A Holistic Perspective of Depression and Anxiety Among a Community Palliative Care Population.

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Declaration

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

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23/4/98

Date

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Abstract

Palliative care patients can experience a wide range of physical and psychological symptoms. Depression and anxiety are two psychological problems reported to occur in palliative care patients (Massie, 1989). With the increasing trend towards community care, approaches to identify and explore psychological symptoms are necessary.

This study set out to explore and describe the extent and associated risk factors which contribute to the development of depression and anxiety among a community palliative care population. The impact of depression and anxiety as experienced by seven community palliative care patients was explored.

The findings from this research highlight the fact that depression and anxiety were a significant symptom among 75 community palliative care patients, with the extent of depression reported at two periods as 19% and 25% and anxiety reported as 16% and 17%. Logistic regression analysis revealed a previous history of depression and a family history of anxiety were the risk factors identified as predictors of future psychological distress. The experience of depression and anxiety among the seven participants was described using unstructured interviews as a reduction in their quality of life and their fear of living with an uncertain future. Despite the hardships faced by these participants, descriptions of how they were able to 'hold on' to their remaining life was revealed.

Implications for clinical nursing practice identified in this research include the importance of psychological assessment, the importance of using screening tools, the importance for nurses to include the family/carers in the on-going assessment and for nurses to incorporate a holistic approach to management of concerns voiced by their patients.

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CHAPTER ONE

Introduction

1.1 INTRODUCTION

Palliative care is the holistic approach to care for patients whose disease is not amenable to cure. Rather than focusing solely on the underlying disease. This care focuses on making the patient comfortable and free from pain in all dimensions, physical, emotional and spiritual. Palliative care patients can experience a wide range of physical and psychological symptoms. Depression and anxiety are two psychological problems reported to occur in palliative care patients (Massie, 1989). Depression and anxiety are conditions that can have a significant impact on the patient and influence the severity and experience of other symptoms such as pain, with the intensity and frequency increasing as the severity of illness increases (Massie, 1989; Moorey, Greer, Watson, Gorman, Rowde, Tunmore, Robertson & Bliss, 1991). Amelioration of distressing symptoms is the cornerstone of palliative care practice. To achieve this there is a need for research that increases the understanding of the extent and impact of depression and anxiety among this patient group.

This thesis will describe and explore the prevalence of depression and anxiety in palliative care patients. It is also the aim of the researcher to determine risk factors which predispose a palliative care patient towards developing depression and/or anxiety, and to explore the patient's experience of depression and anxiety in a community setting.

This chapter describes the impact of depression and anxiety and presents an overview of palliative care practice and the philosophical models for palliative care service delivery. The research objectives of the study are defined, and the significance and purpose of the study and its relevance to nursing and palliative care are discussed. Operational definitions for the purposes of this study will be outlined.

1.2 BACKGROUND TO THE STUDY

It is well documented that the diagnosis of cancer or the knowledge that treatment has failed and the disease has spread, produces significant emotional distress (Breitbart, Bruera, Chochinov & Lynch, 1995; Woodruff, 1993). Ineffective or maladaptive coping is likely to result in intense anxiety, denial, anger or depression (Lazarus & Folkman, 1984). Depression and/or anxiety is cited as a problem often experienced by people with advanced incurable illness and a limited life expectancy (Massie, 1989). Untreated depression and anxiety leads to social withdrawal, intensifies other symptoms and prevents the patient from completing 'unfinished business', thereby negatively impacting on the patient's quality of life and increasing the risk of suicide (Massie, 1989; Wilson, 1989; Valente & Saunders, 1989).

The prevalence of depression and anxiety among cancer patients has been investigated quantitatively, although predominantly in hospital settings with oncology patients (Carroll, Kathol, Noyes, Wald & Clamon, 1993; Ibbotson, Maguire, Selby, Priestman & Wallace, 1994; Moorey et al., 1991; Payne & Endall, 1998; Razavi, Delvaux, Farvacques & Robaye, 1990; Wood & Mynor-Wallis, 1997; Zigmond & Snaith, 1983). Little is known about the prevalence in community palliative care patients (Williams, 1994). There have been many studies which have examined the benefits of specific therapeutic management strategies to help patients through periods of psychological distress (Abraham, Neese & Westerman, 1991; Abraham, Niles, Thiel, Siarkowski & Cowling. 1991; Jones, Johnston & Speck, 1989; Valente & Saunders, 1989). While these results have been useful in directing health professionals towards the management and therapeutic treatment of such distress, there is an absence of descriptive research directly focusing on the experience and the extent of depression and anxiety in community palliative care patients.

1.2.1 Description of palliative care and palliative care services.

Palliative care has been generally defined as the management of people who have a terminal illness which is no longer responsive to curative treatment (WHO, 1990). This definition is now broadening, as palliative care services are offered to patients and their families much earlier in the disease process and in a variety of health care settings (Clark, Neale & Heather, 1995). Although the majority of palliative care patients have cancer, palliative care also supports patients with Acquired Immune Deficiency Syndrome (AIDS), cardiac, respiratory, renal and neurological disorders

(Commonwealth Department of Health and Family Services, 1998). For the purpose of this study, the definition developed by the World Health Organisation (WHO, 1990, p11) is used, defining palliative care as;

> "... the active total care of people whose disease is not responsive to curative treatment. Care is delivered by coordinated medical, nursing and allied health services which are provided where possible, in the environment of the person's choice. Control of pain or other symptoms, and provision of psychological, social, emotional and spiritual support is paramount. Palliative care aims for the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment ...".

Health professionals working in palliative care believe they should approach the management of the dying patient from a different philosophical perspective to that of their colleagues in other specialties. Principally this difference lies in a philosophy of 'care' as opposed to 'cure'. The concept of palliative care is an approach directed towards the totality of the patient and his/her family. Procedures, including radiotherapy, chemotherapy and surgery, have a place in palliative care provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. On the other hand, 'cure' is the search for the root of the cause and ultimate cure of the disease often without reference to the care of psychosocial or spiritual aspects of the patient/family (Saunders, 1993).

In order to provide holistic care successfully a team approach is usually adopted in patient management, focusing on the physical, psychological and spiritual issues aimed at the improvement of a patient's quality of life (Doyle, Hanks & MacDonald, 1995). This holistic care involves the patient, family, or significant others at its centre, with the health care team drawing on the expertise of different disciplines to work towards empowering the patient and family unit to have the utmost support/comfort until death occurs (Gurfolino & Dumas, 1994).

Palliative care services are provided in a variety of settings including hospices, hospitals, clinics, nursing homes and community settings (Commonwealth Department of Health and Family Services, 1998). The demand for palliative care services in the community setting has increased recently due to a number of factors. These include: reduced availability of hospital beds and need to reduce hospital costs; a desire for less intitutionalised care; and an ageing population in whom the morbidity and mortality associated with illnesses such as cancer and cardiovascular disease increase with age (NSW Health, 1993).

Within the guidelines of The National Strategy for Palliative Care in Australia (Commonwealth Department of Health and Family Services, 1998), patient choice and coordination is highlighted as an objective for future strategic planning. The provision of palliative care services need to take into account the individual person's needs, and to respect that person's autonomy and choices wherever services are provided. Several studies have illustrated that people with advanced incurable illness and a limited life expectancy have a preference towards being cared for at home rather than an inpatient setting (Hinton, 1994; Spiller & Alexander, 1993). Hence, to ensure an effective range of palliative care services is offered to a broad spectrum of individuals, community palliative care services will need to review their services to accommodate future demands.

As palliative care can occur in a number of different settings, the palliative care nurse requires broad and expert knowledge. The palliative care nurse is the team member who ministers to the patient more often than any other health professional, this gives the nurse the unique opportunity of getting to know the patient, and to observe what brings discomfort and what brings relief (Hanson & Cullihall, 1995). The nurse must be proficient at assessing both the physical and psychological needs of the patient, coordinating the team and referring the patient and their family to other agencies as required. Providing comfort through supportive listening is a large part of the nurse's role, particularly when physical symptoms are problematic and the death of the patient is near (Davies & Oberle, 1990).

1.3 STATEMENT OF THE PROBLEM

Freedom from depression and anxiety and the ability to adapt and adjust to different stages of illness enables the patient to maintain a better quality of life (Massie, 1989). While palliative care health professionals acknowledge that psychological well-being is an important dimension of the concept of quality of life, there is an absence of descriptive research directly focusing on the experience of depression or anxiety in this population. With a continued emphasis on, and demand for, care of the terminally ill in their home environment, it is important for research to center on this setting.

1.4 THE PURPOSE AND SIGNIFICANCE OF THE STUDY

Literature describing the prevalence of depression and anxiety among palliative care patients is limited and reveals the need for further studies in this field. It is stated in the literature that any person who is suffering from a life-threatening illness is at risk of developing depression and anxiety (Craig & Van Natta, 1979; Degoratis, Morrow, Fetting, Penman, Piasetsky, Schamale, Henrich & Carnickle, 1983; Williams, 1994). Therefore, it can be assumed that many palliative care patients are at risk of developing depression and/or anxiety.

Depression and anxiety can have significant impact on the quality of life of palliative care patients (Hodgson, Higginsin, McDonnell & Butlers, 1997; Kemp, 1995; Massie, 1989; Neale, 1993). Before looking at models for management and therapeutic treatment, there is a need to understand the extent of the problem and the impact this will have on the palliative care patient (experience). Knowledge of depression and anxiety among community palliative care patients will provide increased awareness among health providers and help clarify misconceptions. Exploring how palliative care patients perceive their lives while experiencing depression and/or anxiety can assist in developing future education programs for nurses and enhance the standard of nursing care. With the rising costs of hospitalisation, the trend towards increasing community services, and the patients' preference for home care, research focusing on patients in the community setting will help to enrich the provision of palliative care services provided.

1.5 RESEARCH OBJECTIVES

The objectives of this study are:

1. To explore the prevalence of depression and/or anxiety among community palliative care patients;

2. To determine if a relationship exists between risk factors and depression and/or anxiety in this population;

3. To identify which known risk factors can predict the symptom of depression and/or anxiety in this community palliative care population;

4. To describe the meaning of depression and anxiety as experienced by the palliative care patients.

Prevalence may be defined as the proportion of a population with the condition at a specific point in time and may be used to identify population subgroups for prevention strategies, to track changes in patterns of a disorder over time and to express the burden of a disorder in a population (Irwig, Shelley, Kleinbaum & Lyle, 1995). In this study prevalence is used to describe the extent of depression and anxiety among a community palliative care population on two specific occasions.

1.6 OPERATIONAL DEFINITIONS

For the purpose of this study, the following definitions apply:

Depression: a cluster of symptoms where indicators such as feelings of hopelessness, worthlessness, quilt, loss of self-esteem and inability to enjoy life are present (Massie & Holland, 1992).

Anxiety: a cluster of symptoms where indicators such as; feelings of apprehension, nervousness, restlessness and unease are present (Holland, 1989).

Prevalence: the proportion of a population with the symptom of depression and/or anxiety reported at a given time (Irwig et al., 1995).

Palliative care patient: a patient with a diagnosis of a life threatening illness for whom a cure is no longer possible (Doyle et al., 1995).

Palliative care nurse: a person registered with the Nurses Registration Board of New South Wales who for a period of at least one year has worked as a specialist nurse providing care to palliative care patients.

Community setting: the provision of care within the patient's home environment.

1.7 CONCLUSION

Depression and anxiety are common manifestations of psychological distress as experienced by palliative care patients. Specialist palliative care health professionals strive towards relieving such distress by providing holistic care and support to the patient and family. This study describes the extent of depression and anxiety within a community setting and determines whether previously highlighted risk factors in the literature are applicable to this population. This study also explores the impact of depression and anxiety on the palliative care patient.

In Chapter Two, the study is set in the context of palliative care, palliative care nursing, the psychological impact of a life threatening illness and other research into anxiety and depression.

CHAPTER TWO

Literature review

2.1 INTRODUCTION.

The review of the literature will focus on several areas important to the objectives of the study. First it is important to discuss the historical development of the discipline of palliative care and the developing trends and the role of the nurse in this specialty. Second, depression and anxiety will be defined and the consequences of unresolved depression and anxiety will be explored. Third, a review is made of the prevalence of psychological distress in various populations and settings. Finally, a critique is made of present diagnostic and screening tools used to detect anxiety and depression and the risk factors associated with the development of anxiety and depression are discussed. The following chapter contains a review of the literature related to these areas.

2.2 THE HISTORICAL DEVELOPMENT OF PALLIATIVE CARE.

During the Middle Ages hospices were known as havens for pilgrims and travellers, however, they also welcomed the sick (Mcleod & Glaetzer, 1998). The sick were honured and treated with great care, being valued as persons. At this time doctors did not treat the incurably sick or terminally ill (Saunders, 1993). It was thought to be unethical to treat a patient suffering a deadly disease. In doing so "...the doctor risked paying the penalty awaiting those mortals who challenged nature and the Gods" (Gorer, 1965). Thus, the original hospice care was primarily nursing focused (Redpath, 1998).

The word 'hospice' did not become synonymous with the care of the dying until the nineteenth century when the Irish Sisters of Charity opened a Hospice in Dublin in 1885 (Cavenagh & Gunz, 1988). In the mid 20th century the revolutionary work of Dame Cecily Saunders in the care of the terminally ill was a major milestone for hospice care. Her work and research demonstrated that the quality of life of the dying could be greatly improved by alleviating emotional, spiritual and social distress in addition to physical suffering. This became the driving force behind the hospice movement (Clark, 1993). In 1967 Cecily Saunders opened St. Christopher's Hospice in England, bringing the skills she had acquired in the three disciplines of nursing, social work and medicine (Amenta, 1986). Although the work of Dame Cecily Saunders took a medical perspective, it brought about major changes in the approach to caring for the incurably ill. The concept of caring remained the central issue. Redpath (1998, p.4) describes the concept of caring in palliative care as "... a problem-solving approach to the multi-faceted needs of the dying person".

The hospice movement in Australia dates back to the late 1800s with the establishment of Sacred Heart Hospice in Sydney in 1890 and Caritas Christi in Melbourne in 1938 (Redpath, 1998). Since the 1980s there has been rapid growth in interest and services in Australia largely resulting from influences in the United Kingdom and North America (Cavenagh & Gunz, 1988). Efforts to modernise and extend palliative care services were led initially by the concern of the public and nurses caring for dying patients who felt the need to improve the care and quality of the management of terminally ill patients (Clark, 1993). Health care organisations recognised that there was the possibility for substantial economic advantage, particularly if community services were improved. Patients would be encouraged to spend more time at home in their last months of life, rather than in a hospital bed, reducing healthcare costs. In 1982, the first palliative care nurse specialist position was created for patients in the community (Redman, White, Ryan & Hennrikus, 1995). Palliative Medicine as a specialty was recognised in 1988 by the Royal Australian College of Physicians (Wilkes, 1993).

In the literature, the terms hospice, terminal and palliative care are used synonymously by some authors. However, in Australia and the United Kingdom, the word "hospice" refers to a designated institution where the focus is on the care of the terminally ill. In the United States of America the term "hospice" describes the philosophy of care given to the terminally ill and such care can be practiced in a variety of settings (Magno, 1990). According to Woodruff (1993) and Ahmedzai (1993) the term 'terminal' refers to the final phase of a person's life where death may occur within days or weeks. The World Health Organisation (WHO) strongly recommends the early introduction of the palliative care concept into a patient's management plan, whether this is curative or palliative (WHO, 1990). More recently in response to the

WHO recommendations, the term "palliative care" is increasingly used in a broader sense and encompasses care provided to patients and families throughout the course of a progressively incurable illness, rather than care only in the final phase of the illness (Ahmedzai, 1993).

2.3 THE DEVELOPING TRENDS IN PALLIATIVE CARE.

There are several developing trends occurring in palliative care. These include the medicalisation of palliative care, the increasing prevalence of chronic diseases and an ageing population (Clark, 1993; Commonwealth Department of Health and Family Services, 1998; Field, 1994; Field & James, 1993). Although these trends may influence the future of palliative care services , the most significant trend in relation to this study is the shift towards home-based care.

2.3.1 The shifting focus of the site of care in palliative care.

The shift to community palliative care services is not new. In Canada and the United States community-based programs commenced in 1986 and have rapidly expanded (Roe, 1992). The Canadian and American Health Care systems have promoted palliative care in the home as a means of improving quality of life for the dying and their families, as well as being a more cost-effective option than hospitalisation. For example, Brown, Davies and Martens (1990) state that a home care program in Montreal reported a saving of $650,000 over a five year period to the health care system.

In Australia there is also an emphasis towards providing more palliative care services in the home. This is mainly economics related, with the prospect of reducing health care costs and minimizing the demand on acute care beds (NSW Health, 1993). However, to date in Australia there is limited research that demonstrates the economic value of home care. The results of Aristides and Shiells' (1993) economic evaluation of a domicillary palliative care nursing service in Australia could not demonstrate that home care was able to reduce inpatient costs. A major limitation of the palliative care service studied was that nursing staff were unable to obtain access to anti-emetic and pain controlling drugs outside normal business hours. This may have increased the need for crisis admissions to hospital, in turn increasing economic costs.

There are several studies that indicate that the home is the preferred place for a person with a terminal disease (Brown, et. al., 1990; Dunne & Falkenhagen, 1988; Googe & Varricchio, 1981; Hinton, 1994a; Karlsen & Addington-Hall, 1998; Pringle & Taylor, 1984). Brown et. al. (1990) identified why advanced cancer patients and families preferred having care at home rather than at an institution. These reasons included being able to continue with established systems of interaction, communication, social, and emotional involvement with friends and family. Being able to remain at home enabled patients and family to maintain normality in their lives which was similarly highlighted as important. Patients equated care at home with concepts of freedom and control and family members who were involved in providing care found it gratifying and rewarding to care for their loved one (Brown et al., 1990). James and Field (1992) found that the anxieties and apprehension associated with dying can be substantially reduced for the patient and family when in their own home. Similarly, Hinton's (1994a) research with patients and carers also demonstrated that home is the preferred site of care and enhances their quality of life. However, in circumstances where the illness progressed over time, most patients and families in Hinton's study requested inpatient admission. The main difficulties of remaining at home were related to stress on the family.

Although these studies reflect the home setting is a preferred place to be during the terminal phase of their illness, there are several studies which indicate that the actual place of death is in the hospital setting (Addington-Hall, MacDonald, Anderson & Freeling, 1991; Cartwright, 1991; Dunlop, Davies & Hockley, 1989; Karlsen & Addington-Hall, 1998; Sykes, Pearson & Chell, 1992).

Despite home being the preferred place of care and the possibility of economic savings for health services (Karlsen & Addington-Hall, 1998), the successful provision of care at home depends primarily on the availability and willingness of the carer to provide the care. In particular, the provision of nursing care teams to support the carer at home is required (Hinton, 1994b; Karlsen & Addington-Hall, 1998) For example, Johnson, Cockburn and Pegler (1988) undertook an evaluation of 224 carers of terminally ill patients in the Marie Curie relative support service. They concluded that the majority of carers were female and elderly and were satisfied with the service enabling sixty-two percent of palliative care patients to die in their preferred environment, that is their home. Although there is an increasing shift towards community based palliative care services, to continue achieving the goals of care for the patient and carer, both inpatient and community care will be necessary in the future (Hinton, 1994b).

In summary, the literature illustrates there is a trend towards maintaining palliative care patients within their home environment. Within the community health care setting, it is usually the nurse who ministers to the patient more often than other health professionals (Johanson & Johanson, 1996), therefore, it is important to understand the role of the palliative care nurse.

2.4 THE ROLE OF THE NURSE IN PALLIATIVE CARE.

The central focus of this study is the community palliative care patient. However, because the majority of workers within the health care industry consists of nursing staff (approximately 53% of all staff employed) (National Mental Health Report, 1996) the role and perception of the nurse within the field of palliative care needs to be examined. It is the community nurse who is seen by patients and carers as the most central figure when care is delivered in the home environment (Boyd, 1992; Hanson & Cullihall, 1995; Johanson & Johanson, 1996). The nurse usually collects patient/family information and confers with the patient and family to listen to and acknowledge their concerns and problems and to discuss their goals (Johanson & Johanson, 1996). Such close contact and prolonged communication with the patient and family not only allows for assessment of the patient's physical and functional status, but also draws the nurse closer to the patient. The nurse can become the patient's advocate who can then articulate the patient's and family's needs and concerns, communicating suggestions for management to other members of the health team. Scanlon (1989, p492) describes nursing as a profession which is "... most attuned to the goals of palliative care since the fundamental imperatives of nursing direct us to provide comfort and alleviate suffering". Williams (1982, p9) suggests that in the case of the dying patient the role of the physician diminishes and it is the nurse "... who assumes the dominant complimentary role".

2.4.1 The role of the palliative care nurse.

There remains major deficits in the literature on the role of the palliative care nurse, with limited research in this area. No research has been undertaken that explores what is the role of the palliative care nurse in the identification and management of psychological symptoms such as anxiety and depression. Several authors have presented discussion papers on this role. Williams (1982) suggests that the role of the palliative care nurse is one that is supportive. This is reiterated by McCaffery and Beebe (1989), who also suggest nurses have a placebo effect to pain management by their psychological support in assisting the patient to cope with pain regardless of whether or not the cause is known. A qualitative research study by Davies and Oberle (1990) examined the supportive role as perceived by one palliative care nurse. The nature of a supportive role had a number of dimensions which included valuing the patient as an individual, getting in touch with the patient and family members, being available and spending time with the patient and family. Empowering the patient and family by assisting in defusing problems, giving information and preserving the integrity of the family were also identified as part of the supportive role (Davies & Oberle, 1990). To date, Davies and Oberle's (1990) study has not been replicated on a larger sample of palliative care nurses.

According to Bergen's (1991) literature review of nurses caring for the terminally ill in the community, the majority of specialist nurses working in the community are viewed as supportive and have the primary roles of advisor, counselor, resource and liaison person. Boyd (1992) surveyed the structure and working arrangements of 12 urban hospice-based home care teams in the United Kingdom. Boyd's survey concluded that the staff of the home care services saw their role as giving support and advice to patients and families in the community, with teaching as a another major and important role. This survey did not specifically address aspect related to management of specific psychological conditions.

2.4.2 The role of the palliative care nurse in the management of patients with psychological distress.

Fincannon (1995) in a review of referrals for oncology patients to psychiatric services found while palliative care nurses may not always be able to identify specific psychiatric disorders, they are skilful in the recognition of psychological distress in patients. According to Billings (1995), important indicators for depression include feelings of hopelessness, worthlessness, loss of self-esteem, guilt and wishing to die. Through close contact with their patients, it is suggested that the primary palliative care nurse will be able to detect these feelings and provide psychological support and alert the doctor for appropriate treatment (Fincannon, 1995). This literature review identified the need for research that explores how palliative care nurses perceive their role in the identification of anxiety and depression, the skills required in the assessment and management of these psychological conditions and the effectiveness of palliative care nurses in addressing this area of patient care.

Treatment for depression generally consists of both psychotherapeutic and pharmacological measures (Breitbart, 1989). It has been suggested that palliative care nurses can fulfill the role of an educator, counsellor and advisor by ensuring medications are correctly taken, informing patients of possible side effects of medications, and by contacting medical personnel and discussing the effect of such pharmacological interventions (Massie, Gagnon & Holland, 1994). Psychotherapeutic management focuses on reducing emotional distress, improving morale and regaining a sense of control (Massie, et al., 1994). Massie et al. (1994) outlines the importance of counselling/supportive role of the palliative care nurses, which is supported by Davies and Oberle's (1990) research. While there is little research, it is suggested that the palliative care nurses can assist the patient to review their reversals of roles such as poor health and body integrity, reduced self-esteem, and help plan future directions (Massie et al., 1994). Feelings of uselessness or worthlessness can be counteracted by encouraging patients to verbalise their feelings, an area that palliative care nurses can contribute (Breitbart, 1989).

Although psychotherapy and antidepressant medications are the two major treatments of anxiety and depression, there are everyday nursing interventions which can assist in restoring well-being. Valente and Saunders (1989) suggest encouraging self-care which can demonstrate to the patient that they are able to do something for themselves. However, for the terminally ill patient, physical activity is sometimes difficult, so realistic goal setting is necessary (McVey, 1998). Breitbart (1989) states that depressed patients often view the world in a negative manner. Valente and Saunders (1989) suggest one strategy which can provide positive input is the encouragement of patients to make a list of all the positive experiences that occur during their day.

Finally, nurses need to know if the patient's distress includes suicidal ideations. Valente and Saunders (1989) suggest that there is a belief by some health professionals that discussing the subject of suicide will in fact promote the idea. However, these authors state that most suicidal patients want to talk about their intentions of suicide and by allowing the patient to express this desire the practitioner actually may reduce the likelihood. There is a low rate of suicide ideation reported among palliative care patients (Chochinov, 1992; Lynch, 1995; Massie et al., 1994; Twycross, 1995; Wilson, 1989).

2.5 THE PSYCHOLOGICAL IMPACT OF CANCER.

For most individuals, cancer is among the most feared of all diseases and is equated with a slow painful death (Holland, 1989). Traynor (1992) suggests that the idea of death is generally remote and abstract, but when people are forced to accept its inevitability, it can be traumatic. Massie and Holland (1992) suggest that human beings are orientated toward the future and their behaviour rests on a series of predications. Therefore, when a diagnosis of cancer is given and the realisation of a limited future permeates, the individual's ability to cope successfully with the situation is threatened (Cain, Stacy, Jusenius & Figge, 1990). However, Breitbart, Chochinov and Passik (1998) suggest that it is not death that is feared, but the uncertainty of the process that leads to death. The perceptions associated with this turmoil have been identified in the literature as fear related to a painful death, disfigurement, and increasing disability and dependency (Breitbart et al., 1998; Cohen & Lazarus, 1979; Miller & Walsh, 1991).

For the palliative care patient, being informed that treatment has failed and their disease has spread produces emotional distress (Paton, 1996). The degree of this distress is dependent on the individual's coping mechanisms, medical factors such as site and stage of disease, the presence of pain and the availability and perception of emotional support from family/friends (Breitbart, 1989; Holland, 1989; Massie & Holland, 1992; Woodruff, 1993). Ineffective or maladaptive coping is likely to result in intense anxiety, denial, anger or depression and an inability to resolve problems (Lazarus & Folkman, 1984). Massie and Holland's (1992) review of the most common psychiatric problems in cancer patients suggest that symptoms of depression and anxiety can occur as part of a normal response to crisis and with support may be resolved within seven to ten days. Breitbart (1989) suggests that nearly 90% of the psychiatric disorders seen in the cancer population are either reactions to, or manifestations of, disease or treatment. However, if this reactive distress persists for weeks or months, it is not adaptive and will require treatment, with a thorough evaluation of the duration and severity of symptoms and possibly psychiatric referral (Twycross, 1993).

The impact of a diagnosis of cancer or recurrence of disease not only affects the patient but also the entire family. Kemp (1995) suggests that the psychological needs for the family and individual are similar. For example, Hileman, Lackey and Hassanein (1992) examined the needs of 492 home caregivers of cancer patients. It was found that caregivers identified many psychological and informational needs which changed as the patient's condition changed. As the patient's activity level decreased, the caregiver's psychological needs increased.

A prospective study by Hinton (1994a) of 77 patients and their families receiving palliative care home services indicated that 17% of relatives were experiencing high levels of depression and 14% were experiencing anxiety in the later stages of care. Neale (1993) suggests that the emotional problems associated with caring are likely to be compounded by anxiety over the impending death and bereavement of the cared-for person. According to Seale (1990), patients in their last year of life have particularly high levels of dependency, resulting in severe restrictions in carers' lives. Hodgson et al. (1997) research into the psychological responses by family members caring for relatives with cancer also highlights the negative impact on carers.

Hodgson et al (1997) examined anxiety among family members of 77 advanced cancer patients from six home care services. They reported that family anxiety increased as the patient's physical and psychological symptoms accelerated. Also, family anxiety at referral to the service strongly predicted family anxiety in the last four weeks of life. Lewis' (1990) study into family support needs also concluded that partners experienced more depression and marital discord as the demands on them as caregiver increased. These studies suggest that caring for a dying relative is difficult and becomes more stressful as death draws near, challenging the carer's coping mechanisms and resulting in negative psychological well-being for the family.

2.6 THE DEFINITION OF ANXIETY AND DEPRESSION.

The term 'depression' has been used to describe a symptom, syndrome, emotional state, reaction or disease (Stuart, 1995; Yager & Gitlin, 1995). The use of the word depression to describe feeling sad or low in spirits is part of everyday language and is an experience familiar to nearly everyone (Payne, 1998). A depressed mood is common after a disappointment or a loss. For most people alternative coping strategies and supportive social networks help to alleviate those brief depressive states (Massie & Holland, 1992).

Within psychiatric terminology, depression is a diagnostic category that denotes a mood (affective) disorder (Montgomery, 1990). The symptoms of depression have three components; somatic (loss of energy, anorexia), cognitive (feelings of worthlessness), and affective (sadness, crying) (Blacker, 1997). A criterion for a diagnosis of depression is that symptoms are persistent rather than transient, that is, longer than two weeks (American Psychiatric Association, 1995). Like depression, the term 'anxiety' covers a number of different entities. Anxiety is a state of apprehension, tension, or uneasiness that occurs in anticipation of danger (Cummings, 1995). Anxiety can be characterised by somatic, cognitive, and behavioural symptoms (Yager & Gitlin, 1995), for example, tremours, hot and cold flushes, sweating and palpitations. Cognitively, anxiety is characterised by poor concentration and subjective confusion (Yager & Gitlin, 1995). For the purpose of this study both depression and anxiety will be defined as a cluster of symptoms as defined in Chapter 1, section 1.6.

2.7 HEALTH PROFESSIONALS PERSPECTIVE OF DEPRESSION AND ANXIETY AMONG CANCER PATIENTS.

Depression and anxiety are recognised as common psychological problems among cancer patients (Massie, 1989). For example, Massie and Holland's (1987) study of 215 cancer patients found that 47% of the patients had a clinical psychiatric disorder. Of the 47% of patients found to have a clinical psychiatric disorder, more than two-thirds of these patients had reactive anxiety and depression which were reactions to, or manifestations of, disease or treatment. However, misconceptions exist in relation to depression and anxiety among health professionals. These include beliefs that all cancer patients are depressed, depression is 'understandable', treating depression in cancer patients is ineffective, or that treatment leads to intolerable side effects (Billings, 1995; Lynch, 1995; Massie et al., 1994; Massie & Holland, 1990).

There are several studies which have focused on aspects of these beliefs and offer evidence that they are myths. For example, Popkin, Callies and McKenzie (1985) performed a retrospective survey of tricyclic antidepressant use in 50 medically ill patients (including some cancer patients) who were diagnosed by a psychiatrist as having a major depressive syndrome. In 32% of patients the drugs were withdrawn because of unacceptable side effects such as nausea, vomiting and urinary retention. However, 40% of these patients responded to treatment. Schwartz, Speed and Beresford (1989) retrospective study by of 50 medically ill patients (including 11 cancer patients) with a major depressive disorder who had been given tricyclic antidepressants, concluded that 50% had improved. Therefore, the belief that treatment for depression or anxiety among palliative care patients is ineffective, or leads to intolerable side effects has been demonstrated to be incorrect.

There are also several studies that illustrate that doctors and nurses do not always detect or address the psychological concerns of their patients. Maguire's (1985) study, in which he directly observed doctors and nurses talking with real, simulated or role playing patients suffering from terminal illness, revealed that health professionals consistently used distancing tactics. The doctors and nurses assumed that patients who develop psychological problems will disclose them, so patients were rarely asked directly how they were adjusting emotionally. When a patient spontaneously mentioned both physical and psychological difficulties the doctor or nurse followed up only on the physical problems (Maguire, 1985).

A more recent study by Heaven and Maguire (1997) using a pre-test and post-test design, evaluated the training of 44 hospice nurses' communication skills and the nurses' ability to register the concerns disclosed by their patients. Audiotapes from the nurses' interviews with patients were rated by a trained rater to determine the concerns actually disclosed by patients. These authors found there was a strong bias for patients to disclose physical symptoms and withhold psychological, social and spiritual concerns. When nurses only asked questions regarding the physical condition in the early stages of interviews, patients came to believe that they were only interested in the physical aspects of their illness. Therefore, when the patients were asked more psychologically focused questions later in the interview they believed nurses were not really interested in these aspects. Heaven and Maguire (1997) concluded that further education about appropriate interviewing techniques among health professionals is needed.

Payne and Endall's (1998) study into the detection of depression and anxiety by nine surgeons and 51 carers' of breast cancer patients using quantitative methods, also demonstrated that medical staff failed to recognise a significant proportion of psychological distress in their patients. Hardman, Maguire and Crowther's (1989) study into the recognition of psychiatric morbidity on a medical oncology ward revealed that specialist chemotherapy nurses fared no better than their colleagues in detecting psychiatric morbidity. Reese and Brown (1997) investigated the differences between nurses, social workers and clergy and their ability to discuss psychological and spiritual concerns in a hospice setting. That study revealed evidence that there are varying degrees of emphasis related to these concerns by patients and nurses avoided discussing psychological issues. A study by Alexander (1990) investigating the major sources of stress for palliative care nurses, revealed that 80% of the 61 nurses interviewed reported that psychiatric symptoms such as depression or delusions were more stressful to deal with than physical symptoms.

From the literature review it can be seen that there are misconceptions amongst the health care team regarding the need for treatment for depression in palliative care patients, anxiety and depression are under-diagnosed and under-treated in the oncology and palliative care settings. Research has identified that a possible reason for the lack of attention given to psychological symptoms may be that caring for patients with these symptoms are perceived as stressful for palliative care nurses. This section of the review highlights the overall lack of research that addresses anxiety and depression within the palliative care patients, and the need for further research that investigates how the healthcare team respond the depressed or anxious patient.

2.8 THE PREVALENCE OF DEPRESSION AND ANXIETY.

The most frequently encountered emotional disorders in all medically ill patients are depression and anxiety (Billings, 1995; Lynch, 1995; Moorey, et al., 1991). The intensity and frequency of depression or anxiety increases with the increased severity of illness (Massie & Holland, 1990). A review of the literature identified that despite significant associated morbidity, depression is frequently underdiagnosed in medical settings (Brody & Larson, 1992; Magruder-Habid, Zung, Feusser, Alling, Saunder & Stevens, 1989). Research has shown that clinically significant depressive symptoms are detected in as many as 36% of patients with non-psychiatric general medical conditions (Magruder-Habid et al., 1989). Brody and Larson's (1992) research in the primary care setting revealed that in only one third to one-half of patients with major depressive disorders, was this condition recognised by their clinicians. Research by Zung, Broadhead and Roth (1993) on the incidence of depression among individuals in the primary health setting, illustrated that one in five patients seeing a primary care practitioner has significant symptoms of depression, yet only one in a hundred patients reported depression as a reason for visiting the primary doctor. Therefore, not only is detection by health professionals a problem in this setting, but patient's lack of disclosure of his/her emotional state may also be the problem.

The degree of risk for a major depression in the lifetime of a normal healthy population is 25% to 30% for adults (NSW Health, 1997). In NSW 25% of all hospitalisations for mental illness were among older people (NSW Health, 1997). According to the 1997 NSW Health Department figures on mental health disorders, the most common mental disorders in adults are a major depressive episode, simple phobia, social phobia and alcohol dependence.

The reported prevalence of depression and anxiety within the oncology patient population varies from 4.5% to 58% (Breitbart et al., 1995). There are several possible reasons for this wide variation including problems related to diagnosis, incorrect assessments and misconceptions regarding depression and anxiety by health professionals (Lynch, 1995; Massie et al., 1994; Massie & Holland, 1990). Also, depression and anxiety are associated with higher levels of disability, pain and severity of illness as seen in advanced cancer patients (Breitbart et al., 1998; Needham & Higgs, 1995; Tywcross, 1995; Williams, 1994).

Carroll et al. (1993) screened 806 inpatient and outpatient cancer patients using the Hospital Anxiety and Depression (HAD) scale. The HAD scale is a screening tool used to detect likely "cases" of clinically significant depression or anxiety. Carroll et al. reported that 48% of their sample were depressed and 41% were anxious. Donnelly, Walsh and Rybicki (1995) reported a depression prevalence of 21% and anxiety prevalence of 11% among 1,000 inpatient and outpatient palliative care patients. However, Donnelly and colleagues did not use any specific psychological screening tools or assessment criteria. Their sole judgment of prevalence and severity of the symptom was made using a three point graded questionnaire (mild, moderate, severe) and was completed by different interviewers (nurse/doctor). The researchers acknowledge discrepancies may have existed between interviewers.

Other studies have reported lower levels of depression and higher levels of anxiety in the study populations. Wood and Mynors-Wallis (1997) undertook a pilot study of 24 palliative care patients using the HAD scale, and concluded that only eight percent were depressed and five percent were anxious. The small sample size must be taken into account when considering the results of this study. Moorey et al. (1991) reported a prevalence of 9% for depression and a prevalence of 27% for anxiety in 568 inpatient and outpatients with cancer. Payne and Endall (1998) reported three percent depression and 27% anxiety among 164 females attending a breast clinic using the HAD scale for screening. Ibbotson et al. (1994) reported a prevalence of 17% for a major depressive illness and/or generalised anxiety disorder among 513 patients with cancer by combining depression and anxiety scores. However, the researchers excluded adjustment disorders that is, disorders characteristic of maladaptive reactions to the cancer illness, from their analysis and this exclusion could have lowered the prevalence rate. Cassileth, Lusk and Walsh (1986) investigated anxiety levels in 378 cancer patients at different stages of their disease and concluded that patients receiving palliative care displayed significantly higher anxiety scores than did patients under curative treatment or follow up care. These studies report prevalence rates ranging from 9% to 17% for depression and a significantly higher prevalence of anxiety.

Several researchers have suggested that the difference in the prevalence rates across studies are related to the stage or type of illness, whether or not the patients are receiving treatment such as radiotherapy or cytotoxic therapy, differences in demographic characteristics and variations in the application of diagnostic criteria or clinician reports with an absence of criteria (Chochinov, Wilson, Enns & Lander, 1994; Lynch, 1995). For example, Kathol, Mutgi, Williams, Clamon and Noyes (1990) found a diagnosis of depression in 152 cancer patients differed as much as 13% between diagnostic systems used such as, the Diagnostic and Statistical Manual for Mental Health Disorders criteria version three-revised (DSM-III-R), the Research Diagnostic Criteria and Endicott criteria. Bukberg, Penman and Holland (1984) argues patients who are severely ill are more likely to be depressed because of impaired coping capacities due to illness, grief related to personal loss, anticipation of death and physical impairment. Table 2.1 is a selection of research on prevalence rates of depression and anxiety among oncology and palliative care patients illustrating the variance. Further explanation and discussion of the different studies of diagnostic criteria and screening tools follows respectively in section 2.9 and 2.11 of this chapter.

Table 2.1 A selection of prevalence studies of depression and anxiety among oncology and palliative care patients.

Authors	Sample	Measures	Results	Conclusion
Cassileth, Lusk & Walsh. (1986)	378 oncology outpatients.	Spielberger State -Trait Anxiety Scale.	Tally of scores.	Palliative care patients exhibited higher anxiety scores.
Chochinov et al., (1994)	130 palliative care inpatients.	SADS, semi-structured interviews.	Depression rates determined by RDC and Endicott criteria. RDC: low threshold= 26% depression high threshold = 13% depression Endicott: low=23% depression high= 13% depression	Changing the threshold makes a difference to prevalence rates. Inclusion of somatic symptoms inflates rates in low threshold.
Curtis, Krech & Walsh. (1991)	100 oncology inpatients & out-patients.	Semi-structured interviews.	Subjective rating by interviewer. 31% depression, 20% anxiety.	Authors acknowledged there may of been interviewer bias with the symptom severity rating of depression and anxiety. More males than females were depressed.

Key:
HADS = Hospital Anxiety and Depression Scale.
SADS = The Social Adjustment Scale.
RSCL = The Rotterdam Symptom Check List.
RDC = Research Diagnostic Criteria.

Table 2.1 Continued... A selection of prevalence studies of depression and anxiety among oncology and palliative care patients.

Authors	Sample	Measures	Results	Conclusion
Derogatis et al., (1983)	215 oncology inpatients.	Clinical interview Schedule DSM-III criteria Symptom Self-report Scale (SCL-90-R).	47% of oncology patients received a psychiatric diagnosis	Two-thirds of the diagnoses involved reactive adjustment disorders which are often responsive to psychological interventions. Only 13% were diagnosed with major depression. The use of epidemiological methods in this study and findings represented valid estimates of the phenomena.
Donnelly, Walsh & Rybicki (1995)	1000 palliative care inpatients & outpatients.	Semi-structured interview & Clinical assessment of patient symptoms.	Subjective rating by interviewer. 11%= Anxiety. 21%= Depression	More females than males were depressed and anxious. Patients with advanced cancer were polysymptomatic. Suggest the eight page symptom assessment tool needs refining.
Hinton (1994a)	77 terminal cancer community patients & 77 carers.	Semi-structured interview.	32%= patient depression. 36%= carer depression	17% had tolerable psychological symptoms in the last 8 weeks of life. 11% of patients experienced distressing symptoms including pain, depression, weakness, anxiety & dyspnoea.
Massie & Holland (1987)	546 oncology inpatients & outpatients.	Semi-structured interview and DSM-III criteria.	20% = major depression. 27%- adjustment disorder.	Hospitalised patients more depressed. Once appropriate diagnosis is made correct therapy can be given- psychotherapy, antidepressants.

Key: DSM - The Diagnostic and Statistical Manual for Mental Health Disorders.
SCL - Symptom Self-report Scale.

It has been suggested that inpatients are more likely to be depressed than community patients (Hinton, 1994b). This hypothesis is supported by a study by Carroll et al. (1993), in which the researchers demonstrated that cancer inpatients were significantly more depressed than outpatients (13.9% vs 7.8% respectively), but no significant difference was determined for anxiety scores. On the other hand, Karlsen and Addington-Hall (1998) found no significant difference between reported depression and anxiety in home based cancer patients and hospital cancer patients. It should be noted that Karlsen and Addington-Hall relied on respondents stating they were anxious or depressed, whereas, Carroll and colleagues used the HAD scale to measure depression and anxiety. This measurement difference may account for the inconsistent results.

Shivers (1998) suggests that the negative psychological response by patients who are hospitalised is influenced by several factors such as the seriousness of the illness, the manner of admission to the hospital, the patient's feelings, thoughts and cultural attitudes about the hospital, and information given by family, friends, and the attending doctor. The hospitalised patient assumes the sick role and may experience emotions such as anxiety, fear, loneliness, powerlessness and helplessness. Shivers (1998) claims that the home based patient may also experience these feelings, but usually to a lesser degree.

Depression and anxiety are classified as separate disorders clinically using the Diagnostic and Statistical Manual for Mental Disorders criteria (DSM-IV). However, a review of the literature reveals a strong relationship existing between depression and anxiety. That is, some patients diagnosed with depression also have a degree of anxiety and vice versa, highlighting the need for diagnostic and measurement clarity (Dealy, Ishiki, Avery & Wilson, 1981; Garvey, Tollefson & Tuason, 1987; Stravrakaki & Vargo, 1986).

Schonfield, Verboncouer, Fifer, Lipschultz, Lubeck and Bueschingʼs (1997) study examined the degree to which untreated anxiety disorders and major depressive disorders occurred singly or in combination among primary health care patients. The results reported the prevalence of major depression when an anxiety disorder occurs in 57 % of the 319 patients. Carroll et al. (1993) reported 16.6% (134) of cancer patients in their study had both depression and anxiety scores in the borderline range on the HAD scale and that 4.4% (36) had both depression and anxiety in the abnormal/high range. These researchers also found a significant correlation ($r = 0.519$, $p < 0.001$, $n = 809$) between depression and anxiety subscales of the HAD scale. Massie and Holland (1992) suggest that the patient with cancer who experiences acute pain, or acute or chronic respiratory distress, usually suffers high levels of anxiety.

2.9 THE DIAGNOSIS OF DEPRESSION AND ANXIETY.

The Clinical Interview Schedule is considered the ʻgold standardʼ for diagnosing depression and anxiety (Lewis & Wessely, 1990). It is a semi-structured clinical interview conducted by a specially trained person, in which symptoms experienced by the patient are matched to sets of diagnostic criteria based on the American Psychiatric Association Diagnostic and Statistical Manual for Mental Disorders (DSM-IV) (Lewis & Wessely, 1990; Lynch, 1995). The DSM-IV criteria lists a number of depressive disorders such as, minor depressive disorder, major depressive disorder, dysthymic disorder, bipolar disorder and mood disorders due to a general medical condition (Shivers, 1998). However, the DSM-IV criteria for a depressed mood consists of a number of symptoms including depressed mood for most of the day, diminished interest or pleasure in nearly all activities, changes in appetite, insomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness, hopelessness and helplessness and impaired ability to concentrate (Blacker, 1997). A number of concurrent symptoms experienced during a two week period would indicate a diagnosis of depression (American Psychiatric Association, 1995).

The DSM-IV criteria for anxiety also has a number of classifications of disorders, for example panic disorders, phobias, obsessive-compulsive disorder, acute stress disorder and anxiety due to medical condition (Shivers, 1998). In general, the clinical symptoms of anxiety are too numerous to list in detail, but include physiologic, psychological or emotional, and intellectual or cognitive responses to stress. For example, dyspnea or hyperventilation, weakness or muscle tension, irritability, decreased interest and inability to concentrate (Shivers, 1998). Within the palliative care population where somatic symptoms experienced may be a result of the patient's disease rather than a symptom of depression, the use of diagnostic criteria is difficult.

Clinician rating scales have become popular in research studies to determine depression and anxiety (Snaith & Taylor, 1985). However, it has been recognised that not only do the scores vary depending on the population to which they are applied, but there is considerable variation among clinicians in the way in which these rating scales are applied (Chochinov et al., 1994; Kearns, Cruickshank, Mcguigan, Riley, Shaw & Snaith, 1982). For example, Kathol and colleagues. (1990) found a variation of between 25% to 38% in the diagnosis of major depression in 152 cancer patients, depending upon which diagnostic system was used.

2.10 PROBLEMS ASSOCIATED WITH DIAGNOSIS OF DEPRESSION AND ANXIETY IN PALLIATIVE CARE PATIENTS.

The diagnosis of depression and anxiety in patients with advanced cancer is potentially problematic because many of the signs and symptoms of depression and anxiety such as, anorexia, weight loss, constipation, sleep disturbance, lack of concentration, feelings of guilt and fears about the future occur regularly in such patients (Billings 1995; Breitbart et al., 1995; Kelly, 1995; Massie et al., 1994; Massie & Holland, 1992; Twycross, 1993; Twycross, 1995; Walsh, 1989). Billings (1995) suggests that sleep disturbances may be a result of pain or other physical distress, and these should be excluded. Fatigue and difficulty concentrating may be the result of cancer and its treatment, as anorexia often accompanies advanced cancer. Wilson (1989) suggests that because many physiological symptoms are secondary to progressive disease processes, subjective symptoms become more important for the diagnosis of depression and anxiety in this group of the physically ill. According to

Billings (1995) features such as dysphoria, feelings of hopelessness, and worthlessness, guilt, loss of self-esteem and wishing to die are more reliable indicators of depression in the terminally ill.

The literature also suggests that signs and symptoms of depression and anxiety in the palliative care patient may be caused by many organic factors. These may include central nervous system involvement of a tumour, metabolic disturbance such as hypercalcemia, endocrinologic disturbance such as hypothyroidism, nutritional deficiency of vitamin B12, infection, drug side effects such as corticosteriods and several chemotherapeutic agents (Massie, et al., 1994).

2.11 INSTRUMENTS USED IN ASSESSING DEPRESSION AND ANXIETY.

The use of the DSM-IV criteria classification system or clinician rating scales in the clinical field may not be appropriate. However, self-report instruments are described as having a role in the initial steps in screening for depression and/or anxiety (Breitbart et al., 1995; Massie, 1989). Some commonly used instruments include the Beck Depression Inventory (BDI), the Hospital Anxiety and Depression Scale (HAD), the General Health Questionnaire (GHQ), the Hamilton Anxiety Scale, the Montgomery and Asberg Depression Rating Scale, the Rotterdam Symptom Check List (RSCL) and the Profile of Mood States (POMS) (Breitbart et al., 1995). The advantages of using self-report instruments are that they directly assess the patient's views and ideally require little staff time to administer. The disadvantages of self-report instruments are that the patient may be unable to complete the questionnaire due to a language barrier, motivational or cognitive difficulties.

One of the main difficulties of self-report tools is that they may not be appropriate for the population to whom they are administered. The questions asked in the BDI are specifically related to somatic and cognitive dimensions. Somatic symptoms usually associated with the diagnosis of depression and anxiety, such as anorexia, weight loss, sleep disturbance, lack of concentration and fears about the future may be a result of the palliative care patient's disease rather than symptoms of depression or anxiety (Kelly, 1995; Lynch, 1995; Twycross, 1995; Walsh, 1989). Therefore, tools that include questions about somatic symptoms are problematic in the palliative care setting and may possibly lead to false positive results (Kathol et al., 1990).

An extensive review of the literature revealed that the HAD scale is generally used as a screening tool for oncology and palliative care patients because it specifically excludes references to somatic items (Carroll et al., 1993; Moorey et al., 1991; Payne & Endall, 1998; Razavi et al., 1990; Williams, 1994; Wood & Mynors-Wallis, 1997). A literature review by Payne (1998) investigating prevalence rates of depression among palliative care patients from 1992 to 1996 also concluded the HAD scale was the most frequently used screening tool.

The HAD scale consists of fourteen items, seven of which relate to depression and seven to anxiety. Items for the depression sub-scale concentrate on the concept of anhedonia (loss of pleasure response) since '...this is probably the central psychopathological feature of that form of depression which responds well to anti-depressant drug treatment' (Zigmond & Snaith, 1983, p.362). Items for anxiety sub-scale are taken from the Present State Examination and Zigmond and Snaith's own research into the psychic manifestations of anxiety. It was designed for use in medical out-patient clinics to detect clinical cases of depression and anxiety and to assess the severity of depression and anxiety without contaminating scores by reports of physical symptomatology (Zigmond & Snaith, 1983).

Since the development of the HAD scale, it has also been validated in a multitude of settings and populations, particularly among the oncology population in hospice, hospital and community settings (Payne & Endall, 1998; Razavi et al., 1990; Williams, 1994; Wood & Mynors-Wallis, 1997). A summary of research studies where the HAD scale has been used in the oncology and palliative care populations is provided in Table 2.2. This summary illustrates the variety of cut-off points used to determine clinically significant depression and anxiety and highlights the different settings in which this tool has been used and in some instances validated.

Table 2.2 A summary of oncology and palliative care studies that have used The Hospital Anxiety and Depression Scale.

Authors	Sample	Aim of study	HADS cut-off score	Results	Conclusion
Carroll et al., (1993) Psychiatrists.	809 oncology inpatients & outpatients.	To test HADS as a screening tool for detecting anxiety/ depression in cancer patients.	-HADS scale done at week 4 and 8. - cut-off score 11 for depression & 8 for anxiety.	17% anxiety & 14% depression for in-patients 18% anxiety & 8% depression for out-patients.	Cut-off score for scale can effect the scoring. HADS useful as a screening tool & helpful in assessing changes in mood.
Grassi, et al., (1996) Psychiatrists, Psychologists, Medical Oncologist.	86 palliative community patients.	To examine the prevalence of depressive symptoms and its relationship with quality of life domains in home care patients at advanced disease stage.	- HAD score ≥ 11 used - EORTC Quality of life Questionnaire.	HADS - 45% depressed.	Significant correlation between depression and impairment in most quality of life areas.
Ibbotson et al., (1994) Psychologists.	513 oncology outpatients.	To compare the ability to detect anxiety & depression in cancer patients using three screening tools.	-HADS tool using various cut-off scores - General Health Questionnaire (GHQ 28) - Rotterdam Symptom Check List (RSCL).	17% depression and/or anxiety (combined) scores.	HADS tool overall a good predictor when higher cut-off score (>15) was used.
Moorey et al., (1991) Psychologist.	568 oncology outpatients.	To analyse the subscales of anxiety/depression in HAD scale to determine their separate use in studies of emotional disturbance in cancer patients.	HAD scale done at week 4 & 12 after diagnosis cut-off score ≥ 8.for both depression & anxiety.	27% anxious 9% depressed	Confirmed HAD scale is a useful instrument for measuring anxiety/ depression, but recommend further studies in advanced cancer patients.

Table 2.2 Continued...A summary of oncology and palliative care studies that have used The Hospital Anxiety and Depression Scale

Authors	Sample	Aim of study	HADS cut-off score	Results	Conclusion
Payne & Endall (1998) Nurse Researchers.	164 oncology outpatients.	To examine the ability of surgeons and significant others to evaluate psychological distress in patients attending a breast clinic.	- HAD scale using ≥ 11 as cut-off score - two visual analogue scales - semi-structured interviews with doctors only.	3% depression 27% anxiety	Significant others able to successfully detect anxiety but low levels of depression meant the inability to examine relationships with surgeons and significant others. Interviews revealed barriers to effective identification by surgeons.
Perry (1995) Nurse Researcher.	224 oncology patients.	To evaluate an intervention designed to assess patients psychological preparation for bone marrow transplantation and empower them to take control.	-HAD scale, cut-off score not documented - MAC (Mental Adjustment to Cancer scale).	6% depression 12% anxiety as a measure of outcome after interventions.	Recommends future studies include interstate control groups such as in their study as it makes it possible to have larger sampling size.
Razavi et al., (1992) Psychiatrists, Psychologists.	117 oncology out-patients.	To test the HADS as a screening method in Hodgkin's Lymphoma out- patients.	-HAD scale, cut-off determined by receiver operated characteristic analysis.	47% on treatment & 32.5% off-treatment meet the DSM III-R criteria for psychiatric disorders.	HADS specific, simple and well accepted in this population. A cut-off score of 10 was associated with 84% sensitivity and 66% specificity. Suggest cut-off scores will differ in different populations, recommending ROC analysis in in future studies.
Williams (1994) Palliative Care Specialist.	19 palliative care in-patients.	To assess the psychological status of patients on admission to a hospice.	HAD cut-off score of >9	31% depressed, anxiety not reported.	Pilot study, recommends further studies.
Wood & Mynors -Wallis (1997) Psychiatrist/ Radiotherapist.	24 community palliative care patients.	A pilot study to evaluate a feasible and acceptable brief psychological treatment to treat anxiety/depression.	Randomised to one of two treatments. Outcome assessed by HADS cut-off >10 , POMS & SAS tools.	2 out of 24 depressed as screen by HADS.	HADS correctly identified Depressed patients according to DSM III criteria.

2.12 THE RISK FACTORS ASSOCIATED WITH DEPRESSION AND ANXIETY.

Researchers have identified several factors that predispose a cancer patient toward depression and anxiety such as previous history of depression, previous history of substance abuse, concurrent life stresses, absence of social support, poorly controlled pain, decreased physical performance, length of time since malignant diagnosis, multiple medication side effects and other medical conditions, for example hypercalcemia (Bukberg et al., 1984; Derogatis et al.,1983; Herity, Hillard, Moriarty, Fennely, Conroy & Casey, 1987; Massie, 1989; Massie & Holland, 1992; Zimmerman, Story, Gaston-Johanson & Rowles, 1996). Grassi, Malacarne, Maestri and Ramelli's (1997) study of 113 community palliative care patients one year after diagnosis, concluded that past psychiatric history, early maladjustment to cancer, poor social support and reduced physical functioning were predictors of depressive symptoms.

A study by Glover, Dibble, Dodd and Miaskowski (1995) examined the differences between mood states of 369 adult oncology outpatients who experienced cancer-related pain and patients who were pain free. They assessed mood according to the Profile of Mood rating scale (POMS), Karnofsky Performance Score (a rating scale which measures activities of daily living), and a descriptive numeric rating scale of pain intensity and duration. The results concluded that patients who experienced cancer-related pain reported higher levels of anxiety and depression and were less physically able to perform the normal activities of daily living.

It has been estimated that in NSW around one in four women and one in six men will experience depression in their lifetime (NSW Health, 1997). In persons 15 to 64 years, panic disorders and generalised anxiety account for 7.5% in women and 3.3% for men. However, these documented prevalence rates are estimates only from population surveys in Western Australia (children) and the United States (adults). The Australian National Survey of Mental Health and Well-being is currently conducting a survey to address this deficit (NSW Health, 1997).

It is suggested in the literature that there is a difference in depression and anxiety prevalence rates between men and women. According to Bebbington's (1996) literature review on the origins of sex differences in depressive disorders, higher depression rates among women are related to women's altered biological status postnatal periods, premenstrual periods and menopause. Figures from the National Health and Medical Research Council (NHMRC) (1995a) on gender differences and services for mental health disorders in Australia, indicate that women are twice as likely to experience a nervous or depressive condition and between 1.5 and 1.8 times more likely to have a chronic mental health disorder. Some authors suggest that men are less willing to report symptoms and seek help and therefore, are not being identified as suffering depression (NHMRC, 1995a; Stewart, 1994).

Within a chronically ill population, Nickel, Brown and Smith's (1990) research into risk factors which best predict depression and anxiety, found that significant risk factors included people with a previous history of depression/anxiety and being female under the age of 65 years. Several studies within the oncology population also revealed younger females were more likely to experience anxiety or depression. For example, Donnelly et al.'s (1995) research into the symptoms experienced by 1,000 advanced cancer patients concluded that women 65 years and younger were more likely to experience anxiety. Edlund and Sneed's (1989) research into the emotional response to the diagnosis of cancer among different age groups also concluded that younger patients (under 50 years) experienced more frequent and more severe psychological problems than the elderly. Edlund and Sneed (1989) offer the suggestion that younger individuals may have less experience with illness, or more family and carer responsibilities and therefore experience poorer adjustment. Similarly, in Payne's (1992) research into the quality of life of 53 patients with advanced breast and ovarian cancer receiving chemotherapy, patients under 50 years had more evidence of psychological distress.

Previous history of depression/anxiety has been highlighted as a contributing factor to the development of mental health disorders. For example, Blacker, Thomas and Thompson (1996) investigated the seasonal prevalence and incidence of depression among 2225 consecutive general practice patients. They concluded that 79 % of patients had previously experienced a minor or major depression and also highlighted that winter months were the peak onset for symptoms. Maunsell, Brisson and Deschenes (1992) assessed potential risk factors for psychological distress among 205 patients with newly diagnosed breast cancer at three months and eighteen months after surgery. A previous history of psychological distress was assessed with questions from the Diagnostic Interview Schedule. A history of depression before a diagnosis of breast cancer showed a strong association with psychological distress three months after initial treatment. Of the women with a history of depression, 63% had a high psychiatric symptom index score.

Several studies have illustrated that the level of anxiety or depression may vary depending on the length of time since diagnosis. For example, Herity et al. (1987) found that anxiety was greater among newly diagnosed and terminally ill patients than in the intermediate group. These authors also found that terminally ill patients reported greater depression. Given, Given and Stommel (1994) reported increased depression scores at ten months after diagnosis compared to five months after diagnosis.

Social support is important in determining how individuals cope with stress. Grassi et al. (1997) examined depression and social support of 113 cancer patients by using the Social Support Index one year after diagnosis. The authors concluded that depressed patients reported weaker and less adequate support from both family and close social relationships. Similarly, Godding, McAnuity, Wittrock, Britt and Khansur (1995) reported that social support and quality of life measures accounted for 31.5% of the variance in depression scores in a sample of older male cancer patients.

Previous studies have illustrated a relationship between a reduced physical functioning and levels of psychological distress (Bukberg et al., 1984; Glover et al., 1995; Grassi et al., 1996; Grassi et al., 1997). Bukberg et al. (1984) investigated depression in 62 hospitalised patients using the Karnofsky Performance Score (KPS) which rates patients' physical functioning. They reported a depression rate of 77% of patients who scored between 0 and 40 compared to 23% who scored between 61 and 100. A score from 0 to 40 is defined on the KPS as "unable to care for self, requires equivalent or hospital care".

From the research of oncology and palliative care studies, age, gender, length of time since diagnosis, presence of advanced disease, previous history of depression and/or anxiety, family history of depression and/or anxiety, lack of social support, and presence of an unresolved symptom were identified as factors that could influence the development of depression or anxiety among palliative care patients.

2.13 THE CONSEQUENCES OF UNRESOLVED DEPRESSION AND/OR ANXIETY.

Unresolved depression or anxiety among palliative care patients can lead to increased physical distress by intensifying other symptoms. A survey of the impact of pain in 111 patients with advanced cancer by Twycross, Harcourt and Bergl (1996) demonstrated that severe pain was associated with a greater degree of reduction in activities and enjoyment of life. Peruselli, Camporsei, Colombo, Cicci, Mazzoni and Paci's (1993) research on quality of life assessment of 43 advanced cancer patients using the Symptom Distress Scale, concluded that a reduction in the patient's overall distress was primarily due to improvement in pain, nausea, and bowel pattern.

Chochinov (1992), examined the desire for early death among 130 patients with terminal cancer and found that one quarter experienced a desire for an early death. Of the patients who desired an early death, 65% were found to be depressed.

Anxiety and depression leads to social withdrawal, prevents the patient from completing 'unfinished business' and decreases compliance to treatment modalities, thus reducing their quality of life (Billings, 1995; Twycross, 1993). A study by Payne (1992) investigating the quality of life in fifty-three cancer patients receiving palliative chemotherapy, revealed that anxiety accounted for 82% of the variance in quality of life scores and depression accounted for a further 10%, concluding that in this sample, anxiety and depression were significant inhibitory factors in achieving a good quality of life.

2.14 SUMMARY OF LITERATURE REVIEW.

From a review of the literature it can be seen that:

1. Palliative care arose from the need to improve the physical and psychological care and support provided to the dying and seriously ill.

2. The major role of the palliative care nurse, as described by nursing professionals and palliative care patients and their families, is that of supportive care. This involves the specialist palliative care nurse in maintaining a broad knowledge base

to fulfill the role of advisor, counselor, resource and liaison person. The palliative care nurse plays a pivotal role in optimising the management and intervention strategies of depression and anxiety in this population.

3. There is an absence of qualitative research focusing on the experience of psychological distress and a lack of quantitative research among community palliative care patients within an Australian population which needs to be addressed. For health professionals working in the specialty of palliative care, it is important to understand the experience of anxiety and depression from the patient's perspective before more effective intervention can be achieved.

4. Anxiety and/or depression affects approximately one-quarter of hospitalised cancer patients. However, the prevalence of depression and/or anxiety among community-based palliative care patients is unclear since this area has not been adequately researched.

5. The psychological impact of cancer has been demonstrated in the literature to affect substantially the patients and family/carers' quality of life.

6. The literature revealed deficits in the assessment and diagnosis of depression and anxiety in palliative care patients. This is particularly notable in relation to somatic items included in DSM-IV criteria and many screening tools, resulting in varying

prevalence rates. Overall, the HADS scale is the most commonly used screening tool used among oncology and palliative care patients.

7. Several risk factors have been highlighted which predispose the hospitalised cancer patient to anxiety and/or depression. However, little attention has been given to studies relating to risk factors and the predisposition to the development of anxiety and/or depression among community based patients.

2.15 THE RESEARCH QUESTIONS.

The four research questions to be answered by incorporating quantitative and qualitative approaches were:

1. What is the prevalence of depression and anxiety among community palliative care patients?

2. What is the relationship between depression and/or anxiety and risk factors identified in the literature among palliative care populations?

3. Which risk factors predispose a community palliative care patient towards developing depression and/or anxiety?

4. What is the of the experience of depression and anxiety in the community palliative care patient?

2.16 NULL HYPOTHESES.

From the literature review the following hypotheses were developed. The relationship between risk factors and the development of anxiety and/or depression was expressed in the following way:

1. $\mathbf{H_o}$:There is no relationship between HAD depression or anxiety scores and patients' age.

2. $\mathbf{H_o}$:There is no relationship between depression or anxiety scores and the existence of a previous history of depression or anxiety in community palliative care patients.

3. $\mathbf{H_o}$:There is no relationship between the HAD depression or anxiety scores for patients with a family history of depression or anxiety and those without such a history.

4. $\mathbf{H_o}$:There is no relationship between depression or anxiety scores and gender.

5. $\mathbf{H_o}$:There is no relationship between depression or anxiety scores and the existence of an unresolved symptom in community palliative care patients.

6. $\mathbf{H_o}$:There is no relationship between depression or anxiety scores and the length of time since diagnosis.

7. $\mathbf{H_o}$:There is no relationship between depression or anxiety scores and different malignant diagnosis.

8. $\mathbf{H_o}$:There is no relationship between depression or anxiety scores and perceived social support.

9. $\mathbf{H_o}$:There is no relationship between depression or anxiety scores and the functioning health status of the patient.

10. $\mathbf{H_o}$: There is no relationship between depression or anxiety scores and patients with metastic disease.

The present study will begin to describe the experience of anxiety and depression from the perspective of the palliative care patient and the extent to which this psychological distress exists within a community setting. Details of the research design chosen for this study are presented in Chapter Three.

CHAPTER THREE

Method

3.1 INTRODUCTION.

In this chapter the research design, data collection and analysis for this study are described. It includes details about the setting and the characteristics of the participants involved in this research project. The strategies employed to strengthen the rigour and the ethical issues of the study in conducting this research are discussed.

3.2 RESEARCH DESIGN.

The method used in this study was a exploratory descriptive design using a combination of quantitative and qualitative approaches. The exploratory descriptive design allows the researcher to gain more information about the characteristics within a particular field of study and provide a picture of situations as they naturally occur (Burns & Grove, 1997). When little is known about the topic in question, this design is used to conduct the initial exploration (Roberts & Taylor, 1998). As there is limited nursing knowledge about the extent and experience of depression and anxiety among the palliative care population, this design is appropriate (Burns & Grove, 1997).

3.2.1 Nursing and nursing research.

Donaldson and Crowley (1978, p.113) define a discipline as a "... unique perspective, a distinct way of viewing all phenomena, which ultimately defines the limits and nature of inquiry". Nursing, like any discipline has a unique way of experiencing and viewing the phenomena, and integral to the discipline's ongoing development is the generation of new knowledge and science. This does not preclude the recognition of nursing as both an art and science (Danko, Heidenreiter, Hunt, Marich, Marrier-Tomey, McCreary & Stuart, 1994). The development of nursing knowledge is based upon

> "... a general agreement that the domain of nursing is person, environment, health, and nursing. By specifying the domain of nursing, research and practice should reflect the common goals of providing nurses with knowledge within these four conceptual dimensions" (Kemp, 1983, p.10).

Nursing research is defined as "... the systematic process of inquiry which utilises a variety of methodological approaches to investigate the questions and concepts of interest in nursing" (Hinshaw, 1994, p.302). To develop and use alternate knowledge forms, a full exploration of the range of empirics, is consistent with the aims of human science (Kramer & Chinn, 1994).

The goals of nursing research are to better understand and explain human nature within the health-illness continuum and to provide substantive grounding for therapeutic nursing interactions. Epistemology in relation to nursing is the study of how nurses come to know what they think they know, what exactly nurses do know, how nursing knowledge is structured and on what basis knowledge claims are made (Hinshaw, 1994). Thus, epistemology, as the study of knowing, is irrevocably linked with research and the pursuit of knowledge.

Carper (1978) discusses four knowledge patterns which include, empirical, aesthetic, personal and ethical knowing. Empirical knowledge is based on the science of nursing. This pattern encompasses knowledge derived using an empirical approach through systematic and controllable factual evidence, for the purpose of describing explaining and predicting phenomena, and lends itself to the development of nursing theories. Aesthetic knowing is the art of nursing and the creative way a nurse cares. It involves the nurses' perceptions with an emphasis on how information is formulated to identify what is happening in a given situation. Personal knowledge provides from personal experiences, insight into another's world. This personal awareness and knowledge allows the nurse to reflect on experiences and to connect with others in their world of experiences. Ethical knowing is the focus on what ought to be done. It is the moral component of nursing knowledge which guides the conduct of nurses (Carper, 1978).

Nursing within the practice of palliative care is supported by the philosophical view of care of the terminally ill patient which incorporates the patients and his/her family in their totality, with reference to their environmental choices (Gurfolino & Dumas, 1994). Walker (1992, p.34) argues that the underpinnings of this holistic perspective may be taken to mean that:

> "... theory about man in the health-illness context is adequate only when all aspects of man are caught up in the theory...and encourages nurses to be sensitive to a wide range of cues related to a patient's well-being ..."

Caring for patients and families of patients who have palliative care needs requires knowledge that encompasses physical, psychosocial and spiritual aspects of care. This study draws on empirical knowledge to develop nursing knowledge in the care of palliative care patients who experience anxiety and depression while living in their home environment.

It is apparent from the literature that nursing research originally focused on quantitative approaches which is thought to have been motivated by the influence of the medical model and an attempt to gain acceptability from other health care professionals (Corner , 1991; Gray & Pratt, 1991; Roberts & Taylor, 1998). However, more recently there has been a shift of focus and recognition by nursing researchers of the benefits and quality of information which can be gained from qualitative approaches (Gray & Pratt, 1991). It is acknowledged in the literature that quantitative and qualitative research approaches stem from different paradigms. According to Kuhn (1970) a paradigm structures the questions to be asked within a discipline and systematically eliminates those kinds of questions which cannot be stated within the concepts and tools supplied by the paradigm.

Research paradigms are "... entire constellations of beliefs, values, techniques and so on shared by members of a community" (Kuhn, 1962, p175). The interpretive paradigm is one of the philosophical approaches to qualitative research and is linked to humanistic inquiry (Higgs, 1998). An interpretivist approach is about attempting to discover meaning from human experiences (Schwandt, 1994). The empirico-analytical paradigm is the philosophical approach to quantitative research (O'Brien, 1996). The empirical approach relies on observation and experiments, resulting in generalization about the content and events of the world (Higgs, 1998).

Despite these two apparently opposing paradigms reflecting on the researchers' exploratory/ descriptive design, multiple modes of inquiry were necessary to fulfill the total understanding of the concepts. Within this study of community palliative care patients the researcher has used approaches from two dissimilar paradigms to fulfill the exploratory/descriptive design of the study and develop knowledge for the nursing discipline. Carper (1978) supports the use of qualitative and quantitative approaches in nursing research to develop and enhance patterns of knowing and stipulates "... the teaching and learning of one pattern do not require the rejection or neglect of any of the others" (Carper, 1978, p.22). In multi-method research the epistemic principles are problematic because of philosophical differences among paradigms in the structure and confirmation of knowledge. However, Munhall and Boyd (1993) claim that by adhering to the strict inquiry process of a particular paradigm, the paradigm can actually prevent questions from being answered.

3.3 RESEARCH APPROACHES.

In this study the qualitative approach addresses the experience and the quantitative approach addresses the extent of depression and anxiety, which are then considered together to form the whole of this nursing research.. Utilising both qualitative and quantitative research approaches will therefore facilitate greater understanding of the phenomena.

3.3.1 Quantitative Research.

Quantitative research generates new knowledge in basic sciences which can explore etiologies and predict outcomes of intervention and care (Bockmon & Rieman, 1987). This research method is appropriate if variables are to be tested, quantified and statistically analysed (Davies, Reimer & Brown, 1995). Quantitative research is a formal, objective, systematic process, in which numerical data are utilised to obtain information (Roberts & Burke, 1989). Used to describe and test relationships, quantitaive research examines cause and effect relationships and is objective (Burns and Grove, 1997). The element of objectivity enhances the data collection as it avoids influences from the researcher's personal interpretation. Objectivity is achieved by the researcher remaining detached from the study, avoiding influencing the study with his/her own perceptions and values. Therefore, quantitative research is regarded as being the acceptable method for developing science (Burns & Grove, 1997).

The major purpose for incorporating quantitative approaches in this study was to quantify the extent of depression and anxiety and to statistically determine which risk factors predispose a community palliative care patient to the development of depression and/or anxiety. A large number of research studies regarding the prevalence of anxiety and depression and predisposing risk factors has mainly been inpatient focused with little attention to palliative care patients living in their home environment. According to Burns and Grove (1997, p.55), an exploratory/descriptive method is considered appropriate when used to "... generate new knowledge about concepts or topics that have limited or no research".

3.3.2 Qualitative Research.

Qualitative research explores the human phenomena about which little is known and which can not be broken down into smaller pieces without losing sight of the whole. Qualitative research is based on the premise that knowledge about humans is not possible without describing human experience as portrayed by the individual (Polit & Hungler, 1993). As described by Denzin and Lincoln (1994, p2), "... qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them". Qualitative data consist of information derived from communication or observation of behaviour (Thomas, 1990). The element of subjectivity in qualitative research is the key to this approach. Subjectivity is deliberately sought in qualitative research, as the reality constructed by human beings evolves from their subjective experience (Lincoln & Guba, 1985). Qualitative studies allow research into areas where quantitative studies alone may not yield the depth and richness of the study participant's experience of the phenomena being studied.

In this study of community palliative care patients, unstructured interviews were used to explore and describe the experience of anxiety and depression from the patients' perspective. A qualitative approach was considered appropriate as the researcher was seeking information about the personal experiences of community palliative care patients (Leininger, 1985; Strauss & Corbin, 1990). Also, the subjective experience of depression and anxiety among community palliative care patients has not previously been explored.

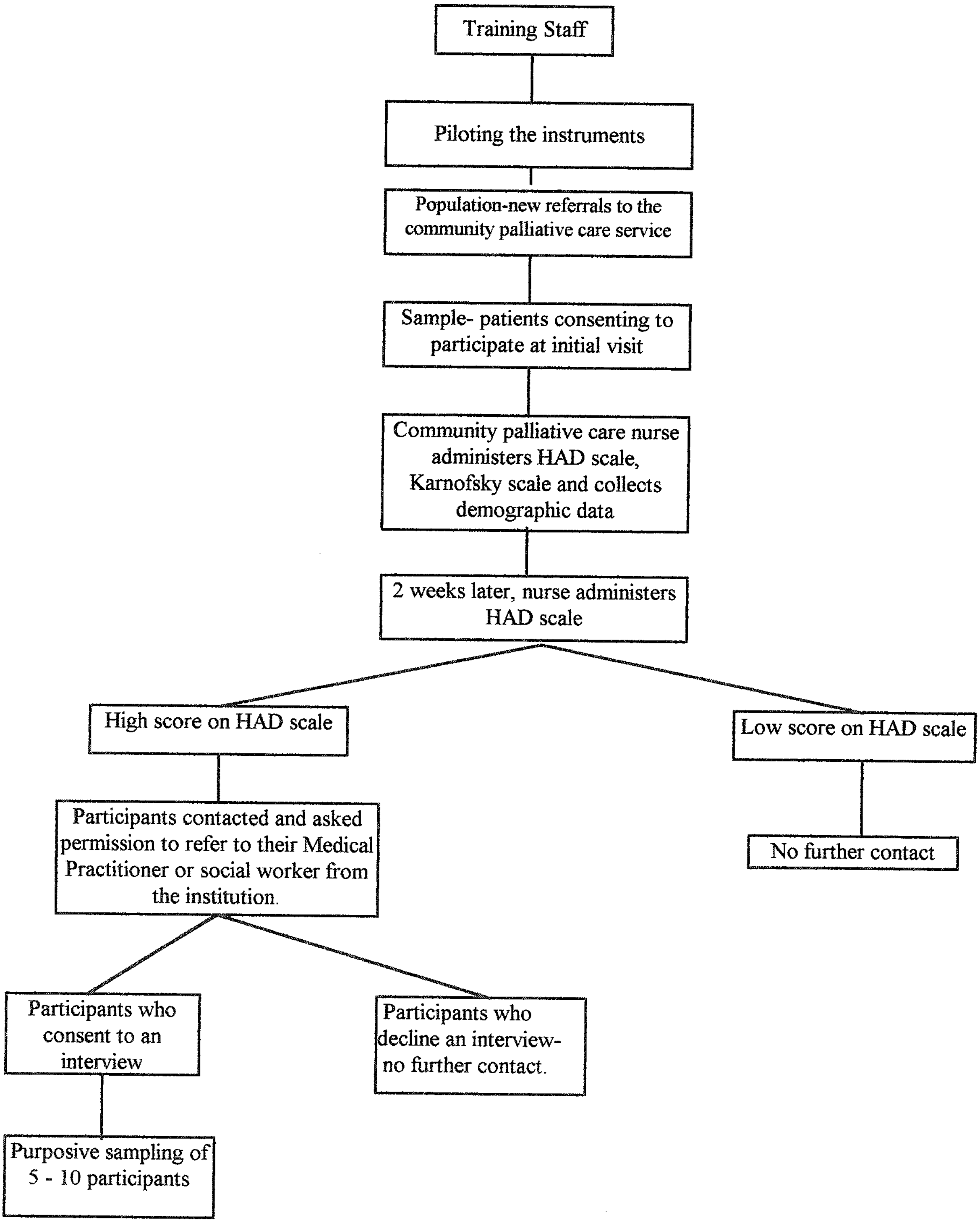
3.4. RESEARCH SETTING.

The study was conducted in a community palliative care outreach service attached to a major hospice in the South-Eastern Area Health Service of New South Wales (NSW), Australia. This community palliative care service was chosen as it is a well established service, and is one of the largest providers of palliative care services in New South Wales. The average number of new referrals to the community outreach team per year is approximately 500 patients of which 84% are patients with a malignant diagnosis.

3.5. METHOD.

In this study there were two phases to data collection and analysis. Each phase will be described in detail. Phase one was undertaken to answer the research questions in relation to prevalence and contributing risk factors of anxiety and depression in the community palliative care population. This involved the collection and analysis of quantitative data. Phase two was undertaken to explore the experience of depression and/or anxiety for a community palliative care patient. This involved the collection and analysis of qualitative data. Figure 1 outlines the research procedure.

Figure no. 1 A flow diagram of the data procedure.



3.6. QUANTITATIVE DATA PROCEDURE: Phase One.

3.6.1 Sample.

The sample for phase one was palliative care patients, with a primary diagnosis of cancer, who were new referrals to the community palliative care service during the specified time frame. Seventy-five patients were recruited from the population of one hundred and fourteen new referrals to the community palliative care outreach service over the six-month period.

3.6.2 Sampling technique.

For phase one of this study, a convenience sample of community palliative care patients from one community palliative care service was used to recruit participants over a six- month period, allowing for seasonal variation. Seasonal variation refers to the fluctuation of the phenomena being studied across changes in one of the four seasonal characteristic weather conditions (Eagles, McLeod & Douglas, 1997). Convenience sampling refers to the most conveniently available people as participants in a study at the time of data collection. Although it is recognised by the investigator that this form of non-probability sampling does not allow results to be generalised for a larger population, the purpose of choosing this sampling method was because the exact number of new referrals to the outreach service could not be anticipated. It was not possible to randomly select the sample as the prognosis of palliative care patients varies substantially. Burns and Grove (1997) state that multiple biases may exist in convenience sampling; however, by developing and adhering to strict entrance criteria, extraneous variables may be overcome.

3.6.3 Exclusion/inclusion criteria.

The selection criteria for phase one of this study included subjects who;

1) had a principle diagnosis of malignancy
2) were between the ages of 18 - 85 years
3) who spoke and read English
4) were not cognitively impaired

While patients with other medical conditions are referred to this service (for example, end stage renal failure and AIDS), cancer patients account for 95% of the referrals. Because of the relatively low numbers of these other diagnostic groups it was considered unlikely in the time-frame that sufficient numbers of patients could be recruited for statistically significant results to be determined.

In this study patients over the age of 85 years were excluded on the basis of increased risk of cognitive impairment. It is acknowledged in the literature that cognitive changes occur with aging; however, there seems to be no consensus regarding what age the decline is likely to occur. Cognitive changes are influenced by the individual's biological and genetic characteristics, and by environmental factors such as educational experience (Hooyman & Kiyak, 1993).

The assessment of the patient's cognitive ability to enter the study was determined by the six community palliative care nurses working in this outreach team involved in data collection. The researcher held a workshop prior to the commencement of the study to develop consensus on what constitutes cognitive impairment. This workshop was held at the workplace and had the approval of the coordinator of the community outreach team. Although tools such as the mini-mental scale are commonly used to assess and determine cognition, in this particular population it was decided not to use another assessment tool, which could contribute to increasing stress. It was agreed that after the initial meeting and evaluation of the patient which may take one to two hours, the community palliative care nurse would be able to determine the patient's cognitive function and at this point ask the patient if he/she would participate in the study. If at any stage during the study, the patient became cognitively impaired they would be withdrawn from the study. During the six months of the study, three patients were thought by the community nurse to be cognitively impaired, and did not enter the study, but no participants were withdrawn because of cognitive impairment.

3.6.4. Determining sample size.

An estimate of the number of previous referrals suggested that during a four month period a sample size of 90 participants could be recruited to participate in the questionnaire. To reflect the current gender mix and number of referrals approximately 40 male and 50 female participants were anticipated. Power analysis using prevalence of 25% for anxiety/depression, with a significance level of 0.05 was selected based on previous research that has identified this figure in oncology patients (Massie & Holland et al., 1994; Twycross, 1995). A variance of 20% between gender was incorporated leading to a sample size of 90 patients being required to obtain a power of 0.80 (or 80% probability of detecting a relationship among the research variables, depression and anxiety). However, this sample size was not met in the time-frame and it was decided to extend the data collection period to six months in anticipation of meeting the required sample size. During the extended time frame period, 75 participants were recruited. A repeated power analysis using a sample size of 75 patients, reduced the probability power to approximately 72%.

3.6.5 Recruiting subjects.

The primary community palliative care nurse invited participation to enter phase one of the study from all new referrals to the service. The primary nurses were encouraged to invite all participants with a life expectancy greater than four weeks and determined the suitability for eligibility dependent on the guidelines for the inclusion criteria. At the initial visit by the community palliative care nurse and after the completion of their routine evaluation, patients were asked if they would voluntarily participate in the research. If they agreed, an information sheet was given to them to read and consent to enter the study was sought at that time. Demographic data was collected by the palliative care nurse at the initial visit when consent was given, followed by the administration of the self-report HAD scale. Although the HAD scale is designed to be completed independently, 23 (31%) subjects required assistance to complete the questionnaire, this consisted of reading the question to the patient or physical assistance with ticking responses.

McCorkle (1987) points out that when using several interviewers to ask questions, the questions may be asked in different ways which can produce random error. However, in Edlund and Sneed's (1989) study investigating the emotional responses to a cancer diagnosis 89% (119) subjects requested the instrument tool be read to them. These researchers felt that this change in the data collection procedure served two important functions. First, it was suggested that it provided a more consistent environment for data collection. Second, it resulted in more useable data since it assured that there was no missing data.

3.6.6 Training co-data collectors for phase one.

The six community palliative care nurses who constituted this particular palliative care service assisted in data collection for phase one of this study. Prior to commencing data collection the six palliative care nurses were fully informed of the purpose, objectives, and research questions involved in this study. The nurses were educated on how to approach participants and ask for their participation in the study. The nurses were also given instructional training on how to administer the Hospital Anxiety and Depression scale (HAD) and the Karnofsky Performance Score (KPS). Three education sessions of half an hour took place at the weekly multi-disciplinary meeting several weeks prior to commencement of the study. The community nurses were also asked to complete the HAD scale themselves, not purposely to determine their psychological status, but to allow the nurses to understand the tool first hand. After piloting the instrument, two further group discussions took place at this specified meeting time to resolve any problems.

3.6.7 Issues in recruitment.

The six community palliative care nurses were the primary nurses for the participants who took part only in Phase One, the questionnaires. The principal investigator also administered the questionnaires in Phase One of the study. As suggested by Burns and Grove (1997), the nurse conducting clinical research may experience a role conflict between clinician role and researcher role. To reduce possible bias during patient recruitment, the patients were asked to voluntarily participate in the study at the completion of the initial visit. Once routine admission discussions were completed, asking patients to voluntarily participate in the research at the end of the visit gave patients an opportunity to decline. The principal investigator was not the primary carer for any participants interviewed. While this was not intentional, patients selected for an interview were aware that the interviewer (primary investigator only) was a member of the nursing community outreach team but also aware that the visit was for research purposes.

3.7. DATA COLLECTION: Phase One.

When palliative care services become involved, patients are generally coping with symptoms associated with advanced incurable illness and a limited life expectancy. Therefore, when identifying a suitable instrument/s to be used in data collection it becomes paramount to take into account that it may be inappropriate to ask patients too many questions, due to the severity of their illness.

For Phase One, data was obtained in three ways. First, the demographic data was collected. Second, the Karnofsky Performance Score assessed the functional health status of the patient. Third, the self-report Hospital Anxiety and Depression (HAD) scale was administered to consenting participants at the time of the initial visit and again two weeks later by the same nurse to screen patients for possible clinically significant depression and anxiety.

3.7.1 Demographic Data.

The demographic information data sheet was developed by the researcher and one of the team of the primary palliative care nurses was required to complete it (refer to Appendix1). This obtained data on age, diagnosis, length of time since diagnosis, previous history of anxiety or depression, family history of anxiety or depression, perceived social support, main carer, number of people providing social support and sufficient space to record the presence of unresolved symptoms.

3.7.2 The Karnofsky Performance Score.

The Karnofsky Performance Score (KPS) was chosen in this study as an objective indicator of the functional health status of all patients in this study. Although there are other instruments available to determine functional health status of an individual such as, the Eastern Cooperative Oncology Group (ECOG) (Zubrod, Schneiderman & Frei, 1960) scale and the Palliative Performance Scale (PPS) (Anderson, Downing, Hill, Casorso & Lerch, 1996), the KPS is the most frequently used tool to assess functional health status among oncology/palliative care patients. The KPS was developed by Karnofsky and Burchenal in 1948 to determine patients' functional activities of daily living. The KPS allocates patients according to function into three categories in terms of their ability to work, to undertake normal activities, and to care for themselves. The scale is further subdivided into deciles from 0 (dead) to 100 (normal, no complaints, no evidence of disease) (refer to Appendix 2).

The KPS has been used as a stratification and selection variable in randomised trials of chemotherapeutic agents (Aisner & Hansen, 1981). It has also been used to evaluate the individual's response to treatment and to evaluate the impact of chemotherapeutic agents on patients' quality of life (Grieco & Long, 1984). More recent studies demonstrate that the KPS is still the most frequent instrument used to assess functional performance and as a longitudinal and predictive tool. Reuben, Mor and Hiris (1988) used the KPS to predict survival in advanced disease. The authors concluded that the best single prognostic indicator of survival is functional status of which, in their study, the KPS correctly predicted participants survival. In reviewing the literature several researchers have used the KPS to determine relationships between functional health status and mood state. For example, Grassi et al. (1997) used the KPS as an instrument in their study to determine whether having a lower functional performance score influenced depression disorders in 113 cancer patients, concluding that a significant correlation existed between these two variables ($r = -0.35$). In this study of community palliative care patients, the KPS was used for similar reasons as Grassi et al. (1997).

3.7.3 The Hospital Anxiety and Depression Scale.

The Hospital Anxiety and Depression (HAD) scale was the instrument selected to assess depression and/or anxiety among the participants (see Appendix 3). The HAD scale was developed by Zigmond and Snaith in 1983 to provide health professionals with a practical tool for identifying clinically significant episodes of depression and anxiety in medical patients (Herrmann, 1997). The HAD scale is a self-report instrument, that consists of fourteen questions, seven which relate to anxiety and seven which relate to depression. This scale requires a tick response and takes five to ten minutes to complete. This was considered extremely pertinent in this population. McCorkle (1987) points out that an instrument that is too long can be both tiring and boring and may reduce the quality of information the researcher is seeking. Each item of the HAD scale is scored from 0 to 3, with the total score ranging from 0 to 21 for anxiety subscale or for the depression subscale, with zero being a doubtful "case" of depression or anxiety, and 21 an adverse score (Wilkin, Hallam & Dogget, 1993).

The HAD scale was administered twice. First, at the initial community nurse visit and again two weeks later. The researcher was advised by a clinical psychologist and psychiatrist who have experience working with palliative care patients with psychological distress, to administer the HAD scale twice. By doing so, the tool would evaluate any changes in mood, compensate for possibly false positives at the initial meeting, when patients may feel anxious about a visit from a palliative care nurse for the first time and help to reduce any inherent bias such as denial or giving socially desirable responses (Limandri, 1989). The researcher was also advised by professionals in the psychiatric field that a shorter than two week follow-up period would introduce type I bias in which there is a high re-call of the questions. Salkovskis, Storer, Atha and Warwick (1990) test retest reliability study of the HADS tool when administered two weeks apart, demonstrated a high correlation coefficient ($r > 0.80$). The scores obtained on the HAD scale were tallied by the investigator. Scores of ≥11 were deemed "cases". For patients who scored less than 11 on the HAD scale on two occasions no further contact was necessary.

In reviewing the literature, a minority of studies using the HAD scale have combined the scores from both depression and anxiety to give a total psychological distress score (Heaven & Maguire, 1995; Ibbotson et al., 1994). However the majority of researchers have separated anxiety and depression scores (Carroll et al., 1993; Moorey et al., 1991; Needham & Higgs, 1995; Payne & Endall, 1998; Wood & Mynors-Wallis, 1997) as intended by the original developers. Depression and anxiety are categorised as separate mental health disorders according to the DSM-IV criteria, thus adding support for separating the total scores of the participants' depression or anxiety (American Psychiatric Association, 1995).

Permission to use the HAD scale in this research project was obtained through the purchase of the unit "Stress, Emotion and Life Events" from the portfolio series of "Measures in Health Psychology" published by NFER-NELSON Publishing Company (Johnston, Wright & Weinman, 1995) (refer Appendix 4).

3.7.4 Piloting the instruments.

Prior to commencing the study, the Hospital Anxiety and Depression scale, demographic data sheet and Karnofsky performance score was piloted with ten new referrals to the community palliative care outreach team. This enabled the principal investigator and the six palliative care nurses to gain experience administering the tools and ensured a smooth running process during the actual data collection.

After completion of the pilot application of instruments, each patient was given the opportunity to discuss the questions and asked whether anything important had been omitted. Three participants commented on questions asked in the HAD scale.

Question 14: *I can still enjoy a good book or TV programme*:

Often

Sometimes

Not often

Very seldom

One participant wrote: “My eyes are playing up at the moment”.

Question 2: *I still enjoy the things I used to enjoy:*

Definitely as much

Not quite so much

Only a little

Hardly at all.

One participant commented that they would have preferred ”not always” as a response. Another participant wrote on the questionnaire “How can I with 3 bags dangling off me”. Another wrote “physically not able to do things now”. In a study by Wood and Mynors-Wallis (1997), using the HAD scale in a pilot study of 24 community cancer patients, the investigators felt that for some, responses to questions in the HAD scale reflected the patient’s physical illness rather than psychological distress, as demonstrated in the above written responses. However, as only two written responses directly related to physical limitations and in view of the copyright laws disallowing omission of any sections of the HAD scale in this research, no changes to the questionnaire were made.

Faull, Johnson and Butler (1994) used the HAD scale among 65 patients admitted to a hospice, and commented on item two (“I still enjoy the things I used to enjoy”) and item eight (“feel as if I am slowed down”), inferring a possible influencing factor, such as physical disability rather than depression. Payne (1998) also reported problems with some of the items on the HAD scale. In particular, the question whether participants still enjoy the activities they used to enjoy. Payne suggests that now the patient is bedridden they may prefer new pleasures such as painting rather than say, playing tennis. Also, Payne feels it is necessary to differentiate between “feeling slowed down” due to depression and “feeling slowed down” as a result of advanced illness. Despite these reported concerns, the researcher agrees with Wood and Mynors-Wallis (1997), that there is currently no other self-report tool suitable for palliative care patients.

On their initial visit, some of the community nurses felt hesitant about asking the patient directly whether they had previously experienced depression. It was decided to add prompts to the demographic data sheet to help provide consistency in the way community nurses asked questions. For example, question five (refer Appendix 1) "History of previous episodes of depression/anxiety", which required a yes/no tick response, the prompt question added was, " Is there a time where you felt really down and how long did it last?".

The primary palliative nurse applied the Karnofsky Performance scale to the patient after a thorough evaluation at the initial visit. The KPS was easily administered by the palliative care nurses, was not intrusive and measured patients' physical performance status.

3.7.5 Reliability and Validity of the Instruments.

Within the context of quantitative research methods the reliability and validity of the instrument used is crucial to the research (Fallowfield, 1993). Reliability of an instrument refers to "... its stability and consistency within a given context" (Brockopp & Hastings-Tolsma, 1995, p. 266), whereas, validity of an instrument refers to the extent to which measures used in the data collection achieve what they set out to do (Roberts & Taylor, 1998). Measures of reliability include: test-retest reliability (or 'stability', a method for determining reliability of a test using repeated applications on the same person); inter-rater reliability (consistency among different users) and internal consistency, which measures the degree to which various parts of a test or scale measures the same variable.

Important measures of validity include the content validity (measures how well the tool is measuring a particular characteristic to be assessed) and criterion-related validity (measures the establishment of a relationship between the instrument and the characteristic). Construct validity is also an important measure of validity. It determines whether the instrument actually measures the theoretical construct it purports to measure, that is, the extent to which a participant actually possess the characteristic under study (Burns & Grove, 1997; Wilkin, Hallam & Doggett, 1993; Wilson, 1987).

Several studies have evaluated the reliability of the HAD scale. Herrmann's (1997) international literature review of validation and clinical results of studies using the HAD scale reported variable internal consistencies of the HAD scale (English and German versions) with acceptable correlation of 0.80 to 0.93 for anxiety and 0.81 to 0.90 for depression subscales. Moorey et al (1991) determined a Cronbach's alpha for the anxiety subscale was 0.93 and 0.90 for depression among 573 people with cancer. Nunnally (1978) recommends that coefficient alpha is at least 0.60, for it to be used as a screening instrument it should be at least 0.8. Moorey et al (1991) claims that adhering to this criteria, both HAD subscales can be justifiably used as a screening tool.

Test retest reliability studies show a high correlation (r > 0.80) up to two weeks (Salkovskis et al., 1990). However, correlation decreases with longer time intervals, for example, greater than two to six weeks (r> 0.73) and greater than six weeks (r > 0.70) (Elliott, 1993; Visser, Koudstaal, Erdman, Deckers, Passchier, van Gijin & Grobbee, 1995). Herrmann (1997) suggests that these results demonstrate that the HAD scale is stable enough to withstand situational influences (Herrmann, 1997).

There are several studies which have examined the sensitivity (the ability of the instrument to detect change over time or across individuals) and specificity (an index of the extent to which an assessment detects only individuals who have a clinical attribute) of the HAD scale. Ibbotson and colleagues (1994) found that for 165 cancer patients receiving active treatment for their cancer, the HAD scale had a 85% sensitivity and a 77% specificity in detecting psychological distress with a positive predictive value of 47%.

However, several studies using the HAD scale have highlighted the variance in sensitivity and specificity depending on the cut-off score applied. A higher cutoff point decreases sensitivity and increases specificity, a lower cutoff increases sensitivity and decreases specificity (Herrmann, 1997; Lynch, 1995). Carroll and colleagues (1993) screened 806 inpatient and outpatient cancer patients using the HAD scale. These researchers reported that 48% of their sample were depressed and 41% were anxious when a cut-off score of eight was used. However, when a higher cut-off score of ≥ 11 was implemented, depression was reduced to 23% and anxiety was reduced to 18%. The optimum cutoff score, or level, at which depression or anxiety is said to be present, using the HAD scale, has been shown at ≥ 11 with a sensitivity of 85% and specificity of 77% (Ibbotson et al., 1994).

The construct validity of the HAD scale as a measure of emotional disturbance was also confirmed in a factor analysis of the responses of 573 oncology patients by Moorey et al. (1991). The HAD scale has been validated against a 20-minute psychiatric assessment and against this standard, the depression sub-scale yielded only one percent false positives and one percent false negatives (Wilkin et al., 1993). Using the same data, the scales were also shown to be satisfactory measures of severity and to differentiate between anxiety and depression (Wilkin et al., 1993). The HAD scale has been proven to be sensitive and specific in detecting clinically significant levels of anxiety and depression according to the Present State Examination, Clinical Interview Schedule and the DSM-III criteria (Ibbotson et al., 1994; Razavi et al., 1990; Razavi et al., 1992; Wood & Mynors-Wallis, 1997; Zigmond & Snaith, 1983) This tool has also been used in a variety of medically ill populations, including cancer and palliative care and in hospice, hospital and community settings (Carroll et al., 1993; Payne & Endall, 1998; Perry, 1995; Razavi et. al., 1990).

The KPS has been widely accepted and used for assessment of the functional health status of cancer patients. The majority of reliability and validity studies of the KPS instrument date back 15 years. Test-retest reliability has not been assessed due to the difficulty of conducting these studies with patients who have an advanced incurable illness (Wilkin et al., 1993). There are reported differences in the inter-rater reliability measures, moderate to good inter-rater reliability appears to be achieved when the patient group is homogeneous and any rater inconsistencies are clarified (Schag, Henrich & Ganz, 1984). A study by Mor, Laliberte, Morris and Weismann (1984) with cancer patients obtained an inter-rater reliability correlation of over 0.97 after a two hour training session with raters, indicating very good inter-rater agreement. In Yates, Chalmer and McKegney's (1979) study of 52 advanced cancer patients reported a inter-rater reliability correlation of 0.69, indicating a moderate inter-rater agreement.

There are also numerous studies showing evidence of construct validity of the KPS. For example, Mor and colleagues (1984) analysed the construct validity of the KPS with the Katz Activities of Daily Living Index and found a strong relationship ($p < 0.001$) between the KPS associated with the ability to perform activities in daily living. Schag and colleagues (1984) found that physician KPS rating scores relating to self care, daily activity, ability to work and evidence of disease were significantly correlated ($p < 0.05$) when analysed against eighteen items from the Cancer Inventory of Problem Situations. A more recent study by Crooks, Waller, Smith and Hahn (1991) evaluated the KPS against the Activities of Daily living (ADL) scale and the Instrument Activities of Daily Living (IADL) scale among 134 geriatric patients. The KPS, ADL and IADL were significantly correlated ($p < 0.05$) with each other, and the KPS showed the strongest associations with functional measures, indicating a strong global application of the KPS scale.

Although the KPS instrument is a brief simple scale to use, accurate assessment can only be achieved with knowledge of the individual. Fallowfield (1993) states an important criticism common to all observational scales is that the assessment involves an entirely subjective evaluation made by the observer. Thus, bias inevitably arises. Fallowfield (1993) claims that clinicians often overestimate the dysfunction and impact that illness exerts on the well-being of patients. However, this bias may be overcome by using trained observers. The KPS was used in this study by the six palliative care nurses collecting the data who made the initial assessment of the patient. The nurses were experienced in assessment of physical functional status using a different scale, so only required one instructional training session to familiarise themselves with the tool was required, before rating consistency was achieved.

3.7.6 The Researcher.

The principal investigator was a specialist community palliative care nurse working full-time with an palliative care outreach team. It was perceived by the principal investigator that being on site was a constant reminder to the community palliative care nurses of the project. Brightly coloured posters were displayed around the office and the researcher changed the colours of the posters every two months, as a reminder to the community nurses about the study. The principal investigator provided progress reports of the study to the community nurses at frequent intervals. This provided an opportunity to inquire whether the nurses were experiencing any difficulties and to ensure that the data collection techniques between the nurses remained consistent. Also the principal investigator's presence at multi-disciplinary meetings enabled reminders to be given to follow up on the second questionnaire.

3.8. DATA ANALYSIS: Phase One.

Descriptive statistics including frequency distribution, measures of central tendency, (mean, mode, median) and measures of variability (range and standard deviation) were initially applied to the data. Frequency distributions were used to describe the components in the sample in which data was systematically arranged from the lowest to the highest, together with a count of the number of times each value was obtained (Burns & Grove, 1997; Polit & Hungler, 1995). In this study of palliative care patients the range and standard deviation were used to describe the variability in relation to patients age, length of time since diagnosis, number of people providing perceived social support to patients and the Karnofsky Performance Score

The participants' HAD depression and anxiety scores were dichotomized into either depressed or not and anxious or not. This left a sample size for the depressed group of 14 and 12 for the anxious group. As the sample size of the study was small and not evenly distributed, non-parametric tests were used to analyze all the quantitative data as suggested by Munro (1997a). The Spearman rho correlation and the Mann-Whitney *U* test were used to test the hypothesis, and logistic regression was applied to the data to determine which risk factors predisposed participants in this sample to anxiety or depression. All statistical analyses were estimated using the Statistical Package for Social Sciences (SPSS 1995, version 7) on an IBM compatible computer. The Spearman rho method is the equivalent to the Pearson *r* (Bailey, 1991) correlation coefficient. The Spearman rho is used in descriptive research resulting in non-paramateric data, where the researcher wishes to compare two sets of rankings to see if there is any type of relationship between them (Bailey, 1991). In this study Spearman rho was used with the continuous data age and depression/anxiety.

According to Crooks and colleagues (1991) *t* tests are more appropriate for dichotomous variables relating to patient two groups. The Mann-Whitney *U* test is the non-parametric analogue for the *t* test (Munro, 1997a). It tests for differences between means on two independent groups (Bailey, 1991). Burns and Grove (1997) state that the Mann-Whitney *U* test is the most powerful of non-parametric tests. A Mann Whitney *U* test was used in this study to investigate differences between patients who were depressed or anxious and ten risk factors.

Logistic regression is used to determine which variables affect the probability of a particular outcome (Munro, 1997b). Logistic regression was considered the most suitable method to use when dealing with multivariate analysis, as there were ten risk factors used to predict a probability of the outcome, that is, depression or anxiety. Logistic regression is a procedure that uses maximum likelihood estimation for analysing relationships between multiple independent variables and a dependent variable that is categorical (Burns & Grove, 1997). Logistic regression '... transforms the probability of an event occurring ... into its odds, that is, into the ratio of one events' probability relative to the probability of a second event' (Polit & Hungler, 1993, p.308). An odds ratio is defined as "... the probability of occurrence over the probability of nonoccurrence " (Munro, 1997b, p.291). Odds ratio are interpreted as, one equals no effect, less than one indicates a decreased risk of development of the outcome and greater than one is interpreted as an increased risk of the development of the outcome (Wright, 1995).

Burns and Grove (1997) state that there are other methods such as discriminant analysis, which may be used to predict group membership. However, Polit and Hungler (1993) point out three advantages of logistic regression over discriminant analysis. First, logistic models are considered more theoretically appropriate than models based on the least-squares approach used in discriminant analysis. Secondly, logistic regression is concerned more with modeling the probability of an outcome, than with the predication of group membership. Finally, logistic regression enables the researcher to generate odds ratios that can be meaningfully interpreted and therefore promote a better understanding of the relationships of variables.

The use of a logistic regression model provides a fast and effective way of obtaining the estimate of probability belonging to a specific population and the estimate of odds ratio (or relative risk) having a specific problem or condition. According to Burns and Grove (1997) there is an increasing interest in predicting outcomes of nursing practice and it is expected that the use of logistic regression analysis will increase for example, Albers, Lydon-Rochelle and Krulewitch (1995) used logistic regression in their study to predict which risk factors contributed to labour complications in healthy primigravidas at term. Yarandi and Simpson (1991) used logistic regression model to predict the odds of testing positive to the Human Immune Virus amongst clients attending an American Local Health and Rehabilitation Unit.

The depression and/or anxiety responses were dichotomised into scores which fall above or below 11 on HAD score. It is suggested in the literature that adjustments in threshold scores (cut-off scores) when using the HAD scale to detect possible "cases" of depression and anxiety should be made according to the disease and treatment status. However, there appears to be a consensus by recent research that a cut-off of ≥11 is appropriate in this population. (Grassi et al., 1996; Lewis & Wessely, 1990; Payne & Endall, 1998; Wood & Mynors-Wallis, 1997).

The selection of the predictor variables (independent variables) was based on knowledge of established relationships between the predictor variables and the dependent variables reported in the literature. The independent variables or risk indicators (length of time since diagnosis, age, gender, perceived social support, physical functioning, advanced disease stage, previous history of depression/anxiety, family history of depression/anxiety, malignant diagnosis and somatic unresolved symptom) were re-coded to fit this procedure and were a mixture of continuous and categorical data.

3.9. QUALITATIVE DATA COLLECTION: Phase Two.

3.9.1 Selecting the participants.

Phase two was undertaken to explore the experience of depression or anxiety for the community palliative care patient. For this phase a purposive case sampling was utilised. Purposive case sampling is the selection of participants who are specifically chosen and are thought to best represent the phenomenon under the study (Roberts & Taylor, 1998; Sandelowski, 1995). Participants were sought intentionally for their ability to inform the researcher about their personal experiences. In this study, patients who experienced psychological distress while living with an incurable illness in the home environment were the participants considered to be good sources of information which would advance the researcher towards the analytic goal of understanding the phenomenon under study. Burns and Grove (1997, p.306) state that this sampling method is often used in qualitative studies "... in order to increase theoretical understanding of some fact of the phenomenon being studied".

3.9.2 Description of participants.

In this study participants were chosen who indicated possible clinically significant depression and/or anxiety as measured by the HAD scale with a score greater than or equal to 11. Of the seven participants in this phase of the study three were female and four were male. The age of the participants in this phase ranged between 55 and 85 years of age. Three participants had both elevated anxiety and depression scores, three had elevated depression scores, and one had an elevated anxiety score. Interviews were ongoing and continued until theme saturation occurred.

3.9.3 Recruitment of participants.

Patients who scored ≥11 on the HAD scale, and who had previously indicated they would agree to an interview were contacted by phone by the principal investigator and invited to participate in phase two. Seven patients were interviewed for this phase of the study.

3.9.4 Number of participants.

For phase two of the study, it was estimated that between 5 and 10 participants who had agreed to participate in an interview and had an elevated score on the HAD scale would be approached for an interview. Sandelowski (1995) discusses appropriate sample size in qualitative data and surmises that it is not the number of participants but the quality of the information sought that is important. Data was collected until saturation of data was obtained, that is, there was no new information arising from the interviews. Saturation of data occurred after seven interviews.

3.10. DATA COLLECTION: Phase Two.

The final data collection method, an unstructured interview conducted by the principal researcher, was used to obtain in-depth qualitative data to provide a focused view of the palliative care patients' experience of anxiety and depression. The unstructured interview was conducted by the investigator within the patient's home environment, at a time convenient to them. According to Morse and Field (1995) unstructured interviews give a greater depth to the research process when there is little known about the topic. On average the interviews took 30 to 45 minutes. This was tape recorded to ensure data collection was recorded accurately.

3.10.1 Unstructured interviews.

The interview began with a single question. Using an unstructured interview technique facilitated in-depth exploration of the essence of the individual's experience of anxiety and/or depression. Active listening and reflection by using the patient's own words to clarify their story and occasional prompting formed the basis of the interview schedule. Examples of the prompts used during the interviews can be found in Appendix 5. At times, the participants sought clarification, direction, or asked for further details of how they should proceed with the interview. The researchers' responses were open-ended but directed towards the participants emotional feelings. For example, asking participants if they would like to continue with the interview or "how did that (situation) make you feel?" Morse and Field (1995) suggest that allowing the participants to speak freely and at length will provide data with greater depth and detail.

The principal investigator also trialed interviewing techniques using unstructured questions, which were later reviewed by the investigator's supervisors and advice and direction for clearer questioning was given.

During the course of the interviews, two of the seven participants interviewed found it difficult to view the interviewer as an investigator but rather as a nurse, asking about minor physical conditions. On the first occasion, the investigator found it difficult not to immediately respond and offered further discussion of the problem, after the interview. On the second occasion, the investigator was able to maintain the researcher role and suggested that further discussion of this issue be with the patient's primary nurse.

3.11. DATA ANALYSIS: Phase Two.

Qualitative research involves a "... systematic, subjective approach used to describe life experiences and give them meaning" (Burns & Grove, 1987, p.35). This study explored and described the community palliative care patients' experience of depression and anxiety. Data analysis consisted of thematic analysis to identify themes in the interviews. Thematic analysis is a method used in phenomenological interpretation (Wilson, 1987). Thematic analysis refers to the process of recovering the theme or themes, by reflectively analysing the text for the embodied meanings of the phenomenon (van Manen, 1990).

The interviews were transcribed verbatim, as soon as possible after the completion of the interviews, using Microsoft Word 6 word processing package. The researcher checked the transcription against the audio recording for accuracy. This allowed the researcher to reflect on the data and immerse oneself in the data. Tesch (1990) claims that when researchers immerse themselves within the data, the rigour of qualitative data is most apparent. Immersion in the data occurs when it is extensively read and re-read, and there is a process of 'dwelling' on the data before focusing attention to detail (Tesch, 1990). The researcher invested time to learn about the participants and had prolonged involvement with the data. The researcher allowed time between transcription and data analysis to foster the reflective process.

The first task using theme extraction was to read and re-read the interviews in their entirety. Each line of transcript was numbered providing organisation and quick reference. From this, a line-by-line analysis uncovering thematic aspects of the phenomenon was conducted. This provided a comparison of the data and helped identify major themes and minor themes and gave insight into the essence of what was being communicated about the experience of anxiety and depression.

Theoretical sensivity based on the researcher's professional palliative care nursing experience is acknowledged. Detachment, that is bracketing, was necessary to question the researcher's own assumptions about the data, even if unconscious (van Manen, 1990). To maintain this distance and be able to discriminate meaningful units in the data, analysis strategies were adopted from van Manen (1990) to the point of developing meaningful themes. The researcher then searched for common threads from the data to obtain a holistic view of the data as minor and major themes. Morse and Field (1995, p.141) describe the process of theme extraction once identified as "... significant concepts that link substantial portions of the interview together".

3.11.1 Rigour in qualitative research.

In qualitative research, instead of using the specific words 'reliability and validity' when referring to measures of evidence of methodological accuracy, the more general term 'rigour' is used (Higgs, 1998). Roberts and Taylor (1998, p.172) define rigour as

> "... the strictness in judgment and conduct which must be used to ensure that the successive steps in a project have been set out clearly and undertaken with scrupulous attention to detail".

In qualitative research rigour is sought through establishing credibility, trustworthiness and demonstrating audit trails (Denzin & Lincoln, 1994).

Within the context of qualitative data there are several steps that may be taken to improve the 'credibility' and 'trustworthiness' of the data and to ensure the research is 'rigourous' (Polit & Hungler, 1995; Sandelowski, 1986; Tesch, 1990). Sandelowski (1986,p.30) identifies the importance of credibility in qualitative studies stating

> "... it present(s) faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognise it from those descriptions or interpretations as their own".

In this context verbatim exemplars from the participants' interviews were used to describe the experience of anxiety and depression among this community palliative care population. Recommendations for establishing credibility according to Lincoln and Guba (1985) include debriefing with peers to provide an external check on the inquiry process. In this study, the researcher approached the supervisors of the project who provided this debriefing role as a check of analysis.

Sandelowski (1993) claims that audibility is another strategy to achieve rigour in qualitative research. Audibility refers to the explanation of a clear decision trail of the progression of events in the study from the beginning to the end. Audibility can be achieved by the description of how the researcher became interested in the subject, how the researcher views the subject matter in the study, the specific purpose of the study, how participants became involved and were approached in the study, how data was collected and for what period and finally, how data was analysed and presented. A synopsis of the participants history with no identifiable features will be used in the presentation of the findings to provide a clearer picture to the reader, which is consistent with other qualitative research studies (Wallis, 1996; White, 1994). Evidence of an audit trail in this study is demonstrated in this thesis report.

3.12. ETHICAL CONSIDERATIONS.

The research proposal was submitted to the Research Committee at the study hospital and to the Research Ethics Committee at the Australian Catholic University, Sydney. Permission to invite community palliative care patients to participate voluntary in the study was granted by both institutions (refer to Appendices 6 & 7).

All participants taking part in the questionnaire and interviews were fully informed regarding the project. An information sheet was provided to each participant in the study (refer to Appendix 8) which was prepared by the investigator outlining the purpose of the project and giving assurance of confidentiality during the analysis and anonymity in published results, according to National Health and Medical Research Council (1995b) guidelines. A written consent form was completed by all participants taking part in the questionnaire and interview (refer to Appendix 8). Participants consenting to take part in an interview were contacted by phone (to confirm their previously expressed wishes). Any person not wishing to take part in the research after initially consenting was assured that refusal would not affect their future treatment or care provided by the palliative care community service in any way.

Should a participant become distressed during the interview, the interview was to be stopped and the participants given the option to suspend the interview and recommence after a short period of time or, terminate and recommence another day or, terminate and withdraw from the study and request that the information collected not be used. The counselling services of the community based institution were informed of the study and agreed to offer emotional support to the participants if required. On two occasions patients became upset and began crying in which case immediate and appropriate support was given. However, these participants requested that they continue the interview as they felt this was the first opportunity to fully discuss the impact of their disease openly and declined the offer of future counselling services. Chapman and Hall (1989) state that emotional release is usually self-limiting and if the person is allowed to cry or get angry, emotions will be expressed and will then gradually subside benefiting the individual. Patients were encouraged to contact the investigator at any time if they had any questions or concerns about the study.

Questionnaires were returned to the office of the community outreach team where completed questionnaires were placed in a locked box and collected by the investigator. Data were recorded by handwritten answers to the questionnaire by patients, and by handwritten answers to the demographic data sheet by community nurses. The individual interviews were carried out by the principal investigator and recorded, using audio-tapes. Data from both sources were transferred to the investigator's home computer files for qualitative and quantitative analysis. Names of participants were known to the community nurse and investigator. However, participants results were known only by the investigator and numerical coding was used to ensure confidentiality at all times.

If the patient demonstrated that they had clinically significant levels of depression or anxiety according to the HAD scale, they were contacted by the investigator who asked for permission to speak to their medical practitioner for further assessment. Two participants were already seeing a psychiatrist and the remaining participants declined permission for the investigator to speak to their medical practitioner.

Audio-tapes, computer discs and computer printouts are retained in a locked filing cabinet at the investigators' university in a security building for five years and are to be destroyed after a period of five years. Participants were informed that results from the study may appear in publications and as part of the investigator's masters thesis as documented in the consent form, but assured no identifying names or personal information will be used.

CHAPTER FOUR

Quantitative Results

4.1 INTRODUCTION.

This chapter presents the results of the Phase One, and the analysis of the data. The results will be presented as follows. First, the demographics and descriptive statistics on the sample of 75 participants recruited to the study, then the descriptive statistics of the anxiety and depression scores at the initial contact and again two weeks later. The results of the tests of the relationship between risk factors and the anxiety and depression scores in terms of the hypotheses (Chapter 2, section 3.16) will then be discussed. The final section presents the results of logistic regression analysis to determine risk factors which predict anxiety and depression in this community palliative care population.

4.2 DESCRIPTION OF THE PARTICIPANTS.

In this study 114 participants were approached over a six month period and 75 participants were recruited. Of the 75 participants who entered the study, only one participant was receiving any form of treatment for depression or anxiety and this consisted of serotonin reuptake inhibitor antidepressants. Of the 39 who did not enter the study, 14 participants were deemed "too ill" by the community palliative care nurse and 24 participants declined stating reasons such as they had recently completed an inpatient questionnaire and did not wish to do another, or that this research involved too many questions. One participant did not like the questions used in the tool, one felt they had nothing to offer the researcher, one participant was withdrawn from the study because of incomplete responses on the questionnaire and the remaining seven participants declined without explanation. Of the 75 participants recruited, 60 participants were able to be followed up after two weeks and completed Phase One of the study. Of the 15 participants who did not complete the questionnaire, one declined further palliative care services, three were deemed "too ill" to complete the questionnaire by the community palliative care nurse and 11 had died.

4.2.1 Demographics.

The distribution of men and women was almost equal. Thirty-eight of the 75 participants were women and thirty-seven were men (Table 4.1). The age of the range of the participants was between 30 and 85 years. For women and men, the mean ages were 67.3 years and 68.4 years respectively. The median age for both was 71 years.

Table 4.1. Age and gender of participants.

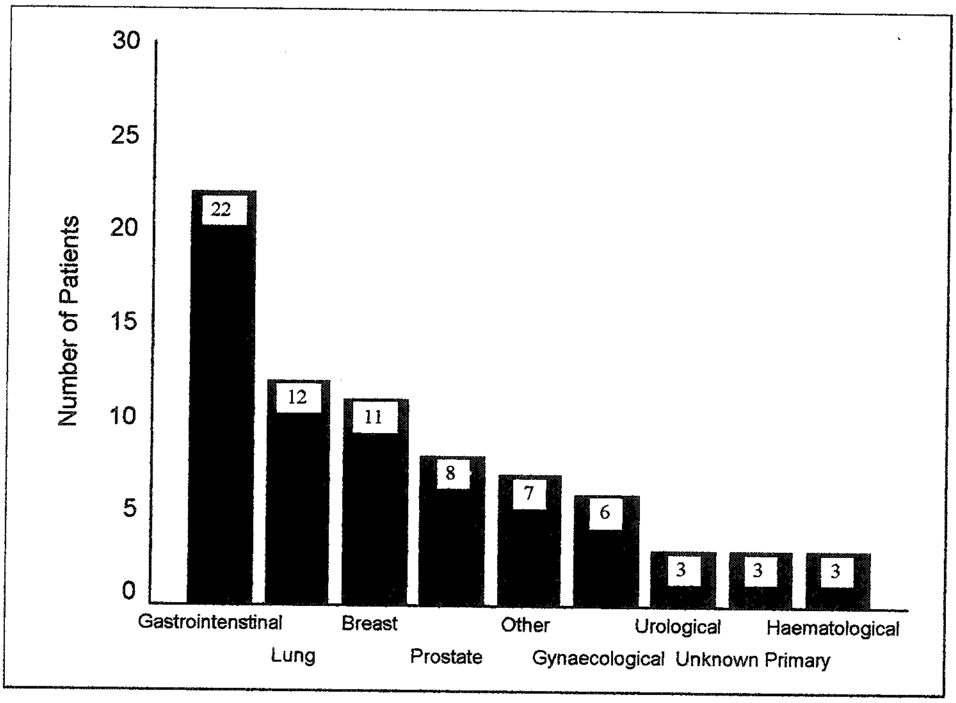
Age	Women (%)	Men (%)	Total(%)
30-40	3 (4%)	2 (3%)	5 (7%)
41-50	3 (4%)	2 (3%)	5 (7%)
51-60	6 (8%)	6 (8%)	12 (16%)
61-70	5 (7%)	7 (9%)	12 (16%)
71-80	14 (19%)	18 (24%)	32 (43%)
>81	7 (9%)	2 (3%)	9 (12%)
Total	**38 (51%)**	**37 (49%)**	**75**

Calculations of the descriptive statistics including frequency distribution, measures of central tendency and measures of variability can be found in Appendix 9.

4.2.2 Malignant diagnosis.

Of the 75 participants, 27 specific cancer diagnosis were recorded. The specific cancer diagnoses were grouped into nine categories as shown in Figure 4.2. The most common diagnoses (75%) fell in to four groups; gastrointestinal cancer 22 (29%), lung cancer 12 (16%), breast cancer 11 (14.7%) and prostate cancer 8 (11%).

Figure 4.1 Grouped diagnoses of community palliative care participants.



The diagnostic group 'gastrointestinal' included anal, colonic, gastric, esophaguoeal, pancreatic and rectal. The 'other diagnosis' group included thyroid, small cell carcinoma/basal cell carcinoma and melanoma. The 'gynaecological' group included ovarian and cervical carcinomas. The 'urological' group included transitional cell carcinoma of the bladder and renal cancer, and the 'haematological' group included Hodgkin's Lymphoma, leukemia and myeloma.

For women, breast carcinoma (29 %) was the most common malignancy. For men, gastrointestinal carcinoma (35%) was the most common malignant disease in this sample.

4.2.3. Metastatic disease.

Of the 75 participants, fifty-nine (79 %) had metastatic disease. Ten (13%) had no known metastastic spread and six (8%) were not recorded. Referral to a palliative care service can occur anywhere across the trajectory of a patient's illness. In this community palliative care population over three quarters of the participants had advanced disease (metastases) at the time of referral to this community palliative care service.

4.2.4 Length of time since diagnosis.

Length of time since diagnosis was recorded at the initial contact with the palliative care patient. It was recorded as days, weeks, months and years which was then re-categorised into six groups as shown in Table 4.2.

Table 4.2 Length of time since diagnosis.

Length of time in months	Number of participants	Percentage	Cumulative Percentage
< 6 mths	23	31	31
6mths - 12mths	14	19	50
13mths - 24 mths	10	13	63
25mths - 36 mths	7	9	72
37mths - 48 mths	5	7	79
> 48 mths	16	21	100
TOTAL	**75**	**100**	

Of the 75 participants, 50% had been diagnosed for 12 months or less. The median time period for length of time since diagnosis was the category 13 months to 24 months.

4.2.5 Previous history of depression and/or anxiety.

Participants were asked whether they had ever experienced depression and/or anxiety in the past. Of the 75 participants, twelve (16 %) stated that they had previously experienced anxiety, while 63 (84 %) had never experienced anxiety before. Thirteen (17 %) participants of the sample stated they had previously experienced depression, while 62 (82 %) had never experienced depression.

4.2.6 Family history of depression and/or anxiety.

Participants were asked to state whether a family member had ever experienced depression and/or anxiety. Of the 75 participants, five (7%) stated they had a family history of depression, while seventy (93%) had no family history of depression. Five (7%) stated that they had a family member who had previously experienced anxiety, while 70 (93%) reported no family members who had experienced any previous anxiety.

4.2.7 Participants reported perceived social support.

At the initial visit, participants were asked how they perceived their social support. They were asked to categorize their response into good, moderate, and poor. No participants perceived their social support as poor. Perceived social support was catergorised as moderate for 23 (31%). The majority of the community palliative care participants perceived they had good social support (70%).

4.2.8 Numbers of people providing the perceived social support to the participants.

Participants were asked to estimate how many people they perceived as providing them with social support as shown in Table 4.3. The mean number of people providing support was 3.4 (the range of people providing support was between 1 to 10 people, and a standard deviation (sd) of 1.85).

Table 4.3. Estimated number of people providing support to the participants.

Number of People supporting participants	Number of Participants	Percentage	Cumulative Percentage
1	9	12	12
2	18	24	36
3	14	19	55
4	20	27	82
5	6	8	90
6	5	8	98
10	2	2	100
Total	**75**	**100**	

Of the 75 participants, a third had two people or less providing support.

4.2.9 Nearest carer.

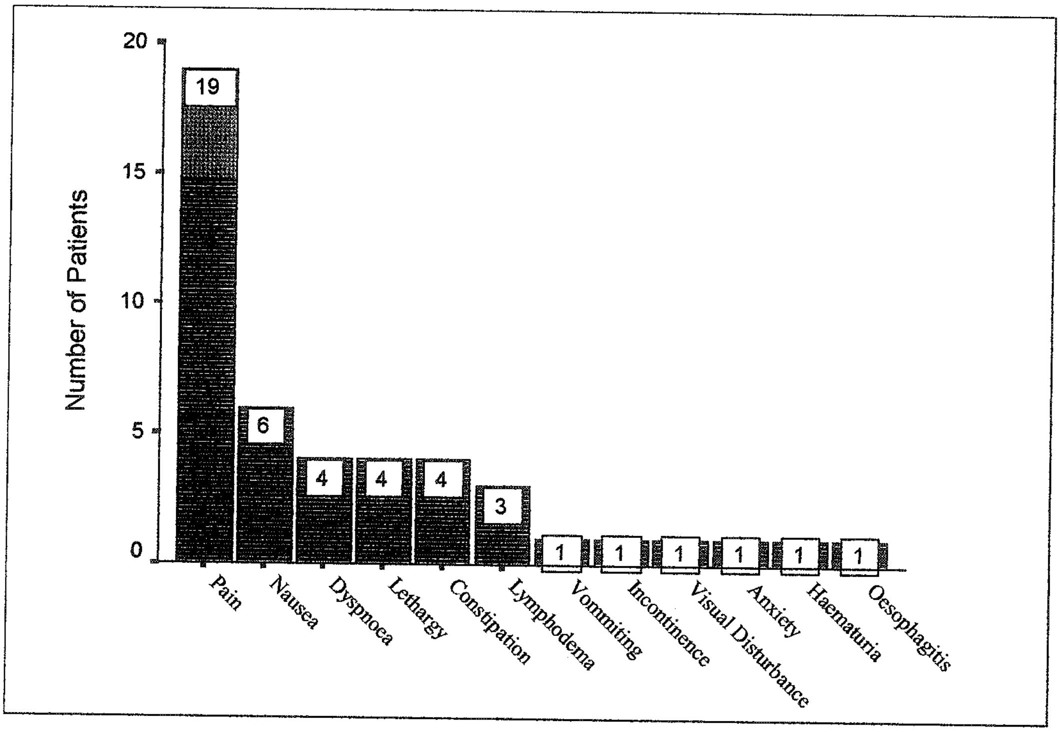
Of the 75 participants, 65 (87%) had carers and ten (13%) did not. The main carers were spouse/partner 39 (60%), daughters 16 (25%), son 5 (8%), sister 4 (6%), brother 1 (1.5%) and friend 1 (1.5%). Of the 65 carers, the majority were female, 44 (68%).

4.2.10 Presence of an unresolved symptom.

At time of referral any existing symptom stated by the patient as unresolved was documented on the demographic form. Of the 75 participants, 46 (61%) participants stated they had an unresolved symptom and 29 (39%) did not report any unresolved symptoms. Twenty-nine participants (39%) reported having two unresolved symptoms at one time and two (3%) of the participants reported having three unresolved symptoms at one time.

Of the 46 participants reporting one symptom, the most common symptoms were pain 41% (19), nausea 13% (6), lethargy 8% (4), dyspnoea 8% (4) and constipation 8% (4) as shown in Figure 4.9.

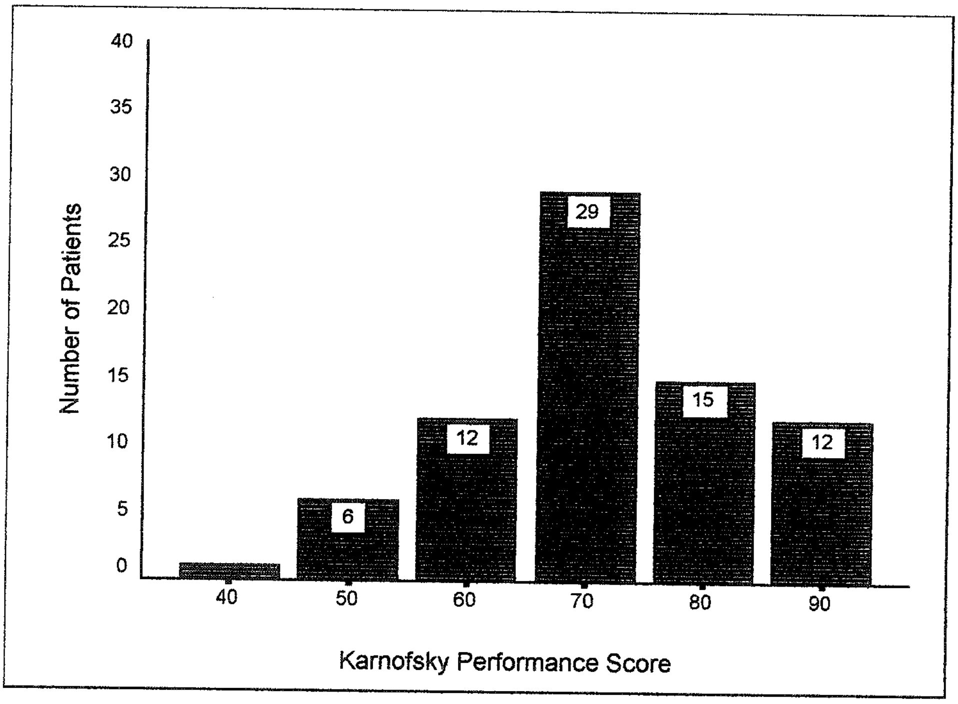
Figure 4.2. The first documented unresolved symptom.



4.2.11 Participants' functional health status.

Karnofsky performance scores which assesses patient functional health status was recorded at the time of referral to the community palliative care service. Results are presented in Figure 4.10.

Figure 4.3. Patient Karnofsky Performance Score at the time of referral.



Seven (9%) participants scored 50 or less on the KPS, and could be categorised as unable to care for themselves. Forty-one (55%) participants scored between 60 and 70 and could be categorised as unable to work, but able to care for most of their personal needs. Twenty-seven (36%) participants who scored 80 or more could be categorised as able to carry out normal activities and did not require any special care.

The range of the functional health status scores was from 40 to 90. The mean KPS was 71.60 and a standard deviation 11.97. Of the 75 participants, 75% scored 70 or higher on the Karnofsky Performance Scale, indicating that the majority were able to care for most of their needs.

4.3 DESCRIPTION OF DEPRESSION AND ANXIETY SCORES

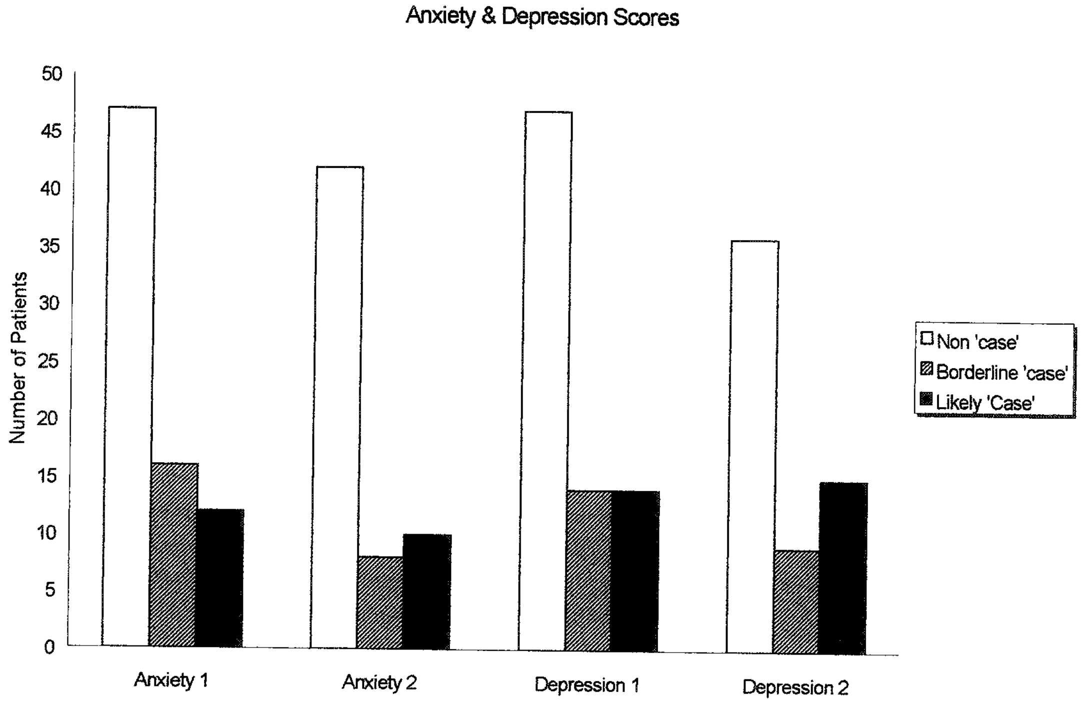
In this study the prevalence of depression or anxiety will be described as the point prevalence. Point prevalence describes the proportion of a population with the attribute at a specific point in time (Irwig, Shelly, Kleinbaum & Lyle, 1995).

4.3.1 Depression and anxiety scores at time of referral.

Seventy-five participants completed the 14 item self report Hospital Anxiety and Depression Scale (HADS). The possible score range is from 0 to 21 for either depression or anxiety. Using established cut off scores of ≥ 11 as an indicator of a "case" of depression or anxiety, 14 (19%) participants were identified as depressed and 12 (16%) were identified as anxious according to the HAD scale as shown in Figure 4.4.

The range of depression scores was from 1 - 15 and the standard deviation was 3.63. The range of anxiety scores was from 0 - 18 and the standard deviation was 4.17.

Figure 4.4 Depression and anxiety scores for the first and second HADS questionnaire



4.3.2 Depression and anxiety scores two weeks later.

Sixty of the 75 participants were able to complete the second questionnaire approximately two weeks later, a response rate of 80%. The difficulties in achieving a higher compliance were related to participant's unavailability. As data collection for this study extended through the Christmas period participants had family commitments and therefore declined visits, went on holidays, or had other commitments such as doctors appointments. Several participants were admitted to hospital for short periods. At times there were difficulties encountered by the inability of the data collectors to arrange the data collection around their work schedule.

There was a relatively small attrition rate of only 20%. A study by Wiley (1998) investigating the impact of informal care on caregivers in a community palliative care population, reported a patient drop-out of 48% over a four week period, indicating that the time-frame between interviews was too long in this population. According to Cassileth and Lusk (1989) and Alexander (1998) sample attrition in the palliative care population is usually very high because patients inevitably physically decline and may die during the course of the research.

The results of the second HAD questionnaire showed that for the anxiety sub-scale, 10 (17%) were anxious and 15 (25%) were depressed as shown in Figure 4.4. The mean anxiety score for the second HAD questionnaire was 5.85 (the range of anxiety scores was between 0 - 21, sd was 4.59). The mean depression score for the second HAD questionnaire was 6.95 (the range of depression scores was between 0 - 20, sd was 4.27).

4.3.3 Previous or family history of depression or anxiety.

Of the 14 participants who were likely "cases" of depression according to the HAD scale, three (21%) had a family history of depression and one (7%) had a family history of anxiety. Of the same 14 participants, six (43%) had a previous history of depression and six (43%) had a history of anxiety.

Of the 12 participants who were "likely cases" of anxiety according to the HAD scale, two (17%) had a previous history of anxiety and four (33%) had previous history of depression. Of the 12 participants, none had a family history of anxiety and one (8%) had a family history of depression. Table 4.4 highlights depression and anxiety "cases" with previous history of depression or anxiety and a family history of depression and anxiety.

Table 4.4 Anxious and depressed participants with a family history or previous history of anxiety or depression.

	Previous Anxiety	Previous Depression	Family History of Anxiety	Family History of Depression
Depression	6 (43%)	6 (43%)	3 (21%)	1 (7%)
Anxiety	2 (17%)	4 (33%)	0	1 (8%)

4.3.4 Gender differences in anxiety and depression scores on first questionnaire.

Fourteen participants scored ≥ 11 for depression on the HAD tool, seven (50%) were women and seven (50%) were men. Of the total female population of this sample (38), 7 (18 %) had a depressed mood while the total male population of this sample (37), 7 (19%) had a depressed mood at the time of the first questionnaire. This indicates no real differences between gender and depression scores.

Of the 12 participants who scored ≥ 11 for anxiety, 5 (42%) were female and 7 (58%) were male, indicating a 16% difference between gender. Of the total female population (38), 5 (13%) were identified as anxious while within the total male population (37), 7 (19%) were identified as anxious mood at the time of the first questionnaire. Although the results of this study indicate that more men than women had scores of clinically significant anxiety, the sample size is too small to draw significant conclusions.

4.3.5 Changes in depression and anxiety scores within two weeks.

Of the 14 participants who were likely "cases" of depression on the first questionnaire, 8 (57 %) remained depressed according to the HAD scale and 6 (43%) improved. Of the 12 participants who had anxiety on the first questionnaire, 6 (50%) remained in an anxious state and 6 (50%) improved.

4.3.6 Gender differences between depression and anxiety scores of second questionnaire

Of the 15 (25%) participants who had a depression score >11 in the second questionnaire, 8 (54%) were female and 7 (46%) were male. Of the total female sample, 8 (21%) were depressed at the time of the second questionnaire. Of the total male sample, 7(19%) were depressed at the time of the second questionnaire, indicating no change in the number of males who were deemed likely "cases" of depression from the first questionnaire.

Of the 10 (17%) participants who had an anxiety score of >11 in the second questionnaire, 6 (60%) were male and 4 (40%) were female. Of the total female sample population, 4 (10%) were anxious at the time of the second questionnaire. Of the total male sample population, 17% (6) had possible clinically significant anxiety at the time of the second questionnaire. This indicates a trend that there were more men who were anxious than women in this study, however no conclusions can be drawn based on the small number.

Overall in this community palliative care population, there were more men than women who were anxious and, more women than men who were depressed (see Table 4.5)

Table 4.5. The gender differences of anxiety and depression on two occasions

Mood	Male (%)	Female (%)	Total (%) *n* = 75
Depression			
1st HADS	7 (50%)	7 (50%)	14 (19%)
2nd HADS	7 (58%)	8 (54%)	15 (25%)
Anxiety			
1st HADS	7 (58%)	5 (42%)	12 (16%)
2nd HADS	6 (60%0	4 (40%)	10 (17%)

4.4 COMPARISON OF RELATIONSHIPS BETWEEN ANXIETY / DEPRESSION SCORES AND THE INDEPENDENT VARIABLES

Non-parametric comparisons using Mann-Whitney *U* test were performed to determine a relationship between the risk factors (gender, functional health status, diagnosis, length of diagnosis, family history of anxiety/depression, previous history of anxiety/depression, perceived social support, and presence of an unresolved symptom) and the outcome of depression or anxiety. The Spearman Correlation Coefficient was used to examine the association between the numeric independent variable age and the depression and anxiety scores.

In this study a statistically significant value was set at $p < 0.05$ as advised by a statiscian and also this value is generally accepted in nursing research studies (Roberts & Burke, 1989). However, Munro, Jacobsen and Braitman (1997) highlight that the probability cutoff has been applied more rigouriously (1%) or more generously (10%) in studies depending on the researcher's own intuition or the purposes and design of their research.

The Spearman Correlation Coefficients indicated no significant correlation between age and the ranked scores obtained for depression and anxiety in this study, the statistical procedure can be found in Appendix 10. A low correlation coefficient between depression and anxiety among the community palliative care participants was determined ($r=.355$, $p <.002$). According to Norbeck, Lindsey and Stotts (1987), in nursing studies involving psychosocial variables, correlations between + 0.5 and + 0.7 or between - 0.5 and - 0.7 are considered strong correlations. On the other hand, studies with physiologic variables rather than psychosocial ones, correlations of less than + 0.85 or - 0.85 are considered weak (Norbeck et al., 1987).

The raw independent variables were transformed into nominal data and the dependent variable, depression and anxiety scores were retained in their interval form, ranging from 0-21. Several relationships were found when Mann-Whitney *U* tests were then applied to the data (refer to Appendix 11).

There was a difference between participants' who were depressed with a previous history of depression (2-tailed $p=.048$, $U=262.5$) and those participants who were depressed but had no previous history at a significance level $p < .05$. Also there was a difference between participants who were depressed with an unresolved symptom (2-tailed $p = .032$, $U= 471$) and those participants who were depressed but had no unresolved symptom.

There was a difference between participants who were anxious with a previous history of depression (2-tailed $p = .015$, $U= 230$) and those who were anxious but had no previous history. Also there was a difference between participants who were anxious and had an unresolved symptom (2-tailed $p = .035$, $U= 474$).

4.5 LOGISTIC REGRESSION ANALYSIS

4.5.1 Introduction

Logistic regression is often used in research to develop predictive models which can then be utilized in similar populations for theory testing and for exploratory research (Menard, 1995). In this study the purpose of using logistic regression analysis was as a vehicle to explore which risk factors predispose community palliative care participants to depression and anxiety where the dependent variable is dichotomous.

A forward stepwise (Wald) logistic regression procedure was applied to the data collected from the 14 participants who were depressed and the 12 participants who were anxious. Several researchers suggest the use of stepwise procedures as a useful tool for exploratory research (Agresti & Finlay, 1986; Hosmer & Lemeshow, 1989). Forward stepwise logistic regression refers to the way predictor variables are entered into the model. In this forward procedure variables are entered by the selection for inclusion or removal based on statistical significance of the coefficient for the variable (Hosmer & Lemeshow, 1989). The end result of this procedure is a calculated odds ratio which may be used to indicate which risk factors contribute to the outcome, or in this study, the development of depression or anxiety. An odds ratio of one is interpreted as no effect, less than one indicates a decreased risk of depression and/or anxiety and, greater than one is interpreted as an increased risk of depression and/or anxiety (Wright, 1995).

For this logistic regression procedure, data transformation of variables into dummy variables was required. The dependent variables, depression and anxiety were dichotomised as a result of their HAD score (cut-off score ≥ 11) to depressed =1, not depressed = 0 and anxious =1, not anxious =0. The independent variables were age (continuous), gender (male =1, female = 2), diagnosis (remained in category groups 1

- 7), length of diagnosis (categorised into 3 groups- 1= < 6 mths, 2= 6- 12mths, 3= > 13mths), previous anxiety (yes =1, no =0), previous depression(yes= 1, no=0), family history of anxiety(yes =1, no=0), family history of depression (yes =1, no =0), perceived social support (good =1, moderate=0), presence of an unresolved symptom (yes =1, no =0) and Karnofsky score (continuous). As there were two dependent variables being tested, a forward stepwise regression was run separately for each dependent variable.

4.5.2 Univariate logistic regression analysis.

Initially univariate analysis was used to test the effect of individual variables on the risk of depression and/or anxiety (refer to Appendix 12). Table 4.6 shows the results of logistic regression for predictors of depression and anxiety with no simultaneous control of other potential confounding factors.

The predictors of depression in this sample of community palliative care participants were a previous history of anxiety (p =0.005), previous history of depression (p=0.009) and family history of depression (p=0.007). However, these results need to be interpreted with caution in respect to the small sample size (14 participants).

Table 4.6 . Univarite logistic regression analysis of risk for depression and anxiety in community palliative care participants- Odds Ratio (95% Confidence Interval).

Risk Factors	Depression	*p*-value	Anxiety	*p*-value
Previous history of depression	5.78 (1.51-22.23)	.009*	3.00 (0.72-12.42)	.122
Previous history of anxiety	6.87 (1.73-27.34)	.005*	1.06 (0.19-1.75)	.945
Family history of depression	24.0 (2.32-248.7)	.007*	1.34 (0.13-13.79)	.801
Family history of anxiety	1.10 (0.10-11.4)	.936	.00 (3.96-4.43)	.806
Age	1.03 (0.97-1.08)	.304	1.00 (0.96 - 1.06	.764
Gender	1.38 (0.42- 4.5)	.592	0.64 (0.18-2.32)	.498
Presence of an unresolved symptom	0.80 (0.24-2.67)	.721	9522 (2.98- 3.04)	.763
Diagnosis				
diagn2(1)	0.71 (0.09-5.23)	.732	992 (1.25- 7.88)	.818
diagn2(3)	2.25 (0.31- 16.39)	.414	1984 (1.57- 2.50)	.800
diagn2(7)	1.80 (0.18-17.77)	.607	7443 (5.97- 9.28)	.766
Length of diagnosis < 1 year	1.90 (0.38- 9.55)	.427	0.98 (0.91-5.11)	.982
Length of diagnosis > 1year	0.90 (0.22- 3.65)	.870	0.42 (0.10-1.83)	.240
Perceived social support	0.51 (0.91- 3.08)	.277	0.86 (0.23-3.31)	.827
Karnofsky	1.01 (0.96- 1.06)	.661	1.00 (0.95- 1.06)	.775

* $p < .05$
$n = 75$

Length of time since diagnosis was not shown to have any statistical significance but the odds ratio (1.9), indicated that a shorter length of time since diagnosis, less than 6 months, is likely to increase the odds of depression almost two-fold. Gender differences in depression scores were shown not to be statistically significant, however the odds ratio (1.4), illustrates that women have 40% higher odds of presenting with depression.

When the dependent variable of anxiety was applied individually to the independent variables, no statistical significance was found. However, being anxious and having a previous history of depression (as indicated by the odds ratio), increased the risk of anxiety three fold, although this was not statistically significant. Also a family history of depression is likely to increase the odds of developing anxiety to nearly 1 1/2, but again this was not statistically significant.

4.5.3. Multivariate logistic regression analysis.

A multivariate analysis using logistic regression was then applied to the data (refer to Appendix 12). A forward stepwise (Wald) selection strategy was used to sequentially add one control variable at a time to a model containing only depression or anxiety. Variables were added to the model based on statistical significance ($p < .05$) until no further variables were contributory. Table 4.7 presents the results of the multivariate logistic regression model applied to the data for the dependent variables depression and the independent risk factors.

Table 4.7. Results of the multivariate forward stepwise logistic regression analysis of risk factors for depression in community palliative care participants- Odds Ratio (95% Confidence Interval).

Risk Factors	Depression	p-value
Previous history of anxiety	6.45 (1.43- 29.15)	0.013*
Family history of depression	22.2 (0.52- 258.06)	0.011*

* $p < .05$
n= 75

Independent predictors of depression in this sample of community palliative care participants were previous history of anxiety and family history of depression.

Participants with a family history of depression, are 6 1/2 times more likely to suffer depression, while a patient with a previous history of anxiety, is 22 times more likely to suffer depression. Again the researcher cautions the reader about the statistically significant findings in relation to the small sample size with this section of data analysis.

In reporting the results of logistic regression the goodness-of-fit statistic and the log likelihood are usually presented. The 'goodness-of-fit' statistic of the logistic regression model refers to how well the model contains those variables that should be in the model (Hosmer & Lemeshow, 1989). The statistic compares the observed probabilities to those predicted by the model (Munro, 1997b). In this study the goodness-of-fit statistic was 74.4 with 17 degrees of freedom which indicates an unsatisfactory fit of the model. The -2 log likelihood is the probability of the observed results (Munro, 1997). A good model is one that "... results in a high likelihood of the observed results" (Munro, 1997b, p.295).

The Nagelkerke R^2 is an analogue to explain variance in regression and is referred to as the explained deviance or pseudo r^2. Deviance compares "... the predicted probability of being in the correct group based on the model to the perfect prediction of 1 ... and can be viewed as a component of the log likelihood" (Munro, 1997, p.295). Large values for deviance indicate that the model does not fit the case well. At the completion of the multivariate analysis when the variables, previous history of depression and family history of depression were included in the model, these variables accounted for thirty percent of the deviance (Nagelkerke $R^2 = 0.304$) in depression of the community palliative care participants (refer to Appendix.12 for statistical calculations). The Nagelkerke R^2 statistic = 0.304 indicates that the model developed during the multivariate analysis explained a substantive amount of the deviance, although a considerable amount remains unexplained. This high level of unexplained deviance indicates why the model fit was declared unsatisfactory in the goodness-of-fit test. Despite this unsatisfactory model fit and the high level of unexplained deviance, in exploratory research using logistic regression, these statistics are not considered important (Menard, 1995).

The independent variables of age, gender, diagnosis, length of diagnosis, previous history of depression, family history of anxiety, perceived social support, presence of unresolved symptom and Karnofsky score were not included in the equation as they did not meet the statistical significance level $p < .05$. When the dependent variable, anxiety was applied to the multivariate analysis using the logistic regression, no statistical significance was found with any of the independent variables.

The lack of statistically significant results in conjunction with large effect sizes is indicative of the small sample size applied to this type of analysis (Wright, 1995). The sample was broken down into risk factors and the outcome factors of depression and anxiety, thus diminishing the counts per cell to be analyzed. In the risk factor data for the functional health status, the majority of the sample were able to care for themselves. As for age, the majority of participants were older than 61 years making it difficult to assess the degree of risk for younger participants. Perceived social support was recorded as good and moderate. No participants recorded poor social support thus making analysis of this risk factor difficult to assess. Therefore, the reduction of available data to be analysed by the small sample size impacted on the significance of the results in this study.

4.6 NULL HYPOTHESES.

The following null hypotheses were tested and resulted in;

1. **Null hypothesis 1 is accepted.** There is no relationship between HAD depression or anxiety scores and patient's age.

2. **Null hypothesis 2 is rejected.** There is a relationship between depression or anxiety scores and patients with a previous history of depression or anxiety.

3. **Null hypothesis 3 is rejected.** There is a relationship between depression or anxiety scores and a family history of depression or anxiety.

4. **Null hypothesis 4 is accepted.** There is no relationship between depression or anxiety scores and gender.

5. **Null hypothesis 5 remains inconclusive.** A relationship between depression or anxiety scores and the existence of an unresolved symptom could not be determined.

6. **Null hypothesis 6 is accepted.** There was no relationship between depression or anxiety scores and the length of time since diagnosis.

7. **Null hypothesis 7 is accepted.** There was no relationship between depression or anxiety scores and different malignant diagnoses.

8. **Null hypothesis 8 was unable to be tested** as perceived social support was ranked positively in all categories.

9. **Null hypothesis 9 is accepted.** There is no relationship between depression or anxiety scores and the functioning health status of the patient.

10. **Null hypothesis 10 is accepted.** There is no relationship between depression or anxiety scores and patients with metastatic disease.

4.7 SUMMARY OF RESULTS.

The scores obtained from the Hospital Anxiety and Depression scale indicated that in this particular community palliative care setting, participants exhibited higher levels of depression (19 - 25%) than anxiety (16 - 17%). Although the HADS scores differed slightly from the initial questionnaire to the second, half of the population remained consistently depressed or anxious over time. In this study more women than men were depressed, and more men than women were anxious.

The non-parametric comparison of the risk factors with the depression and anxiety scores illustrated several results, such as presence of an unresolved symptom and a previous history of depression, were significant at $p < .05$. However, when a multivariate logistic regression analysis was applied to the data, the only significant risk factors which contributed to depression were a previous history of anxiety and family history of depression. The difference of statistically significant results between the Mann Whitney *U* test and the logistic regression analysis can be explained by the transformation of data from numerical to dichotomous data, the statistically different basis of each test, and that data had a skewed distribution. None of the risk factors used in this study were found to be significant in relation to anxiety.

The results of the extent of depression and anxiety and the relationship of the risk factors are discussed in the context of the pertinent literature in Chapter 6. Next, the findings from the qualitative analysis will be discussed in Chapter Five.

CHAPTER FIVE

Qualitative Findings

5.1 INTRODUCTION.

This chapter describes the findings drawn from the interviews of the seven participants who had agreed to be interviewed and were identified as being depressed or anxious according to the HAD scale. As described in Chapter Three, there was a single objective for the patient interviews. This was that participants living with an incurable disease recount and describe their experience of depression and/or anxiety.

In analysing the data the participants' experience of depression and/or anxiety was described in three major themes. These were:

1. Reduced Quality of Life,
2. Facing an Uncertain future, and
3. Holding On.

5.1.1 Conventions.

Exemplars from the transcripts are used to illustrate the findings. The exemplars use participants' own words and were transcribed verbatim. A limitation of this method is that in transcribing verbatim responses the tones and inflections which give meaning to the words are lost. Thus, in reporting this data the researcher will provide clarifying notes with the exemplars. The researcher presents these exemplars as a representative selection, as it is not possible to use all of the exemplars.

To ensure participant anonymity names and other identifying data were removed from the exemplars and the participants are identified by using the pseudonyms Simon, Leonard, Olga, Jeanette, Beth, Mac and Jack. The researcher is identified by using the letter R.

R = Researcher
Pseudonym = Participant

5.1.2 Key for the interviews.

... :	Means that the quote is part of a sentence, or that there are more words following the quote.
[ ] :	Indicates the authors words.

5.2. THE PARTICIPANTS.

5.2.1 Introduction.

Twenty-three participants met the criteria for an interview, seven of these were interviewed. Of the 16 participants not interviewed one participant could not be contacted, three declined an interview, eight were deemed "too ill", three died before an interview could be arranged and one interview was unable to be used due to faulty recording.

Of the seven participants interviewed, three participants were depressed, one participant was anxious and three participants were both anxious and depressed according to the HAD scale. Perceived social support was rated "good" by five of the participants with remaining three rating their support as "moderate". The Karnofsky Performance scores ranged from 60 to 90, of which five participants scored 80 or greater indicating the ability to carry out normal activities with minimal signs and symptoms of disease.

Each participant interview was conducted on a single occasion. The majority of the interviews took place approximately three weeks after referral to the community palliative care service. All seven participants had advanced malignant disease. Most participants found it difficult to give an account of their emotional experiences without first informing the researcher of their full medical background and the steps leading to their diagnosis. The participants felt that this was an important first step in telling their story, so that the researcher would have a greater understanding of the impact of their disease and their psychological experience.

5.2.2 The participants' background.

Jeanette was a widow in her mid eighties with lung cancer. Jeanette was relaxed during the interview and provided candid and open responses to questions asked.

Jeanette was eager to talk to the researcher about her disease, from diagnosis to the present and the impact it had on her life. She repeatedly spoke of her physical weakness and lack of energy which had disrupted her previously active lifestyle and how it impacted on her self-worth. Jeanette acknowledged her life span was limited due to her disease but also felt at her age "you can't expect much". Despite this resignation she spoke of attempting to continue coping with her remaining life and her desire to do so.

Mac was a man in his early seventies with metastatic prostate cancer. He lived with his very supportive wife and their cat, which Mac called "his friend". At the time of the interview with the researcher, Mac was in the process of adjusting to being back home following a four week hospital admission. During the course of the interview it became clear that Mac had been through a very difficult period in his illness. He spoke of the long separation from his wife and cat, and how that had depressed him. He spoke of how his disease and its treatment had physically impacted on his life. Mac's wife interjected several times during the interview to clarify responses made by Mac.

Olga was a women in her late sixties with lung cancer and brain metastases. Olga had been living in Canberra with a friend until she began to have repeated falls. Olga's daughter insisted she move to Sydney and live with her and her two children, so that she could help care for her mother. Olga was very open about the impact of her disease, providing considerable information about her experience.

Simon was a man in his mid fifties, married with one son. Simon was originally from Greece but had settled in Australia ten years ago. His English was quite fluent but the researcher had some difficulty transcribing the interview. During the interview Simon's wife was present and occasionally made additional comments. Simon spoke candidly of the physical impact of his disease. He also spoke of the effect of a cancer diagnosis on his family.

Beth was a 60 year old woman with breast cancer. She has been a widow for five years and her three children in their twenties were still living at home. Beth had worked as a school teacher full-time for the past twenty years until the development of her metastatic disease several months ago. Beth spoke openly about how she had been planning her retirement years but was now in "limbo" due to her disease. Beth was extremely concerned about the future of her children and of the impact her recurrent disease already had on her family.

Jack was a man in his mid sixties, married with two grown up children. Jack had been retired for several years and was in the process of fulfilling his retirement plans such as travelling around Australia in a van, when he was diagnosed with cancer. During the interview Jack's wife was present and at times she interjected to clarify information. Jack was very methodical in relating the history of his disease and candid about how this had impacted on his life. Jack stated he was an "optimist" and that taking back control of his life would help his well-being.

Leonard was a single man in his late seventies with lung cancer and brain metatastes. His responses to questions were very short, however, he was relaxed during the interview. Leonard spoke of the impact of the disease on his life and how it depressed him. Although Leonard spoke of the negative impact on his life, he surmised that the negative changes to his lifestyle would have occurred at some stage and rationalised his misfortune as part of the normal ageing process.

5.3 THE EXPERIENCE OF DEPRESSION AND ANXIETY FROM THE QUALITATIVE DATA ANALYSIS.

Table 5.1 details the major and minor themes which emerged from the data obtained. The experience of depression and anxiety is described in the themes as reduced quality of life, facing an uncertain future and, holding on. Each theme will be discussed in turn, leading the reader through the data to a clearer understanding of this experience.

Table 5.1. Major and minor themes of anxiety and depression as experienced by community palliative care participants.

Major Themes	Minor Themes
Reduced Quality of Life	Physical Adversities Psychological Consequences Stress on the Family
Facing an Uncertain Future	The Meaning of Cancer Fear of the Dying Process Being in Limbo
Holding On	Hope Taking Control

5.4 REDUCED QUALITY OF LIFE.

Reduced quality of life for the participants was a universal theme, and was almost the core of the experience of depression and anxiety. All the participants interviewed described situations which illustrated this theme. A reduced quality of life was related to the impact of the disease process on their physical and psychological well-being and the strain on the participants' family. Three minor themes supported and enhanced the major theme "Reduced quality of life" these were physical adversities, psychological consequences, and stress on the family.

5.4.1 Physical adversities.

The participants readily described the physical impact caused by the disease as a significant contribution to their experience of depression and anxiety. They reported many instances where this negatively impacted on their life. The physical adversities experienced by the participants were highlighted when they spoke of their limited daily activities, treatment and medication side-effects, restricted social activities and the continuum of symptoms which led them to feel depressed and/or anxious about their life. For example, Leonard spoke of being restricted to the house because of his physical limitations, which he resented:

> *... I used to ... walk .. .up to an hour ... I can no longer do that ... simply because I haven't got the energy to ... do it. Nor, in fact the ... the inclination ... I don't mind staying inside but I ... resent the fact that I can't get out very much.*
> [Leonard]

The inability to do simple chores around the house due to the physical adversities of disease was described by most participants, as in Jeanette's quote.

> *Today is a very bad day because ... I feel very exhausted, tired and ... weepy ... I find that the days I do a little more [physically] than usual, the next day I'm pretty flat ... Feeling the way I do at the moment ... worries me ... I start to wash up and I've got to sit down. I half make the bed and I've got to sit down ... as soon as I do a little bit I've got to sit down and then I get upset because I want to do something else but I can't. I just haven't got any strength.*
>
> [Jeanette]

These physical adversities were often cancer related as demonstrated by the physical impact and treatment side-effects which were more severe when the treatment did not work. For example, Jack stated:

> *I went into radiotherapy ... the end product was it shook me up...and sent me down hill quickly [physically]. And in the words of the doctor "it had no real effect .... it was not successful".*
>
> [Jack]

Beth also talked about the side-effects of radiotherapy and how she perceived her health status.

> *I think probably it was the radiotherapy that set me back ... I'm just disappointed that I'm not ... as mobile and not doing as much as I thought I would be doing. I feel as though I've gone down hill.*
>
> [Beth]

The participants questioned their quality of life in relation to the difficulty of controlling pain and the side-effects of the medications. For example, Jack spoke of his difficulties in controlling his pain and felt he was in a no win situation, but had no option but to continue his pain control regime.

> *What ... it used to be was a "catch 22" situation. The body was in pain. I belt bloody morphine and whatever else into me, to try to stop the pain and it wouldn't [work]. So, I'd then sit in a chair and wriggle myself around until I got myself into a position where it wasn't painful. But that position also put me in a prone position that [caused me to doze] off to sleep. So then I'd wake up in pain ... then I'd either take some more morphine if it was time or wriggle myself around to a more ... [comfortable] position and go off to sleep again. So I mean this was like my whole day.*
>
> [Jack]

The experience of depression and anxiety was exacerbated when the participants experienced reduced social interactions. It was mainly the physical limitations imposed on the participants by the disease process which lead to reduced social interactions. When participants' social interactions were restricted, it reduced the enjoyment they had previously experienced in their lives, as seen in the following exemplars:

> *... I was enjoying the life I was leading at the time, being active I mean. And up until now, I have attempted to get down to the surf club once ... a week ... it was ... a social activity as well as a physical activity. I've given away going down there now because ... I'm buggered by the time I get there ...*
>
> [Leonard]

And Jack:

> *... see now, a lot of things [have] been taken out of my life ... I used to be an avid club ... frequenter. I'd go to the RSL club. I don't go to the club anymore, if for no other reason [than] because of the sixth hourly hits of bloody morphine ...*
>
> [Jack]

The physical adversities which negatively influenced the participants' quality of life were highlighted when participants spoke of situations where they experienced a constant, continuation of their symptoms. For example, Jeanette:

> *You see I've had a lot of things [medical problems], just too many things, you know. And ... I just [feel] like an old car, like an old bomb I say. Parts are worn out and there's not much you can do.*
>
> [Jeanette]

And Simon :

> *You try to fix this problem [physical symptom], you [get] another one.*
>
> [Simon]

5.4.2 Psychological consequences.

The experience of depression and anxiety was manifested by a reduced quality in the life of the participants, which was evident in their descriptions of the psychological impact of having a terminal illness. The psychological consequences were very closely related to the physical impact of the disease process. The psychological consequences were described in terms of negative feelings, such as feeling useless, lacking motivation and feeling frustrated. For example, Mac stated:

> *I was hopeless ... I was depressed, lonely, fed up ...*

The researcher then asked Mac to explain what he was *fed up* about.

> *The way I was [physically].*
>
> [Mac]

This view was expressed by other participants as in the following exemplar. Jeanette openly stated she felt *useless* and became *depressed* as a psychological consequence of the physical impact of her disease.

> *I just haven't got any strength to do anything. And it's very ... you have to go through it to know ... And now I just feel like I'm useless ... in desperation I get depressed ... because I'm fed up with myself ...*
>
> [Jeanette]

This was also expressed as a lack of motivation to perform normal everyday activities and the tremendous energy required to consciously make the effort. Beth:

> *... I just haven't had the inclination. I got to psych myself up to have the inclination to go and do things.*
>
> [Beth]

The psychological consequences of the experience of depression and anxiety also affected the participants' capacity to think clearly. In particular, Simon spoke of how he could not function mentally and how soul destroying that made him feel.

> *... having retired ... I've taken on my own little hobbies ... I found that I couldn't do these either. I mean I ... like computers. I've got my own computer in there and I like to work on that ... but I found I couldn't concentrate, I*

> *couldn't comprehend [it]. ... I could not even* **conjure up** *(participant emphasis) in my mind ... I did not know how to start...didn't know how to do anything. Oh the brain ... is frightfully important. ... And then of course that shatters you're confidence. Because you say " Why can't I do that?"*
>
> [Simon]

5.4.3 Stress on the family.

The level of depression and/or anxiety experienced by the participants was varied but several participants spoke of their concern for the stress imposed on their family, as a consequence of the disease process. This stress was related not only to the participants' illness but also to their concern about future strain on the family. For some participants there was a factor of self condemnation for being the cause of this stress. It became clear from the interviews that this stress negatively impacted on the participants' perception of their quality of life, and increased their level of depression and anxiety.

The stress on the family as a minor theme is exemplified in Beth's situation when she discusses the difficulties in maintaining a dual role within her family unit. Beth, a single widowed mother with three children, spoke of her role as a mother and her desire to protect her children.

> *I tried to keep them [children] aware because I don't want them going under false illusions, you know ... I hold back a bit ... if I'm having a bad day ... I hold back. Because after Terry [deceased husband] went ... [I] was always keeping up the stiff upper lip. You know, getting them [children]*

> *through ... and getting myself through too ... I suppose ... you try to take over the role of both people.*
>
> [Beth]

Beth went on to talk about the difficulties of trying to maintain normal house keeping duties and the difficulty in doing things as a result of her disease. She acknowledged that she was having difficulty delegating household duties to her children after many years of doing these things automatically, "as mothers do".

> *And then yelling at the boys " get this house cleaned up"... oh they're lazy I suppose and as I say they have been spoilt. I mean Andrew [son] was only saying last night " it's your fault", he said, "you've always done everything for us". He said " you never made us do anything ... that's why ... you have to get on to us all the time now". So I said, " yeah, I know it's my fault. I did it". That's just the way of being a mother I suppose.*
>
> [Beth]

Part of the experience of depression and anxiety as described by the participants was the stress imposed on the family which was highlighted when participants spoke of the fear of being a burden or becoming a burden to their family. For example:

> *What makes [me] upset ... is I have to [depend] on somebody else ... because when I'm not sick they [family] can do what [they] want to. She [daughter] can go shopping when she wants to, she can do things...but when I'm here ... she's scared to go, she's scared to leave me ... because I can fall, I can ... hurt myself and all that ... she is more nervous than I am. Doctors think I can't be on my own. I have to be with someone. I don't want to [impose] those things to my own family.*
>
> [Olga]

The depression and anxiety that arose from stress on the family was expressed by Beth as the fear of burdening her children and the need to protect them from the stress and the anxiety she feels about her possible physical deterioration.

> *I don't want to be bedridden ... I lost [a] friend around the corner ... from cancer ... you see her deteriorate ... she didn't seem to have any remission ... she just deteriorated ... [she wonders] is that what is going to happen to me? ... I'll go out and run under a bus [laughing]. No that sounds stupid but I ... I don't want my kids to see me ... go through like that.*
>
> [Beth]

The stress imposed on the family led to the participants' exacerbation of their experience of depression or anxiety. For example, Simon spoke of the impact of stress on his wife and son. It was evident that Simon's' family were very close and caring. Simon felt that his wife has physically suffered the strain of his illness, saying that she had aged very quickly. Simon also is concerned about the direct affect on his son.

> *... not only the person [with] cancer [is] effected but all the family ... look at my wife now ... if you look[ed] five years ago ... she [was] like a young girl. Now she's too old. I[have] got boy ... [who] go[es] to University ... [he] doesn't feel [he can] go anywhere ... both of them worry.*
>
> [Simon]

One participant spoke of the distress that stress imposed on the family and believed her illness was to blame for the development of a family member's illness. Beth:

> *... It was because of me that she couldn't cope with the fact of losing me, you know.*
>
> [Beth]

5.5. FACING AN UNCERTAIN FUTURE.

Facing an uncertain future was a dominant aspect of the participants' experience of depression and anxiety. Four minor themes supported and enhanced the major theme 'Facing an Uncertain Future" the meaning of cancer, limited existence, fear of the dying process, and being in limbo.

5.5.1 The meaning of cancer.

The participants readily spoke of what the "meaning" of cancer suggested to them. The participants equated cancer to a "death sentence" and feared what lay ahead. One participant specifically spoke of his fear of the word cancer. Simon;

> *Very hard ... name, you know [*cancer*] ... The word ... These people ... [find out they] got cancer. Straight away the mind says ... oh ... you [are] going ... he or she is going to die.*
>
> [Simon]

Jack also expresses his thoughts about the implication of a cancer diagnosis saying:

> *I did go down eight months of thinking I had a pinched nerve, when in reality I had cancer ... one can kill you and the other can't.*
>
> [Jack]

When participants described their experience of depression and anxiety, they spoke about the meaning of having metastatic disease. In particular, Simon spoke of his understanding that once the cancer had spread to a specific area that was a precise problem and so could possibly be resolved. However, once the cancer had spread to several areas the implications of his future were more serious and more fearful.

> *Simon's wife:* *And doctor say, [that] Simon's cancer[is] very, very slow growing, it's cancer but ...*
> *Simon:* *Very slow growing.*
> *Simon's wife:* *Slow growing ... [that] gives us a chance.*
> *Simon:* *But the slow growing ... what I got ... the bone problem [metastases] ... I got all [through] the body. Out of control ... Like you hear stories ... if [the cancer] goes to one place ... [you] can fix [it] up ... but if [the cancer] goes all [through] the body you can't fix up ... you can't do anything.*
>
> [Simon]

The news of recurrence of the disease was significant and disbelief was felt for some time, as seen in the following exemplar.

> *I had breast cancer eight and half years ago ... I didn't think it would come back on me ... I thought I was sweet after five [years]. Dr * [Specialist] said to me ... "now I've got bad news for you ... it's the cancer back". I mean you could've knocked me over with a leaf. I really didn't expect it (...) sometimes I just think ... surely he's got my file mixed up.*
>
> [Beth]

All participants acknowledged that because of their cancer diagnosis their life was limited and their future was uncertain. Several participants spoke of their life expectations in terms of time-frames given by their doctors, which contributed to their experience of depression and anxiety. For instance, Olga spoke of the dilemma she faced:

> *Like the doctor said ... I got two months ... one month is gone, then I got another month. So I mean it ... it makes me sad and ... frightened and ... all sorts of things. Sometimes you ... you just want to* ***drop dead*** *[participant emphasis]. ... Sometime[s] I wait for the time to come and ... then it's all over. Sometimes I don't ... I want to stay another day longer.*
>
> [Olga]

Leonard also spoke of a specific time-frame given to him by his doctor, but in fact feels the doctor was too generous in his estimation.

> *He said [the doctor] " well judging on other cases similar to yours ... it would be six to twelve months ... If you were to ask me how ... long it would take to get things really severe ... I'd say not very long.*
>
> [Leonard]

5.5.2 Fear of the dying process.

The fear attached to the process of dying was overwhelmingly destructive to a belief in a brighter future for the participants. This was influenced by life experiences and misconceptions about the dying process. Several participants spoke of the perceived difficulties which lay ahead. In particular, participants equated dying with an increase in physical symptoms, especially pain, which contributed to their depression and anxiety. Beth:

> *I've got a friend ... he's very bad [health] at the moment ... he's getting worse and worse and then ... I think, oh I don't want to get to that stage ... You see that's a bit depressing ... because I think , oh I couldn't stand going through that stage ... getting to that stage. I wonder whether I'm having myself on ... he's in a lot of pain and I'm ... I'm not in that pain. So I keep saying to myself, now I'm not in that pain ... I know I'm not at that stage but I think oh God I can't stand the idea of the thought of getting to that stage.*
>
> [Beth]

One participant spoke of the increased level of depression and anxiety experienced in relation to the fear of physical deterioration and the enormous concern that in the terminal phase of his disease, pain medication will not be effective.

> *Afraid, you know ... [when the cancer] gets into the bones [I] can't walk ... I stay like that. I hear stories from people ... from the hospital when I was there ... and from TV [and] newspaper ... the sick people like me ... after a long time ... tablet[s] [are not] working ... very much ... if the medicine is not working ... what happens now?*
>
> [Simon]

However, for another participant, the fear of dying was not utmost in his mind but he spoke of the realisation that his own death would occur, and is questioning what might lay ahead for himself.

> *I've never been aware of just how people die of ... cancer ... cancer of the lung particularly ... I suspect that it is ah ... breathlessness and lack of ... something to do with respiratory matter.*
>
> [Leonard]

For one participant, the fear of the dying process was exacerbated by the unexpected reminders in the media. For instance;

> *... as soon as I see [or] read something from the newspaper ... she died this afternoon from cancer or something on TV ... I panic, I panic, you know. Oh like I say, I am going to die you know ...*
>
> [Simon]

5.5.3 Being in limbo.

Participants described their future as being in "limbo". This minor theme describes the uncertainty felt by the participants about their future and in particular, how they felt at this time regarding their disease. Being in limbo represents an unknown direction for the future and demonstrates that the participants are beginning to doubt favourable outcomes. For instance, Beth comments on the results of her treatment:

> *... I suppose now it's more or less you're like in limbo a little bit because I know he [the doctor] can't tell whether ... the chemo is working ... or not until ... I finish the course [of Chemo] and they do ... more bone scans and everything, you know ... so I know I'm in limbo ... not knowing whether it's working, whether I'm getting better or whether I'm having myself on ...*
>
> [Beth]

Jack also comments on the uncertainty of his health status and questions whether he should be planning for future events.

> *... the cancer ... it's inoperable, it will not respond to chemotherapy and it did not respond to radiotherapy. So tomorrow being ... our visit day ... he [doctor] may tell us*

> *more ... which way I'm going. I mean whether to buy Christmas presents or whether not to, I don't know.*
>
> [Jack]

Simon discusses his fear of the future and is constantly apprehensive about a negative outcome.

> *... sometimes you ... dream something ... straight away [it] comes to your mind ... what happen[s] to me next ... the next day or the next year or the [next month, you know. One [doctor] say[s] your problem [cancer] is very difficult. Another say[s] ... look ... we can't do anything. And all [of] that frightens me ... from the bottom line ... I don't know what's ... what's going on.*
>
> [Simon]

5.6 HOLDING ON.

This theme describes the necessary attributes required by the participants to continue with their lives despite the recognition that they have an uncertain future and are experiencing a reduction in their ability to enjoy their lives. The level of depression and anxiety experienced by the participants was varied, by 'Holding On' this experience was influenced both negatively and positively. The minor themes related by the participants which gave them the ability to hold on were hope, taking control, and coping tactics.

5.6.1 Hope.

For most of the participants, being hopeful that their condition will improve or that their lives would continue for a reasonable time, gave some meaning, positivity, and purpose to their lives, despite the hardships they were facing. Whether being hopeful was realistic was not important for most participants. Being hopeful gave them strength to endure, the ability to carry on without giving up and reduced the experience of anxiety and depression. For instance, Beth describes her hope of physical improvement and then the hope of starting to enjoy her life again. She is hopeful for an extension of life and feels this is not too much to ask.

> *... whatever time I've got left ... I want to enjoy it. I'm going to do all these things when I get better ... So I just hope I'm really going to get better ... [and] once I get more active ... [then] I can ... get back in to gear. I just hope that I can get a couple of years ... if I know I've got a couple of years to go with this ... I'll be quite happy ... quite satisfied. I'm not an ambitious type of person or anything ... I just ... want to do my own little thing ... be happy.*
>
> [Beth]

For some participants, being hopeful was not sufficient. One participant felt compelled to search for hope. This active searching process favourably influenced the participants' experience of depression and anxiety. It gave the participant the ability to maintain his struggle with life.

> *... look this medicine ... [on] the TV or [in] the newspaper ... I like to see ... I like to learn what happens [to other people with cancer] ... I* ***want*** *[participant emphasis] to learn ... maybe I ... see something for my problem. I would like to learn about it [cancer treatments] ... to see if somebody [has] found [a treatment] ... okay it's not one hundred percent ... but maybe ... shows something ... something for pain ... something for ... a better life ... something for a longer life ... I would do anything. There's no answers ... all big hopes ... it's no good for myself ... but I can't do*

> *anything else [but hope]. You have to believe in something or you finish[ed].*
>
> [Simon]

Although hope was an important attribute to holding on to life, at times the participants' belief in hope was threatened. Participants described varying levels of hope which was exacerbated by certain situations and influenced their experience of depression and anxiety, as seen in the following exemplar:

> *I've lost it [hope] a bit ... [the other day] I was sitting here and I said to [the nurse and physiotherapist] ... when I get more mobile and get better I'm going to do this and that. And they just sat there. And I said " Why haven't either of you said anything? Why did you just be quiet? Why, do you think I'm not going to be able to get to that stage? "Oh no, no, no [nurse and physiotherapist] ... And ever since then ... I sort of felt, maybe ... I'm not going to get to that stage. And that sort of put me ... down a bit. I thought maybe I'm having myself on.*
>
> [Beth]

And Olga had lost any hope for the future:

> *... when they found out it [cancer]... went to the brain ... it [will] not [be] the last one ... [it] could happen again, somewhere else, some other places ... So I know when [there] is no ... hope. No more hope for ... getting better but wait.*
>
> [Olga]

5.6.2 Taking control.

Although the participants were dealing with a life threatening disease which lead to depression and anxiety, several participants described their need to take back some control of their lives. To take control meant maintaining a fighting spirit and allowed the participants to feel they were being active in controlling their destiny, and hence reduced their anxiety or depression. For these participants it was more than being hopeful, it was a deliberate action.

> *I'm still trying to fight ... I do ... my best ... to try and ... enjoy what ... what time I can. It's just a matter ... now I think of getting my strength back and ... keep trying ... and that's the best I can do ... [I've been] so lucky to be able to go ... belong to the Hospice. Because everybody has been wonderful. So they do their best to help me ... so you have to do [your] best ... as well ...*
>
> [Jeanette]

Jack commented along the lines of actively taking part in the control of his situation.

> *I'm going to have to get myself down to the stage where I stop this trauma business ... I mean in other words, I'm going to have to take back control ... of the things that are upsetting me.*
>
> [Jack]

Despite several of the participants describing their desire to take back some control of their lives, one participant spoke of her loss of independence and of losing control.

> *When I see people walking on the street ... seeing this old lady doing the shopping, pushing [the] trolley ... makes[s] me sad ... why can't I do some ... I'm sixty-eight [years] and the other ladies maybe [are] eighty-eight or something ... they are still doing things ... what they are suppose to do. Do their own shopping and all that sort of thing ... that makes me sad.*
>
> [Olga]

Participants also expressed the desire for honesty and for more information about their prognosis and current situation. The participants felt that being informed and understanding their current situation would enable them to realistically find strength to hold on to their remaining life. For example, Beth needed to know her current health status. Previously she had been very hopeful but had recently experienced a threat to her hope. She now wanted to know the truth so that she could be realistic about her future.

> *... I don't know whether I'm having myself on ... I'm probably not facing up to the cancer ... And I thought I should have a talk with Dr * [specialist] tomorrow and just say " look how am I going?". I need reassurance, I think ... or the truth.*
>
> [Beth]

Leonard described his need to know his prognosis so he could get aspects of his life in order.

> *... I said to him, now I want to put it to you straight ... I don't mind a good honest answer ... What's ... my life expectation from this point on? ... I wanted to know for a number of reasons. To tidy up a number of ah ... well a couple of financial matters ...*
>
> [Leonard]

This need for information helped to ease the participants' state of mind and favourably influenced their experience of depression and anxiety. However, one participant had conflicting information from various doctors and was now having a difficult time making sense of what information to take on board.

> *... from the bottom line ... I really don't know what's ... going on. One[doctor] says, look okay you got a problem ... you are going to die. And ... another [doctor] ... talk's [about] the problem with the back ... it['s] very hard sometimes ... very hard sometimes to accept too many things ...*
>
> [Simon]

Coping tactics employed by the participants influenced their experience of depression and anxiety. Participants spoke of tactics which they used to distract their thoughts from a negative outlook and gave them the ability to ventilate their despair. Although these measures were temporary tactics, it gave the participants an avenue to hold on to their lives. For instance, Jeanette describes her relief tactic when she is feeling sad:

> *I just get ... like I am now ... I just get weepy. I can control it. I sit down and have a rest. And I think "get on with it Jeanette ... you know ... you know this is no good ... no good for you". I could cry all the morning but you know ... I tried to stop it but sometimes ... my sisters says "well crying does you good" ... well it relieves the tension ... it's like some people scream ... I restrain myself as much as I can. But then like today, when I'm really ... really exhausted, like now when I'm talking, the tears come to my [eyes].*
>
> [Jeanette]

Olga also commented about being sad and her tactics:

> *[when] I feel sad ... that's when I cry ... Normally I go in the room [bedroom], shut the door ... and cry until I can't cry and then just lie down and make myself ... normal again. I just want to be alone. See I can cry ... I can do things when I'm alone you know, ... and I don't want too ... too many people with me because I don't want people to feel ... feel*

> *sorry for me ... And then it's all ... all over for ... for the time being.*
>
> [Olga]

Distraction was another method described by participants that allowed them to improve their coping mechanisms and help to ease their psychological distress. For instance:

> *Simon:* *[sometimes] I feel [it's] very hard to breath, you know. But after a few minutes when I try to forget ... I come back to normal.*
>
> *R:* *... do you do anything to make you forget?*
>
> *Simon:* *I change the program (television) or read the ... newspaper or if somebody come[s] [to visit] we [change] this topic, we .... change the subject, you know ...*
>
> [Simon]

Mac also found watching the television a good method of distraction..

> *[previously talking about his physical restriction] So imagine what that's like. I sit around here ... read the paper and watch tellie. If there wasn't a tellie I'd go mad.*
>
> [Mac]

In conclusion, the community palliative care participants in this study described their experience of depression and anxiety as a reducing their quality of life and of living with an uncertain future. Despite their hardships they were still able to hold on to their remaining life to some degree.

CHAPTER SIX

Discussion

6.1 INTRODUCTION.

This chapter will discuss the results of the prevalence of depression and anxiety and associated risk factors among patients referred to a community palliative care service. The experience of depression and anxiety as described by the patients will be discussed, highlighting significant findings and drawing on pertinent literature.

6.2 THE PREVALENCE OF ANXIETY AND DEPRESSION AMONG A COMMUNITY PALLIATIVE CARE POPULATION.

The community palliative care patients in this study exhibited a point prevalence for depression of 19% and 25% and a point prevalence for anxiety of 16% and 17%, at the initial and second assessment respectively. A depression prevalence of between 19% and 25% is in line with other studies among oncology inpatient populations (Chochinov et al., 1994; Kathol et al., 1990; Payne, 1992; Powers, Kelly, Gilsenan, Kearney, O'Mahony, Walsh & Coakley, 1993). A lower prevalence rate of anxiety compared to depression is also consistent with other research (Donnelly et al, 1995; Wood & Mynors-Wallis, 1997).

The similar prevalence rates of depression and anxiety among this group of community palliative care patients compared to other research, highlights that these psychological symptoms are experienced as commonly in the home environment as with hospitalised patients. Despite the suggestions by some authors (for example: Carroll et al., 1993, and Hinton, 1994a), that there is a lower prevalence of depression among home based patients compared to inpatients, this research revealed there to be little difference in these patient groups.

NSW Health (1997) identify that the risk of major depression in the lifetime of a normal healthy population is between 25% to 30%, and rising. Depression is the most common mental health disorder in adults (NSW Health, 1997) What is surprising is that the community palliative care patient is at no more increased risk than the normal healthy individual.

There is strong evidence in the literature that depression and anxiety co-exist among individuals (Angst & Merikangus, 1997; Dealy et al., 1981; Garvey et al., 1987; Sherbourne & Wells, 1997; Stravrakaski & Vargo, 1986; Wittchen & Essau, 1993). In this study of community palliative care patients a moderate correlation between anxiety and depression scores (r=.355, p < .002) was determined. Fifty percent of the community palliative care patients who were depressed also had a borderline anxiety state and nearly half the patients who were anxious had borderline depression. Six patients had both clinically significant anxiety and depression according to the HAD scale using a cut-off score of greater than or equal to 11. This finding reiterates the close association of the two moods and is consistent with other research in primary health settings and with cancer patients (Angst & Merikangus, 1997; Dealy et al., 1981; Garvey et al., 1987; Sherbourne & Wells, 1997; Stravrakaski & Vargo, 1986; Wittchen & Essau, 1993).

The prevalence and relationship between depression and anxiety in this study has several implications for palliative care nurses. First, community palliative care patients are at risk of developing depression and anxiety and a psychological examination is an important aspect of assessment. Second, the patient who is depressed may also have a degree of anxiety or versa visa, so assessing both depression and anxiety is required. And third, screening tools such as the HAD scale may be useful to assist in the initial detection and ongoing assessment of depression and anxiety. The need to distinguish between depression and anxiety is important as symptoms may be similar but the treatment differs. In this study the HAD scale was an acceptable and simple tool to administer, and demonstrated to be an appropriate research instrument to use among a vunerable population.

6.2 RISK FACTORS AND THE DEVELOPMENT OF ANXIETY AND/OR DEPRESSION IN A COMMUNITY PALLIATIVE CARE POPULATION.

The quantitative analysis demonstrated several key areas relating to the relationship and predictive risk factors that could lead to the development of depression and anxiety among palliative care patients in this particular community setting. There was a significant relationship between the presence of an unresolved symptom and patients who were depressed or anxious ($p < .032$). This is consistent with the findings of previous research (Kurtz, Kurtz, Given & Given, 1995; Peruselli et al., 1993; Zimmerman, Story, Gaston-Johanson & Rowles, 1996). However, no significance was determined for the presence of an unresolved symptom as a predictor of depression or anxiety in the univariate and mutlivariate logistic regression analysis. The different statistical results from the Mann Whitney *U* test and the logistic regression analysis is related to the transformation of data from numerical to dichotomous form.

In this study, 61% of the sample reported the presence of an unresolved symptom at the time of initial referral to the community palliative care service, pain being the most common. While pain has been reported as the most common symptom among palliative care patients in many studies (Curtis et al., 1991; Donnelly et al., 1995; Faucett, 1994; Glover et. al., 1995; Hinton, 1994b; Licther, 1991; Massie & Holland, 1987; Twycross et al., 1996; Peruselli et al., 1993; Zimmerman et al., 1996), several studies have highlighted weakness and lethargy as more distressing and frequent than pain (Dudgeon, Rabertas, Doerner, O'Connor, Tobin & Rosenthal, 1995; Herity et al., 1987; Walker, McGown, Jantos & Anson, 1997). In view of the emphasis patients placed on the loss of physical function and fatigue in the qualitative data, it was surprising that this did not rate higher.

One explanation for the difference in reporting may be in the documentation of symptoms, with the community palliative care nurses documenting only the most problematic symptom at that time. Another possible explanation is that the patients who had been experiencing lethargy for a long time may not have regarded lethargy as something to report, focusing on more immediate problematic symptoms. Problems associated with the assessment of symptom reporting and its impact on the patient is not new, and in particular the symptom of fatigue (Tanghe, Evers & Paridaens, 1998). Richardson and Ream's (1998) discussion paper on cancer-related fatigue highlight that nurses have difficulty in recognising fatigue as a symptom. Magnusson, Karlsson, Palmblad and Paulson's (1997) study investigating nurses' estimation of fatigue as a symptom in cancer patients concluded that the nurses identified the need for an assessment framework to accurately measure this symptom, such as diaries and measurement tools. Studies have identified similar problems in assessment in other symptoms such as pain (Copp & Dunn, 1993; Maestri-Banks & Gosney, 1997; Warden, Carpenter & Brockopp, 1998). The results of these studies provide a strong argument for improving the assessment skills and the need to implement appropriate measurement tools in the assessment of symptoms and their impact on the patient.

Of the patients who reported the presence of an unresolved symptom, two-thirds reported having two symptoms at any one time and three percent reported having three symptoms at once. The multiple reporting of symptoms as experienced by the palliative care patients in this study is consistent with previous research (Curtis et al., Donnelly et al., 1995).

The risk factors which predispose a community palliative care patient to the development of depression in this study were identified as a family history of depression (p < .011) and a previous history of anxiety (p < .013). No risk factors for the development of anxiety could be identified in this community palliative care population using the mutlivariate analysis. Although this result is inconsistent with other research (Donnely et al., 1995; Edlund & Sneed, 1989; Maunsell et al., 1992), this may be explained by the small sample size for the analysis.

A relationship between a previous history of depression and the depression and anxiety scores was significant (p< .048 and p< .015 respectively). A previous history of depression as a predictor of the development of depression is consistent with other research (Bukberg et al., 1984; Grassi et al., 1997; Hardman et al., 1989; Holland, 1989; Maunsell et al., 1992; Nickel et al., 1990).

When a forward stepwise logistic regression was applied to the data, previous history of depression and anxiety remained statistically significant for depression only, and previous history of either anxiety or depression was not significant for anxiety. The final multivariate analysis determined only previous history of anxiety as a significant risk factor for depression. An explanation for this reduction in statistical significance is most probably related to the small sample size and a reduction of the cell size to be analysed. The finding in this study, that a previous history of anxiety is predictive of the development of depression, highlights the importance for health professionals to closely examine the psychological history of their patients.

No relationship between depression and anxiety scores and a family history of depression or anxiety was found using the Mann Whitney test. However, when the data were applied to the univariate logistic regression analysis, family history of depression and being depressed, was statistically significant ($p < .009$). During the multivariate analysis, a family history of depression remained a significant risk factor in the development of depression ($p < .011$). Again, this finding accentuates the importance of obtaining a thorough psychological history from patients, including family history.

6.3 TRENDS ASSOCIATED WITH RISK FACTORS IN DEPRESSION AND/OR ANXIETY SCORES.

There was no relationship between the remaining risk factors of age, gender, site of malignant diagnosis, length of time since diagnosis, stage of disease, perceived social support and physical functioning status and depression and/or anxiety scores. However, several trends were demonstrated in the data analysis.

No significant relationship was determined between the length of time since initial diagnosis and being depressed or anxious. However, an odds ratio of 1.90 in the univariate analysis indicated an increase in the odds of being depressed when the patient has a diagnosis of less than twelve months. This trend has been highlighted in earlier research (for example; Given et al., 1994; Herity et al., 1987).

No relationship was determined between the site of cancer and depression or anxiety scores. This result is not surprising as no other studies could be found which have successfully shown a significant relationship between multiple types of malignancy and psychological distress. However, several studies have focused on one or two particular diagnostic groups and have determined an anxiety and depression prevalence. Holland, Korzun and Tross (1986) found that depressive states were more prevalent in patients with pancreatic cancer than in patients with advanced gastric cancer. In this study of community palliative care patients, both pancreatic and gastric cancer were grouped together under gastrointestinal diagnosis. Interestingly, the univariate odds ratio for the gastrointestinal diagnostic group was 2.25, indicating a higher risk group, but this was not significant ($p< .414$).

6.3.1 Explanations for non-significance of other risk factors.

Analysis of statistical data did not reveal significant differences between depression and/or anxiety levels involving younger patients. Although several studies have demonstrated that younger individuals are at risk of developing depression or anxiety (Carroll et al., 1993; Given et al., 1994; Donnelly et al., 1995; Edlund & Sneed, 1989; Payne, 1992; Walker & Sofaer, 1998), in this study of community palliative care patients, the majority of patients (71%) were 61 years or older, therefore limiting the ability to test the relationship between age and depression or anxiety.

Stage of disease was determined by the presence or absence of metastases. In this study 79% (59) of the population had metastatic disease, in eight percent of the patients this was unknown, as presence or absence of metastases was not recorded. On advice from a consultant statistician, this risk factor was not entered into the statistical data, as missing data may have skewed the analysis.

Patient's perceived support in this study was to be recorded as either poor, moderate or good. However, no poor response was recorded and prior to the analysis, the poor category was deleted. Therefore, two possible categories were used, moderate and good, to be compared with depression and anxiety scores, this resulted in non-significance. The researcher acknowledges that a larger sample might have enabled the investigator to capture individuals' with poor perceived social support. However, what needs to be questioned is whether the patients would be willing to disclose their social support as poor at the initial visit, or does a rapport between the nurse and patient need to be developed first?

Patient functional health status was recorded using the Karnofsky Performance Score (KPS). Previous studies have illustrated a relationship between a low KPS and levels of psychological distress (Bukberg et al., 1984; Glover et al., 1995; Grassi et al., 1996; Grassi et al., 1997). In this study, 75% of the patients scored 70 or more on the KPS, indicating that the majority were able to care for most of their own needs. The researcher acknowledges that the small sample size and lack of sufficient data from low scores of the KPS impacted on testing this variable.

6.5 THE EXPERIENCE OF DEPRESSION AND ANXIETY AMONG A COMMUNITY PALLIATIVE CARE POPULATION.

The experience of depression and anxiety was described by the patients in the themes reduced quality of life, facing an uncertain future, and holding on to life. As described in Chapter Five, reduced quality of life was significantly the focus of the patients experience of depression and anxiety.

The fact that a reduced quality of life featured so extensively in the patients' narratives may be related to many factors. Overwhelmingly it was the physical adversities experienced by the patients which decreased their ability to perform their usual activities and influenced their outlook on life. The physical impact of the disease described by the patients was related to lack of energy, decreased functioning ability, exacerbation of symptoms, side-effects of treatment and medication. The words "lack of energy", "no strength" and " gone downhill" were frequently used by the patients to describe the physical impact. From the extensive disease history described to the researcher by the patients it would seem evident that in the earlier stages of their disease they were relatively symptom free, and able to function normally. With the progression of the disease, physical adversities impacted on the patients' lives and negatively influenced their psychological well-being. The direct impact of the psychological well-being appeared to be related to feelings of uselessness, lack of motivation, depression, or anxiety in response to disease progression. These findings are similar to Ferrell et al's (1996) study that highlighted the impact fatigue had on the physical, psychological, spiritual and social well-being of cancer patients.

While the physical functioning assessed by the Karnofsky Performance scale showed no significant relationship with the quantitative analysis in this study of community palliative care patients, the qualitative analysis strongly highlighted the negative impact of a lowered physical functional status. According to the Karnofsky performance score the majority of patients were rated as being able to care for most of their needs and therefore not be severely impaired by the loss of physical function. Yet, the narratives highlighted that this loss of physical function was having a significant psychological impact and affected the patients' perceived quality of life. However, this difference may be related to the subjective rating by the community nurses. It is possible that the Karnofsky Performance scale was not sensitive enough to detect the physical functional status of this group of community palliative care patients. There was a time lag of approximately three weeks between the initial Karnofsky Performance assessment and the interviews which may account for this discrepancy. The patients' physical functioning ability may have decreased during this period, however all were still self-caring at the time of interview. This highlights the need for health professionals not to solely rely on assessment tools, and reinforces the need for subjective assessment of all symptoms. It also raises questions about the sensivity of the KPS in this patient population.

Despite the consistent emphasis placed by the patients on the negative impact of the physical adversities on their psychological being, within the quantitative data, it was noted that only the Mann Whitney *U* test demonstrated a significant relationship between a patient who was depressed or anxious and the presence of an unresolved symptom. This highlights the specific implications for nurses and health professionals to fully investigate the patient's perceptions and concerns in relation to symptomology and physical functioning and the importance of working towards maintaince of these aspects of the patient's quality of life.

It is also interesting to note that when the patients discussed their fears of the future, several voiced their of fear of worsening symptoms associated with progression of the disease. For one participant in particular who had previously experienced severe episodes of uncontrolled pain, the fear of unrelieved pain in later stages of his disease was overwhelmingly distressful to him. The fear of and expectation that pain would worsen and be unrelieved has been reported in previous research (Strang, 1997; Walker & Soefer, 1998). This highlights the need for nurses to attend to pain promptly, and also the need to explore potential fears and educate patient's about the future and options available to manage pain.

Lichter (1991) suggests that terminally ill patients may well focus on their physical state in order to avoid confronting their emotional turmoil. Therefore, physical symptoms assume paramount importance. In this study of community palliative care patients, fear associated with worsening physical symptoms especially pain and physical deterioration, were discussed by all patients. The fear of pain and physical deterioration associated with advancing disease highlights the need for health professionals to thoroughly assess all aspects of the patients experience and provide ongoing support and explanations.

It is well documented that the impact of cancer not only affects the patient but the entire family unit (Ferrell et al., 1996; Herth, 1990; Kristjanson, Sloan, Dudgeon & Adaskin, 1996; Strang, 1997; O'Connor, Wicker & Germino, 1990; Wiley, 1998). The community palliative care patients in this study spoke of their perception of the stress imposed on their family, which they described as adding to their own psychological distress. Fear of being a burden or becoming a burden to the family was described in the transcripts by all of the patients. This is consistent with the findings of Dudgeon et al., (1995) study who reported patients rated "being a burden" and "the family" their biggest concerns, greater than the pain, suffering or dying.

In particular, the patients' worried about the direct effect on the spouse and children. This is consistent with other research (for example; Cain et al., 1990; Godding et al., 1995) When family members were present at the interview they interjected and down played the stressful impact on their lives when this topic arose. Although the amount of carer stress was not assessed in this study, previous research has highlighted that high stress levels are a major predictor of negative effects on physical and emotional well-being in carers (Hull, 1990; Roseman, Le Broque & Carr, 1994; Williams, 1994). The patients' concern for the stress imposed on the family serves only to strengthen the body of knowledge that within palliative care the focus of care should be extended to the family members.

All patients spoke of facing an uncertain future. The uncertainty about their future was amplified in the presence of a disease with essentially an unknown prognosis. The fear and apprehension associated with the uncertainty of a future exacerbated the patients' experience of depression and anxiety. The patients expressed fear of dying is consistent with multiple studies among cancer patients (for example; Gotay, 1984; Levin, Cleeland & Dar, 1985; Welch-McCaffery, 1989). Mishel, Hostetter, King and Graham's (1984) research among cancer patients, highlighted the fact that patients with more uncertainty had more adjustment problems. Sheppard and Markby (1995) also illustrated that it is not only the patient with cancer who fears cancer and its' uncertainty, they reported fear of cancer as the most significant feeling experienced by cancer patients' partners.

Boyle's (1998) review of the cultural context of dying from cancer highlighted the diversity of beliefs and cultures which impact on the needs of such patients with terminal illness. For example, traditional Chinese culture is characterised by a belief that nature should take its course, especially when a patient is dying. According to Chinese culture experiencing a waiting period before death is important to allow for redemption of sins before passing on to the next life (Nishimoto, 1996). Also within Chinese culture the person/family will choose hospitalisation for the final phase of dying due to their strong belief about ghosts inhabiting dwellings where someone has died (Koeing, Gates-Williams, 1995) The Australian society is comprised of people from over 130 countries (Boyle, 1998). Within the state of Victoria there at approximately 80 ethnic community organisations (O'Connor, 1998). Therefore, the cultural diversity that exists within Australian highlights the need for health professionals to be attuned to different needs. In this study of community palliative care patients ethnic background was not taken into account and the researcher recommends future studies to incorporate this dimension in the research.

Although the patients in this study spoke of their decreased quality of life and the fluctuating fear concerning their future, they also spoke of the need and attempts to hold on to their remaining life. To a degree, holding on gave them a perception of some control over their life and reignited some postivity in their lives. Within the theme holding on, they spoke of several factors which influenced the ability to maintain this perception. These included hope and the need to take control of their situation.

The level of hope is strongly identified in the literature as influencing the level of coping (Brockopp, Hayko, Davenport & Winscott, 1989; Herth, 1989; McGill & Paul, 1993; Owen, 1989). Korner (1970) suggests that hope allows the individual to minimise the stresses and despair associated with the treatment and diagnosis. Post-White et al. (1996, p1571) highlighted the importance of hope, in that "... a sense of hope can provide meaning, direction, motivation, and a reason for being".

Although being hopeful was a dynamic attribute, it is changeable over time and influenced by particular situations. In particular, one participant spoke of doubting and losing hope as a consequence of health professionals' response to her conversations about hoping for a brighter future. Copp and Dunn's (1993) research demonstrated that nurses (generalist, specialist and acute care) caring for the dying, perceived patients having difficulty coming to terms with dying and holding on to unrealistic expectations, as the most difficult problem to manage. Heaven and Maguire's (1997) study illustrated that over fifty percent of hospice nurses continue to use "blocking" behaviours in an attempt to protect themselves from the emotions of their patients, despite communication training. When hope is questioned or doubted, the impact on the patient is devastating as highlighted by one participant in this community palliative care study. This highlights that palliative care patients use hope as a coping mechanism and that nurses need to guard against destroying this hope.

Patients spoke of taking control of their lives. Although hope is associated with control (Flemming, 1997; Rustoen, 1995), the community palliative care patients in this study spoke of 'control' as a deliberate action, for example, seeking information on the internet and plans to commence rehabilitation exercises. The need for information was interpreted as a deliberate action to gain control of their situation. The need for information has been previously described (Cassileth, Zupis, Sutton-Smith & March, 1980; Dennis, 1987; Vess, Schwebel & Kraut, 1988). Allen (1981) suggests that feelings of hopelessness could be overcome if patients played a role in determining their treatment. Young-Brockopp's (1982) study of the psychological needs of cancer patients, found the patients wanted accurate honest information. Kristjanson (1989) reported that families caring for cancer patients need information, that is honest responses when questions are posed and specific information to assist them in caring for the patient. The need for information as described in this study of community palliative care patients, highlighted the participants need for open and honest communication to maintain some control in their lives and illustrated that health professionals need to improve and develop their communication skills to effectively fulfill patient and carers' needs.

In this study of community palliative care patients, crying most often expressed a release of the tension and stresses experienced. Several patients spoke of distraction mechanisms they implemented, such as watching television and reading. Licther (1991) suggests that in other stressful situations, people cope with death using a variety of defense mechanisms to handle unacceptable thoughts regarding death and dying. By enabling such mechanisms, they allow the patient to continue to function without excessive anger, anxiety and depression.

6.6 THE VALUE OF QUALITATIVE AND QUANTITATIVE APPROACHES.

This research highlights the benefits of drawing on two research methods in nursing research. The quantitative approach was able to answer the research question relating to the prevalence of anxiety and depression among a specific community palliative care population. However, it is interesting to note that the quantitative data in this study did not find significant relationships between decreased physical functioning and psychological distress and was inconclusive in demonstrating a significant relationship between depression or anxiety and a presence of an unresolved symptom. Overwhelmingly in the qualitative data, it was the physical impact of the disease and the consequences on other domains of the patients quality of life that shone through all the transcripts. This highlights the more in-depth and subjective outcome from qualitative research approaches.

These discrepancies between the quantitative and qualitative illustrates the advantages and disadvantages of both research methods. The use of two different approaches strengthened and clarified the findings in this study. The use of objective measures such as the KPS tool in palliative care population needs to be re-assessed in light of the results of this study. Strang (1992) highlighted that staff judgments of symptom prevalence or severity can be a poor reflection of patient reports. A symptom prevalence/severity tool may have provided more valuable information for statistical analysis.

The ability of the statistical data to determine relationships between the independent variables and depression and anxiety or the ability of the predictor variables to demonstrate significant results was hindered by the small sample size and a result of data transformation. However, asking the patients to tell their story prevented assumptions being made as to what a community palliative care patient is experiencing and provided a more in-depth understanding of the patients experience. In relation to research among the palliative care population small sample sizes are common (Faithful, 1996; Wilkes, 1998). Palliative care patients are vulnerable research subjects (Kristjanson, 1994). Factors which contribute to this are the severity of the patient's illness and the psychosocial stresses on the carer. Future nurse investigators who study palliative care patients should be reminded of this significant sampling problem and consider alternative approaches to their study, such as the use of multi-centres research.

Rather than looking for deficiencies in either approach, the researcher prefers to highlight the complimentary way each approach sought to highlight aspects of this phenomena which would not have been possible with a single approach, therefore, adding to the unique body of nursing knowledge. The researcher of this community palliative care patient study chose both quantitative and qualitative approaches, so that the findings would compliment and strengthen each other leading to a deeper understanding of the extent and impact of depression and anxiety among this population. The human situation of a terminal illness must be approached in a number of different dimensions. To singularly follow a positivist approach to palliative care excludes the notion of self, self determination and the value of subjectivity. Terminal illness has both medical and non-medical aspects and therefore drawing on the interpretive and positivist paradigms is essential to exploring the human experience.

CHAPTER SEVEN

Conclusion

7.1 INTRODUCTION.

The conclusions of the study are summarised in this final chapter. The strengths and limitations of the study, recommendations for future research and nursing implications in this area are discussed.

7.2 CONCLUSIONS.

This study was undertaken to describe and explore the extent and impact of anxiety and depression among community palliative care patients. It highlighted the fact that anxiety and depression is a significant symptom experienced by such patients, especially in relationship to his/her sense of well-being. In addition, it reveals that a previous history of mental health problems impacts on palliative care patients' depression and anxiety levels.

Although several of the risk factors associated with the development of depression and anxiety supports previous research, the current study differs from others as it collected qualitative data on the patients' experience of this symptom. To date, no other qualitative studies could be located which have previously explored the experience of anxiety and depression among this population.

This study's value has been in obtaining descriptive information about the patients' experience of anxiety and depression and in determining risk factors associated with the development of anxiety and depression among a particular community palliative care population. However, due to the small sample size, the results need to be interpreted with caution in respect of the community service in the study and in other populations. There are lessons and evidence from this study which may be of assistance to service providers and researchers.

This project begins the process of demystifying the symptoms of depression and anxiety among palliative care patients.

7.3 STRENGTHS OF THE STUDY.

The strengths of the study include:

- The qualitative section of this study explored an area not previously investigated, and as such adds to the body of knowledge for nurses, especially palliative care nurses who can now work towards developing interventions to assist community palliative care patients with depression or anxiety.

- The negative impact of anxiety and depression on the community palliative care patient is highlighted. This emphasises the crucial importance for all health professionals in the palliative care field to fully investigate and work towards improving the patient's psychological well-being and not just accept these symptoms as an associated 'expectation' of advanced cancer.

- The inter-relationship between the physical and psychological symptoms was highlighted in this research, reinforcing the need to address both the physical or psychological symptoms.

- The use of both quantitative and qualitative methods complimented the findings and extended the depth of information gained in this study, highlighting the benefits of incorporating both methods in future studies.

- On the whole, the prevalence of anxiety and depression among community palliative care patients was demonstrated to have similar levels as those detected in hospitalised patients and the general community. As the trend for future palliative care services extends further into the community setting this finding has implications for community services and especially for palliative care nurses, highlighting the need for education and training of palliative care nurses in assessment for and management of depression and anxiety.

7.4 LIMITATIONS OF THE STUDY.

The limitations of the study are outlined:

- Inferences from the study were restricted to the population assessed due to the sampling techniques.

- The quantitative analysis was restricted by the small sample and the projected sample size for statistical significance was not met.

- Future research in this area could explore alternative approaches to the assessment of physical performance and functional status.

- In future research, the assessment of the resolution of symptoms and its impact should be incorporated into the study.

7.5 RECOMMENDATIONS FOR FUTURE RESEARCH.

Recommendations for future investigations to assist in obtaining a greater understanding of the research problem include:

- Repetition of this study with larger sample numbers would be beneficial, using a multi-centre approach to determine whether psychological distress is consistent in palliative care patients in other geographical areas.

- Replication of this study including repeated assessment with a more specific functioning health performance tool.

- Research to further examine the impact of anxiety and depression on carers compared to the psychological distress of patients, so that services can focus on maximising the benefits of providing care while minimising the stress on the family caring for palliative care patients.

- Future studies should incorporate cultural aspects within their research of palliative care patients. This is extremely pertinent to Australian studies due to the increasing cultural diversity.

- The input from the community palliative care team was not assessed as this was not relevant to the research questions. Research that explores the palliative care nurse's role and knowledge in the assessment and management of depression and anxiety needs to be undertaken.

7.6 IMPLICATIONS FOR NURSING PRACTICE.

The implications for nursing practice arising from this study are relevant for nurses providing care to patients with life threatening illnesses, particularly in the community setting. These implications include the following :

- Nurses working in palliative care services should be aware that depression and anxiety are symptoms which affect approximately one-quarter of palliative care patients, and thorough assessment, both objective and subjective, and continued observation is essential to optimising care.

- Previous psychological distress or family history of psychological distress is predictive of the development of depression or anxiety. Nurses therefore should routinely examine their patients' mental health history.

- The physical impact on patients with advanced cancer greatly effects the psychological and spiritual well-being of patients. Consequently, palliative care nurses and other health professionals should be aware of the importance of symptom control and ways to assists with physical functioning.

- The potential negative impact on the family of patients with psychological distress emphasises the important role nurses have in ensuring the inclusion of family/carers in their on-going assessments.

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Appendices

Appendix 1:

Copy of the Demographic Data Sheet

Demographic Data Sheet

(to be completed by the community palliative care nurse)

1) Age:_______yrs

2) Gender: M ☐ F ☐

3) Diagnosis:____________________ Metastases Y ☐ N ☐

4) Length of diagnosis:__________yrs__________mths

5) History of previous episodes of depression/anxiety? Y ☐ N ☐
(↑ circle which one or both)
PROMPT: *Is there a time where you felt really down and how long did it last?*

____

6) Family history of anxiety/depression (← circle which one) Y ☐ N ☐

PROMPT: *Has any member of your family ever felt really down in the past and sought help?*
(What is the relationship to the patient)____________________________________
____

7) Social Support (response from patients perception)
Does the patient feel they have enough support? Y ☐ N ☐
Please explain (good, moderate, poor??? How many family/friends are involved with the patient?) ____
____

8) Main carer ____________________

9) Is there any unresolved symptoms? (Pain, nausea etc....) **Y ☐ N ☐**
If yes, state the symptom/s____
____
____
____

10) Karnofsky score______________

Appendix 2:

Copy of the Karnofsky Performance Scale

Karnofsky Index

100 = Normal, no complaints, no evidence of disease.

90 = Able to carry on normal activity, minor signs or symptoms of disease.

80 = Normal activity with effort, some signs or symptoms of disease.

70 = Cares for self. Unable to carry on normal activity or to do active work.

60 = Requires occasional assistance, but is able to care for most of his needs.

50 = Requires considerable assistance and frequent care.

40 = Disabled, requires special care and assistance.

30 = Severely disabled.

20 = Very sick, active support necessary.

10 = Moribund, fatal process progressing rapidly.

0 = Dead.

Appendix 3:

Copy of the Hospital Anxiety and Depression (HAD) Scale

HADS Questionnaire

Name . . . Number . . . . Date . . . .

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel.

Read each item and underline the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':

Most of the time

A lot of the time

From time to time, occasionally

Not at all

I still enjoy the things I used to enjoy:

Definitely as much

Not quite so much

Only a little

Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly

Yes, but not too badly

A little, but it doesn't worry me

Not at all

(continued overleaf)

I can laugh and see the funny side of things:

As much as I always could

Not quite so much now

Definitely not so much now

Not at all

Worrying thoughts go through my mind:

A great deal of the time

A lot of the time

From time to time but not too often

Only occasionally

I feel cheerful:

Not at all

Not often

Sometimes

Most of the time

I can sit at ease and feel relaxed:

Definitely

Usually

Not often

Not at all

I feel as if I am slowed down:

Nearly all the time

Very often

Sometimes

Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all

Occasionally

Quite often

Very often

(continued overleaf)

I have lost interest in my appearance:

Definitely

I don't take as much care as I should

I may not take quite as much care

I take just as much care as ever

I feel restless as if I have to be on the move:

Very much indeed

Quite a lot

Not very much

Not at all

I look forward with enjoyment to things:

As much as ever I did

Rather less than I used to

Definitely less than I used to

Hardly at all

I get sudden feelings of panic:

Very often indeed

Quite often

Not very often

Not at all

I can enjoy a good book or radio or TV programme:

Often

Sometimes

Not often

Very seldom

Now check that you have answered all the questions

For office use only:

D : ☐ Borderline 8–10

A : ☐ Borderline 8–10

This measure is part of *Measures in Health Psychology: A User's Portfolio*, written and compiled by Professor Marie Johnston, Dr Stephen Wright and Professor John Weinman. Once the invoice has been paid, it may be photocopied for use within the purchasing institution only. Published by The NFER-NELSON Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK. Code 4920 03 4

Appendix 4:

Copy of permission to use the HAD scale for the study

This unit is part of *Measures in Health Psychology: A User's Portfolio*, written and compiled by Professor Marie Johnston, Dr Stephen Wright and Professor John Weinman.

Further details concerning other units in the *Portfolio* (code 4920 13 6) are available from the publishers: The NFER-NELSON Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK.

First published 1995

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Appendix 5:

Copy of the Interview question and prompts

Interview question:

“ Tell me how you have been feeling emotionally over the past few weeks?”

Prompts:

Can you tell me more about how that made you feel?

How does that make you feel?

Appendix 6:

Copy of the University letter of approval for the study

AUSTRALIAN CATHOLIC UNIVERSITY
Office of Research

UNIVERSITY RESEARCH PROJECTS ETHICS COMMITTEE
ETHICS CLEARANCE FOR A RESEARCH PROJECT – APPROVAL FORM

Student Investigator:	**Ms Peta McVey**	Campus:	MacKillop
Supervisor:	**Ms Kate White**	Campus:	MacKillop

Ethics clearance has been provisionally granted for the project:

Emotional distress among palliative care patients: A community perspective.

for the period: **20 May 1997 - 19 May 1998** (or twelve months from the date when contact with human participants commences - see below)

University Research Ethics Committee Register Number: **N97 - 011**

subject to the following conditions as stipulated in the *National Health and Medical Research Council (NHMRC) Statement on Human Experimentation and Supplementary Notes 1992*:

a) that principal investigators provide reports annually, on the form supplied by the University Ethics Committee, on matters including:
- *security of records*
- *compliance with approved consent procedures and documentation*
- *compliance with other special conditions; and*

b) as a condition of approval of the protocol, require that investigators report immediately anything which might affect ethical acceptance of the protocol, including:
- *adverse effects on subjects*
- *proposed changes in the protocol*
- *unforseen events that might affect continued ethical acceptability of the project*

and subject to the conditions stipulated by the University Research Projects Ethics Committee:

A Final Report Form will need to be completed and submitted to the University Research Projects Ethics Committee within one month of the completion of the project.
And written confirmation of the following:

a) In attachment 2, last para. of pg. 1, amend "3. Semi-structured interviews..." to read "3. Unstructured interviews...".

b) The following amendments to the Information Letters are required:
- *amend address of Chair of URPEC provided to participants to read:*
  The Chair
  University Research Projects Ethics Committee
  c/- Office of Research
  Australian Catholic University
  179 Albert Road
  Strathfield NSW 2135
- *amend the typo in attachment 3(b), third para., first sentence - delete "be"*

c) The following amendments to the Consent Letters are required:
- *include the following sentence, "participants to sign two copies of the consent form and return one copy to the researcher"*
- *amend the typo in the attachment 3.(a), first para., last sentence - change "ant" to "any"*

d) Tick appropriate boxes on page 8 of 8.

e) Copy to be provided to URPEC of Dr Snaith's consent to use the HAD Scale.

Please sign, date and return this form to the Administrative Officer (Research) to whom you submitted your application in order for your approval to be confirmed and entered into the NHMRC Institutional Register.

Signed:.. Date: 21 May 1997
Administrative Officer (Research)

Appendix 7:

Copy of the Hospital Research Committee letter of approval for the study

St. Vincent's Hospital Sydney Limited

A.C.N. 054 038 872

UNDER THE CARE OF THE SISTERS OF CHARITY

Ms Peta McVey
Clinical Nurse Specialist
Community Outreach Team
Sacred Heart Hospice

26/06/97

Dear Ms McVey,

Thank you for submitting the research proposal titled '*Psychological Distress among palliative care patients: A Community Perspective*' to the St Vincent's Health Care Campus Nursing Research Committee.

The Committee discussed your proposal at the June meeting and has approved the study.

All further documentation/reports should be forwarded to the Secretary, St Vincent's Health Care Campus Nursing Research Committee, c/- Nursing Education Dept, St Vincent's Hospital.

We wish you well with your study and look forward to receiving your report/s.

Yours sincerely

Ms Ailsa Hawkins
Acting Chairperson St Vincent's Health Care Campus Nursing Research Committee

Appendix 8:

Copy of the Information sheet and consent form for Phase One & Phase Two

Sacred Heart Hospice

UNDER THE CARE OF THE SISTERS OF CHARITY

The Sacred Heart Hospice continues the healing ministry of Christ by providing,
through respect and commitment, total care for the terminally ill.

Study information and Consent form

Project title: Psychological distress among palliative patients: a community perspective.

Investigator: Peta McVey
(Registered Nurse, Oncology Certificate, Grad. Dip Palliative care)

Any questions regarding this project can be directed to the
Principal investigator: Peta McVey
Telephone: 9361 9444

Supervisor for this project is: Kate White
Telephone: 9739 2039

I am undertaking a study to investigate the description of emotional feelings of people who have a serious illness. By describing the variety of emotions which can be experienced during the course of your illness, we can develop a better understanding of the needs of patients in similar circumstances. In highlighting your concerns, techniques to help patients and future education programs for the health professional delivering care to patients can be developed.

This study is divided in to two parts. Part A, which requires you to fill out a questionnaire on two occasions. Part B, which may involve participating in an interview if selected in the sampling process with the investigator. You may complete Part A only, with no obligation to continue to Part B.

Part A - you will be asked to fill out a questionnaire about how you have been feeling prior to your contact with the community service and again in two weeks from that date. The questionnaire requires you tick the box opposite the response which comes closest to how you have been feeling in the past week. The questionnaire has 14 questions and should take approximately 5 minutes to complete. The nurse present during the visits will not know your responses, as once the completed the questionnaire will be placed into a sealed envelope and returned to the investigator.

Demographic data in relation to gender, age, diagnosis, length of diagnosis, previous history of anxiety or depression, family history of anxiety or depression and social support will be asked at the first visit only.

SACRED HEART HOSPICE LIMITED. A.C.N. 053 439 820
170 DARLINGHURST RD. DARLINGHURST. SYDNEY NSW 2010. AUSTRALIA TEL: (02) 361 9444 FAX: (02) 361 9555
NSW Hospitals also under the Care of the Sisters of Charity. St Vincent's Hospital. St. Joseph's Hospital. St. Vincent's Private Hospital.

Part B- To enable the investigator to have a better understanding of the experience of emotional distress, a tape recordered interview will be carried out. The interview will ask you to describe in your own words how you have been feeling in the past few weeks. This interview should take approximately 45 minutes. The interview will occur at a time and place convenient to you. If you would like to be contacted regarding participation in an interview please tick the box at the end of this form. Should you consent to participate in the interview you are free to change your mind at any time. This decision will not prejudice your care in any way.

It is not possible to say that you will benefit from this study. However if during the study you feel high levels of emotional distress, the investigator can speak to your Medical Practitioner about further assessment of the problem. You will, however, be assisting health care professionals to understand the emotional distress which can be experienced by patients with serious illness.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission as required by law. If you give me your permission by signing this document, I plan to write up the result as part of a Masters thesis and publish results in an article. In any publication, information will be provided in such a way that you cannot be identified.

All complaints will treated in confidence, investigated fully and you will be informed of the outcome.

Your decision whether or not to participate will not prejudice your future relations with Sacred Heart Hospice. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice.

If you have any questions please feel free to ask us If you have any additional questions later, Peta McVey-9361 9444, will be happy to answer them.

This study has been approved by the Australian Catholic University Ethics Committee and the Committee for Sacred Heart Hospice. In the event that you have any complaint about the way you have been treated during the study, or a query that the principal investigator has been unable to satisfy, you write to

The Chair, Research Projects Ethics Committee
c- Divisional research Officer
Australian Catholic University
PO Box 969 NORTH SYDNEY NSW 2059

You will be given a copy of this form to keep

Project Title: Psychological distress among palliative patients: a community perspective

You are making a decision whether or not to participate. Your signature indicates that you have decided to participate having read the information provided above:

____________________ _______________________
Signature of Subject Signature of Witness

______________________ __________________________
Please PRINT name Please PRINT name

____
Date

____
Signature(s) of Investigator (s)

____
Please PRINT name

The second part of this project will involve individual interviews. If you are prepared to participate please indicate below and provide a name and contact number.

I would like to be contacted for an interview Yes ☐ No ☐

Name:_______________________ Phone No:__________________

REVOCATION OF CONSENT

I hereby wish to withdraw my consent to participate in the research proposal described above and understand that such withdraw WILL NOT jeopardize any treatment of my relationship with Sacred Heart Hospice.

______________________________ ____________________________
Signature Date

____
Please PRINT name

The section for Revocation of Consent should be forwarded to;
Peta McVey
Clinical Nurse Specialist
Sacred Heart Hospice, 170 Darlinghurst Road. DARLINGHURST NSW 2010.

Sacred Heart Hospice

UNDER THE CARE OF THE SISTERS OF CHARITY

The Sacred Heart Hospice continues the healing ministry of Christ by providing,
through respect and commitment, total care for the terminally ill.

Study information and Consent form

Project Title: Psychological distress among palliative care patients: a community perspective.

Investigator: Peta McVey (Registered Nurse, Oncology Certificate, Grad. Dip Palliative care).

Any questions regarding this project can be directed to the
Principal investigator: Peta McVey
Telephone: 9361 9444

Supervisor for this project is: Kate White
Telephone: 9739 2039

Thank you for agreeing to an interview. The purpose of this study is to describe the emotional feelings of people who have a serious illness. By describing the variety of emotions which you experienced during the course of your illness, we can develop a better understanding of the needs of patients in similar circumstances. In highlighting your concerns, techniques to help patients and future education programs for the health professionals delivering care to patients can be developed.

The interview should take about 45 minutes to complete. The interview will be taped recorded to allow for an accurate record and make it easier to anaylse. The interview will be conducted in such a way that you are not placed at any personal risk. It is not possible to say that you will benefit from this study. If you find that during the interview you become distressed you may terminate the interview and recommence after a short period of time or, terminate and recommence another day or terminate and request that the information collected not be used. If after the interview you experience emotional distress, your concerns will be discussed and referral made to your General Practitioner for counselling.

All complaints will be treated in confidence, investigated fully and you will be informed of the outcome.

I agree that research data collected for the study may be published or provided to other researchers in a form that does not identify me in any way.

Your decision to participate or not will not be prejudice your future relations with Sacred Heart Hospice. If you decide to participate, you are free to withdraw your consent and discontinue at any time without prejudice. Confidentiality and anonymity will be maintained.

If you have any questions please feel free to ask me. If you have any additional or subsequent questions later, I will be happy to answer them. I can be contacted (Peta McVey) on 9361 9444.

This study has been approved by the Australian Catholic University Ethics Committee and the committee for Sacred Heart Hospice. In the event that you have any complaint about the way you have been treated during the study, or a query that the principal investigator has been unable to satisfy, you write to

The Chair
Research Projects Ethics Committee
c - Divisional Research Officer
Australian Catholic University
PO Box 968
NORTH SYDNEY NSW 2059

You will be given a copy of this form to keep.

Project Title: Psychological distress among palliative patients:
a community perspective

You are making a decision whether or not to participate. Your signature indicates that you have decided to participate having read the information provided above:

Signature of Subject	Signature of Witness
Please PRINT name	Please PRINT name
Date	Name of witness
Signature(s) of Investigator (s)	
Please PRINT name	

REVOCATION OF CONSENT

I hereby wish to **withdraw** my consent to participate in the research proposal described above and understand that such withdraw **WILL NOT** jeopardize any treatment of my relationship with Sacred Heart Hospice.

Signature	Date
Please PRINT name	

The section for Revocation of Consent should be forwarded to;
Peta McVey
Clinical Nurse Specialist
Sacred Heart Hospice
170 Darlinghurst Road.
DARLINGHURST NSW 2010

Appendix 9:

Copy of statistical calculations of descriptive statistics

Frequencies

Statistics

		AGE	SEX	PEOPLE1
N	Valid	75	75	75
	Missing	0	0	0
Mean		66.97	1.51	2.83
Median		71.00	2.00	3.00
Std. Deviation		13.02	.50	.72
Skewness		-.938	-.027	.276
Std. Error of Skewness		.277	.277	.277
Range		55	1	2
Minimum		30	1	2
Maximum		85	2	4

Statistics

		SSUPP	SYMPT	SYMPT1
N	Valid	75	75	46
	Missing	0	0	29
Mean		1.31	1.39	17.52
Median		1.00	1.00	8.00
Std. Deviation		.46	.49	20.12
Skewness		.856	.475	2.196
Std. Error of Skewness		.277	.277	.350
Range		1	1	78
Minimum		1	1	1
Maximum		2	2	79

Statistics

		DIAGN2	LOD	PREVA
N	Valid	75	75	75
	Missing	0	0	0
Mean		3.52	3.07	1.84
Median		3.00	3.00	2.00
Std. Deviation		2.16	1.93	.37
Skewness		.826	.433	-1.893
Std. Error of Skewness		.277	.277	.277
Range		7	5	1
Minimum		1	1	1
Maximum		8	6	2

Statistics

		PREVD	FAMA	FAMD
N	Valid	75	75	75
	Missing	0	0	0
Mean		1.83	1.93	1.93
Median		2.00	2.00	2.00
Std. Deviation		.38	.25	.25
Skewness		-1.761	-3.546	-3.546
Std. Error of Skewness		.277	.277	.277
Range		1	1	1
Minimum		1	1	1
Maximum		2	2	2

Statistics

		TOTALD1	TOTALA1
N	Valid	75	73
	Missing	0	2
Mean		.19	.18
Median		.00	.00
Std. Deviation		.39	.39
Skewness		1.641	1.718
Std. Error of Skewness		.277	.281
Range		1	1
Minimum		0	0
Maximum		1	1

Statistics

		TOTALA2	TOTALD2
N	Valid	75	75
	Missing	0	0
Mean		.16	.19
Median		.00	.00
Std. Deviation		.37	.39
Skewness		1.893	1.641
Std. Error of Skewness		.277	.277
Range		1	1
Minimum		0	0
Maximum		1	1

Frequency Table

AGE

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	30	1	1.3	1.3	1.3
	34	1	1.3	1.3	2.7
	38	1	1.3	1.3	4.0
	39	2	2.7	2.7	6.7
	44	1	1.3	1.3	8.0
	46	1	1.3	1.3	9.3
	48	1	1.3	1.3	10.7
	50	2	2.7	2.7	13.3
	51	1	1.3	1.3	14.7
	54	1	1.3	1.3	16.0
	55	2	2.7	2.7	18.7
	57	1	1.3	1.3	20.0
	58	2	2.7	2.7	22.7
	59	3	4.0	4.0	26.7
	60	2	2.7	2.7	29.3
	62	1	1.3	1.3	30.7
	63	2	2.7	2.7	33.3
	64	2	2.7	2.7	36.0
	65	1	1.3	1.3	37.3
	67	4	5.3	5.3	42.7
	70	2	2.7	2.7	45.3
	71	8	10.7	10.7	56.0
	72	3	4.0	4.0	60.0
	73	3	4.0	4.0	64.0
	74	3	4.0	4.0	68.0
	75	2	2.7	2.7	70.7
	76	3	4.0	4.0	74.7
	77	3	4.0	4.0	78.7
	78	4	5.3	5.3	84.0
	79	2	2.7	2.7	86.7
	80	1	1.3	1.3	88.0
	81	2	2.7	2.7	90.7
	82	3	4.0	4.0	94.7
	84	1	1.3	1.3	96.0
	85	3	4.0	4.0	100.0
	Total	75	100.0	100.0	

SEX

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	37	49.3	49.3	49.3
	2	38	50.7	50.7	100.0
	Total	75	100.0	100.0	

PEOPLE1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2	27	36.0	36.0	36.0
	3	34	45.3	45.3	81.3
	4	14	18.7	18.7	100.0
	Total	75	100.0	100.0	

SSUPP

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	52	69.3	69.3	69.3
	2	23	30.7	30.7	100.0
	Total	75	100.0	100.0	

SYMPT

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	46	61.3	61.3	61.3
	2	29	38.7	38.7	100.0
	Total	75	100.0	100.0	

SYMPT1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	2	2.7	4.3	4.3
	4	2	2.7	4.3	8.7
	7	19	25.3	41.3	50.0
	9	4	5.3	8.7	58.7
	15	6	8.0	13.0	71.7
	16	1	1.3	2.2	73.9
	20	4	5.3	8.7	82.6
	24	1	1.3	2.2	84.8
	31	1	1.3	2.2	87.0
	39	1	1.3	2.2	89.1
	46	1	1.3	2.2	91.3
	74	3	4.0	6.5	97.8
	79	1	1.3	2.2	100.0
	Total	46	61.3	100.0	
Missing	System	29	38.7		
Total		75	100.0		

DIAGN2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	11	14.7	14.7	14.7
	2	22	29.3	29.3	44.0
	3	11	14.7	14.7	58.7
	4	12	16.0	16.0	74.7
	5	3	4.0	4.0	78.7
	6	6	8.0	8.0	86.7
	7	3	4.0	4.0	90.7
	8	7	9.3	9.3	100.0
	Total	75	100.0	100.0	

LOD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	23	30.7	30.7	30.7
	2	14	18.7	18.7	49.3
	3	10	13.3	13.3	62.7
	4	7	9.3	9.3	72.0
	5	5	6.7	6.7	78.7
	6	16	21.3	21.3	100.0
	Total	75	100.0	100.0	

PREVA

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	12	16.0	16.0	16.0
	2	63	84.0	84.0	100.0
	Total	75	100.0	100.0	

PREVD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	13	17.3	17.3	17.3
	2	62	82.7	82.7	100.0
	Total	75	100.0	100.0	

FAMA

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	5	6.7	6.7	6.7
	2	70	93.3	93.3	100.0
	Total	75	100.0	100.0	

FAMD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	5	6.7	6.7	6.7
	2	70	93.3	93.3	100.0
	Total	75	100.0	100.0	

TOTALD1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	61	81.3	81.3	81.3
	1	14	18.7	18.7	100.0
	Total	75	100.0	100.0	

TOTALA1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	60	80.0	82.2	82.2
	1	13	17.3	17.8	100.0
	Total	73	97.3	100.0	
Missing	System	2	2.7		
Total		75	100.0		

TOTALA2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	63	84.0	84.0	84.0
	1	12	16.0	16.0	100.0
	Total	75	100.0	100.0	

TOTALD2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	61	81.3	81.3	81.3
	1	14	18.7	18.7	100.0
	Total	75	100.0	100.0	

Appendix 10:

Copy of Spearman Correlation Coefficients calculations

Nonparametric Correlations

Correlations

			DTOTAL1	ATOTAL1
Spearman's rho	DTOTAL1	Correlation Coefficient	1.000	.355**
		Sig. (2-tailed)	.	.002
		N	75	75
	ATOTAL1	Correlation Coefficient	.355**	1.000
		Sig. (2-tailed)	.002	.
		N	75	75

**. Correlation is significant at the .01 level (2-tailed).

Nonparametric Correlations

Correlations

			AGE	DTOTAL1
Spearman's rho	AGE	Correlation Coefficient	1.000	.032
		Sig. (2-tailed)	.	.786
		N	75	75
	DTOTAL1	Correlation Coefficient	.032	1.000
		Sig. (2-tailed)	.786	.
		N	75	75

Appendix 11:

Copy of Mann-Whitney *U* test calculations

Par Tests

lann-Whitney Test

Ranks

	KARNCAT	N	Mean Rank	Sum of Ranks
DTOTAL1	1.00	7	24.07	168.50
	2.00	41	24.57	1007.50
	Total	48		

Test Statistics[b]

	DTOTAL1
Mann-Whitney U	140.500
Wilcoxon W	168.500
Z	-.088
Asymp. Sig. (2-tailed)	.930
Exact Sig. [2*(1-tailed Sig.)]	.932[a]

a. Not corrected for ties.

b. Grouping Variable: KARNCAT

Ranks

	METACAT	N	Mean Rank	Sum of Ranks
DTOTAL1	1.00	59	30.00	1770.00
	2.00	0[a]	.00	.00
	Total	59		

a. Mann-Whitney Test cannot be performed on empty groups.

Ranks

	FAMD	N	Mean Rank	Sum of Ranks
DTOTAL1	1	5	55.90	279.50
	2	70	36.72	2570.50
	Total	75		

Test Statistics[b]

	DTOTAL1
Mann-Whitney U	85.500
Wilcoxon W	2570.500
Z	-1.912
Asymp. Sig. (2-tailed)	.056
Exact Sig. [2*(1-tailed Sig.)]	.056[a]

a. Not corrected for ties.

b. Grouping Variable: FAMD

Ranks

	FAMA	N	Mean Rank	Sum of Ranks
DTOTAL1	1	5	32.80	164.00
	2	70	38.37	2686.00
	Total	75		

Test Statistics[b]

	DTOTAL1
Mann-Whitney U	149.000
Wilcoxon W	164.000
Z	-.555
Asymp. Sig. (2-tailed)	.579
Exact Sig. [2*(1-tailed Sig.)]	.599[a]

a. Not corrected for ties.

b. Grouping Variable: FAMA

Ranks

	SYMPT	N	Mean Rank	Sum of Ranks
DTOTAL1	1	46	42.26	1944.00
	2	29	31.24	906.00
	Total	75		

Test Statistics[a]

	DTOTAL1
Mann-Whitney U	471.000
Wilcoxon W	906.000
Z	-2.145
Asymp. Sig. (2-tailed)	.032

a. Grouping Variable: SYMPT

Ranks

	SSUPP	N	Mean Rank	Sum of Ranks
DTOTAL1	1	52	38.77	2016.00
	2	23	36.26	834.00
	Total	75		

Test Statistics[a]

	DTOTAL1
Mann-Whitney U	558.000
Wilcoxon W	834.000
Z	-.462
Asymp. Sig. (2-tailed)	.644

a. Grouping Variable: SSUPP

Ranks

	SEX	N	Mean Rank	Sum of Ranks
DTOTAL1	1	37	34.49	1276.00
	2	38	41.42	1574.00
	Total	75		

Test Statistics[a]

	DTOTAL1
Mann-Whitney U	573.000
Wilcoxon W	1276.000
Z	-1.386
Asymp. Sig. (2-tailed)	.166

a. Grouping Variable: SEX

Ranks

	PREVA	N	Mean Rank	Sum of Ranks
DTOTAL1	1	12	48.38	580.50
	2	63	36.02	2269.50
	Total	75		

Test Statistics[a]

	DTOTAL1
Mann-Whitney U	253.500
Wilcoxon W	2269.500
Z	-1.810
Asymp. Sig. (2-tailed)	.070

a. Grouping Variable: PREVA

Ranks

	PREVD	N	Mean Rank	Sum of Ranks
DTOTAL1	1	13	48.81	634.50
	2	62	35.73	2215.50
	Total	75		

Test Statistics[a]

	DTOTAL1
Mann-Whitney U	262.500
Wilcoxon W	2215.500
Z	-1.978
Asymp. Sig. (2-tailed)	.048

a. Grouping Variable: PREVD

Ranks

	DCAT1	N	Mean Rank	Sum of Ranks
PEOPLE	.00	61	38.92	2374.00
	1.00	14	34.00	476.00
	Total	75		

Test Statistics[a]

	PEOPLE
Mann-Whitney U	371.000
Wilcoxon W	476.000
Z	-.778
Asymp. Sig. (2-tailed)	.437

a. Grouping Variable: DCAT1

Ranks

	DCAT1	N	Mean Rank	Sum of Ranks
DIAGN	.00	61	36.28	2213.00
	1.00	14	45.50	637.00
	Total	75		

Test Statistics[a]

	DIAGN
Mann-Whitney U	322.000
Wilcoxon W	2213.000
Z	-1.433
Asymp. Sig. (2-tailed)	.152

a. Grouping Variable: DCAT1

Ranks

	DCAT1	N	Mean Rank	Sum of Ranks
LOD	.00	61	37.98	2316.50
	1.00	14	38.11	533.50
	Total	75		

Test Statistics[a]

	LOD
Mann-Whitney U	425.500
Wilcoxon W	2316.500
Z	-.021
Asymp. Sig. (2-tailed)	.983

a. Grouping Variable: DCAT1

Ranks

	DCAT1	N	Mean Rank	Sum of Ranks
NCARER	.00	61	36.71	2239.50
	1.00	14	43.61	610.50
	Total	75		

Test Statistics[a]

	NCARER
Mann-Whitney U	348.500
Wilcoxon W	2239.500
Z	-1.159
Asymp. Sig. (2-tailed)	.246

a. Grouping Variable: DCAT1

Ranks

	DCAT1	N	Mean Rank	Sum of Ranks
KARNOF	.00	61	37.77	2304.00
	1.00	14	39.00	546.00
	Total	75		

Test Statistics[a]

	KARNOF
Mann-Whitney U	413.000
Wilcoxon W	2304.000
Z	-.198
Asymp. Sig. (2-tailed)	.843

a. Grouping Variable: DCAT1

Ranks

	SEX	N	Mean Rank	Sum of Ranks
ATOTAL1	1	37	37.14	1374.00
	2	38	38.84	1476.00
	Total	75		

Test Statistics[a]

	ATOTAL1
Mann-Whitney U	671.000
Wilcoxon W	1374.000
Z	-.340
Asymp. Sig. (2-tailed)	.734

a. Grouping Variable: SEX

Ranks

	METAST	N	Mean Rank	Sum of Ranks
ATOTAL1	1	59	35.93	2120.00
	2	10	29.50	295.00
	Total	69		

Test Statistics[a]

	ATOTAL1
Mann-Whitney U	240.000
Wilcoxon W	295.000
Z	-.941
Asymp. Sig. (2-tailed)	.347

a. Grouping Variable: METAST

Ranks

	SYMPT	N	Mean Rank	Sum of Ranks
ATOTAL1	1	46	42.20	1941.00
	2	29	31.34	909.00
	Total	75		

Test Statistics[a]

	ATOTAL1
Mann-Whitney U	474.000
Wilcoxon W	909.000
Z	-2.107
Asymp. Sig. (2-tailed)	.035

a. Grouping Variable: SYMPT

Ranks

	PREVA	N	Mean Rank	Sum of Ranks
ATOTAL1	1	12	45.42	545.00
	2	63	36.59	2305.00
	Total	75		

Test Statistics[a]

	ATOTAL1
Mann-Whitney U	289.000
Wilcoxon W	2305.000
Z	-1.291
Asymp. Sig. (2-tailed)	.197

a. Grouping Variable: PREVA

Ranks

	PREVD	N	Mean Rank	Sum of Ranks
ATOTAL1	1	13	51.31	667.00
	2	62	35.21	2183.00
	Total	75		

Test Statistics[a]

	ATOTAL1
Mann-Whitney U	230.000
Wilcoxon W	2183.000
Z	-2.430
Asymp. Sig. (2-tailed)	.015

a. Grouping Variable: PREVD

Ranks

	FAMA	N	Mean Rank	Sum of Ranks
ATOTAL1	1	5	29.30	146.50
	2	70	38.62	2703.50
	Total	75		

Test Statistics[b]

	ATOTAL1
Mann-Whitney U	131.500
Wilcoxon W	146.500
Z	-.927
Asymp. Sig. (2-tailed)	.354
Exact Sig. [2*(1-tailed Sig.)]	.366[a]

a. Not corrected for ties.

b. Grouping Variable: FAMA

Ranks

	FAMD	N	Mean Rank	Sum of Ranks
ATOTAL1	1	5	46.40	232.00
	2	70	37.40	2618.00
	Total	75		

Test Statistics[b]

	ATOTAL1
Mann-Whitney U	133.000
Wilcoxon W	2618.000
Z	-.895
Asymp. Sig. (2-tailed)	.371
Exact Sig. [2*(1-tailed Sig.)]	.389[a]

a. Not corrected for ties.

b. Grouping Variable: FAMD

Ranks

	AGECAT	N	Mean Rank	Sum of Ranks
ATOTAL1	1.00	20	33.53	670.50
	2.00	55	39.63	2179.50
	Total	75		

Test Statistics[a]

	ATOTAL1
Mann-Whitney U	460.500
Wilcoxon W	670.500
Z	-1.076
Asymp. Sig. (2-tailed)	.282

a. Grouping Variable: AGECAT

Ranks

	ACAT1	N	Mean Rank	Sum of Ranks
DIAGN	.00	63	36.33	2288.50
	1.00	12	46.79	561.50
	Total	75		

Test Statistics[a]

	DIAGN
Mann-Whitney U	272.500
Wilcoxon W	2288.500
Z	-1.530
Asymp. Sig. (2-tailed)	.126

a. Grouping Variable: ACAT1

Ranks

	ACAT1	N	Mean Rank	Sum of Ranks
PEOPLE	.00	63	39.17	2467.50
	1.00	12	31.88	382.50
	Total	75		

Test Statistics[a]

	PEOPLE
Mann-Whitney U	304.500
Wilcoxon W	382.500
Z	-1.085
Asymp. Sig. (2-tailed)	.278

a. Grouping Variable: ACAT1

Ranks

	ACAT1	N	Mean Rank	Sum of Ranks
NCARER	.00	63	37.67	2373.00
	1.00	12	39.75	477.00
	Total	75		

Test Statistics[a]

	NCARER
Mann-Whitney U	357.000
Wilcoxon W	2373.000
Z	-.330
Asymp. Sig. (2-tailed)	.742

a. Grouping Variable: ACAT1

Ranks

	ACAT1	N	Mean Rank	Sum of Ranks
LOD	.00	63	39.34	2478.50
	1.00	12	30.96	371.50
	Total	75		

Test Statistics[a]

	LOD
Mann-Whitney U	293.500
Wilcoxon W	371.500
Z	-1.252
Asymp. Sig. (2-tailed)	.211

a. Grouping Variable: ACAT1

Ranks

	ACAT1	N	Mean Rank	Sum of Ranks
KARNOF	.00	63	37.57	2367.00
	1.00	12	40.25	483.00
	Total	75		

Test Statistics[a]

	KARNOF
Mann-Whitney U	351.000
Wilcoxon W	2367.000
Z	-.406
Asymp. Sig. (2-tailed)	.685

a. Grouping Variable: ACAT1

Ranks

	KARNCAT	N	Mean Rank	Sum of Ranks
ATOTAL1	1.00	7	16.14	113.00
	2.00	41	25.93	1063.00
	Total	48		

Test Statistics[b]

	ATOTAL1
Mann-Whitney U	85.000
Wilcoxon W	113.000
Z	-1.717
Asymp. Sig. (2-tailed)	.086
Exact Sig. [2*(1-tailed Sig.)]	.091[a]

a. Not corrected for ties.

b. Grouping Variable: KARNCAT

Appendix 12:

Copy of Logistic Regression Analysis

```
get file='c:\clients (notebook)\peta\peta3.sav'.
freq lod.
```

Statistics

	N	
	Valid	Missing
LOD	75	0

LOD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	23	30.7	30.7	30.7
	2	14	18.7	18.7	49.3
	3	10	13.3	13.3	62.7
	4	7	9.3	9.3	72.0
	5	5	6.7	6.7	78.7
	6	16	21.3	21.3	100.0
	Total	75	100.0	100.0	
Total		75	100.0		

```
recode lod (3 thru hi=3).

logistic regression var=dcat1 /method=enter age.
```

```
    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:              75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original      Internal
Value         Value
   .00       0
  1.00       1

Dependent Variable..  DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      AGE

Estimation terminated at iteration number 4 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       71.038
```

```
Goodness of Fit       74.585
Cox & Snell - R^2       .015
Nagelkerke - R^2        .025

               Chi-Square   df Significance

Model               1.165    1       .2805
Block               1.165    1       .2805
Step                1.165    1       .2805

Classification Table for DCAT1
The Cut Value is .50
              Predicted
             .00    1.00    Percent Correct
              0 I    1
Observed        +-----+-----+
  .00     0 I  61 I   0 I 100.00%
            +-----+-----+
  1.00    1 I  14 I   0 I    .00%
            +-----+-----+
                 Overall  81.33%

------------- Variables in the Equation -------------

Variable        B      S.E.     Wald   df    Sig      R    Exp(B)

AGE         .0268    .0261   1.0569    1   .3039  .0000    1.0272
Constant  -3.3052   1.8414   3.2216    1   .0727

logistic regression var=dcat1 /method=enter sex /contr(sex)=indicator(1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0

    Number of selected cases:                  75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original      Internal
Value         Value
   .00        0
  1.00        1

                      Parameter
           Value  Freq  Coding
                         (1)
SEX
               1    37   .000
               2    38  1.000

Dependent Variable..  DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.
```

```
Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..     SEX

Estimation terminated at iteration number 3 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       71.913
 Goodness of Fit         74.995
 Cox & Snell - R^2         .004
 Nagelkerke - R^2          .006

                 Chi-Square   df Significance

 Model                 .290    1       .5904
 Block                 .290    1       .5904
 Step                  .290    1       .5904

Classification Table for DCAT1
The Cut Value is .50
                Predicted
               .00    1.00     Percent Correct
                 0 I    1
Observed         +------+------+
  .00      0 I  61 I    0 I  100.00%
             +------+------+
  1.00     1 I  14 I    0 I      .00%
             +------+------+
                    Overall  81.33%

---------------- Variables in the Equation ----------------

Variable          B       S.E.     Wald    df     Sig      R     Exp(B)

SEX(1)          .3203    .5977    .2872     1   .5920  .0000   1.3775
Constant     -1.6420     .4460  13.5560     1   .0002

logistic regression var=dcat1 /method=enter diagn2 /contr(diagn2)=indicator (1).

    Total number of cases:       75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0

    Number of selected cases:                  75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original       Internal
Value          Value
   .00        0
  1.00        1

                       Parameter
            Value   Freq  Coding
                          (1)   (2)   (3)   (4)   (5)   (6)   (7)
```

```
DIAGN2
              1    11  .000  .000  .000  .000  .000  .000  .000
              2    22 1.000  .000  .000  .000  .000  .000  .000
              3    11  .000 1.000  .000  .000  .000  .000  .000
              4    12  .000  .000 1.000  .000  .000  .000  .000
              5     3  .000  .000  .000 1.000  .000  .000  .000
              6     6  .000  .000  .000  .000 1.000  .000  .000
              7     3  .000  .000  .000  .000  .000 1.000  .000
              8     7  .000  .000  .000  .000  .000  .000 1.000

Dependent Variable..  DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      DIAGN2

Estimation terminated at iteration number 7 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       67.450
 Goodness of Fit         69.002
 Cox & Snell - R^2         .061
 Nagelkerke - R^2          .099

               Chi-Square   df Significance

 Model               4.753    7        .6900
 Block               4.753    7        .6900
 Step                4.753    7        .6900

Classification Table for DCAT1
The Cut Value is .50
              Predicted
             .00    1.00    Percent Correct
              0  I    1
Observed        +-----+-----+
  .00      0  I  61  I   0  I  100.00%
             +-----+-----+
  1.00     1  I  14  I   0  I     .00%
             +-----+-----+
                  Overall  81.33%

 ---------------- Variables in the Equation -----------------

Variable          B       S.E.     Wald    df    Sig       R    Exp(B)

DIAGN2                           2.2555     7   .9444   .0000
 DIAGN2(1)     -.3417    .9985    .1171     1   .7322   .0000    .7105
 DIAGN2(2)   -1.1E-16   1.1055    .0000     1  1.0000   .0000   1.0000
 DIAGN2(3)      .8109    .9930    .6669     1   .4141   .0000   2.2500
 DIAGN2(4)    -6.6984  34.8987    .0368     1   .8478   .0000    .0012
 DIAGN2(5)     -.1054   1.3458    .0061     1   .9376   .0000    .9000
 DIAGN2(6)    -6.6984  34.8987    .0368     1   .8478   .0000    .0012
 DIAGN2(7)      .5878   1.1450    .2635     1   .6077   .0000   1.8000
```

```
Constant     -1.5041    .7817  3.7019    1   .0544

logistic regression var=dcat1 /method=enter lod /contr(lod)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:               75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value        Value
   .00      0
   1.00      1

                      Parameter
           Value  Freq  Coding
                    (1)    (2)
LOD
              1     23   .000   .000
              2     14  1.000   .000
              3     38   .000  1.000

Dependent Variable..   DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      LOD

Estimation terminated at iteration number 3 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       71.154
 Goodness of Fit        74.992
 Cox & Snell - R^2        .014
 Nagelkerke - R^2         .022

              Chi-Square    df Significance

 Model              1.049     2        .5917
 Block             1.049     2       .5917
 Step             1.049     2       .5917

Classification Table for DCAT1
The Cut Value is .50
              Predicted
            .00   1.00     Percent Correct
             0  I    1
```

```
Observed      +-----+-----+
  .00     0  I  61 I   0 I 100.00%
           +-----+-----+
  1.00    1  I  14 I   0 I    .00%
           +-----+-----+
                Overall  81.33%

------------- Variables in the Equation -------------

Variable        B      S.E.    Wald    df     Sig      R    Exp(B)

LOD                           1.1052    2    .5754  .0000
 LOD(1)       .6417   .8078   .6311    1    .4270  .0000   1.8998
 LOD(2)      -.1157   .7075   .0267    1    .8701  .0000    .8908
Constant    -1.5580   .5501  8.0218    1    .0046

logistic regression var=dcat1 /method=enter prevacat /contr(prevacat)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:              75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value        Value
   .00      0
  1.00      1

                  Parameter
          Value  Freq  Coding
                        (1)
PREVACAT
            .00    63   .000
           1.00    12  1.000

Dependent Variable..   DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      PREVACAT

Estimation terminated at iteration number 4 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       64.593
 Goodness of Fit         75.000
 Cox & Snell - R^2         .096
```

```
Nagelkerke - R^2        .156

                Chi-Square   df Significance

Model              7.610    1      .0058
Block              7.610    1      .0058
Step               7.610    1      .0058

Classification Table for DCAT1
The Cut Value is .50
                Predicted
               .00   1.00    Percent Correct
                0 I   1
Observed         +-----+-----+
  .00      0  I  55 I   6 I  90.16%
              +-----+-----+
  1.00     1  I   8 I   6 I  42.86%
              +-----+-----+
                 Overall  81.33%

--------------- Variables in the Equation ---------------

Variable            B      S.E.    Wald   df     Sig      R    Exp(B)

PREVACAT(1)     1.9279    .6903  7.7999    1   .0052  .2834    6.8750
Constant       -1.9279    .3784 25.9584    1   .0000

logistic regression var=dcat1 /method=enter prevdcat /contr(prevdcat)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0

    Number of selected cases:                  75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value         Value
   .00      0
  1.00      1

                      Parameter
           Value   Freq   Coding
                          (1)
PREVDCAT
              .00     62   .000
             1.00     13  1.000

Dependent Variable..   DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.
```

```
Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..     PREVDCAT

Estimation terminated at iteration number 4 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood      65.628
 Goodness of Fit       75.000
 Cox & Snell - R^2        .084
 Nagelkerke - R^2         .136

                 Chi-Square   df Significance

 Model               6.575    1      .0103
 Block               6.575    1      .0103
 Step                6.575    1      .0103

Classification Table for DCAT1
The Cut Value is .50
               Predicted
              .00   1.00   Percent Correct
               0  I   1
Observed        +------+------+
  .00      0  I  61 I   0 I  100.00%
             +------+------+
  1.00     1  I  14 I   0 I     .00%
             +------+------+
                  Overall  81.33%

--------------- Variables in the Equation ----------------

Variable            B      S.E.     Wald    df     Sig       R    Exp(B)

PREVDCAT(1)     1.7554    .6731   6.8016     1   .0091   .2579    5.7857
Constant       -1.9095    .3788  25.4068     1   .0000

logistic regression var=dcat1 /method=enter famacat /contr(famacat)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0

    Number of selected cases:                75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value        Value
   .00        0
  1.00        1

                     Parameter
            Value   Freq  Coding
                           (1)
FAMACAT
              .00    70   .000
```

```
               1.00     5  1.000

Dependent Variable..  DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      FAMACAT

Estimation terminated at iteration number 3 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       72.197
 Goodness of Fit        74.997
 Cox & Snell - R^2        .000
 Nagelkerke - R^2         .000

                 Chi-Square    df Significance

 Model                .006     1        .9374
 Block                .006     1        .9374
 Step                 .006     1        .9374

Classification Table for DCAT1
The Cut Value is .50
                Predicted
               .00    1.00     Percent Correct
                 0  I   1
Observed          +------+------+
  .00       0  I   61  I    0  I  100.00%
               +------+------+
  1.00      1  I   14  I    0  I    .00%
               +------+------+
                       Overall  81.33%

--------------- Variables in the Equation ---------------

Variable          B       S.E.      Wald    df     Sig        R    Exp(B)

FAMACAT(1)       .0918    1.1595    .0063     1   .9369   .0000    1.0961
Constant       -1.4780     .3073  23.1265     1   .0000

logistic regression var=dcat1 /method=enter famdcat /contr(famdcat)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0

    Number of selected cases:                   75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:
```

```
Original    Internal
Value       Value
   .00      0
  1.00      1

                 Parameter
          Value  Freq  Coding
                        (1)
FAMDCAT
            .00    70   .000
           1.00     5  1.000

Dependent Variable..   DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      FAMDCAT

Estimation terminated at iteration number 4 because
parameter estimates changed by less than .001

 -2 Log Likelihood       62.420
 Goodness of Fit         75.000
 Cox & Snell - R^2         .122
 Nagelkerke - R^2          .198

               Chi-Square    df Significance

 Model              9.783     1       .0018
 Block              9.783     1       .0018
 Step               9.783     1       .0018

Classification Table for DCAT1
The Cut Value is .50
               Predicted
             .00   1.00    Percent Correct
              0  I   1
Observed      +------+------+
  .00      0  I  60  I   1  I   98.36%
              +------+------+
 1.00      1  I  10  I   4  I   28.57%
              +------+------+
                   Overall      85.33%

---------------- Variables in the Equation -----------------

Variable          B      S.E.     Wald   df     Sig       R    Exp(B)

FAMDCAT(1)     3.1781   1.1690   7.3903    1   .0066   .2732   24.0000
Constant      -1.7918    .3416  27.5177    1   .0000

logistic regression var=dcat1 /method=enter ssuppcat /contr(ssuppcat)=indicator (1).

    Total number of cases:      75 (Unweighted)
```

```
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:             75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original    Internal
Value        Value
   .00      0
  1.00      1

                    Parameter
          Value  Freq  Coding
                      (1)
SSUPPCAT
            .00    23  .000
           1.00    52  1.000

Dependent Variable..  DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      SSUPPCAT

Estimation terminated at iteration number 3 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       71.052
 Goodness of Fit        74.989
 Cox & Snell - R^2        .015
 Nagelkerke - R^2         .025

              Chi-Square   df Significance

 Model               1.151    1       .2833
 Block              1.151    1       .2833
 Step              1.151    1       .2833

Classification Table for DCAT1
The Cut Value is .50
             Predicted
            .00   1.00    Percent Correct
             0 I    1
Observed       +-----+-----+
  .00     0  I  61 I   0 I  100.00%
           +-----+-----+
  1.00     1  I  14 I   0 I     .00%
           +-----+-----+
                Overall  81.33%
```

```
-------------- Variables in the Equation --------------

Variable          B      S.E.    Wald   df    Sig       R    Exp(B)

SSUPPCAT(1)     -.6630   .6109  1.1778   1   .2778  .0000     .5153
Constant      -1.0415    .4749  4.8101    1   .0283

logistic regression var=dcat1 /method=enter symptcat /contr(symptcat)=indicator (1).

   Total number of cases:      75 (Unweighted)
   Number of selected cases:  75
   Number of unselected cases: 0

   Number of selected cases:               75
   Number rejected because of missing data:  0
   Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value        Value
   .00     0
  1.00     1

                     Parameter
          Value  Freq  Coding
                    (1)
SYMPTCAT
            .00    29   .000
           1.00    46  1.000

Dependent Variable..   DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      SYMPTCAT

Estimation terminated at iteration number 3 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       72.077
 Goodness of Fit         74.996
 Cox & Snell - R^2         .002
 Nagelkerke - R^2          .003

              Chi-Square    df Significance

 Model              .126    1       .7223
 Block              .126    1       .7223
 Step               .126    1       .7223
```

```
Classification Table for DCAT1
The Cut Value is .50
              Predicted
             .00   1.00    Percent Correct
              0 I  1
Observed     +-----+-----+
  .00    0  I  61 I   0 I 100.00%
           +-----+-----+
  1.00   1  I  14 I   0 I    .00%
           +-----+-----+
                  Overall  81.33%

------------- Variables in the Equation -------------

Variable           B     S.E.     Wald    df     Sig      R    Exp(B)

SYMPTCAT(1)     -.2143    .6012   .1271    1   .7215   .0000     .8071
Constant      -1.3437    .4584  8.5921    1   .0034

logistic regression var=dcat1 /method=enter karnof.

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:                 75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value         Value
   .00       0
  1.00       1

Dependent Variable..  DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      KARNOF

Estimation terminated at iteration number 3 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       72.009
 Goodness of Fit         74.973
 Cox & Snell - R^2         .003
 Nagelkerke - R^2          .004

                 Chi-Square    df Significance
```

```
Model              .194    1      .6598
Block              .194    1      .6598
Step               .194    1      .6598

Classification Table for DCAT1
The Cut Value is .50
                Predicted
              .00   1.00   Percent Correct
               0 I   1
Observed       +-----+-----+
  .00     0  I  61 I   0 I 100.00%
          +-----+-----+
  1.00    1  I  14 I   0 I    .00%
          +-----+-----+
                 Overall  81.33%

------------- Variables in the Equation --------------

Variable        B      S.E.    Wald   df     Sig      R    Exp(B)

KARNOF       .0110    .0252   .1916    1   .6616  .0000   1.0111
Constant   -2.2682   1.8556  1.4941    1   .2216

cro /tables=prevdcat by dcat1 /cell=count row.
```

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
PREVDCAT * DCAT1	75	100.0%	0	.0%	75	100.0%

PREVDCAT * DCAT1 Crosstabulation

			DCAT1		
			.00	1.00	Total
PREVDCAT	.00	Count	54	8	62
		% within PREVDCAT	87.1%	12.9%	100.0%
	1.00	Count	7	6	13
		% within PREVDCAT	53.8%	46.2%	100.0%
Total		Count	61	14	75
		% within PREVDCAT	81.3%	18.7%	100.0%

```
LOGISTIC REGRESSION VAR=dcat1
  /METHOD=fSTEP(wald) age sex diagn2 lod prevacat prevdcat famacat famdcat
  ssuppcat symptcat karnof
  /CONTRAST (sex)=Indicator /CONTRAST (diagn2)=Indicator /CONTRAST
  (lod)=Indicator /CONTRAST (prevacat)=Indicator(1) /CONTRAST
  (prevdcat)=Indicator(1) /CONTRAST (famacat)=Indicator(1) /CONTRAST
  (famdcat)=Indicator(1) /CONTRAST (ssuppcat)=Indicator /CONTRAST
  (symptcat)=Indicator
  /CRITERIA PIN(.05) POUT(.051) ITERATE(20) CUT(.5) .

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:              75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75
```

```
Dependent Variable Encoding:

Original    Internal
Value       Value
   .00      0
  1.00      1

                      Parameter
              Value  Freq  Coding
                       (1)    (2)    (3)    (4)    (5)    (6)    (7)
DIAGN2
                 1    11  1.000   .000   .000   .000   .000   .000   .000
                 2    22   .000  1.000   .000   .000   .000   .000   .000
                 3    11   .000   .000  1.000   .000   .000   .000   .000
                 4    12   .000   .000   .000  1.000   .000   .000   .000
                 5     3   .000   .000   .000   .000  1.000   .000   .000
                 6     6   .000   .000   .000   .000   .000  1.000   .000
                 7     3   .000   .000   .000   .000   .000   .000  1.000
                 8     7   .000   .000   .000   .000   .000   .000   .000
LOD
                 1    23  1.000   .000
                 2    14   .000  1.000
                 3    38   .000   .000
SYMPTCAT
               .00    29  1.000
              1.00    46   .000
PREVACAT
               .00    63   .000
              1.00    12  1.000
PREVDCAT
               .00    62   .000
              1.00    13  1.000
FAMACAT
               .00    70   .000
              1.00     5  1.000
SSUPPCAT
               .00    23  1.000
              1.00    52   .000
FAMDCAT
               .00    70   .000
              1.00     5  1.000
SEX
                 1    37  1.000
                 2    38   .000

Dependent Variable..  DCAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   72.203

* Constant is included in the model.

Estimation terminated at iteration number 3 because
Log Likelihood decreased by less than .01 percent.

Classification Table for DCAT1
The Cut Value is .50
              Predicted
             .00    1.00     Percent Correct
```

```
              0 I  1
Observed      +-----+-----+
  .00    0  I  61 I   0 I 100.00%
          +-----+-----+
  1.00    1  I  14 I   0 I     .00%
          +-----+-----+
                Overall  81.33%

---------------- Variables in the Equation ----------------

Variable        B      S.E.    Wald    df     Sig      R    Exp(B)

Constant    -1.4718    .2963  24.6653    1    .0000


Beginning Block Number  1.  Method: Forward Stepwise (WALD)

---------- Variables not in the Equation ----------
Residual Chi Square     27.853 with     18 df     Sig =  .0643

Variable          Score    df      Sig       R

AGE              1.0797    1    .2988   .0000
SEX(1)            .2890    1    .5909   .0000
DIAGN2            3.9162    7    .7894   .0000
 DIAGN2(1)          .0020    1    .9643   .0000
 DIAGN2(2)          .5190    1    .4713   .0000
 DIAGN2(3)          .0020    1    .9643   .0000
 DIAGN2(4)         2.0238    1    .1549   .0182
 DIAGN2(5)          .7173    1    .3970   .0000
 DIAGN2(6)          .0172    1    .8957   .0000
 DIAGN2(7)          .7173    1    .3970   .0000
LOD              1.1362    2    .5666   .0000
 LOD(1)           .0356    1    .8504   .0000
 LOD(2)          1.1120    1    .2916   .0000
PREVACAT(1)         9.2372    1    .0024   .3166
PREVDCAT(1)         7.8252    1    .0052   .2840
FAMACAT(1)           .0063    1    .9369   .0000
FAMDCAT(1)         13.2729    1    .0003   .3951
SSUPPCAT(1)         1.2028    1    .2728   .0000
SYMPTCAT(1)          .1273    1    .7212   .0000
KARNOF              .1914    1    .6618   .0000

Variable(s) Entered on Step Number
1..      FAMDCAT

Estimation terminated at iteration number 4 because
parameter estimates changed by less than .001

 -2 Log Likelihood       62.420
 Goodness of Fit        75.000
 Cox & Snell - R^2         .122
 Nagelkerke - R^2          .198

                Chi-Square    df Significance

 Model              9.783     1        .0018
 Block              9.783     1        .0018
 Step               9.783     1        .0018

Classification Table for DCAT1
The Cut Value is .50
```

```
              Predicted
             .00   1.00    Percent Correct
              0 I   1
Observed       +-----+-----+
  .00      0  I  60 I   1 I  98.36%
             +-----+-----+
  1.00     1  I  10 I   4 I  28.57%
             +-----+-----+
                 Overall  85.33%

----------- Variables in the Equation -----------

Variable          B      S.E.     Wald   df     Sig      R    Exp(B)

FAMDCAT(1)     3.1781   1.1690  7.3903    1   .0066  .2732  24.0000
Constant      -1.7918    .3416 27.5177    1   .0000

-------- Variables not in the Equation ---------
Residual Chi Square     17.137 with     17 df    Sig =  .4451

Variable          Score   df    Sig      R

AGE              .9300    1   .3349  .0000
SEX(1)           .0014    1   .9697  .0000
DIAGN2             5.2338    7   .6314  .0000
 DIAGN2(1)          .0444    1   .8332  .0000
 DIAGN2(2)         1.0938    1   .2956  .0000
 DIAGN2(3)          .1618    1   .6875  .0000
 DIAGN2(4)         2.0995    1   .1473  .0371
 DIAGN2(5)          .5224    1   .4698  .0000
 DIAGN2(6)          .3797    1   .5377  .0000
 DIAGN2(7)          .5224    1   .4698  .0000
LOD             1.4421    2   .4862  .0000
 LOD(1)          .0017    1   .9676  .0000
 LOD(2)         1.2662    1   .2605  .0000
PREVACAT(1)        7.1115    1   .0077  .2661
PREVDCAT(1)        2.1069    1   .1466  .0385
FAMACAT(1)         1.9462    1   .1630  .0000
SSUPPCAT(1)         .9839    1   .3212  .0000
SYMPTCAT(1)         .1326    1   .7158  .0000
KARNOF             .0718    1   .7888  .0000

Variable(s) Entered on Step Number
2..      PREVACAT

Estimation terminated at iteration number 4 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       56.570
 Goodness of Fit        74.380
 Cox & Snell - R^2        .188
 Nagelkerke - R^2         .304

                Chi-Square    df Significance

 Model             15.633     2       .0004
 Block             15.633     2       .0004
 Step               5.850     1       .0156

Classification Table for DCAT1
The Cut Value is .50
              Predicted
```

```
              .00   1.00    Percent Correct
                0 I   1
Observed        +------+------+
  .00      0 I  60 I   1 I  98.36%
           +------+------+
  1.00     1 I  10 I   4 I  28.57%
           +------+------+
                Overall  85.33%

--------------- Variables in the Equation ---------------

Variable           B      S.E.     Wald   df     Sig      R    Exp(B)

PREVACAT(1)     1.8644    .7540   6.1139   1   .0134  .2387    6.4520
FAMDCAT(1)      3.1002   1.2265   6.3891   1   .0115  .2466   22.2033
Constant       -2.2198    .4305  26.5858   1   .0000

---------- Variables not in the Equation ----------
Residual Chi Square    11.334 with    16 df    Sig =  .7884

Variable          Score   df     Sig      R

AGE              3.2773    1   .0702  .1330
SEX(1)            .0939    1   .7593  .0000
DIAGN2           3.7608    7   .8069  .0000
 DIAGN2(1)        .2868    1   .5923  .0000
 DIAGN2(2)        .3107    1   .5772  .0000
 DIAGN2(3)        .0004    1   .9848  .0000
 DIAGN2(4)       2.7504    1   .0972  .1019
 DIAGN2(5)        .3427    1   .5582  .0000
 DIAGN2(6)        .0706    1   .7905  .0000
 DIAGN2(7)        .3427    1   .5582  .0000
LOD               .9127    2   .6336  .0000
 LOD(1)           .0008    1   .9770  .0000
 LOD(2)           .8266    1   .3633  .0000
PREVDCAT(1)      1.3289    1   .2490  .0000
FAMACAT(1)       2.8293    1   .0926  .1072
SSUPPCAT(1)      1.0225    1   .3119  .0000
SYMPTCAT(1)       .1017    1   .7498  .0000
KARNOF            .0420    1   .8376  .0000

No more variables can be deleted or added.

logistic regression var=acat1 /method=enter age.

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:                75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value        Value
   .00        0
  1.00        1
```

```
Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      AGE

Estimation terminated at iteration number 4 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       65.858
 Goodness of Fit        74.934
 Cox & Snell - R^2        .001
 Nagelkerke - R^2         .002

                Chi-Square   df Significance

 Model               .092    1       .7617
 Block              .092    1       .7617
 Step              .092    1      .7617

Classification Table for ACAT1
The Cut Value is .50
               Predicted
              .00   1.00    Percent Correct
               0  I   1
Observed        +-----+-----+
  .00     0  I  63 I   0 I  100.00%
            +-----+-----+
  1.00    1  I  12 I   0 I     .00%
            +-----+-----+
                 Overall  84.00%

--------------- Variables in the Equation ---------------

Variable        B      S.E.    Wald   df     Sig      R    Exp(B)

AGE          .0076    .0252   .0899    1   .7643  .0000   1.0076
Constant   -2.1671   1.7366  1.5572    1   .2121

logistic regression var=acat1 /method=enter sex /contr(sex)=indicator(1).

    Total number of cases:     75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:              75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original      Internal
```

```
Value        Value
   .00       0
  1.00       1

                  Parameter
           Value  Freq Coding
                       (1)
SEX
             1    37  .000
             2    38  1.000

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      SEX

Estimation terminated at iteration number 4 because
parameter estimates changed by less than .001

 -2 Log Likelihood        65.486
 Goodness of Fit          75.000
 Cox & Snell - R^2          .006
 Nagelkerke - R^2           .011

                 Chi-Square   df Significance

 Model                 .464    1      .4955
 Block                 .464    1      .4955
 Step                  .464    1      .4955

Classification Table for ACAT1
The Cut Value is .50
              Predicted
             .00   1.00    Percent Correct
              0 I   1
Observed       +-----+-----+
  .00     0  I  63  I  0  I  100.00%
             +-----+-----+
  1.00    1  I  12  I  0  I     .00%
             +-----+-----+
                  Overall  84.00%

---------------- Variables in the Equation ----------------

Variable        B       S.E.     Wald   df    Sig      R    Exp(B)

SEX(1)       -.4318    .6376   .4586    1   .4983  .0000    .6494
Constant    -1.4553    .4198  12.0203   1   .0005

logistic regression var=acat1 /method=enter diagn2 /contr(diagn2)=indicator (1).

     Total number of cases:      75 (Unweighted)
     Number of selected cases:   75
```

```
    Number of unselected cases: 0

    Number of selected cases:            75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original    Internal
Value       Value
   .00      0
  1.00      1

                    Parameter
          Value   Freq  Coding
                    (1)   (2)   (3)   (4)   (5)   (6)   (7)
DIAGN2
            1     11  .000  .000  .000  .000  .000  .000  .000
            2     22 1.000  .000  .000  .000  .000  .000  .000
            3     11  .000 1.000  .000  .000  .000  .000  .000
            4     12  .000  .000 1.000  .000  .000  .000  .000
            5      3  .000  .000  .000 1.000  .000  .000  .000
            6      6  .000  .000  .000  .000 1.000  .000  .000
            7      3  .000  .000  .000  .000  .000 1.000  .000
            8      7  .000  .000  .000  .000  .000  .000 1.000

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..     DIAGN2

Estimation terminated at iteration number 8 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       55.669
 Goodness of Fit         61.001
 Cox & Snell - R^2         .128
 Nagelkerke - R^2          .219

                Chi-Square    df Significance

 Model             10.281      7       .1732
 Block             10.281      7       .1732
 Step              10.281      7       .1732

Classification Table for ACAT1
The Cut Value is .50
              Predicted
            .00    1.00    Percent Correct
             0  I   1
Observed      +------+------+
```

```
  .00    0  I  63 I   0 I  100.00%
          +-----+-----+
 1.00    1  I  12 I   0 I     .00%
          +-----+-----+
                   Overall  84.00%

---------------- Variables in the Equation ----------------

Variable          B      S.E.     Wald   df     Sig       R   Exp(B)

DIAGN2                          4.6288    7   .7052   .0000
 DIAGN2(1)    6.9002  30.0489    .0527    1   .8184   .0000  992.4238
 DIAGN2(2)    7.6987  30.0499    .0656    1   .7978   .0000 2205.3863
 DIAGN2(3)    7.5933  30.0497    .0639    1   .8005   .0000 1984.8477
 DIAGN2(4)    8.5096  30.0647    .0801    1   .7771   .0000 4962.1192
 DIAGN2(5)    8.5096  30.0522    .0802    1   .7771   .0000 4962.1192
 DIAGN2(6)  -1.9E-12  64.8932    .0000    1  1.0000   .0000    1.0000
 DIAGN2(7)    8.9151  30.0494    .0880    1   .7667   .0000 7443.1788
Constant     -9.2027  30.0397    .0939    1   .7593

logistic regression var=acat1 /method=enter lod /contr(lod)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0

    Number of selected cases:                  75
    Number rejected because of missing data:   0
    Number of cases included in the analysis:  75


Dependent Variable Encoding:

Original      Internal
Value         Value
   .00        0
  1.00        1

                     Parameter
          Value   Freq  Coding
                        (1)    (2)
LOD
              1     23   .000   .000
              2     14  1.000   .000
              3     38   .000  1.000

Dependent Variable..   ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood    65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      LOD

Estimation terminated at iteration number 4 because
```

```
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood      64.207
 Goodness of Fit        75.000
 Cox & Snell - R^2        .023
 Nagelkerke - R^2         .039

                 Chi-Square    df Significance

 Model              1.744    2       .4182
 Block              1.744    2       .4182
 Step               1.744    2       .4182

Classification Table for ACAT1
The Cut Value is .50
                 Predicted
                .00    1.00    Percent Correct
                 0  I   1
Observed         +-----+-----+
  .00       0  I  63  I   0  I  100.00%
               +-----+-----+
  1.00      1  I  12  I   0  I     .00%
               +-----+-----+
                    Overall  84.00%

-------------- Variables in the Equation --------------

Variable        B      S.E.    Wald    df    Sig      R    Exp(B)

LOD                           1.6553    2   .4371  .0000
 LOD(1)      -.0183   .8245   .0005     1   .9822  .0000    .9818
 LOD(2)      -.8591   .7314  1.3797     1   .2402  .0000    .4235
Constant    -1.2809   .5055  6.4205     1   .0113

logistic regression var=acat1 /method=enter prevacat /contr(prevacat)=indicator (1).

    Total number of cases:       75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0

    Number of selected cases:                75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value        Value
   .00        0
  1.00        1

                        Parameter
            Value   Freq  Coding
                           (1)
PREVACAT
              .00     63   .000
             1.00     12  1.000

Dependent Variable..   ACAT1
```

```
Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      PREVACAT

Estimation terminated at iteration number 4 because
parameter estimates changed by less than .001

 -2 Log Likelihood      65.946
 Goodness of Fit       75.000
 Cox & Snell - R^2        .000
 Nagelkerke - R^2        .000

                 Chi-Square   df Significance

 Model                .005    1       .9454
 Block               .005    1       .9454
 Step               .005    1      .9454

Classification Table for ACAT1
The Cut Value is .50
               Predicted
              .00   1.00    Percent Correct
               0 I   1
Observed        +-----+-----+
  .00     0  I  63 I   0 I  100.00%
            +-----+-----+
  1.00    1  I  12 I   0 I     .00%
            +-----+-----+
                  Overall  84.00%

---------------- Variables in the Equation ----------------

Variable           B      S.E.    Wald   df     Sig       R   Exp(B)

PREVACAT(1)      .0583    .8479   .0047    1   .9452  .0000   1.0600
Constant       -1.6677    .3448  23.3978    1   .0000

logistic regression var=acat1 /method=enter prevdcat /contr(prevdcat)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:              75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original      Internal
Value         Value
   .00     0
```

```
  1.00      1

                   Parameter
          Value   Freq  Coding
                        (1)
PREVDCAT
            .00     62   .000
           1.00     13  1.000

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      PREVDCAT

Estimation terminated at iteration number 4 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       63.732
 Goodness of Fit         75.000
 Cox & Snell - R^2         .029
 Nagelkerke - R^2          .050

                Chi-Square    df Significance

 Model              2.219     1      .1363
 Block              2.219     1      .1363
 Step               2.219     1      .1363

Classification Table for ACAT1
The Cut Value is .50
                 Predicted
               .00    1.00    Percent Correct
                0  I   1
Observed        +------+------+
  .00      0  I   63 I    0 I  100.00%
             +------+------+
  1.00     1  I   12 I    0 I     .00%
             +------+------+
                      Overall  84.00%

---------------- Variables in the Equation ----------------

Variable           B       S.E.     Wald    df     Sig      R    Exp(B)

PREVDCAT(1)     1.0986    .7104   2.3918     1   .1220   .0771   3.0000
Constant       -1.9095    .3788  25.4068     1   .0000

logistic regression var=acat1 /method=enter famacat /contr(famacat)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:   75
    Number of unselected cases: 0
```

```
    Number of selected cases:             75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original    Internal
Value       Value
   .00      0
  1.00      1

                   Parameter
         Value  Freq  Coding
                       (1)
FAMACAT
          .00    70   .000
         1.00     5  1.000

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      FAMACAT

Estimation terminated at iteration number 7 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood        64.143
 Goodness of Fit          70.001
 Cox & Snell - R^2          .024
 Nagelkerke - R^2           .041

               Chi-Square    df Significance

 Model             1.808      1      .1788
 Block             1.808      1      .1788
 Step              1.808      1      .1788

Classification Table for ACAT1
The Cut Value is .50
               Predicted
              .00    1.00    Percent Correct
               0  I    1
Observed       +------+------+
  .00      0  I  63  I   0  I  100.00%
             +------+------+
  1.00     1  I  12  I   0  I     .00%
             +------+------+
                   Overall   84.00%

--------------- Variables in the Equation ---------------
```

```
Variable          B     S.E.    Wald   df     Sig       R    Exp(B)

FAMACAT(1)    -6.6269  27.0275   .0601    1   .8063  .0000     .0013
Constant     -1.5755    .3171  24.6813    1   .0000

logistic regression var=acat1 /method=enter famdcat /contr(famdcat)=indicator (1).

    Total number of cases:     75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:              75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value         Value
   .00      0
  1.00      1

                        Parameter
            Value   Freq  Coding
                         (1)
FAMDCAT
              .00    70   .000
             1.00     5  1.000

Dependent Variable..   ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      FAMDCAT

Estimation terminated at iteration number 4 because
parameter estimates changed by less than .001

 -2 Log Likelihood        65.890
 Goodness of Fit         75.000
 Cox & Snell - R^2          .001
 Nagelkerke - R^2           .001

                 Chi-Square    df Significance

 Model                .060     1       .8061
 Block               .060     1       .8061
 Step               .060     1       .8061

Classification Table for ACAT1
The Cut Value is .50
                 Predicted
```

```
               .00   1.00    Percent Correct
                0 I   1
Observed         +-----+-----+
  .00     0  I  63 I   0 I  100.00%
            +-----+-----+
  1.00    1  I  12 I   0 I     .00%
            +-----+-----+
                    Overall  84.00%

------------- Variables in the Equation -------------

Variable          B       S.E.     Wald   df     Sig       R    Exp(B)

FAMDCAT(1)       .2933   1.1653   .0634    1   .8012   .0000   1.3409
Constant       -1.6796    .3284  26.1565   1   .0000

logistic regression var=acat1 /method=enter ssuppcat /contr(ssuppcat)=indicator (1).

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:               75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original      Internal
Value         Value
   .00       0
  1.00       1

                       Parameter
            Value   Freq  Coding
                          (1)
SSUPPCAT
              .00     23   .000
             1.00     52  1.000

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood    65.950482

* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      SSUPPCAT

Estimation terminated at iteration number 4 because
parameter estimates changed by less than .001

 -2 Log Likelihood        65.903
 Goodness of Fit          75.000
 Cox & Snell - R^2          .001
```

```
 Nagelkerke - R^2        .001

              Chi-Square   df Significance

 Model            .047   1      .8280
 Block            .047   1      .8280
 Step             .047   1      .8280

Classification Table for ACAT1
The Cut Value is .50
             Predicted
            .00   1.00    Percent Correct
             0 I   1
Observed       +-----+-----+
  .00     0  I  63 I   0 I  100.00%
          +-----+-----+
  1.00    1  I  12 I   0 I     .00%
          +-----+-----+
               Overall  84.00%

------------------ Variables in the Equation ------------------

Variable          B     S.E.    Wald   df    Sig      R   Exp(B)

SSUPPCAT(1)     -.1466    .6711   .0477    1   .8271  .0000     .8636
Constant       -1.5581    .5501  8.0223    1   .0046

logistic regression var=acat1 /method=enter symptcat /contr(symptcat)=indicator (1).

   Total number of cases:      75 (Unweighted)
   Number of selected cases:  75
   Number of unselected cases: 0

   Number of selected cases:               75
   Number rejected because of missing data:  0
   Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value        Value
   .00      0
  1.00      1

                  Parameter
          Value  Freq  Coding
                   (1)
SYMPTCAT
            .00    29   .000
           1.00    46  1.000

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.
```

```
Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      SYMPTCAT

Estimation terminated at iteration number 9 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood      52.807
 Goodness of Fit       46.001
 Cox & Snell - R^2        .161
 Nagelkerke - R^2         .275

                 Chi-Square    df Significance

 Model               13.144    1       .0003
 Block              13.144    1       .0003
 Step              13.144    1       .0003

Classification Table for ACAT1
The Cut Value is .50
                Predicted
               .00   1.00    Percent Correct
                0  I   1
Observed        +------+------+
  .00     0  I  63  I   0  I  100.00%
            +------+------+
  1.00    1  I  12  I   0  I     .00%
            +------+------+
                  Overall  84.00%

---------------- Variables in the Equation ----------------

Variable            B       S.E.     Wald    df      Sig        R    Exp(B)

SYMPTCAT(1)      9.1614   30.5043    .0902     1    .7639   .0000 9522.2102
Constant       -10.2028   30.5025    .1119     1   .7380

logistic regression var=acat1 /method=enter karnof.

    Total number of cases:      75 (Unweighted)
    Number of selected cases:  75
    Number of unselected cases: 0

    Number of selected cases:                75
    Number rejected because of missing data:  0
    Number of cases included in the analysis: 75


Dependent Variable Encoding:

Original     Internal
Value          Value
   .00       0
  1.00       1

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482
```

```
* Constant is included in the model.


Beginning Block Number  1.  Method: Enter

Variable(s) Entered on Step Number
1..      KARNOF

Estimation terminated at iteration number 4 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood       65.868
 Goodness of Fit        74.966
 Cox & Snell - R^2        .001
 Nagelkerke - R^2         .002

                 Chi-Square   df Significance

 Model                .082    1       .7743
 Block                .082    1       .7743
 Step                 .082    1       .7743

Classification Table for ACAT1
The Cut Value is .50
                 Predicted
                .00   1.00     Percent Correct
                 0  I   1
Observed        +------+------+
  .00      0  I  63 I   0 I  100.00%
               +------+------+
  1.00     1  I  12 I   0 I     .00%
               +------+------+
                     Overall  84.00%

---------------- Variables in the Equation ----------------

Variable          B      S.E.     Wald    df     Sig      R    Exp(B)

KARNOF         .0076    .0267    .0817    1    .7750  .0000   1.0077
Constant     -2.2077   1.9574   1.2720    1    .2594

LOGISTIC REGRESSION VAR=acat1
 /METHOD=fSTEP(wald) age sex diagn2 lod prevacat prevdcat famacat famdcat
 ssuppcat symptcat karnof
 /CONTRAST (sex)=Indicator /CONTRAST (diagn2)=Indicator /CONTRAST
 (lod)=Indicator /CONTRAST (prevacat)=Indicator(1) /CONTRAST
 (prevdcat)=Indicator(1) /CONTRAST (famacat)=Indicator(1) /CONTRAST
 (famdcat)=Indicator(1) /CONTRAST (ssuppcat)=Indicator /CONTRAST
 (symptcat)=Indicator
 /CRITERIA PIN(.05) POUT(.051) ITERATE(20) CUT(.5) .

   Total number of cases:      75 (Unweighted)
   Number of selected cases:   75
   Number of unselected cases: 0

   Number of selected cases:                75
   Number rejected because of missing data:  0
   Number of cases included in the analysis: 75
```

```
Dependent Variable Encoding:

Original    Internal
Value       Value
  .00      0
 1.00      1

                    Parameter
            Value  Freq  Coding
                    (1)   (2)   (3)   (4)   (5)   (6)   (7)
DIAGN2
             1    11 1.000  .000  .000  .000  .000  .000  .000
             2    22  .000 1.000  .000  .000  .000  .000  .000
             3    11  .000  .000 1.000  .000  .000  .000  .000
             4    12  .000  .000  .000 1.000  .000  .000  .000
             5     3  .000  .000  .000  .000 1.000  .000  .000
             6     6  .000  .000  .000  .000  .000 1.000  .000
             7     3  .000  .000  .000  .000  .000  .000 1.000
             8     7  .000  .000  .000  .000  .000  .000  .000
LOD
             1    23 1.000  .000
             2    14  .000 1.000
             3    38  .000  .000
SYMPTCAT
           .00    29 1.000
          1.00    46  .000
PREVACAT
           .00    63  .000
          1.00    12 1.000
PREVDCAT
           .00    62  .000
          1.00    13 1.000
FAMACAT
           .00    70  .000
          1.00     5 1.000
SSUPPCAT
           .00    23 1.000
          1.00    52  .000
FAMDCAT
           .00    70  .000
          1.00     5 1.000
SEX
             1    37 1.000
             2    38  .000

Dependent Variable..  ACAT1

Beginning Block Number  0.  Initial Log Likelihood Function

-2 Log Likelihood   65.950482

* Constant is included in the model.

Estimation terminated at iteration number 4 because
parameter estimates changed by less than .001

Classification Table for ACAT1
The Cut Value is .50
              Predicted
           .00   1.00    Percent Correct
            0 I   1
Observed     +-----+-----+
```

```
   .00     0 I  63 I   0 I 100.00%
             +------+------+
   1.00    1 I  12 I   0 I    .00%
             +------+------+
                   Overall  84.00%

-------------- Variables in the Equation --------------

Variable        B      S.E.    Wald    df    Sig      R   Exp(B)

Constant    -1.6582   .3150  27.7172   1   .0000


Beginning Block Number  1.  Method: Forward Stepwise (WALD)

---------- Variables not in the Equation ----------
Residual Chi Square    27.902 with    18 df    Sig =  .0636

Variable           Score   df     Sig      R

AGE                .0901    1   .7641  .0000
SEX(1)             .4629    1   .4963  .0000
DIAGN2            9.2597    7   .2345  .0000
 DIAGN2(1)        2.4554    1   .1171  .0831
 DIAGN2(2)        1.1057    1   .2930  .0000
 DIAGN2(3)         .0457    1   .8308  .0000
 DIAGN2(4)         .0047    1   .9452  .0000
 DIAGN2(5)         .6986    1   .4033  .0000
 DIAGN2(6)        1.4579    1   .2273  .0000
 DIAGN2(7)         .5952    1   .4404  .0000
LOD               1.7178    2   .4236  .0000
 LOD(1)            .8130    1   .3672  .0000
 LOD(2)            .3774    1   .5390  .0000
PREVACAT(1)        .0047    1   .9452  .0000
PREVDCAT(1)       2.5523    1   .1101  .0915
FAMACAT(1)        1.0204    1   .3124  .0000
FAMDCAT(1)         .0638    1   .8006  .0000
SSUPPCAT(1)        .0478    1   .8270  .0000
SYMPTCAT(1)       9.0062    1   .0027  .3259
KARNOF             .0818    1   .7749  .0000

Variable(s) Entered on Step Number
1..     SYMPTCAT

Estimation terminated at iteration number 9 because
Log Likelihood decreased by less than .01 percent.

 -2 Log Likelihood      52.807
 Goodness of Fit        46.001
 Cox & Snell - R^2        .161
 Nagelkerke - R^2         .275

               Chi-Square    df Significance

 Model            13.144     1      .0003
 Block            13.144     1      .0003
 Step             13.144     1      .0003

Classification Table for ACAT1
The Cut Value is .50
               Predicted
              .00    1.00    Percent Correct
```

```
                 0 I  1
Observed        +-----+-----+
  .00      0  I  63 I   0 I 100.00%
              +-----+-----+
  1.00     1  I  12 I   0 I    .00%
              +-----+-----+
                 Overall  84.00%

-------------- Variables in the Equation ---------------

Variable          B      S.E.     Wald   df     Sig      R    Exp(B)

SYMPTCAT(1)   -9.1614  30.5043   .0902    1   .7639  .0000     .0001
Constant      -1.0415    .3358  9.6202    1   .0019

Deleting the least significant variable will result in a model
which duplicates a prior model.

--------- Variables not in the Equation ----------
Residual Chi Square    19.476 with    17 df    Sig =  .3019

Variable          Score    df     Sig      R

AGE               .0981     1   .7541  .0000
SEX(1)            .2465     1   .6196  .0000
DIAGN2           9.4411     7   .2225  .0000
 DIAGN2(1)       2.9142     1   .0878  .1177
 DIAGN2(2)        .2459     1   .6200  .0000
 DIAGN2(3)        .0059     1   .9385  .0000
 DIAGN2(4)        .0060     1   .9385  .0000
 DIAGN2(5)        .6199     1   .4311  .0000
 DIAGN2(6)        .5631     1   .4530  .0000
 DIAGN2(7)        .7380     1   .3903  .0000
LOD              1.8189     2   .4028  .0000
 LOD(1)           .9668     1   .3255  .0000
 LOD(2)           .3045     1   .5811  .0000
PREVACAT(1)       .0264     1   .8710  .0000
PREVDCAT(1)      2.8711     1   .0902  .1149
FAMACAT(1)        .0002     1   .9881  .0000
FAMDCAT(1)        .0873     1   .7676  .0000
SSUPPCAT(1)       .0643     1   .7998  .0000
KARNOF           1.7575     1   .1849  .0000

No more variables can be deleted or added.

cro /tables=famdcat by acat1.
```

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
FAMDCAT * ACAT1	75	100.0%	0	.0%	75	100.0%

FAMDCAT * ACAT1 Crosstabulation

Count

		ACAT1		
		.00	1.00	Total
FAMDCAT	.00	59	11	70
	1.00	4	1	5
Total		63	12	75