studies suggesting that medically ill patients and cancer
patients who develop depression have a different pattern of coping skills
(Parle et al 1996) and which may be improved with focused psychotherapy
(Rosenberg et al 1987).

Adjuvant psychological therapy has been found to be beneficial in patients
with cancer. The theoretical framework is devised from the premise that
cancer related psychological distress stems from the personal meaning of the
disease to the patient and the patient's own coping skills (Greer and Moorey
1997). Patients were seen for six hourly sessions and the main components are
to induce a fighting spirit, encourage expression of emotions, to challenge
negative behaviour and to look at cognitive techniques which may help negative behaviours. In a prospective randomised controlled trial comparing adjuvant psychological therapy with all supportive care, it was found that measurable anxiety fell in the treated group from 46% to 20% at eight weeks after treatment compared to no change in the non-treated group (Greer, Moorey et al 1992). It must be noted however that all patients recruited to this study were estimated to have a prognosis of at least 12 months.

A further study (Moorey et al 1998) found that adjuvant psychological therapy produced significant sustained change in fighting spirit, coping with cancer, anxiety and self defined problems compared to counselling. This later study included patients with different stages of cancer including those with advanced metastatic disease.

It is acknowledged that psychological support is important for all cancer patients and especially those who develop depression - what form this should take, who should provide this support and the value of counselling versus focused psychotherapy is still subject to debate.
1.7.2 Psychotropic Medication and choice of antidepressant

Maguire (1985 b) (Maguire et al 1985) state that the principles of treatment with antidepressant medication in cancer patients should be the same as in any other patient. However, it is widely believed that antidepressants are only prescribed for a minority of patients who may benefit from them. The issues surrounding this under prescribing will be discussed later in this thesis.

In addition to the factors of under recognition of mood disorders in patients with terminal cancer, there are also several misconceptions regarding the prescribing of antidepressant drugs. These views include patients not meriting psychotropic medication as they have an obvious reason for being depressed i.e. having advanced cancer, the belief that psychological treatments are better and that drugs are not compatible with such therapies. In addition, terminally ill patients may have other coexisting pathology which increase the risk of side effects, but newer antidepressant drugs are usually better tolerated.

Finally, there is unfounded concern over addiction and dependence.

Patients commenced on antidepressants have a 70% probability of a therapeutic response which is comparable to that of the general population. In a study of 146 patients with cancer referred to a liaison psychiatry service (Chaturvedi et al 1994) antidepressants were prescribed for 67% of patients with 80% showing a good clinical response to treatment with few side effects. The importance of prescribing an adequate dosage of medication for an adequate length of time can not be over emphasised (Massie and Holland 1984).
As the number of psychotropic drug increase, the choice of antidepressant becomes wider. There are two main classes of antidepressants commonly prescribed which are the tricyclics and the selective serotonin reuptake inhibitors - both appear to be equally efficacious when used in adequate dosages. The tricyclics were developed in the 1950's - they work by blocking the reuptake of monamine oxidase inhibitors thereby potentiating the effects of available neurotransmitters. One of the main disadvantages of tricyclics is the anti-cholinergic side effects e.g. dry mouth and constipation. They are contraindicated in patients with cardiac conduction disease, liver disease and may cause postural hypotension especially if patients are dehydrated. Despite these unwanted side effects, they also have beneficial side effects of weight gain which is advantageous for many terminally ill patients and their sedating effect can be exploited by administering the drug at night. Mianserin has fewer anticholinergic side effects and may be less cardiotoxic. In a study of fifty five patients with early breast cancer, using the Hamilton Rating Scale for depression as an objective measure (Heeringen, Zivkov 1996), Mianserin was significantly better than placebo after twenty eight and forty two days treatment. The side effects of Mianserin matched those of the placebo.

The selective serotonin re-uptake inhibitors were first developed in the 1980's. They work by blocking the receptors for Serotonin, which is a mood enhancing neurotransmitter. They do not have the anticholinergic, cardiac or sedative effects of the tricyclic drugs, but may cause gastrointestinal disturbance, nausea and diarrhoea. They are also safer in overdose, but can
enhancing neurotransmitter. They do not have the anticholinergic, cardiac or sedative effects of the tricyclic drugs, but may cause gastrointestinal disturbance, nausea and diarrhoea. They are also safer in overdose, but can induce anxiety and insomnia in some patients which can be minimised by administering the drug early in the day. Fluoxetine (Prozac) was used in a double blind placebo controlled study of 45 patients (Razavi et al 1996). They were evaluated using a number of instruments including the Hospital Anxiety and Depression scale (HADS) and the Revised Symptom checklist (SCL-90). The majority of patients were not known to have metastatic disease. After five weeks treatment, patients on Fluoxetine showed a marked decrease in their SCL-90 scores but no significant decrease in their HAD scores.

All antidepressants take approximately three weeks to work, however side effects may be exhibited within the first few days making compliance a problem.

Second generation selective serotonin reuptake inhibitors, Nefazadone and Venlefaxine are now available. Nefazadone blocks Serotonin both pre and post synaptically and down regulates the number of Serotonin receptors which potentiates the mood elevating effects of Serotonin mediated neurotransmitters. It quickly reduces anxiety accompanying depression and improves sleep patterns. As the half life is short, it requires twice daily administration. Venlefaxine blocks Serotonin reuptake receptors and weakly blocks noradrenergic uptake receptors which potentiates the mood elevating
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possibly a more useful drug in terminally patients where time is short. (Drugs and Therapeutics Bulletin 1996).

Monoamine Oxidase inhibitors, inhibit the uptake of monamine oxidase resulting in an increase in biogenic amines at the neuroceptor sites and a subsequent increase in mood. Care needs to be taken with foods containing Tyramine where an interaction can cause a hypertensive crisis. These restrictions make this class of drug less desirable in the patient with terminal cancer.

The choice of antidepressant is therefore governed by which drug may be best suited to each individual patient. The selective serotonin reuptake inhibitors appear to be less toxic and better tolerated. A large study of antidepressant use in the community (Martin et al 1997) found that fewer patients were discontinued on the selective serotonin reuptake inhibitors compared to tricyclic antidepressants and that the former appeared to be better tolerated and therefore compliance was improved.
1.7.3 **Psychostimulants**

Psychostimulants such as Dexamphetamine give patients a sense of overall well being, increase appetite and elevate mood. They work by promoting the release of biogenic amines and are administered early in the day to avoid insomnia. The dose is normally maintained for about seven to ten days and slowly reduced. They are generally safe, but care needs to be taken in patients with multiple organ failure. Burns and Eisendrath (1992) reported the beneficial effects of Dextroamphetamine as a treatment for depression in the terminally ill. Psychostimulants are used frequently in the United States, but there is little evidence to suggest they are used in the U.K.

They may have a role in treating depression during terminal illness due to the early therapeutic effect after administration.
1.7.5 Treatment of anxiety

The treatment of anxiety depends largely on its aetiology. Eliciting the patients concerns, supportive psychotherapy and clear information about the illness (Holland 1989) may be adequate therapy in itself. The use of hypnosis, guided imagery and relaxation can also prove to be helpful. Benzodiazepines are considered the drugs of choice in the symptomatic relief of anxiety. Some benzodiazepines are useful for night time sedation e.g. Temazepam whilst other drugs e.g. Lorazepam and Oxazepam have a shorter half life and are useful for day time anxiety. There has been considerable publicity in the last decade of the problems of tolerance and misuse of benzodiazepines however they can be used safely and effectively in patients with terminal cancer.

Other drugs which may be helpful in treating the physical effects of anxiety are beta blockers e.g. Propranolol which block the sympathetic overdrive symptoms for example tachycardia. Neuroleptics such as Thioridazine and Haloperidol are helpful in the management of agitation in the depressed patient.
We have established that there are a wide variety of effective interventions available to treat terminally ill patients with symptoms of psychiatric morbidity.

Why are apparently so few terminally ill patients adequately correctly diagnosed and adequately treated?

The main issue is the difficulty in establishing a diagnosis of an illness where there are no biological markers, physical signs or effective diagnostic test. A number of professionals may be involved with a patient during the last few months of life and there may be a tendency to regard the assessment of psychological distress and depression as somebody else's responsibility. Those professionals who may be closest to the patient and have developed the best rapport and a trusting relationship may not perceive that they have the skills to carry out an adequate assessment of the patient's emotional needs.

Whilst it is acknowledged that some patients with depression may require expert psychiatric assessment, many patients can be adequately assessed by a doctor or nurse who has developed the necessary skills to do so. Ideally there should be an integrated referral system where patients can either be discussed or referred to a mental health care professional and a plan of management initiated.
Haig (1992) proposed the following strategy for the management of depression in patients with advanced cancer:

1) Good rapport should be established
2) Thorough physical assessment and relief of poorly controlled symptoms
3) Underlying organic factors detected and treated where possible
4) Normal sadness and grief at the end of life differentiated from those indicating a depressive disorder
5) Supportive psychotherapy for the patients to reduce sense of isolation
6) Family intervention to support relatives
7) Use of selected antidepressants

Although these guidelines may be helpful, they do not detail what a thorough psychiatric assessment entails. The majority of papers discussing the psychiatric needs of terminally ill patients are written by psychiatrists, but it is not known how many patients receiving hospice care are assessed by a psychiatrist. The study in chapter three will establish the access and input of psychiatrists to Hospices.
1.9 REVIEW OF ASSESSMENT AND RATING SCALES

How can the doctor or nurse working in a palliative care unit establish that a patient is depressed and requires treatment or further assessment? One method of assessment is the use of rating scales. If we are to seek ways of improving the detection of psychiatric illness in the terminally ill population, there is a need to have rating scales with proven validity and established cut off thresholds.
1.9.1 The use of specific diagnostic criteria

The low reliability of diagnostic procedures had been acknowledged in psychiatry. Spitzer et al (1978) developed specific research diagnostic criteria for use in psychiatry research. The use of different research diagnostic systems have previously been reported (Sashidaran 1985) (Dean et al 1983).

Much of the work on examining diagnostic criteria for depression in patients with cancer has been done with those at an early stage of the illness. A review of this work however, is useful to explore the modifications established.

The complex problem of deciding which symptoms may be attributable to the cancer and which may be due to depression had been discussed by Endicott (1984). She proposed that the somatic symptoms listed should be substituted in the patient with cancer i.e.:

Poor appetite / weight gain ; substituted for fearfulness or depressed appearance in body or face

Insomnia / hypersomnia; substituted for social withdrawal or decreased talkativeness

Loss of energy / fatigue; substituted for brooding, self pity, pessimism

Diminished concentration or slowed thinking; substituted for ; cannot be cheered up, does not smile, no response to good news or funny situations

Endicott also stressed the importance of asking patients with cancer about suicidal ideation. In response to Endicott, McKeegney (1984), while agreeing with the above substitution, suggested that patients who were "screened in" as
being depressed should all be seen by a psychiatrist and that pharmacotherapy should only be commenced after consultation with a psychiatrist.

Many psychiatrists in the U.K. would disagree with this due to the vast volume of work it would create and the difficulty in accessing all patients who were screened as being probable cases. Rapp and Vrana (1989) found that using the modified research criteria as described by Endicott in elderly male medical patients, yielded high sensitivity and specificity in cases where the somatic symptoms of depression were ambiguous.

Chocinov et al (1994) compared the research diagnostic criteria with Endicott's revised criteria in 130 patients and suggested that small differences between investigators in the application of symptom severity thresholds can cause large differences in prevalence rates for depression. They also concluded that the inclusion of somatic symptoms only inflates the rates of diagnosis when these symptoms are used in conjunction with what he describes as "a low threshold approach". Cavanaugh (1984) reviewed the diagnosis of depression in the chronically medically ill and concluded that affective and cognitive symptoms are most useful and somatic symptoms although less useful, could be used to support the diagnosis if they were severe and disproportionate to the medical illness. Thus the debate on use of somatic type symptoms and diagnostic criteria still continues.
1.9.2 How can depression be measured

The assessment of depression in terminally ill patients is difficult. Part of this difficulty may be due to a lack of awareness of depression combined with medical and nursing staff in palliative care lacking the skills to undertake assessments of psychiatric morbidity. The use of screening tools to assess for psychiatric morbidity has been advocated (LLoyd-Williams 1994) (Power et al 1993) (Skuse and Williams 1984) (Goldberg et al 1988). Such tools are not developed as diagnostic tools and can only serve to indicate whether a patient has particular psychiatric symptoms suggestive of a diagnosis of depression. The decision should then be taken whether to treat for depression or refer the patient for further assessment. Several instruments have been developed and researched with a particular score or cut off threshold assigned in order to predict a "case" of depression.

The majority of rating scales contain a number of symptoms or feelings on which the patient indicates their own response and the scores calculated by the person administering the scale.

Many of these instruments have been developed and validated on physically healthy patients. Where an attempt has been made to validate instruments which could be used for patients with cancer, much work has been within the context of early disease or patients undergoing active treatment.

For screening tools to be of use, they must fulfil the following criteria of validity and reliability.
1.9.3 Validity

An instrument must have validity i.e. does the scale actually measure what it is designed to measure. The assessment of validity is measured against a predetermined gold standard. There are several criteria of validity which should be achieved: (Bowling 1997)

- Face Validity - Are the indicators or questions being used in the scale reasonable? Do they appear to be measuring what has been claimed that they are measuring? Is the scale relevant reasonable and acceptable for those who will be using the test?

- Content Validity - Do the components of the scale measure all aspects of the variable to be measured? Each item should reflect at least one of the content areas being measured. The number of items should reflect the importance given to each variable and be balanced.

- Criterion Validity - Can the variable be measured accurately? Can the scale be correlated with another measure which is suitable and can be pre-defined as a "gold standard"?

- Construct Validity - This is based on a theory or assumption of the associations and correlations of some items of the scale and is then examined to establish if they are correct. This is usually required when a gold standard test is not available.

1.9.4 Reliability

A measurement scale or tool is tested for reliability i.e. does it give consistent results each time it is used with the same patient and are the results repeatable?
1.9.5 The design of screening tools

There are several methods of assessing depression. There are patients self-reporting of symptoms using questionnaires or structured interviews, the direct observation of the patients and also indirect measures (Dobkin and Morrow 1986). It would be justified to believe that patients should be able to describe their own symptoms, but as discussed earlier many patients with advanced cancer are unwilling or unable to do so. Studies have also shown that patients underestimate their own distress and that asking an informant e.g. close friend or relative is also unhelpful as their estimation of psychological distress is a closer measure of their own distress than of the patients (Parkes 1985) (Faller et al 1995).

There may also be difficulty with professional observer bias as shown by Lewis (1991) in a sample of psychiatrists working in a general medical out-patient clinic. Hoeper et al (1984) found that physicians were influenced by the presence of a previous psychiatric history when making a diagnosis, showing a tendency to over-diagnose patients in whom a psychiatric diagnosis had previously been made. Hoeper also suggested that being screened for mental illness may prompt the patient to disclose more symptoms and concerns and could in itself be a therapeutic process.
1.9.6 **Review of Screening instruments available**

Several studies have looked at different screening instruments and their possible use in patients with cancer. Gottay and Stern (1995) reviewed the instruments that had been frequently used in studies reported in the Journal of Psycho-oncology. They identified seven scales and highlighted several concerns regarding the validity of all these tools in the cancer population. The main concern was the content validity of these scales which were developed primarily for the general population or psychiatric patients and therefore may not be appropriate for the patients with cancer. They believed that some scales could be reduced to avoid the inclusion of redundant items. Gottay and Stern also reported that the over representation of breast cancer patients used in studies limited the generality of these scales to other cancer populations.

The Beck Depression Inventory (Beck et al 1961) consists of 21 items each with a four point scale response and the items are summed to achieve a score. This scale was devised and initially validated for use with psychiatric patients and has suggested cut off thresholds for both research and clinical use and is widely used in research. Kathol et al (1990) examined the diagnosis of major depression in 152 patients with cancer using the Beck Depression Inventory, Hamilton Rating Scale, a structured screening questionnaire according to DSM 111R criteria and the Research Diagnostic Criteria. They concluded that both the Beck and Hamilton were useful tools, but mis-classified patients with depressive symptoms and those with a major depression and that these scales were better when only psychological symptoms were included.
Plumb and Holland (1977) compared 97 patients with advanced cancer, 66 next of kin and 99 psychiatric patients who had attempted suicide. The two groups of patients completed the Beck Depression Inventory and were indistinguishable for somatic depressive symptoms. The non somatic symptoms clearly distinguished the cancer patients from the psychiatric patients. Many of these somatic symptoms e.g. poor appetite, disturbed sleep pattern are also present in medically ill patients with other diagnoses than cancer. Koening et al (1992) devised a scale for use in the medically ill using eleven items. On testing the scale on 78 medical in patients against a structured psychiatric interview, they found their scale to have a sensitivity of 83% and a specificity of 77%.

Elderly medically ill patients are another group where it is believed that psychiatric morbidity is under diagnosed and work has been done in this area on the development and use of rating instruments. Allen et al (1994) surveyed 811 elderly patients to establish which questions could be used as a short assessment scale. They found that eight items could be used to give a high sensitivity and specificity.

The General Health Questionnaire (GHQ) and Standardised Psychiatric Interview were used among 126 consecutive patients admitted to an Oncology ward (Hardman et al 1988). The GHQ consists of a checklist of statements asking respondents to indicate their response on a four point scale.
The GHQ identified 79% of affective disorders and 34% false positives. Medical and nursing staff only identified 49% of patients.

The Rotterdam Symptom Checklist (de Haes 1990) was devised as a tool to measure the symptoms of cancer patients participating in clinical trials. Its initial validation included patients with advanced ovarian cancer and patients receiving chemotherapy and healthy populations. It was found that the psychological dimension of the scale was stable across all disease groups. The psychological scale contains eight items relating to irritability, worrying, depressed mood, nervousness, desperate feeling regarding the future, tension, anxiety and difficulty concentrating. However the scale does not purport to be a rating tool to identify depressed patients and is used predominantly as a measure of quality of life.

Others have developed specific tools to diagnose depression in the terminally ill. Melvin et al (1995) developed the Mood Evaluation questionnaire validating it against the Geriatric Depression Scale. The scale consists of 33 questions all scored on a five point Likert scale. The number of items could prohibit its use in a large number of terminally ill patients. This scale was developed on twenty seven hospice in-patients and has not been formally validated.
The Hospital Anxiety and Depression Scale

The use of this scale with terminally ill patients will be discussed in more detail in chapter 4.

The Hospital Anxiety and Depression Scale (HAD) is a fourteen-item scale devised in 1983 by Zigmond and Snaith for use with medical patients. Its main features are that it excludes symptoms which may have both an emotional and physical aetiology e.g. dizziness or sleep disturbance.

The depression sub scale is based on anhedonia - the complete loss of enjoyment - Snaith (1992) described the concept of anhedonia as the "exclusion from the pleasure dome". The authors of the scale stated that this symptom would indicate which patients may respond to anti depressant medication (Snaith 1987). The HAD scale is now used extensively in Europe and the USA and has been translated into all European languages and Arabic, Japanese, Chinese and Urdu. Although the scale was piloted and devised originally with patients under the age of sixty five years, it has been used in elderly populations (Kenn et al 1987) where a small study of twenty patients showed that the depression sub scale, but not the anxiety sub scale correlated highly with global depression scores using the Montgomery Asberg Depression rating scale as a standard. The scale has also been validated for use in primary care (Wilkinson and Barczak 1988) (Dowell and Biran 1990).
A number of studies have been published using the Hospital Anxiety and Depression Scale in different populations to detect morbidity and to determine at which threshold cases should be identified - a review will highlight some of the difficulties which may occur in using this scale with terminally ill patients.

Lewis and Wessely (1990) studied 173 dermatology outpatients of whom one hundred and seventeen completed both the GHQ and the HAD and the Clinical Interview Schedule as a gold standard. They found both scales to be acceptable for this population and that a cut off threshold of 11 had a sensitivity of 72.3% and specificity of 77.1%.

Two papers by Hopwood et al (1991a and 1991b ) looked at the prevalence of psychiatric morbidity in patients with advanced breast cancer and the validity of the Hospital Anxiety and Depression scale and the Rotterdam symptom checklist. In the initial study on prevalence of psychiatric morbidity , two hundred and twenty two women were recruited and using a cut off threshold of 11 on the HAD scale, eighteen patients scored more than 11 on the anxiety sub scale and a further eighteen on the depression sub scale .Both scales identified similar rates of psychiatric morbidity , but the authors concluded that both questionnaires were not psychometrically robust to give exact prevalence rates of depression in patients with advanced cancer. Their second paper looked at two hundred and four patients with advanced breast cancer comparing them to a psychiatry interview using the Clinical Interview
schedule. All high scores (i.e. a score of greater than 11 on either sub scale) were interviewed by a psychiatrist as were a proportion of low scorers. Eighty one patients were interviewed and using a combined cut off of 18 for the HAD scale, a sensitivity of 75% and specificity of 74% was achieved and the mis-classification rate was 26%.

The authors concluded that the HAD Scale as a screening instrument could be useful, but that specific cut off thresholds needed to be established together with sensitivity and specificity for each specific population. They also suggested that patients with scores above specific thresholds should be further assessed by a trained clinical nurse specialist or psychiatrist.

Ramirez et al (1995) screened patients with breast cancer during the first year after diagnosis and found that using a threshold total score of eleven in patients aged over 50 years, the HAD could identify women at risk from mood disorder in the year after diagnosis. Razavi et al (1990) using the HAD scale in a study to screen for disorders in cancer inpatients, 12.7% of which were described as being in the "pre-terminal phase", found that a total score of 19 gave 70% sensitivity and 75% specificity for major depressive disorders.

Further work was carried out by Razavi et al (1992) screening one hundred and seventeen patients with lymphoma using a clinical interview conducted by a psychologist with a small number of patients (3.4%) in their second relapse.
They found the optimal cut off for screening for adjustment disorder, anxiety and major depressive disorders to be 10.

Ibbotson et al (1994) used the General Health Questionnaire, Rotterdam Symptom Checklist (RSCL) and Hospital Anxiety and Depression scale together with the Psychiatric Assessment schedule. Five hundred and thirteen patients were recruited. The HAD scale performed best in patients who were disease free or receiving active treatment using a cut off threshold of greater than 19 in patients who were disease free.

A large study by Carroll et al (1993) with nine hundred and thirty patients all with a cancer diagnosis found that using a cut off of 11 for either anxiety and depression sub scales, 23.1% had scores higher than 11 with 17.3% likely to have an anxiety disorder and 9.9% a depressive disorder according to DSM III R criteria. The authors reported a high correlation between both anxiety and depression sub scale scores. This paper however has a number of factors which must be considered - there were no clinical psychiatric interviews conducted and although the paper describes patients with "active disease" scoring higher than 11 on the depression sub scale, the extent of their disease is not elaborated.

The use of the sub scales of the HAD scale independently has been evaluated by Moorey et al (1991). This work was carried out almost exclusively on patients with early cancer - 92.5% of the patients studied, patients were expected to survive for at least twelve months and five hundred and seventy five patients were included in the study. A cut off of 8 was used and 27% were
identified as being in the range for anxiety and a small number of patients (8.7%) scored more than 8 on the depression sub scale. They found that all items discriminated well and recorded high alpha coefficient values of 0.93 for anxiety and 0.90 for depression and suggested that both scales could be used as screening instruments. They also commented on the homogeneity of the HAD scale and suggested that important components of depression e.g. hopelessness and guilt have been omitted.

Bramley et al (1988) studied the differentiation of anxiety and depression by rating scales. Forty eight patients were screened in a psychiatric out patient clinic using the observer based clinical anxiety scale and Montgomery-Asberg Depression scale, the HAD scale, the Irritability Depression Scale, the Crown Crisp Experiential Index and the Zung scales for anxiety and depression. They concluded that significant correlations in anxiety and depression sub scales, suggest that the HAD scale does not clearly distinguish between anxiety and depression, but also state that this research was carried out on a sample of psychiatric patients - not a population for whom the HAD scale was developed.

Aylard et al (1987) looked at four different populations attending out patient clinics (excluding cancer patients) using the HAD, GHQ and Irritability Depression and Anxiety scale against an external criteria for validation. They concluded that the HAD is a valid instrument for what it was designed i.e. use in a medical outpatient clinic and has a very small number of mis
classifications. The authors also report caution for the use of sharp cut off thresholds which produce a higher number of mis-classifications. Sharp cut off thresholds are not in accordance with the clinical practice of medicine where there is often more of a suspicion requiring further evaluation rather than definite positive or negative pathology.

Silverstone (1991a) critically examined the concept of anhedonia in a psychiatric population using the Hospital Anxiety and Depression scale and found that anhedonia which is measured by five of the seven items on the depression sub scale is present in 50% of patients regardless of psychiatric disorder and concluded that anhedonia is not pathognomic of a depressive disorder and can not therefore be relied upon alone to differentiate depressive illness from other mental illness.

The HAD scale is widely used, but yields different results in different populations. This thesis aims to establish how the HAD scale performs in the terminally ill population and which cut off threshold should be used.
1.9.8 Why diagnose depression in the terminally ill?

Depression is the most common psychiatric illness in patients with terminal cancer. Patients who are depressed may also have physical symptoms which are difficult to palliate and which may improve as their depression is appropriately treated. Psychological and psychiatric morbidity can be a major source of distress to terminally ill patients and to their relatives and friends. There are many antidepressants available with acceptable side effect profiles and patients identified as depressed even within the last four to six weeks of life may still benefit from treatment.

This emphasises the importance of diagnosis. Valid cut off thresholds on self assessment tool may be a useful aid in the process of diagnosis.

The availability of appropriate psychosocial expertise is also necessary to provide optimum care for terminally ill patients.
I need to know that this body is my body. And I need to know everything that is happening to my body. But most of all I need to know that you know that within my body there is me.

Healing is brought about not just by medicine. It’s not just treatment which cures you, but all that encompasses the human touch. A smile means more than an antibiotic injection, a hug means more than a platelet transfusion. The face - of my friends, my family, my nurses and - yes - even my doctors, shows sympathy, compassion and understanding. This human face contributes so much to healing of the tortured soul.
2.1 INTRODUCTION

In order to provide patients who are terminally ill with optimum psychological care as well as palliation of physical symptoms, health care professionals should have excellent communication and interpersonal skills. For many patients, the presence of a caring, empathic professional who is able to give honest information, sensitively will be adequate and appropriate. However, a significant number of patients may have complex psychological and psychiatric needs either due to long standing difficulties or as a result of their advanced malignant disease. Barraclough (1994) suggested that approximately 25% of patients admitted to a hospice may be depressed.

The need for professionals with specific skills in psychosocial care in addition to those members of nursing and medical staff with generic skills has been identified for some time. The independent nature of the majority of palliative care units means that there are few standardised procedures for management of patients with specific needs. The National Council for Specialist Palliative Care (an umbrella organisation for palliative care representing professionals from different disciplines involved with care of terminally ill patient) set up a working party to look more closely at the issues of psychosocial care and its provision.
They published an occasional paper on psychosocial care (No: 13) which amongst other statements defined psychosocial skills according to the NHS / Department of Health Manpower Planning Advisory Group (DoH 1989: unpublished report).

These skills were specified at three levels:

- Level One skills which are general communication skills desirable for all care-giving staff and volunteers
- Level Two skills including excellent interpersonal and communication skills which are appropriate to staff members with an extensive first line role in palliative care e.g. clinical nurse specialists in palliative care
- Level Three skills which are required by a specialists in psychosocial care.

The Occasional paper further defines - "Central to the application of these skills is the ability by all staff to recognise when they have reached the ceiling of their skills, or the situation has become too complex, and to be able to refer appropriately."

Specialists in psychosocial care are specified as counsellors or family therapists, chaplain or spiritual adviser, psychologist, psychiatrist and social worker.

Nursing and medical staff therefore need to be aware of the patients who may benefit from referral to another professional either from within the team itself, or to a designated person who is known to the unit. It is often relatively straightforward to know when a patient requires intervention from a social worker to help them sort out future care for a dependent relative or financial
support, but it may be more difficult to know when intervention from a 
psychologist or psychiatrist may be required.

This study was carried out to determine the provision of specialist 
psychosocial care with particular reference to the input of psychologists and 
psychiatrists within Hospices in the United Kingdom. The hospice 
multidisciplinary team meetings are an opportunity for all staff concerned 
with the care of a terminally ill patient to get together and discuss the patients' 
needs - the attendance of personnel at these meetings was also established.
2.2 **METHOD**

The questionnaire (Appendix A) was devised specifically for the purpose of this study and was tested for face and content validity both on individual professionals and sent to five Hospices as a pilot study. The face and content validity was found to be acceptable. The questionnaire included questions on the provision of specialist psychosocial care, whether these professionals were full time, part time or available if required. The approximate numbers of patients referred was requested and each unit was asked to define the roles of each professional. Units were also asked if they used any tools to screen for psychosocial distress, if they had access to any other specialists psychosocial services, the year of opening and the number of beds.

One hundred and sixty hospices were sent a questionnaire. These hospices were selected from the Directory of Hospice and Specialist Palliative Care Services (1997) and included units providing different services i.e. home care; day care; in patient beds.

The Hospices were selected from each county from within the U.K. where specialist palliative care provision was available.

A letter and stamped addressed envelope was sent with each questionnaire which was addressed to the Hospice matron or nurse in charge explaining the purpose of the study and inviting them to complete the questionnaire anonymously.
2.3 RESULTS

One hundred and sixty units were sent questionnaires and ninety seven (60%) were returned fully completed.

All units who responded had inpatient beds which ranged from two to sixty four, the mean number of beds was 14, and a median of 12 beds. The majority of units (78%) had been opened within the last 15 years.

2.3.1 Access to Psychosocial Service Providers

All units had access to a chaplain with 83% of units having either a full time or part time chaplain. Social workers were available on a full or part time basis in 75% of hospices. Forty three per cent of units employed full or part time counsellors. Very few units had regular support from psychologists or psychiatrists, but 76% said they could "access" a psychiatrist and 54% access a psychologist if required (Table 2.1). Several units reported difficulties in obtaining psychology or psychiatry consultations when these were required and the time taken for a response to a request for a visit and that "access" was theoretical.

Units were asked to indicate if they had other psychosocial service provision and eight units listed art therapist, volunteer be-frienders and complementary therapists as being available.

Larger units i.e. those with more than 20 beds had access to more psychosocial professionals - this was not statistically significant (p = 0.78).
2.3.2 Multidisciplinary Teams

The attendance at multidisciplinary meetings reflected the psychosocial service provision Table 2.2. Social workers attended these meetings regularly in the majority of hospices (74%). Chaplains attended weekly multidisciplinary meetings in 45% of units and counsellors (where available) attended regularly in 25% of units. Psychologists and Psychiatrists rarely attend multidisciplinary meetings, attending regularly in two units.

2.3.3 Screening Tools

The majority of units did not use screening instruments to assess for psychological distress or psychiatric morbidity (Table 2.3). The most frequent tool was the Hospital Anxiety and Depression scale which was used by fifteen units. A further fifteen units used their own internal measures for psychosocial evaluation and all such units were invited to send copies of their instruments. Two units did send copies - both forms being objective checklists e.g. Patient referred to .... yes / no responses. etc. and could not therefore be described as true screening instruments. One unit used the Support Team Assessment Schedule.
### TABLE 2.1 PATIENT SERVICES

<table>
<thead>
<tr>
<th>Professional</th>
<th>Full / Part-Time</th>
<th>If Required</th>
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</tr>
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<tbody>
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<td>16</td>
<td>0</td>
</tr>
<tr>
<td>Social Worker</td>
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<td>6</td>
</tr>
<tr>
<td>Counsellor</td>
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<td>25</td>
</tr>
<tr>
<td>Psychologist</td>
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<td>53</td>
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</tr>
<tr>
<td>Psychiatrist</td>
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<td>74</td>
<td>14</td>
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</table>

### TABLE 2.2 ATTENDANCE AT MULTIDISCIPLINARY MEETINGS

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<th>Occasionally</th>
<th>If Required</th>
<th>Never</th>
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<td>13</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
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<td>11</td>
<td>18</td>
<td>20</td>
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<tr>
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<td>3</td>
<td>16</td>
<td>31</td>
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</tr>
<tr>
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<td>1</td>
<td>20</td>
<td>37</td>
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<tr>
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<td>1</td>
<td>23</td>
<td>51</td>
<td>20</td>
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### TABLE 2.3 PSYCHOSOCIAL SCREENING TOOLS

<table>
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</thead>
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<td>66</td>
</tr>
<tr>
<td>Hospital Anxiety &amp; Depression Scale</td>
<td>15</td>
</tr>
<tr>
<td>Support Team Assessment Schedule</td>
<td>1</td>
</tr>
<tr>
<td>Others (Units own evaluated tool)</td>
<td>15</td>
</tr>
</tbody>
</table>
2.3.4 Roles of Psychosocial Service providers

Units were asked to describe the roles of each of the psychosocial service providers. All units were able to define the roles of the chaplain who was described as providing spiritual support to all patients, relatives and staff if required. Chaplains were also involved in helping relatives to arrange funerals and in conducting funerals and in some units, provided bereavement support e.g. annual thanksgiving service or bereavement visits. All units also defined the roles of the social workers. The remit of social workers included advising on benefits, organising discharge packages, counselling patients, and additionally supporting relatives and running specific groups e.g. for carers or bereaved children. One unit defined part of the social workers role as providing staff support.

Counsellors had a varied role. Ten units used volunteer counsellors or be-frienders and twenty six units responded that they felt that their medical, nursing and social work staff undertook a counselling role and therefore did not employ specific counsellors. Where counsellors were employed their role was mainly bereavement focused, with some running groups for different needs e.g. bereaved children, bereaved young parents, the elderly etc. Five units indicated that counsellors had a counselling role with patients only and eleven units indicated that counsellors undertook staff support and patient counselling. The role of the counsellor was not defined by forty one units. The majority of units (60%) did not have any figures available on the number of contacts by counsellors, chaplains or social workers with patients.
The psychologist's role was defined as assessing patients with complex emotional needs, providing staff support and teaching and counselling patients, fifty five units did not define this role.

Psychiatrists were predominantly called upon to assess patients, assessment of patients and staff education and provide advice on bereavement issues. A total of forty three units did not define the role of the psychiatrist, and eleven units stated "service difficult to access" when asked to define the role.

In the majority of units no patients had been referred to a psychiatrist or psychologist during the last twelve months (Figure 2.1 and 2.2) Many units additionally commented that they could no remember the last time a psychiatrist or psychologist had assessed any of their patients. The two units which had a high number of referrals employed a full time or part time psychologist or psychiatrist. In these two units, twenty five and thirty patients had been assessed by a psychiatrist and in one unit sixty three patients were reported to have been assessed by a psychologist. All the figures available are illustrated in figures one and two, but may not be totally accurate. Psychologists and psychiatrists were very occasionally requested to see relatives - a total of three relatives were seen.
Figure 2.1

Number of Patients seen by Psychiatrist

<table>
<thead>
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<th>Frequency</th>
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</table>

Service not available

Figures not available
Figure 2.2

Number of Patients seen by Psychologist

<table>
<thead>
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<th>Number of patients seen</th>
<th>Frequency</th>
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<td></td>
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2.4 DISCUSSION

The majority of hospices who responded to this questionnaire had well integrated social work and chaplaincy support with contribution to the multidisciplinary care of patients on a regular basis. A large number of units did not have access to psychology and psychiatry and several identified that advice and support from these professionals was difficult to obtain with a considerable time delay between the initiation of the referral and the patient being assessed. These findings highlight several areas which warrant discussion.

Counsellors were available in 43% of units, but it was not always possible to determine if some hospices were including the skills of their medical, nursing and social work or voluntary personnel. This figure may not be an accurate estimation of the number of counsellors employed by Hospices. The benefits of counselling and whether cancer patients want counselling are still open to debate. There is still little information to suggest that counselling has a beneficial effect on physical or psychological well being since Worden and Weisman's paper in 1980. Much counselling can be seen as more of a befriending relationship and there is also concern within palliative care as to the training and supervision of counsellors and their professional relationships with other staff particularly as regards confidentiality and the sharing of information. Some units also recorded that counsellors and social workers were providing staff support. Whilst much staff support within palliative care is on an informal basis, it is generally acknowledged that structured staff
support should take place away from the internal environment and with an external person (Vachon 1997).

Chaplains were universally available in all units. Many hospices have religious foundations, and some hospices e.g. St. Christopher's in London include worship and prayer as an integral part of their work. Spiritual distress is common at the end of life and the support offered by a chaplain is invaluable to many patients (Clark 1991). Chaplains appear to be an integral part of all hospices, are included as members of the multidisciplinary team meetings and have a well defined role in supporting patients relatives and staff.

The majority of hospices in this study had access to social workers who had a wide remit including discharge planning, financial advice, bereavement support and involvement with specific patients groups e.g. bereaved partners of bereaved children. It is acknowledged that within palliative care, professionals may undertake skills or roles that may not be possible or practical within other settings and therefore have a much wider remit than normal. The National Hospice Study (Greer et al 1983) also noted that patients receiving palliative care received more social work support than other patients. The importance of the role of the social worker within the multidisciplinary team was identified with the high number who attend such meetings.
It was surprising that 60% of units did not keep any statistics on the number of patients seen by their counsellors, chaplains or social workers - all of which were members of the multidisciplinary team. This may reflect the independent nature of units or that the person to whom the questionnaire was addressed (Nurse in charge of the unit) did not have access to these figures.

It appears from this study that psychology and psychiatric support for Hospices within the U.K. are currently very fragmented. It is acknowledged that there are a national shortage of both professional groups and relatively few hospices would be able to recruit and employ a full or part time psychologist or liaison psychiatrist (Guthrie 1998). The potential needs of a significant number of hospice patients for assessment by psychologists or psychiatrists and the role both these professionals have in terms of teaching medical and nursing staff may lead to patients receiving sub optimal psychosocial care.

The majority of units who responded did not refer any patients to psychology or psychiatry when these services were available and a small number of units referred one or two patients in the last twelve months. These figures suggest that either only these small numbers of patients required such support or that the frequent comments regarding the inaccessible nature of psychology and psychiatry services coupled with a long delay between referral and assessment prohibited more referrals from being made. The former however can be refuted by the thirty six Hospices who in replying spontaneously commented
on the difficulty in diagnosing depression and other psychiatric symptoms and their consequent feelings that such symptoms were frequently overlooked. When there is regular provision in terms of psychiatry or psychology, this is welcomed by units and influences both appropriate referrals and treatment decisions (Mitchell 1998).

It is known that relatives of patients with newly diagnosed cancer have high levels of psychological distress (Harrison et al. 1995) and relatives of terminally ill patients may also have similarly high levels of distress. The very small number of relatives seen by either psychologist or psychiatrist probably reflects the lack of provision and accessibility rather than the perceived need.

This difficulty in accessing services may be remedied by having a named "Link" psychologist and psychiatrist who is familiar with the hospice structure, familiar to staff and who is easily accessible. Ramsay (1992) found that when a named liaison psychiatrist was available to a palliative care unit approximately 10% of all patients were referred and she emphasised that the presence of a psychiatrist both helped referral on an informal basis and also highlighted the emotional needs of patients and their families to medical and nursing staff. In his study of hospices, Seale (1989) when discussing psychosocial care concluded that information was difficult to obtain, a finding which is supported by this study, and that there appeared to be a wide variation in the care available and offered to patients.
The Hospital Anxiety and Depression Scale was used by 15 units to assess for anxiety and depression. One unit used the Support Team Assessment Schedule (Higginson 1993) which was devised for use initially for palliative care teams to record and evaluate their care. Fifteen units had devised their own assessment tool and the two which were returned were checklists e.g. has the patient been referred to social worker? etc. and could not therefore be called screening tools. Others have aimed to develop tools specifically to measure psychological adaptation to dying (Dobratz 1990) - there is however a danger in trying to measure all components of distress and not having the means to provide the necessary support required. Maher et al (1996) in a study of unmet need in patients attending for radiotherapy using the HAD scale stated that screening should take place at regular intervals during a patient's illness, but also stressed the ethical dilemma of screening if there was no back up in terms of a liaison psychiatry team or psychology service and a comprehensive range of therapy options available to the patient.

When discussing psychological care it is important to remember that it is the quality of relationship between patients and their doctors which promotes the disclosure of psychosocial information - patients feel able to share their deepest distresses when they sense a caring approach (Doyle 1996) - a finding echoed by (Dobkin and Morrow 1986). This is a variable which is difficult to evaluate and impossible to measure in a study such as this.
However, from this study, patients receiving care from Hospices are unlikely to receive assessment from a psychologist or psychiatrist and treatable psychiatric morbidity may not be detected or treated.

2.4.1 Summary

In a survey of 166 hospices in the United Kingdom, 97 units responded. The majority of hospices have well integrated social work and chaplaincy services. Counselling is available in many hospices, but this may be provided by volunteer counsellors, social workers or by medical and nursing staff rather than by designated counselling staff. Psychiatry provision is available, but difficult to access and consequently very few patients are referred. There is a lack of perceived availability of psychology services and few referrals are made. It is possible that this lack of psychology and psychiatry provision leads to under recognition and under treatment of depression and other psychiatric morbidity.
As time goes by, night follows day, and day follows night - a natural cycle without beginning, without end and without gaps. Life's cycle continues without interruption, or at least it should do. Suddenly illness arrives, uninvited, unexplained. I found myself caught between life and death, light and dark, banished to an unknown place - between night and day. The illness forced itself into my life where there was no place for it. The arrival of illness stole a place and time that should have been destined for better things.
CURRENT PRESCRIBING OF ANTIDEPRESSANT MEDICATION FOR TERMINALLY ILL PATIENTS

3.1 INTRODUCTION

The diagnosis of depression in terminally ill patients is often difficult. The criteria for diagnosis is not standardised and estimates of prevalence vary depending on the diagnostic criteria used. Palliative care physicians caring for terminally ill patients may not be aware of the symptoms of depression or how to interpret them. Derogatis et al (1976) found that physicians working in Oncology rated depression as less severe than the patients treating only those with the most severe symptoms. Once a diagnosis of depression is made, it is important that patients are treated adequately and appropriately.

Historically, there has been considerable concern regarding addiction to and dependence of certain psychotropic medications - both very rare occurrences and of little relevance in the management of the terminally ill patient (Lovejoy and Matteis 1996). There is also concern regarding the polypharmacy of patients with advanced cancer who may have hepatic and renal impairment and other concomitant physical illnesses. Newer antidepressants with fewer side effects are now available and these may be more suitable for use in palliative care. The two or three weeks which elapse before a response is apparent, and the appearance of troublesome side effects may make compliance a problem.
Patients who are depressed need constant evaluation and support as well as clear explanations about their illness and treatment and may require encouragement to continue with antidepressant medication.

Those patients who are suffering from symptoms of severe depression but have a short life expectancy may benefit from psychostimulants - these are used more frequently in the United States than in the U.K. (Noyes and Kathol 1986). When studied in this population (Olin and Massand 1996), eighty-three percent improved within two days of starting treatment with ten percent discontinuing medication due to side effects. This suggests that these drugs may be helpful in treating depression in the terminally ill, however physicians tend to be reluctant to prescribe this class of drugs (Frierson et al 1991).

There are therefore a number of possible therapeutic interventions which can be offered to terminally ill patients who are found to be depressed.

This study was carried out in order to determine the use of antidepressant medication in terminally ill patients whilst receiving Hospice care.
3.2 METHOD

A retrospective case note analysis of all patients under the care of four Hospices in the Midlands region was undertaken. The four hospices were well established units and operated a consultant led service. Three hospices had eighteen beds each and another twenty five. All had high bed occupancies and were in close proximity to either University teaching hospitals or large district general hospitals. Three of the hospices were accredited for Senior Registrar training and all had junior medical staff with regular educational meetings and multidisciplinary team meetings. Two of the hospices had their own home care team nurses and two worked in close liaison with community Macmillan Nurses. All hospices had their own consultant outpatient clinics.

As it was not possible to obtain the community details for patients in those units who did not have their own home care teams, it was decided to look at the pattern of antidepressant prescribing for inpatients. The combined discharge rate for the four units was in excess of 40% with many patients being admitted for symptom control with the expectation of discharge. The prescription cards of each patient admitted to all the units form January 1st to December 31st 1995 were searched. Information was recorded on age, antidepressant prescribed, date of commencement, indications for prescribing, drug name, dosage, reasons for discontinuation and advice given to patients on discharge.

Diagnosis, and previous psychiatric history was also noted.
3.3 RESULTS

The case notes and prescription charts of one thousand and twenty six patients who had been admitted to the four units from 1st January to 31st December 1995 were included. Eight hundred and eighty patients received hospice home care support prior to admission. One hundred and six patients (7%) were prescribed antidepressants during their contact with the palliative care units. Of these 106 patients, twenty two (21%) were commenced on antidepressant medication prior to their admission, and in fourteen cases information they had been prescribed medication for a mean of forty one days (range seven days to four months) prior to admission.

Eighty four patients (79%) were commenced on treatment during their inpatient stay and of these patients, five were referred to a psychiatrist for assessment and were commenced on antidepressant medication on the psychiatrist's recommendation. Seventeen (16%) patients were discharged home on antidepressant medication.

When there was any uncertainty in the case notes as to whether patients had been commenced on tricyclic drugs as co-analgesics, these patients (ten in total) were excluded from the results to avoid confounding the results.

The mean age of patients prescribed antidepressants was 61.3 years compared to a mean age of all patients of 71.4 years (p = 0.001). Sixty three females (59%) were prescribed antidepressants compared to 43 (41%) of males.

Two Hospices used self reporting scales on admission (Hospital Anxiety and Depression Scale) and the score was documented in the notes either on or shortly after admission.
When symptoms of depression had been noted during the admission procedure, there was a mean delay from admission to commencement of treatment of 4.8 days (range 0 days to seventeen days).

Previous psychiatric history was documented in the notes of two patients. Seventy eight patients (73%) who were prescribed antidepressants died within two weeks of commencement and of these fifty six (52%) died within one week. In all the above cases, the medication was discontinued due to the patients deterioration.

Twenty eight patients (26%) were prescribed tricyclic medication and it was noted that all drugs were at low doses e.g. Prothiaden 25mg daily and the doses were not increased.

Seventy six patients (71%) were prescribed Selective Serotonin reuptake Inhibitors. Fluoxetine was prescribed most frequently (56%), Paroxetine was prescribed for twenty one patients and ten patients were prescribed Sertraline. A small number of patients were prescribed other medications i.e. Monoamine Oxidase Inhibitors (two patients), Flupenthixol (one patient) and Phenelzine (one patient).

None of the patients in this study were prescribed psychostimulants.
<table>
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3.4 DISCUSSION

This study shows that a small number of patients receiving hospice based palliative care (including home care) are currently prescribed antidepressant medication. In the majority of cases, medication is commenced so late that there is an insufficient time for a response to prior to the patients death. The findings of this study are similar to other studies carried out in the United States looking at psychotropic medication in cancer patients. Derogatis et al (1979) examined the prescribing practices of psychotropic medication in five major oncology centres where 1,579 case notes were examined. Of a total of 1,696 prescriptions for psychotropic medication only twenty were for antidepressant medication. Goldberg and Mor (1985) looked at the psychotropic use in two hundred and two terminal cancer patients and found that 6% of patients were prescribed antidepressants within the last six weeks of life and 3% within the last week of life. More recently, Steifel et al (1990) looked at the changes in psychotropic prescribing in the United States over a ten year period and found that although there was a 30% increase in psychotropic prescribing, antidepressants were still under prescribed.

Although only two of the hospices had their own home care teams, 880 patients were receiving home care from these two units which enabled information on antidepressant prescribing prior to admission to be obtained. Seventeen patients were prescribed antidepressant medication during their contact with the palliative home care team. In six cases, clear documentation
of low mood was detected by the home care team who liaised with the General Practitioner and anti depressant medication were prescribed.

It was not possible to determine which patients may have been prescribed anti depressant medication prior to their palliative care referral and this medication discontinued. Many patients had attended hospice out patient clinics, but antidepressant medication was not initiated at any of these consultations.

Cancer is predominantly a disease of the elderly and it has been estimated that as many as 50% of all elderly cancer patients will experience significant depressive symptoms (Goldberg and Cullen 1986). In this study the mean age of patients prescribed antidepressant medication was significantly lower than for all patients (61.3 years in the treated group vs. 71.4 years in the non treated group, p = 0.001). The reasons for this are unclear but it may be that depression is not identified as readily in the elderly patient as in the young patient.

Females were more likely to be prescribed antidepressants than males and 43% of antidepressants were prescribed for females with breast cancer, but these accounted for only 27% of all diagnoses. Thus 11% of all females with breast cancer who were in contact with the palliative care units were prescribed antidepressants. Much published research has been carried out on psychiatric morbidity in patients with breast cancer, possibly alerting staff caring for patients to the possibility of depression in this patient group (Hopwood et al 1991a and 1991b). Hughes (1985) found that 16% of patients
with inoperable lung cancer developed a depressive illness. In this study, twenty eight patients (6%) of a total of 414 with lung cancer were treated with antidepressant medication - a lower number than would be expected.

The delay of 4.8 days in prescribing antidepressants after the depressive symptoms had been noted and documented in the notes is worthy of further discussion. The delay may be a reluctance to prescribe yet another drug for patients who may already be taking several other medications or the hope that a patient’s mood would improve during their Hospice admission. It may also indicate the difficulty medical staff may have in distinguishing between sadness and depression. It could also be argued that as the majority of patients were so near to the end of life, the prescribing of antidepressants in these patients was inappropriate. The comments documented in the notes on admission were predominantly non-somatic symptoms i.e. "says he feels helpless and worthless".

There was no evidence in any of the case notes that a psychiatric history or mental state examination had been undertaken. Although all Hospices had good medical notes, in only two cases was a past psychiatric history noted on admission - the lack of information on psychiatric status was also reported by Bolund (1985) who highlighted the difficulty in obtaining information on the mental status of cancer patients as this was not documented in medical case notes.
Two of the hospices routinely used the Hospital Anxiety and Depression scale as an assessment tool for psychiatric disorder. This score however was seldom documented in the notes and therefore a comparison of scores for depressed patients was not possible.

There is no data to support which drug should be used in treating depression in the terminally ill, therefore the choice of drug is often governed by the side effect profile or the preference of the individual physician. A number of patients were prescribed tricyclic antidepressants, but presumably due to inadequate timing, all were prescribed low doses. A review by Breitbart and Jacobsen (1996) suggested that due to their anti cholinergic side effects and the tendency of terminally ill patients to achieve high serum levels at modest doses, care needs to be taken with these drugs. Popkin et al (1985) found that 32% of patients with a medical illness including cancer, discontinued their tricyclic antidepressant medication and also found that only 40% showed a response to treatment - a much lower proportion than that reported by other studies (Chaturvedi et al 1996). It is known that cancer patients respond to lower doses of psychotropic medication due to altered metabolism and may also be more prone to side effect (Razavi and Steifel 1994), but a general population study found that those patients prescribed tricyclic antidepressants at low doses had worse outcomes at four months than either those patients prescribed higher doses of antidepressants or managed without antidepressant drugs (Brugha et al 1992). This should be taken into consideration in patients with a more favourable prognosis.
Of the selective serotonin reuptake inhibitors, Fluoxetine was prescribed most frequently possibly reflecting its high publicity profile. It is also available as an elixir which is easier to administer in the very ill patient. A double blind study by Razavi et al (1996) using Fluoxetine in patients with cancer, did not report any significant change in the baseline HAD scores for depression and anxiety. Sertraline, which has a lower reported incidence of hepatic and renal toxicity was used in a small number of patients.

None of the newer drugs e.g. Venlafaxine which is reported to have a more rapid onset in elevating mood or Nefazadone, which is reported to quickly reduce the anxiety accompanying depression and to improve sleep patterns (Drugs and Therapeutics Bulletin 1996) were used. In terms of efficacy, of antidepressants there is little difference, but the numbers stopping treatment due to side effects are higher in those prescribed tricyclics (Song et al 1993).

There are few studies on the effectiveness of medication in terminally ill patients, but a small study of twenty patients by Carroll (1990) found that the treated group treated using Alprazolam had a significant improvement in their depression scores using the Hamilton Rating Scale as an objective baseline of measurement.

Psychostimulants which are known to work rapidly to elevate mood and also improve a patient’s general well-being and stimulate appetite (Holland 1987) (Burns and Eisendrath 1992) were not prescribed for any patients. A review of Psychostimulants (Satel and Nelson 1989) suggested they were not as
effective as conventional antidepressants in the general population, but may have a therapeutic advantage in certain groups e.g. the medically severely ill patient. Further studies by Bruera and Watanabe (1994) have advocated the role of psychostimulants in potentiating opiate analgesia, counteracting opioid induced cognitive impairment as well in the treatment of depression. Thus the patient group who were prescribed medication during the last few weeks of life may have benefited from psychostimulants acting immediately rather than the antidepressant medication which was discontinued before a therapeutic response could be achieved.

It was not within the remit of this study to evaluate other interventions in the support of the depressed patient, but the role of good communication skills, and caring, empathic medical and nursing staff also help promote recovery of the depressed patient. The role of Cognitive therapies have been reviewed (Mermelstein and Lesko 1992) and many studies have reported significant benefits for patients. The use of complementary therapies are also thought to promote a sense of well being in terminally ill patients and may also be beneficial in those patients who are depressed (Barraclough 1994).

This study was limited. It was a retrospective case note study and whilst all case notes and drug cards were hand searched by the author of this thesis, it was not always possible to ascertain which reported symptoms led to the diagnosis of depression. The lack of information on past psychiatric history in medical case notes was also apparent. It was also unclear whether patients had
been referred for other therapies such as counselling, cognitive therapy or complementary therapy either before or after commencement of antidepressant medication.

A small number of terminally ill patients are currently receiving antidepressant medication and in the majority of cases at a stage in their terminal illness when there is little time for the medication to have effect. Antidepressants were seldom prescribed for terminally ill patients being cared for in the community which may suggest that medical and nursing staff were not aware of the patient's depression.

Depression is a significant symptom for 25% of patients admitted to a hospice (Barraclough 1994) and therefore it appears that a number of patients included in this study were not being treated. There is a general consensus in the mental health field, that there is under recognition and too much diversity in the treatment of depression within different mental health settings (Mayou 1977) (Williams 1979) (Brugha and Bebbington 1992) (Brugha 1995) (Geddes et al 1998). The diagnosis of depression in terminally ill patients is a challenge and it is important that the prevalence and available therapies are highlighted to all medical and nursing staff working in palliative care Lynch (1995).
3.4.1 Summary

One hundred and six patients (7%) of the one thousand and forty six patients whose case notes were retrospectively reviewed were prescribed antidepressant medication. Seventy six per cent were commenced on treatment during the last two weeks of life. Females with breast cancer were prescribed antidepressant medication more than any other group. Psychiatric past history or current psychiatric status was rarely recorded in case notes and there was a delay in symptoms being noted and medication being prescribed. From this study, there did not appear to be any co-ordinated approach to the diagnosis or initiation of treatment for depression in terminally ill patients receiving Hospice care.
4.1 INTRODUCTION

Depression is the most common psychiatric illness in patients with advanced cancer. The estimates of prevalence range from 17% (Hinton 1963) to 45% (Plumb and Holland 1977). The majority of research of psychiatric morbidity in patients with cancer has focused on patients with early disease or those receiving active treatment. It has already been established that there are difficulties in assessing psychiatric symptoms in patients with terminal cancer (Casey 1994). Additionally, patients may be reluctant to disclose their feelings of depression with medical and nursing staff for fear of being perceived as a "bad" or "weak" patient.

The study in chapter two on psychosocial care revealed that few Hospices refer patients to a psychiatrist for assessment. The interest in using screening instruments is increasing and a number of units are using the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983). This scale however has not been tested for its efficacy in the terminally population and there is no published research as to which cut off threshold should be used.

It has been suggested that symptoms such as guilt, suicidal ideation and worthlessness (Casey 1994) may be more useful discriminating symptoms. A scale developed and validated to assess for depression in the postnatal period - the Edinburgh Postnatal Scale (EPDS) - was found to contain questions on these areas (Cox et al 1987). This scale has a similar format to the HAD
scale, is easy and quick to complete and the scoring is also straightforward - these criteria suggested that this scale may be of value in assessing depression in the terminally ill and its validation is a further aim of the study. This scale has not been previously documented as being used with terminally ill patients, but has been validated in women outside the postnatal period and found to have satisfactory sensitivity and specificity (Cox et al 1996). This study will establish if the EPDS in both its original ten item form and an abbreviated seven item scale by removing the three items identical to the HAD scale can be used for the assessment of depression and if so, which cut off thresholds should be used.

Previous research has found that psychiatric morbidity in patients with cancer may be associated with information needs, past psychiatric history and social support - it is not known if these factors are important in terminally ill patients and these factors were also determined as part of the interviews.
4.2 METHOD

4.2.1 Subjects

Patients were recruited to the study from two hospices, the Leicestershire Hospice, Staunton Harold Hospice and from the Oncology Unit of the Leicester Royal Infirmary. The Leicestershire hospice is a twenty five bed unit with its own home care team, out patient clinics and hospital liaison service which was opened in 1985. Staunton Harold Hospice is an eighteen bed hospice which functions mainly as an in patient unit for palliative and terminal care and was opened in 1988. The Leicester Royal Infirmary Oncology Unit treats over 2,500 new cases a year. As this research was carried out on a part time basis, the three units were visited on a weekly basis and all patients who fulfilled the inclusion criteria in each unit were invited to participate in the study. Full ethical approval was obtained for this study (Reference Number 3684 - see appendix C).

The patients were recruited between May 1995 and July 1997 and the majority of patients (76) were recruited from the Leicestershire Hospice.

Patients aged between eighteen and seventy years who had a prognosis of six months or less determined by the consultant in charge of their care were considered eligible to take part in the study. Patients were required to have been admitted for at least 48 hours prior to participating in the study as it was felt that time may be needed for patients to acclimatise to the unit and patients seen immediately on admission may have higher anxiety levels.
Patients were required to be able to understand both written and spoken English, be capable of completing both self-assessment scales unaided and respond to the semi-structured interview.

Patients were excluded if they were already diagnosed as being depressed or were currently taking antidepressant medication. Patients with suspected or confirmed cerebral metastases and those with a prognosis of one week or less were also excluded. All patients were required to complete a written consent form prior to participation (appendix D).

Patients were given the Hospital Anxiety and Depression Scale and the Edinburgh Postnatal Depression Scale to complete unaided and once they had completed these, they were interviewed using the Present State Examination.

Information was also obtained from the patients and their case notes as to diagnosis, extent of metastases, previous psychiatric history and social status.

Patients were also asked two other questions as to whether they felt supported by family and friends and whether they believed they had been given sufficient information regarding their diagnosis and prognosis. According to the protocol for this study, the medical staff responsible for the patient's care was informed of any patients who were found to have a psychiatric diagnosis according to the PSE interview.

All patients' demographic details were coded and the date of death recorded.
4.2.2 The Hospital Anxiety and Depression Scale

This scale was devised by Zigmond and Snaith (1983) for use by clinicians working in medical and surgical clinics as a reliable screening test for psychiatric disorder. The scale is included in appendix E. It comprises of seven questions relating to depression and seven to anxiety and the questions are divided into two sub scales.

The scale does not include any items that could relate to both physical illness and emotional distress e.g. insomnia. The seven items relating to depression are based on the concept of anhedonia - the complete loss of enjoyment. The authors who developed the scale believed this to be the central psychopathological feature of a depressive illness which would respond well to antidepressant medication. Each question has a possible four responses and the score is determined on a zero to three scale - the most negative response receiving the highest score. The initial study and development of the scale was carried out in a general medical out patient clinic with patients aged between 16 and 65. The scale was further validated by paramedical, clerical and hospital technical staff. The thresholds for both sub scales were determined as less than seven for non cases, eight to ten for possible cases and eleven or more for probable cases.

The Hospital Anxiety and Depression Scale is frequently used for studies measuring the prevalence of anxiety and depression in patients with cancer and is also the most frequently used instrument within palliative care from the initial study in chapter 2.
4.2.3 The Edinburgh Postnatal Depression Scale

This scale was devised by Cox et al. (1987). The scale contains ten items selected from the Hospital Anxiety and Depression Scale, The Irritability, Depression and Anxiety Scale and the Anxiety and Depression Scale (Bedford and Foulds 1978). The scale is included in appendix F. It excludes the somatic symptoms of depression and was devised so that it could be administered by health care workers with no prior knowledge of psychiatry. It is scored in the same format as the HAD scale. The original scale was validated on eighty-four mothers in the postnatal period and found to have a sensitivity of 86% and specificity of 78% using a cut-off threshold of 12/13. It has been further evaluated using a large community sample in the U.K. (Murray and Carothers 1990) and in a North American population (Roy et al. 1993) and found to have acceptable sensitivity, specificity and positive predictive rates for depression in the postnatal population. The authors believed it could be used for other populations, but that the scale required validation prior to use. The reasons for using the scale in this study were that it contains questions concerning guilt, helplessness / hopelessness, subjective low mood and thoughts of self-harm. These symptoms are thought to be particularly important diagnostic symptoms of depression in the terminally ill. The Edinburgh Postnatal Depression Scale contains three items identical to the HAD scale - the scale was also validated in both its original ten item form and an abbreviated seven item scale eliminating those questions identical to the HAD scale.
4.2.4 The Present State Examination

The Present State Examination (PSE) is a semi-structured psychiatric interview based on establishing if a range of symptoms are present and if so, the degree of severity (Wing 1976) (see appendix H). It is a clinical instrument based on a method of cross-examination used by psychiatrists to decide if specific symptoms are present. It has been widely used for research purposes and found to be a valid instrument when interviewers had been adequately trained and supervised (Lesage et al 1991). The PSE was selected from other schedules as there are a number of papers reporting its rigor when used as a validation tool. The tenth edition of the Present State Examination consists of two parts - the first section deals with neurotic symptoms, eating disorders, drug and alcohol misuse, with a screen for part two and the second part with psychotic experiences, speech and behaviour. There are three possible time periods, the year before the examination, the month before or present state (Wing et al 1990) - for the purpose of this study the present state was used. The PSE when used by trained interviewers generates information from which it is possible to make a psychiatric diagnosis using a standard classification of the International Classification of Diseases (tenth edition).

The PSE can be incorporated into a computer generated program. The diagnostic information has been found to be highly concordant with clinical diagnoses in many studies (Wing et al 1978) (Wing 1983). It is necessary to undertake specific training in this interview technique and the author of this thesis was trained at the Leicester University centre for PSE training.
4.2.5 Statistical Analysis

Statistical advice was obtained during the planning stage of this work and at regular intervals during data collection and analysis.

It was recommended that one hundred patients should complete both scales and the PSE interview to obtain meaningful results. This would required approximately one hundred and thirty patients to be invited to participate. The results of patients information, support needs and past psychiatric history would be correlated with PSE casesness using Spearman's correlation coefficient as this data was non parametric. Correlations for individual items of the HAD scale and Edinburgh scale with total scores were correlated using Pearson's product coefficient as this data was parametric.

Each item of the Hospital Anxiety and Depression Scale and the Edinburgh were analysed individually for their sensitivity, specificity, positive predictive value and negative predictive values. Factor analysis is another means of testing the validity of a scale by determining whether the components of the anxiety and depression scale are measuring similar constructs by loading onto the same factors. The factor structure of each questionnaire was determined by factor analysis to establish which factors each of the questions loaded on to. The amount of variance extracted by the first factor gives an indication of the homogeneity of the scale (Nunnally and Bernstein 1994).

The internal reliability or homogeneity of both scales were calculated by using Cronbach's Alpha coefficient (Nunnally and Bernstein 1994). Internal reliability is reduced if the items within a scale measure different aspects and do not increase or fall together. Split half reliability allows all items of a scale
to be randomly divided into two halves which are then correlated with each other. If the scale is internally consistent, these two halves should correlate highly with each other.

To ensure a scale can be usefully used within a population, it is important that a cut off threshold is calculated. A number of cut off thresholds were selected for each scale and the thresholds analysed for sensitivity i.e. the number of patients scoring at this threshold or above who are actually true cases; specificity - the number scoring below a threshold who were true non-cases; the positive predictive value - the probability that a score at the threshold or higher would be a true case; and the negative predictive value - the probability that a score below the threshold would not be a case.
4.3.1 RESULTS

One hundred patients who fulfilled the inclusion criteria participated in the study and twenty eight patients who were initially approached by nursing staff declined to participate. A further thirty patients were either unable to complete both questionnaires or the Present State Examination. All patients had metastatic carcinoma and at the time of interview were receiving palliative care only with emphasis on pain relief and symptom control. The age distribution of patients is seen in figure 4.1 together with identified cases of depression and other psychiatric morbidity at each age. Fifty six females and forty four males participated and the mean age of patients was 57.25 years (range 25 - 69 years).

The diagnoses of patients are listed in figure 4.2. Cancer of the lung accounted for 26% of all diagnoses, breast cancer for 14% and 11% of patients had cancer of the colon.

Of the one hundred patients, the majority, (60%) were married, twenty one percent were separated or divorced, eight were widowed, eight had never married and three were cohabiting.
Figure 4.1

Ages of Patients Recruited

- Cases of Depression
- Cases of Psychiatric Morbidity
- Value

Number of patients

Age (years)

25 26 29 33 34 36 39 42 43 44 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 61 62 63 64 65 66 67 68 69
Figure 4.2

Diagnoses and Numbers who fulfilled Criteria for Diagnosis of Depression

Lung  Breast  Colon  Ovary  Prostate  Cervix  Lymphoma  Bladder  Melanoma  Stomach  Sarcoma  Pancreas  Uterus  Myeloma  Testes

Number of patients

Cancer Site
4.3.2 Prevalence of Depression according to ICD 10 Criteria

The prevalence of depression identified by the Present State Examination interview according to International Classification of Diseases (tenth edition) criteria in this study was twenty two per cent - the majority of cases were depressive episode of moderate severity (Table 4.1). A further five per cent of patients were identified as having other psychiatric diagnoses.

There were no cases of adjustment disorder or psychotic disorder identified according to ICD 10 criteria.

The number of patients in each age group can be seen in Table 4.2. The mean age of all patients identified as cases of psychiatric morbidity by PSE interview was 53.9 years (95% C.I. 49.1 - 58.6). This included the two youngest patients in the study aged twenty five and twenty six. The mean age of patients identified as cases of depression were 56.6 years (95% C.I. 52.5 - 60.7).

All patients who were interviewed survived a mean of 32.3 days (95% C.I. 25.8 - 38.8) with a range of two days to one hundred and eighty days and a median survival of twenty three days. The mean survival time for patient who were diagnosed as being depressed was 38 days (95% C.I. 26 - 50 days) and the median survival time was 26 days - this difference was not significant (p = 0.3401). The length of time from interview to death and the number who were identified by PSE as cases of psychiatric morbidity or depression can be seen in figure 4.3. Seven patients in this study survived for more than eighty
days after the interview and of these, two (28%) were identified as cases of depression and one as a case of other psychiatric morbidity.

Six of the fourteen patients with breast cancer (42%) were cases of depression and a further three patients with breast cancer were identified as cases of psychiatric morbidity according to ICD 10 criteria and PSE interview. Patients with breast cancer were statistically more likely to be identified as PSE cases of depression (p = 0.001) than patients with any other diagnosis. Six of the twenty six patients (23%) with lung cancer were cases of depression and 2/11 (18%) of the patients with cancer of the colon were identified as cases of depression. In other diagnostic groups the numbers were smaller, but the prevalence of depression was approximately 20% for each of the diagnostic groups.
<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>ICD 10 Code</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressive episode of moderate severity without somatic symptoms</td>
<td>32.00</td>
<td>13</td>
</tr>
<tr>
<td>Depressive episode of moderate severity with/without somatic symptoms</td>
<td>32.10</td>
<td>7</td>
</tr>
<tr>
<td>Depressive episode with somatic symptoms</td>
<td>32.11</td>
<td>1</td>
</tr>
<tr>
<td>Recurrent depressive disorder currently in remission</td>
<td>33.40</td>
<td>1</td>
</tr>
<tr>
<td>Neurasthenia</td>
<td>48.00</td>
<td>2</td>
</tr>
<tr>
<td>Organic Anxiety Disorder</td>
<td>0.64</td>
<td>1</td>
</tr>
<tr>
<td>Dissociative Amnesia</td>
<td>44.10</td>
<td>1</td>
</tr>
<tr>
<td>Elaboration of physical symptoms with psychological reasoning</td>
<td>68.10</td>
<td>1</td>
</tr>
</tbody>
</table>
**TABLE 4.2 NUMBERS OF PATIENTS IN EACH AGE GROUP**

<table>
<thead>
<tr>
<th></th>
<th>20-30</th>
<th>30-40</th>
<th>40-50</th>
<th>50-60</th>
<th>60-70</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>6</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Other Identified Psychiatry Morbidity</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Non Cases</td>
<td>1</td>
<td>3</td>
<td>9</td>
<td>20</td>
<td>40</td>
<td>73</td>
</tr>
<tr>
<td>All Patients</td>
<td>3</td>
<td>4</td>
<td>15</td>
<td>28</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>
Figure 4.3

Length of time of survival from date of interview

- Cases of Depression
- Cases of Psychiatric Morbidity
- Value
4.3.4 Correlations with past history, Information Needs and Support

Past psychiatric history was recorded in fourteen patients who had previously received medication for a depressive illness. This information was checked with the General Practitioner or was cross checked with the medical case notes (Table 4.3). Past psychiatric history had a non significant correlation coefficient of 0.056 (p = 0.956) with being identified as a case of depression.

The majority of patients (83%) (Table 4.4) felt that they were well supported by family or friends and the presence or absence of perceived support from family and friends did not correlate with psychiatric morbidity - Spearman Correlation coefficient showed a non significant correlation of (0.016) (p=0.869).

Patients were asked if they felt they had enough information regarding their illness - these questions generated much discussion from patients, but Yes / No responses were documented (Table 4.5). The desire for further information was associated with a slightly higher correlation with PSE caseness - the correlation coefficient was 0.118 (p=0.241) which is not significant.

The male female distribution for all the above items were almost identical e.g. 36% of males reported information needs compared to 39% of females.
### TABLE 4.3 PAST HISTORY OF ANTIDEPRESSANT MEDICATION

<table>
<thead>
<tr>
<th></th>
<th>No History</th>
<th>Past History</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not PSE case</td>
<td>63</td>
<td>10</td>
<td>73</td>
</tr>
<tr>
<td>PSE case of depression</td>
<td>19</td>
<td>3</td>
<td>22</td>
</tr>
<tr>
<td>Other Psychiatric morbidity</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

### TABLE 4.4 PERCEIVED INFORMAL SUPPORT

<table>
<thead>
<tr>
<th></th>
<th>Patient Feels Well Supported</th>
<th>Patient Does Not Feel Well Supported</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not PSE case</td>
<td>61</td>
<td>12</td>
<td>73</td>
</tr>
<tr>
<td>PSE case of depression</td>
<td>18</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Other Psychiatric morbidity</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

### TABLE 4.5 INFORMATION NEEDS

<table>
<thead>
<tr>
<th></th>
<th>No Needs</th>
<th>Requests Information</th>
<th>Not Certain</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not PSE case</td>
<td>44</td>
<td>25</td>
<td>4</td>
<td>73</td>
</tr>
<tr>
<td>PSE case of depression</td>
<td>10</td>
<td>10</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Other Psychiatric morbidity</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>

#### 4.3.4 Correlations with past history, Information Needs and Support
4.3.5 The validity of the HAD Scale in Terminally ill Patients

The Hospital Anxiety and Depression Scale was validated at a number of cut-off thresholds to determine the optimum cut-off threshold. The Present State Examination Interview was used as the gold standard. The scores for each subscale were calculated separately and the frequencies of scores for each subscale can be seen in figures 4.4 and 4.5.

The mean score on the depression sub scale was 8.9 (95% C.I. 8.2 - 9.7) (range 0 - 20) and the mean score on the anxiety sub scale was 8.1 (95% C.I. 7.4 - 8.9) (range 0 - 19).

The mean total score for the HAD scale was 16.7 (95% C.I. 15.2 - 18.1) (range 1 - 39). The distribution of total HAD scale scores is seen in figure 4.6. Using previous determined cut-off thresholds of 8 for inclusion of all possible cases on either sub scale of the HAD scale, 53% scored 8 or above on the anxiety sub scale and 63% scored at or above this threshold on the depression sub scale. When a cut-off threshold of eleven which indicates a high probability of having a mood disorder is used, 26% scored at 11 or above on the anxiety sub scale and 32% on the depression sub scale.
Figure 4.4

Distribution of HAD Anxiety Sub Scale Scores

- Cases of Depression
- Cases of Psychiatric Morbidity
- Value

Score

Frequency
Figure 4.5

Distribution of HAD Depression Sub Scale Scores

- Cases of Depression
- Cases of Psychiatric Morbidity
- Value

Number of patients

Score
Figure 4.6

Distribution of Total HAD Scale Scores

- Cases of Depression
- Cases of Psychiatric Morbidity
- Value

Frequency

Score

1 2 3 4 6 7 8 10 11 12 13 14 15 16 17 18 19 20 21 22 23 25 26 28 31 32 33 39
4.3.6 The Depression Sub scale

At all thresholds the sensitivity of the depression sub scale was increased when identifying cases of depression when compared to identifying all cases of psychiatric morbidity (Table 4.6.a). Using a cut off threshold of 11 for cases of depression identified according to ICD 10 criteria, the sensitivity of the HAD scale was 54% and specificity 74% (Table 4.6.b) The specificity, positive and negative predictive values of the depression sub scale were similar for both all cases of psychiatric morbidity and cases of depression. At higher cut off thresholds, the positive predictive value of the Depression sub scale increases, but the sensitivity remains low.
**TABLE 4.6** SCREENING PERFORMANCE OF HADS DEPRESSION SUBSCALE AT DIFFERENT THRESHOLDS

### a. All Identified Cases of Psychiatric Morbidity According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>81</td>
<td>70</td>
<td>62</td>
<td>44</td>
<td>33</td>
<td>33</td>
<td>29</td>
<td>33</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>43</td>
<td>52</td>
<td>64</td>
<td>73</td>
<td>89</td>
<td>89</td>
<td>93</td>
<td>98</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>35</td>
<td>35</td>
<td>39</td>
<td>54</td>
<td>45</td>
<td>53</td>
<td>53</td>
<td>88</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>86</td>
<td>83</td>
<td>82</td>
<td>77</td>
<td>91</td>
<td>78</td>
<td>78</td>
<td>79</td>
</tr>
</tbody>
</table>

### b. Cases of Depression Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>81</td>
<td>73</td>
<td>68</td>
<td>54</td>
<td>45</td>
<td>41</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>42</td>
<td>51</td>
<td>64</td>
<td>74</td>
<td>85</td>
<td>89</td>
<td>93</td>
<td>98</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>28</td>
<td>29</td>
<td>35</td>
<td>37</td>
<td>45</td>
<td>52</td>
<td>61</td>
<td>88</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>89</td>
<td>87</td>
<td>88</td>
<td>85</td>
<td>84</td>
<td>84</td>
<td>83</td>
<td>84</td>
</tr>
</tbody>
</table>
4.3.7 The Anxiety Sub scale

The Anxiety sub scale performed better across all thresholds for identifying cases of depression than for all cases of psychiatric morbidity (Table 4.7a).

The optimum cut off threshold for identifying cases of depression on the anxiety sub scale is ten with a sensitivity of 59% and specificity of 68% (Table 4.7b). Similarly to the depression sub scale, the specificity, positive predictive value and negative predictive values were almost identical for the identification of cases of depression and all cases of psychiatric morbidity.

The positive predictive value of the anxiety sub scale increases to 75% at a cut off threshold of 13, but falls thereafter.
TABLE 4.7 SCREENING PERFORMANCE OF HAD ANXIETY SUBSCALE

a. All Identified Cases of Psychiatric Morbidity According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>70</td>
<td>66</td>
<td>52</td>
<td>48</td>
<td>33</td>
<td>33</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>53</td>
<td>57</td>
<td>67</td>
<td>82</td>
<td>92</td>
<td>95</td>
<td>97</td>
<td>97</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>36</td>
<td>36</td>
<td>36</td>
<td>46</td>
<td>60</td>
<td>75</td>
<td>66</td>
<td>60</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>83</td>
<td>82</td>
<td>79</td>
<td>81</td>
<td>78</td>
<td>79</td>
<td>75</td>
<td>74</td>
</tr>
</tbody>
</table>

b. Cases of Depression Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>77</td>
<td>77</td>
<td>59</td>
<td>54</td>
<td>41</td>
<td>41</td>
<td>18</td>
<td>13</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>53</td>
<td>59</td>
<td>68</td>
<td>82</td>
<td>92</td>
<td>96</td>
<td>97</td>
<td>97</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>46</td>
<td>41</td>
<td>34</td>
<td>46</td>
<td>60</td>
<td>75</td>
<td>66</td>
<td>60</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>89</td>
<td>90</td>
<td>85</td>
<td>86</td>
<td>84</td>
<td>85</td>
<td>87</td>
<td>83</td>
</tr>
</tbody>
</table>
4.3.8 Combined Scores of the HAD Scale

The scores of the HAD sub scales were combined to determine if this improved sensitivity and specificity. The optimum cut off threshold was 19, the combined HAD scale had a sensitivity of 68% for identifying cases of depression, a specificity of 67% and a positive predictive value of 36% (Table 4.8 b). The positive predictive value of the combined scale remained low at all cut off thresholds. It can be seen again that the HAD scale had higher sensitivities for identifying PSE cases of depression than for identifying all PSE cases of psychiatric morbidity (Table 4.8.a).

There were no differences in survival of those patients who scored highly on the HAD scale to all other patients. The mean survival of patients scoring above 19 on the HAD scale was 30 days compared to a mean survival of all patients of 32 days. The Spearman's correlation for agreement were calculated and show a high agreement with anxiety and depression scores and the total score but a smaller agreement of anxiety and depression scores with each other (Table 4.9).
TABLE 4.8 SCREENING PERFORMANCE OF COMBINED SCORES OF HAD SCALE

a. Cases of Psychiatric Morbidity Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19</th>
<th>20</th>
<th>21</th>
<th>22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>81</td>
<td>74</td>
<td>70</td>
<td>66</td>
<td>63</td>
<td>59</td>
<td>48</td>
<td>44</td>
<td>37</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>39</td>
<td>50</td>
<td>51</td>
<td>56</td>
<td>63</td>
<td>65</td>
<td>70</td>
<td>73</td>
<td>82</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>33</td>
<td>33</td>
<td>34</td>
<td>36</td>
<td>38</td>
<td>39</td>
<td>37</td>
<td>37</td>
<td>43</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>85</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>81</td>
<td>78</td>
<td>77</td>
<td>78</td>
</tr>
</tbody>
</table>

b. Cases of Depression Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19</th>
<th>20</th>
<th>21</th>
<th>22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>77</td>
<td>77</td>
<td>72</td>
<td>72</td>
<td>68</td>
<td>68</td>
<td>54</td>
<td>54</td>
<td>45</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>37</td>
<td>44</td>
<td>50</td>
<td>56</td>
<td>63</td>
<td>67</td>
<td>70</td>
<td>74</td>
<td>83</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>25</td>
<td>28</td>
<td>29</td>
<td>32</td>
<td>34</td>
<td>36</td>
<td>34</td>
<td>37</td>
<td>43</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>85</td>
<td>87</td>
<td>86</td>
<td>86</td>
<td>87</td>
<td>88</td>
<td>84</td>
<td>85</td>
<td>84</td>
</tr>
</tbody>
</table>
TABLE 4.9  SPEARMAN'S CORRELATION COEFFICIENT OF SCORES
WITH ICD 10 CASES

<table>
<thead>
<tr>
<th></th>
<th>HAD anx</th>
<th>HAD dep</th>
<th>Total HAD</th>
<th>All Cases</th>
<th>Cases of Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAD anx</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HAD dep</td>
<td>0.6867</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total HAD</td>
<td>0.8094</td>
<td>0.7960</td>
<td>1.0000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Cases</td>
<td>0.2661</td>
<td>0.2816</td>
<td>0.2536</td>
<td>1.0000</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.3062</td>
<td>0.3005</td>
<td>0.7960</td>
<td>0.8733</td>
<td>1.000</td>
</tr>
</tbody>
</table>
4.3.9 Individual Item Analysis of the HAD Scale

The sensitivity, specificity, positive predictive value and negative predictive value for each individual item of the HAD scale were calculated for all PSE cases (Table 4.10) and for cases of depression (Table 4.11). All items are scored on a zero to three scale. Scores of zero or one were considered to be negative scores and scores of two or three were considered to be positive scores. The two sub scales of the HAD are not listed separately in the scale - the odd numbered items are the anxiety items and the even numbered items are the depression items. Two items of the anxiety sub scale (items seven and nine) had very low sensitivities of less than 20%. Item eight states "I feel as if I am slowed down". The sensitivity was 95% for identified cases of depression and 92% for all PSE cases. However seventy four per cent of patients scored three on this question thus the specificity was 12%. Item ten which states "I have lost interest in my appearance" had a low sensitivity for identified cases of depression of 9% for all PSE cases of 14%. Item fourteen "I can enjoy a book or television programme" also has a low sensitivity of 22%.

Therefore on the depression sub scale, two items had low sensitivities i.e. items ten and fourteen. Only one item, item twelve, had a PPV of more than 50%. Item eight although having a high sensitivity of 92%, has a low specificity of 12% and low positive predictive value of 28%.

The sensitivity and specificity of the HAD scale was higher for all items in identifying cases of depression than for identifying all cases of psychiatric morbidity.
TABLE 4.10 SENSITIVITY, SPECIFICITY, PPV AND NPV FOR INDIVIDUAL ITEMS OF HAD SCALE

All Cases of Psychiatric Morbidity Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Item</th>
<th>Sensitivity (%)</th>
<th>Specificity (%)</th>
<th>PPV (%)</th>
<th>NPV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>48</td>
<td>74</td>
<td>41</td>
<td>79</td>
</tr>
<tr>
<td>2</td>
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<tr>
<td>6</td>
<td>48</td>
<td>84</td>
<td>52</td>
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<td>7</td>
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<td>92</td>
<td>45</td>
<td>75</td>
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<tr>
<td>8</td>
<td>92</td>
<td>12</td>
<td>28</td>
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<td>9</td>
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<td>92</td>
<td>28</td>
<td>87</td>
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<tr>
<td>10</td>
<td>14</td>
<td>87</td>
<td>33</td>
<td>77</td>
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<tr>
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<td>78</td>
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<td>12</td>
<td>52</td>
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<td>83</td>
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<td>13</td>
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<tr>
<td>14</td>
<td>22</td>
<td>87</td>
<td>40</td>
<td>73</td>
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</tbody>
</table>
TABLE 4.11 SENSITIVITY AND SPECIFICITY, PPV AND NPV FOR INDIVIDUAL HAD ITEMS

Cases of Depression Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Item</th>
<th>Sensitivity (%)</th>
<th>Specificity (%)</th>
<th>PPV (%)</th>
<th>NPV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>54</td>
<td>74</td>
<td>38</td>
<td>85</td>
</tr>
<tr>
<td>2</td>
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<tr>
<td>6</td>
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<tr>
<td>7</td>
<td>18</td>
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<td>8</td>
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<td>9</td>
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<td>13</td>
<td>50</td>
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<td>39</td>
<td>84</td>
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<tr>
<td>14</td>
<td>22</td>
<td>87</td>
<td>33</td>
<td>80</td>
</tr>
</tbody>
</table>
4.3.10 Internal reliability of the HAD Scale

The internal reliability of the HAD scale was analysed using Cronbach's alpha coefficient. The alpha coefficient for the total scale was 0.8520. When considering each sub scale separately, the alpha coefficient for the depression sub scale was 0.7516 and for the anxiety sub scale 0.8046. The split half reliability was 0.7751 for part one and 0.7072 for part two.

The means for each item show that certain items were scored highly by almost all who took part in this study namely items two (mean 1.8182) and eight (mean 2.6162) (Table 4.12).

Table 4.13 shows the distribution of scores for item eight.
<table>
<thead>
<tr>
<th>Item</th>
<th>Mean Score</th>
<th>Mean if deleted</th>
<th>Alpha if deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>1.2626</td>
<td>15.3535</td>
<td>0.8450</td>
</tr>
<tr>
<td>Two</td>
<td>1.8182</td>
<td>14.7980</td>
<td>0.8433</td>
</tr>
<tr>
<td>Three</td>
<td>1.1515</td>
<td>15.4646</td>
<td>0.8412</td>
</tr>
<tr>
<td>Four</td>
<td>0.8485</td>
<td>15.7677</td>
<td>0.8337</td>
</tr>
<tr>
<td>Five</td>
<td>1.3535</td>
<td>15.2626</td>
<td>0.8338</td>
</tr>
<tr>
<td>Six</td>
<td>1.0606</td>
<td>15.5556</td>
<td>0.8326</td>
</tr>
<tr>
<td>Seven</td>
<td>0.9192</td>
<td>15.6970</td>
<td>0.8452</td>
</tr>
<tr>
<td>Eight</td>
<td>2.6162</td>
<td>14.0000</td>
<td>0.8537</td>
</tr>
<tr>
<td>Nine</td>
<td>0.8182</td>
<td>15.7980</td>
<td>0.8468</td>
</tr>
<tr>
<td>Ten</td>
<td>0.7778</td>
<td>15.8384</td>
<td>0.8519</td>
</tr>
<tr>
<td>Eleven</td>
<td>1.2323</td>
<td>15.3838</td>
<td>0.8429</td>
</tr>
<tr>
<td>Twelve</td>
<td>0.9596</td>
<td>15.6566</td>
<td>0.8360</td>
</tr>
<tr>
<td>Thirteen</td>
<td>1.0101</td>
<td>15.6061</td>
<td>0.8294</td>
</tr>
<tr>
<td>Fourteen</td>
<td>0.7879</td>
<td>15.8283</td>
<td>0.8433</td>
</tr>
</tbody>
</table>
### TABLE 4.13 DISTRIBUTION OF SCORES FOR ITEM 8 OF HOSPITAL ANXIETY & DEPRESSION SCALE

<table>
<thead>
<tr>
<th>Score</th>
<th>Number</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>3</td>
<td>74</td>
<td>74</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>
4.3.11 Factor analysis of the HAD Scale

Factor analysis of the HAD scale was carried out using the Statistical Package for Social Sciences programme (S.P.S.S.). This was to determine if the HAD scale did function as two scales in the terminally ill each measuring a distinct mood state i.e. anxiety and depression. Two methods of rotation of factors are possible. The orthogonal rotation assumes that the underlying factors are not correlated whereas the oblique rotation allows for the possibility that factors may be related. The oblique rotation was therefore carried out and analysis of the HAD showed four factors which accounted for 62.5% of the variance. The loading of items to each of these four factors is seen in Table 4.14. All the depression items loaded most positively onto factor two apart from item eight which loaded onto factor four. In addition to loading onto factor two, item two also loaded onto factor four. Five of the seven anxiety items loaded onto factor one and items three and nine loaded onto factor three.
TABLE 4.14  FACTOR ANALYSIS OF THE HAD SCALE - FACTOR LOADING (OBLIQUE ROTATION)

a. Anxiety Items

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>0.76</td>
<td>0.10</td>
<td>0.12</td>
<td>0.07</td>
</tr>
<tr>
<td>Three</td>
<td>0.61</td>
<td>0.14</td>
<td>0.70</td>
<td>0.08</td>
</tr>
<tr>
<td>Five</td>
<td>0.71</td>
<td>0.36</td>
<td>0.33</td>
<td>0.25</td>
</tr>
<tr>
<td>Seven</td>
<td>0.64</td>
<td>0.41</td>
<td>-0.14</td>
<td>-0.19</td>
</tr>
<tr>
<td>Nine</td>
<td>0.22</td>
<td>0.27</td>
<td>0.86</td>
<td>0.12</td>
</tr>
<tr>
<td>Eleven</td>
<td>0.63</td>
<td>0.25</td>
<td>0.25</td>
<td>0.10</td>
</tr>
<tr>
<td>Thirteen</td>
<td>0.70</td>
<td>0.46</td>
<td>0.43</td>
<td>0.20</td>
</tr>
</tbody>
</table>

b. Depression Items

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two</td>
<td>0.07</td>
<td>0.60</td>
<td>0.16</td>
<td>0.40</td>
</tr>
<tr>
<td>Four</td>
<td>0.55</td>
<td>0.71</td>
<td>0.11</td>
<td>-0.13</td>
</tr>
<tr>
<td>Six</td>
<td>0.57</td>
<td>0.64</td>
<td>0.17</td>
<td>0.11</td>
</tr>
<tr>
<td>Eight</td>
<td>0.22</td>
<td>0.18</td>
<td>0.21</td>
<td>0.83</td>
</tr>
<tr>
<td>Ten</td>
<td>0.07</td>
<td>0.55</td>
<td>0.42</td>
<td>-0.44</td>
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<tr>
<td>Twelve</td>
<td>0.42</td>
<td>0.71</td>
<td>0.21</td>
<td>0.09</td>
</tr>
<tr>
<td>Fourteen</td>
<td>0.21</td>
<td>0.75</td>
<td>0.19</td>
<td>-0.03</td>
</tr>
</tbody>
</table>
4.3.12 The Validity of the Edinburgh Postnatal Scale

One hundred patients completed the Edinburgh postnatal scale. The mean score for the complete ten item Edinburgh scale was 10.9 (95% C.I. 10.01 - 11.96), (range 2 - 25). At a cut off of thirteen, 27% scored above this threshold. The distribution of scores are illustrated in figure 4.7.

In its original ten item form (Table 4.15 b), at a threshold of thirteen, the sensitivity of the EPDS is 81% and the specificity is 79% for identifying PSE cases of depression and a sensitivity of 78% and specificity of 82% for identifying all PSE cases of psychiatric morbidity (Table 4.15 a). When a lower threshold of nine or ten are considered for identifying PSE cases of depression, the sensitivity is 100%, but at the expense of a low specificity. At high cut off thresholds, the Edinburgh scale has high positive predictive values and negative predictive values.

Analysis of the EPDS removing the three items in common with the Hospital Anxiety and Depression Scale was also undertaken. The mean scores were 8.1 (95% C.I. 7.4 - 8.8) (range 1 - 18). The distribution of scores of the abbreviated EPDS are illustrated in figure 4.8. At a cut off of ten, 23% of patients had a score above this threshold.

The abbreviated seven item scale has a sensitivity of 82% and specificity of 81% at a cut off of ten for identifying PSE cases of depression (Table 4.16 b) and a sensitivity of 77% and specificity of 83% for identifying all PSE cases of psychiatric morbidity (Table 4.16 a). Both the ten and seven item
Edinburgh scales had very similar specificity, positive and negative predictive values for cases of depression and all cases of psychiatric morbidity.

Scoring high on the Edinburgh Postnatal Depression Scale did not influence survival - patients scoring above thirteen on the ten item scale survived a mean of 36 days compared to a mean survival of 32 days for all patients in the study.
Figure 4.7

Distribution of Edinburgh Postnatal Scores Ten Item Scale

- Cases of Depression
- Cases of Psychiatric Morbidity
- Value
Distribution of Edinburgh Postnatal Scores Seven Item Scale

- Cases of Depression
- Cases of Psychiatric Morbidity
- Value

Number of patients

Score

142
### Table 4.15 Table of Edinburgh Scores at Thresholds (Complete Edinburgh Scale)

**a. All Cases of Psychiatric Morbidity Identified According to ICD 10 Criteria**

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>96</td>
<td>92</td>
<td>92</td>
<td>88</td>
<td>71</td>
<td>78</td>
<td>66</td>
<td>48</td>
<td>44</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>31</td>
<td>37</td>
<td>52</td>
<td>63</td>
<td>68</td>
<td>82</td>
<td>88</td>
<td>92</td>
<td>96</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>34</td>
<td>35</td>
<td>42</td>
<td>47</td>
<td>49</td>
<td>62</td>
<td>67</td>
<td>68</td>
<td>80</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>96</td>
<td>93</td>
<td>95</td>
<td>94</td>
<td>91</td>
<td>88</td>
<td>83</td>
<td>82</td>
<td></td>
</tr>
</tbody>
</table>

**b. Cases of Depression Identified According to ICD 10 Criteria**

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
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<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>95</td>
<td>86</td>
<td>81</td>
<td>68</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>31</td>
<td>37</td>
<td>52</td>
<td>61</td>
<td>66</td>
<td>79</td>
<td>85</td>
<td>89</td>
<td>94</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>29</td>
<td>31</td>
<td>36</td>
<td>42</td>
<td>42</td>
<td>53</td>
<td>55</td>
<td>58</td>
<td>73</td>
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<tr>
<td>NPV (%)</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>97</td>
<td>94</td>
<td>91</td>
<td>86</td>
<td>86</td>
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</tr>
</tbody>
</table>
TABLE 4.16 SCREENING PERFORMANCE OF SEVEN ITEM EDINBURGH SCALE AT DIFFERENT THRESHOLDS

a. All Cases of Psychiatric Morbidity Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>92</td>
<td>85</td>
<td>77</td>
<td>66</td>
<td>48</td>
<td>29</td>
<td>22</td>
<td>14</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>56</td>
<td>72</td>
<td>83</td>
<td>93</td>
<td>98</td>
<td>98</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>43</td>
<td>53</td>
<td>64</td>
<td>78</td>
<td>92</td>
<td>88</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>95</td>
<td>93</td>
<td>91</td>
<td>88</td>
<td>83</td>
<td>79</td>
<td>77</td>
<td>77</td>
</tr>
</tbody>
</table>

b. All Cases of Depression Identified According to ICD 10 Criteria

<table>
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<tr>
<th>Threshold Scores</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity (%)</td>
<td>100</td>
<td>90</td>
<td>82</td>
<td>68</td>
<td>54</td>
<td>36</td>
<td>27</td>
<td>18</td>
</tr>
<tr>
<td>Specificity (%)</td>
<td>55</td>
<td>70</td>
<td>81</td>
<td>89</td>
<td>97</td>
<td>98</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>PPV (%)</td>
<td>38</td>
<td>46</td>
<td>54</td>
<td>65</td>
<td>85</td>
<td>88</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>NPV (%)</td>
<td>100</td>
<td>96</td>
<td>94</td>
<td>90</td>
<td>88</td>
<td>84</td>
<td>83</td>
<td>81</td>
</tr>
</tbody>
</table>
4.3.14 Individual Item Analysis of the Edinburgh Scale

The individual item analysis of the EPDS included sensitivity, specificity, positive and negative predictive values for each item (Tables 4.17 and 4.18). Items two, three and five had sensitivities of over 70% and items six and seven had PPVs of 50% or greater for identified PSE cases of depression. Of note is the identical sensitivity, specificity, positive and negative predictive values of the last three items of the Edinburgh scale - identified as HADS items reflecting their almost identical scores rated by patients on both rating scales.
### TABLE 4.17 SENSITIVITY, SPECIFICITY PPV AND NPV FOR INDIVIDUAL ITEMS OF EDINBURGH SCALE

All Cases of Psychiatric Morbidity Identified

<table>
<thead>
<tr>
<th>Item</th>
<th>Sensitivity (%)</th>
<th>Specificity (%)</th>
<th>PPV (%)</th>
<th>NPV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>48</td>
<td>67</td>
<td>35</td>
<td>77</td>
</tr>
<tr>
<td>2</td>
<td>63</td>
<td>55</td>
<td>34</td>
<td>80</td>
</tr>
<tr>
<td>3</td>
<td>77</td>
<td>58</td>
<td>42</td>
<td>88</td>
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<tr>
<td>4</td>
<td>63</td>
<td>79</td>
<td>53</td>
<td>85</td>
</tr>
<tr>
<td>5</td>
<td>70</td>
<td>71</td>
<td>47</td>
<td>86</td>
</tr>
<tr>
<td>6</td>
<td>51</td>
<td>86</td>
<td>58</td>
<td>83</td>
</tr>
<tr>
<td>7</td>
<td>26</td>
<td>92</td>
<td>54</td>
<td>77</td>
</tr>
<tr>
<td>HAD 4</td>
<td>33</td>
<td>79</td>
<td>37</td>
<td>76</td>
</tr>
<tr>
<td>HAD 12</td>
<td>52</td>
<td>85</td>
<td>56</td>
<td>83</td>
</tr>
<tr>
<td>HAD 13</td>
<td>41</td>
<td>76</td>
<td>39</td>
<td>77</td>
</tr>
</tbody>
</table>
### TABLE 4.18 SENSITIVITY, SPECIFICITY PPV AND NPV FOR INDIVIDUAL ITEMS OF EDINBURGH SCALE

Cases of Depression Identified According to ICD 10 Criteria

<table>
<thead>
<tr>
<th>Item</th>
<th>Sensitivity (%)</th>
<th>Specificity (%)</th>
<th>PPV (%)</th>
<th>NPV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>54</td>
<td>67</td>
<td>32</td>
<td>84</td>
</tr>
<tr>
<td>2</td>
<td>77</td>
<td>57</td>
<td>34</td>
<td>90</td>
</tr>
<tr>
<td>3</td>
<td>81</td>
<td>57</td>
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<td>91</td>
</tr>
<tr>
<td>4</td>
<td>63</td>
<td>85</td>
<td>44</td>
<td>88</td>
</tr>
<tr>
<td>5</td>
<td>73</td>
<td>69</td>
<td>40</td>
<td>90</td>
</tr>
<tr>
<td>6</td>
<td>54</td>
<td>84</td>
<td>50</td>
<td>86</td>
</tr>
<tr>
<td>7</td>
<td>31</td>
<td>92</td>
<td>53</td>
<td>83</td>
</tr>
<tr>
<td>HAD 4</td>
<td>36</td>
<td>79</td>
<td>33</td>
<td>81</td>
</tr>
<tr>
<td>HAD 12</td>
<td>59</td>
<td>84</td>
<td>52</td>
<td>88</td>
</tr>
<tr>
<td>HAD 13</td>
<td>50</td>
<td>78</td>
<td>39</td>
<td>84</td>
</tr>
</tbody>
</table>
4.3.14 Internal Reliability of the Edinburgh Postnatal Scale

This was calculated using Cronbach's alpha coefficient. The ten item scale has an alpha coefficient of 0.7805. Split half reliability of the ten item scale was 0.6092 for part one and 0.7325 for part two.

The seven item abbreviated scale had an alpha coefficient of 0.6920 and a standardised item alpha of 0.6961. The split half reliability was 0.5045 for part one and 0.6088 for part two, but due to the odd number of items, split halves were of unequal length.

The item with the highest mean score is item three and item seven has the lowest mean score. (Table 4.19)
### Table 4.19 Internal Reliability of the Ten Item Edinburgh Postnatal Scale

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean Score</th>
<th>Mean if deleted</th>
<th>Alpha if deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>1.2600</td>
<td>9.7600</td>
<td>0.7842</td>
</tr>
<tr>
<td>Two</td>
<td>1.4200</td>
<td>9.6000</td>
<td>0.7749</td>
</tr>
<tr>
<td>Three</td>
<td>1.5000</td>
<td>9.5200</td>
<td>0.7574</td>
</tr>
<tr>
<td>Four</td>
<td>1.0800</td>
<td>9.9400</td>
<td>0.7706</td>
</tr>
<tr>
<td>Five</td>
<td>1.3300</td>
<td>9.6900</td>
<td>0.7499</td>
</tr>
<tr>
<td>Six</td>
<td>1.0900</td>
<td>9.9300</td>
<td>0.7536</td>
</tr>
<tr>
<td>Seven</td>
<td>0.5000</td>
<td>10.5200</td>
<td>0.7668</td>
</tr>
<tr>
<td>HAD 4</td>
<td>0.8500</td>
<td>10.1700</td>
<td>0.7570</td>
</tr>
<tr>
<td>HAD 12</td>
<td>0.9600</td>
<td>10.0600</td>
<td>0.7450</td>
</tr>
<tr>
<td>HAD 13</td>
<td>1.0300</td>
<td>9.9900</td>
<td>0.7560</td>
</tr>
</tbody>
</table>
4.3.17 Factor analysis of the Edinburgh Postnatal scale

The factor analysis was performed using an oblique rotation and revealed three factors which accounted for 56.9% of the variance of the scale. Four items (items three, five, six and seven) load onto factor one and three items (items one, two and four) onto factor two (Table 4.20). The three items of the Edinburgh scale which are common to the HAD scale namely the items "I can laugh and see the funny side.\textquotedbl", "I get a sort of frightened feeling..." and "I can enjoy a good book.\textquotedbl" load negatively onto a third factor suggesting that these items may measure a separate construct of depression.
## TABLE 4.20 FACTOR STRUCTURE OF THE EDINBURGH SCALE
(OBLIQUE ROTATION)

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>0.10</td>
<td>0.68</td>
<td>0.20</td>
</tr>
<tr>
<td>Two</td>
<td>-0.12</td>
<td>0.71</td>
<td>-0.15</td>
</tr>
<tr>
<td>Three</td>
<td>0.85</td>
<td>-0.64</td>
<td>0.02</td>
</tr>
<tr>
<td>Four</td>
<td>0.04</td>
<td>0.65</td>
<td>-0.09</td>
</tr>
<tr>
<td>Five</td>
<td>0.66</td>
<td>0.24</td>
<td>0.01</td>
</tr>
<tr>
<td>Six</td>
<td>0.51</td>
<td>0.01</td>
<td>-0.31</td>
</tr>
<tr>
<td>Seven</td>
<td>0.70</td>
<td>-0.06</td>
<td>-0.01</td>
</tr>
<tr>
<td>HAD 4</td>
<td>-0.00</td>
<td>-0.04</td>
<td>-0.88</td>
</tr>
<tr>
<td>HAD 12</td>
<td>0.10</td>
<td>0.31</td>
<td>-0.54</td>
</tr>
<tr>
<td>HAD 13</td>
<td>0.07</td>
<td>-0.02</td>
<td>-0.77</td>
</tr>
</tbody>
</table>
4.3.18 Thoughts of self harm as predictors of depression

The statement on the EPDS scale - "The thought of harming myself has occurred to me " was analysed further to establish if this item independently predicted a patient as being depressed. The number of participants scoring on this item is shown in Table 4.21. The majority of patients (65%) scored negatively on this item, but a total of 35% had at some time during the last seven days had thoughts of self harm. Eight females and five males reported thoughts of self harm sometimes or quite often. The mean age was 59.46 years and 46% of those expressing thoughts of self harm were married. Of those who scored two or three on this item, their mean scores HAD scale scores of 23.4 and mean ten item Edinburgh score of 14.2 were higher than for all other patients. Thoughts of self harm did not influence survival - the mean survival time was 43.3 days and the median survival was 27 days for patients scoring two or three on this item.

Of those responding "hardly ever" to the statement, 23% were cases of depression, of those responding "sometimes", 54% were cases and of the two who responded often, one patient was a case of depression according to ICD 10 criteria. Item seven had a high positive predictive value of 53%. The specificity of this item was 92% i.e. those who responded negatively to this item had a 92% chance of not being cases of depression according to ICD 10 criteria.
The correlations of item seven with item eight of the HAD scale, factors such as perceived social support, past history of antidepressant medication and information needs and with being a case of psychiatric morbidity or of depression can be seen in Table 4.22.

Item seven correlated least well with item eight of the HAD scale - "I feel slowed down".

 Thoughts of self harm showed a significant association with past psychiatric history (p = 0.006) and perceived social support (p = 0.007). Thoughts of self harm were significantly associated with being a case of psychiatric morbidity identified according to ICD 10 criteria and PSE interview (p = 0.005), but were not significantly associated with being identified as a case of depression.
<table>
<thead>
<tr>
<th>Score</th>
<th>Number</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>65</td>
<td>65</td>
</tr>
<tr>
<td>1</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>2</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>HAD 8</td>
<td>History</td>
</tr>
<tr>
<td>----------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>Item 7</td>
<td>0.0694</td>
<td>0.2707</td>
</tr>
<tr>
<td>p=0.493</td>
<td>p=0.006</td>
<td>p=0.007</td>
</tr>
</tbody>
</table>

TABLE 4.22  SPEARMAN'S CORRELATION COEFFICIENT FOR THOUGHTS OF SELF-HARM
4.4 DISCUSSION

The aims of this study were to validate the use of rating scales to identify depression and to estimate the prevalence of depression in a population of terminally ill patients. Using the International Classification of Diseases criteria from the Present State Examination interview, this study of one hundred terminally ill patients found a prevalence of 22% for depression. The majority of cases identified were depression of moderate severity with one case of recurrent depressive disorder currently in remission being identified. A further five per cent of patients were identified as other psychiatric morbidity. Patients who were cases of depression had a mean age of 56.6 years compared to the mean age of all patients recruited of 57.2 years. Correlations with past psychiatric history, perceived support were not associated with caseness of depression, but perceived information needs were weakly associated. Patients with breast cancer were statistically more likely to be identified as cases of depression than patients in any other disease group.

There were five cases of other psychiatric morbidity identified. Three patients with breast cancer were identified as cases of other psychiatric morbidity - one with organic anxiety disorder, one with dissociative amnesia and another with elaboration of physical symptoms with psychological reasoning. The two patients identified as cases of neurasthenia were both young males aged twenty five and twenty six respectively and had diagnoses of cancer of the testes and osteosarcoma. These two patients accounted for the lower mean age of identified cases of psychiatric morbidity than for identified cases of depression. All five patients were referred for psychiatric assessment.
4.4.1 Methodological Considerations - Sample population

Whilst patients were randomly recruited into this study and both the inclusion and exclusion criteria were closely adhered to, it is difficult to be certain of how representative this sample were of all terminally ill patients. The study was carried out on a part time basis over two and a half years and therefore it was not possible to have a consecutive patient sample. However, by diagnosis the sample size is representative of those patients receiving palliative care in Leicestershire.

The sample size of one hundred patients is larger than many samples of terminally ill patients used for research studies and allowed statistical analysis to be carried out, but a larger sample size would have allowed for statistical analysis of disease specific psychiatric morbidity. Recruiting patients who are terminally ill is difficult as many patients are too frail to undergo any form of extensive interviewing.

A prognosis of six months or less was required for participation in the study, but the majority of patients survived for a much shorter period with a median survival of all patients of 23 days. The consultants in charge of the patient's care were alerted to all patients in this study who were found to have psychiatric morbidity. These patients were offered further specific interventions e.g. commencement of antidepressant medication or referral to Psychologist or Psychiatrist as appropriate. As the case studies in appendix G record, this resulted in beneficial effects for those treated.
The main aim of the study was to determine the efficacy of screening tools in this population. Although some of the patients subjectively reported that they found the participation in the study to be therapeutic, it was made clear to all patients that the interview was for the purpose of research only. Factors such as perceived social support and information needs were not obtained by any specific measures but by semi structured interview all carried out by the author. It was felt that this method was more informal and possibly less intrusive for patients. Additionally, the semi structured format of questioning was carried out after the administration of both questionnaires and the Present State Examination by which time the patients had built up a rapport with the author and were able to answer questions readily and freely.
4.4.1 Methodological considerations - the Present State Examination

The Present State Examination (PSE) was devised for research purposes and as a measure and classification of psychiatric symptoms (Wing et al 1974) (Wing 1976). It was selected as the gold standard for this study as it is a well established and recognised psychiatric interview which has been validated as giving accurate diagnoses according to DSM 111R and ICD-10 criteria (Silverstone 1993). The PSE has also been previously used to validate the HAD scale in other populations (Spinhoven et al 1997).

The complete PSE examination consists of twenty six sections each with a screening component which guides the interviewer whether to proceed further with the particular section. The patients in this study were able to understand the nature of the Present State Examination and answer questions satisfactorily to enable the interviewer to rate the interview. Several patients, however were too tired to continue with the interview at one sitting and therefore the interview was terminated until the patient felt able to continue. As none of the patients displayed any psychotic symptoms, it was possible to use the screening questions only for many of the later sections.

Conducting an interview such as this with terminally ill patients was very time consuming for both patient and interviewer. The availability of the interviewer at evenings and weekends enabled as much time to be spent as required, but conducting such interviews as part of an out patient clinic for example, when patients are already tired would have been technically very difficult. None of the patients refused to continue with the interview and many stated they had enjoyed the interview process.
4.4.2 Prevalence of Depression

The findings of a prevalence of depression as defined by the Present State Examination at 22% in this study is similar to that of Barraclough (1994) who found that 25% of patients admitted to a hospice had symptoms of depression. Patients who were currently receiving antidepressant medication were not recruited into this study as it was believed that the medication may obscure symptoms of depression. Routine data on the number of these patients at any time was not collected, however from the study in chapter three looking at antidepressant prescribing and from other studies, it can be assumed that the numbers of these patients were small and that this figure for the estimated prevalence of psychiatric morbidity and depression is reasonably accurate.

A previous study of terminally ill patients found higher levels of psychiatric morbidity than found in this study - (Galusko 1996) with 37% of patients undergoing palliative care at home having a psychiatric disorder. When terminally ill patients were referred to a psychiatrist Hinton (1972) and Ramsay (1992) depression was the commonest diagnosis accounting for 42% to 54% of cases, but these were a selected sample of patients referred for psychiatric opinion. The timing of the assessment of depression has previously been reported to be a factor in the prevalence (Silverstone 1990) and may explain why previous studies have produced such differing estimates for the prevalence of depression as they were conducted at different times during the patients illness.
The vast majority of patients in this study were in the last few weeks of life and therefore they may be a more representative sample of true psychiatric morbidity within this population.

The influence of age on psychiatric morbidity has been previously recorded. Hinton in 1963 found that patients under the age of fifty years had greater emotional distress. Harrison and Magurie (1995) found in their study that cases of anxiety and depression were significantly younger than those who did not have any psychiatric morbidity. In our study 33% of patients in the 40-50 year age group fulfilled ICD 10 criteria for caseness of depression and this compared to 20% in the 50-60 and 60-70 age group. As the number of patients in the younger age groups were so small, it is not possible to make any further meaningful statistical analysis.

Several authors have suggested that female cancer patients are more likely to be diagnosed as being depressed, but a review by (DeFlorio and Massie 1995) of 49 research papers did not support this claim. Pendlebury (1996) suggested that research work looking at anxiety and depression in cancer patients has focused on patients with breast cancer and some of the evidence for females being at greater risk may have emerged from this predominantly female based research work. More recently, population based research has found that younger females were likely to have a greater prevalence of depression than older females (Bebbington et al 1998).
In this study the proportion of cases of psychiatric morbidity was found to be equal for both sexes. However, 42% of patients with breast cancer (all females) and patients with breast cancer were significantly more likely to be identified as cases of depression according to PSE interview criteria. A further three patients with breast cancer were identified as cases of psychiatric disorder as defined by the Present State Examination, suggesting that patients with breast cancer do have higher rates of depression and other psychiatric morbidity during the terminal phase of their illness.

Hopwood et al (1991a) reported that patients who died during their study period had higher HAD scores. Psychiatric disorder did not influence the survival of patients in this study nor did high scores on the HAD or EPDS. The length of time between interview and death showed that 45% of those patients who survived between forty and sixty days and 75% of those who survived between sixty and eighty days were cases of depression compared to 16% of those who survived less than forty days. The possible reasons for this include those who were close to death having reached a level of acceptance where emotional and existential distress was at a minimum, whereas patients who were terminally ill but had a longer prognosis were struggling to come to terms with these issues resulting in escalating feelings of hopelessness, despondency and depression. Patients in the longer survival group were at a stage in their illness when treating the depression could have a marked improvement on their quality of life and antidepressant medication and psychological therapies would have time to take effect.
When considering other predisposing factors, Breitbart et al (1995) suggested that absence of social support may be a predictor of psychiatric morbidity in patients with cancer and that self perceived social support may be important in protecting against anxiety and depression in this population. Studies of patients attending psychiatric out patient clinics (Brugha et al 1997) have found that high levels of social support influence recovery from a depressive illness. Perceived social support and previous psychiatric history were not associated with psychiatric morbidity in this study. This finding is similar to that of Hughes and Lee (1988) who reported that factors including social class, psychiatric history, religion, living alone and satisfaction with information were not significantly associated with depression.

Information needs did have a more positive association, but this was not statistically significant. All patients who wanted further information were reported by the medical and nursing staff caring for them to have been given all information as requested. The presence of anxiety or depression could preclude these patients from expressing their information needs or the presence of a psychiatric illness could prevent registration and recall information. Fallowfield (1997) has shown that patients with anxiety and depression do not register all information given to them. Palliative care teams emphasise the provision of information for patients according to their needs, but also need to be aware that if a patients has a psychiatric illness or is emotionally distressed, this information may not be registered.
4.4.3 Implications of HAD Scores at different thresholds

A screening tool needs to have a predetermined cut off threshold to be useful. This threshold should have a high sensitivity i.e. those scoring at this level or above are very likely to be true cases, and a high specificity i.e. those scoring below this level are very unlikely to be cases. The high sensitivity and specificity ensures that as few patients as possible are misclassified.

Anxiety and depression are often both present in the same patients although they are classified as separate disorders (Stavrakaki and Vargo 1986). The HAD anxiety and depression sub scale scores had a moderate agreement with each other (Table 4.9), and a marginally improved agreement with the total HAD score. Cassileth et al 1984 also reported a correlation between anxiety and depression.

If we look at the predetermined thresholds of eight to include all possible cases of anxiety on the HAD scale, we find that 49% of patients in this study would have been cases of anxiety and if this threshold was increased to eleven to include only those with a high probability of being cases, 15% were probable cases according to the HAD scale. The one patient in the study who was identified as having an organic anxiety disorder scored 11 on the anxiety sub scale, but other high scorers on the anxiety sub scale were identified as cases of depression.

It is more likely that medical and nursing staff working within palliative care are familiar with anxiety in their patients, and therefore the use of rating tools to detect anxiety may not be so important in the clinical setting as in the
research setting (Hamilton 1959) (Snaith and Taylor 1985). There are several components to anxiety and the HAD anxiety scale is known to use mood, cognition and behaviour as constructs of the measure of anxiety (Keedwell and Snaith 1996). It appears however that these may all be a feature of terminal illness, but do not suggest a diagnosis of anxiety.

The HAD depression sub scale using a cut off of eight, 54% of patients were identified as possible cases of depression and at a cut off of eleven, 32% of patients were identified as probable cases of depression. The HAD depression sub scale, therefore falsely identified patients as being cases of depression. Others using the HAD scale have found similar numbers of patients scoring above these thresholds (Carroll et al 1993) and (Moorey et al 1991). Brandberg et al (1992) reported higher proportions scoring above the cut off thresholds in patients with advanced melanoma than those with early disease or healthy controls. The poor discriminatory power of some of the items of the HAD scale and these item's contribution to patient's high scores will be discussed later in the thesis.

Previous studies have suggested that in patients with advanced disease, the combined scores on the HAD scale should be used to determine a threshold. (Razavi et al 1990) reported both high sensitivity (70%) and specificity (75%) at a threshold of 19 for major depressive disorders.

The optimum cut off with the highest sensitivity and specificity in this study is also at a threshold of 19 with a sensitivity of 68% and specificity of 67%
for cases of depression. The positive predictive value is the proportion of patients with positive test results who actually have the disease and is dependent on the prevalence of a disease in the population - thus the higher the prevalence the higher the PPV. The PPV at a threshold of nineteen is 36% and is higher than that recorded by Silverstone (1994) of 25% when using the combined HAD scale in a population of medically ill patients.

Previous work validating the HAD in other populations using the Present State Examination as gold standard has found that the total HAD scale was better than using the depression sub scale alone (Spinhoven 1997) and that is supported by this study. Whilst looking at different thresholds is important, we must also consider what these mean for terminally ill patients. If a screening tool is to be used what is more important, a highly sensitive threshold which detects most cases at the expense of some false negatives or a threshold which has a high probability of only detecting those which truly have a depressive illness? This depends largely on how an instrument is being used and whether cut off thresholds are being used to support clinical assessment or whether they are used instead of clinical assessment - it must be remembered that the Hospital Anxiety and Depression Scale was developed to be used as the former.
4.4.4 Individual items of the HAD Scale

The fourteen items on the HAD scale are divided into an anxiety and depression sub scale. Although screening instruments may be designed to include more than one facet of a psychiatric illness and individual items contribute to the total score and should not be used alone, the majority of the items on the HAD scale have a low sensitivity when analysed against the PSE gold standard.

Nunnally and Bernstein (1994) recommend that for a screening instrument, the coefficient alpha should be at least 0.8 - the HAD scale Cronbach's Alpha is 0.8520 which is acceptable and does not explain why the HAD scale has poor efficacy.

Three items of the depression sub scale relate to subjective well being and activity i.e. item two "I still enjoy the things I used to enjoy", item eight "I feel slowed down", and item ten "I have lost interest in my appearance". The majority of patients scored two or three on items two and eight, but only 12% scored at that level on item ten. Item ten relating to loss of interest in appearance is poorly discriminating in terms of a sensitivity of 9% for cases of depression. Items two and eight can be considered to be almost universally poor discriminators for depression in the terminally ill which is reflected in the number of patients who scored positively on these items. It is understandable why terminally ill patients would respond positively to these three questions due to their physical disease alone.
Anhedonia is defined as a failure to experience pleasure and borders on a number of other constructs i.e. diminution of interest, reactivity of mood, flattening of affect, apathy and anergia (Snaith 1993 b). Anhedonia has further been described as a multivariate dimension (Watson et al 1970). Silverstone (1991a) cast doubt as to whether anhedonia was a good measure of depression and found that although depressed patients scored highly on anhedonia, it was also present in patients with other diagnoses apart from depressive illness.

It may be that at the end of life anhedonia can be considered to be a common or possibly a universal factor and not a specific symptom of psychiatric morbidity which would explain why the Hospital Anxiety and Depression Scale does not perform so well in this population group.

When considering the factor analysis of the HAD scale, Table 4.16 , the anxiety and depression factors do discriminate with the exception of item eight " I feel slowed down" which loads onto a separate "depression factor". Item two on the depression sub scale, "I still enjoy the things I used to enjoy" although loading also loads onto this other "depression factor" .Both these items have low sensitivity and low discriminatory potential with terminally ill patients - loading onto another factor suggests that they are not measuring the same construct of depression as the other items of the depression sub scale.
Items three "I get a sort of frightened feeling as it something awful is about to happen" and item nine "I get a sort of frightened feeling like butterflies in my stomach" both load onto a separate anxiety factor indicating that these items may also measuring another construct of anxiety. The four factors of the HAD scale accounted for 62% of the variance. A study by Moorey et al (1991) with patients undergoing active treatment for cancer, found two factors for anxiety and depression in their group of patients which accounted for 53% of the variance.

The HAD scale, therefore appears to perform differently in those with terminal disease from those patients with stable disease.
4.4.5 Implication of the Edinburgh Scale at different thresholds

The original work devising the Edinburgh Postnatal Depression Scale (EPDS) by Cox et al (1987) suggested that for the ten item scale, a score of twelve or thirteen was most likely to predict mothers in the postnatal period who may be suffering from a major depressive illness and require further assessment. The EPDS was devised for the assessment of depression in the postnatal period and similarly to the HAD scale does not include any somatic questions.

The ten item Edinburgh Postnatal scale was compared to the seven item scale which omitted the three questions which are duplicated in both the EPDS and the HAD scale. The EPDS has been used in women outside the postnatal period and found to have a sensitivity of 79% and specificity of 85% (Cox et al 1996).

Using the original ten item scale at a cut off of thirteen, the sensitivity was 81% and specificity 79%. The Positive Predictive Value at this threshold was 53%. Removing the three items in common with the HAD scale, using this seven item scale, the sensitivity was 82% and specificity 81% for cases of depression - the PPV was 54%.

Twenty seven per cent of patients scored above the cut off threshold of thirteen on the ten item EPDS and 23% above the cut off threshold of ten on the seven item EPDS - the Edinburgh Postnatal Depression scale had a much lower rate of falsely identify patients as being cases of depression than the HAD scale.
The EPDS, in both its original ten item and abbreviated seven item forms, had higher sensitivity and specificity across all thresholds for identifying PSE cases of depression than the HAD scale. Additionally, the PPV across all thresholds is higher for identifying both PSE cases of all psychiatric morbidity and depression, suggesting that the EPDS can be a useful screening tool in the terminally ill population.

All individual items of the EPDS had higher sensitivities than the individual items on the HAD scale. The items with the highest sensitivities were two, three and five i.e. "I have been anxious or worried for no good reason", "Things have been getting on top of me" and "I have felt sad or miserable". These items all relate to subjective feelings of low mood.

The internal consistency of the Edinburgh scale as measured by Cronbach's Alpha for this group of patients was 0.7805 which is lower than that of the HAD Scale and 0.6920 for the abbreviated seven item scale when those items common to the HAD Scale were removed. Nunnally and Bernstein recommend that the alpha coefficient should be above 0.8 for a screening instrument and neither the ten or seven item EPDS satisfies this criteria. However, the internal reliability of a scale reflects the number of items, therefore removing three items as expected reduced the internal reliability. The lower internal reliability of the EPDS in this study did not influence its efficacy.
Factor analysis of the Edinburgh scale, revealed three factors. Items one, two and four and HADS item 12 loaded onto one factor. These items relate to unnecessarily blame, difficulty sleeping and anxiety for no known reason. Item five "I have felt sad or miserable" although loading more positively onto factor two also loaded onto factor one. Two items relating to questions four and thirteen of the HAD scale loaded negatively onto factor three. The first two factors, however only accounted for 52% of the variance, therefore nearly half the variance of the scale is unexplained. There are no published studies on the factor analysis of the Edinburgh Scale in other populations with which a comparison can be made. It is not possible to speculate if the EPDS performs differently in terminally ill patients to other populations.

The Edinburgh scale, which includes items on guilt, subjective sadness and thoughts of self harm appears able to identify terminally ill patients who may be depressed.
4.4.6 Discriminating questions and the meaning of symptoms

The most informative findings are those relating to question eight of the HAD scale - "I feel slowed down ". Patients in the terminal phase of their illness invariably do feel slowed down as a consequence of their advancing cancer and this is reflected in the high number who responded positively to this statement with seventy four per cent scoring three and a further fifteen percent scoring two. The high sensitivity, the number of positive responses and the low specificity suggests that a positive response to this statement is of little value in screening for depression in the terminally ill.

Similarly, statement two of the HAD scale, "I still enjoy the things I used to enjoy ", thirty five per cent scored three on this statement and a further 24% scored two. The terminally ill debilitated patient will respond positively to this statement on the basis of their physical condition alone (Faull et al 1994). All the anxiety item scores were evenly distributed suggesting that the anxiety items of the HAD scale are not subject to the influence of terminal physical illness.

Two out of seven items on the depression sub scale which may not be appropriate for the terminally ill patient reveals why the HAD depression sub scale has poor efficacy in this patient group and falsely identified patients as having a depressive disorder.
When similar score distributions are considered on the Edinburgh scale, the scores were evenly distributed with no questions eliciting a high number of positive responses. All items on the Edinburgh scale apart from item seven had an individual sensitivity of over 50%. The use of questions relating to subjective sadness, guilt and hopelessness appear to be independent of physical disability and a terminally ill patient's positive response is more likely to reflect their low mood.
4.4.7 Which cut off thresholds should be used in the terminally ill

The cut off thresholds for the HAD sub scales have been previously established in the literature as eight for all possible cases and eleven for all probable cases. From the findings of this study, the HAD scale performs differently in those with terminal cancer to those with early or advanced disease. It appears that the core component of the Hospital Anxiety and Depression scale of anhedonia is not applicable to the terminally ill population where anhedonia may be a common feature due to the natural history of disease progression.

This study does not support the use of the HAD sub scales or the HAD scale as a screening tool for all psychiatric morbidity and the sensitivity and specificity suggest that a combined cut off threshold of nineteen should be used when screening for depression in terminally ill patients.

The original ten item EPDS at a cut off of thirteen gives a sensitivity of 81% and specificity of 79%. When the items common to the HAD Scale are eliminated, a cut off of ten on the seven item Edinburgh scale gives a sensitivity and specificity of 82% and 81% respectively.

These two thresholds using both a ten item and seven item Edinburgh Postnatal Depression Scale suggest that both can be considered useful screening tools for depression in the terminally ill patient. The EPDS was developed as a screening tool for depression and this study supports its use as such in the terminally ill population.
4.4.8 Thoughts of Self Harm

At the beginning of this thesis it was stated that thoughts of self harm in the terminally ill would be given special consideration and item seven on the Edinburgh scale asks about thoughts of self harm during the last seven days. The majority of patients in this study (65%) stated they had never had thoughts of self harm. Those scoring positively for thoughts of self harm were older. It may be that older patients are more ready to accept death than younger patients and more likely to contemplate suicide - this finding is however different however to that of Owen et al (1994) who found that a desire for suicide was related to younger age.

Much of the work in this area has focused on patients with HIV / AIDS (Domino and Shen 1996) (Lester 1997), with both studies indicating that disease progression alters patients perceptions towards suicide.

Perceived social support did not appear to influence thoughts of self harm as 69% perceived they were well supported by family and friends. In a study of actual suicides in cancer patients (Bolund 1985a and 1985b) social isolation was not a factor. A past psychiatric history, although having a low agreement with thoughts of self harm was statistically significant (p=0.006), a finding previously reported (Massie et al 1994) (Owen et al 1994). Within the Edinburgh scale, itself, item seven correlated highest with item three "Things have been getting on top of me". An overwhelming feeling of helplessness and hopelessness has previously been reported as an indicator of suicidal risk (Kovacs et al 1975).
Of the two patients who scored most positively to this question, one was a case of depression according to PSE criteria. Item seven had a significant association with all cases of psychiatric morbidity, but not cases of depression identified by the Present State Examination. Block and Billings (1995) stated that patients in saying they want to die are asking for assistance with living and for help in dealing with symptoms of physical, emotional, and spiritual distress. Barraclough et al (1974) looked retrospectively at cases of suicide and found that mental illness was an essential component of suicide. Robins et al (1959), Brown et al (1986) and Chochinov et al (1995) reported that the presence of suicidal thoughts and desire for death were almost exclusively linked to the presence of a psychiatric disorder in the terminally ill patients. It is possible that those patients who report thoughts of self harm may be a different group to the small number of cancer patients each year who actually do commit suicide. Further research on psychiatric symptoms within palliative care is required (Breitbart et al 1995).

Although by no means diagnostic, thoughts of self harm are important predictors of depression in the terminally ill patient and when carrying out any form of psychiatric interview or screening with terminally ill patients, it is appropriate to enquire whether they have suicidal thoughts.
4.4.9 **Use of Rating Scales in the terminally ill patient**

"A good rating scale should consist of not too many items and not too few and they should have been selected by both the intuition of clinical experience and by the statistical process of item analysis, but unfortunately these desiderata apply to very few scales." (Snaith 1981).

Since this was written, the use of rating scales in psychiatry and what they purport to measure has been well documented. Silverstone (1991b) suggested that none of the instruments available can be recommended as a "gold standard" for measuring or screening for in the medically ill. Psychiatry differs from any other speciality in that diagnosis can only be made on the basis of a very comprehensive and thorough history and with very few exceptions, diagnostic tests have no role to play.

The emphasis on case definition and case identification must not obscure what Williams et al (1980) describes as not "Has he got it" or "How much of it has he got", but "what is it" i.e. what exactly are patients experiencing and what are the most appropriate means of helping or treating these patients. In palliative care, the emphasis is not on cure but on palliation and we have enough evidence to suggest that psychological distress is a symptom which needs palliation almost as frequently as pain or nausea (Hinton 1963). Another question which must be asked is what do depression scales measure? The symptoms of depression are not unique and can occur in other psychiatric illnesses - depression scales are therefore non-specific and can not and should not be used for diagnostic purposes (Carroll et al 1973).
Depression is comprised of different constructs and scales have been devised measuring different elements e.g. cognitions, behaviour, somatic symptoms etc., and different scales measure different facets of a depressive illness (Snaith 1993a).

The HAD scale was devised originally for medical out-patients and as previous studies have confirmed, it is valid within the populations for which it was designed (Aylard et al 1987). Rating tools devised for a medical outpatients may not be applicable for patients with terminal cancer - indeed some aspects of psychological distress in terminally ill patients e.g. spiritual distress are distinct and rarely included in assessments and may indeed be impossible to measure (Gottay et al 1995).

Anxiety and depression may assume different weights or significance for patients who are terminally ill and therefore a straight forward summated scale is not practicable. The proliferation of new rating scales and their ad-hoc use needs careful evaluation - some have even called for a moratorium on new scales being developed and for existing scales to be validated and improved (Snaith 1981). In a survey of rating instruments, Meakin (1992) suggested that their increased use should be accompanied by a validation of treatment to establish which patients should be screened in order to benefit from treatment - a concept that is equally applicable in terminal illness as in other physical illnesses.
Hoepner et al (1984) comments that screening has a double benefit of making a patient more aware of psychiatric symptoms and therefore more likely to report them to their doctor and also raises the awareness of the doctor to psychiatric morbidity.
4.4.10 Other methods of assessment of depression

Mahoney et al (1994) and (Chochinov et al 1997) suggested asking patients if they are depressed was a useful indicator as to whether patients may be depressed. However, both authors emphasised that patients only have their own experience by which to judge their response. Additionally, patients with advanced cancer under-report their psychological and psychiatric symptoms (Maguire 1985). Subjective sadness as an item of the Edinburgh scale did however have a high sensitivity for identifying depression. Visual analogue scales have been used both in psychiatric patients (Luria 1975), patients with stroke (House et al 1989) and in patients with cancer (Coates et al 1983), but the subjective experience of the patient may lead to either under or over scoring.

It has previously been documented in chapter two that currently very few palliative care units are able to access psychology or psychiatry expertise. As physicians are responsible for the prescribing of medication and the referral of patients, it is they who are called upon to assess patients. It is outside the remit of this study to speculate as to whether physicians working in palliative care have the necessary skills to undertake a psychiatric assessment. However, a paper looking at the training of palliative medicine specialists (Daley and Lennard 1981) found that only eighteen per cent had undertaken any postgraduate training in psychiatry and that a large number felt such training would have been desirable.
Brugha (1993) in a review paper suggests that doctors working with terminally ill patients may not be confident in eliciting psychological and psychiatric morbidity.

House (1988) states that the majority of physically ill patients with mood disorder are cared for by those with little or no psychiatric training and methods of improving their clinical skills in this area should be explored. A study of General Practice Trainees (Gask et al 1988) found that by using group teaching and a problem based approach with video feedback, significant improvements were observed in the General Practice trainee's ability to detect psychiatric morbidity. Another study used a similar approach but with four sessions of individual instruction in psychiatric assessment and again had a significant improvement in the accuracy of assessments (Goldberg et al 1980).

The foundation of good medical care is excellent communication skills which most Doctors working within palliative care would be expected to possess. However research on improving the communication skills of health professionals caring for cancer patients has shown that workshop based training increases the identification of patients concerns (Maguire et al 1996) and possibly this form of training would be equally valuable for those working in palliative care.
4.4.11 Summary

This study has found that depression is present in 22% of terminally ill patients and is not associated with past psychiatric history, perceived social support or information needs. Other psychiatric morbidity is present in a further 5% of patients. Females with breast cancer were more likely to be identified as cases of depression by Present State Examination than any other disease group. The Hospital Anxiety and Depression Scale sub scales at previously established thresholds of eight or eleven has poor efficacy and three items on the depression sub scale appear to be poor discriminators in this population. Using a combined threshold of nineteen, improves its efficacy but the sensitivity and specificity at this threshold is below 70%. Across all thresholds, the HAD scale performs better as a screening questionnaire for identifying possible cases of depression as opposed to all cases of psychiatric morbidity.

The Edinburgh scale of ten items, has a sensitivity of 81% and specificity of 79% at a threshold of thirteen. When the three items which also appear in the Hospital Anxiety and Depression Scale are removed creating a seven item scale, a threshold of ten has a sensitivity and specificity of above 80% suggesting that both the original and abbreviated Edinburgh scales may be useful as a screening tool for depression in the terminally ill patient.
Between us

Above human reach, where only spirits can fly, stars glitter in the darkness, far higher than this mortal plane, transcending this confusion: lights born out of incredible love and creation between us.

The carer, and the cared for. In sickness and in health. To be cured and to be healed. What everybody has to understand is that physical illness needs emotional tendering as well as conventional treatment.
5. CONCLUSIONS AND RECOMMENDATIONS

5.1 SUMMARIES OF STUDIES

5.1.1 Survey of Psychosocial service provision within palliative care units

Very little is known of psychosocial service provision within palliative care. A questionnaire was sent to palliative care units providing a range of services including day care, in patient and home care services. All units had access to a chaplain with many units employing chaplains in a full or part time basis. The majority of units additionally had social worker support available on a full or part time basis. Forty three per cent of units employed full or part time counsellors. Seventy six per cent of units stated they had access to a psychiatrist and 54% to a psychologist.

There were difficulties in accessing psychiatry and psychology services and consequently very few patients were referred to either with the majority of units making no referrals to psychology or psychiatry within the last twelve months.

The multidisciplinary team meetings reflected this service provision with only two units reporting that psychologist or psychiatrist attended regularly.

The majority of units did not use psychosocial screening tools, but fifteen used the Hospital Anxiety and Depression Scale to screen for psychiatric morbidity. This study suggests that there may be difficulty in recognition and management of depression and other psychiatric illness within palliative care units.
5.1.2 Current Prescribing of antidepressant medication for terminally ill patients

This study was aimed to determine the prescribing of antidepressant medication in terminally ill patients. This was a retrospective study of 1,426 patients within four palliative care units in the Midlands region. Eight hundred and eighty patients had received hospice home care prior to admission. One hundred and six, (7%) of patients had been prescribed antidepressant medication during their contact with the palliative care unit. Of these patients, twenty two were commenced on medication within the community prior to admission, but in the majority of cases (79%) medication had been commenced during the last two weeks of life when there was insufficient time for this to be effective. Five patients were assessed by a psychiatrist before starting treatment.

The majority of patients were commenced on Selective Serotonin Reuptake Inhibitors. None of the patients were prescribed psychostimulants. Patients who were commenced on antidepressant medication were younger than those who were not prescribed antidepressants. Females with breast cancer were prescribed anti depressants more frequently than any other group of patients.

The study concluded that there did not appear to be any co-ordinated approach to the assessment or treatment of depressive illness with antidepressants within the palliative care setting. In the majority of cases, antidepressant treatment is being commenced too late in a patients illness for any therapeutic effect to be achieved.
5.1.3 The use of rating scales to assess for depression and the prevalence of depression in terminally ill patients.

This was a prospective study to determine the efficacy of using rating scales namely the Hospital Anxiety and Depression Scale (HADS) and the Edinburgh Postnatal Scale (EPDS) in the terminally ill patient and the prevalence of psychiatric morbidity within this population.

The Present State Examination, which was used as a gold standard for measuring the prevalence of psychiatric morbidity, identified 22% of patients as being cases of depression and a further 5% cases of other psychiatric morbidity. The majority of patients were identified as cases of depression of moderate severity. Patients with breast cancer were identified as cases of depression more frequently than any other diagnostic group. Factors such as perceived social support, past psychiatric history and information needs were not associated with psychiatric morbidity.

The HADS had poor efficacy for detecting depression using the depression or anxiety sub scale alone but using a combined threshold score of 19, higher sensitivity and specificity were achieved but both were below 70%.

The full and abbreviated EPDS performed better. The ten item scale at a cut off threshold of thirteen had a sensitivity of 81% and specificity of 79%.

Using a seven item abbreviated scale - removing the three items identical to the HAD scale - at a cut off threshold of ten, the sensitivity and specificity were both above 80% suggesting that both the original version and this abbreviated version of the Edinburgh scale may have a role in screening for depression within the terminally ill population.
Thoughts of self harm were present in thirteen patients, but only half were cases of psychiatric morbidity. This question, however, had a high specificity of 92% suggesting that those responding negatively to this question are unlikely to be depressed.
5.2 CONCLUSIONS

In the 1960's, Dame Cicely Saunders identified the need for palliative care within the U.K. She emphasised not only the control of physical symptoms but the importance of achieving peace and tranquillity and alleviating psychological distress at the end of life. The last three decades has seen palliative care grow into an academic speciality with five chairs of palliative medicine within the U.K. and the vast majority of large towns having their own Hospice or Palliative Care Unit. The U.K. is world renowned for the provision of palliative care.

A significant number of patients experience depression and psychological distress during their terminal illness. Apart from the distress that a depressive illness causes in terms of quality of life to the patients and the effects it can have on their family, undiagnosed depressive illness can also lead to poor pain control and difficulty in the control of other symptoms. Distress is a continuously distributed variable. There is still debate as to whether depression is just the tail end of this continuum or a separate condition. It is by having access to a number of professionals possessing a range of skills and acknowledging when one's own skills are no longer adequate that effective palliation of all symptoms can be achieved.

Greater consideration needs to be given to improve training for those working with terminally ill patients, often in relatively isolated units, to be more aware and able to identify psychological distress. Workshops based on the very successful communications workshops (Maguire et al 1996) (Heaven and
Maguire 1996) (Parle et al 1997) could have significant benefits for those working within palliative care.

The absence of Psychiatry and Psychology input into Hospices is notable. It would seem appropriate to encourage those working in palliative care and in Hospices to establish links with local departments of psychology and psychiatry where at all possible and to have joint educational meetings with these professionals.

Once patients are identified as being depressed, they require adequate treatment and this will often involve antidepressant medication. It is not clear whether the findings of the study in chapter three suggest a reluctance to prescribe antidepressant medication or whether it is a problem of not identifying depression. For effective treatment of a depressive illness, treatment needs to be initiated sooner rather than late and the identification and treatment of depression by home care teams and in the out patient clinic is vitally important. Other modalities of treatment of symptoms of depression and psychological distress need to be evaluated. Work by Moorey et al (1998) has shown that adjuvant psychological therapy has significant benefits over counselling in terms of helplessness and anxiety in patients with treatable cancer and possibly such problem oriented therapy could be used to relieve distress in the terminally ill.
The Hospital Anxiety and Depression Scale performs better as a screening tool for depression in the terminally ill when a combined threshold approach is used. Three items of the depression sub scale have low sensitivity and the concept of anhedonia or loss of pleasure appear to be present in terminally ill patients without being indicative of a depressive illness. The findings identified in this thesis suggest that rating scales devised for other populations i.e. the Edinburgh Postnatal Depression Scale can be used to help identify terminally ill patients who may be depressed.

There has been enormous emphasis on the assessment of psychological morbidity and the prevalence and treatment of depression in those patients receiving active treatment. Patients who are terminally ill have similar levels of morbidity, but in many cases, this morbidity is not recognised and therefore not treated.
5.3 RECOMMENDATIONS

1) The prevalence of psychiatric morbidity within terminally ill patients should be highlighted to those responsible for their care including home care nursing teams, Macmillan nurses, General Practitioners and palliative care physicians.

2) Rating Scales should have proven validity for the population in which they are being used and should have pre established cut off thresholds at which a further assessment of the patient is undertaken. The EPDS in both its ten and seven item forms can be a used as a valid screening test for depression in the terminally ill. The HAD scale should be used as a combined scale.

3) Further evaluation of the use of psychostimulants in the treatment of psychological distress and depression in terminal illness should be undertaken.

4) There is a need for different psychological interventions to be evaluated e.g. counselling, adjuvant psychological treatment, cognitive and behavioural psychotherapy. The evaluation should include subjective benefit, improvement in quality of life and also health economics and cost benefit analysis.

There is a need to elicit and more importantly address all the causes of suffering patients may be experiencing during the terminal phase of their illness including spiritual and existential distress.

To achieve all of the above we need to remember that our patients needs extend beyond tests and medication (Saunders 1965) - above all we need to remember to be silent, to listen and to be there.
APPENDIX A

PSYCHOSOCIAL SERVICE PROVISION IN PALLIATIVE CARE

<table>
<thead>
<tr>
<th>Does your unit have access to a clinical psychologist?</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, is the psychologist -</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>[ ]</td>
</tr>
<tr>
<td>Part-time (please indicate no. sessions)</td>
<td>[ ]</td>
</tr>
<tr>
<td>Visits if requested</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

| Number of referrals in last year                        |          |
| Relatives                                              | [ ]      |
| Staff                                                  | [ ]      |
| Patients                                               | [ ]      |

What are the roles of the psychologist within your unit?

<table>
<thead>
<tr>
<th>Does your unit have access to a psychiatrist?</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, is the psychiatrist -</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>[ ]</td>
</tr>
<tr>
<td>Part-time (please indicate no. sessions)</td>
<td>[ ]</td>
</tr>
<tr>
<td>Visits if requested</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

| Number of referrals in last year                        |          |
| Relatives                                              | [ ]      |
| Staff                                                  | [ ]      |
| Patients                                               | [ ]      |

What are the main roles of the psychiatrist within your unit?

<table>
<thead>
<tr>
<th>Does your unit have access to a social worker?</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, is the social worker -</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>[ ]</td>
</tr>
<tr>
<td>Part-time (please indicate no. sessions)</td>
<td>[ ]</td>
</tr>
<tr>
<td>Visits if requested</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

| Number of referrals in last year                        |          |
| Relatives                                              | [ ]      |
| Staff                                                  | [ ]      |
| Patients                                               | [ ]      |

What are the main roles of the social worker within your unit?

<table>
<thead>
<tr>
<th>Does your unit have access to counsellors?</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, are the counsellors -</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>[ ]</td>
</tr>
<tr>
<td>Part-time (please indicate no. sessions)</td>
<td>[ ]</td>
</tr>
<tr>
<td>Visits if requested</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

193
Number of referrals in last year

Relatives [ ] Staff [ ] Patients [ ]

What are the main roles of the counsellors within your unit?

---

Does your unit have access to a chaplain? Yes / No

If yes, is the chaplain -

Full-time [ ]

Part-time (please indicate no. sessions) [ ]

Visits if requested [ ]

Number of referrals in last year

Relatives [ ] Staff [ ] Patients [ ]

What are the main roles of the chaplain within your unit?

---

Do these professionals attend multidisciplinary meetings/ward rounds?

<table>
<thead>
<tr>
<th></th>
<th>Regularly</th>
<th>Occasionally</th>
<th>If requested</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologist</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Social Worker</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Chaplain</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Counsellor</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Does your unit have access to any other psychosocial services? (please specify) Yes / No

---

Does your unit use any screening instruments to assess psychosocial/spiritual distress? Yes / No

(please specify)

---

How many beds are in your unit? [ ]

---

In which year did your unit open? .................
### APPENDIX B

**Antidepressant Prescribing Data Sheet**

<table>
<thead>
<tr>
<th>Reference of Hospice</th>
<th>Patient Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Sex</td>
</tr>
<tr>
<td>Home Care visits</td>
<td>Out patient clinic</td>
</tr>
<tr>
<td>Name of Medication</td>
<td>Dose</td>
</tr>
</tbody>
</table>

Length of administration

If commenced prior to admission, who initiated prescription

Length of time of prescription prior to admission

If medication discontinued - reason why

Number of days from documentation of symptoms to treatment

Any previous psychiatric history noted?

Any rating scales used?

Patient referred to psychiatrist?

Psychostimulants prescribed?
Dear Dr. Lloyd-Williams,

**Is the Hospital Anxiety and Depression Scale a valid tool for the assessment of depression in the terminally ill cancer patient?**

Are some symptoms more discriminating than others for the assessment of depression in this population group - our ref. no. 3684

Further to your letter dated 27th February, you will be pleased to know that the Ethics Committee has approved your request to undertake the above-mentioned research.

I would remind you, however, that your research project has been given approval only in relation to its acceptability from an ethical point of view. If, subsequently, departure from the methodology outlined in your protocol is contemplated, the Ethics Committee must be advised in order that the proposed changes may be approved. Also a report should be made to the Ethics Committee if any significant adverse reactions are noted during the course of the study. In addition, any NHS resource implications of your project must be discussed with the appropriate Trust Chief Executive. Similarly, it may be that the research project has implications for other disciplines and, if so, you are advised to discuss them with the appropriate departmental manager. Researchers should also be able to assure the Ethics Committee that satisfactory arrangements have been made for the labelling, safe storage and dispensation of drugs and pharmaceutical staff are always willing to provide advice on this.

Researchers' attention is also drawn to correspondence from the Regional Director of Public Health dated 28th January, 1991 relating to Clinical Trials which sets out revision of the procedures to be followed, and the Clinical Trials Indemnity Letter and Deed of Guarantee. Researchers should ensure that these indemnity arrangements have been complied with.

Researchers intending to study selective groups of patients in the community are reminded that their first approach should be to the individual patient's general practitioner to ascertain whether the particular patient was suitable for inclusion in the study. Equally, when the researcher contacts the patient it should be emphasised that the approach is made with the knowledge of the General Practitioner, with whom the patient may discuss this research, if the patient so wished.

Yours sincerely,

M. Swans

Dr. M. Lloyd-Williams,
SHO - Department of Psychiatry,
Leicester General Hospital.
APPENDIX D

Patient Information letter

Dear

Doctors are aware that patients often have worries and concerns and that sometimes it can be difficult to discuss these with the doctors and nursing staff. We are trying to find out how we can improve the way which we help and support patients and are comparing two questionnaires which ask about your feelings and worries.

If you agree to take part in this study, you will be asked to complete two questionnaires and Doctor Lloyd - Williams will ask you some further questions about your feelings. This will take about 30 minutes. The Doctor may also need to look in your case notes for additional information.

Taking part in this study is voluntary. Your answers to the questions, what you tell the Doctor and information from your case notes will be confidential and there will be no means by which you can be identified.

If you have any queries about the study, please ask.

If you understand the above and agree to take part, please sign below.
APPENDIX E    HOSPITAL ANXIETY & DEPRESSION SCALE

Please UNDERLINE the answer which comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel tense or “wound up”</td>
<td>I feel as if I am slowed down</td>
</tr>
<tr>
<td>Most of the time</td>
<td>Nearly all the time</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Very often</td>
</tr>
<tr>
<td>Time to time, occasionally</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
<tr>
<td>I still enjoy the things I used to enjoy</td>
<td>I get a sort of frightened feeling like “butterflies” in the stomach</td>
</tr>
<tr>
<td>Definitely as much</td>
<td>Not at all</td>
</tr>
<tr>
<td>Not quite as much</td>
<td>Occasionally</td>
</tr>
<tr>
<td>Only a little</td>
<td>Quite often</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>Very often</td>
</tr>
<tr>
<td>I get sudden feelings of panic</td>
<td>I have lost interest in my appearance</td>
</tr>
<tr>
<td>Very often indeed</td>
<td>Definitely</td>
</tr>
<tr>
<td>Quite often</td>
<td>I don’t take so much care as I should</td>
</tr>
<tr>
<td>Not very often</td>
<td>I may not take quite as much care</td>
</tr>
<tr>
<td>Not at all</td>
<td>I take just as much care as ever</td>
</tr>
<tr>
<td>I can laugh and see the funny side of things</td>
<td>I feel restless as if I have been on the move</td>
</tr>
<tr>
<td>As much as I always could</td>
<td>Very much indeed</td>
</tr>
<tr>
<td>Not quite so much now</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>Not very much</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
<tr>
<td>Worrying thoughts go through my mind</td>
<td>I look forward with enjoyment to things</td>
</tr>
<tr>
<td>A great deal of time</td>
<td>As much as ever I did</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td>From time to time but not too often</td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td>Only occasionally</td>
<td>Hardly at all</td>
</tr>
<tr>
<td>I feel cheerful</td>
<td>I get a sort of frightened feeling as if something awful is about to happen</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very definitely and quite badly</td>
</tr>
<tr>
<td>Not often</td>
<td>Yes, but not too badly</td>
</tr>
<tr>
<td>Sometimes</td>
<td>A little, but it doesn’t worry me</td>
</tr>
<tr>
<td>Most of the time</td>
<td>Not at all</td>
</tr>
<tr>
<td>I can sit at ease and feel relaxed</td>
<td>I can enjoy a good book or radio or TV programme</td>
</tr>
<tr>
<td>Definitely</td>
<td>Often</td>
</tr>
<tr>
<td>Usually</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not often</td>
<td>Not often</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>
APPENDIX G      PATIENT CASE STUDIES

Case Study One

Mr. H. was a 33 year old factory worker who presented to his G.P. with a 3 month history of groin pain. After prolonged investigations, he was diagnosed as having an inoperable intra pelvic melanoma. Mr. H. was offered palliative chemotherapy to which he agreed, but this was discontinued after three sessions due to toxicity. Mr. H. had two small daughters aged 4 and 2 years and while he was undergoing chemotherapy, his wife gave birth to another daughter.

Mr. H. scored 15 on the depression sub scale, scoring three each for "I feel slowed down ", "I still enjoy the things I used to enjoy" and "I can still enjoy a book or T.V. programme " and 8 on the anxiety sub scale. He scored 7 on the Edinburgh postnatal scale, scoring 0 for thoughts of self harm and he was not defined as a case according to ICD 10 criteria.

When interviewed, Mr. H. said he felt well supported by his family and friends but had obvious regrets at not seeing his small daughters grow up and not having had time to get to know his baby daughter. During his time at the hospice he talked openly about his approaching death and wrote letters for his daughters to read when they were older. He also said he felt very peaceful and felt sure he would meet up with his family again in "some other place".

He died peacefully at the hospice, 22 days after being interviewed.
Case Study Two

Miss D. was a 62 year old retired machinist who was diagnosed as having carcinoma of the lung two years ago and had a pneumonectomy at that time. She lived alone since her elderly mother had died, but felt she was well supported by family and many friends. She had no previous past psychiatric history and wanted to know as much about her illness and her likely prognosis as possible.

After falling in the street and fracturing her hip, Miss D. was diagnosed with bone metastases and referred for palliative radiotherapy. Miss D. was interviewed at the Oncology Unit. Prior to starting the interview Miss D. spontaneously said she felt very low, tearful and hopeless regarding her situation and felt guilty as she knew that everybody was doing their best to help her, including her counsellor who she had been seeing regularly for four months. Miss D. scored 19 on the HAD Anxiety sub scale and 20 on the Depression sub scale and 25 on the Edinburgh postnatal scale, scoring two or three on most items including a score of three for thoughts of self harm.

On PSE interview Miss D. was defined as a case of depression of moderate severity without somatic symptoms.

After discussion with her Oncologist, Miss D. was commenced on antidepressant medication and referred to a Psychologist.

She died 26 days later at home.
Case Study Three

Miss. G. was a 34 year old accountant who was diagnosed with breast cancer the day before her 30th birthday. After mastectomy and chemotherapy, she had initially been well, but two years later developed lung metastases for which she was given further chemotherapy and when interviewed was receiving further treatment for liver metastases. Eighteen months ago her long term partner had left her and she felt her friends had not been as helpful as they could have been. There was no past psychiatric history and Miss G. felt informed regarding her condition fully acknowledging that her illness was terminal.

On the HAD scale Miss G. scored five on each sub scale and scored 4 on the Edinburgh scale and was not defined as case according to ICD 10 criteria.

Miss G. was discharged home from hospital and died at the hospice 87 days after being interviewed.
Case Study Four

Mr. M. was a 42 year old married man with four children and worked as a milkman. He was diagnosed with cancer of the colon eighteen months ago and had resection which involved a colostomy and radiotherapy at that time. He recovered well and returned to work, but after repeated chest infections was found to have lung secondaries.

In the past Mr. M. had received treatment for depression from his G.P. and had a six month course of antidepressants at the time of his surgery. He had found his stoma very difficult to manage and over the last three months had withdrawn from family and friends feeling he had no useful function as a husband or father.

Mr. M was from a large family who were very supportive and although he stated he had information needs he stated he did not want to hear any bad news. He was interviewed at the Hospice. He was withdrawn and told me "what's the point of you talking to me - I'm no use to anybody". He scored 12 on the depression sub scale of the HAD scale and 9 on the anxiety sub scale. His Edinburgh score was sixteen. At the PSE interview Mr. M was recorded as a case of depression of moderate severity without somatic symptoms.

Mr. M. was commenced on antidepressants at the Hospice and was also referred to the liaison psychiatry service.

Mr. M. was discharged home and returned to the hospice twenty four hour prior to his death. He survived for 68 days and his wife commented after his death that she believed his quality of life had vastly improved with medication
and psychiatric support. She also commented that she wished "Something could have been done to help his mood earlier ", but that the last few weeks of his life at home had been a "good time" for all the family.
Case study Five

Mr. T. was 69 years old and had been employed all his life in the hosiery industry. He had gone to his G.P. for a medical prior to taking out a second mortgage for a holiday apartment in Spain and was found on routine chest x-ray to have rib metastases. He was investigated and found to have an advanced prostate cancer with extensive bone secondaries. He had been prescribed hormonal treatment and also radiotherapy for painful bone metastases. He was interviewed at the Hospice where he had been admitted for symptom control and was described by medical and nursing staff as being a difficult and demanding patient.

He was happy to be interviewed and said, "at last somebody is doing something to help me". Mr. T. scored 10 on the depression sub scale and eleven on the anxiety sub scale. His Edinburgh score was fifteen and on PSE interview he was identified as a depressive episode of moderate severity.

At the end of the interview when asked about perceived social support and information needs, Mr. T. broke down and said that although he had tried to hide it he knew he was very ill and would not get better.

Mr. T. died unexpectedly nine days after being interviewed.
Case study 6

Mrs. H. was a 56 year old headmistress of a primary school. She was originally diagnosed with breast cancer three years ago, and developed liver and lung secondaries six months ago. Mrs. H was interviewed at the Oncology Unit and appeared very anxious and tearful, but wished to participate.

She scored 11 on the anxiety sub scale of the HAD, 9 on the depression sub scale and had an EPDS score of 7.

Twice during the PSE interview, Mrs. H. became very distressed and the interview was stopped and then recommenced.

Mrs. H. was identified as having an Organic Anxiety Disorder according to PSE interview and ICD 10 criteria.

She was referred to a psychologist and had some sessions of behavioural therapy prior to her being discharged home and dying 30 days after being interviewed.
SCAN record booklet
*Fixed format with names of items*

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6.3 Tearfulness and crying
6.4 Capacity for enjoyment
6.5 Loss of hope for the future
6.6 Feeling of loss of feeling
6.7 Unremitting depression
6.8 Morning depression
6.9 Interference due to depression
6.10 Preoccupation with death or catastrophe
6.11 Suicide or self-harm
6.12 Tedium vitae
6.13 Pathological guilt
6.14 Guilty ideas of reference
6.15 Loss of self-confidence with other people
6.16 Loss of self-esteem

PSYCHOTIC AFFECTIVE SYMPTOMS
6.17 Delusions of guilt in context of depression
6.18 Delusions of catastrophe in context of depression
6.19 Hypochondriacal delusions in context of depression
6.20 Rate congruence of AH with affective state

GENERAL RATINGS OF DEPRESSION
6.21 Depression or anxiety primary
6.22 Age at first onset of depressive symptoms
6.23 Relation of depressive to obsessional symptoms,
6.24 Organic cause of Section 6 symptoms
6.25 Identify organic cause of Section 6 symptoms

HISTORY ITEMS
6.26 Episodes of major affective disorder
6.27 Severity of affective episodes
6.28 Exclusively manic or depressive episodes
6.29 Two or more depressive episodes with recovery
6.30 Response to adequate antidepressive therapy
6.31 One or more manic episode during the course

CHECKLISTS
PERSISTENT DEPRESSIVE STATES, DYSTHYMIA
6.32 2+ years depression; remissions for few weeks only
6.33 A reduction in energy or activity
6.34 Insomnia or hypersomnia
6.35 Loss of self-confidence or feelings of inadequacy
6.36 Difficulty concentrating
6.37 Often in tears
6.38 Loss of interest or enjoyment in sex/pleasurable activities
6.39 Feeling of hopelessness or despair
6.40 Inability to cope with routine responsibilities
6.41 Pessimistic about the future or brooding over the past
6.42 Social withdrawal
6.43 Less talkative than normal
6.44 Poor appetite or over-eating
■ 6.45 Age when present episode of dysthymia began
■ 6.46 Episode of major depression preceded present episode of dysthymia
■ 6.47 Period of remission lasting 6 months or more between two episodes
■ 6.48 Age at first onset of any episode of Dysthymia
■ 6.49 Episode of major depression preceded first episode of dysthymia
■ 6.50 Period of full remission lasting 6 months or more between two episodes

CHECKLIST FOR RECURRENT BRIEF DEPRESSIVE DISORDER
■ 6.51 Brief phase at least once a month during the past year
■ 6.52 Phases of depression have lasted less than two weeks
■ 6.53 Phases not solely with the menstrual cycle

7 Thinking, concentration, energy, interests
■ 7.1 Positive cognitive functioning
■ 7.2 Loss of concentration
■ 7.3 Subjectively inefficient thinking
■ 7.4 Loss of interests
■ 7.5 Subjective feeling of retardation
■ 7.6 Loss of energy (drive)
■ 7.7 Feeling of being overwhelmed by everyday tasks
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